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Evaluation of the East Sussex Carers’ Breaks Demonstrator Site

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1 Introduction

1.1 Introduction

This report presents findings from the evaluation of the East Sussex Breaks for Carers Demonstrator Site as carried out by the Social Science Policy and Research Centre (SSPARC) at the University of Brighton. The project and the evaluation were funded as part of the Department of Health’s Carers’ Strategy from October 2009 to March 2011.

The main aim of the Demonstrator Site is to enable carers of people with dementia to access flexible, short respite support across East Sussex from staff trained and experienced in mental health/dementia. As well as continuing and expanding upon existing pilot services operating through Eastbourne and South Wealden’s Older Persons Community Mental Health Teams (OPCMHTs), the project has replicated this model of provision in Hastings and Rother, Seaford and Ouse and the High Weald area of East Sussex.

1.2 Structure of the report

The report is organised into eight sections as follows:

- Chapter 1 outlines the background to the project and the evaluation and sets out the aims and objectives of the project.
- Chapter 2 presents the research methods employed by the evaluation.
- Chapter 3 presents an analysis of quantitative information collated by the project.
- Chapter 4 focuses on the interviews with carers in relation to their experiences of their caring roles, and the benefits and limitations of support received through the project.
- Chapter 5 discusses the circumstances in which such benefits and limitations have been experienced with reference to interviews with both carers and staff.
- Chapter 6 focuses on interviews with project staff and staff from partner organisations in order to look at features of the model felt to be key to achieving successful outcomes, and to highlight relevant organisational issues.
- Chapter 7 discusses the findings in relation to the aims and objectives of the project and with reference to government policy on supporting carers.
- Lastly, chapter 8 provides a conclusion and suggests some learning points for the project.
1.3 Background

1.3.1 National context

The increasing focus on the role of informal care in recent years is set in the context of the UK policy shift of the 1990s from residential to community care, in the midst of growing concerns around financing the increasing cost of care in an ageing population (Banks, Haynes et al., 2006). In reality ‘community care’ is primarily and largely carried out by family carers (approximately 80% of all support is provided by family members) (Nolan and Keady, 2001 p.161). For community care to work, carers need to be supported through respite breaks and other appropriate support mechanisms (Jeon, Brodaty et al., 2005). The first National Strategy for Carers (1999) was a milestone in carers’ support and has been followed by a number of initiatives and policy developments such as legislation promoting equal rights for carers (Carers (Equal Opportunities) Act, 2004), the second carers’ strategy: ‘Carers at the heart of twenty first century families and communities’ (Department of Health, 2008), and new support services available to carers in the context of the ‘personalisation’ agenda (CIRCLE, 2010 p.4).

One context in which care from family and friends is provided is in the support of people with dementia. Dementia care has been increasingly recognised as a growing strand of informal care. The number of people with dementia in the UK has been estimated as 750,000 (Alzheimer’s Society, 2010). The incidence of dementia increases with age, with 68% of all cases among those aged 80+, and 17% among those aged 90+. One in six people over 80, and one in 14 people over 65 have been found to have a form of dementia, with late-onset dementia (diagnosed over the age of 65) comprising 98% of all cases (Knapp, Prince et al., 2007). Prevalence is higher among women than men which is related partly to the greater average longevity of women and partly to an actual greater incidence rate (National Collaborating Centre for Mental Health, 2007 p.72). It has also been estimated that 63% of all people with late-onset dementia live in private households. Dementia is a condition that can have a profoundly debilitating impact on the capacity to live independently, and family members in the large majority of cases take major responsibility for providing care (Knapp, Prince et al., 2007). In total approximately one million people across the UK are involved in providing informal care to people with dementia (National Collaborating Centre for Mental Health, 2007) and the majority of these are women (Nolan and Keady, 2001 p.161).

The cost of dementia to the NHS and Social Care was estimated at £8.2 billion in 2009 (Public Accounts Committee, 2010). Research has suggested that this would, however, be far higher without the contribution of informal carers. Banerjee et al. (2003 p.1316), for example, estimate that people with dementia who have a co-resident carer were twenty times less likely to be admitted to a residential care facility within a one year period, than those without a co-resident carer.
Research has highlighted the difficulties experienced by carers of people with dementia. These include social and economic strain, as well as a negative impact on health and well-being (Schneider, Murray et al., 1999). Carers are more likely to suffer from depression which may be associated with emotional challenges around coping with a sense of 'living bereavement' and dealing with the changing roles in the relationship between themselves and the person with dementia (Gilliard, 2001 p.86).

A House of Commons Committee of Public Accounts recognised the impact carers of people with dementia had on saving money to the taxpayer through avoidance of the need for residential care. The emotional and physical (as well as financial) cost of this to family carers was also highlighted:

“Informal carers supporting people with dementia save the NHS and social care over £5 billion per year. Without them, the present system of care and support to people with dementia would be unsustainable. But caring can place a heavy burden on the carer’s physical, emotional and mental health, and can lead to depression” (Committee of Public Accounts, 2007-8 p.12).

The Committee thus recognised the need for Primary Care Trusts (PCTs) and local authorities to provide flexible and high quality respite care by skilled workers. It also highlighted that the quality of domiciliary care was often unsatisfactory due to poor training and high turnover of home care staff (due to difficulties around recruitment and retention), and that this could be particularly distressing for people with dementia (Committee of Public Accounts, 2007-8 p.12-13).

Jeon et al. (2004) review the effectiveness of respite support for carers of people with mental health problems including dementia. They find the evidence inconclusive in relation to any association between provision of respite and prevention or delays to residential care. They do, however, find general agreement that respite services are of benefit to carers, but a lack of consensus on the extent to which such services can positively impact well-being. Homer and Gillear (1994), for example, found no marked changes in carer well-being resulting from day care and home respite programmes. However, Gottlieb and Johnson (2000) found that carers of those regularly attending a day care facility for a period of five months showed a significant decrease in anxiety and stress.

A review of the literature prepared for the Audit Commission by Pickard also found the results of respite interventions mixed in relation to the impact upon the psychological health of carers and upon delaying or preventing admission to residential care. She concludes:

“Studies suggest that respite care in general is associated with delayed admission to institutional care, though it may also be associated with increased admission for some groups” (Pickard, 2004 p.22).
It is also important to consider the extent to which interventions designed to support carers may also affect people with dementia. Other untreated health problems may exacerbate dementia symptoms and lead to premature institutionalisation (Parsons, 2001 p.127-128). Therefore engagement with services may help to identify and address such issues and delay residential care. Banerjee (2009) suggests that interventions which result in even slight improvements to the quality of life of people with dementia can lead to reductions in the rates of institutionalisation. Research has also shown that the health of the person with dementia is associated with the well-being of the carer, thus highlighting the need to support both parties in the caring relationship (Cooke, McNally et al., 2001 p.120).

Following a review of the 1999 Carers’ strategy in 2007-8, a more recent development in government policy on supporting carers was the National Carers Strategy 2008. The strategy emphasised the importance of respite care and pledged an increase in allocated funding:

“And above all we recognise the need – repeated so many times throughout our consultation – for better support for respite and short breaks. Too often carers are unable to access the kind of support which allows them to re-charge and renew themselves and, to address this, we are taking immediate action to double our support for respite care over the next two years with an additional £150 million of new funding” (Prime Minister Gordon Brown, DH, 2008).

As part of the 2008 Carers’ Strategy, the Department of Health set up Demonstrator Sites across the country to look at three groups of initiatives to support carers, one of which was around ‘breaks for carers’. A national evaluation is currently underway to test the effectiveness of the initiatives “in terms of results which meet individuals’ needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they care for to be a full and equal citizen” (CIRCLE, 2010 p.4-5). The evaluation is also seeking to measure these benefits in relation to the cost-effectiveness of different types of schemes. Methods being used by the National Evaluation Team (NET) include a survey of carers, and a detailed case-study of selected sites (not including East Sussex). An interim report has been produced by the NET in September 2010 and the final report is due September 2011 (CIRCLE, 2010).

In July 2010 the newly formed Coalition Government pledged to update the National Carers’ Strategy to set out a vision for carers from 2011 to 2015 (Cross-Government, 2010). This is discussed further in chapter 7 with reference to the findings from this evaluation.

1.3.2 Local context

East Sussex has the second highest proportion of people with dementia of any local authority in England (after Torbay), which equates to 9,893 people. This represents 1.99% of the total population and 8.6% of over 65s (10.2% of females and 6.3% of
males over 65) (Alzheimer's Society, 2007). If 63% of those with dementia live in the community (as estimated nationally by Knapp et al. 2007) this would equate to 6233 people across the county.

An extensive mapping study of carers and services for carers in East Sussex also showed the proportion of unpaid carers (i.e. all carers, not only of those with dementia) in a number of areas of the county to be above the national average, particularly in the Wealden area. Those in Wealden were also most likely to spend 50+ hours per week on unpaid caring duties. The study highlighted a particular gap in provision for carers particularly respite and other support services in rural areas (Fyvie-Gauld, Penn et al., 2006).

Following this study, a respite project specifically aimed at carers of people with dementia was successfully piloted in the South Wealden locality (Carers Respite Project /Rural Daycare Project). Discussions in network meetings with family carers from the Eastbourne area identified the need for a similar project to be established there. This was funded by the East Sussex Carers Development Fund for one year (April 2009 – March 2010), having demonstrated the way in which it fit local priorities, and met a gap in service provision (by allowing cared-for people with dementia to access mainstream services, and therefore simultaneously enable carers to benefit from short respite breaks). In addition to feedback from carers and staff involved in these pilot schemes, an East Sussex County Council Adult Social Care consultation was conducted in early 2009 (consulting over 3,000 carers through questionnaires and focus groups). This highlighted the importance of a service enabling carers to receive short regular breaks.

East Sussex County Council submitted a successful bid to the Department of Health in March 2009 for the existing pilot Carers' Breaks projects in East Sussex to be expanded and to become a Carers’ Demonstrator site. The project was established as a Carers’ Demonstrator Site in September 2009 and, following recruitment of staff, referrals were being received by all six OPCMHTs and allocated by the respective project teams by November, i.e.:

- Eastbourne
- South Wealden
- Hastings and Rother
- Seaford and Ouse Valley (Seaford and Newhaven OPCMHTs)
- High Weald
1.3.3 Aims and objectives of the project

Specific objectives of the project include:

- To offer support from a community support worker (CSW) on a 1:1 basis in the carer’s home and to agree with carers an action plan to enable the carer to benefit from regular short respite breaks.

- To support around 80 carers’ planned breaks each quarter in each of the 4 areas.¹

- For CSWs to befriend carers and enable them to benefit from other support available such as ‘Caring and Coping’ courses.

- To offer practical support to carers e.g. offering transportation to medical appointments and supervising the cared for person at the surgery/venue in order to minimise ‘separation anxiety’.

- To offer advice, information and education about mental health/dementia and signpost to other services.

- To assist the cared-for person to engage in mainstream community activities (thus providing the carer with a respite break) where possible and to withdraw when confidence has been established.

- To assist and train those leading the activities to understand the specific needs around the mental health condition/dementia of the cared-for person.

- To support carers through a carers’ support group facilitated by a resource officer and managed by carers – and to run in parallel with an activity for the cared-for person (e.g. coffee-club).

- To assist carers in completing assessments/reviews.

- To work effectively in partnership with relevant statutory and non-statutory groups and services.

The overall aim of these objectives is to deliver the following outcomes:

- To positively impact the health and well-being of carers and those they care for (including those who are currently ‘under-reached’) both during the immediate intervention and over the longer term.

- To prevent carer breakdown and thus reduce the demand on intensive health and social care services such as premature placement in residential care and reactive, emergency interventions.

- For carers to be effectively included as ‘partners in care’.

¹ Originally the project areas were conceived as four teams but these were later organised into five teams.
2 Research Methods

2.1 Qualitative interviews

The findings are primarily based on an analysis of sixty-five semi-structured qualitative interviews. The majority of interviews were recorded, fully transcribed and thematically analysed with the use of the qualitative software NVivo. Carers and workers from the project and from partner organisations were interviewed. These included:

- Twenty-one carers who were initially interviewed with the aim of assessing early thoughts, feelings and impressions of the project and how carers felt this was or may be of benefit to them and to the person they care for (the flow chart below illustrates the selection process).
- Twenty of the initial carers who were followed-up with a subsequent interview to assess how the intervention had progressed, and what difference the support had made to the carer and the person cared-for over a period of time.
- Five CSWs (including one from each area) in order to capture the views and experiences of those delivering the support and how they feel this is beneficial to carers and those they care for.
- The project manager and all four resource officers (ROs) in order to achieve an overview by area of support provided and organisational issues.
- Nine care coordinators from the OPCMHTs who had referred to the project. The aim of these interviews was to enable a number of carers’ cases to be explored in more depth and also to capture reflections on organisational issues from another perspective.
- Four partners from voluntary and community organisations (VCOs) in order to capture issues around partnership working and the impact of this upon service users.
- One steering group member who was also a carer who had received support from the project. This interviewee was therefore able to reflect on her experiences both as a service user and on her wider understanding of the development of the project.

2.2 Other methods

Evidence was also gathered through:

- Field notes of participant observations of ten coffee/lunch groups from across the county.
- Attendance at project meetings and conversations with project staff and others involved with the project.
- Perusal of other relevant documents, such as progress reports, from the project.
manager and feedback forms from carers collected by the project.
- Analysis of data collated by the project in the monthly database, and recorded in quarterly monitoring forms (provided to the NET).
- Attendance at a carers’ support group in order to discuss and capture carers’ reflections on initial evaluation findings.

2.3 Sample selection

2.3.1 Carers

The purpose of the carer interviews was to capture the views and experiences of service users, i.e. both of the carer and of the cared-for person accessing the service. Although ideally it would have been useful to also interview people with dementia about their experiences of the project, it was felt the practical and ethical issues around this (particularly around capacity to consent) outweighed the potential benefits. However, carers were able to comment on the benefits of the scheme for those they cared for from their perspective (staff also expressed some observations in regard to the perceived impact of the project upon people with dementia). Interviews with carers were in most cases arranged during the carer’s break in order to enable the carer to be interviewed alone. However, this was not always possible or desirable on the part of the carer. In three cases, interviews took place with the person they cared for present, and they also made some contributions to the interview.

Carers were selected according to a time sample. This method was chosen to minimise bias in the selection process. It was also considered that choosing carers who had begun to receive support at a similar point in the development of the project would be helpful in terms of achieving a greater degree of comparability across areas. Resource officers were asked to provide contact details of carers whose cases were allocated to a CSW in February 2010, having obtained their consent to be contacted by the evaluator. Project staff considered 16 cases to be inappropriate to take part because of health problems (and in one case because a carer had died shortly after being allocated to the service) or because they were not in receipt of respite services (i.e. only of carers’ assessment). In these cases consent to be contacted was not requested from the carer. Similarly, some carers declined to take part because of illness or other personal problems. In one case, the carer declined because the service had been refused because of the reluctance of the person they cared for. The sample therefore may be skewed towards those who were less likely to be struggling with their caring role because of health problems etc., and towards those who had received a more complete service from the project.

Once details were received, carers were sent a letter (Appendix 1) with an information sheet (Appendix 2) outlining the purpose of the evaluation and what their participation would involve. A consent form (Appendix 3) was also included and participants were asked to sign this before participating in an interview, and to send this to the interviewer by post if to be interviewed by phone. The letter was followed
up by a phone call approximately one week later in order to give the carer time to consider whether he or she would like to take part. If the carer did agree, a convenient time and date was arranged for the interviewer to visit them at home to conduct the interview. Three initial and six follow-up interviews were completed over the phone because this was preferred by the carer.

The aim was to interview at least four carers from each area. For Hastings and Rother, Seaford and Ouse and South Wealden teams, insufficient participants were recruited from the February sample. The sample was therefore extended to March for these areas, and subsequently to April for Seaford and Ouse. Initial interviews were carried out between March and August. Although the aim was to interview carers who had recently begun accessing support, this was not always possible owing to a combination of factors, including delays in receiving contact details, and difficulties in making contact and arranging dates for interviews. There were also variations regarding the timing and amount of support received post allocation date owing to staff resource issues and personal issues concerning the carer and the person they cared for. In one case, for example, although the initial interview had taken place five months after allocation, the support had been put on hold due to illness and hospitalisation (the carer had originally declined participation in the evaluation, but later agreed to take part after the support had been resumed). Therefore relatively little support had been received during that time. Review dates also did not always take place six weeks after allocation as was originally anticipated. Therefore, although the original intention was to follow up after six weeks (and again after three months), this was not always appropriate or possible. Hence, it was decided to follow-up only once, a few months after the initial interview.

Follow-up interviews were carried out between October and November, (between 6 - 9 months after the allocation date and between 3 - 8 months after the initial interview)\textsuperscript{2}. The aim of the follow-up interviews was to identify any difference the intervention had made to the carer and person being cared for, and also whether any benefits had been sustained in cases where the support had been withdrawn. One of the initial interviewees was unobtainable for follow-up despite attempts to contact them by telephone and leaving messages at various times of the day. Two interviews comprised a short telephone conversation and not a full formal recorded interview. In one case this was because the cared for person had died shortly after the first interview. In the other case the carer and her husband had moved out of the area. Therefore these two carers had little to add to the initial interview. See Appendix 4 for the interview schedules for interview 1 and 2.\textsuperscript{3}

\textsuperscript{2} One telephone interview also took place in February 2011. This was conducted later because the participant had moved out of the area and new contact details were received at the end of January. This interview took place 10 months after the allocation date and 8 months after the initial interview.

\textsuperscript{3} It should be noted that the interview schedules were used flexibly, as a guide and some questions from the interview 2 schedule, were used in interview 1 where this was appropriate.
2.3.1.1 Sample characteristics
Table 1 below presents the distribution of the sample by gender, age, relationship to the person with dementia and living arrangements (of adult children). It shows that the sample included ten male (48%) and eleven female (52%) carers. Male carers were therefore slightly over-represented in comparison with the total population of carers referred to the project (see quantitative data section below). Thirteen (62%) carers interviewed were spouses to the person with dementia and eight (38%) were daughters or sons. Three out of the eight who cared for a parent were co-resident, and the other five lived in separate accommodation. Eleven (52%) carers were under 65
years of age, which included all eight adult children plus three of the spouses. Seven female carers, and four male carers were in the younger age group. The ages of carers interviewed ranged from 47 to 92. Eleven (52%) were aged under 65, five (24%) between 70 and 80 years old and five (24%) over 80.

Table 1 Characteristics of carers interviewed by gender, age, living arrangements and relationship to the cared-for person

<table>
<thead>
<tr>
<th></th>
<th>Spouse</th>
<th>Adult child</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Co-resident</td>
<td>Detached</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 65</td>
<td>1</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>65+</td>
<td>6</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>Female</td>
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<td>Total</td>
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<td>4</td>
<td>11</td>
</tr>
<tr>
<td>65+</td>
<td>10</td>
<td>0</td>
<td>10</td>
</tr>
</tbody>
</table>

2.3.2 Staff

The aim was also to interview project staff and those from partner organisations from each team. CSWs and care coordinators were contacted on the basis that they had been allocated to the cases of one or more carers participating in the evaluation. The aim was to build up detailed understanding of specific cases as well as obtaining more generic information about experiences and views of the service. The five CSWs interviewed had between them been allocated twelve of the carers interviewed, whilst eight of the care coordinators interviewed had been allocated to thirteen of the carers interviewed. One care coordinator interviewed stood in on behalf of a colleague with whom the interview had been arranged (because he was unavailable). She had no knowledge of any of the interviewees, but was able to discuss her experiences of the project more generally and in relation to other cases.

CSWs, ROs, the project manager and care-coordinators were contacted by email and sent an information sheet, similar to that provided to carers (as shown in Appendix 2). They were also sent a consent form and an interview schedule (see appendixes 5, 6, 7 & 8). In most cases this was followed-up by one or more telephone calls. One care coordinator requested information to be sent by post. Five out of seven support workers contacted agreed to take part in a full interview (several others provided some information requested in regards to specific cases). Nine out of thirteen care coordinators (the others did not respond) and all ROs/the project manager agreed to take part in an interview. The aim of interviewing at least one CSW and care
A coordinator per area was fulfilled and a range of care coordinators took part, including those working in both mental health (5) and social care (4) roles.

Four community partners were recommended by the project manager. These were all contacted and appointments arranged by telephone. Community partners were also provided with an information sheet and interview schedule (Appendix 9) before being asked to sign a consent form. No community partner was interviewed in the High Weald area as none were identified.

2.3.3 Groups

The evaluator visited ten groups and took field notes of observations. Groups were selected through the recommendation and invitation of project staff, but with the aim of attending a range of types of groups and at least one from each area. Ten groups were attended across the county including seven groups run by the project and three community groups which the project supported clients to attend. Six of the groups observed ran during the afternoon only, and four from morning until late afternoon. Two project run groups were based in Extra Care housing establishments and included residents alongside project clients. Another project run group coincided with an Alzheimer's Society carers group, meeting in the same building.
3 Quantitative data

The project has recorded quantitative data on quarterly monitoring forms for the NET. In addition, it has collected feedback forms from carers and kept a database providing some further information on the numbers and characteristics of service users and carers. This data has been analysed and key results are presented below.

3.1 Number of breaks provided

For recording purposes, a ‘break’ constitutes 2.5 hours of support provided by a CSW to the person with dementia. This could be either one-to-one support or support within a group. It allows the carer to go out somewhere, to relax or pursue other interests whilst the person they care for is with the CSW. The target was for each team to provide 80 breaks per quarter. This target was based on what was considered to be realistically achievable on the basis of work carried out through the previous pilot projects. As shown in Table 2, the overall project target was exceeded in the first quarter and each team exceeded targets by the second quarter. The percentage of the target (400) achieved across county was over 100% from the first quarter and increased each subsequent quarter. Total breaks across the county from commencement of the project until the end of December comprised 11,003.5 which equates to 27,509 hours. The total spend on the project by the end of December 2010 was £453,091.56. Therefore, the average cost per hour of a break provided by the project equates to £16.47. This, however, includes set up and evaluation costs. Therefore, the future cost to the project per hour break is likely to be reduced. The trend towards group work is also associated with a reduction in hourly costs. Project staff carried out a survey of professional staff from OPCMHTs and, on the basis of their views, calculated cost savings of £762,596 resulting from the work of two of the five teams between October 2009 and August 2010. These savings were in relation to prevention of premature admissions to residential/nursing care homes, emergency admissions to NHS assessment units and outpatient appointments (other savings related to care coordinator/social worker time, travel expenses and emergency admissions prevented to adult social care (ASC) respite units were also identified but not quantified) (ESCC, 2010).

Table 2 below presents the number of breaks (i.e. number of 2.5 hour slots of support provided to service users) for each quarter and area in which the project has been operating. It also compares the total number of breaks achieved per quarter to the target number of breaks.
Table 2: Breaks provided per quarter by area

<table>
<thead>
<tr>
<th></th>
<th>E</th>
<th>H&amp;R</th>
<th>HW</th>
<th>S&amp;O</th>
<th>SW</th>
<th>Total</th>
<th>Target breaks</th>
<th>% of target achieved</th>
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<td>140.3</td>
<td>51</td>
<td>70</td>
<td>449</td>
<td>866.3</td>
<td>400</td>
<td>216.6</td>
</tr>
<tr>
<td><strong>Q2</strong></td>
<td>315</td>
<td>381</td>
<td>157.4</td>
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<td>1665.4</td>
<td>400</td>
<td>416.4</td>
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<td>688</td>
<td>332.6</td>
<td>568</td>
<td>573</td>
<td>2615.6</td>
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<td>2697.3</td>
<td>400</td>
<td>674.3</td>
</tr>
<tr>
<td><strong>Q5</strong></td>
<td>465.3</td>
<td>837</td>
<td>502.7</td>
<td>823.6</td>
<td>530.3</td>
<td>3158.9</td>
<td>400</td>
<td>789.7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>1854.3</td>
<td>2727.3</td>
<td>1501</td>
<td>2350.6</td>
<td>2570.3</td>
<td>11003.5</td>
<td>2000</td>
<td>550.2</td>
</tr>
</tbody>
</table>

Figure 2 below, illustrates the number of breaks provided by the project each month per area. It shows that the number of breaks provided increased from October 2009 until June 2010 from 213 to 1033 (385% increase) across the county. This increase in breaks can, in large part, be attributed to the growth of the project, particularly in Hastings and Rother, High Weald and Seaford and Ouse, in which areas the service was not previously established. A reported increase in group provision over the course of the year has also impacted the number of breaks the project has been able to provide. There was a fall in breaks of 17% from June to 853 breaks provided in September, an increase to a peak of 1385 in November, and then a fall of 37% (to 874) in December. The project manager confirmed that overall dips in number of breaks provided were associated with summer and Christmas staff holidays and also with the snowfall in December (which slowed the service for several days). The steep rise in November was attributed to partnership events with the voluntary sector which many clients were supported to attend.
Data on referrals to the project

As of the end of December 2010, 512 partnerships of carers and those they care for had been referred to the project since the demonstrator site was established. This represents around 8% of people with dementia living in private homes in the county. Carers referred to the project included 279 (58%) women, 192 (40%) men and 8 (2%) multiple carers of both sexes (plus 33 for whom data was missing). Information on relationship of carers to those they cared for was missing in most cases and therefore could not be accurately analysed. 92 (18%) carers were recorded as under 65 (however this may be an under-estimation due to missing data). 451 clients were recorded as White British, 57 not recorded or refused, 4 white ‘other’ and 1 as Black Caribbean.

Not all of those referred to the project accepted support or received help in the form of breaks. Some received a carers’ assessment only. Quarterly reporting form 5 (provided to the NET for recording purposes) showed that 290 carers were newly introduced to, and received support from, the project in the form of breaks over the course of the 15 months (October 2009 – December 2010). In addition (as shown in Quarterly reporting form 1), 15 carers who were engaged with previous pilot projects continued to receive support. Therefore through the course of the year a total of 305 carers (59% of referrals) were reported to have been provided with short respite breaks. From this data it is not possible to calculate the number of breaks received per person, since there were variations in the periods of time over which support were received. Information on the number of breaks received per week per person is missing for most cases. However, where this information is given, the average calculated is 1.3 breaks per week which equates to 3.2 hours.
Earliest referral dates were November 2009 for all teams except for South Wealden (earliest dated June 2005) and Eastbourne (June 2009) since these were carried over from previous pilot projects. 219 (43%) of these cases were closed to the Carers’ Breaks project (or on hold) as of the end of 2010. Therefore the majority (294, 57%) of those referred to the project were still open by the end of 2010. The earliest case remaining open had been allocated to the South Wealden team in September 2006. Of those 294 cases which had not been indicated as closed, 97 were missing both allocation dates and the name of the CSW the case is allocated to. This leaves 197 cases which were clearly marked as allocated and currently receiving support from the project. However, the extent to which missing information may have inflated the number of those seemingly waiting allocation is unclear.

Table 3 presents data on the reasons that cases were closed to the project. Reasons were not recorded for 81 cases (37% of those closed). If these are excluded, almost a third (31%) of those remaining did not receive any support from the project in the form of breaks. 15 (11%) declined support and 28 (20%) received a carer’s assessment only. Of the remaining 95 cases, 9 (10%) were reported to no longer require support or to have withdrawn (although the specific reason for this was not recorded), 17 (18%) had died, 11 (12%) had moved, 33 (34%) had been handed over to other services to support them living in the community, and 25 (26%) admitted into a health/care facility (either on a permanent or temporary basis).
Table 3: Reasons for closing cases (or putting on hold) referred to the project, by number and percentage, as of end December 2010.

<table>
<thead>
<tr>
<th>Reason</th>
<th>Number</th>
<th>% of closed cases</th>
<th>Valid(^4) %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support declined</td>
<td>15</td>
<td>6.8</td>
<td>10.8</td>
</tr>
<tr>
<td>Carers assessment only</td>
<td>28</td>
<td>12.8</td>
<td>20.3</td>
</tr>
<tr>
<td>Not/no longer required</td>
<td>8</td>
<td>3.7</td>
<td>5.8</td>
</tr>
<tr>
<td>Withdrew</td>
<td>1</td>
<td>0.5</td>
<td>0.7</td>
</tr>
<tr>
<td>Deceased</td>
<td>17</td>
<td>7.8</td>
<td>12.3</td>
</tr>
<tr>
<td>Moved</td>
<td>11</td>
<td>5.0</td>
<td>8.0</td>
</tr>
<tr>
<td>Introduced to daycare(^5)</td>
<td>17</td>
<td>7.8</td>
<td>12.3</td>
</tr>
<tr>
<td>Handed over to sitting service</td>
<td>6</td>
<td>2.7</td>
<td>4.3</td>
</tr>
<tr>
<td>Handed over to care package</td>
<td>10</td>
<td>4.6</td>
<td>7.2</td>
</tr>
<tr>
<td>Admitted into respite facility</td>
<td>3</td>
<td>1.4</td>
<td>2.1</td>
</tr>
<tr>
<td>Admitted into hospital</td>
<td>3</td>
<td>1.4</td>
<td>2.1</td>
</tr>
<tr>
<td>Admitted into residential or nursing care</td>
<td>19</td>
<td>8.7</td>
<td>13.8</td>
</tr>
<tr>
<td>No data recorded</td>
<td>81</td>
<td>37.0</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>219</strong></td>
<td><strong>100</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

3.3 Types of support provided

As of February 2010, the project was providing ten project run coffee/activity clubs and one Out and About group (South Wealden). It was also supporting clients to attend a community run lunch club (Eastbourne) and a community activity group in the South Wealden area. By Feb 2011, this had increased to twelve project run coffee/lunch/activity groups and seven Out and About groups. In addition, the project was supporting people to attend four community groups and providing one regular day care taster session (Hastings). Owing to the increase in groups and activities established over the course of the project, the project manager reported that the

\(^4\) i.e. % of cases excluding those for which data was not recorded
balance of staff time spent on support had shifted towards an increase in group work, from 60:40 in February 2010 (groups: one-to-ones) to 75:25 by June. The staff ratio within groups was estimated to be 1:4 on average, although this could vary according to resources available through project staff, agency workers and other VCO staff or volunteers. Out and About groups were normally staffed on a maximum ratio of 1:3 since CSWs are only normally able to transport three clients.

Services provided specifically for carers include the carers’ assessment (of which 260 were completed by ROs up to the end December 2010). The minimum statutory requirement is for assessments to be reviewed annually, but these service users may be reviewed more frequently in accordance with identified need. Carers are also supported to attend carers’ groups through providing replica care (i.e. care organised to coincide with the carers’ group, thus allowing the carer to attend). Replica care groups each comprise between 5 and 14 people with dementia (data is not collected on the number of carers supported to attend a group).

Carers’ support groups supported include:

- Hastings and Rother: 1x Alzheimer’s Society; 2 x independent carers group
- South Wealden: 1x Alzheimer’s Society; 1 NHS Carers Group; 1 independent carers group.
- High Weald: 1x Alzheimer’s Society.
- Seaford and Ouse: 3x Alzheimer’s Society.

The Carers’ Breaks project was involved in the setting up three of the Alzheimer’s Society groups, the three independent groups and the NHS group.

3.3.1 Data from feedback forms

Table 4 shows the types of support service users received according to feedback forms collected by the project. 45 forms (15% of clients in receipt of breaks) were collected in total. In addition to the data collected through these forms, some information on the number of breaks provided per week through each type of support was recorded by project staff and collated in the project database. However, due to a large proportion of missing data this was not suitable for analysis. Therefore, data from the feedback forms on type of support is presented below rather than the data on all carers and those they care for.

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5 The project manager reported that a further 52 persons had been introduced to traditional day care services, but this includes open cases.
Table 4: Type of service received by those completing a feedback form*

<table>
<thead>
<tr>
<th>Service</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coffee/lunch group</td>
<td>32</td>
<td>71</td>
</tr>
<tr>
<td>One-to-one</td>
<td>17</td>
<td>38</td>
</tr>
<tr>
<td>Out and About group</td>
<td>18</td>
<td>40</td>
</tr>
<tr>
<td>Memory training</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Help attend appointments</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Carers group</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td><strong>Total feedback forms</strong></td>
<td><strong>45</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

*Clients can receive more than one type of support

3.3.2 Data from carer interviews

Carers taking part in an interview were asked about the type of support their spouse or parent with dementia had been receiving both through the project, and through other services. The table below illustrates the number of service users receiving various types of support at the time of the first and the follow-up interview. It illustrates a reduction in the number of those receiving one-to-one support and an increase in those involved in ‘Out and About’ activities. It also shows a slight increase in the number accessing longer (i.e. morning and afternoon) group support and a slight decrease in those accessing shorter ‘coffee clubs’. The number of those being supported to attend a community group had decreased from three to two. At the time of the second interview no service users had been enabled to continue attending community groups without the support of the CSW, although the researcher was advised that this had subsequently been facilitated in one case.

Nine (43%) people were no longer receiving support from the project by the time of the second interview. This was for a variety of reasons which included admission into residential care (3), death (1), moving out of area (1), support handed over to other services (3 – although these other services had been subsequently discontinued) and support on hold (1) due to physical health problems of the service user.
<table>
<thead>
<tr>
<th>Support from CB project</th>
<th>1st interview</th>
<th>2nd interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>One-to-one</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Out and About</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Project coffee club</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Project day group</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Support to attend community group</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total receiving CB support</strong></td>
<td><strong>21</strong></td>
<td><strong>12</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other support</th>
<th>1st interview</th>
<th>2nd interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day care services</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Sitting services</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Home care</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Residential respite services</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Residential care</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total receiving other support</strong></td>
<td><strong>9</strong></td>
<td><strong>11</strong></td>
</tr>
</tbody>
</table>
4 Experiences of service users

4.1 Challenges of the caring role

In order to put the support into context, carers were asked in the initial interviews (at a time when carers had in most cases recently begun receiving support from the project) about the challenges of their caring role. These were also often talked about in the follow-up interviews. Key themes arising from these discussions are presented below. These themes highlight reasons why carers were in need of support from the project.

In order to protect anonymity the only details of carers presented are the age group (under 55; 55-65; 66-79 and 80+) and the relationship to the person they care for. The interview number (whether 1st or 2nd) is also stated. Where the carer is a son or daughter, living arrangements (co-resident or non-resident) are also specified. Where necessary identifying details in quotations have been removed or altered.

4.1.1 Practical demands

The majority of carers discussed the challenges they face associated with the practical demands of their caring role. For many, the challenges were particularly acute where the carer was in the older age group (80+) and was having to learn new skills in order to carry out tasks previously undertaken by their partner. Partners often found it difficult that they now had to ‘do everything’ whereas previously there had been a division of labour in the household. Husbands, for example, often discussed the difficulties around carrying out household tasks such as cooking and housework which their wives had taken care of. Some female carers had experienced challenges around taking over duties their husbands had taken responsibility for, such as accounting and paperwork, or physical tasks such as gardening. In addition, carers spoke of other practical demands associated with personal care, including dealing with incontinence, and having to respond to continual demands for attention from their relative. The subsequent increase in workload was very tiring for some carers, particularly those who were themselves elderly. Non-resident carers also found the demands on their time difficult to manage alongside other responsibilities.

“The main challenge is really for me is coping with all the things that she would do herself that now I have to do [...]. She will come in and say “can I help?” and she just stands there and I say “OK, put...” you know, “set the table”. Well she can’t do that. You have got to sort of give her the knives and forks and say right you put one fork there and one knife there and one spoon there and even then she will have difficulty even repeating what you do” (Husband, 66-79: Interview 1).
“I’ve just got to get the strength up and carry on (laughs). I get up in the morning, I think ‘Here we go again’, you know, because he doesn’t get up, I do all the jobs before he gets up, get his pills and breakfast out and everything like that, got these pads and what have you, and really I’m a Jack of all trades (laughs). I’m a Girl Friday (laughs)” (Wife, 80+: Interview 2).

4.1.2 Dealing with loss

A number of carers spoke of the emotional challenges of dealing with loss. This encompassed the loss of identity of the person they knew and loved, and of the nature of their relationship with that person. In addition, there was a loss of a personal identity apart from being a carer, since the caring role meant that carers often lost their ability to pursue their own interests. This sometimes led to resentment, and to subsequent feelings of guilt about such resentment. Such emotional challenges often led to depression. Several carers spoke of feeling depressed. Three carers reported taking medication for depression (there may have also been others who did not reveal this to the interviewer) and one reported attending counselling sessions.

“I did get quite depressed around, well just before Christmas and just after Christmas ‘cause I think it was just that the impact of realising that my life was, had changed dramatically really, and I couldn’t make choices for myself any more. I had to make choices for my husband, but my choices had to fit in with his needs, do you see what I mean?” (Wife, 55-65: Interview 1).

“The challenges are really just coping with the amount of time you need in the day to do everything and, you know, losing your identity as somebody who does something besides, you know, washing your mum’s knickers” (Daughter, under 55, co-resident: Interview 1).

4.1.3 Stress and anxiety

A number of carers discussed challenges around dealing with stress and anxiety associated with their caring role. Stress related both to the practical demands of caring and to anxieties associated with the potential harmful behaviour of the cared-for person if they were to be left alone. Carers were often unable to go out and leave their relative because they were unsure what they would do whilst they were out of the house. Fears often centred on the person with dementia using the cooker or wandering off and forgetting their way home. Both live-in and non-resident carers experienced stress related to anxiety over the behaviour of the person with dementia. Those who were co-resident, however, also often described stress experienced through the daily frustrations of full-time caring. Both types of stress were felt to have an impact on health owing to increased tiredness and a reduced sense of well-being.

“I sort of lost the will to live really [...]. I sort of worry all the time if I do leave him to go shopping, he’s maybe done something in the cooker or something or he is about to burn something or, so it is a bit worrying” (Wife, 55-65: Interview 1).
“I do feel stressed, you know, quite a lot and I’ve never been somebody who loses my temper but I do find I lose my temper a lot more than I used to. It’s just very, very frustrating, you know, you just can’t lead any sort of a normal life anymore” (Daughter, 55-65, co-resident: Interview 1).

“I was having real trouble sleeping and that was because I was worrying about what was going to happen to her really, what was going on so, you know, and I think I was just so tired.” (Daughter, 55-65, non-resident: Interview 1).

4.1.4 Social isolation

Many interviewees expressed a sense of isolation, both within the relationship (owing to a reduced capacity for communication) and because they were often unable to get out and engage in social activities. Some described this as leading to loneliness which they felt had a negative impact on their mental/emotional health. Two carers spoke of how it was even difficult for them to speak to friends over the telephone because their parent or spouse would become agitated:

“It is difficult to maintain friendships and it is impossible, virtually impossible, to make new friendships and yeah, it is very difficult to get out. My mum gets angry if I talk on the phone for any length of time if she is here, so even maintaining friendships at a distance is difficult. So my friends pretty much, they don’t call and they wait for me to call them because they know that it is disruptive” (Daughter, under 55, co-resident: Interview 1).

Several carers also spoke of having lost friends. In some cases this was related to old age and having experienced bereavement of friends in their age group. However, some had also lost friends directly as a result of the dementia, since some friends found it uncomfortable to deal with. Some described how family members had been unsupportive and stayed away, perhaps because they found the change in the cared-for person difficult to cope with:

“We had lots of friends, we’ve got lots of friends still, but they tend not to come like they used to because I don’t think they know how to handle it really. And her children are no help whatsoever, so it is just left to me really, [...]. So yes, it is a bit lonely really because, as I say, you’re sitting in the room with somebody and it’s as though they’re not there because she’s not saying anything” (Husband, 66-79: Interview 1).

4.1.5 Complex health problems

Many carers and those they cared for had complex health needs. This was particularly the case where the carers were elderly. One carer, for example, who was over 90 was suffering from a serious health condition and had trouble walking. Another older carer (in her late 80s) was suffering from sight and hearing problems as well as other health complaints which made it harder to care for her husband:
“As you know I have got hearing loss and an eye problem [...]. Sometimes it’s very difficult to keep going, you know, it’s just a challenge really. I mean, I am [in eighties] and he’s [older]. I mean, it’s like the blind helping the blind isn’t it really (laughs)? I mean, a lot of people of my age are in nursing homes aren’t they? But we want to keep going as long as we can.” (Wife, 80+: Interview 2).

4.1.6 Caring and working

Four younger carers were in paid employment alongside their caring role and another was involved with a family business. Two of these lived separately from their parent with dementia and also had other family responsibilities such as caring for grandchildren. Whether living with the person with dementia or living separately, working carers spoke of difficulties juggling care and work. They had developed precarious strategies for cobbling together support, as one co-resident daughter described: “I hire people, I can in favours, I scrape, I beg, I borrow”.

All carers in paid employment had found managing this alongside their caring role stressful:

“I find it very stressful [...] I have a busy job here and I work nine to five, Monday to Friday, often later, with sort of stuff that I need to take home both physically and mentally as well. And my mum is, she is not demanding, but I get sort of a lot of emotional blackmail and I go, I mean I don’t go every night, whereas really she needs it, but I mean I just find I can’t cope. I mean I have tried to explain to her that I have a life too, you know, so it is a balance” (Daughter, under 55, non-resident: Interview 1).

Two working carers reported taking medication for depression. However, carers who were working were also reluctant to leave work, partly because of the financial implications, but also because work was perceived to be important in giving them a sense of identity apart from their caring role.

4.1.7 Insufficient support

“I have to scavenge around that’s what, I am a scavenger you know. There’s nothing, it’s all iffy, iffy iffy” (Wife, 80+: Interview 1).

Most carers spoke of having little informal or formal support to rely upon. Family members such as sons, daughters or siblings often lived at a distance and were unable or reluctant to provide help. In many cases, people with dementia were reluctant to access services such as traditional day care or had been prevented from doing so because of their challenging behaviour or because of transport problems.

One carer described how he had tried a number of different forms of support including day care and home care but none had proved successful:
“We tried short periods [day care] where she’d go for a morning and we’d pick her up in the afternoon but then she just wouldn’t go, she would become awkward and wouldn’t go in at all so that sort of finished. And then we tried a few care services which we had to obviously pay for but none of those worked either. My mother would get very upset with the people being strangers and not settle with them” (Son, 55-65, co-resident: Interview 1).

Carers of those with less complex support needs were also concerned about the appropriateness of day care.

“I wouldn’t want him to go where there were lots of, you know, old ladies sitting around the edge of the room asleep. I wouldn’t want that” (Wife, 55-65: Interview 2).

Other barriers to receiving support described, included a lack of availability (particularly sitting services), poor quality of care (in relation to home care) and the cost of services in some cases.

“It is very difficult finding carers who have the expertise to be able to manage my mum’s condition” (Daughter, under 55, co-resident: Interview 1).

4.2 Experiences of the project

This section focuses on the extent to which the project was found to be successful in addressing the issues discussed above and meeting the needs of carers. This section firstly discusses the positive aspects of the project identified by carers and secondly focuses on some of the limitations of the support described.

4.2.1 Positive experiences and benefits

The large majority of carers reported positive experiences of the project. Key benefits reported are presented below, focussing firstly on benefits to carers, and secondly on carers’ perceptions of benefits to those they care for. There is also a brief discussion of some mutual benefits expressed in relation to support received as a couple.

4.2.1.1 Reported benefits for carers

4.2.1.1.1 Opportunities provided by the break

Carers were enabled to do a range of activities during their breaks. Sometimes carers valued being able to relax at home, catch up with sleep or take the opportunity to go outside for a walk. One carer spoke of how he was enabled to attend a medical appointment (which would have been difficult since his mother would have had to attend also) and a few carers were able to meet up with friends or family. However, as found in previous research (Parahoo, Campbell et al., 2002), carers were most likely to report using their breaks to carry out practical tasks, particularly shopping, rather than engaging in social activities. Nevertheless, the opportunity to catch up on other chores was often greatly valued since it was described as difficult or impossible to
carry out tasks such as shopping, jobs around the house and garden or paperwork whilst simultaneously caring for someone with dementia:

“It means that I can do what I want and catch up on the jobs, some of the jobs that need to be done and frankly a day when I can think about me instead of having to be constantly thinking ‘where are you, what do you want, what’s happening, what’s gone wrong, you know, what can I do?’” (Husband, 65-79: Interview 1).

One carer who did not live with her mother also described how she used the break to clean her mother’s flat which she would not be able to do whilst her mother was at home.

Often, the opportunity to carry out such tasks without being constantly disturbed was considered a relief. Thus to some extent ‘chores’ were associated with enjoyment and relaxation, rather than as ‘work’:

“I do like cooking, I mean people think it’s a chore but to me it is a relaxation you know and I can make the sort of meals for the rest of the week or cakes or anything, and of course paperwork which I can do when I am on my own you see, got all the finances to do and bills to pay and everything like that and I can do it when I am single minded you know” (Wife, 80+: Interview 1).

“I was just relieved to go out for a couple of hours twice a week, you know because otherwise you really are stuck in the house, it does help with shopping and, you know, all the rest of the bits and pieces one needs to do” (Husband, 65-79: Interview 2).

4.2.1.1.2 Health benefits
Most carers felt the breaks received had been beneficial to their health and well-being. In particular, the psychological break from worrying about their relative and being able to focus on themselves was key to relieving anxiety and stress related to their caring role. This included some non-resident carers, who, despite not receiving a ‘physical’ break, reported how the support provided them ‘peace of mind’.

“It took a hell of a burden off me. It is awful to call your mum a burden but you know what it’s like, you can’t, when you are trying to have your own life to have to deal with her, you feel as if you are on call 24 hours a day. At least when I knew she was at the club, I knew that, you know, if there was a problem they would ring me obviously, but I knew she wasn’t at home getting into any mischief” (Daughter, 55-65, non-resident: Interview 2).

4.2.1.1.3 Helping to cope
Several carers felt that the support enabled them to cope with their caring responsibilities and were unsure how they would be able to continue providing care without support from the project. For example, one female older carer (80+) with significant health issues, had been struggling with her caring role and exclaimed in the follow-up interview that if the short breaks were to be withdrawn: “that would
probably be more or less curtains.” Another female carer (55-65) in the second interview stated that she was very worried about how she would cope if the support were to be discontinued, since her husband was reluctant to use other services: “I would have thought it would be going back to how it was I suppose, especially if he won’t go to the day centre. I think it would be a bit grim.”

In three cases, by the time of the second interview, the person with dementia had been admitted into a residential care home. The deterioration in their condition had reached a point at which the carers felt admission was unavoidable. However, in two of these cases the carer felt that the support had delayed the admission for a time:

“It delayed it [admission to residential care] a little while, it meant I could at least go out and leave her, you know, which is something. Because at one stage I couldn’t even go out the house so it did help” (Husband, 66-79: Interview 2).

4.2.1.1.4 Practical and emotional support

Support from the CSW
Some carers spoke of their sense of isolation and expressed how the ‘friendship’ with their CSW was an important ‘life-line’ for emotional support as well as in some cases providing practical advice or information and assistance to gain access to other help available. Several carers spoke of the reassurance from knowing there was someone ‘at the end of the phone’ who they could contact if need be:

“She [CSW] is very likeable because you can be natural with her you know, you do know that really she is on the end of the phone [...]. So you have got a bit of back-up, you know, if I were to say to her ‘look, I’ve got to go to the doctor’s or something” (Wife, 80+: Interview 1).

Support from other carers
As well as feeling they could call the CSW, some carers described being part of a ‘support network’ of carers met through the project, who they also felt they could call for support if they needed someone to talk to. The project offered opportunities for social participation which were felt beneficial to the well-being of carers through reducing the social isolation often associated with the caring role. Some carers attended groups alongside their relative which enabled them to develop friendships with other carers attending. Several carers also spoke of the help received through carers’ support groups which they had been enabled to attend through the project.

Two carers from the same area also spoke of how carers regularly met together outside of meetings whilst those they cared for were attending a project run group. The opportunity to be able to share experiences and gain a sense of reassurance from others who understood the emotional and practical challenges was seen as particularly helpful:
“It’s just it just makes you realise you’re not alone coping with, you know, the things that you, you think “am I the only one that resents this?” And you’re not, you know (laughs), it’s a common thing I think that. […] I quite look forward to that and to chat to all the other carers” (Wife, 55-65: Interview 2).

“It is an opportunity to be with other people who really know and who can offer you, you know, help and support if you need it and I, I wouldn’t have had that if I hadn’t been a part of the Carers Breaks project so it has done that for me too” (Wife, 55-65: Interview 2).

“There are other people there and you can say well you know, ‘This is my problem’ and they say ‘Oh yes, we had that or, and this is how we did with it’ and the interaction of talking about other people’s situations is a big help. […] And I think in some ways it’s, I try not to bottle it all up I think, and by talking to people about it does actually release the tension” (Husband, 66-79: Interview 1).

4.2.1.2 Reported benefits for people with dementia

4.2.1.2.1 Enabling access to services

A number of people with dementia who had previously been reluctant to receive support had been enabled to access services through the project. Some clients with challenging behaviour were also using services they had previously been unable to access. For example, one woman who had previously been prevented from attending a day care centre, because her behaviour on community transport had been considered distressing to others, was able to access services. Another woman, who had been provided with support from the project, had previously refused to attend day care services and had also experienced difficulties accessing home care:

“My mum seems to get on okay with [CSW] so that’s a positive thing, whereas before the carers who have come haven’t really, don’t seem to have much interaction although they were only here for maybe at the most probably half a dozen visits before they… some even refused to come, they send their top person around to do an assessment and they say we don’t feel that our staff are capable, or they didn’t want the responsibility of having to restrain my mum” (Son, 55-65, co-resident: Interview 1).

Several others with less complex support needs had fallen into a gap in provision. Professionals, carers and people with dementia themselves did not think traditional day care services were appropriate for them. At the same time, their condition raised challenges around accessing mainstream provision. Carers often described the person they care for as reluctant to access services but were pleasantly surprised that they had been willing to continue attending project run groups:

“Quite honestly I think it is a jolly good project because my husband is very happy to go […] he’s always a bit apprehensive about going to any of these things, but […] he’s absolutely delighted with it and if you could please him it must be good!” (Wife, 80+: Interview 1).
One carer spoke of how her husband who had previously been reluctant to access traditional day care groups had happily attended the project run group:

“He’s certainly happier going there [than traditional day care], whether it’s the friendly sort of atmosphere there I suppose... Because it’s all, they’re all together aren’t they, and she organises different things happening like they had a magician one week and, yeah, and a dog, and they go for walks along the seafront sometimes. So he seems quite happy going there” (Wife, 55-65: Interview 2).

4.2.1.2.2 Social interaction

Most carers reported that the support, such as the groups and ‘Out and About’ activities in particular, were beneficial because they provided an opportunity for social interaction for the people they were caring for. The interaction with the CSW was also important for those who were only able or willing to receive one-to-one support. However, outside activities were particularly valued not only for giving the carer a break, but also to enable their relative to experience mixing with other people.

“I think it gives him a break from me. I mean it must be just as bad as I am always there so it, it gives him, it gives him something else to think about ‘cause if he is here he usually spends most of the time asleep whereas if he goes out to do something then he is more motivated” (Wife, 55-65: Interview 1).

“I think it is important for him to get to know that he can, that I don’t have to be there all the time for him and other people can help him as well so that’s why I think it is important for him at the moment” (Wife, 55-65: Interview 1).

“It gives her a little bit of an opportunity to mix with other people, she likes being outside so, you know, even if just walking to the car or doing a little walk, she just feels it is an escape” (Daughter, 55-65, non-resident: Interview 2).

4.2.1.2.3 Improvements to mood and sense of well-being

Some people with dementia were no longer able to take part in solitary activities such as reading or even watching television and could become depressed. Several carers noted that the person they care for often sleeps most of the day and felt that it was good for them to go outdoors. Many people with dementia were able to rediscover interests through this project. Carers felt that mental and physical stimulation through involvement in activities engendered a sense of purpose and motivation and thus improved the mood of their relative.

Although those with dementia were not always able to converse with their carers about their experiences of the groups, several carers described how the mood of the person they cared for improved as a result of taking part in such activities. They felt their involvement had a positive impact on their general well-being (which, as a result, also influenced their own well-being). In two cases, similar activities carried out on a one-to-one basis were also reported to have had a positive impact on the mood of the cared-for person. Observation of the groups suggested that the majority of participants
enjoyed the activities which included singing, dancing, games and lively ‘reminiscence’ discussions.

“[Wife] got up and had a dance and [CSW] had a dance with her and so it is all, it is, you know, she does enjoy it ‘cause it is something, somebody there that is occupying her mind whereas I can’t do it all the time, see” (Husband, 66-79: Interview 2).

“Before she started going to the day clubs and that, she was getting very depressed because unless myself or one of the kids was going in every day, she would ring and would say ‘I am on my own again, all day, nobody’s seen me’, whereas at least when she started going to the club and the coffee club and things, she used to ring me all excited you know. She couldn’t remember what she had done but she was excited because she knew she had been out and come home again you know” (Daughter, 55-65, non-resident: Interview 2).

4.2.1.2.4 A bridge to other support
In several cases the service represented a bridge to other forms of support. In particular, the project helped with transition to day care services. For those who were considered likely to benefit from day care services, it was particularly helpful that project run groups were based in the same building. This served as an introduction to attending day care as service users became familiar with the environment. For others, the support was seen to be important in forging a link to services which may become increasingly important over the longer term:

“I thought it was an easy way to lead him into maybe having other people come in and be with him and maybe through that introduce him to a day centre or whatever and if he was sort of in with the service it might make the progress easier as time goes on” (Wife, 55-65: Interview 1).

A number of carers felt that taking part in these activities would enable the person with dementia to remain at home for a longer period of time than would otherwise have been possible:

“So at the moment the club certainly has kind of kept her at home a lot longer I think, it will do, and with the extra day, that will help as well. It’s sort of the in-between stage isn’t it, between being able to cope all the time at home and not being able to cope at home and that seems to be helping with that” (Daughter, 55-65, non-resident: Interview 1).

CSWs were also helpful to carers, and those they care for, in assisting with the often emotionally challenging transition to a respite facility or to residential care where carers felt this was necessary.

4.2.1.3 Benefits of engaging together
Not all carers wanted or felt able to be separated from their relative during the whole duration of the ‘break’. Nevertheless, these carers described their enjoyment of the intervention. In two cases when the CSW visited the home, the carers sat with their spouse and CSW and took part in ‘brain training’ type activities. One of these carers
described how, despite not giving her a physical break, this brought a sense of enjoyment and subsequent relief to both parties:

“I think it is because he is seeing someone else you know like we are always on our own the two of us. And that little bit of gaiety, which he does when we have fun 'cause we have to find the things that match and so on, I think it did him the world of good. In fact for me it is brilliant 'cause he is a different person afterwards” (Wife, 80+: Interview 1).

In addition to involvement in carers support groups, some carers valued involvement with ‘Out and About’ and coffee/lunch club group activities organised for the service users. These carers would on occasion attend alongside their relative for all or part of a session and some contributed to the development of activities. As well as offering opportunities for social participation, this increased the sense of motivation, purpose and well-being of the carer. Some carers appreciated the opportunity to take part in social activities with their spouse since this would otherwise have been difficult due to the limitations and stigma associated with the condition. Some interviewees described this as ‘normalising’ the support. In addition, attending together for part of a day was useful for some carers in minimising separation anxiety, since they could withdraw once their relative settled in and began to feel comfortable. One carer, for example, explains the benefits of spending the first part of the day with the group, and the second apart from the group with other carers:

“It’s nice to see other people and see the same faces and I think [husband] is reassured that I go with him. And it has meant also that in the afternoon myself and two other carers go off into [town] and we have a look at the shops, we have a cup of coffee on our own, and then go back and collect them so that’s good because it has broadened my friendship base really so yeah, I can’t fault it really” (Wife, 55-65: Interview 2).

4.2.2 Limitations and challenges

Although most of the feedback from carers was positive, some limitations or challenges were reported in relation to the support received.

4.2.2.1 Minimal impact on carer

Two of the four carers who did not live with their relative saw the support as useful for their parent but not to themselves. They felt it had a minimal impact on their caring role (although did not necessarily identify as ‘carers’). Where carers did not feel they required a ‘break’ it may raise a question around the appropriateness of the referral. However, these interviewees had experienced very little contact with project workers and this may be associated with their sense of detachment from the project or lack of understanding of it.

“The only help it will be really is, is more help for my mother than me ‘cause I still go round there tonight anyway so it’s not beneficial to me at all” (Son, 55-65, non-resident: Interview 1).
“I mean I think she’s [CSW] been lovely in that she has popped in to see her and it has been another face for my mum to see, but I can’t see, I can’t honestly say I feel I have been, it’s been of enormous help but then as I say, I wasn’t looking for respite myself. [...] I don’t see myself as a carer actually so where, you know when the name Carers’ Break first came, sort of hit my consciousness I sort of thought oh, it didn’t fit in with the whole sort of scenario as I see it, I mean she is just my mum and I do what I can” (Daughter, under 55, non-resident: Interview 1).

One co-resident carer, who himself was suffering from mental health problems, also felt that although his mother benefited from the support, the ‘breaks’ were of little benefit to him as they made no difference to his daily routine:

“I usually sleep in the afternoons though so it doesn’t really... you know, it’s just like another day really but, you know, as long as... I think it cheers mum up, it cheers her up, so it’s good for her, you know, to get out” (Son, under 55, co-resident: Interview 1).

4.2.2.2 Insufficient or inflexible support
Several carers felt that although the support was ‘better than nothing’ it was insufficient to make any real impact in terms of sustaining them in their caring role. Most carers expressed a need for longer breaks in order to provide more options, for example allowing sufficient time to go out somewhere. Some carers would also like greater flexibility in terms of support on a particular day or help in the evenings. Several carers who were in paid employment considered the benefits to themselves as minimal, as the support was insufficient in terms of having a significant impact on their ability to stay in work. However, in one case support from a CSW did enable a carer to return home slightly later. One carer also highlighted the limitations of a short break in terms of what this enabled him to do:

“I don’t often go out anywhere really because by the time I come back, I’m back about eleven o’clock, and then so you’ve got eleven, twelve... you’ve got about three hours, so it gives me a chance to do things indoors really. So it’s not a break really, it’s not as if I was going to say ‘oh, well I can go out with some friends or my sons which I’d like to do” (Husband, 66-79: Interview 1).

It should be noted, however, that the project was making efforts to set up groups which would cover a longer period of the day from morning through to lunch time and afternoon. By the second interview this carer reported that his wife was soon to begin attending another group each week which was to provide him with an extra five hours respite. In several other cases, however, the length of support had not been increased or had even been reduced. This was owing to various circumstances including the deteriorating condition of the person with dementia (so that they could no longer attend a group). One carer said in both interviews that the support was insufficient to be of any significant benefit to herself. The amount of support provided was unchanged by the second interview:
I mean it’s lovely to have any help at all, but I mean frankly it’s not, two hours every week, or whatever it is, an hour, fifteen minutes. [...] It’s lovely, [CSW] seems very nice, [...] but frankly, you know, we are talking about how many hours in a week? It’s a negligible impact. Very, very nice for my mum, but negligible” (Daughter, under 55, co-resident: Interview 1).

4.2.2.3 Lack of routine / consistency
In two cases the one-to-one support which had been agreed with the support worker had not settled into a routine due to staffing issues. Thus, these carers felt they could not rely upon this support and any positive impact was limited. In one case the carer reported that the support had only been provided five times over the course of three months since the previous interview:

“It’s got to be consistent, it’s got to be somebody who will be there from time A to time B every week without fail ready to roll and if it’s not that, it’s nice, but it isn’t actually terrifically helpful because I can’t rely on it so at the moment. I mean I, hopefully it will all work out, but at the moment, as far as I am concerned, it’s been erratic and therefore lovely when it happens, but not actually brilliant, not really helpful” (Daughter, under 55, co-resident: Interview 2).

In one case where several support workers had been involved in providing the one-to-one support, the carer felt this was also problematic in relation to her father building up a relationship of trust with the CSW.

“It hasn’t sort of bedded down into a regular routine at all, it’s been very patchy, [...] I said at the beginning that if possible I wanted the same person to come in at the same sort of time regularly each week and it’s just it hasn’t worked out really [...] It’s nobody’s fault, it’s just commitments and I feel they haven’t got the staff to do it really. [CSW] runs the sort of coffee clubs and things like that and dad won’t go out to anything, so it needs someone to come here to give me a break and I think they’re finding it difficult to find the people to do these things” (Daughter 55-65, co-resident: Interview 1).

4.2.2.4 Separation anxiety
Separation anxiety was a significant challenge to receiving a physical break in four cases. This referred both to the anxiety of the person cared for being separated from their carer, and the carer’s anxieties around leaving the person with dementia with someone else. For these reasons, these carers would normally remain at home with their relative when the CSW visited. One carer, for example, whose mother sometimes demonstrated challenging behaviour, described his need to “be around if anything happened”. Another carer expressed a strong sense of devotion between himself and his wife, and although he said he would trust the CSW to look after his wife he was nevertheless reluctant to leave her for more than a few minutes. He also had mobility problems and described having little need or desire to go out for any length of time:
“There was only one thing I want to do is have a walk up the front, which I am not going to go out of me house to sit up there for three hours, or walk along there for three hours, which I wouldn’t be able to do” (Husband, 66-79: Interview 2).

This couple did however attend some ‘Out and About’ activities together on occasion. Another couple with significant concerns about separation were also encouraged to attend a group together (after the time of the first interview). Although this still did not provide the carer with a physical break from her husband, it nevertheless was valued by the carer (and her husband) as it enabled her to get out of the house and mix with other people.

Another carer who reported significant separation anxiety on the part of his wife was enabled to have a physical break. Although reluctant, the person with dementia was normally willing to attend a group once a week once having been reassured by the CSW. However, when the CSW came to visit, the carer described not being able to go out because of his wife’s paranoia:

“I stay around with her like, you know, I don’t go out, no. ’Cause [if] I go shopping - I come back she moans I been a long time. ‘Where have you been?’” (Husband 66-79: Interview 1).

### 4.2.2.5 Difficulties / reluctance to engage in groups

Several carers were initially concerned about a potential negative impact on the person they cared for mixing in a group with other people with dementia. This was sometimes because they were worried that the others’ condition may be more extreme and they felt this could be distressing for their relatives. For example one carer stated:

“I just think it would be good for him to meet with other people but I don’t think it would be good for him to meet with people who are too impaired because I think it might give him the idea that that’s how he is going to be, and don’t want that to interfere with him too much at the moment” (Wife, 55-65: Interview 1).

In one case, although the person with dementia liked the support workers, she had refused to continue going to the coffee club because she found the behaviour of another client upsetting. In another case, a man suffering from the early stages of dementia, found it challenging to mix with those with whom he could not hold a conversation, and often found the activities to be too basic and lacking in interest. Some other people with dementia were initially reluctant to join a group setting. However, by the second interview some experiences of mixing in groups had been more positive than initially anticipated. For example, one carer who initially described her husband as unsociable and reluctant to participate in groups had, by the second interview, been happily attending for some time.

Nevertheless, it was not always possible to encourage those with dementia to attend a group where they were reluctant to do so. Sometimes there were also practical reasons why it was difficult for people to join in a group. For example, one person with
dementia also had a hearing problem which added to difficulties in taking part in group activities:

“She didn’t like the coffee [group]. She’s quite deaf now and she can’t hear. She can’t wear her hearing, she can’t organise her own hearing aid which I think I talked to you about before, she gets very confused with it and she can’t hear and she said well we all sat in a big circle which probably isn’t a very good idea, you know, I’m not sure that’s a very good idea but, they all sat in a big circle, she couldn’t hear, she didn’t know what was going on” (Daughter, 55-65, non-resident: Interview 2).

Where those with dementia were unable or unwilling to engage in a group, this posed challenges around sustaining individual support on a regular long-term basis due to staffing issues. In these situations support from the project would be discontinued and normally be handed over to agency carers. However, in some cases this created problems as discussed under the ‘withdrawing support’ section below.

4.2.2.6 Lack of involvement and awareness of support available

Four carers had very little or no contact with the CSW. Two of these were non-resident carers. They had received very little information and reported knowing very little about the support their relative was receiving from the project, or about any future plans. According to the project database for February 2011, none of these four requested or received a carers’ assessment.

“[CSW] rang me to say well ‘I have been to see your mum’. Now I actually thought she was perhaps a voluntary helper, I didn’t know really who she is, and I mean I was told ‘Oh no I am [name] from the Carers’ Break project’ which actually didn’t mean anything to me. I didn’t really know. [...] I was so sort of vague about what the entire project is and what their role was in terms of me and my mother” (Daughter, under 55, non-resident: Interview 1).

One of these carers knew little about the project since her husband was limited in his ability to recall and communicate his experiences of the coffee club he attended each week. She had also experienced difficulty attending medical appointments and was not aware this may be something the project could help with:

“I am more or less shall I say in the dark really you know, I haven’t been told very much” (Wife, 80+: Interview 1).

By the second interview this carer, had received no further contact from the CSW and was no better informed about the project. This carer and several others also expressed some confusion about the system in general and about their entitlements to other forms of support such as residential respite care. Most carers were also unsure what a carers’ assessment was, whether they had received one or what impact this may have had. However, according to the database, ten (48%) carers had requested an assessment and seven (33%) of these had received one.
Few of those interviewed were involved in a carers’ support group, some were not aware whether it would be possible for them to attend one and three (all male) reported that they had never heard of carers’ support groups. Those under 65 tended to be most reluctant and unsure whether this would be something they would benefit from. However, the gender and living arrangements of the carer also appeared to be of significance. None of those who did not live with the person they cared for (of both genders) considered a carer’s group relevant to their needs, but the female co-resident carers were either engaged in a group or, in one case, in an email network of younger carers (facilitated by a VCO) through which occasional informal meetings were arranged. The younger male co-resident carers were reluctant to engage in a group.

For example, one man in his 50s was concerned that he would not ‘get on with’ other carers or be able to relate to them. Another co-resident male carer of a similar age had attended a group but felt uncomfortable that he was “the youngest there by at least 15, 20 years” and did not subsequently return to the group. Two male carers in the older age groups also lacked interest in carers’ groups, but most of the other male carers were either involved in a group or interested in finding out more. One male carer had attended groups previously but reported that it was now difficult to attend because the breaks he received did not coincide with the carers’ group. Two older female carers were not involved in a carers’ group, but most of the other male carers were either involved in a group or interested in finding out more. One male carer had attended groups previously but reported that it was now difficult to attend because the breaks he received did not coincide with the carers’ group. Two older female carers were not involved in a carers’ group, but this was because they felt it would not be possible to attend. In one case this was owing to the separation anxiety of her husband, which prevented her from going out. The other felt she could not attend because of sensory problems which she felt would be a barrier to participation, and also because replica care was not available (or she was not aware that it was).

“I’m not much good in a group [...] because of my hearing problem, and apart from that, I mean, I’ve got a patient to look after, and it’s difficult to get away, you know” (Wife, 80+: Interview 2).

4.2.2.7 Relationships with other services

Three carers reported that the support they received from the project conflicted with day care provision they had been allocated, which they felt was problematic. In two of these cases, the carer had difficulty deciding which group to choose. One carer chose the Carers’ Breaks coffee club over day care because she was concerned that if her husband did not like the day care group, he would not be able to later go back to the coffee club:

“He’s been going there so long now, as compared with the day centre, and he likes it there, so why take him away to go to the day centre, which he might not like? And if he didn’t like it there it’s a job to get back into the other. But he couldn’t do the whole lot, you know, he couldn’t have another day of respite, but I honestly don’t know why” (Wife, 80+: Interview 2).

In another case Out and About activities overlapped with VCO day care provision and although the carer felt these were more beneficial, he was concerned what would happen if funding to the Carers’ Breaks project finished. Another spoke of how her
mother had to leave the day care group early in order to attend the project coffee club taking place in the same building:

“What would be much, much better for me and for my mum is if it was something that was consistent and, what’s more if it didn’t overlap, if the coffee thing didn’t overlap with the [day care] thing. I mean that just seems to me to be really odd” (Daughter, under 55, co-resident: Interview 2).

There were also examples of problems co-ordinating home care with Carers’ Breaks services. In one case home carers were visiting a woman to give her lunch at a time which coincided with the CSW arriving to pick her up to take her to the coffee club:

“[On] Wednesdays, which was when she was supposed to be going to [coffee club] it seems that the carer was arriving too late to give her, her lunch, so she couldn’t be ready in time to go out. [CSW] has herself yesterday spoken to the carer agency to change the time and to stipulate that, you know, we require somebody at a certain time on a Wednesday” (Daughter, under 55, non-resident: Interview 1).

4.2.2.8 Withdrawing support
Support was withdrawn from four service users (excluding those who ended the support owing to death or admission into residential care). Withdrawal of support was an objective of the project. However, some problems were experienced in relation to this.

In three cases support was withdrawn because the person with dementia had been unable or unwilling to engage in group activities. Therefore one-to-one support was considered an inefficient use of staff resources. Two were handed over to sitting services by the time of the second interview. One of these, plus the other person with dementia, also continued to receive support from home carers. The two who were handed over to sitting services, however, subsequently asked for the support from the agency to be stopped because they were not happy with their replacement worker. These carers regretted the loss of support from their CSW.

“[CSW] was great, she was really truly great, and when they changed it over it went all to pieces, they just come and sat there. [...]When [CSW] was here I thought right, if I want to go out, I would feel safe, [...] but with the others, I didn’t feel safe. There was something there that I didn’t feel safe, but [CSW] top of the world, I felt top of the world with her. I could have gone out and left [wife] all day with her” (Husband, 66-79: Interview 2).

“She [agency worker] came four times in total, twice she took her out and each time it seemed to get worse and worse and [wife] would say ‘Oh I don’t want to go’ and I would say ‘Come on you’ll enjoy, you will enjoy it’ and she was persuaded to go out. And she would come back and [agency worker] would say, ‘Oh she’s been fine’ and [wife] would go ‘hmmm’. And as soon as she’d gone she would say ‘I don’t like, I don’t want to go out again’ and I’d say ‘No, it’s, you’ll be fine’. But no, it was, no, she couldn’t take to her at all,
which was a shame because it was, previously with [CSW name] and with [other CSW] it was excellent” (Husband, 66-79: Interview 2).

In the other case, support was withdrawn because the service user was introduced to day care (as was the objective of the care plan). However, by the time of the second interview, this service user had been admitted into residential care.

It was also reported (by the CSW) that another service user would be shortly handed over to a sitting service because of a change in her physical condition which meant that she was no longer able to attend groups nor felt to benefit from the efforts of the CSW to provide mental stimulation. Physical health problems of service users had also caused support to be interrupted in other cases, and for one person in particular, who had not been able to take part in an Out and About group since suffering an accident, support had been put on hold for some time.
5  Context and impact

In this chapter we consider the different circumstances of those using the Carers’ Breaks project and how this related to the benefits or limitations reported by carers and workers.

5.1  Capacity and willingness to engage in group activities

The project enabled engagement with those for whom existing services were not appropriate. Traditional day care, for example, was often felt to lack the stimulation and personal interaction which those with less complex support needs required. The interviews suggest that the project was particularly successful in working with this group. However, it was sometimes harder to include those considered to have higher support needs:

"The carer support workers are, I think, working really successfully with people whose level of physical impairment and cognitive impairment may be slightly, I’d describe as moderate rather than severe, and who respond really well to dynamic, stimulating social inclusion type support. [Name] is an example of someone whose needs are too great now to be met by the carer support workers.” (Care coordinator).

Where people needed substantial one-to-one support to engage in group activities, support from the project could often not be sustained. Although there was positive feedback where CSWs had been working on a one-to-one basis with people with higher support needs, this use of CSW time was not considered to be resource effective and therefore could not be continued indefinitely. This was particularly an issue in relation to those with physical disabilities or complex health problems who may be prevented from leaving their home, particularly since the project was not always able to provide transportation.

There is not a straightforward connection between the progression of dementia and capacity to engage with group activities, since dementia can have varying influences upon people’s cognitive ability and emotional stability. The key issue is the extent to which the progression of dementia results in an advancement of challenging behaviour in a group context. The case referred to above, for example, was one in which the cared for person became emotionally anxious and distressed when away from home, and this had a negative impact upon others in the group. In other cases dementia had a relatively severe impact upon the individual but this did not act as a barrier to their enjoyment of participation in a group activity. For example, one man whose carer and care coordinator took part in the evaluation, had very little ability to communicate verbally and yet showed no signs of emotional distress. He appeared to enjoy Out and About activities, and his behaviour was less challenging and easier to manage in a group situation.

To a lesser extent, some challenges were reported involving those with less complex needs arising from their dementia. In these cases the group activities were sometimes
perceived to lack sufficient stimulation, or people were reluctant to participate because of personality issues rather than because their dementia made it hard for them to do so. Placing more able people in an environment with others with more complex problems could cause distress. However, in most cases this was minimised through the relationships established between the CSW, the person with dementia, and their carer which enabled service users to feel more comfortable in a group situation.

The Out and About groups were reported to be particularly valuable for those whose dementia was less advanced, especially since these were often personalised to the interests of the service users. The use of mainstream community settings such as swimming pools, ten-pin bowling alleys, pubs, cafes and museums was felt by some to ‘normalise’ the support and reduce the stigma which, for some service users, was associated with more formal types of support. When those who found larger group situations difficult were enabled to get out into the community either on a one-to-one basis or in a small group, this was felt to be particularly beneficial:

“I mean some people just don’t want to do, they don’t want to sit in a group activity, they would rather go and do something on their own so it’s taking them out and actually, you know, that’s more beneficial to them doing that because they are going out and doing something that they would really like to do rather than sit in a group of people” (CSW).

One CSW emphasised the need to carefully manage the Out and About groups in terms of balancing different levels of need:

“You have to balance the people that you’re taking out and be mindful that you’re not taking on too much as a carer. I wouldn’t take out three people with very high needs because you have to always be mindful of how people can change once they’re out” (CSW).

Most staff and community partners felt that those without, or with less advanced dementia were generally accepting and understanding of others’ disabilities within mixed groups. Community partners noted the importance of maintaining a balance in community settings between those with high and lower support needs:

“It is about 50:50 sort of ratio. [...] I think if it tipped the wrong way it just wouldn’t work. But I think it’s quite good as well because actually arguably if we had more able people and only a few of like the group we are talking about, I think that they actually might get a bit lost in it” (Community partner).

Staff reported that in most cases they were able to resolve any issues around managing challenging behaviour and engaging those of differing abilities. Strategies discussed in interviews and observed in group settings included focussing on activities that all service users could participate in (some with extra support). Musical activities such as musical bingo were found to work particularly well.
“We’ve both been surprised about how well it’s worked. Because you’ve got some people that are dysphasic and they can’t actually string a sentence together but they can, they still seem to be able to do group stuff, and especially with the singing and the music, that seems to be a common thing around them all, and they can actually remember songs even if they can’t string a sentence together. So it’s about sort of common themes of bringing people together and it’s worked really well” (Resource officer).

CSWs sometimes addressed the issue by involving more able users in a ‘helper’ type role, for example assisting with setting up activities or helping distribute refreshments. Another strategy observed to successfully engage those with different levels of dementia was to sub-divide into separate groups, allowing greater and less mentally challenging activities to take place simultaneously. One CSW also described how she had set up a separate group within the community group for part of the day:

“I sort of started up this back end of the room group where I bring colouring in or word search or whatever, I have got hangman today, and that, and that really works really well. So it’s actually helped the group to offer another activity by me being here ’cause we have our after dinner little group at the top now so they have got their scrabble here, they do the bingo, and now there’s this other little activity that I do at the top, so[...], it works quite well” (CSW).

5.2 Quantity and reliability of support

There was some variation in the quantity and consistency of support provided to carers. Some carers received less than one break a week from the project whilst others received more than five. These variations did not necessarily relate to need or to other support received, but to resources available by area. The amount of support considered ‘sufficient’ is also subjective to the individual carer and, except for a minority of cases where the cared-for person was perceived as unable or unwilling to engage in further support, most carers would like more breaks. However, the impact of the support appeared to have had a more significant impact where the carer was enabled to take a break at least twice (two days) a week. It was particularly beneficial for carers to be provided with a break covering a whole or major part of a day. This allowed them sufficient time to go out or to relax at home before having to return home or to go back out to collect their relative from a group. It should be noted that in five cases, support from the project (and/or from other support such as day care) had been extended between the first and second interviews, allowing these carers a greater degree of flexibility.

Regularity and consistency were vital aspects of the support, both for the carer and those they were caring for. This was in terms of time, day and individual CSW i.e. the same person each week. In most cases this was ensured but where demands on staff time led to reduced flexibility, the effectiveness of key aspects of the project were minimised. This is particularly in relation to the necessity to build a relationship of trust with the carers and those they care for, and the need for the carer to be able to
make plans based on having a break at a particular time in the week. Where support
could not be relied upon, this became a source of anxiety for the carer.

Those carers who were dealing with the challenge of maintaining a paid job,
considered the support insufficient to make a real difference to their situation. Three
live-in carers were in full-time employment and all were struggling to juggle their
caring and work (and study in one case) responsibilities. They felt the support from
the project was insufficient to have any real impact on their ability to stay in work. In
one case the arranged one-to-one support (in addition to a coffee group) was only once
a fortnight and sometimes had not happened due to staff absence. Therefore the carer
felt she could not rely upon this. In another case the carer shared their caring role with
other family members and the one-to-one support occurred on the carer’s day off, so
this did not impact significantly on his ability to stay in work. In the other case,
however, the cared-for person received substantially more help through a combination
of support from the project and day care provision, which together amounted to
breaks every day of the working week. In this case the impact was considered to be
more significant.

5.3 Involvement of carers as ‘partners in care’

Some carers had developed a strong relationship with their CSW, whereas others had
little or practically no contact. Some were unsure, and expressed some bewilderment
concerning the roles of various individuals from health and social services involved
with their case. Carers often described feelings of isolation in the midst of this.
However, where they were able to build up a relationship with the CSW and were
better informed about the project this appeared to have a positive impact upon their
well-being. One-to-one introductions were considered important but, in some cases,
CSWs were unable to make initial visits to discuss the project and the type of support
carers would like to receive. One CSW gave an example of this:

“I didn’t have any time to visit them so I just rang them up and I said, ‘It isn’t normally the
way I would do it but if you are free [on specific day] to come along and meet me that
would be fantastic’. So they did, so we met straight away, straight into the group and
got bang straight into the group, I’ve never even been to their home, they came straight
away to my group” (CSW).

Carers tended to be more positive about their experiences where they, and the person
they care for, had been better informed and consulted about the project. Those who
were involved in shaping the provision, through discussing and planning group
activities or developing a carers’ support group were particularly enthusiastic. Some
carers also welcomed the opportunity to attend the group with their relative and stay
for part of the day since this was felt to be beneficial in reducing separation anxiety. It
also built a sense of community among those involved with the group. Although not all
carers wanted to be involved to such an extent, some of those who were involved in
this way expressed a growing sense of control in the face of uncertainties around how
the dementia would affect their lives. At the same time, however, some carers described an appreciation of the CSW taking the initiative in suggesting and planning activities for the person they care for, as this gave them a break from the thinking involved in how to provide motivation and mental stimulation.

5.4 Type of carer

Although carers of all types benefited from the project, the support was particularly valued by older carers who cared full-time for their wife or husband. Older female carers were, however, more likely to report the importance of the personal support received from their CSW and were more likely to be actively engaged in carers’ support groups and/or involved in joining activities with those they cared for. Evidence from staff/partner interviewees reinforced this finding.

Although the support was of particular importance to live-in carers, some carers who did not live with their parent also noted the importance of the support from the CSW. For example, one spoke of how she valued having an extra person to ‘keep an eye’ on her mother whilst she was at work and having been alerted to serious safety issues she would not have otherwise been aware of. Two women carers who did not live with their relative, and who were not in paid employment, had many other family responsibilities including caring for grandchildren. The scheme gave them a psychological break through offering peace of mind through the assurance their parent was in safe hands. One also spoke of how the support gave her a break from phone calls whilst her mother was attending a group, allowing her some space to get on with things she needed to do. In one of these cases the carer reported that support from the project was pivotal in delaying admission of her mother to residential care.

As noted above, most of the younger carers who were in employment found the support less helpful, since this had been insufficient to have any significant impact upon the amount of visits or support the carer was giving, or on their ability to stay in work.
6 Staff perspectives

6.1 What works?

There were a number of ways in which project staff and partners considered the project model to be successful and distinctive in comparison with other forms of support available to people with dementia and their carers. The key factors contributing to the success of the project, when working at its best are:

6.1.1 Building a relationship of trust

The ability to build a friendly, trusting and 'down-to-earth' relationship with the carer and those they care for was essential. The ability of CSWs to interact positively with service users was felt to derive from skills developed through prior relevant experience and from the personal qualities of individual staff. Through initial one-to-one interaction, CSWs are often able to bridge the gap between professional and lay systems of care and overcome reluctance to participate in services.

"The skill is that you can walk into a strange home and talk to people. You have got to build up their trust and you don't want them to think that you are going in there to change the world. As I say, some of them are very nervous when you go in, by the time you have spent time sitting chatting, and they love to talk about experience, experience of the world really you know. These people worked, these people were ones who a lot of them fought for our country - they have so much to give" (CSW).

“One man who hasn’t been out of bed for two years because he was so depressed, as well as his dementia, he suffered with depression. And of course the upshot of that is his carer was depressed. She was at the end of her tether and said she couldn’t continue caring, and the support worker sat on the end of the bed for the first six weeks, just ‘Hello, I’m here’, you know, getting to know him a bit more gradually, making little breakthroughs, and I think that was the key” (Project manager).

“I’ve been grateful for everything I’ve had... and they’ve never made it feel like charity, you know, they’ve always made it feel, they’ve always said ‘well of course you’re entitled to it, but it isn’t that, we feel that we want to help’. So it hasn’t sort of, although I’ve been indebted to them, they haven’t made me feel as if I’ve been a nuisance and a bother... in fact they’ve come into the house as a friend really” (Steering group member/carer).

6.1.2 Working in an integrated way with carer and person with dementia

Staff highlighted the importance of working in a way that acknowledges the importance of the relationship between the carer and person they care for, and is responsive to the needs of both, rather than focussing only on the needs of one or the other. In particular workers felt that carers wanted to be assured the person they care for is enjoying the support, and to feel involved in the process of engaging the person with dementia in new activities:
“I think a lot of it was building the confidence of the carer as well, that actually he [service user] may well enjoy it if he came along, he may well, and if she can somehow sort of coax him with me, we work together” (CSW).

The enjoyment on the part of the person being cared for was particularly important in relieving any sense of guilt on the part of the carer about taking a break. Therefore this was also essential for the carer to experience benefit from the service.

“For them [carers] to see their nearest and dearest out and about enjoying and getting, you know, to come back and talk about something they’ve done and enjoyed it as well as getting the break is fantastic. Too often the support is revolved around, you need a break but, you know, for example, but the client’s really not getting much out of it but the carer’s getting a break which is really important for the overall picture. So we’re getting a balance here, where actually the client’s really enjoying what they’re doing and the carer’s getting a break so the carer doesn’t feel guilty about having a break and that has been an issue in the past” (Care coordinator).

6.1.3 Focusing on the person, not the disease

A person-centred approach to the care provided to people with dementia was deemed essential in order to draw out, respond to, and facilitate the rediscovery of personal interests, and build self-esteem through social interaction. In some cases the carer also took part in activities from which they similarly benefited. For example, some carers and their spouses visited museums in response to the personal interests expressed by the couples involved. Other carers, and those they care for, were involved in a swimming group which was formed in response to the personal interests of one service user and then expanded to include others.

“What I really like is the attitude of the whole project, that just because you’ve got dementia it doesn’t mean to say that you shouldn’t go out in a speedboat or you shouldn’t do whatever. Basically it’s about enabling people and supporting them within the context of their illness, because I think there’s generally a very low expectation of people with dementia, and it’s often not the case. If you can just find them and support them, they’re capable of so much” (Project manager).

“I always take people as they are, people are people, you just deal, because everyone’s different and everyone has got different abilities or inabilities to do things and you just find out what they are and be friendly. I don’t know, just be a person, not worry, and not sort of see “oh this person’s got dementia, I must treat them like this, they’re put in this box and they’re going to be fine or they’re going to wee themselves or whatever” (CSW).

6.1.4 Providing opportunities for social interaction and stimulation

Group activities, particularly Out and About groups, were felt to play a particularly important role in providing opportunities for social interaction and mental stimulation which may not be otherwise available. The psychiatrists interviewed also emphasised the importance of physical exercise upon mental health, even if this only involved
going out of the house and into a different space. Being introduced to a new environment was felt to have a stimulating effect on the brain. Taking part in small group activities was considered beneficial, particularly where these included activities such as music, art, dance, gentle exercise, games and conversation stimulating long-term memories. Such activities were often felt to have a positive impact on the mood and responsiveness of service users. Project staff and care coordinators considered the activities provided by the project were more appropriate and stimulating for service users than those often provided in traditional day care settings. In part this was felt to be related to the more personalised nature of the support, and the smaller ratio between staff and clients.

“I think a lot of my people, actually, they are attending there [project group] and they like it, [...] they are engaging in a chorus or singing by themselves, this actually, it increase their language, their comprehension, their ability to concentrate and their attention. And, again, they feel that they are part of others, it is very good. It is very, very, very good. [...] I believe music and art therapy is important” (Care coordinator).

“They [CSWs] find out somebody likes word searches so they’ll go to the internet, find loads of word searches and photocopy them and bring them in, and some people really like doing that. Some people like quizzes, they like songs, you know. It’s just about, some people like you to read out poetry, going to museums, you know, it’s just about finding out what that person is interested in and trying to link them into it” (Resource officer).

6.1.5 ‘Normalising’ support

Another key feature of the project that was felt to be particularly important was the way in which it helped to ‘normalise’ life for those with dementia and their carers through enabling service users to take part in activities in the community. Out and About groups accessing mainstream community facilities and groups which were mixed (i.e. including those with and without dementia) were found to be particularly useful in order to reduce a sense of stigma.

“It’s that taking away the stigma of having the dementia and going somewhere that looks like a hospital setting but she [service user] has been able to go out for a cup of tea with other people and just be normal if you know what I mean. I think it has made a big difference there really” (Care coordinator).

“I think it gives them a sense of normality especially things like the Out and About group and doing like the one-to-ones where you’re out in the community and I mean I took one lady out and she said ‘oh I haven’t been to the shops in ages.’ [...] She was just happy as anything and she absolutely loved it. She was just bright as a button and really came out of herself, [...] she was quiet and nervous and shaky and then we just went around the shops, nothing major is it? We take it for granted and she was really happy” (CSW).
6.1.6 Supporting carers

Another important aspect of the support was improving the well-being of carers through offering further support specifically to them. This included practical help and advice and a listening ear from support workers, and through the friendship of other carers facilitated by support groups.

“I think it is another person that they can talk to, a lot of the support workers are very supportive of the carers, they can talk about what is happening with the person with dementia to the carers and how they might respond to it for example, so I think that’s a helpful aside” (Care coordinator).

6.1.7 Regaining control

Some workers spoke of the importance of facilitating service users and carers to take more control over their own care and support, through, for example, involvement in planning group activities and developing independent carers’ support groups:

“They’ve also set up a carers support group within that group as well, totally by themselves and they’re gaining such a lot from talking to other carers and they don’t feel so alone and, you know, they’re meeting people in the same situation having the same problems and they’ve all found that really helpful. And they’re actually setting up a weekend away together, they’re all going to go off and have a weekend away, with their partners, their other halves, but they just said ‘We all know the sorts of problems that each other are having so we can all support each other’, and that’s what they want to do. So it’s, they’ve gained an awful, awful lot from it” (Resource officer).

One CSW described her input as facilitator rather than a leader. She described how those with dementia had been taking responsibility for shaping the Out and About group activities that took place each week:

“I’m just the driver, they talk amongst themselves and I just make sure that they’re safe” (CSW).

6.1.8 Being connected

Project staff and partners spoke of the importance of the project being linked in with other services in a way that enables service users to access existing provision such as day care, and other services in the community where possible and appropriate. Staff spoke of the importance of including service users in the wider community. This was made possible through complementing and supporting existing provision and sharing resources.

Staff considered that they had been successful in developing links with statutory and community organisations and finding innovative ways to engage service users. Staff also felt in most cases good working relationships had been formed with OPCMHTs, and that the project had greatly benefited from the supervision and expertise of social care and clinical staff.
“The support that’s a real, it’s a good way of reviewing what you’re doing is right for the people as well, because if you say ‘well I’ve done this, is that what you were thinking?’ And because they’re health professionals or social service professionals you’ve got a back up in a way and it’s kind of, it’s nice to know that you’re doing the right thing really rather than just sort of going in blind and not really knowing what you’re doing. It’s quite difficult I think if you don’t have that back-up from the health professionals” (CSW).

6.2 Organisational issues

Staff and other partners highlighted organisational and logistical issues that needed to be addressed to improve the operation of the project.

6.2.1 Communication

6.2.1.1 Communication with OPCMHTs

6.2.1.1.1 Introducing and promoting the project

Most care coordinators described how they were initially unclear about the remit and detail of the project. Some felt that introductory communication between the team and the OPCMHT towards the beginning of the project had been lacking. This was to some extent attributed to the lack of information conveyed to OPCMHTs prior to establishment of the project, which was the responsibility of operational management.

The breakdown of communication resulted in an initial lack of clarity around the role of the project amongst some care coordinators and led to some concerns around possible duplication and conflicts in provision. Although for the most part it became clear to care coordinators that support from the project was distinct and complementary, some concerns continued to be raised about this. For example one care coordinator reported concerns about a service user who had been placed as low priority for day care because of having received support from the project. It was felt that this would be problematic for this person if project funding came to an end. However, another care coordinator in a different area of the county described how the lack of initial clarity was beneficial because this allowed the team to remain flexible to the needs of the area and responsive to feedback from the OPCMHT. The success of the project was attributed to this flexibility.

“It wasn’t completely clear to start off with how it was going to work, there was talk initially of sort of like short little drop-in day centres type things, carer support workers and of course carer support groups and stuff like that. But it was very much they were open to feedback from us in regards to what we felt our clients and carers needed and that’s why it’s worked so well because they’ve adapted the service to meet this area’s needs” (Care coordinator).

6.2.1.1.2 Ongoing communication

Where the project team and the OPCMHT were based in the same building, care coordinators were generally more positive about communication since this increased
the likelihood of regular face-to-face contact between CSWs and care coordinators. One care coordinator highlighted the importance of being based on the same site:

“Obviously the fact that they’re based in the same building, I think, is fairly imperative really. And, you know, we do work from a multi-disciplinary perspective and incorporated within that, you know, I would see them most days, or they can contact me on my mobile if there’s a problem” (Care coordinator).

A care coordinator who was not based in the same building spoke of how the lack of informal communication limited the effectiveness of communication:

“I think that’s quite often the way that people communicate with each other is through the team meetings but I’m not at whatever meetings they’re at so that doesn’t happen, and I guess because we’re not on the same site I think quite often again people communicate just informally with each other in passing, [...] if you’re working together with someone you just bump in to them and mention something, but I think because they’re not here that doesn’t happen. So you’re a bit restricted really, sort of, probably, yeah there’s no sort of formal feedback from them about how it’s going” (Care coordinator).

Where face-to-face contact occurred less frequently, communication was considered to be less effective. One care coordinator described having experienced some difficulties making contact with a CSW by telephone.

“I would say that’s probably one of the weakest things is the communication because there was someone I referred [...] and I really wanted to get their (CSW) feedback and I really struggled to get hold of them, I think because they’re out all of the time in fairness to them, they don’t tend to be there. But I did struggle to, it took me weeks actually to get, I sort of emailed and I phoned but she wasn’t there” (Care coordinator).

Having two separate computer systems for health and social care was considered inefficient since CSWs were required to record notes on both systems. Where this issue was discussed, all felt that an integrated system would be more helpful. Concerns were also raised about the implications of a possible change to current policy whereby CSWs may no longer be able to access both systems.

“Because we put all our notes on ECPA, so health can see that we’ve been in (to see a client) but if we’re putting it on Care First they won’t know whether we’ve been in or not or how many times we’ve been in, whenever the last visit was or anything like that. So they could then go in for a visit and we could have missed two weeks because we were on annual leave or something and they may not have realised that or whatever because sometimes we don’t get in here every week and they might not have known that and they think ‘Oh well why hasn’t she visited?’ and yeah, it could then cause problems” (CSW).
6.2.1.3 Reviews

Reviews involving the care coordinator, CSW, carer and person with dementia were intended to be conducted regularly in line with the Care Programme Approach (CPA). However, in practice, care coordinators indicated that there were variations in the nature and extent to which cases were reviewed. Most care coordinators understood the support to be ongoing rather than time limited and some were not aware of the policy to review six weekly with support workers, or felt this was not always necessary especially after the initial review. In some cases reviews had taken place involving members of the OPCMHT but not the CSW:

“I think they did talk about six weekly reviews but I think unless that would happen to coincide with the CPA, unless they do their own reviews, I don’t know. I’ve never heard of any reviews that they do, there certainly hasn’t been any joint reviews specifically for the Carers’ Breaks project, for my people anyway, maybe for other people. But it’s just carried on, it’s just gone on, you know, people that I’ve referred, well say six months ago, are still going to the groups” (Care coordinator).

Some care-coordinators described how after an initial review they were happy to hand over to the project since they were confident the project would make contact if there were any problems or changes in circumstance. One care coordinator also felt that issues could be dealt with by the project resource officer and that it was therefore unnecessary for care coordinators to be involved in all cases. However, another care coordinator felt that where cases were ongoing more regular reports (about once every two months) would be helpful to assist with keeping in touch with each case.

6.2.1.2 Communication with community partners

For the most part, communication between the project team and community partners appears to have worked well. However, one community partner noted an apparent breakdown of communication where a service user and carer arrived to access a service (which the project had previously supported the person with dementia to attend) before an assessment had been processed and formal agreement reached that the person with dementia could attend without the support of the CSW. This caused some tension between the partner organisation and the carer who found it difficult to understand why it would not be possible for their relative to continue attending the group before a Care Plan had been put in place. This may also be indicative of a deeper tension between a project seeking to work flexibly and a wider system which is intrinsically less flexible.

6.2.1.3 Communication with service users

Carers and staff emphasised how the support workers were highly skilled with regard to communicating effectively with carers and service users with dementia. However, one CSW also felt that communication with carers could be improved in relation to the way in which carers are introduced to the service. She felt that there were sometimes challenges in explaining the concept of the service to the carer and that it would be helpful to provide carers with a simple and clear leaflet explaining the purpose of the
project. She also felt that this should explain that the support would be time limited in order to help with the problems faced when support was withdrawn.

“The one thing I would like to see, I mean I have spoken to my manager about, is the leaflet to be given to the people before we go. We knock on the door and we are a strange face you know and also they think they have got you forever and that’s the hardest bit when you say ‘no we’re not’. But if we had a leaflet explaining that what we would be going there for, and saying you know it’s only for a short time but they will help you, anything like that, any information about us before we go and then [...] they can sit and read it” (CSW).

6.2.2 Staffing issues

CSWs discussed the challenges of organising their time due to the growing demand for the service. Some CSWs and care coordinators highlighted a tension between seeking to increase the quantity of provision whilst maintaining the quality and flexibility of the service. There was a growing demand for the service evidenced by more referrals, and it was hard to respond to this whilst continuing to provide continuity of support through which relationships of trust can be developed.

“They struggle with time sometimes because you know they’re trying to take on new people, get introduced to new people and setting things up for them and then a lot of it is they transport them around you see so it’s not only just setting up a group, they have to go and pick them up and take them here and take them home and all those sort of things so yeah, it is quite challenging for them” (Resource officer).

The project has attempted to increase staff available to respond to referrals by training agency workers through job shadowing and attempting to handover those requiring long-term one-to-one support to agency workers. Agency workers have also been taken on to assist group work. As of February 2011, the project manager advised that the project was working with fourteen external agencies and also training four volunteers. In the Hastings area in particular, following the loss of a key member of staff, agency workers have enabled the project to maintain service delivery. The aim of this has also been to enable a continuity of care when the needs of the service users change, i.e. where a service user who had been attending a group can be transferred to home based respite with one of the same agency workers who had been supporting the group. Some difficulties were reported in relation to employment of agency workers in group work. The problems highlighted by staff relate to an experience and skills deficit among agency workers. This is understood to result from the inappropriateness of their training which has focused on providing personal care rather than facilitating engagement of service users in stimulating activities.

“I had an expectation that these staff would be able to work at this level, so for me it’s a real learning curve, that their role within the domiciliary care agency is very, very different to our role and the community support worker role, the social engagement, very different” (Project manager).
“It’s become more evident to me since we’ve taken on the agency staff just how experienced our staff are, and that’s been a real eye opener to me. Because the people from the agency, although they have all the NVQs and they’re supposed to have done all this training, they haven’t got, there’s still the interaction skills that my staff have got, and that, as I say just comes with experience I think” (Resource officer).

Some problems had also been experienced by carers in relation to handovers to agency sitting services (see 4.2.2.8). The project is aware of these issues and the project manager noted the need in some cases to go back to the agency and discuss possible reasons for problems identified by the carer.

One care coordinator was concerned that training would be a lengthy investment which may not pay off due to the high turnover of agency workers and it would be more beneficial and possibly more cost-effective in the long run to recruit more fully trained support workers. This person considered that the project was currently ‘reaching saturation point’. Some people also questioned the feasibility of the aim of handing over to community groups after a period of training and introduction to a service user. Community partners were clear that it would not be possible to include people with high support needs without the support of extra staff resources to their organisations.

6.2.3 Transport and other resources

Transport was a problem in all areas where carers were not able to transport their relative to a group. CSWs would often provide transport but capacity issues led to difficulties with providing this in some cases. Where possible, CSWs would refer to the NHS Voluntary transport Service but this was not always available. Sometimes service users were not ready, or were reluctant to leave when CSWs came to collect them. This could delay a CSW arriving at the group. However, some staff also noted the advantages of the CSW taking this role. Where service users were confused or nervous about going to a group, it was particularly important to be collected by someone they felt comfortable and familiar with. In these circumstances being collected by community transport could be problematic.

“Transport tend to not get it right sometimes, they pick the first person up and then go all around the houses so it was quite a long trip for [name] to be on a minibus and she, she was such a good character actually but she did like her swear words at times as well and I think it just got too much for her, it was too long” (CSW).

“When we had to set up transport for her, she wouldn’t come on the transport on her own so it sort of fell apart. [...] She was very reluctant to come and also, it’s very, people find it very difficult to get themselves organised to go out” (CSW).
Transport problems were particularly difficult to resolve in High Weald due to the rural character of the area and fewer resources available in the community. Hence people were often required to travel significant distances in order to attend a group.

“I’d say it’s quite thin on the ground here for the elderly and those with dementia, there are groups and lunch groups that we try and look into, if possible, taking people and engaging with them more, but I’d say it’s quite thin on the ground” (Resource officer).

However, as of February 2011, it was reported that the project was working with a 3rd sector company with the hope of piloting a transport scheme in the High Weald area. In High Weald and elsewhere challenges were also reported around identifying community resources for Out and About groups to link in with during the winter months. However, CSWs had identified a number of indoor facilities available including events in church halls, swimming, ten-pin bowling, museums, tea rooms and pubs.
7 Discussion

7.1 Project aims and objectives

The findings presented in this report have shown a largely positive reception and impact of the service upon carers. This section discusses evidence from the data on the extent to which the three key aims of the project and its specific objectives have been met. It then looks at the findings of the evaluation in relation to current policy objectives.

7.1.1 General aims

- To positively impact the health and well-being of carers and those they care for (including those who are currently ‘under reached’).

Findings have shown that the support is particularly important in reducing carer stress (and in some cases depression), having a positive impact on well-being and thus potentially on health. Several carers noted an improvement in their general well-being and this was particularly notable among those with a full-time caring commitment who previously had little opportunity for social interaction, and received support both from CSWs and from other carers met through the project. In addition, at least one carer interviewed was enabled to attend medical appointments. As may be expected when dealing with the progressive nature of dementia, most carers felt that the health of their relative had declined between the first and second interviews. However, several felt that their general mood and well-being was improved through engagement with the project, and some believed this may have some impact on slowing the speed of the deterioration caused by the dementia.

Comprehensive data is not available to assess the extent to which the project has been successful in benefitting those who were previously ‘under reached’. However, it is clear that several interviewees who reported a positive impact from the service, had not previously been receiving any other form of support and some had experienced problems in engaging with other services. It appears that those from BME communities participating in the project may be under-represented, and this may need to be addressed. However this is unclear owing to the amount of missing data on ethnicity.

- To prevent carer breakdown and thus reduce the demand on intensive health and social care services

It is difficult to make an accurate assessment of the extent to which the support provided has been effective in preventing greater demands on health and social care services. Data from the local authority relating to uptake of relevant services has not been made available. In addition, there is no way of knowing whether serious health issues (which may have led to the need for emergency services) may or may not have
been prevented. However, in September 2010, project staff gathered evidence, based on professional opinion of care coordinators, on the extent to which the intervention resulted in preventing or delaying the need for residential health and social care services. Interviews with 31 care coordinators, who were responsible for 203 service users (in two areas of the project), were carried out. Findings suggested that in 101 (50%) of cases, the demand on intensive health and social care services had been reduced and significant cost savings achieved (ESCC, 2010).

Most carers who were still receiving support by the second interview also felt that the project had significantly contributed to helping them continue to cope with their caring role. In three out of the ten cases that had been closed, this was because the person with dementia had been admitted into residential care by the time of the second interview. However, two of these carers felt the support had helped them to cope for longer and delayed the admission into residential care. In the other case the carer (who did not live with her mother) felt that the support had in fact speeded up this decision since she had been alerted to serious safety concerns which increased her awareness that it was no longer safe for her mother to live by herself. One CSW discussed how she felt that the relationship with the support workers helps carers in some cases to move towards making such a decision. She described how CSWs are sometimes able to help with this process of transition through a gradual increase in engagement with services, and through carers being able to work through associated emotional issues (such as a sense of guilt) through discussing these with the CSW.

Most care coordinators and project staff felt that the project did have a significant impact on enabling carers to cope with their caring role for a longer period of time. It was also felt that crisis situations requiring emergency respite are likely to have been avoided in many cases. One care coordinator also spoke of how the support of a CSW had enabled what would have been a crisis emergency respite situation to be dealt with in a way that ‘normalised’ the course of events and thus minimised the impact on the carer and their relative. Another care coordinator, however, felt that project resources were insufficient to allow the necessary flexibility and quantity of support which would ultimately have a significant impact upon preventing carer breakdown.

The interview data therefore suggests that although in many cases the support enables carers to continue with their caring role for a longer period of time, there is not necessarily a clear and straightforward causal link between the increase in support and a delay in accessing residential care services. However, it also suggests that delaying admission into residential care should not necessarily, in all cases, be viewed as the most beneficial outcome.

- For carers to be effectively included as ‘partners in care’

As discussed in section 5.3, the extent to which the carers were included as ‘partners in care’ varied. Some felt very much included and were involved in shaping the service. Several carers in the Hastings and Rother area for example spoke of how they were
consulted about activities they would like to take part in and involved in developing a carers’ support group. However, some others spoke of having little involvement with the project and receiving very little information about it. One carer, for example, reported that she had only seen the CSW on one occasion and felt ‘in the dark’ with regard to the support her husband was receiving. To some extent the lack of contact between carers and CSWs was related to a lack of capacity among staff to engage with carers in addition to running the groups for people with dementia. Reviews involving both staff and service users were not always carried out, and these would be beneficial in a number of cases in order to strengthen the sense of partnership and improve outcomes.

7.1.2 Specific objectives

- To offer support from a Community Support Worker (CSW) on a 1:1 basis in the carer’s home and to agree with carers an action plan to enable the carer to benefit from regular short respite breaks;

The usual procedure would initially be to offer one-to-one support and to discuss with the carer ways in which they may be able to offer support. Most carers, however, did not feel that they had participated in drawing up an ‘action plan’. This may have been in part owing to the informal nature of the approach taken by CSWs. Although some were happy for CSWs to take a lead, and thus relieve them of some of the burden of decision making, most appreciated some discussion of their needs where this occurred. However, in some cases, initial introductions focused on being presented with a very limited option such as a specific group the person with dementia could join. The limitations in options, flexibility and regularity of support and the minimal contact with a CSW, reported in some cases, appears to have been related in most part to the demands upon staff time.

- To support around 80 carers’ planned breaks each quarter in each of the 4 areas;

As shown in the chapter on quantitative data, targets were exceeded cross-county from the first quarter and from the second quarter in each of the five areas including those in which the project was newly established.

- For CSW to befriend carers and enable them to benefit from other support available such as “Caring and Coping” courses etc.

The sense of friendship between carers and CSWs was strongly apparent in many cases. However, the evidence suggests only a minority of carers have benefited from training courses. Only one of the carers selected for interview reported having accessed a training course and, in this case, this was not accessed through the Carers’ Breaks project. Most of the carers interviewed were not aware of the possibility of accessing training courses. Some CSWs felt such training was not always relevant to carers, but there was also a sense that the formal connotations of the term ‘training’ was a perceived barrier for CSWs to suggest this to carers. There may be a concern that
carers may view such a suggestion as criticism of their caring abilities, which may then damage the relationship between CSW and carer. In the case where training had been received, however, this was described as having been helpful for the carer to better understand the condition, and to help deal with emotional and practical challenges of caring for someone with dementia. Research has also shown that training for carers can equip carers with effective ‘tools’ to assist them in their caring role, and can increase a sense of well-being (Gilliard, 2001). It would be recommended, therefore, for the project to consider how information about such opportunities could be made more widely available.

- **To offer practical support to carers e.g. offering transportation to medical appointments and supervising the cared for person at the surgery/venue in order to minimise ‘separation anxiety’**.

Carers and those they cared for often benefited from practical support such as help with transportation to attend groups. However, none of the carers, or CSWs interviewed, spoke of provision of transport and supervision of people with dementia at a surgery.

- **To offer advice, information and education about mental health/dementia and signpost to other services**.

The extent to which the carers interviewed had received advice, information and signposting to other services was mixed. Where carers were closely connected to their support worker they tended to be better informed and aware of other services. Some also received information and other help through carers’ support groups. Several, however, had no or minimal direct contact with a CSW or with other carers, and expressed a need for further information and support, especially with regard to options around residential respite services and other help to which they may be entitled. Although these issues may be addressed through a carers assessment, the capacity of a CSW to build a trusting relationship with carers places them in an ideal position to discuss any issues of concern, and to help carers access other relevant support. Carers in some cases would therefore benefit from regular short meetings with a CSW.

- **To assist the cared-for person to engage in mainstream community activities (thus providing the carer with a respite break) where possible and to withdraw when confidence has been established**.

In most cases, people with dementia were receiving support through project run groups and/or Out and About activities. In three cases they were reported to be attending community run groups, and all three were described to have found this beneficial. However, by the second interview, none of these carers had been able to continue attending without the support of a CSW. Two were still attending with a CSW, and one case was put on hold whilst awaiting the decision of an assessment. Staff and
Community partners spoke of difficulties around withdrawal of support. For community partners, the main issue was a problem of insufficient staff to cater for people with high support needs. Examples were given by CSWs of leisure activity groups (singing, exercise etc.) to which service users had been introduced, and carried on attending, without the support of the CSW. However these tended to require the carer to continue supporting them to attend and therefore not enabling the carer to have a break. The project did have some success in handing over to traditional day care services, introducing 69 people in total (by the end of 2010).

- To assist and train those leading the activities to understand the specific needs around the mental health condition/dementia of the cared-for person;

The community partners interviewed had not received formal training, nor was this something that had been discussed (although some reported being open to this) with project staff. However, community partners described how CSWs had contributed helpful new ideas for working with people with dementia, or other high support needs. They also felt that project staff and community partners were continually learning from each other through working together.

- To support carers through a carers’ support group facilitated by a resource officer and managed by carers – and to run in parallel with an activity for the cared-for person (e.g. coffee-club).

The project was involved in setting up seven carers’ support groups, and also supported carers to attend three other existing groups. Resource Officers were not currently involved in facilitating any of these groups, as these were being facilitated independently by carers or by other partner organisations. Most carers interviewed did not attend a carers’ support group, and several were not aware of the possibility of this. Most of those who had attended a support group found this to be beneficial as a source of emotional support, friendship and information. Several carers said they valued the small and informal nature of their independently run group, and the development of friendships beyond the boundaries of the meeting. Some carers were not interested or were reluctant to attend a group. This was particularly true for younger male (non-resident or co-resident) and female non-resident carers. There were also barriers to attendance experienced by some carers in the older age group, including separation anxiety on the part of the person with dementia, and a lack of provision available to tie in with the support group (or awareness of this). One older person also explained that it would be difficult for her to participate in a group activity due to a hearing impairment.

Although not all carers may require support from other carers, it may be helpful to consider other forms of carers’ support that could be made available for those reluctant to attend an existing group. For example, one younger carer was involved with an email network of local carers of a similar age which had been initially facilitated by a community organisation. The group would chat online and arrange...
occasional dates to meet up for support, and she found this more informal approach to
be more appropriate and relevant to her needs. Online support may also be of interest
to older carers in some cases.

- To assist carers in completing assessments/reviews.

260 carers’ assessments were carried out by ROs by the end of 2010. This represents
51% of carers referred to the project. Staff felt that this was an important service for
carers. According to the project database, seven (1/3rd) of carers interviewed had
received an assessment. Some of these carers, however, were unsure whether they had
received a carers’ assessment or how this may have benefited them.

- To work effectively in partnership with relevant statutory and non-statutory
groups and services.

Staff from OPCMHTs generally spoke very supportively of the project and felt it had
been of great benefit both to themselves with regard to reducing their workload, and
to the carers and people with dementia they were supporting. VCOs also welcomed the
contribution of CSWs and were positive about the successes of working together to
support service users. However, as discussed above, some issues around
communication could be improved for the benefit of both service providers and users.
The project has plans to develop work with community partners that will be of value to
all partners involved, and to the service users, through providing further opportunities
for social interaction and integration into mainstream community activities.

7.2 Current policy on supporting carers

It is important to set the aims and objectives of the project in context of the wider
policy objectives. The latest policy development has been a review of the Carers’
Strategy commissioned by the Coalition Government. Following a call for views from
relevant VCO and statutory organisations in the summer of 2010, four priority areas
have been identified (Cross-Government, 2010). Findings from the project are
therefore discussed in relation to each of these:

1) Supporting those with caring responsibilities to identify themselves as carers at
an early stage, recognising the value of their contribution, and involving them
from the outset both in designing local care provision and in planning
individual care packages.

Early identification of carers is not a key aim of the service. The project particularly
focuses on those who fall in a gap in provision between those services (such as the East
Sussex Dementia Strategy Demonstrator Site) which work with people who have been
recently diagnosed with the condition, and services focussed on those with more
advanced dementia. Often, those referred to the project are carers of people with
dementia who have been struggling with their situation for some time. In many cases
referrals are made after support from other sources has been unsuccessful owing to
particular challenges around accessing and participating in other services. Therefore, this priority may be less relevant to this project.

However, earlier detection and interaction with services offering mental stimulation for cared-for persons and support to carers have been found to be beneficial (Leifer, 2003). In some cases the carers interviewed were caring for someone experiencing the earlier stages of dementia. In these cases carers described how the project was beneficial both for themselves and for the person they care for. Through linking those with dementia into services at an early stage, the project was felt to enable an easier process of transition to other services (such as day care) at a later stage when these may become necessary. Therefore, there may be a need for more carers, and those they care for, to be referred to the Carers Breaks’ project at an earlier stage. This would, however, be a matter for communication and consultation with care coordinators i.e. in order to consider whether it would be appropriate (with consideration of other provision available) to aim to refer cases at an earlier stage. It could also be considered whether it would be appropriate to expand the service to include referral pathways other than the OPCMHT. If the service were to be expanded in any way, however, this would also require an increase in funding.

The extent to which carers have been involved in designing and planning the support received has been mixed. Some carers interviewed were involved in shaping services such as a carers’ support group facilitated by carers themselves. Others had little direct involvement with the project and would have liked to have been better consulted and advised about the support received by their relative, and of other support that may be available to both the person with dementia and themselves. Others stressed that they wanted access to basic information and advice, but were not interested in ‘planning’ activities since they perceived this to be a burden. Carers expressed a need for help with ‘big decisions’ about the care of their relative with dementia, but said they also valued having a support worker who would initiate ideas rather than asking them what they should do.

2) Enabling those with caring responsibilities to fulfil their educational and employment potential;

The majority of carers supported by the project are over employment age. However, the findings from the evaluation have suggested that there are significant difficulties faced by people attempting to juggle their caring role with paid employment and/or study. The extent to which the project was able to support carers with this depended on the amount of support provided. One short break per week was considered to be of minimal assistance to those in full-time work.
3) Personalised support both for carers and those they support, enabling them to have a family and community life;

The personalisation of care has been key to the success of the project in many cases. Personalising support to the needs of the person with dementia has, in some cases, enabled them to happily take part in the service and to subsequently minimise any feelings of guilt on the part of the carer over taking a break. Some interviewees, however, spoke of feeling isolated and uninvolved and required further support. There is therefore room for improvement with regard to extending this quality of personalised support to all carers and people with dementia involved in the project.

4) Supporting carers to remain mentally and physically well.

The project was reported to have a positive impact on the health and well-being of carers in many cases. However most carers had significant physical and/or mental health problems to begin with, and therefore it was often more a case of seeking to prevent the exacerbation of ill-health than of maintaining good health. A further challenge in achieving this goal was that the benefits of stress relief over time through support received were to some extent offset by the worsening condition of the person with dementia owing to the degenerative nature of the disease. Nevertheless a positive impact upon the well-being of carers appeared to be associated with the extent to which relationships had been established with the CSW and other carers, and with the amount of continued support received. The link between the support and carers’ physical health is less clear. However some physical problems were reported by carers as being exacerbated by the stresses of the caring role. Therefore an improvement in mental health is also likely to have a positive impact on physical health.
8 Conclusion and learning points

8.1 Conclusion

The findings from the interviews indicate that the project has been hugely beneficial to many carers, often increasing their well-being and helping them to continue coping with their caring role. There have also been many examples of a positive impact on the well-being of people with dementia, despite the progressive nature of the condition. In particular the person-centred approach was felt to be key to successfully engaging with people with dementia. It is a model of respite which the interviews suggested worked well, and was helpful to older people who provide full-time care for spouses, as well as to non-resident carers through offering some peace of mind when they are apart from their parent.

The model has been found to have a high degree of success in working with those who had previously been reluctant to access services. This success is related to a number of factors, particularly the vital role of the skilled support worker who is key to building a relationship of trust with both parties in the caring relationship (carer and person with dementia). The personalised and flexible nature of the support and responsiveness to the needs, interests and concerns of service users is also key. In addition, close links with statutory and community services and the supervisory support of clinicians have also been considered critical aspects of the success of the project.

However, a number of factors constrain the impact of the project. In particular, many people need the support offered by the project on a long-term basis. Support can be withdrawn after six weeks, but this appears to be the exception rather than the rule. Challenges around sustainability have sometimes been apparent in terms of difficulties in moving service users onto other forms of support. This has especially been the case in localities where the wider network of support for carers and older people in the community is limited, thus offering fewer appropriate options for future referral.

Community groups are often unable to include those with high support needs without continued support of a CSW due to insufficient staff resources (and sometimes necessary skills) whilst, in some areas, there is a lack of appropriate day care provision. Some examples have been given of high quality day care provision in the county. However, a number of carers noted dissatisfaction with traditional day care services and care coordinators and project staff suggested a need for the good practice of the project run groups (in regard to provision of mentally stimulating activities) to be replicated within other day care facilities.

The continued success of the project depends on being able to link carers and people with dementia into a wider pool of support in order to enable carers to access further and longer periods of respite. As interviewees have emphasised, the prevention of carer breakdown often necessitates access to good quality day care provision, residential respite facilities and sitting services, which are unfortunately not always available. The project has made extensive efforts to work with other agencies and has
had some success in handing over to other agencies such as those providing home based respite and introducing service users to day care services. However, some interviewees noted problems experienced in relation to the appropriateness of this support.

Owing to insufficient appropriate alternative support, it has not been possible to entirely meet the growing demand for the service whilst, at the same time, maintain the high standard of support provided in all cases. Whilst targets have been exceeded, and breaks have been greatly valued, some carers interviewed were still desperate for more support. At the same time the project was not able to meet the needs of some people referred to the project who were waiting to be allocated to a support worker. Staff resources have been stretched to the limit, and there is a crucial need for an increase in staff that are skilled and experienced in working with people with dementia. This is required in order to ensure adherence to the factors that are key to the project’s success, i.e. in terms of the high standard of support provided by CSWs, and to enable expansion of the service in order to meet currently unmet needs of carers requiring support.

An increase in funding is necessary to provide more fully qualified and experienced staff in order to ensure a quality and quantity and consistency of support that will continue to make a real difference to carers, improve the quality of life of people with dementia and enable them to remain in their own homes for a longer period of time where appropriate. If this is not to be made available, it will be important to give closer consideration of ways in which resources may be allocated to those with the greatest needs, and who receive the least amount of other support. The option of charging for the service could also be considered as a means for raising more funds. As staff and carers have indicated, however, it would be vital that any contribution to the cost of services would only be required after an initial trial period and not from the outset.

8.2 Learning points

- A key success factor of the project is the relationship of trust built between the CSW and the carer. But such relationships did not always develop. Some carers did not have regular contact with a CSW because, for example, the carer is working or because the CSW does not provide transportation to the person with dementia (and therefore does not visit the carer’s home). It is therefore important for the project to identify those for whom this is the case and where the carer may be socially isolated. In these cases it would be useful for the project teams to explore means of ensuring that these carers are kept informed and in contact with a support worker. Written information may be useful as well as telephone contact and scheduling face to face meetings and reviews with the carer.

- The amount of support received by carers and service users varied significantly and there did not appear to be a clear correlation between need and amount of
support received. This was rather dependent upon capacity of individual CSWs and availability of appropriate group activities. Data recorded on the project database as to the number and type of breaks received per carer was largely incomplete. It would be useful for CSWs to systematically record the number of breaks received per carer per week/month. This would enable resource officers to have an overview of resource allocation and more easily identify those who may be in need of further support.

- In addition to the degree of contact, the skills and experience of the support workers is also a vital factor in the success of the model. Recruitment of and referrals to agency workers provide a solution to meeting the increasing demands on the service. However often agency workers are less appropriately skilled or qualified for this type of work. This therefore needs to be handled carefully. Where cases are handed over to sitting services, it may be useful for the CSW to remain in contact for a period of time in order to respond to, and report back any difficulties experienced by the service user or agency worker.

- Sufficient staffing is vital for the quality and flexibility of the service to be maintained, whilst increasing the number of people able to receive support. Extra funding is therefore necessary. If this is not available, the project should explore introducing a charge for the services provided. Where this was discussed in interviews, most carers indicated that they would be willing to make a financial contribution. However this would only be appropriate after a trial period, through which carers and service users could build a relationship with a CSW and be made aware of the benefits of the project.

- The success of the project is also dependent on effective links with other services. Although the project has generally worked well with partners, some communication issues were identified. In particular, it is important where CSWs do not normally see care coordinators on a regular basis, for project teams to consider how channels of communication could be improved or existing systems clarified and reinforced. When care plans are created, it may be useful for CSWs and care coordinators to schedule regular telephone or face to face meetings to discuss how cases are progressing.
References


http://www.publications.parliament.uk/pa/cm200910/cmselect/cmpubacc/321/32102.htm


Pickard, L. (2004). *The effectiveness and costeffectiveness of support and services to informal carers of older people*. PSSRU, London School of Economics.

Appendixes
Appendix 1: Letter to carers

01273 644599

Date

Name and address

Dear [name],

**Carers’ Breaks Project Evaluation**

I am a researcher working at University of Brighton and carrying out an evaluation of the Carers’ Breaks Project on behalf of East Sussex County Council. I am writing to you as your [relative] has recently begun receiving help from the project through [her/his] support worker [name] and we would be interested to hear your views about this service. I have enclosed some information about the evaluation, and what taking part would involve.

I will contact you by telephone in a few days to give you a chance to have a read through the information and decide whether you want to take part. If so, we can arrange a convenient time for me to visit you at home, or to carry out the interview over the phone if you prefer. If you would prefer to be interviewed by phone, it would be really helpful if you could send me the enclosed consent form back to me in the post (to the above address) as soon as possible. Otherwise I can collect this when we meet.

If you have any questions about the evaluation that you want to ask before that then please give me a call on 01273 644599. If you would like to speak to someone who is independent of the study you can contact Professor Phil Haynes, Head of School, School of Applied Social Science, University of Brighton, on (01273) 643465.

Kind regards,

Laura Banks
Research Fellow

01273 644599
l.c.banks@brighton.ac.uk
Appendix 2: Information sheet for carers

What is the evaluation about?
The University of Brighton is helping East Sussex County Council to find out what is helpful about the kind of support the Carers’ Breaks Project provides, what might not be working out so well and how services for carers of people with dementia might be developed.

Why have I been approached to take part?
We would like to talk to you about your experiences of having a Community Support Worker to help the person you care for and let you have some short breaks. We are interested in how this may be of help to you and the person you care for or whether there are any other kinds of support that may have helped you more.

Do I have to take part?
No, it is your choice whether you wish to take part or not. You are also free to change your mind about taking part at any time. Your decision will not affect any of the services you are receiving in any way.

What will taking part involve?
We would like to talk to you three times: first when you start to receive help from the project in order to find out how you hope it might help you, and later to find out about your experiences of the project and what difference it has made to you. The interviews will be like a conversation and will last between 30mins to an hour depending on how much you want to tell us. For the first interview we can either visit you at home or we can talk to you by phone depending on which is most convenient for you. For the second interview we would like to visit you at home or another location of your choice. The third interview will be shorter and we can do this over the phone. With your permission we would like to record the conversation as this helps us to make sure we have correctly understood what you tell us.

Your confidentiality
We will ensure that everything you tell us will be treated in the utmost confidence and we will not pass information on to anyone else. The only exception to this is if we were worried someone was in danger, in which case we would talk to the project manager about this. We will write a report about the findings from the interviews but your name or details that would identify you will not be used, although if you agree we may ask to report something you have said as an example. We will also be interviewing Support Workers and other staff about their experiences of the project, and if you agree, it would also be useful if they can share information with us about your situation, such as how they feel the project may have helped you and the person you care for.

How can I find out more?
The researcher on this project is Laura Banks. If you would like to talk to Laura you can call her on (01273) 644599. If you would like to speak to someone who is independent of the study you can contact Professor Phil Haynes, Head of School, School of Applied Social Science, University of Brighton, on (01273) 643465. If you have any complaints you can also contact the Adult Social Care Services complaints team on (01273) 481242.
Appendix 3: Consent form for carers

Carers’ Breaks Project

Consent form for interviews

◆ I agree to take part in the evaluation of the Carers’ Breaks Project in East Sussex.

◆ I have read, or been read, the information sheet, and the researcher has explained to my satisfaction the purpose of the study and what my participation will involve.

◆ I am aware that I will be asked to talk about my own experiences and answer questions. This may mean talking about things of a personal nature.

◆ I agree to the interviews being recorded.

◆ I understand that any confidential information will be seen only by the researcher and no-one 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 am free to withdraw from the interview process at any time without giving a reason.

◆ I understand that I will not be identified personally in the report but that my words may be used as quotes.

◆ I agree that anonymised (not including my name) data collected may be later archived and used by other researchers.

◆ I agree for staff involved with my case to be able to share information with the researcher where this may be useful to the evaluation.

Name (please print) ...........................................................................................................................................

Signed: ...........................................................................................................................................................

Date: ............................................................................................................................................................
Appendix 4: Interview schedule: Carers

Interview 1

- I understand you care for your [husband/wife/parent etc.]. Could you tell me a bit more about your situation? What challenges do you face in caring for someone with dementia?
- Do you receive any help with your caring role?
- How did you find out about the Carers’ Breaks service? What did you first think about it?
- What support have you and your [husband/ wife/parent] received through the project/support worker so far?
- What has been helpful about the support you have received so far?
- Did you agree an initial action plan with your support worker?
- Do you have any worries or concerns about the project?
- How do you feel the Carers’ Breaks service might help you?
- Do you feel it will be of benefit to the person you care for?
- Are there any different kinds of support which you feel may be of help to you or your [husband/wife/parent]?
- On a scale of 1-10 (10 most positive) how positive do you feel about your role as a carer?
- How would you rate your health? (Excellent, very good, adequate, poor).
- Do you feel the service may be of benefit to your health?
Interview 2

- What support have you and your [husband/wife/parent] received through the project/support worker (since last time)?
- What was helpful about the support you received (for yourself and person cared for)?
- How happy were you with the support received through service?
- How well did you find your needs were understood / responded to by the project staff?
- What did the breaks enable you to do?
- How would you rate your health (change since last time)?
- Did you have any worries about leaving your [husband/wife/parent] with a support worker?
- Did your [husband/wife/parent] attend a community group /activities with the support worker? Could you tell me more about this?
- Do you feel your [husband/wife/parent] has benefited in any other way through the project?
- Were you offered / did you receive any useful information or training through the project which helped you in your caring role? Could you tell me more about this?
- Did you attend any carers’ support groups? Could you tell me more about these?
- If the Carers’ Breaks project were not available, how do you think you would you have managed?
- Has your [husband/wife/parent] been receiving any other forms of support?
- Is there anything that could have helped you and your [husband/wife/parent] more than the support received through the project?
- What kind of support do you think you will require to help you in your caring role in the future?
- On a scale of 1-10 (10 most positive) how positive do you now feel about your role as a carer?
Appendix 5: Interview schedule: Community support workers

- How long have you been working as a Community Support Worker?
- How did you find out about the post?
- What type of work did you do previously?
- What sort of training have you received to help you in your role?
- How many cared-for persons with dementia have/do you support?
- What does the support you provide involve?
- Have you introduced any people with dementia to mainstream community groups?
- What has been your experience of working with community groups?
- Have you been able to provide any training around dementia to community group workers? Could you tell me more about this?
- What do you think are the benefits of the support provided for the person with dementia?
- Have cared-for persons you supported been able to continue attending community groups after your support has been withdrawn?
- What do you think are the benefits to the carer of the support provided through the project?
- Were you able to support any carers to complete a carer's assessment?
- What challenges have you faced in your role?
- How do you feel the carers would have managed without the support of the project?
Appendix 6: Interview schedule: Resource officers

- How long have you been working for the project?
- How did you find out about the post?
- What types of work did you do previously?
- What sort of training have you received to help you in your role?
- How would you describe your role?
- How do you envisage the aims of the project/role of the CSW?
- What training has been available to CSWs in your area? Do you feel there are any training needs among your support workers?
- What do you feel have been the greatest successes of the project so far? What have been the reasons for these successes?
- What successes and/or challenges have you faced working with community partners? How can taken forward/addressed?
- What do you think is the value of being based within an OPMHT? Have there been any challenges associated with this?
- What have been the greatest challenges for the project in your area? What steps have been/could be taken to address these?
- How successful do you feel groups have worked in your area? (Any challenges?)
- How do you think the project makes a difference to carers/cared-for persons? How would they manage without the project?
- Do you feel the project offers any advantages over any other kinds of support which is/could be made available?
- How do you make decisions about the level of support attributed to particular service users? Have you faced difficulties in managing resources and how do you deal with these?
- What is the ratio of group activities / 1:1s? Do you feel this is appropriate or are you aiming to change this? If so, why?
- At what point is support from the project usually withdrawn? Which factors are involved in reaching this decision and what have been the difficulties with achieving this in some cases?
Appendix 7: Interview schedule: Project manager

- Could you give me some background to the development of the project?
- How were you recruited? What is your work background?
- How would you describe your role?
- How would you describe the aims of the project?
- How would you describe the role of the CSW/RO?
- What training has been available to support workers? Do you feel there are any training needs among your support workers/ROs?
- What do you feel have been the greatest successes of the project so far and what have been the reasons for these successes?
- What have been the greatest challenges for the project? What steps have been/ could be taken to address these?
- What other support is available for carers/cared-for people in East Sussex and what advantages does the project offer/how does it complement other forms of support?
- How successful do you feel the project has been at establishing links/ working with community partners? Have there been any challenges in regard to this and how have/ could these be addressed?
- What do you think is the value of the project being located within an OPMHT? Have there been any challenges associated with this?
- How well do you feel groups have worked in different areas of the project (Any challenges?). What is the ratio of group activities/1:1s? Do you feel this is appropriate or would you like to see a change in this? Why/ why not?
- How do you think the project makes a difference to carers/cared-for persons? How would they manage without the project?
- How are or how do you feel should decisions be made about the level of support attributed to particular service users?
- If there had to be a reduction to funding for the service, would it be possible to target resources to those with the greatest needs or to charge for the service? If so, how do you think this could work?
Appendix 8: Interview schedule: Care coordinators

- Could you tell me about your role?
- How were you first introduced to the Carers' Breaks project? What did you think about it originally?
- How many people have you referred to the project?
- Why did you think the project would be helpful in these cases?
- How do you think the project has been of benefit to those with dementia that you have referred?
- How do you think it has been of benefit to the carers?
- Have there been ongoing benefits to the clients following the completion of the intervention? What have these been?
- What in particular about the project has been most helpful?
- Do you feel these clients need any further / different kind of support?
- What is your overall opinion of the Carers' Breaks project? What difference do you feel it makes to service users? Do you feel the project offers any advantages over other kinds of support available?
Appendix 9: Interview schedule: Community partners

- Could you tell me about your work with [community group name]?
- How did you find out about the Carers’ Breaks project? What did you think about it originally?
- What has been your experience of working with the project/CSW’s?
- How many people with dementia have/are supported to attend your group?
- Have there been any challenges with including the project’s clients in your group?
- What have been the benefits of involvement with the project?
- Have you been provided any training in working with people who have dementia? Could you tell me more about this?
- Do you feel you require any more support / training around working with people with dementia?
- What do you think are the benefits to the cared-for person of being supported to attend your group?
- Have cared-for persons with dementia been able to continue attending community groups after the support from the CSW was withdrawn?
- What is your overall opinion of the Carers’ Breaks project? What difference do you feel it makes to service users?