

You matter! Training to support family carers of people living with dementia

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You matter! Training to support family carers of people living with dementia

Courses for family carers can help them prepare for the future, build their resilience and equip them for their caring role. **Jennifer Bray**, **Teresa Atkinson** and **Tracey Williamson** (left to right below) evaluated a unique three-day residential course focusing on family carers of people living with dementia. *Carer support*

Caring for people living with dementia can be demanding and the impact of taking on a caring role can be detrimental for many people. Family carers can become emotionally and physically exhausted due to sleep deprivation, taking on more chores and providing practical help, but will often prioritise caring for a family member over their own wellbeing (ARUK 2015). Additionally, many unpaid, informal carers feel lonely or socially isolated as a result of their caring responsibilities (ARUK 2015).

As many family carers find themselves in a caring role rather than actively choosing one, it is perhaps not surprising that a carer's knowledge of dementia can often be limited and based on their own experiences. Carers may not be aware of the wider impact of dementia and so do not associate some symptoms with the condition (ARUK 2015, Stokes *et al* 2014). Many carers choose not to find out more about dementia and what the future may hold, preferring instead to take each day as it comes (Carers UK & Age UK 2015, ARUK 2015).

However, understanding the dementia journey and preparing for its challenges and opportunities can enable family carers to strengthen their own resilience, develop strategies and anticipate future needs for both themselves and their loved ones. One way for these carers to learn more about dementia is to attend a face-to-face or online course.

An initial scoping study of courses available for family carers of people with dementia identified 53 courses in the UK, of which seven were delivered online (Prins 2019). Where more information was available, 35 indicated that they were specifically aimed at family carers while a further nine said that they would be suitable for family carers as well as professionals.

Twenty-one courses were one-off sessions lasting less than half a day and 19 courses comprised multiple short sessions, such as one 2-hour session per week for six weeks. While these courses may meet some carers' needs, opportunities to explore topics in any depth may be few and far between.

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Summary

Becoming a family carer for a person with dementia is not always a choice, but with the role comes a whole host of challenges and demands for which an individual may not be prepared. Having relevant knowledge and understanding of dementia can help family carers prepare for the future, strengthen their own resilience and better equip them for their caring role.

A series of courses to address the needs of family carers was developed and piloted by Dementia Carers Count, including a 3-day residential course. Through interviews with course participants and the training facilitators, two overarching themes were identified.

Firstly, the unique skills and experience of the facilitators were recognised and appreciated by the participants and helped to create a safe environment where carers felt valued. Secondly, the residential aspect gave carers time to make new friendships, have respite from their caring responsibilities, and become immersed in the course.

The unique approach to delivering training for family carers enabled Dementia Carers Count to help this emotionally fragile group feel safe and supported, giving them the time and space to reflect, express themselves and learn from each other. However, the residential course can be an intense experience for the training facilitators, whose needs must be balanced with those of the carers they are supporting.

Key points

- Family members are often unprepared for the transition to becoming a carer
- Courses for carers can improve resilience and equip them for the future
- Successful course delivery requires a strong and knowledgeable team of facilitators with appropriate skills and experiences
- Carers appreciate a safe, supportive space where they feel valued
- A residential course can help to provide an immersive experience for carers, but is intense for the facilitators
- There are considerations regarding the sustainability of such courses, both in terms of staffing and costs.

A different model

The charity Dementia Carers Count (DCC) developed a unique 3-day residential course specifically focusing on family carers of people living with dementia. In developing this core course for carers, DCC drew on the work of the “Going to Stay at Home Program” which had been implemented in Australia (Gresham *et al* 2014).

Going to Stay at Home was a 7-day residential carer training programme based on a model previously reported by Brodaty & Gresham (1989). It had shown a significant reduction in carers’ psychological distress and a delay in admission to residential care for the person living with dementia. DCC hoped to replicate this success.

A carers advisory panel was established by DCC to co-produce their training offer and ensure the courses and their delivery were rooted in the carer experience. A lot of time was invested in choosing course venues which were compatible with the “Enriched Model” (Kitwood, 1997) and person-centred approach.

As Kitwood put it: “The Enriched model recognises the multiplicity of factors which affect a person’s experience of dementia including neurological impairment, physical health, the individual’s biography and personality, and the social environment in which they live” (1997).

While this is aimed at people living with dementia, the underlying principle of valuing a person as a whole should equally be applied to carers, helping them to be seen not as carers but as people first and foremost. Kitwood also identified a set of fundamental psychological and social human needs that should be met for all of us to maintain a good sense of well-being. These are:

Comfort – the need for physical and psychological comfort, which is gained through practical and emotional support and helping a person to feel safe, secure and calm.

Inclusion – having a sense of belonging and connection with others, and being accepted for your uniqueness and individuality.

Identity – recognising that different experiences shape who

we are, and we all have the right to express thoughts and feelings linked to our choices and preferences.

Occupation – being supported to take part in meaningful activity, to help us feel fulfilled and that we have worth and purpose in life.

Attachment – being recognised and valued as a unique person, and being able to form relationships and feel close to others.

Love – being loved and accepted, loving someone, and feeling self-love.

Taking a person-centred approach keeps carers at the centre of what is happening with a focus on their needs and preferences, and treating them with dignity and respect. This meant that when considering venues in which to deliver the courses, DCC had to choose one that worked well for carers and supported them, not the one that was best from a business perspective.

Of three venues that were originally chosen, one was not used as it had a very “corporate” feel which made it unsuitable for this type of course. The remaining two venues were chosen for their proximity and locality, one being in Birmingham and the other in Wiltshire. Both offered training rooms and provided good quality accommodation and hospitality with a homely feel.

Training facilitators were drawn from a range of professional backgrounds, including speech and language therapy, psychology, and occupational therapy, all of whom had direct contact with people living with dementia and their families, which informed their training delivery approach and kept the content of courses grounded in practice.

When piloting the core course, the training facilitators used feedback from attendees to drive changes to course content and delivery. As a direct result of such feedback, the range of courses was expanded to include three one-day courses:

Me, You, Dementia Too, offering the opportunity for the person with dementia to accompany the carer, but be supported on a parallel programme provided by Berkshire Young Onset Dementia Group

Home to Home, focusing on carers supporting a person with dementia who has moved into residential care

Young Onset Dementia, focusing on carers of people living with young onset dementia (diagnosed before the age of 65 years).

People with dementia only attended the Me, You, Dementia Too courses and so residential courses provided time away from the caring role for participants. The residential aspect allowed for more peer support and networking, additional advice from trainers during “down time” and rest and relaxation, in addition to extensive course content.

The impact of these courses on carers was found to be significant and is presented elsewhere (Atkinson & Bray 2019). Here, we will share the learning from the

implementation of the DCC training model together with the facilitators and barriers encountered during delivery of the courses.

Evaluation methods

The Association for Dementia Studies was commissioned to conduct an independent evaluation of the DCC courses, the main aim being to identify any impact of the courses' design and delivery on family carers. A secondary aim was to capture reported impact of course attendance on others such as the cared-for person, family members and course training facilitators. Twelve courses were examined in the evaluation, including at least one of each type.

As part of the evaluation, family carer course attendees were invited to take part in a telephone interview to share their experiences of the training courses. Interviews were conducted by one of two researchers, three months after participants had attended a course.

In total, 19 carer interviews were conducted: nine from the core course; four from the Me, You, Dementia Too course; four from the Home to Home course; and two from the Young Onset Dementia course. Additionally, telephone interviews were conducted at the end of the evaluation period with four DCC training facilitators. All interviews used a semi-structured schedule informed by the literature and DCC's training director, and were recorded with consent, anonymised and thematically analysed (Braun & Clarke 2006, 2013).

Findings

In examining what worked well or otherwise, for whom and why, two key overarching themes emerged from the thematic analysis of all 23 telephone interviews; the unique skills of the team of training facilitators, and the course being delivered as a residential course.

Unique team skills

The unique skills and experience of each of the training facilitators combined to create a strong and knowledgeable team who understood not only about dementia but also about carers and families:

We're all very, very experienced practitioners...that makes a huge difference, we've got such a vast amount of experience to draw from and we've all worked with families, we've all worked with people with dementia (training facilitator).

This level of knowledge and skill was appreciated by carers:

The people that were doing the instruction knew what they were talking about, that filled me with confidence. The content of the course for me was spot on and how it was conducted, I don't know what you'd call it, but there was interaction (family carer, Young Onset Dementia course).

The unique combination of skills was particularly important when supporting an emotionally fragile group of carers:

I think a part of the value is that we've got an OT and speech therapist who specialise in dementia so we're kind of used to

looking...we know the sort of things that do push the buttons and that do upset people and we know how to manage those...but the other real beauty is our clinical psychologist's background isn't dementia, it's resilience and it's dealing with enduring health conditions and end of life so she brings a different set of skills (training facilitator).

Training facilitators felt it was important to invest time to create a safe and supportive environment from the outset, where carers felt valued:

The message from the moment they arrive is very much "you matter...you're important"...a lot of people say they have felt completely lost and they'd forgotten who they are (training facilitator).

Thoughts shared by carers during their telephone interviews reflected the importance of a safe environment:

To be surrounded by lovely people who understood everything...it was just a lovely feeling (family carer, Young Onset Dementia course).

I got a bit upset...I was well supported and supported appropriately because I'm not a hugger and a cuddler whereas the other lady wanted that sort of physical attention and they recognised that as well (family carer, Me, You, Dementia Too course).

Being a residential course

The provision of residential accommodation for carers was felt to be beneficial, not just in terms of enabling carers to absorb and immerse themselves in the learning, but also for their ability to make new friendships and develop networks of support:

I think it made a lot of difference...I think if I'd gone home every night I would have missed out a lot (family carer, Me, You, Dementia Too course).

If it's residential in the evenings when people relax over a meal, that's actually when they often share strategies that they can go away and use themselves or try themselves and personal experiences, so from the resilience perspective it has a huge impact (training facilitator).

Even so, it was also appreciated that being away from a person with dementia for whom you provide care can be a stressful and anxiety provoking experience for some people. It was interesting to find that for carers who were initially very anxious about this aspect, there were unexpected benefits which offered new, previously unexplored possibilities:

Just getting away from home...was the real highlight I think because I didn't think that was possible...to actually be able to stay somewhere else (family carer, Young Onset Dementia course).

The carers who do manage to get other arrangements in place for the person that they're caring for...that also changes the dynamics in their family and it's a very

positive thing for some carers to actually say “I’m going on a course would you come and help me and would you move in for a couple of nights” and then they learn that the whole world doesn’t fall apart if they come away for a couple of nights but also that the family very often hasn’t really appreciated what the work was for the 24/7 carer (training facilitator).

Attending a residential course also provided a respite opportunity for carers:

The courses are really good but what was nice was actually having the time away...so it’s a bit of a luxury...it makes a big difference (family carer, Core course)

The residential aspect may have enabled carers to have a break, but it did mean that carers and facilitators spent a lot of time together. While this was felt to work well from the carer perspective, the intensity of this aspect was not always a positive for the training facilitators as it put extra pressure on them with few opportunities for down time away from carers:

The whole sort of programme...there was no separation; there was no kind of them and us. It was really kind of embodied in the whole experience (family carer, Core course).

We have made changes because no one was getting a break (training facilitator).

A three-day residential course with skilled training facilitators resulted in a relatively high cost per carer which cannot be ignored. During the pilot phase the courses were delivered free of charge to carers, but different funding options were investigated. The interviews explored reactions to a suggested fee and, while six of the interviewed carers said that they would have paid for the course, four said they couldn’t, eight were unsure and one did not comment:

No, not at that price. Definitely not. Whilst I understand it’s very costly, at that point it would have been a struggle to be honest (family carer, Core course).

I think it was only going on the course that I realised how good it was and how much it really benefitted me. I am not sure that I would have taken a punt beforehand if I had to pay for it basically (family carer, Core course)

Discussion

DCC have created a unique approach to delivering training to carers which is fundamentally underpinned by the combination of skills harnessed within the training team. They are able to support what is often an emotionally fragile group of people in a person-centred way which makes them feel safe and supported. Course participants also had faith in the knowledge, expertise and strengths of the training facilitators.

Working from this basis of trust, empathy and respect, training facilitators enabled carers to reflect, express themselves, learn from each other and create a community

of support. A residential component was instrumental in providing a conducive environment for these delicate and complex relationships to develop.

While the portfolio of single day and three-day/two-night residential courses has been successfully implemented by DCC, other organisations considering implementing a similar model would need to take long-term sustainability into account, both in terms of staffing and finances. Delivering a three-day residential course can be an intense experience for training facilitators and boundaries need to be established to preserve down time for all parties. Although the courses are focused on the needs of carers, they should not be delivered at the expense of training facilitators.

Three-day residential courses can also be relatively expensive to fund in terms of staffing and operational costs, presenting a significant issue for other training providers to consider. Attendance at such courses is not without its cost to carers too. Many people caring for a person with dementia will be experiencing financial burden, and self-funding attendance on a course, possibly alongside the cost of arranging care while they are away, may not be achievable for some.

DCC have explored a range of approaches to support travel and avoid levying charges on attendees. For some carers the disruption of attendance will be offset by the benefits in terms of enhanced knowledge and peer support. Carers need to have an understanding of these benefits before they are willing to “take a punt” on attending. Training providers should clearly articulate the likely benefits of course attendance and have an evidence base for claims made about expected outcomes.

Conclusion

Educational courses for family carers are an established and growing means of building knowledge, understanding and resilience to better equip them for their caring role. Finding ways to ensure that courses can be delivered and made manageable for carers can be challenging, but our evaluation provides evidence that a method which works well for both the trainers and participants can be achieved. A pathway to providing courses in such a way as to meet the varied needs of family carers of people living with dementia is possible, but the sustainability of such a model requires further exploration.

This evaluation was conducted prior to the pandemic, since which time DCC have adapted their training offer while remaining true to the underlying principles of their face-to-face approach. The pandemic has been a catalyst for a transition to online learning and, although it may not be appropriate in every situation, it is a pragmatic solution. It may also prove to be a stepping-stone to overcoming some of the barriers inherent for carers who find it difficult to physically attend a face-to-face course.

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