



School of Nursing and Midwifery  
Trinity College Dublin

# Between Worlds: The Experiences And Needs Of Former Family Carers

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# PROLOGUE

At any one time there are an estimated 274,000 Family Carers in the Republic of Ireland providing care and support to loved ones. For some this is a full-time, round the clock commitment, for others this is a less intensive role sometimes shared with other family members. In recent decades, significant progress has been made in state supports for Family Carers. The advocacy and efforts of the community and voluntary sector in securing these gains, and in particular that of The Carers Association, must be credited in this regard.

Once seen entirely in the context of duty and kept exclusively in the private family domain, family care is now more manageable for some thanks to crucial income supports, respite care (both in home and out of home) and other supports, although access to these supports continues to be limited for many with lengthy waiting lists. Many of these services are delivered by vibrant voluntary organisations, many of whom are members of Care Alliance Ireland.

Understandably, we have been less successful in recognising the needs of those whose caring has ceased. The 2006-2016 National Partnership Agreement specifically identifies the need to give support to former carers. *‘Consideration will also be given to enhancing economic and social inclusion supports to people whose caring responsibilities have concluded’.*

This is why we have worked hard to secure funds internally and specifically from the National Lottery and from the Research Council for Humanities and Social Sciences (IRCHSS) to find out more about carers’ experiences and needs in this post-caring transition period.

Care Alliance Ireland’s vision is that the role of Family Carers is fully recognised and valued by society in Ireland. We exist to enhance the quality of life for Family Carers. We achieve this by supporting our member organisations in their direct work with

Family Carers through the provision of information, developing solid peer-reviewed research in the field, sharing resources, and instigating opportunities for collaboration. As part of our Strategic Plan, we have two research objectives, namely; to inform service provision through the development of applied and evidenced policies and position statements based on ongoing qualitative and quantitative research, and to influence the Family Carer research agenda.

Engaging in collaborative research with leading third-level institutions such as Trinity College gives expression to these objectives. There is a continued challenge in bridging the gap between theory, policy and practice, and specifically ensuring that quality evidenced-based research influences the approach to service delivery as well as resource allocation. This is particularly important in times of economic downturn.

Former carers represent a significant yet unquantified and possibly not fully quantifiable cohort of our population. We know that after caring ends many carers’ health and wellbeing often deteriorates.

Care Alliance Ireland is delighted to have embarked on this piece of quality research in collaboration with Mary McCarron and her team in the School of Nursing and Midwifery in Trinity.

As this research progressed, some aspects of carers’ and former carers’ lives became even more apparent; their resilience and their proactive community endeavours after their caring has ended; the real challenges for carers not only to provide care but also to manage the difficulties in preparing for and anticipating loss; the importance of the voluntary sector being clear about the areas in which it can meet needs adequately and which areas only the state can do so. It was heartening to read of the potentially therapeutic impact the research process may have had on the former carers who volunteered to be interviewed. The less than satisfactory experience



with health care professionals, as reported by many of those interviewed, is of concern.

Other findings of note, as detailed more comprehensively later in this report, include;

- The need for more access to pre- and post-bereavement counselling.
- The need for healthcare professionals to make more meaningful attempts at post-caring follow-up and to undergo training in understanding loss as it affects former carers.
- The need to consider extending the timeframe for the payment of the Carers Allowance, post caring.
- The need for those of working age to be actively supported by employment agencies to return to the paid workforce.
- The need to actively facilitate former carers in supporting current carers.
- The need for information to support former carers.

On the latter we are delighted to be able to say that we are currently working with four other carers' organisations throughout Europe to prepare a booklet for former carers, tailored to each country, to be published later in 2011.

The other recommendations will require active effort on all our parts to make them happen. It is reassuring, however, that the new Programme for Government commits to publishing a National Carers Strategy.

The conceptual framework developed in this research has been immensely helpful in our understanding of the issues faced by former carers. At each of the three stages identified – the loss of the caring world, living in loss and moving on – there are various and multiple opportunities for health and social care professionals, as well as family and friends, to reach out and offer support. A timely visit, a meal delivered, a kind letter or even a text, all can make a difference but these need to be more than once-off. Ongoing support to former carers to engage in their new world is important.

We know that while some former carers already receive considerable support from carers organisations, more remain 'below the radar' of both statutory and voluntary health and social care services. Sometimes this is their preference and indeed their right. Others continue to care, for neighbours, other relatives and often by volunteering in their local community.

Many however are not adequately supported, as this piece of research demonstrates, and action is warranted in this regard.

We look forward to working further with Trinity College in bringing further insight to health and social care professionals and the wider community about our collective responsibility to support former carers.

Liam O'Sullivan  
Executive Director, Care Alliance Ireland

# EXECUTIVE SUMMARY

## BACKGROUND TO THE STUDY

The Census 2006 defined a carer as someone who 'provides unpaid, personal help for a friend or family member with a long-term illness, health problem or disability' (Government of Ireland, 2007a, p. 191). However, it is important to note that many people who meet the official criteria do not self-identify as carers, rather they view their caring activities as a central aspect of their family role such as spouse or parent (Hynes et al, 2008).

Health policy trends towards home care, and advances in treatment and technology to support people with advanced chronic illnesses mean that more people with debilitating illnesses are living longer with increased dependency (Department of Health & Children, 2008). Specialist support services for these chronic illnesses are more usually hospital-based and family carers for such patients receive little support in the community. Additionally, a rapidly ageing population and a declining family size mean 'family' as a caring unit in Irish society is undergoing a period of uncertain change (Fahey & Fields, 2008; Timonen, 2008). Higher unemployment rates and reductions in social welfare payments in Ireland further negatively impact on the lives of informal carers (Carers Association, 2010a). These factors highlight the importance and timeliness of researching family care in Ireland.

In Census 2006:

- 161,000 people identified themselves as carers (4.6% of the population).
- 61,000 males and 100,000 females.
- Dominant age cohorts in the caring population are 45-54 years and 55-64 years.<sup>1</sup>
- 93,000 carers provide 1 to 14 hours of caring a week, with 41,000 carers providing over 43 hours per week (Fahey & Fields, 2008).

The Central Statistics Office 2009 Quarterly National Household Survey included a special module on carers and utilised a broader definition (Central Statistics Office, 2010) resulting in an increased prevalence estimate for carers (from 4.6% in 2006 to 8% in 2009):

- 21% (N=4,515) reported that they spent more than 57 hours caring per week
- 38% (N=8,170) reported feeling completely overwhelmed by their caring responsibilities.

Findings here that suggest that the sustainability of informal family care is under severe threat are further supported in the available research; Hynes et al (2008), O'Brien (2009) and O'Sullivan (2008) have all pointed out poor health and wellbeing among Irish carers.

Given the emerging evidence of an at-risk carer population, the postponement of the publication of the National Carers Strategy, and the reduction in carers' social welfare payments are likely to add to existing stress. The paucity of explanatory primary research means more work is needed, including the current research project, which addresses a group of carers who have not been well described; post-caring/care transitions carers.

Although there is not an extensive literature, two primary theoretical models of post-caring have emerged. Larkin's (2009) model focuses exclusively on post-caring after the care receiver has died. Conversely, the Davies & Nolan (2003; 2004; 2006) model outlines stages experienced by carers after their care receiver has been placed in a care facility. The present study incorporates both understandings of the post-caring/care transitions experience and examines life before post-caring/care transitions among carers largely for whom the care receiver has died.

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<sup>1</sup> There are also 3,000 young carers in the State (Becker, 2010; Carers Association, 2009; Government of Ireland, 2007a).

**Study aim:** Describe the experiences and needs of former family carers in the post-caring/care transitions period.

**Definition:** Former family carers are defined as family members who provided physical and/or social care to a family member with an illness or disability in the home for at least six months prior to nursing home/hospice placement or death.

Note: The researchers recognise that the caring role generally continues but in an altered way after at-home caring has ceased and the care-receiver has moved into either a nursing home or hospice.

**Overarching research question:** What are the experiences and needs of former family carers in the post-caring/care transitions period?

## SPECIFIC RESEARCH QUESTIONS:

1. What are family carers' needs in relation to the period following the cessation of caring?
2. What are family carers' experiences in relation to the period following the cessation of caring?
3. What are family carers' perceptions of factors affecting their life quality in the period following the cessation of caring?
4. What interventions do family carers believe would improve their life quality in the period following the cessation of caring?

## METHODOLOGY

This was a qualitative study of the lived experience of former carers. With support from Care Alliance Ireland and the Carers Association, a total of 40 former family carers were identified and recruited. There were two groups: an initial group of 14 participants who formed a focus group and 26 additional carers were subsequently selected for individual interviews.

**Sample:** Seven male and 19 female former carers agreed to individual interviews; their mean age was 57 years but they ranged in age from 33 to 81 years old. The length of time spent caring for the care receiver ranged from six months to 27 years, with a mean of seven years nine months. Most were caring for either a parent or a spouse. Death of the care receiver was the reason for post-caring/care transitions for 25 of the 26 interviews. At the time of interview, the length of time since the post-caring/care transitions ranged from three months to six years with a mean of two years.

**Approach:** A trained facilitator worked with the focus group participants to explore two themes identified from the available literature:

- α) When there was a transition due to nursing home placement – alterations to the carer role, stress related to the transition and to fraught relationships with staff and the need to reconstruct relationships
- β) When the transition was due to death – preparation for bereavement and ability to access socio-emotional and financial support.

Review of the audiotapes of the focus group discussions helped in formulating a semi-structured interview protocol designed to further elucidate and validate issues raised in the focus group and to probe for additional important issues and related details not yet discussed including the experience of caring/transition; needs, factors affecting quality of life, interventions and transition experiences

**Analysis:** Template analysis (Crabtree & Miller, 1999; King, 2004), supported with NVivo 8 software, was the method of analysis employed for the 26 individual interviews. Rather than transcribing interviews, the data was analysed directly from the audio recordings. This approach ensured that the voice, tone and emotion of participants were not lost and had the opportunity to influence the analysis.

## FINDINGS

Two major explanatory themes emerged from the data: being 'worldless' and being 'between worlds', as did three post-caring/care transitions processes: 'the loss of the caring world', 'living in loss' and 'moving on'.

The following diagram illustrates how the loss of the pre-caring world (i.e. life prior to becoming a full-time, primary carer with all its social contacts, employment and other opportunities) is followed post-caring/care transitions with the loss of a "caring world"; daily routines, carer role and identity, close relationship with care receiver, and social network of medical personnel visiting their home have suddenly dissipated. The double losses create a profound sense of loss and emptiness. The loss of the pre-caring world is more distant; the transition is instead between their just-ended caring world and a newly reconstructed world after caring. In this transitional state carers feel 'worldless'; not belonging to any particular place and not having any particular label or identity that applies to them (see Figure 1.1).



**Figure 1.1: Level One of Conceptual Model**



The next level of the conceptualisation captures the ‘between worlds’ state visually represented by the pink-shaded rectangular area in figure 1.1 magnified in figure 1.2 to incorporate the post-caring/care transitions processes of (i) Loss of Caring World, (ii) Living in Loss and (iii) Moving On.

### (i) LOSS OF CARING WORLD

The loss of the caring world occurs at the beginning of the post-caring/care transitions phase. The losses are multi-dimensional; loss of identity as carer, of role as carer, of the close bond with the care receiver, and of the social relationship with the network of healthcare professionals.

### (ii) LIVING IN LOSS

This refers to the process of living in and continually experiencing the losses of post-caring/care transitions. Key features are the emotional reactions to post-caring/care transitions such as guilt, relief and a sense of urgency and anger towards State services. The losses are exacerbated by the perceived dismissal and devaluing of the former carer by State systems becoming a barrier to ‘moving on’ to a new world

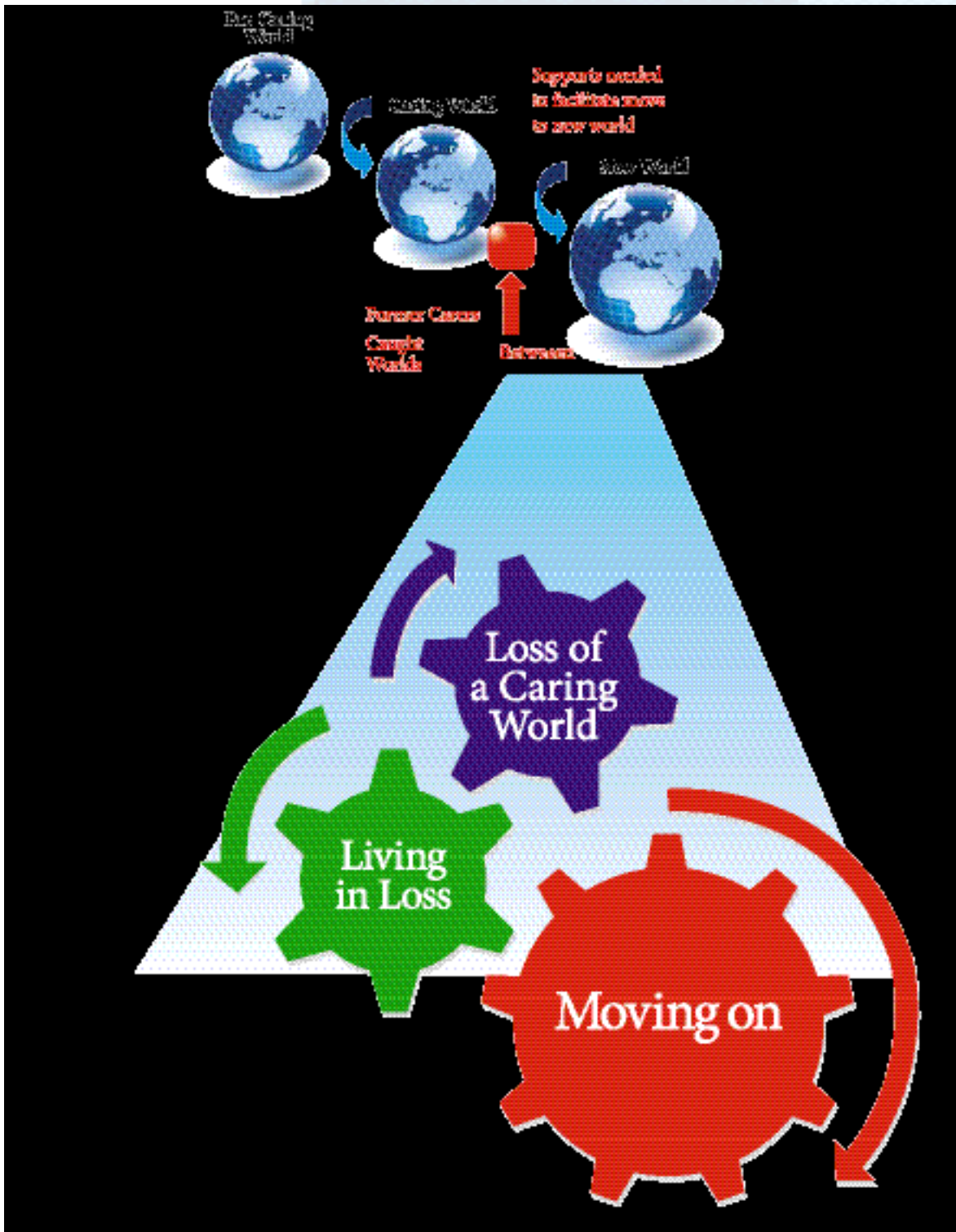
after the cessation of caring. Other barriers include post-caring/care transitions financial difficulties with loss of carer allowances and difficulties returning to the workforce.

It appears that although some former carers ‘move on’, others continually move between the ‘loss of the caring world’ and ‘living in loss’ in a continual, cyclical movement. They become ‘stuck’ in the losses of post-caring/care transitions and do not move on to the third ‘cog’ enabling them to construct a new, post-caring/care transitions world.

Those who ‘move on’ from this cycle move out of the ‘trapped’ space between worlds, no longer viewing themselves as ‘worldless’ and constructing a new world. Facilitators identified included family support and support from carers’ organisations.

[The presentation of this second level of the model illustrates how the post-caring/care transitions phase is a cyclical and interactive process].

Figure 1.2: Level Two of Conceptual Model



### (iii) MOVING ON

This is the concept of former carers proactively beginning to move on to a new world by caring for themselves, keeping active, becoming involved in their community and ‘getting out of the house’. For some former carers, ‘moving on’ involves taking up

other caring activities, such as mentoring other family carers or taking care of grandchildren.

An additional and unexpected finding was that male carers reported equal levels of challenge and stress but also described the support they received from small,

organically emerging, male support groups where two to three men (including widowers and former carers) meet for social outings or in each other's houses; emotional support becomes a by-product of the social occasions.

## CONCLUSIONS

The participants highlighted that there were currently no statutory health or social care services in place for former carers. Given the 'between worlds' experiences described, the sense of being 'stuck' and the financial stress reported by many participants, this is a major service gap. Formal statutory supports and support structures through carer groups aimed specifically at former carers are needed, including bereavement support. A health promotion and self-help toolkit might also help prepare carers for when caring ceases by addressing what the experience will entail and offer signposts for help and advice. Finally, former carers have developed extensive knowledge of the health and social care services system and individual professionals in their locality. Mechanisms were requested by carers to utilise their wealth of untapped knowledge to help advise and guide current carers.

Established local carers' support groups typically have a higher proportion of women than men in attendance but men constitute 40% of carers in Ireland and are therefore under-represented in carer

groups and other services. Findings here offer suggestions for carers' organisations and formal services to consider as they develop options that are more appealing to post-caring/care transitions male carers.

The sampling approach taken in this study meant that the participants were linked to carers' organisations, therefore not necessarily the most marginalised of former carers; future work should reach out to this group. Also, the majority of the interviewees were in the post-caring/care transitions phase due to the death of the care receiver. There was an under-representation of those undergoing post-nursing home placement and post-hospice transition. However, most of the existing literature focuses on post-hospice and post-nursing home placement transitions. This study begins to address the dearth of data on post-caring/care transitions experiences due to death.

A picture emerges of former carers with many strengths that are not well appreciated and utilised, a group where some find themselves stuck between worlds, and in financial and mental health distress, yet a group who have many suggestions for supports that will make the difference. Future research and services must be responsive.

# FIGURES

- Figure 3.1
- Figure 3.2
- Figure 3.3
- Figure 4.1
- Figure 4.2

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# 1

## BACKGROUND TO THE STUDY

### 1.1 INTRODUCTION

This section provides a general introduction to what is known about informal, family carers in Ireland.

- Broad socio-economic trends influencing Irish family carers as well as a statistical profile on the current carer population are presented.
- The social welfare payments available for carers are described.
- The Irish policy context in relation to caring is outlined.

Finally, key findings from Irish research on family carers are discussed.

### 1.2 INFORMAL CARE IN IRELAND

The combination of health policy trends towards home care, and advances in treatment and technology to support people with advanced chronic illnesses, mean that more people with debilitating illnesses are living longer with increased dependency (Department of Health & Children, 2008). Since the specialist support services for these chronic illnesses are more usually hospital-based, family carers for these patients receive little support in the community. Additionally, 'family' as a caring unit in Irish society is undergoing a period of uncertain changes. New demographic trends include a rapidly ageing population and a declining family size (Fahey & Fields, 2008; Timonen, 2008). Recent economic changes in Irish society, such as high unemployment rates and reductions in social welfare payments, have also had an impact upon the lives of informal carers (Carers Association, 2010a). These factors highlight the importance and timeliness of researching family care in Ireland.

The Census 2006 provides figures on family carers in Ireland, in which a carer was defined as someone who 'provides unpaid, personal help for a friend or family member with a long-term illness, health problem or disability' (Government of Ireland, 2007a, p. 191). However, it is important to note that many people who meet the official criteria for being categorised as a carer do not self-identify as such, rather they view their caring activities as being a central aspect of their family role such as spouse or parent (Hynes et al, 2008). In Census 2006:

- 161,000 people identified themselves as carers (4.6% of the population).
- 61,000 males and 100,000 females.
- Dominant age cohorts in the caring population are 45-54 years and 55-64 years.<sup>2</sup> 93,000 carers provide one to 14 hours of caring a week, with 41,000 carers providing over 43 hours per week (Fahey & Fields, 2008).

The Central Statistics Office included a special module on carers in the Quarterly National Household Survey in Quarter 3 of 2009 (Central Statistics Office, 2010). This large-scale survey included a representative sample of private households within the State. This most recent survey reported similar gender and age trends as the Census 2006. However, there was a higher prevalence of carers than had been found in the previous Census (i.e. 8% rather than 4.6%). This could be explained by the broader definition of caring used in the Quarterly National Household Survey.<sup>3</sup> Of the 21,500 carers who responded to this survey:

- 21% (N=4,515) reported that they spent more than 57 hours caring per week
- 38% (N=8,170) reported feeling completely overwhelmed by their caring responsibilities.

2 There are also 3,000 young carers in the State (Becker, 2010; Carers Association, 2009; Government of Ireland, 2007a).

3 The Quarterly National Household Survey referred to 'looking after or give special help to'.

Carer's Allowance and Carer's Benefit are the two social welfare payments available to full-time, informal carers. One either receives Carer's Allowance or Carer's Benefit; it is not possible to receive both.

The Carer's Allowance is means-tested and so not all full-time informal carers receive this allowance. From January 2011, Carer's Allowance for carers aged up to 65 and those over 66 caring for one care receiver amounted to respectively €204 and €239 per week (Government of Ireland, 2010).<sup>4</sup> Those carers who were in receipt of other social welfare benefits were not entitled the full Carer's Allowance.

Carer's Benefit is available to those who have left the formal labour force in order to care full-time, up to a total of 104 weeks. This corresponds with Carer's Leave which is for up to a maximum of two years. From January 2011, Carer's Benefit amounted to €205 per week.

To put these payments in context, from January 2011 the Jobseekers Benefit amounted to €196 per week. The weekly income for someone on the minimum wage was approximately €267.75 (€7.65 per hour x 35) (Government of Ireland, 2010).

In terms of the post-caring/care transitions phase, both Carer's Benefit and Allowance are paid for six weeks after the caring ceases. It has been argued that this is too short a time for carers to adjust and acquire the skills that they need to return to work (Equality Authority, 2005).

There is a Respite Care Grant worth €1,700 available for family carers. It is automatically administered each June to those who are receiving either Carer's Benefit or Carer's Allowance. However, carer groups argue that this grant does not cover the full cost of providing for 4 weeks respite care; 4 weeks being the statutory annual holiday entitlements for employees in the State (i.e. 20 days) (Care Alliance Ireland, 2009; Carers Association, 2008).

### 1.3 IRISH POLICY CONTEXT ON INFORMAL CARE

A number of Irish policy documents are relevant to family carers. As outlined in the Primary Care Strategy (Government of Ireland, 2001), Government policy favours the provision of care in the home for as long as is possible. The National Action Plan for Social Inclusion 2007-2016 (Government of Ireland, 2007b) highlighted the need for financial, educational and training supports for carers to ensure the successful implementation of the Primary Care Strategy. In addition, the Towards 2016 Social Partnership Agreement (Government of Ireland, 2006) is committed to expanding income limits for Carer's Allowance and to increase the Respite Care Grant. The need for respite and day care services to be part of community service, in order to give carers the necessary breaks from their caring role, was underlined by the latest National Development Plan 2007-2013 (Government of Ireland, 2007c).

Other policy documents deal specifically with the issue of family carers. The Joint Oireachtas Committee on Social & Family Affairs (Review of the Position of Full-time Carers) (2003) recommended abolishing the means test for the Carer's Allowance. The committee also suggested greater flexibility in respite care in relation to the evening and weekend, as well as addressing transport issues.<sup>5</sup> In 2005, the Equality Authority published a report advocating more state support for caring and a more equal sharing of the caring role between the State and carers. The report's recommendations included:

- Greater recognition of the diversity of carers (i.e. sometimes there are several secondary carers and one primary carer);
- A new valuing of caring through payment as opposed to the current situation of income maintenance (i.e. Carer's Allowance and Carer's Benefit);
- Eliminating the ten hours restriction on education for the Carer's Allowance.

<sup>4</sup> Both the Carer's Allowance for carers less than 66 years and Carer's Benefit were reduced by €8 per week in the Government's Budget 2011 (Carers Association, 2010b).

<sup>5</sup> Examples of flexibility included reduced taxi fare for rural carers instead of free travel pass due to the lack of public transport.

- Changes to the method of means testing for the Carer's Allowance to facilitate an individualised approach and independence from a spouse's income (Equality Authority, 2005).

Both the Towards 2016 Social Partnership Agreement (Government of Ireland, 2006) and the Joint Oireachtas Committee in 2003 highlighted the importance of developing a National Carer Strategy. The National Strategy was due for publication in 2008 and was to outline the Government's vision for family carers. This document was to establish a set of goals and plans in a range of areas, such as income support, health care and services, transport, programmes of training, labour market issues, and social inclusion. However, in March 2009 the Minister for Social & Family Affairs, Mary Hanafin TD announced the postponement of the publication of the National Carers Strategy due to lack of resources. An important proposed plank of the Strategy was the placement of the carer's needs assessment on a statutory footing through the introduction of a Carer's Bill. The assessment was to include an annual health screening for full-time Carers, an examination of the role of extended family, and a family impact statement (Carers Association, 2008).

The key policy challenge in the Irish context (as is true in many other countries) is the expectation that families will take on the bulk of care in the home with minimal support from the State. This model assumes that the State 'steps in' only when all else fails. Carers' organisations argue that the State should not automatically assume family availability and that a fairer sharing of caring between State and family should be put in place (Carers Association, 2008; Equality Authority, 2005).

#### 1.4 IRISH LITERATURE ON CARERS

Although there has been an explosion of family carer literature in the U.K. over the past 20 years (Nolan et al, 2003), in Ireland there are relatively few primary research studies on family carers. However, there have been some substantial additions in the past three years (Fives et al, 2010; Hynes et al, 2008; O'Brien, 2009; O'Connell et al, 2008; O'Sullivan, 2008; Stokes, 2010). This work is the first Irish study to examine post-caring/care transitions.

Prior to 2008, most research projects were either unpublished, regionally based or focused on one type of caring condition, such as Alzheimer's disease. The

first Irish study to examine caring was O'Connor & Ruddle (1988), which was funded by the National Council for Ageing and Older People (NCAOP). This project focussed on those who care for older people. In 1992, Blackwell et al from the Economic & Social Research Institute (ESRI) conducted the first study that made quantitative comparisons between carers and non-carers. They calculated and compared the cost of care of the elderly at home, with the care involved in hospitals. Ruddle & O'Connor (1993) also conducted a study of carers for people with Alzheimer's. This project was funded by the Alzheimer's Society of Ireland. The NCAOP funded another project in 1994 which examined the support services for carers (Finnucane et al, 1994). Carers in Clare were also researched in an unpublished report funded by Eiri Corca Baiscinn (O'Donoghue, 2003). This report recommended non-means testing of the Carer's Allowance, the availability of more information for carers and more awareness raising about carers.

A qualitative study conducted by Hynes et al (2008) offers an insight into the Irish carer's experience of caring for someone with advanced Chronic Obstructive Pulmonary Disease (COPD) illness. It was found that both carers and care receivers experience social isolation, loss of income and blurring of traditional domestic roles. Carers also lived in a heightened state of anxiety due to the care receivers' advanced COPD, especially fear of breathlessness and fear of death. Other COPD researchers, such as Williams (1993) have underlined the continuous 'clock-watching' and sense of urgency that accompanies the caring role as well as the pangs of guilt they experience when they are away from the care receiver.

Furthermore, the participants in Hynes et al (2008) reported that despite the expertise they had developed in relation to their care receiver's condition, they felt excluded from the care planning and decision-making process. Based on the findings, it was recommended that the carer-patient-healthcare professional triad should incorporate the carer's expertise. It was also proposed that promoting awareness of family carers and their support needs would further combat feelings of social isolation (Hynes et al, 2008).

Also focusing on a specific disease group, in a recent qualitative study of 20 Irish carers of people with Parkinson's disease, most carers viewed their main



contribution to care as allowing the person to remain at home. Although some carers resented the call of family 'duty' to become a carer, few of them considered the option of residential care (Stokes, 2010).

In a 2008 survey of the physical and psychological wellbeing of Irish carers (N=1,411), carers were less likely than the general population to report excellent or very good health (O'Sullivan, 2008). Carers also had a less positive picture of quality of life. They had comparatively high levels of depression, back pain and anxiety. They were at high risk from stress, emotional strain and social isolation. Limited recreational or leisure time appeared to be a contributory factor to poor health and quality of life. Some 76% of the sample (N=1,072) reported providing over 59 hours of care per week. The other major issues that emerged from the findings were carers' feelings of tiredness and a lack of sleep.

O'Brien (2009) also examined the health and wellbeing of Irish family carers. In this sample of 1,990 questionnaire respondents, 59% (N=1,174) worried about the fact that they had no time for themselves. In addition, 56% (N=1,114) worried about becoming ill themselves and the possible consequences for the care receiver. Of the support services made available to respondents for their role as carer, 74% of the sample (N=1,473) felt that these services are inadequate. The findings gave rise to recommendations for supporting carers through:

- Enabling free time of at least 10 hours per week for carers for their own mental and physical health;
- More flexible support service, such as home help and respite care at the weekends and during the evening time.
- Financial and psychological support.

The study highlighted the disparity between the actual organisation of support structures for carers and the need for a more individualised and responsive approach to supporting them.

While the recent research discussed above was directed at the needs and experiences of Irish family carers, these were not explored in the context of post-caring/care transitions. This is despite evidence of many carers caring over long periods. Given the limited financial state support for Irish carers in the post-caring/care transitions period and the impact of caring on health and wellbeing, questions arise as to how carers' experience their world of post-caring/care transitions.

## 1.5 CONCLUSIONS

The statistical profile provided here highlights that the majority of carers are female and over 45% are aged between 45 and 64 years old. However, it is important to recognise the diversity of the carer population. Quite a number of policy documents underline the need for increased supports for family carers. This is further emphasised by recent research studies which have demonstrated that the sustainability of informal family care is under severe threat. For example, Hynes et al (2008), O'Brien (2009) and O'Sullivan (2008) have highlighted the poor health and wellbeing of Irish carers. There is relatively little Irish primary research on carers in general and to date there is no Irish research published on the post-caring/care transitions phase. What research there is, points to a serious impact of caring on carers' health and quality of life. This picture is unlikely to change given the postponement of the National Carers Strategy. The all-encompassing role of informal carer combined with a compromised earning potential raises serious questions about the post-caring/care transitions phase.



# 2

## LITERATURE REVIEW

### 2.1 INTRODUCTION

This section describes the international literature examining post-caring/care transitions. Firstly, theoretical models of caring transitions are presented, including those that focus on the post-caring/care transitions phase. Following this, research on the post-caring/care transitions experience is discussed. Both the nursing home placement and death of care receiver post-caring/care transitions are detailed.

### 2.2 THEORETICAL MODELS OF CARING TRANSITIONS

As caring typically occurs over long periods of time, theorists have conceptualised caring in terms of a 'career', punctuated by key events or transitions (Gaugler & Holmes, 2003). It is recognised that one of the most significant transitions in this career is the movement into the post-caring/care transitions phase (Davies & Nolan, 2004; 2006). This section will firstly present stage models that encompass all elements of the caring career (Aneshensel et al, 1995; Brown & Stetz, 1999; Lindgren, 1993; Nolan et al, 2003). Following this, theoretical models that focus exclusively on the post-caring/care transitions phase (Davies & Nolan, 2004; 2006; Larkin, 2009) will be discussed. An extensive literature search has revealed four theoretical models which describe the characteristics of the initial, middle and final stages of being a family carer.

Lindgren (1993) labelled the first stage the 'Encounter Stage', where the carer confronts the diagnosis and losses of previous lifestyle patterns. It is during this first phase that carers learn home nursing skills. The next stage is known as the 'Enduring Stage', in which carers manage extensive care routines, while simultaneously trying to cope with social isolation and their mental pain. In the final or 'Exit Stage', the carer career is relinquished to some degree by either the death or the institutionalisation of the relative (Lindgren, 1993). However, it is important to note that this model was based on findings from ten semi-

structured interviews with carers caring for their spouses who had either dementia or Alzheimer's disease. These carers were still currently caring and so had not gone through the final stages of the caring career. The interviews were once-off and so the earlier caring stages were described retrospectively. Furthermore, caring for those with dementia or Alzheimer's disease may not reflect the experiences of all carers.

In 1995, Aneshensel et al identified multiple transitions in the 'carer career' including:

1. Assuming responsibility
2. Deciding to become a care-giver
3. Getting through the unfolding series of situations requiring attention and care
4. Relinquishing responsibility to an institution
5. Bereavement

Again, this model was developed from research on dementia carers, but from a three-year longitudinal study which enabled the changes in the carer career to be documented as they occurred.

Brown & Stetz (1999) outlined four phases involved in caring for a person with a potentially fatal illness. These stages were; becoming a carer, taking care, 'midwifing' the death and taking the next step. Indeed, contributing to their relative's quality of life was a pivotal aspect of the carer's role during both the initial phase of the illness and at the time of death. The final stage 'taking the next step' implies that the impetus for change lies with the carer. However, carers may find that the choices open to them are quite limited because of their perceived loss of skills for the workplace as well as loss of their social support network due to the demands of the caring role.

Building on previous work, Nolan et al (2003) proposed a six stage theoretical model of the caring experience, which focused in particular on the shifts in carer-care receiver relations. The six stages are:

1. Building on the past (former relationship)
2. Recognising the need (changing relationships)
3. Taking it on (fundamental change in relationship/ cognitive shift in recognition of caring role)
4. Working through it (carers respond to carer role)
5. Reaching the end (death/placement in a care home)
6. A new beginning (moving on with lives if death has occurred or reconstruction of caring roles after placement).

These temporal models highlight the fact that carer support must respond to the changes in circumstances over time, the trajectory of the illness and the life circumstances of the care-giver. All models view the post-caring/care transitions phase as a crucial element of the total caring experience. The Brown & Stetz (1999) and Aneshensel et al (1995) models see death rather than care facility placement as the end-point of the caring career. Such a view may underestimate the impact of relinquishing the primary carer role on identity, sense of guilt and monetary income. In contrast, Lindgren (1993) and Nolan et al (2003) view the post-caring/care transitions phase as beginning with either care facility placement or death. This latter interpretation of post-caring/care transitions was adopted in the present study. The next section presents theoretical models that focus exclusively on the final stage of caring.

The concept of 'former carer' has been recognised since the late 1980s but there are a limited number of published studies that focus on the topic. These include two theoretical frameworks in relation to the post-caring/care transitions phase (Davies & Nolan, 2003; Larkin, 2009).

Larkin (2009) postulates that the cessation of caring involves three distinct stages, namely, 'the post-caring void', 'closing down the caring time' and 'constructing life post-caring'. These phases are not experienced in a linear way but overlap. The 'post-caring void' is marked by acute loneliness and feelings of loss. The loneliness is due to the fact that carers are no longer part of the social network of healthcare professionals that was built up during their caring years.<sup>6</sup> The

feelings of loss centre on the loss of purpose and the loss of the role of carer, which was a key element of their overall identity.

During the 'closing down the caring time' phase, routines change and closure activities are undertaken. These include things such as no longer buying special foods for their relative in the supermarket. Visitors for the care receiver may initially continue to visit but after several months these visits gradually cease. Other closure activities include organising social welfare benefits and disposing of care related equipment (Larkin, 2009).

The 'constructing life post-caring' stage is highly influenced by families, friends, interests, paid employment and further caring activities. Among the majority of the participants, the amount of time spent on interests expands substantially. Involvement in carer support groups and organisations may continue. Larkin (2009) argued that the structure and routine provided by regular classes and meetings associated with various hobbies were also beneficial during this phase. Half of those in Larkin's (2009) research who returned to work changed their career in order to undertake paid employment associated with caring. Some 70% of the 37 carers had cared more than once and so could be categorised as 'serial carers'. This concept of 'serial carer' refers to the cyclical nature of caring and post-caring/care transitions in the lives of 'serial carers'. In many cases, these individuals indicated that they did not have a choice over resuming their 'caring lifestyle', rather they undertook the role again due to family obligations (i.e. someone close to them needed a carer). In this U.K.-based study, serial caring did not appear to have been linked to the perceived de-skilling or lost confidence for other work after a long period as carer.

Larkin's (2009) definition of former carers is limited to carers whose caring career 'ended with the death of their dependant' (p. 1029). The transition into the post-caring phase via the placement of the care receiver into a hospice, nursing home or other care facility was not addressed. Furthermore, an apparent underlying assumption in Larkin's post-caring trajectory is that all former carers move through the three stages of post-caring and will eventually recover

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<sup>6</sup> Typically, for these healthcare professionals, their engagement with the carer ends abruptly once the care receiver dies or is transferred to hospital.

from post-caring. It could be postulated that this is an overly optimistic view of the experience of former carers.

Davies & Nolan (2003; 2004; 2006) conducted 37 semi-structured interviews involving 48 people who had assisted a close relative to move onto a care home. Eleven of the interviews involved two members of the same family. The findings revealed three perceived phases experienced by carers whose care receiver had entered a care facility. These distinct stages were 'making the best of it', 'making the move' and 'making it better'.

Davies & Nolan (2003) found that in more than half of the cases (i.e. 19 cases or more) it was the primary carer who had to make the final decision in relation to placement. This was usually due to the cognitive frailty of their care receiver. As such, carers had few opportunities to work in partnership with their care receiver to achieve the best outcome. Furthermore, older people rarely have the opportunity to visit the care home prior to moving in and therefore do not figure prominently in the decision-making process. This places even more responsibility on the carer during the 'making the best of it' phase.

The care-giver participants also indicated that they had little opportunity to discuss the emotional impact of this decision. Indeed, several participants indicated that the research interview was the first time they had discussed their feelings. The participants in this study felt that they were under pressure, had inadequate information, felt that things were out of their control and that they were working in opposition to health and social care staff (Davies & Nolan, 2003).

During the 'making the move' phase, Davies & Nolan (2004) found that health and social care practitioners have enormous potential to influence relatives' experiences of nursing home entry. Family carer's experiences were enhanced when they felt that they were working in partnership with the staff so as to ease the transition for the new care resident. For instance, the day of the move into the home can be a particularly stressful time for the carer. As such, practical arrangements for appropriate travel, a warm welcome on arrival and ensuring that the new resident's room is prepared eased the transition considerably. This study highlighted the fact that newly admitted people and their relatives received

very little preparation about the various staff roles in the care home and the expected day-to-day routine. Furthermore, there was a lack of discussions with the former carers about their new role and its expectations within the nursing home (Davies & Nolan, 2004).

The 'making it better' stage involves establishing a new caring role within the care home. The three central aspects to their new role include (a) maintaining continuity; (b) keeping an eye; and (c) contributing to community (Davies & Nolan, 2006). Maintaining continuity involves helping the older person maintain their identity via family relationships and through helping staff to get to know the resident as an individual. By monitoring the care received, former carers 'keep an eye'. They also provide feedback to staff and fill any gaps in their relative's 'case'. Former carers contribute to the community by providing a link to the world outside the nursing home and by interacting with other people in the care facility (Davies & Nolan, 2006).

The theoretical approach adopted in the present study will build on previous conceptual work of Larkin (2009) and Davies & Nolan (2003; 2004; 2006). Whereas Larkin's model focuses exclusively on post-caring after the care receiver has died, the Davies & Nolan model outlines stages experienced by carers after their care receiver has been placed in a care facility. The present study incorporates both of these theoretical understandings.

### 2.3A RESEARCH FINDINGS ON THE POST-CARING/ CARE TRANSITIONS EXPERIENCE – NURSING AND CARE HOMES

The placement of a relative in a care home is often the 'last resort' after all other care options have been exhausted. Research studies have identified factors which increase the likelihood of admission to a care home – for example advanced age, decreasing health status, greater severity of cognitive impairment, being without a spouse and the inability of the family carer to cope (Argyle et al, 2010; Bannister et al, 1998; Buhr et al, 2006; Fjeltun et al, 2009). The negative perceptions of nursing homes have led to a general community disapproval of institutional care. They are viewed as places where people go to die and individual rights are subsumed by institutional



routines and regulations (Pearson et al, 2003). This, along with the high profile media reports of neglect in nursing homes stigmatise admission and adds further stress to the family carer (Sandberg et al, 2002a).

Research findings have demonstrated that the transition from home into the care facility is a major life event which typically occurs very hastily and is rarely planned for. It is the family carer who is most closely involved in the decision-making process. The transition and post-placement period were viewed as an extremely stressful time due to the complex feelings associated with placement as well as the strain of negotiating new relationships with the staff and the relative (Noonan et al, 1999; Pearson et al, 2003; Wackerbarth, 1999). Research studies have also identified a wide array of complex emotions for the carer including guilt, anxiety, sadness, relief, a sense of failure, disempowerment and a loss of control (Argyle et al, 2010; Keefe & Fancey, 2000; Kellett, 1999).

Based on Swedish qualitative work, Eriksson & Sandberg (2008) identified two transitions in the marital relationship experienced by seven husbands who were the primary carers for their wives. The first transition identified was the movement from the mutual loving relationship of being a *loving husband* to that of taking on responsibilities of daily care for their spouse. This phase was labelled as being a *caring husband*. The most difficult aspect of this transition for the husbands was the caring for their wife's body and personal hygiene. The placement of their wife in a nursing home resulted in another change in identity and role. This involved a transition from intimate care to a *relationship based on friendship*. A key difficulty of this stage was that they were no longer responsible for, in control of or influential in their wife's caring situation. They also experienced a sense of loss and that a central meaning in their life had been taken away. These changes resulted in difficulties in defining their new relationship with their wife. The physical and emotional closeness between spouses had also changed as they no longer lived together, and the husband no longer provided daily care (Eriksson & Sandberg, 2008).

Admission into the hospital setting demands a renegotiation of the carer's role rather than a relinquishment of the role of family carer (Ferrell et al, 2009; Keefe & Fancey, 2000; Kong, 2008). The caring that typically occurs during visits is described as 'indirect' including an overseer of care (e.g. advocacy) or 'direct' such as performing specific tasks, such as feeding, brushing hair, going for walks, shopping (Keefe & Fancey, 2000; Kellett, 1998). In their three year study using semi-structured interviews and ethnographic research to examine the effect on carers (N=60) of placement in nursing homes, Pearson et al (2003) found that carers often act as advocates or case managers in care homes.

Keefe & Fancey (2000) interviewed 214 Canadian carers whose care receiver had been placed in a nursing home. They found that if the resident experienced increased mental confusion, the family carer engaged in more advocacy and monitoring of care rather than in direct tasks such as playing cards.

Others have reported a lack of awareness among nursing staff about family carers' stresses and needs such as isolation and separation (Sandberg et al, 2002b). In addition, the knowledge and expertise of carers is not always acknowledged by health professionals in care facilities (Hynes et al, 2008; Sandberg et al, 2003). Family carers may instead be treated as 'just visitors'. In an ethnographic study, Allen (2000) explored the ways in which formal and informal carers negotiated 'care' on an adult medical ward in Wales. Although the nurses in this study were broadly supportive of the involvement of family carers, they found it challenging to involve primary carers in ways that did not undermine their professional identities and their abilities to deal with the practical demands of the role. The findings supported the primary carer's considerable expertise and the strength of their sense of moral responsibility for their relative. Therefore, relinquishing their carer functions to staff challenged their sense of control over the caring process and their involvement in the ward was sometimes difficult. In contrast, there were other examples where other family members and friends integrated well into the caring division of labour on the ward (Allen, 2000).



## 2.3B RESEARCH FINDINGS ON THE POST-CARING/CARE TRANSITIONS EXPERIENCE – DEATH OF THE CARE RECEIVER

At the time of death of the care receiver, family members often react with a mixture of relief and grief. Death provides relief from the relentless strain of caring and relieves the suffering of the care receiver. Nevertheless, this also represents a significant loss to the family, especially the primary carer (Haley et al, 2002; Means et al, 2003). The beginning of the death transition is characterised by a reduction in contact with formal services, as well as the removal of specialist equipment from the home and organising financial matters (Brown & Stetz, 1999). Although Brown & Stetz (1999) contribute substantially to the field, former carers were not the sole focus of the study, but rather one of many aspects of caring that were considered during the research. Their main focus was on the labour of caring.

The adverse psychological, social and physical health consequences of caring included loneliness, loss of confidence, purpose and identity, physical exhaustion and back problems as well as lack of personal growth and lost life opportunities, such as getting married, having children or more children, or employment opportunities (Jenkinson, 2004). Jenkinson's insightful assertions originate from a collection of personal stories of former carers rather than a research study *per se*.

The turmoil of the post-caring/care transitions phase can also be linked to the wide range of negative socio-economic legacies of caring. The existing literature has highlighted the long-term negative financial effects of caring, such as foregoing an income and career advancement as well as limitations on access to pension funds (Lewis & Meredith, 1988; McLaughlin & Ritchie, 1994). As McLaughlin & Ritchie's (1994) data was extracted from a 1989 U.K. national survey, it may differ somewhat from the current situations of former carers. Lewis & Meredith's (1988) book presented carer biographies on daughters who used to care for their mothers and ceased caring in the previous ten years. The many aspects of caring that were probed included the decision to take up the caring role and the changes in the caring role over time. Similar to McLaughlin & Ritchie (1994), Lewis & Meredith's data is over twenty

years old and so its relevance for contemporary former carers may be questionable.

Aneshensel et al (2004) examined survey data from a six-wave longitudinal study of carers (N=291) for those with Alzheimer's disease. They concluded that not all carers respond uniformly after the death of the care receiver. Rather the range of carers' reactions to bereavement are mitigated by a number of contextual factors such as exposure to stressors, prior experiences during caring career and access to resources. Self-esteem, socio-emotional support, as well as higher levels of education and income play protective roles. For instance, a strong sense of self and social ties helps sustain carers during bereavement.

Similarly, carers with few depressive symptoms (e.g. lack enthusiasm, cry easily, low energy levels) before the death of the care receiver tend to maintain these states afterwards. However, carers who were emotionally distressed prior to the death of the care receiver tended to become more distressed after bereavement. In particular, those who had experienced role overload during their caring experiences tended to have a less favourable outcome during bereavement. This can be explained by reference to long-standing problematic life circumstances and compromised emotional wellbeing, as opposed to a necessarily pathological response to the death of the care receiver (Aneshensel et al, 2004).

In a longitudinal quality of life study, Bond et al (2003) found that positive changes in the post-caring/care transitions phase were associated with improved psychological wellbeing and activity participation. Former carers often try to fill the gap with new activities such as voluntary and paid work, as well as taking on another caring role (Arksey, 2003; Hirst, 2005; Lewis & Meredith, 1988).

Field et al's (2006; 2007) U.K. postal surveys underlined the importance of pre-bereavement support offered by health and social care professionals associated with hospices. The preparation for loss was found to be very helpful. The level of compassion and dignity afforded the care receiver in the hospice proved to be highly influential in the family carer's subsequent bereavement experience. Also, Grande & Ewing (2009) surveyed 216 carers three to four months post-bereavement.

They concluded that the level of support, particularly psychological, may be more important for carers' bereavement outcomes than achievement of the preferred place of death for the patient.

After the death of the care receiver, bereavement support for family carers may be delivered in a variety of forms, such as individual support, telephone support, written information, memorialisation events and group support, but most are based on talking (Field et al, 2004). Historically, the majority of health services did not offer bereavement support, with the exception of psychiatric treatment for family members experiencing complicated or abnormal grief reactions. The chaplaincy services in health settings also provided support at the time of death. Up until recently, proactive and reactive bereavement support has been delivered by religious, community or voluntary organisations. In contrast, hospice bereavement support seeks to provide continuity of care for family carers (Payne & Rolls, 2009). Bergman & Haley (2009) found that among bereaved spousal carers of former hospice patients (N=61), nearly half used at least one type of specialised professional bereavement intervention to aid in coping with their loss.

Although hospice programmes offer families considerable bereavement services after the death of a care receiver, few such services are generally offered to families after death in nursing homes and hospitals unless hospice or specialist palliative care staff are involved in care (Haley et al, 2002). Relatively little is known about the needs of family carers whose care receiver is dying in a care home. While a supportive environment is seen as essential, the social, spiritual and psychological needs of families are often overlooked (Hudson & Payne, 2009; Nolan & Hudson, 2009).

## 2.4 LITERATURE REVIEW IMPLICATIONS FOR THE CURRENT STUDY

This review of carer research found two primary theoretical models of post-caring/care transitions. Larkin's (2009) model focuses exclusively on post-caring after the care receiver has died. Conversely, the Davies & Nolan (2003; 2004; 2006) model outlines stages experienced by carers after their care receiver has been placed in a care facility. The present study incorporated both of these theoretical understandings of the post-caring/care transitions

experience. The study examined the post-caring/care transitions phase among carers whose care receiver had either died or been admitted to a hospice/nursing home. The literature also offered some guidance on issues of relevance:

- How the caring role continues but in an altered way during the nursing home placement transition.
  - New caring tasks performed include going for walks, feeding and brushing the hair of their relative.
  - Former carers' guilt for placing their care receiver in a nursing home due to the negative stereotyping of nursing homes.
  - Stress from the often unplanned, hasty manner in which placement typically occurs.
  - Fraught relations between staff and former carers often fuelled by the lack of recognition of the carer's expertise.
  - Former carers' attempts to reconstruct their relationships with care receivers in the care facility. This can be particularly problematic for spouses.
  - Former carers' advocacy role on behalf of their relative.

Equally, there is an intense level of complex emotions experienced by carers during the death transition. The wide array of emotions includes grief, guilt, relief, loneliness, loss of purpose and identity. Issues of relevance here included:

- Carers do not react uniformly to the death of the care receiver.
  - Subsequent successful adaption is influenced by access to socio-emotional and financial support.
  - The post-caring/care transitions phase is characterised by a reduction in contact with formal services.
  - Preparation for bereavement, as well as the bereavement support provided by hospice positively influences carers' experiences of the death transition. In contrast, the lack of these supports in hospitals has a negative impact upon carers.

## 2.5 AIM OF PROJECT AND RESEARCH QUESTIONS

The aim of this study was to assess and describe the experiences and needs of former family carers in the post-caring/care transitions period (i.e. care receiver has recently been placed in a nursing home, hospice or has died).

**Definition:** Former family carers are defined as family members who provided physical and/or social care to a family member with an illness or disability in the home for at least six months prior to nursing home/hospice placement or death. Note: The researchers recognise that the caring role generally continues but in an altered way after at-home caring has ceased and the care-receiver has moved into either a nursing home or hospice.

The following research questions were posed:

## OVERARCHING RESEARCH QUESTION:

What are the experiences and needs of former family carers in the post-caring/care transitions period?

## SPECIFIC RESEARCH QUESTIONS:

1. What are family carers' needs in relation to the period following the cessation of caring?
2. What are family carers' experiences in relation to the period following the cessation of caring?
3. What are family carers' perceptions of factors affecting their life quality in the period following the cessation of caring?
4. What interventions do family carers believe would improve their life quality in the period following the cessation of caring?

# METHODOLOGY

## 3.1 INTRODUCTION

This section describes the approach that was taken to answer the research questions. Firstly, the sample and sample selection approach is described, next the development of the semi-structured protocol is outlined and the analytical procedures adopted are recounted. Finally, the ethical issues pertaining to the study are outlined.

## 3.2 SAMPLE AND SAMPLE SELECTION

The inclusion and exclusion criteria for this study were:

### INCLUSION CRITERIA:

- Carers who provided physical and/or social care for a family member with chronic illness at home for at least six months.
- Carers who were post-caring.
- Family carers who were willing to participate in a focus group and/or individual interview.
- Family carers who were over the age of 18 years of age at time of interview.
- Family carers who were able to articulate their experiences in English.

### EXCLUSION CRITERIA:

- Any person who could not be defined as a family carer in the context of the definition adopted for this study.
- Family carers who were in a caring role at the time of interview.
- Family carers who were under 18 years of age at the time of interview.
- Family carers who were unable to articulate their experiences in English.

Contacts with Care Alliance Ireland and the Carers Association helped to identify potential participants

and these organisations made initial contacts. Next, letters of invitation and participant information sheets were sent by the Trinity College Dublin (TCD) research team to those who had agreed to participate in the study. After seven days, the TCD researchers followed up on these information packs with telephone calls to ensure that the former family carer was still comfortable with participating in the study. The date, time and venue for the interviews were then established.

Through liaising with Care Alliance Ireland and the Carers Association, 40 former family carers were identified and recruited. There were two groups: 14 participants for a focus group, and 26 who subsequently took part in individual interviews.

### FOCUS GROUP PARTICIPANTS

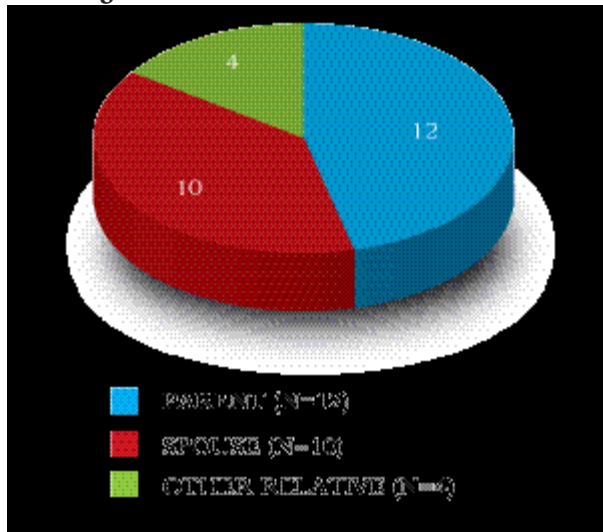
The focus group of former carers was convened in conjunction with Care Alliance Ireland. The demographic profile of the focus group participants reflected that of the interviewees.

### INDIVIDUAL INTERVIEWS

Seven male and 19 female former carers agreed to individual interviews; their mean age was 57 years but they ranged in age from 33 to 81 years old. The length of time spent caring for the care receiver ranged from six months to 27 years, with a mean of seven years and nine months. Most were caring for either a parent or a spouse (see figure 1). Interviews took place across the country, in a wide variety of urban and rural locations.

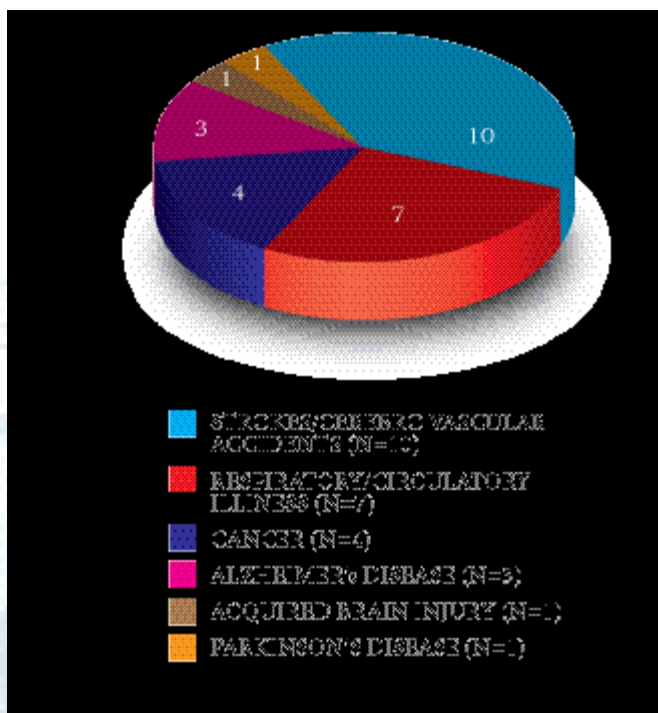


**Figure 3.1: Who Were Participants Previously Caring For?**



There had been a range of illnesses among the care receivers, with stroke (Cerebro Vascular Accidents) and respiratory/ circulatory illnesses most frequent (see figure 3.2). Many carer studies in the literature are primarily on carers of persons with Alzheimer's disease. In contrast this study offers a broader view of illnesses in family caring.

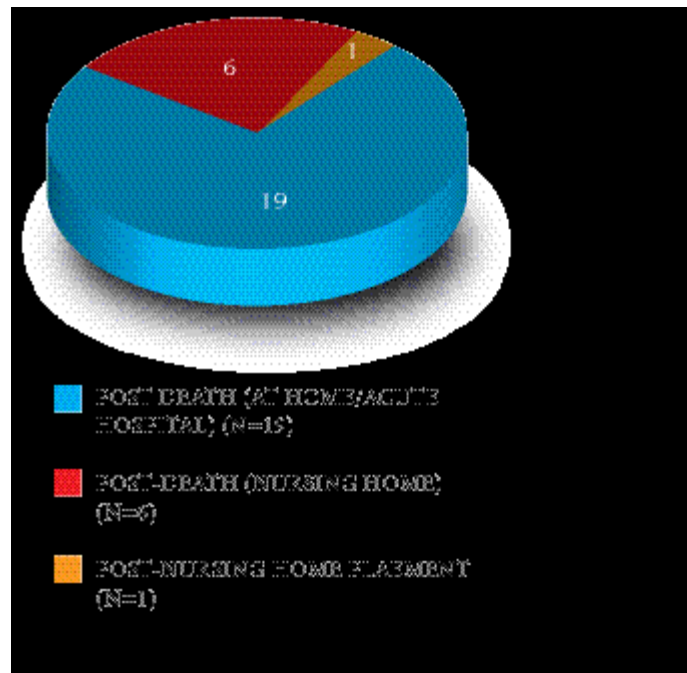
**Figure 3.2: Illness of Care Receiver**



For 25 of the 26 interviews conducted (see figure 3.3), post-caring/care transitions was due to the death of the care receiver. The following graph identifies the particular post-caring/care transitions. At the time of

interview, the length of time since the post-caring/care transitions transition ranged from three months to six years with a mean of two years.

**Figure 3.3: Post-caring/care transitions**



### 3.3. DEVELOPMENT OF INTERVIEW PROTOCOL

The literature review suggested a number of issues pertinent to understanding the experiences of former carers that were the beginning point for the development of a protocol. These were divided into:

- χ) When there was a transition due to nursing home placement – alterations to the carer role, stress related to the transition and to fraught relationships with staff and the need to reconstruct relationships with the care receiver
- δ) When the transition is due to death – preparation for bereavement and ability to access socio-emotional and financial support.

A focus group with 14 participants was then convened to discuss these issues and other concerns the participants wished to raise. The focus group was conducted by a trained facilitator and the discussions were digitally recorded and then transcribed. Analysis of the focus group discussions then informed the development of a semi-structured interview guide for individual interviews designed to help further elucidate and validate issues raised in the focus group and to probe for additional important issues and

related details not yet discussed.

- The interview guide that emerged centred around the following key themes:
- Experience of caring/transition
- Needs
- Factors affecting quality of life
- Interventions
- Particular transitions

(To review the interview guide in full, please consult Appendix 1).

Individual interviews were then arranged with the additional 26 former carers who had agreed to participate. These interviews were held at a place of convenience for the participant (i.e. their place of residence or a local café/restaurant). With the permission of the former carer, the interview was digitally recorded. Each interview lasted approximately 1.5 to 2 hours.

### 3.4 DATA ANALYSIS – INDIVIDUAL INTERVIEWS

Template analysis (Crabtree & Miller, 1999; King, 2004), supported with NVivo 8 software, was the method of analysis employed for the 26 individual interviews. Rather than transcribing interviews, the data was analysed directly from the audio recordings. This approach ensured that the voice, tone and emotion of participants were not lost and had the opportunity to influence the analysis.

The initial template was formulated through an extensive consultation process and a series of work group meetings involving members of the research team. Research team members independently listened to one of the more substantial interview recordings. They then discussed and debated the key themes that might form the initial template, while bearing in mind the project's key objectives. An initial template to be applied to subsequent tapes was established but in keeping with the principles of template analysis, the template was adjusted several times as the analysis

progressed. All iterations and revisions of the template were carefully documented. In total, the template was revised eleven times.

(Please see Appendix 2 for the final version of the template that was produced).

Quotes were then selected that represented typical or common responses. All variations and negative/contrary cases were also described and explained. Data was triangulated with focus group data where it was apparent that such triangulation would help elucidate themes. The final analysis themes and related quotes were then identified. This is deemed the most systematic and reliable way of treating qualitative data, because the findings become more fully explored, explained and evidenced (Denzin & Lincoln, 2003).

### 3.5 ETHICAL CONSIDERATIONS

The study was granted ethical approval by the Ethics Committee of the Faculty of Health Sciences, Trinity College Dublin. Following receipt of verbal and written information on the study, written consent was sought from each participant before holding the focus group or individual interview to ensure the nature and purpose of the research was understood. Participants were advised prior to the focus group and individual interviews that should they become distressed or uncomfortable at any point, the interview would be stopped or terminated immediately if they so wished. At all times, participant wellbeing was a priority during the course of the study. The project's intent to protect anonymity and confidentiality was made clear to all respondents.

### SUMMARY

In summary, 40 former family carers participated in this study. Their ages and duration of caring role ranged from 33-81 years and six months to 27 years respectively. The participants' care receivers had experienced a range of advanced chronic illnesses.

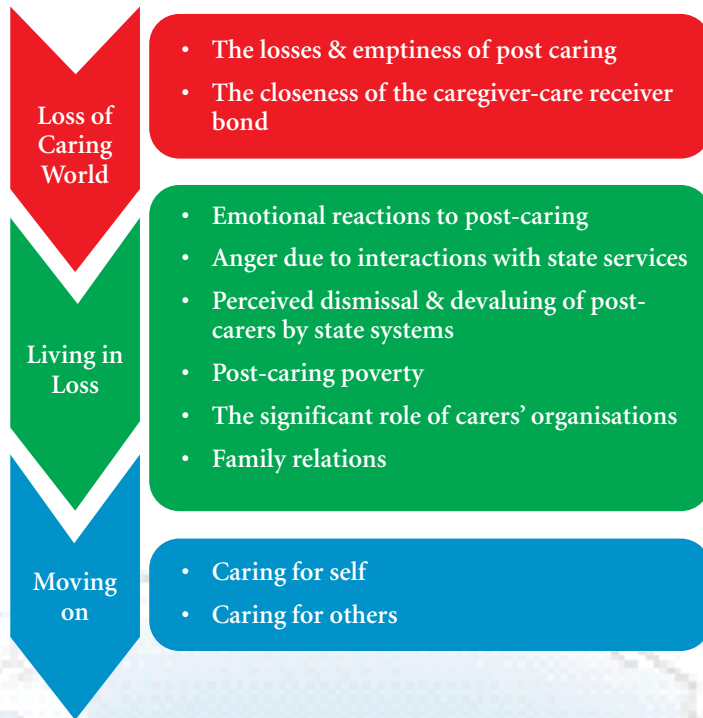
# 4

## FINDINGS

### 4.1 INTRODUCTION

Two major explanatory themes emerged: being ‘worldless’ and being ‘between worlds’, as well as three post-caring/care transitions processes: ‘the loss of the caring world’, ‘living in loss’ and ‘moving on’ (see Table 4.1).

**Table 4.1: Sequence of Themes**



The three post-caring/care transitions processes and their related quotes are explicated following which a conceptual model that locates these processes within the two overarching explanatory themes of being ‘worldless’ and being ‘between worlds’ is presented.

### 4.2 LOSS OF CARING WORLD

The review of the data yielded a picture of the sense of emptiness, loss and loneliness that characterises post-caring/care transitions. Various dimensions of losing the caring world were described, including the loss of identity, routine and the social network of healthcare professionals. An understanding of the

unique, exclusive relationship between carer and care receiver also emerged which helped further understanding of the losses of post-caring/care transitions.

#### 4.2A THE LOSSES AND EMPTINESS OF POST-CARING/ CARE TRANSITIONS

**Losses** – a core element of the post-caring/care transitions experience is emptiness, loss and loneliness. There are multiple dimensions to the losses inherent in the post-caring/care transitions phase. These losses are all-encompassing and include the loss of identity, sense of self, status as ‘carer’, their role in life, the close relationship with the care receiver and their daily routine. It is evident that post-caring/care transitions is characterised by grieving of these immense personal losses.

*It wasn’t only that I lost my mother, I lost my income, I lost my job, I lost my reason for getting up in the morning, I lost my routine, I lost all these things and I’d nowhere to turn. There was absolutely nothing there (Interviewee #6).*

**Enmeshment** – it is apparent that the former carer’s whole sense of self had become enmeshed in the caring role.

*I was a doctor, I was a nurse, I was a psychiatrist, I was a psychologist, I was a chauffeur, I was a chef, I was a counsellor to my Dad and now that’s all gone. And I’ve spoken to other ex-carers and they feel exactly the same, that their reason for existence has gone (Interviewee #3).*

These multi-dimensional losses led to a vacuum in the lives of former family carers. This resulted in a sense of emptiness.

*The way I looked at that hospital was that you went in with something and you came out empty (Interviewee #15).*



**Lost** – the feeling of being lost and ‘empty’ is so profound that some of the participants equated post-caring/care transitions to being ‘world-less’. They have lost their place in the world due to the loss of their carer identity. They feel that they do not belong to any world. Their life, prior to taking on the caring role, has disappeared and now their life as a carer or their ‘caring world’ has also dissipated very suddenly. An analogy can be drawn between post-caring/care transitions and retirement. However, post-caring/care transitions is more akin to an enforced retirement, without any social recognition or financial benefits that typically accompany it.

*You're in no world, your pre-caring world is gone, your caring world is gone, you're left with no world (Focus group #1).*

*I was still in a kind of 'between worlds' type thing. I didn't know if I was coming or going or whatever (Interviewee #6).*

**An Empty Place** – both the homes and lives of former carers feel empty. This is due to the removal of medical equipment and the immediate cessation of home visits by the previous network of medical personnel. During the caring phase, carers had formed relationships with a range of the health and social care professionals who regularly called to the house to attend to the care receiver (e.g. public health nurses, G.P., occupational therapists, home helps). However, once the care receiver dies this social network of regular callers disappears very suddenly.

*You're left high and dry. You don't even get a sympathy card from any of them (Interviewee #10).*

**Loss of supports** – two participants noted that their G.P. or Public Health Nurse visited them in the post-caring/care transitions phase, but this was on their own initiative.

The removal of medical equipment from the home was deeply upsetting for former carers. These pieces of equipment had become a long-term feature of their home and they had begun to see the equipment as belonging to their deceased relative. When these items of equipment were removed, there was a gaping hole or emptiness in the former carers' lives and homes. It appears that the former carers were grieving for their caring worlds and their previous place within it.

*Gran was waked at home. She'd been in the room for four years and her bed and hoist and all the other equipment was removed before the funeral because they were needed by someone else and after the funeral her room was so empty. All her things had gone and all that was left was a picture of her. It all happened so suddenly (Interviewee #10).*

*The house was full up until the Wednesday (day of burial) then it was empty. It was like a shell and it was so silent and so lonely. Then you'd get a phone call regarding her chair and you have to wash them and prepare them for someone else, which makes the house even emptier because they had become part of the furniture too (Interviewee #15).*

Further evidence of **loneliness** as a result of the losses and emptiness of post-caring/care transitions emerged from the data. These feelings were attributed to the loss of the close relationship with the care receiver, the loss of their role in life and the emptiness of their home.

*There's a big heart gone out of my life (Interviewee #19)*

*And it's the loneliness, the loneliness. I don't think anyone anticipates the loneliness because of the amount of years you have given up to look after your Mom, those years have gone, your life has gone. And how do you move on and I'm having difficulty trying to find the answer (Interviewee #15).*

For many, the post-caring/care transitions phase marked the beginning of living alone for the first time. Loneliness is felt most acutely in the evenings and at night time:

*Yeah I do find it very, very lonely. I've never lived on my own before (Interviewee #15).*

*The worse thing that I find is when I come in here at night and there's no-one here (Interviewee #17).*

These findings mirror Larkin's notion of the ‘void’ (i.e. acute loneliness, loss of purpose and lack of social network of healthcare professionals) as being the first stage of post-caring. However, where the present study differs from Larkin (2009) is that this profound sense of loss, emptiness and loneliness is not just limited to the initial aftermath. Feelings of ‘worldlessness’ and being lost appeared to continue into the second or third year of the post-caring/care transitions phase for the participants in this study.

These conclusions are supported in the work of those who have asserted that the death of the care receiver results in the carer experiencing feelings of loneliness, as well as loss of purpose and identity (Haley et al, 2002; Jenkinson, 2004) and that the post-caring/care transitions phase is characterised by the removal of medical equipment (Brown & Stetz, 1999) and a reduction in contact with formal services (Means et al, 2003). Although such literature was theoretical and anecdotal rather than empirical in nature, this study confirms the assertions therein.

#### 4.2B THE CLOSENESS OF THE CARER – CARE RECEIVER BOND

During the caring period, a very close relationship developed between the carer and care receiver.

*I used to say to her 'this is (name)' and she used to smile. So she knew I was there. And then my other brother he'd say the same thing to her but she wasn't reacting to him the way she was to me (Interviewee #18).*

The **strength of the bond** was apparent in the fact that the carer was the only person to engage in certain activities for the care receiver. This closeness included practical, emotional and legal aspects. From a legal point of view, the carer was frequently the next-of-kin and due to inherit the home they both lived in.

*It was our joint home. We bought it. I think other members of the family resented it. If I took on the role I think it was only fair that if anything ever happened to my mother that there was no controversy. I was guaranteed a roof over my head (Interviewee #6).*

In terms of practical and physical closeness, the carer was the only person the care receiver was comfortable with performing intimate care duties.

*So I used to do everything for her, shower her, clean her, dress her, feed her, which wasn't the easiest thing to do because she was a very private person. It was so hard (Interviewee #17).*

An **emotional inter-dependency** existed between the carer and the care receiver. The care receiver only wanted the carer taking care of them.

*So I'd say to Mom and Dad 'I'll be leaving here around 9 o'clock to-night but I'll be back around midnight' but they would not stay there, they insisted on coming with*

*me. They were so entrusting of me that they couldn't have coped without me. They were totally dependent on me (Interviewee #3).*

Similarly, the carer wanted to be the sole provider of care for the care receiver. For instance, when the care receiver was placed in a local nursing home or community hospital for two weeks' respite, the carer still visited every day and performed many of the caring tasks such as feeding.

*I used to put Dad in for regular respite but I'd be up there at 11 and go away around 2 and go get something to eat. I'd be back up again at 4 to give him his evening meal and I'd come away again at 5 and then go up again that night around 7 (Interviewee #3).*

*For the 17 days that my mother was in the hospital I stopped there with her. I slept beside her in a fold-up bed that they made up for me every night. I couldn't see myself coming back home and thinking that was how she'd be until the next morning (Interviewee #18).*

The loss of this uniquely close relationship contributes to the feelings of emptiness, loneliness and loss experienced by former carers. This aspect of the post-caring/care transitions experience has yet to be explicitly mentioned or specifically explored in the existing literature. However, Larkin's (2009) discussion of loneliness has some close relationship connotations. Similarities can also be noted in studies that examined carers' experiences of the nursing home placement transition. For example, Eriksson & Sandberg (2008) found that, among husband carers who recently placed their wife in a care facility, the physical and emotional closeness between spouses had altered, as they no longer lived together and the husband no longer provided daily care.

#### 4.3 LIVING IN LOSS

In describing the experience of 'living in the losses' of post-caring/care transitions, complex emotional reactions were described. These included guilt, relief, a sense of urgency and anger directed at State services. These emotions along with the perceived dismissal, devaluing by State systems and poverty were described as barriers resulting in former carers becoming 'stuck' in living in loss. Facilitators which help former carers move out of the losses of post-caring/care transitions were also identified, including supportive family relationships and carers' organisations.



### 4.3A INTER-LINKED EMOTIONAL REACTIONS TO POST-CARING/CARE TRANSITIONS

A wide array of complex and inter-linked emotional reactions to post-caring/care transitions emerged from the data. These feelings include guilt, relief and a sense of urgency.

**Guilt** – various dimensions of guilt were experienced during the post-caring/care transitions phase. Guilt emerged because former carers began to doubt the care they had provided for their care receiver. The former carers were unsure as to whether there was anything they could have done better to prevent the care receiver from dying, especially in the case of sudden deaths at home.

*My G.P. is always saying to me “how often do I have to say to you it wasn’t your fault he died – it was his time. (Name of deceased husband) wouldn’t want you to be thinking like this” (Interviewee #1).*

*I came in from the porch and he was lying flat on the floor beside the kitchen table and he was lying very strangely, in a very peculiar way. And I couldn’t bend down to check him because of my hip and my crutches.....He went instantly. But it’s the worst thing that could ever happen anyone (Interviewee #2).*

Some of the interviewees were feeling guilty because they felt they could have fought harder for health services.

*The thrush was that bad it was coming out his lip. I suppose I felt very guilty about that. Should I have been more on top of them in the nursing home when they said they put that thing in (the medication)? Were they putting it in? Because obviously they never put it in (Interviewee #24).*

There is a considerable body of literature on the guilt experienced by carers as they place their care receiver in a nursing home (Keefe & Fancey, 2000; Kellett, 1999). However, there is less literature examining experiences of guilt during the post-death transition.

**Multiple transitions** – although only one participant was currently going through the post-caring/care transitions nursing home placement transition, several of the interviewees had previously placed their care receiver in a nursing home and that person had

since died. This meant six of the participants had gone through both transitions – post-nursing home placement and post-death.

**Placement** in a nursing home for participants was only considered after all other options had been exhausted. Typically, the care receiver’s health had deteriorated so much that it was no longer feasible to provide care at home. The placing of the care receiver in a nursing home was described as a very traumatic, guilt-ridden event for the primary carer.

*It got to the stage that if anything happened her during the night, like if she fell, I couldn’t lift her, and if I tried lifting her and my ticker went then both of us were down. But still while it was very logical, it was a heartbreaking decision and quite frankly I cried the day I left her into the nursing home because I was putting someone away (Interviewee #11).*

*It was a big decision and you kind of felt guilty because you’d go in to visit him you know and he’d be asking me when would he be going home. He wouldn’t ask anyone else in the family that – just me (Interviewee #24).*

This reluctance to place a relative in a nursing home appeared to stem from the stigmatisation of nursing homes. This was further compounded by the particulars of the Irish historical context. The local residential care facility was referred to by some interviewees as the ‘workhouse’. This is due to the association of the buildings and grounds of old residential care facilities such as this with famine times and the extreme poverty of the nineteenth and early twentieth centuries respectively.

*It’s the old workhouse and they haven’t done anything with it in years. It’s an old grey derelict building. 1843 is still over the door, that’s the year it was built. It was the workhouse for the famine victims and their families (Interviewee #8).*

The trends noted in this study were similar to those reported in the extensive literature on nursing home placement. For example, the guilt that accompanies a nursing home placement (Argyle et al, 2010; Keefe & Fancey, 2000; Kellett, 1999), the perception that it is the ‘last resort’ (Argyle et al, 2010; Noonan et al, 1999; Pearson et al, 2003; Wackerbarth, 1999), as well as the stigmatisation of nursing homes (Pearson et al, 2003; Sandberg et al, 2002a), have all been well documented.

**Relief** – many of the interviewees reported feeling relieved when the care receiver died as they knew their relative was no longer suffering. The carer had witnessed how much the care receiver's quality of life had diminished prior to their death.

*You know it's nearly a relief to see them going at that stage because there's no quality of life (Interviewee #24).*

*I was happy for her because she was over all her misery; you know Alzheimer's is such a sad disease (Interviewee #11).*

However, along with this sense of relief was a sense of guilt for feeling relieved that their relative had died.

*You even feel guilty for feeling the relief of a weight being lifted from your shoulders (Focus group #1).*

These findings echo what has been found in other studies (Haley et al, 2002; McLaughlin & Ritchie, 1994).

**'Clock-watching'** or a sense of urgency is evident in the data, especially during the beginning of the post-caring/care transitions phase. 'Clock-watching' was a behavioural pattern that developed and was the 'norm' during the caring process. In the immediate aftermath of caring ceasing, the participants reported feelings of urgency and guilt when away from the house. They still rushed home to check on their care receiver. It was only when they arrived home that they remembered they were no longer caring. This finding concurs with previous work on the 'clock-watching' aspect of the caring role and its overlap with feelings of guilt (Williams, 1993).

*Do you see you're still going around on clock-watch. I used to be going into town and thinking I must be back by half-past two because the van will be coming (to collect her son). And sure then I'd think for god's sake what are you rushing home for? (Interviewee #21).*

**Disrupted sleep** patterns were also common during post-caring/care transitions. These sleeping problems were attributed to the poor sleeping patterns that developed during the caring phase. The former carers had become accustomed to sleeping 'lightly' because they were monitoring the care receiver's wellbeing. This ensured that the care receiver did not fall out of the bed and was helped if they wanted to go to the toilet during the night.

*For a long time after he died, I never really slept. And now I'm not as bad as I was. You know when you go to sleep and you're kind of not really asleep but you're listening. And when he was alive I'd think I'd hear the bell and I'd jump up and run down to make sure he was alright but he used to be sound asleep (Interviewee #25).*

These aspects of the post-caring/care transitions experience have yet to be explicitly examined in the published literature. McLaughlin & Ritchie (1994) do note that the anxiety effects of the demands of the caring role only begin to surface during post-caring/care transitions. Despite this, many of their participants reported improved health benefits in post-caring/care transitions due to the removal of anxiety around the care receiver's wellbeing and the opportunity for unbroken sleep. Nonetheless, the present study's finding does relate to studies in the broader informal caring field. For example, O'Sullivan (2008) and Central Statistics Office (2010) statistics report poor sleeping patterns among Irish carers. Also, the carers of people with COPD in Hynes et al's (2008) study reported a heightened state of anxiety due to the care receiver's medical condition.

#### 4.3B ANGER RESULTING FROM INTERACTIONS WITH STATE SERVICES

Conflictual and negative interactions with health and social care service providers during the caring phase resulted in pent-up anger and frustration being experienced in post-caring/care transitions. The first 30 minutes of many interviews involved the former carer releasing the accumulated anger and frustrations they continued to feel, due to their prior interactions with the health services. Thus, the interviews often acted as a cathartic debriefing session for their prior interactions with services.

*I hope I'm not talking too much but I'm like a pressure cooker, you have to get the pressure out. This (the interview) is one way of like therapy. I think it's so important to talk and it's not good to bottle it up inside you (Interviewee #3).*

**Conflictual interactions** with health services were a very dominant theme in the interviews. The caring phase was often characterised by antagonistic relationships with individual health care professionals.

*I met the consultant in the corridor. He's very blunt this particular guy. I never particularly liked him but he*

*didn't pussy foot around with me because we had had one or two run-ins (Interviewee #6).*

The major source of anger and frustration was that former carers had to constantly **'fight'** with healthcare professionals, in order for their care receiver to receive essential services.

*I had to fight tooth and nail for absolutely everything. Tooth and nail. And I worry about older people who don't have anyone to fight for them (Interviewee #10).*

What also fuelled their anger was that they were **unhappy** with the care that was eventually provided.

*He was very sick and we got no help... sometimes I couldn't even get an ambulance to bring him in and he was on oxygen ... he got taken in by ambulance after we had to fight to get an ambulance ... and the ambulance went away and we had no way to get him home, it was awful, we couldn't bring him home ... The people who drive the ambulance are so good and the nurses are so good too but ambulance control in (name of place) don't give a tuppenny. With them it's all about paperwork ... and I feel so, so angry about the way he was treated (Interviewee #26).*

The health care system itself was seen as **under-resourced**. It is important to note that the participants did identify particular healthcare professionals who went beyond the call of duty to help them and their care receiver. In view of the total dataset however, this was the exception rather than the norm.

Many of the interviewees were angry about how important **information** was relayed to them. News of the death of a spouse or a medical diagnosis was communicated over the telephone by healthcare professionals.

*I had the mobile phone beside me in the bed and at 3 o'clock in the morning the mobile rang and they told me he was dead since 1 o'clock, and that they had tried to ring me earlier but they couldn't get through to me, but I had the mobile right next to me (Interviewee #5).*

*After going to (hospital) for about a year or more, one day I said to the nurse have they made a diagnosis at all and she says 'I'll find out for you'. So she rang upstairs and she said to take the call and speak to some doctor. So I spoke to some doctor and she told me that*

*(name of wife) had been diagnosed with Alzheimer's and that's how I got the news, a nurse made a call and gave the phone to me and that's how I was told. Yeah a bit cruel I thought. I never actually met the doctor who made the diagnosis at all (Interviewee #17).*

Another source of anger was the delivery of supplies (e.g. incontinence pads) for the deceased care receiver. Participants realised that this was due to some system breakdown in information transfer, but nevertheless they found it upsetting.

*Oh yeah now this made me very angry. I rang everybody to tell them (that her mother had died). I rang the company that supplied the pads. And they arrived up a month or two later with a whole load of boxes. At the time I didn't know what they were talking about and then I'd seen the boxes (Interviewee #4).*

The issuing of **death certificates** was a further cause of anger, frustration and upset in the post-caring/care transitions phase. The former family carers experienced numerous difficulties and delays in obtaining them. These obstacles correspondingly slowed the processing of legal and property issues (e.g. getting the former carer named as the owner of the family home and changing the name on household bills). There was also a lack of sensitivity when it came to the **terminology** used on the certificate.

*I was very annoyed when the death certificate came out because it said hypo-ventilation due to obesity and something else and then constipation was mentioned as well. That, I found so hard. He had no dignity in life and now he has no dignity in death (Interviewee starts to cry) (Interviewee #26).*

The only reference to anger and conflict with health services in the post-caring/care transitions literature is in relation to former carers' sometimes conflicting relationships with nursing home staff (Nolan & Hudson, 2009). Thus, this issue warrants further investigation.

#### 4.3C PERCEIVED DISMISSAL AND DEVALUING OF FORMER CARERS BY STATE SYSTEMS

The sudden withdrawal of State support once caring ceases, as well as the perceived **devaluing** of former carers by health and social care services predominates in the data. The former carers in this study feel that



they are not provided with any statutory help to help them deal with the difficulties of post-caring/care transitions.

*The bottom line is when you cease to be a carer – there's nothing there, there's no safety net. The State takes care of you for six weeks with the Carer's Allowance and then after that you're on your own kid (Interviewee #6).*

Once the care receiver dies, former carers feel that they are immediately and automatically **'cut-out'** or eliminated from the health and social care system. Suddenly, former family carers find themselves without any support. They feel ill-equipped and unprepared to deal with the challenges of post-caring/care transitions.

*Nobody comes near you. You're just left there to deal with it all yourself...even if someone called in to check up on you to see how you were doing (Interviewee #4).*

*I was not prepared for the afters. I never thought of what would come after. I never thought about how I would feel. I didn't know what to expect (Interviewee #15).*

The lack of preparation provided by State services to enable former carers cope with the **challenges of post-caring/care transitions** is another difficulty for participants. This lack of preparation was a source of resentment and frustration. The interviewees indicated that they require rehabilitation and reintegration into society when the caring role ceases. This absence of statutory support further galvanised the interviewees' feelings about the devaluing of family carers by the State.

*I equated it with the fact that had I been in jail for 25 years, for the 25 years I was caring full-time, before I'd be released from jail I would have gotten all sorts of emotional help, psychiatric help, financial help, medical help, dental help. And then once I'd have been released from jail, I would have someone calling to the house to see if I was adapting to what passes for normality. But when you cease caring, it's as if your reason for existence is gone. That's all I knew (Interviewee #3).*

The perceived **dismissal of carer's expertise** and the contribution they have made by State services emerged from the data. A disregard for the carer's in-depth, intuitive knowledge of their care receiver's condition and of the health services was evident. One former carer recounts the day before her husband died in a nursing home:

*I thought he was very bad that day and I went to the doctor and I said he has that cough, that terrible cough I'd heard a few times before in hospital, in old people that would have gone out in steel boxes from the ward the next day. They told me I was imagining things and that they were quite happy with him and that he will be up around the place tomorrow (Interviewee #5).*

As participants moved into the post-caring/care transitions phase, this lack of recognition continued, especially in relation to their contribution to the health system. It was perceived that there was **no acknowledgement** of the high level of care they had performed and the skills they had developed. This became apparent when applying for jobs in the post-caring/care transitions phase.

*Nobody gives you a bit of credit for what you've done. Even if I was to go for a job, I've got a gap of 4 ½ years on a CV. If you went for an interview, they'd read your CV and say 'you're very good, and you've got transferable skills and you've all these things and they'll be like 'don't call us, we'll call you.' It counts for nothing (Interviewee #6).*

The perceived dismissal of carers' expertise and the contribution they have made to the health system as an aspect of the post-caring/care transitions experience has yet to be specifically referred to in the literature. Some literature on the transition to a nursing home placement alludes to lack of recognition of carer expertise by nursing home staff (Allen, 2000; Sandberg et al, 2003). Difficulties experienced by former carers attempting to enter the formal labour force have also been acknowledged (Arksey, 2003; Bond et al, 2003; Hirst, 2005; McLaughlin & Ritchie, 1994). This finding also ties in with earlier Irish work on the caring role. Hynes et al (2008) found that despite the extensive levels of expertise the carer had developed in relation to the care receiver's condition, they felt excluded from the care planning and decision-making process. Furthermore, the participants in the Hynes et al (2008) study felt that there was a lack of recognition of the contribution informal carers provide to the health system.

The perceived devaluing of former carers by State services was also felt in relation to **social welfare allowances**. A lack of flexibility and humanity around the rules and means testing of various social welfare entitlements was highlighted as an issue for former carers. The rigidity of the social welfare system



is evident in the case of one interviewee who was refused the Respite grant. To be eligible for this grant, the carer needed to be caring on the first Thursday of June. This interviewee had been caring full-time for his mother for five years. However, his mother died on the morning of the first Thursday of June. He was deemed ineligible to receive this grant; even though he had spent the following three days arranging his mother's funeral, which he believes constitutes performing a caring role. It was the principle and the treatment of carers rather than the money, which was most upsetting for him.

*Something that I found very difficult to cope with... They refused me for one day, now don't get me wrong it wasn't the money, it was the principle of it. We actually appealed it and they refused it. It's actually with the Ombudsman at the moment. And it's going on now a long time. My mother's anniversary will have come and gone and it still won't be sorted. I think it's disgraceful that they would refuse you for the one day. I mean I still had to come home and organise her clothes and things – now do they not regard that as caring? (Interviewee #16).*

Also, many former carers have been out of the formal workforce for such long periods of time that they have insufficient levels of PRSI contributions to avail of many State benefits.

*I was told if I paid the bill and went down to social welfare, you'd get a bereavement grant. That was the advice I got. So I borrowed money from my two children and said I would pay them back as soon as I would get the grant, sent off the bill and went down with the form. They sent it to whoever looks at it up high and they wrote back and said because it was paid you'll get no grant. I was very angry about that because we had to buy a plot which was €1,100 and we had to cover all funeral expenses. And nobody cares a tuppenny, nobody cares... So I'm very angry about that as that was what I was advised to do (Interviewee #26).*

Although the lack of statutory supports for former carers has yet to be discussed in the Irish context, the broader literature on Irish carers have emphasised the lack of supports during the caring phase. O'Brien (2009) also asserted that Irish carers require more flexible services as well as more financial and psychological support. Further to this, a number of Irish policy documents have underlined the need for increased supports for family carers (e.g. National

Plan for Social Inclusion 2007-2016; Joint Oireachtas Committee on Social & Family Affairs – Review of the Position of Full-time Carers, 2003). The findings from the present study have demonstrated the need to extend statutory supports to Irish former carers.

#### 4.3D POST-CARING/CARE TRANSITIONS POVERTY

The immediate drop in household income that accompanies the cessation of caring severely impacts upon the finances of former carers. Many of the participants were in a precarious financial situation, with some unable to pay essential household bills such as heating. The findings suggested that post-caring/care transitions may induce poverty.

The Carer's Allowance is currently paid for six weeks after caring ceases. It is apparent from the findings that six weeks is an insufficient amount of time to find an alternative source of income. This is especially pertinent due to the impact that their years of caring have had on former carers' employability and earning power. This is because they may have been out of the formal workforce for several years due to their caring responsibilities. The interviewees indicated how their time as a full-time family carer had a negative impact on their career, on their earning power, on their contribution to a pension and on accessing the labour force.

*I couldn't go back to work because I'd left my work to look after Mom. And with the work situation the way it is at the moment...and the same way, your money is gone – it's a big financial drop (Interviewee #15).*

Furthermore, six weeks appeared to be too short a time to identify a new source of income, given the myriad of psychological impacts of post-caring/care transitions discussed in the previous sections.

*You're asking me how life has been. Totally hard and harsh because you have to pay the bills immediately and that's a worry straight away. So you have to focus on that, even though your heart is elsewhere, you have to get your head around to here (Interviewee #26).*

In addition to this, the free household benefits (i.e. free TV license, free telephone rental, free travel pass), which were available during the caring phase are no longer available in the post-caring/care transitions phase. This has a major impact on former carers' financial situation and their ability to pay household

bills and meet other financial commitments. For example, one participant spoke of how he recently had to choose between paying an electricity bill and buying medication.

*I lost my half of the Carer's Allowance. I lost my father's old age pension. The gas and electricity and phone still cost the same. Last week there I had the option of paying the gas bill or paying for medication. The gas bill won. You have to cut your cloth according to your measure. But medication isn't a luxury, it's a necessity (Interviewee #3).*

The loss of income during the post-caring/care transitions phase was such a major source of worry that many interviewees felt they did not have sufficient time to grieve the death of the care receiver. They reported that immediately they had to start looking for ways to generate an income. One particular participant began worrying about financial issues as the care receiver's health began to deteriorate rapidly. This led to strong feelings of guilt for the carer prior to the post-caring/care transitions phase.

*She's dying there in front of you and you feel so guilty because what you're thinking of is how are we going to make ends meet when my Carer's Allowance stops (Interviewee #10).*

Some participants were full-time homemakers prior to receiving the Carer's Allowance. These individuals pointed out they would find it extremely difficult to enter the formal labour force, especially within six weeks, as they did not have any formally recognised work experience or qualifications. Therefore, they had very few, if any, options when trying to find a source of income to replace the carers' allowance. In addition to this, some social welfare payments that former carers might avail of in the post-caring/care transitions phase (e.g. bereavement grant) are based on sufficient levels of PRSI contributions, which automatically puts former carers at a disadvantage.

*If you're applying for the bereavement grant it's based on your contributions, which I had none of... there should be some facility for people who have given up their own chance to have some money because of caring, they should get expenses. Because I really have to pay my children back, it's not fair because they have their own bills to pay. I would never have expected to have to borrow from my children (Interviewee #26).*

The data highlighted the inflexibility of regulations in relation to the payment of social welfare benefits. This was especially apparent with regard to married carers, as their husbands' income was taken into account when calculating their entitlement to various schemes. Also, the married former carers interviewed were not entitled to receive any social welfare support or access FAS training courses, as their partners' income disqualified them. They had become accustomed to having their own money and were uncomfortable with now being dependent on their partner's income.

*I'm so used to having my own money and I can't get anything from social welfare because of (name)'s income is taken into account. And I can't get on any courses because of his income too. And we're barely able to afford the basics such as food and petrol for the car. There's no such thing as luxuries like getting my hair cut these days (Interviewee #10).*

To conclude, financial problems were a major source of concern for the former carers in this study. The post-caring/care transitions phase appears to be marked by difficulties in paying household bills due to a sharp reduction in income in a short period of time. A reduction in employability and earning power as a consequence of their caring commitments was another contributory factor to the poverty experienced in the post-caring/care transitions phase.

The existing literature has also highlighted the negative impact that caring has on one's earning power, pension entitlements and overall financial situation (Arksey, 2003; Bond et al, 2003; Hirst, 2005; Hirst & Hutton, 2000; Vlachantoni, 2010). McLaughlin & Ritchie (1994) noted that provisions of the social security system for former carers are inadequate. This is especially relevant due to the lack of recognition of the need for any long-term monetary compensation. The insufficient levels of financial assistance for carers provided by the Irish State were also highlighted by both Stokes (2010) and Hynes et al (2008).

Prior studies have indicated that former carers who have access to a variety of personal resources and supports are better able to cope with the post-caring/care transitions phase. Anneshel et al (2004) highlighted the protective role of socio-economic support, strong social ties and high levels of income in alleviating the negative impacts of post-caring/care transitions on the former family carer.

### 4.3E THE SIGNIFICANT ROLE OF CARERS' ORGANISATIONS IN POST-CARING/CARE TRANSITIONS

For many of the participants, their local carers' organisation played a crucial role in helping them deal with post-caring/care transitions. During the caring phase, carers' organisations supplied much needed respite through home help workers, weekends away, carer support groups, carer telephone helplines and carer training courses. Carers' organisations were also seen as an important source of support during the caring phase in Stokes' (2010) study of Irish carers of people with Parkinson's disease.

In the post-caring/care transitions phase, the interviewees indicated that they still felt that they could take part in meetings and felt very much welcomed by the carer organisations' managers and staff. The findings indicated also that the carer centres and organisations provided both emotional and practical support to former family carers. The support groups provided friendship, companionship and emotional help in a safe and familiar environment. Staff also provided advice on post-caring/care transitions issues. Some of the interviewees were completing training courses on caring, which they began while they were still caring.

*I have to acknowledge the support I get from the Carers Association, the empathy and the love and the friendship and the genuine concern I got from those fellow carers (Interviewee #3).*

The co-ordinators of the support groups continued to monitor the wellbeing of former carers. For example, they contacted the former carer if they did not attend support group meetings.

*We can say whatever we like when we meet in the group. And then if I was missing there Wednesday one of the people would ring me and ask where was I today and was I alright (Interviewee #20).*

The psychological support provided by the carers' organisations was seen as significant.

*When there was no-one else there for me, in some cases even family, the Carers Association were there. All I had to do if I felt particularly down or depressed and in one case suicidal, all I had to do was pick up the phone and there was someone at the other end (Interviewee #3).*

It is important to note that not all former carers have links with their local carers' organisation. They may not have been involved during the caring phase and so might have been reluctant to join in the post-caring/care transitions stage. Others may have felt that the carers' organisations were not relevant to their lives anymore and many of the issues discussed at the support groups no longer applied to them. Larkin's (2009) participants similarly indicated that they continued to receive support from carers' organisations into the post-caring/care transitions phase.

### 4.3F FAMILY RELATIONS IN POST-CARING/CARE TRANSITIONS

The absence of statutory support for former carers was in some way buffered for those who had supportive family members. Many participants indicated that their family played a crucial role in helping them deal with the challenges of post-caring/care transitions. Family members were a key source of both emotional and instrumental support during post-caring/care transitions. These supportive activities ranged from regular telephone calls, visits to their home, social outings, being there for them to talk to and financial help.

*My family were very, very supportive. They were considerate of me, they were just superb. They'll ring me every lunchtime – 'are you ok? Is there anything you want?' so they're very caring. They come over for lunch every Sunday. I wouldn't have been able to get through it without the support from my brothers and sisters (Interviewee #16).*

Despite this, not all interviewees had a supportive network of family members to help them cope with the challenges of post-caring/care transitions. In some cases, this was the time in which family conflict surfaced. This conflict was most typically between siblings. There was a lack of understanding among some siblings about challenges, such as financial and employment issues that the former carer now faced:

*And then there's the famous one of 'what's your problem now? You've got your life back now, what have you got to worry about now? Jesus you were whinging when you were looking after her and now you're whinging when you're not' (Interviewee #6).*



Conflict often centred on issues that pertained to the caring phase, for example the unequal sharing of caring responsibilities among family members. In particular, the inheritance of family property was a major cause of arguments during post-caring/care transitions. In many cases, the former carer had inherited the family home. This led to feelings of bitterness and resentment.

*You got the house what more do you want? (Focus group #1).*

In Larkin (2009), three-quarters of the participants (N=28) were more involved with family after entering the post-caring/care transitions phase. This helped them establish new routines and rebuild their lives. Broader literature on informal caring in Ireland has also noted that families play a vital role in helping carers cope with the demands of the caring role (Hynes et al, 2008; O’Sullivan, 2008; Stokes, 2010).

## 4.4 MOVING ON

Some former carers spoke of beginning to ‘move on’ from the losses inherent in the post-caring/care transitions phase and of constructing a new world. Means of caring for the self in post-caring/care transitions were described. These included keeping active and ‘getting out of the house’, for example by enrolling on courses in the community. A tendency for former carers to engage in other caring roles was also described.

### 4.4A CARING FOR SELF IN POST-CARING/CARE TRANSITIONS

Some of the Interviewees proactively developed techniques for taking care of themselves to avoid focusing on the emptiness, loss and loneliness more characteristic of the post-caring/care transitions phase. A wide range of methods was used. Interviewees reported that it was they alone who had to proactively start looking after themselves. This ‘**sink or swim**’ scenario is illustrated in the following quote:

*You have to start thinking positively or otherwise you’ll go down the drain. You can either sit there or go down or you can get out of the house and do something (Interviewee #21).*

One of the most common means of taking care of oneself was ‘keeping busy’ so as to avoid negative and depressive thinking. Participants reported how

keeping busy had proven to be a very successful way of dealing with the emptiness, loss and loneliness of post-caring/care transitions. One of the key aspects of ‘keeping busy’ was that it ensured that the former family carer ‘gets out of the house’ and did not become ‘stuck’ in depressive thinking patterns.

*You get involved in all these clubs and things but you have to, otherwise you’d crack up (Interviewee #21).*

A number of interviewees reported availing of computer training courses in the local library as a way of busying themselves and as a form of personal development. These courses were also free of charge which made them appealing to those who were struggling to cope financially.

*I took up the course just to get me out of the house for a couple of hours a week (Interviewee #15).*

During the post-caring/care transitions phase, the interviewees reported that they have substantially **more time** for themselves.

*I decided to take a rest for myself. So I decided to sit back and this year is for me because it was very stressful. This was my place where I sat and slept every afternoon I wanted to. I did it for me and that was a great help. I just looked after myself. I joined a gym and things (Interviewee #18).*

Many participants indicated that they used this spare time to redress the **neglect of family relationships** during caring. This prior neglect was due to the high levels of demands on family time and energy that the caring role required. For example, former family carers began to spend more quality time with their spouses and children.

*I did things I had neglected. I felt I’d pushed my family away. So I went on a holiday for a month. Myself and my husband went away for weekends ( Interviewee #18).*

The development of, or return to, **hobbies** that were neglected during the caring phase is another way interviewees took care of themselves during post-caring/care transitions.

*I’ve started getting my life back. I’m reconnecting with old friends and I’m no longer exhausted and too tired to enjoy nights out (Interviewee #12).*



**Belief in an afterlife** was also identified as a source of comfort for former carers. Those who had spiritual beliefs reported getting comfort from the feeling that they know their deceased loved one is happy in heaven. They also felt that their deceased relative was taking care of them and still with them.

*I feel that Mam is guiding me and helping me...I feel she's here. She's here beside me now (Interviewee #16).*

*I have actually had to call on it (her faith) and test it out to see if I really believe what I've always said I believed. And I do. I believe that (name of husband) is in heaven. That's the only thing that's happened to him. There's no doubt in my mind that he's in heaven and he can do what he wants (Interviewee #26).*

A frequently reported way of caring for self was by **engaging in other caring roles**. Caring for others, be they grandchildren, friends or neighbours, was viewed as another way to avoid focusing on oneself and a means of 'getting out of the house'. It was also perceived as being intrinsically rewarding. Thus, it helped the former family carer deal with post-caring/care transitions. The two themes of taking care of self and taking up other caring roles are inter-related. This is discussed in more depth in the following section.

*It's very hard to get over, it really is, the only advice I'd give anyone is try and help somebody else and that will help you to cope. Don't always be thinking of yourself, try and reach out to other people, there's always someone who needs help. You're helping them, but you're helping yourself too (Interviewee #2).*

It is important to note that it was former carers themselves who proactively developed and sought out ways to **revalue themselves** and their life world, so as to successfully deal with the challenges of post-caring/care transitions. It is also noteworthy that not all interviewees indicated that they have developed ways of caring for themselves. Possible mediating personality factors such as self-esteem, self-efficacy, resilience and hardiness warrant further exploration in future research, especially given that, Aneshensel et al (2004) concluded that self-esteem plays a protective role for carers experiencing bereavement.

This theme also resonates with the work of Lundman & Jansson (2007). They proposed that the process of 'revaluing of self', involves successful re-adjustment

to an altered life-world, such as lifestyle and daily activities, due to chronic illness. This process involves a revaluation of the self, of prevailing values and a sense of being revalued by the world. Similarly, in this study, the findings demonstrate how former carers reformulated their interests, their daily activities and their role in life.

#### 4.4B CARING FOR OTHERS DURING POST-CARING/ CARE TRANSITIONS

There was a tendency for some former carers to take up a wide range of caring roles. The numerous routes into other forms of caring among the interviewees included: mentoring current family carers, training to be a professional carer, taking care of grandchildren and volunteering in local community groups. There were an accompanying variety of motivations underlying the routes back into various forms of caring.

Those who engaged in formal caring were split into two cohorts: (a) those who took up the role voluntarily because they found the caring experience very rewarding and made a change in their career, and (b) those who undertook formal caring as they felt that due to financial necessity they had no choice and this was the only job for which they had experience.

*All I've done my life-long is care for other people because when my mother got sick I was the oldest daughter and I took care of the younger children because my Dad had to go out to work. Then I cared for my children and then my Gran. That's all I've done with my life. I'm not trained or experienced in anything else (Interviewee #10).*

Professional caring was seen as a very different scenario because the cared for person was not a family member. Also, there was frustration because in the absence of a formal caring qualification their previous years of experience were not recognised by potential employers.

*I went straight into the caring role again because I had to. I had to go out and start earning. It was the only place I could get some money. But caring for strangers is a very different thing altogether. There's all these rules and regulations. And it's not the same, they're not your own (Interviewee #10).*

Others saw their period of time caring as leading to a reassessment of their career direction. These participants found the role of caring so rewarding that they wanted to become or had become a professional carer.

*I know myself how important it is to get just one hour off a day. And they so need that. So, I love doing the respite for the full-time carers because I know how much it means to them. I try and do whatever I can to help... And I've met the most amazing people (Interviewee #13).*

*It was such a wonderful, wonderful experience. It made me realise how unhappy I was in my previous job. This has put me on a new road and I have Mom to thank for it. It was such a wonderful feeling caring for her (Interviewee #16).*

As well as professional caring, interviewees also engaged in informal caring roles. These roles included voluntary work in the community, especially with local carers' organisations. Former carers mentored existing carers, helped with fund-raising and performed administrative functions for their local carers' organisation.

*I met her on the bus and she was in a very bad state, she wasn't doing good at all. She had looked after her daughter for years and she'd just died, so I got her some counselling (Interviewee #2).*

Motivation for engaging in this type of activity was two-fold. Firstly, it enabled the former family carer to 'give back' to the carers' organisation for all the help and support they provided when they were caring. Secondly, being involved in the local carers' group helped combat the loneliness and emptiness of the post-caring/care transitions phase, by meeting other group members, keeping busy and 'getting out of the house'.

*They were so good to me I felt I had to give something back. They asked me to be treasurer and I got busy again (Interviewee #2).*

Other roles taken up outside of the traditional definition of caring include taking care of grandchildren several days a week, while their own grown-up children are at work.

Another finding that emerged from the data was in relation to former male carers. These were described

as small, male support groups that grew organically from shared experiences. Typically, two to three men (including widowers and former carers) met for social outings or in each other's houses. It was during these events that they talked about issues affecting them. The emotional support received was a by-product of the social occasions rather than the main stated objective, as is the case with formal carer support groups. Established local carers' support groups typically have a higher proportion of women than men in attendance. Male carers supporting each other and simultaneously taking care of themselves in the post-caring/care transitions phase may be a response, in part, to the fact that they feel more comfortable talking with other males. Regardless, men constitute 40% of carers in Ireland and they report, as can be seen here, at least equal levels of challenge and distress in the post-caring/care transitions phase. Yet, they are under-represented in the carer groups and other services designed to offer emotional and other supports. There are findings here for carers' organisations and formal services to consider if they are to develop options more appealing to male carers.

*A good friend of mine his mother died too and he's like me, he lives on his own... I go to visit him every evening... And he tells me about his experiences of looking after his mother and I tell him about my mother and it's good. I find this a great help because I could be helping him (Interviewee #19).*

*Since (name of wife) died I started cooking lunch for (name of male friend) and (name of male friend) because they're on their own everyday too and you know it beats eating on your own and for me it has paid dividends in the sense that it's been reciprocated. There's a social dimension to it and a caring dimension to it (Interviewee #11).*

In addition, the acute need for formal psychological support structures for everyone was highlighted by two male former carers who disclosed during their interview that they had previously attempted suicide. It would be appropriate to assume that there are female former carers who would equally benefit from such services.

To conclude, caring for others and caring for self during post-caring/care transitions were overlapping and inter-connected concepts. As the former carers were caring for others, they were also taking care of

themselves by keeping active, staying connected to others and engaged in their community. The findings from this study further develop and build upon Larkin's (2009) concept of 'serial caring', i.e. the cyclical nature of undertaking numerous caring roles due to family obligations. Larkin (2009) found that former carers may not have a choice about their re-entry into the caring role. However, this study features former carers who proactively sought out further caring roles. This study expands and extends the concept of 'serial caring' to include a wide range of caring activities, e.g. caring for grandchildren, mentoring other carers. Engaging in other caring roles enables the former carer to positively contribute to others' lives and the local community, while simultaneously taking care of oneself. Therefore, engaging in various forms of caring is not viewed as being detrimental but rather highly beneficial to the former carer's wellbeing. Other theorists have also noted that former carers engage in new activities such as volunteering and other caring roles (Hirst, 2005; Lewis & Meredith, 1988).

#### 4.5 EMERGENT CONCEPTUAL MODEL

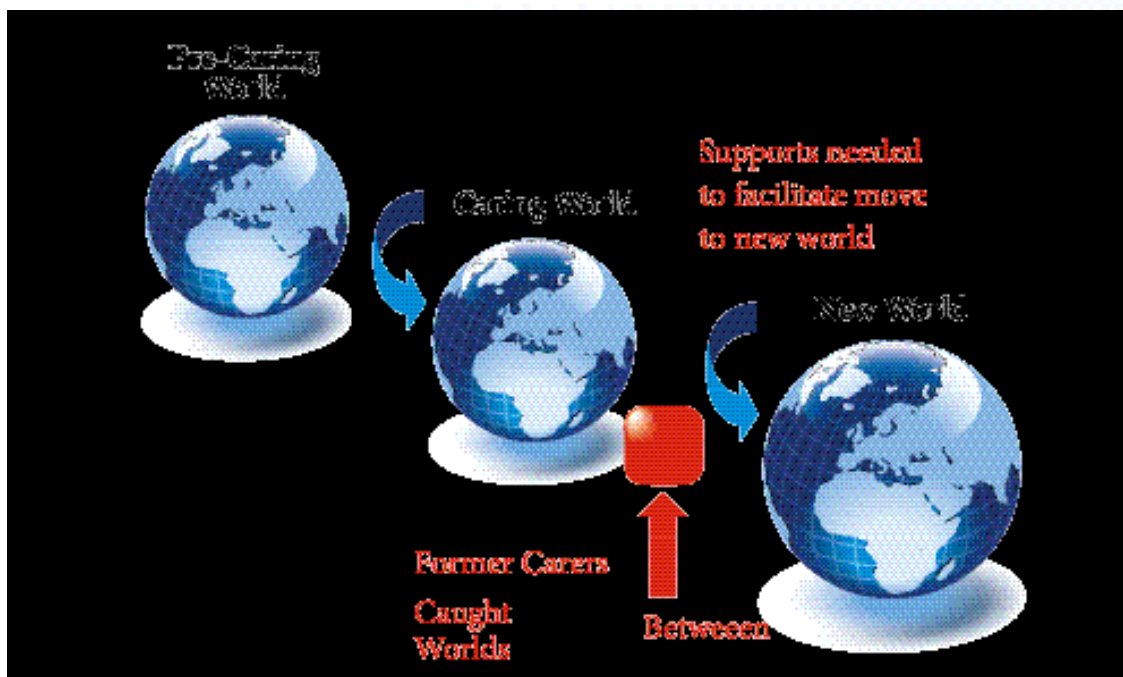
*I was still in a kind of 'between worlds' type thing. I didn't know if I was coming or going or whatever (Interviewee #6).*

*You're in no world, your life before caring is gone, your caring world is gone, you're left with no world (Focus group #1)*

The quotations above capture the essence of a conceptual model, which incorporates the post-caring/care transitions processes formulated from the data. The following diagram illustrates how for the former carer that not only has their pre-caring world (i.e. their life world prior to becoming a full-time, primary carer), with all its social contacts, employment and other life opportunities disappeared but as they move to post-caring/care transitions there is also the loss of a 'caring world'. Their daily routines, carer role and identity, close relationship with the care receiver, and social network of medical personnel visiting their home have suddenly dissipated. The double losses create a profound sense of loss and emptiness that is characteristic of post-caring/care transitions. The data indicates that for former carers, with the pre-caring world lost in the distance, the transition is between the caring world and a newly reconstructed world after caring. In this state, they feel 'worldless'; they do not belong to any particular place and do not have any particular label or identity that applies to them.

Figure 4.1 is designed to capture and present this 'worldless' status.

**Figure 4.1: Level One of Conceptual Model**

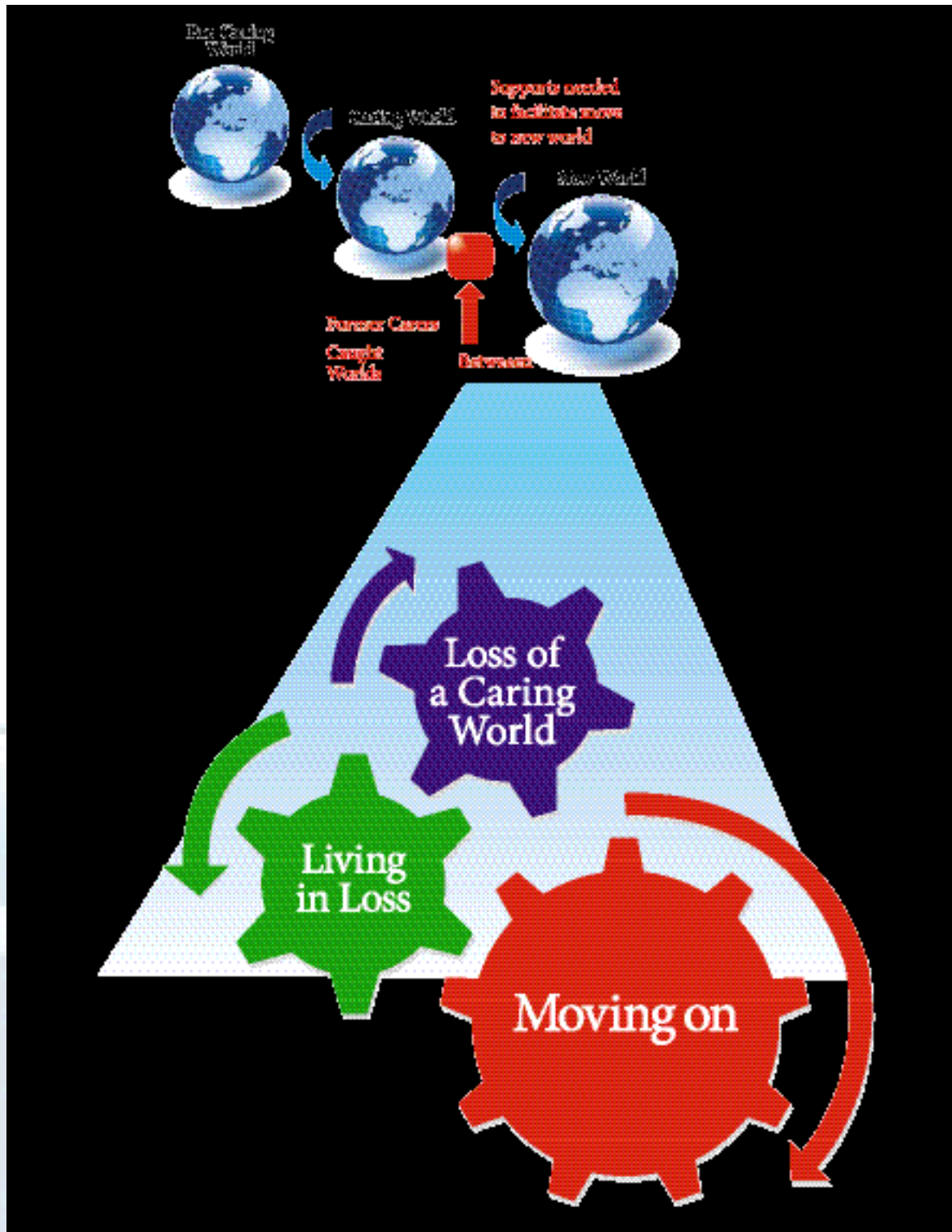




For many former carers, there is not an easy transition and participants in this study often described an extended period of 'between worlds' as the mark of 'worldlessness'. The next level of the conceptualisation captures this 'between worlds' state, represented by the pink-shaded rectangular area in figure 4.1,

between the caring world and new world which is then magnified in figure 4.2 so that incorporation may be represented of the post-caring/care transitions processes of (i) Loss of Caring World, (ii) Living in Loss and (iii) Moving On.

**Figure 4.2: Level Two of Conceptual Model**





The presentation of this second level of the model graphically represents how the post-caring/care transitions phase is a cyclical and interactive process. The final definitions of the three processes are:

### (i) LOSS OF CARING WORLD

The loss of the caring world occurs at the beginning of the post-caring/care transitions phase. The losses are multi-dimensional and include loss of identity as carer, loss of role as carer, loss of the close bond with the care receiver, loss of the social relationship with the network of healthcare professionals and loss of medical equipment.

### (ii) LIVING IN LOSS

This refers to the process of living in and continually experiencing the losses of post-caring/care transitions. A key feature of this part of the post-caring/care transitions experience is the emotional reactions such as guilt, relief and a sense of urgency. Another feature is the anger felt towards State services. This is exacerbated by the perceived dismissal and devaluing of the former carer by State systems. This perception and anger is one of the barriers to 'moving on' to a new world after the cessation of caring. Another barrier preventing former carers from moving on is the financial difficulties that accompany post-caring/care transitions in certain circumstances.

It appears that not all former carers 'move on' but some continually move between the loss of the caring world and living in loss in a continual, cyclical movement. They become 'stuck' in the losses and living in the losses of post-caring/care transitions.

Therefore, they do not move on to the third 'cog' or wheel in the diagram above, which enables them to construct a new life world.

Others 'move on' from this cycle and consequently move out of the 'trapped' space between worlds. Thus, they no longer view themselves as being 'worldless' because they have begun to construct a new world. Some of the facilitators, which aid and help former carers move on to a new world include family support and support from carers' organisations.

### (iii) MOVING ON

This concept incorporates former carers who proactively have begun to move on to a new world. This includes those who have started to care for themselves, by keeping active, becoming involved in their community and 'getting out of the house'. For some former carers, 'moving on' involves taking up other caring activities, such as mentoring other family carers or taking care of grandchildren.

## SUMMARY

For participants, the post-caring/care transitions experience was imbued with loss as a consequence of losing a loved one and losing one's world. Loss of one's world encompassed losing their established social network, sense of identity as carer, purpose in the world and income. Moving on from this loss required a conscious effort to engage with others. For most, whatever skills they had for employment before taking up their caring role had been lost. Thus, moving on did not allow a return to a previous area of employment. Rather, participants viewed their caring skills as a core part of their new world.

# 5

## CONCLUSIONS & RECOMMENDATIONS

### 5.1 MAIN CONCLUSIONS

The project addressed the study research questions by successfully identifying former carers' experiences and needs, the factors affecting their life quality and the interventions required to enhance former carers' wellbeing.

The findings suggest that former family carers feel that they are both 'worldless' and 'between worlds' as their caring world no longer exists and they have yet to construct a new world. This vacuum or state of limbo between the caring world and a new world involves three interacting processes, namely the 'loss of caring world', 'living in loss' and 'moving on'. The loss of the caring world occurs at the beginning of the post-caring/care transitions phase and concerns the various forms of losses that accompany the cessation of caring. Living in loss involves experiencing the emotional reactions to the post-caring/care transitions phase. There are a number of barriers that many former carers experience that prevent them from 'moving on'. As a result of these barriers, the former carer continues to move in a cyclical pattern between living in loss and the loss of the caring world. These barriers include the financial difficulties and complex emotional challenges of post-caring/care transitions. It appears that carers' organisations and supportive family relationships act as facilitators, which help former carers move out of the vacuum between worlds and start constructing a new world. Some of the former carers have proactively developed ways to 'move on' and not become 'stuck' in the losses of post-caring/care transitions. These mechanisms for 'moving on' include taking care of self and others. An understanding of the three processes; loss of caring world, living in loss and moving on, is the main contribution of the work herein.

#### LOSS OF CARING WORLD

The losses of the caring world are multi-dimensional and range from the emptiness of the house due to the removal of medical equipment, to the loss of the social network of regular visitors to the home, to the

loss of one's role in life and sense of self. The loss and emptiness of post-caring/care transitions is so profound that the interviewees equated it to being 'worldless'. The loss of the uniquely close relationship (i.e. practically, emotionally and legally) that had developed between carer and care receiver further compounds the feelings of loss and emptiness.

#### LIVING IN LOSS

Living in the loss of post-caring/care transitions involves experiencing complex emotional reactions such as guilt about the care provided, relief that the care receiver is no longer suffering and a sense of urgency as they still feel 'on duty'. Along with this, prior conflict with healthcare professionals has resulted in high levels of anger and frustration still being felt in the post-caring/care transitions phase. A perceived dismissal of the carer's expertise, skills base and workload is a further source of frustration. This lack of acknowledgement seems to become apparent in the post-caring/care transitions phase, when former family carers are attempting to re-enter the labour force.

The only post-caring/care transitions State support that is provided is the payment of the Carer's Allowance/Benefit for six weeks after caring ceases. The sudden decrease in household income was reported to lead to severe financial problems for some former carers. In many cases, the former carer's earning power and PRSI contributions have been detrimentally affected due to their caring role. It is suggested from the findings that post-caring/care transitions may induce poverty in certain circumstances.

Relatives and carers' organisations act as facilitators, enabling the former carers to construct a new life after caring has ceased. However, not all former carers are involved in their local carers' organisations or have supportive family members. Many familial relationships, especially between siblings, are characterised by conflict during post-caring/care transitions.

## MOVING ON

Some of the participants developed mechanisms to enable them to deal with the challenges of post-caring/care transitions and 'move on' to a new world. The various methods of caring for the self included proactively taking up activities in the community so as to 'keep busy'. Many of the interviewees indicated that 'getting out of the house' eased the post-caring/care transitions emptiness and prevented them from engaging in depressive thinking. Taking up new courses, reconnecting with old friends and engaging in hobbies are other ways that former carers reported managing the emptiness of post-caring/care transitions. Those who had spiritual beliefs found that they gained solace and comfort from these.

Another major theme was the tendency of former carers to take up new caring roles. These roles included mentoring members of the local carers' organisations, looking after grandchildren and becoming a professional carer. Some of those who became professional carers did so out of financial necessity. However, adopting these roles was viewed primarily as a means of 'keeping busy' and thereby coping with the losses of the post-caring/care transitions phase. Indeed, male carers reported on how they were forming social groups so as to help each other deal with the post-caring/care transitions phase. In conclusion, taking care of the self in post-caring/care transitions and taking up new caring roles were inter-related concepts and important contributors to moving on.

It was indicated by the data that the major needs of former carers centred on financial and complex emotional difficulties inherent in the post-caring/care transitions phase. Addressing these needs will usually help former carers 'move on' to a new world after they cease caring and so avoid getting 'stuck' in the losses of post-caring/care transitions.

## 5.2 METHODOLOGICAL ISSUES

The sampling approach taken in this study meant that the participants were in some way linked or known to a carers' organisation. As such, these are not the most marginalised of former carers. Also, the majority of the interviewees were in the post-caring/care transitions phase due to the death of the care receiver. There was an under-representation of those undergoing post-nursing home placement and especially those going through a post-hospice

transition. However, most of the existing literature focuses on post-hospice and post-nursing home placement transitions, with a dearth of data on post-caring/care transitions experiences due to death. Perhaps here the bereaved carers were the easiest to identify for the study's gatekeepers as they are more clearly evident than other types of carers (i.e. post-nursing home placement and post-hospice placement). Also, the 'post-death' carers might possibly have more time available than others to participate in the research study. Regardless, a new perspective has been added to the literature on former carers.

As opposed to having difficulties recruiting participants, the research team was inundated with potential interviewees willing to participate in the study. Most participants were happy to have someone to talk to about their experiences and to help improve the situation for other former carers. There is no term or label of 'post-caring/care transitions' in the general public discourse that former carers can apply to their current predicament. In a way, this study gave interviewees an opportunity to increase recognition of their post-caring/care transitions status.

## 5.3 RECOMMENDATIONS

### 5.3A GENERAL STATE SUPPORT NEEDS

- The participants highlighted that there are currently no statutory health or social care services in place for former carers. This is a major gap in support services given the challenges inherent in post-caring/care transitions that are described in this report. Formal statutory support mechanisms aimed specifically at former carers need to be developed.
- A formalised system of support appears to be needed that would automatically come into play when the payment of the Carer's Allowance for a particular individual ceases. This would ensure that no marginalised former carer 'falls through the cracks' and should address: a) reducing the poverty trap into which carers fall in the post-caring/care transitions period, and b) reducing the risk of long-term unemployment as a consequence of opportunities lost due to extended caring years.
- Organisations such as those that are ageing focused and hospice organisations should be encouraged to explore ways of addressing the post-caring/care transitions experience



specifically in respect of bereavement support and of raising awareness among statutory agencies. Specifically, there is a clear need for timely acknowledgement and notification of the death of the care receiver and the loss this represents for the carer.

### 5.3B COMBATING POST-CARING/ CARE TRANSITIONS POVERTY

- Extension of the payment of the Carer's Allowance for longer than six weeks post-caring/care transitions should be considered. Six weeks may not be a sufficient amount of time to generate another source of income, given the negative impact that long-term caring can have on one's employability and earning power.
- There should be more flexibility in social welfare regulations for former carers, especially in relation to the status of married former carers, payment of the Respite Grant and entitlement to the Bereavement Grant. Special exceptions should be considered for former carers, as their ability to accumulate sufficient PRSI contributions has sometimes been compromised by their caring role.
- It is recommended that a career advice and employment support service, tailored specifically to the needs of former carers should be developed.

### 5.3C INFORMATION PROVISION

- The findings indicated that former carers need some preparation for the cessation of caring. A health promotion and self-help toolkit might be distributed to carers during the final stages of caring. This information pack should detail:
  - What to expect in the post-caring/care transitions experience
  - Signposts on where to get help and advice, especially in relation to social welfare entitlements
  - Organisations, which co-ordinate volunteering and other opportunities for former carers to 'keep busy' and 'get out of the house'

### 5.3D TAPPING INTO FORMER CARERS' SKILLS AND EXPERTISE

- Former carers have developed extensive knowledge of the health and social care services system and individual professionals in their

locality. Mechanisms are needed to utilise their wealth of untapped knowledge to help advise and guide current carers in their locality.

- Establishing a mentoring scheme should be considered where former carers could help guide current carers on their caring journey.

### 5.3E MENTAL HEALTH ISSUES

- A major post-caring/care transitions need that emerged from this study is psychological support, in particular professional counselling and monitoring house calls to deal with the emptiness, loss, loneliness, guilt, 'clock-watching' and anger many reported experiencing.
- The support structures currently offered appear designed for female former carers and are not being accessed by male carers. Given that men represent 40% of carers the design of more appropriate supports should be considered. Men's own efforts (reported on here) to develop social support groups provide an ideal starting point.
- Conflict resolution supports should be available for former carers to better equip them to deal with conflictual family relationships that sometimes characterise the post-caring/care transitions phase.
- Interventions such as sessions on relaxation and stress management should also be available to combat the high levels of urgency, clock-watching and poor sleeping patterns evident at the beginning of post-caring/care transitions.

### 5.3F COMBATING SOCIAL ISOLATION

- Community volunteers or former carers regularly calling into other former carers could help alleviate the feelings of emptiness, loss and loneliness characteristic of the post-caring/care transitions phase. This is also an ideal way to utilise the skills of former carers.
- Post-caring/care transitions support groups focused on post-caring/care transitions issues should be established.
- Although the level of computer use among former carers was not specifically discussed, many reported taking free computer classes. This suggests a possible strategy for reaching isolated former carers may be the establishment of a 'National Former Carers Network' using social networking strategies.



### 5.3G AWARENESS RAISING

- It is recommended that health and social care professionals receive additional education on the experiences and needs of both carers and former carers. Again, this would be an opportunity to utilise the skills of former carers.
- An awareness raising campaign on the psychological aspects of post-caring/care transitions should be aimed at General Practitioners. This will help them to be cognisant of these issues when a carer in their practice ceases caring.

### 5.3H FURTHER RESEARCH

- Further research should attempt to access more marginalised former carers, in particular those who are not involved in any carers' organisations.

- The role of individual differences in former carers' ability to develop ways to care for self and others in post-caring/care transitions requires further examination. Personality factors such as self-esteem, self-efficacy, hardiness and resilience may influence the former carer's tendency to proactively engage in activities that help overcome the challenges of post-caring/care transitions.
- Future research should also focus on the development of post-caring/care transitions interventions. Such research would be best advanced by acknowledging former carers' knowledge and expertise, suggesting the adoption of action research approaches in such studies.

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# APPENDIX ONE

# INTERVIEW GUIDE

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## OPENING QUESTIONS:

- Tell me what life is like for you since you stopped caring for your family member at home and/or
- How do you think ceasing caring at home has affected your life?

## EXPERIENCE OF CARING/TRANSITION:

- Could you please tell me what caring in the home was like for you?
- Place of death – hospice vs hospital death
- What happened immediately after the death/placement?
- When did contact with HSE/social welfare services stop?
- Do you think you were prepared for life after caring?

what would have helped?

## NEEDS:

- How would you compare your life now with your life while you were caring for your family member?
- How would you describe your needs since you are no longer caring for...?
- What is your typical day like now compared to in the past?
- What do you do to occupy your time?
- How do you feel about the fact that you are no longer caring at home?
- What do you think the future holds for you?
- What do you think lies ahead for you in the coming years?
- How would you describe your own health?
- What factors do you see as impacting on your own health?

## OTHER PROBES

- Loss of identity
- Fill the gap/void in daily routine
- Deal with loneliness & isolation
- Deal with complex emotions – guilt/loss/relief/anger
- Financial issues
- Moving on with own life
- Information needs
- Physical health difficulties

## FACTORS AFFECTING QUALITY OF LIFE

- What do you think affects (how you enjoy) your life now?
- What makes you happy/sad these days?
- Do you get any help from family/friends/neighbours/church/government depts.?
- Do you have any hobbies or interests?

## OTHER PROBES

- Family (including extended family)
- Friends/neighbours
- Community support
- Carers' organisations
- Recognition of hard work from State/HSE
- Employers support (if caring part-time)
- Religious organisations
- Hobbies/interests

## INTERVENTIONS

- Could you tell me what is your experience of support since you stopped caring?
- What do you think would help you?
- What types of support would be helpful to you immediately after you stopped caring?
- What types of support would be helpful to you now?

## OTHER PROBES

- Information
- Preparation for post-caring phase
- Carers' organisations
- Financial support
- Return-to-work issues (gender issues?)
- Education & retraining opportunities
- Becoming a mentor for other carers
- Counselling

## PARTICULAR TRANSITIONS

- Different needs/factors/interventions

## NURSING HOME/HOSPICE PLACEMENT

- negotiation with care staff
- new relationship with relative - guilt
- new caring routine/role

Some carers will have gone through 2 transitions –  
e.g. Nursing home followed by death

## CONCLUSION TO THE INTERVIEW:

\*\*\*Make sure to ask the participant before concluding interview if they have anything further to add on any of the issues raised, or perhaps they felt that certain topics were not included in discussion.

- Explain how/when/where interview data will be stored and disposed of
- Answer any questions the participant raises
- Remind the participant that a copy of the interview transcript will be sent to them if they wish
- Check participant wellbeing
- Thank participants for their involvement

# APPENDIX TWO

# FINAL TEMPLATE

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## 1. RELATIONSHIP OF EXCLUSIVITY

- emotional
- practical (intimate care etc)
- legal

## 2. KNOWING WHAT'S BEST

- advocate
- protector

## 3. RECOGNITION

- of doing a good job
- legitimacy of role
- good person

## 4. CONFLICT

- family conflict
- conflict with professionals

## 5. EMOTIONAL RESPONSES TO CEASING CARING

- relief
- sadness
- loneliness/sense of loss
- guilt
- anxiety/inability to sleep
- happiness
- anger
- shock

## 6. IMPACT OF CARING ON SELF

- physical health
- psychologically
- psychological abuse of carer
- socially

## 7. CARING FOR SELF IN POST-CARING

- comfort from spiritual beliefs

## 8. INTERACTION WITH HEALTH & SOCIAL CARE SERVICES

## 9. SUPPORT

- practical support
- financial support
- carer group support
- family support
- friends support
- health services support
- social care support
- workplace support
- emotional support

## 10. TAKING UP NEW CARING ROLES

- professional caring
- informal caring

## 11. NURSING HOME TRANSITION

- attitudes towards Nursing Homes
- experiences of Nursing Home Placement

## 12. EXPERIENCES OF HOSPICE CARE



