



**University of Brighton**

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

**Marian Barnes**

**Flis Henwood**

**Naomi Smith**

**Diane Waller**

**Faculty of Health and Social Science**

**School of Applied Social Science**

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**Marian Barnes, Flis Henwood, Naomi Smith and Diane Waller**

Social Science Policy and Research Centre

School of Applied Social Science

University of Brighton

Falmer, Brighton,

East Sussex, BN1 9PH

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## Section 1 : The evaluation

### 1.1 Introduction

The external evaluation of the CrISP programme commissioned from the University of Brighton commenced on 1st April 2012 and was completed in February 2013. The evaluation was carried out by a team of staff from the School of Applied Social Science under the contract agreed with the Alzheimer's Society on 16th March 2012. This document provides a final report of the evaluation.

### 1.2 Background

The Alzheimer's Society developed the Carer Information and Support Programme (CrISP) following a review of current research findings and a series of focus groups for carers and Alzheimer's Society staff in 2010. The design of the programme was informed by an internal report (2010): 'Information needs of people with dementia and carers' which indicated that 'family carers wanted access to information as soon as possible after diagnosis and preferred printed information and guidance delivered face to face in an environment with peer support' (p 4). Draft materials were developed and trialled with two groups of carers before being piloted at five sites in 2011. These pilot findings then informed the development of the revised programme which was launched in October 2011.<sup>1</sup>

The aims of the programme were 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 sought to facilitate peer support within a shared learning experience and a safe, accessible environment, where information was provided by trained Society staff and volunteers.

Specific aims were to :

- provide and improve access to good quality information
- empower carers to access support services and financial benefits and entitlements
- enable carers to plan for the future
- help carers to feel better informed and less isolated
- help carers to feel that they cope better within their caring role.

The following outcomes were defined that would indicate success in this area:

- Carers are provided with access to a forum.
- Carers are provided with information in an understandable format.
- Carers feel that they have increased knowledge of dementia.
- Where required, carers feel they have been supported to access help and services from the Society and others.
- Carers feel they have been provided with practical information that they can use in coping with living with dementia day-to-day.
- Carers feel that they have received information and an understanding of how to plan with and for the person they care for now and in the future.

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<sup>1</sup> Evaluation Report 2011/12: The outcomes of the Carer Information and Support Programme 1 (CrISP 1v2) Alzheimer's Society 2012

- Carers feel they have benefitted from peer support and sharing experiences.<sup>2</sup>

The programme was designed to be delivered in two parts; the first for carers and family members of those with a recent diagnosis, and the second for those who have been living with dementia for some time. The first part, CrISP 1, comprised four sessions covering understanding dementia, legal and money matters, providing care and support and coping day to day. The second part, CrISP 2, comprised three sessions that explored how dementia progresses, and the changes associated with seeking to live with dementia through such progression.

Between October 2011 and March 2012 the CrISP 1 programme was rolled out across nineteen localities in England and Wales during which time 26 four session programmes were run. The CrISP 1 programme was delivered in four sessions in all areas except three where, due to local commissioning and funding arrangements, an additional two sessions were provided. Whilst this did not alter the content of the course it gave the opportunity to bring in additional local speakers or resources.

At the time of the evaluation the CrISP 2 programme was in the early stages of being rolled out although five pilots had been carried out in 2011. The carers interviewed for the evaluation therefore had attended either the CrISP 1&2 pilots delivered in 2011 or the CrISP 1 courses delivered between September 2011 and May 2012. Of the seven areas chosen for the evaluation three were part of the local funding arrangement that enabled two additional sessions to be offered as part of the CrISP 1 course.

### **1.3 Aims of the evaluation**

The Alzheimer's Society undertook an internal evaluation that covered the CrISP 1 courses run between October 2011 and March 2012. The internal evaluation focused on the content of the sessions and, through questionnaires, covered the issues of increased knowledge of dementia, support to access services, practical information on coping day to day, understanding legal rights and benefits and sharing experiences. The specific focus of this external evaluation was to explore qualitative and subjective assessments of the impact of the CrISP courses on carers and the caring relationship. It addressed questions about the role of information in supporting more effective care giving and more positive caring relationships. Thus we focussed on the experience of caring for a relative with dementia and how access to information in a supportive environment might impact on this.

### **1.4 Methodology**

The evaluation was carried out through an analysis of data from 25 in-depth qualitative interviews with carers who had attended CrISP courses. A narrative approach to interviewing was adopted. We invited carers to offer a brief account of how they came to be a carer, their initial experiences of this and the circumstances in which they found out about and were given the opportunity to take part in the course. The interview then followed on with more specific questions about carers' experiences of the course itself and the impact of the course on their knowledge of dementia and their experiences of caring.

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<sup>2</sup> Support services :Carer Information and Support programme (CrISP), Service Specification, Alzheimer's Society, July 2012

Depending on the time elapsed since taking the course, interviews explored short and longer term impacts, paying particular attention to the impact of the course on changes taking place subsequently. Interview structure was the same for those taking part in CrISP1 and 2 except that some questions were expanded to enable comparison to be made, if possible, of the experience of the two stages of the course.

Our original proposal indicated that, in the case of people with an early diagnosis and with the joint agreement of the carer and the person cared for, we would do a number of joint interviews. In practice the possibilities for joint interviews were very limited and whilst people with dementia themselves were present in a number of interviews there was only one interview in which the person with dementia was able to contribute significantly.

### **Site sample selection**

Early discussions with Alzheimer’s Society staff confirmed that geographical location was not a key issue for recruitment of carers for the evaluation and it was therefore agreed that the evaluation would focus on sites in the south of England. This decision initially maximized the time being spent on interviewing rather than travelling and avoided incurring substantial travel and accommodation costs. The group of sites approached are shown below as Table 1;

Table 1: Sites

<b>Area</b>	<b>Course type</b>	<b>Numbers mailed</b>	<b>Numbers interviewed</b>
Brighton	CrISP1 (2 courses)	14	8 responses from initial mailing. 1 declined and 2 were not interviewed as the circumstances of the person with dementia had worsened. <b>5 interviewed</b>
Havering	CrISP1	9	3 responses from initial mailing. 1 response from reminder mailing but carer declined due to lack of time. <b>3 interviewed (1 Joint)</b>
Dorchester	CrISP1	8	1 response from initial mailing. 1 response from reminder mailing. <b>2 interviewed</b>
Croydon (reserve)	CrISP 1	8	No response from initial mailing. No response from reminder mailing.
Eastbourne	CrISP 1	10	5 responses from initial mailing. <b>5 interviewed</b>
Crowborough	CrISP 1	8	4 responses from initial mailing. 1 declined as person with dementia had very recently died. <b>3 interviewed</b>
Tower Hamlets	CrISP 1 & 2	9	4 responses from initial mailing <b>4 interviewed</b>
Swanmore	CrISP 1 & 2	5	3 responses from initial mailing <b>3 interviewed</b>

### ***Issues arising from site sample selection***

In the areas chosen, the numbers of carers attending the CrISP courses varied from 5 -12 and not all agreed, or were able, to take part in interviews. Some reasons for this are given in the table above. Initially we approached three CrISP 1 areas (Brighton, Havering and Dorchester) with a view to undertaking 5 interviews in each. We followed up with a reserve area of Croydon, but despite a reminder mailing we were only able to secure 10 interviews in these three initial areas.

At the same time, responses were being received from Tower Hamlets and Swanmore, the two areas where both CrISP 1 & 2 courses were piloted in 2011. We were aware that the target of 10 interviews with carers who have completed both courses in these areas would be hard to achieve as there had only been 14 participants in total. In the end we were able to achieve 7 interviews in these two areas.

After some discussion with the Alzheimer's Society we investigated the feasibility of going to North Lincolnshire (one of the only areas outside the pilots to have run CrISP 2 courses at that time), but received insufficient response for the trip to be viable either financially or time wise.

We therefore decided, in consultation with the Alzheimer's Society, to approach two more CrISP 1 sites in Eastbourne and Crowborough and achieved 8 interviews in those areas.

The final 25 interviews therefore represented 18 interviews with CrISP 1 participants from five different areas, and 7 interviews with CrISP 1 & 2 pilot participants from two different areas.

The 25 interviews undertaken covered outer and inner London, and both coastal town and rural areas.

### ***Carer sample selection***

Carers in all areas were approached initially through the local Alzheimer's Society staff with a letter enclosing an information sheet and a contact details form. On return of the form to the University, the research team then made contact with carers directly to arrange to see them. All the paperwork was jointly drafted and approved by the University and the Alzheimer's Society.

Using this method of contacting potential participants meant that the carer sample was self selected. As part of the agreed proposal the research team endeavoured to ensure a range of people were included. That range included:

- Carers who stood in different types of relationship to those they cared for.
- Both co-resident and non co-resident carers.
- Carers in rural and urban areas.

The twenty five carers interviewed had cared for twenty six people with dementia in total, one carer having cared for a parent and a sibling. The carers were a range of people in terms of age, gender and relationship to the person with dementia. Table 2 below gives some detail:

Table 2: Interviewees

Relationship of carer to person with dementia	Total	Living together	Person with dementia living separately
Wife	9	8 (3 died in 2012)	1 in residential care
Husband	3	3	
Son of father	2	1	1 in nursing care
Daughter of father	2		1 lives with wife 1 in nursing care
Daughter of mother	7	4	1 living at home with care 2 in nursing care
Daughter-in-law of father-in-law	1		In sheltered accommodation
Son of mother	1	1 (died 2010)	
Sister	1		Died 2011 in nursing care
<b>Total</b>	<b>26</b>	<b>17</b>	<b>9</b>

Those caring for a parent or parent-in-law were aged between 48 and 66, with the majority being in their 50s. Those they cared for were aged between 78 and 94 with the majority being in their 80s. Those caring for a spouse were aged between 50 and 85 and their spouses were aged between 70 and 87.

Of the group of people with dementia, all had been given, or were understood to have been given, a diagnosis. These were fairly evenly split between vascular dementia and Alzheimer's Disease, although there were a couple of other kinds of dementia. Six of the people with dementia had additional health complications, including four with physical disability and two with long term depression. Twelve had been diagnosed within the last three years, nine in the last five years and the remainder up to ten years ago. Seven of those with Alzheimer's Disease were taking Aricept, or an equivalent drug. Five of those being cared for had died, four since their carer had done the CrISP course and one earlier.

### 1.5 Ethical considerations

The evaluation was covered by full University of Brighton ethics approvals and complied with ethical research requirements of the Alzheimer's Society. There was a fully informed consent process and the research team worked closely with local Alzheimer's Society staff to ensure appropriate follow up support where needed.

Carers were given the option of being interviewed at home or in local Alzheimer's Society venues and the majority opted to be interviewed at home. After home interviews and with carers' consent in most cases the local Alzheimer's Society staff were advised that an interview had taken place. Interviews by their nature covered quite distressing situations for carers and in some cases follow up support was requested for individual carers by the research team.

Support for researchers was provided within the research team.

All the interviews were recorded and fully transcribed. All data are stored at the university to ensure participant privacy and compliance with the Data Protection Act. Data are available only to the

research team and all transcripts were anonymised before analysis began. Pseudonyms are used throughout this report.

## **1.6 Analysis**

The aims of the evaluation were to understand the impact of the CrISP course on the experience of being a carer and the role of information in supporting more effective care giving and more positive caring relationships. Data were therefore analysed thematically against these aims and this report is structured to highlight these issues.

Data analysis was undertaken by the full research team. In the first instance, we analysed a sub-set of transcripts (8), to identify and agree key themes. We then grouped these themes into four broader topics areas (see below) and each team member took one broad area to analyse in greater depth across all 25 interviews. We then came together to agree the final analysis and the structure for the report in which topic areas 1 and 2 were eventually combined.

1. Responses of carers to the process and experience of caring.
2. Carers' experience of the person they care for.
3. Information, knowledge and course specifics.
4. Carers' experience of dealing with other service providers.

It was our original assumption that there would be a significant difference between the experience of the CrISP 1 and the CrISP 2 courses and that these differences would provide us with a focus for comparative analysis. However, it soon became evident that this was not the case so we are not making any comparisons between the CrISP 1 & 2 experiences.

We recruited carers from a range of programmes in order to minimise the likelihood that responses would be 'course specific', but our aim was not to conduct a comparison between courses in terms of the way in which they were delivered and we did not collect data about different delivery approaches. As noted above, three sites included in the evaluation, were part of a funding agreement enabling six sessions to be provided. Additionally these three areas were tutored by the same person. These issues are presented here as contextual information only.

## **Section 2 : Being a carer – the impact of CrISP on care giving and caring relationships**

There is now a substantial body of research that explores how people experience being a carer. Our purpose was not to focus on this experience in its own right, but in order to understand the impact of CrISP on how carers felt about being a carer and the relationships involved in this we did need to understand their responses to the programme by reference to such experiences. In this section we consider the personal and relational impacts of CrISP on carers, including how learning more about dementia impacted the experience of care giving.

Table 2 summarises the circumstances of the 25 carers we interviewed. But their accounts highlighted other aspects of the diversity of care giving that cannot be encapsulated in tabular form. These included the complexity of current circumstances. Some of those being cared for had health problems other than dementia that complicated the difficulties experienced by themselves and their carer, and some carers were disabled or had significant health problems of their own. Some had previous and/or current experiences of caring for other family members or previous spouses, as well as their relative with dementia. And in some cases the relationship that had existed prior to the diagnosis of dementia had been a difficult one. The interviews demonstrated how important it is for most carers to recount their stories and many aspects of these narratives did not relate directly to the CrISP courses or their responses to it. Accounts were emotional: both in the way in which stories were often told, and what they said about the significance of conflicting emotions in the experience of care giving and receiving. They offered a powerful insight into the complexity of experiences associated with care in this context, and the need for some perspective on what any time-limited course can achieve. Responses to the impact of the course ranged from ‘life-changing’, to an inability to identify any way in which it had changed the experience of caring or understanding of dementia. These very different experiences need to be understood in the context of how people responded to being a carer and the extent to which they felt supported in this role.

### **2.1 Caring identities and relationships**

#### ***Husbands, wives and partners***

Although a key objective of the UK carers’ movement has been to encourage people to identify themselves as carers, and to promote the commonalities between carers who stand in different relationships with those they care for, not all those who are now defined as carers identify themselves in this way. It is also the case that people do not always recognise the idea of a ‘before’ and ‘after’ caring. This is one aspect of the differences between spouse/partner carers and those in other relationships. For some husbands and wives, care was an integral part of their relationship:

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

Salim acknowledged that he now had to do things for his wife that he did not do before, but Colin resisted being identified as a carer by minimizing the help needed by his wife. Although towards the end of the interview he acknowledged his resistance to what was happening. He said:

You know, we're a team, we work together as a team. I might be doing more of some of the things but she's, you know (sighs). No, it hasn't really impacted that much because I won't let it, it probably has, I'm probably fooling myself ...

Colin was 50, 25 years younger than his wife, and it is understandable that he found it hard to accept being in the situation of caring for a wife with dementia. It is important to recognise his initial resistance to an invitation to the CrISP course that did not address him as a 'husband', and what lies behind his response that the course had had no impact on how he felt about being a carer. He was angry that the 'completely different sort of love' between husband and wife was not sufficiently recognized: 'There wasn't enough emotion or care for the people that you're actually dealing with.' Somewhat reluctantly he suggested that the course had had some impact on the way he looked after his wife, identifying, as did many others, specific strategies that helped with the day-to-day challenges he faced (see below).

A few spouse carers described caring as something that came naturally, and whilst some emphasised the changes that had taken place in their lives, others expressed a strong desire to sustain continuity in the relationship they have with their husband or wife. Jean and Clive were interviewed together and Jean emphasized the way in which they focused on those things Clive could still do and 'making the most' of the time they had together. Betty (whose husband had died a few months before the interview took place and who had done both CrISP 1 and 2) indicated that the course had had little or no impact on how she felt about being a carer. Her interview suggested no real fracture in the nature of their relationship following Arthur's illness. Their relationship appeared quite self-contained – they had worked together in their own business as well as living as man and wife and they had had no children. She appeared rather bemused by being identified as a 'carer', but showed no sign of either resisting this or of being affected by the course.

There were similarities in Linda's story. She expressed great sadness about what was happening to her husband Walter, but had adopted an approach characterised by coping with things as they happen because it was not possible to predict the future. Whilst she said she learnt from others on the course she did not feel it had had any impact either on how she thought about dementia, or how she cared for her husband.

These relatively unproblematic transitions into caring for a husband with dementia were in contrast to some very difficult experiences. Victoria spoke of aggression from her husband after his illness, and Deirdre was having to cope with the consequences of huge debts caused by her husband's indiscriminate use of a credit card, as well as other impacts of his dementia. Pauline's husband had committed suicide 2 months before the interview took place. Pauline was physically disabled and had previously cared for her first husband who was also physically disabled. She had experienced enormous difficulties in trying to establish the nature of the complex mental health and dementia problems Francis was experiencing, and what had not been an easy relationship was exacerbated by his response to losing control over his affairs. She described his resentment about the apparent power she had as his carer, and this was the only case where the person with dementia both knew and resented the fact that the carer was doing the CrISP course. In this very difficult context she felt that the course had given her a sense of being 'more equipped' to care and she had learnt some useful strategies, including the necessity of building a support network. She acknowledged that she was not good at dealing with the emotional aspect of caring, and in her very difficult situation, it is not surprising that she identified the need for more advanced input in dealing with agitation, in particular.

Anjali's husband had also died in the months before the interview. She too spoke of a difficult relationship prior to his dementia and of having to fight for help for him. Whilst she found the course

helpful in understanding the disease, she felt it had offered more practical than emotional help and had not had a real impact on how she felt about being a carer. She was continuing to see a counsellor to help with this.

Kitty's experience of caring for her husband Matthew was impacted by his resistance to his diagnosis. This was focused around her part in his driving license being revoked. She was trying to enable him to continue to be involved in those aspects of their financial affairs he could manage in order that he did not 'feel useless'. She was worried that she was not helping him: 'sometimes I think I'm making him worse.' So for her the fact that Matthew noted that she started 'being nicer' to him after attending the course was very important. The course had also impacted on her feelings about being a carer by encouraging her to think more about the future. Kitty was probably more self-conscious about aspects of her role as wife/carer because she had also had a job as a care worker. In that role she had received positive feedback from the older people she supported, but it also meant that she understood what the future might bring and she was struggling with this because it made her upset. Whilst she found the course helpful in offering logical suggestions about how to handle aspects of behaviour, the emotionality of the experience of caring for her husband meant this did not always help in practice.

Susan, like Salim, said she had cared for her husband since their marriage, but when asked if the course had impacted the way she felt about being a carer she responded:

I don't like being a carer, it's not something that I enjoy doing, it's just something I have to do. So I don't think it's changed.

Deirdre too talked of caring being a real struggle and she was obviously finding many things hard in looking after Robert. Because this was a joint interview she explicitly declined to talk about some aspects of this experience. However, both she and Susan suggested that understanding more about why things were happening did lead to a greater acceptance.

Salim suggested that knowledge gained from the course contributed to what he described as greater awareness of the responsibilities of being a carer, and he spoke in a way that suggested an enhanced attentiveness to his wife's mood swings. He recognised the tension between such attentiveness and his own needs. His responses reflected what appeared to be a strong bond and an acceptance that caring was part of the role of being a husband. The particular nature of husband/wife relationships can affect how people 'do' caring. For example, Jack said that the pattern of their marriage had been for his wife to leave decisions to him so there was no real change in this respect as she developed dementia. Jean continued to make decisions for both herself and Clive – but had done so throughout their marriage as Clive worked away from home a lot. For Jack, caring for his wife did also mean taking on new tasks – such as helping her to wash her hair, encouraging her to attend to personal hygiene and to eat; and it also involved new anxieties – he described an incident where he had lost her whilst they had been out shopping together. He was having to learn patience and suggested it was possible to get used to anything. Whilst he did not identify any impact on how he felt about being a carer, he did feel that the course had made him more aware of not being alone.

### ***Caring for parents***

The others we interviewed were children caring for one or both of their parents, or in-laws. This can have what one described as a 'life changing' impact. It often encompasses what can be a difficult experience of role reversal. Alison identified a problem of accepting the changes associated with

dementia in someone she loved and had 'looked up to.' For her it was important that her father still acknowledges her:

the thing that I find interesting is there are still the automated responses there because ever since I was a small child, whenever we leave each other, we never say goodbye, we always say au revoir, that's. And I said it to him the other day and he didn't respond and then I said to him again and he did. And I also, I always say to him, 'I love you dad', and he says, 'Love you too babe'. Now I know that that is an automated response but it still makes me feel better.

Some spoke of difficult previous relationships with their parents and the need to work out how to deal with their previous feelings as well as how to respond in the context of the changed circumstances:

when they're frustrated and angry and upset and they want to hurt, and it still does hurt, but now I don't let it. You know, we've actually got to the point where... we went through a phase where I would actually cry and she'd be my mom, but that was exhausting, and so now we actually got to the point where, if she's being a cow to me, I kind of retaliate, which sounds... a lot of people go 'Oh my God, you shouldn't do that', but actually it seems to be what she needs. If she's in a mood she wants... and I don't think it always helps her if she upsets me and I cry. (Georgina)

For Georgina, one value of the course was the way it helped her deal with some of the difficult emotions associated with caring for her mother. The balance between the information and practical solutions offered by the course and the space to address emotional issues was just right for her.

The daughters and sons we interviewed were less likely to resist the identity of carer than some of the spouse carers, although in some situations awareness of this identity had evolved as their involvement intensified. Thus Sarah did not think of herself as a carer whilst she was 'popping in' to see her mother, but did once she moved in to live with her. Some recognised that other siblings were unlikely to take on responsibility and felt a sort of inevitability about this:

I was aware that the responsibility would basically lie with me and I'm someone would take that, I knew I had that responsibility and I knew that dad would have expected me to have done that but he would also have expected my brothers to be more supportive. (Maureen)

Some had made a positive commitment to care for their parents, involving decisions to give up paid work, and including circumstances in which they had been caring for both parents at the same or at different times. Nevertheless, 'being a carer' does not completely subsume other relationships. Jenny started off by supporting her mother in caring for her father who had dementia and severe depression. Her initial description was of caring for her mother, but she also emphasised her relationship as a daughter: 'my role as a carer, but also as a daughter to a father, you see that's when the carer's role that I have expands, yes, 'cos I'm caring for my parents so all the love that I have for my parents, that comes into it'. As the interview progressed Jenny talked about seeing her role as supporting her parents' relationship: 'I just stood there and put both my hands up, you know, and I said, 'Dad, you're sitting there, mum's sitting there and I'm just holding you both up and I want you both to go together like this'. This translated into specific objectives for care, including enabling her parents to be together at home for as long as possible. This explicitly relational understanding of caring was in the context of a supportive family network and a positive experience

of support from the Alzheimer's Society. It reflected a positive choice and commitment to give up paid work and take on the role. Jenny talked about the way in which she used what she learnt on the course to help both her parents make decisions about their everyday lives through acting in a type of mediator role. This reflected the fluctuating mental state of her father (who had depression) and the potential for him to respond to positive support:

I feel I'm supporting them to make these decisions because my father now is able to make more decisions, more of a choice which is what I'm encouraging, I'm encouraging my father to do for himself, this is part of what I call my caring, my caring role, that as I said helping my father to relearn.

Rosemary's experience was also of caring for more than one family member. Her sister, who had had Pick's disease, was dying as she started to take on the care of her mother May who developed vascular dementia. She described the way in which caring for her sister had brought them closer together and she was initially resentful at having to focus on May as her sister was dying. She spoke of a sense of unfairness at having to care for both. She did the CrISP course at this time of transition and said this was a very difficult time for her, but that ultimately she had found the course helpful in the way in which she was able to think about her mother and that she was very glad she had done this.

Geoff, who cared for his father, also spoke about the level of stress he experienced caring for his father and the adverse effect this was having on his relationship with his partner. For him it was a move into residential care that relieved this stress and enabled him to re-establish a more positive relationship with his father through carrying out personal, physical care for him during his visits. Geoff did not consider the CrISP course had helped with the way he felt about being a carer because of the stress at the point he took the course.

Others who did not identify such high levels of stress talked about the impact of the course on the way they experienced this role. They identified ways in which it gave them confidence that what they were doing was right; of feeling stronger about the things they had to do and of being proud about what they were doing. For Audrey, the course had the effect of helping her to separate how her mother was now, from the way she was before. This helped her cope:

Not being tougher but so things like that would make me break down, I'd think oh God, I can't cope with this, I can't be doing with this, made me stronger, it's made me stronger.

Lesley, who had cared both for her father who had prostate cancer and her mother who had dementia, said:

Oh, I would never have categorised myself, when I was working as a tutor, as ever being capable of being a carer. Erm, I'm scared of anything medical, erm... I don't, I didn't do wee and poo and all those sorts of things, erm, you know, I couldn't have imagined that I'd be, erm, capable of, erm, nursing my mum when that's necessary. I still have issues in certain aspects of care, erm, but I'm... I've astounded myself with what I have managed, and I'm quite proud of what I do.

In contrast with Audrey, she still experienced reciprocal care from her mother:

You know, Mum is a joy. Yes, she has bad days, but she smiles, she can hug me, and you know, she tells me she loves me, she worries about me, er, she has all of her nurturing instincts. That's another thing I learnt from the course, you know, the dementia doesn't take away who the person is. It's still my mum, she still can see if I've got pain, and she can see if I'm stressed.

Maureen, like Julie, who was caring for her father-in-law, said she had become more aware of the value of carers, but she also felt she had learnt to recognise more about her mother's responses to having dementia and thus to understand caring as relational. Terry, whose father had cared for him because of his own health problems before he cared for his father, noted that the course had helped his self confidence through enabling him to see more clearly what he was doing and receive confirmation that this was OK. But he also noted that his father was fairly 'laid back' and if he had been caring for his mother he would probably have found it harder. The 'caring bond' that existed between him and his father meant that he did not feel the guilt he observed in some other carers in relation to their caring role.

Both Julie and Terry suggested that experience gained from being a carer and from the input provided by the course could help them find work in this area. Julie had previously worked as a care assistant and talked about the way in which her experiences with her father-in-law had caused her to recognise how valuable this work was and how poorly valued it is. Terry had become a volunteer with the Alzheimer's Society and considered the possibility of taking on paid work in view of the increased need for people with expertise in dementia.

## **2.2 Learning about dementia**

Both spouse and adult child carers found the increased understanding of the way the person they cared for was behaving helpful in building confidence in their caring role. This was in the context of what were sometimes very difficult experiences of trying to get some explanation for behavioural and other changes that they had been aware of for some time. Some described it as a 'fight' to be understood when they reported their experience of 'difficult' or 'strange' behaviour to their GP and other health or care professionals, or to their families. This was exhausting and could cause them to question their own perceptions:

...we talked about diagnosis, and actually getting out there and talking about two years of absolute horror, knowing something's going wrong and the doctor just saying 'No there isn't' and you're like 'Yes there is!' and then you think 'Is it me?' You know, and no one else seemed to be seeing the behaviour I was seeing....' (Georgina).

Securing a diagnosis was often cited as important, but what the CrISP course offered was explanations of what was happening, how things were likely to progress and suggestions about how to respond (see also section 3). This helped to reduce the fear some felt, as well as enabling a greater attentiveness, a better understanding of how the person they cared for was responding to what was happening to them, and how to develop useful techniques:

And I try to, erm, use reinforcing and repetition all the time so that there's some context into what's going on around Mum, so that to me, I want to eliminate as much anxiety and as much fear, and when Dad was looking after Mum he never understood that because he hadn't had it explained to him, as I hadn't. I never thought about telling people, you know, Mum, why I did things. In my head it was just something to be done and I got on with it. But

being able to understand the trauma that somebody with dementia experiences, it really stopped the way that I'd gone about things and I completely changed my approach in how I went about looking after Mum. (Lesley)

In Lesley's case this feeling of greater expertise was associated with feeling more relaxed in the role. For Maureen the course had: 'helped me and it's definitely helped mum and it's helped I think the interaction between us.' Tracie thought that when she started taking more notice of her mum their relationship improved: 'she could talk to me and actually I think she did admit to me that she'd got, she knew that she'd got mental problems and I think it did help a lot.' Julie spoke of becoming more understanding and tolerant in the way she responded to her father-in-law, and that this had also impacted the way she responded to other older people living in the sheltered accommodation where he lived. Susan recognised that she had been angry with her husband as she thought he was being deliberately difficult, but that the course had helped her understand and be more patient. As Salim recognised, the course offered explanations for the difficult mood swings that people with dementia can exhibit, and this can help recognition of what is happening, but this does not mean that advice about 'keeping cool' can always be followed.

Specific learning, for example about perceptual difficulties experienced by people with dementia, offered some quite specific insights that could help carers avoid actions that could contribute to confusion. This included, for example, serving food on plain rather than patterned plates, and avoiding highly patterned carpets and decorations that might contribute to hallucinations. Lesley talked about a particularly useful point in the course when she learned more about how somebody with dementia might see the world:

That's the biggest thing. We talked about practical things, but 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.

The specific example (also cited by others) was of a rug with a pattern that looked, to people with dementia, like a pond with fish. Hence they avoided walking on it. Lesley spoke about how this insight impacted her:

I was able to see that Mum was fearful now...I just thought she was particularly anxious or particularly nervy. But now I can see that what I was doing was contributing to her anxieties because things were happening around her that she had no grasp on....

Carers develop their own strategies based on their own experiences. Georgina, who had done both CrISP 1 and 2, spoke of a continuing learning process through her care giving experience and demonstrated not only what she learnt from the courses but also what she contributed to them. Thus, for example, she spoke about learning to recognise that asking questions can put people on the spot and need to be avoided, and her developing understanding of her mother's frustrations and her own capacity to deal with this '...if she's in a strop, just letting her have a go...' Alison found that one way of managing 'difficult' behaviour was to remove herself from the situation. She agreed with her father even if she knew he was wrong as a way of diffusing anger. This made her life less stressful. Reflecting further on this strategy she said: '...you have to be with them in the moment that they're in'...Kitty reported an experience from one of the group members whose stepmother had refused to get undressed to go to bed: 'Well she's not gonna die is she if she goes to bed in her clothes'. This woman had concluded that if something wasn't life threatening she would just forget about it, let it go. Kitty was trying to do the same but admitted this was hard, especially when her

husband was ill and severely incontinent and she had to deal with the outcome. These examples demonstrate the way in which the CrISP course offered a space in which better understanding of dementia and its impact could be linked with an opportunity to look at the ways in which other carers had already tried to respond to the person they cared for. For some this served to reinforce things they were already doing:

perhaps allowing you to take a step back and thinking how you were doing things, because you sort of just do things blindly ..... and I found that I was doing quite a lot of things I should do and probably very little I shouldn't...(Terry).

In some cases greater confidence led carers to be able to involve other family members in key decision making. Alison spoke of finding it easier to talk to her stepmother, with whom she shared the care of her father, about issues such as 'Do Not Resuscitate'. She said the course had 'given permission' for such things to be talked of. Terry talked of the way in which his awareness of needing to 'think for both of us' led to a determination to get legal powers of attorney sorted in order to do things 'properly.' This also involved discussions with his brother as he was very reluctant to take over sole responsibility for their father's financial affairs. It is not clear whether Terry's determination that his brother should share responsibility was a direct result of the course, but it does indicate the importance of becoming more confident about the legal issues involved and of recognising that there are often others apart from the 'named' carer who have a significant role to play.

There were other instances where carers who had done the CrISP course talked about sharing things they had learnt with friends or other family members who were caring for other people. In this way we can see that the course can have an impact beyond those doing the course, although we can make no comment about how helpful others found this.

### **2.3 Being with other carers**

An acceptance of the identity of 'carer' often comes from being with others in a similar situation. Most of those we interviewed were positive about the opportunity offered by the courses to share experiences with other carers. Being in a group of people who were of different ages and with different caring relationships was highlighted as a valuable supportive and learning experience (see also section 3). This contributed to an understanding of the diversity of what dementia can be and thus different ways of thinking about and understanding it. Some spoke of being able to see their own role and experiences in context as a result of this, or of the value of knowing you are not alone. This comparative perspective could lead to a sense of being 'more content with my lot' (Jack), or to an apparently more 'neutral' understanding of one's own experience in comparison with others:

you're sitting there, you're assessing your role, you're assessing the person you care for, the loved one you care for and you're putting that into, you know, some of the situations are absolutely extreme and that's what you realise, the extent of dementia and Alzheimer's and the impact it can have on people's lives (Jenny).

Jenny went on to distinguish her experience of caring from that of others because of caring for both her mother and her father and supporting the relationship between them. This process of differentiation was also evident in the response of the younger man caring for his older wife. Practically Colin felt that having a full time job made his experience different from others, but of more significance was the impact of what he described as being 'an odd couple':

And of course I don't fit that, um, I have to accept that and because of that I am sort of a bit of loose cannon because of that, that I don't fit into what the normal criteria is, so .....And that is my problem not the society's or whoever's, that's my problem.

Differences between carers could cause problems. One person spoke of the negative responses of other carers in the group to any suggestions about strategies for dealing with difficult behaviour, whilst another talked about a woman whose husband had only recently been diagnosed becoming very upset and frequently crying during the course. Audrey said:

there was a gentleman that was quite elderly and, erm, I found him quite overwhelming in terms of the depression that he was, erm, displaying. I felt I was too vulnerable to sort of absorb negative thoughts at that time.

For Colin, the issue was that he felt it was too early for him to hear the experiences of those further down the line:

I'm not getting any help I'm just being told all these doom and gloom stories that are going to go wrong. Which yeah, okay they're going to happen, I've no doubt about that but it was far too early from my point of view, much too early.

Linda also spoke about not really wanting to hear some of the sad things that other carers were saying. She had little contact with other carers but was not concerned about this because of her approach of 'just getting on with things.'

But it was more usual for interviewees to talk about the benefits of hearing about different experiences and ways in which people responded or coped. Much of the learning about strategies for responding to difficult or puzzling behaviour came from the contributions of other carers. Georgina had done a huge amount of research on her own and thus already had a lot of information before doing the course, but she was very positive about CrISP and spoke of the value of a safe environment in which people could swap stories and help each other out, as well as 'solidifying' her understanding by talking things through. She thought that it was particularly important for CrISP 2 that those following this course knew that they would be addressing more difficult topics with people they already knew and cared about. Many spoke of the importance of reciprocity in the relationships with other carers in the group: this included references to 'sharing', to 'peer support' and to making friends with people who understood what you were talking about. Pauline, who had also done her own research and found out a lot of information prior to the course, spoke of the value of hearing it again with other people there and of 'the people that did the course with me as much value to me as what was in the course.' And even Colin spoke about the reciprocal help available, which might explain his reasons for taking part even though he resisted the identity of carer:

I'm a great believer in listening to people and their experiences because they've been through it and they can help and by the nature of them being there meant that they were the sort of person that would offer help as well. It's a two way, you wouldn't have gone if you weren't going to put something back in. So anybody that goes on something like that it's going to be a two way thing.

Where the course leader was himself a carer the value of his role was seen to be enhanced through an empathy and understanding coming from experience. The importance of being with others who understand because of shared experience is reflected in Lesley's response:

we were given plenty of opportunity to talk. And that is so important because 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, you know, and feeling as I did there, secure and safe, I felt very able to, erm... It was therapy. It really was a therapy session. And I haven't had that opportunity since, and I miss that.

Alison described it as 'liberating' to be with others who understood what you were talking about, who don't question you about it, and with whom you don't have to 'pretend' about the person you care for; whilst Rosemary also referred to the course as proving a 'support group'. Whilst some found the diversity of experiences difficult because it confronted them with the deterioration that they found hard to anticipate, for others it was the diversity that was helpful. Geoff said: 'If everybody was the same you wouldn't have heard the stories...' Lesley's disappointment that contact was not sustained after the course was reflected in comments from many interviewees. This is also relevant in terms of understanding the importance of supportive networks (see section 2.5).

Collectively these responses indicate the way in which CrISP was contributing to a more collective awareness of the value of carers, a shared understanding of the challenges of being a carer for someone with dementia, as well as providing a basis of a support network.

## **2.4 Stages on a journey**

The two CrISP courses were designed to address different issues and information needs at earlier and later stages of dementia. In practice carers doing the first course were aware of being at rather different stages from others within the same group. Jean thought that she and Clive were at an early stage on their journey and knew that things were likely to get worse. Her response to the course was ambivalent – she was not interested in some things, but thought she must have learnt from it. We have noted that for some, in particular Colin, both being with others who were further down the road and being informed about what was likely to happen in the future was very difficult to cope with. Linda also resisted looking forward because of her intense sadness about what was happening to her husband and her desire not to anticipate further deterioration. For some it contributed to a sense that they were not struggling as much as others and thus to a positive comparison of their situation with that of others: 'what I'm coping with at the moment...compared with what some people have got.... very superficial.' (Jack). And Kitty said:

I thought, well really I haven't got much to complain about at that stage, Matthew... 'cos I mean he could still hold quite a sensible conversation with other people, .....but when I heard the stories from the others, particularly one poor lady who I haven't seen for ages, she hasn't been to the carers meetings and I'm just wondering, her husband just won't let her out of the house and he sounds a very domineered, as though he's been a very domineering person all her life and she looked absolutely dreadful, she looked exhausted, you know, an absolute, absolutely drained and I thought well I've got nothing like that to put up with, you know.

In contrast to Colin's response, knowing what the future is likely to bring enabled some to think about and prepare for that future, including reflecting on their capacity to deal with a changing situation and the point at which they might feel unable or unwilling to provide the level of care needed. Julie had committed herself to care for her father-in-law for 6 months and said she would then review the situation. For her, the course was part of a process of learning how things were likely to develop so that she could anticipate and plan her response to this. She, and others, recognised that this might be harder for spouse carers.

Not everyone felt it was possible to plan: 'obviously you can't plan all those years can you because at any time it could change can't it and all of a sudden next year could be different and I know there's be a time I won't be able to cope so I'll cross that bridge when that happens, you know' (Audrey), but the knowledge that they were on a journey with different stages was experienced as helpful. One aspect of that was being able to talk with other family members to prepare them and to anticipate any responses to decisions that they could no longer provide full time care.

In comparison with those who found themselves comparing their situation favourably with others facing more challenges, for Jenny the timing of the course worked precisely because she was feeling particularly 'stretched'. Having made a positive decision to give up her job and look after both her parents, she experienced uncertainty: 'Am I doing this right?' as well as a strong emotional response to what was happening to her parents. The course provided Jenny with an opportunity to talk to others and get some affirmation that she was doing a good job, as well as learning other things that she might try. We have noted that Rosemary too spoke of doing the course at a very difficult time, in her case because of the transition from caring for her sister to her mother, and that the course did help her deal with this.

For others it was a move to residential care that had enabled a more positive relationship to develop. This was the case for Geoff and his father and also for Victoria and her husband Maurice. Victoria visits Maurice virtually every day and spoke of her comfort in knowing he was safe and well looked after. The course had come late for her and she had dealt with many difficult experiences without support. But she still spoke positively about the way in which she had not only learnt practical things from other carers and contributed to their learning, but that it had helped her deal with the emotional impact of what had happened.

Those who had done both courses were, by definition further along the journey and, as we have described, for some (including those who had only done CrISP 1) the journey has reached the point where they are no longer actively caring, although still involved in an emotional journey in terms of dealing with their grief as well as their reactions to having been a carer. Again, these responses reflect the nature of the relationship they had with the person cared for. Betty was obviously sad at the death of her husband, but expressed little sense of anger or conflict about her experience of caring. Anjali in contrast had been seeing a counsellor and Pauline was obviously still needing to process what had been a very difficult experience both in terms of the change in her relationship with her husband and his eventual suicide. Her experience went well beyond what the course was designed to address. Peter did the course after the death of his mother and for him it was part of the process of dealing with his bereavement. Once again, it was important to him to receive affirmation of the value of what he had done.

## **2.5 Caring for self and caring networks**

It is now well recognised that care givers also need to receive care. It is also the case that we need to care for ourselves as well as be attentive to the needs of others. The CrISP course is designed to offer support to care givers and attendance on the course can be understood as one way in which

carers sought to meet their own needs. In addition to the peer support available throughout the course, one session is devoted to encouraging carers to look at their support network and how they can receive care for themselves. In considering the impact of CrISP in relation to carers' capacity to care for themselves, we again need to take account of what carers said about their own personal and social networks, and about health problems that sometimes predate becoming a carer, as well as the impact of care giving on their health and well-being.

There was considerable difference in terms not only of the existence of supportive networks, but also subjective experiences of the need for these. Betty, for example, had virtually no contact beyond her links with the carers group through which the CrISP programme was provided, but evidenced little need for support. Similarly Linda had a limited caring network and showed no particular concern about this or about the need for contact with other carers. She is able to get someone to sit with Walter sometimes so was able to get a bit of time to herself. In contrast, Jack, whose wife was in the early stages of dementia, spoke of being able to build more local connections following retirement and of the way this enabled him to leave his wife for a few hours because a friend will come in and see her to have lunch. He is thus able to follow his own interests in amateur dramatics and bird watching. Others were able to continue to do paid work through sitting support, day centre attendance and help from family.

Even when there is infrequent face-to-face contact, knowing that others are aware and understand is important:

.....me older brother, we have a bit more connection, even though he's far away, it doesn't feel like I'm far away it feels like sometimes he's in the room with me so we have that quite closeness, he can always sense if I'm having a bad week, before I came away to him he knew I was having a bad week, I said how do you know that? I just sensed you were that's all, some people can sense it can't they? (Audrey).

One of the important things about the course for Maureen was the way this helped her realize that she had the resources to make her mothers' life as good as possible, but also that carers have their own needs for support and that she was in a better position than many others to realise this.

But others were clearly isolated and felt an absence of support. Deirdre could only identify their dog as a source of support as she spoke of 'battling along.' Victoria's family asked her why she kept visiting her husband following his admission to residential care. Anjali's difficulties in looking after her husband Michael were compounded by her sense that his family were uninterested in what was happening to him and the contrast with her cultural expectations that it was a family duty to care. She attempted to ensure support and relaxation for herself through yoga and counselling.

For Lesley simply getting to the CRISP meetings was a challenge. She has agoraphobia and the only way she could travel to meetings was by taxi. The willingness of the taxi driver to offer a reduced rate for regular trips, and of the Alzheimer's Society to cover at least part of her travel costs made this possible and the impact of this on her capacity to make time for herself was clearly very important to her:

I have lovely hobbies and I'd not been able to touch them because with my mum and my dad, and then my dad dying, and that took a long time to, to come to terms with the fact that I was now Mum's sole carer. ....But I've sort of come through that now and I've started doing my needlework again and, erm, that gives me huge pleasure, just picking that up, reading a book, erm... and I've learnt to manage time better and to get Mum occupied with

something. No, I can't quite honestly say that I sit and do half an hour's needlework and not have any interruptions, but I build those interruptions around my needlework.

Making time for themselves can be hard for carers not only because of the demanding nature of the role, but also because of difficulties in admitting their own needs. Kitty spoke of feeling guilty about leaving Matthew to engage in recreational activities for herself, but because she was able to define the CrISP course as 'business' she felt able to justify attending that. She spoke of different stresses within her family and of having no caring network. Her anxiety about the future was palpable and whilst she said she thought there would be friends she could speak to, it was very evident that she was struggling to cope and that without ongoing contact with other carers or support workers the course alone had not enabled her develop a strategy for meeting her own needs. Geoff was advised that his father should go into residential care before he was able to recognize his own needs for respite. Susan was also finding it difficult to keep time for herself. When asked about the session on self care she said:

I don't recall a lot about it but I remember that they said that we should make sure that we look after ourselves and do things for ourselves and have breaks and things like that which obviously you do need but it's a very difficult thing to do isn't it in the circumstances.

However, Terry found this part of the course of particular value in developing relaxation strategies. He noted that his experience of being cared for by his father enabled him to recognise the importance of doing 'your own thing at times'. Rosemary found the exercise of identifying who was in her support network very helpful, but this was because she could identify not only family but what she referred to as her 'church family' as sources of support. Whilst developing individual strategies is important, it is clear that carers' capacities to implement these are affected by the nature of the support network in which they are caring for their relative. This reinforces the importance they attached to meeting with other carers during the CRISP programme, and the disappointment of many that these meetings were not sustained.

## **2.6 Summary**

- Any assessment of the impact of CrISP has to take into account the diversity of subjective experiences of care giving, including relational histories, other caring needs and relationships, as well as the nature and extent of caring networks. We have distinguished the responses of spouse carers from those of adult daughters and sons.
- Whilst the majority of responses were positive about the CrISP courses and carers could identify ways in which it had impacted their experience of being a carer, for some it had made little impact.
- Carers taking CrISP 1 were at very different stages on the journey and responded very differently to both the information presented about the likely progression of dementia and what this will involve, and being with carers who were much further down the road.
- Carers' accounts were emotional and emphasised the importance of understanding the emotional dimension of caring. Many highlighted the importance of the CrISP courses by reflecting on the space for emotional support as well as learning and information sharing.

- Developing a better understanding of dementia and its impact on perception and behaviour enabled carers to develop skills and confidence in supporting the person they cared for. There were reports of improved relationships as well as practical techniques that had improved carers' abilities to care well.
- Carers learnt from being with other carers as well as from the more formal input to the courses. The reciprocity of relationships amongst the group was important and carers valued being able to contribute their own experiential knowledge as well as learning from others. The course impacted the development of a shared awareness of both the challenges and value of care giving. But there was also evidence of some distancing from other carers and of difficulties associated with being exposed to others' pain.
- There is some indication that the course may have benefit beyond those doing the course through the broader sharing of information.
- It may be more difficult for CrISP to impact on carers' ability to care for themselves or to benefit from the support of broader networks unless such networks become more available. There was disappointment that there had been no opportunity to sustain links with carers met during the course in many instances.

## **Section 3 : Becoming informed - the significance of information in the context of care and caring**

As was made clear in Section 1.2, CrISP courses are information courses that were designed in response to carers' expressed need for information provided in the context of peer support. In Section 2, we discussed how peer support, sharing with others and reciprocity in relationships between carers were all valued aspects of CrISP courses, enabling carers to develop confidence and skills to support both their care of others and of themselves. We also considered how learning more about dementia can impact on the experience of being a carer. In this section, we focus more specifically on the relationship between information and care as it is experienced by course participants and on the type of information and knowledge about dementia that carers valued.

Overall, the analysis shows that information provided on the CrISP courses can support caring practices and carers' needs, improving their understanding of the disease and its progress over time, helping them to access practical suggestions for supporting someone with dementia on a day-to-day basis and supporting carers to take better care of themselves. However, the analysis also shows that information alone is not enough to support care and the relationship between the two is neither an instrumental nor a linear one. The analysis suggests a more complex relationship between information and care. It shows that some types of information are more useful than others, some means of communicating information and knowledge are more valued than others, and that timing and other contextual factors are important in determining the value of information for carers. The amount of information people can deal with also varies and is influenced by their past experiences of, and present confidence in, accessing, storing and retrieving information as needed. Information was also shown to have an emotional impact- in some cases enhancing confidence and acting to reassure carers that they were caring well; at other times or for some people, information about dementia seemed to increase anxiety, particularly about their ability to cope. What is very clear from the analysis is that 'support' was as important for most as 'information' and that the latter without the former would have been far less useful. Being offered information in the context of a group focused specifically around the needs of carers was key to the success of these courses. In the following sections, these themes are explored in more depth.

### **3.1 Types of information and knowledge valued by carers**

Carers spoke of valuing both the increased understanding and knowledge they gained about dementia and the insights the course gave them about how someone with dementia might be experiencing the world. Taken together, these two types of information or knowledge enabled them to learn new ways of doing things and thus supported their care practices. We deal with each of these in turn, below.

#### ***Knowledge about dementia and its progress***

Most participants valued learning about dementia- both about the different types of dementia and about how the disease progresses. Jean hadn't realised there were 'so many different types of dementia': 'I thought dementia was dementia, that you lost your memory. Now I do understand some never lose their memory'. Geoff appreciated learning about the brain and, in particular, being told about the difference between the frontal lobe and the back lobe, commenting: 'when [the tutor] told you what the front one did, you could relate to the things that my dad was doing'. Tracie also found this insight into the working of the brain important and useful- particularly thinking about

the way the brain 'tangles'; and Anjali found 'understanding what the disease was about' the most helpful aspect of the course.

Lesley reflected that having this improved understanding can really make a difference. It helped her realise that her mother is 'living with dementia', whereas previously she might have thought of dementia as an end point: 'you might as well be six foot under'. She also learnt how she could 'help someone with dementia have a good quality of life', something she had simply not considered before. She later commented that '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'.

Terry reflected that he could 'understand behaviours a lot better' than he had before the course and also understand where his dad was 'going' in terms of his dementia. This understanding about the stages of the disease and what to expect was appreciated by many participants. Jack described how he had learnt that his experience of 'losing' his wife on a shopping trip was not untypical and that the course had enabled him to understand that it's 'a phase which they go through'. He added that this new understanding came principally from other participants on the course:

Oh I did learn things like that on the course, you know I mean, oh it certainly opened my eyes to, um, the way things are likely to go. But again, this came principally from, I don't know what to call it, attendees?

Maureen made a similar point in relation to caring for her mum:

One of the biggest and most important things for me was because, I wasn't, I didn't know where mum fitted on the spectrum, I wasn't, I just hadn't got a clue on that. So to sit with people and listen to people's stories and what they were going through it was very helpful because at that point I was working on a one to ten scale, and at that point I was pitching mum at about a three...

### ***Seeing the world from the perspective of someone with dementia, leading to new ways of caring***

Linked to better understanding of the disease and its progression is the way in which course participants were helped to see the world from the perspective of someone with dementia which, in turn, led them to develop new ways of doing things, of coping with everyday life situations they faced. Again, this 'information' was largely in the form of experiential knowledge offered either directly by the course tutor or from the participants themselves.

Jenny talked about how better understanding of vascular dementia had led her and her father to be able to cope with everyday practical things in a new way:

One of the valuable things I learnt on the course was that people who are diagnosed with vascular dementia... I mean he described it absolutely brilliantly, you know, he said it's just like sort of driving along the road and say there's an obstacle in the way, you can't carry on that way, you've got to find another route so once I learnt that on the course and that twigged.

Alison, who cares for her father alongside her step-mother, found it useful to know not to ask too many questions to someone with dementia as this can cause them to 'go completely to pieces and

have absolutely no idea what to say to you', something Georgina also mentioned. Alison was also extremely positive about a session on perception which illustrated how the placing of a mirror in a bathroom might be perceived as another person in the room, leading someone with dementia to avoid using the bathroom and going to the toilet in inappropriate places:

she didn't realise that that person was her...you know you think 'yes, it makes sense', don't put a mirror opposite the door if you've got somebody that's suffering from dementia because they could misinterpret the situation which is exactly what this lady had done.

Lesley reflected upon how participants were helped to see how a rug with dark centre and defined border might look like a pond to someone with dementia. The tutor had explained that this perception can prevent people with dementia wanting to step onto the rug to get where they want to go (in his story, a 'beautiful conservatory'):

There was nowhere else to get through to the conservatory but to walk on this rug, and I suddenly thought, 'My gosh.' (Pauses) You know, it was like a light-bulb going on. I thought... wouldn't have even given it a thought.

Maureen also spoke about the real practical value of seeing things from the point of view of someone with dementia referring to both the 'white plate' and 'rug' examples that were offered on the course:

**Can you give me any examples of things that you particularly found...?**

Well certainly, yeah, in my interaction, direct interaction with mum, we were questioning, organising things, being more aware of, ah, we haven't got to this stage yet, but a white plate, sort of the very, the practicalities, that was really useful.

**What's the white plate about?**

Having, when you're putting food on, if you've got a patterned plate...

**It can confuse.**

That's right, as in dementia or a rug on the floor, basic depth perception I think it would be and that can, looking at the physical area and how you can actually adjust that, blinds, and so really practical things, that was very, very useful.

Tracie, whose mum was still living at home when she did the course, also spoke of learning new ways of looking at things and of coping: she spoke about how she learnt to see that 'it's an illness and she couldn't help it and different ways of coping with it, to actually listen to mum, instead of just sitting, you know, just panicking and thinking, oh I can't, I don't think I can do this'.

### **3.2 Means of communicating and sharing information and knowledge**

Information was communicated to, and shared amongst, participants by a range of means: leaflets and other written and paper-based materials, visual images, and experiential knowledge offered and shared directly by both tutors and participants.

## **Written information**

While paper-based, written information was valued by some, many found this limited, either because it required further explanation and interpretation to become meaningful to their own situations or simply because there was so much of it and it was not always felt easy to organise in way that would be useful for later use. The challenges of information 'load' and management are dealt with under section 3.4 . Here, we discuss some of the other benefits and dis-benefits of written information.

Many participants did appear to value having access to paper-based information. Anjali remembered being given lots of information leaflets to choose from, saying that 'we had loads of stuff to read so I was grateful for that' and that when they were invited to take whatever they felt was appropriate, she 'kind of like took everything!' Tracie also found the information provided helpful, saying that it acted as a signpost to where to go next which, as for many participants, was most often 'the Alzheimer's Society'. She also appreciated the material handed out on the course for the way it could be used at later date as a 'reminder' that others are going through the same experiences, which itself can help with feelings of guilt, saying: 'the booklets made me feel better because it (sic)was there'.

However, Tracie later went on to suggest there may be limits to what paper-based written information can offer carers, identifying talking with Alzheimer's Society and 'the course' as preferable:

... 'cos when you're first sort of faced with it you don't quite know which way to go, and it wasn't until the Alzheimer's Society and the course really did put me right.

**Do you find it better to have information from somebody talking to you or do you find it easier to read it in a book, how do you like to...**

Actually, I found that much better.

**So the actual somebody telling you?**

And listening, so yeah listening to people's stories and, you know, how they're coping with that sort of same problem.

Pauline also spoke of the value of having information in the context of a specific course for carers and being with others carers:

I mean I do think there's value in face-to-face information...nothing you can get off a computer can really touch being given information by someone's who's got background and the examples that makes it human, in conjunction with other people who are all doing the same.

What is interesting to note in these responses is that, even within this more structured information, which, as we discuss in Section 3.4, they do sometimes return to, carers value other carers' input very highly, as it helps to make the information really meaningful. Lesley expressed this particularly clearly:

We had some wonderful handouts. ..I just valued their content, particularly where there were quotations from other carers' experiences... It was very much brought into real life by

examples or experiences as part of those information sheets. Erm, you know, a professional person can write wonderful, wonderful text, but it doesn't hit home if it's not from the heart. And where other carers have given comments, you think, 'They understand.'

### ***Visual forms of information***

Information that was communicated to participants in visual form, again in the context of discussion, stood out as being highly valued by many. It acted as an aid to understanding, was used to communicate this understanding to others, and was used to assist in the practical tasks involved in caring. The most potent example here was the 'bookcase' image. Deidre found the bookcase image to be 'one of the most useful things' on the course:

... a bookcase which is full of books and then gradually one shelf at a time kind of slightly slides off and then a little bit more goes. And that really for somebody who is not very knowledgeable about it, I think was quite, a very good way of explaining to it because you can visualise that.

Jenny summed up the value of the visual image over the written text in aiding understanding:

everybody has the hand-outs which are great and you can read and read and read, but to actually, to be there and he was demonstrating with his wonderful interpretations of drawings and to be able to break it down to that level you could actually see what you were reading was actually visual for you to understand it more.

Alison spoke of the book case image as her 'abiding memory' of the course, a tool which not only aided her own understanding but also enabled her to communicate this with others:

I just think that is such a stimulating visual on how it works and I wish everybody in the country could see it...you look at it and you think 'oh okay, there's a shelf full of books there' and then you get further and further down and then at the bottom there's just this sort of heap... because it's a visual and because you could take it in... that is my thing in my brain when I talk to people about Alzheimer's or dementia.

Kitty also recalled the bookshelf analogy and had drawn upon it directly in caring for her husband, Matthew:

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', and I found that the other day, that little picture and I thought, 'yes, I can see, I think we're down to the second shelf now'.

### ***Experiential knowledge***

We have already seen how structured forms of information, such as that communicated via handouts and leaflets, were valued by course participants, particularly when made meaningful to the specific caring situations they were engaged in and how information communicated via visual

images was also thought valuable when applied to everyday life experiences. However, many spoke more directly about the value of experiential knowledge.

Julie talked of learning about the value of music from another carer on the course and being able to apply that knowledge to a very real practical problem she was facing, now that her father-in-law was less capable of conversation at mealtimes. She describes how she now puts music on during mealtimes, saying: 'it has resolved that problem for me, and he's humming away to it and it's made that situation easier'. Victoria was also able to draw on others' experiences to help deal with her own challenges in caring for husband, Maurice, who was trying to get up and go out at three in the morning. Following the advice of one woman in particular, Victoria learnt to hide his 'stuff', his clothes and shoes.

Victoria's confidence improved hugely on the course to the point where she now finds she is able to draw on her own experience to help others:

Yeah. Like when I help him shower, it's like in the beginning, in the shower, he was all right but in the end, he start losing his temper and what I've been doing, put the shower to his feet and going up slow you know. And it when it comes to his head it's been all right. When I told them to, the people 'oh that's a good idea'.

### **3.3 Timeliness of information**

The timing and timeliness of information is a complex issue, experienced differently by different people. Some felt happy and even reassured, to know things in advance of its practical use; others wanted to know things only as and when they could put it to use. Jenny is a good example of someone who held the former position, saying how it helped her feel 'prepared':

I think one of the most valuable things the course gave me was all the knowledge, all the understanding I needed to know what could happen along the way... it covered all of that for me it's very, very valuable. That now I, it prepared it, it has prepared me for what could happen

In talking about a particularly difficult time with her father more recently, Jenny reflected on how she was able to draw on resources provided by the course:

So yes I was pulling on my knowledge, not that I just had within myself but what I'd learnt on the course as I said before, the valuable insight of what could happen, right through the processes to the end.

Julie also spoke about how learning how things were likely to develop had enabled her to anticipate and plan her responses and whilst it was acknowledged that 'things change' and there are limits to how much can be planned in advance, most carers did find it helpful to understand about the stages of dementia and what they could well be facing in the future. Exceptions here, already discussed in Section 2, include Linda, who resisted looking forward because of her extreme sadness about what was happening to her husband and Colin, who had a very strong negative reaction to being told so much about the future of the disease when he attended the CrISP 1 course, where, as he put it, others were 'further down the road' than him:

I don't mind saying that by the time we got to the end of the second session I felt like coming out and slashing my wrists because you thought 'this is good, I've got all this to look forward to...it was far too early from my point of view, much too early.

When asked if that meant that the material the course covered was difficult for him to take on board, he replied, 'No, I could take it on board, that was half the problem, I took it on board'. Later he admitted that he found it all 'scary', illustrating the sometimes very negative emotional impact information can have, something discussed in more detail in Section 3.5.

Jack was also much less inclined to want information about issues that were not yet arising:

I think I came to three [sessions on the course] and I was told that the fourth was largely concerned, would be largely concerned, with legal matters which were not applicable to me, well not yet anyway.

Later, he spoke of how distressing it was hearing about what happens to people 'in the last stages', something he preferred to avoid until faced with it in his own situation. Jack was someone who would have preferred information to be staged to meet his particular needs, obviously something that is hard to achieve on a course aimed at groups of people facing different situations at different stages of the disease. Although the Alzheimer's Society is attempting to address this through their two-stage approach to CrISP courses, it is doubtful that it can ever be tailored to the individual in quite the way that Jack would like.

Others who felt that the course came too soon for them spoke of needing a 'refresher' so that the information could be revisited in the CrISP course context and put to use as and when needed:

a refresher would be really valuable... You know, even if it was four, six months down the line, erm, I think these things are so easy to, erm, to miss things that could be useful later on that weren't perhaps relevant at the time. But by having a refresher, where you could be given an opportunity to revisit some of the content (Lesley).

Well I think probably if we were the same group of people I think probably a lot of them might feel like I do, that you need almost a refresher really. Because by the time you've (sighs), even nine months has elapsed, I mean so much has probably changed for everybody, you know, that you almost need to go back (Deidre).

Deidre later acknowledged that some of this 'refreshment' might be found in the materials handed out on the course:

...I did come home with a lot of paperwork and I'm not quite sure exactly, because I've got so many files in there with bits and pieces that probably it might, for my own sake, actually be quite helpful when I get a minute to flick through all that really and look. Because probably at the time as you say it wasn't really applicable but maybe some of the things will be now...

Audrey spoke of a 'big folder' of information which she hadn't yet revisited but which she might need to do at some point in order to 'refresh' her mind.

This last point links to the question of information load and management, which was an issue for many carers. Like Deidre and Audrey, many carers referred to the amount of paperwork they were given and, while most were keen to say how much they valued having it, many were quite vociferous about how hard it was to manage and retrieve when needed, as we discuss next.

### **3.4 Information load and management**

Several participants talked about the problem of information overload. Terry loved the course overall and is very involved in Alzheimer's Society support, but still found it too much information at times: 'too much of a brain dump in too short a time' and 'the second and third modules were too much of a brain dump at once'. Colin also felt overwhelmed by the amount of information provided and his inability to make use of the amount and form in which it was given. He showed the interviewer the big (1-2 inch) folder of information he had and referred to 'little snippets', a 'bit there' before suggesting that it would have been better to have had it organised in a way that could be more easily accessed when needed:

I want a guidebook, I want a handbook...a loose leaf handbook where it's all done on a standard size page, it's indexed and you build up a library of information help sheets...

Maureen, who mainly found the course extremely good, also thought it would have been helpful to have a way of keeping the information organised for future retrieval:

I think it would have been very helpful at the end of the course, I mean we were given lists of Social Services numbers, etc., etc., but I think it would have been good maybe to have had some sort of folder...somehow to have collated, I think, at the end.

Sarah made a more general point about amount of information available nowadays, suggesting that there may simply be 'almost too much':

#### **Mm, too much information?**

Um, well I don't suppose there can ever be too much information, that's a silly thing to say, it's better to have it four times than not at all but, you know...there's St. John's, they've been given money by the government, there's Age UK, there's the Alzheimer's Society, they're all coming at you with information, you know, and I'm sure that's... it's almost as though they could save money perhaps if they pooled it...but having said that I'd rather have the information a lot of times than not at all, yeah.

Some participants, particularly those with good information skills, were happy to find things out for themselves and to sort and manage information for later retrieval. Lesley, who had been an IT tutor and who described herself as a 'problem solver', was confident with the internet and finding information for herself but was concerned about how people with less information skills would manage:

I read information off the internet, because my profession is an IT Tutor so I understand good websites and websites to avoid like the plague... I was able to find out a lot more about specifically vascular dementia...But I did find a lot of stuff that, you know, wasn't very helpful, and somebody without my background could possibly have been ill-informed or frightened by what they'd read.

Julie had been a care assistant working with older people so had existing knowledge she could draw on. She also felt confident to search for information independently, including on the internet, to find 'what would happen when' in terms of the progression of dementia:

I was on the Alzheimer's Society and website and, you know, did quite a lot of research on, you know, what was available and spoke to Age UK and looked on their website, you know, so I did a bit of background. And I think probably because I'd done a bit of care work and I knew, you know, what it can be like.

Peter, whose mother had died 2 years before we interviewed him, also spoke of how he first found information to support him in his caring role by looking at websites and finding out about the Alzheimer's Society, which then led on to him taking part in the Alzheimer's Society events. Pauline, whose husband Francis committed suicide not long before the interview, talked about finding information once they'd had a diagnosis for Francis. Pauline had worked in Adult Education and described herself as someone who was 'used to looking for information':

And of course I went on the internet and found Dementia UK and the Alzheimer's Society, and I sent for the books on vascular dementia because that what we were told it was initially...when he found he'd got Alzheimer's as well...I also... I registered with the Alzheimer's Society forum, and there was a wealth of information from carers.

Pauline went on to describe how she uses that forum every time something 'crops up', saying: 'I would put all that down on the forum and other carers would give me their opinions. And that was actually the best help I had'.

Alison was another of the very few participants who explicitly mentioned using online forums and social networking sites to link her to others in similar situations:

I talk on Facebook to various people all over the world and I made a comment the other day about my father's dementia and about a dozen people said 'oh God, my mother's got that'. And we talk about it, 'Oh what do you do about so and so? What would you?' You know, and I just think that it's, to paraphrase what they used to say on the telly, 'It's good to talk'.

By contrast, Susan and Anjali were less confident with computers and using the internet:

Well I must admit on the very beginning I did look on the Alzheimer's website and I couldn't find anything I wanted but that could be me because I'm not a very good computer person and I used to, when I was trying to look things up I used to get sent around in circles and end up at the beginning and not find anything (Susan)

Well I'm not very good with computers so especially research and things like that. You know, that was difficult for me, I don't know how to type in keywords and things like that and I don't know, understand all that (Anjali)

Our analysis suggests that having good information skills and feeling confident accessing and managing web-based information can support caring and that, conversely, lack of such skills and confidence can inhibit access to information that might support care. However, there is also the question of carers' preferred means of receiving/accessing information. Several carers who had reasonable levels of information skills and could search independently, including online, still expressed a preference for information provided in the context of discussion with others. Linda, who cares for her husband, Walter, is a case in point:

I like these little things we go to where, as I say, they give a talk for an hour, I quite like those. I don't mind the hand-outs as well because then I read, I put it away but then sometimes, like today, I think 'Oh I'll just go back and have a look and see if I can find anything'. So I do find the printed...

**Stuff useful to remember.**

Yeah, I think I'm of that generation that likes a bit of paper. I do look on the internet, um.

**Yeah. But your favourite thing would be for somebody to tell you about it and then to have some information that you could look back at.**

Yeah, I like that, yeah, I personally that's my preference.

Other participants reflected on the importance of human sources of information, especially service providers- GPs, health visitors, CPNs, and staff at the Alzheimer's Society were mentioned specifically, although GPs, in particular, were found by some to be quite dismissive and slow to react to concerns about changed behaviour, leading to delayed diagnosis and additional stress for both carers and cared for. This issue is discussed in more depth in Section 4.

A final issue that arose in the context of information load and management is interesting for the way it brings attention to the question of information 'push' versus 'pull'. Anjali was one of the few who really focused on the need for information to be 'pushed' at people as opposed to the onus being on individuals to 'pull' information, to find things through independent searching. She spoke particularly about the need for more information that can raise awareness on dementia in public places:

I have always said 'Please, please, please, posters, leaflets, wherever you can, in libraries, at the GP surgery essential, hospitals essential', you know, have something and then you can go and ask about it, even if you don't have it in your family. It's not just with dementia, for cancer, for whatever it is, diabetes, diabetes has got things out there, cancer they're bringing up now, but nothing on Alzheimer's or dementia...Is this dementia? Is this Alzheimer's?

### **3.5 Emotional impact of information**

Receiving and sharing information in the CrISP context often brought up strong emotions as was seen in the discussion of 'timeliness' above. Other accounts suggest course participants are really aware of this and it can affect their own information strategies and practices. Colin was asked if he'd

looked for information at time of his wife's diagnosis. He spoke of some of the problems of trying to get the information he needs without upsetting his wife:

it's very difficult to try and protect Mary from it in that I need to find information, I need help, I need to know what we're going to get but I don't want to find lots of things dropping through the door mat, people phoning me up, things doing this that is going to make her agitated because if she gets agitated it gets worse.

In the context of information accessed on the course, many participants spoke of the very positive impact it had had on them emotionally- particularly on their levels of confidence and resilience in dealing with the challenges they faced as carers of people with dementia. Jack spoke of it as engendering a 'positive attitude' and continued: 'this wasn't something which we just had to meekly accept, you could take positive action to ameliorate its effects and I like the sort of optimism that was generated'. Georgina spoke of being given a 'toolbox' and the confidence to use the tools to create a 'Heath Robinson Fix'. Jenny spoke of being able to be more confident in that things she had found out for herself as these were being confirmed on the course and Terry found the course 'reassuring' in that he was doing '95 per cent ok', later adding, 'there's a lot of reinforcing that my behaviours were right, and even where they perhaps weren't right, they weren't far wrong'. Reassurance was also a theme for Peter, who attended both CrISP courses after his mother had died. Peter felt that the course has 'reaffirmed' that what he had done for his mother was 'correct', saying: 'it made me feel I'd done as much as I could'.

Audrey spoke about what we might think of as increased resilience, saying it made her feel more able to cope, to 'feel a bit strong as well' while Lesley also spoke of feeling stronger, more relaxed and more able to cope as her mum's disease progressed. For Lesley, the course helped her deal with her own self-doubt: as she put it, 'who's to say I'm going to be a good carer?...maybe I'm not good at this'. She reported that she now felt 'on a much more solid basis', both in terms of what she knows and where to go if she didn't know and while admitting that she still has 'issues in certain aspects of care', she declared: 'I've astounded myself with what I have managed, and I'm quite proud of what I do...' and that while she knew her mum's dementia could develop into different areas, and this made her fearful, she was now 'pretty confident' that she could manage.

It is clear from many interviews that much of this increased confidence and resilience comes not just from the information and support offered by the tutor but from other course participants. Georgina expresses this clearly when she compares information from books with information accessed through discussion on the course:

it was actually talking through...the basic understanding of what dementia is and how it affects, and a lot of the stuff, I'd got from books...But for me 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.

Lesley describes this combined information and support offered by the course as 'therapy', something she would have liked to continue with:

when a new subject was discussed, when we had overheads and slides and what have you, bullet points and discussion points, we were given plenty of opportunity to talk. And that is so important because 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, (short pause, slight strain in voice) and you kind of hold all of that inside, you know, and feeling as I did there, secure and safe, I felt very able to, erm... It was therapy. It really was a therapy session. And I haven't had that opportunity since, and I miss that.

Not all course participants felt this way about the information and support combination provided by the CrISP course and its ability to increase confidence and resilience. It is important to acknowledge that, for a minority, information, especially when not seen as particularly relevant to individuals' own situations at the time, can actually be perceived as frightening, leading to increased anxiety which would need to be carefully managed. This was particularly the case for Colin and Jack, as was discussed under the section 'timeliness of information', above, as well as in Section 2.

### **3.6 Summary**

- Information is a necessary and important part of supporting carers in caring for people with dementia.
- Information can be provided and accessed in many forms and communicated in many ways. CrISP participants really appreciated having lots of written information, largely because they felt they could look back at it when needed.
- Some experienced the quantity of written information provided as being unmanageable and had interesting suggestions for collating information- for example, into a handbook with index. This would be a possible alternative to web-based information for those less comfortable using the internet.
- Very few participants had made use of social networking sites and other web-based tools for contacting and sharing information with others carers but it might be an interesting option to explore in future CrISP type courses, given the value placed on learning from others.
- Visual information was found to be extremely important and more memorable than written information; the 'bookcase' image was recalled by many and shared beyond the group.
- Structured forms of information- such as handouts and leaflets, had more value to participants when discussed and made meaningful in the context of specific lived experiences shared on the course.
- Experiential knowledge was valued above all others forms and led to the solving of many practical problems faced by carers in the caring situations they encountered.
- Participants found learning about the disease and its progress to be extremely valuable, especially when it was used to think about why particular behaviours were occurring.
- Learning to see the world from the perspective of someone with dementia was found to be really helpful, especially when that understanding led to the development of new ways of doing everyday things, making caring easier.
- The timing of information was critical to its perceived value but this did not work in the same way for all participants.

- Some participants were happy to have information in advance of the need to put it to use; others would have preferred to only access information as and when needed.
- Some found information about future possibilities not only unnecessary in a practical sense but emotionally inappropriate too.
- The need for 'refresher' courses was identified by many participants- both to revisit information and knowledge as it became relevant to their situations, but also to reconnect with other carers who they missed once the course was over.
- Information has a strong emotional impact. This can be both positive and negative.
- For many, having information, especially when provided or generated in the context of a supportive course for carers, made them stronger, more confident and resilient.
- Others felt more overwhelmed and anxious when confronted by both factual information and others' lived experience of dementia.
- Some carers tried to keep written information away from those they cared for, for fear of upsetting them. This is another reason why accessing information in the context of a course aimed solely at carers is preferable to it being sent to carers' homes, for example.
- The 'safe space' offered by CrISP courses was appreciated by all but the most private of people.
- Information, when provided in a caring and supportive context, is much more likely to be beneficial than offering handouts or website addresses alone.



## Section 4 : Dealing with service providers

One aspect of carers' experiences is what can often be a difficult process of securing appropriate help and support from service providers. The interviews provided a picture of some of what that experience had been for these carers.

The services that carers interacted with included GPs, psychiatrists, geriatricians, mental health specialists, community based health and social care staff, social workers and staff managing and running nursing homes. Part of the complexity of carers' experiences was the number of different service providers that they had to interact with, and the fragmentation of the health and social care system, making it difficult for them to put together the combination of care they needed.

In this section we explore examples of carers' experience of service providers and how they viewed their knowledge about dementia. We look at routes through services, the kinds and level of services received and the support from the Alzheimer's Society. Finally we look at the impact of the course on negotiating the system.

### 4.1 Knowledge about dementia

An important theme in carers' narratives was the variable knowledge of dementia that they encountered in their negotiations with service providers. The two significant groups mentioned by carers in terms of their knowledge of dementia were GPs and specialists.

The first contact point for most carers was their GP. Generally GPs were not seen as particularly knowledgeable about dementia although this was not necessarily seen as an issue by all carers. There was an acceptance by some that they were *general* practitioners, but significantly GPs were seen as the *doorway* to diagnosis and specialist support and services. A number of those interviewed made an association between the long term nature of the relationship they had with their GP and the level of support and understanding. These carers felt less worried about their GPs' actual knowledge of dementia as long as they were responsive to the person with dementia and knew where to refer them. Their ongoing knowledge of the person with dementia and their other health conditions also helped carers by ensuring that the day to day medical needs of the person with dementia were not ignored once a diagnosis of dementia had been given:

The GP was excellent, she was fantastic and she cared for dad and was very fond of mum and dad and she was aware that I would have to have a lot of support to support mum. So she was a very good sounding post and would, any questions, if she didn't know the answer she would try to help out. (Maureen)

What was an issue for a number of carers was where the GP was dismissive of *their* knowledge and understanding of the person they cared for, or where the tests done did not reflect the carers' day to day experience. Audrey and Georgina were both caring for their mothers. Audrey felt that it was only when her brother got involved that she was taken seriously and had great concerns about the level of training GPs were given, an issue she came back to more than once:

and he sort of said, 'oh you know, she's just down in the dumps, bit of blues or Christmas and all that' so just didn't take no notice for a bit longer.....yeah, because my brother had to take her back again and he said, 'I'm not happy with this, I think it's something else'. 'Okay then', he said, 'we'll send her up to the hospital and get her an appointment'. It's only because my brother pumped for it, that's why I have not... No, he's a very nice doctor and that but he's got no idea what dementia is about and all that because as I say they haven't got the training, they haven't trained enough(Audrey).

Georgina felt that the GP surgery had labelled her a 'neurotic daughter' because she was insisting on proper assessment for her mother:

knowing something's going wrong and the doctor just saying 'No there isn't', and you're like 'Yes there is!' and then you think 'is it me?' You know, and no one else seemed to be seeing the behaviour I was seeing (Georgina).

Anjali and Susan were younger wives of older husbands and both felt they had to push to be taken seriously:

And I'm saying 'No, it's more than that, please read my notes and check. His walk has gone, his memory is going funny (sounds upset) he's being very difficult about various things, you know, nobody's bothering, please, please, please' (Anjali).

and it, you know, to start with it was very, very difficult because nobody would say what was wrong with him, everybody said I was imagining things (Susan).

Interestingly Jean's husband Clive, who was the only person with dementia able to take full part in an interview, echoed this from his own experience and spoke also of feeling patronised by the medical people he had seen:

and not only our doctor but the majority of the medical practitioners seem very (sighs) I can't think of the word but they didn't want to accept that I was like this, you know what I mean? They seemed to deny that 'oh there's nothing wrong with you, you all get like that when you get to your age', you know (Clive).

Getting through to specialist assessment was of particular concern to those who wanted to access whatever drug treatment was available as early as possible. From what carers told us, about a third of the people with dementia were on Aricept (or an equivalent drug) and of this group at least three carers had had to go to their MP (in more than one area) in order to get access to the drug therapy:

and then I obviously wanted to get her onto whatever medication was available and that was another battle because although the consultants and the surgery agreed that medical help was required, there was a ding dong about who should pay for it. And it was eventually only satisfied when I went to see my MP (Jack).

The issues for carers with specialists were slightly different. Carers valued the detailed medical knowledge that specialists had, but had concerns about how that detail was imparted to them. Some

carers felt that how the diagnosis was given to them by specialists was very clinical and couched in medical terms that they did not understand:

when we went along for the actual session with the consultant we were just confronted with this and I found the whole thing completely unsympathetic and, um, considering that most people have obviously no conception of what this is really and what it involves, I thought it was all rather quick, you know, and to the point. And I think he did have a secretary or somebody in sort of making notes while he went through this with Robert but it, I don't think Robert really comprehended what he was saying and I didn't either (Deidre).

A number also spoke about not being given enough understanding of the exact diagnosis or what the future would look like for the person they cared for:

when you're just told at the Memory Clinic, 'He has dementia,' or, 'He has Alzheimer's,' or whatever, you perhaps always think worst case scenario. And we didn't really get that from the Consultant, what (pauses) the future was (Terry).

Lesley talked about her concern about whether her mother had been assessed by the right specialist 'I was a bit concerned because I thought, you know, psychiatrist, is that the right person to be looking after somebody with dementia problems?' However after a couple of visits she felt there was a more positive discussion which resulted in a clearer diagnosis:

he said, 'Well, it's, you know, obviously some form of a dementia' and I said, 'Well, can we not narrow it down a bit more so that we know if it's Alzheimer's or dementia, because' I said, 'I know that they are different things.' And eventually he agreed for my mum to have a scan done, and then we went back to see him after the scan, and then he said, 'Your mother has a vascular dementia.' So we then had a label (Lesley).

Having an exact diagnosis was important to most carers. When they came to do the CrISP 1 course there was explanation of the different kinds of dementia and their symptoms and many of them spoke positively about how they were then able to relate the *label* they had to the information that was made available to them.

Once they were through diagnosis most carers felt the staff they dealt with in the community were much more knowledgeable about dementia and all carers spoke about the positive support they had from a variety of staff who helped them to understand how best to manage on a day to day basis. In many cases they had been able to help with accessing care services and respite as well as supporting carers and helping them make connections and get benefits.

These practitioners were described by one carer as a 'lifeline' for them. Susan talked about the Community Psychiatric Nurse (CPN) who helped them to get Attendance Allowance, while Audrey felt her CPN had helped her 'feel strong' in herself when she had felt that she was not going to cope. For Lesley there was a Mental Health Care Co-ordinator who they were still in contact with and in Sarah's area the key practitioner had been a Community Matron affiliated to the doctor's practice.

## 4.2 Routes to and through services

The services in the seven areas were configured differently and it was not clear from carers that they knew exactly who ran which services. It was difficult for many of them to know they were getting access to what was available unless they had some help, and there was certainly concern on the part of some who felt that they may have missed out on services. The length of time since diagnosis did also seem to be a factor in this as it was clear that services had been being developed and reconfigured in some areas quite recently in response to dementia service needs and priorities.

The structure and delivery of services also varied, particularly between town and rural areas, and this made it difficult for carers to know where to go, where staff were coming from and the local context of delivery. In one area there was the added complexity that the local authority and health service boundaries did not coincide.

In some areas there seemed to be much more direct and obvious routes through memory clinics based at hospitals or community based mental health services. Many, but not all, of these services would also make direct referrals to the local Alzheimer's Society who then predominantly got in contact with carers directly. The nature of diagnosis also determined whether there was ongoing CPN support and those who were on drug therapy had six monthly monitoring from hospitals. In some areas there were day centre and respite services that were well known and a number of carers were in contact with them and supported through them.

Carers' accounts suggested that once diagnosis was given, but they were still in the early stages, finding their way through to services was a bit hit and miss. Some were very unclear how they were linked in. Linda describes being unsure about whether she should be asking for help or if it should be being offered:

Having said that I do think a little bit, um, once you're diagnosed, and again I suppose it's up to us, but you're sort of left to get on with it then.....

.....we go to our own GP who takes his blood pressure and she does say, you know, 'Is everything all right'. But I don't know I'm not sure, I'm a bit torn I suppose where, I'm quite happy really for us to deal with stuff as best we can until such time as we need outside help. And sometimes I get a little bit, not on my own, but should someone else be asking for something or should I be asking them something? (Linda).

In two areas carers had come into contact with services through being referred after diagnosis into courses for people with dementia and their carers which seemed to be co-ordinated through local and health authorities. In a small number of cases carers had clearly found their way to services through other more general elderly or carers organisations like Age UK, Carers Centres or St John's Ambulance.

The community staff who connected with carers and people with dementia varied in and within each area. Key staff mentioned were an Admiral Nurse (Terry), a CPN (Audrey and Susan), a Mental Health Care Co-ordinator (Lesley) and a Community Matron (Sarah). The difficulties recounted by carers in finding their way to supportive services, and the differences between areas in terms of service configuration, indicate the importance of information about services, but also the difficulty of producing generalisable information that will be useful across different locations.

Susan talked about her difficulties in getting services to accept that her husband had dementia because they claimed not to have been notified. She asked the CPN for help and as a result was able to get copies of the official documentation she needed to be taken seriously and to get the services she needed.

There was significant complexity for a small number of those we talked to where there was a diagnosis of dementia on top of a long running mental health illness. For these people with dementia and their carers having to negotiate two routes to services was hard. Jenny cared for her father who had a history of depression which had made the management of his dementia difficult and, on occasions, confusing. At one point he went into a life threatening crisis and needed immediate support. Not knowing where to turn she described finding the right service, a specialist access service for older people, which she hadn't known existed. She felt it was important that 'we should know more about these places' and was grateful that after a series of examinations it was agreed that her father be admitted to hospital as his depression was significantly worse.

Pauline, on the other hand, describes the limits to what could be offered to her husband Francis, whose depression was deepened by his diagnosis of dementia and who had talked about and did finally decide to take his own life:

It's not good saying 'Francis, don't be silly.' I just let it go, and I told Dr [name] the first time round, and he made a special appointment and increased his dose of antidepressant, but that's all he could do (Pauline).

Carers came into contact with the Alzheimer's Society through different routes, but once in contact with them many carers were actively supported to find the services they needed. Some found their way to them themselves even before diagnosis, particularly those who were information seekers in the early stages:

it didn't take long for the Alzheimer's Society name to come up..... having discovered that they were just around the corner from me I called in here and had a preliminary chat which was very helpful. I did it again about three or four months later (Jack)

In some areas information about the Alzheimer's Society was given at diagnosis or at memory clinics and in a number of areas a direct referral was made which the Alzheimer's Society staff then responded to. In some areas the Alzheimer's Society were based in the same building as the Community Mental Health Services so there was an immediate connection made but this was a very different experience for those in more rural areas where the geography led to both statutory and voluntary services being situated more widely apart.

A number of carers voiced concerns about the need for services to be better co-ordinated. Anjali who had experienced huge frustration in getting both a diagnosis and then care for her husband voiced how she thought services should be:

if there was some kind of a central hub where you had everything. If you contacted one, it would just trigger off to the others and they'd actually, whether you wanted it or not, even if they just sent you a letter saying 'Right, do you want our assistance?' How much, you know, ease of mind that would bring, don't you think? (Anjali).

### 4.3 Nature and amount of support received and changes in that

Where carers were offered CPN support this seemed to taper off after a couple of years in some areas. In the case of both Audrey and Susan they were aware that this was to do with service reductions. Audrey was concerned that she would have to go back through the GP to get the service again:

Oh, for a couple of years we had a CPN nurse, very lovely lady she was, yeah, but now she's gone..... this lady phoned me from the mental health act, oh you seem to be coping quite well, I said well there'll be a time when I won't be able to cope well. Well, you know, your mum goes to day centre three days a week, your brother comes in, your aunt comes in, oh I think you seem to be okay. I went, oh so that means we won't be getting anybody? Well, I don't think you require anybody. I went, oh right okay, so what happens in an emergency situation? You have to go through your doctor (Audrey).

Susan was more understanding of the reason why the service had been stopped. She had recently asked for a reassessment for her husband David and was now getting the CPN support again:

From, you know, they said, 'Oh, you know, we're not actually helping you with anything at the moment so we're so short staffed so that as we're not helping you it's better if we see someone who is in desperate need of help that we can help' so I suppose you can understand it (Susan).

In some areas there were clear links to day care and respite provision and carers seemed to be able to work through reassessment with the staff there to increase or decrease the service or to move between specialist and more generic services. Jenny discussed how she and her father worked through a change in day care with the staff:

we had a talk together at [name] and my father's needs obviously had changed, they felt my father's needs had changed and he had become as they described it more mainstream, so we discussed this at length and my father was, found a place at [name] (Jenny).

Geoff felt that by the time his father got to day care it was too late and mentioned that spaces didn't seem to come up unless someone died:

cos I think when he should have went to [name] Day Centre he was past it then, when he went to the coffee club and they then said he could move into the day centre, I think you had to wait for somebody to die off before you could get in, the coffee club was a feeder into it. But really he should have been in that years ago (Geoff).

Social services staff were generally seen as under pressure and a number of carers clearly felt that accessing their services was more bureaucratic and that services were subject to financial limits.

The expectation that both Linda and Julie had, of being able to register with social services in some form in advance was not met:

getting Walter and me looked at by the Social Services because they used to, as far as I know, used to come and sort of have a chat so you were like on their books albeit you didn't.....and apparently they don't do that anymore (Linda).

So there's no one, and I was surprised actually, I thought there would be somebody, I suppose in this day and age you can't expect it but allocated to you, I suppose even if they are allocated to you the chances are you wouldn't see them (both laugh) very much. You know, with the funds being what they are (Julie).

Deidre and Maureen were both waiting on reassessments at the time of interview. Deidre had received a phone call from her social worker recognising how long things were taking but reassuring her that she was 'getting on with it'. Maureen, who needed the social services assessment before her mum could be given a place at day care, recognised 'how stretched they are and how time is very important' and felt that she 'wouldn't want to call on anyone if it really wasn't needed'.

Georgina also described the pressures she felt Social Services staff were under in her area:

So we have one Social Worker who works for us mainly, who has been off sick for the best part of two years, off and on. Lovely lady. She gets really upset (laughs) because every time she comes to meetings we're all like 'You alright?' She said 'It should be the other way round', but because of all the hassle, I mean, most of our team have been off sick a lot, and I'm sure it's stress related (Georgina).

Anjali's experience was of social services being too bureaucratic

I felt, you know, somebody's identified something, now come on, take that load off my shoulders and push which is why I was not too pleased with my care coordinator. I mean I know she has about 25 people to deal with but..... I was getting a little pissed off with all these, 'Can I come and see you and you talk it over? Shall we do a review of this? Shall I write out a new?' (Sighs) Oh God, the paperwork (exasperated noise) please! (Anjali).

There were a number of carers for whom social services staff had been a key help to them in times of crisis. Geoff had a social worker who encouraged him to let his father be taken into the respite care that helped to reverse the depression he was feeling as a carer:

Yeah, so he would come and he said to me, he says, 'Looking at you' he says, 'you need some respite, and because you don't want to accept the fact that you need a rest' everyone can see it but me and I was just looking after him each day, I was with him 14 hours a day (Geoff).

#### **4.4 Support from the Alzheimer's Society**

Overall, carers had very positive experiences of the Alzheimer's Society and the local services they offered. This caused them to look favourably on the course and on the Alzheimer's Society in the role of a *trusted provider*. Carers characterized the local Alzheimer's Society services they had experienced in a number of ways: supportive and encouraging; available and flexible; experienced and knowledgeable; and non-medical. We discuss each of these, in turn, below.

For some carers the support they had been offered by the Alzheimer's Society and the way that staff had helped and encouraged them in difficult decisions was important:

We had an awful lot of support during that time, wonderful support from the Alzheimer's Society, come and do some home visits to talk to my mother about obviously giving her a broader picture of the reality of father coming home and it was wonderful because it was the lady that came who put that to my mother, the decision has got to be yours, you will have the support, if you say you would like your husband home (Jenny).

Lesley felt the level of encouragement and emotional support she received contributed to her feeling more confident to make an appeal for Attendance Allowance:

they gave me emotional support with that. They weren't able to offer themselves as a support in terms of getting the application passed, but certainly they said, 'No, you try,' you know, 'You have another go,' Erm, and I can't say categorically that that made a difference, but it certainly contributed to me, you know, having that strength (Lesley).

Victoria, who did not read English, explained how the Alzheimer's Society Dementia Support Worker developed a personal relationship with her through visiting her at home. This relationship helped her to feel confident to go on the CrISP course and to deal with her own feelings about having to let her husband Maurice go into care when his behaviour became too difficult for her to cope with:

Oh yeah, oh yeah, she really did and come to my house.....You know to talk to me properly because she know and she said to me 'look Victoria, I come to you', she said 'because your home and you're relaxing in your house', she said 'any day', she said, 'because maybe you're not relaxing properly'. And I'm so pleased because I make them a cup of coffee and a cup of tea for me and we sit down and we talk about it and it was really, really lovely, like I know them for years and years, it was so lovely (Victoria).

The Alzheimer's Society stepped in to help Anjali when she had almost given up hope of getting anywhere with a diagnosis for her husband Michael:

And finally I, you know, not having any information or anything I just thought of Alzheimer's Society, found out where they were, and I'd written up notes as to what I'd been observing so I had about two rows of three sides of A4 and I took it and I gave it to them, I made photocopies of this, handed it over to the GP's and everyone ("waver" in her voice) I could think of and Alzheimer's were the only people who actually made an effort. They contacted the GP, they contacted the memory service and finally, after two years, took about to um, when was it? Um, January, two years ago to finally get him diagnosed (Anjali).

Carers spoke about the availability and flexibility of the organisation. This was both the preparedness of staff to visit them at home, and the availability of phone advice and helplines:

and she said, oh yeah, yeah, always be there she said and they've got a helpline anyway that's open..... seven days a week so, yeah, got all that helpline if I needed advice or help(Audrey).

Colin spoke about seeing the Alzheimer's Society as 'fairly unofficial' which meant he felt able to negotiate the best way to inform himself whilst, as we have seen, protecting his wife Mary from the knowledge of her condition which she was finding it hard to accept.

Carers had confidence in the detailed and specialised knowledge of the Alzheimer's Society and in their practical understanding of the challenges of dealing with dementia. Audrey said: 'they do know what they're talking about, they've dealt with people or they've had family haven't they' and Linda said that she would 'stick with something like the Alzheimer's Society' assuming because of 'what they are and what they do' that they would always be a good starting point.

The fact that they were knowledgeable about dementia but were not health services was also important. Both Alison and Lesley felt that because the Alzheimer's Society was not 'medical' it was un-threatening as an organisation and gave people confidence to ask all those difficult or 'stupid' questions or to talk more freely.

Alison's route through services had been predominantly with support from mental health staff. She felt that if she and her family had been pointed towards the Alzheimer's Society earlier it would have been easier for all of them. She talked about feeling that those 'stupid' questions that she needed to ask to understand what was happening with her father would have been easier to ask of the Alzheimer's Society staff who she felt had more of the day to day experience that would be helpful to her:

asking them what are not stupid questions but could be termed as stupid questions when you're not necessarily in control of the facts. You know my dad's saying such and such, what does this mean? Well had I been in touch with the Alzheimer's Society I could have rung them and said 'Look, you know, what do you think?' (Alison).

Lesley talked emotionally about how a long running relationship between Alzheimer's Society staff and her family had helped. Again, she felt that not having a 'medical connotation' meant that her father had been able to talk to the Alzheimer's Society more openly. That helped him and was now supporting her in the care of her mother:

really the Alzheimer's Society were a lifeline to my dad at that point, erm, because he sort of... I don't know what it was about the organisation, but I think because it didn't have a medical connotation to it he was very happy to talk..... he valued the input that he had from them very much. And they have continued to be supportive when I took over (Lesley).

#### **4.5 Impact of the course on negotiating the system**

Within the context of these different and varied experiences of finding out about what is available, negotiating for services and support and feeling confident that they had the right knowledge, carers spoke about how CrISP had helped them. They recognised that they might not be able to solve all the problems they had recounted, but felt an increased confidence to ask for services and to be assertive in getting what they thought was needed both for the person they cared for and for themselves as a carer.

Thus, Deidre felt the course made her 'more aware' of what she could ask for and Geoff definitely felt it helped him 'ask the right questions'. Jenny felt that the knowledge from the course and her

own efforts to find out more, particularly about the issues for people with mental health problems who develop dementia, had given her confidence as her 'understanding' was greater:

Yes, I feel more confident in approaching them, far more confident and I feel, I've found that a part of that is the knowledge that I was taught on, you know, on the course as well as my own, coupled together has given me the confidence to go out and speak more, 'cos my understanding I think has got greater (Jenny).

Linda felt that having knowledge helped her to assert her needs for information or help:

I suppose it helps because you've got that knowledge behind you but when you don't know anything at all to go somewhere and ask for information or help or whatever, you're a little bit at their mercy where you could be a little more secure, a little bit more confident in what you're asking. Because you've got that behind you, you know (Linda).

Most of the carers talked about feeling more confident because of the course and in particular a number spoke about not just feeling confident but feeling more 'powerful' in their situation and being able to assert themselves and to advocate for the person they cared for. Lesley felt the course had 'empowered' her 'to push forward' when she thought they were entitled or had a right to something, and Susan also felt that she would 'push more' for what her husband needed. Alison felt she would 'fight for' her father more and illustrated this by saying that the course 'gave me the power to say to them, "Okay, (bangs something) what is happening? I want to know what the situation is" '. Jean talked about recognising that it was important for Clive to continue having his own relationship with his GP but how she would step in now when needed:

I don't always go with him, I let him go on his own but when I go he (GP) knows it's going there's going to be trouble (sounds amused) but not trouble that I'm going in and be nasty but something I want....so I do follow those things up yes (Jean).

Finally, Rosemary's husband Laurie, who supported her in caring for the two members of her family who had dementia and with whom she had shared the information and experience of the CrISP course, described a situation where he stepped in to deal with social services in a crisis in a way that he felt they would not have done before because they had more understanding now of the role of Social Services:

It got so bad on one occasion, you was tearing your hair out and I rang Social Services and said 'You need to deal with it'. 'Oh we can't, we haven't got the manpower' .....and I had to threaten to take Rosemary out of the equation for them to do something, and I shouldn't have to do that, but she was my first priority, because I knew if I pulled Rosemary out Social Services would deal with it because they have to, and they did, but we didn't know that the first time round (Laurie and Rosemary).

#### **4.6 Summary**

- Carers did not perceive GPs as particularly knowledgeable about dementia and many felt that their own experience of the person they cared for was unrecognised in the process of diagnosis.

- GPs with a longer term relationship with the family were perceived as being more understanding.
- Carers experienced consultants and specialists as giving limited information about the progress of the disease and valued having a clear label and being referred quickly for appropriate drug therapies.
- Community-based staff were seen as much more knowledgeable about dementia and the day-to-day challenges of living with it and were described as 'lifelines' to carers. These staff were in different roles and agencies in different areas.
- The difficulties recounted by carers in finding their way to supportive services, and the differences between areas in terms of service configuration, indicate the importance of information about services, but also the difficulty of producing generalisable information that will be useful across different locations.
- Levels of support could vary and were withdrawn or reprioritised on occasions. Carers did not always know whether, or at what stage, to ask for help or for re-assessment and this was important where services were under pressure and took some time to respond.
- The Alzheimer's Society staff were experienced positively by carers as supportive and encouraging, available, flexible, experienced and knowledgeable. In particular being seen as 'unofficial' and 'not medical' made carers feel comfortable with them and likely to approach them as a *first port of call* for services and information.
- Carers felt that the impact of the CrISP courses had been to increase their knowledge and understanding of dementia and how to care for someone with the disease. This enabled them not just to cope better but to feel more empowered and confident in their relationships with service providers so that they were more able to be assertive when seeking for what they needed for the person they cared for and for themselves as carers.



## Conclusions

CrISP was designed to provide carers of people with dementia with information and support to help them in their caring role. Thus, emphasis was placed on both increased knowledge, skills and understanding of dementia *and* on the importance of providing this in a context where participants could gain from both peer support and shared learning. The agreed objective of the external evaluation was to understand the qualitative and subjective impacts of CrISP on carers and on their caring relationships. In particular we sought to consider how information provided in the context of a supportive environment might contribute to more effective care giving and more positive caring relationships.

Our findings confirm the value of information as a resource to enable carers both to care well for others, and to recognise their own needs for care. But they also demonstrate that if information is to be experienced as helpful it needs to be shared in a context in which it can be explored with others, and that the emotional impact of information needs to be understood in the context of the emotional experience of caring. Carers valued the new information and increased knowledge about dementia and its progress that they gained from participating on the course, reporting that it helped them to improve their ability to care well - both for themselves and those they cared for. They also valued highly the peer support they gained from participating in the course and their accounts suggest that this 'support' aspect of the course was inseparable from the 'information' aspects, both because of the emotional nature of caring and the caring relationship and because access to new information, whilst often empowering, can also be upsetting and difficult to digest and act upon.

Caring is a complex experience that relates not only to the understanding that carers have of dementia and its effects, but also to the nature of the relationship they have with the person they care for, to their own health, the extent to which they experience being supported in care giving within their own personal networks, and their capacity to secure help from service providers. Our analysis considers the impact of CrISP in these contexts.

Carers felt that developing a better understanding of dementia and its impact on perception and behaviour in particular enabled them to develop skills and confidence in supporting the person they cared for. Being more confident that what they were doing was OK was as important as learning how to do things in new ways they had not previously thought about. Visual information was found to be extremely important in developing this understanding and more memorable than written information. Carers reported that learning to see the world from the perspective of the person with dementia improved understanding within the relationship they had with the person they cared for and helped in developing practical caring techniques and new ways of doing everyday things.

Experiential knowledge was valued highly and led to the solving of practical problems and the development of techniques and ideas that improved carers' ability to care well and enabled them to feel satisfied that they were caring well. This experiential knowledge came from tutor and information input but more significantly from other carers in the group. A number of carers commented that they had received validation for their own ideas and practical ways of coping by sharing them with other carers and receiving positive feedback. The reciprocity of the relationships within the groups was important to many of those we interviewed. Carers' responses emphasised the close connection between feeling understood, being in a safe environment, and being with others who were facing similar challenges, and experiencing benefit from the information that was provided. The minority who did not identify specific benefits, or who suggested negative impacts from the course, were those for whom the course did not feel safe because they felt exposed to information and experiences that caused pain, or because they felt little need to share with others.

For the majority, it was the 'therapeutic' nature of the course that contributed to the value they experienced from receiving information. This also meant that the ending of the course was in itself a loss – its importance was not completed by the communication of useful information, but by the opportunity to continue to share ongoing learning about how to respond to the evolving challenges of dementia. Overall, the interviews highlight the necessity to understand information not simply as a cognitive or practical resource, but as something that can have an emotional impact that can be both positive and negative.

Carers really valued the amount of written information they were given on the course(s) and appreciated having it as reference material to look back at. Many commented on difficulties in organising and collating the amount they had and felt they were not making use of it in an ongoing way. Suggestions were made about more structured ways of storing and retrieving it, for example as a manual or handbook with an index. A small number of carers were overwhelmed by the amount of written information given out and had found that following up the course sessions with one of the Alzheimer's Support staff had enabled them to assimilate it better. Interviews demonstrated the different strategies carers preferred for accessing information, but what was common was the importance of being able to discuss information with others in order for it to 'come alive'. Some responses suggested there may be value in developing on-line networks as a way of enabling such exchanges to take place when face to face interaction is not possible.

The timing of information was critical to its perceived value by carers. Not all wished to receive information in advance of when they saw themselves needing it. For some this was a practical issue, for others it was about being able to retrieve it when they did need it and for a few it was that the nature of the information had too powerful an emotional impact for them at that time. Carers had limited capacity to use the material and experiential resources gathered during the course to develop their knowledge and understanding once the course had finished. People identified the value of follow up in terms of refreshing knowledge and understanding, as well as on-going contact to provide the support that they had valued.

Decisions to take on caring responsibilities relate to the nature of pre-existing relationships and spouses usually feel that this is much less of a 'choice' than do sons or daughters. In some cases filial carers saw access to information as an important factor in decisions about the extent of caring they felt able to offer, and there was some indication that the course might be used as a way of developing expertise to be used in paid or volunteer capacities beyond the immediate caring relationship. There was also indication that information was being shared beyond those attending the course. This sense of 'becoming expert' could also impact carers' confidence in their negotiations with service providers and with others in an actual or potential caring network. It led them to be more confident in their own understanding of the needs of the person they cared for and more assertive in seeking what they needed for them and for themselves as carers. However, these findings were limited and for the majority the focus was almost entirely on the all-consuming nature of the relationship with the person they cared for.

The CrISP courses were designed to respond to the often articulated need for better, more complete and timely information: about services, about entitlements, about the nature of the illness and about effective strategies for relating to someone whose behaviour and indeed personality may have changed as a consequence of dementia. What our interviews demonstrate is that access to information can indeed have a beneficial impact, but that it would be naive to conclude that information can solve the problems carers experience. Our findings also emphasise the importance of recognising that information cannot be understood simply as a neutral resource. It is vital that the programme is understood as both an information and a support programme as its name implies.

## Appendices





**Dear Carer**

**Learning from the Carer Information and Support Programme (CrISP)**

I am writing to you because you took part in a series of sessions that were part of the Alzheimer's Society programme to improve the information available to carers of people with dementia.

We know that carers often say that they need better information – about dementia, about services and the supports that might be available to them. The Alzheimer's Society wants to find out from those who took part whether this programme made a difference to the experience of being a carer.

The Alzheimer's Society has asked researchers from the University of Brighton to carry out an independent evaluation to explore this. The researchers have experience of working with carers, with people with dementia and are familiar with the importance of good quality information. I do hope you would be willing to talk to them about your experience of the programme and the impact this has had.

Accompanying this letter is an information sheet from the researchers that tells you more about what the research involves. If you would like to take part in the research, please fill in the form overleaf and return it by post to:

Naomi Smith  
Social Science Policy and Research Centre  
University of Brighton  
Falmer  
Brighton BN1 9PH

If you have questions before deciding whether to take part please ring Naomi at the University on 01273 644530 and she will be happy to talk to you. You can also email her at : [nms4@brighton.ac.uk](mailto:nms4@brighton.ac.uk)

We hope you will agree to take part in this study, but be assured that, if you decide not to, this will not affect any support you may get from the Alzheimer's Society now or in the future.

With many thanks and good wishes.

Dr Jane Tooke  
Service Evaluation Officer  
Alzheimer's Society





**CrISP External evaluation contact information**

These details have been sent to you by the Alzheimer's Society. If you would be happy to take part in the research please complete the following and return this page to **Naomi Smith, SSPARC, Room 229, Mayfield House, University of Brighton, Falmer BN1 9PH** in the stamped addressed envelope provided.

Your name

.....

Your address

.....  
.....  
.....  
.....

Your phone number

.....

The name of the person you care for

.....

Their relationship to you

.....

Whether they live with you or if not where they do live

.....  
.....  
.....



## **Learning from the Carer Information and Support Programme (CrISP)**

### **Carer information sheet**

#### **What is the study about?**

This study is about the effect that the Carer Information and Support Programme has had on people who have participated in the workshops. The Alzheimer's Society has asked the University of Brighton to carry out an independent evaluation to find out what impact the programme has made on carers' experiences of caring for a relative or friend with dementia. This is important in thinking about how to develop the programme.

#### **What will be involved if I agree to take part?**

We will ask you to take part in a face to face interview. We will arrange a time for this that suits you and that is possible for us in terms of travelling to meet you. We would like to carry out the interview in a local venue used by the Alzheimer's Society, but if this is not possible we can discuss an alternative, such as your home if this was suitable. If required, we will discuss with you whether the person you care for can be supported by someone else whilst the interview takes place.

If you agree, we will record the interview and produce a complete record of this to use in analysis. The interview will take at least an hour, but may be longer if there are lots of things you want to talk about.

The study is focusing on carers' experiences. But in a small number of cases we would also like to speak with relatives or friends with dementia. We will only do this if both of you agree. If you think this might be a possibility in your case we will also provide information about the project for the person you care for and ask them if they would agree to take part. In that case two researchers will visit so we can talk to both of you.

#### **Will taking part be difficult or cause any distress?**

Our approach will be to invite you to tell us your story of becoming a carer and then to follow up with specific questions about the sort of information the programme enabled you to find out and what effect this has had. If you do not want to answer any specific questions, or you want to stop the interview at any time that's fine. We hope that we understand enough about caring for someone with dementia for the interview to be an opportunity to reflect on what impact the programme has had on you and for us to minimise the distress this may cause.

It can be hard to care for someone with dementia and we realise there are times when it can be upsetting to talk about this. Taking part in an interview may cause you to think about things that can make you upset. As you have taken part in the Alzheimer's Society Carer Information and Support Programme we are unlikely to ask you about things you have not thought about or talked about to others. But this is one reason why it might be better to meet somewhere where other people you know are around.

#### **What will happen to what I say?**

We will be writing a report for the Alzheimer's Society in which we will consider how the Programme has impacted on carers' experiences of caring for someone with dementia. In this report we will include quotes from interviews. We will not use people's real names when we quote them, but we will invent names for people as it often brings a report to life to do so. So, for example, if your name is Mary Jones, you may be Susan Evans in the report.

We will include some brief information that is relevant to understanding people's experiences. For example, 'Susan Evans is 75 years old and cares for her husband Reg who was diagnosed with Alzheimers 2 years ago. They live together in the centre of a large city and have adult children living nearby.' As this example illustrates, we will not include specific information that directly identifies people, although if you are well known to the local Alzheimer's Society, a few people may make guesses.

We will write a short summary of the report and send this to you, and we will ask the Alzheimer's Society if they can give you a copy of the full report if you want this. We may also publish articles for others interested in the impact information can have on carers' experiences. These will also use the invented names and it is highly unlikely that anyone reading these would be able to identify you.

Once we have completed the report we will destroy the recordings of interviews. We will keep the transcripts for 10 years. This is in line with our university policy. The transcripts will be kept on computers that can only be accessed if you have the password.

### **Research Ethics**

It is important to us that we carry out the research in an ethical manner. We have had agreement from the ethics committee at the University of Brighton to carry out the work in the way we have described. The Alzheimer's Society is also happy about the approach we are adopting. We will reflect on any ethical issues that may come up as we carry out this work and if there are issues you want to raise with us as we do the research, do let us know.

### **Who are we?**

The team carrying out this research are: Marian Barnes, Professor of Social Policy, Diane Waller, Principal Research Fellow (Emeritus Professor of Art Psychotherapy at Goldsmiths), Flis Henwood, Professor of Social Informatics and Naomi Smith, Research Fellow

If you want to talk to anyone outside the team about the way in which we are carrying this out, please get in touch with Professor Phil Haynes, who is the Head of the School of Applied Social Science at the University of Brighton on 01273 643465.

Thank you

## **Learning from the Carer Information and Support Programme (CrISP) - Information sheet**

We are researchers from the University of Brighton.

We have been asked by the Alzheimer's Society to find out what people think of the Carer Information and Support Programme (CrISP) by talking to people who went on the course and to some of the people they care for.

We would like to ask you about your experience of living with dementia and the care that you need. What we find out will help us understand better the difficulties you experience.

We will talk to you either at home or at a centre where you regularly go. We will record the interview if that is alright with you as it helps us make sure we correctly record what you have said. If you do not want to answer any questions, or you want to stop the interview at any time that's fine.

We will be writing a report about what we find out. You will not be mentioned by name in the report but we may ask your permission to quote something you have said. We will write a short summary of the report and send this to you.

If you have any questions about taking part, you can phone Naomi Smith on 01273 644530

Thank you





**Learning from the Carer Information and Support Programme (CrISP)**

**Consent form (carer)**

- ◆ I agree to take part in this evaluation of the Carer Information and Support Programme (CrISP)
- ◆ The researcher has explained to my satisfaction the purpose of the study and my role within it.
- ◆ I have read the information sheet and I understand what the interview will involve.
- ◆ I am aware that I will be asked to talk about my own experiences and the person I care for. This may mean talking about things of a personal nature.
- ◆ I understand that I am free to stop the interview at any time.
- ◆ I understand that any confidential information will be seen only by the researchers and will not be revealed to anyone else. But if this information raises serious concerns about the safety and well-being of anyone the researcher may need to contact somebody who can help.
- ◆ I understand that I will not be identified personally in the report but that my words may be used as quotes.
- ◆ I agree to the interview being recorded.

Name (please print).....

Signed.....

Date.....

**Name of Researcher**

.....

Date.....

SSPARC, Mayfield House, University of Brighton, Falmer, Brighton BN1 9PH





**Learning from the Carer Information and Support Programme (CrISP)**

**Consent form (person cared for)**

- ◆ I agree to take part in this evaluation of the Carer Information and Support Programme (CrISP)
- ◆ The researcher has explained to my satisfaction the purpose of the study and my role within it.
- ◆ I have read the information sheet and I understand what taking part will involve.
- ◆ I understand that my contributions to the sessions will be recorded and used as research.
- ◆ I understand that I will not be identified personally in the report but that my words may be used as quotes.
- ◆ I understand that I am free to withdraw from the sessions at any time.
- ◆ I agree to the interview being recorded.

Name (please print).....

Signed.....

Date.....

**Name of Researcher**

.....

Date.....

SSPARC, Mayfield House, University of Brighton, Falmer, Brighton BN1 9PH



## Learning from the Carer Information and Support Programme (CrISP)

### Carer interview guide (CrISP 1)

Could you start off by telling me a bit about how long you've been caring for *name* and what your experience of this has been. In particular when you first started to care for him/her, what did you feel you didn't understand, and what you didn't know or felt you needed to know more about in order to care for him/her.

**Check** a bit of information like age and who else is in the caring network, practical circumstances etc.

Have there been any other experiences in your life that you think helped you in terms of the knowledge and information you needed?

Before you went on the course....

How did you go about trying to find out things you needed to know about or understand better?

What did you find it most difficult to get information on or to get explanations that you could understand?

Do you think these difficulties made it more difficult to care for *name*? If so, in what way?

So how did you find out about the course?

Can you tell me in your own words what you thought about the course? **Check about content of course** - can you tell me what was covered in the sessions, what you thought was good and not so good. Did you attend all the sessions? If not was there a reason?

*Follow up probes picking up on what they have said.....e.g.*

- To what extent did the course help with the difficulties you have identified?
- Are there things you would like it to have covered that it didn't?
- Do you think you have benefited from it? If so, in what ways? Can you give me any examples?
- Do you think it has affected the way in which you think about dementia?
- Do you think it has changed the way in which you care for *name*?
- Do you think it has changed the way in which you feel about being a carer?
- Has it changed the way in which you go about trying to get hold of information or to learn more about dementia?
- What was it about the way in which the course was provided that helped or was not helpful? (e.g. group delivery, sharing experiences with other carers, trainers)

Did *name* know you were going on the course? If so, what do you think he/she felt about that?

Did you feel able to share information or understanding from the course with him/her? If so, do you think he/she has found that helpful?

Do you think it has made any difference to the sort of decisions you need to make about his/her care? Do you make any of those decisions together?

Can I ask you about your relationships with paid service providers. Do you think this has changed in any way since you went on the course? If so how?

Have you had any on-going contact with other carers who went on the course? With the Alzheimer's Society who provided it?

Do you ever find yourself in a situation where you are giving advice or information to other carers as a result of going on the course?

How would you describe your current situation in relation to caring for *name*?

Any further reflections on the course and the impact it has had.

***Complete the biographical information form***

## Learning from the Carer Information and Support Programme (CrISP)

### Carer interview guide (Crisp1&2)

Could you start off by telling me a bit about how long you've been caring for *name* and what your experience of this has been. Could you tell me - when you first started to care for him/her, what did you feel you didn't understand, and what you didn't know or felt you needed to know more about in order to care for him/her. As time has gone on have there been other issues that have arisen that you didn't understand or felt that you needed to know more about in order to care.

**Check** a bit of information like age and who else is in the caring network, practical circumstances etc.

Have there been any other experiences in your life that you think helped you in terms of the knowledge and information you needed?

Before you went on the courses....

How did you go about trying to find out things you needed to know about or understand better?

What did you find it most difficult to get information on or to get explanations that you could understand?

Do you think these difficulties made it more difficult to care for *name*? If so, in what way?

So how did you find out about the **CrISP 1 course**?

Can you tell me in your own words what you thought about the course? **Check about content of sessions** - can you tell me what was covered in the sessions, what you thought was good and not so good. Did you attend all the sessions? If not was there a reason?

How did you find out about the **CrISP 2 course**?

Can you tell me in your own words what you thought about the CrISP 2 course?

**Check about content of sessions particularly; differences in content with CrISP 1; issues that were raised; impact on them and whether it felt like a continuation or a different course.**

Did you find one of the courses more useful at the time than the other?

**Probe on timing of the courses as they related to the stage of their caring.**

*Follow up probes picking up on what they have said.....e.g.*

- To what extent did the courses help with the difficulties you have identified?
- Are there things you would have liked them to have covered that they didn't?
- Do you think you have benefited from the courses? If so, in what ways? Can you give me any examples?
- Do you think the courses have affected the way in which you think about dementia?

- Do you think the courses have changed the way in which you care for *name*?
- Do you think the courses have changed the way in which you feel about being a carer?
- Have they changed the way in which you go about trying to get hold of information or to learn more about dementia?
- What was it about the way in which the courses were provided that helped or was not helpful? (e.g. group delivery, sharing experiences with other carers, trainers)

Did *name* know you were going on either course? If so, what do you think he/she felt about that?

Did you feel able to share information or understanding from either of the courses with him/her? If so, do you think he/she has found that helpful?

Do you think it has made any difference to the sort of decisions you need to make about his/her care? Do you make any of those decisions together?

Can I ask you about your relationships with paid service providers. Do you think this has changed in any way since you went on the courses? If so how?

Have you had any on-going contact with other carers who went on the courses? With the Alzheimer's Society who provided it?

Do you ever find yourself in a situation where you are giving advice or information to other carers as a result of going on the courses?

How would you describe your current situation in relation to caring for *name*?

Any further reflections on the courses and the impact they have had.

***Complete the biographical information form***

## **Learning from the Carer Information and Support Programme (CrISP)**

### **Person with dementia interview guide**

- What is your current experience of dementia and what support do you need?
- Did your carer share any of the information from the course with you and if so how?
- Do you feel you have more information now and does that help you understand your dementia better?
- Do you think the information or the course has had any impact on how you and your carer manage the dementia together?
- Are you and your carer making decisions differently?



**CrISP Evaluation – biographical information form**

**Carer Gender**

Male	<input type="checkbox"/>
Female	<input type="checkbox"/>

**Age in years**

**Person with dementia Gender**

Male	<input type="checkbox"/>
Female	<input type="checkbox"/>

**Age in years**

**Carer status**

single	<input type="checkbox"/>
married	<input type="checkbox"/>
civil partnership	<input type="checkbox"/>
Living with partner	<input type="checkbox"/>
widowed	<input type="checkbox"/>
divorced	<input type="checkbox"/>
separated	<input type="checkbox"/>

**Relationship to person with dementia**

**Occupation**

Working full time	<input type="checkbox"/>
Working part time	<input type="checkbox"/>
Unemployed	<input type="checkbox"/>
Retired	<input type="checkbox"/>
Caring for friend or relative	<input type="checkbox"/>
Temporarily sick or disabled	<input type="checkbox"/>
Long term sick or disabled	<input type="checkbox"/>
Voluntary work	<input type="checkbox"/>
Other	<input type="checkbox"/>

**Details of current or previous occupation .....**

**Details of broader caring network e.g. family/friends/community.....**

.....

Live on your own	<input type="checkbox"/>
Live with your spouse/partner	<input type="checkbox"/>
Live with family member(s)	<input type="checkbox"/>

**Living situation**

Live with others  
Other


**Living accommodation**

Council rented  
Housing association rented  
Private sector rented  
Own home  
Sheltered housing  
Other


**How long have you lived in the area .....**

**Financial situation**

Well off  
Comfortable  
Getting by  
Struggling over basics


**Ethnicity**

**Asian or Asian British**

Indian  
Pakistani  
Bangladeshi  
Other Asian background


**Black or Black British**

Caribbean  
African  
Other Black background


**White**

British  
Irish  
European


**Mixed**

White/Black Caribbean  
White/Black African  
White/Asian  
Other mixed background


**Other** (please specify)

**Chinese**

--

**Do you consider yourself to have a disability?**

Yes / No

Note any details

.....





**University of Brighton**

SSPARC Social Science Policy and Research Centre  
School of Applied Social Science  
University of Brighton  
Falmer  
Brighton BN1 9PH  
Telephone 01273 643480  
Fax 01273 643496  
[www.brighton.ac.uk/sass/research](http://www.brighton.ac.uk/sass/research)