

‘Facing dementia Together’: Post diagnostic support pilot for people with dementia and their families in Renfrewshire and East Renfrewshire

Final Project Evaluation Report



Dementia Services
Development Centre



**UNIVERSITY OF
STIRLING**

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EXECUTIVE SUMMARY

This document reports on the evaluation, conducted between January 2010 and April 2011, of a post diagnostic support project for people with dementia and their family carers living in Renfrewshire and East Renfrewshire. Ethical approval was obtained for the evaluation. A comparative design was adopted whereby fourteen people with dementia and twelve carers were interviewed and completed structured questionnaires at two points in time. In addition twenty-two local professionals and frontline workers were interviewed at the beginning and towards the end of the evaluation period to identify their views of post-diagnostic support in the area. Data were analysed quantitatively and qualitatively to allow for comparison in reported experiences over time.

The key findings are:

1. Participants who received interventions and support from the project found the service useful, particularly in enabling them to maintain social contact, engage in meaningful activities and to have an active presence in their communities.
2. The project has been less successful in encouraging carers and people with dementia to plan for the future and in promoting advance care planning.
3. There was a general positive trend in changes in the reported quality of life of individual people with dementia and ability to cope from individual carers, however there was no common pattern reflecting the diverse, individualised and fluctuating experience of living with dementia and caring for a person with dementia.
4. There is a lack of whole hearted engagement from local authority and health workers with the project, demonstrated in lower than anticipated referral rates during the early stages of the project.

Recommendations for professionals:

- More engagement from local health workers and professionals is required if the project is to have long term success. This suggests that close working with or mainstreaming of specialist post-diagnostic support within existing services is vital for the success of a service.
- Recognising that decisions on difficult topics (advance care planning) will take time and allowing people to arrive at a position in their own time is important, and that the presence of a specialist support service does not compensate for wider inter-disciplinary support.

Recommendations for the project:

- Review referral criteria and referral systems to access the project to ensure they are compatible with existing diagnostic processes.
- General project outreach activities to promote the project open to all those with dementia without professional referral may widen the project reach.
- Develop the service to continue to extend beyond functional ability, assessment or medication compliance or monitoring and to promote and prioritise the inclusion of peer support, and support for maintaining social networks and activities.
- Increase activities that enable social networking amongst people with dementia.
- Review the timing of activities to increase participation and widen access.
- Vary the style of presentation of activities e.g. 1-1 and different sizes of groups for group work.
- Allow for flexibility in the level of support offered to meet different and varying needs of people with dementia and their carers at particular times.
- The long term success of community based services requires that support be provided over an extended period to allow people to access information and support, including with planning ahead, as they become ready to do so and in the context of an established and trusted relationship.

1. INTRODUCTION

In support of government policies aimed at improving dementia care, Alzheimer Scotland and the Dementia Services Development Centre (DSDC), University of Stirling were funded by the Scottish Government to conduct post-diagnostic service development work. Three projects took place, in Lothian and Shetland, where work led by DSDC focused on organisational change and in Renfrewshire and East Renfrewshire, where Alzheimer Scotland introduced a two-year post-diagnostic support service¹ (Appendix 1) for people with dementia and their carers. This report presents the evaluation of the Renfrewshire and East Renfrewshire project. The project was staffed with one full-time Post-Diagnostic Practice Manager and one full-time Post-Diagnostic Project Worker and it ran from February 2009 until June 2011.

The aims of the post-diagnostic project were:

- To provide information, advice, signposting, emotional and practical support to help the person newly diagnosed with a dementia and their families/supporters to understand and come to terms with living with dementia.
- To assist people with dementia and their families/supporters to put in place financial and legal arrangements to maximise their control over future decisions made on their behalf (e.g. powers of attorney, advance statements).
- To support people to maintain the important relationships in their lives and remain involved in their communities, continuing to enjoy social and recreational activities.
- To facilitate more detailed advanced planning using person centred planning tools.

As the project evolved, opportunities for peer support were developed including informal drop-in cafes and a series of weekly workshops delivered over six consecutive weeks for people with dementia and family members. Sessions included information sessions and separate peer support groups for people with dementia and family members.

Whilst many service providers take the view that such a service can enhance people's living with dementia, there is little real evidence available on which to draw clear conclusions. Thus, this evaluation of the pilot project provided a particular opportunity to explore the difference (or lack of difference) that post diagnostic support of the type described may make to people's quality of life in the medium term.

¹ The report from Alzheimer Scotland about the pilot intervention provides full details about the project evaluated.

The evaluation set out to examine two dimensions: first the experiences of people with dementia and their carers, and second the views of professionals and front line care workers. The following questions guided our data collection and analysis:

1. People with dementia and their carers

- What difference, if any, does the post diagnostic support service make to quality of life for people with dementia and their carers?
- What difference, if any, does the post diagnostic support service make to service access and service use for people with dementia and their carers?
- What difference, if any, does the post diagnostic support service make to independence and choice for people with dementia and their carers?
- How successfully has the intervention realised its specific intended outcomes for people with dementia and their carers?

2. Professionals and frontline care workers

- What difference, if any, does the post diagnostic support service make for professionals and frontline carers who work with people with dementia and their carers?
- How successfully has the intervention realised its specific intended outcomes for local authority and health staff?

2. STUDY DESIGN

A comparative design was adopted with an intervention group including people newly diagnosed with dementia and their carers who received the post diagnostic support provided through the 'Facing Dementia Together' pilot project whose experiences were compared at two points in time. It was our intention to recruit a comparator group consisting of people newly diagnosed with dementia and their carers who received the usual support in the same area. The aim of the comparative design was to ascertain whether there was any difference in experience from the group who received the intervention from the pilot project and those who received usual support offered to them post-diagnosis.

The evaluation did not follow the planned design (intervention and comparator groups) due to difficulties in recruiting to the comparator group. Recruiting from those using the post diagnostic support project was also more difficult than anticipated due to lower numbers of referrals to the project than anticipated during the recruitment period. However our minimum target sample size was achieved.

The evaluation also included interviews with local professionals and frontline workers (called 'key informants') who worked in the dementia field in this area and who were in a position to reflect on their perspectives on the impact of the intervention.

Ethics approval was obtained from a Local Research Ethics Committee (LREC). All participants had capacity to give informed consent.

2.1 Recruitment

- Key informants

Twenty two key informants were recruited from three clinics providing diagnosis and post-diagnostic support to people newly diagnosed with dementia and their family members. They were recruited by invitation from the researchers via the managers of the clinics. Key informants included memory clinic managers, consultant psychiatrists, care home managers, social workers, lawyers, community psychiatric nurses, allied health professionals, post-diagnostic support project workers and a representative from a carers' organisation.

- People with dementia and their family members

Fourteen people with dementia from the intervention group were recruited, along with thirteen carers. Two participants with dementia had no family members and were happy to be interviewed on their own. One participant with dementia was interviewed along with her two daughters. All participants with dementia completed the existing structured QoL-AD questionnaire (Logsdon et al., 2002) (see Appendix 2) and all carers completed the structured questionnaire known as COPE (Carver, 1997) (see Appendix 3). Completing standardised structured questionnaires at two time periods provides the potential for objective comparison of the two time periods.

Changes in our sample at time period 2 were:

- One person with dementia had died (her family member was interviewed at this time).
- One person with dementia withdrew from the evaluation due to cognitive decline, but was maintaining her involvement with the project.
- One person withdrew from the project but not the evaluation and both he and his family member were interviewed at this time.

The characteristics of participants are presented in Tables 1-3 below.

Table 1: People with dementia: gender

Gender	Number	Percentage
Male	8	57
Female	6	43
Total	14	100

Table 2: People with dementia: age range

Min. Age	Max. Age	Mean Age.
52	83	71

Table 3: Carer: gender

Gender	Number	Percentage
Male	8	57
Female	6	43
Total	14	100

A variety of care relationships were included as can be seen in Table 4.

Table 4: Carer relationship to person with dementia

Relationship	Number	Percentage
Husband	2	17
Wife	7	58
Daughter	3	25
Total	12	100

2.2 Methods

1. People with dementia and their carers

Participants from the intervention group were interviewed shortly after diagnosis using a semi structured interview schedule to ascertain their views about the diagnosis, their current service use, and their expectations and plans for the future (the interview topic guides can be referred to in Appendix 4). In addition, they completed the QoL-AD (Logsdon et al., 2002), a standardised research instrument that has been validated for assessing the perceived psycho-social quality of life for people with dementia. We selected this instrument because it has been used in recent European research (EuroCode) on quality of life for people with dementia and represents a widely respected assessment tool applicable in community settings. For carers of people with dementia, we selected the standard Brief COPE (Carver, 1997), which provides indicators of how carers were dealing with potentially difficult or stressful situations and events. The COPE was selected because it is short and easy to complete and administer and gives an overview of respondents' coping strategies. In this way we collected both qualitative and quantitative data about the

position for the carer and for the person with dementia shortly after diagnosis. We had planned to interview people with dementia and carers separately, to allow for the free and confidential expression of views. However, all but one dyad were interviewed together at their request.

Follow-up interviews were conducted around six months later, and used the same structured research instruments (QoL-AD and COPE – Appendices 1 and 2). A modified version of the interview topic guide (Appendix 5) was used, developed following initial analysis of T1 interview data. In this way we gathered comparative data at each time period.

Initial interviews with participants with dementia and family members were carried out from April –September 2010 and second interviews were carried out from October 2010 – March 2011. While the intention was to have a six month gap between interviews, circumstances such as adverse weather conditions, participant illness or participants’ travels abroad meant some interviews ran just over the six months. Interviews with Key Informants were carried out between March – July 2010 and second interviews were carried out from November – December 2010.

The intention had been to recruit a comparator group of people with dementia and their carers who were not using the project. However after extensive attempts to recruit via memory clinics and stakeholders interviewed for the project only one dyad was recruited. This was insufficient for a comparative design, therefore data from this care dyad is not included in the presentation of findings. With the participants’ consent, all interviews were audio recorded and fully transcribed to facilitate analysis.

2. Key informants

Key informants (22) were interviewed about their role, current practice and their views and experiences of the post-diagnostic support intervention and of the non-intervention services provided in the area (see Appendix 6 for topic guide). As the intervention progressed, we interviewed each stakeholder a second time to examine any changes in their views about the intervention, but also their overview of the impact of the intervention for staff in their workplace. An overview of the work roles of stakeholders is presented in Table 5 below.

Table 5: Stakeholder roles

Roles	Numbers (n=22)
Consultant Psychiatrist	3
Community Psychiatric Nurse/Practice Nurse	5
Practice Manager	2

Social Worker/Care Worker	2
Lawyer/Mental Health Officer	3
Care Home Manager/Carers' Support	2
Occupational Therapist/Physiotherapist/Home Care Provider	3
Project Workers	2

2.3 Analysis

All audio recordings were transcribed verbatim. Transcripts were read by two researchers to identify initial codes and themes based on the topic guides from interviews and issues arising during the interviews. Transcripts were then reviewed by two researchers to identify initial codes and themes based on the topic guides from interviews and issues arising during the interviews. Analytical themes were arrived at by two researchers following coding and initial analysis and checked by a third researcher. One researcher made initial comparisons over two time periods that were then verified by a second researcher. All qualitative interview data were managed using qualitative data management software Nvivo8.

Quantitative data (QoL-AD and COPE scores) were managed using SPSS 19. Cross-tabulations were generated using this statistical package to ascertain the individual and group responses to each item in the structured questionnaires at each time period. Item scores for individuals and the group were then compared at times one and two. The effect size was measured for each item using a gamma test to establish the degree of association between scores over time. Similarly, chi square tests were performed to explore the statistical significance of any variation in scores. The results of these statistical tests should be viewed as indicative rather than definitive due to the small sample size of participants in this study and the absence of a comparator group.

Integration of qualitative and quantitative data was achieved through scrutinising Individual COPE and QoL-AD scores and using identifier codes to link participants' Mean scores and individual item values to their corresponding identifier codes in Nvivo8. This enabled the development of case studies and contextualising of COPE and QoL-AD findings.

3. FINDINGS

Findings from interviews with people with dementia and their family members, along with quantitative data from questionnaires and from interviews with key informants will be presented in relation to the questions that guided the evaluation. Other findings of interest will also be presented.

3.1 Findings from interviews and questionnaires with people with dementia and their carers

Four questions guided interviews with the intervention group and analysis of transcripts. These questions are interrelated in that they all seek to examine the experiences of people with dementia and their family carers. The discussion of findings presented is related to each specific question in turn.

3.1.2 What difference, if any, does the post diagnostic support service make to quality of life for people with dementia and their carers?

To answer this question an analysis of the questionnaire responses completed by people with dementia (QoL-AD) and carers (COPE) at time periods one and two were conducted. QoL-AD and COPE findings in this section are supported by qualitative data from interviews.

QoL-AD findings

This section begins by presenting a comparison of QoL-AD scores for the whole sample at T1 and T2 (Table 6). We then discuss the findings from the questionnaires with interesting or statistically significant changes over time.

Table 6 demonstrates the difference over time for those with dementia as a group.

Table 6: Comparison of ratings over time for QoL-AD items (n = 14)

QoL-AD Item	Rating at Time 1			Rating at Time 2			Significance
	Min. Score	Max. Score	Mean Score	Min. Score	Max. Score	Mean Score	
Physical health	2	3	2.64	1	4	2.58	No significance
Energy	1	3	2.43	1	3	2.33	P=.009
Mood	2	4	2.64	1	3	2.42	P=.058
Living situation	2	4	3.14	3	4	3.17	No significance
Memory	1	4	1.86	1	3	1.92	P=.001
Family	2	4	3.21	2	4	3.58	P=.002
Marriage	3	4	3.80	3	4	3.78	P=.383
Friends	1	4	3.00	1	4	3.00	P=.000
Self as a whole	2	4	2.57	1	3	2.58	No

							significance
Ability to do chores around the house	1	3	2.14	1	3	2.33	P=.427
Ability to do things for fun	1	4	2.71	1	4	2.58	P=.600
Money	1	4	2.71	2	4	2.75	P=.051
Life as a whole	2	4	2.79	2	4	2.92	P=.052

Key: 1 = poor, 2 = fair, 3 = good, 4 = excellent.

Family (n=5), memory (n=4), ability to do chores (n=4) and life as a whole (n=4) had the greatest increase in scores over time. A third of participants were thus reporting more positively in these areas at T2 compared to T1.

Ability to do things for fun (n=4) and money (n=4) were items reflecting the greatest decrease in scores over time (although the mean score for money increased overall between T1 and T2). This indicates that a third of participants felt less positively in these areas at T2 compared to T1.

The items most stable over time included energy (n=8, stayed the same), mood (n=9, remained the same), marriage (scores for seven of nine participants remained the same), friends (n=9, stayed the same).

Physical health, living situation and self as a whole demonstrated more variability across the scores. Approximately a third of scores increased, a third decreased and half remained the same for these items.

Life as a whole

QoL-AD comparison between times 1 and 2 suggests a third of people with dementia were reporting their life more positively at the second data collection time. Scores remained the same for six participants and decreased for two participants. Therefore more than two thirds of people with dementia were reporting their life to be as good or better following the intervention. Effect size was measured using a gamma test to establish a strong positive association ($G=0.704$, $p=.052$) between scores over time that approached statistical significance.

This is generally supported by qualitative data (with the exception of one participant who appeared much more positive about life at T2, but whose score remained the same at fair). There appeared to be different factors influencing participants' perceptions of their quality of life as a whole including the strength of networks and friendships, as this woman with Alzheimer's put it about her friends whom she meets with weekly: '*Yeah, we have good times*'. (Person with dementia 14, 2nd interview)

Energy

Scores increased for two participants and remained the same for eight participants when rating their energy levels. Scores decreased for two participants from 'good' to 'fair'. This indicates that people with dementia were reporting their energy as remaining relatively stable over time. Effect size was measured using a gamma test

to establish a strong positive association ($G=0.862$, $p=.009$) between scores over time that was statistically significant.

This finding is not surprising due to the nature of the condition and it was encouraging to hear, through the interviews, of participants remaining fairly stable over time. A family member of one participant who felt their energy level had risen from 'poor' to 'fair', reported at the second interview that their motivational levels had increased. The family member felt this had resulted from participation in workshops and coffee mornings organised by the project:

'Whenever I used to take her anywhere, she didn't speak. Now, she...you know, she...you don't just speak whenever you're asked a question, you...she actually joins in the conversation, which I don't...I think if you hadn't have been going to those things, I don't think she would have.' (Carer 6, 2nd interview)

This may have resulted in the participant also feeling more energised than previously.

Mood

Scores for this item increased for one participant and remained the same for nine participants and scores decreased for two participants. This indicates that people with dementia were reporting their mood as remaining relatively stable over time. Effect size was measured using a gamma test to establish a positive association ($G=0.625$, $p=.055$) between scores over time and this approached statistical significance. A chi-square test to examine the degree of variance also approached statistical significance at $\chi^2(4, N = 12) = 9.133$, $p = .058$.

One participant who reported a deterioration in mood from 'excellent' to 'good' reported continued ability to live fairly independently (going to the shops, on the bus into the Town) although he expressed some ambivalence about the project, specifically about travelling outwith his familiar area to attend. He reported being contented with his life at present (Person with dementia 9, 2nd interview).

Deteriorating physical health and social isolation was a big issue for one participant who stated:

'I've just been crabby, I've not just been crabby, I've just been very crabby.... I'm not one, well, what I'm saying...[coughing] I'm not one for going out. I used to be one who was never in the house but I just feel as if I'm going to lose my balance, you know what I mean, I just feel...and then if I go out in the cold, that doesn't help me at all.' (Person with dementia 15, 2nd interview)

This participant revealed the inter-connection between his co-morbidity and the degree to which he felt positively or negatively about different aspects of his life,

suggesting the need for a post-diagnostic approach that address multiple aspects of a person's life.

Memory

Scores for memory increased for four participants when rating their memory. Two scores increased from 'poor' to 'fair' and two increased from 'fair' to 'good'. Scores remained the same for five participants and decreased for three participants. This demonstrates that more than two thirds of people with dementia were reporting their memory to be as good or better following the intervention. Effect size was measured using a gamma test to establish a strong positive association ($G=0.758$, $p=.001$) between scores over time that was statistically significant.

Of those who reported improvements in their memory, one was a participant with vascular dementia who reported increased energy levels and a higher QoL-AD score overall, suggesting a move to a more positive outlook on life in general. Of the others, one had Alzheimer's disease and two had vascular dementia. Of those that reported their memory as staying the same four had Alzheimer's disease (treated with medication) and one had mixed dementia (no medications).

Family

Scores increased for five participants when rating their family relationships. One score increased from 'fair' to 'good' and four increased from 'good' to 'excellent'. Scores remained the same for six participants (either 'good' or 'excellent') and decreased for only one participant (from 'good' to 'fair'). This demonstrates that nearly all people with dementia in this study were reporting their family relationships to be as good or better following the intervention. Effect size was measured using a gamma test to establish a very strong positive association ($G=0.905$, $p=.002$) between scores over time that was statistically significant.

During interviews participants stressed the importance of family support, whether it was from their spouse, children, grandchildren or extended family. Family carers reported working to facilitate and maximise contact with other family members, for example they encouraged children who lived further away to come and visit; this was greatly appreciated by participants with dementia.

Marriage

Scores tended to remain the same for the nine participants who were married. These scores were positive, with six people rating their marriage as 'excellent' and one person rating it as 'good'. One score increased from 'good' to 'excellent' and one decreased from 'excellent' to 'good'. This indicates that people with dementia were reporting their marriage as remaining relatively stable in quality over time. Effect size was measured using a gamma test to establish a strong positive association ($G=0.714$, $p=.383$) between scores over time, although this was not statistically significant.

Although these scores look positive, a note of caution needs to be made – all participants opted to be interviewed together, therefore they may have been influenced by the presence of their spouse when completing the questionnaire.

Friends

Scores tended to remain the same for participants when rating their friendships. One score increased from 'good' to 'excellent', while a majority of seven participants rated their friendships as remaining 'good' or 'excellent'. Two scores decreased, one from 'excellent' to 'good', and another from 'good' to 'fair'. This indicates that people with dementia were reporting their friendships as remaining relatively stable in quality over time. Effect size was measured using a gamma test to establish a very strong positive association ($G=0.946$, $p=.000$) that was statistically significant. A chi-square test $\chi^2(9, N = 12) = 21.250$, $p = .012$) showed a statistically significant difference between expected and observed scores over time.

The majority of participants who remained stable reported 'good' to 'excellent' ratings for friendships, while the two participants who reported 'poor' and 'fair' ratings remained stable, they had very different attitudes towards friendships. One reported never having made friends easily:

'I don't make friends easily. I get on alright with people but I don't fuss around them.' (Person with dementia 1, 2nd interview)

This indicates his circle of friends is limited, but not a particular problem for him. Another participant's spouse (Carer 15, 2nd interview) reported that friends no longer visited, possibly due to discomfort with the diagnosis. This left the participant very isolated and suggests a need to offer post-diagnostic support to friends as well as family.

Ability to do chores around the house

Scores increased for four participants when rating their ability to do chores around the house. Two scores increased from 'fair' to 'good', one increased from 'poor' to 'fair', and one increased from 'poor' to 'good'. This indicates that a third of people with dementia were reporting their ability to do household chores more positively at the second data collection time. Scores remained the same for six participants and decreased for two participants. Therefore more than two thirds of people with dementia were reporting their ability to do chores as good or better following the intervention. Effect size was measured using a gamma test to establish a weak positive association ($G=0.357$, $p=.427$) between scores over time that was not statistically significant.

While participants' self-ratings are a useful indicator of how they feel about aspects of their lives, their view may at times contradict the perspective of others. This item was the one that was most often contradicted by family members during interviews,

with little consensus between participants on the actual level of contribution by participants with dementia in chores around the house.

Ability to do things for fun

Scores decreased for a third of participants when rating their ability to do things for fun. One score decreased from 'good' to 'fair', another score decreased from 'good' to 'poor', and two scores decreased from 'fair' to 'poor'. Scores remained the same for five participants (either good or excellent) and increased for three participants. While scores remained the same or improved for two thirds of participants, this item showed one of the biggest decreases in scores across the QoL-AD items. Effect size was measured using a gamma test to establish a positive association ($G=0.600$, $p=.103$) that was not statistically significant.

This finding is not fully supported by interview data, perhaps because ideas about 'doing things for fun' may have differed from questionnaire to interview. For example, one participant whose rating reduced from 'fair' to 'poor' reported taking up drawing and working hard to master his previous skills, looking forward to hosting with his wife a Burns Supper and going on trips out to visit historic houses (person with dementia 4, 2nd interview). Another, whose rating reduced from 'fair' to 'poor' reported enjoying playing chess and working in the garden at the second interview (Person with dementia 1).

Money

Scores decreased for a third of participants when rating their feelings about money. One score decreased from 'good' to 'fair' and three scores decreased from 'excellent' to 'good'. Scores remained the same for five participants (either 'fair' or 'good') and increased for three participants. While scores remained the same or improved for two thirds of participants, this item showed one of the biggest decreases in scores across the QoL-AD items. Effect size was measured using a gamma test to establish a positive association ($G=0.484$, $p=.051$) that approached statistical significance.

This finding is also not fully supported by interview data; all participants who lived with their spouse reported leaving financial issues to them and none reported having financial concerns. Several participants did question what the item meant, which suggests their lack of clarity might have influenced their rating of the item when completing the questionnaire.

Physical health, living situation and self as a whole demonstrated more variability across the scores. Approximately a third of scores increased, a third decreased and half remained the same for these items. Therefore no firm conclusions or inferences can be drawn from these particular scores.

COPE findings

The COPE questionnaire consists of twenty eight items: fourteen that are considered helpful ways of coping, and fourteen that are considered less helpful ways of coping. Within each group of fourteen items, there are seven pairs of items with similar wording. These items were not presented together in the questionnaire, but have been arranged this way in the analysis for clarity of presentation. The two tables list separately the helpful and less helpful ways of coping, and these items are arranged in the order that they appear in the questionnaire. The descriptive quantitative and qualitative analysis of COPE items is subsequently presented in pairs to enable a comparative account of similar items.

Table 7 demonstrates the differences at T1 and T2 for the carers as a group.

Table 7: Comparison of ratings over time for COPE items considered as less helpful ways of coping

COPE Item	Rating at Time 1			Rating at Time 2			Significance
	Min. Score	Max. Score	Mean Score	Min. Score	Max. Score	Mean Score	
Turning to work other activities to take my mind off things	1	4	2.58	1	4	2.17	P=.016
Saying to myself "this isn't real"	1	4	2.00	1	4	1.83	P=.025
Using alcohol or other drugs to make myself feel better	1	3	1.50	1	3	1.42	P=.317
Giving up trying to deal with it	1	2	1.25	1	2	1.08	P=.317
Refusing to believe that it has happened	1	3	1.25	1	2	1.25	P=.027
Saying things to let my unpleasant feelings escape	1	4	2.08	1	3	1.67	P=.003
Using alcohol or other drugs to help me get through it	1	3	1.67	1	3	1.50	P=.001
Criticizing myself	1	4	2.42	1	4	2.42	P=.000
Giving up the attempt to cope	1	3	1.42	1	4	1.50	P=.483
Making jokes about it	1	4	2.25	1	4	1.92	P=.007
Doing something to	1	4	2.17	1	3	2.33	P=.187

think about it less							
Expressing my negative feelings	1	4	2.42	1	4	2.58	P=.692
Blaming myself for things that happened	1	3	1.33	1	4	1.67	P=.004
Making fun of the situation	1	4	2.17	1	4	1.50	P=.235

Key: 1= not doing this at all, 2 = doing this a little bit, 3= doing this a medium amount, 4= doing this a lot

Over time, the largest decrease in COPE scores for less helpful ways of coping related to:

- Item 1: Turning to work to take my mind off things (decreased for four people)
- Item 9: Saying things to let my unpleasant feelings escape (decreased for five people)
- Item 28: Making fun of the situation (decreased for five people)

These items therefore moved in the 'right direction', according to the tool philosophy, for a good number of people in the group, with a third of participants reporting the decreasing frequency with which they used these less helpful strategies.

The largest increase in scores related to:

- Item 13: Criticizing myself (increased for four people)
- Item 19: Doing something to think about it less (increased for five people)
- Item 21: Expressing my negative feelings (increased for four people)

This suggests a number of people were coping less well in these areas at Time 2 compared to Time 1.

The items that seemed most stable over time included:

- Item 4: Using alcohol or other drugs to make myself feel better (scores for nine people remained the same),
- Item 8: Refusing to believe that it has happened (scores for ten people remained the same),
- Item 26: Blaming myself for things that happened (scores for nine people remained the same).

A brief discussion of changes over time in COPE values between Times 1 and 2 will be presented, using qualitative findings from interviews to contextualise these data.

Making fun of the situation

This item showed a strong trend of improvement when people were reporting on whether they continued to make fun of the situation i.e. they were doing this less. Scores decreased for five participants, all of whom changed from 'doing this a little' to 'not doing this at all' following the intervention. Three people continued to 'do this a little bit' and one person continued to 'do this a lot'. This shows that more than half of carers who were previously making fun of the situation were no longer using this means of coping. Effect size was measured using a gamma test to establish a positive association ($G=0.520$, $p=.235$) between scores over time that was not statistically significant.

Making jokes about it

This item also showed an improvement in scores for three people in their description of making jokes about it. Scores for most carers remained the same, with three carers 'not doing this at all', and five carers 'doing this a little bit'. Only one person described making jokes about it more often than before. Effect size was measured using a gamma test to establish a strong positive association ($G=0.700$, $p=.007$) between scores over time that was statistically significant.

Interviews with participants, revealed only one dyad that both made fun of the situation and made jokes about it a lot of the time. This family member reveals how he uses humour to cope with the situation:

'Been fine. Just carry on. There's nothing else you can do, other than just get on with it. Make fun of it.' [Laughter] (Carer 14, 2nd interview)

This suggests that humour is not necessarily the best indicator of coping unless contextualised in subjective understandings of the dementia/caregiving experience.

Turning to work or other activities to take my mind off things

Scores in this item decreased for four participants when describing the extent to which they were turning to work to take their mind off things. Scores decreased for three participants from 'doing this a lot' to 'doing this a little bit', while another person's score decreased from 'doing this a little bit' to 'not doing this at all'. This indicates that a third of carers were reporting that they used this less helpful means of coping less frequently at the second data collection time. Scores remained the same for six participants and increased for two participants. Effect size was measured using a gamma test to establish a strong positive association ($G=0.714$, $p=.016$) between scores over time that was statistically significant.

Doing something to think about it less

A less positive result was found when measuring whether carers did something to think about it less (such as such as going to the movies, watching TV, reading, daydreaming, sleeping or shopping) a way of coping considered to be less helpful. While scores remained the same for five carers and decreased for two carers, five

carers reported doing this more often than before. Two people who had not done this at all previously subsequently reported 'doing this a little bit' after the intervention. Another three people who had only done this a little bit were now doing this a medium amount. Effect size was measured using a gamma test to establish a positive association ($G=0.484$, $p=.187$) between scores over time that was not statistically significant.

While formally viewing this as a displacement activity, this could be seen as a fairly ambiguous strategy in terms of what may be helpful (or not) for carers. For example, one family member reported enjoying logging onto the computer in the evenings while her husband watched the football on the television and by the second interview had increased the time spent on this as this was a source of relaxation and escapism for her. (Carer 9, 1st and 2nd interviews)

Refusing to believe that it has happened

Scores for this item indicate a similar pattern to the previous item, with most carers reporting that they did not refuse to believe that it has happened (nine participants) and one person still 'doing this a little bit'. One person who had previously described not doing this at all when measured before the intervention described doing this a little after the intervention. Another person who had previously described doing this a medium amount before the intervention reported doing this only a little bit after the intervention. Effect size was measured using a gamma test to establish a very strong positive association ($G=1.000$, $p=.058$) between scores over time that was statistically significant. A chi-square test $\chi^2(2, N = 12) = 7.200$, $p = .027$) showed a statistically significant difference between expected and observed scores over time.

Saying to myself "this isn't real"

Scores decreased for three participants when reporting the extent to which they say 'this isn't real'. In positive terms, this demonstrates that a quarter of carers were reporting that they used this less helpful means of coping less frequently at the second data collection time. Scores remained the same for six participants and increased for three participants. Effect size was measured using a gamma test to establish a positive association ($G=0.611$, $p=.025$) between scores over time that was statistically significant.

Interview data indicates that all participants appeared to acknowledge the diagnosis (with one exception – Carer 7). Participants did, however, vary in their degree of acceptance, understanding and attitude towards the diagnosis. This indicates the shift in thinking over time that is required to acknowledge the reality of a situation and reach a state of acceptance.

Using alcohol or other drugs to make myself feel better

Scores decreased for two participants when describing the extent to which they were using alcohol or other drugs to make themselves feel better. Most carers reported

that they did not use alcohol or other drugs to make themselves feel better either pre or post intervention (seven participants). Scores remained the same for another two people; one person still did this a little bit, while another did this a medium amount. Use of alcohol or drugs increased for only one person, from 'not doing this at all' to 'using these a little bit' to make him/herself feel better. Effect size was measured using a gamma test which indicated a very strong positive association ($G=0.923$, $p=.016$) between scores over time that was statistically significant.

Using alcohol or other drugs to help me get through it

Over time, there was an improvement in scores for reports of using alcohol or other drugs to help them get through it, as seen in their reduction of scores over time. Scores decreased for three participants, two who changed from 'doing this a medium amount' to 'only doing this a little bit', and one person who changed from 'doing this a little' to 'not doing this at all'. One person reported 'doing this a little bit' when they had not used this way of coping previously. Half the participants did not do this either pre or post intervention, while another two people reported similar levels of using alcohol or drugs to get them through it before and after the intervention (either a little bit or a medium amount). Effect size was measured using a gamma test to establish a very strong positive association ($G=0.933$, $p=.001$) between scores over time that was statistically significant.

These items raised some discussion, while participants completed the form, on what was meant by 'drugs' – did it mean recreational drugs or medications such as anti-depressants? One participant reported drinking a little alcohol; not as a coping mechanism but because she had always done so (Carer 9).

Saying things to let my unpleasant feelings escape

There was an improvement in scores for carers reporting 'saying things to let unpleasant feelings escape' i.e. they reported doing this less over time. Scores decreased for five participants, four of which changed from 'doing this a little bit' to 'not doing this at all'. This shows that half of carers who used this means of coping before the intervention were using it less frequently following the intervention. Four people continued to use this way of coping a little or a medium amount, while one person described doing this more often than before (increasing from a little bit to a medium amount). Effect size was measured using a gamma test to establish a strong positive association ($G=0.840$, $p=.003$) between scores over time that was statistically significant.

Expressing my negative feelings

On the other hand, a less positive result was found when measuring whether carers were expressing their negative feelings. While scores remained the same for five carers, and decreased for three carers, four carers reported doing this more often than before. These people, who had previously reported 'only doing this a little bit', were now doing this a medium amount or a lot. Nevertheless, two people who had

been doing this a little before were no longer using this means of coping after the intervention. Effect size was measured using a gamma test to establish a weak positive association ($G=0.161$, $p=.692$) between scores over time that was not statistically significant.

Interviews revealed that carers who described their situations as stressful used language that reflected this, for example one participant said of her experiences since her husband's diagnosis:

'I've had to deal with the pieces I've already had to pick up.' (Carer 7, 1st interview)

And:

So I feel it very cruel that having overcome what he's overcome to throw this at him as well, I resent it like hell. I might as well be honest.' (Carer 7, 2nd interview)

While this may reflect a failure to come to terms with the situation, it also, when viewed in the context of a life experience, reveals the complexity of accepting what is a bleak future for people with dementia and their families.

Criticizing myself

A mixed picture emerged about the extent carers criticised themselves before and after the intervention. Three participants who 'did not do this at all' before the intervention were 'doing this a little bit' when assessed after the intervention, while another person who had been 'doing this a medium amount' was subsequently 'doing this a lot'. However, three participants who were 'doing this a lot' previously were only doing this a little or medium amount following the intervention; in these cases showing an improvement in scores. Scores for five people remained the same, ranging from 'not doing this at all' to 'doing this a lot'. Effect size was measured using a gamma test to establish a strong positive association ($G=0.829$, $p=.000$) between scores over time that was statistically significant. This finding could be explained by carers attending workshops and cafés run by the post-diagnostic support project and learning more about dementia and different ways of coping.

Blaming myself for things that happened

Most carers (seven participants) reported never blaming themselves for things that happened. However, following the intervention three carers were doing this more often. Two people who had 'not done this at all' were subsequently 'doing this a little bit', while another who had 'done this a little bit' was now 'doing this a lot'. Effect size was measured using a gamma test to establish a very strong positive association ($G=0.926$, $p=.003$) between scores over time that was statistically significant. A chi-square test $\chi^2(6, N = 12) = 19.111$, $p = .004$) showed a statistically significant difference between expected and observed scores over time.

During the second interview, one participant (Carer 1), whose family member had decided to stop receiving the intervention, who had moved from blaming themselves a little bit to blaming themselves a lot, revealed frustration and anger at how services in general seemed to be failing the family member with dementia. This example also illustrates the complexity of the context of people's lives and external factors and the futility they may feel when unable or unsupported to deal with change and deterioration.

Giving up the attempt to cope

There was an improvement for three people in their scores for reports of 'giving up the attempt to cope', from 'doing this a little bit' to 'not doing this at all'. Most carers (seven participants) never used this way of coping, while scores increased for two people who reported doing this a lot more following the intervention. Effect size was measured using a gamma test to establish a positive association ($G=0.538$, $p=.483$) between scores over time that was not statistically significant. A chi-square test $\chi^2(2, N = 12) = 5.700$, $p = .058$) showed a nearly statistically significant difference between expected and observed scores over time.

Giving up trying to deal with it

Similarly, scores on this item showed that most carers did not give up trying to deal with it either pre or post intervention (eight participants). Three participants, who initially described 'doing this a little bit', reported that they no longer used this means of coping after the intervention. One person who had previously not used this way of coping described 'doing this a little bit' when measured after the intervention. Effect size was measured using a gamma test to establish a very strong negative association ($G=-1.000$, $p=.317$) between scores over time that was statistically significant.

Generally, interviews supported this finding; family members talked of getting on with things, for example, one family member said:

'I've got to the stage now you've just got to get on with it, there's support there if you need it and just take it day by day... I just take it day by day and that's...it keeps you going.' (Carer 15, 2nd interview)

For this family member, the combination of coping strategies, family support and different forms of formal support enabled her to keep going with supporting her husband.

Table 8: Comparison of ratings over time for COPE items considered as helpful ways of coping

COPE Item	Rating at Time 1			Rating at Time 2			Significance
	Min. Score	Max. Score	Mean Score	Min. Score	Max. Score	Mean Score	
Concentrating my efforts on doing something about the situation I'm in	1	4	2.92	1	4	2.33	P=.060
Getting emotional support from others	2	4	2.67	1	4	2.67	P=.533
Taking action to try to make the situation better	2	4	3.33	2	4	3.25	P=.014
Getting help and advice from other people	2	4	3.17	2	4	3.17	P=.396
Trying to see it in a different light, to make it seem more positive	1	4	2.42	1	4	2.33	P=.952
Trying to come up with a strategy about what to do	1	4	2.50	1	4	2.50	P=.239
Getting comfort and understanding from someone	1	4	2.58	1	4	2.33	P=.711
Praying or meditating	1	4	1.58	1	3	1.83	P=.109
Accepting the reality of the fact that it has happened	3	4	3.75	2	4	3.50	P=.235
Trying to find comfort in my religion or spiritual beliefs	1	4	1.58	1	3	1.42	P=.002
Trying to get advice or help from other people about what to do	2	4	3.00	1	4	2.92	P=.108
Learning to live with it	2	4	3.08	1	4	2.83	P=.217
Thinking hard about what steps to take	2	4	3.50	1	4	3.08	P=.257
Looking for something good in what is happening	1	4	2.17	1	3	1.75	P=1.0000

Over time, the largest increase in COPE scores for helpful ways of coping related to:

- Item 10: Getting help and advice from other people (increased for four people)
- Item 27: Praying or meditating (increased for four people)

These items therefore moved in the 'right direction' for a good number of people in the group, with a third of participants reporting the increasing frequency with which they used these helpful strategies.

The largest decrease in scores related to:

- Item 12: Trying to see it in a different light, to make it seem more positive (decreased for seven people)
- Item 15: Getting comfort and understanding from someone (decreased for five people)
- Item 17: Looking for something good in what is happening (decreased for five people)
- Item 25: Thinking hard about what steps to take (decreased for five people)

This suggests a number of people were coping less well in these areas at Time 2 compared to Time 1.

The items that seemed most stable over time included:

- Item 22: Trying to find comfort in my religion or spiritual beliefs (scores for nine people remained the same)

A brief discussion of changes over time in these COPE values between Times 1 and 2 will be presented, using qualitative findings from interviews to contextualise these data.

Concentrating my efforts on doing something about the situation

For this item, just over half of carers (seven participants) reported little change in this means of coping following participation in the post-diagnostic support project. However, three people who were previously concentrating their efforts on doing something about the situation were not doing this at all after the intervention. Another person was only doing this a little bit after initially doing this a lot. One person reported using this way of coping more often following the intervention. Effect size was measured using a gamma test to establish a positive association ($G=0.550$ $p=.060$) between scores over time that was nearly statistically significant.

Taking action to try to make the situation better

Although scores remained the same for most carers (eight participants), this way of coping was reflected fairly strongly in people's responses, with ten carers doing this at least a medium amount after the intervention (two of which had increased in score from before the intervention). Effect size was measured using a gamma test to establish a strong positive association ($G=0.750$, $p=.014$) between scores over time that was statistically significant.

During interviews, family members described going out, whether to play Bridge, visit a sibling or to the shops as a way of removing themselves from the situation, as this family member describes:

‘,,, so I either just say I’m going to the shop and... if I’ve gone up to town, or anything, and he’s been in a strop, he’ll be in a better mood by the time I come in.’ (Carer 15, 2nd interview)

Getting help and advice from other people

There was an improvement in scores for four people in their reporting of ‘getting help and advice from other people’. Following the intervention five people were ‘doing this a lot’ and four people were ‘doing this a medium amount’. Scores for five carers remained the same, with three carers decreasing in the amount of time they used this way of coping. Effect size was measured using a gamma test to establish a weak positive association ($G=0.333$, $p=.396$) between scores over time that was not statistically significant.

Trying to get advice or help from other people about what to do

There was a variable pattern in reports of ‘trying to get advice or help from other people about what to do’. Scores increased for three participants, decreased for three participants and remained the same for six participants. Positively, three people who were ‘only doing this a little bit’ before the intervention were doing this a medium amount or a lot after the intervention. However, two people who had previously been trying to get advice or help were not doing this at all following the intervention, and one person who had been doing this a lot was now doing this only a little. Effect size was measured using a gamma test to establish a positive association ($G=0.586$, $p=.108$) between scores over time that was not statistically significant.

Findings from interviews revealed different practices and attitudes towards seeking advice and help. One participant who moved from getting advice or help from others a lot to not doing it at all also had a parent with dementia and felt well equipped with information to be able to cope with their spouse’s condition (Carer 9). Another participant experienced a sense of information overload with the quantity of information and advice given (Carer 7), while another felt there was insufficient information and advice given following their family member’s diagnosis (Carer 2). Qualitative findings revealed the diversity of need and desire for advice and help in the period following diagnosis.

Trying to see it in a different light, to make it seem more positive

There was a decrease in scores for this item in seven carers when reporting on whether they tried ‘to see it in a different light, to make it seem more positive’. Three people who had been doing this a little or a medium amount were no longer doing this at all, three people who had been ‘doing this a medium amount’ were now ‘only doing this a little bit’, while another had changed from ‘doing this a lot’ to ‘doing this a

medium amount'. Conversely, three people who had not been trying to see it in a different light were now doing this a medium amount or a lot after the intervention. Effect size was measured using a gamma test to establish a weak negative association ($G=-0.022$, $p=.952$) between scores over time that was not statistically significant.

Looking for something good in what is happening

A similar pattern is evident in this item, with a decrease in scores for five carers when reporting on 'looking for something good in what is happening', and an increase in scores for three carers following the intervention. Scores for four people remained the same. Effect size was measured using a gamma test to establish no association ($G=0.000$, $p=1.000$) between scores over time.

Interviews indicated different reasons for these findings, for example one family member who struggled (and most often failed) to persuade her husband to wear his hearing aid has given up sharing her observations of the day with him:

'But I don't do that now, because I think he'll not hear me anyway, so where's the point? So the conversation's going because of not wearing hearing aids.'
(Carer 3, 2nd interview)

Another factor that emerged during interviews is the pragmatism that develops with acceptance of the diagnosis and the use of networks to support participants, possibly resulting in less focus on trying to view things differently or looking for positives in what is happening.

Trying to come up with a strategy about what to do

A variable pattern is also evident in this item, although scores were more stable over time, with six people reporting the same level of reporting pre and post intervention. When reporting on trying to come up with a strategy about what to do, three people who had been doing this a little bit or a medium amount were no longer doing this at all after the intervention. On the other hand, three people who had either 'not been doing this at all' or 'only doing this a little bit', were now reporting using this means of coping a medium amount or a lot following the intervention. Effect size was measured using a gamma test to establish a positive association ($G=0.400$, $p=.239$) between scores over time that was not statistically significant.

Thinking hard about what steps to take

Seven carers were continuing to think hard about what steps to take at least a medium amount following the intervention. There was a large increase in score for one person, who had 'only been doing this a little bit' but was now 'doing this a lot' after the intervention. However, nearly half of carers reported a decline in score over time. Three people who had reported using this way of coping a lot or a medium amount before the intervention were only 'doing this a little bit' after the intervention. Another person was no longer doing this at all after reporting that they had been

doing this a little before the intervention. Effect size was measured using a gamma test to establish a positive association ($G=0.500$, $p=.257$) between scores over time that was not statistically significant.

Interview findings do not necessarily concur with these data; participants talked of the difficulty they had in thinking ahead and considering what steps to take, particularly in thinking about what the future holds. Many participants talked of taking it 'one day at a time'. It also appeared that while some participants were reporting thinking about what steps to take (COPE), when questioned at interviews they talked of not wanting to engage with the idea. For example, this carer reported thinking hard about what steps to take at Times 1 and 2, however when interviewed, expressed the opposite view:

'I think it's just a terrible thought to think ahead and, you know, cause the only thing you've got is what you would probably see and people, you know that's worse off than X, you don't want to think that, I certainly don't want to think about it.' (Carer 5, 2nd interview)

Getting emotional support from others

For ratings of 'getting emotional support from others', carers shows a variable picture, with scores increasing for three participants, decreasing for three participants and remaining the same for six participants. Three carers showed an improvement in scores. They had only been using this way of coping a little bit before the intervention and were now reporting doing this a medium amount or a lot. However, two people who had been 'doing this a medium amount' reported 'not doing this at all' or 'only a little bit' following the intervention. Another person reported getting emotional support from others a medium amount when they had previously been doing this a lot. Effect size was measured using a gamma test to establish a weak positive association ($G=0.250$, $p=.533$) between scores over time that was not statistically significant.

Getting comfort and understanding from someone

There was also a decrease in scores for five carers when comparing scores for 'getting comfort and understanding from someone' before and after the intervention. There was an increase for three carers, with one person who had 'not been doing this at all' now 'doing this a little bit', and two people who had been 'doing this a little bit' now doing this a medium amount or a lot. Scores for four people remained the same. Effect size was measured using a gamma test to establish a very weak positive association ($G=0.152$, $p=.711$) between scores over time that was not statistically significant.

These two items raised some discussion and some family members questioned who they would receive emotional support, comfort or understanding from. This uncertainty might explain the spread of values observed.

Trying to find comfort in my religion or spiritual beliefs

Most carers (eight participants) did not try to 'find comfort in their religion or spiritual beliefs' either before or after the intervention. There was an increase in scores for one person who described 'doing this a little bit' after the intervention and one person continued to do this a medium amount. Two people who described trying to find comfort this way a lot or a medium amount reported only doing this a little following the intervention. Effect size was measured using a gamma test to establish a very strong positive association ($G=0.923$ $p=.002$) between scores over time that was statistically significant.

Praying or meditating

Compared to reports of finding comfort from religion or spiritual beliefs, more people described using praying or meditating as a means of coping. Although five carers did not do this at all either before or after the intervention, four people who had not prayed or meditated previously were now doing this a little or a medium amount. One person continued to do this a medium amount, while two people who had prayed or meditated a lot or a medium amount were only doing this a little bit after the intervention. Effect size was measured using a gamma test to establish a positive association ($G=0.545$, $p=.109$) between scores over time that was not statistically significant.

These items also raised discussion about the difference between religious and spiritual beliefs and praying and meditating and how best to score them, given such differences. No participants talked about using these forms of coping during interviews.

Accepting the reality of the fact that it has happened

Nearly all carers reported 'accepting the reality of the fact that it had happened', with eleven people reporting doing this a medium amount or a lot both before and after the intervention. There was an increase in scores for one person who described 'doing this a lot' after the intervention. Scores decreased for four people. Three people who had been 'doing this a lot' were now 'doing this a medium amount' following the intervention. One person who had been 'doing this a medium amount' was 'only doing this a little bit' after the intervention. Effect size was measured using a gamma test to establish a positive association ($G=0.667$, $p=.235$) between scores over time that was not statistically significant.

Learning to live with it

There was a variable pattern of reporting among carers when describing the extent to which they were 'learning to live with it'. Scores remained unchanged for six people, four of whom reported 'doing this a lot'. Two carers who had been 'doing this a little bit' were now doing this a medium amount or a lot following the intervention. Four people reported a decrease in scores over time. Two people who had previously reported trying to learn to live with it were no longer doing this at all. Two

people who had been 'doing this a medium amount' were now 'only doing this a little bit'. Effect size was measured using a gamma test to establish a positive association ($G=0.436$, $p=.217$) between scores over time that was not statistically significant.

During interviews, participants talked in different ways of how they were learning to live with the diagnosis, while sometimes struggling with specific aspects of it. For example, this family carer states:

'Each day...every...I find every day different. Today could be a thoroughly depressing day and tomorrow could be quite a lot better. And I don't...sometimes I don't know why that is. I think acceptance is a terrible thing to work on. I'm not sure I've totally come to terms with that yet either.'
(Carer 7, 2nd interview)

The variation in pattern of these two items indicates the diversity of experience of participants, therefore generalising from such a small group is difficult.

Comparison of QoL-AD and COPE data from T1 and T2:

A comparison of changes in Mean QoL-AD and COPE scores at T1 and T2 for the eleven dyads in the intervention group reveal that:

- There were three dyads where people with dementia and their carers reported overall improvement.
- There were two dyads where people with dementia remained the same while their carers reported improvement.
- There were two dyads where people with dementia reported improvement while their carers reported a decrease.
- There were two dyads where people with dementia reported no change but their carers reported a decrease.
- There were two dyads where people with dementia and their carers reported a decrease.

These findings indicate a general positive trend in perceived quality of life and ability to cope for some dyads following the intervention, as measured by QoL-AD and COPE. They also indicate the potential for variation within dyads either in their perceived quality of life or in their ability to cope. This suggests the need for a more targeted, and possibly intensive, series of individualised interventions either for the person with dementia or the carer depending on how they report their perceived quality of life or their ability to cope at particular times in their lives.

3.1.3 What difference, if any, does the post diagnostic support service make to service access and service use for people with dementia and their carers?

This, and the next three questions, will be addressed with reference to qualitative data from interviews with participants at T1 and T2. Case studies of specific dyads will be used to illustrate key findings. We will begin by looking at participants' experiences of service access, before looking at their experiences of service use.

- Service access

Carers frequently reported positively on the help received from the project workers with claiming benefits following diagnosis of the person with dementia. Most of the carers who reported positively on this had not known of their entitlements and were therefore delighted with the extra income received. For example:

So the girls came out and they actually helped with filling in forms and things like that. (Carer 9, 1st interview)

For this carer and her husband, this was a valuable exercise, as they had no idea of their entitlements and benefits and the 'wee bit of extra money' was welcomed.

For other carers, information on specific entitlements such as a reduction in Council Tax was welcomed as they had not known of this previously:

But, as I say, there's been one or two things that have come up that's kind of helped and things that probably we would never have thought about, we never thought about the rates, getting a cut in rates. It's only because it was mentioned. (Carer 14, 1st interview)

There was satisfaction with the way the project supported the travel needs of participants, whether by arranging a taxi or giving several participants a lift to and from their destination. This particularly applied to participants who no longer had access to a car, because of no longer being able to drive or because of giving it up for financial reasons. Availability of transport went towards not only alleviating concerns about how to get to the events organised, but also maintained social contact.

Access to the social settings provided by the project (dementia cafés or trips out) was reported by all participants as very valuable. For some participants with dementia, the opportunity to talk 'normally' with other people with dementia came as a surprise to them, thus the social occasions seemed to help break down the barriers associated with dementia including the sense that people with dementia are somehow different. For several people with dementia, this was possibly their only chance to engage with others in the same or similar position as themselves. For example:

No, the odd chat to one another is half the battle isn't it? Mingle with one another. That's a big help itself. When you think of those women that are lonely, left without a man or whatever. Same as men, on their own, things like that. Well that's...they've been in amongst company where they can all chat and that's it. It's a big help. (Person with dementia 9, 2nd interview)

The combination of a social setting along with information and sharing of experiences by other people was seen as useful by some participants, for example:

You get talking to other people and the carers are there as well so you can hear things that they've done, things that you've done, and it kind of passes all round, you know, the things that you don't think about sometimes, somebody comes up with a wee answer for it. (Carer 14, 1st interview)

And:

A lot of the time we were just sitting chatting and drinking coffee and...yeah, yes, that was the best one. Yes. And then they split us up into two rooms and the carers go into one room and the others sit and have a wee chat at the end for about half an hour. No, that's very good. It's very good. (Carer 11, 1st interview)

Access to information, particularly for those who felt let down by the general system, was very much valued by carers, as was the opportunity to speak with people (project workers) who were knowledgeable and readily available.

Several carers also spoke of receiving support with arranging Power of Attorney and valued the input from project workers in negotiating the process. For example:

Tomorrow we've got a lawyer coming in to give me the power of attorney sort of thing so they gave us all that information. (Carer 5, 1st interview)

However, taking this step was not always easy, particularly when the carer felt this was in conflict with the wishes of the person with dementia, indicating the delicate nature of conversations in this area:

No, he's not really interested in Power of Attorney getting done at the moment. (Carer 9, 2nd interview)

From this analysis, the project has been very useful in alerting participants to and supporting them with applying for entitlements and benefits – many participants would not have accessed these had they not been alerted to their entitlement by the project workers. It has also been very useful in facilitating social interaction with other people with dementia and carers and offering information and support when required. Support with accessing other services such as Power of Attorney or home care requires a degree of planning and thinking ahead that many participants were

not able or willing to engage with. This is not surprising given the short duration of the project to date.

- Service use

One participant with dementia who attended art classes only managed to so because the project workers arranged for a volunteer to attend with her. Without this input she would not have been able to attend these classes. Others were supported to go for coffee or lunch, or to their old work place or place of interest thus enabling them to take part in everyday social activity. No other participants reported on any differences in formal service use as a result of the project; this could relate to the relatively early progress in participants' journeys through dementia where they had yet to access many services.

In summary, participants engaged to varying degrees in service use and this seemed to depend on their wishes and requirements for services. There was the sense that, with the support of the project, their needs would be addressed when required and that there was always the named contact and assurance of a response from the project team.

Case Study 1: Access and use of services (Participant 7)

This person with dementia was in his 70s and lived at home with his wife. His physical health had been very poor, but at his second interview he looked fitter, had put on some weight and reported feeling much better. He reported improvement in quality of life measures of memory, family and money. His wife struggled with health problems of her own.

It was clear during the interviews that while the participant with dementia took a pragmatic view of his condition, his wife strongly resisted the diagnosis and expressed anger that this had happened to them. His wife attended carers' classes, although she found some of the content overwhelming, and received copious amounts of information on her husband's different illnesses, which she also found overwhelming. She also felt there was no provision, for example counselling, for her husband, and therefore identified limitations in the support available to her from general services.

While she was initially resistant to the idea of engaging with the post-diagnostic support project, by the second interview she had started to feel able to engage with it and also with other people with dementia and their family members. Her acceptance then allowed access to the project for the participant with dementia. A key point from this case study is the ability of family members (for various reasons) to block access to services such as the post-diagnostic support project and it also illustrates that if lack of acceptance or denial of a diagnosis on the part of a family member delays access to services, there is a need not to have services that have a cut off referral time.

3.1.4 What difference, if any, does the post diagnostic support service make to independence and choice for people with dementia and their carers?

The post-diagnostic support project aimed to promote independence and choice for participants. Examples of independence are a person with dementia being able to go out without the support of a carer, and a carer being able to continue an active life independent of their care-giving responsibilities. Choice relates to the range of services and support available to both carers and people with dementia that meet their individual needs and preferences rather than the availability of sole service solutions.

- Independence

Several participants benefitted from being supported to go out (with a project worker or a volunteer), although it is unsure whether this actually increased their sense of independence. One carer who wished her mother could become more independent, even though her mother had regular trips to the shops or her church with a volunteer organised by the project, was pleased that, over time, her mother has become more outgoing and participated in conversations with other people in the project more often than before:

I think they're great. My mum, whenever I used to take her anywhere, she didn't speak. Now, she...you know, she...you don't just speak whenever you're asked a question, you...she actually joins in the conversation, which I don't...I think if you hadn't have been going to those things, I don't think she would have. (Carer 6, 2nd interview)

Another person with dementia surprised his wife by going to the shops with one of the project workers:

But what he has done is because of the nice way they've gone about it he has gone out for lunch with them and he's popped in for a cup of coffee because it's on his shopping route, you know. He shops at X's so when he goes in has, you know...he would do that. That's the one thing I'm quite surprised about, that he's done that, you know. (Carer 3, 1st interview)

Although these are small steps towards regaining independence they are important for those who are making them and for carers who witness such changes.

- Choice

Participants had mixed opinions on the frequency of services offered to them by the project: some were happy with it but some wanted more frequent opportunities to meet with others in coffee mornings or more frequent group trips out. This is an example of participants expressing their wishes and possibly wanting to exercise

choice and have some control over the types of activities and services offered by the project.

One carer was supported by the project team to use Self-Directed Support to help her to care for her mother in a way that suited them both. Self-Directed Support allows people to arrange some or all of their support instead of receiving directly provided services from their local authority social work or housing department. This had only just got under way when her mother died, but was positively reported on by the carer:

But I'd never heard of self-directed support again until Tracy and Michelle's team came on board. I'd never heard of anything like that. I really just kind of thought that we had to put up with what we had. So they were instrumental in putting that across that no, there are other options out there. You don't need to take the help from the council, you don't need to take the help from Alzheimer's, you can employ someone of your own to come in and do what you want to do. (Carer 2, 1st interview)

However, this was not an option that was universally accepted, as this other carer stated:

This lady come up and gave us a talk, that's what it was and she was talking about the care, you should get somebody in... to, you know, to sit with you or take you out and all that, you know, but you can take that money, you know, I'm saying to myself, I mean I noted a few things down and that and then after just listening to her I went oh Christ you don't want to go down that road, you know, you'd be filling out forms for the tax man to the day you die, you know. (Carer 5, 2nd interview)

People with dementia and their carers appeared to be ambivalent about choice of services and choices available to maintain their preferred lifestyle; whether this was because they were still quite early on in the project or whether having a choice in the type of services received was not a familiar concept is unclear.

Findings from interviews suggest that, for carers and people with dementia, the service has benefitted them socially; through the monthly dementia cafés and information sessions, through meeting other people with dementia and carers, through trips out and through the more intensive one-to-one visits from project workers. This is particularly the case for people with dementia living on their own. Participants with dementia spoke of the friendships developing during the dementia cafés, sometimes with other people with dementia and sometimes with other carers. Carers also spoke of the supportive nature of the project.

Finally, the project enabled individual participants to participate in meaningful activities demonstrating the importance of an individualised and personalised

approach to care provision and support. Of the many positive accounts, the support given to a woman with mixed dementia to attend an art class to rekindle her love of painting stands out as an example of the difference a personalised approach and team working can make in the lives of people with dementia and their carers.

Case Study 2: Independence and choice (Participant 6)

This person with dementia was in her 60s at the time of interviews and lived alone with daily support from her family who lived close by. While having difficulty expressing factual or conceptual points, she was able to clearly articulate how she felt about things that impacted directly on her life such as keeping in telephone contact with her friends, going out for trips with them and what she wanted or did not want in terms of support, for example, when asked about what she would like to see the project offer, she decided:

'Well line dancing would be good.'

And when asked about support in general, she was clear she did not want home support or attend a day centre. This meant that, apart from her family, occasional contact with friends and the recent, although reluctantly accepted, introduction by the project workers of a befriender who came weekly, she spent her days alone watching television. The negative feedback from the participant about the befriender raises important points about introducing a stranger into a person's life and assuming the development of a trusting relationship. With someone with dementia, this type of intervention might need to be introduced and supported over a longer period of time than with other groups using such a service.

For this participant, the most marked change was in her self-confidence and this, her family believed, emerged through attending the workshops and dementia cafes arranged by the project. As her daughter said:

'(She'd) sort of withdrawn into herself. It feels like it's brought her a lot more confidence out on you. There are still situations where she gets nervous, but you don't feel it where you're in there (coffee mornings).'

While, statistically, this family carer's improvement in COPE mean scores was small, interview findings suggest that improvement in the person with dementia's condition, in this case motivation (as reported by the family) and QoL-AD items including energy, living situation, memory, self as a whole, ability to do chores and life as a whole (as reported by the person with dementia), could have had a positive impact of the family's ability to cope generally. These improvements in QoL-AD items, in such a young person, are likely to have a longer term impact on the outlook and coping strategies of family members, therefore supporting and maintaining these will be important.

3.1.5 How successfully has the intervention realised its specific intended outcomes for people with dementia and their carers?

The project intended to:

- provide information, advice, signposting, emotional and practical support to help the person newly diagnosed with a dementia and their families/supporters to understand and come to terms with living with dementia.
- assist people with dementia and their families/supporters to put in place financial and legal arrangements to maximise their control over future decisions made on their behalf (e.g. powers of attorney, advance statements).
- support people to maintain the important relationships in their lives and remain involved in their communities, continuing to enjoy social and recreational activities.
- facilitate more detailed advanced planning using person centred planning tools.

On analysis of interviews, the intervention has been most successful in increasing participants' social contact (particularly with other people with dementia and carers), in enabling people to engage with others 'in the same boat' and develop peer support. Participants strongly valued the sense of being supported by people who really care, are available to talk to and are specialists in their field. Only one participant in the evaluation used Self-Directed Support to arrange services and reported very favourably on this. Although this may be perceived as minimal success, this is a process that takes time and may not have been possible to achieve for many people within the short time of the project.

The main area in which the project has not achieved its intended outcome is in advance care planning. This is not necessarily because the project workers have not broached the topic – they did with many participants, but it may be because it was too early in their participation with the project to expect people with dementia and their carers to have engaged with the topic. People with dementia generally left decisions about services to their carers and carers generally did not want to think too far ahead to the types of services they would require or want to receive.

Interviews over the two time periods revealed no shifting in thinking from those who just did not want to think ahead, highlighting the highly sensitive nature of the topic, the fear of what the future holds and the lengthy timescales required to support people to think ahead. For example:

Well, see I don't like to plan ahead, because I can't say how I'm going to feel, (person with dementia 15, 2nd interview)

And:

We know that things are not going to improve, we know that, it's not like a physical illness that can get better. We know that but maybe I'm just like as ostrich and sticking my head in the sand, I don't know. (Carer 10, 2nd interview)

Case study three provides an example of a situation where the intervention was working well for the person with dementia and his carer, while case study four demonstrates that the intervention may not always be appropriate for everyone and that timing is extremely important when offering help and support.

Case study 3: Example of positive impact of intervention (Participant 4)

This person with dementia was in his 60s at the time of both interviews and lived at home with the support of his wife. Although his QoL-AD scores suggest a perception of moderate quality of life, the difference in his demeanour and outlook on life was quite marked from first to second interviews. The key issue for this participant was accepting his diagnosis and realising it was not a death sentence. This was achieved with the support of the project workers. His wife says:

'When you were first diagnosed, one of the questions he kept asking is, how long have I got, how long have I got. He literally viewed it as a death sentence. And the project workers and the group have been good at both saying to him it's not a death sentence, you know, think positive and get on; and then seeing people and meeting people who, you know ... you realise that it's not the end of the world for you.... So that's been good. Because...I think it just sort of drags you down.'

This seems to have been a momentous shift for both the person with dementia and his family members and has given them renewed purpose and meaning in their lives. The other key point raised by both participants was the value of having support as soon after diagnosis as possible and the importance of skilled, knowledgeable, sensitive project workers to deliver support. As his wife says:

'But they came in and just kind of threw open the door that there's another world out there; yes, you've got it, we can't get away from it, but you've got a life, you've got things to do, and it was just their whole approach... their whole approach, the things they were telling you, the information they gave you, and the way it was done, was the boost or the kick that he needed to get him kind of going again.'

Case Study 4: Example of intervention not being appropriate for this particular person (Participant 1)

This person with dementia was in his 80s at the time of interviews. He lived on his own and was supported by a family member. Although his QoL-AD indicates a small reduction in his perception of his quality of life, interview findings suggest a very pragmatic man who has a clear understanding of his abilities and limitations, but also low expectations for any change. He is also a very private man with no desire to socialise, join clubs, meet new people or engage in any activities on offer for older people. This might explain his reluctant acceptance of conventional services and support (daily home support and a befriender). His observation of the detrimental impact of home support on his ability or motivation to cook is an indicator of the potential for loss of skills with the introduction of home support.

'I used to do quite a lot of cooking but I've gone off it now, they've put me off.'

Supporting him by cooking together rather than de-skilling him might have been a better approach, and this is particularly important for people living on their own.

This participant's family member expressed deep distress during both interviews about the support offered to him by general services and this had intensified by the time of the second interview. The key point raised by the family member was the lack of consultation with the family when decisions regarding care and support are made and the fear that decisions might be being made that are not in his best interests. The sense of carer isolation was very strong, also a hunger for knowledge and a clear understanding that support should be offered as soon after diagnosis as possible.

In cases where there is potential for conflict between family members and professionals, post diagnostic support project workers might be able to mediate (or identify a mediator) to ensure decisions are made following clear processes and with clear consideration of the person with dementia's best interests and regard for the concerns of family members.

In summary, participants reported experiences that suggest the project has been successful in providing information and advice to those with dementia and their families and has enabled many to continue social and recreational activities.

However it has had limited success in facilitating and promoting advanced care planning in part due to resistance from carers and people with dementia to think too far ahead while still adapting to the diagnosis, and also might reflect the relatively short period of involvement with the project and an immediate demand for information and activities rather than forward planning.

3.2 Findings from interviews with professionals working in Renfrewshire and East Renfrewshire

Two questions guide our presentation of findings from professionals interviewed in Renfrewshire and East Renfrewshire. This first is:

- 1. What difference, if any, does the post diagnostic support service make for professionals and frontline carers who work with people with dementia and their carers?**

We present analysis that answers this question by discussing this in relation to the role of the respondent in the diagnostic and post diagnostic process.

Diagnostic process

The diagnostic process is necessarily clinical, with some biographical and contextual history sought from professionals. Due to time constraints, there is limited time to engage in anything other than brief post-diagnostic support or counselling immediately following diagnosis; this, to varying degrees, tends to come in the following days, weeks or months.

Interviews revealed variation in the quantity and type of information given to people newly diagnosed with dementia and their carers; it is often in written format (leaflets and books) or verbal format (information and advice on services and support). The type of information given seemed to differ depending on the role of the practitioner, for example the Community Psychiatric Nurses (CPN) described giving written and verbal information depending on the type of information required, while the occupational therapist or physiotherapist visiting the house to do assessments described using visual prompts as a way of imparting information. It appeared that information giving (quality, type, quantity, timing) was inconsistent at times, with lack of clarity as to the type or quality of information given, or whether information was given at all. For example:

We're supposed to give everybody certain booklets at certain times and record the fact that we have done. So what this states is that all people who receive dementia diagnosis in the last 12 months should be offered...for the person with dementia they should be offered the booklet Facing Dementia... The carer and the relative should be offered Coping with Dementia: A Handbook for Carers, or Caring for a Partner, Relative or Friend with Dementia: A Pocket Book for Carers, and the person with dementia and/or the carer should also be offered the Dementia Helpline card. And we have to have a system in place to record that they have been offered these booklets. But my difficulty with this is that we're not often there when people receive their diagnosis so we don't know if it's happening and we don't know if the consultants are recording it or not. (Memory Clinic Staff 1, 1st interview)

There seemed to be variation in the timescales given for information to be discussed with professionals and the extent to which carers are left to find out information for themselves. This is consistent with reports from interviews with people with dementia and their carers. For example:

... and that is basically the gist of it all and then probably arrange to meet up again in about three months. I mean if the patients are with relatives then we can also direct them to internet websites where they can try and get more information and then bring them back in two or three months time just to discuss if they have any queries and then speak about things like input from social work, power of attorney, driving related issues. (Nurse 1, 1st interview)

There is also the sense from some of the key informants that giving information is sufficient, whereas others recognise that this should just be the start in a process that extends over time. However, with the time-limited nature of many of the key informants' roles, this is difficult if not impossible to achieve.

Post diagnostic process

It is inevitable that different practitioners have different roles in diagnostic and post-diagnostic processes and it was clear from key informant interviews that their roles were important in guiding their practice and influencing their experience.

Often, by necessity, workers and professionals are task orientated, for example the occupational therapist or physiotherapist looks at the person's functioning ability or safety within the home and will assess for aids or adaptations, the CPN's role is predominantly to monitor and offer support with mental health and particularly to monitor medication, the home care worker will work to support the person with making meals or taking medication in their own home, the social worker will discuss benefits and co-ordinate services and a lawyer will offer legal advice or deal with guardianship issues. In many cases professionals reported referring to each other depending on the issue or problem and will work together towards a particular goal.

It was clear from some key informants' accounts that intensive work went into maintaining a person with dementia at home, often involving multi-disciplinary team and family input, but also through building up a relationship with a key person over time. However this is sometimes dependent on the person being in a professional's caseload, for example a CPN's, once the CPN discharges the person from their caseload, the support worker has to stop seeing the person and therefore the person with dementia receives no further or no new support. For example:

If they're discharged, there's no CPN. If the CPNs are not doing anything for that person and they feel, 'Right, okay. I'm not really visiting this person, they're okay. We've this, this, this is in place', or whatever, they will then speak to the client and say, 'Well, you know, at this time I'm discharging you... So yes, once a client gets discharged or go to whatever...long term care

or...you know, services, then you keep getting your new clients. (Support worker, 1st interview)

Workers and professionals held different views on the limitations or strengths of their role, with lack of time and lack of resources being the most commonly cited limitations. Lack of resources, and this can mean a shortage of staff and therefore time available, is also an issue for some professionals and results in them having to discharge patients once their condition is stabilised. How this contributes to later crises is an important question. There is also some recognition that one size does not necessarily fit all, although referral to generic services continues.

Some professionals did not appear to generally recognise that referral to the post-diagnostic support project could be an alternative to general services. Initial comparison between first and second interviews suggests a compounding of the perceived difficulties with referring to the project from one practice manager, although here there is some blurring of reasons for low referrals – on the one hand the referral criteria are seen to be too tight and on the other hand there is low motivation or interest within newly diagnosed people in this community to join the project:

I think that we still understand the referral system and where we have had clients where we would suggest that maybe a referral to the project would have been a good idea hasn't been received particularly well and I think it was for all the same reasons that I had highlighted that there was difficulties before, and I think that again has just substantiated what my understanding of the project was, and also the difficulties that I saw within the criteria that had been set for this project. And the results that we've had with working with the clients that we've had and trying to involve them with the project have not been successful in that people haven't been interested or motivated enough to want to do that and it's for all of the reasons that I stated before. (Memory Clinic Staff 2, 2nd interview)

In summary, key informants describe good inter-disciplinary working to provide some excellent good post-diagnostic support in existing services including rehabilitation, maintaining the person in the community and monitoring of medication. However, this support is most often time-limited and goal oriented. This is not necessarily a criticism, but points to two potential negative consequences for the person with dementia and his or her family. The first is the risk of later crisis occurring when the person has been discharged from the particular intervention and has no identified key person monitoring their well-being and/or coping ability. This applies as much to the carer as the person with dementia. The second negative consequence is the potential for social isolation if the focus remains only on functional ability, assessment or medication compliance or monitoring.

While there is support offered to carers, this is most often in the absence of people

with dementia, meaning the carer has to organise someone to keep the person with dementia company while they are away, if need be. There is also a lack of peer support offered to people with dementia.

2. How successfully has the intervention realised its specific intended outcomes for local authority and health staff?

The project hoped to achieve the following outcomes for local authority and health staff:

- to be better informed,
- to understand the benefits of and be committed to personalisation for people with dementia,
- to be able to inform and support people with dementia and carers in designing creative patterns of services and natural supports which will best support them in the future.

We address this question by examining the views of respondents about the project in relation to the intended outcomes.

All key informants had heard of the post-diagnostic project, although many had not referred people newly diagnosed with dementia. Reasons for not doing so included this not being part of their role, people newly diagnosed with dementia not fulfilling the referral criteria and issues to do with paperwork. There are a range of reported views about the project among the professionals and frontline workers interviewed. The overall viewpoint expressed within each interview (over both time periods) is summarised in Table 9 below. There was very little change in perceptions of the project over time; those who embraced the idea of the project at the outset remained positive at the second interview while those who expressed reservations at the outset continued to critique the rationale for the project at the second time period.

Table 9: Key informants' views of the evaluated intervention

Overall view of project	Number of interviews
Highly positive report	5
Short positive account	4
Appreciated conceptually but not translated into action in the way of referrals	4
Ambivalence	6
Resistors	1
Strong Critique	16

Highly positive reports came from five staff; two of whom provided particular examples of the benefits of intensive work with individuals with dementia. One related to a positive outcome from a crisis intervention and the other to a complex care needs situation. The specialised role of the project workers was noted by a physiotherapist to result in a very individualised type of support, which would not have been possible in usual service provision:

This one particular client, I've never been involved with anyone who's had so much contact, it's very nice. And how very personalised the service is. Because it truly looked at her interests and her social life and her personality, all of that was taken into consideration. And it truly was personalised. It really is a personalised service and meets this lady's needs. The other advantage is you've got consistency of staff. It's the same people that are providing the care as well, which is an advantage. They're building up relationships with the client, which improves the quality of that intervention, it all adds to the quality. She would have been in care if it hadn't been for the service. (Allied Health Professional, 1st interview)

Respondents who highly valued the project talked about the opportunity it gave them to work in a preferred manner and about the positive outcomes for those receiving the service.

Four respondents made positive statements about the nature of the project indicating a conceptual or abstract appreciation of the project ideals. However they had not translated this positivity into any kind of action by referring people with dementia to the project or by engaging directly with the aims of the project.

Eight respondents expressed ambivalence about the project. They could see that it might be beneficial for some people, but had not actually pursued this avenue by referring patients to the service. Two of these eight felt the project should work in conjunction with the services they already provided and two had little awareness of the project apart from its existence and had not referred anyone to it. For example, this Nurse

I haven't referred to the project for some time. It doesn't seem to have a big uptake in this area....Yes, I mean I think a lot of my clients would benefit greatly from the service but they don't feel they need it... and part obviously of the criteria is that people are willing to engage and that they can work with them and have some understanding of what they're going to be doing. (Nurse 2, 2nd interview)

There was one respondent who we have termed 'resistor' as they appeared to hold the view that the project is only useful for a small number of patients, they believe their own service model is sufficient and providing high quality care to patients and, while acknowledging the value of the project, that it should run in conjunction with the established team already working from the practice.

Fourteen respondents critiqued several aspects of the project, nine of whom strongly critiqued the referral criteria processes, particularly that the person has accepted their diagnosis and that they are newly diagnosed with dementia. One respondent had a particular critique about the length of the referral form, two felt that the service was not particularly needed as other services are doing similar work and two cited lack of interest among people newly diagnosed with dementia as supporting their critique.

The project workers anticipated referrals from all three referral sites. However, there were differences in referral rates across the three referral sites, with one site consistently referring more people to the project than the others. Possible reasons for this disparity include:

1. Lack of engagement with the project by those tasked with referring to the project:

And I can't say whether the consultants speak to them about the project or not. I suspect very strongly, some of them do, and perhaps others don't. It depends very much on the psychiatrist that the person's getting the diagnosis, at the second appointment, and the nursing staff are not there. (Nurse 1st interview)

2. More people diagnosed in the 'early stage' in one of the sites, thus meeting one of the referral criteria more easily.

3. Different methods of referral to the project across the sites: in one site all newly diagnosed people are referred and informed they can make up their own mind as to whether they want to be in the project or not once the project workers have contacted them. In the other sites, people are asked at the time of diagnosis whether they would like to be referred and the referral is made, or not, based on their response.

4. Professionals in one area thought that the length of the referral form was a barrier to making a referral.

5. Lack of clarity on who should be referring, leaving it to others who might not be as engaged with the project as they could be.

6. Continued difficulty with referral criteria.

In summary the idea of the project is supported by the majority of professionals and workers interviewed, however this is not always actualised in their practice, nor in their willingness to refer patients to the service. Therefore there is work to be done to 'win over' local health and social care workers and professionals if the project is to maximise the potential acknowledged by many workers in the community and if it is to meet the intended outcomes for local authority and health staff.

4. CONCLUDING DISCUSSION AND RECOMMENDATIONS

4.1 The value of different support mechanisms

From our analysis, it would seem that memory clinics and other health services are constrained in the amount and regularity of ongoing post-diagnostic they can offer. In many cases, the level of support drops off once the person with dementia is stable (medication or functioning) and this seems to be an area of concern, particularly for carers who want a regular point of contact.

Although there was positive feedback on usual services, particularly the response to crises, many participants, particularly those with vascular or mixed dementia had little or no regular contact with memory clinic or other services and this was also the case at T2 interviews:

No follow up appointments, no. No. In fact, I was just thinking I'll wait until near the beginning of the year, and it'll be nearly two years, and then I'll make an appointment to see Doctor X again, because I think after two years we definitely should be seeing somebody, do you not agree? (Carer 11, 1st interview)

She (consultant psychiatrist) explained what vascular dementia was. That's all I remember about her visiting there..I'm thinking a year, maybe longer; it could be two years. (Carer 6, 2nd interview)

Two participants noted that the initial more intensive support from the memory clinic has since stopped:

Yes, it's (initial support) good and then it just stops. If you need them, phone them. That's all. That's it. Nobody pops in, you know, you're kind of just left on your own. To get on with it!... I just feel that once you have been diagnosed you have got no...you know, they don't have any contact with you. They don't...there's nothing. What's the word? There's no after care. (Carer 9, 2nd interview)

The post diagnostic project has the potential to fill possible gaps (declining networks, reducing clinical input) and can offer ongoing, longer-term support, whether through social events, advice, information, help with planning as needed and wished.

All bar one participant put the project ahead of usual services for the value of support they received from them.

While all participants who received support from the post diagnostic project valued the support offered, they also spoke about other avenues of support that they found useful. For many, their families and existing friends and networks were invaluable in maintaining social contact and a sense of normality. Some talked of the joy of seeing grandchildren and of the strength of family support, they talked of regular gatherings with long-established friends, others of the golf or bowling club, others of the Church. For these people, family and networks were most useful for both people with dementia and their carers, followed by the project and usual services.

However, some participants talked of having to give up certain activities, for example Bridge, because of the cognitive difficulties their spouse was experiencing:

We miss our bridge; we used to play bridge a lot. We don't now, so we both miss that. Well he was having problems and we just...and it's a very competitive game, it's not like a wee friendly game of cards, it's not just a wee friendly night out it's a serious thing, and they're picking winners and things like that. But it's...you get the feeling you're spoiling other people's game, if you're not quite a hundred percent, so we've just...just didn't go back. (Carer 11, 1st interview)

Others talked of friends dropping away either because they were ill, had died or were unable to cope with the diagnosis. One participant stopped going to church because she was unable to understand the service, thereby losing a whole network of people. These examples indicate the potential for supportive networks to decline and the importance of having support to maintain or replace these natural supports and other mechanisms in place to take over when decline happens.

In summary, people's family and networks are a valuable source of support, however, for various reasons these may decline or disappear altogether, leaving the person with dementia and their carer at risk of isolation. The post-diagnostic support project provides a resource to enable the person with dementia and their carer to continue activities, to meet new friends and to fill a gap in service delivery following the diagnosis until the dementia progresses and intensive service provision is required.

In summary, it is evident that:

- Those using the project report positively on their experiences
- There was support in principle for the aims of the project from workers and professionals
- There were low referrals/lack of action from many health workers and professionals
- System issues need to be addressed for accessing the project: referral process, forms, inclusion criteria

- A key challenge identified was in the area of advance care planning and use of personalised budgets
- Service users have useful suggestions about future improvements in the project delivery

Allowing two key conclusions to be drawn from this evaluation:

1. That the project is a successful model for people with dementia using the project.
2. That there is a lack of whole hearted support and engagement with the project from local professionals and frontline care workers.

It is not possible to make further generalisations due to the small sample size of participants using the project and the lack of a comparator group. To provide robust evidence would require a larger scale study in the future with a comparator or control group to enable a comparison between variables.

Thus our concluding discussion needs to be contextualised within a small sample size of participants using the post-diagnostic support service (the intervention evaluated) and the lack of a comparator group.

4.2 Recommendations

Recommendations from this evaluation relate to involvement and engagement with professionals and frontline workers and recommendations for the intervention, the post diagnostic support project, if it is funded to continue.

Recommendations for professionals:

- More engagement from local health workers and professionals is required if the project is to have long term success. This suggests that close working with or mainstreaming of specialist post-diagnostic support within existing services is vital for the success of a service.
- Recognising that decisions on difficult topics (advance care planning) will take time and allowing people to arrive at a position in their own time is important, and that the presence of a specialist support service does not compensate for wider inter-disciplinary support.

Recommendations for the project:

- Referral criteria and referral systems to access the project need reviewed to ensure they are compatible with existing diagnostic processes.
- General project outreach activities to promote the project and to open to all those with dementia without professional referral may widen the project reach.

- Develop the service to continue to extend beyond functional ability, assessment or medication compliance or monitoring and to promote and prioritise the inclusion of peer support, and support for maintaining social networks and activities
- Increase activities that enable social networking amongst people with dementia
- Review the timing of activities to increase participation and widen access
- Vary the style of presentation of activities e.g. 1-1 and different sizes of groups for group work.
- Allow for flexibility in the level of support offered to meet different and varying needs of people with dementia and their carers.
- The long term success of community based services requires that support be provided over an extended period to allow people to access information and support, including planning ahead, as they become ready to do so and in the context of an established and trusted relationship.

5. REFERENCES

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Appendix 1: About the Facing Dementia Together post diagnostic support pilot project

Background

The Scottish Government have funded Alzheimer Scotland and the Dementia Services Development Centre at the University of Stirling to run pilot projects looking at practical solutions for deliverable and effective post-diagnosis support services for people with dementia in three NHS Board areas. One of these pilots is Alzheimer Scotland's Facing Dementia Together project in East Renfrewshire and Renfrewshire, based in our Barrhead office. The project will run until March 2011.

The aim of the three pilots is to support improvement in approaches to post-diagnostic support throughout Scotland, and they will be evaluated and the learning widely disseminated.

The project

Working with East Renfrewshire Community Health & Care Partnership and with Renfrewshire Council and CHP, Alzheimer Scotland's Facing Dementia Together pilot will aim to bring the personalisation agenda into the world of dementia services.

The pilot will aim to support, enable and empower people with early dementia, together with their carers/supporters, to be able to take control of the services they need, now and in the future, and to work with a local authority and health board to develop the systems and approaches to make this a realistic option.

Policy background

Key policy drivers such as Changing Lives² and National guidance on self-directed support³ highlight the importance of personalisation as a central pillar of the public service reform agenda. Personalisation is recognised as a desirable approach to support services for all care groups. However, although progress has been made in some fields, for example in the support of people with learning disabilities, there is little evidence that people with dementia are being offered the opportunity to benefit from self-directed support. The National Guidance recognises that although all older people are eligible for self-directed support to meet their assessed personal care needs if they are living at home, currently, very few people accessing free personal care do so via self-directed support.

The Changing Lives Service Development Group⁴ set out the benefits of personalisation as contributing to reducing the need for more costly support packages designed for crisis, devolving more control to individuals and communities

² *Changing Lives: report of the 21st century social work review*, Scottish Executive, 2006

³ *National guidance on self-directed support*, Scottish Government, 2007

⁴ *Personalisation: an agreed understanding*, Changing Lives Service Development Group, 2007

and enabling people to become participants rather than simply recipients of support and thus improving the likelihood of achieving success for individuals first time.

In Control, a UK-based project to develop self-directed support, has been at the forefront in England of establishing Individualised Budgets. In Control has been piloting a radically different way of organising social care that fundamentally changes where the power lies and should leave people who use social care services and their families fully in control of their own lives, funding and supports.

One of the barriers to uptake for people with dementia is the widespread lack of post-diagnostic support for people with dementia, which denies them the opportunity to develop their understanding of the illness, enhance their coping skills and improve their chances of being cared for in their own homes for longer. People with dementia need the tools to become active participants in their own health care and to be supported to maintain or recover control in their lives as much as possible at each stage of the illness. It is particularly important that this support should be provided immediately following diagnosis while the person with dementia has the capacity to make decisions and plan ahead.

A second barrier is the lack of local policies, systems and structures to enable care managers to offer people with dementia the opportunity to be made aware of the budget allocated to their care and to control its spending, either through self-directed support (by directly purchasing services or employing personal assistants) or through being made aware of their budget and designing their own support/care plan with the involvement of their carer and care manager.

The aim of this pilot is to extend the level of self-directed support, using methods such as the In Control approach and/or direct payments, to include the care and support of people with dementia, and to empower people with dementia to feel able to take control and make their own choices.

Approach

The pilot will take place in the NHS Greater Glasgow and Clyde area, in East Renfrewshire and Renfrewshire. East Renfrewshire is already developing the In Control approach for other service user groups. Agreement has been reached with the CHCP to commit to developing the approach for a pilot group of people with dementia. Renfrewshire has also committed in principle to the pilot.

Working with Alzheimer Scotland project staff, East Renfrewshire CHCP and Renfrewshire Council Social Work Department will develop self assessment questionnaires and create a Resource Allocation Model for people with dementia, and use these to offer individualised budgets to people with dementia taking part in the pilot. The pilot will be open to people with dementia of all ages.

A practice development manager and a project worker will be appointed by Alzheimer Scotland. They will work with newly-diagnosed people with dementia one-to-one and in groups, over a period of up to a year, involving their families and carers as appropriate, to support them to:

- Understand and come to terms with living with dementia
- Benefit from peer support from other people with dementia
- Put in place legal arrangements to maximise their control over future decisions made on their behalf (eg powers of attorney, advance statements)
- Plan ahead for their future needs, discuss options for future care and set out their wishes using advance person-centred planning tools to creatively design services and 'natural supports' including support from family, friends and community (recognising that not everyone with dementia will wish to participate).

The practice development manager will also work with local authority and health staff to:

- Ensure clear links and straightforward referrals to the project for people recently diagnosed with dementia
- Raise awareness of the benefits of individualised budgets for people with dementia
- Assist in facilitating a cultural shift towards personalisation of services for people with dementia
- Ensure that people with dementia who participate in the project are offered appropriate individualised budgets or direct payments and supported to design their own pattern of services.

Outcomes

People with dementia will:

- Be better informed
- Be equipped with skills to manage better the challenges of living with dementia
- Have legal and financial arrangements in place for the future
- Be able to make contact with, and benefit from the support of, other people with dementia
- Be in a position to take control, now and in the future, of services to support them to live at home as independently as possible
- Be supported in the best way for each individual, maximising the benefit from the allocated budget and minimising the need for crisis intervention.

Carers will:

- Be better informed
- Be equipped with skills to manage better the challenges of supporting someone living with dementia
- Be involved in helping the person design the service which will best support them in the future.

Local authority and health staff will:

- Be better informed
- Understand the benefits of and be committed to personalisation for people with dementia
- Be able to inform and support people with dementia and carers in designing creative patterns of services and natural supports which will best support them in the future.

Management

The service development manager will be line managed by Alzheimer Scotland's Regional Manager and supported by Kate Fearnley, Alzheimer Scotland's Director of Personalisation.

A reference group will be set up including key contacts from the CHCP and service user and carer representatives.

Forward programme

If successful, the pilot will serve as a model for the roll out of post-diagnostic support services which support the implementation of personalised services for people with dementia throughout their journey of care.

Dissemination of the learning and experiences from the pilot will be planned from the outset, in conjunction with the learning from the other two pilots.

Appendix 2: Quality of Life – AD Questionnaire

QoL-AD

(Interview Version for the person with dementia)

Interviewer administer according to standard instructions.

Circle responses.

1. Physical health.	Poor	Fair	Good	Excellent
2. Energy.	Poor	Fair	Good	Excellent
3. Mood.	Poor	Fair	Good	Excellent
4. Living situation.	Poor	Fair	Good	Excellent
5. Memory.	Poor	Fair	Good	Excellent
6. Family.	Poor	Fair	Good	Excellent
7. Marriage.	Poor	Fair	Good	Excellent
8. Friends.	Poor	Fair	Good	Excellent
9. Self as a whole.	Poor	Fair	Good	Excellent
10. Ability to do chores around the house.	Poor	Fair	Good	Excellent
11. Ability to do things for fun.	Poor	Fair	Good	Excellent
12. Money.	Poor	Fair	Good	Excellent
13. Life as a whole.	Poor	Fair	Good	Excellent

Appendix 3: Brief COPE Questionnaire

Brief COPE

These items deal with ways you've been coping with the stress in your life. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real."
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.

25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.

Appendix 4: Interview topic guide for intervention group Time 1

Renfrewshire and East Renfrewshire Evaluation Topic Guide – participants newly diagnosed with dementia and/or family member

Process of diagnosis

Prompts: Who gave you the diagnosis?

Do you feel you are clear about your diagnosis?

Anything you would change about the way you received the diagnosis?

Post diagnosis – contact

Prompts: What health/social care staff have you seen since your diagnosis (GP, social worker, someone from Alz Sco)?

How often have you seen them?

Would you like to change this?

What have you discussed?

Has this been useful?

Would you like to have discussed anything else?

What?

Have you had any contact with other people who have the same diagnosis/condition as you? If so, did this help? In what ways? If not, would you like to have contact?

Post diagnosis – support

Prompts: **Information** - describe. Useful, timely?

Help/advice from anyone since diagnosis – describe. Useful, timely?

Support services – describe (benefits, services). Useful, timely?

What support would you like to have to improve your life just now? In the future?

Would you like to arrange this yourself?

Do you feel you would like help?

Who would you like to help you to arrange support (if anyone)?

Post diagnosis – control

Prompts: What would you like to be able to make decisions on? e.g. support, services, financial, advance directives, power of attorney?

At what point do you think it is important to make decisions?

Is it important for you to feel in control?

Have you had the opportunity to make your own plans for the future?

What would make this process easier for you?

What input have you had into the planning and provision of services and support you receive?

Have you had support and/or advice with this?

If so, from whom?

How useful was this?

If you needed more support in the future, who would you like to get it from?

When would you like this support?

If you were no longer able to make decisions how would you wish this to be handled?

Appendix 5: Interview topic guide for intervention group Time 2

1. Update on how things are going since first visit – for person with dementia and carer.

2. Follow up on any previous points from first interview

3. Update on any intervention/support from memory clinic.

Describe

Was it useful?

In relation to other interventions/support, what has been the most/least helpful?

Timely?

Any changes you would like to make?

Any comments?

4. Update on any intervention/support from other sources (informal networks, family, church etc).

Describe

Was it useful?

In relation to other interventions/support, what has been the most/least helpful?

Timely?

Any changes you would like to make?

Any comments?

5. Update on any intervention/support from project

Describe

Was it useful?

In relation to other interventions/support, what has been the most/least helpful?

Timely?

Any changes you would like to make?

Any comments?

6. Discussion/comparison of different forms of support across the memory clinic, other networks and project.

7. Most participants in the first round of interviews had not thought about the future, or if they had they were not ready to discuss it or engage in any planning. We need some questions to find out whether they have been able (facilitated) to think a bit further ahead:

The last time I was here, we spoke briefly about the future and about any plans you would want to make for the future. Have you thought any more about this?

Prompts: Have you had any help with this? Who from? Was it useful? Could you suggest any ways in which this could have been made easier for you? Ideally, who would you like to help you with this?

8. If they still haven't thought ahead – why? What would make it easier? (if they wanted to but couldn't).

Appendix 6: Interview topic guide for Key Informants

Recruitment for intervention:

1. How are the respondents recruited for the intervention?

Prompt: From where and whom do you get your referrals?

What selection criteria do you use?

Do you compare the level of cognitive competence of each person?

At Intervention:

1. Please explain what you understand by the “intervention” .

Diagnosis:

1. Who typically gives the diagnosis?

2. How does the person with dementia respond to the diagnosis at this stage?

3. What do professionals explain to the person with dementia about the diagnosis?

4. What do professionals explain to the carer/s about the diagnosis?

5. What is/are your role(s) in the support of the person with dementia and his/her carer?

Post diagnosis: Contact and support

1. During post-diagnosis how often do you meet the person you support?

2. Can the person ask or seek your help in between meetings and after the intervention period?

3. To what extent are these meetings dependent on the needs of the person?

4. To what extent do these include skills to take control of his/her life and to draw out plans for the future whilst still able?

5. What about peer-support and active encouragement for people with dementia/carers to network socially?

Please tell me some of the strengths and weaknesses of your role.