

Knowledge Exchange and Dissemination Report on Key Outputs, Recommendations and Feedback from Family Carer Workshops

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

Author of Report: Kevin Deegan

Position: Project Assistant

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Introduction and Background

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, likely to have a more positive experience of caregiving. The project ultimately culminated in the development of the 'Take Care of Yourself' (TCOY) resource, which was developed with the assistance of the 'Enhancing Carer Resilience' group (EnCaRe).

As an extension of the main project, funding was awarded by the HRB for a secondary project titled the 'Family Carer Knowledge Exchange Project', otherwise known as Knowledge Exchange and Dissemination (KEDS) events. These KEDS events focused 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 obtain the benefits of the knowledge gained from the resilience project and also allow participants to provide feedback on both the research conducted and the TCOY resource.

The main KEDS workshops ran from September 2018 to November 2018, with five workshops in total and 59 family carers taking part in the workshops across Ireland. 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 keys outputs, recommendations and feedback gained from these KEDS workshops, with a focus in particular on the five workshops.



KEDS Project Team

The following were involved in the creation of material for and facilitation of the KEDS workshops:

- Professor Gerard Fealy, Professor of Nursing at UCD, Principal Investigator of the main HRB DEM project
- Ms Sandra McCarthy, HRB DEM 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 carer and how the research compared to their experiences as carers. This was followed by an opportunity to provide feedback on the TCOY resource.

Workshop Outputs, Recommendations and Feedback

Workshop 1

The first workshop took place in Dublin in the Ashling Hotel on 4th September 2018, with a total of 20 attendees. Of those in attendance, 19 were family carers and one was a dementia adviser from the Alzheimer Society of Ireland. Sandra McCarthy facilitated the workshop with

Professor Gerard Fealy and Mr Kevin Deegan acting as co-facilitators. Ms Jenny Smee, a member of the EnCaRe group, was also in attendance at the workshop.

It was evident from the introductions that many of those present were seeking information and some level of practical support for their caring situation. Following the introductions, the facilitator began to describe the project and why the project focused specifically on family carers and what could be done to support carers to weather the adverse effects of caring for someone with dementia.

Concept of Resilience: A brief discussion took place on the concept of resilience and those present agreed that resilience played an important role in caring for someone with dementia. Some people may be more resilient than others due to a number of factors. The group mentioned personality, genetics, upbringing and outlook on life as some of the key factors in a carer being resilient. It was also acknowledged that there are different types of resilience and that the experiences of individual family carers in overcoming challenges will vary.

Research into Resilience and Caring for Someone with Dementia: Many in the group related to the research presented and there was some discussion on the systemic problems which impede carers, which the group agreed may also have a negative impact on carer resilience. Some of the problems mentioned by participants were 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*'. Many of the group also mentioned that '*family carers are not taken seriously by GPs and doctors*' when discussing matters related to the health of their family members.

TCOY Resource: While there were time constraints in this workshop due to the large volume of participants and discussion, there was some feedback provided about the TCOY resource. Jenny Smee provided her own account as a family carer and how she became involved in the project. The resource was received positively, and many mentioned that the resource offered the potential to support family carers in the future. Some in the group mentioned that '*they wished this resource was available to them sooner*'. Another participant mentioned that the '*resource was a great idea and it was good to see all this helpful information in one spot*'.

Feedback from Dublin Workshop:

- It was suggested that including books about dementia on the TCOY website, aimed at children and young people, could be helpful.
- Some mentioned the positive benefits of meditation, which proves helpful in relieving carer burden and stress, and that information about meditation could be added to the TCOY website.

- One participant mentioned that the project liaises with the UCD School of Business in terms of sustaining the website into the future.

Key Points from Dublin Workshop:

- There are different types of resilience. Caring experiences will differ from person to person and will impact on carer resilience in different ways.
- Many in the group related to the research into resilience that was presented. The group discussed how carer resilience is affected by some of the systemic problems that exist for family carers, such as a lack of information or lack of communication.
- The group reacted positively to the TCOY resource, with many highlighting that it is a great place to find all relevant information for family carers of people with dementia in one location.
- Some members of the group remained for lunch after the workshop. There was a healthy and positive atmosphere and some members of the workshop happily shared their contact information to keep in touch in the future.

Workshop 2

The second workshop was held at the Springhill Court Hotel Kilkenny on the 11th September 2018. A total of eight family carers attended, and one was accompanied by a family member. Professor Gerard Fealy facilitated the workshop and Mr Kevin Deegan and a member of the EnCaRe Group acted as co-facilitators.

The facilitator and co-facilitators introduced themselves to the workshops and those present introduced themselves, mentioning briefly their role as a family carer. It was clear from the introductions that there was a wide range of caring experiences. For example, one member mentioned that this was her first ever meeting, with her spouse having been recently diagnosed. Another participant mentioned how they had the responsibility of caring for two people with dementia. One family member spoke at length about her spouse's dementia, including the circumstances in which it first developed and was recognised. The facilitator provided a brief overview of the project and the objectives of the workshop. It was stressed to the group that the workshop was focused on information sharing and that the project team wished to share knowledge from their research on resilience, but also to learn from those present and their experiences of resilience as family carers.

Concept of Resilience: After the facilitator finished presenting material on resilience, the group were invited to discuss their experiences as family carers and what it means to be resilient. There was a healthy and open discussion amongst the group, in which some of the participants spoke at length about their experiences. Group members had differing opinions on the concept of resilience and what it means to be resilient. One member mentioned how 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. There was consensus on the idea that resilience varies in different people. The group agreed that resilience is different for each person and that not every person is resilient, and that it can be very difficult to '*look after yourself at times*'. The discussion was open and non-threatening, and there was agreement amongst the group about the importance of resilience in the context of becoming both an effective caregiver and maintaining one's individuality and wellbeing.

Research into Resilience and Caring for Someone with Dementia: As with the first meeting in Dublin, some in the group related to the research presented. There was open and energetic discussion on the material presented, with some of the participants confirming that the research was consistent with their own individual experiences. One participant mentioned that the research presented appeared counter-intuitive and contrary to her understanding of caring, resilience and quality of life. A common theme emerged from the discussion which highlighted the importance of family carers having a GP or public health nurse who understood dementia and also its impact on the family carer. For example, many in the group offered accounts of

experiences in which the services of GPs were inadequate or not forthcoming when discussing dementia and dementia care.

TCOY Resource: The facilitator provided an overview of the work developing the TCOY resource, and it was stated that this resource was created with the intention of complementing, but not replicating, other available resources. The facilitator invited a member of the EnCaRe group to provide her account of the development of the resource. This EnCaRe member gave a detailed account of her own journey as a family carer and how she became involved in the project. The group reacted positively to the TCOY resource with many of the group wishing to know when the website would go live for general usage. One participant praised the resource for bringing so much information together in a single resource.

Feedback from Kilkenny Workshop:

- The group 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 group member mentioned that it would be a good idea to inform GPs, public health nurses and specialists about this resource.

Key Points from Kilkenny Workshop:

- Some members of the group highlighted how being resilient often does not matter for family carers as *'there is no choice in the matter'* when having to care for a family member.
- Resilience varies from person to person.
- The group highlighted the need to destigmatise the idea of Alzheimer's and dementia as some people are not informed about the disease. More information is better and allows for more understanding.
- It is important to have a GP or public health nurse who understands dementia and also the impact dementia has on the family carers.

Workshop 3

The third workshop was held in the Ambassador Hotel on the 18th September 2018. There were a total of 11 attendees and two members of the project team: Ms Sandra McCarthy and Mr Kevin Deegan. One member of the EnCaRe group also attended as a representative to speak about the development of the TCOY resource. Sandra McCarthy acted as facilitator and Kevin Deegan acted as co-facilitator.

The facilitator began by welcoming everyone to the session and inviting those present to briefly introduce themselves. A number of attendees were in the very early stages of caring for someone with dementia with one attendee in particular still awaiting an official diagnosis of dementia. Following on from feedback from the first session, the facilitator highlighted that this was an information-sharing workshop and that addressing specific questions about dementia may not be within the scope of the team. Following this the facilitator went on to provide a brief overview of the project team and the objectives of the session. There was good engagement with the members in this section with a few questions about the National Dementia Strategy and the Understand Together media campaign from the Alzheimer Society of Ireland.

Concept of Resilience: After the facilitator provided the attendees with a good understanding of what resilience is and why it is relevant to caring for someone with dementia, the group were invited to discuss the role of resilience in caring, drawing from their own experiences. One member of the group mentioned that when compared with the National Health Service in the United Kingdom, the Health Service Executive (HSE) was doing a better job caring for people with dementia, but that there was still a need for better supports to help family carers to be more resilient. Another person mentioned that resilience is innate and more down to a '*person's personality*'.

Many in the group stated that there is a lack of coordinated support across the HSE, which impacts on the ability of the carer to remain resilient. As was mentioned in previous workshops, some attendees felt that GPs should be made aware of the resources available to carers and they could then direct family carers to such supports. There was a consensus that both services and information were fragmented and hard to access and that this was not helpful to carers or their resilience.

Research into Resilience and Caring for Someone with Dementia: The facilitator provided an in-depth look at the research conducted and described to the group the type of things that impact on carer resilience. There were mixed reactions to the research findings. While many of those present identified with the information presented, some of the attendees felt that their own experiences were not reflected in the research. One member took issue with the conclusion that female carers are more susceptible to depression than male carers. The facilitator

acknowledged that male carers can in fact suffer depression and also mentioned that findings from studies are not absolutes. Others mentioned suffering depression and how it is important for 'carers to talk to others' and to seek support and reach out to friends and health professionals.

One participant mentioned that they found the Alzheimer's Café helpful, while others spoke about a dementia stigma as a barrier to reaching out to others. The group were interested in how education can impact on resilience and the facilitator gave examples of dementia-focused training for carers and how understanding how dementia manifests and progresses can help carers be prepared, which can impact on their sense of competence and therefore their resilience. Some attendees felt that knowing too much about dementia could be upsetting and might undermine resilience, while for others not knowing what to expect had been very challenging.

The discussion on research into resilience was in-depth and focused on both formal and informal education and dementia care. The group members offered each other a lot of tips, advice and support and the attendees seemed to really gain from this support.

TCOY Resource: The facilitator gave the group a brief overview of the TCOY resource and described how the project developed through a series of meetings and discussions over an extended period of time. The EnCaRe member was invited to speak about her experience as a family carer and also about her opinion on how the project unfolded. She elaborated on how the resource came to be and spoke about how the TCOY resource was something she was proud of as it signified something that could potentially help others in the future.

Despite some minor audio difficulties in the room on the day, the group responded positively to the TCOY resource and were happy to see such a resource. There were concerns from some of the older attendees that older people might not be able to use the site and mentioned the importance of having a hard copy to share with carers just in case.

Overall the attendees appeared satisfied with the resource and the workshop.

Feedback from Cork Workshop:

- Some of the older participants mentioned that it would be important to have a hard-copy resource to share with older carers, as they may be unable to use web technologies.
- It was suggested that schools could be engaged to share information about this resource and about dementia.
- Books aimed at children on the topic of dementia could be featured on the site to help parents with young children to talk to them about dementia.

Key Points from Cork Workshop:

- There was a lot of engagement throughout the session and attendees appeared interested in the work presented and the topics discussed. It was apparent that much peer support and peer sharing took place and attendees seemed to benefit from this.
- The group raised concerns about lack of respite services and how difficulty accessing respite services impacts on resilience in carers and their ability to look after themselves.
- Concerns were also raised around the difficulty of getting a diagnosis of dementia in the first place and the frustration caused to carers when health care professionals ignore the points made by family carers.
- Some in the group expressed fear of and difficulty in telling people that their loved one has dementia. According to members of the group, this seemed more challenging for spousal carers and seemed to increase their sense of isolation.

Workshop 4

The fourth workshop was held in the Clayton Hotel on the 9th October 2018. There were a total of 11 attendees and two members of the project team: Professor Amanda Phelan and Mr Kevin Deegan. An individual involved in the EnCaRe meetings attended as a representative from the EnCaRe Group to describe the process and development of the TCOY resource. Ten of those in attendance were family carers and one person was a care worker. Professor Phelan acted as facilitator and Mr Deegan acted as co-facilitator.

The facilitator began the workshop by welcoming everyone to the session and invited those present to briefly introduce themselves. As was evident in previous workshops, many of the group sought to gain more information about how to help care for their loved ones. Each participant wanted to learn more about how to overcome a number of problems that they faced caring for a person with dementia. A number of people had never attended a support group or group session like the workshop.

Following introductions, the facilitator gave a brief overview of the project and the team. Professor Phelan clearly signified the aims of the workshop and also highlighted to the group that while information and practical supports would be featured as part of the material presented, it was made clear that this was not the main objective of the session. The facilitator began by placing the project within the context of the National Dementia Strategy, which some in the group were not aware of. The group had varying levels of experience of caring. There was strong engagement from the group, with a number of participants happy to share their experiences and engage in conversation immediately.

Concept of Resilience: The facilitator spoke briefly about resilience and the context of caring, in particular, the relationship between resilience and managing or coping with the recognised challenges of caring for someone with dementia. A number of topics were discussed in this exercise, ranging from the emotional wellbeing of the carer to the financial and legal obligations carers faced. 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 and of what dementia is. One family carer talked about how to adapt and overcome challenges by allowing the family member who suffers with dementia to retain elements of independence, which in turn makes the caring role easier as the family member is less prone to confusion and frustration.

Another member suggested 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 carer for her mother. There was a consensus in the group that there was a need for better support systems to help family carers be more resilient. In one example, some of the group mentioned how it is difficult to care for family members who suffer with incontinence, when there is no suitable apparatus to assist the person. In one example, a family carer was explaining how she was accused of elder abuse *'because she could not find pull-ups'* that fitted her mother correctly, which was an emotional challenge.

There was a strong debate amongst the participants about what made carers more resilient and what resilience was. People mentioned that education and being informed is important. Some also mentioned that looking after yourself was key to remaining resilient, with one member stating that *'even though if sending your mother to respite care makes you feel guilty at first, it is the best thing to do for yourself every now and then'*.

Regarding supports, participants also raised issues that have negative impacts on resilience, specifically, not being aware that some supports exist or being unable to access supports due to finding it difficult and confusing to access them.

Research into Resilience and Caring for Someone with Dementia: Following the discussion on the concept of resilience, the facilitator moved on to elaborate on the research into resilience and caring for a person with dementia, and how resilience is impacted by the negative effects of caring.

The general feedback highlighted that the research reflected the experiences of many, if not all, the participants. One member of the group brought up the fact that it is often carers in Dublin who get access to research workshops and projects, whereas the research groups tend to stay away from the west of Ireland. Mr Deegan accepted that Dublin can be seen as a hotspot for research and that it is often the case that the research is conducted in Dublin and sometimes

fails to make its way to other areas across Ireland. Mr Deegan highlighted that this was one of the key reasons for planning six regional workshops across the country – so that family carers from across the island could have the opportunity to witness the research and the web resource first hand.

One participant mentioned that it was refreshing to see that she was not alone in her experiences as a family carer. As this was her first time attending a group meeting or intervention of sorts, she was happy to see that she was not alone. Many of the other participants offered to share advice and tips with each other. Some of the members shared their personal information directly between themselves and seemed happy at the idea of coming together in the future for a group chat or catch up.

Overall, the participants were happy to see that the research conducted reflected the experiences of their caring journeys. Participants discussed briefly how their own stories reflected each other and that it was good to note that they are not alone in their experiences. Many of the group seemed happy to sit and listen to other family carers share their stories about caring.

TCOY Resource: In this section, the facilitator discussed the development of the TCOY resource. The facilitator gave the attendees a brief overview of this process and how the project team went about developing the resource. The facilitator invited the EnCaRe member to speak briefly about her experiences of being involved with the project. There was strong engagement from attendees as she shared some of her own caring challenges. She described for the participants how she became involved in the project and how the project evolved into a web resource. Following an astute description of the project and the web resource, the facilitator moved on to discuss the resource briefly.

After the EnCaRe member spoke, the facilitator invited Mr Deegan to go through the TCOY resource. Mr Deegan went through the website and explained how the caring journey played a large role in the design of the home page, demonstrating the page to the participants. Mr Deegan next went through various features of the website and then focused on the Carers Stories videos. Some videos were played for the group, and there was a positive reaction throughout as many of the group related to each of the stories presented. The group mentioned that it was good to see videos on the website as it showed others that they may not be alone. The overall feedback on the website was positive, in terms of design and accessibility. One participant raised the question of the future of the website, and the facilitator replied that the resource was designed to be long-lasting and accessible into the future and that there is a potential that key stakeholders may take over the running of the website as this project finishes in the coming months.

Overall, the TCOY resource was received warmly and positively. There was a positive reaction to the Carers Stories section and the design of the resource in particular. There were some concerns about what will happen to the website in the future after the project is completed, with participants airing their concerns that it would be a shame for the website to fall out of action. It was noted that GPs and support groups should know about this resource.

Feedback from Galway Workshop:

- There was consensus that GPs/doctors/healthcare professionals should be made aware of this newly developed web resource to help them develop a deeper understanding of the caring role.
- It was acknowledged that the website is a good thing for increasing knowledge of both dementia and also of the role of family carers. Some in the group mentioned that their opinion had been '*shot down*' by doctors and GPs in the past when trying to explain symptoms of dementia.

Key Points from Galway Workshop:

- Many of the group agreed that there are not enough workshops/seminars about dementia and family caring in the west of Ireland, or rather, there is a lack of communication which meant that family carers do not know about such events.
- Many of the group stated that they only found out about the event through their local parish or newspaper. The co-facilitator, who organised the recruitment of the workshop, thanked the group for their feedback and mentioned that the very reason the workshop was promoted through numerous means such as parish newsletters, newspapers, social media, day centres, community centres, etc. was because of the fear that one avenue of recruitment would not suffice, which turned out to be the case.
- Even if family carers are aware of such events, it can be difficult for them to attend due to caring responsibilities. In one case, a participant mentioned that her husband was in respite the week of the Galway workshop, which allowed her to attend the session, otherwise she would have been unable to attend.
- Being resilient requires you '*to look after yourself, otherwise you cannot look after anyone else*'.
- It was mentioned that one can feel guilty taking time off from caring, even if for a few days, but '*it has to be done or you will end up drained*'. One participant mentioned that she was finding it difficult to '*switch off*' and that she was depressed and tired all the time from the caring responsibility as it was all she was doing. She mentioned how she decided to take a week off and go on holiday just by herself and, despite

feeling guilty doing so, felt it was the best thing she could have done as she was able to ‘*relax and recharge*’.

Workshop 5

The fifth and final workshop was held in the Carmichael Centre on the 2nd November 2018. There were a total of six attendees and two members of the project team: Professor Gerard Fealy and Mr Kevin Deegan. In a serendipitous outcome, a member of the workshop audience had assisted in the filming of material for the TCOY resource. Mr R.D. previously volunteered to help produce videos for the TCOY website but was unaware of the workshops that were taking place but was happy to be taking part in the fifth workshop. Professor Fealy acted as facilitator and Mr Deegan acted as co-facilitator.

Professor Fealy began by welcoming all members of the group to the session. Professor Fealy and Mr Deegan introduced themselves to the group and also invited the group to briefly introduce themselves. As with the previous four workshops, there was a wide array of caring experiences in the group. Many of those present were there to gain new information and also seeking help in some other areas such as how to get a diagnosis.

Following this Professor Fealy began to provide a brief overview of the project and the project team. The facilitator proceeded to discuss how the project was situated within the context of the National Dementia Strategy, which few in the group were familiar with. The facilitator discussed why the project focused on family carers and what could be done to support carers to weather the adverse effects of caring for someone with dementia. There was a positive atmosphere amongst the group and a strong level of engagement. Many of the group had questions about the National Dementia Strategy, the project and also questions on how to find more information for carers.

A good overview of the project was provided to the group, where all the key points were covered. Many in the group were more than happy to participate in conversation in the early moments of the sessions, which proved to be beneficial in helping to ease the group forward to discuss more serious issues about dementia.

Concept of Resilience: The facilitator moved on to discuss with the group the concept of resilience and how it relates to family carers. The aim of this was to provide the group with a clear understanding of what resilience is and why it is relevant to someone caring for someone with dementia. Following a concise presentation on resilience by Professor Fealy, the group were invited to discuss the role of resilience in caring, drawing from their own care-giving experiences.

The group discussed a number of topics and shared many stories of their own experiences of resilience with the group, which allowed for a lively and healthy discussion on resilience in family carers. The group talked about dealing with repetition, and being informed on dementia, support systems and also carers guilt. 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, carers can react negatively to repetition, which in turn can cause further confusion to the person with dementia but also a *'feeling of guilt'* to 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'*. Professor Fealy stated that this is a natural reaction to have when dealing with the repetition and that feeling a sense of guilt is also a natural response, and one which can have an impact on the resilience of family carers.

There was a consensus amongst the group that good supports are key to helping care for their loved ones. However, one participant mentioned that due to the personality of the person she is caring for, her husband, he only *'does things with me, like walks and watches movies but won't do anything else with my daughters'*. The participant stated that it could be hard sometimes being the only one able to care for her husband. Similarly, another participant mentioned that he must also do everything for his wife and that his wife *'would not go into respite'* but that his daughters would sometimes be able to look after his wife. This man stated that while dementia is one of the problems affecting his wife, she must also wear two stoma bags due to surgery, which is a big burden in its own right and which causes stress to the point where he *'is not sleeping at night with worry'*. It must be noted that this participant possessed a positive demeanour and was quite charming with the group as he described experiences of his wife's dementia. Specifically, this man mentioned his wife's lapses in short-term memory and how he reacts with humour and positivity when his wife asks a question about her mother, who happens to be deceased. In this case, reacting in a positive manner, even when his wife forgot who he was while he was driving beside her, helps him *'deal with the situation better'*.

Further to this, many of the participants mentioned that *'some days are easier than others'* and that *'you need to talk, but not always about the family member you are caring for'* and that it is also important to live your own life as an individual instead of just as a family carer. It was mentioned that meeting others caring for people with the condition *'to learn about others from different situations'* is a good way of understanding that you are not alone and that it *'can be worse in some cases'*. There was a strong agreement in the group that *'it is vital to talk to others'*.

Overall there was an excellent discussion on resilience, with various topics covered by the group. It was suggested within the group, and also mentioned in the research and in previous workshops, that being informed, talking to others and reacting with a positive outlook can have a positive impact on a family carer's resilience. This group highlighted in particular the topic of dealing with repetition and how it can put a large strain on a carer's ability to remain resilient. The group agreed that learning to cope with and understand repetition are some of the best ways to enhance a family carer's resilience.

Research into Resilience and Caring for Someone with Dementia: In this section the facilitator presented the research into resilience and caring for someone with dementia. Professor Fealy discussed the systematic review of contemporary literature on resilience and the meta-analysis which was conducted to highlight key findings, and finally information was presented about the national postal survey which was sent to family carers of people with dementia around Ireland. Most of the members related to the research being presented and some mentioned that the research was relevant to their own experiences.

One of the aims of the workshops was to include family carers who care for people with dementia and also to invite these family carers to share their experiences as family carers, if they so choose. Arguably, this was achieved in each workshop and was evident in the final session also. There were multiple avenues of discussion in the group and all members present were happy to engage with the research and also with each other. In reference to the material presented, some of the group mentioned 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. One participant stated that it also '*depends on the willingness of the person with dementia to get support in the first place*' and that while a support group may be helpful for some, it is important to note that some '*people with dementia do not like the idea of a support group*'. One person mentioned how his wife, who has dementia, never wanted to join clubs or groups, and even though she enjoyed herself in a support group on various occasions, he states that she would not go back as '*she did not want to*'.

It was also mentioned that '*it was easier to find support in Dublin*', with greater support present in '*this part of the country*'. This resonates with previous workshops, especially in Cork and Galway, where participants there said that it was difficult to find supports or help, either from support groups or from local GPs. One participant in this workshop stated '*we are in an advantageous situation, living in Dublin*'. Another participant mentioned that it was helpful and refreshing to see that she was not alone in her experiences as a family carer and that this '*workshop is of great help*'.

Overall, the participants were happy to see that the research conducted reflected the experiences of their caring journeys. Many of the group seemed happy to sit and listen to other family carers share their stories about caring. It was positive to see that the participants resonated with the research presented, which was a common theme throughout the five workshops.

TCOY Resource: Following on from the resilience discussion, Professor Fealy next began to describe the process about how the TCOY resource was designed and developed. Professor Fealy described how the resource was designed, with assistance from family carers of people with dementia, to be a one-stop shop for family carers to find information related to many matters that affect the resilience of family carers. Professor Fealy stated that the resource was designed with the intention of being a resilience-enhancing resource.

The facilitator then invited Mr Deegan to go through the TCOY resource. Mr Deegan went through the website while Professor Fealy explained how the caring journey played a large role in the design of the home page, which was shown to the participants. Mr Deegan next went through various features of the website and then focused on the Carers Stories videos. As Mr R.D. was in the group, Professor Fealy asked if he would speak of his own caring experiences and also if it would be OK to play his video. Mr R.D. gracefully obliged and the group watched the video, titled 'Knowing when to Transition to Residential Care'. Mr R.D. further stated that when his wife went to residential care, *'he was able to relax more'* and his wife was able to engage in activities in the residential care, which was *'almost like a hotel'* and that *'she was in a safe place'*. There was positive feedback from each member of the group about the videos in particular, as it helped show that *'they were not alone'*.

After listening to Mr R.D. discuss his caring journey, the group watched more videos. There was a positive reaction throughout as many of the group related to each of the stories presented. The feedback on the website was positive in terms of design, accessibility and usefulness. One participant raised the question of the future of the website, and the facilitator stated that the resource was designed to be long-lasting and accessible into the future and that there was the potential that key stakeholders would take over the running of the website. Another participant mentioned that *'this website would have been very helpful years ago but that she is very happy to see this website now'*.

The TCOY resource was received positively, especially the Carers Stories videos. There were some minor concerns about what will happen to the website after the project is completed as *'it would be a shame for the website to disappear as it looks very helpful'*. It was very good fortune that Mr R.D. was a participant in the workshop as he was able to provide an extra level of knowledge about the making of the website and carer videos. Just as in previous workshops,

it was positive to note that many of the participants would be recommending the resource to others and that they were looking forward to viewing the website themselves at a later date.

Feedback from second Dublin Workshop:

- Many of the participants felt that dealing with repetition can be a drain on the levels of resilience in a carer. In one particular case a participant mentions that she feels guilty when she reacts negatively when the person she cares for is repeating a similar question or action. It is important to understand carers guilt, and that it is often draining to remain positive and supportive, especially if the carer is feeling in any way vulnerable or finding it difficult to cope.
- There was a consensus amongst the group that it is very important to look after yourself, as otherwise you will suffer, and if you are hurt or sick after caring for a loved one then *'you will have no back up plan'* and *'you will be in serious trouble'*.
- The feedback about the TCOY website was positive and many in the group were more than happy to see the development of such a resource. However, the group did highlight the importance of ensuring that the website be accessible to older people who may not be technologically savvy. A hard copy of the resource was thought to be a good idea.
- There was also a concern surrounding the longevity of the website, as many questioned the future of the resource after the project finished. Some of the group stated that it would be a *'shame to lose this resource'*.

Key Points from second Dublin Workshop:

- As with many of the previous workshops, there was a consensus amongst the group that good supports and being informed about dementia are key points to helping care for loved ones.
- Some of the participants agreed that reacting in a positive manner, especially in relation to repetition, can potentially help a person remain resilient as a family carer.
- It is important to also live your own life as an individual instead of just as a family carer. It was mentioned that meeting others with the condition *'to learn about others from different situations'* is a good way of understanding that you are not alone and that it *'can be worse in some cases'*. There was a strong agreement in the group that *'it is vital to talk to others'*.
- Many in the group related to the research presented and could empathise with the experiences of other family carers in the group.
- Some members of the group mentioned that they did not know where to turn at first to get a diagnosis or to get support to help care for their loved ones, so to have a resource which provides much of this information is very helpful.

- There was a positive response to the TCOY website, with one participant stating ‘*this website would have been very helpful years ago but [I am] very happy to see this website now*’.

T +353 1 874 7776

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

A Coleraine House
Coleraine Street
Dublin 7, Ireland
D07 E8X7

Registered Company No
461315
Charity Registration No
20048303
CHY No 14644



Key Points from KEDS Workshops

1. There seems to be a lack of awareness of the National Dementia Strategy amongst many of the family carers who took part in the KEDS workshops. This was brought to the attention of the project team at the beginning of each workshop when the facilitator provided context for the project and how it was situated within the National Dementia Strategy. While some in each group were aware of the strategy, there were others who had never heard of the National Dementia Strategy. Whether this translates to a larger proportion of the population of family carers of people with dementia is something that we will be unable to determine as the sample number of family carers was less than 100. This may be worth noting for future studies or campaigns to raise awareness of the National Dementia Strategy in family carers of people with dementia, since one of the key points gathered from the workshops is that lack of information is a factor impeding resilience in family carers.
2. The workshops highlighted that family carers of people with dementia experience resilience and the care-giving journey differently. Many participants highlighted that being resilient can be due to a number of factors, such as personality, outlook on life, religious affiliation, genetic coding, etc. One of the key points that was made repeatedly in each workshop was the necessity for family carers to look after themselves. There were a number of arguments for and against the idea that an individual can be more or less resilient, as was noted in the research. The concept of resilience in family carers of people with dementia remains fluid and dynamic.
3. It is evident that there is a necessity to not only increase the levels of communication between family carers and GPs, public health nurses, etc. but also to make health and social care professionals more aware of the TCOY resource. Many participants highlighted that there is not enough information for family carers of people with dementia, and that where information is available, it is often difficult to access. According to the family carers, there is a need for GPs to be specially trained to deal with dementia patients and their family carers, as many carers have experienced GPs who do not know how to deal with potential dementia patients.
4. Throughout the workshops, each group highlighted the need to destigmatise the idea of Alzheimer's and dementia, as some people are not well-enough informed about the disease. The groups highlighted that being educated and more informed about the disease will increase levels of resilience in family carers and in people with dementia also as there will be less misunderstanding about dementia. This may result in people being more comfortable with the idea of a person who has dementia and may aid family carers, which in turn may boost the carers' levels of resilience.

5. It was made clear in each of the workshops that the TCOY resource will prove beneficial to family carers of people with dementia. The family carers who participated in the workshops overwhelmingly demonstrated positive feedback to the TCOY resource with emphasis placed particularly on the information contained in the website and its accessibility and functionality. Large numbers of the participants mentioned specifically that it was good to see the Carer Stories videos, as they demonstrated to family carers that they are not alone in their caring journey and that help is available.

