



**Alzheimer Scotland**  
*Action on Dementia*



## **Facing Dementia Together Project**

**East Renfrewshire & Renfrewshire**

**Final Report**

**February 2009 to June 2011**

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# Executive summary

## The project

1. The Facing Dementia Together post diagnostic pilot project was funded by the Scottish Government for February 2009 to June 2011. Working in partnership with East Renfrewshire CHCP, Renfrewshire CHP, and Renfrewshire Council, the project set out to provide support to people who had recently received a diagnosis of early stage dementia, and their families.
2. An independent evaluation was carried out by Dementia Services Development Centre (DSDC). An evaluation report has been produced and is available from the Scottish Government (Innes et al, 2011).

## Background

3. In Scotland there are approximately 82,212 people living with dementia, with 1,548 in East Renfrewshire and 2,575 in Renfrewshire (Kinnaird, 2011).
4. The Scottish Government has made dementia a national priority and launched a National Strategy on Dementia in June 2010 (Scottish Government, 2010). Post-diagnostic support for people with dementia and their carers is one of the two key areas of the strategy.
5. The widespread lack of post-diagnostic support denies people 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. Early identification and intervention in dementia has been shown to improve quality of life, and delay the need for institutionalisation (Department of Health, 2008, and Gaugler et al, 2005). Carer support and counselling after diagnosis can reduce care home placement by 28% (Mittleman, 2007).

## Referrals

6. The project received 66 referrals and supported 133 people, 56 people with dementia and 77 family members.

7. It was anticipated that two thirds of referrals would come from the Renfrewshire area. In fact, sixty two percent of referrals (41) came from East Renfrewshire and thirty eight percent (25) from Renfrewshire.

### **Project activity**

8. The project offered different levels of input, according to need. This included one-off enquiries, a few individual contacts, attendance at workshops, ongoing low level contact and attendance at regular drop-in cafés.
9. Types of support provided included information, advice, signposting, and emotional and practical support to help the person and their families/supporters to understand and come to terms with living with dementia.
10. The project assisted 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).
11. The project supported people to maintain the important relationships in their lives and remain involved in their communities, continuing to enjoy social and recreational activities.
12. For those who were able to and wished to do so, project staff facilitated more detailed advanced planning using person centred planning tools.
13. As the project evolved, opportunities for peer support were developed including informal drop-in cafés 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.

### **Project outcomes**

14. Project outcomes were evidenced by the results of the independent evaluation and by internal evaluation.

15. People with dementia and their families/supporters felt better informed, through the provision of 1:1 information and of workshops.
16. People with dementia and their families/supporters felt equipped with skills to manage better the challenges of living with dementia, though the workshops and through 1:1 advice on and support to implement coping strategies.
17. Twenty three people with dementia were supported to put legal and financial arrangements in place for the future, with guidance through the process of setting up powers of attorney, and in one case, guidance for the family to arrange guardianship. Nineteen people received additional welfare benefits and nineteen received council tax discounts or exemption.
18. People with dementia and their families were able to make contact with, and benefit from the support of, other people with dementia and their families, through dementia cafés, workshops and occasional social events and evaluation showed that this was very highly valued.
19. People with dementia and their families were in a position to take control of the supports they needed not only in the present, but also for the future, enabling them to live at home as independently as possible through individual support, cafés and workshops which gave them the information they needed. Nine people with dementia and their families were facilitated to do person centred planning.
20. Twenty four people with dementia and their families were provided with information on self-directed support (SDS) and one family was supported to receive SDS. This enabled them to shape their support in the best way for their lives, maximising the benefit from the allocated budget and minimising the need for crisis intervention.
21. Family members were fully involved in the process where person-centred planning was carried out. Many others felt unable to think or plan ahead too far in the future.

22. Local authority and health staff were provided with information on the benefits of personalisation for people with dementia through presentations and meetings in a range of settings.
23. Local authority and health staff were involved in the person-centred planning sessions, enhancing their ability 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.

## **Challenges**

24. Key challenges related to the project's innovative nature and short duration, and include slow initial referral rate, lower numbers of referrals than expected in Renfrewshire, and delay in the evaluation getting started.
25. Local authority eligibility criteria limited scope to demonstrate that the provision of a small upfront budget to enable people with early dementia to maintain their lives and natural supports could potentially delay or reduce the need for paid care later in the illness.
26. It takes time for people to want to plan ahead and enabling forward planning is not a straightforward or linear process.
27. Natural supports and previous activities had sometimes been lost by the time the person had received a diagnosis.

## **Key learning**

28. Where people have lost community connections and natural supports, re-establishing old connections was right for some people but establishing new connections was the preference of others, due to their awareness of changes in their abilities and self-esteem.
29. Peer support is of central importance to both people with dementia and to their partners and families.

30. Peer support is helpful in encouraging people to access other supports such as educational workshops.
31. People with dementia and their family members need time to come to terms with and understand their diagnosis and its implications for the future before they are able to plan ahead for their future support needs. Such planning will generally happen only in the context of a supportive relationship with a professional.
32. The value in future care planning has been clearly demonstrated.
33. Person Centred Planning Tools MAP and PATH have been successfully adapted for use with people with dementia.
34. For people with dementia living alone, transport to attend cafés or workshops was important

## **Conclusions**

35. The project found that there is a clear need and demand for post-diagnostic support. People with dementia and their families/friends need significant support, and want ongoing low level input and continued contact with a dementia specialist, who they can ask for information, advice and guidance.
36. Peer support with people going through the same stage of the illness, but also somewhere to get information as required, and be signposted or referred to services as needed is important. Attending cafés and workshops as a couple or family helped families to adapt to the challenges of living with dementia, as each person was able to develop insight into how the other person experienced life with dementia.
37. The project has demonstrated that there are five key pillars of post-diagnostic support which are all essential in a post-diagnostic service. There are:
  - understanding the illness and managing symptoms
  - supporting community connections

- peer support
- planning for future care
- planning for future decision-making.

## **Recommendations**

1. A comprehensive post-diagnostic service should be a mainstream part of the support offered to people with dementia and their partners and families immediately after diagnosis.
2. The post-diagnostic service should incorporate all five key pillars of post-diagnostic support.
3. The service should offer the opportunity for a short period of intensive support for those who need it, but also an ongoing point of contact for light-touch advice, information and support.
4. The person with dementia and their family members should be offered education courses/information sessions that they can both attend. Attending as a couple or family, helps people to adapt to living with dementia as a couple or family.
5. Dementia cafés should be provided to offer ongoing access to peer support for both people with dementia and their partners, families and supporters. Consideration should be given to offering these specifically for people with dementia and their families who are at the same stage of the illness. Consideration should also be given to providing help with transport, particularly for those people with dementia living on their own.
6. Continuation of cafés with a programme of invited speakers beyond the end of the pilot project. The cafés would act as a point of support for those newly diagnosed with early stage dementia and an ongoing point of contact where people can get information, support, advice and guidance as well as being signposted/ referred on to other services as required.

7. Forward planning needs to be offered at the right time, once the person with dementia and their families have been able to cognitively and emotionally process the diagnosis and come to terms with it, and what it means for their future lives.
8. The project should be continued in Renfrewshire and East Renfrewshire, to build on the work of the pilot.

# 1. Introduction

The Scottish Government funded Alzheimer Scotland and the Dementia Services Development Centre at the University of Stirling to run three pilot projects looking at practical solutions for deliverable and effective post-diagnosis support services for people with dementia in three NHS Board areas. The aim of the three pilots was to support improvement in post-diagnostic support throughout Scotland.

The Facing Dementia Together Project was launched in February 2009 in partnership with East Renfrewshire Community Health & Care Partnership, Renfrewshire Council and Renfrewshire Community Health Partnership. The project was initially funded until March 2011. The Scottish Government agreed that project underspend could be used to extend the project until June 2011. This report details the work of the project for its full duration from February 2009 to June 2011. It is also available on the Alzheimer Scotland website [www.alzscot.org](http://www.alzscot.org).

## 1.1 Purpose of report

This report covers the full period of the project, detailing statistical analysis, project activities, key challenges, key learning and personal stories.

## 1.2 Background

Dementia is an international concern for health and social care governance. Worldwide, there are an estimated 35.6 million people living with dementia, costing more than £38 billion, or an aggregate cost of 1% of GDP (Wilmo & Prince, 2010). The disease process itself causes irreversible decline in global intellectual, characterological and physical functioning, causing devastation in the lives of the people with dementia and their loved ones (Schneider et al,1999; Bannerjee et al, 2007). Formal health and social care intervention has been estimated to cost the UK economy £27, 643 for each person with dementia, per annum (Wilmo & Price, 2010).

In Scotland there are approximately 82,212 people living with dementia, with 1,548 in East Renfrewshire and 2,575 in Renfrewshire (Kinnaird, 2011). With the proportion of the population with dementia increasing each year, the Scottish Government has made dementia a national priority and in June 2010 launched its first ever National Strategy on Dementia (Scottish Government, 2010). There are two key areas for the strategy, one of which is following diagnosis, the provision of excellent support and information to people with dementia and their carers. Dementia is also included in a set of Health Improvement, Efficiency, Access and Treatment (HEAT) targets by which the performance of health boards and their respective CHP/CHCPs can be examined. The dementia HEAT target is specifically oriented toward the early diagnosis, intervention and management of dementia.

One of the barriers for people with dementia is the widespread lack of post-diagnostic support, 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.

For people in the early stages of dementia and their family/friends, there is a need for emotional and practical supports that can help people to work through the psychological process of coming to terms with and adapting to the prognosis of the condition. Learning from people with dementia and their families, this approach should include activities that: enhance social contact and peer support to reduce isolation; provide information and opportunities to overcome limitations imposed on them by the disease, and preserve or bolster self-worth by finding ways for them to make a contribution and feel useful (Claire, 2002).

The benefits of adjustment to the diagnosis and planning for the future have been clearly established in respect of stress reduction, improved mood and affective functioning for people with dementia (Ishizaki et al, 2002) and their families (Borden, 1991; Sabir et al, 2003; Powell, Chi & Eysenbach, 2008).

The importance of people who share common illness or stressor coming together not just for emotional support or to share difficulties experienced and ways of coping but to seek friendship and social exchange is well documented in other contexts (Mason et

al, 2005). They propose this is especially so for people with dementia, where cognitive difficulties may hinder people from participating in social networks previously available to them.

A dementia support group for people in early stages can play a particular role in establishing social contacts and building an identity based on social ties with others rather than on the difficulties encountered as a result of the dementia. Integral to this function would be the opportunity to talk about events and experiences unrelated to the diagnosis of dementia, such as 'everyday things' or the past. Groups could also be offered where informal social contact, rather than emotional support or exploration, is a more central component. Such an approach has also been seen in the development of user led groups for people with dementia (Pratt, Clare, & Aggarwal, 2005)

The cognitive difficulties experienced by group members appear also to mean that members require a longer time to establish a sense of familiarity and trust, such that the support functions of the group are able to develop. This would suggest that it may be helpful for groups to be long-term or open-ended, rather than offering a fixed number of sessions over the short term (Mason et al, 2005).

Claire, 2002 outlined four different ways that disease symptoms lead to social withdrawal amongst individuals with dementia: declining language and memory abilities can cause embarrassment; attention difficulties can cause feelings of being overwhelmed; needing help can feel like being a burden; and lowered mood can alter thinking and suppress motivation to interact with the world.

Vikstrom et al, 2008 cited many reasons for people with dementia stopping social contacts including: negative social consequences (e.g. friends become strangers), insecurity about what will I say, questioning if I will be less interesting to friends, experiences of having let friends down due to loss of initiative, strength or forgetfulness (e.g. missed appointments, telephone calls), unnecessary conflicts as result of effects of dementia e.g. arguments with friends due to forgetting. Meeting with friends who were healthier and happier invoked mixed feelings of both joy at seeing them and envy. Some couples had changed their social habits deliberately e.g. quit dinner parties since unable to cook and appear as host in manner they used to.

The person with early-stage dementia recognises how interpersonal relationships change and how others can disregard or disrespect them. Selfhood is managed through the continuation of old roles and the creation of new roles within relationships. Maintaining hope, helping others, and others' acceptance of the disease are primary to how the person sees themselves (Pearce et al, 2002).

Weaks, McLeod, & Wilkinson, 2006 reported that people felt that they were treated differently by others because of their dementia. For example one person reported that he felt that people were waiting for him to make a mistake. Changes in the balance of power and position in relationships and in community were identified as key factors. Major threats to relationships were lack of hope for reciprocity and autonomy and independence. One striking finding in relation to how others reacted to the person with dementia talking about their diagnosis was avoidance and dismissal. People with dementia reported that they needed space to talk about their fears and worries but this was not encouraged or supported by friend, family or other members of the community.

The early identification and intervention in dementia has been shown to improve quality of life, and delay the need for institutionalisation (Department of Health, 2008). According to Gaugler et al, 2005, the early provision of support at home can decrease institutionalisation by 22%. Carer support and counselling after diagnosis can reduce care home placement by 28% (Mittleman, 2007).

### **1.3 About the project**

The project was set up to help people with early stage dementia to become active participants in their own care and to be supported to maintain or recover control in their lives as much as possible at each stage of the illness. By providing support following diagnosis while the person with dementia has the capacity to make decisions, the project aimed to help people live as full a life as possible, stay connected in their local community and to plan ahead for their future needs.

The project aimed to bring the personalisation agenda into the field of dementia and to raise awareness of the benefits of individualised budgets and direct payments for people with dementia, enabling people with dementia to design and tailor support that meets their needs.

The project provided support to people who had recently been diagnosed with early stage dementia and their families/friends. Types of support included providing information, advice, signposting, emotional and practical support to help the person and their families/supporters to understand and come to terms with living with dementia. The project assisted 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). The project supported people to maintain the important relationships in their lives and remain involved in their communities, continuing to enjoy social and recreational activities. For those who were able to and wished to do so, project staff facilitated more detailed advanced planning using person centred planning tools. As the project evolved, opportunities for peer support were developed including informal drop-in cafés 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.

The project was staffed with one full-time Post-Diagnostic Practice Manager and one full-time Post-Diagnostic Project Worker. They both took up post in February 2009.

The pilot aimed to support, enable and empower people with early stage dementia, together with their carers/supporters, to be able to take control of the services they need, after diagnosis and in the future, and to work with their local authority and NHS to develop the systems and approaches to make this a realistic option. Please refer to Aims, Objectives and Outcomes (Appendix 1, pp. 56-57), for further details.

An independent evaluation of the project was carried out by a team of research staff from Dementia Services Development Centre (DSDC) at the University of Stirling, led by Professor Alison Bowes (Innes et al, 2011).

## **1.4 Project steering group and stakeholder group**

A steering group with high-level representation of all the partners was established to guide the project, as well as a stakeholder group with partners and people with dementia to support the project on an operational level. During the second year of the project the two groups were merged into a single steering group. Group membership and remits are detailed in Appendix 2, (pp. 58-60).

## **2. Referrals to the project**

The project received 66 referrals and provided support to 133 people. This includes 56 people with dementia, and 77 family members/friends. The project had face to face contact with 65 of the 77 family members/friends. The remainder of the contact with family members was by telephone and e-mail.

Due to the limited capacity of the pilot project, the source of referrals was focused on the memory clinics operating in each of the two local authority areas, covered by Greater Glasgow and Clyde Health Board. This consisted of Levern Valley Older People Team, Eastwood Elderly Community Mental Health Team and Renfrewshire Memory Clinic. The project also received a number of referrals from Renfrewshire Community Mental Health Team (under 65 years), East Renfrewshire Community Care Social Work Team, Alzheimer Scotland support services and a few self referrals.

The referral process was designed to be straightforward and easy for people to make referrals. The project leaflet welcomed referrals by phone or in writing. The steering group, (which included representation from the memory clinics covering the two biggest geographical areas) agreed that referrals would be easiest if staff used their normal methods of referring, including referral letter or Alzheimer Scotland referral form. Referral criteria and guidelines can be found in Appendix 3, (p. 61). Referrals were invited and encouraged through the wide dissemination of the project leaflet and a series of meetings with staff at the three memory clinics at the start of the project. When it became clear that referrals were slow in the first months of the project, staff met again with memory clinic staff and also met with Renfrewshire CMHT (Older

People) and East Renfrewshire Community Care Social Work Teams to raise awareness and promote increased referral rate.

Charts 1 and 2 (Appendices 4 and 5, pp. 62-63) provide a breakdown of referrals over time. During the first year 28 referrals were received (18 from East Renfrewshire and 10 from Renfrewshire). Chart 3 (Appendix 6, p. 64) shows that the referral rate was initially slow during the first year while the project became recognised and developed relationships with local professionals. This would be expected for a new project to some degree, as it takes time for referral processes to be established. The initial slow referral rate was also in part linked to the delay in the evaluation getting started and to concerns of key memory clinic staff regarding how participants would be recruited to the control group for the evaluation. This meant that referrals were held back until the concerns were addressed. This was reflected in the surge of 19 referrals made in February and March. Had the referral numbers been higher earlier on in the first year, the project would have had the capacity to work with more people over the two years. During the second year 38 referrals were received (23 from East Renfrewshire and 15 from Renfrewshire).

Due to the population sizes and numbers of people with a diagnosis of dementia in each of the two local authority areas it was anticipated that two thirds of referrals would come from the Renfrewshire area. This reflected prevalence rates in each area, which equate to 38% East Renfrewshire and 62% Renfrewshire (Kinnaird, 2011). In fact, sixty two percent of referrals (41) came from East Renfrewshire and thirty eight percent (25) came from Renfrewshire. This is the exact opposite to what was predicted. A more detailed breakdown of referrals by geographical area can be found in Chart 3 (Appendix 6, p. 64) and source of referrals can be found in Chart 4 (Appendix 7, p. 65).

Of the 66 referrals 34 were female and 32 were male. Eighteen percent (12) of all referrals were under the age of 65 years. The breakdown by local authority area for referrals of people under 65 years was six from East Renfrewshire (15% of all East Renfrewshire referrals) and six from Renfrewshire (24% of all Renfrewshire referrals). The percentage of referrals to the project for those under 65 years is four times higher than the prevalence rates for East Renfrewshire and almost six times

higher than the prevalence rates for Renfrewshire. This perhaps reflects a greater identification of need for post-diagnostic support for those under 65 years but begs the question as to why more people over 65 years were not referred. A detailed breakdown of ages of all referrals is provided in Chart 5 (Appendix 8, p. 66).

One third of all people referred (22) lived alone, 19 of whom were female. The breakdown by local authority area of those living alone was 15 from East Renfrewshire and 7 from Renfrewshire.

Of the 66 referrals received five did not meet the project criteria either because their dementia was no longer in an early stage or because they had received their diagnosis several years earlier. All were referred on to Alzheimer Scotland home based support services following discussion with the referrer. Four people declined support, including an initial visit by project staff, stating that they felt they were coping fine and had no need for support. Two of the four stated they did not have dementia or memory problems. One person was admitted to long term care shortly after referral before an initial visit could take place.

### **3. Project Activity**

The project was able to offer different levels of input, according to need. This ranged from one-off enquiries (5), to participation in the workshops (39), and/or ongoing support mostly in the form of drop-in cafés (41), one-to-one face-to-face and telephone support (52), through to much more intensive casework, which included planning for the future and/or exploring self directed support (8). The number of hours of support range from a minimum of one hour for a one off contact to a maximum of 182 hours for someone who has been supported by the project for two years. The mean number of hours of support received was 27 hours.

Following referral an initial home visit was arranged and people would have either individual follow up visits or were seen after the initial visit at cafés and/or workshops, or more typically received a combination of individual and group inputs. For those who chose not to take part in group activities, the input was in the form of follow up home visits.

Five referrals were one-off contacts (three for information on Powers of Attorney and welfare benefits and two for information on assistive technology).

Eight people were discharged during the first two years of the project. The remainder wanted ongoing, low level input. Reasons for discharge include; - progression of dementia beyond early stage (1), admission to long term care (2), death (1), introduction of home support service to help with social activities (2), no further support wanted by client (2).

#### **3.1 The pattern of provision**

Due to the low level of referrals in the first year of the project, much of the initial work was one-to-one. As numbers increased in each of the two local authority areas opportunities for peer support evolved in response to the needs and expressed wishes of the people being supported by the project. Therefore the majority of people received a mix of one-to-one and group interventions.

### **3.2 Individual support**

**“Being involved with the project has changed my life. You have more time to spend than the doctor does so could help us with benefits and sorting out Power of Attorney. That took away a lot of hassle and grief”**

Project staff provided information about dementia, effects and coping strategies (especially memory aids) to the vast majority of people with dementia referred and their families/friends. Everyone referred talked about the experience of receiving the diagnosis of dementia, how that felt and the effects on their lives, with project staff. With almost all referrals project staff provided guidance and modelling of ways of adapting behaviour (in light of the effects of person’s symptoms of dementia on both person and their family).

At all initial visits, staff checked whether the person was receiving all of the welfare benefits he/she was entitled to and found out whether Powers of Attorney had been set up or whether this had been discussed with them.

### **3.3 Signposting**

Signposting and referrals to other agencies/supports included; – carer centres (4), counselling services (3), befriending projects including Reaching Older Adults in Renfrewshire (ROAR) (4), Contact the Elderly (1) and BefriendER (1), Alzheimer Scotland support service (6), Alzheimer Scotland Welfare Rights Service (2), and Dementia Nurse Specialist (2).

The referrals for befriending were to enable the people with dementia to continue activities that they used to enjoy but could no longer do without support, and included swimming, walking, cycling and visiting friends. Reasons for support include mobility problems and difficulty with remembering how to get places or use public transport.

In addition to the use of existing befriender projects, two volunteer befrienders were recruited to the project to meet specific needs that could not be provided by the other projects. This including an “art loving befriender” to accompany a person with dementia to attend a local art group as this person needed support getting there and back due to problems with mobility. This was part of reducing social isolation and reconnecting this person with her local community, whilst enabling her to continue her life-long passion for painting. Further details can be found in the personal story of Isabel (pp 28-30). The volunteers received training and supervision and support from the project.

### **3.4 Peer support**

**“You lose your confidence going out after you get the diagnosis. I have felt a lot better since I started coming here. Meeting people in the same position has really helped me, it makes no difference what is wrong, we are all accepting of each other”**

Opportunities for peer support were provided by the project in the form of drop-in cafés and delivery of a series of weekly workshops over six consecutive weeks. Both the cafés and workshops helped people to regain their confidence in social settings, expand their social network, benefiting from peer and professional support alike. For many of those attending the drop-in cafés and workshops, they had no other regular ongoing input from health or social care services. They identified that having an ongoing point of contact was important and many have said that they see the project as a “lifeline”. When asked what the benefits were and what they had enjoyed the most, people overwhelmingly identified the peer support aspect to the drop-in café and workshops:

**“I used to sit back and take a back seat at first but now I’m much more confident... you can’t shut me up (laughs). It’s great to meet everyone and speak. It helps to know you’re not on your own”**

### 3.5 Cafés



The project set up three dementia cafés, in Barrhead, Paisley and Giffnock. This was in order to provide an opportunity for people with dementia and their families to get together and to benefit from peer support and to access information and support from professionals. The cafés provided an informal gathering for people with dementia and their family/friends in a relaxed atmosphere.

The cafés were first held at Undercover in Barrhead, run by Voluntary Action, which provides a one stop shop for community organisations in East Renfrewshire. This location was chosen as it is a central point for both local authorities and had ideal space for providing a café, with no costs attached. It was decided that help with transport should be provided, particularly to those people with dementia who were attending on their own, as the geographical area covered is large, with poor transport links across one of the local authorities. A contract for transport was negotiated with the local RSVP service, which provided a bus and driver for seven people. In addition staff also provided transport via staff's own cars.

People usually attended for the first time after a couple of individual contacts with project staff. People with dementia and their family members have described growing in confidence through attending cafés, as reflected in developing from initially being very quiet at the first drop-in café to becoming more talkative over time. This was

also observed by project staff. An important aspect of the cafés for people was that they know that the other people attending understand their difficulties and that people feel accepted despite any difficulties with memory or word finding as part of a conversation. A key aspect that people commented on was feeling that they are not alone by spending time with others who are going through a similar experience. The café also offered opportunities for people with dementia and family members to share experiences and coping strategies, make friends and have fun. As the numbers of referrals increased so did the numbers attending the cafés.

The numbers of people with dementia and family members/supporters attending the cafés rose month by month from an initial attendance of seven people (4 people with dementia and 3 family members) to an attendance of 23 (12 people with dementia and 11 family members). Numbers attending were consistently between 15 for cafés in each locale and 22 for the Barrhead café that is central to both areas. Please refer to Table 1 (Appendix 9, p. 68) for a more detailed breakdown of attendance.

A total of 46 people regularly attended the cafés (26 people with dementia and 20 family members including husbands, wives, daughters, one son, one daughter-in-law and one sister). Due to the increasing numbers attending, the frequency of cafés was increased in January 2011 from one a month to three a month. The additional two cafés took place in hotels in the Paisley and Giffnock areas. Whilst everyone was welcome to attend any or all of the cafés, staff were only able to provide transport for those living alone, to the cafés in the person's locale and to the Barrhead café. In response to interest the Barrhead monthly café introduced a programme of invited speakers from January 2011 including a social worker, occupational therapist, Alzheimer Scotland service manager and assistive technology advisor. The speakers were able to talk about their role, services available and how to access them. It was hoped that this would help to break down some of the barriers that face people when accessing services, such as fear of the unknown and not knowing what exists or how to access it.

The project also provided two informal social events at Christmas in 2009 (attended by 4 people with dementia and 4 family members) and at Christmas 2010 (attended by 14 people with dementia and 21 family members). As these events took place in the

evening, family members were able to attend who would be unable to attend cafés during the day. Six people with dementia and eight family members/friends attended a day trip to Inveraray in September 2009. Thirteen people with dementia and nineteen family members attended a day trip to Callander in June 2011. These trips took place at the weekend, enabling those working to attend. Feedback from both trips was especially positive. Staff believed that being with other people who are going through something similar, made the trip more valued, than if the people attending had gone on an organised bus trip without the commonalities that living with dementia brings and the support and organisation by staff

### **3.6 Workshops**



A series of workshops, which consisted of information sessions and separate peer support for people with dementia and family members, was held over six consecutive weeks. This was delivered on three separate occasions to a total of thirty eight people (19 people with dementia and 19 family members). The first delivery of six weekly workshops was attended by nine people with dementia and eight family members. The second delivery of workshops was attended by six people with dementia and seven family members. The third delivery of workshops was attended by four people with dementia and four family members.

The workshops were most successful for people who had already benefited from peer support at the cafés and/or had met individually with project staff. This made people more likely to be willing to attend. Café participation meant that they felt more comfortable with the idea of being in a group setting and of talking openly about dementia issues – they saw the cafés as a “gentle introduction”. Prior knowledge of those attending the workshops helped staff to tailor the sessions appropriately.

The workshops were very successful in providing people with the information and strategies they needed to cope better with the condition. Thirty two of the thirty eight participants completed evaluation forms. Of these:

- 100% felt that overall the workshops were helpful
- 97% felt better informed about dementia
- 97% felt more knowledgeable about strategies and tips for coping with dementia
- 85% felt better informed about healthy lifestyles and relaxation
- 84% felt better informed about Powers of Attorney and advanced statements
- 75% felt better informed about planning ahead for future needs, 25% felt uncertain about this
- 97% felt they had received support from other people who attended

Further details on the workshops can be found in the Workshop Evaluation Report (Appendix 10, pp. 68-79).

### **3.7 Person centred planning**

**“The person centred planning meeting helped everyone to focus on what mum wanted to do in her life - not what I or anyone else thought she should be doing. It gave mum the opportunity to air her views and her feelings. I think it helped me to realise that although someone has dementia , especially at the stage my mum was at, they are still capable of voicing their opinion and should be listened to when deciding what support is required now and in the future.”**

Using person centred planning tools including MAP, PATH and Circles of Support, the project aimed to assist people with dementia to plan ahead for their future needs and consider how they would wish to be supported.

Person centred planning as an approach has hitherto rarely been offered to people with dementia. It was developed originally by those working with people with disabilities who faced issues around social inclusion. The planning is centred on and serves the hopes, dreams and visions of the person and their family, helping the person to design lives that reflect their talents. Project staff adapted some of the person centred planning approach and tools to help people with dementia to think creatively about the support they might require and to make use of 'natural supports' including support from family, friends and community.

Person-centred planning was carried out with eight people and their families, using person centred planning tools including PATH and Circles of Support. This is illustrated in the personal stories of Isabel, and Mary (pp 30-32). Staff had to adapt the tools with Mary, who has a good quality of life at present. In this instance the planning meeting was about thinking about what needed to be put in place to keep all of the important things going in her life as her dementia progressed. Within each family, those who took part in person centred planning meetings described the process as positive, and as helping to facilitate better understanding (of the perspective of the person with dementia but also of one another's perspectives). They also described being better informed (about supports, services, and choices such as self directed support). Many commented that they felt less worried as a result of the process, which helps people to see in a straightforward way the actions that need to be taken and by whom, to make life better. And lastly, in all eight families, people described how the process provided them with hope for the future.

The main tool used was PATH, which stands for Planning Alternative Tomorrows with Hope. Normally, when using this tool, people would be advised to choose a time frame of up to two years when planning. This helps to keep things realistic and achievable, and not too daunting. The process can be reviewed and repeated as

required. The project found that most people who took part in planning using this tool wanted to look at the period of either six months or one year in advance.

### **3.8 Self-directed support**

A key objective of the project was to help people with early stage dementia to feel more in control of their lives. Part of this was through planning ahead for their future, including the support they might need, for example using person centred planning. Although the focus of the project was on early stage dementia, in some cases people were already in need of support services often due to other needs such as poor mobility.

Project staff were instrumental in helping put personalised support packages in place using support services for five people with dementia. These were people who had been offered but had refused daycare. In each case staff were able to work with the person with dementia, their family and care manager to find an alternative support that better suited them. In each case that was about using support worker hours to facilitate what the person with dementia wanted to do. Working in partnership with one person with dementia, her family and the Older People's Team, input from project staff was instrumental in helping to avoid premature admission to a care home and maintaining the person with dementia's independence. Further details can be found in Personal Stories – Isabel, (p.28-30).

## **4. Personal stories**

What follows are three personal stories based on real experiences of people being supported by the project, included with permission from those involved. In some cases names or details have been changed. Isabel's story illustrates some of the more intensive case work that was done with people in the first year of the project. Isabel and Mary illustrate experiences of using person-centred planning tools as part of advanced planning. Helen and Gibb illustrate a typical experience of a husband and wife supported through the project's cafés and workshops. Mary illustrates the experience of someone with dementia attending the cafés and workshops on their

own. In combination the three personal stories reflect the range and levels of post diagnostic support offered by the project.

#### 4.1 Isabel



Isabel is in the centre of the photo and her daughter Zara is on the left of the photo, which was taken at the project's Christmas party in 2009.

When Isabel was referred to the project she was 82 years old. She was a widow who lived alone and had one daughter, who lived nearby. Until two years prior to referral Isabel enjoyed an active social life. She was a professional artist, keen gardener and bee keeper. She loved being outdoors and hill-walking. She was also an active member of her church where she had been a volunteer befriender for older people who were isolated. However during the two years prior to her diagnosis she had become more isolated. This was due to a combination of factors including the fact that many of her friends have passed away, she had given up driving and was unable to go out alone due to her deteriorating mobility and a number of recent falls.

She was diagnosed with early stage mixed dementias and was referred to the project by the Older People's Team. At this point she was depressed, socially isolated and stating that she wanted to go into full-time care. Neither her daughter nor the Older People's Team staff felt that she was ready for long term care. She was started on

antidepressant medication and her Community Psychiatric Nurse (CPN) continued to see her regularly.

Isabel's low mood was related to her sense of isolation, which was compounded by her poor short term memory and concept of time. She called her daughter, distressed, several times a day including through the night. Her daughter, who was her main carer and very supportive, was becoming increasingly stressed.

Project staff encouraged use of a whiteboard detailing the days of the week and activities or planned visits, with times. Isabel used this well and it made a significant difference to her sense of orientation, isolation and mood, which in turn had a positive effect on her short term memory. The number of calls to her daughter greatly reduced and she was no longer distressed when calling. Through this process Isabel and her daughter increased their understanding of the extent to which her short-term memory problems were affecting her life, her mood and self esteem. With support Isabel was able to reach a point of acceptance of her condition and adopted her own deliberate strategy to live in the moment, knowing that even if she couldn't remember what she had been doing, she knew that she would have enjoyed it at the time. This helped her to not get upset when she couldn't remember recent events. She also stopped saying that she wanted to go into a home, saying that she wanted to remain in her own home.

Isabel had stopped painting and had withdrawn from both the art club that she was a member of, and her church. This was as a direct result of her cognitive decline and increasing difficulties, resulting from her dementia. She made it clear to project staff that she was not interested in re-establishing these links because she was aware of both her changed abilities and the changed dynamics within her relationships with others. It was clear that returning to these communities would have had a negative impact on Isabel's self-esteem. She was however happy to look at new opportunities to meet with others who had a love of art.

Staff identified a local community art group and initially supported Isabel to attend. The project then recruited, trained and supported an "art loving" volunteer befriender to accompany her to the weekly group.



A person-centred planning meeting (using PATH) took place with Isabel, her daughter and her CPN. At the meeting they looked at her dreams and fears for the future to ensure that Isabel and her daughter were able to take control of decisions about her future care. Self-directed support, as an alternative to traditional services, was discussed as a more personalised option to the current services that she was already receiving, which included home care. A number of actions were agreed.

During the time that project staff worked with Isabel she had a fall and fractured her wrist. Unable to remain at home alone, she was admitted to a care home for three weeks. Being away from her own home had a detrimental effect on her memory; however this was helped by the project and team ensuring that all of her usual routines and activities were kept in place. Project staff, along with the team supported Isabel and her daughter in pursuing self-directed support. The aim was to use self-directed support for home based respite (for planned and unplanned respite) in the future and to look at more flexible service provision (at times that fitted in with the rest of her life and routines), in place of current home care provision. Sadly Isabel passed away just as these changes took effect.

## 4.2 Mary

Mary is an 82 year old widow, who lives alone. She has one daughter who lives nearby and another daughter who lives abroad. She has a diagnosis of Alzheimer's

disease. When project staff first met with Mary she had post-it notes all over the house in addition to the use of a calendar and diary in an attempt to compensate for her short term memory difficulties. Her systems appeared somewhat chaotic and were not working in a robust way. Much of the support provided by staff was focused on helping Mary streamline, develop and consistently use aids and strategies to help with her short term memory problems, such as the use of calendar and whiteboard and enlisting her daughter to update whiteboard daily. Very quickly staff could see an improvement with fewer post-it notes around the house and Mary getting used to storing important papers in one place. Mary began to feel much more in control.

Mary has a great social network and busy social life, and regularly meets friends to play bowls and bridge and have coffee or lunch. She has always been physically active and loves being outdoors. Although her daughter drops in on her most days, Mary remains very independent in all aspects of her life. Having to give up driving was a loss that she has adapted to well, even making use of My Bus with her friend (arranged by her friend).

Although she has a great circle of friends Mary enjoys attending the drop-in cafés as she enjoys the opportunity to talk with other people who have similar problems as a result of their dementia. She attended the first series of workshops on her own. She reported after each session that she had enjoyed and learned from it but would say that if she were asked later that day what the session was about she would not remember. Systems to back up her learning with written material in a special folder did not seem to help. Individual follow up which involved recapping and how some of the learning could be used in her daily routines was reinforced with discussion involving her daughter, who could remind Mary about what she had learned.

When staff first met Mary she informed them that she had gone on her own to visit a nearby nursing home and had requested an application for a place there. Staff and Mary's daughter recognised that she was nowhere near ready for long term care. Staff were able to provide Mary with information on the different types of support including assistive technology that could enable her to live independently in her own home as her dementia progressed. In a matter of weeks Mary had gone from telling staff that she would have to go into a care home to telling them that if she ever came

to a point where she could no longer stay at home she would go to the care home of her choosing.

Staff facilitated a person centred planning meeting for Mary and her daughter. As she already has a very good quality of life, staff adapted the tools to help Mary and her daughter think about what additional supports from her family and friends could help her maintain that good life as her dementia progressed.

### **4.3 Helen and Gibb**



Helen is 67 and lives with her husband Gibb. She was diagnosed with Alzheimer's disease. This diagnosis came as a shock to both Helen and Gibb as the original diagnosis had been one of depression. Gibb described a marked change in Helen's personality as she had previously been confident and outgoing and had become much more withdrawn and quiet. Project staff initially helped on a one to one basis with the process of applying for Attendance Allowance and Council Tax Discount. Project staff also talked through the process of putting Powers of Attorney in place.

Helen and Gibb attended the drop-in cafés and attended the second series of workshops. Meeting other people recently diagnosed with dementia and learning more about dementia through the workshops, has helped Helen and Gibb to begin to come to terms with Helen's diagnosis. Staff saw a significant increase in Helen's

confidence. One of the benefits of Helen and Gibb attending the workshops was that they were both able to recognise and acknowledge that since her diagnosis Gibb had been taking over many duties from Helen. They both described this as him wrapping her in cotton wool. Through discussion at the workshops they both agreed that it would be in Helen's best interests to do as much as she can for herself.

## **5. Awareness and Involvement**

A short DVD was produced featuring people with dementia and family members supported by the project talking about how post-diagnostic support has helped them come to terms with their diagnosis and plan ahead. The DVD was shown at the joint Facing Dementia Together conference in March 2011 which reported on the work of the three pilot projects funded by the Scottish Government and at the local event in June 2011. Five people who had been supported by the project shared their experiences at the conference as part of two workshop sessions.

Links to the DVD have now been put on websites and copies made available to referrers. It can be viewed at

<http://dementiascotland.org/services/east-renfrewshire/facing-dementia-together/> .

This DVD can be used to encourage others to seek post-diagnostic support and help professionals understand why it's important and what can help.

The project held a local event on 10th June 2011, to report on the work and findings of the project. It was attended by 54 people, which included 24 people who had been supported by the project (13 people with dementia and 12 family members) and 29 professionals. The event featured the project DVD and an interactive drama by Creative Training Unlimited about post-diagnostic support,

Project staff delivered presentations and/or facilitated workshops on post diagnostic support, person-centred planning, personalisation, and self directed support at twelve regional, national and international conferences/events. These included conferences organised by Alzheimer Scotland, Alzheimer Europe, Long Term Conditions Alliance, NHS Glasgow and Clyde, and the University of Glasgow. Along with the

Ayrshire Self-Directed Support Pilot, a consultation event on the Government Strategy on Self-Directed Support was organised, which took place on 30<sup>th</sup> March 2010. A total of 80 people with dementia and family members who were interested in self-directed support attended including six people referred to the project. Six others who were unable to attend asked for feedback from the event.

An awareness raising event was held locally in September 2010, which took the form of a week-long art exhibition of paintings by a person with dementia who was supported by the project to take up her love of painting once again. The volunteer, who supported the woman to attend a local art group, organised and designed the exhibition.

Project staff also gave talks to small groups of carers in Renfrewshire and East Renfrewshire about Alzheimer Scotland Services and the work of the project.

## **6. Project outcomes**

The project set out to achieve a clear set of outcomes (Appendix 1, pp 56-57), and the achievements relating to each outcome are discussed here, based on internal evaluation and feedback from those who used the project. In addition the evaluation carried out by Dementia Service Development Centre is summarised on page 50.

### **6.1 People with dementia and their families/supporters will be better informed**

**“Coming to the groups has opened my eyes ... I’ve realised that you (to his wife) can still do things yourself...”**

Project staff provided information about dementia and its effects to most of the people referred and also to their families/friends. Staff provided information on a wide range of matters as required/requested such as information on different types of dementia, welfare benefits, Powers of Attorney, Advanced Statements, Council Tax exemption/discount, medications, befriending projects, support services, and My Bus

travel scheme. Staff provided information on and introduction to assistive technology for twenty eight people with dementia and their families. Staff supported one person with dementia to visit the Assistive Technology Suite at DSDC to consider equipment that could be used to help that person remain independent living in her own home. Staff provided information on specialist dementia supported accommodation as a potential alternative to long term care to one person.

Thirty three of the thirty eight people who attended the series of workshops completed a pre and post questionnaire, Of the 33 people who completed the questionnaires 97% stated that they felt better informed about dementia, 84% stated that they felt better informed about benefits, powers of attorney and advanced statements and 75% stated that they felt better informed about planning ahead for their future needs.

The independent evaluation of the project reported that “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” (Innes et al, 2011, p30). The evaluation also reported that many participants would not have accessed welfare benefits if they had not been alerted to their entitlement by project staff (Innes et al, 2011, p30).

## **6.2 People with dementia and their families/supporters will be equipped with skills to manage better the challenges of living with dementia**

**“I was terrified when I first heard of mum’s diagnosis but I’m not so scared now”**

With almost all referrals project staff provided information on coping strategies (especially memory aids). Staff provided guidance and modelling of ways of adapting behaviour (in light of the effects of person’s symptoms of dementia on both the person and their family) to almost everyone who was referred to the project. Staff identified solutions to communication difficulties for one person by seeking out

different options including training in the use of computer software and use of Talking Mats ©.

One of the workshop sessions was dedicated to living well with dementia and included discussion of difficulties encountered and possible solutions or strategies that could help, with input from members of the Scottish Dementia Working Group. Of the 38 people who attended the series of workshops 33 people completed a pre and post questionnaire, and 97% of them reported feeling better equipped with skills to manage the challenges of living with dementia,

As a result of direct input from project staff fourteen people successfully implemented use of whiteboards, diaries, and/or calendars at home to help with memory problems and orientation difficulties. Following information and advice from project staff, some people have purchased and are successfully using assistive technology devices such as timed release medication dispensers and simple mobile phones to enable independence with the ability to call for assistance if the person gets lost whilst out alone. Others have sought solutions through discussion with staff regarding safety when cooking and information on accessing devices such as heat, gas, smoke and flood detectors have been provided to enable independence, whilst ensuring the person is safe.

One person who was experiencing significant communication difficulties was supported to learn to use voice recognition software, which enabled her to remain independent and in touch with many of her friends who lived abroad, by e-mail and letter. Three families implemented signage around the home with signs made for them by the project in order to help the person with dementia better navigate their way around their home. Almost all of the family members supported by the project have sought advice and strategies to manage some of the challenges they face, such as how best to respond to repeated questions and statements or communication difficulties. They have reported how use of strategies improved their relationship with the person with dementia. Through attending the workshops many have been able to think about balancing independence with safety and risks and many have described how this has also helped both parties. Staff also observed positive changes over time in relation to independence and communication.

The independent evaluation found that more than two thirds of people with dementia were reporting their memory to be as good or better following support from the project. Of those who reported an improvement three had vascular dementia and one had Alzheimer's disease. 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)" (Innes et al, 2011, p12).

### **6.3 People with dementia will have legal and financial arrangements in place for the future**

Twenty three people with dementia and their families were guided through the process of putting Powers of Attorney in place. Three families were signposted for assistance with application for advice and assistance from the Legal Aid Board to cover the costs of arranging Powers of Attorney. One person and her family were guided through the process of arranging Guardianship. Nineteen people with dementia were referred by project staff to the Department of Work and Pension (DWP) for income maximisation and assistance with applications for Carers/Attendance Allowance. All claims were successful. Nineteen people with dementia were assisted with applications for council tax discount or exemption. All applications were successful. The independent evaluation of the project reported that "Several carers also spoke of receiving support with arranging powers of attorney and valued the input from project workers in negotiating the process" (Innes, et al, 2011, p30)

### **6.4 People with dementia will be able to make contact with, and benefit from the support of, other people with dementia**

**"It has definitely changed my outlook. The minute I was told, it was like a death sentence..... coming here I realise it's not like that at all... I appreciate coming along and talking to other people and realising there are a lot of people in the same boat..... It's been very useful meeting other**

**people.... It has helped me to come to some sort of acceptance. I feel like I'm now at the end of a very long tunnel"**

Opportunities for peer support were provided through the cafés and workshops and occasional social events as described in Project Activity and Workshop Evaluation Report (Appendix 10, pp. 68-79). Of the 33 people who completed the pre and post questionnaires 97% reported that they felt they had received support from other participants attending the workshops. This was also the most commonly cited benefit from those who attended cafés and workshops.

A further questionnaire was completed by 24 of 27 people who attended the cafés seeking their views on whether they found the cafés useful and asking about frequency and venues and times. Of the 24 who completed the questionnaire 100% stated that they found the cafés helpful and wished for them to continue and 100% stated that they would like them to increase in frequency from one per month to three per month. This was actioned by the project in January 2011.

The independent evaluation found that all participants highly valued access to the social settings provided by the project. The evaluation found that the project had 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” (Innes et al, 2011, p35). The evaluation highlighted that people with dementia living on their own had particularly benefitted socially from attending the cafés and workshops and spoke of the friendships developing during the cafés, sometimes with other people with dementia and sometimes with other carers (Innes et al, 2011, p33).

Access to social settings provided by the project were reported by all participants as very valuable (Innes et al, 2011, p29). The evaluation also reported that for some people 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” (Innes et al, 2011, p29). Project staff believe that this helped people to better understand and develop acceptance of their diagnosis,

giving people the message that just because someone has a diagnosis of dementia it doesn't mean the end of a normal life. For the majority of people with dementia and their families attending the cafés and workshops provided them with their only chance to engage with others in the same or similar position as themselves.

### **6.5 People with dementia will 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**

**“When they first came out I was clear what I wanted – Look this is about me – I want to decide how I live my life. It seems that was the way they wanted to work. They help me plan my future, we sit and plan out what I want to do and where I want to go. We look at ways to get around difficulties... now, I don't see myself as somebody like I did at the beginning, someone in dire straits. None of it feels like people coming to help me. We do things together...It's really hard to explain. At the same time I'm trying to do all these things, to re-plan my life, I feel I'm bringing together my own person again. And it feels good!”**

Through individual support, cafés and workshops, people with dementia were able to develop their understanding of dementia, its effects and how it progresses. They were also informed about the different types of supports that could enable them to live at home as independently as possible for as long as possible, including self-directed support. Everyone supported by the project was offered the opportunity to have a person centred planning meeting facilitated for them so that they could plan ahead for their future needs.

As already stated project staff were instrumental in helping put personalised support packages in place using support services available for five people with dementia who had been offered but had refused daycare. In each case staff were able to work with the person with dementia, their family and care manager to find an alternative support that better suited them. Isabel's personal story illustrates how working in partnership with one person with dementia, her family and the Older People's Team, input from

project staff was instrumental in helping to avoid premature admission to a care home and maintaining Isabel's independence.

Project staff facilitated person centred planning meetings with eight people with dementia and their families. Further details can be found in Project Activity and Personal Stories – Isabel (pp. 28-30) and Mary (pp. 30-32).

Staff introduced the value and concept of life story work to eleven people with dementia and their families and ran a five session weekly life story group for five people, which was part of planning for their future support needs. Life story work is a collaborative, creative way of recording a person's life story, which can be a stimulating and enjoyable shared activity in its own right, enabling people to share memories of their lives. Life story work can also be seen as forward planning as it will serve as a useful record that can enable anyone supporting the person in the future to quickly get to know the person, their life and history.

## **6.6 People with dementia will be supported in the best way for each individual, maximising the benefit from the allocated budget and minimising the need for crisis intervention.**

Eligibility criteria in both local authority areas meant that only those with other significant needs in addition to their dementia would be eligible for services and therefore eligible for self directed support. This meant that the majority of people referred to the project, who had recently been diagnosed, were not yet eligible for services. The focus for this area of work was therefore on helping people to look ahead and to understand the support options.

Project staff provided information on self-directed support to 24 people with dementia and their families and guided one family through the process of putting a self directed support package in place.

## **6.7 Family members/supporters will be involved in helping the person design the service which will best support them in the future.**

**“Before becoming involved with the project, I hadn't even heard about self directed support and knew nothing about individual budgets or what support we were entitled to”**

This has been a difficult outcome to achieve. Although project staff discussed this with all family members/supporters many felt they were unable to think or plan ahead too far in the future. This was echoed by the independent evaluation, which reported that “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” (Innes et al, 2011, p35). The evaluation reported no shifting in thinking from those who just did not want to think ahead from initial interview to follow up interview. This “highlights 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 (Innes et al, 2011, p35).

With those people who wanted to plan ahead for their future needs, family members/supporters were fully involved in the planning process, with the person’s permission. Others who did not undertake formal planning sessions sought advice from project staff regarding types of support when planning for the future; on assistive technology, formal services and how to identify a suitable care home or maintain the person with dementia at home. Family members who attended the workshops were provided with information about planning ahead for the future and were given a demonstration of use of person centred planning tools. Seventy five percent of those who attended the session on planning ahead stated that they felt better informed after the session.

## **6.8 Local authority and health staff will be better informed and will understand the benefits of and be committed to personalisation for people with dementia**

Project staff met with and gave presentations (both formal and informal) on the work of the project and the benefits of personalisation for people with dementia to local authority and health staff in a range of settings. These included the Older People's Team, Community Mental Health Teams for Older People, Social Work Teams, Renfrewshire Joint Planning, Performance and Implementation Group, NHS Greater Glasgow and Clyde Dementia Shared Practice event and Renfrewshire Council's Social Work Practice Exchange workshop. However, whether staff felt better informed, better understood the benefits and are committed to personalisation, is not something that the project has been able to measure as no baseline measures were recorded. With hindsight this could perhaps been achieved with a sample of staff either by use of questionnaires or interviews to compare knowledge and practice of staff before and after input by project staff.

## **6.9 Local authority and health staff will 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.**

Project staff worked with health and social work staff on a case by case basis to look at designing creative patterns of services and supports that will best support the person in the future and were involved in person centred planning meetings. Due to the limited number of people who wished to plan ahead for the future, there has been limited opportunity for this. Where local authority and health staff were already involved with the person who wanted to plan ahead, they were given the opportunity to take part in the planning sessions (with the person's permission). In the case of Isabel (pp. 28-30), project staff worked closely with the local authority and health staff, (who had considerable knowledge and experience of helping clients access direct payments but less knowledge or experience of individual budgets), to help the family design a creative pattern of support that fitted their needs best.

## **7. Challenges**

The key challenges for the project related to its innovative nature and short duration.

### **7.1 Slow referrals**

The start up period took longer than anticipated, and the referral rate during the first year of the project was slow. This was to be expected to some extent with any new pilot project and in part was linked to the delay in the evaluation getting started and concerns of key memory clinic staff regarding how participants would be recruited to the control group for the evaluation. This led to referrals being held back by one memory clinic until the concerns were addressed. As is shown in Chart 1 (Appendix 4, p. 62), there was a huge surge in referral of a backlog of people once this was clarified by the external evaluation team.

The external evaluation showed that despite the efforts of project staff, significant misunderstandings existed among some local professionals as to the purpose of the project and modes of referral (Innes et al, 2011, p43).

### **7.2 Lower numbers from Renfrewshire**

The numbers referred in Renfrewshire were significantly lower than expected given the prevalence rates in each of the two local authority areas. This remained so throughout the project, despite attempts by staff to promote increased numbers of referrals in a number of different ways. The independent evaluation reported a number of possible reasons for the differences in referral rates (Innes et al, 2011, p43). These are listed below:

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

### **7.3 Lack of upfront preventive budgets**

Local authority eligibility criteria limited scope for budgets for preventive support. It had been an ambition of the project to demonstrate that the provision of a small upfront budget to enable people with early dementia to maintain their lives and natural supports, could potentially delay or reduce the need for paid care later in the illness. However neither local authority was able to provide such a budget routinely, although both offered the potential for specific supports on a case-by-case basis. However, some small amounts of upfront expenditure (from a small underspend that the project had available) did help to support some people using the project.

It paid for six sessions of counselling for one man who was struggling to come to terms with being diagnosed with dementia at a young age. This meant he was able to access specialist counselling from Alzheimer Scotland's Younger Person service, which operates in Glasgow. Feedback on how this helped him was very positive as he valued having dedicated time with a dementia specialist counsellor to talk about how the diagnosis had affected him and about his fears and worries for the future.

Some of the underspend money was used to pay for volunteer befriender expenses so that two people could be supported to undertake activities within their local

community, that they required support to access. The other main spend was for the costs of helping people to attend the project cafés and workshops who would otherwise have been unable to do so, by providing transport, with a member of staff collecting them and taking them home again. This applied to the vast majority of people with dementia either living alone or attending alone, and was highlighted in the independent evaluation, as something there was much support for. The evaluation reported that availability of transport “went towards not only alleviating concerns about how to get to the events organised, but also maintained social contact” (Innes et al, 2011, p29).

#### **7.4 It takes time for people to want to plan ahead**

The short duration of the project proved a challenge for the aim of assisting people to plan ahead for their future. It was clear from the outset that forward planning must be at a pace that is right for person with dementia. Fluctuating insight, understanding and acceptance of diagnosis and its implications, personal methods of coping such as avoidance, denial, minimisation and not wanting or being able to look too far ahead, along with memory problems, mean that forward planning is not a straightforward or linear process. People with dementia and their families need to be able to emotionally and cognitively process the diagnosis and what that means for their lives before being able to engage in the process of planning ahead. This has implications for discussing and planning for future support needs and self directed support as this can only happen if the person is ready and wishes to look ahead.

There was reluctance by some people with dementia and families to accept support or involve others in forward planning. This had implications for how person centred planning tools could be used. In a longer-term mainstream post-diagnostic service such planning opportunities could be offered at the right point for each person or family, but in the pilot project the slow referral rate early on meant that the majority of people referred were with the project for under a year and many did not reach the point where they were ready to look ahead in this way. However as the case studies show, for those who did, this was a highly successful process.

Resource Allocation Systems were not available in either of the two local authorities, so future care planning could be only broadly indicative in terms of costings.

### **7.5 Making new connections rather than staying connected is sometimes necessary**

Supporting people using the project to stay connected to their communities and activities was not necessarily straightforward. Although the aim was to work with people as early in their journey of dementia as possible, it is the case that people often live with their condition for a number of years before seeking a diagnosis (often because they are reluctant or fearful to seek help). Natural supports and previously undertaken activities are sometimes partly or totally eroded by the time the person has received diagnosis. In some cases the person with dementia and family were resistant to re-establishing old links, preferring support to make new connections. Please see Personal Story Isabel (p. 28-30) for an example of how the project has worked with someone in this way.

### **7.6 Delay in start of evaluation**

There was a long lead-in to the evaluation due to ethical approval and this meant that fieldwork did not commence until March 2010, which was unfortunate and restricted the ability of the evaluation team to follow up the long term impact of the project.

## **8. Key learning**

The project has clearly demonstrated that after diagnosis, people with dementia and their families/friends do need significant support, and want ongoing low level input and continued contact with a dementia specialist, who they can ask for information, advice and guidance. Overwhelmingly those supported by the project have said that one of the main benefits of post diagnostic support is no longer feeling that they are on their own and that they have someone to turn to if and when needed.

Three areas where there has been key learning are supporting community connections, peer support and planning for future care.

## **8.1 Supporting community connections**

Where people have lost some or all of their community connections and natural supports, the project worked to re-establish old connections where this was what the person wanted, but it also became clear that for some people their preference was not to go back, as their awareness of changes in their abilities affected the dynamics in existing relationships and this in turn affected self-esteem. The learning was that it is important to be sensitive to this possibility, and where this is the case, to help the person to establish new connections, as for example the new art group for Isabel.

## **8.2 Peer support**

The project has confirmed the central importance of peer support to both people with dementia and their partners and families. Meeting other people with early stage dementia and their families/supporters challenges people's preconceived notions, stereotypes and myths about dementia and how quickly the condition progresses. This seems to help people come to terms with and understand their diagnosis better. Peer support provides a safe space where people feel accepted and do not have to worry about being judged for forgetting or having difficulties, for example with word finding. In addition peer support provides a forum where people can share their experiences; discuss common challenges and ways of managing these. Having the opportunity to meet with others in the same position can help in terms of shared problem solving and sharing ways of coping/adapting that has been helpful.

Peer and professional support following diagnosis shows people that you can live positively with dementia. It can also help families to think about balancing independence with risks. This was one of the most common issues to be discussed in the peer support at the workshops. People with dementia often talked about well meaning family members taking over and doing things that they were still capable of (in whole or in part, with or without assistance). Family members often remarked that they had been wrapping the person in cotton wool and perhaps doing too much for them. People reported that having a forum where open discussion of these issues can

take place during the project has helped families to cope better, enabled greater independence and reduced frustrations.

Through the workshops it was clear that creating a space where people with dementia could talk freely about any fears and worries they might have, without worrying about the effect this may have on their family members was vitally important. Likewise creating a similar space for family members is also important. Although there are opportunities for family members to discuss their worries at carer support groups, many said that attending carers' groups where there are people caring for someone at later stages does them more harm than good. Many carers reported that they were not ready for much of what was discussed, and described this as traumatic.

Peer support was also found to be helpful in encouraging people to access other supports such as educational workshops. People with dementia and family members remarked on how comfortable they felt coming to the cafés initially and attending the workshops because they had a “gentle introduction”. Being able to meet with project staff individually at least once, seems to help this process as does attending cafés prior to workshops. For project staff, having knowledge of those attending the workshops helped to tailor the sessions to those attending.

### **8.3 Planning ahead for future care**

There are three important areas of learning in planning ahead for future care.

The first is that the clear experience of the project was that people with dementia and their family members need to be able to come to terms with and understand their diagnosis and its implications for the future before they are able to plan ahead for their future support needs. This process takes different times for different people and their circumstances. How far ahead someone is able to or wants to look is also very individual.

Planning for future care will generally happen only in the context of a supportive relationship with a professional, who is first able to help the individual and their

partner or family to come to terms with the diagnosis of dementia and find ways of coping with its immediate challenges. Planning future care is not possible while someone has not accepted their diagnosis or is too afraid of what the future holds to look ahead. This means that there is a need for an ongoing relationship, which may at times be light touch and at times more intensive, in order to allow someone to come to the point where they are ready to plan ahead.

The second is the value in future care planning, which has been clearly demonstrated by the pilot project, in that it allows people with dementia and their families to create a picture of what is important to the person, what they want to achieve, and who is around them to offer support, both natural and in terms of potential services. Recording this information allows people to get to know them, as their needs change and other people are involved in their care and support.

The third area of learning is that the MAP and PATH tools, which have principally been used with people with learning disability, have been successfully adapted by the project for use with people with dementia.

## **8.4 Practicalities**

For those people with dementia living on their own and attending cafés or workshops on their own, staff being able to facilitate transport, has been paramount. With very few exceptions those living alone would be unable to travel independently or organise transport themselves. Key to them being able to attend was staff phoning to give reminders and going to the house and often helping the person to make sure the house is secure and that they had everything they need. Simply sending a taxi or arranging for My Bus to collect them would not be enough for some people, because they would be unable to organise themselves to be ready on time and waiting, without some assistance.

## 9. Evaluation

An independent evaluation of the project was carried out by a team of research staff from Dementia Services Development Centre at the University of Stirling, led by Professor Alison Bowes. The aim of the evaluation was to identify what difference, if any, the post diagnostic support makes for people with dementia and their families, over the year following diagnosis. The main areas that the evaluation focused on were quality of life, service access, independence and choice.

It was initially planned that the evaluation would adopt a comparative design, comparing outcomes for a group of people using the 'Facing Dementia Together' pilot and a comparator group also newly diagnosed receiving the usual support in the same area. However the researchers had difficulty recruiting to the comparator group and the study therefore was unable to compare outcomes as intended.

An evaluation report has been produced for the Scottish Government and one or more papers will be submitted for publication in journals. The evaluation report is available from the Scottish Government (Innes et al, 2011).

The key findings of the evaluation were reported as follows:

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.

Innes et al, 2011, p1.

## **10. Conclusions**

The project has found that there is a clear need for post-diagnostic support. The majority of people wanted and needed ongoing contact, even if this is of a fairly low key nature (e.g. through regular cafés). Creating opportunities for peer support but also somewhere to get information as required, and be signposted or referred to services as needed is important. Attending cafés and workshops as a couple or family helped people to adapt to living with dementia as a couple or family, as each person was able to develop insight into how the other person experienced life with dementia.

The project has demonstrated that there are five key pillars of post-diagnostic support which are all essential in a post-diagnostic service and the value and importance of all of these:

1. Understanding the illness & managing symptoms
2. Supporting community connections
3. Peer support
4. Planning for future care
5. Planning for future decision-making

The lack of uptake on more detailed forward planning reflects the fact that coming to terms with and understanding the diagnosis, is a process which has to be gone through before people are able to think about their future support needs.

## **11. Recommendations**

1. A comprehensive post-diagnostic service should be a mainstream part of the support offered to people with dementia and their partners and families immediately after diagnosis.
2. The post-diagnostic service should incorporate all five key pillars of post-diagnostic support.
3. The service should offer the opportunity for short period of intensive support for those who need it, but also an ongoing point of contact for light-touch advice, information and support.
4. The person with dementia and their family members should be offered education courses/information sessions that they can both attend. Attending as a couple or family, helps people to adapt to living with dementia as a couple or family.
5. Dementia cafés should be provided to offer ongoing access to peer support for both people with dementia and their partners, families and supporters. Consideration should be given to offering these specifically for people with dementia and their families who are at the same stage of the illness. Consideration should also be given to providing help with transport, particularly for those people with dementia living on their own.
6. Continuation of cafés with a programme of invited speakers beyond the end of the pilot project. The cafés would act as a point of support for those newly diagnosed with early stage dementia and an ongoing point of contact where people can get information, support, advice and guidance as well as being signposted/ referred on to other services as required.

7. Forward planning needs to be offered at the right time, once the person with dementia and their families have been able to cognitively and emotionally process the diagnosis and come to terms with it, and what it means for their future lives.
8. The project should be continued in Renfrewshire and East Renfrewshire, to build on the work of the pilot.

## 12. Contact details

If you would like further information about the project please contact

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## Appendix 1 - Aims, Objectives and Outcomes

The project set out to 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 (e.g. powers of attorney, advanced 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 project aimed to 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 were 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 now and 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.

## Appendix 2 – Steering Group and Stakeholder Group membership and remits

### Project Steering Group

#### Membership

Kate Fearnley	Deputy Chief Executive, Alzheimer Scotland
John Patterson	Head of Community Care, Renfrewshire Council
Tim Eltringham	Head of Health & Community Care, East Renfrewshire CHCP
Jan Johnston	Regional Manager, Argyll and Clyde, Alzheimer Scotland
Dr Rob Gray	Lead Clinician, EMI, Renfrewshire CHP
June Findlater	Rehabilitation & Enablement Services Manager, East Renfrewshire CHCP
Dr Julia Gray	Consultant Psychiatrist, East Renfrewshire CHCP
Tracy Gilmour	Practice Manager, Alzheimer Scotland Facing Dementia Together Project

#### Remit

The Practice Manager will report on a 3 monthly basis to the Project Steering Group.

The Group will:

- Provide strategic direction and leadership for the project
- Provide accountability for the project
- Provide accountability for use of project funds
- Oversee the development of a framework for delivery of the project
- Monitor performance
- Provide advice and support to the Practice Manager
- Oversee the evaluation of the project, including consideration of options for the future
- Enable appropriate networking opportunities

- Consider an exit or continuation strategy

## Stakeholders' Group

### Membership

Jan Johnston	Regional Manager, Alzheimer Scotland
Kevin Beveridge	Commissioning & Development Coordinator, East Renfrewshire CHCP
Winnie Burke	Principal Officer for Older People, Renfrewshire
Annette Bonar	Community Care Service Manager
Liz Daniels	Rehabilitation and Enablement Services Manager
Linda McAulay	Alzheimer Scotland Service Manager, Renfrewshire
Eileen Smyth	Alzheimer Scotland Service Manager, East Renfrewshire
Tracy Gilmour	Practice Manager, Alzheimer Scotland Facing Dementia Together Project
Michelle Shaw	Project Worker, Alzheimer Scotland Facing Dementia Together Project
William Dow	Ex-carer
Peter Griffin	Scottish Dementia Working Group
James McKillop	Scottish Dementia Working Group
Heather McKay	Manager, Day Hospital and Memory Clinic, RAH

### Remit

The Practice Manager will co-ordinate/facilitate these meetings a on a regular basis and no less than bi-monthly.

The group will:

- Offer support and advice to project workers
- Provide assistance in planning project delivery/work plan

- Assist with overcoming obstacles
- Signpost staff to local networks
- Assist in promoting the work of the project and cascading information
- Assist in ensuring appropriate referral systems
- Contribute to monitoring and evaluation of project.
- Inform steering group

### **Revised Steering Group (amalgamation of steering and stakeholder groups)**

#### Membership

Jan Johnston	Regional Manager, Alzheimer Scotland
Kevin Beveridge	Commissioning & Development Coordinator, East Renfrewshire CHCP
Winnie Burke	Principal Officer for Older People, Renfrewshire
Annette Bonar	Community Care Service Manager
Liz Daniels	Rehabilitation and Enablement Services Manager
Tracy Gilmour	Practice Manager, Alzheimer Scotland Facing Dementia Together Project
Michelle Shaw	Project Worker, Alzheimer Scotland Facing Dementia Together Project
William Dow	Ex-carer
Peter Griffin	Scottish Dementia Working Group
James McKillop	Scottish Dementia Working Group
Heather McKay	Manager, Day Hospital and Memory Clinic, RAH

#### **Remit**

As previous two groups.

## **Appendix 3 – Referral Criteria and Guidelines**

The Facing Dementia Together Project is a pilot project funded by the Scottish Government, to provide information and support to people who have been recently diagnosed with early stage dementia.

### **Who can be referred to the project?**

The project will work with people of **any age** and **all types of dementia**.

In order to be referred the person must meet **all** of the following criteria;-

- Be resident in East Renfrewshire or Renfrewshire.
- Have received a diagnosis, normally within the last six months, of early stage dementia.
- Is aware of their diagnosis and is comfortable talking about the difficulties that he/she experiences as a result of their dementia.
- Would like post-diagnostic support.

Although the project is aimed primarily at supporting people with dementia there may be times when the project will work with family or friends of someone who has dementia.

### **Who can make referrals to the project?**

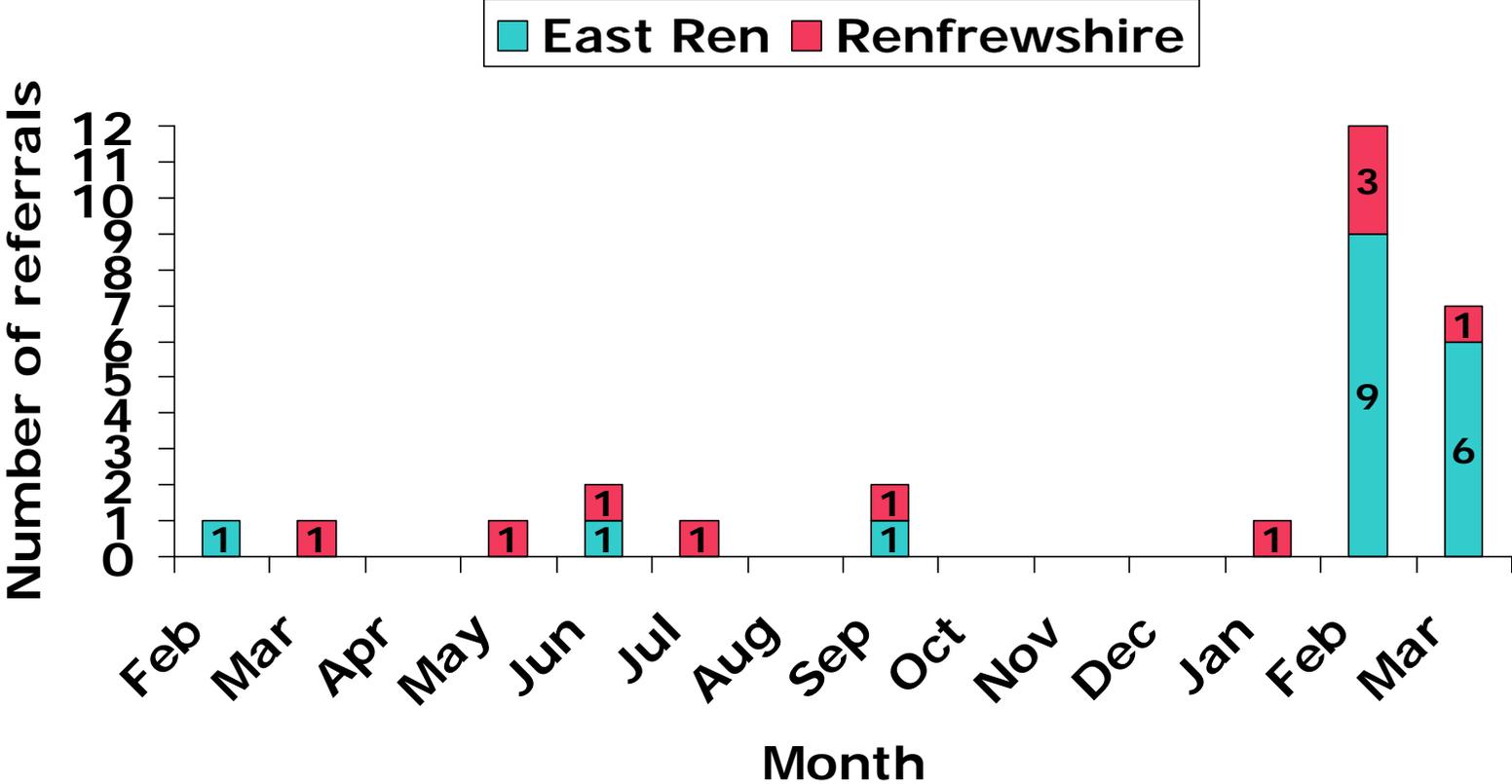
The project will accept referrals from health, social work professionals and Alzheimer Scotland Service Managers (Renfrewshire and East Renfrewshire Services). We expect most referrals will come directly from staff at the memory clinics.

### **How do I make a referral to the project?**

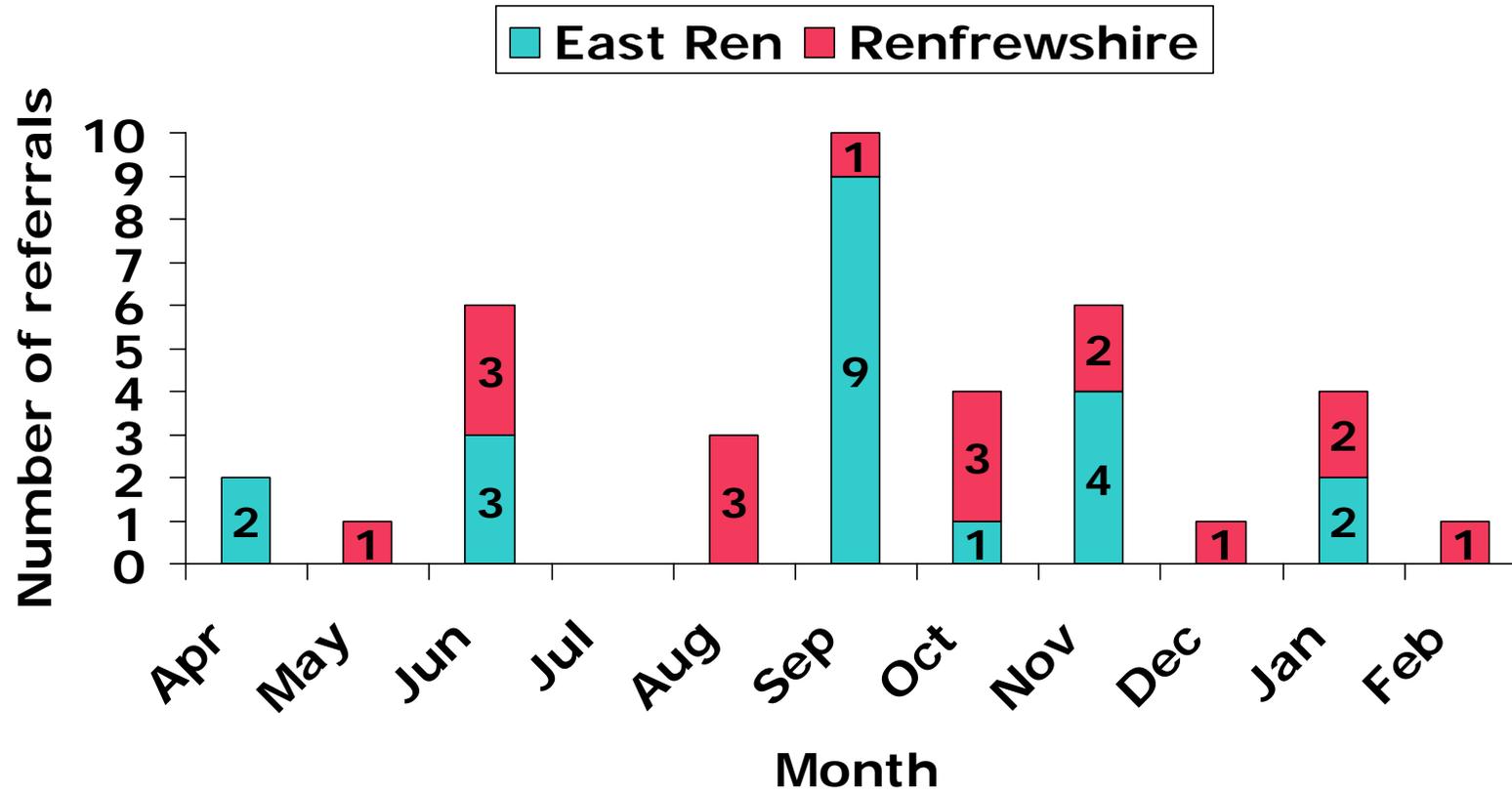
A referral letter or Alzheimer Scotland's *Referral and Service User Information Sheet* should be used. Where a single shared assessment has been completed this should be included with the referral. If referring by letter please include details about the person's diagnosis, whether he/she lives alone, details of medications prescribed and other support services, details of main carer, next of kin and GP. Please also include any other relevant information (e.g. mental health issues, substance misuse issues, relationships difficulties).

The pilot project is being evaluated by the research team from the Dementia Services Development Centre at Stirling University. People who are referred to the project will be asked whether they would be willing to give their permission to be involved in the evaluation. This would involve an initial interview, with follow up interviews at six months and one year. This is voluntary and the decision will not affect the support that the person will receive from the project.

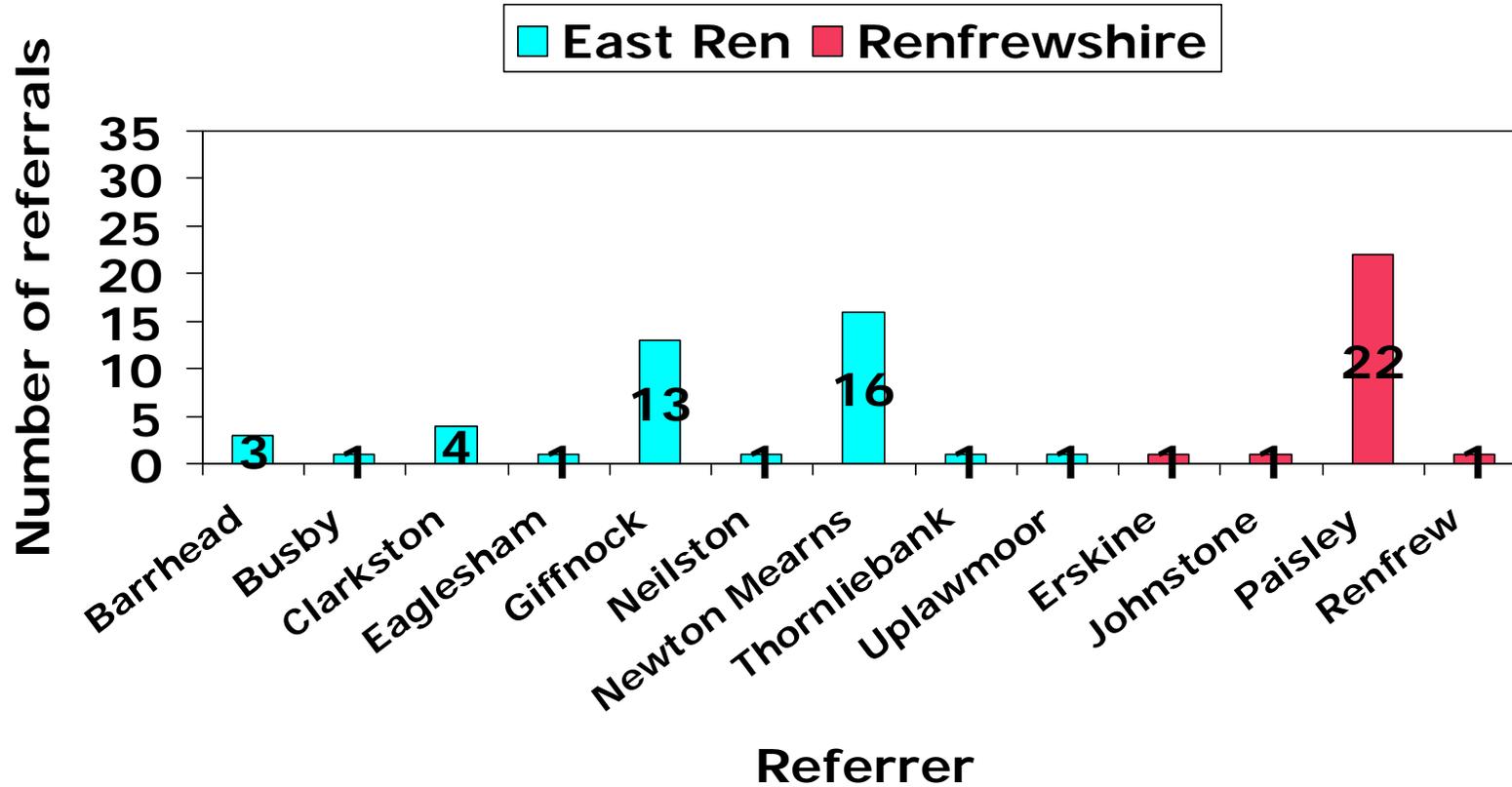
Appendix 4 – Chart 1 – Referral by month and area 2009/2010



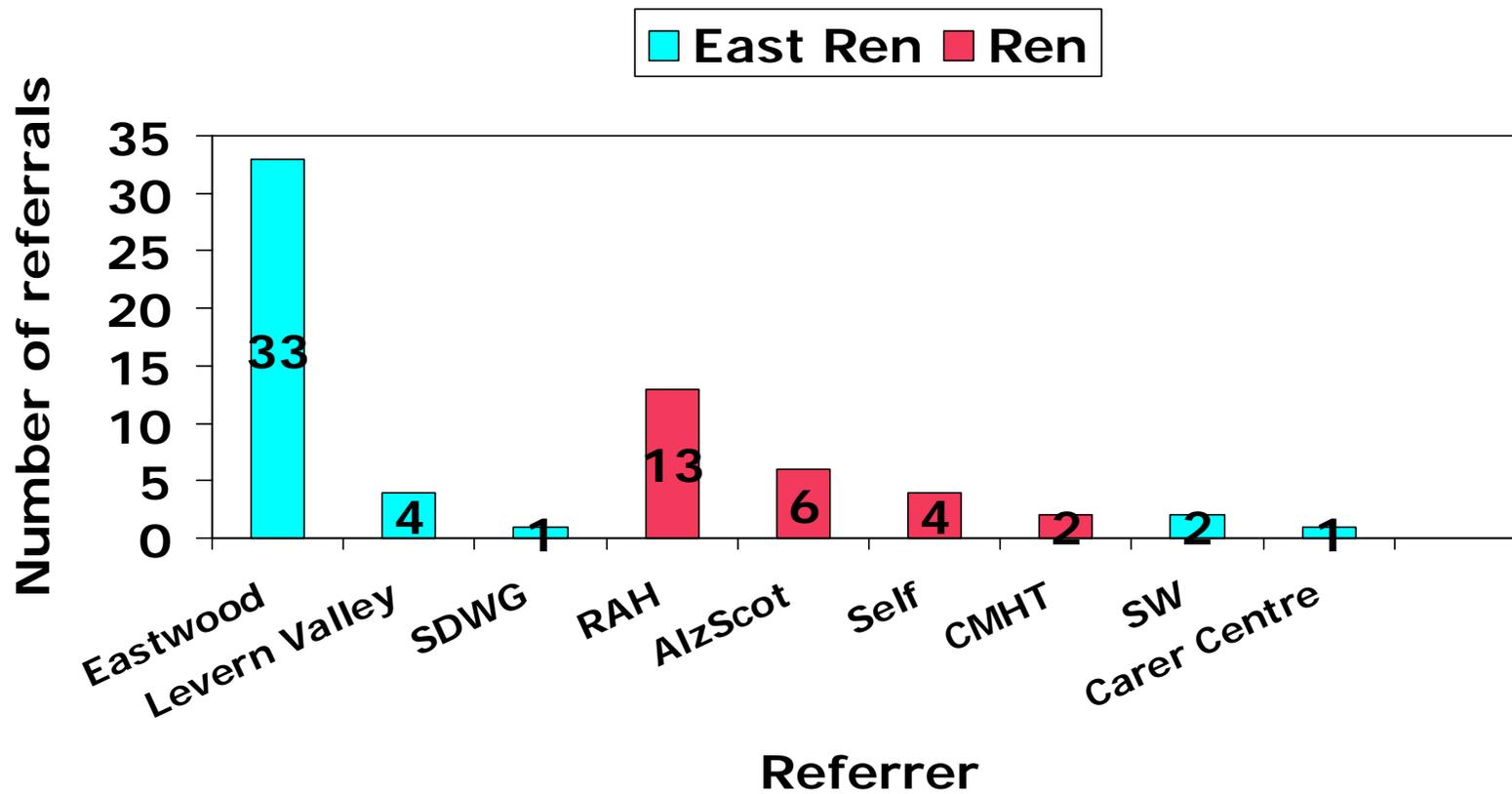
Appendix 5 – Chart 2 – Referral by month and area 2010/2011



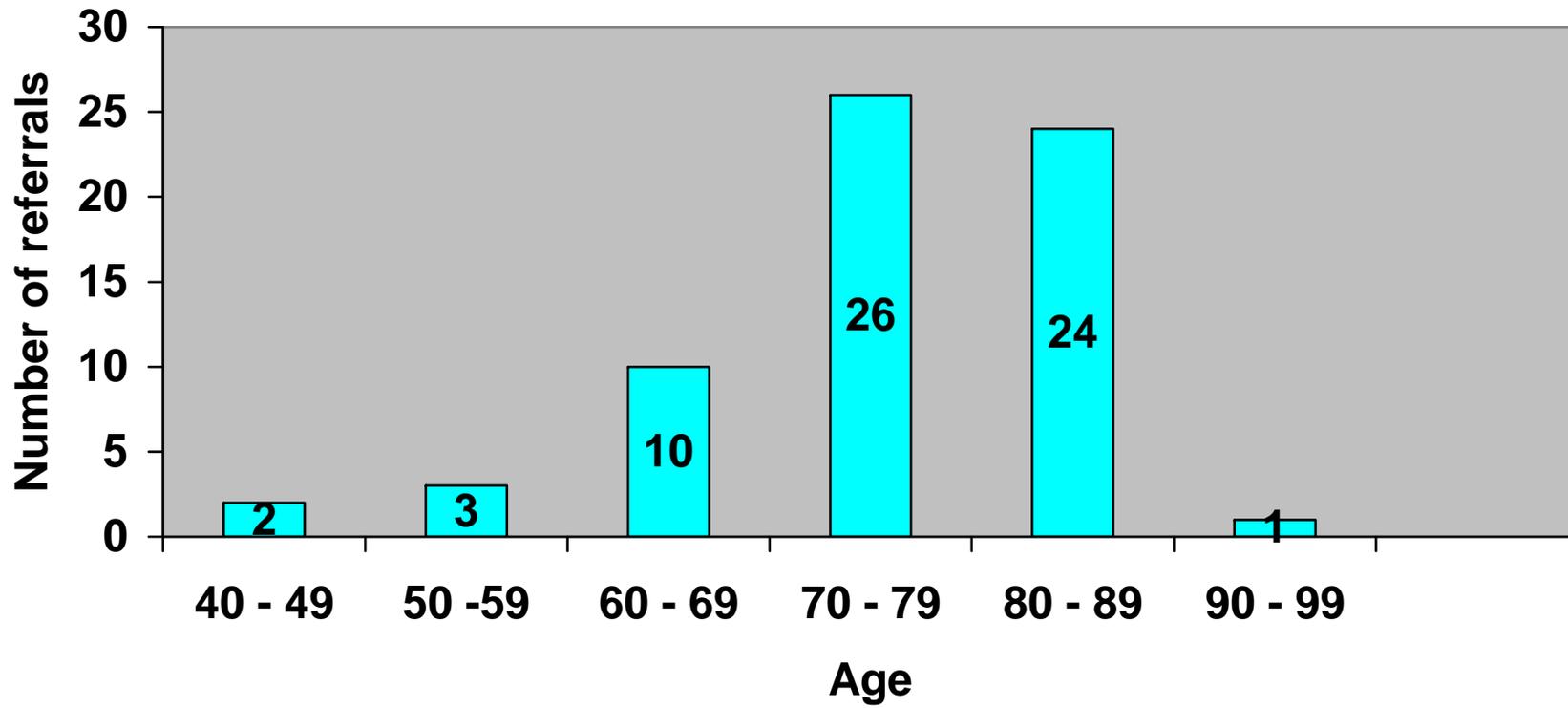
Appendix 6 – Chart 3 – Referrals by geographical area



Appendix 7 – Chart 4 – Source of referrals



Appendix 8 – Chart 5 – Referrals by age



## Appendix 9 – Table 1 – Attendance at drop-in cafés

	<b>Café Location</b>	<b>Person with dementia</b>	<b>Family member</b>	<b>Total</b>
15/04	Barrhead	4	3	7
17/06	Barrhead	6	5	11
21/07	Barrhead	7	6	13
26/08	Barrhead	8	5	13
23/09	Barrhead	9	6	15
11/11	Barrhead	13	7	20
23/12	Barrhead	7	4	11
18/01	Barrhead (icy weather)	7	4	11
25/01	Paisley (trial of venue)	5	4	9
03/02	Giffnock (trial of venue)	7	4	11
15/02	Barrhead	13	9	22
25/02	Barrhead (filmed DVD)	7	7	14
01/03	Paisley	7	7	14
08/03	Giffnock	7	4	11
15/03	Barrhead (snow)	7	4	11
07/04	Paisley	6	5	11
12/04	Giffnock	6	5	11
21/04	Barrhead	9	6	15
05/05	Paisley	7	7	14
17/05	Giffnock	4	2	6
26/05	Barrhead	12	11	23
02/06	Paisley	9	8	17
14/06	Giffnock	5	2	7
21/06	Barrhead	10	6	16

## Appendix 10 – Workshops Evaluation Report



### Facing Dementia Together Workshops

#### Evaluation of Delivery of Series 1, 2 and 3

#### Background to Project

The Facing Dementia Together Project, a pilot project funded by the Scottish Government until the end of June 2011, aims to support improvement in approaches to post-diagnostic support for people with dementia. The project provides information and support to people, who live in East Renfrewshire or Renfrewshire and who have been recently diagnosed with early stage dementia.

#### Workshop Outcomes

Derived directly from the project outcomes, the workshops expected outcomes are:

People with dementia will:

- Be better informed about dementia
- Be equipped with skills to manage better the challenges of living with dementia
- Be better informed about legal matters and arrangements 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 better informed about self directed support and ways of planning for the future

Family members will:

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

## Workshops

### Series 1

The first series of workshops was held over a six week period in August and September 2010. They were attended by a total of nine people with dementia and eight family members. Attendance was consistent (bar three instances of previous commitments) and only one person with dementia chose not to complete the course, missing the last two sessions.

### Preparation

In the months prior to the workshops, information was collected from similar workshops run by other organisations and relevant research papers. Alzheimer Scotland's Seize the Day Project provided particularly useful and relevant information as they deliver self management training and education workshops for people with dementia, their family members and friends.

Questionnaires were distributed to all current service users and family members who had expressed an interest, exploring topics to be covered and the format of the workshops.

From these, it was clear that potential participants wanted time together as well as separate peer support time for people with dementia and their family members. From the information collated 6 workshops were developed:

1. **Introduction to the Workshops.** Getting to know each other. What questions do you have about dementia? Presenters: Facing Dementia Together staff.
2. **What is Dementia?** (Tailored to needs of participants as discussed in Workshop 1) Presenters: Facing Dementia Together staff.
3. **Living Positively with Dementia:** Shared experiences and practical strategies for coping. Presenters: James McKillop and Shelia Piper, Scottish Dementia Working Group.
4. **Healthy Lifestyle and Relaxation:** Healthy eating, exercise and relaxation. Presenter: Munmun Hyder, Health Information Officer.
5. **Legal Matters:** Powers of Attorney and Advanced Statements. Presenter: Andy Paul, Alzheimer Scotland Welfare Rights Team.
6. **Planning Ahead:** Self Directed Support, Person Centred Planning and Workshops Follow Up. Presenters: Zara Buddy (Carer) and Facing Dementia Together staff.

## **Participants**

It was decided that a maximum of 16 participants would best facilitate group dynamics. Places were allocated to participants on a first come first served basis, from those people with dementia and their family members who had attended informal café drop-ins run by the project, or who had had one to one contact with project staff. In the end 17 people attended, because one person with dementia had two family members who each attended most of the sessions, neither of whom could be present for all the sessions.

Of the nine people with dementia, five were female and four male.  
All had Alzheimer's disease, vascular or mixed dementias.  
The age range was from 60yrs – 83yrs.

The eight family members included husbands, wives, siblings and adult children.

## **Venue and transport**

The workshops were held in Undercover in Barrhead, run by Voluntary Action, which provides a one stop shop for community organisations in East Renfrewshire.

This location was chosen as it was already familiar to many of the participants as the project café drop-ins take place here. It is a central location for both local authorities, with good accessible facilities, and incurred no venues costs.

It was decided that help with transport should be provided as the geographical area covered is large, with poor transport links across one of the local authorities. Additionally three people with dementia were intending to attend the workshops without family members and all three lived a significant distance from the venue. Staff provided transport for three people with dementia, who were attending alone via staff's own cars. A contract for transport was negotiated with the local RSVP service, which provided a bus and driver for seven people. .

## **Evaluation**

During the final workshop session an evaluation form was completed by participants, providing feedback on each individual session and on the series of workshops overall.

The series of workshops evaluated very highly.

13 of the 17 participants completed evaluation forms. Of these:

- 100% felt that overall the workshops were helpful
- 92% felt better informed about dementia
- 92% felt more knowledgeable about strategies and tips for coping with dementia
- 85% felt better informed about healthy lifestyles and relaxation
- 85% felt better informed about Powers of Attorney and advanced statements
- 50% felt better informed about planning ahead for future needs, 50% felt uncertain about this
- 100% felt they had received support from other people who attended

## **What aspects of the workshops worked well?**

When asked what the benefits were and what they had enjoyed the most, participants overwhelmingly identified the peer support aspect to the workshops:

**“Just knowing I was not alone”**

**“I liked the company and getting together with other people”**

**“Meeting other people and knowing that we are not alone”**

**“How other people cope with their dementia”**

**“It was helpful to talk to others caring for people with dementia to find out their experiences and tips for making things easier”**

**“It was good to be with other people who understand what it is to live with dementia”**

**“The chance to meet other carers, knowing that what you and the person who has been diagnosed are going through is not different from anyone else”**

Other aspects identified included:

**“It was fun, tailored to our needs”**

**“All arrangements were excellent”**

**“Attending the workshops was a very satisfying way to spend my time”**

**“The helpful and informative support from Michelle and Tracy”**

**“Information about symptoms of dementia, how it affects behaviour and the talks from people living with dementia about things that help them manage”**

**“Both speakers James and Shelia”**

**“Found the speakers of great interest”**

**“Catering spot on!”**

**“Transport, timing, information, baking to go with the coffee and the relaxed atmosphere – all great”**

From the perspective of Facing Dementia Together staff key aspects that worked well were:

- The presence of a volunteer to welcome everyone and provide informal support, particularly for people with dementia attending on their own.

- Assisting with transport no doubt contributed to excellent attendance, although this was time consuming and had costs attached.
- Both 1:1 contact and informal social opportunities, such as café drop-ins prior to the workshops were fundamental in building the confidence of potential participants, which then allowed them to feel able to sign up for and attend the workshops.
- This knowledge of participants arising from prior 1:1 contact was also particularly useful in tailoring sessions such as legal matters, to the needs of the group and increased the awareness of the facilitators of any particular support needs for individual participants.

### **What aspects of the workshops should be changed or improved?**

- It quickly became clear that for people with dementia attending on their own, additional support was required for implementing the course material into their lives. Consequently individual follow up sessions were carried out with those in this circumstance.
- These follow up sessions necessitated comprehensive recapping of the course content and working with the individual to find ways of trying out strategies and tips in their daily lives. The provision of accompanying written materials during the workshops did not appear to assist people attending on their own and in two out of three cases, contact was made with a family member to request some support/input with the strategies. In future workshops, due consideration will be given in advance to identifying an individual or systems to consolidate what has been learnt and ways of implementing this into daily life, for any people with dementia wishing to attend on their own.
- For those people with dementia attending on their own and who also lived on their own, the weekly workshops appeared to provide a positive structured routine. The ending of the workshops created both a sense of loss regarding socialising opportunity and purposeful activity. Support regarding this was provided in the individual follow up sessions and person centred planning sessions have been organised, in part to identify possible alternative purposeful and meaningful activities. Again, in the future due consideration will be given in advance to supporting individuals with this.
- Follow up sessions were also carried out where people had missed a session due to prior commitments.
- Evaluation of the final future planning workshop was not as positive as other sessions. From the facilitators point of view the participants seemed to gain a good understanding of self directed support from the invited carer. They identified this as something that might be of use to them in the future. The

facilitators felt that demonstrating the process of use of the person centred planning tool, PATH didn't work as well. The PATH was being used to help the group think about what, if anything they wanted to happen as a group after the workshops had ended. This process appeared to be difficult for participants because thinking about the future brought up anxieties and worries about the group ending. Staff reflections are that participants seemed to struggle doing this as a group. It may be that participants would be able to better engage in this process on an individual basis. The facilitators felt that this will also require individual follow up sessions for those who want to plan in more detail for their future support needs. The content of this session needs to be changed for a second delivery with a new cohort of participants. The facilitators felt that this will also require individual follow up sessions for those who want to plan in more detail for their future support needs.

- Only one person with dementia chose not to complete the series of workshops. It would be useful to gather feedback on the reasons for this. However attempts to arrange a follow up meeting have so far been unsuccessful. An evaluation form was also sent out for completion but the participant chose not to complete it.

## **Follow Up**

In the final session the person centred planning tool PATH was used to facilitate the group deciding what, if anything, they want as follow up to the series.

The group agreed that they wanted to continue meeting on a regular basis and the PATH was used to explore the potential format, purpose, location and support required for future meetings. The first follow up meeting was arranged for November, 2010. At this meeting it was agreed that participants would like to have monthly meetings, one of them being a very informal café like the current café drop-in provided by the project, and the other a more structured meeting with invited speakers. Participants agreed that staff would be needed to facilitate the cafés in addition to arranging speakers, venues and sending out dates etc. It was felt that transport would be required for people with dementia attending on their own, and for those with additional support needs or for whom there were no easy public transport links. In response to this, and increased numbers attending the drop-in café, as of February 2011, the frequency of cafés was increased from one to three per month. There is now a monthly café held in Paisley, a monthly café held in Giffnock and the monthly café held in Barrhead has a programme of invited speakers.

## **Series 2**

The second series of workshops started in late November 2010. After two sessions the workshops were postponed due to adverse weather and recommenced in January 2011.

## Preparation

As the first series of workshops evaluated very highly, the same structure and a similar content was used for sessions with the second cohort of participants. However, as the final future planning workshop had not evaluated so positively, a number of modifications were made. The content of this session was divided into two separate workshops, the first focusing on self directed support and the second focusing on person centred planning tools. It was also decided to cover these workshops earlier in the programme so that the series could end on the very inspiring “Living positively with Dementia” session. The healthy lifestyle workshop was not included in the second series in order to maintain only six sessions. The final programme was:

1. **Introduction to the Workshops.** Getting to know each other. What questions do you have about dementia? Presenters: Facing Dementia Together staff.
2. **What is Dementia?** (Tailored to needs of participants as discussed in Workshop 1) Presenters: Facing Dementia Together staff.
3. **Legal Matters:** Powers of Attorney and Advanced Statements. Presenter: Andy Paul, Alzheimer Scotland Welfare Rights Team.
4. **Planning Ahead:** Traditional Services and Self Directed Support. Presenters: Zara Buddy (Carer) and Facing Dementia Together staff.
5. **Planning Ahead:** Person Centred Planning Tools. Presenters: Jenny Douglas, Scottish Dementia Working Group and Facing Dementia Together staff.
6. **Living Positively with Dementia:** Shared experiences and practical strategies for coping. Presenter: James McKillop, Scottish Dementia Working Group.

## Venue and transport

The venue and assistance with transport arrangement were kept the same. With the second cohort of participants only one person with dementia and one couple required transport and this was provided by staff’s own cars.

## Participants

The second series of workshops was attended by six people with dementia and seven family members. Attendance was again consistent bar one incidence of ill health.

Of the six people with dementia, four were male and two female. All had either Alzheimer’s disease, vascular or mixed dementias. The age range was 58yrs – 82yrs.

Family members included husband, wives and adult children.

## **Evaluation**

Evaluation forms were completed in the final workshop session by all 13 participants. Once again the series of workshops evaluated very highly. The results were:

100% felt that overall the workshops were helpful

100% felt better informed about dementia

80% felt better informed about Powers of Attorney and advanced statements

85% felt better informed about planning ahead

100% felt more knowledgeable about strategies and tips for coping with dementia

92% felt they had received support from other people who had attended.

## **What aspects of the workshops worked well?**

The participants again identified the peer support aspect to the workshops as being fundamentally important:

**“I realise that we are not alone”**

**“Being around people going through the same things and problems as myself and being able to talk about my thoughts and concerns”**

**“That I was not alone and that I had help from other people who treated me as a normal person”**

**“Making new friends”**

Other benefits identified and comments made:

**“Realising I need to allow my wife to do more for herself and not to wrap her in cotton wool”**

**“I liked the opportunity to divide into separate groups and allow both those affected by dementia and family members to talk openly. Thanks for all your support and help”**

**“I felt I was able to cope better knowing that I had someone to contact if I had any problems”**

**“The workshops were excellent and everyone was so helpful”**

**“Being able to work on understanding dementia and doing that through the workshops as a family”**

## **Staff reflections**

The key positive aspects identified by staff after the first series of workshops held true for the second cohort of participants. Likewise it was true regarding the issues raised for people with dementia attending on their own and individual follow up sessions occurred as the series progressed to assist with implementation of strategies and tips.

Overwhelmingly the main benefit described by those attending was feeling that they were not alone.

For those people with dementia attending with a family member, a positive benefit seemed to be in relation to understanding each other's perspective. As a family or a couple, people were able to understand and learn more about dementia together and this seemed to assist in both adapting behaviours and implementing new strategies in daily life.

The two planning sessions for the future were evaluated more highly by the second cohort. In this series the process of using the person centred planning tool PATH was demonstrated completely by staff and not focused on the group. This appeared to work better and generally participants seemed more positive and receptive to using this planning tool. However, during the four subsequent weeks since the end of the second series of workshops, there has not been an increase in requests by individuals or families to be involved in a PATH for themselves. This may be due to participants continuing to see planning ahead as a future rather than present need and staff believe that dedicated individual follow up sessions will again be required to pursue this.

Staff noted that a particularly meaningful change to the second series was the decision to end with the "Living Positively with Dementia" workshop. Both cohorts of participants have remarked on the inspirational nature of this session delivered by James McKillop and appeared to bring the second series of workshops to an end on a hopeful and optimistic note.

### Series 3

The third series of workshops was held in February and March 2011.

#### Preparation

As the first and second series of workshops evaluated very highly, the same structure and a similar content was used for sessions with the third cohort of participants. However, due to time commitments relating to the original end of project funding in March, the number of sessions was reduced to five. The final programme was:

1. **Introduction to the Workshops.** Getting to know each other. What questions do you have about dementia? Presenters: Facing Dementia Together staff.
2. **What is Dementia?** (Tailored to needs of participants as discussed in Workshop 1) Presenters: Facing Dementia Together staff.
3. **Planning Ahead:** Traditional Services and Self Directed Support. Presenters: Zara Buddy (Carer) and Facing Dementia Together staff.
4. **Legal Matters:** Powers of Attorney and Advanced Statements. Presenter: Andy Paul, Alzheimer Scotland Welfare Rights Team.

5. **Living Positively with Dementia:** Shared experiences and practical strategies for coping. Presenters: James McKillop, Scottish Dementia Working Group and Maureen McKillop.

## **Venue and transport**

The venue and assistance with transport arrangement were kept the same. With the third cohort of participants only one couple required transport and this was initially provided by taxi, but assistance was then offered by other group members.

## **Participants**

The third series of workshops was attended by four people with dementia and four family members. Attendance was consistent by three of the couples. However, one couple attended only one session, due to their own personal circumstances.

Of the four people with dementia, three were male and one female.

All had either Alzheimer's disease, vascular or mixed dementias.

The age range was 59yrs – 80yrs.

Family members included husband and wives.

## **Evaluation**

Evaluation forms were completed in the final workshop session by six of the eight participants. Once again the series of workshops evaluated very highly. The results were:

100% felt that overall the workshops were helpful

100% felt better informed about dementia

100% felt better informed about welfare benefits, Powers of Attorney and advanced statements

100% felt better informed about services, supports and planning ahead

100% felt more knowledgeable about strategies and tips for coping with dementia

100% felt they had received support from other people who had attended.

## **What aspects of the workshops worked well?**

As with the first two series, the participants identified the peer support aspect to the workshops as being fundamentally important:

**“Sense of not being alone, feeling we could call on help if needed”**

**“Not alone and appreciate me being one of the group”**

**“Meeting other people in similar situations”**

**“Meeting other people with dementia”**

**“I found it beneficial to discuss situations with other people”**

Other benefits identified and comments made:

**“All the talks and the socialising”**

**“More information about dementia, benefits and help at home”**

**“Well run and treated as individuals”**

**“Tracy and Michelle could not have been more helpful with information and advice”**

### **Staff reflections**

The key positive aspects identified by staff after the first two series of workshops held true for the third cohort of participants. Once again, the main benefit described by those attending was feeling that they were not alone. The evaluation of each of the series of workshops was increasingly positive and it would appear that the core content has now been refined to a high standard. Staff would propose that professionals supporting people with an early diagnosis of dementia should look at running education and self management workshops that include the person with the diagnosis and significant others in their lives, but most importantly which create the opportunity for peer support.

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