



# CONTINUING TO CARE FOR PEOPLE WITH DEMENTIA

Irish family carers' experience of their  
relative's transition to a nursing home

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## **INFORMATION ON THE RESEARCH PARTNERS**

### **Bradford Dementia Group**

Bradford Dementia Group the academic Division of Dementia Studies at the University of Bradford is an internationally recognised centre for excellence in research, education, training and consultancy in dementia care. We work with individuals and organizations to improve quality of life and quality of care for people with dementia and their families.

### **The Alzheimer Society of Ireland**

The Alzheimer Society of Ireland is a national voluntary organisation and leading dementia-specific service provider in the country. Our mission is to work for and on behalf of people with Alzheimer's disease/related dementias and their carers to ensure they have the necessary supports and services to enable them to maximise quality of life, respecting the needs, rights and dignity of the individual.

**[www.alzheimer.ie](http://www.alzheimer.ie)**

### **St. Luke's Home**

St. Luke's Home is a church-based charity founded in 1872 to provide services for older people in Cork City & County, and beyond. It provides long-term residential care and day care (with specialisms in the care of residents with dementia). The policy of the organisation is to create a home-like environment where all residents feel safe, secure and supported. In recent years, the charity has also been seeking ways to expand its work beyond its current residential home.

**[www.stlukeshome.ie](http://www.stlukeshome.ie)**

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# EXECUTIVE SUMMARY

## Background

There are approximately 38,000 people with dementia in Ireland and a significant proportion of them will live in a care home for the last years of their life. Many carers, therefore, face the experience of placing their relative in a nursing home setting. This experience can be challenging for family carers both practically and emotionally. These difficulties are exacerbated by the commonly held myth that, following nursing home admission, family caring responsibilities cease. Given the key role that nursing homes play in long term dementia care and predicted increases in the proportion of people with dementia in the Irish population, there is a compelling need to explore the experiences of family carers in Ireland.

## Purpose

The purpose of this study is to describe carers' experience of the transition of their relative who has dementia to nursing home care. It is intended that this will provide evidence-based guidance for the development of initiatives to support carers. This aim is addressed by answering the following questions:

1. What are carers' key influences in making the decision for their relative to move to a long stay setting? Who is involved in making this decision?
2. What are carers' experiences of making the transition from caring for their relative at home to them being cared for in a long stay setting?
3. How has the family carer's role changed as a result of their relative's move to a long stay setting?
4. What types of roles do carers want to have?
5. How can carers be supported in these roles?

## Method

Research participants were identified and recruited by The Alzheimer Society of Ireland and St. Luke's Home staff. Principles of informed consent, anonymity and confidentiality were adhered to throughout the research for which ethical approval was granted. As the research aimed to explore the subjective experiences of carers, the study used a qualitative approach using both semi-structured, one-to-one interviews incorporating 'photo voice' method and focus groups. One-to-one interviews were conducted on three occasions with five carers. Two of these carers made the decision to pursue nursing home care and three of whose relatives had been admitted to long stay care in the previous four to six months. Three focus groups were also held in three regions of Ireland with an additional nine family carers, all of whose relatives had been admitted to a nursing home within the last four to six months. Interview and focus group data were transcribed and analysed in accordance with the grounded theory approach.

## Findings

The findings of this research were categorised under the five main research questions and further subdivided in order to reflect themes emerging from the fieldwork findings.

1. The key influences in pursuing long-term care were an accumulation of a range of contributory factors. This decision was most commonly a shared one, with professionals playing a key role in prompting the dialogue with family carers.
2. The process of transition was characterised by conflicting emotions. Carers experienced relief on the one hand and more painful emotions including guilt, bereavement and loneliness on the other hand. The intensity with which these emotions were felt was influenced by the nature of the caring relationship, the perceived attitudes of others and by the passage of time. Carers' adjustment to the process of transition was facilitated by their perceived quality of the nursing home setting, their familiarity with the setting and by the receipt of emotional and spiritual support.
3. The carers' role following transition was characterised by continuity on one hand and change on the other. Carers maintained continuity in their caring role by continuing to spend time with their relative and continuing to perform some practical tasks. The key change to their caring role was in monitoring the quality of care provided rather than being the main provider of this care. These roles took place in the context of changing relationships between the carer and their relative with some reporting improvements in their relationship while others said that they had difficulty maintaining their relationship with their relative. Changing roles also affected carers identity, with some feeling lost and bereft following the process of transition.
4. All carers' wished to be able to continue to participate in the long term care of their relative, and some expressed a desire to participate in the wider life of the care home. Some carers also saw the admission of their relative to a nursing home as an opportunity for them to resume their own lives.
5. Carers felt that their role aspirations could be fulfilled by establishing good lines of communication with staff, having information and education about dementia and dementia care and having ongoing emotional support.

## Discussion

For most carers, the decision to admit their relative to long stay care was a gradual one prompted by a realisation that they were unable to continue to care on their own. The experience of their relative's admission to a nursing home was mixed. While it led to relief from the 24-hour demands of providing care at home, it was accompanied by feelings of guilt and loss, and, particularly for spouse carers, the challenge of adjusting to their life without their partner at home. Carers wanted to continue to have a caring and familial role in their relative's life. To continue this role they required good relationships with the nursing home, an informed and supportive staff group, accessibility to the home, and information and education about dementia and dementia care.

## **Recommendations**

- The Department of Health and the Health Service Executive need to significantly enhance the resourcing of, and access to, community based services for people with dementia and their carers, so that nursing home admission is a proactively planned choice rather than being crisis-driven.
- The Department of Health and the Health Service Executive must recognise that people with dementia and their carers need guidance and support in order to navigate the system and when accessing services both at the pre and post transition stages.
- The Alzheimer Society of Ireland in partnership with other agencies needs to challenge the ignorance and stigma associated both with dementia and with nursing home care.
- Community based practitioners (General Practitioners, Public Health Nurses, Social Workers, Psychiatrists of Later Life) should adopt a persuasive, proactive and preventative approach to people with dementia and their families through the prompt and gradual input of appropriate support.
- Managers of nursing homes need to ensure the provision of dementia specific training and education of their staff in order to promote the provision of quality care which upholds the dignity and humanity of the person with dementia.
- In accordance with HIQA National Quality Standards, nursing home managers and staff must recognise and actively support carers who wish to remain involved in the care of their relative, while respecting the wishes of those who no longer want to play such a role.
- Nursing home providers, the Alzheimer Society and other relevant service providers and agencies need to provide information, education and emotional support to carers at the various stages of the transition process.
- Researchers need to examine this area in greater detail.

# CHAPTER 1: BACKGROUND

## 1.1 Scale of the issue

There are approximately 38,000 people with dementia in Ireland (ASI, 2007) with the vast majority of them (75 per cent) living at home. Family care accounts for over fifty per cent of dementia care provision (NESF, 2005). Many of those living at home have never been formally diagnosed. In addition, the person with dementia often does not come into contact with health and social services until a crisis occurs involving the person with dementia or their carers (O'Shea, 2007). Due to the progressive condition of dementia combined with limited access to support services, the carers of people with dementia often face great demands (Twigg and Atkin, 1994). Consequently, many family carers will face the transition from caring for a relative at home to placing them in a long stay setting. Existing research suggests that this transition can trigger strong emotional reactions and can also be an uncertain and unfamiliar terrain to navigate (Groenewoud and Lange, 2009). For example, Anehensel and colleagues (1995) conducted a longitudinal study with carers of people with dementia in the US. They followed 555 carers over a three-year period with annual interviews and found that almost all carers had concerns about placing their relative in a long stay setting.

## 1.2 Policy context

The stated objective of public policy with respect to the long term care of older dependent people in Ireland since the end of the 1980s has been to allow people to live in their own homes for as long as is possible and practicable. However, O'Shea's analysis (O'Shea, 2007) points to the fact that the ability of dependent older people to remain in their own homes has been compromised by the failure of successive governments to allocate sufficient resources to community care. O'Shea's contention is that the weakness of community care has affected the wellbeing of people with dementia living at home and the lives of families. Only six per cent of the cost of dementia in Ireland is attributable to community care services and in contrast, nearly one third of the burden of care is attributable to residential care (O'Shea, 2007).

The Action Plan for Dementia (O'Shea and O'Reilly, 1999) represented the blueprint for the strategic development and investment needed to meet the needs of people with dementia and their carers in Ireland. Despite some initial improvements, progress on implementing the Action Plan for Dementia has been slow and the resources needed to implement it have not been forthcoming (O'Shea, 2006). Moreover, unlike many other European countries, including England, Scotland, Norway, France and the Netherlands, there is, as yet, no national dementia strategy in Ireland.

## 1.3 Legislative and Regulatory Context

In Ireland, many family carers are struggling with the role and are often isolated, experiencing negative health and well-being and living in poverty (O'Sullivan, 2008). However, there is no specific carers' legislation in Ireland and carers' needs assessments are not a feature in the caring landscape, as is the practice in many other countries. In 2008 the Irish Government withdrew its commitment to publish the National Carer's Strategy thus denying the opportunity for recognition of carers' contribution, the provision of a legislative framework or securing investment in carer supports. Meanwhile, new legislation was introduced in late 2009 to address the funding for individuals needing long term care. This legislation referred to as 'Fair Deal' (HSE, 2009) and the issues that it

raised went to the heart of attempting to address the social policy principles of equity and fairness of access. However, it also established the principle that every person who needs long term care will make a contribution to the cost of their care. This essentially places the onus of responsibility onto the individual, with the state providing support where necessary. It still remains to be seen what impact this new legislation has on the payment for long term care as it is still in its infancy.

The need for greater regulation and protection for older people living in nursing homes has been a major topic of public discourse in Ireland with a number of high profile elder abuse cases and investigations emerging in the media. In relation to the regulatory environment, nursing homes in Ireland are required to be registered and in order to register they must comply with a range of regulations. In addition, the recently established Health Information and Quality Authority (HIQA) published the National Quality Standards for Residential Care Settings for Older People in Ireland in 2009 (HIQA, 2009). These standards set out what a quality, safe service for older people living a residential care setting should be. They clearly point to a role for the continued engagement of the family carer in the care of the person in the nursing home and making the nursing home responsible and accountable on a whole range of care planning, environmental and staffing as well as management issues.

## **1.4 Influences on the decision to admit a relative**

Key influences on making the decision to admit a relative to long term care have been identified by a number of studies including round the clock demands, the strain of caring, conflicting work and family responsibilities as well as health problems (Dellesega and Nolan, 1997; Twigg and Atkin, 1994). Lack of support from family and from professionals has also been cited (Edge, 2007). In Ireland, community support services for people with dementia, such as respite care, are both under-developed and fragmented (O'Shea, 2007). This includes restricted opportunities for respite care (Carers Association, 2005). This reality has often led to premature and inappropriate placement of the person with dementia to nursing home care. There is an added cultural nuance that family carers in Ireland face in relation to deciding to admit their loved one to nursing home care, that is, the perceived stigma of them 'ending up' in a nursing home. This perception has its origins in the historical poor house laws and the fear of the stigma of the 'county home' (Burke, 1987).

## **1.5 Experience of the transition**

Once the decision to place a relative in a long stay setting has been reached, the process of finding a suitable facility and preparing their relative for a move begins. As family care is not only a practical task but also takes place within the context of emotional bonds, long standing relationships and reciprocity (Dalley, 1988), this process often occurs against the back drop of strong emotions and conflicts. Kellett (1999) conducted a qualitative study with 14 carers in Australia who had experience of recently placing a relative in a long stay setting. She identified the tension carers experience, often feeling guilt, sadness and relief all at once. Similarly, in their qualitative study of 26 family caregivers in the Netherlands, Groenewoud and Lange (2009) found that the process of transition was commonly accompanied by feelings of 'fear and dread' amongst research participants.

These feelings can be compounded by the attitudes of others, for as Davies (1995) observes, carers are encouraged to care for their relative at home for as long as possible, through policy, social norms and for economic reasons (Davies, 1995). This can lead to a stigmatisation of long term care and a sense of failure in carers who have made the decision to pursue this option (Victor, 1997). In order

to minimise these feelings, Kellett (1999) found that carers sought a legitimate reason for placing their relative in a long stay setting, sanctioned by health professionals. Similarly Dellasega and Nolan (1997) found that carers felt they had to admit defeat by regarding the placement as being unavoidable. Against this context of emotional turmoil, carers have to negotiate the practicalities of the impending transition, often finding this process to be unfamiliar, uncertain and often embarked upon with very little practical or emotional support from professionals (Rosen et al, 2003; Dellasega and Nolan, 1997). Carers also experience a loss of control and a feeling of disempowerment and are often forced into what they view as a 'negative' choice (Kellett, 1999). While the fact that the decision to place a relative in a long stay setting commonly comes as a result of a crisis (Dellasega and Mastrian, 1995) little time is left for choosing the right setting for making plans.

## 1.6 Post admission

Following transition, in spite of the removal of many of the practical 'burdens' of caring, carers experience many of the same conflicts felt before transition (Kellett, 1999). Dellasega and Nolan (1997) also found that some carers felt lonely and lost without the intimate connection with their relative. Relatives' admission to a long stay setting did not reduce carer depression and anxiety despite the fact they had more leisure time. Adjustment by carers in the post-transition phase is a dynamic process and Woods et al (2008) describe four stages that carers go through after their relative has been admitted:

1. guilt and loss
2. the building of trust
3. increasing confidence in negotiating with staff
4. spouses begin to build their lives around their relative's care and adult children start to develop other areas of their lives

Relationships between care staff and family carers can be fraught during this post transition period. Often care staff have little understanding of the emotional turmoil carers are experiencing. They frequently complain that carers are critical of the care that they offer and what is possible for their relative, without taking account of the distress that lies behind these complaints (Woods et al, 2008).

In spite of the erroneous assumption that family care ceases following care home admission, often carers remain involved in the care of their relative (Edge, 2007; Woods et al, 2008). Carers report carrying out similar tasks to when their relative was living at home including managing money, arranging medical care, transportation and providing social support and physical care. Davies and Nolan (2006) found that this continued caring role tended to be characterised by three components:

- maintaining continuity through visiting
- monitoring care
- contributing to the wider care home community

Carers also take on new tasks as a result of their relative's placement. These tasks include creating a homely environment in the care setting and communicating their unique insights to staff (Woods et al, 2008). These unique insights can enable staff to provide person-centred care for the person with dementia by recognising and responding to their individual needs and preferences (NICE/SCIE, 2006). Family care arises from the bond between carer and cared for (Aneshensel et al.,1995) and, with very few exceptions, carers *care about* (Graham, 1983) their relative, regardless of whether they are *caring for* them through the provision of instrumental care. The stress of witnessing someone

close decline continues after placement in long-term care, but can be exacerbated if their care is not as the relative would wish it to be, and if feelings of guilt and distress about separation persist.

Research has suggested that carers in different countries have different experiences and expectations following the placement of their relative. Davies and Nolan (2004) conducted interviews with 54 carers from the US and 48 carers from the UK. They demonstrated that carers in the US faced greater conflict after admitting their relative to a long stay setting and found it harder to relinquish control. Carers in the UK however, were happier to pass control over to staff. Similarly, a recent study comparing the experiences of the families of dementia care home residents across Europe (Woods, et al, 2008) identified systematic differences in expectations between carers in Sweden, Wales, Ireland and the UK. This study found that Irish carers tended to have relatively low expectations of what support should be available to the resident in a nursing home and needed relatively high levels of support to become involved in these settings. It has also been documented from research in the US and UK that nursing homes often fail to adequately engage carers (Dellasega and Nolan, 1997).

## **1.7 Facilitating carers' involvement**

In order to encourage greater levels of involvement amongst carers in the post transition phase, Woods et al (2008) cite a number of relevant initiatives including groups for relatives and staff (Pillemer et al, 1998), collaborative working (Aveyard and Davies, 2006) and the implementation of relationship centred care (Nolan et al, 2006). Groenewoud and Lange (2009) make similar recommendations which aim to ease the experience of transition for people with dementia and their relatives. However, in spite of the insights and recommendations of existing research on family carers experience of their relative's transition to a long stay setting, the needs of such carers still tend to be neglected by practitioners and policy makers (Edge, 2007). Moreover, existing research in the area tends to focus on retrospective reports of carers experience (Zarit and Whitlatch, 1993) while, with the exception of the work of Woods et al (2008), published research on the specific experiences of carers in Ireland has been lacking.

## **1.8 Purpose of the study**

The purpose of this study is to describe carers of people with dementia experience of their relative's transition to nursing home care and to provide evidence-based guidance for the development of initiatives to support carers going through this process. In addressing these aims the following questions will be addressed:

- What are carers' key influences in making the decision for their relative to move to a long stay setting? Who is involved in making this decision?
- What are carers' experiences of making the transition from caring for their relative at home to them being cared for in a long stay setting?
- How has the family carer's role changed as a result of their relative's move to a long stay setting?
- What types of roles do carers identify they want to have in caring for their relative in long stay settings?
- How can carers be facilitated, supported and enhanced to ensure this is fulfilled?

# CHAPTER 2: RESEARCH METHODS

## 2.1 Design of the study

As we were concerned to elicit the experience of family carers, the study used a qualitative research design using in-depth interviews and focus groups to explore carers' views. In order to elicit carers' experience of their relatives' transition to a long stay setting, a qualitative and participatory research design was used, providing the opportunity to generate unique and rich or thick data. Semi-structured interviews thus allowed us to flag up, explore and probe carers' views on a range of topics, eliciting meanings attached to people, places and events. Participatory research also places the participant in an integral role within the research, as such redressing potential power imbalances between researcher and researched (Glaser and Strauss, 1967).

In this study 'photo voice' methods were used to empower carers to have control over which aspects of their lives are focused on in the final interview. 'Photo voice' is a relatively novel research method which has been used with carers of people with Huntington's disease (Aubeeluck and Buchanen, 2006). The approach facilitates collaboration and deepens the shared understandings between the researcher and researched (Ramella and Olmos, 2005). It involves two key stages, firstly, participants take photographs that represent their experience, secondly these photos are used in a face-face interview to elicit the meaning that these photos have for participants. As such the carer sets the agenda for the interview has the opportunity to explore in depth the issues that were pertinent to them (Baker and Wang, 2006). Participants were asked on the final interview for feedback on the initial data analysis in order to refine our understandings of their experiences. Themes were further pursued with three focus groups with carers at the post-transition stage. These provided participants with the opportunity to collectively construct concerns and experiences (Bryman, 2001).

## 2.2 Recruitment and consent

The Alzheimer Society of Ireland and St. Luke's Home staff identified potential carers from those who access their services. They approached carers in person and explained the study to them and gave them an information leaflet outlining details of the study and relevant contact information (See Appendix A). A few days after explaining the study to them, staff approached the carers either through a face-to-face visit or by a telephone call to ascertain if they were interested in participating in the study. Staff asked interested carers to sign the consent form (see Appendix B). If carers were contacted over the phone the consent form and a stamped addressed envelope was posted to them.

## 2.3 Sample

Fourteen carers were selected to reflect diversity with respect to their age and their relationship to the person they care for. The majority of the sample was female. Spouse carers, sibling carers and adult children carers were represented (Blackwell et al, 1992). All respondents had made the decision to pursue long stay care for their relative and the majority of the sample, twelve, had already undergone this transition in the last four to six months, the remaining two were still waiting for a suitable long term place to become available. Full details of the inclusion criteria are as follows:

- A family carer for a person with dementia (ie. the person who offers the most support to the person with dementia prior to their admission to a long stay setting).

- The decision had been made for the person they care for to move to a long stay setting.
- For those carers who had already experienced the transition to long term care, this transition should have taken place in the last 4-6 months.

All of the participants in this research had relatives who were going to live in a nursing home or who were already a nursing home resident. However, many of the findings of this research are equally applicable to other types of residential care settings. As a reflection of this, the generic terms of 'long-term care', 'care home' and 'long stay care' are sometimes used in this report to refer to the care setting.

**Table 1 Characteristics of family carers (n=14)**

<b>Gender</b>	
Male	4
Female	10
<b>Relationship to relative with dementia</b>	
Spouse (Husbands)	4 (3)
Siblings	2
Adult child (Daughters)	8 (6)
<b>Interviewed</b>	
Prior to admission	2
After admission	12
<b>Form of data collection</b>	
Interviews	5
Focus groups	9

## 2.4 Data collection

### 2.4.1 Interviews

Five carers were selected to take part in one-to-one interviews, two of whom had not yet undergone transition while, for the other three, transition had taken place within the last four to six months. In order to incorporate a longitudinal perspective and to give the opportunity to explore emergent themes, carers **were** interviewed on three occasions: face-face, by telephone and then face-face. Face-face interviews with carers were structured around the five research questions and the themes emerging from these (see Appendix C for interview schedules). In addition, at the time of the initial interview, carers were provided with a camera and asked to take photos over the coming three weeks and to give each photo a title and provide a brief narrative explaining how this image communicated their experience. They were then asked to select four of these images for discussion in the final interview, thus providing carers with the opportunity to direct the interview.

Semi-structured telephone interviews were conducted with carers several weeks after the initial face-face interview exploring how things had gone since the initial meeting. On the third interview, carers were asked to discuss their four key photos, to explain why they have chosen these four and what they communicated about their experience. In cases where the carer had not had the opportunity to engage with the process of taking photos, they were questioned on what picture they would have liked to have taken that best communicated their experience. In addition, carers were shown the themes derived from transcripts of their previous interviews and asked for comments. All interviews were digitally audio-recorded.

#### **2.4.2 Focus groups**

Nine carers attended one of three focus groups taking place in three different regions in Ireland. All had relatives who had undergone transition to care in the last four to six months. The focus group explored the five research questions (see Appendix D for focus group topic guide). Focus groups were facilitated by two researchers and were audio digitally recorded.

### **2.5 Data analysis**

Interview and focus group data were transcribed. In accordance with the principles of grounded theory, data were analysed using the 'constant comparative method' prior to subsequent data collection allowing us to test emergent themes in subsequent interviews (Glaser and Strauss, 1967). Case studies were compiled from the carers interviewed and are used to illustrate the key themes which emerged.

### **2.6 Ethics and research governance**

Ethical approval was granted from the University of Bradford and participants and data were anonymised and treated in accordance with ethical practice. Pseudonyms are used in the report in order to protect the anonymity of participants.

## CHAPTER 3: FINDINGS

Findings are presented according to the research questions posed.

### 3.1 What are carers' key influences in making the decision for their relative to move to a long stay setting? Who is involved in making this decision?

Key influences in making the decision

1. Demands of caring:
  - 24-hour demands
  - providing personal care
2. Declining health:
  - of the carer
  - of the person with dementia
3. Lack of support:
  - formal support
  - informal support
4. Conflicting roles and responsibilities
5. Independent financial means
6. Who is involved in making the decision

#### 3.1.1 The demands of caring

Much research has highlighted the stressors arising from caring. All of the carers cited caring demands as a key factor influencing their decision to pursue long-term care.

##### 3.1.1.1 24-hour care

Carers experienced 24-hour care demands both because of providing personal care but also because of concerns over their relative's safety issues, as two co-resident carers recounted:

*I couldn't really leave him at all, I couldn't go into a shop to look around. I had to stay with him all the time. (wife)*

*I couldn't do anything with him, he was there constant, constant, constant. Took him everywhere. (wife)*

*It was just getting too dangerous. She was running out the door and not giving me any word and we had to lock all our doors. (husband)*

Round-the-clock demands were also apparent amongst respondents who did not live with the person with dementia:

*I could be at home and think everything is rosy in the garden and then my phone would ring and it was one of the carers...I could never sit down and say its my time I was on call 24/7... with mobile phones your available 24/7. (daughter)*

*There was one night when he went out in the middle of the night and eventually a taxi man brought him to a police station. (son)*

*It was a hard decision but I felt it was the right decision for her that she had to be placed somewhere she was safe and secure. (daughter)*

### 3.1.1.2 Providing personal care

24-hour demands did not only arise from concerns over safety issues but also due to the need to provide round-the-clock personal care, particularly relating to continence:

*And we'd have to go into him and bring him into the bathroom or change him. Change the bed or whatever the case may be. So it was coming to the stage we weren't even getting a wink of sleep for the night you know. (daughter)*

*I'm up three or four times a night because she's really gone incontinent now. (sister)*

In addition to its relentless nature the strain arising from the performance of personal care was sometimes exacerbated by the incidence of aggression when these tasks are being performed. For example, one woman regularly had problems in performing these tasks due to the resistance of her sister who had Picks Disease:

*She gets very aggressive and she gave me a slap across the face. (sister)*

As one filial carer recognised, this resistance, may have been due to the fact that her father was embarrassed or lacked understanding:

*I had terrible problems with his personal care, very hard washing him, very hard shaving him... His grooming was 100 percent I cannot give him that 100 percent because he doesn't allow me to I can understand in a way is it that he has got some insight and he's embarrassed or is it he just not understand. (daughter)*

The performance of this personal care to a parent tends to run counter to prevalent social norms and was therefore also difficult for carers themselves:

*I always remember being in the bathroom with my mother and having to try to put on the incontinence pads and having to deal with her lower area and it was just alien it took more out of me than it did her to be honest. (daughter)*

While the major reported stresses of caring were concerned with 24 hour demands and personal care, the performance of other practical tasks were also occasionally cited. For example, once respondent who cared for both of her parents, spoke of the burdens of shopping for them:

*Myself and one of my brothers we shared doing the grocery shopping because with the two of them home full time and all of the people coming in and out, a full grocery shop, because there was tea being made all day when home helps come....so there was a huge load of work besides just the actual being there. (daughter)*

### **My Story: My washing machine**

**“**The most worked item in the house, washing every day, sometimes on a bad day it could be three washes. Doesn't sound like a lot but when you're doing it daily, it is.**”**

### 3.1.2 Declining health

Related to the strains of caring are declines in the physical and mental health of the carer and cared for person, for these declines will in turn make the caring role progressively more onerous to perform.

#### 3.1.2.1 Of the carer

Several respondents spoke of declines in their own health thus highlighting the two-way causal relationship between health and care giving. Some spoke of physical problems arising from the demands of their caring role. Mental health problems such as stress and depression were also alluded to:

*I started getting the pain down my arm that I had before, it's just all stress related because I'm just not able for her any more. So I went down to my doctor on Friday and I just told her I can't do it anymore. (sister)*

*I think I have suffered as well you know. I think my health has suffered...it was darkness and despair, that's what I felt despair and I thought how long can I cope with this. Really and truthfully (daughter)*

#### 3.1.2.2 Of the person with dementia

The declining mental and physical health of the person with dementia was also commonly cited as a reason for seeking long term care. This decline was often seen as inevitable and was exacerbated by the inadequacy of formal support services which implicitly seemed to share this assumption. Thus one respondent referred to the way in which her husband was denied access to rehabilitation during a hospital stay:

*You know they were fulfilling their job function, they were caring for the patients. And it was also a rehabilitation unit so they were more concerned with rehabilitating the ones that were able to be rehabilitated. The geriatrician said my husband isn't being rehabilitated. He won't make any progress, which I thought was a bit harsh because he did make some progress while he was there in walking and so on. But I suppose ultimately he was going to deteriorate. (daughter)*

While onset of dementia tends to be a gradual process, for many carers the impact of this decline in health was often experienced relatively suddenly. For some this was due to a spouse 'covering up' their partners increasing confusion prior to their diagnosis, as a daughter said of her parents:

*She died two and a half years ago but I think he had the Alzheimer's before that but my mother used to do a lot and cover up I suppose. (daughter)*

Similar concealment was also reportedly exercised by the person with dementia themselves:

*He had a great ability to kind of hide the confusion. (son)*

Health crises resulting in hospitalisation were also cited as initiating the process of transition. For example, a spouse carer felt that her husband's nursing home admission was imposed as a result of his hospital admission following an accident:

*So it wasn't really a question of making a decision about him going into care, it was more or less forced on me. (wife)*

The corresponding perception that nursing home admission was unavoidable was commonly expressed and appeared to help reconcile the carer with the challenges faced in the subsequent process of transition. Thus a daughter caring for her father said that his admission was inevitable following the hospitalisation of his wife upon whom he relied:

*It kind of fell into our laps unfortunately when my mother fell and I just said this is it, this is what's going to happen... One or two of my siblings said well maybe we could manage them a bit longer at home, maybe we could do this maybe we could get someone else to come in but you know I knew in my heart and soul that I couldn't have continued much longer. (daughter)*

### My Story: My sister's respite care

“ I'm glad my sister is going to respite care on Friday for ten days. I really need a break as I did not get much sleep at night. I know that I won't be able to look after my sister myself for much longer. I just feel the need to look after my own health and my marriage. ”

### 3.1.3 Lack of support

#### CASE STUDY 1:

##### Problems in accessing formal support

Following the death of her mother, Alison's father became increasingly confused, leading to a progressive intensity of her caring role. Maintaining his safety became particularly problematic leading to 24/7 demands. As a result of these demands she gave up her job and became increasingly isolated and depressed. However, until recently, she was unable to access formal support from home carers or respite provision and in spite of the demands of her role she was turned down in her application for carers' allowance:

*I really felt strongly that they didn't give me the support I needed.*

After a long struggle and contact with GPs and local politicians, she now receives regular respite care and hopes that her father will soon be allocated a permanent place in the respite care setting. She feels very strongly that as a carer, she should have got more help and support and feels that services for older people are inadequate:

*I feel that I have been cut off socially, financially it's harder, socially it's harder, everything's harder, yes and I think you get tired. You get very tired. I think if in the beginning if I had the right information, the right support then it would have been easier.*

As a consequence, she plans to engage in political lobbying and campaigning aiming to redress this issue:

*What I would do is I'd have more time on my hands, I would actually give something back.*

#### 3.1.3.1 Lack of formal support

While for some respondents, receipt of respite care could facilitate the subsequent process of transition to long term care, for others, the lack of access to formal support was a key determinant in initiating this transition with some being unsuccessful in accessing any type of help:

*I don't have no help with him. I don't have a home help to help with showering, personal care or anything. He doesn't go to a day centre nothing. (daughter)*

In addition, most experienced problems in understanding and negotiating the system of formal support and in some cases the perceived inadequacy or inaccessibility of domiciliary support influenced their initial decision to pursue nursing home care:

*They were cutting back in the care full time they were cutting back. So I mean it would have been harder and harder to manage them at home and none of the family were getting any younger, it was getting harder and harder on us to give them the level of care that they needed and deserved at this stage of their life. (daughter)*

This confusion was exacerbated by the fragmentation of provision, bureaucracy as well as by cutbacks in formal support services:

*The red tape was unbelievable and in the end you were just exasperated. That all you were looking for was a home help and yet you had to fill out form after form and in the meantime your mother is going downhill. (daughter)*

Formal services were also highlighted as being inadequate in supporting the carer as well as the person with dementia, as a spouse carer described:

*One of the things that I felt very much was that there was no support before my husband was diagnosed with Alzheimer's disease.... Whether I should've done something to contact the Alzheimer's Society I don't know. But I didn't feel in a position to do it because he hadn't actually been diagnosed. (wife)*

She went on to compare the support she received as the carer of a person with dementia to those experienced by carers of cancer patients:

*For about two months he was admitted into day care which cares for cancer patients. And as soon as he went there we were told that the relatives would have a meeting with staff and they discussed with us possibilities of care and so on....when he was diagnosed with Alzheimer's and went into hospital there was no care for the relatives that you could basically say. (wife).*

One daughter described how the lack of formal support had made her toughen up:

*I'm afraid I've got tougher with people and I'm not as gullible as I used to be which may be a good thing in one way...when you have to fight the powers that be who have only their own interest at heart in that they don't have this compassion for the elderly person. (daughter)*

The greater availability of specialist dementia care home provision was sometimes alluded to, with many respondents having to wait months or even years for a suitable place to become available, even after their relative's eligibility for such a place had been confirmed. With regard to the general adequacy of formal support services at the pre and post transitional stages, better resourcing of dementia care services was a recurrent theme:

*I think basically the system is overloaded you know. The health visitor did the best she could. As soon as he got into the home that was it you know, she was finished with us. (wife)*

*You see carers will do so much. People in and out but there are gaps, there were gaps and with the cutbacks as you know we've no health service practically here at the moment. (daughter)*

The lack of availability of advice and guidance in accessing support for the person with dementia at the pre-admission stage had also made a lasting impression on respondents with most feeling that improvements could be made in this area:

*What I think would be helpful is when people are approaching the stage of their partner entering residential care is to be able to hear clearly the options. (wife)*

Most also felt that greater recognition and support for specifically targeted at the carer should be provided by formal sources during the process of transition. These thoughts were particularly strongly expressed by a spouse carer whose husband had a dual diagnosis of cancer and dementia:

*If you've got cancer, you got that advice and care and an interview and a follow-up to see how you were getting on but there wasn't anything for the other side of the medical system... So the Alzheimer's Society could provide support for carers and find out if they do need more support. (wife)*

She felt that these omissions should be addressed by organisations such as the Alzheimer's Society and by the wider availability of information:

*I think that there could be a system whereby someone puts leaflets or books in the waiting room supposedly to help the carers. (wife)*

However, apart from suggesting the greater availability of relevant information, she was not able to recommend any other means by which this goal would be achieved:

*I think it would be good if there was more care for the carer in some way, I'm not quite sure how. (wife)*

Many respondents spoke of the need for support:

*I feel I haven't had the support that I should have had. (wife)*

Thus, as it has already been seen, several respondents had felt their needs as carers had been neglected by relevant professionals:

*I felt there was very little or no support for carers when I was going, taking him to the hospital to see the geriatrician, it was just for him, there was absolutely no support for me. I'd like the Alzheimer's Society to do something about that. (wife)*

One carer spoke of the desirability of a more universalistic system of service provision that did not require means testing or the use of private funds in order to gain access:

*I mean it should be like Denmark or these northern countries where they just have a standard health system ...no questions asked you know if you have the disease or whatever it is you're entitled to it and you get in...if you've to pay for it with your taxes being slightly higher so be it if you know you're going to get looked after its worth paying isn't it. (daughter)*

Another respondent referred implicitly to the ageism that characterised contemporary society and the correspondingly low priority given to services catering for older people:

*You're talking about people that supported their countries all their life, be it one way or another, work or whatever way they've done it. A lot of them went to England years ago they sent money back to their families to support. So these people have worked, brought up their families they've contributed to society..but when they need security and safety where can they go. (daughter)*

She went on to suggest the need for better resourcing for dementia care services as well the promotion of greater public awareness and professional training in dementia related issues:

*How many people are there out there that are not even diagnosed. I mean I wasn't diagnosed straight away with my dad, so how many other people have gone through the net, its frightening and I think the government needs to take more part in it and the public need to be more aware...but I think its ignorance, I think there's a lot of ignorance out there and I think there needs to be more training, the nurses need to be trained. (daughter)*

In order to play a role in raising the profile of these issues she planned to be involved in fundraising activities for her father's nursing home setting and was already involved in soliciting the support of local politicians. She thus recalled her conversation with a politician who was canvassing in her locality:

*I said "if I vote for you what are you going to do for me". I introduced them to my dad I said "this is my father. My father suffers with Alzheimer's. I care for him 24/7 and when I say 24/7 I mean 24/7. I have nothing. I have no income no nothing". (daughter)*

### 3.1.3.2 Lack of informal support

In the welfare partnership between the family and the state, informal sources help to supplement or even replace formal welfare services. This was apparent not only in the role of primary carers in this research but also from the help they received from their own networks of family friends and neighbours. For example, one carer could not have continued her caring role had it not been for the support of her four siblings all of whom lived locally and who participated in a rota system to provide 24 hour care for their parents. However, after several years in sustaining this routine, things started to break down:

*We were all arguing with one another because you know people felt I'm doing more than you and you're not pulling your weight. (daughter)*

Another respondent felt unwilling to overburden his daughter with responsibility for his father's care:

*She was great but we always felt when we were doing something or going away, just leaving her in charge was a very onerous thing to do. (son)*

For another carer, a complete lack of support from these sources contributed to her decision to pursue nursing home care for her mother for whom she cared, in spite of the fact that she lived in her brother's house:

*We tried to get a home help but my brother and wife didn't want a home help in their house because it was an annex of their house where my mother was living and they felt it an invasion of their privacy so that's where it just had to be a nursing home then really after that. (daughter)*

Even though she had six siblings who lived nearby as well as a job, another carer also found herself lacking support from her family and by the person with dementia's own children:

*There's nobody else because no one else will do it. Nobody wants to do it because my sisters said they won't take it on. No one else will do it you see. (sister)*

These cases highlight the fact that while informal networks can be a great source of support for carers, they can also be a source of conflict.

### 3.1.4 Conflicting roles and responsibilities

Older spouse carers in the sample tended to experience a high degree of satisfaction from caring due to the lack of conflicting work and family responsibilities and an emotional, practical and material interdependence in the caring relationship. For younger carers, conflicting demands were often cited as a factor influencing the decision to pursue nursing home care.

*It was taking its toll on the five of us and the family because four of us are married. We all have children, partners, husbands, wives, whatever. We all have jobs and it had just taken its toll. (daughter)*

Some reported giving up their jobs to accommodate their caring, leading to financial hardship and isolation:

*I couldn't work because how could I work, so I gave up work. (daughter)*

Others reported strains on their marriage:

*I was the main carer really even though I wasn't living with her. I had to go down on a regular basis to her...and then that would ricochet onto my own relationship with my husband. (sister)*

Other potential strains on family members were described, with one respondent reporting on a conversation with a public health nurse:

*She [the public health nurse] said you cannot go on like this she said and at the end of the day your daughters will resent you by having him here...so you need to think about full time care. (daughter)*

### **My Story: My children**

**“** I have two children and always felt that I was neglecting them, I was torn between their needs and my father's needs. **”**

The manner in which these contributory factors are interrelated is exemplified in the following:

*I am 100 per cent sure because I know I have no choice, you see I know at the end of the day I cannot do this long term I have no choice. I've got the girls to think about, I've got myself to think about and I've got to think what's best for him. (daughter)*

#### **3.1.5 Independent financial means**

Due to its impact on the carer's ability to take on paid employment, caring is associated with financial sacrifice and hardship for which benefits do not always compensate. For example, a family carer who cared for her sister gave up her job but was then refused carers' allowance as a substitute income:

*I wasn't entitled to it on the grounds that I'm not giving (my sister) enough care and attention which I thought wasn't a bit fair with all I did. (sister)*

In addition to loss of earnings are the 'one-off' and 'recurrent' costs faced by carers such as home adaptations and home care fees:

*We had been talking about putting a lift in. (daughter)*

Financial resources provide a 'leverage' which carers can use to ease the demands of caring. Some carers spoke of the way in which their lack of money undermined their choice in the type of respite care available to them:

*We would have loved to put her in the other one but we couldn't afford it. (sister)*

Limited access to funds were also a major factor in influencing when the transition to nursing home care took place with the majority of respondents having to wait for a publicly funded bed to become available. Such financial concerns were expressed by a spouse carer for her husband's future placement:

*At one stage my main worry was the finance of the whole thing because I just didn't know if he would get a place here, whether we would need to find money for another private home which would have been very expensive. And even when he was coming here I didn't know at first how much it was going to cost. (wife)*

This respondent was eventually successful in obtaining a publicly funded place:

*We pay a sort of minimum amount which all the public residents pay, apparently they all pay the same regardless of circumstances and then there are a certain number of private pay, private residents, there are 15 private residents out of 120 altogether. (wife)*

Finances also featured very prominently in the choices of another respondent who, due to her unwillingness to wait for a publicly funded bed for her mother to become available, opted for a private bed:

*I'd say in most nursing homes, if they think you've got money of course they'll find a bed for you. (daughter)*

This decision to opt for private funding led her to select the cheapest home she could find:

*It was a truly financial decision ....it was the cheapest place we could get. (daughter)*

Moreover, In spite of her ability to access funds allowing her to independently initiate her mother's transition to nursing homecare she still felt 'disempowered' by the system as she was worried about the future security of the place when her mother's money runs out in a few months:

*The next step is to make sure they don't throw her out, well they probably won't but you still have that fear. (daughter)*

The decision to access nursing homecare was often dictated by the availability of a funded place rather than the result of active decision making. Two respondents were waiting for a place for their relative several months after deciding to pursue such a place. Respondents often described how they had to wait for someone to die before a place became available:

*We didn't know if he would be accepted to long-term care although they said he would. But no one died there for three months so he was three months in the hospital waiting. (wife)*

Due to lack of finances, for most, this place had to be publicly funded:

*It's very hard to get anybody in and it's too expensive to then put her in a private one because I couldn't afford it, I couldn't afford that at all. (sister)*

Thus many saw the system of allocation as being a 'lottery' and considered themselves 'lucky' in gaining access to a suitable placement. One participant was particularly vocal about this issue and felt disempowered by a system they perceived to be 'corrupt' and 'self-serving'. These experiences were accompanied by the belief that if the offer of a place was rejected another offer would not be made again in the immediate future:

*We'll have to take a place otherwise you might be another three years before you'll be offered a place again. (husband)*

*All that came out of the blue, so we were saying like if we don't take the offer we could be another two or three years waiting for another. (daughter)*

As a consequence, the process of transition often took place at short notice. Thus one respondent recalled a conversation with a doctor:

*He says be prepared for a shock or something sudden to happen but he says at some stage or other when he comes in for respite he says, we might decide to keep him in. (son)*

### 3.1.6 Who is involved in making the decision?

The decision to initiate the transition to long term care for their relatives was rarely taken by the carer alone. Instead it tended to be a collective decision:

*We all made the decision. I made it, my daughter made it, the GP the district nurse, we all came to the same decision, it was obvious. (husband)*

For some, family members played a welcome role, helping to absolve the responsibility of the main carer in making such a big decision on their own:

*I knew my mother would have to go into care but I would not have been able to organise it myself so I just did nothing, my family who was a bit removed from it organised it. (daughter)*

For others, the role of family members in helping the carer make this decision was less welcome:

*I want to say it myself when I know it is time to go in but I don't want to hear people say it to me and impose it. (sister)*

Professionals played a key role in helping respondents to secure a nursing home place, especially if that place was publicly funded. As such, they played an important role in decision-making. Thus two respondents recounted their conversations with medical practitioners:

*(The psychiatrist said) 'You know it's really time that you should be thinking about putting him into a home you know. The time has come, you've managed him at home for the past five years and you've done a good job. (daughter)*

*He said to me look he said, were going to keep watching him every time he comes in for respite and he says at some point in time he says when a bed becomes available and we think the time is right well keep him in and effectively that's what happened last April, so it wasn't a decision that I made it was a kind of a shared decision. (son)*

## CASE STUDY 2:

### Influences on deciding to pursue long stay care for their relative

Sheila has been caring for her sister, Ann, who has Pick's Disease for the last four years. She is assisted in her role by day care home helps and regular respite care for her sister:

*She's been going into respite since I've been looking after her. .It was the only way I could look after her and I said I needed a few days a month or a few days every two or three months, I had to have a break with my husband.*

However, in spite of these significant levels of formal support provision, a number of other factors have, in combination, forced her to pursue long term care. Firstly, she lacks support from her four sisters and two brothers. Nor do Ann's children provide her with any help. Secondly, she experiences conflicts as a result of her husband's resentment of her role and his subsequent wish for the person with dementia to be admitted to a care home as soon as possible. A third contributory factor has been the practical strain of caring particularly in providing personal care, problems which have been exacerbated by her sisters increasing weight and decreasing mobility which has in turn impacted upon her own health. Material issues were also a factor for in spite of the demands of her role and the need to give up her job to accommodate them she was turned down in her application for carers allowance because the authorities did not think she was eligible for it. As a result of the combined impact of lack of support, conflicting responsibilities, carer strain, declining health and material sacrifice she eventually decided to pursue a permanent bed for her sister in the same care home that she receives respite care, however, after several months, she is still waiting. When the transition finally take place she is determined to continue in her caring role. She thus recounted a discussion with her husband:

*I can't just leave her there and then I says to him when (my sister) goes into care I'm still going to be her carer and he says, you won't be her carer if she's in there, they're going to look after her. I said but I still want to be her carer.*

## 3.2. What are carers' experiences of making the transition from caring for their relative at home to them being cared for in a long stay setting?

Carers' experiences of transition

1. Mixed emotional responses
  - Relief
  - Ambivalence
  - Guilt
  - Loss, loneliness and bereavement
  - Having to take on new roles

2. Influences on the experience of transition
  - Spouses' experience
  - Adult children's experience
  - Negative attitudes of others
  - Adaptation over time
3. Facilitators to adjustment
  - Quality of care provided in the care long stay setting
  - Good quality care home provision
  - A stimulating environment
  - Familiarity with the care long stay setting
  - Gradual increments of formal support
  - Emotional and spiritual support

### CASE STUDY 3:

#### The experience of transition

Jane, along with her four siblings had cared for both her parents, her father who had Alzheimer's and her mother who was blind. For the past few years they had run a rota system so that one of them slept at their parents' house every night:

*So we would come about half eight or half nine every night and we would take it in turns with all the rotas made out. And we'd take it in turns to come out every night and sleep the night.*

However, due to conflicting family and work responsibilities and the declining health of her parents, she found it increasingly difficult to cope with their care:

*So you forever juggling balls and it just, it was coming to the stage that it was getting beyond us.*

The situation reached crisis point when her mother had a fall and went into hospital. Due to the interdependence of their parent's relationship her father could not be left alone at home and this situation culminated in their permanent admission to a care home . This process was facilitated by their prior familiarity with the long stay setting and their confidence in the care it provided:

*I knew he was in good hands here because it was always recommended as being the best home in the city for people with dementia.*

### 3.2.1 Mixed emotional response

#### 3.2.1.1 Relief

When seen in purely instrumental terms, the experience of transition was perceived as being overwhelmingly positive with all respondents reporting a relief from the practical responsibilities of caring. According to some respondents a pragmatic approach was helpful in this respect:

*You have to be pragmatic, there was no other route, no other route. (husband)*

A sense of freedom, peace of mind and relief from stress were commonly described:

*It was just a huge, huge burden lifted from my shoulders. (daughter)*

*The bottom line is like they're safe, they're looked after and we don't have to worry any more. Peace of mind. Peace of mind. Now we can see them when we want to see them and I think that's the best part of long- term care. (husband)*

#### 3.2.1.2 Ambivalence

Others were more ambivalent about their experiences:

*There's a great peace of mind now even though you can never say you're happy. (son)*

*I feel more gigglier and chattier and relaxed, guilty as well. (daughter)*

Similar ambivalence was expressed by a respondent who anticipated her feelings once the planned transition took place. In doing so, she recognised the mutual dependence that she had developed in caring for her father and the sense of loss that she may experience as a consequence of this:

*It's the letting go isn't it? You're needy, who's the most needy? And I think that's what happens to carers. I think if they care for so long in the long term, it's their needs being met... It's the first time I'll actually be left on my own. So is it a frightening thing or not? Gives me a new lease of life, I can do all the things that I've always wanted to do, but it's going to be different, it's going to have a huge impact on me. (daughter)*

Carers' emotional experiences were overwhelmingly negative with most speaking of feelings of guilt, bereavement, loneliness and a sense of failure during the period of transition

### **My Story: My father's cap (see photo story, page 51)**

“The cap he used to wear when sitting in the sun. He loved the sun. I used to like to see him sitting in the sun, things looked normal.”

#### **3.2.1.3 Guilt**

A daughter spoke of her relief following the admission of both of her parents to a nursing home and also said that she felt that she had betrayed her parents and the bonds of reciprocity that had been established throughout her life:

*There's nothing that makes it easier putting your parents in a home. Nothing. Nothing in this wide, wide world...it's the hardest thing you ever have to do in your life and you know my parents were always good to us they gave us a lovely life we never wanted for anything and so in turn you want to do that for your parents. (daughter)*

*I feel awful and I'm not able to sleep. I feel awful guilty because I want to put her into care because I'm not able to do it anymore. But I feel so bad about putting her in. (sister)*

In spite of the huge relief from burden experienced by the carer following this transition and her confidence in the care home long stay setting, she also confessed to a certain amount of guilt:

*My mother and father would always be very good, good living people; we were always brought up to care for people...to always be looking out for the elderly, the sick and the poor. (daughter)*

This sense of guilt was exacerbated by the attitudes held by some of her siblings and by her mother who had always previously insisted that she and her husband remained at home:

*The geriatrician said "I've asked your mother where she wants to be and she said I want to be in my own home with my family minding us as they have been doing". (daughter)*

In addition to the attitudes of her family, she also spoke of negative attitudes to long-term care held by Irish society as a whole.

#### **3.2.1.4 Loss, loneliness and bereavement**

A more wide ranging interdependence in the caring relationship was referred to by one of the older spouse carers in the sample:

*I mean before he went in you'd be thinking it would be easier if I wasn't looking after him. But it isn't any easier because I have a whole range of new problems, plus being on my own.... because you've had that companionship even though he wasn't able to do much. (wife)*

*She hasn't passed away but you are grieving for somebody that is there physically but not mentally (daughter)*

### **My Story: My father's crucifix (see photo story, page 51)**

“The crucifix outside his bedroom. He used to kiss it every time he passed it, no matter how many times he got up in the night.”

#### *3.2.1.5 Having to take on new roles*

A wife in her seventies caring for her husband spoke of practical and financial concerns as well as loneliness following her husband's admission to long term care:

*He did do a huge amount of organising and I found it a huge strain having to take that over after he became less able. (wife)*

### **3.2.2 Influences on the experience of transition**

#### *3.2.2.1 Spouses' experience*

Spouse carers tended to feel a great sense of loss and loneliness due to the closeness of their former relationship:

*It's depressing in the house because all her things are here but she's not there and there's no probability of her ever coming back, it's really worse than a bereavement because there's no finality to it. (husband)*

*I had to make all the decisions myself about the house and the finance and the bills coming in and so on and I'm still quite lonely when he's not there. (wife)*

Spouses had to take on new roles after their partner was admitted to care. This included financial responsibilities.

### **My Story: My desk (see photo story, page 51)**

“This is where I have had to take responsibility for financial affairs. I also have to make all decisions regarding the care of the house and garden which my husband did previously with some assistance from me.”

Spouses also had to address their need for company and this was often difficult as they were often feeling so low in themselves following their relative's admission.

#### *3.2.2.2 Adult children's experience*

A son caring for his father felt that his relationship lacked the intensity of that between a mother and a daughter making his experience of transition less traumatic:

*There's a mother-daughter relationship and then there's a father-son relationship and they're not necessarily the same. Dad and I had our own different interests even though I was an only son he had hobbies and interests that weren't the same as mine. (son)*

### **My Story: My father's house**

“His home for the last 35 years. Empty now, lonely. I used to be there three to four times a week now I call only every five to six weeks to check on things. Relief not to be there but sad at the reason.”

### 3.2.2.3 Negative attitudes of others

#### **Family conflict**

For some carers the sense of guilt was compounded by the negative attitudes of others with several respondents having to deal with the opposition of other family members in their decision to pursue long-term care:

*My mum's in her eighties and she just doesn't want to see her going in. She just doesn't want her to go into care. She said to me "Do it for another wee while". (sister)*

*My main difficulty really was dealing with my sister because she feels huge guilt she even to this day feels guilty...she would want them at home but she wouldn't want to be the one doing all the work. (daughter)*

#### **Stigma associated with long stay care**

The latter respondent went on to say that she was also led to question her decision as a result of a culture of caring implicitly held by her parents and by Irish society as a whole:

*Maybe in Ireland there's this thing if you put your parents in a home it used to be like you're kind of reneging on them, you're kind of saying 'well I'm not doing it anymore, I'm not minding them, they're too much trouble'...My mother and father would always be very good, good living people; we were always brought up to care for people...to always be looking out for the elderly, the sick and the poor. (daughter)*

Similar stigmatising attitudes were felt by two participants, both of whom had parents living in a nursing home which they said was, at first sight, rather austere and conjured up negative connotations of 'the workhouse':

*There was a lot of people I wouldn't even tell [that] my mother was gone into care, I just kind of hid it..it had a bad stigma attached. (daughter)*

### 3.2.2.4 Adaptation over time

However, over time, after they got to know the residents and staff and the care they provided, they both said that their initial reservations had diminished:

*I hated going in there but then after a while I got to know the other patients and I got to know the staff and as one of the sisters said, its not the look of the place it's the care that they give, and it is, it really is. (daughter)*

*Overall I'm very pleased with where we are now, with the reservations I had earlier on which I don't think will ever go away you know. You know it's not a luxury nursing home. (son)*

*I have visited one or two people in luxury nursing homes who I don't think are getting the same level of care. It may be spotless and it may be very clean and whatever and it may be very modern but I just see them sitting around a room in a circle and I don't see that in [father's nursing home setting]. (son)*

## **3.2.3 Facilitators of adjustment**

### 3.2.3.1 Quality of care provided in the care long stay setting

The main issue referred to in easing the initial experience of transition was the confidence in the quality of the long stay setting. This was closely related to the belief that this setting provided a better standard of care for the person with dementia than the carer themselves could have provided:

*It makes 100 per cent difference and it's about trust, it's about letting go. (daughter)*

Thus many respondents spoke of the person with dementia being 'better off' in long-term care:

*What made it easier for me was the reputation of (the care home long stay setting) that I knew I was putting him into a good place....the home itself looked nice and looked appealing, you know it was a nice modern building....and its nice and warm and welcoming and there are no smells. (daughter)*

Another respondent spoke of the benefits that her father would experience from the transition, contrasting the care that she could provide for him at home to that he would receive in her chosen care home setting, thus highlighting the fact that permanent care home admission can be a positive choice:

*There is no male environment at home for him so that was good and very important. I mean the staff were excellent absolutely excellent. The other good thing he can walk and walk and walk...at home he hasn't got the choice that he has in respite care. Because one night he didn't want to go to bed so they made him comfortable on the armchair and then when he was ready he could go. He can't do that at home...I honestly believe in my heart of hearts that I cannot give him the care that he deserves. (daughter)*

### 3.2.3.2. Good quality care home provision

The main aspiration referred to by carers was for a good quality long stay setting where they could be confident of the care being provided and be reassured that the well being of the person with dementia was being promoted. Confidence in the quality of care greatly helped respondents come to terms with the decision to pursue long-term care as well as helping to ease the demands of their post transitional role.

#### **My Story: My father's care home**

“ It is probably the most, or one of the most, difficult decisions a person will have to make - to put a person in a nursing home. The thing that helped me most was knowing he was getting the best care for a dementia patient and that he was happy. ”

Carers' perception of what constituted good quality care was often gradually acquired following the post admission process, based on their own observations and experiences of the care home environment. These observations were often subjective and therefore difficult to capture in such things as home inspection reports. The need for greater visibility of the quality of care provided in these long stay settings was therefore recommended:

*Visibility of the level of care. Awareness of the care that's available. (son)*

For example, a carer spoke of the way in which the welcoming and inclusive interactions between himself, care home staff and his father following their return from an outing made a lasting positive impression on him:

*I came round and looked in the door and there were two staff nurses, one sitting there and one sitting in front of the desk and I said "we're back" and what you expect would be for one of them to jump up and take Dad and either bring him to his room or bring him into the common room but they didn't. The nurse who was sitting there said, "oh Jim come and sit down here" and she had him sitting beside her behind the desk while we just exchanged pleasantries, you know, and that had a huge impact on me. (son)*

Similarly, a spouse carer spoke of the positive nature of staff interactions with his wife:

*Every time I pass through they would always say hello to her and call her by her name. (husband)*

### 3.2.3.3 A stimulating environment

A number of more tangible issues also emerged as helping to constitute this 'quality care'. The first referred to the provision of activities and stimulation for residents which have been found to be central to promoting the well being of care home residents with dementia and to the implementation of person-centred care. Some expressed satisfaction with this:

*I feel that where he is now in (long term care long stay setting) the activity level is very significant and all the things they do every day you know. (son)*

Conversely, another carer thought that her sister would not be provided with any stimulation in her long-term care placement serving to compound her guilt about pursuing such a placement:

*She's going to be in there now full time and she's not going to be getting out and she's going to be sitting there all day, sitting around with the rest of the patients and I don't think my mum realised how guilty she's making me feel over that as well. (sister)*

A woman whose mother was in a privately funded bed expressed similar concerns about activity levels as well as the fact that her unit was not specifically geared to the needs of residents with dementia:

*She's safe and secure but she's not stimulated in a way that she needs to be and she needs to be in a designated Alzheimer's unit. (daughter)*

The same carer went on to express concerns about the level of the empathy and expertise held by the nursing home staff:

*Does general nursing take in psychology training of some sort? Certainly for Alzheimer's and for those kinds of diseases it would be very much beneficial.....you get some people who are born carers that are just absolutely selfless and when you do meet them it makes up for all the bad people then. (daughter)*

### 3.2.3.4 Familiarity with the care setting

Prior familiarity with the care setting promoted the carers' and their relative's confidence in it:

*I was a volunteer helper here from the time my sister in law came in. I used to come in once every so many weeks on a rota to help with coffee for the residents. So I knew the home very well and all the people in it. (wife)*

For the two respondents who had not yet secured a placement, their current respite care long stay setting was also their preferred option:

*I've got to go start looking at homes. I'd like him to be in [respite care setting] because it's nearer for me and they deal with the Alzheimer's and the staff are lovely and they're geared up and they know how to handle and deal with him especially if he got aggressive or anything like that. So I would love him to be here, this would be my dream come true. (daughter)*

The availability of respite care before the process of transition took place was highly valued by carers because it helped the carer and the person with dementia to become familiar with the setting and the care it provided:

*She's been going into respite since I've been looking after her. it was the only way I could look after her and I said I needed a few days a month or a few days every two or three months, I had to have a break with my husband. (sister)*

### 3.2.3.5 Gradual increments of formal support

Receipt of respite care appeared to greatly ease the process of transition for their relative with dementia as well as themselves. Many carers placed their relative in the same location that respite care for their relative had previously taken place. This made the process of transition a gradual almost imperceptible one. Thus one carer recalled the way in which both her parents were eased into their current care home placement by an earlier respite stay in the same setting:

*They went in for the two weeks in December and they got on OK and they came home. And you know we said at least we've broken the ice you know and my mother knew we all needed a break. (daughter)*

Another carer had benefited from increasingly frequent respite stays for his father as well as regular checkups for him at a day hospital, leading to what he described as:

*Another increment of relief. (son)*

The efficacy of the gradual introduction of services to older people in need of support has been reflected in a number of research studies:

*We'll tell my mother we just can't manage any longer and try and ease them into it, rather than just take them out of home and put them in, we'll try and come to some arrangement. (daughter)*

### 3.2.3.6 Emotional and spiritual support

Emotional and spiritual support played an important role in helping to ease carers through the process of transition. Such support was provided by family and friends, neighbours, counsellors, religion and the care home staff:

*I'm going to ring (ASI support worker) at (ASI unit). She's very good just to talk to her, you know. When I need anyone to talk to she tells me to ring her. So I ring her and it's just nice to talk to someone about it. (sister)*

For example, one spoke of the beneficial role of privately funded counselling, while another carer relied on her neighbour:

*I have a very good neighbour that I can visit at any time....so if I am feeling lonely I can go over to her and just talk. (wife)*

The role of religion was also regularly cited in helping respondents come to terms with the process of transition:

*I don't practice religion at all but since this happened I have I have to admit I just go up to the Catholic Church and just sit there...there is a peace and you feel there's somebody looking after you. (daughter)*

*I've had an awful lot of help from prayer from a prayer group that's going on in our Parish.... We're going to sing in a mass although I'm a Protestant. I didn't know I was a Protestant till I came to Ireland. (wife)*

## My Story: My husband's nursing home

“The care there is outstanding for residents and their relatives. I have received much help and encouragement from staff as I struggled to adapt and adjust to my new situation.”

### 3.3. How has the family carer's role changed as a result of their relative's move to a long stay setting?

Continuity and change in the caring role following transition

#### 1. Continuity

Keep a close relationship with their relative

- Facilitate relatives' engagement in life-long pleasures
- Provide practical support

#### 2. Change

- Take on quality assurance role

Carers' experience after admission was characterised by change and continuity. Carers continued to maintain close relationships with their relative providing companionship, practical support and facilitating their relative's involvement in life-long interests and enjoyments. Many carers reported that while no longer providing personal care, they were now in charge of quality assurance for their relative's care.

#### 3.3.1 Continuity

All carers maintained continuity in their relationship with their relative.

##### 3.3.1.1 Keep a close relationship

Most of the carers continued to maintain close relationship with their relatives by visiting them on a regular basis. This tendency towards high levels of continuing involvement was particularly apparent in spouse carers who were more likely to visit as often as possible. This contrasted with the experiences of sons and daughters who usually had conflicting demands on their time due to work and family responsibilities. Even with these competing demands many adult children strove to retain close contact:

*Now I kind of try and coordinate with my sister because I know my mother likes us to visit as much as we can so there is no point the two of us going one day. (daughter)*

Against this context of continuity, some respondents spoke of how their relationship to the person with dementia had changed following transition:

*The medication she's on now has changed her completely, her sense of humour is back, the stimulation, the company and the medication has brought her back to being a bubbly person and that makes it easier to see her. (daughter in law)*

For some their relationship with their relative had improved:

*[Before their relative's move ] I felt I wasn't their daughter anymore, your role as a daughter was eroded we had become their carers....so now when I come here I've reverted back to being their daughter as opposed to being their carer. (daughter)*

*I suppose it has empowered me really...now that she's in a completely vulnerable position, helpless you know. I have become the mother and she has become the child...it's a kind of warmth coming between the two of us even though she cannot communicate with me but there's an understanding there which sounds weird but that's the one consolation that has come out of this disease. (daughter)*

Carers wanted to remain closely involved with their relative even though it was sad for them to be faced with their relative's changed abilities:

### My Story: My mother's books (see photo story, page 51)

“She had the power of knowledge through her love of books but now due to her illness she can no longer comprehend how to read and this is so sad.”

### My Story: My dad

“My Dad will always be my Dad no matter what. The changes in him have been difficult to watch. It has been hard and lonely but I have accepted it and I deal with it. Sometimes I wish he was the old him but I still love the new him. What is normal anyway? Normal is what you're dealing with in the here and now.”

One husband spoke about how his wife who was no longer able to talk derived great enjoyment from going out for drives with him in his car. He described how when he came to visit she would be keen to get in his car and go for a drive.

There were some carers, who while keen to remain close to their relative, experienced difficulties in achieving this. They reported experiencing difficulties relating to their relative, knowing how to reach them and how to make sense of their relative's behavior:

*I would feel much happier if I felt I could have a better relationship with him but I can't so I have to accept just what I can do. Just sit with him and talk a little bit. But there's no real conversation I can't tell him any of my problems. I can't get any support from him. (wife)*

*If I could see him just a bit calmer, I'd love to go in and like have him smiling but he's not like that and I find that a bit upsetting. (sister)*

*When I visit my husband now although they say he's settled, I'm not happy with him shouting in an aggressive way and for no apparent reason. (wife)*

Their difficulties relating to their relative were compounded by a lack of privacy when visiting and the behaviour of other residents:

*This other woman had continued the whole time saying 'nurse, nurse I'm dying'...so you can't say it's a relaxing thing visiting him you know...You have to cope with what's happening to the other people sometimes....so I'm exhausted by the time I get home sometimes. (wife)*

*He just seems to have settled in well now. I suppose probably one of the negatives and it may not be fair because different people have different types of dementia or Alzheimer's but there are a couple of people who, to my mind, make the environment a bit unpleasant, like there's one person now who screams at me every time I go in. (son)*

As a result, some respondents had cut down their visiting:

*I'm not going up every day but there is no point when she doesn't acknowledge you, doesn't know you, but once a week is enough. (daughter)*

#### 3.3.1.2 Facilitate their relatives' engagement in life-long pleasures

Carers continued to provide companionship and to facilitate their relative's involvement in life-long pleasures:

*He always loved his garden he always loved the glasshouse...when I go to visit him I always bring him for a walk in the greenhouses. (son)*

Similarly, a husband recounted how he watched sports DVDs with his wife when visiting her, something they had always enjoyed together. Not all carers felt as able to engage their relative when they visited:

*He seems unable to take part in various activities on offer and needs constant attention. His walking is very limited and I feel frustrated that there is little I can do with him except sit with him. (wife)*

### 3.3.1.3 Provide practical support

Most carers supplemented the care provided by providing practical support with tasks such as clothing and laundry:

*I take certain garments home, the trousers and cardigans because I thought they're the most likely to get lost and damaged in a big laundry and then I take them back and I check what he has left and if he's got enough shirts or whatever. (wife)*

*If my mother needs anything underwear or clothes I have to go to town and buy them you know. (daughter)*

### 3.3.2 Changed emphasis in role - Quality assurance

Carers took on more responsibility for monitoring and quality assurance of their relative's care:

*I go up with flowers and fresh clothes and just go through a little routine with her and I come out and I feel at ease to a certain extent because I feel I've seen her and she's OK she's safe and secure and she's being looked after. (daughter)*

A woman caring for her sister expressed her determination to continue to be actively involved as her sister and her 'carer' after she was admitted to a nursing home:

*I'm going to make sure that she's looked after properly and we'll make sure her hair is washed when I go in and her hair is cut...and I take care of the money part. I'm going to make sure she has nightdresses, underwear, dressing gown, slippers....there'll be someone going down to see her all the time...if you keep going in she won't forget you. She has to see your face I think... I'm still going to be her carer. (sister)*

## 3.4. What types of roles do carers want to have?

The roles carers want to have in long stay care

1. To participate in the long term care of their relative
2. To participate in the life of the care home
3. To re-establish their own life

All carers wanted to maintain involvement in the care of their relative and some wished for a role in the wider life of the care home.

#### CASE STUDY 4:

##### Adapting to a new role

Margaret, a spouse carer in her seventies provides one example of how respondents experience and adapt to their role following transition. Her husband who has a dual diagnosis of Alzheimer's Disease and cancer was admitted to permanent care following a health related crisis and a three month wait in hospital for a suitable place to become available:

*I wouldn't say forced on me but there didn't seem to be any alternative.*

Typically for spouse carers, she found the transition to permanent care traumatic, reporting a high degree of practical and emotional interdependence in her former relationship with her husband and an unanticipated sense of loss after transition had taken place:

*Sometimes I think I'm completely detached from it and I feel I'm not feeling upset, I'm not feeling depressed and then in a situation like this I realise that I am.*

Although she visits her husband on a regular basis and deals with his laundry she is finding this visiting increasingly difficult due to his unresponsiveness as well as the shouting of other residents. Several months after transition, she is now trying to establish an independent way of life and is a member of community groups such as a prayer group, a choir and a yoga group:

*The carer trying to keep their own life perspectives and not be totally absorbed in their partner is what I've tried to do in keeping up those activities.*

#### 3.4.1 To participate in the long term care of their relative

Carers wish to maintain their involvement with their relative often meant letting go of their role in personal care:

##### My Story: Me and my husband

“ I have to accept that my husband is now cared for by others.  
I have to accept the level of care he gets which is very good. ”

#### 3.4.2 To participate in life of the care home

Several carers wanted to participate in the broader life of the long stay setting and to 'give something back'. This was achieved through such things as involvement in the Alzheimer Society of Ireland and through campaigning and fundraising activities. For example, one carer said that she would like to be involved in a marathon to raise funds for her father's care home:

*So I'd like to give something back and the only way I could give something back is the marathon. (daughter)*

##### My Story: Flowers (see photo story, page 52)

“ This photo reminds me of my mother's favorite colour which was pink.  
The flowers are in my garden and instill a nice memory of my mother. ”

#### 3.4.3 To re-establish their own life

Some carers qualified their wish for involvement in long stay care with a corresponding wish to be given time to maintain or re-establish their own independent lives:

*There are certain things that I'll do that I will make time for but there are some things that I might not you know because my time is limited. (daughter)*

*I'm trying to build up my own life as well as supporting (husband) here. (wife)*

For some carers there was also a sense of ambivalence apparent in these attempts to move on with their lives, due to a lack of finality in the caring relationship:

*Maybe it's a matter of accepting that he's gone basically and yet he hasn't died. So there isn't a finality in that way. (wife)*

### **My Story: The garden shed (see photo story, page 52)**

*“ This is significant because gardening was my husband's interest all his life... Now I carry on alone with occasional help from my son and a gardener. On the other hand there is great therapy for me in caring for the garden. ”*

## **3.5. How can carers be supported in these roles?**

How they can be supported to have these roles?

1. Good relationship with the care home
  - a. Two-way communication
  - b. Acknowledgement of carer's expertise
  - c. Accessibility
2. Information and education
3. Emotional support

Carers described that having an informed and supportive staff group, accessibility to the home, and information and education both about dementia and dementia care helped them in fulfilling their desired roles.

### **CASE STUDY 5:**

The support needs of carers

Due to the strains of caring for her mother, Tina decided to obtain a privately funded care home place:

*The placement officer told me that there were 200 people on the waiting list for a public bed and she intimated from the word go that we'd go down the private route.*

Tina also decided to pay for one to one counselling in order to help her come to terms with the subsequent transition. She thus expressed a sense of anxiety and lack of control over the future security of her mother's placement when her mother's private funds run out:

*We cannot get any confirmation from the health board that they will place her in a public bed once her money has run out.*

Nor did she feel particularly happy about the care her mother receives on her current placement feeling that it lacks stimulation and does not cater specifically for residents with dementia:

*You're not supposed to rock the boat, that's the vibe I get through the nursing home.*

She thus thought that many improvements could be made to the existing system. Her suggestions included more advice and assistance both pre and post transition and a more universalistic and accessible system of service provision in which access to private funds does not play a factor in gaining access:

*If you have money, you'll be looked after, simple as that.*

### **3.5.1 Good relationships with the care home**

#### *3.5.1.1 Two-way communication*

Communication and liaison with the long term care long stay setting is an important factor in maintaining continuity in the caring relationship as well as helping the carer to redefine their role in this new context. Communication was expected to be a two way process with respondents commonly expressing the wish to be actively consulted and kept informed on the person with dementia by the staff team in the long term care long stay setting. For example, a son said that care home staff often acted as a conduit between himself and his father:

*Occasionally I get a phone call, maybe once or twice a week, in between visits "your Dad wants to talk to you" and I talk to him on the phone and I listen to what his problem is and then I tell him "well look I'll be in to you tomorrow and we'll sort that out tomorrow". (son)*

Integral to this continued involvement was the establishment of good lines of communication with care home staff, as this respondent recognises:

*Other than the physical thing of bringing them in and introducing them to the staff and making them comfortable with the staff, getting a relationship going between yourself and the staff, regular contact, phone contact, you know... Well they need to be comfortable to pick up the phone and call you if there's a problem and I think it's better for you as an individual if you know who you're talking to. (son)*

However, lines of communication between staff and carers were sometimes lacking:

*They would just say, you either accept the way we're running this home now or else go somewhere else, that's the vibe I got the whole time up there. (daughter)*

Or if they did exist they could be tokenistic or lacking in clarity:

*I don't want to waste people's time by talking about my problems when I can't see how they're going to solve it. (wife)*

Even when clear lines of communication were made apparent to carers through such things as the identification of key workers, some respondents in this study appeared not to avail themselves of these, even at advanced stages of the post transition process:

*Here there's excellent care and I can talk to (care home nurse) or (care home nurse) the two, I'm not sure what they call them but they are in charge of areas... I can talk to either of them at any time. I don't avail of it because I'm not quite sure where it would get me. I don't know whether it would help me or not. Maybe it would. (wife)*

Some carers expressed an ongoing anxiety about the future security of the care home placement. For example, one carer was concerned that her mother-in-law would lose her publicly funded care home place due to dramatic improvements in her health and well being following her initial admission. Another carer whose mother currently had a privately funded place was also worried that her mother would be made homeless when her private funds ran out and in spite of making repeated requests for information never got a straight answer about this:

*She needs really to be in a designated Alzheimer's Unit but again she has to be put on a waiting list and that waiting list could be up to three years. (daughter)*

### 3.5.1.2 Recognition of carers' expertise

Several respondents referred to the way in which they communicated their knowledge of the person with dementia to staff in the long stay setting. Some carers therefore implicitly or explicitly referred to the need for greater recognition and utilisation of their knowledge and skills by staff in the care home long stay setting as well as the need for a greater clarity in their expected roles and responsibilities. Staff were not always perceived to be receptive or responsive to carers' contributions, which could itself be a source of frustration. For example, one respondent recounted how she was unwilling to 'rock the boat' by making requests or complaints about her mother's care due to fear of negative repercussions:

*They're all very nice to your face but just as people you don't cross them because they know that you're at their mercy...compassion has just disappeared in the nursing world. (daughter)*

### **My Story: The cabinet (see photo story, page 52)**

**“**This is representative of my husband's heritage and is only a small part of it. The responsibility for this weighs on me somewhat – especially trying to remember the history and significance of some of the artefacts.”**”**

### 3.5.1.3 Accessibility

Visiting the care setting was important to carers in helping them to maintain their relationship with the cared for person and their contribution to their care. According to respondents this visiting was facilitated by open visiting hours, the convenient location of the nursing home and a welcoming and pleasant home environment:

*It's not far from here so I could kind of visit her all the time. (sister)*

*Because I don't drive, they had a list of places and there was one way out, I can't even remember where it was. I wouldn't be happy with that because I would have to have some place where it is easy to get to. (sister)*

### 3.5.2 Information and education

Some carers felt that having more information and education on dementia could help to facilitate their involvement in their relative's care and life as it could help them to understand and respond to their behaviour:

*I would be very interested in anything that's to do with finding out more about the causes of dementia. (daughter)*

According to two respondents improved relationships were facilitated by the development of an increased awareness of the best way to communicate with the person with dementia. They described the way in which, on the advice of their respective spouses, they had successfully replaced their previous attempts at reality orientation with a less confrontational approach when visiting their parents:

*I mean like going to her now she'll say 'how's your mother'. At the start I kind of reacted by saying 'you're my mother' but I went home and my husband was saying 'the next time she says it, just say she's fine' and I did do that and it's just as easy because she doesn't know who I am. (daughter)*

*I think one of the big things that you have to get into your mind is that their mental state is always a temporary one and that arguing with them or saying no is no longer necessary. I have to say my wife probably convinced me of this, it took a while to realise it but I used to argue with him and I used to try and rationalise things and then suddenly it just dawned on me that I don't need to do this anymore. Just keep them happy, say something that will make him happy for the next five minutes and in five minutes it won't be an issue anymore. (son)*

Some carers had found education, either through reading relevant literature or by attending relevant talks and courses helped them to better understand and respond to their relative's needs:

*I suppose it was easier for me then because I really understood all of the different stages. Because I mean I suppose once you understand what's happening, it's easier to accept his behaviour. (daughter)*

*There's a lot of pamphlets put out by the Alzheimer's Society which are very good really and there's lots of information on the internet. So you'll find very good information there about Alzheimer's and there's research into Alzheimer's now as well. (husband)*

### 3.5.3 Emotional support

The emotional as well as practical needs of carers were also highlighted by some with one respondent comparing her current caring role with her former paid job in a dementia care setting:

*When you're working you're not emotionally attached. When you're caring you're emotionally attached and you've got all the guilt, the loss, like a bereavement I suppose, you've got all that and you have to deal with all that and still cope with their caring as well. (daughter)*

In order to meet these emotional needs, the receipt of counselling was alluded to as being an important source of help both before and after admission:

*There's nobody out there for the carer but if there was a counselling service that would be huge because you'd have somebody to go to vent your anger on rather than bringing it home and venting to your husband or venting to a member of the family, going around in circles. (daughter)*

While the above respondent explicitly recognised this unmet need for counselling services, others implicitly recognised this void:

*Thank you for your questions because its helped me just to talk about it you know...I hope it is of some use...I shouldn't be on my own with it because I have good friends but it's very difficult just to talk to a friend in a way, in a meaningful way, other than just superficial talk because you don't want to upset the other person. (wife)*

### **My Story: My dog (see photo story, page 52)**

“ This is a photo of my dog. She is my 'soulmate'. During my mother's transition to a long stay setting, when everything looked bleak, my dog was always there for me, giving unconditional support. ”

Certainly in our interviews and focus groups with family carers we were conscious that they seemed to have never had the opportunity to discuss what this experience had meant and continued to mean to them. Many told us they found having such an opportunity helpful:

*It's been a great help to me, it's been like therapy, believe it or not, it's been like therapy...its started my thinking about him my two girls and myself and our futures and the way forward, it really has. (daughter)*

*I will say this, that this is one of the best things that has happened to me since my wife went in, meeting and being able to talk about it. (husband)*

*I suppose you come to understand a lot more about it when you hear people that have gone through it. (sister)*

In spite of their commonly expressed need for adequate and accessible support after their relative's transition, opinions differed on the need for more innovative support. Thus some suggested a wish to be involved in mentor schemes or support groups:

*I think there's a need for advocacy, especially for people in this situation. It's very difficult to advocate for yourself, a mentor or someone just to get you through the stages. (daughter)*

However, others were not interested in this type of provision. For example, one carer who was still waiting for a care home placement said that it was impractical for her to attend support groups due to her caring responsibilities:

*I got a lot of my information on the internet, looking on the internet. I know I can go to the carers' group and all this kind of thing but how? I have to take him with me everywhere. (daughter)*

Similarly two older spouse carers in the post transition phase expressed their reservations about joining a support group:

*I think I'd be very cagey about meeting other groups, you know, I'd have to vet them out first. I mean like minded people are fine and even people who disagree but moaners and begrudgers, not in the mood for them, no. (husband)*

*I think I prefer to be on my own, I don't know, I can't work it out yet (husband)*

As such, while all carers shared the need for adequate and accessible help for their relative, opinions diverged on the need for carer-focused support and the form that it should take.

### **My Story: Sky (see photo story, page 52)**

“ The blue sky in this photo represents for me a brighter outlook, so that even though the transition of my mother to a long stay setting was very hard to deal with there was always the prospect of better days to come. ”

## CHAPTER 4: DISCUSSION AND RECOMMENDATIONS

This discussion will consider the findings linking them to existing research in the area and will be structured around the main questions addressed in this research.

### 4.1 Discussion

#### 4.1.1 Influences affecting carers' decision to admit their relative to long term care

This research suggests that there are a wide range of determinants involved in initiating the transition to long term care. These include the inherent strains of caring, conflicting roles and responsibilities, the availability of a suitable placement and lack of support. For example, in accordance with the arguments of O'Shea (2007) on the inadequacy of community support provision for people with dementia and their carers, many respondents spoke of the lack of such provision or problems in gaining access to it, serving to exacerbate the demands of their caring role. As one respondent said:

*You see carers will do so much. People come in and out but there are gaps, there were gaps and with the cutbacks as you know we've no health service practically here at the moment. (daughter)*

In spite of the implementation of 'Fair Deal' legislation (HSE, 2009) which aimed to address the principles of equality and fairness of access, having independent financial means also emerged as an important influence in the pursuit of long term care. Thus, carers in this research who could draw on their own financial resources were likely to have more choice in determining the timing of transition as compared to other respondents who were reliant on waiting for a publicly funded place to become available:

*If you have money, you'll be looked after, simple as that. (daughter)*

This reflects the findings of other research which suggests that better off carers are likely to have more choice in caring strategies used as compared to their less well off counterparts (Arber and Ginn, 1992; Argyle, 2001). Similarly, the Alzheimer's Society (England, Wales, Northern Ireland) (1993) have found that, due to their enhanced access to 'cultural capital', middle class groups are more likely to have contact with their Society and have a knowledge of the wider welfare system, thus facilitating their access to relevant support and putting them at an advantage as compared to lower socio-economic groups. This situation has been exacerbated by the fragmentation of care provision (O'Shea, 2007). While the rhetoric behind this fragmentation is that it promotes choice and thus enhances quality, for many respondents in this research it simply served to promote confusion and frustration:

*The red tape was unbelievable and in the end you were just exasperated. That all you were looking for was a home help and yet you had to fill out form after form and in the meantime your mother is going downhill. (daughter)*

Due to the combined influence of these multiple determining factors, the need for long stay care home admission often became apparent after a crisis point had been reached. This was compounded by the tendency amongst some care recipients to resist the need for support, a tendency which has been recognised in other research (Clare, 2003):

*He had a great ability to kind of hide the confusion. (son)*

As a result of these factors, the subsequent process of transition was rarely initiated by the carer alone but was usually the result of collective decision making and a suitable place becoming available:

*All that came out the blue, so we were saying like if we don't take the offer we could be another two or three years waiting for another. (daughter)*

#### 4.1.2 The experience of transition

In spite of the fact that their relative's admission to long stay care released the carer from the practical strains of their former role, it was nevertheless, usually accompanied by a range of strong emotions including guilt, loss, bereavement and loneliness. This was also the experience of carers as reported in the report by Nolan et al (2006) for the Alzheimer Society of Ireland. This research also found that frustration and anger relating to service fragmentation appeared to contribute significantly to the overall emotional consequences of dementia. Carer difficulties and isolation were further compounded by the guilt they felt was imposed by societal expectations in relation to caring and putting their relative into nursing home care. Similar evidence of such normative assumptions (Davies, 1995) were apparent for some carers in this research for whom the perceived stigma attached to long term care compounded their feelings of guilt.

The nature and intensity of emotions also differed depending on the carers' relationship to their relative with dementia. Previous research has highlighted that the caring relationship between older spouses is very different to those between other family members, with spouses being interdependent and being less likely to have conflicting work and family responsibilities (Argyle, 2001). In accordance with this, spouses in this study expressed high levels of interdependence and appeared to experience a greater sense of loss and loneliness following their relative's transition to long stay care:

*You've had that companionship even though he wasn't able to do much. (wife)*

Conversely, spiritual and emotional support through religion and counselling were helpful in facilitating the process of transition. The receipt of respite care prior to transition also appeared to ease the process as it provided carers with a degree of confidence in the quality of the care home placement which itself emerged as an important priority for all respondents:

*There is no male environment at home for him so that was good and very important. I mean the staff were excellent absolutely excellent. The other good thing he can walk and walk and walk. (daughter)*

The quality as well as the quantity of care home staff was also an issue for some respondents who expressed concerns about the level of expertise held by staff on dementia related issues:

*Does general nursing take in psychology training of some sort? Certainly for Alzheimer's and for those kinds of diseases it would be very much beneficial. (daughter)*

Other studies have found that care home staff's understanding of dementia and the continuity of care they provided was a major concern for staff and carers alike (Woods et al, 1998). Thus in spite of the fact that two thirds of all care home residents are estimated to have dementia (Alzheimer's Society, England, Wales, Northern Ireland, 2007), research has shown that care home workers lack relevant skills and knowledge in dementia care and still tend to be task orientated in their role (All Party Parliamentary Group on Dementia, 2009). While attempts are being made to improve the skill base of care workers, primary reliance still tends to be on personal experience and past employment in similar settings (Korczyk, 2004).

#### 4.1.3 Carers' roles after admission

Carers' roles after admission were characterised by continuity on the one hand and change on the other. Thus all respondents maintained contact with their relative through regular visiting and the performance of practical tasks such as dealing with laundry and clothing and through the performance of a quality assurance role. Against this context of continuity, carers' relationship with their relative reportedly changed, sometimes for the better and sometimes for the worse:

*It's a kind of warmth coming between the two of us even though she cannot communicate with me but there's an understanding there which sounds weird but that's the one consolation that has come out of this disease. (daughter)*

*I would feel much happier if I felt I could have a better relationship with him but I can't so I have to accept just what I can do. Just sit with him and talk a little bit. But there's no real conversation I can't tell him any of my problems. I can't get any support from him. (wife)*

Some carers acknowledged they had difficulties communicating with their relatives and were curious if they could be helped. Communication with care home staff was also an issue with some finding this to be satisfactory, while others were either reluctant to initiate this communication or were unclear as to what purpose it would achieve.

#### **4.1.4 Carers' role aspirations**

Carers aspired to have a continued involvement in the care of their relative and for those with the time and inclination, an involvement in the wider life of the home:

*There'll be someone going down to see her all the time...if you keep going in she won't forget you. She has to see your face I think... I'm still going to be her carer. (sister).*

However, not all carers were clear what they wished their role to be, possibly due to the fact that they were still getting to know the care home setting and adjusting to this new setting (Seddon et al, 2002). In addition, some carers simply may not want to become involved in communicating their views and expectations to staff and would prefer to leave relevant decision making to the 'experts', allowing them time to reestablish their own lives. Moreover, in spite of the quality standards in Ireland which stipulate that residential care provision should promote the continued engagement of the family carer (HIQA, 2009) some respondents were unsure about how to maintain involvement in their relative's care and how receptive staff would be. This was also reflected in the study by Woods et al (2008), which found that care home staff across Europe sometimes perceived carers' wish for continued involvement in negative terms and as indicative of their difficulty in 'letting go'.

Moreover, while encouraging the involvement of carers, in order to meet the needs of residents who do not have carer support, as well of the needs of carers who do not want to provide it, care homes should obviously not become over reliant on this involvement. One commonly cited way in which this can be achieved is through the implementation of 'shared care' or 'sensitive interweaving' between formal and informal sectors. While this dynamic welfare partnership is commonly associated with community based initiatives it is equally applicable to the care home settings where, with the help of formal input residents and relatives engage in mutually supportive activities through such things as volunteer schemes, support groups and user led initiatives. Similarly, within the UK, the government has placed an emphasis on empowering people with dementia for example through Local Involvement Networks and through the development of initiatives such as the Expert Patients Programme which is delivered by and for people with a long term condition (Litherland, 2008). Living wills and advanced care planning are another way in which people with dementia can influence choices and decisions about their care. The role of carers as an appointed advocate for these choices further emphasises the need for their involvement in the care home setting (Woods et al, 1998).

#### **4.1.5 How carers' aspirations can be achieved**

Carers felt that their desired role in long stay care was facilitated by a positive relationship with the care home. Identified elements of this included the establishment of good lines of two way communication, the acknowledgement of their expertise and an accessible care home setting. In this respect, Woods et al (2008) recommend that dementia care homes should embrace the concept of working with families rather than replacing them by actively seeking the views of carers and acknowledging their input. They go on to point out the positive benefits that will be achieved through these greater levels of involvement through such things as the prevention of duplication and gaps in care provision. All involved parties would also potentially benefit due to increased

job satisfaction for staff, the promotion of person-centred care for residents and a greater sense of inclusion for relatives. Similar recommendations can be made with regard to the promotion of communication between care home staff and relatives which should be an open and two way process and is facilitated through such initiatives as the identification of resident key workers:

*Well they need to be comfortable to pick up the phone and call you if there's a problem and I think it's better for you as an individual if you know who you're talking to. (son)*

The provision of information and education about dementia and dementia care as well as the provision of emotional support also emerged as an important goal. Carers' need for information about dementia and dementia care was often met by carers themselves researching relevant issues on the internet, through organisations such as the Alzheimer Society of Ireland or through their attendance on courses. Care homes could also play a role in this process of education with some recent initiatives introducing collaborative working between relatives and care home staff (Woods et al, 2008) and involving carers and residents themselves in running courses (Brooker et al, 2009; Litherland, 2008). In addition, carers recognised their need for continued emotional support after the transition to long-term care had taken place. For like the process of transition, the post transition phase was also accompanied by many negative emotions such as guilt bereavement and loneliness with many relying on informal networks, religion and formal counselling in order to cope with these feelings. Some also spoke of the beneficial and therapeutic aspects of talking about their experiences as a result of their participation in this research:

*Thank you for your questions because its helped me just to talk about it you know...I hope it is of some use. (wife)*

As Woods et al (2008) recognised this need for ongoing emotional support for carers is an important area for future service development.

## 4.2 Study limitations

This small exploratory study of carers' experience of their relative's transition to long stay care has five key limitations. Firstly, this small sample of carers may be unique in that all had prior contact with either the Alzheimer Society of Ireland or St. Luke's Home and were willing to participate in a study about a sensitive and painful topic. Secondly, by virtue of their participation in this study, they were likely to be relatively 'involved' in their role as carers as compared to other non-participating carers. Thirdly, due to its qualitative nature, the study has been unable to assess the extent to which these research findings reflect systematic differences in the population of family carers in Ireland. In addition, it has been unable to draw any cross-national comparisons. Fourthly, the study has omitted the perspective of people with dementia and their experience of the transition to care. This is a notable omission as not only do some people with dementia not have any available carer but also have a unique perspective which may or may not be consistent with the perspective of the carer. Fifthly, while attempts were made to incorporate a longitudinal perspective, this perspective was limited to a period of a few weeks. As such, greater understanding of carers' experiences may have been achieved if the research had covered a longer time span, particularly at the post transitional stage.

## 4.3 Conclusion

Carers in this study decided to admit their relative to long stay care following an accumulation of inter-related contributory factors. These included the stressors associated with 24-hour care, lack of support, and conflicting roles and responsibilities. The decision was rarely made alone and was frequently facilitated by professionals' involvement. The transition of their relative in to care was fraught with ambivalence. On the one hand carers felt a sense of relief from the practical demands of caring, while on the other they experienced painful emotions including guilt, sadness, loss, loneliness and bereavement. Adjustment to the transition was facilitated by the perceived quality of care provided in the long stay setting, familiarity with the long stay setting, and the provision of emotional support. It was also effected by the nature of the caring relationship, the attitudes of others including the perceived disapproval of society and the passage of time.

All carers were committed to ensuring quality of care and quality of life for their relative. They were keen to stay involved in their relative's life and care. This they thought could be facilitated by an accessible and welcoming care home, a communicative staff group who acknowledges and utilises their expertise and who provide information and emotional support to families. Carers provided a range of examples where the latter might be provided including mentor schemes and peer support groups. However, this wish for high levels of involvement was not shared by all respondents. Thus as Zarit and Zarit (2008) observe, practitioners should recognise the diversity of carers and encourage them to set their own goals and make their own decisions.

Currently, there are 38 thousand people with dementia in Ireland, this is predicted to increase to over 70 thousand by 2026 and to over 103 thousand by 2036 (ASI, 2007). Consequently, there is a compelling need to address the practical and emotional demands of caring for a relative with dementia in the community. There is an equally compelling need to recognise that carers continue to care for their relative after their admission to care. Carers' role in these long stay settings need to be actively facilitated by care home staff and provision made for their involvement. There are a range of actions required in the areas of policy, practice and research which will assist with supporting family carers to care for their relative throughout their journey with dementia.

## 4.4 Recommendations

- **The Department of Health and the Health Service Executive need to significantly enhance the resourcing of, and access to, community based services for people with dementia and their carers, so that nursing home admission is a proactively planned choice rather than being crisis-driven.**

The lack of suitable community based support and services was described as being a key determinant in pursuing long-term care as well as in influencing the ease with which the subsequent transition to this care took place. For example, the benefits of respite care in alleviating carer strain and in easing the process of transition was a recurrent theme for respondents in this research. However, access to services tended to be arbitrary and resource led with luck or access to private financial resources playing an important role. Therefore there is a real need to increase resources and for better planning and regulation of these services at a local and national level. This can be achieved through such things as the widespread adoption of a case management model and through a strategy for dementia care in Ireland which incorporates significant investment and which will meet the current and future needs of people with dementia and their carers.

- **The Department of Health and the Health Service Executive must recognise that people with dementia and their carers need guidance and support in order to navigate the system and when accessing services both at the pre and post transition stages.**

The fragmentation of support services for people with dementia and a lack of guidance and knowledge resulted in confusion amongst carers over what support was available and how it could be accessed. This can be addressed, for example, through the appointment of key personnel in the community, the acute hospital setting and in the nursing home who will be responsible for guiding people with dementia and their carers through the system.

- **The Alzheimer Society of Ireland in partnership with other agencies needs to challenge the ignorance and stigma associated both with dementia and with nursing home care.**

The promotion of awareness and the education of a range of stakeholders is needed, in particular amongst a broad range of health care professionals, in order to challenge the ignorance and resulting stigma associated with dementia. This dementia-specific education could form part of the continuing professional development of relevant personnel both in acute settings and in the community. Work is also needed to address the stigma of nursing home care and to promote the role that good long stay care can have in ensuring quality of life for people with dementia and their families.

- **Community based practitioners (General Practitioners, Public Health Nurses, Social Workers, Psychiatrists of Later Life) should adopt a persuasive, proactive and preventative approach to people with dementia and their families through the prompt and gradual input of appropriate support.**

Older people with dementia and their carers are often reluctant to accept services and can consequently be invisible to service providers until a crisis point has been reached. The receipt of respite care can be hugely beneficial in this respect, not only providing a form of incremental relief to the carer but also promoting confidence in the quality of care provided in the nursing home setting and providing a phased approach for adjustment to changed circumstances. Assessment should also be an ongoing process as people with dementia and their families gradually come to terms with their need for service input.

- **Managers of nursing homes need to ensure the provision of dementia specific training and education of their staff in order to promote the provision of quality care which upholds the dignity and humanity of the person with dementia.**

This can be achieved through responsive and ongoing training and well informed and skilled managers. For this training to be effective it needs to be embedded in the organisational culture through supervision, modeling and continuing quality improvement methodologies such as Dementia Care Mapping (National Institute of Health and Clinical Excellence and the Social Care Institute for Excellence, 2006).

- **In accordance with HIQA National Quality Standards, nursing home managers and staff must recognise and actively support carers' who wish to remain involved in the long term care of their relative, while respecting the wishes of those who no longer want to play such a role.**

Roles that carers wished to perform included care monitoring, advocacy and decision making for the person with dementia and supplementing care both outside the home and within it. In order that these roles can be achieved there needs to be an accessible and welcoming care home environment, an open visiting policy and the provision of opportunities for carers to participate in the wider life of the home. These measures will not only facilitate carer involvement but will also help to forge community links, helping to counter the stigma which some still attach to long term care long stay settings. There is also a need for greater clarity with respect to the respective responsibilities of staff on one hand and carers on the other. This can be achieved through

written agreements, the establishment of good lines of communication between the two groups and the identification of key workers.

- **Nursing home providers, the Alzheimer Society and other relevant service providers and agencies need to provide information, education and emotional support to carers at the various stages of the transition process.**

The Alzheimer Society of Ireland should develop a resource pack/information leaflet that can be made available to families to help guide them through the transition to include not only the practical information but advice and support around handling the emotional and psychological aspects of the transition. 'Letting go without giving up' by Alzheimer Scotland (2005) provides an example of the type of publication that would be useful in this respect. The facilitation of networks of mutual support is also needed, through the establishment of support groups either within or outside the nursing home. These types of interventions meet the carers' commonly expressed needs for information and support. For some people, support groups provide an opportunity for relatives to meet, discuss issues of mutual concern and can also perform an educational role in which people with dementia and their carers are themselves involved in training sessions. Other carers may welcome the opportunity for more one to one dialogue, whether with peers or professionals. The use of web-based information and supports such as on-line forums are an option to consider in this respect.

- **Researchers need to examine this area in greater detail.**

There are four key areas for research coming from this report. Firstly, there is a need to examine the extent to which the findings reported here apply to the broader population of family carers in Ireland, and how these compare with other countries. This will require a quantitative survey of family carers, using the categories identified in this qualitative study. If available, secondary analysis of relevant data sets could be used to identify systematic differences in the characteristics of people with dementia and their family carers who use long stay care. Secondly, given the new HIQA standards, it is timely to focus on strategies for involving family carers in care of their relative in long stay settings. Quantitative, survey research could be conducted which explore factors which facilitate and inhibit carers' involvement in the nursing home setting. In addition, intervention research could compare the effectiveness of different approaches to partnership working with family carers. Thirdly, it would be useful to conduct a prospective, longitudinal study in order to understand how carers' aspirations and priorities change from the pre-transition through the post-transition phase. Fourthly, there is now a compelling need to explore the experience of transition from the perspective of people with dementia. Research of this nature will assist in efforts to ensure that services address the unique needs of people with dementia and will also identify areas of commonalities and differences in the experience of transition.

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# APPENDICES

## Appendix A: Information sheet

### **Who is carrying out the research?**

Professor Murna Downs, University of Bradford  
Elaine Argyle, University of Bradford

### **Who is the Alzheimer Society of Ireland's contact ?**

Annie Dillon, National office  
Tel: 01 2073804  
Email: adillon@alzheimer.ie

### **Who is the St. Luke's Home Contact?**

Julia Horgan, Director of Care, St. Luke's Home, Cork  
Tel: 021 4359444, ext. 506  
E-mail: julia.horgan@stlukeshome.ie

### **What is the purpose of the research?**

Alzheimer Society of Ireland and St Luke's Home, Cork wish to understand carers' experiences of their relative's recent move to a long stay setting. They have asked us to carry out this research.

### **What will I be asked to do in the research?**

You will be asked to take part in a focus group with up to five other family carers. The focus group will be run by the researchers, Murna and Elaine. You will be asked about:

1. How your role has changed as a result of your relative's move to a long stay setting.
2. What types of roles you would like to have in caring for your relative in the long stay setting.
3. What would help you to have these types of roles.

The focus group will last one hour and will take place in your local area. Your travel expenses will be reimbursed and there will be refreshments served.

You may take a break or stop participating any time you wish.

The focus group will be digitally audio recorded.

### **What are the benefits of taking part in the research?**

There are no direct benefits of taking part in this research. That said you will be helping to raise awareness of the issues carers face when their relative has moved to a long stay setting.

### **What will happen to the information I provide?**

The information you provide will be anonymised by removing your name and key identifying information. It will be stored in a locked filing cabinet at the University of Bradford to which only the research team will have access. It will be used to raise awareness of the issues carers face when their relative moves to a long stay setting and it will be used to write academic papers.

### **Who do I contact with any questions I might have?**

Professor Murna Downs, University of Bradford

Tel: 01274 233996  
Email: m.downs@bradford.ac.uk

## Appendix B: Consent forms

### Continuing to care: The perspective of the carer of a person with dementia

**Please circle one:**

- I agree to the focus group being digitally audio recorded yes / no
- I understand the purpose of the research yes / no
- I understand what I am being asked to do in participating in this research yes / no
- I have been given a chance to ask questions about the research yes / no
- I know who to contact about the research yes / no
- I know I can withdraw from the research at any time, I just need to tell the researchers yes / no
- I agree to participate in this research yes / no

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Print name: \_\_\_\_\_

Researcher signature: \_\_\_\_\_ Date: \_\_\_\_\_

Print name: \_\_\_\_\_

**Please circle one:**

- I understand that I am the legal owner of any photographic images I take for the research yes / no
- I agree to my photos being used for:
  - 1. The final report yes / no
  - 2. Presentations yes / no
  - 3. Educational purposes yes / no
- I understand if I don't want any of my photos to be used I just have to tell the researcher yes / no
- I agree to the interviews being digitally audio recorded yes / no
- I understand the purpose of the research yes / no
- I understand what I am being asked to do in participating in this research yes / no
- I have been given a chance to ask questions about the research yes / no
- I know who to contact about the research yes / no
- I know I can withdraw from the research at any time yes / no
- I agree to participate in this research yes / no

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Print name: \_\_\_\_\_

Researcher signature: \_\_\_\_\_ Date: \_\_\_\_\_

Print name: \_\_\_\_\_

## Appendix C: Interview schedules

### First interviews

- What were the key influences in making the decision for your relative to go into a long stay setting?
- Who was involved in making this decision?
- What were your experiences of making the transition from caring for your relative at home to them being cared for in a long stay setting?
- How has your caring role changed as a result of your relatives move to a long stay setting?
- What types of role do you now want to have in caring for your relative?
- How can you be facilitated and supported to fulfill these desired roles?

### Second interviews

- Since we last spoke what has gone well and what has gone less well?

### Third interviews

- Can you talk about your four key photos?
- Why were they chosen and what do they say about your experiences?
- Third interviews were also structured around themes arising from carers' previous interviews.

## **Appendix D: Focus group schedule**

### **General introductions**

- How has your role changed as a result of your relatives move to a long stay setting - is this what you expected prior to the transition
- What do you enjoy or dislike about your current caring role. What types of roles do you want to have in caring for your relative in a long stay setting
- What sort of support do you need in order to ensure that these desired roles are fulfilled
- What influenced the decision to pursue care for your relative– what and who initiated this process
- How was this transition experienced – barriers and facilitators
- How do you think the person you care for has experienced the transition
- Are there any other issues that people would like to raise relating to their caring role

## CARERS' PHOTO STORIES

**My Story: My father's cap**



The cap he used to wear when sitting in the sun. He loved the sun. I used to like to see him sitting in the sun, things looked normal.

**My Story: My mother's books**



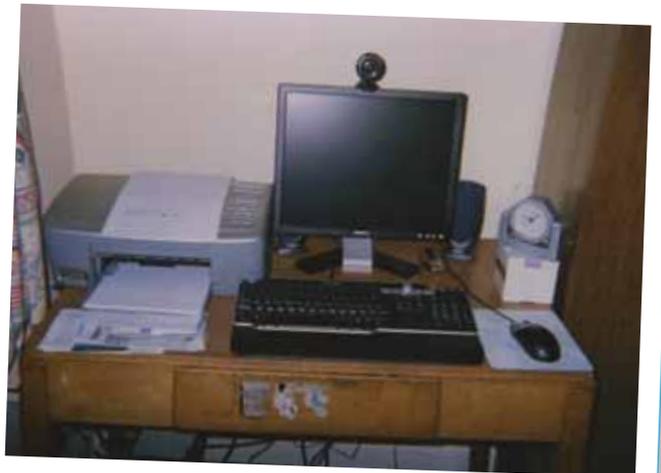
She had the power of knowledge through her love of books but now due to her illness she can no longer comprehend how to read and this is so sad.

**My Story: My father's crucifix**



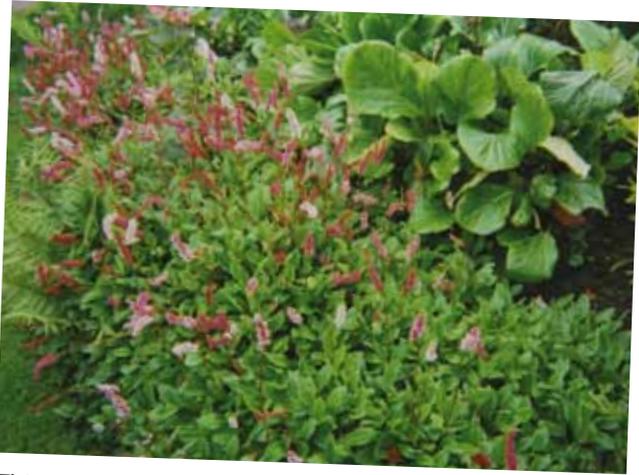
The crucifix outside his bedroom. He used to kiss it every time he passed it, no matter how many times he got up in the night .

**My Story: My desk**



This is where I have had to take responsibility for financial affairs. I also have to make all decisions regarding the care of the house and garden which my husband did previously with some assistance from me.

### My Story: Flowers



This photo reminds me of my mother's favorite colour which was pink. The flowers are in my garden and instill a nice memory of my mother.

### My Story: Sky



The blue sky in this photo represents for me a brighter outlook, so that even though the transition of my mother to a long stay setting was very hard to deal with there was always the prospect of better days to come.

### My Story: The cabinet



This is representative of my husband's heritage and is only a small part of it. The responsibility for this weighs on me somewhat – especially trying to remember the history and significance of some of the artefacts.

### My Story: My dog



This is a photo of my dog. She is my 'soulmate'. During my mother's transition to a long stay setting, when everything looked bleak, my dog was always there for me, giving unconditional support.

### My Story: The garden shed



This is significant because gardening was my husband's interest all his life... Now I carry on alone with occasional help from my son and a gardener. On the other hand there is great therapy for me in caring for the garden.





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