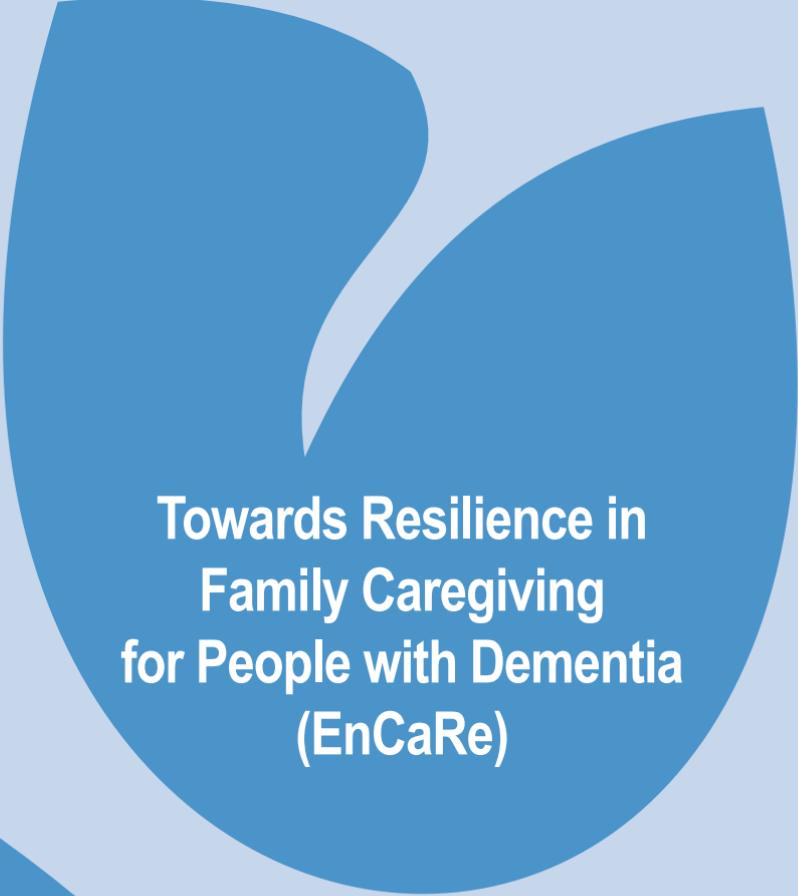


Guiding support for family carers



**Towards Resilience in
Family Caregiving
for People with Dementia
(EnCaRe)**



March 2019



Towards Resilience in Family Caregiving for People with Dementia (EnCaRe) – A Description of the Project

March 2019

Executive Summary

This report describes the 'Towards resilience in family caregiving for people with dementia' project that took place between November 2015 and early 2019. This project resulted in the development of a resilience-enhancing resource for family carers that has reached large numbers of family carers and will continue to reach more over the coming years.

The researchers initially explored recent publications about family caring, dementia and the concept of resilience in family carers of people with dementia. A postal survey of family carers was also carried out.

The research involved the establishment of a group of volunteer current and former dementia family carers, which became known as the 'Enhancing Carer Resilience' (EnCaRe) group. The EnCaRe group and members of the research team (see Appendix I) discussed at length the concept of resilience and developed a definition of resilience. The group also developed a resilience-enhancing programme grounded in carers' own experiences and perspectives.

The research team carried out a feasibility study of the EnCaRe Programme through a demonstration to a group of current family carers of people with dementia. The objective was to establish if the resource achieved what it was designed for, namely, to provide a good quality and easy-to-use information resource which could act as support to family carers of people with dementia. The study was carried out by running three workshops involving family carers, and involved testing the website in relation to its usability and the quality of the online materials. The researchers also conducted several regional workshops around Ireland for family carers of people with dementia as part of the 'Knowledge Exchange and Dissemination Scheme' (KEDS).

Two webinars detailing the project resources were also delivered to health and social care professionals and to family carers.



Take Care of Yourself





Project Description

This applied research project began in November 2015 and was completed in early 2019. Funding was provided by the Health Research Board in Ireland (HRB) under the Applied Research in Dementia Programme, funded by the Department of Health and Atlantic Philanthropies. The project was hosted by University College Dublin (UCD), working with other organisations. The focus was on developing caregiver resilience to ensure that the family carer is a sustainable resource for dementia care in Ireland. When resilience is increased in family carers¹ of people with dementia, they are more likely to have a positive experience of caregiving.² Resilience includes the ability to use family, social and external support systems as a way of coping with stressors. Several social, or 'external', factors contribute to building greater resilience including family and social networks and support from the wider community,³ while secure interpersonal relationships are an important source of emotional support.⁴



When resilience is increased in family carers of people with dementia, they are more likely to have a positive experience of caregiving.

The researchers aimed to develop a resilience-enhancing programme specifically designed for caregivers of people with dementia, based on a real-world description of resilience in dementia caregiving. The research approach was grounded in participatory action, that is, with the active involvement of those affected, to ensure that the programme was created jointly by carers and researchers and driven by the perspectives of carers.

It was thought sensible to carry out a review of the existing research literature. The purpose of the literature review was to ensure that the research conducted conforms

¹ Census 2016 defines carers as "people who provide regular unpaid personal help for a friend or family member with a long-term illness, health problem or disability". For the purposes of clarity and simplicity, we use the term 'family carer/carer' interchangeably in this document. Whilst the vast majority of unpaid care is provided by family members, we do not wish to exclude from our definition others who also provide unpaid care such as neighbours, friends and or partners. We also acknowledge that terms such as unpaid carer and informal carer are used extensively.

² Shim, B., Barroso, J., & Davis, L. L. (2012). A comparative qualitative analysis of stories of spousal caregivers of people with dementia: Negative, ambivalent, and positive experiences. *International journal of nursing studies*, 49(2), 220-229. Abir K. Bekhet and Jennifer Sjostedt Avery, 'Resilience from the Perspectives of Caregivers of Persons with Dementia', *Archives of Psychiatric Nursing* 32, no. 1 (2018): 19–23, <https://doi.org/10.1016/j.apnu.2017.09.008>.

³ Linda Ryan and Marie L. Caltabiano, 'Development of a New Resilience Scale: The Resilience in Midlife Scale (RIM Scale)', *Asian Social Science* 5, no. 11 (19 October 2009), <https://doi.org/10.5539/ass.v5n11p39>.

⁴ G. M. Wagnild and H. M. Young, 'Development and Psychometric Evaluation of the Resilience Scale', *Journal of Nursing Measurement* 1, no. 2 (1993): 165–78.

to contemporary theories and research. Alongside this, the literature review ensures that the researchers are aware of other ideas in the specific field. The literature review also ensures that the author is adding something new and worthwhile to the field of study or is strengthening existing arguments.

Following a thorough, systematic review of the current literature, a postal survey was carried out, to which over 400 family carers across Ireland responded. Through this survey, the researchers discovered a number of factors that are associated with family carers becoming more resilient. For example, family carers who have a good or 'high-quality' relationship with their care recipient are more likely to be resilient than those carers who do not have a good relationship with their care recipient.



Family Carers who have a good or 'high-quality' relationship with their care recipient are more likely to be resilient than those carers who do not have a good relationship with their care recipient.

The research team then established a network of volunteer family carers and former carers to be actively involved in the research. The team called the network of family carers the Enhancing Resilience in Family Carers (EnCaRe) group. Involving carers in this way is known as participatory action research⁵ and is a way for families and those affected by illnesses such as dementia to be involved in research that has direct relevance to them. For this reason, the research had considerable potential to contribute to the understanding of some of the realities of family life as affected by dementia.

The EnCaRe group met on 11 occasions between May 2017 and April 2018. Two members of the team facilitated each group meeting. The group also invited experts to talk about family caring in dementia and to conduct workshops. The workshops involved the family carers and the research team engaging in discussions and activities to gain a deeper understanding of the concept of resilience and its relation to family carers. In particular, the group defined a concept of resilience and discussed what made a family carer resilient. It also came to a consensus that the definition of resilience is ever-changing, and depends on the carer's circumstances. The group agreed that resilience was the ability to 'bounce back' from hardship or misfortune

⁵ Fran Baum, Colin MacDougall, and Danielle Smith, 'Participatory Action Research', *Journal of Epidemiology and Community Health* 60, no. 10 (October 2006): 854–57, <https://doi.org/10.1136/jech.2004.028662>.



and in that way to get on with life; however, the group also understood resilience as a changing concept in relation to family caring, one that could evolve over time. Having agreed on a definition of resilience, the group planned the design and development of a resource specifically designed for family carers of people with dementia. The resource consists of a website containing short videos of family carers' own stories of caring for a family member with dementia, and information on a range of resources and supports. The resource and website are called 'Take Care of Yourself' (TCOY) and are available to access on www.takecareofyourself.ie.



The group agreed that resilience was the ability to 'bounce back' from hardship or misfortune and in that way to get on with life; however, the group also understood resilience as a changing concept in relation to family caring, one that could evolve over time

In addition to publishing journal articles and making presentations at a range of events (for example at a nursing conference and a gerontology conference), the team developed a suite of web-based resources and supports and a small booklet.⁶ The TCOY website⁷ and booklet were developed with the aim of enhancing carer resilience in family caregivers of people with dementia.

To support the spread of information about the new resource and to get further insight from family carers, the team also hosted five regional workshops and one webinar (a seminar conducted over the Internet). The workshops also aimed to secure feedback on the TCOY website and booklet and to allow participants to share their own experiences of resilience and family caring.

Previous family carer studies in Ireland focused on carers in receipt of Carer's Allowance for research and survey participation. Carer's Allowance is a means-tested income support and, as such, a large proportion of full-time family carers do not qualify for it. To ensure a wider pool of participants, a particular focus of recruitment for the workshops and webinar was people not in receipt of Carer's Allowance. The website went live in October 2018 and by the end of that year there were over 1,100 unique visitors to the website resource. The website was promoted primarily

⁶ 'Take Care of Yourself Booklet' (University College Dublin, November 2018), <http://www.carealliance.ie/userfiles/file/EnCaRe%20Brochure%20Participants%20Final.pdf>.

⁷ 'Take Care of Yourself', 2018, <https://www.takecareofyourself.ie/>.

through targeted Facebook advertisements and other social media fora and managed by Care Alliance Ireland. Throughout 2019 Care Alliance Ireland will continue to actively promote the spread of knowledge about the new resource, working with The Alzheimer Society of Ireland.



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Dementia and Caring

In 2012 the World Health Organization named dementia a public health priority.⁸ Recent estimates of the number of people with dementia in Ireland range between 41,000 and 55,000. These figures are expected to rise significantly by 2050.⁹ While old age remains the strongest risk factor for developing dementia, it is estimated that approximately 4,000 people under 65 years of age live with dementia in Ireland.¹⁰

Dementia affects a person's mental and social abilities, including the ability to think clearly, remember and form relationships, and also leads to a decline in physical health. Most people with dementia are cared for at home by a family member.¹¹ Dementia is an overall term for a set of symptoms that are caused by disorders affecting the brain. The symptoms may include memory loss and difficulties in problem solving or language usage, and can be severe enough in some cases to reduce a person's ability to perform everyday activities.

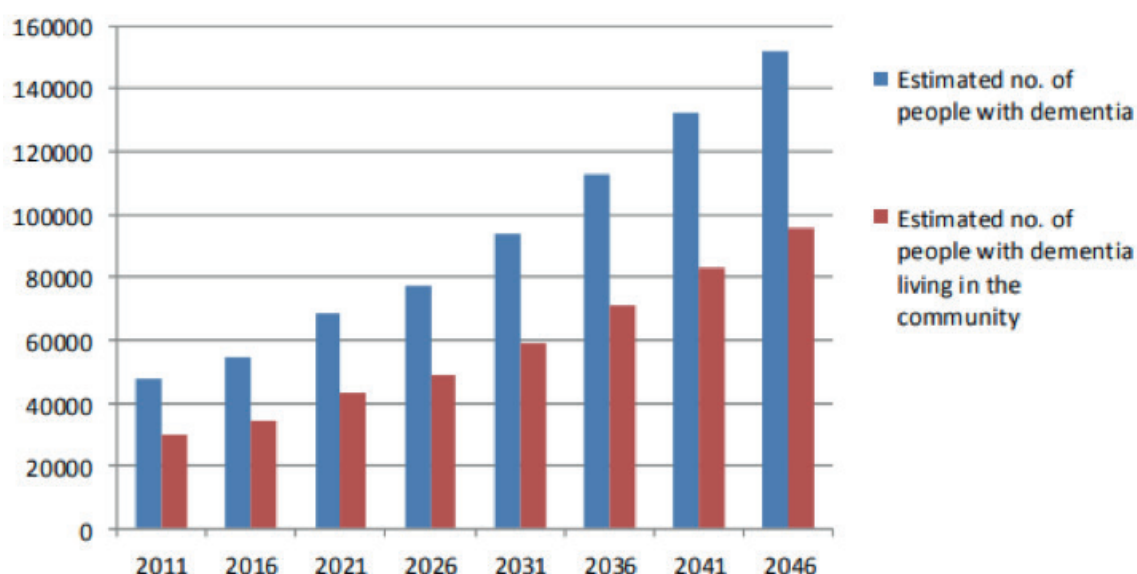


Figure 1: Estimated number of people in Ireland with dementia and living in the community, 2011–2046 (Pierce et al. 2014)

⁸ WHO, *Dementia: A Public Health Priority* (Geneva, 2012).

⁹ Pierce, Cahill, and O'Shea, 'Planning Dementia Services: New Estimates of Current and Future Prevalence Rates of Dementia for Ireland', *Irish Journal of Psychological Medicine* 30, no. 1 (March 2013): 13–20, <https://doi.org/10.1017/ipm.2012.3>.

¹⁰ Dept of Health, 'The Irish National Dementia Strategy', 2014, <https://health.gov.ie/wp-content/uploads/2014/12/30115-National-Dementia-Strategy-Eng.pdf>.

¹¹ Ibid

The most common types of dementia are Alzheimer's disease, vascular dementia, dementia with Lewy bodies, and frontotemporal lobar degeneration, and each affects the brain in different ways and causes different changes at various cognitive levels.¹² The incidence of dementia rises with age, making it increasingly common within the ageing population. The nature of the symptoms means that people with dementia are more dependent and vulnerable, both socially and in terms of physical and mental health, presenting evolving challenges for the people affected, their families, society and healthcare systems.¹



Image 1: Caring for someone with dementia (ASI)

People with dementia are more likely to remain in their own home for longer if their carers can adapt to the physical and psychological demands of caring and are able to cope and adjust; we call these abilities 'resilience'. Given the challenges associated with family caregiving in dementia, improving carers' resilience can ensure that carers are more connected socially and more resourceful in accessing services and supports. This in turn could reduce the burden and isolation of their role. The reduction of burden and isolation is a stated vision in the Government's National Carers' Strategy.¹⁴

¹² S. Shimohama, 'Dementia', *Journal of the Neurological Sciences*, Abstracts from the World Congress of Neurology (WCN 2017), 381 (15 October 2017): 9, <https://doi.org/10.1016/j.jns.2017.08.053>.

¹³ Emma L. Cunningham et al., 'Dementia', *Ulster Medical Journal* 84, no. 2 (2015): 79.

¹⁴ Dept. of Health, 'The National Carers' Strategy' (Ireland, 2012), 2, <https://health.gov.ie/wp-content/uploads/2016/02/National-Carers-Strategy.pdf>



In its strategy document entitled *Future Health*, the Department of Health identified that a key aim of dementia care is to enable people with dementia to stay at home for longer, rather than go into residential care. Since there is a greater emphasis on ensuring that people stay at home for as long as possible, there is also a greater need to ensure that family carers are resilient to allow them to face potential carer burden and to continue to care. Family carers must also be allowed the opportunity to take care of themselves and to live their own lives outside their caring role, hence the growing need for a resilience-enhancing resource specifically designed for caregivers of people with dementia.



Image 2: Family carers need support (The Alzheimer Society of Ireland)

Family Carers in Ireland

Family carers have traditionally assumed caring responsibility for dependent older relatives, and it is anticipated that, as the population of older people increases, there will be a corresponding increase in society's reliance on family carers to care for dependent older people, including people with dementia.

A recent national survey of over 2,300 family carers of older people in Ireland reported that a fifth of carers in the sample (n=485) were caring for a person with dementia.¹⁶ The study authors reported that almost half of the carers provided 80 hours or more of care per week and a third provided care for between 40 and 80 hours.¹⁷ Ireland's most recent Census (CSO, 2016) defines a 'carer' as someone who 'provides regular, unpaid professional help for a friend or family member with a long-term illness, health problem or disability, including problems which are due to old age. Personal help includes help with basic tasks such as feeding and dressing.'¹⁸



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Family carers (sometimes called 'informal' or 'unpaid' carers in the literature) have various relationships with those they care for: they can be the spouse/partner, parent, sibling, friend or child of the care recipient. It is often difficult to identify those receiving care, and even more difficult to identify family carers in the caregiving role. One report found that 86% of carers are family members, with most caring for an ageing parent or a child with high support needs. Females were found to provide around two-thirds of all care hours, increasing to approximately seven in ten hours from age 50, but 40% of family carers are male. There are approximately 360,000 unpaid carers in Ireland, or 10% of the adult population. Carers provide an average of 44.6 hours of unpaid care per week. The financial contribution to the economy of such care has been estimated to amount to upwards of €10bn per year.¹⁹

¹⁶ Lafferty et al., 'Family Carers of Older People: Results of a National Survey of Stress, Conflict and Coping', 2014, https://www.ncpop.ie/userfiles/file/ncpop%20reports/Carers%202014/NCPOP_Family%20Carers%20of%20Older%20People%202014pg%20A4%20FINAL%20PREVIEW_4th%20June%202014.pdf.

¹⁷ Ibid

¹⁸ Central Statistics Office, 'Census 2016', 2017.

¹⁹ Care Alliance Ireland, 'Family Carers in Ireland: Infographic' (October 2017).



Who Cares?

360,000 or
10% of the adult
population

(CSO, 2016a)

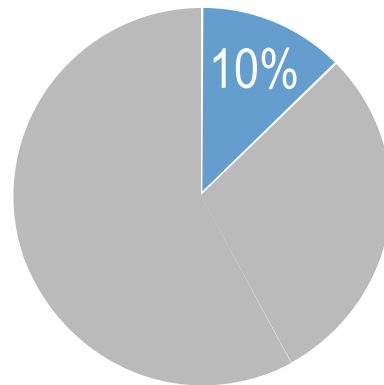


Image 3:

How many family carers? (Care Alliance)



There are approximately 360,000 unpaid carers in Ireland, or 10% of the adult population.

Challenges Affecting Family Carers

A 2017 study of carer wellbeing carried out by The Alzheimer's Society of Ireland (ASI), Trinity College and the Health Research Board (HRB) indicates that 40% of carers experienced mild-to-moderate burden or perceived stress due to the caring role, while 36% experienced moderate-to-severe levels of burden. Such care burden can impact negatively on carers' health putting the carer at risk of burn-out and the person with dementia at risk of neglect. Research carried out in 2009 found that the two strongest reasons for admission to care homes are whether the older person has dementia and whether or not their family carer is coping.²⁰



A 2017 study of carer wellbeing carried out by The Alzheimer's Society of Ireland (ASI), Trinity College and the HRB indicates that 40% of carers experienced mild-to-moderate burden or perceived stress due to the caring role, while 36% experienced moderate-to-severe levels of burden.

With such a heavy responsibility placed on family carers, it is no surprise that over half of carers had a medical problem, with the most frequent being back injury, and that most carers reported that they had no time for themselves due to caring responsibilities. One of the biggest fears carers had was how the person they cared for would cope if they could no longer care due to illness or death.²¹

Caring for someone with dementia can be challenging for carers, often affecting their health and their ability to maintain normal social relationships outside the home. This can lead to the carer becoming unwell and socially isolated, feeling that they are left to care alone and forgotten. This can affect the carer's ability to be an active member of society.²²

²⁰ Jacobs et al. (2009) 'Modernising Social care Services for Older People', *Ageing and Society*, 29, no. 4: 497–538.

²¹ College of Psychiatry of Ireland and Carers Association of Ireland, 'Carers of Ireland – Who Cares?', November 2009, <https://www.irishpsychiatry.ie/wp-content/uploads/2017/12/Carers-survey-final-analysis-summary-booklet-nov-09-2.pdf>.

²² Lafferty et al., 'Family Carers of Older People: Results of a National Survey of Stress, Conflict and Coping', 66.



What Is the Financial Contribution of Family Carers?

€10bn per year (FCI, 2017)

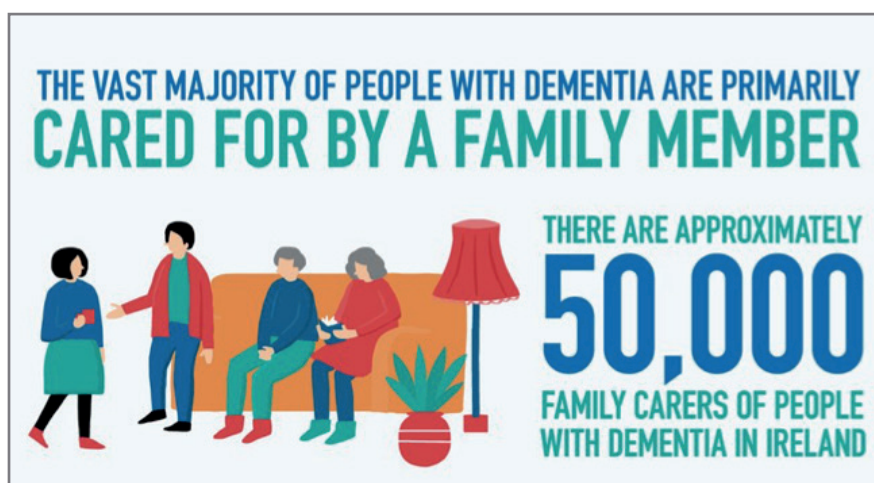


Image 4:
Financial contribution
of family carers
(Care Alliance)

This description of the 'Towards Resilience' project summarises the various impacts of dementia on carers:²³

The Irish National Dementia Strategy recognises that dementia can adversely affect carers' health, social and economic circumstances and relationships, and stresses the importance of 'a whole community approach' in which social connectedness and social environments are the means of ensuring that remaining at home with dementia is a feasible option.²⁴ These outcomes can be achieved if the carer is more resilient, that is, has the resources to counterbalance the negative effects of adversity and make positive adaptation to the demands of caregiving.²⁵ Resilience is a function of the individual's internal resources, such as self-efficacy, and the ability to use external resources, such as services and family and other social support systems as a way of coping with stressors of caregiving.²⁶

Image 5:
Dementia
Family Carers
(ASI)



²³ See <https://www.nmhs.ucd.ie/clinical-engagement/towards-resilience-family-caregiving-people-with-dementia-encare>

²⁴ Dept of Health, 'The Irish National Dementia Strategy', 22. (2014)

²⁵ Cherry et al., 'Factors Influencing the Resilience of Carers of Individuals with Dementia', *Reviews in Clinical Gerontology* 23, no. 4 (November 2013): 252, <https://doi.org/10.1017/S0959259813000130>.

²⁶ Linda, R., & Caltabiano, M. (2009). Development of a new resilience scale: The Resilience in Midlife Scale (RIM Scale). *Asian Social Science*.

Resilience in Family Carers

Despite the challenges facing carers, family caregiving can be a positive and enriching experience. However, many carers find themselves in difficult, challenging and demanding caregiving roles. Lafferty et al. report that a third of carers experienced moderate-to-severe burden and that more than two in every five were at risk of developing clinical depression. Carers who were female, younger and caring for individuals with more severe behavioural and psychological symptoms reported poorer sleep quality.²⁷ However, not all carers experience burden, depression or other negative psychosocial effects of caregiving. Such carers may be considered resilient, that is, they are able to recover from, resist or adapt to the physical and psychological demands of caring.²⁸



Not all carers experience burden, depression or other negative psychosocial effects of caregiving. Such carers may be considered resilient, that is, they are able to recover from, resist or adapt to the physical and psychological demands of caring.

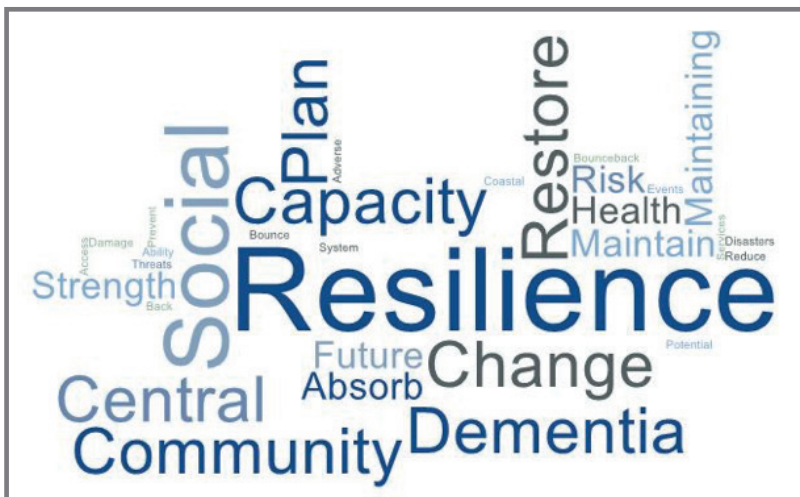


Image 6:
Resilience
word map
(Care Alliance)

²⁷ Lafferty, A., Fealy, G., Downes, C., & Drennan, J. (2014). Family Carers of Older People: Results of a national survey of stress, conflict and coping. NCPop, University College Dublin.

²⁸ See https://www.nursingcenter.com/journalarticle?Article_ID=3467153&Journal_ID=3425880&Issue_ID=3466946
Original source: Herrman, Stewart, and Diaz-Granados, 'What Is Resilience?', *Canadian Journal of Psychiatry* 56, no. 5 (2011): 8.



Carers who care for spouses with dementia and who are more resilient are less likely to experience depression over time,²⁹ and resilience is considered an important factor in suicide prevention.³⁰

The original (2015) proposal for this project, detailed below, outlines in further detail the concept of resilience.

As a construct, 'resilience' emerged from the discipline of developmental psychology and, while research on resilience has increased substantially over the past two decades, the focus has been mainly on children and adolescents. Windle et al. (2011) developed an operational definition of resilience in adults, defining it as 'the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma', or the capacity for adaptation in the face of adversity. Being resilient involves having assets or resources to counterbalance the effects of significant adversity and subsequent positive adaptation or avoidance of negative outcomes.³¹

Studies involving unpaid carers have been unable to explain why some cope well in the face of adversity while others cope less well. Cherry et al. (2013) examined the factors, materials and resources associated with resilience among carers of people with dementia and found that three interrelated factorial domains influence carer resilience. These were: social and cultural factors, such as gender and ethnicity; properties of the care relationship, such as kinship ties, social and formal support; and carers' psychological factors, including attachment style, personality traits, and sense of meaning.³² Given the progressive deterioration in cognitive, somatic and social functioning associated with dementia, caregiving is characterised by 'continuous adjustment and adaptation';³³ hence caregiver resilience is central to how well a carer adjusts and adapts to the challenges of caregiving.

Resilience includes the ability to use family, social and external support systems as a way of coping with stressors. Several social, or 'external', factors contribute to building greater resilience including family and social

²⁹ Norm O'Rourke et al., 'Psychological Resilience Predicts Depressive Symptoms among Spouses of Persons with Alzheimer Disease over Time', *Aging & Mental Health* 14, no. 8 (1 November 2010): 984–93, <https://doi.org/10.1080/13607863.2010.501063>.

³⁰ Judith Johnson et al., 'Resilience to Suicidality: The Buffering Hypothesis', *Clinical Psychology Review* 31, no. 4 (1 June 2011): 587, <https://doi.org/10.1016/j.cpr.2010.12.007>.

³¹ Gill Windle, Kate M. Bennett and Jane Noyes, 'A Methodological Review of Resilience Measurement Scales', *Health and Quality of Life Outcomes* 9, no. 1 (4 February 2011): 8, <https://doi.org/10.1186/1477-7525-9-8>.

³² Cherry, M. G., Salmon, P., Dickson, J. M., Powell, D., Sikdar, S., & Ablett, J. (2013). Factors influencing the resilience of carers of individuals with dementia. *Reviews in Clinical Gerontology*, 23(4), 251-266.

³³ Dept of Health, 'The Irish National Dementia Strategy', 22. (2014)

networks and support from the wider community whereas self-efficacy is one of the 'internal' factors associated with resilience,³⁴ While secure interpersonal relationships are also an important source of emotional support.³⁵



Being resilient involves having assets or resources to counterbalance the effects of significant adversity and subsequent positive adaptation or avoidance of negative outcomes.

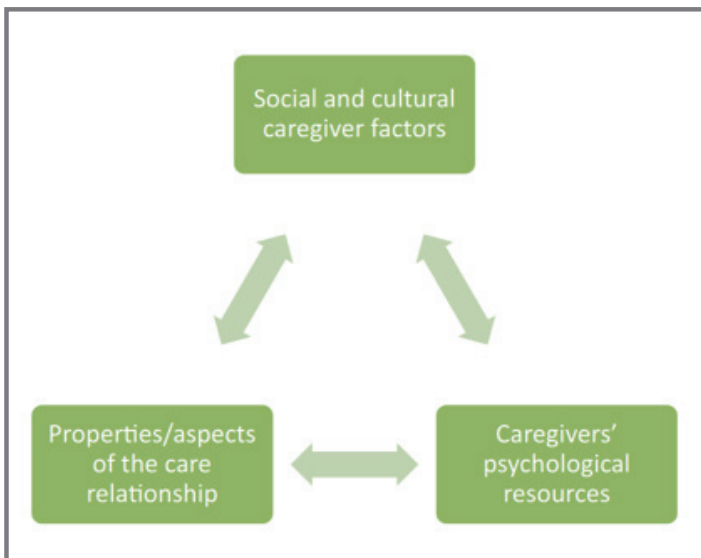


Image 7:
Model of factors
influencing resilience
(Cherry et al. 2013)

The National Dementia Strategy stresses the importance of promoting dementia-friendly communities that are supportive and that adapt to the particular needs of people with dementia so that they can take part as fully as possible in society. Good quality support and relationships have been found to be related to less adverse caregiving experiences and better carer adjustment³⁶ and to benefit caregiver resilience.³⁷

The Strategy incorporates several elements relating to family carers. Among these is the principle that 'as much support as possible should be given to informal and

³⁴ Linda, R., & Caltabiano, M. (2009). Development of a new resilience scale: The Resilience in Midlife Scale (RIM Scale). *Asian Social Science*.

³⁵ Wagnild, G. M., & Young, H. M. (1993). Development and psychometric evaluation of the Resilience Scale. *Journal of Nursing Measurement*, 1(2), 165-178.

³⁶ Kenneth I. Pakenham et al., 'Relations between Social Support, Appraisal and Coping and Both Positive and Negative Outcomes in Young Carers', *Journal of Health Psychology* 12, no. 1 (January 2007): 89-102, <https://doi.org/10.1177/1359105307071743>.

³⁷ Windle, Bennett, and Noyes, 'A Methodological Review of Resilience Measurement Scales'.



family carers who care for people with dementia at home'³⁸ and, accordingly, a combination of formal and informal supports offers the best opportunity to produce the best outcome for the person with dementia and their carers. The Strategy also emphasises the 'dual and overarching principles' of personhood and citizenship which may be promoted through enabling people with dementia to maintain their identity, resilience, dignity and independence as citizens. People with dementia and their carers 'have the right to be fully included as active citizens in society'.³⁹



A combination of formal and informal supports offers the best opportunity to produce the best outcome for the person with dementia and their carers.

It is proposed that maximising carers' resilience and social connectedness is a practical way of enabling carers to make positive adaptation and to forestall the negative impact of caregiving.⁴⁰ Given the challenges associated with family caregiving in dementia, maximising carers' resilience and social connectedness can ensure that they continue to be more connected socially and more resourceful in accessing services and supports to which they are entitled, and that in this way they experience caregiving as less burdensome and isolating.

³⁸ Department of Health, 'The Irish National Dementia Strategy', (2014).

³⁹ Department of Health, 'The Irish National Dementia Strategy', (2014).

⁴⁰ Windle, G., Bennett, K. M., & Noyes, J. (2011). A methodological review of resilience measurement scales. Health and quality of life outcomes, 9(1), 8.

Stage 1: Systematic Review – Resilience and Caregiving ⁴¹

As part of this project a systematic literature review was conducted to explore resilience as it applies to and impacts on caregiving.

Systematic reviews are a type of literature review that use systematic methods to collect secondary data, critically review research studies, and combine studies in a coherent way. Systematic reviews are used to design research questions that may be broad or narrow in scope. They are designed to provide a complete and exhaustive summary of current work and evidence relevant to the question being investigated. In this study, peer-reviewed articles and grey literature (which is material or research produced by organisations outside of traditional commercial or academic publishing channels, such as working papers, government documents and reports) published from 2006 to 2016 were included in the systematic search criteria, and searched for using a range of scholarly databases. Two independent reviewers pre-screened the search results and conducted formal assessments and quality appraisals of the retrieved articles.



Systematic reviews are a type of literature review that use systematic methods to collect secondary data, critically review research studies, and combine studies in a coherent way.

String 1	Dementia OR Alzheimer OR "Vascular dementia" OR "Lewy bodies" OR "Frontotemporal dementia" OR Korsakoff OR "memory loss" OR "mild cognitive impairment"
String 2	Carer OR caregiver OR care-giver OR caregiving OR family OR relative OR kinship OR informal OR spousal OR spouse OR wife OR husband OR daughter OR son OR brother OR sister
String 3	Resilience OR resiliency OR resilient OR protective factors OR burden OR "well-being" OR wellbeing OR "well being" OR health OR "self-efficacy" OR management OR adapting OR interpersonal OR intrapersonal OR self-esteem OR "quality of life" OR "sense of coherence"
Final search	(Dementia OR Alzheimer OR "Vascular dementia" OR "Lewy bodies" OR "Frontotemporal dementia" OR Korsakoff OR "memory loss" OR "mild cognitive impairment") AND (Carer OR caregiver OR care-giver OR caregiving OR family OR relative OR kinship OR informal OR spousal OR spouse OR wife OR husband OR daughter OR son OR brother OR sister) AND (Resilience OR resiliency OR resilient OR protective factors OR burden OR "well-being" OR wellbeing OR "well being" OR health OR "self-efficacy" OR management OR adapting OR interpersonal OR intrapersonal OR self-esteem OR "quality of life" OR "sense of coherence") (2006-2016) (English language)

Table 1: Search terms (Teahan et al. 2018)

⁴¹ We thank the authors for their permission to re-print significant parts of their report. For further details of this systematic review see Áine Teahan et al., 'Resilience in Family Caregiving for People with Dementia: A Systematic Review', *International Journal of Geriatric Psychiatry* 33, no. 12 (2018): 1585, <https://doi.org/10.1002/gps.4972>. <https://www.ncbi.nlm.nih.gov/pubmed/30230018>

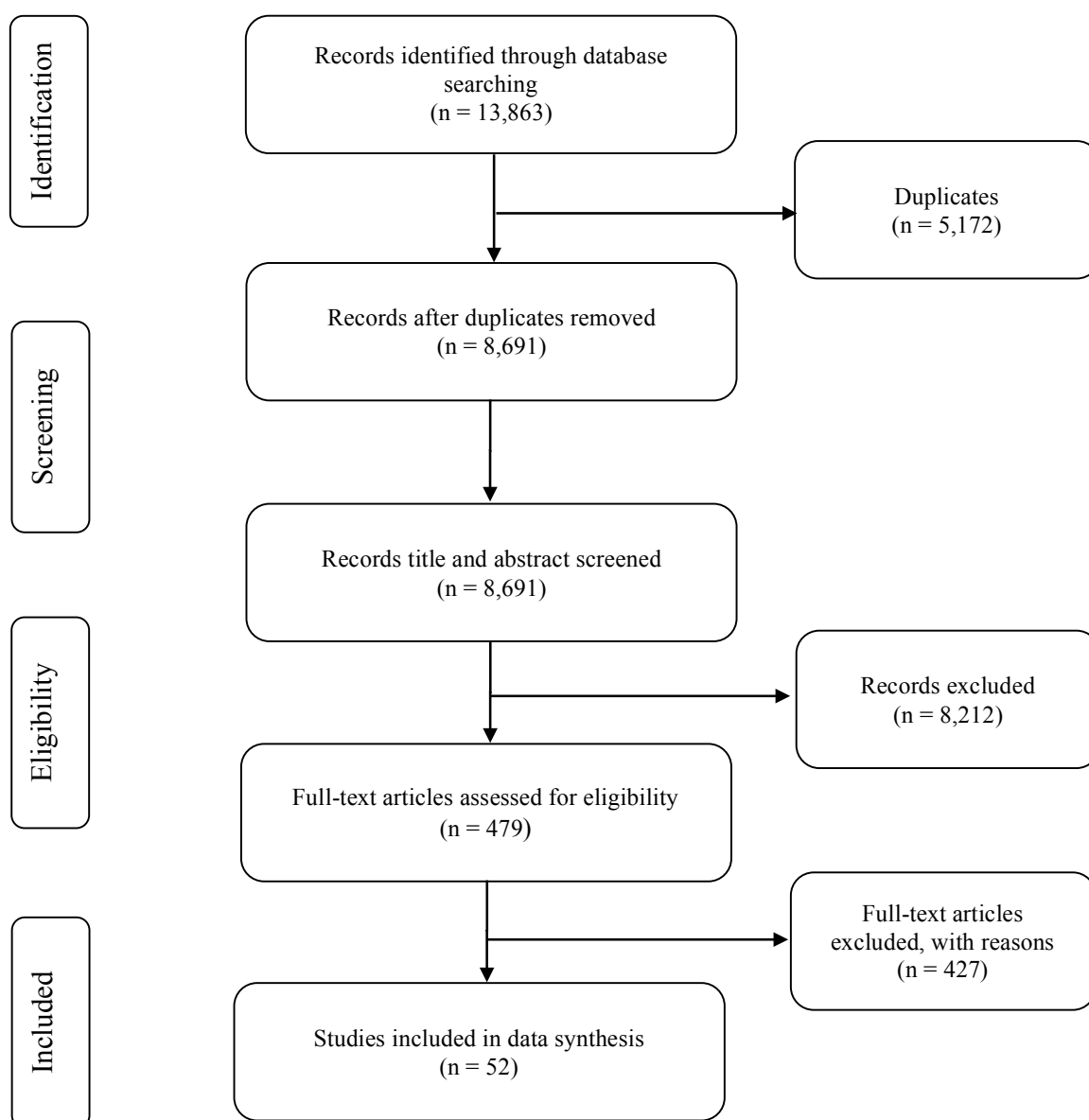


Figure 2: Search strategy (Teahan et al. 2018)

The review found that there is no single approach to enhancing resilience among family carers of people with dementia. Resilience is a multifaceted response to the caregiving role, and is influenced by a multitude of interrelated factors.

Living with the care recipient was associated with lower resilience and depending on the amount of time spent caring, lower levels of resilience were found. Researchers have also reported strong evidence of poorer carer outcomes in female carers when compared to male carers. Several studies suggest that being female was positively associated with higher levels of carer burden, and female carers were more likely to experience lower levels of optimism and poorer health, depressive symptoms, and a more pronounced decrease in sense of coherence over time.⁴² There is some evidence suggesting that religion and/or spirituality positively impact on carer outcomes. There also appears to be a link between carer outcomes and income and higher levels of education were associated with lower levels of depression and lower burden.⁴³ One study found that more avoidance and less active coping strategies contributed to depressive symptoms and poorer perceptions of general health among carers, while some good coping strategies were positively correlated with higher satisfaction in the caregiving role. It was noted that carers who had positive thoughts and attitudes toward their caregiving had lower levels of carer burden, higher levels of resourcefulness, and better mental health.⁴⁴



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The review team identified 24 studies that looked at the effects of interventions on carer resilience. After narrowing down the number of studies, the various types of interventions were grouped as follows:

1. Multi-component, including combining education, support groups, and skills training
2. Education
3. Counselling, including individual and family
4. Alternative, such as meditation.

⁴² Teahan et al., 1591.

⁴³ Teahan et al., 1591–92.

⁴⁴ Teahan et al., 1592.



When the researchers looked at the overall results of all interventions combined, the systematic review and associated meta analysis⁴⁵ resulted in the following findings:

- Overall, the interventions were shown to have a **small but significant effect** on levels of **caregiver burden** before and after the intervention.
- The interventions were shown to have a **significant effect** on **caregivers' depression levels** before and after the intervention.
- The interventions were shown to have a **significant small to moderate effect** on the **general health scores** of caregivers before and after the intervention.
- Although the overall effect on caregivers' **quality of life** was **not statistically significant**, our analysis showed that there was a trend in favour of intervention.

When the researchers looked at the results of each individual intervention type, they found the following:

- Combining multiple interventions did not have a significant effect on burden or quality of life, but had a significant effect on reducing depression and improving general health.
- Educational interventions alone had a significant effect on reducing burden, reducing depression and improving general health, but had no significant effect on improving quality of life.
- Counselling and alternative interventions could not be tested as there were not enough studies.

When the researchers analysed the results of studies, they concluded that interventions had a generally positive effect on family carer outcomes and that different interventions have differing degrees of success when targeted at specific carer outcomes.



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⁴⁵ There was a separate meta-analysis report prepared which was, as of February 2019, under review for publication in *Dementia: The International Journal of Social Research and Practice*. Authorship as follows; Áine Teahan, Attracta Lafferty, Eilish McAuliffe, Amanda Phelan, Liam O'Sullivan, Diarmuid O'Shea, Gerard Fealy

Postal Survey

The project team organised a postal survey to be sent to over 400 family carers around the country.⁴⁶ The survey aimed to examine carers' experiences of caring for a person with dementia. The survey was distributed through the Department of Employment Affairs and Social Protection to carers in receipt of the Carers Allowance/Benefit.

- The average age of family carers was 59 years, with ages ranging from 21 to 89 years
- Half of the carers (50%) were aged between 46 and 64
- Two-thirds of the carers (66%) were female and one-third (33%) were male
- Two-thirds of the carers (66%) were married
- Well over half (58%) were the spouse/partner of the care recipient
- Almost three-quarters (73.5%) lived with the person who had dementia.

Almost all family carers who responded to the survey said that it was their own choice to become a family carer and most made that choice for reasons that included emotional bonds, a personal sense of obligation, a sense of duty and also because it made them feel good. Some family members chose to become carers because of the very high cost of professional care or simply because there was no alternative.



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Just over half of carers surveyed (51.7%) said that if they needed a break from caregiving, they could find someone to help, but with great difficulty. One-third said that they could find someone to help quite easily, but a substantial number (17%) said that they had no one that could relieve them from their caring role. The services most commonly provided for the family member with dementia were GP services, public

⁴⁶ Lafferty, A., Fealy, G., Teahan, A., McAuliffe, E., Phelan, A., O'Sullivan, L., & O'Shea, D. (2016). Profiling Family Carers of People With Dementia: Results From a National Survey. Age and Ageing, 45.



health nursing services, home help services, practice nurse services, and day care centre services.

In terms of family caring and resilience, the researchers discovered through the survey that family carers who have a good or high-quality relationship with their care recipient were more likely to be resilient than those who did not have a good relationship with their care recipient. Family carers who make the choice to become carers were more likely to be resilient than those who take on caring out of necessity. It was also discovered that family carers were more resilient if their care recipient had fewer challenging behaviours to be managed.



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Key Points from Systematic Review, Meta-Analysis and Postal Survey

- The literature review highlighted the variability of the understanding of resilience and how it is attributed to family carers of people with dementia. It is evident that there are a number of factors in understanding resilience in carers.
- Resilience in family caregiving for people with dementia seems to be influenced by social, psychological and cultural factors, and as such there is no apparent single way to enhance resilience in family carers of people with dementia.⁴⁷
- The postal survey highlighted and reiterated the issues facing family carers of people with dementia that were illustrated in the literature review and in previous surveys.

⁴⁷ Teahan et al., 1592.

Stage 2: Development of the EnCaRe Network and Resource for Family Carers⁴⁸

To ensure that any resource created was one that family carers wanted and needed, the team decided that it should be designed by family carers themselves.

To recruit volunteer family carers of people with dementia to the EnCaRe network group, the team created an information sheet stating the aims of the EnCaRe group. The group was originally intended to consist of eight members, with six who were at the time, or had been in the past, family carers of a person with dementia. The remaining two members came from the research team, and supported the EnCaRe network group throughout the various processes of the project. The group took a decision at EnCaRe meetings to add another two family carers, which brought the total to eight family carers and two members of the research team.

The aim of the group was to plan and design a resource based on family carers' own definition of resilience.



The aim of the group was to plan and design a resource based on family carers' own definition of resilience and to ensure that the resource was available to as many carers as possible.

The EnCaRe group met over 11 sessions between May 2017 and March 2018. Each meeting lasted between 2 and 3 hours, and each progressed the development of a carer resilience resource. In the process of creating the Take Care Of Yourself resource, the EnCaRe group discussed various topics relating to the concept of resilience, including the definition of resilience.



The EnCaRe group met over 11 sessions between May 2017 and March 2018. Each meeting lasted between 2 and 3 hours, and each progressed the development of a carer resilience resource.

⁴⁸ Further details on the EnCaRe Group sessions will be made available in a separate publication.



Through the sessions the EnCaRe group slowly began to discuss how and what means would be used to create a resource for enhancing the resilience of family carers of people with dementia. The group discussed their own experiences and explored how best to create a resource that could act as an appropriate source of support for family carers in need of help.



Image 8: EnCaRe network group established

The EnCaRe group learned about the National Dementia Strategy, discussed numerous topics affecting themselves and family carers of people with dementia, sat with specialists and conversed about resilience in caring. One of the primary points made throughout the numerous meetings was that while helpful information did exist for people with dementia, there was little information on help for family carers of people with dementia. In addition, such information as did exist was difficult to obtain and was not gathered at a single location. The EnCaRe group ultimately decided that one of the best ways to help build resilience in family carers of people with dementia was to create a 'one stop shop' where family carers could go to obtain support without going through multiple resources to find the information needed. To implement their decision, the group created a web portal offering help and support to family carers of people with dementia.

The EnCaRe Resource

Working with a team of health professionals and researchers the EnCaRe group planned the development and design of this resource for family carers of people with dementia. The group decided on key topics that were necessary to make the resource a viable avenue of support. Beginning with 'Getting a Diagnosis', the group agreed several tabs and links as the best starting points for the website. The tabs followed a path or journey through the different stages of caring:

- | | |
|----------------------------|-------------------------------------|
| 1. Getting a Diagnosis | 4. Caring for Someone with Dementia |
| 2. Am I a Family Carer | 5. Transitions in Caring |
| 3. Impact of Being a Carer | |



Image 9:
Discussing
resilience in
family carers

The TCOY resource contains short videos showing family carers' own stories of caring and how they managed to continue caring for their loved one with dementia. The videos also present a wide array of information on resources and supports. The seven family carers who told their stories in the videos (who were not members of the EnCaRe network group) were recruited through family carers' advocacy groups such as The Alzheimer's Society Ireland and Family Carers Ireland.



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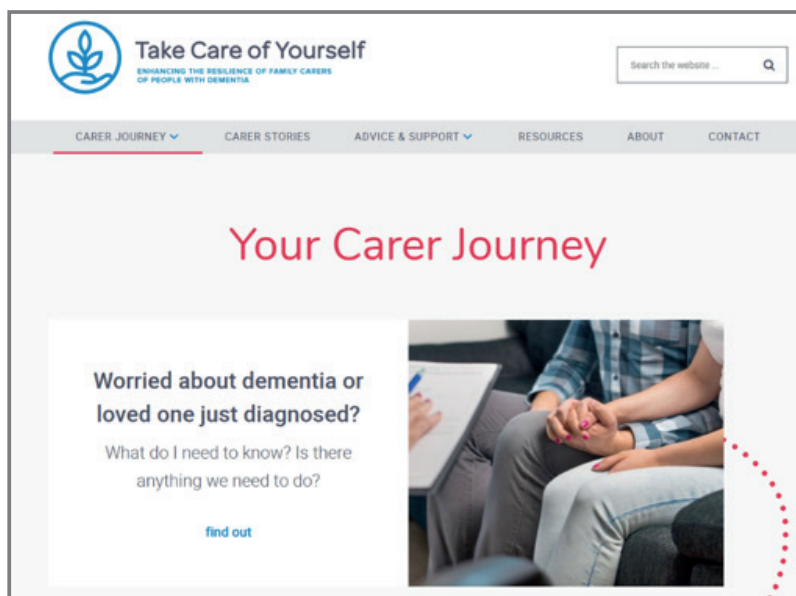


Image 10:
Carer journey
(TCOY website)

The group's facilitators, who were based at UCD worked with a web design company⁴⁹ to build the website and engaged the services of an audio-visual technician to record the carers' videos.

The website was developed with a distinct brand and logo. It was designed to be easily navigated, and contains detailed information on many aspects of caring for a family member with dementia. This includes information on financial supports, legal matters, Health Service Executive (HSE) supports, employment-related supports and practical supports.

Transitions in Caring



Knowing When to Transition to Residential Care



Advice to Family Carers Contemplating Long-Term Care for Their Loved One With Dementia

Image 11: Example of TCOY videos (TCOY website)

⁴⁹ <http://www.daracreative.ie/>

It also contains a list of websites, publications, information sheets and other material that can be downloaded by visitors to the website. The materials are presented with recognition that some family carers are only at the start of their journey while others have been caring for some time or have completed their caring journey. The site also contains resources for carers who are adjusting to life after caring.



The materials are presented with recognition that some family carers are only at the start of their journey while others have been caring for some time or have completed their caring journey.

The website contains 28 short video clips of family carers telling of their own experiences. The seven carers who tell their stories talk about starting out on the caring journey, finding out about the various supports available, and the impact of becoming a carer on their own lives. They also talk about the skills needed to care for a family member who has dementia and offer tips and advice on many aspects of the caring role. Some also speak about the end of caring and how to recognise when a transition in caring is occurring.

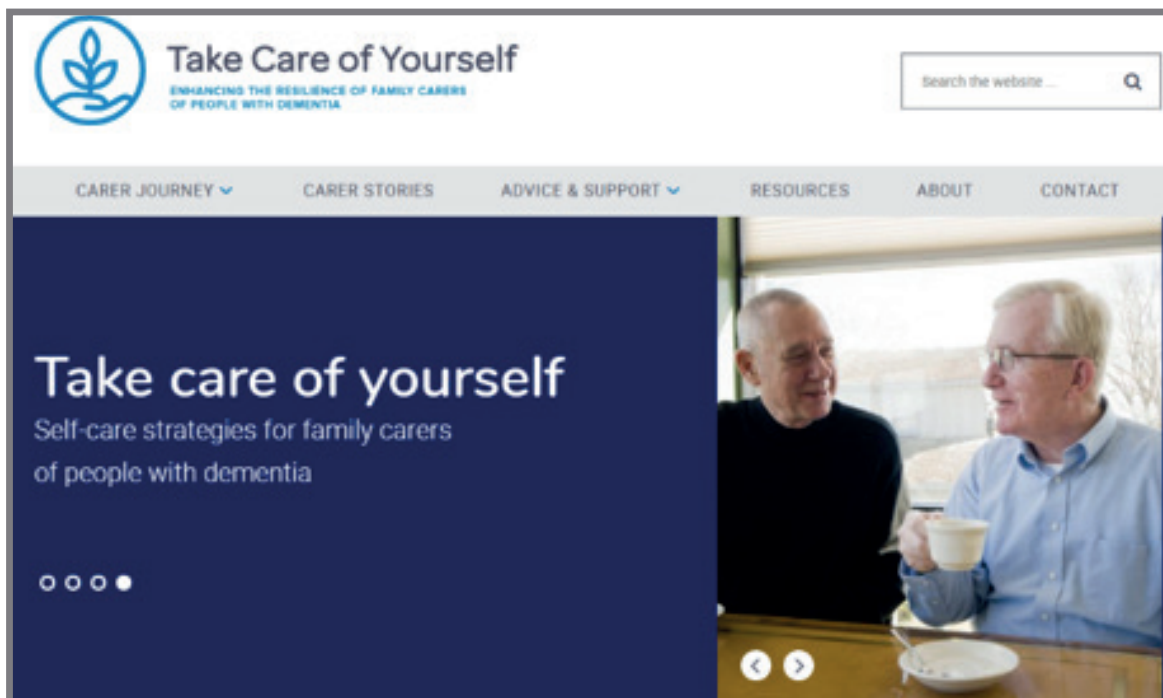


Image 12: Homepage (TCOY website)



The booklet acts as a concise resource where family carers of people with dementia can read and learn about the EnCaRe research and about resilience in family carers in similar circumstances. Included in both the website and booklet are contact information, advice and support for family carers who have questions about caring.

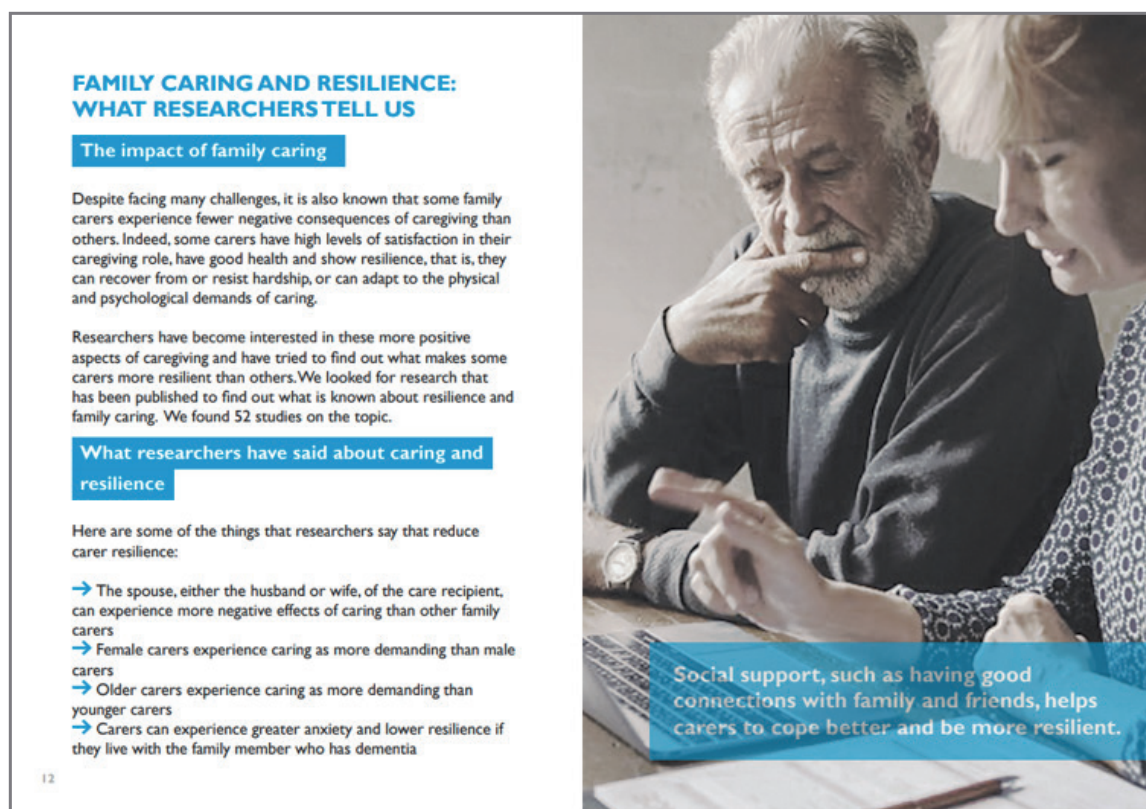


Image 13: TCOY booklet

Stage 3: Feasibility Study and Evaluation of the Take Care Of Yourself Resource

Once the Take Care of Yourself resource was designed it was important to establish that it did what the EnCaRe Network Group had intended it to do; promote resilience in family carers by providing relevant and accurate information to family carers in an easy and accessible way. Family carers who had not been involved in the development of the resource were invited to take part in one of three workshops in UCD. These family carers were currently providing care for a family member with early and later onset dementia and people with mild, moderate and severe dementia living at home. The family carers were recruited primarily through geriatric outpatient clinics as well as through collaborating organisations such as Family Carers Ireland and The Alzheimer Society of Ireland. As part of the recruitment process, the team provided a short explanatory leaflet about the resource and invited carers to take part in reviewing and testing the site.

A total of three workshops were held in UCD with four family carers participating in each one.⁵⁰ The workshops ran for three hours and participants were asked to complete a series of tasks on the site to determine whether the site was easy to navigate. A pre- and post- workshop survey was also administered to determine participants' current information needs and to capture their feedback on the website content. The results of the feasibility study were used to refine the resource and indicated that the resource performed as intended.⁵¹



The results of the feasibility study were used to refine the resource and indicated that the resource performed as intended.

⁵⁰ It must be noted that due to the small sample size, the results cannot be generalised, and that using a sample size smaller than ideal increases the chance of assuming as true a false premise. In other words, an appropriate sample size renders research more efficient, which means a very small sample, such as the one used here, undermines the internal and external validity of the study. Jorge Faber and Lilian Martins Fonseca, 'How Sample Size Influences Research Outcomes', *Dental Press Journal of Orthodontics* 19, no. 4 (2014): 27–29, <https://doi.org/10.1590/2176-9451.19.4.027-029.ebo>.

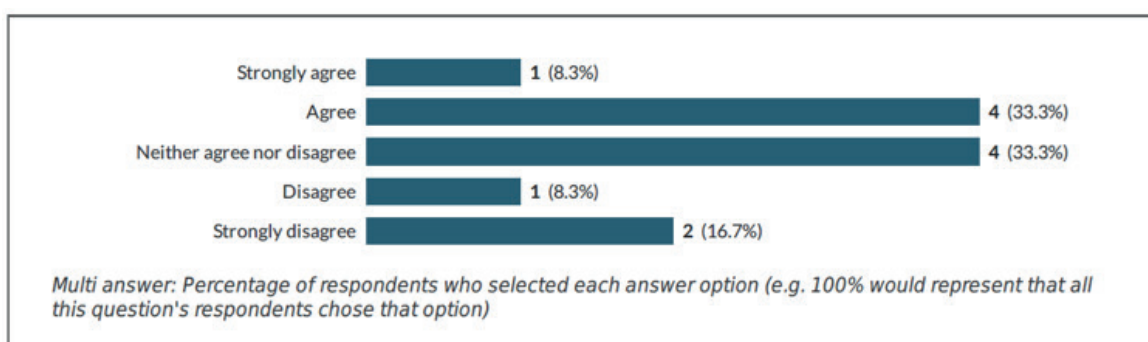
⁵¹ These surveys have not been made public. For information, please email info@carealliance.ie.



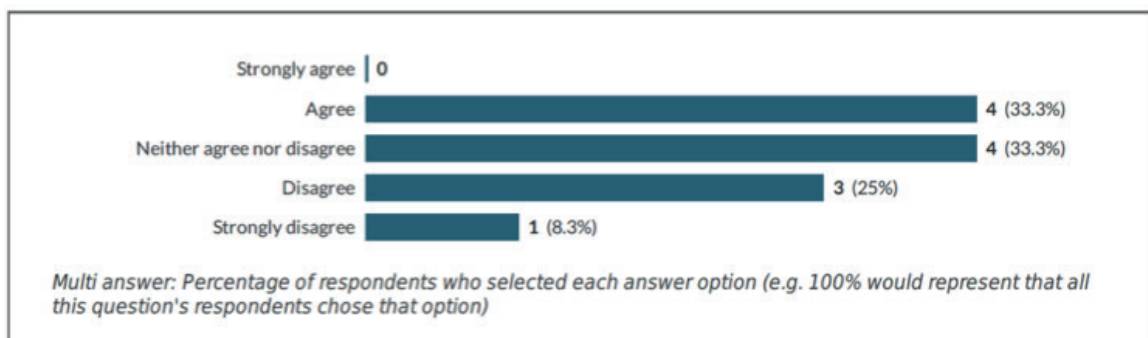
Pre-feasibility Workshop Survey

Though the results of the pre and post workshop surveys were only intended to inform further refinements of the site before it was evaluated and made public, some of the responses are worth noting. The selected statements below were given to participants in the pre-feasibility workshop survey. Each participant responded to each statement by indicating their level of agreement on the scale provided, ranging from 'Strongly disagree' to 'Strongly agree'.

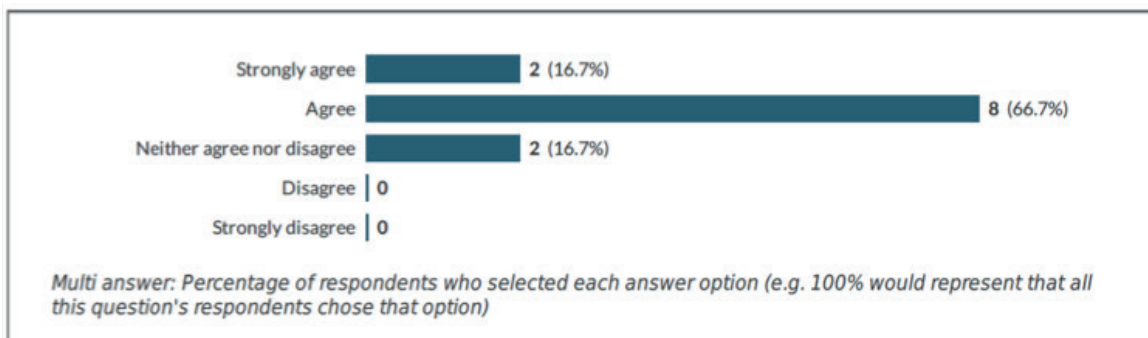
- 'I know where to find information about caring for a person with dementia'



- 'I have the time to take care of my own needs'



- 'I am a resilient person'



In the context of a resource designed to promote resilience among family carers, it is interesting to note that at least four people stated that they found it difficult to find the time to take care of their own needs.

Post-feasibility Workshop Survey

The second survey aimed to gauge the impressions and thoughts of the family carers at the end of the workshop. The results highlighted below indicated that the resource was well received by the participants and suggested that the TCOY resource has the potential to enhance resilience in family carers of people with dementia. As the aim of the small survey was to support further refinement of the site and confirm that the content was easy to navigate and useful to family carers the responses given are not intended to be generalisable to all family carers. However, it is interesting to note some of the feedback given as they offer a degree of optimism for the potential of such a resource.



The resource was well received by the participants and suggested that the TCOY resource has the potential to enhance resilience in family carers of people with dementia.

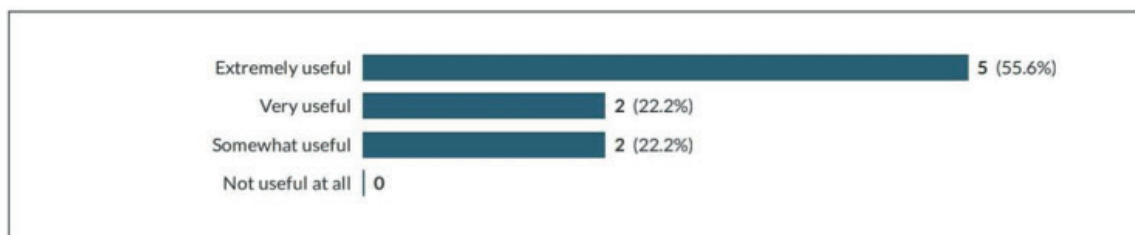
The selected statements were presented to the participants in the post workshop survey. Each participant responded to each statement either by choosing an option from a list or from a scale ranging from 'Not useful at all' to 'Extremely useful' and 'Strongly disagree' to 'Strongly agree'.

- 'What type of information were you able to find on the site?'

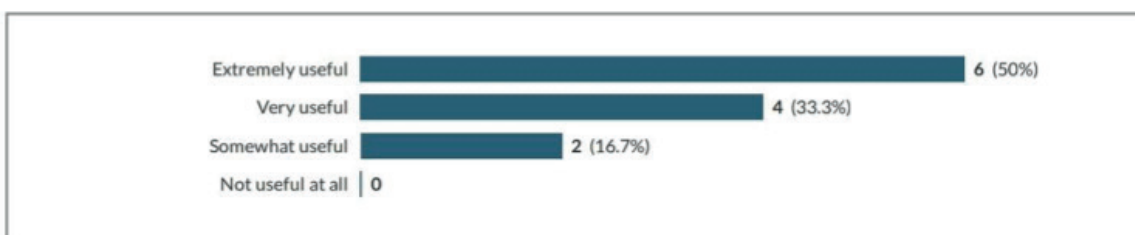




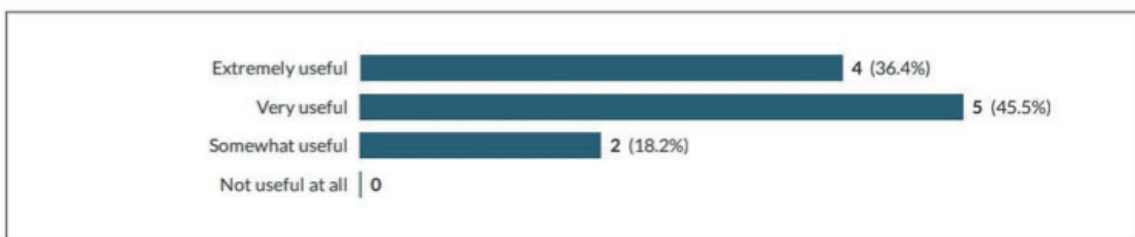
- 'Legal advice for carers'



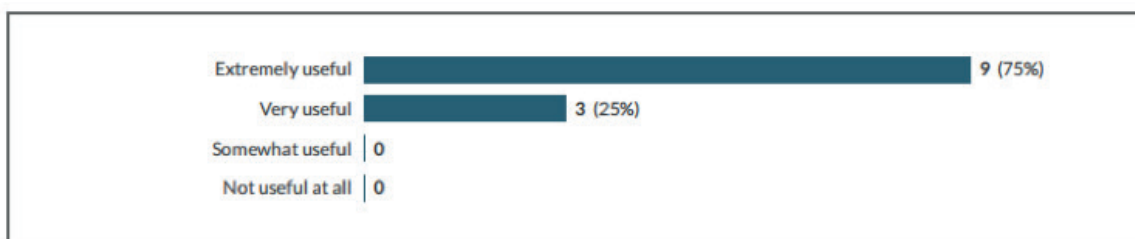
- 'Advice on caring for a person with dementia'



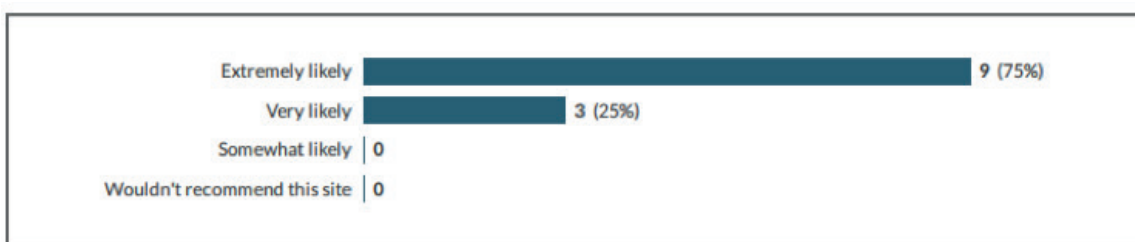
- 'Advice on looking after yourself'



- 'How useful do you think this site is for family carers of people with dementia?'



- 'How likely would you be to recommend this site to another family carer of a person with dementia?'



One person stated '[I] really enjoyed the content and I found information that I didn't know before. I would love to spend more time searching the site and looking at all of the videos. I am delighted that you are putting this together because I feel it is really needed.' Another participant, elaborating on the usefulness of the website, stated that 'the information is very genuine and so many of us carers can and do relate to these truly everyday experiences and questions/feelings'.



The information is very genuine and so many of us carers can and do relate to these truly everyday experiences and questions/feelings.



Evaluation

The results of the workshops indicated that the TCOY resource did what the EnCaRe Network Group had intended it to do and ultimately had the potential to promote resilience among family carers of people with dementia. The final step for the project team was to evaluate the quality of the resource and to establish that the process by which it had been created was effective and inclusive.



The results of the workshops indicated that the TCOY resource did what the EnCaRe Network Group had intended it to do and ultimately had the potential to promote resilience among family carers of people with dementia.

To evaluate the quality of the materials it was necessary to make sure that the input of the EnCaRe Network Group had been genuinely incorporated into the design and development of the resource and that project collaborators had been afforded genuine opportunities to contribute to the process.

Interviews with project collaborators were conducted and EnCaRe members were invited to provide their feedback on the process via an online exit survey.

Of the eight carer members, four completed the exit survey and left valuable feedback for future researchers involved in participatory action research.

The members of the EnCaRe group who completed the survey were overwhelmingly positive in their praise of the development of the resource, with one member stating:

‘The project was skilfully managed from the start with clear documentation outlining what was agreed after each session. Meetings were chaired in a way where everyone could respectfully have their say. There were some personnel changes along the way but there was minimal impact on the participants. My concerns along the way were met. I have been involved in a few research projects and this was the best as it was clear there was going to be a tangible outcome. I feel we have produced a really helpful resource for carers.’

While some criticisms of the process were noted, the overall experience of collaborators and the EnCaRe members indicated that their contributions were heard and incorporated into the development of the TCOY resource.



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Knowledge and Dissemination Exchange Workshops

During the third year of the project additional funding was awarded by the Health Research Board (HRB) to engage in Knowledge and Dissemination Exchange (KEDS) events around the country. The research team sought to spread the new knowledge they had gained about the EnCaRe resource and the understanding of resilience to other family carers of people with dementia.

The researchers carried out an information and outreach campaign in regional centres throughout Ireland, using the support of local networks, print media, parish newsletters and paid social media ads to enhance participation. Knowledge transfer and exchange activities are an important way of bringing the knowledge gained from research to the people who are most likely to benefit from such knowledge.

Care Alliance Ireland, through the employment of a part-time research assistant, led this part of the project. The aim was to design a schedule of knowledge exchange events, deliver workshops to regional groups of family carers of people with dementia, conduct exit evaluations of the workshops, and incorporate feedback from workshops into the feasibility study associated with the main research grant.

The KEDS workshops were organised in the Autumn of 2018. The six venues were selected based on population size in various regions and based on feedback from other stakeholders. The workshops were facilitated by the Principal Investigator and the project manager, with the research assistant acting as co-facilitator. The participants who were invited to take part were seated together at a table and given a pack containing the EnCaRe booklet. The facilitator presented the workshop and discussed the research and the knowledge gained from the EnCaRe project. The group at the workshops were also invited to take part in conversations on resilience and what it means to be resilient as a family carer of a person with dementia. The workshop groups were also given the opportunity to evaluate the website resource. Details of the experience and delivery of the KEDS workshops will form the basis of another report that will be published in the near future.

Conclusion

The EnCaRe project can be described as a successful venture in developing and enhancing our understanding of resilience in family carers of people with dementia. The EnCaRe project has also successfully developed a resource for family carers, which has to date reached significant numbers of family carers of people with dementia.

The Alzheimer Society of Ireland has committed to integrating the EnCaRe video content and support materials into its own main website www.alzheimer.ie

We are confident that the future hosting and dissemination by The Alzheimer Society of Ireland of the resource created by the project team will continue to be a support to large numbers of family carers of people with dementia.

The EnCaRe resource is a step in the right direction, whereby family carers are encouraged to take care of themselves and remain integrated in society. The resource was developed by family carers for family carers. We hope this strategy will be used in other areas, and we support initiatives that seek to treat family carers as partners in care, thus giving expression to Ireland's National Carers' Strategy.



Acknowledgements

We would like to thank everyone who helped with this project and in particular with this publication.

We would like to thank Kevin Deegan and Liam O'Sullivan, Care Alliance Ireland, for co-authoring.

This publication was reviewed by Prof Gerard Fealy, the Principal Investigator of the main HRB EnCaRe Dem project, University College Dublin (UCD), and by Dr. Bernadette Rock, Research Manager of The Alzheimer's Society of Ireland.

Thanks to Zoe Hughes (Care Alliance Ireland) for her comments on the draft report.

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Appendix I

Who Was Involved in the Project?

The Principal Investigator on the project was Professor Gerard Fealy, Dean of Nursing and Head of the School of Nursing, Midwifery and Health Systems. Also involved in this project were Dr. Attracta Lafferty, Professor Eilish McAuliffe, and Dr. Amanda Phelan, all from UCD; Dr. Diarmuid O'Shea (St Vincent's Hospital); and Mr Liam O'Sullivan (Care Alliance Ireland). Sandra McCarthy acted as project manager, organised the day-to-day administration of the project and assisted in facilitating the KEDS workshops along with leading the development of the TCOY resource. Ms. Áine Teahan, acted as research assistant in year one and was involved in synthesising research evidence in the area, administration, co-facilitating and organising earlier EnCaRe groups.

This project structure was novel in that from year two, Care Alliance Ireland employed a part-time research assistant to work toward maximising dissemination and outreach. Others involved in the project included Dr. Emer Begley (National Dementia Office, HSE), Dr. Deirdre O'Donnell (UCD School of Nursing), Mr Pat Dolan (Department of Employment Affairs and Social Protection), Dr. Claudia Cooper (University College London), Professor Walter Cullen (UCD School of Medicine and Medical Sciences), Ms Naomi Feely (Age Action Ireland), Dr. Bernadette Rock (The Alzheimer Society of Ireland) and Mr Diarmaid O'Sullivan (Family Carers Ireland). The project also had a research assistant, Mary Forde, who managed much of the IT aspect in collaboration with Daracreative.ie, and who assisted the project manager in facilitating some of the EnCaRe meetings. Zoe Hughes also supported the project manager in facilitating a number of the earlier EnCaRe group meetings. Dr. Carla Reigada acted as Post-Doctoral Research Fellow in year one. Reá McDunphy and Geraldine Kelly (Department of Employment Affairs and Social Protection) facilitated the postal survey. Regina Lafferty (HSE) facilitated the recruitment of family carers for EnCaRe and for the project advisory group. Aisling Harmon and Robert Cullen family, carers, acted as project advisory group members.

Members of the EnCaRe Group

- Ms. Harriet Conlon
- Mr. Matthew Coyle
- Mr. Ray Cregan
- Ms. Carolann Duggan
- Ms. Orla Norris
- Mr. Éamon Ó Fearghail
- Mr. Norman O'Connor
- Ms. Jenny Smee



Guiding support for family carers

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