



POST-CAREGIVING: FAMILY CARERS' EXPERIENCES OF CESSATION OF THE CARING ROLE

Implications for Policy and Practice

Dr Carol Kelleher and Dr Jacqui O' Riordan
Institute of Social Science in the 21st Century (ISS21), University College Cork

In collaboration with:

West Cork Carers Support Group (Sally Ann Back and Former Family Carers)

Family Carers Ireland (Paul O' Mahoney and Former Family Carers)

Care Alliance Ireland (Liam O' Sullivan and Zoe Hughes)



Funded by the Irish Research Council New Foundations Programme



**Post-Caregiving: Family Carers' Experiences of Cessation of the Caring Role –
Implications for Policy and Practice**

Dr Carol Kelleher and Dr Jacqui O' Riordan

Institute of Social Science in the 21st Century (ISS21), University College Cork

In collaboration with:

West Cork Carers Support Group (Sally Ann Back and Former Family Carers)

Family Carers Ireland (Paul O' Mahoney and Former Family Carers)

Care Alliance Ireland (Liam O' Sullivan and Zoe Hughes)



Funded by the Irish Research Council New Foundations Programme



EXECUTIVE SUMMARY

The central aim of the National Carers' Strategy (2012) is to recognise the value and contribution of family carers to civic society and to support and empower them to participate as fully as possible in economic and social life (p. 2). Post-caregiving involves significant challenges for former family carers, including return to work or education, economic and financial challenges, rebuilding social networks, changed family relationships and dealing with complicated grief and identity rebuilding (Larkin, 2009; Orzeck & Silverman, 2008). However, the far-reaching and complex economic, social and psychological needs of former family carers remain misunderstood and unmet. This participatory action research PAR project seeks to highlight the experiences and preferences of former family carers to inform and address this policy and practice deficit. It is funded by the Irish Research Council (IRC) New Foundations programme and was led by Dr Carol Kelleher, the Institute of Social Science in the 21st Century (ISS21) and Department of Management and Marketing, University College Cork (UCC) and co-researched with Dr Jacqui O' Riordan, School of Applied Social Studies UCC and ISS21 UCC in collaboration with Family Carers Ireland (FCI), Care Alliance Ireland (CAI) and West Cork Carers Support Group (WCCSG).

The specific purpose of this participatory action research (PAR) project, POSTCARE, is to illuminate and give voice to the experiences and needs of former family carers in the post-caring/care transitions period – that is, when the caregiving role has ceased. POSTCARE provides nuanced knowledge of family carers' post-caregiving experiences of loss, role and identity transition upon cessation of the caring role. In this project, we define former family carers as unpaid family members who provide(d) physical and/or social care to a family member with an illness or disability in the home for a prolonged period of time prior to nursing home/hospice/long-term care placement or death and/or to someone who has recovered from their health problem (e.g. fracture) or has gone into remission (e.g. for cancer patients or those with episodic mental health illness) (Larkin & Milne, 2017, p. 1398 adapted).¹ Specifically, this research presents former family carers' perspectives to assist carer organisations' and policy makers' response to aim 1.3.5

¹ The terms family carer /carer and former family carer /former carer may be used interchangeably in the report. The focus of the report is former family carers; however where relevant policy, academic studies and carer organisation literature refer to the terms carer or former carer, these terms have been retained. All such references however refer to unpaid support and care by a family member or friend, thus excluding for example paid professional carers who are independent of family. For further information, please see the Care Alliance Ireland (2015), Defining Carers discussion document: <http://www.carealliance.ie/userfiles/file/CAI%20Discussion%20Paper%201-%20Defining%20Carers.pdf>

of the National Carers' Strategy: 'to review existing transition arrangements for carers at the end of their caring role' (p. 13).

The principles of informed consent, anonymity and confidentiality were adhered to throughout the research, for which institutional ethical approval was granted. As the research aimed to explore the subjective experiences of former family carers, face-to-face semi-structured and video interviews focusing on 20 former family carers' experiences were conducted. Participation in the research was voluntary, with interested interview participants selected by FCI and WCCSG. The caring contexts involved included caring for family members or friends with special needs, stroke and people with dementia and included experiences of both home and residential care. Interview data were transcribed and analysed using interpretative phenomenological analysis.

In line with the recent deeper understanding of the heterogeneity of former family carer experiences, the participants reveal some of the multiple routes to becoming a former carer as identified by Larkin and Milne (2017, p. 1398), namely: when the cared-for person dies, is admitted to a hospital, is admitted to a hospice, is admitted to long-term care (i.e. permanently admitted to a nursing or residential care home or continuing care in hospital), recovers from their health problem (e.g. hip fracture, mental health episodes) or goes into remission (e.g. for cancer patients). In particular, the research revealed the overlapping nature of entering and exiting the carer role, including serial caring (Larkin, 2009) and becoming both a carer and former carer at the same time (e.g. caring for one parent at home, one in a residential setting or deceased). As a result, the experiences of former carers were cumulative, comprised multiple role and identity transitions throughout and beyond the caregiving life course and presented different emotional, economic, physical, financial and social challenges. These also varied depending on the nature of the illness or medical condition and its progression which necessitated care.

The findings revealed that for carer organisations and policy makers to provide appropriate supports to family carers and former family carers throughout the caregiving life course, they need to consider both the role-based *and* person-based identity transitions of family carers. Role-based identity is the socially constructed definition(s) of self-in-role (Ashforth, Kreiner & Fugate, 2000), a persona that one may enact (Ashforth, 2001). Put simply, this is how the person sees and experiences their role as a family carer during and beyond the caregiving life course and critically how others (such as family members, community, others) see family carers and former family carers. What is also important, however, is the understanding and support of the person-based

identity of family carers and former family carers – meaning the personal qualities, needs, experiences and wider social contexts of those who choose to become or who find themselves thrust into the role of family carer and then face the challenges of reconstructing their person-based identity when the carer role ends. This also involves an appreciation that no two role enactments of being a family carer or former family carer are identical, and, therefore, a one-size-fits-all approach in terms of supports or social policy is not appropriate; rather multiple levels of support throughout and beyond the caregiving life course are required. There is, therefore, a need to consider the multiple and cumulative transitions throughout and beyond the caregiving life course, including identity rebuilding.

Through dialogue with former family carers, POSTCARE seeks respond to the issues, challenges and concerns facing former family carers via a series of participant-led workshops and supports as well highlight former family carers' perspectives as input into other national policy initiatives and proposals. The primary outputs of this project include policy, practice, theoretical and media-oriented papers and peer supports disseminated to as wide an audience as possible.

ACKNOWLEDGEMENTS

First and foremost, we wish to especially thank the former family carers who participated in this research and gave freely of their time.

Second, we wish to thank the participants/partners and charitable voluntary organisations (CVOs) the West Cork Carers Support Group (www.westcorkcarers.ie), Family Carers Ireland (www.familycarers.ie) and Care Alliance Ireland (www.carealliance.ie) for supporting and collaborating in this project, for liaising with and recruiting carers and former carers and for your availability and support throughout the project. Special thanks go to Sally Ann Back, Coordinator; Steve Cameron, Development Worker; former family carers and staff; West Cork Carers Support Group; Liam O' Sullivan, Executive Director; Zoe Hughes, Policy and Research Officer; Care Alliance Ireland and Paul O' Mahoney, Campaigns Researcher; and former family carers, Family Carers Ireland.

Third, we wish to thank to Dr Caitríona Ní Laoire and Dr Claire Edwards, Institute of Social Science in the 21st Century (ISS21), University College Cork, for their ongoing support throughout the project.

Fourth, we wish to thank Ciara Hyland (film producer), Matt O' Sullivan (camera man), Gillean Guy (Ludgate Hub) and five former carers from WCCSG for facilitating the production of three videos (peer supports) for current, future and former carers as a result of this project.

Finally, we wish to thank and acknowledge the Irish Research Council for funding this project as part of the New Foundations programme.

TABLE OF CONTENTS

Executive Summary	i
Acknowledgements	iv
Table of Contents	v
List of abbreviations	vii
Project Overview	1
<i>Aims and objectives</i>	<i>1</i>
<i>Overview of chapters</i>	<i>3</i>
Research Design	5
<i>Background</i>	<i>5</i>
<i>Project stages</i>	<i>5</i>
<i>Data collection</i>	<i>6</i>
<i>Data analysis</i>	<i>7</i>
<i>Ethics</i>	<i>7</i>
<i>Project outputs and outcomes</i>	<i>8</i>
Review of Post-Caregiving Literature	10
<i>Introduction</i>	<i>10</i>
<i>Defining family carers and former family carers</i>	<i>10</i>
<i>Post-caregiving</i>	<i>12</i>
<i>Post-caring legacies</i>	<i>14</i>
Supporting Carers and Former Carers – Policy and Carer Organisation Perspectives	16
<i>Family carers in Ireland</i>	<i>16</i>
Health professional awareness and signposting of family carer supports	20
Differentiated supports for different groups of former family carers	21
Counselling and bereavement support	22
Former and informal carer networks	22
Return to work/employment	23
Findings and Analysis	25
<i>Introduction</i>	<i>25</i>
<i>Post-care experiences – Making sense of the caregiving experience</i>	<i>25</i>
Reconfiguring	26

Distancing	27
Reconstituting	31
<i>Overlapping multiple role and identity transitions and routes to becoming a former carer</i>	36
<i>Former family carers advice to current family carers</i>	37
Caring is not for everyone, ask for help	37
Accept you are doing your best and that you can't do everything	37
Avail of the help/supports that are there	40
Critical importance of the supports provided by carer organisations	42
Fight and advocate	43
<i>Former family carers' wish lists</i>	44
More proactive role by health professionals, better access to health/social care supports	44
Courses and resources on caring	45
Forum for sharing experiences and dedicated information for former carers	46
Differentiated supports for former family carers	48
<i>Development of carer-led responses and resources</i>	49
<i>Conclusion</i>	49
Concluding Comments – Project Evaluation	51
Bibliography	52
Appendix 1 – IRC New Foundations POSTCARE Proposal	55
Appendix 2 - UCC Social Research Ethics Committee (SREC) – Ethics Approval Form	62
Appendix 3 – Informed Consent Form for Research Participants	65
Appendix 4 – Interview Protocol	67
Appendix 5 – Specific interventions developed by former carers to support carers and former carers	70
Life-Coaching Workshop for Former Carers	70
Carer Films	71
Participation in Life after Care Project (led by Care Alliance Ireland)	71
Policy Workshop UCC	71
Other Dissemination	72

LIST OF ABBREVIATIONS

CAI	Care Alliance Ireland
CSO	Civic Society Organisation
CVO	Charitable Voluntary Organisation
DAF	Dormant Accounts Fund
DSP	Department of Social Protection
FCI	Family Carers Ireland
ISS21	Institute of the Social Sciences in the 21 st Century
PAR	Participatory Action Research
SREC	Social Science Research Ethics Committee
WCCSG	West Cork Carers Support Group

PROJECT OVERVIEW

Aims and objectives

The central aim of the National Carers' Strategy (2012)² is to recognise the value and contribution of carers to civic society and to support and empower them to participate as fully as possible in economic and social life (p. 2). In addition, the updated national action plan on social inclusion (2015-2017)³ continues to recognise the critical societal contribution of informal and Family Carers in supporting people in need of care to remain in their own homes and communities for as long as possible. At a societal and policy level, family carers currently providing care to family members

The central aim of the National Carers' Strategy (2012)¹ is to recognise the value and contribution of carers to civic society and to support and empower them to participate as fully as possible in economic and social life (p. 2).

are viewed as an important resource essential to the success of current care policies. However once this role ceases, many former family carers are tacitly viewed, from a policy perspective, as 'unproductive' market or economic resources that need to be ushered back to education or the workforce or supported in state pensions in their retirement.

According to Census 2016, the number of people who identified themselves as unpaid carers increased by 8,151 – from 187,112 in 2011 to 195,263 in 2016 – and accounted for 4.1% of the

There are approximately 360,000 family carers in Ireland (Care Alliance Ireland 2017).

population. While female carers continued to outnumber male carers (118,151 and 77,112

respectively), the increase in carers was almost evenly distributed among males and females over the five years. The number of male carers increased by 4,113 between 2011 and 2016, while female carers increased by 4,038. Between 2011 and 2016, the number of people providing more than six hours of caring a day grew from 39,982 persons to 41,185 persons in 2016.⁴ However, a recent

² Department of Health (2012) National Carers' Strategy – Recognised, Supported, Empowered, July

³ Department of Social Protection. (2016). Updated action plan for social inclusion 2015-2017. Department of Social Protection, Dublin

⁴ Census 2016 Summary Results – Part 2, Central Statistics Office, July 2017

review of *Trends in Family Caring in Ireland in 2017*⁵ conducted by Care Alliance Ireland contends that this figure significantly underrepresents the number of family carers in Ireland due to the census question wording and limited focus on personal care. Based on the Irish Health Survey (2015)⁶⁷, over 10% of the population (aged 15+) are providing care (on average 45 hours per week) to someone with a chronic condition or infirmity due to old age. In 86% of cases, the care recipient is a family member. Based on these findings, CAI suggest that there are approximately 360,000 family carers in Ireland.

However, while carers comprise a relatively large proportion of society and are, potentially, a valuable and underused resource (Cavaye & Watts, 2016), little or no support is provided to carers once the caring role ends (Orzeck & Silverman, 2008).

A review of the caregiving literature reveals that post-caregiving involves significant challenges for former carers, including return to work or education, economic and financial challenges, rebuilding social networks, changed family relationships, dealing with complicated grief and identity rebuilding (Larkin, 2009; Orzeck & Silverman, 2008). However, the far-reaching and complex economic, social and psychological needs of former family carers remain misunderstood and unmet. While objective 1.3.5 of the National Carers' Strategy prioritises the needs of former carers and the review of existing transition arrangements for carers at the end of their caring role, there is

Former family carers are unpaid family members who provide(d) physical and/or social care to a family member with an illness or disability in the home for a prolonged period of time prior to nursing home/hospice/long-term care placement or death and/or to someone who has recovered from their health problem (e.g. fracture) or has gone into remission (e.g. for cancer patients or those with episodic mental health illness) (Larkin & Milne, 2017, p. 1398, adapted).

currently no policy that explicitly addresses the needs of former carers. This research presents the perspectives of former carers in order to inform future policy and supports for former carers.

5 Care Alliance Ireland (2017). Overview Report – Trends in Family Caring in Ireland in 2017: Review of Awareness, Self-Identification, Official Surveys and Income Support, September, pp. 6-11. Retrieved from <http://www.carealliance.ie/userfiles/file/Overview%20Report.pdf>

6 http://www.cso.ie/en/media/csoie/qnhs/documents/qnhsspecialmodules/IHS_questionnaire.pdf

7 <http://www.cso.ie/en/releasesandpublications/ep/p-ihs/irishhealthsurvey2015/ct/>

The specific aim of this project, a collaboration between ISS21, WCCSG, FCI and CAI, was to highlight the experiences and voices of former family carers to inform the development of evidence-informed supports and policy to support former family carers post-caregiving. In this paper, we define former family carers as unpaid family members who provide(d) physical and/or social care to a family member with an illness or disability in the home for a prolonged period of time prior to nursing home/hospice/long-term care placement or death and/or to someone who has recovered from their health problem (e.g. fracture) or has gone into remission (e.g. for cancer patients or those with episodic mental health illness) (Larkin & Milne, 2017, p. 1398, adapted). Through dialogue with former family carers, the project incorporates guidelines, an action plan and the co-development of peer-supports to change and influence policy and practice.

The specific project objectives were to

- explore former caregivers' experiences and lived contexts of role and identity transition post-caregiving upon cessation of the caring role, for example when the person they care for dies, moves into a home, recovers or goes into remission or when family carers decide to no longer to be a family carer (e.g. due to personal health or other family reasons);
- co-develop appropriate supports and policy responses for former family carers and
- build capacity for further national/international CVO and research collaborations.

The project followed a PAR approach (Kindon, Pain & Kesby, 2007; Van Katwyk & Ashcroft, 2016) in that it prioritised responsive information exchange with those most impacted by the research, namely former family carers. It built on previous collaborations with ISS21 and FCI (2014-2015) and a preparatory ISS21 workshop on eldercare held in UCC (June 2016).

Overview of chapters

- Chapter 1 – Brief introduction to and overview of Irish Research Council (IRC) New Foundations POSTCARE project
- Chapter 2 - Outline of the project design and methodology
- Chapter 3 –Review of the literature on post-caregiving
- Chapter 4 – Presentation of the research findings and the voices of former family carers
- Chapter 5 – Discussion of the findings and associated implications

- Chapter 6 – Concluding chapter
- Appendices

RESEARCH DESIGN

Background

This PAR project on former carer experiences is funded by the IRC /The Wheel New Foundations 2016 programme (for final research brief, please see Appendix 1). PAR is a collaborative process of research, education and action explicitly oriented towards social transformation (Kindon et al., 2007). In the context of this project, ‘community’ refers to a range of public research stakeholders, including public or professional service and product users, policy makers, civil and civic society organisations (CSOs), CVOs and other actors.

Our PAR approach involved participants and researchers, specifically former carers and their representative associations, in a collaborative process for generating knowledge, construction of meaning and reflections on action (Kindon et al., 2007). In August 2016, we initially established contacts and relations with three carer organisations (one regional, two national) – WCCSG (Sally Ann Back), FCI (Paul O’ Mahoney) and CAI (Zoe Hughes/Liam O’ Sullivan) – to establish a

The participatory action research (PAR) approach adopted engaged former carers and carer organisations in a collaborative process in order to generate knowledge, construct meaning, reflect on action and generate responses and interventions.

common agenda and to collaboratively scope the project research objectives and project time frame. We co-designed the research process and tools and discussed and identified desired action outcomes in advance of the development of the research proposal and commencement of the research. Following this, ethical approval to conduct the primary research was then obtained from the UCC Social Sciences Research Ethics Committee (SREC) in advance of data

collection (see Appendix 2). This group also approved the data consent form which would be presented to participants in advance of their participation in the research (see Appendix 3) and the interview protocol (see Appendix 4) prior to commencement of the interviews with former family carers.

Project stages

The project stages comprised the following:

- Phase 1: Jointly agreed project brief (August 2016) based on the identification and discussion of issues by partner CVOs and institutional ethical approval to conduct the research.
- Phase 2: A review/benchmarking analysis of post-caregiving supports and best practice, nationally and internationally.
- Phase 3: One-to-one in-depth interviews (16) and video interviews (four) with volunteers⁸ from the partner CVOs.
- Phase 4: Participant/CVO feedback sessions to discuss initial findings (June and July 2017).
- Phase 5: Development of peer support videos by former family carers for family carers to be disseminated through social media/partner CVOs' channels⁹ (August 2017).
- Phase 6: Life-coaching workshop for former family carers to facilitate transitioning to life after care (19th October 2017).
- Phase 7: Building on participant feedback, an interactive public workshop with participants/CVOs to discuss initial findings. Expert speakers and policy makers will provide training, facilitate discussion and co-develop supports/policy responses and an action plan (6th November 2017).

Data collection

All three partner CVOs worked together to undertake data collection and to enable the participation of former family carers. In line with purposive sampling, it was agreed that the nominated representatives of FCI and WCCSG would identify and approach former family carers who would be interested in partaking in the research. In total, 16 in-depth interviews with former family carers were conducted between August and December 2016. Specifically, 10 interviews with former family carers from West Cork (five males and five females) and six former carers from Dublin (one male and five females) were conducted in the offices of WCCSG, FCI, some of the participants' homes and public locations of their choosing. The data collection involved face-to-face loosely structured in-depth interviews (average length 90 minutes) conducted in an informal conversational style. In addition, four video interviews (average length 40 minutes) were

⁸ Participants included spouses, women and young carers who have been identified as requiring particular supports post caregiving (Orzeck & Silverman, 2008).

⁹ See Care Alliance Ireland (2016), Online Support for Family Carers: Options and Experiences, Discussion Paper 3, p. 2.

conducted with former family carers, which were also used to make three short films on former family carers' experiences.

Across all 20 interviews, the caring relationships ranged from caring for parents, spouses, adult children or neighbours. The range of caring contexts included care recipients who suffered from stroke, Alzheimer's, cancer and other physical and psychological illnesses. To protect the confidentiality and anonymity of the interviewees, the participant family carers' details are amalgamated and presented collectively and in an anonymised fashion.

Data analysis

The principal objective of the data analysis was to co-create a nuanced and detailed understanding of former family carers' experiences of cessation of the caring role with an emphasis on the convergence and divergence between participants. The second objective of the data analysis was to identify patterns and thematic content from the data that might further illuminate the lived experiences and meaning of loss for family carers. All interviews were recorded with the consent of participants. Subsequently, all interviews were analysed, and emergent themes relating to former family carers' experiences were identified.

In line with the PAR adopted, all partners collaboratively discussed and reviewed the draft findings and possible action outcomes. The insights and findings were presented to two groups of former family carers, and various action options were discussed in two feedback workshops in June and July 2017. Furthermore, participants were invited to document some of the key findings in a short film (community media) providing advice for current and former family carers based on their experiences and outputs.

Ethics

As previously stated, as the research involves human subjects, ethical approval was requested from the UCC SREC (<https://www.ucc.ie/en/research/ethics/>). This involved addressing and highlighting all ethical issues and concerns as well as submitting the proposed research guides, consent forms and interview protocols for approval. Formal written confirmation from the partner CVOs for permission to carry out this research on their behalf as well as their plans to facilitate and allow data collection and dissemination was also included. Participation in the research was

voluntary, and the recruitment of participants was facilitated and managed by partner CVOs. Volunteer participants had the option of withdrawing from the research at any time. All outputs were anonymised to ensure confidentiality. All project outputs were reviewed and cleared with participants prior to dissemination, and each of the partner CVOs was requested to check on any sensitivities. All outputs, as outlined earlier, were anonymised as necessary, and sensitive material was adapted or removed as required by participants/partner CVOs. The dissemination of all materials was discussed and agreed upon with participants.

Project outputs and outcomes

The project outputs comprised the following:

- This POSTCARE report detailing the proposed policy and support responses as well as a summary brief for policy/public awareness exercises, disseminated through the CVO partners, including the following workshop.
- A one-day public interactive workshop organised in conjunction with partner CVOs on post-caregiving in UCC, which prioritised former family carers' perspectives and involved interactive sessions for participants, family carers, policy makers and interdisciplinary researchers in the field (6th November 2017).
- A series of videos featuring former family carers' advice for current or future family carers to be disseminated/promoted by partner CVOs¹⁰.
- A life-coaching workshop for former family carers (19th October 2017) in the Ludgate Centre, Skibbereen, West Cork.
- Article on the project in the winter 2017 edition of *Care Alliance Ireland Exchange*: the only Family Carer sector publication in Ireland that reaches a large number of NGOs and Health and Social Care professionals

¹⁰ For copies and links to the films, please contact Sally Ann Back, WCCSG, email: coordinator@westcorkcarers.com Website: www.westcorkcarers.ie

- Five practitioner/academic conference presentations, including the 7th International Carers Conference 2017 in conjunction with Eurocarers¹¹ in Adelaide, October 2017; the European Sociological Association Conference 2017; the Naples Forum on Service 2017; the Association of Consumer Research Conference 2017 and the Family Carer Research conference in Ireland, University College Dublin, August 2017.
- Two future academic journal articles and one policy-based paper (*International Journal of Care and Caring*) based on the research findings.
- Future opinion pieces for national/regional print media, including the Irish Examiner and the Irish Times – Health Supplement.

We next provide a brief overview on the post-caregiving literature on former carers.

¹¹ The European Association Working for Carers (www.eurocarers.org)

REVIEW OF POST-CAREGIVING LITERATURE

Introduction

Life transitions are key stages of identity formation. Yet, while family carers experience loss when those whom they care for transition from home care to residential care and/or eventually pass on, to date, existing caregiving research and practice has not viewed the post-caregiving stage (i.e. when the caring role has ceased) as part of the larger caregiving life course (Orzeck & Silverman, 2008). Transitioning from life after care includes ongoing identity rebuilding and can vary by caring context and present different practical and emotional challenges for former family carers.

Transitioning to life after care includes ongoing identity rebuilding, can vary by caring context and presents different practical and emotional challenges for former family carers.

Defining family carers and former family carers

An in-depth review of the literature on caring reveals that the definitions of carer and former carer are diverse (Larkin & Milne, 2017). Just as the word ‘carer’ is contested, so too is the definition of former carer. For example, the National Carers’ Strategy defines a carer as:

Someone who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness or disability or frailty. (p. 9)

So, by extension, a former carer was based in the home and is now no longer providing care there. This, however, discounts the caregiving role which continues when someone moves into a home or long-term care or those involved in the episodic nature of caring in incidences of illness remission, recovery or relapse.

Larkin (2009, p. 1029) defines a former carer primarily as someone who has been bereaved:

A former carer is someone who does not necessarily identify him/herself as a former carer but who has experienced an episode of caring in the past that

ended with the death of their dependent. This caring was not carried out on a professional basis and, excluding benefits, was unpaid. ' (Larkin, 2009, p. 1029).

However, as with carers, former carers are a diverse and heterogeneous population, comprising not only those who are bereaved.

Cronin et al. (2015, p. 90) address such deficits by also including the cessation of the caring role when someone moves into long-term residential care as well as when someone dies:

Former family carers are family members who provided physical and/or social care to a family member with an illness or disability in the home for at least 6 months prior to nursing home/hospice placement or death.

More recent work has expanded the different perspectives and routes to becoming a former carer. Specifically, Larkin and Milne (2017) identify six routes to becoming a former carer, namely when the cared-for person

1. dies
2. is admitted to a hospital
3. is admitted to a hospice
4. is admitted to long-term care (i.e. permanently admitted to a nursing or residential care home or continuing care in hospital)
5. recovers from their health problem (e.g. hip fracture)
6. goes into remission (e.g. for cancer patients)

Critically, in their review of the former carer literature, Larkin and Milne (2017) note that much of the existing literature and conceptualisations on former carers focus on the cessation of the caring role as a result of death (1) or when the care recipient moves into longer term residential care (4) and that other routes to becoming a former carer (e.g. 5 and 6, which involve recovery and remission) are understudied (Larkin & Milne, 2017). They further highlight that other groups of former carers are invisible altogether – for example, those who do not ‘fit’ the traditional model of

‘family’, such as ex-partners and those who are ‘former carers’ because they have chosen not to continue to care (e.g. for personal health or other reasons) or have left caring behind (e.g. family breakup etc.). Therefore, the multiple entry and exit routes to becoming a former carer are important as they involve different transitions and experiences for former carers, which, in turn, may require different types of support and policy responses (Larkin & Milne, 2017).

In light of this, for the purpose of this report, we adapt previous definitions of former carers to encompass Larkin and Milne’s (2017, p. 1398) definition of former carers and characterisation of the multiple routes to becoming a former carer and define former family carers as follows:

Former family carers are unpaid family members who provide(d) physical and/or social care to a family member with an illness or disability in the home for a prolonged period of time prior to nursing home/hospice/long-term care placement or death and/or to someone who has recovered from their health problem (e.g. fracture) or has gone into remission (e.g. for cancer patients or those with episodic mental health illness).

In summary, former family carers are not a heterogeneous population and are not uniform in their experiences of and responses to the end of their caregiving. Similarly, some become ‘serial carers’, or the end of the caring role may be temporary. For others, poor psychological wellbeing associated with the nature, duration and chronicity of the illness of the care recipient and pre-existing relationships act as post-caring legacies that frame their experiences as former family carers. Grief and distress are inextricably coupled with the loss that has evoked it, with increasing acknowledgement of the significance of ‘good’ and ‘bad’ deaths for those who are bereaved being able to adjust to the loss (Cavaye & Watts, 2016). For others, the positive gains of caring for a loved one enables them to successfully move on upon cessation of the caring role. We next provide a brief overview of the post-caregiving literature to date.

Post-caregiving

Up until the 90s, caregiving research and practice had typically not viewed the post-caregiving stage (i.e. when the caring role has ceased) as part of the larger caregiving life course (Orzeck & Silverman, 2008). More recent models of post-care typically focus on what happens after the care

recipient dies (route 1) or moves into a long-term residential home (route 4), should the carer not continue to identify as a carer (Larkin & Milne, 2017). For example, Larkin's (2009) post-caring model identified three distinct stages in transitioning to becoming a former carer, namely, 'the post-caring void', 'closing down the caring time' and 'constructing life post-caring'. The *post-caring void* comprises former carers' experiences, including a sense of loss or purpose, identity transition and losing a sense of equilibrium within the family – that is, a form of displacement. *Closing down the caring time* comprises former carers' experiences of changed routines and coping with their own and other family members' grief. *Constructing life post-caring* comprises former carers' experiences of letting go and moving on to reconstruct life post-caring. This phase involves rebuilding family ties, re-uptake of interests, taking part in some other type of care-related activity (e.g. becoming a carer again, performing caring tasks for others [e.g. neighbours/friends/other family members], joining or volunteering with carer/former carer organisations, carer groups etc.).

Similarly, three stages of post-caregiving were identified by Cronin et al. (2015). The first of the three stages is *loss of caring role*, in which former carers' experiences include loss of identity as a carer, of role as carer and of the close bond with the care receiver as well as the social relationship with the network of healthcare professionals. The second is *living with loss*, where former carers experience mixed emotional reactions, such as guilt, relief, anger and a sense of urgency and of economic and social adjustment (e.g. due to lack of carer supports). The third and final stage, *moving on*, entails former carers' experience of reconstructing life post-caring, including experiences of reconstructing one's identity.

More recent research by Larkin and Milne (2017) finds that conceptualising former carers by 'adding' a 'former carer stage' to the end of the caring trajectory ignores the multiple routes to becoming a former carer (outlined earlier).

In summary, we posit that post-caregiving needs to be characterised as comprising ongoing multiple transitions through the caregiving life course that include identity rebuilding. The experience of such transitions varies by caring context and presents different practical and emotional challenges for former family carers. In this report, we build on previous caregiving models to focus on former family carers' experience as being a culmination of many previous stages or transitions. Also, caring and post-caring can be ongoing – for example, some family members care for two parents at a time where one may die and the other still needs a family carer,

or a family carer may care for a parent who dies but also still care for another family member, such as a child with special needs etc. In addition, many family carers who become former family carers may assume the caring role again. Post-caring, therefore, may be open-ended and encompass the cumulative experiences and transitions of caring to date. Critically, Cronin et al. (2015) recommend further research into the ‘legacies of caring’ (outlined next) and the need for targeted support that is sensitive to the different experiences of former carers and to the specific phases of the post-caring experience, which we seek to address in this report.

Post-caring legacies

As outlined, the experiences of former family carers cannot be decoupled from the cumulative caring experience, which can be varied and diverse. Some former carers may look back on caregiving as fulfilling and contributing to personal development, while others may feel a sense of being diminished by the experience (Cavaye & Watts, 2016). In line with Larkin and Milne (2017), we term the experiences of the cumulative caregiving experience which has now ceased as post-caring legacies. Post-caring legacies include loss of social, financial and employment opportunities (Lewis & Meredith, 1994; Larkin, 2009; Larkin & Milne, 2017), which we detail next.

One of the most immediate losses experienced by former family carers relates to financial and economic loss, including cumulative caring expenses over the life course, having to take time off of work or giving up work completely, lack of pension contributions, lack of career development etc.

The experiences of former family carers are diverse and cannot be decoupled from their cumulative caring experiences. Post-caring legacies include social, economic, psychological, physical and financial losses. This diversity of experience means that a variety of supports are needed to support former carers.

In terms of social and psychological losses, caring can increase the risk of social isolation, particularly over the long term, and can lead to a range of complex and conflicting emotions in the post-care stage. Emotional wellbeing may depend on family and socio-economic support, employment and financial situations (Larkin & Milne, 2017). In relation to the transition from home care to residential home, there may be feelings of relief for family carers who are no longer able to cope with

caregiving in the home, but this is tempered by what can be almost overwhelming feelings of guilt,

failure, and helplessness at their inability to continue caring. Together with a sense of betrayal, loss and anxiety about the new care setting, this can impact on family carers' own emotional wellbeing. This may also be marked by a sense of 'displacement' from their role as caregivers and anxieties about how they will fit into the new care regime.

The nature of the care recipient's illness also impacts post-caregiving legacies (Cavaye & Watts, 2016). For example, dementia carers often experience anticipatory grief as their family member slowly and gradually declines. Family carers of those who are chronically ill may face unique risks of complicated grief, which are characterised as intense distress that interferes with function (Ghesquiere et al., 2011). Family carers suffering loss or bereavement may be uncertain as to what is 'normal' and 'expected' in terms of their own bereavement processes (Moss & Moss, 2012).

Finally, some former family carers may choose to become active family carers again once a particular caring role ends (e.g. become vocational carers [Lewis & Meredith, 1994] or serial carers Larkin 2009). In some cases, this may be because the self-identification with the role of carer has become so-ingrained, it may remain someone's primary identity long after the caring role ends. For other former carers, they may wish to 'shed this mantle' and rediscover their new identity now that a particular carer role has ended. This has important implications for supporting former family carers, some of whom may wish to continue the caring role and some who wish to transition beyond the carer role, which we discuss in detail next.

SUPPORTING CARERS AND FORMER CARERS – POLICY AND CARER ORGANISATION PERSPECTIVES

Family carers in Ireland

Policy in the area of former family carers is largely undeveloped in Ireland, and where it is addressed at all, it comes under the more general policy framework pertaining to home care and carers. While the importance of home care has been recognised since the publication of *The Care of the Aged: Report of an Inter-Departmental Committee on the Care of the Aged* (1968)¹², there has to date been limited integrated planning in the area of home care support, the depth of coverage appears poor, accessibility criteria appear insufficiently consistent and official data sources of provision remain quite inadequate.¹³ However, the consultation on home care that was instigated by the Minister for Health, Simon Harris, TD, and the Minister of State for Mental Health and Older People, Jim Daly, TD, in July of this year may address some of these challenges.¹⁴

Up until this year, former family carers have received little policy attention, and the findings from several reports indicate that former family carers feel isolated and are left to continue with their lives with little or no recognition of their caring roles, skills and experiences. This is despite evidence from research in Ireland (e.g. Larkin, 2009; McCarron et al., 2011) and elsewhere that (i) former family carers have a multiplicity of support needs, (ii) their experience, insights and skills gained through their caring roles are not valued and (iii) it is increasing likely that as adults we can expect to move in and out of caring roles throughout the lifecycle. Larkin and Milne (2017) suggests that we conceptualise caring ‘as a continuum from pre-caring to post-caring: post-caring is seen as integral to the overall caregiving career’ (p. 1,400). Adopting such a conceptual model would imply that policymakers recognise this continuum when developing appropriate supports for former carers.

In the *National Carers’ Strategy: Recognised, Supported and Empowered* (2012) there is only direction mention of former carers in *Objective 1.3 Recognise the needs of carers by the provision*

12 Government of Ireland. (1968). The care of the aged: report of an inter-departmental committee on the care of the aged, Dublin: Government Publications.

13 For further information on home care services in Ireland, please see Care Alliance Ireland (2016), Analysis of Home Care Supports Funded by the HSE 2008–2016, June. Copies available at <http://www.carealliance.ie/userfiles/file/Briefing%20Paper%201%20%3B%20An%20Analysis%20of%20Home%20Care%20Supports%20Funded%20by%20the%20HSE%2008-2016%20June%202016.pdf>

14 The closing date for submissions was 2nd October 2017.

of income supports. Under this objective the goal of developing transition arrangements for carers at the end of their caring role was set. Other relevant objectives include *Objective 4.2.4: Explore how back-to-work and education training courses can be tailored to the needs of carers who wish to return to the workplace* and *Objective 4.2.5: Review access by family carers to labour market activation measures*. However, the predominant focus on income and back to work supports negates the multiplicity of other supports that research has identified would be beneficial to former family carers, including social, emotional and psychological as well as financial ones. Nevertheless, this is arguably the first time that the needs of former carers were recognised in policy (Objective 1.3) as a specific sub-group of family carers, thus making their presence ‘policy visible’. So, while the particular objective is both narrowly focused on income supports and broad in that the goal merely states that transition arrangements be set, it does mark an important step in recognising former family carers as a specific group and a sub-group of carers. It has the potential to recognise former family carers’ diverse circumstances as well the cumulative impact of caring on their lives and livelihoods when they transition out of their particular caring roles.

Two key monitoring sources offer information on progress made in the objectives set through the Carers’ Strategy. In the first instance the Department of Health, as the state body with responsibility for its implementation, publish regular Annual Progress Reports. To date they have produced four such reports – in 2014, 2015, 2016 and 2017¹⁵. The other key source of progress monitoring comes in the form of a Scorecard Monitoring Initiative. This is an independent monitoring exercise that has been developed by the National Carers’ Strategy Monitoring Group.¹⁶ This group is made up of family carers and representatives of the FCI and CAI who have experience and expertise in family caring. This group was set up by FCI following the publication of the Carers’ Strategy in 2012 and has since monitored progress on its objectives.

With respect to Objective 1.3 on recognising the needs of former carers through income supports, even though the target was broad, progress on it, initially, was slow. The Department of Health’s second *Annual Progress Report* (2015) indicated that meetings took place between the Carers Association and the Department of Social Protection (DSP) during the period of the review (September 2013–September 2014) to discuss issues and as a forum for information provision. At

¹⁵For copies of the annual progress report, please see <http://health.gov.ie/blog/publications/national-carers-strategy/>

¹⁶ <https://familycarers.ie/national-carers-strategy-monitoring-group/>

these meetings, proposals put forward by the Carers Association on former carers were also considered. There is no indication in this review as to any outcome of these considerations.

The third and fourth *Annual Progress Reports* (Department of Health, 2016, 2017) indicate more development of transition arrangements. This came in the continuation of Carer's Allowances and Carer's Benefits after the formal care role ends. Initially, eligibility for continued payments of both these allowances was extended to cover six weeks following the loss of a loved one (Department of Health, 2016). This provision was later increased to 12 weeks for Carer's Allowance and, for this allowance also, extended to situations where a care recipient transfers to a hospital or nursing home (Department of Health, 2017).

The Scorecard initiative reported on progress a little differently. In the first two Scorecards, covering the years up to September 2014, regressive progress on this objective was reported, highlighting it as one of those towards which little attention had been given. However, in the third Scorecard progress on this objective was found to be good. The Caring Monitoring Group considered that this provision had the potential to 'allow carers to plan, by up-skilling through training, for a future transition from their caring role' (p. 23).

Moreover, the Monitoring Group also recognised the progress that was being made in discussions with the DSP. Through these discussions barriers to transitions from caring roles were highlighted by the Monitoring Group. These barriers related to restrictions on the 15-hour limit per week that family carers could engage in training and remain eligible for Carer's Allowance and Benefits. In their third Scorecard (2016) they commented that 'in a very welcome move, the DSP has acknowledged this issue and has invited FCI to submit a proposal on a pilot project which would allow a small cohort of carers to increase the hours that they work or study from the current 15-hour limit' (p. 23). However, the fourth Scorecard (2017) points to limitations in progress on this objective as the 15-hour limitation continues to apply.

The third Scorecard and the more recent fourth Scorecard also draw our attention to opportunities missed in omitting family carers from the Back to Work Family Dividend. This initiative aims to support transitions from welfare to employment and includes a provision for payments for dependents for those on Jobseeker and One Parent Family payments. The fourth Scorecard states that '[a]n opportunity was missed by not extending the scheme to include family carers and accommodate their transition back into employment at the end of their caring role' (2017, p. 23). Finally, two recent initiatives to support former carers are encouraging. The Dormant Accounts

Fund (DAF) 2017 Action plan announced funding (up to €1,000,000) for additional carer supports and training interventions.¹⁷ Specific measures prioritised include the development of support groups to assist transition at the end of the caring role and bereavement transition planning. Moreover, in summer 2017, the DSP, together with the DAF, invited proposals from national carer organisations to develop post-care transition supports for former carers.¹⁸ The total amount of funding available under this measure was €500,000. The details of the funded proposals will be announced in November 2017 and the supported measures will cover the period to the end 2018. While this development is welcome, the fact that supported measures will be funded for only one year is disappointing. In addition, the call for proposals was restricted to former carers between 18 and 65 years old (pre-retirement age) which means that former carers who were over 65, a large cohort of former carers, were excluded. Many former carers who are over 65 may have been unable to hold down full-time pensionable employment for extended periods of time while caring for family members and as a result are economically and financially impacted in retirement age. In addition to the issue of a more positive policy landscape and available carer supports, it is also important to acknowledge the dual role of care provider and potential care recipient. We also need to acknowledge that the desire to maintain the positive aspects of caring (e.g. an expression of love) may lead to a reluctance on the behalf of family carers and former family carers to seek or accept help. In addition, a number of current and former family carers do not even self-identify as carers.¹⁹ While carer support needs to be assessed independently of the care recipient, it might be more likely to be accepted when it focuses on proactive and preventative caregiving approaches as well as resource and skills building (Grande et al., 2009). Larkin (2009) recommends the adoption of a more holistic approach which focuses on carers' needs. She argues that such an approach would be broader and include and anticipate post-caring needs. Some of the prioritised initiatives to support former carers under the DAF Action plan 2017 are a welcome start in this direction.

All former family carers are transitioning out to 'taking the next step', and the supports that are needed to support them go beyond the policy provisions and progress made thus far. A good

17 See http://opac.oireachtas.ie/AWDData/Library3/AHGdormantaccountsactionplan120717_124641.pdf

18 See call details <https://www.pobal.ie/Publications/Documents/DAF%20Measure%20Guidelines.pdf>

19 For further information on this see Trends in Family Caring in Ireland in 2017: Review of Awareness, Self-Identification, Official Surveys and Income Supports. Care Alliance Ireland, September 2017

starting point in determining the range of supports that would assist in bolstering such transitions would be a consideration of the routes of transition to becoming a former carer (Larkin & Milne, 2017), as detailed in the previous chapter. They offer an insight into the types of transitions, the key reasons for them and the possible transition destinations. Furthermore, the development of policy on carers that does not meet the challenges identified in post-caregiving previously outlined will always be inadequate. These challenges are identified as return to work or education, economic and financial challenges, rebuilding social networks, changed family relationships, dealing with complicated grief and identity rebuilding.

A brief review of some existing supports and recommendations for supporting former carers which illustrate the experiences in Ireland and some other jurisdictions revealed the following.

Health professional awareness and signposting of family carer supports

Larkin (2009) highlights the need for increased recognition of former carers by professionals. She advocates that carers' contact with healthcare and social professionals during caring should not automatically close cases when caring ceases. Follow-up visits could be introduced, during which challenges former carers may face in their post-caring lives and sources of support, such as carer groups, could be explored and addressed. However, in practice, the allocation of resources remains an issue in many jurisdictions. More often than not, the allocation of healthcare resources prioritises treatment for persons with healthcare conditions, support for family carers and then support for former carers. Once caring ceases, carer welfare and support may no longer be a concern of healthcare professionals, or, more critical, healthcare professionals may not be in a position to follow up with former carers due to lack of resources and time.

In relation to the design and delivery of supports, family carer information needs are diverse and vary throughout the caregiving life course, coupled with the fact that family carers, at least initially, might not be aware of the best places to find information. For example, Harrop, Byrne and Nelson (2014) advise the development of healthcare/carer information packs for carers based on the carer assessment tool used in the United Kingdom. They argue that such measures would render carer needs more explicit and also help carers to develop their competence and preparedness for their caregiving journeys. This recommendation is particularly timely in the context of the current roll

out of the Carer Needs Assessment within the wider InterRAI Single Assessment Tool²⁰ recently introduced within the Health Service Executive in Ireland.

In a separate study of carer burden amongst 26 former family carers of family members with dementia, following the transition of the care recipient from home to residential care, the findings revealed that the subjective experience of burden remained long after relocation. This study highlighted the importance of healthcare professionals providing improved information and sustained support to caregivers after relocation, irrespective of care settings. An increased understanding of these issues seems to be vital for reducing the relative's subjective feelings of burden (Andren & Elmstahl, 2002).

In addition, Larkin (2009) recommends that social workers working with those in voluntary sector organisations who support carers, such as carers' centres and carers' groups, should encourage the provision of post-caring support that is responsive to the possible demands on former carers. For example, a qualitative study undertaken in Northwest England, using narrative interviews with current (18) and former (10) carers of a family member with motor neurone disease found that a range of support services are needed for family carers, with clear signposting for them to select those most appropriate for their individual needs (O'Brien, Whitehead, Jack & Mitchell, 2012). Many carers frequently regarded the information they were provided from services as inadequate as the carers had diverse needs at each stage of the illness, and this diversity was not recognised. They recommended that professionals ascertain how much information the family carers need following diagnosis. They also need to monitor this over the course of the disease as information requirements are known to change over time.

Differentiated supports for different groups of former family carers

The International Longevity Centre UK 2015 report recommends that local authorities in the United Kingdom should help former older carers integrate back into their communities. They also advise promoting local groups, activities and volunteering opportunities among former carers so that they are aware of what is available as well as pay for ex-carers to attend classes or activities of their own choosing. The report further highlighted that older carers worry about leaving their loved ones with someone they, and the person they care for, do not know, especially if the person

²⁰ <http://www.hse.ie/eng/services/list/4/olderpeople/sat/>

has dementia. Further development of individualised and appropriate respite services would encourage and enable people to take breaks if individuals could be guaranteed to get the same stand-in carer and standard of caring regularly so that a trusting relationship could be built up.

Counselling and bereavement support

The International Longevity Centre UK 2015 report further recommended that upon the immediate cessation of the caring role following bereavement extra support to help carers with the many practical issues surrounding a death, such as the organisation of the funeral, may be particularly appreciated, as well as access to bereavement counselling services. In a separate qualitative UK-based study, former carers identified the need for counselling and support following the bereavement of care recipients and expressed a sense of abandonment from services once the care and treatment of the patient had ceased (O'Brien et al., 2012). Not surprisingly those who had accessed counselling and bereavement support were very positive about their experiences (O'Brien et al., 2012).

Former and informal carer networks

Being a member of an informal caregiving network can be of increased benefit and support for adult children involved in the long-term care of an elderly parent (both at home and in residential care (Tolkacheva et al., 2011). Many organisations specifically provide information for former family carers. In the Irish context, Care Alliance Ireland were involved in an EU project called 'Life After Care'²¹ and produced a very popular booklet entitled the same.²² This booklet, currently being updated in consultation with former family carers and a range of not-for-profit organisations in a project led by Care Alliance Ireland, has since 2011 been widely distributed to a range of organisations throughout Ireland. It is envisaged that the revised booklet will be available for distribution from mid-2018. Revised content will take account of the latest research on the topic, including this POSTCARE report. Other examples of not-for-profit organisations' resources for former carers include *The Way Ahead* booklet produced and disseminated by Voluntary Service

²¹ <http://lifeaftercare.anzianienonsolo.it/>

²² <http://www.carealliance.ie/userfiles/file/LifeAftercareBookletFinalWebVersionOct2011.pdf>

Aberdeen,²³ the *Letting Go Without Giving Up*²⁴ booklet produced and disseminated by Alzheimer Scotland and the former carers' information booklet²⁵ produced and disseminated by Carers New South Wales. Other carer organisations, such as Carers UK, provide dedicated information for former carers²⁶ as well as manage an online forum for former carers to provide peer support to each other and to share their experiences.²⁷

The International Longevity Centre UK 2015 report also recommended that local authorities develop groups where older carers can chat and exercise together. It may even be appropriate to design some of these groups such that carers could bring the person they care for along with them. Some support organisations, such as the Alzheimer Society of Ireland, do organise such initiatives in Ireland in some areas known as Alzheimer's Cafes. However, a more robust development of them that is adequately funded is advisable. Finally, The International Longevity Centre Report recommends that local authorities ensure suitable transport is available to older carers to visit family members who have been taken into residential care or hospital.

Return to work/employment

Some Eurocarer recommendations²⁸ in relation to return to work include the following:

- Considering the time spent caring in the calculation of pension credit should also be envisaged to prevent old-age poverty and the (gender) pension gap that most carers experience.
- Measures to facilitate return to the labour market are also important, and, incidentally, the validation and certification of the skills gained while caring can potentially lead to carers going back to the labour market.

In summary, conceptualising caring as a phased occupation from 'becoming a caregiver, taking care, midwifing the death and taking the next step' (Larkin and Milne, 2017, p. 1,400) broaden the conceptual model and offers a more holistic understanding of the dynamics of caring within the life course. It can be employed as the basis for the development of a more holistic and

23 <https://www.vsa.org.uk/files/docs/Carers%20docs/The%20Way%20Ahead%20Booklet.pdf>

24 https://www.alzscot.org/information_and_resources/information_sheet/1828_end_stage_dementia_letting_go_without_giving_up

25 <https://www.carersnsw.org.au/Assets/Files/FormerCarers.pdf>

26 <https://www.carersuk.org/help-and-advice/practical-support/when-caring-ends/life-after-caring>

27 <https://www.carersuk.org/forum/support-and-advice/former-carers>

28 Source – Eurocarer white paper – Reconciling work and care: the need to support informal carers (eurocarers.org).

comprehensive set of policy supports for former carers. The provision of carer support has also been highlighted in the literature as potentially beneficial where the family carer's role is changed at the point when the care recipient moves to an institutional care setting. The literature suggests that feelings of guilt and grief by former carers that they may have 'failed' to keep their loved one at home can be overwhelming and lead to elevated levels of distress. Former carers may experience or have experienced stigmatisation in relation to the nature of certain conditions, such as mental health, age, gender and welfare, in relation to their caring role. This may also include perceptions that the carer has 'outsourced' to institutions the care of their loved one, and this associated with emotional withdrawal from the relationship can further exacerbate a sense of failure and inadequacy.²⁹ Recognition of the ambiguous nature of the caregiving role and that the accompanying practical and emotional burden does not necessarily decrease in these circumstances is the first step towards considering the kinds of services and support that could be beneficial. While there is evidence that many former family carers would benefit from more supportive interventions, particularly in bereavement, this is by no means universally illustrative of the multiple domains of bereavement outcomes. Informal caring is very much contingent on opportunity and capacity, all inflected by class, gender, culture and kinship ties – powerful forces in shaping the post-caregiving experience (Cavaye & Watts, 2016) – and mandate a differentiated range of supports for former family carers.

29 Care Alliance Ireland (2016). 'We need to talk about it' – Stigma and Family Care, Discussion Paper 5, December. Copies available at [http://www.carealliance.ie/userfiles/file/Discussion%20Paper%205%20\(Stigma\)%20FA%20Web.pdf](http://www.carealliance.ie/userfiles/file/Discussion%20Paper%205%20(Stigma)%20FA%20Web.pdf)

FINDINGS AND ANALYSIS

Introduction

We next overview some of the key themes that emerged from the project under two main categories – post-caregiving experiences and supports. In line with the previous literature, it is not possible to decouple former family carer experiences from the cumulative experiences of caring (post-caring legacies) and care transitions.

Post-care experiences – Making sense of the caregiving experience

Our conversations with former family carers revealed previously identified staged approaches to becoming a former carer (Larkin, 2009; Cronin et al., 2015) – which we term reconfiguring, distancing and reconstituting – but also identified other transitions and trajectories which revealed the overlapping and fluid nature of the caring trajectories and different routes to becoming a former carer (Larkin & Milne, 2017) (Figure 1). It also became clear that, due to post-caring legacies, the various routes to the cessation of the caring role cannot be decoupled from the cumulative experience of being (or having been) a family carer.

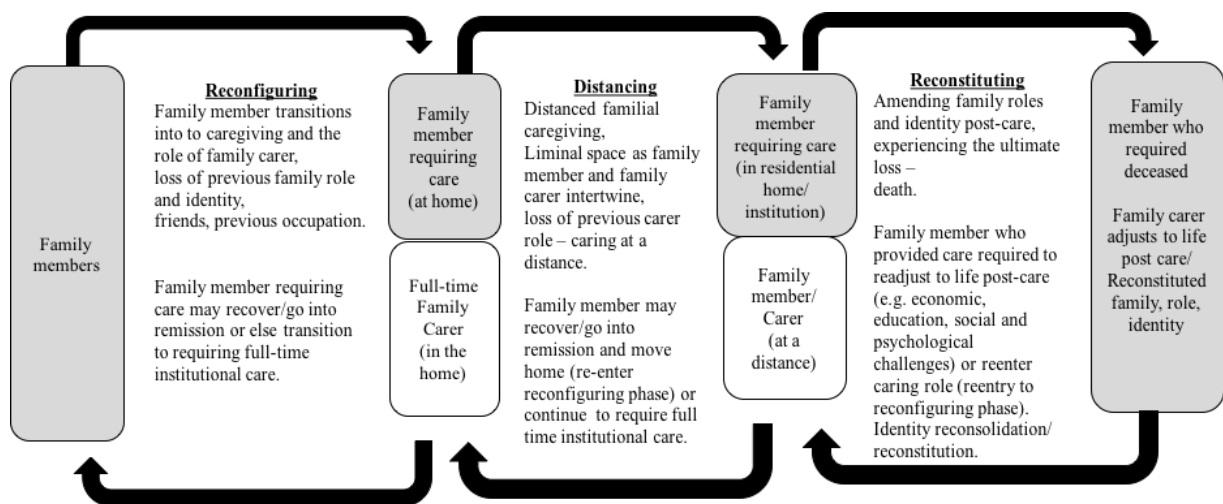


Figure 1 – Cumulative and overlapping role and identity transitions of family carers

Reconfiguring

Stage 1 – Reconfiguring involves family members' initial transition into the caregiving role. During this phase, family members disengage from their previous family identities as they take on the role-based identity of being a family carer. For some family carers, the transition from family member to family carer was subtle and gradual. In certain families, or when caring for friends or neighbours, the caring role and tasks gradually built up over time, with certain family members

Reconfiguring involves family members' initial transition into the caregiving role.

finding themselves positioned in that role, such as an unmarried family member, a daughter or son living nearby etc. Other family carers found themselves thrust into the role of family carer rather suddenly, which

totally transformed family relationships, identities and other roles (e.g. parent, partner, sibling etc.). Many former family carers remarked that initially and throughout the caregiving trajectory they did not self-identify as a family carer, which meant that they did not initially know where to get help, nor did they feel that they had the time to search for help and information as they adjusted to becoming a family carer. The lack of self-identification with being a family carer meant that people did not see themselves as eligible for some of the help available or that available supports were not availed of at all or not until much later during the caregiving life course.

Well I wouldn't even have thought that I was caring before. I wasn't really, you know. I wouldn't have called myself a carer before really.

Once people became family carers, the role quickly became all-consuming. Former family carers reflected that they felt tired and often had little time for anything else, including self-care and holidays, all of which contribute to post-caregiving legacies.

I did feel tired seven days a week.

Other former family carers felt that they became more socially isolated during this reconstituting phase due to the requirement to remain at home or in the home of the care recipient and away from

their own home and to reduce or give up employment as well as the loss of social contact and friends.

I was probably more restricted, like I couldn't go too far away from the house.

Others expressed a sense of 'freedom being gone' or 'always being on call'.

Now I never went on holiday as such because I always felt that if I went away I [might] get a phone call and I [would] be somewhere else I [would] be in a panic. So, I only ever went away for two or three nights at that point, never longer. And for those two or three nights I was always nervous about getting a phone call, you know.

For some former family carers, the caring role ended when the care recipient died, recovered or went into remission. For others, they transitioned to caring at a distance, when their family member moved into respite, hospital or longer-term residential care.

Distancing

Stage 2 –Distancing involves the transition from caring for a family member at home to providing care (at a distance) in a residential home, long-term residential care, hospital or hospice. During this liminal or 'betwixt and between' phase, former family carers experienced feelings of connection yet feeling somewhat apart from what was going on as the dual roles and identities of family member (daughter/son, mother/father, wife/husband) and family carer at a distance (i.e. providing more emotional support as opposed to direct care provision) became entwined.

Distancing involves the transition from caring for a family member at home to providing care (at a distance) in a residential home, long-term residential care, hospital or hospice.

In line with the literature, former family carers' experiences during this and other stages tended to vary according to the different illnesses and caring situations involved. Former family carers

appreciated the sense of relief when their family members, particularly those with Alzheimer's/dementia who could no longer look after themselves independently, went into a home. In such cases, former family carers felt reassured that they were safe and felt relieved that they were not a danger to themselves and were looked after. For example, one former family carer spoke about her mother who lived alone, had Alzheimer's and was increasingly having difficulty living independently and looking after herself.

Physically. Mentally. Everything about her. It was just unbelievable to see how good she was. To be honest, she could have stepped back five years, she was physically and mentally that good. She felt secure. As much as she was not happy initially, she felt safe. She was secure, she had a room, she had her clothes, she had everything there that she needed. She had somebody coming in to dress her, wash her. She had a routine she had this fantastic team around her that had taken all the pressure from her so that's how she was so good. Then they changed her medication for her arthritis, so she was able to walk. So, it was like a miracle, there was no other way of describing it. There was such a sense of relief that she was being looked after and that she was safe.

This family carer also reflected on the difficulty of readjusting from caring for her mother in her mother's home (reconstituting) to caring for her once she moved to a nursing home (distancing) and how she made sense of it.

Since I've come away from the situation, because in my head, Mam was safe, I knew that she was being well looked after, I was starting to come down from the hype, trying to reorganise my own head. Like, I was grieving for my mam even though she was still alive. I had gone from being on the go 24 hours a day to absolutely nothing. I had to, I was exhausted; I had to rebuild that strength and to focus on how I was going to get my life back because I had given up so much. Because in my head my mam was safe, I wasn't doing as much driving to care for her in her home. I was able to refocus, rethink what was happening. I had to adjust to my mam being in a nursing home, but I had to put it into some

kind of context because at the end of the day I knew that she was being very well cared for. I knew that she was safe, that she wasn't going to get lost. God only knows what could have happened if she had continued to live on her own.

Similarly, another former family carer for a family member with Alzheimer's spoke of how he now had more time than his father had transitioned to a home, and he felt happier knowing that he was being well looked after. However, he also felt that feelings of guilt were also inevitable.

I've got a lot of my life back. Now I can go home to my home in the evenings, I can go have a pint without worrying about the phone or somebody ringing you.

So, it has made life easier for me now – and for him – because he has been well looked after, getting 24-hour care, he is doing better...However there was still a feeling of guilt as you were handing over control to somebody else, obviously whoever better capable than I am, but you still feel like you are shifting him, you know.

In contrast, for some participants, the transition from caring for someone at home to them moving into a residential or longer-term care setting was traumatic. One former family carer remarked that the transition from caring for her husband at home to moving him into a care home was one of the most difficult decisions that she had to make in her life, but she knew that it was the right thing to do and was fully supported by her family in the decision.

It was terrible (sobs) it was an awful decision, the hardest decision that I ever had to have to make. It was dreadful. But the family were 100% behind me. I mean they were heartbroken as well but they realised that it was the right thing to do. They kept on saying to me 'mam this is for dad's sake, this is for dad's care that we have to do this'.

For a number of former family carers involved in dementia care, they had time during this distancing phase to come to terms with the forthcoming loss, with one former family carer

describing their awareness of this ‘*slow death*’. This distancing phase provided space for former family carers to adjust and anticipate a future post-caregiving context and time to prepare for the passing of the family member after s/he moved to a nursing home.

Well I think the fact that she had been in the nursing home you know for eight months did make it easier than if she had died here with me, you know.

While the former carer literature, with the exception of Larkin and Milne (2017), does not typically look at relapse and the episodic nature of some illnesses as routes to former caring, our interviews revealed that some transitions, for example reconfiguring to distancing, could be reversed. For example, one former carer became a family carer again when her mother, who suffered with Alzheimer’s, did not settle in a residential home. Her family took her back home without putting care arrangements in place and against the wishes of her main carer, who now was left as sole carer again. For this former family carer, it was very difficult to readjust back again as she had become aware of the emotional toll that caring full time had taken on her and her own family and how unsupported she had been in the caring role heretofore.

Every night was the same thing – ‘I want to go home, I want to go home’. My brother and sister kept saying – ‘she’s not going to stay in there, she needs to come home’. But I just could not go back to where I was. I just couldn’t. I will give any amount of time that I can but not to the same extent of what I was doing previously. Now that I’ve come off that merry-go-round, because that is what it was, it was just going around and around in circles. But since I’ve stepped away from it, I see that I wasn’t doing myself any good, I certainly wasn’t doing my family any good, so I cannot go through that burnout again.

I have to take control back for myself. I’d say it’s harder than before in a different way because before everything came so natural. I got to the destination that I wanted to, that was right for my mother, and I know now that she was being well looked after – to a completely different emotion. You know. And that’s the part that I see, so that’s upsetting as well. Because I never want to have any feelings other than love for my mam, I just feel now that I’ve been

let down badly by my siblings.

Some former family carers exited the distancing phase when the care recipient returned home again after respite/hospital/residential care, recovered, went into remission or died. They then entered the reconstituting phase (next) or reverted to caring for family members at home.

Reconstituting

Stage 3 – Reconstituting comprises the transition from caring for a family member at home or at a distance to the caring role ceasing permanently (e.g. death, recovery) or prior to the former family carer recommencing the caring role again for another care recipient (e.g. what Larkin [2009] terms ‘serial carer’). In the case of bereavement, in particular, former family carers needed time to readjust to their altered situations as many had been caring for so long that the carer role had been a major part of their identity.

Reconstituting comprises the transition from caring for a family member at home or at a distance to the caring role ceasing permanently (e.g. death, recovery). In some cases, former carers may recommence the caring role again in another context.

I was lost in the beginning. Because I had gone from caring for him to my daily routine of going and sitting with him and then (names children) had gone back, and naturally the boys had to get on with their lives, and they had their work to go on with. I just felt absolutely useless. I thought what do I do with myself now? Lost in the awful sadness of him being gone, you know.

Many former family carers initially felt lost and unanchored as they no longer occupied the carer role. Some did not even know who they were any longer.

It is afterwards that it is difficult – because you have lost your role, but that has been your entire role really, and you are happy to be in it, and then

overnight it is gone; it is very odd. It is a strange feeling. I suppose it must be like being in a job you have been in for forty years or something and then you turn up at the factory and then they say it is closed, traumatic, that has been your whole life and your workmates and everything, and it is all gone tomorrow. It must be a bit like that, you know, very devastating when that sort of thing happens to people when a business pulls out and goes somewhere where it is cheaper to employ people, and it does, usually, it closes overnight pretty much don't they?

Overtime, there was an awareness for some former family carers that it was time to focus on reconstituting their person-based identity now that their role-based identity as family carers was no more or beginning to change. This began with an awareness of the need to begin to look forward but also an awareness that this would be a gradual process.

I suppose I am beginning to think now it is time I changed and that, when I stopped minding Mum I felt at a loss as to what do I do now. Whereas now, I know that I have to begin looking after me more now, and it has taken me a while to realise that. If you are a carer it stays with you for a long time, and you see yourself as that is your role for a long time after.

At a financial level, the immediate financial impact of the non-payment of the Carer's Allowance after a short number of weeks (when the care recipient died but also when they moved permanently into a nursing home) was an immediate cause of concern for former family carers as they many felt they did not have adequate time to generate other sources of income and could not immediately return to paid employment. The relatively abrupt ending of the Carer's Allowance in a very short period at the end of the caring role did not provide family carers with adequate time to think about how to financially support themselves (e.g. through returning to work – and, if so, what type of work, returning to education, financing their retirement). The more recent extension of the time family carers remain eligible for payments addresses this to a limited extent.

The person that is caring gets six weeks allowance afterwards, which is great, but then of course it is all gone. It is I suppose a big void as well when you lose that money, what are you going to turn to?

Former family carers further reflected on the cumulative carer burden or post-caring legacies (Larkin, 2009). They reflected on how exhausted they felt upon the cessation of the caring role and gradually came to realise the toll (emotionally, physiologically, socially and financially) that caring had taken on their lives and health. This, again, needs to be recognised by policy makers in terms of the time and space given to former family carers who have to reconstitute their lives and personal identities on cessation of the caring role.

I can honestly say, I don't know how much longer I could have gone on, you know. I never thought like that at the time, but you know I realised how absolutely exhausted I was then, and you know I'm kind of at the stage now where I realise kind of how much longer I could have gone on. I was living on my nerves.

Looking back, for many former family carers, their experiences were unshared and as result sometimes led to unresolved grief, anger, anxiety or frustration. For some former family carers, it took longer than others to deal with or make sense of the emotional toll of sustained caring on their own wellbeing.

I did hide, I suppose now I realise I did hide a lot of it from them (her family) because they worried about me. And I kind of did not want them to be worried so I would hide a lot of it, so I would say it was just something like I'd have to get on with and it's not Dad's fault. But I know, from talking to them now, they knew. And they knew, the boys were always very good, and I mean (names daughter), God love her, she travelled home on many occasions when he'd go back into hospital. Looking back on it, I now know that I consciously tried to hide a lot of it from them. And I mean, naturally, I would get frustrated at

times. You know. And that was hard because I would sit here, and I would be sad over it, but I wouldn't say it to them. ... Which, now I think, I mean, please God I never have to have it again, I probably would do it differently because it probably it would have helped me to share with them at the time because now I know that they knew. You know what I mean? So that was my own fault. I suppose I could have had more help but I was always kind of an extremely independent person and I thought, 'no I can do it'. It was only in the last nine months that I got help. I suppose I could say now, looking back on it, that I probably did make it harder on myself.

Importantly, former family carers highlighted that, looking back, they should have shared their experiences with others to deal with the worries and stress of full-time caregiving. Many were extremely grateful for the peer support of other carers (once they themselves self-identified as carers) and for the support provided by carer organisations, whose staff and members could empathise with and support them and advocate on their behalf. They also felt that healthcare professionals should be more aware of the emotional needs of family carers in addition to those of care recipients, assist and more proactively encourage family carers to look after their own emotional wellbeing and encourage self-care where possible. They considered that some healthcare professionals were excellent in this regard. However, they also thought that many did not fully acknowledge or appreciate the challenges faced by family carers.

Former family carers felt that it was important to highlight also that some of the negative impacts of caring were frequently counterbalanced with a sense that caring was a rewarding and enriching experience.

I think it was, looking after him, was the most rewarding experience of my life, it really was. It was a very special time, and I hope it has made me a bit more considerate of people, less impatient.

But yeah, I am really glad I did it even for myself it has given me a great sense

of, you know Mum could have passed on, and we wouldn't have realised what it meant for her to have been at home and all of that. And I thank God every day that it went so well because it mightn't have; we are a big family and so yeah that is about it, and I mean I would do the same again definitely.

Other former family carers felt a sense of hope and belief in their capacity to move on, albeit with the awareness that moving towards a new and different future and working out how to get there would take some time.

Yes, because you are moving on to something else, and I suppose you have to think of the chrysalis, the moth and the butterfly and everything, and who knows, sometimes after what seems to be a pretty dire situation you can get wonderful wings after it you know I am just hoping that will be the case. A day at a time really, but really, I was going a day at a time really during the illness, and I am still a bit like that now.

Many former family carers felt that support in working out where they found themselves, how to make sense of the carer experience, where to go from here – what options were available etc. would be welcome. While some former family carers had strong social networks and family ties, they seemed to seamlessly transition back to family life. For others, such as those who lost a spouse or who had weaker family ties or who needed to retrain and return to employment, such assistance was welcomed. Also, all former family carers were strongly impacted and changed by the carer experience. Many wanted to give back and assist others who were or who might become family carers. Others felt that they wished to continue the carer role, either professionally or on a more informal basis.

Overlapping multiple role and identity transitions and routes to becoming a former carer

In line with more recent research (Larkin & Milne, 2017), the research findings highlighted the heterogeneity of routes to becoming a former family carer and that some former family carers often re-enter the carer role a number of times. The findings further revealed that the caring phases (reconfiguring, distancing and reconstituting) and associated role and identity transitions overlap and are not as delineated as earlier caring models suggest. They also support Larkin and Milne's (2017) assertion that characterising post-care as a 'bolt on' phase of caring at the end of the

Overlapping multiple and role and identity transitions and routes to becoming a former carer.

caregiving life course (formality) inadequately characterises the heterogeneous experiences of former family carers. Amongst the former family carers interviewed, for example, two family carers cared for both parents concurrently and were therefore now both former family carers and family carers at the same time. Others had become former family carers (e.g. death of parent), had not been a carer for a period but then became a family carer again (e.g. for a parent or other family member).

Well it was easier, I mean that I can't lie. You know one versus two is easier. I mean to get one dressed alone used to take a couple of hours. And then you be in and out to her for breakfast around five times and then would you be in and out to him for breakfast around five times. So that all took a long time to do. So obviously I have more time, I don't have free time, but I have more time as it has been halved, but obviously, it is not the way you wanted. You know you don't want your life to be made easier. At the beginning, it was very tough. I'm used to it now. It was a major adjustment in the beginning. Because obviously you were used to going up and down the stairs to him, you are used to making him his breakfast, his dinner, his tea, dressing him, you know, so it's a major adjustment. But you don't have that much time to dwell on it. And no matter how you feel, you still have to get up at the same time, you still have to give her tablets, check her bloods, you know what I mean? No matter how you feel, you don't have the space to grieve. You just have to keep going. You know the same as somebody who has kids. You can't start bawling crying because if she sees

that you have been crying, she cries. So, you just have to cover it up.

Former family carers advice to current family carers

In making sense of the post-care experience, former carers were asked to reflect on what advice they would give potential future carers. This included the following.

Caring is not for everyone, ask for help

Former family carers, while acknowledging that caring was a rewarding albeit difficult role, felt that it was important for people to realise that caring is not for everyone – it requires a certain disposition and type of person.

Well what I would say to them (potential future carers) is to be prepared to care and if you are not, don't take the job up, you have to have a yen for it, and if you haven't, not to do it. I wouldn't advise anyone to do it unless they make up their mind to do it because some people will be cross and nasty with them and say why did I take up this job? And you know you can't say that either, you don't want to give in to say to the person that you are caring for that you don't want to do the job, that it isn't the job for you. You have to be patient, and there is a lot of patience needed.

It takes a certain kind of person to be a carer, and if you feel that in you, go for it as it is very rewarding.... It's not for everyone, but that's understandable, some people like to be bricklayers, you know, this is what I like to do.

Accept you are doing your best and that you can't do everything

Former family carers strongly advised family carers to be realistic in terms of what they can do and for how long, what supports they need, how to self-care and how to organise respite/breaks

from caring in order to recharge their batteries and to avoid burnout. This, in turn, highlights a policy imperative to support family carer wellbeing throughout and beyond the caregiving life course and to recognise emotional, psychological and social post-caring legacies.

Yes, I probably did a bit too much. Yes, I probably worked a bit too hard at it. Try to get family members to row in, that is the hardest thing because you don't know, it is the hardest thing to keep going twenty-four hours a day sometimes.

There was an acknowledgement that caring can take its toll and reflexivity on why some people might feel that they should and can do it all. There was also a realisation that they might have over-estimated their capacity, may not have realistically assessed their situation, particularly at different stages of the caring journey. One former family carer reflected that if she had known what lay ahead and had listened to the advice of the medical team, she would not have taken on the huge responsibility for caring for both elderly parents concurrently.

I would say don't do it. To be honest I'm glad that neither of them have ended up in a nursing home today. I'm glad that my dad spent pretty much the rest of his life at home – that he died at home. I'm very glad that I did it; however, I now feel like a completely different person. Physically I feel like I'm 50. I have got aches and pains that I never had before. I've got pains in my chest that I never had before. My knees give out when I'm walking up and down the stairs. I get jumping pains in my knees. The stair lift is still there but it takes too long. I'd say 'don't do it'. I was very angry with the doctors initially – I felt like the doctors were giving up on her in the hospital – putting her in a nursing home. But they had a point. They were thinking about me as they also knew that I was caring for another parent at home. And I didn't see that. I thought that they were being negative, and I wanted more optimism – 'oh, we can make it work'. And I have made it work, but there has been a huge price to pay. I would say 'don't do it'; that's what I would say unfortunately.

Due to the multiple post-caring legacies (economic, emotional, psychological, financial, social), former family carers felt that it was critical that family carers took some time out to look after themselves – time for self-care. Otherwise, it would not be possible to sustain the challenges of being a family carer over the caregiving life course. In reality, many former family carers could see this looking back – however, at the time the 24/7 nature of caring often meant that this was not always possible.

Yes, as the public health nurse said right at the start, 'your first priority is yourself'; it sounds awfully selfish, but if you are crocked you are no good for the carer, and, you know, 'don't lift the wheelchair if it is too heavy' or something and get somebody else to help you, which is absolutely true. You do have to look after yourself, don't you?

I would say definitely: take time out – for you – definitely. You have to. I know that sounds harsh, but I'd say 'remember you. You are a person and you have needs. ... and take time out'. Because if you don't take time out, you can't give, you know. You can't. If you're not content with you, and your life, you can't help anybody else. So, in order to be there, and give 100%, look after yourself. I would give that advice – take time out. Meet up at your friends once or twice a month; take a night off. Get somebody else to step in, for one night, overnight... You know. Take time off, ask an aunt, ask a sister, or ask a neighbour – 'would you sit up with my mam for four hours while I meet up with a friend?' I was lucky because there were others, it's not always like that for people. So that's the advice I give – always remember you – because if you are not right, you're no good to anybody else; that's the advice I give them.

Slow down. Don't keep jumping in. Take time and tell people when you are struggling. That was definitely my downfall. I just felt that I was the only one that could help my mam. As much as I was asking for help, and it wasn't coming forward, I should have gone to the doctor's and said – I cannot do it, I need probably respite, or something, somebody to probably come and take my mam for two days a week or whatever it may be.

Avail of the help/supports that are there

Due to the fact that many former family carers did not see themselves or self-identify as carers early on, they did not ask for help, or they sought help later in the caregiving life course, particularly in relation to availing of the Carer's Allowance or applying for home care support. Some were too proud or felt that only they could look after the family member. Looking back, many former family carers realised that it is necessary to ask for help early on – to get to know the landscape and what supports are available. They all felt that carer organisations played an invaluable role in this respect.

If I was doing it now I would seek more help.

It (Carer's Allowance) made a difference because you would have to be putting in so many hours to qualify and totalling up all the different things I did for my mum. I was putting in the hours so it was like an acknowledgement of the work I was doing for her, amazing. I felt really validated I was doing a job that was needed.

Find out what help there is long before you get flaky. I don't mean necessarily

coming in and doing the housework or cleaning the oven or stuff like that, but just find out what help there is there so that when you need it you can ask for it.

That would be the very, very first thing, find out what help there is out there and make a note of it and put it there so that when you need it you can look for it.

In relation to services like home care support (where a paid carer visits and provides care for the care recipient in their home for a contracted number of hours per week), former family carers acknowledged that although it was sometimes difficult to adjust to having strangers come into the home, it was invaluable. However, many noted that the number of available hours were typically insufficient.

Well try to get home help. Fight with your doctor to get home help and the sooner the better because it won't come tomorrow or the next day. It does take time to go through the system.

I suppose like there is home help there and people don't avail of it. I'd say some people don't like people coming to their home, I'd say not everybody, but a few people.

I think the home helps would be a great advantage if the caree would allow them because it would give you more free time to do whatever you want for yourself.

But definitely, it was that four hours on Wednesday really kept me going towards the end because I knew that I had that breakout to look forward to, and it was something. I could arrange to do something because it was four hours. It was absolutely, even more so now when I look back not on it, oh my god, I did not appreciate how great help it was.

Critical importance of the supports provided by carer organisations

Former family carers all highlighted the help and support provided by carer organisations in providing awareness of carer issues and supports, and many expressed the wish that they had known early on about the services they provided. The support provided by the carer organisations and by other family carers was extremely helpful. Such supports included providing a listening ear; opportunities to get things off one's chest; help with form filling, knowing rights, organising events and respite services and other supports, including men's carers' groups and peer support.

We went to the carers' meeting before she moved over to find out where it was and who was running it and so on and what sort of support was offered. And we were amazed because people who they were caring for were in all the different stages and some were quite advanced. We thought we had a hard-enough time with forgetfulness and having to do everything we were doing, but you know other people had a much worse time; I thought wow this is amazing these people are coping, this support group is helping them to cope. That was good.

It has been wonderful meeting other carers, it really has. Because they know what you have been through, they have been through it themselves and they are very friendly and will give you a big hug when you are not feeling great.

However, former family carers were unsure as to whether they as former family carers could still avail of the services provided by carer organisations or the events organised once they ceased caring. This also emerged as an issue for carer organisations, namely whether separate events should be organised for former family carers or how support resources should be shared between current and former family carers. Recognising the complexity of the caring trajectory and multiple possible transitions would go some way towards addressing these ambiguities and validate their continuing support needs.

So, I wasn't really sure whether I should go to the carers' meetings or whether I was invited or whether it was the norm for former carers to go. I still get the newsletters and know that they are online. I suppose the answer is that anything goes, and if you feel you want to come then come. I am not sure about the outings though; I think maybe there is limited places on some of the outings. Maybe the thing to do is to let staff members know that if there is a place and if no one else wants it that they would let you know. You don't want the whole place crowded with former carers instead of carers. I should have left the (names carer organisation) when I am caring for no longer a carer but (the coordinator) said come along. Some former carers don't stay. Some, as soon as their caree passes away, they are gone. But, I just stayed on.

Fight and advocate

Finally, former family carers in Ireland learnt that it was important for family carers and their representative associations to advocate and fight for improved rights and supports for current and future carers.

If I had gotten somebody on the phone there who was putting barriers up to me saying 'no you can't because we have rules and regulations' ... Sell yourself, I am doing you a favour by this, it is the truth. Advocate and be nice and be polite and be respectful and everything else.

Former family carers' wish lists

In conclusion, former family carers were asked what their wish list was – that is, ‘if you had a magic wand and everything was possible, what services and supports would you put in place for carers/former carers?’ Some of the former family carer suggestions are outlined below.

More proactive role by health professionals, better access to health/social care supports

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 has also been highlighted as critical in the post-care literature (Cronin et al., 2015). Many former family carers mentioned that they would like healthcare professionals to be more aware of carer experiences and to play a more proactive role in supporting them – emotionally and physically – throughout the caregiving life course. This has implications for the training of health professionals and for carer organisations to liaise with them to raise awareness of carer issues.

Yes, so really you need to start planning or the HSE needs to start or somebody needs to start looking at the citizens as they reach a certain age or even how infirm they are from the local GP, and I don't know how otherwise you can do it.

One possible way of addressing this would be for policy makers and carers organisations to prioritise the proactive connection of carer organisations to public health nurses/GPs earlier in the caregiving journey. Currently a number of carer organisations raise awareness amongst GPs/public health nurses of the importance of making initial appointments as soon as they identify someone who is caring. Such connections might also be facilitated by better signposting by carer organisations and other organisations of the services offered and increased referrals between the different organisations as appropriate.

In particular, one former family carer expressed a preference for a single point of information for carers – early on – at diagnosis. This is in line with Objective 3.1 of the National Carers' Strategy – promote the availability of user-friendly and timely information and advice – which acknowledges that carers' information needs can span a wide spectrum, and, ideally, information provision for carers should be clear, integrated and accessible from a single point of contact.

Some former family carers felt that family carers would benefit from quicker and easier access to counselling services; indeed, one carer organisation actively provided this service to members.

The GP service is very slow apparently, ages before you get a counsellor if you get referred through your GP.

They also would like access to bereavement visits, such as with some follow-up visits or phone calls once the care recipient had passed away. There was acknowledgement that this was a signposting role (to existing services) for carer organisations as opposed to a service that they provided themselves. To facilitate this, carer organisations would have an important role in signposting such services and facilitating referrals as appropriate. Some partner carer organisations did proactively follow up with family carers once somebody had passed away.

I think also to have sort of phone calls afterwards just to see how somebody is getting on.

They also found that information, such as directories of local healthcare services, in particular for care recipients (e.g. in the case of mental health conditions) as well as other specialist services (e.g. for Alzheimer's, cancer etc.) were very helpful.

Courses and resources on caring

Former family carers also said that, in addition to meeting and learning from other family carers and carer organisations, they would like to avail of more general and specialised (e.g. for particular illnesses) courses. Carer organisations currently offer a range of such courses or have an important role in signposting relevant courses and information provided by other associations, such as the Irish Cancer Society or the Alzheimer's Society.

I think a course could be put on locally by the (names carer organisation) in caring for dementia or just for caring. A course where they could invite speakers; as it is they have speakers that come along to the meetings like

physiotherapy and fall prevention, so if they could organise like a mini-course on the lines of the Alzheimer's course then you know they could run it at different times that would suit different carers that would be free in evenings or mornings or afternoons or whatever. Be more prepared you know isolation could be brought up as a topic, you know, what could you do yourselves, what could you think of. Brainstorming could be done and then you forge links with other carers at these courses which you don't really make on outings.

Some former family carers found books and films on caring from carer organisations' libraries helpful.

The books that are available on the caring experience, they are all out there. They do have a little library; I think I once borrowed aromatherapy or something from them, they have a library of books that (name) brings around with herself and you can borrow things, but more books on the caring experience to be added to that, and I know quite a few. 'My experience as a carer' type of thing.

Forum for sharing experiences and dedicated information for former carers

Former family carers had a strong desire to share their experiences in order to help others who were currently in the caring role and to provide them with peer support. This could involve speaking at meetings organised by carer organisations, online forums or referrals as well as other media (e.g. short films, information leaflets, website information).

The only thing I would say is that part of the reason I agreed to do it so quickly was that I kind of feel that if it helps anyone else that's going into that position, if it helps them to get handle it a bit more, to talk about it more openly and to accept everything that's going on, I think it's well worth doing. Before I had to look after (name), I knew nothing about being a carer. Absolutely nothing. I mean it was totally different with my mam. I went into it blindly; I went into it thinking, I mean I have no choice, I have to do it, and I will get on with it. I

don't think you have to think like that, I think definitely, I would advise anyone to not be pretending that they are stronger than they are kind of thing. Take all the help, and I only see it from that and since (name) died because I say, you really, sometimes I think like how, I'm not be a martyr or anything, but I sometimes think how did I do it? Sometimes it will start at six in the morning, and I'd need to change him, and then: would you like a cup of tea (name)? I bring up a cup of tea, and 6 out of 10 times he'd spill the cup of tea, through no fault of his own, on the bed. And I'd have to sit out and change it stop, so now looking back on it was very difficult so I would advise anyone to take any help. And look for help and be more open about what you're going through. You are really not doing yourself any favours. When I look back on it now you know (short laugh), I know that I did not do myself any favours, at the time, you know, so.

Former family carers felt that they had a lot of experience to share with current or future family carers and would gladly share it as they felt it might help others along 'the road less travelled'.

And even after the person dies, the person having been a carer, their experience is still valuable, the person may still enjoy talking about it. It is like when your kids have left home you still want to talk about what they did.

Many former family carers welcomed further information on former carers on the carer organisations' websites or updated information or links to other former carer supports/information online.

Think the internet solves a lot of these problems just in the day and age that we are now. If you have the ability to use the internet or whatever, it isn't difficult to find resources. They mightn't always be ideal for what you want but you know they refer you to someone else, have you tried this etc.

An example of a former carers' forum can be seen on the Carers UK site:
<https://www.carersuk.org/forum/support-and-advice/former-carers>

Differentiated supports for former family carers

Former family carers requested and would welcome assistance, space and support to move forward (socially, financially, personally) upon cessation of the caring role.
For

Former and current family carers would welcome more respite breaks/services (e.g. the Ballybunion week away in the case of WCCSG), in particular for former family carers, caring in contexts characterised by relapse/remission (e.g. mental health issues or cancer care), recurrent hospitalisation or respite.

Most importantly, former family carers requested and would welcome assistance, space and support in moving forward (socially, financially, personally) upon cessation of the caring role.

It does take time to make sense of it all, to look back and think oh I was doing this, I was doing that, how did I ever do it? You know some people may want some kind of former carers' support straight away, and others may only come to it later. It is also like bereavement, you know, I need to go straight away, you have all these feelings, other people thought they were coping fine, and it is only years later that maybe another thing happens that reminds them so much of this pain, and then they feel the need to go and talk to somebody, so it works in all different ways. Everybody is different, every experience is different, and people may need to come along at different times. It is definitely, sometimes it can be a traumatic experience, some people get hit by the people they are caring for. So, I think sometimes after somebody has died maybe the caring experience the person can make a bit more sense of it and look back and maybe do some grieving then and be ready to go to, I think if the (Carer organisation) made it clear that a former carer is still sometimes doing a lot of caring either administration or visiting or providing whatever the person needs in whatever nursing home they are in etc.

Development of carer-led responses and resources

Following the data collection and analysis, the findings and participant suggestions/wish lists were presented back to the former family carers who participated in the research and to other former carers at interactive workshops in Bantry and Clonakilty (June and July 2017, respectively) as well as to the board of the WCCSG. During these sessions, former family carers debated how best to build on insights/former family carers' wish lists in practical ways. It was debated which supports would be best provided by carer organisations and what insights needed to be represented to policy makers. A number of specific interventions and supports were prioritised as part of this project, including a life-coaching workshop for former family carers, video-based peer supports developed by former family carers for current and future carers and a public policy workshop. For further details, please see Appendix 5.

Conclusion

To better understand and support former family carers, throughout and beyond the caregiving life course, we need to consider former family carers' relational identities or role-based identities (e.g. being a family carer or former family carer), *and* their person-based identities (i.e. who the person is when enacting the role of family carer and after the role ends) if we are to support family carers and former family carers in a holistic way. While former family carers experience multiple identity transitions throughout the family caregiving life course, over time a sense of renewal and positive gain may emerge as former family carers refashion their identities within and beyond the family. The development of supports for former family carers, such as counselling, therapy, coaching, financial and career planning and ongoing information and resources (Orzeck & Silverman, 2008), with relevant professionals might also provide external help and stimuli in certain cases, if and when desired. In terms of the development of social policy to support former family carers, the inclusion of the voices of former family carers and care recipients in the development of strategies and services, in a grounded manner, aims at increasing the visibility of family carers and former family carers. Former family carers have important roles to play in advocacy, awareness and input

into the structure of service provision. Moving beyond a narrow economic conception of policy support for carers/former carers will be beneficial in addressing the broader emotional/social/physical issues raised by family carers. It would also go some way towards

It is necessary to consider former family carers' role-based identities (e.g. being a family carer/ former family carer), and their person-based identities (i.e. who the person was when enacting the role of family carer and who the person now is once the caring role has ended) if we are to support former family carers in a holistic way.

validating their experiences as family carers and the expertise they accumulate through the process. Being a member of an informal caregiving network or carer organisation can be of increasing benefit and support for some former family carers to assist them in facing the many practical and emotional challenges that they will face. The development of services, in conjunction with carer organisations that facilitate the engagement of former carers in supporting current carers, would be particularly welcomed.

CONCLUDING COMMENTS – PROJECT EVALUATION

This collaboration enhances civic society in a national context by delivering on the Irish Government's and policy makers' vision to improve and support family carers in Ireland, as highlighted in the National Carers' Strategy. The jointly developed proposal with partner CVOs prioritises knowledge and information exchange with those most impacted by the research exploration, namely former family carers. Thereby, former family carers are active co-participants in designing and directing the research process and outcomes. Specifically, the knowledge produced through this collaborative project (i) facilitated the clarification of specific issues, challenges and concerns facing former family carers; (ii) jointly developed and disseminated peer and other supports for former family carers; (iii) made former family carers' perspectives and experiences the predominant focus in further research/policy interventions and collaborations directed towards meeting carers' needs and requirements at a national and international level and (iv) increased societal and public awareness of the value and contribution of carers to civic society. Responses to issues identified by former family carers throughout the project were integral to the PAR approach adopted, which prioritised participation, advocacy/action and policy change. The development of an action and training plan and peer videos will enable partner CVOs to improve the delivery of supports for post-carers in accordance with their individual needs and requirements. An interactive public forum, involving participants, CVOs, policy makers, experts and public representatives, will enable the articulation of family carers' concerns and increase societal awareness in relation to carers' contributions and care requirements. Critically, the project provides research outputs and opportunities for citizen education and discussion in relation to caregiving as well as for advocacy for/by former carers amongst policy and healthcare decision makers at a national and international level. Finally, the collaboration seeks to develop capacity and routes for future engagement with ISS21, WCCSG, FCI and CAI on a longer-term basis to develop joint research proposals and projects to be submitted, in the medium and long term, to potential national funders across the jurisdictions involved as well as to international funders such as H2020 (i.e. under the Health, Demographic, Change and Wellbeing societal challenge).

BIBLIOGRAPHY

- Andrén, S., & Elmståhl, S. (2002). Former family carers' subjective experiences of burden: A comparison between group living and nursing home environments in one municipality in Sweden. *Dementia*, 1(2), 241-254.
- Ashforth, B.E. (2001). *Role transitions in organizational life: An identity-based perspective*. New Jersey: Routledge.
- Ashforth, B. E., Kreiner, G. E., & Fugate, M. (2000). All in a day's work: Boundaries and micro role transitions. *Academy of Management Review*, 25(3), 472-491.
- Cavaye, J., & Watts, J.H. (2016). Former carers: Issues from the literature. Families, Relationships and Societies, *The Open University* (Early Access).
- Cronin, P, Hynes, G., Breen, M., McCarron, M., McCallion, P., & O'Sullivan, L. (2015). Between worlds: The experiences and needs of former family carers. *Health & Social Care in the Community*, 23(1), 88-96.
- Department of Health (2012). *The national carers' strategy – recognised, supported, empowered*, July, Department of Health, Dublin.
- Department of Health. (2014). *The national carers' strategy recognised, supported, empowered, first progress report September 2012–September 2013*, Department of Health, Dublin.
- Department of Health. (2015). *The national carers' strategy recognised, supported, empowered, second progress report September 2013–September 2014*, Department of Health, Dublin.
- Department of Health. (2016). *The national carers' strategy recognised, supported, empowered, third progress report September 2014–September 2015*, Department of Health, Dublin.
- Department of Health. (2017). *The national carers' strategy recognised, supported, empowered, fourth progress report September 2015–December 2016*, Department of Health, Dublin.
- Department of Social Protection. (2016). *Updated action plan for social inclusion 2015-2017*. Department of Social Protection, Dublin.
- Ghesquiere, A.H., Yamile, M.M., & Shear, M.K. (2011). Risks for complicated grief in family caregivers. *Journal of Social Work in End-Of-Life and Palliative Care*, 7(2/3), 216-240.
- Government of Ireland. (1968). *The care of the aged: report of an inter-departmental committee on the care of the aged*, Dublin: Government Publications.

- Grande, G., Stajduhar, K., Aoun, S., Toye, C., Funk, L., Addington-Hall, J., Payne, S. & Todd, C. (2009). Supporting lay carers in end of life care: Current gaps and future priorities. *Palliative Medicine*, 23(4), 339-344.
- Harrop, E., Byrne, A., & Nelson, A. (2014). It's alright to ask for help: Findings from a qualitative study exploring the information and support needs of family carers at the end of life. *BMC Palliative Care*, 13(22), 1-10.
- Kindon, S., Pain, R., & Kesby, M. (2007). *Participatory action research approaches and methods – Connecting people, participation and place*. Abingdon, Oxon, UK: Routledge.
- Larkin, M. (2009). Life after caring – The post-caring experiences of former carers. *British Journal of Social Work*, 39, 1026-1042.
- Larkin, M., & Milne, A. (2017). What do we know about older former carers? Key issues and themes. *Health and Social Care in the Community*, 25(4), 1396-1403
- Lewis, J., & Meredith, B. (1988). *Daughters who care*. London: Routledge.
- McCarron, M., Breen, M., Cronin, P., Hynes, O' Sullivan, L., & McCallion, P. (2011). *Between worlds: The experiences and needs of former carers*. School of Nursing and Midwifery, Trinity College Dublin.³⁰
- Moss, M.S., & Moss, S.Z. (2012). Multiple social contexts in qualitative bereavement research. *Journal of Aging Studies*, 26, 459-466.
- O'Brien, M.R., Whitehead, B., Jack, B.A., & Douglas Mitchell, J. (2012). The need for support services for family carers of people with motor neurone disease (MND): Views of current and former family caregivers, a qualitative study. *Disability and Rehabilitation*, 34(3), 247-256.
- Orzeck, P., & Silverman, M. (2008). Recognizing post-caregiving as part of the caregiving career: Implications for practice, *Journal of Social Work Practice*, 22(2), 211-220.
- The Carers Association Family. (2014). *Family Carers' Scorecard what has the national carers' strategy achieved? An assessment of progress from the perspective of family carers*. Carers Association.

30

<http://www.carealliance.ie/userfiles/file/Between%20Worlds%20The%20Experiences%20and%20Needs%20of%20Former%20Family%20Carers%20Full%20Report%20September%202011.pdf>

- Tolkacheva, N., Broese Van Groenou, M., De Boer, A., & Van Tilburg, T. (2011). The impact of informal care-giving networks on adult children's care-giver burden. *Ageing and Society*, 31, 34-51.
- Van Katwyk, T., & Ashcroft, R. (2016). Using participatory action research to access social work voices: Acknowledging the fit. *Journal of Progressive Human Services*, 27(3), 191-204

APPENDIX 1 – IRC NEW FOUNDATIONS POSTCARE PROPOSAL

Irish Research Council Government of Ireland ‘New Foundations’ Scheme 2016 Application Form

1. SUMMARY PROPOSAL DETAILS:		
Name of applicant:	Dr Carol Kelleher (CK)	
Job title/Position:	Lecturer in Marketing Member of Institute of Social Science in the 21 st Century, University College Cork (ISS21 UCC) Ageing Research Cluster Member of Care Alliance Ireland Family Carers’ Research Network Member ISCH Cost Action 1311 Intergenerational Family Solidarity across Europe (INTERFASOL)	
Institution:	University College Cork	
Department/School name:	Management and Marketing	Business and Law
Details of award held within last three years: (Please note evidence of the award must be submitted with this application.)	Award title:	Teagasc Walsh Fellowship funding scheme 2014
	Awarding body:	Teagasc
	Year and date of award:	11 February 2014
	Evidence provided:	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>
Current or previous New Foundations award held:	Year(s) held:	Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Title of proposed proposal:	Post-Caregiving: Family Carers’ Experiences of Role and Identity Transition on Cessation of the Caring Role – Implications for Policy and Practice	
Abbreviation of proposal title:	POSTCARE.	
Proposal abstract (100 words):	Currently we know little about what happens to carers when the caring role ends and how they might be best supported to transition to life after care. POSTCARE will provide nuanced knowledge of family carers’ post-caregiving experiences of loss and role and identity transition upon cessation of the caring role. Using a participatory action research approach, POSTCARE will respond to the issues, challenges and concerns facing former carers via a series of participant-led workshop and supports. Primary outputs will include policy, theoretical and media-oriented papers and peer supports disseminated to as wide an audience as possible.	
Discipline/subject area(s):	Social Sciences	

2. Please indicate which strand you are applying for under the

Scheme	Please tick (✓)
Strand 1: Enhancing Civic Society (in sponsorship with the Wheel and Dóchas)	
Strand 1a: Enhancing Civic Society within a National Context	✓
Strand 1b: Enhancing Civic Society within an International Context	
Strand 2: Marking the Decade of Centenaries 1917-22	
Strand 3: Research without Borders	
Strand 3a: Encouraging Knowledge Exchange and Collaboration between Research Institutions North and South	
Strand 3b: Supporting Participation of Irish Researchers in HERA and NORFACE	
Strand 4: Knowledge Exchange for Impact	

3. SUPERVISOR DETAILS (IF APPLICABLE): N/A

If the applicant is a postgraduate scholar and not a member of staff of an eligible institution, they must identify an appropriate named individual willing to act as a supervisor and principal investigator for the purposes of an award (Section B: Eligibility, Terms and Conditions).

Full name (including title):	
Position held: (including department and institution)	
Telephone:	
Email address:	
Proposed role in proposal:	

4. RESEARCH TRACK RECORD AND OUTPUT TO DATE OF APPLICANT

Please provide a summary of relevant research track record and outputs to date. (100 words)	<p>Background Report on experiences of family carers (2014), Cork Carers Association. Member ISS21 Interdisciplinary Ageing Research Cluster UCC,³¹ Care Alliance Ireland Family Carers Research Network and ISCH Cost Action 1311 Intergenerational Family Solidarity across Europe (INTERFASOL).</p> <p>Teaching and learning: Chair ISS21 Interdisciplinary Workshop on Ageing, Consumption and Service (June 2016).³² Chair Association of Consumer Research (2015) Conference Roundtable: Aging and Consumption, USA, Oct. 2015. Lecturer: Services and Critical Marketing, Marketing and Society</p> <p>Publications on care and service provision: Peer-reviewed journal articles (10); book chapters (3) – including on Aging and Consumption; conference proceedings (47); reports (4) – including on Family Caring and Mental Health.</p> <p>Awards include:</p>
--	--

³¹ <http://www.ucc.ie/en/iss21/clusters/ageing/>

³² <https://www.ucc.ie/en/events/publiclecturesandseminars/businessandlaw/name-640139-en.html>

	<p>UCC Strategic Research Fund – Eldercare Research (€1,081) 2015/16, Strand 1 funding €16,000, Enterprise Ireland €5,000.</p> <p>Best conference paper awards (2)</p> <p>Scholarships (4) – including American Marketing Association (2).</p>
--	--

4a. For applicants to ALL strands: DETAILED PROPOSAL DESCRIPTION (max. \$1,000 words).

1. Aims and objectives:

The central aim of the National Carers' Strategy (2012)³³ is to recognise the value and contribution of carers to civic society and to support and empower them to participate as fully as possible in economic and social life (p. 2). Post-caregiving involves significant challenges for former carers, including return to work or education, economic and financial challenges, rebuilding social networks, changed family relationships, dealing with complicated grief and identity rebuilding.^{34,35,36} However, the far-reaching and complex economic, social and psychological needs of former carers remain misunderstood and unmet. This research addresses this policy and practice deficit.

The aim of this project, a collaboration between ISS21, West Cork Carers Support Group (WCCSG), Family Carers Ireland (FCI) and Care Alliance Ireland (CAI), is to develop evidence-based supports and policy to support former carers' post-caregiving. It specifically responds to Objective 1.3.5 of the National Carers' Strategy: 'To review existing transition arrangements for carers at the end of their caring role' (p. 13). Through dialogue with former carers, the project will incorporate guidelines, an action plan and the co-development of peer-supports to change and influence policy and practice.

The project objectives are to:

Explore former caregivers' experiences and lived context of role and identity transition post-caregiving upon cessation of the caring role when the person they care for dies or moves into a home.

Co-develop appropriate supports and policy responses for former carers.

Build participant capacity for future national and international research collaborations.

2. Proposal implementation plan:

The proposal follows a participatory action research³⁷ (PAR) approach that prioritises responsive information exchange with those most impacted by the research, namely former carers. It builds on previous collaborations with ISS21 and Family Carers Ireland (2014-2015) and a preparatory ISS21 workshop on carer research/securing H2020 funding (June 2016).

33 Department of Health (2012) National Carers' Strategy – Recognised, Supported, Empowered, July.

34 Family Caring in Ireland Report (2015). Care Alliance Ireland.

35 Larkin, Mary (2009). Life after caring – The post-caring experiences of former carers. *British Journal of Social Work*, 39, 1026-1042.

36 Orzeck, P., & Silverman, M. (2008). Recognizing post-caregiving as part of the caregiving career: Implications for practice. *Journal of Social Work Practice*, 22(2), 211-220.

37 Van Katwyk, T., & Ashcroft, R (2016). Using participatory action research to access social work voices: Acknowledging the fit. *Journal of Progressive Human Services*, 27(3), 191-204.

Table 1 – Project Plan

Task	Jun16	Jul16	Aug16	Sep16	Oct16	Nov16	Dec16	Jan17	Feb17	Mar17	Apr17	May17	Jun17	Jul17	Aug17	Sep17
Pre-Planning Phase																
Preparatory workshop																
Project brief																
Protocols, consent forms																
Internal ethical approval																
Project Implementation																
UCCSREC ethical approval																
Literature review																
Interviews (20)																
Transcription																
Analysis																
Participant/CVO feedback sessions																
Write up/ publication report																
Dissemination of Findings																
Interactive workshop																
Peer support videos																
Training materials/handbook																
Journal articles/ conference proceedings																
Evaluation reports																
Post-Implementation																
Workshop H2020 calls																
Marie Curie application																

The project plan involves the following (see Table 1):

Jointly agreed project brief (August 2016) based on the identification and discussion of issues by partner CVOs.

A systematic review/benchmarking analysis of post-caregiving supports and best practice, nationally and internationally.

One-to-one in-depth interviews (20) with volunteers³⁸ from the partner CVOs.

Participant/CVO feedback sessions to discuss initial findings.

Building on participant feedback, an interactive public workshop with participants/CVOs to discuss initial findings. Expert speakers and policy makers will provide training, facilitate discussion and co-develop supports/policy responses.

Development of peer support videos by former carers for carers, to be disseminated through social media/partner CVOs' channels.³⁹

38 Participants will include spouses, women and young carers who have been identified as requiring particular supports post _ caregiving (Orzeck & Silverman, 2008).

39 See Care Alliance Ireland (2016), Online Support for Family Carers: Options and Experiences, Discussion Paper 3, p. 2.

3. Expected outputs and outcomes:

The project outputs comprise the following:

A POSTCARE report detailing the proposed policy and support responses as well as a summary brief for policy/public awareness exercises to be disseminated through the CVO partners, including the following workshop.

A one-day public interactive workshop organised in conjunction with partner CVOs on post-caregiving, which will prioritise former carers' perspectives and involve interactive sessions for participants, carers, policy makers and interdisciplinary researchers in the field.

Series of online videos featuring former carers' advice for carers to be disseminated/promoted by partner CVOs.

At least one theoretical and one policy-based paper to be submitted to the *International Journal of Care and Caring* and the *Journal of Social Policy* based on the research findings.

Three practitioner/academic conferences, including the 8th International Carers Conference 2017 in conjunction with Eurocarers.⁴⁰

Opinion pieces for national/regional print media, including the *Irish Times – Health Supplement*.

Interviews with local/national broadcasters in conjunction with National Carers week (June 2017).

Evaluation reports on all workshops/training provided.

4. Potential impact and benefits:

The project outputs will inform national policy and the delivery of carer supports in Ireland and internationally, thus empirically and practically addressing carer needs as prioritised by the National Carers' Strategy (2012). It also develops research capacity and routes for continued engagement with partner CVOs on a longer-term basis. This will enable the development of joint research proposals/projects to be submitted, in the medium/long term, to national and international funders, such as H2020 (i.e. under the Health, Demographic, Change and Wellbeing societal challenge⁴¹). Finally, this project will form the basis for a follow-up Marie Curie Global Fellowship⁴² application by CK in September 2017.⁴³

4b. For applicants to Strand 1 ONLY (max. 500 words)

This collaboration enhances civic society in a national context by delivering on the Irish Government's and policy makers' vision to improve and support family carers in Ireland, as highlighted in the National Carers' Strategy. The jointly developed proposal with partner CVOs prioritises knowledge and information exchange with those most impacted by the research exploration, namely former carers. Thereby, former carers are active co-participants in designing and directing the research process and outcomes. Specifically, the knowledge produced through this collaborative project will (i) facilitate the elucidation of specific issues, challenges and concerns facing former carers (ii) jointly develop and disseminate peer and other supports for former carers (iii) foreground carers' perspectives in further research / policy interventions and collaborations directed towards meeting carers' needs and requirements at a national and European level and (iv) increase societal and public awareness of the value and contribution of carers to civic society. Responses to issues identified by former carers throughout the project are integral to the PAR approach adopted, which prioritises participation, advocacy/action and policy change. The development of guidelines, action and training plan and peer videos will enable partner CVOs to improve the delivery of supports for post-carers in accordance with their individual needs and requirements. An interactive public

40 The European Association Working for Carers (www.eurocarers.org).

41 Calls being considered by the consortium include: SC1-PM-15-2017: Personalised coaching for well-being and care of people as they age, SC1-PM-20-2017: Development of new methods and measures for improved economic evaluation and efficiency measures in the health sector, SC1-HCO-08-2017: Actions to bridge the divide in European health research and innovation.

42 http://ec.europa.eu/research/mariecurieactions/about-msca/actions/if/index_en.htm

43 The Marie Curie Global fellowship will involve CK spending two years at the Centre for Research on Aging, Policies and Practice [<http://rapp.ulberta.ca>], University of Alberta, Canada, a centre of international excellence in carer research, followed by one year spent as a full time researcher with UCC ISS21.

forum, involving participants, CVOs, policy makers, experts and public representatives, will enable the articulation of carers' concerns and increase societal awareness in relation to carers' contributions and care requirements. Critically, the project provides research outputs and opportunities for citizen education and discussion in relation to caregiving as well as for advocacy for/by former carers amongst policy and healthcare decision makers at a national and European level.

Finally, the collaboration develops capacity and routes for engagement with ISS21, WCCSG, FCI and CAI on a longer-term basis to develop joint research proposals and projects to be submitted, in the medium and long term, to national funders across the jurisdictions involved as well as to international funders, such as H2020 (i.e. under the Health, Demographic, Change and Wellbeing societal challenge).

4c. For applicants who are submitting an application to Strand 2 – Marking the Decade of Centenaries theme (max. 500 words) N/A.

Please outline how your proposal is relevant to Strand 2: Marking the Decade of Centenaries, including:

How the proposed project will complement the ongoing programme of annual commemorations with special centenary commemorative events on the anniversaries of key events

How the proposed project will enhance understanding of and respect for events of importance among the wider population

5. DOES THE PROPOSAL OUTLINED IN THIS SUBMISSION REQUIRE APPROVAL BY THE RELEVANT UNIVERSITY/INSTITUTIONAL ETHICS COMMITTEE?	YES (x)	NO ()
---	----------------	---------------

If there are ethical implications of the proposal outlined above, please provide details of what they are and how they will be addressed:

As the research involves human subjects, ethical approval will be requested from the UCC SREC (<https://www.ucc.ie/en/research/ethics/>). This will involve addressing and highlighting all ethical issues and concerns as well as submitting the proposed research guides, consent forms and interview protocols for approval. Formal written confirmation from the partner CVOs for permission to carry out this research on their behalf as well as their plans to facilitate and allow data collection and dissemination will also be included. Participation in the research is voluntary, and the recruitment of participants will be facilitated and managed by partner CVOs. Volunteer participants will have the option of withdrawing from the research at any time. All outputs will anonymise individual respondents. UCC and partner CVOs will keep all information confidential. Any project outputs will be cleared with participants, and each of the partner CVOs will check on any sensitivities. All outputs, as outlined earlier, will be anonymised as necessary, and sensitive material can be adapted or removed as required by participants/partner CVOs.

In the event of a successful outcome to this application, where relevant, written evidence of such ethical approval must be received by the Research Council prior to confirmation of the grant.

APPLICANT'S DECLARATION

I declare that the above particulars are correct and understand that the circulated 'Terms and Conditions' apply. I accept that failure to abide by the 'Terms and Conditions' may disqualify me from this Scheme. I also authorise the Irish Research Council to verify, if necessary, any of the information supplied in this application.

Signature of Applicant:	
Date:	

ENDORSEMENT BY INSTITUTIONAL AUTHORITIES

I hereby endorse this application to the Irish Research Council in accordance with the circulated 'Terms and Conditions'.

Signature of Proposed Mentor: (where required)	<i>Only to be completed if the applicant is a postgraduate student</i>	
Date:		
Signature of Vice-President for Research or authorised signatory: (please indicate position held)	Print name:	
	Position held:	
	Signature	
Date:		

Institutional Stamp:



FOR STRAND 1 APPLICANTS ONLY: ENDORSEMENT BY CVO or NGO PARTNER

I hereby confirm that on behalf of the below named organisation I support this application to the Irish Research Council in accordance with the circulated 'Terms and Conditions'.

Name of organisation 1:	West Cork Carers Support Group	
Signature of Head of Organisation or authorised signatory (please indicate position held)	Print name:	Ms Sally-Ann Black
	Position held:	Coordinator
	Signature	
	Charity Number	20066710
Date:		

Organisational Stamp:



Name of organisation 2:	Family Carers Ireland	
Signature of Head of Organisation or authorised signatory (please indicate position held)	Print name:	Paul O' Mahoney
	Position held:	Campaigns Researcher
	Signature	
	Charity Number	
Date:		

Organisational Stamp:

Name of organisation 3:	Care Alliance Ireland	
Signature of Head of Organisation or authorised signatory (please indicate position held)	Print name:	Zoe Hughes
	Position held:	Policy and Research Officer
	Signature	
	Charity Number	20048303
Date:		

Organisational Stamp

**APPENDIX 2 - UCC SOCIAL RESEARCH ETHICS COMMITTEE (SREC) – ETHICS APPROVAL
FORM**

UCC Ethics Approval Form

Name of applicant	Dr Carol Kelleher	Date	August 2016
Contact Details	Email carol.kelleher@ucc.ie		
Department/Unit	Management and Marketing		
Title of project	Post-Caregiving: Family Carers' Experiences of Role and Identity Transition upon Cessation of the Caring Role – Implications for Policy and Practice		

		YES	NO
1	Do you consider that this project has significant ethical implications?		X
2	Will you describe the main research procedures to participants in advance so that they are informed about what to expect?	X	
3	Will participation be voluntary?	X	
4	Will you obtain informed consent in writing from participants?	X	
5	Will you tell participants that they may withdraw from the research at any time and for any reason and (where relevant) omit questionnaire items to which they do not wish to respond?	X	
6	Will data be treated with full confidentiality/anonymity (as appropriate)?	X	
7	If results are published, will anonymity be maintained and participants not identified?	X	
8	Will you debrief participants at the end of their participation (i.e. give them a brief explanation of the study)?	X	
9	Will your project involve deliberately misleading participants in any way?		X
10	Will your participants include schoolchildren (under 18 years of age)?		X
11	Will your participants include people with learning or communication difficulties?		X
12	Will your participants include patients?		X
13	Will your participants include people in custody?		X
14	Will your participants include people engaged in illegal activities (e.g. drug taking; illegal Internet behaviour)?		X
15	Is there a realistic risk of participants experiencing either physical or psychological distress?		X
16	If yes to 15, has a proposed procedure, including the name of a contact person, been given? (see no. 23)		

DESCRIPTION OF THE PROJECT

17. Aims of the project

This is a project being conducted under the IRC New Foundations initiative, which seeks to explore the experiences of former carers following the cessation of the caring role.

This is going to be a qualitative study commencing in August 2016 and finishing September 2017.

Preparation for fieldwork will be outlined in an agreed research brief between the researcher, a UCC staff member and the (carer organisations), which will outline how the study will be conducted. The brief is agreed and signed off by both parties.

18. Brief description and justification of methods and measures to be used (attach copy of questionnaire/interview protocol/discussion guide/etc.)

Face-to-face semi-structured interviews will commence in August 2016 and be completed by March 2017.

Interviewees will be provided with copies of the interview transcripts for review upon completion. The findings of the research will also be presented to informants and partner CVOs (Family Carers Ireland, West Cork Carers Support Group and Care Alliance Ireland) once the research is completed.

19. Participants: Recruitment methods, number, age, gender, exclusion/inclusion criteria

Carol Kelleher will circulate the brief to West Cork Carers Support Group and Family Carers Ireland who will identify participant volunteers for the study.

20. Concise statement of ethical issues raised by the project and how you intend to deal with them

Participation will be voluntary.

Informed consent of participants will be sought.

Participants may withdraw from the research at any time.

Data will be treated with full confidentiality/anonymity, including after publication.

Participants will be debriefed at the end of the participation and upon analysis of the findings.

21. Arrangements for informing participants about the nature of the study (cf. Question 3)

Carol Kelleher will circulate the brief to West Cork Carers Support Group and Family Carers Ireland who will identify participant volunteers for the study.

22. How you will obtain Informed Consent (cf. Question 4) (attach relevant form[s])

Consent form attached – will be provided to the Head of the Carers Association for information and also to each informant.

23. Outline of debriefing process (cf. Question 8). If you answered YES to Question 15, give details here. State what you will advise participants to do if they should experience problems (e.g. who to contact for help)

The findings of the research will also be presented to informants and CVO partners once the research is completed.

24. Estimated start date and duration of project

This is going to be a qualitative study commencing in August 2016 and finishing in September 2017.

Signed _____ **Date** _____

Applicant

Notes

1. Please submit this form and any attachments to Dr S. Hammond, Chair, SREC, c/o Miriam Collins, Office of the Vice President for Research and Innovation, Block E, 4th Floor, Food Science Building, UCC, College Road, Cork. Please also forward an electronic copy to srec@ucc.ie

2. Research proposals can receive only provisional approval from SREC in the absence of approval from any agency where you intend to recruit participants. If you have already secured the relevant consent, please enclose a copy with this form.

3. SREC is not primarily concerned with methodological issues but may comment on such issues insofar as they have ethical implications.

This form is adapted from pp. 13-14 of Guidelines for Minimum Standards of Ethical Approval in Psychological Research (British Psychological Society, July, 2004)
Last update: 2011-07-19

APPENDIX 3 – INFORMED CONSENT FORM FOR RESEARCH PARTICIPANTS

Information Sheet

Purpose of the study. This study is concerned with carers' experiences of loss and the cessation of the caring role.

What will the study involve? The study will involve speaking with carers who are members of the West Cork Carers Support Group/Family Carers Ireland to learn about your experiences when the caregiving role ceases.

Why have you been asked to take part? You have been asked because you volunteered to participate in the research and/or were recommended by Ms Sally Ann Back of the West Cork Carers Support Group or Mr. Paul O' Mahoney, Family Carers Ireland.

FAQs

Do you have to take part? Participation is voluntary. I need you to sign a consent form. I will give you an information sheet and a copy of the consent form. You have the option of withdrawing before the study commences (even after you have agreed to participate) or to discontinue after data collection has started. You can also withdraw within two weeks of participation and ask to have your data destroyed.

Will your participation in the study be kept confidential? [Yes! - but remember, there's no such thing as absolute confidentiality.] I will ensure that the data are anonymised and that no clues to your identity appear in the report. Any extracts from what you say that are quoted in the research or publications will be entirely anonymous.

What will happen to the information which you give? The data will be kept confidential and secure for the duration of the study. Upon completion of the research, they will be retained, in an anonymised fashion, for a further three years, and then destroyed.

What will happen to the results? The results will be presented in a report and presentation to the West Cork Carers Support Group. A study may be published in a research journal or presented at academic conferences.

What are the possible disadvantages of taking part? From experience, I don't envisage any negative consequences for you in taking part.

What if there is a problem? At the end of the interview, I will discuss with you how you found the experience and how you are feeling. If you subsequently feel distressed, I will advise you whom you might contact.

Who has reviewed this study? The UCC research ethics committee, West Cork Carers Support Group, Family Carers Ireland and Care Alliance have given approval for the study to take place

Any further queries? If you need any further information, you can contact me: Dr Carol Kelleher, Lecturer in Marketing, School of Management and Marketing, University College Cork, Cork. Email carol.kelleher@ucc.ie. Mobile 086 806 8729

If you agree to take part in the study, please sign the consent form overleaf.

Consent Form

I.....agree to participate in the research study being conducted by Dr Carol Kelleher, School of Management and Marketing, UCC.

The purpose and nature of the study has been explained to me in writing.

I am participating voluntarily.

I give permission for my interview with [*name*] to be tape-recorded.

I understand that I can withdraw from the study, without repercussions, at any time, whether before it starts or while I am participating.

I understand that I can withdraw permission to use the data within two weeks of the interview, in which case the material will be deleted.

I understand that anonymity will be ensured in the write-up by disguising my identity.

I understand that disguised/anonymised extracts from my interview may be quoted in the report and any subsequent publications.

Signed.....

Date.....

APPENDIX 4 – INTERVIEW PROTOCOL

Thank you for taking the time to meet with me today. My name is Carol Kelleher, from UCC. I would like to talk about your experiences of caring and about your experiences after the caring role ended. I will ask you some general questions which are just the starting point for the conversation/discussion. I hope that you feel free to say whatever comes into your mind. There are no right or wrong answers. Take as much time as you need. It is my hope to learn from your personal experiences, feelings and ideas. The information will be confidential and will be used to get a general sense of carers' experiences and, in particular, of the cessation of care. The outcomes of the research may be published in an academic journal and will also be presented to the West Cork Carers Support Group/Family Carers Ireland/Care Alliance upon completion of the research.

Do you have any questions?

Is it OK for me to tape the interview so that I can better listen to you rather than taking notes? Also, could I show you this consent form, which outlines the purpose and use of the research? (Explain form) If you are happy with this, could you please sign it for me? Any questions?

To start, can you please tell me a little bit about yourself and your background – (for example, a little about your family, your occupation/role, age range etc.)?

- Age (will provide ranges, e.g. 30-35, 36-40, 41-45 etc. as sometimes people don't want to give their precise age).
- Gender (Female/Male – so just note)
- Number in family/ describe / paint a brief picture of your family.
- Relationship to the person being cared for, such as before needed care (NB explore pre-caring role and later in interview see how this was sustained/altered).
- Occupation – career/role in family – since when?

Can you tell me a little bit about your experience of becoming a carer? For example, life before you became a carer and then the transition to becoming a carer.

- How would you describe yourself and your life prior to becoming a carer? (e.g. probing for information on role/identity etc.).
- When and how did you become a carer (and solicit descriptive details of caring context, for example).
- Location – in home etc., health issues etc.
- Person cared for – background, age, nature of illness etc.
- Context, such as family member, neighbour etc.
- What was the level of consultation with/role of the rest of the family?
- How did you experience this initially? Vis-à-vis your relationship with the care recipient or in conjunction with them/other members of the family?
- How long were you a carer?
- How would you describe your relationship with (name care recipient) over the years that you cared for him/her?
- Nature of care – that is, how did they care for the care recipient (name)
- Role/involvement of family, neighbours, friends etc. vs sole responsibility

- Nature of care
- Needs of carer
- Positive experiences
- Negative experiences/tensions/challenges – How did they emerge? How were they resolved/managed?
- In what ways did things change/remain the same as before?

Can you tell me a little bit about your experience of being a carer?

- How did things (or you) evolve/change, such as you have described your life (role identity) pre-carer – how is it the same/different or change upon becoming a carer?
- In what ways did your role within the family change/stay the same compared to before? What other roles changed/stayed the same (e.g. work, becoming a breadwinner etc.)
- How did you perceive yourself in comparison to before? Were things the same, different, changed, how?

Can you tell me a little about your experiences of the ending of your carer role?

- Can you tell me the story of (name care recipient's) death/move into care?
- (Circumstances: why care ended – e.g. death, moving into a home)
- Emotions/experiences – how would you describe your experiences before/after?
- In what ways did the caring role continue/end when your family member moved into a home? What things changed, remained the same?
- How would you describe the impact of (name of person's) loss/death – moving into a home on your life – a little/moderate/or a lot?
- Impact personally? Roles? Work? Family? Home? Identity? What remained the same – what things changed?
- Initial impact vs looking back now
- How did a) the care recipient b) other family members feel/respond to the loss/death of (name of person) or their move into a home? Initially? Later on? What were their experiences? How might they describe the impact on you (role, identity other) – what might they think was the impact on you?

Still a carer?

- If so, your experience?
- If not, how has this impacted your life? What has changed? What remains the same?
- Positive experiences (examples)?
- Negative experiences (examples)?
- Role of other family members/friends?

Looking ahead, how do you see your role/yourself now that the person you have cared for is no longer here/has died?

Overall, to summarise what we have talked about today, how has it been and how is it now for you and your family since (name of person) passed away/moved to

Describe your current role/identity/identity within the family.

Thinking about your experiences as a carer/loss/bereavement and looking towards the future, if you had a magic wand, and everything were possible, is there anything a) about the past and b) about the future that you would change?

- Personally/family/neighbourhood?
- For the care recipient (if still alive)

Is there anything else you would like to tell me?

Thank you for your time.

APPENDIX 5 – SPECIFIC INTERVENTIONS DEVELOPED BY FORMER CARERS TO SUPPORT CARERS AND FORMER CARERS

Life-Coaching Workshop for Former Carers

A key theme that emerged from the research was the requirement to support former carers in making sense of the caregiving experiences and support in working out how to move forward (e.g. socially, financially, economically, psychologically) once the caring role ends. To meet this objective, we designed a life-coaching workshop for former carers to help them transition to life after care, which took place in the Ludgate Digital Hub in Skibbereen on 19th October 2017.

In terms of content, the three-hour workshop comprised an introduction to key life-coaching concepts and processes, including the following:

- The Growth Mindset & The Growth Zone
- The Multifaceted Identity (Georgian Windows) & Role Worlds
- The Nature of Transition & Change

The workshop methodology included input from the facilitator, interactive exercises and large and small group discussions with 15 former carer participants. In terms of learning outcomes, during the workshop, former carers were invited to reflect on and begin to answer fundamental questions for themselves, such as the following:

Identity & Role

- How has my experience as a carer benefited me?
- How are things different for me and my family now that I am no longer a carer?
- My role as a carer is finished – so, ‘Who Am I Now?’ and ‘Who Do I Want to Become?’
- What is the difference between my role as a carer and the role I take up for the future?

Transition & Future Focus

- What would be useful to ‘let go of’ from my experience as a carer in order to move forward?
- What would be useful to ‘take on’ to help me move forward?
- What are the opportunities and challenges for me as I move forward?
- What resources and supports will I need for the future?
- What are my next steps?

Carer Films

Finally, the project involved the development of three peer support films (1-minute, 9-minute and 26-minute durations) by former family carers for current family carers to be disseminated through social media/partner CVOs' channels and other carer organisations as well as national media. For further queries or copies of the film, please contact Sally Ann Back coordinator WCCSG (www.westcorkcarers.ie)

Participation in Life after Care Project (led by Care Alliance Ireland)

Also, at a national level, this research was input into a parallel but separate project, developed and led by CAI and funded by the National Lottery of Ireland, involving 10 charitable voluntary carer organisations/individuals (including Dr Carol Kelleher UCC and Sally Ann Back WCCSG) to update the 'Life After Care' booklet⁴⁴. Project targets include the following:

- Updated booklet reflecting the latest research on supporting the needs of former family carers (ca. 36 A5 pages)
- Updated contact details, websites and other relevant details
- A new section on online supports
- 2,000 copies distributed across the country in 2018
- 3,000 downloads of the publication in 2018/19
- National media coverage of the launch of the booklet
-

Policy Workshop UCC

This project, together with a separate IRC New Foundations on mental health services for carers, was presented to policy makers and former carers in UCC on 6th November 2017. The workshop panel comprised Dr Máire Leane, Dean – Office of Senior Vice President Academic and Registrar (Chair); Senator Colette Kelleher; Mick Barry, TD; Zoe Hughes, Care Alliance Ireland; Sally Ann Back, West Cork Carers; and Peter Cox, Family Carers Ireland. The purpose of the workshop was

⁴⁴ For further information on this project, please contact project lead – Liam O' Sullivan, Executive Director, Care Alliance Ireland, email: ndo@carealliance.ie

for policy makers and former carers (project participants) to discuss the project and desired next steps.

Other Dissemination

In terms of academic dissemination, the research was presented in the following fora:

- Family Carers Research Network, 31st August 2017, University College Dublin
- International Carers Conference, Adelaide, 3-5 Oct. 2017 – Presenter: Liam O’ Sullivan, Executive Director, Care Alliance Ireland
- European Sociological Association Conference, Athens, August 2017
- Association of Consumer Research Conference, San Diego, October 2017
- Naples Forum on Service, Sorrento, June 2017

