EXPERIENCES OF CARING FOR A PERSON WITH DEMENTIA

‘The solutions are there somewhere. I just don’t know what they are yet.’

THE PERSPECTIVE OF THE UNPAID CARER
Foreword

The attached report sets out the findings from a series of interviews with unpaid carers of people living with dementia. This work has been carried out in collaboration with the University of West of Scotland and forms part of the Focus on Dementia programme to test the Alzheimer Scotland 8 pillar model of community support for people with dementia.

This work has applicability to the wider policy agenda in Scotland including Scotland’s National Dementia Strategy, Integration of Health and Social Care, Carers Policy and roll out of self-directed support.

About Focus on Dementia

Focus on Dementia is a partnership improvement programme which brings together and maximises the skills, expertise and knowledge of improvement professionals, policy practitioners and the third sector in order to support the continuing transformation and modernisation of dementia services in Scotland. In supporting the implementation of the dementia strategy, the programme is testing Alzheimer Scotland’s 8 pillar model.

8 Pillar Model of Comprehensive Integrated Support

The 8 pillar model was developed by Alzheimer Scotland based on best available evidence and following wide consultation which included people with dementia and carers. It is a comprehensive integrated approach to supporting people with dementia, their families and carers. The model includes the introduction of a dementia practice co-ordinator, who will ensure access to all pillars of support as appropriate to each individual. Other pillars include support for carers, personalised support, community connections, environment, mental health care and treatment, general health care and treatment and therapeutic interventions.

Testing the Model

An improvement collaborative has been established nationally to support the test sites (health and social care integrated partnerships) to inform the testing of this model in practice, and associated improvements, to share data, progress, challenges and opportunities. This is being achieved through a series of learning sessions, action learning sets, webinars and through targeted improvement support.

A key aspect of the work is understanding the experience of family carers and how the 8 pillar model can support and improve this experience. The attached report is an important contribution to this work in providing qualitative data to inform the design of improvements to support the implementation of the 8 pillar model. An external evaluation of the Focus on Dementia 8 pillar testing work is underway and will re-visit carer experience to understand any further implications and impact of this model on carer experience as the model is implemented in the test sites.

Michelle Miller and Eileen Moir

Focus on Dementia
Executive Summary

The report discusses the findings and methodology used to understand the experience of the 14 carers involved in this process. The methodology includes an interview process using emotional touchpoints and photo-elicitation. This interview process was carried out by researchers from University of West of Scotland and two members of the Focus on Dementia team, with the support from 8 pillar test site project managers and a member of the Focus on Dementia team who supported transcription.

A thematic analysis of the interview data was carried out by the 2 researchers at University of West of Scotland and is centred around 4 key areas:

- Quality of life for the person being cared for
- Quality of life for the carer
- Managing the caring role
- Process

The names of people with dementia and carers have been changed within the report to protect anonymity. The use of powerful quotes in the report demonstrate the depth of emotion expressed through the interview process. People’s stories resonated with those in the literature but there were some additional insights which were observed by the researchers. These were primarily related to perceptions by the carer about what support would help which included someone to talk to who understands; having time to just be rather than having a break outside of the caring relationship to do ‘an activity’; knowledge and expertise from the professionals has great value; developing services that respond to what matters to the person (creating dementia friendly environments that go beyond physical alterations); the importance of knowing the people with the caring relationship and ensuring that this is explicitly acted on within the relationship; the value of explicit conversations that explore how people feel about caring; and the enormous impact that positive feedback from professionals that they were doing a good job could have on their ability to feel positive and continue.

The analysis has captured significant outcomes that matter to unpaid carers of people with a dementia. This makes a significant additional contribution to the framework for carers developed by Cook and Miller (2012). The elaboration on the initial themes developed by Cook and Miller could be useful in future carer assessments and development of support.

The sub heading to this report ‘The solutions are there somewhere. I just don’t know what they are yet’ (a quote from carer) was chosen by the researchers as it reflects optimism on the part of many of the carers that were interviewed where they were enormously grateful for the support they did receive but felt there was more that could help them with both practical aspects of caring but more significantly with more nuanced support that comprised opportunities to talk, share and learn to enable them to gain a sense of purpose, achievement and significance in their lives.
Next Steps

This report will now be disseminated widely to inform the testing of 8 pillar model and extended learning to other areas of practice and policy.

Acknowledgements

Our thanks go to the following people who have led and supported this work

- the carers who have participated in this work for sharing their deep insights and experiences
- 8 Pillar Project Managers for their support in identifying and supporting carers to contribute to this process
- Professor Belinda Dewar and Tamsin MacBride, University of the West of Scotland who have led this research
- Focus on Dementia team for supporting the design, interview and transcription process
- NHS Education Scotland Envision Images for the images contained in the document
‘The solutions are there somewhere. I just don’t know what they are yet’.

At this moment I am drawn to something horrible. I need to look for something better. It’s like I’m wandering around in a maze with the same old, same old.

Would like to feel like that wee fellow with the bubbles. That was how our life used to be.
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Acknowledgements

We would like to thank the carers who gave up their time to have such rich and open conversations with us. In addition we valued the support of staff in the test sites who set up the interviews and made us feel so welcome.

Background

With the number of people living with dementia in Scotland predicted to double between 2011 and 2031, dementia continues to be a national priority for the Scottish Government (2013). The 2nd National Dementia Strategy (2013-2016) focusses on addressing three main challenges. Namely; ensuring appropriate care and support is offered to people with dementia and their families and carers; continue to improve support and services for people with dementia including support to carers; and recognition that care provision and support required for people with dementia and their carers will increase over time due to the expected rise in people living with dementia (Scottish Government, 2013).

It is estimated that 17% of the adult population in Scotland are currently an unpaid carer (Scottish Government, 2015) with approximately 670,000 people in the UK acting as the main carer for a person with dementia (Alzheimer’s Society, 2012). Improving support for unpaid carers is recognised as an important focus in recent clinical guidelines (NICE, 2013).

Informal or unpaid carers are defined as ‘people who provide care and support to family members, other relatives, friends and neighbours. The people they care for may be affected by disability, physical or mental health issues (often long-term)’ (Scottish Government, 2015; p.1). In the context of this report we are specifically focussed on unpaid carers of people with dementia.

The impact of the caring experience has been well documented in the literature and an analysis of recent literature reviews provided a useful background for this project. Newbronner’s et al. (2012) review analysed research exploring the experience of informal carers of people with dementia, support and services that supported them and where needs were not met. Key areas identified included support required to deal with the emotional and psychological aspects of caring, coping with difficult behaviours and the physical aspects of caring and support during different stages in the caring journey.

Etters, Goodall and Harrison’s (2008) review into caregiver burden of carers of individuals with dementia identified factors such as caregiver characteristics and behaviour of the person with dementia impacted on the feeling of burden. For example
where the carer experienced aggressive behaviour from the person with dementia this predictably appeared to increase caregiver burden.

The impact of caring on relationships has also been reported in the literature. Quinn, Clare and Woods’s (2009) review focused on the quality of the relationship between the individual with dementia and the carer and how this subsequently impacts on the caregivers’ quality of life. Findings from this review identified a relationship between the pre-caregiving relationship and the caregiving experience, for example where there were high levels of satisfaction with the pre-caregiving relationship, the overall burden of caregiving was reduced. Findings also showed that overall satisfaction with the relationship had a positive impact on carer wellbeing (Quinn, Clare and Woods, 2009). A systematic review that specifically looked at the impact of dementia on marriage discussed two major themes namely transition, which reflected changes in the relationship; and loss which was concerned with the loss of the person but also of the marriage (Evans and Lee, 2014).

Caregiving can impact on the physical and mental wellbeing of the carer. One literature review specifically explored sleep disturbances and caregiving (Peng and Chang, 2012). This literature review found that one of the main factors impacting on sleep was depression but Peng and Chang (2012) also reported that impact of sleep disturbance in caregiving resulted in worsening mental and physical health of the unpaid carer.

Carers also experience a high degree of satisfaction with the caring role (Sano et al., 2013). In contrast to focussing on the problems associated with caregiving, or the ‘burden’ of caring that is widely reported in the literature, Lloyd, Paterson and Muers’s (2014) review explored the positive aspects of the caregiving experience. They found that caregiving could be a positive and rewarding experience with carers demonstrating the ability to cope positively with the challenges experienced (Lloyd, Paterson and Muers, 2014).

Literature also focussed on support associated with caring. For example, Peel and Harding (2014) explored carers experience of health and social care services. Participants reported problems with accessing and navigating services, describing it often as a ‘battle’ and ultimately impacting on the strain of caring (Peel and Harding, 2014). Georges et al.’s (2008) survey reported variation in access to and availability of services with the majority of those carers responding stating they did not have access to residential or day service support.
In relation to developing future support services for both people with a dementia and their carers a personal outcomes approach is advocated in the literature (Scottish Government, 2010). The underpinning principle of a personal outcomes approach is the focus on what matters to the person who uses services i.e. the personal outcomes as key to the services provided to support that individual in order to meet outcomes that matter to them. Hanson, Magnusson and Nolan (2008) and Cook and Miller, (2012) have developed personal outcomes approaches that focuses on keeping unpaid carers and people using services at the very centre of the support they receive.

The experience of being a carer and using services has been well documented. Gaps in the literature are evident however in relation to the effectiveness of interventions aimed at supporting carers with some of the experiences identified in the reviews. In addition there is a need for more inquiry into what personal outcomes matter to carers and how can they work together with professionals to shape support that meets their needs.

**The Project**

This project on the experiences of caring form the perspective of unpaid carers is part of The Focus on Dementia Programme in Scotland. This is a partnership programme between Scottish Government Dementia Policy team, Quality and Efficiency Support Team (QuEST), Joint Improvement Team (JIT) and Alzheimer Scotland. As part of this work the plan is to test an integrated and comprehensive, evidenced based approach to supporting people with dementia and their carers in the community (Alzheimer Scotland 8 Pillar model [Alzheimer Scotland, 2012]). The programme is currently working with 5 health and social care partnerships to test this approach. Capturing qualitative data is a key element of the measurement framework for testing the 8 pillar model. See measurement framework: [http://www.qihub.scot.nhs.uk/quality-and-efficiency/focus-on-dementia/8-pillars/resources.aspx](http://www.qihub.scot.nhs.uk/quality-and-efficiency/focus-on-dementia/8-pillars/resources.aspx). Part of the measurement framework is to explore the experiences of being a carer. This is the aspect that is the focus of this report. We aimed to interview carers of people with dementia to understand their experience, and to carry out thematic analysis and write-up. This enabled the project team to build a picture of how things are from the carers’ perspective across all the test sites. A secondary aim was to identify both good practice in supporting carers and areas for improvement. Further interviews will be carried out with unpaid carers to explore further the experience of caring following the intervention of appointing a Dementia practice coordinator defined by Alzheimer Scotland (2012, p.17) as:
A named skilled coordinator who will lead the care treatment and support for the person and their carer on an ongoing basis, coordinating access to all the pillars of support and ensuring effective intervention across health and social care.

Methodology

The aim of the project was to learn about the experiences of being an unpaid carer for a person who has a dementia. The project manager in each test site (North Lanarkshire, South Glasgow, Midlothian, Highland and Moray) was approached and asked to contact up to 4 carers linked to the service to invite them to participate in an individual interview about their experience of being an unpaid carer. There was no exclusion criteria.

We carried out individual interviews with 14 carers from 5 localities across Scotland.

The numbers of carers who took part in each locality is shown below.

<table>
<thead>
<tr>
<th>Locality</th>
<th>Number of Carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Glasgow</td>
<td>2</td>
</tr>
<tr>
<td>Midlothian</td>
<td>3</td>
</tr>
<tr>
<td>North Lanarkshire</td>
<td>3</td>
</tr>
<tr>
<td>Moray</td>
<td>2</td>
</tr>
<tr>
<td>Highland</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>14</strong></td>
</tr>
</tbody>
</table>

An information sheet giving details of the project and a consent form were sent out to those carers who expressed an interest (Appendix 1). Ethical issues such as informed consent, anonymity, and confidentiality were adhered to. In addition carers were informed that they could stop the interview at any time. The researchers also had contact details of a person within the service who the carer could contact if the interview had raised any issues that they would like to discuss further.

The interviews were carried out in a private room in the locality. In the main two researchers carried out the interviews. The interviews lasted between 40 minutes and 1 hour. Each interview was tape recorded and later transcribed. The transcription in the form of a first person story was then shared with the participant who was able to say if there were any changes they would like to make and to confirm if they were happy for this to be shared anonymously with others within and outside the organisation.
Emotional touchpoints and photo-elicitation were the methods used within the interview to learn about the experiences of caring for a person with a dementia. Emotional touchpoints is a method that helps us to tap into the meaning of an experience in a structured way (Dewar et al., 2010). It focuses on particular points in the experience journey (touchpoints) and asks people to select from a range of emotional words those that sum up what the experience felt like. The storyteller, in this case the carer, is then asked to sum up why they felt that way and if appropriate what would help to make the experience better.

Prior to the interviews the project team met to develop a set of touchpoints that could be appropriate for the carers. This set of touchpoints were then shared with staff from each test site and a carer. Some amendments with regards wording were made and a final set of touchpoints was developed. The touchpoints were:

- Asking for support
- Getting support
- Knowing what’s going on
- Getting to know staff
- My contribution to caring
- Having a voice
- My identity
- My life
- My relationships
- Knowing me
- Safety
- Getting a break
- The future
- Working together

The project team decided that given the time available for the interview and the focus of the study it would be useful to identify 3 touchpoints that were core and asked at all interviews. The other touchpoints were to be used if there was time at the interview to explore further topics of relevance to the carer. In reality there was little time in the interview to focus on more than the 3 touchpoints. The 3 core touchpoints were: caring together, my life and the future. These core touchpoints reflected key themes in the literature.
The interviews did not specifically focus on services per se – but rather their experiences of caring. Throughout the interviews however the carers did make reference to their experiences of services that they received.

At the end of each interview participants were invited to select an image from a selection of 70 generic images taken from the NHS education for Scotland’s Envision cards. Photo elicitation can capture different information that a question alone (Dewar, 2012). The participants were asked to select an image that summed up for them the caring experience.

**Analysis of data**

The data were analysed by 2 researchers. A modified version of Immersion crystallisation technique was used in this study (Borkan 1999). This process (see Appendix 2) helped the researchers to consider initial hunches, open code data, and pay particular attention to things that stood out, and note aspects that were not mentioned and any surprises. From this initial analysis a set of themes and subthemes were developed.

The data generated focused on the carers experience of what mattered most to them about their life, the caring experience and the future. It seemed appropriate to consider the data in the context of outcomes for carers that have been generated in the literature. There is increasing emphasis in policy and practice of the importance of focusing on outcomes based approaches that focus on what matters most to people. The Joint Improvement team at the Scottish Government have developed a framework of outcomes for carers and service users (Cook and Miller, 2012). The framework for carers is shown in Table 1.

**Table 1- Outcomes important to unpaid carers (Cook and Miller, 2012)**

<table>
<thead>
<tr>
<th>Quality of life for person</th>
<th>Quality of life for carer</th>
<th>Managing the caring role</th>
<th>Process (relate to the experience that individuals have seeking, obtaining and using services)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life for the cared for person</td>
<td>Maintaining health and well-being</td>
<td>Choices in caring, including the limits of caring</td>
<td>Valued/respected and expertise recognised</td>
</tr>
<tr>
<td>A life of my own</td>
<td>Feeling informed/</td>
<td>Having a say in</td>
<td></td>
</tr>
</tbody>
</table>

9
Following development of initial themes and subthemes these were then mapped to this personal outcomes framework for carers.

The subthemes for the data were then mapped to these broad themes and can be seen in Table 2 below. This more detailed framework of outcomes for unpaid carers is an important contribution to existing literature and guidance on outcomes. It may be of value in supporting practitioners to more deliberately focus conversations about outcomes for carers around these specific points.

<table>
<thead>
<tr>
<th>skilled/equipped services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive relationship with the person cared for</td>
</tr>
<tr>
<td>Freedom from financial hardship</td>
</tr>
<tr>
<td></td>
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</tbody>
</table>
Table 2 - Themes about the experience of caring from the perspective of unpaid carers

<table>
<thead>
<tr>
<th>Quality of life for the cared for person</th>
<th>Quality of life for carer</th>
<th>Managing the caring role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of life for the cared for person</td>
<td>Maintaining health and well-being</td>
<td></td>
</tr>
<tr>
<td>• It is important that the person I care for is ‘settled’</td>
<td></td>
<td></td>
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<tr>
<td>o Happy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Safe</td>
<td></td>
<td></td>
</tr>
<tr>
<td>o Sense of purpose</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>• I feel able to maintain my own health and well being</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• I am able to stay positive and hopeful</td>
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<tr>
<td></td>
<td>• I get support to cope with stress and exhaustion</td>
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<td></td>
<td>A life of my own</td>
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<td></td>
<td>• I am able to cope with the loss of the life I once had</td>
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<td>• I feel supported to have time for myself</td>
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<td></td>
<td>• I have space in my life to just be me</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Feeling informed/skilled/equipped</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• I feel supported to cope with uncertainty</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• I feel I have the knowledge and skills to care</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• I feel I know who to contact to get help</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Positive Relationships</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• I am able to maintain a positive relationship with the person I care for</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• We are able to do things together</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• I am able to maintain positive relationships with others</td>
<td></td>
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<tr>
<td></td>
<td>• I have people who I can talk to</td>
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<tr>
<td></td>
<td>Satisfaction in caring</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• I feel I get a lot out of caring</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• I am supported to cope with challenges in the caring role</td>
<td></td>
</tr>
<tr>
<td>Quality of life cared for person</td>
<td>Quality of life for carer</td>
<td>Managing the caring role</td>
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<tr>
<td>---------------------------------</td>
<td>--------------------------</td>
<td>-------------------------</td>
</tr>
<tr>
<td>Freedom from financial hardship</td>
<td>I feel financially secure in my caring role</td>
<td>Partnership with services</td>
</tr>
<tr>
<td></td>
<td></td>
<td>I work together with the people who help me to care</td>
</tr>
<tr>
<td>Feeling safe and Secure</td>
<td>I feel safe when caring for the person with dementia</td>
<td></td>
</tr>
</tbody>
</table>

Data to support each of these themes and subthemes is highlighted in the next section.

**Findings**

**QUALITY OF LIFE FOR THE PERSON BEING CARED FOR**

It is important the person I care for is ‘Settled’

Although we did not interview the person with dementia to explore what their experience of being cared for was like, it was evident through our interviews with carers that it was important to them that the person being cared for was ‘settled’. Listening to the carers experiences, this theme of ‘settled’ encompassed the person with dementia being happy and enjoying their life.

*I thought it was important that dad did do a lot of things, went out, visited things, went on holiday, I wanted him to enjoy what he always enjoyed.* (Debbie)

A number of carers talked about how if they knew the person being cared for was happy, it in turn made them happy.

*If she is happy then I am happy.* (Denise)

*When Nora is happy we feel as though we have done something to help her and that is a reason to be happy.* (Colin and Hazel)
It was also important to carers that the person with dementia was safe. This was an area that a number of carers worried about:

"I can relax when I know she is safe. Knowing she is safe is important to me." (Karen)

"I am scared because she is in the house on her own. I don’t know what might happen." (Denise)

Roy getting lost makes me anxious. He got lost this one day and a young couple stopped their car and asked him, “Where do you live?” They saw him stumbling or falling so the young fellow very wisely said to him “have you got a mobile phone?” Roy wears a phone around his neck so the man asked him “what’s your wife’s name?” So he spoke to me and I was already out looking for him. I was there very quickly and here he was sitting in the front seat of the car waiting for me………..It’s very worrying because it might not always be someone so nice. …But these are the things that make you very anxious. You literally cannot let him out of your sight. He speaks so lucidly though and says “don’t be so ridiculous, I’m fine”. But he really cannot go out on his own." (Wilma)

When the person’s safety could not be assured this often became the trigger point for increasing services or the person with dementia moving into residential care. One carer almost described it as the point they had to let go of being the main carer:

"It got to the point where he wasn’t safe anymore so we couldn’t go on holiday anymore. We went on holiday last year but physically he was not safe, when I was sleeping he was getting up and wandering – I came back exhausted…….I couldn’t physically do it any more – he was a danger, he used to get up and go out in the night a couple of times a night – I had to accept he wasn’t safe" (Debbie)

Although a number of carers described the point where the person with dementia required 24 hour care as a ‘last resort’ it did at the same time bring about a sense of relief, knowing the person was safe:

"Knowing she is safe, got 24 hour care, knowing she won’t go out the house." (Karen)

As well as feeling the person they cared for was happy and safe it was also important to unpaid carers that the person with dementia continued to have a sense of purpose:
Bill went to day care ………………. he was enjoying the activities at day care. It was like him going to work, a sense of doing something. (Irene)

Some carers discussed this sense of purpose in terms of previous work or interests that the person with dementia engaged in and how this can be mentally stimulating:

John thought it [the Hub] was his work, he was delighted (Jess)

*My husband is taking on a project to create two spiral staircases, he is a sculptor and can do anything with wood……. even though he has Alzheimer’s and is finding it very difficult, he has this passion and he wants to keep doing it……….I think that helps him mentally active.* (Claire)

One carer also talked about how a sense of purpose could be strengthened by involving the local community:

*I was thinking wouldn’t it be wonderful if we could get funding to reopen the shop and the post office on a local/community basis as opposed to a commercial basis. A local hub where the server knew about dementia and could talk to people, where the person with dementia could help stack shelves, or help tend the gardens or sit and do knitting or have tea or coffee.* (Claire)

Carers emphasised in the interviews the importance of feeling that the person they cared for was settled. The concept of ‘Settled’ had three main aspects. These were that the person being cared for was happy, safe and had a sense of purpose. If these needs were being met then this in turn helped them to feel safe and satisfied in their caring role.

**QUALITY OF LIFE FOR THE CARER**

*Health and well-being*

I feel able to maintain my own health and well being

A number of carers discussed the importance of maintaining their own health and well-being and how sometimes the caring role can impact on this:

*Carers need to think of their own wellbeing and health as they can become worn out by their caring role. They need to consider this when using respite services.* (Tracey)

*Like many other carers, I’m worried about my own health. I’m putting on weight because I’m not getting enough exercise. All the things I would have*
done previously, when I was able to go out on my own isn’t happening and that’s not good for me or for Roy. (Wilma)

Carers recognised the need not just to maintain their own health and well-being for themselves but that this was important for the person they care for.

I am able to stay positive and hopeful
In order to maintain physical and particularly mental wellbeing, some carers discussed the importance of having a positive mental attitude that helped them to stay hopeful and positive:

You can go down the avenue of saying you have had enough and you’ll bring your own health down. Or you can say “I’m in this, I’ll need to get on with this” you’ve got to build yourself up. ..You need to keep cheerful otherwise you’d jump in the Clyde (Tracey)

If I am feeling a bit low or tired, I suppose I give myself a kick up the backside and get on with it. ………… I know Dad won’t live forever, I am going to have to pick up the pieces and get on with life when he goes. I still need ties and other things in my life so I have deliberately made that decision (Debbie)

Some carers discussed this positivity in terms of their intrinsic factors that enhanced resilience:

I look on the bright side rather than the down side of life, and I have a lot of good friends. I have always been quite confident so I think that helps. I am quite resilient. I am happy most of the time. (Jess)

A number of carers talked about particular aspects that helped them maintain a positive relationship with themselves such as their faith or music:

I have the outlets that are important to me such as my faith as a Claretian, I regularly go to church, I pray and read the Bible. I also find reading positive books such as self-help books are important to me. (Tracey)

You do your own things around the house if you’re that sort of person which luckily I am, I can go and play the piano, and I can cope with it. For someone who is desperate to get out and have their life it would be very difficult. (Claire)
I get support to cope with stress and exhaustion

Some carers also talked about stress and anxiety as a result of the caring role that had an impact on how well they felt in themselves:

Both of us felt that things were getting too much for ...we were feeling tense and nervous all the time. (Colin and Hazel)

A number of carers discussed how exhausting the caring role is and how that can impact on their health and well-being.

We got a good night’s sleep last night because she slept all night but the previous two nights we did not get much sleep. This is when I get frustrated and tired. This impacts more than all of the other things that I have told you; the lack of sleep. (Stella)

I was exhausted for over a year, I didn’t know what it was to have a night’s sleep. He would get me up two, three, sometimes four times in an evening because he wanted to use the bathroom. Sometimes he would have accidents and by the time you have cleaned, helped him into clean clothes, you are wide awake. Then just as you are getting to sleep, he wakes you again. I was exhausted. I am sleeping much better now, I have the odd night where it is on my mind. (Helen)

Feelings of exhaustion were common for carers and this was most often described in relation to lack of sleep. The impact of exhaustion could appear overwhelming for carers. Getting support to help her cope with exhaustion was emphasised by one carer:

For the first five weeks, I didn’t have a day off: I was in tears, I couldn’t cope and I was exhausted. I’m quite a strong person and I didn’t think that this could get to me like it did. It’s emotional, it drains you in every way, energy and emotionally, it’s not good. You do need that support because if you don’t get it, it’s not nice. (Stella)

The type of support that would be helpful to carers to relieve feelings of exhaustion would vary from individual to individual. One carer valued, for example, a formal course:
I am on two courses (through Quarriers) at the moment; one of them is for me: it is about wellbeing for carers, telling me how to cope with stress, it’s really good. The other one is for family members, Katy is allowed to come along as well, and it is focused on things you can do together and as groups. (Stella)

The feelings of stress and exhaustion were felt by many carers that were interviewed. More detailed discussions about what might help would be an important part of any support aimed at relieving this and enhancing feelings of well-being.

A life of my own

I am able to cope with the loss of the life I once had
When invited to discuss the touchpoint entitled ‘my life’ carers talked about the impact of caring on their life, expressing this as a loss of life as it was:

*Just the whole Alzheimer’s thing. Just how it affects my life. So much going on and not being able to enjoy my life. It’s not my own life anymore* (Denise)

*We are quite comfy up there, we are fine, but I’m always rushed and I’m always flustered. It could be an awful lot worse. But there is no life, as such* (Claire)

The caring role brought with it a very different life to the one that they had experienced before. There was a general acceptance that things had changed but also a sadness.

I feel supported to have time for myself
A key aspect of a life of my own related to being able to do things and have some time for themselves:

*I felt fed-up - having to be there all the time. Having no time for myself. Bill didn’t like me going out or being on the phone so I felt like I couldn’t do the things I wanted, like visiting friends. (Irene)*

*I felt restricted and at times felt resentful that I couldn’t do something on my own, like go and have a coffee or something like that with somebody, I felt angry with him at times because I felt that he was restricting me. So I blamed*
him in a sense because I couldn’t do anything and it was him who was stopping me. (Helen)

These feelings of resentment could in turn have an impact on the relationship with the person being cared for.

Carers talked about the importance of services in getting a break:

I would be pleased about some respite, a week off, it would feel good. (Karen)

Getting used to the support of day care is, you’ve no idea, it does take the pressure off. (Tracey)

A number of carers selected emotions such as ‘cut off’ and ‘dejected’ when talking about ‘my life’ even when they had support to enable them to do things such as going to work:

I don’t have a life. You get fed up, cut off and dejected from time to time. But because it is something that I want to do, I haven’t been forced into it, I don’t mind. I do feel that the service is hugely supportive during the day. I couldn’t work otherwise. The service could be better but it is absolutely amazing. But you are cut off. (Claire)

This quote raises questions about what support might look like to support people not only to carry on doing things that they value but to feel connections in their life.

Getting a break to have for example a ‘Wilma’ conversation was one area that some carers talked about:

I’m quite a bit younger so I still have a lot of things I would still like to do. On a very simple day to day basis, who do you talk sense to? Every single morning Roy is obsessed with going to work. He was a carpenter so he has to put his tools together, get his sandwiches made, he’s “got a very important job to do”. Of course you have to come up with strategies to divert, distract, go over and over and if you are not doolally yourself, you begin to feel that you are. This is where I think a day centre would break that rhythm of every day having to do this. (Wilma)

When carers talked about getting a break, they often discussed a sense of freedom and independence:

You’re relaxed, you’re a wee bird and you’re free. (Tracey)
My outlet was two nights a week, for a few hours, to go to bingo and I refused to stop that, even though there was pressure on me to stop this. (Helen)

When I come back from a swim, I feel great. I feel as if I have won the lottery. So it’s important. When Roy was well I was going out for a swim three days a week and I treated it very casually. Its only when you can’t do it that you realise how important it is to you. (Wilma)

Many of the carers made a significant effort to get a break and were able to articulate the real benefits of this particularly to their emotional well-being.

I have space in my life to just be me
Getting a break didn’t necessarily mean having time to do certain activities, but also just time to ‘be’, time to yourself:

Time to myself is tops, that’s my priority. Some people have an unhealthy relationship and are dependent on each other, but that’s not me. I know who I am; the real me and that will come back. If I had one day to myself – 2 days would be wonderful – but even one day then I could make a plan. (Wilma)

Knowing my husbands like of sleeping is useful. It gives me some time to myself in the evenings. (Tracey)

She [my mum] goes to the bungalow on a Sunday, that is another day I can chill.... (Karen)

Positive relationships
This theme relates to maintaining positive relationships and the value carers place on this in terms of their quality of life.

I am able to maintain a positive relationship with the person I care for
A number of carers talked about the how the relationship with the person with dementia had changed with some describing it as a loss of the person they once knew:

That was a time when I was really worried and I didn’t know how to approach the whole subject in the very early days. I felt anxious and dejected and thought “oh, no”. You feel as if you have lost the person. (Laura)

I think initially you feel cut off because this person is not communicating with you so therefore whatever you had before is severed. You’re living with a person you don’t know, a shadow/ghost of someone, so you feel completely cut off. (Jess)
We are able to do things together
Although it was evident that relationships changed, a number of carers discussed the value of being able to do things together to help sustain positive relationships:

There is always something on at least four times per month. Whatever we do, we do it together. I take Roy to the theatre but by the time we come out he can’t remember what he’s just seen but that’s not the point. But we are always together.  (Wilma)

If I can take my wife with me to things then I do. (Craig)

I am very fortunate with the Alzheimer’s Scotland groups. They are brilliant. They are very practical. He goes to football memories groups twice a month, singing groups, we’ve got one tomorrow. In the summer we go to allotment groups every week. We go to as many of these things as we can possibly get to. I can talk sense there as there are a lot of carers there. They’re very educated people so it’s great for me and it’s great for him. He actually sits and has a really good laugh at these things because they are geared towards him and I am getting something out of it too. They are first class. We would have gone completely bananas about them. (Wilma)

Interestingly one carer spoke of the dementia diagnosis and progression of the dementia as having a more positive impact on their relationship:

Our relationship has got better since he stopped drinking; it is more relaxing for me …. things have improved when the dementia had progressed and paid carers came in to support my dad. (Mandy)

Another individual spoke of the difficulties encountered when the relationship prior to the dementia had not been particularly positive and the impact this had on the caring role:

I could never tell her how I felt, we were never close enough. (Denise)

I am able to maintain positive relationships with others
In addition to maintaining a positive relationship with the person with dementia, some carers discussed the importance of being able to maintain positive and meaningful relationships with others:

My caring role is not impacting on any other relationships in my life but it can happen. There have been clashes but what I have said, I have made it very clear that my children and my grandchildren come first and they are my priority. But my two girls are very understanding. They have got good jobs
and they don’t depend on me for a lot but my grandchildren like to see me. And I enjoy spending time with them as well. (Laura)

Sometimes maintaining positive relationships meant that the carer felt they had to protect the person with dementia or protect others:

I don’t want to bring my son or daughter in if it can be helped. (Tracey)

What she sees is I am tetchy but I try not to get angry with her. I can’t tell her how I feel. (Denise)

My family have been great – when they realised how bad things had got. I hadn’t told them how bad it was – he’s their Dad after all and I didn’t want to run him down. I didn’t want to be saying things about Bill. (Irene)

Thus maintaining positive relationships with others was more than just being able to see and contact other people. There were aspects about the progression of the disease and the behaviour of the person with a dementia that could make sustaining relationships complex.

I have people who I can talk to

Some of the carers felt a key aspect of having a positive relationship with others was the ability to open up and talk about some of the hidden factors experienced by those caring for a person with dementia:

I only told a close friend some of the things. I was missing the family and had nobody here ‘of my own’ to really open up to. You don’t want to worry the family because they are so far away but then again, it is her dad, I only have the one daughter, and she must know what is going on. So I was worried about that, it was a combination of so much. (Helen)

The hidden aspects that carers talked about included the behaviour of the person with a dementia and negative feelings they themselves had towards the person they were caring for. A number of carers felt that others did not truly understand the experience of caring unless they were living with the person. Thus this hidden aspect of the experience of caring was often not discussed with others:

What the carers and everyone else sees in my mum is not what I see. She’s a charmer to others but I get it in the neck sometimes. (Denise)

Because she was in a home, they did not see half of what was going on. (Stella)
I often left Nora’s house in tears because I took the behaviour personally (Colin and Hazel)

When we moved up here, my wife was giving me a torrid time.......The things my wife said to me really got to me (Craig)

Being able to talk to people who have gone through the experience of caring for a person with dementia seemed beneficial to some carers:

It was nice to sit and listen to individuals who are in the same situation as I am. (Karen)

We would like more help, for example, a class or a group where people could sit down and share experiences. This would also help us feel less isolated and less like we are the only people in this situation. (Colin and Hazel)

I found it supportive to talk to someone else about this. (Craig)

Being able to open up and talk about dementia was also important. One carer talked about changes to how society viewed dementia had altered over the years:

I was shocked when my wife was diagnosed, I didn’t know anything about dementia or Alzheimer’s because in years gone by it was hidden away, it is very open now. (Craig)

In the old days it (dementia) was hidden away in the back street. People used to refer to ‘dottling’. (Craig)

It became apparent through hearing about the experiences of caring that relationships between the unpaid carer and the person with dementia could be complex and often changed over time. Support to maintain positive relationships and be able to open up about experiences appeared to be important aspects to the caring role.

**Freedom from financial hardship**

**I feel financially secure in my caring role**

It was important to carers that they felt financially secure in their caring role, that they did not have concerns about financial matters or have to rely on others:

I’m lucky that I’m in a position where I am financially secure and I don’t have to depend on anyone and I am proud of that as far as that is concerned. I don’t have to depend on anyone or be beholden to anyone and I think that
puts you in a safe place, you’re in a safe area because you’re not depending on anyone so you don’t lose confidence in yourself. I don’t have to worry about bills and I like to know that I am comfortable. (Jess)

One carer talked of the frustration of not having enough funds to be able to do things together that would benefit both the person with dementia and themselves:

I don’t have funding to do what I want to do and go places with her, do the things we would want to together. I would like to be able to take her on days out go on the train etc., but these things are so expensive. I know she would like that and to be taken to different places for a coffee and a biscuit, but to do this is costly because of petrol etc. If you’re not earning, you have to be careful. (Stella)

Another carer talked of how frustrated they were to have to discuss and organise finances, and that this should not have an impact on the care an individual received:

I was annoyed by the situation around the house and the money, as John has the money for his care, he has worked all his life. And then about the nursing home, I didn’t want to discuss the money, houses or me, as my finances were completely separate and nothing to do with me, I said it should be whichever nursing home is best for John we need to look at. However, his son said we would have to talk about money, going so far as to get his father’s will from the solicitor. This sort of thing sticks with you. It hurts but what can you do, you just need to get on with it. That was the hardest part. (Jess)

Another carer talked about other responsibilities in terms of finances and having to prioritise funds that were available:

When the day comes when my mum can’t walk then we will be looking to get a carer in to support her, either living in or covering the hours when I am at work. However any money that is spent on a carer, there will be very little money left for my husband and nothing for me, and I’m an only child with no family. It’s trying to figure out what to do for the best, you’re in a funny position, it’s trying to keep things going as long as possible and then hopefully we can figure out a way to get some sort of care in. (Claire)

Speaking to carers in relation to their financial position varied widely with individuals who felt financially secure and had clear plans in terms of the future but others who relied on funding and the frustrations surrounding this.

**Feeling safe and secure**
I feel safe when caring for the person with dementia

It was also important that the person caring for a person with dementia, themselves felt safe in the caring role.

I’m safe with Roy. Roy’s very good natured. I know a lot of others who have problems in that respect but I know I am safe with Roy. (Wilma)

A number of carers talked about how things could change very quickly and they needed to take care when responding:

Sometimes I feel I am having to walk on eggshells, I need to be careful about saying something, if my husband has an idea of a situation in his head he would not be agreeable (Tracey)

They can turn horribly (Stella)

Carers experiences therefore varied in terms of the behaviour of the individual they cared for, but feeling safe and recognising that this was not always the case was evident through the interviews with the participants.

MANAGING THE CARING ROLE

This theme relates to carers experience of the caring role.

Choices in Caring

I feel I am able to make choices about my caring role

Most of the carers we interviewed talked about their caring role as a positive thing to do (see also quotes under theme of satisfaction).

We’ve been married for 56 years this year, we’ve had a good life together, and I feel it is my duty not to let her down. (Craig)

Some carers however felt that they did not have a choice in taking on a carer role:

If I had a choice I would prefer that it wasn’t me. It’s a big responsibility but I have to. (Denise)

I feel frustrated about what I would have done with my life if I had not been in this situation. This is not the life I would be living if I had the choice. But I don’t have a choice. (Wilma)
Other carers felt that they were the only person that could do the caring thus limiting any ‘real’ choice:

*My granddaughter was going to pay my fare... so that I could attend her wedding, ....... I couldn’t desert him. People say he wouldn’t miss you for two weeks. It’s not the point. How do I know he wouldn’t miss me? You can’t speak for someone who doesn’t understand half of what is going on. Maybe he wouldn’t miss me, I don’t know; but I don’t want to take that chance.*

(Helen)

The feeling of not having a choice seemed to be compounded by the negatively perceived available alternative, which was for the person with a dementia going into long term care. Most of the carers we spoke to had negative views of care homes and saw this as a ‘last resort’. Choosing to give up their caring role at home to opt for a long term option felt like they themselves had failed and that this would not have been what the person with a dementia would have wanted. This feeling of care home being a last resort was articulated by most of the carers:

*All they want, both of them, is to be left alone and left in their own home as long as they possibly can and that’s what I’m trying to do.*

(Claire)

*My son said I shouldn’t feel guilty if I am no longer able to do the caring role and my husband should move into a home.*

(Tracey)

*I’m a bit sad I had to accept he wasn’t safe, and I couldn’t do it... it would have been nice if I could have kept it going.*

(Debbie)

*I promised my mum I would never put dad in a care home.*

(Mandy)

*The mention of care homes or hospitals was taboo and could potentially make her more stressed.*

(Colin and Hazel)

*She would just crumble in a care environment and that’s no disrespect to people who work in these situations and a lot of them do a grand job. It’s just I don’t think it would be good for Nancy.*

(Laura)

Choice in caring seemed to be limited by available alternative options. The negativity surrounding care homes is an area that warrants further exploration with regards to the reasons behind this and what could be done to raise the profile of care homes as a positive option.

Although some of the carers interviewed had already made the transition to care in a care home none of them talked about the help that they received in making this
decision. It seemed that a move to a care home was primarily as a result of safety issues for the person with a dementia needing to be addressed.

Some carers felt they had a choice in getting support for some aspects of the caring role where they felt able to ask for help for specific aspects:

If I do get snowed under or frustrated or uncomfortable I would go for help (Tracey)

Others described having an attitude of ‘just getting on with it’ again suggesting the lack of real choice:

I am fortunate that I am able to cope and just get on with it. (Craig)

It seemed that carers did not feel they had real choices in whether to take on the caring role and how they might share the caring role. Indeed there was a perception by some carers that managing to keep going was as valued by others. Open dialogue about how people feel about caring and what working in partnership to care could look like early on may support carers to feel able to discuss what’s possible and what’s not.

**Feeling informed/skilled and equipped**

This theme relates to how carers described their knowledge and skills that helped them in their caring role.

**I feel supported to cope with uncertainty**

In relation to feeling informed there were a number of uncertainties that carers found difficult to cope with. This included uncertainty about the progression of the disease, continuation of services and the future.

- Uncertainty about progression of disease

 You have to constantly remember, “they don’t know”. It’s frustration really. Not just the language, it’s the illness: it’s unpredictable’. (Stella)

Some carers talked about avoiding thinking about the future progression of the disease:

I don’t know about the future, I don’t like to think about it. ...The idea that it’s terminal and that you don’t really know what you’re facing....’It’s like staring into the fog, you can’t see or touch anything.’ (Claire)

One carer talked about being supported by professionals to understand that there can be no certainty about the progression of the disease:
...nobody is telling me what I’m facing. I was hoping they were going to explain to me what happens at different stages of the illness, because I like to know where I am with things because then I can do things about it. I am gradually coming to realise that no one is going to do that and that’s because there are so many different ways that you go through this. It’s horrible. The mixed diagnosis makes it difficult as well because you don’t know how it is going to progress. (Stella)

It therefore seemed important not only that carers received information about the disease but also recognising the value of conversations that support the carer to cope with uncertainty.

- Uncertainty about continuation of services

Several carers were worried about continuity of services:

*I’ve been worried that services will not continue to be funded and it would be so sad. For people to go there and to pick them up, you knew that they were safe there and the people who went enjoyed it because it was more Wilmal.* (Irene)

Being able to understand why decisions were being made to discontinue services was seen as important:

*I care for Katy together with my husband, we had some support from ‘shared lives’, although they have finished and we need to find out why. We only found out yesterday, she really enjoyed going there and we can’t understand it*. (Stella)

There were also statements made that implied that decisions about continuation of services were outwith the carers control:

*I worry about being ‘dumped’ after the year of Post Dementia Support is over.* (Claire)

One carer had been offered the support of a volunteer so that she could go swimming. The lack of certainty about whether this was temporary support or not was unsettling:

*I can’t really count on the volunteers. They are very good but I can’t count on them. When I come back from a swim, I feel great. I feel as if I have won the lottery. So it’s important. When Roy was well I was going out for a swim three days a week and I treated it very casually. Its only when you can’t do it that you realise how important it is to you.* (Wilma)
Uncertainty about the future/Living day by day

There seemed to be so many uncertainties and questions in looking into the future. The uncertainties were summed up eloquently by one carer:

*There has always been an uncertainty about the future, especially with dementia. About me, what am I going to do, what am I not going to do, what am I prepared to do? I don’t know what’s coming. How is it all going to end? She might be in a home. How much might that cost? I’m on a learning curve. What about her house? Do we sell it/rent it? Will we be able to afford it? What happens if we run out of money? What about when she doesn’t know me? How will I feel? I know it will be gradual. It’s the disease that scares me. I wish it was quick but I know it won’t be. It’s slow.* (Denise)

Many carers talked about not wanting to think about the future and using coping strategies such as living a day at a time to help:

*I don’t look any further than a day ahead, sometimes it may only be half a day.* (Tracey)

*I don’t know if I have really thought much about the future. Right now it’s the here and now.* (Helen)

Carers seemed to acknowledge the uncertainties but appreciated being able to share these experiences with others and talk openly about the way they felt.

**I feel I have the knowledge and skills to care**

Many of the carers spoke about how they felt about their knowledge and skills for caring. Carers knew the person they cared for well and used this knowledge to help them in their caring role:

*When my dad gets confused I say to him let’s sit down and try and put your jigsaw together, you’re trying to take pieces from different parts of your life, and we try together to make sense of things.* (Debbie)

One carer expressed a concern that others did not have the necessary knowledge and skills:

*I was initially anxious because paid carers weren’t doing things as I would and I didn’t feel that it was as good as I had provided. If I can do it like that and it’s not my job, why can’t they do it and it’s their trained job; why can’t they do it as good as me.* (Mandy)
This concern about the knowledge and skills of paid staff was only expressed by one carer. Few of the carers interviewed recognised themselves explicitly as experts. Indeed many of the carers talked about feeling under confident about their knowledge and skills:

I was definitely scared. Scared that I wasn’t up to it. I feel guilty that I haven’t done enough for Bill. (Irene)

I feel so silly because I don’t know how best to deal with this type of thing, how to get it sorted. (Denise)

This was interesting given the emphasis in the literature about carers as experts and the need for professionals to recognise this knowledge and use this to inform caring. The belief that carers already have the knowledge and skills and are experts may mean that a number of assumptions are made:

I was completely shaken because it was unfamiliar territory for me and I didn’t know what to do. It was in myself, even though I did have people to speak to I felt alarmed. With my background I felt I should be able to cope but I couldn’t, there were a lot of folk out there who assumed I would manage to cope. It was not so much the link worker, but more the GPs assumption that I could manage because of my years of experience in mental health. I was shaken that I wasn’t able to cope with this and I had to be honest about it. (Jess)

If you asked anyone to describe me they would have said competent but it’s not me now. Not at this moment but Wilmally it is me. I know it’s who I am and that’s the frightening thing. I’m not personally scared of anything it’s the circumstances that I find myself in that is frightening. (Wilma)

There is a need to check out with carers how they feel about caring and to openly discuss what it might entail, where the carers’ strengths lie and what professionals could support them with.

Indeed many of the carers valued the knowledge of the professionals:

We found it difficult because as Nora’s symptoms and behaviours progressed as a result of the illness, we did not know how to respond appropriately..... we were glad when carers supported Nora, we felt they could learn from them....we got to a stage where we feel they can’t help any further..... it would be beneficial if people in this situation could be given training....we feel like she needs someone there who is able to help or knows more than us who are more capable (Colin and Hazel)
The Link Worker has made a big difference. We’re ignorant – we don’t know what is available, we don’t know and all the form filling, checking attendance allowance etc. I would never have thought to do all of these things. (Claire)

We are caring and doing the best we can because we don’t know what it’s all about. There is only so much we can do to help but that we have reached a point where we don’t know what to do next – a course might help. (Colin and Hazel)

Thus openly valuing what the carers and the professionals each brought to the caring experience seems important.

Carers identified different sources of information that they felt were valuable in helping them to feel they did have the knowledge and skills required for the caring role. Some carers talked about valuable written information and stories they had read:

Sally Magnusson’s book and ‘How many camels are there in Holland?’ and they were very good. Sally Magnusson’s book is the best out of the books that I have read and any it would be well worth having for any carer. I like books that you can pick up and are easy to read and are funny – Sally Magnusson’s book was funny in a sad way. (Jess)

I’d be grateful for any ideas on where to start reading about it. I need to know, but I’m not looking forward to it. I read the Alzheimer (Scotland?) website and the link worker has given me a lot of literature on this, leaflets and things, but it all seems so woolly. (Claire)

Written information was one way of getting knowledge but others valued the opportunity for face to face contact to explore information and issues:

It would have helped if I could have spoken to someone more about it and understood more about it. It’s not getting through to me if I don’t understand what the illness is and what the changes could be. (Helen)

Factual information about dementia was valued and this needed to be communicated and discussed using a range of ways. Carers also valued advice and information about their day to day experiences and challenges that were not necessarily easily accessible in a written format.

Having a person to talk through things that they had tried out in their day to day experiences of caring was seen as important to help carers develop their knowledge and skills:
Sometimes I feel like I do or say the wrong thing and feel I could have dealt with a situation in a different was. (Tracey)

This strategy of trying things out on the job was described by a number of carers to gaining the knowledge and skills to do the ‘job’:

In the past I tried to laugh or make a joke of it (when Katy shouts) but that didn’t always work. Now I go out of the room as that’s all I can do, I don’t know what else to do. (Stella)

This year I am going to try taking her out for shorter periods of time, 45 minutes at a time then a bit of time later, I hope this will work. (Stella)

I think you’ve always got to take a step back and think, “right what’s happening here, is this doing any good, is it going to be useful is it helping her or is it just a minute in time?”. But even if it is just a minute in time, if she is happy, it’s worth it. (Laura)

Many carers spoke about how this trial and error and practicing on the job was a learning experience:

I understand now and it is about learning to pick up these things you don’t know and getting to know their ways. ....It’s a learning game every day; every day is different. (Craig)

My situation is like being on a roundabout, sometimes you will be on the roundabout and sometimes you will be off. Sometimes my husband will react negatively and sometimes positively. You might go into the woods but there is always a way out. You have to learn by experience and may say or do the wrong thing, but you always come again, hopefully wiser. (Tracey)

This valuable knowledge that they gained through learning in action was of course a significant element of their expert knowledge that is often referred to by others but not necessarily recognised as significant by the carers themselves. Having opportunities to share this knowledge and reflect on it to see if there are aspects of this way of doing things that could be used to help other situations might be an important way of both valuing the knowledge and making it more deliberate in the caring experience.

**Satisfaction in caring**

I feel I get a lot out of caring
All of the carers except one talked about the satisfaction they got from the caring for the person with a dementia. Many of the carers used words such as feeling proud and privileged to be able to care:

*I have got stuff out of it – it’s been a privilege for me.* (Debbie)

*It feels lovely caring for my mum.* (Karen)

*I really like caring for them and I wouldn’t have it any other way.* (Claire)

*I’m proud that I’m doing something for somebody else. It makes me feel good about me. Sometimes you could just go “oh no, I could see this far enough” but then you go, and once you’ve done the task you feel good. It’s worth getting through to the other end of it. I feel good about me. I’m getting a reward out of it.* (Laura)

A sense of achievement and getting something personally out of the experience of caring may be important to bring into balance with some of the more challenging aspects of the caring experience that have already been identified in this report and in the literature.

Getting something personally out of the experience was often expressed in relation to an opportunity to grow and develop:

> Now looking back, fortunate is a funny word to use, but I think I am fortunate in a way that I’ve had to go through the process and I’ve come out the other end. I think through life what doesn’t kill you makes you stronger and I think going through this has been quite fortunate because I’m at the other side and I can now separate John from the illness. (Jess)

*I retired two years ago and when I retired initially, I thought “oh god what am I going to do?” Then Nancy’s illness cropped up and I feel strangely enough that that has kept me busy. It’s kept me focused, given me a goal and that feels good. It’s maintained my confidence. I felt when I first retired my skills would just slip away. I felt devalued as in “how do I validate my life anymore”? I feel this has given me confidence. I can pick up a phone and speak to somebody. Of course my work, prior to retirement helped me with that too. I thought those skills are going to leave me but they haven’t. There’s a lot of stuff that’s happening here that’s about me and I’m getting the advantage of it.* (Laura)
Some carers felt pleased about being able to give something back – a feeling of reciprocity:

*I had a wonderful life with mum and dad, they brought me up and I wasn’t giving back a fraction of what they gave me.* (Debbie)

*My mum looked after me till my 30s and now I feel I should look after her. I feel proud about that.* (Karen)

As stated above the satisfaction that carers got out of caring was expressed by all but one carer. With the carer who did not feel this sense of satisfaction, her relationship with the person with dementia had not been strong prior to the illness.

Feeling this sense of satisfaction was important not just to the management of the carer role but also to their health and well-being. Feelings of satisfaction were enhanced when there was recognition from others:

*I do feel proud because when she came out of the care home, she hadn’t slept in weeks. When she came home, she slept solidly for two nights. The doctor commended me because they didn’t think Katy would still be here, let alone look as well as she did. I felt really good.* (Stella)

Particularly powerful was when they got recognition for the person who they were caring for:

*When people say to my wife ‘do you get on alright with Craig?’ she says: ‘I couldn’t do without him, I’d be lost without him’. And that gives me a boost, knowing that she knows.* (Craig)

**I am supported to cope with challenges in the caring role**

The satisfaction that people felt with caring was sometimes clouded by different challenges that they faced in their caring role. Specific challenges included feeling isolated, coping with a change in behaviour from the person with a dementia, and managing physical deterioration. Many carers spoke about the feeling of isolation:

*You wouldn’t see anyone, I didn’t know where to go, I didn’t know what to do, I felt so cut off, it was awful.* (Stella)

Two carers spoke about how they felt when the person with a dementia displayed a change in behaviour:

*I was frightened and intimidated by the behaviour. I don’t know if John knew how he was behaving but he nearly broke my arm one day and after he had been to the GP....... I was worried that the dementia would mean that he
would continue to act in this way, so I was frightened and had that scared feeling within me. (Jess)

The significant issue of incontinence as a physical challenge was commented on by two of the carers:

There are challenges around toileting when caring for my husband, this can cause frustration. His ability to appropriately toilet is hit or miss. (Tracey)

A ‘burden’ has been lifted off our shoulders as social work are going in four times per day to look after her and help with issues of incontinence. (Colin and Hazel)

The issues of isolation, change in behaviour of the person with dementia and challenges with physical aspects of caring were in some ways tangible feelings or experiences that services could offer support with. Many of the carers however described in detail their feelings of the whole caring role and how this could feel overwhelming:

I can hardly breathe, she follows me everywhere. Cleaning the loo is the only time I get away from her. (Denise)

It was a nuisance as you would have to repeat yourself, the television was at full blast, these were all things which were irritating me, which was wrong as it wasn’t his fault but after a while everything gets on top of you and everything gets on top of you. I was ratty and I was irritable. (Helen)

It’s the sheer recognition that tomorrow, tomorrow, and tomorrow there’s going to be this ongoing situation where I’m going to have to distract Roy from. That’s a horrible feeling. There’s no way out. I can’t begin to start a conversation that is going to take us anywhere. We’re stuck in this event going over and over the same things. So I can be so driven to distraction. (Wilma)

I can’t even be out of the room because Roy will have his coat on, and will be out of the door. And that’s quite difficult to deal with. I read a lot and if I get absorbed in a book that’s a problem for him. It’s not that he’s demanding attention but he needs to feel that I’m there, in the room, in his mind I suppose. So anything that takes me away from that is an issue. So we do a lot of going out and doing walking. (Wilma)
I worry about her all the time’ ‘If I go out anywhere I worry about her, I can’t
go anywhere without thinking if she is ok. I worry about her 24/7. (Karen)

Sometimes they are like children (Craig)

There was no doubt that many of the carers got a great deal of satisfaction, learning
and growth from the caring experience. Running alongside this however were a
number of challenges that could tip the balance away from these positive
experiences. Most striking in their accounts was the overwhelming feeling of being
stuck and not being able to find a way out.

Although many of the carers interviewed were already receiving some level of
support these feelings of being stuck and trapped continued to be expressed. There
is scope to think creatively and flexibility about what support might look like to
achieve the outcomes of ‘I feel I get a lot out of caring’ and ‘I am supported to cope
with challenges’.

That said there was a sense of hopefulness among some carers that things could get
better:

The solutions are there somewhere I just don’t know what they are yet
(Wilma)

This quote aptly reflects the fact that there is no easy or one solution that is going to
help relieve some of the challenges many carers face but there may be a number of
strategies we have not discovered yet. Ensuring that we work in partnership with
carers to develop and experiment with a range of strategies based on what matters
to the carer and the person with a dementia will be an important development.

Partnership with services

I work together with the people who help me to care

The partnership of the carer and the people providing the services was an important
aspect of how well the carer felt about services. One of the key things that helped
the partnership work was if the paid carer ‘got along with the person’:

We had difficulty getting a carer mum liked - if you know the carers and if you
like them then you feel confident..... that’s why I would like to meet them; to
feel reassured (Denise)

She is getting on very well with some of her carers, particularly where there
are carer’s who know and share her interests, relating things to her past
(Colin and Hazel)
Getting along with the person with a dementia was important as was the continuity of the paid carers:

Our basic team is excellent. We have really experienced home carers who was a home help for years. She is full of common sense, sees something and does it. There is a fully trained nurse who is in the home care team now and she again is excellent and another lady. Full of common sense, all three of them.

And I think that every client should have their own appointed team, a stable team, with six people per person, to cover a number of people in an area. This would allow a bit of flexibility but keep a core of people who can be drawn on so that the person, families and carers can get to know them. There is a real problem when there are new people or people who you don’t know and also, the carer doesn’t know the house or where things are and it doesn’t allow for ‘teamwork’ between myself and support coming into the house. (Claire)

Further exploration would be helpful to explore how knowledge about the person with a dementia and the carer is shared with service providers and how to support carers to have an open dialogue about what’s working well and what could happen more of the time to improve the experience for everyone.

Getting help when you needed it was another important aspect of the partnership with services. Some of the carers talked about getting the help they needed only after a crisis had occurred rather than a proactive planned approach:

If something happens to me, such as when I was signed off sick, the support came in immediately’ ‘I am getting a life now. We have hit rock bottom and now we are on the way up now that we have got the agencies involved. What could have avoided this? I’m not sure. (Denise)

It would be more comfortable if the decision was made in a planned way rather than in a crisis. Sometimes it has to be a crisis. Sometimes it is a crisis that dictates these things. (Laura)

This opportunity to be prepared and forward plan also related to some practical matters such as obtaining power of attorney:

We were too late to organise power of attorney. We had talked about it. I had asked him about it and he said ‘yes, of course’ we would get this organised but when we went to see about it and the lawyer asked if he knew what power or attorney was he said ‘no’. We were too late. (Irene)
The best thing my mum ever did was doing power of attorney, that’s been fantastic and I couldn’t have operated and be at the stage we are at just now without it. (Claire)

Many of the carers spoke of how much they valued being alerted to this practical step early on in the care experience.

The success of the partnership seemed to rely on the relationship the carer had with the services and whether there was trust within that relationship. What was important to many carers was knowing it was okay to ask questions and not feeling silly or frightened to ask for help.

Knowing I can go to someone and rely on them is reassuring. (Tracey)

All I need to do is lift the phone. (Karen)

I knew the system so I got the support, I didn’t feel frightened to ask for it and I got it, I really got a lot of support, which I was really grateful for. (Jess)

Truly working in partnership often meant recognising your own limitations and the strengths of others. One carer talked about sharing the care and the relief this brought for her:

I’m relieved that I don’t have to do everything for Bill that I had to do. I couldn’t do all that I did in the past. I’m too tired at times now to go to bed. If Bill was here he would be up and down. I couldn’t do that now. When I see the care he is getting in the hospital I just couldn’t do all that I did in the past. I feel relieved. (Irene)

Key aspects such as knowing each other in the partnership of caring, continuity of services, practical knowledge, having a point of contact, having people who are approachable and listen and valuing each other’s strengths within the caring experience were important factors that enables the carer to feel that they worked with the professionals in the context of caring.

**PROCESS**

Process refers to those themes that relate to the experience that individuals have when seeking, obtaining and using services. Some of these aspects have already been identified in other themes above. Specifically this section focuses on data related to feeling valued and respected, having a say in services, feeling that services are accessible, flexible and responsive to need, and that there is a positive relationship with professionals.
Valued and respected

I am valued and respected

Several carers talked about how much they appreciated feeling that they are doing a good job (see quotes under theme of satisfaction). Gaining respect from others was seen by some of the carers to be related to the extent to which you were seen to be coping:

*I think you are respected – I think there is respect for you when you keep chugging along on that road.* (Jess)

This assumption could have implications for the ability carers have to share when things are not going so well. Carers feeling of respect and value was enhanced when this was acknowledged by others, including professionals:

*Any time that I have attended with Nancy and been interviewed by Sara and the doctor they’ve always shown me the utmost respect. They are very courteous, saying “you’re doing a good job” and I suppose in that way I felt respected. They’re no just saying “well it’s your job to bring her up”. There’s an element of support for us as the goal is to keep Marie out of the care system for as long as possible.* (Laura)

I am listened to

Feeling heard was evident in many of the carers’ accounts of where they could just pick up the phone and ask for help and people went out of their way to understand needs and respond to these. Some of the carers did not always feel heard. This seemed to be related to where the carer was feeling increased frustration with the caring experience and feeling listened to only happened at the point of crisis:

*You had to jump through hoops. I had to get signed off before any help came. I could have asked earlier but I wasn’t struggling then. If you are coping you are just left to get on with it. It’s so difficult when it is out with your control like this. Had to hit the wall.* (Denise)

Taking the time to really listen was valued. One carer told us about contrasting experiences she had had with Doctors:

*I felt as though the doctor thought I was exaggerating, overreacting and that he didn’t understand where I was coming from. I wanted to say that this is my experience; you’re not listening to me. So then I just kept quiet and didn’t speak to him about it anymore. One of the doctors [in Golspie] took the time*
to sit and speak with me and explain things and I had found this really helpful. (Helen)

Another carer talked about how adopting an assertive approach resulted in being listened to:

I went to the hospital and demanded support for John and said I’m not budging until something is done. I certainly wasn’t dismissed, I stood my ground, I was included with everything that was going on and still am so that is pretty good. (Jess)

When people were listened to it not only helped people to feel valued and respected but it made a difference to feelings of loneliness for one couple who were carers:

I feel more hopeful than before; I feel people are coming together more now to listen and support us, .... we felt lonely before. Loneliness is a terrible feeling. (Colin and Hazel)

**Having a say in services**

**I have a say in decisions that are made about care**

Carers wanted to feel that when decisions were made they understood why:

The decision seems to have been taken behind doors (Stella)

Carers did not specifically talk about being involved in decisions about care but they did talk about the importance of feeling in control:

I wanted to keep control, I wanted to make sure he got the best care possible as far as I could. I didn’t want to let go of the control (Debbie)

I feel cut off because I’m not there and not the one supervising, I feel detached and cannot understand why things are happening, I’m not enjoying that (Debbie)

If I’m in control then I’m happy (Irene)

I did feel out of my depth but I have got to the stage now that I feel that I am in control. (Laura)

I feel I can make a contribution to shaping services
Some carers were members of larger groups who met to discuss service provision e.g. Alzheimer Scotland and expressed a keen interest in being involved in these discussions. For other carers they wanted people to understand what mattered most to them in an experience so that this could inform delivery of services. One carer talked about how much she wanted to take her relative who had a dementia on holiday but was apprehensive about this and uncertain who to contact:

I would like to take Nancy on holiday. But I wouldn’t know here to start. How you would organise that or how to get there..... It would need to be a place that would accommodate people like Nancy. I would need to be in an environment where there were other people there who would understand our situation..... To look at her she looks fine. She can still feed herself. It’s the mental environment. I’m uncertain and not feeling confident about all that. They have dementia friendly hotels but I think this is about the environment. It would be hard for me if people were staring at Nancy because of her behaviour. This would ruin it for me. I would like to feel calm and confident if we did go on holiday. (Laura)

The importance of not having to explain the behaviour of the person with a dementia was the most important thing for this carer. This raises questions about what dementia friendly means in the context of holiday provision and highlights the importance of hearing the voices of carers and people with a dementia in shaping services.

**Flexible and responsive to changing needs**

I can trust and rely on services to respond to what matters to us

There were many examples of where the service went out of their way to respond to carers needs:

Sara contacted a physiotherapist for me because I didn’t know how to get one. I know it wasn’t her remit but she did get that in place for me because she is in the same building (as the physiotherapist). And the GP does ask me to bring Nancy along once every two months to keep an eye on her general health and he has been more than helpful. (Laura)

When I went to get help it was there, the advice was there and the support was there from different organisations, I never got a bad reaction or got the feeling I was expecting too much, if anything it was often more than I expected. I felt we were supported together, I wasn’t isolated.... If I just picked up the phone I knew they were there to help and support me....anytime I needed support it was just a phone call away which was really important. (Debbie)
I feel relieved, definitely. Because someone else is there to help. For example my mum was up at Dobbie’s with friends and I was supposed to fetch her. I just couldn’t face it though……I called the social worker and she dropped everything to go and get her. (Denise)

Some carers were frustrated by the emphasis on paperwork over practical aspects that seemed to more explicitly meet the needs of the carer:

I see lots of other carers frustrated by the amount of paperwork but very little practical coming out of it. I still have people coming to the house every week. Honestly you wouldn’t believe it if you saw my list. This week a girl came to deliver Roy’s walking aids. Every week I have a couple of visits a week. And Anne-Marie came to pick us up to see you today. I have people coming to fill in bits of paper then I get a letter asking me what I thought of the bits of paper. It’s to do with the emergency care plans and carers assessment. Or that kind of thing, but it is endless. The only thing that happened was that the very last person that came, I’d seen her before and when she came I burst into tears because I was so fed-up of all the whole thing and she was the one contacted the young men who came in last week. So that came out of that and that was useful. That came out of all that box ticking. People need something practical. (Wilma)

One carer talked about how the service could be more responsive to what mattered to people:

I know it is a lot to ask for, but we are always asked if we need different things, but can’t get what we ask for. I can’t get mum to bed at night so I’m often putting her to bed and not getting to bed until 1am or 2am and then up at 5.30 am – 6am, as well as getting up to help mum use to bathroom. ‘It’s bonkers’. You think ‘I can’t do anymore and I don’t know what to do’. There is problem at the care at home office end and I suspect it’s that they don’t have enough staff and that they are trying to cope as best they can by putting staff on the ground where they think they are best placed buy it seems to me as the staff on the ground get pushed from pillar to post and it’s all a bit slapdash. The ladies in the office are lovely but there is some problem in the system. (Claire)

There were other examples of where the service was provided but it did not meet the needs of the carer:

...they would sit in the house and I would have to go out and that didn’t do any good. The person would just sit with a book and put the TV on – this left
John very frustrated. I would have to go out which meant that I couldn’t get anything done and then I would have to deal with him being frustrated in the afternoon. It wasn’t much of a coping situation. The Hub was much better. (Jess)

These quotes emphasise the importance of building services around what matters to people and checking out the extent to which they are helping people to achieve their outcomes.

**Positive relationship with practitioners**

**I have a positive relationship with staff who support us**

Many carers explicitly expressed positive relationships they had with professionals:

*Kerry is great – I can really speak to her. Fiona is good too, she advises me on how to manage these situations, she says “you could try this or that” (Denise)*

*It’s about us all working together and sharing the load (Denise)*

Aspects that people valued seemed to focus on interpersonal skills. Skilled interactions helped people to feel valued, heard and able to have open conversations. The skilled interactions could also help carers to feel that they themselves were being cared for:

*The doctor asked him “how are you” and I can understand what the doctor means because, when you are looking after somebody your needs take third and fourth place. But Jack says “oh, I’m alright”. He said afterwards that he thought the doctor thought he was incapable. But I said no Jack I think it’s more that because you are caring for somebody so much you forget about your own needs. (Laura)*

One carer was concerned about whether these positive relationships would be sustained in the future:

*The Link Worker is fantastic, she’s doing a brilliant job but the thought of losing touch with her after a year, just when the illness is really starting to ‘bite’, then she is going to dump us – I know she won’t as we have spoken about this, but this is the same as the carers team, you get to know them, they get to know you and the house, you build a working relationship, and then it is all change. (Claire)*

**Accessible, available and free at the point of need**

**I know who to contact if I need to**
Knowing who to contact was sometimes difficult for carers. Many frustrations in relation to this theme related to carers not being able to contact home care staff to discuss reasons for paid carers not attending or changes to visits:

On Monday the carer did not arrive in time to get my mum to daycare which means it will be the third week she has been without a bath and having her hair done. I can get my mum into the shower at home however it is dangerous to do so and I don’t like doing it. She would be mortified if I had to call on my husband to help hold her as she got out of the shower. It took five weeks before we got back into a steady rota. They don’t ring you and they don’t tell you. It’s been a bad year through illness, but fundamentally, they do not have enough staff on the ground to cover the level of illness they have had. I accept that however if I know, then I can do something about it. (Claire)

It’s the lack of communication between the care at home office and the client. It’s quite spectacular – the lack of communication and the lack of pick up on information. ……Nobody came on the date that I had requested despite having been in contact and asking them more than two weeks in advance, there was no phone call to say that no one was coming.

Knowing who to contact among the range of professionals was sometimes seen as challenging:

We found the process to be slow and initially it was difficult to get services involved, we hadn’t realised there are so many different departments and services. We felt frustrated that as lay people, we look to professionals (doctors/social work) for support but the process has been long (Colin and Hazel)

I have access to support that meets our needs
There were a number of comments particularly in the north of Scotland about the importance to ease of access to services such as day care and care homes:

I just wish he could get into the care home in Dornoch. It would be easy for me to visit. There are only a few care homes in this area and I want to see him settled somewhere close to home so that I can visit him easily and he’s settled. (Irene)

The public transport is not good and this may be made worse by the fact that the dial-a-bus service may be being cut because so many people depend on the service. John was taken to the door of the croft and then picked up again
and if John wanted to get off at the wrong place, Alex would phone me first that made all the difference. There is no other way to get to these places. (Jess)

I think the one thing that would improve things greatly, but is not available, is a day centre. So John is on a waiting list and some of the waiting lists are about 40 people so it’s very difficult. What’s the way out? If I had one day to myself - two days would be wonderful - but even one day then I could make a plan. (Wilma)

Services such as day care that seemed to be valued by many were available in some areas and not in others.

Other areas seemed to be creative in developing services that met the needs of the person with dementia and the carer:

That was one of the great things about the allotment group; you were outside all of the time. You are getting fresh air, exercise, lots of smashing people to talk to and comfortable chairs for those that couldn’t walk about. I don’t think they appreciate it enough - the people from Alzheimer’s Scotland - who are doing all these things. The very practical things they are doing, the Local Authority should be doing them. (Wilma)

Conclusion

The carers that we interviewed described their experience of caring as one which was exhausting, overwhelming but also very positive. The use of the emotional touchpoint tool helped them to express explicitly emotions they felt such as ‘cut off’ ‘privileged’ , ‘proud’, ‘frustrated’, anxious’ and ‘in control’. Expression of these emotions helped them to articulate why they felt that way. It proved to be a useful way of helping them to articulate their experiences in a focused but deep way.

Their stories resonate with those in the literature but there were some additional insights we learnt in this study. These were primarily related to perceptions by the carer about what support would help which included someone to talk to who understands; having time to just be rather than having a break outside of the caring relationship to do ‘an activity’; knowledge and expertise from the professionals has great value; developing services that respond to what matters to the person (creating dementia friendly environments that go beyond physical alterations); the importance of knowing the people with the caring relationship and ensuring that this
is explicitly acted on within the relationship; the value of explicit conversations that explore how people feel about caring; and the enormous impact that positive feedback from professionals that they were doing a good job could have on their ability to feel positive and continue.

The analysis has captured significant outcomes that matter to unpaid carers of people with a dementia. This makes a significant additional contribution to the framework for carers developed by Cook and Miller (2012). The elaboration on the initial themes developed by Cook and Miller could be useful in future carer assessments and development of support.

We entitled the sub heading to this report ‘The solutions are there somewhere. I just don’t know what they are yet’ (a quote from carer) as it reflects optimism on the part of many of the carers that we interviewed where they were enormously grateful for the support they did receive but felt there was more that could help them with both practical aspects of caring but more significantly with more nuanced support that comprised opportunities to talk, share and learn to enable them to gain a sense of purpose, achievement and significance in their lives.
References


Peel, E and Harding, R (2014) ‘It’s a huge maze, the system, it’s a terrible maze’: Dementia carers’ constructions of navigating health and social care services Dementia Vol. 13(5) pp.642-661


Appendices

Appendix 1 – Consent forms and information sheets

Consent for interview

Dementia 8 Pillars Improvement Project

Introduction

You are being invited to take part in a service improvement project. Before you decide whether to take part, it is important for you to understand why the project is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the project?

The 8 Pillars project is part of the Focus on Dementia project – a partnership improvement project by Scottish Government, Quality & Efficiency Support Team, Joint Improvement Team and Alzheimer Scotland. The 8 pillars work aims to test out approaches to supporting people with dementia and their carers in the community.

Your health and social care team is undertaking service improvement activities intended to improve your experience of dementia services. To help us really understand what it is like using the service, what we do well and where we need to make changes we want to hear about your experiences. This will involve asking a number of carers/family members of people who have dementia about their experience.
We are working with University of West of Scotland to undertake these interviews with support from the Focus on Dementia team.

Do I have to take part?
Participation in this project is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and asked to sign a consent form, a copy of which you will also be given to keep. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?
If you agree to be involved, a time will be arranged to interview you. The interviewer will ask you to tell them about your experiences of care. The interview will take up to one hour, depending upon how much information you have to share regarding your experience of care. If you agree to be interviewed, your permission will be sought to audio record the interview. It is important for you to realise that if you are concerned about any of the questions in the interview, you can skip those questions. Furthermore, you can stop the interview at any time. A scribe will also be in the room, who will be writing down or typing up notes from the discussion.

What will happen to the information I provide
The person undertaking the interview will let you know the name and position of any other people who will listen to the recording. It will not be more than one other person.

The people listening to the recording will work together to identify the main issue that you raised in your interview. A number of other carers are also being interviewed. The people listening to your recording will look at all the interviews together and identify common areas where the service could be improved. These common areas or themes will be grouped together. The themes will be shown to and discussed with your health and social care team to help them identify areas where practice could be improved and areas where things are working particularly well. The themes may also be included in reports or presentations, or made use of in the organisation, again with the purpose of improving services.

What are the possible benefits of taking part?
The information that you provide will help to improve the care co-ordination, safety and experience of people with dementia and their carers.
What are the possible disadvantages and risks of taking part?
We do not think there are any disadvantages or risks to you in taking part in the project.

Will my taking part in this study be kept confidential?
The information collected will be kept strictly confidential, and your responses will not be identified to anyone outside the people identified as those listening to the recording. No individual names, details that would identify specific individuals or details of specific incidents will be included in the themes. All recordings will be destroyed once the themes have been identified. All published and unpublished reports will disguise the identity of individuals. Only aggregate or summary information will be reported.

What should I do if I have any concerns about the project?
If you have any concerns about the project, please contact *8 pillar project manager.

Enter name and contact details here.
Consent form
Dementia 8 Pillars Improvement Project

I confirm that I have read and understand the information sheet for the above project and have had the opportunity to ask questions.

I understand that my participation in this project is voluntary and that I am free to withdraw at any time, without giving any reason, without my care or legal rights being affected.

I agree to take part in the above project.

I agree to the audio-recording of the interview between myself and the interviewer

I agree that themes from the interview will be written up in a report and used as part of presentations. The information contained within these publications will all be anonymous.

<table>
<thead>
<tr>
<th>Name of person</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Name of person taking consent (if different from lead practitioner)</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Name of 8 Pillar Project Manager</th>
<th>Date</th>
<th>Signature</th>
</tr>
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</table>

If you have any concerns about the project, please contact 8 Pillar Project Manager, (name here).
Appendix 2 – Data analysis

The Process of Immersion/Crystallisation as applied in this study

<table>
<thead>
<tr>
<th>Elements of immersion/crystallisation process</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Initial engagement with the topic/reflexivity</strong></td>
<td>Recognising and reflecting on hunches and prior knowledge and experience debated with project team.</td>
</tr>
<tr>
<td><strong>Describing</strong></td>
<td>Each researcher read the transcripts twice. Firstly to get an overview of the data. Secondly to begin to apply open codes to the data. 62 open codes were generated</td>
</tr>
<tr>
<td><strong>Crystallisation</strong></td>
<td>Considered consciously what struck us about the data, are there ‘aha’ moments, what stands out, what is at the heart of what people are saying, are there any surprises? What elicited an emotion for the researchers and why this was the case? Noticing the mundane, noticing the exceptions. For example few carers mentioned anything about them being experts. Many carers spoke about the person being care for – being settled. Checked further in transcripts for their meaning of settled.</td>
</tr>
<tr>
<td><strong>Immersion and illumination of</strong></td>
<td>Systematic review of all data. Read through again</td>
</tr>
<tr>
<td>Elements of immersion/crystallisation process</td>
<td>Activity</td>
</tr>
<tr>
<td>---------------------------------------------</td>
<td>----------</td>
</tr>
<tr>
<td>emergent insights from collected data and texts</td>
<td>each piece of data and began to develop sub-themes from the key messages within each piece of data. Organise sub-themes around main themes. Subthemes and main themes developed</td>
</tr>
<tr>
<td>Explication and creative synthesis</td>
<td>Re-examine initial data analysis and refine themes and sub-themes paying particular attention to overlap, patterns and relationships. Once all data were assigned sub-themes and situated under different key themes these were reread to check that each data entry continued to reflect the overall sub-theme and theme.</td>
</tr>
</tbody>
</table>