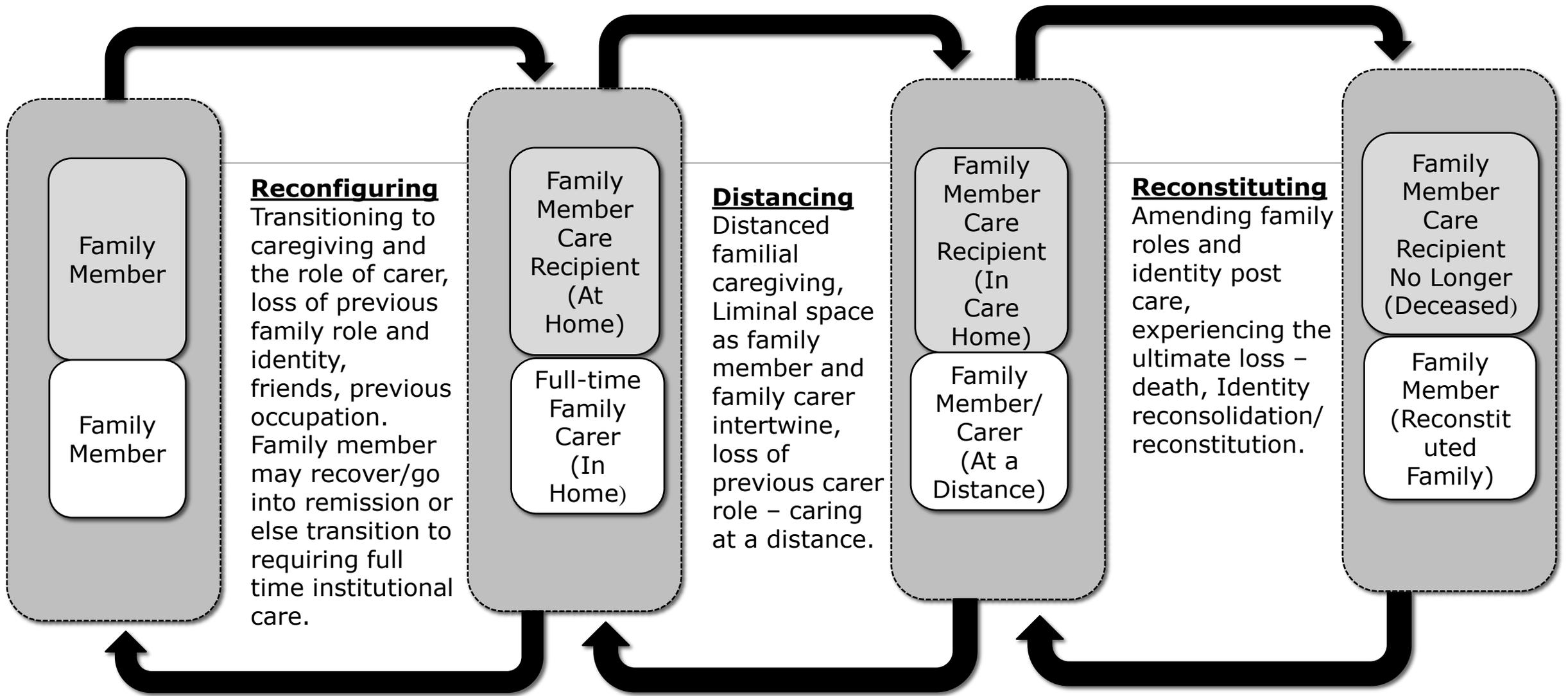


Post-Caregiving: Family Carers' Experiences of Cessation of the Caring Role – Implications for Policy and Practice

Liam O' Sullivan, Executive Director, Care Alliance Ireland
7th International Carers Conference, Adelaide, 5th October 2017

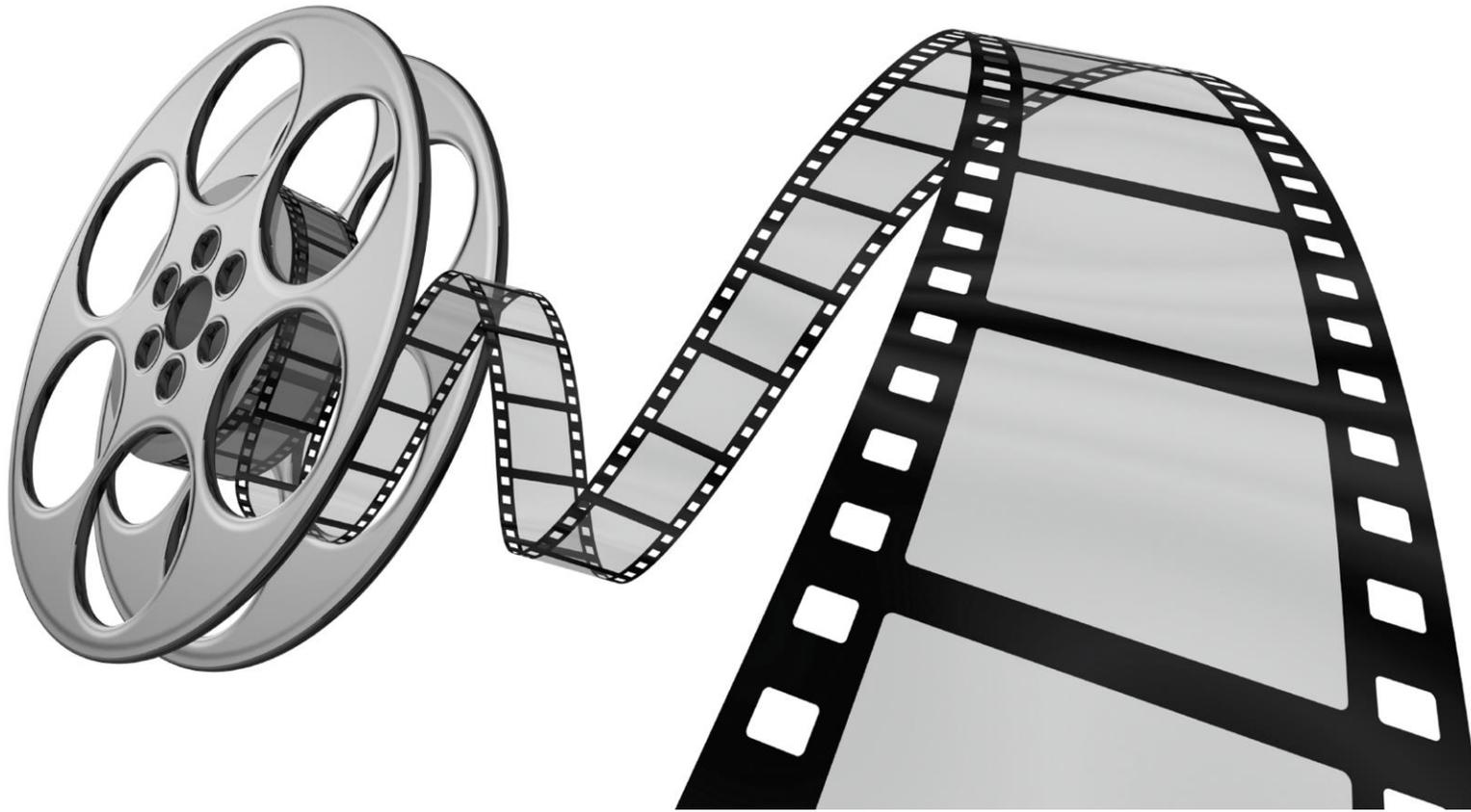






Caring Lives: Looking Back, Moving Forward

Carer-led responses



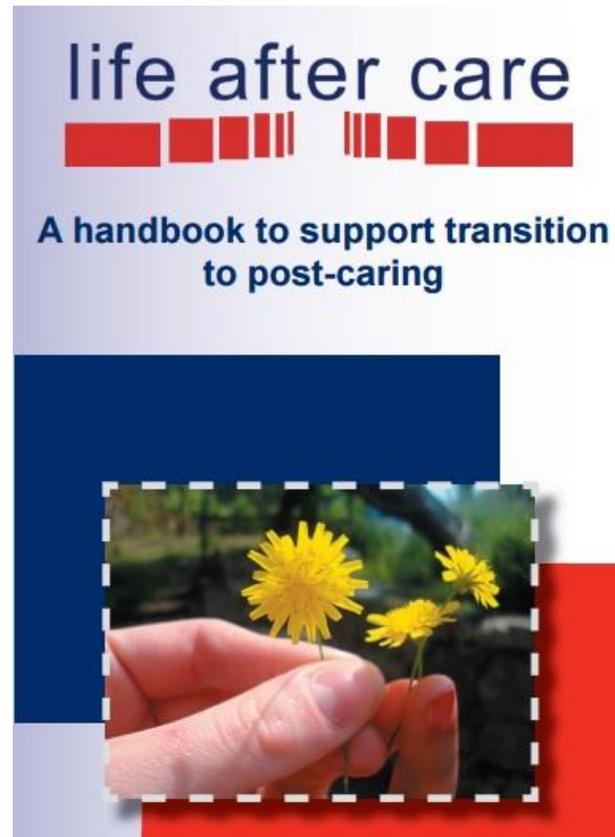
Carer-led responses



Carer-led responses



Carer-led responses





1.

**Need to consider relational identities
i.e. ROLE BASED (CARER/FORMER CARER) Identity AND
PERSON BASED IDENTITY**

If we are to support carers and former carers in a holistic way.



2.

The **dynamic nature of the relational identity changes, preferences and trajectories** need to be supported and considered when designing policies to support both current and former carers.



3.

As there are multiple routes to becoming a former carer and different personal and caring contexts – one size/type of policy response or support does not fit all.

Your Input – Opportunity to Influence Report

- What interventions have you made to support Former Family Carers?
- What have been the learnings?

Thank You!



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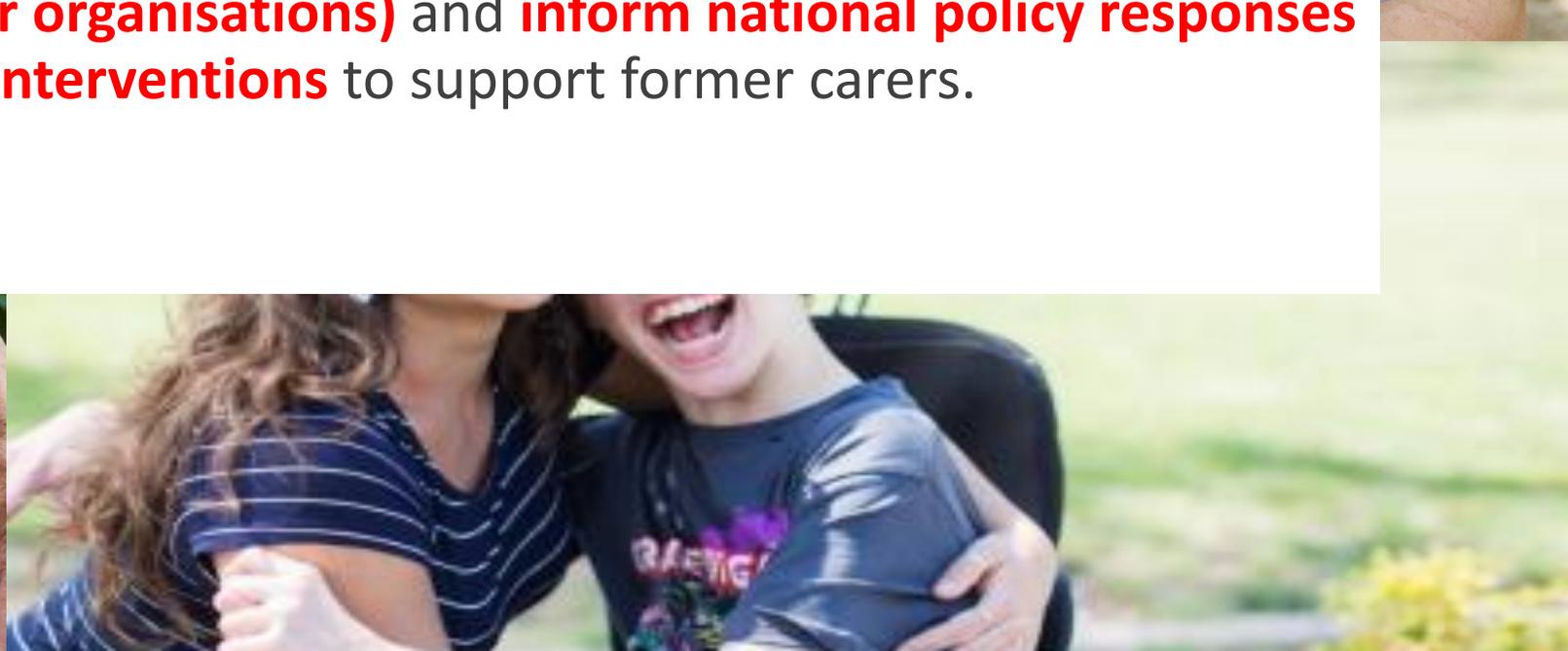
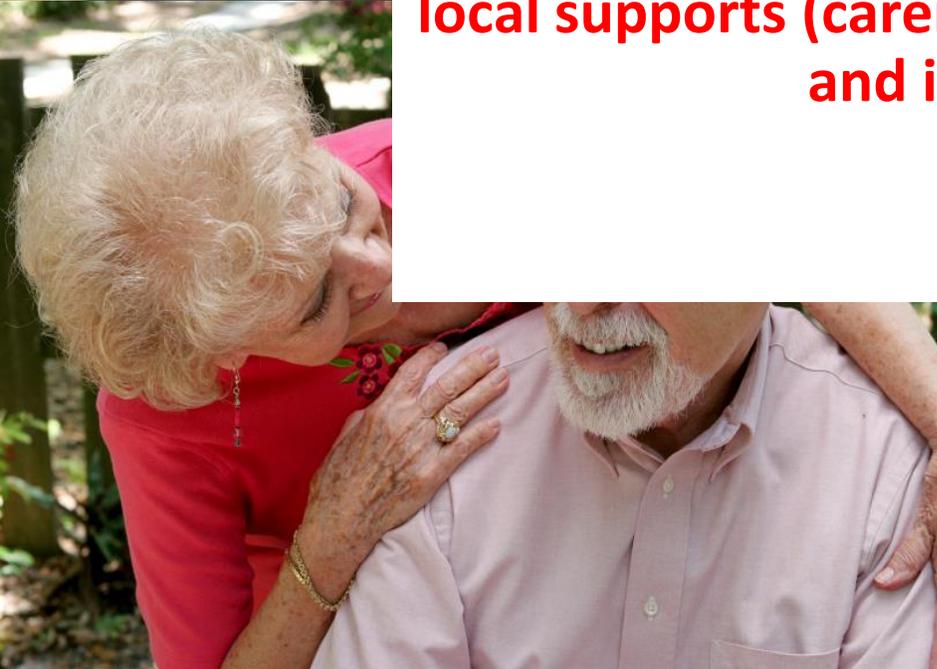
carol.kelleher@ucc.ie

SUPPLEMENTARY SLIDES



Project objective:

to highlight the **voices, experiences** and **needs of former family carers** in the **post-caring/care transitions period** in order to **co-develop** appropriate **local supports (carer organisations)** and **inform national policy responses and interventions** to support former carers.



POSTCARE: Methodology

Irish Research Council /The Wheel New Foundations 2016

Qualitative **participatory action research project** (August 2016 – October 2017):

- West Cork Carers Support Group (Sally Ann Back)
- Family Carers Ireland (Paul O' Mahoney)
- Care Alliance (Zoe Hughes/Liam O' Sullivan)

Engaged research - advanced *with* community partners rather than for them.

- Planned discussion with research participants and co-creation of research question, design, responses to research findings, policy recommendations, former carer awareness film, life coaching workshop and public policy workshop



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POSTCARE: Methodology

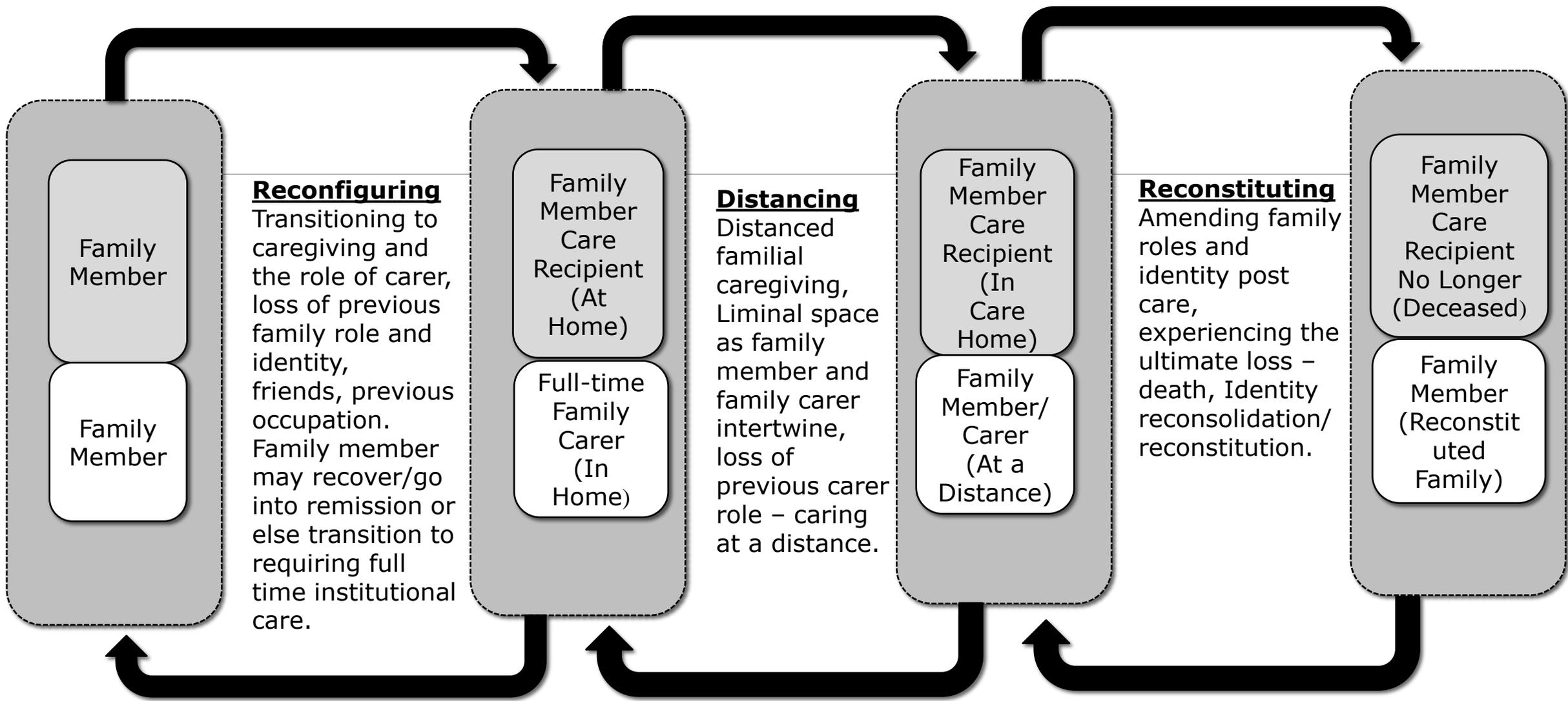
1. **Jointly agreed project brief** (August 2016).
2. A **review/benchmarking analysis of post-caregiving literature**, supports and best practice.
3. **One-to-one in-depth interviews (16)** and **video interviews (4)** with volunteers from the partner CVOs.
4. **Participant/CVO feedback sessions to discuss initial findings** (June 2017).
5. Development of **peer support video/film by former carers** for carer, (August 2017).
6. **Interactive public policy workshop** with participants/CVOs to discuss initial findings (November 6th, 2017).
7. **Life Coaching workshop for former carers** (19th October 2017).



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(Separate Care Alliance led follow up project - Former Carers Support Leaflet – commencing October 2017)



Findings – Move from post caregiving → Multiple trajectories/transitions



Earlier research - caregiving research and practice has **typically not viewed the post-caregiving stage** (i.e. when the caring role has ceased) as part of the larger care giving life course (Orzeck and Silverman 2008).

Extant research - Post caregiving – staged approaches:

- Larkin (2009) - three distinct stages, namely, ‘the post-caring void’, ‘closing down the caring time’ and ‘constructing life post-caring’. These phases are not experienced in a linear way but overlap.
 - Half of those in Larkin’s (2009) research who returned to work changed their career in order to undertake paid employment associated with caring.
- Three stages (McCarron et al. 2011) - Loss of Caring Role, Living with Loss, Moving On

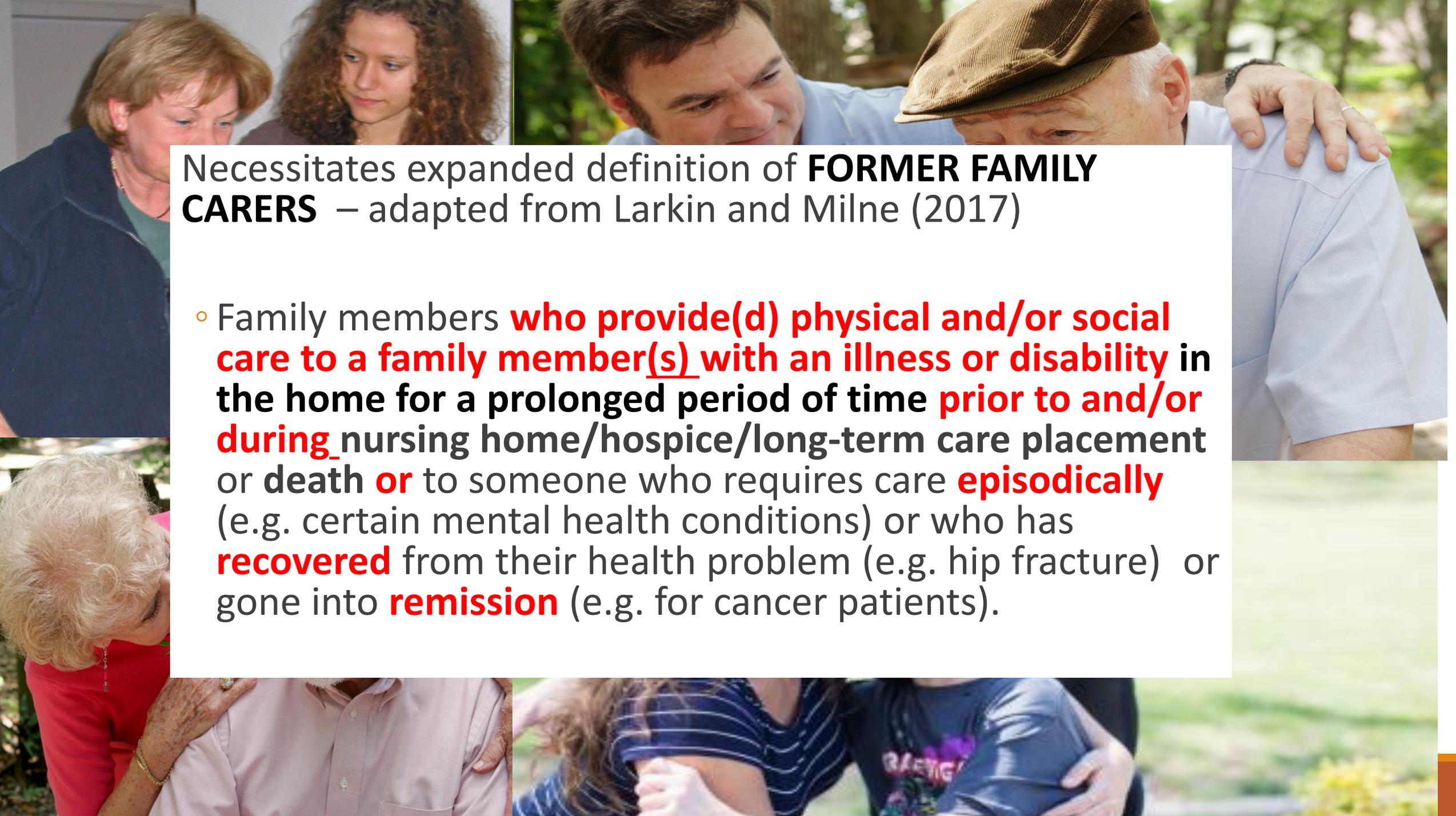
Findings – Move from post caregiving → Multiple trajectories/transitions



Others (Larkin and Milne 2017) see term postcare as problematic and restrictive – **formality** of role at end of caregiving stage.

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 i.e. 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)



Necessitates expanded definition of **FORMER FAMILY CARERS** – adapted from Larkin and Milne (2017)

- Family members **who provide(d) physical and/or social care to a family member(s) with an illness or disability in the home for a prolonged period of time prior to and/or during** nursing home/hospice/long-term care placement or **death** or to someone who requires care **episodically** (e.g. certain mental health conditions) or who has **recovered** from their health problem (e.g. hip fracture) or gone into **remission** (e.g. for cancer patients).

Move from post caregiving → supporting multiple transitions



- Need to consider the situated multiple and cumulative transitions throughout the caregiving lifecourse include identity rebuilding.
- To do this we need to consider **both the role-based AND person based identity transitions** of family carers
 - **Role based identity**
 - Socially constructed definition(s) of self-in-role (Ashforth, Kreiner and Fugate 2000), a persona that one may enact (Ashforth 2001).
 - **Person-based identity**
 - Personal qualities of the role occupant that bear on the enactment of the role-based identity, no two role enactments are identical (Currie, Finn and Martin 2010).

Move from post caregiving → supporting multiple transitions

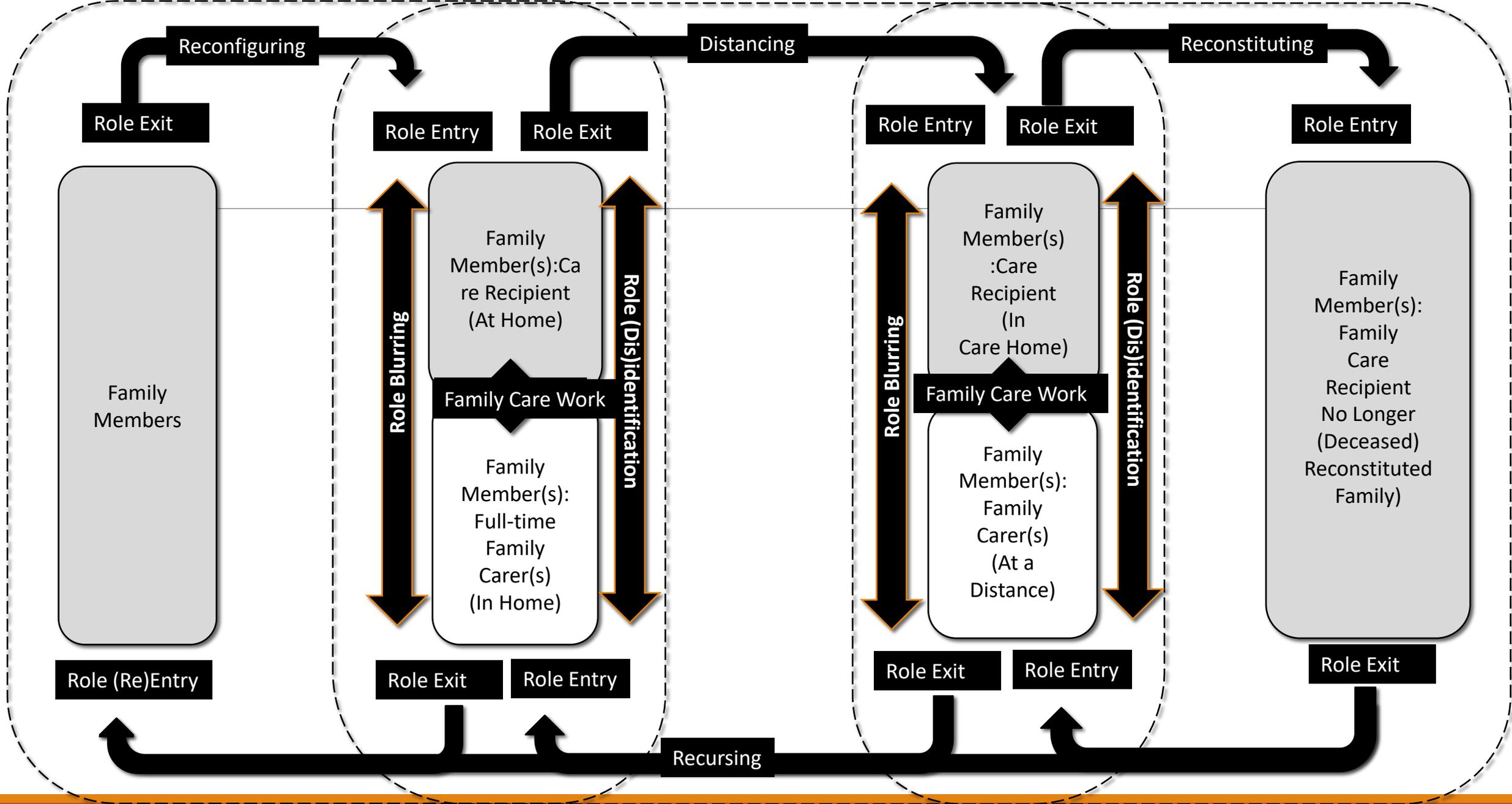


To understand and support current and former carers, need to consider the:

- **Integration of role-based and person-based identities → Relational identities** (Simpson and Carroll 2008; Järventie-Thesleff and Tienari 2016).
- **Multiple transitions - entry and exit into caring roles – continuous and evolving**
- **-> supports required for each of the six routes to becoming a former carer.**

Empirical Findings:

- **POSTCARE report** (copies available)
- **Summary** <https://vimeo.com/233311474> (9 mins)



Multiple role and identity transitions, staged and recursive routes to becoming a former carer, overlapping, fluid.



Discussion: Role and Identity Transition

- **Multiple routes to becoming a former carer** comprising multiple and overlapping role and identity transition phases
 - **Uncertainty** -“normal”, “expected” (Moss and Moss 2012).
 - **Cumulative, multifaceted, prolonged, layered.**
 - **Liminality - multi-directional, cyclical transitions** (Barnhart, Huff and Cotte 2014; Hirschman, Ruvio and Belk 2012).
 - Death of the care-recipient – just one stage in a journey of multiple transitions (Orzeck and Silverman 2008).
- Former carers **more than a “convenient” shadow workforce** (Bookman and Harrington 2007) **facilitating aging in place policies – to be pushed into employment once the caring role ceases Vs. Relational identities count.**



Project outputs: Co-creating responses and interventions together

Voices of former carers

- **Presentation of findings to former carers** - Interactive workshops Bantry/Clonakilty (June 21 2017)
- Built on insights/wish list in practical ways – what can Carer Associations do, what must policy makers do
 - **Carer Associations:**
 - Specific Information for Former Carers and **Signposting** – Separate Care Alliance Led Project - Updating of **Life After Care Booklet**
 - **Updating CVO Website, Handbook and other Training Material Carer Association**
 - Development and dissemination of **peer support/awareness videos** by former carers for carers
 - **Life Coaching Workshop** – 19th October 2017
 - Introduction of **counselling initiative** and **awareness raising amongst healthcare professionals**



Next steps: Co-creating responses and interventions together

Policymakers and public awareness

- **Carer led diverse supports** for other carers – **input into policy making** (e.g. DAF call and other forums)
- **Aggregated report** – all stakeholders and IRC - 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.
- **One day interactive public workshop** with participants/CVOs, expert speakers, policy maker and media – 6th November UCC (open invitation!)

Other

- **European Sociological Association Conference** – Athens August 2017
- **International Carers Conference (Policy Maker Focus)** - Care Alliance Presentation – October 2017
- **Association of Consumer Research Conference** October 2017



Conclusions

- **Postcaregiving – formerality vs recursivity**
- **Multiple role and identity transitions** (*Boerner and Schultz 2009*) – implies multiple and varied ongoing social, economic, psychological and financial supports appropriate to each stage/transition.
- Caregiving can be a source of **chronic stress** for the duration of the caregiving period (six routes to becoming former carer), **implying intensive identity rebuilding within and beyond family networks on cessation of the caring role** (*Orzeck and Silverman 2008*).
- **Over time, a sense of renewal / positive gain may emerge as former carers refashion identities within/beyond the family** (*Bonanno 2004; Ong et al. 2014*).