



# ENHANCING THE RESILIENCE OF FAMILY CARERS OF PEOPLE WITH DEMENTIA



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

## CONTENTS

About Dementia	4
Caring for a family member with Dementia	6
Becoming resilient as a family carer	9
Family caring and resilience: What researchers tell us	12
Supporting family carers: What researchers tell us	15
Family carers supporting family carers	19
‘Take care of yourself’: A resource for family carers	22

## ABOUT DEMENTIA

### What is dementia?

Our brain is the control centre of our body, giving us the ability to walk, talk, see, hear, remember, and solve everyday problems. Like any other organ in the body, the brain can be affected by disease that alters its ability to function properly. This is what occurs in dementia, a disease in which parts of the brain are damaged, affecting our ability to think properly, remember, communicate our ideas and perform everyday tasks, such as washing, dressing and eating.

### How does dementia affect the individual?

Dementia is a progressive disease and its progress varies from one person to another. Therefore, many people with a diagnosis of dementia can continue to live well and perform normal everyday tasks and socialise with family and friends. However, as the disease progresses, the individual is increasingly less able to perform everyday tasks, and there are personality changes and changes in behaviour that affect the person's ability to function socially. These effects result in a greater dependence on others, including family carers.

### Is dementia common?

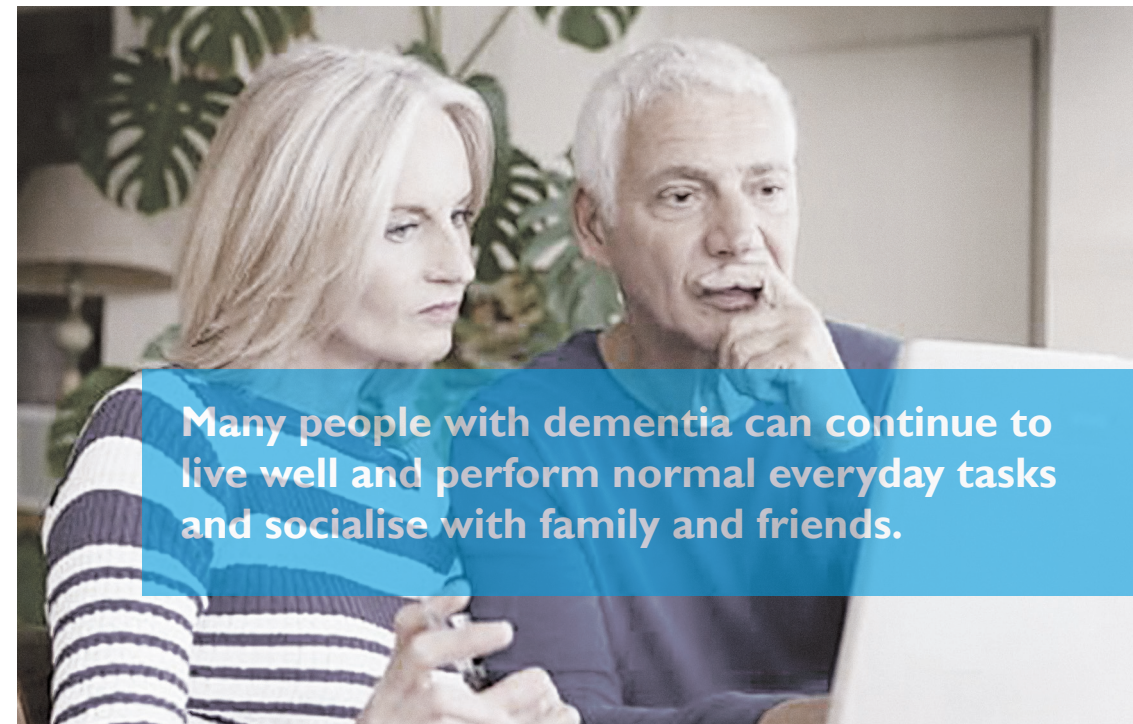
Although dementia is more common in people over the age of 65, it is not exclusively a disease of old age, and it is not an inevitable part of growing old. Over 50,000 people in Ireland live with dementia and we expect that the number of people with dementia will increase in the coming decades.

### Is dementia preventable?

There is evidence that some forms of dementia may be related to one's lifestyle and, like other diseases related to lifestyle, such as heart disease and cancer, dementia may be preventable. Therefore, physical activity, a healthy diet, not smoking, drinking in moderation, and maintaining normal blood pressure are preventable measures. Staying mentally active and staying socially connected can also reduce the likelihood of getting the disease. These preventable measures may also slow the progress of dementia, once it is diagnosed.

### Is dementia treatable?

While there is no known cure for dementia, current medical research is focused on finding drugs that can prevent or reverse the damage to the brain.



**Many people with dementia can continue to live well and perform normal everyday tasks and socialise with family and friends.**

# CARING FOR A FAMILY MEMBER WITH DEMENTIA

## Who are the carers?

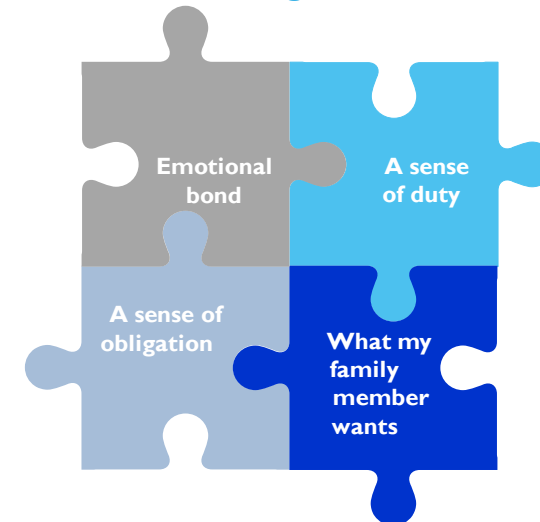
Most people with dementia are cared for at home by a family member. We conducted a survey of just over 400 family carers of people with dementia. Here is what they told us:



## Choosing to become a carer

We asked the family carers why they chose to be a family carer. Here is what they told us:

### Choosing to care



Most of the family carers said that it was their own choice to become a family carer


Most made the choice to become a family carer for many reasons including: emotional bonds, a personal sense of obligation; a sense of duty and because it made them feel good

Some chose because of the very high cost of professional care or because there was no alternative

## Supports for family carers

In our survey, we asked family carers about the kind of supports they receive if they needed to take a break from their caring role. Here is what they told us:





**Almost all family carers said that it was their own choice to become a family carer.**

Just over half of carers (51.7%) said that if they needed a break from caregiving, they could find someone, but with great difficulty.

One third of the carers 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 health nursing services, home help services, practice nurse services, and day care centre services.

## **BECOMING RESILIENT AS A FAMILY CARER**

### **What is resilience?**

People frequently experience personal challenges, difficulties or hardship in their lives, such as a major change in their circumstances, an illness, financial difficulties, or a personal tragedy, such as a death or illness in the family. These challenges can result in stress and an inability to cope or function effectively. Resilience is the ability to recover quickly, or 'bounce back' from hardship or misfortune and, in that way, to get on with life.

### **What does resilience have to do with family caring?**

Caring for someone with dementia can be physically challenging and stressful, affecting the carer's health and ability to maintain normal social relationships outside the home. This can lead to the carer becoming unwell and socially isolated, feeling forgotten and left to care alone, and this can affect the carer's ability to function effectively as an active member of society. Studies have shown that due to the demands of caregiving, family carers can experience stress, and lower levels of mental and general well-being than people who do not have caregiving responsibilities.

However, despite facing many challenges, it is also known that some family carers experience fewer negative effects of caregiving than others. Indeed, some carers have high levels of satisfaction in their caregiving role, have good health and can recover from or resist hardship, or adapt to the physical and psychological demands of caring.

Family carers who can adapt to the demands of caring and adjust

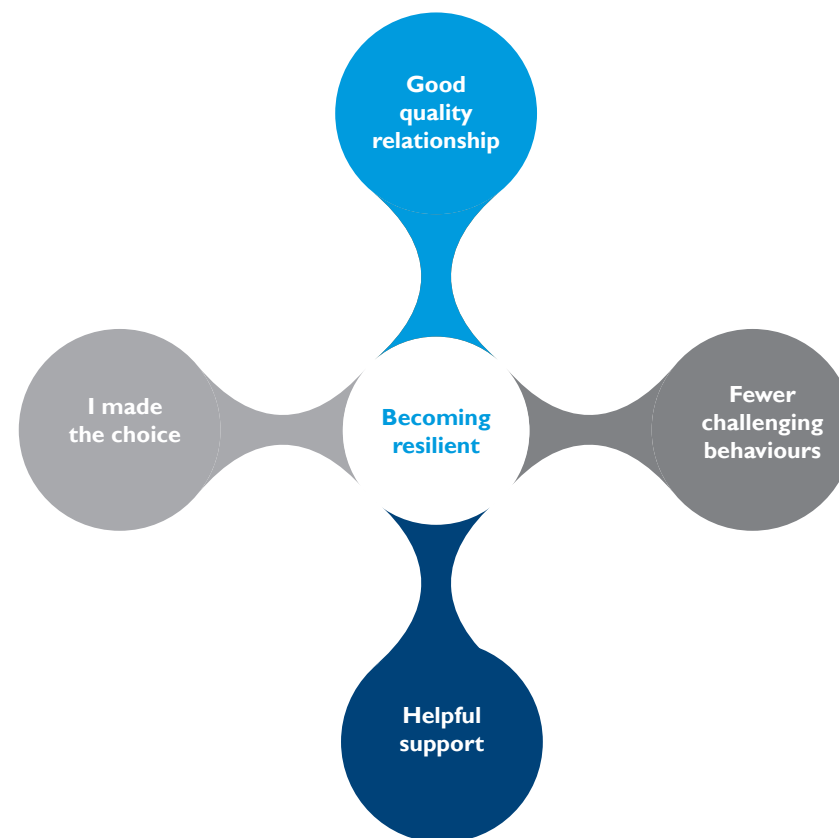
to their situation and cope with the challenges that caring brings are considered as resilient. Being resilient is therefore seen as a personal resource making the carer more socially connected, and more resourceful in accessing support services. This can mean that caring can be a more positive experience.

## What makes family carers more resilient?

A family carer's resilience is influenced by many things, such as whether they are male or female, their living arrangements, social supports and the condition of the family member who has dementia.

We conducted a survey of just over 400 family carers of people with dementia. Two-thirds (66%) were female and one third (33%) were male. Their average age was 59 years, with the youngest being 21 and the oldest 89 years. We asked them about the things that make them more resilient. This is what they told us:

- 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 make their own choice to become a family carer are more likely to be resilient than those who take on caring out of necessity and not their own choice
- Family carers are more resilient if their care recipient has fewer challenging behaviours, i.e. behaviours that are difficult to manage
- Family carers are more resilient if they experience family support as helpful to them in their caregiving role





## FAMILY CARING AND RESILIENCE: WHAT RESEARCHERS TELL US

### The impact of family caring

Despite facing many challenges, it is also known that some family carers experience fewer negative consequences of caregiving than others. Indeed, some carers have high levels of satisfaction in their caregiving role, have good health and show resilience, that is, they can recover from or resist hardship, or can adapt to the physical and psychological demands of caring.

Researchers have become interested in these more positive aspects of caregiving and have tried to find out what makes some carers more resilient than others. We looked for research that has been published to find out what is known about resilience and family caring. We found 52 studies on the topic.

### What researchers have said about caring and resilience

Here are some of the things that researchers say that reduce carer resilience:

- The spouse, either the husband or wife, of the care recipient, can experience more negative effects of caring than other family carers
- Female carers experience caring as more demanding than male carers
- Older carers experience caring as more demanding than younger carers
- Carers can experience greater anxiety and lower resilience if they live with the family member who has dementia



**Social support, such as having good connections with family and friends, helps carers to cope better and be more resilient.**

- When people with dementia have behavioural problems or are unable to look after their normal routine tasks, such as washing and dressing, their family carers can experience greater levels of anxiety and depression
- The greater the amount of time spent on caring, especially hours per day, can reduce the carer's quality of life
- Having additional responsibilities, such as parenting and work, can be stressful

Here are some of the things that researchers say help carer resilience:

- Unity and co-operation within the family helps the carer to be resilient
- Social support, such as having good connections with family and friends, helps carers to cope better and be more resilient
- Family carers' wellbeing can benefit from maintaining interests and hobbies, having time to themselves and taking part in activities that don't involve caregiving
- Family carers' quality of life can be improved if they are able to get support from state ('formal') health and social services
- Family carers who have higher levels of education can experience caring as less demanding
- Family carers who have their own ways of coping, such as knowing when to seek help, are more resilient
- Family carers who have self-confidence in their ability to care and feel that they have control over stressful situations experience caring as less demanding
- Carers who have positive attitudes towards their caregiving experience caring as less demanding, have lower levels of depression and are more resourceful

In summary, there is evidence that resilient carers experience fewer of the negative effects of caregiving and have more positive health outcomes.

## SUPPORTING FAMILY CARERS: WHAT RESEARCHERS TELL US

### The impact of family caring

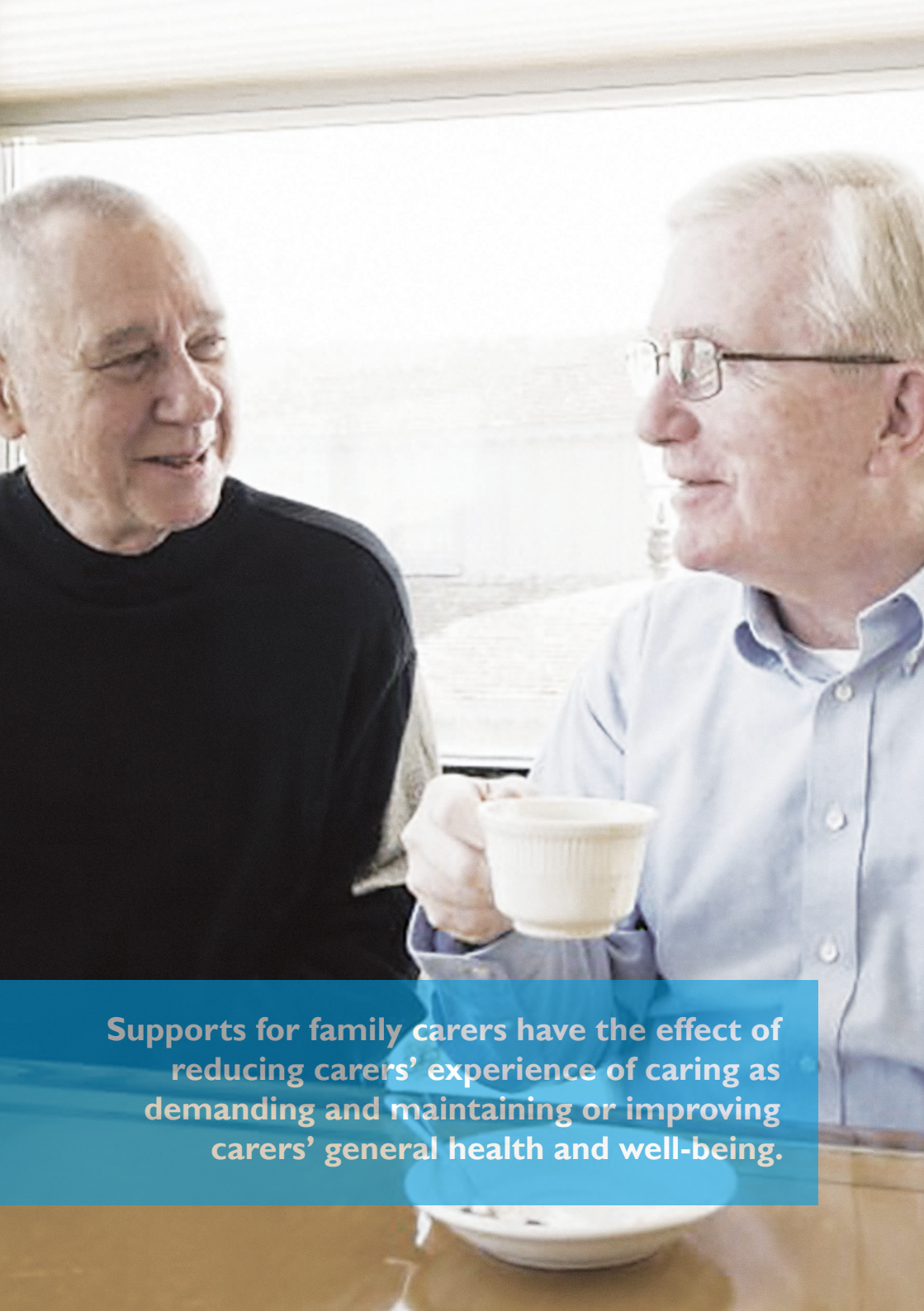
It is known that caring for a family member who has dementia can be challenging, but despite the challenges, many carers are resilient and find caregiving rewarding. Researchers are interested in finding out if certain types of supports for family carers are effective in reducing the negative effects that can sometimes be associated with caring and with improving the health and well-being of carers.



### Why is this kind of research important?

When researchers identify new ways to support family carers of people with dementia, they need to know if they are effective. This typically involves introducing a new family carer support – in research, this is referred to as an intervention– and either comparing the effects before and after the support is introduced, or by comparing the effects on family carers who get the support with family carers who don't. To find out the effects, researchers generally ask carers questions about things like their experience of the demands of caring, their levels of anxiety and depression, their general health, and their quality of life.





**Supports for family carers have the effect of reducing carers' experience of caring as demanding and maintaining or improving carers' general health and well-being.**

We looked for published research to find out the type of supports that have been used to help family carers to become more resilient and to find out how effective they are in improving carers' mental and physical wellbeing and their quality of life. We found 24 studies that looked at the effectiveness of supports for family caregivers.

### **Which supports have been tried?**

The type of resources and supports for family carers included educating family carers about dementia, starting support groups for carers, helping carers to develop their own coping skills and to get the most out of the social services that are available, and providing individual and family counselling.

### **Which supports works best for family carers of people with dementia?**

- Overall, supports for family carers have the effect of reducing carers' experience of caring as demanding, reducing carers' depression and maintaining or improving carers' general health and well-being
- Different types of supports were found to have different effects, depending on the type of support and the type of effect
- Educational supports have the effect of reducing carers' experience of caring as demanding and reducing the carers' level of depression
- Educational supports and meditation and mindfulness training have a significant effect on reducing depression in family carers



→ When different types of supports are used in combination, they are more effective than using a single type of support alone

In summary, researchers tell us that, overall, interventions designed to support family carers of people with dementia have the effect of maintaining or improving the well-being of carers.



To be certain that the resource was what family carers wanted and needed, we decided that it should be designed by family carers themselves.

## FAMILY CARERS SUPPORTING FAMILY CARERS

### A family carers' network group

As health professionals, researchers and advocates for family carers, we wanted to design a resource to help family carers of people with dementia to become more resilient. To be certain that the resource was what family carers wanted and needed, we decided that it should be designed by family carers themselves. We invited eight family carers to take part in a family carers' group and we called the group the Enhancing Carers' Resilience (or EnCaRe) Group. 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.

### How did the EnCaRe Group work?

The EnCaRe Group met on eleven occasions between May 2017 and April 2018. Two members of our project team facilitated each Group meeting. The Group also invited some experts to talk about family caring in dementia and to conduct some workshops.

### What did the EnCaRe Group do?

**Meeting 1** The first meeting was all about 'getting to know you', where each member of the Group introduced themselves and talked about their individual experiences of caring for someone with dementia. At this meeting, the Group also agreed on its aims.

**Meeting 2** The aim of this meeting was to help the EnCaRe Group members become familiar with Government policy on family caring for people with dementia and to get members thinking about how policy can affect carers' resilience. Mr Diarmaid O'Sullivan of Family Carers' Ireland spoke to the Group about the National

## Carers Strategy.

**Meeting 3** For the third meeting, a family carer was invited to speak to the Group about her experiences of caring for someone with dementia. The speaker spoke about the importance of working with professionals, maintaining life as normal as possible, and accepting the role of carer.

**Meeting 4** The meeting looked at resources for family carers, including Understand Together, the HSE website, which is designed as an information resource about all services for people with dementia. The Group discussed the benefits as well as the limitations of the resource.

**Meeting 5** At the fifth meeting, the Group reviewed what it had discussed in the first four meetings and agreed a plan for future meetings. It also looked at supports and activities that are used to promote carer resilience, such as respite services and skills training.

**Meeting 6** The aim of the meeting was to come up with and agree on a working definition of resilience, based on the Group's own discussions up to that point. The Group also discussed sources of information for family carers and the types of resources that are most helpful for carers. The Group agreed to develop a website with videos featuring family carers telling their own stories of caring.

**Meeting 7** This meeting involved planning and deciding on the content and the design of the resource for family carers, based on the idea of 'the caring journey'.

**Meeting 8** The Group reviewed video storyboards that were designed for each video and discussed how the website should be branded and promoted.

**Meeting 9** This meeting involved a 'de-stress and relaxation' workshop, in which the Group members discussed the importance of self-care and the risk of compassion fatigue. Karen Brennan from Self-Care for Carers led the workshop.

**Meeting 10** The Group reviewed the work involved in producing the carers' videos, agreed on the name of the website – 'Take Care of Yourself' – and discussed what it would like the website to achieve for family carers.

**Meeting 11** At this meeting the Group agreed a plan on how to evaluate the new website, before going 'live'.



**The EnCaRe Group discussed the types of resources that are most helpful for family carers.**



## 'TAKE CARE OF YOURSELF': A RESOURCE FOR FAMILY CARERS

### A resource for family carers

The **Enhancing Carers' Resilience** (or EnCaRe) Group was established in 2017 as a small network group of family carers. The aim of the Group was to design a resource to promote greater resilience in family carers of people with dementia.

Working with a team of health professionals, researcher and family carers' advocates, the EnCaRe Group planned the development and design of a resource for family carers of people with dementia. The resource consisted 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 Group's facilitators, who were based at UCD, worked with a web design company to build the website and engaged the services of an audio-visual technician to record the carers' videos. The seven family carers who told their stories in the videos were recruited through family carers' advocacy groups.

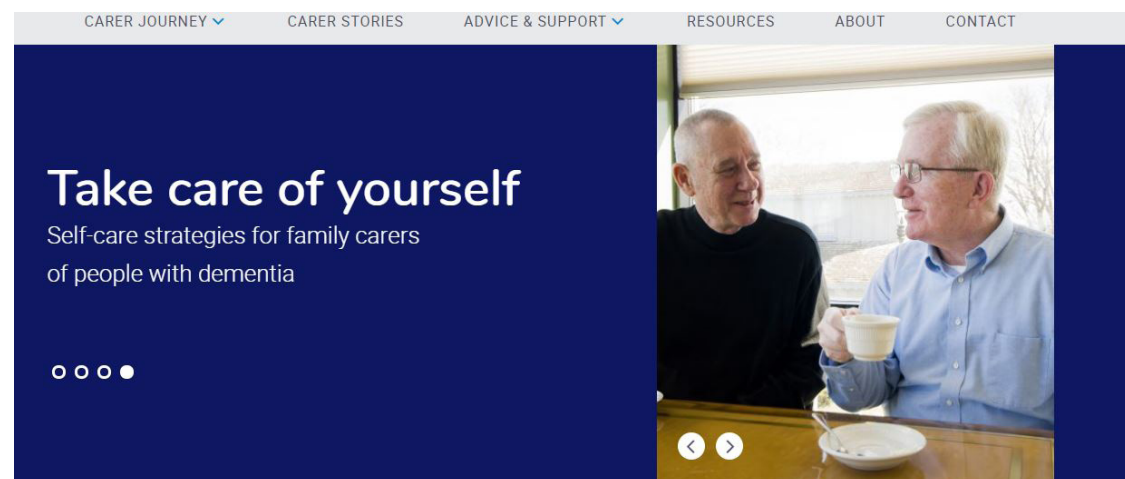


## Take Care of Yourself

ENHANCING THE RESILIENCE OF FAMILY CARERS  
OF PEOPLE WITH DEMENTIA

### Take Care of Yourself website

The website was developed with a distinct brand and logo. It was designed to be easily navigated and it contains detailed information on many aspects of caring for a family member with dementia. This includes information on financial supports, legal matter, HSE supports, employment-related supports and practical supports. It also contains a list of websites, publications, information sheets and other material than can be downloaded. The materials are presented in a way that recognises that some family carers are only at the start of their journey as a carer, while others have been caring for some time, or have completed their caring journey. It also contains resources for carers who have completed the journey and are adjusting to life after caring. The website will be available towards the end of 2018.

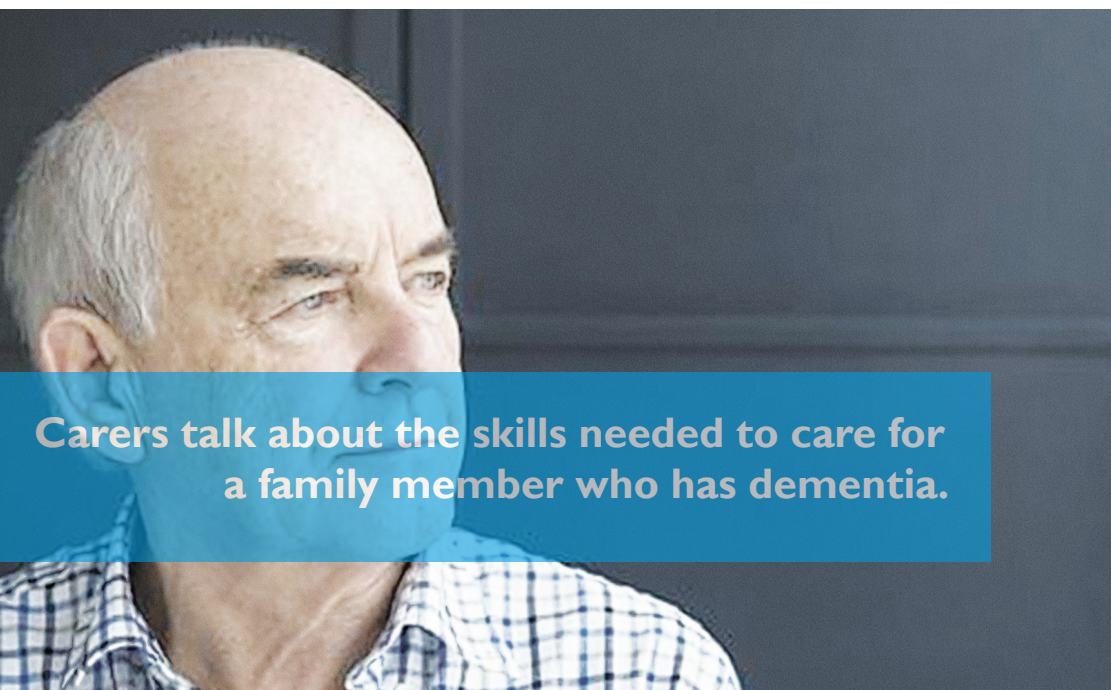


## The family caring journey

The website contains 28 short video clips of family carers telling their stories about their own experiences as carers. The video clips are based on six different stages of the carer journey, as follows: diagnosis, becoming a family carer, the impact of being a family carer, caring for someone with dementia, transitions in caring, and life after caring.

## The carers' stories

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 life. 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 journey from being a carer to no longer being a carer.



**Carers talk about the skills needed to care for a family member who has dementia.**

## Want to know more or have concerns?

If you are caring for a family member who has dementia, there are many supports. These include health and social care services and voluntary agencies. There are also support groups for family carers, including Family Carers Ireland; see: <https://familycarers.ie/>

Alzheimer's Society of Ireland's expert helpline service is available on 1800 341 341. Alternatively, email: [helpline@alzheimer.ie](mailto:helpline@alzheimer.ie) or visit: <https://www.alzheimer.ie/Home.aspx>

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Visit: <http://www.hrb.ie>

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