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THE EVERYDAY SOCIAL GEOGRAPHIES OF LIVING WITH EPILEPSY

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ABSTRACT

Radical, 'eventful' bodily vulnerability has yet to receive sustained attention in contemporary human geography. As one way of addressing the implications of existential vulnerability, this thesis explores the social geographies of people living with epilepsy. It draws upon multiple-methods research comprising an extensive mixed-methods questionnaire and semi-structured interviews, all conducted with people with epilepsy who are members of the charity, Epilepsy Scotland, the project partner. By paying attention to the (post-)phenomenological experience of 'seizures', the thesis argues that a failure to appreciate the complex and often extremely troubling spatialities of epileptic episodes invariably results in sustaining the stigmatisation of epilepsy and the partial views of 'outsiders'. By exploring changed, changing and changeable relations between self, body, space, time and others, the thesis suggests that spatial behaviours in and across different places shift according to various biographical, social and illness experiences and contexts. More specifically, it contends that certain spaces become *risky* some or all of the time because of the body that not only threatens personal disorientation but also the very foundations of the social order. While there is a corresponding risk that individuals with epilepsy will confine themselves within the socially (although not materially) contained homeplace, many adopt active and resourceful practices, taking into account immediate time-space and embodied knowledges so as to resist being told what they can do, where and when. Disciplining the 'epileptic body' and environment to accommodate the unpredictability of seizures are put forward as a challenging case study for thinking through how the vital vulnerabilities of everyday life are made sense of through the very governmental regimes that they will always escape.

CONTENTS

LIST OF FIGURES AND TABLES	v
ACKNOWLEDGEMENTS.....	vi
AUTHOR'S DECLARATION	viii
LIST OF ABBREVIATIONS.....	ix
CHAPTER ONE:	1
INTRODUCTION: PLACING EPILEPSY	
CHAPTER TWO:	16
LITERATURE REVIEW: WHERE DOES EPILEPSY 'FIT'?	
CHAPTER THREE:	46
KNOWING 'ILL' BODIES THROUGH MULTIPLE METHODS	
CHAPTER FOUR:	77
THE PHENOMENOLOGY OF PAROXYSMAL BODY EVENTS: SEIZURE TIME-SPACES	
CHAPTER FIVE:	100
EMBODYING (THE POTENTIAL FOR) DISORDER: THE ANARCHIC BODY IN SEIZURE	
CHAPTER SIX:	132
THE 'LIFE AND TIMES' OF LIVING WITH EPILEPSY	
CHAPTER SEVEN:	164
DISCIPLINING FAMILIAR AND ITINERANT SPATIALITIES	
CHAPTER EIGHT:.....	197
FINDING ONE'S 'WAY' WITH EPILEPSY: A VITAL POLITICS OF EVERYDAY LIFE	
CHAPTER NINE:	227
CONCLUSION: RE-PRESENTING THE 'EPILEPTIC BODY'	
REFERENCES.....	238

APPENDICES

APPENDIX 1: QUESTIONNAIRE COVER LETTER.....	267
APPENDIX 2: POSTAL QUESTIONNAIRE	269
APPENDIX 3: ONLINE QUESTIONNAIRE SCREENSHOTS.....	281
APPENDIX 4: QUESTIONNAIRE DESCRIPTIVE RESULTS.....	282
APPENDIX 5: INTERVIEWEES BREAKDOWN.....	288
APPENDIX 6: SEMI-STRUCTURED INTERVIEW SCHEDULE	291
APPENDIX 7: NVIVO SCREENSHOT	294

LIST OF FIGURES AND TABLES

FIGURES

Figure 1: Auras and Action.....	89
Figure 2: The Significance of where a seizure occurs	104
Figure 3: Comfort with different witnesses to a seizure	106
Figure 4: Comfort talking about epilepsy with different people	109
Figure 5: Simultaneous Temporalities	134
Figure 6: Dynamics of the lifecourse following diagnosis (Wilton 1996: 77)	143
Figure 7: SIGN Guidelines for ‘information to be discussed with patients and carers’	201
Figure 8: Seizure diary.....	217

TABLES

Table 1: Piloting Feedback.....	54
Table 2: Relationship between experiencing seizures and concealing epilepsy	57
Table 3: Contingency Table Displaying Observed and Expected Counts.....	57
Table 4: Relationships between variables	59
Table 5: Interviewee Demographic Information	72
Table 6: Seizure classifications.....	94
Table 7: Seizure Frequency.....	146
Table 8: How much does epilepsy impact on your normal socialising with family, friends or groups?	147
Table 9: How often does epilepsy impact on the types of work (paid or voluntary) you are able to do?	152
Table 10: How safe are the following places relative to the possibility of having a seizure?	180
Table 11: Feelings of safety on a bus.....	191

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Sitting in my usual chair, which long ago lost any semblance of comfortability (it now resembles a cushion-built Frankenstein's monster), I now face up to the very real and imminent threat of life beyond the PhD. It's strange how what initially seemed like a long time to complete one research project has passed so quickly; and yet the matter of days until I finally submit this thesis seem like both an eternity and, worryingly, no time at all. I anticipate feeling a bit lost for a while because, even though I will be happy to submit, I have grown accustomed to these long writing sessions. Hell, I might even enter the outside world for something other than milk.

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partner in art, music, travel, eating, drinking, love, life and times, Anjo: thank you for being so supportive and patient – you can book those tickets now!

AUTHOR'S DECLARATION

I declare that except where explicit reference is made to the contribution of others, that this thesis 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.

Niall Smith

26th June 2013.

LIST OF ABBREVIATIONS

AED – Anti-epileptic drugs

ES – Epilepsy Scotland

ESN – Epilepsy Specialist Nurse

JEC – Joint Epilepsy Council

QoL – Quality of Life research

CHAPTER ONE:

INTRODUCTION: PLACING EPILEPSY

INTRODUCING EPILEPSY AND ITS HISTORY

What do you really know about epilepsy? Hopefully by the end of this thesis, this question will not make much sense. Indeed, there is no ‘epilepsy’ but different epilepsies which are as unique as the individuals who live with them. In many ways, stories of epilepsy are stories of human vulnerability as expressed and shaped at the intersection of geographies of the body, everyday life and wider regimes of (self-)governance. Articulating the ‘fitful’, ‘eventful’ geographies of the ‘volatile’ body¹ is crucial for thinking through the political organisation of social space and the performance of self. Far from positioning people with epilepsy as the ‘other’, this conception brings into focus the taken-for-granted ways in which we all attempt to affect control within our daily lives.

Although the aetiology, or cause, of epilepsy may in some cases be identified by medical apparatus, as with brain trauma, it often remains unknown, leaving scope for varying explanations (Scambler 1993). Epilepsy is also referred to as a ‘seizure disorder’, emphasising its most visible and relatively constant manifestation. Seizures, also called ‘fits’, ‘funny turns’ or ‘attacks’, are themselves quite variable in symptom and severity, although always involve some loss of awareness up to and including the complete loss of consciousness. Experiences of seizures are therefore also variable, ranging from extreme physical disruption (with frequent and severe seizures) to minimal physical incapacity. Efforts to develop acceptable classifications in professional fields have been contested over time because of differences in the purposes for which they were intended.

We now ‘know’ ‘epilepsy’ as a neurological disorder (affecting around 40,000 people in Scotland) requiring clinical intervention, but also recognise it as a social label (Jacoby *et al.* 2005; Rhodes *et al.* 2008a) imbued with cultural, personal, emotional, moral and political implications. For example, it is not uncommon to hear people say things like ‘I was so angry I was going to have a fit’ or refer to a ‘fit of madness’. Such turns of phrase indelibly trace the lineage of current thinking surrounding seizure disorders, not least in the institutional collision of epilepsy and ‘madness’. To be sure, the episodic and unpredictable nature of epilepsy has seen it categorised

¹ Throughout this thesis I deploy various descriptions of the body – ‘deviant’, ‘volatile’, ‘chaotic’ – each of which reflects subtly different ideas, theories and projections.

² Most people tend to have one type of seizure, but it is not uncommon to have more (see Epilepsy Scotland 2010).

throughout history through various medical, theological or superstitious frameworks (Gross 1992). I now briefly outline a broad spatial history of epilepsy (including geographies in and of living with epilepsy), showing how people who tend to have seizures have been particularly marginalised over time in Western contexts (which themselves should not be conflated). Such a history enriches the insights that may be drawn from this thesis.

As Temkin (1971: ix) argues, the construction of epilepsy throughout history must proceed along the lines of what symptoms were attributed to it, how it was explained and how it was treated. One of the first known books concerning epilepsy, *On the Sacred Disease*, was written by a Hippocratic scholar around 400 B.C. and provided a pathophysiology of astonishing complexity. It attacked popular superstitious notions that gods and demons were present during seizures, arguing that medical ignorance fuelled such beliefs. The author explained seizures as being the result of an excess of phlegm in the brain, which, on entering the body's blood vessels, produced the symptoms of the attack (which manifested differently depending on which organs were affected). Nevertheless popular conceptions during Antiquity (Magiorkinis *et al.* 2010) framed epilepsy as 'sacred', providing an insight into how prevailing beliefs were used to explain uncertain phenomena. The 'Christian era' saw epilepsy associated with possession, the intrusion of a god (divine prophecy) or a tormenting demon in reflection of the behavioural changes, whether real or imagined, that accompanied unconscious bodily performance (now known as 'automatisms': see Masia and Devinsky 2000). The Bible tells the story of Jesus casting out a 'foul spirit' that made a boy 'foam at the mouth' and 'gnash his teeth', subsequently paving the way for spaces of 'cure' to be under the authority of religious institutions (involving such practices as exorcism, which still exists today: see Gross 1992). The term 'falling sickness', or 'falling evil', was referenced throughout Medieval literatures, suggesting magic cures involving purifications and incantations (Jacoby *et al.* 2004; Scambler 1993). Further, ideas connecting the periodic nature of epilepsy with the moon (a common 'cause' of disorders, most notably 'lunacy') are traced by Temkin (1971) across astrological literatures dating back to the later centuries of pagan Antiquity. Around the end of the 15th century, in accordance with popularly-held beliefs, epilepsy became linked with witchcraft. On the other hand, studies during the Renaissance focussed on epilepsy and genius, implicating the Islamic prophet Mohammed, Hercules, Plato and Socrates. While documentary resources show explanations of epilepsy holding in tension forces for good and evil, people with epilepsy have always been considered 'unclean' (Magiorkinis *et al.* 2010). The common practice in Roman times of spitting on people with epilepsy to 'throw back the contagion' (Masia and Devinsky 2000: 28) offers a glimpse into the legacy of ideas about proximity to the 'deviant' body, an object of horror and disgust, and something to be hidden from others.

During the 16th century, advances in anatomy and pathology and the development of chemistry, pharmacy and physiology brought epilepsy under the microscope for the first time

(Gross 1992). Clinical observation broadened medical constructions, which began recognising, recording and treating different seizure types. The latter part of the 17th century saw discoveries in the fields of chemistry and physics taken into account, with new theories explaining the seizure as the result of chemical forces, such as effervescences or explosions. In the late-18th century, ‘the neuroses’ became a new category for defining disorders lacking in any obvious localisation or lesion, including epilepsy, hysteria and chorea (Maudsley 1874). Around the start of the 19th century, people with epilepsy became the subject of systematic medical attention. They began being housed in ‘lunatic’ asylums on account of anatomists linking the condition to ‘dangerous’ psychic symptoms, including mania, somnambulism, confusion or ecstatic states (Gross 1992: 72). Before long, however, fears of epileptic contagion led to the separation of people with epilepsy from the insane. Hospitals were then created in the late-1800s for ‘the paralyzed and epileptic’, from Queen Square in London (1860) to Blackwell’s Island in New York in 1867, as well as colonies such as the Craig Colony for Epileptics, also in New York (Masia and Devinsky 2000: 28). In France, hospital-based studies established new seizure terminologies, such as *grand mal* (denoting the loss of consciousness and convulsions), *petit mal* (where consciousness was retained) and ‘status epilepticus’ (or *état de mal*), which are still recognised today (Chaudhary *et al.* 2011).

Over the last 150 years, the development of medicalised thinking surrounding the epilepsies has mirrored the development of ‘neurological’ understanding. From the 1860s, Hughlings Jackson made breakthroughs that have shaped epileptology (the branch of neurology specialising in epilepsy) in its current form (Chaudhary *et al.* 2011). Jackson (in York III and Steinberg 2011: 3109) wrote that ‘Epilepsy is the name for occasional, sudden, excessive, rapid, and local discharge of grey matter’, and thus is commonly cited as the main protagonist in advancing ideas about seizures being the result of ‘mis-firing’ neuronal activity localised in or travelling across distinct hemispheres of the brain. Jackson took earlier clinical observations and fused them with newer physiological data to render a complete pathophysiological model of epilepsy, describing seizure types and epileptic syndromes (comprising more than one seizure type) within still-relevant categories; for example, his observations on ‘dreamy states’ and the ‘uncinate group of fits’ were later refined by others as ‘psychomotor’ symptoms and ‘temporal lobe’ epilepsy (Temkin 1971: chapter 12). These ideas were supported by the successful pharmacological control of seizures by (sedative) bromides and barbiturates (first by Locock: see Gross 1992) in the late-19th century, paving the way for the prevalence of current anti-epileptic medications.

Today, medical-neurological practices focus increasingly on ‘the microscopic worlds of brain receptors, neurotransmitters and cell membranes, molecular genetics, the latest pharmacology and treatment regimens with anticonvulsant medications, and the newest imaging devices’ (Andermann 2000: 170). Neurologists aim to classify epilepsy syndromes by aetiology, the three

main causes being idiopathic (arising from genetic abnormalities in neuronal activity), symptomatic (from identifiable lesions of the brain, such as tumours or scar tissue) or cryptogenic (when a presumed lesion is unidentifiable). ‘Seizure types’² are described as being ‘partial’ or ‘generalised’, so that the neurologist may draw on particular medical ‘scripts’ for prognosis and treatment. The ‘partial’ epilepsies include those seizures (‘simple partial’ and ‘complex partial’) during which only a portion of the brain is affected. The person does not become unconscious, but might lose awareness of their surroundings. Partial epilepsies are variously typified by localised muscle spasms (‘automatic’ movements of the arms, hands or legs), ‘unusual’ sensations in various parts of the body, slurred speech, distorted sight, hallucinations, lip-smacking, picking at one’s clothes or ‘behaviour’ that is frequently mistaken as intoxicated. The ‘generalised’ epilepsies affect the entire brain (and body) and involve the loss of consciousness. These include absence (*petit mal*), clonic, myoclonic and tonic-clonic (*grand mal*) seizures (Schneider and Conrad 1981: 213). ‘Absences’ are typified by the appearance of individuals ‘staring into space’ and being physically and mentally unresponsive to their environment. In contrast, tonic-clonic seizures are significantly more dramatic and visible, and hence dominate popular conceptions of epilepsy, with people losing consciousness and falling to the floor, where the body convulses violently. Such seizures, though not experienced directly, are often preceded by an ‘aura’ (an embodied sensation, such as rising feeling or smell, indicating that a seizure may be imminent) which may be witnessed through physical signs such as involuntary salivation and teeth-gnashing. ‘Auras’ are in fact ‘simple partial’ seizures; and, although they can be experienced in isolation, when they are followed by a ‘generalised’ seizure this is known as a ‘secondary generalised’ seizure (i.e. a ‘partial’ seizure that spreads in the brain and becomes a ‘generalised’ seizure).

By comparing patients’ descriptions (often gained second-hand: more on this below) with the raw data of ‘test results’ (e.g. electroencephalogram tracings of electrical activity in the brain) and available medical classifications, the neurologist can reach a diagnosis which provides them with a ‘cherished roadmap of medical terrain’ (Schneider and Conrad 1981: 213). The individual patient then becomes categorised according to the physiological and behavioural indicators that their diagnostic typology bestows (Porter 1993). The diagnosing neurologist tends to derive information from quality-of-life (QoL) questionnaires, which report on the impact of disease, social factors such as work and marriage and satisfaction with treatments. While serving an important purpose, QoL research is limited by a focus on quantifiable measures and therefore

² Most people tend to have one type of seizure, but it is not uncommon to have more (see Epilepsy Scotland 2010). They can happen at any time, whether the individual is awake or asleep. Each seizure lasts varying lengths of time, usually between a few seconds and minutes (recovery from them can last from moments to days), but becomes a medical emergency, called ‘*status epilepticus*’, when one lasts longer than 30 minutes. In Scotland, around 100 epilepsy-related deaths occur annually, half of which are sudden and unexpected (known as Sudden Unexpected Death in Epilepsy, or SUDEP). Although the cause of SUDEP is unknown, its risk is thought to be reduced with well-controlled epilepsy (through medications and lifestyle choices). When there is a localised seizure focus, surgery may be a treatment option (Noachtar and Borggraefe 2009).

cannot articulate individual experience (Andermann 2000: 271)³. Furthermore, there is little in the way of contextual information in many of these studies, such as the gender and age of particular participants, which leads everyday life with epilepsy to be represented in a rather linear and non-differentiated fashion. These objectified representations and categories are still subject to contestation by medical professionals as ideas and trends in medical fields evolve (Porter 1993). Epilepsy therefore 'needs to be seen as a social construct: as a socially-generated way of grouping phenomena which endows them with a particular significance' (Wright and Treacher, in Llewellyn 1998: 50). The many different descriptions, explanations and treatments applied to epilepsy, shaped by prevailing social beliefs and medical trends, are more than a record of its presence throughout history: they constitute what we mean when we talk about it in any given time and place. There is no epilepsy 'out there', an objective reality free from social meaning. Today, in the Western world, we 'know' that it is caused by abnormal neurological activity, but, as histories have shown, what we 'know' is subject to reinterpretation. The struggle to define epilepsy is hence political (with a small 'p').

The 'object' of epilepsy has provoked many competing claims over mind and body, supernatural and natural, individual rights and social restraint. While the age of Enlightenment 'made demons and witches disappear' (Temkin 1971: 227) from clinical investigation, social attitudes have continued to bear traces of past stigmatisation. Hanson (2000) suggests that across history the medical model has reinforced the classification of people with health problems and disabilities as abnormal, yet for people with epilepsy this has been beneficial: its transference from the superstitious to the medical domain, from 'badness' to 'sickness' (Conrad and Schneider 1992), has almost certainly contributed to its decreasing stigma (Jacoby *et al.* 2004). Yet people with epilepsy are still acutely aware of what being socially labelled as 'an epileptic' means: they are suspected as having learning disabilities and mental health problems, and being 'unclean', unpredictable, isolated (Hayden *et al.* 1992; Rhodes *et al.* 2008; Rätty and Wilde-Larsson 2011). Everyday embodied social responses to people with epilepsy are overtly spatialised when others are reluctant to go near the 'epileptic body' in anticipation of, or in reaction to, seizures. The individual is then painted as unpredictable, risky and potentially dependent on the help of others, whether they like it or not (Jacoby 2002; Jacoby *et al.* 2005). Work on stigma not only describes such processes, but shows that social exclusion is justified through judgements on the moral character of people who experience seizures in public space (Kleinman *et al.* 1995).

The root of moralising perceptions can be traced to the work of pathologists, psychiatrists, anthropologists and sociologists, from the early-19th century until well into the 20th century, who generally subscribed to the notion of 'degeneracy'. Sexual excesses, such as masturbation and

³ This thesis does have commonalities with QoL research in its exploration of the issues that are most important to people living with epilepsy. However, I hope to dig much deeper into everyday life experiences – but *not* for the purpose of calibrating medical models.

immoral behaviour, were thought to be among the main causes of epilepsy (Llewellyn 1998). Psychiatrists at the time were interested in the links between epilepsy and personality, notably violent and criminal tendencies. The condition thus became associated with alcoholism and physical and moral squalor, and was perceived to cause a deterioration that infected descendants. This demonstrates a 19th century trend of explaining social concerns in biological terms (Temkin 1971: 366), reflecting a re-medicalisation of the field with acute socio-spatial implications. In the first half of the 20th century people with epilepsy continued to be labelled deviants and so their marriage and reproduction was restricted by eugenicist medical doctors (Masia and Devinsky 2000). A member of the British royal family, Prince John, developed epilepsy and was largely kept hidden from public view so as not to taint the royal lineage in history books. Negative social attitudes manifested spatially, as evidenced in the 1954-1955 Annual Report of the Scottish Epilepsy Association (now ES):

Persons suffering from epilepsy, if the disability is known, have great difficulty in finding ordinary living accommodation with a landlady or in a hostel. The fact that landladies and wardens shun epileptics as being all alike dominates the situation with the result that some, whether they have work or not, are obliged sometimes to take lodgings distasteful to them or even to give up the chance of work for lack of lodgings. Sometimes an epileptic travelling and requiring to stay away from home for a few days, perhaps for examination or treatment, finds himself [sic] stranded. (p.3)

Working through successive annual reports, it is amazing how little the agenda of epilepsy campaigning has changed: still we see issues relating to employment, driving, police training, marginalisation in the community and so on. It is no surprise, then, that the largest area of current social research on epilepsy focuses on stigma in local and wider community contexts (Ablon 2002; Baker 2002; Birbeck 2006; de Boer *et al.* 2008; Fernandes *et al.* 2011; Grunfeld and Komlodi 2006; Jacoby 2002; Jacoby *et al.* 2005; Kılınc and Campbell 2009; Kumari *et al.* 2009; Lee *et al.* 2005; MacLeod and Austin 2003; Morrell 2002; Rafael *et al.* 2010; Schachter 2002; Smith *et al.* 2009). A major concern for this thesis is to determine the extent to which the somewhat ambiguous and contested nature of epilepsy leaves isolated those people who have been diagnosed. This involves questioning whether policies aimed at moving away from 'segregated' support have 'worked', or whether re-enlivening epilepsy communities through various spaces might allow individuals to (re-)place, (re-)embrace and (re-)value marginalised identities (Chouinard 1999: 142).

A GEOGRAPHY OF EPILEPSY?

A geographical perspective on epilepsy positions its affects and effects not as primarily medical, physical or social, but as intersecting, heterogeneous and variable across time and space. Here I

provide an evocative introduction to this perspective, but, at the close of this introduction, I will summarise each chapter more systematically in a 'route map' of this thesis. Reconstructing the everyday and longer-term social geographies of people diagnosed with epilepsy requires recognition of the diverse temporalities punctuating the complex spatialities in and through which individuals live. A geographical approach contributes to social science research on epilepsy by specifically engaging the heart of what people actually get on with *doing* on an everyday basis, whether or not they are disrupted by seizures⁴. Indeed, the focus of this thesis hence adds nuance to our understandings of the body within social and cultural geography; in particular because of the 'deviant' body's (Dorn and Laws 1994) straddling of concerns arising from existing subfields of geographical research on chronic illness (Moss and Dyck 2002; Crooks 2010), impairment/disability (Gleeson 1999; Kitchin 1998; Parr and Butler 1999) and mental health (Curtis 2010; Parr 1999; Philo [2000a theme issue]; Smith and Giggs 1988). With epilepsy, 'biological dysfunction' (Hughes and Paterson 1997: 328) or 'impairment', such as memory loss, tiredness and pain, seems to come from 'nowhere' but endure over time such that the condition is cast as a chronic illness, which, according to Parr and Butler (1999: 8), is an 'ongoing biophysical or psychological condition, which normally involves therapeutic interventions'. With chronic illness, symptoms and their severity typically fluctuate, altering one's abilities to function relative to one's immediate physical social environment. This is true of epilepsy and yet people might feel completely 'healthy' and able-bodied except for a matter of minutes each year. Wendell (1996: 23) defines disability as 'any lack of ability to perform activities to an extent or in a way that is either necessary for survival in an environment or necessary to participate in some major aspect of life in a given society'. Seizures, to be sure, are disabling in that they terminate the body's routine abilities to perceive the world and perform tasks to any extent, in any environment, in any society. This can happen even when the individual is functioning completely free from impairment during the seconds before. Conversely, people might be perpetually 'able-bodied' (i.e. seizure-free) and yet abruptly experience a (hidden) sense of impairment which in itself can be disabling. I utilise these definitions so as to show how the temporalities of impairment may be far more discreet and/or wildly fluctuating than has thus far been illustrated in the geographies of chronic illness and disability (for example, see Driedger *et al.* 2004: 122 on MS). 'Epileptic episodes' (seizures) might be experienced only at the condition's onset, or else periodically (sometimes decades apart) or constantly throughout; yet, regardless of how, when and if they are embodied, the biomedical 'reality' is that the condition might become 'controlled' but not cured. Hence, people who do not self-define as being disabled, chronically ill or impaired still have to live with and manage epilepsy.

⁴ A geographical treatment could potentially also explore the 'ecology' of epilepsy (its variable presence and treatment, and maybe causes, from place to place/region to region) – but my focus here is ultimately *social* and *everyday*-geographical.

While varying in causes and forms of embodiment, epilepsy remains stigmatised because of its association with seizures, when an individual loses bodily control, which can be deeply disturbing for witnesses unaccustomed to such episodes. In these instances the individual becomes 'out of place', transgressive of expectations about conduct in both society generally and immediate social spaces particularly. Seizures, however, remain an under-theorised aspect of corporeal life, a challenge taken up in CHAPTERS FOUR and FIVE by asking 'what is it about losing bodily control that is so disturbing?' Epileptic episodes, which I describe as troubling 'body moments', are central to the framing of this condition because they remain important material and discursive reference points, even for the 52% of people with epilepsy who no longer tend to have them (JEC 2011). This is in part because of popular dualisms pitting the 'normal' body (that which maintains control) against the 'deviant' body (the one that loses control), the consequences of which converge on the body-self in-place. In CHAPTER FOUR, difficult-to-confront bodily events are engaged through a centred phenomenological approach to re-present the body's changing relationship with space and place in the moments before, during and after a seizure. 'During', individuals become unaware of their surroundings, unable to perform in an orderly and coherent manner, and this unworking leads to anxieties over the unstable locations of the self. Indeed, while physical experiences are usually mediated through an intersubjective social 'reality', seizures offer a striking example of when individuals momentarily cease to be a self-aware, agentic social beings, leaving them vulnerable to the (re)actions (and subsequent descriptions, fundamental for gaining a diagnosis) of others.

This begs the question of how we 'know' the ill body that is made and remade through multiple, sometimes jarring, spatialities. To engage this problematic, I move in CHAPTER FIVE to discussing a de-centred phenomenology that is both complementary to, and at odds with, a centred phenomenology, reflective of how the individual is simultaneously inside and outside of social space; embodying of, and disembodied by, a seizure. 'Affect' is used to describe the pre-filtered, impersonal charge circulating between bodies and space in the moment when a loss of control occurs, and is held in tension with the complex emotional geographies (expressed and captured through regimes of meaning) to which it gives way. Seizures increase the potential intensity with which the body might affect or be affected in different places, and hence a spatial account of epilepsy adds to existing social science scholarship. Further, by attending to the links between psyche and space (following, for example, Wilton 1998; Sibley 1995), I examine how encounters with the body-self that briefly falls outside of consciousness, cognition and volition often lead to socio-spatial exclusion as a result of its unsettling of individual and collective notions of order and integrity. The reactions of others are not inevitable, however, and so a potential contribution of this thesis is to reframe encounters with 'other' people and challenging affects so as to work towards a spatial understanding of how self and other relate to the volatile body.

We know relatively little about the daily lives of people who live with the body that at any time might escape control and thereby the discipline of the social order. In CHAPTERS SIX and SEVEN, I seek to investigate how people with epilepsy (re-)embody illness over time and space, considering how they endeavour, or are forced, to function differently in regards to 'normal' daily routines associated with sleep and standard Western working hours, but also the length of time that people spend occupying everyday spaces. That seizures can occur completely 'out of the blue' calls attention to how people manage with unpredictable temporalities. Social science research (for example, see Rätty and Wilde-Larsson 2011) has a tendency to iron-out effects of epilepsy over time, rather than present them as variable, episodic, erratic, ephemeral, recidivistic, partial, ambiguous, confusing, contradictory, (ir)regular, (un)explainable, (in)tangible, hallucinogenic and sometimes unnoticed (by self and others). In CHAPTER SIX I hope to do some justice to the many overlapping short- and long-term temporalities experienced by discussing the diverse impact of illness onset at different times during the lifecourse. Symptomatic fluctuation is characterised as causing both momentary and sustained upheaval as individuals attempt to stabilise their identity across the numerous stages of everyday life (work, family, social), all the while fighting with or against the chaotic body.

Through an engagement in CHAPTER SEVEN with poststructuralist theories of the body and anti-dualistic discourses (also in feminism), it is shown how people are always simultaneously resisting, negotiating and being pulled in different material and discursive directions, and, because of the highly contingent nature of place, space and the body, the performance of self is here never fully under one's control. 'Biographical disruption' (Bury 1982), then, is experienced not once (for example, at onset) but time and again as the course of illness directs the content of life – what happens and how it is experienced – meaning that socio-corporeal contingency informs renegotiations of what people do, how and when. Individuals work with everyday spaces (including a geography of material reliefs, surfaces, temperatures) that are structured in anticipation of, and reaction to, the immediate and intermediate physical, social and personal effects of 'losing one's place' (relevant both to seizures and cognitive difficulties such as memory loss). It is argued that for people whose bodies may become dis-ordered, keeping to an itinerary facilitates feelings of safety, but that social and self-marginalisation construct the individual as the 'itinerant': one who spends short periods occupying different places without ever feeling as if they belong (or only so long as they uphold the social contract of bodily control).

From these experiential geographies, I draw back in CHAPTER EIGHT to considering the governance of illness. Treading a Foucauldian path, I unpack notions of illness and the autonomous self by assessing the meeting points and departures between biopolitical authority and the vitalities of everyday life. It is shown how various cultural-historical discourses form the social context of epilepsy, in which the legacy of ideas surrounding demonic possession, mental

ill-health and institutionalisation contribute to its continuing stigmatisation and so curious isolation, both in terms of everyday living and the lack of community organisation. Individuals with epilepsy tend to remain relatively uninformed and depoliticised, and hence struggle to resist the authority of the biomedical, despite it being known that interventions aimed at controlling the body can cause neuro-chemical impairment far more disabling than seizures themselves. Biopolitical contestations are framed within wider neoliberal health regimes, which extol the values of 'governance at a distance' and so push forward policies based on self-governance through responsibility (Brown and Baker 2012; Rose 1999: 49). These responsibilities contain a whole host of hidden assumptions about the 'correct' way of being, and thus pressure self and others to police the body that fails to live up to social standards. This means that when breakdowns occur, the individual is less likely further to burden health services and more likely to withdraw from public space because they fail in achieving what is expected of them (i.e. controlling the body). Rather than suggest that the self is always already-constituted and so powerless to resist dominating power, I develop an account of how socio-historical and cultural contexts, medical management and human vitalities become infused such that the management of illness must be seen as involving a dynamic, place-based interplay of contingent factors. For instance, medically-managing epilepsy is but one of many ways of managing the vitalities of the self which episodically cannot perform the neoliberal subject. While such experiences can be disempowering, storying these 'absences' helps to disrupt and re-script others' assumptions concerning how to manage a life with epilepsy.

RESEARCH PROBLEMATICS

The aim is to produce a detailed 'archive' of as-yet little-known information about how epilepsy enters into the time-space fabric of everyday lives, particularly following diagnosis and the experience of epileptic episodes. This archive will be of academic interest to human geography and disciplines concerned with epilepsy, and will also possess considerable policy relevance, not least to the organisation, Epilepsy Scotland (ES: see <http://www.epilepsyscotland.org.uk/>), the partner in this project. Working in partnership with a charity organisation (albeit one with its own politics and concerns) arguably helped to make explicit an ethics of engagement, referring to my sense of responsibility to ES, but also to the requirement for sensitive encounters with participants. ES was consulted in the conception of research aims, which have benefitted from information-sharing between the academic and advocate (more on this in CHAPTER THREE). Not only did ES facilitate this project by granting access to its resources and members' database, ensuring a pre-defined sample of people living with epilepsy who could be contacted, working with ES has allowed a deep immersion in the politics of epilepsy in Scotland today, as well as

insight into how its practices help to shape the discursive and rights landscape. The influence of ES in shaping this research can be felt throughout; for example, I present the word ‘epileptic’ in inverted commas due to the political assertion made by ES (see http://www.epilepsyscotland.org.uk/what-is-epilepsy-/info_13.html) that there are no ‘epileptic’ people, only epileptic seizures. Thus, when referring to ‘epileptics’, the term is used as a provocation, suggesting public ignorance surrounding the condition. More than this, the term ‘epileptic body’ serves a conceptual purpose. Because epilepsy is a ‘hidden’ disability, individuals are generally not socially ‘marked’ as ‘epileptic’ until such time that others become aware of the impact of the condition on that person, oftentimes by witnessing the ‘seized’ body. Stirling (2010: xxii) traces the etymology of ‘epilepsy’ back to the Greek word ‘*epilepsia*’, meaning ‘seizure’, and ‘*epilambanein*’, to ‘seize’ or ‘attack’. ‘Seizures’ have throughout history been linked to hostile assault by external forces, and, in many ways, seizure witnesses often feel that they too are in danger because of the unpredictable geographies of the ‘epileptic body’ (its movements, aesthetics, sounds, secretions). A major challenge is to theorise *why* witnesses feel so ‘seized’ by the aura of the destabilised body, and to then suggest potential interventions for re-presenting and re-scripting ‘other’ bodies, who may not be so different as popular representations would have ‘us’ believe (Baxendale 2003).

While the geographies of chronic illness, disability and mental health have almost exclusively used qualitative methodologies⁵ to construct sensitive portrayals of the social and cultural contexts in which the voices of research participants are placed, I have utilised multiple methods: first to engage members of ES through wide-scale surveying, before narrowing down my investigation through face-to-face interviews. The intention here was productively and creatively to work between methods as a way of co-constructing a rich variety of data that, academically, would marry the power of the general to the nuance of the particular, while also, pragmatically, hoping to appeal within policy circles. In CHAPTER THREE I discuss how these methods were at times complementary, but also revealing of tensions and discontinuities. Working with them in a purposeful manner, I argue that using the mixed methods questionnaire, despite the qualitative geographers’ reservations, is a profoundly embodied task, which can inform and enhance further investigations into the experience of chronic illness and so should be considered as a valuable instrument in the geographer’s toolkit.

Along with key research outcomes, in particular professional development and the stimulation of debate surrounding epilepsy (both inside and outside of key interest groups, not least amongst people with epilepsy), this thesis addresses the following research objectives:

⁵ Although there is an epidemiological, ‘spatial ecology’ tradition (using large data sets), especially in mental health geography.

1. To understand the embodied changes affecting individuals during and after seizures, the varying reactions of others to episodes occurring in different places, and whether individuals attempt to manage where seizures might occur.
2. To explore how living with epilepsy shapes everyday lives; especially how time-space routines are adjusted as individuals endeavour to cope with living with epilepsy, and the extent of the coping adjustments made by individuals: (i) following diagnosis; and (ii) following seizures.
3. To unpack whether changes made to everyday lives close down or widen out possibilities for individuals' lives in the longer term, particularly thinking about the implications of being diagnosed when relatively younger or older in terms of careers, social networking and recreational opportunities.
4. To establish how biopolitical power and rights landscapes are entangled with everyday human vitalities and identities as people seek to come to terms with epilepsy materially and discursively; including whether there are aspects of epilepsy 'community-making' occurring in more or less formal support networks.

ROUTE MAP

Presently, I will provide a more systematic outline of the chapters comprising this thesis, but an initial remark is needed to clarify how the first four substantive chapters (CHAPTER FOUR to SEVEN) are designed as two 'couplets', each of which approaches an issue – 'seizures' first and then the wider 'social geographies' – from two rather different directions. While making sense as stand-alone pieces, each chapter in the two couplets is designed to 'complete' its partner, showing how focussing on one aspect – *either* the experience 'inside' *or* 'outside' of a seizure; *either* the altered temporal *or* spatial geographies of everyday life – only tells part of the whole story. While the ontological and epistemological bases of these chapters are not straightforwardly commensurable, they fulfil a pragmatic aspiration to use the tools at my disposal to construct an overall story. The two couplets here are also designed to complement each other. That concerning seizures is presented first for several reasons, for seizures are the earliest indication pre-diagnosis that one lives with epilepsy, and engaging with these troubling experiences allows the reader in some small fashion also to confront that with which the individual must first 'come to terms'. Seizures may usefully be considered as the 'heart' of the epileptic condition, giving rise to all subsequent actions. Indeed, epileptic episodes may be fleeting, but they provide crucial context for the second couplet, which questions how epilepsy shapes everyday lives. We might say that the pairing of these couplets demonstrates the ways in which distinct moments can significantly influence the wider time-space fabric of life.

To close this introduction, I now briefly outline the contents of each chapter:

❖ FOUNDATIONS

CHAPTER TWO establishes the meta-theoretical foundations and disciplinary fields engaged in this thesis. The strengths and gaps within social research on epilepsy are critiqued so to open up the possibility for a geography of epilepsy. Insights from (post-)phenomenology, affective and emotional geographies, and bio-political and vital geographies are reviewed. A critical appraisal of scholarship surrounding geographies of the body, the daily geographies of living with chronic illness and invoking or re-scripting ill identities is then used as a springboard from which to question our methods of ‘knowing’ the ‘ill’ body.

CHAPTER THREE sets out the methodological foundations of this thesis. People with epilepsy rely on the representations of others to ‘know’ the seized body, and, in many ways, their problem is a central problem for this thesis. I discuss the design and implementation of a mixed methods questionnaire sent to the database of ES members; semi-structured interviews with self-selecting questionnaire respondents; and the written contributions of individuals who were unable to participate by other means. Information is provided to contextualise the participatory research partnership with ES, who play an important role in shaping the discursive terrain of epilepsy governance. An understanding of these methods of ‘getting to know epilepsy’ is crucial for setting up this ‘writing for change’.

❖ SEIZURES

CHAPTER FOUR portrays the lived ‘inside’ experience of different seizures, which are characterised as radical losses of bodily control. The temporalities, namely before, during and after, of these unique and invasive ‘body moments’ are unpacked to show how the anchoring of self-in-world is disrupted when objective and subjective time are brought into stark relief. Such experiences unsettle trust in the sanctity of bodily boundaries, which not only arouses concerns for personal safety and the potential for injury, but also induces existential crises due to disjunctures between body and self. In the face of such anxieties, people construct a kaleidoscope of coping strategies that shift and change according to time-space contingency. Encountering seizures through this interpretative lens adds a socio-spatial, theoretical dimension to existing research.

CHAPTER FIVE seeks to ‘extend the boundaries of the phenomenological focus upon the experiencing subject’ (Lea 2009: 373) to show how experiences of seizures shape and are shaped by affective relations ‘outside’ the body. It is discussed how social contexts and the

reactions of witnesses in part structure how the fragmented self is 'put back together again'. I then draw from a range of 'outsider' and psychoanalytical geographies to consider why losses of bodily control can be so stigmatising. Those who slip outside of the social order seemingly without warning or reason perceive in others (through their re-presented accounts and reactions) a vulnerability similar to their own: a sense of helplessness, of being out of control, of time stretching, of space becoming unpredictable. The anarchic body, then, destabilises the bodily boundaries of witnesses such that they wish to re-establish the 'correct' order of things and so their place in the world. The abject body may come to represent socio-material risk because, in its unpredictability, it embodies the potential for wider disorder.

❖ SOCIAL GEOGRAPHIES

CHAPTER SIX contextualises the seizure event within the longer-term, yet simultaneous, temporalities of living with epilepsy. Discussion is framed around statistical analysis of the questionnaire, which found there to be three foremost variables impacting on the experience of epilepsy: 'seizure frequency', 'current age' and 'age when diagnosed'. The common thread among them is time: how often troubling 'body moments' occur, when and for how long? It is suggested that differences in temporal-spatial lifestyle can be observed between those individuals who in various ways structure their lives around frequent episodes and those for whom seizures are few and far between. Nevertheless, living with epilepsy is far more than experiencing seizures. Whether an adult grew up with epilepsy or was diagnosed relatively recently often has a bearing – though in different ways – on familial and social relations, which are further entangled with long-term prospects (careers, recreation and social networking) and identity.

CHAPTER SEVEN aims to establish how people embody illness relative to the places and spaces (the body, home, workplace) through which they move and that they inhabit. The workplace is discussed for the social and material challenges that it represents for the (re)negotiation of identity. The micro-geographies of these (intended) dots on peoples' everyday 'maps' are complemented by a contemplation of how routes between are traversed. Indeed, while these spaces of transience do not tend to possess significant labels, such as 'home' or 'work', they are an under-appreciated aspect of daily life. It is shown, using the example of public transport, how travelling from station to station is a deceptively complex task for the person who experiences and perceives space differently. Moving from what might crudely be termed the 'public', it is considered how 'private' spaces of the self are re(ordered), first by engaging how the material layout of the home is modified to

accommodate the unpredictable body, and then by discussing the ‘spaces of memory’ designed to keep ‘everything in its right place’ when experiencing memory loss (a common co-morbid symptom).

❖ GOVERNANCE

CHAPTER EIGHT picks up on the empirical themes developed thus far to engage broader theoretical concerns. Drawing on Foucauldian ideas, it is questioned how people with epilepsy come to ‘know’ and self-govern their own embodied vitalities in light of various competing discourses emanating from the state, biomedical practices, third-sector advocates and the legacies of historical stigmatisations. By considering everyday experiences as taking place at the intersection of myriad practices of domination and resistance, the ‘docile body’ is not seen as an inevitable or undifferentiated outcome of external regulation and discourses surrounding the healthy, regulated body. It is argued that to understand experiences of illness, we need to explore place-based opportunities and constraints that facilitate different ways of coping. Spaces of testimony are put forward as an important resource for facilitating feelings of inclusion across various spatial scales; however, at present, access to such spaces is generally limited.

❖ CONCLUSIONS

The theoretical contributions of this thesis are set out to re-state how findings point to a gap in our knowledge concerning troubling ‘body moments’. The ways in which the volatile body impacts on daily life is set between the forces that work within and without the self. Put another way, the meaning of epilepsy is situated in the movement between (de-centred) phenomenology and biopolitics. Working ‘with’ these theories leads to a series of policy recommendations.

CHAPTER TWO:

LITERATURE REVIEW: WHERE DOES EPILEPSY ‘FIT’?

WHAT WE KNOW ABOUT EPILEPSY FROM THE SOCIAL SCIENCES

I open this chapter by offering a thumbnail review of existing social-scientific research on epilepsy, all the time seeking to show a ‘gap’ where sustained geographical attention *should* be found⁶. Epilepsy has been and *is* associated with highly negative personal qualities: mental illness, uncleanliness, violence and criminality (Khan *et al.* 2004; Kobau and Price 2003; Magiorkinis *et al.* 2010; Schneider 1988: 66). The lineage of stigmatising views reflects the socio-cultural tradition of explaining phenomena of ambiguous ‘cause’ in terms of the supernatural (divine punishment, demonic possession). This has given way over time to ideas surrounding contagion (Jacoby *et al.* 2005: 173) and the treatment of epilepsy by psychiatrists as an aggressive personality disorder (Jacoby 1992: 657-658). The constant theme throughout has been professional and social justification for the continuing socio-spatial containment of individuals who embody ‘danger’. While epilepsy is now constructed as a neurological condition in Western thinking (Noachtar and Peters 2009; Porter 1993; Sutula 2005), Reis (2001) discusses how it remains associated with particular character traits that have congealed into the stereotype of the ‘epileptic personality’. This image has in part been maintained through popular media, for, as Baxendale (2008: 168-169) describes, ‘associations of madness, stupidity, and the supernatural seen in ancient texts and artwork are perpetuated in modern literature, movies and television programs’.

In countering these ‘subjective’ misconceptions, much of the social science literature reproduces the clinical ‘gaze’ through the use of models, predictors and classifications. The challenges of living with epilepsy are most commonly elucidated in studies focussing on stigma (Ablon 2002; Baker 2002; Birbeck 2006; Fernandes *et al.* 2011; Jacoby *et al.* 2005; Kılınc and Campbell 2009; Kumari *et al.* 2009; Lee *et al.* 2005; Morrell 2002; Scambler and Hopkins 1986, 1990) and in QoL (Bishop *et al.* 2002; Charyton *et al.* 2009; Jacoby 1992; Schachter 2005). QoL studies tend to identify through quantitative measures the different factors that impact on experience – social anxiety, stigma, employment, seizure worry, self-esteem, self-mastery (Schachter 2005) – yet rarely do they unpack how social contexts and embodied experiences shape ways of being-in-place. Undifferentiated QoL determinants ignore peoples’ varying resources and strategies, in ‘a political project that attempts to negate the relevance of

⁶ Existing historical work on epilepsy has briefly been covered in the INTRODUCTION.

difference' (Rhodes *et al.* 2008b: 17). As such, there remains a challenge for research (and advocacy groups) to balance representations of people with epilepsy in same/different categories (Jacoby 2002) wherein stigma is not seen an inevitable or unalterable product of being diagnosed.

In the literature on stigma, there are two main lines of analysis. On the one hand, perceptions are measured quantitatively through 'stigma scales' (see, for example, Smith *et al.* [2009], who develop Dilorio *et al.*'s [2003] methodology through linear regression analysis). Built into these measures are an appreciation of how not all people experience stigma equally, although rarely are individual, place-based contexts adequately explored to add nuance to statistically-significant categories. The other prevalent tradition in 'stigma' research is drawing on the influential work of Goffman (1959; 1963), who defined stigma as 'an attribute that is deeply discrediting [...] a trait that can obtrude itself upon attention and turn those of us whom he [sic] meets away from him, breaking the claim that his other attributes have on us' (1959: 5). Goffman's distinction between attributes that are 'discredited' (evident to others) and 'discreditable' (differentness not immediately known) has been developed through the concepts of 'enacted' stigma (discrimination) and 'felt' stigma (the expectation of enacted stigma: Jacoby 1994; Scambler and Hopkins 1986). These are particularly appropriate concepts when applied to a condition that is periodically (un)apparent to self and others, and encapsulating of how the fear of a 'spoiled identity' in many cases precedes acts of discrimination. The work of Goffman may usefully be extended in stigma research by assessing how emotional geographies are shaped in and through the performance of identity on multiple 'stages' (perhaps loosely equating the analogy of front and backstage with experiences in public and private) to show how the meanings and consequences of a seizure disorder vary contextually.

Health legislation research is certainly comprised of different 'stages' (although not in a Goffmanesque sense). Losing one's driving license on diagnosis (until seizure-free for over 12 months: see Tatum *et al.* 2012) has a major impact on social mobility, whether geographical or socio-economic. Opportunities within the police force or fire service are usually denied *outright* because the body does not meet minimum medical requirements (Beran 2008). Epilepsy in these cases is a label of sub-standardness, regardless of the 'success' of medical interventions (Smeets *et al.* 2007; although Jacoby [1995] found that people with well-controlled epilepsy do not tend to experience difficulties in employment). The 'epileptic body' is thus unambiguously constructed as a (legal) liability despite the wide-ranging levels of impairment that such a diagnosis may entail. As Beran (2008: 644) remarks, a review of epilepsy and the law reveals how 'epilepsy can actually define who one is rather than what one has'. Labelling heterogeneous persons as 'epileptics', rather than the individual as a 'person with an epilepsy', tends to be disempowering, a point that is now the mantra of resisting advocacy groups. Nevertheless, such is the social import of these labels that in certain contexts epilepsy becomes the primary identity by which people define

themselves (Faircloth 1998; Jacoby *et al.* 2005). Participants in Rhodes *et al.*'s (2008b) study, for instance, drew upon different biomedical and social inscriptions when job-seeking, despite disputing such discourses socially (see also Nijhof 1998). In some cases, people attempt to maintain an 'able' identity by evading having seizures in others' presence (Kilinc and Campbell 2009). Schneider and Conrad (1980) describe this as being 'in the closet' with epilepsy. While summarising different peoples' motivations succinctly, these studies leave the door open for unpacking the spatial behaviours of those wishing either to avoid legal restraint or disclose (perhaps selectively) that they live with epilepsy.

Qualitative sociological research has sought to move beyond the determinism of stigma or QoL models to develop theories of how people with epilepsy, and their families (Thompson and Upton 1992; Hames and Appleton 2009), struggle to make sense of the condition and manage its physical effects (Kobau and Dilorio 2003; Fraser *et al.* 2011; Inglis 2010; Livneh *et al.* 2001) and psychosocial consequences (Baker 2002; Gandy *et al.* 2012; Hermann and Jacoby 2009; Strine *et al.* 2005; Upton 1993)⁷. Faircloth (1998) deconstructs the narratives of three people to show how discontinuities inherent within 'epilepsy' as an illness category lead to different and unique experiences of the condition. Similarly, Nijhof (1998) argues that sociological research tends to overlook individual subjectivities and so the multiplicity of experiences contained within such themes as 'stigma'. He remarks that epilepsy 'appears not to have a precisely defined meaning and therefore not a defined place in social life' (Nijhof 1998: 102). Developing this thought, Kleinman *et al.* (1995: 1328) observe that the social course of epilepsy 'is as distinctive as are different local worlds, different social networks, different social histories'. These progressive conclusions, however, are reached following analyses that reveal little of the complex local geographies in which participants live. Rhodes *et al.* (2008b: 11) hence challenge researchers to disentangle the 'complex mix of physical, environmental and sociocultural factors' that contribute to the experience of epilepsy. Moreover, in discussing the value of contextual narratives, Andermann (2000: 172) all but calls for a geographical perspective when arguing that seizures affect a person's experience of the 'here and now'.

We know from the literature that seizures cause the loss of a cohesive, valued self (Schulze-Bonhage and Anne Kühn 2008) fuelled by fears over when the next one will occur (Newsom-Davis *et al.* 1998). While Rätty and Wilde-Larsson (2011: 1998) identify the scarcity of studies relating

⁷ Moreover, studies have assessed gender differences (Crawford and Lee 1999; Luef 2009; McAuley *et al.* 2012; Thompson *et al.* 2008), especially the practical and moral experience of reproductive health issues for women (although Sare *et al.* [2007] characterise men as 'the lost tribe', whose identities are challenged, for example, by alcohol restrictions); multicultural challenges, especially relating to health care provision and attitudes (Bartolini *et al.* 2011; Chong *et al.* 2012; Chung *et al.* 2010; Epilepsy Connections 2006; Paschal *et al.* 2005); and age-related experiences, particularly with parental over-protection in adolescence (Baker *et al.* 2005; Carlton-Ford *et al.* 1997; Gauffin *et al.* 2010; Pinikahana and Dono 2009; Rodenburg *et al.* 2011). Indeed, 'epilepsy' is not an undifferentiated experience for, as the anthropological literature shows, it is explained and treated in contextually and culturally distinctive ways (Andermann 2000; Baskind and Birbeck 2005; Carod-Artal and Vázquez-Cabrera 2007; Allotey and Reidpath 2007; Mentore 1995).

lived experience to 'life as a whole', they are largely silent on the corporeal manifestations of epilepsy, which may vary with different medications, time-space accommodations or exposure to certain seizure 'triggers'; we are left unaware as to how long participants had lived with epilepsy, whether they were all still experiencing seizures, and, if so, how often and when⁸. Furthermore, there is scant attention paid to the ways in which people *renegotiate* their material and social circumstances in line with fluctuating symptoms, both in the short and long term (which means epilepsy might be viewed more or less positively at different times). In short, embodying epilepsy is potentially more volatile than has been suggested. Mentore (1995: 58) describes the moment of an epileptic seizure as a 'dramatic case of powerlessness [...] An instance of cultural violence, as a traced meaning for bodily pain and as an identifiable obstacle to the fulfilment of a desired social biography'. Reis (2001) asserts that seizures instil a sense of 'placelessness', yet declines to elaborate further. We are generally left with unanswered questions over the variable *meanings* of seizures and what they *feel like* 'internally' (experiences are rarely elucidated beyond discussion of *atypical* symptoms, such as hallucinations: see Kasper *et al.* 2010).

There is relatively more debate surrounding the reactions of witnesses on the 'outside'. Scambler (1989; also Fernandes *et al.* 2011; Jacoby 1992) argues that losses of bodily control represent a threat to the social order: firstly, because of the shock induced when other bodies fail to conform to cultural behavioural norms; and, secondly, because of the ambiguity that is created in taken-for-granted social relationships. Trostle (1997) suggests that seizures transgress cultural values and so present uncomfortable reminders of human vulnerability. Further, Bagley (1972) proposes that witnessing the loss of control in others triggers 'anomic terror' because of the fear that the self might also 'revert to the primitive' (Jacoby 2002: S11). Schneider (1988) discusses how bodily ambivalence creates the *threat* of disorder such that others characterise the individual as perpetually, rather than temporarily or situationally, disabled. The 'epileptic body', then, is *doubly* risky: not only might it lose control, responsibility for it may shift to those nearby. In these studies, it is hinted at, but never stated explicitly, how others seek to maintain their socio-spatial distance from the risky body. If, as is frequently stated in the literature (for instance, in Rätty and Wilde-Larsson 2011: 1994), epilepsy is not merely a medical but also a stigmatised social label, questions remain as to how employers, strangers, friends and family *place* individuals, both socially and spatially.

In this brief summary of social research on epilepsy, I hope to have shown that there is space for a geographical perspective. It has not been my intention to delegitimise areas of research, such as QoL studies, for these offer important insights into the concerns of people living

⁸ Such factors determine the nature and extent of one's dealings with health professionals, carers, friends, family and colleagues, and cannot be separated from identity (re)negotiations (Rhodes *et al.* 2008a), views on treatment and care (Clark *et al.* 2010; McAuley *et al.* 2010; Poole *et al.* 2000; Chappell 1992; Chappell and Smithson 1998; Buck *et al.* 1996) and socio-economic prospects (Begley and Beghi 2002; Heaney and Begley 2002).

with epilepsy. Nonetheless, a contextual, embodied account of the geographies of epilepsy offers possibilities for closer understandings of everyday living. As I have argued elsewhere (Smith 2012), personal testimonies, whether individual (Dennison 2004; Igoe 2008) or collected (notably within the *Brainstorms* series, edited by neurologist Steven C. Schachter), can teach us about how epilepsy is embodied and how individuals in diverse contexts (re)negotiate their social identities alongside shifting material relations. They offer further insights on the 'hidden part of the iceberg' (Aicardi 1999; see also Gauffin *et al.* 2011; McAuley *et al.* 2010), such as experiences of memory loss, that receives much less medical attention than does the suppression of seizures (even though such issues are frequently a *result* of medications: Reynolds 2005). Understandings of the epilepsies as heterogeneous may help to illustrate how adaptability and flexibility are essential for processes of rescripting, and in providing services that accommodate different requirements.

A geographical sensibility brings attention to different embodied experiences of epilepsy, whether 'dramatic' or routine, that are otherwise overlooked by social scientific scholars as being secondary to the social impacts of epilepsy or overly mundane. A primary purpose of this thesis is to make connections between the research discussed above and an everyday geography of living with epilepsy in and through various spatial scales spanning the mind and body, home, neighbourhood, work, city and nationally. Furthermore, by explicitly engaging with theoretical framings as a way of constructing a geography of epilepsy, we may help to unsettle dualisms concerning the biomedical and 'everyday', the mind and body, which seem to hold apart experiences in and between different individuals. Indeed, by working with a range of meta-theoretical frameworks the intention is to both speak to the sub-disciplinary fields of the 'geographies of chronic illness', 'disability geography' and 'mental health geography', as well as connect experiences of epilepsy with broader conceptual concerns pertaining to *every-body*, time, space and place.

META-THEORETICAL FRAMES

PHENOMENOLOGY

Geographers have for some time engaged with phenomenology, which, broadly speaking, 'tries to give a direct description of our experience as it is' (Merleau-Ponty 2002: vii, in Munro and Belova 2009: 88). Merleau-Ponty (1962: 137) argues that 'consciousness is in the first instance not a matter of 'I think that' but of 'I can''; thus 'being-in-the-world' (Heidegger 1962) is an *intentional*⁹ involvement with an environment, including 'things' and other humans. Phenomenological approaches not only describe the impact of sensations on the body-self, but also show how

⁹ This 'intention' is understood less as a cognitively/articulated/will to do/use something, and more a pre-conscious bodily inclination to 'grasp' something.

everyday time-spaces shape and are shaped by altered perception. The 'lived body' (Merleau-Ponty 1962; Sartre 1993) is not an object possessed by the self – it *is* the self; it is the centre of one's world, one's orientation, right here, right now. Hence, one *lives* the body (Toombs 1988). Everything else is relative to the body's placement and actions (Husserl 1982). Surrounding space is thus experienced as functional space that facilitates or frustrates intention.

Phenomenology, with its emphasis on subjectivity and meaning in conscious lived experience, is uniquely placed to assess how illness alters perception and positions individuals *differently*. With 'health', body-world relations are taken-for-granted. This means, as Leder (1990: 53) points out, that the experience of everyday life is characterised by the *disappearance* of the body from awareness. In *illness*, one's spatial understandings are disrupted such that the body becomes ever-present in consciousness: it *dysappears* (Leder 1990: 84). Using the example of pain, Leder points to the sensory intensification that arrests one's attention and holds it within one's fleshy prison (later, I discuss Bissell's [2010] *post*-phenomenological geographies of chronic pain). This fosters an altered being-in-the-world, whereby pain disrupts lived time and space and so the relationship between self and other. In consequence, ill or disabled people are always consciously 'sizing up' the environment to see whether it is accommodating for the changed body (Toombs 1995). As Greenfield (2011: 35) puts it, the nature and course of illness is 'an existentially transformative process or an ontological assault on a person's very sense of being in the world'. Kaufman (1988) emphasises the importance of phenomenology in focussing on the individual's needs. By seeking 'thick description' of subjective experience:

Phenomenological discourse offers an authentic understanding of the patients' existential predicament related to their disability that is grounded in their own life experience, shaped through their own voice, tempered by their own emotions and feelings, and embedded in their own values (Greenfield 2011: 37)

The notion of 'authenticity' is rooted in phenomenology's emphasis on pre-discursive perception (Merleau-Ponty 1962). Here marks the departure point for scholars associated with 'post-phenomenology'. While post-phenomenology is by no means a unified concept, projects commonly disrupt assumptions of a subject that exists prior to the discursive and move towards an examination of the ways in which the individual comes to be in and through social experience almost as a secondary effect (Munro and Belova 2009).

POST-PHENOMENOLOGY

Geographers have already touched upon experiences that trouble distinctions between what may crudely be described as 'internal' psycho-emotional life and 'external' negotiations of social space (Chouinard 2012; Kingsbury 2007; Parr 1999; Parr and Philo 1995; Segrott and Doel 2010; Smith

and Davidson 2006). Attention to experiences of mental illness, such as phobias, obsessive-compulsive disorder (OCD), bipolar or delusional geographies, has shown that the internal and external are involved in fluid relationships, each informing the other, meaning that both must be negotiated in-place simultaneously. Experiencing boundary trouble between embodied self and social environment can elicit fears of great intensity, yet these very real experiences are not always shared by others and so are frequently undermined as 'irrational' (Davidson 2005, 2007; Smith and Davidson 2006). While the above projects on mental ill health do not explicitly mention 'post-phenomenology', they certainly extend 'the boundaries of the phenomenological focus upon the experiencing subject (in place)' by showing 'the ways in which in-human, non-human and more-than-human forces contribute to processes of subject formation, place making, and inhabiting the world' (Lea 2009: 373). Furthermore, these studies have contributed to the geographies of experience by overlapping with emotional geographies and embodied health geographies to account for inter-relations between the body, self, space, time and other.

Simonsen (2013) argues that academic geographers, re-framing phenomenological insights by advancing posthumanist and poststructural viewpoints, have missed that the phenomenology of Merleau-Ponty (1969; 1974) *does* anticipate many of their concerns. Indeed, she states, 'Merleau-Ponty's account of the body is radically intercorporeal and the notion of style is about co-existence, about the position of the body within the order of things or within the unfolding of collective life' (Simonsen 2013: 16). Similarly, Davidson (2000a: 656) insists that the corporeal and performative flavour of Merleau-Ponty's work indeed does provide the framework for theorising the sociality of space. While finding myself in broad agreement with Simonsen and Davidson, I am *also* interested in work by authors who have become dissatisfied with the perceived limits of phenomenology's 'experience as it is'. As with Simonsen, I wish to avoid reifying crude, caricaturistic binaries between these two positions; however, my interest in post-phenomenology stems from the *explicitness* of associated scholars' articulations of the multiply-positioned social being. This does not entail a rejection of the phenomenological (as a realm of experience), but rather proposes a reconfiguration of corporeal experience as unambiguously¹⁰ *more-than-individual*: 'body events' are simultaneously personal *and* inter-personal. It thus seems appropriate for the purposes of this thesis to refer to the 'more-than-phenomenological' or a 'de-centred phenomenology'¹¹. Indeed, while maintaining phenomenological experience as one aspect of sociality, I am particularly interested in how the (partial) de-centring of the body may

¹⁰ Simonsen would no doubt suggest that this move is unnecessary. While Simonsen (2013: 22) is at pains to demonstrate that, for Merleau-Ponty, 'the life-world is not subjective. It is exactly an interworld – intersubjective and intercorporeal – a vibrant field of consensus and conflict as well as an opportunity for agential capacities', drawing from both phenomenological *and* post-phenomenological insights arguably allows for a fuller account of extraordinarily challenging mind/body states, taking into account diverse scholarship broadly associated with *either* emotions or affect (see below).

¹¹ I borrow the latter phrase from the abstract for David Crouch's paper at the 2012 RGS-IGB annual conference session entitled 'Geography and Post-Phenomenology', at which I was not present.

assist in our understanding the meanings of when one's sense of 'I can' is not just disrupted, but completely lost.

Despite its usefulness for explaining destabilisations of conscious being-in-the-world, phenomenology arguably can only tell part of the story of events in 'objective space' involving the body *without* its knowledge or intention (storying by *others* then becomes increasingly important for self-identity). Toombs (1988: 203), for example, argues that 'bodily acts must be understood in terms of their being acts which take place within a certain situation having a certain practical significance for the embodied subject.' While this is normatively the case, the body does not always act under the supervision of the self. Hence, non-cognition, or unawareness, is rendered 'a deficient mode of comprehension' (Levinas 1996: 5) such that these different bodily states are not normally considered as part of everyday spatialities (an exception is Kraftl and Horton [2008] when insisting that the geographies of sleep offer an opportunity to reflect upon, and extend, current interest in more-than-cognitive geographies). The implied dichotomy of consciousness and unconsciousness leads to geographies that are silent on whether the body that is not intentionally directed at anything impacts on the self or the realm of conscious bodies. Seizures offer a convincing case for showing that the non-cognitive, non-directed body interacts with the world, whether in automatism (akin to sleep walking: Gunn and Fenton 1971), convulsion or when the self is 'absent' (Olsson and Campenhausen 1993). While the individual is not perceiving of 'objective' time-space, they may experience *something*, although on some 'other' level or space, 'both within and outside of the mind and body' (Parr 1999: 679). On the other hand, the absented self may experience *nothing*: the unexperienceable void. Thus, I seek to consider the simultaneity of geographies of the self and geographies of the body in ways that challenge conceptualisations of spatiality. This, following Harrison (2007), is a task of relating the non-representational to the representational, and back again.

Phenomenology's focus on pre-discursive experience presumes perceptual accessibility to the 'exterior' world and so may foreclose any possibility of understanding the experience – and cultural oppression – of the 'other'. The individual who briefly falls out of the social order cannot look to inner-directed phenomenological insight to pick up the pieces because of what Harrison (2008: 430) describes as its 'refusal to find or locate the origin of sense and of the will – of meaning, action, and thought – outside the subject'. The meaning of seizures does seem to originate outside the unaware body, and, when the seized individual regains awareness, they are often unusually vulnerable to the embodied actions and discursive constructions of others. Thus, on re-embodiment the self with epilepsy is confronted with the mediating role of human and non-human objects (those witnessing and implicated in a seizure event) in the (re)constitution of their subjectivity (although these meanings and materialities can later be negotiated or resisted, at the moment of re-orientation this is almost impossible).

A post-phenomenological perspective sees the body-subject as being *of* the world, enfolded *with* it, and emergent *from* it (Wylie 2006; Abrahamsson and Simpson 2011). The individual¹² is not the centre of thought and action, nor does (s)he ultimately emerge to reflect back, from a now-detached perspective, upon the affective swirl from which (s)he arose (Wylie 2010: 105). This means that the subject is not the singular point of knowledge or sole authority concerning the ill body – experience is not ‘something’ to be described objectively – but is a story to be told, surfacing from entangled materialities and sensibilities (Anderson and Wylie 2009: 327). The very absence of a closed identity compels individuals to seek to ‘fill the gaps’ through acts of identification and representation, which are ‘retroactively’ constituted (Martin 2005; Laclau 1994; Stavrakakis 1999). Descriptions of self may then be discerned as compensating for an absence, something always just beyond one’s grasp or knowledge. In this sense, people who experience challenging body events should not be considered as being essentially different from others, but on a continuum wherein we are all out of complete control of the self. While this suggests being-in-the-world is *always* displaced from itself because subjectivities are neither pure presence nor total absence (Wylie 2010: 108), the pressing issue here is how the self comes to know and represent the body that unwittingly becomes the centre of *others’* attentions and (partial) articulations.

This task is all the more pressing because a primary role being given to *intentional* action (as emerging from within) in the theorisation of embodiment means we tend to exclude those who embody overtly vulnerable characteristics, which are something to be solved or shunned rather than seen as a normal state of human being (Harrison 2008: 423). In this view, phenomenology, with its individualised focus on ‘actual perception’, cannot say much about the politics of experience because descriptions of discrimination do not necessarily lead to examination of the conditions that *produce* oppression (cf. Simonsen 2013). This is why analyses must not stop at bodily perception: we must move towards social theories of how difference is constructed *between* bodies and reflected in actions and words. Hughes and Paterson (1999: 603), for instance, suggest that exclusionary processes say less about embodied experience than they do socially-constructed norms. The individual becomes aware of their own ‘otherness’ when the external and the internal collide in a moment of self-consciousness at having transgressed bodily conventions¹³. This is not to deny the real experience of the aching, intolerable, painful, body, but to open up a nuanced account of how different bodies might be experienced (and so perform) differently in different places. Indeed, illness is not defined simply by the body, society, culture, history, biomedicine or environment, but all of these things contingently and

¹² This refers to *any* individual, not just the individual with epilepsy – although, in effect, I am looking to use epilepsy as a particularly telling illustration of claims made more generally about the individual human being (via their post-phenomenological perspective).

¹³ To an extent, of course, all of the work on ‘imaginative geographies’ (of us/here defining ourselves through what we negatively project on to them/there) is *also* grappling with this problematic.

contextually. The full sense of others' experiences is impossible to know, but the emotional and affectual responses of self and others to the non-cognitive body has important social, political, and ethical consequences, 'for perception is intimately tied to behaviour, and behaviour to action, and action to change, in the social field' (Stoddart 2009: 2).

THE GEOGRAPHIES OF EMOTION AND AFFECT

The challenge for this thesis is to move between the 'inside' and 'outside' experience of seizures to show how the bodily boundaries of self and other are fluid and dynamic. This involves recreating a broader conceptualisation of the 'event' of a seizure and how it enrolls not just the person seized, but also (often) a cast of others within the local 'ecology' of a place. Considering bodily events as 'emergent phenomena' is 'to set the concordant task of reimagining relations between the material, perceptual, affectual, and discursive' (Anderson and Wylie 2009: 332). Theorising the mutual constitutions of emotion and affect offers potential for developing a more relational ontology based on a kaleidoscope of circulations in and between the intimate scale of bodies and across the realms of 'public space' (in its many differing contexts). The intention is to destabilise dualistic thinking concerning public/private and interior/exterior, and to show how the dynamics of distinctive 'body events' are space and place-making. I seek to position both emotions and affect as constitutive of intersubjective emotional geographies. Emotions are seen as performed, practised and shown, and are entangled with various lived meanings, which are themselves inevitably partial, unstable, highly contingent and uncertain. At the same time, our body-selves are all open to the world and to affect and being affected. Affects are perhaps most obviously *felt* when our bodily boundaries seem to destabilise for whatever reason. At this moment, we are 'seized' by emotions, explicitly affected by them such that our imagined 'control' over their expression is also destabilised to varying degrees.

Work on emotional geographies 'speaks' to the more-than-phenomenological. We are never 'un-touched' by our interactions with others or the world around us (Simonsen 2010: 225; Bondi 2005a). One's own emotions are personal, but they also affect and are affected by other people, thus disrupting any clear distinction between bodily interiors and exteriors. This is not to say emotions are transparent, that others know when one feels this or that, but that we are all positioned by, with and through emotion; different moods do not 'belong' to us but are signifiers of our practical orientation within the world. Health geographers have arguably been foremost protagonists in demonstrating the importance of emotions in representing both the difficulties and everydayness of illness experiences. Work by Dyck (1995a) and Wilton (1996), for instance, has shown how illness alters emotional relations with others at various scales, whether family, friends or colleagues, and whether in the home, neighbourhood or at work. Struggles with or

against the 'deviant body' (Charmaz 1995) impact on self-inscription, which is relative to how one and (how one thinks) others *feel* about their illness. Bondi *et al.* (2005: 3) usefully call for a non-objectifying view of emotions as relational flows, fluxes or currents, in-between people and places rather than 'things' or 'objects' to be studied or measured. Moreover, Davidson and Milligan (2004: 524) state:

Emotions can clearly alter the way the world is for us, affecting our sense of time as well as space. Our sense of who and what we are is continually (re)shaped by how we feel. Similarly, the imagined or projected substance of our future experience will alter in relation to our current emotional state. As studies of phobic and delusional geographies show, for some, the feeling that space is populated with the complex and often contradictory emotional projections of others results in experiences of unbearable intensity and distress that challenge the very boundaries of the self.

Such an understanding of emotion displays remarkable similarities to affectual geographies, in exactly the space others claim the two can never productively meet.

Lorimer (2007: 96) provides an overview of how emotions are accused of being wrapped up in a politics of representation, while affect breaks from the mould by being implicated in non-objectifiable 'instincts, events, auras, rhythms, cycles, flows and codes'. Scholars dissatisfied with the practical language of emotions have sought to mobilise such abstractions so to address those lively, supposedly non-discursive moments that will always escape words and writing. For McCormack (2003: 495), affects exist prior to the rather static and lifeless 'economies of meaning' offered by emotional geographies. Likewise, Massumi (2002: 217) describes affect as 'pre- and postcontextual, pre- and postpersonal' and emotions as the 'sociolinguistic fixing of the quality of an experience which is from that time defined as personal' (Massumi 2002: 28). There is much to admire in affectual geographies; however, there are two points to be made. First, in the rejection of the reductionism of (emotional) language lies a contradiction: affects, which are supposedly beyond articulation, are still written about. This of course is not such a unique predicament, for *no* writing through of research corresponds to an objective reality (Bondi *et al.* 2005). The problem here is that by attempting to erect walls around what can or cannot be succinctly articulated, claims are implicitly being made about the essence of being at the same time as they are being denied.

Secondly, critiques of emotional geographies seem to gloss over many of the claims made by various scholars. Like affects, emotions are described as flowing between people and environments (Anderson and Smith 2001; Bondi 2005a, 2005b; Bondi *et al.* 2005; Davidson 2003; Widdowfield 2000). While geographers draw on the common (Western) cultural language of emotions, no claims are made as to the possibility of re-presenting any simple, internal objects of feeling. On the contrary, emotions are understood through an 'emotio-spatial hermeneutic' (Davidson and Milligan 2004: 524), whereby the sheer contingency of feelings only makes sense in

the spatial context in which they are felt; and, equally, place cannot be experienced without feelings. Thus, like affects, emotions are not certain or inevitable. They can be non-verbally communicated, sometimes intentionally (whether to show or hide how one feels), but sometimes unintentionally (our emotions might escape or betray us); and the meanings others perceive from our emotive performances may contradict our intentions. Accordingly the performance of self, whether bodily or verbal, does not necessarily provide a clear picture of how one feels, nor does the self necessarily understand what or why (s)he is feeling.

Rather than excavate further down into the dense theoretical terrain on either side of the divide, I now wish to draw on literatures that seek to *bridge* emotion and affect with respect to challenging body events. I do not claim to remain wholly faithful to the original meanings of the authors referenced here, nor do I solve their conceptual dilemmas; rather, I suggest that by seeing emotion and affect as two aspects of the same experience, we may be able to say something about challenging bodies and how we respond, 'know' and talk about them (thus I take a pragmatic attitude to theory and knowledge-making: Jones 2008). In so doing, I follow Bondi (2005b: 22) in claiming that affect and emotions, or representations of emotion and the emotions themselves, are not incommensurable. Processes in the field of affective relations are 'simultaneously felt and thought, embodied and abstract, affective and emotional, performative and representational, personally experienced and relational' (ibid.). Such an approach explicitly de-centres the body so that it is not understood as pre-discursive, but constantly involved with other bodies and a myriad of forces that are at once affectual, emotional, social, cultural, political.

As such, I do not straightforwardly follow Pile (2010: 12) in equating emotions with cognition and affect with the pre-cognitive (in part because this seems to *re*-compartmentalise mind and body within a Cartesian dualism – rather, affect '*is* thought in motion': Curti *et al.* 2011: 591). Suggesting that the response to some 'events' can be pre-cognitive is to universalise at the expense of acknowledging the wider cultural processes involved (Smith and Davidson 2006). Indeed, reactions to different bodies can be learned, trained or restrained (Tolia-Kelly 2006). Both emotion and affect, with their hazy, dynamic boundaries may, though, be understood as simultaneously conscious and sub-conscious¹⁴, although to differing degrees. Herein lies the nuances of my understanding. Following Harrison (2007) and Bissell (2010), 'affect' may be utilised productively to imply particular felt changes in inter-relational intensity; an unexpected, excessive charge made possible by the body's openness to the world (this can be during moments of heightened or lowered consciousness, the latter of which is associated with coming-around

¹⁴ In this thesis I use various terms for different mind/body states of being. 'Consciousness' suggests an actively cognising individual, while being 'unconscious', 'unaware' or 'non-cognitive' is when the individual does not have direct sensory perception of the 'external world'. 'Pre-conscious' reactions are those supposedly 'in-built' within humans as a pre-social, evolutionary response. 'Sub-conscious' or 'less-than-conscious' processes (what Wilton [1998], following Freud [1919], refers to as the 'unconscious') denote subjectivities operating below the level of active thought, when individuals are perhaps not immediately aware of why they feel the way they do, as with *unheimlich* or the 'uncanny'.

after a seizure). Put simply, affects arise from, and fall back into, emotion; they exemplify a type of raw, momentarily unguarded socio-emotional response that afterwards demands reflection, although reflection that is in no way guaranteed to elucidate some object of experience (this is perhaps what Colls [2011] has in mind when describing 'force'). Affect is therefore a quality of emotion, but one that overtly impacts on one's sense of being-in-the-world (consistent with Leder's notion of the disappearing body) and gives way to potential emotional and ethical responsibility (it is not my intention to suggest that affects and emotions only arise during notable, uncertain, shocking or surprising bodily events, but that they perhaps do so most forcefully in these moments). This conceptualisation is shaped by the necessity of thinking through split-second, 'instinctive' responses to the shocking body: when the heart leaps and the mundane 'flow' of events is radically disrupted by an 'inaccessible quality' (Dewsbury 2003: 1907).

A key point here is that responsibility flows in and from socio-corporeal performance (Bondi and Davidson 2011: 597, on the performativity of writing). The affective, emotional interactions between relational, contextual bodies are not unproblematic processes of translation: responses to uncertain affects emerge from, and are productive of, different meanings, selves and places. As Bissell (2010: 85, on the geographies of pain) describes, affect can be generative of detrimental effects (*contra* the more optimistic affectual potentials put forward by McCormack 2003; Wylie 2005; Massumi 2002; Anderson 2006). The excess of possible futures generated by negative affects is characterised by a fear that the relatively bounded materialities, structures, presences and routines upon which we rely to get by everyday are always at risk of falling apart, always at risk of being shattered by the unforeseen and unpredictable (Bissell 2010: 85). Far from embracing post-structural celebrations of multiplicity and fluidity, individuals might spend every waking moment battling against such uncertainty (Parr 1999). Such 'boundary anxieties' may be elucidated with psychoanalytical theory.

PSYCHOANALYTICAL GEOGRAPHIES

Something happens. And you could not have seen it coming. The person walking past you suddenly falls to the ground. You recoil. The self dissolves. The social mask momentarily slips. Relationality seems to break down at the very point when the relationship between bodies is magnified. It pushes at the limits of sense and the ability of the self to comprehend (Bissell 2010: 80). The next second, you know you have to *do something*. But you do not want to. You do not know what or how this happened. The social mask cannot straightforwardly be moved back into place because you are shaken and anyway it does not fit any more: the world has changed. *You* have changed. The fallen person has changed – in your estimations, at least.

Recoiling from the 'other' might be seen as an intense expression of (witnessing) disruption to the social order (Smith and Davidson 2006). The de-centred phenomenology of this disruption might be further elucidated through psychoanalytical theory. Sibley (1995) provides a spatial interpretation of socio-embodied relations following the work of Lacan, Kristeva and Douglas. The geographies of exclusion, Sibley contends, are shaped out of variable cultural fears over the 'other', but all stemming ultimately from more foundational psychodynamic encounters between self and world. The categories of the dominant symbolic order are reinforced through the 'othering' of social groups associated with feelings of disgust and danger, thus perpetuating taken-for-granted social boundaries. Following Sibley, recoiling might be seen as an embodied response to violations of the social order, to 'matter' out of its appropriate cultural place (Douglas 1993). It is important to note that recoiling from feared bodies is *not* seen as a psycho-evolutionary response in order for self-preservation (Smith and Davidson 2006). While it may be performed unthinkingly, seemingly 'instinctively', it is understood as a socially-produced, cultural response embodied by the individual based on the fear of contagion (Douglas 1993: 35). Masia and Devinsky (2000) describe the history of disgust relative to the epileptic body, and we may usefully follow them by drawing on Kristeva's (1982: 2) notion of the 'abject' – that which is neither 'subject nor object' – to develop their explanation of responses to the unruly, non-cognitive body.

Exposure to the body that might be described as 'the in-between, the ambiguous, the composite' (Kristeva 1982: 4) sparks in people the compulsion to expel the 'other' so as to re-secure their own ontological borders. This is because the affect of the problematic emergence of the other into direct consciousness, its outward 'dys-appearance' (Leder 1990), threatens the dissolution of the social order and so boundaries of the self. As Wilton (2003: 380) comments, the disabled body becomes a '*symptom*', a site on to which repressed anxieties over human vulnerability are projected. Such a conception holds with the assertion that emotions and affects are partially conscious and sub-conscious. People are not always immediately aware of why they react as they do to disabled and ill bodies, but it is in attending to forceful feelings of disgust, fear and anxiety that we may understand the insidious power and tenacity of prejudice and discrimination (Bondi *et al.* 2005; Wilton 2003). Here I am thinking about the variable *effects of affects*. This is in an attempt 'to think beyond issues of representation to engage more actively with the heterogeneous entanglements of practice' (Latham and Conradson 2003: 1901). Psychoanalytic theory can thus add to our understanding of the motivations underlying the spatial marginalisation and exclusion of ill and disabled people. It also accommodates key questions about how encounters with different bodies are negotiated and/or avoided through the organisation or 'cleansing' of everyday spaces (Wilton 2003).

BIO-POLITICAL AND VITAL GEOGRAPHIES

It is necessary to say something about the wider systems within which challenging bodies are placed, and their 'abjection' sustained. This is to question the systems of governmentality and discursive constructs in and through which human vitalities are constrained or enabled. Indeed, examining peoples' everyday processes, meanings and experiences involves asking about the contexts in which they are made to feel 'in' or 'out' of place because of their body's ever-changing social and spatial status (Del Casino Jr. 2010: 190; Cresswell 1996). By examining 'biopower', we may construct a fuller picture of how affect, emotion, discourse, materiality and embodied relations intersect to give both meaning to the moment and longer-term biographies.

Modern Western scientific medicine – *biomedicine* – is a cultural system constituted by dynamic and fluid processes, all mediated by the advent of scientific breakthroughs, technological advances, and national and international economics and politics. Rose (2007) shows how 'unhealthy' bodies are ascribed different meanings as these processes shift over time and in place. Life itself takes on different meanings as it is re-valued, re-structured and re-organised in line with definitions of the 'healthy', productive citizen. Foucault defined this as biopolitics: the power over life operating at the level of whole populations. As Philo (2001: 485) commentates, this power is rolled out in formal state interventions in the management of populations, and is expressed in all manner of policies designed to monitor, analyse, plan and regulate attributes of population such as birth and death rates, health and intelligence. A whole range of technologies, rights, economics and institutional practices descend on the unhealthy body and designate acceptable 'illness' behaviours and interventions. At the level of the individual, this is always time and space-specific, for experiences are shaped according to local and national policies and opportunities. As Del Casino Jr. (2010: 195) puts it, 'the politics of living with certain diseases thus changes as biomedical interventions change, opening up new challenges for those who are trying to negotiate their health and wellbeing in the contexts of the global politics of disease.'

In contemporary Western society, according to Rose (2007: 3), vital politics are:

[N]either delimited by the poles of illness and health, nor focussed on eliminating pathology to produce the destiny of the nation. Rather, it is concerned with our growing capacities to control, manage, engineer, reshape and modulate the very vital capacities of human beings as living creatures.

This manipulation of opportunities and restraints, or 'vital limits and capacities' (Kearns and Reid-Henry 2009: 556), is a way of regulating the population through the operation of *biopower*. Biopower is defined as the power over life itself; that is, the governance of healthy behaviours (Hoy 2001). According to Rabinow and Rose (2006), biopower entails one or more truth discourses about the 'vital' character of living human beings, and an array of authorities

considered competent to speak about and act upon that truth. When the principles of biopower become diffused throughout a society, individuals end up being encouraged, frightened or shamed into self-controlling their own bodily and mental health in line with seductive cultural imperatives (Philo 2001: 485). Discourses of 'health' entail the exercise of disciplinary power through 'governmentality' (Foucault 1979). This process, paradoxically, produces 'docile bodies' that are once empowered yet subjugated: 'Discipline increases the forces of the body (in economic terms of utility) and diminishes these same forces (in political terms of obedience)' (Foucault 1979: 138; Turner, in Moss and Dyck 2002: 63). Brown and Baker (2012) argue that the 'enforced personal responsibility' that comes with governmentality exacerbates the challenges for individuals who are most vulnerable.

The disciplines of normality (Wendell 1996: 87), including the prescription of 'normalising' medications, regulate the body's contours, posture, gestures and general comportment in space (Bartky 1990: 80). These are internalised by most of us such that we objectify our bodies in order to control them in line with normative physical standards and sustain our positions within modern social institutions. Longhurst describes (2001: 55) how non-conforming bodies are constructed as abject, dangerous, to be feared, and thus need to be controlled and contained. Containment is achieved by raising doubts as to the autonomy of the individual. People are characterised as needing extra discipline, guidance and protection because they are prone to acting irrationally, in ways that may worsen their condition (Longhurst 2001: 61). Thus, individuals and their lifestyles become the subject of the scrutinising gaze of others. Wendell (1996: 107) describes how most people cannot resist suggesting ways in which the illness episodes of others are/were avoidable, implying that the body *should* be controllable and that the individual is to blame. Furthermore, notions of personal responsibility mean the failures of biomedicine in controlling symptoms are transferred to the patient: the problem is not that medicine cannot control the body; it is that the individual's mind/body is working against them (Wendell 1996: 100). This is 'a failure of the self to take care of itself' (Greco, in Brown and Duncan 2002: 366). The myth of control, of self-mastery over the body (Foucault, 1979: 137; Turner 1996: 165; see also Amir *et al.* 1999), is used as a disciplinary technique to sustain socio-spatial organisation through the withdrawal of problematic others from public space. According to Freund *et al.* (1995: 161; Charmaz 1983), people do not usually challenge disabling time-spaces because socio-spatial organisation is assumed as natural and given: the inabilities of individuals to squeeze their bodies and rhythms of movement into public spaces are signs of their *personal* inadequacies.

Kearns and Reid-Henry (2009: 555) call for a geographical perspective on the relationship between individual autonomy and socio-political-economic structures in the (re)constitution of vital limits and capacities. Counter-balancing the perceived limits of Rose's (2007) analysis, this would involve an explicit recognition of how the local, social or material resources available to

some are not available to all, meaning that interpretations of rights and opportunities – life and death – are shaped in diverse contexts and 'knowledge' systems (locatable within a geo-historical matrix). While admitting to the pessimism of Foucault's emphasis on the discourses which 'programme' conduct, peoples' own 'practices of the self' suggest that they draw selectively on the 'helpful discourses' available to them (Sharp *et al.* 2000: 18-19). Howson (1999: 225, original emphasis), for instance, argues that resistance to the deployment of power/knowledge tends to be ignored because social scientists focus on '*practices* of surveillance instead of *experiences* of self-surveillance'. Howson shows, through an analysis of women's feelings about Pap smears¹⁵, that women actively seek out this preventative measure (perhaps influenced by family histories) as a common-sense obligation but also feel *empowered* in taking control of their health care (even if it is a form of surveillance). Arguably, Howson could have gone further in her analysis by engaging the decision-making of individuals who choose *not* to participate in these programmes, since we are still left with the feeling that these might be 'irresponsible' citizens¹⁶. It is perhaps this inescapability of disciplinary discourses, no matter how positively they are framed, that leads Sibley to contend that 'Foucault's analysis of social control is depressing. We are left feeling helpless', or Thrift (2007: 53) to suggest a 'rather gloomy outlook' arising from Foucault's work. Problems with Foucault seem to arise from the impression that subjectivities are always already-formed within discursive landscapes dominated by powerful interests, meaning that there is little scope for thinking or acting outside or against the systems that give life meaning. On the other hand, Philo (2012) addresses the under-represented liveliness and vitality of Foucault's writing to reach the conclusion that the body *is* more than a site of inscription: it is performed and has potential. Indeed, the politics of life itself (Rose 2007) is at once subject to an infinite amount of both micro and macro cultural, social, economic, political and technological imperatives that make implicit claims as to the correct composition of human vitalities; yet, at the same time, theorising 'bodies in context' (Moss and Dyck 2002) tends (partially) to disrupt the programmatic agenda of disciplinary discourses.

A Foucauldian-inspired approach to the social geographies of epilepsy therefore provides the foundation for explorations of individual agency and resistances to prevailing discourses on the 'healthy' body (Brown and Duncan 2002). The space of the body may be seen as the battleground for contested medical relations (Parr 1999; Smith 2012). In spaces of health care, biomedical control may be negotiated to varying degrees ('bioethical' contestations arise over the

¹⁵ Pap smears, or cervical screening, is a screening test used to detect potentially pre-cancerous and cancerous processes in the endocervical canal of the female reproductive system.

¹⁶ While it is doubtful Howson would criticise those who avoid clinical appointments, her analysis would arguably benefit from unpacking the relations of such 'non-conforming' individuals with spaces of health care. Indeed, as Crooks and Chouinard (2006) argue, problematic encounters in health care spaces can be socio-emotionally disabling. It is possible, for example, that, although diagnosis can be a 'rite of passage', 'a crossing of the threshold', 'a ticket for the journey' (Moss and Dyck 1999b: 166), women might actively avoid or delay the potential diagnosis of cervical cancer for fear of the 'psychological trauma' (Wilton 1996: 80) accompanying unforeseen shifts in gendered identity.

extent to which the practitioner may exert power over the patient, usually through pharmacological interventions: Rose 2007: 30); but, away from these spaces, 'care of the self' is mutually constituted with the availability and 'success' of medications *and* local, embodied health-care practices. An extremely complex geography of (living with) chronic illness duly arises. In order to contextualise the corporeal experience of illness, we need to investigate how bodies are organised through the multiple spatialities of medical rationality (see Philo's [2000] discussion of Foucault's geography of the medicalised body). Such 'biopolitics' impact on all aspects of experience, from body knowledge to workplace negotiations.

Rose (2007) describes how new forms of 'biosociality' and 'biological citizenship' are emerging within 'ill' communities across various spaces (notably online), suggesting a shift from state-centred medical care for the collective social body to an emphasis on individual consumerism and medical information (Parr 2002a). This individualisation does not, however, entail a complete rejection of socially-produced norms, for, as Valentine (1999: 330) describes, 'Discourses in the media, medicine, consumer culture and fashion industry map our bodily needs, pleasures, possibilities and limitations to produce geographically and historically specific norms about how the space of the body should be produced'. As Featherstone (1982: 26) notes, this encourages individuals to:

approach their free time activities with a calculating frame of mind. Self preservation depends on the preservation of the body within a culture in which the body is the passport to all that is good in life. Health, youth, beauty, sex, fitness are the positive attributes which body care can achieve and preserve.

With this in mind, biosocial spaces may be examined for how they both reproduce and resist pervasive disciplinary discourses as part the process of individual and collective empowerment through community-making and information-sharing.

Foucault's work (1973, 1988) provides a conceptual basis for ideas concerning how the self is actively shaped according to an 'ideal' (often through the body) in which social and biological processes intersect. However, chronic illness and its treatment both constrains and enables new bodies and spaces, and regulates how various ill subjectivities are constituted in and through the performance of ill identities. Del Casino Jr. (2010: 200) calls for geographers to disentangle further the ever-changing 'politics of life', and to address how the embodied experience of biological citizenship plays out in different places. This includes questions as to *who* is responsible for managing illness (who controls, defines and regulates socio-embodied discourses?) and at what level, with complementary questions over 'biodeviance' (such as non-compliance to medications) and the disciplines of normality. Such questions are inherently relational because of the myriad of spaces, processes and discourses that are embodied and resisted in and through a

variety of scales; in ways that are both 'mundane', that is, embodied on an unthinking everyday basis, but also the basis of active political advocacy. These are issues that strike at the very heart of what it is to live (un)healthily.

SUB-DISCIPLINARY FIELDS

For the remainder of the chapter, I shift down from the meta-theoretical framings to consider more grounded interventions in the 'sub-disciplinary' fields of human geography. There may be a measure of repetition from what has been specified more abstractly, but this is with a view to showing how epilepsy may be tracked and situated systematically across sub-disciplinary terrains. Indeed, I now insert more cross-references to epilepsy specifically because there is virtually no *geographical* work on the condition, besides a thesis by Cristina Del Biaggio (2001) and a subsequent paper by Del Biaggio *et al.* (2002), which, unfortunately for me, are both in French (although the abstract of the latter has an English translation).

THE DEVIANT BODY AND (THE LOSS OF) CONTROL

Work on the geographies of the body encompasses those lived spaces where bodies are located both conceptually and corporeally. Similar to Parr's (2002: 243) notion of the 'sociobiological', Moss and Dyck (1999a: 389) capture how, 'through the corporeal space within and through which bodies live, discourse and materiality constitute and are constituted by, in, on and through the body'. Bodies engage in material practices that (re)produce both the meanings of bodies and the situations within which they are placed, hence bodies and space are always in the 'process of becoming' (Dyck 1999a: 221). This means categories such as being 'able' or 'disabled' are meaningless outside of the contexts in which they are experienced. Furthermore, bodies and space are in a dynamic, shifting relationship: the meanings of space shift (becoming more or less 'accessible') as the body's physical capacities fluctuate, and *vice versa*. Dorn and Laws (1994: 108) suggest 'mapping' the geographies of the deviant body so to rethink 'places as they are contested in embodied social practices.

Being 'in place' is a social ideology expressing the 'correct' way of being or order of things; however, transgressing imagined and/or material boundaries renders one 'out of place' (Cresswell 1996; Kitchin 1998). At the same time, dominant groups construct the 'other', which generally denotes stigmatised groups along the lines of race, ethnicity, gender, sexuality, age, (dis)ability and so on. Foucault, following Canguilhem (see Philo 2012: 503), shows that it is only through identifying and classifying the 'abnormal' (figures showing variations in human bodily form, thought and conduct) that the 'normal' comes to be known and codified. Put another way, the

'same' only really comes to be known or define itself over and against what comes to be taken as the other. Once the same/other has been defined, the boundaries separating them are ready to be 'policed'. Crooks *et al.* (2008) and Moss (1997) describe how the 'deviant body' falls outside of normative ideas of 'health'. The ill body is thus constituted by medicine as the container of symptoms without thought for the social conditions that 'produce' dis-ease in the first place. Medicine attempts to fix faulty bodies, but they remain unruly and indeterminate such that they frequently fail to conform to the social order. The 'social order' (Schatzki 2002; Simonsen 2010: 222) is established through the interweaving of social practice and discursive meaning. Cresswell (1996: 16) describes how places reproduce the meanings associated with them in natural, self-evident and common-sense ways: 'we are silent in a library because we believe it is appropriate to be silent in libraries, and by being silent in libraries we contribute to the continuation of silence'. These cultural norms tend to be self-perpetuating because individuals do not feel adequately empowered to challenge them (although socio-historical studies show that society is in flux and hence norms do gradually change). People who are not confident in their abilities to conform might self-exclude and so remain hidden from view. As a result, exclusionary practices are reproduced by a generally non-reflective population, thus sustaining the socio-spatial order. People, as Kitchin (1998) puts it, come to 'know their place'.

The marginalisation of 'deviant' behaviours renders 'non-conforming' individuals all the more visible and so disruptive of able-bodied norms (Crooks *et al.* 2008; Dyck 1995a; Moss and Dyck 1999a; Moss and Dyck 2001; Longhurst 2001). Alongside 'disability aesthetics' that mark people out as 'broken', 'crumpled' or 'disfigured' (Hawkesworth 2001), Hansen and Philo (2007: 496) comment on the negative attention received by individuals who *do things* differently, perhaps relating to how they move, gesture, speak, 'hold themselves', smell, sound. The suspicions of others often lead to the individual being treated with hostility and being forced to account for their different bodily performances. Furthermore, studies report on peoples' all-too-frequent experiences of being shunned, formally excluded (i.e. sacked from a job), and pressured to perform as 'normally' as they possibly can. On the other hand, there are a great many *hidden* impairments (Stone 1993). As Dyck (1999) describes, if people *appear* healthy, others simply will not believe that they are not, and so will refuse to accommodate their socio-embodied needs, characterising instead the individual as a 'chancer' or a 'hypochondriac'. Further, if disability is hidden it can be kept secret to help preserve one's social identity, although such practices may serve to reinforce the marginalisation of individuals with chronic illness (Moss and Dyck 2001: 232; see also Davidson and Henderson 2010). No matter the extent to which the individual strives to live up to social standards, the body might sometimes escape 'from the discipline that the social order seeks to apply to it' (Smith and Davidson 2006: 63). To varying degrees, 'other' bodies

incite boundary maintenance processes through the exclusion of that which is 'out of place': the deviant body.

Moss (1999) describes how the failure of biomedical discourse to account for *fluctuating* health means others rarely appreciate how much illness involves 'good days and bad days' (Wilton 1996: 78), which render the body-self relatively (dis)abled in particular contexts. This can create problems for people whose 'performance' of illness is under scrutiny in a professional or social capacity. Whereas geographers of chronic illness and impairment have been attentive to the differences between 'visible' and 'invisible' impairment, relatively little has been discussed of conditions involving *both* at different moments in life. Furthermore, there exist conditions not so much defined by good or bad *days*, but good or bad *moments* (i.e. ones that fluctuate aggressively). With epilepsy, people often experience hidden cognitive difficulties as a result of seizures or medications or both, while seizures themselves manifest in the sudden loss of bodily control (ranging from the mild to the dramatic). This means that how the individual responds to *complete* impairment of their body (after being rendered non-cognitive) is regularly performed within periods of *partial* impairment. Individuals therefore have to contend not only with the corporeal and social consequences of their 'deviant' body, but also with negotiating social and material accommodations for either/both their hidden impairments or/and in anticipation of further losses of control. Hence, 'deviance' must be considered contingently and contextually, for what is 'out of the ordinary' in one place might be easily recognisable and manageable (for self and/or others) in another.

BODILY BOUNDARIES

Studying health-related interactions between self, body and environment facilitates increasingly nuanced explanations of the spatialities of everyday life. Work on 'bodily boundaries' is a crucial disciplinary sub-field for tying together the meta-theories engaged in this thesis, particularly in the guise of affective and psychoanalytical geographies which, as described above, usefully explain moments of boundary anxiety. The episodic nature of epilepsy means that concealment or disclosure may be possible (Davidson and Henderson 2010), although performances of the 'healthy' body may unpredictably be destabilised by illness 'episodes'. Davidson's (2000a, 2000b, 2001) work with agoraphobics is invaluable for thinking through the fluidity of bodily boundaries, especially as these relate to distinct bodily 'events' around which one's social geographies become structured. She discusses how fear of the re-occurrence of panic attacks leads to difficulties in traversing social space because of the seeming breakdown of the boundary between the 'inner' self and 'outer' world (Davidson 2000b: 641). In extreme cases, this is experienced as a threat to the person's sense of identity, a form of 'depersonalisation' where they do not feel as if

'themselves' any more: nothing marks out where the body ends and the world begins (Young 1990: 163). Perceptions of surrounding space are altered, such that space appears unfamiliar and distant at the same time as it *consumes* the self. This causes a curious feeling of the simultaneous implosion and explosion of the self's protective boundary, rendering individuals vulnerable to forces beyond their control. Chouinard (2012) elaborates on the paradoxically (*dis*)embodied nature of boundary fluidity within bipolar experiences: mania involves 'internal' mental/physical intensity at the same time as the dissolving of boundaries between body and environment. With the destabilisation of boundaries comes the *search* for boundaries so as to re-establish the self as a social being (Parr 1999). I wish to engage these ideas, first by comparing and contrasting the phenomenological experience of seizures with the work of Davidson, Chouinard and Parr, including individuals' resistance to the dissolution of their bodily boundaries. Next, I wish to de-centre the individual to show that the onset of anxiety (whether with seizures, panic attacks, mania or delusional experiences)¹⁷ is often reflected in witnesses to the unruly body, sparking an equal and opposite desire to reinforce their *own* boundaries so to ward off those uncomfortable, uncanny or *unheimlich* proximities (Freud 1919; Wilton 1998).

With agoraphobia, panic attacks are specific to, and predictable in, certain circumstances, namely public space populated by others. Avoiding certain places, notably the shopping mall (Davidson 2000a, 2001), becomes an important strategy for reducing risks to one's stability and security (individuals may then attempt to identify public time-spaces where and/or when they will be relatively isolated). The boundaries of the homeplace will often consolidate one's bodily boundaries, although this may encourage people to become relatively *housebound* (Davidson 2000a: 35). The advent of seizures is arguably still more complicated because they can be triggered by environmental factors (e.g. heat), material objects (e.g. a flickering television), psychosocial factors (e.g. stress or tiredness in or after work), knocks to one's fleshy exterior (e.g. a blow to the head), the meeting of the 'external' with the 'internal' (e.g. eating Chinese food with mono-sodium-glutamates: Gaby 2007) – or they might *just happen* (for discussions of seizure triggers, see: Aird 1983; Dionisio and Tatum IV 2010; Spector *et al.* 2000). Individuals might identify one or several triggers, or none. Even with certain precipitating factors, management strategies are an inexact science, perhaps exacerbating the sense of one's boundaries as *precarious* and unpredictable. I wish to examine interactions of the body, self and environment in the (de)construction of the bodily borders, which might be relatively more or less stable in different environments, times or corporeal states. Furthermore, assessing peoples' relationship with space and place involves an explicit engagement with 'trust' in the body to stay under

¹⁷ We should not assume that *all* delusional and bipolar experiences are negative, for some of the 'voices' in Parr and Chouinard's projects reveal a powerful sense of euphoria, well-being and/or religiosity. There is also an array of evidence concerning 'ecstatic' seizures (see, for example Hansen and Brodtkorb 2003). However, despite Chouinard's disruption of normative ideas of manic states being 'unwilled', there was no evidence in my research to suggest seizures were ever welcomed by participants.

(potentially varying degrees of) control; or, put another way, confidence in the body to keep the self contained and separate from the external world. In so doing, we might develop ideas of how perceived bodily boundaries might be observed, negotiated or resisted.

DAILY GEOGRAPHIES

Moss and Dyck (2002: chapter 7) discuss how fluctuating bodily boundaries require that subjective physical capacities are monitored in line with the spatial (re)construction of everyday life. Geographers have long argued for analyses to be grounded in the often mundane routines and spaces of day-to-day living so as to illustrate those lived disruptions caused by such conditions as MS and HIV/AIDS (Dyck 1995a; Wilton 1996). Adjustments following illness onset reflect not only how it enters into individuals' embodied and emotional time-space fabric but also the coping strategies enacted, which are embedded in particular places and across various sets of social relations such as gender, ethnicity, class and life stage (Moss 1997). Hansen and Philo (2007: 497) contend that the 'embodied 'art' of managing the time, space and speed realities of 'doing' daily living demands more recognition than it usually receives'. Notably, Moss and Dyck (2001) assess how women diagnosed with chronic illness continually (re)structure their social and material spaces to accommodate the uncertainty and unpredictability of (the physiology of) the disease process. Discontinuities induced by chronic illness may catalyse major renegotiations of the people, places and practices (and so identities) that comprise everyday life, while the psychological challenges associated with diagnoses impose their own spatial constraints upon the individual's daily environment, the extent of which will often vary in accordance with fluctuations in health (Wilton 1996) or entangled experiences of inclusion and exclusion (Parr *et al.* 2004). Everyday time-space routines, then, involve 'individual biographies, social relationships and space [which are] in a dynamic relationship as activity and meaning is reconstructed, and the social and physical environment is remapped in terms of valued resources' (Dyck 1995a: 318). The everyday practices and possibilities of living with chronic illness must therefore be located in and through wider biopolitical regimes, at the same time as recognising the particular contexts within which the individual lives. Spaces at various scales, be it the body, local neighbourhood or city, are implicated in, and partly constituted by, experiences of illness (Parr 1999). Feelings and embodiments of illness have different implications and effects in various places; and, by unpacking the meanings of the spaces that people consider important, we may rethink assumptions as to the fluidity of space, place and self. I now identify the daily spaces to be revisited throughout this thesis (most obviously in CHAPTER SEVEN).

THE HOME

Idealised constructions of the home have represented it as a safe haven, place of sanctuary, independence, well-being (see Blunt and Dowling 2006); in short, it is supposedly the place where expressions of the body-self are least constrained. People tend to experience changing relations with(in) the 'home' due to their increased presence. Crooks (2010), for example, examines the 'unpredictably routine' and 'routinely unpredictable' activities of women after the onset of fibromyalgia. Although participants felt their unpredictable bodies to breed an unpredictable home life, Crooks shows that difficulties in identifying with the fluctuating body obscures how renegotiated practices *do* to an extent structure home life. These relations shift over time, perhaps in accordance with symptom severity. People will often confine themselves to the home to avoid stressful 'external' experiences, although many have then reported feeling socio-spatial isolation due to their reduced social geographies (Dyck 1995a; Wilton 1996), and some have come to think of the home as a space of entrapment: a prison or asylum (Davidson 2000b).

Representations of the home have also engaged embodied encounters with domestic spaces (Imrie 2010). The home does not straightforwardly provide an undifferentiated 'protective zone'. Rather, the space of the home is potentially as 'dangerous' as the outside world, although, being under one's own jurisdiction, individuals tend to have a greater sense of agency:

Boundaries and spatial orderings have to be achieved and worked at (Law 2000), and the home, far from offering these things as a matter of course, merely provides an environment in which such spatial practices might be more successful and its spatial formations might endure. (Segrott and Doel 2004: 605)

Individuals will attempt to work with and discipline the home environment in *lieu* of bodily control. As Moss and Dyck (2002: 147) suggest, this is not so much a *coping strategy* as a re-working of *being*; a *re-situating* of the body within domestic time and space. The ability of the person to control domestic space is, however, entangled with bodily capacities, social situations and wider social processes (including finances, location, ownership [renting individuals are limited] and local housing policies). Moss (1997: 24), for example, shows that restructuring the 'home' after the onset of illness involves not only the physical building but also the variable sets of relations that constitute the household. Further, the disciplining of space is never 'complete', for non-human objects have a relationality of their own. Objects need to conform to particular spatial arrangements, relations, separations and boundaries so as to avoid troubling interactions with the body-self (Segrott and Doel 2004: 607). As stand-alone commodities, many household items are intensely ambiguous, and so can be resourcefully enlisted to perform unexpected roles. On the other hand, it might be through painful experience that they are finally assigned a node in one's map of meaning.

From these understandings we may begin to engage with how disciplining the immediate environment of one's dwelling involves constant vigilance, creative practices and complex interactions with people and diverse materialities. Geographers have effectively shown how individuals modify physical space within the home with a view to facilitating household tasks and reducing perceived dependency on others (Dyck 1995a; Imrie 2010). Less, however, is said about the minutiae of decision-making in light of how people perceive their changing relations with material spaces: peoples' choices remain largely assumed as self-evident. I wish to show how the 'phenomenology' of the volatile body entails disrupted material relations (relative to the hardness, height, temperature, shape and other such qualities of objects), which are partially reinterpreted in terms of their affective, harmful potential. This breeds new practices, not least in the constant monitoring of the positioning and timing of bodily movements in relation to domestic spaces.

(SEMI-)PUBLIC SPACES AND BEING ON THE MOVE

The workplace is a key site of contention and adjustment following the onset of chronic. How these processes 'play out' sometimes, but not always, corresponds with the extent to which the individual's working space is 'private' or public-facing (e.g. being situated in a small office, surrounded by trusted colleagues, is usually experienced as more 'private' than a large, open-planned office or customer service role). Disruptions to one's embodied identity as an 'able' worker can, however, shift one's positioning in *any* labour force. Illness, body and workplace are (re)structured through complex processes that are relatively enabled or constrained by a variety of factors, such as workplace 'cultures', the attitudes of colleagues, the physical working environment and shift patterns. Hansen (2002: 177–179; see also Hansen and Philo 2007; Freund 2001) provides numerous examples of individuals with changed, changing and changeable bodies coping with the demands of 'timing and spacing at work'. The working environment, once taken-for-granted, is reinterpreted relative to one's relative bodily capacities, making important such features as the location of toilets, positioning of furniture, the size of doorways and so on. Workplace tasks that were once carried out almost unthinkingly perhaps need to be renegotiated in terms of how and whether they are completed by that individual. Moss and Dyck (2001: 231; see also Davidson and Henderson 2010) attempt to 'intervene into the process of marginalisation and look at the connection between bodies and environments' in the workplace (I elaborate further on the *precariousness* of forging 'ill' and 'disabled' identities at work below), especially when illness is fluctuating and transitory. I want to elaborate on the various strategies utilised to cope with illness in the workplace, and how far individuals are to able (re)structure the layout and the 'placing' of their body with respect to its potential for 'seizing'. Indeed, workplaces are often

structured around explicit responsibilities and ways of doing things that create continual pressures for people whose responsibilities to the body-self may come into direct conflict with these normative expectations.

Much has been written about the home as an ambiguous 'private' space, and the workplace as one of generally familiar people and place involved in unstable relations (Moss and Dyck 2001). I want to further address how spaces *between* these 'destinations' are negotiated. Dyck (1995a) and Parr (1998) provide convincing accounts of how participants' relationships with places beyond the household, such as one's neighbourhood and the city, also change following diagnosis. Spaces and places are assigned new meanings as individuals leave work, reduce their social networks and use the home and public space differently. 'Getting around' may be(come) difficult because of fatigue, stress or a lack of facilitation or safety in negotiating the physical environment (Dyck 1995a), while the side-effects of medications may impact on one's ability to be away from the home for long (Wilton 1996). Dyck (1995a: 310) describes how the geographical separation of the (perhaps suburban) home and (urbanised) workplace acts as a barrier to continued employment: 'Using public transportation, particularly in crowded, rush-hour conditions, and covering the distance from transit stops or a parking lot to the workplace were problems for some women.' Davidson (2000b, 2001a), meanwhile, shows that spaces such as the shopping mall become 'out of bounds' for agoraphobics because of their socio-economic design logic (for example, a lack of escape routes is thought to increase the likelihood of consumption, yet only increases the anxieties of agoraphobics). In certain public spaces, agoraphobics can partially stabilise and control their bodily boundaries by utilising 'involvement shields' (Goffman 1963: 40) to (re)assert and defend their fragile sense of spatiality (Davidson 2003: 119). Such studies are revealing of the manner in which traversing 'public' space is at once dependent upon the course of illness, local knowledge (including temporal flows of people), the design of the built environment (including accessibility), momentary assessments of the body-space, and the emotional geographies of the self. Moss and Dyck (2002: 146) describe how making sense of chronic illness means embracing *notions* and *practices* associated with volatility, yet stick to deconstructing corporeal renegotiations in generally familiar spaces. To be sure, not only are peoples' bodies volatile, so too are the spaces they traverse. Public places are characterised as relatively less predictable in terms of the composition of people and space, and certainly less amenable to guaranteed bodily accommodations. The potential for becoming 'out of place' at any given moment leads to questions over the use and meanings of time and space, and the extent to which the individual ever truly feels a sense of 'belonging' in 'public' (Glass 1989: 212).

INVOKING/RESCRIPTING ILL IDENTITIES

Biomedicine is a cultural system that regulates both the meaning ascribed to disease (categories, definitions) and power relations in health care spaces. Patients seek out the 'expert' gaze of particular health professionals in particular places (Philo 2000b) and so are complicit in reinforcing dominant 'ways of knowing' illness (Gesler 1999). Where there is a lack of available treatments, explanations or negotiable options, however, health care spaces can be extremely *disempowering* (Crooks and Chouinard 2006: 349). This situation gives rise to an ironic relationship, whereby the individual may be critical of professional practices of labelling and 'designating' illness at the same time as seeking biomedical legitimacy (the 'discursive body' that provides a script for explaining illness to self and other: Moss and Dyck 1999a: 377).

Beyond spaces of health care, people take on, negotiate and resist illness categories as they interweave with corporeal and social experience. There is consequently a need to see the body as more than simply an 'object of science' (Dyck 1999b: 122), to look beyond the medical, 'whilst continuing to engage with it, albeit in a critical capacity' (Parr 2002b: 241; Philo 2007). By exploring non-mainstream views in and across different spaces, the assumptions inherent in dominant categories may be unsettled and so provide the basis for challenging stigmatising attitudes, and assisting helping professionals understand first-person experiences of illness. In her work on Autistic Spectrum (AS) individuals, Davidson (2007; 2008; 2009; 2010; Davidson and Henderson 2010) fleshes out intimate socio-material connections where it is usually assumed there are none, thus disrupting the narrow medical parameters through which such individuals are read by others.

Living with chronic illness or disability further involves the renegotiation of everyday identities, such as 'parent' or 'employee', which are bound up with various sets of expectations and social norms. Dyck (1995a: 317) argues that identity continuity is important for coping; yet coming to terms with one's changing sense of self and physical capacities can be an arduous and emotional process with associated feelings of diminishing self-worth and dependency (Wilton 1996). Crooks *et al.* (2008: 1842) discuss how people resist, to varying degrees, identifying as disabled so as to distance themselves psychologically from such an identity. This is in part a result of the social stigma surrounding disabilities, which essentialises the individual as being 'faulty' and 'less capable' of participating in mainstream social spaces. Some people, however, feel dis-abled in certain places (such as at work) but not in others (e.g. the home), hence self-characterise as being *in-between* 'disabled' and 'not disabled'. Nevertheless, difficulties in completing processes configured around 'able-bodied' conventions marks the individual as uniformly disabled and so threatens both self-identity and financial stability (Dyck 1999b). Workplace policies rarely provide

flexibility in assessing whether or not the 'ill' body is 'able' to work (Crooks *et al.* 2008)¹⁸, and thus the workplace is frequently cited as a space of struggle.

General assumptions positioning the 'working body' as an 'able body' (Moss and Dyck 2001: 232) can be contested by challenging definitions of 'illness' and 'disability'. In performing the ill self, the body can be used as a tool of resistance to widespread assumptions about what an 'ill person' can or cannot achieve, when and where. Moss and Dyck (2001: 232) describe this bodily *self-inscription* as a potentially empowering way of contesting one's own marginalisation in the workplace. Reclaiming the body and workplace as entangled sites of struggle, however, places the individual in a precarious position due to the unpredictability of the disease process and how it is negotiated. In these circumstances, various material and corporeal coping strategies may be utilised. Working life might be re-embodied around one's 'ill' identity by negotiating flexible expectations with employers so as to accommodate sudden symptomatic fluctuations. Another often-cited strategy involves claiming not to have the (stigmatised) condition with which one lives, but another, more 'socially accepted' chronic illness (Moss 1999). By hiding contested illness under the 'mask' of legitimacy, colleagues' expectations and reactions can be managed, allowing illness to be embodied on one's own terms. Some people might even be able to conceal their illness from some or all of their colleagues to preserve an 'able' identity (Davidson and Henderson 2010; Moss and Dyck 2001b). I wish to develop accounts of how people weigh up the decision of whether and how to represent illness and (re)structure their work environment in light of the unpredictable body that may *take away* the element of choice.

DIALOGUING THE EPILEPTIC BODY AS A SPACE OF ENCOUNTER AND POTENTIAL TRANSFORMATION

As new 'representational geographies' are being ushered in around issues of chronic illness, mental and emotional health (Parr and Davidson 2010: 266), the voices of people living with stigmatised conditions are now emerging. Re-writing the 'unhealthy' body is seen as a pathway to empowerment through the destabilisation of common assumptions concerning people living with chronic illness as being 'less than'. This re-imagining is sometimes filtered through the representations and contestations arising from 'user movements', both material and virtual

¹⁸ Besides engaging (re)appropriations of 'illness' categories, we must consider how these interweave with the social categories that 'others' embody. Dyck (1995b: 249), for example, critiques white women's monopoly in feminist geographies by locating immigrants' health experiences across colonial histories, current social policies and the practices of white society that sustain the social and material conditions under which immigrants live. Moss (1997) further seeks to shed light on the marginalised experiences of older women living with chronic illness. It is argued that the aging process is itself gendered, financially-implicated and embodied, and so is an integral experiential characteristic of the body-in-flux. Identity also cross-cuts with 'class': findings indicate (Crooks *et al.* 2008; Moss and Dyck 1999a; Moss and Dyck 1999b) that the more money women make in their professions, the more likely they are to gather information and gain access to disability insurance. Taking account of the complexities of positionality and identity helps to produce nuanced geographies of living with chronic illness.

(Davidson and Parr 2010; Parr and Davidson 2008; Parr 2008). There does not, however, appear to be much in the way of epilepsy community-making (elaborated in CHAPTER EIGHT), although work on the politics of identity is helping to recast 'epileptics' as 'people with epilepsy' and 'service users'. Old ideas about the helpless, unruly body are being re-scripted in modest public campaigns highlighting the successes and abilities of individuals who may otherwise have been turned away because of their diagnosis. However, we must caution against homogenous depictions of 'overcoming', for this so-called 'brightsiding' (Diedrich 2007: 54) might serve to obscure the very real experiences of individuals who experience disabling 'body troubles' and continue to be discriminated against. Given the unintended, unconscious states into which individuals enter, and around which they struggle to build their everyday time-spaces in light of various negative affects and effects, re-encountering the 'unknown', de-centred body through various re-presentations suggests that they are struggling to represent their *own* experiences.

This thesis intends to address the unique challenges of embodying epilepsy socially and materially, both in the immediate and long-term. If *normal* difference (bodily ways of being operating within the boundaries of social acceptability) and is possible to live with, we need to look further to the discourses and practices that sustain *unacceptable* difference (when bodies transgress the range of acceptable norms and so become classified as 'deviant'). I aim to explore the extent to which individuals whose bodies intermittently become 'ungoverned' can feel as if they belong in the community, constrained as they may be by state-centred (and historically and culturally-entangled) ideals of 'active citizenship' and 'productive bodies' (Dear and Wolch 1987; Milligan and Conradson 2006). Key to both my conceptual and empirical foundations is the notion of 'vulnerability', which, as Harrison (2008: 440) puts it, is an inherent and non-eliminable aspect of active corporeal existence – although one that is rarely recognised as such. Contemporary non-representational and post-phenomenological geographies assume conscious performance and practice as an organising principle, but I question the 'co-ordinates' of such conceptual terrains by showing that people with epilepsy at times 'access' the world through the words – the *representations* – of others. Thinking through the vulnerability of the self, not just to the impact of painful body/world collisions, but also to the actions and words of others could have a considerable impact on how we think about embodiment as well as wider processes of subject formation and sociality. Indeed, the radical 'openness' of the body-self to the world, with its fluid boundaries, is not always a cause for celebration, but may be a way of understanding why (re)locating and reinforcing these boundaries is so often a crucial factor in self-other relations. One way of adding empirical rigour to Harrison's conceptual abstractions is by engaging the experiences of and consequences for vulnerable bodies that disturb other people, place and space. Becoming 'unregulated' as a social being is an intense, affecting process, but it should be placed on a spectrum across which *all* bodies are constantly beyond the material and discursive

control of the individual. If all of our 'embodied identities are never secure' (Colls 2006: 533), the heterogeneously embodied epilepsies are a crucial addition to scholarship concerned with how 'different bodies' are experienced and negotiated – ways that may well not be so different after all. Indeed, by addressing the (de-centred) phenomenology of seizure experiences, we may begin to demystify radical losses of bodily control so as to make a humble start at re-writing – re-presenting – epileptic episodes as *everyday* and so perfectly *normal* phenomena, ones that individuals struggle *with* rather than *in spite of*.

CHAPTER THREE:

KNOWING 'ILL' BODIES THROUGH MULTIPLE METHODS

Over the last three decades, qualitative methods have become increasingly prominent within new health geographies. Drawing largely on feminist methodologies, researchers have sought sensitively to unpack the personal and political consequences of becoming ill. The 'wounded storyteller' (Frank 1995) has become a valuable source of insight for promoting ways of 'knowing' the ill body as something more than just a container of symptoms, a 'passive victim' to exclusionary social processes (Shakespeare and Watson 2002), a space on to which discursive representations are etched; to be sure, bodies have been located both conceptually *and* corporeally (Moss and Dyck 1999a). In confronting 'how the body is made and what it is made of' (Hall 2000: 22), the focus has become the *individual*, whose unique contexts (personal, cultural, historical, familial) and place-based ways of living with the 'deviant' body frequently unsettle and decentre biomedical discourse and undifferentiated methods of care delivery (Dorn and Laws 1994; Parr 2002b).

The lifeworlds of individuals are rarely fixed or easily summarised, but rather constituted at the intersection of competing social constructions, representations and performances. This multiplicity means that body-knowledge is both situated and struggled over (Smith 2001). Choosing the means by which to place marginalised 'voices' at the centre of research has roots in the underlying strata of specific views on what 'knowledge' is and what it can be used for. The selection of a particular research methodology is hence (small-'p') political. At the same time, we must always be aware of how particular *ways* of accessing the 'ill' body shape the resulting data. New health geographies have relied almost exclusively on qualitative methods such as ethnographies and semi-structured, face-to-face interviews¹⁹, hoping to approach participants' socio-cultural contexts with sensitivity, while recognising that ideas and behaviours are embedded in place (Dyck 1999a: 247, 2000: 86; Crooks 2010; Wilton 1996). The researcher who enters into the lifeworlds of 'marginal' groups (be it along the lines of gender, class, sexuality, ethnicity or disability) is implicated in defining those who are 'outsiders' (in society generally, but also with-in/outwith that group); and thus issues of positionality have been considered for their impact on the co-construction of data and subsequent representations of how individuals embody 'marginal' categories. No matter how abstract the conclusions, they cannot be divorced from the

¹⁹ Although there has been increasing interest in other methods of data collection, such as written narratives, both in print or online (Smith 2012; Milligan 2005; Davidson 2008; Parr and Davidson 2008) and film-making (Parr 2007).

'nuts and bolts' of the research itself, including the ethical and political dilemmas that inform and arise from its practice. Such ethics of engagement are especially crucial when the research is interested in potentially 'vulnerable' individuals²⁰. This obliges that the specific 'events' – the practical application – of research be considered so that we may broaden understandings on a functional and theoretical level, as well as situating the ethical and political contexts of geographical knowledge production. In what follows, first I discuss my adoption of multiple methods research, including its relative merits and demerits, and second I give details in turn of each method (principally a questionnaire survey, semi-structured interviews and supplementary written testimonies). I finish with reflections on the collaborative process with Epilepsy Scotland (ES).

MULTIPLE METHODS RESEARCH

Carrying out research is an iterative, cluttered, complex, contingent, incomplete, partial process. This should not be seen as a weakness, but as an opportunity for furthering the possibilities of what the research can say or achieve in light of critical reflection. I have harnessed this 'space of potential' through the use of multiple methods, principally questionnaires and interviews, so as to construct a complex picture of what is a complex condition, one at once extensive and intensive, and always polyvocal. Multiple methods research, to borrow Philip's (1998: 264) definition, is when 'a number of complementary methods are employed to address different facets of a research question, or to address the same question from different perspective'. It is often assumed (not unproblematically) that the use of multiple methods *within* one research tradition (i.e. qualitative or quantitative) is epistemologically consistent, while 'crossing over' would inevitably foster incommensurabilities. I wish to argue that qualitative and quantitative methods need not be conflicting, but can be complimentary and productive when negotiated creatively and reflexively. Taking influences from post-structuralist and pragmatist thinking, and drawing on the work of feminists, knowledge is understood as *made* rather than simply revealed, and thus I reflect on various decisions – what worked and what did not – to allow the reader to decide upon the relative merits of pursuing such a methodology.

Critiques of both questionnaires ('quantitative') and interviews ('qualitative') are well-rehearsed. Quantification is commonly associated with large data sets, with worldly knowledge being translated into neat numerical form by an apparently objective researcher. Qualitative techniques are criticised for their subjectivity, wherein potentially numerous misunderstandings between the researcher and researched results in spurious data, which is anyway contingent

²⁰ 'Vulnerable' in a 'sociological' sense rather than a more legalistic-ethical sense (where the individual may be incapable of giving consent); although children and people with learning disabilities were part of the database of people first approached to participate in this research, an issue discussed below.

upon the researcher's own agenda rather than the 'facts'. Despite such parodies, geographers (Hodge 1995; Lawson 1995; Mattingly and Falconer-Al-Hindi 1995; McLafferty 1995; Moss 1995; Philip 1998; Rocheleau 1995) have argued in for the use-value of multiple methods derived from different epistemological traditions in interrogating the partiality of knowledge (Nightingale 2003). While many health geographers remain suspicious of quantitative methods²¹ (with notable exceptions, including Crooks [2007], who used 'sickness impact profiles' in addition to interviews), it is my contention that, when designed carefully, surveying can be a vital part of the researcher's toolkit; one that can be used to inform, enhance, or expand investigations into the experience of chronic illness. If we accept that all research methods will always come up short in representing 'reality', utilising multiple methods may usefully highlight different aspects of the same empirical domains of concern (Hoggart *et al.* 2002: 71). To illustrate, questionnaire-based research cannot fully capture something as complex (and hence unquantifiable) as emotions; and so, while questionnaires can be a functional means to finding out *what* people do, they are not as robust as interviews in getting at *why* people do what they do. It does not necessarily follow, however, that interviewing provides more 'accurate' data. People discuss their lives selectively, depending on whom they are 'telling, who is listening and who might listen' (Hoggart *et al.* 2002: 200), whereas the cloak of anonymity may actually offer questionnaire respondents the opportunity to be *more* honest without the fear of being judged.

Where the data from one method contains silences or gaps, these can be investigated in future methods, or encourage the return to data already gained from other methods. Initial analyses of questionnaire data revealed broad trends, as well as intriguing contradictions and unanticipated concerns (e.g. experiences of memory loss, a largely neglected concern in the epilepsy literature: see McAuley *et al.* 2010), that I wanted to explore further in the 'looser' time-space of the interview. For instance, some participants, somewhat surprisingly, stated that 'this is just what I do' (Hitchings 2012: 64), and that they had *not* altered their daily geographies after the onset of epilepsy. Without the interviewing process, it would have been impossible to tease out the circumstances under which people might find this to be the case (indeed, I found that it was not necessarily that the individual had *never* made adaptations; rather, those adaptations had become so embedded in their everyday routines that they ceased to be noticed). Findings from the interview process inspired my revisiting of questionnaire analyses several times to check on how they 'married up', while encouraging different perspectives on 'old' data in light of fresh insights. Such 'triangulation' of methods can facilitate increasingly robust research and inspire confidence in its 'legitimacy' (Cook and Crang 1995: 75). Triangulation does not, though, explain disjunctures between methods, but in the following chapters I describe, albeit selectively, where gaps remain, and so suggest questions that future research might ask.

²¹ On the other hand, most 'medical geographers' (and indeed most of the 'public health' researchers contributing to a journal like *Health and Place*) remain relatively quantitative.

MIXED-METHODS QUESTIONNAIRE

CONSIDERING SAMPLE AND MODE OF QUESTIONNAIRE

The methods chosen by a researcher not only reflect the participants being engaged but the potential audiences to whom it will be reported. Collaboration with ES entails the expectation of reaching beyond academia to help inform public engagement with media, policy-makers and other charity organisations, many of whom arguably are looking for unambiguous headlines rather than theoretical insight. Fundamental decisions must be made, as Hammersley (1992: 40) observes, concerning 'the particular purposes of the research and the practicality of various strategies given the circumstances in which the research is to be carried out'. The decision to engage participants first through a survey questionnaire sprung from these very contexts: not only would a 'solid' (partially) quantitative foundation offer credibility in the realms of policy-making (qualitative methods, sadly, still suffer from 'feminising' remarks concerning their 'soft', touchy-feeliness), but being granted access to the ES members' database presented an opportunity for reaching many potential participants.

In light of various financial, temporal and geographical restrictions, it was decided that a postal questionnaire, with an alternative online version, was the most practical method of extensive surveying (see APPENDICES 2 and 3). Put simply, postal questionnaires are more time and cost-efficient than face-to-face surveying. While participation by telephone collapses distance, it remains rather time-consuming and expensive. The main outlay of postal surveying is in administration (printing, packing and posting), but once this process is completed letters reach geographically-dispersed respondents at no extra cost. The composite online survey tool, SurveyMonkey, was chosen for its appropriate list of features (including a 'secure link' to transmit data privately) and user-friendliness, even though there was a £30 monthly fee. As it turned out, the online version was just as important as the postal option, accounting for 39% of responses, thus allaying Hoggart *et al.*'s (2002: 176) caution that such a method can be overly expensive and time-consuming relative to the proportion of responses received. While it also hoped that this method allowed respondents to complete the survey at their leisure rather than having to come up with answers on the spot, there are of course various 'come-backs' to this position which I engage in the 'design' section below.

Prior to design, it was vital to consider who was being surveyed. Being granted permission to use ES's database of members, all of whom pay an annual subscription to the charity, meant there was no need for time-consuming negotiations with gate-keepers or contacts 'snowballing'. This not only facilitated the research but *shaped* it, because the 'sample' was pre-selected through ES membership. As the only personal details held on each member was 'name' and 'address' (postal or email), everyone on the ES database would be sent the questionnaire rather

than a portion of that population based on some known attributes (although this meant that some members who did *not* live with epilepsy were contacted)²². As it was not possible to create an overall profile of clients, it was unfeasible to account adequately for who did *not* participate. For instance, all but two of the eventual 144 respondents were of white British/English/Scottish/Irish ethnicity, while the total number of ES members of other ethnic origins remains unknown. It is therefore beyond the scope of this research to explore how people of varying ethnic origin adopt coping strategies or receive information and support in culturally or religiously specific ways. Moreover, due to the requirement of hand-writing or typing responses online, it is likely that a proportion of people with learning disabilities were excluded from the questionnaire and, consequently, interviews. Some members who did not participate may well be more severely affected by stigma than those who did, and their voices will be absent from the project. Recruitment through a charity's database positions respondents as at least being aware of an established source of information and support, whereas individuals who manage their epilepsy outside of any such networks may not. While my approach effectively excluded all non-members, there would have been ethical hazards in attempting to intrude in the lives of potentially un-supported individuals (Davidson 2005: 2157).

DESIGN

Due to the epistemological conviction that questionnaires *are* trying to 'capture' essentially qualitative issues, but usually through a quantitative calibration, I designed the survey with '*mixed methods*'²³ as a bridging mechanism. There are multiple considerations inherent in constructing a questionnaire, including how questions are worded, formatted and arranged on paper. Even though postal questionnaires are formatted consistently and so avoid inconsistencies generated by differing reactions to the researcher's performance (their personality, presence, intonation, social attributes), it is through design that the research relationship is mediated. To avoid suspicions of a superficial encounter (Hoggart *et al.* 2002), I attempted to engage people in a thoughtful manner, both in terms of informed knowledge about epilepsy and the types and variety of information being sought.

While I aimed to gain a flavour of the range of respondents through statistical analysis, my epistemological underpinnings ensured an interest in the words of *individuals*. For this reason, it

²² As it turned out, some questionnaires were returned incomplete, sometimes with explanations that the individual did not have epilepsy. One member explained that their child had died in seizure, and wished to be removed from the database. This is a poignant example of how contacting potential participants is an explicitly ethical issue. To help avert unnecessary future stress, I passed on any such requests.

²³ Using 'mixed methods' is when two or more methods are used to address a research question at the same stage in the research process, in the same place, and with the same research subject (Philip 1998: 264). Arguably, the distinction between 'multiple' and 'mixed methods' is not always that explicitly or consistently preserved in many research projects.

was entirely appropriate to design the survey using mixed methods. Mixing *closed* with *open* questions²⁴ was an attempt to maintain a degree of openness to the unexpected. By providing space for qualitative information to be added to all quantitative inquiries, I hoped to avoid constructing people as medicalised objects whose lives could unproblematically be tied to normative geographies of health care and summarised by the information implied by ticking a box. This meant that, while there was limited opportunity for negotiating the meanings of questions (Kitchin and Tate 2000: 48), preconceived expectations or ambiguities could be challenged within and between the spaces reserved for 'answers'. Moreover, heeding Hoggart *et al.*'s (2002: 199) warning that 'attitudinal questions [...] tear responses from their social context[s]', I aimed to minimise (rather than 'overcome') such concerns by encouraging participants to use the 'additional information' text boxes to contextualise their answers or provide specific experiential examples. Although this did not place responses neatly back within their social context (if such transparency is *ever* 'knowable'), it did provide space for people to engage, or not. Another technique to avoid 'placing people in a box' lay in providing alternatives ('unsure', 'maybe') within closed questions. Indeed, sometimes the answer to questions can be neither 'yes' or 'no', or 'yes' *and* 'no' (this also runs the risk of assuming individuals ought to know or have even thought about such matters), thus encapsulating a key epistemological point about resisting simplistic binary thinking.

Due to the minimal personal details held in the ES member database, I added biographical questions at the start of the questionnaire. This placing was in part a way of 'easing' people in with non-challenging questions (Parfitt 2005: 90), although the decision of what information to request and how to present such questions was by no means straightforward. Descriptive information, such as age, gender and education (loosely, and not unproblematically, considered a signifier of 'class') was certainly not used to define the person, but to 'set up the milieu within which to 'place' in context' (Moss and Dyck 2002: 81) respondents and their accounts.

A major concern when designing questions was that they could apply to any person living with epilepsy. Epilepsy is defined as a 'seizure disorder', yet there are many different types of seizure, some of which cause minimal, momentary physical disruption²⁵, while others last for several minutes and involve the loss of consciousness. Questions, therefore, had to negotiate the

²⁴ Questionnaire data to be analysed quantitatively are usually generated using closed questions, where the respondent is given a set of possible answers, one of which they can choose as the most representative of their facts/views. With open questions, the respondent is asked a question without categories from which to choose their answer. Open questions tend towards qualitative content analysis (as with interview transcripts), but sometimes answers can also be categorised so as to quantify certain types of response (Kitchin and Tate 2000: 49-51). I discuss specific question design later in this chapter.

²⁵ Anticipating that some informants would believe their information was undeserving of further investigation, that it was not 'unusual' or 'interesting', I explained in the cover letter that 'Even if you have well-controlled epilepsy I would still like to hear your views.' In the end, one respondent stated: 'I am not much help to you, as [I have] been clear since 34 years ago.' Another wrote: 'As my experiences of epilepsy have been/are so easily managed I would feel a fraud putting my self forward as someone who has epilepsy.'

space between specificity and inclusiveness²⁶. A question about the type of seizures that people experience was initially designed as a closed 'category' question, but then changed to an open 'information' question. This was after research by my ES supervisor (Cavanagh 2010) showing that people do not always recognise up-to-date medical terms for their seizures. By asking people to write down their seizure types in their own (medical or non-medical) words, it was hoped that both extra information would be gained and that peoples' non-medical descriptions might allow for their translation into classifiers for subsequent coding. A potential weakness of this method was that, 'if questions are left open for respondents to provide answers, people name less items than if a checklist of possible responses is provided' (Hoggart *et al.* 2002: 197). For this reason, I included bracketed 'for example [...]' suggestions, while in other open questions added 'you may wish to talk about [...]' as a prompt (although this may have introduced bias towards discussing or naming my examples).

Constructing questions around peoples' experiences of space and place requires that the researcher be as creative as (s)he hopes informants to be. Cloke (1993: 114; see also Woodward 1996) argues that open questions are key to emphasising difference: 'different experiences, different problems, different experiences of the same problems, etc.'. While closed questions can serve a rather functional purpose, they may also be used creatively in 'scaling' (see Question 14 on the questionnaire: APPENDIX 2), 'semantic differential scaling' (Q.16), 'complex grid and table' (Q.18) and 'contingency' questions (Q.11) (for explanations of these, see Kitchin and Tate 2000: 50). Common scaling systems such as 'not important ... very important' were replaced with emotional categories hoping to elicit different ways of thinking about, and levels of engagement with, individual questions (e.g. in Q.19 and Q.20 I asked about 'confidence' and 'comfort' respectively; in Q.16 'safety'). Spatial (Q.16) and temporal (Q.18) categories were also evoked so as to survey individuals' perceptions of their everyday geographies. These facets of design add nuance to interpretive strategies, but also seek to capture the attention of 'veteran' respondents bored of the same old questionnaires.

The first draft was finalised after checking what surveys ES had sent out in the past so as to avoid repetition (which would likely affect response rates) and learn from their design and phrasing of questions²⁷. Length was an issue, for with 29 questions (each with 'additional information' boxes) ranging over 12 pages this risked lowering response rates. Gillham (2000: 10)

²⁶ Interestingly, one respondent wrote in the 'additional comments' box for a 'semantic differential scaling' question about feelings of safety in different places: 'You are obviously thinking about grand mal [tonic-clonic] seizures. I don't have a problem with safety – mine is more about embarrassment as my seizure is over in two seconds.' This individual seemingly felt that the question excluded those whose symptoms do not fit with the normative imagination of seizures. This emphasises the power of the researcher in framing questions (Cloke *et al.* 2004: 129) but also that authority over the meaning of their words is always incomplete. As both 'research and selves are 'interactive texts'' (Rose 1997: 316) then the above interaction presented an opportunity: while it illustrated ambiguities in design, it was also revealing of how people with 'atypical' symptoms might feel about issues of legitimacy, a matter discussed in later interviews that may not have come up otherwise.

²⁷ Besides this research, ES do use their database occasionally to send out their own surveys, but it is not *over-used* in this regard.

asserts that 'four to six pages (depending on design and layout) is probably the maximum.' However, a lengthier survey was deemed appropriate by ES staff members, who reasoned that, although some individuals may find it challenging to complete, many were extremely committed to the 'cause' and, contrary to received wisdom (Schneider and Conrad 1980), were incredibly open about their condition. Questions were organised into six distinct sections to facilitate the feeling that they could be completed in stages or selectively left out. While restrictions on expensive paper necessitated an 'economic' layout in the postal questionnaire, the online survey was designed so that individuals could skip between differently themed pages at the click of a mouse (see APPENDIX 3). Furthermore, while the online version replicated the postal layout, 'skip logic' meant certain questions were by-passed depending on the previous question's answer. This would show in the progress bar as there being less left to complete, thus hopefully minimising non-response due to 'questionnaire fatigue'.

COLLABORATIVE PILOTING, PREPARATION AND ENCOURAGEMENT

Inherent assumptions or ambiguities in the wording of questions affect how people choose to answer, and may risk lowering response levels. Following early iterations, a process of 'piloting' was undertaken with ES staff (Support Group Leaders, Helpline staff, Training Manager, Outreach Officer, Community Support Manager, Deputy CEO and PR Manager)²⁸. The agenda was both technical (how long did it take to complete?) and specialist (were the questions appropriate?). Even though none of these individuals themselves lived with epilepsy, on the whole their expertise proved extremely useful, leading to the refinement of question phrasing. **Table 1** provides a flavour of ES staff members' suggested refinements. Debating the nuances of design certainly improved the questionnaire; nonetheless, certain obstacles could not be overcome satisfactorily. One 'unknown' was whether returned surveys would always be completed by the named respondent. An early draft sought to account for this possibility by asking who had completed the survey: for example, a carer. On reflection, this question was left out due to issues of space and ambiguities as to what purpose the information would serve (there would presumably be little or no indication of the extent to which the carer had written the person's words verbatim, or if they had answered according to what *they* believed the individual to think).

²⁸ I also sought permission from the webmasters of two online epilepsy forums (run by the Epilepsy Foundation and Epilepsy Association) to pilot the questionnaire by posting a link to the online version. This strategy was to avoid lowering response rates by asking ES members to complete a draft *and* final version. Neither webmaster responded after several emails, and thus the potential for generating discussion online was not realised. An alternative vehicle for piloting was sought through the National Society for Epilepsy. After various delays, my link appeared on their website, but too late for it to impact on the questionnaire design. However, it did serve to recruit two additional respondents.

Omitting surveys where people received help would also prove exclusionary of those uncomfortable with (or incapable of) writing, and hence the issue was 'parked'²⁹.

Table 1: Piloting Feedback

The requirement to use 'plain English': the question, 'What is your gender?' was left open for 'equalities' reasons, but was problematised by the Community Support Manager, who suggested that 'gender' might not be a recognisable word for many of the people with learning disabilities with whom she worked.
ES' Training Manager suggested that the question 'What type of seizures do you have?' be modified to read 'What type of seizures <i>or epilepsy syndrome</i> do you have?' to reflect the different (medical) terms through which people 'know' their epilepsy. Interestingly, this is a <i>more</i> 'technical', less 'plain English' term, but entirely appropriate for this particular cohort (although the opposite can also be the case: see below).
It was suggested that the question 'Have you ever overtly concealed your epilepsy from other people to avoid their negative reactions?' be changed because it assumes people would conceal having epilepsy only to avoid negative responses, which is leading, could bias answers and close down discussion.
Questions could be interpreted unevenly. A Helpline staff member suggested revising an option for the closed question concerning when individuals tend to experience seizures. The option 'During the night, e.g. nocturnal seizures' may have been confused with 'sleep seizures', which can happen when people are sleeping during the day. Data may be skewed when words are misinterpreted, but the direction, magnitude, likelihood and source of these are often unknown before and after (Hoggart <i>et al.</i> 2002: 194), thus emphasising the importance of iterative refinement.

Once final tweaks were made, the physical act of printing and sending the questionnaire was negotiated with ES, who had agreed to take on all expenses. Practical obstacles delayed the letters being sent out (there were hold-ups in receiving quotes regarding varying paper weights and sizes, and envelopes that were ordered did not arrive), especially when ES had to prioritise their own 'mail shots' (Christmas catalogues, monthly newsletters) because of the importance of the revenue generated by these sources to their on-going running costs. Overall, piloting and preparation was fragmented, in part due to my 'outsider' position within a professional charity, whose rhythms of work continued regardless of my own. Despite some frustrations on my part, every possible accommodation was made by ES for this research. Indeed, the demands of preparation and (re)scheduling were performed as a truly collaborative process (see more on collaboration below).

Receiving a questionnaire about epilepsy in the post may spark different feelings. Does it objectify people as 'epileptics', the focus of a researcher who possibly cares little for any other part of their lives besides the data being mined? Does my 'outsider' status (as someone not working for ES) make people feel that their privacy has been invaded? Is it an unwelcome reminder of 'difference'? Or are people happy that the involvement of ES demonstrates a concern for real, on-the-ground issues? Participation requires that people give up their time and personal feelings for someone they do not know, for a purpose that they might not fully understand, and

²⁹ As it happened, four questionnaires were returned with notes indicating they were completed with help. While these four were included in data analysis, I did not include the response of a mother who approximated what she thought were the experiences of her son (he was 'off at university'). I did, however, retain the data for what it might reveal about the expectations and understandings of close family members.

for outcomes that they may not believe will make any difference. For such reasons, postal surveys are notorious for low response rates (Parfitt 2005; Kitchin and Tate 2000). Presentation therefore demanded careful consideration, from the envelope to the introductory letter, so that participants' initial encounter with the questionnaire might draw them in; that it did not appear as mere junk mail.

Impression management was significant, for, as Cloke *et al.* (2004: 146) remind us, 'the paperwork [or email] which is sent is effectively a research encounter by proxy [...] Even without meeting, therefore, a socially constructed relationship will be established between the researcher the researched'. This relationship begins as soon as the envelope reaches the letter box. To boost interest in opening them, envelopes were franked with the ES logo. Recognising that potential respondents would interpret me according to the questionnaire 'package' (just as I would interpret aspects of their lives through their answers), a comprehensive cover letter (APPENDIX 1), on University of Glasgow-headed paper (and emails³⁰), was included to make introductions, set the scene and guarantee confidentiality and anonymity. In so doing I hoped to present myself as efficient and professional, thankful in advance of individuals' efforts, and attentive to the ethical issues that may arise. To add a personal touch, I wrote 'Dear [name]', as well as signing every letter by hand; and to complete the package, a stamped addressed envelope was included for the questionnaire's return to ES. The association with ES is likely to have encouraged participation due to the number of people who pay membership fees, make donations and *care* for the organisation. It is also not unlikely that University of Glasgow research enhanced the professional reputation of ES in the minds of members, many of whom may have felt this was an opportunity to make a difference³¹.

DATA PROCESSING AND ANALYSIS

From 450 questionnaires issued, 144 responses (32% of the members' database) were received, comprising 88 postal and 56 online³². This figure is rather higher than normally expected for such questionnaires, indeed reflecting a real interest amongst ES members in this issue, in having a 'voice'. Questionnaires returned by post were input manually into the online tool, SurveyMonkey, through which the data set could be viewed and analysed in one manageable space. Although data entry was time-consuming, it was invaluable for acquainting myself with different

³⁰ Emails were a slightly altered version of the postal cover letter. They included the link to SurveyMonkey, where responses could be submitted online. The email was sent to 52 contacts, and within 30 minutes three people had completed the questionnaire.

³¹ It must further be recognised – but rarely is – that research is not always about *convincing* people to participate; to be sure, numerous individuals here indicated a strong desire to contribute. The questionnaire was advertised (and later re-advertised) on ES newsletters, Facebook and Twitter pages, at ES AGMs, and through the informal contacts networks of staff. Numerous requests were made by non-members to participate, and this continued long after the research element was concluded.

³² Please see APPENDIX 4 for a breakdown of questionnaire respondents and their answers.

individuals. I attempted to minimise errors, whether by typing, inversion or repetition errors (Kitchin and Tate 2000), by double-checking all entries.

As Woodward (1996: 57) asserts, questionnaire limitations often only become apparent once analysis has started. For example, one respondent answered 'yes' to the question 'Do you consider yourself to be disabled?', but added that their answer was in respect of another impairment, not epilepsy. This served as a reminder of how people are multiply-positioned, but also problematised my coding scheme: the answer was 'yes', but it is not true to say that this person felt disabled because of epilepsy. Hence a dilemma was faced as to whether it should be coded according to the ticked box or by the meaning I interpreted. Either way, a limitation of the question stemmed from the ambiguity of its wording. A more concise question would have been 'Do you consider epilepsy to be disabling?', although this again strays from the path of 'plain English'. While such tensions are difficult to overcome, it is important to be aware of them. Nevertheless, it *was* the case that most 'additional comments' regarding disability referred to epilepsy itself, and thus did not prevent meaningful data construction.

All qualitative responses were coded manually (please refer forwards to my discussion of the 'coding' of interview transcripts, which followed the same process) to allow themes to emerge from the data landscape. The 34,000 words of information provided, whether answering open questions or as additional information adding nuance to closed questions, encapsulates the *scale* of respondents' willingness to provide 'qualitative' responses, and arguably suggests a subject-matter about which people are *aching* to communicate³³. In some cases new coded categories were created to facilitate statistical analysis (Parfitt 2005: 106). Creating codes to summarise a diversity of responses involved 'boiling down' individuals' answers, a method with which I was not entirely comfortable due to the levels of detail that were lost. As a compromise, I have ensured that all quantitative results remain contextualised alongside illustrative quotations so to balance the general with the specific.

Responses to closed questions were first harnessed to produce simple, non-probability-based descriptive statistics, such as raw counts and proportions. Next, inferential statistics were generated in Statistical Product and Service Solutions (SPSS) through chi-square tests, which check whether categorical variables³⁴ are related in some way (Burt *et al.* 2009; Moore 2000; Oppenheim 1992). It was judged that this type of analysis avoids the reductionism of other types

³³ Qualitative data offered as part of a questionnaire is arguably every bit as useful as data from written testimonies (Smith 2012; Chouinard 2012; Davidson 2007) and online spaces (Davidson 2008; Davidson and Parr 2010; Parr 2002a); although, it should be noted, data sourced from books and online forums exists *prior* to *academic* framing, while questionnaires inevitably filter distinct aspects of experience.

³⁴ Categorical variables are those for which numbers are allocated to particular categories (e.g. 1 = seizure-free; 2 = one seizure per month, etc). While it is beyond the scope of this method to assess how 'scale' variables, such as 'age', are related to other variables, ages were categorised into distinct groups: 0-9; 10-19; etc. to act as categorical variables. Prior to chi-square tests, categorical variables are arranged in 'contingency tables' displaying the number of observations in particular categories. Tests are non-parametric (the sample size is not relevant, and they make no suppositions about how variables are distributed) and are considered 'reliable' when the contingency table is made up of over 20 observations, with at least five in each category.

of statistics (for example, linear regression models), which arguably create chasms too great to bridge with qualitative data³⁵. Chi-square tests do not attempt to prove whether one variable is the *cause* of another, merely that there appears to be some kind of relationship that can be further explored. Relationships are established by comparing the difference between what is observed and what is expected if there is *no* relationship between variables (an assumed 'null' hypothesis). For example, to test whether people who have seizures are more likely to conceal that they have epilepsy, the 'null' hypothesis is: 'there is no relationship between whether someone has seizures and whether they conceal that they have epilepsy'. **Table 2** below shows that 22 respondents who have had at least one seizure in the last year have at some point concealed that they have epilepsy, while 47 have not.

Table 2: Relationship between experiencing seizures and concealing epilepsy

	Concealed epilepsy	Not concealed epilepsy
Seizure-free	15	27
Not Seizure-free	22	47

To test whether having seizures and concealing epilepsy are independent or contingent variables, we need to compare our *observed* numbers (above) with *expected* numbers, which are calculated by assuming independence (the probability of an observation falling into category *i* under the independence assumption, multiplied by the total number of observations: see Burt *et al.* 2009; Moore 2000; Pryce 2005). The following 'contingency table' is thereby created:

Table 3: Contingency Table Displaying Observed and Expected Counts

		Concealed epilepsy	Not concealed epilepsy
Seizure-free	Count	15	27
	Expected Count	13.8	27.7
Not Seizure-free	Count	22	47
	Expected Count	23.2	46.3

As there does not appear to be a great deal of difference between the actual counts and expected counts, we can say that the numbers are close to what we would 'expect' if having seizures and concealing epilepsy are not related. A Chi-square test determines whether we can accept this assumption of independence. We reject the null hypothesis if-and-only-if the 'P' value (the probability of a relationship) calculated by SPSS is smaller than the industry-standard 'critical point' (known as a 'significance level', the level of acceptable variance) of $\alpha = 0.05$ (5%). In this

³⁵ Furthermore, 'parametric' tests, such as linear regression, harbour expectations about the 'form' of the data set (normality, independence of error terms, etc.) which was never going to be possible with an 'incomplete' data set such as this.

case, the 'P' value is 0.875, meaning there is an 88% chance of incorrectly assuming that there is a relationship between having seizures and concealing epilepsy, which, statistically-speaking, is unacceptable. In other words, whether or not a person has seizures *does not* affect the probability of whether they have concealed that they have epilepsy.

Table 4, below, displays the results of a series of chi-square tests comparing 'sociological' variables (across the horizontal axis) with those pertaining to one's social geographies (vertical axis). Where indicated by 'Y', there is a statistically-significant relationship, followed by the chance (%) of incorrectly rejecting the null hypothesis that the two variables are independent. Blank spaces in the table indicate that there is no statistically-significant relationship (i.e. where there is more than a 5% chance of stating a relationship incorrectly). Inferential statistics are a tool for establishing likely relationships between variables. They are used in this thesis as part of the construction of conceptual arguments relating to the everyday experience of chronic illness. Variables displaying several (statistically-significant) relationships were afforded special attention because of their importance to peoples' sense of the impact of epilepsy. In **Table 4**, 'Seizure Frequency' has 12 such relationships, while 'Age Category' and 'Age at Diagnosis' show seven and six respectively. These findings facilitate discussion of the time-space experience of epilepsy, especially in CHAPTER SIX, taking into account the most prominent spatial variables, notably work and social spaces (see CHAPTER SEVEN). What the statistics 'reveal' here is necessarily partial because of their inability to explain *why* different aspects of individuals' place-based experience appear to be related, but using this simple statistical analysis of a largish data set has proved invaluable as a first cut at disclosing relationships worthy of further qualitative inquiry (as in CHAPTERS SIX and SEVEN). All statistics were then considered as *framing* for further questions to be asked (in interviews, as well as when cross-referencing results with the qualitative information from the questionnaire). Crucially, they were not used to determine whether or not data was 'useful': that was a matter of personal judgement. That the critical point for rejecting 'null' hypotheses was 0.05 meant various hypotheses were rejected, but only just. For example, tests suggested there was a 6% chance of incorrectly stating a relationship between 'having seizures' and 'whether someone thinks about seizures when planning their day'. Having 'only' a 94% level of confidence inferred a statistically-unacceptable risk of being mistaken. Such a close call points to the subjective core of supposedly objective tests. For this reason, I also manually engaged with the rich variety of patterns illustrated by 'contingency tables'. Indeed, where certain relationships were discounted statistically, questions still remained for me as to whether other factors were to any extent involved in peoples' experiences or behaviours.

Table 4: Relationships between variables

SOCIAL	Gender	Age Category	Age at diagnosis	Epilepsy < 10 years	Epilepsy < 3 years	Education	Seizure-free/ not seizure- free	Seizure Frequency	Type of seizure(s)	Number of significant Relationships
Confidence talking with family										0
Confidence talking with friends	Y (3.9%)									1
Confidence talking with colleagues										0
Confidence talking with potential employer										0
Confidence talking with strangers		Y (1%)							Y (0.8%)	2
Comfort with seizure witness: family	Y (3.5%)									1
Comfort with seizure witness: friends			Y (0.4%)							1
Comfort with seizure witness: colleagues										0
Comfort with seizure witness: potential employer									Y (2.5%)	1
Comfort with seizure witness: strangers										0
Conceal epilepsy										0
Have experienced discrimination		Y (1.7%)	Y (0%)						Y (4.8%)	3
<u>SOCIAL GEOGRAPHIES</u>										
Avoid particular places				Y (1.8%)			Y (0.1%)	Y (0.1%)		3
Feel (un)safe at home			Y (1.2%)		Y (1.9%)					2
Feel (un)safe in the street										0
Feel (un)safe at work										0
Feel (un)safe in a shopping centre									Y (4.2%)	1
Feel (un)safe in a bus										0
Feel (un)safe in a car						Y (1.3%)	Y (1.4%)	Y (0.1%)		3
Feel (un)safe in a GP Surgery			Y (0.5%)		Y (0.3%)					2
Feel (un)safe in a place of leisure										0
Plan routes to manage where seizures occur							Y (0.2%)	Y (0%)		2
Significance where seizures occur										0
Consider seizures when planning day		Y (1.7%)						Y (1.5%)		2
Interferes with socialising (family, friends)		Y (0.3%)	Y (2.7%)				Y (0%)	Y (0%)		4
Interferes with hobbies/recreation		Y (4.1%)					Y (0%)	Y (0%)		3
Interferes with work (paid or voluntary)		Y (1.3%)	Y (0.8%)		Y (1.1%)		Y (0%)	Y (0%)	Y (1.1%)	6
Interferes with household chores							Y (0%)	Y (0%)		2
Interferes with errands/shopping							Y (0%)	Y (0%)		2
<u>SUPPORT</u>										
Support groups attendance							Y (4.6%)	Y (3.3%)		2
Engage in public activities								Y (1.1%)		1
Consider oneself disabled		Y (1.4%)					Y (0%)	Y (0.3%)		3
Number of Significant Relationships	2	7	6	1	3	1	10	12	5	

INTERVIEWS

In human geography there has been a recent trend in developing methods outside or beyond verbal representation because of the belief that interviewing does not and cannot get at the creative ways in which individuals (sometimes unthinkingly) perform their everyday lives (see, for example, Latham 2003; Thrift and Dewsbury 2000). Interviewing – gaining information and ‘evidence’ through talking – was still here considered an appropriate method because of how people who have seizures (which are never consciously performed) consciously or cognitively find out ‘what happened’ through information and ‘evidence’ provided by *others*. How the individual describes their seizures, then, is revealing of how they are unevenly *made* to feel at the intersection of bodies, emotions and socio-cultural discourses. Thus, despite recent preoccupation with moving beyond representation, it is precisely the tyranny of ‘representation’ (Thrift 2000) that I seek to engage. In so doing, I hope to connect the non-representational with the representational, affect with emotion. The language of others, especially concerning the body-self, is constitutive of complex emotional geographies that I investigate through a spoken phenomenology.

Furthermore, the meaning of seizures varies according to the time-space contexts in which they occur (see CHAPTER FIVE), and thus one’s ‘habitus’ (Bourdieu 1990) can rarely be taken-for-granted. The heightened sense of bodily reflexivity thus engendered arguably places interviewees in a unique position to discuss both routine disruptions and disruptive routines (as delineated by self and others). The challenge here was to get beyond the descriptions that most participants were obliged to practice with health professionals in order to gain a diagnosis (although probably in different settings, with different conventions pertaining to language and behaviour). Semi-structured interviews were also a useful way of exploring experiences of epilepsy that had already been touched upon in the questionnaire, while their flexible design allowed space for intersubjective meanings to be created in and through the ebb-and-flow of ‘conversation’ (Cook and Crang 1995).

SELECTING SELF-SELECTORS

The questionnaire facilitated both the recruitment of interviewees and the tailoring of semi-structured interview plans for each individual. At the end of the questionnaire, when asked if they would consent to being contacted for interview, 84 individuals provided their details: an extremely positive response (56% of the 144 respondents), again demonstrating real interest amongst participants. By blending elements of ‘purposive’ and ‘quota’ sampling, I opted for a

multi-rationale sampling strategy, here called a 'purposive quota'. The mixing of sampling traditionally associated with qualitative and quantitative projects respectively was an endeavour to realise the complementary potential of the multiple methods in this research. This strategy ensured that a variety of 'voices' were engaged *and* also that conversations with individuals whose questionnaires were of theoretical interest were developed selectively. While my approach of mixing the supposedly objective and subjective could be critiqued as being incommensurable, arguably that would ignore how researcher decisions frame qualitative and quantitative research alike. Indeed, my choice of sampling aims to advance productively 'in between' these often polarising frameworks.

As questionnaire responses began to arrive, I took note of individuals providing full, informative responses so that they might be approached for interview. Selecting interviewees on this basis is a loose version of what is variously called judgemental, purposive or non-random sampling, the most 'subjective' method. Kitchin and Tate (2000: 54) describe judgemental sampling as choosing individuals based on the sorts of response that they 'are likely to give' and the 'responses the interviewer is looking for'. This suggests researchers are looking for what they already know; that informants are squeezed into preconceived conceptual spaces rather than being the co-constructors of new knowledge. In spite of this lax terminology, marking out particular individuals was justified because of their expected openness (although this did not always 'translate' across mediums), or interesting, unusual or strong views that could be explored further. There remains a danger of my selections coming from a limited social 'grouping' to the exclusion of others³⁶.

The use-value of multiple methods research lies its ability to shed light on particular experiences, to show where complementary data shapes and strengthens an argument, or where conflicting positions arise when the same individuals are engaged in different ways. It was reasoned, therefore, that 'conversations' between questionnaire and interview data in this wide-lensed research (a position negotiated with ES) would be most productive when the proportional make-up of participants was relatively consistent; that dissimilar proportions of people being interviewed could skew or undermine questionnaire results. To that end, elements of 'quota' sampling (Kitchin and Tate 2000) were stirred into the mix. This method usually selects people at random so long as they satisfy a predefined quota, whereas here people were selected according to their biographical information, but judgementally: hence, a 'judgmental quota'.

In what was a genuinely multi-factorial method of selecting interviewees, various individuals and their 'variables' were taken into account as part of the iterative refinement of

³⁶ Valentine (2005: 115) argues that it is useful to recruit interviewees from a wide range of social situations to engage how issues of location, age, class or gender affect individual experience. While this is certainly the case, we must be mindful of Cloke *et al.*'s (2004: 156) warning that 'the idea of spreading interviews across axes of difference – be they geographical, social, identity related, practice related or whatever – soon runs into problems if individuals are somehow being asked to represent their 'category''.

quotas: please see APPENDIX 5 for an illustration of how each category was balanced with individual negotiations. Categories were juggled as people dropped out or did not respond³⁷ (six of my original 30 selections did not participate, while replacements contributed to the overall total of 28 interviews), and so in several cases compromises had to be made about the extent to which interview proportions would replicate those of the questionnaire. While my interview sample broadly reflects the overall respondent 'population' and breakdown of potential interviewees, there are a few notes to be made about the final proportions of interviewees being the result of *intentional decisions*, *acceptable coincidences* and *unavoidable limitations*. The interview sample *intentionally* 'skews' towards individuals with more frequent seizures than the overall 'make-up' of questionnaire respondents still experiencing seizures because of the value of establishing the impact of recurrent epileptic episodes (all six potential interviewees experiencing 'one or more seizure every day' were approached). A greater proportion of people who experience partial *and* generalised seizures are shown in the final interview sample, a coincidence deemed acceptable because of the range of embodied experiences these individuals might reflect upon. In some cases it was simply *impossible* to arrange interviews with a proportionate amount of people, for instance, who were diagnosed aged 60 or over (this may have been entangled with other factors, whether coincidental or linked to socio-emotional difficulties as a result of being diagnosed in later life: see CHAPTER SIX). Similarly, while it was generally easy to arrange interviews in Lothian and Borders and Glasgow and Strathkelvin, it was more relatively more difficult to meet people in Grampian, Highlands and Islands (notably because of practical restrictions such as accessibility, time and funding). Despite this limitation, I remain extremely conscious of the potential differences that place can make in how illness is experienced (as shown, for example, in Parr *et al.*'s [2005: 88] discussion of the experiences of people with mental health problems in remote, rural villages in the Scottish Highlands).

The breakdown of interviewees that I attempted to reconcile with the overall proportions of questionnaire respondents took into account theory and method in sometimes uneven ways. The individuals who gave up their time (and, in some cases, money) to be interviewed are theoretically central to this study; they are illustrative, but not straightforwardly representative, of the range of experiences that people may have with epilepsy. This 'judgmental quota' facilitated the bridging of methods as well as explorations of how men and women of different ages in different places and with different seizure types and frequencies make sense of the

³⁷ Arranging to meet was a surprisingly time-consuming aspect of the interview process. The interview is a social encounter, which, in my case, began as soon as participants first received invitations to complete the questionnaire. It is reasonable to suggest that how people felt about the questionnaire had a direct bearing on whether they provided their details as a potential interviewee; and our subsequent dialogue, whether by phone or email, will have influenced whether they responded affirmatively to my request to meet. On my part, any one interview was being negotiated alongside 27 others, requiring a performance of the easy-going and flexible researcher. On answering their telephones, apparent suspicions (was I a salesman?!) invariably gave way to brightening tones when I introducing the collaboration with ES.

condition. While this study takes as its starting point experiences of the epilepsies rather than existing concepts, which I hope to extend in the course of my engagement with this condition, I certainly do not want to invoke questions of 'typicality', which presumes 'a clear distinction between theory and data' (Moss and Dyck 2002: 71).

The nine 'professionals' also interviewed as part of this research were not self-selecting, but identified by my ES supervisor for their breadth of experience and contact with people with epilepsy from the point of diagnosis onwards. They included two neurologists (one of whom was an epileptologist, i.e. a neurologist specialising in epilepsy), two Epilepsy Specialist Nurses (ESNs), one epilepsy social worker, three ES staff and Epilepsy Connections' Outreach and Liaison Worker, Zareen Iqbal (who requested to be named). Materials from these interviews are interwoven with the voices of people with epilepsy in what follows, and are illustrative of certain 'official' windows, from their own unique situated (professional) perspectives, on biopolitical regimes. These individuals were generally 'representative' of the concentration of epilepsy services in central Scotland, although I was able to interview professionals in less central locations to gain information about the distinct challenges they face.

TAILORING INTERVIEWS

Open-ended questions were developed iteratively and grouped into general themes so as to envisage a 'loose sense of format or structure for the interview' (Cloke *et al.* 2004: 152)³⁸. Questions stemmed from the original research problematics, general questionnaire analysis and the questionnaire responses of the individual being interviewed. Interviews provided a platform for the 'storying' of experiences, sometimes to elucidate, seek elaboration on, or even challenge peoples' previous input. The schedule was constructed around three main topics (see APPENDIX 6): the process of onset and diagnosis (with alternative sections prepared for those who 'grew up' with epilepsy or were diagnosed in later life); the embodied experience of seizures (a step-by-step narrative of the temporalities before, during and after); and longer-term implications (in respect of everyday routines, planning, relationships). An ES staff member living with epilepsy volunteered to 'pilot' the schedule with me, worthwhile not only for thinking through the types of information being offered, while recognising his position(ality) as a staff member, but also for how my conceptual concerns translated from the page to conversation.

Before each interview, I annotated schedules by tailoring existing questions with reference back to individuals' questionnaire responses, prompting further questions, and cross-referencing

³⁸ Project information sheets and consent forms were also designed with much ethical consideration: to gain informed consent, as well as to allow space for sensitive personal requests. For example, since epilepsy is often an 'invisible' condition, people might choose not to reveal to their diagnosis to others, and so confidentiality and anonymity (e.g. using pseudonyms) were emphasised as a way of avoiding (or exacerbating) economic, political and social harm. Similarly, individuals were made aware that they were not required to answer any question, and that they could discontinue the interview at any time and without having to give a reason.

personal information pertinent to what was being asked. This tactic averted unnecessary repetition between research methods and facilitated lines of inquiry that may not have come up otherwise. It was also a means of 'impression management', whereby my intimate knowledge of, and sensitivity to, individuals' situations as revealed by their questionnaire responses helped to establish rapport.

INTERVIEWS AS PART OF EVERYDAY LIFE

To avoid imposing a 'hierarchy of important spatial sites, contexts and experiences pre-selected by the researcher' (Parr 1998: 350), participants were asked to state their preference for how, when and where the interview would take place. On a practical level, it was pointed out that, while we could meet at an ES or university office, my research grant meant that I could travel to save them time and money. As it happened, 16 interviews took place in peoples' homes, seven at ES, two at the University of Glasgow, two in cafes and one by telephone. One person with impaired mobility, Holly, requested that the meeting take place at her home for the sake of convenience (the home here may also have had greater significance: see, for example, Dyck 1995a; Crooks 2010; Imrie 2010). Arranging interviews required negotiation, even while the intentions of participants remained unclear. One participant, Kate, said she would let me know her choice of date after finding out her husband's shift pattern. This was taken as a preference for her husband to be present, when in fact the opposite was true. She later revealed how her family encouraged her to spend the majority of time indoors because of her difficult-to-manage epilepsy, and that she concealed many of her day-to-day activities so that they would not worry. Accordingly, Kate wanted to meet *without* her husband so that she could be candid about her practices. Already, her living with epilepsy had shaped our interaction. In the end, however, her husband was present, perhaps limiting the kinds of information that she was willing to discuss (Aitken 2001). Conversely, Alan requested that his wife be present due to her role in prompting his memories and reflections.

Indeed, flexibility over the contexts of encounter had numerous implications for the resulting data, and revealed something of participants' spatial subjectivities. One person, Sophie, chose to participate by telephone³⁹, which, though not uncommon as a practical strategy (see, for example, Crooks *et al.* 2008; Davidson 2005), may have been for a number of reasons, possibly including gender, age (she was the youngest interviewee, at 19 years old), location (she lived in the north of England), employment/time (she worked full-time) or reluctance at discussing her

³⁹ Far from being a disembodied encounter, persisting technical issues (I had to bend over the table and shout into a microphone, thus was unable to refer to my interview schedule) meant that I was *more* aware of my body. Also, as the participant was using her mobile during a work lunch-break, our conversational thread was frequently lost as she moved around (for reception or privacy), creating uncertainty. Indeed, while a rich terrain for discussion, telephone interviews entail a very different sense of performance, and produce qualitatively different transcripts (see Cook 2009).

condition socially (she disclosed very selectively). Ultimately, Sophie's reasons were unknown, but these hypotheticals demonstrate the *possible* sensitivities or socio-spatial self-protection strategies of prospective interviewees. One participant, Renae, who experienced frequent seizures could only participate if I came to her home, her 'anchorage' for the volatile body and stable environment of the self. Here she was able to *show* what she meant when describing the spatial content of everyday life (involving an interweaving of material objects and embodied movements). The dynamism of her physical demonstrations escaped sound recording, but offered additional dimensions for post-interview annotation.

Setting up interviews also required taking account of the time-space impact of epilepsy on the body-self. For example, several individuals requested not to meet in the morning because that was when they tended to have seizures. On the day of one scheduled interview I called ahead, to be told that the individual had experienced a seizure during the night and would not be up to participating. Aside from the direct effects of seizures, other, less obvious, impacts were observed. A theme that arose *during* interviews was first encountered when *setting them up*: memory problems. On a number of occasions I returned telephone calls at mutually agreed times, but some people did not remember our earlier conversations, citing epilepsy. Individuals' 'spaces of memory' (see CHAPTER SEVEN) became apparent through their requests that an email or letter be sent confirming the interview time/date/location, so that a tangible reminder could be displayed in their home. These examples demonstrate how interviewing does not take place in a vacuum: people *live*, they sometimes forget (as do researchers!) how their contingent, socio-embodied experiences impact on, and carry on regardless of, the potential intrusions of researchers. Yet, through these interactions, we might also learn something of the social geographies of the people we wish to interview, a small participative element within the interviews.

CONVERSATIONAL SPACE AND TIMING

Feminist geographies teach that self-presentation, positionality and self-disclosure (England 1994; Katz 1994; Kobayashi 1994; Parr 1998; Rose 1997; McDowell 1995; Valentine 2005; Widdowfield 2000) influence how knowledge is produced in ethically-aware encounters, working *with* rather than *on* research subjects. 'Interview space' means so much more than *where* it takes place; it also implicates the spatial configuration of bodies and objects (*where* someone sits in the room), appearance and identity (I dressed relatively more casually in interviews with ES members than with health professionals), the spacing of conversation (while allowing room for digressions, I also heeded the warnings of a few interviewees, who explained that they took longer to respond because of cognitive 'fog') and how sense is made of interviewees' spatial accounts (it was

tempting to 'rationalise' peoples' sometimes surreal descriptions of seizures in order to construct orderly accounts: see also Parr 1998).

Even the recording of interviews impacted on the resulting data beyond merely practical considerations, such as battery life. Although all the interviewees agreed to be recorded, the digital device certainly had a presence that seemed to blunt openness. At the beginning of each encounter (before pressing 'record'), inevitably conversations would turn to epilepsy – ground ideally that would be on record. I crafted techniques to transition promptly these moments to 'interview time'; however, when the recorder was turned on, *something changed*: in me, in them, and between us. I found my voice changing to 'professional' mode, no matter how conversational I tried to be. I was not a confidante anymore: I was an interviewer; they were the interviewee. And the recorder sat between us, passively observing, potentially judging. Such issues are worked out with experience and according to the unique circumstances of each interview. Valentine (2005: 119) suggests that an effective way of opening is to ask general descriptive or factual questions signalling to the interviewee that they have the time and space to speak openly and at length. Indeed, I found it instructive to begin by seeking a 'mini-autobiography' about the process of onset and diagnosis to help unpack what people prioritised (or not). As the interview develops and becomes (usually) more relaxed, Valentine continues, this opens space to ask more sensitive or difficult questions, which was indeed my own experience.

At the other end of our encounter, after the digital recorder had been turned off, it was common for further discussion of the issues that had come up. Perhaps it was that the individual now felt more at ease when my professional 'mask' was lowered, when I became more of an opinioned conversationalist⁴⁰, and sometimes these moments were more revealing than the interview itself. Taking away the non-human, although active and disciplining, role of the digital recorder, individuals opened up about a range of issues, often adding to or even contradicting the information offered earlier. This may suggest a variety of influencing factors; for example, perhaps the individual coped with epilepsy by projecting a personal-political identity of positivity, but let down their guard in less formal circumstances. Whatever the reasons, we can certainly point to how identities are performed uncertainly in contact before, during and after research encounters. To avoid missing out on potentially fascinating insights, after 'signing off', I would allow the recorder to continue, perhaps making a cursory nod towards it in attempt to gain implied consent. While this might have been a touch sneaky on my part, everyone obliged, suggesting that it was not so much the content of their words that had held them back as the situation, the format and performance of 'The Recorded Interview'.

⁴⁰ While interviews involve the co-construction of data, I was conscious of giving people space to construct their own stories: I had developed an extensive knowledge of epilepsy that I was keen to explore; but had to be careful to minimise the extent to which people were 'placed' into pre-defined categories.

POSITIONALITIES, ETHICS, EMOTIONS

During the course of an interview new identities are formed and re-formed in and between interviewer and interviewee, and these cannot be disentangled from the larger personal, social, cultural, historical, economic and political processes that frame the encounter. While interviewees all led complex lives, from which discreet aspects could only be extrapolated artificially, 'epilepsy' is what brought us together. It is plausible to assert that my professional connection with ES necessarily *situated* me personally and politically in the eyes of participants. Demonstrating background knowledge of epilepsy as both a medical *and* social condition (Dowler 2001) certainly helped when negotiating an 'insider/outsider' boundary. However, interviewing does not take place in a 'gender vacuum' (Herod 1993: 306, in Winchester 1996: 122), nor one pertaining to such variables as age, ethnicity and class. How I attempted to position myself was demonstrated as partial and incomplete through the competing interests of participants, some of whom were more concerned with my academic motivations than the relevance of findings to the advocacy work of ES. Some people, it seemed, actively sought affirmation of their stories of poor treatment by medical professionals, while others repeatedly referred to my position as a student (conferring normative assumptions of juniority and even character). The research relationship in each case was far more fluid than the 'outsider'/'insider' binary would suggest. I found that power does not always 'belong' to the researcher, because at times I felt relatively *powerless* in guiding the conversation, especially with strong characters. That power *circulates* (Sharp *et al.* 2000) means interviews are spaces of negotiation between social beings. While geographical texts rightly point to the real potential for harm (see below) through *negative* emotions (Widdowfield 2000), interviewees should not unproblematically be constructed as 'other' body-objects being mined for information (Nast 1994; England 1994; Wilton 1999), but instead considered as individuals with their own host of motivations and expectations. In spite of the various positions held by the researcher and researched, the chosen subject matter is what brings them together and usually participants *want* to share their experiences, *value* being a contributor and *enjoy* 'telling their stories' (Bondi 2005a; Dyck 2000: 83).

At the same time, interviewing is an emotion-laden process, especially when people are asked to recount times when they have been discriminated against because of illness. The emotional dimensions of research, although less commonly referenced than issues of 'positionality' are every bit as relevant within the reflexive tradition (Widdowfield 2000). While most scholars are comfortable with reflecting on performing 'feats of mental gymnastics' (Valentine 2005: 120) in the interview, less is said about *emotional* gymnastics (problematic though this metaphor is). This relative neglect is because the interweaving of different bodies and emotions is even more difficult to locate. Reconciling the meaning and consequences of intimate encounters becomes especially tricky when considering that face-to-face contact rarely exceeds

the time-space limits of the interview. The expression of distressing experiences usually involves a degree of trust and complementary responsibility, but it is difficult to establish when research relationships become exploitative (McDowell [1992] argues that non-exploitative research is a rather utopian ideal). Indeed, while interviewees may have come to terms with illness such that they are able to talk it, they may still be vulnerable to others' reactions (Wilton 1999). Yet, notwithstanding the wide range of literature surrounding ethical research encounters, no amount of training can adequately prepare the body-self for unexpected emotions and dilemmas. It is therefore vital that we be open and honest about the limited and partial nature of research, which is perhaps best communicated through specific examples.

Ethical 'boundaries', no matter how concisely articulated on paper, are unclear and vague when confronted with real people, whose own social and bodily boundaries are unknown. Before arranging interviews with self-selecting questionnaire respondents it was deemed appropriate that my choices be discussed with my ES supervisor in case of potential vulnerabilities⁴¹ (people with epilepsy are more likely to live with learning disabilities or mental ill health: see Ettinger *et al.* 1998; Kanner 2009; Lhatoo and Sander 2001). My supervisor chose to accompany me to an interview with Renae, whose questionnaire indicated that she experienced multiple seizures every day, and that it had been completed with help from her SAMH (Scottish Association for Mental Health) social worker. This interview encapsulated numerous tensions. I found the presence of my ES supervisor, with the best of intentions, to be somewhat restrictive even though she created the appearance of detachment⁴². Renae recounted some very upsetting experiences that I found especially affecting, both for their content and the manner in which they were told. I was anxious about not wanting to escalate her distress; yet at the same time, her experiences *were* distressing, and thus there was no reason why she should reveal them with anything other than distress. At no point did I feel Renae's expression of emotion exceeded some imagined limit; however, my concerns about how to manage the encounter limited my capacity to attend effectively to her emotional experiences (Bondi 2005a: 242) – not that I felt qualified to do so on any therapeutic level. At times, I simply listened to Renae speak, without interjecting, so that her feelings were recorded. My not responding was partly considered, partly a consequence of feeling completely emotionally disarmed. As a stand-alone meeting, it is impossible to say whether telling

⁴¹ ES also submitted my details to Disclosure Scotland, who run routine checks on criminal history as a safety precaution on behalf of (potentially vulnerable) research participants.

⁴² My ES supervisor did not speak during the interview, but, on its emotional conclusion, I was happy that she 'jumped in' by discussing with Renae the value of her testimony to ES in its endeavours to represent people with epilepsy. After departing, my supervisor provided general elaboration on the experiences of people with difficult-to-manage epilepsy. We then engaged in something like the 'emotion work' advocated by Bondi (2005a) in order to decode my/our emotional responses. This was undoubtedly important for 'letting off steam', although I would hesitate to suggest that my/our earlier feelings were 'successfully' disentangled from the 'feeling rules' that supposedly shape our immediate responses. As Widdowfield (2000: 202) asserts, there are 'many uncertainties and recognising that emotions may affect the research process is not synonymous with understanding the way such effects are exercised or felt'. Of course, Bondi's point is that we need to attempt to move beyond feelings of being overwhelmed to reflect on the complexity of challenging encounters, even though, as she readily admits, this is no easy task.

her story was in any way cathartic to her or harmful; equally, it is difficult to say whether any attempts to discontinue the interview would have been 'appropriate' or upsettingly censorial (especially after her regret that 'no-one ever asks me how I feel')⁴³. On reflection, the decision to close-off unsettling lines of communication would have been as much for *my* benefit as hers: a socio-emotional desire to allay the heaviness of the situation, to 'look on the bright side', even if for her there was none. While there is no 'transparent self' waiting to be uncovered (Rose 1997), diluting our intersubjectivities would have taken us further from her 'truth' and so the objectives of this research. Hopefully, Renae was perfectly capable of choosing or recognising her own limits; but even though I was overtly and unavoidably aware of my ethical responsibilities, this remains unknown.

Research is not just *about* bodies, it is inherently *embodied*. As noted by Laurier and Parr (1999: 99), the anticipation of embodied difference positions the interviewer prior to the intersubjective encounter. As there was a possibility of a seizure occurring during interview, I attended certified training courses run by ES ('Understanding and Managing Epilepsy' and 'Managing Difficult Epilepsy', which included practical exams on administering emergency treatments and basic first aid)⁴⁴. At certain times early in the interviewing process, I did wonder whether an individual was about to have a seizure, perhaps a consequence of being trained to 'read' the bodily signs and symptoms of epilepsy. Certain behaviours, no matter how innocuous, were coded as potentially *epileptic*; and, by extension, these assumptions about an-other's body meant that I had unwittingly defined the *individual* as epileptic. Proximity to difference, Wilton (1998) argues, sparks feelings of *unheimlich*, of being unsettled, because of a perceived threat to the 'way things ought to be'. In this case, anxieties seemed to arise not from observation but from the *anticipation* of difference – of my spatial imagination of the interview being dis-ordered – and hence this was a potential source of othering within the encounter⁴⁵.

⁴³ Participation in this research created the conditions for Renae to relay her distress, yet beyond this encounter there was no contact to establish that she had not been 'harmful'. Rarely do publications discuss how responsibility may be enacted on an *individual* level beyond research encounters (collectively, 'giving back' tends to be mentioned), and thus future research might engage with these difficult questions.

⁴⁴ These training sessions were crucial in providing some provisional acquaintance with seizures. In fact, and linking in with some of my final conclusions, being shown exactly what seizures look like (on video), and how they are experienced by the individual and witnesses, was vital in helping me to understand my own preconceptions about epileptic seizures.

⁴⁵ Archie had just experienced his first 'epileptic' symptoms in over three years. He did not, however, surrender his license (which would mean not driving until he was symptom-free for over one year). Later, after discussing how he had once experienced bodily paralysis while driving, thus constructing his car as a space of risk, he returned suddenly to this topic: 'Don't worry about being taken back to the train station – I mean, you're OK in the car!' It had not occurred to me *not* to trust his judgement, yet his expectation that I might be concerned was perhaps revealing of how illness entered into the fabric of his social life. Had I declined his offer of a lift, he may have taken that as my doubting his claims to body-knowledge, reifying his anxieties over a spoiled identity. I responded by assuring him that I was not worried. This was perhaps suggestive of my assessing the validity of his claims, reinforcing the binary of abnormal (Archie) and normal (me) (Dyck and Kearns 1995). It is important to consider such issues as constitutive of the research encounter and subsequent outputs. Indeed, I wonder how any suggestion of hesitancy on my part might have impacted on the latter parts of our conversation.

Encountering 'difference', the abject (Worth 2008: 311), provides opportunity for reflecting on one's own ways of making sense of bodies, which also hints at wider social processes. Twice in this research I was witness to the overt manifestations of epilepsy. One participant, Brian, experienced an aura (a 'warning') in isolation from other epileptic activity, while Holly had a complex partial seizure. Both individuals had discussed how seizures were now 'just a part of everyday life', yet my unfamiliarity with how each body was seized meant I could not but 'read' their performances as the experience of distress. It is one thing being told that in seizure one feels no pain, and another to witness the 'pained' expressions and sounds of a person whose relationship with space is drastically altered. This led to uncertainties over how to act, and how to *feel*. In each instance, awareness of my own body-self was heightened by a racing heart and mind; rationalising the situation was tempered by apprehensions over 'knowing what to do', both in terms of acting how the individual would *want* me to act and in following my 'seizure protocol' training. Bondi (2005a: 237), discussing the links between ethics and emotions, seeks to disrupt normative assumptions about how a researcher should feel. At the time, I placed anxiety as a negative, possibly inappropriate, emotion because of a political motivation to demystify the seizure. Accepting such feelings, it is argued (*ibid.*), offers a means to reflecting on the substance of our research. In the very moment of each event, the 'rules of good practice' dissolved in my mind's eye as the surge of the unexpected momentarily took hold in and between our bodies (see CHAPTER FIVE for a discussion of 'affect'). Quickly, I rebuilt the social self, through which my various roles led to a number of competing feelings: I was conscious of not becoming 'the academic voyeur', yet was curious about what seizures 'looked like'; I felt uneasy being confronted with the unknown, and guilty about that uneasiness; was I intruding on an 'intimate' moment or would the person appreciate some help? Reflecting on these tensions reminds us that ethical research is both professional and (inter)personal. Indeed, while interviews do not necessarily come under the purview of ethnography, they should not be taken as being outside of embodied social context. In each instance of altered corporality, my foremost concern was for Brian and Holly respectively, each of whom had kindly invited me into their home and whose openness led to intimate connections⁴⁶. As an aside, these early experiences seemed to lift any anxieties, facilitating greater potential for interview intersubjectivities, but also further analysis of

⁴⁶ Brian and Holly had each said that seizures spark intense feelings of vulnerability, and afterwards fatigue, with a strong desire to 'hide'. Yet, in somewhat conflicting positions, both appreciated when other people stuck around during the sometimes lengthy process of regaining full awareness so that they could experience a sense of continuity 'before' and 'after' (see also CHAPTER FOUR). I had absolutely no expectation of continuing each interview, yet Brian insisted he was unaffected and indeed happy to describe his aura experience. This seemed to facilitate a more relaxed intimacy (Brian even became keen to show me other aspects of his life, like his guitar collection). With Holly, there was no question of continuing as it took much longer for her to return to what she described as 'normality' (the interview was anyhow almost complete). With her husband, Dave, in the room, I took my social cues from them: they seemed happy – keen even – for me to 'hang out' for what became a very enjoyable few hours. I was unsure at first as to whether this would have been Holly's choice, but Holly said she appreciated being able to say goodbye when she would remember me leaving (which would not have been the case an hour previously).

how proximity to 'other' bodies may encourage the revision of negative attitudes (Wilton 1998; Dear *et al.* 1997; see CHAPTER FIVE).

ANALYSIS

As Bird (2005) puts it, transcription of qualitative research is both product and methodological process. All 37 interviews (28 ES members and nine health professionals) were digitally recorded and transcribed verbatim. This proved a lengthy and intense process, but, as with questionnaire data entry, it facilitated an intimacy with the research data. As an inexperienced transcriber, I started out by attempting to 'naturalise' (Oliver *et al.* 2005) re-presentations of interviews by including 'ums' and 'errs' and annotating all silences and interpretations of mood⁴⁷. It soon became evident that a more pragmatic approach would be to annotate *selectively*, even if that risked privileging moments of heightened emotion over more mundane reflection. The switch to 'denaturalised' transcription (*ibid.*) demonstrates a 'grounded' approach (Glaser and Strauss 1967) to assessing the informational content of data ('insider' meaning and perceptions). This choice was also informed by dissatisfaction with the 'naïve realism' (Guba and Lincoln 1994) of early transcripts, in which non-standard English was reproduced phonetically. For example, while it was easy to represent regional accents through altered spelling, other accents, while just as noticeable to the ear, could not be portrayed on paper. These differences immediately jumped out from the page as suggestive of a hierarchy, in which people 'speaking' standard English were placed above those who deviated from the norm, prejudicing (and potentially misleading) the reader's assumptions about the 'class' (education, socio-economic level) status of the individual. While my opting out of the 'naturalised' method could be seen as an erasure of difference, I felt it could not be justified given the unevenness with which it was implemented (although I continued to italicise words that respondents clearly emphasised in their vocalisations).

All transcripts were uploaded on to the qualitative data management program, NVivo[®], and coded manually. The iterative refinement of emic and etic⁴⁸ codes revealed the fluidity, and indeed inseparability, of theory and data. A basic node hierarchy was constructed to organise data under preconceived thematic categories (loosely associated with interview schedules), while allowing room for new nodes to be created as themes 'emerged' from the data (see APPENDIX 7 for an NVivo node screenshot). The three 'parent' nodes created correspond roughly with the thesis structure: 'Seizures' (CHAPTERS FOUR and FIVE), 'Social Geographies' (CHAPTERS SIX and SEVEN) and 'Governing Epilepsy' (CHAPTER EIGHT). Each 'parent' node comprised multiple 'child' nodes, many of which have multiple 'children' to organise and refine thematic content. In total,

⁴⁷ This is also similar to a 'conversation analysis' approach (for example, see Laurier 2001), where the detailed process/conduct/micro-dynamics of conversation are themselves the focus.

⁴⁸ Put simply, emic coding captures how people describe their own worlds, while etic coding annotates data according to established theoretical constructs (Cook and Crang 1995: 82).

there were 131 nodes. This strategy could be criticised for fragmenting and so decontextualising individuals' responses. In light of this potential drawback, the reader might wish to cross-reference the individual 'voices' heard in the coming chapters with selected details in **Table 5**. Furthermore, it is hoped that intensive transcription and coding has paved the way for something of my collaboration with participants, who live in and beyond this research, to come alive in the text (albeit, this is constrained by the limitations of my writing style and content).

Table 5: Interviewee Demographic Information

Pseudonym	Age	Age Diagnosed	Seizure Type(s) ^a	Seizure Frequency ^b	Employment Status	Household Members	Residency
Anna	37	22	2	1	Employed	Self	City
Carol	45	12	3	1	Self-employed	Self	City
Gordon	49	11	1	1	Employed	Self	Town
Archie	63	49	3	1	Early Retirement	Self	Village
Debbie	41	16	2	1	Employed	Self	Town
Margaret	73	50	3	1	Retired	Self	Small Town
Chris	31	28	2	1	Employed	Self, parents	Village
James	66	55	1	1	Semi-retired	Self, wife	Small Town
Sue	53	28	3	1	Employed	Self, husband, two school-age children	Small Town
Jennifer	32	8	1	1	Employed	Self	City
Maureen	63	58	2	2	Early Retirement	Self	Small Town
Joan	55	28	3	2	Unemployed	Self, husband	Town
Ian	35	1	2	2	Employed	Self, wife, two school-age children	City
Nicola	34	18	2	2	Employed	Self	Town
Brian	54	40	3	3	Self-employed	Self, wife, two teenagers	Town
Claire	25	21	2	3	Employed	Self	City
Patricia	52	13	3	3	Early Retirement	Self, husband	Small Town
Robert	49	18	3	3	Unemployed	Self	Town
Steve	47	2	3	4	Volunteers	Self, wife, two teenagers	Town
Patrick	50	8	3	4	Unemployed	Self	City
Gavin	68	19	2	4	Early Retirement	Self, wife	Small Town
Holly	40	12	3	4	Employed	Self, husband	Small Town
Laura	40	15	3	4	Unemployed	Self	Small Town
Renae	51	10	3	5	Unemployed	Self	Small Town
Alan	51	7	3	5	Unemployed	Self, wife	Small Town
Mandy	30	22	2	5	Self-employed	Self, husband, three young children	Town
Kate	45	25	3	5	Unemployed	Self, husband	Small Town
Sophie	19	15	3	5	Employed	Self, parents	City

^a 1 = Partial; 2 = Generalised; 3 = Partial and Generalised; 4 = Other/Unclassifiable.

^b 1 = No seizures in the last year; 2 = Less than one seizure a month; 3 = One or more seizures a month; 4 = One or more seizures a week; 5 = One or more seizures every day.

In this thesis, participant quotes are selected for their aptness and articulation of ideas. They should not be taken as 'unusual' or abstracted from how they were expressed: they are intended to capture concerns, emotions and experiences that came up in questionnaire results

and were frequently discussed in interviews. I have attempted to allow as wide a variety of voices as possible to come through so as to illustrate the 'epileptic' spectrum, which means that many cases, events, and issues here are enriched through more than one example. This strategy of gathering a multitude of voices is a very deliberate effort to be almost 'quantitative' in demonstrating that claims below almost never rely on, say, just one individual or quote. I appreciate how, just occasionally, this can lead to the possibility of overwhelming the reader with detail; yet I hope that this is a price worth paying for demonstrating, indeed 'triangulating', the claims made. Participant quotations are presented with the pseudonym of the participant only, although in certain cases I describe biographical details pertinent to the point being made so that the reader is not burdened by the need continually to cross-reference with **Table 5**. Numerous quotations have been edited to allow ideas to flow without off-topic asides or repetitive phrases (e.g. 'y'know'), indicated by '[...]'. This serves the purpose of allowing shared conversational meanings to come across in prose, all the while remaining faithful to the original content.

ADDITIONAL DATA

Keeping a research diary facilitated the very essence of my writing (seen already, for instance, in my reflections on bearing witness to seizures). The diary was not used as a tool for recording participatory-style accounts of ES as such – that was not part of the agreed methodology – but reference to my work at and with ES will follow to conclude this chapter. Rather, on the bus or train journey home from interviews, I would use a stream-of-consciousness style of writing to connect my experiences with initial conceptual ideas. This writing was not an attempt to recreate blow-by-blow accounts, but to make associations, dissect (my own) emotions or capture non-recorded conversations while my memory of them was still fresh. Further ideas sprung from two ES AGMs, where I presented to an audience of staff, board members, members and interested professionals. These occasions were unique in their mixing of perspectives on the object of 'epilepsy'.

As further testament to the substance of this topic, requests from individuals interested in participating continued throughout the lifespan of this research. Seven people (non-ES members who had come across adverts online) chose to contribute written testimonies. These were negotiated privately by email, generally following my suggestion that they discuss the impact of seizures in the short-term and epilepsy in the longer-term. Beyond that I remained non-prescriptive, yet, to my surprise, each participant provided over 2 pages of A4. I have written elsewhere about the value of written testimonies (Smith 2012); but to 'paraphrase', we may learn much about the experience of illness through written narratives if we see their partial and selective nature not as a limitation, but instead as an opportunity for gauging what people find it

important to tell. Making space for written narratives in qualitative geographical analysis offers room for individuals who otherwise may be unable or unwilling to participate under different circumstances, and presents a different form of insight that cannot but be useful within robust research methodologies (Davidson 2007; Milligan 2005; Latham 2003). Analysis here followed the same coding logic as for other qualitative materials (including the qualitative components of the questionnaire).

WRITING FOR CHANGE: CASE STUDENTSHIP PARTICIPATORY RESEARCH

This chapter has provided an overview of all methods being used to 'know' the 'epileptic body'. During seizure, the individual is invariably unconscious or unaware, and hence descriptions of those momentary 'body events' tend at least partially to reproduce the representations of others. In some respects, their problem is my problem: one can get 'close' to, but never really '*know*', how a seizure is experienced. Theirs, like mine, is a fragmented whole, pieced together from a swirl of simultaneously internal and external words, affects, emotions. *How* people describe their seizures offers insights into the ways in which they respond to and reproduce social, cultural, historical, medical, advocacy and governmental discourses. It seems fitting, then, that multiple methods be used to ask related questions, but from different perspectives, each with its own sets of meanings. In so doing, we may facilitate mutual understandings concerning the experience of seizures as part of the transformation of the 'monstrous' (Shildrick 1997) into a demystified, everyday geography of the unpredictable body.

Making 'space for difference' (Kearns 1995: 249) recognises the liveliness of embodied social performance, and uncovers how social practices and places are contested and embodied as part of the process of *re*-embodiment after the onset of illness (Moss 1997). It is through such a 'microgeography of embodiment' (inclusive of how the body is in part made through social processes and health policy) that a *collective* body politics may be constructed (Moss and Dyck 2002: 169). The sheer diversity of experience encountered in this research only adds to a wider critique of 'ableism', an issue affecting all people at least temporarily, whether through injury or old age (Worth 2008). While stigmatising perceptions are difficult to shift, the challenge is to show that *every-body* is vulnerable; and thus stories of vulnerability are relevant to all of society. Casting a wide net, and utilising methodologies not always associated with health geography to present the unique 'voices' of participants, is all geared to drawing in a diverse audience.

Working *with*, rather than *on* or *for*, a voluntary sector organisation as part of this ESRC-funded CASE (Collaborative Awards in Science and Engineering) Studentship confirms a commitment to emancipatory research practices that move 'toward implementing insights about difference into political actions' (Moss and Matwychuk 2000: 84). As Chouinard (2000: 72, original

emphasis) argues, academics tend to 'exercise a great deal of power over what counts as knowledge, how it is created and *for whom*'. Partnership with a non-academic organisation has opened up the research process (what and how questions are asked, and how results are disseminated) in ways that can be used to promote social change. For the duration, ES provided office space so that the goal of 'applied relevance' might be realised through deep immersion in their concerns, policies and practices. With the supervision of Policy and Development Manager, Anissa Tönberg, ES has placed faith in the value of a geographical approach in gathering materials about a subject matter that is arguably overlooked by much of the social science literature⁴⁹. That is, in examining how people cope with the recursive constitution of volatile body and enviroing space, this study addresses the very heart of *everyday living* that is so rarely elaborated in 'stigma' or 'quality of life' reports.

Using multiple methods to engage the place-based perceptions of people with epilepsy is a means to reaching a diverse audience in and beyond the academy: put crudely, this research has diverse appeal for those who fall on either side of the quantitative/qualitative 'divide'. ES played an active role in identifying relevant research questions (Kesby *et al.* 2005: 146), thus entailing a mutually beneficial relationship that is likely to be a source of credibility in the eyes of policy-makers and academics alike (Klodawsky 2007). Furthermore, interest in the research from various angles has paved the way for the creation of supportive spaces (Chouinard 2000), including a WordPress website (that will be 'launched' at a special event) highlighting individual testimonies and results. This site is not only intended as a non-medical resource for newly-diagnosed individuals, but as a space wherein further debate and feedback is encouraged from the epilepsy community. Furthermore, multiple research products (the website, reports for ES, academic papers and this thesis) are not only different ways of speaking to different audiences (academics, young people, clinicians, policy-makers) through different channels (ES press releases and newsletters, specialist mailing networks, academic conferences), but are also a way of sharing different findings from the research process itself (Cahill 2004). It is hoped, therefore, that both collaborators and people with epilepsy benefit through a wider circulation of action and support (Routledge 2003).

While 'participant observation' was not included in the research methodology, it must be noted that collaboration was an uneven process, although one that was negotiated productively on temporary common ground (Routledge 2003: 70). To be sure, academic reasoning did not always correspond with aspects of the organisational culture of ES. As Cahill (2004) describes, there will always be inconsistencies in collaboration, yet it is important to consider how decisions were reached through the negotiation of power/knowledge (see also Sanderson and Kindon

⁴⁹ While the ESRC CASE Studentship scheme has now been discontinued, Demeritt and Lees (2005: 127) describe how the overwhelming success of human geographers in this competitive programme provided an opportunity for reassessing claims about whether and for whom geographical research is relevant.

2004). Issues included delays in sending out the questionnaire and tensions over the format in which descriptive questionnaire results were reported in the monthly ES newsletter (especially with editorial simplifications). As part of an on-going responsibility to the organisation, I produced a booklet displaying theme-based qualitative information ('experiences of diagnosis', 'seizure experiences', 'issues at work', etc.) from the questionnaire. However, I was uncomfortable with the level to which the ES press office subsequently edited participant responses and omitted testimonies that were considered overly negative in tone. This exposed a point of departure in the aspirations of this research and the discursive conventions of ES PR work. Throughout their campaigning, ES have expressed a positive image of the person who can be normatively successful *in spite* of epilepsy. While including data regarding positive lifestyles, I felt that, by excluding the 'voices' of people experiencing difficulties others would be robbed of the comfort of knowing they are 'not alone' (a significant finding from my work on epilepsy testimonies: Smith 2012; see also CONCLUSION). I discussed these issues with my ES supervisor, who was responsible for all ES-led research, and she admitted to experiencing similar tensions with the press office. We negotiated that I produce two documents to be made available: one over which the ES press office had editorial control, the other my original effort, rebranded under the title of 'Experiences of difficult epilepsy'. These exchanges were revealing of the politics of PR work, an uneven terrain that is by no means the product of outright consensus among staff. Indeed, organisations cannot be considered as homogenous, but complex institutional, political and personal assemblages (Monk *et al.* 2003; Cahill 2007). The compromise that was reached was the result of discussions with several staff, each of whom was situated with respect to their own workplace responsibilities. While it is difficult to say whether the readership of these two booklets would be equal, it is reasonable to suggest that the compromise benefitted both parties and so, hopefully, the wider audience of ES members and contacts.

CHAPTER FOUR:

THE PHENOMENOLOGY OF PAROXYSMAL⁵⁰ BODY EVENTS: SEIZURE TIME-SPACES

Only rarely are the theoretical implications of the existential fact of vulnerability ever factored into our conceptual framework from the outset. As if mirroring the reductive and clinical nature of standard biomedical science, corporeal vulnerability more often than not appears as a problem to be solved rather than as an inherent – and inherently significant – condition of existence (Harrison 2008: 426).

INTRODUCTION

In this chapter I illustrate the lived experience of seizures using the words of participants as far as possible. This serves a variety of purposes, both academic and political. First, it addresses the common criticism of the scarcity of public information about how seizures are variously embodied⁵¹. Second, ambiguous experiences are difficult to diagnose. The *storying* of (possible) seizure experiences is paramount because diagnostic technologies, such as EEGs (electroencephalographs), only observe epileptic activity in the brain, which is episodic and so frequently undetectable⁵². Thus, more research is needed to uncover the discursive repertoires of people attempting to communicate their ‘unusual sensations’. Third, clinically-marginalised first-hand accounts (Bury 2001) hold potential for teaching wider society about the experience of illness (Milligan 2005) and provide a resource for health professionals seeking to understand processes of coping. Fourth, epilepsy is much more than seizures (in fact, 52% of people with epilepsy in the UK *do not* have seizures: JEC 2011), but every-body who has been so diagnosed has had at least two epileptic episodes (diagnoses cannot be made on the strength of a single seizure event due to the high occurrence of psychogenic non-epileptic seizures: Cross 2009). In order to contextualise how epilepsy impacts on peoples’ everyday social geographies, it is crucial first to understand how its *potential* manifestations challenge one’s sense of self: on the one hand, if seizures are uncontrolled, life becomes structured to an extent around their immediate

⁵⁰ ‘Paroxysmal’ events are those characterised by sudden outbursts or the recurrence or intensification of symptoms.

⁵¹ Participants describe their epilepsy in terms of their seizures. Most have a fair idea of clinical seizure names, although commonly use outdated terms, for example ‘grand mal’ instead of ‘tonic-clonic’ (revealing of the era in which a person was diagnosed: see CHAPTER SIX for an account of the difference made by the ‘longevity’ of epilepsy). It is felt across the board that members of the public know little of the various manifestations of epilepsy.

⁵² This matter is complicated when the individual’s first language is not the same as that of the diagnosing physician: difficulties in articulating embodied sensations may delay or prevent diagnosis. In CHAPTER EIGHT I discuss the sometimes ‘ironic’ relationship between seeking the ‘discursive (medicalised) body’ and contesting popular representations of people with epilepsy.

and intermediate affects; on the other, people whose seizures *are* controlled may have little cause to think about epilepsy on a daily basis beyond taking medications (although these can have extreme side-effects), but the reason that most continue to do so is to avoid the *return* of seizures. Accordingly, this chapter includes the testimonies of people who currently experience seizures and those who do no longer. This is because, as I will discuss in CHAPTERS SIX and SEVEN, searching for control implies knowing what it is to be *out of control*.

Seizure experiences do not relate to the ticking of a clock, but to the intensity of socio-emotional and physical affect. Participants are unable to give an accurate report of the *times* of their seizures because their lived temporalities occur in 'inner time' (Toombs 1990). That is not to say experiences are entirely unstructured. In fact, the finite period of these disruptive, paroxysmal 'body events' is referenced by participants in the time-frames of *before*, *during* and *after*. Structuring their accounts in a coherent and linear, albeit partial, story helps people to make sense of their place in the world. Here, describing a clear sequence of events is to some degree disingenuous since, as I contend, the reason seizures are difficult to comprehend is precisely because they emphasise the distinction between objective and subjective time-spaces. Experiences 'inside' a seizure are not comparable in space or time with onlookers' observations⁵³. Attention to epileptic corporeality thus focuses on disrupted experience *within* the body that is at the same time 'observed' publicly as 'out of control'. As Longhurst (1994: 218) argues, people exhibiting 'other' corporealities challenge 'rational' geographical knowledge. Epileptic embodiment is a striking example of ambiguous, *paradoxical* corporealities in that it can at once render experiences both private and public, inside and outside, near and far, relational and non-relational; moreover, people can be simultaneously 'ill' and 'healthy' (Moss and Dyck 2002) in that it is a 'hidden' disability (a partial loss of control) episodically rendered 'visible' by seizures (a complete loss of control).

During everyday life, the body and the self are usually experienced as one: we do not possess a body or a self but, rather, a 'me'. In the moments before, during and after a seizure, self/embodiment is fractured as the body becomes the object of one's own attention: it disappears (Leder 1990). This disruption in moment-to-moment experience, as Toombs (1988) and Leder (1990) affirm, is a threat to lived temporality, spatiality, intentionality and being-in-the-world. Such disturbance is at times uncontrollable, rendering the experience of 'me' chaotic. Seizures can also incite feelings of being invaded by an 'alien presence', a 'not-me', and the consequent sensation is *uncanny* (Honkasalo 2001: 324). I seek to elucidate some of the little-known issues that people with epilepsy face in relocating the boundaries of the body and self

⁵³ Affective and emotional inter-relations with people witnessing seizures on the 'outside' impact on coping strategies of a person with epilepsy immediately following an episode and in anticipation of future episodes. In this chapter I consider the phenomenology of the 'inside' experience, before de-centring the individual to consider processes on the 'outside' in the next.

within their everyday time-spaces. Invariably, participants recall the exact situation of their *first* seizure - where it was, who was there, what was happening - because of the confusion, fear, distress and disturbance it causes (in the moment and longer-term: see Aydemir *et al.* 2009: 158). Even when epilepsy is established as a condition with which the individual will continue to live, seizure experiences never 'flatten'. Indeed, and in line with my aims in unpacking these lived moments, each episode is discussed inseparably from the time, space and social context in which it occurs. There is no single 'epilepsy', rather 'epilepsies'; no 'seizure', but distinct seizure experiences in unique time-spaces that are constitutive of the 'field of potential' of the body to affect or be affected (Bissell 2010). Understanding the meaning of seizures for the individual, then, requires methodologies sensitive to their differentiated and contingent social, material, corporeal geographies⁵⁴.

'WHERE AM I?': BODY TIME-SPACES AFTER A SEIZURE

UNSTABLE LOCATIONS OF THE SELF

It may not be obvious immediately why I should begin *after* the event. I have done so for several reasons. By not starting with the pre-seizure sensations I am making the point that, chronologically, a person's first encounter with epilepsy – *their* epilepsy – can indeed only be *after* the first seizure. The diagnostic process for epilepsy would not be set in motion unless a person reported (with or without the testimonies of witnesses) having regained awareness following an ambiguous 'body event'. Anticipation of the (possible) *next* seizure only comes into one's thinking *after* their previous seizure, the consequences of which inform any subsequent precautions taken. Another reason is that by disrupting the customary flow of order, I hope to achieve an impression of how the body 'lands' back into consciousness, often without direct knowledge or memory of the situation leading up to the episode (although later the 'blanks' start to be filled in by others or as the 'mental fog' after a seizure clears). I want, in some small way, to offer the reader a chance similarly to 'land' in the disorientated aftermath of a seizure, with few clues as to what came before, while knowing that only by rebuilding the boundaries of the body can the self recover and so prepare for the next seizure.

How a person 're-embodies' after seizure is variable, but the experience may in part depend on the type of seizure, how long it lasted, the material environment in which they are positioned and whether anybody is present in an assistive capacity. Of course, not everyone is

⁵⁴ In this chapter I necessarily rely more on my interview data because of the nuances of moment-to-moment experience that could be investigated through this medium; however, I include questionnaire results to contextualise wider concepts.

immediately aware that they have had a seizure, and may simply require a minute or two to recompose following disrupted embodiment:

I thought something must have happened because I felt a bit weird, and it was a minute or two before I could come back to normal again. But most of the time I [...] would just continue doing the same thing, like if you were cooking. (Margaret)

Becoming aware or conscious again can be an extremely ‘internal’ process, when the self fades back in slowly. Different senses may return gradually in waves or stages; one might be first aware of the voices of others enveloping one’s body-space, of the cold and grit of the pavement, of a dry mouth with a painful tongue:

[I first become aware of] voices, I think. But, again, it’s like you’re under water, so sometimes I can’t understand what they’re saying. The very first thing’s if I’ve bitten my lip or not. Like, I bite the inside of my cheek, so, to be honest with you, it’s *sore*. After it, my muscles are just, I don’t know whether they’re just done-in with it or not, but they’ve contracted for that amount of time – it’s sore; it’s painful. (Claire)

With tonic-clonic seizures: that’s when you really feel a sore head and just confusion, and you hear the voices of people before you actually see them. You hear voices, you understand; and you think ‘Right, where am I?’ And it’s usually the ambulance drivers, and you hear the slam of the ramp at the back of the ambulance, and you hear the doors opening; you feel the cold draught. But all this time you can’t see. (Ian)

Regaining some awareness in an ambulance, as various participants have done, can be a distressing time because the body-space is still fragmented and unstable. Because the body is usually ‘intrinsically intersensory’ (Zaner 1964: 181), when individual sense perceptions do not form part of a coherent whole, space cannot be experienced in synthesis. Possibly unable to sit up, to hold a conversation, to get a hold of the situation and their place within it, individuals feel vulnerable to the presence and actions of others as they struggle with every sinew of their disorientated body to re-collect themselves, to become as *one* again.

When Gordon regains consciousness, sensations usually associated with injuring the material body are *absent* due to the cutting off of the body from the self:

You’ve got to remember that with epilepsy it’s like an anaesthetic – you don’t feel anything until the damage is done and you come round. So you can split your skull, but, when you come round from the fit, there’s no pain to it. Then you realise there’s blood. And it’s about time you did something about it, and you inspect it to see how much damage has been done. (Gordon)

Gordon here experienced a breakdown in his bodily boundaries both in terms of the injurious leaking of bodily fluids but also because ‘normal’ feelings escaped him. He felt no pain, yet the thick red liquid emanating from his body-space required inspection to assess the damage. That he could not experience the body as a unified whole, his sense of space was unbound: he did not perceive where the body ended and space began. Thus, following Glass (1989, on delusional experiences; see also Parr 1999), seizure recoveries are spatialised, but not within any precisely defined boundaries; that is, they permeate space but involve the sometimes terrifying struggle to *locate* previously held borders. Whereas normally pain would accompany Gordon’s escaping blood, experienced as ‘*I am my pain*’ (Toombs 1988), the bleeding body became a foreign object of his investigation. When the materiality of the body loses its taken-for-granted status as home of the self, existential anxieties arise. A seizure can take someone *elsewhere*: ‘I sometimes think that I *am* somewhere when I’m coming round; that I am somewhere completely different from where I am: I’ve been dreaming, and I’m somewhere different, and then I come around’ (James). When recovering from this dream-like state, the senses are not quite *here*. Unbound by one’s corporeal walls, the experience leaves one questioning *Where am I?* What does it mean to have personal integrity, to be *me*, when my body becomes estranged? In relation to head injuries, Lindemann (2001: 111) discusses whether identity is always connected to bodily perception and muses, ‘The term ‘intimate stranger’ takes on new meaning when proprioception⁵⁵ is disturbed.’ At root is the fear that the self is *nowhere*, that there is no safe place to protect against threats to one’s very existence.

RELOCATING THE BODY IN TIME-SPACE

Following the breakdown of bodily boundaries, the self struggles to re-establish it-self within the socio-material environment. The question ‘*Where am I?*’, then, also refers to the location of the body-in-space:

When I come round, I just sort of look about and wonder where I am for a wee minute – even though I’m in my house it just sometimes gets confusing. It’s only for a couple of minutes and then it starts to come back, and I think [...] ‘Oh right, I’m in the living room,’ or ‘I’m here,’ or ‘I’m there,’ then I can just go to sleep and I can relax. (Mandy)

Participants feel they lack agency until such time that they can identify their ‘place’: only then can re-building begin so that the body is brought back in line with ‘normal’ spatialities. As Patricia reveals, ‘You were a bit disorientated. If I was on the floor I had to get up, re-orientate myself, and

⁵⁵ Proprioception refers to our corporeal positioning in and through space, which usually operates below the level of consciousness. We perceive lived space through our senses – seeing, hearing, touching and so on – each of which ‘implicates the entire body, is intrinsically intersensory’ (Zaner 1964: 181). Merleau-Ponty (1962: 260) describes the effect of the ‘normal’ coherence of our senses as ‘a unification of these spaces in one lived spatiality’.

then try to carry on as if nothing had happened.’ At its most disconcerting, epilepsy can displace the body-self entirely:

I recovered consciousness and had amnesia: I didn’t know where I was; I didn’t know what my name was [...] I just had to stand there and initially think ‘Who am I? Where am I?’ etcetera, and the vague feeling of ‘Yes, I’ve been here before; but when? And where is this place that I’ve been before?’ And it was fitting everything together. And it was looking down the street and actually recognising the specific shops and thinking ‘Ah, yes, I know that! I know where I am now.’ Again, all these little things [...] and like a jigsaw puzzle it began to fit all together again. And then fear set in at realising what had happened: *how* I had managed to walk all the way up that hill, having crossed a *very busy road*... where had I crossed it? (Patrick)

While attempting to locate himself, Patrick was trapped very much in the present (Leder 1987: 256). He struggled to ‘place’ the self within the body and surroundings in order to give it purpose and meaning, for, as Davidson (2000a: 644) discusses, ‘To act we need a kind of bodily sense of where we are, *i.e.* a proprioceptive awareness of our physical deployment in and through space.’ Patrick knew nothing of the preceding moments and movements that had led him to this place; he anticipated no future while space remained unfamiliar. Our understanding of the self is thus spatially and temporally mediated. Confusion as to space and time compels re-orientation in the *here*, but, also, the *now* (*‘When am I?’*). Seizures are a black hole in the time-space fabric of everyday life such that one embodied action or position, in the blink of an eye, can become another. ‘Missing moments’ (Maureen) were a source of frustration due to their (with)hold(ing) of time:

‘Oh. Where have I been? What happened there?’ - especially if Kerry [Ian’s wife] has led me through the house and she’s got you through here [in the living room]; and I would come out of it and say, ‘What you doing? Why have you got me through here? You’re just wasting time! We’ve got to get the kids up and get out to work!’ Things like that. And it’ll be kind of as if *nothing happened*, but suddenly she’s zapped you through here, somehow; and you shouldn’t *be here* because you know that you’re supposed to be getting the sandwiches ready or whatever – getting changed or things like that. (Ian)

Inferring that in seizure his wife escorts him to another place, this only exacerbates Ian’s sense of being ‘out of synch’. The time-space separating him from what he was doing before stands as a marker of his *intentionality*, his ‘straightforward drive to keep the body and self alive’ (Harrison 2008: 431), being disturbed. Lost time is time lost.

Contrary to the above examples, Brian was alarmed to find himself in the *same space* following a seizure (although at a different time and place) as if nothing had happened:

The train had just moved off from Polmont station, and I sat down at one of these seats with the table, and there's two chairs there and two chairs there [facing each other]. There were these two old ladies and a guy sitting there, and I sat down and joined them. And I'm quite a chatty person, and I said 'Where have you been today, ladies? Have you been out shopping?' And they started talking a bit. [Clicks fingers] Next thing I know, I was sitting in a carriage in Waverley station [the Edinburgh terminus]; all the lights were out in the train and I was on my own. And there was not a soul. And all I heard was the voice on the Tannoy [speaker] system: 'The next train for Manchester will be leaving at blah-de-blah'. How long I was out for there, and how they got out of their seats, I'll never know. So I just had to give myself a wee slap and a wee shake and get the bus home. It was just one of these things. I've had lots of seizures like that. I mean, I could've been there all day. (Brian)

Brian will probably never know exactly what happened. There is a central unknowability about what his own body and others' *did* during the period he was unconscious, in part because he was unable to access witness accounts (see CHAPTER FIVE for a discussion of the unstable relations with others following seizures⁵⁶). I asked Brian to elaborate on his experience. As he alludes, without his wife present (a 'reliable' witness), regaining awareness alone leaves a sense of loss at not being able to fill in the socio-embodied gaps. He was left to hypothesise what happened, and what the ladies thought:

It's difficult to explain, but one minute you're chatting away to these old ladies about their day shopping, and I didn't even feel the symptoms: the rush of blood to the head or whatever. Just nothing. But my wife says I'm quite compliant during a seizure. So they must've got me to my feet and sat me back down again. But I thought that they might at least have phoned for a doctor or something. Maybe a doctor was on the way, I don't know; or they [might have] left me a note. But nothing. I was just sitting there in the dark. All the lights were off in the train. It was in the winter, it was about 4.30 [pm] and the lights were off. I came round and realised that I must have had a seizure because everybody was gone. And I don't remember one inch of that journey. Gone [indicates something leaving his brain].

Finding himself sitting in the same *space*, the passage of time was evident in the change of *place*⁵⁷: Polmont was now Edinburgh. Similarly, 'spaces of evidence' were all around him: a

⁵⁶ Bissell (2008: 1701) discusses how train travel companies promote an 'anticipatory sense of comfort' by representing 'sensibilities such as quietness, solitude, relaxation, slowness, and beauty' in marketing campaigns. Promoting 'gentleness', he continues, 'promises that bodies will not be subject to more agitated forms of movement that could potentially disrupt these desirable comfortable sensibilities'. A seizure when sitting on an aisle table seat in a train will probably disturb such sensibilities, and possibly be perceived as dangerous and obstructing, especially when the individual and their bodily 'performance' is unknown to their fellow passengers. I unpack the impact of the seized body on others in CHAPTER FIVE.

⁵⁷ Conversely, people might remain in the same place, but regain consciousness in a different *space*. This happens during 'complex partial' seizures (see Table 1), when the individual might walk around, embodying what is known as an 'automatism'.

crowded train was deserted, the lights were off, daylight was abruptly dark⁵⁸. Having relocated himself in the present, all that was left to do – though later than intended – was navigate home.

Re-centring the self as the intentional, phenomenological subject does not, however, concretise the body's boundaries. The body takes time to psycho-socially and physically 'settle' following a seizure, even when it is re-positioned in relation to 'normal' time-space. When full spatial awareness is regained the impact of the seizure is felt in the continuing *dys*appearance of the body-self (as well the contingencies of *that* place at *that* time: see CHAPTER FIVE). The urge to sleep is often overwhelming. How soon people are able to rest may depend on where they are and how long their precariously re-formed boundaries can 'hold together':

Exhausted. Exhausted. Really tired, really just want to lie down and go to sleep. [I do that] when I can. I mean, if you're in the middle of an open cast [surface-level pit mine] you can't; you just go to the Land Rover and go to sleep. But if it happens where you can go and sleep, you just go and lie down and go to sleep. (Archie)

Patrick uses the time before post-seizure exhaustion sets in to ensure his corporeal self and home-space are safe and secure. He is so habituated to the embodied effects of seizures that he knows he has 'a window of half an hour to get myself in order', during which time he makes sure no fires have started (if he has been cooking: see CHAPTER SEVEN), checks for injuries that might require medical attention, cleans himself up and then makes his way to bed. This is an essential routine given what might have happened, and what might happen: 'You may have to sleep for 48 hours *after that* in the worst scenarios' (Patrick). The present therefore relates to the past and future as re-securing space takes priority over sleep, but acting *now* on what *has* happened reflects the inevitability of this half-hour 'window' shattering when time runs out.

Disturbance to Claire's proprioception often extends over the coming hours or even days: 'I can't walk after them. My legs just totally don't work. I'd say fully back to normal: about 24 hours. Like, fully back to thinking straight, not being tired, my legs being fine.' Brian revealed he was 'still trying to come back down to earth' five days after his last seizure. Such impaired bodily capacities necessitate the folding-in of recuperative time-spaces within everyday rhythms and routines. For some participants, this means taking it easy (even if this impacts on their social or professional life: see CHAPTER SIX). Several participants even resist their bodily sensations due to determination not to let epilepsy structure their lives beyond the 'time lost/lost time' occasioned

⁵⁸ If the passage of time or changing of space is not noticed immediately, spaces of evidence may become apparent later. Sleep seizures are commonly discerned when waking up feeling 'not right' or being told by one's partner. During waking hours, bodily evidence may be 'uncovered'; for example, Jennifer knew she had had a seizure when she looked in the mirror and saw 'pen marks on my face. So I'd check things out after I had the fit, to see that everything was normal and in place.' If at first there is little to signify a seizure, individuals sometimes actively check the body and surrounding space for anything out of place: 'The body would automatically go through the same check, and then maybe look for something in the room, like maybe a toothpaste knocked over. You would look for something that wasn't the way it was before.' (Gordon)

by a seizure. Holly refuses to let herself rest after a seizure, especially at work, because she does not want to be perceived as *different, less-than a good worker*:

[At] work, I have to force myself to keep going and not just sleep [...] Because of my fierce determination, I have to get on; I always push and push until I'm fully 'with it'. I've actually been told to take time out after a seizure, but I'm not very good at doing that. And I'm probably not as aware as I should be, but I just put it to the back of my mind, eventually. (Holly)

Recognising that her identity is constantly being (re)formed through the ways that she (uncertainly) performs, Holly resists others' recommendations to rest. In so doing, she disrupts their assumptions about the unstable boundaries of the 'epileptic body'. Some participants re-enforce and reinforce their borders by proactively strengthening them. Anna seeks to 'become herself again' through exercise:

The actual seizure itself is over and done within minutes. I feel like I've run a marathon with the muscles contracting; and feeling tired, absolutely knocked-out from that. [...] That can last for a couple of days after. But, you know, exercise over the next couple of days and it's gone; I feel safe, secure. It was, you know, *carry on!* (Anna)

As Parr (1999: 686) remarks, in contrast to celebrations of the fluidity of self in many geographical texts, such experiences must be recognised for how people seek peace of mind and stability by re-asserting their bodily borders and place in time-space. The job of re-orientation not only matters as the self fades back into awareness, but is implicated in how people perform beyond those moments, constrained by the emotional, social and concrete effects and affects of the seizure.

BEFORE A SEIZURE

UNANTICIPATED EPISODES

Knowing what might happen *after*, we may now consider why the time *before* the next seizure might be significant. Harrison (2008: 424) argues that 'thinking through vulnerability could affect how we think about embodiment', a thought that I would like to develop contextually in this chapter and the next. For 30% (n = 37) of questionnaire participants there is never any warning that a seizure is about to occur, hence there is no chance of being able to influence *in that moment* the circumstances of when and where it kicks in. The next thing of which the individual will be aware is what comes *after*, as discussed above. Hermann and Whitman (1992: 1137, in Livneh *et al.* 2001: 535) refer to this as a 'brutal degree of unpredictability'. Specific fears may be associated with public embarrassment, physical harm to oneself or others and even death (Livneh *et al.* 2001: 535). While this research corroborates many of these concerns, it is important to note

that being deprived of a warning does not render the person ‘helpless’. An individual’s first ever seizure sparks what becomes the first layer of temporal complexity in living with epilepsy. Put crudely, one is entered into a cycle wherein the time *after* a seizure is always the time *before the next* (unless they never have another). How people feel about the circumstances of that previous seizure in *retrospect* helps them to prepare for *future* seizures. In so doing, particular places are characterised as being more or less likely to be implicated with triggering a seizure, and more or less acceptable for losing bodily control.

As Toombs (1988: 210) puts it, the volatile body itself can become a ‘restrictive potentiality’. However, the body’s ‘field of potential’ to affect or be affected varies in different places at different times (Bissell 2010) and so must consider the importance of *place* in how seizures are experienced. Based on previous ‘events’, individuals practice anticipatory geographies⁵⁹ by keeping to time-spaces where conditions can be tolerable should a seizure unpredictably strike. Consider the following quote:

I’ve never liked busy places really, but it’s also just in case I have a fit or if something happens in a strange place. Before, I would just walk anywhere and if there was a short-cut, even if it was muddy or secluded it wouldn’t bother me, whereas now I tend to – it sounds contradictory – but stay where there’s people, but not *loads and loads* of people: just so that I have a safe route, if you like. But because I’m that used to it now it’s just something that I always do: just thinking about what *way* to go and *where* to go and *how* to go (Mandy).

Mandy regards safety as paramount and so chooses her routes carefully. She avoids places she envisages will be busy and where seizures have previously been met with negative reactions. Music festivals, for example, are now out of the question because, if a seizure turns into a medical emergency, she is worried that the paramedics may not be able to make it through the crowd (the construction of (un)safe places will be further unpacked in CHAPTER SEVEN). This directly speaks to Del Biaggio *et al.*’s (2002) findings that people with epilepsy tend to avoid busy areas so as to reduce the potential number of seizure ‘spectators’, but may look to inhabit spaces with at least *some* other people in case help is required. It also shows how straightforward dualisms of public/private should be further destabilised in light of ‘epileptic’ spatialities. The relative busyness of place depends on the time of day as well as the location, and so such spatial strategies become complex feats of planning. Indeed, time-spaces *before* a seizure are chosen both through hindsight and anticipation. Living in the present, however, is often problematic for people struggling to cope with the unpredictable body.

⁵⁹ This is a domesticated version of Anderson’s (2010: 777) account of anticipatory action as ‘made and lived in the name of preempting, preparing for, or preventing threats to liberal-democratic life’. I elaborate on longer-term temporal and spatial organisation by people with epilepsy in CHAPTERS SIX and SEVEN respectively.

THE LIVED EXPERIENCE OF BODILY WARNINGS

Auras are embodied ‘warnings’ signalling the temporality preceding a seizure⁶⁰. Intensely and complexly, they (dis)embody the individual, arresting them very much in the here and now, and compel, when there is enough time, a reaction. Of questionnaire respondents, 46% (n = 56) always sense an aura, while 24% (n = 30) do sometimes. As with those who do not experience an aura, functioning-in-place is in part determined by retrospective and prospective readings of space (Chouinard 2012, on bipolar spatialities); however, there is added complexity in that the extent to which the future need be anticipated can be shortened if the individual feels that their aura affords temporal agency in the present. Where this is the case, one can live in the here and now with greater *certainty* (albeit not unproblematically). I first illustrate the lived experience of auras, highlighting different embodiments, before moving on to discussing how individuals negotiate time-space when these contingencies arise.

Auras might spark only a vague sense of perceptual distortion: ‘Honestly, I can’t really explain. It’s just not right: your *head’s* not right’ (Renae). This ambiguity sometimes means that *other* bodily sensations are mistaken for an aura. On the other hand, auras themselves may be presumed to be something else, or ‘nothing’: ‘It’s so subtle one dismisses it out of hand. And then after the seizure you think ‘Ah! That was the warning!’ (Patrick). However, most participants find them to be sudden, intense and unmistakable; as for James: ‘It’s a feeling in my stomach. And it wells up. It’s a dizziness. [...] It’s a feeling you don’t get with anything else.’ In these moments, one experiences time-space in slow motion:

You knew it was coming, but you’re probably talking about three seconds. What you’ve got to appreciate is that time stretched: a lot went on and you felt quite calm, and you thought, ‘Well, how am I going to get out of this?’ And there was nothing you could do. It must be like when folk say they’ve seen an accident coming: for that tiny fraction [of time] before the accident happens everything seems to stay still. (Gordon)

The ‘invasion’ of the body signals disconnection from the material environment, as for Margaret: ‘Nothing seems familiar at all, it just seems alien. And then there’s this feeling of panic and all I remember ever thinking was ‘Oh no! Please, no!’ As Leder argues (1990: 1), normally action and perception is directed *out* from the body, which is seldom the ‘thematic object of experience’ – it disappears – because of its taken-for-grantedness when in sensory equilibrium. Auras (or any

⁶⁰ Auras are actually a type of partial seizure but do not involve the loss of awareness or consciousness (ES 2010). Among the various manifestations named by participants (who could experience one or more different manifestations simultaneously) were headaches, body jerks, rising sensations in the stomach, dizziness, acute anxiety, a taste in the mouth, *déjà vu*. There is a small tradition of writing on migrainous auras and artistry, in which it is identified that visual auras, such as ‘mosaic illusion’ or the breaking-up or deformation of objects, have been used as artistic inspiration (Podoll and Robinson 2000). Podoll and Robinson (1999, 2002) further comment on out-of-body experience and the splitting of the body image during aura. They draw on Todd (1955) in comparing this to Alice in Wonderland syndrome, wherein bodily disturbance and depersonalisation result in visual and temporal disruption.

corporeal disruption) force perception inwards, seizing one's attention, such that the body *dysappears* and becomes at odds with the external world⁶¹. For Brian, auras compromise his very *presence* and access to 'reality':

I said to her 'Natalie, I'm getting some symptoms here' and as I was saying it, it was like somebody else was saying it. So it was like you're getting sucked out of the bubble. You know what I mean?! It's like you're going away and it's like a kind of aura. You know that somebody's there, but it's like a wall's just been built, and *you're* inside the wall. (Brian)

This suggests 'depersonalisation by assimilation to space' (Caillois, in Grosz 1994: 47), when one feels 'temporarily strange, unreal, disembodied, cut off or far away from immediate surroundings, and one's voice sounds strange and distant' (Marks 1987: 342). There is a strong impression of Brian feeling disembodied; that he is not himself in body or mind, that the self is somehow being removed or fragmented as the body is overcome by something or someone else. There is a (dualistic) sense of his bodily borders being broken down, and yet these borders, the 'walls', are the very thing in which he is trapped: the self imprisoned in the peripheries of the body. These incongruous, paradoxical body moments, of simultaneously being removed from and ensnared in space, have a disempowering effect.

In relation to works of art, Benjamin (1936/2008: 200) asserts that 'auratic perceptions' encompass a 'strange web of space and time', a 'distance as close as it can be', and the absorption of the subject in an uncaptured atmosphere. Such inaccessible, elusive qualities (which echo debates in human geography concerning 'affects' and their subsequent re-presentations) can be linked to epileptic 'auratic space', which is deeply *embodied yet disembodied*: one's sense of self becomes out-of-reach at the very moment it is most intensely present; relationality seems to dissolve just as the body's configuration with people and place might become a 'connective event'. (Dis)embodied 'auratic space', then, is '*paradoxical space*' (Rose 1993) wherein the body-self is both centre and margin. As Rose (1993: 160) puts it, 'Space itself [is] insecure, precarious, and fluctuating [...] other possibilities, other sorts of geographies, with different compulsions, desires and effects, complement and contest each other.' Benjamin (1936/2008: 236) positions 'auratic perception' as joyously unreachable, mysterious or transcendent, where the dissolution of objective boundaries signals pure experience: 'we calmly and adventurously go travelling'. This sense of vital wonderment, however, does not represent the epileptic experience: when inhabiting paradoxical space individuals are rarely keen to 'go along for the ride'. The 'auratic space' in which they are enveloped is threatening precisely *because* of the dissolution of bodily

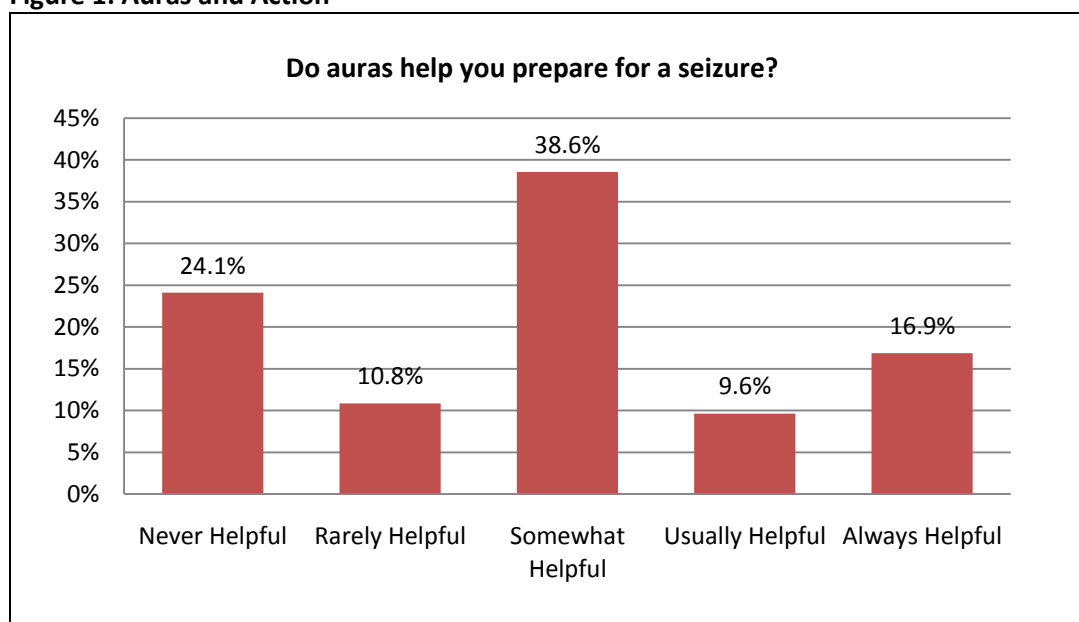
⁶¹ Conversely, auras can impact a *heightened* sense of connection with the world, as is the case for individuals who experience *déjà vu*, when time-space is experienced as radically *predictable*. Joan revealed how 'somebody would be speaking to me, but I would hear it as if it was a film script from a video I'd heard many times'. Kate spoke of being transported into a *déjà vu 'place'*, which, while familiar, resembled a 'horror film' wherein space and time were warped and threatening.

boundaries. Thus, while Benjamin contrasts the joys of auratic perception (as authentic experience) with mechanical re-production (which strips all aura), people with epilepsy often desire that regulation, or ‘mechanisation’, of their bodily boundaries to delimit their inside and outside, and reproduce the socially-acceptable self. Following Glass (1989) and Parr (1999), we may say that to be positioned and stable within the self is desirable and serves as a blockade to ‘invading’ epileptic forces. It must be noted, on the other hand, that auras can be empowering in so far as they offer the possibility of influencing the time-space in which the body loses control.

... BEFORE TIME-SPACE RUNS OUT...

Time and space are key to how participants respond in those limited moments before a seizure. **Figure 1** shows, relatively, the helpfulness of auras in allowing questionnaire respondents to prepare safely:

Figure 1: Auras and Action



Those for whom auras are little help usually reflect on how brief they are. Debbie recalls being rooted to the spot: ‘It’s just like a panic. I don’t even have enough time to think. [...] You think ‘Oh, that’s what’s going to happen’, and then that’s it.’ In some cases auras are just long enough to place the body in a safe position, as for Claire, who will ‘lie on my side and just get into the recovery position.’ On one occasion, Ian had enough time to alert his friend to an imminent seizure:

I was able just to say to George, ‘Here’s my wife’s phone number. Can you tell her because I’m not feeling well?’ And I gave him the phone, and I heard him starting to speak to Kerry, but then, after that, I was just *out*. (Ian)

Here it must be noted that telling other people is dependent on *who* is there, since several individuals spoke of their reluctance to approach strangers to share their warning.

Around 31% (n = 28) of questionnaire respondents are at least sometimes able to resist a seizure's onset through bodily struggle. Despite its precariousness, a common technique is to calm oneself down by taking deep breathes, which can prevent or delay a seizure. Renae confronts oncoming seizures by focussing her energies inwards:

I'd just try my best to react against it. And sometimes, *mentally*, I'm *fighting* it, knowing that it actually could happen. [... I] get somewhere and sit down [and say to myself] 'You're not going to beat me!' (Renae)

As Renae's comments show, resisting bodily forces is part of the *confirmation* of her corporeal boundaries. Rather than meet the seizure head-on in 'battle', several participants feel that mental displacement is the best preventative measure. Concentrating on counting numbers in different sequences, for example, can defer the sequential void of a seizure. This is itself a spatial strategy in that the individual denies the seizure a 'place' to gain hold while the mind is focussed 'elsewhere'. Conversely, Sue focuses *outwards* as a way of delineating the material borders of things and so her relationship which space (which is disrupted in 'auratic space'):

I always seemed to have a capacity that could 'hold on', so I kind of dug the nails in, would sit and kind of question myself: 'Who's this sitting here?' – it's a stupid question – 'I wonder where he's bought his shirt? Would it be the same size as my husband's, or would it be smaller? Why's he got those shoes on and not black shoes on? Is this an IKEA sofa?' Just asking myself ridiculous questions – that kept me in control. (Sue)

Interacting with other bodies can also assist in establishing one's own. Patricia finds that if other people speak to her she is able resist a seizure, although she is also aware of her 'unusual' request being reliant on the goodwill of others. Patrick's family have all learned to read the bodily signs of his aura, at which point *they* seize his attention: 'They say 'Concentrate, Patrick!!' to make me alert. They make me think; they startle me into existence, as it were.' 'Auratic space' hence makes the boundaries of things hazy, such that the individual struggles to gain a hold of the situation (whether 'internal' or 'external' to the body) and their place within it. At stake is one's continuing relationality with people and place.

The above examples are all of squeezed 'auratic' time-spaces, when the perceived range of resistance options is limited to the immediate body-self and surroundings. Auras, however, are usually beyond bodily resistance, but may extend over the course of minutes or even longer such that a repertoire of spatial strategies may be accommodated. In their most stretched form,

people can wake up knowing that ‘today something might happen’, and may then have the opportunity to structure their day in ‘auratic time-space’ as they see appropriate:

There was a clear sequence of events: I would have a night with my feet restless, and swallowing, and grinding my teeth in my sleep. And then I would wake up and maybe get an aura. [...] Those were the symptoms I could spot at the beginning, and that was very handy. Very handy indeed: I’d stay in [the home]. (Joan)

Joan uses enclosure as a spatial tactic, staying inside the home when the body ‘gives notice’ of its unpredictability. Similarly, Jennifer reveals how she will ‘keep myself to myself’ so as to contain the body from ‘external’ intrusions. Such enclosure is the expression of ontological security through the dualism of ‘inside’/‘outside’. Unregulated boundaries in our actions with others, Sibley (2001: 247) argues, can be ‘a source of anxiety’, hence the unruly body is discouraged from ‘taking up space’ or ‘making its presence felt’ (Young’s [1990] phenomenological account of femininity; Rose 1993, on womens’ oppression). Here we might usefully draw on the ways Davidson (2003) and Bordo (Bordo *et al.* 1998) describe agoraphobia as a sort of ‘boundary crisis’. These experiences encourage avoidance tactics, whereby individuals remain in the ambivalent sanctity of the home where sense of self and environment is relatively ‘stable’ (Davidson 2000b)⁶².

When an aura unexpectedly comes on in ‘public’, individuals carry out spatial assessments (Who is close-by? Where might I be safe?) to determine their options in light of their expected ‘time limit’. Enclosure is more or less possible depending on *where* the person is at the time. For example, Jennifer felt unable to ‘escape’ from her job interview because of its socio-spatial configuration:

I would have hoped that it was just a feeling and I wouldn’t go into a fit. You can’t just say ‘Oh sorry, can we stop it here?’ and like run out and quickly get to the toilet before you have the fit. You know, the only option, really, is to stay there and have the fit. I suppose I could have said to her ‘I’m really sorry because I’ve got epilepsy and I’m about to have a fit,’ but I was hoping that I’d go out of it. (Jennifer)

Jennifer felt trapped in the interview time-space because she was already being judged on her performance; if a seizure was unavoidable, she reasoned, either staying *or* leaving would ‘expose’ her. When less confined, Jennifer will attempt to locate a concealed space to minimise the potential number of witnesses to her seizure:

⁶² Most participants see seizures as acceptable within the bounded space of the home (although this can be complicated by other factors, such as wishing to shield one’s family from the ‘realities’ of epilepsy). Nonetheless, the home-space is still potentially hazardous to the body that might lose consciousness. The priority, then, is to ensure bodily safety by moving to safe spaces *within* the home: see CHAPTER SEVEN.

I would try to go to the toilet or hide away somewhere so that I was on my own when I had it rather than being in front of people, especially if I didn't know them. [...] But even if I was with my family I'd still sometimes try and just go to the toilet. [...] There was quite a few times when I'd get the feeling that I was going to have a fit and then go to the toilet, but only get half-way there, and actually have the fit before I actually got the toilet. So I did actually have it, you know, out in the open. So that was very unfortunate. (Jennifer).

While auras can empower the individual to resist the onset of a seizure or prepare the body in some way, they can also 'betray' the individual's sense of agency, leaving them exposed. Nevertheless, most participants refuse to eradicate all sense of risk, resolving instead to work *with* the unpredictable body by making *space* more predictable (see CHAPTERS SIX and SEVEN for elaboration on the ways individuals routinely plan their everyday time-spaces). As Patrick reveals, 'If I'm alone, I do research beforehand. [...] But] I can't just go and do things off the cuff.' Because he experiences multiple seizures everyday (unlike Jennifer, whose intermittent episodes allow her a degree of time-space flexibility), Patrick attempts to control as many eventualities as possible by planning and mapping his everyday environments. He limits his time in unpredictable, unmapped places and positions himself, as often as he can, in relation to pre-designated enclosed spaces:

If you go to town, etcetera, I think 'Ah, yes; *those* shops have a loo; and *those* shops have a loo.' And there's loos in the gardens and things like that. You gear yourself to loos [...] because you've got a very short window before all hell breaks loose. (Patrick)

Patrick's on-going cognitive mapping of public environments means that his spatial separation from enclosed spaces can stretch anywhere within a radius based on the parameters of how long his aura might be and the time it might take to reach his destination ('toilet mapping' is also referenced in literature on people with 'overactive bladders': Milsom *et al.* 2001; Miller and Hoffman 2006). These relational time-space spheres construct a kaleidoscope of constantly shifting and overlapping contingency plans on which the agentive individual may draw. Escaping to enclosed space means containing the unruly body within a protective cocoon. These spaces 'hold firm' when the body-self becomes unbound, and offer a secure location in which the individual can 're-materialise' on their own terms, in their own time, and in their own space.

The mixing of short- and longer-range time-space trajectories associated with anticipating seizures is *embodied* through individuals' routines, and this should be considered as inherent within the remaining chapters. Here, I hope to have shown that 'auratic space' is liminal and uncertain. When in 'auratic space', the relatively bounded materiality of the body and its relational social presence is destabilised because of the fear of an 'excess of possible futures' (Bissell 2010: 86). Epileptic spatialities, here denoted by 'enclosure' and 'interiorisation/exteriorisation', hence aim at closing down those possibilities and (re)securing the

self rather than embracing the multiplicity of possible becomings and identities occasioned by 'auratic space'.

DURING SEIZURE

Whether or not a person experiences an aura, once the seizure begins they will usually be rendered unaware or unconscious (depending on the type of seizure they have). As Ian puts it, 'it's lights out', and the individual enters a timeless, non-cognitive, non-relational state of (human) being. Reflecting on embodied vulnerabilities in such states as insomnia and exhaustion, Harrison decries the 'difficulty if not impossibility in understanding the significance – theoretically, politically, and existentially – of 'regions of existence' that are 'radically unwilled' (Harrison 2008: 424, quoting Butler 2001: 36), 'phenomena which intimate the end of intention and action and which trace a passage of withdrawal from engagement' (ibid.). During seizure, when bodies are overwhelmed by neuro-biological processes, the abilities of self and others to make sense of the experience somehow always fall short. Holly's words are illustrative of a range of participants' testimonies: 'My concept of a seizure is *nothing*. I have no concept of time whatsoever throughout the whole time.' As such, for those whose lived experience is similarly suspended in time, it is the 'before' (if an aura is experienced) and 'after' that gives the seizure meaning. A number of interviewees, however, were able to paint an impression of *something* that they had experienced; although it was difficult, if at all possible, to put its sensational geographies into words. Recollections of seizures are akin to not quite remembering a dream (Pile [2006] has discussed 'dream space'). Indeed, participants frequently qualify that stories cannot do justice to the otherworldliness of their ambiguous impressions, vague flashes of memory, swirling colours, curious sensations, unthinkable terror, euphoria, emotions too distant to name. Undeniably, deciphering the individual's experience of spatial reality is messy and always incomplete; but, as Parr has argued (in relation to delusional experiences: 1998, 1999), unconscious processes are in themselves embodied in time and space and deserving of attention.

Medical definitions and typologies of seizures, to be sure, privilege the descriptive account of the *witness* – detailing what the seized body does – and readings of the brain's electrical activity through technological apparatus⁶³. Rarely do studies address the experiences of individuals in seizure (aside from projects examining 'unusual' seizure manifestations, such as hallucinatory states, e.g. Elliott *et al.* 2009). Denying the 'internal' experience of seizures *doubly* disembodies the individual, for not only is their body rendered asocial, their reality is coded as an 'untruth', something to be glossed-over. The supposed 'truth' of the seizure lies in what can be

⁶³ Latour and Woolgar's *Laboratory Life* (1979) describes how scientific practices, deploying various 'inscription devices', construct scientific 'facts', a form of (technological) witnessing.

observed and classified so to distinguish epilepsy ‘type’ and suggest treatment options. **Table 6**, below, displays typical seizure classifications.

Table 6: Seizure classifications (Source: <http://www.webmd.com/epilepsy/guide/types-of-seizures-their-symptoms>)

<p style="text-align: center;"><u>Partial Seizures</u> (Produced by a small area of the brain)</p> <ol style="list-style-type: none"> 1. Simple Partial (awareness is retained) <ol style="list-style-type: none"> a. Simple Motor b. Simple Sensory c. Simple Psychological 2. Complex partial (awareness is impaired) 3. Partial seizure with secondary generalisation 	<p style="text-align: center;"><u>Symptoms</u></p> <ol style="list-style-type: none"> a. Jerking, muscle rigidity, spasms, head-turning b. Unusual sensations affecting either the vision, hearing, smell, taste or touch. c. Memory or emotional disturbances <p>Automatisms such as lip smacking, chewing, fidgeting, walking and other repetitive, involuntary but co-ordinated movements.</p> <p>Symptoms that are initially associated with a preservation of consciousness that then evolves into a loss of consciousness and convulsions.</p>
<p style="text-align: center;"><u>Generalised Seizures</u> (Produced by the entire brain)</p> <ol style="list-style-type: none"> 1. Tonic-clonic (‘grand mal’) 2. Absence (‘petit mal’) 3. Myoclonic 4. Tonic 5. Atonic 	<p style="text-align: center;"><u>Symptoms</u></p> <p>Unconscious convulsions, muscle rigidity</p> <p>Brief loss of consciousness</p> <p>Sporadic (isolated) jerking movements</p> <p>Muscle stiffness, rigidity</p> <p>Loss of muscle tone</p>

I include this table to contextualise the research materials and show how different seizure typologies are *experienced* (perhaps ‘internally’, but generally as observed by others), as well as noting the social implications of their embodiment. Indeed, the mechanical descriptions above capture little of how seizures are felt.

Seizures that do not impair awareness have an affect, to varying degrees, on one’s embodiment:

What an absence seizure feels like – now that’s not good. [...] I have a kind of octagonal, four-dimensional shape at the back of my mouth that I can sense. I can vaguely see it. The rest of my thought patterns are confused, very confused. [...] I’m conscious of absolutely everything, but there’s an appalling sense of anxiety; but it isn’t like other anxiety. It’s an acute and very specific anxiety, and it’s very, very hard to explain any further than that (Sue).

Patrick’s conscious seizure experiences are coloured by potential injury to the body-space, which is both in *and* out of control:

With another type of seizure that I've had, 'falling epilepsy', I've lost control from the waist downwards and remained conscious. But that is one of the scariest types of seizures because you know what is happening but you cannot do anything about it. [...] You've just collapsed on to the ground and all you can do is try to drag yourself with the arms into a better position so that you don't hurt yourself; or, as you're falling, cover your head so you don't bang into anything as you collapse. *That's* the scary thing (Patrick).

Losing control of any part of the body is frightening as well as potentially problematic for one's socio-economic status. Steve's seizures can paralyse his ability to speak and so interact with others. This happened, notably, when chatting with a guest on-air during his radio show. Reflecting on this experience, he comments, 'It's embarrassing, and it's blank air on the radio. You don't want that.' His perceived ability as a DJ, in filling air-space, may then have come into question. Another interviewee, Archie, also experiences speech and limb paralysis, most frighteningly when he was driving with a passenger (although he regained control before a necessary stop or turn. With a different seizure type, Archie's body-space is disrupted by hallucinatory experiences. In the following excerpt, his fear can be matched by an awareness of the historical-situatedness of prospective social implications:

This female appeared to me: she had no face, no boobs, no outward characteristics to say that she was female; but I knew she was female. It was a feeling of the presence of her being there. I'd be sitting here [at the kitchen table], and I would feel it, and then I would look, and then I would see her. I never told anybody that until last year. [...] *You* don't see it, my *wife* doesn't see it, *nobody else* sees it; and I bolt out of this room because I'm terrified. (Archie)

The boundaries of Archie's world are broken down and overrun by another, but, as he is aware, this is an experience not shared by others, and, moreover, always happening in private space. This problematises the notion of private, enclosed space always being a place of refuge, where the threatening 'outside' may be held at bay. The body is considered the private space of the self *par excellence* and yet it provides no defence against invading forces when awareness is retained during seizure. For participants who lose consciousness during seizure, their vulnerabilities are momentarily relocated, a theme to which I now turn.

SPATIAL ANALOGIES OF UNBOUND EXPERIENCE

Participants frequently use metaphors and similes to explain their unconscious subjective experiences to me and, I suspect, also to themselves. They hesitate and tell me, 'it's difficult to explain what I feel' or 'it's difficult to explain to someone who's not experienced it'. Their subsequent impressions are accordingly of 'the very experiences that language fails to articulate'

(Pile 1996: 62). Nevertheless, metaphors help people to *re-embody* their absences (which momentarily seem to sever ties between the mind and body). Gesler and Kearns (2002: 73) comment that doctors and patients use different 'grammar', and that the patient is usually forced to translate their experiences into clinical language, even if much is lost in translation. Hence there are potential benefits for health care professionals who recognise and work with the metaphors that people use, even if the 'pluralism of possible interpretations' (ibid.) reduces the 'certainty' of pre-defined categories. In explaining what the feeling of being unbound in and between the body and space is *like*, participants draw on spatial analogies. These subtle expressions are revealing of what epilepsy *means* to the individual.

Of course, seizures can instigate radical disembodiment such that the self momentarily ceases to *exist*:

Niall: So can you talk me through almost what it's like to be in one place, and then...

Laura: What it's like to be there and then disappear?

When the self vanishes, the mind/body are rationalised as components of a computer system or video player: the inner mechanics – one's neurobiology – sometimes fails or is turned off such that the interface – the self – will shut down before re-starting: 'The brain has re-booted itself' (Patrick). Objectifying the body as a broken-down machine or system helps people to make sense of the chaotic body and, of course, trust in its restoration:

I've had the absences that are transient and pass: I could just be doing something and then stop; and my husband used to say 'It's just like stopping a film: you're doing something and then you stop.' [...] I think you're just completely not there at all. It's weird, you just shut down, everything just shuts down; and then it switches on again. (Margaret)

For Patrick and Margaret, there is no 'experience' to speak of because the self here is devoid of time-space. A seizure, then, is not so much a mechanical breakdown as a disintegration of one's world (Toombs 1988: 207). At such time, various other participants are transported to *another* place as their social being in *this* world diminishes:

The person [having a seizure] is almost certainly aware of your presence or your voice or something about you; you know, you're still there for them, it's just that there's another universe going on in their head as well (Sue).

Sue describes absences by suggesting a multiplicity of selves that are 'within and outside of the mind and body' (Parr 1999: 679). For Robert, the treacherous body condemns the self to 'other places' that are frightening and torturous: 'It's like going through a hell [... with the] body 'killing' itself.' The sudden and excruciating transition within one's subjective space causes embodied

experience to become *unheimlich* (Freud 1919; Wilton 1998; Davidson 2000a: 646). The 'new' world fractures the link between objective and lived space and saturates one's entire existence, robbing the self of agency. The feeling that somebody or something *else* is stealing one's life away from them is hence common:

Imagine if your life is on the dark carpet there, right. Your whole life: all your hopes and dreams and aspirations are on that carpet. And when you take a seizure it's just like somebody doing this with the rug [motions pulling the carpet away from under my feet], and then you just feel like you're dropping down an endless pit, as if someone's just taken everything away from you. (Brian)

Analogies frequently allude to free-falling. In a literal sense, the onset of a seizure might cause a fall; but the metaphor runs deeper: free-falling suggests that the unsupported body is at the mercy of forces and space both *external* to and *enveloping* of the self. As it falls, the body will instinctively scabble to hold on to something to arrest its tumble 'down a cliff' (Patricia), yet in seizure the 'abyss' is not a tangible geographic space so much as a rift in its fabric (Davidson 2001a: 218).

CONCLUSION

My intention in this chapter has been to explore a nuanced phenomenology of seizures. The multiple embodied experiences re-presented here take place at the intersection of different bodies, objects and time-spaces, and so demonstrate points of connection and divergence (between and within individuals). I have not attempted to construct a universal narrative, but have embraced a multiplicity of retrospective, present and prospective uncertainties. Seizures are more than simply losses of bodily control with associated feelings of illness: the experiences related in this chapter possess inherently political, socio-spatial implications. For example, workplace managers must appreciate something of what it is like to have a particular seizure if they are to accommodate the individual. One health professional describes the ideal situation, whereby people will 'say 'Right, I know a bit about epilepsy,' – *but*, when you meet someone with epilepsy, you say – 'But I don't know about *yours*; so tell me about *your* epilepsy and how it affects *you*.'

What all participants have in common – even if their seizures are experienced and embodied differently – is that they have lived on through and after the halting of their intentionality (Harrison 2008). Consciousness, according to Merleau-Ponty, is always 'intentional'; it is always consciousness of some-thing (Davidson 2000a). During seizure, consciousness may be retained, but *awareness* is lost such that lived experience is *not* directed towards some-thing: intentionality is not only *frustrated*, as Toombs (1988) suggests, it is completely *nullified*. Seizures

hence trouble the recursive relationship between body and mind such that the body no longer seems to demarcate the boundaries of the self: it becomes 'volatile' (Grosz 1994). Participants describe seizures as having agency distinct from the body and, yet, while unconscious, the seizure *is* the body (Toombs 1990: 231, on pain). The body is hence experienced as out of the control of the self. As a result, trust in the sanctity of one's corporeal borders is radically unsettled, giving over to existential crises surrounding ownership of the body. Inhabiting this paradoxical, 'auratic' space, where the body is 'me but not me', is not so much a mind/body split as an erosion of the boundaries by which one defines self and space. The individual experiences 'a heightened consciousness of space and place and [one's] body's relation to them' at the same time as 'the feeling of losing one's place in space and time' (Bordo *et al.* 1998: 74). This happens at each point of the overall seizure experience, albeit in different ways.

The individual is curiously (dis)embodied as their anchorage in the world is destabilised *before* a seizure, and as they seek with every sinew to reclaim their place in time-space *after* a seizure. *During* it, their being-in-the-world is profoundly affected as the self is suspended in time or transported into a netherworld. Such disruption in experiences of the time-space continuum throws objective and subjective time⁶⁴ (and space) into stark relief, giving rise to feelings of loss to which the seizure is culpable. The dimensions of everyday life consequently take on a different character, with the individual perhaps preoccupied with past experiences, trapped in the present moment, or living in anticipation of negative potentials. This is experienced as a chaotic disturbance in one's world, with resulting disruptions to the rhythms of bodily temporality (Toombs 1988: 213) and environmental perception. Rather than 'accept their fate', people resourcefully construct a multitude of overlapping time-space spheres, which revolve in relation to each pre-determined enclosed space, and so seek ways *around* (by negotiation, (re)organisation, reconfiguration) the disempowerment brought on by seizures.

Seizures 'signal a fragmentation of the purposive and the wilful and an exposure of the self in and to its corporeality as subsistent substance' (Harrison 2008: 433). The vulnerabilities of people with epilepsy are a challenging addition to how we theorise embodiment, unsettling of geographies that assume deliberate, conscious action as an organising principle. The phenomenological description of seizures is crucial for understanding the bodily and existential challenges faced by people with epilepsy, yet this only tells half the story. Indeed, we require a complementary and nuanced picture of the ways in which the performance of self (certainly *after* a seizure) is shaped by, and shapes, inter-subjective relations. This is not to suggest that the phenomenological accounts of Merleau-Ponty (who writes of the *sociality* of space: 1962, 1968), Leder (1990), Zaner (1981), Toombs (1988, 1992, 1995) and, more recently in geography, Davidson (2000a) do not recognise the impact of the gaze of the 'other'. Davidson and Milligan

⁶⁴ The unsharability of subjective time in itself reveals a limitation of my interpretive scheme: participants drew upon objective time to communicate the lived experience of 'inner' time.

(2004: 524), for example, discuss how 'space is populated with the complex and often contradictory emotional projections of others [resulting] in experiences of unbearable intensity and distress that challenge the very boundaries of the self.' I am suggesting, however, that it is possible to develop a more vibrant and differentiated geography of emotion and affect surrounding 'ill subjectivities'.

By conceiving of a phenomenology that circulates both inside and outside of the subject – a *de-centred* phenomenology – we may construct a fuller picture of the seizure experience, the job of which has been started, but certainly not finished, in this chapter. During seizure there is usually a phenomenological void, a non-experience; yet for seizure witnesses, this is certainly not the case. When the person with epilepsy regains awareness, the socio-embodied world is a changed place, and the 'cause' of this sometimes drastic change, the epileptic body, can only be known through *others*. Witness' stories of seizures do not convey some inherent 'truth' but convey their impressions of the unruly body as a simultaneously social, discursive, corporeal entity. In CHAPTER FIVE, I address the impact of others' reactions and representations on the ways in which individuals interpret and respond to their (a)social body.

CHAPTER FIVE:

EMBODYING (THE POTENTIAL FOR) DISORDER: THE ANARCHIC BODY IN SEIZURE

And then it's so embarrassing for those at work, not me;
I don't remember, so it doesn't worry me.
But other people get upset,
Don't like to see me flail about
With jerking limbs and staring eyes,
Forcing the unmentionable
To the attention of those who would deny.
They do not mean to be unkind,
They just prefer to turn their blind eye on my situation
And pretend I don't exist – less than normal man;
While I pretend I do not care,
And hide my inner hurts as best as I can.

(Excerpt from 'Living With Epilepsy' by 'Patrick', reproduced with kind permission)

[W]e can also speak of a living person as uncanny, and we do so when we ascribe evil intentions to him [sic]. But that is not all; in addition to this we must feel that his intentions to harm us are going to be carried out with the help of special powers [...] The uncanny effect of epilepsy and of madness has the same origin. The layman sees in them the working of forces hitherto unsuspected in his fellow-men, but at the same time he is dimly aware of them in remote corners of his own being. (Freud 1919: 243, in Wilton 1998: 177)

INTRODUCTION

When an anonymous questionnaire respondent states, 'The consequences of epilepsy can sometimes be more problematic than the epilepsy itself!', there is clearly more at stake than the physical pain or time-space confusion embodied in or after seizure. Within the ever-expanding social science literature on the stigma of epilepsy (Jacoby 1992, 2002; Magiorkinis *et al.* 2010; Kobau and Price 2003) there is a largely unquestioned assumption that seizures *are* disturbing for others. Jacoby *et al.* (2004), in a study of public attitudes in the UK, found that 90% of people without epilepsy think that 'it is frightening to see someone having an epileptic seizure' but do not elaborate on *why*. This chapter explores the situational dynamics that contribute to the stigmatisation of seizure disorders. I investigate the reactions of witnesses to seizure 'events' and how this impacts on the social relations (and their seeming breakdown) emergent in the situation, but also on a wider level (implicating both the individual and society). Building on CHAPTER FOUR, central questions here concern the significance of seizure events beyond their status as an 'absence' of consciousness/awareness and intentionality. I hope to show something of the

cultural construction of responses to the ‘epileptic body’, and how different people bestow meaning upon it (Honkasalo 2001, on pain). Thus, an aim of this chapter is to elucidate how people come to cognise and perform in response to the moment of their own seizure. The manner in which information is relayed about the seized body, where, when and by whom, is a significant aspect of identity-forming processes for the person with epilepsy (and other). It must be further recognised that witness accounts are not only important for how seizures might impact on the social and psychological well-being of the person with epilepsy, but also for gaining an accurate medical diagnosis. As one epilepsy professional explained, ‘different epilepsies have different treatment implications; and in some cases being on the wrong medication can make your epilepsy worse [...] Doctors don’t see seizures – they’re totally reliant on you telling them what you experience or an eye-witness account.’

By illustrating the responses of others to epileptic episodes, but in the words of the people with epilepsy themselves, my focus is reliant on how perceptions of the *more-than-individual* impact on (inter-)subjectivities. While it is problematic to make assumptions about ‘knowing’ how witnesses *feel*, the significance here is how people with epilepsy interpret and respond to the meaning of epilepsy as perceived through witnesses’ (un)conscious performances in relational social space. The writing that follows, then, may be labelled a ‘de-centred phenomenology’, that claims not to ‘give a direct description of our experience as it is’ (Merleau-Ponty 2002: vii, in Munro and Belova 2009: 88) but a ‘version’ of events that recognises challenging ‘body moments’ as simultaneously personal *and* inter-personal, material *and* discursive.

The challenge for this chapter is to move from the ‘inside’ view of seizures (with its broadly phenomenological framing in CHAPTER FOUR) to the ‘outside’ view so as to recreate the basic ‘sociology’ of the seizure ‘event’ in how it enrolls not just the person seized, but also (often) a cast of others and a local ‘ecology’ of place. In re-presenting the often disturbing, confusing, frightening, incoherent interactions between bodies during these radically ‘ungoverned’ moments (when ‘regulatory social fictions’ temporarily dissolve: see Butler 1988), I utilise notions of ‘affect’ to imply particular felt changes in emotional intensity. This position seeks to engage with recent conceptual debates in human geography concerning emotion and affect (Pile 2010) so as to advance our thinking about socially-mediated ‘events’ as being ‘simultaneously felt and thought, embodied and abstract, affective and emotional, performative and representational, personally experienced and relational’ (Bondi 2005b: 22). Emotional geographies are understood as intrinsically fluid, embodied and relational (Bondi *et al.* 2005), while affect (especially as conceptualised by Harrison 2007; Bissell 2010) represents an unexpected, excessive ‘charge’ of inter-corporeal emotion made possible by the (uncanny) openness of bodies to one another and space. Seizures push the limits of the abilities of self and others to make sense of the experience of illness. De-centring the individual with epilepsy is a means to assessing the body-subject that is

of the world, enfolded *with* it and emergent *from* this recursive co-implication (Wylie 2006). As such, the precarious borders of the body are not merely 'felt' internally: 'auratic space' breaches the boundaries of the epileptic body, emerging affectively in and between different bodies and space.

Theorising the 'moment' of a seizure leads on to a different kind of conceptual framing. Understanding affects, in this case, as socially-produced (*not* pre-discursive), cultural responses to embodied 'difference' acts as a bridge in moving from the (de-centred) phenomenological to the (social-)psychoanalytical (after Douglas 1993; Kristeva 1982; Sibley 1995; Wilton 1998). Indeed, the affective relationalities of these disturbing body 'events', as necessarily circling between bodies and across spaces, seem to destabilise the bodily boundaries of the *witness*, as if mirroring the bodily experience of a seizure. This recognition is one route to deconstructing the 'inside/outside' binary, holding in tension the immediately and intimately experienced body with wider forces in the realms of 'public space'. It further offers possibilities for commenting on *the effect of affects*, especially in how sanctions are imposed to safeguard against the spatial transgressions of 'ugly', 'unruled' bodies because they not only inappropriately threaten to inconvenience, harm or 'contaminate' witnesses but also embody the potential for wider social (and moral) dis-order (in certain spaces more than others). I finish by conceptualising the 'anarchic body'. Anarchy is often equated to 'chaos', the opposite of 'order' and 'unpredictability', but, as a political term, 'anarchism' represents the state of being without a leader. The anarchic body, then, is a body that momentarily loses its 'ruler', the rational cogito or ego, and so becomes 'matter' out of its appropriate cultural place.

RE-ENCOUNTERING THE DISRUPTED BODY THROUGH OTHERS

SEIZURE REACTIONS AND THE (UN)FAMILIARITY OF PEOPLE AND PLACE

Bodily performance in everyday life is often uncritically privileged as an act in and between self-conscious agents. Seizures trouble this assumption because the self unconscious is un-self-conscious for that moment. Indeed, the individual in seizure is less immediately, if at all, perceiving of its variable affects than its witnesses⁶⁵. As an epilepsy charity worker, Sylvia, told me,

When we get the partners, family members, parents phoning. Yes, they're worried about implications [of epilepsy]; but they're more freaked out because they're watching seizures happen. But the person with epilepsy doesn't know what they look like when they're having a seizure. They very often don't have a sense of how scary it is to see, especially a tonic-clonic seizure; or how

⁶⁵ To my knowledge, the experiences and feelings of actual seizure *witnesses* is yet to be researched.

strange it is to see them have a complex partial, when they're wandering around and doing bizarre things and undressing and plucking at their clothes.

While the person coming out of a seizure cannot describe the 'electricity' conducted between *their* body, as it clattered to the ground or was rendered silently 'absent', and those of unsuspecting *witnesses*, the subsequent embodied, emotional geographies of both are mutually implicated. The individual with epilepsy may be absolutely mortified by reactions to their momentarily 'unruled' body. For Patricia, 'It's horrible. I mean, other people know more about what you're doing than you do yourself.' But, for the witness, seeing is not necessarily comprehending: in that moment, it is not so much about what the body in seizure *is* as the *affect* it has on the immediate configuration of people and space. During those fleeting instances, witnesses, like the individual seized, cannot unproblematically be considered as reflective subjects in full control of what they are doing; they may act on intuition and do things that they cannot explain rationally (Macpherson 2010: 5). For example, as one Epilepsy Specialist Nurse (ESN), Sharon, explains, 'you ask [the relatives of people with epilepsy] 'Can you describe what happened?' and they say 'Well, no, I ran away!'" For the witness, perception is never neutral, nor can it exist outside of how one responds. Yet, as Taylor (1997: 264, in Stoddart 2009: 3) puts it, "Looking' is always an intervention, whether we like it, or accept it, or not. Not intervening, turning away, is its own form of intervention [...] Our choice is how, not whether, to participate'. Thus, the affects emergent in the time-space of a seizure always compel reactions by witnesses close-by, but these are by no means inevitable (especially given the range of embodied manifestations of seizures).

A common response noted by participants is for strangers to stand over the body and stare, perhaps dumbfounded by the spatial disruption of an unexpected corporeal 'performance'. Laura explains: 'When you come-round from having a seizure you are still a bit embarrassed⁶⁶, especially because usually there are people staring. A lot of people stare.' At the extreme end of the scale, witnesses are *horrified*. Laura describes how:

I've also come-round and there's been people crying. That's because *they're* upset, because *they've* never seen it before. I think it can be quite upsetting for people to see somebody drop and having a fit, especially if you're out, thrashing around and things. It's not very nice.

Oftentimes the anxiety of witnesses exceeds that of the person recovering:

When they see it, people that we know look at me [and ask] 'Are you alright? Are you alright?' [...] It's like 'What's all the fuss about?' Just let me get up, dust myself down, and let me get on with it.

⁶⁶ In the transcript of all 28 interviews, the word 'embarrass'/'embarrassed'/'embarrassment' is uttered 106 times (and 22 times in 'open' questionnaire responses), hinting at the social consequences of the 'unruled' body.

[...] It's the fuss that people make. It's other people that can't cope more than me. That's always been the case. (Alan)

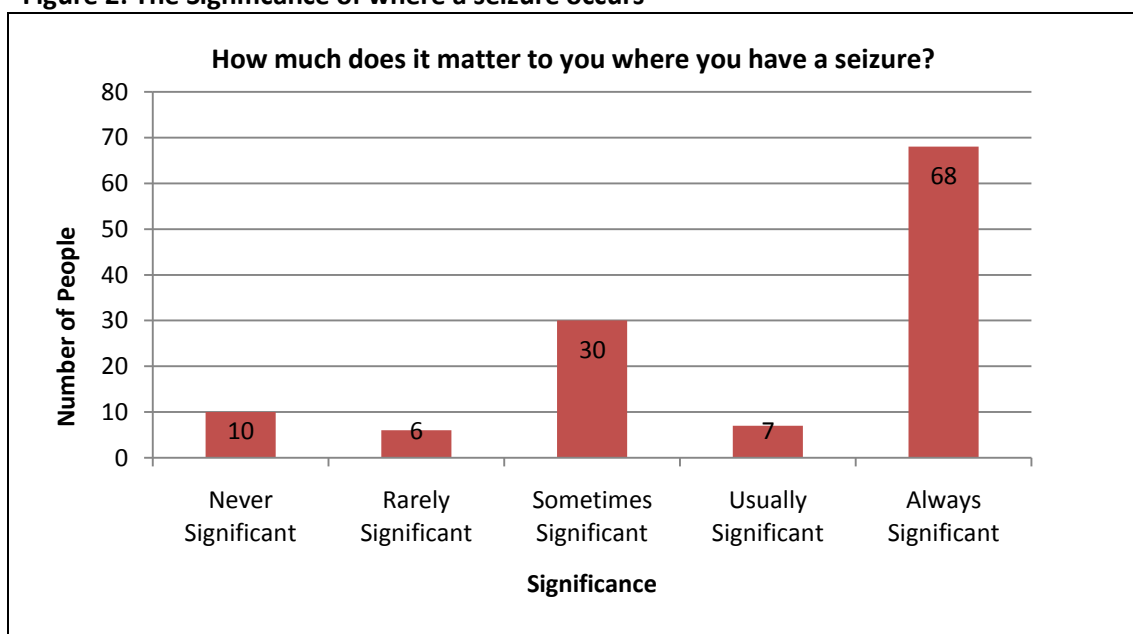
The reactions of such witnesses perhaps represent an overwhelming urge to help 'contain', 'put right' and 're-assemble' the dis-ordered body; yet, for Alan, such emotio-spatial projections on to his 'unruled' body are disempowering. Patricia states that 'The response of other people was more significant than *where* I had seizures'. She elaborates:

I came round to all these faces just looking down at me, which was really frightening. And people staring: oh, they think you're drunk. People don't know how to respond. And let's face it, people stop and look at accidents if they see something unusual. And that makes you feel even worse, because everybody's looking at you. It's very belittling. (Patricia)

Patricia perceived being 'looked down on' both in the literal and metaphorical sense. Her altered spatial configuration – literally, her lying on the ground with others, standing, gazing down at her – led to her 'waking up' to confused, but intense, affective relations with others, leaving her feeling 'exposed'. This spatial metaphor indicates that the significance of other people in shaping the seizure experience *cannot* be separated from space and place.

Robert describes how seizures are '*always* embarrassing, and place and time can affect how badly the seizure affects you.' In emphasising 'place and time' over, say, any physical effects, Robert is referencing the ways other people respond. Even when the physical intensity of different seizures is comparable, affective relationships shift contingently and contextually such that separate, differently-located seizure experiences have a greater or lesser impact on the self. This notion is overwhelmingly corroborated by questionnaire respondents, as shown in **Figure 2**:

Figure 2: The Significance of where a seizure occurs



Participants find that the impact of seizures is dependent on the interweaving of embodiment, people, space and place. Affects usually seem to emerge most forcefully in public spaces⁶⁷ when surrounded by strangers whose distressed reactions intensify the embodied struggle to regain composure. However, seizing in 'open' public space is by no means a pre-condition for intense affective relations. Nicola describes how 'if it has been in a very confined space it has given people a fairly sizeable scare,' suggesting an amplified affective potential in 'close' spaces. Conversely, despite feeling 'restricted' when she had a seizure near strangers on an aeroplane, Sue's subsequent discussion demonstrates that the reactions of different people in different places are unpredictable and variable:

I obviously didn't know anybody else, [so] you just think about who can actually see you. [...] There was one gent, sort of at that angle [diagonally forwards] who could hear and could see. Because I was making funny noises and stuff, he was aware – obviously I wasn't aware of him at all. And he was a nice Glasgow man; and all that happened when I eventually tried to get up, [was] he said 'A'right hen, that didn't look good!' and I thought 'I'd marry him!' just because of the way he dealt with it. There was no drama attached to it at all. (Sue)

Indeed, various interviewees recount overwhelmingly positive experiences regarding strangers' reactions to bodily vulnerability; for instance, Margaret:

I've had seizures all over the place: in the street, in shops, in restaurants. And people have always been so helpful. It sounds unbelievable: years ago, I was walking up the main road and just before I turned the corner into the street I had a seizure there and I didn't know what had happened until I was at the front door and this man was saying to me 'Are you OK now? Where are your keys, where are your keys?' and I said 'In my bag,' and this man let me into the house, sat me down in the chair and said 'Are you alright now? Can I leave you?' And I said 'Yes, I'm fine, I've got epilepsy.' And it turned out he was a lorry driver passing, and I was having this seizure and he stopped and took me home. And he must've gone into my bag and found the address and he actually brought me home. And with things like that, I'm just amazed at how people can be, how understanding. And yet, on the one hand, he didn't know that I had epilepsy – he just saw this woman collapsing in the street.

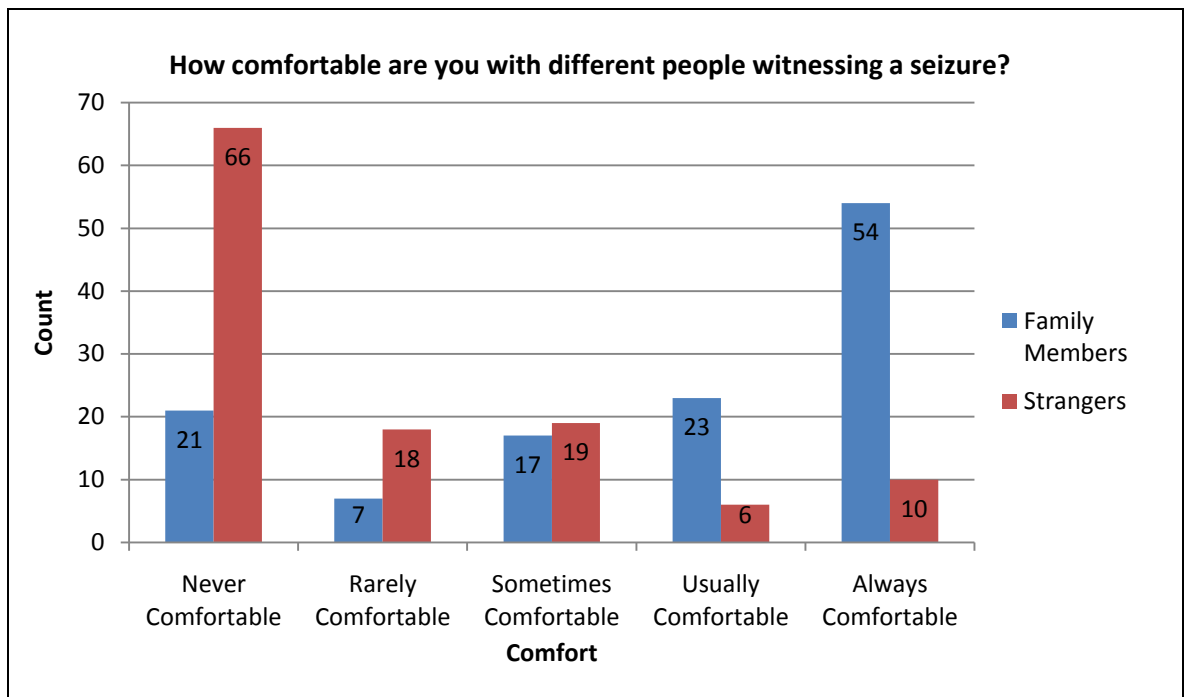
The unpredictability of how people respond indeed shows that differently 'placed' seizures are experienced contingently.

Despite these encouraging interactions, they are by no means 'representative'. To be sure, there is much more at stake than just peoples' immediate reactions. Consider the following

⁶⁷ Although I use the terms 'public' and 'private' as crudely suggestive of spaces comprising, respectively, non-intimate and intimate relations, it is too simplistic to equate these relations straightforwardly with particular spaces (i.e. 'private' = home). Indeed, the theorisation of public/private experiences of epilepsy requires more subtle distinctions than these terms traditionally represent. For example, in public the presence of trusted acquaintances generally impacted positively on seizure experiences, as discussed below.

questionnaire results, showing that some people would ‘never feel comfortable’ with either family or strangers witnessing a seizure:

Figure 3: Comfort with different witnesses to a seizure



How comfortable people feel with being witnessed is in part dependent on the (un)familiarity of witnesses. Thus, *who* inhabits surrounding space is almost as important as *how* they (re)act. This is in part due to the cultural *expectation* that strangers will be unable to understand or respond in an acceptable manner⁶⁸:

My instant reaction is just ‘Let me out of here!’ I want to get back to where I know, or whatever. And it’s difficult if some are people controlling me, because you can get quite aggressive. [...] It’s different if it’s with my family, because they’re so used to it, so I don’t feel too bad about that. But if it’s in places I’ve either not had a seizure before, or with people who don’t know enough about it and who have not seen it, that’s a bit more difficult, and you just want to try and find something you can easily *relate* to. (Steve)

The presence of dependable friends, family or professionals lowers the expected negative potential of seizures considerably, and, to an extent, lessens the significance of where they occur. Such individuals are often trusted implicitly with one’s well-being in several respects: that their initial reaction will not emerge as an intense affect; in their ability to make sure the individual is safe physically; to act as ‘knowledgeable ‘interpreters’’ (Schneider 1988: 72) for the self in the face of others; and to act as a shield from ‘jarring’ intrusions (perhaps others seeking explanations

⁶⁸ Admi and Shaham (2007: 1182) discuss how strangers are considered to hold more preconceived and stigmatising ideas about epilepsy than those close to the individual.

or trying to force the body into a 'correct', upright position). Anna relates that the majority of her experiences occur in the presence of family, who are familiar with her symptoms and so do not perceive them as 'dramatic'. As a result, they react sensitively, gently facilitating her back to awareness:

I've had so many in front of my sister, my mum. So generally, my eyes are shut [and] I'm still lying wherever it actually happened and I've just got somebody touching me constantly, just telling me what happened. So from that point, instantly I know where I am, what's happened, who I'm with. Obviously the time it happened in the shop it wasn't until the ambulance guys were taking me out to the ambulance [that I realised what was happening]. (Anna)

Ian describes how he relaxes on seeing his long-term doctor when regaining consciousness:

Apart from my family, she's one of the faces I always want to see if you're kind of coming out of a fit. You know, if it's been a pretty dramatic one, you're just glad to see her. It's almost as if she's a *constant*. You know, if she's there it's a reassuring sign: 'Oh, it's Doctor [x] – I know I'm in the right place!' [...] But then nurses are different: they change, they go off. [...] And it's really just very confusing because of the change-over. And until you come out of the fit and *grasp* what's going on around about you, then you don't kind of settle down until then. (Ian)

Even if nurses in no way act inappropriately towards Ian, their 'hollow' connectedness means he remains on edge due to the unpredictability of their socio-spatial behaviours. Here, it is not so much the emotional geographies of the hospital ward that disturbs Ian – it is the affective *potential* of unknown others.

This is not to say that trusted, informed witnesses never react inappropriately or that strangers or those with no experience cannot respond exactly as the person with epilepsy would wish; rather, that self/other relations between people with epilepsy and seizure witnesses sometimes change over time. Wilton (1998: 178; see also Dear *et al.* 1997; Sibley 1995) suggests that prolonged exposure 'weakens the social distance between self and other' and so promotes tolerance and understanding. Certainly, seizures can be extremely distressing for close friends and family specifically *because* they know the person. As a result, several participants attempt to shield others from seizures given their perceived difficulties in coping⁶⁹. Mandy, whose eldest sons' first experience of a seizure was when 'he saw blood running down the side of my face', felt that she needed to protect her family; but, over time, relaxed as she witnessed *them* growing in confidence:

⁶⁹ This further appears to have a gendered dimension, for questionnaire data shows that 33% (n = 23) of female participants are 'rarely' or 'never' comfortable with family witnessing a seizure compared to only 10% (n = 5) of men in the same category: Chi square analysis shows only a 3.5% chance of incorrectly stating a relationship between gender and comfort with family witnessing seizures

I don't think anybody's really bothered. I think my son was at the time, with that first one – because we were out in public he got a fright. [...] My husband: he's quite matter-of-fact. He'll just say 'I know you've had a fit because blah-blah-blah; you were shaking,' or whatever. (Mandy)

Nevertheless, repeated experiences of witnessing seizures does not guarantee acceptance. Claire describes how her Mum copes well in 'looking after' her, but cannot help but be affected by the horror of the contorting body:

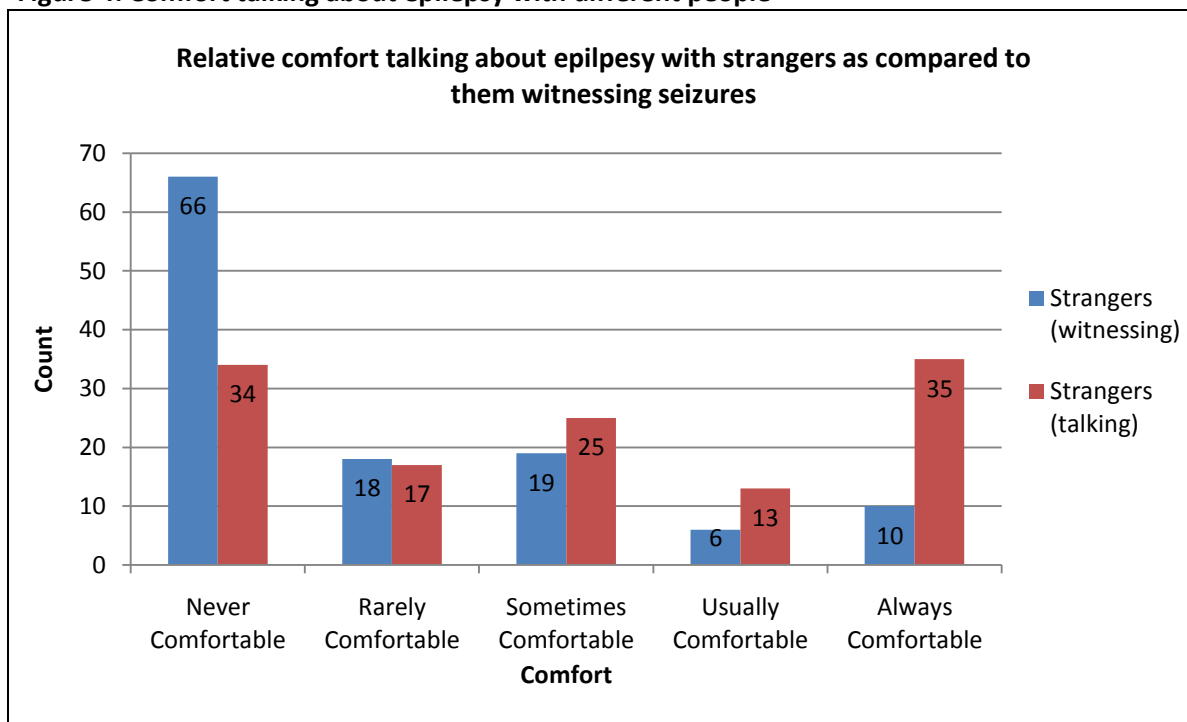
It's my Mum and whoever's there has to piece it together for me. I keep referring to my Mum because she's probably seen the most of them. She would say it's like convulsions. She says she's never seen shaking like it. Just: your eyes will roll back [...] After a seizure my hand will go into some sort of shape, and my pinkie's bent round here and all that, and it takes ages for that to sort of die off as well. [...] Obviously you lose sleep when any child's ill, but she says 'That's just the scariest thing I've ever seen'. (Claire)

For Claire's mum, these intensely 'unnatural' embodied geographies of shape, movement and sound will likely remain harrowing, no matter how 'calmly' she is able to perform afterwards. Indeed, while one can become accustomed to seizures such that the affects emergent in the situation are reduced, their 'uncanny' emotions may never be 'tamed' (I return to this notion of 'uncanny' later in the chapter).

Participants generally find others to be relatively more accepting of epilepsy 'in theory' than as its witness. In turn, many of those people are far more comfortable in divulging epilepsy verbally than for a seizure to evidence their condition. For Claire, the notion of 'seizure as spectacle' is troubling because she has no governance over it:

I'd be happy, really great, in saying to somebody, 'Well this is what epilepsy is, and, you know, you can find out more about it here, and it affects this amount of people, blah, blah, blah' – talking about my personal experience. But, at the same time, I wouldn't want anybody watching me. I wouldn't want it to be a spectator show. (Claire)

This line of thought is clearly demonstrated in the questionnaire results comparing relative comfort levels in talking to strangers about epilepsy as opposed to with them witnessing a seizure. Nevertheless, as **Figure 4** shows, there is an almost equal amount of people who are '*never* comfortable' talking about epilepsy with strangers as are '*always* comfortable'. This is an intriguing finding given that for the individual who slips momentarily 'outside' of consciousness, cognition and volition one of the few ways of 'knowing' their body for that brief temporality is through the words of others, a theme to which I now turn.

Figure 4: Comfort talking about epilepsy with different people

DESCRIPTIONS OF AND FOR THE ABSENT

Here I detail the accounts of witnesses not to undermine the ‘internal’ experiences of seizures, as discussed in CHAPTER FOUR, but to demonstrate the potential consequences of how particular witnesses describe particular bodily aesthetics following the initial affective shock. Following the breakdown of relationality, individuals must *re-encounter* ‘consensual reality’ (Parr 1999: 678); however, the ways in which the seized body is described during this re-encounter may alienate and objectify, deprive people of self-identity, and lead to agonising self-consciousness. For witnesses, seizures have an ‘inaccessible quality [...] which means that after the experience we find it difficult to testify and be its witness’ (Dewsbury 2003: 1907). Thus, ‘subsequent re-presentations are fraught with difficulties most apparent in their seeming inadequacy’ (ibid.). Describing seizures provides clues as to the ways the embodied, socially, culturally and historically-situated witness *sees* the world. Being an ‘eyewitness’ suggests testifying to something that is beyond full comprehension, yet ‘authenticating’ it ‘as it happened’. That such ‘evidence’ can be disputed suggests that no witness is ever ‘reliable’ *per se*: they are always representing a partial, situated perspective once removed from the time-space of the event. To witness, then, is not simply to see a seized body as an object of perception, but to remark upon the very otherness of how the epilepsies are embodied.

To illustrate how the re-presentations of witnesses becomes ‘self-knowledge’, consider the following excerpt from Sophie’s interview: ‘I have tonic-clonic seizures. I don’t get any warning with these – I just go unconscious and start to jerk. They normally last for around four minutes.’

Because Sophie is unconscious, the only way that she can know what her body does (jerk) and how long this lasts (four minutes) is through others' descriptions. Having multiple seizure types means compiling individual 'profiles':

[How witnesses describe seizures] depends on which kind of seizure you're talking about; because I take all types, from the smallest type to the biggest. Sometimes the petit mals are just a stare; sometimes it's just a straight black-out. And sometimes it's the real 'shakies'; and sometimes I've even had what you would say is like pulling away and tugging away at clothes and so forth. And one type of seizure, which I call a 'trance-walk'. (Renaë)

When they are relayed, descriptions are necessarily provided in a more-than-factual manner, including subjective impressions of what a seizure is *like*:

I've just been told I get a funny look on my face. It kind of looks like I'm having a stroke in that one side of my face droops. What comes out of my mouth is a load of rubbish: it never makes sense. (Sophie)

Witness descriptions indicate to the person with epilepsy that their corporeality may have transgressed expectations in social space built by and for the 'able-bodied' (Kitchin 1998). Intersubjective relations are, however, to some extent a matter of negotiation. Sometimes witnesses offer participants descriptions without being asked. Brian, on the other hand, actively seeks out detailed accounts: 'I want to know exactly what happened. What did I say before it happened? When did you notice something went wrong? How long was I out for? What happened after?'

Finding out from witnesses about one's own unconscious body-self can be an uneasy, uneven process. Identities are always-emergent performances in relation to the other and so, as Butler discusses, seeking their words is identity-forming:

To ask for recognition, or to offer it, is precisely not to ask for recognition for what one already is. It is to solicit a becoming, to instigate a transformation, to petition the future always in relation to the Other. (Butler 2003: 44)

Thus, descriptions of seizures offer information about what *is* and what might *become*. Family or friends will sometimes shield people from the 'truth' in case it is harmful to their identity, but these 'protective' measures can have the opposite effect by making seizures a taboo subject, suggesting that whatever happens *is* shameful. As several participants reveal, *not knowing* can be worse than finding out something 'embarrassing'. For example, Gordon describes how at work he found out about his seizures by over-hearing others talking: 'I only found out information by accident. It was never ever discussed.' Gordon admitted needing a 'thick skin' when he did ask

what had happened because ‘I actually used the classroom as a urinal rather than somewhere else because I was not aware.’ He felt that it was even worse finding out later – rather than immediately afterwards – because it meant that others knew and he did not; *ergo* he was deprived of a role in the management of his ‘spoiled’ identity.

Who describes a seizure certainly makes a difference. As Crooks and Chouinard (2006: 347, original emphasis) argue, ‘If bodies and bodily performances are always read and interpreted *from somewhere*, then such attributes of place as *who the audience is* matter in how embodied subjects and their performances are responded to.’ Discussing seizures with acquaintances tends to be less problematic for a sense of self as they are more likely to have an understanding of epilepsy, although it can be difficult if they were unaware of the person’s epilepsy before witnessing an episode. Even when there is not a great deal of understanding, familiar witnesses often use humour when describing seizures as a means of diffusing the uncertainty of the situation (Davidson [2001c] writes about humour as revealing of personal ‘closeness’, whether near or distant, between communicators):

I came down the stairs once, sat in a cupboard on a landing and talked away to myself. I knew nothing about it, but [my colleagues] were all laughing at me after. Because it was funny they were laughing about it, but obviously if you really got them on their own and questioned them about it, I think, you’re still one of their mates, and they don’t like seeing you being like that. (Brian)

When recounted by friends or family, Holly finds stories of her unintended bodily actions amusing:

I can say the most stupid things in my post-ictal period⁷⁰, actually quite amusing things. So I actually like people to tell me what I’ve been saying so that I can get a laugh as well. Dave [my husband] can probably tell you better than me, but I get on about all sorts of weird things, probably from my past I don’t even remember. Completely out of context and things. And I’ll try and walk through doors and things like that. [...] I know that’s a bit sick, but I find it quite funny; because I mean, it must *look* funny: someone trying to walk through a closed door. (Holly)

One time Holly locked herself out of her flat during seizure because ‘I went for a wander’ (she functioned unconsciously) and her husband later found her standing outside in her socks in the snow. In describing this situation, the couple used humour as a conscious, reflective coping strategy to negotiate their relationship, subvert stereotypes of the ‘helpless epileptic’ and relieve anxieties over potential future situations (Macpherson 2008).

⁷⁰ The post-ictal state immediately follows a seizure, during which the individual might be delirious, agitated or aggressive, and may experience co-morbid symptoms such as headaches and tiredness (Fisher and Schachter 2000).

The context in which a seizure is described can be crucial for one's sense of self. The following interview excerpt with Gavin and his wife, Mildred, is revealing of the influence that different people and place hold for his level of comfort in being told what happened:

Niall: How have people described you having a seizure?

Gavin: There's only one person who ever describes it [he looks at his wife, Mildred; we all laugh].

Niall: And what have you told Gavin about it?

Mildred: Well, they can vary. But, if it's one of the ones that are worse, you tend to be maybe making grunting sounds sometimes, and swaying backwards and forwards. That lasts for a little while. The whole thing maybe just lasts for about two minutes, the actual absence.

Niall: Do you do anything during those times?

Mildred: You can't really do anything.

Niall: Does it make you feel any particular way?

Mildred: Well, I never like it. But if we're at home together I just think 'Oh well, Gavin'll come out of it soon.' If we're outside, if you're making some sounds at a time people are being quiet, you wonder how people are reacting; but I haven't found people reacting at all strongly so far.

Gavin: It's hard to hear about that.

Niall: What is it that you find uncomfortable in hearing about it?

Gavin: Just that it's happened at all. I mean, it's a bit of my life that's gone. It's like throwing a couple of minutes of your life in the bin.

Niall: I mean, for example, that was your wife telling you about having seizures – would you feel different if it was someone with whom you're not so well acquainted telling you compared to someone you're close to?

Gavin: Oh, I'd feel even worse if it was some stranger telling me.

Niall: In what ways?

Gavin: If they're telling me at all, I'd just get horribly depressed or angry.

This conversation is instructive of a range of concerns. Comprehending the time lost/lost time of a seizure is an on-going tension for Gavin, who was diagnosed in 1963 at the age of nineteen. Even if, as Mildred explains, other people do not tend to react 'strongly', a stranger describing an episode would leave him feeling 'horribly depressed or angry'. This sense of violation means that he prefers to avoid re-engaging with the 'unruled' body. His main source of information is Mildred, his wife for over forty years; but, even then, it is 'hard to hear'. One explanation for this might be because Mildred admits that 'I never like it', and so describes seizures – and so frames how Gavin makes sense of them – in part according to what she perceives to be 'out of place' behaviour (making 'sounds at a time people are being quiet' in public). *Both* Gavin and Mildred are self-conscious of public episodes, especially those she describes as being 'worse' than others. Even if Gavin is on the 'inside' and Mildred the 'outside', the vulnerability embodied in seizure is considered a private 'body moment' that they share, but one that can also be witnessed by

strangers. Gavin is affronted by such people offering descriptions because of their unwarranted, identity-forming potential. In fact, because strangers do not know the 'real' him, they are considered to define him erroneously by that with which he would separate from the self⁷¹. When others feel compelled to remark upon seizures it testifies to the very otherness of his body and, furthermore, transgresses his boundaries as an autonomous social actor, reducing his abilities for self-definition⁷².

PEOPLE WITH EPILEPSY WITNESSING EPILEPSY

In this chapter I have so far emphasised how people with epilepsy perceive the seized body through the immediate reactions and subsequent stories of witnesses. There are, however, other ways of witnessing episodes. By viewing videos online or attending support group meetings, participants have seen *others* in seizure. This facilitates the projection of self into a seized body. One ESN, Sharon, explains, 'we find that people with seizures don't want to see somebody else have a seizure because they don't want to see what *they* might look like'; nonetheless, several participants have viewed others in seizure, and have been filled with a range of powerful, conflicting emotions:

I cry afterwards. Oh, it's just emotion; it's just raw emotion. Just: that is a horrible thing; that is such a mean, horrible thing, and I know what you feel like. And you feel rotten that someone's going to come round in whatever situation and [they'll] have to scrape themselves off the floor. [...] Not sad for them – it's just empathy, knowing you can't do anything. (Sue)

On witnessing a seizure at a support group, Patrick's disdain for the ways in which he had been treated by seizure witnesses informed his empathy, even if it was a difficult experience:

As somebody who has it themselves, however unpleasant it may be to actually see, knowing that I could actually do it myself. And that is, I suppose, the disturbing thing: the realisation that I could be doing the very same thing that they're doing at the moment. A role reversal, I suppose. But I feel it's my duty to look after them. Other people don't seem to have that civic duty. (Patrick)

For Brian and Ian respectively, witnessing a seizure was both *of* and *other* to the self (recalling a sense of 'auratic space'). They each recognised a seizure but had not previously imagined their

⁷¹ People in interviews often used impersonal pronouns, e.g. 'it', 'the body', when referring to *their* seized body. Seizures were felt to contradict the 'truth' of the self, a form of normality to which they should aspire. I would suggest that this shows a level of dissociation with the unruly body. The efforts of some participants to distance themselves from their seizures are in part a reflection of how epilepsy is negatively constructed and indeed stigmatised.

⁷² As Rhodes *et al.* (2008a: 12) discuss, the classificatory ambiguity of epilepsy, coupled with the option of concealment, enables people to take an active part in the achievement of their own identities. However, the contested nature of disability and the unpredictability and uncontrollability of the human body means that such achievements are fragile and unstable.

own bodily aesthetics as being so outwith their self-conceptions. Feelings of helplessness signified the weight of realisation:

You could tell that she was *non compos mentis*. And you're thinking to yourself 'Crumbs, that's probably what I look like to my wife and my kids, or whoever else is there.' So you do feel for the person who's having it and you wish you could reach out your hand and just *heal* them at that particular moment. (Brian)

I'd never seen it until there was one chap at my work [...] He just fell off his seat and started shaking, and I looked at him and I just *froze*. And I thought 'That's a fit!' [...] I was just, like, stunned and watching it, thinking 'Oh, is that what I look like?' (Ian)

Ian also reveals a curiosity in seeing one of his own seizures simply because it is an unknown. Nevertheless, it remains a scary proposition:

It would have been interesting to have taken a seizure down at Quarriers [assessment centre]; to get it video-taped. But I don't know if I would have liked that or not, if I'm better off maybe not knowing. [...] Maybe it's a bit of vanity really, you know. You don't want to be disappointed in the way that you look when can't do anything about it. (Ian)

This remark is indicative of the feelings expressed by a range of participants: an unresolved tension between wanting to know, to see oneself in seizure, and feeling that it could only lead to disappointment in one's own bodily aesthetics.

As Ian alludes, where technologies are available, it is possible to view a recording of one's own seizure. However, Jennifer found doing so extremely affecting:

When I was younger, I asked my Mum and Dad to video-tape me because I thought it would make me feel a lot better if I knew what I was doing, and know how to react when I came out of it. But they always refused to video me, because it wouldn't make me feel comfortable [...] I had a few fits in the hospital when I was having the tests done [for epilepsy-related brain surgery] and I asked the doctor if I could go in and watch myself on the video camera have one. [...] I had the wire connected to my head. I was trying to pull the wires off. I was pulling faces, I was clenching my fists as well. I think that was a really bad fit that I had, but I think that that made it more difficult for me. [...] I was really upset that I did that, because I didn't think it was that bad. And I don't know if that was because my parents always said 'Oh, don't worry'. I think they tried to make it easier and not so embarrassing. (Jennifer)

Witnessing her unintended actions via the means of technology provided Jennifer with a de-centred phenomenology of the self. Her bodily performance was simultaneously of the self and the 'not-self', giving rise to a graphic horror at being deposed from self-governance. This shattered her faith in her ability to conform to the regulatory fiction of 'normal' corporeal styles,

even though she continues to believe in its necessity (Butler 1988: 522). As such, she seeks to make amends with those witnesses who she might have ‘inconvenienced’. Placing the feelings of others as a primary concern suggests judging oneself through the eyes of ‘normal’ people. I now unpack some of the implications of this ‘being-for-the-other’ (Sartre 1993; also in Davidson 2003; Toombs 1988).

BEING-FOR-THE-OTHER: CONCERN FOR OTHERS COPING WITH THE ‘UGLY BODY’

The focus now turns to how affective relations are informed by the weight of historical, cultural and social processes in constructing epilepsy as something ugly, shameful and disruptive⁷³. When coming-to, the body ‘out of place’ is crystallised through the look of the other. The ‘aesthetic judge’ need not overtly communicate revulsion to the person with epilepsy for them to infer that their seizure was ‘ugly’. As Butler (1997: 141) suggests, ‘speech, precisely because it is a bodily act, is not always ‘knowing’ about what it says. In other words, the bodily effects of speech exceed the intentions of the speaker’. Hence even if the speaker’s intentions are unclear, the societal ‘capturing’ of the representational terrain of/for epilepsy will still impact on how people translate the utterances of others:

We can be ‘taken hold of’ by others, accept their views as our own, see ourselves as they do, and suppress our potential to be anything more. [... This is] life lived under the dictatorship of ‘the they’, as if our being-for-others, our public selves, were all that mattered. (Davidson 2003: 111, on agoraphobia)

This being ‘taken hold of’ is, in a sense, a *social seizure*, the arresting of one’s individual place within society. When Sartre (1993: 222) states, ‘I am ashamed of myself as I *appear* to the Other,’ it is the very presence of the ‘other’ that compels this feeling.

Foucault (in Gilman 1982: 2) states that ‘the face of madness has haunted the imagination of Western man [sic.]’. Popular conceptions of the epileptic body are similarly supported by a long-standing, although partial, ‘vocabulary of images’ (Gilman 1982: 2, on ‘the insane’) which open people ‘to the full force of past and contemporary social prejudice and misunderstanding’ (Trostle 1997: 2183). Young (1990: 145-147) argues that members of social groups become

⁷³ Some scholars (e.g. Trostle 1997) have considered seizures as ‘uniquely dangerous’, universal threats that humans are ‘hard-wired’ to avoid (Jacoby *et al.* 2005: 173), but I agree with Smith and Davidson’s (2006: 56) rejection of the notion that ‘disgust is merely an evolutionary response towards potentially dangerous objects [... because such] reactions are often extremely culturally variable’ (cultural variations in responses to epilepsy are discussed in Carod-Artal and Vázquez-Cabrera 2007; Andermann 1995). My understanding, after Smith and Davidson, is that affective responses are informed in part by aesthetic and moral values as well as by individual and social processes. This explains why particular seizures seem to attract more stigma than others: for example, questionnaire analysis shows a statistically-significant relationship between ‘experiencing discrimination’ and participants who experience both generalised and partial seizures have experienced a statistically-significant level of discrimination, while those who experience partial seizures only have not.

culturally defined as ugly and so are subjected to oppression such that they ‘often exhibit symptoms of fear, aversion, or devaluation towards themselves and towards members of their own groups’. Participants themselves employ stigmatising language regarding their own seizures; for example, Nicola described them as a ‘zombified state’. That people mention fictional beings (ones which always have negative connotations), and yet do not witness this ‘zombified’ state themselves, suggests that they are drawing on both witness descriptions and socio-cultural representations. To have or witness a seizure, then, is a historically and culturally situated *experience*.

In this research, not a single participant said anything positive about the seized body. Debbie’s comment that ‘It probably isn’t a pleasant thing to look at’ is typical. Some individuals say they ‘knew’ seizures are ugly (because of their facial expressions, ‘twisted’ body, dribbling mouth, rolling eyes) but cannot recall a time when somebody described them as such. Others, for example Sue, had been told peoples’ aesthetic judgement in no uncertain terms; notably in this quote (already partially repeated earlier):

There was a young lad who got very upset – actually tearful – and really quite moved by the whole thing, and I said to him afterwards ‘What was your problem?’ He said ‘I’ve never seen it [before]. I didn’t realise it was so *ugly*; and you’re a friend, so it was a horrible combination.’ (Sue)

Changes in the body that elicit negative responses from others paint individuals as less-than-ideal (Goffman 1963). Kitchin (1998; see also Hahn 1987) asserts that the advent of consumerism and associated advertising has helped to place an emphasis upon health and the ‘body beautiful’, further stigmatising people whose disabilities are constructed as aesthetically displeasing. This was a particularly sensitive issue for several female participants, especially as the female body in Western society is obviously subjected to greater objectification (McDowell 1995). The gaze of the other is disabling insofar as it assesses and constitutes the object of its scrutiny according to a (social) body based in contemporary ‘visual culture’, or what Hughes (1999: 164) calls the ‘new tyrannies of normality, truth, beauty and perfection’. Internalising these standards only strengthens their insidiousness because we cannot stand outside of these bodily cultures easily. Self-governance over the body, for example in keeping an upright comportment, is a taken-for-granted spatial aesthetic against which the body-in-seizure is judged. This projection reinforces the binary relationship setting the ‘monstrous body in opposition to the normative body’ (Colls 2006: 531, on ‘bodily bigness’) or, in this case, the self-governed body.

As Schneider (1988: 71) stresses, it is common for people with epilepsy to worry about how others feel because they neither know what they are seeing nor what to do (I discuss below the consequences of *others* feeling out of control of the situation). Aside from making sure the seized body is not in danger, witnesses must ‘learn to ‘do nothing’’ (ibid.). Such counterintuitive actions

are felt to be extremely uncomfortable for friends and family in particular. Brian told me: ‘it’s scary for *them* – I don’t know what it’s like being on the good side of the problem for them; [but] I feel for *them*.’ It is intriguing that Brian identifies people without epilepsy as being on the ‘good side of the problem’ and yet is more anxious about how *they* feel. Steve suggests that this anxiety arises because ‘I don’t want to put *them* under pressure, even if I’ve said to them [what might happen]’. Feelings of guilt imply that the individual is in some way *responsible* even though the very nature of seizures militates *against* being responsible. Because *others* supposedly ‘rule’ their bodies, this leads to self-blame, usually entangled with lifestyle choices. James experienced a seizure after a ‘boozy’ holiday with friends:

When I came-round [my first thoughts were of] how stupid I had been, you know, in terms of not looking after myself properly. So I was upset by that, that I’d been so stupid. It was more a regret that I had done that. I knew that I would lose my driving license again, so I was aware of the consequences of it, again, from being so stupid. Such a stupid thing to do. But also as an affect on my wife. I feel bad about that. That’s probably more about what it’s all about. (James)

Feeling responsible for his body’s momentarily ‘unruled’ state, James spoke of letting *himself* down, and, in turn, *others*. Similarly, Gordon explains, ‘you felt terribly guilty that you’d allowed your body to do it [... because] you’re supposed to be in control of your body. And that’s a social thing, it’s cultural.’

Besides family, relative strangers in social space are likewise the object of participants’ concerns. Brian said of having a seizure in a local shop that he feels ‘sorry for the people, because they’d be feeling a bit awkward; because they’d be thinking ‘Oh, this is the guy who has these funny turns’.’ In this way, he feels that he burdens others with his ugly, volatile body. Indeed, participants suggest that they should just ‘*know their place*’:

Shame, basically at being placed in this position. Everybody knows what has happened and you can’t do anything about it. [...] It’s the embarrassment of *knowing* that I had caused a disturbance. Not my fault; without my *intention*. So because of that fear, I kept away from doing things like [going to the cinema] (Patrick)

Occupying socialising space is not the problem *per se*; rather, anxieties focus on becoming the object of others’ attention in such situations. Momentary bodily ‘differences’ incite feelings that one’s body is ‘not one amongst many but the centre in relation to every location’ (Bannan 1967: 74, quoted in Davidson 2000a: 655). This centring of the body-self exacerbates culpability, as if the attentions of others have been illicitly ‘seized’. Jennifer wishes for more predictable seizure *types* because their unpredictability (i.e. not knowing how disruptive her body may have been)

deprives her of being able to react in how she hopes will be a socially-acceptable way to others. Thus, she attempts to 'read' peoples' reactions:

I was very embarrassed one time when I flying out to Azerbaijan to see my Mum and Dad and I was sat next to this guy and I must have had three or four fits on the plane. And I'd just be sat there. I'd try and go to the toilet, although there was at least once when I sat next to him and I'd kind of look towards him to see what his reaction is. And you don't know whether to apologise or just act like nothing's happened.

To 'soften the blow' for others, some participants perform the 'healthy' body following a seizure:

I know how upset my family and my husband used to get sometimes, and that used to upset me as much as anything else. I thought 'I don't want them to see me like this, I don't want them to be upset,' because I'm alright afterwards; and I used to stress afterwards 'Look at me – I'm fine! I'm fine, don't worry about it!' (Margaret)

Because the distress of others accentuates to Margaret the otherness of her body, she subsequently uses it as a tool to resist an 'ill aesthetic' with the hope of calming them.

It is important to note that participants are not always swayed by others' reactions. Laura resists the regulatory fiction of the infallible body, taking the attitude that:

Now I realise it's nothing to be ashamed of. My point of view on it now is: well, if you don't like it then that's *your* problem, and it's not my problem. I'm not doing anything wrong by having epilepsy. And I think that you've just go to understand that not everybody's going to be perfect. (Laura)

While Laura's words hint at a politicised identity, it is not always easy to separate oneself from the gaze of others. When he loses control publically, Robert feels as if a disempowered, devalued member of society: 'It's like the junkie in the street: their bodies are wrecks. That's how the epileptic body can look. What's the difference?! It's causing too many people too many problems.' That he equates the very obvious figure of 'abjection', the 'junkie', with the 'epileptic body' (the body in seizure, i.e. when epilepsy is not 'hidden' but takes up space) is striking. Robert appears to have internalised negative perceptions of seizures⁷⁴ based on the disciplinary social power of discourses surrounding the 'healthy' body. The price of the illusion that some bodies are healthy and others are *failing* to be healthy, as suggested by Robert, is guilt, shame and stigma. As Wendell (1996: 106) argues, the 'disciplines of normality', 'idealisation of the body' and 'myth of control' leads to the conclusion that 'people can overcome illness if they really want to'. This evaluation 'inflicts a constant fear of losing control' and masks the social and environmental

⁷⁴ Those for whom the onset of epilepsy occurs in later life may already have internalised such perceptions: see CHAPTER SIX.

attributes of disabling time-spaces. It suggests a *moral* aspect to how people with epilepsy are judged, and opens up the possibility of having to account for the 'unruled' body (Schneider 1988).

BORDER AMBIGUITY AND DISGUST

I now build on the previous sections by illustrating a theoretical interpretation of the complex emotional geographies formed in light of the effects (of the affects) of epileptic seizures in different spaces. This is informed by psychoanalytical insights concerned with the role of less-than-conscious processes in the spatial constitution of society (Parr *et al.* 2004; Sibley 1995; Smith and Davidson 2006; Wilton 1998). As has been noted, clinical and even social science literatures assume that seizures *are* disturbing, but their 'ugliness' does not explain fully why individuals are so stigmatised. Cultural constructions certainly play a role in the aesthetic determination of something as 'ugly', and yet there is undoubtedly more going on here. I contend that reactions to the radical loss of bodily control not only expose cultural aesthetic judgements but also a fear of one's own vulnerability.

It is crucial to our understandings that we see the embodied geographies of epilepsy as simultaneously discursive and material. With certain types of seizure, the contorting limbs, bulging veins and laboured breathing of the body viscerally positions it as having unstable, moving, thrashing boundaries which threaten to invade others' body-space and cause them harm. Because it cannot be 'reasoned with' in its non-cognising state, the epileptic body is also seen as threatening, animalistic:

The whole process is very animal-like. And I think there's just a terror in anyone – 'How do I make this thing stop? What am I supposed to do?' [...] I think it's because the *other person* is out of control. (Sue)

Seizures resemble 'those fragile states where man [sic] strays on the territories of animals' (Kristeva 1982: 12) and so 'taint' civilised society with their 'primitive' forms of (human) being, their 'bare life' (Agamben 1998). The 'unruled' body, then, is less-than-human and categorised as one of those abject 'things' that are 'difficult to predict, that surprise by their unannounced presence' (Smith and Davidson 2006: 62):

For the person having the seizure, it's being absolutely out of control. You step out of the social norms. Even when someone's coming out of a seizure, like in the recovery phase of a tonic-clonic, quite often it's like their personality's not quite back 'on-line' yet – it's all instinct stuff. And I think from the person watching's point of view, it's very frightening to see somebody that's totally out of control. People get embarrassed by it; they don't like to see you when your social norms are stripped away, and they're seeing that basic human nature. (Jude, Epilepsy Charity Worker)

If we agree with Smith and Davidson (2006: 48) that the 'symbolic distinction between nature and culture is not just prevalent *within* society, [but] is the founding principle of the 'social' itself', then 'matter out of place' (Douglas 1993) – the epileptic body – infringes upon and threatens the fabric of the socio-cultural order. It is an uncomfortable reminder of our always-incomplete control over nature and that the symbolic order is *perpetually under threat*. If the seized body disturbs modern Western cultural illusions that we (humans) have complete power over our embodied selves and destinies, epilepsy is in some ways an exposé of the crisis of modernity.

Yet any talk of modernity is held back by the shackles of historically-situated notions of demonic possession, when the singular, concrete self gives way to a compromised autonomy. Rather than being one thing or the other, the person or evil spirit, the epileptic body is *both*: the territorial boundary of the self has been breached by an-other, at which point the body is the (unconscious) agent of forces both visible and invisible. This is not to suggest that witnesses actually believe epilepsy to be demonic possession; rather, it is to say that because seizures are understood in reference to long-standing stigmatised concepts, it reinforces the stigmatisation of such liminal, auratic states. The uncertain ontological status of individuals in seizure evidently can be most disturbing. Margaret's husband, on witnessing a seizure, 'thought I was *dying!*' As advanced by Sibley (1995; see also Douglas 1993), the breaching of culturally-specific categories gives rise to 'subjective' feelings of anxiety or disgust because it sits uncomfortably with the ways in which people (need to) make sense of the world. The 'seizing' of cognition blurs the boundaries between consciousness and unconsciousness, life and death, being and not-being. Seizure symptoms are of the body, but the 'place' of epilepsy is the brain; the body is present, but the self is 'absent'. In Shildrick's (2002: 78, quoted in Colls 2006: 542) terms, 'It is the corporeal ambiguity and fluidity, the troublesome lack of fixed definition, the refusal to be one thing or the other, that marks the monstrous as a site of disruption.'

When the boundaries between the cultural and (super)natural are under threat it causes feelings of helplessness, of being out of control. Throughout participant accounts of the affective relations in and between self and others, it is clear that witnesses feel a powerlessness brought on by their inability to comprehend or halt a seizure. Time and space become uncertain as the volatile boundaries of the body 'taken' by intangible forces threaten to invade the social-corporeal boundaries of the *witness*. In such moments, *flow* is interrupted; the taken-for-granted, predictable, comfortable time-space symbiosis between bodies and the social order destabilised aggressively. Thus, the affect of witnessing the breakdown of bodily control in others can have a dis-ordering effect on both space and *self*:

I was frightened in case I made a fool of myself. But I've got a funny feeling that a lot of folk, when they're the other way [i.e. a witness], have the same problem – not that it's as obvious as having a fit – but there's a 'freeze'. (Gordon)

My own experience of it was when I was seventeen: a girlfriend of mine, who I didn't know had epilepsy, suddenly had a tonic-clonic seizure in front of us all. And it was really, really traumatic. I'd thought she was dying. [...] When it's visible it's *very* visible. And there is a sense of helplessness – I certainly felt a sense of helplessness. And if we're used to feeling competent and confident and things, and if there's something going on and you think 'I don't know what to do with that!', you don't want to experience that too often. (Bruce, Social Worker)

The control and regulation on to which people ground their own sense of self is, in effect, *seized*. Hence witnessing seizures in others is the embodiment of anxieties over one's *own* destabilisation. The 'epileptic body' that is seized from sociality – 'seizure' meaning to be 'taken hold of', to be 'attacked' by hostile external forces (Stirling 2010: xxii) – can also be said to cause a *social seizure in witnesses*, who are 'taken hold of' by the affects emergent in the situation, and so are in many ways themselves rendered 'epileptic bodies'.

The loathing that some people feel is their less-than-conscious urge to restore the border separating self and other (Longhurst 2001: 41; Sibley 1995; Smith and Davidson 2006), to vanquish the forces that seem to overwhelm the self in those intense moments. During interviews, there were countless examples of people with epilepsy sensing this disgust:

The girl had come down the stair to tell my wife what had happened, and she'd almost fainted because she feels faint when she sees someone that's ill. (Brian)

[When I regained awareness] I looked about and there was about twenty old biddies [gossipy women] in this café, looking at me *like dirt*. [...] It was the *look on all those old folks' faces*... (Kate)

Witnesses perceive something disturbingly unnatural about 'unregulated' embodiment; consequently, epileptic episodes have an 'invasive presence that disrupts the 'natural' order of things' (Smith and Davidson 2006: 54). Strangers will often observe from a 'safe' distance, fearing injury by getting too close or that there is something 'unclean' about a seizure, suggesting that the perceived vulnerability of one's own body-space increases with proximity. That a witness can feel under threat suggests a contaminating potential. The clothes and skin of the 'collapsed' person may show signs of dirt, but it is the *person* who becomes dirty. Furthermore, sometimes people lose control of their bladder during a seizure. Longhurst (2001: 45) discusses how 'leaky bodies' are not trusted to occupy public space because they defy social conditioning and so might 'contaminate and pollute'. Claire was conscious of potential repercussions when she and her colleagues became aware of her incontinence after a seizure. Such is the social pressure for the 'stable' body to rely on fixed sites of (im)permeability (Butler 1990: 132), Holly once attempted to hide that she urinated during seizure: 'I went back to my desk and sat in my dress, soaking.'

Revulsion at the 'unruled', perhaps leaky body-object 'prompts the distancing inherent in objectification' (Charmaz 1995: 664). Patrick explains peoples' stigmatising attitudes thus: '*They*

don't like it. They fear the unknown. They do not like the actual sight of people having seizures.' Similarly, Gordon states: 'Folk feel uncomfortable with it. You look at the human body and you say, 'That doesn't look right,' and it makes folk sick. And I think that's what happens with epilepsy.' Indeed, one reason why others might recoil from the 'unruled' body is that 'I couldn't help it: it just happens; it could happen to *anybody*' (Margaret). Returning to Shildrick (2002: 6, in Colls 2006: 538): 'alongside the capacity to evoke anxiety and loathing, the vulnerability that belongs to it (the monstrous) is also our own'⁷⁵. Seized bodies merely reflect the uncertainties and insecurities in *all* corporeal experience and identities, especially in the moment of witnessing that which is radically unwilled. The bodily ambiguities experienced *in* seizure, discussed in CHAPTER FOUR, then, are arguably not so different from those experienced on the *outside*. Seizures are not objectively 'ugly' or 'disturbing', but witnesses, as socialised subjects, construct the ungoverned body as 'object' because it threatens the perceived order on which their own self-identities and senses of embodiment are predicated: the seized body is no longer *self*-possessed, no longer 'governed' – it is anarchic.

ABJECTION OF THE ANARCHIC BODY

When people witness seizures they experience them as a dis-order. This is 'disorder' both in the sense of defining and marking the deviant ill body (that appears as if in disequilibrium), but also a dis-ordering of the way that things are 'meant to be' society and space generally. The presence of unsettled and unsettling bodies impacts on one's sense of place. When the boundaries of the affectual, volatile, anarchic body break down, this also renders the bodily borders of the witness vulnerable to the fluidity of (human) *being*. When a body hits the floor, makes unusual and unsolicited noises, halts or moves in an odd manner, it becomes the 'by-product of a systematic ordering and classification of matter, in so far as ordering involves rejecting inappropriate elements' (Douglas 1993: 35). Individuals and groups re-establish the order of things, and so their place in the world, through the 'exclusion from consciousness' (Wilton 1998: 179) of what is socially and physically the 'other' (Smith and Davidson 2006: 59).

As has been touched on earlier in the chapter, the reactions of seizure witnesses are not inevitable; hence I wish to avoid constructing a 'universal' response. There are numerous instances of contrasting respons(ibiliti)es performed by bystanders (whether or not their affectual/emotional reaction is intense or calm) in different *spaces* – the street, a shop, a ticket

⁷⁵ Dixon and Ruddick (2011) also discuss how the 'monstrous' evokes a powerful, visceral response. They argue that a modernist desire to categorise things has been advanced through the rejection of the deviant and ambiguous. As Foucault (in Dixon and Ruddick 2011: 432) observes, 'What defines the monster is the fact that its existence and form is not only a violation of the laws of society but also a violation of the laws of nature [...] the monster is, so to speak, the spontaneous, brutal, but consequently natural form of the unnatural.' As a result, we are witness to increasing inquiry into how we 'make' and 'live with' the monster that defies 'domestication'.

queue, an aeroplane, the workplace – which may in part be shaped by their ‘time demands’ in these places: ‘I don’t have time *here* for this...’ When surrounded by strangers, seized individuals are sometimes ignored, as if nothing is happening:

A man in the queue waiting to buy a [train] ticket took a seizure in front of me and fell on the ground. And the guy at the ticket office just closed his little hatch and moved along to a hatch further down and opened it up. And the whole queue moved over, and this man was just left convulsing on the ground with everyone stepping around him. (Dr. Rivett, Neurologist)

Space around the body clears at that moment, perhaps out of disgust, fear, or simply wishing to avoid having responsibility bestowed on to the self for the ungoverned body by virtue of proximity:

[A relative] had a complex partial in a supermarket when my wife was with him. And the reaction from people: they managed to clear the whole of one side of the supermarket. Everyone just suddenly went and shopped elsewhere, or ‘tut-tutted’. (Dr. Rivett, Neurologist)

In the street, it was just sheer embarrassment. Nobody ever bothered. [...] I had a fit in the middle of the road and nobody helped me. [I was] lying on the pavement for about fifteen minutes. Folk just ignored it. (Gordon)

Seizures destabilise the space surrounding the body, rendering it anarchic. Jacoby *et al.* (2005: 172) discuss how seizures are in some way seen as a *behaviour*, perhaps conferring that the individual is an ‘out-law’, that they do not respect the rules of ‘decent’ society. In particular, participants are accused of being drunk or on drugs by people who witness them staggering erratically, undressing, making unusual noises, or resisting bodily constraint aggressively. Steve, for example, regained awareness only when he was handcuffed in the back of a police van. He had been considered too contaminated by alcohol to discipline his own body, and so was confined by state-sanctioned agents of control. This is no means exceptional:

I usually get accused of being drunk. I’ve had that an awful lot. [...] I’m not aware of it, but people have shouted ‘That’s disgraceful behaviour!’ so God knows what I’m doing; but I must be staggering. (Kate)

These are but a few examples demonstrating the potential implications of being mistaken as intoxicated. In such moments, others are reluctant to help due to connotations of drunken irrationality and volatility, but also culpability:

I’ve seen people walk past people taking fits. And they will just walk off and leave them because they think they’re drunk, but it’s a fit. I stopped one time and was in the middle of phoning the ambulance when two traffic wardens came along and said ‘What do you think you’re doing?’ I said

‘Pardon?! The man’s had a fit.’ [They said] ‘How do you know?’ I said ‘I have epilepsy – he’s just coming-round now.’ [They replied:] ‘Oh! Right! I just thought he was drunk.’ And they said ‘Oh well, in that case, we’ll just take it from here.’ They then called it in on their radios (Laura)

The implication here was that the person on the ground was drunk and so undeserving of help because their embodied state was self-inflicted. The disabled body is treated as disruptive of reasonable conventions and, consequently, *immoral*. When the sudden onset of a ‘body moment’ is perceived as either a lack of care or a behaviour, others might respond negatively if they perceive that responsibility for the anarchic body shifts to *them* (Schneider 1988). As the anarchic body perhaps jerks and expels matter from the inside, nearby witnesses may be anxious that they will be judged as complicit in some deviant, anti-social purpose. At the same time, the fear of being dragged into assisting and then not doing the right thing, of making things worse perhaps, of being deflected from what was their place-based task is at that moment, means that ‘abjection’ may be only one element here.

Nevertheless, people with epilepsy often feel blamed for episodes that somehow signal to others that they have mismanaged their illness⁷⁶. Judgements such as these insinuate that individuals are not trying hard enough to be healthy. Epilepsy is hence constructed by others as a condition that is controllable so long as people take special care in order to protect their bodies (Longhurst 2001, on pregnant bodies). Others seem to find it difficult to accept that disruptive body moments ‘just happen’ and so demand some kind of underlying explanation (Jackson 2005: 339; Wendell 1996: 106). They even try to explain seizures themselves:

Everybody has their theory. It goes back to this ‘everybody kind of knows [about epilepsy]’, but they don’t know. Everybody has to have a reason. It’s a sweeping statement, but it’s generally the case: [people say] ‘Oh well, it must have been the lights’ [I say] ‘No, I’m not photosensitive, the lights don’t cause me a bother – I’ve been to discos and stuff!’ ‘Oh well, you must have been stressed that night.’ ‘I wasn’t’. I was very *not* stressed. There were none of those aspects. [They then say] ‘Oh well, it was the drink.’ ‘No, it wasn’t. Yes it was - if *you* want it to be that, or if you want it to be *that*.’⁷⁷ But everybody wants a reason, and nobody wants to cope with it. I would say it’s quite clever actually: I mean, they’re not very happy about dealing with it, but they want it solved on my behalf, so the consequence would be ‘so don’t go to the show’ or ‘oh well, don’t ever drink again’ or ‘don’t

⁷⁶ The construction of seizures as something to be avoided at all costs, as ugly, perhaps explains the furore over a performer at the 2010 Edinburgh Festival attempting to trigger a seizure on stage. This was considered as irresponsible health behaviour as it flouted conventional ‘safe living’ recommendations (the performer did not take their medication and engaged in alcohol abuse so that it might trigger a seizure). Comments on public forums suggested that ‘allowing’ a seizure to happen was antagonistic to the social order and perhaps should be constrained by outside intervention because it deviated from medically and socially-sanctioned behaviour (Chavkin 1992: 193).

⁷⁷ Here, Sue seems to indicate that she is tired of resisting others’ suggestions. She recognises that others have an overwhelming urge to construct clear boundaries around what is a seizure trigger and what is not so to make epilepsy more ‘predictable’ and less threatening. She seems to indicate that she will just let them think what they want to think – even if she knows they are wrong.

ever go in a plane' and that'll be it fixed. So yes, I think there's a sort of need for people to pigeon-hole it. (Sue)

As Sue suggests, the role of other people attempting to explain why a seizure may have happened⁷⁸ places responsibility on the self, implying that she is somehow at fault; that she should avoid any activities or places that may have causal links to seizures, that she should *know her place*. Sue feels as if others, in light of her supposed failures, attempt to police the appropriate places, spaces and lifestyles of the anarchic body to bring it back under control.

Participants feel the force of others' abject horror through attempts to send them away. Being removed is a way for others to cleanse space of contaminating elements. Disturbed witnesses frequently medicalise the event by calling an ambulance (Schneider and Conrad 1980), which, for some participants, is understandable when strangers think that they are helping:

My wife said [to a passer-by], 'He has passed out, he'll be OK.' But this man phoned, and the ambulance came. So of course the ambulance men got me in the ambulance, and they said 'There's absolutely nothing wrong with you!' I said 'I know – My wife said to the man 'Don't phone,' but he phoned anyway.' And people do it with the best of intentions. (James)

However, at the workplace, such actions can be suggestive of colleagues' lack of tolerance. Holly asserts: 'I get a bit fed-up of people phoning ambulances, because I'm not usually out too long and it's a bit of a waste of their time.' Several interviewees indicate that this will still happen even when they have objected to it previously, and have explained that they are perfectly able to 'pick up where they left off'. In this way, people are not permitted to occupy the same space as those whose bodies are 'self-governed', accentuating their unacceptability to normal space and functioning (Hansen and Philo 2007):

They've had ambulances remove me. But that's the thing at my work: they phone the ambulance right away. There's no wait – it's right away – because that's part of their policy. And they're wasting NHS money. (Claire)

For Sibley (1995), the 'othering' of social groups connoted by danger or disgust is reinforced through the drawing and maintenance of boundaries around the dominant symbolic order (which has both material and discursive implications). If a seizure occurs within these contexts, it only increases the visibility of someone 'who does not belong' and in turn their likelihood of exclusion (Sibley 1998: 120). Claire continues: 'I was stretchered through forty people I work with everyday in an office. They're all looking at you; they're all like, 'What's up with her?' It's embarrassing. I totally hate it'. She does explain, conversely, how the policies enacted in her workplace are

⁷⁸ I return to this notion of seeking explanatory factors for seizures with(out) other people in CHAPTER EIGHT.

neither distinctly inclusionary nor exclusionary: they reveal ambivalent intentions, simultaneously caring yet isolating, respectful yet intrusive:

When I've had a seizure in work it's mainly when I've been at my desk, or I've been at the toilet, or something like that. They just send out an email, which I then get the next day when I go in: 'Claire's had a seizure, don't go into the toilet'. Even though I've told everybody I don't want this [to happen] it's like, 'Give her a bit of privacy; give Claire a bit of privacy – she's had a seizure in the toilet.'

Claire is well aware of the irony of being offered privacy via an email 'telling everybody!' Indeed, it is not always clear for whose benefit strategies of clearing space around the anarchic body are undertaken. Those individuals who have been prevented from continuing public-facing jobs (e.g. Patrick), or who have been segregated from the rest of the audience at a school play and made to sit at the back (Sue), are in no doubt about being confined to 'other' spaces out of public view ('out of sight, out of mind'). A tension arises here because, as is discussed in CHAPTER FOUR, 'epileptic spatialities' are frequently defined by *self*-confinement, yet when the individual is denied the right to self-definition it is extremely disempowering. This is because when others lose trust in the ability of the individual to self-govern their body this implies a loss of trust in the *person* (and so the complete loss of an 'able' identity). To be sure, others become increasingly watchful and wary of the individual who threatens dis-order. Mandy reveals, 'There were some people who I think were scared to be left alone with you, in case you dropped on them and had a fit or anything like that.' Mandy is thus constructed as a liability in reflection of *others'* anxieties. Holly is in doubt about this:

It is other peoples' reactions: it is completely *them*. And it is how they perceive you. I mean, they see other people dancing, getting on with their lives, being perfectly normal. Well, not 'normal', that's a terrible thing to say! But people expect that you could be ill or something's going to happen to you, and they can treat you a bit differently sometimes. (Holly)

Seizures, therefore, encourage both reactive boundary maintenance and proactive avoidance. This is because people who might intermittently yet unpredictably lose control embody the *potential* for dis-order and anarchy.

When bodies fail, sometimes dramatically, to live up to the social/ethical/moral contract of spatial order, the social itself is seen to be under threat. Hence policies are implemented at an institutional level to make issues of responsibility increasingly explicit⁷⁹ and so safeguard against overly 'risky' bodies. Standard medical-administrative categories have also created and reinforced blanket bans on people with epilepsy engaging in diverse activities (Schneider 1988: 72). Various

⁷⁹ ES has now delivered epilepsy training to around 200 Procurators Fiscal, 50 Justices of the Peace and at least 30 Advocate Deputes. They have also helped to ensure that all new police officer probationers receive epilepsy awareness training at the Scottish Police College. Next they are turning their attentions to training operational officers as Scotland moves towards having a single police force: http://www.epilepsyscotland.org.uk/pdf/Epilepsy_News_19.pdf.

participants have lost or cannot find jobs due to the concerns of employers⁸⁰, who represent the issue as a duty of care to *others*:

Employers wouldn't take me on if it was working with machinery and things like that in case I took a fit and put others in danger. And if I was going to be working alone – I would have to work with somebody with me all of the time. (Mandy)

As Sibley (1995: 39) puts it, 'spatial boundaries are in part moral boundaries'. Yet 'health and safety' is frequently used to justify the exclusion of people in the workplace or social spaces even when it is unclear where any risks lie. Jennifer's shocking story is illustrative of the workplace becoming a site of struggle:

I was just like anyone else in the room until I had the fit. [...] I'd worked in a different department as a temp for six to nine months I think it was, and this other department were recruiting for a permanent member of staff, so I applied for it and got the job. And I'd always had epilepsy. [...] Not long after they'd recruited me to that position, it must have been probably a month or two, I actually had a fit. It was quite late in the day. It was about five o'clock in the evening; I think there was only me left and one other lady who was in our department. [...] When I went back into work on the Monday, as soon as I got into the office, I was pulled into a meeting room with my line manager and her boss. I don't know if H.R. were there, but they sat me round a table and told me I wasn't 'fit for work'. [...] So I ended-up calling the union and so had a representative at every meeting I had in the end. But they were just trying to get me to walk out of the job so that they weren't challenged: because it would be *my* decision to walk out. But anyway, I stuck in there, and they suspended me from work for about three months, saying that I wasn't fit for work. They sent me to this psychiatrist, and waited to get the results, and saw that they were OK and took me back on, and that was that. (Jennifer)

Jennifer's seizure in no way endangered others' workplace safety. Because she was completely 'able' to do her job, she had never considered asking for 'reasonable adjustments' from the outset of employment. Instead, as with several other participants, Jennifer only drew on 'Occupational Health' laws (see footnote 80) as a 'last stand' when her employers were looking to remove her as a 'troublesome employees'. By this time, it may be too late for individuals to recover from a (workplace-based) 'spoiled' identity. In one example provided by a health professional, a person with epilepsy was, ironically, considered as a liability within a space that *aimed* to remove the moral limitations imposed on people:

⁸⁰ Epilepsy is covered by the Equality Act (2010), formerly the Disability Discrimination Act, which states that an employer must not ask about an applicant's health until that person has been offered a job (although exceptions include the armed forces and positions relating to 'national security'). Epilepsy is thus covered by the policy of 'reasonable adjustment', whereby employers must support people with disabilities in the workplace, whether the 'disability' is temporary or permanent. See: <http://www.epilepsyscotland.org.uk/pdf/ES-Occupational-Health-Guide.pdf>.

A guy, who I see once a fortnight, went to an adult education facility, which was set up for people who've got health problems, and had a complex partial seizure in the middle of the class. And they handled it really badly. [...] He didn't do anything particularly aggressive or anything, but basically, he was told that he could not come back; that they'd spoken to health and safety and said 'You can only come back if you've got a carer.' And this guy has got his *own flat*. And this was a service that was set up for people with long-term health conditions, mental health problems, people with anxiety disorders, panic attacks, schizophrenia, whatever; and no-one else was asked to have a carer. (Bruce, Social Worker)

This person's condition was considered to be *overly* disturbing (echoing Parr's [2000] findings on how voluntary mental health 'drop-ins' are still being policed, often by service-users, to exclude 'others' for being 'too mad'). It was therefore in the *group's* interests that the person had a carer present to protect against the anarchy of epileptic episodes. Seizures are hence framed as an unacceptable disruption and so excluding or containing the individual becomes a moral imperative.

PLACING THE DISORDERED BODY ON THE SPECTRUM OF ALL BODIES

Maybe people see the people that they know and love having these attacks, and they know that they're OK, they know that they're normal and that they're not demonic or whatever, and therefore it's OK for them to have that. Then they begin to gradually spread that, and the more people they know, the more people they're accepting into 'well, that's within normal limits,' sort of thing. (Sadie, ESN)

This chapter has moved from a phenomenological to a more-than-phenomenological, or de-centred, vantage point. In so doing, I hope to have illustrated something of both the affects and effects of seizures as they are experienced in different places, by different people. By using 'affect' to describe how intensely unwilling, surprising and potentially disturbing bodily 'events' can cause a sudden destabilisation – a seizure – of peoples' less 'event-full' emotional geographies, I have shown how the dynamics of such moments are space- and place-making. I define 'affect' as itself a type of emotion, but one characterised as emerging between bodies most noticeably when one's *own* bodily boundaries momentarily seem to dissolve and the *self is seized* (here, in relation to witnessing the uncanny breakdown of *others'* borders). Hence, the anxieties of numerous witnesses seem to spring from this very real and present danger of one's *own* body-self becoming 'epileptic', of it being 'taken hold of' by seemingly external forces. This shatters the fiction that 'we' are all completely autonomous actors in control of 'nature' and so rocks the very foundations of the social order. When the individual with epilepsy regains awareness amongst these intense anxieties circulating in and between bodies, they may be

unable 'to assert their own subjective spatiality in the face of the spaces of others' (Davidson 2000a: 656), whose reactions, as they literally stand over the individual and gaze down at their body, they *feel* as if their own. This gives rise not only to shame and embarrassment, but disgust at the dirty, disobedient, 'anarchic' body, and a strong feeling of guilt at having '*done this to other people*'. The body-self then often becomes an out-cast amongst social actors, which cannot but shape one's everyday social geographies, a subject to which I turn in CHAPTERS SIX and SEVEN. The socio-corporeal geographies of seizures hence add further nuance to Abrahamsson and Simpson's (2011) conception of the body as part of what we *have* and part of what we *are*; and of how it is worked *upon* from an outside and worked *with* from an inside.

As the surge of affect emergent in that moment slowly dies down, i.e. when the individual begins to regain their *intended* place in time-space (perhaps with a painful and groggy mind/body), the responses and accounts of witnesses become central to how epilepsy is 'evidenced' and experienced in *reflection* of the 'event', both by people who have seizures and their medical carers (perhaps the doctors who prescribe medications based on particular epilepsy 'types'). My account has explained how 'epileptic bodies' become culturally defined as ugly and abject. Witnesses often cannot distance themselves enough from what threatens them, for, as Kristeva (1982: 9) asserts, 'abjection acknowledges [the subject] to be in perpetual danger'. As such, the person with epilepsy who is the focus of others' anxieties, even when not in seizure, embodies the *threat* of the dissolution of (self-)governance: they are the anarchic 'other'. Exclusionary practices, especially in the workplace, let people with epilepsy know that these are 'other people's spaces' (Hansen and Philo 2007: 495) and further safeguard against surges in anxiety over 'our' inability to control our bodies completely, clearly to delineate binaries of me/not-me, intimate/distant, consciousness/unconsciousness, pain/not-pain, life/death.

This chapter has suggested that there is more to the seizure event than simply the aesthetic cultural 'judgement' of the seized body. There is often something about the moment – the affective inter-relationalities – of a seizure that gives way to socio-emotional responses, at root of which is the anxiety that the seized body 'might not be different enough' (Wilton 1998: 178). Here we might look to Dear *et al.*'s (1997) account of how negative attitudes may be revised through prolonged proximity or exposure to someone identified as abject/uncanny because this will overwhelm the symbolic construction of them as 'other' (Wilton 1998: 181). This chapter has provided examples of how people with epilepsy do not always feel disempowered by others' reactions, especially when the configuration of people and place is familiar⁸¹. However, the witness accounts of family members suggest that the uncanniness of the deviant body may be

⁸¹ Responses to and experiences of a seizure are neither predictable nor fixed, but changeable depending on the mixing of place-based, material, social, cultural, personal, political-economic, neuro-biological, body/mind contingencies. In real terms, people defined as abject can potentially disrupt the existing symbolic order through their presence alone, which is in itself a form of embodied resistance in light of others' attempts to send them away.

something that is never fully surmountable. While parents, friends and colleagues can *learn* to perform ‘correctly’ (in terms of the person’s unique needs during and following a seizure, including safety measures and sensitive, relational dispositions), this does not necessarily reduce the impact of the disturbing, ‘out of place’ ‘force’ of the contorting, thrashing, moaning, gasping, leaking epileptic body. While seizures may well be a ‘limit case’ in terms of peoples’ abilities to ‘come to terms’ with the anarchic body, this should not divert us from the political project of rescripting stigmatised bodies. Recognising that seizures seem to be most problematic for witnesses who know little about them, and are ‘pulled-into’ the situation unexpectedly (i.e. when the geographic space between bodies is small but the social distance between them is great), suggests we need to think differently about how to render proximate ‘disturbing seizure aesthetics’ *publically*, in ways that demystify the ‘event’ and enable a more progressive socialisation around ‘anarchic’ bodies (conceivably through advert and poster campaigns). This is by no means straightforward, however, for, as Sibley (1995: 29) warns, a limited or superficial engagement might result in the presumption of knowledge which could be as damaging as ignorance.

I would like to finish by situating the ‘epileptic body’ as being on the spectrum of *all* bodies. ‘We’ are all vulnerable to varying degrees to the (un)expected; ‘we’ all experience moments of discomfort when the body becomes the object of our own and others’ attentions rather than the ‘invisible’ vehicle of the self; ‘we’ all experience our identities as fragmented from time-to-time; ‘we’ can all be ‘taken hold of’ when a disturbing event unfolds before our very eyes. There is more than a grain of truth to the notion that being able-bodied actually means being ‘temporarily and situationally able-bodied’ (Toombs 1998): ‘It’s no big deal, we fall over and we hurt ourselves, and that’s that. We shake ourselves down, and we get on with it’ (Sue). Instead of viewing people with epilepsy as disordered and disordering ‘others’, normalising their experiences is potentially empowering. By acknowledging and respecting difference rather than denying it, we may begin to think *with* disability rather than just *about* it in campaigning for positive change (Hansen and Philo 2007: 502; Smith 2012). Epilepsy studies may usefully be developed alongside a radical body politics that recognises that *all* bodies are involved in complex, relational and intersubjective corporealities (Moss and Dyck 1999a, 2002). One access point may be through an engagement with the work of David Bissell (2008, 2010), who unsettles the body as an ‘active and agential subject’. Indeed, and in line with my arguments so far, we need to help expand embodied geographies that assume conscious or intended action as *the* default state of being-in-the-world. People with epilepsy might have a *heightened awareness* of their own ‘consciousness’ or ‘intension’, but that is because they know the potential affects and effects of ceasing to embody such states. Yet seizures are not so different from other forms of corporeal vulnerability: indeed we can all be ‘seized’, and so in many ways we are *all* ‘epileptic’. As there are no fixed and

immutable boundaries between self and world (Davidson 2000a: 655), *any*-body can be knocked or slip out of consciousness in consequence of bodily (in)action, whether on receiving a blow to the head or simply falling asleep (see Harrison 2007, on vulnerabilities; and Kraftl and Horton 2008, on sleep). We may then conceptualise *every*-body as being never *fully* 'in control': they must always *become* controlled and, therefore, always have the potential to *lose* control. The main issue with epilepsy is that seizures are complex events that do not always sit comfortably or predictably on the continuum of human experiences, but it is this very realisation that makes their conceptualisation inherently political and all the more urgent.

CHAPTER SIX:

THE 'LIFE AND TIMES' OF LIVING WITH EPILEPSY

INTRODUCTION

Living with epilepsy affects temporal as well as spatial experience⁸². The meaning and experience of time itself becomes altered, shattered even. Not only are the body's rhythms of working and sleeping disrupted, but the timing and pacing of tasks (relaxed, urgent) is irrevocably altered. One's experience of time as relatively flowing or fragmented becomes an ever-present concern through the disruption of 'a spectrum of barely or rarely felt rhythms, fluctuations, pulsations, episodes and periodicities' (Zaner 1981: 58). With episodic conditions such as epilepsy, the temporalities of the illness itself becomes a marker of relative 'health' and 'opportunity': people talk about the time *since* their last episode, or the time *between* episodes, as well as anticipating *when* the next one will occur. The (ir)regular nature of epilepsy means seizures are more or less characterised as an imminent and ever-present threat. As Toombs (1988: 212) puts it, the expectation of illness means people may start 'living as if *already* severely incapacitated'. The lived temporalities of past, present and future are re-interpreted, especially when body-self-time-space relations are destabilised so often that time itself becomes completely unmanageable. The individual may feel trapped in the present, the future 'on hold' because of the excruciating hyper-presence of the body; conversely, the individual may be trapped in the future – almost in some cases 'paralysed' by anticipatory fears of what *might be* – so much so that the *present* is put 'on hold' (one cannot 'live for the moment'). In any case, prospective plans are rendered extremely unstable when the body cannot be trusted to maintain 'stability' for any length of time, potentially impacting upon all aspects of peoples' lifeworlds and identities as they interweave with an individual's social and professional geographies.

This chapter builds on the broadly phenomenological insights of CHAPTERS FOUR and FIVE by showing that the momentary intensification of symptoms cannot be disentangled from longer-term biographies such that the geographies of chronic illness and disability must take into account *both* temporalities (short and long). There is no single 'time of illness' but simultaneous trajectories that shape and are shaped by embodied experiences in the short, medium and long-terms. It is argued that identities and opportunities over the lifecourse are mutually constituted

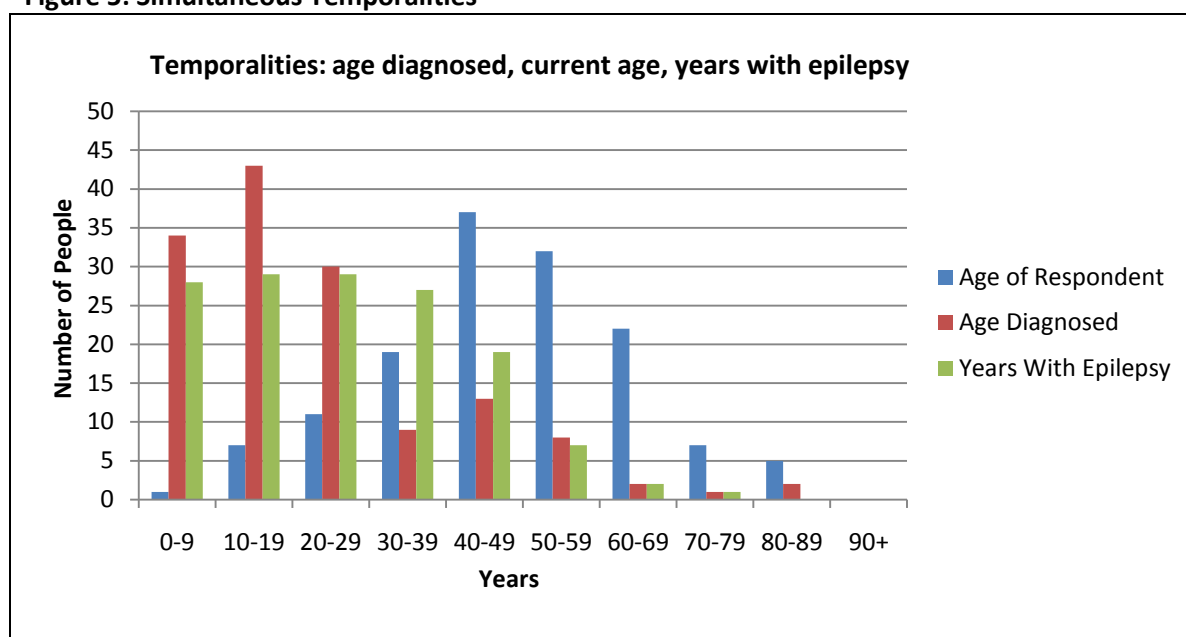
⁸² In this chapter the importance of time in the process of impairment, disability and chronic illness is emphasised, and in the next, space. Their separation is somewhat artificial given their mutuality, but such a 'divorce' is a necessary evil as a means to emphasising their respective significances.

with the (re)negotiation of everyday time-space routines. Analysis of the questionnaire results shows there to be three epilepsy-related variables of elevated statistical significance: 'seizure frequency' (which includes whether or not a person still has seizures, as well as how often), with 12 significant relationships; 'current age', with seven significant relationships; and 'age at diagnosis', with six. The common thread among these variables is *time*. Being diagnosed at a young age has an enduring and shaping effect on one's experiences, prospects and identity throughout the lifecourse. On the other hand, when epilepsy is diagnosed relatively later in life, it 'arrives' on an already developed landscape of *who* a person is (including their bodily capacities, attitudes, social resources, and 'place' within professional, social and familial networks). By comparing each participant's 'current age' with their 'age at diagnosis' it allows us to explore potential attitudinal differences between individuals of varying 'generational' backgrounds and how perspectives may change over time (socio-politically, and in terms of whether one can become accustomed to the bodily impact of epilepsy over the years).

I then narrow my temporal focus to consider how these biographical details interweave with 'current' illness status. That is, I assess how varying degrees of 'seizure frequency' influence the temporal experience of everyday life. The early adaptations of people, who subsequently experience few or no seizures, may cease even to be noticed such that their epilepsy arguably ceases to be 'experienced'. For some participants, this means being able to rescript discourses surrounding the 'epileptic' by emphasising positive lifestyle changes (slowing down, making time for 'other things'), while for others it means being able to ignore or conceal that they live with epilepsy. Because the course of epilepsy may change over time, however, people who in the past were able to control their seizures – and had settled meanings assigned to living with epilepsy – might later have to deal with their unexpected breakthrough. I illustrate this point by discussing the uncertainties of a young woman (who responded to the questionnaire anonymously) who found herself in this liminal period of not-knowing. With *frequent* seizures comes the need to pick oneself up *time and again*, with the cumulative effect that epilepsy becomes the *pre-condition* for everyday rhythms and routines. It is distinguished whether people conceptualise seizures as 'regularly irregular' or 'irregularly regular' as a way of explaining, albeit partially, differences in present coping strategies and plans for the future. In so doing, I engage how individuals conceptualise time, and where they place themselves as being located throughout their *own* time as they continue to adjust to chronic illness (Driedger *et al.* 2004: 124; Charmaz 1991).

LIFECOURSE IMPLICATIONS: BEING DIAGNOSED AT A YOUNG AGE

Before advancing the data-based narrative, it is worth unpacking the (statistical) significance of the variables 'current age' and 'age at diagnosis':

Figure 5: Simultaneous Temporalities

'Current age' (in this sample the mean age is 48) locates one's place in the lifecourse and, therefore, possible temporal settings; for example, whether or not one is of 'working age'. 'Age at diagnosis' (in my sample, the mean age at diagnosis is 22, and the greatest proportion of respondents was diagnosed between the ages of 10 and 19⁸³) helps to illustrate the effects of being diagnosed at a relatively younger or older age in light of immediate or unfolding attitudes and opportunities. Combining these two variables, we also arrive at '*when* a diagnosis was made' and '*how long* the individual has lived with epilepsy' (in my sample, the mean number of years lived with epilepsy is 25, although similar proportions of respondents have lived with epilepsy for less than 10 years as between 20 and 30 years). These variables are useful because comparing the testimonies of people living with epilepsy for long or short periods of time elucidates the extent to which living with unpredictability can ever become predictable, and so 'normal'. They are further revealing of the *era* (and so 'place' of epilepsy in the legal system and popular knowledge) in which a person began the process of coping. People who grew up in past decades were generally exposed to (and their attitudes and behaviours in part shaped by) more stigmatising reactions and misunderstandings (Baker 2002), and hence were more likely to attach shame to, and maybe conceal, their epilepsy.

⁸³ Though perhaps using 'age at diagnosis' simplifies what may have been a long, complex process after the onset of symptoms.

POSITIVE IMPACTS OF PARENTING AND FAMILY STRUCTURES

The meaning of epilepsy for individuals whose diagnosis pre-dates (or coincides with) living memory cannot be disentangled from how they were brought up to 'know' it. Alan, diagnosed at age seven, describes how 'I've never known anything else.' How his familial and social networks perceived and acted in relation to the condition, therefore, must have influenced how he assigned significance to it as a component of self. Various interviewees describe that they were treated no differently from their siblings, and were not restrained from partaking in the same activities as others in their peer groups. In fact, even though they lived with epilepsy, they were just 'normal': 'as far as the family saw it, it was just *me*' (Patricia: diagnosed at 13, now 52). Jennifer had a happy home-life because 'my parents classed me as any other child. I wasn't treated any differently to my sisters. So I never planned anything different if I had epilepsy or not.' Holly felt that being allowed to participate in recreational activities without restriction helped her to develop as a person and make her own choices:

Mum and Dad never stopped me from doing things, like stopped me from riding, canoeing, archery [...] going on deep sea fishing with them, anything like that. That's a point. And if they *had* restricted my life and said 'Oh, she might have fits!', it probably would have made me a lot less capable of coping and having my own independence. (Holly: diagnosed at 12 years old, now 40)

An understanding family has a significant influence on an individual's ability to cope and identify with epilepsy in a positive way. Family compassion, according to several participants, meant that extra (outside) emotional or material assistance was usually not required. Part of this was being able to rely on and talk to family members if problems arose. With her brothers assigned the task of looking out for her, Patricia felt 'very lucky' and 'a lot safer'. Ian found that his family's closeness was enhanced by their place in a Christian community:

Christianity has [helped] my family in holding them together, and supporting me through thick and thin. And my church as well: they're just fantastic people to have round about you. [...] And I suppose that's why I haven't felt the need of some of these support groups; whereas if I hadn't had that support I think I would have. (Ian: diagnosed at 1, now 35)

Anna's family was 'very pragmatic. So it was: we now know what it is, we can deal with it, it can be controlled, and [it is a] minor inconvenience.' This leads on to another aspect of family life: namely, sharing in the responsibility of learning about the condition as an inter-relational coping strategy. Claire's parents became 'epilepsy experts': 'My Mum and Dad are constantly finding out new things, so I'm really lucky that way. So there wasn't anything that I didn't know that my Mum wasn't able to tell me.' While Laura and her mother learned together, 'It was my mother who

went with me originally and got the information on epilepsy for me. She would sit and she would go over it with me.'

AMBIVALENT OR NEGATIVE FAMILY ATTITUDES

Szaflarski *et al.* (2006) find that 'earlier onset and longer duration of epilepsy are associated with better health-related QoL in adult patients', implying that people who have lived with epilepsy since childhood tend to be more accepting of living with epilepsy in adulthood (than those diagnosed as an adult). Emphasising a positive or 'normal' identity can certainly stand a child in good stead for dealing with the long-term impacts of epilepsy, although the determination of a family to be resilient may sometimes *undermine* the embodied experience of epilepsy, leaving the individual feeling isolated:

I think my Mum and Dad – it has its good parts and bad parts – they always treated me like any normal kid. And that's good; but there were times I felt a lot slower when I was on high doses of medication. And I'd speak to my parents about it and they'd tell me I was being silly. I don't know if they weren't accepting of it or whether they just wanted to make me feel like I was normal. (Jennifer: diagnosed at 8, now 32)

Even when a family network is mutually supportive, it can be 'suffocating' if the condition is used as a reference-point continually to remind the young person that they are 'different':

I couldn't even lock the door and have a bath on my own. I've got three brothers, and one of them would always have to sit in the bathroom when I had a bath so that they could fish me out if I went under. It's all those sorts of things. You're not allowed a life of your own. Somebody's got to be there for *everything*. [...] When I was out with friends I had to 'report-in' quite regularly, which made me a bit rebellious – you need a life! (Patricia)

Schneider (1988: 69) describes how children are constantly being told by their parents 'what to do or not to do in case of seizures', contributing to a definition of the self as less-than-fully-able. This is exacerbated when parents are too-keen to 'do' everything for their child. Indeed, when Gavin describes how 'It was thought by a psychologist that my mother was hindering my development,' it was not because of a *lack* of caring. Parents, when they know little about the condition, 'are *bound* to be over-protective and anxious' (Jude, Epilepsy Charity Worker)⁸⁴, but sometimes their anxieties translate as an invasive presence. As one ESN, Sharon, explains, 'You can have parents using baby alarms in adolescents' rooms.' The concerns of parents might be projected on to all

⁸⁴ The heightened efforts of parents also impact on the wider family. Rifts may emerge because the individual is perceived by siblings to be receiving special treatment. The parent of a child with epilepsy and another without explained how 'They're not as close as they ought to be. But I think that's an inevitability of illness, when you've got children and one of them is unwell. It's inevitable that it will upset the dynamics of your family.'

aspects of the child's life, such that they are 'wrapped in cotton-wool' and, as they become teenagers and then young adults, continue to be treated as if they are a child. A long-term danger is that 'it becomes an inter-dependency as well, so that the child or adolescent may sort of feel that they *want* that reassurance' (Sharon, ESN). The process may become self-fulfilling when risk avoidance behaviours implicate activities associated with job-seeking, socialising and recreation. Thus, epilepsy need not be treated as shameful for problematic relationships to develop over time.

Where parents themselves have misconceptions about epilepsy, they may struggle to come to terms with the diagnosis because it does not fit with *their* image of the child, whose future now seems in jeopardy. Accordingly, the child may be taught to keep epilepsy hidden as often as possible. The knock-on effect is that, growing up, (s)he feels the 'internal isolation' of stigma: a disappointment to their parents and a devalued individual with a shameful condition:

I went to the Bible College in Wales thirty years ago. It was a year's course, and that was the first time I'd ever gone away from home; and I wasn't allowed to tell anybody. And so what [my father] did was, before I went away, every two or three weeks he got a prescription for me and he built up my stock of tablets. He built the stock up so that I had enough to do me the whole term up until Christmas, so that nobody needed to know that I had epilepsy, and I didn't need to sign up with a practice at the place I was going to. (Alan: diagnosed at 7, now 51)

Alan was forced into complicity with his father's wishes, and throughout his younger years carried this heavy burden. Due to the pressure applied by his mother not to be witnessed having a seizure, Gordon was never far removed from thoughts of epilepsy:

There is a stigma in Scotland of any illness in the family, so it was kept very hush-hush because it was detrimental to the family's status. [...] It made you aware that 'If I have a fit here, my mother might hear about it and then all I'll hear is the nagging,' and therefore I could never quite escape it. (Gordon: diagnosed at 11, now 41)

One conclusion that may be drawn is the need for parental guidance. As a social worker, Bruce, explains, if *parents* are helped in accepting and understanding epilepsy, then it may be easier for them to facilitate their child's development:

[We] say 'OK, this is what it is, this is how it may affect the child, and this is how it may affect *you*: you might be feeling terrified. [...] As a parent, the important thing is to get back to the way you would normally parent, where you would provide a structure, and you provide the routines for your child.' (Bruce, Social Worker)

Without a doubt, living with a condition where there is such a loss of (bodily) control, that loss extends to the life of the family, whose reaction may be to reinforce their protective boundaries. I

now consider the broader challenges facing young people with epilepsy as they grow up in diverse time-space contexts.

GROWING UP WITH EPILEPSY: A 'CAGED BIRD'?

The very fabric of one's neuro-biology influences the formation of one's present and future personal, social, corporeal life:

The brain controls everything that we do. It helps to regulate our emotions, our behaviours; it affects our attention span, it affects our mood; it affects our ability to develop an emotional intellect, to stick to task – even to hold a pencil. So because of the origin of [seizures], the potential for [epilepsy] to be very pervasive is much more than another long-term condition such as chronic asthma or diabetes. People having seizures will generally say 'Well, I also have *this*; I also have difficulty with my memory,' or 'I also have difficulty socialising.' (Bruce, Social Worker)

The mental well-being of people growing up with epilepsy is part of a recursive relationship with social development and opportunities. One neurologist, Dr. Rivett, opined that, 'If you have epilepsy you are *bound* to accrue mental health problems. It's inevitable.'⁸⁵ This is not to say mental health problems are part of any epilepsy syndrome, but rather that they may be a *consequence* of living with the condition (a 'co-morbidity'). As I am, Carol is wary of entangling epilepsy too closely with other aspects of character development: 'If a tendency to get a little bit more anxious and depressed is part of that, then that definitely had an effect; but you always have that when you're at that age anyway!' At the same time, because she was diagnosed at the age of twelve (she is now 45), we cannot unproblematically *disentangle* different aspects of Carol's experiences. Keeping in mind this cautionary note, we may say there is enough similarity among participants' experiences to suggest *some* relationship between growing up with epilepsy and academic difficulties, restricted aspirations, social problems and bullying.

Academic difficulties were experienced by various participants whose seizures and/or medications hampered their abilities to learn new information and to be consistently present at school. Patricia's stop-start attendance and bodily impairment disrupted the rhythms of her learning:

⁸⁵ While depression is perhaps not 'inevitable', living with epilepsy is clearly problematic for one's mental well-being. Strine *et al.* (2005: 1133) state that 'persons with epilepsy are four times more likely to be hospitalised for depression than are persons without epilepsy and the risk of suicide is estimated to be 10 times higher among persons with seizures than among the general population. Depression in persons with epilepsy may be related to biologic factors (e.g., familial predispositions to mood disorders, the effect of seizures on mood regulation, and the effects of antiepileptic drugs), as well as to psychosocial factors (e.g., fear of experiencing seizure recurrences, stigmatization, employment barriers, and driving restrictions).' See Reilly *et al.* (2011) for a discussion of depression and anxiety in childhood epilepsy.

I was 'zombified' for most of my school years, one way or another, because of the changing of the tablets and trying to get the balance right. I could go something like two weeks at a time, then I'd have to have a week off school to try to recover because I was absolutely worn out. (Patricia)

Both medications and frequent absences from school accounted for participants' perceived 'slowness' to learn new things. Sophie's frustrated attempts to keep up with coursework led her to 'rebel against the fact that I had it. [...] I just threw [my medications] away: I'd had enough.' Several interviewees state that, no matter the extra hours they put in, their 'real' intelligence was never reflected in their grades:

The drugs still slowed you down through your first and second year of university, and you had to really *grind* through to get your result – I only got a 2:2 – and I know I had the brightness to get a 2:1. [...] But you're constantly aware of this lack of contentment with the standard of what you're doing. (Ian)

Laura holds the *social* impact of epilepsy responsible for her perceived academic short-comings and so reduced prospects in the longer-term:

I was in the top 10% at school. And after I was diagnosed with epilepsy, and after they started picking on me, I just started taking days off here and there and not going in because it was easier for me to do that. [...] Because of that, my grades dropped and [...] I could have done a lot better than that. [...] I'm not in a job at the moment, but I certainly wouldn't have been *not* working at the moment [had I not been diagnosed]. I certainly wouldn't have gone for the [menial] job I did. I would have gone down a different path. (Laura: diagnosed at 15, now 40)

Whereas for others the future held a 'world of possibilities', epilepsy represented the curtailing of Patrick's numerous hopes and dreams:

As a child there were lots of things that I had wanted to do, and then when I was diagnosed as having epilepsy, I couldn't be a soldier, I couldn't be a fireman, I couldn't be a doctor, I couldn't be all of these things. I couldn't drive. All these things a normal kid might just take-for-granted. [...] It's ruled my life, basically, from the age of eight-and-a-half [because of] all these restrictions that I have to think about, and barriers and things like that. So I'm just like a caged bird, or animal. (Patrick: diagnosed at 8, now 50)

In feeling that his potential remains locked-up, he is not alone. Gordon even feels that his qualifications have been 'a complete waste of time' because of the reluctance of employers to hire or promote a person with epilepsy (see CHAPTER SEVEN).

Baker *et al.* (2005: 556) argue that adolescents with epilepsy are prohibited from engaging in 'normal' social activities and in preparing for employment, relationships and driving in the same

way as their peers. Experiences at a relatively young age seem to set the tone for continuing sociability. Patrick explains how epilepsy meant that he could not participate in the extra-curricular activities:

Because they were going out to discos and things like that – I couldn't go to discos with strobe lighting – that would trigger fits! I couldn't drink and things like that; all the things that normal teenagers do. [...] I was more a loner than anything else. Didn't have very many friends at school; I kept to myself basically. (Patrick)

Since seizures exacerbated his 'otherness', Patrick avoided interacting in time-spaces where they were most likely to be triggered (see CHAPTERS FOUR and EIGHT), but missing out on peer interactions cast him as an 'outsider'. For Gordon, discomfort at having seizures in the presence of others meant that he passed-up all but the few social opportunities where he was sure of having a plausible excuse for leaving at a moment's notice. Because other people avoided *her*, Renae's loneliness and lack of purpose contributed to her intense vulnerability:

My whole school-life was pure hell. And no social life, basically, because nobody wanted to know me; I had no friends. [...] It was society. They didn't want me to take part. [...] I've actually attempted suicide twice because I felt so depressed and so anxious about everything: what am I doing here? What am I living for? [...] Because, basically, my whole life had been negative as I was growing up. (Renae: diagnosed at 10, now 51)⁸⁶

Epilepsy was used by others as a weapon in bullying⁸⁷. This could be physical: 'At primary school, I needed to get away from school before the other children got out, because I used to get kicked and chased and battered' (Renae); as well as verbal: 'Kids used to walk behind me and shout 'Alan takes epies!'' (Alan). Bullying during formative years in can variously shape one's attitude to disclosure and social life. Patrick tells of an enduring inferiority complex provoked by figures of authority who he would have expected to *shield* him from stigmatisation:

I could understand pupils ridiculing me because of my epilepsy, but when it came down to actual teachers ridiculing me for being an epileptic and being slow because on the drugs, and assuming that I was less than normal, or less than intelligent, that really annoyed me. (Patrick)

⁸⁶ My interview with Renae was extremely sensitive, and required heightened awareness of the ethics of engaging potentially vulnerable people: please see CHAPTER THREE for methodological discussion.

⁸⁷ As well as 'enacted' stigma, we must not ignore that which is 'felt'. For example, even without direct discrimination, the consequences of feeling excluded within religious community spaces as a child may be difficult to overcome. In a rare glimpse of ethnic minority issues in this research, Zareen Iqbal (Outreach and Liaison Worker, Epilepsy Connections) speaks about how 'one BME woman who took her child to the Hindu temple and said he had a seizure and everybody looked so scared; they wouldn't come near and help. And so that put her off ever going back to the temple again with her boy.' Zareen further explains how 'not belonging' or 'having something shameful' could limit one's prospects for marriage and having children: 'For the Asian BME people that I've worked with, the main concern is 'Oh, you wouldn't want to marry someone with epilepsy because you'd be carrying the burden for life.' [...] They definitely think it's going to impact on the future child.'

Without caring friendships, some participants said they 'gave up' (Robert). The difference that friendships make to the experience of living with illness is incalculable. People's attitudes to socialising start being shaped from an early age, although, as Renae reveals, it is never too late: 'It's only just been in the last couple of years that I've actually started to look at life and have a laugh. And I thank my sister for that.'

In contrast to the above testimonies, several participants declared that, despite the relative time-space restrictions presented by seizures and notwithstanding social problems, the legacies of growing up with epilepsy have no bearing on the present (this is also linked to whether seizures are 'controlled': see below). We may therefore ponder whether people can become so accepting and habituated to its effects over time that they cease to recognise its influence. While participants hold epilepsy accountable for their often negative experiences, it is commonly suggested that people without epilepsy have their *own* problems: epilepsy is one influential experience and social label among *many* to which others respond in particular time-spaces throughout the lifecourse. For instance, Alan does not consider epilepsy to be especially disabling because:

It's something that's happened right through my life. It's not something that I've ever thought about – it's just been there and I've just had to live with it. If you asked any of my friends 'How does Alan cope with his epilepsy?' they would say 'Very well: he just gets on with it.' (Alan)

For Jennifer, epilepsy is nothing more than her on-going experience of it:

Because I had it from a young age, I don't think it really clicked that I had something that other people didn't really have or know about. [...] I just learned from my experiences – I don't think I was ever told what epilepsy was, what the impact would be, what people thought about it. I just got on with my day-to-day life and just accepted the fact that I had it. (Jennifer)

If epilepsy is not thought to be *inherently* socio-physically disabling, this leaves open space to negotiate and contest its meanings. Credit is regularly paid to school friends who helped to insulate the individual from negative judgements, encouraging a positive self-identity that defines epilepsy as a constituent of self rather than *the* defining (negative) feature. For Holly: 'If it hadn't have been for the friends I'd made, and who'd got used to me, then I wouldn't have been quite as out-going and continued with my life as much as normal.' Laura, on the other hand, only felt able to assert her individuality after *leaving* the restrictive social space of school. To be sure, the extent to which epilepsy is perceived to enable or constrain the constitution of a 'normal' identity from a young age is shaped in diverse personal, local, social, economic, institutional and familial contexts (Dyck 1995a). At the same time, it is clear that, while epilepsy can represent various obstacles to

one's social and economic development, receiving understanding and acceptance from others at an early stage can be the key to unlocking one's 'caged' identity.

LIFECOURSE IMPLICATIONS: BIOGRAPHICAL DISRUPTIONS BEYOND FORMATIVE YEARS

'IT DID NOT FIT IN WITH MY IMAGE OF ME'

Several participants describe their diagnosis in later life as 'having the rug swept from beneath me', suggesting the sudden destabilisation of their very foundations. Individuals must cope with the sudden onset of bodily disruptions unlike any that they have experienced before, and may elect, or feel compelled, to change (and subsequently re-change) their everyday lives. Someone who has lived their life with a clear sense of themselves and aspirations may then have real difficulties in accepting epilepsy as a diagnosis: they experience the 'psychological trauma' accompanying unforeseen shifts in identity (Wilton 1996: 80). People from older generations, one ESN, Sadie, states, find it even harder to accept, 'even though for them it has less effect on their lives than it does for somebody younger, who's still working.' This is in part due to legacies of stigma:

People born that long ago had a perception of epilepsy as being a mental health problem. [...] The most difficult people I had to talk to, after diagnosis, were people in their sixties and seventies, who wouldn't accept it. There was this lady saying 'This is disgusting I've got this condition. This is appalling, you can't be right. I mean, this wouldn't happen to me, I've lived a clean life.' (Dr. Rivett, Neurologist)

Juxtaposing epilepsy with a 'clean', healthy life suggests that this individual associates epilepsy with dirty, perhaps immoral, behaviours. Not being able to extricate her diagnosis from past misconceptions rendered it problematic for self. Margaret admits to having had (unconsciously) stigmatising attitudes towards 'epileptics', but then *becoming* well-informed after diagnosis. Nevertheless, she chose to keep it hidden at first because of her expectation that *others* would demonstrate misunderstandings similar to her own:

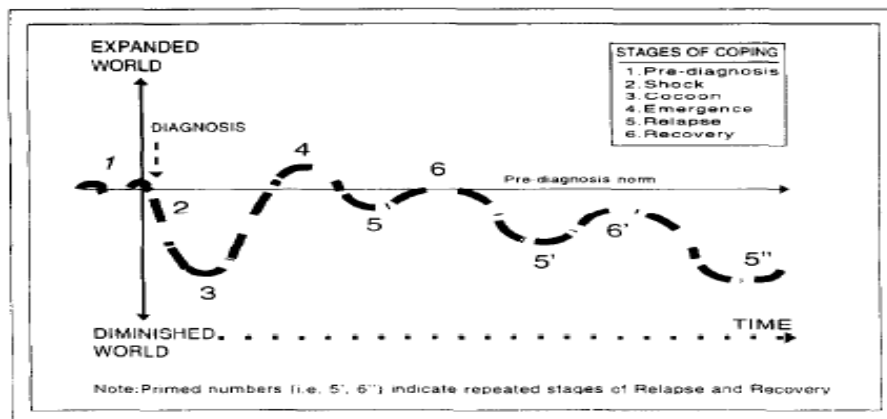
People, as they do, go about thinking that it's one of those terrible diseases and you're actually quite mad. I suppose it was a hangover from the attitudes of people. I was ashamed, [...] which is just not logical, because it's an illness. (Margaret: diagnosed at 50, now 73)

Linking epilepsy to madness, I would argue, is revealing of the legacy of ideas from 19th century diagnoses of 'epileptiform insanity', and maybe associated with syphilis (Newington 1874). Such ideas do not seem to be prevalent among younger participants, whose own generational understandings have been shaped in different temporal contexts. Family and friendship

networks, as for younger people with epilepsy, remain extremely important in how individuals adapt, but different issues now arise. Several participants tend to shield their partners or family from certain harsh realities by downplaying or concealing their epilepsy. This in turn deprives them of the time to talk openly about their condition, which becomes a contained or suppressed aspect of identity.

Newly-diagnosed adults are prone to experiencing a sense of bereavement for the life that they fear is being now left behind. They grieve their 'old' embodied identity. This process⁸⁸ has been identified in work by Wilton (1996), in which he unpacks the dynamics of the lifecourse following the diagnosis of HIV/AIDS by identifying approximate stages of recovery over time (and space): shock, cocoon, emergence, relapse, recovery:

Figure 6: Dynamics of the lifecourse following diagnosis (Wilton 1996: 77)⁸⁹



Epilepsy professionals apply similar knowledges:

People get stuck in the 'anger' phase and they're just angry. And I think a lot of people are stuck there. And then there are some people who are in total 'denial', and who will go out and they'll drink *more* than anybody else because they're trying to prove to themselves that they're normal. (Sylvia, Epilepsy Charity Worker)

Such 'stages' are scattered throughout the testimonies of participants. Claire, for example, spent around 18 months in 'denial':

I would continue to drink on a Friday after work, or a Saturday. And I knew I couldn't. [...] I was in denial for maybe about a year and a half. I didn't take any medication for it, and I thought I don't *need* medication because I don't have this. But after about a year and a half they said, well, 'Look,

⁸⁸ Also the subject of future training for Helpline staff at Epilepsy Scotland and, potentially, a research project.

⁸⁹ The 'spatial' axis in this table shows a lifeworld 'diminishing' in spatial extent relative to a pre-diagnosis state, but doing so unevenly and episodically. I would argue this is not entirely approximate to epilepsy, which is not a condition necessarily involving *real* bio-neurological deterioration over time. For many individuals with epilepsy, diagnosis may entail an immediate 'diminishing' of their lifeworld, which *might* 're-expand' over time (although possibly not back to its 'original' extent) depending on highly contingent, variable and entangled factors such as seizure control, driving license, employment, attitudes of family and friends, etc.

you're gonna have to do it, because it's getting worse.'⁹⁰ [...] I just thought, and this sounds bad now, but I thought people were gonna think I'm disabled; they're gonna think I'm 'not all there' or whatever. (Claire: diagnosed at 21, now 25)

Because she *did not want* this diagnosis, Claire attempted to show the world that she was 'not one of those epileptics' (it is interesting to note also that, as a 25 year-old, she was not worried about being labelled as 'mad' but as 'disabled'). Archie, who had actively *sought* a diagnosis for many years, admits to an enduring 'anger' at the perceived failings of medical professionals. The stress of being held in stasis by his undiagnosed condition, followed by post-diagnosis difficulties in adjusting, is directly related by Archie to the breakdown of his marriage. Epilepsy, then, became objectified as the source of his resentment. Later, after going through cycles of the various stages of acceptance and starting to identify with an 'epileptic' identity, Archie was informed by a doctor that he might not have epilepsy⁹¹. With no other explanation for his symptoms, he continued to live and cope with 'epilepsy', even if he had been returned to a liminal state of not-knowing (Moss and Dyck 1999b: 166). This demonstrates how stages of onset, diagnosis, grieving and 'acceptance' are unstable in that one does not necessarily 'advance' to the next 'node', but fluctuate between them (or show signs of more than one simultaneously) depending on multiple factors, not least due to shifts in symptoms and associated lifestyle changes.

Uncertainties as to the *meaning* of a diagnosis may spark fears that one's whole world is being turned upside down:

I was absolutely horrified at the thought that perhaps I wouldn't be able to continue teaching, perhaps I wouldn't be able to have children; I thought probably I wouldn't be able to drive, and I just was absolutely horrified because it just did not fit with my image of *me* and with the life I had forecasted for myself. (Joan: diagnosed at 28, now 55)

For Joan, being diagnosed was significant because of its potential destabilisation of all her life's plans and expectations, whether professional, social or reproductive. Changing relations with the discursive and material suggested to Robert that he had been 'taking-for-granted a gift from God', which he only realised when his abilities and expectations became suddenly unclear. Archie feels stripped of all that gave his life purposes, stating that 'I'd have been as well dead in 1997': this of course being the year he was diagnosed. The stories that people tell about the loss of

⁹⁰ Both non-compliance and compliance with medications may coincide with increasingly frequent and 'dramatic' seizures, although non-compliance is variably associated with a 'deteriorating' state (Leppik 1988).

⁹¹ Misdiagnosis rates in the United Kingdom, where a diagnosis of epilepsy is incorrectly made, are between 20 – 31% (see JEC 2011: 3). Angus-Leppan (2008), meanwhile, states that, 'Estimates of the rate of misdiagnosis of epilepsy in adults range from approximately one-quarter to three-quarters of patients'. Dickinson *et al.* (2011) discuss how psychogenic nonepileptic seizures are disorders that resemble epilepsy, but do not result from abnormal electrical discharges in the brain. They further suggest that participants who implicitly lived 'as if' they had epilepsy demonstrated less effective treatment expectations and imposed greater life constraints on themselves than the participants who explained their symptoms as 'anxiety attacks'. However, all participants struggled over gaining appropriate treatment and understanding.

independence, work and social life highlight what Moss and Dyck (2002: 129) call a 'presence of absence', when having to give things up unsettles who or what an individual sees themselves as *being*. When this happens, a person feels an 'absence of presence' (ibid.) because of present capacities and plans for the future being rendered indistinct:

It's more or less spoiled my retirement, because I retired early and I was going to do all sorts of things. It's definitely spoiled it. I was going to teach lots of yoga classes and be a shiatsu practitioner and an aromatherapist. I can't even remember the points now because of epilepsy. [...] It's caused all the joint pain⁹² as well, which has made me so painful, so stiff, that I can't do things now. (Maureen: diagnosed at 58, now 63)

For Maureen, the future has been stolen. Epilepsy is responsible for her sudden bodily and social 'decline', leaving her feeling lost, as if her life has become bereft of meaning.

When diagnosed beyond one's formative years, epilepsy arrives on an already-developed terrain of the self, which includes discursive understandings, bodily capacities, material resources and social (and sexual) relations. Such factors shape how people respond. In some cases, diagnosis can give rise to unforeseen benefits. Several participants found, to their surprise, that enforced changes can be(come) beneficial and be seen as a 'turning point'. This was summarised by several participants as involving a shift in the temporal character of everyday life. Indeed, Joan describes her 'biographical disruption' as *affording* her time to have a baby when she had not previously envisaged being able to make the time for doing so: 'It seemed if I was going to be unwell it might be a good time to stop and have my family there and then.' Having newly available time can facilitate changes in the *speed* of life. Brian took his diagnosis as a chance to disengage from the 'rat race' and focus more on what matters:

Your whole life, you feel like you should be nicer to people, show a bit more love and respect; because we're all in this world to keep mucking together and get on. And the more friends you've got the better. [...] People are fragile. And *I'm* fragile, because I've got this illness. There's a lot of folk worse-off than me, so it makes you count your blessings. (Brian)

Taking the time to come to terms with what epilepsy means for the self is, however, not possible for everyone. While this most obviously relates to people who may have to continue eking out a living or looking after their family, and so feel as if they have *no* time, the relative frequency with which the individual experiences seizures has a massive bearing on temporal experience. I now discuss 'seizure frequency' as a major constraining factor in how people iteratively (re)negotiate their routines alongside shifting corporeal experience, first addressing the testimonies of people whose seizures are controlled.

⁹² Joint pain is one of many painful co-morbid symptoms experienced by individuals taking anti-epileptic medications that are not necessarily connected to injuries sustained *during* a seizure (Kobau *et al.* 2004).

(IN)STABILITY IN THE CONTROL OF SEIZURES**STABILITY ACHIEVED?**

This chapter has so far identified the diverse challenges faced by people diagnosed at different points of the lifecourse. To complement this picture, I now elaborate on how different illness trajectories are further shaped by the times of the condition itself. Biomedical authorities situate epileptic episodes as bodily deviations from the ideal; hence, AEDs (anti-epileptic drugs) are prescribed immediately to quell seizure activity. As one neurologist, Dr. Reed, states, 'The only acceptable level of control is complete seizure-freedom.' Where there is success, it is presumed, quality of life is enhanced, or at least unharmed. If the body remains resistant to medications, however, a process of trial and error begins to find the correct drug or combination of drugs to minimise how often seizures occur. It is possible to critique essentialising claims about an apparent absence of illness equating to an improved quality of life, drawing on testimonies advocating the search for an *acceptable balance* that allows individuals to characterise epilepsy as something that they 'live with' rather than necessarily 'suffer from'. Reducing seizure frequency to zero is very often a personal triumph, but we should not ignore those for whom the occasional seizure is preferable to the short and long-term effects of sometimes disabling medications. The study of epilepsy adds to literatures on the geographies of chronic illness and impairment (Dyck 1995a; Moss and Dyck 2002; Moss 1999) by showing how health-related conditions might be experienced intermittently, or controlled completely, but their psychological impact may still persist even when symptoms are entirely absent. How people adapt to the condition, even when their experience of it is minimal, does in part structure the temporal aspects of everyday life, a point deserving of greater attention.

From the questionnaire results, 36% have not experienced a seizure in the year preceding their response⁹³ (see **Table 7**).

Table 7: Seizure Frequency

	Response Percent	Response Count
I have had no seizures	36%	49
Less than one seizure a month	22%	30
One or more seizures a month	17%	24
One or more seizures a week	17%	24
One or more seizures every day	8%	11
Number of responses:		138

⁹³ This is below the 52% of the population of people with epilepsy in the UK who are seizure free (JEC 2011), perhaps reflecting ES's membership, who typically have harder-to-manage epilepsy.

It is worth emphasising the difference that gaining control of seizures can make to the temporal experience of everyday life. For example, consider the following statistically-significant contingency table (for an overview of contingency tables, see CHAPTER THREE) that shows how the normal socialising of seizure-free participants is usually disrupted far less frequently:

Table 8: How much does epilepsy impact on your normal socialising with family, friends or groups?

		Never	Rarely	Sometimes	Often	All The Time	Total
Seizure-free	Count	28	6	7	3	1	45
	Expected Count	14	8	13	5	4	
Not seizure-free	Count	12	16	29	12	11	80
	Expected Count	26	14	23	9	8	
Total		40	22	36	15	12	125

The amount of seizure-free people whose social life is *never* affected is double the expected count, whereas for people who still have seizures the proportion is less than half of what is 'expected'. This is suggestive of the temporal freedoms that seizure-freedom tends to unlock.

If an acceptable balance of medications is found soon after the onset of symptoms, the individual may *never* need worry much about epilepsy. The trajectory of their condition may be rather linear; that is, seizures can be controlled promptly and *stay* controlled. Few changes over time means a person can live relatively free from epilepsy-related constraints, and may feel that their daily routines and life prospects are framed almost completely without regard to the condition:

No, it doesn't affect my life at all. I lead a completely normal life. And I don't really think about it at all; you know, after the initial period. I have confidence in the medication. And it never enters my mind that I might have a problem. (James)

Even if restrictions imposed initially, notably the loss of one's driving license, cause a massive disruption, seizure-freedom means that individuals can *regain* their license after one year and with it a sense of 'normality'. This 'normality' facilitates the retention of pre-symptomatic identities:

From the day before my first seizure until now I don't think there's been a great deal of difference in either my outlook or how I live my life or how I respond to things in my life. So I don't think there's any change, or I don't think it's caused me to become a different person. (Chris)

For Anna, the only 'evidence' linking her to epilepsy is that 'I take my medication. It's part of what I do every day. But, no, from one day to the next it's not on my mind.' Seizure-free interviewees rarely acknowledge that such regular practices impact on everyday life, but – in teasing out the

'mundane' details of their routines – it is revealed how medications are to be taken at particular times, usually in connection with other routines such as eating. Because these practices become 'like clockwork', they are no longer perceived as being linked to 'illness': they represent an *addition* to individuals' lives usually requiring nominal temporal conscientiousness. A greater challenge is presented when routines or practices are *adapted* to accommodate the volatile body. For several participants, subtle changes to their habits (that may or may not have an impact on their epilepsy), including minimising alcohol intake and regulating sleep patterns, are maintained purely for their positive lifestyle outcomes. To this end, routine alterations can seemingly be integrated unproblematically into one's identity and practices. The only time that Debbie is reminded of her condition is when 'filling something in that had a medical aspect to it', or seeking advice based on changes to one's normal routines or functioning; for example, in pregnancy.

With few changes over time, questions arise as to whether one does indeed still 'have' the condition. The relative absence of symptoms instils a socio-temporal distance between self and epilepsy:

As I worked through the survey, I realised all my experiences are very much in the past - and provided I keep up with the medication, I don't envisage any further problems. So feel free to trash this questionnaire if not relevant to your research. (Anonymous questionnaire respondent)

With no apparent symptoms, the withdrawal of medication for some represents the final hurdle in 'leaving behind' epilepsy. All but one seizure-free participant (Jennifer, whose epilepsy has been halted by brain surgery) have not discontinued their medication for any lengthy period of time for various reasons. Debbie, for example, experienced the return of seizures because of her attempted withdrawal:

When I was in my late twenties I decided to go off it because I was on such a small dosage. I said 'I think I'll maybe not continue because I don't really have any need.' And then a year later I was in my work and I had a huge seizure. I didn't really want to be on pills for the rest of my life. I took a chance; it didn't work out. (Debbie)

Reflecting on the lack of disruption that medications pose in her life, Debbie elects never again to take that 'chance'. Other participants feel that they might consider attempting withdrawal in the future, but only after 'enough time' had passed. Until then, it is not worth the risk because of the still-fresh memory of seizures. Furthermore, in possible addition to experiencing disabling withdrawal symptoms, normal routines would be temporally disrupted because of having to suspend one's driving license in case of a breakthrough seizure. Continuing with medications despite an ostensible absence of symptoms places the individual in a somewhat contradictory position: they live with epilepsy, but function fairly effectively, and so are both ill *and* healthy

(Moss and Dyck 2002: 99). So long as medications are taken regularly, losses of bodily control need not be anticipated and the fear of a 'spoiled identity' is suspended.

Contrary to these voices, prolonged periods in reaching and maintaining control tend to leave people with persistent thoughts of epilepsy. For Margaret, knowing what it is to be *out* of control enhances her appreciation of being *in* control:

I was diagnosed with breast cancer and I've had a lumpectomy and I had radiotherapy for it and I'm clear at the minute. [...] I was thinking 'I don't know how I would cope with all these things and then be having seizures as well!' And now I'm on my own [following the death of my husband] it's more important that I don't have seizures; and at the minute I'm not, thanks to the drugs, which is amazing and wonderful! (Margaret)

Gaining control after travelling a stretched, rocky road is for some a cause for celebration. It marks a turning point when, supposedly, the fear of seizures can take a back seat and the individual is relieved from discussing or disclosing their condition as 'problematic'. Claire feels an enhanced sense of well-being having been six months seizure-free, which means, for the first time in a long time, she feels optimism for the future: 'I'm actually starting to think, 'Well, I could actually be driving here!' [...] I've been a lot more positive, a lot more happy. I feel as if I've got this new energy.' However, due to her altered perspective on temporal (in)stability, Claire's joy is always provisional. Despite not having had a seizure since his brain surgery, Gordon discloses that:

I have to live with it all the time because you never know whether it's going to come out from around the door. [...] It ruled my whole life. Even now it *still* rules my life because you sometimes think 'Isn't it great that there are no more fits?!' (Gordon)

The potent biographical disruption marked by the onset and repeated unpredictability of epilepsy means the thought of seizures returning continues to affect Gordon. Nevertheless, he hopes to reclaim the time that he has 'lost': 'I might be able to do what I wanted to do when I was younger: and that was enjoy science.'

Medical belief that control of seizures represents an 'end' to one's struggles must be unsettled. The impact of gaining control is inherently entangled with such variables as those addressed in previous sections, such as the number of years one has lived with epilepsy, not to mention numerous other personal, social and economic attributes. For example, the sudden suppression of symptoms after many years of living with epilepsy might leave an unexpected absence, as the parent of an adult living with epilepsy reveals:

If you take something away from somebody that they've lived with for all their life, you've got to replace it with something. And if you don't replace it with something you can get all sorts of personality issues. [...] If [my son's] epilepsy was to go away tomorrow, [my wife] and I wouldn't

know what to talk about a lot of the time, you know. It's just that our life is built up around it. And if you remove it, then you're removing what has become *just part of us*. You're left with a *vacuum*.

In this remarkable admission, living with illness (one's own or a cared-for person's) is painted as part of an existential condition: its associated affects and effects are a *way of life*. Ironically, the disappearance of a condition to which self and others have become accustomed, especially when the individual does not realise the extent to which it is 'normalised', may *destabilise* identities. Thus, we cannot straightforwardly assume control of seizures equates to an enhanced quality of life. Indeed, symptom suppression, although desired by most, may be achieved by increasing the dosage and number of medications, but sometimes to the detriment of one's sense of embodiment. If we return to the data in **Table 8**, Joan is the one person who, despite being seizure-free, feels her social life to be affected 'all the time' by epilepsy. Seizure control is not the 'be all and end all', for medication side-effects impair Joan's everyday functioning to a greater extent than 'the odd seizure':

I was absolutely fine [...] if you call falling asleep every time you sit down [and] needing match-sticks to keep your eyes open 'fine'. Then yes, I was absolutely 'fine'. But comatose. And so unhappy and fed-up, and putting on weight because every time I sat down I fell asleep. (Joan)

The price of Joan's seizure-freedom is the creation of additional impairments. She feels herself 'a product of the medication,' which, because it affects her memory, means that 'You only live in one day. And it's the same day always, everyday: boring.'

Joan's temporal experience is limited to the moment: she constantly battles her body's urge to sleep, with a knock-on effect for her self-esteem and capacity to work, socialise or plan for the future. She is hence caught in a 'catch-22' situation: because a doctor has 'signed-off' that she is 'seizure free', her entitlement to financial assistance (including her bus pass) has been lost – even though seizure control has reduced her ability to function. Thus, in the current political-economic climate of 'austerity UK', 'I'm *not disabled enough* to get any allowance' (Joan). While Joan and her husband are able to get by on his salary and their combined savings, other participants fear that denial of 'incapacity benefits' and 'disability living allowance' will force them back into the workplace, even though these busy, stressful environments are seizure *catalysts* (Philo *et al.* 2005 similarly find that people with mental ill-health are hurried back into employment). This 'catch-22' demonstrates how becoming seizure-free is not always conducive to a 'healthy' socio-economic situation. Several participants suggest that, because seizure control allows government to withhold financial assistance, it is merely a 'tick-box exercise' acting as a smoke-screen for remaining wilfully ignorant of the lived realities of living with epilepsy.

THE TEMPORALITIES OF INSTABILITY

SEIZURE FREQUENCY AND THE SEIZURE OF SELF

When epilepsy is uncontrolled, the extent to which some sense of a 'steady rhythm' of life may be negotiated depends in part on how often seizures are experienced. Various studies find 'seizure frequency' to be the most consistent predictor of 'impact'. Baker (2002) suggests that people with higher seizure frequencies are more likely to report experiences of stigma, corroborating previous studies showing that seizure frequency is highly correlated with, and predictive of, psychosocial impairment (Jacoby *et al.* 1996; Baker *et al.* 1996; Baker *et al.* 1997). While these studies advance understanding, they afford little attention to how different seizure frequencies relate to what people actually feel and do. 'Seizure frequency' (in this research, statistically the most significant epilepsy-related variable with 12 key relationships) suggests how often episodes tend to occur, but also the time *between* them. If seizures cause almost continuous disruptions, it becomes increasingly difficult ever to establish oneself in the time-spaces of everyday life before another occurs. Time, therefore, is significant not just in terms of how long one has lived with a condition, but also in relation to the times of the condition itself: when it appears, when it is hidden or visible, how often it fluctuates and how this in part affects the (re)negotiation of daily life and functioning-in-place.

'Stability', as discussed in relation to people who are seizure-free, comes from maintaining a sense of self and routine. People who experience seizures (relatively) infrequently perhaps cannot take-for-granted their everyday rhythms, but, with resolve, 'it doesn't necessarily have to be any other problem: it's just that you have a fit every so often. You can overcome it just by the matter of your mind and the way you approach your life' (Holly). On the other hand, the experience and anticipation of frequent epileptic episodes is characterised as not being able to maintain a sense of 'normality' compared to one's previous self because of constant disruptions. For example, frequent seizures make it difficult to find or maintain employment. **Table 9** reveals that experiencing even just one seizure per month – lasting a matter of minutes – renders employment increasingly insecure (see CHAPTERS FOUR and FIVE, however, for evidence that what constitutes a 'seizure' is highly variable and experienced very differently by different people). 85% (n = 17) of people whose seizure frequency is one or more per week find that it impacts on employment 'often' or 'all the time' (see CHAPTER SEVEN for a discussion of the socio-spatial challenges associated with the workplace). When experiencing one or more seizures every *day*, 78% (n = 7) find this to be the case. Livelihood and lifestyle are sustained by one's continuing place in employment, but a few extended and/or frequent but brief absences from the workplace may result in the complete destabilisation of everyday life. In turn, opportunities for socio-economic recovery become limited, as for this anonymous questionnaire respondent: 'Life is very

Table 9: How often does epilepsy impact on the types of work (paid or voluntary) you are able to do?

		Never	Rarely	Sometimes	Often	All The Time	Total
Seizure-free	Count	23	7	5	3	5	43
	Expected Count	11	7	7	7	11	
Less than one seizure a month	Count	3	10	5	2	5	25
	Expected Count	6	4	4	4	7	
One or more seizures a month	Count	2	1	6	7	5	21
	Expected Count	5	3	4	3	6	
One or more seizures a week	Count	0	1	3	6	11	21
	Expected Count	5	3	4	3	6	
One or more seizures every day	Count	1	0	1	1	6	9
	Expected Count	2	1	2	1	3	
Total		29	19	20	19	32	119

unpredictable and I find it difficult to put myself forward for work and have even got house-bound at times.' When people become house-bound, temporal experience is characterised as 'negative' or a struggle: somewhat contradictorily, often the individual feels the need to speed up their 'recovery' at the very moment that their recovery relies on 'slowing down'.

The seizure of self – when epilepsy is experienced as radically restrictive some or all of the time – relates to particular routines and activities. With frequent episodes, individuals may withdraw from social space and relationships because of a loss of confidence:

I was engaged, and I ended a four-year/five-year relationship because I was taking seizures every week at that point, and I thought, 'I'm not having somebody look after me or anything like that.' [...] I was reluctant to meet anybody new because I'd have to go, 'By the way, see if I go out with you then, I've got epilepsy and if I take a seizure [you may have to deal with it].' (Claire)

The embodied affects of frequent episodes may also *impose* temporalities that are detrimental to social life. For example, Patrick finds that he is unable to go out and meet people because of the late nights associated with bars: 'I'm too tired to go out clubbing on the gay scene – it starts at about eleven o'clock at night, so I'm usually tucked-up in bed or watching a DVD at that time.' Further, the neuro-biological effects of recurring seizures impact on general disposition such that people *do not want* to socialise:

There were periods when you just felt unwell for days on end. You just felt really unwell, you were impatient with everybody, you didn't feel right, you didn't want to associate with anybody. You kept to yourself *because* you were unwell. (Archie)

Individuals might then be invited out socially less often because, according to a social worker, Bruce, 'suddenly they're not fun to be around.'

Compromised performative abilities brought on by frequent seizures made Gordon lose all hope:

The big problem was that fits were a bit like getting hit with a baseball bat: you were bruised; you knew the bruising would go away, but no sooner was it away than you were hit again. [...] The worst was at university: I must have had about seven a day. [...] I couldn't have cared if I was here today or tomorrow because I was sick, the body absolutely shattered mentally and physically from one fit to the next. [...] I just wanted rid of it. I was sick of it. It was like a sentence to pain. (Gordon)

Gordon's torturous experiences suggest that frequent seizures completely *shatter* body-self-time-space relations. Epilepsy can seem as if it has a hold of one's life: just as one seizure passes, another arrives. The cumulative effect on the body that needs reordering *time and again* is the seizure of self. The fact that seizures made it so hard to function in any one place, because of having constantly to tend to the body, meant that Gordon was trapped very much in the present, and the longer this continued the less of a future life he foresaw. Holly explains the horrors, frustrations and totally debilitating consequences associated with having seizures so frequently:

From seventeen onwards, I started going up towards sixty a month. So that is when my life basically stopped. And, I mean, I was screaming all the time. I remember screaming because I was having so many in a day; every time one came on I was starting to scream because I hated it so much, and it was taking up so much of my life. [...] Then I had surgery and it dropped down to about thirty a month. It halved them. It might not sound brilliant, but it made a dramatic difference to *me* because I had them in clusters and I'd have three days [seizure-free]. (Holly)

Holly's screams personified her torment at being denied the time to develop a life outside of epilepsy. When she experienced seizures daily, even hourly, her temporalities became *unmanageable*. In essence, time *stopped* because any thoughts of self-regulation were completely remote; all phenomenological content seemed to disappear as the time-bomb of her body exploded in seizure once more.

REGULARLY IRREGULAR/IRREGULARLY REGULAR

Given the potentially debilitating temporalities of living with epilepsy, it is important to establish the extent to which frequent seizures can be managed. How people view the everyday temporalities of living with epilepsy can best be described by characterisations of them as either 'regularly irregular' or 'irregularly regular'. The term 'regularly irregular' stands for when emphasis is placed on making regular plans that are able to accommodate the unpredictable, episodic nature of epileptic episodes. During these times, individuals will attempt as far as possible to work *with* the contingencies of the erratic body by keeping plans as open as possible and warning

others that they are liable to change. When everyday life becomes 'irregularly regular', the individual is more preoccupied with the irregularity with which their life can be regulated without the threat of seizures. This is when the temporalities of living with epilepsy are framed as *confounding* a 'normal' life, and hence are an on-going struggle. These portrayals are important for thinking through how disturbed temporalities, at different points over time, and perhaps relating to fluctuations in symptom frequency, are actually *lived*.

To contextualise the extent to which individuals feel in control of their life and times, it is crucial to appreciate how different epilepsies at different points in the lifecourse give rise to very different levels of impairment and (dis)ability. The frequency with which one has seizures may never reveal a pattern of any kind; or, if one has more than one type of seizure, certain types may come in patterns whereas others appear randomly. Someone might have an identifiable 'seizure frequency', but this can shift suddenly or over an extended period to a different, (ir)regular pattern. One anonymous questionnaire respondent explains how: 'tonic clonic can be once a month, once a week, once every few months, it's very variable but I have several absences/*petit mal* daily,' while another confesses to having 'spates whereby I may go for three months with no seizures then have three in a month.' Renae characterises her symptoms as progressive:

When I was younger, it was only so many times a month, and they were just *petit mal* [absence] seizures. And, as I slowly got older, it was increasing from so many times a month to a *week*. And there was also *petit mal and grand mal*. [...] And then so many times a *day*, which is what I am now. (Renae)

Keeping in mind these *potential* changes over time, I now illustrate the uncertainties of an anonymous questionnaire respondent to show how the onset or *return* of seizures may set in motion quite distinct illness trajectories.

How one defines the past, present and future is integrally linked to one's current illness 'status'. As shown above, the control of seizures does not always assure their absence from one's thinking or that they will *remain* controlled. The following anonymous questionnaire respondent (who revealed she is: female, aged 21; diagnosed aged 11) provides a powerful testimony to the volatile temporalities of epilepsy. When asked her seizure frequency, she responded:

These questions are hard for me to answer because I didn't have to think about epilepsy for six years and in the past two weeks this has all changed. I also don't know if the epilepsy I have now is or will be similar to what I had before.

If this individual had filled in the questionnaire just two weeks earlier, it is safe to assume that her answers would have been very different. Over the past six years she had grown accustomed *not* to having seizures and may reasonably have thought that they were behind her. Their return

meant that both her present and future life became uncertain and unstable; her identity transitory (for a discussion of relapses of MS, see Kalb 2007). Seizures would conceivably reignite on-going processes of (inter-)corporeal struggle and potentially destabilise the socio-materialities of everyday life that she had perhaps begun, once more, to take-for-granted. Furthermore, given that she had not had a seizure since the age of 15, their return at this stage in the lifecourse signalled the *first time* that she was forced not to drive and experienced insecurities in employment. While things remained unclear, her identity emerged unevenly as she negotiated epilepsy materially through her time-space arrangements:

I am currently experiencing fatigue and light-headedness due to starting new medication. [...] I have now significantly reduced my alcohol intake just in case it triggers a seizure. I am also going to try to get more sleep so that a seizure cannot strike if I am run down or tired. [...] I was seizure free for so long that when I applied for jobs etc. it was never an issue so I never had to hide it.

As an *anonymous* response, it is not possible to ascertain whether this was indeed a temporary 'blip' or the beginning of a new cycle of active epilepsy, but using research data constructed with *other* participants we can illustrate different trajectories as they might be played out in parallel time-space continuums.

If the individual experiences a 'blip', it is fair to assume that they will be wary for an extended period that seizures might return, during which time they will perhaps monitor their body closely and practise a more regulated lifestyle (less alcohol, more sleep). Over time, they may tentatively slip back into the same frame of mind as when they 'didn't have to think about epilepsy' (assuming the relative absence of further relapses). This pattern was experienced by James, who, after a mild onset became controlled, had a potent setback and then regained control:

I just took the medication and I was fine. I never did any more because it was only four [seizures] in two years, it was just a few minutes. It was then after I came back from Spain, and I had three or four within a day, I thought to myself 'This is something that I'm going to have to try and get a much better handle on, a much better understanding of.' And just to increase my medication. [...] If I watch myself I'll be OK. (James)

The return of active epilepsy, on the other hand, means coping with seizures on an intermittent, (semi-)regular basis. It could be that within weeks or months a new medication is found to control episodes; however, the trial and error of drugs may impose an unstable cycle of demands or constraints on the person's time (the decrease or increase of seizures, travelling to and from hospital, time off work). The condition may be milder than the 'first time', meaning that the

individual's experience of it is less imposing. Alan, however, had to learn to deal with a whole new catalogue of issues: 'As I've got older, the problems have got more 'up-market'.'

We might speculate that the worst part of the anonymous respondent's experience is *not knowing* if or when another seizure might occur. It is always possible that every seizure is the last; thus, the more time that passes *after* an episode, the more the individual might invest in the hope that the influence of epilepsy is diminishing. For Claire, every seizure means her calendar must be reset to 'day zero': 'I just feel so stung every time that I have one because I just think 'That's another year on to my driving.' I think that at *that time* that's when the consequences just hit you.' Indeed, for a large proportion of participants, the chance of regaining their driving license after being seizure-free for one year represents a massive milestone when counting the days:

I was thinking 'This is great; I'm doing really well, I've not had a seizure since the 27th February, so I'm on a roll here!' [...] That respite in-between: you build yourself up again, and then think 'Maybe that's it this time; maybe I'll get my license back,' and then 'Bang! Bang! Bang!' (Brian)

The precariousness of hope is exemplified by a sense of loss with each breakthrough episode. For Brian, time is a (fickle) healer. The longer he goes without a seizure, the more his sense of self is 'built-up'; but his expectations set him up for a fall, both material and psychological: just when he thinks his epilepsy might have become regulated, he experiences another seizure. Brian is frequently exasperated at his lived temporalities being 'irregularly regular'. If he only knew whether or not to expect seizures, he could cope, but from the seed of optimism springs betrayal. Brian's hopes for the future rise and fall with each period of *détente* because of his refusal to accept that the temporalities of living with epilepsy are, to an extent, out of his hands. He never fails to keep a detailed diary of his seizures, including when, where and possibly why they happen, in anticipation that a pattern might emerge that will allow his daily routines to become '*regularly regular*'.

Several participants, having been disappointed in the past by their unpredictable bodies, explain how they have come to accept and *expect* seizures as inevitable and so deal with them as the contingency arises:

One gets to stage where one assumes that one *will* have a seizure. Therefore, one has to be *prepared* for it. It's strange way of looking at it, but, given the nature of the disability and the unpredictability of it, that's how one slowly grows into the mindset of living with it. (Patrick)

Maureen, for example, treats epilepsy as 'regularly irregular' as a coping strategy: 'I know it can happen at any time. I'm OK until the next seizure, and that's it.' In always being prepared for the contingency of a seizure, she is able to go about her daily routines and accommodate the volatile body when it *does* seize. By making flexible plans, she lives relatively less constrained by the

tyranny of attempting to second-guess the times of seizures – they will happen whether she anticipates them or not. While epilepsy has caused certain embodied constraints, Maureen feels that she 'has' time, and can 'use' it as she wishes. Freeing the self from the quest for control (Charmaz 1995: 674) enables Maureen to experience the *moment* rather than be preoccupied with, and paralysed by, past 'ideals' and future insecurities. While the socio-material impact of epilepsy remains a constant, and sometimes painful challenge, renegotiating her expectations facilitates a new integration of body-self-time-space such that she struggles *with* illness to help regain an implicit sense of control. Hence the strange becomes familiar; the unpredictable becomes predictable; illness becomes subjectivity (Charmaz 1995: 673).

FROM THE MINUTE YOU GET UP TO THE MINUTE YOU GO TO BED: (RE)NEGOTIATING DAILY RHYTHMS AND ROUTINES

The temporalities of everyday life cannot but be shaped by seizures or the side-effects of medication. The difficulties that people experience in fulfilling their 'usual' roles or activities, at the same pace or times, constitute the experience of having epilepsy and associated bodily limits. That individual do perceive 'limits', however, opens up the space for their negotiation. This process is complicated by both fluctuating symptoms and dynamic relationships with others, who regularly undermine the time-space needed in order to maintain a comfortable balance. Whether epilepsy is characterised as being 'regularly irregular' or 'irregularly regular' at different times is particularly meaningful because it is indicative of how easily or not people feel that they can adapt their routines in respect of the (sudden or longer-term) temporalities of their changing bodies. That seizures, and the factors that trigger them, can appear at any time requires the careful and creative management of daily timings, which in some cases helps to tame the volatile body, but may also leave one 'out of synch' with the lives of others or the demands of the workplace.

As Patrick explains, epilepsy 'dictates *how* you live [and] *what* you do on a daily basis. That is why security and stability is so important in an epileptic's life; because it helps them do their daily tasks in a better way.' Different lifecourse contexts are indicative of the types of routines that people (re)structure. During periods of transition – for example, when changing jobs or moving out of the family home – living with epilepsy is a *pre-condition* for how unique circumstances are (re)negotiated. Kate, for instance, plans for new activities knowing full well that 'it does affect everything you do from the minute you get up to the minute you go to bed.' As such, she moulds her days in respect of her expected temporal highs and lows. This is most obviously in reflection of the effects of Kate's medication. For example, she arranged our interview purposefully ahead of her regular medication time: had she not done so, she revealed,

'I'd be lying here, kind of stoned.' Patrick, whose frequent yet 'consistent' seizures means that he lives a rather solitary, home-based existence, describes how:

Usually, after breakfast I sleep for three hours, have lunch, and then sleep for another couple of hours. I only really get going around about five o'clock. And if I'm on the computer, then I can work solid for about four hours; and then I have tea, and then I watch TV for a couple of hours, and then it's bed. And then I'm asleep for about six hours solid or more. And then the whole cycle starts again. [...] Everything is about *timing*. In my daily routine, it's when I'm most alert I do most of my work - around about five o'clock. If I'm not doing anything specific to keep me alert, I'm usually asleep. But when I'm alert, or when the drugs are sufficiently weak within my system so that I become alert, then I take advantage of that period. (Patrick)

Nicola carefully manages her time to avoid triggering episodes by *clearing* time:

Rather than work in the evenings, when I get back [home] I'll purposely just collapse in a heap and I'll try and control things that way. [...] Obviously with planning ahead, when you know work is going to be particularly busy, then try and keep the time clear.

Laura avoids tiredness and stress by taking afternoon breaks. Before doing so, she makes a list of everything that needs to be done, and when. If she decides to have a 'nap', 'I'll maybe put on a load of washing before I go to bed, and by the time I get up that's finished'. Turning on her washing machine for the duration of her sleep means that Laura's methods for control are shaped relative to her household chores: in this way, her 'down time' is not wasted time. Notably, such strategies are shaped according to the time-space contexts of peoples' everyday lives. Laura, for example, reveals that she will not have children or seek a full-time job while her epilepsy-related routines continue to dominate her time; although this is liable to change if and when her epilepsy does.

If symptoms become increasingly aggressive or frequent, daily schedules become difficult to follow in respect of individuals' limited strength. When Gordon feels able, he also feels that he needs to (over-)load his time with activities. His temporal experience is thus characterised as urgent and pressing:

To get things done you'd have to get them done while you were well, which was extra stress on the body. So if somebody asked me to write or to get something done for school I'd get it done today, because if I put it off there might not be another opportunity. (Gordon)

Compressing time in this way, or spontaneously breaking from established routines, can increase the risk of seizures' disruption (due to factors such as tiredness, taking medications irregularly, not eating). Participants are, however, clearly aware of the precariousness of balancing their use of time and the potential aggravation of symptoms. Patricia explains that when she feels ill she

will 'prioritise and decide what definitely needs doing, what is urgent. If I can put things off, I will. Because I do have to slow down.' Alan describes how he anticipates non-regular events by *premeditating* changes to his routines. When he throws dinner parties for friends (which he especially enjoys because he worked in kitchens before being forced to retire), he and his wife, Faye, ensure that he spaces out and times his activities to avert stress from having too much to do in too little time:

Faye: Our routine would be to sort of plan round about it, and just to make sure that there were times when he would be able to rest. If folk are coming round for a meal he'd probably start preparing the week before – the dessert or whatever.

Alan: I'd make a dish that I could put in the freezer. I'll have the table set the night before or during the day when they're coming. And during the day when I'm doing my courses, I'll know that I have a wee bit of time in-between, so I'll go for a wee sleep in the afternoon. She'll be out with her friend shopping, so I'll get peace then. And I'll know when she gets back at five o'clock that I've got everything done.

Faye: It's just a sort of normal.

While this may not be so unusual in comparison with *anyone* throwing a dinner party, the consequences of an 'unsettled' embodiment would require that the dinner party be cancelled.

Settling into a daily rhythm to function with, and contain, illness is held in tension with multiple aspects of identity and socio-material relations. Brian, who was diagnosed at age 40, finds that the timings of his epilepsy are incommensurable with his marital routines, in addition to socialising and finding employment. Tiredness is a cause *and* effect of seizures, and he is frequently caught in a vicious cycle of uneven sleeping patterns:

If I have a seizure it affects my ability to drop off to sleep over the next two or three nights. So you're body-clock is knocked to pot. You go to bed shattered, you're desperate for sleep, but the brain will not switch off. [...] You've just got to get up and go and read a book, play on the laptop until seven [am] or something, then go back to bed. But by this time the birds are all chirping. [...] And when you do get to sleep, you end up sleeping until two in the afternoon. So when your wife goes to bed at eleven o'clock, you're wide awake. [...] And it can take a week to get back to normality. You slowly try to discipline yourself to get to bed at a reasonable time and then get up in the morning. If anyone asks me to come to anything just now in the morning I'm struggling, absolutely struggling. So between the medication and the seizures knocking your body clock out of pot, your whole day is dominated by either being wide awake or knackered. (Brian)

The disempowering temporalities of epilepsy are reflected in Brian's lowered self-esteem. His practices of sleep, sleeping and sleepiness are now fundamentally altered, including his pre- (and now post-) 'bed-time' rituals. Furthermore, he feels as if the embodied intimacy of sleeping

alongside his wife has been disrupted. Kraftl and Horton (2008: 511) note sleep as a causal variable in a 'vast spectrum of physical and emotional ill-health'. Here, disrupted sleep is not so much the 'cause' of ill-health as *entangled* with it. Such is the importance of sleep 'in producing and delimiting the everyday time-space rhythms and rituals' (Kraftl and Horton 2008: 512) of people with epilepsy that everyday relationships, constructions of 'difference' and opportunities are produced through and spaced around their (ir)regular sleeping patterns.

How people work around the temporalities of epilepsy may be contrary to the regulation of employment or established roles. The destabilising of one's gendered role within a family context has repercussions not only for self-worth, but for other people and one's relationship and daily schedules with them. Patricia feels responsible for her entire family's renegotiations, which gives rise to the impression that her role as an 'ill woman' supersedes that of 'mother' and 'wife' (Moss and Dyck 2002: 129):

With the kids getting used to me being able to drive [when my seizures were controlled], and then having to go back to using the bus, it can be very frustrating for *them*, which makes me feel even more useless because I can't do it. Which is another thing: that puts on the emotional pressure and more pressure on my husband. (Patricia)

Valentine (1999) shows how the positive masculinity of a male self can be unsettled and threatened when individuals are forced, through impairment, to spend more time within the feminised sphere of the home than in masculine places of work or sociality. Steve's withdrawal from paid labour means his presence at home has increased; he is 'embarrassed' at not being employed, and feels obliged to justify how he spends his time for validation. Having left his job, Brian feels deprived of male sociality and the sense of achievement associated with completing workplace tasks (for work on masculinities and health, see Courtenay 2000; Thien and Del Casino Jr. 2012). Being 'out of synch' with the (working) world makes him 'feel a waste of space. It makes you feel 'what a lazy, good-for-nothing runt'.' Part of this sense of shame lies in being unable to fulfil his traditional gendered role:

I used to be the provider; so had my father and my grandfather before him. So I've got this work ethic. The male, the man, should be the provider, providing for his family. But when you get hit with this illness, it makes you feel ridden with guilt because you're not earning enough to sustain the house and the family. (Brian)

Brian is certain that the temporal rhythms of the jobs that he is qualified to do cannot be reconfigured in line with the temporalities of living with epilepsy (as a painter, he had been

required to 'get up at six in the morning and drive a builders' van with painters to Hawick or Kelso') and so has never considered exploring the possibilities of 'reasonable adjustment'⁹⁴.

Institutionalised, less male-dominated, settings also have a complex relationship with 'reasonable adjustments' covered by the Equalities Act. Some individuals are able to work around the times of their epilepsy because of organisational policies, such as flexible working hours, which for Ian are 'a God-send!' Others feel that, despite employers making 'positive sounds' about flexibility, the realities and pressures of everyday working are far removed. Patricia purposefully chose a part-time job as a care worker with shift patterns arranged so that she could avoid working late, or for too long. As she found to her detriment, though, shift work meant frequently being 'required' to work according to the shifting needs of the organisation, which were unsympathetic to *her* needs:

I know that if I was having seizures the night before I might not have been on par; but I can't *not* go to work. I don't like letting people down, and I wouldn't 'swing the lead'. People look at me: 'Oh, you *look* alright – you can walk, you can lift.' But looks can be very deceiving. [...] Employers don't understand: they try to get you to do extra hours at unsociable hours when *you* know what you're capable of. There's a reason that you've gone for a job at 22 hours rather than the job at 37. It's not because you only want to work part-time. I know that after a while, if I do do more hours for a long period of time, I'm just going to be laid-up. (Patricia)

Patricia's employers did not appreciate that working longer hours in the short-term would likely become counter-productive in the medium-term after a surge of symptoms. This placed her in a contradictory position, whereby the better she was at limiting her everyday routines, the less seizures she experienced, but this concurrently increased outside pressures to take on additional responsibilities. The last straw came when Patricia found herself compelled to work a night shift during which she was solely responsible for all the patients in a care home. She managed to get through it with the help of understanding others, but the unsympathetic attitude of her boss left the impression that the legitimacy of the temporalities of her (hidden) illness was in question or was being trivialised (Moss and Dyck 1999b; Driedger *et al.* 2004)⁹⁵. After that, she felt that she had little option but to resign for the good of her health (and perhaps for that of her patients). This facet of the geographies of chronic illness and disability enhances research focussing on how

⁹⁴ The Equality Act 2010 requires employers to make reasonable adjustments, whether temporary or permanent, to support disabled people in the workplace. These adjustments can be very specific to the individual, including: allowing a person whose seizures occur while sleeping to start and finish later; setting a fixed shift pattern for people who find their seizures are triggered by tiredness or varied shift work; getting another employee to do part of the person's work that they cannot do because of their epilepsy; re-arranging working hours for a person who has lost their driving licence and cannot get in on time by public transport; providing a quiet place where a person can rest after a seizure; providing a support driver for some journeys where the person cannot drive because of epilepsy and public transport is not practical (see <http://www.epilepsyscotland.org.uk/pdf/ES-Occupational-Health-Guide.pdf>).

⁹⁵ This can also work the opposite way: others may presume to make choices for the individual without first checking that they are appropriate. In her work as a teacher, Sue had her number of classes reduced, 'for the good of my health', without first being consulted.

people might consider themselves as disabled in some but not in other spaces (Crooks *et al.* 2008). Importantly here, some people are disabled or impaired, or feel at particular risk, at some but not at other *times* – perhaps in the *same places* – throughout their daily rhythms and routines.

CONCLUSION: DIFFERENT TIMES, DIFFERENT INTERVENTIONS

Living with epilepsy, whether in the momentary experience of a seizure (CHAPTERS FOUR and FIVE) or throughout everyday routines, can disorientate and even shatter time. The 'pace' or 'speed' of life may change, as well as the duration of tasks. 'We' usually talk about 'having time', but people living with epilepsy seem to *lose* time, whether in embodying 'absences' or because of disrupted sleeping patterns reducing one's potential involvement in and with wider society with respect to socio-economic, circadian rhythms. This makes explicit how people 'use' time, which may be characterised as a 'positive' or 'negative' 'use of time'. People may also be obliged to 'slow' down to relieve stress (and other such seizure triggers) because of the frantic pace of life. As Philo *et al.* (2011, on spiritual practices) suggest, people have to carve out a time for 'slowness' amongst the busyness of everyday life. For some people, *finding* the time to be relaxed is relatively easier or more difficult depending on their inter-relational responsibilities with family, work and so on. The notion of 'time as a great healer' may well be true for some people, whose emotional well-being grows with the relative absence of epilepsy. Yet with frequently repeating epileptic episodes, some people are 'stuck' in time, unable to get on with *living* their life and times, as if experiencing their very own agonising 'Groundhog Day'.

Building on Moss's (1999) critique of the failures of biomedical discourse in accounting for symptomatic fluctuations, this chapter has emphasised the importance of the heterogeneous timings and temporalities of chronic illness, impairment and disability. Understanding any one person's experience of 'disablement' (Driedger *et al.* 2004) requires that we take account of the *long-term*, for there are potential differences between individuals who have grown up with health-related conditions and those who in later life are forced to cope with sudden destabilisations of their body and identity; but also too the *short-term*, for the current status and times of the condition itself (when and how often episodes occur and whether this changes) influences the extent to which illness shapes daily life. We must further recognise that temporal contexts and everyday scheduling implicate *others*: the parents of young people diagnosed (counter-intuitively, barriers to inclusion originate just as much in the family home as in the social environment of school), the partners of adults (in creating relational planning strategies) and colleagues at work (especially those with the power to set shift patterns).

The dynamic interweaving of short and long-term illness trajectories (which may run smoothly or shift abruptly with or without each other) with diverse social relationships is in part constitutive of how much, and how quickly, epilepsy may be accepted as part of one's identity, and therefore embedded within everyday practices. When few, if any, symptoms are present, individuals are (sometimes) able to live relatively free from the constraints of epilepsy. However, the person with epilepsy is all too aware of how quickly the body can relapse in the absence of regulation, and so everyday practices are rarely taken-for-granted. Those for whom the volatile body frequently disrupts temporal rhythms may feel isolated through the loss of previously assumed roles. In this case, the body remains as an enemy to 'normal' functioning; whereas a (re)negotiated identity or role, taking into account the temporalities of instability, may encourage the development of new opportunities.

An appreciation of how people with epilepsy creatively negotiate different temporal contexts may help health professionals and scholars better understand why some are able to move through the stages of 'grieving' for lost identities quicker than are others. In this scenario, seizure control should not necessarily be seen as an 'all or nothing' situation. In fact, individuals whose quality of life is reduced with aggressive seizure suppression provide a compelling case for destabilising medical knowledges that do not recognise living well with active epilepsy as simply *living well*.

CHAPTER SEVEN:

DISCIPLINING FAMILIAR AND ITINERANT SPATIALITIES

INTRODUCTION

Completing the time-space couplet started in CHAPTER SIX (on ‘temporalities’), this chapter aims to establish how people living with epilepsy adapt their everyday practices relative to the places and spaces that they inhabit. On epilepsy, Rhodes *et al.* (2008b: 11) conclude that ‘people were disabled by their fears as much as, if not more than, by any actual physical or social cause and these fears were grounded in a complex mix of physical, environmental and socio-cultural factors that could not easily be disentangled.’ Here I take on the challenge of unpacking this contention with an explicitly geographical perspective. I engage with how people subjectively experience their environments to show how material processes and relationships in disparate spaces are negotiated in dynamic tension with the body that may instantaneously be radically destabilised. With a partial return to the (more-than-)phenomenological frameworks of CHAPTERS FOUR and FIVE, I posit that the meaning of different body/object relations are material, relational and situational, in constant flux according to the dynamic mixing of corporeal and cognitive (in)capacity and place.

This chapter explicitly takes up where work in CHAPTER FOUR left off in detailing how people ‘map’ their everyday spaces. Here, instead of considering *momentary* responses to feelings of destabilisation (in aura), I discuss how individuals get on with using and renegotiating space in light of the *many* impacts of epilepsy. Specifically, problems such as memory loss and other cognitive difficulties are assessed for how they transform relations with familiar objects in ‘functional space’ (Toombs 1988: 210). It is shown how relative mind/body (in)capacities have a huge bearing on individuals’ abilities to complete workplace tasks, and so their identities in these places (recalling Moss and Dyck 2001, on the workplace as a site of embodied struggle). By moving to the domestic sphere, work by geographers (for example, Crooks 2010; Davidson 2003) is engaged for insights into how for ill people the home becomes an ‘ambivalent safe space’. In so doing, I move towards a phenomenological conceptualisation of the home as more than just a space of meaning, but also a space of many materialities that unsettle unproblematic notions of ‘safety’ (also seen, for example, in work by Imrie 2010, on ‘disabled spatialities’). Material objects and spaces (hard surfaces, sharp edges, precarious heights, scalding temperatures), once taken-

for-granted as inconspicuous or unobtrusive, now become potentially challenging, injurious or risky to the changed or changeable body.

By situating the home and workplace as ‘destinations’ on individuals’ everyday maps, I then consider how people living with epilepsy perceive, prepare for and traverse the spaces *in-between* these destinations. This follows Parr and Butler’s (1999: 120) call to dismantle concepts such as ‘place’ into component entities (e.g. home, neighbourhood, street) to ‘map’ material spaces which are simultaneously experienced and negotiated physically and socially. Earlier notions of the destabilisation of bodily boundaries (in and around seizures) are developed to show how feelings of (potential) exposure in public places contribute to experiences of insecurely-bounded geographies. It is suggested that, by *keeping to the boundaries* in certain socio-material environments, the individual *embodies* a marginal identity as a way of maintaining ontological security. Reluctance to ‘take up’ social space for any amount of time positions the individual as an ‘itinerant’, one who moves from place to place without ‘laying down roots’. Finally, the implications of how people do travel to and from their destinations, especially after the loss of a driving licence, are considered. It is argued that the manner in which people do so is mediated through the dynamic interweaving of their current ‘condition’, self-organisation, risk assessment, local contexts, socio-economic status and past experiences of walking and spaces of public transport. I conclude by suggesting that, far from any ‘simple’ geographies of ‘containment’, ‘epileptic spatialities’ are unfixed, on the move and incredibly complicated.

ENVIRONMENTAL RE-COGNITION: MEMORY LOSS EXPERIENCE

LOSING ONE’S PLACE

Memory problems are a much-neglected issue in social science literature on epilepsy, although there are several key studies focussing on the impact of cognitive difficulties. Notably, McAuley *et al.* (2010: 583; see also Helmstaedter *et al.* 2003) state that memory is one of the top three concerns of people with epilepsy, even if this is under-appreciated by medical professionals. Their findings, it is argued, ‘serve as a major ‘wake up call’ to address memory problems in patients with epilepsy, regardless of seizure control.’ Disparities between experience and knowledge leaves some participants wondering ‘what is normal?’, especially as memory loss is associated with normal aging (Lyman 1989: 600). Nevertheless, Sue’s summary of current challenges in living with epilepsy is telling: ‘Memory is definitely the thing that I can’t stress enough has caused me more bother than anything, and continues to do so.’ Here I argue that this bother is not just temporal⁹⁶

⁹⁶ Crang and Travlou (2001) commentate on how the temporalities of memories of the city may be lost amongst spatial metaphors. In addressing the spatialities of memory I am attempting to add to the literature on epilepsy and memory

(linked to past events and knowledge) but also spatial in nature, for memory is inherently linked to place, whether for the purposes of ‘getting around’ or recalling embodied social experience.

Not only is the memory located in the body/mind, it dictates how and where we do things. In terms of *going places*, if one does not remember the route with a clear ‘mental map’, help and directions may be required. As Osborne (2001: 4) puts it, ‘identification with particular places is essential for the cultivation of an awareness – an *a-where-ness* – of identity’. Problems with navigating familiar places impacts on autonomous functioning:

I’ve forgotten half the places I’ve been. That’s another thing that you forget: how to get to places – places that you’re used to going to. When I was still driving I couldn’t remember how to get to Fife.
(Maureen)

Environmental cognition (see, for example, Evans 1987; Moore 1979), i.e. recognising place and space, is influenced by spatial memories. *Disorientation* disturbs the unity between self and body and so can give rise to great anxieties when attempting to re-cognise vaguely familiar landscapes. In an intriguing twist on this, Kate half-jokes that memory problems erase negative experiences in particular places such that she does *not* avoid those places when otherwise she possibly would:

I’ve had that many seizures in that many different types of situations, you wouldn’t do a thing. And I suppose one good thing about the bad memory is you forget. You forget that you’ve possibly made a fool of yourself. (Kate)

However, suspecting that something is amiss, that sensation of ‘hold on a minute!’, leaves one feeling displaced. Even the most everyday of habits, defined through the almost unthinking interaction of body and environment, become disrupted. Patrick’s lifestyle is difficult to regulate when mind/body perception becomes disjointed: ‘You think ‘Why am I here? What was I supposed to be doing here?’ That’s how fast your memory goes!’ When this happens, he ‘loses his place’ and so his ability to carry on with his task.

For several participants this gives rise to anxieties over their performance in social space. In another revealing imbrication of the interview process, Holly was conscious of becoming (un)structured in her performance as interviewee:

Sorry – I go back and forwards in bits – I don’t mean to – it’s just a memory thing! [...] Embarrassingly, when I’m doing anything like this I don’t think I’m as articulate as I can be because [...] I can lose sight of the question. [...] I am aware, inside, that my memory limits me dramatically these days. (Holly)

which explicitly focuses on temporal experiences; yet I explicitly regard temporalities and spatialities as unavoidably folding together.

Holly worries that she loses her 'hold' on the situation, bringing into question her embodied identity. Losing one's place disturbs social intersubjectivities and collective senses of belonging when with familiar friends and family: 'You can't relive enjoyable moments and share those moments with mates because you can't remember being there' (Andrew, in a written testimony provided separately); it also causes embarrassment when meeting new people: 'If I were to leave the room and come back in, I won't recognise you. I'll know I know you, but I won't be able to put why. [...] It's terribly rude. And that would make you uncomfortable' (Gordon). Memory hence impacts on peoples' conduct in different places, and so shapes their emotional geographies. Things just beyond cognitive reach agitate one's consciousness as indistinct, distant objects of memory, making one feel literally and/or metaphorically *lost*. Rose (1995: 87-118) argues that: 'one way in which identity is connected to a particular place is by feeling that you belong to that place. It's a place in which you feel comfortable, or at home, because part of how you define yourself is symbolised by certain qualities of that place'. When feeling lost, then, one is 'out of their comfort zone'; they do not *belong*.

Losing one's place in interactions and space is supplemented by material losses. Sue describes how she is constantly misplacing things, while Kate forgets where she puts her AEDs, which can be debilitating because her seizure control is dependent upon a finely-balanced level of medication in her system. Material losses can also relate to participants' sense of a bit of memory 'gone', as if the jigsaw of self has lost some pieces. Patricia reflects, 'it's almost like there's bits of memory been cut out.' For Ian, 'it's almost as if your memory takes a bit of a battering and you can't take in as much [...] and it's as if it doesn't ever get quite back to what it should be.' Participants frequently explain memory loss by drawing on cultural definitions of dementia, hence implanting expectations of 'degeneration' (although, somewhat contradictorily, this can ease stress by increasing a sense of predictability and control: Lyman 1989: 599). Nevertheless, Holly associates the loss of memory with the loss of *self* and this 'is really scaring me.' Everyday life becomes a struggle insofar as people have to deal with regular ambiguities over body and (im)materiality. Because of embodied uncertainty, people feel as if not 'complete' anymore, disordered by an inability to 'stay on path', to hold together the places of their life (Varley 2008; see also Hoelscher and Alderman 2004; Lindemann 2001; Luntley 2006; Radden and Fordyce 2006). The places where one has been, the embodied activities in which one has participated, all contribute to who one is. Loss of cherished memory disrupts a coherent sense of identity:

I have terrible memory. Now I can't remember places I've been to. And that's quite an impact in some ways because I can't remember things I want to remember. Now my husband's gone, I think 'Oh, I had a lovely holiday there, though I can't remember where we actually went. I know we were in Switzerland, but where did we actually go?' (Margaret)

Indeed, people with epilepsy may be left wondering: if I was somewhere with somebody, but I cannot recall so, how can I say that I was *there* (or that I *know* any-body who I do not recognise)? This implicates future spatial behaviour. Further confinement to the home may be the result of feeling that there is no point in going places or experiencing anything that might be subsequently forgotten. As Andrew puts it, ‘memory is my current big problem. Why bother doing things if you can’t remember them?’

‘A PLACE FOR EVERYTHING AND EVERYTHING IN ITS PLACE’: SPACES OF/FOR MEMORY

While at first Steve may sound like a ‘passive victim’ to his cognitive difficulties – ‘I’ve a memory like a sieve, and that’s quite embarrassing. But there’s nothing you can do about it’ – on teasing out his everyday routines, he reveals a repertoire of resourceful and creative ways in which memory ‘blanks’ are negotiated in practice. Individuals may work with spaces for *keeping* memory, where individuals will turn when in need of a ‘refresher’, and for *practising* memory, to prompt actions and activities⁹⁷. These usually run in parallel as a way of enabling a sense of social and processual control. Where spaces *of* and *for* memory are not in place, the threat of ‘uncertainty’ and ‘indeterminacy’ (Anderson 2010: 4) looms large, in part due to the perpetual threat of bodily disruption.

Participants whose memories escape them place greater emphasis on material-visual prompts, such as photographs, old notes and video-recorded moments:

I definitely find it very difficult to make new memories. It takes an awful lot of prodding for me to remember anything. It takes photographs and things for me to remember, like places we were on holiday. (Sue)

Visual evidence may jog the memory, or at least tie the self to particular places (sometimes in unexpected ways). One’s partner or friends, in the act of speaking or reminiscing, may be valued, active ‘archives’: ‘People who know me well enough will give me a few prompts. And like I say, sometimes it will come back if you just jog my memory a little bit’ (Patricia). Margaret describes how ‘I used to say to my husband that he *was* my memory.’ Over the course of our interview, Holly’s husband, Dave, regularly chipped-in with details or stories relevant to the conversation. The interview transcript is peppered with comments such as: ‘I’m very glad that you did remind me of that one! Sorry, because it does help when he does things like that’ (Holly). I asked if Dave was an important source of memory for her: ‘He is. He’s absolutely fantastic.’ Even if she cannot remember the details, Holly feels an embodied connection to Dave’s stories, fostering a sense of

⁹⁷ ‘Anticipatory action’ matters because geographies are made and lived in the name of pre-empting, preparing for, or preventing threats (Anderson 2010: 1). Anderson’s scope is rather more geopolitical than here; however, his contention is no less relevant within the everyday, perhaps mundane, geographies of daily living.

belonging in the places of their life together. Having someone act as a 'gatekeeper' to a shared archive of memories can, presumably, be both a positive *and* negative, for a careless or controlling 'gatekeeper' might offer reasons not to inhabit certain spaces that are otherwise thought to be 'safe'.

Spaces for keeping, storing and accessing memory run into strategies for *practising* memory. Material aids, such as pill-boxes, are crucial for seizure control. 'MediMemos' are mentioned by several participants as their medication organiser of choice. These are small boxes, in which there are separate compartments labelled with different days and times. The individual can divide up their prescription and place the appropriate pills accordingly (Monday a.m., Monday p.m., Tuesday a.m., and so on); which means that, if they forget whether or not they have taken their medication, they can refer to the MediMemo to see whether or not the pills are still there: 'I take sixteen tablets a day. [...] If I forget, I've got wee books called 'MediMemos' [...] So if I forget, and I look the next time I realise I've forgotten my tablets' (Alan). Even though she uses MediMemos, Joan reveals that she forgets whether she has already taken her medication and, without checking, will also take pills reserved for later. She now uses medication wrappers as a material marker of difference:

I often used to wake up in the morning and take a dose, then go to sleep, then wake up again and take my evening ones, which you don't want to do! But I discovered that if I left the wrapping on the evening pills, then, as it went into my mouth, I thought 'Oh!' and I could get rid of them. (Joan)

Of course, such practices do not safeguard against 'forgetting to remember'.

Keeping to routines is a practical way of (un)thinkingly remembering to do things. Each morning, Joan's husband brings her a hot drink that acts as a prompt for her to take her medication. Holly tops-up her medication box regularly as a way to *aid* memory and *stay* organised:

When I'm doing my medication, I will do two days at a time in the pill box. [...] And at the end of two days, in the evening before I go to sleep, I will fill it up again. I always try to be very regimental in checking to see what I've got left and what I haven't. So I know that formulates my everyday life: making sure I've got enough and I *have* taken it. And I will double-check. (Holly)

Besides agreeing with his wife specific places to keep his medication, Ian prepares for work every morning by *visualising* his routine placing of items on his person, such that he knows if something is absent, even if that 'something' remains elusive. His mental check-list, then, refers to objects being in place:

You feel as if you've tried just about everything. You just know that the rest is down to you to try to perfect ways of trying to remember things. I mean, even going out in the morning I've just got a list,

and it's engrained in my mind: wallet, ID, keys, diary, lunch, tablets, phone, glasses; because, guaranteed, if I *don't* do that, I'm half way up the road to my work and I think 'Oh no, I've forgotten my tablets! I've not got my glasses!' It's things like that. It's like having a place for everything and everything in its place as well – or you just can't find it! (Ian)

By visualising where objects should be, Ian uses spatial reference points to *embody* memories. Even if he cannot *recall* something, he *feels* the absence of matter in its usual place, and so can investigate further.

Keeping diaries is a material space for collecting subject memories *and* a space for keeping the self organised. Several participants reveal how their memory cannot be relied upon for keeping personal arrangements; rather plans 'belong' written down. People actively list their to-dos, meaning that places where they are meant to be can easily be brought to mind even when the memory is blank. The placing of calendars and post-it notes⁹⁸ in strategic spaces is massively helpful for Kate's sense of being 'on-top' of things. She positions calendars beside her phone and on the walls of her everyday spaces. Therefore, she does not need to remember to check her schedule – it is always in front her:

I've got to rely on lists. [...] My diary up there [by the phone] is for appointments, *this* kind of thing [the interview], and 'I must do such-and-such on this particular day'. I've got lists of things I need to do *everywhere*! (Kate)

This approach can aid in managing one's social life, ensuring that one does not need to be in several places at once.

The future and past are constantly being folded into the here and now as a way of placing oneself in the right place at the right time. In anticipatory action, Anderson (2010: 2) sees a seemingly paradoxical process whereby a future becomes cause and justification for some form of action in the present. On an individual level, when prospective plans may be forgotten, anticipating the future through spatial practice is a means to empowerment (although, as noted in CHAPTER SIX, anticipation can also cause 'paralysis' in the present). Indeed, while the 'revelations' in this section might not be anything new to any reader who self-characterises as 'forgetful', they are significant for the people in this research because they specifically relate memory problems as a facet of living with epilepsy. Whereas the future is *never* completely predictable 'as the linear outcome of past conditions or present trends' (ibid.), utilising spaces for exercising self-control of one's plans and activities is highly consequential for people for whom predicting the unpredictable, anticipating the un-anticipatable, is at the very heart of their everyday social geographies. Without the means to organisation, (further) confinement to the home-space may be the consequence of anticipating that one will forget what one does, or plans

⁹⁸ A small pad of paper with adhesive strips for attaching to surfaces.

to do, anyway. Thus, when Anderson cautions against too-rigidly attempting to determine the future by suggesting that life is given meaning through the unexpected, he possibly had not considered those for whom memory is a major obstacle to participation in the places and spaces of everyday life, and for whom the 'expected *unexpected*' is such a control on conduct.

I have so far attempted to show how cognitive and memory space shapes and is shaped by body/world orderings and interactions. Memory is inherently linked to place-based practices and so influences all aspects of life, including navigation through familiar and not-so-familiar places, abilities to connect with others, and workplace performance. Arguably, cognitive challenges carry over into places of employment more so than any other: as Moss and Dyck (2001) describe, one's place at work, and so socio-economic stability, becomes precarious after the onset of illness. Individuals must (re)shape, (re)structure and (re)constitute their spaces and practices at the workplace to accommodate their shifting identities, volatile body and the limits of their memory-in-action. This, however, is rarely straightforward.

RE-SPACING THE WORKING ENVIRONMENT

Results from the questionnaire reveal that the challenges of the workplace (post-diagnosis) are involved in more statistically significant relationships than any other 'space or place' (it has some relationship with: 'age' and 'age at diagnosis', 'less than three years with epilepsy', 'whether or not seizure-free', 'seizure frequency' and 'seizure type(s)'). While I make mention of the workplace in every other chapter, it is worth taking a moment to reflect on how people with epilepsy cope in and with the workplace environment. Moss and Dyck (2001: 232) describe how disruptions to an 'able' embodied identity can shift one's positioning in the labour force to varying degrees. Questions arise over the individual's continuing abilities to fulfil their roles, their 'fitness to work'⁹⁹. Stirling (2010: xxii) comments on the administrative power of the use of the term 'fit', which, of course, is still commonly used by many of the participants in this research as a term for 'seizure'. 'Fitness' means conferring or possessing the ability to survive and reproduce in a particular environment. Included in the list of definitions for 'fit' in the *Oxford English Dictionary*, Stirling continues, are 'angry, desperate, [...] conflict, struggle.' 'Fit', then, is a small word with huge implications. Having a 'fit' (seizure) in a workplace can impact on whether others see the individual as a good fit for their job, with resulting place-based struggles as to what constitutes being 'in' or 'out' of place in that particular environment. For example, Brian's seizure on a busy building site was considered by others to contravene workplace norms:

⁹⁹ 'Fit to work' is a term used by the Department of Work and Pensions for the assessment by health professionals and employers of whether an ill, impaired or disabled person is capable of fulfilling their workplace duties. For more information, see: <http://www.dwp.gov.uk/healthcare-professional/news/statement-of-fitness-for-work.shtml>.

When I woke up there was a sea of faces all around me: labourers, joiners. It was just embarrassing; because you were the centre of attention. And you know how words are powerful: this guy just said 'Building sites aren't the place for you, mate.' And that really kicked me in the teeth. (Brian)

For Brian, workplace organisation, located within social relations shaped by the political economy, and the social practices of the building site, all pointed towards his imminent exclusion (Dyck 1999b: 128). Being told 'building sites aren't the place for you' suggests that this workplace is a space exclusively for the able-bodied: the 'epileptic body' that 'fits' simply does not fit.

While Brian subsequently left his job without challenge, the workplaces of other participants are more explicit in stating upfront and so reifying their 'official' codes of conduct. These are culturally embedded in different institutions usually to restrict rather than enable the range of appropriate behaviours. The workplace can be a place of risk, both because of safety issues and because 'failing' to perform threatens financial stability and consequential access to a range of resources. The individual with epilepsy must then develop mechanisms and accountable techniques that 'maintain the impression that they are living up to the many standards by which they are judged' (Goffman 1959, in Faircloth 1999: 221). Where workplaces are malleable to individual spatial strategies, ways of working are transformed and re-territorialised (Dyck 1999b: 127) to accommodate, and reduce attention to, the limits of the material body (Moss and Dyck 2002: 128-129).

Tensions arise when individuals wish to be accepted as 'normal' but *also* as 'a person with epilepsy' (Crooks *et al.* 2008). Several participants attempt to perform 'socially-valued traits' to challenge conceptions of 'the epileptic' as less capable. For Holly, maintaining her individualism and independence is a source of pride – especially because others frequently underestimate her – but this renders 'hidden' the real challenges that she faces:

It can actually shape your life in a way, but you can use it to help other people by showing them that you can get on with doing things and it's not going to be a barrier [... But] you do have that thing in your head that they're going to think – because there is a stigma attached to epilepsy – that you can't look after yourself and you're not as intelligent as you could be. (Holly)

In this way, 'epileptic' identities can be rescripted through the demonstration of social and technical skills, which are a symbolic means of asserting a sense of belonging in places of everyday life (see also Chouinard 2012). At the same time, Holly feels reluctant ever to ask for accommodations in light of her cognitive difficulties because she has previously come under the 'microscope' for taking too many 'sick days'. Such brushes with 'authority' have demonstrated to her that the policies of her workplace concerning epilepsy do not seem to reflect her experiences of it. In fact, she argues, 'epilepsy' is summarised by a list of specific manifestations, which over-determine particular traits as a way of defining the 'epileptic body' (Mitchell 1997). Because these

policies do not cover cognitive difficulties, she feels that reasoning with her bosses would not help. Thus, she elects to 'fend for herself'. Claire, on the other hand, strives to claim epilepsy as 'her own' by challenging workplace definitions. Her refusal to be submissive in the face of oppression (Crooks and Chouinard 2006: 347) paved the way for renegotiating workplace structures and practices (Moss and Dyck 2002: 133). Initially her experiences were defined by contestations of the deviant body: 'I have been pulled in and out of meetings called 'capability meetings' to see if I'm capable of doing my job.' The discursive category of 'epilepsy' was unfixed and so she was able to help shape new parameters based on her own specific needs. While resisting inflexible workplace policies painted Claire as a trouble-maker, ironically, it contributed to a positive sense of self in place (Dyck 1999b: 121). Resisting workplace assumptions therefore helped to shift the normative spacing of the workplace (Dorn and Laws 1994).

With or without institutional 'backing', how individuals subtly alter their work-spaces exposes the 'hidden geographies' of small, but deceptively important ways of avoiding triggering seizures and coping with cognitive difficulties (Hansen and Philo 2007: 498; Dyck 1995a). For Claire, the position of her body is most important because seizures are triggered by photosensitivity, so 'I don't sit next to a window anymore.' Similarly, she finds the powerful fluorescent lighting in her office troubling, so she negotiated being placed under lights that will not be switched on. To avoid seizures caused by spending too long in front of her computer, Nicola regularly moves away from her work-area:

As a general rule, take a temporary break, head off to a safe part; say, collect the mail from the collection depot at the offices, or equally, just nip into the kitchen and make a coffee or whatever. Get a break that way. (Nicola)

Nicola portrays a sense that the negative, troubling or causative dimensions of a space can accumulate and 'grow'. Indeed, the changing 'intensities' of space sometimes hints to Nicola that she is entering 'auratic space' (see CHAPTER FOUR), signalling to her that a change of scenery might do her good.

Nicola also experiences memory problems, and so uses electronic 'reminders' (that pop up on her computer screen) to warn her well in advance, and then repeatedly, of meetings to help cope with the simultaneous demands of the workplace. In those meetings, she takes a material approach to remembering her tasks: 'Certainly with things like meetings, I have to take relatively detailed minutes, and purposefully type them up pretty quickly while they still make sense' (Nicola). Rather than seizures being her main concern, Holly is more anxious about *not* meeting (ableist) expectations in light of her cognitive difficulties. Thus, she structures her use of energy, social arrangements and spacing of breaks so that she can be at her workspace for *longer*.

Because this increases the likelihood of having a seizure at her desk, however, she has a pillow under her desk that her friend and colleague, Silvia, knows to place underneath her head:

I've gone back to eating on my own again because I tend to take very short breaks so that I can keep up with my work. [...] My only fear is that occasionally [mild seizures] could be happening at work; which is why I will always double-check what I'm doing. [...] I have a 100% accuracy record and I want to keep it that way. I'm probably slower than most people because I double-check to make sure that I have done everything. [My boss] knows I forget. I always think she must get a bit fed-up with me, and she must think I'm very dim. (Holly)

Holly's determination to maintain 100% accuracy is a way of proving to others – and herself – that she is more than capable of doing the job. While everybody makes mistakes, she expects that, if *she* makes any, others will explain it as associated with epilepsy: 'which would be their excuse to finally get rid of me. But, then, that might be paranoia' (Holly). She hence feels that she needs to be 'better than the rest' just to be seen as 'good as the rest'. Ian constantly feels as if he is under-performing and that he has to put in double the effort of others simply to get by. To compensate for 'slowness', Ian organises his working files fastidiously, reasoning that their logical structure will surmount any cognitive difficulties:

It was just the slowness that was the problem in getting through it. [...] Every time I go to my staff review I'm always saying 'I know this is a problem.' And you've just got to try to find ways to work around that, to try and address these situations; and sometimes it's just methods of working that you've got to change. [...] It's just to be almost hyper-organised. I just can't stand an inbox that's got heaps and heaps of things. At home it's like that, but at work it's more important just to know whether I've dealt with it. So my inbox: all that you have is on screen – it doesn't go below the screen. I've allocated it if it's just information: I've got an information section. And there'll be separate parts within the 'financial systems' folder. You know, it'll all be folders within folders within folders within folders. (Ian)

Such precise spatial configurations unsettle the notion that the good working body is the 'healthy' body. The latter has been naturalised to the extent that, even when workplace relations are generally positive, an ill person will remain doubtful about being able to continue in this way (Moss and Dyck 2002: 118). This is in part because, as Hansen and Philo (2007) recognise, their efforts tend to go unnoticed or are unappreciated; their continuing presence at work seemingly being always 'on approval' (even if in truth this is *not* the situation).

HOME-SPACE MATERIALITIES

SPACE TO FALL: A GEOGRAPHY OF SURFACES, SHAPES AND RELIEFS

While the workplace is significant in participant accounts because of the extent to which ‘losing control’ may impact on place-based identities, the home is an important space of the self precisely because it is relatively more open to the order that individuals attempt to impose upon it. Geographers have written at length concerning the rearranging of home-spaces by people with chronic illness, impairment, disability and mental health issues (Crooks 2010; Dyck 1995a; Imrie 2010; Segrott and Doel 2004). Following the onset of illness or, for instance, in pregnancy, the home becomes a space of ‘confinement’ (Longhurst 2001: 36), albeit variably depending on one’s symptoms, perceived level of acceptance and the reactions of friends and family. Confinement entails the shrinking of horizons, withdrawal from the workplace or assertive movements within institutions, the subjugation of the body, emotions and psyche (Angela 1990: 72-73 cited in Longhurst 2001: 36). Davidson (2000b) discusses how, far from being the idealised space of the free, peaceful, tranquil self (Chapman and Hockey 1999), home may come to represent a space of entrapment, a prison or asylum, even when providing a haven from the unforgiving external social environment. However, retreat to the home does not necessarily minimise the risk of seizures as it does agoraphobia-related panic attacks (Davidson 2000a, 2000b, 2003). It is a place where seizures are less *visible* to ‘outsiders’ (and so less problematic in a social sense: see CHAPTER FIVE), but risks associated with painful interactions between the body and space remain in sharp focus. Indeed, far from being a passive stage, the home environment may *become* more secure and predictable (Segrott and Doel 2004) as domestic borders and spacings are achieved and actively worked at (Law 2000; Imrie 2010). Most homes are designed and laid-out relative to various cultural and embodied norms (Imrie 2010), but not every-body conforms to these norms some or all of the time. Unlike with the wheelchair-users discussed by Imrie (2010) and Dyck (1995a), though, people with epilepsy are usually less concerned with corporeal-spatial access than they are with preparing space for when the body unconsciously interacts with things that are hard, soft, sharp, blunt, smooth, uneven, high, low-lying, delicate, sturdy, light, dark, hot, cold, deep, shallow; that is, the materialities of home: its spaces of shapes, surfaces and reliefs.

When seizures rise suddenly in frequency, an individual may become ‘social captive’ (Charmaz 1995: 668) to the precarious body through a reluctance or inability to leave the private home-space¹⁰⁰ (Driedger *et al.* 2004):

¹⁰⁰ Although some more than others are able to monitor the body and negotiate their social boundaries according to corporeal contingency: see CHAPTER FOUR.

It's quite isolating, because there have been days when I daren't go out. Because you've got this feeling in the back of your head, and especially if you've had a seizure the night before, you don't know what's going to happen. And if you go out there's no telling where you might end up. (Patricia)

The homeplace keeps Patricia's body relatively contained, but, if seizures are likely to occur, accommodations must then be made for when the body unintentionally collides with material space and objects. The extent to which homes are restructured depends on the embodied manifestations of seizures; for example, 'Because it's mostly mild vacancies I have, [...] I've not rounded-off corners or fitted handrails anywhere or anything like that' (Brian). Moreover, any modifications are constrained by finances and access to information and resources (the management of epilepsy intersects with class and, as Rhodes *et al.* 2008b show, ethnicity). As Gordon explains, 'There wasn't enough income to allow me to change – I just had to be the way I was, with what I had.' Lack of finances means restructuring home-life using a deliberate and resourceful manner. These contingencies reflect Imrie's (2010: 26) assertions 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'.

For numerous participants, the majority of seizures actually occur at home (due to increased confinement) and so it is at once the place most open to one's own modifications and that requiring of most consideration. Homeplaces are not treated as homogenous, but as constituted by a series of spaces (living room, kitchen, bathroom, bedroom, stairs) and objects (cooking equipment, chairs, storage units) with different meanings and affective potentials (Thrift 2002). Indeed, despite participants' best efforts, arranging spaces and the body's relations with them are a matter of iterative negotiation because many household items are intensely ambiguous, and it might be through painful experience that they are finally assigned meaning (Segrott and Doel 2004). Perceiving and managing risk involves making, (re)arranging and altering space. Patrick explains how he learns to modify his living-space by assessing his bodily injuries or witnessing the destruction, staining or displacement of objects and spaces post-seizure. Regarding objects that cannot be moved out of 'harm's way', the focus is on avoiding materials that, when broken, will potentially smash into sharp pieces:

No glass; or hardly any glass. Posh furniture is very nice, and has lots of glass handles and things like that, but is totally inappropriate for people like me, who, if they had a fit, could crash into them and seriously hurt themselves.

As well as being attentive to building materials, he is also vigilant to the contours of things, which means replacing tables that have sharp-edges or drawers with angular handles or knobs. This is tricky because the design of most furniture does not take into account people who may lose bodily control:

It's soft edges and things like that for me. [...] I suppose these bits of edges [he gestures to his coffee table] are difficult. And so are theses knobs [pointing to his storage unit handles]. But modern furniture is not geared for epileptics. There's nothing. One has to search high and low for something that would be suitable. (Patrick)

Such considerations are more common amongst participants whose seizures involve some loss of muscle tone, because what might obstruct the body on its path to the ground acquires clear significance.

All *horizontal* surfaces, then, are taken into account. Numerous participants relay that they have softened their floors to cushion the impact from a fall; for example, by replacing floorboards with carpets: 'I've now got carpets all over my house – all my laminates needed to come up in case I do take a seizure' (Claire). As Patrick also jokes, 'it's a nice carpet; it's just the right colour to hide all the blood stains.' At the same time, *vertical* surfaces are a concern for Alan and his wife because he will typically walk into walls and rub against their rough surfaces during seizure. For this reason, 'We're going to get the artex [coarsely-textured wall coating] smoothed over.' For Patrick, vertical *objects* needed to have an upright sturdiness. His storage units were chosen so that, if he tries to hold on to them at a seizure's onset, they will not fall on him. Furthermore, 'the reason they are *tall* is so if I banged into them I would fall *down* them rather than on top of them.' Open 'vertical' spaces, notably stairways, are also a concern for participants (which applies outdoors as well). When her symptoms flare, Sophie enlists her mother's help:

If I'm having a bad day when I've had one already, I tend to just really watch when I go up the stairs, because I've had seizures before which have caused me to fall down the steps. I'll just give my mum a shout and she'll come up and she'll just guide me down in case I do happen to fall. (Sophie)

Alan and his wife feel that, although the danger of their stairway cannot be eliminated, the presence of harmful objects at its foot can be reduced, suggesting the detailed planning of 'what if' scenarios relative to their domestic space:

There's a radiator at the bottom of our stairs, and quite often I wonder about whether if Alan were to have a seizure at the top of the stairs he would injure himself against that. So we're going to get the radiator removed. (Alan's wife)

For similar reasons, several participants keep space relatively clear in the areas of their home where they spend most time. Patrick details: 'The living room: space to fall [is important, so I] keep as much open space as possible.' This means moving furniture to the edges of the room and de-cluttering. Individuals are also attentive to their body's placing within the home-space relative to these 'spaces to fall'. Holly habitually positions her body on soft surfaces so that in the event of

a seizure she is safe. She deliberately premeditates space and material objects with her husband's help¹⁰¹, such that the latter learns to 'see' space through the body of the former:

I think we're both very *aware* of [our home's layout]. I mean, we haven't gone so far as putting things on the corners of tables to make them blunt or anything like that. But I've got the space there [a soft multi-sofa combination], and I know if I have a fit in here I can put myself there. I've got space inside my bed, so I try and keep that clear. So I always try, and I know where my spaces are. Over there is the smallest room: usually we're in there, and we're both in there together. Or, occasionally if I'm in there and he's away, I know the space on the opposite side of that table is where I'll be OK.
(Holly)

These habitual spatialities demonstrate that the home is not a homogenous place but a series of dynamic and differentiated spaces defined by their content, surfaces and shapes in relation to their potential interactions with the (changeable) material body. Referring again to Anderson's (2010: 791) work on anticipatory action, participants are not concerned so much with 'preemption' or 'precaution' (actions that aim to prevent the occurrence of a future¹⁰²) as *preparedness*, which does not attempt to prevent a future from happening, but to 'stop the effects of an event disrupting the circulations and interdependencies that make up a valued life'. Maintaining neat and tidy spaces, with objects kept in-place, helps to prevent injury by obstruction, but not all actions can be geared towards possible futures all the time. Indeed, the unexpected transgressive capacities of material space mean risk can never be eliminated.

The kitchen is an obviously problematic space because it is comprised of hard surfaces and sharp instruments, intermittently boiling water and gas flames; nevertheless, one has to eat! Individuals do tend to be on higher alert here: 'It was always the kitchen. I could be out in the car and it didn't matter, but in the kitchen I seemed to be more aware of the health and safety issues' (Gordon). Patrick and Mandy each became aware on several occasions when food had already ignited in the oven or grill. For Gordon, the solution is to use an automatic timer. Mandy now places a greater emphasis on microwave-cooking and pre-cooking when her family are home. Because he lives alone, Archie prepares all his ingredients away from the stove, puts them on to heat, then walks away. The downside for Patrick with shifting to microwave-based meals is financial (they are more expensive) and health-based (less fresh food). Because of this, Renae has stopped eating cooked food almost altogether.

The bathroom too is a concern. Because of the *depth* of bath water, several participants mention the possibility of drowning: a truly dangerous element. Solutions include opting for a

¹⁰¹ Toombs (1988: 209; 1995: 17) describes how she and her husband work 'in sync' to facilitate her passage in and across environments that are unaccommodating for wheelchair users. She further describes how her loss of verticality (upright posture) means strangers will assign her a 'dependent role' by speaking to her husband about her in the third person, as if she has lost all autonomy.

¹⁰² Although 'preemption' and 'precaution' are both implicated in other aspects of epilepsy management, such as medication-taking and lifestyle modifications (see CHAPTER EIGHT).

shower; although for Patricia and Sophie installing a shower (as did Alan and Claire) is not possible financially, but the alternative – leaving the bathroom door unlocked in case of emergency – erodes one's sense of privacy. This challenges the spatial autonomy of the 'rational', competent self in distinctive ways. In fact, as Sophie states, it is as if everything needs to be 'child-proofed'. The anxieties of self and (over-)caring others concerning the body's potential momentary loss of autonomy give rise to frustrations over not being able to do things 'normally', as if one has entered an infantilised state. In effect, several participants, while affirming certain changes as 'pragmatic', are fed up of having to think in terms of making everything more 'accessible' than might normally be true of the rest of 'us' – but this certainly leads to ambiguous and contradictory feelings when not in an environment that they can so readily regulate.

ON THE MOVE: THE DYNAMIC GEOGRAPHIES OF PREPARING FOR AND NEGOTIATING 'OUTSIDE' SPACES

ANTICIPATING THE DIGNITY OF RISK

How individuals order and manage their bodies in anticipation of journeying outside the home is shaped by perceptions of risk, and further implicates spatial behaviour, both intimate and further afield. Living with epilepsy is for some an omnipresent concern that pervades all plans:

The fact that I suffer from epilepsy never leaves me. Not being in control of my body or mind whilst awake is a horrendous, frightening experience. You would just have experience an hallucination in public just once to know that going outside will never be quite the same again. (Archie, questionnaire response)

Archie's anticipation of 'going outside' is forever changed because of altered perceptions of (bodily and social) *safety*. Consider **Table 10** below, showing questionnaire respondents' sense of safe or unsafe places. Notably, 'public' spaces (the street, shopping centre, bus and places of leisure) are generally considered to be relatively more 'unsafe' than private spaces (the home or a GP surgery, where meetings with doctors are 'safe' both physically and socially because of the expectation of first aid expertise and confidentiality). Workplaces, interestingly, for the greatest proportion of respondents are 'sometimes safe, sometimes unsafe', perhaps indicating their straddling of definitions of private and public (they are usually everyday, familiar, 'inside' spaces; although inhabited in many cases by unknown others). The task here is to unpack the many ways in which individuals *prepare* for inhabiting public spaces that might be regarded as 'unsafe' in many ways, whether physically, socially or both.

Table 10: How safe are the following places relative to the possibility of having a seizure?

Answer Options	Safe	Usually Safe	Sometimes Safe, Sometimes Unsafe	Usually Unsafe	Unsafe	Response Count
Home	66	22	21	5	7	121
Street	5	7	25	19	57	113
Work (or school)	15	17	34	10	18	94
Shopping Centre	4	9	29	27	44	113
Bus	4	8	29	24	46	111
Car	11	15	20	20	41	107
GP Surgery	60	24	20	4	5	113
Places of Leisure	8	11	36	16	38	109
Answered Question: 121						

Danger, in part depending on one's seizure manifestations, is anticipated across several distinct spatialities. First, certain *spaces* are more hazardous than others *in case* of a seizure; for example, losing consciousness walking down the street, one might fall on to a busy road. Certain *activities* (themselves space-based) are considered risky because of what might happen to the body if it loses control: 'I just got told not to drive and not to go up ladders and scaffolding, and avoid going out on my own to dangerous places, like the harbour' (Brian). Second, individuals (sometimes) avoid specific *places* because of environmental features linked to their seizure triggers. For Claire, 'close' spaces conducive to heat, flashing lights and alcohol consumption are 'out of bounds':

We always used to go to Sleazies [a Glasgow bar], and obviously that's down the stairs and it's really cramped and it's really claustrophobic. And I knew I couldn't go there because three times I've been in there and I've taken a seizure. [...] So it was just kind of all this stuff, like I couldn't go to gigs, anywhere where it's overly-hot; couldn't be anywhere near strobe lights, couldn't drink. (Claire)

Third, concerns arise where the risk of having a seizure is not only a risk to the body, but also to self. Zareen Iqbal (Outreach and Liaison Worker, Epilepsy Connections) describes how one client averted the risk of a being regarded prejudicially by her own 'ethnic' grouping:

One BME woman [...] didn't go out to an area where there was a high BME population just in case she had a seizure. [...] She says 'I'm not going to Pollockshields,' which, I don't know if you're aware, has a very big BME population. [...] She'll still *manage* where she's going: she'll not go to places that she actually *wants* to go.

Dilemmas over whether to trust the unstable body in different situations leads some to curtail their social geographies (as with Claire, above), while others resist perceived bodily constraints:

People used to say to me ‘How can you go into town? What if you’re crossing the road?’ I said ‘Well, what do I do?! Do I stay in the house forever? Don’t go out the house because anything could happen?’ I said ‘No, I just prefer to take my chances going out.’ (Margaret)

Refusing to live under ‘house arrest’ by the authority of epilepsy, however, opens up multiple concerns, both physical and social (Smith 2012). Seizures are for many generally, and unavoidably, unpredictable, necessitating creative and resourceful practices in preparing to embody the dignity of risk (Wolpert 1980). The unpredictable body renders space unpredictable (see also CHAPTER FOUR), meaning that even the most ‘everyday’ trips, to the most familiar places, must be considered carefully. This involves pre-empting what *could* happen in different places and during different activities and, in some way, organising the body (and social arrangements) accordingly:

I’ve got to control it. I’ve got to be able to plan it. I’ve got to be able to live it. I’ve got to be able to do the things that I do. [...] It’s all got to be controlled and planned around the condition that I now have. (Archie)

Proximity to local shops, transport links, social networks, recreational opportunities and health services all influence experiences of the ‘local’ and thereby enter into participants’ embodied preparations.

Individuals routinely make social preparations for the benefit of self and family or friends. Before setting off to meet friends, Laura always agrees to be in a certain place at a certain time so that, if she does not show-up, the person who she is meeting can attempt to contact her to ensure her safety. Regularly checking-in with close friends or family via mobile phone is another arrangement for both self and other to maintain peace of mind. Claire, for example, feels more secure if her Mum knows where she is and what she is doing (even if she sometimes feels ‘infantilised’): ‘I phone my Mum about every half hour. And I think that’s not me wanting to talk – this is me saying ‘This is what I’m doing *here*, and this is where I am now. I’m in New Look now, I’m in TopShop now.’ By referencing her location, Claire’s Mum is able to infer that she is safe and will certainly not be isolated should a seizure occur. As has been discussed (see CHAPTER FIVE), it is not always obvious to strangers that someone is having an epileptic seizure because of their diverse embodiments. Thus, individuals might choose to prepare for the benefit of self and *strangers* (especially those trying to assist the unconscious self) by carrying epilepsy information cards on their person (pre-packed in their pockets, bags, and attached to jewellery). As Nicola describes, ‘I do purposely carry the ID with me telling people that I have epilepsy and what to do, along with details of the medication, my medical contacts and all the rest of it.’ Nonetheless, Kate points out the futility of carrying cards when others might recoil from the unruly body:

I actually went back into Tesco's and I said 'I'm very sorry about this, but look, see if you'd just looked in my jacket pocket or my handbag, or here or there.' None of them have ever done it. I've had necklaces; you know, the special necklaces. Nobody ever, ever uses them. I suppose it looks bad possibly, you know, somebody rummaging about. [...] But I'm covered in the things usually. (Kate)

Not only, as Kate suggests, are strangers understandably unwilling to 'search' a stranger, participants themselves are wary of including personal details that could be accessed while they are unconscious. Alan discusses how including his home address on the cards, as well as having his keys in his pocket, makes him vulnerable to people with dishonourable intentions. He is quick to point out, though, that this is maybe 'paranoia' and that he has always relied on the kindness of strangers. Another interviewee, Joan, points out that epilepsy-related memory loss prompts her *not* to carry personal information, a diary or keys in her handbag because she often forgets it in random places. Carrying these belongings, she suspects, would 'invite' thieves to know her movements (through her diary); in particular, whether she is likely to be at home (which could be entered using her keys). As such, she 'travels light'. Holly, who during seizure will 'wander', on several occasions found herself locked outside the home. As she is unable to prepare the body for this eventuality, the hotel along the street has been entrusted with a spare set of keys. That hotel becomes a space of salvation.

People frequently organise key items or devices for their use-value before leaving home. In this way, the individual becomes a sort of human-'thing' hybrid, a cyborg (Haraway 1987; Wilson 2009), whose life is shaped in part by non-human assemblages with their own affects and effects. Holly's VNS¹⁰³ magnet, which she takes everywhere, can be attached to her clothes by a clip, so, when preparing to be 'on the move', she intentionally wears garments with a waistband (i.e., not a dress). That way, her magnet is always within arms' reach. Whenever Claire expects to be a car passenger, she self-organises by carrying with her a sun-shield to prevent seizures brought on by photosensitivity:

My Mum's actually got this thing in her car that you can actually pull over [the window] to the near side. She can still see the wing-mirror, but when it comes to things like that I can just pull it over. Things like that you can put on anybody's window while they're driving. If I don't have it, I don't put myself in that position. [...] I take it everywhere I go. (Claire)

Instead of electing not to travel by motor vehicles, this is a way for Claire to ensure inclusion in these spaces. To be sure, though, continuing in certain activity-spaces requires such forethought.

¹⁰³ A VNS, or vagus nerve stimulator, is a small device (similar to a pacemaker), which is inserted in the chest and connected via a wire to the left vagus nerve in the neck. The device has a very low electrical pulse programmed to stimulate this nerve to reduce seizures. A magnet is used to start the electrical pulse if one feels a seizure coming on (http://www.epilepsyscotland.org.uk/a-to-z-of-epilepsy-v/info_185.html).

Because Brian refuses to give up the valued pastime of fishing, before setting out he prepares by dressing in ‘high-viz’ clothing and gathering activity-specific safety equipment:

Take your mobile with you to make sure that you’re contactable by people at all times, and maybe wear a bright day-glow vest, which I use for the bike anyway, so folk can see you in case you did fall off the harbour wall into the deep. But I’d obviously have to find a safe fishing perch with a wall in front of me, or the worst case scenario would be tying a bit of rope around you and lash yourself to a post somewhere so that if you did black-out you wouldn’t go too far. (Brian)

Whereas specifically-planned activities can be considered practically, people do not always know what they are going to be doing before leaving the house. Various participants explain how they prepare for contingencies:

In my hand-bag I’ve always got spare medication. That’s the only thing. I just always make sure I always have some with me because I think I once got caught out when I realised I wasn’t going home, and I needed to get some. But I always just have spares in case it’s like ‘Let’s all go out for dinner!’ You know, in case we do something that’s unplanned. (Debbie)

Indeed, several participants reveal how epilepsy medication will shape their social geographies. If Holly is spending an evening with friends and wants to stay over at their house, she will phone for a taxi to shuttle her to and from her home to collect her medication. Besides routine medication, medical emergencies can be extremely harrowing and disruptive. For Renae, they are neither regular nor rare. For this reason, she always has a bag pre-prepared for hospital stays:

You know, like toiletries; I’ve got a nightie, a dressing gown, slippers, everything. It’s all in a big bag ready for taking to hospital. Because I’ve had that many accidents, and if I’m taken to hospital the bag’s ready; it’s in the room just to take. (Renae)

Although peoples’ routines are intrinsically peppered with expecting the unexpected, holidays perhaps represent the greatest deviation from everyday spaces. Maps (whether paper or on a smartphone) are crucial for Patrick’s ontological security because he feels he needs to place himself at all times. Medication is also a foremost consideration:

When I go on holiday I usually have so much [spare medication] – I usually have so much *anyway* – but I had about four weeks-worth because I kept thinking about the ash cloud last year¹⁰⁴. And I also said to someone here, ‘Right, if we’re still stuck, I’ll have a package and you can post it.’ [...] The thought, ‘I don’t have any medication left and I don’t know where I’m going to get it’: that’s the only thing that bothers me. (Debbie)

¹⁰⁴ In 2010, the air space around many countries in Europe was closed due to fears that ash from a volcanic eruption in Iceland might damage aircraft engines. Many holiday-makers were left ‘stranded’ for weeks.

Steve, because of the possibility of his luggage being lost by the airline, states that 'I end up packing about three lots of medication in each person's case.' Laura always makes sure she takes 'a letter from the doctor saying it is tablets, it *is* medication. You have to have it [so they know] you're not trying to smuggle drugs!' She also phones the airline ahead of her scheduled flight to make sure of her body position in relation to others':

You have to take everything into account. I mean, when I fly, [...] you've got to tell them you've got epilepsy; and even then they'll put me in the middle of the five seats in the middle of the plane. And I would go back to the stewardess and say 'I'm sorry, you can't put me there! I told you all along: I have epilepsy. Now, if you want to take me out of there, kicking and punching whilst I have the fit, that is entirely up to you!' (Laura)

Although certain activities or journeys may be considered 'risky', the greater risk is more often that people stop undertaking them in the first place. Whether anticipated risk is associated with embodied danger *should* a seizure occur or particular places where conditions might *trigger* an episode or the social threat of a spoiled identity, preparations for being 'on the move' are based on socio-embodied knowledge of the different spaces on one's itinerary. It is to the active negotiation of these itinerant spaces that I now turn.

TRAVERSING ITINERANT SPACES

Living with epilepsy is spatialised insofar as people's movements are (often) conditional upon the expectation or likelihood of living 'within' their bodily boundaries. Like the prisoner on parole, their release into the world (from the home, which itself can be a type of prison) is contingent upon the body's good behaviour and continuing compliance to social 'rules'. As Parr (1998: 685) argues, such difficulties can lead to traumatic battles and confusing transitions. In public, individuals are fearful of 'what they might (be seen to) do' (Davidson 2001b: 288; Longhurst 2001) and so are always conscious of normative standards of 'decency'. As Glass (1989: 212) puts it, 'the result is a loss of the self's public being, a reversion to private knowledge systems, and most important, a complete loss of the sense of community'. Thus the wider social geographies of people with epilepsy mirror the 'placelessness' associated with experiences immediately before, during and after seizures, when the individual is unable to 'locate' the self (see CHAPTER FOUR; although, as Reis [2001] remarks, this 'placelessness' may be transformed into a site of identification inhabited by those who have been similarly displaced: see CHAPTER EIGHT for a discussion of community organisation). The consequences for people with epilepsy, whether they conform to or resist perceived pressures to stay out of sight, is that theirs is geography of peripheries and margins, of moving from place to place without ever really feeling that they have the *right* to live in and out of their own bodies in public spaces.

Del Biaggio *et al.* (2002) argue that the person with epilepsy seeks security in their travel movements. I elaborate on this work by establishing how people interpret their environments, and how the meanings that they attach to spaces come to form a 'mental map' of safe and unsafe routes. To paraphrase the old saying, self-knowledge comes from the journey, not the destination. Although this claim perhaps simplifies the complexity of tasks undertaken in 'stationary' places (notably, the workplace and the home, which are themselves comprised of dynamic micro-geographies of the material and social), it is worth pondering the many ways in which individuals with epilepsy monitor and interact with space as they travel from place to place on their itinerary. Similar to the itinerant worker, who is employed for short periods in various places, they are always on the move, never stopping or staying. Arguably, because social conventions prevent the volatile body from becoming established in mainstream spaces (see CHAPTER FIVE), people with epilepsy become 'itinerants' in a pejorative sense. Much like the travellers in the work of Sibley (1992), they are 'outsiders in society and space' in that many will keep to the peripheries, never fully integrating; their spatial freedoms and spontaneity becoming less prevalent because of regulatory socio-political practices and discourse.

Local contexts have a massive bearing on how individuals negotiate their daily paths. The following anonymous questionnaire respondent has lost confidence in leaving the home and exposing their body 'unnecessarily' to the outside world:

I don't tend to hide away but experience has taught me that perhaps going another way and just pre-thinking the plan might have helped, and was the trip, journey or whatever really needed in the first place?

Claire became reluctant to re-cover ground where a seizure occurred previously (in contrast to Kate [earlier] who *forgets* about having seizures in particular places): 'I've actually had a seizure in the middle of Govan Road, about two years ago, and it's funny, like, a lot of people are surrounding you and [...] I was embarrassed, for a while, to go down that road.' Not only did having a seizure impact on how others might look at her, it provoked a heightened sense of socio-corporeal self-consciousness. While this exacerbates anxieties over having another seizure in that place, with much courage, Claire has reverted to her old route. 46% (n = 58) of questionnaire respondents 'always' or 'sometimes' avoid particular places, with one of the most commonly cited reasons being 'embarrassment': the feeling that all eyes are on the body that has previously and could again become 'anarchic'.

Parr *et al.* (2004) have discussed ambivalent feelings of inclusion/exclusion in rural communities, uncovering seemingly contradictory experiences reflecting both tolerance and rejection. Interviewees in this research generally remarked on the *advantages* of living in small communities. With frequent episodes, individuals become 'known' locally; and, despite the

sometimes negative associations of being labelled as an ‘ill’ person, locals learn to recognise seizures and offer assistance:

They’ve kind of got used to me in [in the village] because it’s the same guys in the same office [who tend to see me]; so they’ll keep me with them until I tell them that I’m fine and not been hurt, and then they’ll let me go home – they’ll even give me a lift home. (Holly)

Holly supposes that part of the reason for others’ apparent acceptance was the local social context of understanding mind/body differences¹⁰⁵:

People have been brilliant! I don’t think there’s anyone I had a real problem with. Also, for the size of the community, we have a large centre for people with learning difficulties; and everybody’s used to a lot of them going around town with care workers. So I think everybody is fairly understanding and fairly good with anyone with disabilities. (Holly)

This reflects Dyck’s (1995: 310) assertion that peoples’ ‘actions are shaped within sets of constraints and opportunities, which while experienced locally, are embedded in policies and broader social and economic processes.’ Contrary to Holly’s experiences, Archie feels that his locality is defined by a ‘gossip’ culture (a central issue in Parr *et al.* 2004). He is deeply concerned about becoming the focus of others’ attentions and so has stopped visiting places of social visibility (thus demonstrating similarities to agoraphobics, whose ‘fear of being in the public eye can be severely disabling, often contributing significantly to an overwhelming reluctance, even complete inability, to stray too far from the protection and privacy of their own homes’: Davidson 2003: 108):

In the village I kept it quiet. [...] I’m fortunate: we’re sort of isolated here, if you like. We’re not like in a housing scheme or anything like that. You can be private if you want to be, very, very easily. And I shudder to think: if you’re going out for dinner, you’re always aware of something happening. (Archie)

Whether or not people participate in community social spaces, at least sometimes they still have to traverse and negotiate itinerant spaces – local pathways, pavements, crossings – in order to go places. In light of the dangers of losing bodily control, routes presumed as accessible take on a different *character*, possibly becoming unsafe, some or all of the time. Kate now mentally maps-out her journeys to the local doctor or shops, planning specific routes to coincide with safe crossings, and attempts as far as possible to adhere to her own step-by-step plans:

¹⁰⁵ Some places arguably seem to be able to build ‘cultural capital’ receptive to ‘difference’, while other places do not: this perhaps offers hope along the lines of the discussion in CHAPTER FIVE concerning proximity to difference (Dear *et al.* 1997; Sibley 1995; Wilton 1998).

Look at the clock and plan it like a military operation: go there, there, there; quickly, and back. [...] I know I shouldn't go out a lot myself. Sometimes I've got to though; I've got to go round to the doctors. It's only five minutes walk. I've got to. And I've got to cross the road, and I know there's a couple of places there's traffic lights; and it's a busy junction. So I always use the green man – *try* to use the green man – even if there are no cars there, I will stand [and wait] because I'm trying to condition my brain into 'Wait! Wait on the peep!' because maybe if I'm going into a fit I'll hear the peep and I'll cross. (Kate)

Routes to and from certain locations are planned for economy of movement, while there is an increased awareness and attention to one's materiality (Davidson 2001b: 287). Kate only deviates from her plans if her body allows it: 'Sometimes something will crop-up that I've forgotten. Like when I'm over at the shops, 'Oh, I better buy such-and-such!' And, if I feel OK, I'll go quickly, buy it, and then go back over the road.' Since he always keeps to a plan, Patrick feels his spontaneity is constrained: 'I can't just go and do things off the cuff. I have to make sure that I am safe.' Ian, on the other hand, reveals that, while he feels fairly free to go anywhere, he tends to keep to quieter areas and *locates* himself by checking street names on the move: literally mapping where he is. This ensures that he can phone his wife with his 'co-ordinates' should he require help.

Without a doubt, how people conduct themselves from 'station to station', from A to B, is very much dependent on the local socio-material terrain in tandem with relative symptomatic fluctuations. Safe environments are those that people have already 'sussed out', what Bury (1982: 176) calls 'local and familiar territory', in which the attributes of habitual routes facilitate safe passage: 'I have a bicycle and I usually travel through parks or pathways out of the way of the traffic' (Brian). These spaces are not always *completely* safe because their meaning is dynamically (re)produced through the body's interactions with them. On certain days, or at particular times, *all* spaces may be potentially uninviting or hazardous, and on such occasions being in the company of friends or family may render the spaces less threatening because of the 'safety net' provided by known others (meaning that if the individual falls, having lost their bodily balance on the 'tightrope' they walk on a daily basis, they will be less vulnerable to injury, whether physical or social):

I like to go out with people just for the comfort. And for safety I'd be happier if I was with someone. [...] My mum's been walking me to work because we live on the ring-road, which is a really busy road. And if I go into a fit where I lose mental consciousness, I don't have any idea what's going on, so I can actually walk into the road. (Sophie)

Outside 'local and familiar territory', feelings of vulnerability and exposure are accompanied by a heightened sense of watchfulness. However, Patrick explains how, with company, an altered sense of being-in-place means space is *delineated* differently, thus lifting the 'shackles' and

allowing him to relax and go forth without the same fears: ‘I’ve only once been abroad, to Tuscany, but that was with the family. So I was in a *safe environment*: they would look after me if the need arose, which it didn’t.’ This reveals an extremely limited range of conditions within which Patrick will feel safe. When travelling alone, various participants tend to spend as little time as possible moving through each place so as not to be ‘caught out’ by a seizure and hence classed as an ‘itinerant’, someone who belongs instead on the margins of society. This is why individuals with epilepsy, especially those for whom seizures are frequent, will keep to a rigid time-space itinerary as they travel from (un)safe place to (un)safe place.

NOT SO (AUTO)MOBILE

WALKING AND PUBLIC TRANSPORT

Chronic illness, Charmaz (1995: 675) points out, is characterised by journeys ‘on the same terrain over and over and, also, [individuals] find themselves transported to unplanned side trips and held captives within hostile territories as they experience setbacks, flare-ups, complications’. I here unpack Charmaz’s metaphor in a literal sense by considering the impact of journeying ‘on the same terrain’ after losing the car as one’s foremost mode of transport¹⁰⁶. Surrendering the right to drive was for many participants the greatest disruption to their (pre-epilepsy) daily geographies. Asked what she misses most about having a car, Maureen replies: ‘My freedom. My freedom. I just went everywhere in it! [...] I really miss my car.’ Hence the relative autonomy to travel where and when one chooses is felt to be lost, with considerable implications for how one *feels*:

¹⁰⁶ Individuals diagnosed at a young age, whose seizures have never been controlled, will never have been permitted to drive. This is a source of regret for Holly: ‘I don’t like the fact that I can’t drive. [...] I’d love to be able to get in the car and drive off somewhere.’ For young people, learning to drive might be a rite of passage denied: ‘I was sixteen and I wanted to learn to drive; and I couldn’t learn to drive and I was, like, twenty-one and all my friends were learning to drive. And so those were the things that really bugged me’ (Debbie). Individuals with a driving licence are advised by their GPs, neurologists and ESNs to stop driving and inform the Driving and Vehicle Licensing Agency (DVLA) after their first seizure (which means not driving for 12 months after one’s *last* seizure). As an ESN reveals, some people will actively resist receiving an official diagnosis because of this. Cavanagh’s (2010) Scottish-based research found more people are driving than whose seizures are under control; hence some individuals are driving with the risk of seizure. One epilepsy charity worker, David, discusses this in relation to people living in rural areas: ‘they think they’re playing the odds too; because [they think] ‘there’s less chance of me causing any problems because the traffic’s so sparse, and if I did have an accident it’s probably just going to involve me’. There certainly are people who say ‘I keep quiet about this because we don’t have the public transport, so I just keep doing what I’m doing, and I think I know myself better than anybody else.’ This could be unpacked further by referring to Foucault’s ‘care of the self’ which denotes a series of actions or practices that are ‘exercised by the self on the self’ and ‘by which one takes responsibility for oneself’: see CHAPTER EIGHT for an engagement with (self-)governance. In this research, only Archie mentioned these legal ambiguities. Because he had already started treatment, his doctor seemed to suggest to him that he should hold on to his licence. While he did in fact hand in his license after *diagnosis*, which had a major impact on his social geographies, he chose not to hand it in again when he had a breakthrough seizure years (after reclaiming his license). This was because, this time, he did not live with a wife or offspring who could drive him around.

I'd always driven. I was forty by this time. And not to have a car and not driving was just like the end of the world for me. I was sitting on the toilet one time and I looked across at the razor blades, and I just felt like cutting my wrists because I was that depressed about it. (Brian)

People feel that they need a car to *continue living* in this age of 'automobility' (Edensor 2004). Participants who *reclaimed* their licence also reflect on reclaiming their life and spatial freedom: 'becoming seizure-free and buying a car, in many ways, has opened up so many avenues in terms of: choice of where to live, choice of where to work' (Jennifer). Until this is possible (depending on seizure control, as well as finances), individuals must negotiate alternatives to driving. They may be forced (usually grudgingly) to adapt to a life on foot or on public transport.

Where someone lives in part determines the extent of upheaval of their social geographies. In rural areas, where there is a sparse density of services and amenities, problems are likely to arise that act as obstacles to everyday functioning (see below). In compact cities or towns, however, walking may be a viable option. Anna, who lives in Edinburgh, finds that walking short distances to work and the CBD is preferable to sitting in traffic or fighting for an expensive parking spot: 'I don't need a car living where I live. [...] I just walk everywhere. I live centrally in Edinburgh, and so it doesn't take long to walk places.' Individuals responsible for young families, no matter where they live, find re-organising everyday routines relatively more complex without the convenience of a car. Joan, living in a coastal town on the west of Scotland, is illustrative of a range of experiences. When Joan was diagnosed at the age of 28, losing her license impacted on all areas of her life (especially as her husband did not drive):

We had to get rid of the car. And that was massively frustrating. I mean, having to trundle everywhere with first one child and then two children; you know: oh! Life was hard. It was an awful struggle. [...] We're talking twenty-six years ago, so nurseries weren't established in the way that they are now. Child-minding was not a regular thing. There was just no way that I could possibly manage to run a house *and* look after two children *and* go to work.

All of this, while struggling to cope with a changing and changeable body, meant that quitting her job became the obvious choice. Everything, thereafter, required more planning because she was not only in charge of her own volatile body but also her childrens' safety:

What is five minutes in a car, a half-hour round-trip, you're talking an *hour* round-trip [on foot] by the time you're ready to go out; because you've got to get yourself completely weather-proof, and get yourself out, and, I mean, anything you buy, you're stuck holding it; and I get fed-up with that. [...] The car] was your 'left luggage locker'. (Joan)

The challenges of getting around on foot involve the co-ordination of multiple dynamic spatialities, simultaneously of the body (or bodies), space and place (Urry [2006] refers to the

multiple temporalities of walking). Living with chronic illness produces different capacities to 'walk the walk' (Ingold 2004), and so individuals make use of, and become inter-dependent with, a variety of non-human 'things' (see earlier section on 'anticipating space'); for example, to cope with the demands of looking after her children and shopping, Joan purchased a pram with large storage capacity, which also acted as a 'crutch' when her bodily boundaries seemed to be in danger. With her children now safe, Joan even began to see the positive health benefits of walking, especially as medications had previously rendered her immobile.

People with active epilepsy receive free bus passes in Scotland and are eligible for subsidised rail travel. By forward-planning her rail travel, Laura also pays 'early-bird' prices, meaning that not having a car is economically advantageous. A number of participants are happy to use public transport, especially when it is generally frequent and accessible: 'I'm very spoiled, because there's a bus stop at the bottom of my street. There's regular buses that go to [...] Paisley, right outside my work' (Chris). Location and situation is generally indicative of an individual's attitudes, and will be of elevated significance when *moving* house. A downside for Jennifer is that 'access' issues serve to limit her options:

I always had to ensure that I lived in the centre of Cardiff or wherever, you know, just due to public transport. And that was an issue for me, especially because I was trying to get on the property ladder and it was very expensive in the centre of Cardiff. (Jennifer)

Living in smaller towns, villages or rural areas usually entails less robust public transport (and problems if one's 'stop' is not close-by). This impacts on all aspects of planning and organisation, principally work, family and social life. Indirect public transport routes mean that distances negligible by car become significant. This sometimes results in spatial restrictions, or, when family and friends repeatedly offer lifts, strained social relationships (even if the individual is not treated as a 'burden', they might feel that they are unable to repay favours):

I've got friends that stay in Houston, which is a small village, which as the crow flies isn't that far from where I stay. But if you're travelling by bus you've got to get the bus to Paisley and get a bus through two other villages to get anywhere close to it. So that's problematic. Again, sometimes I'd feel bad because my friends would say 'We'll come and get you,' and so I'm forcing them to do something out of their way. They always insisted that it wasn't a problem but it was something that I was aware of: that it's not just *my* condition in some cases – it's affecting *other people*. (Chris)

Indeed, the extreme *relationality* of living with epilepsy cannot but be reflected in the spatial extent of peoples' everyday lives.

Being able to rely on a partner or friend for lifts is generally helpful, although not always guaranteed. Limited public transport options have an unyielding impact on Maureen's social

geographies. Social occasions are cut short due to having to catch a bus, or else she might end up over-staying her welcome while awaiting another:

I was away in St. Andrews last month and can't get home on public transport on a Sunday, so the only way I can go is if I stay with my cousin on a Sunday night. He's got to come and get me and take me back to his house. There's a lot of things like that. And I can't get to a lot of yoga seminars now because I don't have a car to get there. There are a *lot* of places I just can't get to at all [...] if they're not on the beaten track. (Maureen)

In this case, subsidised public transport is no help because Maureen is concerned more with destination (and returning) than economics. For Joan, these factors are inseparable. Working as a supply teacher on the west coast of Scotland means being called out to various schools in an area dotted with small towns and villages. Consequently, she struggles to get to work on time *and* find new, reachable employment:

It was completely useless. The buses were once every half hour. But to the likes of Rosneath and Kilcreggan, they're only once an hour. That's a heck of a waiting time if you just miss one; then the travel time, then coming back. It ended up that I had to take taxis sometimes to get to schools for nine o'clock in the morning. [...] There certainly have been jobs that I would have gone after with a car that I haven't been able to because I can't get there. (Joan)

Of course, this is not to mention people who are employed in driving-related jobs, such as bus, taxi or lorry drivers, whose diagnosis entails probable unemployment (Cavanagh 2010). For people who cannot access transport to *get to* work, there are but a few possible government-backed solutions¹⁰⁷, but these do not appear to be well known.

BUS-SPACE

Nearby and efficient transport links do not necessarily ease the problems faced by people with epilepsy. Redacted from **Table 10** (above), consider the questionnaire responses pertaining to feelings of safety on a bus:

Table 11: Feelings of safety on a bus

	Safe	Usually Safe	Sometimes Safe, Sometimes Unsafe	Usually Unsafe	Unsafe	Response Count
Bus	4	8	29	24	46	111

¹⁰⁷ The 'Access to work' scheme (<https://www.gov.uk/access-to-work/overview>) was mentioned by Sue as a way to subsidise travel to work: 'When I lost my license: how do we get to Perth everyday? How's that going to happen? You need to understand: there's not a bus, there's not a train, so I can't do it like that. To cut a long story short, because we are now within the Disability Discrimination Act it means, in theory, that you are now eligible for taxi transport if you are not able to get to your place of work by any other means.'

Spaces of public transport are felt by several respondents to be so 'unsafe' that they would never travel that way. Renae's frequent seizures mean that she finds it too risky: 'I didn't even bother. I just avoided it, because I had no reason to go anywhere.' Gordon explains:

You physically couldn't go anywhere because you had to work out whether having a fit in public transport would be worth it [...]. Public transport was just a no-go because you couldn't predict what was going to happen. (Gordon)

There appear to be several entangled reasons behind reluctance to travel on public transport. First, the space of the vehicle itself might be problematic for feelings of phenomenological security. Dobbs (2001, in Gesler and Kearns 2002: 114) examines the structural and cultural barriers faced by people with disabilities using public transport in the city. In regards to accessibility, she finds there is only a half-hearted attitude to catering for the needs of disabled people, with a dearth of appropriate signage and material aids like ramps. In the UK, it is common now for public transport to reserve space for disabled persons, although this frequently relies on the 'good will' of non-disabled passengers vacating such areas. This issue is perhaps more clouded for individuals with hidden disabilities, whose impairments (usually) go unnoticed and are hence frequently *challenged* as non-disabled persons occupying 'disabled space' (for example, when being to asked to vacate such spaces, or when requesting that space be made). Being denied a seat on a busy bus presents a significant risk for people who experience seizures involving loss of muscle tone. As in my discussion of the home, surfaces, textures and spacing are significant. Laura says, 'If you're standing up, you'll wallop yourself one if you take a fit, because the seats are quite close.' The material design of the bus, then, with its metal seat frames, railings and polls is rather precarious for the 'anarchic' body, especially the head. Renae continues:

When my seizures were getting bad the doctors at the hospital even told me not to use the buses because I don't get any warnings before my seizure. I never have. And I've had that many injuries if I've taken a seizure: bashing my head on the metal bars. (Renae)

Here we must consider how the phenomenology of seizures and the micro-materialities of the bus 'collide'. If the seizure manifests in convulsions, there is very little soft or open space on to which the body may fall or be laid, safe from harm. Except for cushioned seats, surfaces are usually hard; plus, only if the body were oriented along the gangway, with no obstructing people or objects, would it have spreading space (although seat legs would again be problematic). Here there are echoes of Kitchin's argument (1998: 348) that poor design or inadequate provision denies disabled people the same spatial choices as are available to 'able-bodied' people.

Public transport, in many respects, is *uniquely* public because of how strangers are packed together in an enclosed space. Goffman (1963: 139) describes the importance of developing 'civil

inattention'; that is, how people avoid paying attention to others with whom they are not in any obvious interaction. Urry (2006) relates this point to train travel, discussing how newspapers, magazines and mobile phones allow us 'to carry around a screen that can be raised at any time to give ourselves or others an excuse for not initiating contact' (Goffman 1963: 139; also in Davidson 2003). Bus-space is a socially organised environment, involving a new dialectic of proximity and 'distance' with strangers (and technologies or landscapes that 'hold' our attentions). The 'performed fiction' of inattention and silence, however, can be shattered by a seizure. Thus for people with epilepsy, bus-space is highly volatile on a social level. Recalling discussion in CHAPTER FIVE (especially with Sue's seizure on an aeroplane) concerning intense affective potentials, individuals will as far as possible conceal that they are going to have a seizure from others, but this may be impossible in close confinement:

I've had seizures on buses and you wanted to tell somebody that you felt symptoms, but they're all strangers and you don't know who to talk to. So you just try and breathe deep and hope that the seizure symptoms will go away. (Brian)

Between bus stops there is no means of 'escape'; for example, to hide or confine the 'anarchic' body in the toilets (as discussed in CHAPTER FOUR). For this reason, Claire avoids the Glasgow Underground: 'I don't take the subway anymore because I thought to myself, 'I couldn't have a seizure with all those people sitting there [... That] just freaks me out.'" Safety concerns are hence not only over physical injury, but, as one anonymous questionnaire respondent elaborates, they also relate to negative affects in relation to other people: 'I have had a seizure on a public bus and unfortunately, someone stole my bag while I was unconscious so it has left me feeling quite vulnerable.' Furthermore, the disruption of a seizure could impact on others because 'you could distract the bus driver and cause an accident' (Renaë).

Another cause for anxiety is the potential for spatial displacement in the event of unconsciousness (see Brian's testimony in CHAPTER FOUR). For Gordon, 'the stress of working out where you were going and when you were to get off would quite often trigger a fit.' Spending time unconscious on a bus entails perhaps not knowing one's own whereabouts on regaining awareness. One anonymous questionnaire respondent, whose seizure led to dis-location, writes:

I have had a seizure on the bus a few times and as a result I ended up miles past my stop. I got off the bus in a semi-recovered state and wandered across a busy street and ended up on another bus, but the wrong one, which took me out of the way again. It can be very confusing.

Joan assesses how buses can be relatively more problematic than trains because of the nature of the service and *route*:

If you're on a train, then at the end of the terminus they would check around to see if all the seats were empty. Whereas if you're on a bus, and it's a circular bus [route], then you can be on it all day and nobody would ever know. Yeah, it was quite alarming that day when I had [... a] seizure on the bus, then I didn't end up waking up until Glasgow. (Joan)

Due to such concerns, Laura now discloses to the driver or conductor of public transport: 'I tell the ticket inspector that [I] have epilepsy: they will keep an eye on you on the train. If you take the bus, you tell the bus driver – if you're going long distance, obviously, it's just safer.' To avoid journeying beyond one's intended stopping point, several participants routinely ask the bus driver to alert them when it was reached. In this situation, it is hoped, the bus driver will locate them if they have fallen unconscious (and others have not warned the driver). However, this entails first warning the driver, who may then have to stop and find or address the individual specifically, rendering them the focus of others' attentions. As such, numerous participants are loath to go down this path:

It's embarrassing to say to the driver 'Oh, I've got epilepsy, Jimmy, do you mind giving me a shout when we get to the Jewel?' or wherever it is you've got to get off. You just show them your bus pass and hope that you'll be conscious when you come to your stop. (Brian)

Furthermore, buses are designed with narrow 'funnel' entrance spaces to compel boarding passengers to queue, hence maximising the efficiency of the driver's time. Holding up a queue to disclose that one has epilepsy (in what is normally a brief, impersonal encounter) can be hugely discomfoting because of implicit pressures to proceed speedily. Hence the design of entrance space coerces one to 'go it alone'. These are but some of the difficulties faced by people with epilepsy on public transport. Whether for fear of being physically hurt, disrupting self and others in enclosed space, social embarrassment or spatial displacement, the availability of local transport does not guarantee safe or comfortable passage to places of work or socialising. As Kitchin (1998: 348) puts it:

The spatial manifestations of inaccessible public transport reproduces unemployment and underemployment amongst disabled people, and restricts their social activities. This, in turn, restricts the ability to earn, and thus confines them to poor, cheap and inadequate housing and welfarist lifestyles.

CONCLUSION

This chapter has spun together a range of 'epileptic' spatialities. First, by considering experiences of memory loss, I mapped the 'other' spaces where people *hold* memories and the spatial configurations that they use to 'organise' possible futures, which they are already in the process

of forgetting. With such cognitive difficulties in mind, I considered the challenges of maintaining an 'able' identity in the workplace. Individuals are frequently forced to construct 'hidden geographies' by subtly altering their workspaces and completing tasks through new, often creative and resourceful mind/body processes. Because the space of the workplace most often belongs to other people and institutions (literally and metaphorically), alterations to space are usually limited by norms and policy conventions. The home is generally a much more permissive environment, where the individual, relatively constrained or enabled by finances and social relations, can work *with* space to bring it under control, countering its potentially damaging interactions with the body that will *lose* control. While participants recognised their phenomenologically altered relationships with a range of materials, surfaces, elements and reliefs, 'accessibility' is only ever a precarious accomplishment given the dynamic relationship between humans and non-human objects. Individuals reflected on ambivalent relationships with the home, but certainly felt more secure there than in the 'outside' world, when travelling between destinations. While participants recognised an inability to control 'external' space as they might the homeplace, they did, however, prepare the body in anticipation of its potential interactions with the threatening 'outside'. As well as averting physical danger, individuals' movements are in part shaped by social anxieties over being witnessed during a seizure. They will often keep to the margins of social space, since moving to the centre represents a great risk to self. Of course, this opens up a contradictory relationship, whereby the individual avoids having a social 'presence' in fear of their social 'presence' being lost. As a result, many feel as if they do not belong, as if they are the 'itinerant' whose short time in each place precludes the formation of meaningful relationships. Being excluded from driving means people have to think about *how* they travel public space. While people with epilepsy may benefit financially from free bus passes, the 'close' social space of the bus provides a case study encapsulating a range of problems for people whose social geographies tend to diminish severely, whether or not by choice.

The chapter has emphasised the unfixed nature of space. Whether referring to the workplace or home environment, preparations for going places, being on the move (either walking or taking public transport), losing and accessing memory, or indeed *the body* itself, there is no space that is unchangeable in terms of personal, social or material arrangement. While this is the case for many of 'us', these issues are greatly heightened for people with epilepsy. For many participants, space can be lost, found, exclusive, inclusive, dangerous, safe, in, out, in-between. Despite various personal, social, economic or political constraints, this suggests a dynamic interaction between self and space that is context-dependent; never pre-determined, but place-*defining*. Thus, normative conceptions of the backward, apathetic, inactive 'epileptic' are redundant: theirs is a geography of access, alteration, timing, negotiation, preparation, ordering, organisation, walking, talking, recording, finding, placing, spacing, navigation, measuring,

anticipating, softening, stabilising, safeguarding, checking, changing. To be sure, people with epilepsy can teach us much about adaptation when faced with difficult emotions or practical obstacles: the challenges that these individuals experience are not so unique but in many cases more explicit.

Practices of coping involve new spatial configurations and, sometimes, modifying existing structures (Crooks 2010). Participants further reveal a continual vigilance to 'internal' and 'external' contingencies. Mundane practices become imbued with meaning, while on-going risk assessments are based on (immediate and longer-term) knowledge of the unstable body in relation to surrounding material space and the proximity of others. The extent of individuals' social geographies, then, vary with fluctuating symptoms, emotions and willingness to take risks in terms of when, where and how often seizures might occur (Smith 2012). Through careful action and adequate resources, people negotiate their social and physical environments to accommodate illness (Moss and Dyck 2002: 123). Geographers have shown how illness and impairment constrain the spatial extent of everyday life (certain places may become 'out of bounds', while others, such as the home, take on greater significance), in which particular spaces are used differently (to manage illness or disability) and perceived in new ways (places may become marked as safe or unsafe). Individuals hence *embody* their fluctuating material and social limits through different spatial scales, including the body, home, locality, mode of transport, paid labour and governmental policies.

CHAPTER EIGHT:

FINDING ONE'S 'WAY' WITH EPILEPSY: A VITAL POLITICS OF EVERYDAY LIFE

It's the day-to-day stuff with which we need help. And if we don't understand what it's like for people with epilepsy, we don't understand the *stories* behind it, we'll keep doing this reductionist science stuff and randomised control trials and all the rest of it, and base everything we're doing on that. But we human beings are much more complicated than that. [...] We need to understand the stories of the *people*, and we need to understand what they *want*; and if we don't have that, how are we meant to manage services? (Sylvia, Epilepsy Charity Worker)

INTRODUCTION

In this chapter, I aim to clarify how complex lived vitalities meet and sometimes clash with diverse governmental regimes, in particular the 'biomedical' but also increasingly in reflection of discourses surrounding the autonomous, responsible neoliberal subject, as they press 'down' upon the vital unpredictabilities of 'epileptic life'. Life takes on different meanings as it is re-valued, re-structured and re-organised so as to discipline the 'epileptic body' (which, in CHAPTER FIVE, is shown to threaten the fabric of the socio-cultural order in its always-incomplete 'regulation') according to definitions of the 'healthy', productive citizen, a process that Foucault defined as *biopolitics*. As Philo (2001: 485) commentates, the 'power over life', this *biopower*, is expressed in all manner of policies designed to monitor, analyse, plan and regulate 'different' bodies. A whole range of rights, economics and institutional practices descend on the unhealthy body and designate acceptable 'illness' behaviours and interventions in line with local and national policies and opportunities. Biopower, according to Rainbow and Rose (2006), entails truth-claims about the 'vital' character of human life, which derive from authorities considered competent to speak that truth. For people with epilepsy, biopower implicates interventions that 'promise' to optimise some form of valued life – regulation of the body – against some form of threat – the unregulated body – so as to make vital life *live*. While biopower exists on many levels of society, the focus here is on how various forms of governance (including biomedical economies and technologies) lay bare the politics and (bio)ethics of controlling 'epilepsy', less as some objective scientific exercise and more one based on judgements of what constitutes a 'correct' level of bodily regulation.

In assessing the politics of neuro-biological life, I follow Philo (2012) in suggesting that 'regulating' frameworks only make sense given the unruly, unpredictable messiness of 'real' vital life; accordingly, Foucauldian analyses allow for bodies to be more rebellious, unpredictable, material and lively than has commonly been depicted. Indeed, biopower is not just a power *over* populations, but can be exercised by diverse actors in the process of self-determination and resistance. By bringing together 'biopower' with 'human vitalities' I engage two ways of addressing the politics of 'life itself', albeit ones that are usually held apart (but see Anderson [2012] for an encounter between affect and biopower). The vital nature of human life, it is argued (Thrift 2004; Thrift and Dewsbury 2000), is affectual, mysterious, lively, performative. Thus, new, creative ways of life are always beyond control and regulation precisely because they only ever appear as they are made and practised, and therefore could not have been *anticipated* by the institutions that would seek to subjugate them. In contrast to vitalism, biopower hinges, to put it crudely, on sustaining life by containing life. I seek to work productively with these two seemingly incommensurate concepts, to show how life is always lived at the intersection of vital and power-full processes. As Anderson (2012: 28; also Philo 2012) points out, while the power of social and institutional discourses construct 'ways of knowing' human life, life is that which exceeds such attempts. Simultaneously, life is also that which is made productive through techniques of intervention.

In various ways throughout this chapter I seek to scramble the binary of the biopolitical/governmental and the vital. First, I engage how the 'the art of seeing, the gaze' (Foucault 1973: ix) of biomedicine is an important factor in shaping Western biopolitics (inclusive of the 'pharmaceuticalisation' of biological citizenship: see Sparke forthcoming; Diedrich 2007). I consider the space, technologies, languages and practices of biomedical interventions in naming and managing the individual's 'options', especially at diagnosis. Over time, phenomenological perception and exposure to other sources of information (including epilepsy community spaces) for some people facilitates contestations of the biomedical, recognising that it is one among many ways for steering the vitalities of 'epileptic life'. On the other hand, I argue that people who experience seizures less often or dramatically frequently distance *themselves* from engaging in biopolitical contestations, either personally or collectively. This leaves people who experience difficult-to-manage epilepsy as the public 'face' of the condition at the same time as socially-sanctioned 'good news' narratives advanced by advocacy organisations, arguably ES included, risk silencing such individuals. This creates, and is created by, a complex politics of representation that serves to isolate many people with epilepsy, whose lack of political organisation is reflective of meagre resources and regional-contextual factors (e.g. urban-rural differences), giving rise to the belief that the condition is a *personal* obstacle.

By thinking through this 'geographically uneven process of embodying, performing and representing ill selves in and through place' (Crooks and Chouinard 2006: 345), it is shown how experiences of illness and disability are not merely personal, medical, political or economic, but always involve the time- and place-specific interweaving of these various influences to construct contested geographies of governing the 'epileptic body'. I move to discussing the neoliberal¹⁰⁸ subject as being embroiled in practices of self-surveillance, self-regulation and self-governance as 'an emergent pattern' arising out of complex negotiations between social actors, groups, organisations and institutions (Rose 1999: 21). Anderson (2012: 29) argues that, 'through neoliberal logics of governing the contingency of life has become a source of threat and opportunity, danger and profit'. Inherent in these cultural logics is the *promise* of living the 'good life' so long as one maximises self-regulation of the body that threatens to become old, fail or fall. The fight to assert one's own neoliberal subjecthood is arguably especially relevant for the individual who in seizure cannot *be* a neoliberal subject. To be sure, the relentless vitality and contingency of everyday life, together with unattainable Western bodily 'ideals' (Wendell 1996), is what both eludes *and* sustains the biopower of various modes of governance. Furthermore, while actions aimed at 'regulating' the body *can* be interpreted as individuals internalising wider injunctions, including ones that tip over into being disempowering, 'moralising' judgements, they may also be interpreted as individuals becoming more self-empowered and able to make informed choices in light of the risks of the 'epileptic body' escaping self-governance.

BIOMEDICAL GOVERNANCE

THE 'REVOLVING DOOR': INFORMATION PROVISION AT DIAGNOSIS

The 'clinic' is the 'meeting place of doctor and patient' (Foucault 1973: 111). This is where the body is objectified and translated in to biomedical knowledge and categories which reduce and abstract the patient's story according to known constellations of symptoms. As Foucault (1973: 8) asserts, '[p]aradoxically, in relation to that which he [sic] is suffering from, the patient is only an external fact; the medical reading must take him into account only to place him in parentheses.' This objectification of the body suggests that the person is not considered as the subject of their

¹⁰⁸ Neoliberalism is a specific type of governance based on the logic of life as contingent, and always working between chaos and regulation. Foucault (2008) shows that in (neo)liberalism the 'market' is perceived in terms of the 'formal game' of competition that becomes the basis of society (Anderson 2012: 36). The neoliberal subject is one who attempts to 'optimise' their body-self by working out the problem of how to make power seemingly work *for* them within the 'principles of a market economy' (Foucault 2008: 131). Neoliberalism is, of course, a contemporary framework within which epilepsy is understood. In the past, epilepsy was not managed by the neoliberal self; for example, Kluger and Kudernatsch (2009: 220) describe how 'in the early and high Middle Ages, in the West, illness was viewed as a punishment for sinful behaviour, considered to be witchcraft or bedevilment. Sacrifice [...] and exorcism of demons/the devil were 'therapeutic' concepts'. Its strong influence on all aspects of social, cultural and political life meant that 'casting out' what is now called 'epilepsy' was under of the jurisdiction of the *church*.

own experiences of illness. The individual is not considered capable of 'knowing' their illness, even if they *feel* it; rather they are the space on to which biomedical inscriptions are etched. Hence, '[d]escription, in clinical medicine, does not mean placing the hidden or invisible within the reach of those who have no direct access to them; what it means is to give speech to that which everyone sees without seeing – a speech that can be understood only by those initiated into true speech' (Foucault 1973: 115). When clinicians, the true speakers, translate patient testimonies but do not then translate their own judgements *back* into lay person's language, the individual is denied the immediate opportunity of comparing and contrasting *their* body with *the* body-object of diagnostic knowledge¹⁰⁹. This commonly means that newly-diagnosed persons listen bemused and so feel incapable of contesting advice or prescriptions that *they* supposedly should accept and practice on the space of *their* body as a way of structuring *their* experience. At this point the individual is 'both subject and object of his [sic] own knowledge' (Foucault 1973: 197), perhaps reacting fearfully when these do not necessarily match up.

Lack of prior knowledge about epilepsy sustains the authority of the biomedical in diagnosing and policing the condition¹¹⁰. Diagnosis can be a hugely distressing process, especially when people are left in the dark as to why they might have developed epilepsy, yet it may also grant optimism for appropriate treatment. It is instructive here to consider exactly what information is offered by neurologists and ESNs (as 'diagnosing professionals')¹¹¹ to the newly-diagnosed, for this in part shapes how people make sense of their experiences and expectations for the future. These specialists are provided with 'SIGN' (Scottish Intercollegiate Guidelines Network) Guidelines (<http://www.sign.ac.uk/pdf/sign70.pdf>) so that they may comply with clinical standards for neurological health services. **Figure 7** displays the SIGN checklist, which marks the professional jurisdiction over epilepsy:

¹⁰⁹ At the same time, the low public profile of epilepsy impacts on how individuals respond to their diagnosis and how experiences of illness are positioned within the epilepsy discourse. As Kiliç and Campbell (2009: 667) show, misconceptions surrounding epilepsy are assigned both to the general public and the recently diagnosed, who represent it as a condition of uncontrolled, abnormal and incoherent 'attacks' brought on by flashing lights. We 'know' this because of cultural factors, such as warnings about flash photography prior to television programmes, even though photosensitivity is a trigger for only 3% of people with epilepsy: see www.epilepsyscotland.org.uk/seizure-triggers/info_18.html.

¹¹⁰ By documenting that an individual has been diagnosed with epilepsy, physicians serve as powerful 'gatekeepers' to a range of social 'freedoms', such as the right to drive, work with machinery and join the armed forces. The definitions, theories, practices and social institutions that maintain this medical 'ownership' of epilepsy constitute an important part of the 'objective reality' with which people so labelled must cope (Schneider 1988).

¹¹¹ Individuals seeking medical advice after a suspected seizure will usually see their GP first, who, if they are satisfied with the available 'evidence' (including witness testimony: see CHAPTER FIVE), will facilitate an appointment with a 'diagnosing professional'/'specialist', most likely a neurologist. After being diagnosed by the neurologist and being offered basic information, individuals will be referred on to an ESN, who will supplement the information already provided. If an individual has subsequent problems with their medication levels or type, they will often have to wait until their next 'check up' with the specialist as GPs rarely intervene on this matter due to a lack of specialist knowledge.

Figure 7: SIGN Guidelines for 'information to be discussed with patients and carers'**6.1.1 EXAMPLE INFORMATION CHECKLIST**

Example checklist that can be used by healthcare professionals to identify what information to give patients and carers:

<p>General epilepsy information explanation of what epilepsy is* probable cause explanation of investigative procedures classification of seizures* syndrome epidemiology prognosis* genetics Sudden Unexpected Death in Epilepsy (SUDEP)*</p> <p>Antiepileptic drugs choice of drug* efficacy* side effects* adherence* drug interactions* free prescriptions*</p> <p>Seizure triggers lack of sleep* alcohol and recreational drugs* stress* photosensitivity</p> <p>First Aid general guidelines* <i>status epilepticus</i></p>	<p>Issues for women contraception* pre-conception* pregnancy and breastfeeding* menopause</p> <p>Lifestyle driving regulations* employment education (e.g. EAS guidelines for teachers) leisure relationships safety in the home*</p> <p>Possible psychosocial consequences perceived stigma* memory loss* depression anxiety maintaining mental well being self esteem* sexual difficulties</p> <p>Support organisations addresses and telephone numbers of national and local epilepsy organisations*</p>
<p>Format appropriate language appropriate size appropriate level of comprehension appropriate format</p>	

* Items marked with an asterisk are considered essential information. The other material should be given when it is relevant.

This checklist constructs an official version of potential obstructions to the healthy body, and points to a professional-led discussion of what measures may be taken to 'discipline' the condition and self (I return to this list below, discussing how it interweaves with 'care of the self'). That certain items (marked with an asterisk) are 'essential information', while others are subject to what the professional deems relevant, shows that the 'policing' of epilepsy is not based entirely on hand-downs from an infallible dominion of biomedical knowledge, but also entrains the subjective decision-making of particular individuals reflecting 'the common representation of the norm in a social *milieu* at a given moment' (Canguilhem 1973: 68, in Philo 2007: 91). This *milieu* is

in part shaped by political and legal contexts; for example, a recent court ruling¹¹² mandated, in somewhat controversial circumstances, that all newly-diagnosed patients be made aware of sudden unexpected death in epilepsy (SUDEP), 'even if they've only had one seizure' (Sadie, ESN). Providing such information is a hugely sensitive task at a time when the patient may already be very upset. In the heightened emotional geographies of the clinic, then, some specialists reveal how they often feel they simply cannot approach this topic. Here, the personal interweaves with the political such that withholding information is framed as an ethically- and legally-dubious decision. For the 'patient', the supposed necessity of becoming informed of SUDEP constructs epilepsy as dangerous, further encouraging them to 'tow the biomedical line' lest they should put their lives in jeopardy.

While the SIGN Guidelines act as a 'cherished roadmap of medical terrain' (Schneider and Conrad 1981: 213, on medical 'typologies') for helping prepare people for living with epilepsy, differences in specialists' knowledge, opinions and intersubjective relationship with the 'patient' mean advice is given out unevenly. Whether information is provided *proactively* or *reactively* often becomes a point of tension between specialists and service-users: neurologists and ESNs are cautious in unpacking potential social, bodily or lifestyle issues that might never apply to that individual; nevertheless, numerous participants feel that the time and information they were afforded after initial diagnosis was completely inadequate¹¹³. As Joan reveals, 'they just left me to hang until my specialist appointment. 'Just keep taking the tablets' – that was it.' At that time, it was impossible to anticipate the course of Joan's condition – whether treatment would work, the different types and frequency of seizures she would experience – and so she faced the limits of biomedical knowledge without recourse to alternative modes of understanding.

In such situations, the power of knowledge remains in the hands of biomedical professionals, with individuals left hanging, in a liminal state, wondering how on earth they are meant to *live* with this condition. A further tension is revealed by participants who were unaware of their potential entitlement to economic assistance, such as free prescriptions and a bus pass¹¹⁴. Specialists are gatekeepers to such information and yet they may only offer it selectively:

¹¹² A 'fatal accident enquiry', published in 2011, was opened as a result of the deaths of two young women in Scotland, neither of whom had been warned of the risks of sudden unexpected death in epilepsy (SUDEP) by their doctor. Although the cause of SUDEP is unknown, seizure-avoidance behaviours (taking medications, avoiding triggers) are recommended.

¹¹³ It must be noted that some interviewees were diagnosed in previous decades, when there was arguably less widely-available public information and professional guidelines.

¹¹⁴ Individuals are eligible for a bus pass when they are prohibited from driving. In Scotland, all prescriptions became free of charge in April 2011. However, erroneously paying prescription charges for AEDs in the past demonstrates a lived socio-economic challenge of living with epilepsy at *that* time (and place). Another issue of biopolitical importance is whether or not a person is eligible for government disability benefits (see CHAPTER SEVEN). Government agencies *appropriate* epilepsy by setting its parameters for socio-economic purposes, and so shape the meaning and consequences of being diagnosed (Moss and Dyck 1999a: 386). This determines the range and amount of benefits available to people, which then implicates not only financial security, but also whether or not a person is deemed 'ill' or 'disabled'. A denied claim suggests that they are neither.

Rightly or wrongly, it's something that I'm a little bit uncomfortable going into too much at that [diagnosis] stage. It's not that I want to deny my patients access to these things, but I think that there is a real danger inherent in the benefit system that you medicalise and make people quite dependent on benefits. (Sadie, ESN)

This is a highly pertinent comment given current political contexts in which there is much public debate about 'benefits scroungers'. Garthwaite (2011) discusses how 'ill' or 'disabled' individuals receiving support can be labelled and portrayed negatively within a wider rhetoric that encompasses governmental, public and media attitudes. The central tension for this ESN is between disempowering people through the denial of information and caution over creating the circumstances for 'learned helplessness' (Miller and Seligman 1975), which in itself can be disempowering. Nonetheless, withholding information is an ethical decision in that it presumes to know what is best for the individual.

There is a central irony to the checklist instruction that information be delivered using 'appropriate language' while ensuring that the patient has a sufficient 'level of comprehension'. Diagnosing specialists (notably neurologists) control and regulate what information they choose to impart, yet this is too often in line with their *own* professional concerns: interpreting 'test results' so as to classify a particular kind of epilepsy. Participants feel treated as symptom classifications (Schneider and Conrad 1981; Porter 1993) rather than as individuals:

I don't recall at any point anyone actually saying 'you have epilepsy', although I had been to the Epilepsy Specialist Nurse at the Southern a couple of times. I think it's maybe just because they're so used to the language of it, the language that the neurologists adopt: they just talk about 'seizures' and 'events', [...] 'lobes' and 'the brain' and 'hemispheres' and 'electrical activity' and stuff like that. I'm not stupid, but some of the stuff that he was talking about maybe was a bit too technical. He's a neurologist, and he's an expert, so he understands everything he's saying. I'm just a lay person. (Chris)

Here biomedical discourse was quite literally a barrier, meaning that Chris's diagnosis remained unfixed and unstable (in contrast with the technical language of neurologists, GPs are commonly criticised by participants for their *lack* of specialist knowledge). Although diagnosis may bring about 'a sense of unity to a particular configuration of symptoms' (Moss and Dyck 2002: 92), social scripts with which to explain illness to self and others are denied or compromised by the use of inappropriate language. Furthermore, the hierarchical and paternalistic attitudes of health-care providers (Crooks and Chouinard 2006: 349) make it difficult for participants to get 'straight' answers to their questions. Not receiving full and timely 'disclosure' in medical settings is *disempowering* (Gesler 1999) precisely because it disadvantages people in their struggles to find out information and manage their illness in *other* everyday spaces.

Restricted consultation times with specialists mean that encounters are inevitably dominated with immediate medical issues (Poole *et al.* 2000; Clark *et al.* 2010). Widespread use of the term 'patient' is indicative of the temporality framing how health professionals engage with people: as long as it takes to classify symptoms or determine the efficacy of treatments in spaces of health care. Beyond that, participants feel, they are *on their own*¹¹⁵:

I've been to appointments where I've waited six months to have a chat, and then it's time-up – you can't ask every question you had. And when you're asking about your body, how your medicine's affecting you, you can't go into that. [...] It's a lack of *help*. When you're seeing these doctors, they can't hear what you're saying. (Robert)

People feel as if they have entered a 'revolving door', whereby they receive a diagnosis at a hospital and come back out in a very short space of time, without a protocol or benchmark for what happens next. Time pressures¹¹⁶ result in specialists *avoiding* the provision of a comprehensive service, as engaging individuals on questions of wellbeing could potentially open a 'can of worms' which they do not feel sufficiently resourced to tackle, possibly explaining the high rates of undiagnosed comorbid symptoms, e.g. depression, among people with epilepsy (Ettinger *et al.* 1998). As one neurologist, Dr. Reed, asserts, 'Time. Simply time: there's not enough time. There's not enough doctors, and too many patients.' Nevertheless, the time afforded to individuals by authoritative medical professionals at, and immediately following, diagnosis shapes early understandings of epilepsy and perceived utility in, or ability to gain, further assistance.

NEUROPOLITICS: A MEDICAL-PHARMACEUTICAL DICTATORSHIP?

The mind/bodies of epilepsy patients are contested sites of control over which medical practices prescribe (and inscribe) alteration and correction (Parr 1999: 193). This is an important geography of epilepsy because the use of medications contributes to the social situation of individuals living with the condition¹¹⁷. 'Seizure control' represents an often unhappy compromise between the socio-moral imperative for a regulated body, the practices of medical-pharmaceutical institutions

¹¹⁵ This signals the importance of charities such as ES, whose free helpline is mentioned by several participants as providing an invaluable source of support and information during times of 'destabilisation'. Nevertheless, while every participant in this research is aware of charity services (as members of ES), not everyone was provided with such information at diagnosis and were left feeling isolated. This suggests that patients could benefit from an increasingly explicit partnership between diagnosing specialists and epilepsy charities, each of whom may then be able to focus their resources more efficiently.

¹¹⁶ Political-economic contexts impact on institutional structures. Shortfalls in specialist provision partially explain why people are afforded little time. 'The Investigation' (Radio Scotland 27/11/11) reported that there are only half the number of ESNs that campaigning organisations have requested for the 54,000 people in Scotland with epilepsy. Similarly, across Scotland there are only five specialist neurologists (epileptologists), whereas ES has campaigned for there to be one in every health board area.

¹¹⁷ There are no known substitutes for AEDs – some participants had tried coming off medications, but unsuccessfully. If scans identify scarring on the brain that is believed to be the 'cause' of seizures, people might qualify for brain surgery. Gordon, Sue and Jennifer each had surgery that halted seizures, while Holly's surgery resulted in a dramatic decrease in their frequency.

seeking to quell 'abnormal' electrical activity in the brain, and the fight for an acceptable quality of life. This is not to say that control by AEDs (anti-epileptic drugs) is necessarily *not* a good thing for the individual; for, as Goodwin *et al.* (2011: 754) describe, 'appropriate diagnosis and treatment helps to minimise social and financial deprivation, stigmatisation, misunderstanding, and promotes independence and employability.' Indeed, AEDs can be a 'god-send':

I just think this is great! I've just got a lot more belief in the medication I'm taking. While I was on topiramate [AED] I was thinking, 'I may as well not take it, because it's not working anymore.' But I feel good on this keppra [AED]! (Claire)

Claire's 'belief' in the power of biomedicine extends beyond immediately medical spaces to the myriad spaces of everyday life. Her diagnostic label enables her to engage the medicalised self, with a view to becoming 'normal' once more.

Biomedicine offers legitimacy for both how a person is feeling and the body is operating, as well as a solution to this 'deviance' (Clarke and James 2003: 1393). Bodies are disciplined through the use of medications to make it possible for individuals to function in the 'correct' embodied state without challenging the social order (e.g. within the workplace: see CHAPTER FIVE) or indeed contesting the appropriateness of their medications (Freund *et al.* 1995: 134). Yet treatment sometimes becomes a *hostile* exercise in disciplining the unruly and economically unproductive body, which is co-opted by a politics of pharmaceutically-mediated control, ensuring the reification of the dominant order, in this case signified by regulated bodies. This is not entirely unrecognised by participants; for example, Gordon asserts: 'I often look at the fact that I was only on medication to make me socially acceptable.' Individuals for whom seizures and side-effects are not brought under control immediately by medications thereby remain *ill*, in need of intervention.

The Joint Epilepsy Council (JEC 2011: 6) reports that in the UK 'only 52% of the population with epilepsy are seizure free,' when, with 'optimal treatment', this figure could be 70%. What constitutes 'optimal treatment' is left to interpretation. It seems, however, that it is based on the individual who takes their medication, in a timely manner, while following the rules of self-surveillance as laid down by the SIGN Guidelines. Dr. Rivett refers to a young woman who, after numerous investigations into her body's resistance to medication, 'admitted' that she had not been following the prescribed course:

If she had taken her pills, she wouldn't have had any fits, and the epilepsy wouldn't have been a problem. There's no comprehending it. But you can't win with some people. [...] They are declining the offer of professional advice, which is obviously their right to do. One has to quietly live with it and encourage them to do otherwise. [... If you suspect they are not taking their medication] you

make it absolutely clear to them that they are lying to you and you *know* they're lying to you. (Dr. Rivett, Neurologist)

Specialists clearly have an important role in facilitating as well as constraining understanding and action around taking medications. Several participants in this research had at some point misunderstood the implications of taking AEDs, or had not taken them 'correctly' for numerous reasons. Margaret had not been made aware that medications might not control seizures, or that control was only ever a tenuous accomplishment. James had not realised that a lack of seizures may have been to do with the medication as opposed to a lack of epilepsy. Claire had only taken her medication 'like paracetamol', i.e. as 'relief' following an episode. Not conforming to biomedical prescriptions due to a lack of information is often portrayed as *deviance*. Thus, if medications do not appear to be 'working', there may be some suspicion on the part of neurologists that the individual is to blame for their own lack of control. As a neurologist, Dr. Reed, asserts, 'Some patients are all concerned about side-effects and take their pills and couldn't care a damn [about 'good practice'] – they continue to smoke their pot and everything else.' Suspicions especially arise when medical knowledge 'fails', as Gordon identifies: 'Doctors didn't know what to do, so you were left as the guilty party. The doctors are trying; it's not working because *you* must be doing something wrong.' Responsibility for regulating the body is duly transferred to the patient: the problem is not that medicine cannot regulate the body; it is that the individual's mind/body is working against them (Wendell 1996: 100). As an explanation for the failure of treatments, the idea that the patient does not have the 'right attitude' is useful in maintaining biomedical omnipotence. In some cases this leads to banishment from medical spaces, as happened to Renae when she was told at the hospital that, 'as far as they were concerned, they'd tried everything and that's all they can do for me, so it's a waste of time. They just said 'Don't come back'.' The implication is that Renae, who experiences multiple seizures daily, is *too* 'epileptic'.

Other individuals continue as subjects through a process of medical trial and error. Certain medications may lower seizure frequency at the same time as inducing severe side-effects; others have little impact on seizures, while causing no adverse bodily effects. While the classification of certain epilepsy 'syndromes' directs the specialist to particular medications, there are no simple 'mechanics' in the control of epilepsy. The process hence becomes a puzzle played out on and in the space of the epileptic body. Several participants report feeling like a 'guinea pig', while Robert criticises the lack of after-care when subject to 'experimentation': 'Too much is trial and error. You're on trial, but you're away from the courtroom. Nobody's actually looking, or seeing, or getting any feedback.' Indeed, participants speak of having to *fight* for the specialist 'judge' to hear their 'evidence', to *fight* for changes in their medication, to *fight* for appointments, to *fight* for their GP to refer them back to the consultant, to *fight* not to be written-off or

'sentenced' as a 'deviant body'. This tiring, time-consuming struggle to be heard, to be empowered through partnership decision-making, is also a *fight* for ownership of one's own body.

Medications alter the body's internal processes, yet individuals are rarely empowered to decide for themselves if potential side-effects are worth the risk of taking a particular medication:

Epilim [AED] – I found out that was a very hard drug to your body. But no doctors told me anything like that. Why? That's a bad, bad sign of the profession. If they're going to put your body under strain, if they're dishing out tablets, they should tell you what these tablets can or may do to your body. (Robert)

Robert reckons that consent to biomedical control of his body is assumed, but without full disclosure. In this way, his questioning centres on *bioethics* (Rose 2008)¹¹⁸. Judgement calls are made on Robert's behalf for what specialists see as pragmatic and practical reasons. Yet being kept in the dark about the impact that medications may have on his body leaves him feeling denied of the opportunity for informed decision-making, and so feeling disempowered by the authority of the biomedical. Time and again, participants reveal their discontent at being told what is good for them, even if it contradicts their own experiences of medication-taking. Consider the following opinions of one neurologist:

Dr. Reed: All the hundreds and thousands of pounds that are being spent on quality of life research have demonstrated that becoming seizure-free makes a difference to your quality of life and everything else is minor by comparison.

Niall: Is becoming seizure-free and taking medications sometimes a balancing act between quality of life and side effects?

Dr. Reed: No, because most drugs don't cause significant side-effects in the vast majority of patients. If you have got significant side-effects you change the drug. So side-effects causing impaired quality of life is an extremely minor issue in someone in whom you are going to get seizure control.

This neurologist's opinions are highly debatable when juxtaposed with a multitude of participant testimonies. The value of life and everyday functioning is very much at stake (Rose 2008: 47-48), especially considering that, like seizures, side-effects can alter phenomenological experience. The following list is a mere snapshot of some of the side-effects with which participants are dealing in the short-term, and about which they are fearful in the long-term: weight gain (Anna; Holly); weight loss (Holly; Kate); teeth and gum damage (Holly; Renae; Patrick); blurred vision, bodily aches and pains (Robert; Kate); fatigue, bruising, hair loss (Nicola); erectile dysfunction (Colin;

¹¹⁸ Bioethics can be used to signify a wide range of ethical decision-making. It can be used as a legitimization device within the regulatory technologies of government as they deal with highly controversial issues of life and its management. Questions of bioethics also frequently arise around the activities of those who want or need ethical clearance for their commercial or human-centred research. Some critics claim that there are certainly moments when bioethicists, and the clean bill of health that they can offer, seem to be for sale (Rose 2008: 47).

Brian); numbness in the extremities, over-heating, head-aches (Chris); swollen joints and sickness (Maureen); sedation and mental 'fog' (Patricia; Ian, Joan, Gordon; James; Brian; Jennifer; Steve; Carol; Renae); shaking (Steve); dizziness (Renae); unintentional over-dosing creating a medical emergency (Joan; Holly; Laura; Gordon); irritable bowel syndrome (Patrick; Maureen); and I could go on¹¹⁹. Medicines, as Reis (2001: 366) puts it, place a 'veil' over the self:

I was absolutely fine after taking keppra [AED] – seven-fifty [milligrams] twice a day, and tegretol, six-hundred – *if* you call falling asleep every time you sit down, needing match-sticks to keep your eyes open 'fine'; then yes, I was absolutely 'fine'. But comatose. And so unhappy and fed-up, and putting on weight because every time I sat down I fell asleep. I mean, just really, really, fed-up. Life wasn't worth living really! [...] Yes, they suppressed my symptoms, but they just about suppressed *me*. It was really awful. (Joan)¹²⁰

Here the regulated body imprisons the (groggy) self. Indeed, such is the preoccupation for a large number of neurologists to suppress the mis-firing neurons causing seizures that vital 'brain life' itself almost becomes an after-thought. Recalling the discussion in CHAPTER FIVE of the 'epileptic body' as a perpetual symbolic threat to social order, when specialists deem that autonomous self-governance is no longer viable, medications can be used to implement corporeal martial law against *neuronal* uprisings or 'matter out of place'. The 'epileptic' or 'auratic' that causes boundary confusion is forcefully suppressed behind reinforced corporeal walls wherein biomedical technologies of control become technologies of *subjectivity*: they create 'our neurochemical selves' (Rose 1997: 22).

This particular medical 'policing' of epilepsy is compelled by taken-for-granted social norms surrounding desirable, 'normal' bodily form, function and aesthetics¹²¹. Control by AEDs reveals a politics of normalisation prescribing correct levels of bodily regulation. Here, the norm stands 'as the instrument of a will to substitute a satisfying state of affairs for a disappointing one' (Canguilhem 1973: 147, quoted in Philo 2007: 87). The power to intervene aggressively in neuronal processes in the name of seizure control sparks neuropolitical contestation. To approach specialists concerning unacceptable side-effects is to contest and negotiate *normality*. Whereas one neurologist, Dr. Reed, states that 'the *only* acceptable level of control is *complete* seizure-

¹¹⁹ These factors contribute to a reduced quality of life. Comorbid symptoms further decrease one's ability to function in place (Crooks 2010) such that additional disabilities are created. Participants report significant psychosocial impact, frequently associated with gendered bodily identity issues (for example, Colin's shame over erectile dysfunction; Nicola's battered self-esteem following hair loss). There are also socio-economic impacts as people may not be able to work, gain promotion, do well in school, and so on (see CHAPTER SIX).

¹²⁰ This section of Joan's testimony is also used in CHAPTER SIX to suggest that controlling seizures through aggressive intervention reveals a political-economic imperative to classify 'governed' bodies as 'work-able' bodies, the implication being that financial assistance may then be withheld. Using Joan's testimony twice adds further nuance to the multitude of forces pressing 'down' on the 'epileptic body' at any one time.

¹²¹ Further, the political economy of bodily control cannot be understood as separate from the wider social, economic and political contexts in which professionals are placed (Philo 2007b: 85). For example, decisions in the field of epilepsy are enabled or constrained by the power of pharmaceuticals companies and markets: see Petryna *et al.* (2006).

freedom', participants challenge what constitutes health/illness, loss of control/control, normal/abnormal:

The advantage of having seizures is that you know what you are going to get. Actual seizures may last three minutes or so, and the recovery period may be forty-five minutes. [...] But, on the other hand, if you have been taking medication which is detrimental to your health, which I have done with the epanutin [AED] – I've got a lasting gum problem now, which cannot be cured – I would prefer to have the seizures than the actual side-effects: because they can be far worse. (Patrick)

Indeed, Patrick finds that it is the *medications* causing long-term corporeal difficulties and thus a 'loss of control', whereas seizures are more predictable and hence manageable. Yet, in spite of such subjective embodiment, negotiating a change of medications is certainly not always 'plain sailing'.

Individuals encounter disabling situations in spaces of health care not only in consequence of struggling for acceptable levels of care and support, but also in attempting to negotiate 'rules of patient behaviour which may conflict with how one understands and relates to the illness experience' (Crooks and Chouinard 2006: 350). Asserting rights to voice, inclusion and enablement¹²² in health care is a courageous act, especially in places of medical care where professional resistance to more balanced relations of power between patient and 'expert' persists (Crooks and Chouinard 2006: 351). Not 'learning one's place' renders negotiating treatments a tense affair:

I got an appointment with [my neurologist], went through and said 'I just can't take them anymore'. And [...] she gave me a row. She said 'You should have been on them by now!' And I said 'If I took these tablets I wouldn't be sitting in front of you now!' [...] I think quite a few people have had this with this Doctor [x] though. [...] I know consultants: when working with them they can get all high-and-mighty. (Kate)

As Philo (2007: 85) discusses, following Canguilhem, it is helpful to conceptualise health as 'what everyday people take as a normal state of bodily and mental functioning relative to the demands of their immediate circumstances.' Kate clearly feels unable to function immediately after taking

¹²² The realisation that medical knowledge is incomplete, and that treatment is based on practical trial and error, compels numerous respondents to seek other sources of information. New cultures of active citizenship mean that people actively research their condition as a way of contesting the practices of, and their relationship with, health professionals. Important here is *how* people gain knowledge and how they use it. From the questionnaire, respondents' main source(s) of information included neurologists (78%), a GP or Practice Nurse (55%), an epilepsy charity (63%), other people with epilepsy (28%: see below for a discussion on community-making) and the internet (35%). While self-researching medical information can be empowering and potentially disruptive to uneven medical power relations (Parr 2002a), it is infused with a politics of knowledge (Davidson and Parr 2010: 68) that can be ambivalent and risky; for example, several specialists bemoan the time spent in dispelling spurious information from external sources. Nevertheless, access to increasingly technical and detailed health information means specialists no longer have a monopoly over this type of knowledge; thus, the nature and flow of communication in doctor-patient interactions is shifting (Radin 2006).

her medications, and so avoids taking them if she has anything important to do. Keeping in mind the realities of the body in pain or discomfort, it is possible for individuals with epilepsy to normalise being 'ill' as it impacts on daily life. For Patrick, being able to negotiate acceptable levels of regulation, rather than have such levels dictated to him, offers the possibility of living with epilepsy in his own distinctive way. He wishes to constitute his *own* normality, even if this contradicts medical 'norms' compelling chemical dictatorship of the body that intermittently 'descends into anarchy':

The amount and the severity of them are acceptable to me at the moment. And the medication is acceptable to me at the moment. [...] Because of the amount that I take, as well as the other side-effects, it is what I classify as '*tolerable*'; the side-effects are tolerable. Because I want some life.
(Patrick)

For many of the participants in this research, asserting the right to shared decision-making or even autonomous control is extremely important given common proclamations that, regardless of outsiders' input, living with epilepsy, by its very nature, is resistant to mutual understanding between different people and institutions.

EPILEPSY IN THE COMMUNITY

REPRODUCING THE (IN)VISIBILITY OF THE 'EPILEPTIC BODY': THE POLITICS OF SAMENESS/DIFFERENCE

Cultural images of the idealised, regulated body limit the transmission of social discourses concerning embodied knowledge of living with 'difference' and so marginalise people with illnesses and disabilities (Wendell 1996: 109). Cultural silence about limitation and pain also increases our fear of them, thus contributing to our need to believe that we *can* control our bodies. Different manifestations of epilepsy are assigned different meanings as bodily performances, and so individuals are subject to social constructions of more or less acceptable ways of being 'epileptic' (Parr 2000, on mental ill-health; see also CHAPTER FIVE). Relief that one's seizure disorder is not as severe as others' suggests, that while recognising oneself as 'ill', there is a simultaneous affirmation of 'functioning relatively effectively', that one is both ill *and* healthy (Moss and Dyck 2002: 99). Parr (2008) and Moss and Dyck (2001) discuss bodily 'self-inscription' as a way for individuals to understand and live with illness in a way that makes sense for *them*. Self-inscriptions can be resistant to cultural inscriptions of what it is to 'have' an illness, and so are revealing of tensions between the biomedical and socio-corporeal. Such practices are discussed by Moss and Dyck in generally optimistic terms (albeit as concurrent with various social and embodied struggles), and certainly in this research some participants reflect positively on

challenging the preconceptions of others. However, I want to suggest that resistance to public representations of epilepsy may also entail a hesitation about identifying with an 'epilepsy community'. In so doing, individuals draw on binary understandings of 'bad'/'not bad' epilepsy, and such a preoccupation with sameness/difference perpetuates difficulties in identifying with other people living with a seizure disorder. As such, epilepsy seems to be a curiously isolating condition in part because of the belief that it is indeed a *personal* obstacle, something which others cannot understand or support. This isolation reinforces the marginal place and politics of people with epilepsy in the community (and in wider 'disability politics'¹²³). It creates a situation where connecting with others would seemingly be admitting to the *failure of self-regulation*.

Despite the fact that 'anyone with a brain can have epilepsy' (Bruce, Social Worker), 'normalising' the condition is fraught with tensions due to public perceptions of 'epileptics' having mental health problems, learning disabilities or even an 'epileptic personality' (Notkin [1928: 799] describes the 'epileptic personality' as displaying 'egocentricity, supersensitiveness, irritability, emotional poverty and stiffness of mentation'). As the aetiology of many cases is unknown, there is no public health education on preventative/adaptive individual behaviours, and so exposure to relevant information and general familiarity with the condition remains limited. Part of the expectation of stigma is that others cannot relate to epilepsy in a tangible way as maybe they would do so with other conditions. When it manifests as seizures, epilepsy appears to straddle what are 'self-evidently' disorders of the body or mind (the unconscious body may become 'unruly' or the person may behave 'peculiarly'). Due to limited knowledge about epilepsy, a destabilised identity influenced Claire's decision to distance herself from others following diagnosis:

This sounds bad now, but I thought people were gonna think I'm disabled; they're gonna think I'm 'not all there', or whatever. [...] I was so ill-informed about it that I thought, 'I'm gonna end up in a wheelchair; I'm not gonna be able to function.' And then I ended a four or five year relationship with somebody I was engaged to because I just thought I don't want anybody to look after me or anything like that. (Claire)

Because of the perception that others cannot easily relate to the 'epileptic body', participants are very much of the opinion that, if one does not 'have' epilepsy, one is unlikely to know much about it (besides public misconceptions). Archie suggests that, 'if I'd have collapsed, fell down, pissed myself, it would have been a lot easier for me, because people just did not know what was wrong.' By contrasting his hallucinatory experiences with a stereotypical image of *the* epileptic seizure, Archie implies that a more 'predictable' constellation of symptoms would allow him to explain his condition to self and others. However, his lesser-known seizure types leave him only

¹²³ In the questionnaire, 31% (n = 38) do consider that they are disabled by epilepsy, 37% do not (n = 46) and 32 (n = 39) do *sometimes*. I unpack 'disabled identities' below.

partially able to draw upon public discourses, and so he is beset by numerous dilemmas of representation and struggles to self-define body and identity.

The ambiguity of epilepsy means that it remains contested along the lines of difference. Brian states that, 'I feel sorry for the folk that have *grand mal* [tonic-clonic seizures]. I'm lucky; I've got *petit mal* [absences]: I just go white and blether a lot of rubbish.' James reveals that, 'I knew of a distant relative who had epilepsy, but she had full, *bad* epilepsy.' This practice of differentiation is in no place so apparent as at the 'Quarriers' disability assessment centre¹²⁴ in Glasgow, where individuals may be invited to stay for varying periods of time to assess their relative needs. Several participants were brought together with people possessing various epilepsies in this environment, a gathering that made Ian realise 'how blessed you were when you saw other people who were just, like, all of a sudden getting up and starting swearing; really embarrassing themselves.' Maureen feels that her four-day stay at Quarriers was inappropriate, reflecting that 'they definitely treat you as if there's something wrong with you.' Divisions between 'difficult' and 'mild' epilepsy mean that individuals may position their identity *away* from those whose condition 'runs their life', feeling themselves to embody epilepsy *differently*. Some participants feel as if they have an *inauthentic* epilepsy because of a lack of symptoms precluding them from sharing a common identity. An anonymous questionnaire respondent states: 'As my experiences of epilepsy have been/are so easily managed, I would feel a fraud putting my self forward as someone who has epilepsy.' This contention seems to essentialise epilepsy as 'experiencing seizures', but misses the fact that taking regular medication *is* also an experience of epilepsy. Indeed, the insidious nature of biopower means that, where possible, the condition is something about which to remain quiet and *forget*. As Parr (2000) notes of attendees at a mental health drop-in centre, even here it is the case that threatening bodily performances are likely to prompt efforts at social and spatial exclusion. Similarly, the image of people embodying 'epileptic extremes' can be interpreted as contributing to feelings of *unheimlich* amongst those with mild symptoms, 'deriv[ing] from the fear that *they might not be different enough*' (Wilton 1998: 178, added emphasis). This conceptualisation, recalling analyses in CHAPTER FIVE, suggests that, not only are individuals subject to othering by people *without* epilepsy, such processes actually occur *between* people *with* epilepsy. The effect of this manoeuvre on a wider scale is to limit the scope of community-making, considered by some as all about a space reserved for 'people who are really bad – I would always put myself in the category of 'it's not really anything'' (Debbie).

¹²⁴ William Quarrier first opened the 'Orphan Homes of Scotland' (now Quarriers) in the early 1870s. Quarrier also opened the first TB sanitarium in Scotland next to the 'orphan village' in Glasgow, followed by a care facility for people with epilepsy in 1906. Major changes in childcare practice and legislation led Quarriers in 1993 to shift their focus to caring for people with a range of disabilities. The Scottish Epilepsy Centre at Quarriers is presently the only specialised residential and assessment complex in Scotland where people can be diagnosed, reviewed and treated. If the specialist is finding it difficult to diagnose or prescribe appropriate medications for the patient, the patient would be referred on to Quarriers for an extended period of monitoring and assessment. At Quarriers, a multi-disciplinary team of specialists take a person-centred approach to epilepsy care. See <http://www.quarriers.org.uk/what-we-do/epilepsy/>.

Processes of complex differentiation increase the social distance in and between people with epilepsy. By counterposing their 'mild' experiences with those of the ill 'other', several participants justify their lack of interest in attending support groups. Others point to the support of their families in helping them feel 'normal'. Some people seemingly harbour preconceived notions of support groups as 'pity parties' (Brian) or 'lonely hearts clubs' (Ian), and Ian opines that, 'rather than get together, why not get on with life?! Do it your own way!'¹²⁵ Indeed, numerous respondents acknowledge their reluctance to characterise a distinct 'epilepsy community' for what it might suggest about their *own* (lack of) personal autonomy; as if identifying with a collective is suggestive of a marginal identity. For example, as an anonymous questionnaire respondent states, 'I don't think people with epilepsy should be a separate community. I'm still the same person as I was before this diagnosis'; while Carol asserts, 'I don't really like being defined by it; I haven't really wanted to meet with people just because I have epilepsy.' This is indicative of Bury's (1982: 173) contention that 'the separation of disease from self is a powerful cultural resource.' For those who hold the condition at a distance, and remain embedded in local contexts rather than connected within wider 'rights landscapes', social intervention is regarded simultaneously as important (for others) *and* unnecessary (for them):

You've all got your own lives to lead, and it's all very well giving money and all the rest of it, being a part of a team, being a member of Epilepsy Scotland. But to actually get actively involved? No, I never have. (Anna, who is seizure-free)

Rejection of an 'epileptic identity' by people whose seizures are mild or under control reproduces the (in)visibility of embodied difference. Furthermore, this means that the most visible epilepsy advocates are those who seem to attract most social stigma, namely individuals with complex needs, rendering it unlikely that newly-diagnosed individuals with 'mild' symptoms will wish to identify with such a group:

¹²⁵ There are at present limited support groups run by charities in Edinburgh and Glasgow, and a few other local, independently-run groups (thus, *where* one lives makes a significant). Two participants in this research, Patricia and Patrick, attend groups, while others mention having attended at least once in the past. Despite possible tensions in support groups (along the lines of embodied differences: see also Parr 2000), Patricia and Patrick suggest real benefits in fostering a sense of collective identity, including new understandings surrounding one's place in the community (see Hall 2004; Parr 2007, 2008; Philo *et al.* 2005). In support groups, both have received a broad education about the various manifestations of epilepsy, and have begun to draw on an altered discourse of heterogeneity as part of the process of 'normalisation'. In generally empathetic, friendly groups, people share their common experiences, beliefs, practices and understandings so as to assist each other in constructing practices of self-care. Individuals can receive emotional support, but also boost their own self-esteem by *providing* support (the 'cared-for' become the 'carers'), which frequently carries across the boundaries of group meeting places into other spaces in the community. Having one's experiences 'confirmed' by others is a source of empowerment for individuals who have been told, sometimes by biomedical professionals, that they are 'wrong' about their *own* bodily sensations (such as medication side-effects). Both Patrick and Patricia report that their hopes for the future are enhanced because collective reciprocity empowered them to negotiate a change of medications with their neurologists that has helped them to work towards an 'acceptable' bodily balance. Moreover, group interactions do not centre only on stories of the body, but also promote information-sharing regarding the 'rights landscape', thus facilitating deeper involvement in epilepsy politics across a range of issues.

If only the people who have the severest symptoms – and can't *avoid* people finding out – if those are the only people [who] people [without epilepsy] hear about, then they're going to assume, as I had done, that it's necessarily one hundred percent awful. (Joan)

At stake here are challenging issues of representation. The condition appears to be struggling with its public identity precisely because it is unclear to the lay person (and even individuals with epilepsy) what exactly it *is*. Health professionals and people with epilepsy themselves differentiate between 'controlled' (good)/'uncontrolled' (bad) epilepsy; and, at the same time, remain unclear as to whether epilepsy is of the mind or body, whether people with epilepsy are not/disabled, whether seizures are not/life threatening. This 'in-between', hazy status carries over into all areas of society and so the consequences of epilepsy remain contested personally, socially, economically and politically.

For advocacy groups, there appear to be almost irreconcilable tensions involved in portraying an image of people with epilepsy as *both* same/different as they relate to both each other and wider society¹²⁶. One strategy followed by charities, what Diedrich (2007: 54) calls 'relentless brightsiding', is a particular source of contention among several participants who *desire* the strengthening of community bonds. These individuals feel that most campaign work tows the lines of 'socially sanctioned illness narratives' by exclusively portraying people who *overcome* barriers to inclusion. At the same time, while charities are keen to point out that 'stigma still exists', their proclamations are rarely backed up with individual testimonies, hence rendering them rather hollow and *disembodied*. Epilepsy is therefore represented as an opportunity to write one's own heroic narrative at the expense of 'uncomfortable' admissions as to the structural, institutional and corporeal processes that repress individuals marked as 'other'¹²⁷.

The projection of such a generally 'positive' image has varying implications. On the one hand, acknowledging that people who live with epilepsy can function effectively in many instances allows for its discursive negotiation, and encourages people to insert their own lived experiences and limitations into the embodied activities with which they engage. On the other hand, this silences individuals who wish to be heard, at the same time as foregrounding the views of individuals practising a (bio)politics of silence surrounding the condition. The stories of people who feel helpless and out of control are afforded little room, with the result that others who feel

¹²⁶ As is mentioned by numerous participants, there is very little by way of celebrity endorsement to encourage the normalisation of epilepsy. Hence popular conceptions remain rooted in history and popular culture (see Baxendale 2003).

¹²⁷ Nevertheless, charities continue to play a key role in shaping the discursive terrain, both politically and socially. One way in which their work extends to the everyday lives of people with epilepsy is through identity politics. Respondents invoke advocacy discourses by proclaiming: 'The 'epileptic' word sounds worse than 'I have epilepsy' because you are the person, you know. It's more important to say 'I have' or 'I am a person with' (Debbie). This affirmation of a life with epilepsy, echoing other health-related politics movements, rejects being defined by the condition and instead presents it as one facet of identity (although many 'disabled people' often prefer *this* term as a political statement).

this way are not comforted by knowledge that they are indeed *not* alone. As a neurologist, Dr. Rivett, suggests, this fact might account for the lack of a cohesive epilepsy community among people who *do* wish to connect with others:

When you look at newsletters and things, when you look at the literature, it's all about somebody who's had a fantastically successful career *despite* epilepsy. [...] And I think that's why a lot of people will turn their backs on organisations – because they don't feel that the organisations are presenting to the world the reality of what they have. (Dr. Rivett, Neurologist)

This claim suggests a 'minor reversal', whereby the epilepsy community's heterogeneities are suppressed in the interests of broader advocacy strategies (Sharp *et al.* 2000: 12). What this political purpose misses is a chance to 'speak' to all individuals with epilepsy, to show them that they need not live in silence. If one's experiences do not match the discourse of 'heroic overcoming', then the lure of charities lessens; one's place in the community (of people with epilepsy and wider circles) remains ambiguous. Atkinson *et al.* (2011: 568) argue that 'dependency and vulnerability still bear negative connotations and reproduce dominant ideas, theoretical categories and subjectivities that continue to devalue care.' Yet, perversely, neoliberal constructions have rendered safe community-making spaces as undesirable, even for people who *desire* them. The gradual contraction, over the last few decades, of community spaces and the marginalisation of embodied knowledge means that the epilepsy 'diaspora' remains disconnected. This 'placelessness' emphasises the importance of the 'the autonomous self', not the collective self, in coping with the volatile body.

SELF-GOVERNANCE

THE LIMITS OF SELF-SURVEILLANCE: KNOW CAUSE, KNOW CONTROL; NO CAUSE, NO CONTROL?

In light of partial medical-pharmaceutical control, limited information provision and the general isolation of people living with epilepsy, how, we might wonder, do individuals actually carve out their own distinctive paths? Various scholars have approached the actions of the seemingly autonomous self as being (re)shaped in the context of neoliberal governance. When the limits of biomedical knowledge become all-too-apparent as a result of an unhappy balance of symptoms and side-effects, individuals' practical knowledge of managing their own volatile body often becomes, and remains, *personalised* (Dyck 1995a, on MS). Yet this personalisation does not imply freeing oneself from the constraints of society or biomedicine, for cultural understandings almost always frame 'healthy' practices, even when *resisting* powerful social discourses. With neoliberal constructions of the autonomous self, '[c]itizens are urged to turn the medical gaze upon themselves' by 'monitoring their own bodies and health states, and taking preventative action in

accordance with medical and public health directives' (Lupton 1999: 57). Consequently, individuals exercise self-surveillance relative to wider governmental discourses surrounding the healthy body and lifestyle choices as a *regulated* freedom (Petersen and Lupton 1996: 11). These seemingly voluntary practices, or 'technologies of the self', involve the objectification, control and regulation of the body so as to perform 'care of the self' in line with social physical standards. With this form of governance, Anderson (2012: 37) muses, institutions purport to govern 'as little as possible' but actually intervene 'all the way down' through 'permanent activity, vigilance and intervention' (Foucault 2008: 246). As such, the neoliberal system of governmentality is far more diffuse than disciplinary apparatus, since it attempts to manipulate the *milieu* within which decisions are being taken (Munro 2012). The citizen becomes:

obliged to inform him or herself not only about current illness, but also about susceptibilities and predispositions. Once so informed such an active biological citizen is obliged to take appropriate steps, such as adjusting diet, lifestyle and habits in the name of the minimisation of illness and the maximisation of health. And he or she is obliged to conduct life responsibly in relation to others, to modulate decisions about jobs, marriage, reproduction in the light of a knowledge of their present and future biomedical make-up. The enactment of such responsible behaviours has become routine and expected, built in to public health measures, producing new types of problematic persons – those who refuse to identify themselves with this responsible community of biological citizens (Rose and Novas 2003: 22).

This brings us to a seemingly contradictory position, whereby individuals are freer to choose their own distinctive paths, but will do so predictably in light of having internalised normalising neoliberal discourses. It is this tension that I discuss for the rest of the chapter by unpacking how people directly manage their unpredictable vital geographies.

The SIGN Guidelines (**Figure 7**) state that diagnosing specialists must discuss the following seizure triggers with participants: lack of sleep, alcohol and recreational drugs and stress. This presents an obvious 'moralising' agenda whereby control of the body is an *individual* responsibility, and remains unconnected to thoughts of how various place-based cultures (e.g. in the workplace) might be damaging or unhelpful. It immediately instils an expectation that, if measures are taken to conform or abstain as appropriate, seizures may well be avoided. Of course, not all triggers will apply to everyone, and therefore individuals are encouraged to engage in self-surveillance so as to enable the observation, and subsequent reduction and avoidance, of seizure triggers. 'Technologies of self' (Foucault 1997a: 224) are resources or sets of practices that can be mastered in order to produce the self-disciplined neoliberal subject¹²⁸. Alan offers one such example of a technology for observing and surveilling the body:

¹²⁸ Foucault identifies equivalent 'technologies of the self' across many different societies and times, hence claims here, about *this* society at *this* time, can be applied more generally than just our contemporary Western neoliberal moment.

I keep a diary. A seizure diary that Epilepsy Scotland give you. Every day, if I have a seizure, I write down what I thought was the trigger, and notes about: where I had it and all the rest of it, and whether it was while I was asleep or whether I was awake. (Alan)

As Glassner (1989) argues, the concern is not with how power operates through force but how 'knowledge' is taken up by the self and used to optimise regulation of the body in light of threats of its *deregulation*. According to Foucault (2007, in Munro 2012: 347), the neoliberal self is thus an entrepreneurial self who harnesses her/his creativity and resources as part of the process of problem-solving, privatising, personalising and responsabilising everyday life. Biopower is thus entangled with the expectation that life can be regulated by attempting to 'seize possession of the future before it occurs and shaping how contingent decisions or events will unfold' (Anderson 2012: 39). The following 'seizure diary' template, while filled-in by Alan and others as a voluntary exercise, makes clear the various ways in which the individual is expected to monitor their body:

Figure 8: Seizure diary (source: <http://seizurediary.org/>)

Date: _____ Time: _____ Length: _____ min. _____ sec.		Flag It
Type: <input type="checkbox"/> Simple Partial <input type="checkbox"/> Complex Partial <input type="checkbox"/> Secondary Generalized <input type="checkbox"/> Atonic <input type="checkbox"/> Tonic <input type="checkbox"/> Clonic <input type="checkbox"/> Tonic-Clonic <input type="checkbox"/> Myoclonic <input type="checkbox"/> Atypical Absence <input type="checkbox"/> Absence <input type="checkbox"/> Infantile Spasms (cluster) <input type="checkbox"/> Unknown		
Mood: <input type="checkbox"/> Good <input type="checkbox"/> Normal <input type="checkbox"/> Bad		OTC Medications: _____
Possible Triggers: <input type="checkbox"/> Changes in Medication (including late or missed) <input type="checkbox"/> Overtired or irregular sleep <input type="checkbox"/> Alcohol or drug use <input type="checkbox"/> Irregular Diet <input type="checkbox"/> Bright or flashing lights <input type="checkbox"/> Fever or overheated <input type="checkbox"/> Emotional Stress <input type="checkbox"/> Hormonal fluctuations <input type="checkbox"/> Sick – Describe _____ <input type="checkbox"/> Other _____ Trigger notes: _____		
Description: <input type="checkbox"/> Change in awareness <input type="checkbox"/> Loss of urine or bowel control <input type="checkbox"/> Loss of ability to communicate <input type="checkbox"/> Automatic repeated movements <input type="checkbox"/> Muscle stiffness in _____ <input type="checkbox"/> Aura <input type="checkbox"/> Muscle twitch in _____ <input type="checkbox"/> Other _____ Description notes: _____		
Post event: <input type="checkbox"/> Unable to communicate <input type="checkbox"/> Remembers event <input type="checkbox"/> Sleepy <input type="checkbox"/> Muscle weakness <input type="checkbox"/> Sleepy Post event notes: _____		
<input type="checkbox"/> Entered @ SeizureTracker.com		

By seeking to explain embodied experience according to a list of medical categories, people are supposedly able to make sense of their illness (Kılınç and Campbell 2009: 667). Participants in this research mentioned various triggers to be avoided, including: heightened emotional states, being 'run down' from other illnesses, lack of sleep or tiredness, alcohol (either in an intoxicated or hangover state), taking medication at irregular times, boredom, caffeine, flashing lights and monosodium glutamate (MSG) in food, among many others. Episodes, although previously unpredictable, might then be rendered predictable and hence manageable through corporeal disciplining (see also CHAPTER FOUR). 'Technologies of the self' then comprise sets of behaviours designed to avoid or remedy such trigger situations: for example, if one is susceptible to seizures

because of an 'irregular diet' the 'answer' is to *regulate* one's practices of consumption. Failing to do so leaves the private, free self in no doubt as to who is to blame. Several participants purport gaining security and embodied pleasure (Williams 2003: 33) from regulating their lifestyle¹²⁹, but also feel guilty for spontaneously 'letting their guard down' if they have 'one drink at the pub too many' because this is seen as an irresponsible, unhealthy behaviour.

Control 'frameworks' are thus put in place as the self becomes used to managing the volatile body. If the body momentarily ceases to be 'regulated' in seizure, one's sense of acting as a successful neoliberal subject can be reinstated so long as the episode is explainable retrospectively according to the categories by which control made sense in the first place. Being able to blame one trigger or another enables the retention of one's locus of control, an important aspect of 'self-esteem and a positive self-concept' (Räty *et al.* 2009: 207). Striving for an explanation, as if the body were a predictable complex of workings, helps to medicalise the body-object and so normalise the course of epilepsy. Compared to biomedical authority, care of self by people with epilepsy is arguably an even more repressive form of governance because of an *internalised* hyper-vigilance. It levels a much more intense and individualistic gaze at the relationship between individuals' own private lives and control of their bodies (Parr 2002a: 248). Thus, self-styling one's own regimes of self-management can lead to a still greater degree of surveillance over such areas as emotional states, spaces of interaction and lifestyle choices.

When the body defies observation through preconceived medicalised categories (such as in a seizure diary), this situation serves as an uncomfortable reminder of one's own vulnerabilities. The neoliberal agenda for self-disciplining bodies disempowers individuals who are unable to identify triggers, for without 'cause' there is no controlling precipitative events; without this control the body is perceived as *chaotic*, and in danger of being negatively judged by others or even formally excluded. It is hence characterised as failing systems of governance rather than it being systems of governance failing the body:

I just can't seem to get a regular pattern when keeping a diary or anything. I can't find anything that triggers it. If I knew then I would try to get into a routine of, sort of, stopping and starting certain things. (Mandy)

If exerting and experiencing control is crucial in epilepsy (as suggested by Faircloth 1998; Jacoby 1994), unknown triggers create feelings of uncertainty, and serve to amplify perceptions of the potential utility of identifying any triggers. Individuals strive to find something – *anything* – that causes seizures over which they may exert control by widening their repertoire of technologies of the self:

¹²⁹ At the same time, several participants diagnosed beyond their early years also lament the loss of previous, more care-free regimes, suggestive of the 'presence of absence' (Moss and Dyck 2002:129); see CHAPTER SIX.

The number of times I wrote a diary and things like that. Especially if I was at university and I had an alcoholic drink, was there some sort of pattern to when I was having seizures or not? I would try and write down things that I was eating, you know, all different sorts of things that might relate to it. But there was never a pattern picked up on why I was having the fits. (Jennifer)

If the self is constituted in part through external 'policing', which is internalised to produce forms of 'self-surveillance', the perception of gaining control of one's body can be hugely personally empowering, or disempowering where that fails. This perception becomes evident, for instance, in the discursive (verbal) construction of oneself as operating (un)successfully as a neoliberal citizen, who is (un)able to manipulate their lived vitalities and so regulate their body and life. Control of seizures produces a subjective position of having the competitive edge over illness and the deviant body (Smith 2012); it allows for a presentation of self in everyday life reflecting a 'preferred' identity (Charmaz 1987) constituted by 'continuity' and 'accomplishment' *in spite* of chronic illness. Biomedical institutions congratulate the individual as a 'success' in that they have played by the rules of the game and so are able to maximise their potential as an entrepreneurial self.

Where, though, does this leave people whose epilepsy seems to be beyond control? The specialists interviewed as part of this research are always optimistic that newly-diagnosed individuals will be one of 'the seventy-odd percent who get complete seizure control' (Dr. Reed, neurologist). It is curious that this often-repeated tagline quotes figures relating to the presumed proportion of people who *could* be seizure-free with 'optimal treatment' rather than the '52% of the population with epilepsy' (JEC 2011: 6) who are *currently* seizure-free. Perhaps it is presumed that by exaggerating the potential efficacy of technologies of the self (including medications), individuals will not stray from the recommended path of self-discipline. Another possible outcome of portraying epilepsy as eminently 'controllable', however, is that it further marginalises and isolates people whose seizures are not controlled because they are seen as failures, professional disappointments. As Robert muses, 'maybe I'm just got one of those unhealthy bodies'. Nevertheless, while the vital body may always escape regulation, it is the *promise* of finding a solution through hard work and self-determination that seems to sustain belief in neoliberal modes of governance.

THE BODY THAT SOCIETY WANTS?

While the SIGN Guidelines do touch on key strategies internalised by individuals as technologies of the self, they are not applied by all participants equally. In fact, people selectively follow certain guidelines but not others, while reshaping some to suit their own bodily ways of being (Castel 1991). As Petersen alludes (1996: 49), persons who are prescribed certain neoliberal health

management regimes are subsequently required to exercise their autonomy and enter into a process of self-governance involving 'endless self-examination, self-care, and self-improvement'. This leaves a great deal of room for suggesting that far from acting as 'passive recipients' to neoliberal constructions, individuals are so actively involved in reflecting on their own 'control' that they cannot be contained by different forms of (bio)power (disciplinary, biopolitical, governmental). Indeed, Philo (2012) argues that a fleshy and performative understanding of Foucault frees us to think about the vital problematics of lively bodies and unpredictable populations, and it is this path that I now tread. However, in doing so, I note the strains individuals are put under when their own ways of doing things seem to fail, leaving them open to socio-moralising judgements over their lifestyles and behaviours. Nevertheless, in recognising the limits of control, individuals take up, negotiate and resist various forms of power such that medical advice, public discourses and policies become *infused with*, rather than dominating, practices of autonomous control over symptomology. As Philo (2007: 88) puts it, 'forms of life are constantly involved in a struggle to change themselves, to foster new possibilities for themselves, new norms – as in being-and-doing in a given environment, or perhaps in other environments that could be occupied.' Consequently, there are no essential, complete ways of being. Bodies are always becoming, in transition, made and remade; hence epilepsy may be conceptualised as resistant to total governance, *beyond* control, which, paradoxically, could be put forward as a means to empowerment.

Changing one's lifestyle, arguably more so when young (see CHAPTER SIX), is problematic for social inclusion and self-esteem. People therefore feel that they have to resist cultural 'urges' if they are to maintain control of their epilepsy. Colin (in separate email correspondence) lists the multitude of knock-on effects as a result of lifestyle shifts:

Told by neurologist that I should no longer drink alcohol because it'd affect my seizures. My social circle drank heavily, I enjoyed drinking alcohol and the advertising world revolved around drinking alcohol. [...] It's the ultimate social lubricant and increases confidence to speak to people and network (vital to my advertising career) and possibly to 'pull' too. Aids revealing emotions, especially in male social circle. Being around drunk people is awful when you're sober (talking rubbish etc) but also others who are drunk feel less comfortable around you because they know that you'll be witnessing them acting like a dick. Social pressure to have a pint when males are getting a round of drinks in. So, I stopped going out, which led to isolation, which led to feeling detached from my friends, which meant I lost self esteem, confidence to go out and meet people, which led to further isolation, which led to poor mental wellbeing.

Discourses surrounding the autonomous, responsible neoliberal subject press 'down' upon the vital unpredictabilities of 'epileptic life', seeking to define what 'correct' behaviours are for the 'healthy', productive citizen. Establishing a norm, such as 'avoid alcohol', stipulates 'acceptable'

boundaries within which individuals may enact 'technologies of the self', lest their behaviours be considered 'risky', 'weird', 'unstable', 'irresponsible', 'deviant'¹³⁰. The principle behind the norm is that somebody else knows what is good for you (Gastaldo 1997: 119); thus ownership of the body becomes an issue for self *and* others because of concerns for the 'correct' way of functioning relative to space and place. To avoid being seen as a failed neoliberal subject, Colin withdrew from the social spaces and practices that were important to him at the expense of his wellbeing. This is broadly Frank's (1998: 331) meaning when he asserts, following Foucault, that 'power operates through the micro-strategies that turn the self, here a prisoner, into its own agent of disciplinary power.' By compelling patients to take up the SIGN Guidelines and monitor the body according to its categories, then, health professionals are recommending methods of self-surveillance and self-regulation as ways to maintain the body that *society* wants.

People with epilepsy are constructed, especially when others tell them they are doing too much, as needing extra discipline, guidance and protection. They are considered as prone to acting irrationally (see Longhurst 2001: 61) in ways that put them in danger (especially prevalent in the testimonies of the women in this research, such as Kate, Renae, Margaret, Sue and Sophie, who have all been told to 'stay home', 'avoid danger', 'not to get worked-up'). As a result, individuals tend to self-police by admitting to 'excess' in their lives; that they should not engage in particular activities; that they are 'a bit too blasé'. Kate describes how 'I take too much stuff on; I probably bury my head a bit. And I know the trigger, this-that-and-the-next-thing, but I probably don't do anything about it' (Kate). James internalises his self-responsibility such that a seizure is explained as his own *irresponsibility*:

I was not looking after myself properly. So I was upset by that: that I'd been so stupid [in drinking alcohol]. It was more a regret that I had, you know, *done that*. [... After that,] I wasn't just going to let it happen. [...] I have no indication at all that it's not controllable and I'm happy that it is under control. And I'm also happy that that rests with *me*. I've convinced myself that I can control it, that it's up to me; that if I watch myself, I'll be OK. (James)

Here, the self is an expression of internalised powers of self-surveillance resulting from various apparatuses available for 'self-knowledge'. By focussing on the individual battle to control the unpredictable body, breakdowns lead to self-blame because of failures to follow one's own rules. In consequence, some participants go into 'lockdown' mode, whereby the shame of failure necessitates self-confinement until such time that they can re-embody the neoliberal subject. Feeling responsible for loss of control of the body suggests little recognition of the wider

¹³⁰ Others deduce preventative actions without regard for the limits of control, indicative of what Hume (1979) describes as the 'ought/is' problem. For example, if alcohol is considered to trigger Mary's seizures, statements to the effect that 'Mary should not drink alcohol' pre-suppose a moral imperative to avoid seizures. Assuming the absence of a universal morality, it is difficult to justify *why* one morally ought to avoid seizures. At root, of course, are assumptions that bodily regulation is the natural and correct way of being, and can be achieved 'mechanistically' so long as component parts are 'in place'.

(‘structural’) forces and discourses that produce the meaning of ‘unregulated bodies’. Hence reclaiming control is a *solitary* endeavour rarely accompanied by the affirmation of a politicised disabled identity. After a period of relative self-discipline, Ian felt as if he had been remiss to let ‘complacency’ set in:

I would say that I took a bit of a foolhardy approach. I wasn’t particularly sensible. I mean, I’m not a drinker or anything like that, but late nights were just a killer – I’m sure you’d understand – and lack of routine. (Ian)

After a seizure which caused temporary paralysis in his left arm, Ian felt that it was time to rein-in what he perceived to be his excesses because he was not only accountable to himself but also his family. Disciplining the body became a socio-moral imperative characterised by ‘responsibility and obligation’ between the scales of the individual and society:

You just thought ‘This is it: I’ve done it this time.’ And it’s when it started getting like that you thought ‘Right, I’ve got to take this seriously!’ You know, because it’s not just *me* that’s at stake, it’s my wife as well as my kids and wider family. (Ian)

Implicated in the types of control people seek (and how they do so) are a series of interweaving personal and societal, ethical and moral concerns. Individuals strive to perform the most desirable ‘self-conduct’ in relation to self and others simultaneously; in so doing, they inevitably exert power *over themselves* (Sharp *et al.* 2000: 10).

That the self is free to exert power over itself means that power can also be used to take up, negotiate and resist social, moral and biomedical discourses. While Foucault (1997b: 282) is dubious as to whether individuals can break from the ‘repressive deadlocks’ imposed by biomedicine¹³¹, stories and practices of living with illness always occur in specific *places*, and thus the impact of socio-discursive influences are variable in and between different people. As Moss and Dyck (1999a: 392) assert, ‘we cannot escape, nor exist outside of, context, discourse, or materiality.’ As such, we can say that there is an uneven ‘local’ impress of governmental regimes – and of possibilities for resistance (or just doing things differently). Indeed, routine activity within a range of local settings is central to how individuals acquire and use knowledge in constructing and acting upon their realities. At the time of diagnosis, the SIGN Guidelines frame individuals’ (biomedical) understandings of how to manage their confused bodily state; yet away from spaces

¹³¹ Frank (1998) argues that this supposes that ‘the self’ is always *already constituted* by medicine and society, and so suggests a certain pessimism concerning resistance to dominating discourses. It may also be suggestive of an essential self with which the individual could be reconciled if not for these invisible barriers. Foucault, of course, would not advocate this line of argument. Diedrich (2007: 2) argues that, for Foucault, investigations into subjugated knowledges in the past opens up a space for thinking, being and doing *otherwise* in the present and future. I am broadly in agreement with this reading, although Diedrich’s articulation has a rather modernist slant, suggesting that *only now* is resistance possible, whereas in the past everybody was subjugated. I would argue that our knowledges at *any* time are always negotiated *between* the power/knowledge nexus.

of health care, as time passes, readings of one's own body-space might lead to divergence from normative biomedical routes¹³². Striving for control, as Foucault (1988: 259, original emphasis) states, involves the very '*art of existence* or, rather, *technique of life*', suggesting a creative process of 'self-fashioning', 'self-stylisation' and 'self-control', utilising the tools at one's disposal (Sharp *et al.* 2000: 9). This is a 'geography of the possible' as it relates to what one has and what one might be able to do:

Every individual's different. You know, if I was in a factory job or something like that, my *means* or my little ways of coping and remembering things or whatever: that would be different from what it maybe is in the office. So I suppose it depends on your environment and what works for you. [...] As you get older you feel as if you've tried just about everything. So you just know that the rest is down to you to try to perfect ways of [doing] things. (Ian)

Ian takes pride in his resistance to being told by others that he should not work, and relishes the challenge of finding distinctive and creative ways of getting around 'problems'. This relish forms part of his wider 'rescripting' of 'epileptic' ways of being in place. A politics of difference frames his understandings of a future that is not (entirely) preordained by biomedical or legal discourse, but at least partially by his own ability to act within his body *and* local sets of constraints and opportunities. This is perhaps what Philo (2012: 508) has in mind when discussing Foucault's use of the term *milieux*, which is suggestive of topographies 'full of lively, risky, unpredictable 'stuff' whose co-incidental juxtapositions can release all manner of disruptive effects.' To be sure, individuals with epilepsy frequently refuse to live as passive victims to external conditions and events, but engage in active, constructive and selective practices (Robinson 1990: 1185), taking into account local, embodied knowledges (Smith 2012: 16). The individuality of bodies and the different epilepsies means that biomedical discourse can only go so far. Generic advice is registered, but then *translated* into diverse, personalised embodied performances. This entails that 'technologies of the self' reflect a simultaneous working *on*, and work *of*, the body; the self *between* discourse and practice, one's actions *between* prescription and autonomy.

Subjective accounts of illness are not straightforward revelations of a 'true self'; rather, agency is situated 'in the possibilities of resignification opened up by discourse' such that 'we derive agency from the very power regimes that constitute us' (Butler, in Chouinard 2012: 146).

¹³² Furthermore, individuals may draw selectively on 'helpful discourses' (Foucault 1986: 101), such as those offered within online communities. For example, even though she does not participate, Mandy gains bodily empathy (Parr 2002b) by reading chat forums: 'I read through them and sometimes read about other peoples' experiences, like if they're on the same medication and they're having the same side-effects and things like that.' Here, the emergence of new forms of biopower (in 'ill' communities) is bound up with new organisations of human vitalities. In taking a vicarious position, Mandy does not need to be concerned with others' interpretations of her online performance or representations of her embodied symptoms: she can simply 'dip in', without significant time or material commitment, to gain information about how *others* have self-managed their symptoms. Because online she has time to unpack certain information, Mandy feels empowered in that she can appropriate 'expert' knowledges in order to *contest* specialist-patient relations and so feel an active participant in the regulation of her 'volatile' body.

As such, participants' narratives only partially appeal to and/or contest dominant representations of living with epilepsy (see also Chouinard 2012 on bipolar 'madness'). Biomedicine makes retrospective sense of seizures by invoking discourses *juxtaposing* 'control' with 'loss of control'. Yet, while participants do to an extent adopt biomedical discourses of illness, abnormality and diagnostic criteria to give their stories 'authority', they also *resist* these representations by arguing that seizures are *beyond control* (some or all of the time) and *just happen* no matter how well they may practice care of the self. While continuing to implement 'technologies of the self' designed for maximum control, individuals are often empowered by the realisation that seizures are *not their fault*. In this way, as Aujoulat *et al.* (2008) argue, reconciling the self with illness is simultaneously a 'holding on' (by learning to control the body and treatment regimes) and a 'letting go' (to the notion that one is ever fully in control). Individuals may then feel more able to resist the moral 'shepherding' of medical professionals, friends, family, colleagues and strangers when they offer advice suggestive that losses of control nullify one's right to autonomous control of one's own body. Responding to this 'public propriety', Jennifer rescripts 'epileptic' ways of being in place by asserting the right to self-governing *her* body, in *her* time-spaces:

Often people felt that they knew better than you: because you had epilepsy and they had this general picture in their head about people with epilepsy, they would tell me things that I should be doing or should be thinking about with my epilepsy. But, you know, it wasn't *their* life, and they hadn't experienced what *I* had experienced. And I think that to tell me what to do when there are so many different sorts of epilepsy and ways of living with epilepsy is difficult. (Jennifer)

CONCLUSION: ON ONE'S OWN WITH EPILEPSY

Life with epilepsy is governed through the complex and sometimes contradictory interweaving of biopolitical interventions, neoliberal state regimes, popular discourses, charity organisations, (lack of) sources of support and practices of self-surveillance and re-scripting. These elements do not agglomerate into a single 'ill' identity; rather they represent platforms for the performance of multiple identities, each with its own material and emotional dimensions. In the different spaces of everyday life, individuals with epilepsy are told by others what *they* consider to be appropriate behaviours and levels of control; and, due to most peoples' lack of support (especially relating to any politicised 'epilepsy communities'), it is apparently up to them as autonomous actors to self-govern their own vitalities.

Nevertheless, this self-governance is constrained by powerful discourses surrounding the 'healthy body'. The power of the biomedical is such that 'normality' itself is open to modification, and dictation, by medications. As Canguilhem (1994: 319) states, 'interpreted in a certain way, contemporary biology is, somehow a philosophy of life'. In turn, the biomedical proves not to be

a higher realm of knowledge, but a partial perspective on the idealised body, which in unique ways is shaped by prevailing social, economic and political regimes. Participants' criticism of poor communication or inappropriate treatment by doctors does not, however, entail a total rejection of the biomedical: these individuals continue to struggle across various spatial scales (the body, health care spaces, non-health care spaces) to make the biomedical somehow work for *them*. For this reason, it is important that we continue to engage with the medical, 'albeit in a critical capacity' (Parr 2002a: 241). I therefore agree with Philo (2007) in envisaging a 'minor return to medical geography' because the practices and institutional contexts of medicine (such as the spatial distribution of facilities and the physical instruments of control) *do* influence the subjective experience of illness¹³³.

Coping with epilepsy is complicated by popular discourses representing dualisms such as control/loss of control or disabled/non-disabled. Rejection of the 'negative' half of a dualism often entails the distancing of oneself from people embodying that half. Numerous participants refuse to see epilepsy as a disability (and so remain ineligible for financial or employment-based support) even though their seizures might be extremely disabling; even more so when set in combination with the negative reactions of others. This reluctance is due in part to a 'hazy' politics of representation, whereby it is felt by charities that attaching 'disability' to an already stigmatised condition may disempower people even further. On the contrary, following Holt (2010: 158) on young people with behavioural difficulties, incorporating people with epilepsy into the disability framework might help better to conceptualise and politicise their experiences through critical understandings of disability as situated in society, space and bodies. The common absence of epilepsy from this framework limits the resources that individuals can utilise to challenge disabling and exclusionary practises. At the same time, people are forced into the conceptual framework of a political project that attempts to negate the relevance of difference in favour of positive stories of 'overcoming' that in no way 'represent' their experiences. Thus, individuals simultaneously struggle to define epilepsy while feeling alone in such an undertaking. Public discourses emphasising the heterogeneity of the epilepsies, somewhat ironically, may be one path to uniting 'epilepsy' as a political construct. In turn, by highlighting how different embodiments give rise to similar social issues, individuals may come to directly empathise with similar, yet different, 'others'¹³⁴.

¹³³ There is clearly a desire for greater attention to be paid to issues of everyday life and functioning as this relates to medication side-effects and bodily, temporal, social and economic limitations. One route to this outcome could be if health professionals provide not only full information and opportunities of negotiation regarding treatments, but if they also invite their patients to reveal what they see as the major challenges in coping with illness in order to assist them in living the lives that *they* want, not ones determined solely by socio-moral imperatives. The current thesis is seen as a minor contribution to such an agenda.

¹³⁴ The deficit of information encouraging wider understanding of the epilepsies also means that individuals are arguably less able to search effectively for specific information concerning *their* own epilepsy, while filtering out information which does not apply.

The story of epilepsy, in many ways, is a story of competing claims to being able to regulate the body. Individuals are increasingly exposed to ideals of the autonomous neoliberal subject and to biomedical-economic logics of pharmaceutical control, thus revealing the multiplicity of 'parties' involved in the politics of life. By participating in and fostering the 'myth of control' (Wendell 1996), each of these parties makes certain truth-claims about the efficacy of their own ways of doing things, but in doing so overwhelmingly neglect the fullness of everyday life with chronic illness, especially as treatments or strategies relate to quality of life. In effect, each seeks the power to articulate, invest, control and harness 'life itself' (Anderson 2012: 29), to draw the very boundaries of what is an acceptable level of cognitive functioning, or 'brain life', to 'make live and let die' (Foucault, in Philo 2012: 505).

My aim in showcasing less-than-positive experiences (of the body, of the messages of campaigning organisations, of professional/patient relationships in spaces of care) – those less on the 'brightside' – is a provocation to (re)thinking and unsettling the boundaries separating the vital and biopolitical, which are mutually implicated in living with epilepsy. Assuming that biomedical governance is an 'imperfect science', it is just as important to confront what it does *not* know or represent as what it *does*. As Wendell (1996: 111) suggests, by facing the lived realities of illness, people may begin to embody it in their own terms. Indeed, being told that epilepsy can be unpredictable (rather than 'we should be able to control it') might render its unpredictability more predictable. This forms part of an ethical project, wherein the individual should be encouraged to insert and assert their *own* practical experiences and knowledges into their everyday practices rather than see them as potentially undermining of responsible citizenship. In so doing, people may *harness* biopower by re-drawing their own vital boundaries, accepting of the fact that 'losses of control' are natural and not uniquely pathological (Philo 2007). On a wider level, attending to vital politics allows us to theorise how life is always enabled and constrained at the same moment, as Foucault (1978: 143) puts it, 'it is not that life has been totally integrated into techniques that govern and administer it; it constantly escapes them.'

CHAPTER NINE:

CONCLUSION: RE-PRESENTING THE 'EPILEPTIC BODY'

This thesis has located itself amongst the daily geographies of chronic illness, finding there the body whose meaning and materiality can at any time radically disrupt experiences of time and space. While illness of all kinds is usually characterised as a partial loss of bodily control, as perceived and described by the self-aware individual, seizures cannot be directly experienced by the person affected and so unsettle a number of assumptions about how we know our own bodies as social beings. Phenomenological experience is forever changed as people with epilepsy are forced to work with the risky body whose 'normal' relationship with space and time may abruptly be *lost*, and hence the intentional performance of self *halted*. Biomedical and neoliberal forms of governance increasingly attempt to discipline the body that intermittently cannot be responsible for itself, especially in cultures that valorise 'ideal' forms of embodiment. Yet the vital nature of human bodies means dominating power is never complete, and, in fact, is transgressed creatively in locally and temporally specific ways as a means to living with the body that escapes control.

Throughout, we have witnessed how the two poles of 'inside' and 'outside' are constructed as people seek to understand their place in the world. Seizures cannot be 'shared' in their eventhood, and hence there are 'internal' (self) and 'external' (other) perspectives of them that change the meaning and experience of the (a)social body (relating to research objective 1). The 'outside' world (public) may be seen as more dangerous than the 'inside' (private) space of the home, even though the unpredictable body renders *all* space unpredictable and so potentially risky (research objective 2). In reflection of personal histories and present contexts, individuals see themselves as operating inside or outside of the spatialities and temporal rhythms of everyday society (including social groups and Western capitalist workplaces: research objective 3). Furthermore, people see themselves as succeeding in or failing to control the body in light of biopolitical constructions of the 'healthy body', which has a direct link to whether the person feels that they do or do not experience 'epilepsy' as an everyday reality (research objective 4). In each chapter, constant tensions are revealed in the words of participants, who wish at once to belong to mainstream society *and* live as a 'person with epilepsy' in their own way. The key theoretical contributions of this thesis spring from an engagement with the corporeal self as a site of fleeting stabilisations of particular meanings; for example, when the body is constructed as being 'in' *or* 'out' of control, able *or* disabled, safe *or* unsafe. The momentary experience of the seizure event,

detailed in CHAPTERS FOUR and FIVE, contextualises the wider geographies of everyday living and self-management strategies (CHAPTERS SIX, SEVEN and EIGHT) to show how corporeal meanings of epilepsy are contingent and emergent in spatio-temporally specific, and often contradictory, ways (thus one is not 'in' or 'out' of control, able *or* disabled, safe *or* unsafe, but *all of the above*). This helps to unsettle a range of binaries that shapes much of our taken-for-granted thinking, demanding that we conceive of the body that is neither one thing nor the other, but constantly fluctuating *between*.

Advancing this view, there is a necessity, at least partially, to excavate the multiple and contested meanings of 'epilepsy' specific to this Scottish-based research. Seizure disorders have been explained and treated in historically and locally distinctive ways (Andermann 2000; Baskind and Birbeck 2005; Carod-Artal and Vázquez-Cabrera 2007; Mentore 1995; Allotey and Reidpath 2007), the legacies of which continue to be felt in present contexts. In Western societies, epilepsy has been defined as a form of demonic possession (demanding that the devil be 'cast out') and, later, 'madness', requiring that the self be managed in institutional confines (Temkin, 1971; Jacoby *et al.* 2004; Scambler 1993) so as to contain the 'epileptic's' troubling of popular dualisms of ill/healthy, abled/disabled, in/out of control, conscious/unconscious, mind/body. Situating the body within current political-economic contexts demonstrates a shift towards regimes of neoliberal *self*-management. The pervasiveness of social and biomedical discourses across time and space demands that the 'ill' body be interpreted as simultaneously discursive and material.

Recognising the body's differentiated openness and vulnerability (Harrison 2008: 426) to material affects and discursive regimes – its 'auratic space' (CHAPTER FOUR) – as an inherent condition of existence enables the emergence of the body-self that is never fully one thing or another with fixed and immutable boundaries, but instead *always-becoming*. Indeed, while people may want nothing more than to 'fit in', to conform to society's expectations of 'normal' bodily conduct (Davidson 2003b: 137), I follow Bondi (2005c: 146) in suggesting that it might be therapeutically *limiting* to hold bodily control as the desired opposite of 'disorderly' spatial experiences. Accepting the *simultaneity* of inside/outside relations and their paradoxical workings may then assist in helping people to begin to occupy space *with* the (in)coherent body. This conceptualisation leaves space for human vitality that is more resistant to biopolitical power than is generally admitted. Indeed, the 'epileptic body' not only escapes the self but also the society that seeks to tame it. As such, we need to be attentive to the multiple dimensions of human embodiment (including the non-representational and non-relational) rather than seek to locate our understandings within pre-programmed structures that constitute what Thrift and Dewsbury (2000) describe as 'dead geographies'. Admitting to the limits of biomedical, social and personal control of the volatile body, then, posits it as *beyond* total control (see CHAPTER EIGHT) and a space of *potential* identity.

Dialoguing the ill body as a space of encounter and potential transformation is an original contribution of this thesis. To capture something of the liveliness and non-inevitability of the body that is both 'between' and 'beyond', I have engaged how individuals re-present the body that episodically leaves the self exposed¹³⁵ to the representations of others. Seizures push the limits of sense and the body's capacity to understand and account for itself by signalling 'the end of intention' (Harrison 2008: 424), the stripping of one's abilities to perform 'regulated fictions' (Butler 1990: 175). Hence they offer a striking case study of how 'qualities of feeling are as incomparable as they are indescribable' (Améry 1980: 33), and yet how words continue to play a vital role in constructing 'ill' identities (in positive and negative ways). Representing seizures produces unusually complex philosophical questions concerning self-knowledge (an 'insider' perspective) precisely because individuals rely on second-hand accounts ('outsider' testimonies) to describe their own seizing bodies¹³⁶. Indeed, the stories partially re-presented in this research are of partial re-presentations (by participants) of partial representations (of potentially multiple, individual seizure witnesses). This is because 'no object ever unlocks the entirety of a second object, ever translates it completely and literally into its own native tongue' (Harman 2002: 223, in Shaw 2012: 620). This means people reduce each other to caricatures – they literally 'objectify' each other – as part of the inevitable reductionism of representation. Coming to terms with 'absence', then, necessarily involves translation and meaning-making, whereby gaps are 'precariously bridged' (Rose 1997: 315) and new identities formed and re-formed in and between the individual seized and seizure witnesses. Stories of the 'displaced' body are told not by a transparently knowable self, but constructed through the stitching together of various subjective perspectives to perform a 'seamless' *version* of self. These performances are enabled or constrained depending on the audience and time-space context (see Frank 1998), but are frequently used as an ethical-political device (or 'evidence': see Harrison 2007: 605), perhaps aimed at re-scripting others' impressions of the 'epileptic body' or softening the impact of the self-declaring as 'ill'.

Methodologically, I have developed a de-centred phenomenology to take on the 'task of reimagining relations between the material, perceptual, affectual, and discursive' (Anderson and Wylie 2009: 332). To get at the complex geographies of living with epilepsy we must consider each of these relations as mutually constitutive of experience. This acts as a connective tissue

¹³⁵ In this research, people who self-defined as 'living with epilepsy' were invited to participate because of an aspiration to bring to light challenging emotio-sensorial experiences which must be considered as part of our understanding of the body. Here, 'identity is used strategically to achieve interim political goals' (Spivak 1987: 211) and is necessarily a *translation* of individuals' experiences.

¹³⁶ Future research may take into account the perspectives of people *without* epilepsy to engage responses to illness by people who self-define as healthy, and so deconstruct the ways in which feelings of belonging to a/the dominant group sustain processes of marginalisation. Furthermore, the study of people without epilepsy is central to the story of epilepsy because of how close family and friends co-constitute coping processes and strategies as 'interdependence' (Power 2010, on learning disabilities). In so doing, we may seek to establish how barriers to and possibilities for living in the community, and strengthening self and collective identity, are constructed (Chouinard *et al.* 2010: 5).

between my 'empirical' thesis chapters, which started off by emphasising the 'event' of the ill body, before moving on to contextualising 'events' within wider power relations and socio-economic structures and discourses that further impact on how individuals structure their everyday geographies. Mapping subjectivities across diverse contexts begins to reveal the complexities of experience rather than reproducing a straightforward picture of the agentic individual who supposedly says '*I can*', regardless of the body that becomes 'unregulated' and so the object of others' negative constructions. Hence, I have engaged stories of self that do not emerge from the singular, pre-social body, but from multiple perspectives on the *process* of embodiments that momentarily solidify in their re-telling. In Harrison's (2007: 591) terms, this is an exercise in relating the 'non-relational' to the 'relational'.

Experiences of seizures pose considerable challenges to the epistemological and ontological foundations of human geography, not least in attending to the dynamic interplay of bodies in a world that endures even when one's perception of it halts. I have begun to motion in geographies of the unresponsive, non-cognate, non-directed body¹³⁷ by showing how space shapes and is shaped by (un)conscious bodily (in)action. The idea is to demonstrate that stigmatised bodies do sit comfortably within the normal range of human experience (if not policy agendas). We are all *temporarily* conscious or unconscious and *situationally* able-bodied or disabled (Toombs 1998); thus, every-body is in a perpetual state of becoming: we are all 'normal' and 'abnormal', dependent on time-space contexts. Nevertheless, making space for the voices of people with epilepsy on a continuum of (human) experience does not lessen the importance of recognising that the embodied impact of epilepsy often gives rise to 'troubling' emotions and physical feelings (including extreme anxiety, pain, disorientation). Of significance here is both how the individual responds to their own socio-corporeal challenges as well as how the body with epilepsy becomes 'other'. This requires a scaling-up from the immediacy of the phenomenological body (as one ontological space meriting attention) to the realms of public space. To bridge that gap (between 'inside' and 'outside' perspectives), notions of affect were deployed to explain how the intense, impersonal charge flowing *between* bodies, surrounding space and objects during 'epileptic' episodes gives way to extreme anxieties over the apparent breakdown of the socio-embodied boundaries on which self and society are predicated. While affect precedes (and indeed evades subsequent) articulation, it is vital to think through the effect of affect; that is, how people with epilepsy interpret and respond to others' responses. As has been discussed (especially in CHAPTERS FOUR and FIVE), different time-spaces (inclusive of contingent relations with people, place, material objects and institutions) provide the *possibility* for different affects to emerge, and so our understanding of the many struggles and negotiations of the volatile body must be framed

¹³⁷ We can here imagine ways in which Kraftl and Horton's (2008) essay on sleep could have been extended to include discussion of such conditions as narcolepsy, wherein socially-constructed circadian rhythms are powerless in the face of sleep attacks, even accepting they *do* frame understandings of the 'out of place' sleeping body.

within a wider geography of epilepsy. That the social meaning of seizures is unfixed and unpredictable leaves room for an optimistic politics of representation aimed at reducing the stigma surrounding the body that drops out of social consciousness, in terms of both the experience of seizures and public knowledge of them.

There is clearly a huge task in re-presenting epilepsy to wider society. If, as Sibley (1995; see also Kitchen 1998; Cresswell 1996) argues, exclusionary practices concerning the deviant body are unconsciously reproduced by the population as something natural, even commonsense, then it stands to reason that publicly exposing these practices may help to unsettle them. Most people, to be sure, refer to *the* embodiment of epilepsy (*the* seizure, i.e. the tonic-clonic) essentialised in the popular imagination, even though some seizures are barely visible and, furthermore, some people *with* epilepsy do not 'seize'. It may therefore be helpful to discuss not 'epilepsy', but the 'the epilepsies' (plural) as a way of encouraging people to rethink what they 'know' about this multifarious condition. To return to the opening provocations of this thesis, re-engaging the public imagination is nonetheless an extremely delicate task. While Dear *et al.* (1997) and Wilton (1998) propose that proximity to difference enables new tolerance and understandings, we must be mindful that the witness accounts of family members discussed in this thesis suggest that acceptance of the seized body is rarely straightforward. This necessitates that public education about seizures be supplemented with information about the lives of people with epilepsy, including experiences of discrimination. This is different from the current focus of campaigning, which emphasises 'success stories' (see CHAPTER EIGHT) and so normalisation, the emphasis being resolutely on so-called 'brightsiding'. Such a strategy is understandable given current neoliberal regimes surrounding illness self-management, but arguably sustains the marginalisation of individuals who fail to live up to the idealised body. We might, then, imagine a media-friendly poster and advert campaign, comparable to 'See Me', an anti-stigma mental health campaign in Scotland, to show how disrupted, 'disturbing' bodies and stigmatising reactions to them are part of the lives of individuals with epilepsy in community and mainstream social spaces. One approach could be in highlighting the incommensurability between the vital unpredictabilities of the 'epileptic body' (a de-centred phenomenology) and the workings of biopolitical/governmental regimes that posit complete bodily control as the natural and correct way of being (CHAPTER EIGHT). Juxtaposing the material and discursive may here serve to disrupt what people understand about epilepsy, how it is regulated and experienced, and so the appropriateness or otherwise of moralising judgements when 'regulation' fails.

MOVING BETWEEN THEORY AND POLICY

As Gleeson and Kearns (2001: 74) argue, recognition of the value of pluralism in policy contexts does not mean the abandonment of progressive aims. Emphasising how different people experience the same seizure episode differently, I have shown that giving voice to individuals with epilepsy allows viewpoints to be heard that may otherwise be silenced or excluded (Winchester 2000). Participants' stories demonstrate changing relations with space and time, a point deserving of the close attention of clinical and social support professionals. CHAPTER SIX unpacked the temporalities of living with illness so to develop nuanced understandings of how 'biographical disruption' is not simply a turning point (coinciding with diagnosis) but something which people experience time and again over a kaleidoscope of shorter and longer-term trajectories. This has important implications for peoples' continuation in the workplace or access to incapacity benefits. For example, in the current contexts of 'austerity UK', the tightening of definitions of what it is to be 'able' to work makes worse the plight of people who are denied benefits, but whose seizures may either be exacerbated or *return* if they are forced back into the workplace, where policies rarely provide flexibility for coping with the temporal variability of the epilepsies (this echoes Philo *et al.*'s [2005] concerns for the dangers of premature or inappropriate returns to work for people with mental health problems).

Aspects of affect arising from seizure moments (CHAPTER FIVE) must be coupled with cultural understandings and social contexts (for example, whether the person is of school or working age) to ascertain fully the impact of epilepsy. Further, it is important to consider *when* and *how often* bodily disruptions occur, and how actions in the present refer to past events and future risk. The experience of 'having' time is lost when frequent bodily 'startings and stoppings' become entangled in an asynchronous dance with how regular, lengthy and paced may be the tasks of a life. Time takes on new, although variable and contradictory, significance as being positive and/or negative, and so speaks to a central challenge for this thesis: namely, the extent to which individuals may become habituated to living with unpredictability. Addressing how people with epilepsy creatively negotiate different temporal contexts may help health professionals and scholars better to understand processes of coping. There is much work to be done, for at present there remain incommensurabilities between experiences of epilepsy in 'subjective' time, punctuated irregularly with partial and radical disruption, and how health professionals seek to relate to symptoms in regular, 'objective' timeframes (Toombs 1990: 237).

Notable 'body moments', here signified by seizures, have wider implications for the geographies of care and caring. I hope to spark debate relevant to living with conditions punctuated by, and to an extent structured around, dramatic intermittent effects, be it sleep attacks with narcolepsy, asthma attacks or hypoglycaemia with diabetes (the latter of which is the subject of an on-going University of Glasgow thesis by Mark Lucherini). While epilepsy resonates

with studies of many other health conditions, ones where people experience 'good days and bad days' (see, e.g. Wilton 1996), it highlights the need for a broadened understanding of bodily impairment as being either visible or invisible (epilepsy can be both, perhaps at the same or different times) and of the uncertain course of illness, including symptomatic fluctuations. Indeed, seizures instantly transform *loss of complete* control into *complete loss* of bodily control. The moments before a seizure (if an aura is experienced) may be heart-stoppingly, gut-wrenchingly disturbing as the body threatens dis-order, a somewhat contradictory sensation of radical disembodiment and unbearable embodiment as the world turns in on the body-self. Immediately after, too, the body seeks to re-locate itself through the mental fog obscuring its coordinates, screaming out for familiarity to counteract the sometimes jarring intrusions of unfamiliar people and space. Such moments, no matter how fleeting, not only shape, but are shaped by the individual's wider social geographies.

People exercise control over the consequences of seizures by controlling where they go; hence certain places or situations may be avoided altogether if experience has taught that the 'epileptic body' may become too out-of-place. The extent of peoples' everyday movements, then, varies with willingness to take risks, delineated in light of self-knowledge and surrounding space (Smith 2012), and all pertaining to *where* seizures might occur. In this way, CHAPTERS FOUR and FIVE complement and contextualise CHAPTER SEVEN, which details how individuals *embody* their fluctuating material and social limits in and through different spatial dimensions, including the body itself, home, paid labour, local movements and modes of transport. The unpredictable body means that there is no completely safe haven, and thus, unlike with agoraphobia-related panic attacks (Davidson 2000a, 2000b, 2003), retreat to the ambivalent space of the home does not necessarily reinforce the boundaries of the volatile body. It is a place where seizures will be less visible to 'outsiders' (and so less challenging in a social sense), but material hazards remain in sharp focus. Work *on* the body is therefore supplemented by work *with* its surroundings (including textures, shapes, elements and positionings). Such results speak to geographies of the self and bodily boundaries, and show how care of the (dis)abled body becomes a *pre*-condition for one's spacings and placings¹³⁸.

Using a phenomenological approach to gain insights into *what it is like* to live with illness helps us to consider how best to offer the support that individuals *want* (Toombs 1998; Zaner 1993). While dialoguing with illness can be a useful means to 'seeing through the eyes of the other', competing biomedical and experiential perspectives in the clinical encounter have proven, in some cases, to be disabling, especially when health professionals are under-equipped (socially and time-wise) to address existential crises (see CHAPTER FOUR). As Zaner (1993: 144) puts it:

¹³⁸ For example, see the special issues of *Social & Cultural Geography* (12(4), 2011a) on 'The limits of the body: boundaries, capacities, thresholds' and on 'Care of the body: spaces of practice' (12(6), 2011b).

People who are sick or injured not only want to know what's wrong, why they're hurting, what can be expected, what can and should be done about it, but they also want to know whether anybody *cares*, whether the people who *take care of* them also care *for* them.

The sometimes dispassionate attendance of biomedical professionals can suggest to the patient that emotional experience should be separated from the objectified body. Nevertheless, as discussed in CHAPTER EIGHT, people tend to know little about epilepsy besides stereotypical representations, and so the process of diagnosis is characterised by feelings of great instability. Participants reflect on being left wondering how on earth to manage their time and space knowing full well that these could be rendered (even more) chaotic at any moment. Common insecurities (which differ with sociological variables such as 'age': see CHAPTER SIX) focus on: What caused this? Why me? If I want to have children, will they also have epilepsy? Will I be able to continue working? How can people put their trust in me if I cannot even stay in control of myself? How am I going to cope with not driving? When will I have my next seizure? Will it always be like this? Is there a cure? How will I continue to socialise if most of my friends drink alcohol socially, and yet I have been told I should refrain? How will I find a romantic partner now? What are these medications doing to me? How can I be safe, even in my own home? In light of guarded optimism for immediate medication-based seizure control on the part of health professionals, when epilepsy does not become 'controlled' tensions arise because of mis-communication, different expectations and competing ideas about how to manage the condition (Buck *et al.* 1996; Chappell 1992; Choi-Kwon *et al.* 2001; Goodwin *et al.* 2011). Behaviours associated with seizure reduction (see CHAPTER EIGHT) are never guaranteed, and it may become counter-productive to one's on-going mental well-being to promote false hope. This is not to advocate the abandonment of hope; but rather, if people were helped to set more realistic expectations and, with a better understanding of epilepsy as *inherently* unpredictable from the outset, they might not perceive the same level of setback with each seizure. If persistent seizures are framed less as failures of the self or of medication to regulate epilepsy, this reframing might impact positively on peoples' abilities to accept, rescript and disclose their condition. In so doing, professionals may take a more pragmatic approach to managing peoples' expectations for the coming days, weeks, months, years and decades.

TOWARDS SPACES OF TRANSLATION

In this thesis I have worked across registers, moving from the phenomenological to the biopolitical. Recommendations arising from this thesis, then, are in reflection of what these interweaving contexts have taught: namely, that the individual with epilepsy struggles for re-presentation, whether through the self, from others after a seizure, advocacy groups (whose

'positive' depictions may at times be exclusionary rather than inclusionary) or biomedical professionals (whose compulsion to control seizures frequently supersedes appreciation of how individuals live *with* epilepsy). The sheer diversity and changeability of experiences of epilepsy, ones simultaneously embodied, social and personal, mean that finding out about one's own condition is a complicated, uneven, confusing, desperate, frightening process, which often leads people to feel as if they have *nowhere to go*. In such moments, individuals require support, but not necessarily the type(s) of support that can be accessed in biomedical spaces.

Parr and Davidson (2010: 271) discuss how the dismantling of the 'asylum' as a container of difference has not straightforwardly led to the reappraisal of difference in proximate community spaces. In fact, difficult encounters in close quarters, in some cases, arguably render the 'other' body *further* from the possibilities of understanding and acceptance¹³⁹. Parr and Davidson point to various local and national 'movements' (in combination with cultural and policy contexts) in empowering 'mental patients' and helping gradually to redefine 'mad identities', but 'epilepsy communities' appear to be lacking in any such organisation (CHAPTER EIGHT). The words of people with epilepsy in this research highlight the intense affective and emotional challenges and difficulties in fostering a sense of 'belonging' in community space, as well as in the construction of meaning-full lives. 'Epileptic bodies' offer a further striking example of both the *limits* and *necessity* of representation. For individuals whose 'active citizenship' (Milligan and Conradson 2006) may literally and metaphorically be destabilised, we need to think differently about how to translate their experiences and so facilitate senses of stability and belonging.

Given that the current 'age of austerity' shapes the realities of campaigning organisations (the continuing *existence* of ES is precarious at best) and people with epilepsy alike, we need a radical yet pragmatic vision of the possibilities for re-imagining encounters with epilepsy. In light of the challenges faced by people with epilepsy in representing themselves to themselves, other people with epilepsy and the wider public, we might look to construct new spaces of translation across various online¹⁴⁰, educational and arts networks, wherein people may re-find the importance of collective spaces. Just as Clark (2011: 73, in Shaw 2012: 624) writes of natural disasters, a seizure can be an 'event so severe that in its tearing away of the foundations, structures and relations that make the world legible, it also deprives those it afflicts of their capacity to absorb and process the event, to render it intelligible'. This intelligibility usually means

¹³⁹ These arguments are positioned within wider debates on care in the deinstitutionalised community (Clapham *et al.* 1990; Conradson 2003; Dear and Wolch 1987; Eyles 1988; Gleeson and Kearns 2001; Philo 1997). This research has revealed conflicting attitudes to 'appropriate' health services between people with epilepsy and governing institutions (charities, health care providers), sustaining oppositions over exactly what is 'right' for the individual: segregation/integration, dependency/independency, normalisation/personalisation. Frequently the opinions of the individual on how to manage their epilepsy are directly contradicted by health professionals who see seizure control as being the 'be-all-and-end-all' (see CHAPTER SIX and CHAPTER EIGHT). Individuals, however, often feel that they lack the knowledge or informational resources to contest professional positions.

¹⁴⁰ While data in this research suggests that individuals do not use online spaces for community-making, Escoffery *et al.* (2008) and Wicks *et al.* (2010) offer optimistic illustrations of the (potential) use of online spaces by people with epilepsy.

that one's *own* representations are limited by the seeming necessity of positive 'spin' aimed at 'normalising' epilepsy (as in the 'bright-siding' discourses of campaigning organisations) or by the job of 'translating' diverse witness testimonies into the vocabulary of health professionals. The increased circulation of first-person insight, even if detailing confused, ambiguous or 'negative' experiences, may spark overwhelmingly *positive* reactions because, finally, the reader with epilepsy does not feel so alone in experiencing something that otherwise cannot be shared. The potential impact on well-being and sense of belonging, whether in 'illness' or wider communities, may be great. By connecting with disparate individuals face-to-face or online, people with epilepsy may then feel empowered to unsettle and contest social constructions of sameness/difference.

This thesis is one such 'space of translation' that takes up the challenge of re-scripting the experience of radical socio-corporeal vulnerability, whether focussing on 'the event' of a seizure or across the everyday spatialities and temporalities that are structured *around* these confusing moments. Furthermore, the thesis website¹⁴¹ showcasing participant testimonies, which can be usefully enrolled by charities, arts organisations and educational facilities, is a tentative step towards and suggestion of a space of 'communion' (even if it does not represent an 'epilepsy community' space *per se*). It may even serve as a platform for networking within the open spaces reserved for user comments and debate. The website is intended as a space that others may view so as to reflect on the (unedited) experiences of particular individuals *and* common aspects of experience and concern (grouped thematically).

The newly-diagnosed in particular might benefit from reading about the experiences of others, and, in recognising the sheer variety of experience across the testimonies, may be able to draw on *particular* tactics in *particular* places that have been established by others to meet their own *specific needs*. Thus, newly-diagnosed individuals who are struggling to come to terms with the meaning of epilepsy may begin to recognise that living with epilepsy involves being simultaneously independent *and* inter-dependent, 'normal' *and* embodying of social difference. While health professionals are loath to 'alarm' patients by discussing corporeal challenges that may never be faced, my conclusions point to Wendell's (1996: 111) assertion that coping is made easier by learning about the lived realities of embodying illness. Indeed, for many participants it is the *unpredictability* of living with epilepsy that is most unnerving and unexpected. Without a source of empathy, many individuals are left in a perpetual state of anxiety because of the perception that *they* are somehow to blame for the failure of medical-pharmaceutical intervention, and thereby that their own way of living with epilepsy is *wrong*. As a result, acceptance that seizures *just happen*, that they are 'regularly irregular' (see CHAPTER SIX), that

¹⁴¹ In production at the time of writing, this will be a blog-based WordPress site (with permanent blog posts turned into the equivalent of website pages). ES have committed to publicising the website on their own website and across various 'mail shots' and press releases.

unpredictability is to be expected *regardless* of 'moral' self-governance strategies, remains problematic.

By drawing attention to a range of coping strategies, people may develop a vocabulary for articulating their experiences both to themselves and to others, leaving behind the implicitly negative constructions that participants used in my study to describe their 'not-normal' embodiments (indeed, participants were frequently self-conscious about reflecting on their 'silly', yet essential, coping strategies). Circulating testimonies may also help significant others – partners, friends, family, colleagues – begin to understand the ways in which they might not only help construct *relational* coping strategies but also *understand* (Davidson 2003: 121). As this research has demonstrated through the often humbling co-construction of participant testimonies, individuals with epilepsy are often incredibly keen to share their experiences because simply being *listened to* can offer extremely positive results for the self; at the same time, the thought of helping *others* is what motivates many of the participants to speak optimistically about the politics of epilepsy. Far from suggesting the emancipatory potential of abandoning representation, sometimes re-presentation is all we have. Proximities to the intermittently 'unregulated', 'anarchic' body may well continue to have disturbing affects on self and social space, but what is 'disturbing', I have argued, is a cultural response to uncanniness. These responses are not 'natural' or 'inevitable' but shaped over time through cultural 'ideals' and biopolitical interventions, which, as history has shown, are subject to change.

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APPENDIX 1: QUESTIONNAIRE COVER LETTER



3rd November 2010

Dear

Introduction and Information

I would like to invite you to complete an **anonymous questionnaire** for a research project about everyday life with epilepsy. Many studies look at the medical issues associated with epilepsy, but few address the challenges faced by people who have been diagnosed, and how they cope with and manage their seizures. Projects like this can be used by policy-makers and charities, such as *Epilepsy Scotland*, to ensure the needs of people with epilepsy are addressed, and that they receive the right sorts of information and care. This questionnaire seeks to find out about *your* experiences of living with epilepsy and what issues are most important to you in the place where you live. Even if you have well-controlled epilepsy I would still like to hear your views.

About the Researcher

My name is Niall Smith, and I am a PhD research student from the University of Glasgow. This project is funded by the Economic and Social Research Council (ESRC), and will run until December 2012. Contact details for me and my advisors are below. Although I do not work *for Epilepsy Scotland*, I will be working closely *with* them during this project. Please be aware that this research is completely separate to any of *Epilepsy Scotland's* services, and you are in no way required by *Epilepsy Scotland* to participate.

Confidentiality

If you choose to return a completed questionnaire, it will be completely anonymous and no-one will be able to identify that you took part in this research. The only time I might be able to identify you is if you choose to give your contact details at the bottom of the questionnaire. By returning a completed questionnaire you are consenting to your answers possibly being used as materials for reports, websites and papers as part of the project, but your contribution will be included under a false name. You are free to express any opinion with no risk to yourself or your identity. Only I will have access to returned questionnaires, and any that are completed online will be saved on to a private computer protected by password. Returned questionnaires will be destroyed after the project is over, and you may request a written summary of the findings of the research.

The questionnaire should take 15-20 minutes to complete, and you may leave out any question you do not want to answer. Please return completed questionnaires in the stamped, self-addressed envelope provided. If you choose to participate, please can you return completed questionnaires by **Friday 19th November**.

SCHOOL OF GEOGRAPHICAL AND EARTH SCIENCES
Main Building, University of Glasgow, Glasgow G12 8QQ, Scotland, UK
Head of School: Professor T B Hoey
Departmental Office: 0141 330 4782 / 5436; Fax: 0141 330 4894 / 4817; University Switchboard: 0141 339 8855

Alternatively, you may submit your response **online** via the following secure link:

<https://www.surveymonkey.com/s/lifewiththeepilepsy>.

If you want to tell us more...

At the end of the questionnaire, there is a space to put your details if you would also like to take part in an interview about your experiences of living with epilepsy. You can *only* be contacted if you supply your name and contact details. An interview will be between you and myself (you may also wish to bring along a friend or carer), and will be like an informal and friendly conversation with a few guiding topics, such as how epilepsy affects your daily routines and relationships. An interview will last approximately 1 hour and can be conducted at one of *Epilepsy Scotland's* offices, or any other place that we agree. With your permission, I will tape record the interview to help me remember what you have said. Your name, and anyone you talk about, will be changed in all materials resulting from the interview. Participation is entirely voluntary and you are free to refuse to take part or to withdraw from the study at any time without having to give a reason.

Contact Details

If you have any more questions about the research, or if you would like to request alternative ways to complete the questionnaire, for example, by telephone or large print pages, please do not hesitate to get in touch, by phone, email or letter.

My project supervisors at the University of Glasgow and *Epilepsy Scotland* are:

Professor Chris Philo
Department of Geographical & Earth Sciences
East Quadrangle, University of Glasgow
University Avenue
Glasgow, G12 8QQ
Email: Chris.Philos@ges.gla.ac.uk
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Anissa Tonberg
Epilepsy Scotland
48 Govan Road
Glasgow
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Email: atonberg@epilepsyscotland.org.uk
Tel: 0141 427 4911

If you have any concerns about the way the research is conducted and feel you have in any way been treated unfairly, you have the right to contact Dr. John McKernan, the convenor of the College of Social Sciences Ethics Committee at the University of Glasgow to discuss your concerns. This person may be contacted on 0141 330 6029 or John.Mckernan@glasgow.ac.uk.

Thank you for taking the time to read this information, and please keep this letter for reference. I hope that you will be able to participate in this study.

Yours sincerely,

Niall Smith

Tel: 0141 427 4911, **Email:** nsmith@epilepsyscotland.org.uk

APPENDIX 2: POSTAL QUESTIONNAIRE

Everyday Life with Epilepsy Questionnaire

Before deciding whether or not you would like to fill out this questionnaire, please take time to read through the information on the accompanying letter.

By returning a completed questionnaire you are consenting to your answers possibly being used as materials for reports, websites and papers as part of this project, but your contribution will be attributed under a false name. Returned questionnaires will be treated with the strictest confidence, and no-one will be able to identify that you took part.

You may leave out any question you do not want to answer.

The deadline for returned questionnaires is: **Friday 19th November, 2010.**

1. Are you: (please tick)

Male? ☐ Female? ☐ Transgender? ☐

2. What is your ethnic group? (please state, for example, White Scottish, Polish, Pakistani, African, Mixed or Multiple ethnic backgrounds)

3. Where about did you finish your highest level of education? (please tick)

- a. secondary school ☐
- b. additional training (apprenticeship, college course) ☐
- c. university undergraduate ☐
- d. postgraduate training ☐

4. What is your age? (please state) _____

5. At what age were you diagnosed with epilepsy? (please state) _____

6. What type of seizures or epilepsy syndrome do you have? (please list all, for example, simple partial, tonic-clonic, absence)

Additional Comments

7. Over the past year, how often do you usually have seizures? (please tick)

- a. I have had no seizures ☐
- b. Less than one seizure a month ☐
- c. One or more seizures a month ☐
- d. One or more seizures a week ☐
- e. One or more seizures every day ☐

Additional Comments

8. If you have seizures, when do your seizures usually occur? (please tick all that apply)

- a. Morning ☐
- b. During the day (e.g. work/school hours) ☐
- c. Evening ☐
- d. During the night (e.g. sleep seizures) ☐
- e. Random ☐

Additional Comments

You, Your Body and Seizures

9. Please describe what you feel to be the main physical effects of living with epilepsy (you may wish to discuss the effects of seizures, or the side-effects of medication)

10. Please describe what, if any, actions you take to avoid triggering a seizure (you may wish to discuss any relevant plans or adjustments you make on a daily basis)

11. Do you have a warning (aura) before a seizure (smell, feeling, sensation, etc)?
(please tick)

☐ Yes ☐ No ☐ Sometimes

If “yes” or “sometimes”, is the warning (aura) helpful; for example, does it allow you to prepare safely for a seizure? (please circle)

No help		Somewhat helpful		Very helpful
1	2	3	4	5

Additional Comments (for example, you may wish to describe how much of a warning you get, and what actions you take when preparing for a seizure)

12. Is there anything you can do to avoid or delay the onset of a seizure after experiencing an aura/warning? (please tick)

☐ Yes ☐ No ☐ Sometimes

If “yes” or “sometimes”, please describe what you do:

Places You Go

13. Are there particular places where your seizures tend to occur (for example, in bed, at work, in the street)? (please tick)

☐ Yes ☐ No ☐ Unsure

If "yes", please state what place(s), and whether they are associated with particular seizure triggers:

14. How much does it matter to you *where* you have a seizure? (please circle)

Never significant		Sometimes significant		Always significant
1	2	3	4	5

Additional Comments

15. Are there any particular places that you avoid because of the risk of having a seizure? (please tick)

☐ Yes ☐ No ☐ Sometimes

If "yes" or "sometimes", please state the places, and why:

16. If you had a seizure in the following places how safe or unsafe would you feel?
(please circle if applicable)

	Safe			Unsafe	
Home	1	2	3	4	5
Street	1	2	3	4	5
Work	1	2	3	4	5
School	1	2	3	4	5
Shopping Centre	1	2	3	4	5
Bus	1	2	3	4	5
Car	1	2	3	4	5
GP Surgery	1	2	3	4	5
Places of leisure (e.g. pub, cinema)	1	2	3	4	5

Additional Comments

17. Do you plan where you are going to go before you leave the house to control/limit/manage where seizures might occur (for example, do you pre-plan safer routes when going places)? (please tick)

☐ Yes ☐ No ☐ Sometimes

If “yes” or “sometimes”, please describe

Daily Activities

18. How much: (please tick)

	Never	Rarely	Sometimes	Often	All the time
do you think about whether you might have a seizure when you plan your day?					
does epilepsy interfere with your normal socialising with family, friends, or groups?					
does epilepsy interfere with your hobbies or recreational activities?					
does epilepsy interfere with the types of work (paid or voluntary) you are able to do?					
does epilepsy interfere with your household chores?					
does epilepsy interfere with your errands and shopping?					

How You Feel About Living With Epilepsy

19. How confident are you in talking about your epilepsy with: (please circle)

	Not at all confident			Very confident	
Family members	1	2	3	4	5
Friends	1	2	3	4	5
Colleagues	1	2	3	4	5
A potential employer	1	2	3	4	5
Strangers	1	2	3	4	5

20. How comfortable are you about the following people witnessing you having a seizure? (please circle)

	Not at all comfortable			Very comfortable	
Family members	1	2	3	4	5
Friends	1	2	3	4	5
Colleagues	1	2	3	4	5
A potential employer	1	2	3	4	5
Strangers	1	2	3	4	5

21. Would you say that you've ever experienced discrimination because you have epilepsy? (please tick)

☐ Yes ☐ No ☐ Unsure

If "yes", please describe

22. Have you ever tried to hide that you have epilepsy to avoid peoples' reactions?
(please tick)

☐ Yes ☐ No ☐ Unsure

Additional Comments

Epilepsy Support and Communities

23. What have been your main sources of information about epilepsy? (Please tick all that apply)

- a. GP/ Practice Nurse/ Health Centre ☐
- b. Hospital Doctor (e.g. neurologist) ☐
- c. Epilepsy Specialist Nurse ☐
- d. Epilepsy Charity ☐
- e. Information Leaflets ☐
- f. Internet ☐
- g. Other People with Epilepsy (e.g. support groups) ☐
- h. Other (please state)_____ ☐

24. Do you make use of internet chat rooms/forums to discuss epilepsy? (please tick)

☐ Yes ☐ No ☐ Sometimes

Additional comments

25. Do you attend any support groups associated with epilepsy? (please tick)

☐ Yes ☐ No ☐ Sometimes

If “yes” or “sometimes”, please state what type(s) of group:

If “no”, would you attend support groups if you had more information about them? (please tick)

☐ Yes ☐ No ☐ Maybe

Additional comments

26. Have you been involved in any public activities (e.g. campaigns, signing petitions) associated with epilepsy? (please tick)

☐ Yes ☐ No ☐ Unsure

If “yes”, please describe

27. Do you feel part of a community of people living with epilepsy (including face-to-face and internet groups)? (please tick)

☐ Yes ☐ No ☐ Unsure

Additional comments

28. Do you feel you share a common identity with other people living with epilepsy? (please tick)

☐ Yes ☐ No ☐ Sometimes

Additional Comments

29. Do you consider yourself to be disabled? (please tick)

☐ Yes ☐ No ☐ Sometimes

Additional Comments

Do you have any comments about this questionnaire, or is there any other information that you think would be useful?

Finally, would you be interested in talking to the researcher about your experiences in an informal and friendly interview (please see the accompanying Information Sheet for details)?

If you are interested in taking part, please fill in your details below. You can **only** be contacted if you give your contact details.

Name: _____

Address: _____


Email: _____

Telephone number (mobile or home): _____

APPENDIX 3: ONLINE QUESTIONNAIRE SCREENSHOTS

[SURVEY PREVIEW MODE] Everyday Life With Epilepsy Survey - Google Chrome

www.surveymonkey.com/s.aspx?PREVIEW_MODE=DO_NOT_USE_THIS_LINK_FOR_COLLECTION&sm=k1BBIKwrmQsNQKoRprv%2f1mRxxzStPzcSRyxExZaZkAYo%3d

 University of Glasgow

Exit this survey

Everyday Life With Epilepsy

1. Before you start...

Before deciding whether or not you would like to complete this questionnaire, please take time to read through the information on the accompanying email.

By completing this questionnaire you are consenting to your answers possibly being used as materials for reports, websites and papers as part of this project, but your contribution will be attributed under a false name. Submitted questionnaires will be treated with the strictest confidence, and no-one will be able to identify that you took part.

You may leave out any question you do not want to answer.

Next

Powered by **SurveyMonkey**
Check out our [sample surveys](#) and create your own now!

[SURVEY PREVIEW MODE] Everyday Life With Epilepsy Survey - Google Chrome

www.surveymonkey.com/s.aspx?PREVIEW_MODE=DO_NOT_USE_THIS_LINK_FOR_COLLECTION&sm=k1BBIKwrmQsNQKoRprv%2f1mRxxzStPzcSRyxExZaZkAYo%3d

Everyday Life With Epilepsy

3. You, Your Body and Seizures

9. Please describe what you feel are the main physical effects of living with epilepsy (you may wish to discuss the effects of seizures, or the side-effects of medication)

10. Please describe what, if any, actions you take to avoid triggering a seizure (you may wish to discuss any relevant plans or adjustments you make on a daily basis)

11. Do you have a warning (aura) before a seizure (smell, feeling, sensation, etc)? (please tick)

☐ Yes ☐ No ☐ Sometimes

Prev Next

APPENDIX 4: QUESTIONNAIRE DESCRIPTIVE RESULTS

Table A1: Gender of questionnaire respondents

Gender	<i>n</i>	%
Male	63	44.4%
Female	79	55.6%
Transgender	0	0%
	142	100.0%

Table A2: Highest level of education of questionnaire respondents

	<i>n</i>	%
Secondary school	46	33.3%
Additional training (apprenticeship, college)	42	30.4%
University undergraduate	24	17.4%
Postgraduate training	26	18.8%
	138	100.0%

Table A3: Age category of questionnaire respondents

Age Category	<i>n</i>	%
0-9	1	0.7%
10-19	7	5.0%
20-29	11	7.8%
30-39	19	13.5%
40-49	37	26.2%
50-59	32	22.7%
60-69	22	15.6%
70-79	7	5.0%
80-89	5	3.5%
90+	0	0.0%
	141	100.0%

Table A4: Age at diagnosis of questionnaire respondents

Age	<i>n</i>	%
0-9	34	23.9%
10-19	43	30.3%
20-29	30	21.1%
30-39	9	6.3%
40-49	13	9.2%
50-59	8	5.6%
60-69	2	1.4%
70-79	1	0.7%
80-89	2	1.4%
90+	0	0.0%
	142	100.0%

Table A5: Seizure Types of Questionnaire Respondents

Seizure Type	n	%
Partial	18	12.5%
Generalised	69	47.9%
Partial Seizures & Generalised Seizures	48	33.3%
Other/Unclassified	9	6.3%
	144	100.0%

Table A6: Seizure frequency of questionnaire respondents

	n	%
I have had no seizures	49	35.5%
Less than one seizure a month	30	21.7%
One or more seizures a month	24	17.4%
One or more seizures a week	24	17.4%
One or more seizures every day	11	8.0%
	138	100.0%

Table A7: When seizures usually occur

	n	%
Morning	30	24.6%
During the day (e.g. work hours)	34	27.9%
Evening	27	22.1%
During the night (e.g. sleep seizures)	37	30.3%
Random	70	57.4%
	122	100.0%

Table A8: Experience an aura (warning)

	n	%
Yes	56	45.5%
No	37	30.1%
Sometimes	30	24.4%
	123	100.0%

Table A9: How helpful is an aura for preparing safely?

	Never Helpful	Rarely Helpful	Somewhat Helpful	Usually Helpful	Always Helpful	
n	20	9	32	8	14	83
%	24.1%	10.8%	38.6%	9.6%	16.9%	100.0%

Table A10: Can you avoid or delay the onset of a seizure when experiencing an aura?

	n	%
Yes	7	8.2%
No	59	69.4%
Sometimes	19	22.4%
	85	100.0%

Table A11: Are there any places you avoid because of the risk of having a seizure?

	n	%
Yes	42	34.4%
No	66	54.1%
Unsure	14	11.5%
	122	100.0%

Table A12: How much does it matter where seizures occur?

	Never Significant	Rarely Significant	Sometimes Significant	Usually Significant	Always Significant	
n	10	6	30	7	68	121
%	8.3%	5.0%	24.8%	5.8%	56.2%	100.0%

Table A13: Are there any places you avoid because of the risk of seizure?

	n	%
Yes	34	27.6%
No	66	53.7%
Sometimes	23	18.7%
	123	100.0%

Table A14: How safe do you feel in the following places?

	Safe	Usually safe	Sometimes Safe, Sometimes Unsafe	Usually unsafe	Unsafe
Home	66	22	21	5	7
Street	5	7	25	19	57
Work (or school)	15	17	34	10	18
Shopping Centre	4	9	29	27	44
Bus	4	8	29	24	46
Car	11	15	20	20	41
GP Surgery	60	24	20	4	5
Places of leisure	8	11	36	16	38

Table A15: Do you plan where you go to control or limit where seizures might occur?

	n	%
Yes	17	13.9%
No	84	68.9%
Sometimes	21	17.2%
	122	100.0%

Table A16: How much does epilepsy impact on:

	Never	Rarely	Sometimes	Often	All the time
Daily planning?	54	30	23	10	8
Normal socialising?	40	23	38	15	12
Recreational activities?	39	21	41	12	13
Types of work you are able to do?	29	20	22	19	32
Household chores?	55	21	27	10	11
Errands and shopping?	46	25	35	7	13

Table A17: How confident are you in talking about your epilepsy with:

	Not at all confident	Rarely confident	Sometimes Confident	Usually confident	Very confident
Family Members	7	3	18	14	85
Friends	7	6	29	13	71
Colleagues	12	11	29	16	48
A Potential Employer	29	15	22	16	24
Strangers	34	17	25	13	35

Table A18: How comfortable are you about the following people witnessing you having a seizure:

	Never Comfortable	Rarely Comfortable	Sometimes Comfortable	Usually Comfortable	Always Comfortable
Family Members	21	7	17	23	54
Friends	19	16	30	16	39
Colleagues	33	19	28	13	14
A Potential Employer	61	15	16	5	7
Strangers	66	18	19	6	10

Table A19: Have you ever experienced discrimination because you have epilepsy?

	n	%
Yes	61	47.7%
No	43	33.6%
Unsure	24	18.8%
	128	100.0%

Table A20: Have you ever tried to hide that you have epilepsy to avoid peoples' reactions?

	n	%
Yes	38	29.9%
No	77	60.6%
Unsure	12	9.4%
	127	100.0%

Table A21: What have been your main sources of information about epilepsy?

GP/ Practice Nurse/ Health Centre	72
Hospital doctor (e.g. neurologist)	101
Epilepsy Specialist Nurse	58
Epilepsy Charity	82
Information Leaflets	58
Internet	45
Other People with Epilepsy	36
Other (please specify)	17

Table A22: Do you make use of internet chat rooms/forums to discuss epilepsy?

	n	%
Yes	5	3.9%
No	117	92.1%
Occasionally	5	3.9%
	127	100.0%

Table A23: Do you attend any epilepsy support groups?

	n	%
Yes	19	15.2%
No	82	65.6%
Sometimes	24	19.2%
	125	100.0%

Table A24: If "no", would you attend support groups if you had more information about them?

	n	%
Yes	19	15.2%
No	82	65.6%
Sometimes	24	19.2%
	125	100.0%

Table A25: Have you been involved in any public activities associated with epilepsy?

	n	%
Yes	47	38.2%
No	69	56.1%
Unsure	7	5.7%
	123	100.0%

Table A26: Do you feel part of a community of people living with epilepsy?

	n	%
Yes	24	20.5%
No	67	57.3%
Unsure	26	22.2%
	117	100.0%

Table A27: Do you feel you share a common identity with other people living with epilepsy?

	n	%
Yes	53	44.2%
No	33	27.5%
Unsure	34	28.3%
	120	100.0%

Table A28: Do you consider yourself to be disabled?

	n	%
Yes	38	30.9%
No	46	37.4%
Sometimes	39	31.7%
	123	100.0%

APPENDIX 5: INTERVIEWEES BREAKDOWN

The graphs below illustrate those categories I was attempting to balance while negotiating with the individuals I hoped to interview. The first bar in each displays the breakdown of questionnaire respondents, followed by the make-up of people who self-selected for interview (the second bar) and the final proportion of interviewees (the third bar):

Figure A1: Interviewees by 'Seizure Frequency'

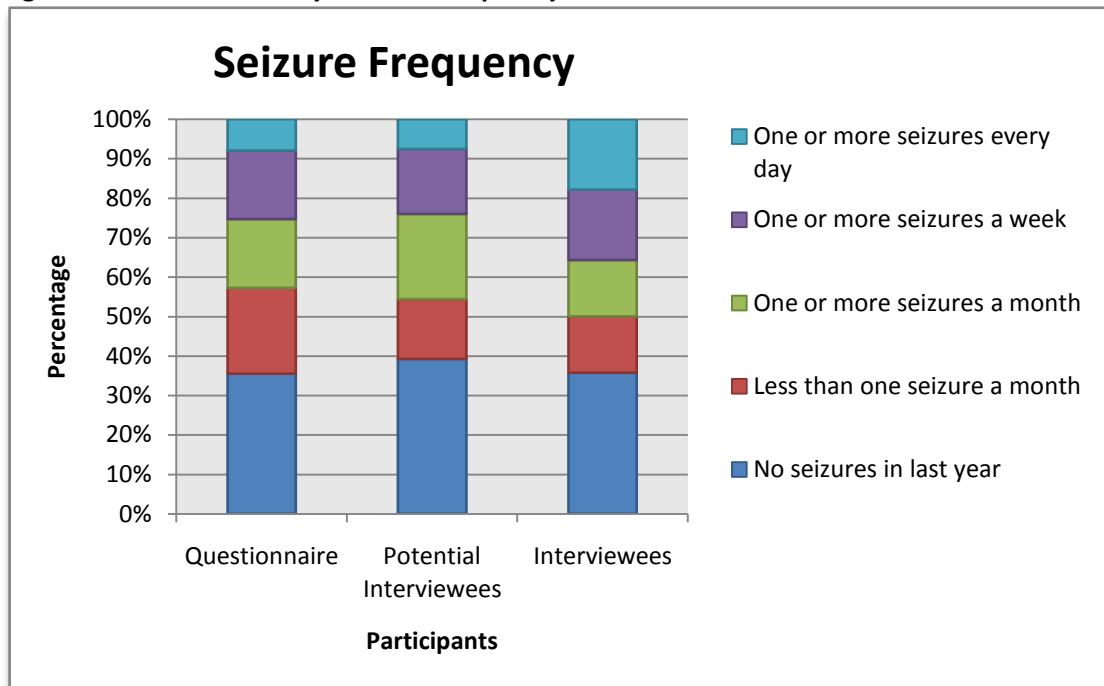


Figure A2: Interviewees by 'Gender'

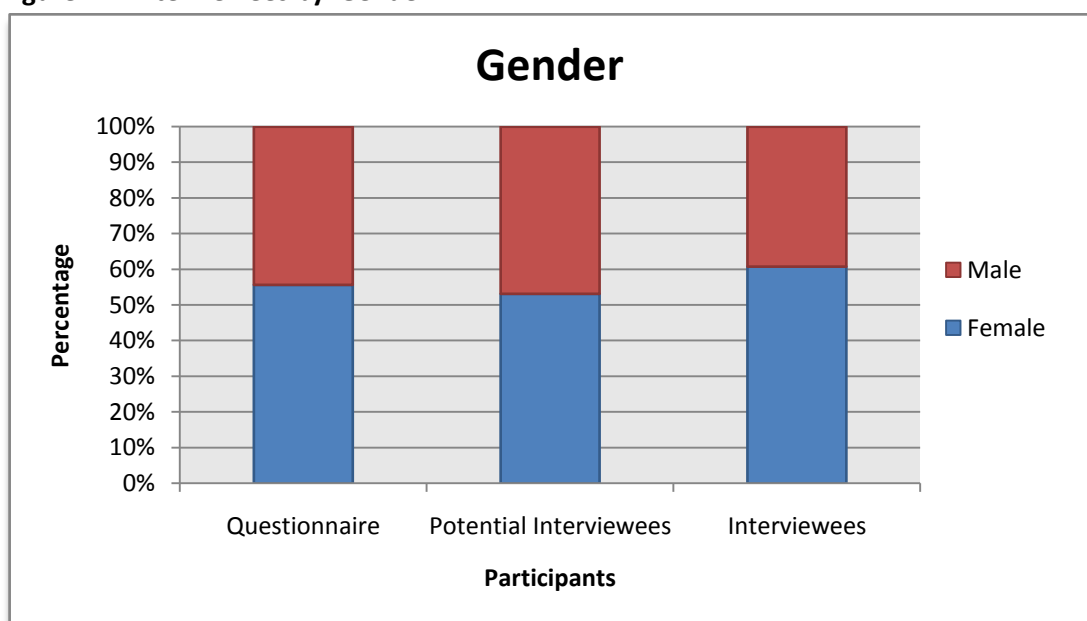


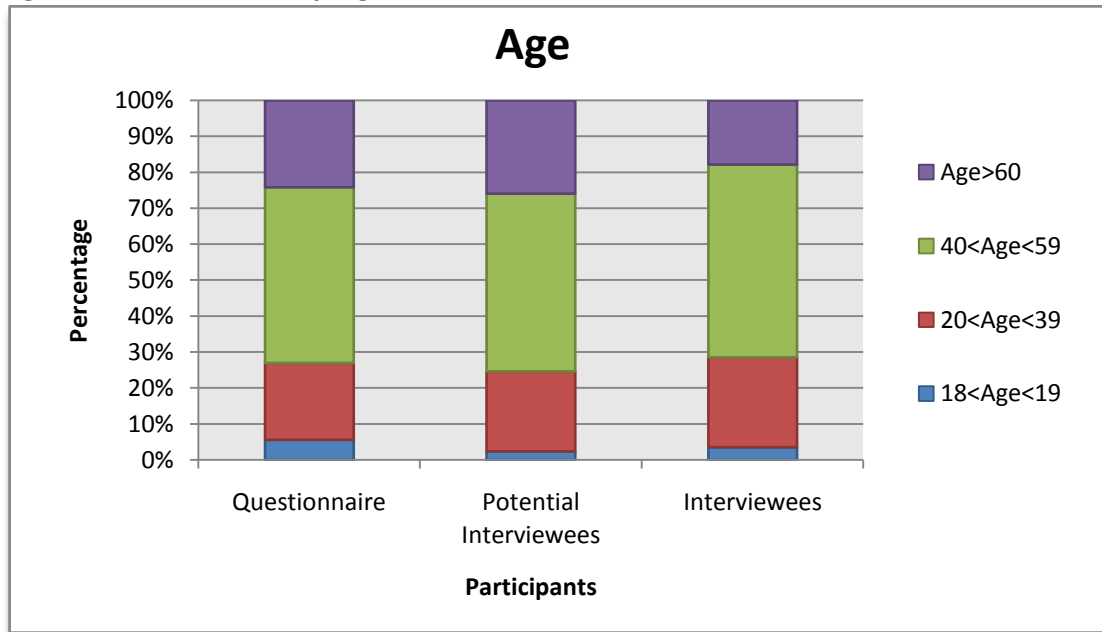
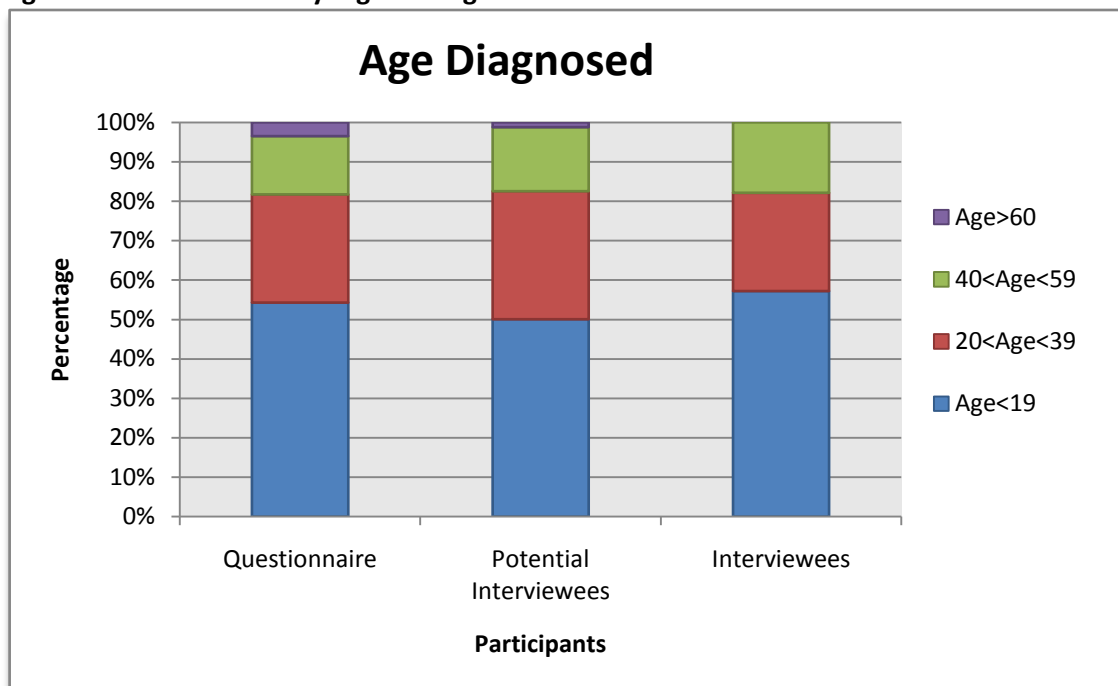
Figure A3: Interviewees by 'Age'**Figure A4: Interviewees by 'Age at Diagnosis'**

Figure A5: Interviewees by 'Seizure Type'

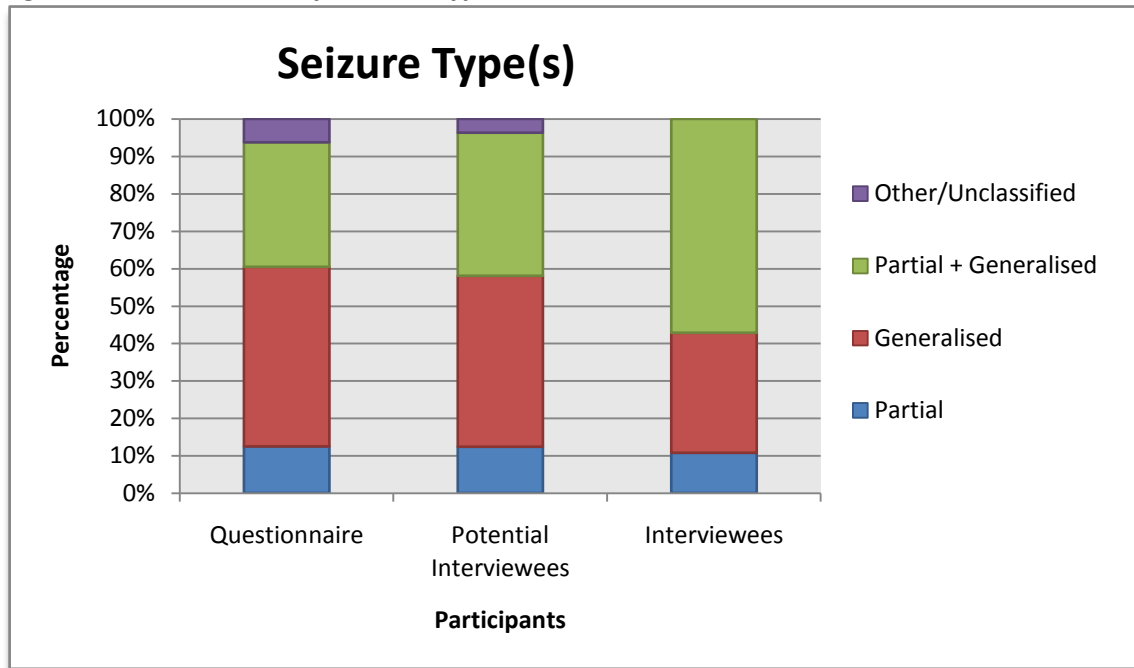
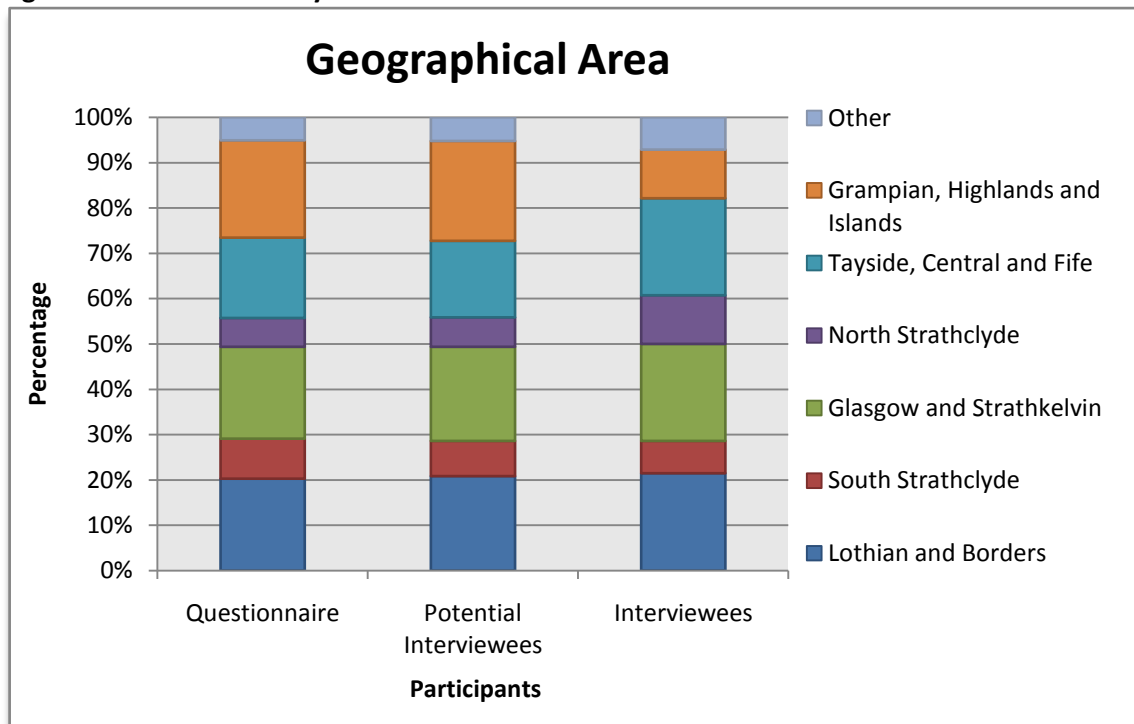


Figure A6: Interviewees by 'Location'



APPENDIX 6: SEMI-STRUCTURED INTERVIEW SCHEDULE

Opening Statements and Questions

- Statement about research project and nature of partnership with Epilepsy Scotland.
- Statement about confidentiality and anonymity.
- Confirmation of informed consent (signed consent form).
- Ask about emergency medication and usual seizure activity.

Onset and Diagnosis

Onset

“Tell me about the period when epilepsy first became part of your life?”

Key points:

Description of first time something happened that felt different from normal (what, when, where, how it felt).

Your reaction; how you explained it?

Did you tell friends, colleagues, etc. – how did they respond?

What was going on in your life at that point: work, living/social arrangements?

At what point did you seek (medical) advice?

Diagnosis

“Tell me about how you obtained a diagnosis?”

Key points:

How was epilepsy identified? How long did it take?

How did you feel when epilepsy was named? What did you know about epilepsy? Did your expectations for the future change?

What information did you receive about how epilepsy might impact on your day-to-day life?

Did you feel the advice/treatment plan you received was appropriate?

Have there been times when you went against or disagreed with medical advice? Or times when you negotiated different treatments?

To what extent do you feel you have an expert knowledge of your own condition? What has contributed to that (personal research?)? What barriers have you faced (info., other people)?

Has that involved connecting with and sharing knowledge with others in any way? Have there been opportunities/missed opportunities?

Or, if diagnosed at young age

Growing up with epilepsy

Tell me about when you first became aware of having epilepsy?

What did your parents tell you about it?

How did family and friends treat you? What was their attitude to epilepsy?

Did you have to do anything different from other people your age?

How has your knowledge about epilepsy changed over the years? Have there been key moments when things changed? Have there been times when you went against medical advice or negotiated different treatments?

To what extent do you feel you have an expert knowledge of your own condition? What has contributed to that (personal research? Drs?)? What barriers have you faced (info., other people)?

Has that involved connecting with and sharing knowledge with others in any way? Have there been opportunities/missed opportunities? Political?

Overall, what effect did epilepsy have on your young life?

Before, during and after seizures

Step-by-step narrative of seizure event

What type(s) of seizure do you have?

Do you get a warning (e.g. an aura)? If so, can you describe exactly what you sense? Are there changes in sight, smell, taste, bodily feelings (where?)? Does your self-awareness change? What is your relationship with surrounding space – do you become more aware of features of the environment, or other people? Do you follow a strategy when you have an aura?

Are you conscious/aware to any extent during seizure?

The minutes, hours, days after seizure(s)

Can you talk me through exactly what you experience on regaining awareness? What of your senses comes back first? What do you first become aware of (other people? The space surrounding you? Sensations in your body)? Does it all 'come back' at once, or slowly over time?

What you do after a seizure?

Are there after-effects? How long do they last?

Witnesses

How do witnesses describe seizures (body movements?)? What is their (emotional) reaction?

How you feel about their reactions? Are people helpful/informative, or do they make you feel uneasy?

Does the way people react influence changes to anything you do on a normal day?

Body and environment**Placing Seizures**

Have seizures (frequency, type, control) always been like this? Have there been periods when things have been different?

Is there anything that triggers a seizure for you? Are these triggers linked to any places, features of the environment or emotional states? Do you do anything differently because of these triggers? What happens if you are unable to respond (e.g. unable to keep to your routine)?

Can you tell me about the extent to which you can predict your seizures? Do you do anything differently at times when you feel a seizure is more likely (the things you do, or the places you go)?

Does how you would feel about having a seizure change in different places? What are the main issues: Other people? Place? Personal safety? All of the above? Does that change at different times?

Is there anything that you have to consider before going places? E.g. do you make particular choices in regards to routes/transport/activities/etc.? Do you do anything in terms of self-organisation (do you take anything with you)?

Everyday Planning

Since first being diagnosed, to what extent would you say you have altered your daily routines, if at all? What changed? Driving?

From when you wake up, at what points during the day does anything epilepsy-related come into your thinking? E.g. do you have any set routines, do you need to remember to do anything (e.g. medication), and are there times of day or activities when you need to take special care?

Have you changed the way you organise space in your home? Have you made any modifications to rooms to accommodate possibly having seizures?

Are you currently working? Do people at work know of your condition? (YES) How do feel about people knowing? How do you think they feel about it? Have any workplace arrangements or accommodations been made?

Are you currently working? Do people at work know of your condition? (NO) Have you any concerns about people finding out? Is there anything you do to make sure people don't find out? Is there anything you do to hide your condition? Under what conditions might you feel comfortable telling people about epilepsy?

Final question:

If you were to tell me the story of your life, what part would epilepsy play? How has epilepsy impacted on you as a person?

**Respondent opportunity to raise issues that were not covered in the interview.
Statement about report writing and accessing research results.**

APPENDIX 7: NVIVO SCREENSHOT

The screenshot shows the NVivo software interface for a project titled "The Everyday Social Geographies of Living with Epilepsy.nvp". The left sidebar contains navigation options: Nodes, Sources, Classifications, Collections, Queries, Reports, Models, and Folders. The main workspace displays a hierarchical tree of themes and a corresponding data table.

Themes Table:

Name	Sources	References	Created On	Cr	Modified On
Social Geographies	0	0	14/06/2012	N	14/06/2012
Different times & Rhythms of Everyday Life	26	103	15/06/2012	N	30/07/2012
Disclosure	0	0	15/06/2012	N	15/06/2012
Educating others	14	26	15/06/2012	N	27/07/2012
Qualified deception & Selective disclosure	20	36	15/06/2012	N	30/07/2012
Economic Implications	0	0	15/06/2012	N	15/06/2012
Access To Benefits	16	26	15/06/2012	N	31/07/2012
Other issues affecting personal finances	10	14	20/06/2012	N	30/07/2012
Political or Economic Contexts That Might Affect Access To Benefits	6	10	15/06/2012	N	30/07/2012
Family Relations	1	1	14/06/2012	N	18/06/2012
Accepted	17	30	15/06/2012	N	27/07/2012
Ambivalent	19	42	20/06/2012	N	31/07/2012
Not Accepted	8	20	15/06/2012	N	30/07/2012
Identity	2	5	15/06/2012	N	18/06/2012
How big an impact on life	35	186	15/06/2012	N	31/07/2012
Rescripting - High aspiration as compensation	12	44	15/06/2012	N	19/07/2012
Role	12	28	18/06/2012	N	30/07/2012
Tensions between epilepsy & mental illness or disability	16	33	18/06/2012	N	31/07/2012
Long-Term Implications	2	2	15/06/2012	N	20/06/2012
Avenues Opened Up	11	17	15/06/2012	N	19/07/2012
Possibilities Closed Down	27	91	15/06/2012	N	31/07/2012
Others Perceptions of Epilepsy	3	3	15/06/2012	N	18/06/2012