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The everyday social geographies of living with Long Covid

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Submitted in Fulfilment of the Requirements of the Degree of Doctor of Philosophy (PhD)

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Abstract

Although the COVID-19 pandemic was widely framed as an acute, time-limited crisis, for many people its effects persisted, giving rise to Long Covid — a novel, heterogeneous and often contested chronic condition that continues to shape everyday life long after the pandemic is widely assumed to be over. This thesis offers the first sustained geographical analysis of Long Covid grounded in the everyday lived experiences of those affected. Drawing on 26 in-depth qualitative interviews and four online focus groups with people living with Long Covid in the UK, it examines how the condition reshapes the spatial, temporal and embodied organisation of everyday life. Adopting a qualitative geographical lens, the thesis understands Long Covid not simply as a biomedical aftermath of infection, but as a lived, relational and unevenly distributed experience shaped by fluctuating bodily capacities, institutional uncertainty and broader socio-spatial inequalities.

Central to the analysis is the framing of Long Covid as an energy-limiting condition. Across participants' accounts, energy emerged as a scarce, volatile and costly resource that reorganised everyday routines, relationships and participation across domestic, workplace, clinical and digital environments. These new and uncertain energy limits produced a profound bio-geo-graphical disruption, requiring participants to re-learn how to live with their bodies, time and spaces in the absence of coherent clinical knowledge or recovery trajectories. Energy was not only materially constrained but affectively lived — anticipated, exhausted, feared and hoped for — shaping how bodies attuned to limits and possibilities in everyday life. Developing this insight, the thesis conceptualises energy as a biopolitical currency that is continually banked, withdrawn, expended and mis-spent as individuals navigate care, work, legitimacy and survival through both intimate and collective embodied knowledge amid evolving, often contested and inconsistently applied forms of clinical guidance.

Conceptually, the thesis contributes to health and cultural geography by advancing new energy geographies that foreground energy, affect and everyday labour at the intimate embodied scale of chronic illness. Methodologically, it offers insights into conducting ethical and inclusive qualitative research with people living with chronic, fluctuating and energy-limiting conditions. Taken together, the findings demonstrate that Long Covid is not only a biomedical condition but a profoundly geographical one, lived through disrupted relations between energy, body, space, time and power, and argue for sustained attentiveness to the everyday geographies through which chronic, energy-limiting illness is lived, negotiated and endured.

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List of Abbreviations

Abbreviations

CT scan – Computed tomography scan
ECG – Electrocardiogram
ELC – Energy-limiting condition
ELCI – Energy-limiting chronic illness
DWP – Department for Work and Pensions
GP – General practitioner
ME/CFS – Myalgic encephalomyelitis/chronic fatigue syndrome
MS – Multiple sclerosis
NHS – National Health Service
NICE – National Institute for Health and Care Excellence
NRT – Non-representational theory
ONS – Office for National Statistics
PEM – Post-exertional malaise
PESE – Post-exertional symptom exacerbation
PoTS – Postural tachycardia syndrome
PPP – Planning, pacing, prioritising
WHO – World Health Organisation

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And finally, to Grandad and Colin – I did it.

Author’s Declaration

I hereby declare that, except where explicit reference is made to the contributions of others, this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Signed: Ellys Feather

Chapter 1: Introduction

1.1 Living with Long Covid

> I want to be heard as someone with Long Covid. No one's ever really heard me for this long about it [...] Not friends, family, and no one's ever, in any healthcare setting, even in the mental health side of things, really asked me my opinions on things [...] So, I just wanted to be able to talk and put my side across. When I first went back to work, [...] I was having a bad day, and my pain was bad, and she [my manager] just sort of said, 'I don't really understand it. How exactly does it affect you?' I said to her, and she was like, 'Oh goodness, I can't believe you're still coming to work. You wouldn't know to look at you.' [...] Even sitting here talking to you, I'm in extreme pain, my heads fuzzy, I'm stammering, [...] but I just get on with it.
>
> (Theresa)

For many people living with Long Covid, the everyday reality not only involves managing debilitating pain, fatigue and cognitive impairment, but to be recognised at all — by clinicians, employers, family members and wider society. As Theresa's account makes clear, Long Covid is lived through ongoing negotiations of visibility, legitimacy and endurance, often under conditions of disbelief and misunderstanding. These negotiations are spatial, relational and deeply embodied: they unfold at work, at home, in clinical encounters, in social interactions and online. As such, the voices of lived experience lie at the heart of this thesis, treating them as essential to understanding the everyday realities of living with Long Covid – a novel, elusive and often contested chronic illness.

In early 2020, the outbreak of COVID-19, a severe acute respiratory infection caused by the novel coronavirus SARS-CoV-2, triggered an unprecedented global pandemic. In March 2020, COVID-19 was formally declared a pandemic by the World Health Organisation, prompting governments worldwide to introduce extensive public health measures aimed at limiting transmission (WHO, 2020b). In the United Kingdom, the government introduced a series of national lockdowns that radically reconfigured social, spatial and temporal worlds by confining much of the population to their homes (Andrews et al., 2021). Movement was restricted, workplaces and schools were closed and eventually moved online, and public spaces were tightly regulated, reshaping how people moved through and experienced space and time (Rose-Redwood et al., 2020). These measures were widely framed as exceptional and temporary responses to a

global health crisis and were accompanied by narratives of collective endurance and eventual recovery (Jarvis, 2022).

At the height of the pandemic, COVID-19 was therefore widely understood by clinicians, policymakers and the public as an acute, time-limited respiratory infection (Callard and Perego, 2021). Yet, as lockdowns were gradually lifted and restrictions eased over the course of the following year, the effects of COVID-19 did not recede evenly. Instead, a growing number of people reported persistent and fluctuating symptoms that did not align with this acute model of illness. Through patient-led accounts shared on digital platforms — many of whom were also clinicians — people living with persistent symptoms documented, compared and made sense of their experiences, from which the term “Long Covid” was articulated in mid-2020 (Callard and Perego, 2021). Patients thereby named and defined a new chronic illness category that disrupted dominant biomedical assumptions about recovery, temporality and the boundaries of illness itself. For many people, notably, the COVID-19 pandemic did not end with acute infection and a relief of government-enforced lockdowns, but instead continues to shape, and often constrain, everyday life through the ongoing and uncertain realities of Long Covid – a novel, complex and debilitating chronic illness.

Long Covid is marked by considerable heterogeneity. Over 200 symptoms have been reported – including severe fatigue, cognitive impairment, pain and post-exertional malaise – affecting individuals in diverse, uneven and often elusive ways that vary both between people and from day to day, with no two people experiencing the condition in the same form, combination or severity (Medinger and Altmann, 2022; WHO, 2022). While symptom profiles vary widely, this diversity is nonetheless structured by a shared impairment of the body’s energy. At its core, Long Covid is an energy-limiting condition (ELC) in which fluctuating and unpredictable bodily capacities profoundly shape how everyday life is organised and lived (Evans et al., 2023). As I contend throughout this thesis, these ongoing effects not only impact physical and cognitive capacities, but profoundly disrupt how bodies move, how time is inhabited, which spaces remain accessible and how social relations are reconfigured and sustained.

As a novel illness, Long Covid initially lacked a clear clinical definition, leaving both clinicians and patients without established frameworks through which to understand,

diagnose or manage its symptoms. Unlike acute COVID-19, Long Covid has no definitive diagnostic test and frequently eludes standardised biomedical investigation due to the absence of clear or consistent biomarkers. As a result, symptoms are often classified as medically unexplained (NIH, 2024) and remain largely 'invisible' within clinical encounters, despite being experienced as debilitating. Consequently, many people living with Long Covid navigate prolonged periods of uncertainty in which their condition is difficult to legitimise within existing biomedical frameworks, problematically shaping both healthcare experiences and everyday life. Long Covid, or 'Post COVID-19 condition', is now formally recognised by the WHO (2025) as a diagnostic category. In the UK, Long Covid is generally approached with General Practitioners (GPs) acting as the primary point of contact and assessment involving symptom history, clinical examination and selective referral for further investigation or specialist services (NHS Scotland, 2025). However, due to its variable, invisible and contested nature, diagnostic pathways and access to care remain uneven, and treatment is primarily oriented toward symptom management rather than cure (Calabrese and Mease, 2024). As a result, many people living with Long Covid continue to encounter disbelief, dismissal and institutional neglect, and are compelled to self-manage a novel, complex and unpredictable condition in the absence of coherent clinical guidance. Clinical contestation and uncertainty therefore reverberate beyond medical settings, shaping experiences of social stigma, marginalisation and exclusion in everyday life.

At the forefront of the Long Covid movement, the social sciences have been crucial in documenting these disruptions, highlighting the epistemic injustices, emotional distress and social suffering that shape life with Long Covid (Ladds et al., 2020; Rushforth et al., 2021; Cheston et al., 2025; Stutzin Donoso, 2025). Qualitative studies have illuminated how individuals navigate fragmented healthcare systems, how digital communities function as spaces of collective witnessing and activism, and how responsibility for care is increasingly devolved onto individuals, while also suggesting that the impacts of Long Covid are unevenly distributed across social, economic and occupational contexts, intersecting with existing inequalities in health, work, care and access to support (Lupton, 2025). Yet, despite this growing body of work, the spatial dimensions of Long Covid remain underexplored. In particular, there has been limited attention to how illness is lived through everyday geographies: how homes, workplaces, clinics, digital environments and social spaces are reconfigured through

fluctuating bodily capacities; how time is experienced as non-linear; and how power operates through spatial practices of recognition, invisibility and exclusion.

Drawing on 26 in-depth qualitative interviews and four focus groups with individuals who have lived experience, this thesis explores these everyday lived realities through a geographical lens to understand how Long Covid is lived, negotiated and understood across intersecting spatial, temporal, embodied and social contexts. In doing so, this thesis represents the first sustained geographical analysis of Long Covid grounded in the everyday lived experiences of those affected. This study hence recognises Long Covid not only as a biomedical concern, but as a profoundly geographical phenomenon. Central to this analysis, as I shall argue, is the concept of energy. Across participants' accounts, energy emerged as both a corporeal resource and an affective force shaping everyday routines, roles and relations as they learned to live with Long Covid. Energy was described as scarce, volatile and costly, requiring continual practices of planning, pacing and prioritising, adapted through embodied knowledge, while also structuring experiences of confinement, adaptation and epistemic empowerment. By foregrounding energy as a relational and biopolitical resource, this thesis contributes to emerging work on ELCs and extends geographical understandings of energy, chronic illness, embodiment and affect.

Methodologically, the research is grounded in a qualitative design that reflects both the conceptual focus on energy and the ethical and practical challenges of researching a variable and unpredictable ELCs. All data collection was conducted online, a decision shaped not only by practical considerations but by participants' fluctuating energy levels, mobility constraints and symptom unpredictability. Conducted through in-depth interviews and small focus groups, I adopt a flexible and participant-led approach that prioritises participant wellbeing and foregrounds participant agency. In doing so, I also contribute methodological insights into how social research can be conducted ethically and inclusively with people living with chronic, contested and energy-limiting illnesses.

Throughout this thesis, I frame Long Covid as an ELC, denoting a chronic illness characterised by energy impairment and debilitating fatigue (Hale, 2021; Evans et al., 2023). This framing is both empirically grounded in participants' accounts and identified as a conceptually developed thread weaving throughout the everyday

geographies of living with Long Covid. I do not seek to deny other biomedical or experiential framings through which Long Covid can be understood — including inflammatory, autoimmune, neurological or cardiovascular accounts — nor do I suggest that energy limitation wholly captures bodily change, impairment or suffering. Rather, I argue that energy provides a particularly instructive lens through which the spatial, temporal, affective and political dimensions of Long Covid become visible. By foregrounding energy as something that is depleted, negotiated, rationed and unevenly distributed across everyday life, this thesis offers *one* way of conceptualising Long Covid through an embodied, relational and affective lens. This focus on energy is therefore a deliberate conceptual intervention, illuminating how Long Covid is lived, managed and made meaningful in everyday life, while opening space for dialogue with other ways of knowing and framing the condition, and ultimately, better supporting those who live with it.

1.2 Terminology

Multiple nomenclatures, spellings, abbreviations and capitalisations are used to refer to this chronic condition across institutions (e.g. the WHO, NIH and NHS) and within the academic literature. Throughout this thesis, the term “Long Covid” is used consistently; where terminology differs, this reflects the specific usage of the institution or study being cited. This choice reflects fact that “Long Covid” is a patient-made term and is widely preferred by people living with the condition (Callard and Perego, 2021). Given the thesis’ focus on the lived experiences of those with Long Covid, the use of this terminology supports a participant-centred and empowering approach to language.

COVID-19 is an acronym in reference to ‘coronavirus disease 2019,’ the clinical illness first identified in 2019 and caused by infection with the SARS-CoV-2 virus (WHO, 2020a). I consistently use capitalised “COVID-19” to maintain this conceptual clarity, but often reproduce the term “Covid” as used by participants in quotations, to show how the terminology has been absorbed into everyday language and lived experience.

SARS-CoV-2 refers to ‘severe acute respiratory syndrome coronavirus 2’, the virus responsible for COVID-19 (WHO, 2020a). In other words, SARS-CoV-2 is the viral pathogen, whereas COVID-19 refers to the disease it causes.

A central characteristic of Long Covid for all participants was post-exertional symptom exacerbation (PESE), otherwise referred to as post-exertional malaise (PEM). This is experienced as a worsening of symptoms following physical, cognitive or emotional exertion, which may occur immediately or be delayed and can significantly limit everyday functioning (World Physiotherapy, 2021; Long COVID Physio, 2024). Throughout this thesis, I use the terms “PESE,” “PEM” or “symptom exacerbation” as general descriptors, while prioritising and reproducing the specific ways participants described these experiences. Participants referred to various intensities of symptom exacerbation, such as “flare-up” or “crash,” with meanings shaped by individual experience and context. Where relevant, these distinctions are clarified. Of these, “crash” was the most commonly used colloquial term among participants, which I commonly adopt throughout this thesis.

‘Brain fog’ is a colloquial term adopted by participants, and used throughout this thesis, to describe cognitive impairment — a common symptom of Long Covid. I frame brain fog not only as a symptom, but as an affective register through which Long Covid is negotiated and managed in everyday life.

1.3 Research aims and objectives

Accordingly, the thesis is guided by the following research objectives:

1. Explore how Long Covid disrupts relations of time, space and body, and the consequences of these disruptions for everyday lifeworlds and identity.
2. Analyse how people living with Long Covid manage limited and unpredictable energy through spatio-temporal reconfigurations of everyday life.
3. Explore the extent to which Long Covid is rendered (in)visible across clinical, social, domestic and digital time-spaces, and how individuals navigate these spatial politics of invisibility.
4. Understand how people living with Long Covid negotiate biomedical uncertainty and experiential knowledge within the context of Western evidence-based medicine.

In the following section, I outline a thesis roadmap, detailing how each chapter develops and addresses these objectives.

1.4 Thesis roadmap

In Chapter 2, I build the conceptual foundations for a social geography of Long Covid that form the architectural framework for the subsequent empirical chapters. Firstly, I

situate this thesis within interdisciplinary bodies of social scientific, clinical, sociological and geographical literature to develop a conceptual framework for understanding Long Covid as a spatial, embodied and political condition. I trace shifting social and clinical understandings of Long Covid, foregrounding the uncertainties and inconsistencies that render it a contested and often invisible illness, before engaging with geographical scholarship on chronic illness, disability and socio-spatial disruption. Drawing on sociological debates around biographical disruption, I extend this concept through the geographical notion of bio-geo-graphical disruption to emphasise how illness unsettles not only life-course trajectories but also everyday relations of time, space and identity. I further situate these embodied disruptions within broader biopolitical contexts, attending to processes of responsibilisation and self-management amid institutional neglect. Through engagement with non-representational approaches within affect theory, the chapter foregrounds energy, anticipation, chronic pain and brain fog as central to living with Long Covid. Finally, I highlight the significance of online spaces as epistemic, affective and social arenas through which knowledge, legitimacy and support are negotiated. In doing so, the chapter identifies a critical gap in geographical scholarship and establishes the foundations for the empirical analyses that follow.

In Chapter 3, I outline my methodological approach for researching Long Covid as an energy-limiting and often contested chronic condition. This chapter details the use of online qualitative methods – in-depth interviews and focus groups – and explains how these were employed to capture both individual and collective experiences of living with Long Covid. It reflects critically on the ethical, reflexive and practical considerations involved to prioritise participants' wellbeing throughout the research process. The chapter also outlines my analytical approach, emphasising the iterative and relational nature of qualitative analysis that underpins the empirical chapters that follow.

In Chapter 4, I adopt a bio-geo-graphical framework to examine the profound disruptions to time, space and body following the onset of Long Covid, unsettling everyday routines, relationships and identities amid ongoing uncertainty, as participants quite literally learned to live with a novel and poorly understood condition in real time. I explore how disrupted home, workplace and social worlds were re-navigated through an energy-limited body in attempts to establish new bio-geo-graphical flows, further questioning the extent to which participants were able to adapt

to — and accept — their new corporeality and illness identity. In doing so, I highlight how many participants came to feel temporally, spatially and corporeally stuck within their new realities as Long Covid 'bodies under lockdown'.

In Chapter 5, I examine how participants navigate the various disruptions of Long Covid through a specific energy-management strategy: the three Ps principle of planning, pacing and prioritising. Enacted through everyday spatio-temporal reconfigurations, this strategy forms a cohesive narrative thread with the preceding chapter, revealing how individuals cultivate an anticipatory attunement to their body's fluctuating capacities. Through this lens, this chapter foregrounds an affective framework, adding corporeal depth to the analysis and enabling a more nuanced understanding of how time–space–body routines are organised around a variable and volatile illness. I conceptualise Long Covid as *predictably unpredictable*, suggesting that while the three Ps offer an illusion of control, they nonetheless provide temporary release from the condition of the 'body under lockdown'.

In Chapter 6, I explore the contours of invisible illness, attending to the interconnected physical, biomedical and social dynamics that constitute invisibility. I analyse how (in)visibility emerges unevenly across a range of spatial, temporal and embodied contexts — from clinical consultations to workplaces, social environments and moments of rest at home — and how participants navigate these relational time-spaces through which their experiences are negotiated, contested and made (in)visible through an inherently spatial politics. I further investigate the paradoxical socio-spatial masking practices through which participants conceal Long Covid, inadvertently reinforcing its invisibility, while simultaneously pursuing visibility, recognition and legitimacy through diagnostic and social advocacy.

In Chapter 7, I explore how participants turn to a range of digital platforms — including online health information, wearable technologies and biosocial communities — as alternative sites of care, sense-making and connection in the broader context of clinical uncertainty, institutional neglect and social marginalisation. I attend to the spatial, relational and affective dimensions of these engagements to analyse how online spaces function as both extensions of everyday illness management and as distinct socio-spatial arenas through which experiential and biomedical knowledge are negotiated. This chapter foregrounds the ambivalent and uneven nature of these

digital geographies, examining how participation is shaped by embodied energy limits, emotional capacity and broader social inequalities, and how online interactions reverberate into offline lives.

In Chapter 8, I draw the thesis together by reflecting on its overarching contributions, methodological insights and future directions. I revisit the core arguments developed across the empirical chapters, tracing new energy geographies as the conceptual thread that binds together the empirical analyses. This lens is central to developing a social geography of Long Covid, through which everyday relational reconfigurations of embodiment, space, time and power can be understood. The chapter then reflects on methodological implications and considerations for researching an energy-limiting and contested condition, while acknowledging limitations and ethical considerations. Finally, I consider the wider implications of this research for geographical scholarship and public health practice, outlining potential avenues for future research and concluding with final reflections on what it means to take the everyday geographies of Long Covid seriously.

Chapter 2: Concepts for a geography of Long Covid: disruption, invisibility and affective worlds

2.1 Introduction

In this chapter, I review the bodies of literature that collectively inform my inquiry into the everyday geographies of Long Covid. I begin by tracing the conception of – and shifts in thinking about – Long Covid within the social sciences, before turning to clinical understandings of the condition and foregrounding the inconsistencies, uncertainties and ambiguities that contribute to its contested status. These clinical and social framings set the foundation for examining how disability and chronic illness have been theorised within geography. Tracing the emergence of social-spatial analyses in this field, I highlight how chronic illness is shaped by intersecting socio-spatial and temporal forces that are relational, uneven and embedded within wider power structures. In relation to Long Covid specifically, I explore geographies of contested and invisible illnesses and consider the role of online communities as significant epistemic and affective spaces for exchanging both knowledge and support. I then return to sociological debates, examining the concept of 'biographical disruption' and its relevance for understanding the profound destabilisation of lifeworlds following the onset of chronic illness. In dialogue with geographical scholarship, I extend this concept to the notion of 'bio-geo-graphical disruption and flow', foregrounding how place, alongside time, shapes how individuals navigate ruptures to everyday socio-spatial rhythms and identity. Within this discussion, I position embodied disruption within a broader biopolitical frame, drawing on Foucauldian notions of governmentality and the responsibilisation of the 'biological citizen'. These dynamics become particularly salient for individuals living with Long Covid who are compelled to self-manage in the absence of coherent clinical pathways. Finally, I turn to non-representational theory and affect studies, identifying concepts potentially central to understanding the lived and ongoing experience of Long Covid, including anticipation, energy geographies, brain fog and chronic pain. I conclude by synthesising these strands and arguing for the urgent need to articulate a geography of Long Covid as a spatial, embodied and political condition — a significant lacuna in both Long Covid scholarship and the wider discipline of human geography.

2.2 The genesis of Long Covid

While early research on COVID-19 was dominated by epidemiological, clinical and quantitative methodologies (Craddock, 2021), Long Covid was born in the social sciences, which have been instrumental in illuminating the heterogeneous lived experience of this fluctuating, yet highly debilitating condition. Qualitative studies not only capture the diversity of experiences but also expose how uncertainty, stigma and disbelief shape the everyday psychosocial dimensions of this newly recognised and often contested illness (Lees et al., 2021). Indeed, what makes Long Covid unique in contemporary medicine is that it was the first illness to be collectively named and made visible by patients themselves (Callard and Perego, 2021), signalling the crucial role of lived experience in its emergence. Reflecting this trajectory, the chapter begins by tracing the emergence of Long Covid through the expanding body of social science scholarship, before turning to examine how the condition is understood clinically.

At the height of the coronavirus pandemic, both clinicians and the wider public largely understood COVID-19 as an acute, time-bound respiratory infection. Global health guidance reinforced this framing, suggesting that most cases were 'mild' or flu-like, with a two-week recovery period, and only a minority of severe cases requiring hospitalisation (Callard and Perego, 2021). As the months progressed, however, a growing number of individuals began to report persistent symptoms online that did not fit neatly into the prevailing acute-care model. The term "Long Covid" was first used on 20th May 2020 by Elisa Perego, an Honorary Researcher at University College London, who used the hashtag #LongCovid on Twitter to describe her own ongoing, cyclical and progressive symptoms following her acute SARS-CoV-2 infection. Her use of the term was not only descriptive but ontological: it directly challenged how COVID-19 was being conceptualised, the 'reality' being depicted, contesting the dominant mild/severe dichotomy that had structured clinical and media narratives (Perego et al., 2020). What followed was an unprecedented act of collective knowledge production. Within days, the hashtag was adopted by others with similar experiences, forming a transnational patient network who used digital platforms to compare symptom trajectories, document recovery attempts and collectively articulate

a new illness category. These experiences gave rise to the collective naming and definition of the post-viral sequelae, “Long Covid.”[1]

This grassroots mobilisation quickly moved beyond social media. Within three months, Long Covid had travelled from Twitter feeds and blog posts into news reports, scientific preprints, government briefings and even WHO discussions. Clinicians who themselves developed Long Covid played a key role in legitimising the condition by drawing on their dual positionality as both patients and medical professionals, ultimately, foregrounding embodied experience in ways that initially challenged prevailing medical assumptions that framed such symptoms as primarily psychosomatic (Alwan et al., 2020; Garner, 2020)[2]. Their testimonies blurred the boundaries between experiential and professional knowledge, serving to shift ‘anecdotal’ accounts to the centre of biomedical and policy discourse (Rushforth et al., 2021)[3]. Callard and Perego (2021) describe this shift as a reconfiguration of epistemic authority during a global health emergency, in which individuals used digital platforms to collectivise experience, bypass conventional biomedical pathways such as clinical trials and produce new forms of medical knowledge.

As Long Covid gained visibility, early comparisons were drawn with narratives of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in attempt to make sense of the condition by recognising their connective tissues (Callard, 2020; Davis et al., 2021; Komaroff and Bateman, 2021; Komaroff and Lipkin, 2021). Both share similar symptomatology, diagnostic ambiguity and social challenges, including stigma and disbelief (Wong and Weitzer, 2021; Roth and Gadebusch-Bondio, 2022; Cheston et al., 2025), yet Long Covid has achieved formal recognition far more rapidly, exposing how social, historical and political contexts shape which illnesses gain legitimacy and which remain marginal (Dumit, 2006) and hence the long-standing marginalisation of conditions such as ME/CFS. Long Covid indeed travelled a markedly different trajectory. It gained formal recognition more swiftly due to its

[1] Individuals also coined the term “Long-haul Covid” and referred themselves to as “long haulers” (Callard and Perego, 2021, p.2) which carries intriguing geographical and temporal connotations reflecting the arduous journey-like dimensions of navigating enduring symptoms within uncertain biomedical and social contexts.

[2] It should be noted that Garner’s (2021) later work moves towards understanding Long Covid as, broadly speaking, psychosomatic.

[3] There are indeed accounts of doctors themselves not being believed (Taylor et al., 2021).

emergence during a global pandemic, which lent political urgency, heightened institutional attention and opened pathways for patient-led knowledge to be taken seriously. Clinician-patients lent additional authority, and the sheer scale of COVID-19 infections meant that persistent symptoms affected individuals across diverse professions, social groups and countries (Cheston et al., 2025). While initial comparisons proved useful – for example, recognising the prominence of PEM in both Long Covid and ME/CFS to suggest similar rehabilitative management strategies (Proal and VanElzakker, 2021) – as institutional recognition grew, Long Covid advocates engaged in strategic "boundary work" (Roth and Gadebusch-Bondio, 2022, p.4) to avoid having their condition folded into ME/CFS[4]. Their aim was to preserve a distinct illness identity (Callard and Perego, 2021) and to shield people with Long Covid from the stigma and marginalisation historically directed at ME/CFS patients (see MacKian, 2000) – while still enabling both groups to benefit from increased visibility and recognition (Hunt et al., 2022). For example, the manifesto *From Doctors as Patients* (Alwan et al., 2020) called for unbiased scientific inquiry into persistent COVID symptoms, equitable access to care regardless of acute COVID-19 test status and patient involvement in research design. Through such "evidence-based activism" (Roth and Gadebusch-Bondio, 2022, p.2), patients and clinicians co-produced new forms of medical knowledge that reconfigured traditional hierarchies of expertise. These developments have had practical consequences: they contributed to the rapid establishment of research funding streams, government recognition and the development of specialist Long Covid clinics across the UK, USA and Europe (Roth and Gadebusch-Bondio, 2022; Cheston et al., 2025). The inclusion of lived experience in guideline development and clinical research entails an emergent patient-centred model of care that values experiential evidence.

[4] Paul Garner's (2021) account of his Long Covid recovery — in which he described using mind–body techniques and reframing psychological responses to overcome symptoms — has been influential yet controversial. Many in the ME/CFS and Long Covid communities expressed dismay and anger, arguing that such testimony risks shifting the focus away from biological inquiry and may be misinterpreted as suggesting that lingering symptoms are primarily psychological or reversible through cognitive change alone (Johnson, 2021; Jefferies, 2025).

2.2.1 Long Covid in the social sciences

Social science studies identify three central themes characteristic of the lived experience of Long Covid: the condition's debilitating and fluctuating effects; systemic gaps in healthcare provision; and the role of digital technologies for collective mobilisation and making sense of illness experience. Ladds et al. (2020) conducted one of the earliest lived experience studies of Long Covid at a time when biomedical, institutional and governmental recognition was minimal. Through in-depth interviews and focus groups with 114 lay individuals and healthcare workers in the UK, participants described the illness as frightening, unpredictable and life-altering, characterised by fluctuating symptoms, cycles of relapse and profound fatigue and cognitive impairment. Building directly on this work, Rushforth et al. (2021, p.5) re-analysed the same dataset through a narrative lens[5], examining how participants constructed meaning from fragmented and uncertain illness experience. They characterised this non-linear[6] experience: a recurring pattern of optimism followed by disappointment, described as "the cruelty of hope." Studies also highlight a consistent absence of healthcare recognition or, as Rushforth et al. (2021) describe, the absence of a clinical witness. During the pandemic's early months, healthcare systems prioritised acute, life-threatening cases, while those with lingering symptoms were often excluded from medical attention (Kingstone et al., 2020). As a result, patients' stories frequently lacked professional acknowledgment, which intensified their wider sense of enduring disbelief and isolation. Similarly, Roth and Gadebusch-Bondio (2022, p.1) described individuals without a positive COVID-19 test to evidence their symptoms as existing in a "diagnostic limbo." Rushforth et al. (2021, p.5) further note that encounters with healthcare were often experienced as a "lottery" of recognition, in which being believed or dismissed depended largely on an individual clinician's awareness of Long Covid. As such, participants further portrayed the NHS as a "mis-cast" character — an institution ostensibly designed to provide care yet ill-equipped to meet the needs of those seeking validation and rehabilitation.

[5] This study adopted three narrative frameworks: socio-narratology (Frank, 2010), therapeutic emplotment (Mattingly, 1998) and polyphony (Bakhtin, 1984).

[6] In this thesis, "non-linear" refers to experiences or processes characterised by fluctuation, interruption, uncertainty and that unfold unevenly and unpredictably over time, while "linear" refers to processes which assume an orderly, sequential progression and predictability, often toward a defined outcome.

Ladds et al. (2020) further explained how the struggle for acknowledgement from healthcare professionals led to feelings of shame, anger and a loss of identity, especially among those who had previously considered themselves healthy and active. This study thus reveals a deep epistemic dissonance between participants' lived experiences and the limited scope of early scientific understanding. Despite the expansion of research and public awareness in subsequent years, many individuals with Long Covid continue to encounter comparable forms of disbelief and marginalisation within healthcare settings, reflecting what sociologists call an example of Fricker's (2007) hermeneutical 'epistemic injustice' (Jayadeva and Lupton, 2025; Stutzin Donoso, 2025). Recent studies show that patients still report experiences of stigma, dismissal and inadequate recognition of the condition's legitimacy when seeking medical support, with symptoms frequently psychologised (Mullard et al., 2023; Clutterbuck et al., 2024), highlighting too that women, people of colour and other marginalised groups are disproportionately affected (Bergmans et al., 2024; Jayadeva and Lupton, 2025), reflecting broader structural inequalities within medical institutions. As such, Long Covid is not merely a biomedical condition, but also a profoundly social-spatial one, exposing systemic inequities and institutional failures to provide support, empathy and care.

Ladds et al. (2020) observed that the absence of medical recognition compounded distress, imposing a heavy burden of self-management on individuals forced to navigate a novel illness with little guidance from fragmented healthcare systems. Four years later, however, Jayadeva and Lupton (2025) found that, despite significant advances in research and awareness, individuals with Long Covid continue to shoulder much of the responsibility for managing their own health due to persisting gaps in formal healthcare. Consequently, the role of online spaces and digital technologies to self-manage emerged as another consistent thread across the social science literature. Online connectivity enables individuals to share illness experiences and mobilise a collective identity (Ladds et al., 2020; Callard and Perego, 2021; Rushforth et al., 2021; Roth and Gadebusch-Bondio, 2022; Cheston et al., 2025), while digital tools allow them to track symptoms and monitor their condition, potentially providing clinicians with symptomatic evidence (Jayadeva and Lupton, 2025). Many participants find validation and empathy in online peer-support communities, exchanging emotional support, experiential knowledge and practical coping strategies

in the absence of formal healthcare (Russell et al., 2022). Rushforth et al. (2021) argued that, without clinical witnesses, these online communities function as collective witnesses where shared storytelling fosters empathy, moral solidarity and activism. Within these digital spaces, individuals can transform chaotic, fragmented experiences into coherent collective narratives. Through hashtags, blogs and online forums, individuals cultivate biosocial communities with a shared illness identity that offers both emotional support and advocacy.

These online networks also illustrate how social media infrastructures have transformed modes of health activism. Whereas earlier patient movements relied on physical protest and lobbying, Long Covid activism evolved through online networks that have enabled rapid mobilisation and transnational reach (Roth and Gadebusch-Bondio, 2022). This shift has practical implications for individuals with Long Covid, many of whom simply do not have the energy to participate in more traditional spaces and means of activism, a key theme explored in Chapter 6. Jayadeva and Lupton (2025) further highlighted how these online Long Covid communities and self-tracking technologies support self-management by facilitating knowledge exchange, sense-making and coping. Their findings also demonstrated, as noted above, how data generated through such technologies can serve as evidence of symptoms – particularly for individuals experiencing Postural Orthostatic Tachycardia Syndrome (PoTS) – for clinicians to validate their experiences and provide appropriate care, which I also examine in Chapter 7. This persistence of self-management in the face of clinical uncertainty and neglect underscores the ongoing gap between scientific progress and the lived realities of individuals living with Long Covid.

Qualitative research has been vital in illuminating the lived realities of Long Covid, capturing dimensions of the condition that remain obscured in biomedical and epidemiological accounts. By revealing how uncertainty, stigma and institutional neglect shape everyday experiences, such studies show how illness is experienced, interpreted and negotiated within broader cultural, institutional and political contexts. Patient storytelling through blogs, testimonies and social media has shifted the pandemic's public narrative from acute infection to chronic illness (Callard & Perego, 2021), offering both therapeutic and epistemic benefits: helping individuals process disruption, produce knowledge and demand recognition (Rushforth et al., 2021). Digital spaces and technologies have been central to this process, enabling individuals

to identify the condition, exchange information, gain support and mobilise collective action, transforming marginalised stories into shared knowledge and meaningful narratives (Roth and Gadebusch-Bondio, 2022), thereby redistributing epistemic authority (Jayadeva and Lupton, 2025). Yet despite these advances, many continue to face stigma, dismissal and diagnostic barriers, again disclosing ongoing struggles for epistemic justice (Jayadeva and Lupton, 2025). The current social science literature shows that Long Covid is not merely a biomedical phenomenon, but a profoundly social, cultural and political condition, deeply entwined with power relations.

2.2.2 Clinical understandings of Long Covid

Long Covid (also referred to in the medical literature as 'post-acute COVID-19 sequelae' (PASC)) is formally classified in the World Health Organisation's (WHO) International Classification of Diseases (ICD-11, 2025) as 'Post COVID-19 condition.' It is a chronic, multisystem condition characterised by the persistence or emergence of medically unexplained symptoms following an acute SARS-CoV-2 infection (Peluso and Deeks, 2024). According to ICD-11 (2025) diagnostic guidance, the condition typically arises within three months of the acute infection, lasts for at least two months and cannot be explained by an alternative diagnosis. Symptoms are diverse, with over 200 different symptoms reported that significantly impair daily function (WHO, 2022). These symptoms may differ substantially from those experienced during the acute phase of infection and can affect multiple organ systems, including respiratory, neurological, musculoskeletal and cardiovascular (Lescure et al., 2020; Marini and Gattinoni, 2020; Rajan et al., 2021). Most commonly reported symptoms include fatigue, cognitive impairment (colloquially known as 'brain fog'), dyspnoea (breathlessness) and muscle pain (Crook et al., 2021). Since it was first recognised in 2020, there has been significant progress in understanding the epidemiological, biological and pathophysiological characteristics of Long Covid, with research shedding light on immune dysregulation, viral persistence, mitochondrial dysfunction, microbiome dysbiosis, endothelial inflammation and autonomic instability as potential mechanisms (Al-Aly et al., 2024; Peluso and Deeks, 2024). A significant symptom of Long Covid experiences is post-exertional malaise (PEM) or post-exertional symptom exacerbation (PESE) (World Physiotherapy, 2021), which can typically be defined as a deeply debilitating exacerbation of symptoms, triggered by physical, cognitive or

emotional exertion[7]. The worsening of symptoms may happen immediately, or it can happen 24-72 hours following exertion and can disable individuals for hours, days, weeks or even months (Long COVID Physio, 2024). Due to the multifaceted nature of Long Covid, PEM can be characterised by any of the possible 200+ symptoms and feel different to each individual, with fatigue, cognitive impairment and muscle pain being the most common (Medinger and Altmann, 2022).

Studies have also identified that new-onset, secondary conditions are also common outcome of Long Covid, including cardiovascular, thrombotic and cerebrovascular disease, type 2 diabetes, ME/CFS, dysautonomia and postural orthostatic tachycardia syndrome (PoTS) (Davis et al., 2023). In both clinical and experiential terms, Long Covid is increasingly recognised as a chronic condition marked by a "wide range of persistent, cyclic symptoms" (Krishna et al., 2023, p.6). Findings from a large-scale survey of 2550 participants by Ziauddeen et al. (2022) further emphasise the fluctuating or relapsing of illness rather than a steady trajectory of recovery, underscoring the uncertain, non-linear nature of Long Covid. In summary, Long Covid is a heterogeneous condition, with a complex aetiology and pathology, marked by enduring and fluctuating symptoms that may differ substantially from those of the acute COVID-19 infection.

Definitions of what constitutes 'long', and which symptoms qualify, nonetheless remain inconsistent. For instance, the UK's National Institute for Health and Care Excellence (NICE, 2025, p.6) distinguishes between "ongoing symptomatic COVID-19" (lasting 4–12 weeks) and "post-COVID-19 syndrome" (more than 12 weeks), while the WHO (2022) defines "Post COVID-19 condition"[8] as when symptoms persist longer than 3 months. Other frameworks divide "post COVID" or "Long Covid" into two stages: with "post-acute COVID-19 syndrome" between 3 and 12 weeks, and symptoms extending

[7] Exertion is triggered by mundane activities that could be previously tolerated, such as showering, getting dressed or loud noises (as I explore in Chapter 5). The Long COVID physio (2024) cautions against comparing PEM with "boom-and-bust" cycles of over-activity, as such perspectives are rooted in ableist assumptions and place blame on the individual.

[8] Attempts by organisations such as the WHO and NICE to rename the condition as "post-Covid syndrome" have sparked debate in the social sciences. As Perego and Callard (2021) note, the term "long" is purposefully defined by patients to capture the temporal openness of the illness, whereas terminology such as "post" or "chronic" imposes biomedical closure or diagnostic certainty, which presupposes that the body can be 'fixed'. This tension between patient-made language and institutional classification illustrates the ongoing struggle over who controls the narrative of illness.

beyond 12 weeks described as “chronic COVID” (Raveendran et al., 2021, p.870)[9]. Nevertheless, while definitions of ‘chronicity’ in relation to Long Covid vary, emphasis on ongoing morbidity and management to improve quality of life, rather than cure and recovery, remains central to the Long Covid experience (Stutzin Donoso, 2025)[10]. This narrative is then further complicated by emerging accounts of individuals who have indeed achieved recovery (Garner, 2020; Medinger and Altmann, 2022), revealing tensions between adaptation and acceptance as individuals learn to live with Long Covid, as I explore in Chapters 4 and 5.

Estimates suggest that between 10–20% of those infected with COVID-19 experience Long Covid (WHO, 2022), although incidence is influenced by multiple factors, including severity of the acute infection (hospitalisation), vaccination status and underlying health and social vulnerabilities (Davis et al., 2023). Research indicates that individuals with low socioeconomic class, comorbidities, women and healthcare workers are disproportionately affected[11] (Whitaker et al., 2022; Shabnam et al., 2023; Dempsey et al., 2024). Prevalence is highest among working-age adults, particularly those aged 35–69, with many struggling to return to employment. A UK-based study found that only around 30% of those with Long Covid working in health, social care and education sectors had resumed work (either fully or partially) by 2021 (Lunt et al., 2024). This has prompted Reuschke and Houston’s (2023) call for Long Covid to be recognised not only as a pressing public health concern but also a significant labour market challenge requiring employment protection and financial support.

Diagnosis (in the UK)

Unlike COVID-19, there is no definitive test for Long Covid. It commonly eludes standardised testing due to the lack of clear biomarkers, meaning that symptoms are

[9] Griffin (2024) even identifies a “medium COVID phase” lasting 3-8 weeks post-acute infection.
[10] Clinical trials are slowly starting to take place understand, diagnose, prevent and treat Long Covid (see NIH, 2025).
[11] While Black, Asian and Minority Ethnic (BAME) groups have been disproportionately impacted by COVID-19 overall (Navarro and Hernandez, 2022), large-scale data from the Office for National Statistics (ONS, 2023) and UK cohort studies (Evans et al., 2021; Whitaker et al., 2022) do not indicate that Long Covid prevalence is higher among these populations. Qualitative research further suggests that disparities among BAME individuals are more likely driven by intersecting social determinants and structural inequalities, such as low socioeconomic status, barriers to healthcare and discrimination, rather than biological differences between BAME and non-BAME populations (Smyth et al., 2022; Lotankar et al., 2025).

often considered medically unexplained (NIH, 2024)[12]. As a result, Long Covid is generally considered a diagnosis of exclusion, meaning that clinicians must rule out other conditions before a positive diagnosis is made (NHS Scotland, 2025). In the UK, General Practitioners (GPs) play a central role in assessment as patients' primary point of care. The UK NHS (2025; 2025) diagnostic process typically involves: (1) reviewing the patient's history, symptoms and their duration; (2) conducting a clinical examination of physical and mental health, including measuring blood pressure, heart rate, blood tests and oxygen levels; (3) further investigation using standardised tests such as electrocardiograms (ECGs) or X-rays, which may be conducted by a specialist clinician, a or multidisciplinary team in tertiary care, or a specialist Long Covid service; and (4) supporting symptom management of symptoms as there is currently no cure, although treatments can help relieve symptoms. Patients should receive a personalised care plan from their GP if they have received specialist training, a multidisciplinary team in tertiary care or specific Long Covid clinic services. Management strategies include fatigue management, physiotherapy, cognitive behavioural therapy (CBT), cognitive rehabilitation, support for smell recovery, dietary guidance, symptom-tracking tools and access to practical and social support (NHS, 2025). Although Post COVID-19 condition is recognised as a diagnostic label by the WHO (2025), as noted, it is inconsistently treated in medical practice (Calabrese and Mease, 2024). The biomedical nosology of Long Covid hence remains elusive and – both clinically and socially – contested, which I explore further in Chapter 6.

2.3 The geographies of chronic illness and disability

Sociologist Charmaz (1995) notes that the onset of chronic illness unsettles "taken-for-granted assumptions about possessing a smoothly functioning body." It is experienced as a profound biographical disruption (Bury, 1982), requiring renegotiations of identity and self (Charmaz, 1995, p.657). Charmaz conceptualises this as a three-stage process of experiencing, addressing and affirming an altered body – a process which develops over *time*. For geographers, this process also unfolds across *place*, reshaping the spatio-temporal rhythms of everyday life (Driedger

[12] Although some of the new-onset, secondary conditions can be identified through clinical testing, participants in this study reported that clinicians were ill-informed of conditions such as PoTS and still had to fight for appropriate testing and a diagnosis (see Chapter 6) – which was also observed by Jayadeva and Lupton (2025).

et al., 2004; Moss, 1997). Chronic illness experience is hence a crucial avenue of enquiry for geographers.

One[13] key contribution of a geographical perspective on chronic illness – the one most directly shaping my own approach – addresses the impact of ill-health on everyday time-space rhythms, contending with the heterogeneous, intersectional and visceral geographies of the everyday. Reconstructing the everyday through the lens of chronic illness draws attention to the diverse, relational spatialities and complex temporalities that punctuate everyday social being or 'lifeworlds'. However, Moss (1999) explains that biomedical discourse seldom accounts for fluctuations, while Hansen and Philo (2007, p.497) further elaborate how the "embodied 'art' of managing time, space and speed realities of 'doing' daily living demands more recognition than it usually receives." Wilton (1996, p.78) similarly urges for further attention to chronic illnesses that disrupt everyday time-space rhythms with variable and unpredictable "good days and bad days" rendering the body varyingly dis-abled. In what follows, I trace the development of medical geography from its traditional spatial-scientific roots to the emergence of socio-cultural health geographies, illustrating how understandings of health and illness have evolved from objective patterns of disease distribution to lived, embodied and place-based experiences. Building on this trajectory, I work towards an embodied geography of disablement — a key aspect of the chronic illness experience — before attending to the diverse literatures surrounding the social geographies of invisible and contested chronic illness[14]. I then explore the role of online spaces in everyday illness realities as sites of community and epistemic agency.

2.3.1 Towards a 'new' geography of health

Historically, geography's engagement with health was dominated by spatial epidemiology — mapping disease incidence and distribution (Mayer, 2010). Rooted in spatial science, this *medical geography* sought to quantify health. Kearns (1993), however, argued that such quantitative public health models were incomplete without socio-cultural context, with Kearns and Joseph (1993) calling for geographers to

[13] There are of course other possible contributions - such a spatial epidemiology.

[14] Scholarship on the geographies of hidden/invisible illness and disabilities encompasses diverse conditions, including mental illness and neurodivergence (Kenna, 2023). In this thesis, however, I employ the term more narrowly to refer specifically to chronic illnesses that are poorly understood, may elude biomedical detection and therefore are often contested in biomedical discourse and have profound socio-spatial implications.

reconceptualise health research not only in relation to location but through *place* — the lived, social and emotional dimensions of space. This paradigmatic shift towards *health geography* carried both methodological and ethical implications, storying the lived experiences of health while treating research participants as "persons rather than patients" (Kearns, 1995, p.252). Across three 'progress papers', Parr (2002a, 2003, 2004) argued that medical and health geographies are not necessarily distinct, but rather intimately entangled through shared attention to the body and its care. She urged geographers to "think beyond usual boundaries of medical beliefs, treatments, bodies and authority" (2004, p.253), encouraging a critical re-engagement with both theory and practice and encouraging geographers to step outside of the 'traditional' biomedical approaches. In this sense, health geography is still grounded within biomedical science but now also stirs in the social, cultural and emotional experience of place.

The evolving geographies of HIV/AIDS illustrate this transformation. Early studies used GIS and spatial modelling to map disease diffusion (Gould, 1989; Gould et al., 1991; Gould and Wallace, 1994), treating people as biological hosts. Notably, many of these studies were conducted early during the AIDS epidemic – a time when HIV/AIDS was surrounded by discourse, stigma and shame, especially around the visual physicality of the 'infectious' HIV-positive body (Alonzo and Reynolds, 1995). Later, Wilton (1996, 1999) engaged in a qualitative inquiry to re-centre the everyday lived experiences of HIV/AIDS, paving the way for intersectional, queer and visual analyses of the queer body (Butler, 2005; Sothern, 2007; Todd, 2024). This trajectory reveals the transformative potential of social and cultural geographies to unpack the lived, relational and political dimensions of health and illness.

2.3.2 Towards an embodied geography of disablement

Traditionally, the medical model of disability has dominated both academic and societal discourse, framing disability as an individualised problem. Rooted in biomedical discourse, this perspective conceptualises physical and cognitive impairments as pathological, locating responsibility within the individual's body or mind, which is perceived as damaged and in need of repair (Kitchin, 1998; Shakespeare, 2013). Disability is therefore constructed as a personal tragedy, with disabled individuals portrayed as passive recipients of medical intervention (Butler and Parr, 1999). Within this perspective, bodies and minds are socially constructed as

abnormal, deviant or undesirable – as something to be fixed or 'normalised', reinforcing the marginalisation and exclusion of disabled bodies (Goodley, 2024). While influential, the medical model largely obscures the societal and spatial factors that contribute to disablement.

Oliver's (1983) social model of disability emerged as a seminal critique of this individualised framework, reframing disability as the product of societal structures rather than an inevitable consequence of impairment. Disability, from this perspective, is not an inherent deficit but the result of compounding social, environmental and attitudinal barriers that restrict participation (Crow, 2010). By distinguishing between impairment — the functional limitation of the body — and disability — the restriction of opportunities imposed by society — this perspective foregrounds how social structures *produce* disablement (Chouinard et al., 2010; Hall, 2014). Politically, the social model has been transformative, providing a foundation for collective identity, activism and legislative reform, enabling disabled people to challenge exclusion (Butler and Parr, 1999). Health and disability geographers have been largely persuaded of the merits of adopting the social model, as became apparent from early exchanges on this matter in the *Transactions of the Institute of British Geographers* (Golledge, 1993; Butler, 1994; Imrie, 1996; Gleeson, 1996), where medicalised approaches were increasingly challenged in favour of social, relational and spatial accounts of disablement.

Critical geographies of disability and chronic illness then build on this foundation by shifting the analytical focus from biomedical pathology to social and spatial barriers (Chouinard et al., 2010). In this view, disability is not only socially constructed but *spatially* produced — an effect of exclusionary environments, infrastructures and discourses that privilege able bodies and minds. The physical design of environments — cobbled streets, narrow alleyways, uneven pavements and inaccessible transport — can restrict mobility and participation, rendering certain spaces off-limits (Kitchin, 1998; Hall and Bates, 2019). As Meijering et al. (2017) elaborate, such spatial exclusions are deeply tied to embodiment and change over time. Following a stroke, for instance, once navigable landscapes can become disabling, as both material objects (such as steps, walls or uneven surfaces) and immaterial conditions (such as icy weather) emerge as new obstacles to mobility and autonomy. This aligns with a broader body of work on disabling environments and "ableist spaces," illustrating how built and natural environments are often designed without consideration for diverse

embodied experiences (Chouinard, 1997; Imrie, 2001; Crooks and Chouinard, 2006). Beyond the built environment, social expectations and normative ideas of the 'able-body' create exclusionary dynamics in public spaces, producing feelings of non-belonging and social marginalisation (Butler and Bowlby, 1997; Chouinard, 2018). These interactions illustrate that disablement emerges through the interplay of bodies, society and space, situating disability as a profoundly geographic phenomenon (Gleeson, 1996; Anderson, 2001). Disability geographies, therefore, attend to both material and social environments, revealing the many ways in which spatial arrangements and cultural norms shape experiences of inclusion and exclusion.

While the social model has provided critical insights, its marked distinction between impairment and disability has been critiqued for downplaying the lived realities of bodily difference (Crow, 2010). By separating biological "impairment" of the body from social constructions of "disability," disability is reframed as not inherently biological, but rather a social construct which can be potentially ameliorated through social change (Chouinard et al., 2010). Geographers highlight in response how this social model risks portraying all disabled people as uniformly disadvantaged and as passive victims of social and environmental structures beyond their control (Imrie, 2001; Hall, 2025). While social change can mitigate these constraints, lived experience demonstrates that disability cannot be fully explained by social barriers alone. For instance, stroke survivors may confront both environmental obstacles and embodied limitations, including fatigue and memory impairments, illustrating that biological realities intersect with social exclusions (Lock et al., 2005; Meijering et al., 2017). As such, Hall (2000, p.28) reminds us to take the body seriously, situated in "its fleshy reality," and to centre the lived, affective and relational experiences of disabled bodies, accounting thereby for both material and social dimensions of embodiment. As a result, geographers do tend to favour what can be cast instead as a 'biosocial model' of disability and its lifeworlds. Scholars such as Moss and Dyck (2003) and Crooks (2010) extend this argument, meanwhile, urging attention to how space, gender and chronicity intersect to produce uneven geographies of care and belonging. Feminist and queer further advocate for more nuanced, intersectional and relational approaches that attends to the diversity of disabled and chronic illness experiences (Clare, 2001; Moss and Dyck, 2003; Hall and Wilton, 2017).

2.2.3 Crip time and energy-limiting conditions

Building on the previous sub-section, Hall and Wilton (2017) argue that embodied and relational perspectives allow geographers to see social environments as contexts in which people perform and enact embodiment, simultaneously transforming themselves and their surroundings. Hansen and Philo (2007) deploy the phrase, "the normality of doing things differently" to describe how disabled people adapt to and challenge environments in ways that question ableist assumptions. Such arguments resonate with crip theory, which emerged from disabled and queer activism that reclaims the term 'crip' from the ableist slur 'cripple' (Kafer, 2013). Within this, the concept of 'crip time' foregrounds how disability is lived in relation to time. Crip time draws attention to altered rhythms of pace, interruption, recovery and withdrawal, acknowledging that disabled and chronically ill bodies inhabit and experience time differently from the linear, accelerating temporalities privileged in able-bodied society (Kafer, 2013, 2021). Although, as Gahman (2017, p.701) observes, "geographers have been slow to take up crip theory as a theoretical tool,"[15] Evans et al. (2024) offer one of the first explicitly geographical mobilisations of crip time. Writing reflexively as disabled academics, they theorise the experience of being "left behind" within neoliberal academia, where cultures of hyper-productivity, linear career progression and unspoken expectations of constant energy expenditure conceal deeply ableist temporal norms. The authors describe feeling out of sync with institutional temporalities that presume 'able-bodiedness' and 'able-mindedness' — assumptions that many academics with energy-limiting conditions (ELCs) cannot meet. For Evans et al. (2024), the everyday negotiation of energy impairment requires continual spatio-temporal management, including pacing[16] and withdrawal. Their analysis demonstrates that time, like space, is socially and materially produced. Rhythms of fatigue, recovery, care and withdrawal shape how illness and disability are lived and how bodies move through, inhabit and are positioned within academic spaces, determining who can keep pace, who falls behind and who is excluded. Crucially, they argue that crip time is not simply "extra time" (2024, p.7) but a fundamentally different

[15] (see Evans et al., 2024; Gahman, 2017; Hall and Wilton, 2017; Loftus, 2022; Senanayake, 2022; Sothern, 2007)

[16] 'Pacing' refers to the management of everyday activities through the intentional slowing down or spacing out of tasks to conserve energy and prevent symptom exacerbation. This concept is explored in greater detail in Chapter 5.

temporal *relation,* one that foregrounds fluctuation, unpredictability and the need for temporal flexibility. In so doing, crip time reveals how “compulsory able-bodiedness and able-mindedness” (2024, p.6) are maintained through temporal as well as spatial norms, opening new possibilities for understanding geographies of staying, leaving and being left behind.

These insights provide an important foundation for attending to ELCs – also referred to as energy-limiting chronic illnesses (ELCI) – a term used to conceptualise a growing category of chronic illnesses wherein energy impairment and debilitating fatigue are central features (Hale, 2021). Such scholarship is currently being led by a team of geographers at the University of Liverpool who are advocating for better recognition of ELCs, including, but not bound to, ME/CFS, fibromyalgia, autoimmune diseases and Long Covid. Evans et al. (2023) note that according to the Department for Work and Pensions (DWP), one in three disabled individuals in the UK experience impairments in stamina, breathing or fatigue, and that the COVID-19 pandemic has significantly expanded the population living with ELCs[17], yet this growing portion of the disabled population remains largely overlooked and under-recognised in policy, healthcare and wider society.

These researchers recently hosted a roundtable, *Imagining Better Futures of Care For and With People with Energy Limiting Conditions* (DaDa, 2025) and have produced an evidence briefing (Evans et al., 2023) outlining their ongoing research. Their work underscores the systemic inequalities faced by people with ELCs, particularly women and LGBTQ+ individuals navigating patriarchal and discriminatory healthcare systems. Participants reported widespread disbelief, dismissal and misdiagnosis, with delays in diagnosis frequently exceeding a decade, frequently driven by healthcare professional scepticism rather than diagnostic complexity. The routine attribution of physical symptoms to mental health conditions adds to harmful treatments and erodes trust in healthcare providers. Importantly, these processes — seeking care, challenging misinterpretation, advocating for basic support — themselves demand significant energy, compounding illness severity and narrowing participation across everyday spaces. The briefing further highlights how Patient and Public Involvement

[17] The report draws on the most recent available ONS data from 2022. Updated estimates as of March 2023 indicate that 1.9 million people (2.9% of the UK population) are living with Long Covid (ONS, 2023).

and Engagement (PPIE) practices and research governance structures often remain inaccessible to those with ELCs, reinforcing their exclusion from the very systems designed to represent them. Collectively, these findings reveal energy impairment as both a material bodily experience and a socio-political condition shaped by ableist institutions and temporal norms.

In this thesis, I extend this work by focusing on the energy impacts of Long Covid — as an ELC — not only within healthcare and workplace institutions, but across the everyday geographies that people must continually manage and negotiate through embodied knowledge and, what I call, affective forecasting. Building upon existing scholarship on temporality, I develop an explicit socio-spatial orientation to energy impairment, exploring the nuances of how people plan, pace and prioritise their activities around a fluctuating, unpredictable and often volatile energy-limited body. This approach situates energy within the emerging field of 'new energy geographies' (which I elaborate later), recognising different energy registers – such as fatigue, vitality, depletion – as spatial, temporal and affective processes that fundamentally shape everyday embodied capacities.

2.3.4 The geographies of contested and invisible chronic illnesses

Contested and invisible chronic illnesses – such as ME/CFS, fibromyalgia and Long Covid – are long-term health conditions that lack medical explanation, often eluding biomedical detection and leaving little or no visible trace on the body. Because their aetiology is difficult to establish and they remain poorly understood, their legitimacy is frequently called into question (Lupton, 2025) and often characterised instead by medical professionals as psychiatric or psychosomatic (Dumit, 2006). They are of particular interest to human geographers as they complicate both embodiment and identity because symptoms are often hidden and/or unpredictable. The variability of illness renders the body unstable in both time and space, challenging the ability to conform to normative expectations of performance, productivity and social presence (Moss, 1999). Invisibility therefore becomes a spatial and relational problem: it shapes how bodies are perceived, how identities are negotiated, and how spaces are inhabited. While the previous section positioned ELCs in relation to crip time and embodied temporalities, many ELCs also exemplify the dynamics of contested and invisible chronic illness, marked by diagnostic uncertainty, fluctuating symptoms and persistent scepticism within biomedical systems.

Within their feminist-materialist conceptual framework, Moss and Dyck (2003) work towards a ‘radical body politics’ to expose the instability of invisible chronic illnesses, illustrating how bodies are simultaneously lived materially and constituted discursively. To understand these everyday lived realities further, Moss and Dyck (1999), draw on 25 in-depth interviews with women across Canada diagnosed with ME/CFS, investigating how they navigate everyday home, workplace and healthcare spaces. Central to their analysis is the concept of diagnosis as a form of bodily inscription, through which medical discourse both legitimises and constrains embodied experience. Diagnosis offered participants a degree of validation, explaining why their bodies could no longer perform previously mundane tasks and, in some cases, facilitating access to resources such as medication, workplace accommodations or financial support. At the same time, however, diagnosis also functioned as a discursive ‘filter’, narrowing the range of legitimate embodiment by ‘scripting’ illness through biomedical norms of visibility, stability and functionality. Moss and Dyck (2003) argue that diagnosis thus operates as both a material and discursive inscription, rendering the chronically ill body intelligible while simultaneously delimiting how illness can be lived and recognised.

Crooks and Chouinard (2006) extend this argument through research on women with marginalised arthritic conditions – including fibromyalgia, lupus, osteoarthritis and rheumatoid arthritis. Their work adds nuance by showing how biomedical recognition — or its absence — shapes women’s lifeworlds both within and beyond healthcare spaces. Clinical verification enabled participants to explain their illness to others, including employers and family members, while a lack of recognition intensified exclusion in workplaces and communities, effectively shrinking women’s everyday socio-spatial worlds (Dyck, 1995). Crucially, even where diagnosis was secured, insufficient or ambiguous medical guidance remained profoundly disempowering, particularly in occupational contexts where fluctuating symptoms were poorly accommodated. Across these studies, healthcare professionals were shown to discursively position women as either “disabled” and unfit for work or “able” and therefore expected to perform, flattening the inherent variability of chronic illness experience. This rigid categorisation not only misrepresented participants’ lived realities but also exacerbated the material consequences of illness, as women found themselves increasingly dis-abled across spaces beyond the clinic.

Together, these findings exemplify Moss and Dyck's (2003) contention that chronic illness cannot be understood by separating the discursive from the material. Illness and health, ability and disability, blur and coexist. Chronic illness is lived corporeally — through sensation, fatigue, pain and emotion — while simultaneously articulated through discourse — through language, diagnosis and representation. These domains are mutually constitutive, as bodily sensations are interpreted through available discourses, while discursive framings are themselves felt and embodied. As Moss and Dyck (2003, p.40) note, the chronically ill body is not 'fixed' in time or space, but continually shifts as symptoms emerge, change, recur or recede, moving between states socially and medically (re)cast as "explained" or "unexplained."

Embodiment therefore emerges as a deeply relational and spatial process. Through their radical body politics, Moss and Dyck resist framing the ill body as deviant or lacking, instead conceptualising it as "merely being": a lived, negotiated process shaped across bodies, places and institutions. They describe bodies as produced through the interrelated forces of "embeddedness" (a state of being) and "inscription" (a process), such that corporeal space becomes a relational terrain where material and discursive forces intersect — where bodies are "neither wholly idealised, nor utterly fleshed" (Moss and Dyck, 2003, p.54). Yet, as their work shows, institutions and workplaces frequently fail to accommodate this variability, reproducing binary distinctions between ability and disability that their framework explicitly seeks to unsettle.

Dyck's (1995) work on the 'hidden geographies' of women living with multiple sclerosis (MS) echoes these arguments by examining how chronic illness is negotiated through everyday corporeal spaces. She shows how women's 'lifeworlds' often contract following withdrawal from paid employment, as bodily capacities no longer align with workplace expectations. This spatial narrowing renders everyday lives increasingly hidden from public view, producing what Dyck (1995, p.308) terms "spaces of silence." In this context, the home becomes a central site of chronic illness experience, operating simultaneously as a space of constraint and adaptation. Women actively remap domestic spaces and routines to accommodate fatigue, mobility limitations and fluctuating symptoms, employing practices such as pacing, delegating labour and reorganising everyday rhythms.

Drawing on feminist–Foucauldian approaches to the body as both lived and regulated, Dyck demonstrates how power operates through spatial arrangements, material conditions and discourse, while also opening possibilities for agency. Everyday micro-geographies are shaped by intersecting structural forces – including gendered labour expectations of care and productivity, workplace norms and biomedical authority – that operate alongside embodied experience to constrain or enable action. In her later work, Dyck (2002) extends this analysis to the workplace, showing how women with MS navigate environments organised around able-bodied norms through practices of self-surveillance, selective disclosure, pacing and spatial reconfiguration. These embodied strategies function as disciplinary performances that temporarily reinscribe the body as 'able', echoing Butler's (1990) notion of performativity, where social norms are continually enacted, while exposing workplaces as "spaces of risk" where visibility, legitimacy and stigma are continually negotiated.

Across Dyck's work, invisibility emerges as an inherently spatial condition, produced through architectural design, organisational practices and social norms that privilege visibly able bodies. At the same time, resistance figures as a central mode of agency. Women reclaim their illness identities by challenging the gap between biomedical inscriptions and lived realities — whether through negotiating flexible work arrangements (Moss & Dyck, 1999), engaging in strategic concealment, spatial reconfiguration or selective disclosure (Dyck, 2002), or seeking alternative knowledge and support in online spaces (Moss and Dyck, 1999; Crooks & Chouinard, 2006). These practices illustrate that disablement is not a passive outcome of impairment but an ongoing, relational process of identity and place-making, shaped through material, temporal and spatial negotiations.

Taken together, these empirical studies exemplify Moss and Dyck's (2003) notion of "bodies in context," foregrounding that embodiment is dynamic, relational and situated within spatial and social relations. Chronic illness is lived through shifting capacities and fluctuating intelligibility within biomedical and social worlds. In this sense, invisibility is both material and discursive — a lived and spatial 'filtering' between being seen or unseen, legitimised or invalidated. However, these accounts have not yet fully considered how energy limitation, ongoing diagnostic uncertainty and fluctuating chronicity operate as active spatial forces through which (in)visibility is continually produced, managed and contested. In Chapter 6, I build upon and critically rework

these foundational contributions, advancing a spatial politics of (in)visibility that foregrounds the negotiation of energy, stigma and discrimination across biomedical, work and social environments, positioning invisibility as a relational, shifting and politically charged process rather than a fixed attribute of particular bodies or conditions.

2.3.5 Online spaces

As briefly suggested above, online environments have become crucial “alternative” or “additional” spaces for understanding or negotiating illness. Parr (2002b) outlines that biomedical authority historically monopolised the production of medical knowledge, later elaborating that biomedical practices, institutions and spaces form the foundational pillars through which health and illness are understood, reproducing hierarchical relations in which knowledge flows from practitioner to patient (Parr, 2004). Within this hierarchy, legitimacy is conferred through biomedical recognition — the diagnosis, prescription and surveillance of the ‘expert gaze’ (Philo, 2000). Seeking biomedical validation therefore reinforces the authority of medical discourse, positioning illness within institutionalised regimes of nosological classification. As I outlined in the previous section, when biomedical knowledge, recognition or treatments are absent for illnesses that are novel, contested or medically unexplainable, such spaces become disempowering and inherently political (Crooks and Chouinard, 2006). Individuals excluded from care in this way are *forced* to assume ‘biological responsibility’ (Rose, 2007), seeking out alternative sources of information, support and knowledge production beyond the clinic – a point to which I return later in this chapter.

From the 1990s, early text-based online health forums, email lists and bulletin boards provided the digital infrastructure through which ‘biosocialities’ (Rabinow, 2010) could crystallise, enabling geographically dispersed individuals to become part of a shared, embodied online biosocial community. Through an ethnographic study of MS chat rooms, Parr (2002b) contends that the Internet can transform the social geographies of illness experience, producing ‘new body geographies’, where digital and physical spaces are intertwined. She observes the ‘emancipatory’ potential of online communities as individuals exchange coping strategies, treatments and offer emotional support, which are enacted and embodied in ‘real’ space. Developing patient-made, embodied knowledges that challenge the hierarchies of expertise

embedded within biomedical structures allow users to reshape both their social scripts and corporeal experience – the discursive and the material. In this context, online environments emerge as vital alternative spaces through which patients reassert epistemic agency. Crooks and Chouinard (2006) extend these insights, noting that women with chronic arthritic conditions use online resources not only to access information but also to cultivate a sense of control and belonging, empowered by their knowledge acquired in digital space to gain recognition in healthcare and everyday interactions. Such practices highlight the relationality between the virtual and the material as embodiment is negotiated across multiple sites (Parr, 2008). Madge and O'Connor (2005, p.93) further add that online communities operate as "generative spaces" in which users can experiment with social roles and identities, normalise their thoughts and feelings (Madge and O'Connor, 2002) and re-script their subjectivities (Parr and Davidson, 2008; Skelton and Valentine, 2010; Campbell and Longhurst, 2013). While acknowledging the often-contradictory feelings about online spaces, Parr (2008) further observes that these spaces are not only sites for gaining information but also for cultivating emotional connections, self-reflection and belonging, highlighting the potential for virtual engagement to influence positively both online and offline lives.

Stevenson et al. (2007) are critical of how individuals use online resources as "additional" rather than alternative forms of knowledge, but other studies offering experiential illness accounts suggest a more nuanced picture. For example, Lucherini (2015) show how people living with diabetes draw on online forums to share experiences of home remedies and self-devised treatment regimes, not merely supplementing medical advice but actively experimenting with and redefining it. These practices demonstrate the participatory and embodied nature of online illness communities, where experiential knowledge circulates as a form of collective expertise. Importantly, regardless of whether such spaces are used for additional or alternative knowledge, with reference to social anxiety, Boyle (2019a) discloses the significance of the internet as an affectively and sensorially *safer* environment. In contrast to physical spaces that may be "overwhelming, socially stigmatising, and so disabling" (Parr and Davidson, 2008, p.63), online communities can offer 'virtual trust' through anonymity and mutual understanding, fostering belonging and solidarity. These studies suggest that online spaces are dynamic sites where knowledge, identity and sociality are exchanged and negotiated, providing illness communities with

opportunities to challenge biomedical hierarchies, cultivate agency and reshape the social and spatial geographies of illness.

From the mid-2000s, technological advancements enabled more dynamic, interactive and user-generated commercial platforms – including social media, blogs and video-sharing sites – reshaping these biosocial geographies. Platforms such as Facebook, YouTube, Twitter/X, and later Instagram and TikTok each developed their own distinct cultures of real-time text, photo and video-based sharing, along with their own algorithmic logics (Oksanen et al., 2024). Together, these digital spaces have dramatically accelerated the formation of online communities and heightened their visibility, helping to forge more fluid and immediate biosocial forms of belonging, often experienced in real-time. Deborah Lupton's (2017) work on "digital health" extends discussions to broader technical developments in wearable self-tracking devices and mobile social media apps within a pervasive ecology of digital technologies positioned as enabling people to generate, access and interpret data about their own bodies. Designed to motivate healthier lifestyles, these digital tools contribute to the rise of the "quantified self," offering individuals unprecedented opportunities to monitor diet, sleep, heart rate, exercise, menstrual cycles, blood pressure (Lupton, 2015, 2016) and, more recently, even conduct basic electrocardiograms (ECGs) (Dahiya et al., 2024). In doing so, they give users new forms of epistemic agency as they can understand and act on their own health data rather than relying solely on clinical encounters. These technologies foster new forms of digital biosociality as users share biometric and activity data with others. Communities increasingly form around shared datasets as much as shared diagnoses, generating spaces where individuals support one another, exchange interpretations and experiment with health practices that may extend beyond conventional biomedical frameworks (Ajana, 2017). Lupton (2017) nonetheless emphasises that, while self-tracking technologies can meaningfully empower individuals and communities through access to personal health data, it is also entangled with surveillance and unequal access. The very tools that empower those users who do indeed have the requisite online access to track and make sense of their bodily data also shift responsibility for health away from institutions and onto these individuals (Lupton, 2015, 2016). She contends that understanding digital health requires attending to this complexity — recognising both its capacity to democratise

health knowledge and its potential to reinforce existing neoliberal pressures of health governance and self-responsibility.

The transformative potential of digital environments became particularly evident during the COVID-19 pandemic, which accelerated the emergence of large-scale biosocial communities, most notably among those with persistent symptoms now known as Long Covid. During national lockdown, platforms like X/Twitter, Facebook groups and TikTok became key avenues where individuals could collectively document symptoms, compare illness trajectories and define a new illness at an unprecedented speed. These communities did more than provide mutual support: they actively shaped the contours of the illness, challenged research priorities and applied pressure on public health institutions. They represented a new phase of digital biosociality under conditions of a global crisis, formed through the systemic failure of biomedical infrastructures to respond adequately. Research also demonstrates that people with Long Covid have used self-tracking technology not only to monitor symptoms but also to generate situated knowledge that contests biomedical authority, enabling individuals to make sense of fluctuating symptoms while reclaiming a sense of agency, control and validation (Homewood, 2023; Homewood et al., 2024). Such forms of knowledge are then circulated within the relevant community, enabling collective learning, shared care and the co-production of lay expertise (Jayadeva and Lupton, 2025). Online spaces thus offer safety (Davidson & Parr, 2010) – from both contagion and institutional neglect – and social support that real space could not afford during a global pandemic[18]. Together, with digital technologies, this emergent digital health ecology has afforded individuals new forms of epistemic agency (Parr, 2002b) and authority (Jayadeva and Lupton, 2025).

Long Covid represents a distinctive moment in the geographies of health and illness as one of the first large-scale conditions to be collectively named and mobilised largely through online spaces. By generating subjective evidence that filled crucial global health gaps, this large scale biosocial community transformed the broader landscape in which illness can be conceived, understood and acted upon, extending Moss and Dyck's (2003) radical body politics into the digital realm. Much of this work on biosociality, however, has tended to foreground the generative, empowering and

[18] This remains the case for many people living with Long Covid beyond the pandemic, for reasons explored later in the thesis.

connective dimensions of digital engagement, often treating online participation as broadly accessible and beneficial, while paying comparatively less attention its constraints (Meleo-Erwin, 2020), including uneven, affective and energetic costs of sustaining engagement in these spaces, particularly for those living with chronic, fluctuating and energy-limiting conditions. This gap is significant in the context of Long Covid, where online environments have simultaneously functioned as crucial sites of recognition, care and collective meaning-making, and as spaces of emotional saturation, epistemic governance and exclusion. By attending to these ambivalences in Chapter 7, I examine how participation in online illness communities is paradoxical: enabled by both belonging, community and agency, yet constrained by energy limitation, affective labour and epistemic authority — opening up new directions for understanding the spatial politics of digital health and illness.

2.4 Bio-geo-graphical disruption, responsibilisation and subjective suffering

2.4.1 Biographical disruption

Influential to medical sociology, Michael Bury (1982, p.169) conceptualises the sudden onset of chronic illness as a "disruptive" event to everyday "taken for granted assumptions and behaviours." This framework attempts to depart from sociology's oversimplification of disablement as a stable and linear process, which fails to capture the fluctuations, uncertainties and variabilities central to chronic illness experience. Drawing on rheumatoid arthritis, Bury defines three distinct but interrelated ruptures intrinsic to everyday life: (1) habits and routines, particularly everyday embodied practices that are brought into consciousness when disrupted; (2) self-understanding and imagined life trajectories; and (3) the mobilisation of cognitive and material resources to manage the chaos created by the first two disruptions. These ruptures collectively produce a novel illness identity that reshapes social relationships, life trajectories and knowledge — all key components of an individual's biography and sense of self.

Central to Bury's concept of "biographical disruption" is the "problem of uncertainty**"**: uncertainty about the self and uncertainty stemming from biomedical knowledge. The sudden onset of chronic illness disrupts self-understanding when it does not align with prior life experiences or assumptions. In his study of rheumatoid arthritis, Bury (1982,

p.171) notes that younger participants often interpreted their diagnosis as “premature ageing,” disrupting their anticipated life trajectories. Individuals therefore typically turn to medical professionals for explanations that legitimise the body’s ‘deviant’ behaviour and shift blame away from the self. As Bury observes, however, separating the self from disease produces a paradox: the condition is simultaneously external and deeply invasive, affecting every aspect of daily life. This tension is echoed in Dumes’ (2020) empirical study of chronic Lyme disease, where participants conceptualised the Lyme bacterium as inhabiting their bodies, interacting with the immune system and altering physiological states. For Bury, the search for causation represents a broader quest for meaning — an attempt to answer philosophical questions such as “why me?” — which is further complicated when medical knowledge offers incomplete or contested explanations. Thus, while medical legitimacy can support a re-evaluation of self, the lived experience of disease often remains elusive, particularly in poorly understood or contested conditions.

Chronic illness often challenges the reciprocal nature of support networks as individuals become more dependent on friends, family and colleagues. Paralleling the aforementioned studies in the geographies of chronic illness, Bury identifies medical diagnosis as a crucial resource that allows individuals to inform their social networks, particularly when symptoms are doubted (see Scarry, 1985), psychologised or stigmatised by others. Disruptions to familial, social and work relationships are compounded by the embarrassment that individuals feel when mundane tasks, work outputs or social interactions become difficult to perform. In response, participants in Bury’s study often confined themselves to familiar, local environments to avoid scrutiny, with some withdrawing entirely from social spaces. Illness experience is therefore frequently characterised by social isolation (Strauss, 1975). Paralleling Smith (1979), Bury argues that the ability to cope — through mobilising cognitive and material resources — depends on social and occupational status, including support networks, which can either mitigate or exacerbate disablement. Consequently, biographical disruption not only profoundly reshapes self-understanding but also fundamentally alters relationships between the self and others.

Since its conception, biographical disruption has been widely adopted by sociologists to understand a range of illness experiences, including HIV/AIDS (Weitz, 1989), fibromyalgia (Asbring, 2001), motor neuron disease (Locock et al., 2009), mental

illness (Perry & Pescosolido, 2012) and breast cancer (Liamputtong & Suwankhong, 2015). Bury's original theorisation has been subject to various critiques, however, and in the context of stroke, Faircloth et al. (2004) argue that Bury's framework may be too simplistic, since the symbolic significance of illness onset may vary considerably between individuals. While some may experience the onset as a major disruption, others may accept illness as a natural stage in their life course – as a new embodied phase rather than a rupture. This is particularly evident in studies of older populations for whom illness and physical decline are often *expected* parts of ageing (Adamson & Donovan, 2005; Pound et al., 1998; Richardson et al., 2006). This is not to suggest, however, that age precludes experiences of disruption, and Meijering et al. (2017) demonstrate that older individuals can still experience biographical disruptions, particularly through limitations to hobbies and social engagements following a stroke. Further critiques of Bury's work highlight the limited attention to intersectional factors such as gender (Wilson, 2007), class (Williams, 2000) and co-morbidities (Faircloth et al., 2004).

In a study of 36 post-operative transplant patients, Engman (2019, p.122) adopts an *embodied* perspective to investigate *why* illness is often experienced as disruptive. By attending to the organisation of habitual daily routines prior to illness onset, she poses the question: "what, precisely, is being disrupted?" Embodiment, she contends, is hence crucial to understanding why illness can be so potentially disruptive to everyday structures, self-understandings and perceived life trajectories. The term *potentially disruptive* is also key here, since Engman's diverse sample illustrates that illness is not always experienced as a disruption *per se*. Some symptoms, she notes, develop gradually and are perceived as "novel but not severe" (p.120) and their effects are incrementally incorporated into daily routines rather than abruptly imposed. In this way, Engman expands on Bury's original framework, suggesting that biographical disruption is not inevitable but instead reflects how illness interacts with pre-existing embodied habits and experiences. These critiques highlight that Bury's concept of biographical disruption remains influential for understanding the onset of chronic illness and its effects on selfhood, it offers a relatively limited account of how disruption is lived through space and place. In focusing primarily on temporal rupture, identity and meaning-making, Bury's framework underplays how everyday environments, mobility and spatial relations shape experiences of disruption. A geographical

perspective therefore offers important scope to extend biographical disruption by foregrounding how illness is negotiated across interconnected spaces, and how disruption is unevenly produced, sustained or managed through relationships to place. It is this spatial reworking of biographical disruption that underpins the bio-geo-graphical approaches discussed in the following section.

2.4.2 Bio-geo-graphical disruption and flow

Faircloth et al. (2004) introduces the concept of "biographical flow" to highlight the intersecting and oscillating temporalities that shape individuals' illness experiences both before and after a stroke. Building on this move, Meijering et al. (2017) draw attention to the importance of the broader spatial context in understanding these nuances more fully. As a health geographer, Meijering brings an explicitly spatial lens to Bury's framework, extending biographical disruption and flow through attention to place, mobility and the relational production of embodied experience. By combining the spatial and temporal dimensions of biographical disruption and flow, Meijering et al. (2017, p.7) propose a "bio-geo-graphical" perspective which centres on "the extent to which relational experiences of space/place are disrupted by changes in the life course arising from disability, as well as by how taken-for-granted embodied states have to be renegotiated at any other place anew." In doing so, they coin the terms "bio-geo-graphical disruption" and "bio-geo-graphical flow," extending existing theorisation to suggest that biographical disruption and flow not only shape relationships with the self and others but also profoundly influence one's relationship with *place*.

Accordingly, Meijering et al. (2017) explore the spatio-temporal relationship between pre- and post-stroke embodied experiences and the rural environment as individuals attempt to return to pre-stroke 'normality'. While the natural environment is often understood as therapeutic, health-promoting and *enabling*, this study focuses specifically on more *disabling* disruptions to various 'therapeutic' activities such as cycling, sailing and everyday community encounters. Echoing the aforementioned critical disability literature on disabling environments and 'ableist spaces', the authors demonstrate how material, natural and social features of the rural landscape can become disabling for the post-stroke body, as impairments render previously taken-for-granted spaces inaccessible. They find that the socio-spatial disruptions to once-therapeutic environments are experienced as a loss of place, thereby unsettling stroke

survivors' individual biographies and sense of self. Nevertheless, despite barriers imposed by impairment, Meijering et al. (2017) illustrate how individuals (re)negotiate these places so as to (re)establish a sense of bio-geo-graphical flow. For example, some participants substituted more energy-demanding forms of social interaction, such as conversations, with gestures such as waving to people from a distance during daily walks, a practice that conserved limited bodily energy while still sustaining affective ties and feelings of social inclusion within the rural community. These small, adaptive practices underscore the profound affective entanglements through which social connection, belonging and place are maintained, even as interaction is reconfigured through bodily constraint, illustrating how flow is not a return to 'normality' but an emergent, negotiated condition. Others developed new cycling 'techniques' to navigate challenging hilly terrain and busy roads. In this way, *potential* disruptions to social encounters and belonging were transformed to renewed states of bio-geo-graphical flow, as, through adaptation, participants (re)gained access to 'lost' meaningful activities. Meijering et al.'s study therefore echoes Parr et al. (2004) in demonstrating that rural environments can be simultaneously socially inclusive and exclusive: the physical, natural and social characteristics of rural landscapes hold the potential to be both enabling and disabling. The study also extends Bury's notion of biographical disruption by embedding it within a spatial framework, proposing that the embodied experience of illness is not only temporally situated but also deeply relational to place. In doing so, Meijering et al. (2017) arguably advance a still more dynamic understanding of embodiment — one that recognises how narratives of bio-geo-graphical disruption and flow evolve over time and space as individuals continually (re)negotiate the meanings of illness, identity and belonging.

Meijering et al. (2019) extend this argument further through the lens of acquired brain injury (ABI) experiences, shifting the analytical focus from a sense of *self* to a sense of *place.* The authors hence further emphasise that experiences of bio-geo-graphical disruption and flow are not static; rather, they unfold through everyday meaningful places. Disruption and flow, they argue, can occur both within and between places, and individual illness narratives are rarely characterised by one or the other alone. Drawing on qualitative interviews and place-mapping with 18 ABI survivors and their significant others, Meijering et al. (2019) explore how meaningful everyday places and corresponding identities are maintained, lost and (re)gained between pre- and post-

injury. Building on their earlier study with stroke survivors, the authors show how various visible and invisible impairments, such as weakness, walking difficulties, memory problems and fatigue, create barriers to accessing significant places, whether physically, affectively, cognitively or socially. The authors acknowledge how the broader ABI literature suggests that, while survivors often recognise physical and cognitive changes, some continue to experience a sense of pre-ABI identity continuity — an inner self-alignment that resonates with the notion of bio-geo-graphical flow. Accordingly, Meijering et al. (2019) contend that disruption may emerge in some places while flow persists in others, as identity is simultaneously lost and sustained. This duality once more underscores the fragmented and dynamic nature of embodied experience, although it risks underplaying the extent to which structural inequalities and broader social factors may constrain an individual's capacity to (re)negotiate these spaces.

Echoing scholarship in the geographies of chronic illness, the authors reveal that as participants seek to reconnect with meaningful spaces and places, spatial relations are inherently reciprocal. For instance, one participant's return to full-time work — a place associated with belonging and flow — subsequently rendered the home a site of disruption, as limited energy depleted familial engagement. The interplay between disruption and flow is therefore intrinsically relational, situated between places and the social relationships embedded within them.

(Re)engagements with everyday places are thus characterised by simultaneous experiences of loss, disruption, gain and flow, as identity remains continually in flux. Because ABI survivors' sense of self is deeply tied to their functional and affective connections with meaningful places, Meijering et al. (2019) indeed argue for this theoretical shift from a *sense of self* to a *sense of place* as a means of foregrounding identity, belonging, and becoming. While this perspective offers a valuable extension of biographical disruption through place, it risks underplaying the impact of intersecting dimensions such as socio-economic class, which I identify as a key thread woven throughout the empirical chapters, shaping how disruption and flow are differentially experienced, negotiated and sustained across the lived experience of Long Covid as a novel, energy-limiting and contested illness. Finally, in acknowledging a key limitation, the authors identify the need to consider the role of virtual spaces in the renegotiation of place, suggesting that digital environments may substitute for

inaccessible physical ones — a recognition particularly pertinent to this thesis (Chapter 7).

What is distinctive about Long Covid — and the bio-geo-graphical disruption it produces — is the uncertainty generated by its novelty and unpredictable trajectory. People expected to recover from acute COVID-19 yet, because Long Covid was novel, they had no personal experience, medical knowledge or established illness narratives from other patients to draw upon. Without these individual or collective precedents, they were unable to anchor their experiences within any shared understanding of what the illness 'normally' entails. This absence of social and medical knowledge has clearly intensified uncertainty, exacerbating the temporal, spatial and biographical dislocation produced by emerging symptoms. As a result, Long Covid proved particularly disruptive to everyday life and sense-making processes. Participants were required to learn, often without precedent or guidance, how to live with a novel and poorly understood condition, at the same time as both their embodied experiences and wider medical knowledge were evolving in real time. While Meijering et al.'s bio-geo-graphical framework offers a crucial spatial reworking of biographical disruption and flow, it offers more limited insight into how disruption unfolds under such conditions of ongoing uncertainty. I therefore extend their work by examining how disruption and flow are negotiated in real time, foregrounding the role of energy limitation, unpredictability and institutional uncertainty in shaping how individuals (re)engage with meaningful places and sustain a sense of self across interconnected home, work, social and digital spaces.

2.4.3 Disruption, biopolitics and responsibilisation

While Meijering et al.'s (2017, 2019) theorisation of bio-geo-graphical disruption and flow situates Long Covid within spatio-temporal relations of embodiment and place, it is also crucial to recognise how this disruption unfolds within broader biopolitical frameworks. Foucault's work has long informed geographical engagements with the entanglements of bodies, space and power (Driver, 1985; Sharp et al., 2000), providing a foundation for understanding how 'disrupted' bodies are located within broader systems of governance. His analyses of disciplinary power and anatamo-politics, most notably through his reading of Bentham's Panopticon, illuminate how bodies come to internalise norms through surveillance and self-regulation (Foucault, 1995). While Foucault's later work on biopolitics and biopower marked a conceptual

shift towards the regulation of populations, a continuity can nonetheless be traced between panopticism's demand for the interiorisation of discipline and contemporary forms of responsibilisation[19].

Modern Western biomedicine, a dynamic scientific, cultural and political formation plays a key role in this process by continually recalibrating normative understandings of what counts as healthy, productive and responsible (Rose, 2007). Foucault (1976) termed these dynamics as 'biopolitics': the regulation and management of populations through expert knowledge, surveillance and classification that seeks to shape the conduct of bodies deemed 'unhealthy'. Biopolitics operates through biopower – the power over life itself – exercised through diverse technologies that govern and normalise healthy behaviours (Rabinow and Rose, 2006). As these forms of power are diffused throughout society, individuals are "encouraged, frightened or shamed" into adopting self-regulatory practices aligned with cultural norms, disciplining 'docile' bodies through the avoidance of 'deviant' behaviours (Philo, 2001, p.485). Foucault's (1995, p.209) reading of the Panopticon[20] illustrates how this disciplinary power becomes internalised through "a network of mechanisms [...] everywhere and always alert, running through society without interruption in space or in time" – including schools, prisons, hospitals – compelling individuals to govern themselves through everyday self-surveillance. Under neoliberal rationalities, these forms of governmentality operate not through overt coercion, but through subtle mechanisms of 'responsibilisation' that recast social risks, such as illness, as matters of individual management rather than collective care. Individuals are thus compelled to monitor, optimise and govern their biological lives in accordance with biomedical norms, as a good 'biological citizen' (Rose, 2007). It is within this biopolitical landscape that contemporary experiences of illness can be understood.

Reading illness through this lens foregrounds how biopower intersects with bio-geographical disruption. Illness is therefore not simply an embodied condition. Rather, it

[19] While Foucault's own writing does not explicitly theorise 'responsibilisation' in neoliberal terms, this concept has been developed most fully by later Foucauldian scholars. I hence trace continuities between disciplinary power, panopticism and contemporary responsibilisation as an analytical move rather than a claim made directly by Foucault himself.

[20] Foucault draws on the example of Mettray, a nineteenth-century reformatory, to show how surveillance is internalised. Rather than relying on constant external control, individuals regulate their own behaviour through everyday self-surveillance (Foucault, 1995).

is mediated through institutional practices and socio-spatial arrangements that determine whose experience is recognised, legitimised or rendered invisible (Dyck, 1995). These dynamics become particularly salient when considered alongside Bury's (1982) third rupture — the mobilisation of cognitive and material resources, or more specifically, medical and personal knowledge. Here, biopolitics operates less through stark distinctions of who is 'made to live' or 'let die' (Foucault, 1978), and more through everyday judgements about who is deemed deserving of care, legitimacy and support. In the face of illness and uncertainty, individuals typically turn to clinicians for knowledge, diagnosis and explanatory frameworks that can help stabilise the chaos of illness, yet this is furthermore shaped by the biopolitical conditions that governs whose narratives of illness are validated and whose remain marginal.

The framework of neoliberal governance and the associated responsibilisation of the 'biological citizen' hence provides the most instructive analytical lens for this thesis. Rose and Novas (2005) describe 'biological citizenship' as a state in which individuals must articulate and evidence their biological condition to make claims for recognition, care and social legitimacy. Diagnosis here functions not only as a clinical label but as an institutional credential that confers legitimacy and grants access to support (Philo, 2000). Rose (2007) frames this as part of a broader reconfiguration of health governance in which individuals not only make claims for legitimacy, but are also encouraged to manage, optimise and govern their bodies 'responsibly'. This marks a shift from state-centred health provision towards more individualised, consumer-oriented modes of self-management (Parr, 2002b). Building on Rose, Greenhough (2011) stresses that biological citizenship is spatially produced through everyday encounters with institutions, technologies and discourses. In Western neoliberal contexts, individuals are incentivised to manage their own care, but this ostensible 'autonomy', however, is highly conditional. Greenhough (2011, p.156) describes these expectations as forms of "biological governance," whereby individuals are encouraged to self-manage, monitor and optimise their health, but only in ways that align with institutionalised biomedical norms. To be recognised as a 'good biological citizen', individuals must behave within the prescribed institutional boundaries. Those whose knowledge, practices or illnesses fall outside biomedical norms risk being dismissed or effectively abandoned by the medical system, hence exposing the limits of agency within neoliberal 'responsibilisation'.

By placing Bury's account of biographical rupture in dialogue with geographical analyses of biopolitics and biological citizenship, I argue that the third rupture is not merely experiential but fundamentally biopolitically charged. In the case of emergent or elusive illnesses such as Long Covid, medical resources are incoherent, unstable or unavailable and, therefore, cannot be easily mobilised. When diagnostic criteria are ambiguous, treatment pathways unclear and clinical expertise inconsistent, biomedical institutions may intensify, rather than relieve, disruption by failing to provide recognition, meaningful support and guidance (see Chapter 4). In such contexts, individuals are *compelled* to develop their own bodies of knowledge: piecing together fragments of biomedical information, experimenting with self-management strategies (see Chapters 5 and 7) and seeking out alternative forms of validation and expertise – particularly online (see Chapter 7). Here, a paradox emerges. While individuals are effectively made responsible for navigating their illness alone, the alternative knowledges and practices they develop are often viewed with suspicion by biomedical authorities, and may even be framed as irresponsible or illegitimate. Responsibilisation in this context is therefore not empowering; it is *imposed*, arising from institutional absence rather than choice. Responsibilisation is thus deeply political, revealing how biomedical authority determines who is recognised as a legitimate patient and who is left to navigate illness alone, and therefore systemically invisibilised (see Chapter 6). In the context of biomedical and social neglect, I therefore explore how individuals living with Long Covid turn to online spaces as both a medical resource and biosocial community, as crucial epistemic spaces in which knowledge is exchanged, and care and legitimacy is negotiated outside conventional medical frameworks.

2.4.4 (Re)conceptualising 'suffering'

Western evidence-based medicine (EBM) emerged from a historical shift in the late nineteenth century from individualised understandings of disease — grounded in biography, heredity, physiology and the body's relationship with its environment (or miasmas) — to the development of germ theory, centring the microbial pathology of disease (Gaynes, 2023). Germ theory provided the scientific foundation for Western EBM, treating disease as a material and objective entity discoverable through scientific endeavour (Singer, 2004). Within this framework, there exists a hierarchy wherein scientific objectivity supersedes subjective lived experience. This division produces epistemic and embodied tensions, particularly for individuals with conditions that lack

identifiable biological markers. As highlighted in Dumes' (2020, p.6) anthropological work on chronic Lyme disease, patients with contested illnesses engage in ongoing "boundary work" between what is recognised as scientific and non-scientific, navigating the dissonance between subjective symptoms and absence of objective signs (or 'biomarkers'). Falling on the 'wrong' side of this boundary can render patients not only illegible but 'irresponsible' or non-compliant within dominant biomedical logics. These dynamics closely parallel the experiences of people living with Long Covid as another biologically rooted, contested chronic condition that exposes the epistemic limits and normative assumptions of Western EBM.

These dynamics also resonate with broader critiques of how Western medicine interprets and manages chronic suffering. In the conclusion of his essay, Bury (1982) argues that key characteristics of chronic illness, such as pain and suffering, require further elaboration. The etymology of "pain" itself reflects a deep moral and historical dimension: derived from the Latin *poena* ("penalty") and the Old French *peine* ("suffering"), pain in Middle English came to signify "suffering inflicted as punishment for an offence." Pain, therefore, has long carried connotations of transgression and consequence. Elaine Scarry (1985, p.53) captures this duality, explaining that, although pain is "indisputably real to the sufferer," it remains "unreal to others" unless made visible through bodily damage or diagnostic labels. Pain's elusiveness, Scarry (1985, pp.13–14) argues, lies in its resistance to language: "to have great pain is to have certainty; to hear that another person has pain is to have doubt". This doubt, often reproduced within biomedical settings where patients' narratives are perceived as unreliable, produces a secondary form of suffering — what might be understood as the social equivalent of physical pain.

Building on this, Dumes (2020) proposes that invisible and contested chronic illnesses generate somatically diverse experiences characterised by both physical and social suffering, where "being doubted" becomes a defining feature of divided embodiment. When the epistemic — how patients and physicians "do" disease (Mol, 2002) — and embodied dimensions of illness come into tension, the resulting disputes over biological legitimacy can amplify suffering beyond the body. Doubt from clinicians, family or wider society may erode not only the credibility of symptoms but also the individual's sense of self (Charmaz, 1983; Cheston et al., 2025). This engagement, first suggested by Bury and brought into sharper focus by Dumes, underscores the

urgent need for a paradigm shift in Western medicine, away from the linear “germ causes disease, body overcomes disease” model (O’Rourke, 2022, p.43) and toward more holistic, relational understandings of chronic illness. Such a perspective foregrounds the invisibility of elusive illnesses and compels us to reconsider what suffering looks like on the body, and what it sounds like in patient testimony. As Dumes (2020, p.155) puts it, there is a paradox in “looking fine” yet “feeling unwell,” a reminder that suffering is an embodied negotiation between visibility and invisibility. This negotiation is the central thematic of Chapter 6.

Within this re-framing, Dumes (2020) further argues that we must move beyond linear biomedical narratives of ‘cure’ and ‘mortality’ towards ‘healing’ and ‘morbidity’ – connoting chronicity and endurance – by reconceptualising suffering and survival through a qualitative lens. This necessitates rethinking what it means to *live* with illness, rather than simply to overcome it. The philosophical groundwork for such rethinking can be traced to Canguilhem and Nietzsche, who both reject standardised notions of “normal” health. Medical philosopher and historian, Canguilhem (1991), identifies two interpretations of normality: the first, a quantitative model in which disease is considered a deviation from statistical norms; the second, a qualitative, relational model in which health is defined by an organism’s capacity to adapt to its environment. Critiquing the former view of normality, Canguilhem (1991, p.186) argues that “disease is not a variation on the dimension of health; it is a new dimension of life”, another way of phenomenologically *being* in the world. Health, he argues, is “the possibility of tolerating infractions of the habitual norm and instituting new norms in new situations [...] health is a way of tackling *existence*” (Canguilhem, 1991, pp.197–201, emphasis added). It is, therefore, a creative adaptation to disruption rather than a return to equilibrium. In this sense, Canguilhem argues that we should express such differences in nature and health qualitatively “because we are not comparing like with like” (Philo, 2007, p.86).

Nietzsche (2001, p.177) articulates a similar position, insisting that “there is no health as such,” for what health means depends on one’s “goals, energies, drives and ideals ... there are innumerable healths of the body.” Health, in this sense, is plural, contextual and deeply subjective. From these perspectives, health and illness are not merely individual or fixed, but relational states negotiated through the individual’s capacity to reorient within specific temporal and spatial circumstances — to adapt,

endure and redefine meaning within shifting conditions of embodiment. This conceptualisation resonates with the notions of bio-geo-graphical disruption and flow, where the boundaries between body, self and environment are continually reconstituted. Just as Meijering et al. (2017, 2019) demonstrate that disruption and flow can oscillate across different places and relationships, Canguilhem and Nietzsche remind us that health and suffering is not merely located *in* the body, but rather lived through dynamic spatial, temporal and, as I foreground in this thesis and particularly revisit in my final conclusion, *energy* relations.

Echoing Canguilhem and Nietzsche, Dumes (2020, p.111) takes direct influence from the anthropologist and sociologist, Fassin, and the philosopher, Derrida, to suggest that suffering should not be measured in relation to others but rather according to individual potential — relative to "the most intense life possible." Reconceptualising suffering in this way demands that we also rethink survival. Biomedicine positions survival as an endpoint — statistically measured and temporally bounded – yet chronic illness reveals survival as an ongoing, qualitative practice of *living with*, extending metrics of survival beyond 'cure' and 'mortality', to consider 'healing' and 'morbidity' in terms of *qual*-ity of life (Dumes, 2020). In Dumes' (2020) ethnography, participants became students of their own bodies in response to medical doubt, learning to "enact" (Mol, 2002) their illness through experimental self-care, alternative therapies and everyday health routines, to create "the most intense life possible." Rather than simply *having* a body, healing is about *knowing* your body. Healing, in this sense, is not synonymous with curing but with cultivating embodied knowledge in relation to its environment – physical, social and even digital. It is an ongoing process of negotiating bio-geo-graphical flow, as individuals reclaim agency within spaces of exclusion and disbelief.

For individuals living with Long Covid, these negotiations are particularly pronounced. The condition's variable nature, often invisible symptoms and contested legitimacy continually unsettle the body, biographies and everyday geographies. Individuals must adapt to disrupted routines, fluctuating capacities and reconfigured relationships with work, home and social space — each reorientation a small act of survival within an uncertain terrain. My approach to Long Covid thereby seeks to understand how suffering is lived through bio-geo-graphical disruption: where illness reconfigures bodily capacities, redraws the boundaries of the self, and transforms the spatial and

social rhythms through which everyday life unfolds. Accordingly, shifting emphasis from mortality to morbidity, from the *end of life* to the *compromised life*, aligns with the broader argument of this thesis: that chronic illness experiences must be understood through their qualitative, relational and spatio-temporal dimensions. By situating suffering and survival within the framework of bio-geo-graphical disruption, this project takes the interplay of physical, emotional and social suffering seriously; the individual's bodily capacity to endure and adapt; and the relational, socio-spatial negotiations, often in the horizon of an unsympathetic biopolitical regulation, that shape everyday survival.

2.5 The affective geographies of Long Covid

Although affect has been variously conceptualised across human geography – through emotional, feminist and psychoanalytical perspectives, to name a few – the strand most pertinent to this thesis arises from Thrift's (2004, p.62) provocation: "to affect or be affected." This statement captures an ontological shift within human geography that underpins non-representational theory (NRT). Drawing on Spinoza and Deleuze, Thrift's NRT moves beyond the linguistic and symbolic focus that once dominated cultural geography, emphasising instead the pre-cognitive, sensuous and embodied ways in which the world is felt, lived and known. Central to NRT is the idea that affect precedes emotion or sentiment. In this context, affect refers to the collective, relational capacity of bodies to affect and be affected — circulating between people, spaces and objects as sensed, non-verbal and pre-conscious intensities — whereas emotion denotes the more individualised, reflexive experience that can be recognised, named and articulated (Pile, 2010). In the Spinozan-Deleuzian sense, to affect or to be affected is to recognise that space is relational and dynamic, continuously produced through the exchange of sensations, intensities and energies circulating between human and non-human bodies before crystallising into feeling or meaning (Massumi, 2002). In this sense, NRT is less concerned with what space means but with what it *does* – its very capacity to act and to be acted upon – centring the spatial relations that take shape through forces that are felt before they are known. For this thesis, affect provides a conceptual framework for understanding Long Covid as an embodied and energy-limiting condition. Living with Long Covid entails fluctuating energy states of vitality, fatigue and symptom exacerbation, where bodily *capacities* shift unpredictably and the boundaries between wellness and illness blur. The Deleuzian

(1988) question, “what can a (chronically ill) body do?” (Bissell, 2009, p.919), becomes central here: not simply what the body *is*, but what it can *become*[21] within its socio-spatial environment. Affect thus offers a vocabulary for understanding how these capacities are felt, negotiated and reassembled in everyday life.

2.5.1 Non-representational geographies of health

Focusing on movement, performance and practice, Thrift (1997, p.92) calls for an attentiveness to the “practical rather than cognitive,” to those fleeting embodied and experiential affects that exceed representation yet structure how life unfolds. This shift towards the lively, sensuous and atmospheric has since animated a wide range of geographical scholarship, drawing attention to how affective forces circulate between bodies and shape space and subjectivity beyond conscious articulation. In this sense, what is sometimes described as ‘affective atmospheres’ refers not only metaphorically to a shared mood or tone, but materially to how embodied signals — such as gestures, glances, pauses or tones of voice — move between bodies and condition how spaces are felt and inhabited (Anderson, 2009). Thrift’s emphasis on process and performance underscores how everyday life unfolds through rhythms and flows of affective force rather than through static representation.

This sensitivity to the relational capacities of bodies not only enriches understandings of everyday spaces but also opens productive avenues for health geographies. While health geographers have long engaged with phenomenological, embodied and experiential approaches to understand health, illness and care as lived and relational processes, NRT offers a distinctive affective orientation for attending to how health and illness are continuously produced through relations between bodies, environments and care practices beyond representational or fixed accounts (Lea, 2018). While health geographers have long examined the spatial dimensions of care, embodiment and wellbeing, explicit engagement with NRT has been comparatively recent (Andrews et al., 2014; Kearns, 2014; Hanlon, 2014; Andrews, 2018). Doel and Segrott (2003) were among the first to suggest that health geography might benefit

[21] This emphasis on bodily capacity resonates, albeit within a different conceptual horizon, with Canguilhem’s (1989) understanding of health not as a fixed norm but as the capacity to establish new norms in response to changing bodily and environmental conditions. While Canguilhem’s work is grounded in medical philosophy rather than affect theory, both approaches foreground bodily variability, adaptability and becoming, and therefore offer complementary lenses for this thesis, which is concerned with the embodied and affective dimensions of chronic illness.

from a non-representational vocabulary, one capable of opening up foundational concepts such as health, illness, body and place. In doing so, they reposition the body not as an object of biomedical scrutiny but as a site of unfolding relations and capacities.

Andrews et al. (2014, p.213) advance this agenda by conceptualising wellbeing, not as a fixed psychological state, but as something that arises through encounters. For them, wellbeing emerges from interactions between human and non-human bodies as "an energy and intensity ... and is experienced as a feeling state." Rather than being inherent to individuals or environments, wellbeing materialises within an affective atmosphere of everyday socio-spatialities. This shift challenges the idea of wellbeing as a personal possession, instead emphasising its relationality to everyday encounters. Kearns (2014) cautions that such a focus on wellbeing can risk eclipsing the realities of pain, constraint and suffering that characterise much of the lived ill-health and disability experience, but agrees that NRT holds the potential to re-orient embodiment, moving beyond deterministic models of wellbeing and showing how material assemblages shape health experiences. Hanlon (2014) echoes this, contending that NRT has the capacity to capture the "more-than-rational" registers of health — the affective, emotional and material entanglements through which life is sustained. Furthermore, Andrews et al. (2014) identify key conceptual characteristics of NRT – including onflow, relational materialism, transpersonal sensation, vitality and wonderment – that together highlight both the liveliness of the world and how wellbeing emerges through ordinary, embodied routines. Bringing together NRT and geographies of disability, Hall and Wilton (2017, p.729) use affect to challenge assumptions about the 'able body', showing that disability is produced through everyday "relational connections between heterogeneous bodies, objects and environments," rather than through opposition to a normative ideal. They draw attention to the diversity of bodily capacities, highlighting differences in "sensory activities, cognitive abilities, mental states, illnesses, injuries and other differences" (Hall and Wilton, 2017, p.736) to suggest that *all* bodies can be dis/abled by their everyday geographies. Through this affective lens, dis/ability becomes something constantly made and remade in the ordinary rhythms of social and spatial life.

Collectively, this epistemological reframing brings a particular sensitivity to rhythms, assemblages and capacity through which health and illness are continuously produced

(Lea, 2018). From this perspective, the body is neither a pre-given biological entity nor a mere vessel of experience, but a relational node within complex assemblages of human and non-human relations. Kearns (2014) thus suggests that, learning from NRT, embodiment can be understood as a connective field that comes into being through its relations with others. This builds upon Dewsbury's (2000, p.485) proposal that the body be approached as a *subject* rather than as a passive *object of* knowledge, so that the "biological flows of energy, matter and stimulating chemical fluids," are incorporated into our understanding. This orientation invites attention to bodily knowledges — habitual, intuitive and energetic understandings – that resist standardisation yet are fundamental to how health is lived. This non-representational framing is particularly instructive for my thesis in foregrounding affect, corporeality and bodily capacity, particularly through the Deleuzian question, "what can a body *do*?" Although, I also argue that for people living with Long Covid, bodily potential is often limited, unstable and uneven, meaning that what a body can do is frequently constrained.

2.5.2 New energy geographies

Directly relevant to the non-representational orientation of this thesis is the conceptualisation of "new energy geographies" (Philo et al., 2015), which discerns forms of bodily knowledge that do not align neatly with the non- or pre-cognitive, instead tracing those that circulate as relational energies. This perspective offers a pivot from "old" energy geography, traditionally focused on the spatial distribution, production and consumption of inanimate energy sources such as wind, solar or hydraulic power, toward attention to the vital, affective and emotional energies animating everyday life. In this reframing, energy is not merely material or economic but rather a relational force flowing through and between bodies, places and practices.

New energy geographies thus foreground the animate intensities underpinning human experience: flows of vitality, depletion, exhaustion and renewal that shape how people move through the world. In this conceptual framework, Philo et al (2015) conceive the body as an open system, continuously traversed by palpable energies that flow in, around and through the relational exchanges of people, places and objects. Rather than treating health as a mere objective physiological state, new energy geographies draw attention to the felt and non-quantifiable qualities of energy as they are subjectively perceived, registered and then managed in everyday life. As Philo et al.

(2015) acknowledge, energy is ambiguous, often sitting at the edges of what is deemed empirically or scientifically credible. Yet, this ambiguity offers an affective lens to rethink health beyond pathology and mortality towards alternative perspectives on healing and morbidity. For this thesis, such an approach opens up a more holistic understanding of health and wellbeing, encompassing physical, emotional, psychological and spiritual dimensions, tied up with individuals learning to live *with* Long Covid.

In this context, everyday energy geographies provide a valuable conceptual lens for examining how participants living with Long Covid manage and reconfigure their energy-limited bodies. The fluctuating and unpredictable symptom intensities described in later chapters, particularly in relation to fatigue and brain fog, speak directly to this energetic sensibility: how energy is experienced through embodied knowledge and consequently managed, depleted, restored and shared across everyday spatial and temporal rhythms. While energy is not always addressed explicitly in each empirical chapter, it nonetheless runs alongside the analysis as a connective thread, shaping participants' capacities, choices and relations. Attending to these lived energy flows extends the non-representational focus of this thesis, casting the lived experience of Long Covid as an ongoing energetic negotiation of being and becoming in the world rather than a static condition, or to simply 'be' in the world. It is through pulling these threads together that energy comes to assume a more central analytical role in the concluding synthesis of the thesis.

2.5.3 Anticipatory geographies

Anderson's (2010a) affective concept, 'anticipatory geographies', is also particularly instructive for this thesis. Anderson shifts discussions of affect towards *temporality*, exploring how futures are sensed, embodied and acted upon in the present. Anticipation involves an attunement to the felt potential of what may come. Anderson identifies three subtly different forms of anticipatory logic – pre-emption, precaution, and preparedness – that guide present action in response to imagined futures: pre-emptive and precautionary actions aim to prevent future occurrences, whereas preparedness attends to the aftermath of what does occur. Anderson's framing is situated on a macro-scale, examining the geopolitical context of anticipated threats to liberal democracy, illuminating how states, institutions and systems mobilise the future in the present through anticipatory logics as modes of governance. These logics

legitimise intervention in the “here and now” in reference to imagined futures (Anderson, 2010a, p.778). At this level, Anderson’s work foregrounds how anticipation becomes embedded within technologies of power and infrastructures of security to manage populations and environments. This macro-scale orientation has informed geographical analyses of anticipatory governance across domains such as national security (Anderson, 2010b), disaster preparedness (Adey and Anderson, 2012) and artificial intelligence and urban governance (Xu et al., 2025).

Subsequent scholarship has extended these insights into more situated and embodied contexts, tracing how anticipatory logics materialise within the micro-scale rhythms of everyday life. Health studies, in particular, have been attentive to how anticipation is lived, performed and felt through the body. Locock et al. (2016) identify how sensory cues in medical settings (sounds, spaces, diagnostic technologies) evoke affective anticipations — unease, anxiety, or resignation — long before clinical outcomes are known, while Parker and Pausé (2018) explore how biomedical discourses of preparedness shape the governance of pregnant bodies. Within health geography more specifically, Evans (2010) highlights how anticipatory rationalities underpin public health interventions for obesity prevention, where risk is projected into the future and inscribed into everyday practices of self-care.

Drawing on intimate experiential accounts of epilepsy, social anxiety and eating disorders, respectively, Smith (2013), Boyle (2019a) and I (2024), in research separate from my thesis, extend existing scholarship by foregrounding the affective and embodied qualities of anticipation, providing key insights for this thesis. While situating the epileptic body within a broader biopolitical framework, Smith’s analysis of epilepsy emphasises how anticipatory experiences shape both the social and spatial worlds of those affected. He illustrates that seizures themselves are unknowable to the individual during the event, becoming perceptible only beforehand through anticipation or ‘aura’, and afterwards as awareness gradually returns. Importantly, Smith’s participants were less concerned with preventing seizures (through pre-emption and precaution) than with preparedness – mitigating the spatial consequences of an event, such as injury, through careful management of material surroundings. The unpredictability of the epileptic body resonates strongly with the time-space-body uncertainties experienced by people with Long Covid. Just as seizure risk is managed through mapping safe time-spaces, individuals with Long Covid negotiate fluctuating

symptoms and energy levels, making it difficult to plan, be present or take part in everyday activities and routines (see Chapter 5).

Boyle (2019a) highlights that Anderson's anticipatory logics assume coherence, whereas in social anxiety, the future is often experienced as incoherent, destabilising and fraught with uncertainty. Boyle demonstrates that for individuals with social anxiety, anticipation is deeply relational and embodied, unfolding through the social and spatial worlds as people re-experience past events, rehearse for imagined futures and adjust routines in response to perceived threats, shaping both bodily sensations (palpitations, sweating) and social behaviours (withdrawal). This iterative process continuously rewrites how time, space and social interactions are navigated, producing a pervasive sense of instability that underpins anxious geographies. Like people with social anxiety, individuals with Long Covid draw on embodied knowledge to manage uncertainty, structuring daily routines, pacing activities and prioritising tasks to mitigate the impact of unpredictable symptoms (see Chapter 5). Feather (2024) similarly notes that during the COVID-19 pandemic, women with eating disorders experienced distress when the lockdown predictability of routines was disrupted and restrictions eased, illustrating how carefully structured routines can be destabilised by broader, uncontrollable changes. In both cases, even with embodied knowledge and meticulous planning, time-space and embodied futures remain inherently uncertain and fractured, disclosing the limits of anticipatory logics and the constant need to adapt to shifting social, temporal and bodily conditions. At this experiential level, anticipation is not necessarily a coherent logic, but a lived affective condition: felt, embodied and often unpredictably messy. Together, Boyle and Feather contend that the future is something not only imagined or regulated but also felt as a tension, unease or threat that shapes the present, affecting bodily states and how individuals living with social anxiety or Long Covid navigate social and spatial engagement.

2.5.4 Chronic Pain

Linking back to earlier remarks about pain, its experience and expression, Bissell (2009, 2010), drawing reflexively on his own embodied experience, demonstrates how chronic pain reconfigures the body's spatial and temporal capacities. Rather than locating pain solely within the corporeal self, he conceptualises it as a relational intensity that ebbs and flows through embodied experience. In contrast to transient pain, which is diagnostic, predictable and indicative of repair, Bissell (2009, p.911)

suggests that chronic pain “territorialises” the body in a state of uncertainty. Chronic pain disrupts predictable trajectories of embodiment, narrowing anticipatory potential and rendering the future uncertain; and yet, as Bissell (2010) argues, in acknowledging such unpredictability, there lies capacity for change.

To conceptualise these uncertain, fluctuating and non-linear qualities of chronic pain, Bissell (2009, 2010) adopts an affective ontology of “intensity.” Intensity describes the non-representational forces or sensations that can either enhance or deplete life, tracing how bodily experiences shift between heightened and diminished states. Within this framework, chronic pain emerges as an affective force that simultaneously constrains and enables new possibilities for being, revealing bodily capacities *to affect and be affected*. This is crucial in understanding the affective dynamics of chronic illness more broadly.

Here, it is important to clarify how this thesis analytically mobilises chronic “pain” in relation to Long Covid, particularly in Chapter 5. While Long Covid is frequently characterised by experiences of pain — including musculoskeletal pain, migraines and headaches — it is also marked by profound exhaustion, cognitive impairment and post-exertional symptom exacerbation, which are not always described as “pain.” Crucially, these experiences vary widely between participants as Long Covid does not impact any two bodies in the same way, and the intensity, form and persistence of symptoms fluctuates both between individuals and within individuals over time. I therefore distinguish between the obdurate realities of chronic pain and the obdurate realities of living with a severe, fluctuating ELC, while recognising that these experiences often coalesce in everyday life. In line with my earlier conceptualisation of suffering, and drawing on the etymological roots of pain, this thesis recognises pain as encompassing corporeal, cognitive and affective dimensions, rather than a discrete bodily sensation. Accordingly, I use the term “pain” more broadly to capture the intensity of individuals’ symptom experiences at a given moment, as lived and communicated by participants.

Like other emerging post-viral conditions, Long Covid exemplifies Bissell’s (2009, p.911) characterisation of the “obdurate” nature and unpredictable temporality of chronic pain. Although rooted in a known biological source (SARS-CoV-2), manifestations of Long Covid diverge radically from the acute infection, defying typical

understandings of recovery. Chronic pain, in this sense, is, as Bissell (2009, p.912) describes, “redundant,” lacking the reparative intentionality of transient pain and undermining conventional trajectories of cure and recovery. This remark further aligns with Bissell’s (2010, p.85) claim that the uncertain nature of chronic pain comprises an “embodied, involuntary and pre-cognitive affective condition” that contracts the body’s capacity to act, rendering both the present and future unstable, and is therefore central to understanding the experience of the body in pain.

Bissell (2009, p.920) adopts Deleuze and Guattari’s (1987) notion of “deterritorialisation” to trace how pain may be ‘decentred’ from the body through three embodied pain-management strategies – pacing, shaping and repositioning. In Chapter 5, I focus on the embodied practice of “pacing” as a mode of reconfiguring the relationship between the body, time and space, and extend Bissell’s ideas with reference to the widely circulated ‘three Ps principle’ – planning, pacing and prioritising – for Long Covid management, whereby participants renegotiate everyday time-space rhythms and routines to manage fluctuating symptom intensities through new forms of control and agency. While such practices do not eliminate pain, they reorient its relation to the body, rendering intensities more tolerable. In this process, participants shift from narratives of cure and recovery toward practices of healing and rehabilitation, reframing Long Covid as a condition to be lived with and regulated.

By bringing together Anderson’s work on anticipation and Bissell’s work on intensity, this thesis situates Long Covid management within a broader set of affective and temporal horizons. In the absence of clear clinical pathways, Anderson’s (2010) anticipatory logics — pre-emption, precaution and preparedness — illuminate how participants more-or-less deliberately use embodied knowledge to mobilise the future and act in the present. Meanwhile, Bissell’s (2009, 2010) notion of intensity helps to explain how these spatio-temporal adaptations manifest corporeally, given that shifting affective states can either energise or exhaust everyday life.

2.5.5 Brain fog

Bissell’s (2025) later work on what has increasingly been termed ‘brain fog’ extends these ideas into the cognitive domain, framing cognitive impairment as an affective and spatial condition. Describing sensations of slowness, disorientation and an inability to hold a thought, where “memories enter a shredder rather than a shelf,”

Bissell (2025, p.1) reveals how brain fog manifests as an altered mode of being in and with the world, what he terms a “geography of being out of it.” Brain fog foregrounds moments when the body’s relation to space and time becomes unsettled, when thought loses its grip, and the self becomes estranged from its own capacities. As such, rather than interpreting these sensations as dysfunctions, he treats them as reconfigurations of relational life; moments when normative temporalities of attention and productivity are interrupted. As such, brain fog exposes the cultural valorisation of speed, clarity and cognitive control that underpins neoliberal subjectivity — conditions that Bissell reflexively describes as having intensified under the ‘work-from-home’ ethos of lockdown.

Responding to Bissell’s provocation, Parr (2025) attends to Bissell’s call to think *with* brain fog within the realm of mental (ill) health and seasonal affective disorder (SAD). Drawing on her earlier work on the embodied time-spaces of delusion (Parr, 1999), she foregrounds disrupted embodied experiences and blurred affective states of ‘dislocation’ from the self, positioning brain fog within these “foggy in-between[s]” (Parr, 2025, p.2). Parr further suggests situating such affective disorientations within everyday experiences of menopause, addiction, exhaustion and stress, thereby broadening the terrain of foggy geographies. In the context of her more recent research on living with SAD (Bodden et al., 2024a, 2024b), she highlights the seasonal and temporal dimensions of brain fog, typified by how the winter months may compel withdrawal into familiar spaces when feeling ‘out of it’. In doing so, Parr advocates for empathy, solidarity and a practical geography of recognising the suffering associated with brain fog. Together, Bissell and Parr conceptualise brain fog not as mere cognitive dysfunction but as an affective and spatial reconfiguration of relational life. In contrast to accounts that foreground brain fog primarily as a symptom, I show that for individuals living with Long Covid, brain fog also functions as an anticipatory register, signalling the body’s energy limits and potential. I show how brain fog is actively learned, monitored and negotiated over time, becoming a practical means through which individuals attempt to manage and mitigate symptom exacerbation and navigate everyday life under conditions of chronicity, energy limitation and uncertainty.

Bringing these strands together — energy flows, anticipatory logics and affective intensities — collectively illuminates the lived experience of Long Covid. Thrift’s insistence on practice and movement, picked up by Andrews, underscores that health

unfolds through the micro-routines and rhythms of everyday life. Anderson's anticipatory geographies remind us that health is not only experienced in the present but is continually shaped by the affective attunement to what lies ahead. Bissell's affective accounts of chronic pain and brain fog discern that illness is a site of *becoming*, where the body's energetic limits and possibilities are constantly being redrawn. Long Covid bodies are thus continually negotiating capacity, managing uncertainty and adapting relationally to spatial, temporal and social rhythms. Chronic illness is therefore understood not as a fixed state but as an ongoing, affectively mediated process, in which bodies, spaces and energies are entwined and continually reconfigured. Taken together, this conceptual synthesis offers an affective framework through which to explore the embodied, temporal and relational dimensions of chronic illness — the shifting ways in which bodies can affect and are affected.

2.6 Towards a geography of Long Covid

I develop an everyday social geography of living with Long Covid by conceptualising it as an ELC that reshapes bodily capacities, affective relations and spatial practices across everyday life. The growing social science literature has documented the lived, epistemic and political dimensions of Long Covid, showing how the condition produces profound biographical disruptions in individuals' life courses as they confront debilitating symptoms and an uncertain illness trajectory. Research has also highlighted the mental health consequences of this disruption, as well as the institutional and societal neglect experienced by those living with Long Covid amid broader pressures to 'move on' from the pandemic (Burton et al., 2022; Kennelly et al., 2023). Such dynamics contribute to persistent issues of institutional abandonment, social isolation and invisibility (Lupton, 2025). While many of these social challenges — particularly those concerning identity, belonging and the indeterminate question of how 'long' Long Covid lasts — address the temporal aspects of the condition, its spatial dimensions remain largely unexplored. The perhaps surprising absence of Long Covid in recent geographical texts including, *Pandemic Geographies* (2021) and *Health Geographies and the COVID-19 Pandemic* (Digby and Gatrell, 2022), illustrates this gap in scholarship, fuelled perhaps by the aforementioned societal desire to move beyond the collective trauma pandemic, leaving those with lingering illness behind. Accordingly, I frame Long Covid as an ELC, an embodied state that profoundly shapes bodily capacities, and I adopt the concept of bio-geo-graphical disruption to capture

how the energy-limited Long Covid body unsettles not only individuals' biographical trajectories but also their spatial relations, routines and orientations in everyday life.

Through an affective lens, moreover, I illuminate how individuals learn to live with Long Covid, drawing on embodied knowledge and affectively forecasting within the spatio-temporal 'three Ps principle' – planning, pacing, prioritising – as a crucial energy management strategy. Further building on prior inquiries into the social geographies of chronic illness, I attempt to uncover the hidden geographies of Long Covid, complicating its invisibility by showing how it is produced and reinforced both socially and spatially through clinical uncertainty, institutional neglect and the marginalisation of those whose illness does not fit dominant spatial-temporal norms of recovery. Finally, I extend this affective lens to online spaces, considering the nuances of digital environments as sites of knowledge exchange and community support, examining how digital environments mediate feelings of (in)validation, (in)visibility and solidarity while simultaneously shaping the spatial, emotional and energy contours of living with Long Covid. Through this geographic lens, I therefore interrogate how Long Covid is experienced, navigated and governed across everyday spaces, connecting individual embodiment with broader institutional, political and social structures that impact exactly who is seen, heard and believed. Through these routes, grounded in the above literature, I work towards an everyday social geography of living with Long Covid, developed through the empirically focused chapters that follow the subsequent methodological account.

Chapter 3: Researching Long Covid

3.1 Introduction

As demonstrated in the preceding chapter, Long Covid is a condition that cannot be adequately understood through biomedical or epidemiological frameworks alone, underscoring the importance of qualitative research in capturing the heterogeneous, complex and often contested everyday lived experiences of Long Covid. Building directly on this literature, this research was organised into two stages: first, individual interviews with people who identified as having, or having had, Long Covid; and second, focus group interviews with returning participants. This two-stage design enabled a dialogue between individual and collective accounts, allowing themes emerging from one-to-one interviews to be explored, negotiated and elaborated through shared discussion.

This chapter outlines the methodological approach adopted to research the everyday social geographies of Long Covid as an energy-limiting, embodied and relational condition. As discussed in Chapter 2, energy geographies form a central analytical lens within this thesis, which also holds methodological significance. For people living with Long Covid, participation in research itself requires the careful management of limited and fluctuating energy. Time, pace and capacity were therefore both ethical and methodological considerations throughout the research. Accordingly, participants were placed at the core of the research design, with particular attention paid to their voices, health and wellbeing. In response, I sought to adopt a participant-led approach, allowing individuals to guide the direction, pacing and depth of discussion alongside, while also enabling the research process to evolve through participant feedback.

The chapter proceeds by outlining my reflexive positionality as a non-disabled researcher before detailing recruitment strategies, data collection methods and analytical approaches. In doing so, it provides the methodological foundation for the empirical chapters that follow, which together advance an everyday social geography of living with Long Covid — one attentive to energy, embodiment and the collective conditions through which illness is experienced, negotiated and made meaningful.

3.2 Researcher vulnerability: control

Throughout the research process, I often felt overwhelmed by the need for control over my research and my data – which I elaborate in discussion around data analysis. From the beginning, I recognised this research is characterised by uncertainty, heterogeneity and therefore, complexity, which at times was overwhelming and perplexing. I wanted to know my participants, and their individual stories, in as much detail as I possibly could, to the extent that I even stressed over their pseudonyms: "do they look/sound like an Alexandra?" When I thought of quotes to embed in the empirics, I followed their voice to the transcript to where I could find it. I acknowledge it is not a realistic expectation to know the depths and details of 26 participants' different stories, but for me, it is my way of really getting to know my data as I feel it is within my integrity as a researcher to represent participant's stories justly. I felt overwhelmed by the diversity of experiences, as Long Covid is formidably variable across spatial, temporal and social scales – from person to person, place to place, day to day. I found myself questioning, how do I compare one experience with another? However, Gillespie (2023) reminded me that individual experience is relative and that parallels can be found through the collective. Similarly to Gillespie's work on embodied facial difference, the relative, individual and collective experience will be threaded throughout this thesis.

3.3 Reflexivity in (health) research

Reflexivity plays a crucial role in ensuring that health research is ethically sound and that the methodologies used are inclusive, critical and accessible. Feminist reflexive (Kohl and McCutcheon, 2015) practice challenges the researcher's interpretative authority by stressing the importance of understanding how a researcher's positionality influences their interactions with participants and shapes knowledge production. A feminist perspective recognises that knowledge is always situated and partial, inevitably impacted by the dynamics between the researcher and the researched (Haraway, 1988; Rose, 1997; Bondi, 2009). Furthermore, feminist reflexive practices highlight the significance of understanding how multiple intersecting identities — such as gender, race, socio-economic status, (dis)ability — affect the researcher-research relationship and shape the ways in which knowledge is collected, interpreted and produced (Madge, 1993). Rose (1997) argues that these positions occupied by the researchers and researched are intrinsically fluid and, to some extent, unknowable,

which complicates transparency in reflexivity. Acknowledging this limitation, however, can open up space for more nuanced insights into the research process

Wolch and Philo (2000, p.149) warn against becoming overly self-aware, where the researcher may become “paralytically self-reflexive.” Lynch (2000, p.47) also cautions against “confessional modes of self-reflection” that can inadvertently reinforce objectivity, rather than challenge it. While these critiques highlight the dangers of excessive self-focus, reflexivity also has the potential to challenge the dichotomy of subjective versus objective, encouraging researchers to embrace the ‘messiness’ of lived experiences (Parr, 1998). Reflexive practice can hence create a space for understanding both the conceptual and emotional dimensions of research, allowing for a more nuanced exploration of lived (health) experience (Harris et al., 2023).

I recognise that my position as a researcher *of* Long Covid, without having personally experienced the condition, presents challenges for reflection and representation, and requires sustained attention to reflexive practice. Ongoing self-awareness is crucial for maintaining researcher integrity from initial stages of research design to dissemination of findings (Berger, 2015). Reflexivity, in this context, is a tool for ensuring ethical conduct, especially when working with marginalised groups, such as those affected by Long Covid, who may have been previously dismissed or stigmatised. Reflexivity ensures that research does not perpetuate these harms, but instead fosters empowerment. However, reflexivity is not straightforward. As Mallon and Elliot (2019) note, there is a particular tension in re-telling others’ stories in health research; a tension compounded by feelings of guilt and responsibility to justly represent participants’ lived experiences. I resonate with this concern as participants trusted me with their deeply personal, emotional and, at times, distressing experiences, while sacrificing their limited energy to participate in an interview. And for many participants, not just once, but twice. For example, Alexandra shared that she cleared her entire week to participate in an hour-long interview:

> I had nothing yesterday, I had nothing on Wednesday, so that I could definitely keep this commitment … and I’ve kept my weekend free, just in case this ends up being too much for me. I’m very aware that this could be an hour or more of talking, and that comes with its own fatigue. There’s also the mental and emotional impact of it. I don’t know how I’ll respond to that.

Listening to accounts such as Alexandra's heightened my awareness of 'energy', not only as a central theme in participants' lives, but also as a reflexive concern within my own research practice. I was acutely conscious of the uneven energy capacities between myself and participants, particularly given the emotional labour involved in witnessing distress, worrying about participant wellbeing and the responsibility of holding and representing their voices with care. These interviews often generated my own health-related anxieties, as well as a sense of pressure to do justice to the significance of what participants were sharing. As a result, I had to be attentive to my own energy levels, deliberately building in time to pause, reflect and take breaks between interviews. This was especially important given that, in order to accommodate participants' fluctuating health and schedules, I was often conducting two or three interviews in a single day. Reflexive awareness of my own limits therefore became a necessary ethical practice, enabling me to remain emotionally present, attentive and respectful throughout the research process.

Furthermore, I am conscious of the potential for my research to be seen as an 'academic voyeurism,' where I risk objectifying the sensitive lived realities of participants for academic gain (Kitchin, 1999), especially as participants asked about my personal reasons for conducting this research, or about the potential impact of my research beyond academic output. At times, I felt guilty about how much I was giving 'back' to participants compared to what they were giving me (Ratnam, 2019), and continually questioned how to navigate the challenges of interpreting and presenting deeply sensitive lived experiences in a way that is fair, meaningful and ethically respectful.

However, many participants thanked me for giving them a voice; space and time to share their story. FG4[22] even discussed how participating gave them a sense of purpose:

> Alexandra: I feel quite positive. I feel the energy from the group, we're all trying to pass on information to Ellys that might help, well help *her* hopefully [laughs]. And I'm contributing. Today, I'm contributing something worthwhile.
>
> Group: Yeah.

[22] Throughout this thesis, I explicitly reference quotations from focus groups either directly or by the notation "FGX," where X denotes the focus group number. It can be assumed that all other quotations are from individual interviews.

> Arun: Yeah, we're feeling part of life again. We're seeing faces, we're seeing people. We're hearing, we're talking, we're doing things that we should not be doing, right? Which makes us feel worthy or, makes us feel valued in some way.
>
> Alexandra: Yeah, that's it.
>
> Arun: Even if it might be just to help Ellys so she can have a nice few extra letters after her name [laughs]. No, I'm joking, but yeah, honestly.

Arun's jovial remarks reminded me that participants were not naïve to the nature of the interview exchange and that giving their story, time and energy had its own value for them. Value is relative and I feel that, in this situation, I cannot easily compare the value of intrinsic voice and purpose with extrinsic academic research output. I would suggest, however, that this research was arguably more empowering than disempowering to participants.

These reflections also prompted me to consider more explicitly what it might mean to 'give back' beyond the research encounter itself. While the scope of this doctoral project is temporally limited, I am mindful of participants' interest in how their contributions might extend beyond academic output. Where possible, I intend to pursue dissemination routes that are accessible and meaningful, including peer-reviewed publications and the development of policy-relevant briefings drawing on connections established during my internship with the Scottish Government. Should such outputs be produced, these would be shared with relevant policy and advocacy networks and made available to participants who expressed an interest in receiving them. At the same time, I recognise that the capacity to undertake such impact-focused work is shaped by practical constraints, including time and financial resources. Acknowledging these limits is itself part of a reflexive and ethical research practice, while still affirming a commitment to extending the reach of participants' voices wherever feasible.

Reflexivity is not only a methodological tool, but an ongoing practice of self-awareness and engagement with researcher positionality and negotiating ethical responsibility to participants. As I reflect on my own role in researching Long Covid, I recognise the inherent 'messiness' of this process — of how fluid researcher-researched 'positions' are inevitably entangled within, and shape, knowledge production and ethical conduct. By acknowledging the complex interplay of power, responsibility and situational

vulnerability within the research process, reflexive practices work towards a fair and just representation of participants' lived experiences. While the tensions of interpreting and representing these experiences are real, reflexivity also offers opportunities to empower participants and foster transparency. Despite somewhat paralysing challenges, reflexivity remains an essential component of ethical research, particularly when navigating sensitive topics like Long Covid, where the emotional and physical toll on participants is significant. Albeit complex, this chapter outlines how I continuously and critically developed reflexive practices through adaptive research methods to chronic illness and disability, while maintaining a participant-led approach. In doing so, I aim to create a more nuanced and ethical exploration of the embodied lived realities of living with Long Covid.

3.4 Vulnerable populations

The concept of 'vulnerability' occupies a contested position within research ethics, particularly within health and social research. While vulnerability is often used to denote groups considered at heightened risk of harm through research participation, scholars have critiqued the term for being overly broad, vague or reductive when not applied critically (Schroeder and Gefenas, 2009). Some health researchers advocate, rather, for relational and contextual understandings of vulnerability, emphasising that it cannot be meaningfully defined in advance or abstracted from the specific circumstances of a research encounter (Luna, 2009; Bracken-Roche et al., 2017). From this perspective, vulnerability is better understood not as a fixed label but as layered, emergent and shaped by power relations between researcher and participant (von Benzon and van Blerk, 2017).

This research engages with participants living with Long Covid, a population that may be considered 'vulnerable' regarding their health condition, though not in a legal sense associated with an inability to provide informed consent – at increased risk of harm in certain research contexts, rather than inherently vulnerable. Through accessible, plain language information sheets and continuous written and verbal reminders of their right to withdraw from the research at any point, participants were fully able to understand the aims of the research and to make informed decisions about their participation. However, forms of vulnerability arose through overlapping and intersecting layers, including ongoing physical illness, cognitive impairment, emotional distress, experiences of medical dismissal, stigma and marginalisation across healthcare,

occupational and social structures. These dimensions of vulnerability were not uniform across participants, nor static over time, but emerged relationally throughout the research process.

Long Covid is characterised by uncertainty, fluctuating symptoms and limited institutional recognition, all of which can intensify feelings of precarity and exposure. Participants frequently described fatigue, brain fog, anxiety and emotional exhaustion, which shaped not only their everyday lives but also their capacity to participate in research. In this sense, vulnerability was closely bound up with questions of energy, capacity and timing. Recognising this, the research design sought to remain inclusive, flexible and responsive, allowing participants to choose interview timings, formats and pacing in ways that accommodated their health and energy levels.

Given the sensitive nature of participants' experiences, it was anticipated that interviews would involve emotional labour and potentially distressing reflections. Ethical approval was obtained through institutional review processes, with careful consideration given to issues of informed consent, data protection and participant wellbeing. As Pascoe Leaghy (2022) has noted, however, vulnerability cannot be fully anticipated or mitigated through procedural ethics alone. Rather, it unfolds within the research encounter itself, requiring ongoing attentiveness and reflexive judgement on the part of the researcher.

Interviews were conducted remotely, a methodological choice shaped both by the geographically dispersed nature of participants across the UK and by the access needs of participants living with chronic illness. While remote interviewing introduces particular challenges — especially when discussing sensitive or emotionally charged topics — it also offers important advantages. For many participants, being interviewed from their own homes reduced the physical and cognitive demands associated with travel and face-to-face interaction and allowed greater control over the interview environment – which I elaborate in what follows. Nonetheless, navigating moments of emotional distress within a remote setting required careful ethical judgement. There were instances where participants became visibly or audibly upset when recounting experiences of illness, loss or marginalisation. In such moments, I remained attentive to participants' cues, reiterated their right to pause or discontinue the interview, and sought explicit consent before continuing with sensitive lines of discussion. These

moments underscored one of the central ethical tensions of qualitative health research: deciding whether to pursue narratives that elicit strong emotions, or to step back in order to prioritise participant wellbeing (Pascoe Leahy, 2022).

Alongside concern for participants, I was also reflexively aware of my own emotional and ethical responses during these encounters. Feelings of anxiety, responsibility and guilt frequently accompanied interviews, particularly when participants expressed gratitude for being listened to or articulated hopes that the research might contribute to wider change. Such reactions are not uncommon in qualitative research and have been described by Laurier and Parr (2000, p.99) as a "classic interviewer's emotion." These feelings were often intensified by the awareness that participants were expending limited energy to take part and by the structural constraints limiting what I could realistically offer in return beyond careful listening, respectful representation and future dissemination. At the same time, many participants described the interview space itself as meaningful, cathartic or validating. As outlined earlier, being given time and attention to narrate experiences that had often been dismissed or minimised elsewhere appeared to hold intrinsic value for some participants. For example, Arun jokingly remarked, "I don't know, I'm kind of using you as counselling [laughs]," signalling an awareness of the interview as a space for emotional release as well as research exchange. While this should not be conflated uncritically with therapeutic benefit (Birch and Miller, 2000; Bondi, 2013), it nonetheless complicated simplistic assumptions about harm, burden or exploitation within research encounters.

Overall, conducting research with participants living with Long Covid required an ongoing, relational ethics grounded in reflexivity, care and attentiveness to shifting capacities. Vulnerability was not treated as an inherent characteristic of participants but recognised as situational and unevenly distributed across the research process. By adopting flexible methods, foregrounding consent as an ongoing practice and remaining reflexively engaged with both participant and researcher wellbeing, this research sought to navigate the ethical complexities of working with a population living with chronic illness in a manner that was respectful, inclusive and ethically grounded.

3.5 Vulnerable researchers

Building on the preceding discussion of vulnerability as layered, relational and emergent, this section turns attention to the position of the researcher within such

research encounters. While vulnerability is often framed as a characteristic of participants, qualitative health research has increasingly acknowledged that researchers themselves may also experience forms of emotional, ethical and embodied vulnerability through sustained engagement with sensitive topics (Laurier and Parr, 2000; McDowell, 2010). Reflecting on researcher vulnerability is therefore not intended to collapse distinctions between researcher and researched, but to recognise how such dynamics shape the research process, ethical decision-making and researcher wellbeing.

As such, this project also prompted reflection on my own position as a researcher engaging closely with uncertain and contested illness narratives following a shared pandemic. While I care about my own health[23] and attempt to live a healthy, active lifestyle, I would not consider myself someone with health anxiety. However, having lived through the COVID-19 pandemic and having contracted COVID-19 myself, this research often acted as a reminder that I was not immune to re-infection and therefore Long Covid. The unpredictable nature of Long Covid is also evident in the lack of clear patterns about who is more susceptible to it than others. As a result, hearing the stories of everyday individuals, particularly those with similar ages, passions and lifestyles to my own, sometimes generated anxiety about the possibility of being affected by Long Covid myself. For example, Helena succinctly shared:

> I don't get why it affects some people like this, and not others, because everyone else obviously in my house has had Covid and come out the other end of it, so it's weird. And I'm glad, obviously, that it hasn't affected my kids or my husband, because I wouldn't want them to have this, but I don't understand why I just didn't come out the other end of it like them. It doesn't make any sense to me [...] I had a healthy diet. I exercised lots. [I] Have lots of friends, very happy, got really good life […] Maybe if I was smoking and drinking and didn't eat any fruit and vegetables, and my immune system was rubbish, then I could kind of rationalise that in my head. But there's no logical reason on paper why I should get Long Covid as opposed to anybody else in society.

Helena's account reflects the profound uncertainty surrounding Long Covid and the difficulty of locating illness within familiar narratives of risk, responsibility or health behaviour. Listening to such accounts often unsettled my own assumptions about health, control and vulnerability, particularly as Helena's reflections closely mirrored

[23] And, of course, others' health, hence the research interest.

aspects of my own life. While I felt a sense of gratitude for my physical health, there were times when I had to step back from this research for the sake of my mental well-being.

Though taking a break was sometimes necessary, it often left me feeling guilty. In acknowledgement of my relative health privilege, I did not want to appear as if I was dismissing Long Covid or distancing myself from participants' experiences for my own comfort. At the same time, I sometimes found it difficult to fully separate the research from intrusive thoughts such as, "this could be me." I am even fraught with guilt in admitting this point, wondering whether this is an appropriate confession for my thesis. Yet, reflecting on these responses is important, as they shaped how I engaged with the research, including decisions to pause and take time for emotional processing. Upon reflection, I should have also kept a personal field diary as a way of more systematically journalling and dealing with my emotions, be that anxiety or guilt, but in practice my field notes at the time only sporadically covered such matters.

3.6 Online research

I employed a fully remote methodology. Of the 26 individual interviews, 21 were conducted on Zoom (camera on), three on FaceTime (camera on), one on MS Teams (camera didn't work) and one via telephone. All four focus groups were conducted on Zoom, with cameras on throughout. While Zoom was initially suggested to participants, the use of these platforms was guided entirely by individual preference, and there were no instances where participants expressed discomfort with having their camera on. Indeed, Ruth noted that due to her Long Covid she generally preferred video calls to phone calls, explaining that seeing emotional responses and body language made the interaction feel more engaging. Kristina expressed similar preferences for video-based communication for more personal reasons, remarking that she disliked phone calls as they felt like "a disembodied voice."

Qualitative research experienced something of a paradigm shift during the COVID-19 pandemic, as in-person encounters pivoted online, prompting methodological reflection on access, ethics and digitally mediated research encounters within geography and the social sciences (Rose-Redwood et al., 2020; Lupton, 2021). Although this research was conducted post-pandemic, the decision to employ a remote methodology was informed by three interrelated considerations, briefly

introduced earlier. Firstly, I aimed to recruit participants from across the UK, making a remote approach the most effective way to overcome spatial distance barriers and facilitate participation in the research encounter. Although some participants were based in relatively close proximity to me – three in Glasgow, one in Tullibody, one in Edinburgh – I felt that online interviewing remained the most practical and inclusive method for engaging with individuals living with an ELC. This decision was therefore informed not only by geographical considerations, but by an awareness that participation itself required the careful management of limited and fluctuating energy reserves.

This leads to my second, interrelated consideration concerning participants' wellbeing. I recognised that travelling to an interview location may be fatiguing or risk symptom exacerbation before the interview had even begun. Given that many participants described living with depleted, unpredictable and finite energy capacities, devising a methodology that respected these limits was central to the ethical conduct of this research.

Finally, I was mindful of participants' potential discomfort in public or unfamiliar spaces, particularly in relation to fears of COVID-19 contamination – an issue explored further in focus group discussion – as well as the challenges of sharing intimate, sensitive and often stigmatised experiences of their contested condition in public settings. Such environments may place additional emotional and energetic demands on participants, further constraining their capacity to engage in sustained or meaningful discussion.

Adapting the research design to an online format was therefore central to creating an inclusive and accessible research process for individuals living with Long Covid, facilitating participation in ways that reduced stress, mitigated fatigue and promoted comfort. More broadly, this approach sought to acknowledge and respect participants' depleted energy levels by minimising unnecessary exertion and facilitating engagement on their own terms. This was reinforced by Lu (FG2), who shared that her home is where she feels safest and least affected by her condition:

> My home's always been my safe space, before and after [Long Covid] […] I don't feel like I have Long Covid at home […] being too far away from home gets me stressed, because in my head, I'm thinking, 'what if you're ill? You can't get home,' because the condition is unpredictable […] [in] places where I don't know, or I'm not familiar with.

Not every participant echoed Lu's experience of feeling free from Long Covid at home. For some, the home served as a constant reminder of their condition, which I explore further in Chapter 4. Alongside the reasons previously outlined, however, I contend that conducting research online was the most appropriate methodological choice given participants' need for comfort, familiarity and the importance of conserving limited physical, cognitive and emotional energy. Of course, conducting individual interviews in participants' homes could have been an alternative, though this option brings its own ethical considerations and spatial obstacles. Focus group interviews were also conducted online, for similar reasons, enabling me to bring participants together from across the UK to share their diverse localised experiences, including variations in healthcare access and service provision.

While adapting the research design to an online format enhanced accessibility and comfort for many participants, I was nonetheless mindful that this methodological choice also carried the potential to exclude others. I was therefore aware that recruiting participants and conducting research online might exclude individuals who lack internet access, have limited digital literacy, or are unaware of – or do not engage with – online Long Covid support groups, preferring instead to manage their condition through offline spaces. I therefore initially anticipated a potential disconnect with older populations, but the average age of participants was 49, with the oldest participant being 71. This suggests that aging populations are becoming increasingly technologically connected, particularly under conditions of COVID-19 pandemic as lockdowns heightened reliance on digital technologies for social connection and support (Kung and Steptoe, 2023).

3.7 Recruitment

Within days of advertising for individual interviews with Long Covid participants on X in April 2024, I was inundated with emails from willing participants, and soon learned that my digital poster (see Appendix A) had been shared across Facebook and WhatsApp platforms, notably in Long Covid support groups, as recruitment 'naturally' snowballed[24]. Within two weeks, I had 30 willing participants. This overwhelming response was reflected not just in the volume of emails, but their content. As Monica

[24] Notably, 12 of the 26 participants were teachers (including one retired prior to Long Covid), which I later understood to be a result of snowball recruitment, with my poster being shared within a specific teachers' Long Covid WhatsApp support group.

outlined: “I’d love to tell you the impact of Long Covid on my life! I’m slightly worried just how much I want to tell you!” When I asked Monica what she meant by this during her interview, she responded:

> I think it's because not very many people ask. And there’s not very many people who’ve got the time to listen to it all. And also, it’s quite interesting, when you've had something like this, that you tell the whole story because you very, very rarely do that.

Many participants echoed Monica’s experience, explaining they had only ever discussed Long Covid with healthcare professionals, or supportive friends and family members, but in small segments, emphasising the importance of this interview for participants on an individual level, which offered time and space to be heard.

Some participants sent long emails detailing their symptoms and how Long Covid had affected their lives, often attempting to justify their eligibility to participate in the research. As Hannah emailed: “I completely understand if, due to my medical condition/needs, I wouldn’t be a suitable interview candidate,” a response that reflects participants’ prior experiences of dismissal or disbelief within personal, professional or medical networks. I recruited individuals regardless of medical diagnosis and the overall criteria was intentionally broad: participants needed to be an adult living in the UK who identified as having, or had, Long Covid. This inclusive approach differs markedly from biomedically oriented research on Long Covid, which often prioritises diagnostic certainty and standardised measures of ‘objectivity’, such as those employed in clinical trials or epidemiological studies (see Lavretsky, 2025). Even where diagnostic certainty remains uneven or evolving, biomedical oriented studies also identify Long Covid through healthcare records, including coded diagnoses, symptom reporting and clinical notes (see Shah et al., 2023), thereby privileging biomedical recognition over self-identified lived experience. In contrast, my study aligns with qualitative approaches within the social sciences that centre lived experience, self-identification and participant narratives as valid and meaningful forms of knowledge (see Chapter 2).

The immediate response from the very beginning of the recruitment process emphasised the significance of this research to those affected by Long Covid who wanted to share their experiences and have a voice. I ceased recruitment after 30 volunteers, as I was mindful of the volume of data that in-depth interviewing would

generate. This was not an easy decision, as I was conscious of participants' evident enthusiasm to contribute to the research. However, no further expressions of interest were received following this point, meaning that I did not have to decline participation.

Of the 30 people who volunteered, 26 were ultimately interviewed, with participant demographics presented in Table 3.1[25]. One withdrew without providing a reason, exercising their ethical right to do so; two 'rescheduled' due to illness, but did not get back in touch; and one enquiry was made by a mother on behalf of her 13-year-old daughter with Long Covid, who, as a minor, was not eligible to participate within the ethical remit of this study.

Indeed, when the seemingly prospective participant called to discuss my research further, I assumed she was enquiring for herself. Rather, she was a concerned mother seeking answers for her teenage daughter who was affected by Long Covid. Although I was restricted by my ethical remit and unable to offer her an interview, I listened to their story for an hour. She shared the challenges that her and her daughter have faced: the unpredictable nature of Long Covid; the various challenges of living with Long Covid in a rural area and trying to obtain a diagnosis; ruminations of "why her?"; the lack of support from school and; the overall lack of awareness and support for children with Long Covid. The concerned mother expressed feeling "stuck" and insisted: "I have a voice as well." She asked for my research findings – seeking solutions that could possibly help her and her daughter – but I was in the early stages of my data collection and had none to offer. I felt helpless and fraught with guilt, but she still expressed gratitude for my time, my listening ear and the validation of her family's experiences. This encounter made me reflect on the potential impact of this

[25] Table 3.1 from left to right: participant name or pseudonym; age at the time of interview; gender identity; ethnic identity; home location at the time of interview; occupation at the time of COVID-19 infection (with changes to working status detailed where appropriate throughout the empirical chapters); date of acute COVID-19 infection believed to be linked to Long Covid sequelae; presence of a Long Covid diagnosis, if applicable; attendance at Long Covid clinic; and significant symptoms discussed during interview. This symptom list is not intended to be exhaustive, as participants frequently described living with numerous, fluctuating symptoms that were not always articulated in full. As Theresa explained, "There was a list somewhere once of over 400 symptoms [...] I went through it, and I had 62 of them, but I don't have 62 of them every single day. I might have maximum eight of them a day, but I've got 62 of them [laughs]." Similarly, Alexandra noted: "I can play the piano but only one piece at a time because I've got terrible muscle pain in my shoulders. I didn't mention that. You see the list gets too long. It's boring," while Louise also reflected: "I've not really helped you have I with the symptoms? […] I just live with the symptoms now, I don't think about them as much, if you know what I mean [laughs]? I just plod about with them."

postgraduate research. While I questioned the broader significance, I realised the value I could offer on an individual level, providing a space and opportunity for people to share their stories and be heard. This reflection was reinforced throughout one-to-one and focus group interviews, to which I return later in this chapter as I reflect on researcher sensitivity.

Reflecting on the recruitment phase and the sample of participants ultimately interviewed, it is important to acknowledge that this research is shaped by certain subjectivities and potential limitations, which are considered further in the thesis conclusion. As alluded to previously, recruiting primarily through digital platforms favoured individuals who were digitally literate and engaged with online forms of communication and support, potentially excluding those who manage their condition through offline networks or who have more limited access to digital resources. In addition, it is possible that this recruitment approach particularly attracted individuals who had not previously found sustained opportunities to articulate their experiences of Long Covid, and who were seeking a space in which their accounts could be heard and validated. As outlined in Table 3.1, the participant group was also predominantly female, with fewer men represented, alongside relatively limited participation from younger individuals, and limited ethnic diversity. This composition may also reflect the uneven reach of online recruitment and Long Covid support spaces. These characteristics do not detract from the value of the research, however, but rather they suggest that the findings are informed by particular Long Covid subjectivities, giving rise to distinct nuances within the empirical material that follows, particularly in Chapter 7, which centres on online spaces and digitally mediated forms of connection.

3.8 Individual Interviews

Interviews were adopted as the primary research method to explore the everyday lived realities of living with Long Covid. Within qualitative human geography, interviews are widely used to generate in-depth insight into how individuals experience, interpret and organise their social and spatial worlds (Mason, 2017). In particular, interviewing allows for attention to the embodied, emotional and relational dimensions of everyday life, making it especially well-suited to research concerned with health and illness. Semi-structured interviews were employed to facilitate a conversational exchange, enabling participants to shape the direction and emphasis of the discussion while allowing common themes to be explored across accounts (Cloke et al., 2004). As

feminist geographers have long emphasised, interviews are not neutral data-gathering tools, but complex social encounters shaped by power relations and positionalities (Rose, 1997; Moss, 2002). This understanding informed my reflexive engagement with interviewing as an intimate and potentially sensitive encounter (Pascoe Leahy, 2022),

Pseudonym[26]	Age	Gender[27]	Ethnicity	Location	Occupation	Acute COVID-19 infection	Long Covid diagnosis	Long Covid clinic	Symptoms and secondary conditions	Notes
Alexandra	56	Female	White British	Devon	Primary teacher	Mar-22	Yes	Yes	Brain fog, breathlessness, fatigue, headaches, memory loss, muscle pain.	“I’m usually at my best between 11am and 2pm.”
Amanda	63	Female	White British	Manchester	Invigilator/ Retired teacher	Feb-20	Yes	Yes	Asthma, dysautonomia, breathlessness, heart palpitations, pericarditis.	Requested two 30-minute interviews.
Amy	40	Female	White British	London	Teacher	Feb-20	Not official GP diagnosis, but confirmed verbally by respiratory consultant	Yes	Fatigue, lung issues, severe asthma.	
Arun	50	Male	British Indian	Essex	Unemployed	Mar-20	Yes	No	Brain fog, bladder issues, emotional dysregulation, fatigue, headaches, light sensitivity, nausea.	“I am pretty flexible (unfortunately).”
Cath	45	Female	White British	North Yorkshire	Local dairy factory worker	Nov-20	Yes	Yes	Alopecia, brain fog, brainstem dysfunction, breathlessness,	Requested patience for fatigue.

[26] Participants were offered the choice to use a pseudonym or their own name as part of their participation. In recognition of participants’ differing preferences around anonymity and advocacy, this table does not distinguish between real names and pseudonyms.

									dizziness, headaches, high heart rate insomnia, lung damage[28], memory loss, osteoarthritis.	
Charlotte	37	Female	White British	Leicester	Primary teacher	Nov-21	Yes	Yes (phone)	Brain fog, breathlessness, dizziness, headaches, high heart rate, insomnia, lung damage[28], memory loss.	
Chloe	41	Female	White British	Bournemouth	Primary teacher	Oct-21	Yes	Yes (online)	Brain fog, fatigue, joint pain.	
David	45	Male	White British	Glasgow	Senior healthcare support worker	Sep-21	No	No	Fatigue, headaches, nausea.	
Farrah	39	Female	White / Middle Eastern	Plymouth	Police force	Nov-21	No – GP verbally confirmed, but not on medical record as	Yes	Ambulatory wheelchair user, blurred vision, brain fog, cramps, fatigue, memory loss, muscle soreness, nerve	

[27] Only individuals who identified as men or women participated in my study; however, Jayadeva and Lupton (2025), who interviewed 30 participants, found that non-binary individuals were also affected by Long Covid.

[28] Described by participant as “air pockets in lungs”, but no specific diagnosis stated. Therefore, in accordance with https://www.hopkinsmedicine.org/health/conditions-and-diseases/coronavirus/what-coronavirus-does-to-the-lungs [Accessed 9 January 2025], I have generalised this description as ‘lung damage’.

							“no test to prove it”		pain, tremors, tinnitus.	
Fiona	58	Female	White British	Birmingham	Housing rights worker	Sep-21	No; verbal GP CFS/ME diagnosis	“Long Covid service”	Brain fog, dizziness, emotional dysregulation, fatigue, headaches, insomnia, joint pains, muscle aches.	
Hannah	32	Female	White British	Yorkshire	Primary teacher	Sep-21	Yes	Yes	Brain fog, breathlessness, disturbed sleep, dizziness, flared eczema, gastro problems, heart palpitations, joint and muscle pain, migraines, numbness, non-epileptic seizure disorder.	“I completely understand if, due to my medical condition/needs, I wouldn’t be a suitable interview candidate [...]”
Helena	44	Female	White British	Lancashire	Language teacher	Jan-23	Yes	Yes	Brain fog, breathlessness, fatigue, headaches, PoTS.	
Kamy	43	Female	White Bulgarian	Edinburgh	Restaurant supervisor	Apr-21	Yes	Yes	Brain fog, fatigue.	“I have to admit, I’m excited about our upcoming conversation.”

Kate	46	Female	White British	Pocklington	Assistant head primary teacher	Jan-22	Yes	Yes	Brain fog, fatigue, PoTS.	
Kristina	60	Female	White British	Northumberland	Counsellor	Jun-20	Yes	Yes	Brain fog, fatigue.	Requested a break or possibly two shorter interviews.
Louise	51	Female	White British	Tullibody	Guidance teacher	Dec-20 (Hospitalised)	No	No	Adrenal insufficiency, brain fog, hair loss, joint pain, long term oxygen therapy, lung damage.	
Lu	52	Female	White British	Essex	Primary teacher	May-23	Yes	Yes	Breathlessness, brain fog, fatigue, migraines.	
Marg	71	Female	White British	London	Retired nurse	Jul-22	Yes	Yes	Brain fog, fatigue, PoTS.	
Mary	30	Female	White British	Glasgow	Student	Oct-21	No	No	Brain fog, fatigue.	
Mark	57	Male	White British	Bristol	IT trainer	Dec-22	Yes	Yes	Breathlessness, chest tightness, fatigue.	After 10.30am; prefer afternoon. Requested a break.
Megan	41	Female	White British	Essex	Primary teacher	Dec-22	Yes	Yes	Brain fog, fatigue, tinnitus.	
Molly	51	Female	White British	Derby	Accountant	Jun-22	No	No	Headaches, migraines, sight problems, tinnitus, pins and needles.	
Monica	56	Female	White British	Glasgow	Former GP	Mar-20	No	Yes	Brain fog, fatigue, migraines.	“I’d love to tell you the impact of Long Covid on my life!

										I'm slightly worried just how much I want to tell you!"
Ruth	62	Female	White British	North Yorkshire	Music teacher	Jan-22	Yes	Yes	Fatigue, brain fog.	Morning preferred; requested break or two shorter interviews.
Sheila	54	Female	White British	Glasgow	Retired nurse	May-20 (Hospitalised)	No	No	Brain fog, fatigue, hair loss, long term oxygen therapy, post-COVID pulmonary fibrosis.	Morning preferred.
Theresa	45	Female	White British	Portsmouth	NHS admin manager	Nov-20	Yes	No	Brain fog, fatigue, gut complications, tremors.	"Thanks to Long Covid, most of my evenings are free."

Table 3.1: Participant demographics

particularly in the context of researching a contested and often emotionally charged condition such as Long Covid.

3.8.1 Interviews design and implementation

I conducted 26 interviews with people living with Long Covid, both self- and formally diagnosed (see Chapter 6 for more details), over the course of five weeks following recruitment. Through initial email exchanges, I introduced the research aims to emphasise the social rather than medical perspective of this research. I also provided concise plain-language participant information sheets and a consent form, with participant energy and cognitive dysfunction in mind to ensure fully informed consent. As part of my ethical duty of care, I also included interview themes on the consent form that participants could choose to 'opt-out' from. Given the potential impact of 'brain fog' on participants, I was also mindful that some might want to make preparatory notes. This practice varied from person to person, as Megan shared: "I wrote some notes so that I wouldn't forget," while Alexandra admitted, "You're gonna laugh, I can't remember what the focus of your study is about."

I aimed to keep the research design as flexible, inclusive and accommodating as possible. When scheduling, I emphasised that I was happy to work around participants and that they could indicate their optimal time of day, which was most commonly late morning or early afternoon. When designing the interviews themselves, I anticipated 60 to 90 minutes of in-depth conversation. Therefore, in consideration of potential participant fatigue, I also offered the option of two shorter interviews and breaks. If participants had specifically requested two interviews or breaks in our initial email exchange, I attempted to keep the interview under one hour and prioritise key questions as I wanted to mitigate the impact on participant wellbeing. I would also inform participants when I only had one or two questions remaining, so that they felt reassured about not needing to exert much more energy. Sometimes, interviews would continue after my final question as participants asked me questions about the research, often leading to further discussion about their experiences. One participant in particular, Helena, seemed reserved in her initial responses to questions, but, when I thought our interview was coming to an end, she asked about my research motivations, leading her to open-up significantly about her experience, effectively doubling the length of her interview. Given the highly contested nature of Long Covid,

I felt that some participants, like Helena, needed time to build rapport and understand my intentions before they felt comfortable disclosing their personal stories.

In the end, all participants followed through with one in-depth interview between 45 and 90 minutes long. Even so, I contend that shorter interviews and breaks should always be considered within Long Covid research design, especially as I received feedback from Ruth over email:

> As Long Haulers we are our worst enemies [...] Achieving something and finishing it is such a massive goal ... so self-care goes out of the window. Despite you regularly offering a shorter session, I wonder if it might be an idea to just set shorter sessions rather than leaving it to the 'client' because often adrenaline and enthusiasm takes over and we can mask the real picture of remaining energy […] In hindsight I was wrong to not divide up the session […] but being me, I wanted to finish in one go.

As one of my initial interviews, Ruth's feedback made me reconsider whether I should take more control over interview length and breaks. At times, I felt that paralysis again, questioning whether I was causing more harm than good, especially as I knew that participants like Chloe will "need a sleep after," or paranoid that the interview would trigger a crash[29] for which I would feel personally responsible. As a non-disabled researcher, however, I was also conscious that it was not my prerogative to assert authority over participants' time or capacity, as if I knew what was best for them, while recognising that the potential impact of interviewing someone affected by Long Covid would vary significantly from person to person. Rather than imposing rigid controls, I sought to remain sensitive to individual needs and to prioritise participant agency through a participant-led approach. I continually reminded participants of their ethical right to pause, stop or reschedule the interview, and from the outset, adopted a flexible approach to scheduling, always prioritising times and days that worked best for participants. Throughout the process, I emphasised that the interview was theirs to manage; they were the experts in their own lives, and this was their opportunity to share their experiences in the way they felt most comfortable.

As discussed earlier through Alexandra's example, clearing her whole week to participate in an interview, many participants echoed how the interview would affect

[29] 'Crash' is a common colloquial term used to describe post-exertional malaise (PEM), or post-exertional symptom exacerbation (PESE) (see Chapter 2).

their energy levels. These reflections therefore highlight just how crucial sharing their story was as participants were very aware of their limited energy and the effort involved in managing it, which reinforces the importance of considering participant wellbeing carefully in research design. Researching Long Covid demands patience and flexibility as participants may need multiple interviews, breaks or even simply to cancel last-minute due to illness. A couple of participants even completely forgot about their interviews.

I conducted all interviews from my home to ensure privacy as the audio-recordings made it necessary for the conversations to be loud and not conducted through earphones. I recorded all interviews using a Dictaphone, which was uploaded to the OneDrive on my laptop and then wiped from the Dictaphone immediately. In further accordance with data management protocols, all audio-recordings were wiped from the OneDrive following transcription. I did not use the automated transcription function available within Zoom, as I have found such tools to be insufficiently accurate and often incomplete, particularly when working with emotionally nuanced, lengthy and detailed qualitative interviews. This decision was informed by my previous experience during my Master's research, where reliance on automated transcription required substantial correction and risked misrepresenting participants' accounts. I therefore opted to produce my own carefully constructed transcripts to ensure accuracy and clarity to participants' words.

During the initial interviews, I became acutely aware of my conduct as a researcher, as my Zoom screen also offered a small window into my own home and personal life. Notably, the hiking photos displayed behind me on the wall caught the attention of some early participants, such as Mark and Charlotte, who commented on them as a shared interest. I became concerned that some participants might find these photographs insensitive, particularly those who were grieving such activities in which they could no longer engage. I worried that it could even lead them to question my trustworthiness as a researcher. While participants never explicitly expressed this concern, I decided to 'blur' my Zoom background for subsequent interviews to maintain my integrity as a sensitive and respectful researcher.

I adopted a hybrid narrative/semi-structured interview approach, inspired by Anderson and Kirkpatrick (2016). The authors outline a four-part interview – introductions; the

narrative; question phase; conclusion – as a participant-led approach to exploring stories of health and wellbeing. In the context of my research, this approach began with a broad question: “From the beginning, please share your story of Long Covid,” inviting participants to offer a timeline of their experience, while giving them control over the interview to focus on the aspects of their experience that they considered most significant. Participants spent anywhere between ten minutes and one hour answering this initial prompt. However, I gained the impression that most people were expecting a more traditional question-and-answer style interview, so the ‘hybrid’ approach allowed elements of this format to remain. The subsequent semi-structured phase of the interview was centred around broad themes of discussion (see Appendix B), with questions adapted and tailored to each individual’s narrative shared in the opening phase. Taking this intentionally broad and flexible approach enabled the participants to influence both the direction of the interview and wider research, as a means of “levelling the fielding” in the sensitive research encounter (Dickson-Swift et al., 2007, p.333). While the interview design foregrounded narrative storytelling, the subsequent analysis adopted a thematic rather than narrative approach, as discussed later in this chapter.

As mentioned earlier, I had a busy schedule of interviews, often speaking to two or three participants in one day. Admittedly, I was excited by the positive response to recruitment which can be a significant challenge in qualitative research, and I was concerned that prioritising my own energy levels, by spreading out and delaying interviews to fit only one or two per day might cost me participants. As a consequence of these time pressures, and impact on my own energy levels, I conducted all interviews before transcribing them. This ordering contrasted with my previous, and preferred, approach during my undergraduate and Master’s research projects, where I would transcribe interviews between data collection, which previously enabled ongoing reflection on my interview practice and the opportunity to refine questions and prompts iteratively. I therefore adapted my reflexive approach through field diary reflections, noting down my own memory of the interview encounters, which informed subtle adjustments to subsequent interviews. I elaborate further on transcription and data analysis in the sections that follow. When I listened back to interviews during transcription, however, I became aware of ‘missed opportunities’ to ask particular questions and, at times, began to regret aspects of my research approach, wishing

that I had taken more time, reflection and energy between interviews. I did, however, transcribe all individual interviews in full before commencing the second data collection phase through focus group interviews. This process enabled me to identify recurring themes and gaps within the individual interviews and hence 'focus' the group interview themes of discussion to explicitly address issues that had not been fully explored in the initial interview phase. For example, while I initially asked about everyday symptom management in individual interviews, I later focused discussion more specifically on practices of planning, pacing and prioritising as forms of energy management that commonly emerged across participants' accounts (see Chapter 5).

3.9 Focus Groups

In their most basic form, focus groups are "a one-off meeting of between four and eight individuals who are brought together to discuss a particular topic chosen by the researcher(s) who moderate or structure the discussion" (Bedford and Burgess, 2001, p.121). Kitzinger (1994) highlights that focus groups have been historically employed as a cost- and time-effective technique for interviewing multiple people at once. Methodological scholarship has therefore increasingly emphasised that focus groups are not simply efficient data-gathering tools, but socially situated encounters in which meaning is produced through intersubjective interaction (Wilkinson, 1998). As Hollander (2004, p.631) reminds us, "participants in a focus group are not independent of each other, and the data collected from one participant cannot be considered separate from the social context in which it was collected." The focus group has therefore been critiqued in relation to the degree of "truth" it generates, due to what Hollander (2004, p.608) terms "problematic silences" (withholding speech) and "problematic speech" (withholding truth within speech). Group composition, dynamics and social pressures may lead participants to withhold, modify or exaggerate their accounts. Rather than offering unmediated access to individual thoughts or feelings, focus groups are thus particularly valuable for examining social interaction and the ways in which consensus and dissensus are collectively negotiated (Hopkins, 2007). Despite this, the influence of social context[30] on focus group data is not always fully acknowledged in research practice (Hollander, 2004).

[30] I also acknowledge that all qualitative methods are socially situated.

While it would be naïve for me to claim the degree of “truth” that emerged from my focus groups, I believe that these discussions nonetheless generated rich empirical material in both their interactional dynamics and substantive content. In relation to what Hollander terms “problematic speech,” I noted that many participants repeated stories across both individual and group interviews. More compellingly, when I asked participants how it felt to share their thoughts and experiences with others affected by Long Covid, each focus group independently contrasted the positive, supportive nature of the group discussion with their more ambivalent or negative experiences of online Facebook support spaces — a comparison that also echoed themes raised during individual interviews, to which I return in the empirical chapters and final conclusion. If the validity of focus group data is therefore called into question on the basis of social influence, the same scrutiny then must also be applied to individual interviews, which are similarly socially situated encounters, as Kitzinger (1994, p.173) contends, “differences between interview and group data cannot be classified in terms of validity vs. invalidity or honesty vs. dishonesty.” This reflexive stance aligns with wider qualitative methodological scholarship that emphasises that all qualitative data are co-produced, context-dependent and subject to interpretation, rather than neutral representations of experience (Braun and Clark, 2022; Silverman, 2022). Acknowledging repetition across interview contexts, alongside the development of trust and rapport with returning participants, suggests not a distortion of accounts, but a degree of consistency and confidence in what participants chose to share.

When considering “problematic silences”, I observed that participants who appeared more confident leading one-to-one interviews also tended to dominate focus group discussion, while quieter voices needed gentle prompting in both contexts. This pattern highlights how focus groups can reproduce existing communicative hierarchies, while also offering opportunities for these dynamics to be negotiated. Although some participants may feel reluctant to disclose sensitive or emotional experiences in group settings, others may find that the presence of empathetic peers enables disclosure and reflection (Barbour, 2007).

One participant in particular, Chloe, was noticeably more reserved in her individual interview, especially when discussing the emotional consequences of Long Covid. I believe that this hesitance may have reflected the fluctuating cognitive and emotional

impacts of Long Covid, or because she had not yet fully accepted the impact of the condition on her sense of self and purpose. As she shared:

> I can't think about it [losing my job] too much though, because I do get some dark, dark days, I suppose, where I'm just like […] What is the purpose of it all? […] Because I'm not, as I said, making that difference, do you know what I mean? As a teacher, you like to think you're making a difference […] And that's kind of been taken away.

Despite occasionally needing prompts, Chloe spoke more openly during the focus group setting, which I interpret as being linked to a developing sense of shared experience, collective validation and even perhaps, acceptance (see Chapter 4). In this respect, the focus group appeared to offer an empowering space in which participants could recognise their own experiences through those of others (Barbour and Morgan, 2017) – a point to which I return later in this thesis.

Moderating focus groups on sensitive topics requires careful attention to creating a supportive and non-judgemental environment (Morgan, 1995). I sought to foster such a space through my research design and facilitation, including sharing discussion prompts in advance to allow time for reflection, remaining attentive to group dynamics, and actively encouraging quieter participants to contribute. By understanding focus group interaction through the dual lenses of problematic speech and silence, I recognise the importance of empathy, repetition and relational trust in shaping what participants felt able to share. While no research encounter can fully resolve questions of truth or representation, I contend that these focus groups provided a safe and generative setting in which participants could articulate, negotiate and validate their experiences of Long Covid.

3.9.1 Focus group design

I employed focus groups in triangulation with individual interviews to generate greater insight into people's social and spatial worlds (Hopkins, 2007). More specifically, I sought to move iteratively between individual and collective methods, allowing insights generated in one research encounter to inform and resonate with the other. As previously mentioned, I transcribed all individual interviews before conducting focus groups, which allowed me to 'focus' group interview discussion themes, and hence fill important gaps that may have been missed in initial individual interviews. This sequencing facilitated a more deliberate dialogue between methods, allowing insight

into the interplay between individual experiences and their collective articulation. In this sense, these focus groups functioned as a second interview, not as a repetition of individual accounts, but as a space in which participants could reflect upon, respond to, and negotiate shared experiences in relation to others

Interview participants were given the option to opt in to being contacted for a follow-up focus group interview, with 25 of the 26 participants choosing to do so. While all 25 expressed willingness when contacted, only 17 were ultimately able to participate due to factors including illness, work commitments and last-minute cancellations. This willingness to participate again, despite the energy demands involved, suggested that participants experienced the individual interviews as a safe and supportive space, and that a degree of rapport had been established.

In practice, focus group sizes vary but as outlined above, typically consist of four to eight individuals, with 'larger' groups comprising six to ten individuals (Cameron, 2005) and some even involving as few as two (Longhurst, 1996), which are usually facilitated by one or two researchers (Conradson, 2005). Through the individual interviews, I learned that many people living with Long Covid find larger group discussions overwhelming or cognitively demanding. As Ruth explained, "I *really* struggle with conversations involving more than one person at a time," while Sheila similarly noted, "if there's another two or three people chatting at the same time, I can't follow the conversation." As such, I organised groups of four to six people (see Table 3.2)[31], with scope for one or two to cancel (Conradson, 2005). While participants had consented to taking part in a group interview, this knowledge nonetheless made me apprehensive about the potential impact of group discussion on participants' wellbeing. As part of my ethical duty of care and commitment to researcher integrity, I made explicit in all participant communications that groups would remain small, ensuring transparency around the conditions of participation. I also introduced a set of ground rules at the outset of each focus group to help minimise feelings of overwhelm or overstimulation, which I elaborate upon later in this chapter.

[31] Table 3.2 from left to right: Focus group number (in chronological sequence); broad time of day the session was conducted; participant composition (names and pseudonyms); and participants cancellations.

Group	Time of day	Participants	Cancelled
FG1	Late morning	Amanda, Helena, Kristina, Mark, Sheila	
FG2	Evening	Charlotte, Lu	Theresa, Molly
FG3	Late morning	Chloe, Louise, Marg, Monica	Farrah
FG4	Early afternoon	Alexandra, Arun, Hannah, Kamy, Kate, Megan	

Table 3.2: Focus group composition

One of my intentions was to organise groups that were socially similar, which, as Hollander (2004) suggests, is more appropriate for discussing sensitive topics. This approach aimed to foster "a climate of mutual respect" (Morgan, 1997, p.61), while recognising that difference and disagreement may still emerge within group discussions. The intention was therefore not to eliminate contention altogether, but to avoid introducing overtly oppositional positions that might risk creating awkward, silencing or distressing encounters for participants. For example, I was particularly mindful of the potential impact of grouping individuals living with Long Covid alongside healthcare professionals or Long Covid sceptics, whose perspectives might fundamentally challenge participants' lived experiences within an already complex and contested field. By coordinating groups with shared experience, I sought to create conditions in which participants could speak openly, respond to one another and engage critically without feeling required to defend the legitimacy of their illness.

Focus group design can be tailored to different research aims. For instance, groups may be structured to emphasise heterogeneity where the objective is to explore a wide range of perspectives, or homogeneity where the aim is to examine shared experiences within particular social or demographic contexts (Conradson, 2005). When organising my focus group composition, however, I prioritised participant wellbeing over analytical comparison. Through the individual interviews, I became aware that participants' daily rhythms and physical and cognitive capacities varied considerably. Many participants described functioning best either in the late morning or early afternoon, while those who had returned to work were typically only available in the evening. For this reason, I organised focus groups around times of day that

broadly aligned with participants' capacities, scheduling both daytime and evening sessions in order to minimise fatigue and maximise comfort.

At the same time, I remained attentive to the implications of this temporal and spatial organisation. As Hopkins (2007) highlights, the geography of focus groups — their location, timing and spatial organisation — is integral to how discussions unfold and to who is able to participate. As previously noted, conducting focus groups online enabled participants to join from across the UK, introducing geographical diversity through participants' differing localised experiences of healthcare access and support. However, I was conscious that prioritising participant wellbeing in terms of group timing might also shape the composition of each group in more subtle ways. Participants' availability often aligned with broader social and illness circumstances, particularly whether or not they had been able to return to work. As such, evening sessions were more likely to include participants in paid employment, while daytime groups tended to comprise those in earlier stages of recovery or those no longer able to work. While this was not an intentional strategy of analytical division, it raised important reflexive considerations regarding how shared temporal capacities might shape group dynamics, comparison and discussion. Rather than treating these similarities as methodological limitations, I approached them as part of the circumstances shaping how participants were able to engage in discussion and articulate their experiences. This approach allowed focus groups to remain ethically attuned to participants' capacities, while still generating rich discussion that reflected the complex and uneven realities of living with Long Covid.

Despite some overlap in participants' social and illness circumstances, I was nonetheless able to create groups that were diverse in terms of age, ethnic background and occupational history, and in two of the four groups, gender (FG1 and FG4). Even where participants shared similar social positions — for example, Focus Group 2, which comprised two women who had both returned to work as teachers — discussion remained nuanced and generative, reflecting the heterogeneity and unpredictability of Long Covid experiences.

Indeed, shared circumstances within focus groups often proved productive on an individual level, fostering a sense of validation, recognition and hope. As Lu (FG2) reflected:

> I think it's quite a lonely illness, because it's so misunderstood and it's so new still. So, when you hear some people go, 'oh yeah fatigue, I get fatigue,' and you think, 'oh my God, thank you!' It's really nice to hear other people, and how they learn to deal with it. And the fact that you're a teacher, [Charlotte], gives me hope as well […] Not that I wish you ill, but you definitely feel less lonely.

This sense of belonging was echoed across all focus groups, with participants valuing the opportunity to share experiences with others who could understand them without explanation or justification. As Helena (FG1) similarly expressed:

> It's really helpful to listen to other people and listen to their experiences and how they manage those experiences as well […] hearing how people have adapted their lives and what they've done, and the things they do, and seeing that things are possible beyond the illness.

Taken together, these experiences reaffirmed the importance of prioritising participant wellbeing when researching a highly stigmatised and contested condition such as Long Covid.

3.9.2 Focus group implementation

As previously discussed, I began each focus group with a few ground rules to establish shared expectations and group consensus as well as mitigate unnecessary deviation from the interview schedule. I outlined what the focus *was*, and was *not*, intended to do, emphasising that all participants had previously taken part in an individual interview in which they shared their Long Covid story in detail. The focus group therefore offered an opportunity to move beyond individual narratives and explore some emerging themes in greater depth through collective discussion. In this respect, working with returning participants proved particularly effective. Not only had rapport already been established, but I was also able to contextualise comments made within the group in relation to participants' individual accounts.

I began each session with brief introductions, asking participants to share their name, where they were based, and something about themselves, starting with myself. Mindful of participant wellbeing and energy, I chose not to include a separate ice-breaker exercise. Instead, I opened with a question that functioned as a "focusing exercise" (Hollander, 2004), presenting a statement previously made in an individual interview and inviting participants to respond:

> One participant said to me, ‘I am a Long Covid sufferer or survivor, depending on how you look at it.’ What are your thoughts on this statement?

This opening prompt encouraged participants to reflect on their relationship to their terms “sufferer” and/or “survivor,” easing them into discussion, welcoming opposing opinions between strangers, while also establishing trust around a sensitive and contested topic. From this point, conversation developed readily as I worked through a series of structured questions (see Appendix C).

Morgan and Kreuger (1993, p.7) also explain that “a good moderator will strive to create an open and permissive atmosphere in which each person feels free to share her or his point of view.” As such, at the beginning, I emphasised at the outset that participants were encouraged to share experiences, opinions and perspectives that might differ from those of others, framing the focus group as a space to explore nuance rather than consensus around issues related to Long Covid.

At the same time, I acknowledged that group discussion can be cognitively or emotionally demanding for some people living with Long Covid. To help minimise overwhelm, I asked participants to take turns when speaking, while recognising that interruption can occur naturally in conversation, particularly when individuals feel strongly about a topic. This consideration was reflected across all groups, with participants actively making space for one another. In some cases, those who spoke more frequently demonstrated reflexive awareness of their participation, as Mark (FG1) noted:

> E: Does anyone else have any thoughts about their home?
>
> Mark: I do. I just didn’t want to feel like I was talking the whole time.

Similarly, interruptions were typically polite and self-aware, as demonstrated in FG4:

> Kamy: That's why, sorry for interrupting, but that's why…

Overall, the focus groups were characterised by respectful and considerate dynamics.

Conducting focus groups therefore required a shift in my researcher role. This was the first time I had facilitated focus group interviews, having previously relied solely on one-to-one interviews during my undergraduate and master’s research. During individual interviews, I adopted a largely participant-led approach, allowing interviewees to guide the conversation. In contrast, focus groups required a more

directive role, involving active facilitation and occasional intervention to manage time, balance contributions and steer discussion back to the topic at hand. While this approach was necessary — particularly given concerns around participant time, energy and wellbeing — it did not always sit comfortably with me. At times, I worried that I was interrupting or curtailing contributions from participants with whom I had previously built trust and rapport. This sense of authority felt at odds with my earlier commitment to participant-led discussion. In practice, however, participants responded positively to this structure and often demonstrated their own awareness of time and conversational flow, as reflected in FG2:

> E: I am getting quite mindful of time, because we are only on question two.
> Group: [laughter]

As previously noted, there is more to focus group discussion than the spoken word alone. Meaning is also conveyed through emotional tone, figures of speech, interruptions, silences and bodily cues. As such, focus groups are often facilitated by two researchers: one to moderate discussion and another to take notes (Hollander, 2004). In this research, however, I combined these roles. Since I had already established rapport with participants through individual interviews, I did not want to introduce an unfamiliar researcher who might create additional barriers to open discussion. I relied on the audio-recorder to capture verbal cues such as tone, interruptions and silences, while I focused on noting visible bodily responses, including head nodding or shaking. While this inevitably divided my attention between what was said and how it was communicated, the more structured nature of the focus groups enabled this division.

Each focus group lasted between 60 to 90 minutes. In one case (FG4), discussion continued for an additional 30 minutes beyond the planned questions, with some participants choosing to leave once they felt that further discussion would be too demanding. While focus groups were necessarily less flexible than individual interviews — given the need to accommodate multiple participants simultaneously — I ensured that breaks were offered throughout and that participants felt able to step away if needed.

Taken together, conducting both individual interviews and focus groups required me to adapt to differing researcher roles and responsibilities. While the shift from active

listener to moderator was at times uncomfortable, particularly in relation to authority and interruption, I am confident that across both methods sufficient space was created for participants to share their experiences in ways that felt safe, respectful and meaningful. The following section reflects on why these methods ultimately proved complementary.

3.10 (Dis)similarities between focus group and individual interviews

Similarly to the one-to-one interviews, I sent focus group questions in advance, giving participants the option to think about their answers and take notes. In contrast to the individual interviews, however, focus group discussions were more structured by design. While there was scope for some unplanned questions, in practice these were used primarily to prompt, clarify or elaborate on points already raised. I was also mindful of participant time and energy, and therefore sought not to deviate too far from the planned questions. As a result, there was less opportunity for participants to direct the course of the discussion when compared to the individual interviews. I would nonetheless argue that participants continued to shape this part of the research to an extent, as the focus group questions themselves were informed by dominant themes emerging from the individual interviews that I wished to explore further. In this sense, the methodological contrast between interviews and focus groups mirrors a broader shift from individual narrative construction towards collective sense-making.

Unsurprisingly, focus group participants contextualised their thoughts with brief snippets of their Long Covid stories, which others present were curious to ask about and explore further. This form of peer-led curiosity was welcomed as part of the focus group dynamic. That said, there were occasions where discussions veered off on tangents, or where certain voices dominated the conversation. As discussed previously, in these instances, I stepped in as a moderator to redirect discussion or to encourage wider participation.

Hopkins (2007) suggests that, when compared to an individual interview, focus groups may offer relatively limited depth into a topic as participants may be less willing to share personal details, or dominant voices may silence others. However, as discussed earlier, my focus groups were overwhelmingly open, respectful and amicable and, at times, particularly productive. For example, in her individual interview, Sheila emphasised that she disliked the term “Long Covid”: “I hate the term ‘Long Covid.’

What does it even mean? […] It could mean anything. [...] I don't know why I hate it, but I do [laughs]." During her individual interview Sheila had struggled to articulate exactly *why* the term felt problematic to her, yet these ambiguities were more fully explored and collectively articulated during the focus group discussion:

> Sheila: As I've said to you before, Ellys, I have a real issue with the term 'Long Covid.' […] I don't know why. I feel as if it's just a label. It's an umbrella term that could mean absolutely anything, and it doesn't actually pinpoint what is wrong with people […] And I just think it's not right? I don't know.
>
> E: Does anyone have any thoughts about what Sheila has said?
>
> Helena: […] with the whole Long Covid thing, that term in itself is really unhelpful because it makes people think that you've just got some ongoing version of Covid that they might have experienced themselves, when *their* Covid might have been nothing like yours. And actually, for me, my Long Covid is I now have dilated cardiomyopathy because it affected my heart […] It's so wide ranging that Long Covid to one person, and probably to all of us in this group, means completely different things.
>
> Sheila: Exactly, exactly.

This example demonstrates how the focus group functioned as a form of second interview, allowing both myself and participants to revisit, refine and collectively develop themes initially raised in one-to-one encounters. Here, meanings that were tentative or difficult to express in isolation became clearer through dialogue with others. While individual interviews often enabled more sustained depth in relation to sensitive, personal and emotional experiences, the focus groups offered a different form of insight grounded in collective reflection and shared articulation. While I agree with Hopkins (2007) that focus groups may not always elicit the same depth of personal narrative as individual interviews, there were instances in this research where they enabled a different kind of nuance — one rooted in relational exchange rather than individual introspection. Taken together, the contrast between individual interviews and focus groups offers insight into the dynamic relationship between individual experience and its collective articulation. When treated as complementary rather than hierarchical methods, the two approaches open windows onto how lived experiences of Long Covid are both personally felt and socially negotiated, enriching the overall research findings.

3.11 Health care professionals: failures and opportunities

After speaking to people who were living with Long Covid, I intended to speak to UK health care professionals – clinicians, nurses, physiotherapists, occupational therapists – about their experiences of treating patients, the training they are offered and their broader understandings of Long Covid. My aim was to triangulate the voices of those affected by Long Covid with those who treat Long Covid, to bridge two different forms of 'expert' knowledge, thereby attending to a significant epistemic gap. I had School rather than NHS ethical approval, meaning that I was permitted to recruit health care professionals via personal networks, but not directly through NHS channels. I shared my recruitment poster (Appendix D) on social media platforms – X, Instagram and LinkedIn – and asked a few friends, who are clinicians and physiotherapists, to circulate my poster through their own social networks as well. I eventually realised that my poster was shared among a Long Covid clinic and Long Covid physiotherapist team[32]. My hope was to recruit a few participants through these personal channels, and 'snowball' thereafter, aiming to speak with circa. 10 health care professionals in total. Despite this attempt, however, I failed to recruit a single participant. After six weeks, I decided – in consultation with my PhD supervisors – to terminate this phase of the research and to focus solely on the narratives of those living with Long Covid as I was coming to the end of my fieldwork year. Other than reapply for an NHS ethics application, which, as a lengthy and arduous process, I did not have the time within the remains of my fieldwork year, I felt there was little more I could do.

Naturally, I was disappointed by this failure to recruit, but I began to reflect on possible reasons behind it. Initially, due to the contested nature of Long Covid, I anticipated that I would attract participants who sat strongly on either side of the divide – those who believed in Long Covid and those who were sceptical about its legitimacy. I soon realised, however, that the issue was more complex and nuanced than this. During a personal appointment with a nurse, she naturally asked about work. When I explained that I was a PhD researcher studying experiences of Long Covid, she shared with me that she had treated many patients but felt that all she could offer was an inhaler. She also noted that she could not refer *everyone* to the Long Covid clinic, otherwise they'd

[32] For ethical purposes, I have chosen to preserve the anonymity of these two Long Covid teams.

have an endless list. Following this conversation, I now believe that I struggled to recruit healthcare professionals because many themselves did not feel like an 'expert' in the subfield, and therefore would have little to contribute. Unbeknown to them, of course, these uncertainties and incoherent knowledges were precisely the types of discussion that ideally, I was seeking for my study. If this were the case (indeed this is speculation), it would echo the experiences of those to whom I spoke who were affected by Long Covid. I also speculate that Long Covid sceptics may feel reluctant to volunteer their opinion, either because they do not feel strongly enough to give their time to an interview or because strong deniers may not want to expose themselves on such a controversial topic, despite being offered anonymity and confidentiality.

While questioning why healthcare professionals might feel apprehensive about participating in research surrounding a contested chronic illness – may it be time constraints, potential stigma, the ethical implication of discussing controversial topics, or perhaps my own personal recruitment strategy failure – I also recognise that these perceived failures or silences are revealing in themselves and offer further research opportunities.

First, I considered hierarchies of knowledge and the epistemic authority healthcare professionals hold over societal perceptions of Long Covid. I questioned how their personal beliefs, potential knowledge gaps and attitudes may influence public perceptions of Long Covid's legitimacy, especially when certain views are amplified through media discourse. Does this recruitment challenge suggest that the medical community is still grappling to understand Long Covid? If so, how might this uncertainty affect governmental and medical perceptions, influencing research funding, policy decisions and support for those affected by the illness? This not only impacts financial and medical support, but also social support shaped by public perception. This issue also interacts with the intersectionality of Long Covid, as the lived experience can vary by socioeconomic status, age, race and access to healthcare. Would an interview force healthcare professionals to confront these biases, and how they may intersect with the treatment and support of Long Covid patients? These questions highlight the various ethical dilemmas health care professional may potentially face when engaging in such research.

This recruitment challenge further emphasises the epistemic gap between patient and healthcare professional knowledge. It calls into question the sufficiency of knowledge circulating UK medical circles, and the impact of this gap on the confidence and ability of healthcare workers to treat Long Covid. Furthermore, the apprehension of professionals to engage may reflect their own insecurities around treating elusive illnesses in a Western system of evidence-based medicine. This silence, in turn, accentuates the importance of patient voice, emphasising the role of patients as experts in Long Covid research. How do the lived experiences of Long Covid challenge traditional biomedical models of disease, and what insights can patient narratives offer about the existing gaps in biomedical knowledge? Which further affirms that in studies like this one, the patient voice is central to understanding Long Covid.

3.12 Data transcription, organisation and analysis

I personally transcribed the audio-recordings of all 26 individual interviews and four focus groups, verbatim, deliberately choosing not to outsource this task, despite this being a possible use of research support funding. This decision was informed both by my ethical conduct – allowing me to retain control over the handling, anonymisation and pseudonymisation of sensitive personal narratives shared by participants – and by the value of transcription as a key stage of analytic immersion. Although transcribing is laborious, it allowed me to deeply immerse myself within my data. Transcribing is an integral part of 'getting to know' your data and should not be overlooked as the initial phase of an in-depth data interpretation and analysis. For me, data analysis is an ongoing, iterative process that began long before the formal analysis stage, naturally occurring during data collection and transcription.

In relation to transcription, Ferrie and Greenwood (2025, p.26) usefully remind that "the words we hear and the words we record […] are part of our subjective relationship with the data." As I was primarily concerned with *what* participants said in individual interviews, compared to an in-depth analysis of *how*, I decided to omit certain disfluencies in speech (e.g. stuttering, hesitations), unless important to the context of the interview. In instances where symptoms such as 'brain fog' became visible through speech itself, these moments were retained. Ruth's reflection illustrates this: "I lost my smell and taste, that was really disabil-- [laughs]. Here we go, words, *debilitating*…". I also chose to omit 'filler' words and phrases such as "like" or "you know" for ease of reading. I added italicisation when participants have emphasised words or phrases,

alongside emotional cues including “[laughs]”, “[sigh]”, “[sobbing]”, as here, *how* things are said can often convey more about how the participant *feels* than what was explicitly stated in the verbatim script, adding nuance to *how* participants attach meaning to their story, especially as I came to realise humour was often used as a coping mechanism. Quotations in the following chapters have been reproduced with some text omitted, indicated by ‘[…]’.

I adopted a constructivist approach to grounded theory (Charmaz, 2006), rather than objectivist, which emphasises that “the patterns, themes and categories of analysis come from the data; they emerge out of the data rather than being imposed on them prior to data collection and analysis” (Patton, 2002, p. 306). This approach reinforces researcher reflexivity, as I was forced to step back from pre-existing assumptions and expectations that could influence the interpretation and representation of the data. For the subsequent formal data analysis, I used NVivo (version 14)[33], which is a qualitative data analysis software commonly used to organise, manage and support analysis of textual, audio and visual materials. I employed NVivo primarily for data organising and manual thematic coding, rather than automated analytical tools within the software.

From my initial engagement with the data during transcription, I began to identify recurring themes and patterns. I organised codes hierarchically using ‘parent’ and ‘child’ codes but treated these as relational rather than fixed or discrete categories. For example, from the parent code **‘**bio(geo)graphical disruption’, branched various sub-codes including: ‘disrupted spaces’, ‘disrupted time’, ‘disrupted identity’, ‘disrupted mobility’ and ‘disrupted relationships’. As analysis progressed, it became clear that these disruptions were rarely experienced in isolation but were instead entangled across multiple aspects of participants’ lives. At times, analysis felt overwhelming. I found myself immersed in cycles of identifying, organising and re-organising sub-codes, uncertain where analytical boundaries should be drawn and conscious of the risk of becoming lost in what felt like coding chaos. In this respect, I resonated with Parr’s (1998, p.29) assertion that qualitative research is inherently “messy.” I therefore turned to my supervisors for support. Following their guidance, I stepped back from the desire to impose rigid order and instead embraced the coding chaos, allowing themes and connections to emerge more gradually through iterative engagement with

[33] NVivo 14, QSR International. See: https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software.

the data. Over time, I began to recognise patterns across disruptions to key spaces — such as home, work and social environments — and their connections to shifts in identity, purpose, mobility, dependence and relationships. Importantly, while these codes were deeply interconnected, they were not synonymous, and maintaining analytical distinction between them remained a central concern. To further support this process, I developed a codebook (see Appendix E), through which I defined themes and sub-themes, clarified their meanings and reflected on the relationships between codes. I was reluctant to simplify or overly systematise the data in ways that might flatten the richness and complexity of participants' accounts, but this process helped me to maintain a degree of distinction between codes, while also acknowledging their interconnections.

This iterative process of revisiting the data, refining the codebook and identifying recurring and relational themes allowed me to substantiate and consolidate the empirical structure of the thesis. Once key 'emic' and 'etic' codes grounded in participants' accounts and the literature respectively had been established (Strauss and Corbin, 1998), I adopted axial coding to organise and relate core themes across the dataset (Cloke et al., 2004). Four over-arching themes form the empirical architecture of chapters which follow: Chapter 4: Bio-geo-graphical disruption; Chapter 5: Energy management; Chapter 6: Invisible illness; Chapter 8: Online spaces. Crucially, these chapters are interconnected and relational, working together to trace the interplay between individual and collective experience, through which the everyday geographies of living with Long Covid are produced.

Chapter 4: Bio-geo-graphical Disruption

4.1 Introduction

Participants had varied experiences with acute COVID-19 infection, including the timing of contraction (see Table 3.1), the confirmation of a positive test, the symptoms experienced and their severity. Nonetheless, the unexpected and somewhat sinister onset of Long Covid sequelae was a shared experience. Many anticipated a "normal" (Kate) recovery in the weeks or months following their acute infection. As Arun explained, "I thought I'd be on the way up, and not down," while Amanda articulated her experience: "All my [Long Covid] symptoms just sort of came one by one, gradually, and I just got worse and worse and worse." As such, the "common-sense [COVID-19] guidelines are no longer sufficient" (Bury, 1982, p.170). Bury's original conceptualisation of biographical disruption highlights the "insidious" nature of chronic illness, noting that it does not "break out" suddenly, but rather "creep[s] up." The *unexpected* development of Long Covid, pertaining to its novelty and uncertainty, exemplifies an "insidious onset," creating "a biographical shift from a perceived normal trajectory [of acute COVID-19 infection] through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging" (Bury, 1982, p.171).

Moss and Dyck (2003, p.87) describe the onset of chronic illness as "loss of being able to do regular, everyday things," which reflects Bury's first tenet of disruption. This refers to the disruption to everyday structures – the mundane, taken-for-granted habits and rhythms that are typically seamless but suddenly brought into awareness. Long Covid profoundly impacted participants' everyday lives. As Helena expressed, "there's no aspect of my life that is anything like what it was before I got Covid," while Sheila (FG1) echoed, "my life's been turned upside down." The biographical disruption caused by Long Covid is severe, positioning individuals with a new illness identity that sharply contrasts with their former selves.

Typically, participants in this study understood themselves as physically active across domestic, work and social spaces. As Anna shared, "I always was a super active person and did one million things all the time, running around and always have multiple jobs […] which is just totally impossible now. I think that makes the shock […] harder." Here, Anna emphasises the profound impact of Long Covid's onset as a "shock", which destabilised her sense of self and how she managed her daily life, again

exemplifying Bury's (1982) first tenet of biographical disruption. Her once fast-paced, multi-tasking and physically demanding routines were suddenly disrupted by Long Covid and brought into consciousness, creating a stark contrast with her previous identity. This disruption forced a wedge between her "internal and external" corporeal reality (Bury, 1982, p.171), revealing a dissonance between her self-perception and the limitations imposed by Long Covid. As Anna elaborated:

> Especially with young people [like me]. If you look at an old person who's just tired or all the time, then you can kind of understand that the body just starts to give up […] but for someone who looks alright, and in their late 20s or something, it's hard to imagine, and I think that's the hardest thing to live with.

In comparing the embodiment of everyday space to that of an "old person," Anna emphasised that she was not only struggling with the physical limitations of Long Covid, but also the psychological impact of trying to navigate an energy-limited body that is no longer able to keep up with her previously active lifestyle. This shift further indicates the intimate connection between disrupted mobility and disrupted sense of identity. Participants' perceptions of their bodily capacities are destabilised as their external corporeality sharply contrasts with their internal connection to their relatively younger self. This contrast reflects a significant temporal disruption in their chronological progression and life trajectory, exemplifying Bury's (1982) second tenet of disruption, which challenges understandings of the self and future imaginations. In discussing her fatigue, Anna suggested how her experience contradicts typical disease pathology, as her internal, young and physically active biography offers no biological basis for her illness experience (Bury, 1982). Anna further articulated the complexity of fatigue as the "interplay between the physical and the mental […] because it's a physical fatigue, but it's a mental response to it as well." This insight reveals that fatigue is not merely a physical experience, but also involves mental and emotional energies, affecting individuals on a both corporeal and cognitive level, emphasising that the mind and body are indeed intimately connected.

This narrative, as shared across participant stories, parallels the work of Moss and Dyck (2003, p.128) who further assert that the onset of illness "brings into focus the social and physical milieu through which issues about self and identity surface." This loss, or disruption, is therefore not only experienced in terms of physical abilities but also is emotionally and socially charged. As Amanda eloquently explained: "There's a

lot of suffering with Long Covid. It's emotional suffering, it's physical suffering, social suffering. Your whole life is changed beyond recognition, really." This chapter will therefore explore the complex contours of suffering that characterise the lived experience of Long Covid, as they are "anchored in a particular time and place" (Dumes, 2020, p.156).

In what follows, this chapter will detail the impact of Long Covid on everyday spaces, routines and relations that allow individuals to engage in the world meaningfully, which often define their sense of self. I use a bio-*geo*-graphical perspective to examine "the extent to which relational experiences of space/place are disrupted by changes in the life course arising from disability as well as by how taken for granted embodied states have to be renegotiated at any other place anew" (Meijering et al., 2017, p.7). This is particularly profound in Long Covid experience, as its novelty means many do not have a prior concept of what it is or how it will affect them. I explore the spatial, temporal and material disruptions experienced by participants following the onset and development of Long Covid, which fundamentally destabilises how individuals relate to the world around them. More specifically, I trace the extent to which everyday meaningful domestic, work and recreational places, routines and relationships are disrupted and re-negotiated. In doing so, I question the extent to which individuals accept their new illness identity and create a sense of bio-geo-graphical flow by re-configuring everyday spaces, routines and relations. Furthermore, I explore the symptomatic and structural barriers participants face, alongside the uncertainties surrounding recovery trajectories, to better understand the extent to which participants feel spatially, temporally and corporeally 'stuck' within their Long Covid experience.

4.2 Domestic routines, roles and relationships

It has been well acknowledged within human geography that the home is a significant space which provides meaning in everyday life (Domosh, 1998; Blunt and Varley, 2004; Duncan and Lambert, 2004; Blunt and Dowling, 2006; Massey, 1992); Massey, 1992). The 'idealised' home is often imagined as a place of privacy, independence and sanctuary[34] (McDowell, 1999). While a house can be considered a physical container, a *sense* of home is created through "personal meanings and associations"

[34] Many studies have criticised this 'idealised' notion, exploring multiple meanings of the home, included, but not limited to, the home as a space of fear, violence, terror and confinement (Chapman and Hockey, 2002; Price, 2002; Parr et al., 2003; Blunt and Dowling, 2006; Brickell, 2012).

(Domosh and Seager, 2001, p.xxii), shaped by social routines, roles and relations (Meijering et al., 2019). The meaning of the home is therefore multifaceted and understandings are not fixed, and may be challenged by the onset and development of chronic illness and bodily impairment (Angus et al., 2005), prompting Imrie (2004) to contend that domestic experiences should be considered through corporeality and (dis)embodiment. Crooks and Chouinard (2006) echo that embodiment is central to understanding how individuals[35] live their disrupted lives following the onset of chronic illness. As such, this thesis defines embodiment as "ways of expressing particular experiences, roles, identities and feelings through the body" (Crooks, 2010, p.56), drawing attention to the different ways participants in this study navigate bodily expressions and bodily expectations associated with their everyday routines, roles and relations.

The home[36] became a key site of Long Covid experience, as physical and mental limitations created barriers to engaging in other significant work and social spaces (examined later in this chapter). At the onset, participants described physical limitations, particularly pertaining to fatigue and reduced energy levels, which restricted individuals to their homes. As Arun shared, "I was struggling to even walk to the bathroom, never mind the idea of going out of the house or doing something." Long Covid therefore destabilised traditional understandings of the home, towards it comprising a more problematic space of confinement. Participants not only felt confined to their homes, but many also described being restricted to a single room – often the bedroom or living room – and, more specifically, micro-spatiality – typically the bed or the couch – especially in the early stages of developing Long Covid or when experiencing a 'crash'. Arun, Farrah and Kate all spoke of being "bed bound" for certain periods, while Amanda shared, "the first two years I was just like a zombie really, just sat on the settee day and night." The next subsection will therefore consider further how understandings of the home were destabilised through disruptions to everyday domestic routines, roles and relations. I acknowledge that disruptions at home are not

[35] Crooks and Chouinard's (2006) study is centred around women's specific forms of embodiment, but the broader dynamics of embodiment of which they speak are arguably integral to the disruptive chronic illness experience of everybody, all genders included.
[36] It is worth noting that all participants in this study had access to some form of stable housing. A study focusing on individuals with Long Covid who are unhoused or experiencing homelessness may yield significantly different insights.

experienced in isolation to other significant work and social spaces, to which I will return later in this chapter and subsequent chapters.

4.2.1 A disrupted sense of home

As already outlined, participants often described feeling confined to their homes throughout their individual interviews. I therefore asked focus groups to discuss how they viewed their homes in relation to their Long Covid. I directly asked if their homes felt more like a "trap" or "sanctuary," or if they had another word to describe it. The responses were mixed. Some participants described home as their "safe space." As Lu (FG2) articulated:

> I'm really successful at home. I don't feel like I have Long Covid at home, because I can put the washing on, I can do the ironing, I can cook a meal for the family. I can do all that. So, when I'm at home, it's like going back. I feel like I haven't got it.

For Lu, the home represented familiarity, routine and a connection to her former self. This space enables a kind of temporal relocation, reinstating the body as it was before illness and effectively forming a shield around her experience of Long Covid. For others, however, the home often acted as a reminder of their illness and of the spaces and routines they could no longer access. As Helena (FG1) shared:

> I don't like mine, just because it reminds me that I'm here and I'm not actually at work. It makes me feel sad in the day when I'm at home [...] because it's just a constant reminder that everybody else is out at work, doing, living their lives, and I'm here still after Covid all this time.

Arun (FG4) further remarked on feeling trapped during a crash at home:

> I think the worst period is when you're in a crash in your bedroom […] When you're staring at the same four walls and you're not able to go downstairs. You are in a room, and that's when I feel like the prisoner element comes in, because you are trapped, effectively.

As Arun explained, when he crashes, he is physically stuck in his bedroom. Participants also shared experiences of being in a crash for days, weeks or even months. Kate elaborated on the focus group discussion, noting, "like Arun was saying […] when you do crash, it's so hard because you don't know when that's going to end." The crash also entraps individuals in time, as they are unable to predict how long it will last. Kamy (FG4) added, "I don't even have the energy to think how to get out of it." During a crash, Kamy is disembodied – she is both physically and mentally

incapacitated. The crash thus creates a sense of corporeal incarceration, not only in the body, but also in mind, as individuals lack both the physical and mental energy to escape it. Therefore, the crash intensifies material domestic entrapment, confining individuals in space and time, mind and body; they are disempowered and stuck within the confines of their body. I return to the concept of feeling spatially, temporally and corporeally 'stuck' in what follows.

For most participants, the home was experienced as a paradoxical space. It was both a carceral trap – a constant reminder of a former life and time-space routines they could no longer access – but also a refuge from the outside world and the unpredictable nature of Long Covid. As Kate (FG4) shared:

> I think for me it's mixed as well, really. It is that feeling of being trapped when you want to be out and doing things, and when you used to be busy and active, in that sense, it feels like you're trapped, because you're looking out at what you could be doing, really. But on the other side, when I could come downstairs and use the living room, and I filled it with plants, they were the things that just made it feel like a sanctuary. And this is where I have my yoga mat on the floor, my cushions and blankets, and I do my recovery […] So I relate that now to feeling calm and being able to do the things that helped me to cope with it. And so, for that reason, I think it also feels like a safe place when perhaps sometimes out of the house doesn't feel quite as safe, when it's unpredictable, I know I can rest here.

Echoing Helena, Kate described her sense of entrapment as a lack of autonomy and control, as she is spatially reminded of all the things that she can no longer do due to her physical limitations. Paralleling the work of Crooks (2010) on women with fibromyalgia, increased time spent at home signified, for many, the loss of other significant socio-spatialities outside of the home, such as paid labour and community participation. This shift indeed transforms meanings ascribed to the home as a place of refuge to one of confinement. However, by making physical adaptations to her living room environment – by filling it with plants and using the space to practice yoga – Kate has now recovered a sense of calm and control. These small adaptations agentically shift her experience in support of her health and wellbeing in-place. Her home, sometimes understood as disabling and a space of confinement, is thereby transformed into a place of rest and recovery, restoring Kate's sense of safety and re-defined her sense of home. As participants' testimonies highlight, the home is a complex and ambivalent space.

Kate further positioned her sense of familiarity, safety and control at home in stark contrast with her unpredictable body, one that renders outside unfamiliar spaces as unsafe, with unpredictable implications for the ill and precarious body. As participants come to understand the material limits of their body through the context of (un)familiar spaces, they began to experience their illness directly through *embodiment.* As such, the palpability of Long Covid extends beyond, and rebounds back upon, the individual's body, shaping how individuals' perceive their immediate surroundings, as either safe and controlled, or limiting and unsafe (Moss and Dyck, 2003), which I explore further in the following chapter.

Participants also experienced physical barriers to mobility within their home, as spatial challenges for their energy-limited body, that contributed to experiences of overwhelming fatigue. The stairs, typically seen as a mundane micro-architecture of the home that provides access between spaces, became a significant physical barrier. Many participants described the stairs as a dreaded obstacle they had to overcome to engage with other domestic areas and routines. As Sheila shared:

> I know that in the very early days for me, I mean, if I got down the stairs, because in the very beginning, *if* I come downstairs, I would look at the stairs and think, 'how am I going to get back up them?' Because it was literally [like] climbing Mount Everest.

Sheila's hyperbolic comparison of her stairs to Mount Everest emphasised the physical energy demands required to climb them. She continued, further reflecting upon her taken-for-granted relationship with her stairs prior to the pandemic: "when I think of my life pre-COVID, when you just run up the stairs, now it's a bigger deal [laughs] […] it takes me a *lot* longer." This experience illustrates how her once seamless mobility around the house was disrupted, making the simple act of walking, not even running, up the stairs a conscious effort. This awareness forced participants to consider whether the energy required to climb the stairs is worth the physical toll.

When previously mundane home features, such as the stairs, are redefined as an energy-demanding obstacle through painful bodily experiences, they alter the meaning of the home (Segrott and Doel, 2004). As such, when the physical layout creates barriers to mobility and movement, individuals may experience their home as a disabling space (Imrie, 2004). This change reflects Imrie's (2010, p.26) assertion that, "the body, and its interactions with domestic space, reflects a complex conjoining

of physiological and social and cultural relations to produce specific, person-centred, meanings of the home," as a safe, autonomous and health-promoting space. These findings further align with Crooks and Chouinard's (2006, p.346) view of disablement as "an embodied process of becoming ill and being ill in place(s) and over time in ways that have disabling outcomes for individuals." In the context of my study, many participants did indeed experience the home as a disabling space, altering their experience of health and illness at home.

Crooks (2010) argues that we can understand disablement by conceptualising the interconnectedness of the mind, body and lived reality, including how individuals navigate their embodiment of space. In response to the physical demands of the stairs, some participants made physical adaptations. For example, Cath and Theresa installed handrails, while others adjusted the typical layout of their homes. As Mark (FG1) explained:

> I've got a Victorian house, which has a challenge with the steep stairs, which is a physical issue there. And I've had to, and I still do, keep some things upstairs and some things downstairs, so I don't have to keep going changing floors to get something. Last summer, I had my suncream lotion upstairs and downstairs. I had one in each floor, so that I didn't have to keep … I have some cleaning fluid in the living room. I still do that. So, if something goes, I don't have to go to the kitchen. So, I've adapted. Perhaps, as I'm saying it now, I didn't realise how much I've actually done so I don't have to get up, to go upstairs or go to another room, just small things like that. I get really annoyed when I leave something in another room and I gotta go to all the effort to go to get it again or go upstairs again[37].

Mark's experience highlights how these adaptations serve to manage energy levels by reducing the effort required to handle everyday domestic responsibilities, especially as he lived alone with no one to offer support. Similarly, other participants who also lived alone made adaptations to mitigate the energy required for home routines. Monica hired a cleaner, Fiona installed a shower stool, while Theresa and Megan resorted to ordering more takeaways when they lacked energy to cook.

Furthermore, participants living alone relied heavily on the mobilisation of medical and governmental support to provide guidance and help them qualify for financial

[37] I use "..." (without square brackets) to indicate a pause in the participants speech, whereas "[...]" signifies a deliberate abridgment of the quote.

assistance. Many participants emphasised the role of occupational health, often facilitated by Long Covid clinics, who made suggestions of various adaptations. As Fiona explained: “I also realise now, the physical impact, the load that was on me, of silly things, which I didn't know to look for, but the OT[38] at the Long Covid [clinic] did.” Modifications were hence subject to access to information and resources, alongside government support and finances. Therefore, managing Long Covid intersects with social class, to which I return in what follows.

Although adaptations were not limited to those who lived alone, it was evident that the impact of physically adapting to Long Covid was felt more acutely by those without familial support, both socially and financially, to assist in everyday domestic routines such as cooking and cleaning. Kristina and her husband adapted by moving home, from a flat with stairs to a single level “compact lodge” in a more rural area. She shared:

> Once I’m on that one level, and everything’s so close, I can get around because, I think the physios called it ‘furniture surfing,’ I can get around without having to cross rooms and things. So, in terms of my balance, that works better for me. But it does mean as well, if I do a 50-minute session with a client in here, I can go make myself a cuppa and I can go and sit on the decking when it’s dry [laughs]. And I’ve got this massive view over the golf course and over the woods. It’s just open spaces and I don’t feel like I’m trapped anymore. I felt trapped in the flat because I couldn’t get out.

Kristina no longer feels trapped because she has the freedom to move freely around her new, single-level home. This new space allows her to “furniture surf” and access open areas of her rural surroundings from her doorstep. Like Kate, Kristina has re-gained a sense of autonomy and safety, overcoming the feeling of confinement by moving to a new living space which accommodates her limited mobility and energy levels.

Similarly to Kristina’s move to a rural location, many highlighted the garden as a significant extension of domestic space, offering a sense of sanctuary. As Amanda (FG1) stated:

> I feel very lucky because we’ve got a garden. It’s only a little garden, but it is very important to me. I can’t do the garden anymore, but I do like to sit in the garden and look at the garden and supervise [laughs] […] Although I do feel can’t really maintain it any longer, but it’s still nice to have.

[38] Occupational therapist.

While Amanda can no longer care for the garden she still finds joy by spending time there, supervising her husband while he tends to it. For Amanda, the garden is a continuation of her home – an integral outdoor extension to her spatially-limited life now largely confined to the home space. Her presence in this space fosters a sense of bio-geo-graphical flow, offering both sanctuary and refuge within the home and its immediate environs. These experiences emphasise the importance of the home's quality (Imrie, 2004), and how it connects to nature (Parr, 2007), for physical and mental wellbeing.

Participants have shared how the experience of Long Covid, particularly at the onset, disrupted the typical meaning of their home, transforming it from a sanctuary into a space of confinement. The stairs, once a symbol of mobility, became a barrier to mobility, contributed to a sense of entrapment as certain domestic spaces and time-space rhythms become inaccessible and disembodied – or at times, even more profoundly embodied – as the physical energy demands of the stairs to access other spatialities of the home intrude on an individuals' sense of self and capacity. A previously seamless activity is brought into full bodily consciousness. The social model of disability posits that disablement results from the built environment, which creates physical barriers to accessibility and hinders participation (Oliver, 1990). However, this model often portrays individuals as oppressed 'victims' lacking control over their surroundings (Imrie, 2004). In contrast, participants in my research have demonstrated agentic capacity to adapt their domestic spaces in a way that preserves their efforts and energy to re-claim embodiment of their home. For example, physical adaptations such as handrails or moving home, *increased* mobility between spaces and overall accessibility of the home, while other adaptations, such as rearranging the layout of the home or buying pre-chopped vegetables, helped to *reduce* mobility demands and preserve energy, which ultimately allowed participants to re-engage in everyday domestic time-space rhythms. Adaptations such as hiring a cleaner or ordering takeaways offered individuals opportunities to dis-embody everyday routines during periods of low energy and when no familial support was available.

The disruption to the home as it became more akin to a space of confinement was further ameliorated through outdoor spaces. Amanda's story exemplified how participants were able to re-embody the garden as a domestic space through a more passive role of sitting and supervising instead of actively maintaining the space

themselves, allowing them to foster a sense of bio-geo-graphical flow within (and around) the disrupted home space. These physical and social adaptations played an important role in allowing participants to (dis)embody domestic spaces and routines, regaining control and autonomy over their home environment. Participants' experiences further indicate that, while their sense of home evolved from a place of safety and independence to one of confinement and restriction, this shift in meaning is certainly not static.

Instead, the sense of home is dynamic, continuously shaped by changing socio-spatial and temporal contexts, which was vivid within Hannah's experience. Initially, Hannah's cottage in the remote countryside[39] was a place of autonomy and independence, where she enjoyed spending time exploring the outdoors. However, following the onset of Long Covid, Hannah experienced non-epileptic seizures which left her unable to drive and with no access to public transport[40]. Hannah explained that she hence felt isolated and trapped in her beloved countryside and therefore moved closer to her parents to gain access to support which "on a practical level, […] has really helped." Echoing earlier testimonies, Hannah elaborated how "everything's [now] all on one level [...] so it's still a sanctuary, me coming back to my little flat." Nonetheless, this move presented new frustrations. As Hannah shared, "On a wellbeing level, to some extent it has led to other frustrations, because I was so independent before [...] I felt like I was a teenager again having to rely on them [her parents]." Further complicating this experience, when her parents were away, they would become concerned about Hannah leaving the house, pressuring her to stay indoors and enforcing a sense of restriction that she likened to "Covid lockdown all over again" – a spatio-temporal continuation of the pandemic, which I unpack in what follows. While her single-level home offered a stable physical sense of safety, her dynamic sense of confinement reflected her evolving needs and complex family dynamics throughout her illness experience. She felt pressured to conform to her parent's concerns about her health and safety, and so her feelings of stuckness were not only physical but also psychological. As she sometimes feels trapped and isolated within the walls of her

[39] This study does not offer a traditional rural/urban geographical contrast in shaping the experience of Long Covid, as the sampling framework does not allow for a rigorous evaluation of such differences, which varied significantly across participants' broader social contexts. As with Hannah's case, geographical references will be included only when they are contextually and empirically relevant

[40] See Niall Smith's (2013) study on the everyday geographies of epilepsy.

home, she reported also feeling emotionally constrained by her increasing dependence and a regressive sense of biochronology, of feeling like “a teenager again,” further restricting her autonomy, reveals ongoing tensions between her need for support and desire for independence.

To overcome her parental gaze and pressure, Hannah hired a support worker, which allowed her to freely access the community “on my terms” and to regain a sense of control. However, rather than feeling like a teenager relying on her parents, Hannah faced an opposing disruption, comparing her new situation to that of an 80-year-old. Yet this shift did not resolve her sense of temporal dislocation; instead of feeling like an adolescent reliant on her parents, she now compared herself to an 80-year-old, describing a different but equally constraining form of dependence. Hannah’s story thus illustrates profound temporal disruptions and chronological reworkings, as she becomes caught between contradictory identities of adolescence and old age. While hiring a support worker expanded her agency and reshaped her experience of confinement and isolation, it simultaneously underscores that she remains dependent, but just in a different way. These temporal dislocations reflect Samuels’ (2017, n.p.) description of how “crip time is time travel”, wherein disability and illness extract individuals from normative, linear life-course expectations. Hannah has been thrust into the embodied losses more commonly associated with older age while still young, and being positioned, socially and emotionally, in a childlike role regardless of her actual age. Her account therefore evokes Samuels’ (2017, n.p.) description of crip time as a “wormhole of backward and forward acceleration” marked by stops, starts and abrupt shifts, where autonomy contracts and expands unevenly.

The additional caveat to this new found freedom, moreover, is that her support is personally financed rather than government funded. She explained that “when my savings run out, that’s it.” Her freedom is therefore contingent on financial circumstances, which is subject to change in the future, especially if she is not granted the government support that she needs[41]. Her autonomy is therefore precarious and contingent, and not fixed. Like many others affected by Long Covid, Hannah’s dynamic experiences of stuckness and freedom are seriously complicated by various socio-

[41] Although the DWP recognises Long Covid as an eligible condition for financial support, participants nonetheless reported significant challenges in accessing government benefits.

economic factors such as personal, family and financial resources, all of which are subject to change.

The experience of bodily impairment at home is also fluid, as these contexts either reinforce the impact of Long Covid or offer a shield, thereby variously influencing the (dis)embodiment of their former selves. This situation suggests that the embodiment of Long Covid is fragmented, with bio-geo-graphical disruption and flow shifting within and between domestic spaces, roles and relationships. Echoing the findings of Meijering et al.'s (2019) study on the bio-geo-graphical disruption of ABI survivors, the meaning of the home is continuously maintained, lost and/or re-gained.

4.2.2 Disrupted roles and routines

As suggested, Long Covid not only disrupted participants' mobility but also deeply impacted their domestic routines, roles and relationships. Everyday habits and routines, once taken-for-granted, were brought into consciousness (Bury, 1982). As Ruth explained, "there's so many things you have to do that were automatic before. So, I've had to relearn." Many participants became dependent on family support for everyday tasks like gardening, cooking and cleaning. Some also became financially dependent when they were no longer able to work. The disruption to participant independence and autonomy had emotional and psychological impacts, especially through disruptions to intergenerational roles. Helena recalled: "I couldn't even look after my children. I couldn't get off the sofa to even make them food." Others shared their experience of reversed parent-child caregiving roles. Megan, who lived alone, became increasingly dependent on her aging parents. She shared, "That's the hard part […] When they're retired and they're coming to do my hoovering, it should be the other way around [laughs]." Megan struggled to accept care from her parents as an adult, feeling that she should be reciprocating care in their retirement. This experience reflects another disruption of biochronology, unsettling the expected caregiving roles typically associated with different stages of life.

Conversely, Arun became dependent on his teenage son. He articulated how the reversal of domestic roles affected him:

> My son, he's 17, but he's my carer more than anything […] Instead of me being the parent and provider and helping him, he has to bring me breakfast every morning before he goes to school. He leaves me some snacks on the side before he goes for lunch, because, for example, last week, I've been downstairs

> once in the week. And he'll make me dinner and deal with it. He's got exams at the moment, it's not fair, it's not really ideal.

Arun's story reflects the impact of Long Covid on both his physical capabilities and domestic life. His experience of having only been "downstairs once in the week" echoes earlier discussions about the role of the physical home layout in shaping everyday experiences of Long Covid, with the stairs acting as a barrier to other domestic spaces. These everyday domestic spaces, key sites of family interaction and routine activities such as cooking, have become inaccessible. Arun is segregated from the rest of his house, both physically confined and socially isolated upstairs, relying on his son to manage domestic responsibilities and offer care, emphasising his socio-physical disablement. This shift in responsibility has emotional and psychological consequences for both parent and child, as Arun feels he is burdening his son with parental tasks that he himself should fulfil, especially when his son is already under the pressure of school exams.

Interpersonal relationships within the home hence changed significantly, as many could not fulfil their productive bodily expectations associated with their roles as partners/spouses[42], (grand)parents and caregivers (Crooks, 2010). Many discussed their partners or children taking on more domestic responsibilities, such as cooking, cleaning and caregiving, while some, like Arun, expressed feelings of guilt for placing additional domestic demands on their family members who already had other work or schooling responsibilities. This reversal in familial roles reflects broader emotional and social geographies of chronic illness and care, where usual caregiving dynamics are disrupted (Stables and Smith, 1999; Guest and Corrigan, 2018). This shift complicates the experiences of both parent and child. Such changes in domestic roles highlight how illness can deeply affect one's sense of self and personal identity as it relates to independence and autonomy, which is intensified when core responsibilities like parenting and caregiving shift. As Kristina shared, "I really struggled with this whole adjustment thing because I've been a carer all my life […] and I just can't get used to

[42] There was little discussion regarding the sexual dimension of partner/spousal relationships, which in itself reveals boundaries of what participants may be willing to disclose or withhold within the interview context. When sexual intimacy was mentioned, it was in the context of altered appearance and feelings of (un)desirability, which corresponds with later discussions about the challenges of forming new romantic relationships. However, there is also reason to assume that changes in libido – conceived here as a form of sexual 'energy' – may also impact intimate relations. This points to an interesting avenue of future research into how Long Covid, as an ELC, shapes and potentially hinders (new) intimate and sexual relations.

being on this side of that divide." The shifting of domestic roles and responsibilities therefore creates a severe bio-geo-graphical disruption as everyday time-space routines are destabilised.

Arun's sense of socio-spatial isolation was shared by many participants, particularly those who lived alone[43]. In the context of women's experiences of fibromyalgia, Crooks (2010) explored both desired and undesired isolation at home. Hannah, who experienced non-epileptic seizures as one of her Long Covid symptoms, expressed feelings of fear and guilt about putting her friends and family in a position where they were exposed to one of her seizures. She explained, "I don't want to put the impact of what I'm going through onto other people." As a result, her isolation, which she had previously found desirable due to living alone, was further compounded by her undesired withdrawal from both work and social environments. Despite not wanting to further isolate herself in this way, she made this choice to avoid feeling like a burden to others. Monica (FG3) expressed similar concerns about not wanting to burden or disappoint her loved ones with her variable illness, but she also noted the undesired nature of her isolation when her symptoms worsened, with no one to care for her. She confessed: "I thought I was all right on my own, but I think I've had a whole new sense of what that actually means to be on your own when you're ill in a recurrent capacity." For Monica, her illness transformed her perceptions of home from a space of desired solitude to undesired isolation, as she shared: "sometimes it can feel like a real, trapped space." This hence contributes to perceptions of the home as a carceral space within Long Covid experience.

Megan drew a parallel between her experience and pandemic lockdowns. She articulated, "Now I can't go out, and now I can't do this. And now I've been forced back into isolation because I've got Long Covid." Because of her bodily limits, Megan feels spatially stuck at home as the spatio-temporal dynamics of pandemic lockdowns effectively persist, a theme I explore later in this chapter. Participants also discussed experiences of isolation pertaining to the novelty and elusiveness of Long Covid. Incoherent medical knowledge and support meant that participants felt that they were "left" to deal with Long Covid on their own, with many, especially in the early stages of the pandemic, feeling that they had few, or no one to empathise with or offer support.

[43] David, Fiona, Hannah, Mark, Megan, Monica and Theresa all lived alone.

Therefore, feelings of isolation were closely linked to the mobilisation of social and medical support in online spaces to provide much-needed validation and empathy – which I unpack further in Chapter 7.

4.2.3 Relational disruption and disrupted relationships

These narratives of individuals becoming more dependent and family members taking on more active domestic roles further demonstrate that bio-geo-graphical disruption is deeply relational. Participants agreed that disruption stretched beyond themselves. As Alexandra shared: "the suffering is beyond me […] it's had a huge impact on my family." Although I did not speak directly to relatives, relational disruption, and broader social and emotional suffering, was clear throughout participant narratives. When I asked Marg about her progress and recovery, she responded: "If I was to ask him [my husband], I don't know. […] I think, he wants me to be able to do more." Similarly, Amanda shared how Long Covid disrupted both her and her husband's future:

> It's hard for him because it's not the life that we were expecting. We just retired and we were very active. We used to go on walking holidays […] We did everything together really. So, it's been very hard for him. At the beginning, he just kept wanting me to get better, but now he sort of does understand, and I think he's come to terms with it.

These experiences exemplify a temporal incongruence between intimates' expectations of recovery and participants' lived reality of corporeal restrictions and slowed daily rhythms that contradict with their past life. Participants' partners perceive a curtailed future, wanting, and often encouraging, the individual affected by Long Covid to participate in former time-space rhythms that their body will no longer permit. Kate explained that her close relations encouraged her to "push" herself to aid her recovery, referencing their lack of understanding surrounding Long Covid, which often contradicts the typical recovery trajectory seen with acute illnesses:

> I think about the amount of people – my husband, my mum, friends – that have said, 'No, push yourself, you should feel uncomfortable' […] And I think, 'I can't even ride [a bike].' I did try riding a bike last year. 10 minutes I was out[side] […] But I crashed […] I can't push myself, and I find that really hard, being around people who can.

When participants "push" beyond their corporeal boundaries and limited temporal rhythms, it can often result in a crash. These narratives furthermore demonstrate that bio-geo-graphical disruption extends beyond the individuals living with Long Covid,

impacting not only those directly affected, but also their family and social networks. They reveal that families not only experience socio-spatial disruption in their daily lives, but also a temporal disruption, reshaping their perceptions of the future (Bury, 1982).

Alexandra expressed deep concern for her place in her family's future. She feared that her value was diminishing, feeling she was unable to offer the same version of herself to her family:

> I am scared that I'm just going to be sat in this corner, and their lives will go on and gradually, the time for me will peter out. And I wouldn't blame them, because what can I ...? I've got good sense of humour, but apart from that, I can't do very much […] I'm feeling a little bit sad saying out loud, I suppose. And it's funny, isn't it, talking to strangers, you talk in a different way than you would ever admit otherwise. But yeah, I feel like I'm a bit like a shadow really. I'm just looking around my room and it's all […] our family stuff, and I feel like I'm a bit absent[44].

Through her deeply emotional narrative, Alexandra powerfully conveys how Long Covid has created what Moss and Dyck, (2003, p.129) describe as a "presence of absence," as she feels her sense of self missing within her family space and memorabilia. Her story highlights the emotional impact of Long Covid, not just on the individual, but on broader relationships and identity, feeling like a "shadow" within her family, but also a "shadow" of her former self who can no longer fully participate in family life. Her use of the term "shadow" evokes a profoundly dark hauntological metaphor, suggesting a peripheral sense of existence – being present, but not fully there. Her description suggests a phenomenological shift – a disembodied way of being-in-the-world, where she is no longer an active participant within her own lifeworld, or her family's. Rather, she becomes a passive observer, viewing her place in her family through photographs and memories, now following others from the margins. This point echoes Bissell's (2025, p.6) analysis of "feeling out of it," where individuals experience affective displacement and disengagement even within familiar domestic spaces that would typically offer ontological security. In these spaces,

[44] Despite this research being conducted remotely, Alexandra - who participated from home - highlights the power of home-based interviewing in shaping memory and narration. This dynamic echoes Rose's (2003) observation that photographs can convey the corporeal distance between there-then and here-now, powerfully evoking a liminal sense of both presence and absence through disruptions to bodily capacities. Although Alexandra is physically present in body, she experiences a mental, emotional and energetic absence – "feeling out of it" (Bissell, 2025, p.6) – which impacts her very ability to embody presence within her family space.

Alexandra experiences a liminal subjectivity, where her body remains physically present, yet she is detached from the agency or engagement that once structured her everyday life. Through the likes of photographs, the home becomes a material archive of Alexandra's former self, offering proximity to who she once was, while simultaneously amplifying the dissonance between her past and present embodiment. Her bio-geo-graphical disruption is thus experienced in both place and body, but also in her temporal and affective orientations, creating ruptures in how both her and her family perceives the present and also envision their future.

The majority of participants expressed having sympathetic and supportive families, but Alexandra's fear of her family moving on without her due to her perceived inadequacy was indeed the reality faced by some. Arun's experience of Long Covid impacted his marriage, which ultimately ended in divorce. The remainder of this sub-section, concerning disrupted familial relationships, will hence centre his experience. Arun attributed the disruption of his marriage to both the COVID-19 pandemic and the implications of Long Covid:

> When Covid came along, her head was like, 'I need to live my life. I could die tomorrow.' And then there's me [laughs], lying there, with Long Covid and what am I offering her? Life? Loads of experiences and enjoyment and whatever that comes with married life? No. I'm offering her nothing.

Similarly to Alexandra, Arun expressed feelings of inadequacy to participate fully in married life as he once used to. These feelings were exacerbated by a lack of empathy. He noted: "Every time I tried to talk to her about it, there was just a blank. Did she want to talk about it? No. Does she even accept that I have an illness? I don't know." This lack of support intensified his physical suffering, leading to more frequent "crashes."

The legal and financial implications of divorce compounded the existing stresses of Arun's Long Covid experience, stripping him of any energy to engage in a legal battle:

> She took me to court over finances. So not only now do I have to deal with Long Covid, angry teenager, divorce coming up, I have to now fight a court case […] In the end, I couldn't take the stress of it all, and we ended up agreeing something.

Complicating Arun's situation further was the severing of significant social connections following the divorce, leaving him feeling isolated. He shared: "For 19 years I

socialised with her family, built up connections. But when we split up, all that disappeared. Her family stopped talking to me, everyone." The loss of his social support network added to the weight of his experience, as he was left to navigate his Long Covid alone with the added responsibility of his three children, of whom, Arun had primary custody. Arun's bio-geo-graphical disruption was multifaceted, layered with physical, social and emotional suffering. Long Covid not only placed strain on his relationship, but also left him bereft of the energy to fight for his marriage or better manage the many stresses associated with eventual divorce. His suffering was exacerbated further as he was left isolated to manage his Long Covid, family responsibilities and the emotional toll of divorce.

The disruption to intimate relationships was echoed by some single participants[45], who shared the emotional impact of perceived barriers to forming new relationships. Mark expressed his feelings:

> I've got no chance of being in another relationship now for the time being because I'm just too tired to go out and do an awful lot. But it's impacting me. I'm slightly reconciled to that […] It really frustrates me […] I try not to think about it […] If I think about it, I feel very sad. I keep that quiet to a lot of people, but I really do feel sad about that.

Mark feels like he is physically unable to engage in activities like dating or maintaining a romantic relationship. Although he expressed his sadness to me, he often hides his emotional suffering from others, frustrated by his lack of control and inability to change his prospects for future relationships. Theresa shared a similar experience to Mark. She explained: "as soon as I mentioned the Long Covid, they suddenly lose interest." She pondered that her difficulty in forming new relationships might be linked to her weight gain, which resulted from reduced activity levels and having to rely on takeaways when she has little energy to cook after work. She articulated:

> No one wants to, in my mind, maybe date a woman who, you know, I've put on a lot of weight. I used to be a size 14. I'm now a size 18, ordering a 20, because I cannot exercise, because if I exercise, I can't cope the next day. It affects my body. Now, obviously I'm eating a lot of takeaways. Not the best eating, because it's quick, easy foods all the time. So, when you start talking about

[45] At the time of interview, Arun, Fiona, Hannah Mark, Megan, Monica and Theresa were all single and lived alone. Arun, Mark and Theresa mentioned their frustrations about future relationships and challenges of being isolated at home. Romantic relationships were not explicitly discussed by Fiona, Hannah or Monica, only the impact of their isolation.

> having a chronic illness, I think for a lot of men at my age, it's still very, 'that's not what I want. I want someone I can go [out] ...'

As Theresa feels unable to fully participate in an active relationship, like Mark, she joked, "are there no men out there that are just wanting to sit on the sofa? Why have all men suddenly joined the gym and taken up cycling? [laughs]. I can't do that sort of thing." There is a disconnect between her lived reality and the societal expectations of a partner, which hence reinforce Theresa's feelings of isolation.

Theresa's reflection of "in my mind" suggests that her reasons for difficulty in forming new romantic relationships are based on assumptions rather than explicit communications from others. This nuance could hence possibly indicate that her experience may be closely tied to broader societal perceptions, stigma and misunderstandings surrounding Long Covid. It emphasises a crucial aspect of the social geographies of Long Covid, as an invisible illness, which is highly stigmatised, marginalised and undervalued within society. These societal attitudes contribute to Theresa's feelings of isolation and rejection, with her illness-associated weight gain further reinforcing her perceived undesirability as a potential partner. These experiences therefore highlight that individuals affected by Long Covid not only struggle to form new relationships due to physical energy limitations imposed by Long Covid, but also face additional barriers stemming from societal attitudes and assumptions. These experiences were not limited to intimate and familial relationships, extending to the disruption of friendships and social networks, which I will explore further in the subsequent empirics.

4.3 Disrupted workplaces

4.3.1 Ableist workplaces

Moss and Dyck (2001) explain that, following the onset of chronic illness, an individual's position in the workplace, and consequently their socio-economic stability, becomes precarious. Many participants lost their careers[46,47] because of Long Covid, while others were forced to take reduced roles[48] or reduced hours[49]. Before exploring

[46] Alexandra; Chloe; Fiona; Hannah; Helena; Kamy; Kate; Louise; Mark; Megan; Ruth.
[47] I specify "careers" here, as many participants have found alternative paid labour.
[48] Farrah. Helena initially returned to work in a reduced role from a teacher to a teaching assistant, but eventually also had to leave this role.
[49] Anna; Cath; Kristina. Amy, David, Lu, Molly and Theresa have all returned to former working patterns following a period of sick leave and phased return to work.

the disruptive impact of career loss, it is crucial first to address the discrimination that many participants encountered in their ableist workplaces. Some participants had supportive employers who adjusted their working environments and patterns, often following a period of sick leave and phased return to work, enabling them to continue their employment, but other participants chose to leave their paid labour or reduced their working hours due to their health, feeling that they could no longer meet the demands of their role[50]. As Cath explained, "I've had to cut down my work completely, I simply just can't manage." Others were "basically sacked" (Ruth) or forced into reduced roles due to ableist workplaces that were unable or unwilling to accommodate their new disabilities. While some participants framed these decisions as personal choices, I contend that they were also shaped by wider ableist structures. Even when employers were not directly responsible for pushing individuals out, the inflexibility of workplace cultures and the structural demands embedded within certain roles effectively *forced* participants into leaving or reducing their hours. In this sense, the inability of workplaces to adapt to fluctuating needs — particularly given the dynamic and shifting nature of Long Covid — is a form of systemic ableism. Over time, these external pressures were not only encountered but also internalised and re-framed as a personal 'choice' or the 'right decision,' reflecting how dominant ableist narratives become embodied as self-regulation. Their withdrawal from paid labour can therefore be understood not only as a response to personal health limitations, but as the outcome of an ableist meta-narrative that governs what counts as a 'capable' or 'productive' worker — one that participants were compelled to accept both externally and internally (Hall, 2005).

Evans et al. (2024, p.1) emphasise that disabled people are often rendered "out of sync" with the spatial and temporal rhythms of neoliberal institutions, where speed, presence and productivity are the norm. Their conceptualisation of crip time, not as "extra time" but as a fundamentally different temporal relation shaped by fluctuation, fatigue and unpredictability, provides a powerful lens for understanding how Long Covid disrupts workspaces, collegial belonging and imagined futures. Drawing on their analysis of feel "left behind" from academic temporal and energy norms, this section

[50] I acknowledge that this 'choice' does not diminish the intensity of the disruption experienced.

examines how Farrah and Chloe's experiences expose the intertwined spatial and temporal dimensions of workplace ableism.

Farrah, who began using an ambulatory wheelchair due to the pain and difficulty that she experienced while walking, clearly encountered deeply entrenched ableism that exists within many workplaces:

> I'm obviously now, as I say, an ambulatory wheelchair user. I have been working from home since July 2022, because there are no police stations in [my area] that are wheelchair accessible for staff members […] Because I'm at home, I'm by myself, I'm feeling very isolated from my team. I can't attend training. I have had to pass up jobs that I've desperately wanted for the whole time I've worked in the force, because I'm not in an office. I'm working from home, so I can't do the role […] There's no reason I can't do any job in the police force, obviously other than patrol, but in a wheelchair. And the only thing that's holding me back is the accessibility.

Farrah shared how she was excluded due to the inaccessible design of her workplace which did not accommodate for her wheelchair. She also faced discrimination when she was forced to take a reduced role, working from home, merely on the basis that her workplace was inaccessible and *they* could not offer reasonable adjustments. This has both financial and social implications, as Farrah noted: "I had to take pay cuts," while also feeling "isolated" from her colleagues and unable to advance in her career. This spatial exclusion is intricately linked to a broader temporal disruption, disrupting her imagined future career progression as envisioned prior to Long Covid. She elaborated, "I've been stuck at home now for nearly two years," further emphasising the increasing centrality of the home within Long Covid experience.

Farrah's situation exemplifies a profound ableist geography. Because she could not be physically present in the office, not due to inability but due to inaccessible design, she was unable to progress. Her isolation and stalled career trajectory show how spatial barriers produce temporal consequences, leaving her – quite literally – "left behind" (Evans et al., 2024). In this way, her experience underscores the Evans et al. argument that institutional time assumes and demands able-bodied rhythms of presence and mobility.

Chloe's narrative further illustrates how ableism manifests in workplaces when dealing with the uncertainty and variability of chronic illness. She described how, upon

receiving her diagnosis, she thought her employer might be more understanding but found the opposite to be true:

> They were being quite aggressive, and [pressing] 'when will you be able to come back?' […] And so, I thought, when I got that diagnosis, it might make them back off a bit. But if anything, it actually made them worse, because then I had this diagnosis, which, clearly there's no end point to, is there?

Chloe thought that by acknowledging her discursive illness, her workplace would be able to make accommodations for her material reality, but "in the end, they got rid of me, because I wasn't adding value." Chloe's experience demonstrates how the nature of Long Covid, regarding its unpredictability and lack of clear end point, is treated as disruptive to the time-space demands of neoliberal productivity (Evans et al., 2024), emphasising the broader issues of discrimination faced by those with chronic illnesses like Long Covid.

Chloe's account highlights the other side of the temporal exclusion that Evans et al. (2024) identify: when employers value predictability, linear progress and stable energy, chronic illness becomes unintelligible to institutional time. Her employer's insistence on knowing 'when' she would return, and their frustration when no such timeline could be provided, reflects the neoliberal fixation on certainty, progress and productivity. In the context of crip time, where symptoms fluctuate and recovery is non-linear, Chloe's inability to offer a definitive endpoint was read not as a need for accommodation, but as a lack of productivity and value that neoliberal workplaces demand.

Both Farrah and Chloe's experiences reflect Evans et al.'s (2024) contention that being "left behind" is not merely about physical barriers, discriminatory attitudes or even individual capacity, but rather about institutional norms that refuse to accommodate crip time. Both their lived realities align with concerns expressed by other participants, who feared that disclosing their condition would raise doubts about their abilities and negatively impact their careers (Hansen and Philo, 2007). Molly, for example, was reluctant to fully disclose her condition at work, fearing potential stigma from employers and colleagues:

> I've never really mentioned 'Long Covid' verbally at work […] because I thought, if they think this is something long term, and something that I'm not going to

> shift, I don't want them to think badly of me or think any differently towards me or, think that I'm not going to be capable of doing my job.

This remark reflects the ableism that pervades workplaces, where the particular stigma associated with many chronic illnesses – enduring, open-ended, without easy solutions – positions disability as indeed a barrier to productivity. However, Molly has found legitimacy in her workplace accommodations, such as a new chair and more flexible working patterns, through partial disclosure of her symptomatic migraines. Her concerns around fully disclosing her Long Covid reflects similar fears (and concealments) as charted in the broader geographies of chronic illness and disability literature (Dyck, 2002; Moss and Dyck, 2003; Dyck, 2005; Wilton, 2006; Crooks et al., 2008), where individuals with hidden or fluctuating impairments worry that disclosing their illness may jeopardise current or future employment, which was indeed Chloe and Farrah's experience.

Molly's hesitation further reflects the recognition within the geographies of chronic illness and disability, and broader disability studies, that individuals often feel compelled to maintain an 'able' identity to avoid discrimination, often exacerbating their physical and emotional distress. Those participants who had returned to work often dismissed their bodily experiences of pain, fatigue and discomfort so as to maintain a sense of productivity and 'normalcy'. Through both the reluctance to fully disclose their Long Covid and their attempt to perform an able-bodied identity with the intent to mitigate the risk of losing their job, individuals spatio-temporally reject both the discursive and material reality of their illness in the workplace. I explore the nuances of such partial disclosure and able-bodied performance as key masking strategies in Chapter 6.

The discriminatory experiences endured by participants highlight two key aspects of ableism: the conjoint challenge of what Mowl and Fuller (2014, p.177) calls "stairs and stares," capturing both physical (in)accessibility and social (un)acceptability (Hansen and Philo, 2007). The barriers encountered were not only physical, but also socially and culturally embedded within capitalist workplace structures. Therefore, ableism in the workplace is not only about the failure to accommodate physical needs, such as wheelchair accessibility, or variable working patterns, but also exists within the neoliberal devaluation and marginalisation of disabled people within capitalist society (Gleeson, 2002; Evans et al., 2024).

Some participants indeed faced ableist pressures and expectations to resume their roles as ‘normal’ upon returning to work, while additional work pressures arose from their colleagues’ “limits of tolerance” (Bury, 1982, p.177) who, having returned to work following their ostensibly ‘relatable’ and indeed ‘recoverable’ acute COVID-19 infection, failed to offer sympathy or social support, undermining the debilitating effects of Long Covid. Both these pressures stemmed from, and were exacerbated by, the invisible nature of Long Covid – a theme addressed in Chapter 6.

Ruth also shared her experience of feeling unjustly discriminated against when she was “basically sacked” from her teaching role. She lamented, however, that “it wasn't worth arguing the case, because it would have been too stressful.” While Ruth did not want to submit, she also did not want to risk the health consequences of negotiating her workplace oppression, emphasising both the emotional and physical toll of dealing with workplace discrimination while also managing Long Covid. This finding contributes to understandings of disablement which assess the agency (or otherwise) of chronically ill women seeking to negotiate everyday practices and relationships despite facing stigma and oppression (Crooks and Chouinard, 2006), particularly around workplace structures and accommodations (Moss and Dyck, 2003). Similarly, Ruth’s refusal to contend with her employer should not be seen as a passive response to workplace oppression. Rather, she felt empowered to prioritise her health, using her time and energy to rest and focus on returning to her self-employed role as a music tutor when she felt ready. As such, Ruth maintained control over her circumstances, rather than succumbing to pressure from an employer to conform to a ‘normal’ working identity, as many others experience. Crucially, though, she admitted that “we don't need the money, so it's alright,” suggesting that part of her empowerment was shaped by her financial security, which of course not all individuals are afforded.

Ruth’s experience parallels Arun’s multifaceted struggles of divorce. For participants in this situation, they were faced with the difficult choice between advocating for themselves or prioritising their health and wellbeing, with the risk of ‘crashing’ and further deteriorating at stake. The complexity of managing Long Covid is hence amplified by the many challenges it presents, which often demand more energy than what the individual can muster. This creates a contradiction between the reality of living with Long Covid, where personal energy is limited, and the societal expectations placed on individuals, which require seemingly more energy than before.

4.3.2 Lost sense of self

Chloe experienced a profound bio-geo-graphical disruption when she “lost” her teaching career and in effect, became misplaced within her lifeworld. She shared, “I was good at teaching, I was good at my job. […] I loved it, and so I’ve lost that. I have lost that bit of me, which was my life for 20 years.” The onset and development of Long Covid not only disrupted everyday meaningful time-space routines, but also personal narratives. As Chloe suggested, the loss of her job also led to her sense of self and identity becoming misplaced. She elaborated, “my entire identity, right or wrongly, was in and around my job.” This bio-geo-graphical disruption resonates with notions of the “lost” or “shattered” self following injury or illness (Medved and Brockmeier, 2008). Many participants grieved over their previous embodied identity; over the “loss of a part of yourself and your sense of being” (Anna). These experiences emphasise the understanding that disruption to identity following the onset of chronic illness is a complex, ongoing process, rather than a fixed event (Moss and Dyck, 2003).

Participants’ socio-economic positions shaped how they navigated this disruption. Some, like Ruth, did not feel the urgent need to return to work due to financial stability. She admitted: “I didn’t need to push to get back to work, even though that's what I really wanted to do.” However, for others in more precarious economic positions, such as Chloe, employment was a necessity. Chloe took on various part-time roles in tutoring and administration, which offered her the flexibility to accommodate her variable energy. She noted: “I’m lucky that I’ve got some skills I could fall back on” which enabled her to take alternative jobs and earn income. However, these roles did not provide her with the same personal fulfilment that teaching once had. As she solemnly reflected, with a sense of loss: “But, it's not teaching.”

Some participants felt somewhat un-employable, believing their ELC hindered them from participating in typical working time-space rhythms. As Louise confessed: “I’m always looking at jobs, I just don’t like being idle […] but nobody will give me a wee shot.” As discussed earlier, these experiences reflect the socio-cultural perspective that disabled individuals are undervalued within a capitalist system that prioritises productivity over well-being, contributing to their marginalisation and exclusion from employment (Hall, 2005).

Arun described the financial and emotional toll of his perceived unemployability, as he was left to survive on benefits:

> I'm staring at years of sitting on benefits. Living, existing and hoping they give me PIP[51] and renew it […] But this is what my brain wrestles with is, how can I survive and live? Without being left in... I think the worst thing for me is knowing that I can't do anything. Even if I wanted to do something, I couldn't do it, because financially, yes, I can just about pay the bills and exist. But can I do anything with the kids? Go out for meals? […] I've just never been in this position in life where you're just living hand to mouth. It's not sustainable, is it?

Arun's experience echoes Chloe's earlier sentiment of being excluded from meaningful participation in life due to socio-economic barriers, capturing the interconnectedness between embodied (in)capacity and financial (in)capacity. Arun's disablement is made palpable as his access to spaces outside the home are restricted both physically and financially. This point reflects Driedger's et al. (2004, p.121) contention that disablement, as a result of chronic illness, leads to "spatial deprivation and socio-economic exclusion," unfolding across space and time. Such processes shape an individuals' immediate sense of place within the physical surroundings, but also their broader sense of (dis)placement in broader familial and social worlds. This is reflected in Arun's sense of home, within which he feels confined, isolated and dependent, as discussed earlier. These findings are consistent with that of Crooks (2010), who foregrounds the prominence of the home in everyday life through loss of, or limited, access to other everyday meaningful spaces.

Not only is Arun's life disrupted, but so are his children's, emphasising again that the disruption caused by Long Covid is complexly relational. He elaborated: "I cannot support them financially at university, help them get on the housing ladder etc […] Things would have been so different if I was able to work and provide that security." Here, Arun further delineated the psychological impact of his limitations, that he cannot fulfil his role as the parent and provider in the way that he intended before the onset of Long Covid.

This narrative further indicates that not only has Arun's physical and financial wellbeing been impacted, but so too has his mental health. He referred to himself as "existing"

[51] Personal Independence Payment (PIP) offered by the government for individuals in England, Wales and Ireland with long-term conditions or disabilities which impair the ability to do everyday tasks (UK Gov, n.d.). The Scottish equivalent is called Adult Disability Payment (ADP) (Scot Gov, 2025).

rather than “living,” emphasising his daily struggle for mere survival due to the lack of social and financial resources to live his life beyond his home. Charmaz (1991) explains that “existing day-to-day,” as opposed to “living day-to-day,” signifies merely getting by, with life feeling beyond one’s control. This consideration highlights the embodied experience of physical, social and emotional suffering, such that Arun’s potential to live beyond mere survival is curtailed by both his body limits and also his socioeconomic position, the two being complexly interconnected. I develop these ideas in Chapter 5, examining the psychological and social dimensions of living versus existing with Long Covid.

Arun’s experience further demonstrates that structural inequalities exacerbate an individual’s suffering. His narrative aligns with the third tenet of Bury’s (1982) biographical disruption, which asserts that the nature and intensity of disruption caused by chronic illness is shaped by an individual’s ability to mobilise cognitive and material resources. In Arun’s case, his limited access to socio-economic resources, relying on benefits, emphasises that chronic illness experience is shaped by socio-economic class[52]. His struggle to secure financial stability and meaningful participation illustrates the disparities that arise from the intersection of chronic illness and social class, revealing how those with fewer resources may be disproportionately affected by the disruption of their lives, emphasising that chronic illness experience is not only of medical concern, but also socio-economic.

Regardless of socio-economic status and employability, the narratives shared thus far further indicate participants’ desire to work as a means of self-actualisation. As Kristina succinctly explained, “the reason that I so desperately want to keep working, because it’s the only time I feel like me [sobbing].” To continue working, Kristina adapted her former time-space routine of her counselling business by transitioning online, enabling her to work from home, reducing her working hours and incorporating more regular breaks. She also delegated additional administration work for which she no longer had the mental energy:

[52] Two threads of socio-economic class can be identified throughout this chapter: the pre-Long Covid class position, shaping the resources and social status that can be mobilised following the onset, and post-onset class position that emerges as a consequence of the condition. For example, before Long Covid, Arun was socially endowed within his marriage, even though he was financially dependent on his partner. After developing Long Covid, the consequential divorce removed both his social support and financial stability, leaving him without income or employment.

> I'm doing 10 client hours a week instead of 20. I'm not doing my admin at all. […] I look at the screen of my accounts, and the numbers just jumble, and I cannot make sense of it, and I used to be good with numbers, and I just can't. So that's where the acceptance comes in.

Kristina's experience demonstrates her acceptance of her new energy limits, permitting her to reconnect with her inner sense of self. This example suggests that, by adapting her spatio-temporal working patterns, Kristina was able to create a sense of bio-geo-graphical flow and continuity of the self as "the essence of who they were ha[s] remained intact" (Gelech and Desjardins, 2011, p.68). However, this sense of flow has its own temporality, as Kristina articulated, "I can still be that person, even if I can't be that person for the same number of hours that I used to." Her experience illustrates the fluid relationship between bio-geo-graphical disruption and flow, a dynamic observed across other participants' stories who were able to accept, adapt and re-create meaning in new time-space rhythms. These adaptations enabled Kristina to negotiate her fatigue on a daily basis, which I elaborate in the following chapter.

Similarly, Megan (FG4), who lost her teaching role, was able to manage her workplace disruption by engaging with new creative activities in her own time and space. As she reflected, "I think I've kind of taken it and seen it as a blessing […] It's given me the time and the space to actually write again." Adapting to new workspaces and routines has of course not always been possible for participants, as Alexandra responded in focus group discussion:

> Oh Megan, it sounds wonderful what you've got. I wish I had the energy to do that. I really do. I'd love it to be an opportunity to do stuff. For about 20 years, I've had, like we all do probably, a novel in my head. And I can't put ideas together. I can't. It takes so much effort to compose a paragraph [...]

In contrast to Megan, Alexandra does not have the mental or physical energy to engage in new creative opportunities, highlighting the variability of Long Covid experiences between participants. Their juxtaposed narratives further disclose the elusiveness of time in relation to chronic illness experience (Charmaz, 1991), revealing a profound disruption to individual conceptions of time. As Arun (FG4) put it, "I've got plenty of time [laughs], but who's got energy […]?" Many participants shared this experience, feeling they have abundant time but lack the energy required to embody newly meaningful spaces and routines for which others seemingly do have capacity.

Alexandra further commented, "[…] But that's today, maybe in six months' time," indicating her hope for future progress and recovery. These sentiments help Alexandra to shift her focus away from fearful thoughts about the future, like those discussed earlier in the context of disrupted domestic relationships. Therefore, I am cautious about sensationalising the 'tragedy' of Long Covid experiences, as participants' stories also include positive coping strategies centred around humour, hope and finding joy in the mundane, to which I return in what follows.

4.4 Disrupted social and recreational spaces

Discussions about disrupted workplaces extend moreover to the impact on significant social spaces of pastime and recreation, which are also deeply connected to individual identity and sense of self. Participants shared how activities associated with such spaces that once brought them meaning and fulfilment became difficult or even completely inaccessible. These activities ranged from everyday pastimes such as cooking, reading and watching TV to more physically demanding activities such as running, hiking and traveling — many of which were inherently social activities.

Participants struggled with the mental and intellectual energies required for mundane activities such as reading, often attributed to brain fog and mental fatigue. Charlotte shared: "I'd read the words, but nothing would go in. I just couldn't comprehend what it was that I was reading, which was a *big* [...] thing for me." She elaborated that her brain fog affected not only her intellectual ability to access information through reading, but also her cognitive capacity to effectively to *convey* information in social settings – both significant disruptions that undermine her previously "articulate" sense of self:

> I was always quite articulate, and I think for me, that's what makes it then quite hard […]. It's just then that sense of identity, isn't it? You suddenly look like you're a little bit slow, and you know that you're not, but it's literally that I haven't got the words in my head, and that's how it feels […] When you're meeting new people, and they don't know anything about Long Covid, that's when it's tricky.

Charlotte highlighted the emotional and psychological frustration felt when she is unable to access and convey her intellectual abilities. This narrative reveals the tension between how individuals internally perceive themselves and their cognitive capabilities versus what they can demonstrate outwardly, and hence how they are perceived by others. These tensions are further complicated by the invisibility of Long Covid, which is not immediately apparent in social settings.

Linking moreover to the destabilisation of domestic routines, many expressed the physical and mental demands now involved in cooking. Farrah, whose pastimes included both cooking and weightlifting, was particularly shocked by the loss of her physical strength: “I couldn’t use a knife because I didn’t have the strength in my arms to cut.” Amy also experienced mental barriers to cooking:

> I love cooking. I just can’t […] I don’t know why I can’t do it. I can’t seem to stand there and cook. I find it really hard now to plan things. So, before, I’ve never really done meal planning, but I would just have in my head, ‘Oh, yeah, I know what I'm cooking this week.’ I liked cooking lots of different things. Now, it’s almost like my brain has switched off to be able to do that. And so, my husband has to do most of the cooking now, apart from on the days that I’m off [work], where I can just throw jacket potatoes in the oven […] So I think probably what my brain finds hard now is having to do step by step plans […] I can look at recipe, I can follow the recipe, I can do the cooking for the recipe, but I can’t even almost get to that stage of thinking, ‘I know, I’ll pick up a recipe book.’ Almost the effort of having to do that is too much to then make a decision about what we’re doing.

Amy’s love for cooking has been disrupted by its now fully *present* cognitive demands, meaning that a once taken-for-granted, spontaneous pastime has been brought into consciousness and is no longer simple, thought-less and therefore enjoyable. In their efforts to rationalise such experiences, participants underscored the interconnectedness of everyday, meaningful spaces. Amy succinctly observed how “home life, work life, social life is also interconnected,” while Farrah added that “I noticed the more I worked, the less I was able to do at home.” Hitherto, this chapter has explored the disruption to various spaces in isolation, but I must acknowledge that everyday meaningful spaces are deeply interconnected. As such, participants struggle to access each of their significant home, work and social spaces, and need to prioritise on a daily basis. This sudden impossibility of previously routine multitasking, now experienced as energy intensive, requires crucial time-space separation, which I develop further in the subsequent chapter.

These experiences reflect the profound impact of Long Covid on everyday pastimes and routines, highlighting both the physical and mental energy demands of former mundane activities, ones which were previously automatic, that have been brought into awareness, drawing participants’ attention to their bodily state (Bury, 1982). That

is, drawing attention to individual physical, mental and intellectual capacities, as even everyday tasks have more energy demands and consequences than before.

Charlotte also explained that Long Covid disrupted her ability to run, an activity she pursued primarily for her mental health and wellbeing. However, as a physically demanding activity, Charlotte found herself having to scale back on running and adjust to new activities:

> I've tried, and every now and again I'll have a good run of running, and then it's like [sigh], nothing for months. And I think I'm slowly sort of realising I'm probably never actually going to be able to […] So it's just been finding other things. So, now I've got an allotment with my dad. So, I'll go to the allotment instead, and I'll walk and things like that […] It comes with acceptance, I suppose, and that acceptance comes with time.

In this sense, some participants were able to negotiate their identities and find meaning in new recreational spaces and activities which were less energy demanding but served a similar purpose, in Charlotte's case, to improve her mental health and wellbeing. Often, alternative activities occurred at a slower pace, such as walking instead of running, and hence had less physical energy demands. The emergence of these altered temporal geographies illuminates a shift in the body's relationship to time, space and energy, where slowness, rest and reduced intensity become central facets of everyday life. These reconfigured temporalities disrupt former narratives of productivity and instead foreground slower rhythms of spatial practice aligned with the energy limitations imposed by Long Covid.

Ruth explained how her pastime of singing in a choir was layered with disruption. Firstly, she was re-learning to drive independently, having initially lost the physical and mental capacity, and therefore relied on others for transportation to choir practice. Her participation was hence contingent on the mobilisation of social resources and support, signalling the third principle of Bury's (1982) biographical disruption. For Ruth, standing in a choir strained her energy levels. She shared: "I can't stand up and sing, because it uses too much brain and energy, but I can sit to sing," so she has thereby modified the corporeal demands of her participation. She explained that sometimes she would "opt out, follow everything until my brains had a bit of recovery and then come back in," participating at a pace that aligned with her energy levels. She thereby adapted both her spatial and temporal embodiments of choir practice in a way that

aligns with her new body limits, but she readily admitted that “it is hard,” acknowledging that she cannot fully participate in a way that she once did, she remains positive in her incremental progress. As she also noted: “slowly, I’m managing [choir] runs better.”

Chloe’s experience starkly contrasted with that of Ruth. Before developing Long Covid, she and her partner purposefully chose to live by the sea to enjoy seaside walks in their leisure time, which highlights the therapeutic potential of coastal environments in enhancing both place-identity and wellbeing for those who choose to live there (Bell et al., 2015). Yet, due to her fatigue, and therefore energy limits, Chloe stated that “I can go and sit by the sea and have a short walk.” Similarly to Ruth and Charlotte, Chloe adapted her routine around the spatial and temporal embodiment of the seaside through the simple practice of sitting and having shorter walks. Nonetheless, she reflected, “it’s not what it was,” highlighting that her sense of identity, as it relates to place, is also importantly tied to *how* place is embodied and experienced.

Similar to Ruth’s choir participation, Fiona emphasised the importance of support and empathy from others in her community church to help her to navigate energy levels and facilitate a sense of bio-geo-graphical flow in social spaces. As Fiona shared:

> I’m very social in church. And after services, I do sit and have a cup of coffee with the ladies, and we have a chat afterwards. But they know when I’ve had enough. I mean, a community of people that do get it. They don’t say, ‘oh, why are you limping?’ Which I got all the time at work. I’m still the person I was yesterday, I’ve still got the same thing. The ladies at church, I'll just say, ‘I’m not gonna stay today after service.’ And they’ll say, ‘Are you gonna go back to bed? We’ll pray for you.’ And that’s nice, because you know they get it. When people get it, it halves the workload.

Fiona’s reference to “workload” is a metaphor used to describe the energy involved in community participation. In these spaces, engagement in the community becomes easier and requires less emotional energy, as individuals do not need to justify their illness or cope with the judgement, misunderstandings and stigma associated with Long Covid, which she had experienced in her former workplace. This sentiment echoed across participant narratives, emphasising the importance of relational acceptance, understanding and empathy. As Monica (FG3) noted, “It’s very hard to explain it to people […] because it takes a lot of energy [group collectively nodding heads].” These experiences underscore the importance of acceptance, not only on an individual level, but also from others, in facilitating bio-geo-graphical flow. Relational

acceptance, especially in relation to stigma and the energy it relieves or consumes, clearly played a crucial role in how participants learned to navigate the disruption created by Long Covid. Relational acceptance was furthermore important for mobilising social support and resources, as already exemplified across home, work and social spaces.

These stories centred around the actual and potential loss of meaningful places of work and activity, clarifying the intimate connection between place and identity. Participants shared how the loss of access to meaningful work, leisure and social spaces resulted in a profound bio-geo-graphical disruption to their personal narratives. The main structural barriers to engaging with significant places were related to both physical access and socio-cultural systems that discriminated against and excluded individuals. Meanwhile, the symptomatic barriers were largely invisible, requiring both physical and mental energy to overcome. While some participants were able to adapt and re-create meaning in both old and new spaces, others struggled to adapt to their new lived reality, feeling that their former self had been almost or entirely lost. I have traced this struggle primarily through Chloe, who experienced a profound loss to her sense of self through the disruption to significant work and leisure spaces:

> It's very hard to find things that you like, because I don't even have the energy to begin to think, 'what do I like?' Or 'what would I like to do?' […] So even trying to re-find identity, with a lost identity, it just feels impossible sometimes.

Chloe's energy-limited condition constrains her, both physically and mentally, from re-negotiating her sense of self and identity. This restriction reveals that adapting to Long Covid is not an inevitable process and achieving a sense of bio-geo-graphical flow, where individuals experience a continuity of the former 'normal' self or create to a 'new' sense of self, is not always realised. Participants' experiences also highlight that places can be simultaneously characterised by loss and gain, disruption and flow, especially when new spaces, routines and identity are found, but do not necessarily offer the same sense of fulfilment. It is therefore too simple to claim that Long Covid stories are dominated by either disruption or flow, as in practice these states vary between individuals, are neither inevitable nor fixed, and are contingent on different social, spatial and temporal contexts (Meijering et al., 2019). As Anna expressed:

> It goes up and down. Because sometimes I feel like okay, I will have patience, and there still are other things to enjoy […] But sometimes […] I think about things that I found meaning in before and then I really miss those.

These fluid experiences capture the complexity of Long Covid's impact on identity, emphasising that illness experience is marked by continuous (re)negotiation of the self in relation to meaningful places, time-space rhythms and relationships.

While there are many shared narratives about navigating and re-configuring bio-geo-graphical disruptions in both work and recreational spaces, what separates these spaces is the purpose they serve for individuals. Workplaces are essential for personal and familial financial stability, and in some cases, purpose, while recreational spaces primarily serve for enjoyment and wellbeing. Therefore, while both spaces are crucial for fulfilling purpose and identity, there are significant differences in how these disruptions vary between individuals depending on their socio-economic status. For individuals in lower socio-economic groups, the need to continue working is more pressing, placing additional strain on the physical and emotional challenges of Long Covid. Work itself has a significant impact on energy levels, especially when balancing with other home and social responsibilities – which I explore more in the following chapter – while additional work-related disruptions often bring financial stress and insecurity. Moreover, there are heightened psychological and emotional stresses of being unable to provide for oneself or one's family with their desired standard of living. In contrast, while those in higher socio-economic groups, who have financial security, face similar disruptions to identity through the loss of career and increased dependency, they are afforded more time to rest and recover, which can alleviate some of the physical and emotional strain associated with working while managing a chronic illness. These narratives therefore reveal the significant disparities in the lived experience of Long Covid across different socio-economic class.

4.5 Acceptance

So far, in exploring the bio-geo-graphical disruption to the structures of everyday life, I have suggested that sentiments of bio-geo-graphical flow are closely, if not exclusively, tied to acceptance. I have also alluded that acceptance has its own spatiality, temporality and corporeality, is subjective to the individual experience and is deeply relational, claims upon which I will now elaborate further.

The spatiality and corporeality of acceptance are intrinsically connected. Earlier, I discussed Lu's experience of feeling "successful at home […] it's like going back. I feel like I haven't got it [Long Covid]." Similarly, Sheila explained, "I certainly don't fully accept it. When I'm doing what I [would] normally [do], like when we were talking about swimming earlier, I feel fine […] I don't mind at all." These domestic and recreational spaces remind participants of their 'normal' former selves, before the onset of Long Covid, since they can still be embodied in such a way that participants feel a connection between their 'internal' and 'external' mind and body experiences. Many participants indeed described what Moss and Dyck (2003, p.129) term an "absence of presence," in which the individual focuses primarily on their past self, and their future recovery, merely getting through the present. This was echoed by Cath, as she shared: "It's a life that you don't want to have to be doing, but you have to do. You just got to sort of plough on through it."

Acceptance is also a temporal process. Charlotte previously noted that "acceptance comes with time," which was certainly reflected across many participant stories. Monica echoed how "I can *be* with the experience much better than I could do two years ago, [or] four years ago." Over time, Monica was able to accept and "be" with the lived experience of Long Covid, a finding that arguably recalls Canguilhem's (1991, p.186) assertion that "disease is not a variation on the dimension of health; it is a new dimension of life" – a different way of phenomenologically *being* in the world. For Canguilhem (1991, pp.197–201), health is not some correspondence to a fixed norm but rather "health is […] the possibility of tolerating infractions of the habitual norm and instituting new norms in new situations […] health is a way of tackling existence". In this sense, Monica has come to accept that she has not returned to her former 'normal' health and self. Instead, she has learned to accept a new normal, a way of existing and being in the world *with* Long Covid, in a manner that is seemingly less true for other participants in my inquiry.

Although many participants used their former 'normal' self as their benchmark for recovery, Lu developed a different perspective, one focused on accepting her new self. She explained: "I don't think I'll ever be that person, because even if my fitness got to where it was, it's changed me and how I am." By shifting her benchmark of recovery, Lu was able to accept her new recovery, although not without its challenges. As such, she was able to value her new life in other ways:

> You need to look to where you were when you were at your worst and not where you were before you got ill. Because I kept thinking, 'I want to be back what I was doing,' and I might never get back to being that person, so I've had to accept that. […] It does make you value the little things, like being able to go for a walk. I look at that as a whole new experience, because I couldn't do any walking at all for four months. […] And I think things like this are really important if we're going to educate people as how to cope with it.

Lu reframed her recovery by focusing on the progress she has made since developing Long Covid, grounding herself in the present rather than dwelling on her past or imagining an idealised future. Rather than striving to reclaim her former sense of health or identity, she acknowledges the visceral changes the illness has brought and accepts that she may never return to who she once was valuing instead the small improvements made since the onset of her illness. By noticing and valuing small, everyday improvements, she has developed a more compassionate measure of recovery — one that highlights incremental gains and supports her growing acceptance. Through the challenges of chronic illness and the coping strategies that she has cultivated, Lu has redefined her sense of self, creating a 'new normal' that reflects her ongoing journey towards acceptance and states of bio-geo-graphical flow.

These testimonies emphasise the importance of capturing the experiential accounts of Long Covid, highlighting the differences and complexities within this qualitative health study. As Philo, (2007, p.86) notes, "because we are not comparing like with like," the relationship between acceptance and time is subjective, and varies from person to person. For example, Amy, who had pre-existing chronic co-morbidities, found acceptance more easily than others, whereas for most individuals, with no such prior experience of living with ill-health and limited capacity, acceptance was a relatively slow, gradual process following the disruptive onset of Long Covid. As Kate explained:

> I think I deal with it better now than when I did, because the first sort of year it, I was just in turmoil about it: 'I must get back to it. I have to get back to work.' And the doctor would sign me off for three months, and I'd go out almost laughing, thinking, 'I'm not going to stay off three months [laughs].' Because I just thought, if I worked hard enough and I did enough to get better, I'd be better, because that's what normally happens, and that's what you expect to happen.

When Kate first learned of her Long Covid, she had temporal assumptions of recovery consistent with that of a typical post-viral illness – relatively quick and linear – as she

would ‘normally’ experience in such a situation. This assumption reflects a common temporal framework where recovery is anticipated as a steady return to normal health, where individuals can “work” to “get better,” while further reflecting that they need to “work” to negotiate and accept Long Covid – which hence requires energy. As I explore in the following chapter, however, this mindset of ‘working though’ illness can actually be counter-productive in the context of Long Covid, as overexerting energy can lead to worsening symptoms and trigger setbacks in recovery. Unlike acute illness, Long Covid recovery is comparatively slow or even unrecognisable, characterised by uncertainty and non-linearity, and is therefore experienced as atypical to the ‘normal’ expected trajectory. As such, the process of acceptance did not necessarily align with a continuous, linear recovery. If acceptance does emerge, it often does so without the usual markers people associate with getting better — such as clear improvement or a return to previous health.

Many participants, like Alexandra, described reaching a “plateau,” while Arun, Hannah, Helena and Kate all similarly characterised their progress as existing in a state of “limbo.” In the context of chronic illness, “limbo” refers to a hiatus state where individuals feel disconnected from their past but also their future, intensifying the dislocation of the self, which can feel potentially disempowering and isolating (Kralik and van Loon, 2010). As such, many participants felt compelled to accept their new normal as a means of coping with their present situation – resigning themselves to a static recovery in order to move on with life, paradoxically accepting their fixed bodily state in order to move *forward*, despite not knowing how long this state of limbo would last. As Kristina (FG1) explained: “if I don’t accept where I am now, then I will not be able to live as I am now, and that’s what I needed to come to terms with.” Amanda (FG1), who had been living with Long Covid for five years, agreed with Kristina in a focus group discussion: “it’s not the life you want […] you’ve just got to put up with it for now and keep hoping.” Kamy also reflected that “you have to accept the new life, but it doesn’t mean that you have to accept the new identity, the new self.” Kamy’s reflection here highlights another complexity of acceptance: accepting the realities of a new life does not necessarily equate with accepting the imposition of a new identity. In this sense, acceptance is conditional, hinging on a ‘suspension’ of self, while holding onto the hope and possibility of returning to former occupations of time, space and body. These attitudes therefore reveal a shared attitude of acceptance “for now” but

not for-*ever.* Participants recognised that they had to learn to live with Long Covid in the present, living day-by-day in the hope that their divided internal-external corporeality is re-connected in the future, and that recovery is thereby attained. Because Long Covid is a novel and evolving illness, this day-to-day orientation is intensified by the absence of established illness pathways or shared cultural narratives that indicate what the illness trajectory 'normally' entails – resources that often help people with more familiar chronic conditions make sense of their embodied disruption. Across narratives, accepting these discursive and material realities allowed participants to begin managing Long Covid, a process I explore further in the following chapter.

All this said, I am cautious about sensationalising this concept of acceptance "for now," as it is complicated by the slow, uncertain and non-linear nature of Long Covid recovery. When I asked participants about their recovery, many shared that they tried to avoid thinking about the future and instead emphasised their focus on the present. Megan shared, "you can't plan [...] now it's more about seeing what's happening today," while Theresa observed, "[I'm] trying to just kind of deal with what I can deal with at the moment." Alexandra added that, "if I thought that I was really going to be living my life like this forever, I think it would send me really into a black hole or under a rock or something." These experiences align with Kralik and van Loon's (2010) assertion that dwelling on a seemingly permanent state of limbo can have negative implications on mental health and wellbeing. Therefore, maintaining a positive mindset, while holding onto hope and finding joy in the mundane, were crucial coping mechanisms for managing and accepting Long Covid "one day at a time" (Kate). As Lu agreed, "I think when you get poorly, really poorly, it does make you appreciate the basics," such as "celebrating things like a leaf on a plant, a new leaf on a house plant, or a bird going past, or the sky is blue" (Kate), while Alexandra recognised that "the sun shines each day as well and that is absolutely lovely. And later on, the blackbird will come, and he'll perch outside my back door wanting sultanas [...] So, I am able to take pleasure in small things." Ultimately, these positive reflections underscore the importance of finding meaning and solace in everyday moments amid the challenges of Long Covid, helping to foster a sense of resilience and emotional wellbeing.

4.6 Stuck in time, space and body.

Throughout this chapter, I have explored how participants experienced a sense of spatial confinement at home, temporal stagnation in relation to their life trajectories, and the physical limitations of an energy-limited body, restricting the extent to which individuals can engage in, and re-negotiate, everyday spaces, routines and relations. Here, I also frame the Long Covid 'crash' as an intense state of material entrapment and draw upon participants' perceived sense of "limbo" to show these physical, temporal and corporeal constraints reverberating as emotional and psychological suffering. I now want to augment these experiences, contending that, for many, the lived reality of Long Covid is often characterised by a pervasive sense of feeling 'stuck': that is, geographically anchored in space and time, mind and body.

In the context of disclosing chronic illness at work, Charmaz (2010, p.12) conveys a covert geographical perspective on the liminality of chronic illness experience:

> People with serious illnesses have changed relationships with space, time […] They may discover that their experiences are profoundly dislocating and subsequently lose connection with spaces, places, and people […] Under these conditions, they occupy a liminal space where earlier rules, routines, and meanings do not apply.

This sense of liminality recurs throughout much of what my research participants have shared with me and with each other, as observed when Alexandra reflected on one aspect of her Long Covid experience, her practice of keeping a diary:

> At the start of the year, I started writing every evening […], even when I really was dead to the world and couldn't manage, I'd make myself write something about the day. And then after, I'd say, four weeks had passed, I printed it all out and read it, and it was like a kick in the teeth, because, like I said, I get up each day and it's a new day, and we'll see what happens. I hadn't realised how bad I was until I read this diary, and that took some real coming to terms with. Because I thought, 'oh well, yeah, didn't I go out last Wednesday? Oh no, no, that was the Wednesday before. Oh god, I actually haven't been out of the house for two and a half weeks, and that was for a medical appointment, wasn't it.' And so that diary had a *huge* impact on me where I thought, 'okay, I really am properly ill. Properly ill. And so, I need to absolutely focus on being the best person ever in the world at resting' [laughs].

Alexandra's experience of keeping a diary to track her daily life highlights a sense of unchanging time and space. The days between significant events outside her home,

like that of a medical appointment, seem to blur together. Since she spends most of her days at home, demarcations of time and space are lost, causing her perception of time to stretch and leaving her effectively stuck in a dimensionless present, living day by day in a state of limbo (Charmaz, 1991), where both time *and* space feel suspended. This experience brings her illness into stark focus, emphasising the slow pace of her recovery, if indeed she is recovering, and her perceived 'plateau' where her body seems unable to move beyond its limits, rendering her corporeally trapped in a state of stagnant (non)progress.

Others also highlighted the nuances of this temporal suspension, not merely as a static plateau, but as a relentless cycle of recurring highs and lows, caught between moments of improvement and continual setback, reflecting Wilton's (1996) diminished worlds, where, in the context of HIV/AIDs, he conceptualises patterns of recovery (into an expanded world) and relapse (into a diminished world). As Charlotte described:

> There have been times where, more so just in the early days, when I first had it, I genuinely couldn't see that I would *ever* get better again [...] When you would feel like you're getting there, and *then* you would have a crash, after going weeks being alright. And then you're just absolutely floored to the point where you just can't get out of bed and you're like, '[sigh] we're back here again.' [...] There have been times I have thought, 'I'm never getting out of this cycle. This is constantly now going to be my life.'

This cyclical pattern reflects a profound sense of dislocation. While participants were able to identify a clear onset, or 'beginning', to their illness, their experiences were marked by fluctuating symptoms – periods of perceived improvement followed by unpredictable setbacks. These fluctuations between good days and bad days, expanded and diminished worlds (Wilton, 1996; 1999) echo a broader experience reported in the Long Covid social science literature, of individuals being trapped on rollercoaster or a "coronacoaster" (Howell, 2022, p.218). This temporal intrusion, in which participants cannot locate a clear 'end', contributes to an ongoing sense of temporal and corporeal 'stuckness' within a novel and uncertain illness trajectory. The feeling of being 'stuck' is further exacerbated by the novel, uncertain and contested nature of Long Covid, which leaves individuals without a clear treatment path for recovery or definitive cure. As a result, many participants expressed feeling "left" to manage Long Covid themselves, essentially becoming a clinician of their own body and illness (see Chapters 5 and 7). Self-management, which involves a frustrating

process of trial and error (which I elaborate in Chapter 5), often creates a cyclical sense of stuckness, wherein incremental improvements are followed by crashes or setbacks. Such uncertainty intensifies the affective distresses associated with this stuckness, especially when, as Charlotte outlines, hope is repeatedly undermined by relapse, reinforcing the perception of life as indefinitely suspended, with no roadmap to restore a sense of control.

Participants further articulated this experience of feeling stuck within their own body. Recalling a point made earlier in this chapter, Megan compared her bodily limits to that of pandemic lockdowns: “It’s like I’m back in isolation, because I physically can't do the things I like […] because my body won’t let me.” She expressed feeling isolated at home because Long Covid limits her body from doing the things that she enjoys, effectively creating a sense of confinement akin to being under quarantine. She not only emphasised her physical limitations, but also how she feels disconnected from her inner sense of self, capturing – in line with various materials presented above – the divide between her internal drive for activity and autonomy and her external lived reality constrained at present by her body’s limitations. Similarly, Kate felt corporeally restricted. She explained: “The most important thing for me is to recover so that I can have that choice and have that freedom in my body to do the things that I want to do.” She hence framed her recovery as not only returning to physical health, but also re-gaining agency over her body. Both experiences elucidate that Long Covid not only limits individuals’ energy but also disempowers individuals from having control over their own bodies. These experiences therefore demonstrate how physical suffering of Long Covid extends affectively beyond the body when individuals are stripped of their freedom to participate meaningfully in everyday life.

This emotional and psychological toll deeply resonated across participants’ experiences. Despite accepting the reality of their Long Covid, Marg expressed that, “I just want my life back,” while Arun pleaded that, “I'm just aiming for, just some life, just being able to do some basic functions and have a life instead of being stuck indoors.” These reflections underscore a collective longing to break the cycle within which they are stuck; for an ‘end’ to Long Covid, a sense of normalcy and control over their bodies and to participate in life as they had before. Arun’s repetitive use of “just” emphasises the profound impact of Long Covid on his daily life and conveys his desperation for the most basic, mundane human “functions” that would allow him to

re-engage in and with the world. This emotional sentiment echoes his aforementioned feelings of “existing” rather than “living,” trapped in a state of mere survival, waiting for the return of normalcy and autonomy. These testimonies suggest that individuals become “social captives of their sick bodies” (Charmaz, 1995, p.668).

Bringing together these experiences, I contend that this pervasive sense of ‘stuckness’ is, for many participants, inseparable from the social and cultural conditions of the COVID-19 lockdowns. While UK state-imposed lockdowns were temporary and collective, the isolation imposed by Long Covid is seemingly indefinite, deeply individual and often invisible. This gives rise to what I conceptualise as *bodies under lockdown*: a state in which individuals are constrained by pathology rather than public health policy, trapping individuals within a state of corporeal confinement long after formal restrictions have been lifted. Paralleling Megan’s earlier corporeal resonance of being “back in isolation,” many participants explicitly likened their enduring chronic illness experience to being re-confined – not by the state, but by the limitations of their own bodies. Hannah reflected, “It’s like COVID lockdown all over again.” This narrative return to a renewed sense of confinement illustrates how the spatial, temporal and corporeal restrictions of Long Covid discussed throughout this chapter continue to govern participants’ lives, as Helena (FG1) pleaded: “I’m here still after COVID all this time.” This dimension marks a shift in the collective experience of quarantine at the population level to a private ongoing reality that is not widely shared, visible or acknowledged. This form of chronicity blurs the boundary between pandemic crisis and private suffering, especially within a society eager to ‘move on’ from the pandemic (Lupton, 2025), which was reinforced by participants in my study. As Amy remarked: “The narrative, I would say in this country, feels very much like, “COVID is over. The pandemic is over.” But for people who now have Long Covid, it’s very much part of our day to day lives, it’s still not over [...] For me, it’s definitely not over.” For these individuals, the pandemic is not a historical event, but rather an ongoing embodied reality. Moreover, as participants feel “left to it” by institutional and social support systems, they re-experience the material and affective contours of lockdown but without the same solidarity, support or anticipated endpoint that characterised the COVID-19 pandemic. In this post-pandemic corporeal lockdown, individuals remain suspended in a prolonged state of isolation and disconnection as the world around them ‘moves on’. In this way, Long Covid is not only a chronic illness: it extends the

pandemic as an ongoing temporal, spatial and affective reality. It produces conditions of embodied suspension where normative trajectories of recovery are disrupted and time itself feels stalled. This temporal disjuncture, as I return to in the conclusion, placed individuals “out of sync” with the rhythms of post-pandemic life (Evans et al., 2024, p.1).

4.7 Conclusion

Throughout this chapter, I have explored how Long Covid has destabilised the structures of participants’ everyday lives through the lens of bio-geo-graphical disruption. I have examined how Long Covid’s insidious onset and development have upset everyday home, work and recreational spaces, alongside once taken-for-granted routines and significant relationships that shape individual meaning and identity. Furthermore, I have investigated how participants adapted their spatial and temporal engagement with meaningful spaces and routines to cultivate a sense of bio-geo-graphical flow and (new) normalcy, while recognising that such experiences of disruption and flow are contingent on individual social, spatial and temporal circumstances. I therefore contend that the extent of bio-geo-graphical disruption and flow within Long Covid experience varies greatly between individuals, for a complex mix of personal and contextual – including socio-economic – reasons, and that individuals have the potential to experience both loss and gain, often simultaneously, as neither state is fixed.

Throughout this chapter, I have considered meaningful home, work and social spaces in isolation. However, when these spaces are considered together in the normal weave of life and lifeworlds, the centrality of the home becomes evident, as work and social spaces have become less accessible or completely inaccessible to my participants. Paralleling Crooks' (2010) study on fibromyalgia, these findings elucidate that the home assumes greater significance in the everyday experience of Long Covid. Not only does the home space become more prominent, its meaning is also drastically altered as everyday routines, roles and relations become significantly disrupted, destabilising participants’ productive identities as parents, partners and caregivers. Such narratives also collectively reveal how Long Covid disrupts normative temporalities and biochronology, as individuals find themselves inhabiting life stages out of sync with their chronological age — embodying the limitations of old age, confronting reversed caregiving roles, or oscillating between dependent adolescent

and elderly identities — ultimately unsettling expected trajectories of independence, activity and relational roles in adulthood. Therefore, the negotiation of the home space becomes multifaceted, complex and relational, challenging an individual's core sense of self.

Traditional understandings of the home as a space of family, sanctuary and autonomy were also disrupted as participants became socio-spatially isolated, dependent and trapped, transforming the home into a carceral space. These experiences of disablement, that is the physical and emotional challenges of bodily pain and limitations, can also have a negative impact on how individuals experience health and wellbeing at home (Crooks, 2010). As participants adjusted to their illness, however, through physical adaptations and emotional coping mechanisms[53], some were able to re-negotiate the home as a safe space of rest, recovery and sometimes even productivity – thus, making it a health-promoting environment. As the home was a safe space for learning to live with an ELC, the unpredictability of Long Covid rendered many spaces outside of the home unsafe. Retreating from spatial engagement outside of the home furthers the sense of confinement to the home, but I have argued that these feelings of confinement are not fixed, are often negotiated and are therefore fluid, always set in the context of participants' variable illness experience. This finding supports the understanding shown by studies on the geographies of chronic illness and disability, which disclose that individuals may feel disabled in some spaces but not in others (Crooks et al., 2008). It further suggests that individuals may feel disabled across particular *temporalities* within a single place, such as the home, in tandem with the variable nature of Long Covid.

Within these disruptions, I have introduced the relationship between Long Covid and energy – which emerged explicitly from participants' narratives – emphasising the constraints placed on participants' physical, mental and intellectual capacities as once taken-for-granted routines and activities becoming increasingly energy-intensive. I have also alluded to the body's shifting relationship to time and space in the context

[53] Lazarus and Folkman (1984) propose two main types of coping: problem-focused coping and emotional-focused coping. The former focuses on managing stress, while the latter addresses the emotional response to it. In this chapter, I have introduced some emotional-focused coping strategies such as finding joy in the mundane. In the following chapter, I explore a key problem-focused coping strategy denoted the 'three Ps principle'. It must also be noted that these concepts are not mutually exclusive.

of energy limitations – such as slowing down the pace of spatial practices and the emergence of crucial time-space separations necessitated by the new energy-demands of multitasking. I will develop these themes both empirically and conceptually in the following chapter. This shift in the body's energy creates a dissonance between participants' internal sense of autonomy and their external capabilities, resulting in feelings of disempowerment and loss of control over their bodies. As a result, participants are forced to accept their new body limits and adaptations to cope with Long Covid 'for now' but not forever. They hold on to the hope that they will eventually reconcile the disconnect between their internal and external selves, regain control over their bodies, and re-engage in fundamental human functions. Acceptance was nonetheless also contingent on individual spatial, temporal and corporeal circumstances, complexly relational, and therefore, not always realised.

By bringing these experiences together, I have conceptualised the lived reality of feeling spatially, temporally, corporeally and affectively 'stuck' as an ongoing embodied post-pandemic lockdown – what I term 'bodies under lockdown'. This state of corporeal, spatial and temporal suspension resonates with disability scholars' theorisation of crip time – a non-linear, unpredictable experience of temporality shaped by chronic illness and bodily constraint, out of sync with normative, productive rhythms (Kafer, 2013; Samuels, 2017; Evans et al., 2024). In light of Long Covid's novelty and ongoing uncertainty, I develop this theme of feeling 'stuck' throughout the following empirical chapters. In Chapter 5, I explore how participants attempt to regain a sense of bodily control through self-management strategies such as planning, pacing and prioritising. In Chapter 6, this sense of suspension extends into the spatial realm, where I trace the invisible and hidden geographies that shape how Long Covid is recognised, accessed and lived. Chapter 7 then highlights how, in the absence of clear clinical pathways, responsibility is increasingly placed on individuals themselves who feel "left to it," prompting participants to turn to online spaces in order to make sense of their illness, seek guidance and fill epistemic and support gaps left by institutional uncertainty. Together, these chapters show how the experience of being 'stuck' is produced not only through bodily and temporal disruption, but also through institutional uncertainty, invisibility and marginalisation within a post-pandemic landscape.

Chapter 5: Planning, pacing, prioritising

5.1 The three Ps principle

In the previous chapter, I explored how participants experienced a severe bio-geo-graphical disruption upon the onset and development of Long Covid, impacting their everyday meaningful spaces, routines and relations – the essence of how people live their daily lives and form their sense of purpose and identity. Throughout these narratives, participants made various references to the impact of Long Covid on how diminished physical and mental energy capacities fundamentally impacted their ability to embody former time-space rhythms. This chapter now shifts focus to *how* participants self-managed these new energy limits through a socio-spatial, and crucially temporal, energy management strategy that they consistently referred to, both explicitly and implicitly, as "planning, pacing, prioritising" (PPP), highlighting its significance across their Long Covid stories.

The World Physiotherapy's guidance promotes PPP as a central rehabilitation strategy for Long Covid, offering a symptom-contingent intervention to minimise post-exertional symptom exacerbation (PESE). It "encourages engagement in activities guided by perceived symptom levels to avoid worsening symptoms, conserve energy and enable participation in meaningful activities" (2021, p.9). This guidance compellingly links the three Ps principle to bio-geo-graphical flow, framing PPP as a strategy to help individuals re-engage with meaningful spatial, temporal and social rhythms in their everyday lives, while re-connecting with their bodily capacities. Pacing, as one core element of PPP, is a widely used term in rehabilitation for various chronic conditions, including ME/CFS, cancer, fibromyalgia, chronic obstructive pulmonary disease (COPD) and heart disease, to characterise the management of everyday activities, energy conservation and symptom prevention through the slowing down or 'spacing out' of everyday activities. Both planning and prioritising – referring respectively to the organisation of time-space routines, and the selection of tasks based on their importance – are integral to the PPP framework but tend to be less explicitly discussed in broader chronic rehabilitation and are often assumed components within pacing strategies. Although specific practices may vary across conditions (Long COVID Physio, 2023), pacing has been specifically endorsed by the World Health

Organisation (WHO, 2023a, p.9) as part of broader PPP framework, while the NHS[54] (2024; 2025) explicitly endorse the three Ps principle for Long Covid management.

In the broader social science literature, sociologist Charmaz (1991, p.161) alludes to the three Ps principle through her discussion of "juggling and pacing" as strategies for managing time in the context of chronic illness. These concepts encompass reorganising, rescheduling and regulating activities, where "juggling" captures the process of prioritising and planning, and pacing is reflected in the controlled rate of activity. Building on this explicitly *temporal* framing, I offer a *geographical* extension of these ideas in the context of Long Covid, exploring how individuals manage time, space and bodily energy through planning, pacing and prioritising. Throughout this chapter, I demonstrate how the application of these principles in everyday Long Covid management is characterised by re-learning how to live – by slowing down and meticulously planning around one key activity per day, with little to no room for spontaneity. I also consider how the unpredictable nature of Long Covid challenges the apparent control that PPP offers. Across individual interviews[55], participants discussed how they utilised PPP to help them reorganise and restructure everyday time-space rhythms with the aim of mitigating symptom intensity and exacerbation, or a 'crash'. However, while analysing and reflecting upon the initial interview transcripts prior to organising focus groups, I was struck by the underlying connotations of PPP – order, structure and control. These connotations sit uneasily with my understanding of Long Covid as an inherently unpredictable and variable condition that I assumed to be disordered, unstructured and therefore unamenable to PPP. This dissonance prompted me to re-introduce the concept in focus group discussion as I sought a

[54] For formatting purposes, while preserving full citations, "NHS" used in-text here refers to multiple NHS Trusts: Guy's and St Thomas' NHS Foundation Trust (2024), Royal Cornwall Hospitals NHS Trust (2025), and Mersey Care NHS Foundation Trust (2025). The inclusion of multiple NHS sources underscores the locally adapted nature of NHS service provision across the devolved health systems of the UK.

[55] In individual interviews, several participants referred explicitly to PPP: Alexandra, Helena, Kristina, Lu, Marg, and Mark. Others discussed specific components of PPP: Amanda, Anna, and Ruth discussed "pacing"; Charlotte, Hannah, Kamy, Molly, and Theresa mentioned both "planning" and "pacing"; Monica discussed both "pacing" and "prioritising"; Amy, Kate and Megan focused on "planning," while Fiona spoke about "prioritising." Across interviews, all participants implicitly applied these principles in their everyday management of Long Covid. They often described adjusting the rate of activities through strategies such as "resting," "slowing down," or becoming more aware of the proportionate energy demands of activities, with some specifically referring to the metaphorical 'energy envelope' or 'Spoon Theory', which I elaborate in what follows. All focus group participants (cf. Table 3) demonstrated familiarity with PPP and reflected on how it shaped their daily life.

deeper understanding of how this energy management strategy was negotiated across participants' everyday lives. To unpack these tensions, I conceptualise Long Covid as *predictably unpredictable* and examine how PPP offers an *illusion of control* within the daily realities of self-management. Throughout this chapter, I do not aim to evaluate the clinical effectiveness of the three Ps principle, but instead explore the complexities and nuances of how this self-management strategy plays out across participants' lives. In doing so, I build upon the previous chapter, forming a cohesive narrative thread.

5.2 Bringing energy into consciousness

At its core, PPP is a self-management strategy[56], centred around monitoring subjective and perceived *energy* levels (World Physiotherapy, 2021). The World Physiotherapy briefing paper on safe Long Covid rehabilitation (2021) makes several references to "energy," including the metaphorical "energy envelope" theory[57], which serves to help individuals subjectively calculate and manage their perceived physical, mental and emotional energy levels. Participants in my study also made various references to energy when narrating their Long Covid stories, particularly as previously taken-for-granted time-space routines now *felt* more physically and cognitively demanding when undertaken through an energy-limited body. Importantly, this was not because everyday activities suddenly required more energy in absolute terms, but because they were being undertaken in relation to profoundly diminished and unpredictable energy reserves following the onset of Long Covid. For example, Kamy emphasised how she had to re-think every aspect of her life in terms of both physical and mental energy:

> It [Long Covid] doesn't function like a normal human being. You have to start to think that speaking on the phone, thinking, breathing, that all use energy. Walking, energy. Putting on clothes, energy. Watching telly, energy. Absorbing information, energy.

Kamy's perspective reflects a broader shift in participants' awareness of their bodies and energy needs. Basic activities that were previously taken-for-granted, such as thinking and breathing, as well as everyday tasks such as getting dressed, now seemingly demand significantly more energy than before. This heightened awareness

[56] I must also emphasise that PPP is a lifestyle-related rehabilitation and management strategy as opposed to a specific treatment.
[57] Originally developed by the ME/CFS community, the 'energy envelope' is a metaphorical tool to help individuals subjectively calculate and manage their daily energy. I discuss such metaphors and analogies later in this chapter.

of energy among participants extended beyond mundane routines to more significant events, with participants noting how different activities now have contrasting energy demands than before. Emphasising new physical demands, Lu shared that "I've never seen walking as exercise. I find it really hard that since being ill with Long Covid, my body sees walking as exercise," while Amy emphasised the mental and cognitive energy demands required of her in social settings:

> I hadn't realised before all of this, how much energy being social takes up [...] I'm quite extroverted, and being social with people comes naturally, and I enjoy it, and it used to recharge my batteries, seeing lots of people. But now, even if a friend comes over for coffee, I can feel myself zoning out completely.

This shift in Amy's experience clarifies how socialising, once an energising activity that used metaphorically to "recharge" her "batteries," now drains her energy, clearly reflecting a bio-geo-graphical disruption to her former extroverted identity. Participants also noted how different socio-spatial factors – notably group settings, loud noises and bright lights – were overstimulating and contributed to depletion of already limited physical and mental energy reserves. As Megan elaborated:

> If I was going out with large groups of people, […] that was taking all of my energy. Too much noise, too many people. If they're touching, if they're too close, I find that too much. And bright lights, if I was in a cafe, if a blender was going, I couldn't talk at the same time. […] That would just zap me as well.

These experiences highlight a profound shift in participants' awareness of energy, as previously simple activities and seamless social interactions are now experienced as energy-demanding and depleting. The sensation of energy, as participants have suggested, flows around and through the environment, material objects and interpersonal exchanges, acting either to vitalise[58] or to deplete the body[59]. Energy also has the connective potential to be shared *between* bodies. It therefore transpires as a deeply embodied and affective experience as it is *lived* through rather than

[58] Throughout this thesis, I use the term "vitalise" in its everyday sense to reflect participants' experiential descriptions of feeling enlivened or energised, rather than as a conceptual engagement with *vital geographies* or philosophical accounts vitality associated with authors such as Canguilhem.
[59] Throughout this thesis, I refer to the flow of energy between bodies – both material and immaterial – as it circulates through affective atmospheres in ways that can either vitalise or deplete the Long Covid body. This use of energy should not be confused with the scientific definition used in thermodynamics. According to the first law of thermodynamics, energy cannot be created or destroyed, only converted (NASA, 2021). My use of the term, nevertheless, does *not* contravene this principle. Terms such as vitalise or deplete are used to describe experiential and affective shifts – transfers of subjective immaterial energy – rather than literal physical conversions of measurable energy.

universally defined or measured (Philo et al., 2015). Therefore, what vitalises one body may drain another. To articulate these sensations, participants frequently adopted energy-related metaphors, such as those aforementioned: “recharge my batteries,” “zoning out” and “zap.” As Philo et al. (2015, p.39) suggest, communicating energy in this analogous manner can seem imprecise or woolly to more scientifically-minded audiences, and yet it serves as a crucial tool for patient-experts attempting to make sense of the disruptions to their “corporeal, psychological, emotional and spiritual system,” especially in the context of a novel, elusive and contested illness like Long Covid. These narratives hence support the concept of everyday energy geographies as one compelling framework for this chapter and broader theme of this thesis, where energy is experienced as a relational and affective force that circulates between the body and its spatial, social and temporal surroundings. This is especially pertinent given that Long Covid is also widely recognised as an ELC, in which persistent energy impairment shapes how individuals navigate daily life and space (Evans et al., 2023). Such narratives further reveal how participants become self-clinicians, crafting personal vocabularies to bridge the gap between embodied and incoherent biomedical knowledge. By claiming vocabulary in this way, participants transform energy – an ephemeral and immaterial force – into a tangible materiality that can be affectively felt, experienced, *shared*.

As symptoms and illness severity varies between participants, PPP is highly subjective and individual, further underscoring the centrality of participants’ self-clinician role. In contrast to transient pain, which is often diagnostic, predictable and indicative of repair, Bissell (2009, p.911) suggests that chronic pain “territorialises” the body, takes it over, even colonises it. Similarly to chronic Lyme disease, yet separate from many other chronic illnesses, Long Covid has a known pathogenic aetiology, with chronic manifestations of Lyme disease caused by the *Borrelia burgdorferi* bacterium (Dumes, 2020) and Long Covid linked to the SARS-CoV-2 virus. Regardless, as a novel chronic illness, with symptoms that often differ greatly from acute infection, Long Covid is typical of other chronic illnesses in that it is uninvited, defies meaning and has no clear trajectory. Long Covid resonates with the dynamics Bissell’s (2009, p.911) describes in chronic pain as “obdurate,” redundant and highly unpredictable. As such, participants further emphasised the importance of ‘listening’ to the body as there is no precise way accurately to quantify the Long Covid body’s energy levels. As Megan

explained, “There’s no system. There’s no, ‘if I do this, this is going to happen,’ because you have no idea. It’s just really, really unpredictable,” while Arun elaborated that “There's no device, that’s the thing [...] You have to judge it by listening to your body as carefully as you can.” Bissell (2010, p.85), therefore, suggests that uncertainty “is key to understanding the experience of the body in pain,” as it evokes a different kind of embodied and affectively experienced pain in contrast to accompanying transient pain.

Similar to the aforementioned energy envelope, some participants also adopted *The Spoon Theory*[60] analogy to navigate the body’s energy levels in proportion to the energy demands of various daily activities. As Kamy explained:

> Have you heard about The Spoon Theory? That’s the best way [to] explain how much energy. To go outside, for example, uses four or five spoons. But if I have two spoons today, how to spend four? I can’t. Like the phone or the watch[61], 30% battery, you’re left with 15, put phone on charge. And if I sleep 20 hours, it doesn’t mean I’ll gain the energy back. So, if you overload the day before, and you overload today, you will trigger a crash or a post-exertional episode. If you crash, you go away two days, but if it’s a post-exertional episode, it can last three months.

In this analogy, Kamy compares her body to a phone battery – something that is quantifiably drained and recharged. She emphasises, however, that unlike a phone or smartwatch, there is no simple way to translate her energy levels into a battery percentage or indeed to recharge her body. Measuring subjective and fluctuating energy levels in and of itself is a complicated process. However, the Long Covid body’s energy is a somewhat more complicated matter, especially as energy demands on activities and associated bodily sensitives can shift from day to day (Medinger and Altmann, 2022). As Megan lamented, “It’s just really, really unpredictable.” Although

[60] The Spoon Theory was originally by Christine Miserandino (2003) in a blog post and later published as a chapter in *Beginning with Disability* (2017). It serves as a metaphor to describe the mental and physical energy capacities of individuals with chronic illness. Spoons are used as a visual representation of units of energy, symbolising how much energy an individual has to spend each day, with different activities requiring varying numbers of spoons, depending on their energy demands (see Appendix F). The Spoon Theory is therefore used to help people with chronic illness manage and preserve their energy, while also helping others to understand their energy states. The analogy has since been applied to other invisible disabilities, mental health conditions and neurodivergence.

[61] Smartwatches (e.g. Garmin) have also popularised metrics such as “Body Battery.” Although Kamy (FG4) later described a mismatch between these quantified measures and her embodied experience of energy. While she attempted to use a Garmin to track how much energy she could conserve or expend in routine activities, she found that such devices failed to provide precise or meaningful data, noting that “It’s not helping [...] even the best device doesn’t give you exact measurements and data.”

rest and sleep might seem like obvious solutions to replenishing energy, as suggested in Miserandino's (2003) *The Spoon Theory,* sleep does not necessarily offer Kamy's Long Covid body the revitalisation that may be assumed. This is furthermore supported by The World Physiotherapist briefing paper (2021). Therefore, Kamy must remain *constantly* aware of her body's specific needs and capacities around the most minutiae of daily tasks which either deplete or recharge her energy levels; that either use or offer spoons. Kamy also realises that she must not "overload" or fall into what Miserandino (2003, n.p.) terms "borrowing against tomorrow's spoons." For the Long Covid body, borrowing spoons may result in symptom exacerbation, which typically manifests anywhere from 20 minutes to 48 hours later (Medinger and Altmann, 2022).

Participants stressed this constant consciousness of their physical and social environments, their mental and physical capacities and the energy required for every action. As Charlotte (FG2) noted, "it's just about constantly being aware," while Lu (FG2) agreed that "it's a 24-hour thing." Fiona further shared, "the biggest paradigm shift I had was learning that the days I'm doing nothing, that doesn't exist, because on those days I'm recovering. So, I am doing *something* [emphasis added]." Heightened awareness of energy and the body is an ongoing process, even on days spent resting, hence transforming rest into an active process of energy replenishment and recovery rather than passive inactivity. These testimonies therefore suggest that Long Covid has completely re-shaped how individuals embody everyday significant spaces, with the constant self-monitoring of energy levels becoming a defining aspect of their daily life. For these individuals, lifeworlds cannot be separated from Long Covid; it is a constant, inescapable reality that requires an *ongoing* awareness of the body's energy levels.

These narratives further emphasise that lived experience is used as a subjective basis for learning to live with Long Covid; for participants to understand and accommodate their new bodily limits. As Merleau-Ponty (1962, p.169) asserts, the body is not simply an object in the world but the *subject* through which we experience and act in the world — it is our "general medium for having a world," grounding our lived experience. Fiona echoed this sentiment, explaining that, alongside advice from her occupational therapist to plan, pace and prioritise, coupled with her own additional research, she truly came to *know* her Long Covid body and learn how to manage her energy through her embodied experience of a crash. As she elaborated:

> The crash was the best thing for me, because it actually got me to *understand* what I've been experiencing. You can experience all sorts in life, and you don't have a clue what's going on, but actually all the bits came together with that big crash. But then I started learning about baseline therapy: find out what you can do with the minimum impact on your system, and then, as your symptoms do show themselves again, that's just flares. And as you're alert to them, you can modify what you do to suppress the flares and then work from that baseline. And then gradually, incrementally, increase what you do.

Participants learned about PPP (or individual components) through various sources: occupational therapists, Long Covid clinics, support groups and their own research (see Chapter 7). Regardless of the source, however, Fiona supposed that embodied knowledge enabled her to understand *her* Long Covid body and its energy limits. In doing so, she transformed her physical pain and suffering into a form of knowledge and empowerment to act as a self-clinician, the patient-expert. These experiences further confirm that Long Covid ontologies are diverse, highly individual and subjective, and are developed through both embodied and epistemic forms of knowledge.

Through his affective framing of chronic pain, as distinguished from transient pain, Bissell (2009, 2010) explores experiential and embodied dimensions of chronic pain discourse. While transient pain can be signified and known, chronic pain often eludes fixed meaning, emerging instead through affective practices and performances under uncertain conditions. This process gives rise to new ways of *knowing*, focusing on *becoming* rather than striving for signification. Drawing on Scarry's (1985) assertion that pain is fundamentally unshareable, that we cannot feel someone else's sensation, Bissell (2009) proposes the concept of "intensity" to capture the qualitative experiential dimension of affect — how pain can be heightened or diminished, either enhancing or depleting life. This point aligns with Moss and Dyck's (2003) contention that the chronically ill body is not "fixed," but in a state of flux. Influenced by McCormack (2003), Bissell emphasises process over fixity, highlighting how intensity, akin to energy, moves and coheres across and through bodies in relational assemblages. This relational framework thus prompts us to consider how corporeal experiences are formed, sensed and narrated, offering a means of tracing the complex assemblages that shape the corporeal experience of chronic pain. Rather than relying on "fixed" accounts of embodiment, Bissell (2009, 2010) invites an appreciation of the multiple and uncertain ontologies of chronic pain, which can be (dis)abling through different orientations, anticipations and dispositions. Yet, he also cautions that, while this

perspective can expand our understanding beyond normative discourse and signification, we must remain attentive to *precisely* how such differences are represented so as to avoid being folded into universalising frameworks. Bissell's framework of intensity is hence particularly relevant for conceptualising Long Covid experiences which vary greatly between individuals. Affective intensities offer a layer of corporeal depth to the experiential complexities and nuances of how individuals collectively manage, make sense of and share their experiences of Long Covid.

As Fiona additionally suggests, past experiences inform participants' awareness of energy levels, shaping present routines of energy management to mitigate PESE. As such, "anticipatory geographies" are central to Long Covid management because participants are constantly "pre-empting, preparing for, or preventing" (Anderson, 2010a, p.777)[62] symptom exacerbation through spatial and temporal reconfigurations structured around the three Ps principle. That said, as already noted, the chronically ill body is not "fixed" in time or space, especially as symptoms emerge, develop and change (Moss and Dyck, 2003). As such, embodied knowledges are continually written, unwritten and rewritten. Learning how participants navigate time-spaces around their learned energy budget and (un)predictable symptom intensities and exacerbation, I explore how anticipatory geographies are both deeply embodied and affectively forecasted. In what follows, I therefore reconceptualise the clinical framework of PPP through a geographical lens, as a spatial and temporal reconfiguration of everyday spaces and routines that become complexly shaped through both affective and embodied experiences

5.3 Planning, pacing and prioritising in practice

5.3.1 Re-learning to live

As explored in the previous chapter, the majority of participants in this study were once accustomed to relatively high levels of activity, productivity and multitasking, and hence experienced profound bio-geo-graphical disruption due to severe physical and cognitive impairments, particularly at the onset of Long Covid. Many described being unable to perform daily tasks, such as walking, or recalling simple words or names.

[62] Anderson's focus is geopolitical. Nevertheless, his argument remains highly relevant to the geographies of everyday, and more particularly the subjectivities of health and illness (cf. Boyle, 2019a; Feather, 2024; Smith, 2013).

The destabilisation of everyday tasks and routines forced participants to re-navigate what they previously understood as common sense (Moss and Dyck, 2003). As such, participants were forced to confront and even resist their inhibitions and deeply ingrained habits by remaining constantly aware of the proportionate energy demands that those activities place on their bodies. For many, this was reflected in practices such as engaging in only one task at a time, slowing down activities with rest in between, or leaving tasks unfinished. As Lu (FG2) articulated this awareness, "I think if you're not like that by natural ways, you're having to relearn how you live," while Kamy added:

> You have to break yourself and forget yourself, and you learn like a baby how to portion your day. It's really hard. You do stuff by inertia, by a habit, or by beliefs, or because you don't like to leave things undone or unfinished, and all of a sudden, you're realising that it just makes you way worse.

By pacing, participants are forced to confront the reality of chronic illness, as they learn what it means to navigate their ill-health. Paralleling findings in the previous chapter, Kamy's reference to a "baby" reflects a bio-geo-graphical disruption to individuals' biochronicity, identity and independence, a regression to a form of 'babyhood'. Rather than maintaining a sense of autonomy, participants are faced with the reality of their increasing dependence and fragility as their ill-bodies contradict how they previously embodied everyday meaningful spaces and their inner sense of self. Therefore, applying the three Ps principle did not come easily to the majority of participants in my study[63], since re-structuring their everyday time-spaces completely contradicted how they understood themselves, how they previously managed everyday life and also their typical approach before to managing (acute) illness (as discussed in the previous chapter). As a result of these new common sense boundaries, participants commonly overestimated their new energy levels and capacities, especially in the beginning. As Amanda (FG1) shared in a focus group discussion:

> It took me a long time to get the hang of it, because before you're ill, well I don't know about everybody else, but I was really active [group nodding]. I was walking everywhere, going to the gym, swimming. I was a teacher. I was busy all the time. And so, when you get poorly and people say to you, 'plan, pace and prioritise,' you think you're actually pacing because you're not doing a lot of the things you *were* doing, but the amount of pacing that I've had to do, I've

[63] With the exception of Amy who was living with co-morbid chronic arthritis and therefore was already familiar with managing her energy levels.

> had to draw it right back. And I think it took a long time for me to actually realise how strict you've got to be with yourself. Well, for me anyway. I know everybody's not the same, but I *do* have to plan and pace, and if I don't plan and pace, I'm out for months.

Amanda's testimony reflects Moss and Dyck's (2003) contention that re-defining common sense is filtered through *embodiment*. Her account highlights the attentiveness required to manage the body's shifting energy levels as individuals must pace activities more slowly than what they would intuitively assume or have come epistemically to understand. Former inhibitions, routines and activities can no longer be performed automatically. Instead, they must be approached with meticulous planning and with acute awareness of bodily signals so as to develop an embodied knowledge of pacing aligned with new energy limits and sensitivities. Otherwise, participants risk the debilitating effects of symptom exacerbation, which Amanda experiences as being "out for months." This reflection therefore suggests that pacing is also traced through affective "intensities" serving either to enhance or to deplete life. As outlined earlier, chronic pain territorialises the body. Therefore, Bissell turns to Deleuze and Guattari's (2004) concept of "deterritorialisation" to trace how pain may be decentred through three pain-management strategies – pacing, shaping and repositioning. However, for the purposes of this thesis, I will draw only on his exploration of the embodied practice of pacing, extending his ideas through the three Ps principle, for specific Long Covid management, as a means of understanding the relationship between the body and pain. In doing so, I consider the extent to which participants (re)gain agency and control over their ill bodies through the complex feats of enacting the three Ps around a highly unpredictable chronic illness, shaped by fluctuating embodied experiences and affective intensities.

What Amanda's narrative further reveals is a somewhat counter-intuitive notion that for individuals to 'speed up' their recovery, they need to 'slow down' the pace of their life. As Ruth further articulated, "I then just literally went *back* 20 steps in order to get better." Fiona further illustrated the slow and fragmented nature of pacing everyday activities as she attempted to walk to her local botanical gardens:

> At one point, I could walk for five minutes and sit for ten minutes, walk for five minutes. So, I didn't get to the Botanical Gardens, but I got a quarter of the way there. A day like that would be an active day, and then the following day, I would

> do nothing. And then the following day, I would walk ten minutes, and then I would do nothing the following day.

Fiona's experiences reiterate how Long Covid has severely impaired her physical abilities, resulting in debilitating bodily limitations in stark contrast to her previously healthy, strong and fit corporeality. Therefore, as she embodies a new way of navigating everyday activities, she emphasises that pacing is a reconfiguration of time, space and the body, characterised by radically slowing down, partitioning activities with rest, being patient and leaving tasks incomplete. These embodied strategies echo Moss and Dyck's (2003) analysis of how women with chronic illness accommodate the shifting capacities of their "chaotic" bodies by reorganising everyday routines around bodily limits and redefining what is considered "common sense" in relation to domestic work, such as leaving chores unfinished or lowering domestic standards, particularly when tasks are undertaken by partners or children. These embodied negotiations described in both Moss and Dyck's (2003) and my own study reflect a resistance to dominant discourses of domestic productivity whereby individuals with chronic illness craft new bodily temporalities that prioritise energy preservation that enable spatial engagement beyond the home.

Fiona further shared that incrementally pacing everyday activities, such as walking to the local botanical gardens, helped to incrementally extend her physical capacity:

> So gradually, I've got to the point I can vacuum two rooms, and then do nothing the following day. Then gradually, you can build up and you can do vacuuming one room, each day, with no breaks, so you do consecutive days.

Her experience emphasises that previously mundane activities, such as vacuuming, became significant milestones in her rehabilitation. Her improved mobility and endurance enabled her to re-engage in everyday spaces and routines, revealing that recovery is both physical and embedded in time-space rhythms. As Fiona's energy capacity increased, her subsequent need to pace decreased, clearly evidencing the role of pacing in recovery and rehabilitation. Similarly, Sheila, who is on long-term oxygen therapy, related her journey of pacing and gradually re-building her swimming endurance:

> 18 months ago, when I first got in the pool, I did a couple of strokes and I thought I was going to die [...] So then I thought, I'll crank my oxygen up a bit and see if that helps, and then I managed to do a few more, and I've just built up, built up. And then, yesterday, I did 140 lengths.

Akin to Fiona's walk to the Botanic Gardens, swimming for Sheila was more than a recreational activity, but also a self-managed form of rehabilitation. As she improved her physical strength, balance and mobility through swimming, she explained that she can now walk independently from her walker and crutches. The swimming pool for Sheila became a transformative space, symbolising health, vitality and belonging. As she reflected, "apart from being attached to a big bit of tubing [...] when I'm in the pool, I feel the same as everybody else." Rehabilitating her swimming endurance through pacing enabled Sheila to re-connect with her former identity, experience a sense of normalcy and reinstate a sense of bio-geo-graphical flow. These narratives reveal that participants' embodied understanding of Long Covid rehabilitation is inherently temporal – requiring slow, partitioned pacing – but also deeply spatial, as re-building physical abilities through pacing enabled participants to re-engage in former significant spaces such as the botanical gardens or swimming pool, representing recovery, identity and wellbeing. Through the three Ps principle, participants work to reclaim agency over their bodies and re-engage in meaningful spatio-temporal rhythms. As Helena powerfully expressed, "I'm determined to keep getting fitter, because I want my life back."

Alongside physical impairments, Ruth described cognitive impairments which particularly impacted her memory, verbal communication skills and intellectual capacity to embody her previously articulate self. She explained:

> Two of my boys described understanding a conversation as if it was like [...] you'd gone to IKEA [...] You bought a wardrobe, you come home, you have no instructions. You kind of made it, because you knew what the picture was going to be, and all the parts are there, 'but you've still got three screws missing, Mother' [...] And it does, it feels like, you know you've got the bits but can't put them together.

Ruth's account of her brain fog, as illustrated through her children's IKEA metaphor, reflects a spatial and structural disruption to her cognitive function – she possesses all the mental "parts" but lacks coherence to put them together. This experience reflects Bissell's (2025) work on brain fog to conceptualise a geography of being "out of it." In stark contrast to her former articulate self, Ruth's internal cognitive map is complexly dislocated, or as Bissell (2025, p.10) describes, "displaced," as thoughts, words, instructions have lost their affective "stickiness," slipping away before they can settle, leaving her, in effect, "cut off" from her cognitive bearings.

Paralleling the above narratives, participants described efforts to rebuild mental and intellectual capacities through temporal reconfigurations of slowing down, pacing and gradually regaining cognitive function. Fiona noted, “I literally did do colouring books and dot-to-dots to get my head working again, and then I worked up from there. And *then* I started reading research papers and being really nerdy about it.” Similarly, Ruth shared, “I did actually try to start doing jigsaws, on my phone basically, so that I could achieve something, but I couldn’t achieve much else.” These experiences of doing simple cognitive tasks like colouring books and jigsaws to rebuild cognitive competence echo with Kamy’s earlier description of somewhat returning to a bio-chronicity resembling ‘babyhood’, of relearning fundamental cognitive functions. Ruth further admitted how she continues to negotiate this disruption to her intellectual identity:

> I couldn’t speak in sentences properly. And even now, if I’m tired, that just goes. [...] And I’d speak really slowly, so that people couldn’t guess I was completely stupid. And then, that way, I had time to think about words. So that you had a thinking space before you said something [...] Only a few people noticed [laughs].

As Long Covid affects cognitive functions, everyday actions that were previously automatic, such as speaking or remembering, can become fragmented, significantly laboured and newly demanding in relation to constrained cognitive energy capacities. Ruth described how she adapted to this disruption by deliberately slowing her speech to support her cognitive processing, while maintaining an outward impression of competence. In doing so, she creates “thinking *space*,” carving out both time and cognitive space to manage her capacities. Bissell (2025, p.8) conceptualises such brain fog is an affective and spatial form of “dispossession” of bodily capacities to think, act and sense. Ruth’s experience exemplifies this cognitive dispossession, as her previously automatic fluency becomes fragmented and laboured, requiring conscious effort. As Bissell notes, such cognitive fragility is often incompatible with capitalist expectations of ‘normative’ productivity, coherence and lucidity. Ruth’s experience extends these ideas, highlighting the ongoing social pressures to perform as though her cognitive capacities have not been impaired. Her temporal and spatial strategy is not simply a response to these social expectations, but also part of her broader emotional and affective struggle to preserve her inner sense of self. Ruth’s pacing thus becomes a “quiet” form of resistance (Bissell, 2025, p.7) — an embodied negotiation

of social expectations and personal identity in attempting to reclaim agency over her cognitive and embodied experience. By slowing down and creating space, she reasserts a sense of control and gradually re-connects with a version of self that feels somewhat dispossessed, yet not completely displaced, as she reflected: “I do feel that I'm going faster now, which is almost up to the speed I used to be.”

Bringing together Ruth’s concept of “thinking space” and earlier references to the mental energy demands of busy and loud physical spaces, it is possible to underline how much mental and physical spaces intersect. Just as Ruth needs more time between her thoughts and words, many participants also described needing quieter, slower or predictable physical environments to manage mental and cognitive fatigue as they relate to sensory overload. As such, the reorganisation of thinking time and space may be further supported by the reorganisation of physical space, often by withdrawing from unpredictable, loud and busy social spaces and retreating to the safe and more controlled home space, to which I return in what follows. These findings clarify that Ruth’s “thinking space” is not only internal or cognitive, but also embodied, relational and *situated* in broader socio-spatial contexts that shape illness, memory and fatigue, either enabling or hindering cognitive capacities (Dyck, 1995; Atkinson, 2013). Building on these insights, I propose that cognitive time-*spaces* are also deeply affective: charged with emotion, labour, frustration and hope, complicating individuals’ ongoing efforts to preserve a coherent sense of self. Long Covid is therefore not confined to bodily experience but is complexly *lived* through both mental and physical time-spaces.

Although participants emphasised the slowness of Long Covid rehabilitation and recovery, some at least sensed themselves to be ‘recovering’. As Mark (FG1) explained, “I actually think I'm getting better. So just really slowly. Really, really slowly.” What they also identified, however, was the non-linearity of recovery, especially pertaining to the variability of symptoms and cyclical nature of relapse and recovery, as described in the previous chapter. As Anna added:

> It’s sometimes hard to see the progress because it goes so slowly and goes through the ups and downs and sometimes, I have to remind myself, ‘okay, a year ago, it was really worse, so maybe it’s getting better.’

These accounts reflect the temporal disruptions inherent to chronic illness, where time is stretched, fragmented, non-linear (Charmaz, 1991) and even cyclical (Wilton, 1996;

Moss and Dyck, 2003). Anna's reflection captured how this non-linearity complicates the emotional geographies of living with Long Covid. Participants often struggle to situate themselves in time, oscillating between moments of perceived improvement and persistent bodily limitation, such that they are subjectively "*both* ill *and* healthy" (Moss and Dyck, 2003, p.99).

These findings closely parallel the temporal and corporeal liminality that I discussed in the previous chapter. When recovery is experienced as slow, non-linear, cyclical and uncertain, temporal boundaries – between past, present and future – collapse, and participants feel suspended in a liminal state between recovery and illness. In this perceived liminality of time and body, progress becomes ambiguous, and recovery remains elusive and undefined. While pacing was commonly adopted to manage symptoms, some participants experienced continuous, albeit gradual, improvement, while others – as mentioned earlier – experienced a sense of plateau or stasis. As Amanda emphasised, "Pacing does help. It helps you control your symptoms, but it doesn't help you get better. It just means you have to live a different life." Similarly, as Amy reflected, after feeling "stable" for one year, "I reckon I'll either always be like this now, or it will just really slowly, and probably hardly noticeably, get better [...] So any improvement is in negligible increments." These reflections hence illustrate that the concept of slowing down to speed up does not necessarily lead to an inevitable recovery, a return to pre-illness normalcy, but instead represents an *ongoing* management strategy with an undefined end point. These experiences duly underline the shared sense of corporeal and temporal 'stuckness' felt by many participants in this study. As such, living with Long Covid is not merely about managing symptom intensities, but also about an ongoing negotiation of life in a suspended, liminal, stuck state for which conventional understandings of progress and recovery no longer apply[64].

These experiences reveal the complex entanglement between the physical sensations of pain, as understood in biomedical terms and to the affective and emotional

[64] Patient testimonies (Garner, 2021; Edgar, 2024; Gawthorpe, 2024; Stanisforth, 2024) indicate that some individuals do recover from Long Covid. I recognise that there may be a selection bias in my study as those who have recovered may be less likely to engage with Long Covid social media platforms, hashtags or support groups through which my recruitment poster was shared. They may also be less motivated to participate than individuals who are currently affected by Long Covid. Nevertheless, the key takeaway from these findings is that some people do experience an elusive, undefined recovery, reaching a state of plateau or stasis.

sensations of pain. Aligning with Bissell's (2009) affective framework, which suggests that pain-management strategies, such as pacing, do not serve to eliminate chronic pain but rather reconfigure it in relation to the body, participants who reach a state of plateau or stasis may find that the sensation of pain becomes more manageable through intentional modulation of its intensity, as Amanda and Amy's accounts illustrate. By listening to the body, consciously slowing down and breaking up activities in a time-space reconfiguration that is far from common sense or habitual rhythms, the three Ps principle can enhance the body's capacity to generate more tolerable intensities through control and agency over the body. Through regulating intensities, participants can navigate the uncertain, ambiguous and elusive discourses of recovery that are central to many individuals' experiences of Long Covid without submitting to the need to find meaning, resolution or signification.

5.3.2 Prioritising one activity per day

In the previous chapter, I alluded to the concept of planning, pacing and prioritising when reflecting on Kristina's story of adapting her working time-space routine – shifting her counselling business online and working from home while reducing her working hours to accommodate her bodily limits. Here, I will elaborate how her adaptation of planning and pacing around her working routine, as her daily priority, has played out in her everyday life. Kristina (FG1) prioritised her daily routine around work, as she explained: "I'm our main breadwinner, so I need to still be able to bring in enough money to be able to pay our bills." Work was therefore her daily priority over other meaningful everyday socio-spatialities, and to meet that priority, she needed to make major 'workplace' adaptations:

> I will have my client list sort of planned out with lots of gaps in between, and I'll see a client for an hour, and then I'll go and lie down for two hours, and then I'll come back to Zoom and I will see another client, and then I'll go lie down for another two hours, and then I'll see somebody else in the evening, and that's me completely done for the day, and that's all I have done for the day.

Not only did Kristina reduce her working hours to accommodate her bodily limits, as detailed in the previous chapter, she reorganised the temporal rhythm of her typical working patterns by spacing her clients throughout the day, leaving periods of rest in between. She also indicated that working is the *only* thing for which she has energy in that day, a claim echoed by many participants who had also returned to work. As Lu

noted, “If I’m working it’s: work, home, rest, recharge, work.” For participants who had to prioritise their energy for work, time after work was typically spent resting and recharging for work again the next day. The result hence involved a fundamental restructuring of time-space routines, as Anna, a PhD student, shared: “[it] is a very different sort of arrangement of priorities than I had before, because my studies were always just *one* of the many things that I was doing.” As suggested in the previous chapter, these narratives exemplify how former routine multitasking is now experienced as time-space intensive and energy-demanding. As such, everyday routines now require crucial time-space separations.

In the previous chapter, I also discussed home, work and social spaces in isolation, whereas these experiences reveal the inherent relationality of everyday spaces. Amy acknowledged that she uses all her “brainpower” in work, therefore “the balls that are getting dropped are things like being able to have a social life and being able to do other things around the house.” Like many other participants, Molly ventured her experience of “not being able to have any energy left for the nice stuff.” These testimonies offer intimate insights into the social geographies of chronic illness, since the prioritisation of work-rest rhythms redefines other meaningful social and familial spaces, rendering those secondary to caring for the ill body, which is focused on work and rest. In what follows, I also explore the converse of prioritising meaningful spaces and relations over caring for the ill body.

Charlotte and Lu (FG2), sharing a similar experience as teachers who had both returned to work, discussed how their new structured routines impacted their social potential to live spontaneously in spatio-temporalities beyond the workplace:

> Lu: It’s kind of the spontaneity of things. Like before, if I was at work and someone said, ‘do you want to come for a coffee tonight?’ ...
>
> Charlotte: Yeah.
>
> Lu: ... And you would say ‘yeah.’ Whereas now, unless I’ve kind of planned before and after to just do nothing, I have to go, ‘No, I can't,’ because I know if I go, and I’ve not banked some time or got some time to bank afterwards, I won’t enjoy it, and then I’ll be poorly. So, I think I miss that, ‘fancy going for a mooch round the shops?’ or ‘I’m gonna go do this, and then this, and then this.’ It has to be one thing, and that can be the thing, and then you go home. So yeah, I think probably, like you [Charlotte], some days it’s easier than others.

These experiences reinforce the understanding that managing Long Covid requires a constant awareness of energy levels and an intense management of everyday activities. Lu's account underscores a 'tyranny' of planning – having meticulously to manage when, where and how energy is expended and conserved. This effect is double-edged: while daily (and even weekly) pre-planned routines allow participants like Lu to maintain a sense of stability, they also restrict how time can be used, and which spaces can be occupied as routines become increasingly regimented and constrained. As such, participants were stripped from the freedoms of being spontaneous, constrained by making 'choices' that prioritise what their body can handle rather than what they would otherwise have chosen. Therefore, prioritising one activity per day, such as work, often necessitates socio-spatial withdrawal from additional or last-minute plans. The experience of being denied both the time and space to live spontaneously beyond their illness plainly traps individuals into a highly regimented present, living in fear of symptom exacerbation and perceived potential regression of their recovery. Spontaneous geographies, that is, the ability to participate in activities or go places within short notice and with minimal planning, are indeed severely curtailed (Lucherini, 2015) for people affected by Long Covid, constantly shadowed by the affective fears, anxieties and anticipations (Boyle, 2019b) of symptom intensity or exacerbation.

After two years of trial and error with her work routine, Kristina explained that she wants to re-engage in other spaces and activities *beyond* her job; ones that potentially will bring her meaning and fulfilment beyond what she can derive from the job itself. She explained that, "At one point, the only thing I was doing was planning and pacing and prioritising around my client hours, and there was nothing else in my life, and I couldn't do that. I needed to rethink it." As a result, she restructured her working week to four days, Monday through Thursday: "I do not work [now] on a Friday [...] because if I've had a particularly emotional set of clients over four days, then on Friday, I know I'm going to crash." Not only is Kristina planning and pacing her working time-space routine so that she can be productive, but she is also anticipating and setting time aside for a potential crash at the end of the week, ensuring she has energy left at the weekend for, as Molly coined, "the nice stuff." Kristina articulated:

> It's taken me probably the last two years to figure out a way to keep working and actually have a life outside of that as well [...] I'm told this is the wrong way

> to do it, but this is my version [laughs]. This is *my* version of planning and prioritising [...] I will burn myself out for four days, crash completely on the fifth day, and then know that at least I've got a chance of doing *something* over the weekend that is just for me.

Although Kristina has prioritised work throughout her weekdays, emphasising that is the only thing she can do on those days, adapting her life in this way reflects a conscious negotiation of her energy limits in a manner allowing her to create meaning and purpose beyond merely managing her Long Covid. In her version of PPP, therefore, a bespoke organisation time and space enables her to care for her chronically ill body while meeting her familial obligations as the primary breadwinner, and also finding further meaning, purpose and a sense of self in socio-spatialities beyond her working routine.

Central to Kristina's narrative is her use of anticipatory strategies. Firstly, she applies what Anderson calls (2010a, p.790) "pre-emptive logics [...] by unleashing transformative events in order to avoid a rupture in a valued life." As such, she plans and paces her working routine to mitigate symptom exacerbation so that she can fulfil her breadwinner role. However, drawing on deeply embodied knowledge of how both her job and her illness can unfold unpredictably, she also goes beyond pre-emption and is "prepared" for a *potential* crash on a Friday. As Anderson (2010a, p.791) explains, "[u]nlike precaution or preemption, preparedness does not aim to stop a future event happening. Rather, intervention aims to stop the effects of an event disrupting the circulations and interdependencies that make up a valued life." While Kristina employs pre-emptive logics to mitigate the risk of symptom exacerbation during her working week, she also recognises that they cannot always be prevented despite diligently adhering to *her* three Ps principle. She prepares the temporal organisation of her week, accordingly, in acceptance of this uncertainty. These anticipatory and temporal strategies hence enable her to engage in meaningful socio-spaces at the weekend that offer her this "valued life" beyond her working routine. Through anticipatory strategies grounded in bodily awareness, Kristina nurtures an affective understanding of the relationship with her body, connecting her pain with work demands. Rather than seeking to eliminate unpredictable crashes, she uses the three Ps principle to *decentre* them. By deliberately setting time and space aside for a potential crash on Fridays, Kristina reduces the affective intensity experienced, if they do indeed occur. By accepting the inevitability of crashing, thirdly, Kristina

deterritorialises her pain by exerting control over its spatio-temporal dimensions. In doing so, her Friday 'crash' has a degree "intentionality," and feels relatively more manageable than before (Bissell, 2009, p.912). This adjustment is hence *enabling*, fostering more positive affective orientations rooted in vitalism, as Kristina is able to live a meaningful life beyond the constraints of Long Covid.

The concept of prioritising one key activity per day was shared across participant narratives. However, while Kristina's narrative aligns with stories from other participants who had returned to work, some individuals did not exhibit the same level of energy or activity. In comparison to the scale of work, which is typically understood even by non-disabled individuals as mentally and physically demanding, participants also had to restructure the temporalities associated with other segments of their lives and thereby to partition previously seamless mundane activities. One of the most common overlooked activities that necessitated the implementation of the three Ps principle was taking a shower, casting into stark focus the profound impact of Long Covid on even the most taken-for-granted routines of daily life in the privileged Global North. For Kamy, "the shower is like running a marathon," while Kate expressed that, at the beginning of her Long Covid experience, "I felt like I was drowning, you really just can't get any breath, and my heart rate would go like 180, standing in the shower." This remark emphasises the significant physical toll that even the simplest of tasks can have on individuals living with Long Covid. The act of showering, which many unthinkingly incorporate into daily hygiene, becomes a daunting challenge that demands significant energy. As a result, showering requires careful planning and reprioritisation, often forcing participants to sacrifice other everyday activities such as cooking or leaving the house. The significance of this shift was highlighted by Alexandra, who reflected: "when did my world become choosing a day to be clean?" This statement emphasises the profound shift in how individuals with Long Covid navigate even the most minutiae aspects of everyday life.

Mundane tasks such as showering not only require careful planning and prioritisation but also pacing. As Helena explained:

> When you're used to being able to have a shower all in one go or get dressed all in one go, you have to get used to living your life in small chunks, like have a shower, sit down, put your socks on, sit down, put your top on, sit down. You do everything, and everything takes longer. Nothing is easy anymore.

Rather than remaining a simple part of an everyday morning routine, getting clean and dressed has become a physically demanding routine in and of itself that requires careful planning and pacing, when actively prioritised. For many, such tasks must indeed be broken down into manageable chunks, spaced throughout the day with rest in between, becoming its own structured routine. Helena's narrative emphasises the physical and emotional burden of Long Covid as the significance of everyday tasks is profoundly re-defined. Previously thought-less routines such as showering have become a significant site of decision that requires regulation through time and energy management. The application the three Ps principle to something as basic as showering indicates the broader struggle of managing an illness that destabilises the most taken-for-granted time-spaces.

Tellingly, Kristina admitted that she still sometimes overestimates her energy levels:

> There will still be days when I have done that, and I wake up the next morning and it's, I can't do today. I overdid it yesterday [...] I did too much, and I'm kicking myself, and it's like, do I need to cancel clients? And I hate myself when that happens, because I feel like I've got it wrong.

After two years of listening to her body and finding a routine allowing her to manage Long Covid while still being able to live a full life, Kristina still experiences an exacerbation of symptoms as a consequence of unknowingly overestimating energy levels. Therefore, subjectively attuning to the flow of energy to, from and around the body is further complicated by the invisible, variable and unpredictable nature of Long Covid. Like Kristina, many participants concurred that, even when attuning to their bodies, they can still get it wrong. As Arun lamented:

> There's times, like I said, you feel rubbish, and you've got a little bit more in the tank, and there's times you feel better, but then you realise you don't have much. So yeah, who knows what you really have? But it's trial and error, that's what it's been. Experimenting, pushing, failing, whatever, trying again, getting back up, going through the cycle again and repeatedly.

These experiences reiterate the cyclical nature of Long Covid wherein the three Ps principle is characterised by listening to the body through a frustrating process of trial and error and further complicated by the highly unpredictable nature of Long Covid. Therefore, while anticipation offers *enabling* dispositions of "being in the world" or future becomings that help individuals to deterritorialise their chronic pain (Anderson, 2006), Bissell (2010) reminds us that there are negative dispositions of uncertainty,

unpredictability and incoherence that can be equally *disabling*, contracting future imaginations and closing down the possibility for particular bodies, in particular times, spaces and corporealities, to affect and be affected. In what follows, I elaborate on this frustration through an exploration of the various barriers to managing Long Covid.

5.3.3 Spatio-temporal contingencies of planning

Hitherto, I have explored how participants learn, through embodied knowledge, to meticulously plan, pace and prioritise the most minutiae of everyday day tasks and routines, centred around rest and energy management, as a result of new common-sense boundaries. Building on the example of working routines, these boundaries also relayed to 'bigger' social spaces and events. In what follows, I explore participants' spatial and temporal contingencies that significantly impact how they plan around their social life beyond the home space. For example, Anna, whose social life was previously centred around late-night clubbing, admitted, "I used to love to party or to hang out all night, then just sleep a few hours and be fine the next day, but now it'll just take me days to recover." Amanda echoed these new temporal limitations, recounting that she had to avoid evening plans: "I'm just too tired [...] I'd be bad for months." The time of day for functioning was significant to participants, as testified in their preferred interview times. Many requested mid-morning to late afternoon, allowing enough time to gain energy after waking, but also at a time before they were drained of energy later in the day. Further illuminating the concept of slowing down to speed up, Sheila related that it has taken her from the onset of Long Covid until only just prior to our interview (approximately four years) to build up her time tolerance before she needs to rest: "Up until very, very recently, I could not make it past four o'clock in the day [...] If I take it a bit easier during the day, I now manage a dinner out."

Social engagement was not only temporally contingent but also spatially. As previously suggested, certain aspects of physically built environments, such as stairs or busy, loud spaces, can render certain social spaces – such as theatres, festivals and cafes – energy demanding (and hence "unsafe"). As such, participants stressed the importance of spatial predictability. Amanda, for example, chose to socialise only in quiet environments: "we might go to a restaurant, just a little quiet restaurant, not a noisy one, and have a meal out." Participants employed many spatial metaphors to reflect these new spatial boundaries. Amy remarked that parties are "not within my

radar," implying not only the physical exertion required to attend but also the cognitive burden of social interaction. Similarly, Anna explained that she now stays within her "radius" as, alongside her new temporal boundaries, she also asserted new spatial boundaries, noting that she prefers to remain in spaces closer to home, emphasising the "safety" of the home space within illness experience (Crooks, 2010).

Travelling *between* spaces also emerged as both a significant temporal and spatial consideration when planning. This point was reaffirmed by Kate, who explained how travelling on the bus was cognitively demanding and often contradicted with her cognitive impairment relating to memory loss:

> [L]ast year [...] I managed to go to Hull, on a bus, on my own and walk to the centre, but I didn't manage to get back okay [laughs]. I needed help because it all went wrong. [...] I have to practise it. I have to have a lot of support. I've got it here. That's my notebook [...] It's like every detail mapped out to the minute [laughs]. And then it's all alerts on my phone, 'now you need to go there,' because I can't, my memory is so bad. And then also my husband is on the end of the phone saying, 'this is where your bus is. You're in the right place. I can see you on the tracker.' But now I am able to do that on my own.

Kate's account also highlights how cognitive impairments such as memory loss, as a result of brain fog, produce forms of both *literal* and *affective* displacement (Bissell, 2025). Her experience of becoming physically dislocated when she is unable to make it home on the bus illustrates how cognitive impairment can interrupt an individual's capacity to remain oriented within wordly space. To counter this problem, Kate relies on an assemblage of planning and support – from her notebook, phone alerts and her husband's remote guidance – to remain anchored in both time, space and cognition. Brain fog reshapes Kate's relationship to places, unsettling her sense of orientation and rendering public transport a challenging geography of the 'in-between'. In this context, familiar environments become unpredictable and require intensive forms of planning, mapping and cognitive effort to navigate safely, thereby amplifying the overall energy demands of everyday mobility. For Marg, travel demands energy, not only in terms of the planning itself, but also because it is difficult to pace and take breaks because travelling requires constant alertness to location and responses to stimulation. Marg explained that the physical toll of travelling from London to visit her family, most of whom live in the English Midlands, is what forces her to withdraw from many family gatherings that she would otherwise attend. Anticipating symptom

exacerbation *after* social engagements was accepted as part of her condition, and she even reflected that, “I don’t mind the crashing, in a way. It’s part of it.” This claim aligns with Anderson’s (2010, p.778) anticipatory sensibility of preparedness which “does not aim to stop a future event happening,” but rather works with a logic that “prepares for the aftermath of events.” Similarly, Theresa planned and prepared for symptom exacerbation after her holiday by taking an additional week of annual leave when she returned, as she acknowledged: “I know I’m going to be no help to anyone.” It is nonetheless the uncertainty of symptom manifestation or exacerbation *during* social engagements (especially with the added physical toll of travel) that forces participants, like Marg, to withdraw. As she stated, “it’s knowing that I might do that [crash] that stops me.” Therefore, while participants feel they can prepare for anticipated symptom exacerbation *after* social interactions, the inability to retreat quickly to the safety of home when unpredictable symptoms arise in the event or situation itself renders certain socio-spatial environments, particularly those far from home, unsafe, forcing them to withdraw. Withdrawal in this context also aligns with Anderson’s (2010a, p.789) precautionary principles: “Precaution begins once a determinate threat has been identified,” and, “even if that threat is scientifically uncertain [...] precautionary logics act before the identified threat reaches a point of irreversibility.” As such, if participants anticipate that unsafe or unpredictable environments may lead to symptom intensity or exacerbation, regardless of the uncertainty about whether that *would* be the outcome, they may withdraw or cancel beforehand as a precautionary action with the potential value of participation not deemed worthy of the risk.

Not only were participants conscious of their energy limits across time and place, they were also aware of the impact that others had on their energy levels. As Lu (FG2) reflected, “some people tire me out more than others.” This awareness meant that participants became more selective about *who* was worth the expenditure of their social energy. Lu compared this shift to the period following the COVID-19 pandemic lockdowns: “A bit like you did after Covid. Initially, after lockdown, I started being really choosy about who I was going to spend my time with.” The experience of lockdown forced several reconstructions of people’s social worlds, altering of interaction between the self, friends, family, community, work colleagues and more (Schneiders et al., 2022). This testimony showcases again, a temporal and spatial *continuation* of pandemic-style lockdowns throughout participants’ Long Covid lifeworlds, given that

their social worlds have become reconfigured, and somewhat shrunken, around an energy-limited body. For some, indeed, their experience, as noted earlier, has effectively been that COVID-19 lockdown never ended.

Lu hence elaborated how she consciously prioritises her limited energy for socio-spatial relationships that she considers genuinely meaningful:

> I really kind of make choices around, if I'm using this time, [I need] to enjoy it [...] I actually kind of think, 'spending two hours with you, is that going to be good for me? Is it that kind of relationship? If it's not, then let's do it via text or quick coffee.' And I've actually said to some people, 'I can do half an hour, let's go for coffee, half an hour, but then I want to come back and lie down.'

This perspective discerns that certain social interactions are experienced as emotionally and physically draining, with potential negative impacts on Lu's health. As a result, these interactions are often temporally curtailed or relocated to less demanding digital spaces. Lu's attitude exemplifies a shared approach to how participants strategically reserve their time and energy for relationships that are reciprocal, mutually supportive and contribute to their overall wellness. In particular, participants like Monica (FG3) highlighted the negative impact of certain people on their energy levels, to whom they feel compelled to explain and justify their illness:

> It's very hard to explain it to people. And sometimes I've gone through phases with it where I felt the need for people to understand, like I really tried to get them to understand. And I think I don't do that as much now, which is good. I just kind of think, 'well, if you get it, fine. If you don't get it, that's fine as well,' because it takes a lot of energy [group nodding] [...] I find it quite hard to say [to family], 'I can't go' [...] And when you do explain it to someone, and they get it, it's like, wow! [laughs] [...] Yeah, it's not very often that that happens [laughs].

Contributing to the extensive work within health geography on the social and emotional labour involved in illness experience (Parr, 2000; Parr and Philo, 2003; Parr et al., 2005; MacKian, 2004; Segrott and Doel, 2004; Dyck, 2005; Milligan, 2005), Monica's account clarifies that geographies of inclusion and exclusion are not solely shaped by spatial, temporal and corporeal boundaries, but also by the relational affective labour involved in negotiating illness within everyday interactions and relations. Empathic and supportive friendships were less energy demanding as participants did not feel the need to justify their ELC. This common experience therefore reveals the importance of care, support and empathy within the geographies of inclusion, and hence the need

for those in close social networks to understand an individual's new energy limits, structured temporalities and restricted spatialities. Such understanding, in turn, has a positive impact on participants' energy levels and wellness.

In the context of Long Covid experiences, certain people, places and temporalities that deplete energy are positioned as social threats, becoming affectively present through the anticipated "reoccurrence" of symptom intensity and/or exacerbation (Anderson, 2010a, p.793). Therefore, as participants develop embodied knowledge, they can apply pre-emptive anticipatory logics to make decisions about the planning, pacing and prioritising of everyday activities. Botterill et al. (2019, p.473) explore how practices of self-securitisation among ethnic and religious minorities in Scotland serve as pre-emptive strategies. They elaborate that in "anticipating certain futures, individuals calculate risk, taking into account a series of imagined futures," to preserve a sense of "ontological security" amid uncertainty. The implication for my study is that anticipation is not merely centred around the management of Long Covid, it is also deeply visceral, embodied and affectively forecasted through everyday socio-spatial experiences. As such, participants draw temporal, spatial and social boundaries around their everyday lifeworlds, preserving their limited time and energy for meaningful relations and life 'events'.

Thus far, I have discussed managing social engagements in relation to controlled temporalities, spatialities and socialisations. However, this form of structured planning is not always possible as both Long Covid and everyday realities are chaotically incoherent, destabilising and uncertain. Lu complained that "anything that's unplanned adds to my stress," while Charlotte (FG2) agreed that, "when something comes along that's unexpected that you couldn't have planned for, or you didn't know you needed to pace for, then it sends everything in turmoil again." Similarly, Chloe (FG3) recognised that her degree of control over social plans was limited, and that the unanticipated geographies of social environments created stress and anxiety:

> So, when you're planning [...] I suppose it's the anxiety around situations as well, but I get quite fixated on things. Food is my particular one that I get fixated on. If people are coming or going out or whatever, what's the food situation going to be like? Am I going to have to cook? Are we going to have to walk a long way to get dinner? Because those are things that people, I think, just take for granted, but actually, again, cooking is standing up. I find standing up really hard, so that takes a lot out of me.

Chloe underlined that, despite her efforts to plan ahead, social environments remain inherently unpredictable and filled with potential activities that she cannot always plan for, anticipate or control. These fluctuating social geographies are further complicated by the invisibility of chronic illness, meaning that others often forget about her illness and accommodations – a key consideration that I centralise in the following chapter. Chloe's narrative discloses the un-anticipatory logics that characterise living with Long Covid, as she constantly negotiates the unknown, unplanned and uncertain energy demands of everyday socio-spatialities. As Boyle (2019a) recognises, by defintion, Anderson's anticipatory logics assume a degree of (chrono)logical coherence, for which events can be pre-empted, planned for, or appropriate preparations put in place. Conversely, participants' stories reveal that Long Covid corporealities commonly reflect incoherence, where the body's energy capacities and everyday social activities are often uncertain, unpredictable and unstable, especially when faced with 'new' spatio-temporal encounters. Theresa echoed this sentiment when she reflected on planning her first holiday in three years. Despite understanding her Long Covid body, she still feels "fear [...] of not knowing how my body's going to react to that new thing." She appreciated that embodied knowledge is not fixed, but continually written, unwritten and rewritten in response to an illness with often varying and fluctuating symptoms and changing socio-spatial demands.

Hannah further shared how her withdrawal from socio-spatialities was shaped by past experiences of stigma surrounding her non-epileptic seizures, when she feared being a burden to her social relations with her unstable illness[65]. Similarly, as Molly echoed, "There's lots of things that I cancelled or put off [...] because I didn't know how I was going to be feeling." She further expressed the emotional impact of her voluntary social exclusion: "It was pretty horrible [...] you just feel like you're not gonna enjoy it and it will just be miserable for everybody else going with you." These experiences encapsulate the deeply emotional and affective geographies of *anticipatory* social exclusion (Parr, 2008a), wherein individuals pre-emptively remove themselves from particular socio-spatialities through affective forces of fear, shame and guilt that contribute towards participants feeling like a social "burden." Participants indeed

[65] Although Hannah's seizures are diagnosed as non-epileptic, her experience parallels Smith's (2013) work of the everyday geographies of epilepsy. Smith's analysis shows that individuals with epilepsy organise their time-space routines in microscopic detail to avoid the possibility, and associated stigma, of having a seizure in public or social spaces.

collectively stressed how particular – loud, busy, distanced, unpredictable – spaces are rendered unsafe, while other – quieter, closer, predictable – spaces, particularly those of the home, are rendered safe (Smith, 2013). Further echoing the work of Boyle (2019a), these narratives hence convey that the anxious and anticipatory geographies of Long Covid are dynamic, affectively experienced (through fear, uncertainty, guilt) and embodied across (un)stable, (un)certain and (un)safe socio-social contexts, but also temporalities. Anticipation is therefore felt as a pervasive threat, especially in its incoherent assemblage.

The temporal, spatial and social boundaries discussed throughout this section often resulted in the disruption to, or the loss of, ostensibly meaningful friendships. Anna regretted that, as a result of not being able to participate in late-night clubbing, she has also lost her associated social connections:

> Some people I've become less close with because of these changes, right? Normally, a lot of my friends were concentrated in the music scene, and those are just not the most sustainable friendships when you don't have energy to go to all the parties and the gigs and everything.

Many participants also reported being less frequently invited to social events, as Sheila added: "I think people probably don't invite you because [...] they're like that, 'oh, she goes to her bed'," while Louise lamented that "[a] lot of people, when you're not wanting to go out and be bothered, they just forget about you." In other words, social exclusion was not only anticipatory but sometimes also involuntary, although many participants reframed these socio-spatial losses as *positively* clarifying rather than negative, revealing their sustainable relationships under new temporal and spatial conditions. As Lu summarised: "[G]ood friends have got it. The people who haven't got it, I don't see anymore."

Participant stories align with Wilton's (1996, p.69) concept of "diminished worlds" – introduced in the previous chapter – in which individuals withdraw from certain environments, not only due to physical illness and constraints, but also because of limited social support and shifting relational dynamics. I wish to extend Wilton's ideas by foregrounding the affective and relational processes through which "diminished worlds" are also lived and negotiated. In particular, I suggest that these worlds are shaped by fears and anxieties associated with uncertain, unsafe or unpredictable spaces and social stigma, but also by freeing and energising affectual relations with

safe, empathetic and supportive socio-spatialities. Viewed in this way, diminished lifeworlds are not only spatial, but also deeply temporal, relational, emotional and affective. Furthermore, As Wilton (1996, p.73) elaborates, illness experiences are complex, undulating and not always solely negative. They are engendered with both "good days" and "bad days," enabling lifeworlds to stretch and contract across different temporal scales. Through the three Ps principle, everyday meaningful spatialities are re-prioritised, activities take longer, and, due to reduced spontaneity and increased withdrawal, socio-spatial worlds shrink, as Fiona concisely captured, "it might have made the world seem much smaller [...]". Within these diminished lifeworlds, participants experienced many 'losses' to their identity, meaningful spaces and relations. Yet, rather than submit to the territorialisation of pain over the body, these rehabilitation strategies sometimes also offered a way to reclaim agency and exert greater control over altered lifeworlds. In doing so, participants were able to reframe their "diminished" worlds and lessen the intensity of their physical, social and emotional suffering ultimately to *enhance* their new lifeworld. As Fiona continued, "[...] but you put a different value on what you can do in it."

Similarly, Megan reflected positively on altered temporalities, especially when she was unable to return to her teaching role. Through her Long Covid experience, she became aware of the pressure and stress that teaching had placed on her body and came to appreciate slower rhythms that have now opened her lifeworld to new routines and activities that often serve as a form of embodied 'healing':

> It's just nice to live on a different, slower pace, really. I'm reading more [...] I couldn't get through a book when I was teaching because I had so much other stuff going in my head [...] It's just like, oh, wow, there's other things in the world.

This perspective on the everyday speaks to a broader coping strategy in response to the unpredictability of Long Covid, with mundane routines and relations developing new significance under conditions of illness and shrinking spatio-temporal worlds in a way that affectively enhances life with Long Covid. These accounts illustrate a shared, embodied knowledge of living with an energy-limited body, one that requires constant negotiation with fluctuating capacities and the need for contingency across social, spatial and temporal planning. Such accounts further reveal how the geographies of chronic illness are not merely about absence or loss, but also about reconfiguring what spatialities, temporalities and socialities can be rendered meaningful, energising and

enabling. Therefore, despite various spatial, temporal, and social constraints, I extend Wilton's (1996) work to argue that the everyday geographies of chronic illness are dynamic and contingent, shaped by the possibility of lifeworlds that are indeed diminished, yet still hold potential to be meaningfully enhanced[66].

5.4 Barriers to PPP

5.4.1 Symptomatic barriers

PPP is fundamentally an adaptation strategy to help individuals manage the time-space fabrics of daily life. When done effectively, giving people the capacity to reorganise time-space structures, slow down and shift burdens if needed, PPP can allow individuals to gain a sense of independence, remain active and pursue meaningful everyday activities as bio-geo-graphical flows. They are able to contain and manage their illness while still preserving chunks of their former selves (Charmaz, 1991). However, participants often reported that symptomatic barriers posed challenges to monitoring and managing energy levels, pertaining to the embodied symptoms themselves, alongside their often invisible and fluctuating nature. Monica shared that "there's not an alarm that goes off when you're doing something," while Lu added that "your skin doesn't go blue to tell you, 'You need to stop'." As a result of such symptomatic barriers, participants commonly misplaced the temporal and spatial anticipations of their energy limits. For example, Ruth explained that brain fog impacted her memory: "I'd forget I'd done something in the morning," meaning that she would sometimes over-exert her energy in the afternoon as a result. Charlotte (FG2) elaborated that the absence of visible or even palpable bodily signs on a seemingly "good day" presented similar challenges:

> The problem is, when I'm having a good day, I forget that I'm ill, and then I think, 'this is fine, this is great.' And then suddenly I feel really shit, because I've forgotten that my body is not where[67] it was.

The invisible nature of Long Covid poses not only a perceptual challenge for others, but also makes the condition difficult for individuals to recognise themselves, reflecting what Moss and Dyck (2003, p.129) term a "presence of absence" of symptoms (I

[66] I emphasise "possibility" and "potential" here because, as highlighted throughout this thesis, this was not the lived reality of some participants who continued to experience severely disabling Long Covid symptoms.

[67] The use of the term "where" carries spatial connotations, suggesting that illness is experienced as a displacement from a former embodied position, rather than simply a change in bodily capacity.

explore the nuances of invisibility in the subsequent chapter). Many participants shared Charlotte's experience of having a "good day," momentarily forgetting they were ill, or even mistaking their improvement as a sign of progress and recovery, only unknowingly to push beyond their bodily limits and even to crash later. Participants therefore often found themselves in the complex, somewhat deceiving and liminal position of being – to reiterate – "*both* ill *and* healthy" (Moss and Dyck, 2003, p.99), where material limits are invisible, or unpalpable, and often misalign with discursive inscriptions of ill/wellness. Bodily limits are easily misread and hidden symptoms can later re-emerge, often with greater intensity, resulting in exacerbations or crashes, making the chronically ill body unpredictable, untrustworthy and unreliable (Smith, 2013).

Participants reflected upon the psychological and emotional challenges of wanting to re-engage in meaningful activities on their perceptually good-health days. As Monica (FG3) shared: "I feel okay and I want to do things, especially because you haven't done things, and then I crash because I've been doing too much. That's the thing that I find the most difficult." Alexandra echoed this sentiment:

> Occasionally, I'll get a day where my head feels a bit clearer, and the world seems a bit brighter. And I just have that taste of, it's not normality, but a sense of me again. And then you have to be really careful not to overdo it [laughs] Because it's very easy to think, "Yes! I'll go and have coffee with a friend," "Oh, I'll plant something in the garden," all those normal kinds of things that you like to do [...] But you have to be really wary, because [...] you can overdo it so easily and then pay for it.

These temporary feelings of normalcy are affectively charged with both hope and nostalgia. These charges are also ambivalent, however, as the desire to re-engage in everyday activities and to re-claim a former sense of self is then placed in tension with the fear of "overdo[ing] it." The decision to stay at home rather than go for coffee or work in the garden is not only an act of managing and preserving energy, it is a form of spatial avoidance or withdrawal enacting a deeply emotional negotiation between affective experiences of hope, desire, fear and anxiety. Thus, even prior to bodily signals, individuals living with Long Covid must still negotiate everyday spaces in relation to their new bodily capacities.

This finding once again affirms that living with Long Covid involves constant awareness and attunement to the body's shifting capacities. Even when symptoms

are seemingly lessening, participants must remain conscious of their bodily limits and anticipate potential energy exertion. As Lu stated, “I’m trying to listen to my body better and almost rest before I need to,” with the pre-emptive practice of resting *before* body signals emerge. As Bissell (2009) suggests, such anticipatory actions emerge through learned bodily sensations and memory. Drawing on past experiences, participants affectively sense “a present that is unbalanced by potential threats” and pre-emptively rest, “in order ...,” revisiting a phrase used previously, “... to avoid a rupture in a valued life” (Anderson, 2010, p.790). In this way, the body indeed becomes a site of anticipatory governance, where future symptom intensities are affectively forecasted through embodied knowledges rather than merely reacted to in the present. These practices are gradually learned and consciously performed, rather than habitually formed. Here, anticipatory sensibilities are grounded in embodied knowledge, allowing participants to manage Long Covid not only in response to bodily signals but even in the mere anticipation of them. These narratives furthermore demonstrate that anticipation is not only embodied and affective, but also deeply temporal – resting *in advance* – and socio-spatial – withdrawing from everyday activities or social encounters. Therefore, the anticipatory geographies of Long Covid are decisively shaped by the interplay between body, time and space, where the present (here-and-now) is geared towards managing a potentially volatile future (there-and-then). Here, I therefore extend Anderson’s work to conceptualise, what I term, *chronic sensibilities,* where anticipation becomes a key embodied and affective condition of Long Covid experience.

Despite the frustrations caused by invisible and variable symptoms, Kristina (FG1) was in no doubt that “[PPP] does at least mean that I can *live*. I can live to that extent. I can *manage* my life.” And, as previously demonstrated through Kristina’s story, PPP can enhance life by reducing painful intensities. Effectively implementing PPP, however, requires individuals to have a degree of control and bodily predictability that some participants in this study were not afforded. Lu and Charlotte (FG2) emphasised the diversity of Long Covid experiences in focus group discussion, as they agreed:

> Charlotte: To some extent, the planning and the pacing really does work [...] And I think you would find that that would be on a case-by-case basis.
>
> Lu: Yeah.

> Charlotte: I think some people, it wouldn't work at all. Well, I think they would find that there is no correlation to how much they could do, how much they needed to rest. And then there's others who, by the sounds of it, like me and Lu, who, actually we can, to some extent, do that. And for *us*, that works.

For many participants, the severity and unpredictability of symptoms made applying the three Ps principle extremely challenging, and, at times, seemingly impossible. Kamy's Long Covid experience exemplifies such profound bodily instability. Despite her efforts to manage energy through The Spoon Theory, as aforementioned, Kamy (FG4) reflected on her failed attempts to apply self-management strategies:

> I planned in May, for a whole week, to go out. As you said, no getting up, no showering, no nothing. I went out for a couple hours, and I still can't recover from May[68]. So, what's the planning and the pacing if you can't recover for that many months?

Kamy's account calls into question the underlying assumptions of PPP, which, as already acknowledged, do rely on a degree of bodily predictability and stability. She continued:

> It doesn't matter how much I want to plan, pace or prioritise, it's impossible to be honest [...] You put something that is very important, and you plan and focus on it so you can achieve it, but it doesn't mean that you can make it.

Kamy's account reveals how the logics of PPP fail when the body, territorialised by obdurate chronic pain, resists control. Alongside physical limitations, Kamy's brain fog further undermines her agentic capacity to manage symptoms. Thus, echoing Ruth and Kate's experiences of memory lapses, Kamy described how her brain fog undermines her capacity to enact even the most basic management strategies:

> Especially with my foggy brain [...] The second I'm trying to think about something, the first second, it's gone. So even if I try to write it, then I forget where I wrote it down [...] Although it's a good strategy to put in place, when you're not in a good day, you can't use this strategy.

Kamy's body is constrained by persistent brain fog, resisting the kind of self-regulation and self-governance that PPP demands. She experiences brain fog as both form of affective dispossession – in which her cognitive capacities to think, remember and act are severed in moments of heightened impairment – and affective displacement as,

[68] To re-iterate my methodological timeline, this focus group interview was conducted in September, four months after said experience in May that same year.

even when her thoughts momentarily cohere, they do not “stick” in the way they once did (Bissell, 2025, p.11).

Kamy still attempts to implement PPP strategies, such as writing things down in attempt to materialise and repossess her thoughts, but brain fog renders even this effort inaccessible, displacing her not only from the thought itself but from the memory of where it was stored. In this way, she is “cut off” from these everyday knowledges that support the care of her ill body. Megan (FG4) resonated with Kamy in focus group discussion, berating the redundancy of Long Covid management on “bad days” or when experiencing symptom exacerbation:

> I’ve got my kitchen, I call it my ‘crazy room’ because I’ve just got Post-it notes and bits of writing and dates and reminders of, ‘when this happens, you need to do this. When this happens, you need to do ...’ Because, like you’ve said, when you’re crashing, you’ve no thought. You can’t think for yourself. You can’t talk to people. You can’t say, ‘I need help.’ So, I’ve got Post-it notes all over my kitchen just to help me, be my reminders, which is my planning, but it doesn’t help, *really*.

These accounts reveal the emotional and cognitive toll when the Long Covid body becomes unreliable, remains obdurate and resists self-management. They underscore a profound disjuncture between the lived realities of Long Covid cognitive impairment and the ‘normative’ assumptions embedded in PPP discourses that privilege individual lucidity, coherence and control. Rather than empowering participants, PPP often becomes a source of further frustration, disappointment and emotional exhaustion, especially when rehabilitative efforts to rebuild are set back during a crash. As Kamy noted:

> You just basically start from scratch every single second [...] And it’s very frustrating, to be honest. Very disappointing and extremely challenging for me to try, at least, to plan simple things, let alone serious things.

For Kamy, “there is no way to adapt. It doesn’t exist as a possibility.” As Kamy feels stripped from opportunities to “live” like other participants in this study, she described her life as “bare existence,” echoing Agamben’s (1998) biopolitical notion of “bare life” — a point to which I return below — which reveals how Long Covid has denuded Kamy’s bodily existence down to what she perceives as merely a biological state where her lifeworld is oriented around mere survival and existence. Arun echoed Kamy’s despair, sharing a similar loss in vitality:

> I exist. Existing isn't really what I want to do in life, what's left of it. So, no, going back to the dark thoughts. Have I thought about ending my life? Yes, I've thought of ending my life. Have I acted on it? No. But the back of my mind is like, if this is the position in a year, two years, three years, I cannot do this. This life is, there's no enjoyment or fun or nothing to look forward to. There's nothing to get up for, there's nothing to fight for [...] I mean, there is some emotional stuff here, Ellys, and I've only shared some of the stuff, not any of the gory details, but you get a flavour and sense of what it's like, so make sure you also take time during this research because it is emotional. If you were gonna live, not knowing what every day is going to bring you, most of your days, I'd say 90% of my time is in bed.

These dark and deeply emotional narratives underscore the embodied limitations of the three Ps framework, which implicitly assumes a degree of bodily stability and control to implement self-management strategies. While the three Ps may be a fruitful management strategy for some, offering a degree of control to deterritorialise and decentre pain, for others, with severe and volatile symptoms, it can be ineffective but also emotionally and cognitively burdensome, taking a severe toll on individuals' mental wellbeing, as evident in Arun's story. As Bissell (2009) outlines, when intensity does not subside, individuals can experience despondency. When pain remains obdurate and inert, imaginations of the future contract, impacting individual capacities to affect and be affected. Such experiences give rise to negative affective orientations of despair, which, in turn, heighten intensities. These intensities are profoundly disabling, resulting in a diminished sense of agency. These findings hence challenge assumptions of control implicit within dominant rehabilitative and recovery discourses. The effectiveness of PPP is not simply a matter of an individual's mental will or physical adherence but is also shaped (or constrained by) the multiple, uncertain and incoherent ontologies of Long Covid.

An illusion of control

As participant testimonies throughout this chapter have thus far suggested, despite efforts to plan, pace and prioritise, and listen attentively to their bodies, several have been left feeling disappointed, despondent and disempowered by their unpredictable, chaotic bodies. Participants described a variety of experiences in which they would diligently apply the three Ps principle, yet still experience symptom exacerbation or, conversely, believe that they have over-exerted their bodily limits yet experienced no consequences. Alexandra (FG4) duly expressed that applying the three Ps principle

offers an “illusion of control [...] Sometimes it might work and other times it might not,” to which the other participants in her focus group vehemently agreed: “pacing and prioritising is an illusion. It’s not an actual thing you can actually apply and stick with and follow it” (Kamy), while Kate (FG4) declared that “you think you’ve got it under control, and then you have, bang! That’s it, time out.”

Participant testimonies hence reveal that establishing a sense of control over their Long Covid does not ensure symptoms will remain controlled, meaning that Long Covid is rarely absent from their thinking (with the exception of the aforementioned situation when participants mistake an absence of symptoms on “good days” for improved health). As such, these ongoing anticipatory geographies around the volatile temporalities of Long Covid re-define individuals’ understandings of present and future as uncertain and unstable. Therefore, revisiting findings in the previous chapter, participants feel somewhat trapped in the present, with Long Covid bodies still under a form of lockdown, such that the negotiation of time-spaces becomes an ongoing, grinding and relentless corporeal struggle as participants are continually confronted here-and-now with the potential destabilisation of everyday socio-materialities.

These testimonies further align with Crooks’ (2010, p.59) understanding of women’s daily lives with fibromyalgia as relatively spatially structured yet temporally-dynamic, which she respectively terms as simultaneously “unpredictably routine” yet “routinely unpredictable.” Crooks identifies how the fluctuating nature of chronic illness obscures women’s home routines as perceived non-routines. Instead, she found that women with fibromyalgia do, to an extent, develop routines around activities and rest that were far from unpredictable and instead follow a clear, repetitive socio-spatial organisation of bodies, objects and spaces. This was also common across interviews in my study. When I asked participants about their new daily routines with Long Covid, many described not having a strict routine because every day is different. Yet, as I discussed earlier, many participants lived through structured spatio-temporal rhythms of: pre-emptively pacing and planning rest – even on “good days” – to mitigate symptom exacerbation and to maintain a sense of control over the body; tactically centring the day around one socio-spatial activity; and pre-emptively planning to withdraw from engagements that are secondary or out with socio-spatial, temporal or corporeal boundaries. Returning to the notion of ‘common sense’ time-space rhythms, these routines are consciously monitored, negotiated and altered through evolving

embodied knowledge. This closely parallels with Boyle's (2019b) work on the (un)habitual geographies of social anxiety disorder, where routines are made, unmade and remade to maintain a sense of stability. I therefore extend Crook's framework to suggest that this ongoing negotiation is not only bodily but also deeply affective and relational, as participants crucially negotiate energy, not only in relation to themselves, but also relative to broader temporal and socio-spatial contexts. As such, anticipating and planning for potential symptom exacerbation renders social engagement spatio-temporally conditional, embedded with contingencies and caveats. I therefore build on Crooks' work and contend that the corporeal experiences of Long Covid are *predictably unpredictable.* As participants acknowledge the "illusion of control," they accept the uncertain and unpredictable nature of living with Long Covid. Individuals remain acutely aware of their bodily limits and structure daily, and sometimes weekly, routines pre-emptively to either mitigate or make time for potential symptom exacerbation. Therefore, participants consciously plan, pace and prioritise around their embodied knowledge, which enables affective anticipatory forecasting of unpredictable symptoms, prompted by what I earlier termed *chronic sensibilities*. Therefore, managing the predictably unpredictable nature of Long Covid is an ongoing embodied, affective and relational negotiation.

That said, surrendering to the illusion of the three Ps principle allows participants to feel somewhat freed from, rather than constantly frustrated by, the pursuit of control (Charmaz, 1995). As Alexandra (FG4) reflected, "even though you might have to change it all, the pacing makes you think that you can do something. And I honestly do think it's psychologically more important than anything." Therefore, while the socio-material impact of Long Covid is accepted as ongoing, surrendering to the illusion of control, and hence the incoherent anticipatory geographies of Long Covid, at least offers an implicit sense of control and agency over the body, somewhat releasing individuals from a sense of existential precarity, as described by Cheston et al. (2025). Through acknowledgement and acceptance of the illusion of control, participants are still able to transform their affective suffering from negative charges of anxiety and despair into positive affective charges of hope and potential, recentring uncertainties around empowerment rather than constriction. This tacit therefore demonstrates that unruly intensities still hold potential to be lessened and affirms Bissell's (2009) contention that affective charges are not static but, rather, contingent upon how they

are perceived and navigated in different contexts. Therefore, as embodied knowledge is rendered ongoing and evolving, “illness merges with subjectivity; it *becomes* subjectivity” (Charmaz, 1995, p.673) and the unpredictable becomes predictable.

The *predictably unpredictable* paradox is not a contradiction to be resolved through the three Ps principle, however, but rather a reality of living with Long Covid, wherein individuals continually negotiate their chaotic bodily limits in relation to everyday time-space rhythms and social relations. In this way, the concept of the predictably unpredictable itself becomes routine, an affective orientation through which participants structure their spatio-temporal and social environments. These reconfigurations heighten spatial, temporal and relational vigilance, where past experience – of previous flare-ups, symptom exacerbations, crashes – informs ongoing awareness and decision-making in the present, often curtailing spontaneous social geographies.

By acknowledging the “illusion of control,” Megan (FG4) felt empowered to re-interpret the three Ps principle in a manner that better reflected her lived experience. She shared: “It’s just really, really unpredictable. And I kind of change the words, because those [PPP] aren’t my words. My words are, ‘resting, healing, waiting’,” words which arguably do capture the elusive nature of Long Covid, where recovery is non-linear and a definitive cure remains unknown. She further joked: “And what I’m waiting for, I’m not sure [...] [laughs].” Megan’s articulation of “waiting” – marked by uncertain means and end – disrupts conventional, linear and bounded understandings of recovery. She reframes an alternative corporeal and temporal logic, oriented towards healing and morbidity rather than cure and mortality (Dumes, 2020) – which I elaborate in what follows. This perspective resonates with Bissell’s (2007, p.285) reframing of economic, idealist understandings of waiting as “dead time” to be overcome or productively utilised in the context of transport spaces. Drawing on Deleuze and Guattari’s notion of “haeccity,” Bissell (2007, p.291) reconceptualises time as rhizomatic: non-linear, unbounded and embodied. In this view, waiting is not merely a pause between the past and an anticipated “event-to-come” (p.282), but an ongoing present – what he terms as the immanence of “not yet” (p.292). While some participants in my study described micro-scale periods of resting as deliberate uses of time to manage energy, Megan’s perspective frames the broader chronic illness trajectory as one of temporal ambiguity, marked by acquiescence and withdrawal from

normative rhythms of productivity and recovery. Her mantra, “resting, healing, waiting,” can thus be further understood within a framework of crip time – as a temporal orientation that diverges from linear progression and instead reflects what Bissell (2007, p.279) calls a “variegated affective complex” – a form of corporeal dis/engagement that encompasses both activity and acquiescence. Rather than focusing on a clearly defined end, such relations to the future remain both empty and open – affectively uncertain yet quietly hopeful.

Megan’s reframing resonated with others in the focus group, conveying a shared sensibility around recovery’s ambiguity. Drawing on Anderson (2006), Bissell (2010, p.85) suggests that hope can emerge through a “feeling of possibility,” that enables bodies to persist despite pain and unpredictability. While Long Covid intensities remain unruly, and sometimes exceed attempts at control, the illusion of control arguably continues to create new emancipatory potentials for management strategies that embrace uncertainty, while fostering hope and autonomy. This acquiescence effectively deterritorialises the body from pain by loosening attachment from normative expectations of progress and control, opening space for alternative, dynamic temporalities that are uncertain yet hopeful.

Bringing together these themes with earlier participant testimonies of perceived bodily stasis – an experience of being corporeally trapped in conditions of chronicity with no biomedical resolution – I extrapolate Megan’s alternative three Ps principle, “resting, healing, waiting,” and introduce the *healing versus curing* binary as central to the geographies of Long Covid. While participants remain hopeful of a biomedical cure, many, like Megan, indeed pivot their focus to healing: a slower, temporally and socio-spatially grounded process of self-care, adaptation and embodied management. In the context of chronic Lyme disease, medical anthropologist Dumes (2020) suggests that this orientation towards healing aligns closely with Fassin’s *Ethics of Survival* (2010). Extending Dumes’ ideas with a geographical perspective, Fassin’s work foregrounds the geographies of suffering — physical, social, emotional, affective and relational — especially when systemic biomedical support for marginalised or contested illnesses proves inadequate. Fassin’s framework is not concerned with moral judgement, but rather with the ethical practices that individuals adopt to endure a limited life marked by precarity, uncertainty and marginalisation. Therefore, within this framework, the geographies of healing, rooted in temporal and spatial practices of self-management,

social networks and bodily attunements, can be understood as ethical practices of survival. Healing is thus not only an approach to manage and care for the chronically-ill body, but is also an attitudinal ethical stance – a choice to persist, adapt and sustain a limited life, under conditions of chronicity, marginalisation and systemic neglect. Through this shifting narrative of cure (and mortality) to a more rehabilitative orientation of healing (and morbidity), participants are empowered to affect new ways of being in the world, perhaps opening up the body to new, more tolerable intensities (Bissell, 2009).

5.4.2 Everyday life barriers

As I have thus far indicated, to effectively implement PPP, there is already an assumed degree of control that individuals possess over their everyday lives. As Helena (FG1) shared:

> It's very frustrating when you listen to the professionals, because you kind of think, 'I wish you'd come and live my life and tell me how to prioritise stuff,' because I just feel like I have stuff that I *have* to do. I *have* to get up. I *have* to get my children to school. I don't have an option. I can't endlessly ask all of my friends to get up and take my kids to school, so then you *have* to force yourself to do it. And then, it's that kind of thing where if I take them to school, then I've got to come back and go to bed and sleep it off, and then I've done too much. But, how do you prioritise and plan not to do too much when you just *have* to meet the requirements of life? People who have to get up and have to work and have to feed their kids.

Helena emphasises the tensions arising between the three Ps principle, as suggested by medical professionals, and her reality as a mother, given that she has much less control over every time-spaces than what is typically assumed. There is a clear disconnect between her lived experience, where she must prioritise the care of her children, and medical advice assuming that she has the time, space and support to prioritise and plan her day around caring for her *own* ill body. As Helena has suggested, the availability of support and ability to shift responsibilities also impacts the fruition of the three Ps principle. This issue becomes particularly complicated for individuals living alone, or in households where partners have taken on more work responsibilities, leaving domestic and childcare responsibilities to the person affected by Long Covid. Therefore, three Ps-type expectations become unrealistic when individuals have everyday obligations, such as familial and work responsibilities, which operate within inflexible spatial and temporal structures and hence limit individual

autonomy. Arun's (FG4) account reinforces the disconnect between such structured frameworks and the unpredictable, emotionally taxing nature of real life:

> I've been through a divorce in the last three years. I've had to sell my house in the last few years. There's a lot that life throws at you, which, you can put all the planning and predictability you want, but things happen, and you've just got to find the strength to deal with it, and then suffer the consequences. You are going to be in a crash, and you are going to be recovering.

His reflections underscore the limits of PPP among the realities of everyday life demands such as divorce, financial instability and emotional strain which often leave little room for methodical energy management, and instead call for forms of resilience that fall outside idealised clinical frameworks presumptive of control. In the context of the workplace, Lu (FG2), a teacher, added:

> It [PPP] does work, but we don't live in a world anymore that allows a lot of structure, because we have emails, we have phones, so a lot of things come through last minute. You don't have on a Monday, 'oh, on Wednesday, at four o'clock, this parent will turn up to see you,' and that means that I can think, 'right, from 3:30-4:00 I'm gonna have some quiet time,' because it doesn't happen like that. That's not the nature of school life or family life a lot of the time.

Through earlier discussions around planning and spontaneity, I suggested that the contingent nature of everyday life presents barriers to time-space control, which hence further challenges the idealisation of the three Ps principle supposing that individuals have full autonomy to plan, pace and prioritise care effectively for their chronically ill bodies. As the demands of everyday life create sporadic barriers to effective implementation, not all individuals are privileged with the time, space, energy and support to exert meticulous control over the minutiae of daily life. Managing Long Covid is therefore complexly tied up with aspects of daily life that cannot necessarily be anticipated or controlled, especially as it is an illness in itself that is incredibly variable and uncertain. As Charlotte succinctly reflected: "Life is a bit unpredictable. Life coupled with an unpredictable illness, so it does make it harder."

These accounts reveal that everyday life barriers are structural rather than individual constraints, and hence foreground the classed dynamics embedded within the three Ps principle. As outlined in the previous chapter, participants who did not need to work and who had access to familial support were consequently privileged with time to rest,

although not necessarily the energy required to make use of that time. The assumption that individuals possess the temporal autonomy, social support and material resources to organise their day around illness management rests on a largely middle-class model of flexible labour and delegable responsibilities. Participants such as Helena and Lu, however, illustrate how working and lower-middle-class conditions — non-negotiable childcare duties and rigid occupational schedules — constrain their capacity to implement PPP in the ways that clinicians may imagine. Similarly, Arun's experiences of housing instability and emotional strain reflect how life events shaped by financial precarity further destabilise the structured predictability that PPP requires. Thus, the capacity to plan, pace and prioritise is not merely an individual skill but is profoundly shaped by classed access to time, space, stability and support.

5.4.3 Psychological and emotional barriers

Within these everyday barriers, I have also identified psychological and emotional barriers to managing Long Covid. Linking back to discussions of acceptance in Chapter 4, pacing was not necessarily adopted with ease following the onset. For example, Monica initially perceived pacing as "giving up or giving in," admitting that "it took me about two years to [pace], because I was refusing to accept what was going on [...] Because I thought that if I started to pace myself, I'd just become an old person." She expressed feeling in "denial" about pacing as, for her, it meant giving up her former active and busy self and disrupting the temporality of her bio-chronicity by embodying the fragility and dependency of an "old person." Similarly, Helena did not want to comply with the three Ps principle as it felt incompatible with her life as a mother to young children. While the other participants in her focus group discussed the importance of slowing down, Helena (FG1) expressed reluctance to accept new temporal, spatial and social limitations in adherence to Long Covid management:

> I think probably listening to everyone, I'm maybe in a different boat in that I don't think I've accepted it. So, yeah, I keep making the same mistakes over and over again, because I don't think I want to accept it. So, I have a young family. I've got kids that are little that need me, so I still keep doing the same things like taking them out, and feeling dizzy, and being stood up too long, and knowing that I shouldn't be doing it and I don't have the spoons, and crashing, because my children are so young that I don't want to miss out on their life. And I don't feel like I can accept it and follow the prioritising and pacing and everything that they tell me, because I don't want to. I want to do everything that I want to with

> my kids. [...] I don't think I've accepted it at all. It's really annoying. I know I need to.

Helena's narrative crystallises the emotional and psychological conflict between caring for her ill body and fully participating in her children's lives. Her internal conflict reflects Anderson's (2010, p.789) logics of precaution whereby "[t]here is a need, therefore, to constantly assess the balance between what the threat could become and the costs of (in)action in the present." In Helena's story, the potential threat of symptom exacerbation (there-and-then) is outweighed by the fear of missing out on her children's lives (here-and-now). Her decision to not fully comply with the three Ps principle thus parallels her priority of maintaining pace with her children rather than slowing down. These accounts reveal that emotional, psychological and social barriers complicate participants' experiences as they often struggled to accept their ill bodies while attempting to maintain the pace of their previous self, and of others, to lead a 'normal' life. In doing so, they are working to conceal their discursive and material illness to maintain both public and personal inscriptions of a healthy and normal body.

Building on my earlier discussion, participants expressed a tension between merely existing – when adhering to the three Ps principles – and truly *living*. Participants described instances where they would ignore the three Ps principle, breaking away from experiential existence, or mere survival, choosing to engage more fully in life. Alexandra (FG4) shared that she would often ignore her routine pacing to spend time with her daughter. For her, the physical costs are outweighed by social and emotional fulfillment, as she expressed: "If I don't push through for things like that, what the hell is the point of me being alive anymore?" Her narrative suggests just how temporally, spatially and socially limited her life becomes when managing her Long Covid "in tune with what my body *needs*," which feels fundamentally at odds with experiences that bring her joy, meaning and connection. As she admitted, "the two don't work together very well." This sentiment was affirmed by Arun (FG4): "eventually you go, 'I cannot just do nothing, or not take part in life, or not have a life, so yeah, I'll take the consequences.'" These negotiations are acts of agency and resistance as participants choose to prioritise meaningful experiences, even at the risk of intensified symptoms. Similarly to Helena's story, participants indeed weigh up "costs of (in)action in the present" (Anderson, 2010a, p.789). The act of compromising physical wellbeing to alleviate social, emotional and relational suffering demonstrates how participants exert

control over their lives, as Alexandra powerfully reflected: “I’m making conscious decisions [...] But I’ve got to *live*. You can’t just exist.”

These accounts indicate that participants’ moments of pushing back against the three P’s principle practices can be considered temporal socio-spatial and embodied examples of what Del Casino Jr. (2010, p.200) terms “bio-deviance,” where participants choose to deviate from rehabilitative practices supposed to care for their chronically ill body and thus resist biopolitical expectations of responsibility and self-management associated with ‘good’ biological citizens (Rose, 2007). While a fuller theorisation of these dynamics is developed in the final thesis conclusion, it is important to signal here that such acts of deviation hold political and ethical significance. They reveal how participants negotiate the boundaries of bare existence to open up small but meaningful spaces for autonomy, vitality and connection, that temporarily release participants from their bodies under lockdown.

These practices respond to Del Casino Jr’s (2009) call for geographers to disentangle the “politics of life” from the embodied experiences of biological citizenship across different places. Whereas conventional accounts of biological citizenship emphasise compliance with biomedical authority, under the biomedical gaze, many participants living with Long Covid found themselves ‘left’ to self-manage their illness amid medical uncertainty, marginalisation and disbelief. In this context, moments of bio-deviance — where participants chose social connection, joy or emotional wellbeing over care for the Long Covid body — became empowering acts of reclamation. As participants inhabit a liminal, uncertain and undefined state of morbidity (a compromised life), stuck within states of existence disruptive of dominant discourses of recovery, cure and mortality (Dumes, 2020), they carve out alternative ways of living beyond passive states of “resting, healing and waiting.” In doing so, biological citizenship is reframed, not through biomedical compliance, but through everyday health routines of care, resistance and vitality.

While this framing speaks to empowerment on a structural, bio-political level, participant experiences also resonate with emancipatory potentials on the everyday corporeal level by deterritorialising the body from pain. At the onset of Long Covid, chronic pain as a result of engaging in previous habitual routines was experienced with heightened intensity. As participants manage their illness over time, however,

they come to recognise the affective reality of their compromised life within strict spatial and temporal boundaries and ambiguous recovery frameworks centred around healing rather than curing. These conditions are accepted as their new 'normal' life with Long Covid (even if that acceptance is only provisional, "for now"). While some participants, such as Fiona, have been able to place new value on their diminished worlds, by finding joy in the mundane, I have also emphasised how this experience is not fixed but processual (McCormack, 2003), continually shaped by temporal, socio-spatial and bodily contingencies. Nevertheless, some participants do indeed encounter the lived embodied reality of 'mere' existence. As they come to understand the intimate connection between the body and pain through everyday lived experience, their deliberate detachment from pain-management strategies are agentic, life enhancing acts. By weighing up the cost of (in)action in the present through new anticipatory dispositions, they are empowered temporarily to break free from the constraints of pain-management strategies – which reinforce their bodies under lockdown – in order to re-engage meaningfully in life. The resulting consequences of symptom intensity can therefore be considered relatively intentional and desirable, and as a result diminished (Bissell, 2009).

5.5 Conclusion

Building on the previous chapter, I have explored how participants have discerned and navigated bio-geo-graphical disruptions through the three Ps principle – a rehabilitative self-management strategy. In the absence of clear biomedical treatments or recovery trajectories, PPP became a central feature of participants' daily lives. It involves the temporal and spatial reorganisation of daily routines of altered bodily capacities and energy limits. Whether learned through Long Covid clinics, occupational therapists, support groups or personal research, PPP is a self-management strategy at its core, grounded in embodied knowledge, developed through lived experience and sustained bodily awareness.

Influenced by the work of Anderson (2010a) and Bissell (2009, 2010), I have also examined the affective dimensions of Long Covid, considering the extent to which participants can affectively anticipate symptom intensity and exacerbation and adapt their individualised energy-management strategies accordingly. Through everyday anticipatory practices of what I call *affective forecasting*, participants have endeavoured to reclaim a sense of control over the chronic pain and energy

impairment that has territorialised their bodies. In this sense, I explored the extent to which participants could reclaim a sense of control over the pain that has territorialised their bodies and lessen the affective intensity by reconfiguring the intentionality and desirability of these affects. This chapter hence offers a prominent example of how participants often adopted the role of the self-clinician, bridging the gap between formal medical knowledge and the intimate, embodied and affective knowledges of their own bodies.

The adoption of PPP gave rise to new spatio-temporal rhythms: activities were spaced out across the day with scheduled rest, limited to one primary activity per day, and bounded by newly defined socio-spatial and temporal limits. For participants in this study, who were formerly accustomed to routines of high activity, productivity and multitasking, this shift represented a profound re-learning of how to live. Therefore, building on the previous chapter, this adjustment was emotionally and psychologically challenging, as rethinking and resisting former inhibitions and common-sense boundaries in this way – by slowing down and shifting everyday roles and responsibilities – contradicted inner active and independent identities. Despite efforts to slow down or reduce demands, participants often spatio-temporally misplaced their corporeal energy limits, particularly in the early stages of illness. As a result, implementing PPP was characterised by a frustrating process of trial and error, frequently leading to unintended symptom exacerbation. Given the radically slow, non-linear, and sometimes even imperceptible, development of Long Covid, and the shifting nature of symptoms, participants' embodied and affective knowledges were continuously written, unwritten and re-written.

Building on the previous chapter, for some, strict adherence to new temporal, spatial and social boundaries reinforced feelings of entrapment, a profound sense of being confined to everyday routines of bodily care, with little space left for meaningful living. Some participants described their corporeality as reduced to mere biological existence. In response, many developed anticipatory logics, strategically setting aside time and space to crash around their structured routines so that they could re-engage meaningfully in everyday life, temporarily freeing themselves from their body under lockdown. In this way, participants were empowered by their increased spatio-temporal autonomy over symptoms. In a similar capacity, some participants actively chose (temporarily) to ignore their new routines centred around PPP, to be a bio-

deviant, and to engage in life meaningfully and accept the later consequences of symptom exacerbation. In a somewhat paradoxical sense, when symptoms were anticipated and hence intentional outcomes of meaningful activity, their affective intensities lessened. Participants felt empowered and enabled to live an enhanced life despite ongoing illness.

Further building upon the concept of liminality within the context of slow, uncertain and non-linear trajectories of Long Covid, some participants felt empowered to reframe dominant narratives of cure and mortality into more nuanced understandings of healing and morbidity. As discussed in the previous chapter, participants were often willing to accept their current limitations temporarily: for now, but not forever. This more hopeful attitude centred around healing thereby enabled participants to endure the challenges of their novel, incoherent and uncertain of illness and perceived bodily stasis. For some participants with highly unpredictable and volatile symptoms, however, managing Long Covid was seemingly impossible, as their bodies resisted attempts at control. This sense of resistance also surfaced when participants struggled to relinquish control within constantly shifting socio-temporal conditions, or even symptoms – even after developing familiarity with the Long Covid body. When pain could not be decentred from the body, participants felt disempowered and sometimes despondent, even to the point of momentarily contemplating 'ending it all'. Such experiences were therefore disabling as participants were stripped from their agentic capacity to lessen affective intensities. Deterritorialising pain was not always possible for participants in this study, and was hence spatially, temporally and corporeally contingent. These particular experiences highlight a stark disconnect between certain embodied realities of Long Covid and those 'normative' PPP discourses that assume individual autonomy, lucidity and coherence.

Participants clearly acknowledged that, while the three Ps principle works to an extent, it merely offers an *illusion of control*, leading me to conceptualise everyday Long Covid routines as *predictably unpredictable* – an ongoing embodied, affective and relational negotiation of everyday life. By acknowledging this illusion, some participants were able to reclaim agency by releasing themselves from the constant pursuit of control. This shift demonstrates that even unruly intensities still hold potential to be reframed and lessened. By transforming affective charges of fear and despair into hope and potential, participants recentre uncertain and incoherent knowledges of Long Covid as

a space of possibility (Anderson, 2006). Bringing together insights from the geographies of chronic illness with more conceptually-charged inputs from elsewhere in contemporary human geography, I have demonstrated that neither the embodied nor affective experiences of Long Covid are static. They are fluid and responsive to the socio-spatial, temporal and corporeal contexts through which they are lived, negotiated and understood.

Chapter 6: The spatial politics of (in)visible illness

6.1 Introduction

> ‘You look well,’ came a chatty voice from a well-meaning chap.
> I once would have taken this as a compliment, but now it is frustrating.
> He can't see the pain I hide inside: the physical, the emotional.
> My glasses hide the grey circles under my eyes, my words avail over how I truly feel.
> He can't see the daily battles with pain, fatigue, seizures.
> That is the problem with non-visible disabilities.
> You managed okay before, but was it safe?
> You need to learn to manage it better.
> The comments, the unsolicited advice, this is what I have to deal with.
>
> (Hannah, FG4, “You Look Well.”)[69]

In the previous chapter, I explored how participants manage their chronic Long Covid symptoms through the three Ps principle – planning, pacing and prioritising – through both an embodied and affective lens. As an elusive, contested and marginalised illness, this perspective shifts focus from what chronic pain *means*, to what chronic pain *does* to the body – how it moves, shapes and conditions bodies (Bissell, 2009). This position was significant for participants in my study who rarely questioned, “why me?” I furthermore suggested that the invisibility and variability of symptoms presented challenges to participants who would listen intently to their bodies in order to effectively manage their energy-limiting illness. In summary, I explored how the frequent lack of visible bodily markers of these subjectively experienced symptoms meant that participants had to rely on bodily signals, which was complicated by the variability and unpredictability of Long Covid on deceptively ‘good days’, meaning that participants had to further learn to affectively forecast their symptoms through embodied knowledge. Therefore, I have demonstrated how the invisibility, variability and uncertainty of Long Covid presents challenges to the *self* – complicating how Long Covid *feels* and therefore what it precisely *does* to the body. Building on the previous chapter, I furthermore emphasised that we cannot *feel* someone else’s pain. Scarry (1985, p.4) elaborates that the experiences of both the individual in pain and those who observe that pain are “incommensurate.” The invisibility, variability and

[69] A poem written by Hannah as a creative means of coping with her new lived reality, which she shared in focus group discussion.

uncertainty of Long Covid to the witness of *others* complicates this matter further, calling into question, how do we attempt to empathise with one's pain if we cannot see it? Therefore, throughout this chapter, I will now consider what chronic pain and illness *looks* like as it is lived across everyday time-spaces and what pain *sounds* like when articulated through testimony.

Invisible illnesses, or invisible disabilities, typically refer to medical conditions that are not outwardly apparent to others and therefore challenge normative assumptions of what illness 'looks' like. They include a range of physical, mental and neurological conditions and can significantly impact a person's daily life, health and wellbeing (Disability Unit, 2020). Chronic invisible illnesses typically fall into two broad categories: those with medically explainable symptoms, and those characterised by medically unexplainable symptoms (MUS). MUS are typically understood as persistant physical symptoms lacking identifiable organic pathology (Nimmo, 2015) and can therefore be described as idiopathic in nature (Cleveland Clinic, 2025). Long Covid, however, is not considered idiopathic as it follows a clearly identifiable acute infection with SARS-CoV-2. Nonetheless, it does indeed share features with idiopathic conditions and may include chronic symptoms that are medically unexplained. As post-viral sequelae with known aetiology, Long Covid occupies a complex position within medical categorisation, often blurring the boundaries between traditionally 'explainable' and 'unexplainable' illness categories. Nevertheless, this ambiguity reinforces a hierarchy of chronic conditions within Western evidence-based biomedicine, which privileges detectable [70] diseases such as cancer and diabetes,

[70] Here, I want to draw attention to the subtle nuances between (in)visible, detectable, measurable and legible. In this chapter, I use the term "invisible illness" to describe conditions that are not immediately discernible on the body's surface — those that do not outwardly manifest through visible signs or symptoms. This 'invisibility', however, is nuanced, as discussed earlier in the context of Long Covid, where some participants display outwardly visible signs through physical changes or medical interventions. This is also true for other medically explainable invisible illnesses, such as cancer or diabetes, which may become visibilised through physical changes or medical treatments — for example, bodily weakness, hair loss resulting from chemotherapy, or the presence of an insulin infusion pump. When I refer to such medically explainable illnesses as "detectable" or "measurable" through technology, I am drawing attention to the role of biomarkers and diagnostic instruments that render illness legible to clinicians. This stands in contrast to medically unexplained illnesses — such as ME/CFS, fibromyalgia, and Long Covid — which often elude biomedical technologies in the absence of identifiable biomarkers and are therefore diagnosed largely through exclusion. These diagnostic tools make what is otherwise invisible to the lay eye "visible" within the epistemic frameworks of medical practice — visible or clinically legible, that is, to those trained to interpret such

over elusive illnesses such as Long Covid, fibromyalgia and endometriosis, which remain poorly understood and often contested (Goffman, 1963).

In this biomedical framework, medically unexplained conditions are often framed as "illnesses" (subjective experiences of bodily distress), rather than "diseases" (objective conditions that warrant medical intervention) (Dumes, 2020). This distinction reflects a hierarchy that values objective evidence over subjective experience (Greco, 2017). As a result, such conditions face ongoing medical and cultural scepticism, leading to stigmatisation, dismissal and exclusion from essential biomedical and social support systems. Throughout this chapter, I therefore explore the nuances of living with Long Covid, a chronic, debilitating condition that is often invisible to, or misunderstood by others, highlighting the tensions between its embodied reality and external perceptions.

The geographies of chronic illness and disability have long shaped critical, embodied, and socially-situated understanding of impairment, illness and disability, highlighting how socio-spatial forces influence the lived experience of illness (Chouinard, 2018). Although hidden disabilities and illnesses are widely recognised within this body of work (Dyck, 1995, 2005; Edwards and Imrie, 2003; Parr, 2000), there remains scope to further develop the nuanced relational geographies of invisible, contested chronic illnesses. This is particularly true for Long Covid — a newly emergent and still-evolving condition — where little geographical scholarship has yet engaged with its complexities. As such, this chapter contributes to the growing need for critical geographic engagement with the lived realities of this relatively new and still poorly understood condition.

To address this lacuna, I explore what Megan (FG4) succinctly described as the many "layers of invisible illness," focusing on the complexly interconnected physical, biomedical and social contours of invisibility. I explore how (in)visibility emerges *unevenly* across different spatial, temporal and corporeal contexts – from clinical encounters, workplace environments, social spaces and moments of rest within the home space – and how participants negotiate these deeply relational time-spaces, through which their lived experience is negotiated, contested and rendered (in)visible.

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biomedical inscriptions — and thus illnesses that are ostensibly invisible on the bodily surface may become rendered visible through medical technology.

At the intersection of space, body and illness, I further examine the paradoxical ways participants navigate socio-spatial 'masking' strategies to conceal Long Covid – contending they are thus complicit in reinforcing its invisibility – while simultaneously seeking visibility, recognition and legitimacy through forms of diagnostic and social advocacy.

To contest the legitimacy of an illness, that is, to question and decide whether an illness is real or not, is deeply political. I therefore frame the lived experiences of Long Covid through a *spatial politics of invisibility*, which refers to the ways in which spatial configurations and socio-cultural power dynamics determine what, and who, is rendered visible, recognised and validated across everyday spaces. By considering the tensions between both invisible and variable bodily experiences, alongside the hidden geographies of Long Covid, this chapter contributes to and extends existing geographical scholarship on invisible chronic illnesses and disabilities.

It is important to acknowledge that the meaning of 'invisible' illness varied between participants in this study. While the majority experienced Long Covid as biomedically invisible, some participants – though not without struggle – had symptoms, or secondary conditions, that were eventually offered medical explanation (see Table 3.1). Furthermore, although most participants' corporeality appeared outwardly unaffected, others used visible physical aids, such as long-term oxygen therapy[71] (Louise; Sheila) or mobility aids[72] (Arun; Farrah; Kate; Sheila; Theresa) or displayed other observable signs of illness resulting from their symptoms, such as alopecia (Cath) or a drooping eyelid (Farrah). Nevertheless, all participants encountered some degree of invisibility and contestation — whether biomedical, social, or both — throughout their Long Covid experience. Accordingly, throughout this chapter, I aim to capture the complexities and nuances of (in)visible Long Covid experiences to conceptualise an enriched spatial politics of (in)visibility.

[71] Long-term oxygen therapy is necessitated by secondary chronic respiratory conditions (see Table 3.1). For both participants, this involved the continuous use of supplemental oxygen, delivered via a nasal cannula (tubing in the nostrils) from a portable oxygen cylinder (NHS, 2023).

[72] Mobility aids, such as wheelchairs, walkers or crutches, were often used in specific spatio-temporal contexts by participants. Specific details will be detailed where relevant (see also Table 3.1).

6.2 Medical invisibility

Throughout this chapter, I consider two key corporeal layers of invisibility: surface-level physical invisibility, or not visibly apparent on the body, and also a deeper biomedical invisibility that exists at the cellular level, where the medical practitioner, or advanced diagnostic technologies cannot detect, and hence 'see', the illness (Masana, 2011). While surface invisibility may be considered the most immediate layer, I begin this chapter by addressing the deeper, biological layer as hegemonic biomedical knowledge plays a central role in shaping the socio-cultural construction of illness. Drawing on the often-contested biomedical legitimacy of Long Covid, I subsequently explore how dominant medical discourses influence broader socio-cultural perceptions.

6.2.1 Uneven landscapes of healthcare

Medical invisibility stems from the lack of objective biomedical markers that could provide a definitive diagnosis, prognosis and treatment plan. As the first point of contact for the majority of people in the UK, the general practitioner (GP) plays a crucial role in offering primary care, by conducting initial tests and coordinating referrals to appropriate secondary (hospital) or tertiary (specialist) care (Kearns, 2018). However, many participants in my study described instances where standard testing failed to identify any biomedical evidence to account for their symptoms. As Mark explained: "I had chest X-rays, had blood tests and cardiac tests [...] [but] [n]othing significant came back," while Kristina noted, "the only thing showing up on my bloods is the fact that my cholesterol is high and I'm pre-diabetic." Molly, who experienced blurred vision and migraines, also echoed: "there's no evidence there's anything wrong with my eyes." These examples indicate how the absence of objective signs complicated the diagnostic process (see Chapter 2), which, albeit, differed among participants.

Participants' experiences of diagnosis generally fell into one or more[73] of four broad categories: (1) a formal Long Covid diagnosis, regardless of standardised testing; (2) a formal diagnosis of a secondary condition related to their documented symptoms;

[73] Some participants experienced a series of categories across different doctor-patient relations. Eventually, some fell into a singular category or both category 1 and 2, or 2 and 3. Participants in category 4, with no formal diagnosis, were typically self-diagnosed.

(3) an informal diagnosis, where a clinician verbally confirmed a likely Long Covid diagnosis, without a formal record; or (4) no diagnosis or validation at all. Yet these categories were neither fixed nor linear, as participants navigated a fragmented, uncertain and an often-contested healthcare landscape.

Across all categories, seeking a diagnosis demanded time, energy and emotional resilience. Participants reported feeling neglected by the healthcare system which typically dismissed their experience when initial standardised testing failed to evidence their experiential symptoms, rather than investigating further. Cath, for example, described her encounter with a respiratory consultant:

> I thought, out of all of them, he might have been a bit more understanding of Long Covid, but he was just more like, 'Oh, I've done testing, your lungs are okay,' and that's it. I'm still complaining that I've got pain in them and I'm still complaining that I'm out of breath a lot, still complaining of various shortness of breath and things [...] but it's just kinda like, 'well, I've done my bit, see someone else.' [...] I felt quite let down, almost like he wasn't doing his job properly because he didn't want to know about anything else [...] It wasn't like, 'all right, you've still got pain, what else can we do to help?'

Anna echoed this disappointment, highlighting a broader critique of Western evidence-based biomedicine, which operates as the dominant framework across the UK NHS healthcare system:

> I think there's people in Western healthcare who just really only read results and tests and things, so they fail to look to your whole health or the whole body or listen to your complaints, even if they're not visible. And I think most GPs, they just don't have patience for that, or they're just educated in a very Western medicine kind of way, so they're just not very holistic.

Participants reported collective frustration from the repeated dismissals from clinicians, despite knowing that there was indeed something wrong with their changed bodies. For example, as Chloe recalled about one encounter with her GP: "I know my body and I'm sitting here telling you something that's not right with it, and you're trying to fob me off, and I'm telling you, that's not the case." Therefore, participants reported needing to self-advocate for a diagnosis or appropriate care, as Lu (FG2) reflected: "I had to fight to get referred to the Long Covid clinic at my doctor." Therefore, obtaining some form of diagnosis (for Long Covid or a secondary condition) or further testing often required persistence, multiple appointments with different doctors, self-advocacy

or even going private[74]. Repeated dismissals and the need to self-advocate, however, pressed heavily on participants' already limited energy reserves and took a significant emotional toll. As Chloe further emphasised, "you've only got so much energy, there's only so many times you can go and say the same thing." Therefore, re-iterating earlier themes, it became clear that having the energy to seek a diagnosis was one challenge but having the energy to 'fight' for that diagnosis, at the risk of worsening their health, was another that required careful deliberation. These dynamics parallel Dumit's (2006) analysis of how individuals with contested illnesses must continually navigate institutional and epistemic uncertainty, expending significant effort to make their experiences legible and legitimate within biomedical and bureaucratic systems.

This struggle to secure recognition and legitimacy in the face of institutional uncertainty reflects what Dumit (2006) identifies as the "expensive struggles" sustained by patients navigating contested illnesses, where biomedical ambiguity and bureaucratic exclusion compound the exhaustion of illness itself. While Dumit's analysis, situated in the US context, emphasises the financial costs of such struggles for patients – on doctors, lawyers, and insurers — the notion of "expense" can also be extended beyond the monetary. Although participants did indeed identify other forms of financial "expenses" while navigating the UKs fragmented care system – what Farrah termed her "disability tax" – my focus here is on the expenditure of energy itself, which I later theorise in the conclusion as a biopolitical currency that must be 'saved' or 'banked'.

Many participants described feeling invalidated by healthcare professionals. As Kristina remarked, "You couldn't see anything, so it wasn't real." Aligning with research on other elusive chronic illnesses, such as ME/CFS and fibromyalgia (Åsbring and Närvänen, 2002), many participants in my study reported having their symptoms misattributed to psychosomatic or mental illnesses, further impeding the path to recognition and care. For example, Ruth reflected on her encounter with one of the many GPs she spoke with before getting her diagnosis:

[74] Megan and Molly both eventually accessed private health care after NHS care proved inadequate. While the experiences of only two participants are insufficient to draw substantial conclusions, their accounts suggest a comparatively more supportive and attentive health care experience than that reported by participants who relied exclusively on NHS services, which were often inconsistent. This observation aligns with findings from Rushforth et al (2021, p.5), who describe how experiences of NHS healthcare among people with Long Covid resembled a "lottery," with highly variable quality of care, which led many to seek out private healthcare.

> A young doctor registrar [...] kept telling me I was depressed. And he'd sit there with his pen, and going, 'let's go back to mood' and drawing circles, and circles, and circles, and circles, scribbling round it. [...] He said, 'you are depressed.' He said, 'consider your age.'

Such dismissive explanations, often rooted in gendered assumptions, were common, but not exclusive to the women in this study as participants across genders reported being told their illness was as the result of mental ill health, such as depression or anxiety. Helena similarly recalled being told it was "in your head." Participants understood these responses as implying that their condition was illegitimate or imagined (Nettleton et al., 2004). In this sense, the attribution of symptoms as 'psychological' ultimately places blame on the individual, implying that their symptoms are somewhat within their control (Masana, 2011). These dynamics also reveal how illness is not only biologically experienced but also socially and spatially constructed. The body becomes a contested site where biomedical authority, cultural meaning and personal experience intersect (Moss and Dyck, 2003). As I have suggested, participants navigated a fragmented healthcare landscape, moving between GP surgeries, hospitals and even private healthcare providers, seeking validation and recognition. These healthcare spaces are imbued with institutional power and discursive authority, shaping which bodies and experiences are legitimised or dismissed. Rose (1993) argues that such spatial relations and representations give meaning to bodies, including medical spaces shaped by dominant – often, masculine – forms of knowledge and power that determine who is seen, heard and believed. Within the context of Long Covid, many participants in my study found themselves in various healthcare spaces where their embodied knowledge was often dismissed in favour of dominant biomedical narratives. As a result, their experiences were rendered medically unexplainable, which as Jayadeva and Lupton (2025) and Stutzin Donoso (2025) argued in the context of Long Covid, reflect Fricker's (2007) hermeneutical "epistemic injustice," wherein prevailing discursive frameworks lack the resources to render patients' material experiences intelligible, leaving their testimonies difficult to articulate, easy to dismiss and limiting their epistemic authority within clinical settings.

These experiences signal a spatial politics of (in)visibility that challenges standard binary understandings of invisibility. Rather than being simply visible or invisible, (in)visibility exists on a continuum, where some bodies are rendered visible – through scans, tests and biomedical validation – while others remain invisible, not due to an

absence of symptoms, but because their experiences fall outside the scope of the biomedical gaze (Foucault, 1973). As such, some visibilities coexist with persistent invisibilities, revealing the contested and complexly layered nature (in)visibility and recognition within medical (and social) spaces, as previously described by Megan.

The disruption that Long Covid poses on the boundaries of clinical spaces resonates with Longhurst's (2001) analysis of fluid and unruly bodies. The unpredictable, often immeasurable and therefore elusive Long Covid body becomes a site of epistemic tension, 'leaking' beyond the spatial and diagnostic boundaries of Western evidence-based clinical practices. In being somewhat seemingly undefinable within the structures of biomedicine, its symptoms cannot be easily measured or treated. The Long Covid body therefore does not 'fit' into standard biomedical practice and its symptoms are thus frequently dismissed as psychological, exaggerated or illegitimate experiences. Thus, the dismissal of Long Covid patients' embodied experiences exposes not only the diagnostic limits of standardised clinical practice, but also the spatial and epistemic injustices embedded within hegemonic healthcare systems – unfolding across bodies and broader social worlds. Therefore, Long Covid is not merely of medical concern, but is also deeply spatial, political and socio-cultural.

As participant accounts reveal, the diagnostic ambiguity and often invisible pathology of Long Covid contributes to ongoing divisions within the medical community regarding the condition's legitimacy. David's healthcare experience eventually fell into the third diagnostic category noted above: "The GP said 'you probably have Long Covid but there's nothing to say you definitely have it. We can't diagnose you because there's nothing showing up', so they were just going with my words." Although the GP feels that they cannot offer David a formal diagnosis, this verbal acknowledgement was nonetheless validating. Farrah shared a similar experience, as her GP sympathised with the limitations of current medical knowledge:

> My GP also said, 'years ago, people, doctors didn't believe that fibromyalgia existed until they found a test that showed it up.' He said, 'what you've got, we don't have the right test to prove it yet, but I know you've got it.' And that was really reassuring that actually, yes, I'm not making this up, it is not in my head. It's just, science hasn't caught up.

This exchange captures a nuance of Long Covid's invisibility – a condition awaiting recognition, but not inherently unknowable, just as fibromyalgia once was. These

narratives reveal that some clinicians acknowledge the limitations of current Western medical practice, as its evidence-based framework cannot *yet* fully account for conditions that extend beyond its epistemic reach. Within these doctor-patient interactions, Long Covid is made partially visible through verbal validation of participants' embodied experiences, despite the absence of objective signs (Masana, 2011). Crucially, these accounts highlight the authority of a doctor's speech in shaping medical narratives and conferring legitimacy. In the absence of biomedical 'proof', the clinician's verbal affirmation powerfully validates the lived reality of Long Covid and reassures the patient that it is not imagined. This epistemic authority, governed by medical professionals, operates as a discursive power, determining whose experiences are rendered legible within clinical settings. As such, medical authority is exercised through verbal validation to make illness visible, even when it eludes objective detection. While verbal affirmations are seemingly informal, they play a crucial role in disrupting, or at least temporarily suspending, the epistemic injustice embedded within biomedical discourse.

Although Long Covid or "Post COVID-19 condition" is recognised as a diagnostic label by the World Health Organisation (2025), participant testimonies indicate that its incorporation into clinical practice remains incomplete because many UK-based healthcare professionals continue to operate within an evidence-based framework that privileges measurable pathology. In contrast to chronic conditions, like cancer or diabetes, which are made biomedically legible through advances in medical imaging technologies such as X-rays, CT scans and NMR, Long Covid often eludes such forms of biomedical detection. Without the biomedical evidence to translate subjective illness symptoms into a recognised disease category, patients face substantial barriers to legitimacy, recognition and care. While some GPs offered verbal acknowledgement and empathy, or alternative diagnoses such as PoTS, many still refrained from definitively or even provisionally assigning a formal "Long Covid" diagnosis, reflecting the ongoing incoherence within clinical practice. Therefore, despite formal WHO recognition, the biomedical nosology of Long Covid indeed remains elusive, contested and inconsistently applied in medical practice (Calabrese and Mease, 2024). This diagnostic ambiguity further demonstrates the dominance of the evidence-based framework that underpins the NHS, despite the WHO institutional recognition and formal nosological classification, which complicates the epistemic space for Long

Covid beyond the structural confines of evidence-based medicine. Tensions between individual clinicians and broader institutional authorities like the WHO has significant implications beyond the clinical setting – particularly in relation to accessing financial support (see Reuschke and Houston, 2023), workplace accommodations (see Chapter 4), and other forms of governmental support which often rely on documented medical evidence, while also reinforcing socio-cultural stigma and marginalisation.

In the search for clarity and certainty, some participants expressed a desire for diagnoses of other well-defined illnesses that carry greater biomedical legitimacy – conditions with defined symptoms, diagnostic markers and established treatment pathways. For example, Arun remarked, "I was hoping I had diabetes because, there's cures for that [laughs]. I was hoping, 'give me, tell me something I've got that explains a lot of this.'" Similarly, Fiona suggested:

> I think people will be more happy if there was a tear in their heart or there was lung scarring. I think if they saw those things on a scan, they would feel more validated. And so, with the medics, 'oh, right, yeah, you've got scarring on your lungs, we know what we can do about that.'

Despite the severity of conditions like diabetes or lung damage, participants emphasised the importance of certainty, a clear explanation and validation of their symptoms that is typically offered with other ostensibly invisible, yet medically explainable, illnesses. Kamy echoed this frustration as she lamented the absence of clear clinical pathways, "Every condition is treated under these clinical ways, right? [For Long Covid], [t]here is no such thing. I've checked every medical book possible, every NHS website, every page that's possible." These reflections reveal the profound spatial and epistemic challenges faced by individuals living with Long Covid. Their desire for diagnoses of medically explainable illnesses reveals a longing for inclusion, where biomedical visibility offers legitimacy of their embodied experience and clear routes to care. In contrast, those without definitive diagnostic markers are marginalised, 'left' to navigate a fragmented geography of healthcare characterised by incoherent knowledge, lacking the clarity that recognised diagnoses offer. Kamy's experience illustrates this exclusion, as she attempts to find direction in a system that offers no healthcare map – no spatio-temporal route – or ontological security that comes with recognised diagnoses.

Collectively, these testimonies reflect existing understandings in the social sciences (Nettleton, 2006; Masana, 2011; Greco, 2017) that healthcare professionals may operate within a hierarchical system of 'invisible' chronic illnesses, where conditions that are medically explainable (and therefore biomedically visible) are more readily accepted than those that are medically unexplainable (and therefore biomedically invisible), producing an uneven landscape of medical legitimacy, which has further implications on the socio-cultural construction of illness (Goffman, 1985) – a point to which I return. Ultimately, the pursuit of a diagnosis is not simply about access to treatment: it is about being seen, believed and situated within a healthcare system that otherwise leaves patients feeling marginalised, neglected and out of place.

6.2.2 Negotiating the spatiality of biomedical testing

As I have outlined thus far, many participants had to 'push' or fight' for a Long Covid diagnosis or even further investigation. In some cases, this meant speaking with several GPs before finding one who was supportive and cooperative rather than dismissive. In others, this meant pushing for spatially reconfigured modes of testing. Here, I turn to the 'visible' medical realities of Long Covid. Participants in this study collectively described the default static spatiality of initial biomedical tests – ECGs, CT scans, X-rays, blood tests – which were often conducted when sedentary or 'at rest'. Some participants, including Helena and Lu, recognised that the spatial assumptions of these standardised tests failed to capture their lived, embodied experiences of Long Covid symptoms that typically emerge under exertion, precisely when the body is not 'at rest', speaks to broader questions about the relationship between Long Covid and energy levels. As Lu emphasised: "the problem is, all the tests they do are when you're stationary." The remainder of this sub-section will focus primarily on these two participants' health care experiences.

Parallelling many participants' healthcare experiences, Helena recounted how her persistent symptoms of heart palpitations and breathlessness were initially dismissed by her Long Covid physiotherapist as anxiety when her standard blood tests returned as 'normal'. However, Helena, who identified as young and fit, insisted that there was something physically wrong with her body. As she continued:

> He huffed and he puffed, and he pulled me into his office and said, 'right, well, we'll do this Sit to Stand Test,' and as soon as he did it, my blood pressure was ridiculous. It was 190 over 110. My heart rate was 180 [bpm]. I couldn't sit and

> stand without getting out of breath. And he went, ‘Oh, you’re gonna need to see a cardiologist.’

It was only after the physiotherapist offered Helena a spatial alternative, the Sit to Stand test, that the reality of her physical condition was acknowledged and she was referred onto specialist care. As Helena put it:

> The medical professionals look at me and they see nothing wrong with me, and yet, if you physically attach things to me, you can see that there’s stuff going on that shouldn’t be, but their immediate assumption is that it must be [psychologically] in your head.

Lu described a similar struggle to have her symptoms recognised within a clinical system that privileges testing stationary bodies. Despite being referred for ECGs and the like, each test was conducted while she was at rest, and therefore produced ‘normal’ results. As she noted: “It’s fine when I’m sat down, I’m absolutely fine. But I can’t walk the way I used to.” Therefore, the results of her stationary tests did not marry-up with the reality of her physical bodily limits. As outlined earlier, Lu reported having to “fight” for further testing, which demanded significant energy. After being prescribed multiple inhalers to treat what clinicians assumed was an exacerbation of her existing asthma, Lu’s symptoms only became visible when a nurse finally asked her to walk around during an appointment. As Lu recalled: “She was the first person to put an oxygen reader on my finger, made me walk around the room, and within two minutes my oxygen hit 75%. And then they kept me in for seven days.”

Both Lu’s and Helena’s experiences illustrate that the diagnostic visibility of Long Covid is not inherent, but spatially contingent. Their symptoms, initially framed as psychological or exaggerated under standard sedentary conditions, only became clinically legible when the spatial logic of testing was altered to accommodate their embodied realities of exertion. This situation reveals how conventional biomedical routines structured around passive bodies reinforce the invisibility of elusive conditions such as Long Covid. When patients’ symptoms do not manifest under these static conditions, they are not only undetected but also delegitimised. Therefore, in such circumstances, I contend that (in)visibility is structurally embedded and reproduced within the spatial assumptions of standard clinical practice, marginalising certain forms of embodied knowledge that resist sedentary diagnostic norms. These narratives therefore reveal how the spatial norms of healthcare not only fails to accommodate

the lived realities of Long Covid bodies which do not typically 'fit' (Longhurst, 2001), but also actively contributes to their contestation, invisibility and marginalisation.

Through patient-led resistance, Helena and Lu redefined the medical 'testing space'. By advocating for spatially alternative, embodied forms of testing that involve movement and exertion, they visibilised symptoms that often elude conventional biomedical assessment. Here the work of medical anthropologist Annemarie Mol (2002, p.33) on how we "do" disease is particularly relevant. Mol argues that disease is not a singular biological truth to be discovered but is instead "enacted" through everyday clinical practices, tools and spatial arrangements. In this context, Long Covid is not merely a stable entity waiting to be discovered. Rather, it is enacted through spatially alternative, embodied testing, when movement – such as the Sit to Stand test or walking – is introduced to the diagnostic practice. In stationary tests, symptoms may appear absent, yet they may emerge in movement-based tests, becoming clinically apparent and validated. Through self-advocacy, participants not only redefine the medical 'testing space' through more appropriate diagnostic recognition, but also co-produce knowledge itself by bridging the gap between embodied and epistemic understanding. By challenging these spatial norms of how we "do" disease, they push the boundaries of where and how illness can be recognised, enacting a version of Long Covid that can indeed be seen, measured and acted upon by biomedicine.

Participants' stories hence represent a struggle for the epistemic legitimacy of their lived, embodied experience because their symptoms are not immediately visible to biomedical technologies or the clinician's gaze. In this context, visibility is not merely about biomedical evidence or data, but about being *seen* and validated within a system whose spatial norms obscure certain realities. The reconfiguration of diagnostic spaces therefore challenges the spatial politics of (in)visibility, where healthcare spaces, and their stationary testing protocols, often fail to evidence or validate embodied experiences of Long Covid. As medical institutions often act as gatekeepers of illness legitimacy, patients are forced to engage in a form of 'diagnostic activism'[75]. By asserting agency through embodied knowledge, participants reconfigure spatial enactments of Long Covid by challenging the standard spatial practices through which it is recognised and understood (Mol, 2002). In doing so, they further reframe the body,

[75] Of course, many simply do not have the energy - physically, emotionally, 'intellectually' - to self-advocate, to resist – a point to which I return in the final conclusion.

not simply as a passive biological object under clinical investigation, but rather as an active, lived space through which illness manifests and becomes knowable (Dyck, 1995; Krieger, 2005). Through diagnostic activism, participants reclaim visibility of their illness within a system that has otherwise rendered them invisible, revealing the radical potential for spatial and epistemic reconfiguration in chronic illness care.

6.3 Social invisibility

In this section, I explore the spatial politics of bodily invisibility as experienced by participants across everyday environments. I begin by unpacking the surface-level bodily invisibility to *others* – how individuals navigate the embodied paradox of "looking fine" yet "feeling terrible" (Dumes, 2020, p.113) and how this dissonance affects participants' re-entry to the workplace, the "second" social environment to the home. I then examine how this dynamic plays out across "third places," the informal social environments that typically foster a sense of community and personal wellbeing (Oldenburg, 1999). Across these contexts, I consider the hidden geographies of Long Covid: the spaces through which illness is strategically concealed through embodied 'masking' practices[76] of non-disclosure, performativity and spatial strategies, alongside the spatio-temporalities through which corporeal visibility emerges. Across these complex hidden geographies, I reveal the uneven and contested socio-spatial landscape through which Long Covid is 'seen', legitimised or dismissed.

6.3.1 Workplace invisibility

As explored in Chapter 4, participants' workplace roles and relations were profoundly disrupted. These disruptions were intricately entangled with the embodied invisibility of Long Covid. Here, I want to return to Chloe's story from Chapter 4, who was dismissed from her work when she disclosed her Long Covid diagnosis. Chloe elaborated how both the invisible and variable nature of her illness complicated the process of returning to work and obtaining reasonable adjustments, with colleagues questioning the legitimacy of her illness when she appeared 'well' in online meetings:

> It was almost like [...] I was lying [...] I was having the attendance meetings online, and maybe rested the whole time before. I'd sit up and have a bit of a conversation, and they were seeing 'okay', but I wasn't okay.

[76] There is also an extensive body of literature on 'masking' neurodivergence (Davidson and Henderson, 2010; Sedgewick et al., 2021)

Wendell (1996) suggests that subjective bodily experiences often require medical validation to be recognised as legitimate, but even when Chloe disclosed her medical diagnosis, colleagues continued to question the legitimacy of her disabilities because they lacked visual evidence of an ill body. This issue is further complicated by the online nature of Chloe's work meetings, which provided only a limited 'snapshot' of her body and condition – typically just her face, neck, shoulders and upper torso. This is a central issue for the lived experience of Long Covid, as 'online' and 'hybrid' working cultures, although not new, became significantly more prominent during COVID-19 pandemic lockdowns and have continued as a 'new normal' structure for many workplaces. Working from home allowed Chloe to present her partial body when sitting or lying down, moreover, thereby concealing the extent of her physical disabilities. This detail is significant as Chloe noted across her testimony that both standing up and walking were energy-demanding tasks. Therefore, the partial frame of online meetings prevented her colleagues from witnessing the embodied realities of her condition that may be more apparent in physical space. I would therefore argue that this disjuncture between online and offline embodiment contributes to the ongoing invisibility of Chloe's embodied reality and workplace discrimination.

Chloe's testimony further reveals the complex geographies of invisible chronic illnesses – of what her colleagues can and cannot 'see,' and therefore do or do not understand or believe, regardless of her testimony. When she presents her partial body online, she looks "okay" to her colleagues' gaze. What they fail to recognise, however, is the preparatory rest and recovery involved so that she could indeed endure that meeting. They perceive her external corporality as "looking fine" within online work time-spaces but fail to recognise her internal corporeality of "feeling unwell" (Dumes, 2020, p.113) beyond these spatial and temporal boundaries (I explore these hidden geographies further later in this chapter). This limited visibility led Chloe's colleagues to doubt the legitimacy of her illness, even with a medical diagnosis. This tension is also indicative of the increasing standardisation of white-collar work in the early twenty-first century, where much labour is expected to be conducted at a desk and, especially now in a post-pandemic era, often through digital platforms such as Zoom or Microsoft Teams. Drawing on Dyck's (2005) observations, at a time when working culture was was largely conducted in person and within shared physical spaces, that women with MS were eventually unable to conceal their illness as their

symptoms progressed, I speculate that earlier spatial configurations of work may have allowed for greater variability in how and where tasks were performed, potentially making illness and its impacts more visible within everyday work practices.

In a different but related vein, Megan noted that during her absence from work, her responsibilities were shouldered by her colleagues while her visible presence on social media, despite being unable to work, led some colleagues to question the legitimacy of her illness. As she recalled:

> Because I wasn't there, she [my colleague] was then getting my work. And she did snap at me at one point and sort of suggested that people were talking about me at work, and people were saying, 'you're on Instagram, but you can't be at work.' [...] [But] I think it was actually her that couldn't deal with it.

This experience reflects a broader theme across stories from other participants' who expressed that they feared appearing 'well' outside of the home, whether in public spaces or on social media, would undermine the credibility of their illness in the eyes of colleagues or employers. As Charlotte reflected: "I was getting to a point, as well, where I didn't want to do anything for fear of [...] anyone in work seeing me and be like, 'but you're supposed to be poorly' sort of thing." Similarly, Helena described how moments of perceived wellness could lead to misjudgement:

> I was always worried that if somebody saw me, for example, if I had a day when I was feeling like I could move out and about a bit, and I drive to the supermarket and be seen in a shop, I'd be thinking, 'well, people think I'm well enough to go into work.' They wouldn't know that actually, I might need to go home and sleep after I'd been in the shop [...] They only see you're functioning in certain situations, and they can't think that actually you might not be able to function in other situations or other times [...] So therefore, they just think, 'oh, you can't be bothered,' or 'you're not trying hard enough,' or 'you're not making enough effort,' or 'you just don't want to.' And none of those things are true.

Participants' narratives reveal how the nuances of variable illnesses are lost under the social gaze when brief moments of apparent well-ness in public spaces may be interpreted as evidence of health, recovery or exaggeration, and thus invite questions of legitimacy in the workplace. Megan's account extends existing discussions in human geography around the social construction of illness across both everyday time-spaces, including the workplace or home, and digital spaces. It highlights how social media platforms can complicate the spatial boundaries of sick leave, blurring the boundaries of public and private life, as individuals are also expected to conform to

their illness-related absence online. Social media therefore becomes an extended site of visibility, surveillance and moral judgement. This politics of visibility across both physical and online spaces may generate spatial tensions, especially with colleagues who are taking on additional workload. Appearing well outside the home during periods of sick leave, or while receiving reasonable time-space accommodations, often invites suspicion about the authenticity of participants' already contested illness and reaffirms preexisting judgements such as "you can't be bothered." These assumptions intensify participants' affective experiences of moral scrutiny, guilt and stress when they are 'seen' as 'looking fine' across either physical or virtual spaces, regardless of whether they are indeed, temporarily, feeling well. Therefore, participants' narratives reveal that they are not only expected to *be* ill, but also *appear* ill in the 'right' way, at the 'right' times and in the 'right' places (Nettleton, 2006).

Social construction in the workplace

As a chronic illness, Long Covid is unique in its emergence from a global pandemic, an unprecedented and socially 'relatable' experience. According to estimates from the Office of National Statistics (ONS, 2022b) by 2022, over half of the UK population had contracted COVID-19[77]. As a result, many citizens felt they had the experiential knowledge and authority to dictate the validity and credibility of participants' 'claims' about their novel chronic condition. For example, the legitimacy of Kristina's Long Covid was questioned through invalidating remarks such as "You didn't actually have Covid, did you?" because she obtained a negative COVID-19 test[78] result during the pandemic. By doubting the legitimacy of her acute COVID-19 infection, they are actively accusing Kristina of lying about her enduring Long Covid experience.

[77] Cumulative incidence data in the UK is analysed up to 2023, when the WHO (2023b) declared the virus no longer a "global health emergency." It is important to note that these statistics are based on clinical NHS Test and Trace data. Given the variable testing capacity over the course of the pandemic, these statistics likely underrepresent the true incidence as they do not account for individuals who did not undergo COVID-19 testing. Additionally, the data only accounts for infections occurring in private households, and excludes cases from hospitals, care homes and other communal spaces. Nevertheless, the data presented here serves to highlight the widespread and 'relatable' nature of COVID-19 infection, which impacts the stigma surrounding 'invisible' Long Covid.

[78] To avoid reproducing the same narrative, it is important to acknowledge that the accuracy of self-administered COVID-19 RT-PCR tests was questioned during the pandemic. The ONS (2022a) reported a sensitivity range of 85% to 98%. However, a systematic review and meta-analysis of data from 32 studies indicated that up to 58% of COVID-19 patients may have received initial false-negative PCR results, albeit with low certainty evidence (Pecoraro et al., 2022). These findings suggest that the reliability of self-administered testing remains uncertain.

Furthermore, when Theresa returned to work, some colleagues trivialised her ongoing symptoms. As she shared:

> I was basically treated like I'd been off skiving for 18 months, and I didn't really get any support when I went back again [...] One of the women walked into the office [...] and said, 'Oh, maybe I'll catch it this time, and I can have a lot of time off work.'

Such comments are deeply invalidating of participants' experiences, serving to undermine personal narratives and reinforce broader cultural discourses that contest the legitimacy of Long Covid. As COVID-19 was a widespread acute illness, Theresa's colleagues struggled to relate to her prolonged chronic symptoms. Instead, they misunderstood the severity of her chronic condition and dismissed her time off as "skiving" – not through their direct accusations, but through passing comments and remarks that implied she was exaggerating or avoiding work.

This was also a profound aspect of Helena's story, who described how the invisibility of her persistent Long Covid symptoms affected her work relations. She shared that her colleagues pressured her to return to work, just as they had done after their own COVID-19 infection: "I was getting text messages when I was off ill from people telling me *they'd* had COVID, and *they* didn't feel well, and *they'd* gotten themselves back in." This expectation not only placed pressure on Helena but also invalidated her lived experience. When she eventually managed a phased return to work, her colleagues expected her to perform her role as 'normal': "people pretty much just expected exactly the same of me as before I went in." This sentiment was echoed by other participants who returned, or attempted to return, to work. For example, although Lu's colleagues acknowledged her illness and accommodations, she explained that, "because you look fine, they forget." Therefore, her line manager would often place demands on her that she could not meet:

> My line manager knows my condition, knows my problem, and then we'll be downstairs and then say, 'Oh, assembly is on the second floor, can you go and lead it in two minutes?' And I'm like, 'but we're on a ground floor, and I can't do that in two minutes. That's why I use the lift.' So, somebody *that* close to me forgets without that visual reminder.

Lu's account highlights how the invisibility of her symptoms such as fatigue, pain and brain fog can lead others to overlook her ongoing socio-spatial and temporal limitations as she is unable to move across the school at pace, especially when stairs are involved

(see Chapter 4). She needs timely notice and rest between duties, yet without visible reminders, these needs are often forgotten. When Lu referred to "somebody *that* close to me," she refers not only to physical proximity, working alongside her line manager daily, but also to their social closeness. As someone she trusts to understand her condition, this forgetting can feel especially disappointing, emphasising how even supportive relationships can sometimes fail to fully accommodate invisible illnesses without a "visual reminder." Similarly, Anna noted that while her PhD supervisors were supportive by validating her illness and offering to accommodate her needs, their expectations often contradicted their understanding. As she articulated, "but then they will still expect me to progress as normal." She therefore elaborated: "If I did not have legs, it would be very clear that there's a lot of jobs that I can't do but, with this, it's not very clear to people what it means and what your limits are." Parallelling many participants' experiences, these narratives demonstrate how the lack of visible signs can obscure Long Covid bodily boundaries and the consequential socio-spatial and temporal limits – to which I return later in the context of 'relatable' fatigue.

Helena's experience somewhat contrasted with that of Lu and Anna, as her colleagues did not respect her illness, nor her accommodations. Even though Helena returned to work with reasonable adjustments – including micro-breaks, reduced duties and a later start time to ease the physical strain on her body – she still encountered stigmatising and discriminatory attitudes from colleagues who questioned the legitimacy of her chronic condition:

> I'd have to listen to people commenting that I just work when I felt like it and I just couldn't be bothered to come in the morning like everyone else [...] They'd stand in corners and corridors and talk about it, but loudly enough so that I could hear to make sure that I knew that they weren't happy with my reasonable adjustments.

Through their perceived COVID-19 'relatability', Helena's colleagues believed she was just "shirking," "lazy" or "being a diva" when she needed rest. Lu echoed this experience of judgement through her spatial negotiation of the workplace when using the lift instead of the stairs to preserve her energy: "People [say], 'are using the lift again?' [...] They associate it with not being fit."

As such, Helena felt inclined to prove her illness to her colleagues – to make her illness visible – by sharing medical documentation:

> I think the *only* time that it started to dawn on people, and I would never do this normally, is they sent me for a seven-day ECG when I went back to work as part of going into cardiology [...] and it came back with a serious fault [...] I actually sent it into my workplace because I was so cheesed off with people saying, 'she's just been off with stress,' or 'she just works when she wants to.'

Despite sharing medical evidence[79] of her high heart rate, which causes dizziness, fatigue and breathlessness (and was later diagnosed as PoTS), Helena's colleagues continued to dismiss her symptoms: "they don't understand it, they just think, 'she's just a bit unfit because she's had Covid.'" This reveals a paradox: (in)visibility is not necessarily determined by observable evidence but is rather socially constructed through cultural interpretations of illness (Masana, 2011) and wider normative expectations of what constitutes a 'competent' working professional. Helena elaborated that her colleagues' inability, or refusal, to acknowledge her chronic condition reflected a deeper resentment towards her reasonable adjustments and accommodations. Having recovered from acute COVID-19 themselves, they struggled to imagine a different, ongoing illness trajectory, even in the face of clinical evidence.

Stutzin Donoso (2025, p.239) acknowledges that Long Covid, as a novel condition, may initially be misunderstood due to a "hermeneutical lacuna" — a gap in shared understanding. She argues, however, that persistent disbelief in the presence of evidence constitutes a deeper form of Fricker's (2007) epistemic injustice, rooted in socio-spatial power dynamics that determine whose lived reality is recognised and validated. Helena's story exemplifies this injustice: her colleagues do not simply lack understanding, but actively refused to acknowledge her lived experience. Linking explicitly to the spatial politics of (in)visibility, Helena remarked: "They couldn't *see* that. They couldn't understand that battle." Her efforts to make Long Covid visible were dismissed and reframed as stress, laziness or attention-seeking, rendering her condition spatially invisible in the workplace.

The familiarity of the virus paradoxically undermined Helena's workplace experience: because her colleagues recovered and returned to work as 'normal', they assumed

[79] After pushing for medical investigation, Helena was eventually diagnosed with postural tachycardia syndrome (PoTS) – a secondary condition of Long Covid. This testing and diagnosis provided a form of medical visibility and clinical validation for some of her symptoms. Although, this is not a shared experience for all participants in my study living with Long Covid.

she should be able to do the same. Their own experiences with COVID-19 limited their ability, or willingness, to imagine a prolonged and disabling embodied reality. In this way, although Long Covid emerged from a globally shared pandemic, it has paradoxically become a contested condition marked by disbelief and stigma. This is compounded by the condition's physical invisibility, further obscuring its enduring and debilitating impact, as described across participants' accounts. Even when Lu's and Anna's colleagues recognised their condition, or when Helena presented medical evidence, their experiences were still met with a lack of meaningful support and even scepticism. Recognition, therefore, does not necessarily translate into validation or accommodation in the workplace. Despite attempts to make their illness visible, it is often dismissed or forgotten in the absence of "visual reminders" and is ultimately rendered invisible. This reiterates that Long Covid is not inherently invisible but may become *spatially* invisibilised in the workplace. Helena captured this ongoing erasure with a solemn reflection: "Until people understand Long Covid, I don't think there'll be any sympathy in the workplace for people like me [laughs]."

Maintaining invisibility in the workplace

In my study, although some participants expressed a desire to hide or disguise their illness or disabilities in the workplace, most were ultimately unable to do so. This was largely due to the sudden and severe onset of symptoms, which significantly disrupted their ability to perform 'normal' or routine work tasks, making concealment difficult or impossible, regardless of whether they had a formal diagnosis. This disruption often forced them into initial, or sometimes indefinite, periods of leave (see Chapter 4). Therefore, attempts made to conceal the true nature or the extent of their illness occurred on their return to work. The findings presented here hence partially contrasts with Dyck's (2005) study on women with MS. As a contrastingly *progressive* neurological chronic condition, some women in Dyck's study were able to manage the situational visibility of their symptoms and maintain an 'able-bodied' identity following their diagnosis for a period of time. Those who decided not to disclose their MS diagnosis also employed spatial strategies to hide their disability and to continue meeting workplace expectations, at least temporarily. While concealment of new bodily limitations from clients, colleagues or employers was impossible for the majority of participants in my study, those who were able adopted a range of strategies – such as partial disclosure, spatial management and performativity – to invisibilise the *extent*

of their condition and to protect their career prospects. For example, Kristina, a self-employed online counsellor, admitted that when she yawns because of her fatigue, she often tells clients that she has "breathing problems" rather than disclose the full extent of her Long Covid diagnosis. She also admitted: "I go [drinks from mug], and I hide behind the mug. I'm sure we all have our strategies for getting around this." These concealment tactics of deferred disclosure to breathing problems or spatial strategy of hiding behind her mug allowed Kristina to hide her illness so that her clients would not doubt her professional credibility.

On the other side of the workplace coin, participants also attempted to conceal the true nature of their Long Covid from employers. Paralleling Kristina's strategy of deferred disclosure, Molly, an accountant who works from home, was able to sidestep potential discrimination from her 'Long Covid' non-diagnosis[80] strategically by describing her more socially accepted symptoms, such as migraines and body pain, to her boss. Despite being recognised by the WHO as a legitimate illness, there was rationale for her decision, shaped by witnessing how others with Long Covid were treated. As she reflected: "based on other people's reactions, I didn't want to get a reaction at work as well." She expressed concern that the lack of clear medical knowledge, particularly the uncertain trajectory, alongside the invisible nature of Long Covid, would invite suspicion or undermine her credibility:

> I thought, if they think this is something long term, and something that I'm not going to shift, I don't want them to think badly of me or think any differently towards me or, think that I'm not going to be capable of doing my job [...] It will always be a mystical illness. Probably one that's not going away [...] I probably don't want to say it in a work sense so that they don't think I'm going to be a sick note for the rest of my work life [laughs].

Molly's strategic navigation of the workplace closely mirrors the feminist-interpretive dynamics of Foucault's (1972, 1978 cited in Dyck 2002) disciplinary power and self-surveillance elaborated by Dyck (2002). Her actions can be read as a form of embodied resistance to dominant illness scriptings, as she attempts to reinscribe her body as 'able' within an environment shaped by ableist performance norms. By

[80] Molly has self-diagnosed with Long Covid but has not pushed for a formal diagnosis, as she is concerned about the potential discrimination if it appeared on her medical record. She also feels a Long Covid diagnosis is not necessary since she is already receiving medical investigation and treatment for her chronic migraines.

deliberately playing on these semantics, Molly was able to secure the necessary support and accommodations, such as flexible working patterns and new equipment, while avoiding judgement, stigmatisation and discrimination that others, particularly participants in this study (see Chapter 4), experienced as a result of the Long Covid label. She strategically utilised the absence of a formal Long Covid diagnosis to partially perform and inscribe an 'able-bodied' identity. Although she did not present fully as such, she masked the true nature of her condition by actively deflecting disclosure to seemingly more transient and treatable symptoms. In doing so, she resisted a 'fixed' disabled identity and preserved the integrity of her social identity as 'able', through strategic partial disclosure of certain symptoms, while simultaneously making her specific needs visible.

Similarly, although Amy disclosed her diagnosis to colleagues, she strategically leveraged their limited understanding of Long Covid and its invisible nature to maintain the appearance of an 'able' identity:

> My line manager can see how badly it affects me when I get repeated COVID infections, but she hasn't got any understanding of Long Covid, or even anything similar like ME, or other just general autoimmune diseases or chronic illness.

Therefore, she admitted: "I probably don't say as much as I probably should to help them understand, because I don't ever want to be in a position where my ability to do my job is questioned." As a teacher, Amy expressed feeling secure in her job, yet still explained: "I just would never ever want anyone to even have the slightest inkling that, 'oh, she might not be up for this promotion,' or 'we've got an exciting project coming up, but oh, we won't ask Amy because she won't manage it with her health.'" She deliberately refrained from talking about her condition in order to preserve its invisibility – encouraging colleagues to overlook or forget about her illness. This mirrors the aforementioned experiences of other participants in this study, whose colleagues often forgot about their illness due to its apparent physical invisibility. Echoing Molly's motivations, Amy's wanted to dispel any doubts from colleagues about her capabilities that could negatively impact her future career development.

These behaviours strongly reflects Dyck's (2002) findings that women with invisible disabilities, such as MS, often engaged in concealment strategies in anticipation of negative responses from employers and colleagues. In both cases, the performance

of partial or conditional able-bodiedness emerges as a tactic to preserve employability and social legitimacy within ableist institutional structures. Dyck conceptualises this as a form of self-surveillance, where individuals internalise workplace norms and adapt their identities accordingly, often reinscribing the body as 'able' in order to align with unspoken performance expectations. I further build on Dyck's work by illustrating how the ambiguity of a formal diagnosis (or lack thereof) can paradoxically create a space for resistance — enabling participants to manage the visibility of their condition on their own terms while still obtaining support. Participants tactically navigated the (in)visibility continuum described previously, actively controlling how their condition is seen or unseen. Rather than simply conceal their condition out of fear, they manipulate this continuum as a calculated negotiation of power within ableist institutional structures However, this dynamic also feeds into a core theme of this chapter, wherein participants become complicit in the 'invisibilisation' of their own condition – to which I return in what follows.

As Dyck notes, however, such strategies are ultimately constrained by the broader disciplinary power of workplace environments that continue to marginalise disabled identities unless systemic norms are challenged. As such, Amy also described feeling pressure to perform an 'able identity' and resist the biomedical inscription that positioned her as 'disabled'. Reflecting on the high-paced, productivity-driven culture of her workplace, she felt compelled to match the performance of her colleagues:

> The expectation is that [...] I'm working 100 percent [...] I'm running my classroom really well. I'm not boasting, but I mean that I'm doing it to the best of my abilities and putting all my effort into that so that that ball doesn't drop.

This narrative further reveals a spatial politics of disability, where the workplace becomes a key site in which normative assumptions about ability, productivity and embodiment are reinforced. Amy feels pressure to consistently and visibly perform at the pace of her non-disabled colleagues to protect her future career prospects, describing herself as putting on "[a] complete mask," albeit at the potential cost to her overall wellbeing. Her subjectivity can be interpreted through Butler's (1990) lens of performativity, which emphasises that identity is not fixed nor innate but rather enacted through socio-culturally accepted behaviours. Amy's performance of a productive, fast-paced able identity is culturally shaped and spatially situated, enabling her to maintain an appearance of 'well-ness' in the workplace while resisting a 'fixed'

disabled identity. I further contend that masking in the workplace is not only a spatial negotiation, but also temporal, since Amy is attempting to maintain credibility within a workplace structure that rarely accommodates for the non-linear, fluctuating reality of chronic illness. Even so, this ‘mask’ becomes a form of embodied labour: not merely a physical performance but also one with energy cost. As outlined previously, Amy’s expenditure of both physical and mental energy to suppress signs of illness in the workplace impacted her role and relations in other domestic and social spaces. These relational energy strains align closely with the concept of “crip time,” which highlights how disabled and chronically ill individuals experience and inhabit time differently from normative, able-bodied rhythms (Kafer, 2013; Samuels, 2017; Evans et al., 2024), resulting in what Hansen and Philo (2007, p.493) describe as “the normality of doing things differently.” Crip time challenges the assumption that productivity must be fast, linear, or uninterrupted, yet Amy feels compelled to contort her body and energy in synchronicity with workplace rhythms inherently exclusionary of non-conforming disabled bodies. In doing so, she performs health and productivity at the expense of her limited energy resources and broader socio-spatial relations.

As workplace experiences are shaped by the authoritative yet uncertain biomedical and socio-cultural narratives surrounding Long Covid, these discourses often cast individuals as unpredictable and unreliable due to the condition’s fluctuating, undefined trajectory and contested legitimacy. In response, participants employed deferred disclosure, spatial management and performativity to actively resist those discursive inscriptions that position them as ‘dis-abled’, asserting agency over how their bodies and capabilities are perceived in professional space. However, this resistance is indeed double-edged: while it may potentially deflect discriminatory treatment in the workplace (and beyond), it simultaneously risks reinforcing the very ableist cultural standards that render chronic illness invisible and unintelligible (Butler, 1990). Individuals are therefore caught in a tension between resisting biomedical and cultural discourse and reproducing the workplace’s discursive and spatial norms through which cultural narratives of the ‘able body’ serve to regulate and marginalise disabled bodies (Chouinard, 1997). I return to this paradox of invisibility later in what follows.

As outlined at the beginning of this sub-section, the extent to which many individuals in my study could suppress their illness and negotiate workplace identities was often

constrained by the sheer severity of their Long Covid, which varied significantly among participants. Although only a few participants were able to situationally conceal their Long Covid identity, I argue that 'masking' through partial disclosure, symptom deferral and performativity are significant concealment strategies for managing the lived experience of Long Covid in the workplace when and where possible. Further research is needed to substantiate this claim and to explore how such strategies operate across different workplace subjectivities. Nonetheless, these initial findings are particularly compelling given that participants reported using similar concealment strategies outside the workplace to avoid social stigma, as I now discuss.

6.3.2 The body as a site of recognition

Participants framed the social invisibility of their illness in relation to both unacquainted others and familiar others. That is, the perceptive invisibility of their disabilities to those who are unaware of their Long Covid and to those who are aware, respectively. In relation to unacquainted others, Amanda shared how the invisibility of her illness impacts her occupation of public space:

> If I've been trying to cross the road, and because I can't walk fast but I look all right, I've had people beeping at me, shouting abuse at me, all sorts of stuff. And I have to park the car near to where I'm going because I can't walk, people get cross. There's all sorts of consequences of you not looking ill. Because I think if you look poorly, people sort of understand, don't they? But when you don't look poorly, you can get a lot of abuse.

As a result of her illness, Amanda navigates public spaces by parking her car closer to her destination to reduce the distance she needs to walk, and whatever distance she does need to walk is at a relatively slow pace in accordance with her body limits. Because these spatial strategies and embodied movements lack an immediately visible reason, however, unacquainted others perceive her occupation of public time and space as socially unacceptable, and she often receives abusive behaviours as a result. Participants described various forms of judgement from strangers in public places. Megan (FG4), for example, explained that when she requested a disabled badge from Citizen's Advice, she was met with the response: "Well, you have got two arms." In the same focus group discussion, Hannah and Alexandra described the judgements, through looks or comments, received when using the disabled toilet, while Arun shared that when he asked to use a public wheelchair to support his mobility around the supermarket, "they looked at me and went, 'Oh, you know you have to be

disabled to use one of those?'" Participants hence felt judged because their outward appearance contradicted their inward corporeality. As Arun elaborated: "You look too young, or you don't look like you can't walk."

Even when participants' familiar networks were aware of their condition, the absence of visible signs or clear markers of severity still frequently led to their disabilities being forgotten, undermined or even met with disbelief. Kate, for example, reflected on an encounter with her friends when she was going to the pub with her husband:

> We bumped into two friends [...] and she says to me, 'So, what's Steve having for tea then?' And I was like, 'I don't know,' 'What? You've not made him his tea?' Because, of course, I'm not at work, so I should be looking after him, doing all these things [laughs].

Here, Kate's friends have not forgotten about her illness. Rather, they undermine the severity of her condition because of her outward appearance as looking 'fine'. They are "not wanting to see, nor to recognise, nor to accept, despite knowing" (Masana, 2011, p.134). Kate's experience therefore highlights how the social acceptance of illness is often contingent on its physical, surface-level visibility, here complicated by her seemingly 'fine' occupation of public space, even when she is inwardly experiencing a profound corporeal struggle, as she described herself as "hanging on by a thread." When her friends ask about her assumed domestic labour while she is off work, they delegitimise the extent of her disabilities:

> I know that sounds like nothing, but it's like [they're implying], 'you're obviously not that bad,' 'Well, are you back at work now, then?' And these are people that are *supposed* to know, or I thought understood. People just don't get it.

Alexandra resonated with Kate's experience, as her sister, who she described as her "best friend," also does not understand her new illness:

> My sister doesn't get it. We've been best friends for years, me and my sister, and she *doesn't* get it. She gets tired. She works. She's got family. She works. She gets tired. And she says to me, 'I think it's probably your age.'

This kind of verbal invalidation from familiar others was common across participants' testimonies, as many recounted similar dismissive comments such as, "you don't look ill," (Fiona), or "I've felt a bit tired before" (Lu). Drawing on the work of *Chronic Illness Inclusion* (Hale, 2021), Evans et al. (2024, p.4) use the term "energy impairment" to capture the qualitatively and biologically distinct fatigue experienced in chronic illness,

which is often flattened by universal understandings of tiredness within medical and social discourse, obscuring its profoundly debilitating nature. Paralleling the earlier theme of 'relatable COVID-19', participants' accounts indicate how their severe fatigue as an energy impairment was consistently misinterpreted through this lens of everyday tiredness. Because tiredness is a familiar, shared experience, participants' fatigue was perceived through an able-bodied lens, as ordinary and manageable rather than a deeply disabling form of fatigue that shaped their daily lives.

Participant testimonies therefore demonstrate how the lack of biomedical consensus shapes socio-cultural interpretations of Long Covid. As Molly elaborated, "it just seems like a mythical thing that isn't recognised [...] people would perhaps just think, 'well, just get on with it. Surely can't be that bad.'" Such responses reflect expectations that participants should be able to 'push through' and cope just as they would do on a daily basis when they are 'tired', while also sometimes undermining symptoms through attributions to aging, poor fitness or laziness. Building on geographical work that examines how social expectations of the 'able body' underpin subtle forms of exclusion and marginalisation (Butler & Bowlby, 1997; Chouinard, 1997; Chouinard, 2010), these narratives highlight how, when others understood fatigue only in relation to their *own* tiredness, participants were similarly positioned against normative ideals of energy and stamina – expectations deeply rooted in capitalist logics that value productivity, output and endurance. Within this framework, chronic illness fatigue is not recognised as a legitimate limitation, but rather something to be overcome through willpower, discipline or better time management. This reinforces ableist assumptions that the chronically ill body should perform as if they were healthy, obscuring the profound embodied constraints imposed by ELCs.

Attempting to empathise with her friends, Kate speculated:

> It's so invisible. If I look at pictures of when I was struggling to sit up [...] I think, 'I look so well.' I'm sitting up and I look fine, smiling for a picture somebody's taken, and you would never know. And I can see that, but inside, everything, you feel like you're not going to survive. It's that intense, the feelings, and it's like that every day [welling up].

By looking at photographs, Kate recognises the difficulties that others face in perceiving the hidden nature of her illness, bearing witness to her seemingly 'normal' body which guises the intensity of pain and fatigue that she experiences internally.

Nonetheless, the lack of empathy and understanding from participants' closest family and friend networks exacerbates participants' emotional and social suffering as they implicitly question their moral integrity. These narratives demonstrate how biomedical nosology can become secondary to socio-cultural perceptions of illness (Masana, 2011), with even most intimate social circles doubting the reality of their illness. These accounts therefore reinforce how the social treatment of the body is configured by both biomedical and socio-cultural discourses contingent on detectable biomarkers and surface visibility.

Negotiating hidden geographies and illness identities

As participant narratives reveal, Long Covid experiences are often shaped by stigma and disbelief. Amanda once disclosed her condition to a neighbour, who dismissed it when they responded: "Oh, I believe it's all in the mind, and if you just push through, you'll be alright." Echoing participants' strategies of non-disclosure in the workplace, Amanda now avoids using the term Long Covid with anyone outside of her close network of family and friends: "I never tell anybody now that I meet out, or if they ask me, 'what's wrong?' [...] I just say, 'I've got a chronic illness,' because of the stigma of Long Covid. Because people don't believe in it, they just think you're making it up." Mark has also faced a form of stigma based on his history of mental health struggles, as his initial efforts to seek a medical diagnosis and explain his condition to family were met with dismissal. His symptoms were attributed to mental health issues emerging from the pandemic rather than a definitive chronic illness. Because of such experiences, he is now selective about to whom he discloses his condition. Mark (FG1) deliberately describes his symptoms rather than disclosing Long Covid specifically, which often leads to more empathy and understanding:

> There was some building work I had done with my neighbours [...] And the estate agent said, 'why can't you go up and inspect it?' I'm not telling them anything about Long Covid. I said, 'I've got a long-term health condition that stops me going up a ladder,' and that shut them up. So, I don't have to tell them anything about Long Covid. I tell them a symptom, and people actually do understand if it's a symptom, much more than if you say, 'I've got Long Covid.' [...] And if they do ask, then I might tell them. It depends who they are, whether I think they're likely to be sympathetic or not.

Participant narratives collectively illustrate that in the workplace and beyond, it is not only the invisibility of Long Covid symptoms that shapes how others respond, but also

the power of the label itself. The term Long Covid clearly carries social stigma that can undermine credibility, leading individuals to carefully manage disclosure in order to protect themselves from social judgement and marginalisation.

Many participants discussed that stigmatisation due to the invisible nature of Long was further exacerbated by its variable and fluctuating nature. As explored in the previous chapter, engaging in social spaces often required significant planning, pacing and prioritising. A significant aspect of preparing for a social event, whether a casual gathering for a meal or an organised family event, typically involves resting at home before and after. For Chloe, this means leaving even the most mundane household labour, such as cooking and cleaning, to her partner so that she can rest in preparation for social engagements. FG1 discussed their shared experience of appearing 'well' and displaying a healthy body in social spaces. As Chloe noted in this discussion:

> If I do a family event, I mean, I'm not saying I'll be life and soul of the party, but people are like, 'there's nothing wrong.' [...] My brother, he got married last year, [I] went to the wedding, and so that was all fine. And then there was another family gathering about a week later, and I had to cancel that because I couldn't get out of bed. But I know they didn't believe me, that that's why I was cancelling, if you see what I mean, because they'd seen me the week before.

Louise agreed with Chloe: "why can they not understand that I did all of that the week before? I really can't do it again the next week because it's too much for me [laughs]." Alongside resting at home before social events, Chloe added, "they don't see the crash that comes after." These accounts highlight how the (in)visible occupation of time-spaces influences familiar others' – those who do not share a home with participants – and their common (mis)understanding of Long Covid. The Long Covid body appears 'normal' or 'healthy' in social time-spaces, while also exposing normative temporal assumptions about illness – particularly the belief that a body cannot suddenly 'collapse' in this unpredictable way. What remains obscured are the hidden geographies of the Long Covid body's altered spatio-temporal rhythms: the energy-conserving rest in the private home space prior to events, or the post-event 'crash' at home when the body is forced into a state of dislocation and withdrawal as time-space and mind-body realities collapse (see Chapter 4). These experiences hence reveal the political contours of (in)visibility, as it is not only the surface-level corporeality when sharing space with others that obscures Long Covid realities, but also the invisibility of bodily occupation in relational time-spaces. It is across these complexly

interweaving (in)visible time-space-body realities that social attitudes are shaped, generating public discourses of contestation, stigmatisation and marginalisation.

Megan (FG4) admitted that she felt complicit in keeping the realities of her Long Covid hidden, as she often socio-spatially withdraws when her symptoms intensify:

> They don't know what happens when you're crashing. They don't know when you're on your own. And I think I deal with that on my own all of the time, so it's not visible. And I think, I don't know if 'guilty' is the right word, but I think I am a little bit guilty of that, because I don't want people to see that side of it, so it does make it invisible.

Megan's reflection reveals that she feels responsible for sustaining the hidden geographies of Long Covid, an illness that is already problematically invisible, contested and stigmatised. Building on discussions of 'masking' in the workplace, participants also admitted to masking their illness from others in social spaces to conceal outward perceptions of their ill-body. In such spaces, participants adopted spatio-temporal strategies to manage how their bodies were perceived by others. For example, as discussed in the previous chapter, Ruth would speak slowly around others to manage her brain fog symptoms and present a more articulate self. She elaborated on this form of self-regulation: "you act, doing what you want people to think. Which is what I do all the time now." Similarly, Louise (FG3) admitted, "it's just what you do because you think it's the better option." For many, masking enabled participants to avoid questions, judgements or feeling like a social burden. As Theresa shared, "I just didn't want to be the sick person [...] I didn't want to be the party pooper. I didn't want to be the one who couldn't do things." Drawing again on Butler's (1990) notion of performativity, these acts of masking can be understood as complex embodied negotiations of identity, strategic performances that align with normative ideals of health, competence and sociability. While Theresa acknowledged that she did not want to burden others with her illness, her narrative also reveals that she also does not want to detach from her former, outgoing and social self, paralleling earlier discussions of 'acceptance' (Chapter 4). Louise (FG3) echoed this sentiment as she noted that, for her, performance of a healthy body allows her to re-engage with, "the sort of aspect that you lose for yourself when you have Long Covid."

Collectively, these accounts reveal that spatio-temporal practices of masking constitutes both affective and embodied labour. Participants evidently feel both self-

and social pressures to perform health and wellness. They described the emotional strain of not wanting to burden others with their illness yet feeling guilty about concealing an already elusive illness. Ruth also highlighted the physical toll of performance:

> It takes such a lot of energy to do this, to pretend to be who you were in your head [...] It means that you are like that while you're with someone, and then afterwards, you fall apart. But I think that's how I cope.

Through strategies of selective non-disclosure, socio-spatial withdrawal and performance of a healthy body, masking emerges as a form of managing invisibility and social belonging, enabling participants to protect their social identities and avoid social marginalisation, while simultaneously obscuring the realities of Long Covid. In this way, masking – whether in the workplace or broader social environments – operates as a spatial-temporal practice that resists dominant narratives surrounding Long Covid and productivity but also inadvertently reproduces the material invisibility of illness alongside discursive frameworks that render it unintelligible.

6.3.3 Visible

The spatial politics of (in)visibility was further implicated when close relations became witness to the physical manifestation of symptoms or crashes. As Monica (FG3) reflected in focus group discussion:

> I look after my mum, and I don't think she believed me, understood, whatever phrase you want to use, until I started crashing in front of her. And, I don't know about you, but I go really pale, just when the energy starts going. And ever since then, she's understood that there's something wrong, and it's just because I changed colour in front of her.

Mark also shared his experience of visibility:

> I think my friends are better actually than my family [laughs]. They could see me; they could see it. And neighbours as well, some neighbours are very good here [...] And they can see me struggling and everyone can see that I've improved over the time. So that's really good. But even so, even with being sympathetic, as somebody said online, they still don't really know what it's like.

These accounts reflect participants' earlier testimonies, who speculated that living with their illness would be easier for others to recognise if they had a constant visual

reminder of their disabilities, such as a leg brace[81]. Many participants, like Monica and Mark, described receiving greater understanding and empathy in home or community environments where others could witness the bodily manifestation of symptoms as they either temporarily intensified or gradually improved over time. This suggests that social recognition of Long Covid was closely tied to the legibility of their embodied experiences across different temporal and spatial contexts, particularly those that were proximate. For many, validation of Long Covid was indeed contingent on being seen in moments of ill-ness. These stories emphasise the role of domestic or neighbourhood settings as sites where illness can become legible when compared to private spaces that are otherwise 'hidden' from public view, work colleagues and more distant familial and social networks. Within the hidden geographies of Long Covid, the home space and broader community environment are key sites of Long Covid experience (see Chapter 4), where symptoms typically intensify or exacerbate, and are also often observed and validated by others. These findings hence enrich inquiry into the spatial politics of (in)visibility, as participants typically found greater recognition in neighbourhood, community or domestic environments where bodily change was experienced, witnessed and shared. This furthermore emphasises the uneven landscape of (in)visibility across everyday relational home, work and social spaces through which people are differently 'seen', believed and legitimised.

However, this experience was not shared by all participants in this study. After being hospitalised with COVID-19 and left on long term oxygen therapy as a result of her lung damage, making Louise's *disability* visible, her *Long Covid* was still doubted:

> Well, I have to wear something visible [...] I'm on oxygen, 24/7. I'm permanently attached. In the house and out, and when I go out, I've got to carry a six-kilogram tank, and you're already exhausted [...] I was at a birthday party for an uncle two weeks ago, and somebody went, 'so, why do you need oxygen?' And you're like, 'Covid,' and they're like, 'oh, but it's not real.'

When considered alongside the accounts of others who chose to disclose only their symptoms rather than naming "Long Covid" in order to avoid judgement, stigmatisation and marginalisation, Louise's experience reifies the ongoing social stigma surrounding

81 Echoing Helena's above testimony, Kate re-iterated, how her illness may be easier for others to understand and empathise with, if it was visible: "People don't have any understanding or empathy. You're treated very differently when it can't be seen. If I was walking around with my leg in a pot, people would just be able to see there was something wrong, and then they're a bit more understanding."

Long Covid. This stigma endures despite the condition's official recognition by the WHO, a clear aetiological link to the COVID-19 virus (from which she was hospitalised) and even the visible marker of long-term oxygen therapy necessitated by lung damage. Paradoxically, the (in)visibility of Long Covid is not simply determined by medical or physical evidence, but rather through a social gaze shaped by dominant cultural understandings about the illness itself (Masana, 2011). Collectively, participants' experiences reveal the complexity of semantics: while disclosure of described invisible symptoms was met with understanding, the term "Long Covid" carries significant social stigma, frequently associated with anxiety, laziness or a lack of personal integrity, and at times dismissed as vague. Taken together, these accounts highlight a reversal of the usual relationship between diagnosis and authority described in the geographies of chronic illness in which diagnosis usually legitimises illness. For Long Covid, it is the symptoms and behaviours that carry authority, while the diagnostic label itself triggers doubt and stigma. As outlined earlier, socio-cultural perceptions were often informed by the shared, yet unevenly lived experience of the global COVID-19 pandemic. This disjuncture between biomedical visibility and social legibility points to a broader spatial politics in which certain illnesses remain invisible, not because of a lack of symptoms, physical markers of visibility or diagnosis, but because of the socio-cultural and relational frameworks through which they are perceived, stigmatised or denied. This issue further reinforces that the spatial politics of (in)visibility operates across an uneven socio-spatial and relational landscape through which individuals are 'seen', (in)validated or dismissed.

6.4 Making Long Covid visible through activism

6.4.1 "The pandemic is over"

A common theme that emerged from participants' testimonies was a sense of being invisibilised by society's desire to move on from the pandemic. When the WHO declared that COVID-19 was no longer a global emergency, there was a widespread desire to leave behind the profound experiences of the pandemic in the UK, marked for majority of the population by spatio-temporal stagnation, confinement and, at times, widespread fear of contagion from a novel virus. Yet, as I analysed in Chapter 4 as 'bodies under lockdown', the pandemic continued for the participants in this study. Although institutional declarations and public discourse signalled an 'end' to the pandemic, this shift did not align with participants' lived realities. Participants' ongoing

embodied experiences of Long Covid continue to unfold across intimate, everyday spaces – often confined to the home – reflecting a continuation of the pandemic in both spatio-temporal and corporeal registers (see Chapter 4). Ruth echoed this sentiment, describing herself as a "Long Hauler," a term evoking a compelling spatio-temporal dislocation; an ongoing experience marked by spatial constraint and temporal uncertainty. This disjuncture between the global, national and everyday discourses produces a form of political suffering and marginalisation. Participants felt invisibilised by a society that wants to move on from a traumatic reality that they are still living daily. As Alexandra (FG4) succinctly put it:

> I think because people want to forget about Covid, that we're almost a bit of bloody nuisance, really. That, 'Oh God, you still got that have you?', 'You still feeling a bit tired? Oh dear.' [...] [I]t's invisible because people don't want to know about it, and we're stuck indoors suffering.

As I have outlined throughout this chapter, participants' accounts revealed a distinct stigma associated with the name "Long Covid," particularly when compared to the relative acceptance received when partially disclosing, less politically charged, invisible chronic symptoms. Collectively, these narratives underscore how the term "Covid" serves as a reminder of the pandemic's spatio-temporal realities that broader society now wants to eschew. As Alexandra's testimony suggests, this societal desire to 'move on' deepens the sense of neglect, marginalisation and invisibility for those still living with Long Covid. Her experience of being 'stuck' at home – spatially, temporally and corporeally – highlights how the Long Covid body becomes hidden from the public gaze, further reinforcing this sense of social invisibility and marginalisation.

Kristina felt particularly invisibilised by her close social network when she attended the funeral of a friend who had sadly passed away from cancer:

> I had to sit there and listen to the fact that everybody had rallied around. Everybody had looked after her [...] And I'd just been ghosted by everyone [sobbing], because it feels like Long Covid isn't real. Cancer is real.

While her friend's illness had mobilised a collective response of care and support, Kristina's experience of Long Covid had not elicited the same recognition. Instead, she felt "ghosted" – a colloquial term used to refer to the sudden end of communication and contact with another person with no warning or explanation – deepening her sense

of exclusion and disbelief. Resonating with Alexandra's earlier account of feeling like a "shadow" (see Chapter 4), this experience carries dark phenomenological connotations. It suggests a disembodied way of being-in-the-world – a translucent presence in the lives of her former close friends; still somewhat perceptible, yet no longer fully there.

This disjuncture, between cancer as a culturally recognised illness and the socially contested nature of Long Covid, reveals a hierarchy of illness legitimacy shaped by both biomedical discourse and social attitudes (Goffman, 1963). It also reflects what Chouinard (2005, p.292) calls a "corporeal class system" in which bodies of difference are assigned unequal value. This suggests that the geographies of visibility exist on an uneven landscape, where Long Covid's visibility, and the intimate social care elicited, is spatially contingent on prevailing cultural, political and institutional discourses.

Kristina further reflected on support received by her sister-in-law for her terminal cancer to capture more about how both biomedical and social support for invisible illnesses is unevenly distributed: "She's got lots of support. And so, she should [...] She's got people rallying round, she's got the services rallying round, she's got doctors and nurses rallying around." While expressing no resentment, positioning herself within this support network, Kristina reflected upon her own relative social and institutional neglect:

> There are times when I think, 'if this was called something else, would it make a difference?' Because people just don't want to know anything that has the word 'Covid' in it [...] It just feels like for Long Covid, there's nothing. Nobody wants to know. The services that were in the Long Covid clinics, I get it, nobody knew what to do [laughs] [...] [I]n medical terms, it's still new and unknown and being researched. But now the fundings been taken away from that as well. There isn't a clinic anymore.

As Kristina reflects on the dissolution of services and the waning of public concern, she feels neglected and a sense of erasure, as she lamented: "Am I supposed to not exist anymore [sobbing]?" The withdrawal of funding from Long Covid services, such as Long Covid clinics, deepens Kristina's socio-political marginalisation. Her narrative indeed highlights how the unequal geographies of care operate through a corporeal class system that decides which bodies matter, and are therefore 'seen', in a post-pandemic society. Kristina's experience therefore speaks to multi-scalar socio-political

exclusion: broader exclusion from state support, but also from intimate everyday social support, instead only receiving care within the domestic space where her illness is acknowledged. This point reinforces my earlier argument that the visibility of Long Covid is spatially contingent, influencing where care is legitimised. In this sense, as the UK, both state and population, attempt to 'move on' from the pandemic, I contend that participants feel 'left behind'. Their ill bodies are socio-politically devalued and neglected, leaving them 'stuck' in spatio-temporalities where their experiences are rendered invisible and they are 'left' to manage illness on their own (see Chapter 5) as broader society attempts to 'move on'.

6.4.2 Negotiating spaces of political action

The narratives presented throughout this chapter reveal the deep social barriers embedded within ableist discourse; barriers rooted in the stigma, judgement and lack of empathy attached to the specific "Long Covid" label. This stigma not only intensifies participants' socio-spatial isolation, but also positions them as 'burdens' to society who are eager to distance themselves from the ongoing reality of the pandemic. In response to such marginalisation, participants emphasised the importance of public advocacy to assert the legitimacy of their illness. Advocacy served to reclaim discursive space — affirming the visibility of their embodied experiences while simultaneously challenging discourse that serves to delegitimise their lived realities. Returning to Alexandra's (FG4) narrative of feeling 'stuck' at home, she remarked:

> I think the invisibility of the illness is the fact that we are all in our own little places. Because of the nature of the illness, we're not out there running marathons with great big pink T shirts or whatever. We're not very noticed.

Fiona agreed with Alexandra: "if we were rioting on the streets, they might listen to us, but we're all too tired [laughs]." As I have suggested throughout this chapter, these reflections reiterate how the invisibility of Long Covid is not only material, but also fundamentally *spatial*. When individuals are confined to their "own little places" – such as domestic spaces (see Chapter 4) – by their energy-limited body they are 'hidden' from the public gaze and discourse in "spaces of silence" (Dyck, 1995, p.308). Participants' health condition is so depletive of energy that such activity is not possible. As Chouinard (2005) notes, geographical isolation, especially within the home, can act as a powerful socio-spatial barrier to political engagement and visibility. Yet, it can be argued that all participants in this study are activists. By simply choosing to share

their experiences and engage in research, they asserted the value of their voices in a society that frequently silences those with contested, chronic illnesses. The adoption of an online methodology was not only pragmatic (see Chapter 3), but also politically significant, as it enabled participants to engage in a form of activism from within the confines of their homes, effectively overcoming socio-spatial barriers that might otherwise be excluding them from public engagement – a point to which I return in the final conclusion.

As such, digital spaces emerged as crucial political tools within the geographies of visibility. The boundless nature of online spaces, particularly social media platforms, offer alternative means of overcoming spatial and political isolation. Not only did these spaces foster connection and validation through biosocial communities (see Chapter 7), but they also allowed individuals living with Long Covid publicly to communicate their experience, challenge discourse and make Long Covid visible to the broader public. This claim resonates with the grassroots, patient-led naming and recognition of Long Covid on Twitter at the height of the pandemic (Callard and Perego, 2021), which demonstrates how digital geographies can offer an alternative online arena for political engagement and discursive visibility when traditional political time-spaces are inaccessible.

6.5 Conclusion

Through a sustained engagement with the (in)visible bodily experiences and hidden geographies of Long Covid, I have developed a nuanced spatial politics of invisibility, traced across the continuum of spatial relations that shape everyday life. I began by demonstrating how the dominant evidence-based framework operating throughout the UK healthcare system has contributed to the marginalisation of people living with Long Covid, as elusive, unpredictable and seemingly immeasurable Long Covid bodies which do not 'fit' within standard testing are often rendered invisible to the biomedical gaze. Experiences of symptom dismissal in the absence of objective signs, yet presence of WHO recognition, emphasises that NHS spaces are shaped by institutional norms and medical discourses existing within the Western evidence-based framework which continue to contest, neglect and dismiss the lived realities of elusive chronic illnesses such as Long Covid. As these spaces and power relations continue to determine whose embodied experiences are acknowledged and whose

are dismissed, I therefore posited that the Long Covid body becomes a political site of epistemic tension.

As subject to such epistemic injustices, I have also shown how participants navigated a fragmented healthcare landscape and reclaimed the medical visibility of their illness through 'diagnostic activism'. They challenged how clinicians "do" Long Covid (Mol, 2002) through standardised stationary testing, by advocating for further, spatially alternative and embodied methods are potentially able to capture symptoms as they manifest through exertion and energy expenditure. These findings reveal that the invisibility of elusive illnesses is not necessarily inherent, but rather, is structurally embedded and spatially contingent. Furthermore, in doing so, patient-experts help to bridge the epistemic and embodied divide between clinician knowledge and patients' lived experience. This move also disrupts the notion of the Long Covid body as a passive object for biomedical investigation, to be defined by medical authority. Instead, through spatially reconfigured forms of testing that reveal seemingly 'invisible' biomarkers, participants assert the body as a dynamic, lived space through which illness manifests and is made legible.

I have also shown how Long Covid is not inherently invisible across everyday work and social spaces. Despite institutional recognition by the WHO, instances of biomedical evidence and diagnosis, and even visible markers of illness, the name "Long Covid" continues to be contested across public, work and social spaces. These findings reveal that the (in)visibility of Long Covid is not solely a matter of medical legitimacy or bodily appearance. Illness experiences are also socio-spatially legitimised or dismissal. This spatial politics is socially constructed through cultural perceptions that are shaped, in part, by the deeply relational, yet unevenly shared, global COVID-19 pandemic. As a result of this existing stigma, complexly intertwined with participants' negotiation of their 'disabled' identity, I explored how participants engaged in various 'masking' practices – such as deferred disclosure of symptoms, spatial strategies and performativity of a healthy body – to maintain the material invisibility of Long Covid across work and social environments. I therefore extend the work of Dyck (1998; 2005) by demonstrating that, in contrast to the 'first' home space, – which is away from the public gaze – the 'second' workplace and 'third' social places – spaces of heightened social gaze – are also key sites of negotiation and performativity for individuals living with Long Covid. These masking strategies serve

to shield participants from workplace precarity and social marginalisation, particularly under dominant cultural discourses that frame Long Covid as illegitimate and stigmatises individuals as unreliable, lazy or mentally ill. While acts of masking can empower individuals by allowing them to resist such stigmas and exert control over how their bodies, abilities and identities are perceived, they also have a paradoxical effect. By sustaining the material invisibility of Long Covid, masking practices reinforce discursive frameworks that render the condition unintelligible, thereby perpetuating the marginalisation of disabled bodies in public discourse.

Participants acknowledged their own complicity in complicating these hidden geographies of illness, by concealing their variable illness from the broader social gaze. Yet, as I have shown, the (in)visibility of Long Covid is also deeply spatial and political. Participant narratives reveal that Long Covid is more socially legible in domestic and community environments, spaces where temporary symptom intensity or longer-term patterns of improved health can be readily observed, recognised and validated by others. Through these everyday relational contexts, I illuminated the uneven spatial politics of (in)visibility, as participants' embodied experiences are perceived differently across interconnected home, work and social spaces.

As participants emphasised the state and public desire to 'move on' from the pandemic, I have also shown how participants attempt to make their illness visible through social and public advocacy efforts. Ultimately, the spatial politics of visibility for people living with Long Covid are shaped by intersecting forces of stigma, contested knowledge and energy limitations. Yet, through strategic use of digital spaces and selective advocacy, participants actively resist invisibility and reclaim legitimacy on their own terms – in their own times and in their own 'safe' spaces. Although participants often feel 'stuck' and 'hidden' at home, digital geographies offer an empowering spatial arena for political action. By reconfiguring traditional time-spaces of activism, participants are challenging the spatial contexts that determine who can be 'seen' and heard in public and political life.

Taken together, these findings demonstrate that (in)visibility is neither binary nor fixed but shifting, relational and politically charged. By drawing out the nuances and layers of invisibility, I challenge simplistic understandings of (in)visibility and argue that the 'invisibility' of Long Covid is produced through spatial contingencies and socio-cultural

power dynamics – between patient and practitioner, employee and employer, and across broader social hierarchies.

Throughout this chapter, I have exemplified participants' paradoxical negotiation of (in)visibility, as they actively attempted to conceal their illness in work and social spaces to protect themselves from potential discrimination and marginalisation, while also striving to make their illness visible through diagnostic recognition and public advocacy. These tensions are deeply spatial and socio-political as participants are constantly navigating uneven landscapes of legitimacy and recognition central to understanding the complexities and nuances of how individuals living with Long Covid manage the geographies of both presence and absence in everyday life.

Chapter 7: Digital geographies of Long Covid

7.1 Introduction

Throughout this thesis, I have traced the uneven geographies of Long Covid healthcare, as linked to participants reporting a spectrum of clinical encounters, ranging from supportive to dismissive and contradictory to cooperative experiences. A common thread woven through these accounts is the experience of systemic uncertainty, neglect and contested clinical knowledge. As previously discussed, participants often described feeling 'left' to manage Long Covid on their own in the absence of comprehensive clinical care, effectively becoming 'self-clinicians'. I have also shown how this clinical incoherence extends beyond the healthcare spaces, engendering broader social stigma and contestation and, in turn, disrupting existing networks of social support and intensifying the relational and affective dimensions of social suffering. Together, these dynamics contribute to what I conceptualise as the spatially contingent invisibility of Long Covid – an illness that is often rendered illegible within dominant biomedical and social discourse, despite its growing institutional recognition and significance. Building on the growing social science literature that foregrounds the significance of online biosocial communities in shaping the lived experiences of Long Covid (Rushforth et al., 2021; Ireson et al., 2022; Jayadeva and Lupton, 2025), participants in my study also frequently turned to digital spaces in the search for alternative sources of knowledge and support, which forms the focus of this final empirical chapter.

Given the emergence of Long Covid – as explicitly identified and named – from an online patient community, it would be remiss not to consider the 'place' of virtual spaces within participants' Long Covid narratives and their implications in 'post-pandemic' 'real space'. As Parr (2002b) argues in her prescient work on embodied online spaces, the internet has significantly reshaped how individuals engage with medical knowledge through two key developments: the democratisation of health information and the emergence of online biosocial communities. For individuals living with a medically unexplained chronic illness, digital spaces offer not only access to information beyond formal healthcare settings but also a means of making sense of their altered bodies (Crooks, 2006). Such engagement represents a struggle for recognition and inclusion, particularly when individuals feel neglected or marginalised

by mainstream healthcare systems (Crooks and Chouinard, 2006). Research in wider digital health studies also emphasise that individuals with illness turn to the internet for multiple, overlapping reasons which typically fall into three broad categories: information-seeking, community engagement and advocacy (Ziebland and Wyke, 2012; Foster, 2016; Kingod et al., 2017). In the previous chapter, I considered how online spaces enabled participants to transcend the traditional boundaries of political action from the confines of their homes (in part because their low energy levels made other modes of information-seeking, community engagement and advocacy almost impossible/inaccessible). In this chapter, I examine the extent to which these same digital platforms can empower participants with epistemic agency and cultivate vital biosocial media communities grounded in shared experience.

Digital technologies have shifted the agentic capacity of the patient's role, from a traditional passive recipient of care to an active seeker and producer of alternative forms of knowledge, entailing a foregrounding of lay expertise (Crooks, 2006). While this is a UK-based study, the near-boundless nature of the internet has the potential to expand its boundaries to an international scale, thereby extending the epistemic space of Long Covid beyond a Western framework of biomedicine. As Farrah observed, "what's interesting is how different countries treat it all over the world, because it's an international one." Individuals hence draw not only on biomedical sources, but also 'other', holistic or experiential understandings of illness, diagnoses and treatments, often situated outside of traditional Western medical knowledge. The internet provides a vital space for health information, especially for individuals managing "stigmatised illnesses" (Berger et al., 2005). Biosocial communities serve as crucial platforms where participants can share their experiences, explore treatment options and develop coping strategies — resources that are often limited or unavailable in offline settings (Parr, 2008). These virtual spaces not only foster solidarity and mutual care, but also disrupt conventional medical hierarchies by foregrounding embodied and experiential knowledge within broader health discourses (Wikgren, 2001).

Recent studies on Long Covid echo these dynamics, emphasising the central role of online resources and illness communities as offering alternative spaces of knowledge and support (Rushforth et al., 2021; Ireson et al., 2022; Jayadeva and Lupton, 2025). Building on these empirical insights, I explore how participants engage with digital

platforms to make sense of their illness by curating new epistemic spaces in response to medical uncertainty. Online biosocial media communities – most notably, Facebook forums and WhatsApp group chats – also featured in 25[82] of my 26 participants' stories, which is perhaps unsurprising given the online nature of my recruitment across social media platforms. The significance of these virtual spaces, however, was much more nuanced than existing studies suggest. Rather than being inherently supportive, participants also described the complex relational and negative affective entanglements that extended into their offline lives. By foregrounding these dynamics, I extend the previous chapter by uncovering the particular hidden social geographies of online Long Covid communities. I conceptualise these geographies as ambivalent and contradictory spaces — marked by both epistemic solidarity and tension; community inclusion and exclusion; with energy-promoting and energy-draining affects. These spaces hence carry affective contradictions, offering validation and connection while also provoking emotional distress and strain. By tracing the affective reverberations of these online interactions into 'real' space, I build on existing scholarship in health geography and broader digital studies (Parr, 2002b; Madge and O'Connor, 2005; Lupton, 2017). In doing so, I further respond to Meijering et al.'s (2019) call to examine whether virtual spaces may enable alternative biogeographical flows that counter the spatial disruptions and mobility constraints imposed by Long Covid, as previously discussed in Chapter 4.

7.2 Digital engagement in Long Covid epistemologies

Participants, especially those who developed Long Covid at the early stages of the pandemic, faced profound uncertainty, navigating not only a lack of formal knowledge, but also minimal awareness or guidance surrounding the duration and lingering effects of COVID-19. As Amanda shared:

> At the beginning, there was no advice. Nobody knew anything about it. So, it was a long time where I was just trying to carry on with my life and taking vitamins, and just thinking, 'you'll get better in a bit, you'll get better,' because nobody knew what it was like. But it just kept getting worse and worse.

[82] With the exception of David, who admitted he had no prior contact with anyone experiencing Long Covid and only became aware of my research through his partner's referral.

Participants also reflected on how this absence of medical direction may have contributed to their current condition or hindered their overall recovery. As Arun, speaking now with more embodied knowledge of his illness, elaborated:

> On reflection, there was moments where I could have done things differently. But did I have any guidance? Did I have any medical advice? Did I have anything to go on? No. So yeah, I'm left in this state now.

When I asked participants about their current understanding of Long Covid, they easily identified the onset of their illness with the acute COVID-19 infection[83], indicating strong embodied knowledge. Even among clinical uncertainty, they rarely questioned "why me?" instead accepting their lived reality (for now). Many participants, however, described feeling 'stuck' in clinical uncertainty, unable to locate an 'end' to their condition. Alexandra expressed the emotional toll of this ambiguity: "If I was told by specialists, [...] 'We give you four to five years, and then it's probably going to kill you.' [...] I could accept that. But nobody knows." Theresa resonated with Alexandra's frustration, noting that even four years on from the pandemic, "they [clinicians] *still* don't know what to do with this."

Through these accounts of profound clinical uncertainty, I frame the uneven geographies of healthcare as liminal epistemic spaces, ones in which patients feel compelled to seek out alternative knowledge. In accordance with current understandings in health geography, participants turned to the internet to make sense of their embodied illness experiences in the absence of clear clinical guidance. Health geographers have examined the role of digital environments as repositories of past experiential knowledge. Unlike established chronic conditions such as ME/CFS or fibromyalgia with longer histories, however, Long Covid remains a novel, variable illness, impacting no two people the same. Understanding Long Covid is therefore unique in that patient 'expertise' is collectively unfolding in real time, being learned, shared and adapted as it is currently lived. While some individuals have recovered and share their experiences retrospectively (see Medinger and Altmann, 2022), Long Covid's novelty means it is characterised by evolving knowledges — both patient-led and biomedical. As Alexandra eloquently explained:

[83] This included participants both with and without a confirmed positive COVID-19 test. Kristina, for instance, tested negative but believed the result to be a false negative and still traced her Long Covid back to that infection.

> I think at the moment, we're writing another bit, and that bigger picture isn't available to us as a society. And I just feel like I'm this tiny little component of it, if you like, experiencing what I'm experiencing. I don't know what the outcome's gonna be.

This sub-section hence traces how participants use online spaces in an attempt to make sense of their complex and variable illness through a process of 'responsibilisation' (Rose, 2007) where the individual has been institutionally neglected and 'left' to take responsibility of their own chronic illness care. I first consider more formal[84] sources and digital technologies before exploring the nuances of online communities as a key epistemic space of knowledge exchange and solidarity. In doing so, I reveal that, although the collectivisation of knowledge occurs across various scales, it is deeply situated at the scale of the body through embodied difference. Attending to such difference, moreover, I explore epistemic tensions arising between the global circulation of online advice – curated through biomedical and lay knowledge – and the intimate variability of lived experience as individuals negotiate their own embodied geography of Long Covid.

7.2.1 Biological citizens

In addition to participating in online biosocial communities, which I address in what follows, participants engaged with a range of digital information sources, including academic articles, medical literature and experiential accounts found in blog posts and podcasts. This self-directed research demanded significant physical and cognitive energy and therefore reflects the urgency and desperation of participants to understand their changed bodies in the absence of clear clinical pathways. Kate curated a body of information to deepen her own understanding and also to share with her GP. Her experience will shape the focus of this sub-section.

Kate researched and proposed treatments to her GP, including hyperbaric oxygen, histamine blockers and nattokinase supplements:

> When I went back to the GP, I told her about this, and I was telling about the mitochondria [laughs], and I've heard about all these things and, 'can you prescribe these?' And she just said, 'yeah, it's worth a try.'

[84] Formal' sources refer to official, governmental and biomedically authorised channels of information, including academic journals, policy documents and clinical guidelines.

Kate's experience is illustrative of a broader epistemic shift, in which the clinic becomes a site of negotiation as *she* offers alternative knowledge, disrupting traditional medical hierarchies where knowledge is passed from clinician to patient. Kate also collected ECG data using her Apple Watch when conducting a self-administered stand test[85], which she presented to another GP in her practice alongside a detailed self-assessment of PoTS[86]:

> I ticked all the boxes on the PoTS criteria so [...] I said, 'I think I have this [laughs]. Here are my ECGs, will you look into some other things?' And he made the referral to the cardiologist in York based on that, but he'd never heard of it. He didn't know what PoTS was. So, I told him that I knew there was a specialist in York, so they did make the referral.

Kate's experience aligns with Crooks and Chouinard's (2006) analysis of the relationality between healthcare and everyday spaces. Like other participants in this study, Kate used her personal time and energy resources to engage with biomedical and experiential research about her chronic illness and possible treatments. Her example extends Crooks and Chouinard's argument by showing how wearable technologies such as the Apple Watch decentralise diagnostic practices, relocating them from clinical settings into everyday environments. Further extending discussions in Chapter 6, these devices act as a means of visibilising Long Covid (or in Kate's example, PoTS) — legible and interpretable — beyond the diagnostic spaces of the clinic. Her experience demonstrates how such technologies enable new modes of diagnostic testing and data generation outside traditional healthcare settings, further blurring the boundaries between patient and practitioner, and between home and clinic.

Kate's account thus exemplifies not only the neoliberal process of responsibilisation (Foucault, 2010) whereby the burden of care is displaced from institutions onto individuals, but also the conditionality of Rose's (2007, p.160) notion of "biological citizenship," in which those able to actively self-manage, evidence and govern their

[85] Kate's account of conducting an active stand test at home to render her symptoms legible through ECG data resonates with discussion in Chapter 6 on reconfiguring the spatiality of clinical testing to reflect the embodied realities of exertion: "It took me a while to be able to do it because I couldn't stand up. It was like it was 10 minutes. You start, you lay down, you measure it, you stand up. But you're supposed to stand up for 10 minutes, and standing up for 10 minutes was torture. It was absolute torture [...] I couldn't breathe. It was really scary."

[86] Postural tachycardia syndrome.

biomedical lives are recognised as legitimate citizens, while those who cannot, or who refuse, risk being rendered failed, non-responsibilised subjects and effectively excluded from care and social legitimacy. However, in Kate's case, as with many other participants, responsibilisation is compelled rather than chosen, as she is forced to manage her own health, recognition and survival in order to secure diagnosis, treatment and referral for specialist care in the face of institutional invisibilisation and neglect.

Kate's curation of knowledge through various digital technologies represents an emerging form of digital biopolitics (Ajana, 2017), wherein medical labour is spatially redistributed into domestic and digital spaces. Here, the home effectively becomes an extension of the clinic, and the patient assumes responsibility not only for symptom management but also testing, interpretation and advocacy. Yet, this ostensible 'autonomy' – where participants assist in their own diagnosis – is granted only insofar as their knowledge, data and practices remain clinically legible, such as the mobilisation of ECG data, and aligned with the epistemic frames and expectations of biomedical experts.

Foucault's (1976) account of biopower shows how contemporary health governance increasingly operates not only through institutions but also through individuals' self-regulation and body monitoring. When participants' experiential knowledge is dismissed, particularly in the absence of clinical markers, they are forced to self-manage, and if able, quantify their symptoms through digital technologies that translate embodied experience into legible biomedical data in order to be taken seriously in clinical environments. Therefore, in contrast to Crooks and Chouinard (2006), however, who argue that the negotiation of doctor–patient relations can be empowering, I adopt a more critical stance. While such dynamics may offer moments of empowerment, I align with Schermuly et al. (2021) in suggesting that these practices – of what I call 'diagnostic activism' (see Chapter 6) – are less a reflection of agency than of structural necessity. Participants like Kate are not simply empowered by epistemic agency, they are compelled to become self-clinicians, produce biomedical data and construct diagnostic narratives that ultimately must remain legible within biomedical frameworks.

It is also significant that Kate's experience was facilitated by GPs who were willing to cooperate and relinquish some of the traditional boundaries of medical authority — a privilege not shared by many other participants in this study. This difference reveals an uneven distribution of epistemic authority across participants' narratives, highlighting how individuals living with Long Covid continue to be structurally and spatially marginalised within a healthcare system that privileges biomedical certainty over embodied knowledge. As discussed in Chapter 6, this often rendered participants effectively invisible as their chaotic and ambiguous bodies do not 'fit' within conventional biomedical frameworks.

Access to digital tools and health information are also crucially shaped by intersecting axes of difference, including socioeconomic status, education, ethnicity, gender, age and disability (Warf, 2019). These digital divides further constrain who can participate in digitally mediated forms of diagnostic activism, limiting the capacity of many individuals to generate data, engage with online discourses or self-advocate within clinical settings. Such disparities expose the structural contingencies that determine who is recognised, or excluded, in healthcare systems, especially in the context of a novel, poorly understood and often contested chronic illness. These dynamics reflect deeply entrenched structural inequalities in access to care, medical legitimacy and epistemic authority, exemplifying Fricker's (2007) "epistemic injustice," where patients' experiential knowledge is systematically devalued unless it can be translated into institutionally legible forms of evidence. Kate's account also brings into focus the labour of such responsibilisation. Managing her own diagnosis and care demands significant cognitive and physical energy, intensifying the burden placed on an already energy-limited body. This burden of biological citizenship is thus contingent and unequally distributed, shaped by disparities in energy, digital access, health literacy and clinical cooperation.

7.2.2 Online communities: epistemic solidarity and tensions

While many participants referred to formal sources of information on the internet, they also noted the intense cognitive demands that such sources required[87], especially in the early stages of illness before building up their own cognitive capacities. Crucially,

[87] Such demands apply to the general population but may be especially burdensome for individuals with chronic conditions affecting the likes of fatigue, brain fog or migraines, making information-seeking even more challenging.

this highlights that exertion under conditions of Long Covid is not only physical but also mental, with processes of reading, interpreting and evaluating information constituting forms of embodied labour that themselves drain limited energy reserves. These energy demands were compounded by the ongoing uncertainty of biomedical understanding. Online communities therefore played a central role in offering accessible, experiential and hence collective forms of meaning-making. As Kate reflected:

> Initially, finding out information, because there's nothing out there, you have to find it yourself. It was really helpful to have that point of reference, if you like. Somewhere to go where you could find out more about it, or people sharing videos or information about work, things like that.

Amanda echoed this sentiment, citing her local WhatsApp group as a key source of embodied knowledge exchange: "You can share tips, and you can get tips to help you." These testimonies highlight how online biosocial media communities can transform individual experience into a collective resource, offering practical advice and guidance when biomedical knowledge remains sparse and uncertain. In contrast to most formal sources of knowledge, online groups offer information in more manageable forms – including short posts, quick tips, helpful videos or podcasts – making them more accessible as everyday sources of knowledge. In this way, online platforms served as accessible epistemic spaces, bridging the gap between biomedical and lay understandings, while reducing the energy demands on the Long Covid body and thereby highlighting the relationship between online spaces and the body's materiality.

For some participants, these spaces became sources of experimentation of alternative treatments and management strategies as members of these online cohorts offered their own embodied knowledge of various tried-and-tested methods (including PPP discussed in Chapter 5). Farrah, for example, obtained "practical advice" on mobility aids and an anti-inflammatory diet. Although she continued to experience pain and muscle cramps, she agreed that these tools gave her "more [...] mental energy" to spend meaningful time with her family that she would have previously spent in bed. Monica also credited the suggestion of a UV lamp with giving her "a bit of energy." This collectivisation of experiential knowledge operates across multiple scales – from the global reach of open social media platforms, such as Facebook, to the more

nationally-bounded exchanges in closed WhatsApp groups[88]. Participants' testimonies illuminate how knowledge circulates across scales, moving from the intimate body to wider digital publics and back again, as individual experiences are shared, adapted and re-circulated. As Megan continued, "I'm then trying to put it out there for other people." This process underscores the situated nature of collective understanding, producing a geography of knowledge that is both global and deeply entangled with the everyday embodied negotiations of chronic illness. Online communities can thus be conceptualised as embodied epistemic spaces: digital arenas in which biomedical knowledge is made accessible and lay knowledge is exchanged. In this way, these groups function as epistemic spaces of solidarity, where the collective negotiation of knowledge and experience enabled participants to support one another in managing chronic illness.

Participants' accounts further reveal the relational energy geographies of everyday online-offline realities. First, participants are able to consume accessible information in ways that are less energy-demanding and more attuned to their Long Covid-affected cognitive capacities. Second, they are able to regulate their spatial and temporal participation in response to fluctuating energy levels. As Fiona reflected, "When I get saturated[89], it's like, 'yeah, I can do that tomorrow, it'll still be there.'" Finally, as both Farrah and Monica described, the sharing of everyday practical management strategies enabled some participants to regulate their energy in real space.

This perspective on online communities was not evenly shared among participants in my study. Some individuals, including Lu and Shiela, expressed disappointment with online support groups, citing a lack of practical "ideas" or "solutions," and instead emphasised their more negative atmosphere – a point I return to below. Arun echoed this sentiment: "people have tried various things to try recover, but there's nothing that I've ever got out of there." Participants acknowledged that, although various sources of medical and experiential knowledge indeed do exist across virtual space, Long Covid is novel, variable and deeply individual, making it difficult to relate to others' embodied experience. As Anna explained, "I think the other issue is that for everyone,

[88] I acknowledge that WhatsApp also has a global reach, however, in my study, participants only discussed UK-based WhatsApp groups.

[89] Fiona uses the term "saturation" in relation to her metaphorical "energy envelope," to refer to a state in which she has expended all her daily energy.

it is really different [...] which makes it harder to relate to others or relate even to healthcare advice." Helena echoed this perspective, describing how some community advice did not fit her lived experience:

> People will say 'yeah, you definitely need to be out exercising because that will help,' but actually for somebody like me, that wouldn't [work] [...] I don't think people get that in some of these groups. They're passionate because something has worked for them, and was right for them, [and] they'll be telling people this is what they *have* to do, but it actually might not be right for someone else.

These narratives reveal a fundamental tension between the collectivisation of knowledge (both clinical and embodied) and the heterogeneity of Long Covid, with participants reflecting on just how deeply – and hence variably – situated embodied knowledge of the condition is (Haraway, 1988). Drawing on Mol's (2002) concept of the "body multiple," we see how the body and illness are enacted differently across various contexts, underscoring that knowledge and experience are always partial and situated rather than universal. While online spaces enable the exchange of knowledge and support, operating as what Madge and O'Connor (2005, p.93) terms a "generative space" capable of producing and supporting diverse epistemologies, they also expose epistemic tensions within the community. As Helena observed, well-meaning advice can often carry assumed epistemic authority grounded in personal experience, an intervention that may obscure the variability of others' conditions. Experiential knowledge holds particular value for the community in the absence of clinical certainty and consensus, but it may also function as a form of epistemic governance – positioning certain experiences as universally applicable while marginalising embodied realities that do not align. In this way, even as these generative spaces produce new forms of collective meaning, they can also reproduce exclusionary dynamics, inadvertently flattening bodily difference and privileging dominant illness narratives over less typical experiences.

These dynamics reveal a broader spatial politics of collective knowledge production within digital communities, whereby epistemic authority and governance may reproduce similar biomedical and social exclusions participants are seeking to escape. Although knowledge is shaped collectively, it remains evolving, situated and not necessarily transferrable as lived realities unfold and shift in real time. Through the governance of situated knowledges, these platforms hence serve both as spaces of

epistemic solidarity and sites of friction. While online communities expand the spatial scale of Long Covid knowledge – beyond both physical geography of place and distance and the Western biomedical institutions – this collectivisation remains anchored in localised embodied experiences. Knowledge exchange is therefore made accessible, but is continually negotiated, reflecting its evolving and relational status. Crucially, this spatial politics of knowledge production governs who is enabled, or excluded, from co-producing and sharing experiential knowledge, particularly when these dynamics discourage or constrain participation.

These spaces had further affective implications. While online communities often offer solidarity, access to new knowledge and practical advice, they also became sites of emotional saturation. For some, like Theresa, the ongoing uncertainty of emerging research only amplified, rather than relieved, her anxiety and distress:

> The support group share stuff, articles and things, and some of them say, 'it's affecting your muscle cells, and it's causing this, and it might have an effect on this and it's damaging your lungs,' and you just think, 'well, in five years, am I going to be at a point where I can't breathe properly because it's had so much of an effect on my lungs? Am I going to end up in a wheelchair because my muscle pain is going to get that bad?'

Anna similarly explained how exposure to online information often becomes an affective negotiation:

> I read a bit about it online, but I also try to be careful to not read too much about it, because it is still quite poorly understood, or at least over the last two years, it was. I think it's getting better [...] I don't want to fall into the kind of doom thinking.

Anna's reference to "doom thinking" reflects the psychological toll of ongoing uncertainty. She elaborated:

> At some point you're just fed up talking about it […] fed up making this the central aspect of your life which you don't want it to be [...] I think I might benefit more from distractions that are realistic in terms of how much energy they take.

This further highlights how sustained engagement with illness knowledge can become both exhausting and bio-geo-graphically intrusive, as always-accessible digital spaces can serve as constant reminders of illness that threaten to colonise time, space and limited energy reserves. In this sense, participants' regulation of their exposure to online information emerges as a strategy of energy conservation, through which they

seek to manage not only symptoms but also the affective and spatial reverberations of illness into everyday life.

Together, these narratives suggest that the circulation of both biomedical and experiential knowledge within support groups does not necessarily produce clarity or reassurance. Rather, in the context of a novel and poorly understood condition, online spaces of knowledge exchange can exacerbate uncertainty and distress. Participants therefore regulated their exposure to online knowledge in recognition of their emotional and cognitive energy capacities, further emphasising how online spaces have to be carefully negotiated – not just in terms of the content but also their affective consequences. It highlights an overarching theme of this chapter: the intimate relationality of digital spaces and affective embodiment, where participation in online communities is carefully shaped and negotiated in relation to the affective atmosphere of both online exchange and the 'offline' embodied consequences – a central theme to which I return in what follows.

7.3 Affective and energetic entanglements

As highlighted throughout this thesis, many participants felt invalidated by everyday support networks across domestic, work, social and biomedical spaces. This consistent lack of understanding and empathy led to feelings of invisibility (see Chapter 6) and, at times, isolation (see Chapter 4). In response, participants also turned to online spaces for validation, belonging and emotional support that they were not otherwise receiving in their physical environments. This shift initially had a positive impact, as Charlotte explained:

> When I got it, Long Covid was still... I mean, it's not even really openly talked about now. And it's not something that really gets recognised [...] And when I caught it [...] I did start thinking, 'actually, is it me?' [...] You did sort of have that feeling of, 'am I the only one?' And I found the [Facebook] group, and to know that you weren't the only one did, it was a comfort.

Similarly, Chloe described how engaging with online communities affirmed her sense of reality and self-advocacy when offline networks failed to believe her experiences: "it's that kind of reassurance that you're not going mad [laughs]." Like Charlotte and Chloe, many participants described feelings of relief, reassurance and recognition in Long Covid online communities. Fiona reflected that "I was getting lots and lots of affirmation and validation, hearing everybody else," while Theresa cast the group as

“a mental lifesaver, because there are these other people that are saying and feeling and thinking and experiencing the same stuff I am.” Mark simply noted that “it makes you feel a bit less lonely.” These accounts illustrate how online spaces functioned as key sites of social and emotional solidarity, making participants’ experiences visible, alleviating self-doubt and validating their subjectivities through collective witnessing and sharing. Mere passive engagement – rather than engaging in the practice of “writing the self,” as Parr (2008, p.158) describes it – enabled participants to feel acknowledged and supported in ways that everyday offline environments often failed to provide.

These testimonies resonate with existing studies in health geography, which emphasises how virtual spaces can offer individuals senses of inclusivity and belonging (Madge and O’Connor, 2002), especially for those living with contested or stigmatised conditions (Parr, 2008). They also align with Rushforth et al’s (2021) analysis of online Long Covid communities, where fragmented and incoherent personal experiences are reassembled into meaningful illness narratives through collective sharing. They found that bearing witness to others’ stories, and seeing their own reflected back, fostered ‘biosolidarities’ and a collective illness identity that challenges biomedical dismissal and neglect.

Beyond mere presence within these communities, participants also reflected on reciprocity. Cath articulated how online connections offered alternative support from her existing relationships, allowing her to feel less of a burden with people who genuinely empathised with her illness experience:

> You’ve got medical people to talk to, and you’ve got friends, but your friends only know so much, and obviously they’ve got their own lives and their own worries [...] So, you feel like you don’t want to burden them all the time [...] [I]t’s sometimes hard to communicate with others and really explain what you’re thinking about, and what’s going on mentally in your head and things. Especially when it’s hard to sort of get your words together, and you get a bit mixed up at times [...] Whereas Long Covid people, they know, and they get it. [...] [I]t’s good to have a little connection like that.

Louise also explained how she contributed to the support of others: “You can cheer each other up in a different way, just by knowing how they feel.” These accounts of empathy and reciprocity underscore how online support groups are deeply relational and discloses the spatial complexities of these digital spaces where the boundaries

between virtual and physical worlds are increasingly blurred (Parr, 2002b). They align too with Valentine and Holloway's (2002, p.316) argument, arising in their research on so-called 'cyberkids', that "virtual activities are not in practice disconnected from offline identities and relationships." Rather, they are intrinsically entangled with, and embedded within, offline socialities. The online interactions described by participants were not experienced as separate from their 'real' lives, but deeply connected to their embodied experiences of care, emotional support and validation, especially given the pandemic context. For many, turning to online spaces was shaped by a confluence of structural and embodied factors: government-imposed restrictions during lockdown, the physical limitations imposed by Long Covid, and the social exclusion often encountered in everyday spaces. In these contexts, virtual communities were not merely substitutes, but instead, crucial extensions of sociality – spaces where the emotional and relational gaps of offline life could be virtually bridged. In this way, online biosocial communities became key sites through which marginalised individuals negotiated the bio-geo-graphical disruptions to care, support and connection within 'real' space, as described in Chapter 4.

Participants reported, however, that this sense of solidarity was not necessarily sustained. In contrast to Rushforth et al.'s (2021, p.6) analysis of Long Covid online communities as "a safe space in which stories could be shared and believed," participants' online experiences in my study reveal more nuanced, complex and often contradictory spaces. While these communities were initially valued for offering knowledge, empathy and a sense of belonging, many participants came to experience them as emotionally draining and sometimes even exclusionary. For example, Charlotte and Lu (FG2) described Facebook forums as a "toxic" space:

> Charlotte: [...] It sort of got to a point [...] where they were almost like, 'well, you're not as bad as me, so you can't have Long Covid' ...
>
> Lu: That's why I came off it, because it was so depressing ...
>
> Charlotte: [...] It was like Top Trumps of Long Covid [...] You'd say that you'd be having a bit of a bad day or whatever, and then they'd be like, 'Well, I haven't been able to do anything for three months.'
>
> Lu: Yeah!

Charlotte's Top Trumps[90] metaphor captures how online communities can reproduce competitive hierarchies of suffering, or what Charmaz (1999, p.368) discerns a "hierarchy of moral status" wherein individuals assess each other's relative ill-ness to determine whether they are deserving of recognition and support. When Charlotte's health improved, her lived experience became subject to moral scrutiny and her 'place' within the online community questioned because she was no longer regarded ill 'enough'. These tensions reveal that even within seemingly empathetic and understanding communities, individuals still fight to be seen and validated, highlighting the pressure placed on this marginalised community continually to 'prove' their illness, even among those with similar experiences, in order to maintain recognition and moral legitimacy. Ruth perceived these competitive Long Covid spaces as "abusive," as Charlotte further elaborated: "if you say that you're better, or that you're even marginally better, it's almost like they get offended. And it's like, 'well, how bad were your symptoms?' And it always becomes a bit of a competition." This dynamic hence inadvertently risks marginalising those who are not deemed 'ill enough', meaning that these 'safe' spaces that individuals turn to for solidarity can reproduce the same hierarchies and exclusions of offline settings that individuals sought to escape.

These findings contrast with Crooks' (2006) study on women with fibromyalgia using the internet, in which women online did not need to be concerned with how others read their physical presence or embodied performances of illness. In my study, however, some participants remained highly attuned to how their illness was perceived and performed, even in digital spaces. Illness had to be continuously narrated in ways that signalled 'authenticity' and justified belonging so as to retain moral legitimacy within the community. This connects to findings in Chapter 6 on invisible illness, moreover, where participants expressed anxiety about being seen as 'well' in public spaces — particularly outside of work — fearing moral scrutiny from those who might question the legitimacy of their condition. Rather than being freed from the burdens of performing illness in supposedly empathetic online environments, recognition continued for some to hinge on sustained displays of suffering and perceived

[90] Top Trumps is a card game where players compare statistics on their cards, with the higher value 'trumping' the other. Metaphorically, to 'trump' someone in this context captures how people may rank their illness experiences or suffering against others', deciding who is more affected by Long Covid — and, by extension, who does or does not belong in the online group.

authenticity. As such, both online and offline contexts demanded ongoing embodied and moral labour to navigate competing expectations of illness, visibility and credibility.

Across both interviews and focus groups[91], participants consistently reflected on the dual nature of online communities, where initial feelings of connection were increasingly overshadowed by stories of hardship, despair and emotional strain. As Marg explained, “There’s positives in it and there’s negatives, but most people are sort of having a tough time,” while Arun concurred that “there were some few positive posts, but not enough.” Participants frequently described the dominant content in these online forums as centred on physical suffering, medical neglect and social isolation[92]. Paralleling Lu’s (FG2) earlier description, many characterised these space as “depressing,” noting the deadening impact on their own mental health. This dimension led participants to disengage or participate sparingly, as Kate (FG4) admitted: “I’m not in any of those [Facebook] groups anymore because I couldn’t cope with some of the stories.” Helena (FG1) similarly shared, “I get very depressed very quickly if I read how hard it is for everyone, especially because I’m at the start of the journey,” while Arun added how, “emotionally, it just made me feel worse.” Although these forums initially offered a positive affective atmosphere, over time participants perceived them as echo chambers of negativity. However, this shift should not be understood as residing solely in the forums themselves or the content they circulate. Participants’ accounts suggest that their relationships to these spaces were shaped by changing personal needs, bio-geo-graphical positioning and evolving understandings of their own experiences. Narratives that were initially affirming or reassuring could, over time, become emotionally difficult to engage with, particularly as participants moved through different stages of their illness journeys. As such, the affective weight of others’ stories was not

[91] Further emphasising the significance of online communities in participants’ stories, each focus group independently introduced Facebook forums as a topic of discussion when I asked them to reflect on their focus group experience. This aspect is perhaps unsurprising, given both the social-media recruitment and the fact that focus groups followed individual interviews, where online spaces were initially discussed. Participants consistently agreed that the focus group setting was supportive and energising, positioning it in stark contrast to their more ambivalent or negative experiences within Facebook communities.

[92] Participants also recognised why these spaces may at times function as negative echo chambers, where knowledge production and community engagement is entangled with presence, absence and selective participation. As Molly critically reflected, “the people who post regularly will be those who aren't getting better. And those who get better will have left and not commented. So, I have to kind of use that balance of, don't get too drawn into the doom and gloom of some of those posts.”

static, but contingent on how participants situated themselves in relation to both those narratives and their illness at particular moments.

Charlotte captured this shift:

> To start with, it was a great help, but then the more you go into it [...] it is almost like a depressive cycle where you're reading other peoples' sob stories constantly, and nobody really wants to celebrate the getting better.

In this sense, the movement from engagement to distancing was rarely linear. The benefits participants initially derived from these forums — validation, recognition and a sense of shared experience — may also have heightened their sensitivity to the presence of hardship and despair. What once felt connective could later feel overwhelming, not necessarily because the spaces had changed, but because participants' capacities, priorities and orientations towards their illness, and futures, had shifted. Distancing, therefore, can be read less as a rejection of online communities and more as a reflexive understanding of their emotional and energetic boundaries.

The overwhelmingly negative atmosphere of these forums had broader affective consequences on participants' wellbeing[93]. Sheila remarked that "a lot of them suck the life out you," while Lu reflected how "it doesn't uplift me and make me full feel full of joy." As such, individuals navigated these communities with caution, mindful of their potential emotional and energetic toll. As outlined earlier, Anna even avoided online communities altogether, explicitly noting "how much energy they take" and admitting that she preferred to prioritise her limited energy for her in-person connections and other meaningful activities – resonating with themes around embodied energy management discussed in Chapter 5.

Participants also encountered these spaces as sites of social comparison. Paralleling earlier accounts of the distress caused by uncertain knowledge, Helena described how reading others' distressing experiences amplified her own fears about the uncertain trajectory and severity of Long Covid. In contrast, Fiona found it difficult to read stories

[93] I am cautious of disparaging clinical accounts that dismiss Long Covid by framing it in relation to mental health problems, and of the tendency within such accounts to read these forums as symptomatic of poor mental health. Importantly, these affective responses should not be read as symptomatic of poor mental health, but as emerging from engagement with negative online posts that depleted participants' emotional energy and reverberated corporeally, with consequences for wellbeing.

of recovery or progress that she had not yet reached, specifically mentioning her need to disengage from certain posts about others receiving organ transplants:

> I have to look away from that, because I think, 'well, that's not me at the moment. And I don't need to be involved in this conversation,' because I know the impact it might have on me, and I'm not going to expose myself to that threat on my energy levels.

For Fiona, exposure to such content carried negative affective consequences, threatening her already limited energy reserves, and prompted protective spatial boundaries around her engagement with online space to preserve embodied resources for dealing with her offline reality. Chloe similarly resonated with the challenges of encountering others' recovery: "that can be hard; do you know when people are like, 'Oh, I'm really tired because I was in work today,' and I just want to be like, 'at least you're in work' [...] [laughs]." Despite some participants valuing their place within online communities – for example, Fiona described feeling a "massive sense of belonging" – participants' accounts reveal that even hopeful narratives can be emotionally and affectively taxing for participants, serving as reminders of their own uncertain trajectories.

Yet not all experiences of social comparison were demoralising. Many participants, including Monica, relayed how hearing about others' suffering offered perspective and gratitude: "partly, you kind of felt, 'oh my god, I'm not as bad as they are,'" while stories of recovery instilled hope: "I think until people started saying they were getting better, that was quite encouraging." These findings echo existing research on chronic or terminal illness, wherein it is registered that social comparisons can engender both upward hope and downward fear (Carmack Taylor et al., 2007; Locock and Brown, 2010). These accounts underscore the nuanced affective labour involved in navigating both positive *and* negative content online, revealing the complex emotional and affective entanglements between virtual and physical spaces, as well as the embodied consequences that this relationality can affect. In this way, online biosocial communities shaped participants' emotional wellbeing and illness experience, becoming spaces where energy, hope and distress were constantly negotiated. As Theresa admitted, "it sounds awful, but I don't want to read about someone's bad day, because I'm actually having a good day."

7.3.1 The limits of online connection

Stories shared thus far have focused on text-based online communities – primarily Facebook forums. It is important to recognise how different digital formats can shape the emotional and relational dynamics of these spaces. Text-based platforms, as discussed, often intensified feelings for participants of comparison, competition and moral scrutiny. These findings contrast sharply with participants' experiences in the project's video-based focus groups, which, as outlined in Chapter 3, were consistently described as more collaborative, energising and emotionally sustaining. As Helena (FG1) lamented:

> I think this has helped me, hearing how people have adapted their lives and what they've done [...] and seeing that things are possible beyond the illness. This kind of thing, to me, is *much* more helpful than a Facebook Long Covid group.

During the focus groups, I observed the empathetic and reciprocal sharing of experiences, wherein participants felt seen and heard. Unlike the asynchronous and emotionally charged dynamics of online forums, these real-time reciprocal video conversations[94] appeared to foster connection rather than comparison, solidarity rather than surveillance. Returning to narratives introduced in Chapter 3, participants described the positive impacts on their energy and emotional wellbeing. Alexandra (FG4) reflected, "I feel quite positive. I feel the energy from the group," to which Arun (FG4) responded that "we're feeling part of life again. We're seeing faces, we're seeing people. We're hearing, we're talking, we're doing things that we should not be doing, right?" In this context, "should not" reflects activities typically constrained by participants' usual energy limits and the restrictions imposed by the socio-spatial structures of PPP. Others echoed this sentiment, including Marg (FG3), who described the group as "warming," while Louise (FG3) added: "It does lift your spirits [...] We've had a wee giggle at some of the things that we've said, so I always think that's really important." In this sense, the focus groups reveal how video-based online spaces could carry positively affective charges, grounded in real-time reciprocity and embodied presence, that text-based platforms often struggle to sustain beyond initial

[94] It is important to reiterate that real-time video interactions can also be significantly energy-draining for individuals living with Long Covid due to the high levels of stimulation and sustained engagement that they require (see Chapter 3) and may exacerbate physical and cognitive symptoms including fatigue, brain fog and migraines. I will also revisit this issue in the thesis conclusion.

encounters. While forums frequently exacerbated emotional strain, these small, real-time interactions provided a sense of belonging, care and positive affective energies.

Crucially, however, it was not just the *video* format that mattered, but also the design and structure of the groups, as I methodologically reflected in Chapter 3. Participants contrasted the focus groups with other video-based health interventions that were less effective due to size, length or emotional tone. For example, Monica (FG3) noted:

> I did the NHS eight-week Long Covid clinic online, and I thought that that might be helpful in terms of sharing your experience [...] The first session was just loads of people, and my brain just couldn't cope with it [laughs].

While Marg also reflected:

> I joined one Zoom meeting [...] just to see what it was like. But I found that a bit depressing, really, because, well, there was a few people who were just in bed with oxygen on, and they just didn't want to say anything [...] It was surprisingly long. I thought it was going to be an hour long, but it was three hours long [...] And I remember thinking, 'that's a long time for people with Long Covid to be sitting at a screen three hours.'

These reflections highlight that it is not only the format, but also the scale, duration, and emotional tone of digital spaces that shape the relational and affective geographies of online interaction. Large group sizes and extended sessions placed considerable cognitive and emotional demands on participants, particularly in contexts where attention was directed towards others' visible suffering. As Monica's account suggests, navigating many voices at once could quickly become overwhelming, while Marg's reflections point to how prolonged sessions sat uneasily with the embodied constraints of Long Covid. In this sense, the emotional tone of these digital interactions was often experienced as heavy or difficult to sustain, contributing to participants' decisions to limit or withdraw from engagement.

The focus groups demonstrate how intentionally curated video-based spaces can foster forms of support and connection often missing from both large-scale video sessions and text-based forums. Juxtaposing these online environments reveals how digital formats mediate the affective geographies of biosocial communities, as well as inflecting the online–offline relationalities central to contemporary digital health geographies. This points to the need to attend not only to the content of digital care,

but also to the medium and design through which community and connection are created.

While forms of online social connectivity discussed thus far offered participants meaningful and immediate forms of experiential knowledge, empathy and validation, they can, nonetheless, become relatively superficial in that they often lack sustained intimacy, depth or offline continuity (Parr, 2008). Some participants, however, spoke of more intimate relations that developed online and later extended into their offline worlds, demonstrating the potential of virtual connections to evolve into tangible, real-world forms of support and companionship. Recalling Arun's divorce from Chapter 4, he further shared how a connection developed with a woman during a video-based breathing exercise session connected to the Long Covid Facebook group:

> There's a happy ending here [...] There's this person on the video chat, she's in Argentina [...] There's only about four of us on the group, but we were just left, me and her, just talking [...] [And afterwards] I messaged her [...] She was having marriage issues at the time [...] Her partner [also] didn't really understand the illness and stuff, so there was some commonality. I just tried to help her and support through what I knew or learned with Long Covid [...] She split up from her partner and we stayed friends, and then eventually we kind of kind of made a romantic connection [...] So I've been in this relationship with her since about May 22, something like that. And I have been to Argentina, twice. Crazy, right?

For some participants, digital spaces hence served as a platform for forging, sustained proximate connections that translated into 'real space'. For others, the latter, 'real space', still holds the most significant keys to dealing with their Long Covid challenges. While Fiona felt a sense of connection and belonging to her online community, she reflected on the limits of text-based connection. Despite virtual support, she described feeling "emotionally dislocated," and expressed a strong desire for physical presence and embodied connection:

> I really crave the physical company of people [...] We all need to be in a community, and we can't always get that connection just through the screen [...] I don't know how it happened [laughs], but we've just gone through our third in-person meeting in Birmingham. There's only a little handful of us. There's different faces each time.

Hannah similarly echoed this shift from digital to embodied forms of connection: "When I was living down South, it was all online, which was helpful in some respect, but I've

always preferred to be in the room with people." These perspectives emphasise the value of embodied in-person connection beyond the screen. Participants' feelings of emotional and embodied dislocation, despite active online participation, underscores that affective and energetic entanglements of community often remain spatially and socially situated off-line. Louise (FG3) similarly described a local support group in her village called 'The Hope Café', designed to foster positive in-person support: "they can bring their families and things, so that they can all see that they're not alone." Although Monica (FG3) lived in a bigger city, she reflected on the challenges of forming in-person communities: "I think it's quite funny that you read about how many millions of people have it, and I hardly ever meet anyone that has it [...] I would say maybe five people."[95] She was therefore intrigued by the in-person community that Louise mentioned, emphasising too the power of the focus group for sharing the possibility of such resources. Echoing Fiona's feelings of emotional and embodied dislocation, Monica emphasised the importance of in-person engagement in comparison to her previous experience with the NHS online organised group: "I think just going somewhere where people have got it [laughs] would be the most useful thing for me. I wouldn't even care what it was they did when you got there." While online biosocial communities offer valuable platforms that transcend traditional geographical boundaries, they cannot fully replicate the proximate, embodied and affective forms of mutual interaction fostered in physical space. These testimonies hence offer valuable insight into the relationship between health and place, challenging human geographers to rethink the boundaries of place and community, emphasising that digital embodiment reshapes, but does not replace, the face-to-face affective and embodied connections.

In Chapter 5, I highlighted how socialising can place significant energy demands on individuals, particularly when they are forced to navigate social pressures, manage stigma, mask symptoms or justify their illness. In contrast, Long Covid communities –

[95] Participant testimonies, however, depicted mixed and, at times, contradictory urban–rural differences, highlighting an uneven geography of access to in-person Long Covid communities. For example, Kristina (FG1) reflected, "I'm in rural Northumberland. It's kind of a bit difficult to do the social thing with anyone else [laughs]." In her account, smaller populations, persistent stigma and the additional energy required to travel and engage socially shaped the feasibility of sustaining such communities. When Mark (FG1) joked that in Bristol "every other house seems to have Long Covid in it [laughs]," Kristina added that "that must help as well, in terms of the people who believe in it." Taken together, these reflections point not to a straightforward urban–rural divide, but to uneven and context-specific distributions of embodied community and affective connection for people living with Long Covid. I return to these uneven geographies in the concluding chapter.

both online and in-person – were often described as less energy demanding as they are grounded in empathy and shared understanding. Participants did not have to 'perform' wellness or explain their illness, they could just simply 'be'. As Fiona discussed:

> We don't all sit down talking about how ill we are. We sit around talking about whether this is a really good cup of coffee and who's having a raspberry doughnut and who's having a blueberry muffin. That's what we do, like normal people would, surprisingly. It's just a place where, if you do forget your train of thought, if you have to leave because you're saturated[96] [...] it's fine.

In contrast to the organised, large online group settings, Fiona's description of her in-person group interactions were characterised by a different emotional and energetic tone. Conversations were often oriented towards everyday topics that explore identities beyond their illness, creating spaces that felt more ordinary and less emotionally demanding. Such interactions allowed her to participate without sustained focus on illness and to disengage or leave when "saturated," without explanation or judgement.

Megan described feelings of inclusivity with her new network of friends, those she jokingly calls her "sick friends," as they are more understanding and responsive to her everyday fluctuating energy levels than is the case with her usual friendship connections. The support from her "sick friends" was flexible, offering a mix of in-person and online interactions: "we'll do yoga, we have a coffee, we go home. If it's too social, then it gets too much, so we'll drop voice notes to each other, WhatsApps every now and again." Similarly, Kate (FG4) emphasised the positive power of shared understanding and empathy in these communities: "Everybody here absolutely gets it, don't they? And I think that's really powerful." These reflections resonate with emerging scholarship on new energy geographies, which examines how human bodies and social relations are responsive to flows of physical, emotional and social energy (Philo et al., 2015). In this way, Long Covid communities – both online and in person – can be understood as inclusive and empowering everyday energy environments, where energy is conserved, restored and even shared through supportive, non-judgmental and embodied interactions.

[96] As above, Fiona refers to saturation of energy.

These spaces not only foster wellbeing, but challenge dominant models of care, as Fiona explained:

> I can sit in CBT [Cognitive Behavioural Therapy] for the rest of my life, but if I don't have a community of people that get me, and I get them... And that's why these in person meetings once a month are *so* important.

Similarly, Hannah also noted the therapeutic quality of her monthly in-person Long Covid support group who meet for different social activities such as lunch or Tai Chi yoga:

> Members just started what they coined as a 'sharing circle,' so almost like a therapy session where people can share their experiences to help voice what they are going through, but in a sort of relaxed and [with] no sort of unsolicited advice being given.

Participants' narratives emphasise the therapeutic quality of these energy-positive in-person communities, suggesting a possible framing of offline Long Covid community spaces as therapeutic energy landscapes. Crucially, these spaces were not only valued for social connection, but for their material and organisational features that enabled participation. Fiona, for example, highlighted the importance of good quality air, wheelchair accessibility, appropriate facilities and the availability of food that accommodated a range of sensitivities, noting how such features made the space accessible even for those with significant physical impairments. Attention to these embodied and infrastructural details opened up new embodied possibilities within social space.

This perspective potentially enriches thinking in health geography by demonstrating how the spatial organisation of affective social energy is central to the lived experiences of illness, care and community – particularly in the context of chronic, stigmatised illnesses such as Long Covid. It suggests the value of moving beyond traditional clinical interventions such as CBT to manage the wellbeing repercussions of living with chronic illness, in addressing the wellbeing repercussions of chronic illness, and instead foregrounds the role of accessible, public community spaces in enabling care, recognition, and mutual support.

It compels us to reconsider what kind of public, accessible community spaces are needed to support those living with chronic and contested conditions, and also challenges the assumption that online connectivity is sufficient in a post-pandemic

digital era. Digital spaces can facilitate vital forms of connection, but they cannot fully supplant the embodied, empathetic and energy-affirming encounters that shared physical spaces still tends to offer.

7.4 Conclusion

Throughout this chapter, I have examined the use of digital technologies as information sources, everyday diagnostic tools and generative spaces of experiential knowledge and social connectivity. Taken together, participants' engagements with this diversely constituted digital arena reveals the complex, ambivalent and often contradictory nature of online spaces in the context of Long Covid. I began by exploring how individuals navigated the digital landscape in an effort to understand and manage their novel chronic illness — engaging with formal medical information, wearable technologies and biosocial communities that functioned as sites of both epistemic solidarity and affective labour. These platforms offered critical avenues for collective meaning-making, support and the circulation of both biomedical and lay knowledge, particularly during a period marked by profound clinical uncertainty and systemic gaps in care. Yet the very need to seek out these sources reflects a deeper structural reality: the responsibility for making sense of illness was placed on individuals. In the absence of clear clinical pathways or sustained medical recognition, participants were compelled to navigate fragmented, complex and often incoherent information arenas, curating their own treatment and management strategies and even producing their own biomedical data using everyday wearable technologies – all while managing severe fatigue, cognitive impairment and emotional distress. As such, while digital spaces do indeed emerge as sites of empowerment, they more significantly operate as extensions of the broader responsibilisation of health under biomedical uncertainty. Participants were not simply exercising agency, but forced to become "biological citizens" (Rose, 2007, p.165), who must advocate for their own scripting and care in the absence of sustained institutional support.

The spatial redistribution of care into domestic and digital environments entails what Ajana (2017) describes as "digital biopolitics," in which individuals can obtain biomedical legitimacy by producing data through everyday wearable technologies. Crucially, this form of diagnostic advocacy is not evenly distributed: it is shaped by access to digital tools, cognitive energy capacities, technological literacy and, importantly in the context of a biomedically contested illness, medical cooperation.

These capacities are deeply entangled with intersecting axes of inequality – including socioeconomic status, race, gender, age, disability and education – which mediate who is enabled or excluded from participating in these digitally mediated forms of care. As such, while digital technologies may offer alternatives to clinical incoherence or neglect, they can also reproduce structural inequalities, limiting who is able meaningfully to contribute to the production of legitimate knowledge about their condition.

Online biosocial communities, more specifically, allowed participants to access and contribute to evolving knowledge in ways that were more accessible and manageable than formal medical sources, yet these communities also surfaced epistemic tensions and affective burdens. While they served as important sites of solidarity and experimentation, they also became spaces of emotional saturation and, at times, exclusion — shaped by the epistemic governance and authority of dominant illness narratives. In this way, the very processes of collectivising knowledge, while generative, could inadvertently produce normative scripts that flatten bodily difference and marginalise those whose experiences do not align. These dynamics foreground the relational geographies and spatial politics of digital knowledge production, where participation is not evenly distributed but is deeply shaped by who is able to produce, share and be heard. Knowledge in these spaces is not simply exchanged, but actively negotiated through embodied difference, energy limits and affective capacity. Participation was attuned to the fluctuating materialities of illness, as individuals regulated their engagement not only in terms of content but also alert to emotional and cognitive impact. As such, digital communities can be both enabling and exclusionary, expanding the spatial and epistemic reach of Long Covid knowledge beyond traditional biomedical and geographical boundaries, while remaining anchored in the situated, embodied realities of participants' lived experience.

These findings also foreground the complex relationship between individual and collective narratives. Aligning with Rushforth et al. (2021) in their study of Long Covid narratives, participants described how online communities transformed their isolated narratives into collective resources through knowledge sharing and mutual support, illuminating the enduring importance of collectivism in the context of Long Covid following its original emergence online. My study extends the affective online-offline nuances of these findings, however, demonstrating that these groups functioned as

embodied epistemic spaces where formal resources were made accessible and individual experiences were collectivised into shared understandings, enabling meaning-making in the absence of biomedical certainty. This collective dynamic helped to alleviate individual cognitive and energy burdens, making information more accessible and manageable for those living with Long Covid. All this being said, my study also found that collectivism was complicated by the heterogeneity of illness. Variable experiences sometimes produced both epistemic tensions and contested forms of epistemic governance and authority. These realities complicate claims that individualism dominates contemporary self-help and online health communities (Williams, 1989). Rather than being inherently individualising, digital engagements in my study were grounded in situated collectivism – led by knowledge sharing but shaped by individual variability. The relationship between the individual and collective was not oppositional, but deeply relational — characterised by ongoing, situated negotiation shaped by bodily difference and emerging resources. This chapter thus demonstrates that support – both online and offline – for this Long Covid is not linear, stable or predictable. It is relational, evolving and as unique as the embodied realities through which it is lived. Therefore, while online Long Covid spaces offer crucial alternatives to formal clinical epistemologies, they are not universally empowering. Rather, they are deeply contingent — shaped by epistemic governance, the material and affective conditions of illness and the ongoing negotiation of what it means to live with and make sense of a condition still in the process of being understood.

This chapter also contributes important nuance to current debates in digital health studies in human geography and beyond, demonstrating that, while online communities are vital to the everyday management of illness, they cannot be assumed to offer universally positive or sufficient forms of support. While text-based forums such as Facebook initially offered participants much-needed validation, empathy and connection absent in their offline lives, they frequently became ‘toxic’ spaces marked by competition, moral scrutiny and affective labour. Participants’ paradoxical experiences of validation and solidarity alongside moral scrutiny and emotional strain complicate understandings of online peer support as predominantly positive and empowering. Instead, online Long Covid forums often produced negative embodied and affective consequences, requiring participants in my study to carefully negotiate their engagement in relation to their fluctuating wellbeing, energy and embodied

capacities. In contrast, participants described more positive experiences within smaller, reciprocal WhatsApp chat groups or real-time video-based platforms – such as the ones that I was able to curate in the focus group settings – which offer a greater sense of community, emotional resonance and support. By conceptualising online Long Covid communities through affective and energetic entanglements, I add nuance to existing discussions in human geography around the relational geographies of online-offline spaces — where digital connection is experienced through, and in constant negotiation with, the material realities of illness, including energy capacities and emotional wellbeing, as set within broader structures of institutional marginalisation and social exclusion. The emotional and energetic labour involved in navigating these spaces hence reveals the spatial politics of participation in biosocial communities, highlighting that connection, care and community are deeply situated, relational, contingent and cannot always, everywhere be guaranteed.

Even when participants experienced a sense of belonging online, however, they frequently reported a sense of emotional, embodied and energetic disconnection, underscoring that digital interaction, while meaningful, cannot fully substitute the affective depth of embodied, in-person connection. This finding does not reflect the shortcomings of technology *per se*, but instead reveals the significance of place, proximity and physical presence in everyday practices of care, community and wellbeing. For some, however, particularly those living with ongoing concerns about contagion[97], offline spaces may feel inaccessible or unsafe. In these cases, online communities – particularly those grounded in reciprocity and small-scale interaction – can transcend geographical barriers and provide vital forms of solidarity, knowledge-sharing and care. Yet, they still remain partial. Taken together, these insights point towards the need to more carefully attend to the spatial organisation of embodied energy, relational affect and care. This raises questions about what kinds of spaces — digital, physical or hybrid — are able to meaningfully support people living with Long Covid, and under what conditions such spaces become accessible, sustaining and affirming. The findings of this chapter suggest that a complementary mix of digital and in-person spaces, each addressing the limitations of the other, may offer a more

[97] Not explicitly addressed in this chapter as it did not emerge as a common theme across participants' narratives, although it was mentioned by some.

supportive configuration of care – a proposition to which I return in the concluding chapter of the thesis.

Chapter 8: Conclusion

8.1 Introduction

Across this thesis, I have traced how Long Covid reshapes the spatial, temporal and embodied conditions of everyday life. Rather than treating Long Covid solely as a biomedical aftermath of an acute infection, I adopted a qualitative and geographical lens to understand it a lived, relational and unevenly distributed experience shaped by fluctuating energy capacities, institutional uncertainty and broader socio-spatial inequalities. I analysed how Long Covid disrupts and reorganises everyday routines, relations and rhythms: where people can go, how they can participate, how time is anticipated and endured, and how bodies are rendered visible or invisible across clinical, domestic, workplace, social and digital environments. In doing so, energy emerged as a central analytic through which the everyday politics of care, legitimacy and survival are negotiated.

Chapter 4 examined the bio-geo-graphical disruptions that emerged at illness onset, exploring how participants' temporal rhythms, spatial routines and bodily capacities were unsettled, often experienced as an extension of pandemic lockdown conditions. Chapter 5 then followed how participants navigated these disruptions by negotiating their subjectivities through energy, showing how 'planning, pacing and prioritising' were adopted as affective and rehabilitative strategies for managing the energy-limited body. Chapter 6 shifted to the spatial politics of (in)visibility, analysing how the recognition of Long Covid is unevenly distributed across biomedical, work, social, home and community environments, and how invisibility functions as a relational and spatial force rather than a simple absence of visible symptoms. Chapter 7 explored the nuances and affective consequences of navigating digital ecologies – a key terrain of Long Covid experience – as alternative sites of knowledge, connection and legitimacy, with particular attention to participants' fluctuating energy capacities. Together, Chapters 6 and 7 demonstrated how online spaces enabled participants to resist invisibility and engage in new forms of energy-attuned activism. Collectively, the empirics elucidate how Long Covid is lived through complex entanglements of energy, embodiment, space and power, providing the empirical grounding for the theoretical contributions interwoven within them.

I now turn to broader theoretical contributions centred on energy as a 'biopolitical currency', before outlining key methodological insights arising from the research. I then acknowledge this study's methodological and analytical limitations and consider future directions for geographical scholarship and public health practice. I conclude this chapter, and the thesis as a whole, with final reflections on the ethical and political responsibility of geographers to take seriously the everyday realities of those enduring chronic, energy-limiting conditions, positioning energy as a key ethical, empirical and conceptual concern.

8.2 Theoretical contributions

8.2.1 New energy geographies

Across this thesis, energy has emerged as the conceptual thread weaving together the spatial, temporal and embodied disruptions of Long Covid discussed. "Energy" first surfaced repeatedly across participant testimonies – explicitly, metaphorically and anecdotally – to describe the impact of Long Covid on their bodies and their changing relations to everyday lifeworlds. It was not only described as a biomedical impairment, but also resonates with how Philo's et al (2015) conceptualised energy as an affective force moving through, between and across everyday online/offline environments, people and objects, shaping how my participants inhabited their lifeworlds. Participants also described energy as a scarce resource that had to be carefully managed. They explicitly spoke of energy "cost," "expenditure," "budgets," and "banking energy," associated not only with 'doing' everyday activities but also with the labour of *fighting* for certain conditions within their lives: maintaining jobs and relationships, pursuing diagnosis and securing legitimacy in familial and social circles. This resonates with Dumit's (2006, p.577) notion of the "expensive struggles" of contested chronic illnesses. In my study, however, 'expense' is experienced primarily as embodied and affective rather than financial.

Across the empirics, I have also highlighted how physical, social and emotional suffering are deeply interconnected, revealing how suffering extends beyond the corporeal, from the symptomatic to the affective. These dynamics thus expose the affective contours of energy itself: how it is felt, anticipated and negotiated across different everyday socio-spatial relations and temporalities. Through these negotiations of everyday energy geographies, I contend that living with Long Covid

demands a form of biopolitical labour, in which energy can be conceptualised as a *biopolitical currency*.

In reframing energy as an embodied, affective, relational and political force, this thesis contributes to "new energy geographies" (Philo et al., 2015) which extend beyond infrastructural or material understandings of energy to the intimate scales of bodily capacity and affective relations. It also builds on scholarship on ELCs by demonstrating that energy impairment is not merely physiological but spatially and temporally lived, organising where people can go, how long they can remain in particular spaces, how they interact with others both online and offline, and which socio-spatial worlds remain accessible or restricted. By conceptualising energy as a biopolitical currency — budgeted, saved, expended, justified and morally defended — this thesis advances a geographical account of energy that foregrounds the intimate corporeal, affective and relational dimensions of living with an ELC, while situating these experiences within the wider structural terrains of (bio)power, inequality and chronicity.

Bodies under lockdown

It is through this energetic economy that Long Covid produces what I conceptualised in Chapter 4 as *bodies under lockdown*: bodies whose movements, temporalities and socio-spatial worlds are constrained not by the state, but by the fluctuating and deeply limiting capacities of an ELC. By tracing the contours of disruption experienced at the onset of Long Covid through a bio-geo-graphical lens, I conceptualised how participants' sense of being 'stuck' in time, space and body was commonly experienced as a continuation of pandemic conditions. Many found themselves confined to their homes and restricted to familiar, local and safe temporalities and socio-spatialities, echoing the conditions of lockdown. Yet these constraints are indeed not imposed by public health governance, but by their energy-limited bodies, as 'bodies under lockdown'. This framework challenges culturally dominant narratives of productivity and linear recovery, revealing the uneven, hidden and ongoing realities of Long Covid 'bodies under lockdown'. While broader public narratives insist that "the pandemic is over," the energy impairment that structures daily life for people with Long Covid ensures that many remain 'locked down' in different temporal, spatial and corporeal ways.

At the same time, participants described feeling “left behind” by a society eager to move on from the trauma of the pandemic and “left to it” by institutions to self-manage their own condition. Drawing on how Evans et al. (2024) account for feeling “left behind” by neoliberal academia, I extend their framework of crip time – where time is understood as socially, materially and affectively lived – to capture the temporal, spatial and corporeal forms of ‘left-behindness’ that shape Long Covid subjectivity. Such left-behindness includes not only living “out of sync” (Evans et al., 2024, p.1) with post-pandemic societal rhythms, but also navigating a spatially contingent invisibility that shapes whose experiences are recognised or dismissed, leaving many compelled to take responsibility for their own care and to fill the epistemic gaps of fragmented healthcare systems, mobilising their own embodied knowledge and online networks in order to make sense of an illness marked by uncertainty.

In this context, the assumption of individual responsibility cannot be understood simply as the agency exercised by a ‘good’ biological citizen, but as a process of responsibilisation compelled by institutional neglect. As healthcare systems failed to offer coherent pathways of diagnosis, care or recovery, participants were increasingly required to govern their own bodies, energies and futures to endure everyday life. Responsibilisation thus emerged as a biopolitical necessity for survival under conditions of institutional uncertainty, abandonment and invisibilisation.

In this context, the third dimension of bio-geo-graphical disruption – the mobilisation of resources – is not only about navigating or accessing existing forms of support, but about generating entirely new cognitive, social and material resources in the absence of consistent and coherent institutional guidance. Participants were not simply dependent upon pre-established pathways of care; they were actively co-producing knowledge with online communities, experimenting with alternative treatments and sometimes using digital technologies to bring elements of the clinic into the home to make sense of an illness that remained poorly understood. Unlike many other chronic illnesses with established prognoses or treatment trajectories, Long Covid offers no clear roadmap. Those living with its ongoing effects are, in many ways, producing the ‘model’ for what long-term chronicity may look like in five, ten or even thirty years. Mobilising resources thus becomes a form of biopolitical labour — shaped by both disruptions to the now energy-limited body and by institutional gaps, uncertainties and

exclusions that compel individuals to govern and care for themselves in place of absent or inadequate health systems.

Energy as a biopolitical currency

Building on this mobilisation of resources as a form of biopolitical labour, participants commonly turned to the rehabilitation strategy of planning, pacing and prioritising to manage their energy-limited bodies and navigate the spatial, temporal and embodied forms of confinement they experienced. PPP offered a means of reclaiming agency over the energy-limited body and expanding their lifeworlds: affectively forecasting symptoms through embodied knowledge and cultivating predictably unpredictable time-space-body routines to re-engage with lifeworlds. Yet participants emphasised that the unpredictability of Long Covid, coupled with the unpredictability of everyday life itself, often destabilised the forms of temporal and spatial control that PPP attempted to secure. Consequently, these strategies often intensified participants' sense of being stuck in the 'here-and-now' of the body. Participants nonetheless persisted with PPP because, even when their agency remained an 'illusion', the careful organisation of daily time-space rhythms temporarily reduced the affective intensities of chronic symptoms, fear and despair, offering more fleeting affective dispositions of hope and vitality. Such relief indeed allowed participants to be relieved, albeit momentarily, from their bodies under lockdown.

Participant narratives also revealed, however, that strict compliance with what is deemed to be required from PPP often intensified corporeal and socio-spatial confinement, reinforcing a state of mere biological survival that mirrored the conditions of 'bodies under lockdown.' They therefore admitted sometimes departing from the rigid structures of PPP routines, which prioritise caring for their chronically ill body, to re-engage with 'normal' socio-spatialities and temporalities. Reflecting what Del Casino Jr (2009, p.200) terms "bio-deviance," participants resisted the demand to conserve, manage and regulate energy at all times rather than complying with rehabilitative advice as 'good' biological citizens (Rose, 2007), allowing them, albeit momentarily, to *live* rather than merely *exist.*

To conceptualise this tension between living and existing, I want to return to Fassin's *Ethics of Survival*. Drawing on Derrida's final interview, Fassin (2010, p.82) reframes survival as "not simply what remains" but as "the most intense life possible." For

Fassin, this perspective breaks away from dominant biopolitical frameworks, such as those afforded by Agamben's (1998) "bare life," where "life" is often reduced to mere biological existence, defined in binary opposition to death. Fassin (2010, p.89) instead opens up an ethical space to consider the nuances of survival between life and death: "to be still fully alive and to live beyond death. It is [...] the pleasure of living." This reframing opens-up the nuances of vitality; the subjective ways in which individuals inhabit life in conditions of chronic illness that resist collective abstraction into binary oppositions of life and death. Therefore, when participants momentarily break from the three Ps principle – despite the embodied energy cost – they reclaim their bodies, time and space to *live,* however briefly, their "most intense life possible" (Fassin, 2010, p.82). Here, I wish to highlight some tensions between Bissell's and Fassin's work centred around "intensity." Fassin's work is representational, centred around structural biopolitics, ethics and judgement, whereas Bissell's (2009; 2010) "intensity" explores the everyday non-representational and pre-personal embodied sensations that do not fit easily into discursive or representational frameworks. Yet, I would argue that these affective intensities are not separate from the ethical conditions that Fassin describes. The ethical and political dynamics shaping survival can be felt through affective charges such as fear, despair and hope. Together, then, Bissell and Fassin offer complementary lenses for understanding how participants oscillate between mere biological survival and fleeting experiences of embodied vitality, revealing the deeply affective labour of living under constraint.

Through this lens, PPP itself can be understood as a biopolitical technology that mediates this energy economy – one that structures life through the expectation of responsible self-regulation, energy discipline and anticipatory control. Here, responsibilisation operates through everyday practices of planning, pacing and prioritising, positioning individuals as accountable for managing risk, relapse and recovery within conditions forced upon them. Yet, participants also resisted PPP when it restricted their ability to live fully, choosing connection, meaning and joy despite the energetic cost as a micro-political refusal to conserve, govern and regulate energy responsibly at all times. These acts temporarily broke the stasis of bodily lockdown, producing moments of vitality within the enduring constraints of an ELC.

8.2.2 Re-imagining the spaces of activism

Even participation in this research had an energy cost. As Kamy explained, “we need to sacrifice our energy in order that someone can hear us.” The willingness of participants to engage in this research, and for many, on two occasions through individual interviews and follow-up focus groups, emphasises the value that they placed on being heard and contributing to wider understandings of Long Covid. Expending such energy, despite the risk of symptom exacerbation, constitutes a powerful political act in itself, and affirms the importance of centring Long Covid lived experiences. By sharing their stories, participants redistributed labour to the researcher, as Helena noted: “I wanted to tell you so you can share that with other people.” In doing so, participants reimagined activism, not as sustained visibility and public presence, but as a relational and collective practice of energy-distributed advocacy. Building on this point, I contend that participants’ engagement in this study constitutes a subtle but significant form of spatial resistance, challenging normative assumptions about who can be politically active and where activism can take place. As Alexandra (FG4) reflected, “we are all in our own little places,” often confined to their homes by their ELCs, feeling invisible or ‘hidden’ from the public gaze. Yet, despite corporeal and spatial constraints, online spaces became alternative terrains of political action, ones in which an individual’s presence is not always physical, but rather, mediated, distributed and shared. From the genesis of Long Covid, digital spaces have enabled individuals with lived experience to assert the legitimacy of their illness, resist invisibility, form solidarities with others and participate in research. As such, participants navigated the political landscape of visibility on their own terms and within their own time-spaces, underscoring the profound entanglement between energy, embodiment and political possibility.

8.2.3 Complicit (in)visibility

I developed the notion of a *spatial politics of invisibility* to capture how Long Covid is often rendered both unseen and unheard across clinical, occupational and social environments. Although participants actively attempted to make their condition visible through both social and diagnostic activism, dominant biomedical and socio-cultural discourse have continued to dismiss and stigmatise their experience. However, my findings complicate and further layer this dynamic. In seeking recognition while simultaneously attempting to mitigate stigma, discrimination or feeling like a social

burden, participants, who were able, often engaged in various ‘masking’ strategies – practices of self-invisibilisation – including deferred disclosure to symptoms such as chronic fatigue, breathing difficulties or migraines, reconfiguring their use of space and time, or performing able-bodiedness under the gaze of others in everyday environments. While intended as self-protective, these strategies paradoxically undermine collective advocacy efforts to legitimise Long Covid as a distinct chronic illness category and secure its wider intelligibility. In doing so, I argued that participants reinforce the very invisibility that they otherwise aim to resist. Importantly, however, drawing on insights from the social model of disability (Oliver, 1983), such masking practices should not be understood simply as individual choices but as responses to the broader ableist social and attitudinal barriers. Within contexts where illness legitimacy is questioned and stigma persists, concealing symptoms may be considered a necessary strategy for navigating ‘normative’ and ‘productive’ able-bodied expectations that demand continual energy, and otherwise risk exclusion and marginalisation for those unable to meet them – a reality indeed experienced by some participants in this study. In this sense, the dominance of ableism within society may render masking a more viable response than sustained forms of collective advocacy, particularly given the considerable energy required to participate in such efforts while living with an energy-limiting condition. Masking therefore reflects the structural pressures of ableism that shape how illness can be disclosed and is recognised and may function as a form of self-protection that enables continued participation in everyday socio-economic environments.

These strategies are not only social negotiations, but energetic ones, as concealing symptoms emerges as a form of embodied labour, linking to the broader theme of energy as a biopolitical currency. Masking practices redistribute the burden of illness management into hidden spaces and private relations — most notably the home — where the energy ‘costs’ of maintaining visibility and legitimacy manifest out of public view. This finding, though, is also more nuanced. Masking strategies are further complicated by the broader theme of acceptance that runs throughout this thesis as many participants resisted detaching from their previously ‘active,’ ‘sociable’ or ‘productive’ selves. Masking was therefore not only a response to the fear of stigma and discrimination, but also a means of momentarily re-embodying these former identities. Such performances allowed participants fleetingly to re-engage with

versions of their former selves that they valued and sought to preserve, even though these practices simultaneously contributed to the ongoing invisibilisation of their condition.

This dynamic was further shaped by the material realities of employment. For many participants, masking in the workplace was not simply about identity or stigma, but a necessary strategy for economic survival. Appearing 'well' enabled some participants to avoid workplace discrimination and scrutiny, and hence retain employment and income. Within labour markets that privilege productivity and reliability, masking symptoms became a deeply biopolitical negotiation, placing the preservation of health, care and recognition in tension with securing the material means to live. In this sense, the workplace became another space in which participants were compelled to perform able-bodiedness — not always necessarily through desire to embody their former selves, but because their livelihoods depended upon it.

When read through Fassin (2010, p.82), masking emerges as another way participants sought to "live the most intense life possible" within the constraints of energy-limited bodies. Much like departing from PPP, masking enabled a brief connection with their productive selves, despite the energetic cost that spills into other everyday relational spaces. Here, the affective intensities described by Bissell — hope, despair, fear, joy — intersect with the ethical conditions outlined by Fassin, revealing masking as not only an embodied practice, but also a deeply economic and social negotiation shaped by the need to avoid the consequences of discrimination within ableist social and economic environments.

8.2.4 Thinking *with* brain fog

Throughout this thesis, I have attended to Bissell's (2025) call to think *with* brain fog, initially as a symptomatic disruption of Long Covid that manifests through experiences of disengagement, dispossession and displacement. Drawing on Bissell's framework, I have mapped these three dimensions across participants' accounts, contributing to a geographical understanding of being 'out of it.' For example, Alexandra's sense of becoming a "shadow" in her own family exemplifies disengagement – a feeling of being physically present but affectively absent within her own lifeworld. Ruth's struggle to piece together thoughts and words, mirrored in her children's IKEA metaphor, illustrates dispossession — the loss of cognitive coherence and a sense of being "cut

off" from her own mental bearings. Kate's experience of getting lost on the bus underscores displacement, as cognitive impairment unsettled her orientation in space and required intricate planning and support to navigate everyday environments. Together, these narratives show how symptomatic brain fog transforms familiar spaces into unpredictable landscapes, producing a geography of being 'out of it.'

Building on this analysis, I also attended to brain fog not merely as a symptom of Long Covid – often experienced as "cognitive fogginess" (Bissell, 2025, p.15) – but as an affective register through which participants learn to manage fluctuating energy capacities in everyday life. Alongside other symptoms, experiences of cognitive slowness and haziness became affective cues through which individuals developed embodied knowledge and an affective forecasting capacity to adapt routines, pace activities, prioritise key tasks and anticipate their spatial, temporal and corporeal limits. In this way, brain fog exemplifies how anticipation, intensity and embodiment intertwine to produce new forms of bodily knowledge and agency. Through this lens, brain fog can be understood as lending itself to embodied and affective practices of living with an energy-limiting and unpredictable chronic illness, which in turn reconfigure how bodies, spaces and futures are inhabited.

Here, I extend these ideas further to the 'crash' as a state of spatial, temporal and material entrapment. The crash can be understood as an intensified configuration of disengagement, dispossession and displacement — a hyper-embodiment of being 'out of it' marked by affective suspension. In this state, energy can no longer be meaningfully negotiated, intensifying the condition of the 'body under lockdown' which becomes untethered from familiar temporal and spatial coordinates.

8.2.5 The injustice of Long Covid disruption

Through the voices of my participants, I now want to rethink Moss and Dyck's (2003, p.88) description of the onset of chronic illness as the "loss of being able to do regular, everyday things." In Chapter 4, I explored the contours of loss that my participants experienced – relationships, career, identity, energy, autonomy – encapsulated in Louise's stark reflection: "I lost everything." However, I want to reconsider what "loss" means in the context of Long Covid through Cath's perspective, who described feeling "robbed" by Long Covid. She elaborated on how "everything's sort of being taken away from me step by step." This distinction between losing something and having it taken

away implicates a deeper sense of injustice. Loss implies an accidental misplacement and places responsibility on the individual, whereas having something that is taken away shifts this blame to an external force – disease, system or another person. This tension was apparent across my participants' narratives, as many recognised that there was no individual cause for their development of Long Covid. As outlined, most[98] participants understood themselves as previously healthy and active and could not make sense of their new contradictory self. Crucially, because Long Covid has no clear aetiology, participants rarely questioned "why me?" when attempting to understand and rationalise their experience, which, in turn, supported their move toward acceptance (for now). This shift in responsibility, however, also intensified the emotional weight of their condition, framing Long Covid not as a personal fault but an unwanted, enduring reality imposed upon them. While attributed to the acute COVID-19 infection, its persistence was shaped by uneven landscapes of care and institutional neglect which systemically 'left' many to self-manage, self-regulate and self-govern in conditions of biomedical incoherence, uncertainty and invisibilisation.

8.2.6 Socio-economic class

One overarching finding of this thesis is that Long Covid intersects with socio-economic class. Two interrelated threads of socio-economic class[99] can be identified throughout this thesis: first, participants' pre-Long Covid class position, shaping the financial, social and educational resources that they could mobilise following the onset; and second, the post-onset class trajectories that unfolded as a result of Long Covid, including the loss of careers, savings and relationships. My findings suggest that the disruptive and disabling effects of Long Covid were felt most acutely by participants with limited access to social and financial resources, particularly those without immediate familial support. Such support — whether through practical help with daily routines or contributing to household income — enabled some participants to reduce domestic and professional labour, conserve energy and create more time and space for rest, recovery and meaningful activities, but this option was far from universal. Even

[98] Amy, as an exception, had pre-existing chronic arthritis, meaning that Long Covid developed as an additional comorbid condition.

[99] Here, I understand "class" in a dual sense. On the one hand, it refers to a socio-economic position reflected in material indicators such as income, housing security, employment conditions and educational attainment. On the other, class is relationally and socially shaped by unequal access to resources within contemporary political–economic capitalist structures. This dual understanding positions class not only as an individual attribute, but as a structural condition that shapes differential capacities to manage illness.

some participants living in family households still had to maintain paid work or resume childcare and domestic responsibilities, leaving them with limited capacity to care for their chronically ill body. Socio-economic privilege further shaped certain participants' ability to adapt to illness and care for their ill bodies, whether through accessing alternative treatments not available on the NHS, such as hyperbaric oxygen, wheelchairs and digital technologies to self-track symptoms. Some participants moved to a more accessible home, outsourced domestic labour to cleaners and support workers, or ordered takeaway meals to preserve energy – expenses which Farrah referred to as the "disability tax." Yet even those who recognised their financial privilege expressed anxiety about the sustainability of such expenses, ones often funded by their savings or credit cards, particularly in the absence of adequate government support.

Class privilege therefore afforded some participants the crucial time, space and energy needed to rest, recover and also access meaningful socio-spatialities that cultivate a sense of bio-geo-graphical flow, while those without such resources were left navigating Long Covid with far greater precarity. Although these dynamics are not straightforward, as even some participants with spatio-temporal privileges lacked the bodily energy needed to mobilise their time meaningfully[100], identifying an abundance of time but an absence of bodily capacity to utilise it – a core "presence of absence" (Moss and Dyck, 2003, p.12) shaping the lived experience of Long Covid experience whereby the absence of energy itself is palpable. This consideration reiterates how socio-economic class intersects with the three Ps principle, determining who can pace, plan and prioritise effectively, who can affect and be affected, and who remains confined by their energy-limited body. Together, these socio-economic, spatio-temporal and energetic inequalities underscore that Long Covid is not only a biomedical condition but a deeply political one, lived through uneven capacities to rest, recover, advocate and endure. Many of course simply do not have the energy – physically, emotionally, 'intellectually' – to self-advocate. This uneven distribution is hence a key determinant of whose voices are heard and whose experiences are

[100] Here, I use the word "meaningfully" to denote everyday life rhythms, routines and relations that give life purpose and allow participants to live their "most intense life possible" (Fassin, 2010, p.82) with Long Covid. I purposefully refrain from the word "productively" to avoid reinforcing neoliberal discourse that frames time as something that should always be optimised, measured or converted into economic value.

visibilised, based on who has the energy to advocate and fight for recognition. It also reveals a limitation of this online study: the voices most able to participate were often those already positioned within a white, middle-class, previously 'active' subjectivity — one that is already more visible, legible and institutionally recognisable — thereby eclipsing other lived realities of Long Covid that are less visible, less privileged and therefore less likely to appear within research.

8.3 Methodological insights

Attentiveness to fluctuating energy levels was central to the research design. Participants consistently reflected on the effort required to participate and the need to carefully manage their energy before and after interviews. This dimension dovetails a key methodological insight: research with people living with Long Covid must be designed around individuals' symptoms, specifically their variable energy capacities and limits to ensure inclusivity and accessibility. Without such accommodations, research risks reproducing the exclusions and harms that participants described encountering in medical and social contexts. This attentiveness to the specificities of my participant cohort informed my decisions around interview format, pacing and flexibility. Participants were offered breaks, shorter interviews or the option to split interviews across multiple sessions. While all ultimately completed a single in-depth interview, participant feedback highlighted the risk of overexertion driven by enthusiasm or a desire to 'achieve' completion of the interview that risk ethical tensions between respecting participant agency and exercising researcher responsibility for wellbeing. As a non-disabled researcher, I approached this tension reflexively, favouring participant-led decision-making while recognising the limits of this approach.

I hence adopted a participant-led approach grounded in continual consent, flexibility and responsiveness to individual needs. Participants were repeatedly reminded of their right to pause, reschedule or withdraw, and interviews were framed as theirs to manage, which also helped to build trust around a deeply sensitive and highly contested topic. Conducting interviews online also had ethical significance, as they were deliberately designed to reduce physical, cognitive and emotional burden by allowing participants to engage from familiar and 'safe' environments. In the context of Long Covid, where symptoms are unpredictable, this research demonstrates that online methods can function as an ethically responsive choice rather than a methodological compromise.

A further methodological insight concerns focus group size. ‘Smaller’ groups of three to five participants were most appropriate when researching Long Covid as participants themselves repeatedly described how larger group settings intensified symptoms through overstimulation, including fatigue and brain fog. Smaller groups therefore reduced cognitive and social demand and enabled a slower, more manageable pace of discussion. This format also supported more equitable participation, enabling all individuals to contribute without competing for space. This participant-informed insight suggests that conventional assumptions about optimal focus group size should be reconsidered when working with populations with ELCs, and that smaller groups function as an ethically responsive and analytically productive choice rather than a limitation.

That said, here I must also acknowledge a key limitation of this study which relied primarily on synchronous, video-based methods. While this approach facilitated rich relational engagement, real-time interaction can be energetically demanding for people living with Long Covid and may exacerbate symptoms such as fatigue, cognitive overload and migraines. This concern emerged in a small number of instances of that I am aware. Following an individual interview, Ruth reflected in a follow-up email that her desire to ‘complete’ and ‘achieve’ the session, despite my consistent offers of breaks, led her to overexert and mask her remaining energy, retrospectively recognising the need to pace the interview across two days (see Chapter 3). Similarly, Hannah left her focus group early due to the onset of ‘aura’ as a signal of her Long Covid-related seizures. Although such experiences were not reported systematically across participants, they nonetheless highlight how synchronous methods may inadvertently place responsibility for energy management onto participants themselves. Offering asynchronous modes of participation, such as email or written diaries, may therefore enable the inclusion of participants for whom sustained real-time or digital engagement is not possible and help mitigate the risk of symptom exacerbation in future research.

This research further demonstrates that language functions as a methodological intervention rather than a neutral descriptor. By explicitly centring people living with Long Covid, I resisted sensationalised and pathologising narratives that often dominate public and biomedical discourse. Drawing directly on participants’ own language, I avoided terms such as ‘sufferers’, ‘survivors’ and ‘patient’, which risks

positioning individuals as passive, helpless or wholly defined by illness. Instead, I adopted first-person framings such as ‘people living with ...’ or ‘people affected by Long Covid’ to decentre the condition and foreground lived experience as ongoing, fluctuating and contested. This terminological decision aligns with my participant-led epistemology that recognises lived experience as a legitimate site of knowledge production.

The recruitment process revealed how contested legitimacy shapes participation. When volunteering, some participants felt compelled to justify their eligibility through detailed accounts of symptoms and impairment, often reflecting on prior experiences of dismissal and scepticism. By recruiting on the basis of self-identification rather than medical diagnosis, this research positioned lived experience as authoritative. For many participants, the interviews offered the first sustained opportunity to articulate their experiences across both medical and social worlds. Taken together, this circumstance demonstrates the methodological importance of inclusive recruitment practices in contexts where formal diagnosis is uneven or contested, accenting the individual-level significance of research that creates time and space for people to tell their story.

Finally, I contend that studying Long Covid demands patience, adaptability and an acceptance of unpredictability. Participants may need to cancel at short notice, forget scheduled interviews or require smaller focus groups. These methodological insights insist that flexibility should be understood not as a limitation, but as an ethical and epistemological necessity when researching Long Covid.

8.4 Limitations

This study has several limitations that warrant acknowledgement. While specific methodological limitations have been discussed, it is important to acknowledge their broader analytical implications. The reliance on synchronous online methods and visibility of certain Long Covid subjectivities within an online study shaped not only the data collected but also the forms of Long Covid experience that became most visible. Together, these limitations highlight how both methodological design and structural inequalities shape participation, visibility and voice, particularly privileging those with sufficient energy, digital access and socio-economic resources to engage in research.

Another limitation concerns the absence of a gendered analysis. While the majority of participants identified as women (23 of 26), and many described experiences of clinical dismissal framed through mental ill-health or accusations of exaggeration, the empirical material did not support a robust gendered difference. Accounts of dismissal and misrecognition were shared by both women and men in the study, and the small number of male participants limited the scope for meaningful comparison. Future research with larger and more gender-diverse samples could more fully explore how Long Covid experiences – including socio-spatial disruption, care, energy limitation, productivity expectations and clinical legitimacy – are shaped by gender.

Similarly, I did not undertake a systematic urban–rural analysis. While participants' accounts pointed to uneven geographies of access to support and resources – particularly in-person communities – experiences were mixed and highly context-specific, cutting across both urban and rural settings. This reflects the broad research design which prioritised in-depth engagement with a small cohort of people living with Long Covid across the UK, rather than the recruitment of a spatially segmented sample. Rather than treating location as a primary explanatory variable, the findings suggest that access to care and support networks are shaped less by location alone than by the presence of specific local infrastructures and forms of social recognition. Further research could examine how these dynamics unfold across different geographical contexts.

A further limitation relates to the participant cohort composition, particularly in relation to socio-economic class and prior experiences of disability. Although I have already argued that Long Covid intersects with socio-economic class in important ways, the study was nonetheless dominated by participants from professional or middle-class backgrounds. For many of these individuals, the sudden loss of work, income and professional identity following illness onset represented a profound rupture in previously stable socio-economic trajectories. Experiences of navigating welfare systems or seeking financial support were therefore, for some, unfamiliar and disorientating processes. These experiences may differ from those of individuals already living with chronic illness or financial precarity prior to illness onset, whose relationships to work, welfare and survival strategies may be shaped by longer histories of structural marginalisation. Future research that more deliberately engages with participants from a wider range of socio-economic backgrounds could therefore

offer deeper insights into how class shapes the uneven geographies of living with Long Covid.

Similarly, the majority of participants in this study described transitioning from a previously healthy or non-disabled identity into life with a chronic, energy-limiting condition. As a result, the research offered limited opportunity to explore the experiences of people who were already living with disability prior to the onset of Long Covid. For example, Amy — the only participant living co-morbidly with an existing chronic illness — appeared to navigate some aspects of disruption differently, having already encountered the contingencies of health, bodily limitation and the need to adapt to an ableist world. While Long Covid still introduced significant challenges, Amy's account signalled a degree of familiarity with negotiating fluctuating capacity and embodied limitation that others in the study were encountering for the first time. Had the study included more participants connected to disabled people's movements or disability rights movement – for example through recruitment via disability organisations – additional insights may have emerged regarding the management of disruption, internalised ableism and the need to mask illness. Such perspectives may have illuminated how prior experiences of disability, or engagement within disability communities, can shape understandings of illness, identity and collective advocacy in ways that differ from those newly encountering disability through Long Covid.

8.5 Future orientations for geography and beyond

8.5.1 Rethinking the clinical testing space

This thesis (particularly the findings of Chapters 6 and 7) suggests the need to rethink how Long Covid, and other elusive ELCs, are assessed and cared for within public health systems. Participants' engagement in what I have described as 'diagnostic activism' revealed how static, sedentary testing practices often fail to capture exertion-related symptoms, rendering Long Covid invisible within clinical encounters. By advocating for spatially attuned movement-based forms of assessment, participants fought to make their symptoms legible under conditions that reflected the embodied realities of exertion. In some cases, this involved individuals undertaking their own movement-based tests in everyday environments, such as at home, supported by wearable technologies, and taking the resulting data into clinical consultations, effectively relocating elements of diagnostic practice beyond the clinic. Incorporating

movement-based assessments — such as Sit-to-Stand tests or short walking tasks — into routine clinical pathways could offer one way of bridging the gap between clinical expertise and lived experience. Such approaches have the potential to strengthen diagnostic recognition, support earlier intervention and referral, and contribute to more equitable care for people living with Long Covid and other ELCs. Importantly, these practices reframe the body as a dynamic site of knowledge, rather than a static object of measurement, opening space for embodied and epistemic knowledge to be shared between patients and clinicians.

At the same time, I also recognise the variability of Long Covid experiences, and therefore the potential of movement-based testing may be more limited for those without cardiovascular-related dysfunction, meaning that care must be taken not to impose new normative expectations of bodily performance. Nonetheless, given the high prevalence of fatigue and exertion-related symptom exacerbation among people living with Long Covid, the implications of spatially and bodily attuned diagnostic practices should still be acknowledged. Further geographical enquiry — such as in-depth patient narrative studies or clinical ethnographies within Long Covid healthcare settings — would be valuable in substantiating these findings and exploring how diagnostic practices might be reconfigured in ways that are more meaningful for both the individual and the clinic.

Taken together, these insights open up new directions for health, digital and cultural geographies by foregrounding diagnosis – of ELCs in particular – as an energy-dependent process and spatial negotiation. Geographical research could build on this by examining how diagnostic practices are reassembled across domestic, digital and clinical spaces, and how affect, energy and institutional authority shape who can be seen, heard and cared for within contemporary healthcare systems.

8.5.2 Spaces of care

This thesis also demonstrates that both online and offline spaces play a crucial role in enabling support, reciprocity and recognition for people living with Long Covid. The affective and relational qualities of these spaces were not universal, but rather, were shaped by the format, scale and design through which support was organised. Participants' accounts revealed important differences between text-based forums, large-scale digital interventions and small, curated, real-time encounters, with the

latter more consistently fostering connection, mutual recognition and positive affect. In-person connections were also described as therapeutic because of their embodied, affective and relational qualities allowing support to be felt and shared in ways not always possible online. Across both digital and physical contexts, the therapeutic value of such spaces was also shaped by their materiality, particularly in relation to low-energy demands including accessibility, manageable group sizes and the option to disengage without explanation or judgement. Building on these insights, I suggest that hybrid configurations — combining both digital and physical elements — may extend some of these therapeutic environments to those unable to consistently access in-person support due to fluctuating energy or mobility constraints. From a public health perspective, such arrangements offer a flexible form of care while acknowledging that therapeutic landscapes are not universally or continuously accessible. Attending to hybrid spaces of care therefore involves not only accessibility provision, but careful consideration of how relational and affective qualities — including recognition, pacing and non-judgement — might be sustained across both physical and digital environments.

These findings also open up future geographical orientations that foreground care as relational, affective and energy-dependent, inviting health geographers to attend more closely to hybrid spaces of care that cut across digital and physical environments, to the role of energy and pacing in shaping spatial participation, and to the conditions under which support becomes enabling or disabling. While I have not explicitly analysed affective atmospheres as such, my findings point to their relevance for future geographical work on ELCs. Spaces of support were experienced not only through physical interactions, but through broader affective qualities, including intensity, saturation, comfort and exhaustion, which shaped who could participate, for how long, and at what energetic cost. Attending more directly to affective atmospheres may therefore offer a productive way for health geographers to explore how energy, affect and care circulate across such spaces, and how certain environments become enabling or constrain participation for people living with fluctuating ELCs.

In relation to spaces of care, although this study did not include interviews with relatives, it nevertheless evidences significant relational disruptions to familial roles and life trajectories. Participants' accounts point to subtle but profound shifts in everyday care relations, as partners, parents and children are drawn into caregiving

roles, reshaping not only their everyday lifeworlds but also their own imagined futures. These findings indicate the need for greater geographical attention to the uneven ways illness reshapes familial and household geographies of care and suggest that future research drawing on similar frameworks — alongside public health initiatives — should consider how families affected by Long Covid might be better supported, both physically and mentally, in adapting to such bio-geo-graphical disruptions.

8.6 Final thoughts

Throughout this thesis, I have shown that Long Covid is not only a biomedical condition, but a profoundly geographical one, lived through disrupted relations between energy, body, space, time and power. By foregrounding everyday experiences, I have demonstrated how fluctuating energy capacities reorganise where people can go, how they can participate, and which forms of life remain accessible. Attending to Long Covid through a geographical lens reveals the intimate ways in which energy-limiting chronic illness is shaped by broader political, economic and spatial arrangements, exposing how responsibility for care, recovery and survival is increasingly placed onto individuals navigating fragmented systems of support.

By centring lived experience, this thesis highlights the need for public health responses that move beyond traditional understandings of responsibility, productivity and care, towards approaches that are attentive and adaptive to uneven spatial, temporal, socio-economic and energy resources. As Long Covid continues to shape lives long after the acute phase of the pandemic, the experiences documented throughout this thesis offer important insights into how societies might better recognise, support and care for those living with chronic, uncertain and elusive ELCs.

Ultimately, I argue that taking Long Covid seriously requires more than clinical recognition alone. It demands sustained attentiveness to the everyday geographies through which illness is lived, negotiated and endured, and to the ethical imperative of listening to those whose lives continue to be shaped by a pandemic that is widely assumed to be over. Central to this attentiveness is energy itself, which, across this thesis, I have approached as an ethical, empirical and conceptual concern. I have conceptualised energy as a biopolitical currency: one that is continually budgeted, banked, expended, mis-spent and depleted as people navigate everyday socio-spatialities under conditions of uncertainty and institutional neglect. Living with Long

Covid involves the ongoing management of energy — deciding when it can be expended, when it must be saved, and when it has been spent — across social, workplace and institutional contexts that rarely recognise or support this labour. Taking Long Covid seriously therefore also requires societal and institutional commitments to creating conditions in which this biopolitical currency can be more sustainably 'banked' and withdrawn, rather than continually extracted from already energy-limited bodies. By foregrounding energy as an ethical, empirical and conceptual concern, this thesis calls for geographical scholarship and public health practice to attend to the uneven, ongoing and deeply political conditions under which people continue to live with chronic, energy-limiting illnesses.

Bibliography

Adey, P. & Anderson, B. (2012) Anticipating emergencies: Technologies of preparedness and the matter of security. *Security Dialogue*. 43(2), 99–117.

Agamben, G. (1998) *Homo Sacer: Sovereign Power and Bare Life*. Werner Hamacher & David E. Wellbery (eds). Stanford, California: Stanford University Press.

Ajana, B. (2017) Digital health and the biopolitics of the Quantified Self. *DIGITAL HEALTH*. [Online] 32055207616689509.

Al-Aly, Z. et al. (2024) Long COVID science, research and policy. *Nature Medicine*. 30(8), 2148–2164.

Alonzo, A. A. & Reynolds, N. R. (1995) Stigma, HIV and AIDS: an exploration and elaboration of a stigma trajectory. *Social Science & Medicine.* 41(3), 303–315.

Alwan, N. A. et al. (2020) From doctors as patients: a manifesto for tackling persisting symptoms of covid-19. *BMJ (Clinical research ed.)*. [Online] 370m3565.

Anderson, B. (2006) Becoming and Being Hopeful: Towards a Theory of Affect. *Environment and Planning D: Society and Space*. [online]. Available from: https://doi.org/10.1068/d393t (Accessed 19 May 2025).

Anderson, B. (2009) Affective atmospheres. *Emotion, Space and Society*. 2(2), 77–81.

Anderson, B. (2010a) Preemption, precaution, preparedness: Anticipatory action and future geographies. *Progress in Human Geography*. 34(6), 777–798.

Anderson, B. (2010b) Security and the future: Anticipating the event of terror. *Geoforum*. 41(2), 227–235.

Anderson, C. A. (2001) Claiming disability in the field of geography: Access, recognition and integration. *Social & Cultural Geography*. 2(1), 87–93.

Anderson, C. & Kirkpatrick, S. (2016) Narrative interviewing. *International Journal of Clinical Pharmacy*. 38(3), 631–634.

Andrews, G. J. (2014) Co-creating health's lively, moving frontiers: brief observations on the facets and possibilities of non-representational theory. *Health & Place*. [Online] 30165–170.

Andrews, G. J. (2018) *Non-Representational Theory & Health: The Health in Life in Space-Time Revealing*. Geographies of Health. London: Routledge. [online]. Available from: https://www.routledge.com/Non-Representational-Theory--Health-The-Health-in-Life-in-Space-Time-Revealing/Andrews/p/book/9780367592639 (Accessed 8 January 2026).

Andrews, G. J. et al. (2014) The ‘taking place’ of health and wellbeing: towards non-representational theory. *Social Science & Medicine*. [Online] 108210–222.

Andrews, G. J. et al. (eds.) (2021) *Pandemic Geographies: COVID-19 and Similar Futures*. Global Perspectives on Health Geography. Springer.

Angus, J. et al. (2005) The personal significance of home: habitus and the experience of receiving long-term home care. *Sociology of Health & Illness*. 27(2), 161–187.

Anon (2025) *Imagining Better Futures of Care For and With People with Energy Limiting Conditions*. [online]. Available from: https://www.youtube.com/watch?v=wdrYc9qc17E (Accessed 19 November 2025).

Åsbring, P. & Närvänen, A.-L. (2002) Women’s Experiences of Stigma in Relation to Chronic Fatigue Syndrome and Fibromyalgia. *Qualitative Health Research*. 12(2), 148–160.

Atkinson, S. (2013) Beyond Components of Wellbeing: The Effects of Relational and Situated Assemblage. *Topoi*. 32(2), 137–144.

Barbour, R. (2007) *Doing Focus Groups*. [Online]. SAGE Publications Ltd. [online]. Available from: https://methods.sagepub.com/book/mono/doing-focus-groups/toc (Accessed 7 January 2026).

Barbour, R. S. & Morgan, D. L. (eds.) (2017) *A New Era in Focus Group Research*. [Online]. London: Palgrave Macmillan UK. [online]. Available from: http://link.springer.com/10.1057/978-1-137-58614-8 (Accessed 7 January 2026).

Bedford, T. & Burgess, J. (2001) ‘Using focus groups in qualitative research’, in C Dwyer & M Limb (eds) *Qualitative Research in Geography*. Harlow: Longmans. pp. 121–135.

Bell, S. L. et al. (2015) Seeking everyday wellbeing: The coast as a therapeutic landscape. *Social Science & Medicine*. [Online] 14256–67.

von Benzon, N. & van Blerk, L. (2017) Full article: Research relationships and responsibilities: ‘Doing’ research with ‘vulnerable’ participants: introduction to the special edition. *Social Currents*. 18(7), 895–905.

Berger, M. et al. (2005) Internet use and stigmatized illness. *Social Science & Medicine*. 61(8), 1821–1827.

Berger, R. (2015) Now I see it, now I don’t: researcher’s position and reflexivity in qualitative research. *Qualitative Research*. 15(2), 219–234.

Bergmans, R. S. et al. (2024) ‘I’m still here, I’m alive and breathing’: The experience of Black Americans with long COVID. *Journal of Clinical Nursing*. 33(1), 162–177.

Birch, M. & Miller, T. (2000) Inviting intimacy: The interview as therapeutic opportunity. *International Journal of Social Research Methodology*. 3(3), 189–202.

Bissell, D. (2009) Obdurate Pains, Transient Intensities: Affect and the Chronically Pained Body. *Environment and Planning A*. 41(4), 911–928.

Bissell, D. (2010) 'Placing Affective Relations: Uncertain Geographies of Pain', in *Taking-Place: Non-Representational Theories and Geography*. Routledge. pp. 79–97.

Bissell, D. (2007) Animating Suspension: Waiting for Mobilities. *Mobilities*. 2(2), 277–298.

Bissell, D. (2025) Feeling out of it: Displacement, disengagement and dispossession in experiences of brain fog. *Dialogues in Human Geography*. [Online] 20438206251321091.

Blunt, A. & Dowling, R. (2006) *Home*. London: Routledge.

Blunt, A. & Varley, A. (2004) Geographies of home. *cultural geographies*. 11(1), 3–6.

Bodden, S. et al. (2024a) 'Feeling SAD: Embodied geographies of seasonal affective disorder', in Candice P. Boyd et al. (eds) *Routledge Handbook on Spaces of Mental Health and Wellbeing*. 1st edition London: Routledge. p. Chapter 16.

Bodden, S. et al. (2024b) In a positive light? experiencing Seasonal Affective Disorder (SAD) and the promise of biosolidarity. *Social & Cultural Geography*. 25(10), 1594–1612.

Bondi, L. (2009) Full article: Teaching Reflexivity: Undoing or Reinscribing Habits of Gender? *Journal of Geography in Higher Education*. 33 (3), . [online]. Available from: https://www.tandfonline.com/doi/full/10.1080/03098260902742417 (Accessed 13 January 2026).

Bondi, L. (2013) Research and Therapy: Generating Meaning and Feeling Gaps. *Qualitative Inquiry*. 19(1), 9–19.

Botterill, K. et al. (2019) Young people's everyday securities: pre-emptive and pro-active strategies towards ontological security in Scotland. *Social & Cultural Geography*. 20(4), 465–484.

Boyle, L. E. (2019a) *The social and anticipatory geographies of social anxiety*. University of Glasgow.

Boyle, L. E. (2019b) The (un)habitual geographies of Social Anxiety Disorder. *Social Science & Medicine.* [Online] 23131–37.

Bracken-Roche, D. et al. (2017) The concept of 'vulnerability' in research ethics: an in-depth analysis of policies and guidelines. *Health Research Policy and Systems*. [Online] 15(1), 8.

Braun, V. & Clark, V. (2022) *Thematic Analysis*. UK: SAGE Publications. [online]. Available from: https://uk.sagepub.com/en-gb/eur/thematic-analysis/book248481 (Accessed 7 January 2026).

Brickell, K. (2012) 'Mapping' and 'doing' critical geographies of home. *Progress in Human Geography*. 36(2), 225–244.

Burning Nights (2025) *Using Spoon Theory to Explain Chronic Illness*. [online]. Available from: https://www.burningnightscrps.org/support/news-and-blog/article/using-spoon-theory-explain-chronic-illness/ (Accessed 25 March 2025).

Burton, A. et al. (2022) Factors shaping the mental health and well-being of people experiencing persistent COVID-19 symptoms or 'long COVID': qualitative study. *BJPsych Open*. [Online] 8(2), e72.

Bury, M. (1982) Chronic illness as biographical disruption. *Sociology of Health & Illness*. 4(2), 167–182.

Butler, J. (1990) *Gender trouble: feminism and the subversion of identity*. New York; London: Routledge.

Butler, R. E. (1994) Geography and Vision-Impaired and Blind Populations. *Transactions of the Institute of British Geographers*. 19(3), 366–368.

Butler, R. (2005) 'Double the trouble or twice the fun? Disabled bodies in the gay community', in Ruth Butler & Hester Parr (eds) *Mind and Body Spaces: Geographies of Illness, Impairment and Disability*. London: Routledge. pp. 203–220.

Butler, R. & Bowlby, S. (1997) Bodies and Spaces: An Exploration of Disabled People's Experiences of Public Space. *Environment and Planning D: Society and Space*. 15(4), 411–433.

Butler, R. & Parr, H. (eds.) (1999) *Mind and Body Spaces: Geographies of Illness, Impairment and Disability*. London: Routledge.

Calabrese, L. H. & Mease, P. J. (2024) Improving the nosology of Long COVID: it is not so simple. *Annals of the Rheumatic Diseases*. 83(1), 9–11.

Callard, F. (2020) Epidemic Time: Thinking from the Sickbed. *Bulletin of the History of Medicine*. 94(4), 727–743.

Callard, F. & Perego, E. (2021) How and why patients made Long Covid. *Social Science & Medicine*. [Online] 268113426.

Cameron, J. (2005) 'Focusing on the Focus Group. In Hay, I., Ed., Qualitative Research Methods in Human Geography, 2nd Edition, Oxford University Press, Melbourne, 116-132. - References - Scientific Research Publishing', in Iain Hay (ed.) *Qualitative Research Methods in Human Geography*. 2nd edition Melbourne: Oxford University Press. pp. 116–132. [online]. Available

from: https://www.scirp.org/reference/referencespapers?referenceid=3092296 (Accessed 7 January 2026).

Campbell, R. & Longhurst, R. (2013) Obsessive–compulsive disorder (OCD): Gendered metaphors, blogs and online forums. *New Zealand Geographer*. 69(2), 83–93.

Canguilhem, G. (1991) *The Normal and the Pathological*. New York: Zone Books.

Carmack Taylor, C. L. et al. (2007) A social comparison theory analysis of group composition and efficacy of cancer support group programs. *Social Science & Medicine.* 65(2), 262–273.

Chapman, T. & Hockey, J. (eds.) (2002) *Ideal Homes?: Social Change and the Experience of the Home*. London: Routledge.

Charmaz, K. (1983) Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health & Illness*. 5(2), 168–195.

Charmaz, K. (1991) *Good Days, Bad Days: the Self in Chronic Illness and Time*. New Jersey: Rutgers University Press.

Charmaz, K. (1995) The Body, Identity, and Self: Adapting to Impairment. *The Sociological Quarterly*. 36(4), 657–680.

Charmaz, K. (1999) Stories of Suffering: Subjective Tales and Research Narratives. *Qualitative Health Research*. 9(3), 362–382.

Charmaz, K. (2006) *Constructing Grounded Theory: A Practical Guide through Qualitative Analysis.* London: SAGE Publications. [online]. Available from: https://www.scirp.org/reference/referencespapers?referenceid=1690485 (Accessed 7 January 2026).

Charmaz, K. (2010) Disclosing illness and disability in the workplace. *Journal of International Education in Business*. 3(1/2), 6–19.

Cheston, K. et al. (2025) The Long or the Post of It? Temporality, Suffering, and Uncertainty in Narratives Following COVID-19. *Journal of Medical Humanities*. 46(1), 3–20.

Chouinard, V. (1997) Making Space for Disabling Differences: Challenging Ableist Geographies. *Environment and Planning D: Society and Space*. 15(4), 379–390.

Chouinard, V. (2005) 'Body politics: disabled women's activism in Canada and beyond', in Ruth Butler & Hester Parr (eds) *Mind and Body Spaces: Geographies of Illness, Impairment and Disability*. [Online]. London: Routledge. pp. 267–292.

Chouinard, V. (2018) 'Mapping life on the margins: Disability and chronic illness', in Valorie A Crooks et al. (eds) *Routledge Handbook of Health Geography*. 1st edition London and New York: Routledge. pp. 172–178.

Chouinard, V. et al. (2010) *Towards enabling geographies: 'disabled' bodies and minds in society and space*. Geographies of Health. Farnham: Ashgate.

Clare, E. (2001) Stolen Bodies, Reclaimed Bodies: Disability and Queerness. *Public Culture*. 13(3), 359–366.

Cleveland Clinic (2025) *What Does Idiopathic Mean?* [online]. Available from: https://my.clevelandclinic.org/health/articles/idiopathic (Accessed 11 September 2025).

Cloke, P. J. et al. (2004) *Practising Human Geography*. London, UNITED KINGDOM: SAGE Publications, Limited. [online]. Available from: http://ebookcentral.proquest.com/lib/gla/detail.action?docID=354901 (Accessed 7 January 2026).

Clutterbuck, D. et al. (2024) *Barriers to healthcare access: findings from a co-produced Long Covid case-finding study*. p.2024.01.03.24300767. [online]. Available from: https://www.medrxiv.org/content/10.1101/2024.01.03.24300767v1 (Accessed 10 November 2025).

Conradson, D. (2005) 'Focus groups', in *Methods in Human Geography*. 2nd edition Routledge. pp. 128–143.

Craddock, S. (2021) 'Textures of an Epidemic: On the Necessity of Qualitative Methods in Making Better Pandemic Futures', in Gavin J. Andrews et al. (eds) *Pandemic Geographies: COVID-19 and Similar Futures*. Global Perspectives on Health Geography. Springer. pp. 401–407.

Crook, H. et al. (2021) Long covid-mechanisms, risk factors, and management. *BMJ (Clinical research ed.)*. [Online].

Crooks, V. A. (2006) "I Go On The Internet; I Always, You Know, Check To See What's New": Chronically Ill Women's Use of Online Health Information to Shape and Inform Doctor-Patient Interactions in the Space of Care Provision. *ACME: An International Journal for Critical Geographies*. 5(1), 50–69.

Crooks, V. A. et al. (2008) Understanding, embracing, rejecting: Women's negotiations of disability constructions and categorizations after becoming chronically ill. *Social Science & Medicine*. 67(11), 1837–1846.

Crooks, V. A. (2010) 'Women's Changing Experiences of the Home and Life Inside it after Becoming Chronically Ill', in Vera Chouinard et al. (eds) *Towards Enabling Geographies: 'Disabled' Bodies and Minds in Society and Space*. Geographies of Health. Surrey, England: Ashgate Publishing Ltd. pp. 45–61.

Crooks, V. A. & Chouinard, V. (2006) An embodied geography of disablement: Chronically ill women's struggles for enabling places in spaces of health care and daily life. *Health & Place*. 12(3), 345–352.

Crow, L. (2010) ‘Including all of our lives: Renewing the social model of disability’, in Jon Rix et al. (eds) *Equality, Participation and Inclusion 1*. 2nd edition London: Routledge. p.124-140.

Dahiya, E. S. et al. (2024) Wearable Technology for Monitoring Electrocardiograms (ECGs) in Adults: A Scoping Review. *Sensors (Basel, Switzerland)*. [Online] 24(4), 1318.

Davidson, J. & Henderson, V. L. (2010) ‘Coming out’ on the spectrum: autism, identity and disclosure. *Social & Cultural Geography*. 11(2), 155–170.

Davis, H. E. et al. (2021) Characterizing long COVID in an international cohort: 7 months of symptoms and their impact. *eClinicalMedicine*. [Online] 38. [online]. Available from: https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext (Accessed 19 November 2025).

Davis, H. E. et al. (2023) Long COVID: major findings, mechanisms and recommendations. *Nature Reviews Microbiology*. 21(3), 133–146.

Del Casino Jr, V. J. (2009) ‘Living with and Experiencing Disease’, in *A Companion to Health and Medical Geography*. [Online]. John Wiley & Sons, Ltd. pp. 188–204. [online]. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1002/9781444314762.ch11 (Accessed 5 May 2025).

Deleuze, G. (1988) *Spinoza: Practical Philosophy*. San Francisco: City Lights Books.

Deleuze, G. & Guattari, F. (1987) *Anti-Oedipus: capitalism and schizophrenia*. Continuum impacts. London: Continuum.

Dempsey, B. et al. (2024) Long COVID among healthcare workers: a narrative review of definitions, prevalence, symptoms, risk factors and impacts. *British Medical Bulletin*. 151(1), 16–35.

Dewsbury, J.-D. (2000) Performativity and the Event: Enacting a Philosophy of Difference. *Environment and Planning D: Society and Space*. 18(4), 473–496.

Dickson-Swift, V. et al. (2007) Doing sensitive research: what challenges do qualitative researchers face? *Qualitative Research*. 7(3), 327–353.

Digby, B. & Gatrell, T. (2022) *Health Geographies and the COVID-19 Pandemic*. Top Spec Geography. Geographical Association. [online]. Available from: https://portal.geography.org.uk/shop/view/P9871783394263 (Accessed 10 November 2025).

Disability Unit (2020) *Living with Non-Visible Disabilities – The Disability Unit*. [online]. Available from: https://disabilityunit.blog.gov.uk/2020/12/17/living-with-non-visible-disabilities/ (Accessed 8 July 2025).

Doel, M. A. & Segrott, J. (2003) Beyond Belief? Consumer Culture, Complementary Medicine, and the Dis-Ease of Everyday Life. *Environment and Planning D: Society and Space*. 21(6), 739–759.

Domosh, M. (1998) Geography and gender: home, again? *Progress in Human Geography*. 22(2), 276–282.

Domosh, M. & Seager, J. (2001) *Putting Women in Place: Feminist Geographies Making sense of the world*. New York: The Guilford Press.

Driedger, S. M. et al. (2004) Engaging in the disablement process over space and time: narratives of persons with multiple sclerosis in Ottawa, Canada. *Canadian Geographies / Géographies canadiennes*. 48(2), 119–136.

Driver, F. (1985) Power, Space, and the Body: A Critical Assessment of Foucault's Discipline and Punish. *Environment and Planning D: Society and Space*. 3(4), 425–446.

Dumes, A. (2020) *Divided Bodies: Lyme Disease, Contested Illness, and Evidence-Based Medicine*. Duke University Press.

Dumit, J. (2006) Illnesses you have to fight to get: Facts as forces in uncertain, emergent illnesses. *Social Science & Medicine*. 62(3), 577–590.

Duncan, J. S. & Lambert, D. (2004) 'Landscapes of Home', in *A Companion to Cultural Geography*. [Online]. John Wiley & Sons, Ltd. pp. 382–403. [online]. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1002/9780470996515.ch25 (Accessed 26 February 2025).

Dyck, I. (1995) Hidden geographies: The changing lifeworlds of women with multiple sclerosis. *Social Science & Medicine*. 40(3), 307–320.

Dyck, I. (1998) 'Women with Disabilities and Everyday Geographies: Home Space and the Contested Body', in Robin A. Kearns & Wilbert M. Gesler (eds) *Putting Health into Place: Landscape, Identity, and Well-being*. Syracuse University Press. pp. 102–119.

Dyck, I. (2002) Beyond the Clinic: Restructuring the Environment in Chronic Illness Experience. *OTJR: Occupational Therapy Journal of Research*. [Online] 22 (1).

Dyck, I. (2005) 'Body Troubles: Women, the Workplace and Negotiations of a Disabled Identity', in *Mind and Body Spaces: Geographies of Illness, Impairment and Disability*. London: Routledge. pp. 119–137.

Edgar, K. (2024) My story of living with and recovering from Long Covid- Guest Blog by Dr Kate Edgar, Clinical Psychologist. The Wellbeing Rooms [online]. Available from: https://www.thewellbeingrooms.org.uk/post/my-story-of-living-with-and-recovering-from-long-covid-guest-blog-by-dr-kate-edgar-clinical-psycho (Accessed 26 November 2025).

Edwards, C. & Imrie, R. (2003) Disabilities and Bodies as Bearers of Value. *Sociology*. 37(2), 239–256.

Evans, B. (2010) Anticipating fatness: childhood, affect and the pre-emptive ‘war on obesity’. *Transactions of the Institute of British Geographers*. 35(1), 21–38.

Evans, B. et al. (2023) *Full Report: Disbelief and Disregard: Gendered Experiences of Healthcare for People with Energy Limiting Conditions*. [online]. Available from: https://disbeliefdisregard.uk/wp-content/uploads/2023/09/ELC-Report.pdf (Accessed 19 November 2025).

Evans, B. et al. (2024) Being left behind beyond recovery: ‘crip time’ and chronic illness in neoliberal academia. *Social & Cultural Geography*. [Online] 1–21.

Evans, R. A. et al. (2021) Physical, cognitive, and mental health impacts of COVID-19 after hospitalisation (PHOSP-COVID): a UK multicentre, prospective cohort study. *The Lancet Respiratory Medicine*. 9(11), 1275–1287.

Faircloth, C. A. et al. (2004) Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of Health & Illness*. 26(2), 242–261.

Fassin, D. (2010) Ethics of Survival: A Democratic Approach to the Politics of Life. *Humanity: An International Journal of Human Rights, Humanitarianism, and Development*. 1(1), 81–95.

Feather, E. (2024) Containment, control and surveillance: a qualitative inquiry into eating disorders and the COVID-19 pandemic. *Social & Cultural Geography*. 25(9), 1374–1394.

Ferrie, J. & Greenwood, S. (2025) ‘To be honest, it’s complicated’: training postgraduate students to work with emotions in qualitative research. *Teaching in Higher Education*. 30(1), 19–34.

Foster, D. (2016) ‘Keep complaining til someone listens’: Exchanges of tacit healthcare knowledge in online illness communities. *Social Science & Medicine*. [Online] 16625–32.

Foucault, M. (1995) *Discipline and Punish: The Birth of the Prison*. 2nd edition. New York: Vintage Books.

Foucault, M. (1972) *The Archaeology of Knowledge & Discourse on Language*. New York: Pantheon Books.

Foucault, M. (1973) *The Birth of the Clinic: An Archaeology of Medical Perception*. R.D. Laing (ed.). London: Routledge.

Foucault, M. (1978) *The History of Sexuality Volume 1: An Introduction*. New York: Random House.

Foucault, M. (2010) *The Birth of Biopolitics: lectures at the Collège de France, 1978-79*. Michel Senellart (ed.). Basingstoke: Palgrave Macmillan.

Fricker, M. (2007) *Epistemic Injustice: Power and the Ethics of Knowing*. [Online]. Oxford University Press. [online]. Available from:

https://doi.org/10.1093/acprof:oso/9780198237907.001.0001 (Accessed 29 August 2025).

Gahman, L. (2017) Crip Theory and Country Boys: Masculinity, Dis/Ability, and Place in Rural Southeast Kansas. *Annals of the American Association of Geographers*. 107(3), 700–715.

Garner, P. (2020) Paul Garner: Covid-19 and fatigue—a game of snakes and ladders. The BMJ opinion [online]. Available from: https://blogs.bmj.com/bmj/2020/05/19/paul-garner-covid-19-and-fatigue-a-game-of-snakes-and-ladders/ (Accessed 11 December 2022).

Garner, P. (2021) Paul Garner: on his recovery from long covid. The BMJ Opinion [online]. Available from: https://blogs.bmj.com/bmj/2021/01/25/paul-garner-on-his-recovery-from-long-covid/ (Accessed 26 November 2025).

Gawthorpe, S. (2024) A Doctor's Story of Recovery from Long Covid. Living Proof: New Insights into Chronic Pain and Illness [online]. Available from: https://www.livingproof.org.uk/post/dr-sarah-recovery-story (Accessed 26 November 2025).

Gaynes, R. P. (2023) Google-Books-ID: NX22EAAAQBAJ. *Germ Theory: Medical Pioneers in Infectious Diseases*. John Wiley & Sons.

Gelech, J. M. & Desjardins, M. (2011) I am Many: The Reconstruction of Self Following Acquired Brain Injury. *Qualitative Health Research*. 21(1), 62–74.

Gillespie, K. (2023) *'With this face, can I take up space in the world?': Embodied geographies of facial difference*. UK: University of Glasgow.

Gleeson, B. (1996) A Geography for Disabled People? *Transactions of the Institute of British Geographers*. 21(2), 387–396.

Gleeson, B. (2002) *Geographies of Disability*. [Online]. London: Routledge.

Goffman, E. (1963) *Stigma: Notes on the Management of Spoiled Identity*. Simon and Schuster.

Golledge, R. G. (1993) Geography and the Disabled: A Survey with Special Reference to Vision Impaired and Blind Populations. *Transactions of the Institute of British Geographers*. [Online] 1863.

Goodley, D. (2024) *Disability Studies: An Interdisciplinary Introduction*. 3rd Edition. London, UK: SAGE Publications.

Gould, P. (1989) Geographic Dimensions of the AIDS Epidemic. *The Professional Geographer*. 41(1), 71–78.

Gould, P. et al. (1991) AIDS: Predicting the Next Map. *Interfaces*. 21(3), 80–92.

Gould, P. & Wallace, R. (1994) Spatial Structures and Scientific Paradoxes in the Aids Pandemic. *Geografiska Annaler: Series B, Human Geography*. 76(2), 105–116.

Greco, M. (2017) Pragmatics of explanation: Creative accountability in the care of 'medically unexplained symptoms'. *The Sociological Review*. 65(2), 110–129.

Greenhough, B. (2011) Citizenship, care and companionship: Approaching geographies of health and bioscience. *Progress in Human Geography*. 35(2), 153–171.

Griffin, D. O. (2024) Postacute Sequelae of COVID (PASC or Long COVID): An Evidenced-Based Approach. *Open Forum Infectious Diseases*. [Online] 11(9), ofae462.

Guest, C. & Corrigan, O. (2018) Extraordinary normalcy: Home, relationships and identities in narratives of unpaid care. *Health & Place*. [Online] 5371–78.

Guy's and St Thomas' NHS Foundation Trust (2024) *Coronavirus (COVID-19) recovery: Extreme tiredness (fatigue)* [online]. Available from: https://www.guysandstthomas.nhs.uk/health-information/coronavirus-covid-19-recovery/extreme-tiredness-fatigue (Accessed 14 July 2025).

Hale, C. (2021) What are energy impairment and ELCI? Chronic Illness Inclusion [online]. Available from: https://chronicillnessinclusion.org.uk/2021/04/28/what-are-energy-impairment-and-elci/ (Accessed 19 November 2025).

Hall, E. (2000) 'Blood, brain and bones': taking the body seriously in the geography of health and impairment. *Area*. 32(1), 21–29.

Hall, E. (2005) 'Workspaces: Reconfiguring the Disability-Employment Debate', in Ruth Butler & Hester Parr (eds) *Mind and Body Spaces: Geographies of Illness, Impairment and Disability*. [Online]. London: Routledge. pp. 138–154.

Hall, E. (2014) 'Geographies of Disability and Impairment', in *The Wiley Blackwell Encyclopedia of Health, Illness, Behavior, and Society*. [Online]. John Wiley & Sons, Ltd. pp. 686–691. [online]. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1002/9781118410868.wbehibs254 (Accessed 30 October 2025).

Hall, E. (2025) 'Geographies of Disability and Impairment', in *The Wiley Blackwell Encyclopedia of Health, Illness, Behavior, and Society*. [Online]. John Wiley & Sons, Ltd. pp. 1–6. [online]. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1002/9781118410868.wbehibs254.pub2 (Accessed 17 November 2025).

Hall, E. & Bates, E. (2019) Hatescape? A relational geography of disability hate crime, exclusion and belonging in the city. *Geoforum*. [Online] 101100–110.

Hall, E. & Wilton, R. (2017) Towards a relational geography of disability. *Progress in Human Geography*. 41(6), 727–744.

Hanlon, N. (2014) Doing health geography with feeling. *Social science & medicine (1982)*. [Online] 115144–146.

Hansen, N. & Philo, C. (2007) The Normality of Doing Things Differently: Bodies, Spaces and Disability Geography. *Tijdschrift voor Economische en Sociale Geografie*. 98(4), 493–506.

Haraway, D. (1988) Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective. *Feminist Studies*. 14(3), 575–599.

Harris, H. et al. (2023) Meaningful engagement through critical reflexivity: Engaging people with lived experience in continuing mental health professional development. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*. 26(5), 1793–1798.

Hollander, J. A. (2004) The Social Contexts of Focus Groups. *Journal of Contemporary Ethnography*. 33(5), 602–637.

Homewood, S. (2023) 'Self-Tracking to Do Less: An Autoethnography of Long COVID That Informs the Design of Pacing Technologies', in *Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems*. CHI '23. [Online]. 19 April 2023 New York, NY, USA: Association for Computing Machinery. pp. 1–14. [online]. Available from: https://dl.acm.org/doi/10.1145/3544548.3581505 (Accessed 21 November 2025).

Homewood, S. et al. (2024) 'The Unanticipated Use of Fitness Tracking Technologies During Post-COVID Syndrome', in *Proceedings of the 2024 ACM Designing Interactive Systems Conference*. DIS '24. [Online]. 1 July 2024 New York, NY, USA: Association for Computing Machinery. pp. 556–570. [online]. Available from: https://dl.acm.org/doi/10.1145/3643834.3661617 (Accessed 21 November 2025).

Hopkins, P. E. (2007) Thinking Critically and Creatively about Focus Groups. *Area*. 39(4), 528–535.

Howell, J. (2022) COVID-19 narratives and layered temporality. *Medical Humanities*. 48(2), 211–220.

Hunt, J. et al. (2022) Long Covid at the crossroads: Comparisons and lessons from the treatment of patients with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). *Journal of Health Psychology*. 27(14), 3106–3120.

Imrie, R. (1996) Ableist Geographies, Disablist Spaces: Towards a Reconstruction of Golledge's 'Geography and the Disabled'. *Transactions of the Institute of British Geographers*. 21(2), 397–403.

Imrie, R. (2001) Barriered and Bounded Places and the Spatialities of Disability. *Urban Studies*. 38(2), 231–237.

Imrie, R. (2004) Disability, embodiment and the meaning of the home. *Housing Studies*. 19(5), 745–763.

Imrie, R. (2010) ‘Disablement, embodiment and the meaning of the home’, in Vera Chouinard et al. (eds) *Towards Enabling Geographies: ‘Disabled’ Bodies and Minds in Society and Space*. Geographies of Health. Surrey, England: Ashgate Publishing Ltd. pp. 22–44.

Ireson, J. et al. (2022) Exploring invisibility and epistemic injustice in Long Covid-A citizen science qualitative analysis of patient stories from an online Covid community. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*. 25(4), 1753–1765.

Jarvis, L. (2022) Constructing the coronavirus crisis: narratives of time in British political discourse on COVID-19. *British Politics*. 17(1), 24–43.

Jayadeva, S. & Lupton, D. (2025) ‘Most People with Long COVID Are Their Own Doctors’: Self-Tracking and Online Patient Groups as Pathways to Challenging Epistemic Injustice. *Sociology*. [Online] [online]. Available from: https://journals.sagepub.com/doi/10.1177/00380385251351252 (Accessed 10 November 2025).

Jefferies, E. (2025) The ME Association fervently refutes the psychosomatic model of causation applies to ME/CFS or indeed Long Covid. The ME Association [online]. Available from: https://meassociation.org.uk/2025/03/the-me-association-fervently-refutes-the-psychosomatic-model-of-causation-applies-to-me-cfs-or-indeed-long-covid/ (Accessed 7 January 2026).

Johnson, C. (2021) Explaining Paul Garner’s Long COVID Recovery Story (???) Plus What Does It Mean? Health Rising [online]. Available from: https://www.healthrising.org/blog/2021/02/01/garner-recovery-long-covid-recovery-story/ (Accessed 7 January 2026).

Kafer, A. (2013) *Feminist, Queer, Crip*. Indiana University Press. [online]. Available from: https://www.jstor.org/stable/j.ctt16gz79x (Accessed 18 June 2025).

Kafer, A. (2021) After Crip, Crip Afters. *South Atlantic Quarterly*. 120(2), 415–434.

Kearns, R. A. (1993) Place and Health: Towards a Reformed Medical Geography∗. *The Professional Geographer*. 45(2), 139–147.

Kearns, R. A. (1995) Medical geography: making space for difference. *Progress in Human Geography*. 19(2), 251–259.

Kearns, R. A. (2014) The health in “life’s infinite doings”: A response to Andrews et al. *Social Science & Medicine*. [Online] 115147–149.

Kearns, R. (2018) ‘The Place of Primary Care Clinics’, in Valorie A Crooks et al. (eds) *Routledge Handbook of Health Geography*. London and New York: Routledge. pp. 244–250.

Kearns, R. A. & Joseph, A. E. (1993) Space in its place: Developing the link in medical geography. *Social Science & Medicine*. 37(6), 711–717.

Kenna, T. (2023) Neurodiversity in the city: Exploring the complex geographies of belonging and exclusion in urban space. *The Geographical Journal*. 189(2), 370–382.

Kennelly, C. E. et al. (2023) The lived experience of long COVID: A qualitative study of mental health, quality of life, and coping. *PLOS ONE*. [Online] 18(10), e0292630.

Kingod, N. et al. (2017) Online Peer-to-Peer Communities in the Daily Lives of People With Chronic Illness: A Qualitative Systematic Review. *Qualitative Health Research*. 27(1), 89–99.

Kingstone, T. et al. (2020) Finding the 'right' GP: a qualitative study of the experiences of people with long-COVID. *BJGP Open*. [Online] 4 (5), . [online]. Available from: https://bjgpopen.org/content/4/5/bjgpopen20X101143 (Accessed 6 November 2025).

Kitchin, R. (1998) 'Out of Place', 'Knowing One's Place': Space, power and the exclusion of disabled people. *Disability & Society*. 13(3), 343–356.

Kitchin, R. (1999) 'Moral and ethics in geographical studies of disability', in James D. Proctor & David Marshall Smith (eds) *Geography and Ethics: Journeys in a Moral Terrain*. Psychology Press. pp. 223–236.

Kitzinger, J. (1994) The methodology of Focus Groups: the importance of interaction between research participants. *Sociology of Health & Illness*. 16(1), 103–121.

Kohl, E. & McCutcheon, P. (2015) Kitchen table reflexivity: negotiating positionality through everyday talk. *Gender, Place & Culture*. 22(6), 747–763.

Komaroff, A. L. & Bateman, L. (2021) Will COVID-19 Lead to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome? *Frontiers in Medicine*. [Online] 7. [online]. Available from: https://www.frontiersin.org/journals/medicine/articles/10.3389/fmed.2020.606824/full (Accessed 19 November 2025).

Komaroff, A. L. & Lipkin, W. I. (2021) Insights from myalgic encephalomyelitis/chronic fatigue syndrome may help unravel the pathogenesis of postacute COVID-19 syndrome. *Trends in Molecular Medicine*. 27(9), 895–906.

Kralik, D. & van Loon, A. (2010) 'Transitional Processes and Chronic Illness', in Debbie Kralik et al. (eds) *Translating Chronic Illness Research into Practice*. UK: Wiley-Blackwell. pp. 17–36.

Krieger, N. (2005) Embodiment: a conceptual glossary for epidemiology. *Journal of Epidemiology and Community Health*. 59(5), 350–355.

Krishna, B. et al. (2023) Long COVID: what is known and what gaps need to be addressed. *British Medical Bulletin*. 147(1), 6–19.

Kung, C. S. J. & Steptoe, A. (2023) Changes in Internet use patterns among older adults in England from before to after the outbreak of the COVID-19 pandemic. *Scientific Reports*. [Online] 13(1), 3932.

Ladds, E. et al. (2020) Persistent symptoms after Covid-19: qualitative study of 114 “long Covid” patients and draft quality principles for services. *BMC Health Services Research*. [Online] 20(1), 1144.

Laurier, E. & Parr, H. (2000) Disability, Geography and Ethics: Emotions and interviewing in health and disability research. *Philosophy & Geography*. 3(1), 98–102.

Lavretsky, H. (2025) *A Pilot Randomized Trial of rTMS for Fatigue and Brain Fog and Neuropsychiatric Symptoms of Long-COVID.* [online]. Available from: https://clinicaltrials.gov/study/NCT06586398 (Accessed 6 January 2026).

Lazarus, R. S. & Folkman, S. (1984) *Stress, Appraisal, and Coping*. Springer Publishing Company.

Lea, J. (2018) ‘Non-representational geographies of health’, in Valorie A Crooks et al. (eds) *Routledge Handbook of Health Geography*. 1st edition London and New York: Routledge. pp. 144–151.

Lees, S. et al. (2021) Key social science priorities for long-term COVID-19 response. *BMJ Global Health*. [Online] 6(7). Available from: https://gh.bmj.com/content/6/7/e006741 (Accessed 6 November 2025).

Lescure, F.-X. et al. (2020) Clinical and virological data of the first cases of COVID-19 in Europe: a case series. *The Lancet Infectious Diseases*. 20(6), 697–706.

Lock, S. et al. (2005) Work after stroke: focusing on barriers and enablers. *Disability & Society*. 20(1), 33–47.

Locock, L. & Brown, J. B. (2010) ‘All in the same boat’? Patient and carer attitudes to peer support and social comparison in Motor Neurone Disease (MND). *Social Science & Medicine*. 71(8), 1498–1505.

Locock, L. et al. (2016) ‘I knew before I was told’: Breaches, cues and clues in the diagnostic assemblage. *Social Science & Medicine*. [Online] 15485–92.

Loftus, S. (2022) Re-examining ethical challenges of using ethnography to understand decision-making in family caregiving networks of children with feeding tubes. *Children’s Geographies*. [Online] 1–13.

Long COVID Physio (2023) *Pacing* [online]. Available from: https://longcovid.physio/pacing (Accessed 20 March 2025).

Long COVID Physio (2024) *Post-Exertional Symptom Exacerbation* [online]. Available from: https://longcovid.physio/post-exertional-symptom-exacerbation (Accessed 19 November 2025).

Longhurst, R. (1996) Refocusing groups: pregnant women's geographical experiences of Hamilton, New Zealand/Aotearoa. *Area*. 143–149.

Longhurst, R. (2001) *Bodies: Exploring Fluid Boundaries*. Critical Geographies. London and New York: Routledge.

Lotankar, Y. et al. (2025) Intersectionality and Long Covid: Understanding the Lived Experiences of Ethnic Minority Groups in the United Kingdom. *Health Expectations : An International Journal of Public Participation in Health Care and Health Policy*. [Online] 28(5), e70413.

Lucherini, M. (2015) *The everyday geographies of living with diabetes*. University of Glasgow.

Luna, F. (2009) Elucidating the Concept of Vulnerability: Layers Not Labels. *International Journal of Feminist Approaches to Bioethics*. 2(1), 121–139.

Lunt, J. et al. (2024) What workers can tell us about post-COVID workability. *Occupational Medicine (Oxford, England)*. 74(1), 15–23.

Lupton, D. (2015) Quantified sex: a critical analysis of sexual and reproductive self-tracking using apps. *Culture, Health & Sexuality*. 17(4), 440–453.

Lupton, D. (2016) *The Quantified Self: A Sociology of Self-Tracking*. Cambridge: Polity Press.

Lupton, D. (2017) *Digital Health: Critical and Cross-Disciplinary Perspectives*. [Online]. London: Routledge.

Lupton, D. (2021) *Doing Fieldwork in a Pandemic*. [online]. Available from: https://papers.ssrn.com/abstract=4228791 (Accessed 6 January 2026).

Lupton, D. (2025) 'The Social Aspects and Impacts of Long COVID', in Deborah Lupton (ed.) *Long COVID and Society: International Perspectives*. [Online]. Singapore: Springer Nature. pp. 3–31. [online]. Available from: https://doi.org/10.1007/978-981-96-9168-5_1 (Accessed 20 November 2025).

Lynch, M. (2000) Against Reflexivity as an Academic Virtue and Source of Privileged Knowledge. *Theory, Culture & Society*. 17(3), 26–54.

MacKian, S. (2000) Contours of coping: mapping the subject world of long-term illness. *Health & Place*. 6(2), 95–104.

MacKian, S. (2004) Mapping reflexive communities: visualizing the geographies of emotion. *Social & Cultural Geography*. 5(4), 615–631.

Madge, C. (1993) Boundary Disputes: Comments on Sidaway (1992). *Area*. 25(3), 294–299.

Madge, C. & O'Connor, H. (2002) On-line with e-mums: exploring the Internet as a medium for research. *Area*. 34(1), 92–102.

Madge, C. & O'Connor, H. (2005) Mothers in the Making? Exploring Liminality in Cyber/Space. *Transactions of the Institute of British Geographers*. 30(1), 83–97.

Mallon, S. & Elliott, I. (2019) The Emotional Risks of Turning Stories into Data: An Exploration of the Experiences of Qualitative Researchers Working on Sensitive Topics. *Societies*. 9(3), 62.

Marini, J. J. & Gattinoni, L. (2020) Management of COVID-19 Respiratory Distress. *JAMA*. [Online] 323 (22), 2329–2330.

Masana, L. (2011) 'Invisible chronic illness inside apparently healthy bodies', in Sylvie Fainzang & Claudie Haxaire (eds) *Of Bodies and Symptoms: Anthropological Perspectives on their Social and Medical Treatment*. Tarragona: Publicacions URV. pp. 127–150.

Mason, J. (2017) *Qualitative Researching*. 1–288.

Massey, D. (1992) A place called home. *New Formations*. 173–15.

Mayer, J., D. (2010) 'Medical Geography', In T Brown, S McLafferty, G Moon (Eds.). *A Companion to Health and Medical Geography*. Chichester: Blackwell Publishing Ltd. pp. 33-54.

McCormack, D. P. (2003) An event of geographical ethics in spaces of affect. *Transactions of the Institute of British Geographers*. 28(4), 488–507.

McDowell, L. (1999) *Gender, Identity and Place: Understanding Feminist Geogrphies*. Minneapolis: University of Minnesota Press.

McDowell, L. (2010) 'Interviewing: Fear and Liking in the Field', in *The SAGE Handbook of Qualitative Geography*. [Online]. 1 Oliver's Yard, 55 City Road London EC1Y 1SP: SAGE Publications, Inc. pp. 156–171. [online]. Available from: https://methods.sagepub.com/book/the-sage-handbook-of-qualitative-geography-srm/i956.xml (Accessed 6 January 2026).

Medinger, G. & Altmann, D. (2022) *The Long Covid Handbook*. UK: Penguin Random House.

Medved, M. I. & Brockmeier, J. (2008) Continuity Amid Chaos: Neurotrauma, Loss of Memory, and Sense of Self. *Qualitative Health Research*. 18(4), 469–479.

Meijering, L. et al. (2017) Interpreting therapeutic landscape experiences through rural stroke survivors' biographies of disruption and flow. *Journal of Rural Studies*. [Online] 51275–283.

Meijering, L. et al. (2019) Re-engaging with places: Understanding bio-geo-graphical disruption and flow in adult brain injury survivors. *Social Science & Medicine*. [Online] 23122–30.

Meleo-Erwin, Z. C. (2020) Bariatric Biosociality: Pushed Together, Pulled Apart. *Sage Open*. [Online] 10(1), 2158244019899060.

Merleau-Ponty, M. (1962) *Phenomenology of Perception*. Donald A. Landes (ed.). New York: Routledge.

Mersey Care NHS Foundation Trust (2025) *Conserving your energy after COVID-19 guide* [online]. Available from: https://www.merseycare.nhs.uk/patient-leaflets/conserving-your-energy-after-covid?back=2455 (Accessed 14 July 2025).

Milligan, C. (2005) 'Without these walls: a geography of mental ill health', in Ruth Butler & Hester Parr (eds) *Mind and Body Spaces: Geographies of Illness, Impairment and Disability*. London and New York: Routledge. pp. 217–235.

Miserandino, C. (2003) The Spoon Theory written by Christine Miserandino. The Spoon Theory [online]. Available from: https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/ (Accessed 24 March 2025).

Miserandino, C. (2017) 'The Spoon Theory', in Lennard J. Davis (ed.) *Beginning with Disability: A Prime*. 1st edition New York: Routledge. p. Chapter 18. [online]. Available from: https://doi.org/10.4324/9781315453217.

Mol, A. (2002) *The Body Multiple: Ontology in Medical Practice*. Duke University Press.

Morgan, D. L. (1995) Why Things (Sometimes) Go Wrong in Focus Groups. *Qualitative Health Research*. 5(4), 516–523.

Morgan, D. L. (1997) *Focus Groups as Qualitative Research*. [Online]. SAGE Publications, Inc. [online]. Available from: https://methods.sagepub.com/book/mono/focus-groups-as-qualitative-research/toc (Accessed 7 January 2026).

Morgan, D. L. & Krueger, R. A. (1993) 'When to use focus groups and why', in *Successful focus groups: Advancing the state of the art*. Sage focus editions, Vol. 156. [Online]. Thousand Oaks, CA, US: Sage Publications, Inc. pp. 3–19.

Moss, P. (1997) Negotiating spaces in home environments: Older women living with arthritis. *Social Science & Medicine*. 45(1), 23–33.

Moss, P. (1999) 'Autobiographical Notes on Chronic Illness', in *Mind and Body Spaces: Geographies of Illness, Impairment and Disability*. London: Routledge. pp. 151–162.

Moss, P. (ed.) (2002) *Feminist Geography in Practice: Research and Methods*. Malden, MA: Wiley-Blackwell. [online]. Available from: https://www.wiley.com/en-us/Feminist+Geography+in+Practice%3A+Research+and+Methods-p-9780631220206 (Accessed 7 January 2026).

Moss, P. & Dyck, I. (1999) Body, Corporeal Space, and Legitimating Chronic Illness: Women Diagnosed with M.E. *Antipode*. 31(4), 372–397.

Moss, P. & Dyck, I. (2001) ‘Material Bodies Precariously Positioned: Women Embodying Chronic Illness in the Workplace’, in Isabel Dyck et al. (eds) *Geographies of Women’s Health*. Routledge international studies of women and place. London and New York: Routledge. pp. 231–247.

Moss, P. & Dyck, I. (2003) *Women, Body, Illness: Space and Identity in the Everyday Lives of Women with Chronic Illness*. USA: Rowman & Litterfield Publishers, Inc.

Mowl, G. & Fuller, G. (2014) ‘Geographies of disability’, In R Pain, J Gough, G Mowl, M Barke, R MacFarlene, D Fuller (Eds.). *Introducing Social Geographies*. Routledge. p.164-186.

Mullard, J. C. R. et al. (2023) Towards evidence-based and inclusive models of peer support for long covid: A hermeneutic systematic review. *Social Science & Medicine*. [Online] 320115669.

NASA (2021) *Thermodynamics* [online]. Available from: https://www.grc.nasa.gov/www/k-12/airplane/thermo.html (Accessed 26 November 2025).

Navarro, S. A. & Hernandez, S. L. (eds.) (2022) *The Color of COVID-19: The Racial Inequality of Marginalized Communities*. [Online]. London: Routledge.

Nettleton, S. et al. (2004) Enigmatic Illness: Narratives of Patients who Live with Medically Unexplained Symptoms. *Social Theory & Health*. 2(1), 47–66.

Nettleton, S. (2006) ‘I just want permission to be ill’: Towards a sociology of medically unexplained symptoms. *Social Science & Medicine*. 62(5), 1167–1178.

NHS (2023) *Home oxygen therapy* [online]. Available from: https://www.nhs.uk/tests-and-treatments/home-oxygen-treatment/ (Accessed 17 June 2025).

NHS (2025) *Long COVID* [online]. Available from: https://www.nhs.uk/conditions/long-covid/ (Accessed 7 November 2025).

NHS Scotland (2025) *COVID-19: Long covid (Guidelines)* | *Right Decisions* [online]. Available from: https://rightdecisions.scot.nhs.uk/tam-treatments-and-medicines-nhs-highland/adult-therapeutic-guidelines/covid-19-coronavirus/covid-19-primary-care-community-and-care-home/covid-19-long-covid-guidelines/ (Accessed 7 November 2025).

NICE (2025) *COVID-19 rapid guideline: managing the long-term effects of COVID-19*. p.50. [online]. Available from: https://www.nice.org.uk/guidance/ng188 (Accessed 6 November 2025).

Nietzsche, F. W. (2001) *The gay science: with a prelude in German rhymes and an appendix of songs*. Cambridge texts in the history of philosophy. Bernard Williams & Josefine Nauckhoff (eds). Cambridge, UK; New York: Cambridge University Press.

NIH (2024) *Routine lab tests are not a reliable way to diagnose long COVID* [online]. Available from: https://www.nih.gov/news-events/news-releases/routine-lab-tests-are-not-reliable-way-diagnose-long-covid (Accessed 17 November 2025).

NIH (2025) *RECOVER: Researching COVID to Enhance Recovery* [online]. Available from: https://recovercovid.org/ (Accessed 17 November 2025).

Oksanen, A. et al. (2024) Online communities come with real-world consequences for individuals and societies. *Communications Psychology*. [Online] 2(1), 71.

Oldenburg, R. (1999) Google-Books-ID: o4ZFCgAAQBAJ. *The Great Good Place: Cafes, Coffee Shops, Bookstores, Bars, Hair Salons, and Other Hangouts at the Heart of a Community*. Hachette Books.

Oliver, M. (1983) *Social Work with Disabled People*. [Online]. London: Macmillan Education UK. [online]. Available from: http://link.springer.com/10.1007/978-1-349-86058-6 (Accessed 30 October 2025).

ONS (2022a) *Accuracy of COVID-19 tests and how to identify different variants - Office for National Statistics* [online]. Available from: https://www.ons.gov.uk/aboutus/transparencyandgovernance/freedomofinformationfoi/accuracyofcovid19testsandhowtoidentifydifferentvariants (Accessed 19 June 2025).

ONS (2022b) *Coronavirus (COVID-19) Infection Survey technical article: Cumulative incidence of the number of people who have tested positive for COVID-19, UK - Office for National Statistics* [online]. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/coronaviruscovid19infectionsurveytechnicalarticlecumulativeincidenceofthenumberofpeoplewhohavetestedpositiveforcovid19uk/22april2022 (Accessed 3 June 2025).

ONS (2023) *Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK - Office for National Statistics* [online]. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/2february2023 (Accessed 7 November 2025).

O'Rourke, M. (2022) *The Invisible Kingdom*. New York: Riverhead Books.

Parker, G. & Pausé, C. J. (2018) Pregnant with possibility: Negotiating fat maternal subjectivity in the "War on Obesity". *Fat Studies*. 7(2), 124–134.

Parr, H. (1998) Mental Health, Ethnography and the Body. *Area*. 30(1), 28–37.

Parr, H. (1999) Delusional geographies: the experiential worlds of people during madness/illness. *Environment and Planning D: Society and Space*. 17(6), 673–690.

Parr, H. (2000) Interpreting the ‘hidden social geographies’ of mental health: ethnographies of inclusion and exclusion in semi-institutional places. *Health & Place*. 6(3), 225–237.

Parr, H. (2002a) Medical geography: diagnosing the body in medical and health geography, 1999–2000. *Progress in Human Geography*. 26(2), 240–251.

Parr, H. (2002b) New Body-Geographies: The Embodied Spaces of Health and Medical Information on the Internet. *Environment and Planning D: Society and Space*. 20(1), 73–95.

Parr, H. (2003) Medical geography: care and caring. *Progress in Human Geography*. 27(2), 212–221.

Parr, H. (2004) Medical geography: critical medical and health geography? *Progress in Human Geography*. 28(2), 246–257.

Parr, H. (2007) Mental Health, Nature Work, and Social Inclusion. *Environment and Planning D: Society and Space*. 25(3), 537–561.

Parr, H. (2008a) *Mental Health and Social Space*. 1st edition. [Online]. John Wiley & Sons, Ltd. [online]. Available from: https://onlinelibrary.wiley.com/doi/10.1002/9780470712924 (Accessed 7 May 2025).

Parr, H. (2008b) ‘Virtual Communities: The Internet and Online Geographies of Self-Help’, in *Mental Health and Social Space: Towards Inclusionary Geographies?*. RGS-IBG book series. [Online]. John Wiley & Sons, Ltd. pp. 135–161. [online]. Available from: https://onlinelibrary.wiley.com/doi/abs/10.1002/9780470712924.ch6 (Accessed 6 August 2025).

Parr, H. (2025) Thinking with the foggy space between. *Dialogues in Human Geography*. [Online] 20438206251364959.

Parr, H. & Davidson, J. (2008) ‘*Virtual trust: online emotional intimacies in mental health support*’, in J. Brownlie et al. (eds) London: Routledge. pp. 33–53. [online]. Available from: http://www.routledge.com/books/details/9780415958516/ (Accessed 20 November 2025).

Parr, H. & Philo, C. (2003) Rural mental health and social geographies of caring. *Social & Cultural Geography*. 4(4), 471–488.

Parr, H. et al. (2003) ‘That awful place was home’: Reflections on the Contested Meanings of Craig Dunain Asylum. *Scottish Geographical Journal*. 119(4), 341–360.

Parr, H. et al. (2005) ‘‘Not a Display of Emotions’: Emotional Geographies in the Scottish Highlands’, in *Emotional Geographies*. Routledge. pp. 87–101.

Pascoe Leahy, C. (2022) The afterlife of interviews: explicit ethics and subtle ethics in sensitive or distressing qualitative research. *Qualitative Research*. 22(5), 777–794.

Patton, M. Q. (2002) *Qualitative research and evaluation methods*. 3rd edition. Thousand Oaks, CA: SAGE Publications. [online]. Available from: https://www.scirp.org/reference/ReferencesPapers?ReferenceID=757192 (Accessed 7 January 2026).

Pecoraro, V. et al. (2022) Estimate false-negative RT-PCR rates for SARS-CoV-2. A systematic review and meta-analysis. *European Journal of Clinical Investigation*. 52(2), e13706.

Peluso, M. J. & Deeks, S. G. (2024) Mechanisms of long COVID and the path toward therapeutics. *Cell*. 187(20), 5500–5529.

Perego, E. et al. (2020) Why we need to keep using the patient made term “Long Covid”. The BMJ Opinion [online]. Available from: https://blogs.bmj.com/bmj/2020/10/01/why-we-need-to-keep-using-the-patient-made-term-long-covid/ (Accessed 21 November 2025).

Philo, C. (2000) ‘The Birth of the Clinic’: An Unknown Work of Medical Geography. *Area*. 32 (1), 11–19.

Philo, C. (2001) Accumulating populations: bodies, institutions and space. *International Journal of Population Geography*. 7(6), 473–490.

Philo, C. (2007) A vitally human medical geography? Introducing Georges Canguilhem to geographers. *New Zealand Geographer*. 63(2), 82–96.

Philo, C. et al. (2015) New Energy Geographies: A Case Study of Yoga, Meditation and Healthfulness. *Journal of Medical Humanities*. 36(1), 35–46.

Pile, S. (2010) Emotions and affect in recent human geography. *Transactions of the Institute of British Geographers*. 35(1), 5–20.

Price, J. M. (2002) The Apotheosis of Home and the Maintenance of Spaces of Violence. *Hypatia*. 17(4), 39–70.

Proal, A. D. & VanElzakker, M. B. (2021) Long COVID or Post-acute Sequelae of COVID-19 (PASC): An Overview of Biological Factors That May Contribute to Persistent Symptoms. *Frontiers in Microbiology*. [Online] 12698169.

Rabinow, P. (2010) Artificiality and Enlightenment: From Sociobiology to Biosociality. *Politix*. 90(2), 21–46.

Rabinow, P. & Rose, N. (2006) Biopower Today. *BioSocieties*. 1(2), 195–217.

Rajan, S. et al. (2021) *In the wake of the pandemic: Preparing for Long COVID*. European Observatory Policy Briefs. Copenhagen (Denmark): European Observatory on Health Systems and Policies. [online]. Available from:

http://www.ncbi.nlm.nih.gov/books/NBK569598/ (Accessed 5 November 2025).

Ratnam, C. (2019) Listening to difficult stories: Listening as a research methodology. *Emotion, Space and Society*. [Online] 3118–25.

Raveendran, A. V. et al. (2021) Long COVID: An overview. *Diabetes & Metabolic Syndrome: Clinical Research & Reviews*. 15(3), 869–875.

Reuschke, D. & Houston, D. (2023) Full article: The impact of Long COVID on the UK workforce. *Applied Economics Letters*. 30(18), 2510–2514.

Rose, G. (1993) *Feminism and geography: the limits of geographical knowledge*. Cambridge: Polity Press.

Rose, G. (1997) Situating knowledges: positionality, reflexivities and other tactics. *Progress in Human Geography*. 21(3), 305–320.

Rose, G. (2003) Family Photographs and Domestic Spacings: A Case Study. *Transactions of the Institute of British Geographers*. 28(1), 5–18.

Rose, N. (2007) *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-First Century*. [Online]. Princeton University Press. [online]. Available from: https://www.jstor.org/stable/j.ctt7rqmf (Accessed 13 November 2025).

Rose-Redwood, R. et al. (2020) Geographies of the COVID-19 pandemic. *Dialogues in Human Geography*. 10(2), 97–106.

Roth, P. H. & Gadebusch-Bondio, M. (2022) The contested meaning of “long COVID” – Patients, doctors, and the politics of subjective evidence. *Social Science & Medicine*. [Online] 292114619.

Royal Cornwall Hospitals NHS Trust (2025) *Long COVID Rehabilitation Guide: Patient Information*. [online]. Available from: https://doclibrary-rcht.cornwall.nhs.uk/DocumentsLibrary/RoyalCornwallHospitalsTrust/PatientInformation/Therapies/RCHT3036LongCOVIDRehabilitationGuide.pdf (Accessed 14 July 2025).

Rushforth, A. et al. (2021) Long Covid – The illness narratives. *Social Science & Medicine*. [Online] (286).

Russell, D. et al. (2022) Support amid uncertainty: Long COVID illness experiences and the role of online communities. *Ssm - Qualitative Research in Health*. [Online] (2).

Samuels, E. (2017) Six Ways of Looking at Crip Time. *Disability Studies Quarterly*. [Online] 37(3). Available from: https://dsq-sds.org/index.php/dsq/article/view/5824 (Accessed 14 May 2025).

Scarry, E. (1985) *Body in Pain: The Making and Unmaking of the World*. Oxford, UNITED KINGDOM: Oxford University Press, Incorporated. [online]. Available

from: http://ebookcentral.proquest.com/lib/gla/detail.action?docID=472372 (Accessed 15 May 2025).

Schermuly, A. C. et al. (2021) ‘I’m not an activist!’: digital self-advocacy in online patient communities. *Critical Public Health*. [Online] 31(2), 204–213.

Schneiders, M. L. et al. (2022) Between division and connection: a qualitative study of the impact of COVID-19 restrictions on social relationships in the United Kingdom. *Wellcome Open Research*. [Online] 76.

Schroeder, D. & Gefenas, E. (2009) Vulnerability: Too Vague and Too Broad? *Cambridge Quarterly of Healthcare Ethics*. [Online] 18(2), 113–121.

Scot Gov (2025) *Adult Disability Payment* [online]. Available from: https://www.mygov.scot/adult-disability-payment (Accessed 25 November 2025).

Sedgewick, F. et al. (2021) Google-Books-ID: 5As4EAAAQBAJ. *Autism and Masking: How and Why People Do It, and the Impact It Can Have*. Jessica Kingsley Publishers.

Segrott, J. & Doel, M. A. (2004) Disturbing geography: obsessive-compulsive disorder as spatial practice. *Social & Cultural Geography*. [Online] 5(4), 597–614.

Senanayake, N. (2022) Theorising liminal states of health: A spatio-temporal analysis of undiagnosis and anticipatory diagnosis in the shadow of toxic pollution. *Transactions of the Institute of British Geographers*. [Online] 47(2), 363–377.

Shabnam, S. et al. (2023) Socioeconomic inequalities of Long COVID: a retrospective population-based cohort study in the United Kingdom. *Journal of the Royal Society of Medicine*. [Online] 116(8), 263–273.

Shah, A. D. et al. (2023) Long Covid symptoms and diagnosis in primary care: A cohort study using structured and unstructured data in The Health Improvement Network primary care database. *PLOS ONE*. [Online] 18(9).

Shakespeare, T. (2013) *Disability Rights and Wrongs Revisited*. 2nd edition. [Online]. London: Routledge.

Sharp, J. P. et al. (2000) ‘Entanglements of power: geographies of domination/resistance.’, in Ronan Paddison et al. (eds) *Entanglements of Power: Geographies of Domination/Resistance*. Critical Geographies. London and New York: Routledge. pp. 1–42. [online]. Available from: https://www.routledge.com/Entanglements-of-Power-Geographies-of-DominationResistance/Paddison-Philo-Routledge-Sharp/p/book/9780415184359 (Accessed 18 November 2025).

Silverman, D. (2022) *Doing Qualitative Research*. 6th edition. UK: SAGE Publications. [online]. Available from:

https://www.scirp.org/reference/referencespapers?referenceid=3283805 (Accessed 7 January 2026).

Singer, M. (2004) The social origins and expressions of illness. *British Medical Bulletin*. [Online] 69(1), 9–16.

Skelton, T. & Valentine, G. (2010) '"It's my umbilical cord to the world … the Internet": D/deal and hard of hearing people's information communication practices.', in Vera Chouinard et al. (eds) *Towards Enabling Geographies: 'disabled' Bodies and Minds in Society and Space*. Ashgate Publishing, Ltd. pp. 85–105.

Smith, N. D. (2013) *The everyday social geographies of living with epilepsy*. PhD thesis. University of Glasgow. [online]. Available from: https://eleanor.lib.gla.ac.uk/record=b3004343 (Accessed 9 April 2025).

Smyth, N. et al. (2022) Exploring the lived experience of Long Covid in black and minority ethnic groups in the UK: Protocol for qualitative interviews and art-based methods. *PLOS ONE*. [Online] 17(10).

Sothern, M. B. (2007) 'HIV+ Bodyspace: AIDS and the Queer Politics of Future Negation in Aotearoa/New Zealand', in G Brown et al. (eds) *Geographies of Sexualities: Theory, Practices and Politics*. Ashgate. pp. 181–193.

Stables, J. & Smith, F. (1999) '"Caught in the Cinderella Trap": Narratives of Disabled Parents and Young Carers', in Ruth Butler & Hester Parr (eds) *Mind and body spaces: geographies of illness, impairment and disability*. London: Routledge. pp. 256–268.

Stanisforth, A. (2024) Trust the Process: How I beat Long Covid. Adversity Adventurer: Alex Stanisforth [online]. Available from: https://www.alexstaniforth.com/long-covid/trust-the-process-how-i-beat-long-covid/ (Accessed 26 November 2025).

Stevenson, F. A. et al. (2007) Information from the Internet and the doctor-patient relationship: the patient perspective--a qualitative study. *BMC family practice*. [Online] 847.

Strauss, A. & Corbin, J. (1998) *Basics of Qualitative Research Techniques and Procedures for Developing Grounded Theory.* Thousand Oaks, CA: SAGE Publications. [online]. Available from: https://www.scirp.org/reference/referencespapers?referenceid=1643862 (Accessed 7 January 2026).

Stutzin Donoso, F. (2025) 'What can the lived experience of chronicity teach us about long COVID?: From illness narratives to structural injustice in chronic disease', in Silvia Camporesi et al. (eds) *Crisis, Inequity, and Legacy*. 1st edition [Online]. Oxford University PressNew York, NY. pp. 229–246. [online]. Available from: https://academic.oup.com/book/60858/chapter/530101864 (Accessed 26 August 2025).

Taylor, A. K. et al. (2021) ‘Reluctant pioneer’: A qualitative study of doctors’ experiences as patients with long COVID. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*. [Online] 24(3), 833–842.

Thrift, N. (1997) ‘The Still Point: Resistance, expressive embodiment and dance’, in S Pile, M Keith (Eds.) *Geographies of Resistance*. Routledge. p.124-151.

Thrift, N. (2004) Intensities of Feeling: Towards a Spatial Politics of Affect. *Geografiska Annaler. Series B, Human Geography*. 86(1), 57–78.

Todd, J. D. (2024) Exploring young trans people’s everyday experiences of ‘out-of-placeness’ and socio-bodily dysphoria. *Transactions of the Institute of British Geographers*. [Online] 49(2), e12662.

UK Gov (n.d.) *Personal Independence Payment (PIP)* [online]. Available from: https://www.gov.uk/pip (Accessed 25 November 2025).

Valentine, G. & Holloway, S. L. (2002) Cyberkids? Exploring Children’s Identities and Social Networks in On-line and Off-line Worlds. *Annals of the Association of American Geographers*. [Online] 92(2), 302–319.

Warf, B. (2019) Teaching Digital Divides. *Journal of Geography*. [Online] 118(2), 77–87.

Whitaker, M. et al. (2022) Persistent COVID-19 symptoms in a community study of 606,434 people in England. *Nature Communications*. [Online] 13(1), 1957.

WHO (2020a) *Naming the coronavirus disease (COVID-19) and the virus that causes it* [online]. Available from: https://www.who.int/emergencies/diseases/novel-coronavirus-2019/technical-guidance/naming-the-coronavirus-disease-(covid-2019)-and-the-virus-that-causes-it (Accessed 7 January 2026).

WHO (2020b) *WHO Director-General’s opening remarks at the media briefing on COVID-19 - 20 November 2020* [online]. Available from: https://www.who.int/news-room/speeches/item/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---20-november-2020 (Accessed 5 January 2026).

WHO (2022) *Post COVID-19 condition (Long COVID)* [online]. Available from: https://www.who.int/europe/news-room/fact-sheets/item/post-covid-19-condition (Accessed 6 November 2025).

WHO (2023a) *Clinical management of COVID-19: Living guideline*. [online]. Available from: https://files.magicapp.org/guideline/be40cb35-5101-4307-8ae6-06b5694bf575/published_guideline_6915-7_0.pdf (Accessed 18 March 2023).

WHO (2023b) *WHO Director-General’s opening remarks at the media briefing – 5 May 2023* [online]. Available from: https://www.who.int/director-

general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing---5-may-2023 (Accessed 3 June 2025).

Wikgren, M. (2001) Health discussions on the Internet: A study of knowledge communication through citations. *Library & Information Science Research*. [Online] 23(4), 305–317.

Wilkinson, S. (1998) Focus group methodology: a review. *International Journal of Social Research Methodology*. [Online] 1(3), 181–203.

Williams, G. H. (1989) Hope for the humblest? The role of self-help in chronic illness: the case of ankylosing spondylitis. *Sociology of Health & Illness*. [Online] 11(2), 135–158.

Wilton, R. D. (1996) Diminished worlds? The geography of everyday life with HIV/AIDS. *Health & Place*. [Online] 2(2), 69–83.

Wilton, R. D. (1999) Qualitative Health Research: Negotiating Life with HIV/AIDS. *The Professional Geographer*. [Online] 51(2), 254–264.

Wilton, R. D. (2006) Disability Disclosure in the Workplace. *Just Labour*. [Online] [online]. Available from: https://justlabour.journals.yorku.ca/index.php/justlabour/article/view/107 (Accessed 3 April 2025).

Wolch, J. & Philo, C. (2000) From distributions of deviance to definitions of difference: past and future mental health geographies. *Health & Place*. [Online] 6(3), 137–157.

Wong, T. L. & Weitzer, D. J. (2021) Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)—A Systemic Review and Comparison of Clinical Presentation and Symptomatology. *Medicina*. [Online] 57(5), 418.

World Health Organisation (2025) *International Classification of Diseases, Eleventh Revision (ICD-11)*. [online]. Available from: https://icd.who.int/browse/2025-01/mms/en#2024855916.

World Physiotherapy (2021) *World Physiotherapy response to COVID-19: Briefing Paper 9*. [online]. Available from: https://world.physio/sites/default/files/2021-07/Briefing-Paper-9-Long-Covid-FINAL-English-202107.pdf (Accessed 20 March 2025).

Xu, Y. et al. (2025) The Emergence of Artificial Intelligence in Anticipatory Urban Governance: Multi-Scalar Evidence of China's Transition to City Brains. *Journal of Urban Technology*. [Online] 32(3), 9–33.

Ziauddeen, N. et al. (2022) Characteristics and impact of Long Covid: Findings from an online survey. *PLOS ONE*. [Online] 17(3), e0264331.

Ziebland, S. & Wyke, S. (2012) Health and Illness in a Connected World: How Might Sharing Experiences on the Internet Affect People's Health? *The Milbank Quarterly*. [Online] 90(2), 219–249.

Appendices

Appendix A: Call for participants living with Long Covid

Appendix B: Individual interview themes

1. Your story living with Long Covid – impact on everyday life.
2. Adapting your life with a new chronic illness.
3. Your experience of healthcare spaces, diagnosis and treatment (both doctor-prescribed and experimental).
4. Managing, coping and recovery.
5. Experience of (online) support.
6. Understanding Long Covid.
7. Reasons for participating in this research.

Appendix C: Focus group interview schedule

1. One participant said to me, “I am a Long Covid sufferer or survivor, depending on how you look at it.” What are your thoughts on this statement?
2. Have you accepted a new life/illness identity with Long Covid?
3. How do you “plan, pace and prioritise” around an illness which is so unpredictable and so variable?
4. What it is like living with an invisible illness, or what does the term “invisible illness” mean to you?
5. How has your relationship to your home changed since Long Covid – does it feel more like sanctuary or a trap, or do you have another word to describe your home?
6. One participant said to me, “with Long Covid, the pandemic isn’t over”, how do you relate to this statement?
7. How has it felt sharing your experience today with others who are affected by Long Covid?

Appendix D: Call for healthcare professionals to participate

Appendix E: Codebook excerpt

Codes	Meaning	Related codes	Sub-codes	Meaning	Related codes
Acceptance (lack of)	The extent of acceptance; spatially and temporally bound; here, "for now."	BGG disruption; coping mechanism; stuck in space and time; new normal; unfulfilling.	**Grief**	Grieving over a loss of a previous life/identity; struggling to accept	Sense of self
			Learning to live	Learning to live with LC as means of acceptance	BGG flow; new normal; PPP
			Relational acceptance	Other people accepting your illness	Awareness (lack of); invisible illness; relational impact; misunderstanding; support
			Relative illness	Comparing individual LC to other people/other illnesses as a means of accepting their degree of illness ("not that bad compared to others")	
			Questioning	The extent to which participants look for an explanation as to why they are affected by LC, or their attempts to manage	Acceptance (lack of); understanding LC
Advocating	Reasons for advocating; needing others to advocate for them when they can't advocate for themselves	Understanding LC; energy geographies	**Voice**	Wanting to have a voice and be heard	
Biogeographical disruption	General discussions about their biography/previous self/significant aspects of everday life that have been disrupted; living a limited life; relational disruptions. (This theme is very relational and interconnected, and sub-themes formed mostly to find things easier, but many experiences fall into severl sub-themes).	Acceptance (lack of); energy geographies	**Disrupted identity**	Disrupting their sense of self	Disrupted purpose; disrupted work
			Disrupted independence	Depending on support	Support
			Disrupted mobility	Disrupted ability to move; from home, in a car, being active, by themselves	Disrupted independence; disrupted hobbies
			Disrupted purpose	Can no longer fulfil their previous life purpose - work, family, hobbies etc.	Disrupted identity; disrupted hobbies; disrupted work; disrupted relationships.
			Disrupted relationships	Broken relationships or tensions created between partners, family, friends	Friends/family support; disrupted purpose
			Disrupted spaces	Disruption to everyday routine spaces - (subcodes for home; hobbies; social; work).	Disrupted purpose
			Disrupted time	Slowing down; having time but no energy; PPP as a means of adapting; can't be spontaneous; future?	PPP; energy geographies

Appendix F: The Spoon Theory

Figure 1: An illustration of Miserandino's The Spoon Theory, demonstrating how everyday activities require varying amounts of 'spoons' (energy) (Burning Nights, 2025 [Accessed 25th March 2025]).

Figure 2: An illustration of spoons as a representation of the body's batter, depicting how, similar to a conventional battery, spoons (or energy) are depleted through everyday activities (as shown in Figure 1) (Burning Nights, 2025 [Accessed 25th March 2025]).