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**UNIVERSITY OF SOUTHAMPTON**  
**FACULTY OF SOCIAL AND HUMAN SCIENCES**  
**SCHOOL OF EDUCATION**

**The Experience of Caring for Someone with Dementia:  
A Biographical Study**

by

**Gillian Constable**

Thesis for the degree of Doctor of Education

October 2011



**UNIVERSITY OF SOUTHAMPTON**  
**FACULTY OF SOCIAL AND HUMAN SCIENCES**

School of Education

Doctor of Education

**ABSTRACT**

**THE EXPERIENCE OF CARING FOR SOMEONE WITH DEMENTIA: A BIOGRAPHICAL STUDY**

BY GILLIAN SANDRA CONSTABLE

This research was about the lived experience of caring for someone with dementia. Six informal carers of people with dementia were interviewed. The carers were defined as 'informal' as they were family and friends, and therefore unpaid. Five of the carers were women who had or were supporting their mothers, and one was a man, who had cared for a friend. Three carers identified as lesbian or gay. I wanted to hear the stories of a group that are generally neglected in research (Turnball, 2002). Carers are diverse with a range of needs, and I wished to discover if services were 'gay friendly' or implicitly heterosexist. In addition I wanted lesbian and gay carers' stories to be heard and their contribution to be recognised. The research is important as there are an estimated 750,000 people living with dementia in the UK and 500,000 partners, family members and friends are involved in caring for someone with dementia at a value of £6 billion a year, if care was provided by health and social care services (Department of Health, 2009).

The research method was biographical in relation to the participants' caring role. It explored three areas: the experience of caring, coping approaches and encounters with health and social care services. The interviews with carers took place in 2010 and the cared for had, or were living in: London, Wales, south-east and north-west England. The theoretical perspective of the research was person centred (Kitwood, 1997) set within the legislative and social policy framework for carers. The data was analysed primarily through pre-determined codes arising from the interview schedule and Skills for Care 'Core Principles for Carers' (2010) but also searching for patterns within and across cases.

The findings were that the carers did not experience the person with dementia as a burden, but contact with health and social services was often problematic due to the fragmentation of services, lack of one practitioner co-ordinating care, and an absence of knowledge about carers' legal entitlements. In addition services adopted a medical model of care focusing on the dementia of the cared for with limited interest in the cared for or carer's biography, consequently services were not person centred, or gay friendly. Carers' commitment to the person with dementia was on a continuum between the obligations of kinship and unconditional love. Positive aspects in the relationships endured in particular humour and shared activities.

The messages for practice were that health and social care practitioners require training in person centred practice, as well as the legislation and policy framework for carers. Personalisation of services provides opportunities for shifting services from a task centred to person centred approach, including the development of gay friendly services.



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# DECLARATION OF AUTHORSHIP

I, Gillian Sandra Constable declare that the thesis entitled: Caring for Someone with Dementia: A Biographical Study and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
- I have acknowledged all main sources of help;
- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
- none of this work has been published before submission

Signed: .....

Date:.....



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# **Chapter 1: The Experience of Caring for Someone with Dementia: A Biographical Study**

## **Introduction**

This thesis reports research focused on the lived experience of caring for someone with dementia, as many people with dementia are cared for within their family and social networks (Department of Health, 2010c). Six carers of people with dementia were interviewed using a biographical research approach. The carers were defined as 'informal' as they were family and friends, and therefore unpaid. Five of the carers were women and one was a man: three carers identified as lesbian or gay. The carers had all cared for, or were still supporting a parent or parents apart from the male carer where the cared for person was a friend. One criterion for inclusion in the research was that the carer had maintained a relationship with the person with dementia throughout the illness.

## **Why this Research Matters**

There is considerable public interest and concern about dementia in the UK, which is proportionately affecting more people as the British population ages, as its prevalence increases with longevity (Department of Health, 2009). It is estimated that there are 750,000 people living with dementia and 500,000 partners, family members and friends are involved in caring for someone with dementia at a value of £6 billion a year, if care was provided by health and social care services (Department of Health, 2009).

This area of research is significant to me as I am a social worker and teach social work students. Increasingly social work practice in Local Authorities involves safeguarding adults with special needs. People with cognitive impairments are especially vulnerable to emotional, financial, sexual and physical abuse, as well as neglect (Pritchard, 2007). People are made vulnerable not by their needs but by the environments they find themselves in and the services they receive:

it is societal processes which create vulnerability. People who are called 'vulnerable adults' may be in need of community services to enjoy independence, but this is not what makes them vulnerable. What makes them vulnerable is the way they are treated by society generally and more specifically by those that support them. Vulnerability is therefore also a particular form of oppression (Martin, 2007: 16).

This has been confirmed by my experience. One of my first jobs as a young person was working in a care home for older people. A significant proportion of the residents had dementia. The care home was a large Victorian house arranged on three storeys, entirely unsuitable for older people with mobility difficulties as there was no lift, and therefore no access to a garden or the world outside. The female residents were on the floor above the men. I was allocated to the women's floor which was referred to by some staff as the 'babies' floor', which was highly demeaning and stigmatising. The women shared large rooms which accommodated up to four people. The floor was linoleum and the environment sparse and bleak. These women were state funded and afforded no privacy or dignity. The routines of the home were inflexible and boring. Even to this day I can remember the women's names and I felt a great sense of affection for them. They were highly individual, and the factor of their dementia did not diminish this. My memory contains sadness, as they deserved much better care. They were abandoned by family and friends, as there were few visitors. Some of the care assistants were emotionally disengaged and assumed that acts of frustration and aggression were premeditated by the residents rather than indicators of distress. These staff could be critical and disparaging towards the residents, as if their cognitive impairments made them less than human. Many of these attitudes stemmed from a lack of knowledge and understanding about people's needs, as no training was provided, but I remember three members of staff in particular, who were young like me and very kind in their treatment of the residents. To see this type of compassion in practice in an environment that was the antithesis of homely was significant for me, as I wanted to be like those staff.

My experience in that care home 31 years ago gave me a profound and enduring insight into the importance of empathy in the support provided to people with dementia (Sheard, 2007). The quality of care is sadly still highly variable, and a lack of emotional closeness and interaction has been identified, as a continuing cause for concern in the support that people with dementia experience (Commission for Social Care Inspection, 2008). This led in 2009 to the publication of the National Dementia Strategy. It highlighted that people with dementia living in the community require their carers to be supported by health and social care services and is cross-referenced to the Carers Strategy (Department of Health, 2008a). Carers are entitled to have their needs assessed, and to be supported to remain in employment, education and able to participate in leisure activities, as well as provided with short term breaks from caring. Since 1995 there have been three pieces of legislation as well as policy building on the entitlements of carers to be

supported in their role. The Coalition Government has broadly supported recent policy both in terms of people with dementia and carers (Department of Health, 2010a, 2010c). In spite of the legislative and policy framework to support carers, services are inconsistent and inadequate due to a lack of political priority given to carers (Carers UK, 2009). These factors added to my interest in this area of research given that carers receive inadequate information, advice, emotional and practical support from the state. I was curious to understand more about the emotional resilience that enabled carers to maintain a relationship with the person with dementia, as the illness progressed, which inevitably resulted in the relationship changing with the cared for person becoming more dependent. My motivation to undertake this research was professional rather than personal. I wanted to enhance my understanding and develop approaches to support person centred practice through learning from the lived experiences of people with dementia and carers, so this could become embedded in my teaching of social and health care staff.

## **The Aims of the Research**

The core purpose of the research was for me to understand the lived experience of being an informal, unpaid carer, the coping approaches that family members or friends used and the resilience they developed to go on caring, and carers' views of health and social care services. I wanted issues of diversity to be reflected in terms of sexuality, so I ensured that half of the carers identified as lesbian or gay. I wished to capture the particular experiences of this group, which generally is neglected in research (Turnball, 2002). It is important not to assume carers are all the same with similar needs, consequently one aspect of the research was to discover if the carers had found health and social care services 'gay friendly' (Age UK, 2010). Heterosexism in my experience is often implicit in health and social care services, and I wished to give lesbian and gay carers a presence in the research. This was not just in recognition of their existence, but more a positive validation of the emotional and practical contribution that they too make as carers. It is my belief that there is more commonality between people than differences, and being a carer illustrates this point. For example one lesbian carer speaking of supporting her partner with dementia described it as: 'like walking on thin ice and the ice is getting thinner and thinner but you don't especially notice – until suddenly you fall through, and your world is suddenly so, so very different' (Dixey, 2010:49). This powerful image expresses loss and fear by using ice as a simile, and could probably be expressed by many carers irrespective of their sexuality. Nevertheless for lesbian women and gay men they may experience discrimination, marginalisation and invalidation of their relationships due to their sexuality, which only makes caring more fraught and distressing. For these reasons their stories should be heard. My initial research plan was to interview three heterosexual and three



lesbian/gay partners of a person with dementia. Although I made strenuous efforts to locate partners I was unable to achieve recruitment of participants caring for their partners irrespective of sexuality. Instead, while I recruited participant carers who were heterosexual and participants who were gay five of the carers were daughters and one carer was a friend of the person with dementia. This meant I could retain my concern to represent diversity in the sexuality of the carers, but their sexuality became less of a focus for the research than was initially intended. Furthermore only two people with dementia were still alive and they were in care homes. I concluded that the demands of caring for someone with dementia are such that it may be easier emotionally to engage in research once the caring has ceased. Consequently the research took on a different perspective as the dominant relationships were between daughters and mothers, apart from the male carer who was caring for a friend.

I wanted to develop an understanding of the experience of caring for someone with dementia, as the illness progressed, as a social worker I am aware that carers' capacity to continue to care varies, and I wanted to gain a sense of what motivates and enables some people to continue to care irrespective of the challenges and personal costs to them. I consequently only interviewed carers that had sustained their relationship with the person with dementia throughout the trajectory of the illness. I found research participants by designing and distributing two leaflets setting out brief details of the research project. One leaflet was targeted at the lesbian and gay community, so was explicit in this being a criterion for inclusion (Appendix A). Both leaflets stressed the need for the carer to have maintained their relationship with the person with dementia (Appendix B). I publicised the research project with the support of organisations such as the Alzheimer's Society Lesbian, Gay, Bisexual and Transgender (LGBT) Network, LGBT Older People's Forums, Gay and Grey Forum, Age UK LGBT Network, Skills for Care, Day Centres, Home Care Services, Social Work Teams, friends and colleagues. A snow-balling approach was used, and people contacted me for further information.

The carers were White/British/European, with professional backgrounds. For ethical reasons it was important that I did not place carers under any pressure to engage with the research, as I recognised that people would need to feel both ready and prepared to talk about their caring role. I did not want the research to cause harm or distress. The people that came forward to be interviewed were therefore self-selecting, and not diverse in terms of ethnicity or social class. Further research should seek to access carers who are diverse in terms of ethnic origin and social class, as the impact of factors like poverty and isolation can create added strain and difficulties, for example if people have limited financial means they are unable to purchase additional services (Department of Health, 2005a).

## **The Research**

The thesis is structured in chapters which include a review of the literature, research methods and methodology, analysis and discussion of the research findings. It concludes with messages for policy and practice to improve the quality of care provided by health and social care services. A key finding was the need for a shift from medical approaches to dementia to person centred thinking and practice, which recognises the importance of maintaining personhood through curiosity and knowledge about people's biographies. The findings from the research are being used in my teaching with social care and social work students, and indeed one of the interviewed carers is telling his story to the students. The aim is to enable practice to be inclusive and gay friendly by recognising the importance of life stories, and consequentially valuing the knowledge carers hold about the person with dementia. This enables a sense of identity to be sustained, and enhances well-being; moreover it offers person centred practice to both the carer and the person with dementia.



## Chapter 2: Literature Review

### Introduction

I have structured this review of the literature on carers of people with dementia by adapting Erben's (1998: 7) schema for biographical research. This enables me to reflect on the lives of carers within their social, political, cultural and personal contexts. In this research I have adopted a dyadic approach where the relationship between the person with dementia and their carer is understood as one of interdependency, where personal histories and identities are seen as co-existing (Brooker, 2007; Piiparinen and Whitlatch, 2011). I critically examine different theoretical and policy approaches to dementia and ageing, as well as being a carer, in order to enhance understanding of the experience of caring in the context of supporting someone with dementia, in contrast to another disability. The incidence of dementia increases with age, so theories of ageing and social policy perspectives pertaining to old age are explored.

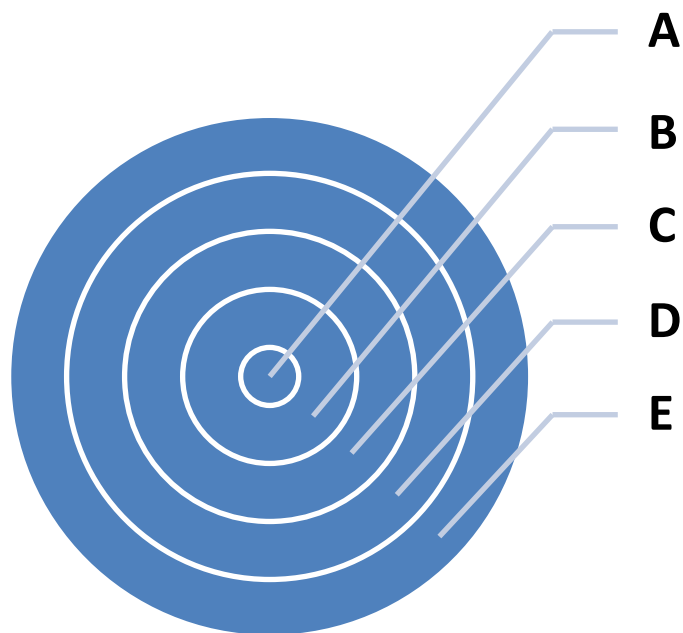
I include a focus on lesbian women and gay men as carers, as often heterosexist and familial assumptions are made about caring and the life styles that people have experienced (Harrison, 2006; Fannin *et al.*, 2008). These aspects of the review will address 'cultural system, societal context and chronology' of caring (Erben, 1998: 7). The review then moves to 'specific events' and 'local context' to explore issues of identity, resilience and coping strategies adopted by carers. The intention is to acknowledge both the challenges and rewards of caring, as carers 'protect people with dementia from potential harms of society, a society that fears deviance and disorder, and craves control and conformity to the cultural 'norms', a set of fears and values that dementia undermines' (Innes, 2009: 61).

An important role of carers is to support the person with dementia to sustain a sense of their identity and well-being. This is achieved through an understanding of the person's biography, their interests, preferences and skills, so that their illness does not become their identity, resulting in labelling and social exclusion (Kitwood, 1997).

### Erben's Schema of Biographical Research

I have adapted the schema developed by Erben (1998: 7) to provide a framework for the literature review and the research overall. The rationale for its adoption is that it firmly locates the individual within their social context, and provides a systematic process of ensuring that the carers' narratives are evaluated against the backdrop of the time in which they are living.

**Figure 2-1: Biographical Schema for Carers**



**Key**

- A:** Specific events
- B:** Local context
- C:** Societal context
- D:** Cultural system
- E:** Chronology

Adapted from Erben (1998: 7)

The Schema is used in the review of the literature for interrogating:

- Societal context and cultural systems impacting on the notion of caring and dementia, set within a chronology.
- Specific events and local context of the personal experience and challenges of caring with reference to identity, sexuality and coping strategies.

## **Prevalence of Dementia and Issues of Identification**

Dementia is a collective term for a syndrome that causes a range of illnesses which impact on the cognitive abilities of the person, resulting in the decline of memory, reasoning, communication skills and the capacity to undertake daily living activities. The condition is

enduring and progressive. People may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering. It is estimated that there are 750,000 people with dementia in the UK; two thirds live in the community, while a third live in care homes and 64% of people in care homes have dementia (Alzheimer's Society, 2010). The numbers of people with dementia are set to increase to 1.4 million in the next 30 years (Department of Health, 2009). The likelihood of acquiring dementia increases with age, which is the one consistent predictor of the illness. Table 2.1 sets out the prevalence rates of dementia that demonstrate the linkage between age and the illness.

**Table 2.1: Prevalence Rates of Dementia According to Age**

<b>Age</b>	<b><i>Prevalence Rates</i></b>
40 – 65 years	1 in 1,000 people
65 – 70 years	1 in 50 people
70 – 80 years	1 in 20 people
80 years +	1 in 5 people

(Commission for Social Care Inspection, 2008a)

Only one third of people with the condition ever receive a diagnosis. Cheston and Bender (1999) argue, based on research in the UK, that this is due largely to the stigma of the illness, and to ageism. Williamson (2008) found that 50% of people in Britain believe a diagnosis of dementia is stigmatising. The writer Terry Pratchett, speaking about his own diagnosis of dementia, said: 'It is a strange life; when you "come out" people get embarrassed, lower their voices, get lost for words' (Williamson, 2008: ix).

The use of the term 'coming out' has been adopted by lesbian women and gay men when they tell families, friends and work colleagues of their sexual identity. A participant in the Gay and Grey research project in Dorset said: 'Coming out is a continuous process of negotiation and deciding on a daily basis as to whether it is worth the risk of revealing myself' (Fannin *et al.*, 2008: 14). The decision to 'come out' about a diagnosis of dementia is similar, as the person will assess the risks as opposed to the benefits, and how other people will react to them (Harrison, 2006; Scholl and Sabat, 2008). This appears to me to be an issue of social justice where people

experience a sense of anxiety if they disclose pertinent issues pertaining to their sexual identity or health needs.

Mackenzie's (2006) research involving twenty- one carers from East European and South Asian communities in the north of England highlighted the impact of stigma that resulted in reluctance to identify dementia and access services. The consequence was that carers adopted coping approaches that were specific to their cultural norms. For example in the South Asian community there is no word for dementia, so the term "memory problems" was used. In these communities religious ideology also meant that the person with dementia was seen as being punished for misdeeds in a previous life and their current reincarnation was viewed as evidence of this. In the Polish and Ukrainian communities the extreme suffering experienced during the Second World War had resulted in a culture where: 'Sharing inner feelings with people outside of a close family group becomes an invasion of the other's private space and invades their strategies for managing the lasting effects of trauma in their own biographies' (Mackenzie, 2006: 239).

The coping strategies used were to explain the condition as a physical illness, and, when this was no longer feasible, to isolate the person with dementia from the wider community. Another approach was to maintain an appearance of normal life. One Polish husband would accompany his wife with dementia to a day centre, so the neighbours thought they were going out together. It provided the husband with the opportunity to be in a 'dementia safe environment' (Mackenzie, 2006: 242) where he could relax and socialise with other people. The fear of stigma beyond the immediate family caused considerable anxiety. Because of the small sample of carers, these findings cannot be generalised to the wider communities, but nonetheless they afforded valuable insights.

## **Conceptualising Dementia**

Innes (2009) points out that the academic study of dementia has taken place around three theoretical perspectives: biomedical, social-psychological or psycho-social and social-gerontological. These approaches influence how people with dementia are supported. The biomedical approach sees dementia as a progressive disease and focuses on the declining abilities of people to undertake tasks required for daily living, and therefore is a deficit model. Social-psychological approaches see the maintenance of personhood as paramount, and incorporate the person's biography and personality to maintain personhood through empathetic care that enhances well-being. Social-gerontological perspectives include social, economic and political factors and assess how they determine the experience of ageing in different societies.

Ballenger (2008:494) argues that dementia has been 'framed' throughout history:

Frames are the concepts and metaphors that allow human beings to understand reality, transforming the indecipherable complexity into a comprehensive pattern that we can recognize. Frames shape what counts as common sense, and as a result they shape our goals, and our plans and actions for reaching them.

How dementia has been understood impacts on the treatment provided; support given to carers, and the development and implementation of social policy. O'Connor *et al.* (2007) argue that a framework for dementia research should comprise: the subjective experience of the person with dementia; the immediate environment and its impact on social relationships; and the socio-cultural context in terms of how dementia is socially constructed. However, seeking a cure for the illness has been the priority for research in the USA and UK rather than providing high quality support for people with dementia and their carers. Kitwood (1997: 43) vividly demonstrates that:

Medical approaches in psychiatry have, however, brought their own problems ... simplistic views of organicity, research led not so much by theory as available technique, and exaggerated hopes that science will deliver wonder-cures. Often personhood has been disregarded, particularly when the 'patients' cannot easily speak in support of their own interests. It has become all too easy to ignore the suffering of fellow human beings and see instead a merely biological problem, to be solved by some kind of technical intervention.

The medicalisation of dementia has resulted in people frequently being provided with care that is underpinned by 'malignant social psychology' (Kitwood, 1997: 45; Doherty *et al.*, 2009) that fails to recognise the human need for social interaction, emotional warmth and validation. Furthermore, Kitwood suggests that this has led to the inappropriate use of medication to reduce behaviour that is challenging rather than seeing it as an expression of an emotional need. Means *et al.* (2008) argue on the basis of UK research that the priority for health research funding has been into acute rather than chronic health conditions, and there has been 'a long history of neglect' (p.21) of services for older people resulting in 'family members that have long shouldered the burdens of caregiving ... finding it difficult to access services that help them continue to provide care' (Ballenger, 2008: 505).

This leads to service shortfalls or provision that does not meet the needs of the person with dementia and their carer, such as a lack of diagnosis, and therefore inadequate or inappropriate treatment. Insufficient community-based services including respite care have led to early long

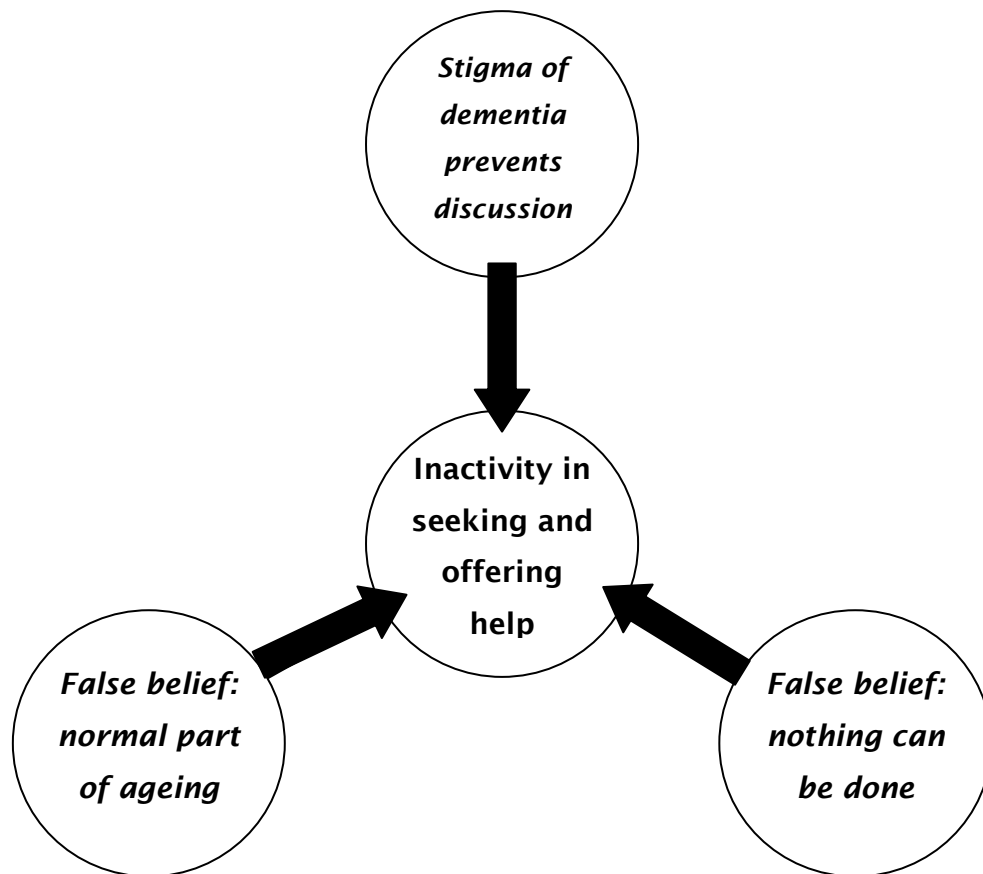


term admission to care homes. The Alzheimer's Society (Quince, 2011) surveyed 2,000 carers, people with dementia and care home workers about their experience of dementia services in the community, and found that 52% of carers said they received insufficient support. This resulted in 63% of carers stating that this had a negative impact on their general health, and culminated in the person with dementia being admitted to a care home earlier than necessary, as well as leading to unnecessary admission to hospital. In spite of the fact that 83% of all respondents stressed that being able to continue living at home was very important to the person with dementia. Furthermore domiciliary care services can be task orientated and inflexible without taking into account the person's needs or preferences, or that of the carer (Quince, 2011). Antipsychotic drugs have been used inappropriately in hospital and care homes to manage behaviour rather than assessing if the behaviour was due to pain, physical illness or anxiety. This type of medication can double the risk of death, triple the risk of having a stroke and hasten cognitive decline, and are inappropriate in the treatment of dementia (Banerjee, 2009). For people to receive inappropriate or incorrect treatment is an abuse of their human rights. People with dementia can be excluded from services such as Intermediate Care Schemes (Commission for Social Care, 2008a; Department of Health, 2009). These services prevent hospital admission, support hospital discharge, provide re-enablement and rehabilitation services.

Biomedical ideologies that see dementia as a progressive disease can develop into cultures of care that are maintained by the power of the medical profession, the privatisation of care services and the interests of pharmaceutical companies (Kitwood, 1997). Such attitudes fail in the main to respond to people with dementia and carers at an emotional level where 'feelings matter most' (Sheard, 2008: 48). The cultures of many care homes are institutional and the model of care is poorly defined. People with a diverse range of needs are placed together in an environment with 'elements of a hospital, prison, hotel and a person's own home ... [which] often become muddled into a care home' (Sheard, 2009: 60).

The first policy strategy for dementia in England and Wales was launched by the Department of Health in 2009. It seeks to reduce the stigma of the illness, provide early intervention to diagnosis, enhance the quality of services through improved support to carers, and provide better training of the workforce. The strategy follows the trajectory of the illness from diagnosis to end of life care. The title of the strategy and an underlying theme is the concept of 'living well' with dementia by challenging the stigma that prevents discussion of dementia. This can induce feelings of isolation and helplessness. The strategy places an emphasis on enabling people to better understand the illness, and the resources and services that support people with dementia and their carers. Common understandings of dementia and their impact are presented by Figure 2.2 that has been taken from the strategy:

**Figure 2-2: Current Understandings of Dementia**



(Department of Health, 2009: 26)

The diagram illustrates myths about dementia such as that it is a normal part of ageing, and that there is nothing that can be done to ameliorate its impact. This results in the condition not being diagnosed at its outset, which reduces people's capacity to plan for their future. The National Dementia Strategy (2009) challenges these misconceptions and is entitled 'Living Well with Dementia'. There is now far more public discussion of the illness but in my experience there is still considerable fear and misunderstandings about the illness. This needs to be addressed as it is estimated that 500,000 partners, family members and friends are involved in caring for someone with dementia (Department of Health, 2009). The National Dementia Strategy (2009) stipulates that the 'Carers at the Heart of the 21<sup>st</sup> Century Strategy' (Department of Health, 2008a) is implemented for carers of people with dementia. The commitments include information and advice that is relevant to where the carer lives; short break provision; increased

integration of health and social care services; GP provided health checks for carers, and opportunities for carers to take up paid employment and educational opportunities. Furthermore it outlines improvements to services that offer emotional support, as well as more targeted support to young carers with the provision of training for carers, to enable them to undertake their role and empower them to work with professionals. The Carers' Strategy acknowledges that little is known about lesbian, gay, bisexual and transgendered carers, but does not address this further. Recent Department of Health policy stresses whole family approaches, carers as experts and the importance of personalised support for carers and the cared for. Issues of diversity are not addressed (Department of Health, 2010c, HM Government, 2010).

In the next section I consider ideologies of ageing and how these inform 'societal contexts and cultural systems' for people with dementia and carers (Erben, 1998: 7). This contextualises the experience of ageing and gives a critical overview as to the possible reasons why traditional dementia services that provide 'dehumanising care practice' are able to develop, and have not been eradicated (Brooker, 2007: 15).

## **Ideologies of Ageing**

As dementia is a condition that particularly impacts on older people, carers are invariably older too if they are partners or middle aged offspring. The process of ageing affects everyone, but it is debatable as to how it should be defined. Lives are structured by chronological age although the meanings given to different ages are socially constructed as a result of societal complexity, political and cultural diversity. As such, old age does not have a universal definition, but is dependent on the cultural and social context of the person, and their own understanding of old age (Dalrymple and Burke, 2006; Hughes, 2006).

The most common definition used in the organisation and delivery of education, health and social care services is chronological. In western societies people are allocated to particular services on the basis of both need and age. Retirement from work for the majority of people occurs in their sixties, and occupational and state pensions then become available. How age is defined in the UK is determined by organisational factors that are designed (in theory) to ensure an effective and efficient infrastructure. Definitions of old age do change over time for political and economic reasons. An increasingly ageing population will create demands for people to work longer, and older people to support each other even more than they do now (Tanner and Harris, 2008).

Life expectancy in the UK is currently 81 years for women and 77 years for men, in contrast to sub-Saharan Africa where the average age on death is the early 40s (Lawrence and Simpson, 2009). This statistic is startling and demonstrates the scale of global inequality. Being old in sub

Saharan Africa will not be understood in the same way as being old in the UK. In addition far fewer people will be affected by dementia due to the lower life expectancy.

Age discrimination can be defined as discriminatory attitudes; behaviour and inequalities in terms of entitlements; choices and services towards people based on age. It can affect younger people as well as older people.

Age is a social division; it is a dimension of the social structure on the basis of which power, privilege and opportunities tend to be allocated. Age is not just a simple matter of biological maturation – it is a highly significant social indicator (Thompson, 2001: 88).

Causes of age discrimination are related to economic factors in capitalism. Citizens are valued as workers: if not in paid employment people are perceived as not contributing. Culturally, older people are seen as taking health and social care resources from other sectors of the population (Tanner and Harris, 2008). Older people are regarded as a burden because of ageing populations in the western world, and these sentiments are expressed by terms such as 'an ageing world' or 'global greying' (Graham, 2007: 144). Such a view ignores the contributions that older people make to their families, friends and communities. Discrimination can focus on interpersonal factors with older people being thought as the 'other', because of fears about ageing and death.

Age discrimination is now unlawful in employment, education and training (The Employment Equality (Age) Regulations (2006), and consequently the retirement age has changed. It is less about social justice and more a response to an increasingly ageing population, with governments needing to reduce spending on pensions, benefits and public services (Tanner and Harris, 2008). Age discrimination means that people are denied the rights that other citizens have on the basis of age, whereas ageism identifies oppressive attitudes, values and beliefs that are culturally reinforced and impact negatively on the well-being of older people.

The concept of old age is often disparaged and not accorded respect. Harrison (2006: 44) makes links between dual oppressions:

[D]iscussions of ageing frequently centre around costs, fears and even 'tidal waves' which conjure up notions of impending doom and gloom. Rarely are older people regarded as a resource, a source of positive societal input, or a demographic cohort of which to be proud. Ageism itself impacts on social and political understandings around the construction of age as something to be

feared and avoided, rather than celebrated. In this respect, ageism and homophobia share common characteristics.

Furthermore a series of cultural assumptions are made about older people that encapsulate ageism (Thompson, 2001; Drummond, 2006; Harrison, 2006). When these cultural assumptions are applied to people with dementia they replicate aspects of the seventeen elements of 'malignant social psychology ... treachery, disempowerment, infantilization, intimidation, labelling, stigmatization, outpacing, invalidation, banishment, objectification, ignoring, imposition, withholding, accusation, disruption, mockery and disparagement' developed by Kitwood (1997: 46- 47), which reflect how people with dementia can be treated. I have added to the cultural assumptions developed by Thompson (2000: 90) in relation to people with dementia.

- 'Old equals useless' – this links with economic factors that perpetuate age discrimination. Older people are seen as unproductive. This assumption fails to acknowledge the contribution that older people make within their families and the community such as being grandparents, carers, volunteers, consumers.
- 'Old equals childlike' – this can result in older people being infantilised, when their experience, knowledge and skills are not recognised, valued or fully utilised (Askham *et al.*, 2007).
- 'Old equals ill' – here health needs are put down to old age, and therefore health complaints are not taken seriously and treatment not provided.
- 'Old equals not ill' – ailments are assessed as due to old age and therefore not worth treating. For example only one third of people with dementia obtain a diagnosis and are provided with appropriate treatment. This results in people not being able to make choices or plans for their future (Department of Health, 2009).
- 'Old equals lonely' – such a view ignores older people's networks and contacts, and it assumes that older people do not make new friends. Loneliness is clearly not just experienced by some older people it can affect many people at different stages of life including the young.
- 'Old equals unintelligent' – older people can be seen as slower in their comprehension and this misconception can lead to a patronising approach, and assumptions made that older people are confused and unreliable when providing information. This concept gets

played out in common sayings such as, 'I am just having a grey moment', as an explanation for forgetting a piece of information.

- 'Old equals inhuman' – by placing older people in a separate category through the use of terms such as 'the elderly', 'elderly mentally infirm', or 'geriatrics'.
- 'Old equals poor' – while a significant number of older people live in poverty there are over five million people of retirement age living abroad many of whom have migrated with amassed wealth and occupational pensions (Lawrence and Simpson, 2009). An assumption of poverty can prevent older people accessing choices and options such as purchasing support services privately that can enhance and maximise their independence.
- 'Old equals asexual' - a belief that older people have no interest in sex (Phillips and Marks, 2006). Lesbian, gay or bisexual people have a sense of identity and community, which is more than sexual orientation (Commission for Social Care Inspection, 2008b). Sexuality is part of being human and to deny this in older people is to treat them as less than human.

Older people can internalise feelings of ageism and experience a loss of self-esteem. This will impact on their sense of identity: 'no self or personal experience story is ever an individual production' (Denzin, 1989: 73). Cultural assumptions can become beliefs held by older people and if partly confirmed by how older people are treated by others they become self-narratives, and this has particular implications for people with dementia. To illustrate this point, Richards *et al.* (2007) analysed data from 30 interviews with health and social care staff and found that their understanding about older people was founded on personal experience and practice without reference to theoretical or research based knowledge of ageing and old age. This is likely to impact on their ability to work with older people in an empowering and sensitive manner. Furthermore, interviews with people who had a diagnosis of dementia found that the impact of negative cultural stereotypes of older people was compounded by a diagnosis of dementia (Scholl and Sabat, 2008). This leaves people at risk of negative self-stereotyping, which can be heightened if they access services such as memory clinics and day centres where people are in the more advanced stages of the illness. Scholl and Sabat (2008) argue that if ageing were viewed more positively the stigma pertaining to dementia would reduce. They suggest that carers can help the person with dementia by supporting them to gain a sense of internal control over their reducing memory, allocate the cared for areas of responsibility and encourage them to make decisions.

## Social Policy Context

Social policy has shifted from care provided in institutions through workhouses in the 19<sup>th</sup> century, to individualised care with the personalisation of care services in the 21<sup>st</sup> century (Gardner, 2011). The notion of family obligation, and expectations by successive governments that families should continue to care so the concept of family is not undermined, have been consistent factors in social policy, for example, 'social care is not solely the responsibility of the state' (Department of Health, 2010b). An emphasis on family obligation is a powerful economic driver, so that costs are not all met by the state, but by individuals and families too.

The cultural legacy of institutional care remains a factor for many older people as a result of their memories of subnormality hospitals (sic) and mental asylums (sic). Although the old institutions are largely gone, inpatient care is provided in the NHS, private and third sector care homes. The average number of beds in a private sector care home in the UK is 40 for older people (Innes, 2009). According to government figures, one-third of people with dementia live in care homes, and at least two-thirds of all people living in care homes have a form of dementia (Department of Health, 2009). Goffman (1961: 17) defined total institutions as:

A basic social arrangement in modern society is that the individual tends to sleep, play, and work in different areas, with different co-participants, under different authorities, and without an overall rational plan. The central feature of total institutions can be described as a breakdown of the barriers ordinarily separating these three spheres of life.

Goffman's characterisation of an institution could be used to describe the cultural regimes in many care homes where older people are often passive, bored and socially isolated. This type of culture has been identified as a priority for improvement, as has the need for greater social interaction given that 'the typical person in a care home spent just two minutes interacting with staff or other residents over a six-hour period of observation (excluding time spent on care tasks)' Department of Health (2009: 58).

This type of care is colloquially known as 'warehousing' where only people's basic physical needs are met. It is well established that high quality dementia care should focus on all aspects of the person's needs through an understanding of their biography, by engaging with the carer, family and friends. Positive interactions are fundamental to the well-being of people with dementia. Bryden (2005: 127), who has early onset dementia, advises:

How you relate to us has a big impact on the course of the disease. You can restore our personhood, and give us a sense of being needed and valued.

There is a Zulu saying that is very true, 'A person is a person through others'.  
Give us reassurance, hugs, support, a meaning in life. Value us for what we can  
still do and be, and make sure we retain social networks.

One of the positive aspects of community care services, which support people to remain within their own homes, has been the acknowledgement that people who use services should be central to the process. For carers there has been an explicit recognition of their role, which subsequently led to legislation providing them with entitlements to financial and practical support. Social policy recognises that people should not be fitted into existing provision, although the resources to develop innovative and person centred services were not sufficient (Gorman and Postle, 2003). Eligibility criteria to access an assessment for services has become increasingly restrictive, so that only people with the highest level of need are assessed for services, and services provided by Local Authorities are means-tested. In 2010 HM Government published research based on the views of 4,000 carers, about the priorities for service delivery. It found that insufficient assistance was provided, many carers were not routinely offered a carer's assessment, and there was a shortage of high quality respite care or domiciliary care (Gardner, 2009; HM Government, 2010).

Carers' experience of hospital provision does not fare any better, although people with dementia aged over 65 years occupy 25% of hospitals beds at any one time. Evidence provided by 2,000 carers (Lakey, 2009) showed that 54% said that a stay in hospital for the person with dementia created more confusion and dependency, and 47% said that the person's general health declined. It was found that 77% of carers were dissatisfied with the overall quality of care provided for the person with dementia in hospital. They complained of nursing staff having little understanding of the impact of dementia; a lack of person centred care; limited social interaction; not being supported to eat or drink; both the person with dementia and the carer being excluded from decision making, and overall the person with dementia not being treated with dignity and respect. It is evident that the closure of institutions and the implementation of care in the community have not led to the development of high quality services for older people and in particular people with dementia (Means *et al.*, 2008). There is a mismatch between social policy and the lived experience of people requiring support in the community. This was highlighted by Rolph *et al.* (2005: 21) in their research tracking the lives of people with learning disabilities and their families from 1920 to 2001: 'Most accounts of social policy, however, have tended to focus on the "high politics" of policy evolution, with much less known about implementation at local level, including the role played by service users, families and communities'. They suggest that there is an 'official history' (p.19) that implies services are continually improving through an enlightened understanding of the needs of disabled people and carers, which is evidenced by social policy, legislation and records. In reality the experience of disabled people and carers shows that social inclusion and person centred service provision have not been realised.



Doherty *et al.* (2009: 503) mapped the experience of two people with dementia through health and social care services observing that:

the illness journey is a new experience through uncharted territory – there is no A-Z or road atlas ... From diagnosis, through treatment and to the end of life, the path is often not easy, and may be seen as a journey of epic proportions by those facing it

They found services fragmented and uncoordinated and made the following recommendations: the person with dementia should be provided with a key worker to ensure on-going support. Relevant information including obtaining a Power of Attorney should be given. Direct payments should always be offered, so the person with dementia and carer can arrange services. Night services should be provided and flexible transport to day care centres that fit with carers' work patterns. Services to be developed that meet the needs of people from black and minority ethnic communities. Care in the community has now developed into the concept of personalisation in the assessment, provision and funding of services. A contextual factor is demography, as people are living longer, and with increasing age more demands are made on health and social care services (Department of Health, 2010b). By 2022, 20% of the population in England will be over 65 and the government acknowledge that while 'the Community Care legislation of the 1990s was well intentioned, it has led to a system which can be over complex and too often fails to respond to people's needs and expectations' (Department of Health, 2008b; Gardner, 2009).

The aim of personalisation is the development of service provision that meets individual needs through self-assessment and the increased use of direct payments and individual budgets, so that people can purchase their own services (Department of Health, 2008b). There are significant benefits to this approach, especially where services are not meeting identified need, as already highlighted for people with dementia, but also in terms of marginalised groups such as lesbian women and gay men, and people from black and ethnic minority communities. The success of this approach will require sufficient government funding. The concept of the 'big society' developed by the Coalition Government suggests increased responsibility for the provision of social care services will fall to families and communities. 'We can transform care, not by looking upwards to the state, but outwards to open communities – by empowering individuals and unlocking the power and creativity of neighbourhoods' (Department of Health, 2010b: 9). This ambitious aim does require sufficient state funding. The government views local authorities as the engine to develop the big society and the role of national government is 'to facilitate, assure and support' (Department of Health, 2010b: 32); however this shift in responsibility emerges during a period of severe reductions in government funding to local authorities.

## Conceptualising Carers

The concept of 'carer' as applied to care provided by family and friends is a recent one, and is socially constructed, as a term that encapsulates people's experiences and is used in policy (Bytheway and Johnston, 1998). The Carers National Association was established in 1986, which provided a pressure group that sought to improve the financial, social and emotional support provided to carers. The assumption being that most carers were women and that caring was a one-to-one relationship rather than involving other family members and friends (Finch *et al.*, 1983). The General Household Survey (1985) challenged these cultural assumptions by reporting that 40% of carers were male, although there was some dispute about the figure as men may have defined themselves as carers more readily than women when they had to undertake domestic tasks not previously their responsibility.

There were debates between feminists regarding women and care. Some argued that care in the community required women to support older and disabled people, who were conceptualized as a burden. For example, Finch (1984) and Dalley (1987) advocated the use of residential care for disabled people, to ensure that women were not required to be unpaid carers, and excluded from the labour market. This was subjected to a robust critique led by the disabled feminist Morris (1991) who argued that very often disabled and older people were themselves carers, that disabled people wanted to be independent and self sufficient. For this reason care in the family may not be the preferred option for many people in old age, although notions of responsibility are linked with kinship (Letherby, 2002). Difficulties were, and still are caused by social environments and government policy which excluded and marginalised disabled and older people. Implicit in these views was an 'us and them' perspective which did not reflect that these able bodied women may themselves become disabled as they grew older, and that many of the cared for were women (Morris, 1991: 154). The relationship between the cared for and carer can be blurred with a mutual dependency, and needs to be re-conceptualised further:

We may also want to expand our definition of caring for to encompass not just physical tasks but also the emotional part of caring for relationships. Research carried out by disabled feminists would, therefore, focus not so much on *carers* as on *caring* (Morris, 1991: 167).

Care is often seen as a one to one relationship when it is more appropriate to think of a 'caring system'. Research in South Wales found that care is often provided by a range of people rather than a single carer, and that gender was less important than issues of capacity and other commitments; for example people without paid employment and who did not have other caring commitments tend to provide more care (Bytheway *et al.*, 1998). There can be an 'hierarchy of care' in terms of expectations of caring responsibilities, with the partner or relative living in the

same house being seen as the main carer, followed by daughter, then daughter-in-law, son, other relative and finally non-relative. These expectations become disrupted in families where relatives are not all living in the UK, or if the family members do not live nearby (Stalker, 2003). This links to Finch's (1984) notion of family obligations which are implicit understandings within families about who is responsible for the bulk of caring with more traditionally expected of women than men.

Most research regarding the experience of caring has consisted of small scale studies often confirming each other (Stalker, 2003). The dominant models for interpreting caring have been that of caring as experienced in the same way by everyone, or that of caring as a burden, however, caring needs to be understood in the context of the relationship between the cared for and the carer (Twigg and Atkin, 1994). In the case of dementia it is essential to recognise that this is especially challenging because the cognitive abilities of the person being cared for are in decline, creating particular stress for the carer as dependency on them increases.

Burton (2006), in research using a focus group and interviews with fourteen carers, emphasises that the relationship between the cared for and carer is paramount in understanding the experience of caring, and maintains that not all carers experience a sense of burden. Relationships can be ones of interdependency and mutual reward. Burton's carers identified their difficulties as lack of information about health conditions: limited understanding of the roles of health and social care professionals, and an absence of emotional and practical help. In Switzerland, Perren *et al.*, (2006) used a random controlled study with carers and found that carers reported that they benefited from support and information provided through structured sessions, in contrast to those carers who were not provided with this service.

Thomas (2010: 131) writes of her 'rage' about the care that her mother received, and her own lack of understanding about her mother's health needs, or how to effectively advocate for her in the nursing home where she was placed:

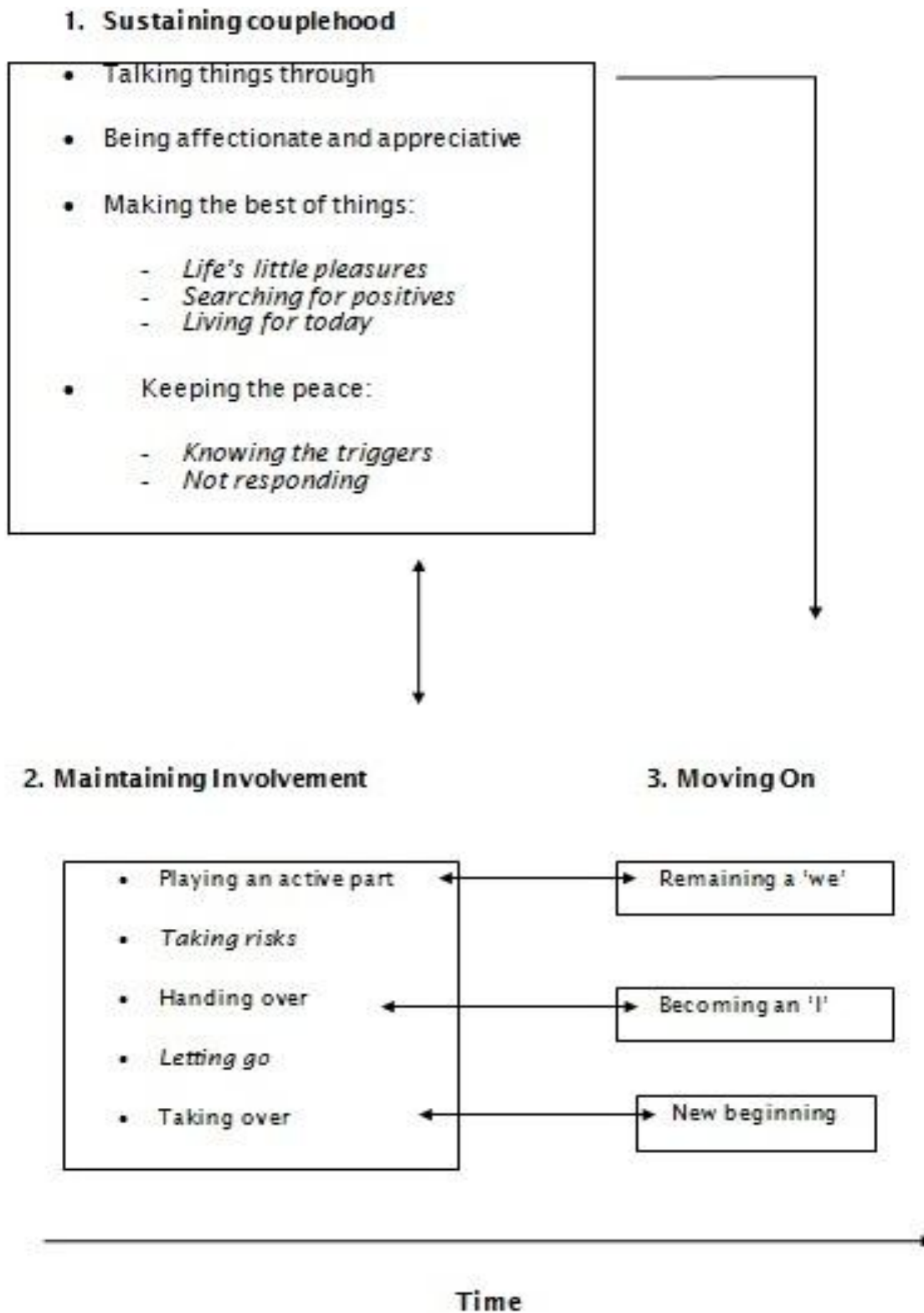
Even though it was written in her notes that she was to be washed and toileted by women only, my mum – who wouldn't enter a lavatory in her own house if there was anyone there to observe her doing so – was handled by men daily. I remember one particular example. Some relatives were visiting from America and Mum had been dressed in a beautiful, expensive frock, which before she went into hospital she had been keeping for a special occasion. She was so nervous that she asked to go to the toilet, but instead of wheeling her into the one opposite, the two male carers pushed a commode into her room just as her visitors arrived. We waited outside until they brought out the uncovered receptacle and told us to go in. I rushed to open the window as we tried not to retch. Mum was deeply humiliated, mortified, the visit was ruined...

Poor Mum. She slipped further and further away from me, from reality. 'This place is closing down next week,' she'd tell me. 'I could do with some runner beans. I've got a nice leg of pork to cook lunch for Beryl'. Why did no one ever tell me that I shouldn't have corrected her when she said irrational things? Even a leaflet would have helped. I know now that I should have behaved as if she were being sensible. 'Am I talking rubbish *again?*' she'd ask. I know it made her not want to speak (Thomas, 2010: 132 -134).

This deeply distressing account illustrates the importance of carers being informed and educated about dementia, as well as what to do if services are degrading and poor in quality. The development of personalisation as the future direction of health and social care services is underpinned by person centred care practices that recognise the interaction and interdependency between the person with dementia and other people. These are of course universal human needs (Department of Health, 2010c). Nolan *et al.*, (2001) have developed the concept of relationship-centred care, which highlights the importance of positive relationships for the person with dementia and the carer. This can be linked back to caring as a system which may involve informal carers such as family and friends as well as formal (paid) carers. This approach resonates with 'whole-family approaches' (Bytheway *et al.*, 1998; Department of Health, 2010c:7).

Hellström *et al.*, (2007) undertook research that did not just take account of the carers' views but also those of the person with dementia and in so doing sought to avoid their marginalisation from the research. Twenty couples were interviewed over five years in Sweden. The findings provide a challenge to the stress/burden model of care giving, and offer a more optimistic analysis of how dementia is managed on a daily basis. The research focused on how couples used a range of strategies to live positively. There are three phrases to the model, which does not necessarily proceed within a clear time frame. This is set out in figure 2.3. Men as well as women carers tried to sustain the relationship with the person with dementia. Hellström *et al.* made a recommendation that service providers adopt a relationship-centred approach so that partnerships could be better supported and maintained. The sexuality of the couples is not discussed in the research, but the tone of the research suggests that the couples were in the main heterosexual and married. They found that most of the couples in their sample had positive relationships, but where this was not the case if more had been known by the professionals, any difficulties would have become apparent earlier and alternative care could have been provided. As changes take place in the relationship, and the carer has to adjust to life without the cared for, but the model does emphasise how people sought to live companionably together in spite of the dementia.

Figure 2-3: Couplehood in Dementia



(Hellstöm, *et al.*, 2007: 390)

This process was not always consistent, but the research found that this was overall an observable pattern within relationships. As already stated the research pertained in the main to heterosexual couples, as has been the case with the other research considered.

Chung *et al.* (2008) developed a model that also follows the trajectory of the illness. It is based on the data following interviews with thirty carers. They understood their relationship with the person with dementia through a continuum of activity patterns, as the dementia progressed shared activities between the carer and cared for became progressively more difficult. The carers' 'sense of self through their past relationship with the relative faded in front of their eyes, removing a life support and making the carers feel even more isolated' (Chung *et al.* (2008: 377). The activity patterns of the person with dementia went through five stages where it became increasingly difficult for the carer and cared for to do things together on an equal basis. This had an emotional impact on the carer and at each stage they formulated different strategies to cope. The activity patterns are as follows:

1. Usual activity pattern
2. Recognizable pattern of activity
3. Illogical pattern of activity
4. Irresponsible pattern of activity
5. Dispossessed activity pattern

Chung *et al.* (2008) concluded that the activity continuum was useful for health and social care practitioners as it gave them insight into the carers' experience, so they could offer appropriate support to carers at different stages of the continuum. Chung *et al.*'s research did not identify sexuality as an important factor in the identity of the person with dementia and their carer, so the focus of the review will now move to carers who identify as lesbian women and gay men.

## **Contextualising the Experience of Being Lesbian or Gay**

The experience of being lesbian or a gay male is explored using Erben's Schema (1998) to reflect on the impact of societal context and cultural ideologies, and how these shape a sense of identity informed by experience that through time can change and develop.

When thinking of sexuality it is useful to recall its many dimensions. As part of an inner world of thoughts and feelings, sexuality fuels wants and desires. It holds a meaning that is intimate and personal. As an aspect of identity,

sexuality imbues self-image and social relations and is a key feature of biography and life experience. At a structural level it serves as an axis upon which power relations are organized in society (Ward *et al.*, 2005: 49).

Historically lesbian and gay sexuality was understood as a perversion, and evidence of immorality and vice. The 1885 Criminal Law Amendment Act made sexual acts between men unlawful, while sexual acts between women were assumed to be non-existent (Turnball, 2002; Manthorpe and Price, 2005). For lesbian women and gay men born after the First World War their sexuality became defined as a disease, and secrecy and discretion in relationships were required. Persecution by the Nazis in the Second World War resulted in the death of 50,000 gay men in concentration camps.

The Gay Liberation Manifesto (1979) identified sources of external oppression including the family, school, church, media, language, employment, law, physical violence and psychiatry, culminating in self-oppression. Homosexuality was classified as psychiatric disease (and remained so until 1973) to be treated with psychotherapy or aversion therapy. Goffman (1963: 15) argued that even if the gay person receives psychiatric treatment and becomes 'normal' they still assume the status of once being 'blemished' (p.20). He went on to explain that the impact of the self-oppression and stigmatisation leads people to feel uncomfortable and ill at ease, vulnerable to victimisation, medical cures or faith treatments. Goffman discussed how there are opportunities to 'pass' as heterosexual, but how those choosing to pass 'must necessarily pay a great psychological price, a very high level of anxiety, in living a life that can be collapsed at any moment' (Goffman, 1963: 108). Thus 'heteronormativity is transmitted by the norming practices and standards which privilege heterosexuality and heterosexual citizenship and relegate homosexuality to the ranks of ranks of 'other' (Tolley and Ranzin, 2006: 79). This leads to the creation of dual identities. Clarke's (1996) research into the lives of lesbian Physical Education teachers demonstrates how the impact of 'holding dual identities i.e. pseudo-heterosexual and lesbian has the potential to create great dissonance and personal turmoil' (p.196). The women used a range of strategies to disguise or deny their sexuality including the continued use of married status after divorce or the invention of a male partner. These types of 'passing' strategies were also articulated in research by Hunt *et al.*, (2007) commissioned by the Department of Health, where twenty-one health or social care workers commented on the general culture and direct harassment they had experienced. The eradication of homophobia was not a priority. There was an absence of equality policies and training courses pertaining to sexuality. An 'out' lesbian or gay identity could adversely impact on career progression, and led some workers like the teachers to keep quiet about their sexuality. These attitudes were not confined to staff but included the patients:

Before every shift starts – you have to hand over every patient – and if we do happen to have a gay person on the ward it's always mentioned. *Joan (District Nurse) North West*

A patient explaining that she lived with another woman was described by a clerk as 'disgusting' in front of the podiatry manager - which he did not challenge. *Nancy (Community Specialist Podiatrist) North East*

These working environments, which are part of the education and welfare infrastructure, are emotionally unsafe cultures where to be or thought to be lesbian or gay can result in harsh punitive attitudes and behaviour. This impacts on the quality of the services provided if staff discriminate against colleagues it is probable that:

[W]e're discriminating against potential patients really because of these people (who) hold these views about gay colleagues it's going to transmit down to the patients eventually because when they are dealing with them they're not maintaining professionalism. *Sharon (Pharmacist) North East (Hunt et al., 2007: 7)*

Discriminatory social attitudes are likely to make lesbian women and gay men hesitant about how open they should be about their sexuality. The Equality and Human Rights Commission (2009) has compiled research findings including an online survey of 5,000 people. The purpose of the research was to identify what needs to be done to deal with discrimination and disadvantage experienced by lesbian, gay and bisexual people, and what changes should be put in place within organisations to achieve the changes required. The report acknowledges the citizenship rights that have been achieved by lesbians, gay and bisexual people in the last five years: civil partnerships; the entitlement to be considered as an adoptive parent; right of succession as a housing tenant for same sex couples; protection against discrimination in employment, facilities and services (Employment Equality (Sexual Orientation) Regulations 2003), and the repeal of Section 28 of the Local Government Act (1988).

There is greater understanding now of human sexuality, and established religion exerts less influence in matters of sexual preferences. Legislative and policy changes have helped to bring about enlightenment. The civil rights movement with the Stonewall Riots in 1969 was seen as a turning point, where lesbians and gay men resisted against a culture of intimidation that required secrecy about their sexuality (Gaine, 2010). As more lesbian women and gay men have become open about their sexuality in some social environments it ceases to be seen as exceptional. In 1987 when questioned if they thought being lesbian or a gay man was wrong 75% of people said yes; by 2008 this had reduced to 32% (British Social Attitude Survey, 2008),



but these welcome signs of progress need to be viewed with caution in light of the high incidence of hate crime, with one in eight lesbian women and gay men experiencing a crime or incident in 2007/08 (Dick, 2009). Ellison and Gunstone (2009) found the fear of abuse or attack results in only 25% of lesbians and 29% of gay men feeling safe in their own communities; as a consequence couples felt harassed and unable to publicly express their affection for each other in public such as holding their partner's hand walking down the street, common place for heterosexual couples. The impact of homophobic attitudes and behaviour found that 47% of lesbians and 42% of gay men surveyed stated that they had experienced stress because of their sexuality with 16% of lesbians and 9% of gay men reporting a current mental health difficulty, in contrast to 6% of heterosexual women and 4% of heterosexual men (Ellison and Gunstone, 2009).

In 2007 Stonewall surveyed 1,658 lesbian, gay and bisexual people in the UK about their views of entering politics. It established that most people believed they would face opposition from all political parties if they wished to be selected as a member of parliament, especially in terms of the Conservative Party (Hunt and Dick, 2007). There are few 'out' politicians of any party, and this lack of access to political power means that issues pertaining to equality and citizenship rights for lesbian women, gay men and bisexual people have not been given sufficient political priority, compared with other marginalised groups.

It is unsurprising that many older lesbian and gay men have reduced expectations of social justice in contrast to younger people, as for much of their lives they will have experienced discrimination, oppression and heterosexism (Hughes, 2006). Hunt and Dick (2007) found that two in five lesbian women and gay men over the age of 50 years have low expectations of the Police if they reported a homophobic hate crime. Furthermore, one in fourteen lesbian women and gay men of all ages expects that their treatment will be worse if they are seeking health care.

The Equality and Human Rights Commission (EHRC) (2009) recommends that for equality to be achieved, organisations need to monitor sexual orientation, and should develop policies to support diversity. In addition, the delivery of services should be audited to check if equality standards are met, and staff training on sexuality should be provided. This is to eradicate bullying as reported by nearly 37% of lesbian women and gay men, 38% have felt frightened and 42% have suffered from low self-esteem. The EHRC recommend that specific research be undertaken to capture the experiences of older lesbian women and gay men, including those with dementia and their carers as:

[H]istorical silencing of lesbians and gay men in social discourse and in mainstream research and health and social care provision is another key reason for the invisibility of this substantial group ... once a person has

dementia, the diagnosis and its presumed personal and public consequences somehow become a person's chief defining characteristics. Other social identities are perceived as less important, or at least less pressing, and are thus extinguished in the observer's eye –a response, perhaps, to the persuasiveness and power of the stereotypes, stigma and discrimination that surround the condition (Price, 2008: 1340).

The impact of dementia on identity for the cared for and the carer is complex and difficult to manage. When this is coupled with being a lesbian woman or gay man this can be especially problematic, for the person's sexuality may be stigmatised, or may not be publicly acknowledged by health and social care services. Moore (2002: 26) writes that he had an 'epiphany' on realising that support services for carers of people with dementia simply assumed heterosexuality for the person with dementia and the carer. A similar realisation came to Age Concern UK (2001) and in response they developed a resource pack for staff and volunteers, which acknowledged that many older lesbian women and gay men had led restricted public and social lives as a result of legislation, policies and attitudes which have criminalised, stigmatised and pathologised their sexuality. The aim is to provide information '[to] lead the way and to *throw open new doors*' (Smith and Calvert, 2001:12). The resource pack deconstructs 'myths and misinterpretations' about lesbian women and gay men (Smith and Clavert, 2001: 8-12), which I will now review, paying particular attention to the needs of carers of people with dementia.

**Myth 1: '*There aren't any round here*':** this is an assumption based on the belief that lesbian women and gay men are easily identified by their appearance and behaviour. It feeds into stereotypes pertaining to 'butch' lesbians and effeminate gay men. Furthermore, there can be assumptions that most lesbian women and gay men are primarily city dwellers, which is not the case. (For example, Age UK Berkshire has an active lesbian and gay older people's group.) This myth, that there are no lesbian women and gay men, will impact on the type of services commissioned, developed and provided. In addition older lesbian women and gay men are not routinely represented in advertisements and web sites where older people are often depicted as white, heterosexual, middle class and healthy, and therefore an explicit visual message is given as to whom services are targeted at (Ward *et al.*, 2005; Phillips and Marks, 2006).

**Myth 2: '*They can look after their own*':** underpinning this myth is a similar rationale to that used in the dearth of services for people from black and ethnic minority groups. This has led lesbian women and gay men to develop services to meet social care and health needs (Terence Higgins Trust, National Gay Funeral Helpline) and political campaigning organisations (Outrage!, Stonewall). For carers of someone with dementia specialist support and provision is likely to be necessary at some stage in the progress of the illness, and person centred care should be provided to both the person with dementia and the carer. The majority of research

and policy documents pertaining to people with dementia and carers are heterosexualist and assume 'traditional' family relationships.

**Myth 3: 'We're open to everyone anyway':** again there are links to the justification given to not assessing and providing culturally appropriate services to people from black and minority ethnic communities. Some lesbian women and gay men living in care homes 'may feel compelled to veil their sexuality' and this could well apply to their carers too (Ward *et al.*, 2005: p.53). Sexualised behaviour of residents can be seen as part of their dementia and 'labelled as disinhibition' (p.58). Archibald (2006: 22) recounts the story of one woman who was thought to be lesbian by the staff in a care home. Her behaviour was assessed as sexualised and focused on female staff:

... when Christine asked me to accompany her to her bedroom, I initially hesitated. I recorded my thoughts afterwards:

Was there some sexual aspect as staff had said? But then I said, 'Come on' and just as quickly dismissed the sexual connotations. I did go with her, helped her undress and placed her on the commode. I spent 20 minutes with her talking to her about her family and past, As I was leaving she said 'Thank you for talking to me'.

Christine's needs, irrespective of having dementia and possibly being a lesbian woman, were simply a wish for positive interaction, and reminiscing.

**Myth 4: 'No-one's ever asked for specific services for lesbian and gay men so obviously there is no need':** lesbian women and gay men are not a homogenous group and do not have one collective voice. Disputes can arise between friends and families, as illustrated by a friend of an older gay man:

I was the close friend, 'significant other', referred to as the patient's 'carer' and 'advocate' by social services. The family, having had little contact with social services throughout the previous eight years he was in care, suddenly objected to my being in any way involved, receiving information or representing him as had happened over the previous nine years (Commission for Social Care Inspection, 2008b: 34-35).

In this case, the social services department agreed with the family and the friend was prevented from continued involvement. The man in care died before this

was resolved. The friend took his case to the Local Government Ombudsman, who criticised the council's handling of the situation. Lipinska (2009: 78), in her role as a counsellor for people with dementia has witnessed the following regarding the partner of the person with dementia:

In some cases, men and women whose same sex partner develops dementia may find themselves on the fringes of care, concern, services and legal provisions if there is not a civil union or clear 'Advanced Directives' to indicate who can make medical and care decisions if the partner is not 'next of kin'.

Underpinning family attitudes can be an assumption about the true value and legitimacy of relationships, so a hierarchy of relationships can develop (Finch, 1983) lesbian and gay partnerships and friendships may not figure in this.

**Myth 5: '*We already have lesbian and gay clients – they just don't flaunt it*':** a familiar and popular critique of lesbian women and gay men has been the 'flaunting' of sexuality. This is part of a view that suggests that discretion is paramount and that being a lesbian woman or a gay man is about sex, rather than comprising a social identity. Ironically heterosexuality is pervasive in the media and arts and 'flaunted' to market merchandise and so on, unlike lesbian and gay sexuality that is rarely featured. For example research that looked at the brochures of thirty older people's care homes in Australia found that non-heterosexual identities were excluded with the assumption that the 'heterosexual experience is the norm and the only legitimate worldview and reality' (Phillips and Marks, 2006: 71). This explains the following observation:

No other group of people is expected to leave a significant part of their identity outside the front door in order to feel comfortable gaining access to services. There is a big difference between 'flaunting' one's traits and habits, and feeling comfortable enough to be oneself (Smith and Clavert, 2001: 10).

Goffman (1963: 112) spoke of 'living on a leash' unable to relax socially with others, and referred to 'disclosure etiquette' (p.124) where information is shared on the basis that the reaction will not be hostile. Only when lesbian women and gay men feel comfortable with their sexuality do they reach a state of 'above passing' (p.125).

**Myth 6: '*They keep themselves to themselves*':** this again resonates with statements that can be made about particular ethnic or cultural groups, and used to justify ethno-centric health and social care provision. Lesbian women and gay men carers invariably have to 'come out' to multiple professionals, as a result of assumptions of 'compulsory heterosexuality' (Butler, 1993), as illustrated below:

Although we had taken out a power of attorney on behalf of each other (that is a legal document to ensure that either of us could administer the other's legal affairs in the event of serious illness), my early attempts to get help were marked by a failure, or even an unwillingness, by the various authorities to recognise my rights in dealing with David's condition, and accompanying that was a need to explain to everyone I had to deal with, what exactly the nature of my relationship was with him. In other words every new meeting became a demand to tell people that I was gay; so was HE; and we were PARTNERS. Can you imagine the stress and potential difficulties that situations might produce? (Newman, 2002, quoted by Turnbull, 2001: 8)

This experience is unique to lesbian women and gay men and produces additional stressors that are on-going aspects of care giving not one off events (Harrison, 2006; Phillips and Marks, 2006; Zarit and Zarit, 2008), that are not found in heterosexual relationships. Moore (2002) established a telephone support group for five lesbian women and two gay male carers who were supporting partners with dementia in rural North Carolina in the USA. The group was set up because services for carers were being 'created within a heterosexual framework in which older lesbians and gay men are placed in a position of either denying or concealing their sexual identity' (Moore, 2002: 26). The Alzheimer's Society withdrew its support due to 'concerns about professional appearance, propriety, and fund raising' (p.27). The carers spoke of their isolation when attending support groups with other carers who identified as heterosexual:

You can't imagine how I felt [when they] started to introducing themselves. Since most were either married or indicated they were there because either their mother or dad had Alzheimer's, I recognized I was different. I just froze. Should I tell them about my partner? Should I just say I have a friend and want more information about the disease? ... All I knew was how we have tried to be discreet and quiet about our private lives all these years (Moore, 2002: 29).

When the nature of their relationship became known, this could result in health staff looking quizzical and asking questions in a hesitant manner. One carer described being older and lesbian as a frightening experience:

"We were the side show," she added, recalling several particular situations. After admission, the caregiver spoke to the patient's primary nurse case manager about staying overnight since the patient sometimes became more agitated and confused at night. The nurse responded condescendingly, "Honey, you know we can only allow a relative to stay with the patient. We know how to

take care of your older friend.” The next morning the same caregiver overheard the nursing students chuckling in the hallway, “In this room we have a pair of old gray lesbians.” Their attitude was that older lesbians shouldn’t be affectionate with each other, as if “after 50, passion, caring, and tenderness dry up.” She noted that being an older lesbian is frightening because “physicians and nurses see us differently” (Moore, 2002: 31).

This is a small scale piece of research, but illustrates the change required by some organisations before it is understood that services need to ‘come out’ as lesbian and gay friendly rather than expecting older people to ‘out’ themselves. The impact of the group on the carers was positive as they reported feeling less isolated and confirmed their commitment to support their partner at home as long as possible. The approaches that carers utilise to support the person with dementia will be considered next.

## **Carers’ Approaches to Caring**

The coping approaches used by carers of people with dementia are developed through values, beliefs, attitudes, understanding and experience which then impact on their behaviour. Folkman and Lazarus (1984, quoted by Norman *et al.*, 2004: 20) define coping as ‘the cognitive and behavioural efforts to manage specific external and / or internal demands appraised as taxing or exceeding the resources of the individual’. As previously identified, there are particular complexities in caring for someone with dementia (Perren *et al.*, 2006). Carers in research by Perren *et al.* described the difficulties of adjusting and their feelings of loss as their partner’s sense of identity changed, and the emotional distress of not being recognised by them. For many as the dementia became more advanced they lost friendships, independence and a sense of self worth. Additional difficulties were also evident by the decline of physical health with ageing, and the onset of depression caused by the diagnosis of dementia. One coping approach identified by people with dementia and their carers was acceptance, which included a philosophical approach to active engagement in civil rights campaigning. The support of family and friends, with specialist advice, information and assistance from health and social care services were also seen as essential. A further strategy of coping was a sense of humour (Williamson, 2008).

Carers may not identify themselves as carers, and indeed might resent this categorisation. Carers can feel guilt if the cared for person no longer lives with them this particularly impacts on women (Hanmer and Statham, 1988). Ungerson (1987) found that male carers tended to see their caring role as if it were a job. This enabled them to achieve some emotional distance from

the strains of caring. This finds resonance in Marriott's (2003: 76) work on being a male carer to his wife, who lives with Huntington's disease:

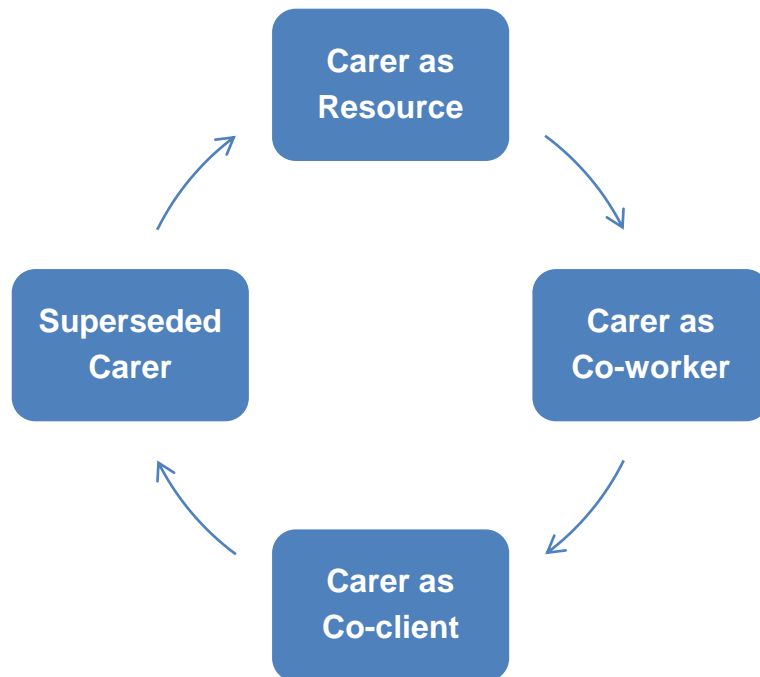
Carers who think of themselves as valued professionals are much less vulnerable than those who see themselves simply as relations or good neighbours.

If you are professional, you're protected from some of those wounding self-doubts. There's a bit of distance between you and some of the hardest-to-bear aspects of caring. And when you itch to be doing another job, or living another life, then reflecting on the importance of the one you've been landed with may help your frame of mind.

Twigg and Atkin (1994) have identified three approaches to caring: balancing/boundary setting, engulfment mode and symbiotic mode. Marriott's attitude to his role of carer would be identified as the balancing/boundary setting mode where caring is viewed as a job, in contrast to the engulfment mode that is characterised by the person's self identity being defined as a carer where 'their emotional identification with the cared for person was often so close that they found it difficult to separate themselves from the cared for person's pain and suffering', and is more prevalent with women than men (Twigg and Atkin, 1994: 122). It entails an inability for carers to articulate their own needs; difficulty in accepting services and an overwhelming sense of responsibility for the cared for person. This contrasts with the 'symbiotic mode' (p.125) where there are positive mutual benefits for both the carer and the cared for. In these circumstances carers are able to accept services for the cared for person, but services for themselves are seen as unnecessary, as they derive benefits from their role, although for carers of people with dementia it is highly improbable they will be able to continue to care without support for the duration of the illness.

Tanner and Harris (2008) have developed four models that describe the identity and role of carers that impact on how health and social care professionals interface with carers, which in turn will affect the carers' sense of self-identity. I have presented this as a diagram (figure 2.4) to demonstrate that the models are not fixed, but can move and change over time. If this is related to a carer of a person with dementia this course may be followed as the illness progresses.

**Figure 2-4: Models of Carers of People with Dementia**



Adapted from Tanner and Harris (2008:178)

These models are found within legislation and policy (Phillips *et al.*, 2006). The NHS and Community Care Act 1990 envisaged carers as providing services at no cost to the health and welfare system; when legislation developed that saw carers as citizens the concept of carer as co-worker developed (Department of Health, 2010c). In social policy terms this has moved through into carer as co-client with an acknowledgment of their needs, and finally to carer as superseded, where carers give up the role of carer. These stages and processes are complex and can be experienced as highly emotional and distressing for carers. This model can be linked to Hellstöm *et al.*'s (2007) framework of 'couple-hood' in dementia where the impact of illness changes the nature of the relationship.

It is a common sense notion that where the relationship between people prior to the dementia has been affectionate and mutually supportive, carers are motivated to sustain their relationship over time. Interestingly some carers, primarily daughters and sons, have stated that their relationship with their parent improved as a result of the dementia:

I never imagined I would be grateful for any illness. But my mother, who never was a real mother, never baked cookies after school or told me she loved me, never played with me or thought I was pretty or bright. She was jealous of me and my dad, said mean and hateful things ... she wanted a son, you see. I guess I was the competition. She never really took to me. Now she loves me,



she really does! She stands at the door and throws her arms open and smiles and smiles and hugs me tighter than I could imagine. 'Here's my girl', she says (Lipinska, 2009: 56).

Menzies's (2009) account of caring for her mother with dementia, and the effect that this has on her and her siblings, demonstrates a similar transformation in her relationship. Her mother lacked emotional warmth towards her children. She was a domineering parent, but dementia enabled a very different type of relationship to develop:

I'd discovered the lovely landscape of sitting side by side with Mum on her single residence bed, just holding hands. When a stroke and a broken hip took her down further, we became so attuned to each other it was though the umbilical cord that had connected us at the beginning of my life had grown back between us at the end of hers (p.9).

These examples provide an interesting insight into the interdependency between adult daughters and their mothers. The case histories of Stokes (2008) explicate problematic behaviour of people with dementia through the use of biography and an understanding of their personality. They demonstrate the range of responses that partners in particular have towards the person with dementia. These ultimately determine the nature and duration of support provided. Many carers feel that they have lost the person they once knew and loved, and that someone else is in their place. Kitwood (1997: 141) suggests this stops carers from being able to mourn and prevents the 'growth of a new kind of relationship more empathic and intuitive than before'. This requires carers to be able to accept the changes that the illness has brought while recognising and responding to the continued emotional needs of the person. Malthouse (2011) writes of her epiphany when she accepted the impact of dementia on her mother's speech which had become repetitive; instead of being irritable and trying to fight the consequences of the illness she accepted the changes in her mother's behaviour.

Askham *et al.* (2007) used participant observation and interviews with twenty carers. They analysed the data against Goffman's (1961) definitions of the characteristics of institutional care: routinisation of daily activities: surveillance of the person's behaviour and enforcement of self, that is, the carer maintaining a distance or expressing open hostility. All these behaviours were found, the most extreme being physically abusive, and examples of Kitwood's (1997: 45) 'malignant social psychology'. The researcher wrote in field notes:

During a conversation about politics, the grandmother with dementia said, 'Tony Blair [the British Prime Minister] used to live in the flat below me.' There was first silence and then three responses: (i) Mrs Y (grandson's mother-in-law)

looked at the speaker and said, ' Don't be stupid, of course he didn't'; (ii) R (granddaughter) quickly said in a soft voice, 'Oh, did he?' ; and (iii) B (son) said laughing, ' Don't be draft, he lived in Islington' (Askham *et al.*, 2007: 16).

The granddaughter's empathy for her grandmother is contrasted starkly with the disparagement and mockery of the other family members, although there are examples of carers displaying compassion within the research. To use Goffman's definitions of institutional relationships is a particularly bleak frame of reference, as interactions and behaviours are assessed against these negative constructs, without any counterbalance of positive interactions. This could impact on the focus of the research.

The importance of specialist training in dementia care was highlighted in research by Scott *et al.* (2011) involving analysis of questionnaires responses from 112 nurses and care assistants supporting people with dementia in care homes in Northern Ireland. They found that 69% had been involved in an incident where they feared for their safety, 71% witnessed an incident where they were anxious about the safety of a colleague, 34% had felt unsafe and 18% terrified. In 17% of incidents the person with dementia had used an object such as a walking stick, zimmer frame, shoes, crockery and chairs. The triggers for aggression were getting the person with dementia out of bed, preventing fights amongst residents and stopping unsafe activities such as tampering with electrical equipment. The triggers were known in half of the incidents, whereas a number of the incidents the staff reported had happened unexpectedly. The researchers concluded that some of the incidents had occurred because 'sensitive situations requiring diplomacy appear to have been handled tactlessly, i.e. taking items from residents' (Scott *et.al.*, 2011: 265). Following an incident the staff would avoid the person with dementia so there was an absence of positive interaction, and tasks were done quickly thereby deskilling the person, who could have done the task with support. The person with dementia was excluded and outpaced (Kitwood, 1997). Scott *et al.* (2011) recommend that staff receive specialist training in dementia that includes communication skills, as well as opportunities to develop understanding, compassion and empathy. In addition that guidelines and support need to be provided to staff when confronted with aggression. An important reflection point here is that most informal carers do not receive any training in caring for someone with dementia or the management of complex behaviour.

## **Carers' Belief Systems**

Belief systems affect carers' capacity to sustain relationships with the cared for person. This is evidenced in a range of research studies such as that undertaken with 43 carers from the African American community in Chicago. Farran *et al.*, (2003) found that some carers had a 'personal spiritual philosophy' expressed as follows:

- 'I am too blessed to be stressed',
- 'This too will pass'
- 'You need a sense of humour. Without God and a sense of humour, care giving would be really too hard to do.'
- 'Anger only destroys you. Instead of "Why me?" I would have to ask "Why not me?" ... We were married for 29 years – 26 without disease. Why should I be exempt from hard times?' (Farran *et al.*, 2003: 365-368).

These beliefs were underpinned and sustained by religious faith. The carers were actively engaged with their church that ministered to the black community. Farran *et al.* argue that as black churches in the USA have survived slavery, responded to discrimination and oppression, as well as provided life- long support, they are significant spiritually, socially and politically.

Stuckey (2003: 344) found that it is not necessary to have a spiritual faith, but rather a sense that 'life is an ethical and moral journey' - a theme derived from interviewing 32 spouses where the partner had dementia. The beliefs that were significant to carers were the importance of people looking after each other during difficulties; the need to find some 'meaning and purpose even amid pain and suffering' (p.350), and supporting the well-being of the person with dementia, as this was felt to be purposeful and morally right:

If you cannot change something, if you can just stop struggling for a moment and be still and let it evolve, it might evolve into something really good for you. And I think [care giving] is the same thing ... I can't see anything good coming out of this, but the simple fact of the matter is that I can't change it. So if I do my best within the context of it and stop struggling and really try to enjoy the time with him that I have, to the best of our abilities to enjoy it, then that's enough. And I will see what happens down the line ... things have always been okay. I'm kind of a survivor (Female Agnostic Caregiver) (Stuckey, 2003: 345).

The above quote from a carer demonstrates a positive belief system, the ability to endure even when faced with extreme difficulties, as well as an acceptance and empathy towards the person with dementia.

## Summary

The review of the literature of carers of people with dementia has been placed within a social, political, cultural and personal context. The relationship between

the person with dementia and their carer is seen as one of interdependency, where there be mutual benefits in the relationship rather than the person with dementia being seen as a burden. The incidence of dementia increases with age; consequently different social policy and theoretical approaches to dementia and ageing are considered. I have argued that ageism impacts on the self-esteem of older people and when this is coupled with a diagnosis of dementia it further reduces people's sense of well-being and confidence. One aspect of identity highlighted relates to lesbian women and gay men who are carers. A connection is made between having an illness such as dementia and sexuality, as both can result in stereotyping, labelling and stigmatisation. This results in the person having to make a conscious decision about whether to 'come out', thereby 'expos[ing] affected individuals to inspection, interrogation, interpretation, and violation of privacy' (Couser Thomas, 2006: 400). The review of literature explored issues of belief and coping strategies adopted by carers, which enabled them to continue to care. I will now consider the methodology and methods used for the research with six carers. I explore the research areas and rationale for the approach adopted, building on the findings from the literature review.



# Chapter 3: Methodology and Methods

## Introduction

This chapter provides my rationale for the qualitative research approach and biographical method that I used when I interviewed carers of people with dementia. The sampling process that I adopted is explained together with my reflections on the interviewing method as a research instrument, and my role as the researcher in the process. This is followed by a critical overview of the limitations and strengths of the research methodology. Ethical issues are explored in the context of the overall process and my responsibilities as the researcher. In addition the process of data analysis and the development of categories to detect patterns, themes and dissimilarities are discussed. Finally a consideration of the theoretical perspectives used to interpret the carers' stories is introduced.

## Research Approach

The research method and approach clearly needed to be appropriate to meet the research aims, which were to understand the experience of caring and what enables carers to continue to care for the person with dementia as the illness progresses and to identify health and social care practice that was helpful, and supportive with the purpose of utilising this knowledge in health and social care education. Research should have relevance, validity and be feasible to undertake (Denscombe, 1998). The prevalence of dementia is increasing due to an ageing population (Department of Health, 2009). The economic significance of carers supporting disabled people is £87 billion per annum, an average of £15,260 per carer (CarersUK cited by Galpin and Bates, 2009). As such the research had relevance due not only to the economic importance of carers, but the positive impact of continuing social relationships for people with dementia (Kitwood, 1997).

Throughout the course of the research I sought to implement criteria to assess validity developed by Etherington (2004), who states that the researcher's reflexivity should be apparent by demonstrating an awareness of how they impacted on the research process, and conversely how the process affected them. The social, cultural and political context in which people live: 'the variety of communities they inhabit (and which inhabit them)' and their relative power or powerlessness needs to be acknowledged with a recognition that the outcomes of research can achieve changes to power (Griffiths, 1998: 95). Moreover research should give voice to a range of different perspectives with opportunities for creativity in their expression, so that new learning and knowledge is obtained. Griffiths (1998: 129) argues research should achieve 'better knowledge', and aim to enhance social justice by being underpinned by a series of ethical principles. She defines social justice as 'what is good for common interest, where that

is taken to include the good of each and the good of all, in an acknowledgement that one depends on the other' (p.95). One of the aims of my research was to better understand the experience of caring so this could inform health and social care practice.

The research was feasible as I found six carers who were prepared to be interviewed, of these two identified as lesbian women and one as a gay man. Being lesbian or gay was a criterion for half of the participants, as the views of lesbian women and gay male carers are rarely prominent in the research literature (Cass *et al.*, 2008). The study was located within the context of social work research that:

aims not only to support practice but also to transform it. Social work with its ethical imperative towards challenging social injustice requires social work researchers to examine both the socially excluded and the powerful elites who decide upon their social exclusion (McLaughlin, 2007:13).

The methods needed to capture carers' stories in a way that could change and enhance my teaching of social care and social work students, by providing a more authentic account of how carers viewed their experience of caring for someone with dementia, and what helps in terms of health and social care practice, on which I could draw. As Steedman (1986:6) states: 'Personal interpretations of past time – the stories people tell themselves in order to explain how they got to the place they currently inhabit – are often in deep and ambiguous conflict with the official interpretative devices of a culture'.

Steedman was writing about how working-class lives had been defined by male historians, who wrote only about the lives of men, and which bore no relationship to the reality of her working-class mother. In a similar way there are also common cultural assumptions about carers held by health and social care staff, for example, that the majority of carers are women, that care is based on family obligation and all care is burdensome (Dalley, 1987). In fact one in eight people are carers - six million people in the UK - of whom 42% are men and 58% are women (CarersUK cited by Galpin and Bates, 2009). Although being a carer can be stressful and difficult, carers do report satisfaction that relates to their personal relationship with the cared for (Nolan *et al.*, 2001).

The selection of a research method is based on the aims and objectives of the research and ethical implications for the research participants. In my view a positivist scientific approach would have been inappropriate as the research was attempting to understand experience rather than prove anything. 'Quantitative research aims to show you what is happening. Qualitative research on the other hand, sets out to tell you why it is happening' (Moore, 2000:121). The idea that research can be unbiased, 'scientific' and that distortion can be eliminated with the

findings being reliable and valid is open to challenge (Briggs, 2003). For example the outcome of interviews may reflect more about the researcher than the interviewee. Letherby (2004) reminds us that research methods should fit the aims and objectives of the research, and additionally how the method is used will impact on the knowledge gained: 'what we do affects what we get: the relationship between process and product / doing and knowing' (p.183). There may be an imbalance of power in so far as the researcher has formulated the questions asked and the probes that are used to extract more information. Furthermore there may be differences in social class, gender, ethnic origin, as well as theoretical perspectives between the interviewee and researcher. The latter might be seeking to confirm views already held. These issues are especially problematic when the research participants do not have access to the means by which stereotypes can be challenged, as only the voices of the powerful are heard. 'When interviews provide the nation-state and its institutions with representations of marginalized populations, the possibilities for constructing a 'minority voice' that confirms the hegemonic status quo is thus acute' (Briggs, 2003: 243).

As the researcher I needed to be reflective, open minded with a willingness to learn and conscious of my own values (McLaughlin, 2007). This perspective is congruent with the principles of anti-oppressive practice which are entrenched in social work's values (Braye and Preston-Shoot, 1995). There is a growing awareness about the effective engagement of users and carers in the research process, which is being: "'internalized" by researchers informing their way of thinking' (Morgan and Harris, 2005). Beresford (2005: 8) describes the 'democratic approach' in research, as the commitment to a shift of power and control towards those that access social care services and this is the approach that I sought to follow through my choice of the kind of interview I would conduct. Leamy and Clough (2006) found this approach had positive benefits for older people, as it led to increased political awareness, a sense of optimism about the ability to effect change and enjoyment at working collaboratively with other people. A similar situation was reflected in my study whereby the carers were active in the interviews, and narrated their story using the interview schedule loosely. They were not viewed by me as objects of data, or controlled in the process (Letherby, 2004; McLaughlin, 2007).

Simons (2009) suggests that the study of the individual is important, as it demonstrates how policies and procedures are implemented and their impact. For example only one of the carers had definitely been offered a carer's assessment, one other carer suspected that they might have been offered one, but could not confirm this. This has been a legal entitlement since 1995 but for these carers this aspect of government legislation and policy was not being implemented. Research that engages with the individual gives access to the 'lived experience' (p.75) of the person and offers 'insight into the idiosyncratic nature of particular events and experience that cannot be captured by other means. Its value lies in enabling us to understand, how a study of the particular yields universal understanding' (Simons, 2009: 77). The carers' stories provided a rich commentary about the reality of being a carer to someone with dementia.



They highlighted health and social practice that were at times in variance with social policy intentions.

## Research Design

Research needs to have a design and process developed so it can achieve the researcher's aims and objectives. Punch (2000: 23) suggests that a 'hierarchy of concepts' be developed to guide the research. I have adapted this into a framework through which I sought to move the research from general aims to specific areas of investigation that addressed: namely what enabled the carers to continue to care, and their experience of health and social care services. The research framework was developed into an interview schedule that sought basic details about the carer and the cared for as well as a self-classification of ethnic origin, gender, sexual orientation and age. A participant information sheet about the research and consent form was included with the schedule (Appendix C). The carers were sent the interview schedule approximately ten days prior to the interview, so they were fully informed about the research areas. The intention was that this would enable them to begin the process of organising their thoughts and, as a consequence lead to a more coherent interview (Atkinson, 1998). Table 3.1 sets out the research framework together with the interview schedule that developed from it.

**Table 3.1: Research Framework**

<b>Level 1: Research Area</b>	Caring for someone with dementia, as an informal carer, that is in an unpaid capacity.
<b>Level 2: Research Topic</b>	The experience of carers who define themselves as lesbian women or gay men, who have cared for someone with dementia. (This will form half of the sample of carers.) At least half the sample of carers will have cared for someone with dementia in the last five years. This will capture the impact of legislative and social policy changes on the experience of caring.
<b>Level 3: General Research Question</b>	What is the experience of caring for someone with dementia?
<b>Level 4: Specific Research Questions</b> <i>Can you describe what it is like to be a carer?</i>	Supplementary questions: <ul style="list-style-type: none"> <li>• What are the practical implications in terms of daily living e.g. household tasks, financial implications, work and social life?</li> <li>• What is the emotional impact on you and the person you care for?</li> </ul>

<p><i>Has your relationship changed, if so how?</i></p>	<p>Supplementary questions:</p> <ul style="list-style-type: none"> <li>• Describe any changes in terms of your one to one relationship with the cared for, and with friends and family?</li> <li>• Have you received any feedback from other people about how you have changed through being a carer?</li> <li>• Any changes in roles?</li> <li>• What are the things you cannot do together any longer?</li> <li>• What do you miss most?</li> <li>• What do you still do together?</li> <li>• Are there changes in your relationship that you feel are positive?</li> </ul>
<p><i>What enables you to continue to care?</i></p>	<p>Probes:</p> <ul style="list-style-type: none"> <li>• Personal support of friends and family</li> <li>• Personal values</li> <li>• Attachment to the person</li> <li>• Meeting with other carers</li> <li>• Other interests such as work, leisure activities, cultural activities</li> <li>• Spiritual beliefs</li> <li>• Other beliefs (humanitarian, political etc)</li> <li>• Health and social care services</li> <li>• Other support not mentioned above</li> </ul>
<p><i>How does caring impact on you? What coping strategies do you use?</i></p>	<p>Supplementary questions:</p> <ul style="list-style-type: none"> <li>• How do you cope with stress?</li> <li>• Are there practical things you do such as talk with someone, ask for help? (accessing external resources)</li> <li>• Are there ways that you manage by yourself, for example do you have approaches to calm yourself down, look after yourself? (internal resources)</li> <li>• What is the balance between external and internal resources that enables you to go on caring?</li> <li>• Can you describe some approaches that you use when things are difficult for you?</li> </ul>
<p><i>What support do you receive as a carer?</i></p>	<p>Probes:</p> <ul style="list-style-type: none"> <li>• What services are the most helpful?</li> <li>• What services are the least helpful?</li> <li>• If you were able to plan services to support carers what would you provide?</li> <li>• Do societal attitudes need to change e.g. how generally are you and the person you care for treated – with kindness, understanding, indifference, hostility, disrespect?</li> </ul>

<p><i>What have you learnt from being a carer?</i></p>	<p>Probes:</p> <ul style="list-style-type: none"> <li>• Can you identify how you have changed through being a carer e.g. less optimistic, more fearful, prone to despondency, developed new practical skills, assertiveness, self-awareness, empathy, feeling stronger emotionally.</li> <li>• Better understanding of the health and social care system.</li> </ul>
<p><i>What is your experience of health and social care services?</i></p>	<p>Supplementary questions:</p> <ul style="list-style-type: none"> <li>• How have health and social care staff engaged with you and the person you care for, e.g. has your expertise as a carer been recognised?</li> <li>• What services have been the most helpful? Why?</li> <li>• Do you feel informed about dementia? Do you know how to obtain information about the illness, resources for the person you care for and yourself?</li> <li>• Do you feel that there are any gaps in the knowledge and skills of health and social care staff?</li> </ul>
<p><i>*What are the learning and development needs of health and social care staff?</i></p> <p>(This question only relates to carers that define themselves as lesbian women or gay men)</p>	<p>Supplementary questions:</p> <ul style="list-style-type: none"> <li>• Is your experience as a carer recognised?</li> <li>• As a lesbian woman or gay male carer do you feel that you are treated differently?</li> <li>• Is your relationship with the cared for recognised and validated?</li> <li>• Have you been provided with information, advice and support that meet the needs of the person with dementia, and you as a carer?</li> <li>• If not what suggestions can you make about training for health and social care staff?</li> <li>• Do you feel that health and social care staff understand about the impact of homophobia and heterosexism?</li> <li>• If not what training is required?</li> </ul>
<p><i>Is there anything else that you would like to tell me?</i></p>	
<p><b>Level 5: Data Collection Method</b></p>	<p>Actions:</p> <ul style="list-style-type: none"> <li>• Face to face semi-structured interviews</li> <li>• Location and time to suit the carer</li> <li>• Interviews are taped and transcribed with permission</li> <li>• Transcript sent to the carer to be checked</li> <li>• Amendments made by the researcher</li> <li>• Final transcript sent to the carer in hard copy</li> </ul>

<b>Level 6: Data Analysis</b>	Actions: <ul style="list-style-type: none"> <li>• Analysis of the data using codes</li> <li>• Identification of themes</li> </ul>
<b>Level 7: Report Writing</b>	Actions: <ul style="list-style-type: none"> <li>• Themes cross-referenced to Skills for Care (2010) 'Common Core Principles for Carers'</li> <li>• Findings recorded in writing</li> </ul>

The interview questions were piloted with a group of colleagues to assess whether they were open and accessible in meaning, and if they flowed smoothly from one area to another. My aim was to produce a research framework that would shift:

the researcher from 'knowledge-privileged investigator' to a reflective position of passive participant/audience member in the storytelling process. The interviewer as writer/storyteller then emerges later in the process through her/his retelling of the story as a weaver of tales, a collage-maker or a narrator of narrations (Jones, 2002: 2).

In terms of the researcher being a 'weaver of tales' it was necessary to consider whose stories I wanted to capture, and how I could ensure that the carers felt comfortable meeting with me. I offered the carers a choice of where we met. They all invited me to their homes. This involved travelling some distance to meet with three of the carers. I ensured that my partner was aware of where I was going, and had contact details including the address and name of the carer. I carried a mobile phone with me for health and safety reasons. I realised that it was important for both the carers' comfort and convenience that the interviews took place in a location of their choosing. None of the carers had the person with dementia living with them, but if they had I would have asked that we met when the cared for was not present so they were not marginalised and objectified by the interview. Prior to the interviews I had spoken to the carers and usually exchanged emails too. I verbally explained how the interview would be conducted and their entitlement to withdraw at any time; the interview schedule was also posted to them. My approach to the interviews was to allow the carers as much time as they needed to tell their story. Most interviews lasted two hours, although one was more than five hours and the shortest interview was an hour. The interviews were all taped with the carers' consent. I paid for the interviews to be transcribed primarily due to my shortfalls as an audio typist and time constraints. The person transcribing the tapes signed a confidentiality agreement in respect of each tape (Appendix F).

Etherington (2004: 77) starts her interviews by asking: 'Where does your story begin?' which was an approach I did not adopt but in hindsight would be an effective first question, as it puts the research participant at the centre of interview. One curious factor I noted when I read the transcripts of my early interviews was how verbose and complex my questions appeared, yet the carer always understood what I was trying to ask, and never sought clarification, as the interviews progressed I tried to ask more concise questions. My approach throughout the interviews was to be relaxed and focus on the carer, appearing interested and encouraging them to tell their story through my attention to them. My research practice was informed by 'feminist ways of working, where there is a focus on collaboration and dismantling hierarchies' (Ramsay & Letherby, 2006: 27). Hence I chose not to take notes, as I wanted to be able to maintain eye contact, and I felt that it may impede their flow of speech if I was writing. Moreover, I needed to be able to observe the carers' facial expressions and body movements throughout the course of the interviews as, while recognising that non-verbal communication is 'culture specific' I was also aware that where a 'statement is made verbally which is contradicted by body language, it is generally the body language which is given credence' (Thompson, 2003: 100). I was particularly alert to signs of distress, and wanted to convey an empathetic response, as I knew that 'the process of dementia is also the story of a tragic inadequacy in our culture, our economy, our traditional views about gender, our medical system and our general way of life' (Kitwood, 1997: 41). I wanted the carers to know that I was authentic and non-judgemental towards them in my wish to hear about their experiences (Egan, 2010). The process of the interviews is explored in more detail later in the chapter.

## **Selection of Research Participants**

Liamputtong (2007: 27) developed the concept of the 'sensitive researcher' where the subjects of research are people who are socially marginalised, and often disempowered by cultural and interpersonal attitudes towards them. By explicitly ensuring that half the carers defined themselves as lesbian women or gay men this situation was in part avoided as it enabled their views to be heard. As shown in the review of literature much of the research assumes that carers are heterosexual. A leaflet I developed about the research was distributed to lesbian and gay organisations and through informal networks and contacts (Appendix A). Snowballing took place and carers started to contact me. Another criterion was that at least half the carers had been caring in the last five years, as I wished to assess the impact of recent legislation and policy. The carers were all actively involved in the lives of the person with dementia, or had been if they had died. A general leaflet was developed appropriate to all carers (Appendix B).

I was mindful that for all carers it was likely that questions developed through the Users' and Carers' Involvement Movement (Beresford, 2005) were likely to figure in their decision about

whether to be involved in the research. The five questions developed by Crepaz-Keay (2006), who is active in the Involvement Movement, were adapted for this research:

- What is the point of being involved in the research?
- Who should be involved? (Am I the best person to do this?)
- What is entailed? (Is this a postal questionnaire, telephone conversation or a face to face interview?)
- What can the research achieve? (Is it worth doing?)
- Is it safe? (Is this research ethical and confidential?)

As already stated the carers approached me usually by email, which was often followed by a telephone conversation where the above questions could be explored. The interview schedule containing information about the research project was sent (Appendix C). These discussions and exchanges of information were essential in enabling the carers to have an accurate sense of the purpose of the research, and an understanding of what it could achieve. The fact that I teach social care and social work students implicitly suggested to the carers that their stories could have an impact on practice.

## Biographical Research Method

A biographical research method was used, that was limited in focus to the period of time that the interviewees had been carers. Biographical research uses narratives in the way in which people describe and explain their lives. It requires:

a critical scrutiny of the self. Indeed, those who protect the self from scrutiny could be considered self-satisfied and arrogant in presuming that their presence and relations with others are unproblematic. Auto/biography, then, enables us to locate the contextual within the personal (Ramsay and Letherby, 2006: 29).

Through the carers' stories patterns and themes emerge which are culturally and time specific (Erben, 1998; Plummer, 2001). It provides general information about the culture and society in which the person lives, as well as recording the individual's experiences. Bingley *et al.* (2008: 654) explain the nature of storytelling noting that stories appear:

to be sparked by experiences of a 'breach' or 'disruption', however minor, in our usual patterns of life. Stories, therefore, gain a particular relevance at times of life transition or change, seemingly as a way of 'sense-making' or attempting to re-shape and manage the shifting grounds of our lives.

The diagnosis and onset of dementia are life-changing events, as described by Bingley, not just for the person concerned but for partners, family and friends. The progressive impact of dementia is often described by carers as losing the person they once knew. For example,

When David's behaviour started to show signs of a fundamental change, it didn't take long before that well-established pattern of our lives began to fall apart. We had built a wall around our relationship which made us feel that it was easy being a gay couple and we truly believed that that was how it was going to be ... The onset of David's dementia, however, turned everything upside down ... having no real knowledge of the condition, my first reaction to his changed behaviour was to feel that he had decided that the relationship was over, and consequently I left him (Newman, 2010: 146).

Newman's account vividly and movingly describes how his partner's sexual behaviour with other men became more extreme and how emotionally damaged he felt by this. Denzin (1989: 70) stresses the importance of turning points or 'epiphanies: interactional moments and experiences which leave marks on people's lives'. These, he notes, 'are often moments of crisis'. In Newman's account there is the turning point of his partner's behaviour followed by the 'epiphany' of understanding, when he realises the impact of dementia on David's behaviour. Newman went on to care for David and established the Lesbian, Gay, Bisexual and Transgendered (LGBT) Group at the Alzheimer's Society.

Epiphanies offer a valuable method or concept in understanding aspects of the carers' stories. The carers chose to remain involved with the person with dementia, which prevented the person becoming socially isolated, which often occurs (Commission for Social Care Inspection, 2008a). Some of the carers were able to state that they had consciously made this decision, which was an epiphany or turning point for them. They recognised the changes that would take place in their relationship to the person, which involved an increased dependency on them. Denzin (1989) defines four different types of epiphanies, which I have illustrated through their application to the stories of the carers I interviewed. The first is a *major event* which impacts on every aspect of the person's life such as the onset of dementia. Another epiphany is a *representative act* when a crisis occurs. A *minor event* epiphany is an occurrence that encapsulates a significant issue in the person's life which in itself does not seem important, but

represents a defining moment in time - *reliving the event* is remembering an incident with the associated emotional impact.

One of the strengths of the biographical method is that it allows complexities to be studied in depth and understood. The social and cultural context of people's lives underpins their stories. Plummer (2001) highlights the importance of memory and identifies different types of memory, such as collective memories of particular experiences, that groups of people have had who have a shared identity, such as being a lesbian woman or gay man. Plummer develops the concept of 'transformative remembering' (p.237) - an active process that enables memories to be shaped by increased self-knowledge. I wanted the carers to benefit from their participation in the study and the feedback that I received from some of the carers was that it had been helpful to tell their stories, as reflecting back had developed their sense of self, indeed the more the carers spoke so their confidence and understanding appeared to increase. Moon's (1999:157) earlier research identified the outcomes of reflection as self-development, empowerment and emancipation where 'transformative learning' can take place through a critical self-appraisal, and evaluation of social and political contexts. Such outcomes were evident for some of my research participants.

I learnt from the research process too and reflecting back on the experience I concur with Etherington's (2004: 78) rationale for the use of this research approach:

my intentions in gathering data in this way is that, in telling their stories, participants (and researchers) may also gain something for themselves. It seems to me the very best possible outcome of research is that it provides an opportunity for growth and learning for both the researcher and researched as well as the wider community.

Etherington gives an example of the impact of being a researcher. One of her students, who was training to be a counsellor and therefore had to receive counselling herself as part of the course, said being a researcher increased her autonomy, self-awareness, reflexivity and problem solving skills more than receiving counselling. She developed criticality through developing connections in the analysis of the data and ultimately making sense of her research findings. These comments find resonance in my own experience of hearing the carers' stories, as a researcher rather than in my previous professional role of social worker, as in the latter role I would have felt compelled to do *something* rather than 'valuing narrative ways of knowing' that allowed me to simply listen to the 'lived experiences' of the carers (Etherington, 2004: 74).

For research to have credibility it needs to be accurate in reflecting the situation, relevant, timely, useful and trustworthy. It becomes 'intrinsically qualitative' when 'subjectivity,



emotionality and feeling' are stressed (Simons, 2009:129). On the other hand Plummer (2001: 234) views 'narrative memory' as consisting of stories that we chose to remember, and of course 'memory may reify the life into something it is not'. Life stories are constructed by the teller, so there may be limited historical objective truth. This contrasts with positivist research that is assessed against the criteria of reliability, validity, objectivity and whether it can be replicated. However, the purpose of the research was to understand the *experience* of the carers as they understood it themselves, with the recognition that 'memory is no simple "psychological faculty" from within – it is shaped through and through by setting, society and culture' (Plummer, 2001: 236). I ensured that I knew when the carer had been caring and for how long, as this enabled me to cross-reference their experiences of services within a legislative and policy context for themselves as carers, as well as the person with dementia. As already stated, a criterion for the sample was that a proportion of the carers had been caring in the last five years since the implementation of key policy and legislation, which may have impacted on their experience (Mental Capacity Act 2005; Department of Health, 2008a, 2009).

## Interpretation of the Carers' Stories

In hearing the carers' stories I adopted an interpretive approach reflecting my desire to understand the purpose and the context of the carers' stories. Plummer (2001: 233) makes the point that: 'Life story work involves recollecting, remembering, re-discovery, along with the active process of memorializing and constructing history' so from a sociological perspective it is not just the unique nature of individual lives but their social context (Roberts, 2002).

Narrative is organised around plots, characters, themes and genres. Stories personalise people's experiences, and provide access to people's thoughts and feelings. They are coherent through being placed in chronological order. The telling of stories enables people to bring order to difficult events, so they can better understand them and emotionally process them.

Marginalised groups can define significant issues for them and their community (Plummer, 2001). The carer who was a gay man in particular was able to contextualise the impact of homophobia on the cared for and himself. Gibbs (2007: 57) suggests that stories have 'dramatic and rhetorical force', as they are authoritative and their delivery conveys more meaning than the actual language. An example of this was when one carer's tone of voice suddenly changed and she sounded very angry about her mother's expectation that she should care for her.

Simons (2009) stresses the importance of the researcher needing to recognise themselves as the instrument of data collection, observations, interactions and the interplay of one's values and perceptions within the research process. As the researcher I was not disembodied but came with my personality, values, beliefs and expectations. One carer spoke at great length of her sadness about her mother's abandonment of her as a teenager and now her mother had dementia her mother would not be able to explain why she had behaved like this. I remember

thinking that even without the dementia that her mother probably would not have been able to provide that explanation, and how sad that this daughter was so emotionally occupied by such an intractable difficulty. 'It is when our emotions and feelings are aroused that we know our subjectivity is engaged' (Simons, 2009: 82), therefore my awareness of this was important so that I monitored my own emotional state, and its influence on the interaction. This was the carer's time to tell me her or his story from her or his own perspective without me offering advice, guidance or reassurance.

It is the carers' memories that organise the story into events, conversations and provide a time sequence. They understand their lives through the meanings that they give to events, for 'human identity is narrational, lives being composed of the narratives by which time is experienced' (Erben, 1998: 11). Biographical research requires an understanding of the facts, the use of imagination and an analysis of the person's story by the researcher. Indeed Erben (1998) stresses that to be able to interpret and develop the ideas from the research into a coherent narrative imagination is required. This involves engaging with and trying to understand the experience of the carer, and starts with attentive listening through recognising the emotions being expressed and assessing if any themes are emerging. Then reflecting back what has been understood about the emotional impact of the interviewee's experiences, as well as checking that what is being told has been correctly understood.

Rogers (1980) views empathy as the most important factor in a relationship to support change and learning, this includes research and teaching as well as therapeutic interventions. He defines empathy as:

to perceive the internal frames of reference of another with accuracy and with the emotional components and meanings which pertain thereto as if one were the person, but without ever losing the "as if" condition. Thus it means to sense the hurt or the pleasure of another as he (sic) senses it and to perceive the causes thereof as he (sic) perceives them, but without ever losing the recognition that it is as if I were hurt or pleased and so forth (Rogers, 1959 quoted in Rogers, 1980: 210-211).

To engage effectively with the carers needed my full attention and sensitivity so that I could, as Egan (2010:183) describes 'tune in carefully, both physically and psychologically', while avoiding being over identified with the carer's emotional state, using my imagination but retaining an 'as if' attitude (Rogers, 1959: 21; Erben, 1998). It also required me to be aware of my judgements and biases, as 'bias comes not from having ethical and political positions – this is inevitable – but from not acknowledging them' (Griffiths, 1998: 133). I return to the concepts of bias and reflexivity later in the chapter.

## Researcher as Guide

Atkinson (1998: 32) describes the researcher as a guide leading the participant through the interview by knowing what to ask, how to ask, the use of supplementary questions and recognising when there should be encouragement to give more information or to move on, as well as offering reassurance. Prior to our meeting most of the carers had made notes about what they wished to say on the interview schedule. One carer for instance provided photographs of his friend, and copies of documents relating to his contact with the Local Authority and the National Health Service, as he thought these would help me to understand his experience. This carer was guiding me, other carers had particular concerns that they wished to convey, or examples of how they had been effectively supported.

Rogers (1980) identifies the following elements that comprise effective communication skills: attentive listening, non-judgemental attitude, unconditional positive regard towards the person being interviewed, empathic understanding, genuineness and trust. The latter is achieved by treating information that is given by the participant as confidential. These approaches in attitude and behaviour are supported by the use of open questions that enable people to give expansive responses without being judged or contradicted by the researcher. I was persuaded by Atkinson (1988: 41) of the need for a 'thematic framework' to questions that ensures that one theme is covered at a time, which focuses on thoughts, feelings and understandings, as the most effective approach. I was further guided in my approach by Atkinson's (1998: 34) attentive listening, which requires concentration but which raises the self-esteem of the participant in so far as 'it gives people being listened to the feeling that they really matter, that what they have to say is important, and the listener really likes them'. Listening enables the researcher to build a 'bridge of trust' between the researcher and participant, and inevitably 'emotions emerge' (p.35). Most of the carers became emotional at some point in the interview, and for some they expressed their feelings of being upset, as if taken by surprise. Often during this time there was silence which can have different meanings such as the person feeling they have said enough on a topic, needing time to think, feelings of anger, self-protection and having shared information that is highly emotional and needing time to process it (Lishman, 2009). My observation was that some carers were overwhelmed by their feelings, and were finding it difficult to articulate them. Sometimes they expressed feelings of distress or anger about how they had been treated in the past by the cared for person or other people, while for others there was an intense sense of loss about the death of the person. I waited for the carers to indicate that they were ready to carry on, so they were in control of the pace of the interview.

Research is frequently evaluated in terms of how representative it is - the extent to which it reflects, or can be related to, the general population. In biographical research however, 'insights, understandings, appreciation, intimate familiarity are the goals and not 'facts', explanations or generalizations' (Plummer, 2001: 153). When life stories are written they

provide opportunities for interpretations and theorising, and information about the inner experience of the person, even though anecdotal evidence is often denied validity, as stated earlier particular experience may have general or universal application on the experience of others (Simons, 2009). Some of the accounts that the carers gave had marked similarities: for example social care staff asking the carer to speak to the person with dementia about their behaviour, when it had presented problems for the care staff, as if the cared for person were a misbehaving child. There was little, or no, understanding on the part of the staff of the absurdity of the request, nor any reflection on what may have triggered the behaviour in the first place.

Returning to the concept of bias Griffiths (1998) identifies how bias can operate at different levels in research. To begin with the research process and procedures may have bias if particular groups of people are excluded or stereotyped. Bias can occur due to the values of the researchers and their political perspectives, and finally research that has been commissioned may require evidence to be produced that meets the funders' needs rather than the participants of the research. The carers were self-selecting with three criteria being in place which were that half the carers should identify as lesbian or gay, that they had retained a relationship with the person with dementia throughout the illness, and at least three of the carers had been caring in the last five years. The carers that approached me offering to be interviewed were, or had been in professional occupations, five were women with just one man, and they were all white. I used a range of methods to advertise for participants which included leaflets, web-sites, professional and personal networks (Appendice 1 & 2). I was clear that for ethical reasons I wanted carers to offer to be participants. I did not wish to pressurise people, as I felt this to be wrong, as I suspected that the carers' stories would provoke strong emotional memories for them, which proved to be the case. Griffiths (1998: 129-130) explains: 'Opinions give a clue to values ... Opinions set the research off and motivate it' which seem apposite comments on my own rationale for how I engaged with the participants, but in addition to this I visualised the interviews as being a source of great sorrow. I was uncertain if I could bear to hear these stories. It was the process of reflecting back on my 'subjective selves' (Simons, 2009: 93) and using images to represent how I felt at the time that I have become aware of my apprehension, consequently I had to know that the carers really wanted to meet with me. The research was not externally funded, and therefore the requirements of commissioners were not an ethical issue that I had to confront and manage.

Oakley (1981) argues that effective interviews are achieved when the relationship between the researcher and the participant is non-hierarchical, and the researcher is prepared to provide some information about themselves, especially when people are being asked to disclose personal details. Oakley is highly critical of traditional social research interviews where the participant is passive, and is seen as a source of data. She maintains that the key role of the interviewer is to develop rapport and ask questions. Bias in the interview process is inevitable,

and this needs to be recognised by the researcher and taken into account in the analysis of research findings:

the mythology of 'hygienic' research with its accompanying mystification of the researcher and the researched as objective instruments of data production be replaced by the recognition that personal involvement is more than dangerous bias – it is a condition under which people come to know each other and admit others into their lives (Oakley, 1981: 58).

Malseed (2004) comments that Oakley's critique is unfair to social researchers, as a range of interview approaches can be used depending on the nature and purpose of the interview. Oakley (2004) commented in response to Malseed that often formal interviewing techniques are seen as the norm for traditional research subjects, whereas informal interview approaches are seen as deviations. One example of Oakley's research involved interviews with women about the transition to motherhood. To gather in depth information she needed to develop a personal relationship with the women to obtain their views about maternity and ante-natal services. Service improvements would not have come about without these insights. Further a lack of 'bias in research could only be possible if researcher and informant were mechanical robots a researcher without a face to give off feelings' (Plummer, 2001: 156). On the other hand, Letherby (2004: 180) argues that: 'a mutually exclusive divide between "qualitative" and "quantitative" is epistemologically debilitating as it results in a knowledge cul-de-sac.' I have used statistical information pertaining to the incident of dementia, numbers of carers and their financial value to the UK economy, as this gives a context to the carers' stories, highlighting why the research is significant and relevant. Letherby (2004: 179) stresses: 'it's not what you do but the way that you do it' that matters.' This will be discussed in more detail in terms of ethical research practice.

Biographical research interviews such, as those I engaged in, are similar to getting to know someone socially where there will be a specific focus on exploring particular aspects of the person's life (Gearing and Dant, 1990). 'Experience is the meaning maker in our lives' (Atkinson, 1998: 45), thus enabling people to talk about their experiences in an open and accepting manner gives them an opportunity to make sense of what has occurred, develops the person's self-awareness and enables them to articulate their learning from the experience. The biographical research method that I adopted 'rests on a view of individuals as creators of meanings which form the basis of their everyday lives. Individuals act according to meanings through which they make sense of social existence' (Roberts, 2002: 6). I found this to be true for myself as the researcher, as the process gave me self-knowledge, as well as an understanding of carers' lives, and curiously the interviews were not as emotionally enervating as I had imagined.

## Ethics as a Process

The subsequent recording and interpretation of the research findings needs to be undertaken ethically. Clarke (1998), in her research account of the working lives of lesbian women teachers of physical education makes a powerful case, arguing that 'how these stories are told is crucial if these seemingly private issues are to become public issues. Since how we write creates a particular and partial view of reality' (p.68).

How the carers' stories are presented is important as this will impact on their influence with a wider audience. To minimise the complexities of caring for someone with dementia presents the role of carers as unsubstantial, while focusing on the negative aspects of caring emphasises caring as a relentless burden. I wanted to be able to learn the different ways in which, carers experience caring, and were able to identify health and social care practice that was positive, as well as unhelpful approaches.

The research framework outlined earlier integrated ethical principles into the design and delivery plan for the research. This drew upon the British Sociological Association's (2004) procedures for researchers, which includes ensuring that the interests of the interviewee are paramount and that informed consent is obtained. The concept of not harming participants through the research process is emphasised by the British Sociological Association:

In many of its forms, social research intrudes into the lives of those studied. While some participants in sociological research may find the experience a positive and welcome one, for others the experience may be disturbing. Even if not harmed, those studied may feel wronged by aspects of the research process. This can be particularly so if they perceive intrusions into their private and personal worlds, or where research gives rise to false hopes, uncalled for self-knowledge, or unnecessary anxiety (British Sociological Association, 2004: 4).

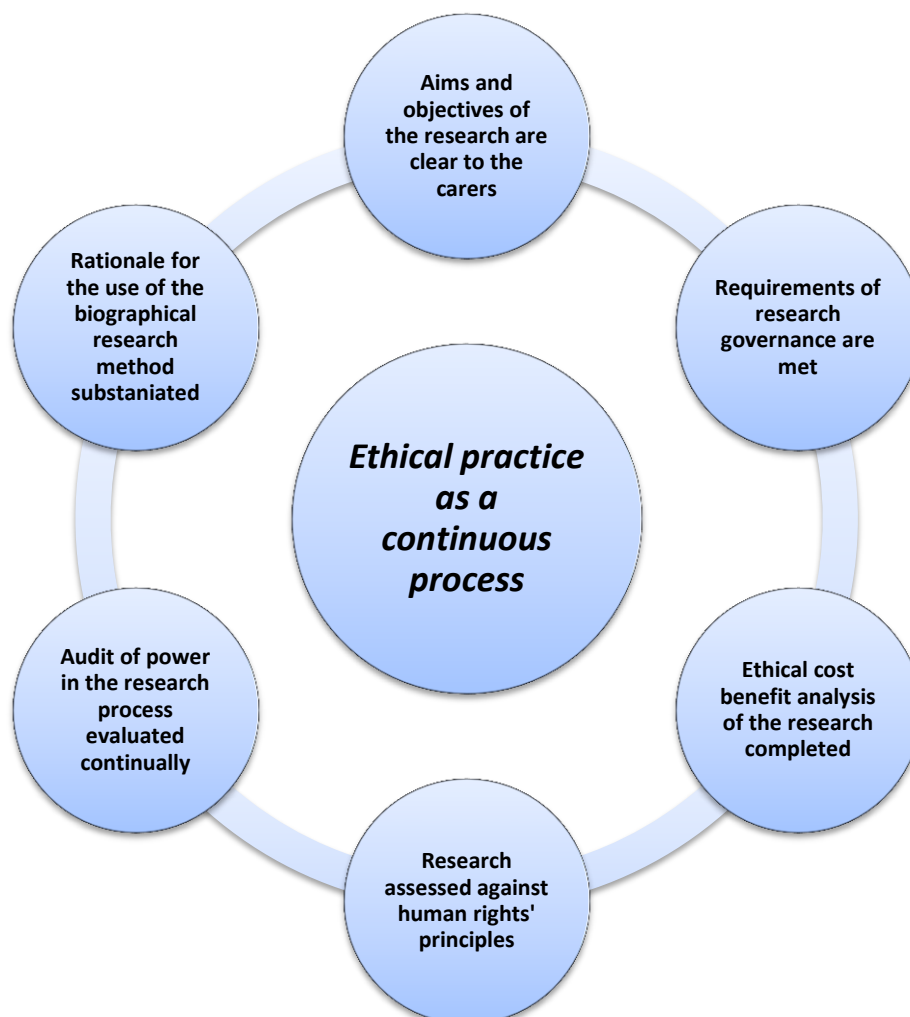
Ethical practice is how we behave throughout every aspect of the research (Letherby, 2004). Although the research was approved through a university ethics committee such committees rarely check what has actually taken place during the course of the research and cannot 'govern ethical behaviour through forms and procedures' (Simons, 2009: 120). The principle of doing no harm could be expressed more positively by doing research *with* people rather than *to* them (Simons, 2009). Moreover the aim of the research should be 'to minimize the harm or cost and maximise the benefit' (Gibbs, 2007: 101). This concurs with Griffiths' (1998: 129) research principle of 'better knowledge' that improves the quality of people's lives and assists in the achievement of social justice. In spite of the time commitment for the carers, as well as the

emotional impact of telling their stories, they were keen to participate, as they thought the telling of their stories could help other people.

The ethics protocol, which met the requirements of the British Education Research Association Ethical Guidelines (2004), was approved by the University of Southampton, School of Education Research Ethics Committee prior to the research commencing. The governance process included completion of a risk assessment and ethics checklist. The University of Southampton approved the undertaking of the research on the 26<sup>th</sup> August 2009 (Appendix E). A Research Governance Project Plan was submitted to West Sussex County Council which was approved. This enabled the research leaflets to be distributed throughout the County Council's services (Appendix D).

I regarded ethical practice in the research process as continuous and in need of ongoing evaluation as the research proceeded. The range of ethical issues that I was required to address as the researcher is presented in figure 3.1.

**Figure 3-1: Conceptual Ethical Framework**



It was important that I made clear the aims and objectives of the research to the carers. Walmsley (1993: 47) states:

In all research situations how we explain our research, and how the people being researched explain it to themselves is a subject worthy of attention, more attention than is usually given to it. It is a crucial determinant of what we discover.

Ethically the carers needed to understand the purpose of the research, and its limitations in terms of impact. The research was for academic purposes rather than having been



commissioned by the Department of Health, so it was not likely to lead to policy or national practice changes within the health or social care professions.

The carers gave informed consent in writing and, as stated I advised them that they could cease to be involved at any stage of the research without the need for explanation. Biographical interviews are likely to produce sensitive information from people who may feel vulnerable about aspects of their lives. There are issues of power between the researcher and participant, but I was mindful that the researcher always retains the real power as they have the data (Letherby, 2004) because of this the transcript was sent to them for checking. The carers' privacy was respected and anonymity protected in the research report through the substitution of their real names and geographical location with pseudonyms. Nevertheless it is important to recognise that the biographical approach provides personal and individualised information, so that carers could recognise themselves within the research. It is not possible to provide the same kind of anonymity that occurs in large scale quantitative research (Gibbs, 2007). A distinction needs to be drawn between confidentiality around personal and sensitive information that the researcher can be careful to protect and not discuss or use, and anonymity where names and places are changed, but inevitably the carer will recognise themselves and possibly other people will too (Simons, 2009). The carers were advised what would happen in the course of the research, how the data would be stored and managed. In spite of this, as the researcher I could not foresee how they might feel when reading the transcripts of the interview, even though I did anticipate that this may provoke concerns. In the event, only one carer requested something be changed.

An ethical dilemma highlighted by Etherington (2004) is when one person's story is bound up with another person. This was an issue for me, irrespective of whether the person with dementia was alive, or had died. Although most of the carers were compassionate and kindly in their descriptions of the person with dementia, one carer expressed extreme frustrations with the person, while another at times spoke with a disparaging tone. I recognised in part their comments reflected their disappointments about the person with dementia, either having never met their emotional needs, or no longer being able to do so. It still made me feel uncomfortable, as if I was colluding with the objectification and exclusion of the person with dementia as there was no one to speak up for them (Kitwood, 1997).

In the following section I describe an ethical costs benefits analysis of the carers' engagement in the research.

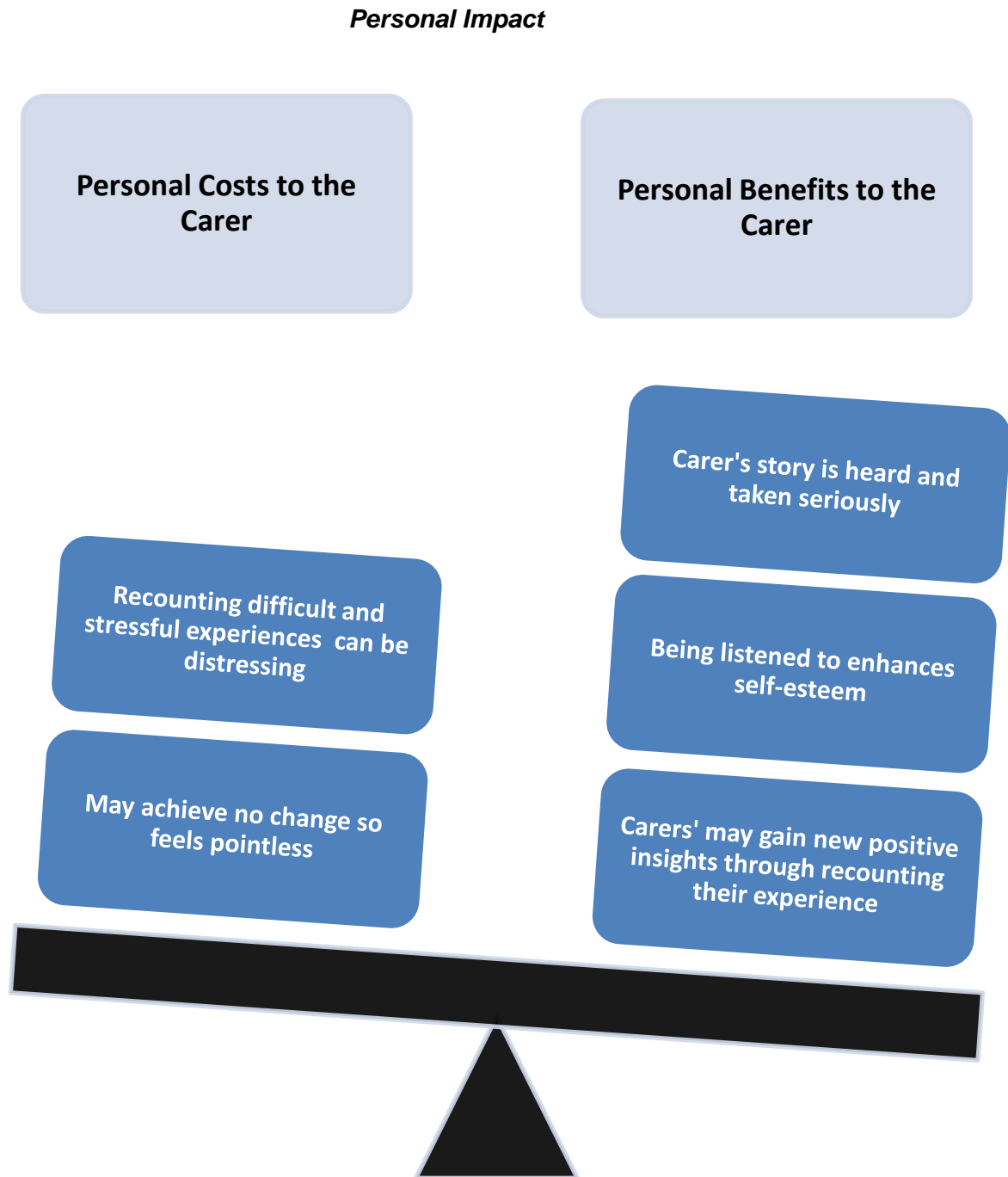
## **Ethical Cost Benefit Analysis of the Research**

Ethical considerations should be evaluated at every stage of the research (Liamputtong, 2007). The medical sciences have recognised that harm can occur through testing for example

particular drugs or interventions, but more recently, as earlier discussed, it has been acknowledged that social science research can cause harm too (British Sociological Association, 2004). This has to be weighed up against not seeking the views of marginalised groups, and thereby denying them opportunities to be heard, which impacts on their capacity to achieve social justice (Griffiths, 1998).

It was possible to undertake a cost benefit analysis of the possible risks and benefits of the research to the carers. In this assessment, costs are defined as those things that have the potential to do harm, and benefits are activities that promote well-being. Liamputtong (2007) suggests that any research implications should be considered in terms of the personal, interpersonal, community and political impact of the research on the participant. These criteria have been used to evaluate the research and are represented visually in figures 3.2-3.5.

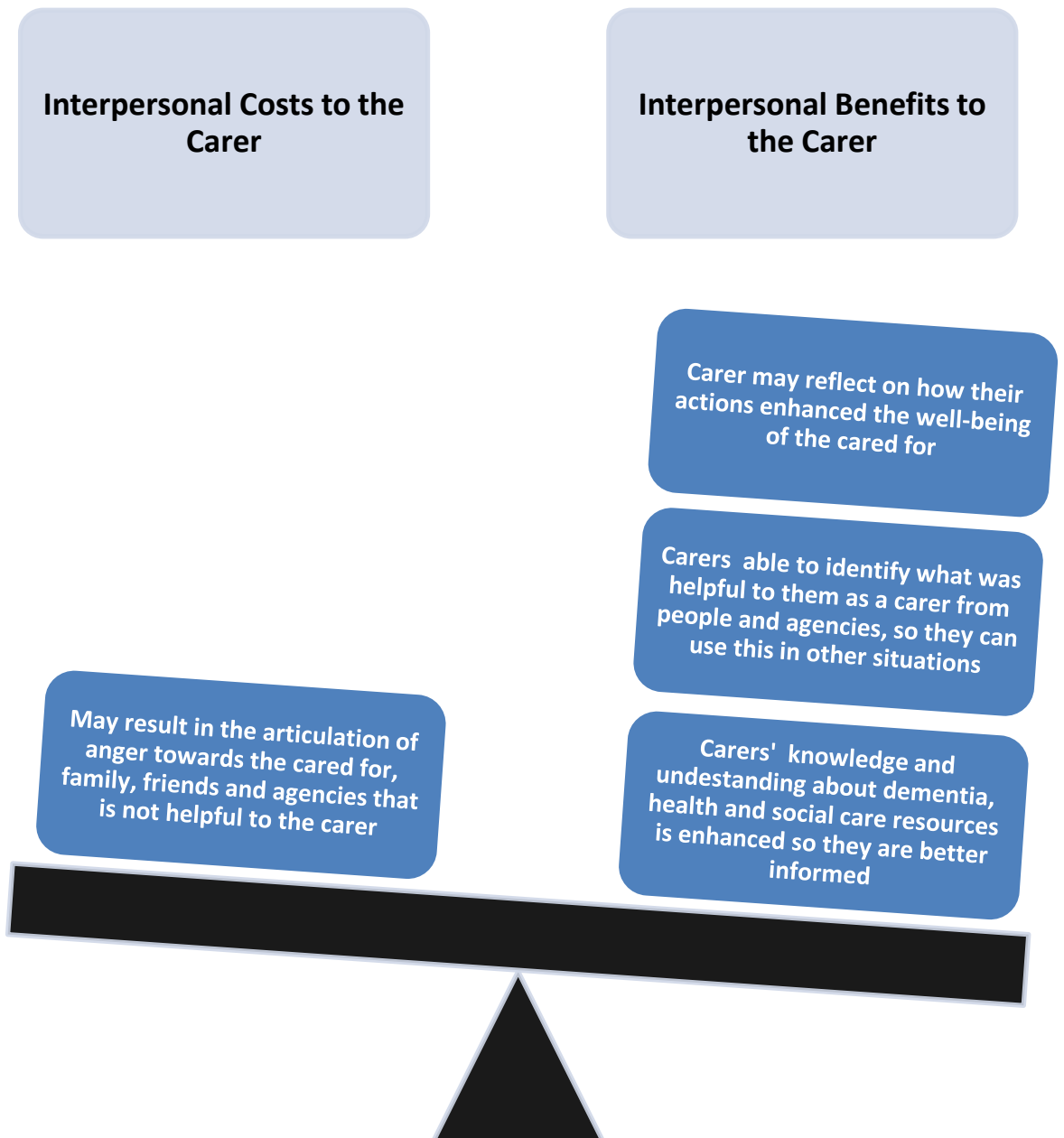
Figure 3-2: Cost Benefit Analysis of the Research



Adapted from Liangputtong (2007)

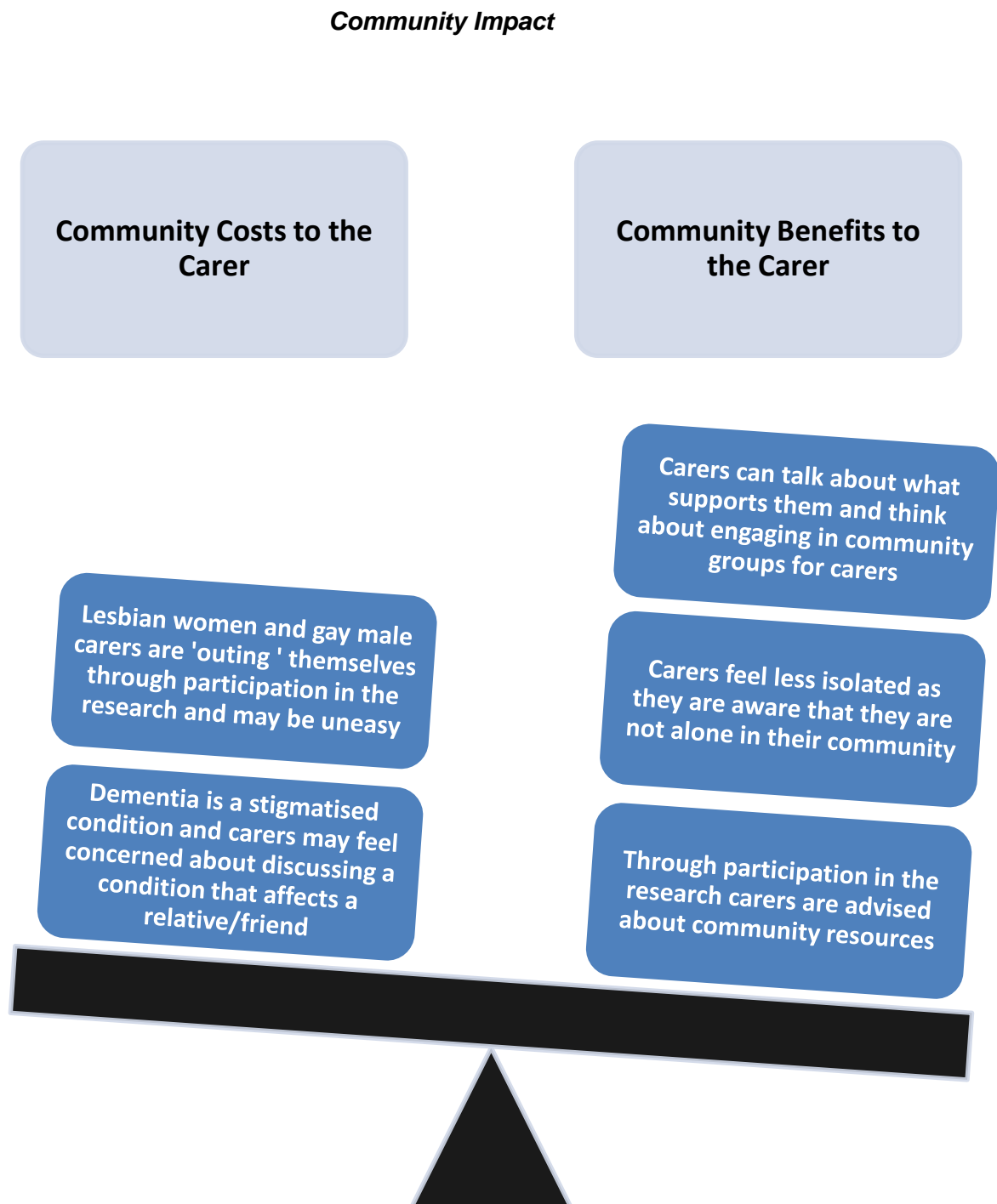
Figure 3-3: Cost Benefit Analysis of the Research

*Interpersonal Impact*



Adapted from Liamputtong (2007)

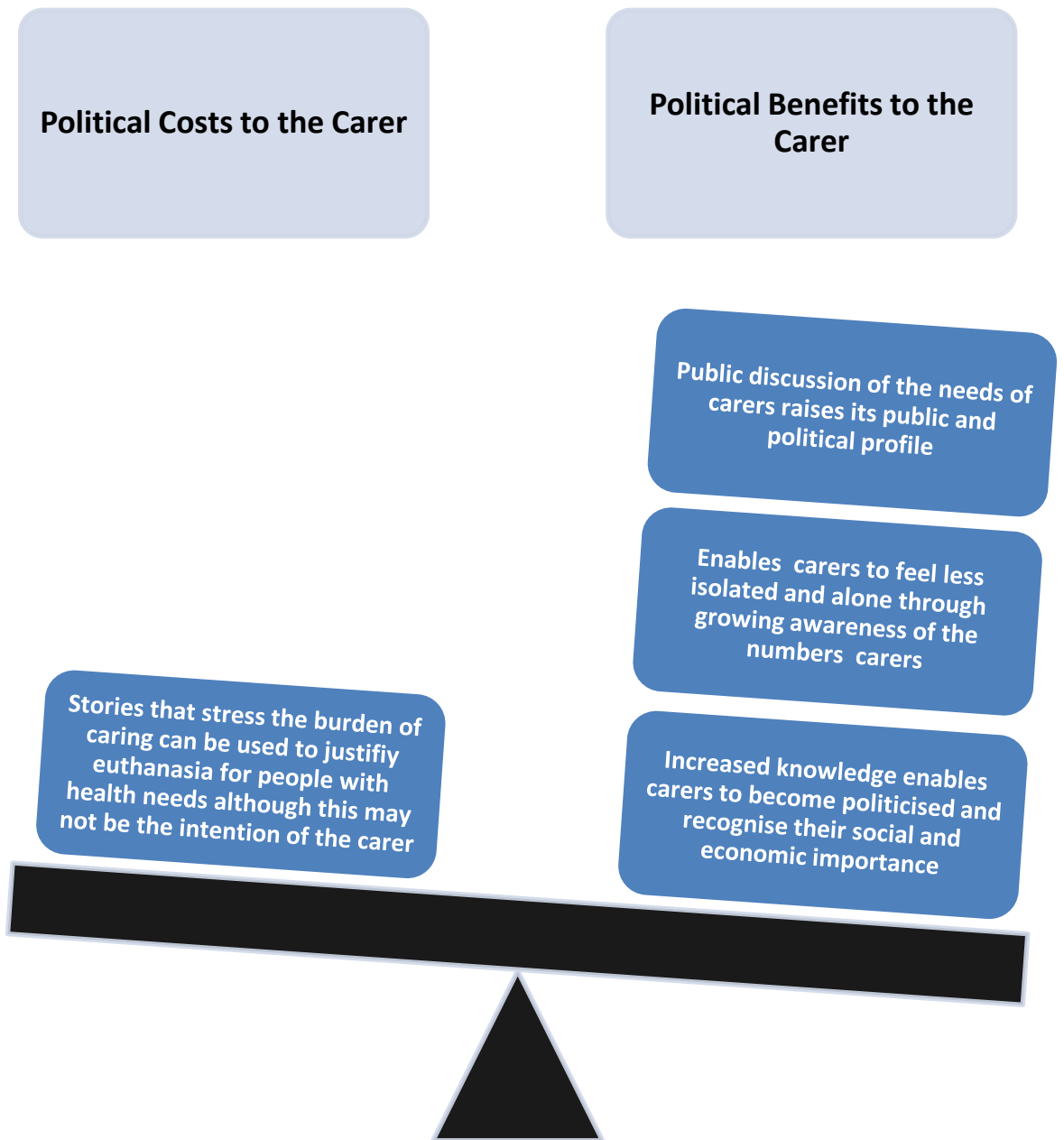
Figure 3-4: Cost Benefit Analysis of the Research



Adapted from Liamputtong (2007)

Figure 3-5: Cost Benefit Analysis of the Research

*Political Impact*



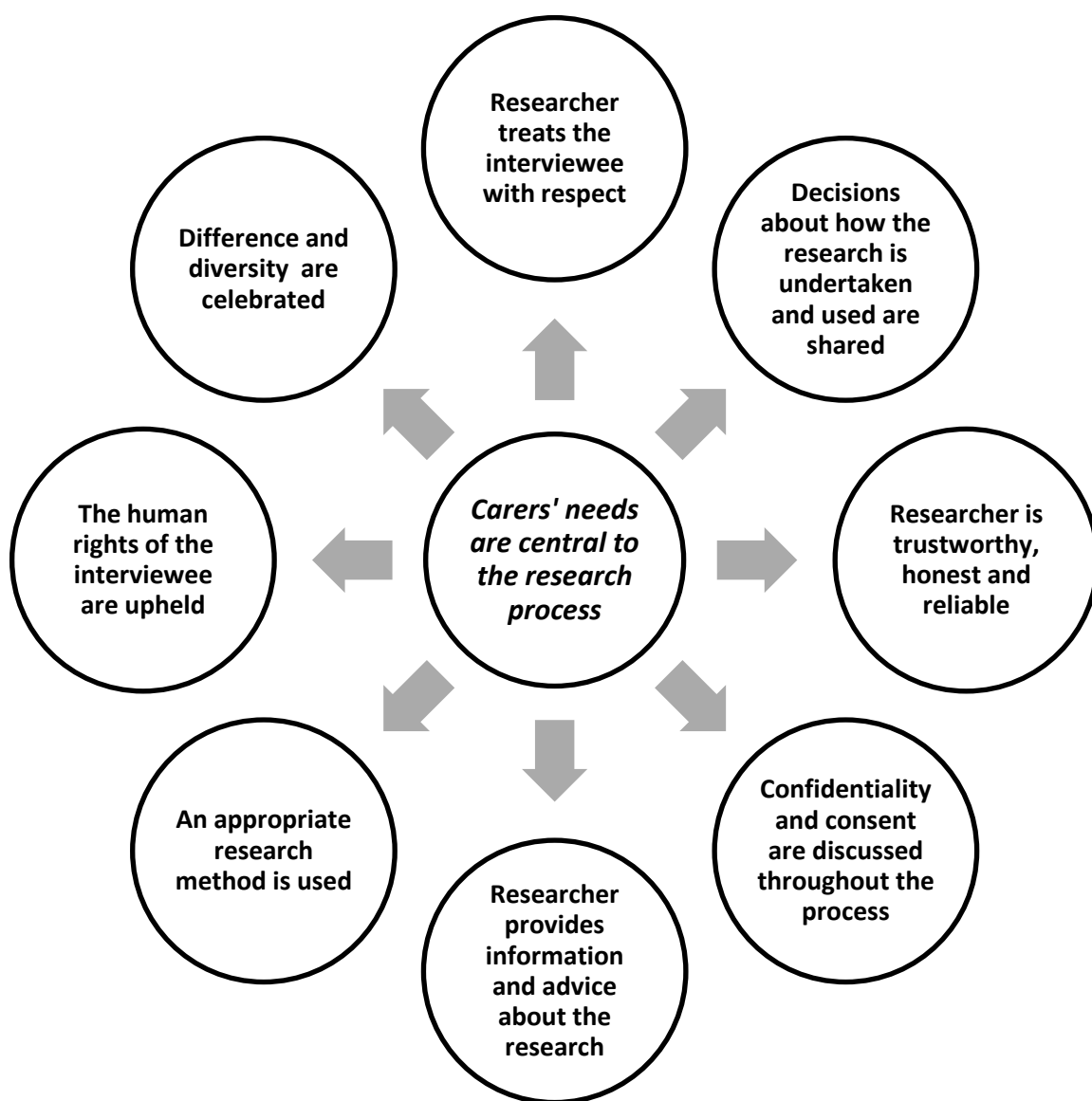
Adapted from Liamputtong (2007)

The cost benefit analysis illustrates that there were positive reasons for the carers to be consulted about their experience that outweighed the negative impact for either them, the person for whom they cared, or on a wider social and political level. The impact of not engaging with particular groups, such as carers or people with dementia, reduces their capacity to articulate their concerns, and have their needs given social recognition and political priority, as their experience remains hidden and marginalised (Griffiths, 1998). A concern with human rights is 'at the root of all emancipatory and anti-discriminatory research' (Witkin, 2000: 205). Three approaches to achieve this are: human rights as the goals of research, as evaluative criteria and as a guide to conducting research. The concept of human rights are the values placed on equality between people irrespective of health needs, sexuality, gender, ethnic and cultural origin, social class and marital status, consequentially Witkin (p.208) argues that: 'Social research is a value-based culturally situated process whose knowledge claims are inherently political ... researchers both reflect and shape the social landscape.' Research should provide 'transformative criticism' that challenges assumptions and 'generative theory' by offering alternative ideas and perspectives (Witkin, 2000: 211). These concepts were accepted as goals for my research and underpinned the messages for practice to health and social care services towards carers of people with dementia.

## **Self-Audit of Research Practice**

There are differences in power and inequalities between people with dementia, carers, health and social care professionals. This revolves around hierarchies of knowledge and access to resources, that can be heightened by differences in class, gender, age, sexuality, disability, culture and ethnic origin (Thompson, 2001). Braye and Preston-Shoot (1995) have developed principles to assess social care organisations against criteria of anti-oppressive practice so as to empower people that use services, and carers. Empowerment in this case is seen as a process that treats people with dignity and respect rather than objects to be controlled, manipulated or exploited. It comprises human rights, social justice and equality, which are the values that underpin social care practice (General Social Care Council, 2010). The following self-audit process (figure 3.6) has been adapted to assess my behaviour towards the carers at each stage of the research process. It also drew on the ethical requirements of the British Sociological Association (2004).

**Figure 3-6: Self-Audit of Research Practice**



Adapted from Braye and Preston-Shoot (1995)

Throughout the research process I audited my ethical practice against the principles set out in figure 3.6. I behaved in a manner that was congruent with the written information about the standards that the research would operate to. For example: I asked the carers to specify where they would like the interview to take place. I was reliable and punctual for appointments. I dressed as I would for work in smart clothes, as I felt this showed respect towards the carers and demonstrated the importance of the interview to me. I adopted an open, transparent, friendly and approachable manner, as ultimately the interview is based on collaboration between the interviewee and the researcher (Roberts, 2002). I advised the carers that I was not



going to transcribe the tapes, so another person would hear the interviews, but the person transcribing would sign a confidentiality agreement (Appendix F). I provided the carers with a transcript of the interview in their preferred method (electronically or hard copy) that they could amend and change. I then sent them a final printed copy in the post to save them having to print a copy off from their computer at home with a letter thanking them for their time and engagement. I sought to build and sustain a positive relationship with carers based on trust, and recognised the concept of 'complex integrity' that requires the researcher to do more than simply follow ethical procedures (Simons, 2009: 110). This acknowledges the complexity and diversity of human experience, and that ethical practice should be our way of being not simply something we affect for the purposes of the research.

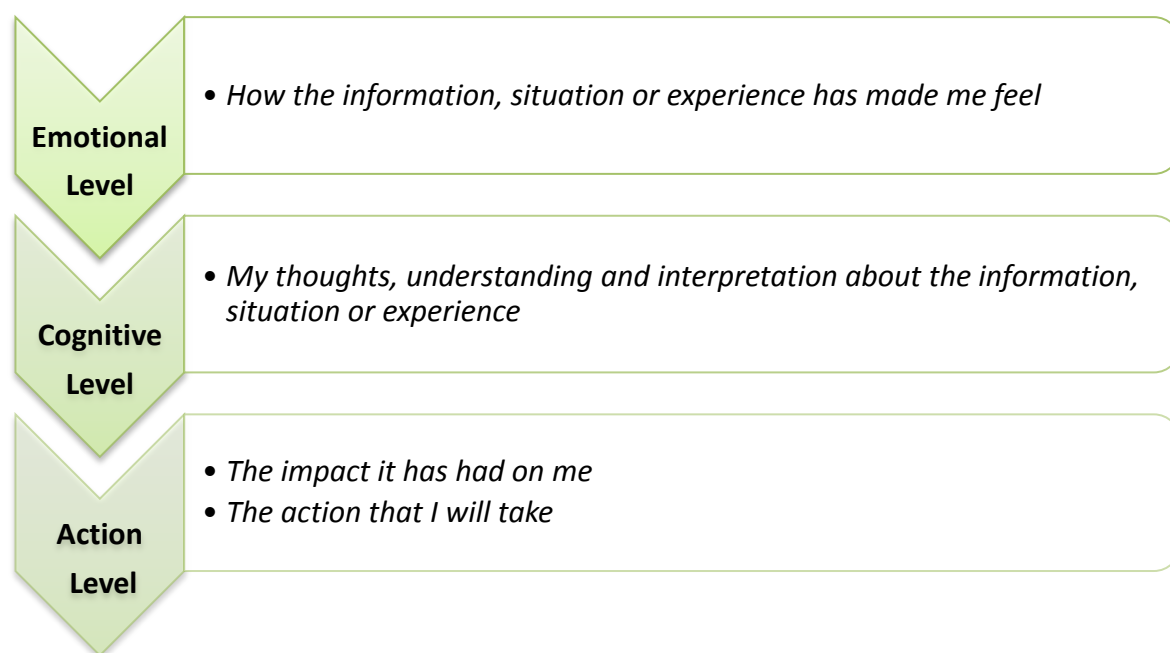
Etherington (2004: 227) says 'if we stumble carelessly into intimate personal research relationships we take the risk of leaving participants worse off by our encounters with them'. Participants may disclose information that they did not intend, or have new insights that cause discomfort, therefore the opportunity for the carers to remove parts of the transcript was important, as was advising them that at any stage in the research process they could withdraw and all documentation and tapes would be destroyed. In addition I gave the carers information about support services and resources pertaining to dementia and carers that they could access, if the interview had in anyway caused them distress (Appendix G). I advised the carers that data was stored securely and would be destroyed at a specified date.

Ethical practice in the research process is intertwined with reflexivity, which enables an understanding to develop of how interactions with other people impact on us, and how we affect others (Schön, 1983). One method that I used to support reflexivity was a research journal that included the use of writing and images.

## **Becoming a Reflexive Researcher**

I used a journal to record experiences with a reflective component as writing provides an opportunity to consider a situation from different perspectives. It can take place at three levels: emotional, cognitive and the impact on behaviour (Waines, 2004). This has been adapted and used as a structure for my research journal as shown in figure 3.7

**Figure 3-7: Journal Structure**



Adapted from Waines (2004)

This format was helpful, as it provided a process for my emotional and cognitive responses to a situation and enabled me to plan a course of action. I realised the importance of self-awareness that ‘inner sense of knowing who we are and how we define what is important to us – those values, emotions and ways of thinking and being that affect how we live and act’ (Simons, 2009: 82). I developed increased awareness of the research’s impact on myself through writing and the use of visual images (Etherington, 2004; Simons, 2009). These images became metaphors for how I was left thinking and feeling about the carers’ stories, and they summarised my emotional responses to them in their role of carer. Furthermore I was able to visualise the changes that occurred for me as a researcher from the start of the research process to the end, where I became less an ‘objective’ observer and more an engaged researcher caught up in their stories and learning from them. These images developed following my analysis of the data and can be found in Chapter 6: Summary and Conclusion.

## **Research Analysis**

The research topic, research areas, research approach, data collection method and ethical issues have already been addressed. I consider next the process that I used to analyse the data from the semi-structured interviews with the carers. This will move the research into the empirical stage, where themes emerge from the carers’ experiences.

## Content Analysis

Content analysis is the method that I used to analyse the transcripts of the interviews. While I did not transcribe the interviews as a first stage of the familiarisation with the data, this was not a problem, as my memory of the interviews was vivid. I had them available to listen to again as well as viewing the transcripts. It was important for me to read the transcripts to assure myself that I had clearly understood what the carers were saying, and not making assumptions about what I thought they said. This required detailed reading on a number of occasions. When each transcript was completed I would meet with the person who had transcribed the interview to exchange payment for the transcript. I realised the transcriber had been affected by the interviews and felt the need to talk through her feelings. This highlighted an ethical issue as it is not just the participants and researcher that can be affected by the research (Gibbs, 2007). We established a pattern of meeting and having a coffee together, and discussed the interviews and the progress of the research. This was helpful as together we processed our emotional responses.

Transcripts do not readily provide additional data afforded by video such as body language, tone and pitch of voice, but Silverman (2000) suggests that this assumes that video recording is definitive when in fact it may be selective in terms of the sequences that are filmed. I chose to analyse the transcripts using the responses to the research questions, which I then compared against each carer's response. Etherington (2004:80) explains that 'narrative analysis' focuses on the story of an individual with the aim of understanding their experience from their unique viewpoint, and in depth. Life is viewed as socially constructed and this approach seeks to understand the social reality of that individual. This is in contrast to an 'analysis of narratives' that draws out concepts and themes to develop knowledge and understanding, so narratives can be compared for their similarities and differences in experience. This latter method met the aims and objectives of my research. Cohen *et al.* (2007: 476-483) set out an approach to content analysis, which I adapted when I analysed the carers' transcripts.

### **Step 1: Establish the Research Questions**

The rationale for selecting the research questions was to understand the experience of caring for someone with dementia, the coping strategies that were employed, and carers' encounters with health and social care staff.

### **Step 2: Identify the Written Material for Analysis**

The transcripts of the interviews with the carers were analysed having first been checked, and approved by the carers.

### **Step 3: Identify the Components of the Analysis**

The transcripts were structured around the research questions, which were cross-referenced to the 'Carers' Common Principles' (Skills for Care, 2010) developed by the national social care

workforce organisation that has responsibility for the curriculum for training of social care staff. The practice of social care staff when working with carers should be underpinned by these principles which are list below:

#### ***Skills for Care Carers' Common Core Principles***

- Principle 1: Carers are equal partners in care. Carers become experts with skills that are acknowledged, valued and appreciated.
- Principle 2: No assumptions regarding a carer's capacity or willingness to take on or continue with the caring role should be made.
- Principle 3: Support carers to be physically and mentally well in order to prevent ill health.
- Principle 4: Involve carers in making decisions and choices at all levels and at all stages of the caring role, following best practice in sharing information.
- Principle 5: Provide care and support in a personalised way that reflects the circumstances, cultural background and lifestyle of the carer and person being cared for.
- Principle 6: Respect carers' own needs, rights and aspirations, which may be different from those of the person being supported.
- Principle 7: Identify and protect children and young people who are carers, ensuring they have the support they need to enjoy positive childhoods.
- Principle 8: Recognise the experience of carers as the caring role changes or ends. After it has ended, offer support to carers accordingly.

#### **Step 4: Develop the Codes to be used in the Analysis**

Codes are words that abbreviate a concept, and were developed from the research questions. They denote relationships or social structures and ideas that are held by the interviewee (Cohen *et al.*, 2007).

#### **Step 5: Identify the Codes**

This required a line by line analysis to assess if there were words that fitted into the codes (concepts). Colour coding was used to indicate different codes that became themes. This is set out in a table below which indicates the colour highlighter that was used when analysing the transcripts.

**Table 3.2: Codes and Themes**

<b>Codes</b>	<b>Themes</b>
Turning points	<b><i>Experience of caring</i></b> (highlighted in yellow pen)
Changes	
Remembered	
Isolation	
Endurance	
Validation	<b><i>Being lesbian or gay</i></b> (highlighted in pink)
Homophobia and heterosexism	
Coping	<b><i>Coping approaches</i></b> (highlighted in orange)
Beliefs	
Support by partner, family and friends	
Partnership	<b><i>Carers' Encounters with health and social care services</i></b> (highlighted in green)
Capacity	
Support by professionals	
Choices	
Transitions	

#### **Step 6: Conducting the Data Analysis**

When a code was repeated this was likely to be significant for the carer, and when it occurred within the transcripts of the other carers a theme started to emerge suggesting a similarity of experience.

#### **Step 7: Summarising the Main Components of the Text**

The analysis enabled themes to be developed across the carers' stories. These themes were cross-checked with the Skills for Care (2010) 'Common Core Principles for Carers'. These highlighted how the carers' experience correlated against the benchmark standard of support that social care staff should offer to carers.

## Analysis of the Data

The data analysis process is illustrated in summary form in figure 3.16. To recap the carers were asked questions relating to each research area. Their responses to these questions were analysed and concepts identified as codes. This enabled themes to be identified, that demonstrated the emergence of similarities in the carers' stories. The data analysis process established that the Skills for Care (2010) 'Carers' Core Principles' were not being implemented in the practice of social care staff in any area on a consistent basis. This finding was especially concerning given that the carers and the cared for person lived in different parts of the UK, consequentially this does not suggest a localised shortfall in service, but rather something that is more pervasive in how carers experience health and social care services.

**Figure 3-8: Diagram of Data Analysis**



The carers' interviews followed the format set out in the research framework (table 3.1). Emerging from the analysis were codes (concepts) that developed into themes when repeated by more than one carer, as illustrated by figure 3.16. Some of the carers' thoughts and feelings that emerged during the course of the interviews may not have been conscious to them prior to the interview hence they are represented as below the surface of the funnel in the diagram.

Plummer (2001: 251) developed evaluative questions for life stories in the media and I adapted these not only to assess the reliability and consistency of the stories told by the carers in terms of individual stories, but also to assess the similarities and differences between stories. I used these evaluative questions, as reflection points when analysing the data.

- What moral dilemmas are happening here?
- Does the story have new insights?
- Who is telling the story?
- Who does it belong to?
- Who has been written out?
- Who are the other people in the life story?
- Does the story have depth and a broad context?
- Is the carer reflective?
- What truth claims are being made?
- Is the story located in time and place?

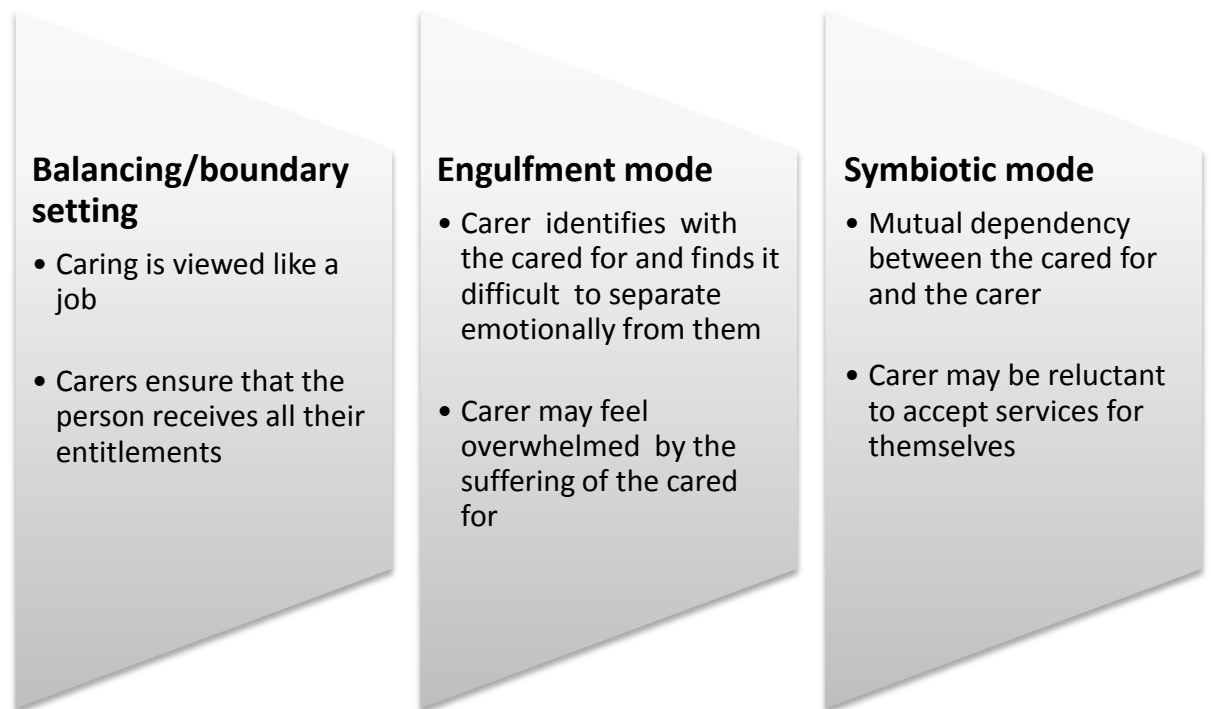
These evaluative questions were a valuable additional process to interrogate the findings that enabled me to assess my own interpretations, and reflect on my responses to the carers' stories. Gibbs (2007: 67) describes stories as being structured with a beginning, middle and end. In the course of the story they can 'ascend' or 'descend' depending on whether events are positive or problematic. Frank (1995) identifies three common stories relating to ill health: the restitution narrative where the person is ill but recovers; the chaos narrative where the person is ill and nothing improves and the quest narrative where the illness is like a journey where the person suffers, learns to overcome their difficulties and is finally restored having gained strength and wisdom. Stories do of course ascend and descend as they follow the story teller's memories of events. For most of the carers their stories had ascended in the end. Many aspects of their stories contained the elements of quest narratives in the way that the carer told the story, notwithstanding this for one carer (Elaine) my interpretation of how she saw her story fitted more with the chaos narrative. These stories are hard to hear, as there is no resolution to the bleakness of the experience.

## Theorising the Carers' Stories

I identified a number of theories relating to caring in Chapter 2 while reviewing the literature. In Chapter 5 I return to these theories while analysing the findings from the interviews with carers. To recap, Twigg and Atkin (1994) identified three approaches to caring which I drew on to explain the carers' experience of their role and how they managed emotionally and practically. This highlighted the belief systems of carers. The model is reproduced as figure 3.17. The

carers often demonstrated more than one approach at a time. I found this an effective method to gain an insight into how the carers at a personal level coped over the longer term.

**Figure 3-9: Approaches to Caring**



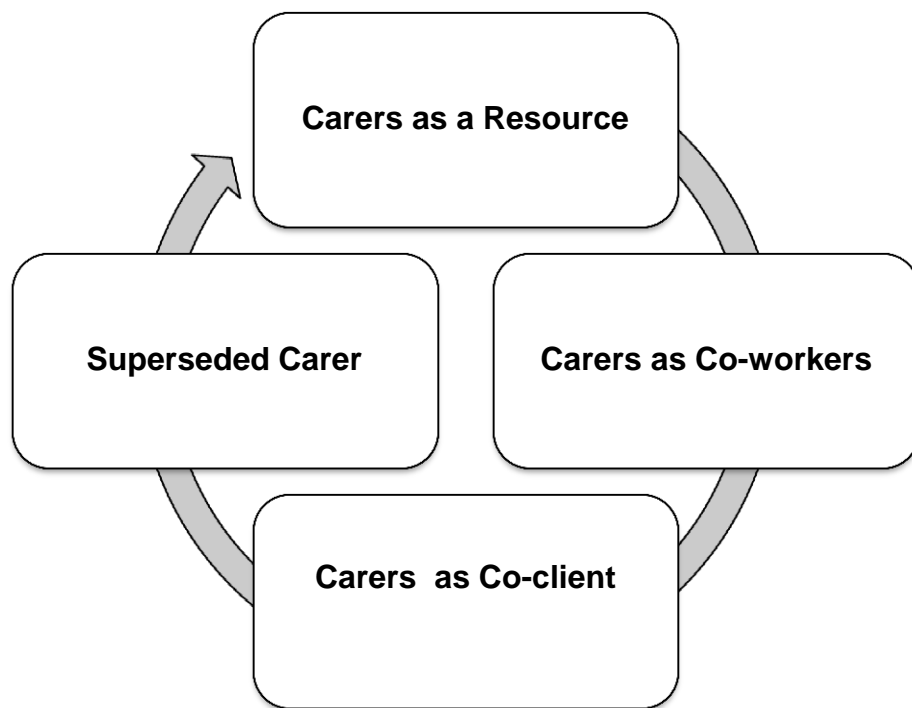
(Adapted from Twigg and Atkin, 1994)

## **The Support that Carers Receive as Their Role Changes**

When placing the carers' experience against health and social care practice I found Tanner and Harris's (2008) model effective in highlighting their experience. The model suggests that a systematic process is followed by health and social care staff in their engagement with carers, which I used to assess their actual experience. The model is reproduced as figure 3.18.



**Figure 3-10: Carers of People with Dementia**



(Tanner and Harris, 2008:178)

## **Managing Transitions**

The final model that I used to track the changes to the relationship between the carer and the person with dementia, as the illness progresses, was developed by Hellström *et al.* (2007). It illustrates the coping strategies that carers used, and arose from the findings of Hellström *et al.*'s research that was described in Chapter 2. The model is set down again as figure 3.19.

**1. Sustaining couplehood**

- Talking things through
- Being affectionate and appreciative
- Making the best of things:
  - *Life's little pleasures*
  - *Searching for positives*
  - *Living for today*
- Keeping the peace:
  - *Knowing the triggers*
  - *Not responding*

**2. Maintaining Involvement**

- Playing an active part
- *Taking risks*
- Handing over
- *Letting go*
- Taking over

**3. Moving On**

- Remaining a 'we'
- Becoming an 'I'
- New beginning

Time

85

These theoretical perspectives enabled me to develop 'ways of knowing' (Fook, 2002: 68) about the carers' experiences. I was supported in my understanding and able to reflect on aspects of their experience that I was curious about, and consequently hypothesise about their motivations and coping strategies. This was valuable knowledge as it enabled me to consider what constitutes best practice in the support to carers.

## **Summary**

This chapter discussed the rationale for a biographical research approach with carers of people with dementia. It demonstrated how this approach is best suited to my research intentions, which were to understand the experience of caring, how carers cope, and their encounters with health and social care staff. I have outlined how the data was cross-referenced to the Skills for Care (2010) 'Common Core Principles for Carers'. An examination of the ethical issues and benefits of the research was considered with reference to human rights. How the data was analysed and evaluated was explained. I concluded by detailing three theoretical models that assisted me to make sense of the overall findings of the research, which Chapter 5 will explore by looking in detail at the analysis of the interview data.

## Chapter 4: Profiles of Carers

### Introduction

In this chapter I profile the six carers including their relationship to the person with dementia. The research was positioned within its social policy context as ‘a life that is studied is the study of a life in time’ (Erben, 1998: 13), therefore the timeframe of caring was cross-referenced to successive pieces of legislation and policies that have sought to support carers and enable them to access services and resources.

The carers were given pseudonyms and the precise details of where they or the cared for person lived is not given. This was to ensure that the carers were not easily identifiable. The carers all agreed to provide personal details and completed a brief questionnaire defining their ethnic origin, sexuality, sex and age. Social class was not included in the personal details that carers gave, although the carers during the interviews gave information about their occupations, which were professional. It would be appropriate for future research to consider the impact of social class on the experience of caring.

### Aggregated Information about the Carers

Table 4.1 below provides personal information about the carers. At the time of interview their ages spanned three decades, although for four of the carers the person with dementia had died. Two of the carers identified as lesbian women and one as a gay man. Two were heterosexual while one carer did not wish to disclose her sexuality.

**Table 4.1: Personal Information about the carers**

Carer	Age	Gender	Ethnic Origin	Sexuality	Partner	Occupation
Ruth	61	woman	British	lesbian	yes	university lecturer (retired)
Susan	53	woman	British	heterosexual	yes	social worker
Angela	60	woman	All White Groups	prefer not to say	no	student/ writer
Nick	72	man	British	gay	yes	university lecturer (retired)
Theresa	54	woman	British	lesbian	yes	retail manager (retired) health therapist
Elaine	51	woman	Welsh	heterosexual	yes	university lecturer / counsellor

Table 4.2 sets out the relationship between the carer and person with dementia. The five women carers were all supporting their mothers, and Theresa was caring for her father too. Nick was caring for a friend. The table provides information about where the cared for person lived. The table also provides information about the length of time people were caring.

**Table 4.2: Relationship to the Person with Dementia**

<b>Name of Carer</b>	<b>Relationship to person with dementia</b>	<b>Region where person with dementia lives/d</b>	<b>Environment</b>	<b>Length of time caring for the person with dementia</b>
Ruth	daughter	north west England	urban	6 years
Susan	daughter	south east England	urban	6 years
Angela	daughter	south east England	urban	on going
Nick	friend	London	urban	10 years
Theresa	daughter	north of England	urban	13 years
Elaine	daughter	Wales	rural	on going

## Contextualising the Carers

As already stated the analyses of the carers' narratives has been placed in their social, political, cultural and personal context as this provides the opportunity to reflect on how these contexts have been influential on carers in terms of their caring experiences, the choices and opportunities available to them, as well as their strategies for coping (Erben, 1997).

Figure 4.1 locates the period of time the carers were caring in relation to legislation that has been developed to support carers. Each successive piece of legislation has entitled carers, at least in theory, to increased support such as an assessment of their needs; access to social care services; assistance to stay in employment or training, and the maintenance of leisure and social interests.

**Figure 4-1: Period of Time Caring**

The Carers (Recognition and Services) Act 1995	The Carers and Disabled Children Act 2000	The Carers (Equal Opportunities) Act 2004
<ul style="list-style-type: none"><li>• Theresa</li><li>• Nick</li></ul>	<ul style="list-style-type: none"><li>• Nick</li></ul>	<ul style="list-style-type: none"><li>• Susan</li><li>• Ruth</li><li>• Elaine</li><li>• Angela</li></ul>

Significant changes have been made to legislation and social policy from the 1990s to 2000s with increased entitlements for carers through each additional piece of legislation. The Carers (Recognition and Services) Act 1995 gave new duties to local authorities to assess carers' needs and to take account of them in any services provided when the cared for needs were being assessed under the NHS and Community Care Act 1990. It did not entitle carers to have an assessment in their own right, so if the cared for did not want services from the local authority the carer could not be provided with support. This was addressed by the Carers and Disabled Children Act 2000, which enabled carers to have an assessment in their own right regardless of the views or wishes of the cared for. The Carers (Equal Opportunities) Act 2004 enables the needs of carers to be recognized in terms of work, training and education, in the same way as other citizens (Pierson & Thomas, 2010). Consequently carers who have recently been caring or are currently caring should have different experiences of health and social care services compared with carers, who were caring prior to legislation being implemented.

## Profiling Individual Carers

Set down below is a brief profile of each individual carer, gathered through the questionnaire that they completed and the information that they gave to me. These profiles have been structured around family background, employment and the quality of the relationship with the cared for person.

### Ruth

Ruth grew up with her mother, father and brother in the north west of England. Her relationship with her mother had always been difficult, as she was emotionally and physically abusive to Ruth and her brother as children. Following the death of her father Ruth became estranged from her mother. Her identification as a lesbian woman had created additional difficulties in her relationship with her mother.

Ruth was retired from an academic career and lived in the south east of England. She had acquired knowledge about health and social care services from her career and felt that she put that knowledge to good use in supporting her mother. She became a long distance carer to her mother following her mother's admission to hospital and diagnosis of dementia. Her brother, although living locally to his mother, was unable to maintain a relationship with her due to the impact of her emotional abuse. The co-ordination of care and management of practical tasks was managed between Ruth and her sister-in-law. When the interview took place Ruth's mother had died, so she was looking back at their relationship and the experience of being a carer.

## **Susan**

Susan was brought up by her mother and father. She had an older sister and the whole family lived in the south east of England. Her relationship with her parents had been warm and very affectionate. When her father died she maintained a close relationship with her mother who lived locally, and found her a source of calm wisdom and support.

Susan was married with two adult sons. She was employed as a social worker working in a community team, primarily supporting older people. The onset of her mother's dementia meant that Susan lost a trusted confidant, as she noticed slight changes to how her mother responded to her. The poor quality of care that Susan's mother received, delivered by private sector domiciliary care agencies, precipitated Susan moving into her mother's home and caring for her. Susan experienced social work services from the perspective of a carer and found them wanting. At the time of the interview Susan's mother had died, so she like Ruth was looking back on her experience of caring.

## **Angela**

Angela was an only child. In her completion of the questionnaire about herself she was reluctant to disclose too much information of a personal nature. She was a lone parent with two teenage children, one of whom had learning difficulties. Angela's mother had always been a very sociable woman, who made demands of her husband in terms of attention. Following his death her mother assumed that Angela would fulfil her father's role by supporting her emotionally.

When her mother was diagnosed with dementia Angela moved herself and the children into her mother's home. In many senses Angela felt as if she had no choice but to do this, as it was what her mother demanded. The relationship was clearly complex, and stressful for Angela, especially as the dementia progressed. She was a part-time mature student and wrote for a publication, and these activities including her interest in art offered some respite from caring for her mother. At the time of the interview Angela's mother had settled into a care home locally. Angela visited her on a regular basis, and identified her admission to care as the most helpful service to her as a carer.

## **Nick**

Nick was brought up by his parents in Wales, and has a brother. He became carer to his friend of 40 years, Simon. Both men identified as gay, but they had never been partners. Nick was a retired academic working and living in London.

Nick provided support to Simon over the course of his illness, and was the only consistent carer that he had. Simon's family appear to have been neglectful, and found it difficult to accept his sexuality. Nick's friendship with Simon was of long duration, and he was able to provide person centred and creative approaches to support his friend, and enhance his well-being. The total rejection and exclusion of Nick by Simon's family clearly had a considerable emotional impact. Social Services failed to support Nick, which resulted in Nick successfully complaining against Social Services and being awarded compensation following the involvement of the Office of Local Administration (Ombudsman), which Nick gave to charity. Nick, like Ruth and Susan, used his professional skills to access resources and advocate for Simon. At the time of the interview Simon had died and Nick was reflecting back on his experiences.

## **Elaine**

Elaine was brought up by parents in Wales with a younger sister. Her mother left the family when Elaine was thirteen years old, and Elaine took on the role of caring for her father and sister. Both parents appear to have found life problematic and Elaine felt a heavy weight of emotional and practical responsibility at a young age. This culminated in her having a 'breakdown' as a young woman and leaving Wales. She did return only to leave again, due to the demands that her mother made on her. By this time Elaine had married and had her own children. Elaine felt that her mother had abandoned her and her sister when she left the family having met another man. Elaine's professional background as a social worker and counsellor gave her a particular insight into her own emotional development, as well as a strong sense of what was ethically right to do in terms of her mother's plight. Although she lived in the south east of England Elaine phoned and visited her mother in Wales on a regular basis, and worked with her sister to provide as much support as possible. Elaine's mother had recently been admitted to a care home, as she had become isolated and lonely living a home.

## **Theresa**

Theresa was an only child, who became a carer in her thirties. This was initially for her mother and then for her father. She had a successful career which necessitated her moving around Britain. Her father had worked for the same company, and much of the time she lived with her parents, who moved with her. Theresa had a deep emotional attachment to both parents, and realised that they would be unhappy if they were separated, so she chose to care for them both at home, as she recognised that the family did not have sufficient financial resources to purchase high quality care in a nursing home. Theresa took redundancy from the company, and



provided care to both parents that included nursing tasks. Following her parents' death Theresa resolved to find a partner and settle down. When interviewed Theresa was able to discuss her experience of caring as well as the experiences of other lesbian, gay, bisexual and transgender people that she had supported through a national organisation for people with dementia and their carers.

In the next chapter I will consider the findings from the interviews that the carers gave about their experience of caring.

# Chapter 5: Findings and Discussion

## Introduction

This chapter sets out the analysis and discusses the findings following the interviews with the six carers that were profiled in Chapter 4. The data were analysed by drawing out concepts that were placed into codes and themes began to emerge about the carers' experiences. I started by seeking to understand how the carers had chosen to continue their involvement with the person, and accept their role as a carer. It appeared to me that this was a turning point or epiphany in so far, as a decision was made either consciously or otherwise to continue with the relationship, and an acceptance that the relationship would change. This enabled me to begin the process of understanding about the experience of caring, which was an objective of the research. The first example of turning points relates to Elaine who had always felt she was her mother's carer, and comes from an earlier time in her life. The chapter goes on to explore the experience of caring and the coping approaches that carers adopted. It sets out the carers' involvement with health and social carer services. I then critique the research and identify shortcomings with suggestions as to how this may be met in further research. I conclude with messages for practice with a particular emphasis on the implementation of person centred approaches to improve practice and enhance the well being of people with dementia and carers.

## The Experience of Caring

Elaine's memory of always being a carer to her mother was 'transformative remembering' (Plummer, 2001: 237) as her increased self-awareness enhanced her understanding of her relationship with her mother, and the impact that it had on her emotionally. Elaine felt trapped by the emotional needs of her mother and there was a role reversal. She mothered her mother and felt responsible for her. A turning point occurred when Elaine left Wales to create some physical distance between herself and her mother. This was for Elaine a 'major turning point', as defined by Denzin (1989:71) as it impacted on every area of her life. She realised that by leaving her mother she would no longer be drawn into her emotional and practical difficulties:

I think probably when I was twenty five I eventually decided that something had to give, but during that time I had also got married and divorced and decided that I wanted to go away and do something ... I was getting back into the patterns, the old ways of being ... so I made the deliberate choice to move to England ... She's [her mother] had lots of crisis in her life ... I would go and visit and find that her and her new partner had split up, so she'd need a lift to her

new accommodation, or she'd want to go back to my father ... There was also things like not taking responsibility for paying bills, or the practical day to day things you need to do in order to either run a home or just to sustain living.

There is some similarity between the strategies Elaine used to deal with a problematic relationship, and those of Ruth.

Ruth left the north west of England, and moved to the south east as Elaine had done, but unlike Elaine she ceased to have contact with her mother. This was due to the verbal, emotional and sometimes physical abuse of Ruth's mother. Ruth's mother was admitted compulsorily to a psychiatric hospital, and she was contacted as the next of kin following her mother's hospital admission. Her mother's house had become home to feral cats; the toilet was blocked and there were several hundred bottles of sour milk found in the house. The hospital admission and poor condition of the house became 'representational acts' (Denzin, 1989:71) as this was a crisis, and it became a turning point when Ruth's mother asked for her help to stay at home rather than be admitted to institutional care. Ruth made the decision to re-establish a relationship with her mother, as she realised that her mother was fearful of institutions, as she remembered the cultural legacy of long stay hospitals for people with mental health needs and learning disabilities (Means *et al.*, 2008).

There was another 'major turning point' (Denzin, 1989: 71) for Ruth with the sudden realisation about her relationship with her mother and her sense of self:

you see this once very powerful person is now a frail, little person, little old vulnerable person, for all their rage and anger that they're still able to show. Because the rage and the anger earlier in life were the things that terrified you of her, but you start to see them differently, and so it puts you in a completely different position, and I suppose you see yourself differently in that case yeah? So you realise that actually you are capable of a lot of compassion and forgiveness, and that actually feels quite good.

Interestingly Ruth speaks in the third person as if looking at herself and her mother objectively from a distance. Ruth and Elaine both became long distance carers separated by several hundreds of miles, although they both were actively involved in working with other family members, social and health services to support their mothers. Angela's relationship with her mother was fraught following the death of her father as her mother expected her to move into her home, although she had two adolescent children. These three carers felt a family obligation to care, that Means *et al.* (2008) suggest has been reinforced through government policy that strengthens a cultural norm.

Susan, Nick and Theresa had less complex relationships with the cared for person, as there were strong emotional ties of many years' duration. Susan described her mother as: 'the lynchpin of the family. She was the most wonderful mother, a lovely mum, very unassuming, very gentle.' She felt that she was returning to her mother the care that she had received all her life. Theresa was an only child whose parents had a very close relationship and would not have been able to live happily apart. The impact of dementia on her mother was that: 'if anything she became sweeter in character. She was always a lovely lady, but somehow she became the essence of sweetness.' For Susan a major turning point came when she moved into her mother's home to care for her, due to the inadequate care provided by a domiciliary care agency, similarly for Theresa, who gave up her career so she could care for her parents.

Nick experienced a series of 'minor events' (Denzin, 1989:70) that became a turning point when he understood that his friend, Simon, would not receive any emotional or practical support from his family because of his sexual identity as a gay man. Nick stepped into the role of carer, and this was for many years reinforced by health and social care services, who involved him in care planning and acting as an advocate for Simon, until the family requested that this level of engagement cease.

### **Changes in Relationships**

The historical context of the relationship and its continuation as the dementia in the cared for progresses is significant. The proximity to the cared for as well as familial relationships are often determining factors in terms of whom is seen as the main carer in an hierarchy of relationships used by health and social care services (Finch and Groves, 1983; Letherby, 2002). This concept enabled Simon's family to request that Nick's involvement with Simon be reduced to simply visiting him on the hospital ward rather than supporting him more fully even though the family only visited Simon very infrequently. Nick believed this attitude developed due to the family perceiving Simon as 'blemished' (Goffman, 1963: 20) as he was a gay man, as well as concerns that they should be sole recipients of his inheritance.

Elaine's younger sister received more communication about her mother than she did, as she lived near her mother. As Ruth's sister-in-law was local to her mother she was called upon in the event of difficulties. The distance from the person with dementia was a factor in how health and social care services worked with the carer. Bytheway *et al.* (1998) found that time as well as proximity was significant in terms of who cares. Ruth had a brother and sister-in-law that lived locally, as did Elaine, while Susan's husband and sister supported her. Theresa, Angela and Nick were lone carers.

The child carers' relationship with their parent/s changed as their emotional and physical dependency increased as the dementia progressed. Angela spoke of her frustration with her mother who followed her around the house and her constant repetition. She described her mother as always being 'really possessive' with a tendency towards jealousy which had resulted in her father calling her 'the green eyed monster'. This behaviour intensified over time, although she felt able to manage the behaviour of her son who had special needs:

I've endless patience with my son, and it always amazed me that I couldn't have the same sort of patience with my mother but I didn't ... I think one expects one's parents to always be better, superior, more able, more composed than one is oneself.

This change in the dynamics of the relationship finds resonance in Susan's comments. She felt guilty that she had failed to realise that her mother was developing dementia, but noticed that the quality of their relationship was different:

Inside you know, not something that you can speak about, but you just notice that there is a reason that you are withdrawing from someone, it's that they're not able to give you something that they used to before.

Susan noticed that her sister was 'struggling' caring for her mother and she increased her involvement when she perceived that things were problematic and finally moved in with her mother to provide care.

Elaine spoke of her immense sadness about her mother following the diagnosis of dementia of 'losing her all over again' when there may have been a chance for a different and closer relationship. Elaine spoke with emotion of finding:

some sort of resolution and recognising that I couldn't, because I couldn't have what I wanted I had to love and respect and cherish the bits of her that I loved. She is my mother, I will always love her ... but she could never be what I wanted her to be ever.

Elaine's regret about her relationship with her mother was a consistent theme:

I couldn't ever make her have a relationship with me in the way I wanted you know you can't make somebody else do that can you? You can only go with

what they are giving or offering, and she didn't have much to offer really you know.

In the past Elaine's mother had cancelled social arrangements with her daughters if a better social outing was on offer, but now their mother was socially dependent on them. Therefore there were changes in the power and the control in the relationship.

Nick spoke with great compassion about the changes wrought on his friend Simon by the illness, especially the poor quality care he experienced in dilapidated NHS in-patient provision. He recalled that in one psychiatric hospital, which is now closed, Simon's clothes had to be destroyed, as he became infected with lice on three occasions. Nick was witness to his friend's increased cognitive and physical decline in care environments that were environmentally depressing, but he continued to visit. 'I would come back sometimes and I would be terribly despondent, I might weep, you know what on earth am I going to do about this?'

Simon's psychiatrist was supportive and hopeful. He told Nick that what was needed was 'social medicine' and that a great deal could be done to enhance Simon's life. Nick fulfilled this by visiting Simon in different care settings, and took him out to social places such as a familiar gay pub where they played a simple game of dominos. Nick stated that when he asked Simon if he was happy, he would reply: 'happy when I am with you.' Their friendship was of long duration and provided a bed rock for Nick's continued involvement. He described Simon as someone who:

had a lot of care for the underdog yes, he'd always been a kind person and somebody who would, I mean if somebody was being attacked in the street he would go in and have a go, or if you were driving past it would be, 'stop the car we have to go and help those people!' Now that's something that not everyone else might do, so I think it became more pathetic, it was still there, but it became even more poignant and pathetic, when he was in this desperate state in a way.

Simon's sexuality was usually ignored, and did not feature in the care and support that he received apart from the day centre he attended, who took an interest in his life story, and established a support group for lesbian women and gay male carers. The general lack of interest in Simon's sexuality confirms the view that 'old equals asexual' (Thompson, 2001: 90) and encapsulates the ageist view that to be older is to be less than human, whereas sexuality shapes identity, self-image and social relations. At a structural level there are implications for lesbian women and gay men who in the past have experienced discrimination and oppression through state institutions (Ward *et al.*, 2005). Simon's family viewed his sexual identity as

stigmatised, and his life story as a gay man was known by Nick alone. The importance of a shared history has multiple benefits for the person with dementia, as it preserves their sense of identity, provides reassurance and comfort.

As dementia progresses, it becomes more difficult to hold on to the stories of one's life and to be able to tell others of the defining moments that shaped our identity. One of the jobs of caring for someone with dementia is to learn these key stories and hold this narrative for them. This can be used to improve self-esteem and to maintain an identity in the face of increasing confusion (Brooker, 2007: 58).

This has resonance for all people with dementia, but there are particular implications for a lesbian woman or gay man, as their cultural history may be ignored, marginalised or devalued. Nick sought to provide Simon with a continued sense of himself and happy memories as a gay man by putting photographs up in his room on the ward of their outings, work colleagues and familiar places. On one of the rare occasions that Simon's family visited they took these photographs down and replaced them with photographs of Simon with a girl he had last seen forty-five years ago and his sister, and family weddings, which had no meaning for Simon. Nick stated: 'There it was Simon is *not* a gay man.' Nick interpreted the action as unkind and a denial of who Simon was, as it produced confusion and was removing from Simon his life story, and images which he could relate to that gave him pleasure.

Theresa was 36 years old when she became a carer to her mother aged 61 years and her father who was 65 years old. She had tried to tell her mother about her sexuality when she was in her twenties, but her mother did not want to discuss it. It then became too late due to her mother's dementia, and her life 'went into a complete hold as a carer.' She explained that she had 'a rather closeted and somewhat limited life when it came to sexuality.' Theresa adopted a pragmatic and highly organised approach to the change in her relationship with her parents. She gave up a career and worked hard to meet her parents' needs by living with them, until they died. She ensured that their usual pattern of family life continued for as long as possible through outings and holidays until this was no longer possible. Theresa took up Tai Chi taking her parents with her. Theresa's transition into being a carer displays no sense of regret for time lost. Her engagement and commitment to both her parents were highly apparent even though her father who outlived her mother had multiple needs and could be 'un-cooperative.'

## Being Remembered

One result of dementia that can be especially difficult for carers is the anxiety that the person will forget who they are. This was expressed by Ruth:

I suppose one has a particular, well horror is the wrong word I suppose, but concerns that somehow the person is suddenly not going to know you or something like this. But that didn't happen to her, she always knew who I was.

Clearly it had been important and significant to Ruth that her name or presence was never forgotten. Nick described Simon's delight at seeing him. Simon would spring up from his seat, giving him a hug and greet him by name enthusiastically. Susan, Angela and Theresa stated that their mothers remembered them. Elaine phoned her mother each day, and she always recognised her voice, but she thought that her mother was having difficulty in remembering her in person, as she had adopted an approach that she had seen her use with other people:

she ... employed that way she speaks when she meets people on the street, you know, 'oh hello, and how are you, I haven't seen you for a long time.' Which is what she says to people when she kind of knows she recognises them but hasn't seen them for a long time, and is not sure who they are. That hurts, that definitely hurts.

This is a common factor for carers and may impact on how close they feel to the person with dementia, and equate this with a loss of love. Bryden (2005:109), who has dementia, suggests:

I know faces and know I connect with them somehow, but not why I know them and what I know about them. It is a world in which I know that I know you, but not why I know you. I need time and clues, not questions. Try to chat about our shared experiences, so that I can find out why I know you.

This was an approach that Elaine was beginning to use with her mother. She felt that her mother was remembering her sister and her children more than her own. This made Elaine feel envious especially as her mother was telling her sister things about her background that had never been discussed before. There had been some tension between Elaine and her sister and ongoing discussions about who takes responsibility for what. Elaine was keen to play her part, and supported her mother to create a life story book with the use of photographs to capture her memories of the past. She recalled that her mother felt she had lost her family due to her



parents' death, as if Elaine and her sister and their children were not family. Morris and Morris (2010: 44) write of the 'felt experience of carers' of distress and loneliness when some memories can no longer be shared. The identity of the carer is bound together with the cared for person. Elaine's ambivalence about whether her mother had felt unconditional love for her was being raised again by her suspicion that her mother was starting to forget her, and would soon no longer recognise Elaine's children.

Ruth's response to the change in her relationship with her mother was to work out areas of responsibility with her sister-in-law and organise practical aspects with considerable effectiveness ensuring that her mother received technological aids and adaptations, and appropriate domiciliary care services that could meet her needs. There was conflict as her brother and sister-in-law wanted her mother to be placed in a care home, primarily as there were a range of practical problems; for example, the Fire Brigade was called as foil had been placed on food in the microwave and heated for some time causing smoke in the kitchen. Also, she was reluctant to take any medication, receive personal care or use services such as day care. Ruth reflected on her brother and sister-in-law's anxiety:

I used to feel quite guilty as I was the one who insisted she stay at home, it's causing their stress, and it's causing me stress, but you know there's our mum who just wants to stay at home with her cat, you know a difficult balance.

Susan also had difficulties with her relatives, who thought that her mother should be in a care home. Her mother stayed with her aunt for a short holiday, which Susan had advised against as she anticipated that this would confuse her further, however she was overruled by her aunt. The stay was highly problematic:

My cousin rang and said I was ill treating mum, how dare I not have her in a home ... mum got so distressed that she started to crawl, which was behaviour I had never seen before, around my aunt's house. So I went and picked mum up and my aunt said, 'we must be ill treating her to be going around on the floor on all fours.'... all that part of the family, mum's sisters and my cousins who have been close to my mum, didn't come to the funeral even and have not spoken to us since.

Susan interpreted their behaviour as an indication of their ignorance about dementia.

Nick was keen that Simon should be remembered by his family, so that his sense of identity could be strengthened, but his request to the family to visit Simon and send him a card at

Christmas and so on went unheeded. He placed an advertisement in Simon's home town's local paper asking, if anyone knew him as a child. He received a number of letters from local people, and he found an Irish society in London that they both could attend. This provided pleasurable social events and enabled Nick to develop a greater understanding of Simon's childhood, and build up 'little islands of memories' that he could talk to Simon about. Nick felt that the family in Ireland may have become embarrassed that Simon was living in a care home and felt some unease about his sexuality. The result was that the family asked Social Services and the NHS to ensure that Nick was not to take Simon out, or have any involvement in his care. Nick explained 'Simon's life without these things is so much poorer, he loves going out, this is his life.'

Although Nick was Simon's main carer the family's views were paramount, as he was caring prior to the implementation of the Mental Capacity Act 2005, which would have provided an opportunity to assess the appropriateness of the family's views and involvement. It is clear why Simon chose to hold 'dual identities' (Clarke, 1996: 196) rather than being an openly gay man at work and with his family due to societal and hostile family attitudes (Dick, 2009). Theresa and Angela as only children were sole carers. They assumed responsibility for their parents and although this was stressful and at times isolating they did not need to negotiate with siblings or with other family members.

## **Social and Emotional Isolation**

The carers were all aware of the increased social isolation of the cared for as the dementia progressed. Although Elaine's mother had always been very sociable, a 'bright and intelligent' woman who loved music and dancing, since the onset of dementia her closest friend was unable to cope with her repetitive speech, and the fact that she would get on the wrong bus when they planned to meet. In the case of Ruth's mother she had struggled with relationships throughout her life. There had been a friend who visited down the road but her mother would be 'bad mouthing her as soon as she had gone ... she didn't really appreciate people.'

Angela's mother had a wide circle of friends, but now she only saw them once or twice a year. She had become deaf and had difficulty wearing her hearing aids so this 'closed her off from communication.' The carers recognised the increased dependency on them as one of the most significant social relationships that the person with dementia had, so carers too felt socially isolated due to supporting the person with dementia. Theresa spoke of an aunt and cousins who would on occasions come over and sit with her parents so she could go out:

They didn't want to do any hands on caring; they didn't want any of that. They were always very keen to get away at the end of it, which I can understand fully.

And I appreciated the bits they did, but I did get very tired of being told how good I was ... I don't want to be an angel, I felt so angry all the time I could punch somebody, but who have I got to actually do that with and to, how do I release it?

This view was echoed by Susan: 'I think one of the other things that really started to annoy me, was that everybody started to pity me.' She went on to speak of her own social isolation:

Friends dropped off, we used to be invited out for meals, and I used to go out for meals with people. We couldn't invite people home, because there wasn't enough space, and also I felt that it would be worrying for mum. So we didn't manage to do that, and I realised the knock on effect of that, mainly after mum died, was that we'd lost friends, we retained good friends but I also had not realised the knock on effect for my children. Both were going through some difficult times and they only had scant time from me, and when I was ready to start being mum again they had moved on and it's taken a time for me to establish my relationship with them.

Susan experienced a sense of guilt towards her own children, which is a theme that re-emerges, and finds a resonance with Elaine's expressed guilt for not bringing her mother into her own home to be cared for. I felt that their expectations of themselves were harsh given that they both had or were providing substantial practical and emotional care. It was as if they were measuring themselves against a gendered stereotype of what is both a moral and biologically driven understanding of what it means to be a woman. This reminded me of Hanmer and Statham's (1988: 62) view - 'caring for adults is taken to be as natural for women as caring for children. Because this view is often internalised, if the act of caring is unsuccessful, women blame themselves. The failure is personalised.' Moreover Lafrance and Stoppard (2007) argue that the social and political position of women creates a narrative of the 'good woman identity' (p.30), which I sensed both Susan and Elaine assessed themselves against.

## **Enduring Aspects of Relationships**

The carers were able to identify examples of fulfilling activities and factors about their relationship with the cared for person. Humour was mentioned by several carers. Ruth said of her mother: 'she had a good sense of humour she could laugh, although she was quite eccentric!' Elaine was able to engage with her mother in a humorous manner:

we have a similar sense of humour so we would meet at that level, and maybe laugh over something that's silly ... because she has a great sense of humour I think that's partly where I get my sense of humour from.

Theresa spoke of maintaining a pattern of activities for her parents so they were physically and socially active:

We went out virtually every day, because I'm a great believer, just as my parents before me in fresh air, and it transpired you know, being out in the sunshine and fresh air it makes for a better sleeping pattern at night. So they weren't particularly fractious at night, in fact my mother didn't try and wander at night ... they went out to family parties, we went out every day. We would go and visit places that wasn't an issue, this was part of normal life. My father was in a wheelchair, we did go on holiday with him in a wheelchair so that we could go to the seaside ... I was never ever going to try to limit their lives because of the health issues that they had.

Theresa consistently expressed the importance she attached to the maintenance of the quality of her parents' lives together, so as well as introducing new activities such as Tai Chi, she continued with a similar pattern of daily life for as long as possible. Nick spoke about his friendship with Simon:

you imagine having a friend and you could call in any hour of the day or night and say, 'We are going to Greenwich' 'Yes! Let's go now!' We don't have friends like that for the most part, so anything you wanted to do, it was, 'Yes! Let's do it now where's my coat?' And although Simon might be surly and difficult with some people, he never was with me. And that was very, very positive, and also I thought that the quality of his thought and feeling at times with this massive limitations were just very fine, and he would see somebody ... who was having a difficult time, he'd go and just put his hand around them and just say 'what's the matter?' and he was just not capable of taking in what was the matter, but just to comfort them.

Nick and Simon especially enjoyed activities that took them out of the care environment in the same way that Theresa's parents benefited from the stimulation of being out of the house. These perspectives contrast with those of Angela, who had always experienced her mother as requiring a lot of attention, which had been met by her father while he was alive, but with the onset of dementia her mother became 'increasingly anxious and increasingly repetitive.' As time

went on Angela found it more difficult to remove herself from her mother to read quietly. She felt considerable relief when her mother moved into a care home, whereas Susan was able to recount moments of intense joy with her mother:

we got at a relationship a lot of the time where we had enormous fun, because I realised if we joined in her communication needs, we spent an awful lot of time laughing and doing daft things, what about? I haven't a clue! But we seemed to enjoy ourselves together.

A number of the carers used their knowledge of the cared for to build on areas of interest or pleasure. Ruth recognised that the common ground for anyone trying to develop a relationship with her mother was to talk about animals. For Elaine it was her mother's pleasure in music and horses. Nick ensured that Simon could watch musicals in the care home, as these had a calming effect and gave Simon great pleasure. Most of the carers were able to identify how their personal knowledge of the cared for enabled them to create, as Nick stated 'little islands of memory in this great sea of confusion' which maintained and supported positive aspects of the relationship between the carer and person with dementia.

In the accounts that the carers gave there were examples of how they were able to 'tune in carefully, both physically and psychologically' (Egan, 2010: 183) so they could understand the perspective of the person with dementia. This enabled them to sense how the person was feeling and why they behaved in particular ways. Many of the carers showed empathy, which is paramount in building and sustaining relationships (Rogers, 1980). The relationship between the cared for person and the carer is fundamental to how the experience of caring is perceived (Burton, 2008). Angela found caring for her mother was stressful and for Ruth troublesome and worrying, whereas the other carers were able to identify the demands and difficulties but also the aspects of the relationship that remained rewarding. I will now consider the coping strategies that carers used that enabled them to continue to care.

## **Coping Approaches**

The approaches that the carers used to cope with meeting the needs of the person with dementia, and their own needs, required them to adjust their behaviour and be flexible. Coping has been defined as:

a process of shifting behaviours, thoughts, and feelings that individuals use in interaction with their situations to avoid being harmed by life stressors (Abbott, cited by Canda, 2009: 87).

Susan exemplified flexibility in her thinking and behaviour after being told by the Alzheimer's Society to 'walk over a bridge' into her mother's world. This was echoed by other carers who choose not to contradict the cared for person, but rather went with them to where they currently were. Nick spoke of Simon thinking he was on holiday in North Africa, when in fact he was in hospital. Nick engaged with him in these conversations, which reassured him.

## How Carers Cope

In the same way that the carers had been able to describe the enduring and positive aspects of their relationship with the person with dementia, they also identified what had been challenging, difficult and stressful, and the beliefs and resources they had been able to call upon. Theresa spoke in practical terms of how she organised and supported her parents until eventually they came to live with her. As her parents' health deteriorated she developed approaches to solve difficulties for herself and her parents, although she was finally providing nursing care and not getting more than four hours sleep night. She explained:

I think quite unconsciously the Karate and Tai Chi helped me to release the tension. Plus I have always been given a great sense of my own abilities by both parents. I have always been told that you set your mind to something and make a plan. I am a great problem solver, I have done it all my life in my career, and as consequence I treated each challenge as that, a problem to be solved.

The skills that Theresa had acquired in her professional life were transferred to her role as a carer and her approach was highly pragmatic. Ruth spoke of 'absorbing a lot of the stress' when social care staff and family expressed concerns about her mother. Her approach to dealing with this was 'to go and have a ciggie and a drink.' Nick spoke of having a couple of glasses of wine and taking a Valium tablet. Ruth and Nick both stated that the stress was not emanating from the person with dementia but rather from family, health and social care services.

Angela found some of the ideas of Buddhism useful, such as impermanence, as a concept, and the importance of not becoming attached to difficult thoughts and feelings, but she did not use any spiritual practices. At one stage she sought counselling, which she found supportive. Elaine spoke of Buddhism too and the importance for her of learning from her life experiences, and finding an 'inner voice' that is able to connect with something greater linked to a common purpose. A primary source of strength was her belief in the concept of hope.

Nick identified his humanitarian values, as the motivation for him to care for Simon. He expressed uncertainty about his sense of any personalised God:

in so far as I feel there is something special, and something that transcends and something very powerful, God is love. And that's the only way in which I can really explain being the best of me in my personal life. So that's really what it means, that's the thing that moves me and makes me want to do things, that's the best of me.

The concept of love as a factor that motivates and underpins humanitarian values, was also expressed by Susan, as she talked about her love, and the strength of character that her mother had given her. She spoke of the impact for her and her mother when she moved into her house to care for her:

I think all the way through there was resentment, but also a lot of love and a lot of joy. But the worry that fell from mum's face, all the worry lines, she'd got a very lined face before just went away and she had her beautiful face back again.

Susan spoke of spiritual connections between the family in life and death, which gave her solace and a sense of continuity. What enabled her to cope as a carer was her compassion for others: 'I think once you are a carer you always carry on caring, and you look for someone else to care for, it's a bit like a bug, you can't seem to get rid of it.' This view was not expressed by any of the other carers.

Stuckley's (2003) research with 32 spouses where a partner had dementia, found that it was not necessary to have a spiritual faith, but it was important to live life with a commitment to help others when in difficulty, as well as being able to derive some meaning and understanding from the situation. The carers saw their engagement with the person with dementia as the morally right thing to do, and in cases where there had been a substantial emotional involvement based on deep affection such as for Susan, Theresa and Nick, this gave the caring its own momentum. However, for Angela, Ruth and Elaine the relationship was more complex and their motivation was partly due to their sense of family obligation, which was stronger than their previous difficulties with their mothers. For example Angela spoke of feeling coerced and emotionally manipulated by her mother, who had cared for Angela in the past and now expected this to be returned:

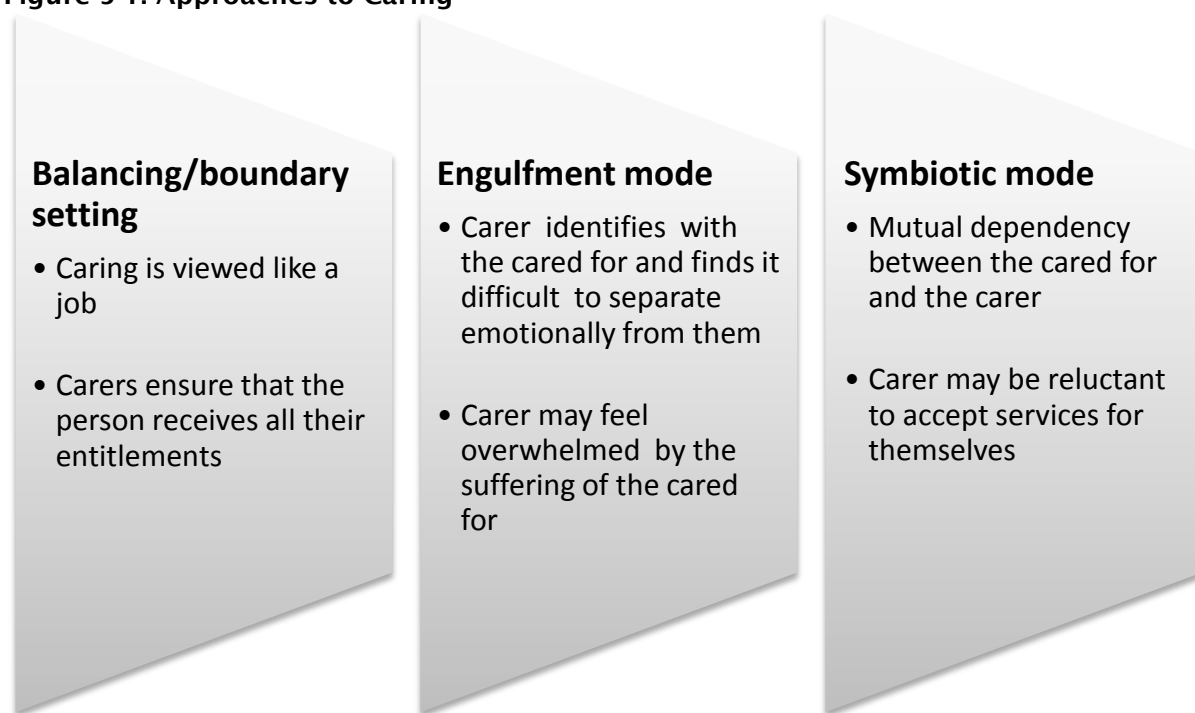
she would put on the pressure of, 'well I took care of you when you were ill, now you should come and take care of me, that's what you have to do!' That's what she would say ... that's just what you do, that's what you do in families.

Angela had internalised the belief that family members are obligated to each other and was resentful of her mother's expectations of her, but she still expected her oldest child in the future to care for their sibling with disabilities.

## Analysis of Beliefs about Caring

In Chapter 2 and 3 I drew on the work of Twigg and Atkin (1994). They identified three approaches to caring that have enabled me to theorise the carers' experience of their role. Carers can demonstrate more than one approach at the same time. The approaches with the resultant behaviours are reproduced again in figure 5.1.

**Figure 5-1: Approaches to Caring**



(Adapted from Twigg and Atkin, 1994)

The balancing/boundary setting approach results in carers being informed about the cared for's health needs and entitlements. The carer develops a professional relationship with health and social staff. For example Nick advocated for Simon and suggested to his psychiatrist that he be



discharged from hospital into a care home prior to the implementation of the NHS and Community Care Act 1990, as funding would be simpler. He arranged for him to attend a day centre, monitored his financial affairs with Social Services and purchased clothing for him. When Nick was undertaking these activities he was in the balancing/boundary setting mode; however there were times when Nick felt overwhelmed and found himself emotionally engulfed as a consequence of Simon's vulnerability especially when his caring role was rejected by the family:

When they [Simon's family] were trying to take me away from Simon's care they were really in a sense removing the one person who has this shared history and could make things happen for Simon. Even when it came to conversation, I was able to talk to Simon because I knew the things that had been important to Simon. The things that he'd had enthusiasm about and was able to discover, the fragments in his memory of those things that were still left. Without that shared history, you know it's not just taking somebody, knocking somebody out looking at a piece of bureaucracy, you know watch our backs and get him out of the way. You know you are taking the core out of someone's life

Nick as a gay man was able to share with Simon the cultural history of oppression and discrimination that gay people have experienced. They had both lived through a time when homosexuality was criminalised and categorised as a mental illness (Turnball, 2001). Nick's belief in love was the motivating force for his compassion and is evidenced in his behaviour towards Simon, and validates Kitwood's (1997) view that love should be an essential element of person centred care for people with dementia.

Ruth was motivated by her mother's request not to be moved into an institution, and by her belief that her knowledge of health and social care services would ensure that her mother could receive services that would enable her to stay at home with her quality of life maintained. Her approach falls within the balancing/boundary setting mode, and when she did experience feelings of engulfment these were caused by family and social care staff's concerns that her mother should be moved into a care home. Ruth co-ordinated the care her mother received from health and social care services.

Angela found her mother's demands increasingly difficult to manage. She expressed gratitude to the services that supported her, such as the Carers' Centre, day centre and care home. She was emotionally engulfed by the impact of her mother's behaviour on herself. Her engagement with her mother was based on a belief in family obligation in the same way as Ruth and Elaine.

Feelings of engulfment were also expressed by Elaine, but less in terms of her mother's illness and more about her own sense of loss. She stated a belief that families should look after each other, and felt guilty about her mother living in a care home.

Theresa received minimal support from health and social care services. Her approach was balancing/boundary setting which ensured that her parents would be able to remain living together. She had problem solving skills that were transferable from her career as a manager. Theresa undertook most of the personal and practical care of her parents.

Susan's approach to caring for her mother was motivated through her belief in the importance of love, which was articulated with the same strength of feeling as Nick for Simon. She ensured that the services her mother received were appropriate and met required quality standards, so in that sense she was balancing/ boundary setting. She felt engulfed when care services were delivered in a way that was disrespectful and demeaning to her mother.

The symbiotic mode between carers and the cared for where there was a mutual dependency was less evident, although there were many examples of an intuitive understanding by the carer of the person with dementia's needs. Susan for instance spoke of an observation a friend made to her that she was 'always able to second guess' what her mother wanted most of the time.

## **Carers' Support Systems**

The carers were able to identify activities that they engaged with that provided diversion from the responsibilities of caring. Elaine watched television that was entertaining and played repetitive games. Angela found that studying and reading provided a mechanism for her to reduce her stress levels, but as her mother became more restless this became increasingly difficult to do. Nick enjoyed going to the cinema or having a meal out with his partner. Theresa's interest in Tai Chi became a regular activity. Susan found going into the garden provided an emotional release from the care of her mother.

Support at a personal level was important for all the carers. Susan stated that seeing how gentle her husband was with her mother and herself brought them back together, as they had been planning to separate. Ruth's partner provided practical support in cleaning her mother's house so that it was habitable again. In addition she enabled her to understand her mother better:

She was very kind to my mother, she would say things to my mother that nobody had ever said to her, like she mattered or that she was a valuable

person and such things ... So she kept me going because I started to understand my mother a bit better.

The carers were able to identify how they had developed as people through the experience of caring, and for some such as Ruth and Elaine it was the knowledge that they were prepared and able to support their mothers even though they had not received appropriate care as children. Nick and Susan identified that they had become more assertive and better able to 'take people on.' Nick had developed skills in writing in a manner that made bureaucratic organisations such as Local Authorities and the NHS take account of his concerns. Angela learnt to take care of herself so that she could care for others, while Elaine learnt the importance of communication and that caring has to be shared. Theresa explained that the experience of being a carer had made her grateful that she had been able to care for her parents so they could remain together.

Grateful that I could do for them what I did, but sad that it has not changed significantly, because I know that we had the wherewithal to do certain things because of the jobs we'd had, we'd had good salaries for years, but also because of who I was. If you are not somebody who copes well with change, as a carer, then it's hellish. If you are not somebody who has the resources, I mean emotionally as well as financially to do what you like to do. Then the strain becomes doubled ... trebled. If you are somebody who is not a natural carer, then it should be okay to say so, and I don't think it is ... I think that I learned that caring is really not for everybody, but that I am glad that I did it.

Local Authority eligibility criteria to access an assessment for services for people with dementia and carers have become increasingly restrictive. Care services are means tested and there are difficulties in carers receiving high quality domiciliary care and respite care services (House of Commons, 2008). I will now relate the carers' experiences of health and social services.

### **Carers' Encounters with Health and Social Care Services**

An analysis of the carers' experiences and views of health and social care services was achieved by adapting the Skills for Care (2010) 'Carers' Common Core Principles', which I referred to in Chapter 3 when discussing research methods and methodology. I have taken the principles and compared them with the carers' experiences.

## **Carers as Equal Partners in Care**

The expectation implicit in the principle that carers are equal partners in care is that the expertise of carers is acknowledged and validated; furthermore, their knowledge about how best to meet the needs of the person with dementia is sought. This expectation is underpinned by the social model, as opposed to the medical or individual model of disability (Oliver and Sapley, 2006). A key element of the medical model is that professional expertise is seen as dominant in the assessment and management of the person's care, irrespective of the person's views or that of the carer. An example of the medical model underpinning practice was given by Nick:

I would go in there and they would say, 'we've had great trouble with Simon, now just listen to this, this morning we have washed all his clothes, we have ironed them and I gave him this pile of clothes and I told him go upstairs and put them in his chest of drawers.' Well Simon for a start didn't know where his room was in the house, he didn't know where he was, let alone where his chest of drawers was! So can you imagine the kind of tensions, and I obviously thought, well what can we do about this? I said to them, 'but he doesn't know where his room is.' And I tried to say as gently as possible, but they were really thinking that I was being over sympathetic to Simon and not understanding their problems.

Nick described feeling as if he were 'walking on egg shells' with the staff, and although he sought the support of Simon's social worker, she appeared busy and disengaged. Nick's view was that the expectations that the care staff had of Simon were unrealistic and how they managed his care precipitated his violent outbursts. In the end a Community Psychiatric Nurse (CPN) advised the staff how to manage his behaviour and not to 'corner him in any way.' Although Nick had sought to act as an advocate for Simon in an attempt to ensure that his care was appropriate, the advice of the CPN had more credibility than that of the carer.

The importance of positive engagement with the person with dementia especially when they are being washed and dressed, so they understand what is happening and do not think they are being assaulted, is a basic requirement of dementia care (Morris and Morris, 2010). Susan's decision to move into her mother's home to care for her was as a result of an especially distressing incident where her mother had been left naked:

what had happened was that the carers had come in and left mum with no clothes on, because she hit them. And my sister rang me to say that mum was sitting in the lounge with no clothes on, because she hit them ... And mum had started to hit out, and I did say to the carers, 'that mum will hit out if you keep

trying to wash her in the living room with the net curtains, she can see out and the world she thinks can see in ... But if you always go how we've asked you to do it ... let her smell the soap, let her get her head around what she is doing, then she'll wash. But if you start to undress her then she will start to hit you because as far as she is concerned, you are just coming out of the blue, trying to take her clothes off! ... you'd have to reassure her and try to keep her modesty as best you could.

Susan explained that the most effective way to encourage her mother to do things was to dance with her. She would put the radio on and dance with her mother who then became relaxed and co-operative. Susan spoke of her mother getting a 'bad reputation' as she would hit the transport men who came to take her to the day centre, but as Susan explained 'if you are dozing in the chair and you wake up because you hear the key and two burly men come in you would.' When Susan cared for her mother these incidents did not occur and she found it especially sad as the lack of person centred care, that is care that is tailored to meet individual needs and preferences, made a gentle person aggressive. This is a vivid example of Kitwood's (1997:45) 'malignant social psychology' where the care practices are devoid of social interaction, emotional warmth and validation of the person's feelings.

The importance of knowing the person's personality and biography were further illustrated by Susan when she explained that her mother had been house proud and liked to have plastic flowers around the house. After the onset of dementia she would put 'dolly mixture' sweets around the house, and she screwed paper up into balls and put them on the stairs. Susan knew that this was her mother making her home look attractive, whereas care staff thought she was untidy, and wrote this in the daily record kept in the house even when asked not to by Susan. A consistent factor for the carers was that the biography of the person with dementia was not routinely sought by health and social care staff. The person's life story and preferences in daily living routines and diet, which helped to explain their behaviour and enabled their needs to be sensitively met, were not obtained (Brooker, 2007). The care staff's task became more challenging and difficult, but more importantly the well-being of the person with dementia was adversely affected.

The carers were able to provide a limited number of examples where individual staff had engaged with them, as equal partners in the process of caring for the person with dementia. Theresa spoke of the occasion when she creatively used a sterile urinary catheter to keep her father's stoma open after he had pulled the tube out. This impressed the medical and nursing staff who found this inventive. Theresa received insufficient assistance with care tasks, in spite of both parents having complex nursing needs. She was provided with minimal training by nursing staff, for example in peg feeding.

Ruth found the last social worker involved with her mother to be supportive, as she reinforced Ruth's view to the care workers that complaints would not be made by her about her mother's poor hygiene if she refused to be assisted with washing. Ruth was clear about the services her mother needed and who should deliver them, especially after a private sector domiciliary care agency failed to visit her mother for several weeks due to staff sickness. Ruth insisted that the Local Authority's domiciliary care service support her mother:

I think the social care people probably saw me, as a bit more, 'this is what I want, and this is what I'm having!' because I wasn't prepared to have what they'd offered her before, because I knew it won't work. So I had to put my foot down and be very firm.

Because she understood the workings of the health and social care system Ruth was able to advocate for her mother and ensure that practical services were provided, so that her mother was able to remain living in her own home. She commented that no one was co-ordinating her mother's care apart from herself.

Nick spoke of how he had given Simon baths in the care home. He was closely observed by the care staff, who recognised by this stage that they required his assistance if outbursts from Simon were to be avoided. In fact Nick provided training to staff as to how best to approach Simon.

in those days you could smoke, so I used to give Simon a cigarette and some green grapes and tell him he was going to have a bath and he'd say, 'no no I had a bath this morning,' and I'd say, 'ah just come on with me.' And sometimes he would and sometimes he wouldn't, and so sometimes I would just lure him along showing him the grapes you see, and he'd follow me along the corridor, and we would get to the bathroom and then he'd sit down on the loo, and then I would gradually undress him, and give him a cigarette, and light the cigarette and say, 'come on very, very quickly, let's just have a very quick bath, just to please them,' and so then he'd have a bit of a bath.

The care staff watched outside the bathroom, until they felt confident enough to undertake this task. Nick suggested that the one male member of staff gave Simon a bath as he 'was very kind, very patient' and so would avoid Simon being 'manhandled and having his clothes pulled off.' Both Nick and Susan suggested that health and social care staff should ask carers how best to undertake personal care tasks. Ruth commented 'there is a need for training about how to give somebody an all over wash without humiliating them.'

The carers stated that in the main health and social care staff did not ask them

about the cared for person's daily routines, hobbies, interests, previous occupation, life story, and the best way to complete personal and practical care tasks.

## **Carer's Capacity to Continue with the Caring Role**

The above Skills for Care (2010) principle requires that an assessment should be made about the capacity of carers to continue to care, so support can be provided. The carers felt in the main that their needs were not a concern for health and social care staff. There was a lack of curiosity about them. Theresa said:

To be honest I could just as well have been a block of wood ... I don't mean to say that they were cruel or unkind ... I could have been a bug eyed man from Mars, as long as I was doing that and I was doing it to an acceptable level, just go away and do it, that was the impression I was given.

Ruth spoke of assumptions made by the first social worker who had assessed her mother under the Mental Health Act 1983, and arranged for her admission to hospital.

the social worker made comments to me about, 'oh you know this must have been a lovely family home?' There was definitely a whole thing of disapproval there; you know 'how could you have let your mother get herself into this state?' Without any understanding whatsoever of the dynamics of that relationship, and how she pushed everyone away, and how in fact it became impossible to continue a relationship with her.

These assumptions of family obligations were echoed by Elaine who had tried to explain the difficulties in her relationship with her mother to a member of the care home staff:

she said, 'oh well my dear, it doesn't really matter what sort of relationship you've had with your mother really, because it is still your responsibility.' Hang on a minute; I am not sure it is and those were the bits that have really jarred me, because where was her responsibility when I was thirteen and she wasn't caring for me, where was her sense of responsibility? That does colour how I might see my sense of responsibility, I don't think that is irrelevant I think it's very relevant.

This member of staff's attitude concurs with cultural assumptions around the role of the family: 'The idea that kin support is founded, in whole or in part, upon duty and obligation, implies that there 'is something special' about social relationships which we have with kin, which makes them distinctively different from all other relationships (Finch, 1989: 212). This assumption can be challenged, for example Nick's commitment to Simon was not born of kinship. Many lesbian women and gay men do invest in friendships and social networks as they may not have children, and have experienced rejection from their families (Turnball, 2002).

Susan was employed as a social worker by the Local Authority where her mother lived, however, rather than a source of support she found this created particular stresses. Her colleagues were unable to maintain the boundaries between her professional and personal roles. She felt that her situation was known about in the office but little real support was provided:

I think most people saw me as resilient, most people saw me as coping because that's the face you wear as a carer especially if you're scared, well actually the [domiciliary care] agency has written bad things about your mum, your mum's been labelled as aggressive so you are a social worker so you should be managing it all a bit better, you've cracked up at work a few times, so maybe there is a question mark over your ability.

The experience of being a carer has informed Susan's social work practice. 'I think I listen, and I can hear, there is listening and hearing isn't there? And I think I can hear what they're asking, and I can ask the questions ... 'what can I do?'

The time period when the carers were supporting the person with dementia varied, but they should all have been offered a carer's assessment. Susan was offered a carer's assessment, and Angela suspected that she might have been assessed.

Theresa, Nick, Ruth and Elaine were not offered a carer's assessment, so their capacity or wishes to continue to care was not discussed with them.

## **The Support Provided to Carers to Prevent Ill Health**

Angela sought counselling for herself as a result of the emotional impact of caring for her mother. Susan spoke of her physical exhaustion:



There were times when I was so tired in the morning and mum would wander into our room and it would be half past five, and it had taken her a little time to have gone off to sleep. You don't sleep well and you've always got one ear out in case she wants to go to the toilet or you need to change her or something you know, or she's not sleeping or just walking around ... So half past five, six o'clock especially at the weekend when it was time to get up, I felt like it was trying to walk through not only treacle but like a straight jacket just trying to get out of bed and plod.

Theresa talked about only ever getting four hours of sleep a night. She had a baby alarm in her bedroom, and could hear her father if he became distressed in the night, and she would go through to him. There was a lack of understanding by health and social care services about the strain of caring. Theresa said:

All of these things are not considered as kind of an ongoing downward spiral for a carer ... you have to be at screaming point before you are given a break, and then having been given a break, you are somehow miraculously meant to be reborn to this new fresh, fit, eager for the next round new person, instead of which of course, what should be is regular breaks, established straight at the beginning and increased as developments happen in the disease.

As Simon was cared for in various institutions it was not the physical exhaustion of caring for him daily that affected Nick, but rather his own removal by the family and Social Services from any involvement in the management of Simon's care. Following a hospital admission the care home would not readmit Simon. He was placed on a long stay ward in a psychiatric hospital which Nick described as bleak. The difficulties in bathing Simon recurred. Nick explained:

And he was incontinent back and front and it would have been far easier, pretty unpleasant though, but far easier to let me wash him. And as it was he could see these people coming towards him with these gloves and everything, and he would start to shout, rant and rave, 'you are not touching me!' and they used to take him away physically. Whereas I think I could have persuaded him to have some kind of shower, gone into the shower room and put on a pair of trunks and everything and got wet myself and washed him. But they weren't allowed to do that, he used to shout and rant and swear, and then I could hear him in the shower room screaming with fear and with rage.

Nick found these incidents very distressing and left the ward returning when Simon had been bathed. Simon's fears could have been reduced and the delivery of personal care made much

easier for the staff, if Nick had been allowed to be involved. Just as the emotional impact of hearing Simon's screams on Nick were not acknowledged by staff, neither was Susan's need for reassurance and comfort identified. She said:

I needed someone just to hold my hand and say, 'don't be scared, it's alright.'  
But it wasn't there ... I just wanted the old Florence Nightingale, I wanted a nurse to sit with me and talk to me, I wanted them to be gentle with mum, I wanted them to treat her like a person that she was, right to the end.

These comments from carers demonstrate how important it is that health and social care staff understand the physical and emotional demands of caring. It tended to be particular staff rather than whole services that were singled out, as being sensitive and reassuring. These small acts of kindness were remembered and valued. Susan recalled:

the occupational therapist was excellent. And I remember he used me and popped me in the hoist so my husband could practice with me, and it was a sheepskin and I was in the air, I felt so peaceful, I thought, 'I am so comfortable, just leave me here, everyone go and leave me in this hoist, no one can get me, I can't get down and I am safe up here!' Really weird, but I felt cocooned and I don't want anyone to talk to me anymore, yes the occupational therapist was brilliant.

Nick found the guidance and validation as a carer given by Simon's psychiatrist helpful. He was advised to read a particular book about dementia and ways of dealing with Simon's behaviour. He was told that the 'social medicine' he provided was benefiting Simon greatly.

Elaine stated that the social worker had insightfully articulated how she and her sister felt about her mother's dementia and their sense of losing her again as they had as children. The community psychiatric nurse was described as kind, but caused confusion by providing inaccurate advice. But Elaine went on to say:

she is very sweet, lovely and she calls me darling and everything ... she's got just a sort of quiet, calm voice and when I've been upset on the phone, she says, 'alright darling, it's okay darling, don't worry', and I thought I'd be really irritated with it, but I wasn't!

Elaine was reassured and comforted. Ruth spoke of the staff on the ward when her mother had been hospitalised:

They were actually lovely; they even let me take her cat in to visit her ...

I'd arrive on time and I had been running around like a lunatic, doing all sorts of things, I am shifting furniture to a point where I couldn't cope anymore. And I got to the hospital and I just burst into tears, and they were really really caring towards me, and they would take me in and give me a cup of tea, and asked me how I was and all the rest of it.

An incident was recounted by Nick:

there was a Hungarian woman, quite bent and quite old, and she shouldn't have been working at all, and obviously in handover time they got to know that the family wanted to cut me out. And I remember taking Simon out of the building on one occasion just to this little seating area outside, and she came across and said, 'I am finding this difficult to tell you,' she said, 'I know what's going on and I think it's quite terrible, you've known Simon as a friend all these years, and I think it's absolutely awful, awful and we all do.' And she just broke down in tears.

When Simon died the family removed his body and cleared his room prior to Nick getting to the hospital, without any word of where he had been taken:

The staff said, 'what can we do for you?' And I said 'I don't think there's anything you can do for me really, you've done a great deal for Simon and all the rest of it. And they said, 'well at least we can make you a cup of tea,' and somehow the kind of pathos of that was great. And you know we sat there and drank tea, and that was a kind of sharing somehow at the end.

These small acts of concern were remembered and assumed an importance for the carers, as they were emotionally validating and demonstrated an understanding of their feelings.

One notable finding from the research was that carers were often asked to speak to the cared for if there had been incidences of problematic behaviour rather as if the person with dementia was a wayward child. Ruth and Susan were contacted by social care staff about their mother's behaviour. Susan talked about the care workers thinking that she should be able to get her 'mum to behave.' This is an example of 'infantilization – treating a person very patronizingly... as an insensitive parent might treat a very young child' (Kitwood, 1997:46). On one occasion, Elaine contacted her mother on the telephone at 7.00pm at the care home. She was told that

she could not speak to her as she had been 'agitated' at 3.00pm. It was pointed out by Elaine this was some time ago and when her mother did come to the phone 'she is all sweetness and light she can't remember what's happened five minutes ago let alone what happened an hour ago!'

## **Carers' Choices and Involvement in Decisions**

As already stated the experience of carers suggests that individual staff from health and social care services did engage with them, but in terms of a whole systems approach to work collaboratively with carers this did not occur. Nolan *et al.* (2001) emphasise the importance of relationship-based care, which stresses the need for positive relationships for the person with dementia and the carer. Elaine remembered unexpectedly heartening conversations that brought a sense of support to her, for example when she spoke to a member of staff in the care home where her mother was having respite care:

I had this long conversation with this one carer, and she was saying her father had died from dementia about a year ago, now sometimes I don't think that's appropriate and I don't think that's helpful because it can close people down. But actually how she used it was very helpful because we had a long conversation and kind of compared notes in some ways which was really helpful, so that was alright.

There were other examples where the carers felt that at an individual level they were provided with information, but the interviews revealed that often the person with dementia's care was uncoordinated. For example Ruth said:

I was left to pull all the pieces together. She'd fallen down the stairs and the stairs were not great and after some discussion it was thought, 'yes she should be downstairs.' So I had to go and move her furniture around, buy her a new bed, and rearranging somebody's house to downstairs is really quite hard ... I also had the OT [occupational therapist] in so I had the sockets raised so she wouldn't fall doing them, and grab rails put in various places. I had Careline come in and had various monitors put in the house, so heat and cold, very cold house that, and a mattress monitor, a pendant, a belt one ... basically I was left to do all that and also I insisted she was not coming out of hospital until they got in Local Authority health care [domiciliary care], I was not having agency [private sector domiciliary care] again. They had fallen to pieces, absolutely; she had been left for weeks on end with nobody coming in.

The need to co-ordinate services and the consequences of poor quality domiciliary care were experienced by Susan too. She was surprised by the response she received from the community nurse when asked to visit to check if her mother was getting a bed sore. She was told to take a photograph of her mother's buttocks and send it to the community nursing staff so they could make an assessment. Susan thought this undignified for both herself and for her mother, but was unable to complain, as she felt 'frightened' that her complaining might exacerbate the situation.

Nick said that when Simon was admitted to the care home there was a care plan, but he was not asked to contribute to it, even though he knew Simon's life story and there was no other carer or family member actively involved.

I was saying to them you see, 'how about this, how about that, does anyone sit down for example and talk to Simon at any time?' 'We've got a care plan' was always the answer, which otherwise means it's not your business, and I was saying to them, 'would it be helpful, because I know it's very difficult for him to engage in conversation with people, would it be helpful if I wrote down some questions and answers you will get, because then it will give you some kind of scenario, because then you can play this little drama daily and it will give you an opportunity to get to know Simon' and I said, 'also he doesn't know anyone's names, and to be honest I forget the names, could you wear name badges? That was a very prickly suggestion to make re the name badges, there was this idea and it's handed down that 'we know what Simon's needs are, we are the professionals.'

The staff difficulties caring for Simon would have been reduced if they had engaged with Nick, and made use of the information he held about him. For Nick as a carer his expertise and knowledge were not accessed, nor was there any understanding of Simon's sexuality. The care home was not 'gay-friendly' (Lavin, 2008:57) and chose to ignore Simon and Nick's sexuality, conversely the day centre that Simon attended recognised this was part of Simon's identity. Simon's psychiatrist was keen for Nick to be involved. He reviewed Simon's medication at Nick's request and involved him in review meetings. In a medical report he wrote that he 'could not speak too highly of the support given by Simon's devoted friend.' Nick appreciated this recognition.

Angela found services provided by the voluntary sector and GP helpful, but from the social worker she received limited help as her mother had financial resources:

there has to be some sort of difference in the way people behave towards people that have their own resources and people that don't have resources. I just didn't think it was fair, when I was phoning people they were saying, 'I just can't help you.' You ring them up and they just send you a manual and then that's it.

They are not allowed to give any information about any of the care homes, and it's extremely frustrating and is very difficult so if there was some sort of pool of information about what the care homes are like that would be really good.

Angela did say that the social worker had informally directed her to care homes, but had explained that they should not be doing this, as they could be seen to be promoting particular homes in a competitive market.

## **The Quality of Support Provided to Carers**

The carers experienced a lack of curiosity about them from health and social care staff. This then impacted on the quality of support provided, although as already indicated individual professionals were validating of the carers. Theresa in her role as a volunteer with carers made a number of points about the importance of seeing people holistically:

If social services and health care services professionals treat people as human beings and treat them in the round, then they are going to actually recognise that they have many more lesbians and gay, bisexual, transsexual and transgender people that they are dealing with on a daily basis ... They may ask the question of 'how long have you been looking after your friend?' Start your conversation so that you may lead to a point where you can actually ask, so, 'how long have you been living together, so do you think of yourselves as partners?'

Theresa went on to discuss health and social care staff feeling uncomfortable when talking about sex with carers whose partner had dementia. She pointed out that sexual violence on the part of the partner with dementia could occur. 'It is a matter of getting things in the wrong order, foreplay gets lost somewhere. But nobody is talking about sex.' This relates not only to the sexuality of people but their age too. Theresa commented it is 'as though there is a cut off point for physical intimacy, it doesn't mean having sex, it can just be physical intimacy.' This resonates with 'old equals asexual' where culturally older people are assumed to have no interest in sexual relationships (Thompson, 2001: 90). Theresa explained:

I have had nursing homes who separate two women just for holding hands on a sofa. Not just because the other residents are bothered by it or even the nursing staff may not be bothered by it. But because Mrs Smith's family doesn't like the fact that Mrs Smith holds hands with Miss Jones, because Mrs Smith has got a family, so she can't be like that. Well catch a clue, maybe she was always like that but in her younger years she was kind of expected to get married, but maybe Mrs Smith was always like that, maybe she wasn't, it doesn't matter. The fact is that Mrs Smith gets a great deal of comfort and emotional support from holding hands with Miss Jones. What's wrong with that?

The above characterises care that is not supporting the needs of residents but rather the expectations of their families, as if dementia precludes people from making choices about their relationships. Nick was surprised that the Local Authority with responsibility for Simon's care was unable to provide any sign posting or information about services for lesbian women and gay men. He recalled an allegiance based on a shared sexuality that developed in the hospital where Simon died:

There was one guy who was very blunt, a real 'Bill Sykes' kind of character, very difficult, and when I went there first of all, very brusque, quite aggressive, in even answering the simplest question. And then he got to know that Simon was gay, he'd obviously been to the handover meetings, and he got to know I was gay and was just so kind, he was gay himself.

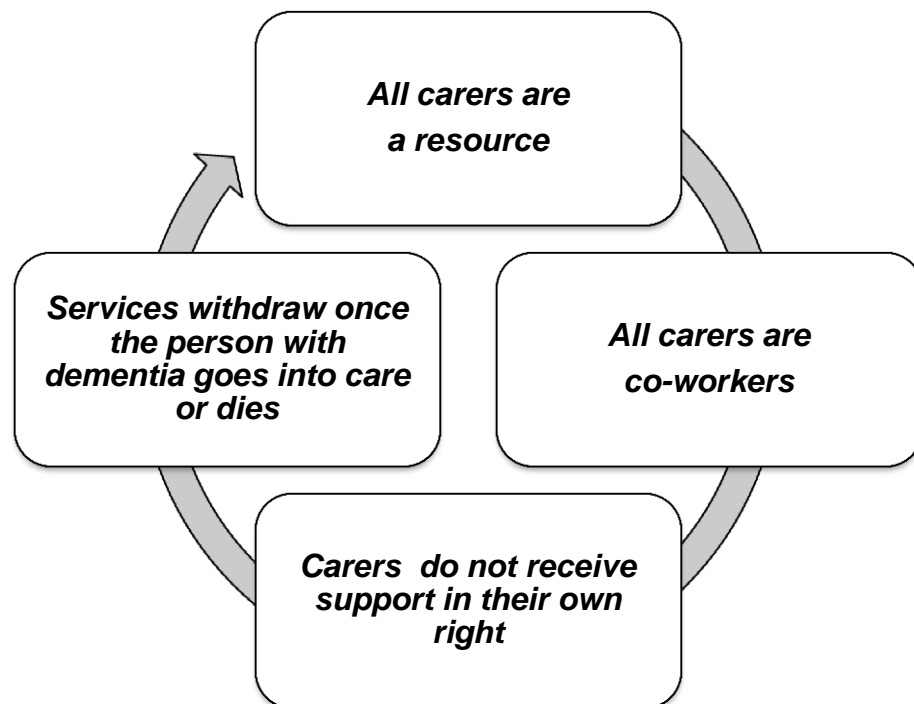
This is a positive example of the belief that 'they can look after their own' (Smith and Clavert, 2001:8-12) moreover it demonstrates solidarity and a sense of community in a bleak institutional hospital environment.

## **The Support that Carers Receive as Their Role Changes**

In none of the carers' accounts was there any indication of a systematic process implemented by health and social care services in supporting carers to manage the transitions precipitated by the illness, but there were examples of individual staff offering support. Susan spoke of the kindness of a nurse in the final weeks of her mother's life who explained what to expect. Nick related the incident of staff on the ward giving him a cup of tea after Simon died. The focus of health and social care staff was on caring for the person with dementia rather than engaging with their carers too. Once the person with dementia died health and social care services withdrew.

In Chapter 3 when discussing research methods and methodology, I reproduced the trajectory of caring that was developed by Tanner and Harris (2008). To re-cap, health and social care services view the carer initially as resource providing care, as the needs of the person increase they become a co-worker, clearly the pressures of caring can become overwhelming for carers such that they are in need of services themselves. Finally health and social care services assume responsibility for the person with dementia as the complexity of their needs increase. This process was not as simple or continuous for the carers I interviewed. As a consequence I have amended Tanner and Harris's model to show their experiences against this cyclical process in figure 5.2. When services were provided this was to support the person with dementia rather than assist carers sustain a life away from caring. Once the person with dementia was in care or had died services such as bereavement counselling were not offered.

**Figure 5-2: Caring at Different Stages**



(Adapted from Tanner and Harris, 2008:178)

Ruth spoke of having to provide support to the carer who was present when her mother died rather than receiving any support herself: 'I said to this carer at the time, what a fantastic gift she had given my mother to actually be with her when she died.' Ruth suggested that there should be training to support carers with managing end of life care.



Simon's family removed his body from the hospital and did not advise Nick of any funeral arrangements or invite him to the memorial service. He found these actions personally rejecting and unkind. Three and half years later the family placed Simon's name on the family gravestone, prompted by correspondence from Nick: 'they'd airbrushed him out of their lives and they'd airbrushed after death, and not even giving him a funeral which was attended by people he knew, or people who were nearest to him.'

Bereavement is an emotionally difficult time, but generally other people are sympathetic but for lesbian women and gay men this may not be the case (Hicks, 2008). It could be argued that given the difficulties that Nick had experienced with Simon's family because of their homophobia a particular responsibility lay with health and social care services to have offered some information and advice about bereavement services that he could have accessed. However, Nick like the other carers had no expectations about being supported to manage change for either themselves, or the person for whom they cared.

## **Managing Transitions**

Hellström *et al.*'s (2007) research on how changes are experienced in relationships was discussed in Chapter 2 and 3. To state again briefly it comprises three phrases that carers' experience with the cared for. During the first phase of the model: 'sustaining couplehood' people try to maintain the relationship. If there had been difficulties in the relationship between the cared for and carer prior to the onset of the illness, plans can be made supported by health and social services, to meet anticipated needs. Such an approach would have been useful to Ruth and Elaine, as they both had had a difficult relationship with their mother prior to the onset of dementia. Susan, Nick and Theresa spoke of the approaches that they used to maintain their relationship with the cared for throughout the illness with an emphasis on positive activities to circumvent difficulties.

In the second phase: 'maintaining involvement', there is a growing realisation of the changes that the dementia is causing to the cared for person. Susan and Theresa were able to recount instances of their physical exhaustion and Angela spoke about her mother's need for attention. In the third phase: 'moving on', the carers' sense of their identity changes and they start to re-evaluate their life without the responsibility for the person with dementia. One consistent factor for all the carers was a sense of satisfaction that they had maintained their relationship with the person throughout the illness. This was a comfort to them if the person was no longer with them.

Notwithstanding this the analysis of the carers' experiences against the Skills for Care (2010) 'Carers' Common Core Principles', has demonstrated that the delivery of health and social care services, has in the main, not been informed by these principles.

## Summary

This chapter analysed and discussed the findings following the interviews with six carers that explored the experience of caring, coping approaches, and carers' encounters with health and social care services. The findings indicated similarities of experience that developed into themes. The final part of the analysis adapted the Skills for Care (2010) 'Carers' Common Core Principles.' This acted as an evaluative measure as the principles were compared against the experience of the carers. The importance of previous emotional ties and an understanding of the person's life story, preferences and needs, as well as their personality emerged as paramount in ensuring good quality care for the person with dementia. The dominant model of care provided by health and social care services that emerges from the carers' stories is a task orientated approach within the medical model. The unique needs of the person with dementia and their carer were often disregarded with the result that the delivery of some services was of poor quality. Consequently, carers experienced stress and anxiety, and in some cases had to proactively manage the care of the person. There was a consistent lack of interest or curiosity about the needs of carers by health and social care staff, who made assumptions about the carers' ability to continue to care. These issues are explored in the messages for practice in Chapter 6.



# Chapter 6: Summary and Conclusion

## Introduction

In this concluding chapter I summarise and reflect on the findings from the research. I begin by recapping on the topic, focus and purpose of the research. I then critique the research through an evaluation of the methodology and methods and considered what worked well and where there were shortfalls. I suggest how these might be addressed. The chapter concludes with messages for policy and practice emerging from the research.

The research centred on the lived experience of six carers of people with dementia: five women and one man, three identified as lesbian or gay. They were informal unpaid carers. Five carers were or had been caring for their mother, and one cared for a friend. The carers had all retained a relationship with the cared for person throughout the duration of the illness. My original intention had been to interview three heterosexual and three lesbian/gay partners. I was not able to find partners irrespective of sexuality to be interviewed, which did impact on the research, as the relationships were between daughters and mothers, and one friend. Notwithstanding this, I still found valuable information about the experience of caring, but further research into partnership caring with a comparison between the experiences of heterosexual, lesbian/gay couples would be worthwhile as it would highlight similarities and differences in experience, and recommendations about service improvements.

## The Experience of Caring

The motivation for caring among participants varied along a continuum of strong emotional bonds to a sense of obligation towards the cared for, that was linked to the concept of hierarchy in family relationships based on familial ties rather than affection. This echoed Finch's (1989) research with health and social care services responding to this hierarchy in relationships too. Conversely, families were able to curtail and control support where the carer was not family. This was evident in the relationship between the two friends, Nick and Simon as the illness progressed, changes occurred in how Nick (the carer) related to Simon. Some carers lost the emotional support the cared for person had provided before the illness, and found their relationship was reversed, with this person now dependent on them. For one carer the fear which her mother had instilled evaporated, and she suddenly saw her mother as frail and vulnerable. An anxiety the carers expressed was that the person with dementia would cease to recognise them. The 'horror' of not being remembered, as expressed by Ruth, indicates how identities between the carer and cared for are bound up with each other (as discussed by Morris and Morris, 2010). Most of the carers adjusted to these changes, as evidenced by their continued affection for the person with dementia, without dwelling on regrets for the person lost.

Social isolation is often an issue for people with dementia, and this became the case with some carers too as they had less time for friends and family due to their caring responsibilities. The enduring and positive aspects of the carers' relationship with the person with dementia focused on shared humour, as well as supporting the cared for to enjoy favourite activities.

## **Coping Approaches**

The carers adopted a number of short and longer term approaches enabling them to cope, such as having a drink or cigarette; going into the garden and thereby removing themselves; seeing a counsellor, or developing plans in response to problems. The motivation to continue to care varied among the carers; key drivers appeared to be love for the cared for person, and family obligation. Using the work of Twigg and Atkins (1994: 122) I was able to theorise the carers' attitude to their role, identifying the 'boundary setting' mode where the carer develops knowledge and skills enabling them to behave as a professional in their caring role, and 'engulfment' mode, where the carer is overwhelmed by the needs of the cared for person. Four of the carers presented as boundary setting most of the time, while two talked of feelings of engulfment, intertwined with boundary setting. The carers identified a range of simple activities and significant relationships that had given them pleasure and support. The carers reported that the act of caring had made them more assertive, knowledgeable, and had enhanced their self-esteem and self-reliance, while one carer spoke of her gratitude for being able to care, so that she could keep her parents living together.

## **Carers' Encounters with Health and Social Care Services**

There were consistencies in the experiences the carers had of health and social care services. They were generally not treated as equal partners in the caring process; moreover the biography of the cared for person was not sought, and the carers' views and advice were not considered. They were not routinely involved in the development of care plans. This led to instances of poor quality care, particularly around bathing, which were abusive in the case of Simon and Susan's mother. Carers found that care was not co-ordinated by one professional and services were fragmented. Care practice was underpinned by the medical model of care; so the focus of intervention was on the dementia, without a holistic assessment of the person's needs or story.

There was generally felt to be a lack of interest in the person with dementia and their carer among professionals. Consequently Simon's sexuality was not perceived as significant even when his family imposed constraints on Nick's contact. This was not challenged by Social

Services despite Nick's feeling that there were elements of homophobia at play. Carers told of expectations that they would continue to care, without professionals checking whether they required further support. There was an underlying assumption that the carers who were daughters had filial responsibilities, irrespective of the history of the relationship which was never sought anyway. Two carers were asked to speak to the cared for about their behaviour, as if they were misbehaving children, which demonstrates ignorance about the nature of the illness.

Only one of the six carers had defiantly been offered a carer's assessment, their legal entitlement (Department of Health, 1995; Department of Health, 2005; Department of Health 2008a). On the whole, the carers' experience contradicted both the spirit and aims of legislation and social policy, which are for health and social care services to work with carers as equal partners by valuing their expertise, and recognising their need for support. There were instances when individual professionals were compassionate in spite of the overall system being disjointed.

## Images as Metaphors of the Caring Role

When I had analysed the data the images below came to my mind as representations of my view of the carers in their caring role, and equally my progress as a researcher where the process enabled my understanding to change and develop. These simple and sometimes humorous pictures convey particular meanings to me beyond the data portrayed in the literal form.

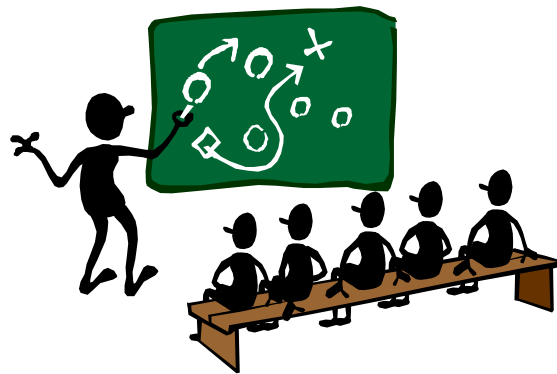
**Figure 6-1: Nick in the Role of Carer**



This image made me think of Nick caring for his friend Simon. When I recalled how he would take Simon out to his favourite haunts from the care home or hospital. Nick spoke with such

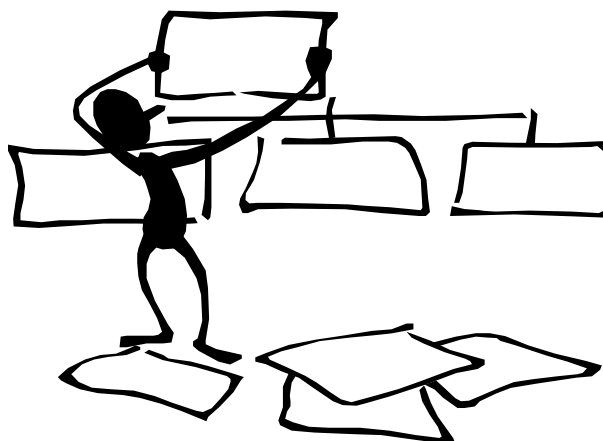
pleasure about these outings. I felt that Nick knew Simon so well that he was able to provide him with a range of positive experiences and was empathetic to his needs. What is more even though Simon's dementia had changed their friendship it had not diminished it.

**Figure 6-2: Ruth in the Role of Carer**



The image of Nick and Simon contrasted quite sharply with how I saw Ruth, as I perceived her as very effectively organising and co-ordinating her mother's care. She felt that support from health and social care services was very variable and ultimately she had to take control. When I reflected on this it was clear she was often more knowledgeable about what was available than the health and social care staff, and had to inform them about resources. I could see that they would respond to her as if she was in charge.

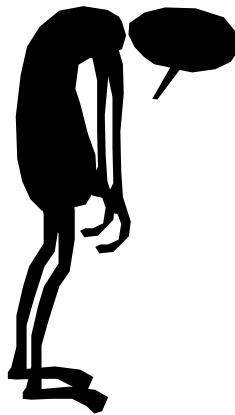
**Figure 6-3: Theresa in the Role of Carer**



Theresa struck me as very resourceful and resilient. She was caring for her mother and father when she was in her thirties. Her response to problems was to develop a plan, and often she came up with creative ideas to best meet her parents' needs. I saw her as a practical and

capable person, who always found a way through, and managed to keep her parents together with her throughout the duration of the illness.

**Figure 6-4: Elaine in the Role of Carer**



I saw Elaine as cast down by the weight of her history with her mother. Her sense of being abandoned as a teenager by her felt very alive and present. The interview seemed like a circle that kept returning to Elaine's hurt and confusion. It was rather like someone talking about an unrequited love, and constantly wondering what went wrong without being able to accept the situation, and the fact that maybe she never would know the reasons. It was perpetual grief, and this was the image that came into my mind. I felt intensely sad for Elaine as she was clearly a very caring person, and was doing all she could now to support her mother.

**Figure 6-5: Angela in the Role of Carer**



Angela seemed at times reluctant to give very full answers to questions. She would then suddenly change from being repressed in her responses to making very passionate statements



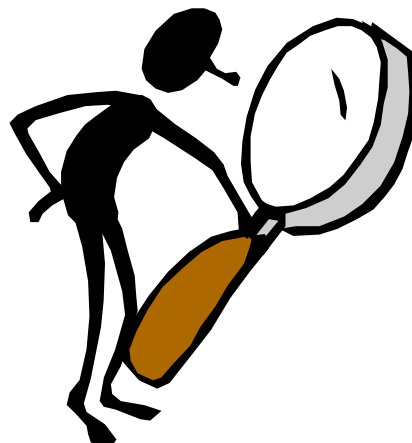
that were unexpected. Underlying her reticence I felt that there was considerable frustration and anger, which in part had been ameliorated by her mother's admission to a care home.

**Figure 6-6: Susan in the Role of Carer**



Susan like Ruth had arranged much of her mother's care, but unlike Ruth she had also provided most of the personal care. Essentially I felt that Susan's caring for her mother had been rewarding to her, and was an expression of her love. I had a sense that she had enabled other people to support her, and her mother too, such as her husband. In addition to this she was able to work collaboratively with people without telling them what to do rather leading them, hence this cheerful picture of a group being led by Susan where everyone is moving forward in the same direction.

**Figure 6-7: The Objective Researcher**



This image is of me as the researcher when I first began the process. I was distant and impersonal and assumed that this would be me researching other people and coming to a series of conclusions. I was engaged at a cognitive and action level, but not emotionally, as I became more reflexive that changed in a process similar to that documented by Waines (2004). I realised how much the experience of the carers was prompting quite profound philosophical

thoughts about the connection between personal values and choices that the carers had made, as well as the stories they told me about what the person with dementia had given to them.

**Figure 6-8: The Reflexive Researcher**



This final image came to represent me in terms of the dog being sheltered by the person (carer) with the umbrella. I felt that particular carers had shared their wisdom, and demonstrated such humanity that I learnt something about the importance of relationships during stormy times, and how values inform our actions. Their approaches to coping symbolised by the umbrella enabled them to keep the person with dementia safe, while they remained protected against the rain. I have learnt from them, and I am grateful for this new knowledge just as the dog is enjoying the social interaction while remaining dry. Furthermore becoming a researcher has given me confidence and a wish to share my understanding and knowledge with others. To this end I have developed both university accredited modules and short courses about positive dementia practice, delivered conference papers and facilitated seminars about the research findings. One of the carers in this study now speaks to the social work students in the university where I teach. In addition I involve a person with dementia in my teaching, so that his experiences of health and social care services can be shared. I am part of a multi-agency workforce development group on dementia and together we have organised training events and conferences. I have written chapters for three social work textbooks where dementia is the focus. In summation, I feel that the research process and relationships that I have developed have given me so much in both a personal and professional capacity. I am keen to share what I have learnt with other people with the aim of enhancing the well-being of both people with dementia and carers.

## Critique of the Research

The research method was semi-structured interviews following a questioning schedule sent to the carers beforehand (Appendix C). This allowed them to prepare for the interview, which was ethically appropriate, as they were informed and able to assert control on the process, especially if there were areas that they did not want to discuss. Interviews varied in length from an hour to five hours and the carers were seen on one occasion. This approach generated considerable data, thus enabling the objective to be met of contrasting carers' stories and enabling themes to emerge, inviting the carers to provide a narrative of their experience, without any structuring through questions may have been less effective for this. The carers were white, middle-class and from professional backgrounds; consequently issues of poverty, disempowerment and environmental stress did not feature. Other less formal approaches, however, could have resulted in a more diverse group of carers being prepared to be interviewed; I might then have gained greater insight into a carer's day-to-day experience. An important future area of research would be to capture the views of working class carers from different ethnic or cultural backgrounds. An example of an alternative research approach could be the adaption of the walking interview (Clark and Emmel, 2010) which would have enabled me to be with carers over a longer period of time. For example, we might have returned to places that had been significant for the carer and cared for, or I may have accompanied the carer when visiting the person with dementia. Letherby (2004) found in her research with childless women that she had assumed all the data would be collected through interviews, whereas some participants corresponded with her, and altered some questions so they could write about issues especially pertinent to them. Letherby (2004) found that the voices of the women who corresponded had equal weight to those interviewed when she analysed her findings. Dewaele *et al.* (2011) found that the use of questionnaires via an internet site that explored the social networks of Flemish lesbian women, gay men and bisexual people achieved a response rate that was surprisingly high. Dewaele *et al.* (2011) concluded that using the internet and printed questionnaires was an anonymous process allowing information to be gathered on sensitive issues. Had I used some adaption of these approaches they may have been experienced as less pressured and intense for participants and I might have achieved a socially more diverse group of participants.

## Messages for Practice

There were some striking similarities between the carers in their experiences and themes did emerge notwithstanding that they were caring at different periods of time and lived in various regions in the UK. I start with the legislative and policy narrative of caring, and contrast this to the actual lived experience of caring.

The concept of carer was recognised and enshrined in law and social policy beginning with the Carers (Recognition and Services) Act 1995. This has been complemented by additional legislation and social policy supported by research. Carers' entitlements include support that enables them to gain employment, education and access leisure activities. Fundamental to this is the right to have their needs assessed. In spite of these legal entitlements the actual experience of caring is very different. What emerged from the carers' stories is a disjuncture between legislation, policy and practice. Further research could discover whether health and social care staff are simply unaware of the legislation and policy in relation to carers, or they assume that assessing carers' needs has a limited impact due to financial and resource constraints. Carers' assessments give the carer the opportunity to explain their needs, and be advised about financial benefits and resources. The act of being listened to as a carer can reduce feelings of isolation and gives opportunities for problem solving; equally it enables the carer to advise professionals about the needs of the person with dementia.

## Person Centred Practice

Sanderson *et al.* (2008: 50) describe person centred thinking as identifying what is *important to* the cared for person, as well as what is *important for* the person. The latter often dominates, resulting in services that only meet people's physical needs with an emphasis on assessing risks, but fail to take account of the personal preferences of the cared for. In the carers' stories there were examples of health and social care staff not taking the advice of carers resulting in abusive practice; for example Susan's mother was left naked by domiciliary care workers as they could not wash her, even though they had been advised by Susan of an approach that worked, and of what was *important to her*.

There are opportunities for innovative changes to be made through the personalisation of services that enable carers to receive funding to employ and manage personal assistants, but equally there are concerns that funding may not be adequate to ensure sufficient care of the required quality, especially as the government has no plans at present to regulate personal assistants (Gardner, 2011). Notwithstanding this, there are practical approaches that support person centred thinking and planning that could be successfully used for people with dementia and carers. For example, simply recording what works and what does not work in how care is delivered to the person would have prevented the repetition of poor and abusive care practices highlighted by carers. Services were not gay friendly and indeed displayed a lack of interest or curiosity in the intimate networks of either the cared for or the carer. Consequently, the most pressing message to emerge from the research was the need for person centred thinking and practice to become embedded within the leadership, management and delivery of services.

## Conclusion

Much of the practice experienced by carers interviewed for this study was founded on a medical model of intervention focusing on the dementia of the cared for. In spite of this the carers interviewed showed resilience and commitment. They advocated and safeguarded the person; moreover most of the carers derived continuing pleasure from their relationship. They all identified increased self-esteem because they had supported the person throughout the illness. I learnt through hearing the carers' stories how emotional bonds between people endure; people with dementia show us what it is that we all need - love, acceptance and the capacity to enjoy the moment. The loudest message for research and practice is that person centred thinking needs to be at the very heart of how we engage with people with dementia and their carers.

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## **Appendices**

### **Appendix A: LGBT Carers' Leaflet**

# **BEING HEARD**



**I am researching the lives of lesbian women and gay men who have cared for someone with dementia. Would you be prepared to tell your story?**

**If you would like to know more about the research project please contact:**

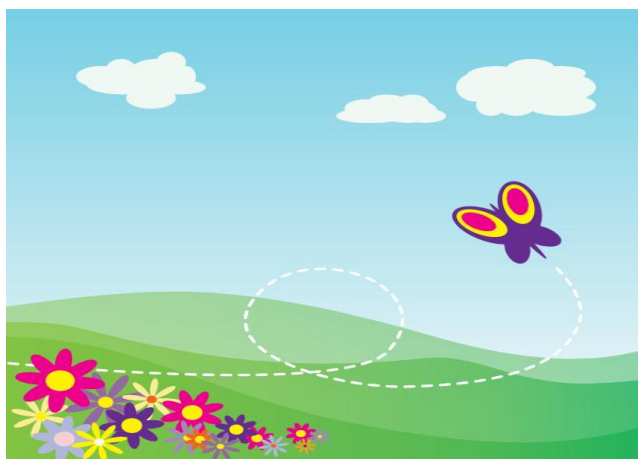
**Gill Constable  
Senior Lecturer Social Work  
University of Chichester**

**Tel: 01243 816354**

**Email: [g.constable@chi.ac.uk](mailto:g.constable@chi.ac.uk)**



# HAVE YOU A STORY TO TELL?



**I am researching the lives of family, friends and neighbours who have cared for someone with dementia. Would you be prepared to tell your story?**

**If you would like to know more about the research project please contact:**

**Gill Constable  
Senior Lecturer Social Work  
University of Chichester**

**Tel: 01243 816354**

**Email: [g.constable@chi.ac.uk](mailto:g.constable@chi.ac.uk)**

UNIVERSITY OF  
**Southampton**  
School of Education

**The Experience of Caring for  
Someone with Dementia:  
A Biographical Study**

**RESEARCHER'S  
INTERVIEW SCHEDULE  
INCLUDES PARTICIPANT  
INFORMATION AND CONSENT  
FORM**

# **Contents**

## **1. Basic Details about the Participant**

## **2. Research Areas**

### **Appendices**

**Appendix 1: Letter to participants about the research project**

**Appendix 2: Consent form that participants must agree and sign  
prior to the interview/s**

## Guidance

This Interview Schedule comprises the following:

1. **Participant Information Sheet (Appendix 1)**  
Prior to the interview being arranged. The researcher will discuss the research with the participant and go through the letter, and clarify any points raised.
2. **The Consent Form (Appendix 2)**  
This will be explained to the participants by the researcher and completed prior to the commencement of the interview. The principles of the Data Protection Act 1998 will be adhered to.

The researcher will complete with the participant:

3. **Basic Details about the Participant (pages 4- 6)** prior to the interview.
4. **Research Areas (pages 6- 8)** these questions will be asked during the interview. Supplementary questions and probes will be utilised where appropriate.

The interview will be recorded with permission and transcribed in full and the participant will be given a copy to check the content, if necessary changes will be made in consultation with them. Participants will be given a copy of Appendices 1 and 2.

### 3.1 Basic Details about the Participant

<b>Name of Participant:</b>	
<b>Name of the person they care for:</b>	
<b>Relationship to the cared for:</b>	
<b>Address of the participant:</b>	
<b>Address of the cared for:</b>	
<b>Date and time of the meeting:</b>	
<b>Location of meeting:</b>	

### 3.2 Basic Details about the Participant

1. What is your gender?

Female ☐

Male ☐

Other ☐

2. What is your date of birth? ...../...../.....

3. What is your relationship to the cared for person? .....

4. How long have you been a carer for the cared for person?: .....

5. How would you describe your sexual orientation:

Heterosexual ☐

Lesbian/ Gay ☐

Bisexual ☐

Transexual ☐

Prefer not to say ☐

### 3.3 How would you describe your ethnic origin?

<b>WHITE</b>	Tick /specify as appropriate
British	
Irish	
Any other White background	
All White groups	
<b>MIXED</b>	
White and Black Caribbean	
White and Black African	
White and Asian	
Any other Mixed background	
All Mixed groups	
<b>ASIAN OR ASIAN BRITISH</b>	
Indian	
Pakistani	
Bangladeshi	
Any other Asian background	
All Asian groups	
<b>BLACK OR BLACK BRITISH</b>	
Caribbean	
African	
Any other Black background	
All Black groups	
<b>CHINESE OR OTHER ETHNIC GROUP</b>	
Chinese	
Any other ethnic group	
All Chinese or other ethnic group	
<b>Prefer not to say</b>	

#### **4. Research Areas**

##### **1. Can you describe what it is like to be carer?**

###### ***Supplementary Questions:***

- What are the practical implications in terms of daily living e.g. household tasks, financial implications, work and social life?
- What is the emotional impact on you and the person you care for?

##### **2. Has your relationship changed, if so how?**

###### ***Supplementary Questions***

- Describe any changes in terms of your one to one relationship with the cared for, and with friends and family?
- Have you received any feedback from other people about how you have changed through being a carer?
- Any changes in roles (who does what in the home etc)
- What are the things you cannot do together any longer?
- What do you miss most?
- What do you still do together?
- Are there changes in your relationship that you feel are positive?

##### **3. What enables you to continue to care?**

###### ***Probes***

- Use genogram if appropriate
- Personal support of friends and family
- Personal values
- Attachment to the person
- Meeting with other carers
- Other interests such as work, leisure activities, cultural activities
- Spiritual beliefs
- Other beliefs (humanitarian, political etc)
- Health and social care services
- Other support not mentioned above

##### **4. How does caring impact on you? What coping strategies do you use?**

###### ***Supplementary Questions***

- How do you cope with stress?
- Are there practical things you do such as talk it through with someone, ask for help? (accessing external resources)



- Are there ways that you manage by yourself for example do you have approaches to calm yourself down, look after yourself? (internal resources)
- What is the balance between external and internal resources that enables you to go on caring?
- Can you describe some approaches that you use when things are difficult for you?

**5. What support do you receive as a carer?**

*Probes*

- What services are the most helpful?
- What services are the least useful?
- If you were able to plan services to support carers what would you provide?
- Do societal attitudes need to change e.g. how generally are you and the person you care for treated – with kindness, understanding, indifference, hostility, disrespect?

**6. What have you learnt from being a carer?**

*Probes*

- Can you identify how you have changed through being a carer e.g. less optimistic, more fearful, prone to despondency, developed new practical skills, assertiveness, self-awareness, empathy, feeling stronger emotionally?
- Better understanding of the health and social care system

**7. What are the learning and development needs of health and social care staff towards lesbian and gay carers of people with dementia?**

*Supplementary Questions*

- Is your experience as a carer recognised?
- As a lesbian or gay male carer do you feel that you are treated differently?
- Is your relationship with the cared for recognised and validated?
- Have you been provided with information, advice and support that meets the needs of the person with dementia, and you as a carer?
- If not what suggestions can you make about training for health and social care staff?
- Do you feel that health and social care staff understand about the impact of homophobia and heterosexism?
- If not what training is required?

**8. Is there anything else that you would like to tell me that we have not discussed?**



## **Participant Information Sheet**

### **The Experience of Caring for Someone with Dementia: A Biographical Study**

**Researcher: Gill Constable**

**Ethics number: RGO 6683**

***Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.***

#### **About the Research**

The research project is seeking to use a biographical approach in the interviewing of carers of people with dementia. The purpose of the research is to better understand what enables carers to continue to care for the person with dementia as the illness progresses. An intended outcome is that this knowledge can be used to support other carers, which will also support the cared for person.

#### **The Researcher**

My name is Gill Constable and I am a doctoral research student at the University of Southampton. I am undertaking this research project as part of an Education Doctorate. I work as a lecturer at the University of Chichester where I teach social work and social care. This research is not being funded by an outside body.

## **The Research Areas**

1. What is it like to be carer?
2. The caring relationship
3. Continuing to care
4. Coping strategies
5. Supporting carers
6. Learning from being a carer
7. Learning and development needs of health and social care staff

## **Selection of Research Participants**

I would like to interview six carers who define themselves as a lesbian woman or gay man, and are or have been caring for a person with dementia. The reason for this is to capture the particular experiences of this group, which generally is neglected in research. The purpose of the research is to better understand how carers go on caring, and therefore it is important not to assume carers are all the same with the same needs.

The following selection criteria have been developed:

- Carers who identify themselves as having managed (where the cared for person has died) or managing with the impact of caring for someone with dementia.
- Carers who define themselves as having a significant relationship and attachment to the person with dementia.
- It is not necessary that the person with dementia lives with the carer, but if the person with dementia is in a care setting that the carer visits them on a regular basis.

If the carer lives with the person with dementia it is requested that interviews take place when the carer is alone. (This is to prevent interviews taking place with the person with dementia being present and feeling excluded by the process, as the research is focusing on the carer.)

## **What the Research Involves**

The research will initially involve me visiting you and explaining the research process, so that you can think if you would you like to be involved. If you agree, we will meet for about two hours on at least two occasions although shorter interviews can be arranged. Where we meet will be your decision, but we will need to be somewhere that is quiet which does not include other people in the same room.

The interview meetings will be taped with your permission, and then transcribed. Once the interviews have been transcribed I will send them to you, so you can check, and make any changes you wish. Once the research is completed I will send you a summary of the research findings and recommendations.

## **Are there any benefits in my taking part?**

I hope that you will feel that the research is worthwhile. There will be no financial benefits to you, but the findings will add to knowledge and may assist other carers and people with dementia.

## **Are there any risks involved?**

The interviews will be focused on your biography or life story, and how you manage as a carer. I will be particularly interested to hear about your life as a carer and that of the person you care for, as well as the support that you have as a carer.

Sometimes when we reflect about the past, present or think about the future we can evoke both happy and sad memories. My own view and that of other researchers is that it is 'good to talk' to someone who listens and tries to understand our experiences and feelings. My hope is that you will find this research interview useful, and we will agree together how each session will end so that we always part on a positive note.

## **Will my participation be confidential?**

The information that you share with me will be taped and transcribed. It will be kept confidential on a password protected computer. Your name will not be used and anything that indicates your identity will be made anonymous. The principles of the Data Protection Act 1998 will be adhered to. All the data will be securely stored in my office at the University of Chichester. I will have help to transcribe the tapes but the person doing this work will be required to sign a confidentiality agreement.

If during the course of our discussions you were to disclose any information that suggested that you, or the person for whom you care for, is at risk of harm I

would discuss this with you, and then pass this onto to the Local Authority's Adults' Services Department as a safeguarding issue. In those circumstances I could not guarantee confidentiality.

### **What happens if I change my mind?**

If you decide that you no longer wish to be involved in the research you can immediately withdraw without any "cost". I will ensure that any transcripts or other information is destroyed.

### **What happens if something goes wrong?**

In case of concern or complaint about aspects of the research process you can contact:

**Dr Gill Clarke, Chair of Ethics Committee, School of Education, University of Southampton**

### **Where can I get more information?**

If you would like further information about the project you can contact me:

Gill Constable  
Senior Lecturer Social Work  
University of Chichester  
Bishop Otter Campus  
College Lane  
Chichester  
West Sussex  
PO19 6PE

tel: 01243 816354 or email me at: [g.constable@chi.ac.uk](mailto:g.constable@chi.ac.uk)

## CONSENT FORM

**Study title:** The Experience of Caring for Someone with Dementia:  
A Biographical Study

**Researcher name:** Gill Constable

*Please initial the box(es) if you agree with the statement(s):*

1. I have read and understood the Participant Information Sheet dated 2<sup>nd</sup> April 2010, and have had the opportunity to ask questions about the study.

☐

2. I agree to take part in this research project and agree for my data to be used for the purpose of this study

☐

3. I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected

Name of participant (print name): .....

Signature of participant: .....

Name of Researcher (print name): .....

Signature of researcher: .....

Date: .....



## Research Governance Project Plan Form

**Title of project/study:** The Experience of Caring for Someone with Dementia: A Biographical Study

**Name of main researcher:** Gill Constable

**Status:** Senior Lecturer Social Work

**Organisation address:** University of Chichester, Bishop Otter Campus, College Lane.  
Chichester, West Sussex, PO19 6PE

**Department/location:** Social Work and Social Care Team

**Telephone:** 01243 816354 **Email:** [g.constable@chi.ac.uk](mailto:g.constable@chi.ac.uk)

**Name of research supervisor:** Dr Gill Clarke

**Status:** Reader in Education

**Organisation address:** University of Southampton, Highfield Campus, Southampton,  
SO17 1BJ

**Department/location:** School of Education

**Telephone:** 023 8059 3475 **Email:** [gmc@soton.ac.uk](mailto:gmc@soton.ac.uk)

**Name(s) of any co-researcher(s):** N/A

**Status:**

**Organisation address:**

**Department/location:**

**Telephone:** **Email:**



**Who will fund your project?** Self-funded

If your project is part of an academic course, please complete this section.

**Course:** Education Doctorate      **Year:** 3

Expected start and completion dates of your research.

**Start:** March 2010 **Completion:** June 2011

### Background

(Relevance of your study/What similar previous studies have there been?)

The research project is seeking to use a biographical approach in the interviewing of carers of people with dementia. The purpose of the research is to better understand what enables carers to continue to care for the person with dementia as the illness progresses. An intended outcome is that this knowledge can be used to support other carers, which will also support the cared for person. The focus of the research is lesbian and gay men caring for a partner, as there is a gap in the literature pertaining to this group. Their experiences will be compared with research that is already available on heterosexual couples (Davies & Nolan, 2008, Hellström *et al.* 2007).

### The Research Areas

1. What is it like to be carer?
2. The caring relationship
3. Continuing to care
4. Coping strategies
5. Supporting carers
6. Learning from being a carer

### Points to consider

Why is this topic important?

What is your particular area of interest?

What other projects/studies have been carried out in this area (if any)?

How will your research add to any previous work?

What is the main question you wish to answer?

What specific questions will you ask to address the main question?

### Strategy

#### Selection of Research Participants

I would like to interview three carers who define themselves as a lesbian or gay man, and are or have been caring for a partner with dementia. The reason for this is to capture the particular experiences of this group, which generally is neglected in research (Turnball, 2002). The purpose of

### Points to consider

Who are you targeting?

How are you going to select your sample?

How many people will be involved?

<p>the research is to better understand how carers go on caring, therefore it is important not to assume carers are all the same with the same needs. The research is important as there is a gap in this area, and one outcome of the research will be able to assist health and social care providers to make their services more accessible, person-centred and inclusive to lesbians and gay men.</p> <p>The following selection criteria have been developed:</p> <p>Carers who identify themselves as having managed (where the cared for person has died) or managing with the impact of caring for someone with dementia.</p> <p>Carers who define themselves as having a significant relationship and attachment to the person with dementia, as a partner.</p> <p>It is not necessary that the person with dementia lives with the carer, but if the person with dementia is in a care setting that the carer visits them on a regular basis.</p> <p>If the carer lives with the person with dementia it is requested that interviews take place when the carer is alone. (This is to prevent interviews taking place with the person with dementia being present and feeling excluded by the process, as the research is focusing on the carer.)</p> <p><b>What the Research Involves</b></p> <p>The research will initially involve the researcher visiting the interviewee and explaining the research process, so they can think if they would like to be involved. If they agree, the researcher will meet with them for about two hours on at least two occasions although shorter interviews can be arranged. Where the researcher and interviewee meet will be the decision of the interviewee, but it will need to be somewhere that is quiet which does not include other people in the same room.</p> <p>The interview meetings will be taped with the interviewee's permission, and then transcribed. Once the interviews have been transcribed it will sent to the interviewee, so they can check it, and make any changes they wish. Once the research is completed the researcher will send the interviewees a summary of the research findings and recommendations.</p>	<p>Where will your study take place?</p> <p>What sort of data will be collected? ie will it be in terms of numbers (eg how many etc.) or will it be in words (descriptive eg what is happening etc.) or is it a mixture of both?</p>
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<p><b>Methods (Ethics)</b></p> <p>Participants will be invited to participate in the research through:</p> <p>Contact with voluntary sector organisations such as the Alzheimer’s Society Lesbian, Gay, Bisexual and Transgender (LGBT) Network, LGBT Older People’s Forums Hastings and Rother, Gay and Grey Forum, Age Concern LGBT Network</p> <p>West Sussex County Councils Day Centres, Home Care Services, Adults’ Services Social Work Teams</p> <p>Friends and colleagues (snow balling approach)</p> <p>The County Council’s Equal Opportunities Policy will be implemented throughout the research project.</p> <p>A Participant Information Sheet has been developed to manage issues of informed consent and the participants’ entitlement to withdraw from the project. A Consent Form has been developed.</p> <p>These documents are contained in the Researcher’s Interview Schedule.</p> <p>The principals of the Data Protection Act 1998 will underpin the research.</p> <p>Data will be collected through interviews that will be recorded and transcribed. The participants will receive a copy of the transcript to check for accuracy, and will be able to make changes.</p> <p>There will be no financial benefits to the participants, but the findings will add to knowledge and may assist other carers and people with dementia.</p> <p>The interviews will be focused on the participant’s biography or life story, and how they manage as a carer. A Risk Assessment has been completed for the project. There are no risks identified.</p> <p>Participants will be informed that they can complain to Dr Gill Clarke Chair of the Ethics Committee, School of Education, University of Southampton (See Researcher’s Interview Schedule).</p> <p>The research has been approved by the University of Southampton’s Research Governance, which includes their Insurance Department.</p>	<p><b>Points to consider</b></p> <p>How are you going to recruit your participants?</p> <p>How will this comply with Equal Opportunities Policy? (See Code of Conduct)</p> <p>How will you obtain <b>INFORMED CONSENT?</b> (See Code of Conduct)</p> <p>Are you going to involve your participants in planning the way in which it will be carried out?</p> <p>Will you be paying your participants?</p> <p>How are you going to collect your data? eg survey, interview, consultation, case file audit, etc.</p> <p>What potential risk or harm is there to your participants or to yourself?</p> <p>Will your participants be given an opportunity to complain if they feel the need to do so?</p> <p>Have you checked your organisation is insured should they need to pay compensation or insurance?</p>
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<p><b>Methods (Collecting Data)</b></p> <p>The participants will be interviewed using the Researcher's Interview Schedule attached. The interviews will be taped and transcribed. The Research Schedule has been piloted. The data will be analysed against codes and categories to establish if themes and commonalities emerge in terms of carers' experience and the management of caring.</p> <p>The research is being undertaken as part of an Education Doctorate at the University of Southampton. It is hoped that a paper will be produced for publication in a health or social care professional journal.</p> <p>The data will be stored in a cabinet in my locked office at the University of Chichester. It will be held in paper form, on computer and information stick. The data will be kept until June 2012. Anonymity and confidentiality will be assured as real names and locations will be not be disclosed. I will have ownership of the data.</p> <p><b>Project Plan</b></p> <p>October 2009 – April 2010 review of the literature  May – June 2010 methodology  April 2010 – October 2010 interviews of participants  November 2010 analysis of data  December 2010- April 2011 discussion of findings  May 2011 completion of thesis</p> <p>The findings will be used in teaching at the University of Chichester. I will have ownership of the data. There will be no financial benefit to anyone from the research.</p>	<p><b>Points to consider</b></p> <p>How exactly are you going to collect your data? eg questionnaire, interview etc.</p> <p>Will recording or video equipment be used?</p> <p>How are you going to test whether the method you choose works?</p> <p>How are you going to make sense of your data?</p> <p>Will your data be used for any purposes other than your study?</p> <p>How do you propose to store your data? eg on database, hard files, etc.</p> <p>How long will you keep the data?</p> <p>How will you ensure confidentiality and anonymity of the data?</p> <p>Who will have ultimate ownership of the data?</p> <p>How will you present the findings of your research? eg presentation, report, journal</p> <p>Will the way in which you present your findings be appropriate to your audience ie simple language, Braille, etc.</p> <p>Will you or anyone else benefit financially from your study?</p>
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**NB YOU MUST INCLUDE A PROJECT TIMETABLE WITH YOUR APPLICATION**

<p>Is this your first application for registration for this project? YES</p> <p>Date of previous application:</p> <p><b>I have read the Researcher's Code of Conduct, Research Governance Standards, Data Protection and Caldicott Guardian general principles and the Roles and Responsibilities documents. I agree to carry out my study in accordance with West Sussex's Research Governance Policy and I understand that failure to do so could result in serious consequences.</b></p> <p>Principal Researcher's signature: Gill Constable</p> <p>Date: 11<sup>th</sup> March 2010</p> <p>Supervisor's signature: Gill Clarke</p> <p>Date: 20<sup>th</sup> March 2010</p>	<p>Please return your application form to:</p> <p>Chris Rainey Research Unit West Sussex County Council Sussex House Crane Street Chichester PO19 1LJ</p> <p>Please mark your envelope:</p> <p>Research Governance</p>
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## Checklist

<p>Have you ...</p> <p>Talked your idea over with your Manager/Research Unit?</p> <p>Looked at what studies have been carried out in this area before?</p> <p>Considered funding issues?</p> <p>Considered time/commitment issues?</p> <p>Made arrangements for supervision?</p> <p>Thoroughly read the Research Governance Application Pack?</p> <p>Signed your Project Plan?</p> <p>Does your project consider how you will inform participants about ...</p> <p>What the purpose of the study is?</p> <p>Providing additional information and advice where appropriate?</p> <p>Why they have been selected and how this is in accordance with Equal Opportunities?</p> <p>How the study will be carried out?</p> <p>What commitment their involvement will require?</p> <p>What inconvenience/discomfort they may</p>	<p>Does your project plan include ...</p> <p>Details on how exactly you are going to collect your data including location?</p> <p>Consideration of the needs of your target sample in preparing any materials concerning the research?</p> <p>What you are going to do with your data?</p> <p>How you will make sure the data is kept confidential?</p> <p>How the data will be stored and who may have access to the data?</p> <p>How you will test out your method?</p> <p>Who will own your findings?</p> <p>What arrangements are in place for compensation both for participants or yourself?</p> <p>Have you included with your project plan ...</p> <p>A timetable for the project?</p> <p>An example of your letter of consent for participants?</p> <p>An example of your questionnaire (if appropriate)?</p> <p>A copy of any indemnity insurance from</p>
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<p>experience?</p> <p>What harm or risk may be incurred?</p> <p>Their right to withdraw/refuse to take part?</p> <p>Whether or not they will be compensated?</p> <p>How confidentiality, anonymity, privacy will be maintained?</p> <p>How the data will be used/stored?</p> <p>Who will have access to the data?</p> <p>Who they can complain to if necessary?</p>	<p>your employer (if appropriate)?</p> <p>A copy of any research contract (if appropriate)?</p>
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**Appendix E: University of Southampton Research Governance Approval 26th August 2009**



Ms Gill Constable  
School of Education  
University of Southampton  
University Road  
Highfield  
Southampton  
SO17 1BJ

RGO Ref: 6683

26 August 2009

Dear Ms Constable

**Project Title The Experience of Caring for Someone with Dementia: A Biographical Approach**

This is to confirm the University of Southampton is prepared to act as Research Sponsor for this study, and the work detailed in the protocol/study outline will be covered by the University of Southampton insurance programme.

As the sponsor's representative for the University this office is tasked with:

1. Ensuring the researcher has obtained the necessary approvals for the study
2. Monitoring the conduct of the study
3. Registering and resolving any complaints arising from the study

As the researcher you are responsible for the conduct of the study and you are expected to:

1. Ensure the study is conducted as described in the protocol/study outline approved by this office
2. Advise this office of any change to the protocol, methodology, study documents, research team, participant numbers or start/end date of the study
3. Report to this office as soon as possible any concern, complaint or adverse event arising from the study

Failure to do any of the above may invalidate the insurance agreement and/or affect sponsorship of your study i.e. suspension or even withdrawal.

On receipt of this letter you may commence your research but please be aware other approvals may be required by the host organisation if your research takes place outside the University. It is your responsibility to check with the host organisation and obtain the appropriate approvals before recruitment is underway in that location.

May I take this opportunity to wish you every success for your research.

Yours sincerely

A handwritten signature in blue ink, appearing to read "L. Dalen", with a long horizontal flourish extending to the right.

Dr Lindy Dalen  
Research Governance Manager

Tel: 023 8059 5058  
email: [rgoinfo@soton.ac.uk](mailto:rgoinfo@soton.ac.uk)

## Appendix F: Confidentiality Form (Transcriber)



### CONFIDENTIALITY FORM

**Study title:** The Experience of Caring for Someone with Dementia:  
A Biographical Study

**Researcher name:** Gill Constable

*Please initial the box(es) if you agree with the statement(s):*

1. I agree that the information that I am transcribing will remain confidential, and that I will not discuss the contents of the interviews.

☐

2. While I am transcribing the interviews I agree to keep them secure on my computer and in my home.

☐

3. I agree to return all the verbal and written interviews to the researcher and to remove them from my computer.

☐



Name of the person transcribing the interviews (print name):

.....

Signature of the person transcribing the interviews:

.....

Name of Researcher (print name): .....

Signature of researcher: .....

Date: .....

## **SOURCES OF INFORMATION ABOUT DEMENTIA**

This leaflet gives sources of information about dementia. It has been organised into services, organisations and books.

### **Services and Organisations**

#### **Alzheimer's Society**

[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

This is the leading organisation for dementia in the UK. It provides information sheets about different types of dementia. There are also leaflets about assessing good quality care homes for people with dementia through the use of a check list. There is a help line.

#### **Dementia Advocacy Support Network International**

[www.dasinternational.org](http://www.dasinternational.org)

This is an international support network for people with dementia and their carers.

#### **Carers UK**

[www.carersuk.org](http://www.carersuk.org)

This is a comprehensive web site with information about resources including financial benefits for carers, as well as emotional and practical support.

#### **Princess Royal Trust for Carers**

Provides information and support to carers, and funds local Carers' Centres.

#### **Care Quality Commission**

[www.cqc.org.uk](http://www.cqc.org.uk)

This is the regulator of care services. You can obtain the inspection reports of different services via their web site.

#### **Care and Social Services Inspectorate Wales**

[www.cssiw.org.uk](http://www.cssiw.org.uk)

This is the regulator of care services in Wales. You can obtain the inspection reports of different services via their web site.

## **Counsel and Care**

[www.counselandcare.org.uk](http://www.counselandcare.org.uk)

This is a charitable organisation that works to support older people. There is a help line and information about all aspects of care for older people including residential and nursing care homes.

## **Social Care Institute for Excellence**

[www.scie.org.uk](http://www.scie.org.uk)

A Dementia Care Portal has been established on this web site, which is excellent it provides a wide range of information about the illness, best support practice, and the importance of environmental factors such as lighting, colours of decorations and furnishings for people with dementia.

## **Books**

**Bryden, C. (2005) *Dancing with Dementia*. London: Jessica Kingsley**

This book is written by a person with dementia, and gives an insight into the illness. It is positive and hopeful.

**James, O. (2008) *Contented Dementia*. UK: Vermillion**

This book gives a particular approach that carers can use with the person with dementia that enables them to provide calm and reassuring support.

**Kitwood, T. (1997) *Dementia Reconsidered*. Buckingham: Open University Press**

This is a classic book that sets out a person-centred approach to meet the needs of people with dementia.

**Stokes, G. (2008) *And Still the Music Plays*. London: Hawker Publications**

This is an insightful book written by a psychologist using a case study approach to explain the behaviour of people with dementia. It comprises twenty-two different stories, and is highly accessible. It helps to explain puzzling behaviour.

## **Publishers**

Jessica Kingsley Publishers produce a wide range of practical and helpful books on supporting people with dementia that include art and creative approaches.

Hawker Publications produce books and a very accessible and interesting magazine 'The Journal of Dementia Care'. They also organise conferences about dementia, which are highly informative and focus on best practice.