



University of Brighton

External Evaluation of the Alzheimer's Society Carer Information and Support Programme (CrISP)

CrISP sought to respond to carers' identified needs for better, earlier information to help them care for people with dementia. Carers had spoken of the need for information with support. This evaluation explored the impact of the courses on carers and caring relationships. It addressed the role of information in supporting more effective care giving and more positive caring relationships. It also considered how access to information in a supportive environment impacted the experience of caring for someone with dementia.

Key findings

- Carers valued equally the new information and increased knowledge they received about dementia and the way that information was imparted in a supportive peer group environment where it could be explored with others.
- Carers felt developing a better understanding of dementia and its impact on perception and behaviour enabled them to develop skills and confidence in supporting the person they cared for.
- Visual information was found to be extremely important in developing this understanding as it was felt to be more memorable than written information.
- Experiential knowledge was valued highly by carers. Hearing about the experiences of both facilitators and other carers assisted with the solving of practical problems and the development of techniques and ideas that carers felt improved both their ability to care and to feel satisfied that they were caring well.
- Carers valued the written information and reference material the courses provided, although some experienced difficulties in organising and collating this in ways that made it easy to retrieve, as needed, at a later date.
- The timing of information was critical to its perceived value by carers. Whilst some found it helpful to have information to prepare them for the future, a minority experienced this as adding to their distress.
- The courses led carers to be more confident in their own understanding of the needs of the person they cared for and more assertive in seeking the services and support they needed for them and for themselves as carers.
- There was a less obvious impact on carers' capacities to secure support for themselves and many were disappointed to lose the contact and support offered by the courses.

**Research
Findings**

February 2013

Background

The CrISP Programme aims to improve the knowledge, skills and understanding of those caring for a person with dementia, by providing effective support and up-to-date, relevant and evidence-based information. It also seeks to facilitate peer support within a shared learning experience and a safe accessible environment.

This evaluation, commissioned by the Alzheimer's Society was carried out between April 2012 and February 2013 by a team of researchers from the School of Applied Social Science at the University of Brighton.

Research methodology

The research team carried out 25 in-depth interviews with carers who had attended CrISP courses. Interviews used a narrative approach enabling carers to talk about their experience of caring and reflect on the impact of the courses on that experience.

Carers were invited to take part through information circulated by the University through the Alzheimer's Society local staff. Interviews were carried out in seven areas in London and the South of England including urban, rural and coastal areas.

The 25 carers were wives, husbands, daughters, sons and siblings of a person with dementia and were aged from 48-85. Those they cared for were aged between 78-94, with a variety of diagnoses. 68% of carers lived with the person they cared for.

Our findings

Overall the analysis showed that the information provided on the CrISP courses supported caring practices and carers' needs, improved their understanding of dementia and its progression, and helped them access practical suggestions for support of the person with dementia. A few found the information difficult to handle.

The environment in which information was provided was important. Hearing from and sharing information and experiences with other carers and a knowledgeable facilitator contributed to understanding, enabled reciprocity and made carers feel supported. The detailed findings of the report covered three main areas:

Being a carer– the impact of CrISP on care giving and caring relationships

Carers described different experiences of and responses to care giving. Not all identified

themselves as carers, in particular some of those who cared for spouses saw care as integral to their relationship since its inception:

I think I have been caring for my wife for as long as we have been married (Laughs), as simple as that. (Salim)

A number of those caring for wives or husbands had found the transition into caring relatively unproblematic but others had very difficult experiences as a result of changed behaviours and increasing financial and legal responsibilities. In some cases the situation was complicated by other health problems.

Those caring for a parent had different experiences, which some described as '*life changing*' and encompassing difficult or saddening role reversals. For both spouse and filial carers, caring was impacted by the nature of the relationship before the dementia. It is important to understand the impact of CrISP in the context of both shared and different experiences of care giving:

.....caring is a hugely isolating role. It's very, very lonely, very lonely. And there are things that you have to do for the person that you care for that are really private and personal things, and you kind of hold all of that inside, (Lesley)

Both spouse and adult child carers particularly valued learning to understand dementia and to be able to see how it had changed the person they cared for:

....the insight that I have gained, to understand what is going on in my mum's mind, has been the most revelatory thing I can ever recall happening in my life. (Lesley)

This understanding helped them to build confidence in their caring role and had a significant impact in helping them accept and develop a relationship that they could sustain:

...it's definitely helped mum and it's helped I think the interaction between us. (Maureen)

Learning about dementia alongside other carers of all ages and relationships was valued highly. Although for some, being exposed to what was likely to happen in future and to others' distress, was difficult. Being able to see their own situation in the context of others in similar situations enabled carers to feel less isolated. They identified practical ideas and insights into different ways of caring on a day-to-day basis that were helpful to them:

...the people that did the course with me were as much value to me as what was in the course (Pauline)

The two CrISP courses were designed to address different information needs at different stages of dementia. In practice, carers attending the first course were at very different stages, and some of those they cared for were already in full time care or had died by the time we interviewed them. The stage of the dementia and the length of the caring history impacted on what carers took from the courses. For some its value was in dealing with grief and the experience of having been a carer.

Carers valued the opportunity to consider the need to care for themselves and to explore and document their own caring networks. This had enabled some to feel less guilty about arranging to share care with others and more assertive with protecting time for themselves. But others were quite isolated and the ending of the course represented a loss of support as they reported little of this available from within their own networks.

Becoming informed—the significance of information in the context of care and caring

The analysis showed a complex relationship between information and care. Some types of information were more useful than others, some means of communicating information were more valued than others and timing and other contextual factors were important in determining the value of the information to carers on the courses.

Carers particularly valued gaining knowledge about the different types of dementia and how each might be expected to progress:

....oh it certainly opened my eyes to, um, the way things are likely to go. (Jack)

Being helped to see the world from the perspective of someone with dementia helped them adjust their behaviours:

.....being able to understand the trauma that somebody with dementia experiences, it really stopped the way that I'd gone about things (Lesley)

Both these kinds of information helped carers gain insight into how the disease affected the person they cared for and how they might use that knowledge to understand and care for them better:

.....you have to be with them in the moment that they're in (Alison)

Information was communicated through written forms and visual imagery. Experiential knowledge was offered and shared by both

facilitators and participants.

Whilst written information was valued highly by many, particularly as a reference resource, the information presented in visual form stood out as particularly memorable. Many interviewees recollected the following image:

He showed you this bookcase which made sense, you know, with all the books sort of gradually falling off and I thought 'yes, I can see that' (Kitty)

Many carers spoke about the value of experiential knowledge. They spoke about how they had taken ideas that others had used and adapted them successfully in their own situation:

....when you're putting food on, if you've got a patterned plate...it can confuse. (Maureen)

....it has resolved that problem for me, (mealtimes) and he's humming away to it (music) and it's made that situation easier (Julie)

It was actually talking through some of the things I have been doing and just feeling more confident, and the reassurance that, yeah, actually that works. (Georgina)

The timing of information was important to carers. For some, it was just the right time:

I needed to know what could happen along the way... it covered all of that for me it's very, very valuable....it has prepared me for what could happen (Jenny)

For others, the information provided on the course came too soon:

It was far too early from my point of view (Colin)

Carers differed in the way in which they managed the amount of information and some would have liked a more structured resource to take away with them:

It would have been good to have some sort of folder....to have it collated at the end (Maureen)

Most would have liked a 'refresher' opportunity to revisit some of what they had been given and to reflect in the light of changing experiences. Those who continued to be in contact with the Alzheimer's Society spoke positively of opportunities to revisit some of the information with their staff.

Receiving and sharing information in the CrISP context often brought up strong emotions. The experience of caring is an emotional one and it was important to carers to feel safe in exploring new information in the context of such caring relationships, and the changes that were happening within them.

Dealing with service providers

One of the difficult ongoing aspects of carers' experiences is dealing with and securing services and support for the person they care for.

Those we interviewed had found variable knowledge of dementia amongst services providers. Carers felt that GPs often lacked knowledge about dementia. The specialist knowledge of Consultants was valued, but they were not always respectful of carers' experience and knowledge when making a diagnosis:

.....knowing something's going wrong and the doctor just saying 'no there isn't' and you're like 'yes there is! (Georgina)

Community-based practitioners were seen much more positively and as a 'lifeline' by many. These practitioners were seen as key in helping carers to navigate the configuration of services and the levels and types of provision available in their area so that they could access appropriate services.

Carers' experiences of the Alzheimer's Society local staff and services were very positive and most had found their way to, or been connected with them very soon after diagnosis. Carers spoke of a variety of services and support but mostly of the approachability and availability of the staff and services. They saw the organisation as expert and 'unthreatening' and felt able to ask all the questions that they needed to without feeling 'stupid'.

Carers saw significant impact from the CrISP courses on how they dealt with service providers. The courses provided them with knowledge about treatments, services and legal and financial rights helping them to 'ask the right questions' and feel more empowered and confident in their relationships with service providers. With the increased knowledge and understanding of how the disease was affecting the person they cared for, carers felt much more secure in speaking up for what they felt was needed for them and to support themselves as carers.

Conclusions

- Information is a valuable resource, contributing to carers' capacity both to care well for others, and to recognise their own needs for care.
- Information needs to be provided and time offered to enable this to be explored within a supportive environment.
- Carers valued understanding more about dementia and its impact on the brain and on behaviour as this enabled them to adjust their behaviour and responses in helpful ways.
- The experiential knowledge of carers is as important as more specialist knowledge in enabling carers to develop their capacity to care.
- The ability of carers to absorb and benefit from the information offered by CrISP needs to be seen in the context of their emotional and practical experience of the caring relationship and the stage of the journey with dementia of the person they care for.
- The content and style of delivery of the CrISP courses successfully provided carers both with information and resources about dementia and the opportunity of sharing and discussing that information and their experience with other carers. Overall carers felt that this combination enabled them to develop knowledge and understanding that positively impacted on their ability to care well and develop more positive caring relationships.
- The continuing and changing challenges of caring for someone with dementia mean that carers would have valued the opportunity for 'refresher' courses and/or on-going contact with the other carers beyond the four or six weeks of the course.

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To find out more about the Alzheimer's Society Carer Information and Support Programme (CrISP), contact your local office. Details are available at www.alzheimers.org.uk or from the National Dementia Helpline on 0300 222 1122