

## Life After Caring - What The Research Tells Us

March 2018

This document has been created in parallel with the publication *The Way Ahead - A Resource to Support Former Family Carers*, launched in Dublin, Ireland, in March 2018 and available to download from our website [www.carealliance.ie](http://www.carealliance.ie).

Research can be a valuable tool in helping us understand how best to support former family carers. In recent years a number of people in Ireland and beyond, have undertaken research in this area.

Increasingly this research is being used to help inform health and social care professionals on how best they can understand the lived experience of former family carers. It can also be a tool in advocating for improved recognition, awareness, as well as supports and services.

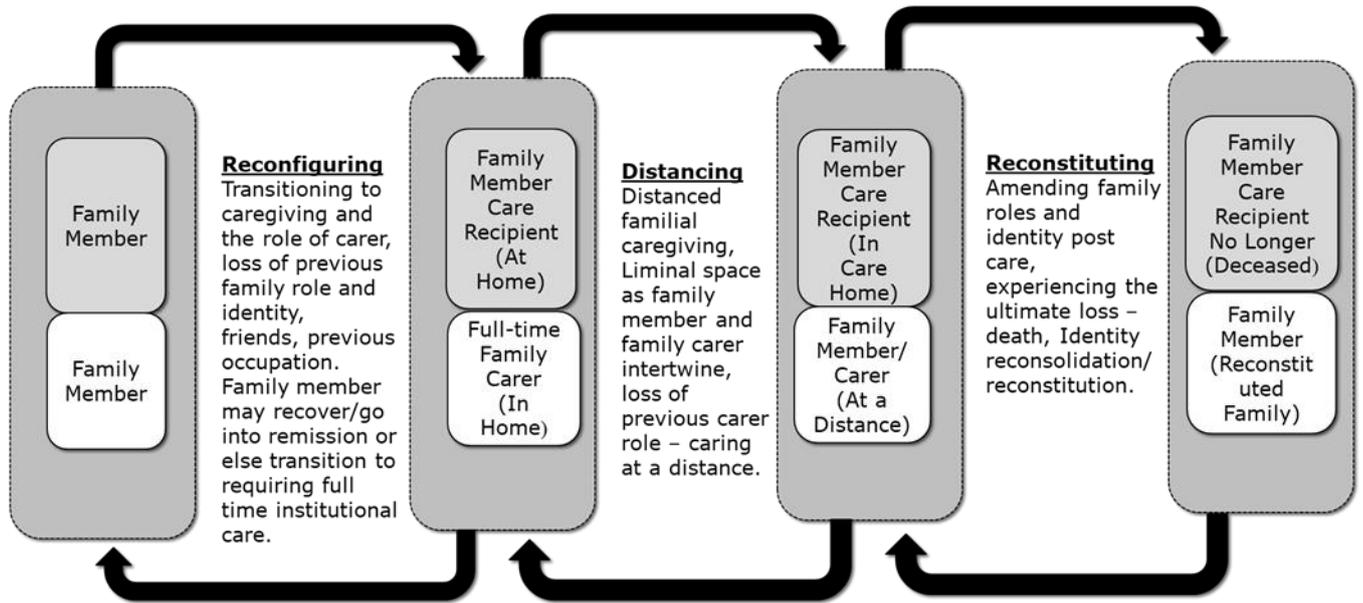
Below we attempt to summarise some of the key research in this area. Whilst little formal research has been undertaken and or published in this area, the list below is not entirely exhaustive. We would welcome being informed of any current and or proposed further research in this area.

### **Post-Caregiving: Family Carers' Experiences Of Cessation Of The Caring Role - Implications for Policy and Practice (Kelleher, C. & O'Riordan, J, 2017)**

Most recently, Dr. Carol Kelleher and her team in UCC undertook qualitative research in this area. They have developed the idea of there being cumulative and overlapping role and identity transitions of Family Carers, as seen below.



'Guiding support for family carers'



**Source:** *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, Family Carers Ireland and Care Alliance Ireland. Full report available to download from [http://www.carealliance.ie/publications\\_formercarers](http://www.carealliance.ie/publications_formercarers).

### Routes to becoming a carer (Larkin, M. and Milne, A., 2017).

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
  1. 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)

**Source:** Larkin, M., & Milne, A. (2017). *What do we know about older former carers? Key issues and themes.* Health & Social Care in the Community. <https://www.ncbi.nlm.nih.gov/pubmed/28226406>

### **Post Caring Model (Larkin, M., 2009)**

This 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 postcaring 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.

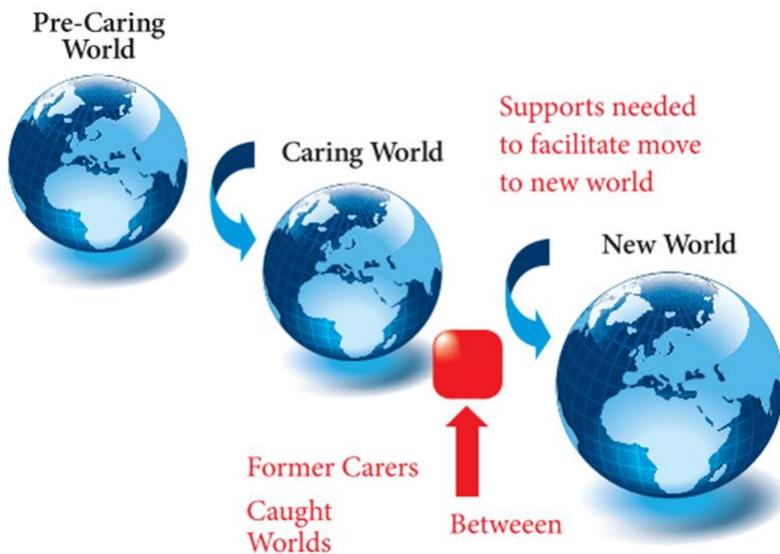
*Constructing life post-caring* comprises former carers' experiences of letting go and moving on to reconstruct life post-caring. This phase involves rebuilding family ties, re-uptake of interests, taking part in some other type of care-related activity (e.g. becoming a carer again, performing caring tasks for others [e.g. neighbours/friends/other family members], joining or volunteering with carer/former carer organisations, carer groups etc.).

The term 'serial carer' has been coined by Larkin to describe how some family carers after their caring ends for one person recommence the caring role again for someone else.

**Source:** Life after Caring: The Post-Caring Experiences of Former Carers, Mary Larkin, The British Journal of Social Work, Volume 39, Issue 6, 1 September 2009, Pages 1026–1042, <https://doi.org/10.1093/bjsw/bcn030>

### **Three post-caring stages: 'the loss of the caring world', 'living in loss' and 'moving on' (Cronin et al., 2015).**

This primary research, undertaken in collaboration with Care Alliance Ireland, represented the first formal research to be published in Ireland on this topic, and involved interviewing a number of former family carers of people with Parkinson's disease.



#### Loss of caring world

- Losses and emptiness of post-caring
- The closeness of the care-giving and care recipient relationship



#### Living in loss

- Emotional reactions to post-caring
- Anger resulting from interactions with statutory services
- Devaluing of post-carers by state
- Post-caring poverty
- Significance of carer advocacy groups
- Family relations



#### Moving on

- Caring for self
- Caring for others

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.

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

