

Dementia Carers Count:

Evaluation of the Dementia Carer's Support Courses

'Before I went on the course, I felt like I was drowning in a sea of treacle.....now I feel completely different....I feel better able to cope....I needed life skills to get me through each day'

Dementia Carer's Support Courses: Impact Report

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Executive Summary

The Dementia Carers Count – Dementia Carer’s Support Courses

Dementia Carers Count (DCC) are committed to working with and supporting carers of people with dementia to help them strengthen their own resilience, develop strategies and anticipate future needs for both themselves and their loved ones. As a result of this commitment, DCC developed a Dementia Carer’s Support Course using an evidence-based approach. This core course was delivered over three days and residential accommodation was provided for course participants. The course was designed and revised with input from family carers of people living with dementia. In addition to a core course, three bespoke courses focusing on different aspects of dementia were also developed:

- **Me, You, Dementia Too** which offers the opportunity for carers to take with them the person with dementia that they care for. The person with dementia is then supported on a parallel programme by Berkshire Young Onset Dementia Group.
- **Home to Home** which focuses on carers who have cared for a person with dementia that has moved into residential care.
- **Young Onset Dementia** which focuses on carers of people living with young onset dementia (diagnosed before the age of 65 years).

The Course Evaluation

The Association for Dementia Studies, University of Worcester was commissioned to conduct an independent evaluation of the impact of the DCC Dementia Carer’s Support Courses. The evaluation findings have been presented in two separate reports “*Dementia Carers Count: Looking after the Big Fish*” which is an internal report on findings relating to the course facilitation and this “*Dementia Carers Count: Evaluation of the Dementia Carers Support Courses*” which is a publically available report on findings in relation to course participants.

The evaluation combined quantitative and qualitative data collection methods, exploring multiple aspects of carer outcomes including knowledge of dementia, quality of life, psychological distress, health, resilience and mental wellbeing. In addition to participant’s completion of a booklet of validated measurement tools, telephone interviews were carried out with carers across all courses.

During the evaluation period of June 2018 to June 2019, 12 courses were delivered:

- **Core courses:** Delivered eight times.

- **Me, You, Dementia Too:** Delivered twice.
- **Young Onset Dementia:** Delivered once.
- **Home to Home:** Delivered once.

Overall, measurement tool data from 85 carers was included in the evaluation, together with telephone interviews with 19 carers which were completed three months after attending the course.

Impact of the Courses

The quantitative outcomes for almost all of the validated measures used indicated that the Dementia Carer's Support Courses had a positive impact on carers in a number of areas. This was especially true when comparing outcomes to the pre-course results. Improvements were generally maintained over time to some extent, although the low number of measurement tools completed after 12 months (eight participants) makes it difficult to have full confidence in the longer-term impact. The only exception to the pattern of results came from the mental wellbeing measure as it showed an overall decline which appears to be at odds with the rest of findings.

The telephone interviews reinforced that the courses helped to improve carer confidence by improving their knowledge and skills, with carers reporting that they felt looked after and supported throughout the courses. The carers also learned how to look after themselves and increase their own resilience, making them feel better able to care for the person living with dementia that they cared for. Anecdotal evidence suggests that carers have put new ideas and strategies into practice following the courses, such as setting up social networks e.g. WhatsApp groups.

Why the Courses Worked Well

DCC have created a unique approach to delivering training to carers, and three key components were identified as to why the Dementia Carers Support Courses have worked well:

1. **The training is fundamentally underpinned by a unique combination of skills within the training team.** As a group of professionals, this team are able to support an often emotionally fragile group of people, making them feel safe and supported. They are able to do this in a person-centred way, responding at the individual level.
2. **Carers have faith in the knowledge, expertise and strengths of the training facilitators.** Working from this basis of trust, empathy and respect, the trainers enabled carers to reflect, express themselves, learn from each other and create a community of support.

3. **The residential component is instrumental and crucial in nurturing these delicate and complex relationships.** From these strong foundations, an educational component is introduced which affords carers the opportunity to focus on themselves; feeling safe and not alone. They are able to safely share their experiences with others in a similar situation and to be able to create sustainable friendships.

Recommendations for the Future

Although the Dementia Carer's Support Courses have evaluated very positively, several areas were identified for consideration or potential development in the future.

Communication and Managing Expectations

Prospective participants need to fully appreciate the benefits of the courses before attending, especially if any plans develop to charge for attendance in the future. Sharing positive experiences more widely may be a role for DCC Ambassadors who could assist with future course recruitment.

Expansion of the Courses

A number of training models for the future have already been explored including:

- Development of a two-day course.
- Bolt-on sessions to the core course.
- One-day workshops – Caring about Eating, Drinking or Swallowing Difficulties; Caring about Relationships and Feeling Secure; Caring about Choosing the Right Care Home.
- Carer Support Plans.

Carer feedback suggests that there would be interest in a number of additional models such as:

- Courses for family groups or adult children.
- Courses for people with the same diagnosis.
- Courses for people at the same stage of the dementia journey.
- Refresher days.

Course Content and Intensity

Some areas of interest mentioned by carers were very specific but could easily be incorporated into courses in the future:

- Familial Alzheimer's disease.
- Bereavement.
- The later stages of dementia.
- Changes in behaviour and how to respond to this.
- NHS continuing care.

However, any additional content should be balanced against carers feeling that the existing three-day courses were already very intense. Reviewing the course content could also be beneficial when tailoring courses to particular audiences.

Setting the Scene/Venue

It will be important that future courses are able to recreate a similar, positive residential experience which was not only appreciated by carers as respite from their caring role but also afforded an opportunity to create mutually supportive friendships and continuing bonds.

Sustainability

There is a need for a sustainable costing model for future DCC courses. In addition, future sustainability will also depend upon staff retention and future recruitment of suitably skilled training facilitators, enabling DCC to continue to offer their unique model of expertise and support which carers value and have reported as beneficial.

The Dementia Carer's Support Courses

Introduction

Dementia Carers Count (DCC) has a long and rich history continuing the charitable work of the Royal Surgical Aid Society founded in 1862. At the 150th anniversary of the organisation a decision was taken to diversify from care home provision to supporting carers of people living with dementia. The new focus was marked with the launch of a new service under a banner to create a research centre dedicated to the needs of carers and to create evidence base to raise the profile of carers which could be influential at both policy and practice level. Creating services for family and friends providing support and care to people with dementia is at the heart of this new service. To address the lack of good quality research into the experiences, needs and outcomes for carers, a partnership with the Association for Dementia Studies (ADS) was established to jointly appoint the DCC Professor of Family Care in Dementia to develop a research function at DCC.

DCC's vision is that all family carers of people with dementia will feel confident, valued and heard. Their mission statement is that they will provide a space for family carers of people with dementia to inspire them to learn, connect and receive practical support to feel empowered in their caring role.

In 2017 ADS were commissioned by Dementia Carers Count to evaluate a pilot series of educational courses for carers of people living with dementia. The purpose of the evaluation was to consider changes in knowledge, resilience and well-being amongst carers and to explore facilitators and barriers to course implementation. This evaluation built on a literature review undertaken by ADS on behalf of RSAS in 2016 (Association for Dementia Studies, 2016) which highlighted the impact of the caring role.

Background

DCC is a responsive organisation established within a context of increasing concern as the numbers of people diagnosed with dementia globally continues to rise. Whilst there are an estimated 50 million people living with dementia worldwide, this figure is anticipated to triple by 2050 (WHO, 2019). The World Health Organisation (2019) note not only the cost to the public purse but also that dementia is a *'major cause of disability and dependency among older people and can devastate the lives of affected individuals, their carers' and families'* (p.3). Set against this backdrop, the aims of DCC as an organisation have significant importance; supporting those caring for someone with dementia not only improves their own well-being but also enables the person with dementia to live at home for longer.

Dementia is an umbrella term for a progressive degenerative condition which is currently incurable. There are many types of dementia, all of which result from cell death in the brain. Alzheimer's disease is the most common type of dementia accounting for 62% of all dementias (Alzheimer's Society, 2014). People living with dementia can experience a range of symptoms, including memory loss, cognitive difficulties, sensory changes, communication difficulties and behavioural issues, which impact on their ability to function and enjoy a full, meaningful life. However, with support, many people are able to lead a full and active life, with the majority of people currently remaining within their own home (Alzheimer's Society, 2013).

Caring for people living with dementia can be demanding; understanding this journey and preparing for its challenges and opportunities can enable carers to strengthen their own resilience, develop strategies and anticipate future needs for both themselves and their loved ones. There are around 7 million informal carers in the UK, saving the economy £132 billion per year. However, the impact of taking on a caring role can be detrimental for many people. Sixty-five percent of older carers (60-94 years) have a disability or long-term health problems of their own and, as a result of caring, whilst 72% of carers report experiencing mental ill health with 61% reporting physical ill health (Carers Trust, 2015; Carers UK, 2015).

From a dementia perspective, 11% of carers in the UK are caring for a person with dementia, equating to around 700,000 informal carers. Forty-five percent of carers aged 75 and over are looking after someone who has dementia. Around two thirds of people with dementia live at home, most of whom are supported by unpaid carers. Most carers of people living with dementia are women (60-70%). As many carers find themselves in a caring role rather than actively choosing it, it is perhaps not surprising that carers can have a limited understanding of dementia. Instead, their knowledge is mainly based on their own experiences, so they may not be aware of the wider impact of dementia and not always associate some symptoms with the condition. While improved knowledge may help carers, many choose not to find out more about dementia and what the future may hold, preferring instead to take each day as it comes (Dementia Statistics Hub; Carers UK and Age UK 2015; Alzheimer's Research UK, 2015).

Caring can be emotionally and physically exhausting due to sleep deprivation, taking on more chores and providing practical help, but carers often prioritise caring for a family member over their own wellbeing. There can also be a sense of guilt about putting own needs first, combined with feelings of duty and responsibility to care for their loved one. This can prevent some carers from making use of respite care. This is concerning as carers who take a break from caring are less likely to experience mental ill health than those who do not take a break, and a carer's ability to care can be affected by poor mental and physical health. Additionally, many carers feel lonely

or socially isolated as a result of their caring responsibilities (Alzheimer's Research UK, 2015)

An initial scoping study of courses available for dementia carers identified 53 courses in the UK, of which seven were delivered online (Prins, 2019). For those 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, while 19 courses comprised multiple short sessions, e.g. one 2-hour session per week for six weeks. While these courses may meet the needs of carers in various ways, it is likely that in some cases there may only be enough time to provide an overview of a topic rather than having the opportunity to explore it in any depth. The scoping study therefore indicates that the DCC three-day residential courses specifically focusing on family carers are a unique offer for UK-based carers.

The DCC Courses

In developing a 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). This was a seven-day residential carer training programme based on a model previously reported by Brodaty & Gresham (1989). The latter programme had shown a significant reduction in carers' psychological distress and a delay in admission to residential care for the person living with dementia.

Additionally, DCC established a Carer's Advisory Panel to ensure the courses and their delivery were rooted in the carer experience. The Carer's Advisory Panel was instrumental in co-producing the original DCC core course. Course development was ongoing whereby feedback from those attending the courses was utilised by the course trainers to drive changes to course content and delivery. Later courses were developed as a direct result of such evidence. During the evaluation reported here, 12 core and bespoke courses were delivered:

- **Core courses:** Delivered eight times between June 2018 and February 2019.
- **Me, You, Dementia Too:** Delivered twice in July 2018 and February 2019. This course offered the opportunity for the person with dementia to accompany the carer. The person with dementia was supported on a parallel programme provided by Berkshire Young Onset Dementia Group.
- **Young Onset Dementia:** Delivered once in October 2018. This course focused on carers of people living with young onset dementia (diagnosed before the age of 65 years).
- **Home to Home:** Delivered once in November 2018. This course focused on carers supporting a person with dementia who has moved into residential care.

Methods

The Association for Dementia Studies was commissioned to carry out an independent evaluation of the Dementia Carers Support courses. The aim of the overall evaluation was to consider changes in knowledge, resilience and well-being amongst carers and to explore facilitators and barriers to course implementation. This report is focused on the outcomes and perspectives of the course participants.

Data relating to the outcomes of the courses were captured via a mixed methods approach using both quantitative and qualitative methods.

Validated Outcome Measures

In conjunction with Dementia Carers Count, the Association for Dementia Studies undertook a cyclical process to identify and decide on the outcome measures for the evaluation, combining both academic and practice perspectives of what was relevant and appropriate. Outcomes are things that the course could be expected to make a difference to such as knowledge and attitudes.

The measures were compiled into a booklet for ease of completion and covered:

- Dementia Knowledge Assessment Scale (DKAS) – a 19-item measure aimed at assessing the carers' knowledge of dementia.
- Carers – DEMentia Quality Of Life (C-DEMQL) – a 40-item measure with 6 sub-scores aimed at measuring the quality of life of people caring for someone with dementia.
- Kessler Psychological Distress Scale (K10) – a 10-item measure of distress experienced by a person.
- Short-Form Health Survey (SF12) – a 12-item measure with 2 sub-scores used to evaluate a person's health.
- Brief Resilience Scale (BRS) – a 6-item measure to assess a person's ability to bounce back or recover from stress.
- Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS) – a 7-item measure used to monitor mental wellbeing.
- Reisberg Global Deterioration Scale (GDS) – a 1-item measure used to indicate the level of cognitive impairment experienced by the person with dementia.

The measures were completed by carers on a 'self-reporting' basis at different time-points throughout the evaluation depending on when the course was delivered in relation to the project timescales. Typically measures were taken pre-course and immediately after completion and repeated at 3 and 6 months. Only participants from the first two courses completed measures at 12 months post-course.

Table 1: Evaluation measures at different time points

Type of course	Course dates	Pre	Post*	3 month	6 months	12 months
Core	5-7 June 2018	✓	✓	✓	✓	✓
Core	18-20 June 2018	✓	✓	✓	✓	✓
Core	4-6 July 2018	✓	✓	✓	✓	
Core	16-18 July 2018	✓	✓	✓	✓	
Me, You, Dementia Too	28-30 July 2018	✓	✓	✓	✓	
Core	15-17 October 2018	✓	✓	✓	✓	
Young Onset Dementia	22-24 October 2018	✓	✓	✓	✓	
Core	5-7 November 2018	✓	✓	✓	✓	
Home to Home	24-26 November 2018	✓	✓	✓	✓	
Core	28-30 January 2019	✓	✓	✓		
Me, You, Dementia Too	15-17 February 2019	✓	✓	✓		
Core	26-28 February 2019	✓	✓	✓		

* At this time-point only the DKAS tool was completed as the carers would not have had the opportunity to put what they had learned into practice.

To encourage completion of the measures, they were made available in paper and online format. A copy of the measures can be found in Appendix 1.

Demographics Booklet

As part of the evaluation, basic demographic data (participant characteristics) were captured to provide context for their responses to the measures. The evaluation demographics were combined with additional demographics requested by Dementia Carers Count into one booklet. Only the evaluation demographics are included within this report.

This booklet was completed by the carers on a 'self-reporting' basis and available in paper and online formats. The booklet was completed once by each participant towards the end of a course. A copy of the demographics booklet can be found in Appendix 2.

Interviews with Carers

All carers who had agreed to take part in the evaluation were invited to take part in a telephone interview to share their experiences of the DCC training courses. An initial target of ten interviews was set, but following the later development of the bespoke courses this was revised to ensure that all courses were represented. Participants who expressed an interest in a telephone interview were contacted with a date being arranged where possible. This process was continued until there was sufficient representation from all four types of course offered by DCC, with numbers being affected by the number of courses of each type. In total 19 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.

The telephone interviews were conducted three months after a carer had attended the course, using an agreed semi-structured schedule (see Appendix 3). The average length of interview was 16 minutes with the shortest interview being seven minutes and the longest being 28 minutes. All carers signed consent forms which gave permission for the interviews to be audio recorded. Recordings were professionally transcribed then anonymised.

Data Analysis

Descriptive statistics were used to provide an overview of the demographics data relating to the carers, people with dementia and caring relationships. The scores from the outcome measures were analysed using 'Pairwise t-tests' to explore potential changes over time. This means that a carer's score for an outcome measure at one time point is compared against their score at a different time point.

The interview transcripts were analysed using Thematic Analysis (Braun & Clarke, 2006; 2013). This is an approach which aims to identify themes and patterns of meaning across datasets. It is concerned with context and uses a 'bottom up' approach rooted in the words and meaning of the carers to generate a set of themes which is representative of their collective experience.

Ethical Approval

Approval for the evaluation was sought from the University of Worcester Health and Science Research Ethics Committee (HSREC). Approval was obtained on the 14th March 2018 (HSREC Code: SH17180013). All carers were provided with information about the evaluation and required to sign a consent form in order for their data to be included in the analysis.

Evaluation Findings

The following quantitative findings are based on the demographics booklets and booklets of validated outcome measures received as of 17/06/19.

The Carer Participants

Overall 117 carers attended one of the 12 courses delivered during the evaluation period. The majority of these attendees (78%) were on the core courses. While 80% of attendees gave consent to be involved in the evaluation, several were unable to proceed or continue for various reasons including the death of the person with dementia. In total, 85 course attendees (73%) completed the evaluation. Forty-nine percent of respondents provided information using the paper booklets whilst 51% used the online option.

The evaluation findings are based on the information from the 85 evaluation participants unless stated otherwise. As demographic information about the attendees who declined to be part of the evaluation was not available, it is not possible to know whether the participants are representative of the whole group of attendees. When considering the following findings it should therefore be kept in mind that they relate to the evaluation participants and not necessarily reflect the views of the whole group.

Due to the absence of accurate national statistics for carers of people with dementia it has not been possible to judge whether the characteristics of the evaluation participants reflect the national picture. However, a good level of diversity amongst evaluation participants has been achieved.

Table 2: Evaluation participants for courses delivered between June 2018 and February 2019

Type of course	Number of courses	Number of attendees	Number of evaluation participants
Core	8	91	65
Me, You, Dementia Too	2	12	11
Young Onset Dementia	1	4	3
Home to Home	1	10	6
Total	12	117	85

Demographics Data

One carer did not complete a demographics booklet, so the following information is based on the responses from 84 carers.

Carers

Carers who took part in the evaluation represented a wide variety of ages, ranging from 20 to 82 years (Figure 1). However, the majority were over 45 years with the average age being 56 years. Eighty-three percent of the participating carers were female, which is slightly higher than the national picture of an estimated 60-70% of carers of people with dementia being female.

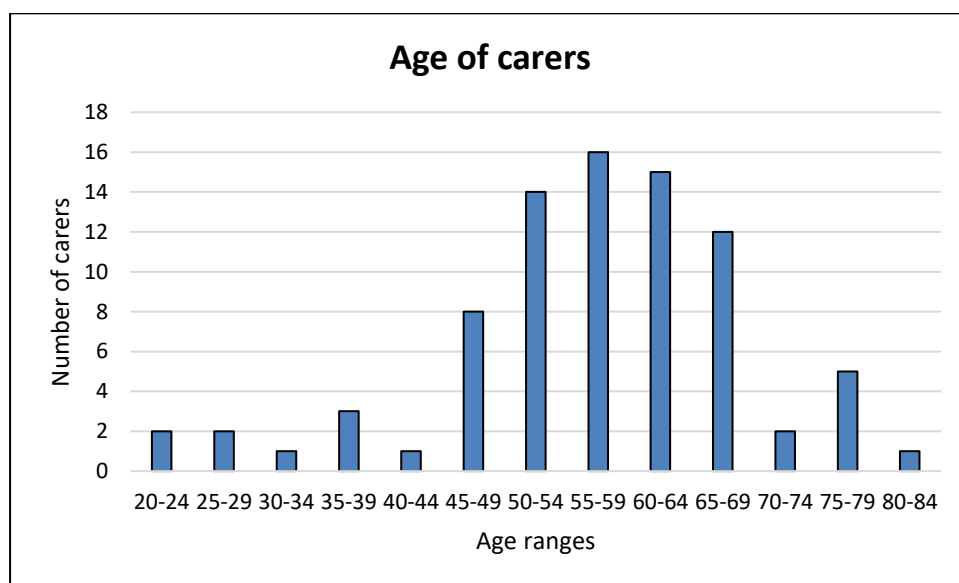


Figure 1: Carer ages (n=84)

Reflecting the range of ages, the employment status of the carers was quite varied with 33% being retired, 31% being employed and 22% not being employed.

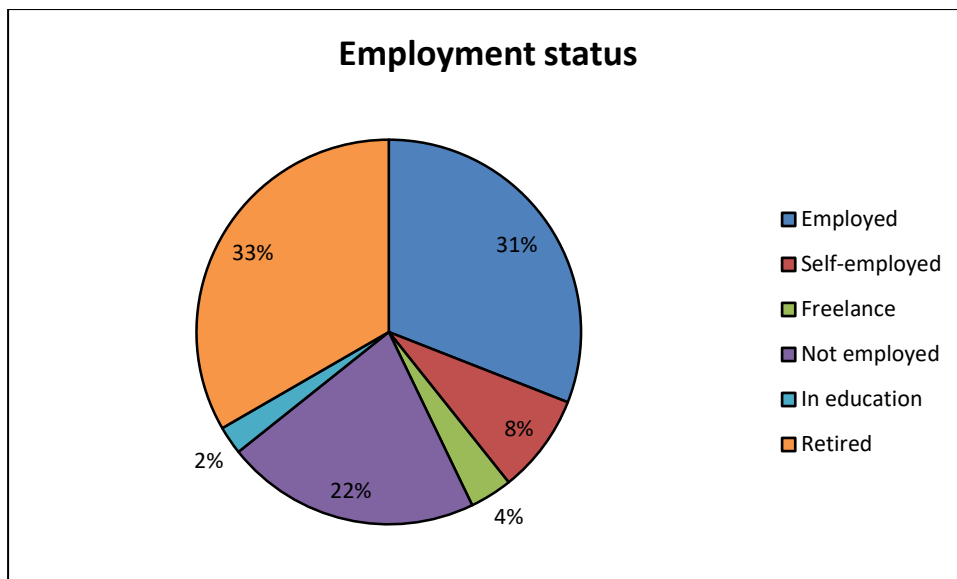


Figure 2: Carer employment status (n=84)

Only 6% of carers were registered disabled, but 31% reported having a long-term health condition. This is lower than the national picture of 65% of older carers having a disability or long-term health problem, which is not surprising as the age profile of the course attendees is generally younger with fewer than half of the evaluation participants being classed as an 'older carer', i.e. aged 60-94.

Of those carers with a long-term health condition, 58% had multiple conditions. The most common conditions reported were:

- Arthritis/osteoarthritis – 10 carers
- High blood pressure – 5
- Back pain – 3
- Depression – 3
- Anxiety – 3
- Fibromyalgia – 3

Other conditions included ME/chronic fatigue, joint problems, mental ill health, diabetes, asthma, cancer, macular degeneration, glaucoma, an ear condition, COPD, endometriosis, carpal tunnel syndrome, mobility issues and stress.

People with Dementia

Of the people with dementia being cared for by the carers attending the courses, 86% had a diagnosis of dementia. The most common diagnosis was Alzheimer's disease, followed by mixed dementia (generally Alzheimer's disease and vascular dementia together).

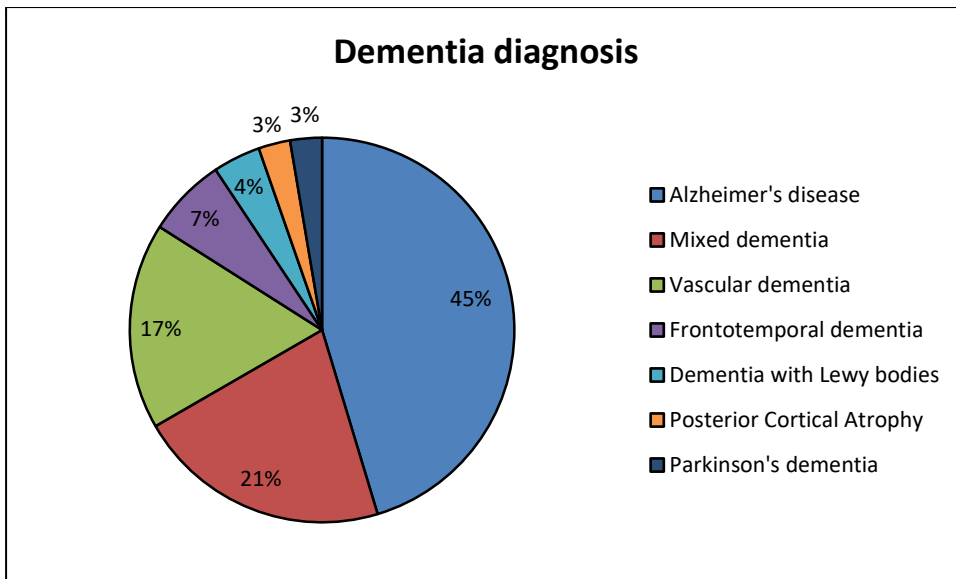


Figure 3: Dementia diagnosis (n=75)

The average age of individuals when they received their diagnosis was 74 (range 51-92), having experienced symptoms for an average of three years (range 1 month to 11 years). As assessed by the carers, the most common GDS score (Global Deterioration Scale indicating the level of dementia) was 5 with people tending to be towards the more advanced end of the scale (a higher score represents more advanced dementia).

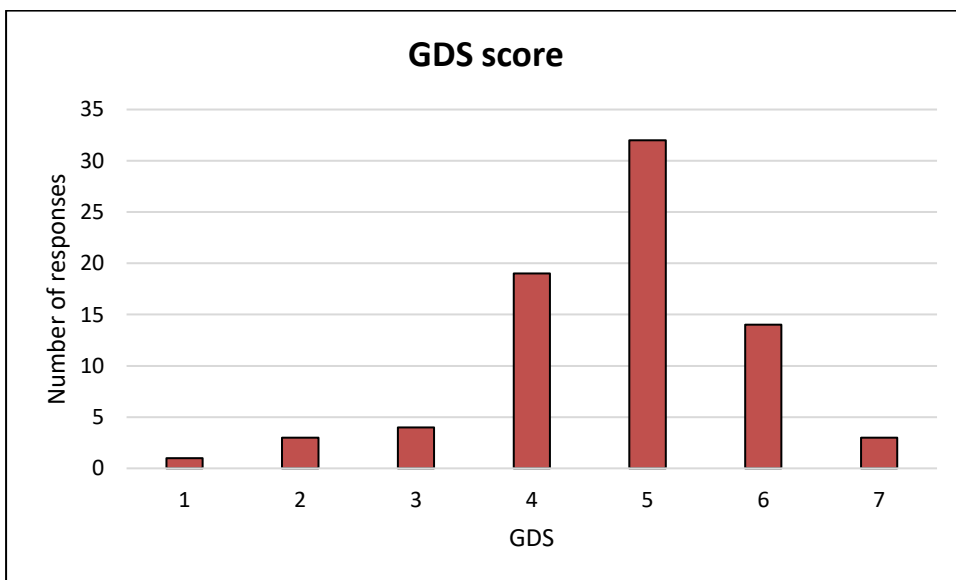


Figure 4: GDS score (n=76)

Seventy percent of people with dementia were reported to have another long-term condition, with 64% of those having more than one other condition. The most commonly reported conditions were:

- Heart conditions – 18 people with dementia
- High blood pressure – 14
- Arthritis/osteoarthritis – 14
- Diabetes – 13
- Mobility issues – 8
- Sight issues – 6
- Cancer – 6

Other conditions reported included osteoporosis, stroke, asthma, Parkinson’s disease, hearing loss, Chronic Obstructive Pulmonary Disease, incontinence, back issues, kidney failure, cholesterol, Sjogren’s syndrome, anxiety, depression, breathing problems, frailty, prostate, epilepsy, thyroid and stress

Caring Relationship

The majority of carers reported caring for a parent with dementia (57%), with a further 35% caring for a spouse or partner (Figure 5). Seventy-seven percent of carers reported being the main carer, with 47% saying they were the only carer. Forty-five percent of carers lived with the person they were caring for. On average, carers had been in a caring role in relation to dementia or other conditions for just under 4 years and 8 months (range 7 months to 35 years).

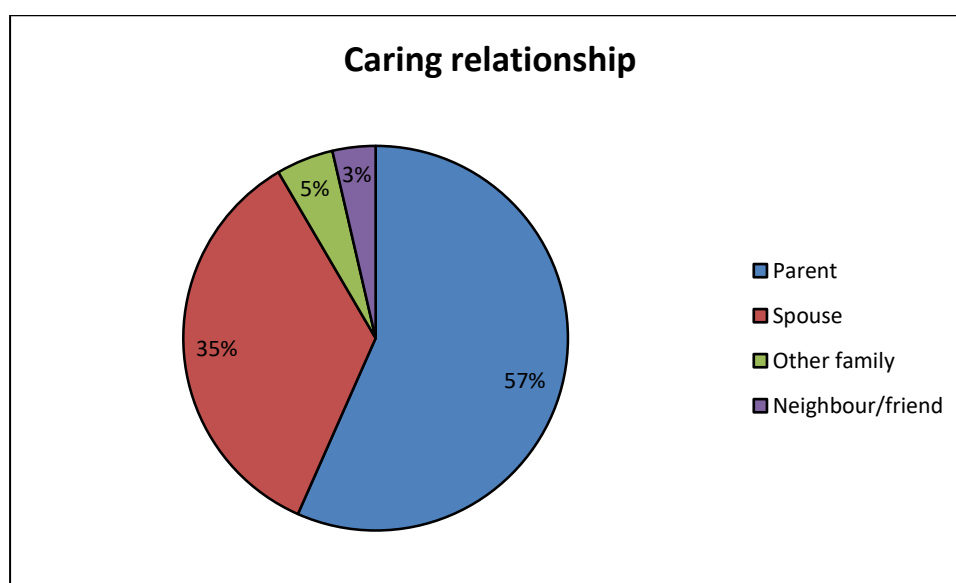


Figure 5: Who the carer is caring for (n=83)

In terms of caring activities, carers were least likely to help out with physical care, but it is unclear whether this is because assistance is not required or is provided by someone else.

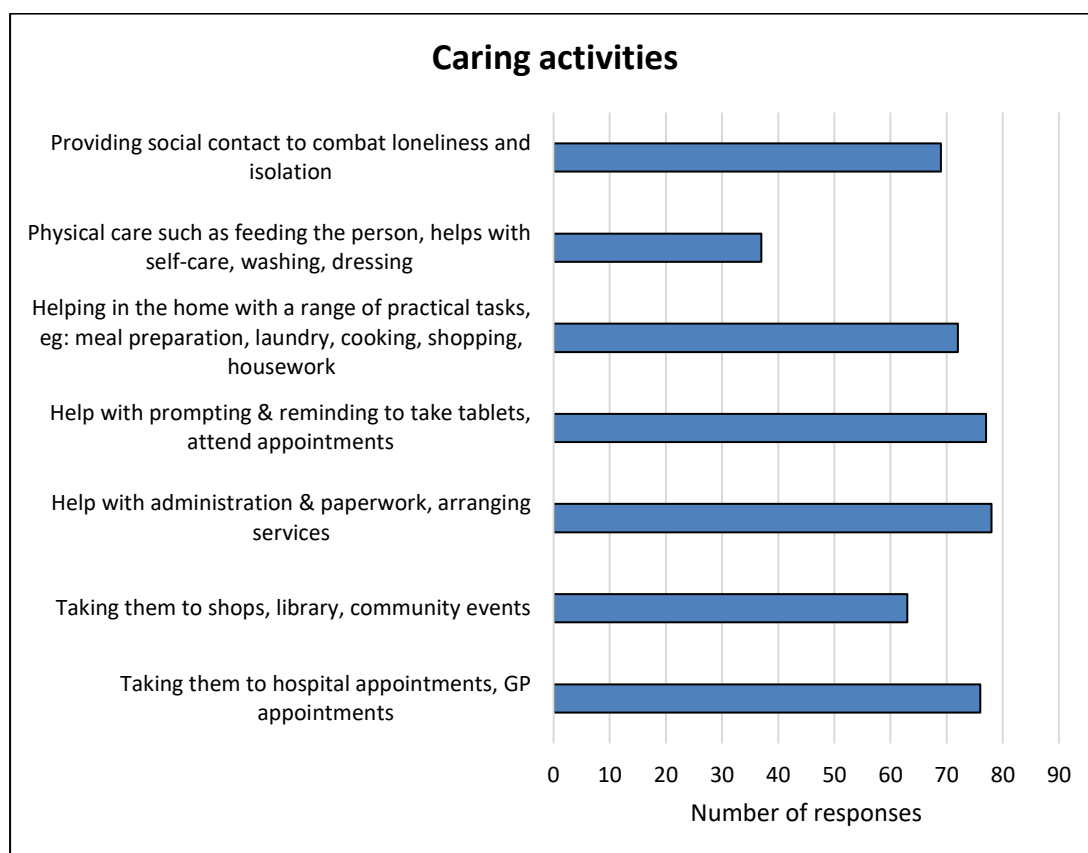


Figure 6: Caring activities undertaken (n=84)

Sixty-percent of carers spend up to 7 hours caring per day, with 21% providing care around the clock (Figure 7). Indeed, 76% of carers who provide care 17-24 hours a day reported doing this 7 days a week. Similarly, many carers who care for fewer hours per day do this on almost a daily basis.

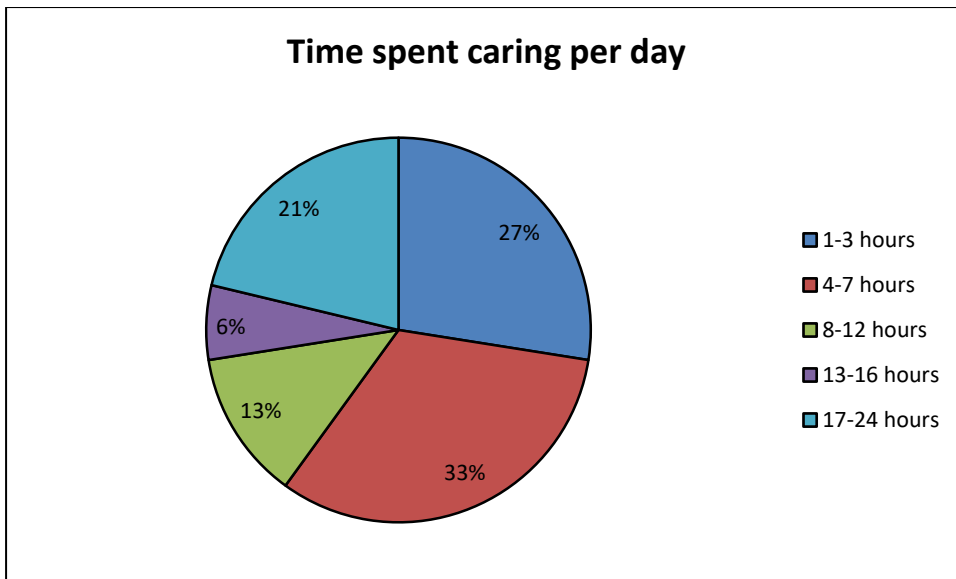


Figure 7: Caring per day (n=84)

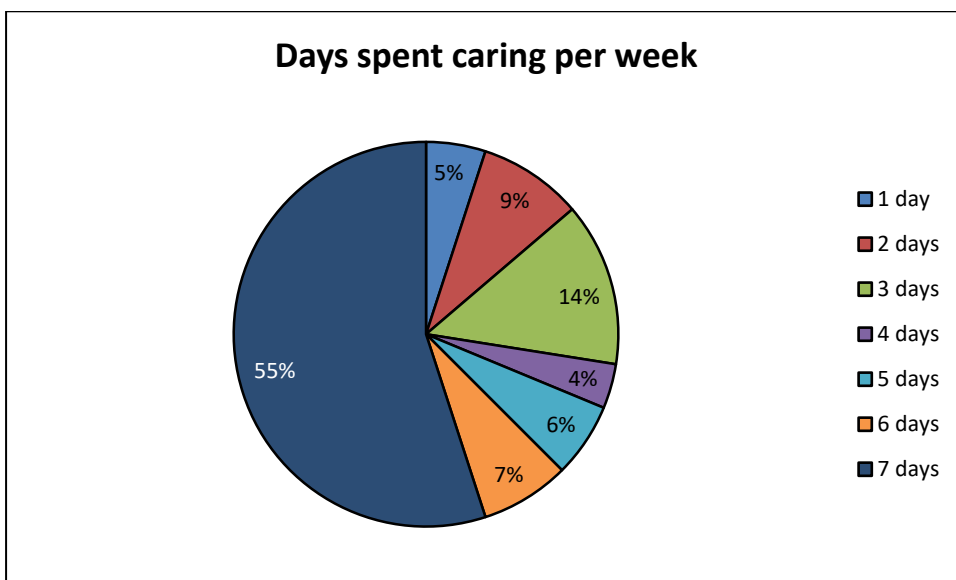


Figure 8: Caring per week (n=84)

Carer Outcomes Based on Validated Measures

Despite best efforts to encourage completion, one set of ‘pre’ measures and five ‘post’ sets of measures were not returned, slightly reducing the amount of data available for analysis. There was also a natural ‘tail off’ in completion of the booklets at 3, 6 and 12 months as it became less of a priority for carers, but the response rate was still strong. It should be noted that by using ‘Pairwise t-tests’, carers were only included if they had a valid response at both relevant time points.

Due to the small numbers of outcome measure booklets for the ‘non-core’ courses it was not always appropriate to separate the responses according to course type, but any findings related to specific types of course have been reported. In addition, the relatively low number of responses at 12 months should be taken into account when looking at the significance of any results, as small group sizes could artificially skew the findings.

Table 3: Evaluation measures completed at different time points

Type of course	Course dates	Pre	Post	3 months	6 months	12 months
Core	5-7 June 2018	3	3	1	1	2
Core	18-20 June 2018	9	9	5	5	6
Core	4-6 July 2018	14	14	12	11	
Core	16-18 July 2018	13	12	8	6	
Me, You, Dementia Too	28-30 July 2018	7	7	6	7	
Core	15-17 October 2018	1	1	1	1	
Young Onset Dementia	22-24 October 2018	3	3	2	1	
Core	5-7 November 2018	9	8	3	3	
Home to Home	24-26 November 2018	6	6	4	3	
Core	28-30 January 2019	10	9	2		
Me, You, Dementia Too	15-17 February 2019	4	4	3		
Core	26-28 February 2019	5	4	3		
Total		84	80	50	38	8

Knowledge of Dementia

Results indicate that the carers’ knowledge of dementia was improved by attending the courses. When considering the DKAS scores prior to attending, there was a significant improvement in scores immediately after the courses, 3 months later and 6 months later. While the improvement was not statistically significant after 12 months, it still showed a positive outcome. The picture is slightly different when comparing the post-course scores with carers seeing a decline after both 3 and 6 months. While this may initially seem concerning, the results need to be considered in the wider context. It appears that the DKAS scores peaked post-course when information was still fresh for the carers then dipped slightly over the longer term,

but remained higher than their pre-course level of knowledge throughout. This indicates that the courses had a positive long-term impact on the carers' knowledge of dementia.

No significant difference was seen between carers when considering the following groupings:

- Men vs women
- Core vs bespoke courses
- Caring for a parent vs caring for a spouse/partner

Table 4: DKAS scores compared at different time points

	Post	3 months	6 months	12 months
Pre	Significant improvement (p<0.05, t=-9.54) (n=79)	Significant improvement (p<0.05, t=-6.18) (n=48)	Significant improvement (p<0.05, t=-6.18) (n=38)	Improvement (p=0.06, t=-2.36) (n=7)
Post		Significant decline (p=0.02, t=2.36) (n=48)	Decline (p=0.42, t=0.82) (n=38)	Improvement (p=0.06, t=-2.38) (n=7)
3 months			Improvement (p=0.29, t=-1.09) (n=32)	Significant improvement (p=0.04, t=-3.36) (n=4)
6 months				Improvement (p=0.72, t=-0.40) (n=4)

Quality of Life

A positive impact from the courses was also seen on the carers' quality of life. There was a significant improvement when comparing the pre-course scores to the scores after 3 months, with an improvement still being seen after 6 and 12 months. As with the DKAS results, there appears to have been a peak improvement followed by a tailing off as the scores began to decline after 3 months, but it is again helpful to know that even after 12 months the carers rated their quality of life as higher than it had been prior to the courses. It should also be born in mind that due to the progressive nature of dementia, a decline in the carers' quality of life would be expected in many cases.

As with the DKAS, there was no significant difference between carers when considered in terms of different groupings.

Table 5: C-DEMQOL total scores compared at different time points

	3 months	6 months	12 months
Pre	Significant improvement (p=0.01, t=-2.93) (n=41)	Improvement (p=0.14, t=-1.50) (n=35)	Improvement (p=0.71, t=-0.38) (n=8)
3 months		Decline (p=0.76, t=0.31) (n=30)	Decline (p=0.25, t=1.43) (n=4)
6 months			Significant decline (p=0.04, t=3.04) (n=5)

In terms of the sub-scores for the C-DEMQOL quality of life measure, there were some variations as indicated in Table 6. Positive feelings about 'role' and 'support' were less likely to be maintained in the long-term, while 'wellbeing' was the only individual sub-measure to see a significant decline. The most positive sub-score was 'feelings about the future' which saw at least some level of improvement at almost every stage.

Table 6: Overview of C-DEMQOL sub-scores compared at different time points

	Overall quality of life			Responsibilities and overall needs		
	3 months	6 months	12 months	3 months	6 months	12 months
Pre	I	I	I	I	I	I
3 months		D	D		D	D
6 months			D			D
	Wellbeing			Role		
Pre	SI	I	I	I	I	D
3 months		D	D		I	D
6 months			SD			D
	Feelings about the future			Support		
Pre	SI	I	I	I	I	D
3 months		I	I		I	D
6 months			D			D

Psychological Distress

Although no significant differences were seen, the carers' psychological distress improved following the courses, with the improvement being sustained over the long-term. While the decline between the scores pre-course and after 6 months may seem like an issue, it should be noted that for the 38 carers included at this point the mean K10 score only changed from 22.53 to 22.66 (lower scores are better for this measure), so the decline was very slight. Overall, prior to the courses the carers' scores were at the higher end of the range for 'mild' psychological distress, but by 12 months later they were at the higher end of the range for 'good' psychological distress.

Analysing different groupings of carers did not indicate any significant results.

Table 7: K10 scores compared at different time points

	3 months	6 months	12 months
Pre	Improvement ($p=0.33$, $t=0.98$) ($n=45$)	Decline ($p=0.87$, $t=-0.16$) ($n=38$)	Improvement ($p=0.22$, $t=1.36$) ($n=8$)
3 months		Improvement ($p=0.97$, $t=0.04$) ($n=31$)	Improvement ($p=0.06$, $t=2.54$) ($n=5$)
6 months			Improvement ($p=0.34$, $t=1.09$) ($n=5$)

Carer Health

As for the psychological distress scores, no significant changes were seen for the carer health scores. However, there was an overall improvement compared to the pre-course scores which was again maintained over time to some extent. As seen previously, nearly a third of carers reported having at least one other long-term condition, so it is perhaps not surprising that there were no significant improvements. Again, no significant differences were seen between different carer groupings.

Table 8: SF12 total scores compared at different time points

	3 months	6 months	12 months
Pre	Improvement (p=0.52, t=-0.65) (n=45)	Improvement (p=0.63, t=-0.49) (n=38)	Improvement (p=0.31, t=-1.09) (n=8)
3 months		Decline (p=0.57, t=0.57) (n=31)	Improvement (p=0.59, t=-0.58) (n=5)
6 months			Decline (p=0.21, t=1.50) (n=5)

In terms of the sub-scores for the SF12 outcome measure,

Table 9 indicates that more improvement was seen for mental health than physical health. This is perhaps to be expected as the majority of other long-term conditions experienced by the carers were physical rather than mental, and there was no specific focus within the course to address these types of conditions.

Table 9: SF12 sub-scores compared at different time points

	Physical health			Mental health		
	3 months	6 months	12 months	3 months	6 months	12 months
Pre	D	I	I	I	I	I
3 months		D	I		D	I
6 months			D			D

Carer Resilience

The resilience scores followed a similar pattern to other carer outcomes, with a non-significant improvement being seen compared to pre-course scores, and some degree of improvement being sustained over the longer term. While the declines seen for 3 months vs 12 months and 6 months vs 12 months indicate that there was some 'tail off' in scores, the 12 month scores remained higher than those of the carers prior to the courses.

Although based on a small sample of eight carers, a significant difference was seen between male and female carers in terms of changes in their resilience scores from pre-course to 12 months later. It indicates that while two male carers increased their BRS during this period, the six female carers saw a slight decrease. While this is interesting and hints at a possible difference between genders, the small and

unbalanced group size makes it difficult to draw any firm conclusions from this finding. No other significant differences were seen for other carer groupings.

Table 10: BRS scores compared at different time points

	3 months	6 months	12 months
Pre	Improvement (p=0.22, t=-1.24) (n=45)	Improvement (p=0.54, t=-0.62) (n=37)	Improvement (p=0.62, t=-0.53) (n=8)
3 months		Improvement (p=0.59, t=-0.55) (n=30)	Decline (p=0.24, t=0.82) (n=5)
6 months			Decline (p=0.64, t=0.56) (n=5)

Mental Wellbeing

Somewhat surprisingly, the results relating to mental wellbeing show the opposite picture to the other outcome measures. Taking the SWEMWBS results as a whole, there appears to be an initial decline followed by a degree of improvement, although mental wellbeing remains lower than levels seen prior to attending the course. While the reason for this slightly negative set of results is unclear, it does appear to tie in with the 'wellbeing' sub-score of the C-DEMQOL which saw a decline. It is also important to note that none of the declines were significant.

Analysing different carer groupings resulted in two significant findings:

- Comparing pre-course and 3 month scores, male carers (n=8) saw an improvement in their mental wellbeing, while female carers (n=37) saw a decline.
- Comparing pre-course and 6 month scores, people caring for a parent (n=19) saw an improvement in their mental wellbeing, while people caring for a partner/spouse (n=15) saw a decline.

The unequal sizes of the male/female groups makes it difficult to draw any firm conclusions from this finding, but the second finding is interesting. It suggests that more may need to be done to help support spousal carers, or that people in different caring relationships may require different forms of support. This will be considered in conjunction with the qualitative findings.

Table 11: SWEMWBS scores compared at different time points

	3 months	6 months	12 months
Pre	Decline (p=0.42, t=0.81) (n=45)	Decline (p=0.96, t=0.05) (n=38)	Decline (p=0.41, t=0.88) (n=8)
3 months		Improvement (p=0.69, t=-0.41) (n=31)	Improvement (p=0.70, t=-0.41) (n=5)
6 months			Decline (p=0.05, t=2.75) (n=5)

Carer Interview Findings

In total 19 interviews were conducted, representing 22% of the 85 evaluation participants. This included: nine from the core course (14% of evaluation participants on this type of course); four from the Me, You, Dementia Too course (36%); four from the Home to Home course (67%); and two from the Young Onset Dementia course (67%).

The demographics for the 19 interviewees indicate that they are representative of the wider evaluation participants, being similar in terms of average age, split of men and women, employment status and disability. A slightly lower proportion had a long-term health condition than the wider group at 21% compared to 31%. The group was also representative in terms of the diagnoses for the people with dementia being cared for and the caring relationship, suggesting that their views, opinions and perspectives should be typical of the wider group of carers.

Thematic analysis of the carer interviews considered the outcomes for those who attended the full range of courses offered by DCC. Three overarching themes were identified, together with a variety of sub-themes as indicated in Figure 9.

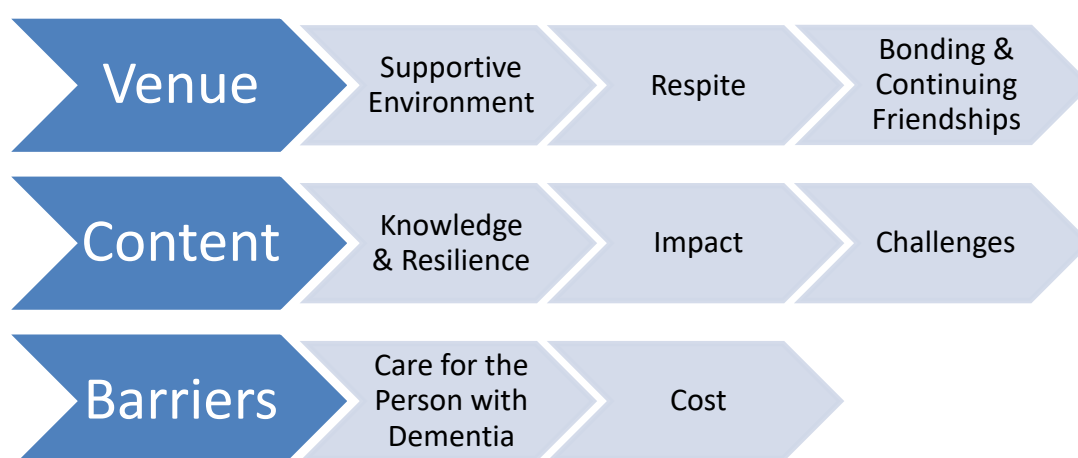


Figure 9: Outcome themes from carer interviews

Venue

Venues for course delivery were considered and chosen carefully by DCC training facilitators prior to course delivery, with two venues being chosen in Birmingham and Swindon. Whilst the physical aspects of these venues in terms of location, setting and staffing were appreciated by carers, this theme considers venue in terms of its functionality for carers by exploring the ways in which the residential course and its delivery impacted upon their experience.

Supportive Environment

Training facilitators were mindful to create an environment where carers felt safe and valued. Thoughts shared by carers during interviews reflected that this had been achieved:

'The environment was so supportive....I knew I could ask anything, say anything and no one would throw their hands up in horror.' (Young Onset Dementia course)

'To be surrounded by lovely people who understood everything....it was just a lovely feeling.' (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.' (Me, You, Dementia Too course)

An element of the supportive environment was achieved through the benefit of the course being residential, which meant carers could absorb and immerse themselves in the learning:

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

Being residential, the carers and facilitators spent a lot of time together, but this was felt to work well from the carer perspective:

'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.' (Core course)

Respite for Carers

Respite through the residential course was a serendipitous outcome for carers:

'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.' (Young Onset Dementia course)

'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.' (Core course)

'I loved it....it just felt like a bit of respite as well.' (Core course)

Bonding and Continuing Friendships

Having a residential venue afforded carers the opportunity to spend extended time with people who have similar caring experiences:

'Being residential, we were able to meet other people who were in a similar circumstance....it was very empowering to hear other people's perspectives.' (Core course)

'Being with people who are in the same situation....I felt very isolated up to that point.' (Core course)

There was an opportunity for friendships to be forged which can provide alliances and support for the future. Many of the carers continued to remain in contact following the course through various social media or email:

'We've been in touch ever since....that's been a highlight to be honest...you can still be in contact with people who you've actually built that trusting relationship with.' (Core course)

'Never really been much of a joiner....but I quite like the fact that I can keep in touch with what's happening with them.' (Core course)

'I've met one lady twice actually....then she came and stayed over with us as well, which was great...we had one get together in October and we've got one at the end of February.' (Core course)

Content

Knowledge and Resilience

Carers valued the content of the course and the knowledge this provided. As one carer noted:

'No one prepares you to be a carer; you're in a new game and you don't know the rules.' (Young Onset Dementia course)

They appreciated and benefitted from way in which this was delivered:

'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.' (Young Onset Dementia course)

'I love the way they taught us to meditate and to breathe properly but for me, the most informative, were the sort of science part...the way the different types of dementia affect your brain and hence the behaviour.' (Core course)

'There are pieces of information that they're going to give that will frighten people but they seemed as a group to be able to unravel that fear and take time out with people....that's where the strength is.' (Me, You, Dementia Too course)

'The discussion sessions seemed to draw an awful lot of things out in a very safe environment.' (Core course)

'The session on bereavement was put on as a trial and that was very good.' (Core course)

The whole experience combining the content and the residential aspect worked well for the carers:

'It was really breath-taking in terms of the experience and just perfectly executed and well balanced because you were fed, you were looked after and you were informed.' (Core course)

'It's head and shoulders above any of the others I've been to.' (Young Onset Dementia course)

Impact on Themselves

The skills, knowledge and strategies gained through the course enabled carers to feel more confident in themselves. The carers had the opportunity to benefit from some self-reflection and understand the need to prioritise their own health needs:

'It gave me more insight...as a result of going on the programme I've pushed for some counselling for myself ...the course highlighted to me that I wasn't alone.' (Me, You, Dementia Too course)

'Before I went on the course, I felt like I was drowning in a sea of treacle....now I feel completely different....better able to cope....I definitely do...I needed life skills to make it through each day.' (Young Onset Dementia course)

'I have made a decision to do more self-care...I was putting my mother before me all the time...when I rang up the dentist they told me I hadn't been for over two years, same with the eye test...whereas I've made sure mum has seen a dentist and an optician every year.' (Home to Home course)

One carer shared a story of how they had witnessed this change first hand:

'I'll tell you a little story...there was this lady there....and you know how you sum people up when you first meet them? She looked miserable and I was introduced to her and I thought, you poor soul, I really did, she looked downbeat. At the end of the course I could see a change in her so I guess the same thing happened to me...she was brighter...she was more animated.....she was bubbly and she was absolutely good fun.' (Young Onset Dementia course)

The change was also noticed by the training facilitators:

'You see people arriving on the first day looking very anxious, looking a bit downtrodden, a bit exhausted, a bit worried and by day three, they look different – there's just something about them; there's more sparkle about them, they seem more confident, they look more confident, they're walking more confidently.'

Impact on their Caring Role

There were many ways in which the carers could illustrate how the course content had impacted on their ability to care for their loved one on a number of levels. Carers saw benefits for the person with dementia which resulted from doing things differently:

'I feel my interactions with my mum are more empowering for her...I don't try and do everything for her.' (Core course)

'The way I approach her.....not coming in from the front.' (Home to Home course)

The change in how carers interact with their loved on was also noticed by the training facilitators:

'One of the carers shared with the group that she'd had the best conversation with her mother that she'd had in a very long time....just on the phone....she was about to say to her mother, have you had your tablets, had you had your dinner, and she stopped herself and said 'are you hungry?' and 'how are you feeling?'.....at the end of the call her mother said 'and by the way, you left

your scarf here'. When the person with dementia isn't under pressure to keep retrieving information they actually start to remember things.'

Improving their knowledge of dementia and understanding how this affects a person also helped carers to adjust their expectations:

'I feel more relaxed....lowered my standards I suppose, my expectations because I realise that was causing more friction.' (Young Onset Dementia course)

'It's made us realise his perspective a bit better....just understanding how the disease affects them and not letting it get to you anymore.' (Core course)

Carers were also able to reflect on how a change in their own well-being would have an impact on the person they were caring for:

'When I'm in burnout, he can sense it; when I come out of burn out, I take him with me.' (Young Onset Dementia course)

Challenges Encountered

Any learning trajectory will have inherent challenges for learners and these courses were no exception. This was mainly expressed in relation to the emotional nature of the course content and the extent to which carers felt overloaded. Some carers felt that there was too much content squeezed into the three days, but all had valued the range of topics covered.

'It was quite an emotional sort of course...it would be nice to have a little bit more of a break....it was like overload.' (Me, You, Dementia Too course)

'I thought that each part was pretty interesting so if anything it was like too much, trying to cram it in, it felt like it was galloping through stuff sometimes.' (Home to Home course)

'Because it was so time sensitive.....I personally didn't have time to make notes otherwise I'm missing out on the next bit.' (Me, You, Dementia Too course)

'It felt quite intense.....it would have been nice to have time to catch up somehow.' (Core course)

While carers enjoyed and appreciated the courses, individual circumstances meant that not all content was relevant to everyone and some areas of interest could be missed. This was particularly noticeable in the early days of delivery where participants attended the core course rather than the bespoke courses which evolved later. However, the following quotes identify some of the areas where

participants felt they would benefit from further information including early or late stage dementia, dealing with behaviours that challenge, continuing care and Familial Alzheimer's:

'I think all our circumstances were quite different...maybe sort of tailoring future courses for those things....people who are sort of at early stage.' (Core course)

'There wasn't much about Familial Alzheimer's – I would have liked more of that and the genetic implications.' (Young Onset Dementia course)

'The later stages.....it wasn't really gone into too much.' (Core course)

'Dealing with confrontation and difficult behaviour.' (Me, You, Dementia Too course)

'I probably would have like a bit more information on NHS continuing care.' (Home to Home course)

Participants recognised that being on a course with people in the same situation was helpful:

'There was a couple which was very interesting to me...their partners had young onset Alzheimer's which is what my brother has got and there's a different set of problems involved in that.' (Core course)

To some extent the courses could be seen as a victim of their own success, with carers valuing them so much that they were concerned how they could receive a similar level of support in the future.

'It was such a good course, but where was I going to get the support once it had finished?' (Core course)

'Have the courses regularly as a top up....you do feel alone and things change...if they were happening twice a year it would be very helpful.' (Core course)

Barriers

Caring for the Person with Dementia in the Absence of the Participant

The courses were designed to meet the needs of carers who support a person living with dementia. The very nature of this relationship introduces a challenge in finding support for that person whilst the carer is away from the home. This challenge is not only expressed in financial terms but was also experienced in relation to *who* would be able to step into that caring role whilst the main carer attended the course.

'The main thing was that I had to do something with my wife...if I'd got carers in she wouldn't have liked it.....anyway, it would have cost a fortune for the weekend.' (Me, You, Dementia Too course)

'The only barrier would have been if I hadn't been able to get someone to have my dad.' (Core course)

'I've got a really supportive family....if I didn't have that support it would have been a real struggle.' (Core course)

'My children, grown up children, have not done it before, I mean, not overnight anyway.' (Young Onset Dementia course)

Cost of the Courses

Courses during the evaluation were provided free of charge. During this period a number of funding options were explored by DCC including payment for the course or discretionary donation. When asked whether they would be willing to pay for such a course, six participants said they could pay, four participants said they couldn't pay, eight were unsure and one person didn't comment. The six carers who responded affirmatively indicated that they would have had no difficulties paying or being willing to pay for the course. Four people said they would have been unable to pay with two making the following observations:

'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.' (Core course)

'Probably not, because I'm actually not working at the moment.' (Home to Home course)

Eight participants were unsure. For two, it would be dependent upon the actual charge levied and the ability for them *and* other family carers to attend:

'Depends on price. Might not have been able to afford for us both to go and my daughter cares for her dad as well.' (Core course)

'To be honest, I don't know, because we haven't got a lot of money ourselves. I would have said I would have wanted to, but we probably wouldn't have both gone, but even then I'm not sure.' (Home to Home course)

For the following participants, their concerns about cost were based on the fact that they were not sure the course would be worth the cost *prior* to having attended:

'Difficult to say...with the benefit of hindsight, and the benefits, I would probably have tried to scrape it together.' (Young Onset Dementia 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. I think, sort of, probably testimonials from one of the people because I know when I sort of came back and was telling people about the course and I was sort of saying that, you know, it was free but had it been like £250 and in fact had it been more, I probably would have paid having gone because I felt that my experience for me was so positive.' (Core course)

'I probably wouldn't have gone, however, I'd have missed something really valuable. I think that especially when you do have to pay, or at least make a contribution, it really needs to be sold better. So you need to understand what you'll get out of it before you go. And that way, you won't put people off.' (Core course)

Two carers felt there were moral issues attached to a fee structure:

'It felt to me that some people were there because it was a free course, if I'm honest, and they didn't really contribute very much to the group.' (Core course)

'Some of the people who were on the course I really sort of felt that there were people who needed to be on it and couldn't afford to. It's those people who really need it, and there were several on the course, but can't afford it. I think that maybe, you know, sort of some kind of subsidy, something along those lines, I think, you know, would be helpful, you know, or even like people who could afford it, if they're willing to subsidise other people, you know, something along those lines, or...Yeah, and I think, you know, people who basically are sort of maybe lower down the income level who probably need it more.' (Core course)

Bespoke Courses

Me, You, Dementia Too

Participants attending this course reflected that they would not have been able to attend training had they not been able to bring their loved one with them:

'It was the only course I've ever come across that took both of you.'

'My understanding was that it was just for carers...which is just relatively impractical but then I hear from a friend that she'd booked onto this course where the spouse goes too and I thought well that sounds much better.'

The logistics of taking the person with dementia was not always without its challenges:

'I felt to some extent that the total separation of us was difficult for him. The level of activities that have been designed for the dementia sufferers were too low a level and he got quite worried. So I was in a position where I was in a room and could see him wandering round the gardens.'

'My wife has posterior cortical atrophy....she can't read or play games so most of what they brought with them to do were things she couldn't really engage with.'

This however was not the experience of all participants:

'It did work out well – he enjoyed being with other people. Initially, I may have been a little bit tentative about it but at the end of the sessions, when we met up, I could see that he was fine.'

'I concentrated on the course – I wasn't worried at all about him.'

Case Studies

Pseudonyms have been used in the following case studies to protect identities.

Case Study 1: Family

Jenny attended a Me, You, Dementia Too course with her husband, Peter who has young onset dementia. She was really pleased that she was able to attend with him but Peter found it difficult:

'He found being put in a group of other people with dementia a challenge. He is not very badly affected....the level of activities that have been designed for dementia sufferers for want of a better word was too low a level. One of the activities was chopping up fruit to make a fruit salad. Peter does most of our cooking so he actually got quite worried about that and said he wasn't bloody doing it.'

Jenny's brother-in-law, David, had already attended the core course earlier in the year. Jenny and David were able to compare their experiences of attending the courses:

'David valued a lot more time in the evening when people were just chatting casually. The programme that Peter and I went on, there wasn't much time for that because in the evening they got a guitar and some singalongs which Peter didn't enjoy at all. So there wasn't time as couples....we couldn't go off in a huddle then start talking about each other's partners so it was a very different dynamic.'

David found the core course very insightful in helping him to support Jenny and Peter:

'Sometimes I'd get really short tempered so it's helped me adjust, I think, to be more aware of the changes and the moods and the mood swings.'

David felt that sharing his experiences of supporting Peter with others in similar situations had been beneficial:

'I think for me, the best bit was being with people that were able to talk about the problems that we are also facing....they were at sort of various stages of caring....there was a couple whose partners had young onset Alzheimer's which is what Peter has got and there's a different set of problems involved in that because of issues with children or work or money.'

Jenny was grateful that David had been able to attend a course as she had seen the benefits they could both bring to Peter's life:

'He's an amazing support for us and he gained so much information about this condition from going on that programme.'

Case Study 2: Sisters

Sharon attended the Home to Home course with her sister Elizabeth. She noted that there were other carers attending whose relative was in the same care home:

'I was with my sister and there was another set of sisters from the same care home.'

Kathy and Patricia were also sisters attending the same course. Kathy felt it was beneficial that they had attended together:

'They did some work on our own personalitiesI'm a very difference character to my sisterit's appreciating each other's strengths and weaknesses.....I think that was quite useful.'

Patricia reflected that she felt it was important to have a course tailored to their specific situation:

'We weren't going to feel uncomfortable by going somewhere and sort of listening to people talking about how hard it was to care for someone in their (own) home.'

With the benefit of having a relative in the same care home and being part of a sibling group, the four carers have exchanged contact details and stay in touch.

The introduction of cost at one point during the trial period prevented a sibling couple from attending:

'I've got two brothers who haven't been on the course because they would have to pay for it now. If it had been free I think they would have gone as well. So their awareness in some respects frustrates me because they don't have the same viewpoint that I do.' (Core course)

Case Study 3: Young Onset Dementia

Where families are supporting a person with young onset dementia, their experiences can be significantly different to families supporting an older person. In particular, families may still have children living at home, be of working age and be responsible for household finances. This was acknowledged by the training facilitators who devised a course specifically for those with a young onset diagnosis.

Michelle's husband was diagnosed with dementia at the age of 51 years. Michelle's children Oliver and Trudy are 26 and 18 years respectively. Michelle works full time and had to juggle her responsibilities to be able to attend the course. She was only able to do so because her children were at home to care for their father:

'That was the big problem....I work full time but it also had to be in a time when my children, who still live with me, were able to care for my husband.'
(Core course)

Carol has a similar situation and had not had any previous experience of leaving her older children to care for their father overnight:

'My children....they've not done it before, I mean, not overnight anyway.'
(Young Onset Dementia course)

Michelle felt that a course to improve the understanding of her older children would be beneficial:

'I'd love my kids to go to anything like that, you know. I'm very conscious that it's all me, me, me that has all of these courses and go to the support group and my kids are doing a wonderful job with him.' (Core course)

Discussion

Overall, both the quantitative and qualitative analysis demonstrate that attending the DCC Carers Support Courses has a positive impact on carers. As shown in Table 12, which focuses on comparing outcomes at different time points with outcomes prior to attending the courses, almost every outcome measure and sub-score saw an improvement. The improvement was maintained to some extent over time, and although was seen to ‘tail off’ in some cases the carers generally remained in a better physical, mental and emotional situation that they were before the courses. The overall pattern for the results is suggested in Figure 10, with the SWEMWBS measure for mental wellbeing being the only difference.

Table 12: Summary of outcome measures at key time points

Outcome measure	Pre vs Post	Pre vs 3 months	Pre vs 6 months	Pre vs 12 months
DKAS (knowledge)	SI	SI	SI	I
C-DMEQOL total (quality of life)		SI	I	I
Overall quality of life		I	I	I
Responsibilities and overall needs		I	I	I
Wellbeing		SI	I	I
Role		I	I	D
Feelings about the future		SI	I	I
Support		I	I	D
K10 (psychological distress)		I	D	I
SF12 total (health)		I	I	I
Physical health		D	I	I
Mental health		I	I	I
BRS (resilience)		I	I	I
SWEMWBS (mental wellbeing)		D	D	D

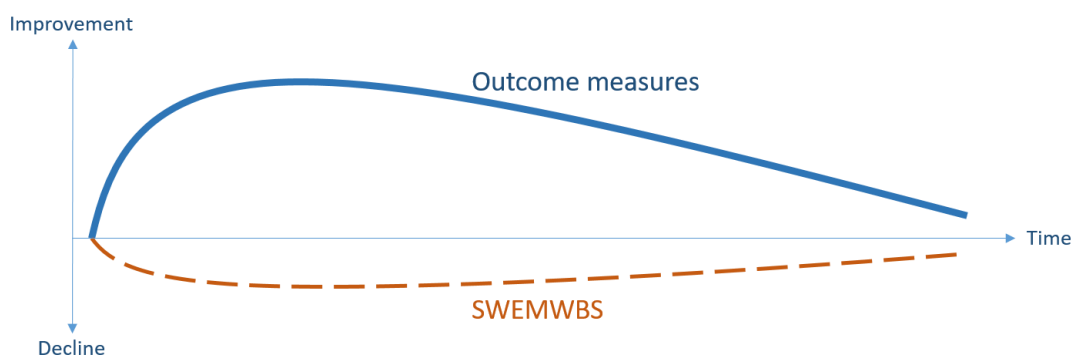


Figure 10: Indication of results patterns

It should however be noted that the outcome measures relied on carers self-reporting, so results may be influenced by how a carer was feeling at the particular time they completed the outcome measures booklet. The small number of returns at 12 months also means that caution should be used when considering the long-term impact beyond 6 months.

Thematic analysis from the carers' interviews demonstrated that the DCC training facilitators have combined a set of components to create a unique approach to delivering training to carers. This approach is fundamentally underpinned by a unique combination of skills harnessed within the training team. As a group of professionals, this team are able to support an emotionally fragile group of people, making them feel safe and supported. They are able to do this in a person-centred way, responding at the individual level.

Carers had faith in the knowledge, expertise and strengths of the training facilitators. Working from this basis of trust, empathy and respect, the trainers enabled carers to reflect, express themselves, learn from each other and create a community of support.

A residential component is instrumental in nurturing these delicate and complex relationships. From these strong foundations, an educational component is introduced which affords carers the opportunity to focus on themselves; feeling safe and not alone. They are able to safely share their experiences with others in a similar or relatable situation and often create sustainable friendships. The supportive combination of these components is summarised in Figure 11.

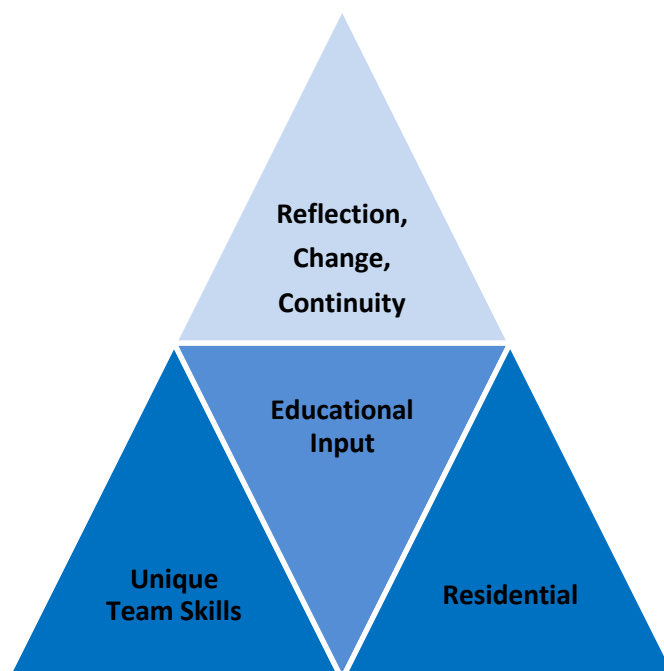


Figure 11: Interaction of the key course components

One aspect to draw out from both the quantitative and qualitative findings relates to different groups of carers having slightly different needs. While the quantitative results indicated that people in different caring relationships may require different forms of support, the qualitative interviews found that the relevance of some course content was influenced by carers' individual circumstances. Some carers found it helpful to be on a course with people in the same situation, suggesting the importance of peer support or the need to tailor courses to certain groups. Whether this is achieved through different courses for different groups or adapting the content of existing courses, it would not alter the fundamental role of the underpinning course components.

Recommendations

Communication and Managing Expectations

If a decision is taken to introduce a cost for future courses, it will be important for prospective participants to fully appreciate the benefits of the courses in order for them to be willing to fund attendance. Many people caring for a person with dementia will be experiencing financial burden and self-funding course attendance, possibly alongside caring costs, may not be achievable. Sharing positive experiences more widely may be a role for DCC Ambassadors who could assist with future course participant recruitment.

While it is not possible to promise that courses will improve outcomes for carers, the positive quantitative and qualitative findings from this evaluation could be used to support future promotion of courses.

Expansion of the Courses

A number of training models for the future have already been explored including:

- Development of a two-day course.
- Bolt-on sessions to the core course.
- One-day workshops – Caring about Eating, Drinking or Swallowing Difficulties; Caring about Relationships and Feeling Secure; Caring about Choosing the Right Care Home.
- Carer Support Plans.

Carer feedback suggests that there would be interest in a number of additional models. This range of courses could help to address the quantitative findings that people in different caring relationships may require different forms of support, with each course being tailored to the specific group of carers:

- Courses for family groups or adult children.
- Courses for people with the same diagnosis.
- Courses for people at the same stage of the dementia journey.
- Refresher days.

Course Content and Intensity

Some areas of interest mentioned by carers were very specific but could easily be incorporated into courses in the future:

- Familial Alzheimer's disease.
- Bereavement.
- The later stages of dementia.
- Changes in behaviour and how to respond to this.
- NHS continuing care.

However, any additional content should be balanced against carers feeling that the existing three-day courses were already very intense. Reviewing the course content could be beneficial when tailoring courses to particular audiences, especially as there were indications of differences in some of the outcome measures for people in different caring relationships and for male and female carers.

Setting the Scene/Venue

It will be important that future courses are able to recreate the same residential experience which was not only appreciated by carers as respite from their caring role but also afforded an opportunity to create mutually supportive friendships and continuing bonds.

Sustainability

There is an obvious cost element to the future sustainability of the DCC educational courses. In addition, future sustainability will also depend upon staff retention and future recruitment of specialists, enabling DCC to continue to offer the unique model of expertise and support which carers value and have reported as beneficial.

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Appendix 1: Evaluation Booklet



7-14 Great Dover Street

London SE1 4YR

Evaluation of DCC Pilot Dementia Carers Support Course

Course Participant Evaluation Booklet

(Pre Course Questions)



Participant
identifier:

(DOB & initials)

The Dementia Knowledge Assessment Scale

The scale has been designed to find out what people know about the most common forms of dementia (forms of dementia that occur most frequently). Understanding knowledge of dementia is essential for developing education for students, family members, health professionals, and the general public. The survey has been developed at the Wicking Dementia Research and Education Centre, University of Tasmania.

It is important that your current understanding of dementia informs the answers you provide.

Please read each statement carefully and tick (✓) the appropriate box to indicate how true or false you believe each statement to be. Please answer each question to the best of your knowledge.

If you do not know how to respond to a statement, please show us that you **don't know** by ticking (✓) the box on the right of the page.

	Statements about dementia	Response scale (Please tick one box ✓)				I don't know
		False	Probably false	Probably true	True	
1	Dementia is a normal part of the ageing process.					
2	Alzheimer's disease is the most common form of dementia.					
3	People can recover from the most common forms of dementia.					
4	Dementia does not result from physical changes in the brain.					
5	Most forms of dementia reduce the length of a person's life.					
6	Planning for end of life care is generally not necessary following a diagnosis of dementia.					
7	Blood vessel disease (vascular dementia) is the most common form of dementia.					
8	Most forms of dementia do not generally shorten a person's life.					
9	Having high blood pressure increases a person's risk of developing dementia.					
10	Maintaining a healthy lifestyle does not reduce the risk of developing the most common forms of dementia.					
11	Symptoms of depression can be mistaken for symptoms of dementia.					
12	Exercise is generally beneficial for people experiencing dementia.					
13	Early diagnosis of dementia does not generally improve quality of life for people experiencing the condition.					
14	The sudden onset of cognitive problems is characteristic of common forms of dementia.					
15	It is impossible to communicate with a person who has advanced dementia.					
16	A person experiencing advanced dementia will not generally respond to changes in their physical environment.					

	Statements about dementia	Response scale (Please tick one box ✓)				I don't know
		False	Probably false	Probably true	True	
17	It is important to correct a person with dementia when they are confused.					
18	People experiencing advanced dementia often communicate through body language.					
19	Uncharacteristic behaviours in a person experiencing dementia are generally a response to unmet needs.					
20	People with dementia are unlikely to experience depression.					
21	Medications are the most effective way of treating behavioural symptoms of dementia.					
22	People experiencing dementia do not generally have problems making decisions.					
23	Movement is generally affected in the later stages of dementia.					
24	People with advanced dementia may have difficulty speaking.					
25	People experiencing dementia often have difficulty learning new skills.					
26	Difficulty eating and drinking generally occurs in the later stages of dementia.					
27	Daily care for a person with advanced dementia is effective when it focuses on providing comfort.					

C-DEMqoL – Quality of life in carers of people with dementia

Please think of how things have been and how you have felt in the past 4 weeks. Of course, there might have been good and bad days, but the questionnaire intends to capture a snapshot of how you have felt on a typical day during the past month.

For each question, tick (✓) one option that best describes how you feel.

- There are no right or wrong answers, so please be as open as you can, and try to answer all the questions to the best of your judgement.
- If you feel that a question does not apply to you or to the person you care for, write "N/A" (standing for Not Applicable) next to the question.

CARER OVERALL QUALITY OF LIFE

First, we would like to find out about your quality of life as a carer for a person with dementia. We understand that there may be other things that affect your quality of life; however, please try to think of yourself in your caring role only. Select one option that best describes how you feel.

1. My quality of life as a carer during the past 4 weeks has been...

very good quite good fair quite poor very poor

2. How do you feel your quality of life as a carer has changed in the past 4 weeks?

got a lot better got a little better not changed got a little worse got a lot worse

CARER RESPONSIBILITIES AND PERSONAL NEEDS

In this section, we would like to know how you feel about your caregiving responsibilities, which may include managing medications, providing help with washing and dressing, medical visits or social outings, and also anything you need to do for the person who is in a care home.

We would also like to know how your caregiving responsibilities affect your ability to have time for yourself, and doing the things that you enjoy or want to do, in particular activities that are important to your quality of life.

Again, think how things have been in the past 4 weeks.

3. I consider the physical demands that caregiving places on me...

very light quite light moderate quite heavy very heavy

4. My time has been organised around the needs of the person I care for...

not at all a little to some extent considerably completely

5. Carrying out my caregiving tasks and responsibilities takes up...

very little of my energy some of my energy a considerable amount of my energy most of my energy all of my energy

6. Being a carer for the person with dementia takes up...

- very little of my time some of my time a considerable amount of my time most of my time all of my time

7. Meeting my own needs (for doing things I enjoy) whilst also caring has been...

- not a problem for me quite easy a problem at times quite difficult very difficult

8. Thinking of my ability to do things I enjoy, I have felt...

- free to do them when I want restricted in a little way by my caring duties restricted to some extent by my caring duties restricted a lot by my caring duties unable to do them due to my caring duties

9. In terms of freedom to do things I enjoy, my caregiving responsibilities have had...

- no impact on my freedom little impact on my freedom some impact on my freedom a significant impact on my freedom restricted my freedom completely

10. Thinking of my ability to do activities I enjoy whilst also caring, I feel that...

- all of my needs are met most of my needs are met some of my needs are met only a few of my needs are met none of my needs are met

CARER WELLBEING

In this section, we will ask about **your wellbeing** and how this has been affected by your caring role. Again, think about the **past 4 weeks**.

11. I consider the emotional demands that caregiving places on me...

- very light quite light moderate quite heavy very heavy

12. In terms of my wellbeing, meeting the demands of caregiving has been...

- not at all stressful a little stressful quite stressful stressful very stressful

13. I have been having emotional problems (such as feeling sad, stressed or anxious)...

- none of the time a little of the time some of the time most of the time all of the time

14. Thinking of the physical and emotional demands of caregiving, I feel that they have...

- no impact on my health little impact on my health some impact on my health a significant impact on my health a very significant impact on my health

15. Looking after my own health whilst also caring has been...

- not a problem for me quite easy a problem at times quite difficult very difficult

16. Whenever I need to get away from the person I care for, I feel...

- not at all guilty a little guilty quite guilty guilty very guilty

17. Thinking of changes in the person I care for due to dementia (such as changes in ability, memory, or behaviour), I find them...

- not at all upsetting a little upsetting quite upsetting upsetting very upsetting

CARER ROLE

Now we would like to find out how you feel about being a carer for a person with dementia. This includes how you feel about your relationship with the person you care for, and your feelings about him or her.

Again, think about the past 4 weeks.

18. Considering all the demands that caring places on me, I feel that overall I have...

- coped very well coped quite well coped OK coped quite poorly coped very poorly

19. When thinking of my present role as a carer for a person with dementia, I feel...

- not at all resentful a little resentful quite resentful resentful very resentful

20. My relationship with the person I care for in the past 4 weeks has been...

- very good quite good fair quite poor very poor

21. During the past 4 weeks, my relationship with the person I care for has...

- improved a lot improved a little not changed deteriorated a little deteriorated a lot

22. I feel appreciated by the person I care for...

- always or almost always often sometimes once in a while never

23. I feel frustration toward the person I care for...

- none of the time a little of the time some of the time most of the time all of the time

24. When thinking about whether the care I give to the person with dementia has positive impact on his or her quality of life, I...

- feel relaxed have only a few worries have some worries have significant worries worry a lot

25. When thinking about whether I am meeting the needs of the person with dementia, I...

- feel relaxed have only a few worries have some worries have significant worries worry a lot
-

FEELINGS ABOUT THE FUTURE

In this section, we would like to know how you feel about your own future as a carer, and the future for the person you care for.

Again, think of how things have felt for you in the past 4 weeks.

26. When thinking about meeting the future care needs of the person with dementia, I...

- feel relaxed have only a few worries have some worries have significant worries worry a lot

27. I worry about how I will be able to cope emotionally as the dementia gets worse in the future...

- none of the time a little of the time some of the time most of the time all of the time

28. I worry about what may happen to the person I care for in the future...

- none of the time a little of the time some of the time most of the time all of the time

29. I anticipate that trying to meet the needs of the person with dementia in the future will be...

- not at all difficult a little difficult quite difficult difficult extremely difficult

30. Thinking of my health and physical ability to provide care in the future, I...

- feel relaxed have only a few worries have some worries have significant worries worry a lot

31. When thinking of making important caring decisions in the future, I...

- feel relaxed have only a few worries have some worries have significant worries worry a lot

32. When thinking about the future impact of caring on my finances, I...

- feel relaxed have only a few worries have some worries have significant worries worry a lot
-

CARER SUPPORT

In this section, we would like to know how you feel about the help and support that you may need as a carer. This includes the help and support you may need from family members, support from health and social services, and wider social and support networks (for example, local community support groups).

Again, think of how things have felt for you in the past 4 weeks.

33. In the past 4 weeks, my need for support in caring for the person with dementia has been...
- very low quite low moderate quite high very high
34. In the past 4 weeks, my need for support in looking after my own health while caring has been...
- very low quite low moderate quite high very high
35. Overall, my needs for support have been met...
- completely considerably to some extent a little not at all
36. I feel supported by family members...
- completely considerably to some extent a little not at all
37. I feel supported by my friends...
- completely considerably to some extent a little not at all
38. I feel supported by wider social networks (for example, community support groups)...
- completely considerably to some extent a little not at all
39. I feel supported by professionals (for example, doctors)...
- completely considerably to some extent a little not at all
40. The level of professional support offered or provided to me has met my expectations...
- completely considerably to some extent a little not at all

K10 – Kessler Psychological Distress Scale

These questions are concerned with how you have been feeling over the last month. Please tick (✓) a box for each question to indicate how you have been feeling.

During the last 30 days:	None of the time	A little of the time	Some of the time	Most of the time	All of the time
How often did you feel tired out for no good reason?					
How often did you feel nervous?					
How often did you feel so nervous that nothing would calm you?					
How often did you feel hopeless?					
How often did you feel restless or fidgety?					
How often did you feel so restless you could not sit still?					
How often did you feel depressed?					
How often did you feel that everything was an effort?					
How often did you feel so sad that nothing could cheer you up?					
How often did you feel worthless?					

Health Survey Questionnaire

The following questions ask you for your views about your health, how you feel and how well you are able to do your usual activities.

If you are unsure about how to answer any questions please give the best answer you can and make any of your own comments if you like. Do not spend too much time in answering as your immediate response is likely to be the most accurate.

1. In general, would you say your health is:

- Excellent Very Good Good
 Fair Poor

2. Health and Daily Activities

The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much? (Please tick **one** box for each question)

a) Moderate activities such as moving a table, pushing a vacuum, bowling or playing golf:

- Yes, limited a lot Yes, limited a little Not limited at all

b) Climbing several flights of stairs:

- Yes, limited a lot Yes, limited a little Not limited at all

3. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? (Please answer yes or no to each question)

a) Accomplished less than you would like

- Yes No

b) Were limited in the kind of work or other activities

- Yes No

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)? (Please answer yes or no to each question)

a) Accomplished less than you would like

- Yes No

b) Didn't do work or other activities as carefully as usual

- Yes No

5. During the past 4 weeks, how much did pain interfere with your normal work (including work both outside the home and housework) (Please tick one box for each question)

- Not at all A little Moderately
 Quite a bit Extremely

6. These questions are about how you feel and how things have been with you during the past month. For each question please indicate the one answer that comes closest to the way you have been feeling. (Please tick one box for each question).

a) Have you felt calm and peaceful?

- All of the time Most of the time A good bit of the time
 Some of the time A little of the time None of the time

b) Do you have a lot of energy?

- All of the time Most of the time A good bit of the time
 Some of the time A little of the time None of the time

c) Do you feel downhearted and low?

- All of the time Most of the time A good bit of the time
 Some of the time A little of the time None of the time

d) Has your health limited your social activities (like visiting friends or close relatives)?

- All of the time Most of the time A good bit of the time
 Some of the time A little of the time None of the time

Brief Resilience Scale

Please respond to each item by ticking (✓) one box per row.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
I tend to bounce back quickly after hard times					
I have a hard time making it through stressful events					
It does not take me long to recover from a stressful event					
It is hard for me to snap back when something bad happens					
I usually come through difficult times with little trouble					
I tend to take a long time to get over set-backs in my life					

The Short Warwick Edinburgh Mental Well-being Scale

Below are some statements about feelings and thoughts. Please tick (✓) the box that best describes your experience of each over the last 2 weeks.

	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future					
I've been feeling useful					
I've been feeling relaxed					
I've been dealing with problems well					
I've been thinking clearly					
I've been feeling close to other people					
I've been able to make up my own mind about things					

The Reisberg Global Deterioration Scale

Please indicate the level of cognitive impairment that the person with dementia experiences:

Level	Clinical Characteristics
<p>1</p> <p>No cognitive decline</p>	No subjective complaints of memory deficit. No memory deficit evident on clinical interview
<p>2</p> <p>Very mild cognitive decline (Age Associated Memory Impairment)</p>	Subjective complaints of memory deficit, most frequently in following areas: (a) forgetting where one has placed familiar objects; (b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.
<p>3</p> <p>Mild cognitive decline (Mild Cognitive Impairment)</p>	Earliest clear-cut deficits. Manifestations in more than one of the following areas: (a) patient may have gotten lost when traveling to an unfamiliar location; (b) co-workers become aware of patient's relatively poor performance; (c) word and name finding deficit becomes evident to intimates; (d) patient may read a passage or a book and retain relatively little material; (e) patient may demonstrate decreased facility in remembering names upon introduction to new people; (f) patient may have lost or misplaced an object of value; (g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview. Decreased performance in demanding employment and social settings. Denial begins to become manifest in patient. Mild to moderate anxiety accompanies symptoms.
<p>4</p> <p>Moderate cognitive decline (Mild Dementia)</p>	Clear-cut deficit on careful clinical interview. Deficit manifest in following areas: (a) decreased knowledge of current and recent events; (b) may exhibit some deficit in memory of one's personal history; (c) concentration deficit elicited on serial subtractions; (d) decreased ability to travel, handle finances, etc. Frequently no deficit in following areas: (a) orientation to time and place; (b) recognition of familiar persons and faces; (c) ability to travel to familiar locations. Inability to perform complex tasks. Denial is dominant defence mechanism. Flattening of affect and withdrawal from challenging situations frequently occur.
<p>5</p> <p>Moderately severe cognitive decline (Moderate Dementia)</p>	Patient can no longer survive without some assistance. Patient is unable during interview to recall a major relevant aspect of their current lives, e.g., an address or telephone number of many years, the names of close family members (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place. An educated person may have difficulty counting back from 40 by 4s or from 20 by 2s. Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouses' and children's names. They require no assistance with toileting and eating, but may have some difficulty choosing the proper clothing to wear.
<p>6</p> <p>Severe cognitive decline (Moderately Severe Dementia)</p>	May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10, both backward and, sometimes, forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance but occasionally will be able to travel to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment. Personality and emotional changes occur. These are quite variable and include: (a) delusional behaviour, e.g., patients may accuse their spouse of being an impostor, may talk to imaginary figures in the environment, or to their own reflection in the mirror; (b) obsessive symptoms, e.g., person may continually repeat simple cleaning activities; (c) anxiety symptoms, agitation, and even previously non-existent violent behaviour may occur; (d) cognitive abulia, i.e., loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.

<p>7</p> <p>Very severe cognitive decline (Severe Dementia)</p>	<p>All verbal abilities are lost over the course of this stage. Frequently there is no speech at all -only unintelligible utterances and rare emergence of seemingly forgotten words and phrases. Incontinent of urine, requires assistance toileting and feeding. Basic psychomotor skills, e.g., ability to walk, are lost with the progression of this stage. The brain appears to no longer be able to tell the body what to do. Generalized rigidity and developmental neurologic reflexes are frequently present.</p>
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Thank you for completing this booklet

Please hand this back to the Course Trainer

Please remember to detach and retain the information sheets

Appendix 2: Demographics Booklet

The evaluation questions are highlighted by the red boxes. All other questions were collected on behalf of Dementia Carers Count.



7-14 Great Dover Street
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DCC Dementia Carers Support Course

Participant Information Questionnaire

Thank you for taking time to complete this questionnaire, which includes questions about you, and about the person living with dementia who you care for.

Collecting information from everyone who participates in our Dementia Carers Support Course is important, as it helps us to understand more about who is using our services as well as ways to develop, improve and promote our courses.

All the information that you provide is used and stored anonymously. If you have any questions or concerns, please ask a member of the course team, who will be happy to help.

With thanks, The DCC Team

Participant identifier:

.....
(DOB & initials)

1. Information about you

1.1 Your current age years	1.2 Gender Male <input type="checkbox"/> Female <input type="checkbox"/> Other <input type="checkbox"/> Prefer not to say <input type="checkbox"/> Prefer to self-describe:	1.3 Employment status – tick all boxes that apply Employed <input type="checkbox"/> Self-employed <input type="checkbox"/> Freelance <input type="checkbox"/> Not employed <input type="checkbox"/> Retired <input type="checkbox"/> In education <input type="checkbox"/>	Full-time <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	Part-time <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
1.4 Current occupation/occupation before retirement:				
1.5 Ethnicity Prefer to self-describe: Prefer not to say: <input type="checkbox"/> Asian/Asian British: Indian <input type="checkbox"/> Chinese <input type="checkbox"/> Pakistani <input type="checkbox"/> Other <input type="checkbox"/> Bangladeshi <input type="checkbox"/> Black/Black British: Caribbean <input type="checkbox"/> African <input type="checkbox"/> Other <input type="checkbox"/>		Mixed: White & Black Caribbean <input type="checkbox"/> White & Black African <input type="checkbox"/> White & Asian <input type="checkbox"/> Other <input type="checkbox"/> White: British <input type="checkbox"/> Irish <input type="checkbox"/> Gypsy/Irish Traveller <input type="checkbox"/> Other <input type="checkbox"/> Other ethnic background: <input type="checkbox"/>		

<p>1.6 Sexual orientation</p> <p>Prefer not to say <input type="checkbox"/></p> <p>Prefer to self-describe:</p> <p>.....</p> <p>.....</p> <p>Bisexual <input type="checkbox"/></p> <p>Heterosexual <input type="checkbox"/></p> <p>Homosexual <input type="checkbox"/></p> <p>Other <input type="checkbox"/></p>	<p>1.7 Do you have a faith or belief system? If yes, please say what it is:</p> <p>.....</p> <p>.....</p> <hr/> <p>1.8 Are you registered as disabled person?</p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>If yes, please provide details:</p> <p>.....</p>
<p>1.9 Do you have any long-term health conditions that affect your ability to be a carer?</p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>If yes, please provide details:</p> <p>.....</p> <p>.....</p>	

2. Information about the person living with dementia

<p>2.1 Dementia diagnosis</p>	<p>The person I am supporting has not been formally diagnosed <input type="checkbox"/></p> <p>If there is no diagnosis, how long has the person you are supporting been experiencing symptoms of dementia years months</p> <p>If the person has a diagnosis please tick what this is:</p> <p>Alzheimer's disease <input type="checkbox"/> Vascular dementia <input type="checkbox"/></p> <p>Dementia with Lewy bodies <input type="checkbox"/> Frontotemporal dementia <input type="checkbox"/></p> <p>Other:</p> <p>.....</p> <p>How long was the person you are supporting experiencing symptoms before diagnosis? years</p>
<p>2.2 Age of person with dementia</p>	<p>Age now years</p> <p>Age when diagnosed (if known) years</p>
<p>2.3 Gender of person with dementia</p>	<p>Male <input type="checkbox"/> Female <input type="checkbox"/> Other <input type="checkbox"/></p> <p>Prefer to self-describe:</p>

<p>2.4 Does the person you are supporting have any other long term health conditions or disabilities?</p>	<p>Please provide details:</p> <p>.....</p> <p>.....</p> <p>.....</p>
<p>2.5 Please comment on how this impacts on the person</p>	<p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>

3. Your relationship with the person living with dementia

<p>3.1 How long have you been in a caring role? (e.g. providing help for the person with dementia to cope in their day-to-day life)</p> <p>Number of years:</p>	<p>3.2 The person with dementia is my:</p> <p>Partner/spouse <input type="checkbox"/> Parent <input type="checkbox"/></p> <p>Other relative <input type="checkbox"/> Neighbour <input type="checkbox"/></p> <p>Friend <input type="checkbox"/> Other:</p>
<p>3.3 Are you the main carer for the person living with dementia?</p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>Are you the only carer for the person living with dementia?</p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/></p>	<p>3.4 Do you live with the person with dementia?</p> <p>Yes <input type="checkbox"/> No <input type="checkbox"/> Sometimes <input type="checkbox"/></p> <p>If you do not live with the person you are supporting, how far away are you from where they live? miles (approximately)</p>
<p>3.5 How would you describe your caring role? Tick all boxes that apply:</p> <p>Taking them to hospital appointments, GP appointments <input type="checkbox"/></p> <p>Taking them to shops, library, community events <input type="checkbox"/></p> <p>Help with administration & paperwork, arranging services <input type="checkbox"/></p> <p>Help with prompting & reminding to take tablets, attend appointments <input type="checkbox"/></p> <p>Helping in the home with a range of practical tasks, e.g., meal preparation, laundry, cooking, shopping, housework <input type="checkbox"/></p> <p>Physical care such as feeding the person, help with self-care, washing, dressing <input type="checkbox"/></p> <p>Providing social contact to combat loneliness and isolation <input type="checkbox"/></p> <p>Please say more about your caring role if not described fully enough above:</p> <p>.....</p> <p>.....</p>	

3.6 Approximately how much time do you spend helping with the above tasks? (Please tick)

Please include the hours when you are not with the person but are doing things for them.

In hours per day:

- 1-3 hours 13-16 hours
 4-7 hours 17-24 hours
 8-12 hours

Days per week:

- 1 day 4 days 7 days
 2 days 5 days
 3 days 6 days

4. A bit more about you

4.1 Where have you got your information from to help in your caring role so far?	How helpful has the information from each source been?
Tick all boxes that apply:	Please circle: 10 = very helpful 0 = not helpful
GP <input type="checkbox"/>	10 9 8 7 6 5 4 3 2 1 0
Hospital Consultant <input type="checkbox"/>	10 9 8 7 6 5 4 3 2 1 0
Admiral Nurse <input type="checkbox"/>	10 9 8 7 6 5 4 3 2 1 0
Community Psychiatric Nurse (CPN) <input type="checkbox"/>	10 9 8 7 6 5 4 3 2 1 0
Social Worker <input type="checkbox"/>	10 9 8 7 6 5 4 3 2 1 0
Speech and Language Therapist <input type="checkbox"/>	10 9 8 7 6 5 4 3 2 1 0
Occupational Therapist <input type="checkbox"/>	10 9 8 7 6 5 4 3 2 1 0
Carers Group <input type="checkbox"/>	10 9 8 7 6 5 4 3 2 1 0
Carer Support Service <input type="checkbox"/>	10 9 8 7 6 5 4 3 2 1 0
Memory Assessment Service/Clinic <input type="checkbox"/>	10 9 8 7 6 5 4 3 2 1 0
Charity website <input type="checkbox"/>	10 9 8 7 6 5 4 3 2 1 0
Dementia cafe <input type="checkbox"/>	10 9 8 7 6 5 4 3 2 1 0
Charity face-to-face <input type="checkbox"/>	10 9 8 7 6 5 4 3 2 1 0
Other: 1)	10 9 8 7 6 5 4 3 2 1 0
Other: 2)	10 9 8 7 6 5 4 3 2 1 0
Other: 3)	10 9 8 7 6 5 4 3 2 1 0
4.2 Do you use the following to access information? Tick all boxes that apply Websites <input type="checkbox"/> Internet searches <input type="checkbox"/> Facebook <input type="checkbox"/> Twitter <input type="checkbox"/> Instagram <input type="checkbox"/>	Please add any further information about how you access information online:

<p>4.3 Do you read any newspapers regularly?</p> <p>Please list them here:</p> <p>1.</p> <p>2.</p> <p>3.</p> <p>4.4 Do you read any magazines regularly?</p> <p>Please list them here:</p> <p>1.</p> <p>2.</p> <p>3.</p>	<p>Do you read these:</p> <table border="0"> <tr> <td style="text-align: center;">In Print</td> <td style="text-align: center;">Online</td> <td style="text-align: center;">Both</td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> </table>	In Print	Online	Both	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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5. About the RSAS Dementia Carers Support Course

<p>5.1 How did you find out about the course?</p> <p>.....</p>																																									
<p>5.2 How far did you travel for this course and how long did it take to get here?</p> <p>Miles (approximately) Time: I travelled by:</p>																																									
<p>5.3 The RSAS Dementia Carers Support Course costs our charity £650* per person to provide. How much would you be prepared to contribute for attending this programme?</p> <p><i>*Estimated current cost subject to change, depending on location, participant numbers and other factors</i></p> <table border="1" style="width: 100%;"> <thead> <tr> <th colspan="2" style="text-align: right;">Please tick:</th> </tr> </thead> <tbody> <tr><td>£100</td><td></td></tr> <tr><td>£200</td><td></td></tr> <tr><td>£300</td><td></td></tr> <tr><td>£400</td><td></td></tr> <tr><td>£500</td><td></td></tr> <tr><td>£600</td><td></td></tr> <tr><td>£650/the full cost</td><td></td></tr> <tr><td>I could not afford to contribute</td><td></td></tr> <tr><td>Prefer not to say</td><td></td></tr> </tbody> </table> <p>I do not think it appropriate for me to pay for this because:</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>	Please tick:		£100		£200		£300		£400		£500		£600		£650/the full cost		I could not afford to contribute		Prefer not to say		<p>5.4 How much would you be able to contribute towards the cost of having the person* you care for accompany you to cover participating alongside you and/or in parallel organised activities?</p> <p><i>* The person must be self-caring and independently mobile as RSAS is unable to provide any medical, nursing or practical care</i></p> <table border="1" style="width: 100%;"> <thead> <tr> <th colspan="2" style="text-align: right;">Please tick:</th> </tr> </thead> <tbody> <tr><td>£100</td><td></td></tr> <tr><td>£200</td><td></td></tr> <tr><td>£300</td><td></td></tr> <tr><td>£400</td><td></td></tr> <tr><td>£500</td><td></td></tr> <tr><td>£600</td><td></td></tr> <tr><td>£650/the full cost</td><td></td></tr> <tr><td>I could not afford to contribute</td><td></td></tr> <tr><td>Prefer not to say</td><td></td></tr> </tbody> </table> <p>I do not think it appropriate for me to pay for this because:</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>	Please tick:		£100		£200		£300		£400		£500		£600		£650/the full cost		I could not afford to contribute		Prefer not to say	
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Prefer not to say																																									

6. Your thoughts?

6.1 I would prefer the group size to be:					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		
5-10	10-15	16-20	20-25		
6.2 I would like the option of attending the RSAS Dementia Carers Support Course along with the person I care for.					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Comments:		
Yes	No	I'm not sure		
6.3 I would be interested in accessing one-to-one support from this charity to receive counselling.					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not interested	During the course	By phone after the course	By video call after the course	In my own home	By visiting the Dementia Carers Centre
6.4 I would be interested in accessing one-to-one support from this charity to receive an assessment followed by individualised dementia support plan for the person I am supporting.					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not interested	During the course	By phone after the course	By video call after the course	In my own home	By visiting the Dementia Carers Centre
6.5 I would prefer to attend the course in a group with other people of a similar age to me.					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
Yes	No	No preference			
6.6 I would prefer to attend the course in a group with other people with a similar relationship to the person with dementia as me e.g. parent/spouse.					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
Yes	No	No preference			
6.7 I would prefer to attend the course with other people whose family member has the same type of dementia as the person I am supporting.					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
Yes	No	No preference			
6.8 I have improved my knowledge of dementia through attending the RSAS Dementia Carers Support Course.					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
Yes	No	I'm not sure			

<p>6.9 I feel better equipped in my caring role through attending the RSAS Dementia Carers Support Course.</p> <p style="text-align: center;"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure </p>
<p>6.10 I understand how to look after myself better as a carer through attending the RSAS Dementia Carers Support Course.</p> <p style="text-align: center;"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure </p>
<p>6.11 I would recommend the RSAS Dementia Carers Support Course to other carers.</p> <p style="text-align: center;"> <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I'm not sure </p>
<p>6.12 Is there a particular community group that you would like us to offer support to? (Please give details)</p> <p>.....</p> <p>.....</p> <p>.....</p>
<p>6.13 Are there any other services you would like us to provide?</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>
<p>6.14 What was the best thing for you about attending the RSAS Dementia Carers Support Course?</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p> <p>.....</p>

Thank you for completing this questionnaire.

Appendix 3: Carer Interview Schedule

Dementia Carers Count: Evaluation of Dementia Carer Support Course

Telephone interview with course participants

Thank you for completing the consent form and spending the time to share your experiences with us. I hope you have had chance to read the information sheet that was in your evaluation booklet. Some of the questions today may overlap with those you previously answered. For the purposes of this interview could you please confirm that you are happy for the interview to be audio recorded? The recording will be transcribed and used for this project. No one will be able to identify you from the information given to us and the data will be held securely. Please remember you that your participation is voluntary and you may withdraw from the interview at any point.

Background
1. Name
2. Relationship to person with dementia
3. Length of time of diagnosis
4. Do you live with the person?
5. How did you find out about the course?

Tell me about your experiences of attending the course (logistics)
6. Prior to booking, was there anything about the logistics of the course that you found problematic?
7. Did you have all the information you needed prior to the course?
8. Did you have any difficulties making arrangements to attend the course?
9. If there had been a cost to this course, would you still have been able to attend?
10. Did you take advantage of the accommodation provided with the course? Did that pose any challenges?
11. Did anything or would anything potentially have prevented you from attending?
Prompts: <ul style="list-style-type: none">• Travel to get to the course• Person to contact if had any questions• Arranging alternative care for the person with dementia

What did you think about the course content?
12. Was the content of the course what you expected?
13. Was there any particular content missing?
14. What were the highlights of the course for you?

15. In what ways did the content of the course differ from other courses you have attended relating to dementia?

16. If you haven't been on any other courses, what made you choose to attend this one?

17. Was there anything in the content which made you feel apprehensive about the future?

Prompts:

- Range of topics covered
- Time spent on each topic
- Any supporting handouts to take away/make own notes on
- Try to keep focus on content rather than other aspects of the course

How do you think the course could be improved?

18. Can you tell me about anything which would make your experience of the course better?

Prompts:

- Information provided prior to the course
- Course content
- Course materials, e.g. course handbook
- Group size
- Mix of attendees
- Learning methods used, e.g. PowerPoint slides, video clips, exercises
- Length of day
- Number of days

Tell me about ways in which the course has affected you in your role as a carer (Impact)

19. Talk me through some of the benefits you have found from attending the course?

20. Have you seen any negative aspects since attending the course?

21. Have your feelings changed towards the person with dementia that you take care of?

22. Have you noticed any changes in the way you communicate with the person with dementia that you take care of?

Prompts:

- Impact on yourself? Examples (positive or negative)
- Impact on the person with dementia? Examples (positive or negative)
- Impact on your wider family/friends? Examples (positive or negative)
- How you feel about your situation
- Health impact
- Social impact
- Know more about assistance available – and if made use of it

Coping in the future

23. Will you maintain contact with any of the other course participants in the future?

24. What strategies have you learned that you will continue to use in the future?

25. Is there any further information that you feel would help you in the future?

26. What advice would you give to someone who is looking for support in their caring role?

Prompts:

- Exchanging phone numbers/connecting on Facebook etc.
- Has the post-course peer support network been helpful – all the courses set up a network at the end of each course (it was either WhatsApp, email or Facebook)
- If not keeping in touch, is it by choice or just not thought about it?
- Most important thing they took away from the course
- Where would they go if they needed further advice?

Thank you for taking the time to talk to me about your experiences today