

Knowledge Exchange and Dissemination Report on Experiences of Family Carers who Participated in Workshops

Project Title: Family Carer Knowledge Exchange Project (KEDS – 2017 – 034)

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Introduction

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 overarching focus of the project was on developing caregiver resilience in order to ensure that the family carer is a sustainable resource for dementia care in Ireland. By becoming more resilient as carers of people with dementia, family carers are, in some cases, more likely to have a positive experience of caregiving.¹ The project ultimately culminated in the development of the 'Take Care of Yourself' (TCOY) resource,² which was developed with the assistance of the 'Enhancing Carer Resilience' group (EnCaRe).

As an extension of the abovementioned project, a secondary project was awarded funding by the HRB, titled the 'Family Carer Knowledge Exchange Project', otherwise known as Knowledge Exchange and Dissemination (KEDS) events. These KEDS events focussed on sharing the knowledge learned from the 'Towards resilience in family caregiving for people with dementia' project, throughout Ireland. The aim of the KEDS project was to undertake an information and outreach campaign in regional centres throughout Ireland, using local networks and modern communication technologies, such as webinars and the internet, so that a larger audience would gain the benefits of the knowledge learned from the resilience project, and also allow participants to provide feedback on both the research conducted and the TCOY resource.

¹ Bomim Shim, Julie Barroso, and Linda L. Davis, 'A Comparative Qualitative Analysis of Stories of Spousal Caregivers of People with Dementia: Negative, Ambivalent, and Positive Experiences', *International Journal of Nursing Studies* 49, no. 2 (February 2012): 220–29, <https://doi.org/10.1016/j.ijnurstu.2011.09.003>; Abir K. Bekhet and Jennifer Sjostedt Avery, 'Resilience from the Perspectives of Caregivers of Persons with Dementia', *Archives of Psychiatric Nursing* 32, no. 1 (February 2018): 19–23, <https://doi.org/10.1016/j.apnu.2017.09.008>.

² www.takecareofyourself.ie

The main KEDS workshops ran from September 2018 to November 2018, with five workshops in total and 59 family carers taking part. A webinar aimed at family carers of people with dementia was hosted in UCD, with 25 people taking part. Aimed at health and social care professionals, a second webinar was hosted in UCD in March 2019 with a total of 23 people engaged in the session. This webinar was designed to raise awareness of this newly developed resource. In total, 107 people took part in the KEDS workshops and two webinars.

This report discusses the experiences of family carers who participated in the five workshops. To complement this report, an analysis of exit survey data was also completed to gauge an overall view of the experiences of the family carers who participated in the workshops.



Project Team

The following members of the project team were involved with the creation of material for and facilitation of the KEDS workshops:

- Professor Gerard Fealy, Professor of Nursing at UCD, Principal Investigator of the project
- Ms Sandra McCarthy, Project Manager
- Mr Liam O'Sullivan, Executive Director of Care Alliance Ireland
- Mr Kevin Deegan, Research Assistant, Care Alliance Ireland
- Dr Attracta Lafferty, UCD, Research Fellow
- Professor Amanda Phelan, UCD, Head of Subject for Older People and Associate Dean for Global Engagement
- Professor Eilish McAuliffe, UCD, Professor of Health Systems
- Dr Diarmuid O'Shea, Consultant in Geriatric Medicine at St Vincent's University Hospital

Workshop Plan

Each KEDS workshops was divided into the following parts:

1. Project Overview
2. Resilience
3. Research into Resilience and Caring for Someone with Dementia
4. Developing a Resource to Promote Carer Resilience

In each workshop the facilitator provided an overview of the project and the outputs to date, and then highlighted why the research is relevant to family carers and their lived experiences. The facilitator also provided an opportunity for discussion and feedback on the topics covered. For example, after each part was completed, the facilitator allowed for knowledge exchange moments where the participants discussed what it means to be resilient as a family carer and how the research compared to their experiences as carers, which was followed by an opportunity to provide feedback on the TCOY resource.

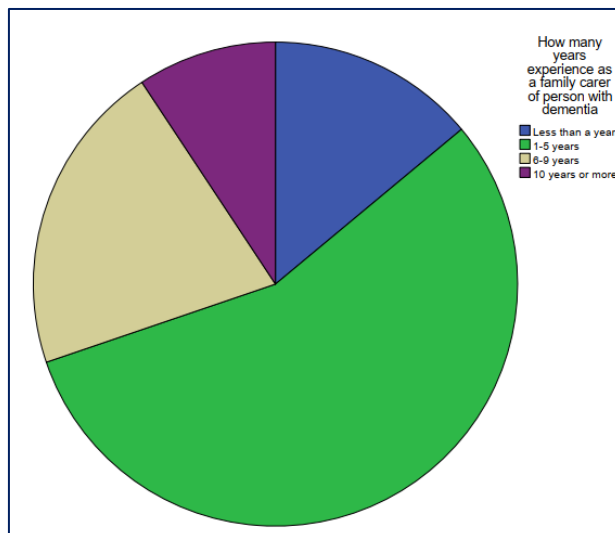
At the end of each workshop, the group was invited to complete an exit survey, not only to gauge their impressions of the TCOY resource, but also to determine their overall experiences of the KEDS workshops. This report discusses the family carers' experiences, which cover a range of topics and themes from dealing with repetition to transitioning to residential care. In order to ensure anonymity and confidentiality, participant names are not used throughout the report.

Experiences of Family Carers in Workshops

The KEDS workshops provided an opportunity for family carers of people with dementia to provide feedback on the TCOY resource. The group was also invited, but not obligated, to share their family caring experiences with others in the group. This report will examine some of the experiences and comments made by the group in each of the sessions. Alongside this, the report will use exit survey data from the workshops to better inform our understanding of the family carers' experience of the KEDS sessions.

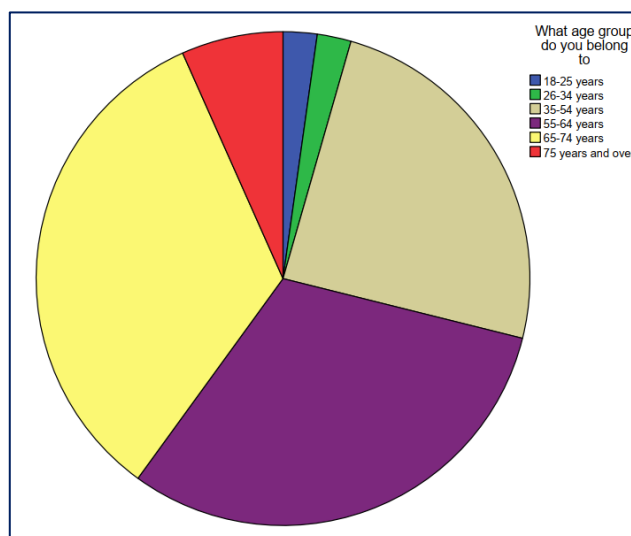
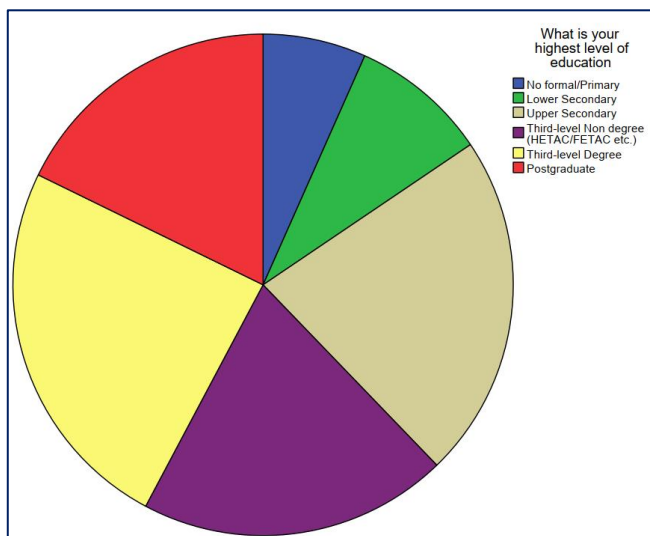
Background: Family Carers of People with Dementia

One of the purposes of the workshops was to invite family carers of people with dementia who were not in receipt of Carer's Allowance to provide feedback on the TCOY resource, but also to share their caring experiences if they wished to do so. As a result, there was a wide range of caring experiences at each workshop, with some people caring for years and others only starting in their caring role. In each workshop there was a mixture of male and female carers, as well as a mix of those caring for spouses and those caring for parents, and there was a varied level of education. In such a diverse group of people, there was much discussion and many different points of view. The varying level of caring experience and ages is illustrated by the graphs below.



In the first workshop, one attendee noted from her experience that young children are often impacted by dementia yet supports are not tailored to their needs. She gave as an example that the violent outbursts of a person with dementia in her family could be seen as a child-protection issue and

- 13% had less than a years' experience
- 52% had 1-5 years' experience
- 19.6% had 6-9 years' experience
- 8.7% had 10 years or more experience

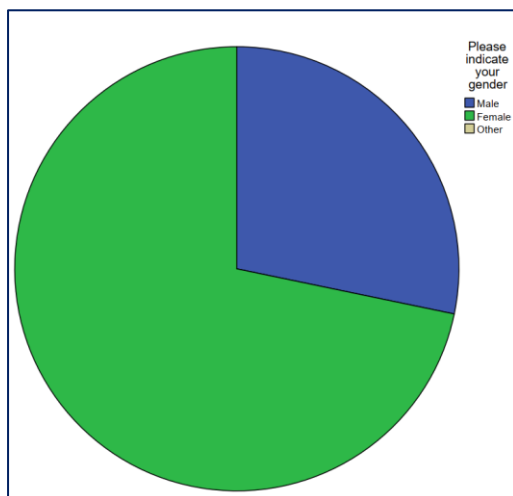


- 6.5% No Formal/Primary
- 8.7% Lower Secondary
- 21.75% Upper Secondary
- 19.6% Third-level degree (HETAC/FETAC etc.)
- 23.9% Third-level degree
- 17.4% Postgraduate

- 2.2% between 18-25
- 2.2% between 25-34
- 4.4% between 18-34
- 23.9% between 35-54
- 30.4% between 55-64
- 32.6% between 65-74
- 6.5% 75 years and over

yet there is no clear signposting for families on where to go for support for such situations. Many participants raised the topic of family conflict and caring for someone with dementia. Some family carers noted that often the caring role falls to one person and it can be very hard to engage other family members and find support when it is needed. One participant noted that while she was unable to provide full-time care to her parent with dementia, she helps and does what she can when possible. However, her sibling who is the primary carer is very resentful of this and she worries how their relationship will be impacted in the long-run.

One member of the group in the third workshop mentioned that in comparison with the National Health Service in the United Kingdom, the Health Service Executive was doing a 'better job



- 71.7% Female
- 28.3% Male

at caring' for people with dementia, but there was still a need for better supports in the Irish system to help family carers be more resilient.

A number of people had never previously attended a support group or group session like the workshop. One participant from the fourth workshop mentioned that it was refreshing to see that she was not alone in her experiences as a family carer; this was her first time attending a group meeting or intervention of sorts and she was '*happy to see that she is not alone*'. Throughout the workshops it was clear that many people had never been to a support group, dementia café, etc.

The varying levels of caring experience ensured there were multiple points of view on each topic discussed, which will be further elaborated on below as we discuss some of the common themes which arose over the five workshops.

Themes

Dementia Diagnosis

One of the core concerns raised by a number of family carers revolved around the issue of getting a dementia diagnosis. A number of participants in the first workshop stated that the capacity tests³ were ineffective as many had stories of their loved ones with dementia '*passing*' these tests with '*flying colours*', and once outside the doctor's office not knowing where they were or why they were there. Many family carers shared the same stories and expressed the frustration that this can cause to the caregiver. Some suggested that the testimony of carers should be factored into any assessments carried out. The idea that some people with dementia can '*do well*' at the capacity tests came up across multiple workshops and was one of the core issues highlighted by many participants. Many in the first workshop stated that '*family carers are not taken seriously by GPs and doctors*' when discussing matters related to their family members' health and well-being.

Throughout the workshops, the difficulty of getting a dementia diagnosis was highlighted, as well as the frustration caused to carers when their insights and reports of worrying behaviour

³ For example <https://www.alzheimers.org.uk/get-support/legal-financial/assessing-capacity>

were ignored by health professionals in favour of standardised tests which the person often passed. In the fourth workshop, one person stated that when trying to get a dementia diagnosis for her husband their local GP asserted that *'it is just old age'* causing the lapses in memory, which she found very upsetting and disconcerting.

Participants in the fifth workshop highlighted that they did not know where to turn at first to get a diagnosis or where to get support to help care for their loved ones after getting a diagnosis.

Getting a dementia diagnosis proved to be a lively topic of discussion in each workshop, with many family carers stating how they had difficulty getting a diagnosis and found it hard to get support from local health nurses or GPs.

Resilience as a Family Carer

As resilience was the main focus of the project and the KEDS workshops, it is no surprise that there was plenty of discussion on the topic. In the first workshop, the group agreed that resilience plays an important role in caring for someone with dementia. Many in the first group stated that there are different types of resilience and that the caring experiences of family carers will vary from person to person, as will a person's ability to remain resilient in the face of burden and negativity.

One member mentioned in the second workshop that it doesn't matter whether a person is resilient and that *'there is no choice in the matter'* when it comes to caring for a family member, which caused some contention within the group as some agreed and some disagreed with the idea that there was no choice regarding caring for someone. This is also considered in the research presented at the workshops – that some people demonstrate more resilience when they make the choice to care for their loved ones. Despite the argument about whether there is a choice to care or not, there was a consensus amongst the second group that levels of resilience vary from person to person.

In the third workshop, one individual mentioned that it is vital to look after one's own health as a family carer. Some in the group shared stories about how they suffered with depression and anxiety when caring for someone with dementia and highlighted how important it is to talk to others and to *'reach out to friends, family and health professionals'* when you need help.

One participant in the fourth workshop relayed how he adapts and overcomes challenges by allowing the family member he cares for to retain some elements of freedom, which in turn makes the caring role easier for him, and also his family member is now less prone to frustration and confusion. In contrast to this, another participant stated that it can be *'frustrating to have to remember two shopping lists'* and that it is hard to be in two frames of mind as a mother who

needs to care for her own children and also act as a carer for her mother. This participant stated that this impinged on her ability to remain resilient and positive at times as a family carer.

Many people were concerned about feelings of guilt for taking time off or passing the buck of the caring role, even if only for a matter of a few days. One person highlighted that while it may make you feel guilty at first, taking breaks '*has to be done or you will end up drained*'. Another stated that it can be difficult to '*switch off*' and that she was tired and depressed all the time due to her caring responsibilities. She has learned to take care of herself and she decided to take a week off and go on holiday by herself and, despite feeling guilty doing so, felt that it was the best thing she could have done as she was able to '*relax and recharge*'.

While the necessity to take care of yourself and take breaks was a common theme across the workshops, a number of people mentioned that it was not an option for them. In the fifth workshop, one man detailed how he must do everything for his wife and that his wife '*would not go into respite*'; he said that his daughters can sometimes help but that they live away from home and are unable to care their mother for extended periods of time due to them having their own families to take care of. This man further discussed how, while dementia is the main issue affecting his wife, she must also wear two stoma bags, which are an added burden. He said that the stoma bags are causing greater stress than the dementia and that he '*is not sleeping at night with worry*'. One way in which this man cares for his wife is to remain upbeat and positive as much as possible. He gave an example concerning an occasion when he was driving the car and his wife asked where her late mother was. Reacting in a positive and humorous tone while trying to remain calm and collected is the way this man tries to care for his wife and allows him to '*deal with the situation better*'.

Throughout the workshops it was highlighted that '*some days are easier than others*' and that you need to speak with others and ask for help when it is needed. However, in workshop five it was noted that while it is important to talk, it is also important to talk about things unrelated to the family caring role or the person with dementia. One person said, '*you need to talk, but not always about the family member you are caring for*', and that it is important to live your own life as an individual instead of just as a family carer. Many mentioned that meeting others in the same situation is a good way of '*learning about others*' and that '*it could always be worse in some cases*'. Throughout the five workshops, there was strong agreement that '*it is vital to talk to others*' and that looking after yourself is a very important thing to do as there is a chance that you also could become hurt or sick, which would mean '*you will have no backup plan*' and then '*you will be in serious trouble*'.

Dealing with Repetition

Many in each workshop discussed how dealing with repetition can be burdensome and frustrating for the carers and for the person with dementia. In workshop five, many of the participants felt that dealing with repetition can be a drain on the levels of resilience in a carer. One participant stated that to be resilient as a family carer of a person with dementia, *‘you must be able to deal with the repetition’* that can arise as a result of dementia.

Another participant highlighted that *‘it is important to remain calm’*, but on some occasions when resilience may be low, they react negatively to repetition, which in turn can cause further confusion to the person with dementia but also cause a *‘feeling of guilt’* for the carer as the person with dementia *‘does not know what they have done’*. Another attendee added that it is sometimes like dealing with a *‘bold child that doesn’t know what they are doing’*.

Destigmatising Alzheimer’s/Dementia

Many family carers in the five workshops described how they feared neighbours, friends and other family members finding out their loved one had dementia, due to the stigma and lack of knowledge around the illness. Some mentioned that while some campaigns have been good at highlighting what dementia is, such as the ‘Understand Together’ campaign from the Health Services Executive (HSE), there is still a misunderstanding of the illness in many parts of the country.

In the second workshop, the group highlighted that many are still ill-informed about what dementia is and that *‘more information is better and allows for more understanding’*. For example, one woman discussed how she would take her husband shopping and how he likes to wander around the shop. When she informs the staff in the store that her husband has dementia and that he will be walking around the shop, they are happy to be of assistance as far as possible. This woman highlights that she is able to go shopping, content in the fact that her husband is being looked after and won’t wander out of the shop and if he does, that there are people to bring this to her attention. However, this woman also mentions how her neighbours *‘knew about my husband’* before she had even mentioned his dementia to them, based on the evidence and having been close prior to her husband’s diagnosis. She said that now they seem uneasy at the idea of her husband having dementia, which she says would not be the case if more information about dementia was made available.

The role of support groups was also brought up when discussing the stigma of dementia. It was mentioned by many across the groups that it can be difficult to go to support groups or seek support, especially for those living in small communities. Many of the family carers said they feared how some people would react to the news of their loved ones having dementia and that

their *'loved one would become a source of gossip'*. A number of people spoke of the stigma of dementia acting as a barrier to reaching out to others.

Accessing Information and Supports; Lack of Knowledge and Education

Throughout the workshops, many in each group described how difficult it is to obtain information and support in regard to dementia. In the first workshop, some, participants mentioned that *'information on dementia for family carers was difficult to find'*, that *'there was not enough information about dementia'* and that there is a need *'for more training for GPs when it comes to dementia'*. This was further highlighted in the second workshop, with many participants stating the importance of family carers having a GP or public health nurse who *'understood dementia and also its impact on the family carer'*. Many of the group offered examples of experiences in which the services of GPs were inadequate or not forthcoming when discussing dementia and dementia care.

Concerns were presented in the third workshop that even where supports exist and information is available, there is a lack of coordination across the health service which impacts on the ability of carers to remain resilient. Many in the third workshop stated that gaining access to support and resources can be difficult, especially where communication between services and carers are poor. Some argued that GPs should be made aware of the resources available to carers and they could then direct carers to them. Throughout the workshops there was an understanding that both services and information for dementia and dementia care was fragmented and hard to access and that this was not helpful to carers or their levels of resilience.

When discussing education and knowledge of dementia in the third workshop, there was also the fear of *'knowing too much'* and that it may be upsetting and undermine resilience. In contrast, others stated that not knowing what to expect had been *'very challenging'*. These two parallel but diverging statements on knowing too much versus not knowing enough underscore the individuality of each family carer's experiences. For example, one carer stated that they felt more isolated when they attended an Alzheimer's Café because they were the only one with a loved one with Lewy Bodies dementia. This made them feel more isolated than before as their experiences were very different to the other carers and families in attendance.

In the fourth workshop, one of the participants mentioned that to care for a loved one with dementia requires a person *'to be very understanding and aware of the illness of what dementia is'*. Many people indicated that there was a need for better support systems to help family carers be more resilient. One person mentioned how it is difficult to care for family members who suffer with incontinence, where there is no suitable apparatus to assist the person. A family carer explained how she was accused of elder abuse *'because she could not find pull-ups'* that fitted her mother correctly, which was an emotional challenge. As

mentioned in previous workshops, it was reiterated that family carers should be made aware of supports by GPs, public health nurses and dementia advisers, as many family carers are unable to access supports because they are unaware that they exist or simply because they find them difficult and confusing to access. Some people, for example, have difficulty accessing online resources.

Throughout the workshops, participants highlighted that supports are key to helping care for their loved ones, whether formal supports such as GPs being more aware of dementia and dementia care, or informal supports such as family members assisting the primary carer, thus allowing them to take time off or switch off. One family carer in the fifth workshop highlighted the significance of the person with dementia being willing to access supports, saying: '*[it] depends on the willingness of the person with dementia to get support in the first place*'. Another family carer added to this by stating that the willingness of the person with dementia is important as regards activities and accessing supports. One woman mentioned how her husband only '*does things with me, like walks and watches movies but won't do anything else with my daughters*'. Another participant added that his wife, who has dementia, never wanted to join clubs or groups, and even though she enjoyed herself singing in a local support group on various occasions, he states that '*she did not want to [go back]*'.

The ability to access services was highlighted throughout the workshops. In the final workshop one man who is a former carer succinctly explained that '*it was easier to find support in Dublin*' and another participant added '*we are in an advantageous situation, living in Dublin*'. This builds on previous comments in earlier workshops that Dublin gets access to research, workshops and supports to a greater extent than the west of Ireland or rural areas

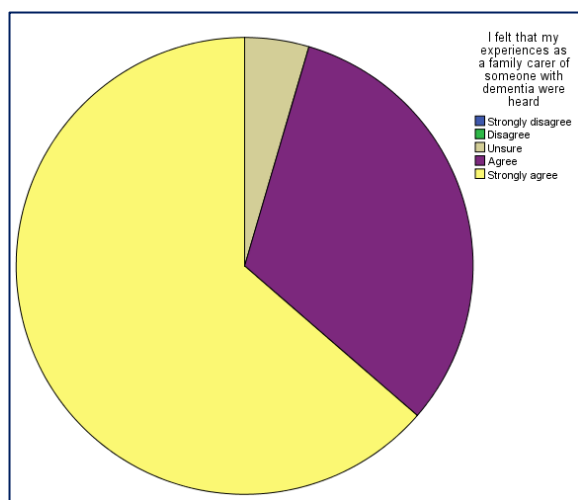
Views of Research Presented

Throughout the five workshops there was positive feedback in relation to the research presented, with many family carers in each workshop stating that the research related to their experiences as carers.

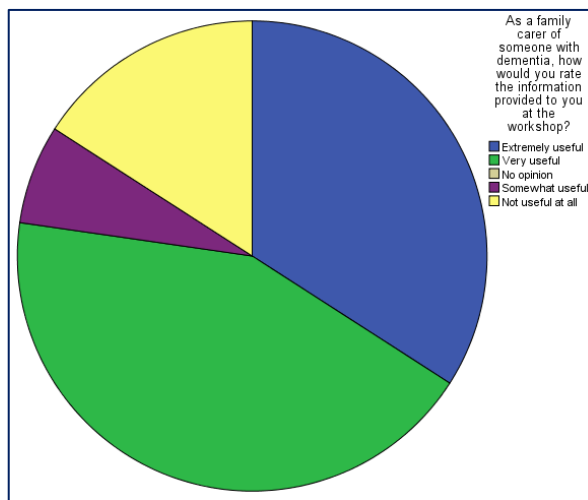
In the first workshop, many in the group discussed the systemic problems that they believe hamper dementia care and have a negative impact on carer resilience. While there was near unanimity that the research presented reflected the experiences of family carers, one participant in the second workshop mentioned that the research presented appeared counter-intuitive and contrary to her understanding of caring, resilience and quality of life.

In the third workshop, another participant took issue with the conclusion from the systematic review that female carers are more susceptible to depression than male carers.

As mentioned above, in the fourth workshop it was stated that it is often carers and families in Dublin who get access to research workshops and projects, more so than in the rest of Ireland. From the graphs provided below, it is evident that the majority of family carers felt that their experiences were reflected in the workshops. Overall, most of the participants related to the research presented and felt that the research was relevant to their own experiences. Alongside this, over 80% of the participants found the information provided at the workshops useful.



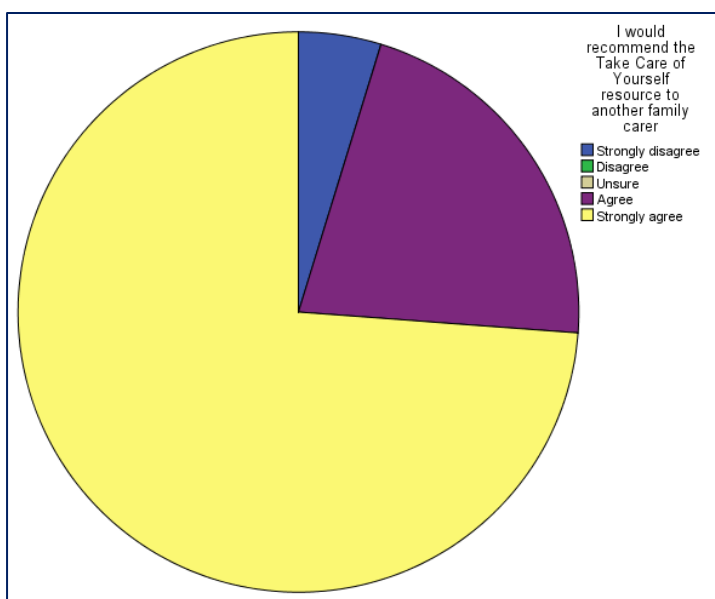
- 60.9% Strongly Agree
- 30.4% Agree
- 4.3% Unsure



- 41.3% Very Useful
- 32.6% Extremely Useful
- 15.2% Not Useful at all
- 6.5% Somewhat Useful

Views of TCOY Resource

One of the main aims of the workshops was to promote the TCOY resource and invite the participants to provide feedback on the resource as family carers of people with dementia. Over the five workshops, the resource was received positively, as shown by the graph below, with over 85% agreeing that they would recommend the TCOY resource to another family carer.



- 67.4% Strongly Agree
- 19.6% Agree
- 4.3% Strongly Disagree

In the first workshop, many mentioned that the resource offered the potential to support family carers in the future. One family carer mentioned that *'they wished this resource was available to them sooner'*, while another stated that the *'resource was a great idea and it was good to see all this helpful information in one spot'*.

This was further illustrated in the second workshop when the group reacted positively to the TCOY resource with many wishing to know

when the website would go live for general usage. One participant praised the resource for *'bringing together so much information in a single resource'*. However, it was also highlighted that it would be important to ensure that the website receives

adequate support as it would be a shame to lose the TCOY resource. One participant mentioned that it would be a good idea to inform GPs, public health nurses and specialists about this resource.

In the third workshop, the group present responded positively and were happy to see such a resource being developed. While there were some concerns about accessibility for older people, many were happy to see that there was a hard-copy booklet created to demonstrate what the resource contains and how to go about finding more information.

In the fourth workshop, there was a positive reaction to the Carer Stories section and the design of the resource in particular. The group mentioned that it was good to see videos on the website as it showed others that they may not be alone also. This was further discussed in the fifth workshop with many stating that they were happy to see that *'they were*

not alone'. There were some concerns about what would happen to the website after the project was completed, with participants airing concerns that it would be a shame for the website to fall out of action. One person stated that *'this website would have been very helpful years ago but that [she is] very happy to see this website now'*.

One participant in the fifth workshop mentioned that *'it would be a shame for the website to disappear as it looks very helpful'*. Many stated that they would be recommending the TCOY resource to others and that they were looking forward to viewing the website themselves at a later date.

Views of the Workshops

Many of the participants viewed the workshops in a positive light and benefitted from the opportunity to share their experiences and speak with other family carers of people with dementia, especially those who had never previously met other carers in a support group or workshop setting. In the first workshop, many members remained to have lunch and shared further experiences as family carers; some also happily shared personal contact information to keep in touch in the future.

Across the five workshops, many people remained for lunch and refreshments. After each workshop, family carers shared their personal stories of caring and there was a positive and supportive environment overall. Many participants had never taken part in a workshop or attended a support group, which was illustrated by a participant in the fifth workshop stating that it was refreshing and helpful to see that she was not alone in her experiences as a family carer and that the *'workshop was of great help'*.

Post-Workshop Follow-up

Co-facilitator Mr Kevin Deegan sent an email two weeks after each event to order to update the participants on the workshops and also to see if they had any further opinion on the workshops or TCOY resource. This email was also sent to thank the family carers who took part in the workshops. Several people replied with positive comments and feedback, as outlined below:

- *'Thanks to all of you for today. Well done. The site looks great. The workshop was great, it was lovely to chat to other carers and hear how they cope. I would be interested in attending any other workshops you may be organising in the future.'*
- *'I would like to say how fantastic the workshop was in the Ashling Hotel. I found it was enormously helpful. Everything was just perfect from start to finish. The website is going to be a tremendous help and support to carers. The work*

you guys have done and are doing is so empowering for carers and inspirational to medical/clinical professionals. Many thanks once again.’

- *‘Absolutely wonderful website, it is a real treasure – so much work, detail and information included; heaven sent is what I would say.’*
- *‘I’ve had a quick look at the link [TCOY Website] and it looks very good. Most of all I want to thank you for the workshop. I found it very informative and it was great to meet other people in the same position. I thought that it was very well run and there was great respect and empathy for everyone who spoke. I would be delighted to hear about any future events.’*
- *‘I really enjoyed the workshop and found it really helpful. Thanks so much to all involved. The website looks great – I love the layout. Simple and clear and the videos are great. I’d love to be informed when it goes live.’*
- *‘It looks good to me, if you have any further events in this area please let me know.’*
- *‘Thank you for a very interesting workshop last week. I really enjoyed meeting them [other family carers]. They are inspirational! Thank you again, and every good wish for your ongoing work.’*

Exit Survey from Workshops

Please indicate which of the following best describes you

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Current carer of person with dementia	35	76.1	81.4	81.4
	Former carer of person with dementia	3	6.5	7.0	88.4
	Other	5	10.9	11.6	100.0
	Total	43	93.5	100.0	
Missing	Missing	3	6.5		
Total		46	100.0		

If you selected Other please specify

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Awaiting diagnosis	1	2.2	16.7	16.7
Building awareness of Dementia	1	2.2	16.7	33.3
Cared for wife for 8 years – she's now in a home	1	2.2	16.7	50.0
I am supporting my mom in caring for my dad	1	2.2	16.7	66.7
I give assistance when needed. I try and keep the social element alive for the PWD	1	2.2	16.7	83.3
Son of person with dementia	1	2.2	16.7	100.0
Total	6	13.0	100.0	
Total	40	87.0		
Total	46	100.0		

What is your relationship to person you care for?

	Frequency	Percent	Valid Percent	Cumulative Percent
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Valid	Spouse	25	54.3	55.6	55.6
	Mother/Father (you are their son/daughter)	17	37.0	37.8	93.3
	Sibling	1	2.2	2.2	95.6
	Relative	1	2.2	2.2	97.8
	Friend	1	2.2	2.2	100.0
	Total	45	97.8	100.0	
Missing	Missing	1	2.2		
Total		46	100.0		

How many years' experience as a family carer of person with dementia?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than a year	6	13.0	14.0	14.0
	1–5 years	24	52.2	55.8	69.8
	6–9 years	9	19.6	20.9	90.7
	10 years or more	4	8.7	9.3	100.0
	Total	43	93.5	100.0	
Missing	Missing	3	6.5		
Total		46	100.0		

What age group do you belong to?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	18-25 years	1	2.2	2.2	2.2
	26-34 years	1	2.2	2.2	4.4
	35-54 years	11	23.9	24.4	28.9
	55-64 years	14	30.4	31.1	60.0
	65-74 years	15	32.6	33.3	93.3
	75 years and over	3	6.5	6.7	100.0
	Total		45	97.8	100.0
Missing	Missing	1	2.2		
Total		46	100.0		

What is your highest level of education?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No formal/Primary	3	6.5	6.7	6.7
	Lower Secondary	4	8.7	8.9	15.6
	Upper Secondary	10	21.7	22.2	37.8
	Third-level Non degree (HETAC/FETAC etc.)	9	19.6	20.0	57.8
	Third-level Degree	11	23.9	24.4	82.2

	Postgraduate	8	17.4	17.8	100.0
	Total	45	97.8	100.0	
Missing	Missing	1	2.2		
Total		46	100.0		

Please indicate your gender

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Male	13	28.3	28.3	28.3
	Female	33	71.7	71.7	100.0
	Total	46	100.0	100.0	

Where do you live?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	A small town	11	23.9	23.9	23.9
	A large town	11	23.9	23.9	47.8
	A major city	18	39.1	39.1	87.0
	Other	6	13.0	13.0	100.0
	Total	46	100.0	100.0	

If you selected Other, please specify

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid				
Countryside	2	4.3	28.6	28.6
On a farm outside of village; 10km to town	1	2.2	14.3	42.9
Rural	2	4.3	28.6	71.4
Small village	1	2.2	14.3	85.7
Suburb of Dublin	1	2.2	14.3	100.0
Total	7	15.2	100.0	
Missing	24	52.2		
Total	46	100.0		

How do you access the internet/computer or laptop

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid				
Computer	33	71.7	71.7	71.7
Laptop	13	28.3	28.3	100.0
Total	46	100.0	100.0	

How do you access the internet/phone

T +353 1 874 7776

E info@carealliance.ie
W www.carealliance.ie

A Coleraine House
Coleraine Street
Dublin 7, Ireland
DO7 E8X7

Registered Company No
461315
Charity Registration No
20048303
CHY No 14644



	Frequency	Percent	Valid Percent	Cumulative Percent
Valid Phone	24	52.2	52.2	52.2
No	22	47.8	47.8	100.0
Total	46	100.0	100.0	

How do you access the internet/tablet-iPad

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid iPad	16	34.8	34.8	34.8
No	30	65.2	65.2	100.0
Total	46	100.0	100.0	

How do you access the internet/no access

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid No Access	3	6.5	6.7	6.7
Have Access	42	91.3	93.3	100.0
Total	45	97.8	100.0	
Missing Missing	1	2.2		
Total	46	100.0		

Are you in receipt of Carer's Allowance?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	13	28.3	28.3	28.3
	No	33	71.7	71.7	100.0
	Total	46	100.0	100.0	

The objectives of the workshop were made clear to me from the beginning

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Unsure	5	10.9	11.6	11.6
	Agree	12	26.1	27.9	39.5
	Strongly agree	26	56.5	60.5	100.0
	Total	43	93.5	100.0	
Missing	Missing	3	6.5		
Total		46	100.0		

The workshop was informative

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Agree	17	37.0	40.5	40.5

	Strongly agree	25	54.3	59.5	100.0
	Total	42	91.3	100.0	
Missing	Missing	4	8.7		
Total		46	100.0		

The facilitator was well prepared

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Agree	8	17.4	18.2	18.2
	Strongly agree	36	78.3	81.8	100.0
	Total	44	95.7	100.0	
Missing	Missing	2	4.3		
Total		46	100.0		

The facilitator guided the session effectively

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Agree	10	21.7	23.3	23.3
	Strongly agree	33	71.7	76.7	100.0
	Total	43	93.5	100.0	
Missing	Missing	3	6.5		

Total	46	100.0	
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I felt that my experiences as a family carer of someone with dementia were heard

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Unsure	2	4.3	4.5	4.5
	Agree	14	30.4	31.8	36.4
	Strongly agree	28	60.9	63.6	100.0
	Total	44	95.7	100.0	
Missing	Missing	2	4.3		
Total		46	100.0		

The objectives of the workshop were achieved

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Agree	19	41.3	44.2	44.2
	Strongly agree	24	52.2	55.8	100.0
	Total	43	93.5	100.0	
Missing	Missing	3	6.5		
Total		46	100.0		

I am satisfied with my participation in the workshop

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Unsure	1	2.2	2.3	2.3
	Agree	18	39.1	40.9	43.2
	Strongly agree	25	54.3	56.8	100.0
	Total	44	95.7	100.0	
Missing	Missing	2	4.3		
Total		46	100.0		

As a family carer of someone with dementia, how would you rate the information provided to you at the workshop?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Extremely useful	15	32.6	34.1	34.1
	Very useful	19	41.3	43.2	77.3
	Somewhat useful	3	6.5	6.8	84.1
	Not useful at all	7	15.2	15.9	100.0
	Total	44	95.7	100.0	
Missing	Missing	2	4.3		
Total		46	100.0		

The information presented reflects my experiences as a family carer of someone with dementia

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	1	2.2	2.3	2.3
	Unsure	4	8.7	9.1	11.4
	Agree	18	39.1	40.9	52.3
	Strongly agree	21	45.7	47.7	100.0
Total		44	95.7	100.0	
Missing	Missing	2	4.3		
Total		46	100.0		

I would recommend the Take Care of Yourself resource to another family carer

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly disagree	2	4.3	4.8	4.8
	Agree	9	19.6	21.4	26.2
	Strongly agree	31	67.4	73.8	100.0
Total		42	91.3	100.0	
Missing	Missing	4	8.7		
Total		46	100.0		