

Oxfordshire Dementia Friendly Communities – what works and what doesn't

A project report

May 2015



(Clanfield Cares 2014)

Introduction by Healthwatch Oxfordshire

Healthwatch Oxfordshire is an independent organisation, established under the Health and Care Act 2012. Like Healthwatch organisations all over England, it exists to find out about people's experiences of publicly funded health and social care, and to use that information to bring about improvements to these services in its local area. It gives the people of Oxfordshire a powerful voice in shaping decisions affecting vital services.

Healthwatch Oxfordshire sets aside £25,000 a year to fund projects which enable community groups and community based organisations to undertake small scale service evaluation projects with particular groups of services users. The aim of these studies is to gather intelligence about people's experience of care, particularly from seldom heard groups, and to produce reports which shed light on those users' experiences of services. Where appropriate, these reports contain recommendations from participants, or from the report authors, about how such services might be improved. They are also a means to celebrate examples of excellent care.

The views and opinions expressed in this report are those of the participants in the study, and of Oxfordshire Rural Community Council. Healthwatch Oxfordshire will ensure that local providers and commissioners receive the report, and that they are alerted to the recommendations this group has made, and to the experiences the project participants describe. We will also follow up with those commissioners and providers on a regular basis, over time, in order to see what changes they make as a result. Finally we will report to the report authors, through our website and via the local media on actions taken by providers and commissioners to deliver the report's recommendations. Where necessary, we will also highlight that no action has been taken, in order to continue to try and improve the efficiency and effectiveness of local services for local people.

Rachel Coney – Chief Executive



Contents

Executive Summary	3
Introduction and Methodology	5
Findings and Discussion	9
Conclusion	26
Appendix 1	Social Prescribing
Appendix 2	Survey Questions

Executive Summary

There are approximately 5,000 people with dementia in the county and this number is set to increase significantly. Both primary and secondary care agencies are concerned about improving timely diagnosis (currently at 54% - below the end of year target of 60%) and there is an ever increasing need to find better ways of supporting people living with dementia at home. Dementia is also associated with delayed discharge from hospital, a problem the Oxfordshire Clinical Commissioning Group (OCCG) is very keen to reduce.

As part of the Prime Minister's Dementia Challenge Fund, Oxfordshire Rural Community Council (ORCC) managed a 1 year pilot project (Dementia Friendly Communities, which will now be referred to as DFC) in 2013-14. The project involved training nearly 900 people in 58 community and workplace settings. By the end of the project 21 DFC groups had made action plans on how to support their communities.

Following on from the 1 year pilot project, this grant from Healthwatch Oxfordshire enabled us to get in touch with the existing DFC communities to capture their views of what worked and what did not during and after the lifetime of the project.

The project showed that, of the groups involved in this project, over 25% of respondents said the training and actions undertaken had made a difference for people with dementia and their carers by normalising the characteristics of living with dementia within the community. Respondents were however clear that ongoing support was needed for their groups to be sustained; 75% of respondents in groups said they would appreciate the support of a community development worker and the help of specialist dementia services.

To ensure community support groups, such as DFCs, can (a) be sustained over time and (b) help people with dementia and their carers feel actively supported by their communities, we have made 4 key recommendations.

RECOMMENDATIONS

1. Oxfordshire health and social care commissioners should **commission community development work** (such as the work carried out by ORCC and partners) and provide funding to provide support to develop DFC support groups, and to help them access training, cover incidental costs and recruit new members. The work of DFC groups and other dementia friendly community activities can make a major contribution to helping people with dementia live well at home.
2. **A debate on, and an increase in social prescribing** (see Appendix 1) should be initiated with all GPs. Some initial steps have been taken, but more needs to be done by OCCG and GP Federations to debate how social prescribing can be increased as a means to help improve outcomes for people diagnosed with dementia. OCCG and NHS England should consider funding a targeted trial of social prescribing in one locality, with the practical support of ORCC or Age UK Oxfordshire.
3. There should be a **nominated person in each GP** who takes the lead, and is responsible for, building relationships and links between the practice and the DFC support groups and other community support groups available in the catchment area.
4. Formal **referral systems** between local GP practices and local community support groups should be developed. A formal referral system would ensure community support for dementia patients is properly linked into the full range of dementia services provided by the County Council and NHS. The roles of those involved in providing these services should be clarified and communicated widely. The role the Dementia Advisor plays in the system should be crucial. We have created a model (see page 5) as a starting point to suggest where DFC groups and other community support should sit.

Oxfordshire's New Dementia Support Service 2015

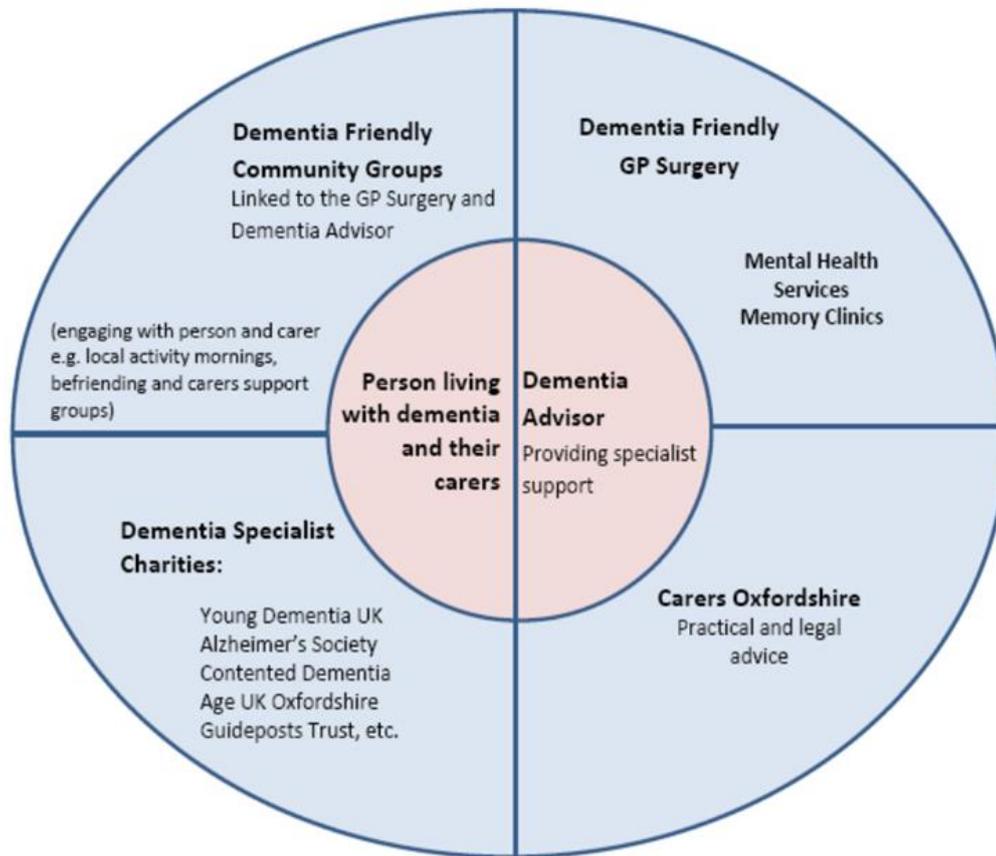


Fig 1. ORCC model for DFC 'community support' as part of the Oxfordshire dementia service

1. Introduction and Methodology

1.1 Between June 2013 and June 2014, 891 people in Oxfordshire took part in specially created training in dementia awareness to enable them to develop dementia friendly communities. Motivated by family needs, community spirit and simple curiosity, they turned out to village halls and workplace meetings to find out more about dementia and to meet to new and old friends. By the end of the project, there were 58 community and workplace groups established and 21 groups had either created dementia action plans or were working on what their next steps should be.

1.2 The external evaluation of the project in 2014 by the Institute for Public Care (IPC) at Oxford Brookes University, concluded that

“Overall the project appears to have been successful in meeting its objectives and contributing to more dementia friendly communities in Oxfordshire, as defined by the interviewees, with greater awareness and understanding of dementia, and a more proactive approach to supporting people with dementia and their carers”.

IPC noted however *“in the longer term, there may be concerns about how to maintain the momentum of the project in order to ensure its longer term sustainability.”*

This report was commissioned to see what had happened to the groups in the 18 months since the project commenced, and to produce recommendations about what the sector as a whole can do, in the long term, to meet the needs of people with dementia and their carers in a sustainable way.

Methodology

1.3 The project consisted of:

- mapping the DFC groups and individuals that currently exist in the county and involving them in this evaluation project.
- administering a 'What works' DFC survey for dementia-focused organisations who were members of the Oxfordshire Dementia Action Alliance (ODAA).

- holding focus groups around the County and inviting representatives from existing DFC groups.
- carrying out an online survey using Survey-Monkey with community members unable to attend the focus groups.
- carrying out telephone interviews for people not wanting to attend focus group meetings.
- collating quantitative and qualitative data along with additional relevant research work.

1.4 ORCC identified people from the 58 groups who had agreed to be consulted. ORCC sent a link to an online survey to 97 email contactable members. 28 of the 97 individuals contacted responded to the surveys which was a return of 28.8%. The project worker rang 87 members who could be contacted by phone. 32 of these were interviewed either at home or on the phone. A modified version of the questionnaire was used in face to face and telephone interviews. 32 people were interviewed between February and April. All respondents were promised anonymity so they could be candid in their responses. The survey questions in the survey are in Appendix 2.

1.5 Data from these **60** individual respondents was analysed together. In addition, it was agreed to survey the organisations in the Oxfordshire Dementia Action Alliance. A separate online survey was developed for them. This was sent to 6 dementia support focused organisations, of which 5 organisations responded. Data from these **5** organisational respondents was analysed and is included in the report.

Design of Online Surveys

1.6 The online survey was developed through SurveyMonkey with an advisory group of Dementia Friendly Communities members. The final version comprised 41 questions grouped around four major areas: the experience of setting up and maintaining a group and any future plans for the group; the relationship with the Oxfordshire dementia pathway, whether through contact with a doctor's surgery or with outreach workers from Age UK Oxfordshire, Carers Oxfordshire to Alzheimer Society support

workers; the perceived value of the dementia awareness training; and the subsequent activities in the community.

1.7 The original version was amended after feedback revealed that the first questions about the group were off-putting to those members contacted who had not become part of a continuing group. In the second version, an electronic filter in SurveyMonkey allowed people to skip these questions. Data from these two versions have been treated as identical.

1.8 A second online survey with 7 open ended questions was designed and sent to members of the Oxfordshire Dementia Action Alliance and 5 responses were returned.

Focus Groups

1.9 Six focus groups were originally planned but only 3 took place because there were too few people willing to travel, preferring to be interviewed by phone. The three were held in Witney (4/3/15), Tadmarton (11/3/15) and Long Wittenham (26/3/15). **20** people took part in total. Each meeting lasted two hours and focused on three themes: how the group was set up, maintained and sustained; what relationship or links the group had to other professional dementia services, in particular to local doctors, and what types of activities had they undertaken to promote a dementia friendly community.

1.10 As part of the original Dementia Friendly Communities project funds, we set aside a small pot of funds to support ongoing DFC groups and their activities. We were able to offer, at the time of contacting them with this project, a grant of up to £300 to be used to support their DFC activities. In addition, the Oxfordshire Skills and Learning Service, one of the DFC project partners, offered free First Aid classes to all DFC groups as part of the original DFC support package. The sessions were recorded and analysed by the project worker. Selected quotations from these respondents

have been transcribed where they illustrate points raised. The anonymity of individual contributors is preserved.

Representation of DFC Groups

1.11 Nineteen dementia friendly community groups are represented by respondents in this report. 61% (11) had formed into Active groups, 11% (3) were No Longer Active, and 28% (5) had Never become Active.

CAVEATS

1.12 The numbers participating in this project were small, only 80 or so individuals, but they each gave a lot of time in the interviews – up to an hour - and their responses were often very detailed. In reporting the results there were some overlaps in people who had both completed the online survey and came to a focus group or had been interviewed. A third of the surveys were partially completed.

1.13 We have used both percentages (where there has been over 50% in responses) and frequency numbers (where there is a small number of responses) to represent the qualitative data collected. Where a theme has emerged from the qualitative data and is shared by three or more respondents we have treated it as a finding. We have written up three illustrative case studies and anonymised these.

2. Findings and Discussion

2.1 The findings from this project can be set under two main sub-headings: links with professional dementia services; and successfully setting up and maintaining a DFC (community support) group.

Links with professional dementia services

2.2 As the need for integrated approaches to support people with dementia and their carers grows, there is increased focus on the role of GP surgeries. GP surgeries are a central hub and first point of call for people with dementia, their carers and their families. As there are few drug treatments and medical interventions presently on offer, the feedback we have received suggests that GPs would find it helpful to understand more fully the role of community support and activity (social prescribing) as an additional way to help an individual function more effectively while living at home. One example of supporting people with dementia is through active social and creative (singing, art and drama) therapies. In some areas of mental health, the concept of social prescribing has been developed to reduce loneliness, depression and isolation. For this to work, the doctor needs to value, and be aware of the, social activities available in the local area and to link people up with them.

2.3 Respondents in the survey and focus groups were asked about their experiences with GP surgeries and other dementia health services;

What links are there between your group and the local GPs surgery? (Q 10)

“Some of us said what about GPs? But there are none in this village so we don’t have any links.”

How could it work?(Q 13)

“GPs could steer people towards a group that might be helpful towards them.”

“ We could say we are concerned about x – we don’t know what surgery they belong to.”

Of the 11 active groups 6 had not made any attempt to make a link with the local GP. 2 respondents did not know if links had been attempted or not, and 3 had made unsuccessful attempts.

“We tried to make some links but haven’t succeeded”

A member of one group had made a personal contact with a GP who was prepared to tell suitable individuals, mainly family carers, about the group in the village.

‘Community Support’ CASE STUDY

Taking on Ada on the Farm

Ada is 107 years old. No-one knows for sure. She had been a widow since 1974. What used to happen is that you’d visit her and find she hadn’t got up. We rescued her three times. In 1994 we decided to keep her here at the farm. She agreed to stay. She has no children. We’ve given her a family.

We have created an annexe for her. We feel more people could be supportive of single people in their community but they say “we need a life too”. People are very selfish. I am horrified when I hear about nursing homes. We have always had an old person living with us. My children will do the same.

Some people who visit here are frightened of her and don't know what to say. We say let her talk. People get uncomfortable after five minutes. They are having to shout all the time. But she appears bright.

About four months ago a nurse was called out to Ada. We are not related but I am her carer. The GP called to speak to us as Betty is very deaf. I think the GP should visit someone in their own home. Well, months ago he said "I'll call round one day" and he hasn't done so yet.

The training was very useful. It has helped me to be more patient and understanding. Not to get overtired. I share the care with my husband and son. We have a routine with this lady so she is comfortable and relaxed. She loves the animals on the farm.

You can come and look at the set up if you want.

The 3 groups who had made an effort to contact their GP felt they had been rebuffed by gatekeepers such as Practice Managers or Receptionists.

“I did get some dementia booklets and offered a sample of one to the practice managers and one of the doctors and no one came back to me,”

2.4 We have taken from these findings that a more open and responsive link with the GP, and other dementia related health services is needed to better utilise the community support (DFC group) on offer.

2.5 In the DFC training, information about who to contact for help and advice was given and copies of the Guideposts Trust publication of Oxfordshire Dementia services were distributed. Nevertheless, 12 people said that it would be good to know where to go if they came across someone who needed more help than they felt they could offer informally. Oxfordshire County Council Joint Commissioning employs 7 Dementia Advisers to give Information Prescriptions (providing relevant information of organisations and groups available) to people newly diagnosed with dementia. Across the County their roles overlap with Support Workers from the Alzheimer’s Society and Outreach workers from local voluntary agencies such as Carers Oxfordshire and Age UK Oxfordshire.

I did contact a (named) Community Dementia Adviser and (named) Alzheimer Support Worker to help with a specific problem. They were a bit elusive and I had a lot of answer phones. There was a slow response which when it came was at a point which it was not needed. I thought they were probably inundated with work.

I don’t have a telephone line to call in a crisis (when the researcher suggested the Dementia Helpline the respondent said that they thought the response would not be timely.)

2.6 However, one year on from the training, only 25% of the respondents had heard of the Dementia Advisers and did not know exactly who they were or how to reach them. A slightly larger number 28% knew who their local Alzheimer’s Society Support Worker was. In one group the local Alzheimer’s Support Worker was a member of the group in a personal capacity. These respondents also knew who their local Age UK support worker was. The

single respondent who knew their Community Dementia Advisor, local Alzheimer Society Support Worker and Community Psychiatric Nurse was a paid coordinator for volunteers and had done the training but did not now belong to a group themselves. 58% of the respondents had heard of the Dementia Friends initiative by the Alzheimer's Society. 2 respondents were Alzheimer's Society Dementia Friends before the training.

2.7 When respondents were asked how they thought such a link might work they were unclear.

“Unsure. It could be a positive link to and from the GPs to our group as both are essential to the client and carers well being. A referral to the group from the doctor might make it easier for the client and the carers to seek help from our group.”

2.8 When the ODAA members were asked how the volunteers could develop trusted links with doctors, Community Dementia Advisers and local health professionals, they were more positive.

“80% of support for people with dementia comes from family, friends and neighbours. They are the most important network. Perhaps professionals should start by a recognition of this - (they) should include the wider network.”

2.9 Several individuals expressed concern about being seen as interfering by referring people into the health system.

How to support a person in a community without being intrusive “without taking over peoples lives” or being “bossy neighbours”. What are the boundaries? How far to go?

CASE STUDY

Belinda's dilemma

Belinda (not her own name) is a well-known member of her church who came to all three dementia awareness training sessions. She is not part of her village DFC group although it is active. She organises the delivery of the church magazine. Someone reported to her a person in a house in the village who "got into a terrible state". The woman couldn't open the door to the deliverer. The deliverer of the church magazine was upset.

She told Belinda she didn't know very much about this woman but she thought of Belinda as someone who might know what to do next. Belinda found out from a neighbour that the woman in the house used to be a teacher but she "started wandering". The neighbour said that the police returned her to her house. She is locked in during the day by her husband. She goes to a Day Centre. The person who comes to collect her for the Day Centre has a key.

How should Belinda assess this information? What should she, a caring person, do with this knowledge, if anything? She does not want to be seen as interfering but she is worried about the safety and well-being of this woman. Who can she talk to about this in the dementia pathway who might be trusted to manage the situation discreetly, sympathetically and non-intrusively?

2.10 The findings in this section suggest that, one year on, most groups and individuals felt they were "on their own" as far as referring people to the information and advice services currently provided by the health, social and voluntary organisations. This was the view despite the promotion the Dementia Web Oxfordshire website, which holds information on key contacts and some activities. This suggests that firstly, better integration of dementia services is needed and, secondly, DFC groups, part of a wider network of community support activities needs to be supported financially and through community development support in order to become part of the dementia service model (as suggested in the recommendations made).

Successfully setting up and maintaining a DFC (community support) group

2.11 The key findings from the survey responses and focus group discussions found that a successful DFC group needed to be (a) supported and linked in to other dementia services, (b) have better links with GP surgeries and (c) be better connected to community development support. Another key finding is that the most successful groups moved away

from defining the group with the word 'dementia' and used 'good neighbour group' or 'care/support group'. This seemed to increase the accessibility of these support groups to all community members regardless of their health needs.

The findings in detail are set out below.

How the groups were set up, maintained and sustained over the 18 months from the original training?

2.12 There was no blueprint for a successful group. Each group was invited to find its own way forward after the training had brought the individuals together. Different groups had differing ideas about their aims and purpose. Three key approaches were evident in the responses: Some groups (4) wanted to provide regular get-togethers for people with dementia or carers or both, such as coffee mornings; some groups (7) wanted to provide a source of education and awareness raising ; (5) other groups saw their aim to seek ways to make their existing village activities more inclusive.

Naming of groups?

2.13 There were 11 active groups in the 19 represented. 22% of respondents said their training did not result in a group at all, a further 8% of respondents knew there was a group but didn't know its name.

One respondent said

"we did not realise we were going to be asked to form a group"

"(we) never got going, as we did not have official backing, no funds"

One group resisted the notion of a group

"(we are) not really a specific group but a "coming together" of interested folk"

One respondent of a group that did not form felt there were different needs within the training group and these were met in different ways. All of them shared a drive to learn but they didn't see how their experiences and approaches would involve a shared activity.

One workplace group said that they did not form a group but

“It was also nice to realise so many other people in my workplace had similar family situations”

“Thank you for running the dementia awareness sessions in my workplace- it made it very easy to attend”

2.14 Of those 11, 8 had given themselves a name: only 3 used the word “dementia” in their name, although 46% of respondents said they did not have a problem about using the word dementia. Two groups use memory problems to describe the condition.

“We found our name of 'Good Neighbour Group' was more friendly and more welcoming of dementia clients and their carers, many of which are intimidated by terms like 'dementia' or 'memory problems', especially for those who are recently diagnosed. We advertise or invite the required people (mostly known by members of the group) to an afternoon tea which allows for smaller support groups at these meetings. We try to incorporate all in a comfortable, safe environment, trying to cope for different needs: some just want a tea and change of environment; or a listening ear or sharing with others in the same situation (clients or carers). In our initial meetings I found the carers felt uncomfortable talking about their role as a carer. They worried others would be judging them or that they would have to admit that they were not coping. I found this upsetting as we can only help to ease their burden by hearing their stories. We thus need to find other ways to help these people who suffer alone.

2.15 The discussion around the naming of the group and how to make it as inclusive as possible is clearly indicative of the blurred boundaries between being a good neighbour within an ageing population and being part of a group specifically focussed on dementia.

What do you understand by the term “dementia-friendly community”? (Q 26)

2.16 This blurred boundary between being a good neighbour and the specific focus on dementia was further demonstrated when the question of how do you understand the term “dementia friendly community”. There was quite a strong agreement about what a dementia

friendly community would look like: Key words were empathy, understanding, feel comfortable, feel welcomed, respect and dignity.

A community that is empathetic, caring and understanding of people that have dementia and their families and carers. A community that gives these people respect and dignity and recognises that they are a meaningful part of society

A community which is sympathetic to the condition and even if you don't realise there is a dementia you can pick up on the signs and become a more caring community.

"A community who appreciate that dementia is an illness and needs to be handled sensitively and with compassion"

Some definitions focused on practical actions:

*Shops and the general public having patience with people who have dementia.
People having contact numbers for carers*

A community where people with memory problems are able to comfortably live, shop, move around, etc.; where they can rely on folks in the community to help if they run into trouble

Group numbers and who was likely to become a member (Q 5 – 8)

2.17 7 groups out of the 11 Active groups had more than 6 regular members, 2 had 2 – 5. When asked to describe their role in the group: 5 said they were Active Members but did not have an organiser. 6 said they were an Organiser or a Key Volunteer assisting the Organiser. 4 respondents said they had organised the training in the first place but were not in a group now and one respondent described themselves as

"(an) interested villager wanting to know more about the subject, also with an interest in older people via the local [named] Church"

2.18 Participation in the survey corroborated another common finding around community volunteers. Those who participate in community action are often involved in more than one

local group. 36% were involved in 2 or more other local groups, 25% in 3 or more other groups. Only 15% of respondents said they had not been engaged in other local activity before this group. The range of these other groups was eclectic from organised lunch clubs to adult education such as University of the Third Age to community singing to conservation. For most, the dementia friendly communities group was seen as simply another community activity.

2.19 In addition there were some concerns about volunteers being given too much responsibility for providing services which should be provided by paid professionals. The sense that volunteers were being asked to take on more of the support services and at a level that was beyond their competence was reported in 20% of discussions. One respondent linked to a volunteer drivers group commented:

“stop surveys on volunteers, just get more skilled paid people to care for folk with dementia, properly”

This respondent reported that “

“we have wondered about this, but again, more being expected on volunteers, as a drivers group we have to drive, not give 1st aid, as a GNS group we help people to the shops or have a cuppa and a chat, not take the place with 1st aid training it's all a step towards liability of anything goes wrong, we are not covered to be the 6 emergency service as most volunteer work in (village name) is done by retired people”

These concerns should be taken into consideration when implementing the 4 key recommendations.

2.20 The busy lives of volunteers were also given as a reason one group did not emerge despite some initial motivation.

There were a few people who were keen to set up a group after the training but that didn't really follow through as the people who turned up to the training already did a lot of "helping" within the community and my view is that they felt (at the time) that

they had had enough of volunteering for this and that and didn't have enough time or energy to take on more commitment.

2.21 To further understand how local networking and members sharing might work, the Active groups themselves were asked if they were collaborating with any other local groups. The results were: church 50%, school 10%, village hall committee 30% Parish or town council 50%. One respondent said “*It’s a fairly small village and we know the groups*”. 50% of active groups said they shared members and shared notice-boards with other village institutions.

“These relationships are done as part of preparation, organisation or funding of the group and its activities.”

“We are in contact and have had conversations about specific activities. Received some funding from the community cinema group and some other groups.”

How could more people living with dementia be involved?

2.22 There is a powerful ethical drive to involve people living with dementia in the development of their services – “*nothing about us, without us*”. The Alzheimer’s Society Involvement work and the Rowntree Foundation DEEP project in Leeds have produced guidelines for good practice. The initial training was open to people with dementia and in at least four groups there were people who self-identified as having a diagnosis. There were probably many others in the groups who were worried about their memory and had come for reassurance and support. Involving people with dementia in the running of the groups was something which people were in principle very happy with but did not know how they could put into practice.

Unsure, but by aiming to incorporate more people living with dementia into the running of the community group can only improve their well-being. They long to be themselves as long as possible. Even in more severe cases, all clients, even when unable to articulate or remember, they all desire respect, love and patience. We need to provide this always.

One person thought it would be good to invite “*people with dementia to talk about their experiences [because] people like real stories*”.

2.23 All the groups were new – in that they came into existence after the project. Most people thought the training was a good way to found the group. There is clear evidence that the more active groups had an overlapping membership with other village groups and were in contact with two or more village institutions such as the church or parish council, and worked collaboratively on activities.

What was the value beyond the training sessions?

2.24 The majority of the village training was supplied by NewDementiaCare and some of the training was supplied by Guideposts Trust. Both groups were offered three sessions covering physical and emotional impact of the illness and approaches for caregivers to reduce stress, improve communication and sources of information. A second objective was to encourage the establishment of groups by creating an action plan. Groups wanting to make an action plan were offered an additional support session for this. None of the groups interviewed reported that they had used this option.

2.25 The 11 active groups in the survey had all held a meeting within two months of the end of the training to decide how to go forward. Groups that did not meet within this period seemed not to be active. One member said she was hoping to revive the group now, given the additional peer support.

2.26 Evaluations done at the end of the three training sessions showed a high satisfaction rate. Eighteen months on all the respondents valued the training highly on a personal basis. 40% felt it had had an impact on the community. 5% of respondents felt the training had not had any impact on stigma and fear in the community. 95% of respondents felt that media coverage had made talking about dementia more normal. This had the biggest impact in the last year on dementia awareness.

It was an excellent training which gave me the basics about handling dementia. I learned how a dementia sufferer struggles to cope with problems. I learned better

ways to engage them in conversation, to find out what they need/want and how to support them in a kind but reassuring way. Very worthwhile training!

2.27 Below are two further 'value' examples:

To Not Put My Foot In It!

One respondent summed up the value to her by reporting that she had more insight into the effect on people, more tools to use to communicate and have confidence in being with people with dementia.

I learnt how not to put my foot in it"

"It was useful in just knowing what help to offer. In the past I have shied away from offering help if it wasn't someone I knew that well. The training gave us tips for communicating more effectively which I thought was great!"

A Pebble in a Pond!

Talking with people unearthed many anecdotes about the reach of the training beyond the people in the room. People spoke of conversations passing on information and practical tips which had been valuable to others. 75% of respondents gave examples of training going beyond the group. One described the effect of the training as "a pebble in a pond" where the knowledge and skills rippled outwards.

"Those that went on the course are more savvy". If members of the (care) home next to the church wander into the village, people are very good at taking them in and resolving the problem."

CASE STUDY

Jim's headache

Jim works as an estate manager. His boss has undiagnosed dementia, but he and his wife manage it through avoiding both the name of the illness and refusing to acknowledge the severity of the symptoms. This causes Jim and his estate team a headache.

“I think we have to use the word dementia - if only the boss's wife would recognise it – we could all relax. She calls it memory loss. He drove through a red traffic light. She said – Oh Jim, we all drive through now and again”

Staff in the house have moved on so we don't know how they are coping now.

Before the training we didn't know what to do. He would make illogical decisions. For example, he asked us to remove trees we knew he had planned and planted. We had “major battles”. We didn't know if it was us or him. Many members of staff did not know what to think when they were getting contradictory instructions. When we obeyed him, and he saw the trees we had cut down, he was devastated. We were upset because he was upset but he could not remember giving the instruction.

Now we have shared the knowledge from the training and have changed our working practices. First, we are more patient, we go along with what he is saying, act more cautiously, considering the instruction in the light of what we know he had previously wanted. Secondly, we created a written plan, “coping strategy” with the involvement of the son. We have to manage the risk and safeguard our jobs. We teach new staff what to expect and how to manage him compassionately. He has lost some authority but we try to maintain his sense of autonomy

Jim and a colleague came to the training and have been passing on the skills to his team. He has not become part of the community group. He says he feels like the training was “a pebble in a pond”. The knowledge ripples out across the community.

People were asked to share examples of changed attitudes (Q 14,15)

2.28 Although 85% of respondents thought there had been a positive change in attitudes

(reduction in stigma and fear) only 40% of respondents added information:

I feel happier saying my mother has dementia because I have come across so many people my age who have had experience as a carer of someone with dementia

Community training has removed some fear of dementia. Media coverage and the talk thereof has hugely affected people's view of the disease as more normal. However, there is still great fear and stigma. Carers, especially family members,

have a big problem to admit that they are not coping and need help. They see such an admission as a judgement against themselves and a failure to their loved ones.

I think people realise that we have to face it...it is out there and affecting lots of very different people. I still think it's the beginning but at least people are more aware

What difference has a DFC group made?

2.29 We asked what difference had the group made. A quarter of respondents gave detailed answers to this question and felt that they had made a difference. Most seemed unable to decide if it had made a difference.

It is difficult to say. However, we have made a big difference to a set number of people, those living with dementia and their carers and families. It is probably a drop in the ocean in relationship to the bigger picture of this cruel disease. Every person we touch is still a major indentation into the problem. We offer love, attention, support, availability, understanding, non-judgement, friendship, a listening ear and a genuine will to enrich and improve their lives.

In this village dementia is no longer mentioned in hushed tones. It's a facet of people's lives that has to be coped with. "He's managing very well" is more widespread, people seem to have better understanding and a more practical approach. They are more sympathetic. It is a more acceptable state of affairs

Was your group a success? (Q 16,17,18,19)

2.30 45% of individuals answered this question cautiously. 25% felt their group was a success, a further 65% didn't know and 10% felt their groups were not a success. One of these described what has become an "email group" and not met up through lack of time and leadership. The person who responded was herself a full time carer who had wanted the information for her own needs initially.

We have not met as a group since the training though we know each other. We just did not follow this up as an idea for our group to do. I have an email distribution list of about a dozen people that I send interesting websites or emails to eg Dementia Awareness Public Open Day at JR Hospital in Oxford but we don't meet as a group. I organised the training but could not carry on because my (parent) needed me as a carer. I was not prepared to ask for donations for paying for a meeting place. Perhaps it would have worked. No one else would take it on.

Another respondent said that the group was too new to judge whether it was a success.
“Not long enough in existence yet to know”

2.31 The success factors included good leadership, friendships made quite quickly, and a shared vision. One respondent wrote

“(we had) A conviction and care of people with dementia and their carers, to enrich their lives and make their journey smoother and fulfilling.

2.32 When the groups were asked what would help the group to develop, an overwhelming 75% of the active groups said they would value the support of a community development worker. 75% would like the support of a specialist dementia worker to answer questions, 40% felt access to resources in the way of money would help, only 1 respondent thought access to a place to meet was important. 60% wanted more community members to get actively involved, 75% wanted more information on what other groups had done.

2.33 The findings from the discussion with DFC groups on how best to support their community work clearly shaped the 4 key recommendations made.

Action Planning (Q20)

2.34 Only about a third of the groups surveyed had drawn up an action plan. Some of these were informal ‘to do’ lists. Others were more formal frameworks with tasks, timeframes and people allocated to tasks which were then assessed and ticked off or moved onto the next month’s action plan. One person who relished setting up the action plan process explained they were *“trained in the military”*.

Activities

2.35 Social interaction and remaining part of one’s community are evidenced-based ways to reduce the negative impact of the symptoms of dementia. All the groups wanted more older people with memory problems to take part in regular inclusive events held within walking distance. They did not know how to attract this hard to reach group. In general, people did not wish to stigmatise the activities they promoted by attaching the word dementia to them. They felt it was a reductive term and off putting.

2.36 There were many examples of group members drawing on their own resources and skills to shape their contribution and to move the group towards a favourable end. Those who preferred running coffee mornings had often run similar activities previously.

2.37 10 of the 11 active groups had decided to set up Information Points. These were in post offices, village halls and churches. Several others said they had advertised a contact person and number for their group in the local newsletter or on a parish noticeboard.

We have set up an information point in [named butchers] in [the village] and have dementia leaflets there from Guideposts

4 groups were thinking about how to organise a regular place to meet for people with dementia and their carers.

There has been an expressed desire to have a memory cafe or some such in Charlbury. The nearest are in Chipping Norton or Witney.

A place for a person living with dementia to meet others. One day we will have a new Village Hall in Harwell that will include smaller meeting rooms where this could happen

One group is working on how to provide a local assistance and befriending service.

(carers) knowing where to go for help, able to safely recruit people to look after the person whilst you go out

Clanfield Cares was one of the most active groups, and a case study of the group is set out on the following page.

CASE STUDY

Clanfield Cares

Clanfield Cares – we liked the alliteration and although we don't have a problem using the word dementia, and we focus on dementia awareness raising, we wanted to feel and be inclusive of other people. We have a key volunteer and an organiser and a group of 4 of us who meet on the first Monday in the month at the Plough Hotel, Clanfield at 7.30. We work together on specific actions with other groups in the village.

First we met immediately after the last training session. Then we decided to keep meeting together. We set up an information point in the village.

In May 2014 working with the Alzheimer Society we organised and ran a Dementia Awareness Week. All the village organisations were notified and invited to take part. This resulted in two school assemblies in the primary school in two age groups; memory activities in the adult Art class; Toddlers Group; Women Institute meeting, and finally we ended on the Saturday with a Vintage Tea Party in the village hall with memory games, myth busting slogans and displays of memory boxes. A memory trail took place around the village. Money from donations (unsolicited) was given to the Alzheimer's Society. We had a display later in June with hand/eye coordination games, memory and dementia facts at the village fete.

Through the summer there was much conversation in the village about dementia. We had good publicity on a regular basis about the group and dementia in general. We had very proactive members willing to go into new situations/places such as the lunch club and school to talk about Clanfield Cares and its role in the community. We felt we needed more links with the GP and support services

Conclusion

Oxfordshire is one of the most rural counties in England. There are increasing numbers of people living in small villages who are developing dementia. The estimated 8,000 people living with dementia in the county is expected to increase by 20% over the next 6 years. Many of these people are at high risk of social isolation unless their communities rally round.

The report looked at what works and what does not work in developing new rural and urban based DFC community support groups. The groups that worked well demonstrated the creative efforts of neighbours in developing innovative local approaches for people with cognitive impairment in well-knit communities. Those groups with strong vision and leadership achieved more than those who were unclear about their aims or had no individual willing to assume the key responsibilities, and this is where community development organisations could offer support, if they were financially supported. The most positive aspect of the dementia awareness training was the personal changes in people's attitudes and their willingness to share their new knowledge with others. There was substantial evidence that there was a lack of communication between GPs, health professionals and volunteers in general.

It is likely that GPs will have a greater responsibility for diagnosis and management of the illness in the future. If this is the case, then it is crucial that GPs, and indeed the dementia support service as a whole, work closely with their patients and local community support groups. A formal referral system, as part of a process of social prescribing, could enable people with dementia and their families access to local community support and social activities.

The recommendations this report has provided will complement what is currently a heavily medically- focused model for dementia support.

ORCC

May 2015

Appendix 1

What do we mean by social prescribing?

“Social prescribing is a mechanism for linking patients with non-medical sources of support within the community. These might include opportunities for arts and creativity, physical activity, learning new skills, volunteering, mutual aid, befriending and self-help, as well as support with, for example, employment, benefits, housing, debt, legal advice, or parenting problems. Social prescribing is usually delivered via primary care – for example, through ‘exercise on prescription’ or ‘prescription for learning’, although there is a range of different models and referral options.

Social prescribing for mental health provides a framework for:

- developing alternative responses to mental distress;
- a wider recognition of the influence of social, economic and cultural factors on mental health outcomes across the whole spectrum of disorders; and
- improving access to mainstream services and opportunities for people with long-term mental health problems.”

The above extract is taken from the Care Services Improvement Programme (CSIP) and their report Social Prescribing for Mental Health – a guide to commissioning and delivery.

For further information please go to:

<http://www.centreforwelfarereform.org/uploads/attachment/339/social-prescribing-for-mental-health.pdf>

Appendix 2

A list of the survey questions asked during the research

Survey for DFC respondents

Thank you for agreeing to complete this survey.

This is a second version of the survey which has been improved after feedback. If you completed the first version, many thanks for your comments - you don't need to complete this one too!

You have been asked to take part because you came to a community group in your village in 2013-14 that received three free sessions of dementia awareness training. One aim of the project was to create self-sustaining informal dementia-friendly community groups. We hoped some of these groups would find ways to improve their local social and physical environment for people living with dementia and their families.

Some groups have kept going and have achieved some wonderful creative things. We want to hear about, celebrate and share these ideas.

Not all groups were able to keep going. However, these provide lessons which are essential to understanding what works and what doesn't.

There are 40 questions which should take around 20 minutes, if you wish to complete every one.

You may feel that some questions do not apply to you, so feel free to skip them.

We really appreciate any examples you can give us of concrete actions that came out of the training. We are as interested in how someone helped another in tiny but valuable ways. However, please do not identify anyone specifically within your responses.

At the end is a short three question evaluation of the survey itself.

If you would rather do the survey as a phone interview or face to face, then please get in touch with Catharine Arakelian on 07751 809271 to arrange a time to do this.

Off we go!

Q1

1. What is the name of your group?

- For various reasons, we didn't form a group
- Our group hasn't got a name
- There is a group here, but I don't know its name
- Our name is below

Please tell us the name of your group and add anything interesting about the process of

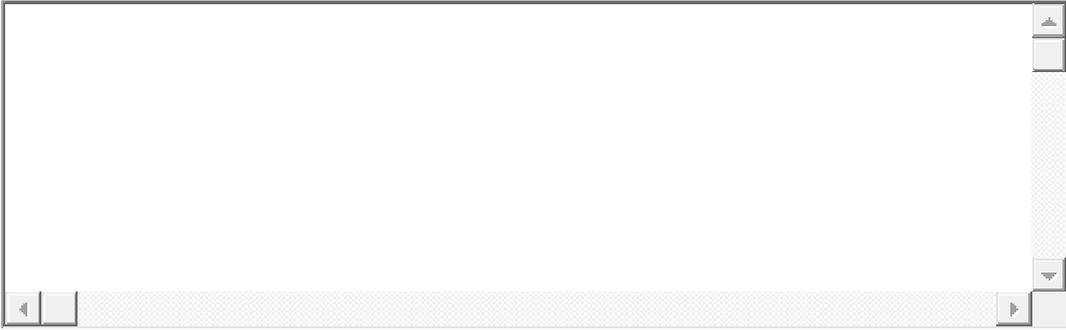
naming



2. How do you feel about having the word or not having the word "dementia" in your group's name?

- We don't have a problem using the word "dementia"
- We've discussed it but we think it's OK
- We fear it is off putting to the public
- We use "memory problems"

Other (please

specify) 

Q3

3. How many members are there in your group now?

- Just one
- Two to five
- Six or more

Other (please

specify) 

Q4

4. How regularly do you meet?

- We had just one more meeting after the training
- Once a week
- Once a month
- Less than once a month
- When we have something to discuss or organise

Other (please



specify)

Q5

5. How would you describe your role in the group?

- Organiser
- Key volunteer supporting the organiser
- Active member
- I attend as a community leader, such as vicar or GP
- I attend as an outreach worker for another organisation, such as Age UK or Alzheimers Society

Other (please

specify)



Q6

6. How many other organisations do you personally belong to in your community?

- None
- One
- Two
- Three or more

Please tell us about some of these groups



Q7

7. Is your group in contact with other local organisations?

- None
- Church group
- School group
- Village hall committee
- Parish or town council
- Charity or local voluntary organisation
- I don't know

Other (please



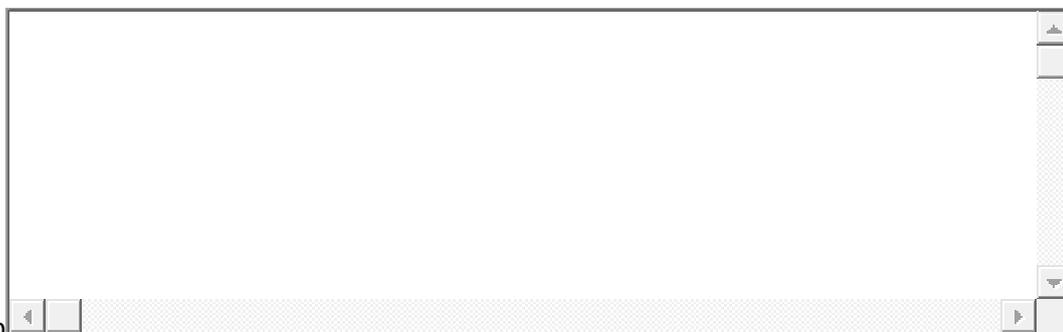
specify)

Q8

8. What sort of relationship does your group have with these organisations?

- We share members
- We have an informal information exchange, for example, share a noticeboard
- We hold irregular meetings
- We hold regular meetings
- We work together on specific actions

Please tell us more about the most fruitful



relationship

Q9. Is your group in touch with or known to your local dementia advisers or outreach workers?

- Yes, but I don't know who exactly
- No
- The Alzheimer Society support worker

- Age UK support worker
- Oxfordshire Community Dementia Adviser
- Community Nurse or other health worker

Other (please

specify)



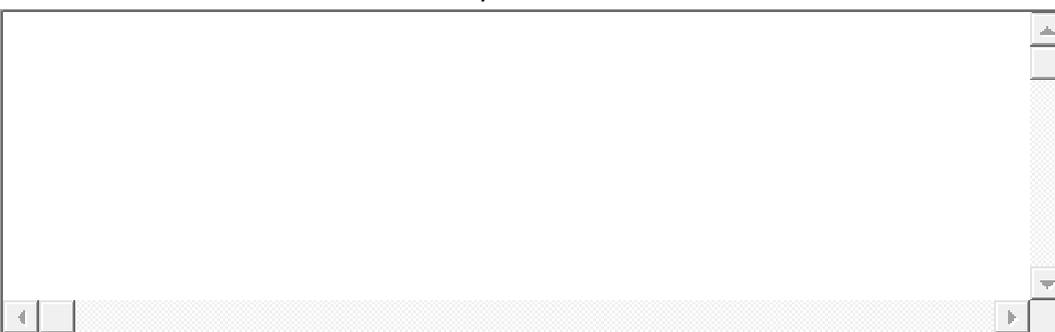
Q10

10. What links are there between your group and your GP surgery?

- None
- Yes, we have links
- We don't have any links yet but we are working on it
- We tried to make some links but haven't succeeded
- I don't know

Please describe the nature of the link or why it was hard to form a

link



Q11

11. If there are links, has the local GP or health professional referred people living with dementia or family carers of people with dementia to your group?

- Yes
- No
- Don't know

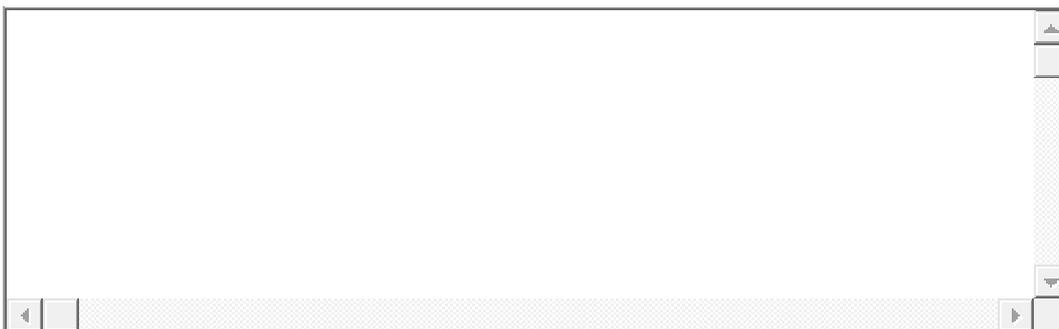
Q12

12. If there are links, has anyone in your group referred someone, a person living with dementia or a family carer, for example, to the local GP or health professional for help?

- yes
- No
- I don't know

Q13

13. How could this connection with the local GP work better for the group?



Q14

14. In your experience, has the social stigma and fear associated with dementia in your community changed in the last year?

- Yes
- No
- Don't know

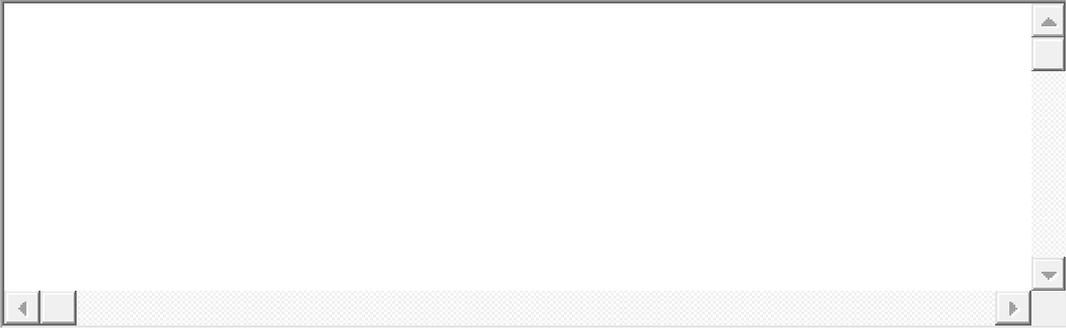
Q15

15. How do you explain this change?

- Training at community level has removed some fear of dementia
- Improved media coverage has made talking about the disease more normal
- There has been little change in social attitudes
- Fear and stigma has increased

Please tell us about an example of changed

attitudes



Q16

16. Would you say your group has been a success in your village?

- Yes
- No
- Don't know

Q17

17. If it wasn't a success, why do you think things didn't go right?

- We didn't have enough active members
- We lacked leadership
- We needed more expert follow-up support for an action plan
- We needed more resources - money
- We needed more resources - a place to meet

Other (please



specify)

Q18

18. If the group has been a success, what would you say was the secret of your success?

- We were already an established group before becoming the dementia-friendly community group
- We had the strong leadership of one or two people
- We were already friends or we quickly became friends
- We had a shared vision
- Our members had good knowledge and links within the community

Other (please



specify)

Q19. Who or what would help you develop your group?

- Support from a Community Development Worker
- Support from a Dementia Specialist for example, to answer questions
- Access to resources - money

- Access to resources - a place to meet
- More community members taking an active interest
- Information about what other groups have done

Other (please

specify)



20. Has your group drawn up an action plan?

- Yes
- No
- Don't know

21. What type of actions have been proposed?

- To keep meeting together
- To set up an information point in the village
- To organise a regular carers support group
- To organise a dementia café for people living with dementia
- To run an information stall at a coffee morning or fete

- To set up an informal neighbourhood befriending service

Please tell us about any specific activities you have carried

out



22. What community support do you think is still needed for a person living with dementia and their family in your area?



23. How could more people living with dementia be involved in the running of the community group?



24. What difference has the group made in the area?

25. What would you like to do next with the group?

My Experience of the Dementia Awareness Training

26. How many of the three dementia awareness training sessions did you attend?

- All three
- Two
- One
- None
- I had done awareness training previously

27. What difference did the dementia awareness training make to you?

28. What difference did the dementia awareness training make in your community?

29. What do you understand by the description "dementia-friendly community"?

30. Did the project reach enough of the people who were interested in becoming a dementia-friendly community?

Yes

No

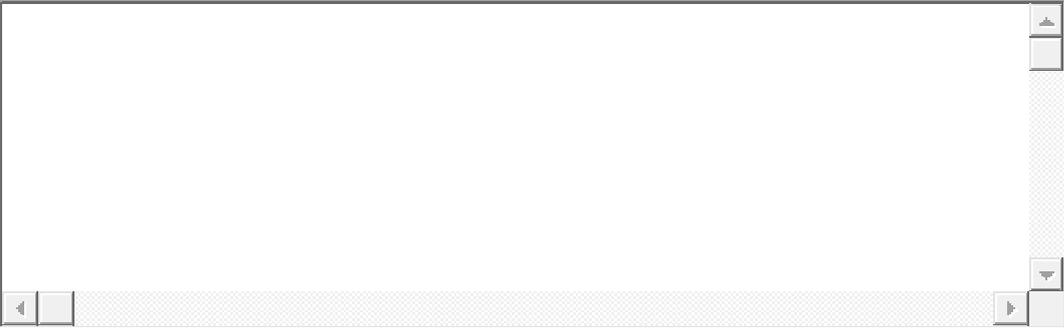
Other (please

specify) 

31. What else would you like to learn about?

- More about how to support people living with dementia
- More about how to support older neighbours
- Mental health and illness in the community
- Stroke
- Diabetes

Other (please

specify) 

32. Have you heard of the Alzheimer Society Dementia Friends initiative?

- Yes
- No
- I am an AS Dementia Friend
- I am an AS Dementia Champion

33. In the last year, have you helped a family member who is living with dementia in their own home?

Yes

No

34. In the last year, have you helped a person (not a family member) who might have memory problems in your community?

Yes

No

35. How do you feel if you come across a stranger clearly struggling with symptoms of dementia or memory loss in a street or shop?

I feel able to help them myself

I feel able to find help for them

I feel uncomfortable

I feel anxious

Other (please

specify)

36. Did the training help you signpost others to relevant information?

Yes

No

If you answered yes, please give some more details here if you can - without revealing the identities of the

people involved

37. Is there anything else you would like to add?



Grants For Future Activities and Free Training

Please complete the personal information only if you feel comfortable. It will be held securely and not used for any other purpose.

If you would rather not give personal data through the web, feel free to ring Catharine or Emily. Our contact information is below.

38. There are ten grants of up to £300 available to existing DFC groups to stimulate further activity. Would you like more information about them? Please give the name and email or phone contact number of the person who would like to receive the information.



39. There is free First Aid Training available to groups in Oxfordshire. Would you like more information about this? Please give the name and email or contact phone number of the person who would like to receive this information.



40. There are six meetings organised in March to encourage people who did the training last year to get together. We will hear about what their groups have done in the last year, and to share any lessons learnt. There will an opportunity to ask questions about dementia in the community. Whether your group has been active or not, please come and join us.

- Yes, I can attend the meeting in Witney at the High Street Methodists Church on Wednesday 4 March 10am - 12pm.
- Yes, I can attend the meeting in Harwell Village Hall on Friday 6 March 2 - 4pm.
- Yes, I can attend the meeting in Tadmarton Village Hall on Wednesday 11 March 10am - 12pm.
- Yes, I can attend the meeting in Long Wittenham Village Hall on Thursday 26 March from 2 - 4pm.
- Yes, I would like to attend the meeting in Goring Village Hall on Thursday 26 March from 10am - 12pm.
- I'm sorry, I cannot attend any of the meetings because they are not at the right time for me
- I'm sorry, I cannot attend any of the meetings because they are not in the right place for me
- I'm sorry, I don't want to attend any of the meetings.

Please give your name and email or contact number here. Your information will only be used in relation to the

DFC project.

41. Thank you for taking time to complete this survey. Please rate your experience so we can improve our surveys in the future.

	I completely agree	I agree	I'm not sure	I disagree	I completely disagree
The questions were clear	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
*Thank you for taking time to complete this survey. Please rate your	The questions were clear I agree	The questions were clear I'm not sure	The questions were clear I disagree	The questions were clear I completely disagree	

experience so we can improve our surveys in the future. The questions were clear I completely agree

The survey was the right length for me	<input type="radio"/> The survey was the right length for me I completely agree	<input type="radio"/> The survey was the right length for me I agree	<input type="radio"/> The survey was the right length for me I'm not sure	<input type="radio"/> The survey was the right length for me I disagree	<input type="radio"/> The survey was the right length for me I completely disagree
I was happy to be contacted for this survey	<input type="radio"/> I was happy to be contacted for this survey I completely agree	<input type="radio"/> I was happy to be contacted for this survey I agree	<input type="radio"/> I was happy to be contacted for this survey I'm not sure	<input type="radio"/> I was happy to be contacted for this survey I disagree	<input type="radio"/> I was happy to be contacted for this survey I completely disagree

How could we improve the

experience?

ORCC DFC RESEARCH PROJECT 2015: QUESTIONS for members of the ODAA

The Dementia Friendly Communities (DFC) Project in 2013-2014 created 58 community and workplace learning groups with basic training in dementia awareness. Our aim was to raise dementia awareness and create self-sustaining groups to initiate actions within the community to improve the social and physical environment for people with dementia in their community.

ORCC are now carrying out small research project, funded by Healthwatch Oxfordshire, to re-engage with the DFC community groups to find out what worked and what did not work with the DFC project and what they may need to support them to make their community dementia friendly (e.g. better links with GP Surgeries and the Dementia Advisors).

As part of our research we would like members of the ODAA, all of whom are experienced practitioners in the dementia field of work, to complete a brief survey to help us understand your views on the DFC project and where you see the support being most effective and sustainable within the (unwritten) dementia care pathway. Your feedback will help shape any future support for a DFC model.

1. What do you think are the differences between a community which is good at looking after the needs of its older members and a "dementia friendly" community (DFC)?
2. What do you think is important to your organisation of a DFC group existing in a community?
3. Are there actions that the DFC project could deliver which it does not currently address?
4. What forms of support are needed to help retain DFC volunteer work?
5. How could your organisation help more people living with dementia contribute to the development of the community group?
6. How should the DFC volunteers develop trusted links with the GPs, Dementia Advisors and local health professionals?
7. Overall, how do you see the work of these informal groups fitting into the existing dementia pathway in Oxfordshire?