

# Carers' Stories



Carers' Stories:  
Walking Alongside a Person with Dementia

By

Gill Constable

**CAMBRIDGE**  
**SCHOLARS**

---

P U B L I S H I N G

Carers' Stories: Walking Alongside a Person with Dementia,  
by Gill Constable

This book first published 2013

Cambridge Scholars Publishing

12 Back Chapman Street, Newcastle upon Tyne, NE6 2XX, UK

British Library Cataloguing in Publication Data  
A catalogue record for this book is available from the British Library

Copyright © 2013 by Gill Constable

All rights for this book reserved. No part of this book may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, without the prior permission of the copyright owner.

ISBN (10): 1-4438-5149-3, ISBN (13): 978-1-4438-5149-7

This book is dedicated to the carers that gave so generously of their time. They revisited events that were often emotionally challenging for them. Their motivation in doing so was so that we could learn from their experiences, so that the needs of people with dementia and their carers could be better understood and met.

I want to thank Gill Clarke and Melanie Nind for their scholarly guidance throughout the research process.

I am very grateful to my partner Isla Duncan for her constant support, patience, wisdom and encouragement, which has made the publication of this book a reality.



# TABLE OF CONTENTS

List of Figures and Tables .....	xi
Introduction .....	1
<b>Chapter One</b> .....	<b>5</b>
<b>Dementia, Ageing and Sexuality</b>	
Introduction	
Using Erben’s Schema of Biographical Research	
Prevalence of Dementia	
Conceptualisation of Dementia	
Ideologies of Ageing	
Contextualising the Experience of Being Lesbian or Gay	
<b>Chapter Two</b> .....	<b>27</b>
<b>The Concept of Caring</b>	
Introduction	
Developments in Social Policy	
Conceptualising Carers	
Theorising Carers	
<b>Chapter Three</b> .....	<b>39</b>
<b>Reflections on the Research Process</b>	
Introduction	
Research Approach	
Research Design	
Selection of Carers	
Biographical Research Method	
Interpretation of the Carers’ Stories	
Researcher as Guide	
Ethics as a Process	
Ethical Cost Benefit Analysis of the Research	
Self-Audit of Research Practice	

<b>Chapter Four</b> .....	65
<b>Carers' Stories</b>	
Introduction	
The Carers	
Profiling Individual Carers	
Ruth	
Susan	
Angela	
Nick	
Elaine	
Theresa	
The Experience of Caring	
Changes in Relationships	
Being Remembered	
Social and Emotional isolation	
Enduring Aspects of Relationships	
<b>Chapter Five</b> .....	85
<b>Coping Approaches</b>	
Introduction	
Approaches to Stress	
Carers' Beliefs about Caring	
Carers' Support Systems	
<b>Chapter Six</b> .....	97
<b>Carers' Encounters with Health and Social Care Services</b>	
Introduction	
Carers as Equal Partners in Care	
Carers' Capacity to Continue with the Caring Role	
Support Provided to Carers to Prevent Ill Health	
Carers' Choices and Involvement in Decisions	
The Quality of Support Provided to Carers	
Support that Carers Receive as their Role Changes	
Managing Transitions	
Summary	

<b>Chapter Seven</b> .....	113
<b>Messages for Practice</b>	
Introduction	
The Experience of Caring	
Coping Approaches	
Carers' Encounters with Health and Social Care Services	
Images as Metaphors of the Caring Role	
Messages for Practice	
Person Centred Practice	
Conclusion	
Bibliography.....	123
Index.....	135



## LIST OF FIGURE AND TABLES

- Figure 1-1: Biographical Schema for Carers
- Figure 1-2: Current Understandings of Dementia
- Figure 2-1: Couplehood in Dementia
- Figure 2-2: Activity Patterns Dementia
- Figure 2-3: Approaches to Caring
- Figure 2-4: Models of Carers of People with Dementia
- Figure 3-1: Conceptual Ethical Framework
- Figure 3-2: Cost Benefit Analysis of Research –Personal Impact
- Figure 3-3: Cost Benefit Analysis of Research –Interpersonal Impact
- Figure 3-4: Cost Benefit Analysis of Research – Community Impact
- Figure 3-5: Cost Benefit Analysis of Research – Political Impact
- Figure 3-6: Self-Audit of Research Process
- Figure 4-1: Period of Time Caring
- Figure 5-1: Approaches to Caring
- Figure 6-1: Caring at Different Stages
- Figure 7-1: Nick in the Role of Carer
- Figure 7-2: Ruth in the Role of Carer
- Figure 7-3: Theresa in the Role of Carer
- Figure 7-4: Elaine in the Role of Carer
- Figure 7-5: Angela in the Role of Carer
- Figure 7-6: Susan in the Role of Carer
- Figure 7-7: The Objective Researcher
- Figure 7-8: The Reflexive Researcher

### **List of Tables**

- Table 1-1: Prevalence Rates of Dementia According to Age
- Table 4-1: Personal Information about the Carers
- Table 4-2: Relationship to the Person with Dementia



# INTRODUCTION

This book focuses on the experiences undertaken by carers supporting someone with dementia. It has been written using a biographical approach of caring, which places caring within a social, cultural and personal context. It considers how change is managed and the coping strategies utilised; how carers developed their understanding of what is important in life, and made sense of their experiences. The role of health and social care services was reflected upon by the carers, who identified what was unhelpful, as well as supportive and effective practice and resources.

By hearing these stories we can enhance our knowledge and understanding of how to best support carers and by doing so support the person with dementia. The term carer is used to describe a family member or friend who is caring for someone based on their relationship rather than a paid carer. I have used a biographical or life story approach to frame the experiences of carers, as this is person centred and recognises the unique individuality of people. The audience for this book is anyone who supports a person with dementia in a paid or unpaid capacity, or has a role in the provision or commissioning of services and wants to understand better the legislative and policy context for carers, as well as the strategies that support people with dementia to maintain a sense of identity and wellbeing. Living alongside a person with dementia helps us to develop knowledge about what is really important in people's lives, including our own, and what gives joy and contentment. It challenges the notion that all care giving is a burden and that supporting people with dementia is tragic with dire consequences for the care giver (Netto, Goh and Yap, 2009).

This work is significant to me as I teach students who are training to be social workers. 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 many 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 in

England. 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 current 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 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.

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).

I wanted to understand about the lived experience of being an informal, unpaid carer, the coping approaches that family members or friends used; the resilience they developed to go on caring; their views of health and social care services, whether they felt partners in the co-production of care (Needham and Carr, 2012). I wanted issues of diversity to be reflected in terms of sexuality, so I ensured that I heard the stories of carers who 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 book. 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.

There is a 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 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. We will now explore the impact of dementia, the experience of ageing and sexuality.

# CHAPTER ONE

## DEMENTIA, AGEING AND SEXUALITY

### Introduction

This chapter explores dementia, ageing and sexuality. I have adapted Erben's (1998: 7) schema for biographical research, as this provides a framework that enables me to reflect on the lives of carers within their social, political, cultural and personal contexts. 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 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.

There is 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 will be addressed by examining the "cultural system, societal context and chronology" of caring (Erben, 1998: 7). In the following chapters we will then move onto the "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).

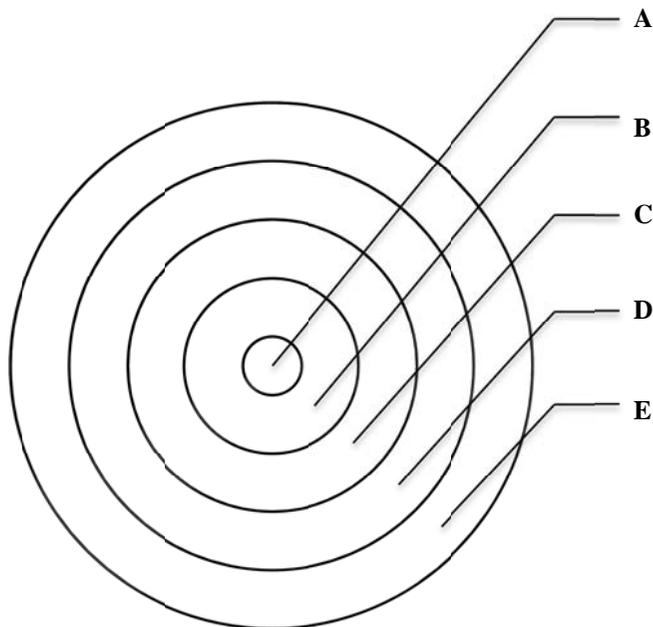
The importance of being present for the person with dementia "... letting go of the constant doing involved in dementia care and become involved in being with the person" to sustain a sense of their identity and well-

being (Mackinlay and Trevitt, 2012: 206). 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).

### Using Erben's Schema of Biographical Research

I have adapted the schema developed by Erben (1998: 7) to provide a framework to map the journey of people with dementia and carers. 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 1-1: 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 so we can review the:

- 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

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 1.1 sets out the prevalence rates of dementia that demonstrate the linkage between age and the illness.

**Table 1.1: Prevalence Rates of Dementia According to Age**

Age	Prevalence Rates
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 is 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).

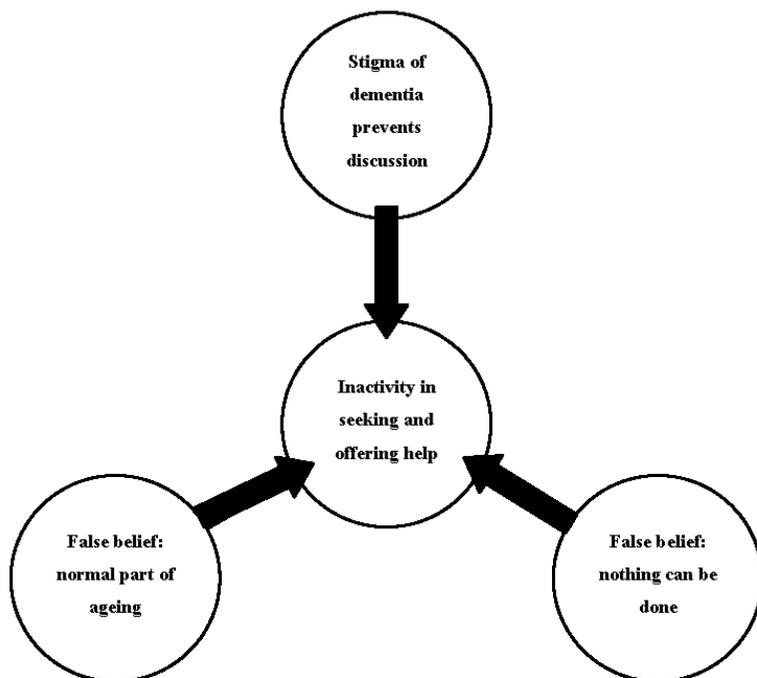
This leads to service shortfalls or provision that does not meet the needs of the person with dementia and their carer, such as a lack of diagnosis, and therefore inadequate or inappropriate treatment. Insufficient community-based services including respite care have led to early long term admission 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 is 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 also 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 1.2 that has been taken from the strategy.

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 misunderstanding 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

**Figure 1-2: Current Understandings of Dementia**

(Department of Health, 2009: 26)

for carers of people with dementia. The commitments include information and advice that are 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 is 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. We now move on to consider the impact of sexuality on identity.

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

Erben's Schema (1998) is again used to explore being a lesbian woman or a gay male as once more it allows us to reflect on the impact of societal context and cultural ideologies, and how these shape a sense of self 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 ‘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 does impact 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