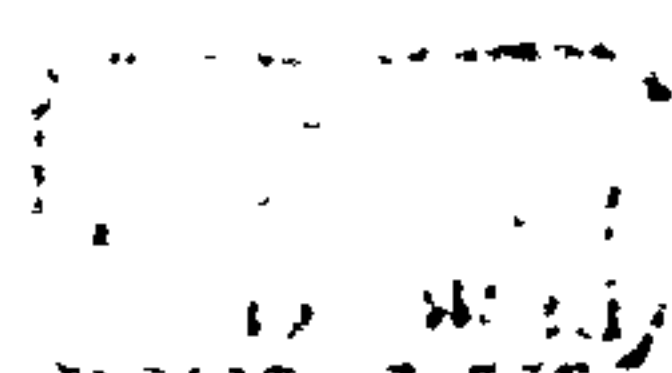


The Values History: An Empowering Approach for People with Dementia

James Robert Boyd

**Community Care Works
Dept of Law, Business Studies and Social Sciences
University of Glasgow**

**Doctor of Philosophy
2007**



Acknowledgments

Firstly, I would like to thank Dr. Alison Petch for her support and encouragement throughout the course of this research. Her guidance was invaluable and she had the perfect balance between supporting and challenging me where appropriate. Secondly, I would like to thank Dr Charlotte Pearson for her assistance, especially over the last year of the study during the writing up period.

I would also like to thank the managers of Greater Glasgow NHS and Clyde for giving me the time to undertake this study and especially my colleagues at Eastvale Resource Centre for their support and participant referrals. In particular, I would like to thank my good friend Fergus Maitland for proof reading this thesis and Dr Graham Jackson for his encouragement. Thank you also to Eileen Richardson, for her assistance at the Dementia Services Development Centre.

Debts of gratitude are owed to the participants. To all the participants with dementia and their relatives – a sincere thank you for sharing your innermost thoughts and feelings with me. To all the professional participants in the study – thank you for taking the time out of your busy schedules to be interviewed, and particularly, for ‘doing your homework’ beforehand.

Finally, had it not been for the love, support and understanding of my wife Sarah, my children Matthew and Rachel and my parents, I would not be writing these acknowledgements. Thank you!

Abstract

This thesis discusses the Values History as an approach to empower people with dementia, enabling their voices to be heard should they no longer be able to articulate their wishes. The Values History was originally developed to identify core values and beliefs which are important to individuals with terminal illnesses as a basis for medical treatment should they lose capacity (Doukas and McCulloch, 1991).

The research shows that the standard paradigm of empowerment, which involves individuals with dementia having a clear understanding of the prognosis of the illness to make plans for the future, is complex. Twelve people diagnosed in the early stages of dementia were interviewed twice to complete individual Values Histories. Their carers were interviewed separately and then together with the participants with dementia. Despite knowing their diagnosis and appreciating the opportunity to discuss their current feelings about the illness, only a few participants with dementia were able to discuss, or indeed wanted to discuss, the prognosis or future in relation to dementia. No participants wanted to view long term care establishments. However, the research showed that the vast majority were clearly able to document their values and aspects of future care related to old age rather than dementia. Carers confirmed accuracy of their values. One area of concern was that some participants appointed specific family members as power of attorney out of obligation rather than them being the best person to represent their interests. The study also found that some participants with dementia found it difficult to honestly record poor family relationships and religious values.

With regards to the impact of Values Histories on future caregivers, forty professionals were interviewed. Two Values Histories were shared with the participants and vignettes were used to explore the extent to which they would refer to individuals' past values and wishes. The study showed that the vast majority of professionals would refer to the documents and find them useful. The majority would attempt to maintain past wishes and values, although not if it caused agitation or distress to the person. General values, medical values, family relationships, religious values and end of life decisions were areas within the Values Histories that were

considered most beneficial. The person's perception of independence and future risk taking were the areas that caused most controversy.

As an alternative area of discussion this thesis also explored the 'person centred' approach to empowerment, which suggests that knowing the previous values of people with dementia is imperative to entering the person's 'frame of reference' but not at the expense of their current feelings (Morton, 1999; Kitwood, 1997). This approach also allows people with dementia the opportunity to record their values without being fully aware of the prognosis or being held to their previously stated values should they deteriorate.

Chapter 1 **page**

Legislative changes related to dementia care

Part One

1.1 Introduction	1
1.2 Mental Health (Care and Treatment) (Scotland) Act 2003	2
1.3 Adults with Incapacity (Scotland) Act (2000)	3
1.4 Mental disorder	6
1.5 Continuing and Welfare Power of Attorney	7
1.6 Nearest relative	9
1.7 Named person	9
1.8 Advocacy	10

Part Two

1.9 “Present and past wishes”	14
1.10 Proxy or surrogate decision making	15
1.11a Advance Directives –legality in Scotland	17
1.11b Advantages and disadvantages of Advance Directives	19
1.11c End of Life Decisions	21
1.12 Advance Statements	23
1.13 Values Histories	26
1.14 Summary	30

Chapter 2

Medical advances in the treatment of Alzheimer’s disease

2.1 Introduction	31
2.2 Background and History of Anti-dementia Drugs	32
2.3 NICE (2005) recommendations	33
2.4 Memory clinics	37
2.5 Early diagnosis	39
2.6 Sharing the diagnosis	41
2.7 Do professionals regularly share the diagnosis with people with dementia?	43
2.8 Do families want the person with dementia to be informed of their diagnosis?	45

2.9 Do people with dementia want to know their diagnosis?	47
2.10 Is lack of insight an inevitable symptom of dementia?	49
2.11 Psychosocial factors which influence awareness	53
2.12 Denial - a coping mechanism which influences awareness	53
2.13 Does lack of information influence unawareness?	56
2.14 Do people with dementia want to plan future care?	57
2.15 Summary	58

Chapter 3

The “new culture” of dementia care

3.1 Introduction	60
------------------	----

Part one

3.2 “Person centred” approach to care	61
3.3 The “organic model” of care	62
3.4 Components of “person centred” care	65
3.5 “Person focussed” care for people in the early stages of dementia	67
3.6 Are Values Histories person centred?	69

Part Two

3.7 Introducing the concept of empowerment	73
3.8 What is empowerment?	73
3.9 Three components of empowerment	76
3.10 Is the legal process in Scotland empowering?	80
3.11 Advance planning and Values Histories in the context of empowerment	82
3.12 Summary and research questions	85

Chapter 4

Methodology

4.1 Introduction	89
4.2.1 Key methodological issues underpinning the study	89
4.2.2 Theoretical perspectives for the study	93
4.2.3 Theoretical Perspective: Focus groups	97
4.2.4 Theoretical Perspective: Interviews	99
4.2.5 Theoretical Perspective: Vignettes	101
4.2.6 Theoretical Perspective: Questionnaires	103

4.3.1 Ethical Considerations	104
4.3.2 Ethical approval	105
4.4.1 Research Design: Stage One	106
4.4.2 Inclusion criteria	106
4.4.3 Format of interviews	103
4.5.1 The Pilot Study	110
4.5.2 Pilot Study: Interviews with two people with dementia and their partners	110
4.5.3 Pilot Study: Focus groups	115
4.5.4 Summary of Pilot Study	119
4.6.1 Stage one - process of interviews	120
4.6.2 Stage two - research design	126
4.6.3 Format of the professional interviews	126
4.6.4 Format of Vignettes	127
4.7 Codes for participants	131
4.8 Analysis and contemplation of data	134
4.9 Summary	139

Chapter 5

Sharing the diagnosis and discussing the future with people with dementia

5.1 Introduction	141
5.2 Sharing the diagnosis - the perceptions of professional participants.	142
5.3 Who should share the diagnosis?	143
5.4 Sharing the diagnosis - the perceptions of participants with dementia.	152
5.5 Sharing the diagnosis – carers’ perceptions	153
5.6 Dilemma – a relative asks that the diagnosis is not shared with the person with dementia	155
5.7 Medication for dementia - a way to open up dialogue?	158
5.8 Discussing the future – the perspectives of the professionals	160
5.9 Discussing the prognosis with people with dementia	162
5.10 Discussing future care with people with dementia	170
5.11 Summary	174

Chapter 6

Independence and Safety

6.1 Introduction	177
6.2 Perceptions of people with dementia about their independence and safety	178
6.3 Perceptions of carers to the independence and safety of people with dementia	187
6.4 Perceptions of professionals to independence and safety	191
6.5 Sylvia's Values History- vignette	194
6.6 Summary	200

Chapter 7

Families and relationships

7.1 Introduction	203
7.2 AWI (Scotland) Act 2000:- current and future impact of the Act.	204
7.3 Power of Attorney - discussing finances with people with dementia	210
7.4 How do professionals engage with people with dementia about their welfare?	213
7.5 Engaging with people with dementia to document how they feel about their family and relationships	216
7.6 Carers' experiences advocating for people with dementia	218
7.7 Sylvia's vignette- exploring the issues recorded in Sylvia's Values History	219
7.8 Summary	223

Chapter 8

Medical Values

8.1 Introduction	225
8.2 General medical values	225
8.3 Complementary therapy	229
8.4 End of life decisions	234
8.5 Marie's vignette	236
8.6 Summary	243

Chapter 9

Values

9.1 Introduction	245
9.2 Recording values of people with dementia	246
9.3 Recording spiritual values of people with dementia	251
9.4 The extent to which professionals record spiritual values	253
9.5a Professionals' perceptions of values	256
9.5b Professional's perception of values - related to dementia	258
9.6 Sylvia's values vignette - her appearance	261
9.7 Marie's values vignette - her faith	268
9.8 Summary	275

Chapter 10

Practical implications for the use of the Values History and the researcher's reflections as a practitioner

10.1 Introduction	278
10.2 Professionals' preferences regarding the writing of the documents	279
10.3 Researcher's experience of writing the Values Histories	281
10.4 Researcher's previous knowledge of the participants with dementia	283
10.5 To what extent would professionals refer to the Values Histories in practice?	285
10.6 Do professionals feel that Values Histories could empower people with dementia?	291
10.7 General concerns regarding the Values Histories.	292
10.8 Would professionals choose to have a Value History should they develop dementia?	295
10.9 Summary	297

Chapter 11

The Values History: an empowering approach for people with dementia?

11.1 Introduction	299
11.2 How do professionals engage with people with dementia to discuss and make plans for the future?	300
11.3 To what extent are people with dementia able to discuss the future?	302

11.4 Are people in the early stages of dementia able to discuss and record their values?	304
11.5 To what extent should past wishes and values be promoted when a person loses insight into their condition?	307
11.6 Is the Values History a practical way to empower people with dementia as their illness progresses?	312
11.7 Practical implications of Values Histories	319
11.8 Summary	321

Tables

	page
Table 1. Focus group codes: social workers participants	115
Table 2. Focus group codes: medical and psychology participants	116
Table 3. Focus group codes: CPNs and health care assistant participants	116
Table 4. Stage 1 codes: Participants with dementia and their nominated carers	131
Table 5. Stage 2 codes: Professional Participants	132
Table 6. How useful do professionals feel a Values History would help to plan care for a person with dementia?	285
Table 7. To what extent would professionals refer to a Values History?	286
Table 8. To what extent do professionals feel a Values History could empower a person with dementia?	291

Appendices

Appendix 1- The Extended Values History

Appendix 2- Information sheet

Appendix 3- Consent from

Appendix 4- Folstein Mini Mental Status Examination

Appendix 5- Insight rating scale

Appendix 6- Interview schedule

Appendix 7- Questionnaire

Appendix 8- Malcolm's Values History

Appendix 9- Jack's Values History

Appendix 10- Sylvia's Values History

Appendix 11- Marie's Values History

Introduction

It is estimated that over 62, 000 people in Scotland have dementia, with at least 29,000 carers providing a regular and substantial amount of care (Alzheimer's Scotland –Action on Dementia, 2005a). As yet there is no cure for most dementias and it envisaged that with an increasing older population, particularly those over 85 years, the number of people with dementia will increase to approximately 84,300 by 2025 (Alzheimer's Scotland – Action on Dementia, 2005b).

Dementia is a syndrome which may be caused by several different illness, the most common being Alzheimer's disease. Other causes may include vascular dementia (including multi infarct dementia), dementia of lewy body type, Pick's disease, and alcohol related dementia, plus other less commonly known dementias (Jacques and Jackson, 2000). Dementia is usually chronic or progressive in nature and can cause disturbance in multiple cortical functions, calculation, learning capacity and judgement. It can also be accompanied by deterioration in emotion control, social behaviour and motivation (World Health Organisation, 2005).

Dementia is also considered by some as a social disability (Cheston and Bender, 1999). Attitudinal and environmental barriers can increase the disability experienced by people with dementia (Wilkinson, 2002). Often they can be disempowered at various stages of their illness (Mason and Wilkinson, 2002). One way that this can happen is by excluding their views from decisions about their own future (Wilkinson, 2001). Even well meaning and caring relatives can add to this by adopting a paternalistic attitude (Burton, 1997). Whilst there is no doubt that the vast majority of carers and professionals want what is best for the person, often they find it hard to differentiate between what they want for the person and what the person, in fact, would want for themselves (Brandon, 1995; Ivers, 1995; Rankin, 1989). Therefore, the main purpose of this research is to attempt to include the "voice of people with dementia" to explore the feasibility of engaging with them in the early stages of the illness to elicit their values and care preferences and to ascertain if the Values History could be used to empower them (Docker, 2000; Goldsmith, 1996; Doukas and McCulloch, 1991; Lambert et al., 1991).

The present study has emerged due to three aspects which have major implications for people with dementia, namely, the legal process in Scotland, medication for Alzheimer's disease and the 'new culture' of dementia care. The first three chapters review the literature on these themes.

Chapter one explores how the Adults with Incapacity (Scotland) Act (2000), which was implemented in stages between April 2001 and October 2003 (Scottish Executive, 2004a), sets out a legal framework for professionals to include individuals with incapacity in decision making. One of the main principles of the Act and driving forces of this research is that when determining any intervention, account must be taken of:

“the present and past wishes and feelings of the adult so far as they can be ascertained by any means of communication, whether human or by mechanical aid (whether of an interpretative nature or otherwise) appropriate to the adult”
(AWI Act, 2000:1.4a).

Clearly taking in to consideration the person's past wishes indicates that anyone acting on the person's behalf should have a high level of knowledge and understanding about their personality, values and wishes for the future before they lose capacity. This theme is explored throughout the thesis and, in particular, the extent to which professionals would adhere to past wishes and feelings when they may conflict with the person's current feelings or those of their carer. The second part of the chapter looks more specifically at advanced directives and statements from a legal perspective in Scotland and evaluates their usefulness for empowering people with dementia.

The research also emerged due to a change in practice whereby people with dementia are being diagnosed earlier and the diagnosis is more likely to be shared with the person. Chapter two argues that this change is, at least in part, due to the inception of medication for Alzheimer's disease which is indicated for those in the early to moderate stages of the illness. It argues that the medication for Alzheimer's disease has contributed to openness with people with dementia, possibly due to some professionals feeling more comfortable discussing the illness, feeling that medication

gives hope to the person despite not being a cure. Clearly, this change in practice has opened the door for discussions to take place with individuals at a time when they are able to articulate their views and possibly make plans for the future.

Chapter three explores issues around the “new culture” of dementia care, which has evolved due to pressure from dementia advocacy groups and academics. Indeed, as this research progressed, several studies have given valuable insight into the perspectives of people with dementia diagnosed early in their illness. It also discusses two approaches to empowering people with dementia. The first approach involves the individual having a clear understanding of the diagnosis and prognosis of the illness and the second follows a “person centred” approach which does not rely solely on cognitive skills.

The first three literature review chapters also allude to the Values History as being one way to empower people with dementia. Chapter three concludes with the research questions, the overarching question asking whether the Values History can, in fact, be used to empower people with dementia.

Chapter four describes the methodology for the research which was conducted between Oct 2000 and July 2004. The pilot study took place between October 2000 and February 2001. It involved interviewing two people with dementia and their carers to complete two Values Histories. Thereafter, the two Values Histories were shared with professionals in three focus groups. The main study was carried out between May 2001 and July 2004 and included two main stages. Firstly, twelve people diagnosed in the early stages of dementia were interviewed twice to complete individual Values Histories. Their carers were interviewed separately and together with the participants with dementia. Secondly, forty professionals were interviewed and their views sought on two completed Value Histories. Vignettes were used to draw out scenarios related to the documents.

Chapters five through ten presents the findings of the research thematically. Chapter five explores how it feels for people with dementia to discuss the diagnosis, prognosis and future care, incorporating the views of their carers and professionals. Chapters six through nine draw on aspects contained within the Values Histories, namely,

independence and safety, family and relations, medical values and general values. Chapter ten predominantly brings out the researcher's own perspective on how it felt as a practitioner carrying out research. It also discusses their practical use in a clinical environment. Chapter eleven concludes the thesis by answering the research questions and discusses implications for future research.

Chapter 1

Legislative changes related to dementia care

Part One

1.1 Introduction

1.2 Mental Health (Care and Treatment) (Scotland) Act (2003)

1.3 Adults with Incapacity (Scotland) Act (2000)

1.4 Mental disorder

1.5 Continuing and Welfare Power of Attorney

1.6 Nearest relative

1.7 Named person

1.8 Advocacy

Part Two

1.9 “Present and past wishes”

1.10 Proxy or surrogate decision making

1.11a Advance Directives – legality in Scotland

1.11b Advantages and disadvantages of Advance Directives

1.11c End of Life Decisions

1.12 Advance Statements

1.13 Values Histories

1.14 Summary

1.1 Introduction

This research has emerged, in part, due to legislative changes which have taken place in Scotland. The main focus of this chapter explores aspects of how the Adults with Incapacity (Scotland) Act 2000 relates to people with dementia. It also draws on aspects

of the Mental Health (Care and Treatment) (Scotland) Act 2003, which was implemented in October 2005 (Scottish Executive, 2005a).

The chapter is split into two parts, the first of which explores how both Acts relate to dementia care and, in particular, the legal and ethical issues of people with dementia appointing someone to look after their interests should they lose capacity to make decisions for themselves. The second part of the chapter looks more specifically at advance directives and statements from a legal perspective in Scotland and evaluates their usefulness in empowering people with dementia. It concludes by discussing the merits of Values Histories, and evaluates whether they could be adapted to empower people with dementia, should they no longer be able to articulate their own views.

1.2 Mental Health (Care and Treatment) (Scotland) Act 2003

The MHCT (Scotland) Act 2003 arose out of recommendations from the Millan Committee's review of the Mental Health (Scotland) Act 1984, which was set up to update legislation in relation to changes in the 1990s, incorporating principles from other legislation such as the Human Rights Act 1998 and Disability Discrimination Act 1995. The Committee recognised that through the NHS and Community Care (Scotland) Act 1990, more people with mental impairment were being treated in the community. In the report *New Directions*, the main principles recommended by the Committee were the use of "least restrictive" measures, promoting user "autonomy and empowerment", having the "best interests" of the individual, "reciprocity" and "protecting from abuse and neglect" (Scottish Executive, 2001a:1.10).

Although the MHCT Act was intended to reform the procedures concerning detention under mental health law, the Millan Committee recognised there would be significant areas of overlap with the AWI (Scotland) Act, as in, some areas the AWI (Scotland) Act had replaced part of the Mental Health 1998 Act, particularly in relation to guardianship and management of patients' funds (1.25). Regarding significant areas of overlap, the report stated:

“Both Acts allow certain types of medical treatment to be administered without the consent of the patient and both Acts allow a third party to determine that the person will reside in a particular place, again without their consent. Both Acts contain special provisions for exceptional treatments” (Scottish Executive, 2001a:1.24).

Rather than the two Acts work against each other, the Committee recommended that there should be a “coherent framework” (1.26) and suggested that after the introduction of the MHCT Act (2003), consideration should be given to consolidate the two pieces of legislation (1.30). Furthermore, the Committee suggested that although the principles within the two Acts are not identical, the MHCT Act (2003) has been influenced by the principles within the AWI (Scotland) Act (2000) (1.28).

1.3 Adults with Incapacity (Scotland) Act (2000)

The title of the AWI (Scotland) Act was altered to reflect the aspect of *partial* incapacity as opposed to *total* incapacity, whereby a person will be able to continue to make some decisions affecting their lives, but not others (Scottish Executive, 1999a). This is based on a “functional approach” which looks at the specific situation that the person may encounter, or decision which the person has to make, and the extent to which the person’s capabilities meet the requirements involved in making the decision (Winick, 1995). Winick (1995) described it as “contextualised inquiry”, which infers that competence should not be seen as meaning the same thing in each context, but should be time and situation specific. This also indicates that, rather than using global assessment to assess cognitive abilities, assessments should be related to making specific decisions. Moreover, it presumes that the person has capacity unless a clear reason can be given to the contrary. In such circumstances the Act makes legal provisions for decisions to be taken for the person should they become incapable, but only in these specific aspects of their lives. For the purposes of the AWI (Scotland) Act "incapable" means incapable of:

- (a) Acting; or*
- (b) Making decisions; or*
- (c) Communicating decisions; or*
- (d) Understanding decisions; or*
- (e) Retaining the memory of decisions (AWI Act, 1.6)*

Moreover, the Act states that “incapacity” would be by reason of ‘mental disorder’ or an “inability to communicate because of physical disability” (1.7). The MHCT Act, rather than using the term “incapacity”, uses the term “significant impairment” of the person’s “ability to make decisions”. Concerning compulsory treatment orders the MHCT Act states that:

“because of the mental disorder the patient's ability to make decisions about the provision of such medical treatment is significantly impaired” (57.3d).

Furthermore, the Act states that treatment should either prevent the mental disorder worsening, alleviate the effects or symptoms of the disorder and that if the treatment were not provided there would be significant risk to “the health, safety or welfare of the person; or safety of any other person” (57.3 a, b, d). Unlike the AWI Act, the MHCT Act does not mention inability in relation to “communicating decisions”, which could specifically relate to people in the latter stages of dementia (Mitchel, 2003; Volicer et al., 2001). The AWI Act also indicates that effort should be made to communicate with the person “by any means of communication, whether human or mechanical” (1:4). Clearly, this infers that rather than attempt to make decisions for the person who appears to be lacking capacity in specific areas, effort should be made to present any information in a way that they understand, assisting the person to communicate their wishes, and thus improving capacity (Atkinson, 2001; Wong and Clare, 1999). Moreover, according to Atkinson:

“There is no individual or societal agreement about the balance between respecting the autonomy of the individual, protecting that individual from harm, or indeed,

protecting others from harm. This is reflected by the fact that legal standards for capacity vary” (2001:12.21).

This infers that in defining capacity a balance has to be struck between the rights to freedom of decision making and a right to protection from harm (Wilkinson, 2001). Moreover, since there are no standard measures of competency or decision making capacity that relate to legal standards, decisions can hinge on value judgements, usually by psychiatrists (Wilkinson, 2001; Moye, 2000; Marson et al., 1994). For example, Moye compared assessments of an individual with complex needs and found variance in assessments of competency. Moye further suggest that the variance was for many reasons, including potentially different life perspectives, values and cognitive processes between evaluators and patients. Similarly, Marson et al reviewed literature on concepts underlying competency and suggest that physicians frequently disagreed with each other in their assessments of competency, particularly for people in early and moderate stages of dementia. Furthermore, Marson et al suggest that the variance was contextual rather than an overall judgment of competency. It is noteworthy that there are several contexts in which capacity assessments can have an influence, including the interview setting, time of day and the presence of other parties, as well as the person’s anxiety or co-existing health complaints (Stokes, 2001). Indeed, it should be acknowledged that assessments can also take place in hospital settings where people with dementia are more likely to be disoriented (Jacques and Jackson, 2000). Moreover, perceived behaviour problems, such as agitation and aggression can be viewed as neurological in nature, when they may be related to psychological factors and environmental changes such as hospital admission (Morton, 1999; Steele et al., 1990).

Another factor which has to be considered is that assessments of capacity invariably take into consideration the accounts of others, especially close family members (Royal College of Psychiatrists, 2005a). However, several authors suggest that family members are more concerned with the person’s safety than the person’s expressed wishes to remain independent (Stevenson, 1999; Lawson, 1996; Carson, 1996). In such cases professionals may feel under pressure to remove the person to a place of safety for fear of

negligence should an incident take place (Titterton, 2005; Strachan and Tallant, 1997). Moreover, requests for assessment of incapacity can be precipitated by crises, with relatives pleading for respite or long term care for the person (Stokes, 2001). Whilst the Royal College of Psychiatrists recommended that assessments of capacity should be a continuous clinical process, frequently they will be one-off assessments, as in the case of hospital admissions, often depending on the emotive views of relatives (Royal College Psychiatrists, 2005a; Stokes, 2001).

The aforementioned aspects underpin the complexities of determining capacity and allude to the possibility that the voices of people with dementia can be lost in the process. This theme is further developed throughout the course of the literature review, in particular chapter three which explores the concept of empowerment. The remainder of the first part of this chapter continues to explore aspects of the AWI (Scotland) Act that pertain to people with dementia, at times drawing on the MHCT Act.

1.4 Mental disorder

Interestingly, both Acts use the term “mental disorder”, when referring to conditions to which the Acts pertain. According to the Millan Committee, the reason both Acts adopted this term as opposed to “mental health problems”, or “mental illness”, is because it makes no assumptions as to the cause or permanence of the disability and is not bound by any particular diagnosis classification. For the purpose of the Acts “mental disorder” encompasses: mental illness, learning disability and personality disorder (Scottish Executive, 2001a:4.2). It also covers dementia and acquired brain injury with associated mental symptoms (Scottish Executive, 2001a:4.27). This is interesting given that dementia is not classified as a mental illness as such, but as “organic brain disease” (Jacques and Jackson, 2000). It therefore can be classed as “mental disorder”, but not specifically as a “mental illness”. Indeed, the MHCT Act mentions “associated mental symptoms”. It is well documented that people with dementia can suffer “accompanying” mental health symptoms such as psychosis, depression and mania, the symptoms of which could be “treated or alleviated” in a hospital setting (Jacques and Jackson, 2000).

However, one area of concern relates to possible psychiatric hospital admission and treatment should a person with dementia be unable to give consent. The anomaly is whether such hospital admissions would be undertaken under the auspices of the AWI (Scotland) Act, in that, a welfare guardian along with nominated medical practitioner has the authority to make medical decisions in the person's "best interests", or detaining the person under the MHCT Act. For example, the AWI (Scotland) Act gives powers for a person to be admitted to hospital without their consent (Davidson, et al., 2004; Scottish Executive, 2001b: 2.51). If the person is clearly resistive or their past wishes have been very opposed to a particular form of treatment (e.g. Electro-convulsive Therapy) then consideration should be given to admission under MHCT (Gordon, 2004). However, there is no clarification with regards to degrees of resistiveness or the extent to which the person might have been "very opposed" to a particular form of treatment. Clearly, making decisions about the treatment of individuals concerning their treatment "is one of the more complex interfaces of both Acts" (Gordon, 2004:37.3).

Both Acts state that the views of others involved in the care of the person must be sought and their views considered when making decisions about the care or treatment of the person. The AWI (Scotland) Act specifically identifies the person's "nearest relatives", "primary carer" and "guardian of attorney with relevant powers" where it is "reasonable and practical to do so" (4b). The MHCT Act similarly states that the views of "any carer" of the patient, any "guardian", and "welfare attorney" should be considered. In addition it states the views of the "named person" should be considered, a new role which is not mentioned in the AWI (Scotland) Act. The following section considers the aforementioned roles.

1.5 Continuing and Welfare Power of Attorney

The AWI (Scotland) Act specifically addresses people with Alzheimer's disease and dementia as a group who could potentially lose capacity (Scottish Executive, 2004a Killeen et al., 2004a). It recommends that people who might experience future incapacity

should appoint a “continuing” Power of Attorney and welfare attorney (Killeen et al., 2004b). The concept of looking after “welfare” is a completely new aspect of the Power of Attorney in Scots Law. In a broad sense this includes all but the most sensitive of health and social care matters (Scottish Executive, 2001b). As highlighted in the previous section, placing someone in a mental hospital against the person's will would be one such issue (AWI Act, 14:5). The Act states that welfare attorneys have to be “individuals” whereas a body, such as a firm of solicitors, could be appointed as an attorney with financial responsibilities (Scottish Executive, 2001b).

Similar to the continuing power of attorney, the appointment of a welfare attorney is only valid if expressed in a written document which is subscribed to the granter and incorporates a statement which clearly expresses the person's intention to whom the welfare power applies (AWI Act, 2000:14). Clearly, this indicates that the granter should have a level of awareness and have the capacity to decide who would best represent their views should they lose insight and become incapacitated. A solicitor should assess the person's capacity to ascertain that they have an understanding of the implications of appointing an attorney. Whilst their assessment should hinge on the same aspects as highlighted in section 1.3, it should be highlighted that there can be conflicts between the legal and medical professions' definitions of capacity, which tend to hinge on their personal values judgments (Wilkinson, 2001; Marson et al., 1994). Moreover, there is a dearth in the literature concerning how much thought people with dementia give to appointing an attorney and the extent to which solicitors ascertain the person's level of understanding and choice (Weiler and Buckwalter, 1994).

Mason and Wilkinson (2002) in a study looking at the characteristics of people with dementia who are users and non users of the legal system, noted that a large proportion of people with dementia who had appointed a Power of Attorney had an increased awareness of legal issues through past experience of dementia or advice from friends or family, as opposed to professional advice. Regarding those who had not appointed a Power of Attorney, there was a presumption that their next of kin would be able to deal with legal and financial matters without formalising the arrangements. Moreover, those

who considered themselves not to have financial assets were less likely to formalise arrangements. Clearly, this indicates that more information and discussion is required at the time of diagnosis.

1.6 Nearest relative

The AWI (Scotland) Act states that the views of the “nearest relatives” should be taken into consideration (1:4) in any actions under the legislation. It also states that the “primary carer’s views” should also be taken into consideration, which acknowledges that the nearest relative might not be the main carer (Nolan et al., 1996). The primary carer is defined as “the person or organisation primarily engaged in caring for an adult” (AWI Act, 87:1). However, the MHCT Act does not include “organisations” or someone employed to look after the person, but refers to a person’s carer as “someone who provides on a regular basis a substantial amount of care and support to the person” (329:1).

The *Report on Incapable Adults* noted that carers and relatives should not assume to have automatic rights to make decisions for a person with incapacity (Scottish Executive, 1995). However, it is interesting to note that in a study carried out in an intensive care unit in a Glasgow Hospital, 88% of 100 relatives (next of kin) questioned believed that they could give consent on behalf of an incapacitated adult (Booth et al., 2004). Moreover, only 10% were aware of legislative changes related to the AWI (Scotland) Act. In addition, although only 13% had discussed life sustaining treatment with their relative, 84% thought that they could accurately reflect their wishes. Issues around surrogate decision are further explored in section 1.11.

1.7 Named person

Unlike the AWI (Scotland) Act, the MHCT Act creates a new role of a “named person”, who will be able to represent the person if they are being treated under the Act, although not whilst being treated informally, and will not necessarily be a family member (Scottish

Executive, 2004b). The “named person” will be nominated by the person whilst they have capacity to decide and understand the responsibilities of the role (Scottish Executive, 2005a). They will be entitled to act independently of each other (NHSed, 2005). If no individual is chosen by the person the “primary carer” will be appointed and in their absence (or if unwilling) the Mental Health Officer will have the responsibility to appoint someone, although not professionals involved in the person’s care (Scottish Executive, 2004c; Scottish Executive, 2004d).

Whilst there are some similarities with the role of the welfare attorney, there are two main differences. Firstly, although the named person is able to represent the interests of the person whilst they are detained or under a treatment order, they do not take the place of the person in the same way that a welfare attorney has the authority to make health and social care decisions for the person with incapacity (NHSed, 2005). Secondly, the named person has no legal status under the AWI (Scotland) Act, whereas the welfare attorney should be involved at various stages throughout the MHCT Act (Gordon, 2004). However, in reality, both welfare attorney and named person are likely, although not necessarily, to be the nearest relative or primary carer and the principles of both Acts incorporate consulting them (MHCT: 38.4; AWI Act: 87.1).

1.8 Advocacy

Under the MHCT Act anyone with a mental disorder whether receiving compulsory treatment or not, is entitled to receive an advocacy service. The role of independent advocates will be to give support and represent the person’s views, wishes and feelings (MHCT: 259). However, the role of the advocacy service differs from that of the “named person” in that the independent advocate will have no rights to receive information or make decisions about the person’s care or treatment (Scottish Executive, 2005a). Under the legislation Mental Health Officers and Health Authorities will have a duty to ensure advocacy services are available (MHCT: 259). Akin to this the Scottish Executive established the Advocacy Development Project which was established to support the NHS boards and local authorities in developing and implementing advocacy plans

(Scottish Executive, 2001c). In 2002 funding was granted for the Advocacy Safeguards Agency and the Scottish Independent Advocacy Alliance (Scottish Executive, 2002).

Although the AWI (Scotland) Act encourages advocacy to “stand alongside the adult to have his or her voice heard” (Scottish Executive, 2002:8), there is no similar legislation for an advocacy service within the AWI (Scotland) Act. However, the Sheriff may appoint a “safeguard” to look out for the interests of the person, which could include conveying the person’s views to the court (AWI; 3:4, 5). Gordon (2004) suggested that people subject to the AWI (Scotland) Act might benefit from increased access to advocates, and it might be appropriate to update the AWI (Scotland) Act guidance due to the increased prominence given to advocacy within the MHCT Act 2003. Eighteen months after the implementation of the Act a report by the Scottish Executive, stated:

“There is also little evidence of the use of independent advocacy to support the adult, which may reflect a lack of local knowledge about services or the patchy provision of such across Scotland” (Killeen et al., 2004b:6.16).

Clearly, the report highlights that advocacy was not being taken up by people with dementia or not being encouraged, due to lack of knowledge, and recognised the provision of services was “patchy”. Another report by the Scottish Executive (2005b) also recognised the lack of provision and specifically highlighted older people and people with dementia as groups who needed advocacy. The report recommended that services should be designed in a way that responds to need and that does not discriminate against people who fall outwith the 16 - 65 age range.

Several authors and organisations recognised that people with dementia are a vulnerable group who would benefit from advocacy (McDonald, 2004; Alzheimer’s Scotland – Action on Dementia, 2000; Counsel and Care, 1992; Philipson, 1990). According to Alzheimer’s Scotland – Action on Dementia, people with dementia need advocates for four key reasons:

1. They may be vulnerable to physical, emotional and financial abuse
2. They need support at times of transition when a major decision about their future care has to be reached
3. To ensure they receive their legal entitlements
4. To safeguard the quality of their care (Alzheimer's Scotland – Action on Dementia, 2000:4.1)

It also highlights that family members are not always the most appropriate people to offer advocacy. Indeed, at times, the role of an advocate is needed to represent the persons' views to their family (Brandon, 1995; Ivers, 1995; Rankin, 1989). Akin to this, Burton (1997) stated that one of the differences between guardians and advocates is that guardians can take powers to decide what are the "best interests" of the person - a paternalistic role, whereas advocates seek to learn what the person's wishes are and then facilitate them - an empowerment role.

Some professional groups, especially within nursing and social work, believe that they are in the best position to occupy the role of advocate, often viewing their position as mediating between the patient and medical staff (Mallik, 1997; Copp, 1988). However, whilst professionals and relatives often see themselves as advocates for people with dementia, some authors suggested that conflicts of interest can arise and their stance can become paternalistic (Burton, 1997; Brandon, 1995; Ivers, 1995; Rankin, 1989). Moreover, professionals may perceive independent advocates as threatening their role (Rankin, 1989).

One difficulty concerning advocating for people with dementia is that often the person is referred at a time of crisis, in the middle or later stage of the illness when communication and their level of understanding can be impaired (Burton, 1997). However, this should reiterate the importance of advocating for them, since the purpose of advocacy is to represent the views and interests of vulnerable people who risk social exclusion (O'Brien, 1984). Another difficulty may be that due to lack of insight into their condition the people with dementia might not feel they need an advocate and be unwilling to appoint

someone (Alzheimer's Scotland – Action on Dementia, 2000).

Some authors argued that advocacy is specialised and needed at “critical transitions” or specific periods throughout the person's illness, particularly when accessing services, problems of financial management, considering (or feeling pressurised) to enter residential care or hospital care, and to assist the person to express their views of the care they are receiving whilst in long term care or in hospital (Riddell and Pearson, 2005; Dunning, 1995; Phillipson, 1990). However, Russell (1994) warned that, especially within hospital settings, offering an advocacy service could be viewed as “fashionable”, giving “token support” rather than to genuinely empower.

Similarly, whilst the policy paper *Our National Health, A Plan for Action, A Plan for Change* (Scottish Executive, 2000b) required all Health Boards to ensure that independent advocacy was available to all patients by December 2001, a study looking at hospital policies in relation to cardiopulmonary resuscitation in 22 hospital Trusts noted there was little evidence of this taking place (Riddell and Pearson, 2005). The study, conducted in 2003, concluded that the Trusts needed to review their policies to ensure that staff were aware of patients' rights to advocacy and to ensure that advocates were available. Moreover, the possibility of a family member or friend acting as legal proxy was not routinely considered. Clearly this indicates that some Trusts give “token support” not only to advocacy, but also to encourage the appointment of surrogate decision makers (Russell, 1994).

The first part of this chapter explored how the legal system in Scotland is designed to promote autonomy and protection for people with dementia. It highlights that measures, such as appointing a welfare attorney, “named person” and advocates can fulfil such a function, especially when discussions take place with the person to ascertain their views. However, an underlying theme throughout the literature review is that, often, the voice of people with dementia can be lost and they can be disempowered through “value judgments” of professionals and relatives regarding what are in their “best interests”. This then is further developed in chapter three.

The remainder of this chapter examines provisions to include people with dementia in the decision making process and in particular the use of advance directives and statements to represent their views should they lose capacity to make decisions for themselves. It begins by highlighting the main principles of both Acts that should be considered at all stages throughout the legal process. It also highlights the difficulties in achieving this.

Part two

1.9 “Present and past wishes”

One of the main principles contained within both Acts that sets the theme for the proposed research is concerning “the present and past wishes and feelings” of the person (AWI 1; MHCT 3a). According to the AWI (Scotland) Act:

“A person proposing to do anything under the legislation must take into account the present and past wishes and feelings of the adult with incapacity, so far as these can be ascertained.”

This statement is directed to “anyone doing anything” under the legislation. However, it is interesting to note that the aforementioned study looking at policy guidelines relating to cardio pulmonary resuscitation within Health Care Trusts, notes that reference to AWI (Scotland) Act differed considerably across hospital Trusts (Riddell and Pearson, 2005). Whilst the duty to seek the “present and past wishes” is emphasised in some documents, over half of the 22 hospital Trusts had no reference to the legislation in their policies. Moreover, how views might be sought from people with communications difficulties was rarely mentioned.

It should be noted that seeking the “present and past wishes” of the adult with incapacity is not only the duty of professionals involved with the legislation such as legal, medical, nursing, mental health officers, but also relatives, carers, attorneys and the “named

person". Furthermore, carers and relatives have to give not only their own views regarding care and treatment, but should be able to express what they feel the person's past wishes would have been, in effect being a surrogate decision or proxy decision maker. The following section explores what this entails and some of the concerns about surrogate decision making.

1.10 Proxy or surrogate decision making

According to Tomlinson et al (1990) the standard required from the proxy decision-maker is for:

"the decision maker to attempt to make the same decision as the incompetent patient would make about his own care, from knowledge of that person's values and preferences" (1990:60).

Theoretically, the advantage of appointing a proxy decision-maker is that the proxy will act on the patient's welfare and act on the values of the person. Taking into account the *present and past wishes* of the person implies a high level of knowledge about the person's identity and values and an ability to empathise with them and represent their views. However, Tomlinson et al's (1990) study shows that close family members performed only slightly better in reflecting the elderly patient's interests than physicians. The study also compares close family members' substitute judgements, with a nominated decision-maker chosen by the patient. No significant difference was found between the two groups. High and Turner (1987) argue that elderly people choose a certain family member as a proxy because of "tacit understanding" between them. A person may therefore choose a specific family member to act on their behalf, but this does not guarantee accurate substitute decision making. Indeed, an individual may feel obliged to choose a spouse as a Power of Attorney, although another family member may well represent their values more accurately.

With regards to discrepancies between family members and the elderly patients, the

study, which was dealing with life and death situations, found that the types of error in substitute judgement tend to favour treatment over non-treatment. Thus, a family's substitute judgement is more likely to violate the person's wishes to reject treatment than it is to violate his or her desire to have treatment. They point out that this error may be more acceptable to the courts, although not to the patients who favour non-treatment.

Other studies have shown that, especially in relation to end of life decisions, there are discrepancies between what a person would choose for themselves and a surrogate decision maker would choose for them (Hare et al., 1992; Seckler et al., 1991; Zweibel and Cassel, 1989). Grossberg (1998) suggested that these difficulties can arise because of poor and inadequate communication prior to the progression of the illness. Moreover, conflicts of interests on the part of the surrogate decision-maker could arise. They point out that it is extremely difficult to choose what another person would choose in a critical medical situation, even with a good knowledge of the person's values, religious beliefs and lifestyle.

Pearlman (1994) pointed out that difficulties can often arise because proxy decision makers find it difficult to discuss the topics of incapacity and mortality openly with the relative before they become incapacitated. Moreover, there have been appellate court decisions related to proxy refusals of treatment, which have been premised on strong doubts about the family member's ability to render an accurate substitute judgement. Independent evidence of what the person's wishes were, would have been sought on such occasions (Rhodan, 1988).

As an alternative or adjunct to appointing a proxy, advance directives have been suggested as a way to represent a person's wishes should they become incapacitated (Fagerlin and Schneider 2004; Zronek et al., 1999; Docker, 1996). The following three parts of this chapter explore the advantages and disadvantages of completing a directive and how they pertain to people with dementia. Firstly, it discusses the legality of their use in Scotland.

1.11 Advance directives - legality in Scotland

The Law Commission's paper on Mental Incapacity (Scottish Executive, 1995) initially appeared to look favourably upon legislating for living wills and advance directives, recognizing that the law at that time was outdated and needed re-examining. However, in response to the recommendations, the government proposed in *Making the Right Moves* (Scottish Executive, 1999b) that due to the division of public opinion, it was not appropriate to legislate on advance directives. It was argued by those opposed to advance directives that there was not enough widespread support for their use, and that they tended to be backed by "special interest groups". One of the main concerns highlighted was that living wills could not cover all possible situations which might arise. Indeed, it was argued that, in some cases, advance directives could produce "unintended and undesirable results" (Scottish Executive, 1999a:6.14). Moreover, the report recommended that, rather than legislate further for their use, consideration should be given to the British Medical Association (BMA) *Code of Practice* (BMA, 1995) and guidance from "case law".

The British Medical Association, whilst "welcoming" the Government's recognition of its Code of Practice, stated they would have found it "helpful" to have limited legislation to translate common law into statute to clarify the non liability of doctors who act in accordance with the directives. Clarifying the legal position of advance directives in common law the BMA Code of Practice stated:

"Common law establishes that an informed refusal of treatment made in advance by an adult who understands the implications of that decision has the same legal power as a contemporaneous refusal. In order to be legally binding, the individual must have envisaged the type of situation which has subsequently arisen. In all circumstances, a contemporaneous decision by a competent individual overrides previously expressed statements by that person" (2003:4.1).

Similar to the AWI (Scotland) Act (2000) and the MHCT Act (2003), the BMA Code of Practice stated that practitioners must ascertain the *past and present wishes and feelings of the individual* (3.3). The code further stated that “carefully discussed” advance statements can have an “important place” in creating a more “balanced partnership” between patients and health staff (8.1). It also stated that an individual must have an “understanding of the implications” of their statement in relation to their choice of treatment or non-treatment and only then can “significance be attached to it” (8:1). Indeed, this is similar to the legislation within the AWI (Scotland) Act (2000) regarding a person appointing a welfare attorney or continuing power of attorney and the “named person” within the MHCT Act (2003), whereby the individual must demonstrate an awareness of the functions and role of the appointee. With regards to the validity of advance directives, many court cases have concentrated on the person’s capacity at the time when completing the advance directive and their level of understanding about the implications for the future (Treloar, 1999).

Whilst some authors recommended that all people should consider completing an advance directive (Knox, 2003; Kuczewski, 1994) others argued that it is more appropriate for a person to complete an advance directive if they have been diagnosed with a disease or disability (Jacobson et al., 1996; Schonwetter et al., 1995). This appears to be the stance taken by the BMA (2003a), stating that any diagnosis of life threatening illness or foreseeable deterioration of mental faculties should be “raised sensitively” by medical staff, and backed up with “support and information” so that people can plan ahead without being pushed into committing themselves to a particular course (6.3). However, advance directives are only one option which the person can consider, as well as generally making their thoughts known to the medical team and families and having their views recorded in medical notes (BMA/RC/RCN, 2001). Conversely, some opine that recording information in medical notes is open to objectification and depersonalisation of the person and may obscure their fundamental values (Polkinghorne, 1996).

Concerning the use of advance directives, people with dementia are often highlighted as a group who could benefit from them when they reach the terminal stage of the illness (Mitchel, 2003a; Grossberg, 1998; Dresser, 1995; BMA, 1995). This would allow them the opportunity to discuss all the implications of the disease and future treatment options with their doctor while they have capacity to make decisions (Mitchel, 2003a; Dresser, 1995). However, several authors pointed out that planning for future care requires a sophisticated understanding of the options of care and treatment with which even cognitively intact people can experience difficulties (Cohen-Mansfield et al., 2003; Silveira et al., 2000; Appelbaum and Grisso, 1995). The aspect of discussing the future with people with dementia is further explored in chapter two.

As highlighted in this section, there has been much debate about the use of advance directives over the years (Mitchel, 2003; Cohen-Mansfield, 2003; Grossberg, 1998). The following section explores this debate looking at the advantages and disadvantages of advance directives.

1.11b Advantages and disadvantages of advance directives

One of the main arguments put forward by those advocating advance directives is that the person will have autonomy over their life and death should they become incapacitated. This in turn can have positive psychological benefits, giving the person a degree of control and peace of mind regarding the future (Volicer et al., 2001, Rushton, 2001; Emanuel and Emanuel, 1992; Doukas and McCulloch, 1991). In some cases this can be precipitated by lack of trust or satisfaction with care received (Hauser et al., 1997), and in others through fear of developing a specific illness, such as dementia, or a fear of an undignified or prolonged death. A study by Schiff et al (2000) showed that developing dementia was the most feared disabling condition, in which the vast majority (78%) of elderly participants would not want active treatment in the latter stages. Moreover, Hiller et al (1995), in a vignette study ascertaining physicians' preferences regarding treatment options for chronic conditions, reported that dementia was consistently the condition in which most medical staff would not want to be resuscitated should they have a

myocardial infarction. Freeing family and health staff from the burden of having to make difficult decisions is also seen as a benefit (Docker, 1996).

The disadvantages of advance directives are well documented and include areas such as the person's views changing without them updating it to reflect the change, a person may also feel under pressure to complete the document to free their family from the burden of watching them suffer, a badly drafted advance directive can lead to confusion and result in the person being treated differently from the way they intended, they might not understand the implications of their advance statement, technology may change and new treatment options might not be reflected in their advance directive, documents can either be too detailed, not allowing for every eventuality or too vague, not giving any directions (Fagerlin and Schneider, 2004; Zronek et al., 1999; Docker, 1996).

Another aspect is that the person might not receive the outcome they desired, for example, the refusal of antibiotics for a chest infection could lead to a more stressful death as opposed to a "dignified" or peaceful death (Treloar, 1999). Akin to this Thompson (2003), in a small qualitative study in Glasgow, found that decisions made by health professionals about the "right thing to do" when confronted with a hypothetical advance directive applied to a critical care vignette, varied widely. The study found that participants differed in their interpretation of ambiguous phrases such as "life threatening" and "severe degenerative disease". The question of whether antibiotic treatment was palliative and therefore allowable under the terms of the advance directive was also ambiguous, with five of twelve interviewees favouring antibiotic treatment for the patient's pneumonia, whereas six opposed it. Finally, it can be argued that a person is unable to anticipate or envisage how they would feel if incapacitated (Berghmans, 1997; Dresser, 1995). This is further explored in chapter three.

Section 1.11 highlighted that some relatives find it difficult to differentiate between their own values and the person with incapacity (Hare et al., 1992; Seckler et al., 1991; Zweibel and Cassel, 1989). Moreover, it is noteworthy that doctors' values can range from those who believe in euthanasia to those who believe in the sanctity of life, which

can influence their perceptions of quality of life and the circumstances in which efforts should be made to prolong life (Riddell and Pearson, 2005). However, whereas in the past medical staff were relatively free to make clinical judgments on end of life issues, there is an increased emphasis on the rights of individuals to have the final say with regards to whether life sustaining treatment is carried out or not (Caron et al., 2005; Riddell and Pearson, 2005). The following section explores some of the issues concerning end of life decisions and hearing the voice of the person with dementia.

1.11c End of Life Decisions

As highlighted in section 1.11a, the Scottish Executive decided not to legislate for advance directives, indicating that to do so could “produce unintended and undesirable results in individual cases” (Scottish Parliament, 1999b:91). The report also mentioned “the withholding or withdrawal of treatment from patients who may be in a persistent vegetative state” alluding to the false assumption that advance directives are only related to withholding treatment. However, at times the opposite may be the case. For instance, it has been suggested that disabled people benefit from living wills to inform doctors that they want to be resuscitated in the event of cardiac arrest (Riddell and Pearson, 2005). This is due to concerns that systems used by health economists to prioritise patients for particular procedures, based on quality of life years, are biased against disabled people. Their argument is that the system could result in some doctors judging the lives of disabled people to be lower in quality than non disabled people, due to lower life expectancy (Disability Rights Commission, 2002). Indeed, there have been instances where some have written living wills to ensure that their wishes to have life supporting treatment are respected. In one recent case a terminally ill man, who feared that one day medical staff would stop feeding him, won a “landmark judgment” through the English courts for his living will and his wish for treatment to be respected (Dyer, 2004; Meikle, 2004).

Concerning end of life care, the code clarifies that although the law is not clear, people should not be able to instruct a refusal of ‘basic care’ (BMA 2003:2.3). Although the

code states that defining basic care is “problematic” it clarifies that “basic care” includes procedures which are essentially designed to keep an individual “comfortable” and generally includes aspects such as warmth, shelter, pain relief, management of distressing symptoms, such as breathlessness and vomiting, and hygiene measures, such as management of incontinence (2.3). The code also includes the administering of medicine which is “solely or primarily” designed to improve comfort or “alleviate the person's pain, symptoms or distress”.

Concerning nutrition and hydration, the code states that it should be “made available”, but not given to a person whose advance directive indicates opposition. It points out that close consideration should be paid to the person’s verbal and non verbal communication. Should the person indicate desire for nutrition, their current desire would supersede their advance directive. The code states that invasive measures such as tube feeding should not be instituted contrary to a clear advance refusal (BMA, 2003:2.3).

According to some, along with the use of antibiotics, enteral (or tube feeding) is one of the main issues involved in sustaining life in the terminal stage of dementia care (Mitchel, 2003b; Volicer et al., 1998; Zanetti and Bianchetti, 1996). Survival can be prolonged for up to six years (Peck et al., 1990). The Alzheimer’s Society in its response to the Joint Committee on the Draft Mental Capacity Bill stated that they had “serious concerns” about the frequency with which people in the terminal stages of dementia are artificially fed and hydrated by tube (Alzheimer’s Society, 2005a).

A study in Italy, by Zanetti and Bianchetti (1996), claimed that 73% of geriatric nurses, from a total of 232 nurses, felt it was appropriate to use enteral feeding to severely demented patients. It is interesting to compare this with a study by Low (2003) which showed that the majority of elderly people would not want their life sustained this way. The majority (38) of elderly participants felt it was appropriate to receive antibiotics in the latter stage of dementia, but only 12 from a total of 52 participants felt Percutaneous Endoscopic Gastroscopy (peg) feeding was appropriate.

Furthermore, a study by Mitchel (2003a) showed that there was an association between nursing homes with a lower prevalence of residents with advance directives and a greater use of tube feeding. Other studies report that the absence of living wills, do-not-resuscitate orders, and specific directives against artificial nutrition are associated with an increased likelihood of tube feeding (Ahronheim et al., 2001; Gessert et al., 2001). However, one cannot presume this would be the same in the UK, due to geographical variances in the use of advance directives and artificial nutrition in the latter stages of dementia. For example, research by Collins et al (1999) found that Scottish GPs questioned the status of advance directives, and did not consider that they should guide subsequent clinical decisions, whereas in the USA all federally funded health institutions have a duty to ascertain if patients have completed an advance directive and notify patients of their right to have one (Atkinson et al., 2003).

1.12 Advance statements

It is interesting that the Scottish Executive recommend that the person appointing a welfare attorney should be encouraged to “keep a note” of their views on how they would “hope to be cared for in the future, religious or spiritual matters and any particular difficulties in family relationships” (Scottish Executive, 2004e). Clearly, this indicates that whilst the person still has capacity and insight into their condition there should be in depth discussion and open dialogue about the future prognosis of the illness. However, they do not specifically recommend that the person with dementia should make an advance statement. This is in contrast to the MHCT Act (2003) which actively encourages the person with mental impairment to make an advance statement (275.1) and sets out legal measures to which the tribunals may refer. According to the Act the definition of an advance statement is:

“Advance statement: a written, witnessed document made when the patient is well, setting out how he or she would prefer to be treated (or not treated) if they were to become ill in the future” (Scottish Executive, 2004f:3).

It is noteworthy that the statement should be made when the *patient is well*. Unlike dementia which is a progressive illness (Jacques and Jackson, 2000) many mental illnesses fluctuate and are episodic (Kessing, 2004; Jibson and Tandon, 2002). Indeed, the guidance notes to the MHCT Act (2003) indicate that people who have experienced recurrent hospital admission will be in a better position to complete advance statements. Furthermore, the BMA Code of Conduct makes reference to a person with mental illness “regaining insight”, and then making an advance statement about their preferences and future treatment options. Adverse effects of medication and the person’s view on Electro-convulsive Therapy are two examples which could be recorded (7.5).

The concept of advance statements, within the legislation, has been broadly welcomed by mental health advocacy organisations such as the Manic Depressive Fellowship, National Schizophrenia Fellowship and MIND (Atkinson et al., 2003). Moreover, the National Institute of Clinical Excellence (NICE) and the Health Technology Board for Scotland have recommended their use in relation to antipsychotic drugs which can have marked side effects and the BMA strongly supports their use seeing them as a way of patients with mental health problems exercising autonomy’ (BMA, 2003b; NICE, 2002).

As highlighted, the AWI (Scotland) Act (2000) did not legislate for advance statements, which could have possibly benefited people with dementia. Indeed, it is possible that some people with dementia could have been prescribed psychiatric medication for illness such as depression and anxiety, before the onset of dementia and have clear views on future treatment (Cannon-Spoor, 2005; Heun et al., 2003). Moreover, chapter two highlights that insight and awareness can fluctuate and therefore some people with dementia could be in a position to complete them during lucid periods. Lewi-body dementia, for example, is characterised by the person having acute confusional states, followed by periods of lucidity and insight (Jacques and Jackson, 2000). It is interesting to note that the Alzheimer’s Society in their comments about the draft Mental Capacity Bill (England) stated that the Bill would be improved if its proposals were broadened to include advance statements and not just advance directives (Alzheimer’s Society, 2004). Furthermore, the Scottish Executive report comparing the two Acts suggests that, in view

of the MHCT Act legislation, advance statements are likely to become “good practice” and will “require revision” within the AWI (Scotland) Act (Gordon, 2004:3.6.4).

According to the BMA Code of Practice advance statements “can list the individual’s values as a basis for others to reach appropriate decisions” and can be “particularly helpful” in determining what is in the person’s best interests (2003:7.1). In a similar vein High (1994) suggested that one should “seriously consider” advance directives for people with dementia which include information other than preferences regarding where they would want to stay as the illness progresses. Knox (2003) also opined that including people’s values and personal information would have more impact with medical staff.

Atkinson et al (2003) note that the term “advance statement” and “advance directives” can have different connotations, both within the UK and internationally. Indeed, another term which is used in the MHCT Act is for a “personal statement” to accompany the advance statement. This does not have the same standing in law and does not need to be signed or witnessed. Aspects of the person’s life which are important to them, such as spiritual values, dietary needs, hobbies and family life are some of the examples given in the guidance to patients (Scottish Executive, 2004e).

Akin to this, several authors have discussed the benefits of biographical and life story work with people with dementia (Carlyle and Schofield 2004; Godwin, 2002; Winner 1996; Pietrukowicz and Johnston, 1991), the benefits of which will be explored in more detail in chapter three. Moreover, chapter two highlights that people with dementia are being diagnosed earlier and there is therefore the possibility to engage with them to complete advance and personal statements before they lose capacity (Ashley and Schofield, 2002; Winner, 1996).

Winner (1996) suggested that a partnership should be built with people with dementia from as early a stage of the disease as possible to establish the person's views and preferences. This early intervention and partnership approach would allow the practitioner to build a rapport with the person and to understand their communication

pattern (Ashley and Schofield, 2002). Winner (1996) further suggested that precise documentation and sharing of information regarding the person's views and their lifestyle choices and preferences. This would allow staff to see the whole person and build a profile or biography of the person which could form a future point of reference for the individual, their carers, relatives and professionals (Carlyle and Schofield 2004; Godwin, 2002). Winner (1996) continued that the record could be called up and pondered over when communication becomes impaired in later stages of the illness. Akin to this, one such approach discussed in the remainder of this chapter is the Values History (Thompson, 2003; Docker, 2000; Lambert et al., 1991; Gibson, 1990).

1.13 Values Histories

The Values History takes a goal base rather than a prescriptive approach, giving guidance on policy to be implemented, rather than specific instructions. It identifies core values and beliefs which are important to the individual (Thompson, 2003; Docker, 2000). It can be used either as an adjunct to the advance directive or an independent document, (Lambert et al., 1991; Gibson, 1990). The values are recorded as a basis for medical treatment, should the person lose capacity (Kolarik et al., 2002; Doukas and McCulloch, 1991). According to Doukas and McCulloch:

“The validity of Values History is based on a basic ethical consideration: the Values History enhances the autonomy of the patient in a way that advance directives do not, by clarifying for the health care team the patients expressed values, underlying decisions to be carried out when decision making by the patient is no longer possible.” (1991:124)

Similarly, Gibson (1990), although an advocate of advance directives opines that whereas advance directives deal with hypothetical situations which may not arise, the Values History deals with “who the individual is now”. He therefore suggested that the Values History should be completed to complement the advance directive, allowing health care professionals to know the underlying attitudes of the person, and thus empathise with

their situation. Schneiderman et al (1992) also asserted that an advance directive is based on treatment preferences, but does not elicit the state of health that the person would find acceptable. However, a Values History could enhance the autonomy of the person and allow clinicians to manage more reliably the uncertainties which surround advance directives. On the other hand, it could be argued that by being subject to interpretation by health care staff, it is open to “vagaries of acceptance and non acceptance” (Docker, 1996:198).

Others have argued that Values Histories can be used independently to describe, not necessarily the medical conditions with which they would not want to live, but the deep rooted beliefs which are important to them, addressing their goals, hopes and fears (Dickens, 1993; Keilstein and Sass, 1993). According to Keilstein and Sass:

“Since story based assessments do not provide ready made recipes for medical intervention, they challenge good clinical practice to integrate value assessment with medical assessment, and improved physician-patient interaction into ongoing stories of cure and care” (1993:313).

Dickens (1993) also argued the same point, but criticises advance directives for being too specific and detailed. He argued that the more detailed the advance directive, the more likely it is to vary from the events that actually occur. He opined that the Values History, on the other hand, allows the person to express themselves in their own terms and will be less off putting to those without medical or legal knowledge (Dickens, 1993).

According to Docker (1996) some of the preferences which could be documented within Values History include customary routines, preferred activities inside and outside the home, religious and spiritual values, personal privacy issues, preferences regarding use of medication, (possible trade off between minimising pain and maximising functioning), anticipated events or milestones, important events, preferences regarding involving or not involving family in indirect care, preferred characteristics and components of direct care providers, features related to a living environment, and preferences for who should be the

proxy decision maker, if needed.

Although Advance Directives and Values Histories were developed to enhance the autonomy of the terminally ill, some authors recognised that they should be developed for use other than life sustaining treatment (Docker, 1996; High, 1994). Akin to this, Kane and Degenholtz (1997) developed a Values Assessment to be used by care managers in a long-term care program in the USA. Unlike the aforementioned Values Histories, which are predominantly used in advance health planning for end of life decisions, the purpose of the values assessment is to pave the way for dialogue between professionals and patients regarding their long term care needs. To quote:

"The values assessment is done in recognition that long term care can rob recipients of their identity. So much attention is paid to getting practical services to clients that it is easy to forget the possible negative effects of arranging intimate services without reference to why the client holds important in actually living their lives" (Kane and Degenholtz, 1997:20).

According to Kane and Degenholtz (1997) the values assessments were completed by case managers as appendices to their traditional assessment for long-term care. Some of the care managers argued that values would automatically be elicited from a comprehensive assessment and did not require a separate appendix. They also worried that it could be construed as prying by the participant, as values and preferences could be considered too personal to share with a stranger. Kane and Degenholtz (1997) however, argued that care managers are asking intimate questions as part of their comprehensive assessment (i.e. continence, family relationships, physical and mental illness), so asking questions about values is not any more personal in nature. They also argued that by completing the assessment separately, it allows the participant to realise that their views are being listened to and viewed as important.

One of the main reservations expressed by the care managers, based on a feeling of impotence, was that they might not be able provide services in accordance with the

client's values and preferences. There was also a recognition that, at times, practitioners have to act in complete contrast to the participant's preferences, for example an emergency admission to a nursing home or hospital might have to take place, despite the person stating that they have an abhorrence to such an admission. In response Kane and Degenholtz (1997) pointed out that it does not make it easier for the person by not discussing their values. By paying attention to the person's values, they point out that it could make the professionals and carers more creative in planning care. Even when a decision has to be made in contrast to a stated value, other values can still be pursued.

Another reservation about the assessment was that people's values and preferences can change. Indeed, other authors argue that placing too much emphasis on previous values and biographical accounts devalues the person with dementia's current situation (Berghmans, 1997; Dresser, 1995; Parfit, 1984; Nagal, 1979). According to Berghmans it could be seen as a sign of "disrespect towards the interests and experience of the demented self" (1997: 285). Berghmans therefore indicates that the ideas, preferences, values and concerns of the person before the onset of dementia have no special relevance to how the 'demented self' ought to be treated. Furthermore, the onset of dementia has been described as the "birth" of a new person, indicating a new personality with different values (Parfit, 1984). On the other hand some warned that one must not misconstrue resignation to different values as a shift in values (Kane and Degenholtz, 1997). This is further explored in chapter three.

Proxy decision making is another area in which Values History can be beneficial (Kolarik et al., 2002; Lawrence et al., 2002; Pearlman, 1994). For example, Lawrence et al (2002) suggested that Values Histories can be used as a "structure" to facilitate discussions between families of HIV patients and professionals for end of life care. Pearlman (1994) put forward the argument that the channels of communication can be opened between the person and the surrogate decision maker, by discussing a profile of values. A study comparing the use of Values Histories with advance directives indicated that people with terminal illnesses had more confidence in their proxy decision maker representing their views, by giving them "a framework of goals through which to approach complex and

specific treatment decisions” (Kolarik et al., 2002:620). Similarly, Caron et al (2005) noted that advance directives and previous conversations between relatives and the person with dementia can be valuable and make proxy decision making easier for them when the individual loses capacity.

1.14 Summary

The first part of this chapter gives a broad outline of provisions within Scottish legislation which relate to people with dementia. However, whilst the process is designed to maximise the decision making capacity of people with dementia an underlying theme is that often the voice of people with dementia can be lost and they can be disempowered through “value judgments” of professionals and relatives regarding what are in their “best interests”. This is further explored in chapter three.

The second part of this chapter sets the theme for this research, which is to ascertain ways in which the “present and past” wishes of people with dementia are heard. It highlights some of the pros and cons of advance directives as one such way. It shows some of the complexities of the process, from the individual understanding the implications of their choices to professionals referring to them in relation to end of life decisions. However, the purpose of this research is to hear the voice of people with dementia, not just concerning end of life issues, but at the various stages through the journey of dementia, when the person may no longer be able to articulate their views. Moreover, this chapter discussed the possibility of advance statements, personal statements and, in particular, Values Histories as ways to record the preferences of people with dementia, allowing their values to be taken into consideration when decisions are being made in their best interests. This aspect is further developed in chapter three.

The following chapter discusses how medical advances in the treatment of Alzheimer’s disease have afforded professionals the opportunity to engage with people with dementia at an earlier stage of their illness and thereby offer individuals the opportunity to make future plans if they so wish.

Chapter 2

Medical Advances in the Treatment of Alzheimer's disease

- 2.1 Introduction**
- 2.2 Background and history of anti-dementia drugs**
- 2.3 NICE (2005) recommendations**
- 2.4 Memory clinics**
- 2.5 Early diagnosis**
- 2.6 Sharing the diagnosis**
- 2.7 Do professionals regularly share the diagnosis with people with dementia?**
- 2.8 Do families want the person with dementia to be informed of their diagnosis?**
- 2.9 Do people with dementia want to know their diagnosis?**
- 2.10 Is lack of insight an inevitable symptom of dementia?**
- 2.11 Psychosocial factors which influence awareness**
- 2.12 Denial - a coping mechanism which influences awareness**
- 2.13 Does lack of information influence unawareness?**
- 2.14 Do people with dementia want to plan future care?**
- 2.15 Summary**

2.1 Introduction

This chapter explores the introduction of medication indicated in the treatment of Alzheimer's disease which has precipitated a possible change in culture, opening the door to engage with people with dementia about their future health and social care planning.

The chapter begins by looking at the history of anti-dementia treatments and how they have precipitated early and accurate diagnosis of dementia. It then highlights the growth of memory clinics, specialised clinics and support for people diagnosed in the early stages of dementia and explores the issue of sharing the diagnosis with people with dementia and the prognosis of the illness. The chapter then concludes by exploring the issues around engaging with people with dementia to discuss future health care planning.

2.2 Background and history of anti-dementia drugs

In 1997 the first anti-cholinesterase to be licensed in the UK was Aricept (Donepezil), which was indicated for the treatment of “mild to moderate Alzheimer’s disease” (Roger et al., 1998; Corey-Bloom et al., 1998; BNF, 1997). However, two key areas of concern were expressed about the drugs, notably, their efficacy and the cost implications.

With regards to their efficacy, several studies indicated that approximately 40% of sufferers prescribed the cholinesterase inhibitors demonstrated an improvement in their cognitive abilities or experienced no cognitive deterioration over a six month period (Corey-Bloom et al., 1998; Rodger and Freedhoff, 1996). The changes seen with those prescribed the medication varied greatly between no noticeable improvements to significant improvements (Denning and Lawton, 1998). However, it should be noted that many of the studies were funded by drug companies and therefore their findings were questioned by the NICE (2005), which is explored in section 2.3.

Concerning cost implications, the first of these drugs cost approximately £1000 per year per person with potentially 500,000 eligible for prescription (Burns et al., 1999). There was also the additional expense of secondary services such as psychiatric consultations and diagnostic testing. Furthermore, there were no guidelines regarding when the drugs would be considered ineffective, as the people with Alzheimer’s disease would inevitably deteriorate whilst taking the medication (Harvey, 1999). A study funded by Glaxo Wellcome Research and Development concluded that the cost of care for a person with Alzheimer’s disease was directly linked to the severity of the illness: the more severe the disease, the higher the cost (Soueter et al., 1999). The implications, therefore, were that keeping people functioning at a higher level for a longer period of time would reduce social care costs and also delay expensive institutional care. However, their conclusions were also questioned by the NICE (2005), which is explored in section 2.4.

In 1998 the Standing Medical Advisory Council (1998) (SMAC) issued guidelines which recommended that a strict inclusion and exclusion criteria should be adopted, similar to procedures for drug trials (SMAC, 1998). Moreover, in 2001, NICE instructed that the drugs should only be prescribed after a person had been assessed and diagnosed as having Alzheimer's disease "in a specialist clinic" by either a psychiatrist, geriatrician or neurologist (1.1.2). Thereafter, the person should be assessed between two and four months after reaching the maintenance dose and only continue on treatment if there had been an improvement or no deterioration on Mini Mental State Examination (MMSE) score (Folstein et al., 1975), together with an improvement on the basis of a functional assessment (NICE, 2001:1.5).

These recommendations underpinned a change in practice whereby people with dementia required an accurate diagnosis, preferably in the early stages of dementia to benefit from the medication (Passmore and Craig, 2004; Warner, 2003; Philips and O'Brien, 2002; Jha et al., 2001; Gilliard et al., 1998). The recommendations were welcomed by most professional bodies and advocacy organizations caring for people with dementia (Royal College of Psychiatrists, 2001; HTSB, 2001). These changes in practice are the driving force behind this research, particularly in relation to a "gateway" being opened to engage with people in the early stages of dementia, and will be further discussed in the second part of this chapter. The following section considers the draft NICE (2005) recommendations, which could potentially undo some of these positive changes.

2.3 NICE (2005) recommendations

Whilst in January 2001 NICE recommended that the three drugs Donepezil, Rivastigmine and Galantamine should be made available on the NHS to help in the management of those people with mild and moderate Alzheimer's disease, in 2005 NICE, in their Appraisal Consultation Document based on the recommendations of Southampton Health Technology Assessment Centre (SHTAC), retracted its previous guidance and recommend that the drugs should not be prescribed on the NHS (NICE, 2005:1.1). Regarding the guidance they stated:

“The main purpose of the review was to compare the evidence of clinical effectiveness of treatment with cost effectiveness of the drugs and the ‘efficient use of NHS resources” (4.31).

They considered a range of published and unpublished trials including data from the AD2000 study group, as well as submissions from drug manufacturers and professional and support organizations, when developing the draft guidelines. However, NICE (2005) stated that many of the randomized controlled trials reviewed were of "mixed" quality. The group also suspected “selection bias”, “measurement bias” and “attrition bias” in a number of the reviewed studies.

Concerning the cost effectiveness of the drugs, NICE (2005) claimed that there was little evidence of financial savings from delayed institutional care. They based their cost effectiveness findings on the QALY (Quality Adjusted Life Years) and estimated that Donepezil, Rivastigmine, and Galantamine had a cost per quality adjusted life year gained of £48000, £32000, and £38000 respectively. Furthermore, they stated that if their proposals were adopted, the NHS could save £15 million in the first year, £45m in the second, and more than £60million in the third.

The proposals received widespread criticism from dementia advocacy groups and professional bodies. Alzheimer’s disease advocacy groups stated they were ‘stunned’ by the recommendations which they considered ‘drastic’ and vowed to campaign to have the drugs made available on the NHS (Alzheimer’s Society, 2005b; Alzheimer’s Scotland – Action on Dementia, 2005d). Whilst there were several criticisms of the NICE draft guidelines this section examines three which are pertinent to this research.

Firstly, the emphasis which the committee placed on the QALY in the ‘cost benefit analyses’ of prescribing the drugs is strongly dependent upon proxies or carers responding on behalf of the person with dementia. It should be noted that chapter one of this research highlighted that many studies have shown major inconsistencies and

disagreements with very poor correlations between proxies (Hare et al., 1992; Seckler et al., 1991; Zweibel and Cassel, 1989). This was also pointed out by several organizations who criticized the usage of the QALY (Royal College of Psychiatrists, 2005b; Alzheimer's Scotland - Action on Dementia, 2005d). The College further added that it was 'unacceptable and totally inappropriate' to use the QALY as it "made a variety of unknown and untested assumptions about how quality of life relates to dementia severity" (Royal College of Psychiatrists, 2005b). Similarly, this review has shown that the opinions of people with dementia have often been omitted from research, but their views and perspectives can be obtained through qualitative interviews conducted by skilled researchers who have an awareness of skills needed to elicit their views (Wilkinson, 2002).

Furthermore, the College recommended the need for development of a specially designed "quality of life" assessment which could include the views of the people with dementia, possibly including aspects of personhood and care mapping (Kitwood, 1997). It is interesting to note that the MRC Health Service Collaboration was awarded £8 million to look at disease specific measures of health quality of life, with one of its major projects being to validate such measures for older people.

Secondly, it was argued that NICE did not take sufficient account of the benefits experienced by those people with Alzheimer's disease who have responded positively to treatment (Royal College of Psychiatrists, 2005b; Alzheimer's Scotland - Action on Dementia, 2005d). It should be noted that the Committee recognised that a small minority of people were observed to "benefit significantly" (NICE, 2005:4.3.6) from the medication. However, the draft guidelines did not recommend widespread use for the "few" who might benefit. This has major implications for those who could benefit from the medication and an increased quality of life, but will be deprived of this opportunity. Moreover, such ones could potentially be in a better position to make provision for the future.

It is noteworthy that when NICE calculated their statistics in relation to the 'average' cognitive improvement in Alzheimer patients they included those who tried medication but did not respond to it. According to the Royal College of Psychiatrists, the statistics used were not in keeping with clinical practice, and if non-responders are included in the statistics then the mean ADAScog improvement is around 3 points with a natural deterioration delayed by 6 months. If the non-responders are removed from the statistics the mean ADAScog improvement is 4-5, which results in a 9-12 month naturalistic deterioration. This therefore indicates that a large group of people with Alzheimer's disease could have up to one years improved cognition and the opportunity to make health plans for the future if they so wish (Passmore and Craig, 2004; Warner, 2003; Gilliard et al., 1998).

The final concern relates to the additional benefits that the medication has brought to people with dementia, in particular, improvements in practice. This is particularly pertinent to this thesis as the secondary benefits of the medication include engaging with people in the early stages of dementia to offer support and discuss their views about future planning. It is noteworthy that the College, in their response to NICE (2005), pointed out that, as well as "pure science", they should take into account the 'wider societal perspective': the way people with dementia are valued and viewed by society. Furthermore they suggested that medication has given patients and carers 'hope' for a terminal disease for which there is no cure (Royal College of Psychiatrists, 2005b). It could also be argued that by giving "hope" to individuals with dementia, some professionals no longer feel impotent and are more likely to engage with them at an earlier stage in their illness (Wilkinson et al., 2002).

Several responses to the NICE (2005) recommendations point out that dementia care could be set back by a decade if the recommendations go ahead. They also pointed out that since the inception of medication for dementia, it has "transformed the management" of dementia care. According to Alzheimer's Scotland - Action on Dementia:

“There has been a positive change in attitudes about how people with dementia should be treated. If the NICE recommendations are acted upon in Scotland, they could take us back to a time when people with dementia and their families were ignored and left to cope as best they could” (2005d:3).

Both professional groups and dementia advocacy groups suggest that there have been “positive changes” and much wider benefits for patients and their carers since the inception of medication for Alzheimer’s disease. The NICE (2005) report also referred to this by specifically mentioning the expansion of memory clinics and other specialized services offering early diagnosis, advice and support for people with dementia and their carers, which they considered ‘worthwhile’ and would hope to continue despite their recommendations (NICE, 2005:6.4)

The driving force behind this research is related to these changes in clinical practice. The remainder of this chapter looks at another two of the changes which have taken place in relation to the inception of cholinesterase inhibitors; the expansion of memory clinics in the UK and possible changes in practice related to cholinesterase inhibitors.

2.4 Memory clinics

Memory clinics began in the 1970s in the USA as part of academic research initiatives looking at Alzheimer’s disease, often for drug trials (Beese, 2000). The first memory clinic set up in the UK was in 1983. Primarily they were set up to gather information for research purposes, although possibly not to the same extent as in the USA. Initially they were criticized for being medically oriented, offering little in the way of social support (Cheston and Bender, 1999). However recent literature indicates newer clinics tend to operate on a multidisciplinary model, involving assessment, investigation and information giving (Philips and O’Brien, 2002; Corey-Bloom et al., 1998).

There is a general acknowledgment that the number of memory clinics has substantially increased in the UK and the inception of cholinesterase inhibitors has been one of the main factors in this growth (Royal College of Psychiatrists, 2005b; Lindesay et al., 2002).

A survey carried out by Lindesay et al (2002) shows that from 1993 to 2000 the prevalence of memory clinics in the UK had increased from 20 to at least 58. Although the survey indicates a clear increase in clinics, questionnaires were only sent out to specific areas, as recommended by organizations such as the College of Old Age Psychiatrists' Directory of Dementia Care Service, where there was the possibility that memory clinics were established. The survey showed that approximately 50% of the new clinics had been set up after 1997, which was when cognitive enhancers were licensed in the UK. Of those surveyed, 39% stated they had set up the clinics specifically to initiate and monitor the treatment of Alzheimer's disease. It can therefore be presumed the number is much higher and has continued to grow since the survey was carried out, especially since NICE 2001 (Passmore and Craig, 2004).

Whilst memory clinics have been criticized for being medically oriented (Cheston and Bender, 1999), the literature suggests that unlike the earlier memory clinics which seemed to focus on drug research and information gathering, newer clinics tend to operate on a multidisciplinary model involving assessment, investigation and information giving (Philips and O'Brien, 2002; Corey-Bloom et al., 1998). They differ however in specialties, the exact protocol applied, the time spent on assessment and advice offered (Hout, et al., 2001). For example, according to Lindesay et al (2002), the initial assessment visit can vary from one to seven hours. Moreover, whilst some only take direct referrals from within the NHS, other clinics tend to focus on a self-referral basis (Mullins and Fitch, 2000).

One of the main areas relevant to this research is the aspect of advice and support following diagnosis. Some clinics offer support and counselling as part of their service, others refer on to other agencies (Lindesay et al., 2002; Moniz-Cook and Woods, 1997). According to Lindesay et al, approximately half of the clinics offered memory retraining and anxiety management within their clinics and a small number offered psycho-social educational programmes, but these were more often aimed at caregivers and relatives. Some also offered pre-diagnostic counselling, support groups, psychotherapy and

cognitive behavioural therapy. Moreover, 33% of clinics routinely followed up all their patients, with the remainder following up only uncertain cases or selected diagnostic cases (Lindsay et al., 2002). This therefore indicates a wide variance in the level of support given to people newly diagnosed with dementia.

Akin to this, Philips and O'Brien (2002:1131) discuss Clinical Governance in relation to memory clinics and highlight the value of "non pharmacological aspects of care", such as advice on legal issues, finances, driving, carer stress and counselling. They also suggested that the monitoring and auditing of 'pathways of care' and suggest the memory clinics should be the start of a 'seamless service that integrates into existing community services'.

Another area which they suggest could benefit from the Clinical Governance framework is the process of diagnosing and sharing the information with people newly diagnosed as having dementia. They recommended that a multidisciplinary and holistic approach should be used and written information about tests and procedures should be given. Regarding the sharing of information with the person with dementia, Philips and O'Brien stated:

"The extent to which diagnostic information is available to them should be negotiated individually and sensitively in response to their wishes" (2002:1131).

This therefore indicates that before a diagnosis is made, an open dialogue should be established to ascertain how much or little information the person with possible dementia would want to have. The remainder of this chapter therefore explores the extent to which diagnostic information is shared with people with dementia.

2.5 Early diagnosis

As highlighted, with the introduction of the cholinesterase inhibitors, it is crucial that people with Alzheimer's disease receive an accurate diagnosis, rather than a vague

diagnosis of “dementia syndrome” or “memory problems” (NICE, 2001; Harvey, 1999; Lovestone, 1998). The literature appears to indicate that clinicians are diagnosing people with dementia earlier and with more accuracy, particularly since the inception of cholinesterase inhibitors (Passmore and Craig, 2004; Warner, 2003; Philips and O’Brien, 2002; Jha et al., 2001; Gilliard et al., 1998). According to Warner:

“Early treatment with cholinesterase inhibitors may confer greater benefit than delayed treatment and provides the patient and family with a longer lucid time to make plans, do the undone, discuss treatments, and come to terms with the diagnosis” (2003:413).

Furthermore, Warner also stated that there could be a case for highlighting people who are at risk of developing dementia before it is diagnosed with a view to start treatment as early as possible. He reported that some people will pass through a stage of “pre-dementia” stage, also referred to as ‘questionable dementia’ or ‘possible dementia’. Mild cognitive impairment, benign senescent forgetfulness and age associated memory impairment are other, subtly different, re-workings of the same phenomenon which could be early predators of dementia. This is in contrast to a decade ago when several studies indicated that there was reluctance on the part of GPs to pursue early intervention and diagnosis of dementia, partly due to a nihilistic attitude and no available treatment options (Lovestone, 1998).

As well as receiving an accurate diagnosis, there is the possibility that people attending memory clinics are being diagnosed up to two years earlier, are younger and are less cognitively impaired than those attending traditional Old Age Psychiatry Services (Luce et al., 2001; Mullins and Fitch, 2000). This is an important factor as it indicates that those being diagnosed earlier will have better judgment, less memory impairment and there is more scope for them to make future plans if they so wish (Passmore and Craig, 2004; Warner, 2003; Philips and O’Brien, 2002).

There are three possible reasons why people worried about their memory are more likely

to attend a memory clinic, resulting in an earlier diagnosis. Firstly, it has been suggested that “memory clinics” appear more socially acceptable than “psycho-geriatric services” or “psychiatric services” and the name itself can encourage people in the early stages of dementia to visit (Beese, 2000). Secondly, there is the possibility that if it has a self-referral system then it is more likely to attract people with mild cognitive impairment, who will subsequently receive an earlier diagnosis (Mullins and Fitch, 2000). It should be noted however, that many people attending memory clinics, who are worried about possible dementia, will have treatable conditions, such as depression and anxiety. In the case of one clinic, approximately 25% of attendees were diagnosed with depression (Mullins and Fitch, 2000). Thirdly, with the introduction of medication for Alzheimer’s disease there is a realization that treatment can slow down progression of the disease and give individuals more hope for the future (Royal College of Psychiatrists, 2005b).

As well as a reluctance to pursue diagnosis, there has been much debate over the years about the appropriateness of sharing the diagnosis with the individual concerned (Meyers, 1997; Rice et al., 1997). It should be noted that engaging people with dementia to discuss future health care planning hinges on them being aware of the diagnosis. The following section explores the main issues concerned with sharing the diagnosis.

2.6 Sharing the Diagnosis

Sharing the diagnosis of dementia has often been compared to the reluctance to share the diagnosis with cancer sufferers in the past, particularly when no treatment options were available (Fearnley et al., 1997; Emmanuel and Kass, 1993). Rather than consulting the carer to decide whether to disclose the diagnosis to the person, some argue that, following the principles of any other illness or medical information, it should be the sufferer who is informed in the first instance of the diagnosis and their permission sought to inform their relatives (Fearnley et al., 1997). However, when giving a diagnosis of dementia, there is not only the aspect that it is a progressive degenerative terminal disease, but it can also reduce their understanding, ability to remember, make judgments and have insight into their condition, which further adds to the debate (Pinner and Bouman, 2003a). Fear of

causing distress or reducing hope or motivation are some possible reasons for practitioners' reluctance to share the diagnosis. Fear of causing detrimental outcomes such as depression, anxiety and catastrophic reactions, such as suicide, (Cutliff and Milton, 1996; Maguire et al., 1996) are other factors that may instill reluctance to share the diagnosis.

The review of literature does not find any major evidence to substantiate claims that sharing a diagnosis with the person with dementia will exacerbate depression or suicide, more than disclosing other illnesses or diseases in the general population (Slinn et al., 2000; Cutliff and Milton, 1996; Holroyd et al., 1996). Although there is an increased prevalence of depression among people with dementia, it is often associated with the disease process, and losses experienced, and is not related to whether the diagnosis is shared or not (Huin et al., 2003; Maguire et al., 1996).

A study by Bachman et al (2000) found that, upon hearing their diagnosis, only 5.1% were described by their relatives as 'very upset' and a further 25.7% as "a little upset". Another study, by Jha et al (2001), which compared sharing the diagnosis of depression with that of dementia, found that people diagnosed with depression as well as dementia were significantly more upset upon receiving their diagnosis. This therefore indicates that depression should be considered as a factor before disclosure, and possibly treated before the diagnosis is shared.

Akin to this, Maguire et al (1996), opined that the risk of suicide should seriously considered, especially for those people who have a higher than normal degree of insight. However, he clarified that the risk of suicide should be seriously considered after the disclosure of any progressive disease. Moreover, Meyers (1997) acknowledged that people with dementia will initially be shocked after the disclosure of the diagnosis, but opines that they will not experience any long lasting effects from sharing the diagnosis with them. Whilst people with dementia are bound to be upset, as is the case with "breaking the bad news" of any terminal illness or degenerative illness, there appears to be no evidence of any long-term psychological damage (Bahro et al., 1995).

The remainder of this chapter explores the attitudes of professionals and relatives concerning disclosing the diagnosis. It is generally accepted that until the 1990s there was reluctance amongst professionals and family members to share the diagnosis with people with dementia. This section highlights that over the past decade there has been a change in attitude, although improvements are still required, particularly regarding the level of information given to people with dementia.

2.7 Do professionals regularly share the diagnosis with people with dementia?

Most surveys regarding sharing diagnoses with people with dementia tend to pre-date the NICE (2001) recommendations. For example, in Scotland a national survey of NHS psychiatrists found that less than half of those returning questionnaires made it their practice to inform patients of their diagnosis (Clafferty et al., 1998). A review of practice arrangements at memory clinics in the UK found that diagnosis was normally relayed to the carer and thereafter left to the carer's discretion to tell the person with dementia (Wright and Lindesay, 1995). However, a survey carried out in 2000 reported that 96% of 56 memory clinics routinely fed back results of initial assessments to patients, although only 55% had an explicit policy for doing so (Lindesay et al., 2002). This appears to indicate a major change in attitudes regarding sharing information with people with dementia. The survey however, did not clarify what information was given to people with dementia or exact details of how the diagnosis of dementia was relayed. Also anecdotal comments from a variety of authors indicate that since the inception of cholinesterase inhibitors and particularly the NICE (2001) report's validation of them, psychiatrists are more likely to share the diagnosis with people with dementia (Pinner and Bouman, 2003b; Warner, 2003; Philips and O'Brien, 2002).

Regarding GPs, there has been less evidence that they are more likely to share the diagnosis with people with dementia (Downs et al., 2002; Fortinsky et al., 1995). For example, the Scottish study by Downs et al, examined what GPs told people with dementia and their families about the illness. Of the 114 questioned, 99% said they

informed the person with dementia's family of the diagnosis, but only 55% told the person with dementia. Those who claimed to disclose the diagnosis tended to be younger. It should be noted that the GPs surveyed were attending a dementia awareness event and therefore possibly had an interest in dementia and did not necessarily reflect the opinions of all Scottish GPs.

It is interesting to note that of the 55% who claimed to disclose the diagnosis, more than a third used euphemistic terms, such as "memory problems" or "confusion". This is interesting, in that one could argue that they were, in fact, not sharing the diagnosis with the person, although they claimed that they were disclosing the diagnosis (Lovestone, 1998).

The same study showed that almost all the GPs gave the families more information than the people with dementia and were more likely to use medical terms and discuss the prognosis with the families. There was also a tendency to "normalize" the experiences of the person, "protecting" them from potentially frightening information, painting a more positive picture than they would give to the families. This is similar to a study involving Community Psychiatric Nurses, the majority of whom were reticent to give information which could upset the person or cause them "harm" (Keightley and Mitchel, 2004). This is an important aspect of the literature review as this attitude could be viewed as disempowering people diagnosed with dementia, by depriving them of the opportunity to receive accurate information to make plans or, more importantly, to have the choice to make plans (Mason and Wilkinson, 2002; Fitzsimmons and Fuller, 2001; Wilkinson, 2001).

However, some GPs stated that they would tailor the information to the person's level of insight and understanding of the condition. This appears to be the approach suggested in the literature; in that practitioners should attempt to find out how much the person is aware of their deficits, their knowledge of the illness and how much information they would want (Lingard, 2002; Lovestone, 1998; Fearnley et al., 1997). Furthermore, it is suggested that, prior to a diagnosis being made, the person should be aware of the reasons

for referral, explanation as to the process of establishing a diagnosis, their permission to have a relative present and to ascertain, through gentle probing, whether the person wants to know their diagnosis. Whilst people with dementia have a right to know their diagnosis they also have a right 'not to know' (Lovestone, 1998; Fearnley et al., 1997). Moreover, written information should be made available, such as details of counselling and support groups (Husband, 1999; Yale, 1998; Goldsmith, 1996).

This section highlights the general change in attitudes regarding sharing the diagnosis with people with dementia amongst psychiatrists, and to a lesser extent amongst GPs. However, there is dearth of literature concerning the information that is given to them. It is also noteworthy that some in the medical profession have felt under pressure from individuals' families not to share the diagnosis (Lovestone, 1998; Fearnley et al., 1997). One of the main questions underpinning the position of family members centres on their role in the process of diagnosis. The following section shows that there is possibly a change in trend and more families are recognizing the person's right to know their diagnosis.

2.8 Do families want the person to be informed of their diagnosis?

A survey of carers' attitudes towards disclosure found that 83% of relatives of patients recently diagnosed did not want the patient to be told. Conversely, the majority of relatives would wish to know if they developed the condition (Maguire et al., 1996). Maguire et al commented that the inconsistency may reflect a desire to protect the patient from the reality of the condition or reluctance of the relatives to deal with the patient's knowledge and grief.

The study by Maguire et al is often cited in literature to highlight the overprotective attitudes of carers who desire the person to be shielded from the truth (Pinner and Bouman, 2003b; Fearnley et al., 1997). However, recent literature indicates that there is an increased awareness from family members that the diagnosis should be shared with the person (Dautzenberg et al., 2003; Holroyd et al., 2002).

Dautzenberg et al conducted a questionnaire survey of fifty carers and relatives of people attending a memory clinic in Holland. Of the forty six who completed the survey, 100% of spouses and 96% of non spouses felt it was right for the person to be informed of their diagnosis. Similarly, Holroyd et al (2002) conducted a telephone survey, in Virginia, USA, of 57 relatives of people who had recently been diagnosed with dementia. They reported that 71% of family members felt it was appropriate for the person to know. It is interesting that the majority of participants did not feel that sharing made any significant difference to their relatives, however they considered it “right” that they should be informed, possibly indicating a shift in societal values regarding sharing. Moreover, a study of fifty relatives of people attending memory clinic in Nottingham found that 92% expressed the wish for the person to be informed (Pinner and Bouman, 2003b). These studies are considerably more positive than the study by Maguire et al (1996) and indicate a reversal of opinion to that previously reported.

It is interesting to note that a British study by Fahy et al (2003) found that only 54% of carers would want the person with dementia to know their diagnosis. Although this seems relatively low compared to the other three studies, an important finding was that the more confused the person with dementia was (as per MMSE lower than 17), the less likely families would want the person to know. The study concluded that the earlier the diagnosis is made, families would be more likely to want the diagnosis shared with the person. This is particularly relevant as the driving force behind this research is to engage people in the early stages of dementia to discuss planning for the future, which involves them receiving a diagnosis.

Until recently, most research focused on the perceptions of carers and professionals and whether the diagnosis should be shared with people with dementia. The following section concentrates on the views of people with dementia. To begin with it shows that the vast majority of people with dementia would rather be informed of their diagnosis and thereafter it explores some individuals’ experiences of being told.

2.9 Do people with dementia want to know their diagnosis?

As highlighted, the literature appears to suggest that the vast majority of people with dementia feel that they should be informed of their diagnosis. For example, the aforementioned study of fifty people with dementia attending a memory clinic in Nottingham found that 92% of patients wanted their diagnosis disclosed, whilst another study of patients attending a memory clinic in Holland found that 96% of patients would rather be told their diagnosis (Pinner and Bouman, 2003b; Dautzenberg et al., 2003). These studies help validate the literature which suggests that people have a right to know their diagnosis (Fearnley et al., 1997; Emmanuel and Kass, 1993). Furthermore, there has been some qualitative research exploring the experiences of people with dementia, including the aspect of hearing about their diagnosis (Wilkinson et al., 2002; Husband, 1999; Gilliard, 1995).

Gilliard (1995) interviewed nine people with dementia and suggested that by knowing their diagnosis they were less troubled by their symptoms and it allowed them to make sense of what was happening to them. Husband (1999) interviewed three people with dementia and also reported that giving the diagnosis could allay patients' fears of "going mad" or "being stupid" if it is seen in the context of a physiologic illness rather than negative personality characteristics. Wilkinson et al (2002) interviewed twenty four people who were aware of their diagnosis and found similar patterns. They report that although many initially experienced shock, fear, anger and depression, many then went on to feel a sense of relief and validation for their memory difficulties and behaviour. Many also felt that the diagnosis allowed them the opportunity to develop memory aids and prompts, and deal with financial and legal matters. Being able to make the most of their time and abilities remaining were also expressed by some.

Limitations of knowing the diagnosis expressed by those informed of their diagnosis tended not to outweigh the opportunities of knowing. Some reported an increased awareness of their limitations and activities of daily living, a lack of confidence, partly caused by how they felt they would be viewed by others. Akin to this, Husband (1999)

reported that the effect of the diagnosis on reduced social standing, self esteem and personhood seemed more. This is further covered in the next chapter where Kitwood (1997) described “malignant social psychology” and the depersonalizing affect that a diagnosis of dementia can bring to the person, which can be more disabling to the person than the physiological symptoms of the disease. Fear of social embarrassment, long term dependency and not being listened to were the most common worries.

Although the majority of literature suggests that people would rather know their diagnosis, the study by Wilkinson et al (2002) pointed out that many people who had been informed of their diagnosis would understand if other people with dementia would rather not know. It should also be noted that the selection criteria for qualitative research into the experiences of people with dementia will involve the participant’s co-operation and a degree of insight into their condition. The research will rarely involve those who refuse to attend clinics for diagnosis and those with a lack of awareness or in denial of their symptoms (Vogel et al., 2004)

This section clarifies that the vast majority of people with dementia would rather know their diagnosis. Part 2.8 highlights that recently there has been change in attitude amongst professionals and relatives, in that there is a general acceptance that people with dementia should be informed. However, it also highlighted that there is a dearth of literature regarding the information that is given to the person. The limited literature, however, suggests that people with dementia are not given as much information about the prognosis as relatives. One possible reason is the presumption that they will not understand the information or have insight into their condition (Winner, 1996). The following section shows that whilst it can be the case that some people with dementia lack awareness due to physiological changes in the brain, this attitude will prevent practitioners attempting to engage individuals to discuss the prognosis and the future. Moreover, it shows that if they take social and psychological factors into account they may be more likely to discuss the future.

2.10 Is lack of insight an inevitable symptom of dementia?

Prior to the 1980s much of the dementia literature highlighted that lack of insight was an inevitable symptom of dementia. Hence, for a person to have insight into their cognitive impairment would be either 'unusual' or suggest a diagnosis of "pseudo dementia" (Roberts, 1984). However, since then there has been general recognition that insight is not an 'all or nothing' phenomenon, and should not be considered as a single entity (Howorth and Saper, 2003; Clare, 2002; Bucks, 1998). For example, some people with dementia might recognise they have problems with their memory, but not recognise the true extent of the difficulties. Similarly, others may deny any impairment, but when confronted with difficult tasks may show some awareness of dysfunction (Verhey et al., 1993). There can also be day-to-day variations, with periods of lucidity followed by periods of confusion (Bucks 1998). Moreover, some might be aware of their deficits, but not aware of the impact their problems are having on others, such as carers (Fairbairn, 2000).

Furthermore, Bond et al (2002) described how people labelled as lacking insight into their dementia will consequently experience more depersonalization, loss of independence, loss of social and political rights and will have their behaviour individualised. Similarly, according to Fairbairn, lack of insight can be a crucial factor in deciding when a person should be institutionalised and often the person's 'lack of cooperation' due to these difficulties can lead to packages of care being rejected which could otherwise maintain them at home. Additionally, Winner (1996:72) suggests that people with dementia are excluded from decision making because it is presumed they are 'unlikely to have insight into their own situations' and therefore require protection. Bearing this in mind, the remainder of this section explores reasons why it is presumed people with dementia have a lack of awareness.

One strand of thought focuses on the person's level of insight being a biologically determined symptom, specifically related to damage to the brain (Rankin et al., 2005). Mention is often made of frontal lobe and right hemisphere dysfunction as being

particular ‘pathways’ in the brain which relate to loss of insight, also termed ‘anosognosia’ (Rankin et al., 2005; Fairbairn, 2000; Holden and Woods, 1995). To reinforce this field of thought, loss of insight has been reported in people who have experienced stroke or brain damage in these specific parts of the brain and observed through neuro imaging and CT scans (Buxbaum et al., 2004; Trouillette et al., 2003).

It has been reported that people suffering from frontal lobe dementia, Korsakoff’s psychosis, and dementias where the person experiences agnosia (difficulty in appreciating the meaning of objects) have significantly lower levels of awareness, all of which appear to have more of an effect in the frontal or temporal lobes of the brain (Vogel et al., 2004; Holden and Woods, 1995). With early and moderate dementia the presumption would be that ‘the pathways’ are similarly affected although not as obvious in neuroimaging. Whilst some people in the early stages of dementia appear to have a reasonably high level of insight, others appear to have little (Vogel et al., 2004). According to Vogel et al:

“The variability may be caused by lesions in different regions of the brain, some more important than other” (2004:185).

It should be noted, however, that lack of insight is often viewed as a “symptom” of other psychiatric disorders such as schizophrenia, delusional and psychotic disorders (Rickelman, 2004; Amador et al., 1993), where there are no obvious signs of “brain pathways” being affected and in the case of those in early dementia there is no obvious way of proving damage to specific parts of the brain (Chertcow, 2001). Furthermore, determining a person’s level of insight relies on clinical assessments usually by psychiatrists, often incorporating the views of family members (Clare, 2000; Cheston and Bender, 1999). According to David (1990), the person’s level of insight will be determined by the following three aspects, all of which are open to interpretation by others:

“Their ability to re-label mental events as pathological

The recognition by the patient that he or she has a mental illness

The extent to which he or she complies with the appropriate medical treatment for that illness” (David, 1990, cited in Cheston and Bender (1999:157).

These aspects have been criticized as being “value laden” (Clare, 2002; Cheston and Bender, 1999). According to Clare the assessments rely on the person, in essence, agreeing with the psychiatrist’s judgment of their cognitive state and agreeing to whatever intervention they recommend. Clare further adds that individual coping responses and the role of social and cultural factors are often not considered and little reference is made to the nature and context in which the level of insight is elicited.

Several studies have focused on trying to establish correlations between insight and given factors, such as age of onset, pre-morbid intelligence, gender, affect and cognitive impairment. The link here is not conclusive: for each study that finds a correlation, others fail to find any significant relationship (Clare, 2002). Whilst most studies predict a steady decline in the level of insight related to a decline in cognitive abilities (Vogel et al., 2004; Starkstein et al., 1997), some researchers report a fluctuation of insight, especially in the early and moderate stages (Derouesne et al., 1999; Correa et al., 1996; Killick, 1994). Some also indicate that where a person with dementia experiences additional psychiatric symptoms, such as delusions or psychosis, insight is reduced (Hartwood et al., 2000). Some studies indicate that people with a higher level of insight are more prone to depression whilst others opine that people with a greater awareness are more likely to benefit from counselling and support groups and therefore become more accepting of the condition (Yale, 1998). One possible reason for the variation in findings is that most research relies on rating scales to assess the person’s level of awareness of which there are three main types, all of which rely on value judgments being made by others (Derouesne et al., 1999; Bucks, 1998; Verhey et al., 1993).

The first involves asking the person’s carer or relative, or professionals to rate the person’s level of insight on a scale according to their interpretation and knowledge of the person (Verhey et al., 1993). The second involves asking the carer or relative specific

questions regarding the person's problems, particularly activities of living and comparing their answers with the person with dementia. A discrepancy usually indicates lack of insight. The third scale similarly involves comparing the person's level of knowledge about their deficits, with observed behaviour or actual ability. Again a discrepancy between the perception of the person with dementia and the actual findings would indicate a lack of insight (Derouesne et al., 1999; Bucks, 1998).

Bucks (1998) also pointed out that even healthy people have difficulty judging their own abilities and gave the example of the majority of people believing they are good drivers! Another possibility is that the person with dementia might not have a lack of awareness but have difficulty admitting their deficits or simply forget at the time when they are asked about the problems they are experiencing. They could, however, be aware at the times they are experiencing difficulties (Howorth and Saper, 2003; Phinney, 2003). The person with dementia could also have difficulty understanding the questions or communicating their difficulties (Bucks, 1998). Furthermore, the relationship that the person with dementia has with the interviewer can have an impact on their response and the extent to which the interviewer challenges them about their deficits (Clare, 2002).

Interestingly, a study by Derouesne et al (1999) highlighted the variability within the assessment process. They found that, when comparing three assessments of 88 people with Alzheimer's disease, awareness of cognitive deficits varied greatly between participants depending on the assessment methods used. It was therefore concluded that assessment of insight should be made on a case by case basis. Similarly, a study by Howorth and Saper (2003) found variations in assessments used for measuring insight and recommended the use of qualitative research, in particular interviewing people with dementia, to supplement quantitative findings and incorporate their own experiences. The following part of this review shows how the use of qualitative research has added to understanding the awareness of people with dementia.

2.11 Psychosocial factors which influence awareness

In the past decade there has been an increased involvement of people with dementia in research, particularly in respect of psychosocial factors, discussing their experiences of receiving the diagnosis and the impact of the illness on their lives (Hellstrom et al., 2005; Wilkinson et al., 2002; Gilliard, 1995; Bahro et al., 1995; Keady et al., 1995). Rather than presume “anosognosia” is specifically related to neurological changes in the brain, several authors have alluded to “unawareness” as being complex and involving cognitive, behavioural and social aspects, as well as psychological defences and that people with dementia should not be presumed “unaware” on the basis of our limited information and interaction with them (Howorth and Saper, 2003; Clare, 2002; Bucks, 1998; Kitwood, 1997a). According to Clare:

“Awareness is not a symptom that can be objectively isolated and assessed, but a reflection in which the person constructs an account for his or her experience in a given time and in a given context” (2002:34).

Furthermore, Kitwood (1997a) acknowledged that cognitive processes can cause a lack of insight, but cautioned that emphasising biological factors can lead to an approach whereby people with dementia are treated in a dehumanizing manner if it is assumed that they are not aware of what is happening to them. He further described how an impoverished care environment can perpetuate denial of their situation. The following section further explores how denial is a common psychological defense mechanism used by people with dementia (Cheston and Bender, 1999; Coleman, 1996).

2.12 Denial - a coping mechanism which influences awareness

According to Coleman (1996), the onset to any severe or life threatening illness can be seen as a threat to the person and often many people refuse to acknowledge the impact or outcome of the illness, or attribute changes to trivial causes. Cheston and Bender (1999) further added that individuals have not only to deal with neurological changes, but with

other losses such as loss of role in life, reduced social status and social contacts. Furthermore, they opined that having complete insight into the condition could represent an enormous emotional challenge and denial can be a way in which people with dementia can protect themselves against something that is too traumatic to be able to deal with. According to Cheston and Bender:

“Denial prevents the individual being overwhelmed by the emotional consequences of the losses they have suffered or the threat that the dementing process represents” (1999:159).

Furthermore, they also argued that denial could be described as “psychological time out” to allow individuals time to develop other strategies to cope with their situation. If however, the person has few resources either personally or socially to deal with the losses, it can become habitual and permanent. Hence, they alluded to creating a supportive environment to allow the person to explore various strategies to come to terms with the illness. This indicates that practitioners should attempt to explore with the individuals how they feel about such losses in their lives, to enable them to develop coping strategies.

Like insight, some authors have pointed out that denial is not an “all or nothing” phenomenon (Howorth and Saper, 2003; Clare, 2002; Bahro et al., 1995). Howorth and Saper, for example, interviewed 32 people with dementia. They reported that some of this group, whilst acknowledging cognitive deficits, spontaneously mentioned other problems such as sensory and physical difficulties as being more significant to them. Howorth and Saper emphasised that in mentioning these factors the participants were not necessarily in denial, but their comments seemed to reflect a genuine order of their priorities, which they considered had more of an impact on their lives.

In the same study Howorth and Saper found that some people with dementia, although aware of their diagnosis, were unable to make the connection between themselves and other members of their families who had suffered the same condition. The authors

conclude that they were unable to ascertain if their lack of response was due to a psychological defence or an organically determined failure to understand the implications of the illness. Similarly, some, although aware of their deficits, did not appear perturbed by their problems. Again the authors were unable to ascertain if this was due to apathy associated with the neurological process of the illness, depression or denial of the impact that it was having on their lives. On the other hand, some were very defensive regarding their inability to carry out certain tasks. However, at the time of carrying out the tasks they expressed frustration and anxiety, indicating an awareness at one level but not another. Howorth and Saper (2003) described this as having awareness at an emotional level, but not cognitively.

Several studies, although not specifically looking at insight or denial, highlighted that the vast majority of people with dementia felt it was their right to know their diagnosis with many experiencing a sense of relief after being told. This therefore indicates that they had awareness about their condition and cognitive deficits (Wilkinson et al., 2002; Gilliard, 1995; Bahro et al., 1995; Keady et al., 1995). Many claimed to be aware of deficits before diagnosis, with some claiming they were aware “something was wrong” before being told. Although most participants in the research were conscious of their diagnoses, there were wide variations in the levels of knowledge participants had about their conditions.

Bahro et al (1995) described how seven people with Alzheimer’s disease coped with their illness. They described how some avoided naming the illness, did not seek out any information, minimised the severity of their functional levels and were generally vague when discussing their symptoms. Avoidance, somatisation, self blame, displacement, disassociation of affect and denial were therefore some of the coping mechanisms used by the participants.

Similarly, Keady et al (1995) interviewed eleven people with dementia and described how many chose to keep secret their real fears, feelings and needs, not only to protect themselves from the full implications of the illness but often to protect the person with

whom they were living. It was therefore interesting to note that many felt they would find it easier to discuss their concerns with detached professional confidants rather than family.

Another factor is that unawareness can occur from not knowing the relevant information, or being given the opportunity to discuss the illness (Clare, 2002). It should be noted that this review repeatedly shows that people with dementia are treated in a paternalistic manner by professionals and relatives. The remainder of this chapter shows how lack of information can influence the person's awareness of their current situation and deny the individuals the opportunity to discuss the future.

2.13 Does lack of information influence unawareness?

Downs et al (2002) concluded in their study of how much information GPs shared with people with dementia that they were less likely to give them information, used euphemisms and presented the future more optimistically than they did to carers. It therefore might not be surprising that some will lack a degree of insight if not given relevant information about the condition. Howorth and Saper (2003) also describe how many people with dementia "normalised" their condition as a way of dealing with its emotional impact. Although recognizing their deficits, many reported that their decreased functioning was due to advancing age. Whilst at one level this could be seen as denial, the study by Downs et al showed that some professionals colluded and encouraged this way of thinking. Whilst it could be viewed as 'being kind' it also has implications for people with dementia being given the opportunity to make provisions for the future.

Hellstrom et al (2005), in a study exploring the impact of dementia on the everyday life and relationships of older spousal couples, suggested that, in the early stages of dementia, awareness is not simply a matter of knowing the diagnosis, but dependent on the level of openness and sharing of information between partners. They further suggested that where there is no "sharing of perceptions" couples may drift apart and the relationship is

more likely to become fraught as the illness progresses. Conversely, those couples who “worked together” were more likely to seek help from professionals and receive information. Interestingly, several couples only sought limited information or as much as they could deal with at the time. The authors suggested that this was an active choice based on a mutual acknowledgement of the condition, but not allowing it to dominate their lives. This indicates that, for some, having the choice and opportunity to receive information is more important than actually receiving it.

In line with this, one field of thought is that, although not forced to discuss their deficits, people with dementia should be allowed the opportunity to discuss and plan for the future (Wilkinson et al., 2002; Husband, 1999; Gilliard, 1995). Some however advised caution. According to Fairbairn:

“If loss of insight is one of the few protections in this terrible illness, is it appropriate to try and improve insight, presumably for the purpose of allowing the tidying up of their personal life and the opportunity to sort out personal affairs?”
(2000:16).

The final part of this chapter attempts to answer this question. However, as this review has highlighted several times there is a dearth of literature regarding whether people with dementia want to plan ahead.

2.14 Do people with dementia want to plan future care?

One of the main reasons highlighted for sharing the diagnosis with people with dementia is to allow them to plan for future care or take control over future health care and related personal decisions (Lingarde, 2002; Wilkinson, 2001). The literature often highlights financial planning, appointing a welfare attorney, making a will and advanced directives (Mason and Wilkinson, 2002; Meyers, 1997). However, few people with dementia appear to complete advance directives (Mitchel, 2003a; Grossberg, 1998; Dresser, 1995). Moreover, despite an increasing amount of literature including the experiences of people

with dementia, exploring their feelings about receiving the diagnosis and the impact on their lives, rarely does it discuss the type of care they would want if their condition deteriorates and if they do, in fact, want to make plans.

Husband (1999) touched on future care options in his study, but concluded that making plans did not seem a major preoccupation for the three people with dementia that he interviewed and that they were more concerned with how they were perceived and treated by others. Similarly two studies which explore how people with dementia felt about the services they were receiving highlighted that they were rarely interested in the physical aspects of their care but more on social aspects, such as their relationships with staff and other clients, their need to feel valued or the type of companionship they favoured (Goldsmith, 1995; Sperlinger and McAuslane, 1994).

However, Downs et al (2002) pointed out that GPs gave little medical information to people with dementia and rarely discussed prognosis, tending to paint it in optimistic terms. Whilst this could be perceived as “protecting” or “being kind”, it should be noted that it could also be viewed as paternalistic and subsequently make it difficult for the person with dementia to plan ahead or have the choice to plan (Fearnley et al., 1997). It is therefore inconclusive if people with dementia do not plan future health care because they genuinely do not want to or are not encouraged or given the opportunity, by professionals.

2.15 Summary

In conclusion, this chapter highlights that the inception of cholinesterase inhibitors has initiated a change in culture relating to dementia care. There has been an increase in memory clinics (Lindesay et al., 2002) and more people are being diagnosed in the earlier stages of the illness with more accuracy (Passmore and Craig, 2004; Warner, 2003; Philips and O’Brien, 2002). Some professionals, psychiatrists in particular, are more likely to share the diagnosis with people with dementia, although it is uncertain as to whether this is the case with GPs (Lindesay et al., 2002; Downs et al., 2002). An

increasing number of family members appear to recognize that people with dementia have a right to know about their condition (Dautzenberg et al., 2003; Holroyd et al., 2002; Turnbull and Wolf, 2002), and the vast majority of people with dementia would rather know about their diagnosis (Wilkinson et al., 2002; Gilliard, 1995).

This chapter also highlights that there is a dearth of literature concerning what information is actually given to people with dementia. The study by Downs et al (2002), highlights that although many GPs stated that they shared the diagnosis with the person, often they used euphemistic terms such as 'memory problems' which is not specifically regarded as sharing the diagnosis. Furthermore, they paint a more optimistic impression to the people diagnosed and gave them less information than they gave to their relatives. The literature review does not highlight whether this is also the trend in memory and specialised clinics, but notes that there were few written policies related to the information that the person was given upon diagnosis.

Moreover, this chapter shows that early diagnosis and the possibility of some people responding to medication has given them an opportunity to plan for future care (Passmore and Craig, 2004; Warner, 2003; Lingard 2002; Department of Health 2001). It also points out that by presuming lack of awareness is specifically a biologically determined symptom, professionals will be less likely to attempt to discuss the future. However, if they acknowledge that lack of awareness is, at least in part, due to psychosocial factors, there is more scope to discuss the future (Clare, 2002; Bucks, 1998).

Finally, there is a lack of literature in relation to whether people with dementia want to plan future care and the practicalities of involving the newly diagnosed in this process. This chapter therefore does not clarify whether the lack of literature is a result of the recency to which some professionals have started disclosing the diagnosis to people with dementia. One possibility which must be considered is that the majority of people do not wish to make plans for the future (Husband, 1999). However, it is also possible that they are not given the information about the prognosis and/or encouraged by practitioners to plan ahead and therefore denied the choice (Downs et al., 2002, Winner, 1996).

Chapter 3

The ‘new culture’ of dementia care

3.1 Introduction

3.2 Person centred approach to care

3.3 The ‘organic model’ of care

3.4 Components of the ‘person centred’ approach to care

3.5 ‘Person focussed’ care for people in the early stages of dementia

3.6 Are Values Histories person centred?

Part Two

3.7 Introducing the concept of empowerment

3.8 What is empowerment?

3.9 Three components of empowerment

3.10 Is the legal process in Scotland empowering for people with dementia?

3.11 Advanced planning and Values Histories in the context of empowerment

3.12 Summary and research questions

3.1 Introduction

This chapter looks at the emergence of the “new culture of dementia care”, a perspective which has challenged the traditional medical model of dementia and placed greater emphasis on socio-political factors that mediate the experiences of dementia (Cheston et al., 2000; Bartlett and Martin, 2002 in Wilkinson, 2002; Kitwood, 1997). The “new culture of care” has evolved predominantly through the inclusion of people with dementia in research. Previously their voices did not feature in research and instead were presented by family and caregivers (Bartlett and Martin, 2002). The ‘new culture of dementia care’

is therefore underpinned by debates around the individual's sense of self, their rights and values to be gained from a concern with their perspectives (Downs, 1997).

The driving force behind this research is to evaluate the feasibility of engaging with people with dementia to make provision for the future, within the context of a person centred approach. Planning for the future is also viewed as an empowering approach (Downs et al., 2002; Wilkinson, 2001). This chapter explores the issues around "person centred care" and the concept of empowerment relative to health care planning. Chapters one highlighted the benefits of Values Histories as a possible way of empowering people with dementia, in the same way that they are perceived to benefit people with terminal illnesses. The chapter will therefore also explore Values Histories and advanced statements within the context of person centred care and empowerment.

The chapter is split into two parts. The first part begins with an overview of person centred care, contrasting it with the medical model of care. It highlights eight components of the person centred approach and describes 'person focussed' care which is particularly pertinent to people diagnosed in the early stages of dementia (Cheston and Bender, 1999). Thereafter it describes some biographical approaches which claim to be person centred and finally discusses whether Values Histories could be classed in this way. The discussion concludes by focussing on the concept of empowerment and ends with the research questions.

Part One

3.2 Person centred approach to care

Whilst "person centred" has become a popular phrase associated with dementia care (Kitwood 1995), some authors have admitted a degree of unease with the use of the term, feeling that many involved in academic and clinical practice feel obliged to identify their particular approach as "person-centred" to have any credibility (Morton 1999; Packer 1999).

Morton (1999) states that the phrase has become synonymous with “good quality” care in order for new initiatives (albeit good innovations) not to be seen as “old fashioned” or associated with older medical models of dementia care where people were seen as “suffering” from dementia, the tendency being to focus on their cognitive deficits, often associating the illness as a ‘living death’.

The term “person centred” is often viewed it by some as knowing the person with dementia’s previous personality, their personal history, achievements and life story (Benson, 2000; Costello, 1996). Alternatively it is seen as a refusal to correct or interpret confused speech and behaviour, looking for meaning behind their communication, such as validation therapy (Cheston and Bender, 2000; Dewing, 2000). It may also be seen as the maintenance of people with dementia’s rights and choice (Baker, 2003; Radar, 1995). Morton however argues that whilst these perspectives are valuable, the “person centred” approach is quite distinct from that implied by many in dementia care. The following section therefore explores the concept of “person centred” care and in particular draws on the work of Kitwood (1997) who is seen by many as the originator of the person centred approach in relation to caring for people with dementia (Cheston and Bender, 1999; Morton, 1999).

3.3 The “organic model” of care.

According to Kitwood there are two main “ingredients” for person centred care which are interconnected: an ethic and social psychology. Ethically he asserts:

“...all human beings have absolute value, regardless of how good or bad, how able or disabled they may be. We thus have an obligation to treat each other with deep respect; as ends and never as means to some other end” (1995:12).

Regarding social psychology he states it:

“is a body of knowledge which shows in detail how people with dementia can live out their lives in the most fulfilling way (maintaining relationships, exercising choice, experiencing satisfaction and so on)” (1995: 13).

Kitwood (1997; 1995) argues that “knowledge” which overemphasises the neuroscientific aspects of dementia can have a “dehumanising effect”, which enhances the “ill-being” of people with dementia. He refers to this as “the standard paradigm”, or the “organic model”, which does not take account of the psychosocial or social factors of the illness. He also argues that there are changes in the psychosocial environment and in patterns of relationships and interaction with others, which can have a depersonalising effect and equally add to the process of dementia. Moreover, he also states that the medical process of diagnosing and assessing people with dementia can be ‘degrading’ and is the beginning of the depersonalizing process. Cheston and Bender (1999) also allude to the same point and further add that memory clinics do not adequately tackle the social and psychological needs of people newly diagnosed with dementia. Interestingly, other writers espoused the benefits of people with dementia receiving early and accurate diagnoses of dementia (which would include such “degrading tests”), believing this to be a way of empowering and allowing them to come to terms with the illness (Pinner and Bouman, 2003; Fearnley et al., 1997).

When looking at the medicalization of dementia, Kitwood (1995) argues that it can lead to an approach which depersonalizes people with dementia, particularly as the condition progresses and they are admitted into long term care settings. He describes how their “wellbeing” can be eroded, and people with dementia can be seen as a set of “symptoms” rather than people. He uses the term “malignant social psychology” to describe attitudes which whilst not deliberate are none the less damaging, can erode people with dementia’s “personhood”. Kitwood describes aspects such as treating the person as if they are a diseased object or as a baby, using deception to manipulate the person, not allowing the person to use their abilities, using fear or physical power in order to coerce the person, labelling, by means of describing a person with dementia or their behaviour, giving too much information and putting the person under pressure, failing to acknowledge their

reality or how they are feeling and not treating the person as a sentient being as some of the main elements of this approach (Kitwood and Brendan, 1992).

Concerning the effects of “malignant social psychology” Kitwood (1997) opines that this approach can have “devastating effects” on the personhood of people with dementia and that that no individual will be able to withstand its undermining effects over the course of years. Whilst Kitwood’s description of “malignant social psychology” is seen by some as the beginning of a “new culture”, many of his criticisms have similarly been described in literature pertaining to other groups of people receiving institutional care in large hospitals, particularly people with mental illness or learning difficulties (Adams, 1996; Goffman, 1968). Adams, for example, argues that whilst Kitwood’s work has done much to increase understanding of dementia, he has merely ‘continued the work of the anti-psychiatry movement of the 1960s, by extending its work to dementia’ (1996:952). It also should be noted that whilst Kitwood is critical of the attitudes that the medicalization of dementia brings to the care setting, many carers report a degree of comfort from medical explanations of behavioural problems which their loved ones experience and report being more tolerant with the person, especially at the start of caring (Nolan et al., 1996). Furthermore, some people with dementia report similar feelings of comfort after receiving medical explanations, allowing them to “make sense” of their experiences (Robinson, 1997).

One of the main features of a person centred approach relates to the relationship between the “therapist” and the “person” (Morton, 1999). Rather than emphasising the therapist’s knowledge of the disability or technical expertise, it emphasises the personal qualities and attributes of the therapist. The therapist would attempt to create a “helping relationship” and guide the person towards a better understanding of him or herself (Morton, 1999). By way of exploring the components of “true” person care, the next section highlights four aspects from the work of Morton (1999), who in turn drew on “person centred therapy” as described by Rodgers (1957) and the writings of Kitwood (1997).

3.4 Components of the person centred approach to care

1. *A non judgmental acceptance of the unique aspects of each individual person.*

Morton (1999) pointed out that this involves more than recognising who the person was before the onset of the illness, but including the stage that their personality has reached and suggests that process of dementia is a further stage of the people with dementia's personality. He further added that there is need for people with dementia to be seen as more than a set of symptoms or as a body in which the "former occupant has departed". Instead he mooted that there should be recognition of the qualities that make up the person and the highly individual way they can react to their predicament, which would involve respecting the sense that they make of their situation. Kitwood also alludes to the uniqueness of each individual person. He states:

"Each person has come to be who they are by a route that is uniquely their own; every stage of the journey has left its mark" (1997:15).

Moreover, Kitwood suggests that rather than looking for neurological reasons for "behavioural problems" associated with dementia, professionals should firstly consider the uniqueness of the person's personality and attempt to enter into their world and the way they perceive it.

2 *An emphasis on seeing the person "as a whole".*

According to Morton:

"Person centred care of older people with dementia will prize each individual's history, their unique life story. This is not to diminish their present by accentuating their past but rather to acknowledge that each persons present identity is a function of their past, and that interpretation and evaluation of one's past life is an essential part of revising the self concept" (1999:14).

“Life Story” work and recording people with dementia’s histories and biographies are seen by many as ways of promoting a more individualised approach to their care (Pietrukowicz and Johnston, 1991). Akin to this, some studies have shown positive responses from nursing home staff when given background information, tending to see the ‘person’ rather than the illness (Carlyle and Schofield, 2004; Godwin, 2002). Kitwood (1997) also discusses “identity work” and “holding on to who we are”. He states that to encourage a true person centred approach for people with dementia one must be able to consider not only the life story “facts”, but how they coped with previous crises throughout their lives and emotional reactions to stressful situations.

3. Entering another’s “frame of reference”.

This term is based on a respect for the subjective experiences, perceptions and inner world of the individual, based on the belief that to understand an individual requires one to empathise with the person’s inner world in an attempt to view it as they do (Rodgers, 1957). The therapist does not need to hold an opinion, but should try to make sense of the person with dementia’s reality and gain an insight into their world unlike those engaging in cognitive enhancing approaches such as reality orientation. Moreover, although communication can be impaired in the latter stages of dementia, with speech appearing meaningless and garbled, some authors suggest that by listening and observing an individual in a non judgemental manner, often such meaningless communication has a far deeper meaning than first indicated (Kitwood, 1997; Killick, 1994).

4. A non directive approach.

Morton (1999) states that a person centred approach will enhance the feelings that individuals with dementia have of being in control of their lives and maximise their autonomy. He emphasises the role of the professional as an “enabler or facilitator”, who should recognise that responsibility and power lie with the person. Regarding communication, he recommends that in conversations with people with dementia they

should be encouraged to set the agenda and ‘regardless of factual accuracy’ staff should try to address and explore their current concerns. Discussing residential care, he suggests that more thought should go into planning and designing buildings by adapting them to allow people with dementia maximum independence and facilitate a non directive approach. Similarly, Marshal (1999) has also written about designing buildings and improving environments in such a way to increase safety in the least restrictive way, but also maximise the individual’s independence. Some also argue that dementia should be viewed as a disability rather than a disease, and as such the person’s environment should be seen as the problem rather than the person with dementia (Bartlett, 2000; Marshal, 1999).

Much of Kitwood’s (1997) work concentrates on people with dementia living in institutional care and ward environments. However, Chester and Bender suggest that waiting until a person with dementia is confined to an institution “is leaving matters too late” (1999:122).

The following section concentrates on people in the early stages of dementia and in particular the work of Cheston and Bender (1999) who describe ‘person focussed’ care.

3.5 Person ‘focussed’ care for people in the early stages of dementia

Similar to the person centred approach, the central task for professionals is not to guess which part of the person with dementia’s brain is damaged or not functioning, but to understand the subjective world of the person. Chester and Bender opine that professionals should try to see the people with dementia in their cultural and social context and try ‘to make sense of the world in which they inhabit’ (1999:111). To enable this to happen they recommend three principle areas which professionals and carers should attempt to learn about people with dementia:

- 1. their life history, its major events, its crises and how it has formed the person.*
- 2. their present concerns and worries.*

3. *their present network of relationships* (Cheston and Bender, 1999:113).

They argue that by focussing on these subjective aspects of ‘the person’, those working with people with dementia will become more empathetic and in turn improve their approach when offering psychosocial interventions. Furthermore, professionals are encouraged to consider people with dementia’s loss of social role, which they define as “aspects of the person’s affect, meaning and behaviour systems in which they structure their interpersonal world” (1999:123). Aspects such as being a worker, provider, parent, spouse, professional, member of an organisation, association and role within the wider community are typical example of loss of role which people with dementia may face when first diagnosed. Interestingly, these are losses which are not only faced by people with dementia but often older people in general (Norman, 1980). They also argue that people with dementia can experience a “devalued social identity” which restricts their lives and the opportunities available to them, even in the early stages of the illness when first diagnosed. This is a similar approach to those who advocate that dementia should be viewed as disability and, as such, are subject to the same barriers and social exclusion as people with a disability (Bartlett, 2000). Moreover, chapter two highlighted that carers and family members can become paternalistic and place unnecessary restrictions on people with dementia, often being overly protective, fearing for their safety despite no significant incidents having occurred (Strachan and Tallant, 1997; Lawson, 1996).

Chester and Bender (1999) also advocate for assessments and care to be carried out in the individual’s home environment, arguing that they will be less anxious and generally more oriented. However, some of their suggested interventions could cause potential conflict with carers. For example they opine that no respite care should take place outwith the person with dementia’s home, and advocate home based respite. Whilst this might be preferable from the person’s point of view it does not take into account the wishes of the carers who could possibly feel the need for a complete break from caring, to relax in their own homes or catch up with household chores (Berry et al., 1991). Indeed, carers’ needs are not necessarily the same and can differ, as can their needs differ from the person with dementia (Berry et al., 1991). It is also interesting to note that although Chester and

Bender (1999) use the term ‘respite’, this could have negative connotations and imply a “burden” of care (Archibald, 1996), and is a contrary message to the one put forth in their writings.

One of the main areas which Chester and Bender (2000) feel needs addressing is the process of diagnosing dementia. They criticise memory clinics and neuropsychological tests for being ‘demeaning’ and promoting anxiety to the person being diagnosed, arguing that the tests reinforce the person’s sense of failure and inadequacy. However, rigorous neurological tests can rule out pseudo dementias, such as depression and tumours (Bullock, 2002). Instead they promote functional assessments. However, they fail to point out that these assessments can also be stressful and threatening to people with dementia (Jacques and Jackson, 2000). Furthermore, they advocate that the diagnosis should be shared with the people with dementia in the first instance and only after their consent should their relatives be informed or be present during the initial discussions. Although the benefits of sharing the diagnosis with people with dementia are well documented (Fearnly et al., 1997; Drickamer and Lachs, 1992), Cheston and Bender (2000) do not go into details of how they would include relatives in the process should individuals with dementia be in denial about their diagnosis or have a lack of awareness of their problems (Clare, 2002; Starkstein et al., 1997; Migliorelli et al., 1995).

As indicated in the introduction, the driving force behind this research is to evaluate the feasibility of engaging with people with dementia to make provision for the future, within the context of a person centred approach. In considering this, the remainder of part one of this chapter describes some biographical approaches that claim to be person centred and, finally, discusses whether Values Histories could be classed as person centred.

3.6 Are Values Histories person centred?

As highlighted in chapter one, Values Histories were originally designed to increase the autonomy of people with terminal illness should they not be able to make decisions for

themselves (Dickens, 1993; Keilstein and Sass, 1993). Unlike advanced directives which are more prescriptive, they allow professionals and family members whilst making decision for the person, to be more flexible and take the person's previous characteristics into consideration (Docker, 1996). Whilst the term "person centred" is not specifically mentioned in the literature pertaining to Value Histories, it is alluded to. For example, when describing the impact of Values Histories on the person's proxy, Kuczewski states:

"Thus the patient's interests, values, and to some extent personhood survive in the deliberative process of the proxy" (1994: 42).

A strong case could be made, based on Kitwood's (1995) model, for person centred care, that by prizing each individual's unique life story and accentuating their past values and characteristics, the person's self concept will be enhanced and the care they receive from others will be more 'personal' as the illness progresses. Thus it could be claimed that by adapting Values Histories for people with dementia it could be classed as 'person centred', similar to the following three examples which claim to be person centred (Carlyle and Schofield, 2004; Godwin, 2002; Gödel, 2000).

One example of a detailed biographical assessment, which claims to be person centred, is "memoraid" described by Godwin (2002). A cross between a life story book and detailed care plan, it records information which staff in long term care settings should know about a person with dementia. Information, such as their likes and dislikes, family history and preferences in food, music and religious beliefs were included. One hundred and forty five people's information was gathered, partly from people with dementia and their carers at various stages of their illness. The study showed that staff felt they got to know the people within their care better and in a shorter period of time. Staff also felt that having this information helped reduce agitation by knowing the idiosyncrasies of the people in their care. Some relatives also felt a degree of 'freedom' by being able to pass on information to staff.

An approach described by Carlyle and Schofield (2004) is Personalised Care Pathways (PCP) in which staff asked relatives prior to the admission of the individuals with dementia to fill in a lifestyle audit, describing personality traits of the person including aspects such as how they like to sleep, sense of humour, their likes and dislike. After the person was admitted into care, staff were encouraged to record the person's likes and dislikes and approaches that individual staff members found effective in promoting better communication with the individual.

Another approach is SPECAL, portrayed as a way of “maintaining well-being” in dementia and to take into account of how the person was before the onset of dementia (Gödel, 2000). The aim of this approach is to ease the transition from home to long-term care. It claims that “carers provide the key” by giving information that unlocks details of the person's life before the onset of the illness. Staff or ‘companions’ use the information over a twenty-four hour period in the context of prompts and cues to stimulate long-term memories and use language which the people with dementia would know and recognise. Again staff and relatives viewed this very positively.

Similar to these approaches, one could argue that Values Histories are also based on a person centred or person focussed model as they include biographical accounts and recording the likes and dislikes of people with dementias (Kitwood, 1997). Furthermore, additional weight could be added to this argument as Values Histories can also include the “feelings” of individuals and how they coped with difficult situations in their lives (Morton, 1999). It is noteworthy therefore that any biographical account of people with dementia could claim to be person centred, in that the accounts will enable staff to see the ‘whole person’ (Morton, 1999). However if one considers the process of obtaining the information and how the information is used there could be aspects of the process that are not truly person centred. According to Kitwood:

“the ethic alone might provide a motive, but the practical insight and skill to do the task well could be lacking” (1995:12).

If one takes into account the components of person centred care, then having “the practical insight and skill” will involve the person obtaining the information in a “non judgemental way”, entering the person’s “frame of reference” and allowing the person with dementia to “set the agenda” (Morton, 1999). Staff should therefore be aware that their own past events and values could influence the process of gathering and recording the information (Polkinghorne, 1999). Moreover, chapter one highlighted that relatives’ perceptions can be different from the person’s (Brandon, 1995; Ivers, 1994; Rankin, 1989) and therefore the extent to which they are involved in the process could be a factor in determining whether the process is person centred. These aspects will be further explored in chapter four.

Another area which should be considered in relation to whether Values Histories are person centred is how staff react to the information when the person is no longer able to communicate and in particular if the person’s past values and wishes change as their condition deteriorates. This is an area which Kitwood (1997) does not address in detail. Whilst the person centred approach recognises that in many cases knowing a person’s life story and values will help professionals “enter the frame of reference” of the people with dementia, he argues that such information should not “diminish their present by accentuating their past” (Morton, 1999:14). One should therefore consider whether the aspect of trying to encourage the person to hold onto previous values, as recorded at an earlier stage of the illness, is in contrast to Kitwood’s model for person centred care. This will be further explored in section 3.10

As highlighted in section one, the term “person centred” has become synonymous with the “new culture of dementia care”, often associated with “good quality care” (Morton, 1999; Kitwood, 1997). In a similar vein the emergence of the concept ‘empowerment’ has become a fashionable term associated within the “new culture” of care (Chaston et al., 2004; Lingard, 2002; Wilkinson, 2001). The second part of this chapter explores the concept of empowerment within the field of dementia care, at times drawing comparisons with person centred care.

Part Two

3.7 Introducing the concept of empowerment

Similar to the “person centred” approach, the concept of empowerment questions many of the assumptions of the traditional medical model, such as the value systems that purport to respect the rights, dignity and self determination of patients (Wilkinson, 2001). It addresses the power imbalance whereby professionals are viewed as the experts and purports that people in general have the right to make decisions for themselves (Fitzsimmons and Fuller, 2002). It also questions paternalistic views not only of the medical profession, but other professionals, family members, carers and society in general towards vulnerable groups of people

Whilst there are wider political implications for the concept of empowerment such as combating stigma, injustice and oppression on an individual and collective level (Chaston., 2004; Ward, 2000), this review concentrates on the individual with dementia. It should be noted, however, that it is only by exploring common concerns of groups of people that individuals can benefit from empowerment and “personal troubles can be translated into common concerns” (Mullender and Ward, 1991:12)

It also draws together aspects from previous chapters such as the legal system in Scotland, the importance of early diagnosis and information regarding the prognosis of dementia, and advanced planning for the future. It concludes by looking at Values Histories in the context of empowering people with dementia. Firstly, this section gives a brief overview of the concept of empowerment.

3.8 What is empowerment?

From the 1990s, and in particular with the introduction of community care, government policy focused on empowering individuals to become consumers within the wider context of citizenship (Barnes, 1997). It also emphasised aspects such as user involvement,

autonomy, choice and needs led provision (Priestly, 1999). Whilst each of these aspects can have differing underlying ideological positions, collectively they describe the extent of peoples' involvement in the decision making process and control over the services they receive (Ward, 2000). Moreover, the concept of empowerment became synonymous with 'hearing the voice' or 'understanding' the needs of vulnerable groups of people (Goldsmith, 1996; Rappaport, 1990). According to Rappaport:

"To be committed to the empowerment agenda is to be committed to identify, facilitate or create contexts in which heretofore silent and isolated people, those who are 'outsiders' in various settings, organisations and communities, gain understanding, voice and influence over decisions that affect their lives" (Rappaport 1990, cited in Fitzsimmons and Fuller, 2002:483).

It is generally recognised within the literature that people with dementia are considered a "vulnerable group" who, due to their potential cognitive decline, are at risk of having their autonomy constrained by others through disempowering behaviour and attitudes through out various stages in the illness (Mason and Wilkinson, 2002). It is also generally recognised that literature, especially prior to the last decade, tended to focus on the 'burden of caring' and their needs rather than people with dementia (Mace and Rabins, 1985).

When looking at "contexts" for empowerment to be facilitated, Rappaport indicates that contexts can be situation specific and will vary under different circumstances. Furthermore, these contexts can be seen both as a process and an outcome (Fitzsimmons and Fuller, 2001). The process refers to the way in which people, organizations or communities gain the skills, strengths and resources to have greater control over their lives and goal attainment.

Moreover, aspects such as self determination, promoting choice and autonomy and 'control over destiny' underpin empowerment (Syme, 1998; Winner, 1996). The concept of control over destiny refers to the influence that people have over events that occur in

their lives (Syme, 1998). Akin to this, several studies have indicated that having control over one's own destiny is related to an increased quality of life and relates to a sense of being valued as a person (Fitzsimmons and Fuller, 2001; Marmot et al., 1997; Jackson, 1993). According to Fitzsimmons and Fuller, participation in decision making leads to:

“a sense of being valued and respected by others, of being able to make an impact, a sense of connection towards others” (200:486).

They also suggest that empowerment can lead to a more positive sense of self concept and increased self esteem. Disempowerment on the other hand has been described as a “secondary disability” which is imposed on individuals in the same way as Kitwood (1997) described “malignant social psychology”, which can erode the “personhood” of people with dementia. Disempowerment can also lead to feelings of low self esteem, depression, feelings of hopelessness and alienation (Fitzsimmons and Fuller, 2001; Seeman and Seeman, 1983).

Furthermore, an empowerment approach recognises the power, capabilities and values that the individual possesses and attempts to facilitate these within the constraints of the individual's circumstances (Dunst et al., 1994). For people with dementia, it recognizes that they retain their “sense of self” despite cognitive losses and maintain the ability to communicate their views and feelings, albeit with difficulty (Morton, 1999; Kitwood, 1997). Moreover, it encourages professionals to develop an attitude whereby they recognize that people with dementia have abilities to make some decisions with or without their support (Wilkinson, 2001). The concept of empowerment underpins a respect for the rights of the individual and recognizes that they should have maximum control over their lives (Fitzsimmons and Fuller, 2001; Wilkinson, 2001).

According to Fitzsimmons and Fuller (2001:486) there are several components of empowerment. The following section considers three of these components and how they relate to people with dementia.

3.9 Three components of empowerment

Firstly Fitzsimmons and Fuller suggest that individuals should have:

“an increased understanding and awareness of ones own interests, and one’s position in relation to others” (2001:486).

This indicates that for empowerment to take place individuals should have an “awareness” of their own interests. However, chapter two highlighted that a significant proportion of people with dementia do not receive their diagnosis and therefore are not being “made aware” of their condition and therefore not given the opportunity to make provision for the future and therefore disempowered. Mason and Wilkinson (2002), in a study looking at the characteristics of users and non users of the legal system, pointed out that sharing the diagnosis with the person was pivotal in preserving the person’s right to “self determination”. Regarding those who did receive their diagnosis, they specifically mentioned the importance of support following diagnosis to facilitate empowerment. They stated:

“If we are to develop and support more inclusive legal and social systems where individuals with cognitive impairment are empowered in practical ways to maintain autonomy, then diagnosis and the support that follows clearly needs to underpin the implementation of new legislation” (2002: 62).

Although Mason and Wilkinson recognised that the legal provisions within the (Scotland) Act (2000) should improve the autonomy of people with dementia they indicated that this could only happen if professionals offered “support” following diagnosis to ensure people with dementia were well informed about the impact of the illness on their daily living and what such a diagnosis could mean in terms of their future and thus allow the person to then make his or her own personal decisions. However, they found that many people with dementia experienced ‘communication with authority

figures that was disempowering' (2002:50) and reported that the infrastructure of providing support and information was 'fragmented and medically orientated'.

The second aspect which Fitzsimmons and Fuller suggest that individuals require to be empowered is:

"the acquisition of the skills and competencies needed to achieve desired outcomes (e.g., interpersonal, practical, political, personal development skills)" (2001:486).

As highlighted throughout this review there is a dearth in the literature regarding how much information is shared with people with dementia about the prognosis and possible outcomes of having dementia. The concept of empowerment however implies that people with dementia need to acquire "the skills" to make plans for the future and therefore be empowered (Fitzsimmons and Fuller, 2001). Acquiring "the skills" infers having an accurate knowledge of the condition, prognosis and care options and being able to make informed decisions. Winner (1996) suggests for this to take place individuals must receive "accessible information" to make choices about the services they will need and they require and be encouraged to "make judgments which advance their own self interests" (1996:71).

Mason and Wilkinson (2002) called for 'practical methods' to involve people with dementia in decision making about their future and highlighted that healthcare professionals as those in the best position to achieve this. The literature review however has indicated that professionals tend to give more information to relatives than they do to people with dementia and tend to be more optimistic when discussing prognosis with them than they would with relatives (Downs et al., 2002). Chapter two also highlighted that the biological model of 'lack of insight' can be an excuse for professionals not to discuss the future, whereas if one considers psychological or social aspects as possibilities for a lack of awareness there is an opportunity to engage with people in a therapeutic way to facilitate discussion about the future (Clare, 2002; Bucks 1998). However, this involves practitioners spending quality time with people with dementia, using leading questions to draw out the person's feelings and presenting the information

in a clear manner, possibly several times, followed up by written information (Husband, 1999; Lovestone, 1998). Moreover, whilst some people with dementia might find it too traumatic or not have the mental capacity to discuss the prognosis or plan for the future (Fairbairn, 2000) it could be argued that by giving them the opportunity in a skilful and tactful manner, professionals are adopting an empowering and person centred approach (Fitzsimmons and Fuller, 2001; Cheston and Bender, 2000; Kitwood, 1997).

The third component of empowerment relates to the outcome for the individual. According to Fitzsimmons and Fuller there will be:

“evidence of positive outcomes for the individual such as the acquisition of competencies, changes in circumstances or the achievement of goals” (2001:486).

Again “changes in circumstances or achievement of goals” can only be attained if people with dementia are aware of future implications of the illness. It is noteworthy that Mason and Wilkinson (2002:62) used the term “pathways” when discussing the process of involving people with dementia in the decision making process. Similarly the term empowerment implies a “process” (or pathway) leading to an “outcome” rather than a single entity, in which people have control and self determination over any intervention that affects their lives (Fitzsimmons and Fuller, 2001:483). Mason and Wilkinson suggested the medical profession could ensure the “gateway is open” for people with dementia. However, they point out that for pathways to be considered empowering the system would need to be coordinated and clearly identify professionals given the responsibility to provide advice, information and support. Moreover, there are numerous possible individuals and organisations that will be involved in offering support along the pathway or journey of dementia. In the course of anything from a few months to several years a person with dementia may have “a career” within the system, including health and social care workers, solicitors, informal and formal carers, voluntary organisations and long term care providers (Cheston et al., 2000).

Similarly, there are numerous possible areas throughout the journey of dementia where individuals can either be empowered or disempowered, from encouraging the person to decide what clothes to wear to deciding where to live (Wilkinson, 2001). The process would therefore involve giving the person information, choices and eliciting their views, for which there would be “evidence of positive outcomes” for the person i.e. that their views had been taken into consideration (Fitzsimmons and Fuller, 2001.486).

It should be noted, however, that throughout the person’s journey through dementia some outcomes are predictable, such as a reliance on others due to a gradual decline in the person’s cognitive state (Voysey, 1975), and some unpredictable, such as whether the person will experience behaviour or psychiatric problems (Jacques and Jackson, 2000). Moreover, some “goals” may incorporate the person having a detailed knowledge of the process of dementia, whereas others will be more general, possibly related to advancing years and poor health (Fagerlin and Schneider, 2004; Zronek, 1999; Docker, 1996).

There is also the aspect of unrealistic goals, such as a refusal to acknowledge that they might require long term care in the future. Moreover, some goals could cause conflict with others, such as the risk that the person with dementia is willing to take to preserve their autonomy (Lawson, 1996; Norman, 1980). Furthermore, the person will have to consider whether the carer will have the health, skills or motivation to care for them at home and whether the appropriate services and support will be available (Nolan et al., 1996).

The remainder of this chapter explores areas where there is potential for empowerment to take place, but often the opposite is the case. It explores the legal system in Scotland, but specifically focuses on welfare attorney and advanced planning.

3.10 Is the legal system in Scotland empowering?

One process which can potentially empower vulnerable people is the legal system which purports to recognise and enhance the rights of individuals and support individual capacity for as long as possible (Wilkinson, 2001; Scottish Executive, 1999b; 1995).

According to Wilkinson:

“An empowering system would allow people with cognitive impairment the maximum amount of control within the decision making process that is possible for the individual at that time” (2001:324).

This is very much in keeping with the principle within the AWI (Scotland) Act, mentioned several times throughout this literature review, in that anyone proposing to do anything under the legislation “must take into account the present and past wishes and feelings of the adult with incapacity” (AWI Act, 2000:1). However, Wilkinson points out that whilst the legal process in Scotland is intended to empower individuals and maximise autonomy it is also designed to protect them through the concepts of ‘beneficence and non maleficence’. Beneficence can be defined as “doing good for others, preventing harm and actively intervening to positively benefit another” and non maleficence as “causing the least harm to the person in question” (Fitting, 1984 cited in Wilkinson, 2001: 324). Whilst it is necessary to protect people with dementia from harm, in many instances it can lead to disempowerment and paternalism, especially if professionals and carers are over cautious or overprotective regarding the risks they feel the person should be allowed to take to continue to live at home (Lawson, 1996; Norman, 1980). Moreover, disempowerment can occur when their views, either past or present, are either not listened to or not considered, and at various stages throughout their “journey” though dementia (Mason and Wilkinson, 2002; Fitzsimmons and Fuller, 2001).

Some of these goals can be addressed by the individual with potential incapacity appointing a welfare attorney or proxy decision maker to represent the person’s wishes

should they deteriorate. However, following the three principles recommended by Fitzsimmons and Fuller (2001), for the process to be truly empowering for people with dementia they would have to be given clear information about the prognosis of the illness, have a clear understanding of the powers vested in the appointed person and confident that the proxy would represent their wishes and achieve “positive outcomes” on their behalf. Whilst these aspects are underpinned in the AWI (Scotland) Act, 2000, chapter two highlights that many relatives and carers can indeed find it difficult to represent the person with dementia’s views accurately. Moreover, many relatives find it difficult to discuss aspects such as future care and dying with the person with dementia whilst they have capacity, According to Wilkinson:

“There is a difference between doing what we think is the right thing for an individual and what that person might have wanted if they were to express autonomy” (2001:324).

Moreover, according to the Act the person should not be coerced into appointing someone (AWI Act 2000:14.3). In a similar vein, Winner (1996) discussed the aspect of empowering people with dementia by giving them choices regarding services they receive. Winner suggests that “passive consent” is used as way of getting individuals to receive services, but argues that this is, in fact, denying the individual a choice as it involves minimal negation. In the same way there is a dearth of literature regarding the extent in which ‘passive consent’ takes place at the point that the person with dementia is the signing the legal documents to appoint an attorney. It is noteworthy to mention that chapter one highlighted conflicts between the legal and medical professions’ definitions of capacity, which tend to hinge on their personal “values judgments” (Wilkinson, 2001; Moye, 2000; Marson et al., 1994).

Chapter one also drew attention to advanced directives and advanced statements as possible ways for empowering people with dementia when they no longer have the capacity to make decisions (Volicer et al., 2001, Rushton, 2001; Emanuel and Emanuel,

1992; Doukas and McCulloch, 1991). The remainder of this chapter examines advanced directives and Values Histories in the context of empowerment.

3.11 Advance planning and Values Histories in the context of empowerment

Advance directives are viewed by many as ways of increasing the autonomy and empowering people with dementia, giving them a degree of control and peace of mind regarding the future (Volicer et al., 2001, Rushton, 2001; Emanuel and Emanuel, 1992; Doukas et al., 1991). It is noteworthy that the BMA Code of Practice (2003) recommends that when an individual is completing an advanced directive it should be “carefully discussed” with professionals and the person should ‘understand the implications’ of their decisions (8.1), which seems to fit in well with the concept of empowerment, especially in relation to ‘having an awareness and understanding of one’s own interests and ‘the acquisition of the skills and competencies needed to achieve desired outcomes’ (Fitzsimmons and Fuller, 2001:486). It is also interesting to note that one of the main concerns with advanced directives is related to the person not having sufficient knowledge at the time of documenting their wishes (Fagerlin and Schneider, 2004; Zronek, 1999; Docker, 1996). For advanced directives to be truly empowering the person therefore needs to make informed decisions.

The code further points out that health care professionals are legally bound to comply with the person’s wishes as for some people advanced directives are the “only means of expressing what they wish to happen” (BMA, 2003:1). For the purpose of the empowerment process this could be classed as the ‘outcome’ (Fitzsimmons and Fuller, 2001). Moreover, BMA states that “in all circumstances a contemporaneous decision by a competent individual overrides previous statements by that person” (4.1). Whilst this could be relatively straightforward in the instance of someone in a coma, this research is looking more specifically at the use of advanced statements to empower people throughout the journey of dementia. Ashley and Schofield recommend that when planning care, people with dementia should assume that a moderate level of dementia has been reached and that they will “still be able to understand and appreciate to some extent

their environment” (2002:21), which could possibly be in a residential or nursing home. As previously highlighted, capacity to make decisions in dementia is situation specific, can fluctuate and is often dependent on the value judgements of professionals (Wilkinson, 2001). This therefore requires skill on the part of professionals to ascertain the person’s current wishes. Whilst the concept of empowerment appears to indicate the “acquisition of skills and competencies” for an individual to make an informed decision, it should be noted that adopting a person centred approach involves not only verbal communication but non-verbal communication, observation of the persons reactions and an attempt to “enter the persons’ frame of reference” (Morton, 1999; Kitwood, 1997; Dresser; 1995). It could be argued that by not attempting to gain the person’s current wishes and relying solely on the advanced directive it is disempowering to the person at that time to “ignore” their thoughts (Fitzsimmons and Fuller, 2001; Rich, 1998; Dresser, 1995).

In a similar vein, the usage of Values Histories can increase autonomy “by clarifying for the health care team the patient's expressed values underlying decisions to be carried out when decision making by the patient is no longer possible”(Doukas et al., 1991: 145). With regards to the empowerment process, this would indicate that the person should have an understanding and awareness of their own interests and be given appropriate information to make informed choices, and record aspects of their lives which are important to them (Fitzsimmons and Fuller, 2001). When the person with dementia is no longer able to understand or verbalize their values, professionals should refer to the Values History (Thompson, 2003; Docker, 2000; Gibson, 1990). This could be referred to as the “outcome” (Fitzsimmons and Fuller, 2001). Similarly, one of the main principles of the person centered approach is to acknowledge how the individual’s life events and values “formed the person”, which should help professionals ‘to make sense of the world that they inhabit’ (Cheston and Bender, 1999:111). The literature on person centred care therefore clarifies that knowledge of a person’s values is useful. However, there are two aspects of Values Histories where there is a possible conflict between the person centred approach and the concept of empowerment.

Firstly, one of the main principles of empowerment is that the people with dementia will have the ability to understand the information and make judgments (Fitzsimmons and Fuller, 2001). A person centered approach, however, contradicts this as it recommends that, despite the individual's cognitive impairment and factual accuracy of their communication, the person should be allowed to 'set the agenda' (Morton, 1999; Kitwood, 1997). Morton, however, argues that this also is an empowering approach as it encourages professionals to recognize that responsibility and power lie with the person with dementia and allows the person to feel in control.

Secondly, the empowerment approach indicates that if a person is aware that they have dementia, have an understanding of the prognosis and specifically express a wish for their values to be maintained when they become incapacitated, a 'desired outcome' would be for their wishes to be considered (Fitzsimmons and Fuller, 2001). A person centred approach however indicates that, whilst the person's past is an important aspect of 'understanding their unique journey', the person's current concerns and feeling are more important (Morton, 1999; Kitwood, 1997). Similarly, one of the main principles of person focused care is to focus on their 'present concerns and worries' (Cheston and Bender, 2000:113). Whilst the AWI (Scotland) Act states the 'present and past' wishes and feelings of a person who loses capacity to make decisions should be considered, it does not specifically address which should take precedence if past values have changed through the course of the illness. This could potentially become an issue should the person have specifically requested that their values are maintained while they had an awareness of their condition.

Furthermore, some authors argue that placing too much emphasis on previous values and biographical accounts devalues the current situation of the person with dementia and could be viewed as 'disrespectful' to the person at that time (Berghmans, 1997; Dresser, 1995; Nagal, 1979). Some also argue that as the condition of the person with dementia deteriorates, the individual's personality evolves and they, in effect, become a different person (Berghmans, 1997; Parfit, 1984; Nagal, 1979), indicating that even if the person

has an awareness of the prognosis of the illness when completing the Values History they cannot envisage how they will feel as the condition deteriorates.

Finally, it is also interesting to note that in the study undertaken by Mason and Wilkinson (2002) very few people had made any plans for their future health and social care and only one of sixty six people with dementia interviewed had completed an advance directive. This therefore indicates that professions are not taking the initiative to start the empowering process, by 'increasing their awareness of their own interests' and competencies to plan ahead (Fitzsimmons and Fuller, 2001). In a similar vein, the literature review has highlighted that although planning for the future is seen as empowering for people with dementia there is a lack of information regarding practical ways to achieve this.

3.12 Summary

This chapter explored aspects of the 'new culture' of dementia care specifically looking at the concept of empowerment and the person centred approach. It clarified the main components of each concept, which will be further developed in the methodology chapter in relation to using Values Histories as a way for people with dementia to document their feelings about future care. Whilst most authors suggest that empowerment entails the individual being aware of their own interests and being given relevant information to make informed decisions (BMA, 2003; Fitzsimmons and Fuller, 2001; Dunst et al., 1994), the person centred approach, which is also viewed as empowering, does not rely on the person with dementia having cognitive abilities (Morton, 1999; Kitwood, 1997). These differing concepts have implications for people with dementia in relation to possible changing values and behaviour during the process of the illness and could lead to a conflict between their 'present and past wishes' (AWI Act 2000). The empowerment approach, as suggested by some authors, indicates that when the person no longer has capacity to articulate their views their previous wishes should be followed. The person centred approach however suggests that the process of dementia is an evolution of 'self'

and indicates their current feeling are more important, despite cognitive awareness. Both these aspects will further be developed throughout the course of the dissertation.

In summary, this literature review highlighted that people with dementia are being diagnosed earlier and with more accuracy and, more often than not, the diagnosis is being shared with the individual (Passmore and Craig, 2004; Warner, 2003; Philips and O'Brien, 2002). The review has shown that this change in trend has come about particularly due to the inception of medication for Alzheimer's disease, and an increased understanding of the needs of people with dementia through academic writings (Lindesay et al., 2002; Wilkinson et al., 2002; Downs, 1999; Husband, 1999; Kitwood 1997b). Although one of the perceived benefits of early diagnosis is that it allows people to plan for the future, there is little information as to whether this takes place or the level of thought which people with dementia put into appointing welfare attorneys. Moreover, it highlighted that people with dementia are not given as much information about the prognosis as relatives, either because they are perceived not to understand the information or to protect them from the truth (Downs et al., 2002). There is also the possibility that many would prefer not to plan ahead and to leave future decisions up to their families; however it is unclear if this is because they are not given the opportunity to discuss the future in depth or record their views.

Whilst the AWI (Scotland) Act 2000 states that the 'present and past wishes' of the adult should be considered when making any decisions, most of the information is obtained from family and professionals. One of the underlying themes throughout the literature review is that people with dementia are often subject to a paternalistic attitude and 'value judgments' from professionals and relatives, albeit in their 'best interests' (Wilkinson, 2001; Moye, 2000; Brandon, 1995; Ivers, 1995; Rankin, 1989). Hence, the purpose of this research is to explore the issues around engaging people in the early stages of dementia to discuss the future. It is noteworthy to reiterate Mason's and Wilkinson's call for practitioners to develop 'practical methods for involving the person with dementia in making decisions' (2002:62). The main focus of this research is to evaluate one such

practical method - the Values History. To begin this process the last section in this chapter poses the research questions which will be answered throughout the remainder of the thesis.

Research questions

How do professionals engage with people with dementia to discuss and make plans for the future?

To what extent are people with dementia able to discuss the future?

Are people in the early stages of dementia able to discuss and record their values?

To what extent should past wishes and values be promoted when a person loses insight into their condition?

Are Values Histories a practical way to empower people with dementia to maintain their values as the illness progresses?

Chapter Four:

Methodology

4.1 Introduction

4.2.1 Key methodological issues underpinning the study

4.2.2 Theoretical perspectives for the study

4.2.3 Theoretical Perspective: Focus groups

4.2.4 Theoretical Perspective: Interviews

4.2.5 Theoretical Perspective: Vignettes

4.2.6 Theoretical Perspective: Questionnaires

4.3.1 Ethical Considerations

4.3.2 Ethical approval

4.4.1 Research Design: Stage One

4.4.2 Inclusion criteria

4.4.3 Format of interviews

4.5.1 The Pilot Study

4.5.2 Pilot Study: Interviews with two people with dementia and their partners.

4.5.3 Pilot Study: Focus groups

4.5.4 Summary of Pilot Study

4.6.1 Stage one- process of interviews

4.6.2 Stage two- research design

4.6.3 Format of the professional interviews

4.6.4 Format of Vignettes

4.7 Codes for participants

4.8 Analysis and contemplation of data

4.9 Summary

4.1 Introduction

As indicated in the literature review the main purpose of this research was to explore issues in relation to engaging with people with dementia to discuss and document their future. The literature review also indicated that Values Histories (Appendix 1) could be one possible method to empower people with dementia. However, for empowerment to be meaningful, chapter three highlighted that there are three components that should be considered. The first two involve engaging with the person with dementia and the third aspect relates to stakeholders involved in their care.

For this reason the research was split into two parts. The first part involved interviewing twelve people with dementia and their potential carers, which enabled the first three research questions to be addressed. The second part answered the final research question by way of interviewing forty professionals who could potentially be involved in the care of people with dementia; social workers, psychiatrists, GPs, CPNs, residential care staff, district nurses, nursing home staff and voluntary care managers. In general, this approach could be described as ‘mixed methods’ or ‘pluralistic evaluation’ (Smith and Cantley, 1991). Where appropriate the research also draws on some principles of ‘action research’, in particular practitioners carrying out research (Butler, 2003; McNiff et al., 1996).

4.2.1 Key methodological issues underpinning the study

Eaterby-Smith et al (1997) highlight three reasons why the researcher should explore and understand philosophical ideology before undertaking a study. Firstly, it can clarify the overall research strategy to be used. For this study, which aimed to explore whether the Values History could be used to empower people with dementia, it helped clarify the type of evidence to be gathered, its origin, the way it was to be interpreted and how the evidence would answer the research questions. Secondly, understanding of research philosophy ensures that the researcher explores different methodologies by identifying the limitations of particular approaches at an early stage and avoids inappropriate use.

Prior to deciding to undertake a pluralistic evaluation the researcher attended Philosophy of Social Sciences classes at the University of Glasgow as part of the doctoral training programme. Being aware that the primary focus of this research would be driven by qualitative methodology he was able to explore various qualitative strategies, such as: phenomenology, ethnography, grounded theory, discourse analysis and participant observation (Morse, 1998). Thirdly it can assist the researcher to be innovative and more creative in their choice of methods that were previously outside their experience. The decision to adopt a mixed methods approach reflects this.

Whilst there is ongoing debate with regards to the advantages and disadvantages of qualitative and quantitative research, arguments tend to focus on methods (i.e. surveys versus free flowing interviews) rather than an exploration of the underlying philosophy. However, although research methods can be described, considered and classified at different levels, the most basic level of classification is the philosophical level (Clark, 1998). These distinctions tend to focus on the differences between positivism (associated with quantitative research) and post positivism (associated with qualitative research) (Polit, et al., 2001).

In general term 'positivism' assumes that 'things' can be studied as hard facts and the relationships between these facts can be established in scientific laws. Such laws have 'status in truth and social objects can be studied in much the same way as natural objects' (Smith, 1998). Within this kind of approach, epistemological assumptions conform to the belief that objective reality exists which is independent of human behaviour and is therefore not a creation of the mind. The use of mathematics and formulae logic to provide analytical statements in induction are means of generalisation and laws. Moreover, the aim of the positive approach is to cleanse scientific knowledge of speculation and subjectivity (Silverman, 2000).

Post positive approaches assume that a dependence on purely quantitative methods may neglect the social and cultural constructions of aspects of the variables that they seek to correlate through scientific methods (Silverman, 2000). It also assumes that that reality

is multiple, subjective and mentally constructed by individuals. It aims to describe and explore in depth phenomena, cognising that reality is co-constructed between those being researched (often called actors) and the researcher (Slife and Williams, 1995). The epistemological assumptions of the post positivist paradigm is that social knowledge is subjective and is shaped by the views of the values, beliefs and biases of the researcher. It also may only be valid for the specific 'actor', and shaped within the cultural context at that specific time. Moreover, where the positivist approach is concerned with validity, generalability and reliability, allowing for replication of findings the post positive approach allows for alterations in the design of the study as themes emerge, which are not always apparent at the beginning of a study (Silverman, 2000; Clarke, 1998). Popper (1959), for example, asks the researcher to avoid being dictatorial in research and to be intentionally critical, to test ideas to the limit.

Although the positive and post positive views are often seen as polarised, some view the philosophies as overstated (Green and Carcacelli, 1997; Gilbert, 1996). Indeed, some argue for the 'a paradigmatic stance', where the question of philosophy is ignored and methods are adopted as considered appropriate to answer the research question (Patton, 1990). Others argue that without a clear and stated philosophical base for the research, this may lead to lack of rigor and focus (Trinder, 1996). Given that this study was to explore multiple realities, perspectives and experiences of people with dementia, their carers and professionals, it was heavily weighted to the post positive approach. However, as indicated in the last chapter, there was a practical element to the study and the need to 'measure' usefulness of the Values History in relation to empowering people with dementia, a solely post positive approach would be limiting. Indeed, even within the field of qualitative research the researcher would draw on several different methodological approaches, although not claiming that any specific approach could answer his research questions in full.

For example, although not claiming to be a phenomenological study it certainly drew on some of the principles, which not only involves the researcher attempting to uncover the meanings of individual human experiences, but to gain understanding of the meaning of

these experiences in relation to the wider context of other people and situations (Slife and Williams, 1995). The study also draws strongly on the both the feminist (Rigger, 1992) and community methodologies (Ducket and Fryer, 1998), both of which attempt to address the inequality of the research, by 'developing empowering methods and contextualising the experience of research participants' (Pratt, 2002:166). In the case of participants with dementia, this involved creating safe contexts where their thoughts and feeling could be expressed, bearing in mind the potential for distress. Moreover, although not claiming to be based primarily on a social constructionism approach, the research certainly drew on some of the principles, in particular, by adopting a collaborative approach of interaction with the people with dementia and their carers, built up over a period of time, with a degree of reflexivity by the researcher (Jankowski, Clark and Ivey, 2000).

In striving to understand how to equate the differences in philosophies and draw on the strengths of multiple approaches, including both qualitative and quantitative approaches, the philosophy of Pragmatism was considered as a basis from which to proceed. Although this approach has been criticised for lacking 'epistemological discussions' and based on 'technical rather than epistemological or ontological grounds' it gives a sound underpinning for the use of a mixed methods study (Trinder, 1996).

Pragmatism describes a principle that determines value by assessment of usefulness or practicality (Johnson and Onwuegbuzie, 2004). It also asserts that it is inappropriate to ask questions unless some useful function or distinction can be made and the outcome has practical application. A pragmatic approach therefore evaluates theories and beliefs in terms of their practical success. According to the philosophy the world should be viewed from a pluralistic standpoint and is more complex and diverse than experiments allow. This is a view shared by the researcher. Moreover, 'truth' within this paradigm is considered to be relativistic and varies from person to person. Truth is mutable and relative to a conceptual scheme (Wikipedia, 2007). Fuller and Petch (1995) for example,

within the context of social work practice argue that , with the context of social work there can not be one view of ‘success’ amongst stakeholders and similarly, there is no ‘one user view’. Therefore, the pragmatic approach does not necessarily assume that results of a research project are generalizable and transferable, but are contextual. The important aspect is how to make the most appropriate use of that knowledge in different circumstances ‘working back and forth’ between specific results and there more general implications (Morgan, 2007: 72). Finally, a pragmatic approach would deny that there is any prior basis for determining limits on meaningful communication between researcher who pursue different approaches (i.e. qualitative and quantitative approaches), instead placing emphasis on ‘ shared meanings and joint actions’(Morgan,2007: 67).

The decision therefore to adopt a mixed methods approach, is driven by the belief that at a philosophical level, a pragmatic/pluralistic approach can provide a greater depth and understanding of the phenomenon being explored than could have been achieved using a singular approach. It suggests that the researcher takes an eclectic approach to methods selection, placing emphasis on the research questions and thereafter how the conduct of the methods can answer these questions, by the most practical methods, not being bound by a specific stance i.e. positive or post positive. Whilst it allows for a degree of creativity, it also calls for reflexivity on the part of the researcher and the need for the researcher to be knowledgeable across several methods of data collection and analysis. This obviously calls for the researcher to receive a high level of support which was given throughout the research.

The following section describes why a ‘mixed methods approach’ or ‘pluralistic evaluation’ (Smith and Cantley, 1991) was considered appropriate to answer the research questions. It also describes draws on some principles of ‘action research’, in particular practitioners carrying out research (Butler, 2003; McNiff et al., 1996).

4.2.2. Theoretical perspectives for the study

Smith and Cantley (1991) describe pluralistic evaluation as an approach that provides ‘complicated but realistic’ answers to the question as to whether a service or model of

care is successful or not. For the purpose of this research the model of care is current practice regarding how people with dementia are involved in planning their care and whether Values Histories could be used a tool to facilitate this. Smith and Cantley also recommend that the researcher must identify major constituent groups of the policy initiative, and compare them with each other, the comparisons being based upon the ideological perspectives that they hold and the operational strategies they adopt. For example, it is well documented that health and social work professionals have different ideological perspectives (Glasby, 2003; Marsh, 2003; Schon, 1983).

One of the main principles of pluralistic evaluation is that notions of success are not a singular measure, but a pluralistic notion, based on several measurements of success or failure (Greene and Carcelli, 1997). It is therefore sensitive to the importance of understanding the interpretation which different groups of professionals, planners, clients and their carers place on the particular model being evaluated. Furthermore, pluralistic evaluation must take into account the principles of methodological triangulation (Smith and Cantley, 1991). Methodological triangulation's relevance to pluralistic evaluation is that each source of data is tied to the interest of one group rather than another (interest bound), and also reflects one group's perspective on desirable modes of operation rather than the perspectives of other group (ideologically bound). Smith and Cantley (1991) put forward the argument that, by using pluralistic evaluation, the researcher can give reasons, by some criteria, why aspects of a service are succeeding or failing, and not merely the service outcome. This in turn opens the way for change and adaptation.

Similar to pluralistic evaluation, 'action research' highlights the value of using a variety of methods of data collection to enhance the validity of the research findings (Butler, 2003). According to Butler, 'methodological eclecticism' helps to achieve the building of a complete and detailed picture of the research issue. However, unlike pluralistic evaluation, the ultimate goal of action research should be to reflect on current practice and through research initiate positive changes, often with action and critical reflection taking place in turn (McNiff et al., 1996). Whilst this research does not claim to be a

piece of action research, it draws on the principles of practitioners carrying out action research, which pluralistic evaluation does not address in detail.

Practitioners carrying out research and reflecting on their practice is an area that is central to action research (Butler, 2003; McNiff et al., 1996). For example Butler states that action research 'acknowledges the role and effect of the researchers' personal values and beliefs in planning and conducting research' and 'the problems that may occur if viewing the researcher as the expert decision maker' (2003:1). However, one of the main drawbacks of practitioners carrying out research is that they cannot claim to be totally impartial and could be seen to have a vested interest in the findings (Butler, 2003). Furthermore practitioners can become so involved in the process that they attempt to prove their findings to change practice. Conversely, one of the main benefits of practitioners conducting research is that the approach is particularly useful for evaluating and improving practice, providing the practitioner with a 'powerful tool for change and improvement at a local level' (Lathlean, 1994 in Bulter, 2003:5).

Other advantages of practitioners carrying out research are that they can have increased awareness of problems and issues related to their clinical practice, well developed skills of problem analysis, interviewing, recording and filtering out the irrelevant. Moreover, practitioners often have better access to data than external researchers, which was the case within the current study (Fuller, 1999). However, according to Fuller they need to realise that their relationship with a patient has a different focus than that of a researcher, they can have a lack of research knowledge and confidence to carry out research, and there can be conflicts of allegiance when switching from the role of practitioner to researcher. Moreover, practitioner research studies tend to lack financial and academic resources available to external researchers. On the other hand the studies are usually smaller scale and local, often encouraging critical evaluation of services or innovative practice (Fuller, 1999; Cheetham et al., 1992).

With regards to the problems associated with the researcher viewing himself as an 'expert', or being 'partial', action research requires constant monitoring and evaluation of

the activity. One key component is that it requires critical self reflection on the part of the research practitioner, which becomes one of the themes throughout the research (Butler, 2003). Drawing on Schon's (1983) 'reflection in action' the practitioner has to acknowledge that they have an interest in transforming the situation from what it is to something they like better. Through his transaction with the situation he shapes it and makes himself part of it. Whilst on the one hand the researcher tries to control variables for the sake of objectivity, on the other hand the sense he makes of the situation must include his own contribution to it. For the purpose of the present study the researcher was not only interviewing participants to gather information, but also exploring issues in relation to engaging people with dementia from a clinical perspective.

Some caution that reflective practice lacks the rigour of empirical science (Newell, 1994). However, Schon (1983) argues that there are two types of knowledge: technical rationality and tacit knowledge. Whilst technical rationality is associated with empirical science, tacit knowledge is a way of knowing and understanding that which cannot always be articulated, but guides practice and is linked to experience and expertise. Schon argued that by reflecting on practice, practitioners can become aware of their tacit knowledge and thereby experience the dilemmas inherent in professional pluralism. Moreover, studying the ways in which professionals frame problems and roles may help them become aware of and criticise their tacit frames. According to Schon, one of the most important types of professional research relates to methods of inquiry and overarching theories of phenomena, from which practitioners base their professional decisions in specific situations. Regarding reflective research he states:

"Description and analysis of images, category schemes, cases, precedents and exemplars can help to build the repertoires which practitioners bring to unique situations" (1983:309).

Furthermore, rather than providing specific answers to set questions, reflective and action research would aim to develop themes from which, in specific situations, practitioners may construct theories and methods of their own. This sort of research may help others

in the same field to enter into a way of seeing, reconstructing and intervening which they may wish to adopt or consider.

The present study is therefore a pluralistic evaluation of a new approach to documenting values, and preferences of care of people with dementia. For the purpose of evaluation, carers, medical staff, social work and nursing staff are stakeholders in their care. Different groups of stakeholders were interviewed taking into account their ideological perspectives and their subjective criteria of success or failure. It drew on pluralistic methodology, using primarily qualitative aspects of research, but also a degree of measurement where appropriate (Parry-Langdon et al., 2003; Green and Caracelli, 1997; Smith and Cantley, 1991; Gilbert, 1996).

As outlined both pluralistic evaluation and action research call for mixed methods or 'triangulation' to enhance the generality of findings and to provides a means of validating information from different sources using several methods within one study (Butler, 2003; Smith and Cantley, 1991). Using different methods also allows for the weaknesses and strengths of different data collection to be balanced (Cheetham et al., 1992). For the purpose of this research the views of people with dementia, their possible carers and professionals were sought. Methods such as focus groups, semi structured interviews, vignettes and questionnaires were used. The following section explores the theoretical reasons behind their use, beginning with focus groups.

4.2.3 Theoretical Perspective: Focus Groups

There are many definitions of focus groups within the literature, but features such as organised discussion, collective activity and interaction between participants identify the contribution that focus groups make to research (Powell and Single, 1996; Kitzinger, 1994). According to Powell and Single a focus group is:

"a group of individuals selected and assembled by researchers to discuss and comment on, from personal experience, the topic that is the subject of the research"
(1996: 499).

However, unlike group interviews where a number of people are interviewed at the same time, focus groups rely on interaction within the group based on topics that are supplied by the researcher (Morgan, 1997). Moreover, focus groups elicit a multiplicity of views and emotional processes within a group context and are particularly valuable where participants have a common knowledge, but different views on a set topic (Morgan and Kreuger, 1993).

Some of the disadvantages of focus groups are that participants might not feel able to express their views openly, due to lack of articulation, lack of confidence or feeling others' views are more pertinent than their own, particularly where others are perceived as being more powerful in a professional sense. Participants also might not be as honest in a group setting as they would be interviewed privately. Moreover, some individuals may dominate group discussions, requiring the facilitator to ensure all of the group are allowed to express their views.

One of the main advantages of focus groups is that they enable the researcher to gain a larger amount of information in a shorter period of time (Race et al., 1994). Although they may be used as a method in their own right for research, some recommend that they may be used at the beginning of a study, to evaluate research or complement other methods. They are particularly useful for triangulation and validity checking, which is pertinent to pluralistic evaluation (Burton, 2003; Morgan and Kreuger, 1993; Smith and Cantley, 1991).

Bearing this in mind, three focus groups were conducted at the pilot stage of the study to ascertain the feelings and views of medical, nursing and social work professionals regarding the use of Values Histories and their implications for practice. Unlike the interviews in the main study, participants were asked their views on the research and asked for advice on the selection of candidates, the content of the Values Histories and the appropriateness of questions and vignettes. This is viewed as a benefit of focus

groups, in that they are a way to elicit information that allows the researcher to find out why an issue is salient (Morgan, 1997). Their responses are explored in section 4.6.3.

As alluded to, focus groups were used to point the researcher in the right direction as a preliminary measure to ensure that the information he was seeking was appropriate and relevant to practice, prior to conducting interviews. Section 4.1 highlighted the importance of conducting interviews to answer the research questions. The following explores the theoretical context for using interviews in the study.

4.2.4 Theoretical Perspective: Interviews

Although structured interviews are sometimes criticised for not leaving enough room for the interviewees to express their own opinions in a manner of their choosing, the main advantage is that they allow data to be gathered in such a way that it admits comparability between responses (similar to surveys and questionnaires). Very structured interviews are seen primarily as a quantitative approach (Sapsford and Jupp, 1996). At the other end of the spectrum, an unstructured interview allows the interviewee the opportunity to talk about a subject in his or her own frames of reference. Flexibility and the discovery of underlying meanings characterise this approach. This approach is seen primarily as a qualitative approach (Slife and Williams, 1995).

However, the approach adopted for the research includes semi structured interviews that allows the researcher the ability to probe and clarify answers, but still provide the structure to allow comparability of data (Robertson and Dearling, 2004). Interviewees were therefore able to answer on their own terms, but provide a greater structure for comparability. Given the greater degree of latitude offered to the interviewer, it is recommended that the interviewer is usually the researcher who will need to have an understanding of the content and context of the interview, and knowledge of the information which needs to be elicited (May, 1993). Ackroyd and Hughes give a definition of this type of interview as:

"Encounters between a researcher and a respondent in which the latter is asked a series of questions relevant to the subject of research. The respondent's answers constitute the raw data analysed at a later point in time by the researcher"

(Ackroyd and Hughes, 1983:66).

Furthermore, Ackroyd and Hughes advise that the researcher should, when analysing raw data, make comparisons between the influences and variables, drawing out themes from interview transcripts. However, a cautionary warning given by Slife and Williams (1995) is that the researcher should avoid the temptation to quantify phenomena, which is initially presented for qualitative research. They describe these types of interviews as:

"procedures for investigating human action that do not involve measurement and quantification, but allow subjects to describe their own behaviour and experience in their language" (1995: 200).

It could also be described as a phenomenological approach, which involves the researcher attempting to get at the meanings of human experiences by analysing these experiences in relation to the wider context of other people and situations (Slife and Williams, 1995).

As indicated throughout the literature review, it has only been over the past decade that people with dementia have been included in research. Prior to this, views of people with dementia were often sought from proxies (Wilkinson, 2002). Whilst several authors give advice on how to communicate with people with dementia and interview them for medical and social purposes (Cheston et al., 2000; Morton, 1999; Killick, 1994), at the time of the study there was a dearth of information regarding how to include people with dementia in research. However, after the interviews were carried out, Wilkinson (2002) edited the publication *'The Perspectives of People with Dementia: research methods and motivations'*, which described the skills that researchers need and methods they can use when seeking to draw out and validate the views of people with dementia. Some of the challenges mentioned within the book were very similar to those experienced within this study. However, it should be noted that whilst the interviews with people with dementia,

their potential carers and professionals could be classed as 'semi structured' the approaches to each group required different skills on the part of the interviewer. These differences are further explored in the latter part of this chapter.

With regards to the interviews with the professionals, Smith and Cantley outline one of the principles of the study, based on the concept of pluralistic evaluation:

"The research must identify the major constituent groups to the policy initiative and, throughout the research, compare them with each other, both in the ideological perspectives that they hold and in their operational strategies"
(1991.124).

As highlighted in section 4.1, groups of professionals identified as stakeholders in the care of people with dementia are from medical, social work and nursing backgrounds. Comparisons were not only made relating to their professional and ideological backgrounds, but how they viewed 'successful' care of people with dementia (operational strategy). Comparisons were also made between the different professional groups' attitude towards the Values Histories. In particular, by using vignettes, attitudes were elicited from professionals to establish whether Values Histories would influence their decisions regarding the care of people with dementia should they lose insight. The following section discusses the pros and cons of using vignettes in research.

4.2.5 Theoretical Perspective: Vignettes

Vignettes have been used to study attitudes, perception, beliefs and norms within social science (Finch, 1987). In social research they have been used to simulate real life events to hypothetical situations. Unlike their use in quantitative research where participants are given a set of predetermined choices, qualitative research can be used to stimulate discussion and elicit the interviewees' values, allowing them to expand and explain their thoughts (Wilks, 2004).

Those who advocate the use of vignettes state that they come closer to real life situations than generalised questions used in questionnaires or surveys. They also point out that vignettes can cover a wider range of situations than would crop up in direct observation (Holland, 1996). Moreover, some describe them as valuable, providing that it is general imagery that the researcher wishes to tap, and not the final detail (West, 1982). Another advantage is that they provide a way to elicit material about intimate details, values and attitudes, which it is difficult to gain access to in an empirical study (Voysey, 1975).

One of the main criticisms of vignette studies relates to the validity of the findings (Finch, 1987). These can be influenced at two levels. Firstly, one must consider the realness of the situation depicted in the vignette and the extent to which the vignette accurately represents the phenomena being explored. Secondly, there is no guarantee that the responses given to a vignette will mirror the actual behaviour of the interviewee in their practice (Wilks, 2004).

Concerning the realness of the situation, some have attempted to face this challenge by asking experts or professionals who have been in similar situations to evaluate the appropriateness of the hypothetical situations before the research is undertaken (Wilson and While, 1998). Similarly, this was the method chosen for this research, by way of focus groups in the pilot study, which explored situations professionals had encountered within their practice. Moreover, to add to the 'realness' of the vignettes the two Values Histories used had been completed by people with dementia, with only slight changes made to their backgrounds to protect anonymity.

With regards to the candidate's responses not mirroring their practice, it must be acknowledged that this is possibly one of the weaknesses of this research. Whilst professionals could claim that they would refer to the documents, in practice they might not. However, it is interesting to note that Gould (1996) argues one of the benefits of using vignettes is that, especially when looking at ethical dilemmas, hypothetical situations allow the participant to be freer in their responses because it is not personal and is less threatening than in practice. It should be noted for the purpose of this study that

the researcher probed the professional interviewees, many of whom gave candid accounts of what they would hope to happen and what they believed would actually happen in practice. These aspects will be further explored in chapter ten.

The final part within this section considers the rationale for using questionnaires within the study.

4.2.6 Theoretical Perspective: Questionnaires

One of the key elements to using questionnaires within the context of pluralistic evaluation is that the findings do not stand alone, but are used to validate or point the researcher in a specific direction (Parry-Langdon et al., 2003; Smith and Cantley, 1991). Some researchers use questionnaires and surveys as their primary source of data, using interviews and qualitative methods to add depth (Johnson et al., 2001; Mark et al., 1997). Others use questionnaires as tools to add strength and clarity to qualitative research (Arksey et al., 2004; Greene and Carcelli, 1997). Similarly, for the purpose of this research, questionnaires were used to add strength and to ‘yield summary’ to the respondents interviews (Cheetham et al., 1992:41).

For this research, questionnaires were included only for two key purposes. Firstly, rather than read a list of possible groups of people whom the participants felt would be appropriate to complete a Values History with a person with dementia, they were given a checklist to complete. Secondly, questionnaires were used to clarify and measure key aspects of the research which could be compared with their interviews. Professionals were therefore asked to score their strength of feeling regarding the extent to which they would refer to a Values History and the extent to which they felt Values History could empower people with dementia, if their condition deteriorated and they could not represent their views. Ordered and numeric rating scales are viewed positively within the literature as a way to ascertain participants’ attitudes to given topics and well documented (Moore and McCabe, 1998; Henerson et al., 1987). Participants were asked to complete

the questionnaires after the interviews as it was anticipated that they would be more aware of the purpose of the Values History (Henerson et al., 1987),

It should also be noted that the questionnaires were not anonymous. One of the disadvantages of this is that participants are less likely to be honest (Cheetham et al., 1992; Henerson et al., 1987). However, the advantage for this research was that the questionnaire could be viewed as the final process of the interview, allowing a degree of comparison with their responses throughout their interviews.

The following two sections discuss ethical considerations related to interviewing people with dementia.

4.3.1 Ethical Considerations

Prior to the research commencing, one area that had to be considered was ethical approval and consent of the participants with dementia to participate in the research. It should be noted that although the AWI (Scotland) Act (2000) makes provision for informed consent by a legal representative of the adult with incapacity, for the purpose of this research participants were in the early stages of dementia and able to give consent. Indeed, people in the early stages of dementia should not automatically be presumed incapable because of their diagnosis (Wilkinson, 2002; Bartlett and Martin, 2002). However, one key principles of the Act is that the research is 'likely to produce real and direct benefits' to the adult with incapacity (48:1a; 48:3a). For the purpose of this research the benefits included having their voices heard and possibly empowering them so that their views and values could be taken into account when decisions are made about their care in the future. It also informs service delivery, policy or practice which is viewed by some as an empowering process (Wilkinson, 2002). Moreover, the research gave individuals the opportunity to discuss their feelings about their illness and worries about the future.

According to Bartlett and Martin (2002) the process of gaining informed consent involves three aspects. Firstly the person should be fully informed about the research, secondly

consent is given freely and thirdly the person is competent. It should be noted that all participants were deemed competent to participate by a psychiatrist before the research was undertaken. It is noteworthy that consent should be viewed not as a single event but a continual ongoing process (Kayser-Jones and Koenig, 1994). For example, a person with dementia may forget that they have given consent, or the purpose, of the study and may need to be reminded or the issue of consent renegotiated at each visit. This is further explored in section 4.5.4.

Another aspect that needed to be considered regarded the researcher interviewing people with dementia from his own caseload. Potential participants could feel under pressure to participate in the research and there could be an element of confusion regarding the researcher's role (Butler, 2003; Hubbard and Martin, 2002). To combat this an information sheet highlighted that the individual's relationship would not be affected with their CPN should they decide not to be interviewed. This was further reiterated verbally to all the participants and at the time of consent and on other occasions when they forgot.

4.3.2 Ethical approval

For any research involving patients or carers to be undertaken within the Primary Care Trust the proposal has to be registered with the Research and Development Directorate and submitted to the Ethics Committee for approval. The proposal was therefore submitted in July and granted in September 2000 subject to slight changes. These included; the insertion of the Trust logo on the information sheet, the removal of the participants' date of birth and address from the consent form, and altering the phrase in the second line of the information sheet from 'you will require' to 'you may require' an element of care in the future (Appendix 2 and 3). In retrospect the researcher was pleased that the Committee had noticed this, realising that the change in wording was more tactful.

4.4.1 Research Design: Stage One

The following four sections describe the inclusion and exclusion criteria for stage one of the research, some information about the participants and the format of the interviews.

4.4.2 Inclusion criteria

Criteria for diagnosing dementia

All psychiatric patients who have been diagnosed by a psychiatrist within the Primary Care Trust are allocated an ICD10 number, which is a mechanism for categorising mental illness. For the purposes of the research a diagnosis of dementia as substantiated within ICD10 was acceptable. Dementia included Alzheimer's disease, vascular dementia or Lewy body dementia. The participants' diagnoses were confirmed by their psychiatrist and their agreement was sought to clarify that the individual would be suitable for the research and able to give consent.

Mini mental state examination (MMSE)

The mini mental state examination is one of the most widely used assessment tools for screening cognitive performance in people with dementia (Folstein et al., 1975) and, according to the British National Formulary (1997), a score between 14 and 26 indicates the early stages of dementia. However, for the purpose of the study it was felt that this would only be a general rule and one person was included without assessing their mini mental state as the person experienced dysphasia and would have found the assessment too distressing. Moreover, it is generally recognised that some people with dementia who experience communication problems can score lower on the MMSE due to an inability to articulate their thoughts rather than cognitive impairment (Pratt, 2002; Jacques and Jackson, 2000). One person was included with a MMSE of 29 out of 30. It is noteworthy that at the time of his referral he scored 26 out 30; however, after commencing on a cholinesterase inhibitor his cognitive state improved.

Insight

All participants were aware of their diagnosis and had at least a moderate degree of insight into their condition. The literature review highlighted that some researchers reported a fluctuation of insight throughout the course of the illness (Markova and Berrios, 1995; Killick, 1994), whilst others predicted a steady decline in the level of insight related to a decline in cognitive abilities (McDaniel et al., 1995). A recognised scale to categorise level of insight was designed by Verhey et al (1993). The scale involves asking the person's carer or health care professional to rate the individual in one of four categories, saying how aware the person is of their impairment. Those who are categorised having an 'adequate' or a 'mildly disturbed' level of self-awareness were selected for the study (Appendix 5).

Access

Medical and nursing staff at Eastvale Resource Centre were informed of the proposed research at regular research meetings. The locality manager gave agreement for the researcher to ask colleagues for referrals. Medical and nursing colleagues agreed to vet their current caseloads and new referrals for potential participants who fulfilled the inclusion criteria.

Informal carers

Traditionally the concept of caring is task oriented and focuses on activities, such as lifting, bathing and cooking (Quershi and Walker, 1989; Finch, 1987; Evendrouet et al., 1986). However, Twigg and Atkin (1994) distinguished between physical and mental illnesses and suggested that most people with mental illnesses do not require assistance with physical tasks. They suggested that two criteria, namely kinship (the emotional obligation) and responsibility are more apparent. According to Twigg and Atkin:

"in the case where the 'cared for' person has no need for physical help, the sense

of being responsible, is the primary element of care giving, and we would argue, represents the core feature that underlines all care giving” (1994:9).

In the case of early dementia, individuals may not require assistance with physical tasks, but require supervision, monitoring and co-ordination of services (Jacques and Jackson, 2000; Cheston and Bender, 1999). Twigg and Atkin (1994) also point out, that a feeling of responsibility for the person's conduct and actions can be as demanding on the carer as carrying out physical tasks for the person.

For the purpose of the present research an absolute definition for an informal carer was not required. It should be noted that although the term ‘carer’ is used throughout the thesis, at the time of the research many relatives were not providing physical care and did not perceive themselves as carers. It was acceptable for the potential carers to either be living with the person or separately.

Prior contact

The researcher had varying degrees of contact with participants prior to study, ranging from no contact to over three years contact, with six participants known to the researcher beforehand in his capacity as a CPN.

Source of referrals

- 6 from study conductor's caseload
- 5 from other CPN's caseloads.
- 1 from carers' organisation

4.4.3 Format of interviews

A total of five interviews took place for each unit (person with dementia and carer) of the research. Similarly, Gibson (1990) recommended that it could take up to five interviews

to complete a Values History with individuals with terminal illnesses, albeit to include an advance directive. One of the advantages of this approach is that it allows the repetition and confirmation of issues (Marquis and Jackson, 2000). Marquis and Jackson suggested that 'prolonged engagement' is a minimum of two interviews with the same person and is particularly useful where there is concern about the stability of the perspective of the individual and the accuracy of the information. Moreover, it may help to build a trusting relationship whereby the interviewer is entrusted with access to the private domains of the interviewee's life and thoughts (Clarke and Keady, 2002). The format of the interviews was as follows:

Interview one

An initial interview took place with the person with dementia and their carer to explain the format of the research, the background of Values Histories and to answer questions about the research. MMSE was carried out on the person with dementia and their level of insight in to their condition established (appendix 4 and 5). Written explanations were left for the person with dementia (as it was presumed they were experiencing some memory problems). The person with dementia and their carer completed consent forms.

Interviews two and three

Two further interviews were carried out with the person with dementia alone to complete a written Values History and explore their feelings about having dementia and the future.

Interview four

This was conducted with the carer alone to discuss the Values History in relation to their perception of their person with dementia. The carer was then asked to discuss the Values History with the person with dementia without the researcher being present. They were encouraged to discuss the Values History with any other significant family member

that might be involved in the person's care in the future.

Interview five

The final interview was conducted with the person with dementia and their carer to discuss the Values History and ascertain if it raised any issues between them and to evaluate how accurately it represented the person's values.

Prior to undertaking the main study a pilot study was carried out. The following section describes the purpose of the pilot study, the format and themes which emerged during the process and how they related to the main study.

4.5.1 The Pilot Study

The primary aim of the pilot study was to evaluate the design of the main study and to ascertain if the methodology chosen would allow the research questions to be answered. It included interviewing two people with dementia and their wives. Thereafter a selection of health and social care staff were consulted by way of three focus groups to ascertain their view of the Values History documents and the design of the research.

4.5.2 Pilot Study: Interviews with two people with dementia and their partners.

Format of the Interviews

The format of the study included an introductory interview, two interviews with the person with dementia, an interview with the carer and a final interview with the person with dementia and their carer. This was the same format as the interviews for the main part of the research.

The participants

Both Malcolm (appendix 8) and Jack (appendix 9) lived with their wives and both participants chose them to be their proxies should their condition deteriorate. They were both from professional backgrounds and were aware of their diagnosis. However, it is interesting to note that Malcolm, although aware of his diagnosis, denied that he had Alzheimer's disease, choosing to believe that his symptoms were related to a sports injury several years earlier. Despite this, he was able to give a clear account of how the illness affected his life and was comfortable with the interviewer using the term Alzheimer's disease.

It should be noted that the researcher had known both Malcolm and Jack for about three months prior to the research. Both were aware that they were assisting in the pilot stage of the study and the researcher was looking for advice from them regarding the questions and format of the interviews. Malcolm understood this throughout his interviews and having a background in university research, appeared to enjoy the opportunity to discuss his PhD and the importance of research in general. On the other hand Jack's awareness appeared to fluctuate, at times completely understanding the purpose of the pilot study, and at other times believing that his interview was related to a dementia support group which the researcher facilitated. Although he claimed to enjoy participating in the research, in hindsight the researcher realises that one of the possible problems associated with practitioners carrying out research is that participants may feel obliged to participate due to the previous relationship and possible confusion as to the role of the researcher. The information sheet therefore clarified that should a person not wish to participate their relationship would not be jeopardized (appendix 2).

The researcher was also aware that he had chosen Malcolm and Jack for the pilot study because he felt relaxed in their company and they were open about discussing their illness. The researcher also realised during transcription of the tapes that he had prompted Jack and Malcolm on several occasions during the interviews based on his previous knowledge of them. He therefore was aware that it would be imperative to

interview people not known to him to compare the difference that a working relationship and prior knowledge of the participants made to the process of writing the Values Histories. This theme is explored in chapter ten.

The remainder of this section discusses the format of the five interviews from a methodological perspective.

Interview one

The initial interviews with both Malcolm and Jack were fairly straightforward and both understood the questions. Jack needed to be reminded by his wife of the purpose of the interview on more than one occasion. This did not cause any problems, but the researcher did realise that this could cause someone living alone, without a spouse to remind them, a degree of anxiety. Both men scored within the MMSE criteria for the research, but it was suggested by Malcolm's case notes that his low score on the MMSE might give a false impression of his level of confusion because of dysphasia. It was therefore decided that, although, in general, participants selected would have scored between 14 and 30 out of 30, selection would be more flexible if dysphasia was present. This also allowed an evaluation of the difficulties which could arise compiling a Values History with people who have communication problems.

Interviews two and three

Jack and Malcolm both had fairly good concentration and were able to recall much of the material from one week to the next. However, it was recognised that other participants within the main study would not necessarily be able to recall information, which was the case with some participants within the study. The time period between interviews was approximately seven days. The length of the interviews was between 3/4 hour and 1 hour and the interviews took place in the participants' homes. This was satisfactory and the researcher managed to get all the information required for the research during this time.

Whilst both participants were able to discuss the impact of the illness, their values and aspects of their lives that were important to them, both had difficulty recalling specific background facts, especially in relation to names of places, family members and dates. Headings and themes from the Values History document were used as a basis for the interviews. However, the third interview differed with each of the participants. Whereas Malcolm's interview had consisted of completing the second half of the document, Jack had completed the document during his second interview and therefore the third interview recapped on the previous information. It is interesting to note that upon recapping, Jack expressed similar values as he did in the first interview. It was therefore decided that, where possible, the latter approach would be used as this could explore continuity of participants' values from one interview to the next.

One point made by Malcolm was that the proxy could die before the person with dementia. This was a valid point and the document was adapted to include a second nominee should this happen.

Interview four

The main purpose of the interview with the carers was to discuss the values of the person with dementia as a way to compare their knowledge of the values of the person with dementia with their own. Again the Values History form was used as the format for the discussion. Another aspect of the research was to ascertain if it had opened up a degree of discussion between them and what the person with dementia had expressed any anxieties about the interview. These aspects are further explored in chapter 10.

In general the interviews with carers in the pilot study were successful and the format remained the same throughout the research. However, one area which became a theme throughout the research was striking a balance between obtaining information for the research and providing carers with information about the illness. Whereas Jack's wife often apologised for asking questions and left her questions till the end of the interview, Malcolm's wife chose to use the interview as a way to obtain information from the

researcher about the prognosis and support available and the researcher often found he was speaking more than the interviewee. This interview lasted approximately ninety minutes. Aware of this in the main study, the researcher tried to encourage carers to leave questions till the end of the interview. However, in practice many carers used the interview as means of sharing their problems and seeking information about dementia.

Interview five

The final interviews were designed to ascertain how accurate the participants felt the complete Values History was, general comments about the use of Values Histories, the interviews and whether the process had prompted discussion between the couples. Again this proved a useful approach and the format remained the same throughout the research. However the pilot highlighted two points which needed consideration.

Jack's wife suggested that his Values History did not reflect a pedantic side to his nature which she felt would be important for other to know about him. However, whilst the researcher could see how this information would be useful, the purpose behind the Values History is to document the views of the person and not the carer. This point was discussed with professionals in the focus groups.

Malcolm suggested that prior to the interviews they should be given a copy of the questions to prepare for the interview. However Jack stated that he preferred the conversational aspect of the interview. Moreover, his wife stated that Jack panicked when he received paperwork to deal with and thought it would confuse him. It was therefore decided that the participants should be given the choice of a list of themes, which they might or might not choose to read.

Another area highlighted was the fact that, since the onset of the disease, Malcolm had experienced a degree of dyslexia and dysgraphia (Jacques and Jackson, 2000), which caused him difficulties when checking over the document. Whilst his wife took time to read and explain the document to him it could not be anticipated that all carers would be

so diligent. However, within the main study it was noteworthy that the vast majority of carers took their responsibilities seriously to assist the person with the document.

Summary

In summary it was felt that the process of conducting five interviews, incorporating minor changes, was appropriate for the main study. However, prior to commencing the main study, the Values Histories were shared with professionals in three focus groups.

4.5.3 Pilot Study: The Focus groups

Three focus groups were conducted between December 2000 and February 2001, and included medical, social work, psychology and nursing staff. Some of the comments are included in the remainder of the thesis. However, this section clarifies how information from the focus groups helped to shape the research design. The focus groups consisted of the following professionals:

Focus Group One: Social Work (table 1)

Profession	Code
Senior Social Worker	FSW1
Senior Social worker	FSW2
Basic Grade Social Worker	FSW3
Social Work Assistant	FSW4
Community Care Manager	FSW5

Focus Group Two: Medical and Psychology (table 2)

Profession	Code
Consultant Psychiatrist	FMed1
Staff Grade Psychiatrist	FMed2
Senior Registrar	FMed3
Senior Psychologist	FMed4

Focus Group Three: CPNs and Health Care Assistants (table 3)

Profession	Code
G Grade CPN	FN1
G Grade CPN	FN2
E Grade CPN	FN3
E Grade CPN	FN4
B Grade Health Care Assistant	FN5
B Grade Health Care Assistant	FN6

Immediately prior to the focus groups commencing the participants were given the two completed Values Histories to read. At the beginning of the sessions the participants were informed of the general purpose of the research and that the information from the groups would help give focus to study, which was still in tentative stages regarding methods. He therefore asked them to be as critical as they could and that suggestions would be helpful. He asked open ended questions regarding the general usefulness of the Values Histories, their practical value and what they saw as the main issues for professionals, carers and people with dementia. He referred to the subheadings in the Values Histories, again asking how appropriate the information would be to them in their practice. Finally he asked for their opinions on the research design, in particular, the professional groups that should be included in the study.

The groups were tape recorded and transcribed by the researcher. Thereafter, he analysed the data by highlighting themes and colour coding the information. He was able to look at general trends across the three focus groups and ones which were specifically related to each group. The focus groups were particularly useful in assisting the researcher to decide the information which was incorporated in the Values History documents and questions for the professional interviews. Three useful themes that emerged from the groups were; i) general comments regarding values, ii) the information regarding proxies and iii) the structure of the Values Histories. The following section summarises some of the points.

i) General comments regarding values

In general, the Values Histories were viewed very positively by all staff. However, after the initial positive responses from staff, they were encouraged to think more deeply about the wider concept of values and whether they change as the illness progressed. This proved very useful, in that there was a lot of debate around the issues as to whether values change over time, and if past wishes should have precedence over present should the person lose insight. Responses ranged from those who felt previous values should always be upheld to those who thought that the current values of the person were more important as the dementia progressed. There was also debate around the type of values which could change and those which were less likely. Some of these included religious values, family values, morals and independence. This therefore clarified for the researcher that the theme of the main research would include a selection of these values and possible scenarios to elicit professionals' opinions.

ii) Information regarding proxies

Another area that provoked debate and discussion within the groups was concerning people with dementia appointing a proxy. There was general recognition that the information regarding a proxy would be very useful and many had described scenarios and experiences where there had been conflicts between different family members'

wishes for the patients and suggested that a written document stating the person's chosen proxy could have helped. There were three key points which would be expanded upon in the main part of the research.

Firstly, the majority of staff admitted that they rarely asked the person if there was anyone specifically that they would want to represent them should their condition deteriorate, with many suggesting that they presumed the relative either accompanying the person to a consultation or living with the person should represent them. Secondly, the degree of acceptable risk that some carers felt the person with dementia should be allowed to take to remain at home often conflicted with the person's own views. Several staff reported that carers often considered the person's safety more important than freedom to take risks and resulted in premature applications being made for long term care placements. According to one social worker:

"It amazes me how families often break their necks trying to get the burial right or follow the person's wishes to scatter their ashes in the right place and yet they're not as staunch when he wants to stay in his house for as long as possible" (FSW 4).

Thirdly, some concern was expressed that the Values History may put some carers under undue pressure to keep the person at home longer than they were either able to care for the person (or wanted to). Several suggested a separate Values History for the carers, or using the Values History as the beginning of a 'contract'. One social worker suggested that it would be appropriate to record how the carer sees the future and how involved they would like to be in the person's care. One doctor suggested that the Values History could be used therapeutically to 'discuss problems while there is still time and the person is aware' (FMed2).

iii) The Values History Documents

The vast majority preferred the form which was written in the first person (Malcolm), believing it to have more impact on them. Jack's document was written in the third person due to dysphasia and all agreed that the quotes helped to personalise it. It was also felt that the author could change grammar, but it would lose effect if the person's words were changed too much. In general, staff felt the documents were the right length and easy to read. However, many felt that GPs would not read the documents in their entirety and suggested an abridged version. All staff felt that the documents would be particularly useful for long term care providers and carers, many of whom would never have known anyone in the early stages of dementia. All felt it was very appropriate to include their views in the study. Many also clarified that the voluntary sector should be included in the study as they provide much of the direct care for people with dementia in their homes.

Whilst none of the participants recommended the removal of any information from the Values Histories, some pointed out additional information could be included. For example, one doctor suggested that spiritual matters could be expanded to include the person's views and feelings on life after death and how their faith affects their life. He felt that the section read more like a report and missed how the person felt about their beliefs in God etc. He stated that it was 'almost there, but not quite enough'. In addition he felt that more details regarding the person's spiritual beliefs could help the family cope with difficult decisions should he require life-extending treatment. More background information and past traumas and challenges which have shaped their lives were also suggested to give more appreciation 'for the person'.

4.5.4 Summary of Pilot Study

In summary, the focus groups helped to clarify that the main aims of the research were topical and relevant to practice. The practical advice regarding the writing of the documents was adopted, including more background information, thoughts regarding

medical treatments, whether individuals would want to be informed if their condition deteriorated and more in-depth discussions about spiritual matters where appropriate. Moreover, where possible, the documents would be written in the first person, with personal quotes when written in the third person.

One suggestion by social work and medical staff was that a separate Values History should be completed for the carers. However, although the researcher felt this was a valid point, the main focus of the research was to empower people with dementia and to document their values and views before their condition deteriorates. Rather than complete a separate Values History for their carer or dilute the person's Values History the researcher decided to give carers the option to include an appendix with their comments.

With regards to the second stage of the study, the researcher clarified that using Values Histories was an effective way to promote discussion. It also showed that perceptions differed about how much emphasis should be placed upon the previously expressed values of people with dementia and whether or not they change as the illness progresses.

As highlighted in section 4.1. the main study was carried out in two phases. The first phase involved interviewing twelve people with dementia and their carers, the second phase interviewing forty professionals. The following section describes phase one and section 4.7.2 describes stage two.

4.6.1 Stage one- Process of interviews

As highlighted in earlier chapters, prior to the research being carried out there was a dearth in the literature regarding carrying out research with people with dementia. However, over the past few years, researchers who have conducted studies have discussed some of the challenges of how to engage with individuals with cognitive impairment to carry out qualitative interviews. It is interesting to note that many of the challenges were similar to those found in this research.

With regards to cognitive abilities, it is well documented that people, even in the early stages of dementia, may experience short and long term memory impairment, difficulty understanding and comprehending information and difficulty concentrating (Jacques and Jackson, 2000). Chapter two also highlights that fluctuating awareness and denial are common in the early stages of dementia (Howorth and Saper, 2003; Clare, 2002; Bucks, 1998). Moreover, whilst communication difficulties and apraxia are more likely to be associated with moderate and latter stages of the illness, some may experience this in the early stages. This in fact was the case with two of the participants, who had difficulty expressing their thoughts. These aspects are discussed throughout the remainder of the thesis as they are directly related to the research.

All the interviews took place either in the person's own home or, in the case of two participants, in their relatives' homes. Similarly, others have recommended that interviews should take place in a familiar environment (Cotrell and Schulz, 1993). In general the interviews lasted approximately one hour. However, some lasted longer with one lasting up to two hours. It is interesting to note that whereas some researchers recommend that interviews should be relatively short, possibly 45 minutes to accommodate for concentration problems, others report interviews lasting up to two hours (Clarke and Keady, 2002; Robinson, et al., 1997). Clarke and Keady state that the timing of the interview should be set by the interviewee to allow them to feel in control. In this study most wanted to continue for longer than the allotted 45 to 60 minutes and enjoyed the opportunity to talk and reminisce beyond the time of the interview. Similarly, Clarke and Keady suggest that interviews should be seen as more than tape recorded time, with time for social engagement at the beginning and end of interview. They state that leaving too quickly can result in the person feeling 'used'. However, this caused the researcher some difficulty as, at times, participants gave valuable information after the 'recorded time'. Moreover, this has wider implications for the writing of Values Histories, especially if written in the first person. This is further discussed in chapter ten.

Clarke and Keady also suggest that there will be times when the tape recorder is turned

off during the interview, possibly due to the emotional content of the discussion. They suggested that the interview should be seen as a process of negotiating any information which the individual would not want recorded or used for the research. This happened on several occasions throughout the research. In particular, two participants became upset, one whilst discussing the death of his wife and the other discussing relationship problems within his family. The researcher therefore switched the tape recorder off during these times and gave them the opportunity to discontinue. Both however chose to resume the interview. Similarly, Froggatt (1988) states researchers need to acknowledge that the interview will have an emotional impact on the person and themselves.

One of the main difficulties experienced by people in the early stages of dementia is short term memory impairment (Jacques and Jackson, 2000). Although the majority remembered the purpose of the interviews, some forgot at various stages and needed to be reminded. Clarke and Keady (2002) suggest that the interviews should be seen as a continual process of negotiation. In particular, one participant forgot several times the purpose of the interview and expressed suspicion regarding the use of the tape recorder. On each occasion he was reminded the purpose of the interview and was given the option to discontinue or be interviewed without the tape recorder. Each time he was easily settled and expressed a wish to continue. Similarly Pratt (2002) suggests that the interviewer needs to continually re-establish who they are and the reason for the interview and consent should be seen as an ongoing process.

One of the main areas where many participants' memory impairment became apparent was when asked for background details, especially in relation to giving dates, names and places. This is an area where the researcher had to be flexible in the questions asked and to consider early in each interview how much information the person would be able to give. The researcher also had to be aware of how individuals reacted when they could not recall information and adapt his style accordingly. Whereas some were able to joke and use humour when they could not recall information, others appeared distressed. Several other researchers have also reported that recalling information can be stressful for people with dementia and suggest that in such cases participants should be encouraged to

discuss feelings and experiences rather than fact (Bender, 2003; Clarke and Keady, 2002). However, one of the purposes of the research was to study the process of completing Values Histories with people with dementia and the extent to which they were able to give details was an important aspect of the findings. This is further discussed in chapter nine.

One aspect of the research methodology that differs from other research is that of discussing the diagnosis with participants. Several authors recommend that the diagnosis should only be discussed if the person mentions it in the first instance (Pratt, 2002; Mason and Wilkinson, 2002; Wilkinson et al., 2002). However, in this study the researcher specifically mentioned the diagnosis to the participants. It should be noted that it had been clarified beforehand that all participants were aware of their diagnosis and the information sheets stated that the reason they were being interviewed was because they had dementia. Their reactions were relevant to the research findings and are discussed further in chapter five.

It should also be noted that one participant was particularly difficult to engage with and possibly became too confused for the study despite initially having a MMSE of 24 out of 30 and classified as having a moderate degree of insight by her CPN. She experienced difficulty answering basic questions, expressing her thoughts and following themes. She experienced some thought blocking, often stopping mid sentence. On several occasions she walked towards her window, was wringing her hands and appeared agitated. It is noteworthy that Bartlett and Martin (2002) mention that the researcher should be aware of participants' non verbal communication and look for signs of distress. On several occasions the researcher asked if she would prefer to stop the interview. However, she wished to continue stating that she enjoyed the company! After the interview the researcher telephoned her daughter and was informed that the participant had been agitated due to a change in home help, which upset her routine. Furthermore she informed her daughter that she enjoyed the interview and was looking forward to the next one. Pratt (2002) states that allowance should be made for people with dementia 'having a bad day'. However, on the next occasion her behaviour was the same. After this

interview the researcher initially thought that another participant should be selected. However, on the contrary this proved to be a learning curve for the researcher as he realised that the research was about presenting the positive and negative aspects of documenting people's values and to exclude this participant would present the research in a false light. Moreover, despite many inaccuracies in her Values History her daughter felt that the expressed values were accurate. This was pertinent to the research and further discussed in chapter eleven.

Another example where the researcher initially felt that he had made an inappropriate selection of interviewee was related to a couple who were experiencing relationship problems. The couple were arguing at the time of the researcher's arrival to interview the participant with dementia. Although the researcher gave him the option to make another appointment, he agreed to the interview taking place. However, during the interview the participant's wife entered the room and stated that he should not say anything which would present her negatively and again they started arguing. Moreover, both participants spoke at length about their marital problems during their interviews. At the time the researcher thought that due to their relationship difficulties it might not be appropriate to include them in the study. However, upon reflection he decided to include them and this became one of the underlying themes to emerge from the research, namely, how honestly can people with dementia record relationship problems and appoint a proxy.

Another aspect of the research, similarly highlighted by Pratt (2002), is for the interviewer to be prepared for difficult questions. According to Pratt it is up to the researcher to be honest without providing information that is outside their knowledge. One of the most common questions participants asked was about the prognosis and possible deterioration. This is one area where the researcher initially felt awkward. However, after conducting several interviews the researcher learned to reflect questions by asking the participants what they knew about the illness. He also learned that an effective way to approach such questions in an honest way without frightening the person was to give examples of people he had known who had deteriorated quickly and some where there had been minimal deterioration over the years. He also gave examples of

people he had known who lived independent lives and others who required long term care. This is discussed further in chapter ten.

Whilst the interviews of people with dementia could be classed as semi structured they differed somewhat from the carer and professional interviews and were less structured. This allowed participants to 'tell their story' in their own time (Pratt, 2002) and possibly leaned towards unstructured or informal interviews (Robertson and Dearling, 2004). Similarly, many carers digressed from the questions during their interviews. Several carers used the opportunity to ask questions about the prognosis of the illness and report some of the problems they were experiencing and the impact the dementia was having on their lives. Moreover, some of the carers that the researcher had known beforehand as a clinician, asked for booklets and details about medication and found it difficult to separate the role of the researcher from practitioner. This however did not cause any problems, but several interviews lasted approximately ninety minutes instead of the allocated sixty. Similarly, Clarke and Keady (2002) report that interviews with relatives may need to be lengthy as they struggle to understand the minutia of the person's illness and try to come to terms with their condition. However, upon analysing the interviews thereafter the majority had given the appropriate information for the study.

Another aspect that is noteworthy regards the interviews which involved both carers and participants. Several participants with dementia were notably quieter and tended to leave their carers to speak for them, often deferring to them when asked questions. Moreover, at times, when the person with dementia stated something which they considered inaccurate the carer would use non verbal communication to indicate to the researcher that the information was wrong. In particular, one person with dementia spoke of various siblings being alive. His wife indicated by eye contact that they had in fact died. However, some carers were open, and tactfully corrected the person in such circumstances. It is clear that there is no right or wrong way for relatives to deal with forgetfulness (Bender, 2003).

4.6.2 Research design: Stage two

The second stage of the research involved interviewing forty professionals, all of whom worked in the south side of Glasgow. As highlighted in section 4.2 of this chapter, one advantage of practitioners carrying out research is that they often have better access to participants (Fuller, 1999). The researcher approached the vast majority of the professionals to be interviewed directly; the remainder were contacted by colleagues. However, it should be noted that the researcher knew several of the participants on a professional basis beforehand, particularly those within the mental health field. Whilst one could argue that in such cases participants could try to please the interviewer in their response, one could also argue that they are more likely to be honest (Robertson and Dearling, 2004). This approach can best be described as ‘convenience sampling’ (Fuller and Petch, 1995). It should be noted that, although some might consider sample methods adopted by practitioner researchers inferior to those adopted by general social welfare researchers, Fuller and Petch state that of more importance is the necessity for the researcher to have a clear understanding of what can be concluded from the sample under scrutiny. Moreover, they opine that the researcher should be aware of the extent to which it is appropriate to draw out generalisations. However, for the purpose of this study generalisations are only made occasionally and the information is presented thematically in the hope that it may help others in the same field to enter into a way of seeing, reconstructing and intervening with people with dementia (Schon, 1983).

The following section describes the process of the professional interviews. As indicated in section 4.2 the interviews were semi-structured (appendix 6), based on progressive vignettes using two Values Histories.

4.6.3. Format of the professional interviews

The two documents chosen by the researcher for this stage of the study belonged to Marie (appendix 10) and Sylvia (appendix 11). As highlighted in both the literature review and the focus groups, aspects such as relationships, family values, attitude towards risk, and

religious values were aspects where Values Histories could be particularly relevant with people who have dementia. Whilst many of the Values Histories could have been used, Sylvia had expressed particularly strong views regarding her independence and Marie had very strong religious values, which the researcher thought could be expanded upon by way of vignettes. Both had also expressed their feelings about having dementia, which were also used successfully for discussion.

Semi structured interviews with the professionals took place either at their place of employment or a mutually arranged venue. Participants were given the two Values Histories to read approximately a week prior to their interviews. The vast majority had read them beforehand with only a few reading them at the beginning of their interviews. Some staff had however put effort into their task, having highlighted points within the documents and notes of reference. Interviews lasted between 45 to 60 minutes and were tape recorded and thereafter transcribed onto a PC using Nud#ist, the social science software package designed to allow coding of descriptive material, which can then be analysed and comparisons made when all data has been collated.

4.6.4 Format of vignettes

The two Values Histories were referred to throughout the interviews. Within each interview a series of progressive vignettes were shown to the candidates depicting various scenarios related to people with dementia's care in the community. Their opinions were sought on how they would manage the scenario if they were faced with similar situations. By introducing Values History progressively into the scenarios, the impact of the professional groups has been evaluated.

The document relating to Sylvia highlighted that she trusted her daughter in law and son 'with her life'. Participants were asked to imagine that Sylvia's condition had deteriorated and her family had unsuccessfully tried to persuade her to accept home care. Sylvia then accused them of interfering and refused to have contact with them. Participants were asked if they would still have contact with her family and to what

extent. They were then informed that Sylvia had specifically requested that she did not want them to have any contact with her family. This led on to general discussions about appointing a proxy and the usefulness of her statement.

Sylvia's document highlighted the importance that she placed on her appearance and hygiene and how she had a fear of becoming dirty as the illness progressed. Participants were asked to imagine that Sylvia's appearance had deteriorated to the extent that she was unkempt and had a distinct body odour. They were also informed that she was content and believed that she still had a shower each day. Participants were asked how they would deal with this situation. They were then informed that she became upset and agitated when it was suggested to her that she was neglecting herself. Participants were asked how relevant her statement was and if it would be in her best interests to cause her a degree of agitation to respect her past wishes. They were also asked if it would be relevant to tell her 'white lies' to persuade her to bathe.

Sylvia's document highlighted her fervent desire to live independently and stay at home 'until the Good Lord takes her'. Her document also stated that she was willing to take an increased degree of risk to live at home as long as she was not putting anyone in danger. Participants were asked how feasible it was for her to record this information and if it would make any difference to the level of risk she should be allowed to take. They were then informed that Sylvia had been 'wandering' and a case conference was being held to consider her for residential care, to which she was opposed. They were asked if it would be appropriate to refer to the document at the conference and if they felt her past wishes would make a difference to the outcome. Conversely, they were asked if the document would make a difference to the outcome if Sylvia had stated that safety was more important to her than independence.

Marie's Values History highlighted the section where she stated that she favoured homeopathic medication to conventional medication. Participants were asked to imagine that Marie was admitted to residential care and had no awareness of medication she was prescribed. They were asked if her previous wishes should be adhered to, and to what

extent, if she required medication for either agitation or a chest infection. It was noteworthy that most stated they would ask her family. The question was therefore changed and they were asked to imagine that she never had a family and if the Values History would stand alone to represent her wishes.

Marie's document also highlighted that she never celebrated Christmas due to strong religious convictions and asked to be excluded from celebrations. Again participants were asked to imagine that she was in residential care and had minimal awareness. They were informed that Marie appeared to forget her religious values and was happy to join in Christmas parties, enjoying the Christmas carols. They were asked if her previously expressed values should have precedence over her current enjoyment. Again the question was adapted and they were asked to imagine she had no family and they had to decide what was in her best interests.

Finally, Marie's document highlighted that although she did not believe in euthanasia, she did not want her life prolonged 'beyond her natural time'. Participants were asked to imagine that Marie was in the latter stages of dementia, was doubly incontinent, could not communicate and had no mobility. They were informed that she suffered a stroke and had lost her swallowing reflex. They were further informed that a case conference had been called to discuss the possibility of an operation to insert a peg feed, which would prolong her life. They were asked whether it would be appropriate to refer to the documents at the meeting and how much weight should be given to her statement. Also they were asked how they would interpret her opinion in this instance. Furthermore, they were informed that her family wanted her to have the peg feed.

As highlighted in section 4.2.4, at the conclusion of the interviews participants were asked to fill in a questionnaire (appendix 7). Approximately half the participants completed it whilst the interviewer was present. A total of 28 out of 40 were returned. The first three questions were answered without difficulty. However, the checklist which categorised various professional groups whom the participants considered would be able to assist a person with dementia to write a Values History proved more difficult. Many

commented that it would be dependent upon the skills of the individual and whether they had the time to commit to such a task. It became apparent that this aspect of the questionnaire could not be analysed and instead their comments were included in the study.

As highlighted in section 4.2.3, although the interviews with people with dementia and professionals could be classed as semi structured, their structure was quite different. In some respects the interviews with people with dementia verged on being ‘unstructured interviews’, and allowed them to tell ‘their story in their own time’ (Robertson and Dearling, 2004). On the other hand the interviews with the professionals followed a structured pattern, with questions being asked about each vignette in a methodical way.

Another area where they differed related to professional interest in the research process, in that, some participants often asked questions about the implementation of Values Histories. The researcher was aware throughout the interviews that he should present the material and answer such questions in such a way that would not lead the participants or allow them to believe he had a vested interest in ‘proving’ Values Histories worked. Robertson and Dearling point out that the use of particular words or phrases, as well as non-verbal expressions of approval or disapproval, can influence participants’ responses. This can lead to an ‘eagerness of the respondent to please the interviewer’ (Robertson and Dearling, 2004:128). Bearing this in mind, the researcher often reminded participants that the main aim of the research was to evaluate the documents and any problems or difficulties they could foresee with their use was particularly helpful to the research.

The following tables describe the coding system for the participants from stage one and stage two of this study which is referred to throughout the remainder of this thesis.

4.7 Codes for participants

Stage One: Participants with dementia and their nominated carers

Table 4

Pseudonym	Age	Living circumstances	Nominated carer	Diagnosis	MMSE
Marie	76	lived with her husband	husband	Alzheimer's disease	N/A
Sylvia	82	lived alone	daughter in law	Alzheimer's disease	24
Bill	82	lived with his wife	wife	Alzheimer's disease	22
Elizabeth	76	lived with her husband	daughter	Alzheimer's disease	24
Jim	66	lived with his son	son	Mixed Vascular/Alzheimer's	22
Robert	78	lived alone	daughter	Alzheimer's disease	26
John	83	lived with his wife, Mary, whom also had dementia	daughter	Vascular Dementia	25
Mary.	80	Lived with her husband, John, who also had dementia.	daughter	Alzheimer's disease	24
Helen	61	lived alone	daughter	Alzheimer's disease	22
Walter.	66	lived with his wife	wife	Vascular Dementia	25
Howard	77	lived alone	daughter	Alzheimer's disease	29
Alex	76	lived with his wife	wife	Alzheimer's disease	23

Age range 61 to 83

Mean age 76

MMSE range from 22 out 30 to 29 out 30 (excluding one person with dysphasia)

Mean MMSE 24.

Stage Two: Professional Participants

Table 5

COD E	PROFESSION	sex	CODE	PROFESSION	Sex
Psych 1	Consultant Psychiatrist	M	GP1	General Practitioner	M
Psych 2	Consultant Psychiatrist	F	GP2	General Practitioner	M
Psych 3	Consultant Psychiatrist	F	GP3	General Practitioner	M
Psych 4	Senior Registrar	M	GP4	General Practitioner	M
Psych 5	Staff Grade Psychiatrist	F	GP5	General Practitioner	F

COD E	PROFESSION	sex	COD E	PROFESSION	Sex
CPN 1	G Grade Community Psychiatric Nurse	f	DN1	G Grade District Nurse	F
CPN 2	G Grade Community Psychiatric Nurse	f	DN2	G Grade District Nurse	F
CPN	G Grade Community Psychiatric Nurse	m	DN3	G Grade District Nurse	F
CPN 4	G Grade Community Psychiatric Nurse	f	DN4	G Grade District Nurse	F
CPN 5	E Grade Community Psychiatric Nurse	m	DN5	G Grade District Nurse	F

COD E	PROFESSION	sex	COD E	PROFESSION	Se x
NH1	Nursing Home Manager	F	Res1	Residential Home Manager	F
NH2	Nursing Home Manager	F	Res2	Residential Home Manager	F
NH3	Nursing Home Owner	F	Res3	Residential Home Manager	F
NH4	Ward Manager	F	Res4	Residential Home Manager	F
NH5	Ward Manager	M	Res5	Residential Home Owner	F

CODE	PROFESSION	sex	CODE	PROFESSION	Sex
Vol1	Voluntary Sector Community and Day Care Manager	F	SW1	Senior Social Worker	F
Vol2	Voluntary Sector Community and Day Care Manager	M	SW2	Senior Social Worker	M
Vol3	Voluntary Sector Community Care Manager	M	SW3	Care Manager	M
Vol4	Voluntary Sector Community Care Manager	F	SW4	Social Work Assistant	F
Vol5	Voluntary Sector Dementia Outreach Care Manager	M	SW5	Social Work Assistant	F

4.8 Analysis and contemplation of data

From the outset the researcher was aware of two potential flaws to avoid whilst analysing the data. Firstly, that he should avoid adopting a 'neo-positive' approach to quantify qualitative research (Richards and Richards, 1993). Secondly, that he should avoid 'anecdotalism' when reporting his findings (Silverman, 2000; Trinder, 1996). According to Trinder:

"It requires careful and comprehensive analysis of the data generating categories and building up the analysis from the bottom. Without that effort and understanding there is a temptation to under analyse and 'cherry pick' data, by selecting dramatic and interesting quotations and capturing superficial understandings" (Trinder, 1996:242).

To combat 'anecdotalism' Silverman (2000:188) discusses five ways of thinking critically about qualitative data analysis in order to strengthen the findings. These include; the refutability principle, the constant comparative method, comprehensive data treatment, deviant case analysis and using appropriate tabulations. By adopting these principles the researcher was able to conduct a critical investigation of all the data. With regards to tabulation, tables were only used to report findings from the questionnaire. Concerning the data from the interviews, the researcher at times used simple counting techniques to survey the whole corpus of data to highlight general areas of agreement and patterns that emerged. For example, chapter nine highlights that the 'vast majority' of professional participants did not believe that behavioural changes could be perceived as changes in values, with only 'two' out of the 'forty' respondents believing it could be viewed this way. It was hoped that this way of reporting would convey to the reader the strength of feeling amongst participants, and thus not to quantify the findings.

As highlighted in this chapter, all the interviews were tape recorded, transcribed by the researcher and the management of the data was facilitated by the use of NUDIST, a software package designed to assist in the analysis of text based data. The researcher

attended classes at the University of Glasgow as part of the doctoral research methods programme. It is noteworthy that whilst NUDIST can assist the researcher to manage the data it does not analyse the data. Often the researcher preferred to listen to the tapes repeatedly whilst reading the transcribed interviews, referring to his diary and taking notes. This assisted him to get a better 'feel' for contexts and themes from the discussions. This was more prevalent for the participants with dementia and their carers, where often the silences, moments of hesitance, flow of conversation and one word answers had as much meaning in 'telling the story', as the transcribed comments. Moreover, by referring to his notes from the interviews the researcher was able to recall the general feel that he got from the interviewees through their non verbal communication and demeanour. Similarly, Silverman states:

"When people's activities are tape recorded and transcribed the reliability of the interpretation may be gravely weakened by a failure to transcribe apparently trivial, but often crucial pauses and overlaps" (2000:187).

NUDIST also allows for memos and comments to be added to the transcripts throughout the process. Although this was useful, the researcher often printed off the transcriptions and thereafter took notes; colour coded and highlighted emerging themes and unique responses.

To analyse the data, two 'projects' were created on NUDIST; one to manage the data from the people with dementia and their carers, and the other for the forty professional interviews. Initially, broad categories were coded. As highlighted in section 4.2.3, although the interviews in both stages could be classified as 'semi structured', stage two interviews were more structured than stage one interviews and therefore initial categories were easier to create sequentially from the data. However, stage one interviews was less structured, requiring more in-depth surveying.

Interestingly, whereas some claim that theory can only emerge from data (i.e. grounded theory) others challenge this believing that ‘prior theory’ is encapsulated in ‘starter codes’ (Richards and Richards, 1993; Strauss, 1987). As further codes are developed they are kept in orderly lists and the search for unifying categories is done by ‘pattern coding’. Ultimately any emerging pattern can be tested by all instances that fit that theory. Although both approaches are ‘not incompatible’ (Richards and Richards, 1993:44), this research drew more on the latter approach.

For stage one initial categories or ‘starter codes’ included: thoughts and feelings regarding the diagnosis; knowledge of prognosis, planning the future; independence and safety; family relationships; expressing values; end of life decision; thoughts regarding the Values History and discrepancies between person with dementia and their carer. Initial categories for stage two included; participants thoughts regarding whether values change throughout life, older age and with dementia, general comments regarding Values Histories, issues around sharing the diagnosis, discussing the future, findings from the vignettes (medical, appearance, risk, spiritual and end of life decision) and family and relations.

Thereafter, ‘trees’ and ‘nodes’ were created as the researcher analysed and broke down the data. Categories, codes and nodes were compared and merged. New nodes (or pattern codes) were developed as new themes emerged. For example, stage two responses to the four vignettes were initially broken down into ‘positive’, ‘negative’ and ‘unsure’ responses for each stage of the vignettes. Thereafter, their reasons for positive or negative responses could be broken down further and themes developed, such as Values Histories putting ‘pressure on families’ from ‘negative responses’ and ‘hearing the voice of the person’ from positive responses. This allowed for comparisons within each individual’s interview, regarding whether or not they would abide by information in the Values History for one vignette but not another. It also allowed for interdisciplinary comparisons and comparisons between vignettes.

Another example of how a theme was developed and analysed is highlighted in chapter five, namely, that knowing the diagnosis does not necessarily mean understanding it. It also showed that whilst some participants with dementia did not want information, some used the opportunity to seek more knowledge and discuss their concerns. This theme initially became apparent to the researcher whilst conducting the first few interviews. As the research progressed he attempted to draw the remaining participants out more regarding their understanding of the condition and prognosis. During the analysis stage he was able to compare comments from within each individual's own responses to ascertain their level of knowledge and whether they sought more information. He was also able to compare their carers' understanding about the person with dementia's level of knowledge. This highlighted a general trend among several carers to protect the individuals from potentially bad news. It also highlighted a unique case whereby the person with dementia's carer was particularly open with the person, resulting in the person with dementia having high level of knowledge about the condition and potential for the future.

Given that the theme emerged during the interview stage of the study (resulting in the researcher adopting a more open style of interviewing) he was also able to compare the comments of those that he interviewed earlier on in the study with those towards the end. Additionally he was able to compare his own interview techniques and wording of questions from earlier interviews. This showed clearly that some participants used the opportunity to ask questions and gain more information about dementia. Furthermore, the researcher was able to further develop the theme by exploring the data from the professional interviews, which indicated that, although the majority share the diagnosis with people with dementia, few gave more information about the condition unless specifically asked.

Initially the researcher envisaged that the findings from stage one and two would be analysed and written separately, however, as the aforementioned example highlights, it was beneficial to compare data from professional interviews (stage 2) with the people with dementia and their carers (stage 1) and examine where the different data intersected.

Silverman describes this as attempting to get ‘a true fix’ on a situation by ‘combining different ways of looking at it or different findings’ (2000:177). The findings are therefore discussed thematically from chapter five to nine.

Chapter ten is slightly different, in that, it encompasses the views of the researcher. As highlighted at the beginning of this chapter, the researcher was also a practitioner and was aware that some of the challenges interviewing the people with dementia could also be faced by practitioners when assisting individuals complete their Values Histories. Therefore, this collaborative approach of interaction, built up over several interviews, required a degree of reflexivity by the researcher (Jankowski, Clark and Ivey, 2000) and should be viewed this way rather than ‘findings’. As previously stated, the researcher kept a dairy and recorded his thoughts after the interviews, more so, with participants with dementia and their carers. With assistance from his supervisor, which he found invaluable, he was able to discuss his thoughts and explore themes that were specifically related to the research as opposed to his practice. He found this particularly beneficial when discussing his prior knowledge of some of the participants, his own biases and values. For this reason it is included in the research, based on a ‘pragmatic’ or practical outcome for the research.

Chapter ten also discusses the how ‘practical’ the professionals within the study found the Values History. As highlighted in Section 4.2.5, questionnaires were given to professional interviewees at the conclusion of their interviews. Twenty-eight out of a total of forty interviewees returned their questionnaires (70%). The first two questions on the questionnaire used ordered rating scales and the third a numeric scale (Moore and McCabe, 1998; Henerson et al., 1987). With regards to the ordered rating scales, the data for each professional group was totalled allowing for comparisons across professional groups and presented as tables (1 and 2) in chapter 10. Similarly, for the numeric rating scale, scores were totalled and presented in a table according to professional groups (Table 3). Thereafter, the range and average (mean) for the twenty-eight participants was calculated. As indicated throughout this research, questionnaires were used to add strength and to ‘yield summary’ to the respondents interviews (Cheetham et al., 1992:41).

The results of the questionnaires were therefore also compared with both written comments in the questionnaires and individual interviews.

4.9 Summary

In summary this chapter has described the process of how the research was conducted. In total 110 interviews were conducted, plus three focus groups. Although the design of the study was effective to answer the research questions there were some aspects which the researcher would change. For example, prior to the study commencing, the researcher felt obliged to compile a rigid inclusion and exclusion criteria for ethical approval. He therefore chose the MMSE and insight rating scales which are both established measures. However, in reality he could have asked colleagues to refer people from their caseloads who were aware of their diagnosis and able to discuss the illness. Moreover, a sixth interview would have been useful for several participants to allow them to digest the material and make further changes to the documents. It should be noted that there are other aspects which the researcher would have changed in the methodology, but these are more directly related to the writing of the Values Histories rather than the research process and will be discussed further in chapter 10.

With regards to the twelve interviews with people with dementia the researcher found this to be about the right number to answer the research questions. The amount was large enough to allow themes to be developed, but small enough to be manageable, allowing them to be interviewed several times. Whilst several studies have been conducted by interviewing fewer participants (Smallwood, 1997; Husband, 1996; Sperlinger and McAuslane, 1994), each interview was unique and brought different perspectives to the research, which would have been missed with a smaller study. For example, Marie's non mainstream religious values allowed the researcher to develop a vignette based on her feelings about Christmas. Also relationship problems within two couples allowed the theme of honesty to be developed. Moreover, it could be argued that other themes might have emerged by interviewing more people.

Concerning the professional interviews, the vignettes were a successful way to get the participants thinking about some of the issues in relation to Values Histories. They also were effective in promoting discussion, encouraging many to relate personal experiences. It is interesting to note that some participants who were initially very positive about Values Histories expressed some doubts towards the end of the interview, whereas others who were unsure of their purpose became very enthusiastic. This is further explored in chapter 10. However, from a methodological perspective this indicates that the vignettes fulfilled their purpose by encouraging participants to think more deeply about the Values Histories than they would otherwise.

The main area which the researcher would change in the design of the research is the questionnaire which he asked professional participants to complete. Whilst the first three questions were useful, the research is qualitative and the comments from participants added depth to their questionnaire responses. It also became apparent throughout the research that the checklist of possible professionals who could complete a Values History was more complicated than ticking boxes.

The following six chapters discuss the main themes from the research beginning with the theme of 'sharing the diagnosis and discussing the future with people with dementia'.

Chapter 5

Sharing the diagnosis and discussing the future with people with dementia

5.1 Introduction

5.2 Sharing the diagnosis- the perceptions of professional participants

5.3 Who should share the diagnosis?

5.4 Sharing the diagnosis- the perceptions of participants with dementia

5.5 Sharing the diagnosis- the perceptions of carers.

5.6 Dilemma- a relative asks for the diagnosis not to be shared with the person with dementia.

5.7 Medication for dementia- a way to open up dialogue?

5.8 Discussing the future- the perspectives of the professionals

5.9 Discussing the prognosis with people with dementia

5.10 Discussing future care with people with dementia.

5.11 Summary

5.1 Introduction

As highlighted in chapter two, one of the perceived benefits of disclosing diagnosis is to give people with dementia the opportunity to plan for the future (Lingard, 2002; Drickamer and Lachs, 1992). Although 'planning for the future' is established as one of the main benefits to encourage practitioners to share the diagnosis with people with dementia, the literature review shows very little in relation to how people with dementia feel about its affects and in particular how they feel about the future. The purpose of this chapter is therefore not only to explore issues around disclosure from the perspectives of people with dementia, their carers and professionals, but also to look beyond the diagnosis and explore how appropriate it is to look to the future when many of those diagnosed will not, in fact, reach the terminal stages of the illness. The chapter begins by exploring how professionals share the diagnosis with people with dementia. It should be noted that professional participants had varying degrees of experience working with

people in the early stages of dementia and therefore the questions were tailored to their level of knowledge and experience.

5.2 Sharing the diagnosis –the perceptions of the professional participants

For the main part GPs, psychiatrists, CPNs and social workers were more likely to diagnose and/or offer post diagnosis support to people with dementia and therefore the questions were more detailed than with the other professional participants. Participants in residential and nursing homes had limited contact with people in the early stages of the illness and questions were put to them from a theoretical point of view. Professional staff in the voluntary sector could not be categorised so easily as their client groups varied and the ethos of their organisations differed. i.e. one organisation was an advocacy project which offered support to people in the early stages of dementia and was therefore heavily involved in offering support to people newly diagnosed, whereas three other voluntary groups saw their role as offering support to carers. The fifth offered support to elderly people in general. District nurses, whilst having high levels of people with dementia on their case loads, did not see their role as offering support or counselling to people with dementia.

The general feeling amongst the forty professional participants was that the diagnosis should be shared with the people with dementia. In fact, no-one interviewed felt that the diagnosis should be kept from the person. Several staff mentioned that individuals with dementia had ‘a right to know’ their diagnosis and there was a general recognition that there had been a change in culture over the past ten years or so with staff being more open with people with dementia, informing them of the diagnosis. One psychiatrist who recognised this change in attitude stated:

“I say there’s a whole cultural change in our handling of dementia. We’re more open now.” (Psych3)

Another comment from a nursing home manager reflected many of the professional views and indicated that knowing the diagnosis would allow people with dementia to make plans for the future. She stated:

“I would say being open gives them the chance to make arrangements... sort out their belongings...their finances or even their funeral. There might be things they want to discuss with their families while they still can.” (NH1)

This also reflected the opinions of some authors who opined that sharing the diagnosis with people with dementia allowed them the opportunity to make plans for the future and resolve family conflicts or personal matters (Lingard, 2002; Mason and Wilkinson, 2002; Meyers, 1997). This is explored further in section 5.10.

Although there was a general agreement that people should know their diagnosis, there were variations in the strength of feelings expressed by professionals. The majority of professionals who had practical experience of working with people in the early stages expressed stronger feelings that the diagnosis should be shared with people with dementia. The following two quotations highlight this viewpoint:

“I feel it’s extremely important for people to be told. They have a right to know....to get their affairs in order and adopt certain strategies to cope with it. In my experience, over the years, those who are told their diagnosis earlier are easier to work with. They accept services and develop strategies for when the bad days come.” (Vol 1)

“I would say everyone has a right to know and what they choose to do with that information is up to them. If they don’t want to discuss it again that’s up to them, but they have a right to know the diagnosis.” (GP5)

Interestingly both comments use the phrase ‘right to know’, which was a phrase used by many participants. Indeed, this underlines the key arguments from dementia advocacy

groups and literature in the 1990s (Pinner and Bouman, 2003; Fearnley et al., 1997; Husband, 1996). The first comment alludes to empowering the person with dementia, by giving them the opportunity to make plans for the future, whereas the second indicates that, whether or not people with dementia choose to act upon the information, it is a basic 'right' for them to be informed.

Some staff in residential and nursing homes (who were less likely to have worked with people in the early stages of the illness) were not aware that people would be able to comprehend the diagnoses. Some claimed they had never known anyone in the early stages of the illness, not having been in the position to discuss it with them. Some claimed to be 'intrigued' and 'surprised' by the awareness and insight expressed by the people with dementia in their Values Histories and some asked if they were 'normal' and if the diagnosis was shared regularly. One residential home owner stated:

"I was surprised that both people knew that they had dementia. I haven't experienced that. By the time they come in here they forget that they have an illness or the word Alzheimer's doesn't mean anything to them." (Res1)

This view was echoed by most staff working in residential care and nursing homes, with the exception of some who had known relatives who had suffered from dementia and been aware of their illness from the early stages. Only two members of staff could recall people with dementia who could openly discuss their diagnosis whilst in care. Indeed, one ward sister could only remember 'about three people' in her thirty year nursing career and a residential care home manager could recall only one person.

This section clarified that professionals in the study felt that people with dementia should be informed of their diagnosis. The remainder of the chapter explores the practicalities of sharing the diagnosis and discussing the future with people with dementia beginning with who the professionals felt should share the diagnosis in the first instance.

5.3 Who should share the diagnosis?

The vast majority of participants felt that the diagnosis should be shared in the first instance by a medical professional. The most commonly cited reason was because they considered it a ‘medical’ condition. One comment which reflected this was:

“In medical terms if you had cancer you’d expect a doctor to tell you so it should be the same with dementia” (Res3)

This comment indicated that the diagnosis of dementia should not be trivialised or treated differently from any other major illness. Interestingly, many other participants also related sharing the diagnosis of dementia to that of cancer, a comparison that is also reflected in the wider literature (Evans, 1998; Fearnley et al., 1997; Emmanuel and Kass, 1993).

In general GPs and psychiatrists were cited as the most appropriate professionals to share the diagnosis, with geriatricians and neurologists also mentioned by some participants with a health background. All GPs referred people with suspected dementia to psychiatrists to be diagnosed and there was a general presumption that the person would receive their diagnosis from the specialist. According to one GP:

“I think the person who makes the diagnosis should be the one to tell them.” (GP1)

Some thought that it would be appropriate for CPNs to share the diagnosis in the first instance if they had a particularly good relationship with the person, but the general trend was that it should be medical staff. CPNs, social workers and specialised counselling groups were seen as the most appropriate groups to offer support once the diagnosis had been given. Two comments included:

“Initially the doctor and thereafter we follow up with support. I think older people view their doctors a certain way, with respect and accept their advice. It’s important to them.” (CPN 5)

“I think the doctor in the first instance, because it’s bad news and I would hope that the CPN is there to give support and be their friend and give them support along the way....not the bearer of the bad news.” (GP4)

These comments therefore indicate that medical staff would not necessarily have the time or be in a position to offer counselling or support to the person post diagnosis, but would be expected by professionals, and possibly people with dementia, to share the diagnosis with people with dementia in the first instance. Given that GPs and psychiatrists were seen by the majority of respondents to share the diagnosis with people with dementia, medical staff were asked if they did this regularly. All reported that they would inform the person with dementia if they were asked by them. However, there was a tendency for the GPs not to actively tell the person unless asked outright what was wrong with them. According to one GP:

“I don’t routinely share the diagnosis, but if they asked I would tell them the truth. I wouldn’t lie to them. If they said the word dementia then that’s fine, but I wouldn’t necessarily want to. It is after all a devastating diagnosis and perhaps one of the most difficult to give.” (GP 3)

Similarly, another GP stated:

“Very few times have I sat someone in front of me and told them that they have a dementing illness. Perhaps it often reflects the stage that they are at in their illness.” (GP1)

Two out of the five GPs reported that they had never shared the diagnosis of dementia with a patient. One however had only been practicing as a GP for about a year and stated

he would have 'no problems' in sharing the diagnosis, although again only 'if asked'. In contrast, the other GP who had 15 years experience stated:

"That's interesting, because I've never told a person in a consultation that they have dementia. Anyone you suspect has dementia you would send to a specialist. Actually I couldn't tell you if they're told if they have dementia or not." (GP 2)

Similarly, Downs et al's (2002) study examining attitudes of GPs towards sharing the diagnosis in Scotland, reported that a large proportion of GPs avoided using medical terminology with people with dementia, tending to 'normalize' their experience. Others also opine that much work is needed to encourage GPs to be more proactive regarding disclosure of diagnosis (Wilkinson et al., 2002; Lingard, 2002; Fortinsky et al., 1995). The only GP who routinely shared the diagnosis had previously consulted in a memory clinic, and tended to be proactive about giving a diagnosis, having a belief in opening up a dialogue with the person from the onset of the illness. He stated:

"More often now you would tell a patient with a malignant disease why you're sending them for tests. It's the same with dementia. If you're sending them to see a psychiatrist it's not to get their teeth brushed! You tell them the issues and why you are sending them there." (GP5)

Again, this GP, like many other professionals, compared sharing the diagnosis of dementia to other 'malignant' diseases. Interestingly, he appeared to be preparing the people with dementia for the diagnosis by telling them the reasons why he was sending them to see a specialist, the inference being that they would have some advance warning and it would not come as a shock to the person. It is noteworthy that whilst several authors discuss the benefits of post diagnosis counselling and support, few discuss pre diagnosis counselling.

All five psychiatrists interviewed felt it was their role to share the diagnosis with the person. This reflected a significant cultural change in practice over the past few years. One consultant psychiatrist reported:

“I’ve been a consultant for six years and back then we never really told someone unless specifically asked and even then you’d be a wee bit wary. Now I think people have the right to know and always tell them. It’s a whole cultural change in dementia and people have a greater awareness than they used to.” (Psych 3)

This comment indicates a change in attitude regarding sharing the diagnosis among psychiatrists, which is similarly reported by other authors (Pinner and Bouman, 2003; Warner, 2003; Philips and O’Brien, 2002). Again the phrase ‘right to know’ was used by this psychiatrist.

Psychiatrists had adopted their own styles for informing the person of the diagnosis, some being very open from the beginning before they sent the person for tests and others waiting until there was a definite diagnosis. Two different approaches were highlighted in the following responses:

“If I was reasonably sure of the diagnosis I would say yes, in fact if I was pretty sure then I would tell them. If the diagnosis was only a probability I would not say ‘this is possibly Alzheimer’s’ unless they asked me.” (Psych5)

“You make sure that they understand why they are there to see you... ‘Do you wonder what might be wrong with you? Have you heard of Alzheimer’s disease?...even before you have done any tests. If they say they wouldn’t want to know at least you’ve asked them. It’s important to get that right. I think most people want to know.” (Psych4)

One ward sister reported that she had never known any of the consultant geriatricians to share the diagnosis. She felt it would ‘make it easier for nursing staff’ if the consultants

did share it as people would be able to come to terms with it and make plans for the future. The sister, who had a career spanning thirty years in nursing stated:

“I think I’ve only known about 2 or 3 people who’ve ever known their diagnosis or discussed it anyway. I don’t even know how they knew or if they were told by a doctor.” (NH4)

This is an area that needs further research. Whilst there have been several British studies regarding the attitudes of GPs and psychiatrists, there is a dearth of research regarding geriatricians in the UK (Downs et al., 2002; Lindesay et al., 2002; Clafferty et al., 1998). The majority of nursing and residential home staff had never discussed the diagnosis with a person with dementia. The reason cited was usually ‘the stage’ they were at in their illness or being too confused to understand. Two comments included:

“We don’t use the term dementia or ask if they know.... most are confused...we avoid the subject....it’s not mentioned.” (Res5)

“When they come into residential care they forget they have an illness or the word Alzheimer’s does not mean anything to them.” (Res2)

The tendency was for nursing home and residential staff to minimise anxiety for the person, not wanting to upset them, often trying to divert the person from talking about the illness. Situations where the diagnosis had been shared with the person tended to be isolated. However, this did not prevent them from telling a person they had ‘memory problems’ or ‘the brain cells are not working properly’ and trying to help the person by having calendars or note books for example. Some expressed surprise that people in the early stages knew they had dementia and were able to discuss it.

Social workers also felt that people with dementia were referred to them at the stage when they lacked insight, often in a crisis and usually provoked by carer distress. In

general they would take the lead from the family and person, only using the term dementia if the family or person did. As one social worker explained:

“I try to take the lead from the family as to how the older person is about it....and what their attitude is would often determine how I spoke about the illness.” (SW3)

Although they would not initiate discussions regarding the diagnosis with the person, they would try to find out from the person the level of knowledge that they had about their illness, by asking leading questions. As one social worker described:

“You have to sound the person out to see how much they know. That’s something which develops with experience...perhaps the more people you’ve been out to see the comforter you are with it. You can lead a person along until they are actively discussing the illness and the impact on their life.” (SW5)

Three of the five social workers felt that there was a lack of information from health staff and those making referrals regarding whether or not the person knew about their illness. They felt that it would make it easier to engage with the people with dementia as they would know the reason for the referral and possibly be more inclined to accept services. One comment included:

“I wouldn’t know for the majority of referrals if the person knows if they have dementia.... they don’t stipulate it if the person knows their diagnosis...it makes it difficult because you’re going in there talking about services and why they need them...but skipping about the issue....I would rather be up front and honest...tackle things head on, but in a sensitive way....sometimes there can be a bit of conflict though” (SW3)

Similarly, district nurses would only use the term dementia if the family or person used the term. Most had not been in the situation where they had discussed the illness with a person with dementia, although two drew on their personal experiences within their

families which made them feel that they would have confidence to discuss the diagnosis with others if required. One stated that she would not discuss the diagnosis with people with dementia and would feel ‘uncomfortable’, preferring to refer to a specialised service. All district nurses drew on their experiences of discussing and offering support to cancer sufferers and people with terminal illnesses. According to one district nurse:

“I’ve never had to, but I’m comfortable with it. Years ago I couldn’t handle someone saying to me ‘I’m going to die’ but I think it’s something you learn to deal with, with experience. I’m sure it’s the same like heart failure its’ terminal to a certain extent. We’re allowed to talk to people now and are educated to be more open....doctors as well.” (DN 5)

All participants felt that carers should be involved in the initial sharing of the diagnosis with the people with dementia to a greater or lesser degree. All psychiatrists stated they would prefer a relative to be with the people with dementia when they informed them of the diagnosis, partly to offer support at the time, but also to remind the person of the discussion thereafter. One psychiatrist who highlighted this stated:

“I think it should be done in conjunction with the person who is the closest carer or friend because they might be the one who will have to pick up the pieces when the person goes home.” (Psych2)

Similarly, much of the literature suggests that family and potential carers should be involved in the process of sharing the diagnosis with the person (Jacques and Jackson, 2000; Lovestone, 1998). However, it is also noteworthy that it should not always be presumed that there are good relations within families (Pratt, 2002). This theme is further explored in the following section. Chapter seven also explores how professionals encourage people with dementia to appoint a representative should they lose capacity.

5.4 Sharing the diagnosis – the perceptions of participants with dementia

This section explores issues around receiving a diagnosis from the perspectives of people with dementia. Initially participants were asked if they felt they should have been informed of their diagnosis. The vast majority of people with dementia felt that it was their right to be informed of the diagnosis. However, although some had forgotten the circumstances surrounding this time, others remembered quite clearly or had a vague recollection. There were variations in their strength of their feelings regarding being told. Some felt they were ‘glad’ indicating that there was a sense of relief, knowing within themselves that something was wrong beforehand. Examples of these responses included:

“Yes, I’m glad I know. I knew myself before I was told. I think it’s just one of my weaknesses. Perhaps it’s meant to be although I still can’t believe it’s happened to me.” (Marie)

“I knew something was wrong for about a year before I was told. I think it’s better to know than to wish you knew.” (Elizabeth)

Others, whilst believing it was better that the diagnosis was shared with them, did not express any strong feelings about receiving it, often not expanding on their responses. Only two people stated that they would rather not have been told. One participant stated she was a ‘coward’ and ‘hated bad news’ and another participant stated that he doubted the diagnosis and felt he had been ‘stigmatised’ and ‘hated the word dementia’. However, he acknowledged that ‘if’ he had dementia then it was ‘probably’ better that he knew and the diagnosis should not be kept from him. Similarly, Wilkinson et al (2002) reported that even those participants within their study who felt depressed after hearing their diagnosis still felt it was right that they were informed.

However, it should be acknowledged that only those people with dementia who had been informed of their diagnosis, had a degree of insight into the illness and a willingness to

openly discuss how they felt about the illness were selected for the study. Due to the small sample it cannot be presumed that their attitudes are representative of the majority people in the early stages of the illness. This is a possible downfall of all research with people with dementia as selection criteria will almost inevitably exclude those who have minimal insight into their condition or refuse to engage with services. Moreover, the participants were selected from the same geographical area, the majority of whom had been diagnosed by one psychiatrist who claimed to be open about sharing the diagnosis and therefore the participants were more likely to have received a diagnosis.

Only one of the twelve people with dementia (Helen) interviewed claimed to have a negative experience of receiving the diagnosis, claiming that the doctor 'blurted it out' and never gave her any support or time to ask questions. Yet, her daughter did not feel this was true and stated that the doctor informed her whilst she was present and that he explained it fully and tactfully to her and gave her information leaflets regarding Alzheimer's disease. It was therefore difficult to ascertain if she was recalling a different situation or if it was a false memory. However, it should be noted that other information during the interview was also deemed inaccurate by her daughter.

Although all participants were aware of their diagnosis, their understanding of the condition is further explored in section 5.10 of this chapter. The following section explores the carers' feeling regarding sharing the diagnosis with the person with dementia.

5.5 Sharing the diagnosis - the perceptions of carers

All the carers interviewed felt that the people with dementia had the right be informed of the illness. Some however admitted a degree of anxiety beforehand about how the person would react to the news, although not to the extent that the person should not know. Again due to the small sample and selection criteria it cannot be presumed that this is the case with all carers.

Some carers (about a third) felt that the person did not fully understand, or grasp the diagnosis when they were informed, whereas others felt that the people with dementia understood the implications of diagnosis quite clearly. Some carers had chosen not to discuss the diagnosis in detail after it was given to the person, tending to use terms such as ‘memory problems’, whereas at the other end of the spectrum some carers had discussed the diagnosis with the person in great depth. One person with dementia (Sylvia), who appeared to have a very high level of insight into her condition and was able to discuss the diagnosis in more detail than any of the other participants, had in fact been educated by her daughter-in-law. Her daughter-in-law stated that initially when Sylvia was given the diagnosis she did not understand the implications of it and, the diagnosis did not have any great impact. She doubted whether her mother in law would have had the volition to find out any information about it had she not been proactive in going through the material with her. She stated:

“The first port of call for me was the library. It gave me a depth of understanding. We shared the information, discussing things and talking over the problems. I think that’s why she understands it and can talk about it. We are very open with her.... I remind her about it when she forgets.” (Sylvia’s carer)

Whilst other carers had a high level of understanding of dementia, none of them shared the information to the same extent with the individuals as Sylvia’s carer did.

Although all the carers in the study felt that it was the person with dementia’s right to know their diagnosis, some literature prior to 2000 suggests that carers were reticent about the people with dementia being informed of their diagnosis (Maguire et al., 1996; Husband, 1996). Upsetting the person, depression and fear of the people with dementia committing suicide are reasons cited for this (Pinner and Bouman, 2003). However, this study backs up more recent literature that suggests that this trend is possibly changing (Dautzenberg et al., 2003; Holroyd et al., 2002). The following section explores how professionals would deal with a request from a carer not to inform the people with dementia of their diagnosis

5.6 Dilemma – a relative asks that diagnosis is not shared with the person with dementia

Participants were asked to imagine that they had received a phone call from a relative asking them not to share the diagnosis with them. It should be noted that for medical and nursing staff, and to a lesser extent social work staff, this was a practical situation that they could come across (Pinner and Bouman, 2003). However, for residential, nursing home and some voluntary staff, the question was possibly hypothetical and more a matter of their personal opinions.

In general, the overwhelming majority of staff reported that they ‘would not lie’ to the person newly diagnosed if asked by a relative not to tell. A comment which reflected most opinions was:

“I would say ‘it’s not our privilege to keep the truth from the patient. I will bear in mind what you said, but will not lie if given a straight question.’” (GP5)

Only two of the forty staff interviewed said they would completely go along with the relative. A district nurse felt that the person with dementia’s family would ‘know the person best’ and the other professional, who was a voluntary organisation coordinator for carers, stated:

“We would do what the carer wanted. We work round them. No we wouldn’t mention it if that’s what they wanted.” (Vol3)

She further explained that her role was to protect the interests of carers and reduce any stress or anxiety they were experiencing and whilst she felt that from the people with dementia’s point of view it would be better they knew their diagnosis, she would go along with the family’s wishes.

Although the majority of professionals stated they would ‘not lie’ or ‘not make any promises’ to the relative it appeared that most of them would not actively pursue discussing the diagnosis with the person with dementia. It appeared that most professionals would not use the term ‘dementia’ unless they were specifically asked what the diagnosis was or the subject was brought up by the people with dementia. Typical comments included

“I would go along with it to a point, unless the person asked directly.” (CPN4)

“I would talk around the subject with the person.” (CPN1)

The majority of professionals stated that they would try to convince the carers of the advantages of being open with the people with dementia and use it as an opportunity to discuss the carer’s anxieties and fears. A typical comment made by a GP was:

“I would tell them that I understand why they feel that way and inform them that I’m not able to tell lies or be dishonest with the patient. It’s been researched and if they ask it means they already know. I would maybe try to explore why they felt that way.” (GP 4)

Several staff highlighted a well known piece of research which found that although many carers try to protect the person from the anxiety of knowing their diagnosis, if they had dementia they would want to know (Maguire et al., 1996). As one social worker put it

“It’s not good enough a reason to say they’d be upset. I’d say ‘why do they think they’re going through all these tests?’ I would put them in the situation and ask how they’d feel if it was withheld from them?” (SW2)

Psychiatrists were least likely to go along with the carers’ requests not to inform the people with dementia and the majority of them felt they had a duty to inform the person despite the carers’ wishes. They appeared to be more proactive than the others

interviewed (including GPs), often being the ones to diagnose the person and feeling they had an obligation to let the person know. The majority of psychiatrists had experienced such situations. Two comments which alluded to this were:

“It’s quite awkward. What I often say to the families is that they should recognise it is their problem and their distress, rather than the person themselves and that it is better to be open and honest. Sometimes you can see the families looking aghast when they realise you’re going to tell the person, but usually the person who has got the illness accepts the news relatively well and it’s more the family’s anxiety.”
(Psych1)

“I think if the family asked you there would need to be very strong reasons for you not to. I can’t think of any!” (Psych 3)

However, one newly qualified psychiatrist said he would take the lead from the family and not necessarily use the term dementia or Alzheimer’s disease. Compared to the other psychiatrists he was less vociferous about the need to share the diagnosis and inform the person. He stated:

“I would certainly listen to them and if there was some valid reason why the family felt the person could not deal with it. Relatives can give you that feeling. You can give them the information telling them that its hardening of the arteries without using the term.” (Psych4)

None of the district nurses (in their professional capacity) had discussed the diagnosis with a person with dementia, but felt they could relate the question to people with cancer or terminal illnesses. Most had been in situations where a family did not want the person to know about their illness. Again they would not directly go against the family’s wishes by telling the person, but would ‘not lie’ if the person asked them outright what was wrong with them. One district nurse stated that ‘the doctor always comes first’ and would refer the person to the doctor for further advice.

Unprompted by the interviewer, approximately a quarter of professionals interviewed compared sharing the diagnosis of dementia to informing a person that they had cancer or a terminal illness. In particular some of the ‘older’ and more experienced professionals interviewed recalled times when people with cancer were often not told their diagnosis, whilst their family and friends knew. There was general agreement that for a person with cancer not to be told their diagnosis in present times would be ‘unacceptable’ and that the same appeared to be happening with dementia sufferers. As previously stated in section 3.3, ‘a change in culture’ and being ‘more open with people’ were reasons given for this. According to one psychiatrist:

“I’ve come in a time when it’s more likely to share the diagnosis no matter if it’s cancer or dementia. I think there is a move towards sharing information with people in general.” (Psych 5)

As well as the ‘right to know’ movement (Fearnley et al., 1997) the evidence within the literature seems to indicate that medication for Alzheimer’s disease has resulted in professionals being more open with people with dementia and possibly encourage medical staff in particular to be more proactive in sharing the diagnosis (Passmore and Craig, 2004; Warner, 2003; Philips and O’Brien, 2002; Jha et al., 2001; Gilliard and Hughes, 1998). The next section explores this concept further.

5.7 Medication for dementia- a way to open up dialogue?

All those involved in prescribing and administering medication for Alzheimer’s disease (GPs, psychiatrists and CPNs) were asked if they felt that the inception of cognitive enhancers had made them (or in theory should make them) more proactive about sharing and discussing the diagnosis. The overwhelming majority of them reported that it had. Two comments included:

“Yes there’s a change, partly because we see them earlier and discuss the information about it. You can’t exactly give them Aricept without telling them what it’s for...they just need to read the patient leaflet.” (Psych4)

“I think the answer is definitely. It’s like chemotherapy. You couldn’t give it without telling the person what it’s for.” (GP2)

There was a general scepticism about the effectiveness of the cognitive enhancers, but some of the participants felt that the medication had helped open up dialogue with the person because there was something medical which they ‘could do’ for the person. A typical response from one GP was:

“In a sense it has changed....it’s become more medicalised because there’s something you can do....I’d like to say it’s because its an effective medication, but it’s not and the results are not the answer at the moment...it would be different if it was a cure or slowed it down.” (GP3)

This seemed to be common theme among those who prescribed cognitive enhancers- that they opened the way for dialogue. Giving people with dementia ‘hope’ was also seen as a benefit of the medication. The following comment highlights this:

“I think it must give them a bit of hope because they’re getting some treatment and feeling that something is being done to help them.” (Psych3)

The majority of non medical participants also thought that medication for dementia would make it easier for medical staff to share the diagnosis, although this was based on their feelings rather than practical knowledge. One participant from a voluntary advocacy project, which offered post diagnosis counselling, stated:

“People are being diagnosed a lot earlier and I would say with more accuracy as they need to be eligible for the tablets.” (Vol1)

Again several authors appear to agree that the inception of cognitive enhancers has underpinned a change in practice whereby they require an accurate diagnosis, preferably in the early stages of dementia to benefit from the medication (Passmore and Craig, 2004; Warner, 2003; Philips and O'Brien, 2002; Jha et al., 2001; Gilliard and Hughes, 1998).

The remainder of this chapter explores issues in relation to discussing the prognosis and future with people with dementia. Similar to the first part of the chapter, the remaining sections look at how professionals engage with people with dementia to discuss the future and how people with dementia and their carers feel about the prognosis.

5.8 Discussing the future -the perspectives of the professionals

The majority of professional participants felt that it was appropriate to discuss the prognosis and future care with the people with dementia. However, most of them felt that information should not be 'forced on the person' and many stated it would depend on 'the individual' and how much they wanted to know or 'could cope with'. Unlike sharing the diagnosis, which was seen as medical responsibility, there was a general acceptance that discussing the prognosis could be widened to include CPNs, social workers and voluntary groups. However, most specified that it should be someone with knowledge of dementia, who either has a good relationship with the person or has time to establish a relationship (which appears to be one the main barriers for medical staff).

There was a tendency amongst those professionals with experience of sharing the diagnosis (mostly psychiatrists) and sharing information about the illness (mostly CPNs) to take the lead from the people with dementia and not actually bring the subject up unless the person with dementia initiated the conversation or asked questions about the future. Most stated that they were more likely to discuss the prognosis with the person's family. Two typical comments included:

“Interestingly enough I would say in my experience the actual person with the illness does not ask. It is often the carers that are asking about the future rather than the person. I suppose my principle would be guided by what they were asking me rather than volunteer information.” (Psych5)

“I would discuss it with the family, but I wouldn’t mention the moderate to end stages with the person unless they wanted to know. There’s no guarantee what will happen. I sometimes go into the financial side with them.” (CPN5)

These comments seem to indicate that many people with dementia choose not to ask questions about the future. Furthermore, the comments substantiate other studies which indicate that there is a tendency to ‘normalize’ the experiences of the person, ‘protecting’ them from potential frightening information, painting a more positive picture than they would paint to the families (Keightley and Mitchel, 2004; Downs et al., 2001). Interestingly, although the vast majority of medical and nursing staff would only discuss the prognosis if the person actively initiated the conversation or asked questions about it, there was a general acceptance that they could be more proactive in certain circumstances. Two comments that highlighted this were:

“I think it’s something that is very important, but I don’t know if it’s something that I or the medical profession have been doing.” (Psych5)

“I don’t do it, but I think it’s feasible, especially when Sylvia says ‘I don’t want to go into my daughter’s home’ or what type of care home she would like.” (DN2)

The most often cited reason for not discussing the future in any great depth with the people with dementia was ‘their age’ and the possibility that other conditions could supersede the end stages of the illness. One psychiatrist stated:

“Everyone is getting older and there is a degree of uncertainty about the future. The diagnosis is life changing and they’re going to be thinking it anyway, even if we don’t ask.” (Psych3)

However, some psychiatrists and CPNs appeared to have developed skills such as ‘hinting’ that the condition might deteriorate and allowing the person with dementia to choose whether or not to pick up on the cues and ask questions about the condition. As one CPN explained:

“You have to give people hope. I don’t tell people ‘you’re going to deteriorate and die or need care’, but I do drop hints.” (CPN)

Another approach was to give the people with dementia booklets which explained the diagnosis and prognosis allowing them to decide whether or not to read the information and at their follow up appointment ask questions about the illness if they so wish. According to one psychiatrist:

“I think the booklets help. When I give them to the person I’ll say to them that it’ll tell you about all the stages of the illness, but a lot will not apply to them. They can choose to read it and relate the information to themselves or not as the case may be for most.” (Psych1)

These comments reflect guidance from several authors regarding sharing the diagnosis and discussing dementia with people who have been newly diagnosed (Lingard 2002; Lovestone, 1998; Fearnley et al., 1997). The following section explores how the participants with dementia felt discussing the future.

5.9 Discussing the prognosis with people with dementia

One of the challenges when discussing the future with people with dementia was to open up dialogue in such a way that they might ‘think about the possibility’ of deterioration

and future care, but to do so in such a way that would not provoke fear for those people with dementia who did not want to discuss it or still had hope that they would not deteriorate. The challenges from the researcher's point of view are further discussed in chapter ten. The remainder of this chapter explores the feelings of the participants with dementia about the future.

Although there was an acknowledgment amongst most of the participants that the condition could deteriorate, there was a wide range in their level of understanding of how it could affect them in the future. The majority were aware that the illness affected their memory whereas only a few were aware it could affect other aspects of their cognitive functioning and aspects of daily living. One participant with dementia who was aware that the illness could progress to affect aspects other than memory had nursed her mother, who also had dementia. She stated:

"My mother had dementia. People say you don't get it from your family, but I think you must. She never had it for long before she died, so it never got to the bad stage. I know it affects my memory. Sometimes I get confused, but I can live with it."
(Helen)

Knowing someone with dementia therefore appeared to be a factor in people with dementia understanding the implications of dementia. Similarly another participant, Sylvia, had spent time in nursing homes entertaining the 'old folk' and recognised that the illness could progress to the same stage as the residents in the homes she visited. She opined:

"I keep saying when it comes make it quick. I know I have no jurisdiction but I would hate to get to stage where I didn't know who or where I was or if Brian came in and I never recognised him...although maybe by that stage I wouldn't know anyway."

She further stated:

“I know it’s the grey cells that start to go in the brain and there’s not much I can do about it. I imagine once it starts it tends to deteriorate.” (Sylvia)

Sylvia was the only participant able to speak in greatest depth about the prognosis and possible outcome. In contrast to this, some claimed to have no knowledge of the prognosis of the illness. For example, two participants stated:

“I’ll be honest, I know very little about it. As far as I was concerned I was a OK. No-one has given me an answer. How long will this last? Will it get better or gradually worse?” (Jim)

“No it doesn’t bother me. Jean always talks about it. She says I’ve got it, but I don’t know much about it. I can’t say what it’s about.” (Alex)

For some it appeared to be an active decision not to think about the future with some alluding to being frightened to think too far ahead. Two examples of this came from Bill and Robert. They stated:

“I don’t like thinking too far in advance...it frightens me” (Bill)

“As far as I’m concerned I know I have it, but I’m not aware how it affects me. I don’t think about it. I don’t know much about it and I don’t really want to know. I know it sounds a bit Irish, but if you don’t know about it won’t happen!” (Robert)

Interestingly during Bill’s first interview he did not admit being scared or thinking about the future and asserted that he would rather ‘pass’ when asked about the prognosis. However, after the interview was over he became emotional and admitted being ‘frightened’ as he was aware that he got confused and disorientated at times, and in particular admitted that he did not recognise his house in the evenings. His main worry was that this could progress and he might eventually not be able to recognise his family. (Bill’s ‘opening up’ after the interview has implications for writing Values Histories,

which is further discussed in chapter ten). Robert, on the other hand, was fairly jovial and light-hearted when asked about the future and claimed he did not want to know about it or be given any information. His daughter however stated that he probably was frightened but was not the ‘type of person’ to admit his fears, either to herself or others.

Another way that some people with dementia appeared to cope with having dementia was to put the illness down to ‘their age’ and generally ‘getting old’. An example of this was Howard, who had previously stated that he felt the term ‘dementia’ was a ‘stigma’ and he felt that memory loss was age related and should not be classified as an illness. He stated:

“I don’t look upon this as an illness, just part of my nature. Everyone has various things which affect them.” (Howard)

Another example was Walter, who also felt that dementia was related to his age. Although he was aware that he had received a diagnosis of dementia, he claimed not to worry about the future, alluding to the possibility that at his age ‘anything could happen’. Like many he tended to trivialise the problems associated with dementia and stated:

“I don’t think my memory is that bad, but Sadie and my family do. I remember the important things like Clyde winning five nothing! ... At sixty six I don’t worry about the future. I just take life as it comes.” (Walter)

Although the majority felt that the condition was only affecting their memories some were aware that they had deficits other than memory problems. Marie spoke about the ‘loss of her skills’ and being no longer able to cook meals or sew. Jim spoke about lack of concentration and getting mixed up when trying to follow a conversation. Malcolm was aware that he had communication problems. Mary mentioned ‘drifting off’, or what could be described as possible hallucinations. She stated:

“I sometimes see people who aren’t there and have a long conversation with them, perhaps my brother or someone in the family. I can go away for a while into a long story and have quite a discussion. It doesn’t upset me at the time but I can feel quite frightened when I come to and there’s not a soul in the house.” (Mary)

Interestingly, although Mary was aware that she got confused and knew the illness could progress she did not want to make any plans for the future or accept any assistance at the time. She further stated:

“I don’t like to speak ahead, I’d rather wait until the thing comes on us.” (Mary)

Like many Jean thought that she would have an element of control and be able to take cognisance to make important decisions ‘at the time’ of deterioration. Mary’s husband John also suffered from dementia and likewise did not want to look ahead or make any plans of the future. Like Mary he had the hope that his memory would not deteriorate. He stated:

“I don’t worry about my memory getting worse because I’m coping fine at the moment. I know it’s not at the serious stage, but if I deteriorated I would worry. I like to think it won’t get much worse.” (John)

This was a common theme with the vast majority of the participants, that they were ‘coping at the moment’ or would rather deal with the ‘here and now’ and ‘not think too far in advance’. Another typical comment was from Alex, who also realised he could deteriorate but wanted to ‘hope for the best’. He stated:

“I didn’t realise it as happening until it was pointed out to me. No one knows how long it will take. I’ve just got to hope for the best.” (Alex)

As highlighted in chapter two, it is widely accepted that ‘denial’ is the main coping strategy used by people diagnosed with dementia (Howorth and Saper, 2003; Clare, 2002,

Bucks, 1998). It is generally accepted that denial can be used by people with dementia at any stage in the illness either before, during or after diagnosis and in a number of ways. One of the main challenges for the research was ascertaining when people with dementia were in denial of symptoms, lacking insight or generally forgetting (Rankin et al., 2005; Clare, 2002; Fairbairn, 2000; Bucks, 1998).

An example of one participant with dementia possibly lacking insight was Jack, from the pilot study. He stated that his memory was 'very good' and denied any problems with activities of living, claiming that he was fully independent and 'great for his age'. Although in his first interview he was aware he had dementia, during his second he could not recall being diagnosed and stated that he must have 'got better'. Indeed, he stated this despite mentioning on several occasions how much he enjoyed attending the 'dementia support group'. However, his wife stated that he had been given booklets about dementia but he did not read them nor did he relate the information to himself. She felt that due to his level of understanding and short term memory problems, he could not comprehend the information. She chose not to confront him about his deficits and let him believe that he was still functioning at his previous level, before the onset of the illness.

Another participant (Malcolm) who also claimed to have a 'good memory' was aware that he had been diagnosed with dementia. Having an academic background he claimed to have studied in great depth the information on Alzheimer's disease but had come to the conclusion that he had been misdiagnosed. He was aware that he had poor concentration and hesitancy in his speech, but felt his symptoms were related to a head injury which he sustained over twenty years before he was diagnosed. He therefore did not feel that his condition would deteriorate. His wife however reported that his condition had deteriorated quite rapidly since he was diagnosed and he was experiencing some visio-spatial problems and difficulty reading which he either was unaware of or denied. Similar to Jack's wife she also colluded with Malcolm, reinforcing that it was the head injury which was causing his problems.

Although both people with dementia were reluctant to consider a possible deterioration in their condition it appeared that with Jack there was possibly a lack of insight whereas with Malcolm an element of denial (Rankin et al., 2005; Clare, 2002; Fairbairn, 2000; Bucks, 1998).

Although most people with dementia admitted memory problems, many denied that the dementia was affecting their activities of living. According to Walter's wife he needed some assistance with dressing as he was 'getting mixed up'. However, Walter reported that he dressed himself and it was difficult to ascertain whether there was an element of denial or due to the memory impairment he simply 'forgot' that he needed help. Similarly others needed assistance with shopping and paying bills, however related the assistance to generally 'being old' rather than dementia.

One of the main underlying themes of the research was that most people with dementia found it easier to discuss physical aspects of future care rather than problems associated with confusion. Regarding personal care and dressing all the participants reported that they would accept assistance with dressing, if they were physically unable to do so i.e. suffering a fracture or due to mobility problems. However, the majority of them found it difficult to imagine getting muddled or forgetting to change their clothes. Two comments which indicated that they could not foresee a time when their conditions would deteriorate to the extent that they would need assistance were from Howard and Elizabeth. They stated:

"I'm very particular about my clothes and I don't think that would happen."
(Howard)

"I couldn't see that happening to me. My appearance is very important to me."
(Elizabeth)

Even Sylvia, who appeared to have the highest level of awareness about dementia, felt that she 'would always' be able to dress herself properly. Indeed, some participants

appeared rather awkward when the subject was initially brought up and two participants were very evasive about possible future care in general. Although participants were initially defensive about the possibility of forgetting to change their clothes, in general after given information about the potential symptoms of the illness, most agreed that they would rather they were reminded to change than 'go dirty' or go out inappropriately dressed. Typical comments included:

"Yes I wouldn't be annoyed if they were serious about itI would rather it was brought to my attention. I don't have that bother though." (John)

"I would rather be told than go dirty. Cleanliness is very important to me" (Sylvia)

When asked 'how' they would prefer it was brought to their attention most were able to articulate how they preferred to be approached. 'With humour', 'in a straight forward way' and 'nicely' were some of the approaches that participants favoured. This indicated that although most people with dementia found it difficult to imagine the condition deteriorating and requiring assistance, they were able to give some information which could possibly guide future carers in their approach.

One carer pointed out that, although her mother had stated in the Values History form that she would rather be reminded if she was experiencing difficulties with personal care, her daughter had been met with resistance in the past when she suggested to her mother that she needed assistance. After reading the document her daughter stated:

"My mother's comments about accepting help was interesting because I know how stubborn she is about accepting help...I thought the 'besom', because any time I've suggested help in the past she's refused" (Mary's daughter).

This seemed to be a pattern with several people with dementia who stated that they would consider assistance 'in the future' if they deteriorated, but were reluctant to accept help, even although their families felt they needed it at the time of the interview. Interestingly

approximately three quarters of the people with dementia stated that they would want to be informed by medical staff if the illness progressed. The presumption was that ‘at that time’ they would be able make plans or look at care options and be able to make important decision related to their future. Only a few participants anticipated the possibility that ‘at that time’ they might not be able to comprehend or understand the information, most tending to think that they would be able to do so. This was also the case when discussing the aspect of ‘safety and independence’ which is explored further in chapter six.

Due to the small sample one cannot make broad generalisations; however one of the themes to emerge was that people with dementia whose families were more open with them and discussed the diagnosis and prognosis, appeared to have more awareness into their condition, whereas those whose families colluded with the people with dementia’s perception of themselves had less awareness of their conditions. Sylvia, Helen, Jim and Marie’s families, for example, were particularly open with them and discussed the prognosis in depth with them, more so than the other participants. Some authors report that it is easier for people with dementia to deny their condition if unchallenged by others (Howorth and Saper, 2003; Clare, 2002), which is more likely to be the case when someone lives alone. However, it could also be argued that many carers (similar to the professionals in the study) preferred to take their lead from the people with dementia, discussing the prognosis in as much or as little detail as the individual felt able to discuss.

Following on from discussing the prognosis and future with people with dementia the last part of this chapter looks more specifically at future care.

5.10 Discussing future care with people with dementia

One of the main themes of this research was that, although many were unable or did not want to think about the future, they were still able to discuss characteristics of people who could potentially be involved in their care, whether it was for dementia or physical aspect of care. ‘Respectful’, ‘honest’ and ‘trustworthy’, as well as ‘good-humoured’

were the most frequently mentioned characteristics that people with dementia would look for in carers. An example of this was Elizabeth who initially stated in her first interview that she could never envisage herself 'getting lost' or forgetting to change her clothes. However, during her second interview when she was asked to 'imagine' that she needed assistance due to generally 'getting older' she was able to articulate the type of support that she would prefer and the personality traits of those providing this. Moreover, although it cannot be claimed that she had a clear understanding of the reasons that she might need assistance in the future, this information could possibly assist care providers adopt a person centred approach to future care. (This theme is explored in chapter eleven). Similarly others, although reluctant to think about the future, could be drawn out in a similar manner.

Only a few of the participants with dementia claimed to have thought about the possibility of residential care in the future. It was interesting to note that none of them had considered viewing establishments whilst they were still in the early stages of the illness. Moreover, only one long-term care manager recalled one person in the early stages of dementia viewing her home, while she still had the insight and ability to select one.

Marie was one participant who was aware that she could not manage to live alone without help from her husband. Initially when asked how she would manage without his assistance she suggested that 'a friend' could move in with her. When it was suggested to her to 'imagine' that her friend could not move in with her, she was subsequently asked whether she would then consider residential care and what she would look for in a residential home. She stated:

"I have purposely not thought about it. There are homes for Jehovah's Witnesses in other areas, but they are too far away. I wouldn't want to go far and would rather stay in the area. I've got so many friends here. I don't see myself in a place with 400 people." (Marie)

Although Marie claimed not to have ‘thought about’ residential care she was able to clarify points which were important to her. Moreover, the possible presumption could be made from her statement that if she eventually needed residential care she would prefer a small residential home, near her friends, where staff would respect her faith.

Another participant admitted having a fear of going into residential care. He emotionally recalled a ‘bad period’ in his life when he was admitted to a psychiatric hospital, due to depression after the death of his first wife. When asked about residential care he stated:

“I would be frightened to be locked in somewhere. I remember being in hospital and not being allowed my clothes or to go home...that scared me.” (Jim)

When discussing residential home staff he added:

“I think a lot depends on the staffs’ attitudes. It's important for them to approach you in-case you feel awkward to approach them.” (Jim)

This further indicates that Jim could find it hard to approach staff and the statement indicates that he would require them to take the initiative to approach him.

Another person with dementia who was opposed to entering long term care was Howard. He was one of the most adamant out of all the participants that he would never consider residential care or leave his house. During the interviews he reminisced about the ‘Anderson Shelter’ which used to be situated in his back garden and how the house was passed from his parents to himself when they died. He felt the term dementia was a ‘stigma’ and felt his memory impairment was due to his age. In discussing his future support options he clearly he found it difficult to envisage a time when he would require care because he felt his family would look after him. Hence, although he was opposed to residential care he opined:

“I have never given it any thought. I suppose I wouldn’t want to be confined to the one place, but it depends how mobile you are. Probably something self-contained with access to a garden would be important to me” (Howard)

He was therefore able to give some information, albeit minimal, regarding possible residential care. Again, much as he was opposed to any form of home support he was able to articulate that he would like ‘honest’ and ‘jovial’ girls, ‘like his daughters’. He also joked that if he was unable to leave the house, someone who could buy him the occasional bottle of whisky and ‘put a line on at the bookies’ would be important to him.

It should however be noted that a few people with dementia indicated that they did not want to discuss residential care or were too emotional when discussing the prognosis or ‘the future’ so were not asked about this area. As highlighted in section 5.10, possibly these participants had a fear of the future or entering residential care.

Finally, Sylvia, who was possibly the most articulate respondent and appeared to have thought in most detail about the prognosis of dementia and the future. Although she was determined to stay at home ‘until the good Lord’ took her, she was aware that she might require long term care in the future and recorded aspects of residential care which would be important to her (see appendix 10). Due to her experience of entertaining elderly residents in various nursing homes she was able to note the differences in levels of cleanliness in the homes. One obvious theme which stood out throughout her Values History was the importance of cleanliness and a pleasant environment. It was also interesting to note that she would trust her son and daughter in law to ‘do the right thing’. This was an opinion expressed by majority of participants with dementia, in that they would trust their families to organise care should their condition deteriorate. This is further explored in chapter six which looks at proxies and relationships within the families.

This section has shown that making plans for the future did not seem a major preoccupation for the participants. Similarly, Husband (1999) in his study of three

people with dementia, found that the participants were more concerned with how they were perceived and treated by others, than physical aspects of care. Moreover, some studies looking at evaluation of services indicate that people with dementia are more interested in social aspects, such as their relationships with staff and other clients, their need to feel valued or type of companionship they favoured rather than structures and specific aspects of care (Goldsmith, 1996; Sperlinger and McAuslane, 1994). However, this chapter has highlighted that by engaging with people the early stages of dementia, in non direct way, valuable information can be gained which could have an influence on their future care. For example, whilst participants did not necessarily want to view care establishments, information such as characteristics of caregivers and aspects which they would like or like in a residential care can be elicited if it is presented in a non-threatening way. It also showed the benefits of prolonged engagement with participants as a way to explain their feelings and views about the future, as some only opened up to the interviewer after the second interview (Marquis and Jackson, 2000).

5.11 Summary

This chapter clarified that the majority of respondents thought it was the role of medical staff to share the diagnosis with people with dementia. Likewise the interviewees in all groups felt that those experiencing dementia had the ‘right to know’ their diagnosis. Medication for dementia was seen as a way of opening up dialogue with people with dementia. However, one of the themes to emerge is that although one of the perceived benefits of disclosing the diagnosis to people with dementia is for them to make plans for the future professionals do not actively encourage it. This is not necessarily due to antipathy or apathy, but perhaps just ‘not thinking’ about it. Whilst some professionals gave people with dementia the opportunity to ask questions, no professionals in the study actively encouraged them to make plans for the future (apart from financially, which is explored further in chapter seven). Indeed, it is noteworthy that none of the participants with dementia interviewed wanted to make any formal plans for the future. It is therefore possible that professionals are taking the lead from them and going along with their ‘hope’ that they might not deteriorate.

Another theme to emerge was that knowing the diagnosis does not necessarily mean understanding it. Although a few had a high level of knowledge and understanding about the possible prognosis and future, most did not. A large factor was 'denial', which is a recognised coping mechanism for dementia, as well as lack of insight into the condition. However, for some it appeared to be a lack of understanding, whether deliberately 'not wanting to know' or for others due to a lack of information. For those who did not fully understand the diagnosis this could have implications for some of their statements within their Values Histories regarding future care, possibly not having the same credence as someone with a high level of insight.

One of the main themes to emerge was that although none of the people with dementia wanted to make any definite plans for the future, all of this group were able to give some information about how they would like to be approached by professional carers and the types of people that they would like to be involved in their future care should they require it. However, many found it hard to imagine a time when they might need care related to dementia, with most finding it easier to imagine help for physical conditions. Whilst it could be argued that the information some of the respondents gave was not specifically related to deterioration in the dementia, the information could be adapted to the illness and, in particular, characteristics of professional carers could have potential benefits for professionals appointing them. This is further explored in chapter eleven.

Finally, another theme to emerge, which also surfaced in other chapters, was how open and honest people with dementia can be with the interviewer. The relationship with the interviewer, the length of time spent with the person and the ability of the interviewer to draw out the person's feelings are practical areas which will be considered in chapter ten.

Whilst this chapter looked at the feasibility of discussing the future with people with dementia, one of the main causes of anxiety to professionals and carers alike is the 'risk factor' associated with people with dementia living at home (Stevenson,1999). The next

chapter explores the theme ‘independence and safety’, which is one of the sections in the Values History and particularly pertinent for people with dementia.

Chapter 6

Independence and Safety

6.1 Introduction

6.2 Perceptions of people with dementia about their independence and safety

6.3 Perceptions of carers to the independence and safety of people with dementia

6.4 Perceptions of professionals to independence and safety

6.5 Sylvia's Values History- vignette

6.6 Summary

6.1 Introduction

This chapter explores the issues in relation to 'independence and safety', which is one of the sections within the Values History. Issues around independence and safety are particularly pertinent to people with dementia as due to lack of judgment, disorientation and lack of awareness, they are not always able to perceive potentially risky situations (Jacques and Jackson, 2000; Stevenson, 1999; Lawson, 1996). However, chapter three highlighted that, whilst it is necessary to protect people with dementia from harm, in many instances it can lead to disempowerment and paternalism, especially where professionals and carers are over cautious or overprotective regarding the risks they feel the person should be allowed to take to continue to live at home (Mason and Wilkinson, 2002; Lawson, 1996; Norman, 1980). Moreover, disempowerment can happen when their views, either past or present, are either not listened to or not considered (Mason and Wilkinson, 2002; Fitzsimmons and Fuller, 2001). Therefore, one of the main purposes of this chapter is to explore the feasibility of engaging people with dementia to discuss and record their feelings regarding safety and future risks.

The literature review also highlighted that one of the most difficult dilemmas faced by professionals, with regards to people with dementia, is the extent to which they should intervene to make decisions for people with dementia at the time when potentially risky

situations are taking place (Mason and Wilkinson, 2002; Wilkinson, 2001; Stevenson, 1998). Moreover, chapter one highlighted that the concepts of autonomy, beneficence and non-maleficence should underpin interventions for people with dementia, especially in relation to the legal process in Scotland (Wilkinson, 2001). This chapter therefore also explores how appropriate professional participants and carers felt it was for people with dementia to record their feelings about independence and safety.

The first section explores how important it is for people with dementia to remain independent, what independence means to them and the impact that the illness has on their independence.

6.2 Perceptions of people with dementia about their independence and safety

Participants were initially asked how important it was for them to remain independent and to clarify what it meant to them. Although a few stated that it was not particularly important to them the overwhelming majority reported that they wanted to remain independent. Two comments included:

“I’m sure most people like to hang on to their independence for as long as they can. I don’t like to depend on people... I have this self-will to carry on.” (Jim)

“It’s more important to me than anything else (to remain independent) I like my home comforts and if things stay the same I would stay here for ever... but I suppose no-one knows what’s round the corner. It just wouldn’t be the same if we had to get someone in to help us. I wouldn’t say we that won’t accept help, but we like to live in our own house and look after ourselves.” (John)

Both comments were interesting, in that they associated lack of independence with others giving them assistance and not depending on others for help. These comments differed from a study by Glendinning (2003) which reported that for some older people independence was related more to choice and control rather than others carrying out

tasks. Glendinning also reported that large proportion of older people receiving support and services still 'felt' independent. This was the case with one participant within this study, who stated:

"I know that I rely on my daughter for a lot of things now...but I still feel independent. Linda brings me in meals and all I have to do is put them in the microwave. I try not to rely on her too much." (Robert)

It was interesting to note that Robert's daughter had tried to persuade him to accept a home help, but he declined believing that was managing well with his daughter's assistance. However, his daughter, who worked full time and had a family, admitted that she was finding it difficult to maintain the high level of support. Similarly, other participants with dementia felt that by accepting home helps or paid help they would 'become dependent' on others.

The following section explores how the participants felt about the possible loss of independence related to the dementia.

Dealing with loss of independence

There was a general acceptance by most participants that they had lost a degree of independence. According to one participant:

"I can't say that I've totally come to grips with the loss of independence yet. I think it's something on the outside of the door waiting to come in. It's like everything else, it will creep in before you know where you are... like the beginning of the illness." (Jim)

Although the majority acknowledged that they had lost a degree of independence they did not all relate it specifically to dementia. Robert, for instance, who stated he 'relied on his daughter' felt this was due to his age and his wife dying. However, his daughter stated he

coped independently for several years after his wife died. Moreover, one of the first symptoms that drew her attention to him developing dementia was that he stopped cooking. Therefore, it was due to the dementia that she was helping him and not the death of his wife.

Similarly, approximately half the participants highlighted other reasons for dependency on their families rather than confusion or dementia. This was an underlying theme from chapter five where a large proportion of the participants with dementia were more able to imagine physical reasons for requiring care in the future than confusion related to dementia.

For example, one participant reported that he required his wife to go out shopping with him because he was deaf and could not hear the traffic. However, his wife reported that he had lost his confidence due to disorientation and confusion, thus requiring her to accompany him. Another participant cited difficulty standing at the cooker due to dizziness, whereby his carer reported that he was having difficulty operating it. Rather than highlight dementia for loss of independence some participants related the loss to generally 'getting old'. This attitude was also highlighted in the previous chapter with several people with dementia trivializing the diagnosis of dementia as a natural part of the ageing process. It was difficult to ascertain if these attitudes were coping responses, lack of insight or if they were perpetuated and encouraged to think this way by their families.

However, some people with dementia gave very candid accounts of their loss of independence and recognised problem areas caused by the dementia. Two comments included:

"I know that I've got to accept help from Mary, because there are things I just can't manage now. Sometimes if I try to get out of that little heap by myself it will just come back on me."(Bill)

"I used to be very independent and for a long time I sewed all my own clothes. I

loved that, but I don't do that now. That place in my mind has gone. I've lost all my skills." (Marie)

Both Bill and Marie were emotional whilst describing their loss of independence and recognised that they could not live alone without their partners' assistance. One participant who lived alone stated that she had taken several measures to remain at home. She stated:

"I stopped using the cooker and only use the microwave now. Nothing happened.... I just had a fear of leaving it on. I know my limitations. I've decided not to be silly." (Sylvia)

It therefore appeared that Sylvia had, in effect, given up a degree of independence to remain independent. Initially it appeared that that Sylvia's comment backed up Glendinning's (2003) study which reported that some older people view independence as being able to make choices and having control rather than others carrying out tasks. However, it became apparent throughout the interview that she had, in fact, given up independence due to fear of being admitted to residential care. Her comments are explored further in the next section of this chapter.

According to three participants (males), the loss of independence which they found most difficult to deal with was stopping driving. All three believed that they still had the skills and experience to drive and two expressed anger towards medical staff for initiating the loss of their licenses. This finding supports debate in the literature which indicates that that being instructed to give up driving is a traumatic experience for many people with dementia (Mason and Wilkinson, 2002; Pinner, 2000; Johnson and Bouman, 1997).

Although the majority of participants were able to comprehend and express their feelings about their current loss of independence, only a minority were able to envisage a further deterioration and potential risks associated with the illness. As highlighted in chapter five, some participants with dementia whose families had discussed the illness and

prognosis with them in depth, appeared to have more awareness of the potential risks. It is noteworthy that although some claimed not to have any knowledge of deterioration resulting in inability to make decisions some were able to discuss the ‘possibility’ of future risks. In particular, two participants asked the interviewer questions about the future and implications for their safety. Chapter ten discusses how the interviewer dealt with such questions. As noted in the previous chapter some people with dementia preferred not to discuss the future and/or risks associated with dementia.

As highlighted in chapter three, disorientation to place or ‘getting lost’ is one of the main risk factors associated with dementia (Miskelly, 2004; Silverstein et al., 2002). A survey carried out in 1998 suggests that 40% of individuals with dementia will become lost at some point in their illness and 70% of those who repeatedly get lost will be admitted to institutional care (MWC, 2004). Therefore, the remainder of this section explores the feelings of participants with dementia about the possibility of ‘getting lost’ in the future and the feasibility of discussing it with them.

Getting lost

Only a few participants acknowledged that they had experienced disorientation or that they had a fear of ‘getting lost’. Three comments included:

“If I got lost when I was out it would make me very wary of how far I could go in the future. I stopped going into the town for that reason, in case I got lost.”
(Sylvia)

“I went into town about a year ago. I was meant to be going to the Victoria Infirmary and got lost. I was crying and in a terrible state. I won't go into town again by myself and would ask my daughter to come. I carry identification with me now. I still go out to the shops and I feel fine in Castlemilk.” (Helen)

“I wear a chain around my neck with my name and address on it in case I get lost. I

know plenty of people in Rutherglen who could help me. I know I could walk out the door and get lost. I don't worry about it but my family does." (Walter)

Although Sylvia reported that she had stopped going into town 'in case' she got lost, her daughter in law reported that she had possibly got lost on one occasion and had forgotten or did not admit it. Helen, on the other hand could recall an incident of disorientation very clearly. However, both continued to go for walks within their own localities. Walter had never got lost, but at his family's insistence only walked to the local shops. It is noteworthy that in the cases of Sylvia and Walter, potential conflicts with their carers could arise in the future, which will be further explored in section 6.3.

Malcolm, from the pilot study, admitted getting lost on one occasion. However, he was very adamant that it was a 'one off' incident and specifically related the disorientation to moving house and not to the dementia. Although he had a good knowledge of dementia he could not foresee the same happening again, feeling he would 'concentrate harder' and not allow it to happen. Interestingly, his wife stated that since the incident he had not attempted to leave the house unaccompanied, which possibly related to a lack of confidence.

Similarly, many participants denied that there was any possibility of them getting lost, believing that they would have a degree of control over their symptoms and /or be able to understand the implications of wandering at the time. For example Mary stated that she would have to 'be firm' with herself and 'not allow it to happen' and Elizabeth commented that it 'definitely wouldn't happen to her'.

Overall, the majority of participants either found it difficult to imagine that they could get lost or expressed feelings of discomfort discussing the subject. (Two participants were emotional when discussing their feelings about dementia and therefore not asked about their views on the possibility of getting lost). Responses included 'I don't know', 'I couldn't really say' or 'I know the area so well'. One person asserted 'I think I'll leave that one for now' (Bill) indicating an element of fear about the future. These comments

indicated a belief that their condition would not deteriorate to the extent that they could get lost, particularly in their own localities. This was also true for other situations such as leaving the cooker on, not dressing appropriately to go out and general home safety.

As chapter five highlighted, many participants did not feel that it was necessary to make plans for the future as they hoped that their condition would not deteriorate to the extent that they would require assistance. Indeed, some felt that they would have the abilities to make decisions, related to risks, at the time when a situation arose. According to Robert:

“It's hypothetical...I would need to take advice at the time.” (Robert)

Robert's comment is interesting, in that, although he had an awareness of the progression of the illness and possible cognitive decline, he believed he would be able to make important decisions related to risk in the future. This reflects findings in a study by Howorth and Saper (2003), which found that, although many people with dementia were aware of their diagnosis, they were unable to make the connection between the diagnosis and the deficits they were experiencing. The authors were unable to ascertain if their lack of response was due to a psychological defense or an organically determined failure to understand the implications of the illness. Husband (1999) also reported that there was a general reluctance for participants within his study to plan for future care. This study also indicated that for the majority there was a reluctance to consider aspects related to potential risks associated with the illness.

Only a few people with dementia were able to envisage and discuss potential risks in the future, although it is also possible that others who did not openly discuss the future could have had an awareness but used 'denial' or did not want to discuss it, preferring to deal with the 'here and now'. Although only a few were able to discuss risks, this differed for Gilmour et al (2003) who found that none of their ten participants with dementia interviewed showed any concern about risks. However, it should be noted that Gilmour et al only interviewed participants on one occasion so may have missed important

information which can be obtained through prolonged engagement (Marquis and Jackson, 2000).

Of the few people with dementia who openly discussed risks Sylvia, who had a particularly high level of insight into her condition, and was possibly more aware of the 'risk element' than the others, stated:

“As soon as I received my diagnosis I told my friends and neighbours. I told them so that if they saw me doing something wrong they could see me right.....perhaps bring me home if I got lost. Fortunately that hasn't happened yet. If they didn't know that I had Alzheimer's disease then they might not want to interfere. Now I feel if I do something wrong they would try to rectify it.”(Sylvia)

It appeared that Sylvia had pre-empted dangers and risks related to the dementia. This was due to a fervent desire to continue living at home and in some ways she had given up part of her independence to remain independent. Notably, her decision to stop using her cooker *‘for fear of leaving it on’*, is a clear example of this. However, it became apparent that her daughter-in-law had educated her and warned her of the dangers of using the cooker, as Sylvia had, in fact, burned some pots on a few occasions. Due to her fear of going into care she therefore decided to ‘be sensible’ and comply with her daughter’s wishes. However, she was the only participant in this study who presented this type of input as most tended to downplay the potential risks associated with the progression of the disease.

A similar pattern of attitudes towards risk by older people has been described by Wynne-Harley (1991). Some, like Sylvia, had imposed constraints on themselves out of fear of being admitted to long term care or hospital, whereas others had refused to take any action to protect themselves, insisting on the right to maintain their normality. Similarly, Kane and Degenholtz (1997), in a study which evaluated values assessments completed on cognitively intact older people by case managers, reported that the question of the trade-off between safety and independence tended to raise ambivalent feelings in clients,

to the extent that they were not able to categorize approximately a third of the assessments. However, unlike this study, Kane and Degenholtz did not specifically ask participants about the aspect of getting lost, and instead focused on how important it was for them to 'feel free to come and go', with approximately a third believing this was more important than safety.

Another participant with dementia (Marie) also recognised that she had 'lost her skills' and relied heavily on her husband. Her condition was more advanced than Sylvia's and she recognised that she would not be able to cook or live alone should anything happen to her husband and was aware that it would be dangerous for her to live by herself. She therefore accepted that under such circumstances she would require residential care for her own safety.

For some there were inconsistencies on their thoughts regarding risk. An example of this was Jim who admitted that he relied heavily on his wife and daughter 'for everything'. During his first interview he stated that he could 'not cope' if left alone and admitted that he would not feel safe and would prefer to go into care if anything happened to his wife. He also expressed that he would be embarrassed if he was ever to 'get lost' when out with the house and did not feel that it was acceptable to take such risks, and in such circumstances would prefer residential care. However, during his second interview he stated that although he had not cooked for many years, he had cooked 'in the army' and would be able to look after himself and live independently. He also felt that he could not foresee a time when he would get lost in his own locality and if he did he would 'stop going out', feeling he would have an element of control over the symptoms of the illness.

This section has shown that there were varying degrees to which participants were able to discuss future risk associated with dementia, ranging from those who felt awkward discussing potential risks to those who were able to discuss aspects of future safety without difficulty. It also showed that the majority, even those who had a good knowledge of the illness, felt they would have a degree of control over their decision making abilities in the future.

The following section explores the perceptions of carers regarding the safety of their relatives with dementia. It begins by contrasting the views of participants with dementia with their carers.

6.3 Perceptions of carers to the independence and safety of people with dementia

Concerning general home safety, there was an acknowledgement amongst people with dementia that their carers worried about their safety more than they did (which was confirmed during the carer's interviews). According to Elizabeth:

"I'm a bit casual that way. I know that I take risks and am not as safe as I could be. I say things are fine because I know that they will be made fine. My daughters check up on me and I am happy for them to do so...You've got to have some kind of courage." (Elizabeth)

Elizabeth, like many of the participants, did not feel that leaving the cooker on 'occasionally' or forgetting to lock her door when going out with her home were particularly serious problems and admitted being 'casual that way'. However, her daughter was tearful when recounting how worried she was about her mother's safety and felt the need to check on her mother several times a day to ensure she 'came to no harm'. Moreover, she felt so anxious about mother's safety that she considered residential care 'in case' anything happened although no serious incidents had taken place at the time of the interview. On a similar vein, Gilmour et al's study found that, although all ten participants were deemed to be 'at risk' by their relatives, no serious incident had, in fact taken place. When it was put to her that a home help or carer could assist her mother she stated that Elizabeth had refused this service because she did not feel it was a problem.

Other people with dementia and their carers also had differing views on the level of risk, which they would consider acceptable for the person with dementia to take. For example, Walter stated that he wanted to continue to go out for walks by himself, even if he got

lost occasionally. However, his wife had the opposite view and stated if he ever got lost she would not allow him to go out by himself. She stated:

"I wouldn't let him go out again. No that would be it. I would have to go out with him."(Walter's wife)

Similarly, Sylvia and her daughter-in-law's views differed. Sylvia had informed her neighbours of her diagnosis 'in case she got lost' and set out in her Values History that she was willing to accept the possible risks associated with getting lost. However, her daughter in law stated that whilst she would do all in her power to go along with Sylvia's wishes in other respects, she would have strong reservations about allowing her mother in law to stay at home if she started wandering. She commented:

"I think I would throw in the towel. At the moment we are at the 'home support' stage, but if an incident took place (i.e. wandering) then I think we would have to look for a nursing home." (Sylvia's daughter-in-law)

Clearly this comment indicates a discrepancy between the wishes of Sylvia and her daughter in law regarding the level of acceptable risk which Sylvia should be allowed to take to continue to stay at home. In effect Sylvia's daughter in law would attempt to overrule Sylvia's statement recorded in the Values History should she 'get lost'. Although Sylvia's daughter in law would possibly see this as looking out for her Sylvia's best interests, this has been portrayed in different ways in some of the literature. Lawson (1996) and Norman (1980), for example, have highlighted that this type of attitude is a form of 'paternalism'. Moreover, others suggest that, in general, older people are subject to 'ageism' and that they are restricted in their abilities to make choices about the level and types of risks that they consider acceptable (Butler, 1987; Norman, 1980).

Although all the participants with dementia felt able to go out by themselves, at least in their own localities, there was a tendency for carers who lived with the person with dementia to accompany them to minimize any potential risk of the person wandering. In

some ways this group had lost a degree of independence in advance of those living by themselves. According to Bill's wife:

"I would worry about him (out alone)... we're together all of the time anyway."
(Bill's Wife)

Despite Bill's awareness that he could no longer go into town or any great distance by himself, he still felt he was able to go out by himself locally. However, his wife did not allow him to do this by himself despite acknowledging that he would 'probably' be safe and 'worst case scenario' if he did get lost, he was well known in the area. Furthermore, it became clear throughout her interview that curtailing Bill's independence was related to her perception of his awareness of danger and possibly related to her anxiety rather than his safety. Bond et al (2002) also reported that carers' understanding of the person's loss of insight may influence the way they deal with risk during care giving.

Although all the participants with dementia, who were living alone, were able to go outwith their homes unaccompanied, the majority of their carers appeared to be 'waiting' for them to 'get lost'. This appeared to be one of the main areas cited as causing carers not living with the person most anxiety. Indeed, some stated that this would be the point when they would consider residential care for the person. Aspects such as cooking and home security were also mentioned by many carers as a cause of anxiety. These issues reflect the areas covered in other studies (Gilmour et al., 2003; Wynne-Harley, 1991; Neill et al., 1988). For example, Wynne-Harley (1991) in the study examining attitudes towards risk taking and the safety of older people, reported that families tend to worry prematurely about relatives living alone, even when healthy and in their late fifties. Likewise, Neill et al found that greater anxiety is often shown by those relatives who are geographically separated from older people, often being concerned with physical or mental welfare of the older person.

On the other hand carers living with a person with dementia expressed less concern about these aspects, possibly due to them being more accessible and able to offer a higher

degree of supervision. This group of carers tended to report the day to day strain of dealing with symptoms of the illness, such as repetitiveness and changes in the person's personality as causing them more anxiety. Neill et al (1988) similarly found that those carers who are most involved with the person are more likely to worry about their own health, the changing need of their own family or exhaustion with their role as a carer.

All carers had received some information about the possible risks associated with dementia although knowledge varied significantly. Younger carers, for example, appeared to have the greatest awareness, with many having access to the internet. Whilst knowing 'potential risks' seemed to cause some carers more anxiety 'waiting' for an incident to take place, it allowed others to look ahead and ultimately reduce their anxiety by putting mechanisms in place to reduce potential risks, such as insisting the people with dementia carried identification, replacing gas cookers etc. However, some relatives preferred to 'wait and see', actively deciding not to seek information or think too far ahead and deal with the 'here and now'.

Experience of either caring for or knowing someone else with dementia was also a major factor in awareness of possible risks. However, previous knowledge affected carers in different ways as the next two examples highlight.

Robert's daughter reported that her grandmother had dementia and she felt that in hindsight the family had tried to keep her at home 'too long'. She recalled instances of her grandmother becoming disoriented to time, becoming aggressive and being generally difficult to manage. She also recalled the anxiety which it caused her family and she admitted a 'dread' that her father's symptoms could manifest themselves in the same way. She stated:

"Basically I'm dreading what's going to happen in the future. I know it's not going to be easy... I'm just trying to deal with just now... although I know we'll need to talk to him now... before he gets worse... to see what he wants." (Robert's daughter)

She alluded to not being able to cope with her father should he experience the same problems which were manifested by her grandmother and would look for residential care before it got to that stage.

However, another carer who also had experienced dementia with her grandmother had the opposite view. She recalled her grandmother being admitted to hospital and declining significantly both mentally and physically and being 'miserable' whilst being in long term care. She stated that her experience had caused her to have a strong aversion to residential care and she would 'exhaust all avenues' and do all within her power to keep her mother at home. Although her mother had got lost on one occasion she felt that the risk element was worthwhile to keep her at home.

This section highlighted the high level of anxiety which many carers experienced anticipating risks in the future. In some cases a degree of paternalism had already taken place. It also highlighted potential conflicts which could arise in the future, should a person with dementia choose to continue to live independently without support. On the other hand, it also showed that with many participants with dementia there was an element of denial regarding their safety as the illness progressed.

The following section explores how professionals view the independence and safety of people with dementia.

6.4 Perceptions of professionals to independence and safety

Similar to other studies which examined how people view risks associated with dementia, the majority of staff recognised that professionals, carers and people with dementia approach risk from different perspectives, often with each party having difficulty understanding the other's perspectives (Clarke and Hayman, 1998; Carson, 1996; Wynne- Harley, 1991). Two comments which illustrated this were:

“Attitudes vary within professionals, carers, in fact everyone. A lot of people see an old person falling as grounds for going into care. You can fall anywhere, even in a nursing home!” (CPN3)

“How you view the world is where you’re standing from. Families are looking at a dramatic change in the person, whereas we might think ‘so and so’ is more demented than ‘so and so’ and she’s managing. The social work might have budgetary constraints.” (GP2)

The GP’s comment reflected findings in a qualitative study by Clarke and Hayman (1998) which compared perceptions of risk between professions and family carers of people with dementia. They found that professionals and carers view risk differently. Whilst professionals’ judgements are primarily based on their knowledge of other people with the same condition in similar situations, carers base their judgments on past experience of the individual.

Approximately half the participants felt strongly that some people with dementia were admitted into long term care too early. The reason cited most often for this was due to high levels of anxiety which some family members experienced, feeling it was the ‘safer’ alternative for them to be admitted into residential care. ‘Panicking’, not being ‘equipped’ to care, ‘not wanting’ to care or not being ‘a natural carer’, distance or feeling under pressure from neighbours were other explanations given for some carers wanting the people with dementia into care sooner rather than later. Several professionals mentioned that some people with dementia were ‘pressurised’ to go into long term care by their families. As a group, CPNs appeared to have the strongest feelings about this. For example, as one stated:

“I can see a lot of mine heading that way, having mild to moderate dementia and managing fairly well, but the families are pushing for care. I guess it happens about half the time if not more.” (CPN5)

Approximately a quarter of participants, mostly district nurses, felt the opposite. For example:

“I think more carers want to hold on to them. You feel the carer should let go, but they won’t and maybe they’d be better cared for in care.” (DN1)

District nurses, as a group, are often more likely to be involved with individuals during latter stages of the dementia when they experience physical problems associated with the conditions such as incontinence, feeding problems and falling. Therefore, their perception could be influenced by the heavy burden which some carers are faced with at this stage. Similarly, Gilmour et al (2003) reported that some district nurses within their study were more likely to want to establish rules about risk management for people with dementia. Gilmour et al reported that two of their main concerns were people with dementia falling and ensuring adequate nutrition, which was also reflected in this study.

Several participants, particularly in long term care settings, had noticed that the timing of when people with dementia were admitted to care often depended on the philosophy of the individual social work department and the level of services provided by home care. In such cases, some were seen as being more flexible and imaginative than others at keeping the people with dementia at home. Moreover, several staff suggested that attitudes were changing, with people with dementia being sustained at home longer now than in the past. This was highlighted by a residential home manager:

“There’s been a great change. In the past I think we listened to the family more. Now I think it’s the person. I think the social work will do their best to keep the person at home. A person centred approach is what we’re geared to.” (Res1)

Admission to hospital was often viewed as pathway to residential care. This was seen by some as a way to admit some people with dementia whom were considered ‘at risk’ into long-term care, but was viewed negatively by others. The following comments from two GPs highlight these opposing views:

“I can think of cases where people are in the community too long and have been at risk too long, more often because the person has been resistive to move. Most cases are resolved by some sort of crisis....self neglect and admitted into hospital then care.” (GP2)

“I think you see that not infrequently. A person extracting themselves from hospital is not easy and people assume that the path of lowest risk is hospital to institutional care. I think it’s appalling when you think of what you or I would want.”(GP4).

Clearly, these two GPs viewed hospital admission and subsequent admission to long term care differently. These two examples highlight how, even within the same professional group, personal values and opinions could have an effect on whether someone with dementia considered at risk could be discharged home or not. Moreover, it clarifies that often decisions regarding people with dementia are value laden and not necessarily consistent.

The remainder of this chapter explores the feasibility of people with dementia recording their views about their independence and safety whilst in the early stages of the illness. As highlighted in chapter five only a few people with dementia were able to envisage and discuss fully the potential risks associated with dementia, one of whom was Sylvia. To facilitate discussion with professionals, they were shown her Values History (appendix 10), which highlighted her strong desire to stay at home and her awareness that there would be risks involved in her doing so. In the first instance participants were asked if they thought it was feasible to discuss and document her attitude towards risk whilst she was in the early stages of dementia.

6.5 Sylvia’s Values History-vignette

Many of the participants, particularly those in long term care settings, stated they were surprised that someone with dementia could have such a high level of insight into their

condition, many never having had the opportunity to have discussions with people with dementia in the early stages of the illness. For those who did have experience working with those in the early stages of the illness, most had not discussed the potential risks involved with them, tending to discuss the risk factors with family members. The majority of psychiatrists and CPNs stated that they occasionally discussed the future with people with dementia, but usually only if the person initiated the conversation, which was not very often. They however felt that informally they developed a picture of the person with dementia over a period of time and knew without asking directly how the person felt about risk factors and their desire to stay at home. Several staff, especially social workers, reported that often when they became involved with people with dementia it was during a crisis, often resulting from an individual's loss of insight into their condition or the condition being too advanced to reason with them and have meaningful dialogue.

GPs rarely discussed potential risks with people with dementia but two of them used the analogy of frail elderly people with mobility problems, the similarity being that often the person was quite content to take the risk (falling) whereas families felt the person's care needs could be better met in long term care.

The vast majority of professionals stated that they considered it feasible for a people with dementia to record how they felt about risk factors associated with dementia. Being 'person centred', 'giving the person a voice', 'taking cognisance' or 'thinking about the person' were reasons cited for referring to the document by the majority of participants. According to one social worker:

"Yes absolutely... other people would have things to say about the risk which would have a bearing on the possible outcome. This brings in the individual." (SW5)

Whilst the majority stated that they would refer to the document and would find it useful to have the information, there were varying strengths of feeling regarding the impact that the information would have on decision making and the eventual outcome. Approximately a quarter of participants felt very strongly that, as far as possible, the

wishes of people with dementia should be adhered to, and made comments such as ‘I think you’d pull out all the stops if you knew this’ and ‘you’d be duty bound to go the extra mile’. Several interviewees mentioned that it would free them from an element of guilt, particularly because it was in writing. Some felt that, even although the Values History was not a legal document, it would add weight to any difficult decisions to keep the people with dementia at home when there was pressure from others to have individuals admitted to long term care. According to one psychiatrist:

“I think it’s got more clout the fact that’s in writing. In this day and age unfortunately being sued has become an issue... it would make you feel more comfortable because you can say you are doing it to go along with the person’s wishes. Quite apart from the legal thing there is a defence in your own conscience.”
(Psych1)

The psychiatrist pointed out that, although he would go along with her wishes to the best of his abilities, a time could come when he would have to take legal steps for her to be admitted to care. Similar to other professionals who stated that it would force them to ‘listen to her voice’ he stated:

“Yes you may have to overrule her, but I see it as a positive step. It’s not just ‘not listening’ to her wishes, it overruling them.” (Psych1)

This comment is a key point of the study. It indicates that he would have to make an active decision to overrule her wishes rather than passively ignoring her previous wishes, which could possibly be the case if her wishes were not in writing. Although the concept of empowerment indicates that an individual’s view should be taken into consideration and listened to, it does not necessarily mean that they have to be followed (Wilkinson, 2001; Fitzsimmons and Fuller, 2001). This theme is further explored in chapter eleven.

However, the remainder felt that although the document should be referred to, several other factors should be taken into consideration. One of the main concerns expressed by

several participants was that the person's family should be involved in the process from the beginning as it could have an effect on their relatives' lives as well. One psychiatrist pointed out that often people with dementia found it difficult to see the impact that their illness had from their family's point of view, even in the early stages, but particularly as the illness progressed. Two staff, both advocates for carers, opined that families could feel under pressure to keep the person at home, feeling they had to go along with the person with dementia's wishes. One stated it could lead to carers feeling 'guilty' if the person had to go into care and another felt it could be seen as 'emotional blackmail'. On the other hand many participants felt that the statement could be used to relieve the family of guilt should something happen to Sylvia and possibly be used as a way of 'reminding them' or 'focussing the family' that Sylvia's wishes were to stay at home as long as possible and it was 'her choice' to take the risks associated with the condition.

Another concern expressed by several staff was the people with dementia's level of understanding at the time of writing, possibly not being aware of the full potential of the illness. Several staff expressed the same opinion as one district nurse who stated:

"I think it would need to spelled out to her that there might come a time when she would have to be removed into a home for her own safety." (DN3)

This was, in fact, the case with some of the people with dementia who had been interviewed. Sylvia did have a particularly high level of insight and was aware that a time might come when she would need nursing care, however some other participants with dementia, were not aware (or were in denial) that their condition could deteriorate to that extent. This aspect was discussed in more detail in chapter four.

Some also felt that, even although Sylvia had a high level of insight, she could not envisage how she would feel in the future. One psychiatrist stated that, on the one hand she would feel obliged to refer to the document, but on the other hand expressed some doubts. She stated:

“It’s hard to imagine how you’ll feel until you’re in a situation. Some people say they never want go into a home, but further down the line they’re terrified to be alone. Things do change. Anyone who does a living will is doing it with their understanding at the time. It’s not black and white. There are numerous things to consider.” (Psych 2)

One of the district nurses, who did not feel Sylvia’s comments on risk were relevant, gave a similar opinion as the psychiatrist stating:

“They’re not in the situation and they could probably never envisage that they could be like that.” (DN2)

Although both comments were alluding to the same point, the psychiatrist still felt it was preferential to have Sylvia’s comments and to refer to the document whereas the district nurse felt it was inappropriate.

One of the aspects which came across during the interviews was that most participants felt that people with dementia should be maintained at home for as long as possible and felt that Sylvia should be allowed to take a high level of risk to do so. It became apparent that most staff had similar opinions to Sylvia and strongly identified with her feelings. Two CPNs with strong feelings stated:

“No matter who it is you should be trying to maintain them at home as long as possible. It’s proven that people do better at home. Only if after a big package of care is broken down would I look at long term care.” (CPN4)

“I would always go for the person who has dementia. It’s their life. I’ve got a strong bias against nursing homes. I’d rather see someone fall over five times and be happy at home, rather than end up in care and hating it. It happens all the time and it depends on the family and how much pressure they put on them.” (CPN3)

It is therefore possible that some participants were vehement in their support of Sylvia remaining at home because of their own values. As this possibility emerged approximately half of the participants were asked if Sylvia had stated the opposite, that she valued her safety more than anything, and would rather be in residential care if she was ever at risk, would they still feel as strongly about the information in the Values history?

The majority stated that they would take the information into consideration and pursue residential care for Sylvia earlier than if she had not made the statement. Most of those who were positive about her accepting a high level of risk because it was 'according to her wishes', had the same enthusiasm for her going into care because it was 'according to her wishes'. According to one social worker:

"If I knew that person had a desire to be somewhere safe I would go down that direction a bit earlier...if the person's views and wishes had been expressed it would certainly influence me and I would hope it would influence the decision about the person's future." (SW1)

Several participants, especially those in long term care settings, discussed the guilt that carers experience when a relative has to enter long term care and suggested that the statement could relieve them of some of the guilt. However, one GP questioned Sylvia's motives for pursuing residential care, feeling that it might be to relieve pressure from her family rather than what she really wanted. Indeed, many studies show that being a burden to relatives is a fear of many older people (Glendinning, 2003; Wynne-Harley; 1991). Moreover, one of the themes to emerge from this research was how honest people with dementia can be when recording their values and family relationships. Furthermore, a comparison could be drawn with advanced directives. Chapter one highlighted that one of the arguments against advance directives is that some individuals could request not to have their life sustained to protect their families rather than what they want for themselves. Similarly, some people with dementia could record that they would want residential care at an early stage in their illness to relieve burden on their relatives, rather

than what they want.

6.6 Summary

In summary this chapter looked at risk from the perspective of people with dementia, their carers and the professionals involved in their care. In discussing potential risks associated with the condition with people with dementia there are several factors which need to be considered.

The first is related to the point initially highlighted in chapter four, namely, knowing the diagnosis does not necessarily mean the individual with dementia understands the prognosis or indeed wants to know. For such participants, raising issues of future safety could lead to fear and anxiety, by forcing them to discuss aspects which they did not feel comfortable discussing.

Secondly, and again due to the people with dementia's level of understanding and insight, some were inconsistent in their remarks about possible future risks, which could result in their opinion being taken out of context if based only on a single interview. Interestingly, respondents' views on risk and future care were the only areas within the Values Histories where some people with dementia were inconsistent in their replies. Moreover, for those with a limited understanding of the future risks, general opinions such as 'never wanting to go into a nursing home' could possibly have less substance and meaning to professionals than those people with dementia who were aware of the risk elements and thought carefully about their statements.

Finally, some people with dementia, albeit the minority, were easy to engage with and able to have a frank and open dialogue about potential risks associated with the illness. Some of this group claimed to know the potential risks prior to the interview and had clearly thought about their future. Notably, others became aware of the risks during the interview by asking the interviewer questions about dementia and the prognosis. For this group the information in their Values Histories regarding their future safety could be

interpreted as ‘empowering’ as it infers that that they had an accurate knowledge of the condition and possible risks associated with the illness (BMA, 2003; Winner, 1996). This in turn, gave them the opportunity to ‘make judgments which advanced their own self interests’ (Winner, 1996:71).

From the carers’ point of view, this part of the study showed that even in the early stages of the illness there was an element of ‘paternalism’ with some carers trying to protect the people with dementia from risks. With some carers and people with dementia there was already the beginning of conflict concerning their safety. However, there was a general acknowledgment from the majority of carers that the Values Histories accurately represented the views of the individuals.

Finally, from the professional participants’ point of view the section on ‘independence and safety’ proved to be the one in which they were more cautious in their enthusiasm. Whilst the majority of professionals claimed that they would refer to the documents, there were varying degrees of opinions on whether the information would make an actual difference to the outcome should an individual be on the verge of being admitted to residential care. For those who were most sceptical of this section of the Values History, one of the main reasons cited was that the statement could put families under pressure to keep the person longer at home than they could manage. The main prerequisite put forward by professionals was that families should be involved in the early stages of completing the document when the people with dementia were writing their feelings about safety.

One of the main points which emerged is that it would make them ‘think’ about the person or ‘consider the people with dementia’s feelings’ even if they had to be over ruled in their own best interests. The chapter also raised the possibility that professionals’ own values and feelings about individuals’ safety could have an influence on the strength of their feelings about their statements. This theme is further developed in chapter nine. Moreover, the idea that a person’s ‘past wishes’ should have precedence over ‘here and now’ and the relevance of asking the person about care which they ‘might’ want, without

them actually being in the situation was raised. This is explored in more detail in the following chapters.

Chapter 7

Families and relationships

7.1 Introduction

7.2 Adults with Incapacity (Scotland) Act 2000 :- current and future impact of the Act.

7.3 Continuing Power of Attorney - discussing finances with people with dementia

7.4 How do professionals engage with people with dementia about their welfare?

7.5 Values Histories - ‘family and relationships’

7.6. Engaging with people with dementia to document how they feel about ‘family and relationships’

7.7 Carers’ experiences advocating for people with dementia

7.7 Sylvia’s vignette- exploring the issues recorded in Sylvia’s Values History

7.8 Summary

7.1 Introduction

The AWI (Scotland) Act 2000 suggests that individuals with dementia should consider appointing a ‘continuing power of attorney’ to look after their financial interests and a ‘welfare attorney’, to represent their health and social matters (Alzheimer’s Scotland, 2004b; Scottish Executive, 2004a). As highlighted in chapter one, the concept of ‘welfare attorney’ in relation to individuals with incapacity appointing someone to look after their medical and social interests is a totally new concept in Scotland (Ward, 2004; Scottish Executive, 1999a). In the *Code of Practice for Continuing and Welfare Attorneys* it emphasises that people acting on the person’s behalf ‘need’ to:

“take the opportunity of the original discussion to gain as much information as possible about the granter's wishes at the time of making the grant” (Scottish Executive, 2001:3.19).

The purpose of this chapter is therefore to explore the issues related to engaging with people in the early stages of dementia whilst they have ‘insight’ into their condition, with regards to appointing someone to look after their interests. This is explored from the perspectives of professionals, carers and people with dementia. Furthermore, one of the sections within the Values History gives individuals the opportunity to document how they feel about ‘family and relationships’. This chapter also examines the feasibility of participants with dementia documenting their feelings and, by the use of a vignette, ascertained how relevant professionals felt the information would be to their practice. It also touches on whether or not past wishes (as documented by individuals in their Values Histories) should be more prevalent than their current wishes (when the individual has lost capacity to make decisions), a theme which is developed in the next two chapters. To begin with participants were asked in general views about the AWI (Scotland) Act 2000.

7.2 Adults with Incapacity (Scotland) Act 2000 - current and future impact of the Act

Given that the interviews took place between 2001 and 2002 and the AWI (Scotland) Act (2000) had only been part implemented in April 2001, with Part Five of the Act in July 2002, few participants claimed to have a good knowledge of it. This is not surprising given that Riddell and Pearson (2005) found that in 2003 there was little reference to the AWI (Scotland) Act (2000) in local NHS trust policy documents on DNAR (do not attempt resuscitation) in Scotland.

The majority of participants had some knowledge of the Act, but two district nurses, one voluntary worker and two residential home staff had never heard of it. Most participants

needed basic explanations of the Act, particularly in relation to welfare and medical attorney and taking into account the ‘present and past wishes’ of the person when doing anything under the Act. Knowledge of the Act also appeared to vary according to professional background with GPs and Psychiatrists having the greatest level of knowledge and district nurses and residential home staff having the least. The majority of carers and all but one person with dementia had not heard of the Act.

Professional participants were initially asked if they felt that the Act would make any major difference to their practice. The majority of GPs did not feel it would make any major differences, although there was recognition that they would have to involve people with dementia and their carers more in decision making in the future. Two GPs who highlighted this commented:

“I don’t believe doctors or others would go out their way to harm a person, so it’s not going to make that much difference to the person. It will benefit the relatives in that you’ll have to involve them more... Before the AWI you could bypass the family. You did what you thought was best. Now I would need to consult them. Most are happy with what you suggest, but that gives them a bit more empowerment.” (GP1)

“Yes and no. In the Act is a code of good conduct, which is enshrined in good practice anyway. It’s about doing no harm and doing your best for the patient, respecting their values and speaking to their families. Where you have a treatment plan or the more prescriptive parts you’ll need to get the family to consent, there could be issues with that for some families.” (GP4)

By mentioning ‘good conduct’ and ‘not going out of their way to harm people with dementia’, the GPs possibly alluded to the belief that their current practice was satisfactory and adequate in looking after the interests of people with dementia. However, some also mentioned that because of the Act they would have to consult the relatives of people with dementia and receive their consent prior to procedures. It

appeared that they believed in most instances this would be a cursory procedure, although with some relatives there could be issues. None of them claimed to feel threatened by this and felt it would give the relatives more autonomy and empowerment. Interestingly none mentioned that it would actually empower people with dementia.

Some GPs pointed out that despite individuals with dementia appointing a person to look after their medical interests they would still have to discuss procedures with them until the point when they lost capacity to make decisions. According to one GP:

“If you take it to its logical conclusion then it shouldn’t make a difference because as long as the person has the capacity to decide then they should be making the decisions. A person can appoint someone but I still think you have the authority to decide if that person has their best interests” (GP2)

This comment reflects the principle in the Act which states that practitioners must ensure that they try to involve the person with dementia as much as possible, therefore encouraging them to make their own decisions about treatment. This GP also indicated that despite a person with dementia appointing an attorney he would still have the professional autonomy to decide if the attorney had their best interests. However, according to the Act he would have to refer to the local authority social work department, which should investigate. If the social work department does not investigate, or the investigation is not satisfactory, the Mental Welfare Commission can intervene and, if necessary, can thereafter be referred to a sheriff (Scottish Executive, 2004e).

Although this GP did not feel there would be any major changes to their practice, apart from consulting families more, one of the GPs who had been involved in writing certificates of incapacity had concerns, in particular the additional paperwork. He stated:

“I don’t think seven months ago I would have felt it wouldn’t have made a difference, but if I hadn’t done these AWI forms recently and realised how complex they could have been if the patient hadn’t consented to it” (GP3)

Interestingly ‘workload pressure’ was one of the main concerns raised by medical staff who had been consulted by the Scottish Executive in relation to implementation of part 5 of the Act, with particular emphasis on the process of completing incapacity certificates (Drinkwater et al., 2004). This GP also stated:

“I think it would change my practice now. I would be more likely to encourage the person to choose someone to represent them. The power of attorney is far less of a burden and less costly to the family than that of going down the road of the public guardianship. Doctors and psychiatrists’ reports all cost money.” (GP3)

This opinion was also expressed by other professionals, more so psychiatrists, who had practical experience of completing paperwork related to the Act, feeling that encouraging the person with dementia to appoint someone in the early stages of the illness would simplify potential procedures should their condition deteriorate.

Psychiatrists, in general, felt the Act would make a difference to their practice. Similar to GPs they felt that they would have to encourage people with dementia to choose a representative for medical and welfare decisions and involve the individual’s proxy more in decision making, but would have the additional role of assessing a person’s capacity to make various decisions related to their health and welfare. This is in line with the principles of the Act which states that capacity is a complex issue, in which the person can have capacity to make decisions in one aspect of their life, but not in others. Although the psychiatrists felt that they were already doing this informally, the general feeling was that they would have to formalise arrangements. Two comments which indicated this included:

“There would be some who would be thinking that way anyway, particularly along the lines of finances, but in general I think we’ll need to talk through things with

them more in relation to the Act.” (Psych 3)

“I tend not to say to a person formally ‘is this person you want to represent you in this or another area?’ Even if it’s not openly discussed you do get a feeling who that person is. I think with the Act it will need to be formalised early on.” (Psych5)

Although these two psychiatrists felt that in the future it would make a difference to their practice, two psychiatrists stated that they had already started to change their practice. According to one of them:

“I’ve changed my practice and am encouraging people to look at power of attorney earlier on. I think now that we’ve got welfare it is more important.” (Psych2)

This psychiatrist alluded to the same point made by GP3, who felt that due to his experience of completing lengthy paperwork related to the Act, he would change his future practice by engaging with individuals in the early stages of the illness to encourage them to appoint a power of attorney, feeling this would simplify procedures when they lose capacity.

Some nursing and residential home staff felt the Act would influence their practice (or medical staffs’ practice) having to be more accountable for their actions and having to share information with the person with dementia and /or their families. Practical implications for them seemed to relate more to medical procedures. Comments included:

“I think legally people will have to think about decisions before they make them. The medical staff will need to make decisions about how competent the person is to make decisions and in what respects.” (NH5)

“I think it will affect us when someone has to go into hospital. Sometimes we don’t give them all the facts because it’ll upset them. That’s something we’ll have to look at and quite rightly so. We’ll need to be more cautious about why we withhold information.” (Res2)

These two comments indicated that they would have to actively decide the level of understanding that the person with dementia had about the proposed medical procedures and should they not understand, legally deem them incapable, rather than passively presuming they would not understand or protecting them from information for fear of upsetting them.

About half the social workers and CPNs had received training about the Act. In general, they did not feel the AWI (Scotland) Act (2000) had made any impact on their current practice at the time of the interviews. Like medical staff, they could see it affecting future practice in relation to additional paperwork and having to consult people with dementia and their families more. Social workers felt that they were less likely to be involved with people in the early stages of the illness and acknowledged that this was the crucial time for a person with dementia to appoint someone to represent them. Two comments which indicated this were:

“I think it’s going to go back to relying on identifying cases that are at an early enough stage for people to take out the power of attorney and have a named person that will take charge of particular aspects of their lives. That should happen at diagnosis knowing that they’ve got the illness. But unless that is done early enough you’re still limited” (SW1)

“In terms of practice I would certainly be advocating for people at a very early stage to consider appointing someone.” (SW5)

Social workers spoke only of isolated cases where people with dementia had been referred to them in the early stages of the illness, at a time when they were able to influence the person to appoint power or attorney. They felt therefore that in most instances their condition was either too advanced or were referred for 'crisis' intervention. The inference from their comments was that the professionals involved with people in the early stages of dementia should be encouraging them to appoint someone to look after their interests, or refer them to the social work department at an earlier stage in their illness.

Whilst this section explored general feelings about the Act the next two sections look more specifically at participants' views on the appointment of continuing and welfare attorneys.

7.3 Continuing Power of Attorney- discussing finances with people with dementia

Although CPNs were the most likely group outwith medical staff to be involved in counselling and giving information to people with dementia in the early stages of the illness, none of them had discussed the possibility of any of their patients appointing someone to look after their welfare or medical interests. There was an acknowledgement that their practice would change in the future as a result of the Act, with all seeing their role as giving out booklets and information, which would include advice on how to go about appointing a power of attorney. Three of the five CPNs had been to AWI (Scotland) Act (2000) awareness sessions, but none of them felt competent, at the time of their interviews, to give such advice.

One area in which medical, social work and CPNs were proactive, was encouraging the person to appoint a continuing power of attorney to look after their financial affairs. However, upon closer examination it appeared that this advice was usually given to carers, as opposed to individuals with dementia, and it was thereafter left to the carer to persuade the person to accept assistance. Psychiatrists were more likely to discuss this with the person with dementia (usually along with their carer); however, other

professionals tended to discuss this with the families. According to one CPN:

"I do it more so with the family - the sons or daughters. Often the person's not going to want it anyway." (CPN3)

The CPN inferred that people with dementia often require persuasion to appoint a power of attorney and he felt that their families were in the best position to do this. Interestingly none of the CPNs had known of a person with dementia actively requesting or initiating the appointment of a power of attorney.

With regards to the participants with dementia, only three had legally appointed a power of attorney to deal with their finances. Although all three had arranged power of attorney at the instigation of their carers, the participants were completely aware of why they had taken these legal steps. They were aware of the future implications of the illness and were currently experiencing difficulties or potentially knew that they might not be able to manage their finances in the future. According to two participants:

"I've always been independent and it's so difficult to give up, but I realise I've got to. Anne has taken on the big responsibilities, the money side of things. She's given up her time to do that, so that I don't need to worry." (Sylvia)

"My brother deals with that. I know that I couldn't cope now." (Marie)

Both were aware that they could no longer deal with their finances. In the case of Sylvia, although her daughter-in-law dealt with her banking, pension and savings, she was able to have 'money in her purse' to buy groceries. As highlighted in chapter six she still 'felt' independent despite having to give up some of her independence. Marie on the other hand, was aware that she 'could not cope' with her finances and her carer reported that, due to her being a partner in a family business, her brother had arranged power of attorney soon after she received the diagnosis. It is interesting that Sylvia had appointed her daughter in law and Marie her brother. This differed from Mason and Wilkinson's

(2002) study that indicated that having a spouse was a facilitator towards people with dementia appointing a power of attorney.

Approximately half of the people with dementia were happy for their families or partners to deal with their finances, some having a high level of insight about the future or 'never having dealt with the money side of things anyway'. However, some carers and people with dementia did not see a need to formalise it by way of power of attorney, choosing to opt for joint bank accounts and standing orders to pay bills. Similarly, Mason and Wilkinson (2002) reported that some carers within their study were imaginative in finding resources to ensure minimal intervention rather than appoint power of attorney.

Some participants with dementia felt that since they were currently coping, they did not see any need to plan ahead perhaps not realising the full implications of the illness. Comments such as 'I think that's further down the road' (Jim), 'I don't need to think about that just now' (Bill) and 'I'd take advice at the time' (Howard), indicated that they thought they would be able to make decisions about appointing someone to look after their finances as the illness progressed rather than taking the legal steps in the early stages whilst they still had capacity to decide. As discussed in chapter five, this was a pattern amongst many people with dementia, who thought that they would be able to make important decisions if and when their condition deteriorated.

Some carers reported difficulties 'trying to persuade' the person with dementia to formally accept power of attorney or informally to accept some assistance to deal with their finances. Interestingly no spouses reported any major problems. However, other family members, more so sons or daughters looking after a parent living alone, experienced difficulties, particularly in relation to dealing with the individual's bank accounts and pensions. As already highlighted, this was often due to the person with dementia wanting to remain independent or, in the case of some, believing that they would not deteriorate to the extent that they would no longer be able to deal with financial affairs. Unlike those who felt they could 'wait and see', these participants could not envisage a time when they would not be able to cope. A typical comment from one

person with dementia who felt this way stated:

“I can’t see that happening. I’m very good with money.” (Robert)

However, his carer reported that, at that time, he was experiencing difficulties and large sums of his money could not be accounted for. Whilst he was aware that he had dementia, his desire to remain independent meant that his daughter was unable to convince him to let her deal with his finances. Although in such cases relatives can apply to the Office of the Public Guardian to access their relatives’ accounts, Robert’s daughter, like other relatives, did not feel the person with dementia was at that stage or level of incapacity and felt it would be too stressful for them and the person involved to pursue this action.

The following section explores the extent to which professionals engaged with people with dementia to appoint welfare attorney or nominate someone to look after their medical interests.

7.4 How do professionals engage with people with dementia about their welfare?

Professionals were asked about their current practice regarding how they engaged with people with dementia to ascertain who could best represent them in the future. It should be noted that the time of the interviews part five of the Act, which involved people with incapacity appointing a welfare attorney, had not been implemented.

None of the professional participants reported that they officially or regularly asked a person in the early stages of the illness who they would like to represent or advocate for them, but would usually ask the person whom they would consider to be their ‘next of kin’. There was a presumption by all groups of staff that if a family member accompanied the person to an appointment or outpatient clinic then ‘that person’ would be considered a ‘carer’ and should have their best interests. Medical staff reported that they would often ask the person with dementia if they would prefer their family member

to sit with them during the consultation. Some psychiatrists also interviewed the 'carer' separately and /or gave the carer the opportunity to phone them at a later date. They did not see this as a breach of confidentiality but as a way to elicit information from the carer to get a clearer picture of the problems associated with the illness and to assist them diagnose the person. Social workers and CPNs tended to contact the next of kin or, as was the case with most referrals from GPs and psychiatrists, the person who initiated the referral who was often a member of the family. Thereafter these people were often seen by the professionals as the 'carer' and/or the representative of the person with dementia. Most professionals actively sought out a relative or someone within the family to contact. According to one psychiatrist:

"Usually the person brings someone with them and I will ask who is the person most involved and I will take their names and telephone number. I would actively look for someone in the family to contact. The person has the opportunity to reject whether they want the person involved. They seldom do." (Psych3)

Interestingly although most professionals actively 'looked for someone' in the person's family to contact and asked their permission to contact them, they did not actively ask the person with dementia if this was the person that they would like to represent them or 'knew them best' should their condition deteriorate.

Some admitted a dilemma when speaking to relatives about the person with dementia, especially someone whom they had not met or did not know the extent to which the relative was involved with the person with dementia, and the nature of their relationship. According to another psychiatrist:

"I find that very difficult and tend to be quite cautious about being forthcoming on information. You don't know the previous contact or the nature of their relationship. My view is I will listen to what they're saying, but not actually give a lot of information. I'm not going to be unfriendly but the important thing is confidentiality." (Psych5)

Most staff stated that they would go by their ‘feelings’ or ‘instinct’ to ascertain if the family member had the person with dementia’s best interests at heart. There was a general recognition that, at times, their initial instincts could be wrong but, over a period of time, it would become apparent how genuine the relative’s motives were. According to the same psychiatrist:

“There is a presumption or a hope, but at the back of your mind and in time you might think that they could have other issues.” (Psych3)

One area where several staff felt it would be useful for the person with dementia to appoint welfare attorney was where there was family conflict, and the staff members were receiving conflicting views from different members of the same family about what was in the person’s best interests. This was expressed more so by staff in residential and nursing homes where the person with dementia was less able to give their opinion and staff had to rely on the family for information.

Many staff reported times when they felt that person with dementia needed an independent advocate to look out for the individual’s interests. The most often cited reason for this was due to carers being ‘over anxious’ or ‘overprotective’. A few also mentioned abusive relationships and financial exploitation. Some long term care staff, CPNs, and social workers saw it as their role to protect the interests of person with dementia, seeing themselves as advocates, albeit unofficially. Several staff saw it as the role of social workers to be their advocates. Two participants (CPN and psychiatrist) recalled situations where people with dementia without social workers and were admitted to residential care against their wishes. In both cases the individuals did not require financial assistance to enter residential care and thus did not require social workers or community care assessments. They opined that in such cases social workers could have advocated on the person’s behalf and arranged packages of care to keep them at home. Clearly these two examples highlight the protective role of social workers.

The remainder of this chapter explores one of the sections within the Values History, which allows individuals to record relationships within the family. Participants with dementia were asked to record the role that their families play within their lives and the extent to which they would like them involved in their future care. Section 7.6 explores carers' views regarding their experiences of advocating for people with dementia and finally section 7.7, by way of Sylvia's vignette, explores whether the information in the Values History would influence professionals' judgement and decision making.

7.5 Engaging with people with dementia to document how they feel about 'family and relationships'

Initially some people with dementia could not see why they would need to nominate someone to look after their welfare, possibly due to lack of insight or an element of denial that their condition could deteriorate to that extent. Similarly chapter five highlighted that many participants found it difficult to imagine a possible deterioration in their condition and plan for the future. Moreover, many felt that their relatives would look out for their interests and they did not need to formalise arrangements. However, when it was explained to participants that deterioration was 'only a possibility' the majority of individuals could see the benefits of appointing someone and there was a general acknowledgment amongst them that 'anything could happen', particularly of a physical nature as opposed to the dementia.

It was noted that the majority were able to state very clearly the people they felt knew them best and would be able to represent them in the future, particularly where there were good relations within the family and/or marriage. However, one person stated he felt 'obliged' to record in the Values History that his wife should represent him because she was living with him and would ultimately be his carer and in control of his life, having to make decisions about his future. He recognised that there had been relationship difficulties for most of their married life, having separated on several occasions. He did not feel she would look out for his interests in the future and felt she would 'put him into a home' should the dementia cause any difficulties. He also felt that his son and daughter

would 'take her side' should any problems arise in the future and that no-one in his family 'knew him well'. He declined to accept the offer of an independent advocate to look after his welfare, but recorded that he would like his wife and children to consult his daughter-in-law when making any decisions as he trusted her judgement.

Another person with dementia, who had also experienced marital problems, originally opted for her daughter to represent her welfare as opposed to her husband. However, this caused friction between her and her husband as he felt 'excluded' as he saw himself as the main carer. She therefore included him in her Values History.

These two examples highlight the difficulties that people with dementia could potentially experience in being honest when nominating someone to look after their welfare, feeling 'obliged' to nominate a family member who is presumed to have their best interests and/or through circumstances is the person's carer, but does not necessarily know them best. Being able to record honest information was an underlying theme which has implications for the writing of Values Histories and is further discussed in chapter eleven.

Furthermore, some felt where offspring were concerned that to nominate one person could be seen as 'favouritism' by others in the family and chose therefore not to differentiate between them, stating in their Values History documents that they would want their family to make 'joint decisions' about their future care. It is noteworthy that one participant felt her son who lived in the South of England knew her better than her daughter who was her main carer and felt that her son would look out for her interests more than her daughter. Again she could not record this in the document for fear of upsetting her daughter.

Another participant with dementia appreciated the opportunity to nominate his daughter to look after his welfare stating that he had limited contact with his other three children since he divorced his wife and he would not want them involved in any decisions about his future. Some participants also recorded who they would like their first nominated person to consult should they need advice. For the majority they stated other members of

their family, but some stated their CPN or medical staff and one person stated a close family friend, whom she felt could be 'more objective'.

One married couple, both of whom had dementia, wanted to nominate each other to look out for their future interests. However, when the implications of this were pointed out to them, they nominated their daughter as the second person should their partner not be able to make decisions for them.

7.6 Carers' experiences of advocating for people with dementia

Initially, participants with dementia and their carers were asked if they had received any information on welfare attorney. None of the people with dementia or carers had heard of it and most presumed that the carer or family would be able to represent the person if their condition deteriorated. Similarly, Mason and Wilkinson (2002) reported that a large proportion of participants with dementia within their study did not see a need to formalise welfare attorney and presumed that next of kin would have the legal authority to make decisions for them. However, all participants appeared to understand the theoretical reasons for legally formalising this arrangement and could see the wider benefits of 'any older person' considering it.

Although some carers reported difficulties initially gaining access to speak to the person with dementia's GP prior to them receiving their diagnosis, the majority of carers felt that after the person had received the diagnosis their opinions and feelings were considered and thereafter felt involved in the person's care. This differs from some studies where carers reported difficulties accessing GPs, information and support (Teel and Carson 2003; Thompson and Lovestone, 2002; Haley et al., 1992). For example, Teel and Carson reported that carers encountered marked obstacles and delays obtaining a diagnosis, which resulted in feelings of mistrust toward the medical community. Haley et al also reported that families frequently received only a vague diagnoses and insufficient referrals for supportive services.

However, two carers felt that their views had not been taken into consideration when their husbands had been admitted into hospital. In one situation the carer reported that her husband was refused a heart operation and the consultant would not discuss his reasons for this with her, having claimed to having discussed it with her husband. She felt her husband had been refused the operation because he had dementia and that he did not fully comprehend the implications of surgery.

The other carer reported that despite her concerns about the medication her husband was receiving, her opinions were overruled because he agreed to take the medication, a decision she felt he was unable to make. She was also angry that nursing staff continually gave her husband information which he would later forget and that they accepted his perception of his independence without consulting her. She stated that she had learned to assert herself and reported that she continually had to inform staff that her husband had dementia and that she should be consulted regarding his care. In both cases the carers felt that if they had legal responsibility for their husbands' care, it would have been of benefit to their husbands' treatment.

The remainder of this chapter explores professionals' views on the relevance of recording the information on 'family and relations' within the Values History.

7.7 Sylvia's vignette- exploring the issues recorded in Silvia's Values history

To stimulate discussion participants were shown Sylvia's Values History (appendix 10) and the section about her 'family and relationships' was highlighted to staff. In it she documented the close relationship which she had with her son and daughter in law, stating that she would 'trust them with her life'. She also stated that she would want them to represent her should she become incapacitated. Initially professional participants were asked if they felt this information was relevant and if they would refer to this section in the document.

Responses were positive from all staff regarding this section and all participants felt it

was appropriate for Sylvia to record how she felt about her family. The most enthusiastic groups of professionals about this information were social workers and long term care providers, and in particular nursing home managers. As outlined in chapter five, these would be the least likely groups to be involved with people in the early stages of the illness and often become involved with person either during a crisis or when their condition has deteriorated to the extent that they are not able to articulate the information, due to their level of mental impairment. According to two nursing home managers:

“That would make a huge difference because in nursing homes you just don’t get that information” (NH2)

“It would be very useful. We have no mechanisms for this. We tend to go with the family member who is most dominant.” (NH1)

Both participants felt that the information which they received prior to the person with dementia entering care was limited and they would therefore have to rely on family members’ versions of their relationship with the person. It is interesting to note that professionals involved with people in the early stages of the illness possibly know this information, but either do not record it or pass it on to other professionals as the person’s condition deteriorates. Clearly this is an area that requires further research.

Participants were asked if Sylvia’s condition was to deteriorate and she fell out with her daughter-in-law and son accusing them of interfering, would they still have contact with them and would the information about their relationship as documented in the Values History influence them. This question was included to highlight a possible conflict between a person’s ‘past wishes’ (as recorded in the Values History) and ‘present’ wishes (her thoughts the time when the illness has progressed). This theme is also further developed in chapters eight and nine.

There was recognition by some professionals that family relationships can change with

the progression of the illness and that to know how the person with dementia viewed family relationships before the illness progressed would be useful. According to one participant:

“The problem with dementia is that the relationship will change with the course of the illness, so we can only go by their wishes at the time. I don’t see what else you can do other than find out what the person’s wishes are for the future.” (GP2)

Several participants gave examples of friction which had occurred between people with dementia and their families, often related to family members trying to persuade the person to accept services or residential care. Social workers in particular often experienced this problem and many saw their role as mediating and looking for compromises between families and persons with dementia.

With regards to whether or not the professionals would still have contact with her daughter-in-law if Sylvia fell out with her, the vast majority stated that they would still have contact with her and would do so even without the information in the Value History. Several participants stated that they would investigate the accusations and, if in their own judgment they were unfounded, they would keep in contact with the daughter in law, with many feeling that she would require support. However, many stated that without the information in the Values History they would feel ‘uncomfortable’ doing so, as they would be dependent on Sylvia’s daughter in law’s perception of their previously close relationship, which might not be accurate. The vast majority stated that the Values History would ‘add weight’ or make them feel that they were doing the right thing by keeping contact with the daughter. According to two social workers:

“Yes I think so. It would indicate that she had trust and there was a history of trust and that she had been supportive. Someone who was genuine involved with her and not just appeared from nowhere.” (SW5)

“Yes it would because where you have two or three different siblings telling you

who is the main carer and then another relative appears and takes over, which can be difficult. With this the client is saying who is closest to me.” (SW3)

Several participants also mentioned the dilemma of having to deal with the children of people with dementia who often had ‘different ideas’ about how the person’s care should be managed. Similar to the above social worker’s comment, many felt that the Values History would assist them in knowing who to deal with i.e. the relative ‘closest’ to the person with dementia. Moreover, several participants reported occasions when ‘a relative appears’ that they have never had contact before and opined that the information in the Values History would be useful to offer them guidance about how much contact to have with the relative.

Only a few participants would go by her current wishes i.e. not to have contact with her daughter. Some medical staff within psychiatry and GPs stated that they would feel ‘uncomfortable’ going against Sylvia’s current wishes, mentioning ‘confidentiality’ as their reason for this. They stated that they would ‘listen’ to the carer and give general advice about managing dementia, however would not pass on any information. According to one psychiatrist:

“There is a significant difference between her daughter phoning me and giving me information and me giving her confidential information about Sylvia. In saying that I think what has gone on before is important, how their relationship was and her involvement. The Values History would make that a lot clearer.” (Psych4)

GPs in particular suggested that they would look for advice from psychiatrists to assess Sylvia’s capacity to make decisions. Interestingly some psychiatrists, however, stated that they would also be in a dilemma and not necessarily be able to make that judgement without a full knowledge of the person’s background. Several differentiated between people with dementia that they had built up a relationship with and individuals that they had only seen once or twice. According to the same psychiatrist:

“If you see a person over a period of time you are able to bring these things up, but if only a couple of times, it could become clumsy, unless you formed a particularly good relationship with the person. I think perhaps someone like a CPN. Someone who’s seeing them regularly and has a relationship” (Psych4)

This comment demonstrates the complexities and difficulties which psychiatrists experience when assessing a person with dementia’s capacity to make decisions, especially on an individual assessment. It also highlights their reliance on other members of the multidisciplinary team, who might be in a better position to ascertain the individual’s views, particularly regarding the person that could best represent the interests of the individual with dementia.

7.9 Summary

Firstly, none of the professionals involved with people in the early stages of dementia specifically asked who the individual would like to represent them medically or socially in the future. There was a presumption that next of kin would represent them. Moreover, although some professionals had a good knowledge of family relations through prolonged dialogue there did not appear to be mechanism for relaying this information as the illness progressed. Secondly, although professionals claimed to give information concerning appointing an attorney, they tended to give this to family members and it was left up to them to ‘persuade’ the person to appoint someone. Clearly, both these points indicate that more effort is needed to engage with people in the early stages of the illness to discuss family relationships and this information should be recorded for future reference. Indeed the vast majority of professionals working in long term care settings and social workers felt there was as a dearth in the information they received.

It was interesting that the majority of staff felt that their practice would change as a result of the AWI (Scotland) Act 2000, in that, they would become more proactive in trying to engage with people with dementia in the early stages of the illness, particularly to encourage them to appoint a welfare attorney, albeit possibly because of the ‘burden’ of

paperwork. It would be interesting to revisit this in the future to ascertain if it does change practice.

Another underlying theme, which also emerged in other chapters, was the aspect of how honest people with dementia can be when giving personal information which will be read by others. Although those with good relationships were able to record their views quite clearly, it appeared that a few participants with dementia who experienced marital or family difficulties, could not honestly record how they felt. This could have major implications not only for the writing of Values Histories, but for some people with dementia appointing a welfare attorney. This is further explored in chapter eleven.

Finally, concerning people with dementia's preferences for family involvement in the future it would appear that the vast majority of professional participants were fervent they would go by the person's past wishes. This contrasts 'independence and safety' where feelings were less strong and several participants expressed doubts about the appropriateness of recording their wishes. This theme of 'past' versus 'present' is further developed in the next two chapters, the first looking at medical values and the next looking more generally at values and the potential for them to change as the illness progresses.

Chapter Eight

Medical Values

8.1 Introduction

8.2 General medical values

8.3 Complementary therapy

8.4 Marie's vignette

8.5 End of life decisions

8.6 Summary

8.1 Introduction

This chapter begins with exploring the issues related to individuals with dementia discussing and documenting their feelings about medical treatments and to explore professionals' views regarding the possible impact of Values History on medical decisions. It should be noted that the Values History allows for a degree of flexibility and gives a picture of the person and their values and feelings rather than a set of medical paradigms (Doukas and McCullough, 1991). To further explore the impact of the information on their decisions, Marie's feelings regarding complementary medication and terminal care were highlighted in her Values History and these were shared with the professionals

8.2 Medical Values

All twelve people with dementia were given the opportunity to record their feelings about medical treatments. It was pointed out to them that the Values History was not an advance directive and was not designed to go into minute details about procedures. However, whilst this was pointed out none of the participants thought this was the case.

In general, the majority of individuals were able to articulate their feelings about medical

treatments, although many did not see them as specifically related to them having dementia. As highlighted in the last chapter, some people with dementia were aware that their condition could deteriorate to the extent that they might not be able to represent themselves in the future, whereas others could not see a time when they would not be able to do so. Interestingly, many of those who could not envisage a time when they would not be able to represent themselves expressed positive comments about recording their thoughts and feelings, believing it would help their doctor to know them better ‘at the time’ and not necessarily in the future. For example, one person stated:

“I think it would be useful for the doctor to know how you feel about things just now and your feelings on independence because sometimes that doesn’t come up in conversations with the doctor. If she knew it would save her having to ask questions.” (John)

This comment did not specifically relate to the section on ‘medical values’ but to the general information as documented in the Values Histories and the section on ‘independence’, which could also have a bearing on future hospital treatment or long term care, both of which would require some input from a GP. Interestingly, he stated that ‘these things don’t come up’ and alluded to ‘time’ as being the main barrier. As highlighted in chapter five this was also mentioned by most GPs as being one of the main reasons why they found it difficult to discuss the prognosis and future with people with dementia.

There was a wide variation in how well participants with dementia felt their GPs knew them, some claiming to have minimal contact and others feeling that they knew them very well. However, the majority had faith that their doctors would make the right decisions for them and the majority of individuals did not have any strong views about treatments and would take their GP’s advice or ‘stick to the doctor’s decision’. Two typical comments were:

“She gives me the impression that she has time to listen. Although I don’t visit her

much I have great faith in her. I'd be guided by her." (Mary)

"If the doctor says 'that's for you', then it's for me." (Bill)

The majority of participants with dementia reported that they had good relations with health staff, with only one stating that she did not have any faith in her GP as she found him to be 'intolerant' and 'unapproachable'. Interestingly she chose not to record this, instead recording positive qualities she would look for in medical staff. Moreover, the carer of another person with dementia, who had stated during his interview that he had faith in medical staff, reported that he had a 'mistrust' of the medical profession and 'hated' taking medication. His Values History was also amended to include his feelings regarding medication but not the medical profession. This was an underlying theme throughout the research that some people with dementia could not be totally honest when recording information which might be viewed negatively by others or cause offence. Indeed, one must consider that this might not relate only to people with dementia but possibly to others who may complete Values Histories, such as those with terminal or chronic illness.

However, two of the participants wanted to record that they had a fear of being admitted to hospital. One stated that he suffered from panic attacks and nausea, which affected him to the extent that he could not visit friends or family members in the event of them being admitted to hospital. His carer confirmed the importance of this information stating that it could have major implications if he ever had to be admitted into hospital again or residential care.

One participant had completed an advance directive, and had given a copy to her GP, to instruct that she would not accept a blood transfusion under any circumstances. In her Values History both the participant and the researcher agreed that she would record her religious feelings behind her decision, rather than specify areas of treatment which were acceptable or not. Similarly, Mason and Wilkinson (2002) reported that only one person out of sixty-six people with dementia interviewed in their Scottish study had completed

an advanced directive, also for religious reasons.

However, in general, most participants did not have any strong views about medical treatments and ‘had faith’ in their doctors making ‘the right’ decisions, seeing them as the ‘experts’. The majority mentioned values such as practitioners being ‘honest with them’, ‘being open’ and generally ‘being friendly’ towards them.

Concerning the impact of the illness, several participants reported they needed more time to talk things through, especially during hospital visits. According to two participants:

“Sometimes I just give up when speaking to people. I’ve had a couple of bad experiences in hospitals. They just don’t give me enough time to talk.” (Malcolm)

“Time, time, time... the answer is at the back of my head but it just takes a while to come out.” (Jim)

Again these comments related to how the individuals would like to be approached rather than specific medical treatments. As highlighted at the beginning of this chapter, Values Histories are designed to guide professionals but should be differentiated from advanced directives or living wills. Whilst it could be argued that people with dementia could be prompted to imagine some medical situations to encourage them to articulate their medical values, ‘prompts’ could also be seen as ‘leading’ the person. This is further discussed in chapter ten. However, two areas of medical care which were explored further with the participants at this stage related to complementary therapy and end of life decisions. This reflects a wider shift in opinion. For example, according to one survey in England conducted in 1998, complementary therapies were estimated to be used by 10% of the population (Thomas et al., 2001), and ‘end of life’ planning is generating an increased interest (BMA, 2003). The rest of this chapter concentrates on these issues.

8.3 Complementary therapy

Participants with dementia were given the opportunity to record if they favoured alternative or complementary treatment. Although the majority of participants had tried alternative and/or complementary therapies in the past, such as homeopathy, herbal treatments, acupuncture and aromatherapy, only one person, Marie (the same person who had completed an advance directive to decline blood transfusions) practised it on a regular basis. Indeed, she stated in her Values History that she would prefer homeopathy to be used 'in the first instance'. Her current GP was aware of her preference, although he did not practice himself. However, she had she attended a homoeopathic doctor privately for a number of years and with support from her family continued to do so.

For the purpose of the research, Marie's Values History was chosen to be shared with professional staff to highlight the relevance of the information about her request for homeopathic treatment 'in the first instance' should she lose insight into her condition. Initially professionals were asked if Marie was admitted into residential care and lost insight into her condition, would it still be relevant to pursue her previous wishes for homeopathy.

The vast majority of professional participants reported that they felt it was the individual's 'right' to have their previous wishes respected regarding having homeopathic treatment, even if the person lost insight. Two social workers who felt this way commented:

"Yes I would want to go along with it if the person felt strongly about it. I think it's important even if the person doesn't know what's going on around them." (SW2)

"Yes I think because it's been a part of their life and she's still the same person. Because they're notable to do it for themselves we should be trying to do it for the person, especially if they've been like that from a very young age." (SW3)

It was interesting that even those professionals who were opposed to homeopathic treatment expressed views that the person's wishes should be adhered to. According to one psychiatrist who admitted being very sceptical of homeopathy:

"The principle should be for them to approach a homeopath. With the AWI Act you have to take into account the person's past wishes and discuss treatment with the family." (Psych3)

The psychiatrist therefore referred to the AWI (Scotland) Act 2000 as being the main reason for considering Marie's 'past wishes'. This sentiment was also echoed by other professionals, particularly psychiatrists. The majority also felt that it was appropriate for the person to record 'any' medical wishes (values) in the Values History and that it would encourage staff to 'think about' the care they were giving to individuals. Several professions stated that because her wishes were 'in writing' they would be more likely to be complied with. Two comments included:

"I think because it's written down it makes you more aware. It makes you think about things you wouldn't normally look at. Not deliberate, just not normal practice." (CPN4)

"I think it would make her case stronger. It's like in all these cases, it's much easier to spell out to people if it's in writing." (CPN3)

Although the majority of professionals felt that Marie should have her wishes respected, there was a general scepticism that it would happen if she was admitted into long term care. Most professionals stated that they would expect the person's family to contact the homeopathic practitioner, but when asked if the Values History would 'stand alone' without the intervention of the family, the majority felt sceptical that long term care providers would carry out the person's wishes. 'It's just not going to happen' or 'ideally it should' were typical responses. 'Professional accountability' and the practicalities of contacting a practitioner, as well as having access to the person's finances were seen as

barriers to home staff acting as an advocate for the person with dementia and contacting a homeopath.

Several participants pointed out that whilst selecting a residential home, the person with dementia should ascertain the home's policies on homeopathy. It was suggested that this would be pivotal in ensuring whether or not her wishes were carried out, should she lose insight. It was also suggested that if the person had a named practitioner prior to entering residential care who could be contacted by residential home staff, then she would be more likely to receive the specified care. Moreover, the selection of a progressive GP or one who would support the person's decision was seen as influencing factors.

When looking at the vignette, professional staff answered the question from different perspectives. Medical and long term care providers could possibly be faced with the situation whereby a person in their care had completed a Values History, had no family and had lost insight into their condition. From the medical perspective (GPs and psychiatrists) they could be asked for advice on medical treatment. From the remaining professionals' points of view the question was hypothetical in nature, asking them to 'put themselves in the position of a residential home manager'.

None of the medical participants stated that they would have any objections to residential home staff contacting a homeopathic practitioner and felt it would be right for them to do so if it was the person's previously expressed wishes. However, the majority of them did not see it as being their role to contact a practitioner and stated if they were asked to visit the person for medical advice they would prescribe conventional treatment for the person. A comment from one psychiatrist was typical of several medical staff:

"As long as it's in her best interests and they could, then it would be OK for them to do so. I'm cynical though and don't know if it works. As long as it's not detrimental to her health. If I was involved in her care I would bypass it. If I was asked for my opinion I would prescribe conventional. I would have no problems if they asked someone else (a homeopath) though."(Psych2)

This psychiatrist therefore stated that she would 'bypass' Marie's request for homeopathic treatment in the first instance. However, it is noteworthy that she would 'have no problem' if the residential home staff were to organise homeopathic consultation in the first instance. Clearly this has implications for residential home staff, the majority of whom have no medical or nursing background, having to make a decision that it would cause 'no harm'. Other medical professionals also expressed similar views. According to two GPs:

"No, because I know nothing about homeopathy. If they had a private homeopath coming in then that's fine because that person's wishes. However, as a health professional who doesn't think it works it just wouldn't be an issue to me." (GP4)

"I would give my advice on what I know about. I would expect the care home to sort it out for them (contacting a homeopath) in the first instance." (GP2)

However, two stated they would seek advice from GPs within their practices that prescribed homeopathic treatment or knowing the person's wishes in advance would refer Marie to them. Both stated that it would depend on the reason for their visit and severity of the condition. According to one of the GPs:

"There is a trade off between protecting life and staving off deterioration. I mean if she had a rip roaring pneumonia you're not going to, but if she had something chronic in nature and we can go according to their wishes, then that's fine." GP4

This view was echoed by the majority of participants and many pointed out (rightly) that this would also be according to Marie's wishes, as stated in the Value History where she stated she was not totally opposed to conventional treatment but had always tried homeopathy in the 'first instance'. Although the question was not asked, clearly the issue poses ethical dilemmas for professionals should she have stated in the Values History that she only favoured homeopathy.

As already highlighted in this section, most professional participants were sceptical that long-term care providers would go along with the Marie's wishes to arrange homeopathic treatment. However, this was not the case, particularly in residential and smaller nursing homes. Two comments that highlighted this were:

"Absolutely we would go with that. When it's been documented that these have been her wishes in the past we should discuss the situation with her GP right away when she comes in. It is what she favoured in the past...I think every human being has the right to refuse treatments... You have to take into account their past wishes. You might not be able to carry out for an emergency but you have to give the option as far as possible." (NH2)

"Yes I would change her over to homeopathic doctor no matter how advanced her dementia was. ...medicine and diet in particular. What they have practiced throughout their lives, we would go along with that." (Res5)

Three of the ten long-term care managers did not feel they had the autonomy to make arrangements to comply with Marie's wishes, therefore suggesting that it should be a medical decision. However, all three stated that they would point out her medical preference to the doctors. There was a general scepticism by all three managers that the medical staff would comply with Marie's Values History unless family members advocated for her and arranged for a private homeopath.

Interestingly one GP who had been the responsible medical officer for a large nursing home for several years stated that he had 'never known' of any of his patients to receive homeopathic treatment and did not know if any of them practiced it before entering care. This is interesting given the statistics that 10% of the population regularly use complementary therapies (Thomas et al., 2001). From these figures it could be assumed that at least some of his residents would have favoured homeopathy in the past, prior to being admitted into long term care.

The remainder of this chapter explores issues around 'end of life' decisions, firstly by way of engaging with people with dementia to discuss their feelings and secondly by using Marie's Values History to stimulate discussion with professionals.

8.4 Discussing 'end of life' decisions with people with dementia

Participants with dementia were asked if they had any strong views or values related to 'end of life' decisions. Whilst some literature suggests that many older people appreciate greater openness and honesty about death and dying (Seymour and Hanson 2001; Diamond et al., 1989) it became apparent during the interviews that the participants had varying degrees of ease with which they felt comfortable discussing the subject. Some appeared to be open and relaxed, whereas others came across as being awkward, indicating they did not want to pursue the topic further or, as in the case of many, had no views, choosing to leave future decisions up to medical staff or to 'go with the flow' (Jim).

Those who felt at ease discussing it tended to make general comments about being pain free, dying at home or with family around them. According to two participants with dementia with contrasting views:

"I keep thinking 'lord when it's my time please take me quickly'. I've seen people in old peoples' homes, just sitting there and I've thought... that's no life...if it was me I'd rather go. I would hate to get to the stage where I didn't know who I was or where I was. My ambition is to die in my own house in my sleep, but I know that we've got no control over that."(Sylvia)

"Probably I would hope they did everything they could for me to keep me alive. I imagine I wouldn't want to know if there was anything seriously wrong with me."
(Robert)

Sylvia's views appeared to be influenced by her experience entertaining elderly residents in nursing homes to the extent that she had thought in depth about the latter stages of the illness and had strong views about how she would like to die. Robert, on the other hand, although he was aware that he had dementia, previously claimed that 'as far as I know if I don't think about it I don't have it' indicating a totally different approach to coping with the diagnosis and not wanting to know if he had any serious conditions.

In line with Robert's views, approximately half the participants claimed they had never thought about the end of their lives and two people questioned the reasons why they were being asked, one appearing upset. As highlighted, this differed from other studies. For example, Diamond et al (1989) interviewed thirty-nine older people recently admitted into nursing homes and found that the majority willingly stated their preferences regarding the end of their lives. However, it is possible that participants within their study were more able to imagine death and dying, because they were living in nursing homes and possibly closer to death. Participants within this study were reasonably independent and living in their own homes.

The participant who was upset appeared to have a degree of emotional liability and was also upset when discussing the prognosis of the illness. Clearly when addressing this issue tact and sensitivity were required, on the one hand allowing the person with dementia the opportunity to express their views, but on the other hand not forcing them to discuss the topic, or making them feel awkward. This was similar to other sections in the Values History, in particular discussing future care and the implications of the diagnosis.

As highlighted, some of the people with dementia were able to express clearly how they felt about the end of their lives. One person was Marie who had a strong belief in God and recorded in her Values History that she did not believe in any form of euthanasia, believing that life was 'sacred' and a 'gift from god'. She also stated:

"It's about quality of life. I would hate to be kept alive beyond my natural time, especially if I couldn't speak or lost my motions. I would rather just slip away. It's

different for a young person, perhaps in a coma, where there's a chance of recovery. I would hate to be in pain and would want good pain relief."

Whilst Marie did not believe in euthanasia she clearly stated that she would not want to live beyond her 'natural time'. In keeping with the ethos of Values Histories she did not go into minute details of specific treatments she would or would not want, which would be more in keeping with a living will. (As highlighted she had, in fact, completed an advanced directive, but it was specifically in relation to blood transfusions and not end of life care).

Because of Marie's strong feelings it was therefore decided to highlight her comment, as recorded in her Values History (appendix 11) and share this with professionals, with a view to eliciting their views on whether they thought it would have any impact on her future care should her condition deteriorate.

8.5 Marie's Vignette

Professional participants were given the scenario that Marie's condition had deteriorated to the extent that she was admitted into a nursing home. They were informed that she had become doubly incontinent, was unable to walk and relied on staff for full nursing care. They were also informed that she had suffered a stroke and lost her swallowing reflex. They were next informed that staff were faced with the decision to peg feed (Percutaneous Endoscopic Gastrostomy) her to keep her alive or to let her die. In the USA much of the research shows that people with very advanced dementia receive aggressive interventions in the terminal stages of the illness (Mitchel, 2003). However, in the UK this procedure is more common in care of older people in acute hospitals and, similar to many invasive procedures, related to family's expectations for 'treatment' for their relative. Whilst it is recognised that the procedure may sustain life, families often feel they have been rushed into the decision and thereafter can be faced with a more difficult ethical dilemma of withdrawing the tube (Cook and Cox, 2002). Furthermore it has been suggested that while late stage dementia is fairly rapid without tube feeding an

individual can be maintained for long periods of time with peg feeding - as long as six years (Peck et al., 1990).

The section was therefore highlighted in Marie's Values History, in which she stated that she wanted to 'die at her natural time' and 'would not want her life sustained', although she specifically stated that she did not believe in euthanasia. Initially participants were asked if they felt it would be relevant to refer to the Values History if they were involved in her care at that time.

The vast majority of participants claimed that they would refer to the document should Marie's condition deteriorate, and they all felt that it would lead to discussion about what she would want if she was reaching the end of her life. 'Going by her wishes', 'her choice' and focussing on 'the person' or 'the individual' were cited as reasons for referring to the document. The majority of participants reported that they would have hoped that discussions would have taken place with her family whilst completing the document so that they were aware of her thoughts before the situation arose. The vast majority of participants felt to a greater or lesser degree that the statement 'should' influence decision-making about her end of life treatment. Some also expressed the opinion that the Values History would 'relieve' care staff of the burden of having to decide what was in her interests and help point them in the right direction. Two typical comments included;

"I think going back to it (the Values History) frees up a lot of your responsibility, when you can keep referring back to the person's wishes." (Voll)

"They're making these choices without background information from the person and it must be difficult for them to make that decision...I think if consultants had this document in black and white." (NH2)

Only three professionals stated that they did not feel it was appropriate to refer to the document for end of life issues. The main reason cited by all three was that Marie's

thoughts were in the past and did not necessarily relate to the present. According to one voluntary manager who was very positive about other aspects of the document:

“I think at this stage I’d come away from the document. We can say a lot of things and we can change our minds in older age. I’d trust the professional people to make that decision.” (Vol4)

This is also one of the recognised criticisms of advanced directives (Rich, 1998), in that people can change their minds when faced with a situation that they had only ‘imagined in the past’ (Nagal, 1979). It is interesting that in relation to Marie’s choice for homeopathy and the vignettes concerning ‘appearance’ and ‘spiritual aspects’ she felt strongly that her past wishes should be adhered to, possibly because these were life long values and not a hypothetical situation which the person had never experienced. On the other hand some who were sceptical about the maintenance of other values had stronger feelings about complying with her end of life wishes.

Although the majority felt that the document ‘should’ be referred to, there were varying strengths of feeling concerning complying with her wishes. The majority were very positive in their comments, to the extent that they stated they would advocate for the person and actively try to put forward her wishes to others in the team. Examples of positive comments included:

“Definitely. It’s a huge decision that the person has made and I would go along with it.” (SW2)

“Yes I think nurses would take this on board. We’ve changed over the years and see ourselves fighting for the patients and what they want. You can’t follow the person’s every instruction but at least they should be discussed.” (NH5)

Some felt that her wishes should be read and listened to, but treated cautiously (similar to the group who did not feel the document was appropriate for end of life decisions).

According to one psychiatrist who recognised the importance of taking into consideration patient's past wishes in other aspects of the Values History,

"Yes you would still have to look at it and look at what she said, but you would have to explore further and remember that's what she said at the time. You've got to remember at what stage in their lives they've made these decisions." (Psych2)

The vast majority of staff felt that Marie's statement indicated that she would not wish to be peg fed and that by doing so would be going against her wishes to die naturally. However, two participants felt that it would be a form of euthanasia to deprive Marie of a peg feed if it was to keep her alive, in the same way that depriving someone of medication could lead to the person's ultimate death.

To ascertain whether the Values History would 'stand alone' the question was further developed to ascertain if Marie's family specifically requested that she was peg fed and they were involved in her care, would the family's wishes or the person's recorded feelings be more relevant in deciding treatment.

The majority of participants stated that the person's views 'should' be paramount, but over half the participants felt that the family's views would have more of an influence on the medical staff than the Values History and the eventual outcome. Most of them stated they would use the Values History as a means of discussing the person's wishes with the family, using it to 'remind the family' of the person's values and to try to persuade them to go along with Marie's wishes. Three comments included:

"I would point out that it was quite clear in her Value History, but I'd leave it with them and if they wanted to go ahead I think it would be up to them. I'm not God either so I couldn't make the decision." (CPN2)

"I would like to see this listened to but realistically I think it would be the family who would decide." (DN2)

“I think the document should be there for discussion, but I think the family could overrule it...but they shouldn’t really.” (Vol2)

Each of these comments alludes to the Values History being used as a means of communicating with relatives. It is interesting that the initial aim of Values Histories was to convey the person’s feelings to professionals; however, these statements indicate that it could also be used to convey feelings to relatives, who potentially have more influence over decision-making.

Several professionals questioned the legalities of the document, suggesting that if the person signed the document it would have more authority. Two GPs suggested that if it was signed and ‘more formal’ they would be more influenced by it, and in a stronger position to comply with the person’s wishes and ultimately go against the family’s wishes. They stated:

“Undoubtedly I would refer to it, but I would hope at some stage they would make it more formal, which would make things easier to carry out at the time.” (GP5)

“If I had this document and it was signed I would go by that. It would be taken out of their hands. As long as it was legal I wouldn’t go against her wishes.” (GP1)

Two consultant psychiatrists had opposing views about the consequences of going along with the person’s wishes as opposed to the families. They stated:

“I’d try to discuss it with the family and bring her views in to it, but it’s a difficult situation because living wills don’t have any validity legally, and I suppose to go against the families’ wishes could have legal consequences. I’d need to seek legal advice.” (Psych2)

“I think if it was a vague or informal statement you’d have to go by the family...”

unfortunately. If it was signed, then I'd go for the document." (Psych1)

It is interesting that the first psychiatrist stated that living wills have no legal validity, whereas the second indicated that he would go along with the document if it was signed by the person, indicating that legally he would feel in a stronger position. (As discussed in chapter one, advanced directives are legally valid under Common Law as long as specific criteria are met). The first psychiatrist stated she would feel more duty bound to go by the relative's wishes, whereas the second explained that he would be more influenced. He further stated:

"Yes I would tend to go with the patient's wishes very much so. Again going back to the getting sued bit. I think you would be more likely to be sued if you went against the person's wishes." (Psych1)

One of the underlying themes of this part of the research seemed to indicate that many of the professionals had their own strong values regarding sustaining life with a peg feed, and perhaps their strong views in favour of Marie's case were related to their own beliefs. The majority of staff indicated that they agreed with Marie's stance about not having her life sustained and they felt it would be wrong to keep her alive with no quality of life. Two examples included:

"Life is about quality and once you've lost your swallowing reflex you should just be keeping them comfy." (GP1)

"Yes it's something I would relate to myself and something that I feel very strongly about that I wouldn't want my life to be sustained to live in a vegetative state." (SW1)

Akin to this, other studies have shown that many staff working with frail elderly and people with dementia tended to favour non invasive procedures and symptomatic relief (Cox and Cook, 2002). As the research evolved some participants were also asked if

their own views had an impact on their positive response to Marie's Values History. According to one psychiatrist:

"Yes they are my own views, but peg feeding is drastic and people can't give consent and don't understand why they have a tube in them. It's difficult not to take your own views into it." (Psych1)

Towards the end of the research an additional question was asked to some of the participants who expressed positive responses about Marie's Values History. They were asked if she had said the opposite, in that if in the Values History she had stated she would want her life sustained 'under any circumstances', would they advocate as strongly for her. Berhmans (1997), for example, suggests that proxies can underestimate the zeal that some older people have for life, and suggests that some proxies can wrongly assume that the person would forgo curative interventions. All five reported that they would still go along with her Values History, although some were perhaps less enthusiastic in their responses.

Some participants also expressed the opinion that decisions regarding whether to peg feed or not were dependent upon the personal preferences of the consultants. This was validated by one ward manager, who stated, that in the case of one patient who had completed an advanced directive:

"It was completely overruled. It wasn't even discussed. It was awful." (NH5)

This however appeared to be an isolated case as all the other long term care managers felt that decisions were made by 'the teams' and families were consulted before any procedures took place, with most feeling that the Values History would be referred to by all involved in the person's care. Interestingly the British Medical Association suggest that although families have a key role in end of life decisions, the 'treating team' has the ultimate responsibility for decision making (BMA, 2003). The isolated case however indicates that in some cases the outcome of 'the team' could depend on the individual

personality of the consultant and whether or not they refer to the rest of their team.

8.6 Summary

This chapter showed that although approximately half of the participants with dementia had no strong values and were content to leave future decisions up to medical staff and their families, some were able to go into more detail and appeared to appreciate the opportunity to document their views. In particular, two participants admitted their fears about being in hospital and one person documented her religious feelings behind her refusal to accept a blood transfusion. Others documented their feelings about complementary therapy and end of life decisions. Moreover, several stated they needed more time for discussion during consultations, due to the dementia and communication difficulties. Clearly these aspects could have implications for medical treatments or should they be admitted into long-term care the future.

Another theme to emerge was the degree to which the person should be prompted to think about 'end of life' issues. As noted, some enthusiastically appreciated the opportunity to articulate their views, whereas others felt threatened or were ambivalent. This has implications for the interviewer in terms of getting a balance between allowing the individual the opportunity to discuss delicate matters, but not forcing them to talk about situations they feel uncomfortable discussing or have not thought about. This was similar to 'discussing the future' in chapter five and is further explored in chapter ten.

Again the theme of how honest people with dementia can be when recording their opinions emerged in this chapter. Documenting poor relationships with medical staff emerged as a possible area where some people with dementia could not be honest, possibly in case it further strained relationships with their doctor should they read the person's Values History.

Finally, when exploring 'end of life' decisions and homeopathy, Marie's vignette showed that the majority of professionals felt impelled to go by her previous wishes. With

regards to homeopathy, although most opined it was 'her right' and she 'should' receive it, many felt that if she did not have family to represent her wishes it would not happen if she was admitted into long term care. Indeed, although most medical staff were sceptical of homeopathy and would not actively arrange it, they would not object to family or residential home staff calling in an independent practitioner. Clearly this indicates that a Values History with the support of family is more a more effective way to empower person with dementia than the Values history alone. However, unlike the homeopathic issue where medical staff would have 'no objections' to Marie receiving homeopathic treatment, in the case of end of life decisions most would 'actively' advocate for her wishes. It was difficult to say whether their feelings were stronger because her values were similar to their own or because the 'end of life' issue was seen as a more important 'past wish'.

Similarly, the following chapter develops the theme of 'past wishes' versus 'here and now' in relation to people with dementia's general values and whether the Values History would influence their care.

Chapter 9

Values

9.1 Introduction

9.2 Recording values of people with dementia

9.3 Recording spiritual values of people with dementia

9.4 The extent to which professionals record spiritual values

9.5a Professionals' perceptions of values

9.5b Professional's perception of values- related to dementia

9.6 Sylvia's values vignette- her appearance

9.7 Marie's values vignette- her faith

9.8 Summary

9.1 Introduction

Whilst the last chapter explored the issues in relation to people with dementia discussing their feelings about medical treatments, this chapter looks more generally at values and aspects of their lives which the individuals feel are important to them. The chapter also explores whether professional participants would find this information useful, especially when planning care for people with dementia.

To facilitate discussion with the professional participants, sections were highlighted in Sylvia's and Marie's Values Histories. Sylvia's section highlighted the importance she placed on her appearance and Marie's section, the importance that her faith played in her life. In both cases situations were explored where professionals were asked to 'imagine' that Marie and Sylvia had lost insight into their condition and staff had to rely on the information in their Values Histories.

Before considering the professionals' views as to whether or not the information would have any impact, it is imperative to start with the person with dementia and examine the

feasibility of individuals discussing and recording their values. It should be highlighted that the aim of this section is not to compare the values of people with dementia, but evaluate the feasibility of engaging with them to document their values.

9.2 Recording values of people with dementia

Initially participants with dementia were asked if they had any ‘deep rooted’ values which they considered important in their lives (Ogletree, 1995). Some were able to articulate their views quite easily without any encouragement, in particular the importance that their families played in their lives. Moreover, many seemed to associate values with having a religious belief and described the varying levels which their faith held in their lives. Recording spiritual values is explored in more detail in section 9.3.

Values such as independence, privacy, being treated with dignity, honesty, kindness and manners were also expressed by the participants and easy to define as values or ‘deep rooted beliefs’. However, other aspects such as love of sport or music, physical appearance and preferred company could not be defined as values as such but were considered equally, and in some cases as more important to some of the participants. An example of this was Bill’s love of music. He stated:

“Music has been my life and there has never been any point in trying to discover anything else. I love music, good music... operatic and classical. I listen to Classic FM every morning and that sets me up for the rest of the day. Mozart, operas, Scottish songs, light classic and musical comedy... these are what I enjoy.” (Bill)

Whereas this could not be classified simply as a ‘value’ or ‘deep rooted belief’ as defined by Ogletree (1995), it could possibly be defined as a ‘preference’. However, Ogletree states that preferences were ‘more likely’ to change over time, whereas values would more often remain static. Therefore, it could be argued that whilst Bill’s taste in music could change, his love of music was intrinsic to his personality and enjoyment of life.

Although some were able to express their values without much encouragement, in the case of the majority of participants it was only when other themes were explored throughout the course of the interviews that their values became apparent. An example of this was Mary, who initially found it difficult to articulate what was important to her and did not feel she had any particularly strong values. However, when she discussed her thoughts about medical treatments it became apparent that she had very strong feelings about people being honest with her, not just in medical situations but in general. She stated:

“Honesty is very important to me. I like people who are dealing with me to be honest. I don’t like being fooled or ‘taken round the corner’. Even if you don’t agree about something I would rather the person was honest..... I would rather you came in and told me all the bad things you’d done than tell me stories that are not true.”

(Mary)

Another example of this was Elizabeth, who also initially stated that she did not have any strong values. Throughout the course of the interviews, particularly when she was asked how she liked to spend her time, it became apparent that privacy was very important to her and her need to spend time alone. She stated:

“I need time to myself. I always have. When I was a wee girl I would spend hours alone in my room. Even now I need time in my bedroom by myself, away from my husband, not doing anything really...just mucking about and tidying up.”

(Elizabeth)

Similarly, Kane and Degenholtz (1997), in their study which examined values assessments of older people, found that many case managers preferred to integrate values questions within their general assessments rather than ask fixed questions. Whilst Kane and Degenholtz suggest that this approach is not reliable, as the interviewer cannot assume that the person will reveal their values, this study showed that for some participants a non direct approach is more effective for revealing their values. In

particular one of the themes for discussion which seemed to have the most success for drawing out participants' values was the type of company they favoured. For example, Walter, who again did not feel he had particularly strong values, stated he had a strong aversion to people swearing and discussing sexual matters. According to Ogletree (1995) this could be defined as a 'disvalue'. The participant stated that he was not religious and although he worked in factories all his life where he had to 'put up' with swearing, he was selective about the company with whom he chose to socialize. He stated:

"I don't like arguing or people swearing. If I go into a pub and men are fighting or swearing I'll get up and sit in the corner. Jean will walk away too. I don't like 'sex talk' either." (Walter)

Similar feelings were expressed more commonly by those with strong religious values. On the other hand one participant (Howard) who was very involved in his church, did not have any strong views or objections to people swearing or the type of company he favoured, although he did see this as a gendered issue. Howard stated:

"You shouldn't condemn them... I was in the army for four years and at work too. It's a male thing. Most people are different and have different ideas. It doesn't make them bad." (Howard)

These two examples highlight the varying degree of values that participants expressed which could be seen by some as inconsistent with their backgrounds. For example, some participants who attended church on a regular basis did not necessarily believe in God, attending perhaps for the social element, whereas some who did not attend church on a regular basis appeared to have a strong faith in God.

To clarify continuity of the values expressed by participants they were asked again during their second interview about values and aspects of their lives that were important to them. Some people with dementia recalled the contents of the first interviews whereas some

only had a vague recollection and some none. It was interesting to note that, with the exception of one participant, each person expressed similar values to the ones they had expressed during their first interview, often expanding upon their values or giving additional information. This was interesting because, whereas some were inconsistent when discussing the future and possible care, they were consistent when it came to discussing their values.

Similarly, Whitlatch et al (2005) interviewed 111 people with cognitive impairment and found that over the course of two interviews those with mild to moderate impairment were able to respond consistently to questions about demographics and basic preferences. However, it should be noted that Whitlatch et al only asked basic multiple choice questions, which allowed them quantify their findings. By using a qualitative methodology this study was able to identify that values were expressed consistently in free flowing interviews and therefore likely to be important to the participants. Likewise, Smallwood (1997) interviewed 11 people with dementia and concluded that issues of lasting significance were more likely to be repeated in a second interview than passing concerns.

Carers' perceptions of the accuracy of the individuals' recorded values were largely positive with all stating that they felt the information recorded in the documents was accurate. This is in contrast to the 'background information' in which many of the Values Histories needed minor corrections or gaps filled in. Some expressed surprise that their relatives were able to give so much information about their values and some stated that they were unaware of the strong feelings that the individuals that they cared for had about certain values. In such cases the carers tended to acknowledge that the person had strong feelings, but they had 'never thought about it' or only realised after it was pointed out to them.

An example of this was Howard's daughter who stated:

"There were one or two things I hadn't realised, but I should have known. There

... were issues about independence and how important it is to him. When the home help started I wished she'd let him do the shopping because I can see that's important to him." (Howard's daughter in law)

Therefore, Howard's daughter inferred that she knew within herself how important it was for her father to remain independent, but seeing the information recorded in the Values History had made her think about it. On the other hand some carers were often able to point out values that the person had omitted to record in their Values History. In such cases they reminded the person, allowing them to express and expand upon the values in their own words. An example of this was Elizabeth, as previously referred to, who did not feel she had any strong values. However, her daughter pointed out to her mother that she was very open minded and non judgmental of others. This prompted Elizabeth to speak about her liberal attitudes and how she 'hated' any form of bigotry or cruelty, which she admitted were very strong feelings. It is noteworthy that had her daughter not prompted her, this information could have been missed.

Another example was Malcolm, from the pilot study. Although Malcolm stated in his Values History that his living environment was important to him, upon reading his Values History, his wife felt it was not expressed strongly enough. She reminded Malcolm that he would only consider staying in very good quality hotels whilst on holiday and 'could not stand' inferior service. Therefore, Malcolm was able to express how important it was for him to live in 'pleasant surroundings', how he 'detested' bad manners and also, again after being prompted by his wife, how he felt very irritable in a noisy environment and liked tranquility. Again these were strong values which could have been missed had his wife not prompted him.

One of the suggested sections to be completed in the Values History is 'spiritual and religious beliefs'. The following section explores the feasibility of documenting spiritual values with the participants with dementia.

9.3 Recording spiritual values of people with dementia.

Participants were given the opportunity to comment on whether they felt it was too intrusive or personal for them to discuss their religion, although found this not to be the case. In contrast Kane and Degenholtz (1997) found that a large proportion of care managers felt that asking clients about their values was too intrusive. But this study indicates, this was a false assumption by the case managers and possibly related to their own insecurities or perceptions of how clients would feel. However, although participants did not find the questions intrusive, some questioned why others would want to know how they felt about such matters, believing they would still be able to express their views in the future, even if their condition deteriorated. This group, who possibly had a lower level of awareness into their condition, felt the same about Values Histories in general - hoping or believing that they would be able to express how they felt in the future and that their condition would possibly not deteriorate to that extent.

Other participants, particularly those who had a higher level of awareness that their condition could deteriorate, appeared to appreciate that a time might come when they would not be able to express their thoughts. The majority of participants who had a particularly strong faith, or were from a non mainstream religion, considered it very important that their beliefs were documented. Indeed, the importance of this was understood by Sylvia, who expressed her religious values very clearly:

“Yes, I know it’s in my benefit and might help people understand me more..... I’m just glad I’m compos mentis enough to talk to you.” (Sylvia)

Only one person later admitted to a carer that she felt embarrassed when asked about her faith. Her carer explained that the reason for this was that she did not have any strong beliefs and felt that it was expected that she should. However, in general participants were able to articulate quite clearly whether or not they had a faith and how important or relevant it was in their lives. Similarly, Katsuno (2003) interviewed 23 people with early stage dementia to explore how their spirituality helped them cope with having dementia

and found that the majority were able to discuss religious matters freely and in depth. However, as with the majority of qualitative studies involving people with dementia, participants were selected who had a willingness to share their experiences and therefore it cannot be generally presumed that all people with dementia would be willing to discuss spiritual aspects of their lives.

Similar to the accuracy of values in general, all the carers agreed that the information in the Values Histories accurately represented the participants' thoughts on spiritual matters. One carer stated that she had always known how important her mother's faith was to her, but that by seeing it documented made her take cognizance that it was possibly even more important than she realised. However, one carer felt that the information was too personal and persuaded her husband to omit the information. She stated that she felt that the information could make support workers biased towards him, as he was a practicing Free Mason, which she felt could be viewed negatively by others. She stated:

"That's the only thing that I don't want in. I think it's between him and I and no one else. It could give a false impression of Walter and it's not relevant to any one else. No one needs to know that." (Walter's wife)

However, it should be noted that during Walter's interview he reported that the Masonic Lodge was one of the most important aspects of his life, attending several meetings a week. Although he had no objections to recording the information, he omitted it at the instigation of his wife. Clearly, this raises the issue of how honest some people with dementia can be when recording their beliefs, feeling that it could cause offence to others. It also raises the issue of carers influencing the information documented in the Values History, albeit with good intentions. The issue of how honest people with dementia can be and carer influence on documenting values were two of the main themes to emerge from the study and are discussed in chapter 11.

The following section explores the extent to which professional participants discussed and recorded the spiritual values with people with dementia.

9.4 The extent to which professionals record spiritual values of people with dementia

The majority of professional staff reported that they did not record in depth information about how people with dementia felt about spiritual matters, tending to record their religious persuasion and special instructions regarding their religion, such as dietary restrictions and last rites. Several of the professionals involved with working with people in the early stages of dementia, pointed out that they would know the same level of information which was recorded in the Values Histories about some of the people with dementia on their caseloads, especially if they knew them well or if the person actually brought it up, but would not record it. Some individual professionals (excluding GPs) also stated that part of their social or activities assessment would incorporate the spiritual components. It was expressed by those professionals that if the person was heavily involved in their church or attended a church regularly the presumption would be that they would therefore have strong spiritual values. However, one psychiatrist pointed out:

“Yes I know a lot of my patients this well, but I don’t always record it. In the background, if necessary, their faith maybe, or their church, but not how important it is. A lot of people attend church but it doesn’t mean anything to them. I think its spiritual rather than religion, which I would differentiate between.” (Psych2)

This was, in fact, the case with some participants with dementia. As previously highlighted, some attended church for the spiritual element, some for social element, or as in the case of one person, for the choir. Moreover, participants from a religious background expressed varying attitudes towards swearing and the company they favored or disliked. Akin to this, Katsuno (2003) reported that whilst some people with dementia in their study claimed to draw closer to God, their faith becoming stronger, others either became angry at God or stopped believing in him. Clearly this indicates that although most assessments would record whether or not someone was a member of a church and how often they attended, they would not accurately reflect their motives for attending

church, their strength of feelings regarding their religion or how important the person's faith was in their lives.

GPs as a group, were least likely to know or record the individual's spiritual values. Whilst all GPs cited lack of time as the main reason for not recording spiritual matters, many did not feel comfortable or that it was appropriate to discuss spiritual matters. Two comments, which highlight these thoughts, were:

"In a ten-minute consultation it would take years to build up that information."
(GP3)

'The region of spirituality is not something you want to bring in these days because you very much don't want your own spirituality to impact on your care for someone. I think we shy away from it.' (GP2)

As a group, residential home staff appeared to record the most information about the spirituality of residents with dementia. Indeed, several staff saw their role as trying to encourage the person to continue practicing their faith after they entered residential care, especially if it had been an important aspect of their life prior to being admitted. However, most of the information came from family and friends. A typical comment by one manager was:

"Yes we do have this information. We get it mostly from family and friends, although occasionally from the residents as well. The good thing about this document is that it comes from the person. We can't get it from our residents to that degree and have to rely on the family." (Res1)

In general, all the professionals interviewed felt it was worthwhile to have the spiritual information, most feeling it would be particularly relevant for long-term care providers. This was, in fact, the case and long term care providers were the most enthusiastic about being recipients of the information. Two managers who highlighted this stated:

“People going into nursing homes have very little background information... I think it’s very important because you can’t say just because someone is of a certain religion that they all should all be treated the same way. Everyone’s level of religion is different.” (NH1)

“Yes the second that’s she’s admitted you’d have to put a lot more thought into it. When someone’s admitted the social work give you a Community Care Assessment, but it doesn’t tell you much about their values. If we had a church service this afternoon, we wouldn’t give it a thought if someone was a protestant, catholic or a Jew. We’d just take it for granted that it was an activity and that they enjoyed singing carols.” (Res5)

Both comments indicated that there is a dearth of information about people with dementia when they are admitted into long-term care in relation to their values and, in particular, spiritual matters. Indeed, Rich (1996:82) states that by the time an elderly person is admitted into long-term care it is ‘often too late for a Values History’. The second comment indicated that more thought would be put into planning care for activities if this type of information was shared. Akin to this, a voluntary organisation manager stated:

“It would be good as a tool to help appoint staff....for them to see a bit more about the person.” (Vol5)

This was a view expressed by many professionals, not specifically related to the spiritual values but to the Value Histories documents in general. The vast majority of professionals believed that the background information and knowledge of hobbies and personality traits would assist them to match professional carers and key workers to the individuals, possibly improving communication and allowing the staff to engage with them.

As highlighted in the introduction, advocates of values based assessments suggest that

values ‘tend to remain static’ over one’s adult life (Kane and Degenholtz, 1997). The following section explores, from the professional participants’ points of view, whether they agree with this thought, particular whether they view potential changes in personality and apathy regarding the individuals’ values, as a change their values.

9.5 Professionals’ perceptions of values

Firstly participants were asked how they felt values were formed. Whereas some thought that values were formed from early adult life and remained fairly static, others thought that values changed and evolved during adult life, as indicated by the following two comments:

“You have your values that you’ve been brought up with that your parents instilled in you, to be good and polite and kind and you know how to treat people. I think these stay with you all your life.” (Psych5)

“When you’re younger it’s more your parent’s values, but when you’re older things aren’t black and white. I’m forty now and I think my values are balancing out.” (DN2)

However, the remainder (slightly less than half) felt it was ‘a bit of both’, in that some values would change and some remain static. According to one participant:

“I think some will change and some won’t. The way you perceive things is related to how they relate to you. At forty death doesn’t relate to me but at seventy and eighty it will, seeing peers and friends dying becomes part of your life. In saying that I think that religious beliefs don’t change. They’re imprinted in your mind. You either believe in God or you don’t.” (GP1)

This comment is interesting in that he mentions ‘age’ as being a factor in how one perceives the world, and alludes to facing one’s mortality as being a factor which could

change one's values. Participants were then asked if they felt people's values changed as they became older, particularly from sixty five years of age and onwards. Whereas a slight majority of participants thought that people under sixty five were forming and changing their values, the opposite was the case, in that a slight majority felt that values were less likely to change as people got older. Although there was a recognition that 'some values' could change the majority of participants thought that strong values were 'less likely' to change as a person entered older years. One comment included:

"I think at that stage you would have gone through a substantial number of experiences and would be fairly clear about where you want to be in life." (GP4)

Some also suggested that with age, older people were more confident within themselves and more honest about their values. According to one social worker:

"I think when you're older you can be who you are. Older people tend not to worry what other people think and they say what they think when they think it!" (SW1)

Although said with humour this comment was echoed by several professionals that some older people are more forthright in expressing their opinions, having firmer and stronger values than younger people. However, some thought that values were not related to age and felt that, as with people under sixty five, it was very much related to 'the individual' and their attitude towards life. According to one participant:

"I think it's very individual. I've known some who've moved with the times and accept that their son or daughter is living with someone, their grand daughter having a child outwith wedlock, whereas some are entrenched and won't change with the times." (NH2)

There was also recognition by most participants that there could be certain events in an older person's life which could have a major influence on their values. Death of loved ones was one of the most frequently mentioned aspects that could change someone's

values as they got older, but health problems and retirement were also listed by several participants. Two participants who highlighted this stated:

“I think for most people they stay fairly static, but there are occasions where perhaps someone had a faith and lost someone and the person can’t believe God would allow certain things to happen although that could be a temporary thing...part of grief.” (Res2)

“At that age people contemplate their mortality and with retirement their priorities change, but I think values like morality and religious values will be about the same. Retirement is such a huge life change.” (GP3)

As already highlighted, only a minority of participants thought that values were ‘more likely’ to change as the person entered older age or ‘a new phase in their life’. A voluntary organisation manager stated:

“I think as people become older they develop new values. The family shrinks and have new interests. They don’t want to be a burden but want to be around them. New thought patterns develop.” (Vol 3)

Whilst this section looked at older age in general, the next section explores professional participants’ views more specifically in relation to dementia.

9.5b Professionals’ perception of values- related to dementia

As highlighted in chapter three some people with dementia can experience personality changes, apathy and, due to memory impairment, possibly ‘forget’ their values (Jacques and Jackson, 2000). Participants were asked how they viewed perceived changes in a person’s values associated with dementia.

The vast majority of participants did not view changes in behaviour as changes in the

person's values. Many gave the explanation that although some individuals might 'forget' their values, had the person not developed dementia, their values would still be the same. Two comments included:

"No, I would say that if someone had reached older age and still had the same values throughout their life I would say it was the illness and not a change." (CPN2)

"No I would medicalize it...it's not the person who's thinking in an informed intellectual way. It is a reaction to their illness or the environment." (Res1)

Both comments indicated that for values to change the person would have to make a conscious decision, which the person with dementia might not be able to make. The second comment is interesting in that it reflects some authors' views on the process of formulating personal values. For example, Verplanken and Holland (2002) state that a value must be 'cognitively activated' and should be central to an individual's self-concept. Moreover, many professionals stated that 'lack of insight' and lack of judgment or understanding were reasons why values appear to change. According to two participants:

"No their whole world changes, they accepted before what would not be acceptable or never accepted the acceptable. They lose insight and don't have the same understanding of things." (DN3)

"I would make the assumption that her own judgment, her own mental faculties had caused the changes rather than a deliberate change in her values." (Psych5)

Several staff gave examples of behavioural changes associated with dementia which could not be perceived as changes in values, such as previously mild mannered people being aggressive, losing social graces, neglecting hygiene and previously religious people

becoming sexually disinhibited and/or swearing. According to one nursing home owner:

“If they lose their skills to use a knife and fork and eat with their hands they’d be appalled if they could see themselves. Their brains have been compromised. It is changes in their brain and the same with their values.” (NH3)

Another reason cited by some for perceived changes in values was that some people with dementia might not be able to communicate or articulate their values or preferences, especially in the latter stages of the illness. The suggestion was that the person could have lucid moments and have periods of insight, where they were aware of their values.

Two professionals who felt this way stated:

“It’s not so much that their values change. Maybe they can’t communicate and they’ve given in to it. It important that shouldn’t happen.” (Res5)

“In the very early stages I think the person’s values will remain the same. Even until the very end there will always be a wee window there where people will remember their likes and dislikes and preferences and I don’t think they will ever change.” (SW1)

The first comment was interesting in that the home owner suggested that individuals could ‘give in’ to changes in their values. According to Kane and Degenholtz (1997) there is a danger that a shift in values could be misconstrued as a change in values and it can only be through repeated discussions and dialogue with a person over a period of time that one can decide if their values have changed. However, Kane and Degenholtz related this to older people in general and not specifically people with dementia who could possibly have communication problems and, especially in the latter stages of the illness, have difficulties comprehending information.

Only two of the forty participants suggested that perceived changes could be viewed as changes in values. However, both participants appeared to put forward this argument as

an alternative option and not necessarily what they believed. One of them stated:

“Both because as some people get older things like hygiene can change even without the diagnosis of dementia and it’s not necessarily due to that... although it may be.” (Psych1)

The psychiatrist was one of the few who thought that values continually evolved throughout life, including older age, and argued that perhaps some people with dementia’s values changed in the same way that values can change with old age or any illness. Interestingly, although he stated this he was one of the most enthusiastic participants for recording people’s values and would ‘definitely’ refer to the document.

Although the vast majority of staff reported that they did not feel perceived changes in behaviour were associated to changes in the person’s values there were varying strengths of feeling regarding the extent that one should go to allow the person to adhere to their previous values. Some differentiate between values. One participant stated:

“I think credence should be given if it’s important values such as religious beliefs or what happens when they die, but if it’s other day to day matters their comfort at the time is more important.” (CPN3)

The comment by this CPN indicates that he would make a judgment on the level of importance that the people with dementia placed on different types of values before the onset of the illness, perhaps placing more emphasis on religious values. The next two sections will explore professionals’ views on two quite different values expressed by two participants with dementia. The first is related to ‘appearance’ and the second to ‘spiritual’ values.

9.6 Sylvia’s values vignette- her appearance

The purpose of this section of the research is to explore how professionals felt about the

information in Sylvia's Values History (appendix 10) regarding her appearance and cleanliness and to explore the impact of her feelings on possible future care.

In her Values History Sylvia stated that her appearance and hygiene were 'very important' to her. She stated that she was 'not conceited' but liked to look good and could never 'slouch about any old way'. She felt it 'bucked up her morale' when she was complimented. She had a fear of being 'dirty' as the illness progresses and that she stated that she would 'definitely' want assistance should she experience any problems in the future. Firstly participants were asked how relevant it was for the information to be included in the Values History and if they felt it would influence their management should her condition deteriorate.

The vast majority of participants stated that the information about the importance of hygiene and appearance was useful to have. As a group GPs were the only exception, not feeling the information would be useful to them as such, although they all felt it was appropriate for those involved in the direct care of Sylvia. The most commonly cited reason that the information was useful to have was that it would be important for staff who did not know Sylvia before the onset of the illness to know what her previous standards were should her condition deteriorate. Several staff recalled incidents of their own family members or patients with dementia who had been admitted into long term care and dressed inappropriately or in manner that they had not been used to i.e. dressing a man in a track suit who had been used to wearing a shirt and tie all his life. Others also reported that it would be a good 'benchmark', in that a change in her appearance or hygiene would indicate a worsening of her mental or physical state. Seeing her as an individual and knowing how to approach her were mentioned by several participants. According to one nursing home manager who felt this way:

"Yes it gives you an idea of how to approach her. What would make me feel good would not be good for someone else. Some people don't like you mentioning their appearance but Sylvia would." (NH5)

Another reason mentioned by several participants was that her appearance was how she was ‘viewed by others’, especially family members and friends and therefore it could be distressing to them should they notice a marked decline in her standards. Two comments which highlighted this:

“It’s important for the person, but for the relatives as well, to see that they’re still the same person.” (Res5)

“One would always want to put yourself in the family’s position and how you appear to them is what gives you person or personality, and it would give her comfort to know that when she doesn’t care about her appearance others would care for it. It might help her contentment and happiness at the time.” (GP2)

How people with dementia ‘were viewed by others’ was an underlying theme throughout the research, in that, some professionals expressed the view that values should be maintained to please family members, as at the time the person with dementia might not be aware of their values. The second comment is also interesting, in that the GP suggested that an individual could get a degree of comfort from knowing that their standards would be maintained should her condition deteriorate. This, in fact, was the case with Sylvia, who stated she was glad she could give the information while she was ‘compos mentis’ and whilst she had faith that her family would represent her well, understood the purpose of recording information in the Values History.

The majority of staff also felt that they would make ‘more effort’ to help with her appearance if they had the information from the Values History. According to two professionals:

“Yes because the carer has a clear description of what the person was like. They might not have much success but they would put more effort into it.” (Res1)

“Yes I think it has to because if we are working with a person we have to know that

this isn't an acceptable thing and what we need to do is to develop a care programme that allows support to enable that to continue... just because they develop dementia they shouldn't lose that...we need to look at innovative ways to address it.” (SW3)

Both comments, whilst indicating that they would be inclined to put ‘more effort’ into tending to Sylvia’s hygiene, alluded to practical difficulties in them achieving their goals especially if she was opposed to them assisting her as the illness progressed. Looking at ‘innovative’ ways and putting in ‘more effort’ indicate that the information about her past values would have an impact on their motivation and their management of her care, whilst recognising that they might only have minimal success.

Only a few felt that the information would not have any impact on their care for Sylvia. The main reason highlighted by all of them was that they felt that the importance that Sylvia placed on her appearance was not particularly unique to her and the same standards should be achieved for all patients. Two comments which highlighted this were:

“I think most people want to be presentable and as well turned out as they can... I think it would be a basic human right that she is well turned out if there’s ten people in the ward they should all get the same attention.” (GP3)

“You would hope that even if you never had that information whoever was involved in her care would be addressing her appearance or hygiene.” (Psych5)

However, it was interesting that some participants felt that there would be cases where some individuals, who had never put any onus on their appearance, could be forced to pay more attention to it than they would have before the onset of the illness and it would be of equal importance to know their previous standards. Some gave examples of older people being forced to bathe every day in nursing homes whereas before the onset of the illness they were content to bathe once a week or as in the case of some men, being

shaved daily where they would prefer to shave every few days. Again there was an inference that the emphasis on the person's appearance could be to please other people and not necessarily the person.

To ascertain the extent to which staff felt her previous values would relate to her condition should it deteriorate they were asked to imagine that she had become unkempt and had foul body odour. They were informed that due to her memory problems and she was forgetting to bathe, although she still believed that she was bathing daily and was unaware of the changes in her appearance. Participants were asked if they felt it would be in Sylvia's interests, if her condition deteriorated to cause her a degree of agitation or upset her, to go by her previous values

There was no professional pattern to the responses, with the majority feeling that her 'feelings at the time' or 'and her 'contentment and happiness' at the time were more important than her previous values and to cause her any degree of agitation would be against her best interests. According to one participant:

"It's not ignoring what she wanted in the past; it's just respecting what she wants at the time." (Res2)

Another also stated:

"I think her contentment and happiness at that stage would be more important than causing her to undue distress and upsetting her and trying to maintain what was previously important to her...it's not a life or death situation even if she would be horrified to think that's how she was." (Psych5)

Approximately a quarter of participants thought that her previous values should be paramount to the extent that a degree of agitation would be in her interests with the remaining participants 'unsure' or unable to comment unless they were in the situation at the time. For those who thought her previous wishes should be paramount there were

varying strengths of feeling ranging from ‘definitely’ to ‘possibly’, with the majority feeling it should only be as last resort. According to one participant who felt ‘definitely’:

“I would be willing to go through the agitation to be the way I would want to be. I wouldn’t want someone to say ‘she’s happy like that’. I would want someone to give me the agitation.” (Res4)

And another who thought ‘possibly’:

“It would depend upon the agitation, but yes because she said that she might not agree at the time in her Values History, and I know she would want it.” (SW2)

Participants were also asked if it would be in Sylvia’s interests to ‘hoodwink’ her or tell ‘white lies’ into helping with her hygiene as an alternative to causing her agitation and the example of telling her that she had a ‘skin complaint’ and needed ‘treatment’ for it was put to the participants. The majority felt that this would be appropriate, although most stressed that they would try ‘cajoling her’ or try ‘different approaches’ in the first instance. ‘Causing her least distress’ or ‘without hurting her’ or ‘to make it more pleasant for her’ were the most often cited reasons for participants to tell ‘white lies’ to try to maintain her values and standards. Many of those who thought it would not be acceptable to cause her agitation to maintain her previous values felt this approach would be more acceptable. Two responses included:

“I think we have to change our approach as the person changes. If we can lessen the distress to bring them up to their previous standards that they had in the past. and we’ve got to remember the people coming in to see them.” (SW5)

“Yes I think there are ways around it and I don’t see any harm in it if it helps her. I think you can use people’s dementia to your advantage to try to maintain the standards that were there before, as long as it wasn’t causing her any problems for the future.” (Vol5)

Similarly, Cutliff and Milton (1996) used vignettes to ascertain if there were cases for telling lies to cognitively impaired patients in nursing homes and found that there may be some situations (for example putting medication in their tea) where the principles of non-maleficence and causing least agitation to the person were more important than respect for autonomy.

Although the majority stated that they felt it could be justified to hoodwink Sylvia to help her achieve her previously high standards, for some it was not necessarily because of the information in the Values History. 'Backing up' and having 'more concrete reasons' were expressions used by some participants, which indicated that the Value History would help them to justify within themselves that they were making the right decision and feel better about 'hoodwinking' her. However, others felt that the information would have a direct influence on their decision. According to one psychiatrist:

"I would encourage and push more whereas someone in a geriatric squalor might be content to be in that situation, with Sylvia I would imagine I'd try harder. It's important for the family to see that you're trying to maintain these (her values)...for their sake as well." (Psych4)

Only a small proportion of participants thought that it would not be appropriate to hoodwink Sylvia to maintain her previous values. The most common phrases used were that it was 'unethical' or 'just not right'. Some also mentioned that they would consider it but only in extreme circumstances where her level of hygiene became detrimental to her health. However, this was not related to previous knowledge of her values but to basic standards of care for all people with dementia. One residential home owner stated:

"If it's affecting her physical health and she has sores etc then I think duty of care comes into it. You need to do something. If she's got three days' spills down her jumper then we've got to be careful between what we see as nice and what she feels comfortable with." (Res4)

This comment also indicated that maintaining a person's appearance can be to please others and what 'we see as nice' rather than in the person's interests. However, unlike previous comments which looked upon this favourably, this participant suggested that it would not always be in the person's best interests at the time, even if appearance was important to the individual prior to the onset of the illness.

In the following section participants were shown Marie's Values History (appendix 11) and the section on her 'spiritual and religious' beliefs was highlighted.

9.7 Marie's values vignette- her faith

In the document Marie had stated that due to her religious beliefs she had never celebrated Christmas or birthdays, viewing them as pagan. She stated that it was 'a way of life' and 'very important' for her to continue practicing her faith should she ever be admitted into residential care. Whilst she was aware that there were long term care homes specifically for Jehovah's Witnesses in England she felt they were too far away and stated that if she was admitted into care she would appreciate it if staff respected her beliefs. Professionals were asked to 'imagine' that she had been admitted into residential care and she became 'unaware' of her surroundings and appeared to enjoy Christmas parties and celebrations unaware of the religious element and was happy to join in the festivities. The purpose of this question was to ascertain if they felt that her past wishes were more important than 'here and now'.

In general all the participants stated that they would try to go along with Marie's values as long as she had insight and awareness into her condition. Although this was not specifically answering the question, their responses indicated that they would refer to the Values History and attempt to find out if she understood the meaning of the celebration and give her the opportunity to leave, rather than simply presuming that she was happy. Two social workers, who felt this way, stated:

“We wouldn’t want to put her in a situation that would make her feel awkward and against her values. If she had insight I’d ask her how she felt and give her the opportunity to leave.” (SW1)

“I think I would weigh that one up. If she still had some insight into her religion yes, but if she never I’d probably leave her. I’d perhaps take advice from others in her church, but then again you’re speaking to people who aren’t experiencing dementia.” (SW3)

The second comment is interesting in that the social worker initially stated she would seek advice from someone in Marie’s church but thought they might not understand from the perspective of someone with dementia. Similarly, some authors argue that no one really understands how it feels to have dementia (Kitwood, 1997; Berghmans, 1997). For example, Berghmans suggests that the ideas, preferences, values and concerns of the person before the onset of dementia have no special relevance to how the ‘demented self’ ought to be treated.

To explore further whether Marie’s ‘past or present wishes’ should have prevalence if she lost insight, professionals were informed that she ‘definitely’ did not understand. Again many did not answer the question specifically in relation to the Values History and stated that Marie’s family should be consulted to offer some guidance and possibly offer some support to provide alternative activities for the person. One psychiatrist felt quite strongly that it was the family’s ‘responsibility’ to look after the individual’s spiritual needs. She stated:

“I think that’s where families come in. They have a responsibility and they should be aware that staff can’t always be there to make sure someone prays at a certain time of day or whatever. If they wished the person to continue in their faith they would need to support the staff.” (Psych5)

However, the questions were further developed to explore whether the information in the

Values History would ‘stand alone’ if the professional was not able to refer to the family and had to base their decision on the Values History.

A large group of participants found this question difficult to answer, some changing their minds as they thought about the implications of their answers. An example of this was a district nurse who stated:

“I would let her sit but perhaps feel a bit uncomfortable with it, but I think you’ve got to look at whether she’s happy or not. I think there comes a time when their current happiness is more important... on the other hand I don’t suppose you should expose her to something that she wouldn’t normally do... actually I just don’t know.” (DN1)

In general there were a wide variety of views, with just under half the participants feeling that the person’s previous values should still be adhered to if the person lost insight and the remainder feeling that they should go along with how the person felt at the time. As expected for this part of the research, there was no significant professional pattern to their responses, although there were slightly more participants within the ‘here and now’ group from those who worked (or had previously worked) with people with dementia in long-term care, perhaps looking at things from a more practical point of view. Interestingly there was a degree of scepticism by some non long term care participants that the Values History would make a difference although many stated ‘it should’. According to one voluntary manager:

“Yes, I think they (residential home staff) should. I don’t think it would, but I think it should be taken into consideration.” (Vol5)

However, as highlighted, long term care participants were only slightly more prone to go by the here and now, but not considerably more. They also were one of the most enthusiastic groups for having the information as recorded in the Values Histories.

Within each of these stances ('previous values' versus 'here and now') was a wide variety of conviction, ranging from very strong to very weak. A view expressed by some of those participants with a strong belief that previous values should be adhered to, was that the person might have periods of lucidity which could upset them, the person knowing that they were going against their previous values. According to one GP:

"When it comes to matters of spirituality you might not know if she is aware or not know and the truth of the matter is you don't know. The staff caring for her should know these things and you should go by her previously expressed wishes." (GP)

Another GP also stated:

"Yes I think in matters of spirituality you've got to go along with it. If someone is Jewish and they're dead, their bodies aren't allowed to be touched for 24 hours. The fact is that they're dead, but you don't just ignore their spiritual wishes." (GP2)

Others also felt 'it was right' but could not give any explanations for their comments or, as in the case of many, felt that if the person felt strongly enough to document how they felt about religious matters then they should be taken in to consideration. An example of this was a comment from a voluntary organization manager who stated:

"I think it would be sad if she had gone to the bother of documenting her beliefs and they couldn't be upheld. It's important to see the person. They should be trying to help her if she felt strongly." (Vol5)

Although some felt that her beliefs should still be upheld despite losing insight, they were less strong in their convictions. One residential home manager stated:

"I would definitely go by the document as far as I could but if I found her dementia was getting worse and she never understood or became agitated I would possibly allow her rather than upset her. I wouldn't see the point in telling her 'this is what

you believe.” (Res2)

Slightly more than half the participants felt that they would go by the ‘here and now’ and not by her past wishes or values should she lose insight. Being ‘happy’ and ‘content’ or ‘minimizing agitation’ were the most often cited reasons for their responses. Two comments included:

“I would go with her feeling at the time.... as long as she’s happy and feels comfortable I wouldn’t take her away.” (CPN5)

“If she was happy and it wasn’t causing her any distress I’d go by that. I wouldn’t say to the staff that you must go by what she previously thought.” (GP3)

Although this ‘here and now’ group of participants said they would go against her previous values, most of them stated that it was appropriate for them to have the information, and to be able to refer to the document even if the person had lost insight. Indeed, several from this group mentioned ‘thinking about the person’ and ‘making a conscious decision’. Two comments that indicated this were:

“I’ll be honest. I would like her to join in the festivities. It’s not because it’s right or wrong, it’s a personal decision. The guilt would be mine, because otherwise she could be sitting in a room alone and I wouldn’t like that. But with this document I would make a conscious decision, which is part and parcel of the job. The guilt would be mine.” (SW2)

“I think it would force you to think about the person, even if you went against her wishes.” (SW5)

There was also recognition by some that their belief systems were different from the case studies, and that they would have to be aware that their reasons for ‘not going along’ with her previous values were in the person’s interest and not because of their own values.

“I know my belief system is different from this lady’s so I would have difficulty understanding why she wouldn’t want to be involved. I’d have to ensure that I wasn’t going along with it because it’s not important to me.” (SW5)

“Yes I think it’s even more important with someone with a different belief system to have it recorded like this so that you can understand.” (GP3)

The comment by the GP in particular seemed to indicate that those in non mainstream religions or with cultural needs would benefit the most from having their religious beliefs documented and help care staff ‘understand’ their values which would in most cases differ from their own. However, a small minority of participants from the ‘here and now’ group admitted that they could not understand why Marie would not want to be involved in Christmas festivities, possibly having difficulty differentiating between their own values and Marie’s. One psychiatrist stated that he disapproved of segregating people for religious reasons under any circumstances, feeling that it leads to stigmatization and intolerance of such ones. He gave the example of Roman Catholic or Jewish children being educated in a protestant school, but having to leave class to go to separate services. When it was put to him that it had been an important aspect of Marie’s belief system throughout her life, he stated:

“If you made it harder and said that her family didn’t want her involved either I’d discuss it with them and point out that she’s sociable and enjoying being with people. I’d give my reasons why I think it would be good for her to join in. I would point out why I would overrule her (as documented in her Values History), but let the family make the final decision.” (Psych1)

The vignette which was put to the participants only highlighted the situation of Marie, who was one of Jehovah’s Witnesses. Participants were therefore also asked whether their responses would be similar for people of other faiths, particularly those from a ‘non mainstream’ background, who had also recorded special instructions should they lose

insight into their condition. For example, the importance of some Muslims to engage in prayer at a certain times of the day, or someone who had previously abstained from alcohol for religious reasons asking for some at a party. The majority of participants from both the 'here and now' and 'previous values' groups stated they would still go along with their previous responses although some felt they genuinely could not answer unless they were in the situation.

A few participants also differentiated between physical aspects of care, which were relatively easy to manage, for example dietary restrictions, as opposed to less visible indicators of religious beliefs, such as allowing a person to sit in a religious ceremony in which they would not have participated, prior to the onset of dementia. One social worker stated:

"I think if it was a feast of pork you could make a point of not giving it to them, but if they were sitting whilst something religious was going on you could just let them enjoy the stimulation." (SW3)

Some participants working in long-term care had experienced dilemmas relating to people with dementia's previous religious values. One nursing home manager recalled a lady who was a member of the Free Church of Scotland. Initially her care plan stated that she should not watch TV or read a newspaper on a Sunday. When the lady was first admitted into care she had insight into her condition and still followed her faith. However after she lost insight she did not realize when it was the Sabbath and would forget soon after being told by staff. The care staff therefore allowed her to read newspapers etc on the Sabbath and would not point out her previous beliefs. After discussions with her family it was decided that this was the most appropriate course of action. Another residential home manager reported that her staff had given a lady alcohol at a social event; in the past she had always abstained (due to religious reasons). Due to her family's strong convictions they avoided giving her alcohol again.

These examples highlight the strong influence that families have in deciding whether the

person's previous values should be adhered to or not. Both managers felt that in such cases if the individuals had completed Value Histories they might have 'tried harder' to go by their previous values, but family views would ultimately have more influence on the individual's care. Again it was suggested by some participants that one of the main reasons for maintaining values of the person with dementia was to please their family and to promote to the wider community the 'person' behind the illness and how they are perceived rather than for the person's own benefit. This was an underlying theme through this section, in particular the importance of maintaining the appearance of people with dementia, to please their family and reinforce 'the person' is still the same.

9.8 Summary

Firstly from the perspectives of the people with dementia, unlike discussing the diagnosis and the future, exploring their values appeared to be less threatening to them. Although some were able to articulate their values very clearly, many needed prompting and their values were drawn out whilst they were reminiscing or discussing aspects of their lives such as 'friendship' or 'company they like'. Moreover, with some participants their Values Histories were enhanced by information or prompts from their carers, by reminding the person of aspects of their lives which were important to them. Whilst this was a positive aspect for the majority, there is the possibility for some people with dementia that they could be unduly influenced by their carers or the interviewer. This is explored further in the chapter 11.

Again the underlying theme of how honest people with dementia can be when discussing their values and how much information they would be comfortable for others to know about them was raised in this chapter. In this instance it was concerning values which could be viewed as 'controversial' by others, perhaps being viewed negatively by future care staff. Although not part of the research, it would be interesting to know if such values would in fact influence the person's care.

Concerning professional participants, it is interesting to note that the vast majority of staff

would welcome the information and even those who thought that values could possibly change throughout adulthood claimed that they would refer to the documents when planning care, and try to maintain values 'up to a point' especially when there was a possibility that the person still retained insight. However, it is noteworthy that most professionals would only try to maintain previous values if it was in the best interests of the person with dementia at the time and would consider reducing agitation more important than trying to maintain past values. This is possibly more in line with a person centered approach whereby it should be acknowledged that each person's present identity is a function of their unique past, but in such a way as 'not to diminish their present by accentuating their past'(Morton,1999:14). However, comments such as 'making a conscious decision' and 'force you to think about the person' indicated that rather than passively ignoring the person's wishes they would make a conscious decision to go against their wishes based on the person's best interests. This theme is further discussed in chapter eleven, notably whether 'listening' to someone's wishes, albeit overruling them in their best interest, can be viewed as empowering.

Another theme to emerge was that despite professionals appreciating the information in the Values History many would still seek guidance and direction from relatives. Moreover, several participants suggested the possibility that attention should be paid to Sylvia's appearance to please her relatives. Whilst this could be viewed as looking out for relatives' best interests as opposed to the person with dementia, some authors point out that this is fundamental to maintaining the 'person' and how they are outwardly viewed by the world has an impact on how they are treated and approached by others (Cheston and Bender,1999; Kitwood, 1997). Furthermore it clearly indicates that a Values History backed by a supportive family is more empowering than a Values History alone.

Moreover, the purpose of this research is not only to evaluate Values Histories from a theoretical or academic point of view, but to evaluate the practical usage of Values Histories. One of the fundamental principles of establishing a 'person centred approach' in dementia care is for those working with people with dementia to create a 'helping

relationship'(sic) and to 'enter into the world of his feelings'(sic) and 'see the world as he or she does'(sic) (Morton, 1999:17). The next chapter therefore explores some of the practical issues of engaging with people with dementia to complete a Values History, at times drawing on the researcher's personal observations and feelings.

Chapter 10

Practical implications for the use of the Values History and the researcher's reflections as a practitioner.

10.1 Introduction

10.2 Professionals' preferences regarding the writing of the documents

10.3 Researcher's experience of writing the Values Histories

10.4 Researcher's knowledge of the people with dementia

10.5 To what extent would professionals refer to the Values Histories in practice?

10.6 Do professionals feel that Values Histories could empower people with dementia?

10.7 General concerns regarding the Values Histories.

10.8 Would professionals choose to have a Values History should they develop dementia?

10.9 Summary

10.1 Introduction

Since one of the main purposes of this research is to evaluate whether the Values History can be used as a practical tool to empower people with dementia, the researcher at times drew on his own personal observations and feelings. It should be noted that the researcher is not only a 'researcher' but a 'practitioner' with experience of working with people with dementia. As discussed in the chapter four, many studies within social policy and health have similarly been carried out by practitioners (Butler, 2003; Schon, 1983).

This chapter therefore begins by looking at the general layout of the Values History. As highlighted in previous chapters the professionals were given two documents to read in advance. Both documents were written in slightly different styles, with one written in the first person and the other in the third person. The different styles are evaluated from both

the practical aspect of the researcher writing them and the professionals' views as to the writings of the documents.

Sections 10.6 and 10.7 explore the professional participants' thoughts regarding the general usefulness of the documents and whether or not they would refer to them in their day to day practice. Interestingly, prior to the interviews the vast majority of professionals had, in fact, 'done their homework' as asked to by the researcher, with many preparing questions to ask about the documents. Whilst they had taken the time to read them prior to their interview for the purpose of the research, they were asked if they would refer to the documents in their day to day practice.

Finally the chapter concludes by asking whether the professionals felt Values Histories could be used as a tool to empower people with dementia should their condition deteriorate. This was one of the main research questions of the study and is developed more fully in the final chapter. In addition professionals were also asked if they were to develop dementia, would they consider completing a Values History.

To begin with professionals were asked whether they preferred the Values Histories written in the first or third person.

10.2 Preferences regarding the writing of the documents

Approximately two thirds of participants preferred the Value History which was written in the first person. 'It's more personal', 'it builds up a better picture of the person' and 'more powerful' were typical reasons from those preferring it as opposed to the one written in the third person. According to one social worker:

"I think it's more personal and you can see it's coming from Sylvia. Sometimes if you write a report about someone it can become as if the person is lost in the words. It almost becomes other people's opinions rather than that of the person." (SW4)

One psychiatrist who also preferred the Values History written in the first person compared it to writing psychiatric reports. He stated:

"I think the first person. If you say Joe Bloggs is suffering from persecutory delusions it doesn't have the same impact as 'the Martians are pursuing me because...' their own words are better than filtered." (Psych4)

A social worker, who also preferred it written in the first person, felt that this style would have more impact with inexperienced nursing assistants and support workers, because it might 'force them' to look at the person as an individual. Other staff also alluded to the same point stating that they could 'see the person', 'imagine' them or felt that they 'knew Sylvia as a person'.

Interestingly although some staff initially claimed to prefer Sylvia's document because it was written in the first person, they admitted that their feelings could be partly be related to them having empathy for the feelings expressed by Sylvia in her Value History and possibly due to the content of the Values History, rather than the way it was written. This was an underlying theme throughout the research in that some professionals found it easier to relate to values which they themselves also held.

The remaining third of participants did not feel that writing the Values History in the first or third person made any major difference to the impact which the documents had on them, and only two participants actually preferred it written in the third person. For those who felt there was no difference, the majority stated that Marie's and Sylvia's values came across equally in both documents. Most participants reported that the quotes in Marie's document helped to personalise the information and highlighted the strength of her feelings about matters which were important to her. *'The quotes help make her values more solid'* and helped to *'make her values stand out'* were typical comments (CPN1, Res3). According to one social worker:

“No I don’t think it makes a difference. The fact that there are quotes is good. It gets over the meaning of the thing. I think it’s not so important how it is written as long as it gets over their wishes.” (SW3).

Some recognised that Marie’s condition might have been more advanced than Sylvia’s and that her communication might not have allowed for the Values History to be written in her own words. This was in fact the case and is further explored in section 10.3.

The two participants (both psychiatrists) who preferred the Values History written in the third person stated that they were more comfortable reading reports, which possibly related to their medical background. One of the psychiatrists admitted being sceptical of writing which claimed to be written in the first person, feeling that, after grammatical corrections and rewriting the material, it would be more likely to be in the writer’s words rather than those of the individual concerned. The next section explores this point further.

10.3 Researcher’s experience of writing the Values Histories

By taping the interviews, direct quotes were taken from the participants with ten of the Values Histories being written in the first person. Writing in the first person proved more difficult and time consuming, in particular because the interviews were semi structured and often the information did not come in set order and themes were often returned to through out the course of the interviews. As highlighted in chapter nine, some people with dementia initially did not feel they had strong values when asked directly, but became apparent when discussing life events.

Furthermore, background information tended to be gained throughout the course of the interviews and for some participants there were gaps in the information, which were filled in by their relatives. In such cases the background information was documented in the third person as not all information came from the individual.

Another example, as cited in chapter five, was Bill who initially stated that he had no fears about the future whilst being interviewed. However, when the interview was finished he admitted being scared at nighttime due to feelings of disorientation. Fortunately this was after the first interview so during the next meeting the interviewer was able to remind him of the conversation and he expanded upon it allowing a direct quote to be used. However, it would have been difficult to record his exact words had he divulged how he felt after the second interview, or had he not further expanded upon how he felt during the final interview.

Two Values Histories were written in the third person, as both participants with dementia had a degree of expressive dysphasia and needed prompts and encouragement to communicate their values and preferences. In the case of Marie she was unable to express her religious beliefs in a manner that would have written well and her beliefs could only be ascertained with help from her husband and some prior knowledge from the interviewer. However, with these prompts she was able to state quite clearly how strongly she felt about her faith. To quote:

“I’ve always loved the truth and it’s never been a trial for me to continue. It’s just marvelous for me to know the truth. It’s a precious thing and something that we should hold on to.”

Another area which made writing in the first person more difficult was where the person with dementia used grammatical errors and colloquialisms. On the one hand recording their statements verbatim could possibly enhance their Values Histories by making them personalised and natural but, on the other hand, could detract from the information if left uncorrected. In a similar vein, some people with dementia were less articulate and the language used might not have ‘read well’. Similarly, one could possibly embellish the statements, but the wording would therefore not be the individual’s words. However, if left unchanged the Values Histories could possibly appear unprofessional. It would have been interesting to compare examples of each to ascertain the views of the professional

participants, whether including grammatical errors and colloquialisms would, in fact, have detracted from the information or enhanced it.

10.4 Researcher's previous knowledge of the people with dementia

Another aspect of the research, which must be acknowledged and considered, is the interviewer's level of knowledge about the participants and his relationship with them prior to conducting the interviews. Five of the twelve participants with dementia were known to the researcher prior to the interviews, ranging from one month to over two years. With these participants the researcher was able to give more prompts, particularly in relation to obtaining background information, and remind them of aspects which he knew were important to them from previous discussions.

Marie, as previously mentioned, had been known to the researcher for over two years and experienced a degree of dysphasia. The interviewer was able to use her family's names and prompt her with questions related to important aspects of her life. Moreover, prior to the first interview Marie had expressed her feelings about her faith on several occasions to the interviewer, so he was able to use terms such as 'kingdom hall' instead of 'church', 'the truth' instead of religion - terms which she was comfortable with and had used in past discussions with him. Furthermore, by being aware of her religious convictions, in regards to not celebrating Christmas and other mainstream religious festivals, she was asked specifically how she felt about being included in these festivities. This allowed her to expand on her strong feelings such as '*I just couldn't be there*' and how '*awkward*' she would feel if placed in these situations.

Upon reflection, the researcher recognises that he specifically asked Marie her feelings about Christmas based on his prior knowledge of her values and he never specifically asked any of the other interviewees about Christmas, presuming that they would celebrate it (rightly or wrongly). It is difficult to know if Marie would have brought this up without prompting, and whether or not an independent interviewer completing the Values History without knowledge of Marie's faith would have encouraged her to expand upon

her answers. This however appeared to be a positive aspect of prior knowledge about the person.

Another example of the researcher having prior knowledge about a participant was with Walter. In hindsight the researcher's previous knowledge and relationship with him and his family could have initiated him to 'lead' the person rather than 'prompt' him. Through discussions with his family the researcher was aware that Walter had an aggressive manner and therefore, because of this, asked him what sort of things irritated him. Initially he could not define anything other than being a bit 'rough' in his manner. Whilst the same question was asked to other participants it was probed further with Walter because of the specific knowledge about him. From the interviewer's point of view, it was felt that should Walter be admitted into long term care in the future, it could be useful for staff to know how to approach him and possibly to minimise aggression. In hindsight, however, the researcher realises that he encouraged Walter to document this because he viewed it as important information, rather than taking the lead from Walter.

It also indicates the influence that the practitioner could have in directing the statements based on his or her own judgement. This would not be in harmony with a true person centred approach, whereby the person with dementia should be encouraged to 'set the agenda' and not the practitioner (Morton 1999; Kitwood, 1997). It could also be seen as 'manipulating' the person, albeit with good motives, to record information about themselves that others (either family members or the practitioner) deem useful, which is also not in the accordance of person centred care as described by Kitwood (1997).

Interestingly, the Values Histories from people with dementia known to the researcher beforehand were not deemed any more accurate by their carers than those participants not known to the researcher and there were not any major differences in corrections made to their Values Histories. Moreover, Sylvia, who was not known to the interviewer, had very few corrections to her document whereas Bill, who was known to the interviewer for over a year, had several corrections related to his background information. However, it should be acknowledged that, in general, from the researcher's point of view, he found it easier

to engage with people known to him beforehand, particularly in relation to exploring their feelings about having dementia, knowing how direct he could approach the subject.

The following section attempts to clarify how useful professionals found the document and how often they would refer to it should the person with dementia’s condition deteriorate.

10.5 To what extent would professionals refer to the Values Histories in practice?

Whilst the research is primarily qualitative in nature, the methodology chapter highlighted the benefits of a pluralistic evaluation and ‘mixed method’ approach (Greene and Caracelli, 1997). In an attempt to clarify the extent that professionals would refer to the document the forty professionals were left a questionnaire to clarify how useful they found the document and how often they would refer to it should the person with dementia’s condition deteriorate. Twenty-eight out of a total of forty interviewees returned their questionnaires (70%). The following two tables show the results.

Table 6

In general how useful do you feel a Values History would be in helping you to plan care for a person with dementia?

	Very useful	useful	Partially useful	Not very useful	No use whatsoever
GP	1	3			
Psychiatrists	4				
D N	4				
CPN	2				
N Home	4				
Res Care	3				
SW	3	1			
Voluntary	3				
totals	24	4			

All responders were very positive about the general usefulness of the Values Histories in helping them to plan care and all stated that the document would be ‘very useful’ (24) or ‘useful’ (4). Interestingly, three of the four professionals who defined it as ‘useful’ were GPs, and perhaps less enthusiastic. As highlighted in previous chapters, the majority of GPs felt that the documents would be particularly useful for other professional groups, such as long term care providers. Indeed, they all stated that they would rather have the documents than not have them.

Table 7

To what extent would you refer to a person with dementia’s Values History if their condition deteriorated?

	Very frequently	frequently	occasionally	seldom	never
GP			4		
Psychiatrists	2	1	1		
D N	1	3			
CPN	1	1			
N Home		4			
Res Care	2	1			
SW	2	1	1		
Voluntary	3				
totals	11	11	6		

The above table shows that the vast majority would refer to it either ‘frequently’ (11) or ‘very frequently’ (11), with only a few stating ‘occasionally’ (6). Five of the six who responded ‘occasionally’ were medical staff (four GPs and one psychiatrist). They were however additionally asked how useful they would find Values Histories when writing reports related to the AWI (Scotland) Act (2000) and all defined it as ‘very useful’.

Although the above tables give a snapshot of how the Values Histories were viewed by the professionals, the interviews provided reasons and meanings behind their answers (Mark et al., 1997). For example, the vast majority of participants reported that they would read the documents, find them useful and refer to them when planning care. GPs, whilst claiming to find them useful, would only refer to them ‘occasionally’. All five stated, during their interviews, that finding time to read them was the main barrier. According to one GP:

“Truthfully, I’d read the first paragraph and the last one. It’s like rheumatology letters, three pages long. What I want to know is what’s wrong with them and the treatment plan. The fact that she lives with her mother is nice, but it’s not what I’m looking for.” (GP5)

Two other GP’s gave similar analogies of having large reports to read, but in respect of lengthy psychiatric letters. This supported views expressed by most participants with dementia and their carers that their GPs would not have time to read the documents.

Although all five GPs stated that they would probably not routinely read the document at the time, four of them stated that they would like to have the document to refer to in the future should any problems arise. According to two of them:

“They were very powerful and it’s good to have an insight of the person. I probably wouldn’t read it there and then, but it would be useful to have in the file if a situation arose where you weren’t sure how management should proceed.” (GP4)

“I don’t think I would. In saying that with the AWI Act upon us it would be helpful to have as a reference.” (GP3)

Two of the GPs also suggested that the document could be shorter, one suggesting a single page with specific information, particularly related to guardianship. The other GP

suggested that the quotes should be shorter and for the headings to stand out in bold print to make for easier reference. The remaining GPs however felt that it should be left in its entirety. According one GP who felt that way:

“No, I think you need all the verbatim stuff. It comes across more powerful and if you relay just six points you would lose something. I think what makes it is that you can see the person saying it that way.” (GP4)

One psychiatrist also felt that the document was too long for medical staff to read and suggested an abridged version for medical notes and the complete Values History for those involved in caring for people with dementia. She stated:

“The details of this might be more useful to other staff than me. An abbreviated version of this would be very helpful and I think in long term care setting these would be invaluable.” (Psych2)

The other psychiatrists however, whilst agreeing that GPs might not have the time to read a lengthy document, felt that the information in its entirety should be retained and referred back to. According to two psychiatrists:

“This is the sort of information which should be in the front of their notes with the core information like date of birth etc. It’s important enough that it should be there because some things do get lost in the notes.” (Psych1)

“Seeing this in someone’s notes would be very valuable. ... Seeing their journey through to the end when they might not be able to say what’s important to them....if you were at an important crossroads you could refer back to it.” (Psych4)

With the exception of one district nurse, who thought her role was ‘task orientated’ and did not feel she needed to know people’s values, the remaining participants stated they would refer to the Values Histories and did not feel the documents were too long. Those

most enthusiastic in their responses were long term care providers and those responsible for placing carers with people with dementia in their own homes. ‘Definitely’ and ‘absolutely’ were common responses when asked if they would refer to Values Histories. Some nursing home staff felt that knowing people with dementias’ past lives, routine and values could reduce agitation and aggression. Two responses included:

“Yes, I think as much information as possible. If you have someone agitated and pacing about the ward, then you find out she walked her dog every day for miles, that could help. I think you could rationalise why people are behaving in a certain way.” (NH5)

“I think it would cut down on a lot of aggression displayed, because I think they still know themselves inherently what they like, but can only express it by lashing out.” (Res3)

This is interesting because some studies have shown that having accurate background and biographical information of people with dementia who are in long term care settings can help staff gain a better understanding of individuals in their care and reduce agitation (Godwin, 2002; Gödel, 2000).

Several long term care providers stated that they would base their care plans on the information. According to two residential care managers:

“Definitely, it would be into their file and the relevant areas integrated into their care plan.” (Res4)

“Yes, the second they’re admitted you could put more thought into it... I would highlight a lot and advise staff how to deal with the person.” (Res5)

Some, particularly those in residential homes, had used life story books and described reminiscence folders, which were used to bring back memories to people with dementia.

It was also felt that, along with photographs of the person with dementia, the Values Histories could be used to personalise the care and remind care staff that the person was an 'individual' and not just a 'dementia patient'. Again the literature review highlighted the benefits of life story work and biographical information having a 'personalising' effect on the care that individuals with dementia receive in care homes (Carlyle and Schofield, 2004; Morton, 1999; Rich, 1996; Kitwood, 1997).

Several participants involved in planning community care packages, particularly social workers, CPNs and voluntary organisation managers, also stated they would refer to the document, especially at times when planning care or at review meetings. A typical response from a voluntary organisation manager was:

"I would definitely go back to it and as her circumstances changed we would refer back and see what she wanted. There would come a time when she wouldn't know, but she's a human being and these are her preferences and as long as we could we would." (Vol3)

One CPN, who also stated that he would refer to the document, felt that often the views of people with dementia were not taken into consideration at multidisciplinary meetings. He stated:

"You have to look at what she wants and not what the family want. That's the easy solution. It doesn't mean that what she says will actually happen, but I think you should refer back to it at any stage in her illness." (CPN5)

The question of whether it is empowering for the Values History to be 'referred' to although not specifically adhered to is explored further in chapter eleven. Indeed, the main research question of this thesis is to ascertain if the Values History can be used to empower people with dementia should their condition deteriorate to the extent that they are not able to articulate their views. The following section compiles the responses of

twenty-eight participants who returned their questionnaires answering whether they believed Value Histories could empower people with dementia.

10.6 Do professionals feel that Values Histories could empower people with dementia?

Table 8

On a scale of one to ten, to what extent do you feel a Values History could empower a person with dementia if their condition deteriorated to the extent that they were not able to articulate their views?

	1	2	3	4	5	6	7	8	9	10
GP						1	1		2	
Psychiatrists							1	3		
D N							1	1	2	
CPN										2
N Home						2	1		1	
Res Care								1		2
SW							1		1	1
Voluntary								2		1
totals						3	5	7	6	6

The table shows that the responses were very positive, with an average score of 8 out 10 (range 6 to 10) and no obvious differences in professionals’ scoring. Similar to tables one and two this gives a snapshot of how the Values Histories were viewed by the professionals. However, chapter four highlighted that the questionnaires were used within the study only as tools to add strength and clarity to the research (Arksey et al., 2004; Greene and Caracelli, 1997). The interviews provided reasons and meanings behind their answers (Mark et al., 1997) and are further explored in chapter eleven.

Due to the positive nature of the responses to the Values History participants were asked if they had any concerns about the documents. The purpose of this was to ascertain if there was an element of idealism or possibly giving the answers ‘they anticipate the interviewer wants to hear’ (Fielding, in Gilbert, 1996:113). The following section explores some of the participants’ concerns regarding Values Histories.

10.7 General concerns regarding the Values Histories.

Responses were still, on the whole, very positive although participants did express some concerns. However, one of the main concerns expressed by several participants was putting family members under pressure to go along with the wishes of the person with dementia. One nursing home manager, who was very positive about Values Histories, conceded:

“The downside is that a very caring family member who genuinely felt that to do something in their mum and dad’s best interests might not tie in with the document. This could cause them a great deal of stress and guilt when, in fact, because of a change in circumstances they are doing the right thing.” (Nh3)

Several participants mentioned the possibility of a person with dementia stating in their Value History that they would ‘never’ or ‘under no circumstances’ want to go into long-term care. This of course could be unrealistic on the part of the person with dementia, and put carers under intense pressure to keep the person at home beyond a time which was possible. Several gave examples of carers they had known who had tried to go along with their relatives’ wishes to stay at home and eventually when they were unable to manage, felt extreme guilt. Some felt that if the person’s wishes were ‘in black and white’, as recorded in the document, this guilt could possibly be even more extreme.

One voluntary manager stated:

“I think because I’m seeing it from the carer’s point of view all the time, I’m seeing it very much from their point of view. I can see marriages being destroyed, losing children, all because they’re trying to carry out the wishes of their mum.” (Vol3)

Several participants also suggested that the person’s level of insight at the time of writing and their level of understanding of the condition would be of paramount importance. This was shown in chapter four to be a valid point in that some of the people with dementia interviewed had varying levels of awareness of the implications of the

condition. However, the professionals who highlighted this still felt that, after weighing up the pros and cons, it would be more advantageous to have the document than not. According to one CPN:

“You would talk around the issue more rather than just accepting things. I think you could use it as a point of reference, but it comes back to their perception at the time of writing.” (CPN1)

Some also pointed out that with the process of dementia there could be a drop in the individual's standards, i.e. hygiene, and whilst on the positive side recording their previous values could be a good benchmark for professionals and informal carers to achieve, there could be disappointment and guilt if the person's previous standards were not reached. One participant who had worked with carers felt that often carers who were able to accept that there would be a drop in their relative's standards seemed to cope better than those who continually strived to reach 'unrealistic' standards. 'Resources' and 'lack of services' were also mentioned by some as a reason why standards could not be met, and again could lead to disappointment.

Another area of concern, from a residential home manager, was that under certain circumstances she thought that Values Histories could be too personal and she questioned who would be allowed to read them. She stated:

“The only thing is that these are two people are very positive and relationships are good, but if you had to put down a relationship which upset you, who would be able to get their hands on it?” (Res2)

This was, in fact, the case for one participant with dementia who did not feel he could be honest when recording relationship problems with his wife for fear of upsetting her. Indeed, the issues around honesty when discussing family relationships became an underlying theme of the research.

Although the majority of interviewees were positive in their responses, stating that they would refer to the document and that it would influence their care, some felt that other professionals might not refer to it. GPs were the most frequently mentioned professional group that other professionals thought would not refer to it; likewise many staff in community settings felt that long term care providers may also not refer to the document. According to two community staff:

"I think they would say they never had time, that they were too busy. They are task oriented. I think in the ideal world we would all refer to this and treat people as individuals." (DN2)

"I don't know if people (long term care staff) would take the time. Even when we send in an assessment I think they pick out the bits that they need to know." (SW4)

Despite community staff's scepticism about long term care staff referring to the documents, the long term care participants were one of the most enthusiastic professional groups for having the Values Histories, stating that they would refer to them and, as in case of most homes, claimed that they would base their care plans on them. For example, one nursing home manager suggested:

"I think any nurse with any compassion or integrity would be affected by this and read and refer to it." (NH5)

Similarly, Rich (1996:82) suggests that Value Histories encourages long term care staff to have 'empathy' to engage with residents as 'unique individuals who are in the process of shaping their last, and hence vitally important phase of their lives'.

This section therefore clarified that the vast majority of participants would refer to Values Histories and claim that they would find them 'useful' for planning care, despite some concerns. The final section chapter, and indeed the final question put to all the professional participants, was whether they would chose to have a Values History should they develop dementia. Morris (2005) opines the 'golden rule test' for deciding if

something is good is whether the person would ‘choose to be on the receiving end of the action and it’s potential consequences’ (2005:6). Indeed, the late Iris Murdoch, writer and philosopher, who developed Alzheimer’s Disease, suggested that in order to have true empathy a person must ‘imagine’ and ‘mentalize’ what it would be like to be in another person’s position (Murdoch, 1971; Lita, 2003) .

10.8 Would professionals choose to have a Value History should they develop dementia?

Only two of the forty participants stated that they would definitely not want a Value History should they develop dementia, with three quarters stating that they would want one and the remainder ‘possibly’ or ‘not sure’.

The two participants who felt that they would not want Values Histories stated that they would rather leave decisions up to their families, as they felt that a Value History could put them under pressure. Interestingly one of them, a psychiatrist, stated that she thought it would be comforting and therapeutic to sit down with her family to go through the process of documenting her values and wishes for the future, but would have reservations about the information being shared with others.

The majority of participants who were in the ‘unsure’ category also stated that they would hope their families would be able to represent them should they develop dementia. Two comments that highlight this were:

“On one level yes, but I’d be disappointed if I thought there wasn’t someone in my family who could represent me.” (GP4)

“Yes I think so, but the reason I hesitated is because my gut feeling is that my husband knows everything about me and maybe by that time my two daughters will. I hope that people round about me will know me....but then again when I see carers about me with their own agendas and emotions.” (Psych2)

However, the vast majority stated that they would ‘definitely’ or ‘absolutely’ consider having a Values History. Freeing their families from responsibilities, knowing their views would be taken into consideration and not having to rely solely on other people’s views were the most often cited reason. Some comments included:

“I would want people to know my views were being expressed when I couldn’t. You can’t always rely on someone else to give them.” (CPN5)

“It’s funny as I was reading through this I thought it would be useful for us all to do this in our lives. I have two sons and I don’t know if they would know what I want in life.” (Res1)

“Absolutely. We do this for wills, why not for our personal wishes while we’ve got our faculties.”(Vol2)

A large proportion also mentioned the importance of including family in the process partly to make them aware of their thoughts, but also free their families from any pressure and guilt. Two comments included:

“I wouldn’t want that responsibility put on my family and would do it in consultation with them. I wouldn’t want them to have anything on their conscience.” (CPN4)

“Yes but I’d do it in such a way that my family wouldn’t feel guilty if they had to put me in care.” (Res4)

Interestingly this is also one of the recommendations made by advocates for usage of Values Histories for people with terminal illness: where possible, they should involve family members, one of the benefits being to relieve ‘burden’ of carers having to make difficult decisions (Hare et al., 1992; Doukas and McCulloch, 1991). Chapter seven

however highlighted the possibility that a minority of carers could influence the content of the documents. This is discussed further in the final chapter.

10.9 Summary

This final analysis chapter could claim that adapted Values Histories for people with dementia are an overwhelming success and should be implemented straight away! This could seem feasible considering the vast majority of professional participants reported that the documents were either ‘very useful’ or ‘useful’. Furthermore, they claimed that they would refer the documents either ‘very often’ or ‘often’ in their day to day practice, with a only a few GPs stating that they would refer to them only ‘occasionally’ but also reported that they would ‘definitely’ refer to them if asked to complete reports related to the AWI (Scotland) Act 2000. However, the purpose of this research is not to prove that Values Histories ‘work’ or are ‘good’ but to evaluate the overall process, from engaging with people with dementia and documenting their values to assessing whether the documents could make a difference to their care. Moreover, given that several studies indicate that professionals working in care settings appreciate background information, life story books and details of individuals’ likes and dislikes (Carlyle and Schofield, 2004; Godwin, 2002; Gödel, 2000), the positive responses from professionals are not totally surprising.

Professional responses were also very positive with regards to the possibility that Values Histories could empower people with dementia, with an average score of 8 out 10. However, as highlighted in previous chapters, some professionals would not go along with previously expressed values as documented in the Values Histories in certain situations. Can one therefore rationally argue that under such circumstances the individual with dementia is empowered by completing a Value History? This is further explored in the next chapter.

This chapter also highlighted some of the challenges faced by the researcher when engaging with participants with dementia to record their values. One of the main themes

to emerge was the influence which the researcher, or practitioner, could have on the content of the Values History. This theme emerged in previous chapters in relation to family members similarly having an influence on the content, which could be perceived as being out of harmony with the principles of a person centred approach (Morton, 1999; Kitwood, 1997).

It also touched on the implications for future practice should Values Histories be implemented. For the purpose of the research, the researcher had the luxury of spending time with the people with dementia and members of their families, taping the interviews, transcribing them, analysing them, writing the Value Histories, ensuring accuracy and correcting errors. This begs the question as to whether practitioners could feasibly spend this amount of time to go through the process of completing Values Histories in addition to their workload or whether it should be a specialised role? It is interesting that the vast majority of participants thought that the Values Histories contained the correct amount of information and abridged versions could lose some of the depth which they contained. These aspects are further explored in the final chapter.

Chapter Eleven

The Values History- an empowering approach for people with dementia?

11.1 Introduction

11.2 How do professionals engage with people with dementia to discuss and make plans for the future?

11.3 To what extent are people with dementia able to discuss the future?

11.4 Are people in the early stages of dementia able to discuss and record their values?

11.5 To what extent should past wishes and values be promoted when a person loses insight into their condition?

11.6 Are Values Histories a practical way to empower people with dementia as the illness progresses?

11.7 Practical implications of Values Histories

11.8 Summary

11.1 Introduction

This final chapter brings together the main aspects of the study from which to answer the research questions outlined in chapter three. Whereas the previous six chapters presented the research thematically and drew on relevant literature to compare and contrast the findings, this chapter focuses on some of the main research themes and how they relate to practice. It is noteworthy to mention that the main aim of the study was to evaluate whether Values Histories could be used to empower people with dementia, should their condition deteriorate and they are no longer able to represent their views. The intention of the study was not to 'prove' that Values Histories are effective, but to explore the issues around completing Values Histories with people with dementia and whether they could be one way to give people with dementia 'a voice'. This can all too often be lost amidst the opinions of well meaning relatives and professionals (Goldsmith, 1996). The

study is ‘original’, in that, it is the first study to broadly evaluate the issues around the impact of Values Histories specifically for people with dementia, looking at the implications from both the perspectives of themselves and of the professionals involved in working with people with dementia in both the early and latter stages of the illness. Moreover, as highlighted in the previous chapter, the researcher was able to reflect on his practice, in relation to the process of discussing the future with people with dementia and the process of completing Values Histories (Butler, 2003; Fullar, 1999; Schon, 1983).

As highlighted in chapter three, the concept of empowerment cannot be seen as a single entity, but is a process which begins at the individual level, with the person acquiring knowledge, skills and competencies to address their concerns, thus having a degree of ‘control over destiny’ (Fitzsimons and Fuller, 2001; Syme, 1988). Therefore to answer the main research question, which asked whether or not Values Histories can empower people with dementia, it was imperative to explore how people with dementia felt about discussing the future and the opportunities that they had to do so under current arrangements. This therefore is the main focus of the following section. Thereafter this chapter explores the feasibility of individuals with dementia recording their values and the extent to which professionals would take cognizance and promote past wishes and values when a person loses insight into their condition. It concludes by answering whether the Values History can empower individuals with dementia and the implications for practice.

11.2 How do professionals engage with people with dementia to discuss and make plans for the future?

Before one can begin to discuss the future with people with dementia it is generally recognised that sharing the diagnosis is the first step of empowerment (Wilkinson, 2001; Fearnley et al., 1997; Emmanuel and Kass, 1993). In the first instance this research clarified that the vast majority of professionals believe it is the person’s right to know their diagnosis, and only in exceptional circumstances should it not be shared with individuals. Clearly, this indicates a change in attitude regarding disclosure, unlike the early 1990s where professionals and families were reluctant to share with the individuals

(Fearney et al., 1997; Clafferty et al., 1997; Emmanuel and Kass, 1993). Recent literature, around the same time as this study, also picked up on this trend (Pinner and Bouman, 2003; Lindesay, 2002). The study also confirmed anecdotal evidence which suggests that medication for Alzheimer's disease is, at least in part, responsible for this change in trend (Wilkinson, 2001). Moreover, the study highlighted that psychiatrists and CPNs tend to be more proactive regarding disclosure than GPs, who 'wouldn't lie', but wait for the person to ask before volunteering information. Again other authors have suggested that many GPs tend to be reticent about sharing the diagnosis, preferring to normalise the person's experiences (Downs et al., 2001).

However, one of the main findings of the research was that there is still reluctance on the part of most professionals, including psychiatrists and CPNs, to actively discuss the prognosis of the illness with individuals and to encourage them to plan for the future. Clearly this indicates that, whilst there has been a change in attitude regarding disclosing the diagnosis, there is still an element of complacency and paternalism concerning the need to engage people with dementia to plan for the future. The research highlighted that many professionals 'did not think about it' or believed it to be 'kinder' not to suggest the possibility of a decline in their condition. This indicates that whilst many authors opine that one of the benefits of sharing the diagnosis is to allow individuals with dementia the opportunity to plan for the future, it is possibly more complex than they suggest (Wilkinson, 2001). For example, Wilkinson states that people with dementia are 'now having greater opportunities to plan and make decisions about financial management and welfare' (2001:322). However, even psychiatrists within this study, who as a group appeared to be the most open with people with dementia regarding discussing the prognosis of the illness, tended to wait for the individuals to ask questions about the future or gave information to relatives, leaving the decision up to them to decide the extent to which to share the information.

It was noteworthy that the vast majority of professionals gave information about continuing power of attorney to families, therefore passing on the responsibility to families to give information and/or persuade the individuals to accept power of attorney.

Moreover, few professionals asked the person with dementia who they would like to represent them in the future should their condition deteriorate, and often presumed that either the relatives accompanying them to appointments or their next of kin would represent them. This has major implications for the appointment of 'Welfare Attorneys' under the AWI (Scotland) Act, 2000. Whilst solicitors have an obligation to make sure that adults with incapacity are not signing under duress, the possibility must be considered that some people with dementia are passively going along with their relatives' wishes without having the opportunity to discuss in detail their values and wishes with someone impartial, especially regarding whom they feel could best represent them in the future.

Akin to this, chapter six highlighted that some people with dementia felt obliged to nominate a spouse or family member and not necessarily appoint the person who would best represent their wishes. The chapter also showed that some did not have a full understanding of the powers bestowed upon the Welfare Attorney. However, it is noteworthy that many professionals recognized that they would need to engage more with people with dementia in the early stages of dementia due to the introduction of the Act. This is an aspect which warrants further research as at the time of the study the concept of Welfare Attorney was in its infancy and had not been fully implemented in Scotland.

11.3 To what extent are people with dementia able discuss the future?

Although the research showed that most professions did not actively encourage individuals with dementia to discuss the future it should be noted that this is clearly the right approach for some individuals. Indeed, all participants with dementia described good relations with psychiatrists and CPNs and felt able to ask them questions, although to a lesser extent with their GPs. Moreover, during their interviews some participants actively avoided discussing the future and appeared awkward and evasive when the interviewer alluded to the possibility that their condition could deteriorate.

Knowing the diagnosis does not necessarily mean understanding it

One of the main themes to emerge was that knowing the diagnosis does not necessary mean understanding it or, in fact, wanting to understand it. Moreover, chapter five gave examples of how denial and lack of insight accounted for some participants feigning lack of awareness. It also clarified that lack of awareness is not an all or nothing phenomena, as indicated in recent literature (Clare, 2002; Bucks, 1999). This highlights the complexities of discussing the future with people with dementia and indicates that it is not simply a matter of giving information in one or two sessions, but in choosing the right moments to discuss the prognosis, giving the person time and going over the information several times in order for them to retain it.

Lack of information perpetuates lack of understanding

However, more importantly, this study showed that, for some, lack of information and opportunity to discuss the prognosis also perpetuates a lack of understanding. It was noteworthy that approximately half of the participants were only able to discuss their fears about the illness when prompted and thereafter many asked questions about the future and appeared to appreciate the opportunity. Possibly this is one area where this research differs from other dementia research. Whereas some researchers recommend when interviewing people with dementia that researchers should not mention the diagnosis unless the person does in the first instance (Pratt, 2002; Mason and Wilkinson, 2002), in this study the researcher specifically reminded participants that they had dementia and gave them the opportunity to discuss the future. This had to be handled sensitively, but clearly showed that some participants used the opportunity to seek information and discuss aspects of the future.

However, it should be noted that there was wide variation in the depth that participants wanted to discuss the prognosis and only a few wanted to make specific plans for the future. Even those who were able to discuss their prognosis in detail were reluctant to make specific plans, and interestingly none wanted to view nursing homes. However, despite this, it is important to acknowledge that the vast majority could discuss aspects of

care which would be important should they ever 'have' to go in to care, describing characteristics of care staff, physical environment and social factors without difficulty.

One aspect of the research which stood out was that whilst many participants could not imagine themselves receiving care because of the dementia, especially in relation to confusion and their safety, the vast majority were able to envisage needing support due to general old age or physical ailments and discuss the care they would prefer. Whilst valuable information was obtained regarding aspects of care which would be important to them one must consider whether obtaining this information under the guise of physical ailment is empowering or disempowering. This is further discussed in section 11.5.

The remainder of this chapter looks more specifically at the usefulness of Values Histories, beginning with the feasibility of people in the early stages of dementia discussing and recording their values.

11.4 Are people in the early stages of dementia able to discuss and record their Values?

The study showed that people in the early stages of dementia, particularly those with strong values, were able to articulate their values. It is noteworthy that the vast majority of individuals were consistent in the values which they expressed which indicated the importance they placed on them and that they were 'deep rooted' (Marquis and Jackson, 2000). However, the research also highlighted that many did not feel that they had strong values and needed encouragement from the interviewer to express them. Often by exploring other topics, such as reminiscing about family, friends and life situations, their values become apparent. From a practical point of view, this indicates two points which need to be considered.

Firstly it highlighted that, despite the person's level of awareness or willingness to discuss the illness and prognosis, they were able to discuss their values. However, this

has implications for empowering people with dementia. For example, whereas some were able to stress how important their values would be to them in the future if the illness progressed others, although able to articulate their current values, did not fully understand the extent to which they could be held to their past values. This is further discussed in section 11.5.

Secondly, from a practical point of view, the research showed that more time and assistance is needed for the interviewer to establish a rapport with the people with dementia. However, chapter nine reported the importance of how the interviewer could possibly 'prompt' as opposed to 'lead' the person. It also showed that prior information can both enhance the information, but on the other hand encourage the interviewer to obtain information which they considered appropriate rather than the person with dementia. Clearly, this indicates that the role of the person assisting the individual with dementia to complete a Value History should either be specialized or, at least, they should have specialized training before undertaking it, which should include having awareness of this possibility. A comparison could possibly be drawn with social workers assisting a person to complete a needs led assessment, having to be aware that they do not prompt clients due to their preconceived notions regarding available services. The principles of advocacy should also be considered. One of the differences between guardians and advocates is that guardians can take powers to decide what are the 'best interests' of the person - a paternalistic role, whereas advocates seek to learn what the person's wishes are and then facilitate them - an empowerment role (Burton, 1997).

The research also showed that family involvement can be useful to draw out the values of their relatives with dementia, although not paramount. It is noteworthy that some relatives felt they could complete a Values Histories with the person, albeit with professional guidance. Moreover, the study highlighted that families can assist to 'fill in gaps', especially in relation to background information and 'facts', which many participants with dementia forgot. However, the study also showed that, in a small minority of cases, some relatives might try to change or add in parts which they considered important. Clearly this shows that a balance between receiving information

from family and the person with dementia needs to be struck, in such a way as to enhance the Values History.

Honesty

One of the main underlying themes of the research was how honest people with dementia could be when recording information. Whilst in the majority of cases it appeared that participants were able to give an honest account of their values and aspects of their lives which were important to them, some felt unable to record specific information. The main areas highlighted within this research were: appointing a welfare attorney, describing relationships with family, relationships with professionals, and recording religious beliefs.

Section 11.2 highlighted how professionals often presume that an individual's next of kin or a relative accompanying them to an outpatient's appointment has their best interest and will act on their behalf. It also pointed out that often information is given to the 'carer' and thereafter it is left to them to persuade the person to legally appoint an attorney. However, a few participants within the study described marriage problems and problems within their families which indicated that they were not the best person to look after their welfare. Some also felt that a particular son or daughter knew them better than others in their family. In these instances the participants did not feel able to honestly record how they felt. Three main reasons were highlighted. Firstly, fear of offending the person, secondly, causing friction within their family and thirdly, not wanting others to know intimate details of their family or personal life.

Similarly, chapter 5 highlighted that one participant with dementia was unhappy with the care he received from his GP. However, he did not want to change to another practice, and did not want to criticize his GP in the Values History, and thus did not feel able to be honest. In this instance the interviewer wrote positive qualities that the person would look for in medical staff rather than personalize his statement.

With regards to religious beliefs, although some participants appreciated the opportunity to document their religious beliefs in the hope that future carers would help them maintain their values, one participant's spouse did not want it recorded in her husband's Values History that he was a Free Mason, fearing that future carers could pre-judge him. Although this was a relative, it does highlight that there could be circumstances where people with dementia might not be honest in case future care staff, or those with access to their Values Histories, pre-judge them. Indeed, this was not an area which was explored, but could create a dilemma for future carers should a person's Values History contain information which conflicted with their own convictions.

For example, should a person with dementia be encouraged to honestly record information, such as, a dislike for a certain race, religion or sexual persuasion, possibly requesting that certain groups of people are excluded from their future care? Furthermore, would professionals feel obliged to maintain values which were fundamentally opposed to their own? These were not areas covered in this study but certainly warrant further research.

Whilst this section shows that people in the early stages of dementia are able to record their values, the following section explores the usefulness of professionals knowing the values of people with dementia, particularly as the illness progresses.

11.5 To what extent should past wishes and values be promoted when a person loses insight into their condition?

To answer this question the research looked at five main areas, namely: appointing a proxy, religious and medical values, end of life decisions, perceptions of future risk and personal appearance. There was no doubt that in all areas, although to a lesser extent in perceptions of future risk, that the vast majority of staff reported they would find it very useful to know the person's past wishes and values and would promote them, especially in circumstances where the person appeared to have forgotten their values and needed reminding. For example, Marie's vignette showed that most professionals thought it was

morally right to remind her of her religious values and remove her from the Christmas festivities. Similarly, Sylvia's vignette showed that the majority would make more effort with her personal care based on her past wishes. It was also interesting to note that, even if they lost insight, most felt that the past wishes of people with dementia should be adhered to. Moreover, whilst there were mixed views regarding whether values changed throughout life, the vast majority did not feel that perceived changes in values or behaviour associated with dementia could be viewed similarly.

However, three key themes emerged where professionals would have difficulty maintaining past values, namely: where the person appeared agitated or distressed, where there was a conflict with their professional accountability and where the dementia could have an effect on others, particularly their families.

Agitation or distress

In instances where it was suggested that in order to maintain past values the person became agitated or upset, feelings were either less strong that values should be maintained or current happiness was considered more important. It was noteworthy that even participants who felt strongly that previous values should be upheld if the person lost insight into their condition, tended to feel that causing agitation was inappropriate. However, it was also noteworthy that many said they would still try other ways to maintain the person's previous values in ways so as not to cause distress. Clearly, this indicates that the majority would not simply ignore past values, but make a decision based upon the person's welfare at the time. This seems more in line with a person centred approach, whereby past values should be considered to paint a picture of the person, but their present feelings are paramount (Morton, 1999; Kitwood, 1997). This leads on to the second theme, which was professional accountability.

Professional accountability

As indicated in the last section, the majority of participants would professionally have difficulty sustaining previous values in instances that would cause the person with dementia distress or anxiety. Other areas where many felt that they had an ethical and professional responsibility were to ensure the person's health or safety.

For example, whilst participants felt that it was Marie's right to receive homeopathic treatment and would not criticize others for arranging this, they felt that if her health was in danger they would be obliged to prescribe conventional treatment, even if it was going against her previous values. Similarly, with regards to Sylvia's safety, whilst the majority stated that they would refer to the document and possibly 'try harder' or 'pull out all the stops' only a quarter felt that they would definitely go by her wishes. Indeed some even felt that this was the one area of the Values History which they would be unable to comply with. In such instances most felt that professionally they would need to 'weigh up the facts' and the decision should not be left up to one person but all those involved in her care. This is, in fact, the approach recommended by many writers regarding risk (Titterton, 2005; Prichard, 1999). However, it would appear that, at least, the person's views would be considered, even if eventually overruled. Clearly, this indicates that whilst it is appropriate for people with dementia to record their thoughts about future risk and safety, they should be made aware that there may be times that their wishes would be overruled.

Interestingly, one of the main reasons why some thought that it was difficult for people with dementia to plan for future risk was that the person would not know how they would feel in the future, as the dementia progressed. Some pointed out that even those with a high level of insight and awareness of the prognosis would not necessarily know how they might feel in the future. However, concerning end-of-life decisions most suggested that the individual's views should be adhered to. Indeed, one could argue that the person with dementia would similarly not know how they would feel in the future at the time of writing about end of life decisions. Professional participants were not asked specifically

why this was the case: however there were two possible reasons, both related to the effect of the person with dementia's condition on others.

Effect of dementia on others

Firstly, many felt that the person's views on risk and safety could have an effect on others, such as neighbours and friends, but particularly the individual's family, and their views should also be considered. This contrasts with the person's views on end of life decisions which only directly affected their own quality of life. Secondly, some felt that family members or carers could feel under pressure to keep the person at home longer than they were physically or emotionally able to manage. As highlighted in chapter 6, many professionals gave examples of such cases. Clearly this indicates that, whilst it is beneficial for people with dementia to record their views on future safety, they should be aware of the impact their illness could have on others. Indeed, this was the case with some participants with dementia. For example, whilst Sylvia expressed a strong desire to stay at home, she recognized that a time might come when she was not able to make decisions and left all decisions up to her son and daughter in law, and knew they would select an appropriate home for her. Conversely, it would appear that a personal statement, which did not take into consideration others, would be less likely to be adhered to.

Although the vast majority of staff stated they would refer to the Values History and try to maintain the person's values, it appeared that having a family member to advocate for the person on their behalf was the first choice for many professionals when difficult situations arose. It was interesting that when professionals were faced with dilemmas, as presented in the vignettes, the majority stated they would refer to the person's family for their opinion. Often, it was only after the vignettes were further developed to exclude family from their answers did they give their opinions.

For example, when faced with the dilemma of Marie becoming agitated when removed from Christmas celebrations, in accordance with her previous wishes, many reported that

they would be happier to let her participate if her family also agreed. Conversely, many stated that if she had a supportive family who wanted her values maintained they could be involved in her care, possibly distracting her or providing an alternative to the festivities. Similarly, although the majority felt that her wishes regarding homeopathy 'should be respected' many felt her family should arrange the homeopathic treatment. Clearly this indicates that having a family member to advocate on the person's behalf, would be the first option for many professionals. Certainly, it would appear that a well thought out Values History, with a family member to advocate on the person's behalf would be the most effective way to empower people with dementia.

Interestingly the one exception to this was regarding end-of-life decisions where the vast majority of staff stated that they would advocate for Marie's wishes, even if her wishes contrasted with the views of her family. Although most felt that decisions should ultimately be made jointly by the medical team and family, many suggested that the Values History could be used to remind the family of her wishes in an attempt to persuade her family to comply with her wishes. Certainly, one could argue that, even if her wishes were not specifically adhered to, they would be taken into consideration. Moreover, it indicated that good communication between the person with dementia and their family at the time of completing the Values Histories is imperative for them to succeed fully.

Pressure on Families

One of the main downsides of Values Histories, which was expressed by some professionals, was that some information could pressurize families to comply with the person's wishes, adding to their stress. In particular, it was suggested that the person's documented views on 'independence and safety' and possibly 'never wanting to go into a nursing home' could cause guilt to their family if they were unable to maintain the person at home. Clearly this indicates that families need to be involved in such circumstances where the person's values could have an impact on their life. Interestingly some professionals suggested that there should be an adjunct or separate Values History for the

carer. There is no simple answer as to whether this is necessary. On the one hand it could be argued that carers are entitled to a separate Community Care Assessment to look at their needs and therefore should be entitled to a separate Values History. However, on the other hand the purpose of the Value History is to give the person with dementia a 'voice' when they are no longer able to articulate their views at a time when it is presumed that carers will still, in fact, have their voice.

Moreover, it is noteworthy to point out that the driving force behind this research was to explore practical ways to empower people with dementia. At the embryonic stage of the research the author had a tentative idea of enabling people with dementia to record their views about the future, possibly similar to advanced directives. It was only after reviewing the literature that he explored the possibility of the Values History being one such tool. The final research question brings together the main issues of Values Histories in relation to empowerment.

11.6 Are Values Histories a practical way to empower people with dementia as the illness progresses?

As highlighted in chapter 10, the vast majority of professionals interviewed expressed positive views that Values Histories could be used to empower people with dementia. Indeed, based on their questionnaires one could argue that Values Histories are, in fact, a very effective way to empower people with dementia when they are no longer able to articulate their values and wishes. However, chapter three pointed out that empowerment is not a single entity, but a 'process' leading to a series of 'outcomes' (Mason and Wilkinson, 2002; Fitzsimmons and Fuller, 2001) and the following points should be considered.

Increased understating of their condition

Firstly individuals should have 'an increased understanding and awareness of their own interests', and their 'position in relation to others' (Fitzsimmons and Fuller, 2001:486). Moreover, chapter three pointed out that receiving an early diagnosis and subsequent

support was pivotal in preserving the person's right to 'self determination' (Mason and Wilkinson, 2002: 61). However, this research showed that whilst all participants were aware of their diagnosis, only a few had a very clear understating of the prognosis and the impact it could have on their lives and family. Moreover, it highlighted that, for some, being aware of the diagnosis does not necessarily mean understanding it. Clearly, this indicates that those with a good understanding of the prognosis were making 'informed choices' and therefore the process of completing a Values History could be considered more empowering than for those with limited understanding. However, the second aspect of empowerment is possibly the one which promotes more discussion.

Acquisition of skills

The second aspect which Fitzsimmons and Fuller suggest that individuals require to be empowered is:

"the acquisition of the skills and competencies needed to achieve desired outcomes (e.g., interpersonal, practical, political, personal development skill)" (2001:486).

Acquiring 'the skills' infers having an accurate knowledge of the condition, prognosis and care options and being able to make informed decisions (Winner, 1996). Moreover, for the purpose of this research it infers having an understanding and acquiring the skills to complete a Values History. In this respect two main points emerged.

Firstly, section 11.2 highlighted that at least half the participants within the study were able to discuss the prognosis and future in more depth when prompted by the interviewer and given time to ask questions. Therefore this showed that, to varying degrees, those participants were able 'acquire skills'. Clearly, for these individuals the process could be viewed as empowering as not only did they acquire skills but they also made choices based on their increased knowledge and were aware that their Values Histories could influence their future, therefore having a measure of control over their destiny (Fitzsimmons and Fuller, 2001; Marmot et al., 1997; Jackson, 1993).

Secondly, although the vast majority of participants understood the purpose of Values Histories and were able to articulate their values and aspects of their lives which were important to them, many did not relate it specifically to dementia, having only partial understanding of the condition. For example, the study showed that, for many, having insight was not an all or nothing phenomena, as awareness, understanding of the illness and the extent to which the participants felt able to discuss the condition fluctuated. Although these participants were able to acquire some skills they did not fully comprehend the possible outcome of the condition. However, these individuals were able to express characteristics of paid carers and imagine future care related to general old age and infirmity rather than confusion and cognitive impairment. They were also able to express their values without difficulty. Whilst on one level it could be argued that the information in their Values Histories could be empowering should they suffer any illness (one of which could include dementia), it could also be argued that they did not make informed 'judgments to advance their own self interest', specifically for dementia (Winner, 1996:71). Certainly, if one views Values Histories similarly to advanced directives and statements, then for them to be truly empowering and thus any 'significance' be attached to them, the person must 'understand the implications and envisaged the type of situation which have subsequently arisen' (BMA, 2003:4.1), which some participants did not fully comprehend. This is one of the main areas where there does not appear to be a definitive right or wrong answer as to whether Values Histories are truly empowering.

For example, Howard, like all the participants, was aware of his diagnosis and was given the opportunity to discuss the prognosis. However, he declined, possibly through denial that his condition would deteriorate or because he 'didn't see the point in looking ahead'. This in itself could be seen as empowering as he was given the opportunity to discuss the prognosis and exercised his right not to discuss the future (Lovestone, 1997). He was very independent and could not envisage a time that he would not be able to communicate his values or be in control of his life. He also found it hard to imagine the potential problems he could experience related to dementia, in particular, those related to

his safety. However, he was happy to complete the Values History and realised it could be generally useful for professionals to have a record of his values, more as an 'aide memoir' than to represent his views should he lose capacity. Moreover, unlike some others, he was unable to state how important he perceived his values would be to him should he deteriorate in the future.

This example highlights the complexities of Values History in relation to empowering people with dementia. If one simply views Values Histories as a way of giving background information to enable any professional involved in their care to know the person better, then possibly it could be viewed in a similar way to a life story book or biographical account of their lives (Godwin, 2002; Benson, 2000; Costello, 1996). Moreover, it could be viewed as 'person centred' as it would acknowledge that their present identity is a function of their past, but not in such a way that it 'diminishes their present by accentuating their past' (Morton, 1999:14). Moreover, a strong case could be made, based on Kitwood's (1995) model, that by prizing each individual's unique life story and recording their past values and characteristics, the person's self concept will be enhanced and the care they receive from others will be more 'personal' as the illness progresses. However, if one places more significance on the person's statement, thus an empowering approach based on accurate knowledge, (Fitzsimmons and Fuller, 2001; Marmot et al., 1997; Jackson, 1993), the inference is that the person should have an awareness of the condition and the implications of their values statement for the future. Indeed, if the person expresses a desire to have their values maintained as the illness progresses then their Values History could be viewed similarly to advance statements and directives. Possibly one solution is for the Values History to state at the outset the person's level of awareness and the circumstances to which they would like their values maintained. This leads to the third component of empowerment, which relates to the 'outcome' for the individual.

Evidence of positive outcomes

According to Fitzsimmons and Fuller there will be:

“evidence of positive outcomes for the individual such as the acquisition of competencies, changes in circumstances or the achievement of goal” (2001:486).

Again ‘changes in circumstances or achievement of goals’ can only be attained if people with dementia are aware of the future implications of the illness and the purpose of completing a Values History. The ultimate ‘goal’ for the person would be that their values are considered in any decisions made about their care, and possibly maintained should that be their wish. However, unlike advanced directives, which give specific instructions regarding specific treatments, the purpose of the Value History is to direct professionals to take into consideration individuals’ values, which are deep rooted to them when making any decisions, addressing their goals, hopes and fears (Dickens, 1993; Keilstein and Sass, 1993).

This research clearly showed that the vast majority of professionals would take the person’s values into consideration. Comments such as ‘definitely’, ‘absolutely’, ‘it would make you think about the person’ or ‘take cognisance’, were expressed by most participants and, as highlighted in chapter 10, the vast majority believed that Values Histories could empower people with dementia. To varying degrees, professionals stated they would try to maintain values, based on the vignettes. Two typical comments included:

“I think it would force you to think about the person, even if you went against her wishes.” (SW5).

“Yes you may have to overrule her, but I see it as a positive step. It’s not just ‘not listening’ to her wishes, it’s overruling them” (Psych1).

However, is this truly empowering, if the psychiatrist would ‘overrule’ an individual’s wishes and the social worker might ‘go against’ the person’s wishes? It is interesting to

draw a parallel with the guidelines for advance statements, as outlined in the Mental Health Care and Treatment (Scotland) Act, 2003. The guidelines state that a Tribunal or any doctor treating a patient 'must send the Commission a written record of the ways they have worked out with these instructions and the reasons why, if the advanced statement is not followed' (Scottish Executive, 2004f:3). This indicates that rather than passively ignoring the patient's views they have to refer to the person's wishes, and only if it is in the person's best interests, based on their professional opinion, should their wishes be overruled. Similarly, the above two comments indicate that Values Histories, although not legal documents, would make them take cognisance of the individual's wishes and actively overrule rather than passively ignore or not know what the person's wishes would have been.

It is noteworthy that, although the concept of empowerment indicates that an individual's views should be taken into consideration and listened to, it does not necessarily mean that they have to be followed (Wilkinson, 2001; Fitzsimmons and Fuller, 2001). For example, Wilkinson (2001) argues that although an empowering system would allow people with cognitive impairment maximum involvement in decisions about their future, decision making should be seen as a joint or collaborative process. Indeed, Wilkinson argues that, in the context of dementia, to rely solely on the views of a cognitively impaired person in certain situations may actually disempower them. Clearly this indicates that the Values History can only be empowering if people with dementia are aware at the outset that, although their values may influence future decisions, there may be times when professionals will have to make decisions that are contrary to their values.

Moreover, one could argue that it could be disempowering to the person at the time of their illness should they be bound by previous values and, in effect, indicate that they become a 'non person' (Berghmans, 1997; Dresser, 1995; Nagal, 1979). For example would it be disempowering to cause Sylvia a degree of distress and upset her to maintain her previously held values, even if she expressed her wishes when she had insight? Interestingly if one adopts the same principles as those set out by BMA for advanced

directives, then professionals are not only duty bound to consider past wishes, as documented in advanced directives, but attempt to communicate with the person at the time to ascertain their views. Although the guidelines do not specifically mention those with cognitive impairment, they indicate that all aspects of communication should be explored to find out the person's current feelings before any advanced directives take effect. Whilst the guidelines mention 'competency', a person centered approach indicates that through observation of body language, non verbal communication and their feelings at the time should also be considered. In this regard Value Histories could also be viewed as 'person centered' as the vast majority of professionals indicated that at times when the person appeared distressed or agitated they would put their current happiness first, even if their decision went against their previously recorded values. However the research showed that there were varying degrees regarding the extent to which professionals felt past or present wishes should be paramount, with many believing it would be right in certain circumstance, but wrong in others to adhere to past wishes. For example, some thought it would be right to cause Sylvia a degree of agitation to improve her hygiene, according to her previously held values, but wrong to let her take risks to remain at home, despite her previous value of independence. However, this could possibly be viewed as strength of Values Histories, rather than a weakness. Indeed, it could be argued that no one really knows how it feels to be in the latter stages of dementia (Berghmans, 1997; Nagal, 1979). Moreover, the research showed that Values Histories could get the professionals 'thinking' about what the person *wanted at the time*, whilst looking at their current situation, therefore bringing their *present feelings* and past 'voice' into the debate.

The research questions also asked whether Values Histories are a 'practical' way to empower people with dementia. Chapter 10 highlighted some of the challenges which the researcher experienced while assisting people with dementia to complete Values Histories. This last section will therefore summarize these in relation to practice.

11.7 Practical implications of Values Histories

At several stages within this study, the importance of the person assisting an individual to complete their Values History was highlighted as pivotal in its success or failure. For the purpose of the study, the researcher had the luxury of spending time with individuals with dementia, taping the interviews and analyzing their responses. Many participants had a degree of expressive dysphasia and needed prompts and encouragement to communicate their values and preferences. Indeed many were aware that they needed 'time' to gather their thought to express themselves. However, many professionals, whilst indicating they would have the skills and knowledge to be able to assist people with dementia to complete Values Histories, stated that 'time' would be their main barrier.

Kane and Degenholtz (1997) suggested that a values assessment could be added as an adjunct to a social work assessment for cognitively intact older people in the USA. This study clearly shows that this is not the right approach for people with dementia who need time, not only to discuss and document their values but to discuss the diagnosis, prognosis and future care. Notably Gibson (1990) suggests up to five interviews to complete a Values History along with an advance directive for individuals with terminal illness. This study indicates that Gibson's recommendations are also realistic for people with dementia. Moreover, it also indicates that professionals involved in the person's either require to set aside time specifically to assist the person to complete the Values History or it should be viewed as a specialized role for someone specially trained to counsel people with dementia, such as an advocacy worker. It was also interesting to note that the vast majority of professionals preferred Values Histories written in the first person and viewed direct quotes positively, believing that it made the documents more 'personal'. However, it is noteworthy that this emerged by chance, as the interviews were taped and transcribed primarily for research purposes. From a practical point of view it is highly unlikely that professionals could tape and transcribe interviews as an adjunct to their practice. This further backs up the case for a specialized worker to dedicate time to Values Histories.

Concerning family involvement, the research showed that in most cases relatives' knowledge of the person was particularly useful, especially to prompt the person and

remind them of factual elements. However, the study highlighted that in some cases family relations were poor and some could try to influence the information. Again this highlights the role of the one assisting the individual to spend time with the person to ascertain the degree of family involvement that they would like. It is important to acknowledge that many relatives felt they could assist the person to complete a Values History with professional guidance. Again flexibility seems to be the key and as long as this is the person's choice and not due to obligation.

Lastly, chapter 10 highlighted that one of the benefits of practitioners carrying out research is to be able to reflect on their practice. Despite over ten years experience working with people in the early stages of dementia, the researcher was aware when transcribing the tapes that some people with dementia wanted to explore issues in relation to their illness in more depth, but he had not picked up on their feelings at the time. Moreover, he was aware that at times he led the person rather than let them 'set the agenda', which is one of the main principles of person centered care (Morton, 1999; Kitwood, 1995). Further research is required to ascertain if the professional background of the interviewer could influence the content of the Values History. However, the researcher was also aware that as he conducted more interviews his communication skills improved and he was able to introduce the possibility of deterioration more tactfully and sensitively, and draw out their values and thoughts concerning the future. Again this reiterates the case for a specialized role to assist people with dementia to complete Values Histories. Furthermore, it indicates that professionals cannot be too complacent regarding their practice. Indeed, section 11.2 highlighted that many professionals within the study were aware that they could do more to engage people with dementia to discuss the future, partly due to fear of upsetting the person, but perhaps an element of complacency.

11.8 Summary

This study showed that Values History can indeed be an effective way of empowering people with dementia, as was the case for approximately half of the participants. Indeed,

this is especially true if the individual has an awareness of their condition, is able to discuss the issues related to their future, understands the purpose of the Values History, considers their family's feelings and involves them in the process where appropriate. The individuals should also be aware that although their values will be 'considered' when decisions are made about their care, at times, they may have to be compromised if family or professionals feel it is in their best interests. Moreover, the study highlighted that having a supportive family who refer to the document and advocate on the person's behalf appears to be the most empowering approach.

However, the research highlighted that there could be instances where Values Histories could be disempowering and highlighted three main areas. Firstly where individuals never fully understood their prognosis, secondly where they could not record honestly how they felt, and thirdly where they felt under pressure from family or professionals to omit or include information.

With regards to individuals not fully understanding their prognosis, it could be considered cruel or disempowering to try to force understanding upon the person merely for them to state their views about the future. Indeed, these participants were still able to discuss and document their Values Histories. Possibly, one way around this is to record that this is how the person feels at the time and record their level of understanding to allow professionals scope to decide how relevant. It should also be noted that Values Histories are not advanced directives, but were initially developed to build a picture of the person, thus allowing their values to be taken into consideration at a time when they are no longer able to express them. Therefore, if one considers the person centered approach of empowerment, which is not related to cognitive awareness or understanding when the person completes it, then this would encompass all people with dementia and not just those with an understanding. Moreover, if one adopts the person centered approach which considers the information is to build a picture of the person's past but not at the expense of their current feelings, again this could incorporate all people with dementia, as long as they were aware of this at the time of writing.

Concerning honesty and, in particular, where individuals are reluctant to record poor family relationships, there is clearly a case for advocacy or possibly for this information to be recorded elsewhere, in medical or social work case notes. Furthermore, the research clearly showed that professionals tend not to discuss with individuals the implications of appointing a welfare attorney or who they would like to represent them should they deteriorate. This is one area where more effort is needed on the part of professionals. Unfortunately this study was carried out whilst the AWI (Scotland) Act (2000) was in its infancy. It was noteworthy that some professionals alluded to the possibility that their practice would have to change as a result of the Act. Clearly this is an area that requires further research. Moreover, it is interesting that Gordon (2004) suggests a merger of the Act with the Mental Health (Care and Treatment) (Scotland) Act (2003) in the future. Certainly the principles of advocacy, named person and advanced statements could be considered for people with dementia or at least warrants further research.

Finally, as indicated in chapter four, the preferred method of research would have been to conduct a longitudinal study beginning with participants with dementia completing Values Histories and thereafter interviewing professionals involved in their care throughout their 'journey of dementia'. However, time would not have allowed for this to take place, so vignettes were used to elicit the views of professions. Indeed the vast majority of professionals were very positive about the information in the Values Histories, with many stating they would strive to maintain individuals' recorded values and even those who felt values were inclined to change over time claimed they would refer to the documents and 'think more' about the person. However, the only way this can be truly evaluated is for a longitudinal study to take place from the onset of dementia till their final days.

Whilst it was initially envisaged that a longitudinal study may have taken up to ten years to complete, possibly this would not have been the case and could have been undertaken in less time. Of the fourteen people with dementia interviewed for the research, a few are

still living at home, with support from professionals and family, some are now living in nursing and residential care, and many have died.

Sadly, both Marie and Sylvia, whose Values Histories were the basis of the vignettes throughout this study, died. Marie died in a nursing home approximately two years after her interview. Marie's wish was to be cared for by her spiritual 'brothers' and 'sisters' but knew this would not be possible as the only nursing homes for Jehovah's Witnesses were in England. However, her family, after careful consideration, chose a nursing home which was walking distance from her 'Kingdom Hall', where her 'brothers and sisters' could visit her on a regular basis. Sylvia who stated in her Value History that her 'goal' was to 'stay at home 'til' the Good Lord took her' died peacefully in her sleep, at home, having enjoyed a game of bowls the previous day. Both her son and minister referred to and quoted her Values History at her funeral.

References

- Ackroyd, S. and Hughs, J. A.** (1983) 'Data collection in context', in H. Kemshall and J. Prichard (eds) *Good Practice in Risk Assessment and Risk Management*, London: Longman.
- Adams, T.** (1996) 'Kitwood's approach to dementia and dementia care: a critical but appreciative view', *Journal of Advanced Nursing* 23: 948-953.
- Ahronheim, J. C., Mulvihill, M., Sieger, C., Park, P. and Fries, B. E.** (2001) 'State practice variations in the use of tube feeding for nursing home residents with severe cognitive impairment', *Journal of American Geriatric Society* 49: 148-152.
- Ahujn, A. and Williams, D. D. R.** (2000) 'Disclosing the diagnosis of dementia', *British Journal of Psychiatry* 177: 565.
- Alzheimer's Scotland- Action on Dementia** (2000) 'Advocacy and Dementia: An Executive Summary', Edinburgh: Alzheimer's Scotland- Action on Dementia.
- Alzheimer's Scotland- Action on Dementia** (2003) 'Postcode Prescribing Still Persists', Edinburgh: Alzheimer's Scotland- Action on Dementia. Available on: <http://www.alzscot.org/pages/policy/ppp.htm> [cited 12 Jan 05]
- Alzheimer's Scotland- Action on Dementia** (2005a) 'What is dementia?', Edinburgh: Alzheimer's Scotland- Action on Dementia. Available from: <http://www.alzscot.org/pages/info/whatis.htm> [cited 20 Nov 05]
- Alzheimer's Scotland- Action on Dementia** (2005b) 'Growing number of people with dementia', Edinburgh: Alzheimer's Scotland- Action on Dementia. Available from: <http://www.alzscot.org/pages/media/growingnumber.htm> [cited 21 Nov 05]
- Alzheimer's Scotland- Action on Dementia** (2005c) 'Signposts to Support: Understanding the special needs of carers of people with dementia', Edinburgh: Alzheimer's Scotland- Action on Dementia. Available from: <http://www.alzscot.org/pages/policy/signposts.htm> [cited 21 Nov 05]
- Alzheimer's Scotland- Action on Dementia** (2005d) 'Alzheimer's Scotland's views on the NICE Appraisal consultation document on Donepezil, Rivastigmine, Galantamine and Memantine for the treatment of Alzheimer's disease', Edinburgh: Alzheimer's Scotland- Action on Dementia. Available from: www.alzscot.org/pages/policy/nice0305.htm [cited 20 Nov 05]
- Alzheimer's Society** (2004) 'News and Campaigns: New rights a step closer', Vol. 17 Dec 2004: London: Alzheimer's Society. Available from: http://www.alzheimers.org.uk/News_and_campaigns/News/041217mentalcapacityvote.htm [cited 20 Nov 05]
- Alzheimer's Society** (2005a) 'Making decisions alliance - the campaign for mental capacity legislation', London: Alzheimer's Society. Available on: http://www.alzheimers.org.uk/News_and_campaigns/Campaigning/mentalcapacity.htm [cited 5 Jan 06]
- Alzheimer's Society** (2005b) 'Press Release: NICE declares drugs for dementia too expensive to be prescribed on NHS', London: Alzheimer's Society. Available from: <http://www.alzheimers.org.uk/NewsandCampaigns/News/050228Nice.htm> [cited 27 Nov 05]

- Amador, X. F., Strauss, D. H., Yale, S. A., Gorman, J. M. and Endicott, J.** (1993) 'Assessment of insight in psychosis', *American Journal of Psychiatry* 150: 873-879.
- Appelbaum, P., S and Grisso, T.** (1995) 'Comparison of standards for assessing patients' capacities to consent to treatment', *New England Journal of Medicine* 319: 1635-1638.
- Archibald, C.** (1996) 'Home and away: people with dementia and their carers', in K. Stalker (ed) *Developments in Short - term Care*, London: Jessica Kingsley Publishers.
- Arksey, H., Jackson, K., Croucher, K., Weatherly, H., Golder, S., Hare, P., Newbronner, E. and Baldwin, S.** (2004) *Review of respite services and short- term breaks for carers for people with dementia*, NHS SDO, London.
- Ashley, P. and Schofield, J.** (2002) 'How to plan your own future dementia care', *Journal of Dementia Care* 10(2): 20-22.
- Atkinson, J.** 2001 *Review of literature related to mental health legislation*, Edinburgh: The Scottish Executive Central Research Unit.
- Atkinson, J., Garner, H., Patrick, H. and Stuart, S.** (2003) 'Issues in the development of advanced directives in mental health care', *Journal of Mental Health* 12(5): 463-474.
- Bachman, D., Wagner, M., DePalma, M., Spangenberg, K., Hendrix, S. and Perlman, D.** (2000) 'Caregivers attitudes about patients told they have Alzheimer's disease after truth disclosure', *Journal of Clinical Geropsychology* 6(4): 309- 313.
- Bahro, M., Silber, E. and Sunderland, T.** (1995) 'How do patients with Alzheimer's disease cope with their illness? A clinical experience report', *Journal of American Geriatrics Society* 43(1): 41-46.
- Bailey, D., Kavanagh, A. and Sumbly, D.** (1998) 'Valuing the Person: Getting to know their life', *Journal of Dementia Care* 6(5): 26-27.
- Baker, C., Edwards, P. and Packer, T.** (2003) 'Assessing needs and providing person-centred support', *Journal of Dementia Care* 11(1): 16-17.
- Bamford, C. and Bruce, E.** (2001) 'Older people with dementia want to maximise their autonomy', *Care Plan* 7(3): 29-30.
- Barlett, H. and Martin, W.** (2002) 'Ethical issues in dementia care research', in H. Wilkinson (ed) *The Perspectives of People with Dementia: Research Methods and Motivations*, London: Jessica Kingsley Publishers Ltd.
- Bartlett, R.** (2000) 'Dementia as a disability: can we learn from disability studies and theory?' *Journal of Dementia Care* 8(5): 33-35.
- Barnes, M.** (1997) *Care, communities and citizens*, London: Longman.
- Beese, R.** (2000) 'Memory clinics: a potential 'one stop shop' for services', *Journal of Dementia Care* 8(2): 33-35.
- Bender, M.** (2003) *Explorations in dementia*, London: Jessica Kingsley Publishers Ltd.
- Benson, S.** (2000) *Person-centred care: creative approaches to individualised care for people with dementia*, London: Hawker Publications.
- Berghmans, R.** (1997) 'Ethical hazards of the substituted judgement test in decision making concerning the end of life of dementia patients', *International Journal of Geriatric Psychiatry* 12(3): 283-287.
- Berry, G., Zarit, S. and Rabatin, V.** (1991) 'Caregiver activity on respite and non respite days: a comparison of two services approaches', *Gerontologist* 31(6): 830- 835.

- British Medical Association (2003)** *Advance statements about medical treatment - code of practice: Report of the British Medical Association, April 1995*, London: The British Medical Association. Available on <http://www.bma.org.uk/ap.nsf/Content/codeofpractice> [cited 10 July 2005]
- British Medical Association (2003b)** *Working with carers: Guidelines for good practice*, London: The British Medical Association.
- BMA/RC/RCN (2001)** *Decisions related to cardiopulmonary resuscitation: A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing*, London: The British Medical Association.
- British National Formulary (BNF) (1997)**, London: British Medical Association and Royal Pharmaceutical Association.
- Bond, J., Corner, L., Lilley, A. and Ellwood, C. (2002)** 'Medicalization of insight and caregivers' responses to risk in dementia', *Dementia* 1(3): 313-328.
- Booth, M. G., Doherty, P., Fairgrieve, R. and Kinsella, J. (2004)** 'Relatives' knowledge of decision making in intensive care', *Journal of Medical Ethics* 30: 459-461.
- Brandon, D. (1995)** *'Advocacy: Power to people with disabilities'*, Birmingham: Venture Press.
- Bucks, R. (1998)** 'Insight in Dementia', *Signpost* 3(1): 20-23.
- Bullock, R. (2002)** *Building a modern dementia service*, Middlesex: Altman Publishing.
- Burns, A., Russell, E. and Page, S. (1999)** 'New drugs for Alzheimer's disease', *British Journal of Psychiatry* 174: 476-479.
- Burton, A. (1997)** 'Dementia: A case for advocacy?', in H. Susan (ed) *Dementia: Challenges and New Directions*, London: Jessica Kingsley Publishers.
- Butler, J. (2003)** 'Action Research: An introduction to the approach and its application within mental health practice learning and development', *Mental Health Training Unit*. Available at: <http://www.mhtu.co.uk/Journal%202003%20Introduction%20to%20Action%20Research.pdf> [cited 5 Feb 2004]
- Butler, R. N. (1987)** 'Ageism', in G. Maddox (ed) *Encyclopaedia of Ageing*, New York: Springer.
- Buxbaum, L. J., Ferraro, M. K., Veramonti, T., Farne, A., Whyte, J., Ladavas, E., Frassinetti, F. and Coslett, H. B. (2004)** 'Hemispatial neglect: Subtypes, neuroanatomy, and disability', *Neurology* 62: 749-756.
- Cannon-Spoor, H. E., Levy, J. A., Zubenko, G. S., Zubenko, W. W., Cohen, R. M., Mirza, N., Putman, K. and Sunderland, T. (2005)** 'Effects of Previous Major Depressive Illness on Cognition in Alzheimer's Disease Patients', *American Journal of Geriatric Psychiatry* 13: 312-318.
- Carlyle, R. and Schofield, J. (2004)** 'A quiet revolution', *Saga March*: 127-129.
- Caron, C. D., Griffith, J. and Arcand, M. (2005)** 'End-of-life decision making in dementia: the perspective of family caregivers', *Dementia* 4(1): 113-136.
- Carson, D. (1996)** 'Risking legal repercussions', in H. Kemshall and J. Pritchard (eds) *Good Practice in Risk Assessment and Risk Management*, London: Jessica Kingsley Publishers.

- Cattel, C., Gambassi, G., Sgadari, A., Zuccala, G., Carbonin, P. and Bernabei, R. (2000)** 'Correlates of delayed referral for the diagnosis of dementia in an outpatient population', *The Journals of Gerontology* 55A(2): M98-102.
- Chapman, A., Gilmour, D. and McIntosh, I. (2001)** *Dementia Care: A professional handbook*, London: Age Concern England.
- Chaston, D., Pollard, N. and Jubb, D. (2004)** 'Young onset dementia: a case for real empowerment', *Journal of Dementia Care* 12(6): 24-26.
- Cheetham, J., Fuller, R., McIvor, G. and Petch, A. (1992)** *Evaluating social work effectiveness*, Buckingham: Open University Press.
- Chertkow, H., Bergman, H., Schipper, H. M., Gauthier, S., Bouchard, R., Fontaine, S. and Clarfield, A. M. (2001)** 'Assessment of suspected dementia', *Canadian Journal of Neurological Sciences* 28(1, Feb): S28-41.
- Cheston, R. and Bender, M. (1999)** *Understanding dementia: The man with the worried eyes*, 2nd Edition, London: Jessica Kingsley Publications.
- Cheston, R., Bender, M. and Byatt, S. (2000)** 'Involving people who have dementia in the evaluation of services: A review', *Journal of Mental Health* 9(5): 471-479.
- Clafferty, R. A., Brown, K. W., and McCabe, E. (1998)** 'Under half of all psychiatrists tell patients their diagnosis of Alzheimer's disease', *British Medical Journal* (317): 603.
- Clare, L. (2002)** 'Unawareness' in early-stage dementia: symptom of disease, or meaningful psychological response?', *Journal of Dementia care* 10(4): 31-35.
- Clarke, A. M. (1998)** 'The qualitative- quantitative debate: moving from positivism and confrontation to post positivism and confrontation to post positivism and reconciliation', *Journal of Advanced Nursing* 27:1242-1249.
- Clarke, C. L. and Heyman, B. (1998)** 'Risk management for people with dementia', in B. Heyman (ed) *Risk, Health and Health Care: A Qualitative Approach*, London: Arnold.
- Clarke, C. L. and Keady, J. (2002)** 'Getting down to brass tacks: a discussion of data collection with people with dementia', in H. Wilkinson (ed) *The Perspectives of People with Dementia: Research Methods and Motivations*, London: Jessica Kingsley Publishers Ltd.
- Cohen-Mansfield, J., Libin, A. and Lipson, S. (2003)** 'Differences in Presenting advance directives in the chart, in the minimum data set, and through staff's perceptions', *The Gerontologist* 43(3): 302-308.
- Coleman, P. G. (1996)** 'Identity management in later life', in R. T. Woods (ed) *Handbook of the Clinical Psychology of Ageing*, Chichester: Wiley.
- Collins, K., Lightbody, P. and Gilhooly, M. (1999)** 'Living wills: A survey of the attitudes of General Practitioners in Scotland', *British Journal of General Practice* 49 (445): 641-642.
- Copp, L. A. (1988)** 'The nurse as advocate for vulnerable persons', *Journal of Advanced Nursing* 11(3): 255-263.
- Correa, D. D., Graves, R. E. and Costa, L. (1996)** 'Awareness of memory deficit in Alzheimer's disease patients and memory-impaired older adults', *Aging Neuropsychology Cognition* 3: 215-228.
- Corey-Bloom, J., Anand, R. and Veach, J. (1998)** 'A randomised trial evaluating the efficacy and safety of ENA 713 (rivastigmine tartrate), a new acetylcholinesterase inhibitor, in patients with mild to moderately severe

- Alzheimer's disease, *International Journal of Geriatric Psychopharmacology* (1): 55-65.
- Costello, J. (1996) 'Hiding in the depths of distress', *Journal of Dementia Care* 4(5): 24-25.
- Cotrell, V. and Schulz, R. (1993) 'The perspective of the patient with Alzheimer's disease: a neglected dimension of dementia research', *Gerontologist* 33(2): 205-211.
- Courtney, C., Farrell, D., Gray, R., Hills, R., Lynch, L., Sellwood, E., Edwards, S., Hardyman, W., Raftery, J., Crome, P., Lendon, C., Shaw, H., Bentham, P. and AD2000 Collaborative Group (2004) 'Long-term Donepezil treatment in 565 patients with Alzheimer's disease (AD2000): randomised double-blind trial', *Lancet* 363: 2105-2115.
- Cox, S. (1997) 'Entering the world of dementia', *Care Plan* 3(3): 15-18.
- Cox, S. and Anderson, I. (1999) 'Creating a value framework with the person at its centre', *Journal of Dementia Care* 7(6): 14-15.
- Cutcliffe, J. and Milton, J. (1996) 'Comment: In defence of telling lies to cognitively impaired elderly patients', *International Journal of Geriatric Psychiatry* 11(12): 1117-1118.
- Dautzenberg, P. L., van Marum, R. J., van Der Hammen, R. and Paling, H. (2003) 'Patients and families desire a patient to be told the diagnosis of dementia-a survey by questionnaire of a Dutch memory clinic', *International Journal of Geriatric Psychiatry* 18(9): 777-779.
- David, A. S. (1990) 'Insight and psychosis', *British Journal of Psychiatry* 156: 798-808.
- Davidson, S., Mason, A., Wasoff, F., Wilkinson, H. and Drinkwater, H. (2004) *Review of the code of practice for part five of the Adults with Incapacity (Scotland) Act 2000 and related issues: Analysis of written submissions to consultation*, Edinburgh: Scottish Executive: Social Research.
- Davis, K. L., Thal, L. J., Gamzu, E. R., Davis, C. S., Woolson, R. F., Gracon, S. I., Drachman, D. A., Schneider, L. S., Whitehouse, P. J., Hoover, T. M., et al. (1992) 'A double-blind placebo-controlled multicenter study of Tacrine for Alzheimer's disease', *New England Journal of Medicine* 327(18): 1253-1259.
- Dening, T. and Lawton, C. (1998) 'Doctors want to offer more than sympathy', *BMJ* 317(Oct): 945.
- Denzin, K. and Lincoln, Y. (Eds.) (1998) *Strategies of Qualitative Inquiry*, London: SAGE Publications.
- Department of Health (2001) *National Service Framework for Older People*, London: Department of Health.
- Derouesné, C., Thibault, S., Lagha-Pierucci, S., Baudouin-Madec, V., Ancrì, D. and Lacomblez, L. (1999) 'Decreased awareness of cognitive deficits in patients with mild dementia of the Alzheimer's type', *International Journal of Geriatric Psychiatry* 14(12): 1019-1030.
- Desai, A. K., Grossberg, G. T. and Sheth, D. N. (2004) 'Activities of daily living in patients with dementia: clinical relevance, methods of assessment and effects of treatment', *CNS Drugs* 18(13): 853-875.
- Dewing, J. (2000) 'Promoting wellbeing in people older people with cognitive impairment', *Elderly Care* 12(4): 19-22.
- Diamond, E. L., Jernigan, J. A., Moseley, R. A., Messina, V. and McKeown, R. A. (1998) 'Decision making ability and advance directive

- preferences in nursing home patients and proxies', *The Gerontologist* 29(5): 622-626.
- Dickens, B. M.** (1993) 'A response to the papers of Molloy and colleagues (Canada) and Cranford (United States) on Advance Directives', *Humane Medicine* 9(1): 78-84.
- Docker, C.** (1996) 'Advance directives/Living wills', in S. McLean (ed) *Contemporary Issues in Law, Ethics and Medicine*, Aldershot: Dartmouth Publishing Company.
- Docker, C.** (2000) 'Decisions to withdraw treatment: Values histories are more useful than advance directives', *BMJ* 320(7226): 54-55.
- Douglas, R. and Brown, H. N.** (2002) 'Patients' attitude towards advance directives', *Journal of Nursing Scholarship* 34(1): 61-65.
- Doukas, D. J. and Gorenflow, D. W.** (1993) 'Analysing the values history: an evaluation of patient medical values and advanced directives', *Journal of Clinical Ethics* 4: 41-45.
- Doukas, D. J. and McCulloch, L. B.** (1991) 'The values history: The evaluation of the patient's values and advance directives', *Journal of Family Practice* 32(2): 145-150.
- Downs, M.** (1997) 'The emergence of the person in dementia research', *Ageing and Society* 17(5): 597-607.
- Downs, M.** (1999) 'How to tell? Disclosing a diagnosis of dementia', *Generations* 23(3): 30-34.
- Downs, M., Clibbens, R., Rae, C., Cook, A. and Woods, R.** (2002) 'What do general practitioners tell people with dementia and their families about the condition?', *Dementia* 1(1): 47-58.
- Dresser, R. S.** (1995) 'Dworkin on dementia: Elegant theory, questionable policy', *The Hastings Centre Report* 25: 32-38.
- Drickamer, M. A. and Lachs, M. S.** (1992) 'Should patients with Alzheimer's disease be told their diagnosis?', *New England Journal of Medicine* 326(14): 947-951.
- Drinkwater, H., Wilkinson, H. F. Wasoff, F. A. Mason, A. and Davidson, S.** (2004) *Review of the code of practice for part five of the Adults with Incapacity (Scotland) Act 2004 and related issues: Analysis of written submissions to consultation.*, Edinburgh: Scottish Executive, HMSO.
- Ducket, P. and Fryer, D.** (1998) 'Developing empowering research practices for people who have learning disabilities', *Journal of Community and Applied Social Psychology* 8:57-65.
- Dukoff, R. and Sunderland, T.** (1997) 'Durable power of attorney and informed consent with Alzheimer's disease patients: A clinical study', *American Journal of Psychiatry* 154: 1070-1075.
- Dunning, A.** (1995) *Citizen advocacy with older people*, London: Centre for Policy on Ageing.
- Dunste, C. J., Trivette, C. M. and Deal, A. G.** (1994) 'The meaning and key characteristics of empowerment' *Supporting and strengthening families: methods, strategies and practice*, Brookline: Cambridge.
- Dyer, O.** (2004) 'Man wins battle to keep receiving life support', *BMJ* 329(309): 1136.
- Easterby-Smith, M., Thorp, R. and Lowe, A.** (1997) *Management research; An Introduction*, London: Sage Publications.

Eaton, L. (1997) 'Health authorities call for extra funding to meet £200 million cost of Alzheimer's drug', *Health Service Journal* 107(6).

Emanuel, L. L. and Emanuel, E. J. (1992) 'Proxy decision making for incompetent patients: an ethical and empirical analysis', *Journal of the American Medical Association* 267(15): 2067-2071.

Emmanuel, E. J. and Kass, F. (1993) 'Ethical and legal aspects of caring for patients with cancer', *Cancer Medicine*, Vol. 2, 3rd edition, Pennsylvania, USA: Lea and Febiger.

Erde, E. L., Nadal, E. C., and Scholl, T. O. (1988) 'On truth telling and the diagnosis to patients with Alzheimer's disease', *Journal of Family Practice* 26: 401-406.

Evendrouet, M., Arber, S., Dale, A. and Gilbert, G. N. (1986) *Who cares for the elderly: family care provision and receipt of statutory services in dependency and old age*, London: Croom Helm.

Fagerlin, A. and Schneider, C. E. (2004) 'Right to die: advance directives', Vol. 34: Hastings Centre Report.

Fahy, M., Wald, C., Walker, Z. and Livingston, G. (2003) 'Secrets and lies: the dilemma of disclosing the diagnosis to an adult with dementia', *Age and Ageing* 32: 439-441.

Fairbairn, A. (2000) 'Insight and dementia', in M. Marshal (ed) *State of the art in dementia care*, London: Centre for Policy on Ageing.

Fearnley, K., McLennan, J. and Weeks, D. (1997) *The right to know? Sharing the diagnosis of dementia*, Edinburgh: Alzheimer Scotland- Action on Dementia.

Finch, J. (1987) 'The vignette technique in survey research', *Sociology* 21(21): 115-124.

Fitzsimmons, S. and Fuller, R. (2001) 'Empowerment and its implications for clinical practice in mental health: a review', *Journal of Mental Health* 11(5): 481-499.

Fleischner, R. D. (1998) 'Advanced directives for mental health care: an analysis of state statutes', *Psychology, Public Policy and Law* 4(3): 788-804.

Folstein, M. F., Folstein, S. E. and McHugh, P. R. (1975) 'Mini Mental State', A practical method for grading the cognitive state of patients for the clinician', *Journal of Psychiatric Research* 12: 189-198.

Fortinsky, R. H., Leighton, A. and Wasson, J. H. (1995) 'Primary care physicians' diagnostic, management and referral practices for older persons and families affected by dementia', *Research on Ageing*(17): 124-148.

Froggatt, A. (1988) 'Self awareness in early dementia', in B. Gearing, M. Johnson and T. Heller (eds) *Mental Health Problems in Old Age*, Buckingham: Open University Press.

Fuller, R. (1999) 'Practitioner research: toward reflexive practice', in M. Potocky-Tripodi and T. Tripodi (eds) *New Directions: for social work practice research*, Washington: NASW Press.

Fuller, R. and Petch, A. (1995) *Practitioner research: the reflexive social worker*, Buckingham: Open University Press.

Gessert, C. E., Mosier, M. C., Brown, E. F. and Frey, B. (2001) 'Tube feeding in nursing home residents with severe irreversible cognitive impairment', *Journal of American Geriatric Society* 48: 1593-1600.

Gibson, J. (1990) 'Values history focuses on life and death decisions', *Medical Ethics* 5: 1-2, 17.

- Gilbert, N.** (ed) (1996) *Researching Social Life*, London: SAGE Publications.
- Gilliard, J., Hughes, A., Duff, F. and Winning, F.** (1998) *Life After diagnosis- A report on meeting the needs of people in the early stages of dementia*: Alzheimer's Scotland-Action on Dementia.
- Gilmour, H., Gibson, F. and Campbell, J.** (2003) 'Living alone with dementia: a case study approach to understanding risk', *Dementia* 2,(3): 403-420.
- Glasby, J.** (2003) 'Bringing down the 'Berlin Wall': the health and social care divide', *British Journal of Social Work* 33: 969-975.
- Glendinning, C.** (2003) 'Declarations of independence', *Community Care* (8-14 May): 40-42.
- Godel, M. D.** (2000) 'A SPECIAL way of maintaining well-being in dementia', *Journal of Dementia Care* 8(5): 20-24.
- Goffman, E.** (1968) *Asylums: essays on the social situation of mental patients and other inmates*, Harmondsworth: Penguin.
- Goldsmith, M.** (1995) 'Slow down and listen to the voices of people with dementia', *Journal of Dementia Care* 4(4): 24-25.
- Goldsmith, M.** (1996) *Hearing the voice of people with dementia*, London: Jessica Kingsley.
- Godwin, B.** (2002) 'Memoraid - Person-Centred Dementia Care in Action', *Signpost* 6(3).
- Gordon, J.** (2004) *A comparison of the Adults with Incapacity (Scotland) Act 2000 and the Mental Health (Care and Treatment) Act 2003*, Edinburgh: Scottish Executive.
- Gould, D.** (1996) 'Using vignettes to collect data for nursing research studies: how valid are the findings?', *Journal of Clinical Nursing* 5: 207-212.
- Greene, J. and Caracelli, V.** (eds) (1997) *Advances in mixed-method evaluation: the challenges and benefits of integrating diverse paradigms*, San Francisco: Jossey-Bass Inc.
- Grossberg, G. T.** (1998) 'Advance directives, competency evaluation and surrogate management in elderly patients', *American Journal of Geriatric Psychiatry* 6(May): S79-S84.
- Haley, W. E., Clair, J. M. and Saulsberry, K.** (1992) 'Family caregiver satisfaction with medical care of their demented relatives', *Gerontologist* 32(April 2): 219-226.
- Hare, J., Pratt, C. and Nelson, C.** (1992) 'Agreement between patients and their self-selected surrogates on difficult medical decisions', *Archives of International Medicine* 152(May): 1049-1054.
- Hart, D. and Kennedy, T.** (2003) 'Vast majority of patients with dementia want to be told diagnosis', *The Royal College of Psychiatrists*, London.
- Hartwood, D. G., Sultzer, D. L. and Wheatley, M. A.** (2000) 'Impaired insight in Alzheimer's disease: association with cognitive deficits, psychiatric symptoms and behavioural disturbances.' *Neuropsychology, Behaviour and Neurology* 13: 83-88.
- Harvey, R.** (1999) 'A review and commentary on a sample of 15 guidelines for the drug treatment of Alzheimer's disease', *International Journal of Geriatric Psychiatry* 14: 249-259.
- Hauser, J. M., Kleefield, S.F., Brennan, T. A. and Fischbach, R. L.** (1997) 'Minority populations and advance directives: insights from a focus group methodology', *Quarterly of Healthcare Ethics* 6(1): 58-71.

- Health Technology Board for Scotland**, (2001) *Comment on the National Institute for Clinical Excellence Technology Appraisal Guidance on the use of Donepezil, Rivastigmine and Galantamine for the treatment of Alzheimer's disease*, Edinburgh: Health Technology Board for Scotland
- Hellstrom, I., Nolan, M. and Lundh, U.** (2005) 'Awareness context theory and the dynamics of dementia', *Dementia* 4(2): 269-295.
- Henerson, M. E., Morris, L. L. and Fitz-Gibbon, C. T.** (1987) *How to measure attitudes*, London: SAGE Publications.
- Heun, R., Kockler, M. and Ptak, U.** (2003) 'Lifetime symptoms of depression in Alzheimer's disease', *European Psychiatry* 18(2): 63-69.
- High, D. M.** (1992) 'Research with Alzheimer's disease subjects: informed consent and proxy decision making', *Journal of American Geriatric Society* 40(9): 950-957.
- High, D.** (1994) *Families' role in advance directive*: Hastings Centre Report.
- High, D. M. and Turner, H. B.** (1987) 'Surrogate decision making: the elderly familial expectations', *Theoretical Medicine* 8: 303-320.
- Hiller, T., Patterson, J., Hodges, M. and Rosenberg, M.** (1995) 'Physicians as patients - Choices regarding their own resuscitation', *Archives of Internal Medicine* 155(1289-93).
- Holden, U. and Woods, R. T.** (1995) *Positive approaches to dementia care*, London: Churchill Livingstone.
- Holland, C.** (1996) 'Use of vignettes in ageing research', *Generations Review* 6.
- Holroyd, S., Snustad, D. G. and Chalifoux, Z. L.** (1996) 'Attitudes of older adults being told the diagnosis of Alzheimer's disease', *Journal of American Geriatric Society* 44: 400-403.
- Holroyd, S., Turnbull, Q. and Wolf, A. M.** (2002) 'What are patients and their families told about the diagnosis of dementia?', *International Journal of Geriatric Psychiatry* 17: 218-221.
- Holroyd, S., Turnbull, Q. and Wolf, A. M.** (2003) 'Attitudes of elderly towards 'truth telling' for the diagnosis of Alzheimer's disease', *Journal of Geriatric Psychiatry and Neurology* 16(2 June): 90-93.
- Hout, H., Vernooij-Daasen, M., Hoefnagels, W. and Grol, R.** (2001) 'Measuring the opinions of memory clinic users: patients, relatives and GPs', *International Journal of Geriatric Psychiatry* 16: 846-851.
- Howorth, P. and Saper, J.** (2003) 'The dimensions of insight with people with dementia', *Ageing and Mental health* 7(2): 113-122.
- Hubbard, H. and Martin, W.** (2002) 'Ethical issues in dementia research', in H. Wilkinson (ed) *Including people with dementia in research: methods and motivations*, London: Jessica Kingsley Publishers Ltd.
- Husband, H. J.** (1996) 'Sharing the diagnosis- how do carers feel?', *Journal of Dementia Care* Jan/Feb: 18-29.
- Husband, H. J.** (1999) 'The psychological consequences of learning a diagnosis of dementia: three case examples', *Ageing and Mental Health* 3: 179-183.
- Iliffe, S. and Manthorp, J.** (2004) 'The hazards of early recognition of dementia: a risk assessment', *Ageing and Mental Health* 8(2 March): 99-105.
- Ivers, V.** (1994) *Citizen advocacy in action: working with older people*, Stoke on Trent: Beth Johnson Foundation.

- Jackson, R. and Baldwin, B.** (1993) 'Detecting depression in elderly medically ill patients: the use of the Geriatric Depression Scale compared with medical and nursing observations', *Age and Ageing* 22: 349-53.
- Jacobson, J. A., Kasworm, E., Battin, M. P., Francis, L. P., Green, D. and Botkin, J.** (1996) 'Advance directives in Utah: information from death certificates and informants', *Archives of Internal Medicine* 156(16): 1862-8.
- Jacques, A. and Jackson, G.** (2000) *Understanding dementia*, Third Edition, Edinburgh: Churchill Livingstone.
- Jankowski, P., Clark, W. and Ivey, D.** (2000) 'Fusing Horizons: Exploring Qualitative Research and Psychotherapeutic Applications of Social Constructionism', *Journal Contemporary Family Therapy* 22:241-250.
- Jha, A., Tabet, N. and Orrell, M.** (2001) 'To tell or not to tell: comparison of older patients' reaction to their diagnosis of dementia and depression', *International Journal of Geriatric Psychiatry* 16.
- Jibson, M. and Tandon, R.** (2002) 'Treatment of acute psychotic episodes', in J. Csernansky (ed) *Schizophrenia: A new guide for clinicians*, New York: Marcel Dekker.
- Johnson, H. and Bouman, W. P.** (1997) 'Driving and dementia', *Geriatric Medicine* 6: 59-60.
- Johnson, J., Smith, P. and Goldstone, L.** (2001) *Evaluation of MS specialist nurse: a review and development of the role*, London: South Bank University.
- Johnson, R. and Onwuegbunzie, A.** (2004) 'Mixed methods research; A research paradigm whose time has come.' *Educational Researcher* 33:14-26
- Kane, R. A. and Degenholtz, H.** (1997) 'Assessing values and preferences: should we, can we?', *Journal of American Society on Aging* 21(1): 19-24.
- Kapp, M. B.** (2000) 'Advance medical directives for college students: It's not your father's living will', *Journal of American College Health* 49(1): 44-45.
- Katsuno, T.** (2003) 'Personal spirituality of persons with early-stage dementia: is it related to perceived quality of life?', *Dementia* 2(3): 315-335.
- Kayser-Jones, J. and Keonig, B.** (1994) 'Ethical issues', in J. Gubrium and A. Sanker (eds) *Qualitative Methods in Ageing Research*, London: Sage.
- Keady, J. and Nolan, M.** (1995) 'FADE: a strategy for action in the mild stage of dementia', *British Journal of Nursing* 4(22): 1335-1339.
- Keady, J., Nolan, M. and Gilliard, J.** (1995) 'Listen to the voices of experience', *Journal of Dementia care* 3(3): 15-16.
- Keightley, J. and Mitchell, A.** (2004) 'What factors influence mental health professionals when deciding whether or not to share a diagnosis of dementia with the person', *Ageing and Mental Health* 8(1): 13-20.
- Keilstein, R. and Sass, H.** (1993) 'Using stories to assess values and establish medical directives', *Kennedy Institute of Ethics Journal* 3(3): 303-325.
- Kelner, M., Bourgeault, I., Herbert, P. and Dunn, E.** (1993) 'Advance directives: the views of health care professionals', *Canadian Medical Association Journal* 148(8): 1331-1338.
- Kessing, L. V.** (2004) 'Subtypes of manic episodes according to ICD-10 prediction of time to remission and relapse', *Journal of Affective Disorders* 81(3): 279-285.
- Killeen, J., Myers, F. and MacDonald, F.** (2004a) *The Adults with Incapacity (Scotland) Act 2000: implementation, monitoring and research*, Edinburgh: Legal Studies Research Programme.

- Killeen, J., Myers, F., Brisbane, A., Coulson, K., Keith, D., Mclean, J., Thom, M., Fearnley, K., Gordon, J. and Woodhouse, A. (2004b) *The Adults with Incapacity (Scotland) Act 2000: learning from experience*, Edinburgh: Scottish Executive.
- Killick, J. (1994) 'There's so much to hear when you listen to individual voices.', *Journal of Dementia Care* 2(5): 12-14.
- Killick, J. (1997) *You are words*, London: Hawker Publications.
- Kitwood, T. (1993) 'Towards a theory of dementia care: the interpersonal process', *Ageing and Society* (13): 51-67.
- Kitwood, T. (1994) 'Discover the person, not the disease', *Journal of Dementia Care* 1(1): 16-17.
- Kitwood, T. (1995) 'Building up the mosaic of good practice', *Journal of Dementia Care* 3 (5): 12-13.
- Kitwood, T. (1997a) *Dementia reconsidered: the person comes first*, Buckingham: Open University Press.
- Kitwood, T. (1997b) 'The experience of dementia', *Ageing and Mental Health* 1: 13-22.
- Kitwood, T. and Brendan, K. (1992) 'Towards a theory of dementia care: personhood and well-being', *Ageing and Society* 12(3): 269-187.
- Kitzinger, J. (1994) 'The methodology of focus groups: the importance of interaction between research participants', *Sociology of Health* 16(1): 103-21.
- Kmietowicz, Z. (2005) 'NICE proposes to withdraw Alzheimer's drugs from NHS', *British Medical Journal* (330): 495.
- Knapp, M. J., Knopman, D. S., Soloman, P. R., Pendlebury, W. W., Davis, C. S. and Gracon, S. I. (1994) 'A 30-week randomised controlled trial of high dose Tacrine in patients with Alzheimer's disease: The Tacrine Study Group', *Journal of American Medical Advances* 271: 985-991.
- Knox, G. (2003) 'Advance directive needs to include additional elements', *British Medical Journal* (327): 1407.
- Kolarik, R. C., Arnold, R. M., Fischer, G. S. and Hanusa, B. (2002) 'Advance care planning: a comparison of values statements and treatment preferences', *Journal of General International Medicine* 17(8): 618-624.
- Kuczewski, M. (1994) 'Who's will is it anyway? A discussion of advanced directives, personal identity, and consensus in medical ethics', *Bioethics* 8(1): 27-48.
- Kuhn, D., Ortigara, A. and Kasayka, R. E. (2000) 'Dementia care mapping: An innovative tool to measure person centred care', *Alzheimer's Care Quarterly* 1(3): 7-15.
- Lambert, P., Gibson, J. McIver and Nathanson, P. (1991) 'The values history: an innovation in surrogate decision making', *The Pennsylvania Nurse* 46(3): 16-21.
- Lawrence, W., Hutton, N. and Kass, N. (2002) 'Preliminary study of a Values History Advance Directive interview in a Paediatric HIV clinic', *AIDS and Public Policy Journal* 17(1): 17-30.
- Lawson, J. (1996) 'A framework for risk assessment and management for older people', in H. Kempshal and J. Prichard (eds) *Good practice in risk assessment and risk management*, London: Jessica Kingsley.
- Lindesay, J., Marudkar, M., van Diepen, E. and Wilcock, G. (2002) 'The second Leicester survey of memory clinics in the British Isles', *International Journal of Geriatric Psychiatry* 17(1): 41-47.

- Lingard, J.** (2002) 'Tell me the truth'-empowering the person with dementia', *Journal of Dementia Care* July/August: 18-20.
- Lita, A.** (2003) "Seeing" human goodness: Iris Murdoch on moral virtue', *Minerva - An Internet Journal of Philosophy* 7: 143-172.
- Lovestone, S.** (1998) *Early diagnosis and treatment of Alzheimer's disease*, London: Martin Dunitz Ltd.
- Low, J. A.** (2003) 'Treatment of recurrent aspiration in end stage dementia: preferences and choices of a group of nursing home residents', *International Medicine Journal* 33(8): 346-349.
- Luce, A., McKeith, I. and Swan, A.** (2001) 'How do memory clinics compare with traditional old age psychiatry services', *International Journal of Geriatric Psychiatry* 16: 837-845.
- Mace, N. L. and Rabins, P. V.** (1985) *The 36 hour Day*, London: Hodder and Stoughton.
- Maguire, C. P., Kirby, M., Coakley, D., Lawlor, B. and O'Niel, D.** (1996) 'Family members' attitudes towards telling the patient with Alzheimer's disease their diagnosis', *British Medical Journal* (313): 539-530.
- Mallik, M.** (1997) 'Advocacy in nursing: a review of the literature', *Journal of Advanced Nursing* 25(1): 130-138.
- Mangone, C. A., Hier, D. B., Gorelick, P. B., Ganellen, R. J., Langenberg, P., Boarman, R. and Dollear, W. C.** (1991) 'Impaired insight in Alzheimer's disease', *Journal of Geriatric Psychiatry and Neurology* 4: 189-193.
- Marilyn** (2002) 'Windows into Alzheimer's disease: inside looking out', *Alzheimer's Care Quarterly* 3(2): 95-102.
- Mark, M. M., Feller, I. and Button, S. B.** (1997) 'Integrating qualitative methods in a predominantly qualitative evaluation - a case study and some reflections', in J. C. Greene, and V. J. Caracelli, (eds) *Advances in mixed method evaluation: The challenge and benefits of Integrating Diverse Paradigms*, San Francisco: Jossey-Bass Inc, Publishers.
- Markova, A. and Berrios, G.** (1995) 'Insight in psychiatry', *Journal of Nervous and Mental Disease* 183: 743-751.
- Marmot, M. G., Bosma, H., Hemmingway, H. and Brunner, E.** (1997) 'Contribution of job control and other risk factors to social variations in coronary heart disease', *Lancet* 350: 235-239.
- Marquis, R. and Jackson, R.** (2000) 'Quality of life and quality of service relationships: experiences of people with disabilities', *Disabilities and Society* 15(3): 411-425.
- Marsh, J. C.** (2003) 'Organisational and Institutional Factors in the Development of Practice Knowledge and Practice Guidelines in Social Work', in A. Rosen and E. Proctor (eds) *Developing Practice Guidelines for Social Work Intervention*, New York: Columbia University Press.
- Marshal, M.** (1999) 'Person centred technology', *Signpost* 3(4): 4-5.
- Marshal, M.** (1999) 'What do service planners and policy makers need from research?', *International Journal of Geriatric Psychiatry* 14: 86-96.
- Marson, D. C., Schmitt, F. A., Ingram, K. K. and Harrell, K. K.** (1994) 'Determining the competency of Alzheimer's patients to consent to treatment and research', *Alzheimer's Disease and Associated Disorders* 8(4): 5-18.
- Martyn, H.** (ed) (2000) *Developing reflective practice: making sense of social work in a world of change*, Bristol: The Policy Press.

- Mason, A. and Wilkinson, H. (2002)** *The characteristics of people who are users and non-users of the legal system - a feasibility study*, Stirling: Centre for Social Research on Dementia, University of Stirling.
- May, T. (1993)** *Social research: issues, methods and process*, Buckingham: Open University Press.
- McDaniel, K. D., Edland, S. D. and Heyman, A. (1995)** 'Relationship between level of insight and severity of dementia in Alzheimer disease.', *Alzheimer Disease and Associated Disorders*, 9: 101-104.
- McDonald, C. (2004)** *Older people and community care in Scotland - a review of recent research*, Edinburgh: Scottish Executive.
- McNiff, J., Lomax, P. and Whitehead, J. (1996)** *You and your action research project*, London: Routledge.
- Meikle, J. (2004)** 'Patient wins 'right to life' ruling: judge criticises guidance on withholding treatment' *Guardian*, London.
- Melzer, D. (1998)** 'New drug treatments for Alzheimer's disease: lessons for health care policy', *British Medical Journal* 316: 762-764.
- Meyers, B. S. (1997)** 'Telling patients they have Alzheimer's disease: importance of planning their future and no evidence of ill effects', *British Medical Journal* (314): 321-322.
- Migliorelli, R., Teson, A., Sabe, L., Petracca, G., Petracchi, M., Leiguarda, R. and Starkstein, S. E. (1995)** 'Anosognosia in Alzheimer's disease: a study of associated factors', *Journal of Neuropsychiatry and Clinical Neurosciences* 7: 338-344.
- Miskelly, F. (2004)** 'A novel system of electronic tagging in patients with dementia and wandering', *Age and Ageing* 33(3): 304-306.
- Mitchel, S. L. (2003a)** 'Financial incentives for placing feeding tubes in nursing home residents with advanced dementia', *Journal of American Geriatric Society* 51(1): 129-131.
- Mitchel, S. L. (2003b)** 'Nursing home characteristics associated with tube feeding in advanced cognitive impairment', *Journal of the American Geriatrics Society* 51(1): 75-79.
- Mitchel, S. L., Viely, D. K. and Lipsitz, L. A. (1997)** 'The risk factors and impact of survival of feeding tubes in nursing home residents with severely advanced dementia', *Arch International Medicine* 157: 327-332.
- Moore, D. S. and McCabe, G. P. (1998)** *Introduction to the practice of statistics*, 3 Edition, New York: W. H. Freeman and Company.
- Moniz-Cook, E. and Woods, R. T. (1997)** 'The role of memory clinics and psychosocial intervention in the early stages of dementia', *International Journal of Geriatric Psychiatry* 12 (12): 1143-1145.
- Morgan, D. L. (1997)** *Focus groups as qualitative research*, 2nd Edition, London: Sage.
- Morgan, D., L. (2007)** 'Paradigms Lost and Pragmatism Regained Methodological Implications of Combining Qualitative and Quantitative Methods' *Journal of Mixed Methods Research* 1:48-76.
- Morgan, D. L. and Kreuger, R. A. (1993)** 'When to use focus groups and why', in D. L. Morgan, (ed) *Successful Focus Groups*, London: Sage.
- Morris, T. (2005)** 'Doing the right thing leads to personal power, prosperity, and a life of meaning.', *Realtor Magazine online* (May): 1-6.

- Morse, J.** (1997) 'Designing Funded Qualitative Research.' in '*Strategies of Qualitative Inquiry*', edited by K Denzin and Y Lincoln. London: SAGE Publications.
- Morton, I.** (1999) *Person-centred approaches to dementia care*, 2 Edition, Bicester: Winslow Press.
- Moye, J.** (2000) 'Mr Frank refuses surgery: cognition and values in competency determination in complex cases', *Journal of aging studies* 14(4): 385-401.
- MPS**, (2005) 'Changes to the Adults with Incapacity Act are constructive', *Check up-Scottish Parliament Bulletin from MPS* (March 2005).
- Mullender, A. and Ward, D.** (1991) *Self directed groupwork: users take action for empowerment*, London: Whiting And Birch.
- Mullins, A. and Fitch, F.** (2000) 'Diagnosis by request: a self referral memory clinic', *Journal of Dementia Care* 8(2, March-April): 30-31.
- Murdoch, I.** (1971) *The sovereignty of good*, London: Routledge.
- Murphy** (1995) *Written answers to questions*, London: Parliament.
- Murphy, C. J.** (1994) '*It started with a sea shell*' - life story work and people with dementia, Stirling: Dementia Services Development Centre.
- Mental Welfare Commission.** (2004) *Safe to wander? Principles and guidance on good practice in caring for residents with dementia and related disorders where consideration is being given to the use of wandering technologies in care homes and hospitals*, Edinburgh: Mental Welfare Commission for Scotland. Available on:
<http://www.mwcscot.org.uk/web/FILES/mwcstw.pdf> [cited 20 Oct 2005]
- Nagel, T.** (1979) *Mortal questions*, Cambridge: Oxford University Press.
- Neill, J., Sinclair, I., Gorbach, P. and Williams, J.** (1988) *A need for care? Elderly applicants for local authority homes*, London: Gower.
- Newel, R.** (1994) 'Reflective practice: Art, science and pseudoscience', *Nurse Education Today* 14: 69-81.
- NHS Education** (2005) *Mental Health (Care and Treatment) (Scotland) Act 2003: education for frontline staff*. Available from:
<http://www.nes.scot.nhs.uk/mha/> [cited 12 March 06]
- NICE** (2001) *Guidance on use of Donepezil, Rivastigmine and Galantamine for the treatment of Alzheimer's Disease. Technology Appraisal Guidance no 19.*, London: National Institute For Clinical Excellence. Available from:
www.nice.org.uk/pdf/ALZHEIMER [cited 15 May 06]
- NICE** (2002) *Guidance in the use of newer (atypical) antipsychotic drugs for the treatment of schizophrenia*, (43) London: NHS National Institute for Clinical Excellence. Available from:
<http://www.nice.org.uk/page.aspx?o=ta043> [cited 11 Nov 05]
- NICE** (2005) *Appraisal consultation document: Alzheimer's Disease- Donepezil, Rivastigmine, Galantamine and Memantine (review)*, London. Available from: www.nice.org.uk/page.aspx?o=245908 [cited 15 May 06]
- Nolan, M., Davies, S. and Grant, G.** (1996) *Working with older people and their families: key issues in policy and practice*: Open University Press.
- Norman, A.** (1980) *Rights and risks: A discussion document on civil liberty in old age*, London: Centre for Policy on Ageing.
- O'Brien, J.** (1984) 'Building creative tension: the development of citizen's advocacy programme for people with mental handicap', in B. Sang and J.

- O'Brien (eds) *Advocacy; The UK and American Experiences*, London: Kings Fund Centre.
- Ogletree, T. W. (1995) 'Values and Valuation', in W. T. Reich, (ed) *Encyclopaedia of Bioethics: Revised Edition*, New York: McMillan.
- Packer, T. (1999) 'Worldwide spread of the new culture of care', *Journal of Dementia care* 7(1): 14-16.
- Packer, T. (2000) 'A person-centred approach to the people who care', *Journal of Dementia Care* 8(6): 28-30.
- Packer, T. (2001) 'From outside looking in: recognising skills in dementia care', *Journal of Dementia Care* 9(2): 29-31.
- Panke, J. and Volicer, L. (2002) 'Caring for persons with dementia: a palliative approach', *Journal of Hospice and Palliative Nursing* 4(3): 143-149.
- Parfit, D. 1984 *Reasons and persons*, Oxford: Oxford University Press.
- Parry-Langdon, N., Bloor, M., Aydney, S. and Holiday, J. (2003) 'Process evaluation of health promotion interventions', *Policy and Politics* 31(2): 207-216.
- Passmore, A. P. and Craig, D. A. (2004) 'The future of memory clinics', *Psychiatric Bulletin* 28(10 October): 375-377.
- Patton, M. Q. (1990) 'Qualitative evaluation and research methods.' California: SAGE Publications
- Pearlman, R. (1994) *Are we asking the right questions*: Hastings Centre Report.
- Peck, A., Cohen, C. E. and Mulvihill, M. N. (1990) 'Long term enteral feeding of aged demented nursing home patients', *Journal of American Geriatric Society* 38: 1195-1198.
- Philips, A. and O'Brien, J. T. (2002) 'Memory clinics and clinical governance-a UK perspective', *International Journal of Geriatric Psychiatry* 17: 1128-1132.
- Phillipson, C. (1990) 'Approaches to advocacy', in M. Bernard and B. Glendinning (eds) *Advocacy, Consumerism and the Older Person*, Keele: University of Keele.
- Phinney, A. (2003) 'Fluctuating awareness and the breakdown of the illness narrative in dementia', *The Journal of Social Research and Practice* 1(3 October): 329-344.
- Pietrukowicz, M. E. and Johnson, M. M. (1991) 'Using life histories to individualize nursing home staff attitudes toward residents', *The Gerontologist* 31(1): 102-106.
- Pinner, G. (2000) 'Truth-telling and the diagnosis of dementia', *The British Journal of Psychiatry* 176: 514-515.
- Pinner, G. and Bouman, W. P. (2003a) 'What should we tell people about dementia?', *Advances in Psychiatric Treatment* 9: 335-341.
- Pinner, G. and Bouman, W. P. (2003b) 'Attitudes of patients with mild dementia and their carers towards disclosure of the diagnosis.', *International Psychogeriatrics* 15(3): 279-88.
- Polkinghorne, D. E. (1996) 'Use of biography in the development of applicable knowledge', *Ageing and Society* 16: 721-745.
- Polkinghorne, D. E. (1999) 'Traditional research and psychotherapy practice', *Journal of Clinical Psychology* 55(12): 1429-1440.
- Polit, D. F., Beck, C, and Hungler, B, P,. (2001) 'Essentials of Nursing Research: Methods, Appraisal and Utilization.' Philadelphia: Lippincott.

Popper, K. R. (1959) *'The Logic of Scientific Discovery.'* New York: Routledge.

Potocky-Tripodi, M. and Tripodi, T. (eds) (1999) *New directions for social work practice research*, Washington: NASW Press.

Powell, R. A. and Single, H. M. (1996) 'Focus groups', *International Journal of Quality in Health Care* 8(5): 499-504.

Pratt, R. 2002 'Nobody ever asked how I felt', in H. Wilkinson (ed) *The Perspectives of People with Dementia: Research Methods and Motivations*, London: Jessica Kingsley Publishers Ltd.

Pratt, R. and Wilkinson, H. (2001) *'Tell me the truth' - The effects of being told the diagnosis of dementia from the perspective of the person with dementia*, London: Mental Health Foundation.

Prichard, J. (1997) 'Vulnerable people taking risks: older people and residential care', in H. Kempshal and J. Prichard (eds) *Good Practice in Risk Assessment and Risk Management 2*, Vol. 2, London: Jessica Kingsley Publishers.

Priestly, M. (1999) *Disability politics and community care*, London: Jessica Kingsley.

Quershi, H. and Walker, A. (1989) *The caring relationship: elderly people and their families*, Basingstoke: Macmillan.

Race, K. E., Hotch, D. F. and Parker, T. (1994) 'Rehabilitation program evaluation: use of focus groups to empower clients', *Evaluation Review* 18(6): 730-40.

Radar, J. (1995) *Individualised dementia care: creative, compassionate approaches*, New York: Springer.

Ramcharan, P. (1993) 'Citizen advocacy for people with learning disability in Wales', in D. Robbins (ed) *Community Care: Findings from DHSS funded Research, 1988-1992*, London: HMSO.

Rankin, K. P., Baldwin, E., Pace-Savitsky, C., Kramer, J. H. and Miller, B. L. (2005) 'Self awareness and personality change in dementia', *Journal of Neurology Neurosurgery and Psychiatry* 76: 632-639.

Rankin, M. (1989) *Advocacy: a case study*, London: Volunteer Centre, UK.

Reed, J. (1998) 'Care and protection for older people', in B. Heyman (ed) *Risk, Health and Health Care: A Qualitative Approach*, London: Arnold.

Reid, D. (2003) 'Coming to terms with dementia: a social researcher's perspective', *Generations Review* 13(3): 4-8.

Rethink (2002) *Advance directives, statements, agreements, and crisis cards*: National Schizophrenia Fellowship.

Rhodan, N. K. (1988) 'Litigating life and death', *Harvard Law Review* 102: 375-446.

Rice, K., Warner, N., Tye, T. and Bayer, A. (1997) 'Telling the diagnosis to patients with Alzheimer's disease: geriatricians' and psychiatrists' practice differs', *British Medical Journal* (314): 376.

Rich, B. A. (1996) 'The Values History: Restoring Narrative Identity to Long term Care', *Journal of Ethics Law and Aging* 2(2): 75-83.

Rich, B. A. (1998) 'Personhood, patienthood and clinical practice: reassessing advance directives', *Psychology, Public Policy, and Law* 4(3): 610 -628.

- Richards, L. and Richards, T.** (1993) 'The transformation of qualitative Researchers: Computation paradigms and research processes' in Fielding, N. G. and Lee, R. (Eds.). 1993. *'Using Computers in Qualitative Research'*. London: SAGE Publications.
- Rickelman, B. L.** (2004) 'Anosognosia in individuals with schizophrenia: towards recovery of insight', *Issues in Mental Health Nursing* 25(3, Apr-May): 227-242.
- Riddell, S. and Pearson, C.** (2005) *Do not attempt resuscitation decisions and disability in Scotland*: Disability Rights Commission.
- Rigger, S.** (1992) 'Epistemological debates, feminist voices.' *American psychologist* June: 730-740.
- Riter, R. N. and Fries, B. E.** (1992) 'Predictors of the placement of cognitively impaired residents on special care units', *Gerontologist* 32: 184-190.
- Roberts, J. K.** (1984) *Differential diagnosis in neuropsychiatry*, New York: John Wiley.
- Robertson, D. and Dearling, A.** (2004) *The practical guide to social welfare research*, Dorset: Russell House Publishing Ltd.
- Robinson, P., Ekman, S., Meleis, A. I., Winblad, B. and Wahlund, L.** (1997) 'Suffering in silence: The experience of early memory loss', *Health care in Later Life* 2(2): 107-120.
- Rogers, S. L. and Friedhoff, L. T.** (1996) 'The efficacy and safety of Donepezil in patients with Alzheimer's disease: results of US multicenter, randomized, double-blind, placebo-controlled trial', *Dementia* 7: 293-303.
- Rogers, S. L., Farlow, M. R., Doody, R. S., Mohs, R. and Friedhoff, L. T.** (1998) 'A 24-week double blind, placebo-controlled trial of Donepezil in patients with Alzheimer's disease', *Neurology* 50(1): 136-145.
- Royal College of Physicians of Edinburgh** (2001) *College response to major consultation documents: Adults with Incapacity (Scotland) Act, 2000*, Edinburgh: Royal College of Physicians of Edinburgh.
- Royal College of Psychiatrists** (2001) *New drugs and better diagnosis key to treatment of dementia*, London: Royal College of Psychiatrists. Available from:
<http://www.rcpsych.ac.uk/pressparliament/pressreleasearchive/pr240.aspx>
[cited 10 Oct 05]
- Royal College of Psychiatrists** (2003) *Press Release: Vast Majority of Patients with Early Dementia want to be told their Diagnosis*, London: Royal College of Psychiatry. Available from:
<http://www.rcpsych.ac.uk/pressparliament/pressreleasearchive/pr394.aspx>
[cited 10 Oct 05]
- Royal College of Psychiatrists**, (2005a) *Forgetful, but not forgotten: assessment and aspects of treatment of people with dementia by a specialist old age psychiatry service: prepared by a working group of the Faculty of Psychiatry of Old Age Psychiatry of the Royal College of Psychiatrists*, London: Royal College of Psychiatrists. Available from:
<http://www.rcpsych.ac.uk/pressparliament/pressreleasearchive/pr676.aspx>
[cited 12 Nov 05]
- Royal College of Psychiatrists** (2005b) *Royal College of Psychiatrist's response to the proposal to the National Institute of Clinical Excellence (NICE) to withdraw treatments for Alzheimer's disease from NHS- College strongly disagrees with preliminary recommendations*, London: Royal College of

Psychiatry: Press Release. Available from:
<http://www.rcpsych.ac.uk/pressparliament/pressreleasearchive/pr653.aspx>
[cited 15 Oct 05]

Rushton, P. (2001) 'Advance directives: their importance for both patients and health care providers', *Utah Nurse* 10(April-June): 5-6.

Russell, P. (1994) 'Still a bridge too far', *Care weekly* Feb. (3rd): 13.

SAMH (2004) *Scottish Association of Mental Health- response to Scottish Executive consultation on MHCT Act Draft Code of Practice Volume One*, Edinburgh: Scottish Association of Mental Health.

Sapsford, R. and Jupp, V. (eds) (1996) *Data collection and analysis*, London: SAGE Publications.

Schiff, R., Rajkumar, C. and Bulpitt, C. (2000) 'Views of elderly people on living wills: interview study', *British Medical Journal* 320: 1640-1641.

Schneiderman, L. J., Pearlman, R., Kaplan, R., Anderson, J. and Rosenberg, E. (1992) 'Relationships of general advance directive instructions to specific life sustaining treatment preferences in patients with serious illness', *Archives of International Medicine* 152(Oct): 2114-2122.

Schon, D. A. (1983) *The reflective practitioner: how professionals think in action*, London: Ashgate Publishing Ltd.

Schonwetter R. S., Walker R. M. and Robinson B. E. (1995) 'The lack of advance directives among hospice patients'. *Hospital Journal*. 10(3): 1-11.

Scottish Development Centre for Mental Health (2003) *Developing Collective Advocacy for People Who Fall Within the Remit of the New Mental Health (Scotland) Bill*, Edinburgh: Scottish Development Centre for Mental Health. Available on: <http://www.shstrust.org.uk/pdf/DCAreport141.pdf> [cited 10 July 05]

Scottish Development Centre for Mental Health (2005) *Research and evaluation: mental health law*. Edinburgh. Available on: <http://www.sdcmh.org.uk/research&evaluation/pgs/mentalhealthlaw.html> [cited 3 March 06]

Scottish Executive (1995) *Report on incapable adults*, Edinburgh: Scottish Law Commission: Scot Law Com no 151. Available on: <http://www.scotland.gov.uk/rightmoves/docs/ria-01.htm> [cited 2 March 2003]

Scottish Executive (1999a) *Press release: ministers outline plans for Adults with Incapacity*, Edinburgh: Scottish Executive.

Scottish Executive (1999b) *Making the right moves: rights and protections for adults with incapacity*, Edinburgh: Scottish Parliament. Available on: <http://www.scotland.gov.uk/rightmoves/docs/mrmm-00.htm> [cited 2 May 05]

Scottish Executive (2000) *Adults with Incapacity Act (Scotland) 2000* Edinburgh: Her Majesty's Stationary Office.

Scottish Executive (2000a) *A guide for commissioners: a guide for health boards, NHS Trusts, local authorities and anyone involved with advocacy*, Edinburgh: Scottish Executive.

Scottish Executive (2000b) *Our National Health: a plan for action, a plan for change*, Edinburgh: Scottish Executive. Available on: <http://www.scotland.gov.uk/library3/health/onh.pdf> [cited 6 May 05]

Scottish Executive (2001a) *New directions: Report on the review of the Mental Health (Scotland) Act 1984*, Edinburgh: Scottish Executive. Available on: <http://www.scotland.gov.uk/library3/health/rhmls-00.asp> [cited 5 May 2005]

- Scottish Executive (2001b)** *Adults with Incapacity (Scotland) Act 2000: Code of practice for continuing and welfare attorneys* Edinburgh: Scottish Executive.
- Scottish Executive (2001c)** *Press release: Chisholm signals further support for advocacy development*, Edinburgh: Scottish Executive. Available on: <http://www.scotland.gov.uk/news/2001/02/se0451.asp> [cited 4 May 05]
- Scottish Executive (2002)** *News release: Advocacy services for vulnerable patients*, Edinburgh: Scottish Executive. Available on: <http://www.scotland.gov.uk/News/Releases/2002/02/1062> [cited 4 May 05]
- Scottish Executive (2003)** *Mental Health (Care and Treatment) (Scotland) Act 2003* Edinburgh: Her Majesty's Stationary Office.
- Scottish Executive (2003)** *Adults with Incapacity (Scotland) Act 2000: Review of Code of Practice for part five - medical treatment and research - and related Issues*, Edinburgh: Scottish Executive, Health Department and Public Health Division.
- Scottish Executive (2004a)** *News report: report on Adults with Incapacity Act*. Edinburgh: Scottish Executive
<http://www.scotland.gov.uk/News/Releases/2004/10/28101510>
- Scottish Executive (2004b)** 'Mental Health (Care and Treatment) (Scotland) Act: draft code of practice. Volume one' Edinburgh: Scottish Executive.
- Scottish Executive (2004c)** *The New Mental Health Act: what's it all about?* Edinburgh: Scottish Executive.
- Scottish Executive (2004d)** *The New Mental Health Act: a guide to named persons*. Edinburgh: Scottish Executive
- Scottish Executive (2004e)** *About welfare power of attorney*, Edinburgh: Scottish Executive.
- Scottish Executive (2004f)** *The new Mental Health Act: a guide to advance statements* Edinburgh: Scottish Executive.
- Scottish Executive (2004g)** *Adults with Incapacity (Scotland) Act: frequently asked questions*, Edinburgh: Justice.
<http://www.scotland.gov.uk/Topics/Justice/Civil/16360/4927>
- Scottish Executive (2005a)** *Reforming mental health law: Newsletter 8*, Edinburgh: Scottish Executive. Available on: <http://www.scotland.gov.uk/Publications/2005/06/24104033> [cited 5 Jan 06]
- Scottish Executive (2005b)** *Better outcomes for older people: framework for joint services*, Edinburgh: Scottish Executive
- Scottish Parliament (1999a)** *Research note: Adults with Incapacity (Scotland) Bill Part 5: medical treatment, care and research*, Edinburgh: Scottish Parliament. Available on: http://scottish.parliament.uk/business/research/pdf_res_notes/rn99-47.pdf [cited 20 May 05]
- Scottish Parliament (1999b)** *Adults with Incapacity (Scotland) Bill Policy memorandum SP.Bill.5PM*. Available on: <http://www.scottish.parliament.uk/business/bills/billsPassed/b5s1pm.pdf> [cited 6 May 05]
- Seckler, A. B., Meier, D. E., Mulvihill, M. and Paris, B. E. C. (1991)** *Substitute judgement: how accurate are proxy predictions?*, *Annals of International Medicine* 115: 92-98.

Seeman, M. and Seeman, T. E. (1983) 'Health behaviour and personal autonomy - a longitudinal study of the sense of control in illness', *Journal of Health and Social Behaviour* 24: 144-160.

Seymour, J. and Hanson, E. (2001) 'Palliative care for older people', in M. Nolan, S. Davies and G. Grant (eds) *Working with older people and their families*, Buckingham: Open University Press.

SHS (2003) *Developing collective advocacy for people who fall within the remit of the new Mental Health (Scotland) Bill*, Edinburgh: Scottish Development Centre for Mental Health.

Silveira, M. J., DePiero, A., Gerrity, M. S. and Feudtner, C. (2000) 'Patient's knowledge of options at the end of life: ignorance in the face of death', *Journal of the American Medical Association* 284: 2483-2488.

Silverman, D. (2000) 'Doing qualitative research: a practical handbook.' London: SAGE Publications.

Silverstein, N. M., Flaherty, G. and Tobin, T. (2002) *Dementia and wandering behaviour: concern for the lost elder*, New York: Springer.

Slife, B. D. and Williams, R. N. (1995) *What's behind the research: discovering hidden assumptions in behavioural sciences*, London: SAGE publications.

Slinn, R., Maguire, C. P. and Wilcock, G. K. (2000) *Informing patients with dementia or cognitive impairment of their diagnosis does not affect levels of anxiety or depression*: The Royal College of Psychiatrists: Press Release.

Smallwood, J. (1997) *Initial report on obtaining the views of activities undertaken while in care from people with dementia*, Birmingham: Birmingham Mental Health Services for Older Adults, Quality Department.

Smith, G. and Cantley, C. (1991) 'Pluralistic evaluation', in J. Lishman (ed) *Evaluation: Research Highlights in Social Work* 8, London: Jessica Kingsley Publishers.

Smith, M. J. (1998) *'Social Sciences in Question'*. London: SAGE Publications.

Souetre, E., Thwaites, R. M. and Yeardley, H. L. (1999) 'Economic impact of Alzheimer's disease in the United Kingdom: cost of care and disease severity for non-institutionalised patients with Alzheimer's disease', *British Journal of Psychiatry* 174: 51-55.

Sperlinger, D. and McAuslane, L. (1994) 'Listening to users of services for people with dementia', *Clinical Psychology Forum* Nov: 2-4.

Standing Medical Advisory Committee (1998) *The use of Donepezil for Alzheimer's disease*, London: Department of Health.

Starkstein, S., Chemeinski, E., Sabe, L., Kuis, G., Petracca, G., Teson, A. and Leiguarda, R. (1997) 'Prospective longitudinal study of depression and anosognosia in Alzheimer's disease', *British Journal of Psychiatry* 171: 47-52.

Statham, D. (1992) *What if they hurt themselves?*, London: Counsel and Care.

Steele, C., Rouner, B., Chase, G. A. and Folstein, M. (1990) 'Psychiatric symptoms and nursing home placements of patients with Alzheimer's disease', *American Journal of Psychiatry* 147: 1049-1051.

Stevenson, O., (1999) 'Older people at risk', in P. Phyllida (ed) *Risk Assessment in Social care and Social Work*, London: Jessica Kingsley.

Stokes, G. (2001) 'Difficult decisions: what are in a person's 'best interests'?', *Journal of Dementia Care* May/June.

- Strachan, R. and Tallant, C.** (1997) 'Improving judgement and appreciating biases within the risk assessment process', in H. Kemshall and J. Prichard (eds) *Good practice in risk assessment and risk management* 2, Vol. 2, London: Jessica Kingsley.
- Stroup, S. and Appelbaum, P.** (2004) 'The subject advocate: protecting the interests of participants with fluctuating decision making capacity', *A Review of Human Subjects Research* 25(3 May-June): 9-11.
- Syme, L. S.** (1998) 'Social epidemiology and the work environment', *International Journal of Health Services* 18: 635-645.
- Teel, C. S. and Carson, P.** (2003) 'Family experiences in the journey through dementia diagnosis and care', *Journal of Family Nursing* 9(1): 38-58.
- Thomas, K., Nicholl, J. and Coleman, P.** (2001) 'Use and expenditure on complementary medicine in England: a population based survey.', *Complementary Therapies in medicine* 9(1): 2-11.
- Thompsonsell, A. and Lovestone, S.** (2002) 'Out of sight out of mind? Support and information given to distant and near relatives of those with dementia.', *International Journal of Geriatric Psychiatry*, 17(9): 804.
- Thompson, T.** (2003) 'Adherence to Advance Directives in Critical Care Decision Making: Vignette Study', *BMJ* 327(7422): 1011.
- Titterton, M.** (2005) *Risk and risk taking in health and social welfare*, London: Jessica Kingsley Publishers.
- Tomlinson, T., Howe, K., Notman, M. and Rossmiller, D.** (1990) 'An empirical study of proxy consent for elderly persons', *The Gerontologist* 30(1): 54-64.
- Treloar, A. J.** (1999) 'Advance directives: limitations upon their applicability in elderly care', *International Journal of Geriatric Psychiatry* 14: 1039-1043.
- Trinder, E.** (1996) 'Social Work Research: The state of the art (or science).', *Child and Family Social Work* 4:233- 242.
- Trouillette, R., Gely-Nargeot, M. C. and Deouesne, C.** (2003) 'Unawareness of deficits in Alzheimer's disease: a multidimensional approach', *Psychologie et Neuropsychiatrie du Vieillessement* 1(2): 99-110.
- Twigg, J. and Atkin, K.** (1994) *Carers perceived: policy and practice in informal care*, Buckingham: Open University Press.
- Verhey, F. R., Rozendaal, N., Ponds, R. W. and Jolles, J.** (1993) 'Dementia, awareness and depression', *International Journal of Geriatric Psychiatry* 8: 851-856.
- Verplanken, B. and Holland, R. W.** (2002) 'Motivated decision making: effects of activation and self-centrality of values on choices and behavior [personality processes and individual differences]', *Journal of Personality and Social Psychology* 82(3): 434-447.
- Vinen, J.** (2002) 'Advance care planning and advance directives: time for action', *International Medical Journal* 32(9-10): 435-436.
- Vogel, A., Hasselbalch, S. G., Gade, A., Ziebell, M. and Waldmar, G.** (2003) 'Cognitive and functional neuroimaging for anosognosia in mild cognitive impairment and Alzheimer's disease', *International Journal of Geriatric Psychiatry* 20(3 March): 238-246.
- Vogel, A., Stokholm, J., Gade, A., Andersen, B., Hejl, A.-m. and Waldemar, G.** (2004) 'Awareness of deficits in mild cognitive impairment and Alzheimer's disease: Do MCU patients have impaired insight', *Dementia and Geriatric Cognitive Disorders* 17: 181-187.

- Volicer, L., Mckee, A. and Hewitt, S.** (2001) 'Dementia' *Neurological Clinics*, Vol. 19, Boston: Boston University School of Medicine.
- Voysey, M.** (1975) *A constant burden*, London: Routledge and Keagan.
- Wallace, D.** (1996) 'Perfect manners demand a first class service', *Journal of dementia care* 4(4): 18-19.
- Ward, A.** (2004) *Extract from current law statutes, Adults with Incapacity (Scotland) Act 2000 (asp4)*, Scottish Executive: Justice.
- Ward, D.** (2000) 'Totem not token: Groupwork as a vehicle for participation', in H. Kemshall and R. Littlechild (eds) *User involvement and participation in social care*, London: Jessica Kingsley Publishers.
- Warner, J.** (2003) 'Current research on diagnosing dementia', *Journal of Neurology, Neurosurgery and Psychiatry* 74(4 July): 413-414.
- Weiler, K. and Buckwalter, K. C.** (1994) 'Use of substitute decision makers by the mentally ill rural elderly: an issues of concern for mental health nurses', *Issues in Mental Health Nursing* 15: 215-227.
- Wertheimer, A.** (1993) *Speaking out: citizen advocacy and older people*, London: Centre for Policy on Ageing.
- West, P.** (1982) *Reproducing naturally occurring stories: vignettes in survey research*. Aberdeen: MRC Medical Sociology Unit.
- Whitlatch, C., Feinberg, L. F. and Tucke, S.** (2005) 'Accuracy and consistency of responses from persons with cognitive impairment', *Dementia* 4(2): 171-185.
- Wikipedia: the free online encyclopaedia (2007) 'Pragmatism.'
(<http://en.wikipedia.org/wiki/Pragmatism>). Cited 26/04/07
- Wilkinson** (2001) 'Empowerment and decision making for people with dementia: the use of legal interventions in Scotland', *Ageing and Mental Health* 5(4): 322-328.
- Wilkinson, H.** (2002) 'Including people with dementia in research: methods and motivations', in H. Wilkinson (ed) *The Perspectives of People with Dementia: Research Methods and Motivations*, London: Jessica Kingsley Publishers Ltd.
- Wilkinson, H., Pratt, R. and Milne, A.** (2002) 'Do people with dementia want to know their diagnosis?', *Signpost* 6(3): 36-38.
- Wilks, T.** (2004) 'The use of vignettes in qualitative research into social work values', *Qualitative Social Work* 3(1): 78-87.
- Wilson, J. and While, A.** (1998) 'Methodological issues surrounding the uses of vignettes in qualitative research', *Journal of Interprofessional Care* 12: 79-87.
- Winner, M.** (1996) 'User choice, care management and people with dementia', in J. Phillips and B. Penhale (eds) *Reviewing care management for older people*, Wiltshire: Cromwell Press.
- Wong, J. G. and Clare, I. C. H.** (1999) 'Capacity to make health care decisions: it's importance in clinical practice', *Psychological Medicine* 29: 437-446.
- World Health Organisation** (1993) *The ICD-10 classification of mental and behavioural disorders.*, Geneva: World Health Organization. Available on: <http://www.who.int/classifications/icd/en/HistoryOfICD.pdf> [cited 12 Dec 2005]
- World Health Organisation** (2005) *Mental health and substance abuse, facts and figures. Alzheimer's disease: the brain killer*, Geneva: World Health Organization. Available on:

<http://www.searo.who.int/en/Section1174/Section1199/Section1567/Section1823.htm> [cited 10 Jan 06]

Wright, N. and Lindesay, J. (1995) 'A survey of memory clinics in the British Isles', *International Journal of Geriatric Psychiatry* 10: 379-385.

Wynne-Harley, D. (1991) *Living dangerously: risk-taking, safety and older people* London: Centre for Policy on Ageing.

Yale, R. (1998) *Developing support groups for individuals with early-stage Alzheimer's disease*, London: Health Professionals Press.

Yang, Y. and George, L. K. (2005) 'Functional disability, disability transitions, and depressive symptoms in late life', *Journal of Ageing and Health* 17(3): 263-292.

Zanetti, O. and Bianchetti, A. (1996) 'Geriatric nurses' attitudes towards the use of nasogastric feeding tubes in demented patients', *International Journal of Geriatric Psychiatry* 11(Dec): 1111-1116.

Zronek, S., Daly, B. and Lee, H. (1999) 'Elderly patients understanding of advance directives', *JONA's Healthcare Law, Ethics and Regulation* 1(2 June): 23-28.

Zweibel, N. and Cassel, C. (1989) 'Treatment choices at end of life: a comparison of decisions by older patients and their physician selected proxies', *The Gerontological Society of America*.

Appendix one

The Extended Values History

A form to assist you in making health care choices in accordance with your values

It is important that your medical treatment be your choice. The purpose of this form is to assist you in thinking about and writing down what is important to you about your health. If you should at some time become unable to make health care decisions, this form may help others make a decision for you in accordance with your values.

The main section of this form provides an opportunity for you to discuss your values, wishes, and preferences in a number of different areas, such as your personal relationships, your overall attitude towards life, and your thoughts about illness. Towards the end of the form is a space for indicating whether you have completed an Advance Directive (Living Will) and where such documents may be found.

The Extended Values History Form is not copyrighted. You are encouraged to make additional copies for friends and relatives to use.

Signature:

D.O.B.: Today's Date:

If someone has assisted you in completing this form, please fill in his or her name, address, and relationship to you:

Name:

Address:

Relationship:

OVERALL ATTITUDE TOWARDS LIFE AND HEALTH

What would you like to say to someone reading this document about your overall attitude towards life?

What goals do you have for the future?

How satisfied are you with what you have achieved in your life?

What, for you, makes life worth living?

What do you fear most? What frightens or upsets you?

What activities do you enjoy (eg hobbies, watching TV)?

How would you describe your current state of health?

If you currently have any health problems or disabilities, how do they affect:
You? Your family? Your work? Your ability to function?

If you have any health problems or disabilities, how do you feel about them?

What would you like others (family, friends, doctors) to know about this?

Do you have difficulty in getting through the day with activities such as:
eating? preparing food? sleeping? dressing and bathing? etc.

What would you like to say to someone reading this document about your
general health?

PERSONAL RELATIONSHIPS

What role do family and friends play in your life?

How do you expect friends, family and others to support your decisions
regarding medical treatment you may need now or in the future?

Have you made any arrangements for family or friends to assist in making
medical treatment decisions on your behalf? If so, who has agreed to assist
in making decisions for you and in what circumstances?

What general comments would you like to make about the personal
relationships in your life?

THOUGHTS ABOUT INDEPENDENCE AND SELF-SUFFICIENCY

How does independence or dependence affect your life?

If you were to experience decreased physical and mental abilities, how
would that affect your attitude toward independence and self-sufficiency?

If your current physical or mental health gets worse, how would you feel?

LIVING ENVIRONMENT

Have you lived alone or with others over the last 10 years?

How comfortable have you been in your surroundings?

How might illness, disability or age affect this?

What general comments would you like to make about your surroundings?

RELIGIOUS BACKGROUND AND BELIEFS

What is your spiritual/religious background?

How do your beliefs affect your feelings towards serious, chronic or terminal illness?

How does your faith community, church or synagogue support you?

What general comments would you like to make about your beliefs?

RELATIONSHIPS WITH DOCTORS AND OTHER HEALTH CAREGIVERS

How do you relate to your doctors? Please comment on: trust; decision making; time for satisfactory communication; respectful treatment.

How do you feel about other caregivers, including nurses, therapists, chaplains, social workers etc?

What else would you like to say about doctors and other caregivers?

THOUGHTS ABOUT ILLNESS, DYING AND DEATH

What general comments would you like to make about illness, dying and death?

What will be important to you when you are dying (eg, physical comfort, no pain, family members present etc)?

Where would you prefer to die?

How do you feel about the use of life-sustaining measures if you were: suffering from irreversible chronic illness (eg Alzheimer's disease)? terminally ill? in a permanent coma?

What general comments would you like to make about medical treatment?

FINANCES

What general comments would you like to make about your finances and any costs connected with your health care?

What are your feelings about having enough money to provide for your care?

FUNERAL PLANS

What general comments would you like to make about your funeral and burial or cremation?

Have you made your funeral arrangements? If so, with whom?

OPTIONAL QUESTIONS

How would you like your obituary (announcement of your death) to read?

Write yourself a brief eulogy (a statement about yourself to be read at your funeral).

What would you like to say to someone reading this Extended Values History Form?

HEALTH CARE DECISION DOCUMENTS

Have you signed a Living Will?

Yes No

Where can it be found?

Name:

Address:

Phone:

Appendix two

Information sheet

TITLE OF STUDY

**VALUES HISTORIES - A WAY OF EMPOWERING DEMENTIA SUFFERERS?
A STUDY TO EVALUATE THE IMPACT OF VALUES HISTORIES ON
DEMENTIA SUFFERERS AND THE STAKEHOLDERS IN THEIR CARE.**

You may recently have been diagnosed suffering from an illness, which indicates that you may require an element of care in the future, i.e. dementia or stroke disease. The illness might also indicate that, due to progressive memory problems or confusion, you might have to increasingly rely on others to make decisions about your care. The general aim of the study, is to establish how health care professionals can elicit patients' values and care preferences in such a way that they can be taken into consideration in the future. It is also the intention of the study to look at ways of improving communication about future health planning between patients, carers and health professionals. The assessment which we have chosen is, the 'Values History', and with the help of twelve patients and their carers we will evaluate whether it is a useful assessment or not.

What will be expected of my carer and me?

Interviews will be conducted with you and your carer. The interviews will take approximately an hour each. The focus of the interviews will be to discuss your values and care preferences should your health deteriorate. The object of the first interview will be to discuss the study and answer any questions you have about the study. During the next two interviews a 'Values History' form will be completed with you as the sole participant. The next interview will be conducted solely with your carer, to discuss the completed Values History form. Finally the document will be discussed together with yourself and your carer together.

What is a Values History form?

The Values History form was originally developed at the Centre for Health, Law and Ethics, University of New Mexico. It was initially produces to assist those suffering from terminal illnesses to have their values represented in the latter stages of their illnesses. For the purpose of this study, however, the form will be adapted to consider how to represent your values in relation to community care (values being deep held beliefs, which we feel strongly about either positively or negatively).

Typical questions will include;

What role do family and friends play in your life?

How important is your religion or faith?

What are your fears and hopes for the future?

What if I can't answer the questions?

You will not be expected to answer all the questions, only the ones which are relevant to your own values and beliefs. The purpose of the research is to establish how it feels for you to discuss personal values and care preferences with health care professionals. It will therefore still be useful for us to know how easy or difficult you find it to answer the questions.

What if I don't have a carer?

For the purpose of the research a carer can include a 'potential' carer or someone whom you would trust to look after your interests should you no longer be able to.

Why do you need to interview my carer?

One area of the research is to establish how aware your carer is of your values and care preferences. Another aim is to establish if the Values History can be used to improve communication between yourself and your carer.

Where will the interviews take place and what will be the format?

They will take place wherever is most convenient for you and your carer, possibly at your home or at the Resource Centre. The interviews will be very informal. To assist with recall, they will be tape recorded. We will use a Values History form as the basis for discussion. Interviews will take approximately an hour.

Is the information confidential?

The researcher is the only person who will need to know your name and is the only person who will require to listen to the tape. Relevant information will be incorporated as part of a thesis but fictitious names will be used. Your consent will however be required for the information to be discussed with your carer.

What will happen to the completed values history form?

Information in the forms will be used for research purposes as part of a thesis, but fictitious names will be used. You will however be given a copy of the form which you may wish to give to your GP, nurse, social worker or members of your family (this is what the form is intended for).

What if I change my mind and do not want to continue with the research?

You can discontinue the research at any time you want and this will not affect your health care treatment.

Who is conducting the research?

Robert Boyd, a Community Psychiatric Nurse with 15 years nursing experience, will be conducting all the interviews.

He is currently undertaking a post graduate degree at the University of Glasgow and has received support from the Primary Care Trust to look at ways of improving patient care for older people. He can be contacted at

Eastvale Resource Centre,
130 Stonelaw Road,
Rutherglen,
Glasgow Tel 531 4100

Appendix three

Consent form

Name

I have been given a personal copy of the information sheet and read it in full. I have discussed the research with Robert Boyd and had the opportunity to discuss the study with him and ask questions about it. I agree for the information from the Values History to be shared and discussed with my carer. I am aware that the information will be incorporated into a thesis, but will be treated with confidentiality and my name will not appear in the thesis or any subsequent publications. I understand that I can discontinue the research at any time and it will not affect my relationships with health care professionals. I will be given a copy of the completed Values History document.

I therefore give my consent to participate in the research.

Signed (participant)

Witness (preferably carer)

Date

Appendix four

Folstein Mini Mental Status Examination

Task	Instructions	Scoring	
Date Orientation	"Tell me the date?" Ask for omitted items.	One point each for year, season, date, day of week, and month	5
Place Orientation	"Where are you?" Ask for omitted items.	One point each for state, county, town, building, and floor or room	5
Register 3 Objects	Name three objects slowly and clearly. Ask the patient to repeat them.	One point for each item correctly repeated	3
Serial Sevens	Ask the patient to count backwards from 100 by 7. Stop after five answers. (Or ask them to spell "world" backwards.)	One point for each correct answer (or letter)	5
Recall 3 Objects	Ask the patient to recall the objects mentioned above.	One point for each item correctly remembered	3
Naming	Point to your watch and ask the patient "what is this?" Repeat with a pencil.	One point for each correct answer	2
Repeating a Phrase	Ask the patient to say "no ifs, ands, or buts."	One point if successful on first try	1
Verbal Commands	Give the patient a plain piece of paper and say "Take this paper in your right hand, fold it in half, and put it on the floor."	One point for each correct action	3
Written Commands	Show the patient a piece of paper with "CLOSE YOUR EYES" printed on it.	One point if the patient's eyes close	1
Writing	Ask the patient to write a sentence.	One point if sentence has a subject, a verb, and makes sense	1
Drawing	Ask the patient to copy a pair of intersecting pentagons onto a piece of paper.	One point if the figure has ten corners and two intersecting lines	1
Scoring	Total Possible Points		30

Appendix five

Insight rating scale (after Verhey et al, 1993)

Score	Health Care Professional	Carer Rating
4 Adequate	Patient has adequate knowledge of his/ her cognitive deficits. Complains spontaneously about memory or other cognitive difficulties.	Your relative has adequate knowledge of his or her memory problems. She/he complains spontaneously about memory or other difficulties.
3 Mildly disturbed	Patient has some knowledge of his/her cognitive deficits, but with some gaps. Complains spontaneously about memory difficulties. History of difficulties given by the patient shows some discrepancies with eh history given by the carer.	Your relative has some knowledge of his or her memory problems, but with some gaps. She /he may complain about these difficulties. Your relative sometimes disagrees with you about whether she/he has forgotten something.
2 Moderately disturbed	Obvious discrepancies with history given by carer.	Your relative has only a vague awareness of his or her memory problems. She/he admits to difficulties only when questioned about them.
1 Severely disturbed	Patient denies any deficits. Does not complain about memory whatsoever, even after being questioned about it.	Your relative has no awareness of memory difficulties. She./ he may deny any problems with memory.

Appendix six

Interview schedule

Send two Values Histories prior to interview

General thoughts regarding values

Do values change throughout adult life?

Do values change in older years?

In your experience do the values of peoples with dementia change as the illness progresses?

Would you view a change in a person's behaviour as a change in their values? Examples

Is it useful to record the values of people with dementia?

Should we try to maintain a person's values even if it does not appear to matter to them as the illness progresses?

General comments about the two Values Histories

Would you know this type of information about your patients? Explore

Would or should it be recorded elsewhere or in their notes?

Would you refer to this document in the future if their condition deteriorated?

Does it have more impact in the first person or third person?

Sharing the diagnosis

Refer to Sylvia's Values History, section highlighted 'attitude towards dementia'

How appropriate do you feel it is to have this information?

Who's role do you feel it is to give the diagnosis and information about dementia?

How do you (or do you routinely) inform a person that they have dementia?

Why share/not share?

Give examples of situations where you would or would not share diagnosis

If a relative asked you asked not to share the diagnosis with the person would you go along with their wishes? How would you deal with this situation?

How or do discuss the prognosis and future care with the person with dementia?

How do you decide how much information to give the person with dementia?

Sharing diagnosis is often compared to telling someone they have cancer. What in your view are the differences or similarities?

Do you view dementia as a terminal illness? explain

How or should we involve people with dementia in planning their care?

Sylvia's appearance and hygiene

Refer to section highlighted 'How important is your appearance?'

Is this information useful? Is it appropriate to record it?

Would this statement have any impact on Sylvia's future care?

Imagine Sylvia becomes unkempt and neglects her hygiene due to forgetfulness. She is happy and unaware that she is dirty.

Should she still be bound by her previous values?

How should the situation be dealt with?

Is it worthwhile causing her agitation or distress to bring back to previous standards? If so to what extent? Explore

Family and Relationships

Refer to section regarding 'family relationships'

How usefulness is it to know this information. Is it appropriate to record?

Sylvia condition has deteriorated and she no longer has insight into her condition. She is neglecting her hygiene and been wandering in the local area. She is well known and people bring her back to the house. She refuses services although accepts meals on wheels. She has fallen out with her daughter and refuses to let her into her house accusing her of being interfering. She told you she does not want you to discuss her care with her daughter.

How would you deal with this situation?

Would the information in the Values History influence how much contact you would have with her daughter?

Would you respect her current or past wishes?

How do you encourage the person to choose a proxy?

How do you know if the person's relative has their best interests?

How do you obtain the balance between the needs of the carer and the person with dementia?

How do you seek the person with dementia's consent to discuss their condition with their carer?

Have you experienced any situations where you felt that carers did not have the person's best interests?

Have you experienced any situations where you felt that a person with dementia required someone to represent him or her independently rather than family?

Have you come across any instances where carer's views were put before person with dementia? Was it appropriate?

What impact do you feel the Adults with Incapacity (Scotland) Act will have on people with dementia? Do you feel it will change your practice?

Independence and safety

Refer to section within Sylvia's Values History regarding 'Independence and safety'

How appropriate do you feel it is to record this information?

Do you think it would have any impact on her care?

If a review meeting was held to discuss Sylvia's safety do you think it would be appropriate to refer to the document? Do you think it would (or should) influence decision?

Does the fact that it is recorded make any difference?

Do you feel it is feasible or appropriate to ask a person in the early stages of dementia what risks that they would be willing to take to stay at home?

To what extent would you go along with Sylvia's wishes if it conflicted with her carer's wishes? e.g. wandering, home security,

What do you think is an acceptable level of acceptable risk for a person with dementia to take to stay at home?

Have you come across conflicting attitudes regarding acceptable risk i.e. differing professional attitudes nurse v doctor carer?

Residential care

In your experience are people with dementia admitted into residential care either prematurely or left too long in the community?

What were the circumstances and what would have prevented this? examples

How do you deal with situations whereby a family might request residential care for the person, but the person refuse to enter?
What factors influence their capacity to decide?
How relevant or irrelevant do you feel the information in the Values History would be for a person after they have been admitted into residential care?

Marie's personal care

Refer to section where Marie records her views about 'personal care'.
Marie states that she does not want her family to assist with personal care, especially in relation to incontinence. She wants them to 'remember her the way she was'. She loses insight into her condition and does not recognise her family.

Is it appropriate for Marie to record this information?
Should her family respect her previous wishes or assist her?
What would you recommend if her family asked for your opinion?
Would it be appropriate for Marie to ask for only females to be involved in her care?

Marie's religious values

Refer to section where Marie records her 'religious beliefs'.
Is it appropriate to record religious values?
Do you ask patients about their religious values?
Is this information recorded?

Imagine Marie's condition has deteriorated to the extent that she does not recognise her husband and believes that her children are her brothers and sisters. She has been admitted to residential care. She however believes that she is in a hotel and that the residents are fellow witnesses. She enjoys sitting in the lounge with the residents and appears to enjoy birthday parties and religious celebrations.

To what extent should her previous religious wishes be considered as recorded in her Values History?
How would you deal with his situation?
Should she be removed from the festivities?
Would it make a difference if she became upset or agitated when removed?
To what extent should her family's views be considered?
What if they were not Jehovah's Witnesses?

Marie's medical values

Refer to the section in Marie's Values History regarding 'homeopathic treatment'.
Is it appropriate to record this information?
Should her medical values be maintained if she has lost insight into her condition and not aware what medication she is receiving?
Do you think her views would be respected in a residential care home?
Marie has become very agitated and staff would like medication prescribed to settle her.
To what extent should her views regarding homeopathy be considered?
What if she had a chest infection or a serious illness?

Marie's end of life values

Marie's condition has deteriorated to the extent that she is doubly incontinent, does not appear to recognise anyone in her family and cannot walk. She has been transferred to a nursing home. She has difficulty swallowing and two of her children have requested that she receives a peg feed (similar to some other patients in the ward). Others in her family have concerns about this stating that this would be going against her wishes.

Is it appropriate to record Marie's views about the end of her life?

To what extent should her views in the Values History be taken into consideration regarding end of life decision and proxy medical decisions.

Imagine there was a review meeting to discuss her condition.

Should the Values History be referred to?

What would your opinion be regarding peg feeding her?

Imagine her all of her family wanted her peg fed. Do you think her family's opinions or Marie's statement in the Values history would carry more weight?

If you developed dementia would you want to complete a Values History (or record your wishes)?

Appendix seven

Questionnaire

- 1. In general, how useful do you feel a Values History would be in helping to plan care for a person with dementia?**

Please Tick

Very Useful

Useful

Partially useful

Not very useful

No use whatsoever

- 2. On a scale of one to ten, to what extent do you feel a Values History could empower a person with dementia if their condition deteriorated to the extent that they were not able to articulate their own views?**

i.e. 1 = no extent whatsoever 10 = to a significant extent

1 2 3 4 5 6 7 8 9 10

- 3. To what extent would you refer to a Values History if the person's condition deteriorated?**

I would refer to it very frequently

I would refer to it frequently

I would refer to it occasionally

I would seldom refer to it

I would never refer to it

- 4. Which groups of staff do you think should receive a completed Values History (with the person's consent)?**

Social Workers

Voluntary organisation staff

Home helps/carers

GPs

Residential/nursing home staff

CPNs

Day Care staff

District Nurse

Hospital doctors

Hospital nurses

Psychiatrists

Other (please state)

5. Which people/organisations do you think would be the most appropriate to assist a person with dementia to complete a Values History?

Family member

Close friend

Voluntary organisation i.e. Alzheimer's Scotland

Advocacy worker

Social worker

CPN

GP

Psychiatrist

Day care staff

Other (please state)

Appendix eight

Malcolm's Values History

The purpose of this form is to provide an opportunity for those involved in Malcolm's care to know about his values, wishes and preferences in a number of areas. It is not designed as a substitute for communication, but to enhance communication. The form is not a living will and is not designed to prescribe future care, but to allow those reading it to adopt a person centred approach, considering Malcolm's feelings and values.

The form was completed over several interviews with the assistance of his CPN, Robert Boyd. An appendix with comments from his wife is also included.

Background

Malcolm is married to Mary and has four grown up children from a previous marriage. He is a retired senior university lecturer and researcher, who excelled in biochemistry. He has an international standing in his field, having written and presented major papers. Malcolm enjoyed his University days at Cambridge, where he obtained his doctorate. He did research for private companies and also worked at St Mary's Hospital, London. He has chosen to live in Glasgow for the past thirty years and considers it his home.

Initially Malcolm presented 6 years ago with reports that he had not been functioning as well as he could at work, finding it difficult to conduct lectures and organise himself. He had noted increasing memory problems e.g. forgetting people's names, word finding difficulties and lapses in concentration. When Malcolm initially presented for the tests he self-diagnosed Alzheimer's disease. He thought it was significant that there was a family history of both paternal grandparents suffering from the disease. He also reported a head injury, which he felt precipitated the onset of the illness. He was eventually diagnosed 3 years ago and subsequently granted early retirement

Overall attitude towards life

I think that physically I have good health. My quality of life is good. I don't get ecstatic any more, but I have contentment. An evening in with my wife watching TV, going to the garden centre, planting shrubs, going for drives- the simple things. University days were good, but I don't crave them. Cambridge was one of my happiest times.

I have occasional bouts of anxiety. Sometimes I can lie on my bed and by concentrating intensely it will leave me. Otherwise I have no techniques for dealing with it.

I do not suffer from serious depression.

I do not think I am irritable, although loud noises and people annoy me.

I like peace and quiet, although not all the time.

I like classical music and music which is easy to the ear. The Beatles were okay. I hate jazz

Family and relationships

My wife knows me better than anyone. We spend all of our time together. I also enjoy my family's company. A goal is for me to increase my contact with them in the future. It was difficult when my first marriage broke up, but I'm having more contact now they're older.

Proxy decision making

I have chosen my wife Mary to represent me should my condition deteriorate. I feel that she knows me better than anyone else. Should anything happen to Mary I think my sister Sarah would best look after my interests. If Mary needs advice I would like her to consult my sister Sarah or her cousin, who is a retired GP, or my mother who still is a very sharp lady. Mary has Power of Attorney, however, she consults me and we both tend to deal with the finances together at present.

Friendships

Friends tend to change over the years as circumstance change. I have lost contact with most of my older friends, but have made new ones. Mary and I are quite self sufficient that way. I don't like being in the company of loud mouths although I'll let them have their say. I am a democrat that way. I am a fairly quiet person

Religious background and beliefs

I have a scientific background and no religious beliefs. I have spent a large part of my life associated with the Liberal Party (local councillor) and would describe myself as tolerant, unless I have a cause to fight. I consider other people and adopt a humanist approach.

Relationships with doctors and other health care givers

I have worked closely with doctors doing research at various hospitals in London. On the whole I trust doctors' judgements, particularly my GP's. I don't necessarily trust hospital doctors. I have had a couple of bad experiences in hospitals. They don't always allow me time to communicate effectively. I would hope that they have my medical history to understand the extent of my problems.

Thoughts about medication and treatment

I usually check the chemical components of the medication, but on the whole have a natural meekness towards accepting the doctor's choice of medication.

I do not accept homeopathic medication as an alternative treatment.

I have a fair tolerance of pain, but will take painkillers when required.

Mary and I have similar views on health and medication. We are compatible that way.

I don't like hospitals. They are too noisy. Noises are very distracting.

Thoughts about having Alzheimer's disease

I was aware that I was not functioning properly at work, although I feel I could have gone on a little longer. I have a clear understanding of the pathology of the disease from the lab, although I feel there was a misdiagnosis. I received a head injury whilst playing hockey about 15 years ago and I feel this was a precursor to the symptoms I am experiencing. My father and grandfather had Alzheimer's disease

Thoughts about illness dying and death

I have no strong feelings about the end of my life. You can't lay down a rule. There are only two decisions really. Mary would be able to make medical decisions on my behalf. She knows me best.

Independence and self sufficiency

I like to know that I have independence, although I don't crave it. I do not have any strong inclination to take risks, especially as I get older.

I like to be consulted. I carry documentation when I go out.

Living environment

I've moved houses quite a lot during my life, so I don't become too attached. It's who you're with that's important. I do like having space for my books and a room to paint in. I appreciate a nice garden as I'm getting older.

Future care

At one time I would have worried about the future. Now I'm not sure. I think Mary will try to do her best for me in the future. She will be the faithful wife.

She will have a breaking point. She may appear calm on the outside. If she became ratty she would need away for a while. I would consider respite. I would consider

someone coming in to help. I'm sure Mary would agree. A lot would depend on the people in question. I can't say that there are any hard and fast rules about when one would consider going into residential care. We discuss these things openly.

What would you like people reading this form to know about you?

Communication is very frustrating. People don't always give me time to communicate. This is a symptom associated with the disease. At times I cannot find the words to express myself. Sometimes I just give up when speaking to people.

Comments from Malcolm's wife

Malcolm's wife has read over the Values History in detail with Malcolm and believes it to represent his values accurately .She would like to stress that he is an intelligent man and remains so despite his illness. She feels that communication is his biggest problem and would like people reading this form to be aware that his communication improves when he is feeling relaxed and deteriorates when anxious or put under pressure .He communicates well with people who know him.

Appendix nine

Jack's Values History

The purpose of this form is to provide an opportunity for those involved in Jack's care to know about his values, wishes and preferences in a number of areas. It is not designed as a substitute for communication, but to enhance communication. The form is not a living will and is not designed to prescribe future care, but to allow those reading it to adopt a person centred approach, considering Jack's feelings and values.

The form was completed over several interviews with the assistance of his CPN, Robert Boyd. An appendix with comments from his wife is also included.

(Names and some background details have been changed to protect anonymity)

Background information

Jack was diagnosed suffering from dementia of Alzheimer's type in May 2000. He had first noticed memory problems about a year prior to this. He feels his main difficulties are finding the right words to express himself, problems handling money and recalling information. He has a moderate degree of insight into his condition and has adapted his life accordingly to his limitations. He is a very sociable man who enjoys company, but has curtailed many of his previous interests.

Jack lives with his wife, Elizabeth, in a semidetached house in Rutherglen. He has always lived in Glasgow. They have a 36-year-old daughter, Jane and a 34year-old son, Mark, both of whom are in regular contact with them. They have two grandchildren. Jack is a retired civil engineer, having worked for British Gas until 6 years ago. Jack was commenced on Aricept 5mg daily and after three months he subjectively felt his cognition had improved, as did his wife. He felt his thinking abilities and concentration were clearer, although he has not notice any improvement in his memory.

Overall attitude towards life

Jack believes that he has had a good life- 'great times and not just in the early days'

His main achievements are bringing up his family and maintaining friendships.

He has happy memories of holidays spent with the family and wants to continue having holidays for as long as possible. Holidays and outings have always played a big part in his life.- 'My wee holidays tell a big story for me'.

He enjoys good service and quality hotels whilst on holiday and will pay extra rather than accept inferior accommodation

He has always been someone who gets involved in the community and is sociable.

His main interests have been golfing, boating, the 'Haggis Club' and Christian Aid.

He previously took leading roles in these organisations.

He received regular promotions at British Gas , where he worked for 33 years as an engineer.

He recognises his life is changing, but does not want to 'cry about it'. Although he has given up roles, which involve a high level of communication, he still experiences pleasure in other ways.

He enjoys when his grandchildren visit, going out for long walks and trips to town.

He also enjoys the theatre and church. He enjoys watching sport on television.

He describes himself as being 'quite easy going' person.

He feels he is good humoured and is 'not depressive' although 'has ups and downs like anyone else'.

He gets frustrated by his memory problems, but tries not to dwell on the feelings of frustration.

Privacy is important to Jack and he enjoys being able to sit alone at times to think or read.

He enjoys music, such as Frank Sinatra, but 'definitely not modern music.'

Family and relationships

Jack's wife, two children and grandchildren are what make his life worth living. He believes that his wife knows him better than anyone else and is his 'best friend'. He

would like her to represent him financially, medically and socially should his condition deteriorate. He also believes his son and daughter could represent his views well. He would like his wife to take advice from his son and daughter if she had difficult decisions to make in the future.

Jack has mixed with a variety of people throughout his life and does not favour any particular personality type and enjoys the company of quiet and outgoing people alike. In general he has not mixed with people who swear, but points out that 'we can all mutter the odd expletive'. In general he prefers people with a friendly disposition.

Religious background and beliefs

Jack attends his local parish church and has been an elder for over 30 years. He attends most Sundays. He used to attend more often, particularly helping out with practical aspects. He was an office bearer and also involved in raising funds for Christian Aid and building projects. He believes it is a better way of life. He is pleased his daughter and her family are taking an interest in the church.

Relationship with doctors and other health care givers

In general Jack has had favourable experiences in his dealings with medical and nursing staff. He trusts his GP's judgement and believes that in general health staff are looking out for his best interests. He complies with treatment and takes their advice. He has no strong views about alternative or complimentary medicine, but would take advice from his GP. At times he would like more information, if possible written information

Jack admits that he is experiencing difficulties communicating effectively. He recognises that his difficulties are accentuated when he is in situations where he feels anxious. In particular he experiences difficulties finding the right words to express himself, although he knows what he wants to say. He feels that he can communicate better with people who know him well and at times when he is feeling more relaxed. He prefers his wife to accompany him to medical appointments.

Attitude towards the illness

Jack is aware that he has dementia. He was upset when he was diagnosed but as time has passed he thinks 'it's not too terrible.'

He gets frustrated by his poor memory, but even more so by his word finding and communication difficulties. Until recently he has not known anyone else who suffers from the illness, but now enjoys the company of other people in the same situation at a local support group. He describes his attitude towards the illness as 'philosophical'. 'People may think I should be down in the mouth about it, but I'm not letting it get to me'

Thoughts about illness dying and death

Jack has no strong views about end of life decisions.

Independence and self sufficiency

Jack is aware that he has lost a lot of independence. He recognises that Elizabeth has taken over a lot of the organisational side of things.

'The bigger things are becoming more difficult.'

He values being useful and helping around the house. He does not have a strong desire to be independent or to take unnecessary risks in life but wants to continue live in his house, which he has lived in for 40 years

Living environment

Jack enjoys living in a pleasant environment. He does not like clutter and likes his home to be orderly, but comfortable. He enjoys 'peace and quiet.' Privacy is very important to him and for this reason he enjoys sitting in his conservatory looking out at the back garden, which is fully enclosed. He wouldn't describe himself as a gardener but enjoys that 'Elizabeth keeps it nice.'

.

Future care

Jack has chosen not to discuss future care with his family in too much detail. He has expressed some reservations and feelings of guilt about this as he realised this may put pressure on them to anticipate his needs in the future.

‘Its not so good of me while I can still talk about it’.

He however feels that they would look out for his best interests. He feels that Elizabeth is coping well at the moment and believes that she could cope with ‘a bit more.’ He cannot predict what Elizabeth could cope with in the future, but would expect his son and daughter to advise Elizabeth if she was struggling.

‘My biggest problem would be if Elizabeth's health deteriorated.’

He would consider respite or home support if it helped Elizabeth.

‘I don’t think Elizabeth would want to do it, but would consider it if the rest of the family asked her.’

What would you like people reading this form to know about you?

Comments from Jack's wife

Jack's wife has read over the Values History in detail with Jack and overall believes this to be a true representation of Jack's values. She feels, like Jack, that she would rather not look too far ahead into the future. She feels that the only aspect, which is not fully represented about Jack's character in the Values History, is that he can be quite fastidious. He likes things to be organised well in advance and to know what his plans are for the day. He does not like to be kept waiting and can become agitated if waiting without explanation. She feels these traits have accentuated since the onset of his illness.

She would like people reading this form to be aware that Jack likes friendly people who are polite and respectful.

Appendix ten

Sylvia's Values History

The purpose of this form is to provide an opportunity for those involved in Sylvia's care to know about her values, wishes and preferences in a number of areas. It is not designed as a substitute for communication, but to enhance communication. The form is not a living will and is not designed to prescribe future care, but to allow those reading it to adopt a person centred approach, considering Sylvia's feelings and values.

Background and overall attitude towards life

My mother brought me up in the west end in a room and kitchen, but she died when I was in my teens. My mother was a smart lady. She was very talented and artistic. She used to take samples of fabrics to big houses and was like a modern day interior designer. We always had a lovely house although we never had much money. She was only forty six when she died. My father died when I was a baby, so I never knew him. I remember going to London to see his relatives when I was a wee girl. I also had a brother who died before I was born. My only sister, Jane, married when my mother died, and I lived with them for a while, but her husband wasn't too keen for me to live with them. I lived with my aunt for a while, but she wasn't used to having children and that was difficult. When my girlfriend married I used to help her mother who was crippled with arthritis. Her mother asked me to move in with her. I don't know what I would have done without her. It was good for me and good for her. I lived with her until I married Robert.

Robert was a wonderful husband. We had one son, David. We initially stayed in Govanhill and then moved to Rutherglen. I worked in Rolls Royce during the war and in a biscuit factory for about five years. I never worked while David was young. Robert had a good job in the civil service and I never needed to work. When David was older he married Janet. She is like the daughter I never had. I love her as much as David and could not manage without her.

After David left home I got a job putting leaflets through doors. I didn't need to work, but enjoyed being out and about with people. I then decided to train as an enrolled nurse and worked in a nursing home for fifteen years. I loved that job. I was sad when I had to retire. I loved helping people and my colleagues were great.

How satisfied are you with what you have achieved in your life?

I've had the odd knock now and again, but the good times outweighed the bad. I was unlucky losing my father and mother so young, but I had good times with my mother when she was alive. Everyone's life is different and it's up to you to make the most of it.

What activities do you enjoy?

The choir is very important. We go out once a week singing to the 'old folk' in residential homes. Some of them don't have any visitors and it can brighten up their week. We have a great laugh. It keeps you going and you have the company. We make fun of each other when we make mistakes. When I found out that I had Alzheimer's disease I told them I was going to give up the choir because I know it can be annoying if someone is repeating themselves all the time. They said 'no way' and I'm really pleased about that. I love the fun and I feel we are giving pleasure to others and giving them a laugh. I think it's nice for people in nursing homes to know that someone is thinking about them.

Holidays....that's what I miss the most. I loved going abroad, mostly for the heat. It's not been the same since Robert died...nothing has really...I loved seeing the different countries and the people. I've been away with people from the church and David and Janet. That was good.

What frightens or upsets you?

I must admit working as a nurse has given me a fear of ending up in a nursing home. The indignity that some of the old folk had to go through. I hope I die before I reach that stage.

What, for you, makes life worth living?

My daughter-in-law Janet and my son David are the most important people to me. They make my life worth living.

What else is important to you?

My appearance is very important to me. I'm not as smart as used to be but I'm not the type to slouch about any old way. Even if I'm in the house I like to look nice. It bucks up your morale. It's nice when people say 'you're looking nice to-day Sylvia'. I'm not conceited, but I wouldn't go out the door unless I was dressed properly.

My home is very important. It may sound boring to other people, but I love tidying it up and polishing my ornaments and just generally pottering about. I have so many memories here.

Religious background and beliefs

What is your spiritual/religious background?

I attend the Church of Scotland. It's always been very important to me from when I was a wee girl. Don't misunderstand me I'm not a Holy Willy or anything, but I like to go regularly and it makes me feel good.

How does your faith affect your feelings towards illness?

I say my prayers every day and thank Him for another day. I always feel He is looking over me. I don't know what happens after death, but I wonder what it's really like. If someone doesn't believe in God then that's up to them, but I don't really understand why some people cannot believe in a creator.

How does your church support you?

I enjoy the company and I attend the guild. I like the fact that everyone knows you. I enjoy helping other people. A visit or sending flowers can make all the difference to someone who's housebound.

What general comments would you like to make about your beliefs?

I'm quite open and I don't mind talking about things. I have a very strong faith, but recognise that we all have different views and I'm not the type of person to say I'm right and everyone else is wrong.

If your condition deteriorates would you want to continue to attend church?

I would take a day at a time. If I could dress my self and someone pick me up then I would still want to go. If I couldn't manage then I still have my bible.

Family and relationships

What role do family and friends play in your life?

My daughter- in law Janet and my son David are the most important people to me. Janet is like a best friend to me and we've always got on extremely well. We've never had a cross word. I'm very fortunate that I have her.

Friendship is also very important. I feel sorry for people who don't have company. It's nice to know that there are people there if you need them. In the past I used to know a lot of neighbours but they're all out working now.

I don't need company every day. I'm quite content to be alone as well. I don't moan about it. I've been alone for 13 years now. I enjoy chatting at the choir and I get all my chatting done at the weekends when I stay with Janet.

What type of company do you like?

I don't care who you are, what your religion is, whether or not you have money. These are earthly things and don't bother me.

I don't feel comfortable in drunken people's company especially if they are obstreperous. Drink is okay in moderation. I enjoy a Baileys every now and again. I wouldn't be nasty to a drunken person, but I would hold back. If someone was drunk in the street I would help them. There's nothing wrong with anything in moderation.

I don't like company where there is a lot of swearing, although I suppose that's life now.

I couldn't go into company if I felt I wasn't wanted. I would hold back. I would need to be invited. I'm not the type of person who would push myself into company. I'm quiet that way.

I like chatty and quiet people alike. It's easier if you're with someone chatty and you can get a laugh, but if someone was sad I would try to console and comfort them.

I love a good laugh.

I'm not a loner by nature. I'm alone but not a loner.

I don't need company every day, but I make the most of it when I get it.

Relationship with doctors and other health care givers

How do you feel about doctors and caregivers?

I feel doctors and nurses are trying to do their best for you and trying to do good. I would never ignore their advice. I feel if you do that you're wasting their time.

What are your feelings about having dementia?

I know it's the grey cells that start to go in the brain and there's not much I can do about it. I imagine once it starts it tends to deteriorate. I wish I knew what triggered it off though. I've accepted it though and I'm otherwise healthy for my age... and I still have a life!

As soon as I received my diagnoses I told my friends and neighbours. I told them so that if they saw me doing anything wrong they could see me right...perhaps bring me back home if I got lost. Fortunately that hasn't happened yet. If they didn't know that I had Alzheimer's disease and I was doing something wrong or silly then they might not want to interfere. Now I feel that if I did something wrong they would try to rectify it. The most important thing is for me to continue living at home and will do anything to ensure that happens.

If your condition deteriorates would you want to know?

Oh yes because I think it's important that you know your limitations. I think I would know within myself

Who would you want to represent you medically if you were unable to do so?

Janet and David.... no-one else. I have no qualms that they would do the right thing by me. They would not do anything unless it was right for me

Independence and self sufficiency

How does independence or dependence affect your life?

Independence is very important to me. I can do what I want to when I want to. I have freedom of choice. If I want to help someone I can do that. I've always been very independent, possibly because I was left alone when I was young.

If your current physical or mental health gets worse, how would you feel?

I'd hate it but know it might happen. This place of mine is so important to me and I'm so grateful to still be living at home at my age. I know my limitations though. I hope to stay at home until the Good Lord says 'Sylvia your time is up'. That's my ambition. I know there are risks, but as long as I'm not disturbing other people I want to stay at home. I'd accept any help to keep me at home.

If I got lost when I was out it would make me wary of how far I could go in the future. I stopped going into town for that reason... in-case I got lost, but I do feel it's my right to take that risk.

I stopped using the cooker and now only use the microwave. Nothing happened..... it was my decision.... but I had a fear of leaving it on. I know my limitations. I've decided not to be silly. I get pleasure from my house and want to stay at home for as long as I can.

If you were to experience decreased physical and mental abilities, how would that affect your attitude toward independence?

I would accept help, but I feel I don't need it just now. If Janet thought that I wasn't coping I would need to abide by her decision. She would say 'right you need someone in or need to go in somewhere'.

If you had difficulty dressing would you want someone to help or correct you?

Definitely. My daughter- in law checks everything and she gives up her time to make sure I'm alright.

If you had difficulty with your personal hygiene would you want someone to help you?

Definitely. Physical cleanliness is very important to me. I have a shower every day. I would be very embarrassed if I needed assistance, but I would prefer that than going dirty. Janet visits once a week so I would probably need someone to come in a few times a week. I would have to accept help and overcome my embarrassment

Who would you want to look after your finances if you were unable to do so?

Both Janet and David, although Janet would probably deal more with the day to day things.

Who would you want to look after your welfare if you were unable to do so?

I've always been close to Janet. She would know what is important to me. She could decide what care I needed..... although, who knows, I could renege at the time.

Living environment

What general comments would you like to make about your surroundings

This house of mine is very important to me. I am most grateful that I can still stay at home. I know where everything is and have no fears being alone. I love the freedom, being able to potter about and do my own thing. I'm content to be here alone and don't need much else to occupy me.

How might illness, disability or age affect this?

If I live long enough I might have to give it up, but I want to stay here till I can't manage and I want to stay at home as long as I canthe way that I am. I wouldn't want to go into a home. I hate having to think about it.

If you had to go into a home what would be important to you?

If I really had to go in somewhere I wouldn't want to go into any old place. Somewhere nice and clean where I could be well looked after. I think the most important thing would be the staff. They could either help or mar the place. I imagine by that time it wouldn't matter to me where I was. Probably somewhere near Janet and David, for their needs, would be better. I would leave it up to them. I have no qualms that Janet would do the right thing by me and she wouldn't do anything unless it was in my best interests.

Would you want to live with your family?

No way.... it wouldn't be fair for Janet and David. We are close, but there are limitations. They have they're own lives to live.

Thoughts about illness dying and death

What general comments would you like to make about illness, dying and death?

I keep thinking 'Lord, when it's my time please take me quickly'. I've seen people in old peoples' homes, just sitting there and I've thought... that's no life...if it was me I'd rather go. I would hate to get to the stage where I didn't know who I was or where I was. My ambition is to die in my own house in my sleep, but I know that we've got no control over that.

What would you like people reading this form to know about you?

I'm not a pushy person. I like to be friendly and I enjoy fun. I will hold back if I feel I'm in company where I'm not wanted. If I can do anything to help someone I will. I believe what goes around comes around. There is always someone worse off than yourself. You can be helping someone and someone else can be helping you. I feel good comes around in a circle. I think I am a modest person. I take one day at a time.

If you had to go into a home what would be important to you?

If I really had to go in somewhere I wouldn't want to go into any old place. Somewhere nice and clean where I could be well looked after. I think the most important thing would be the staff. They could either help or mar the place. I imagine by that time it wouldn't matter to me where I was. Probably somewhere near Janet and David, for their needs, would be better. I would leave it up to them. I have no qualms that Janet would do the right thing by me and she wouldn't do anything unless it was in my best interests.

Would you want to live with your family?

No way.... it wouldn't be fair for Janet and David. We are close, but there are limitations. They have they're own lives to live.

Thoughts about illness dying and death

What general comments would you like to make about illness, dying and death?

I keep thinking 'Lord, when it's my time please take me quickly'. I've seen people in old peoples' homes, just sitting there and I've thought... that's no life...if it was me I'd rather go. I would hate to get to the stage where I didn't know who I was or where I was. My ambition is to die in my own house in my sleep, but I know that we've got no control over that.

What would you like people reading this form to know about you?

I'm not a pushy person. I like to be friendly and I enjoy fun. I will hold back if I feel I'm in company where I'm not wanted. If I can do anything to help someone I will. I believe what goes around comes around. There is always someone worse off than yourself. You can be helping someone and someone else can be helping you. I feel good comes around in a circle. I think I am a modest person. I take one day at a time.

Appendix eleven

Marie's Values History

The purpose of this form is to provide an opportunity for those involved in Marie's care to know about her values, wishes and preferences in a number of areas. It is not designed as a substitute for communication, but to enhance communication. The form is not a living will and is not designed to prescribe future care, but to allow those reading it to adopt a person centred approach, considering Marie's feelings and values. Marie hopes the following information will help people know a little more about her.

Background and overall attitude towards life

Marie was born and brought up in the South Side of Glasgow by her parents Sarah and Donald, and is the older sister of Timothy and Michael. Both her parents were Jehovah's Witnesses and her earliest memories are of being out with them 'preaching the Good News of the Kingdom'. Marie recalls that her mother was a 'wonderful person' and someone whom she has attempted to model herself upon, especially her skills as a homemaker and teacher of the bible. Marie dedicated her life by way of adult baptism in 1946, a decision which she has never regretted.

Marie attended her local high school and after studying home sciences at college decided to pioneer rather than work secularly. She spent some time pioneering in County Durham and after marrying Ian in 1955 spent five years as a missionary in India. Her first son, John, was born in India and on returning to Glasgow in 1961 she went on to have Michael, Robert and Rose. Although she is glad that she spent time in India, she was glad to be back home in Glasgow and found her life to be very fulfilling bringing up her family and 'serving Jehovah' in Glasgow.

Over the years Marie's immediate family have moved from Glasgow. John lives in Stirling and the others now stay in the South of England. She has five grandchildren-

Paul, John, Daniel, Sarah and Marion. She does not see too much of them, but 'loves their company' when she sees them

Marie used to get 'great pleasure' from reading, especially the bible and bible publications, but now experiences difficulties reading. She enjoys it when Ian reads to her. She prefers silence when she is trying to read or work about the house. Although occasionally Marie likes 'easy listening' and classical music she finds too much noise irritating.

'I couldn't stand a lot of music all the time ...I'd hate it.'

Marie won prizes for sewing and cooking whilst at college. She continued to get great pleasure from these activities throughout her life, however, now experiences difficulties.

'For a long time I sewed all my own clothes. I loved that, but I don't do that now. That place in my mind has gone. I've lost all my skills.'

Religious background and beliefs

Marie feels that the most important thing in her life is 'serving Jehovah'. Her earliest memories are speaking to people in the South Side of Glasgow about the bible with her parents. Her father was one of the first Jehovah's Witnesses in Glasgow. She does not consider it to be a religion, but 'a way of life' and often she refers to it as 'the truth'. She calls those 'in the truth' her 'brother and sisters'. Regarding her faith she states:

'We've had it all our lives and it's a wonderful position to be in. It's a great privilege and very few people have had that. As a girl my time was spent preaching and it's continued on through me and now my family. I've always been aware that I received something extra because I was taught from infancy.'

'I've always loved the truth and it's never been a trial for me to continue. It's just marvellous for me to know the truth. It's a precious thing and something that we should hold on to.'

Marie has never doubted her faith, 'never one bit', and has spent her life teaching people the bible. She believes that the earth will eventually be ruled by God and will become a paradise. Marie thought it might have happened when she was younger but states:

'It doesn't matter when it comes. It's getting there that's important and what we do with our lives meantime.'

Marie does not celebrate mainstream religious festivals like Christmas and Easter or birthdays and does not take part in political festivals. She would feel awkward if placed in a situation contrary to her beliefs.

'I wouldn't want to offend anyone. If someone tried to involve me in a situation contrary to my beliefs I would explain my beliefs to him or her and excuse myself. If I didn't know them I would say I was in a hurry and excuse myself.'

Family and relationships

Marie has maintained friendships over the years and feels very close to the brothers and sisters in her congregation. Marie particularly enjoyed attending large conventions and has memories of attending assemblies in Poland, Moscow and New York and has kept in contact with many of the brother and sisters. Throughout her life she has believed in being hospitable and had pioneers and missionaries staying with her from other parts of the country and overseas. She was taught to be hospitable by her mother. She enjoys receiving letters and, until recently, enjoyed writing to her friends 'sharing bible and preaching experiences.' Marie believes that she gets on well with most people and cannot specify a particular type of person that she favours. Over the years Marie has mainly socialised with other Jehovah's Witnesses stating that 'it's a lovely thing to be with people who believe the same thing'. However, in general, she enjoys the company of 'pleasant and friendly people.'

Marie does not like aggressive people and could not be in the company of someone who used bad language.

'I just couldn't stand it. I couldn't have association with anybody who swears. It's just not right.'

Marie likes company, but 'not too much'. She prefers small gatherings. 'A few people, but not too many'. She likes time to herself but 'not too much.'

Finances

Marie has arranged for her husband Ian, her brother Timothy and her son Michael to have Power of Attorney to look after her financial interests. Marie is a partner in a long established family business.

Relationship with doctors and other health care givers

Marie reports that past relationships with the doctors and health staff have been good and she usually complies with their advice. However, she has clearly stated over the years that she would not under any circumstance accept a blood transfusion. Until recently Marie signed a wallet card stating that even if she were in an accident she would not accept a blood transfusion. She is unable to sign her name now but is still of the same opinion.

‘I view it very seriously. I just wouldn’t accept it (a transfusion) and would not allow it to happen. I would be very adamant.’

Marie is aware that there are various forms of non-blood management, which would be acceptable to her, but is unable to recall any. In the event that she required such treatment she would be happy for Ian and her family to decide upon the most appropriate management, knowing that they would comply with her religious beliefs.

More recently Marie has found it difficult to communicate with people, particularly professionals and people she does not know well. She is aware what she wants to say but sometimes ‘finding the right words can be awkward’. She believes that, in general, people who know her well give her enough time to find the words, ‘mostly, but not always’. She sometimes feels that people ‘talk down’ to her.’

‘People who know me well are good with me. Mostly I prefer to find the words myself, but sometimes it’s awkward and I like people to help me.’

Marie prefers Ian to accompany her to medical appointments and would like Ian to represent her should her condition deteriorate, although is also happy for any of her four children or her brother to represent her.

Marie is happy to receive conventional medical treatment but in the past has always tried complimentary treatments in the first instance. Over the years she has attended a homeopathic doctor in Troon for various skin conditions, anxiety problems and insomnia. With regards to homeopathy she states:

‘I’ve taken it in the past and it’s been very good for me’

Feelings regarding dementia

‘I knew something was wrong for about a year before I was told. It’s better to know than to wish you knew. Now it’s just become the normal for me and I’ve settled into it. I just made up my mind not to worry. What good does it do? Mind you, sometimes I about think about things..... about the things that other people can do that I can’t manage now. I’m not perfect..... If I never had the truth then things would be terrible.’

Independence and self sufficiency

Marie recognises that she has lost a degree of independence and relies on Ian to look after her. She also recognises that he will need a break in the future. In the first instance she would rather stay with friends or family to give him a break, but appreciates that this might not be possible. Regarding respite she states:

‘I would definitely consider it. I understand it is just to give the person a break. I’ve never done any thing about it but I know it will come and I don’t know when. Ian is doing more for me than men normally have to do. Ian is very good, although

occasionally becomes a bit ratty! Who wouldn't? I know he occasionally needs a break. It's only fair.

If Marie's condition deteriorates she would prefer assistance from fellow Jehovah's Witness's. Her appearance is very important to her.

'I like to look nice...oh definitely... no matter where I'm going'.

Marie states she would accept more help with her personal care if her condition deteriorates. At the time of writing Marie has a friend who helps her with some 'lady's things'. Regarding Helen, Marie states:

'I love her and she loves me. She is a real blessing to me she does my hair and all the lady's things that Ian can't manage. She has been great and keeps me right.... in a nice way.'

Marie realises that Helen might not be able to increase her level of input in the future. She also knows that it might not be possible to receive assistance from a fellow Jehovah's Witness.

'I wouldn't say no if it was someone nice, although I would much rather it was someone in the truth'.

With regards to the future Marie would like Ian to consult her family if he needs advice. She worries that he will not know when he needs help. She cannot differentiate who in her family could give the best advice to Ian.

'They all know me so well. I've no way to differentiate. Timothy, my brother, also gives good advice'

Thoughts about illness dying and death

Marie has no fears of death due to her strong faith. She believes she will wake up in a paradise earth. She does not believe in euthanasia which is 'against God's law', but would not want to have her life sustained 'beyond her natural time.'

Living environment

Marie is happy living in her home with Ian. She likes her home because it is spacious and has 'lots of sunlight'. She likes the area because 'it's quiet', which is very important to her. She also knows her neighbours well and feels safe knowing they are 'on hand'. Marie recognises that she could not live alone and a time may come when she needs more care than Ian could provide at home. She does not want to make any plans for long-term care.

'I have purposely not thought about it. There are homes for Jehovah's Witnesses in other areas, but they are too far away. I wouldn't want to go far and would rather stay in the area. I've got so many friends here. I don't see myself in a place with 400 people. I don't look ahead.... Jehovah will look ahead for me.'