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# Dementia Capable Communities

## The views of people with dementia and their supporters

February 2011

# Contents

# Executive Summary

People told us about the things which make the difference in a dementia-capable community:

- The physical environment
- Local facilities
- Support services
- Social networks
- Local groups

People told us that they kept in touch with their local communities:

- Through local groups
- Through the use of local facilities
- Through walking
- Through the use of support services

People told us they had stopped doing some things in their community because:

- Their dementia had progressed and they were worried about their ability to cope
- They were concerned that people didn't understand or know about dementia

People told us that they would like to be able to:

- Pursue hobbies and interests
- Simply "go out" more
- Make more use of local facilities
- Help others in their community by volunteering

People told us that 1-1 informal support was the key to helping them do these things.

People told us that communities could become more dementia-capable by:

- Increasing its awareness of dementia
- Support local groups for people with dementia and carers
- Provide more information, and more accessible information about local services and facilities
- Think about how local mainstream services and facilities can be made more accessible for people with dementia.

…and they told us that in order to do this:

- Communities need knowledgeable input, not least from people with dementia
- There needs to be continued media attention and public awareness campaigns
- Dementia needs to be “normalised”
- Communities need more funding for supporting people with dementia
- Communities should make better use of existing resources
- Organisations should work together more effectively

## Background

In late 2010, Innovations in Dementia (CIC) was commissioned by Claire Goodchild, National Programme Manager (Implementation) at the DH National Dementia Strategy Team to seek the views of people with dementia about the idea of Dementia Capable Communities in 3 settings: rural, small market town and an urban area. We were asked to focus on the social and cultural environment more than on the built environment.

We wanted to find out:

- What did the idea of a dementia capable community mean to them?
- What are the things that make for a good community for people with dementia?
- How can things be made better?

### What did we do?

We talked to people with dementia and their supporters at:

- A memory café – South Molton in a rural part of Devon
- At a drop-in service in Cranleigh – a small town
- At the EDUCATE group in Stockport – an urban area.

We carried out telephone interviews with two people with dementia and two carers

We did face-to-face interviews with a couple living with dementia.

We also wanted to see people out in their own communities. To help us with this people from the EDUCATE group kindly:

- Took us for a coffee in Sainsbury's
- Took us to their local library.
- Took us for a meal in the pub
- Took us to the gym

We also conducted an online survey, and 47 people responded.

In total we heard from:

- 24+ people with dementia
- 36+ supporters of people with dementia
- 26+ people who work or volunteer with people with dementia

The figures are presented as "+" because two of the responses to the online survey were filled out on behalf of memory cafes – we have no information about the numbers of people with dementia, supporters and professional involved.
We wanted to talk to people from different kinds of communities to get a feel for the differences between rural and urban areas, small towns and suburbs.

People described themselves as living in:

| | |
|---|---|
| Rural areas | 16 |
| Urban areas | 28 |
| Small towns | 25 |
| Suburbs | 15 |

## What is this report about?

This report is about what people with dementia and their supporters told us about their communities, and what it was like to live where they do.

It is about the obstacles that people face in staying connected to their communities, and the things that help and hinder them in doing so.

It is about what people think should happen in order to make our communities a place for everyone to live well.

## What is in the report?

The main body of this report looks at the responses we gathered to a range of questions about dementia-capable communities.

We have also included some ideas about dementia-capable communities from a meeting of memory café organisers in Devon.

Finally – there are accounts of the outings which members of EDUCATE organised for us – and which illustrate very vividly the challenges people with dementia face in their communities, and the spirit and determination with which they are tackling them.

## About the information in the report

We have tried as much as possible to let people's words speak for themselves, but we do try and tease out common themes

We decided not to list themes in order of incidence, though we do make occasional reference to "barn door" themes where they are un-missable. We made this decision as not only was there some degree of crossover and ambiguity in many of the responses, but we didn't want the reader to infer a rigorously quantitative methodology.

Conversations are reported verbatim, as in the case of written responses.

## About the people with dementia who responded

This is not a representative sample.

People with more advanced dementia are unlikely to have been heavily represented, if at all, in the responses we received.

It is likely that most of the people with dementia that responded were in the earlier stages of dementia – and their comments must be understood in that light.

## What makes my community a good place to live for people with dementia?

> *“This is town with a 'heart' - where the High St is the hub and where there is a community centre, health centre and day centre with regular events and services which are well-publicised”  (supporter from a small town)*

Things which make communities good places for people with dementia to live fell into 5 main categories, all of which were common across the different types of communities.

- The physical environment
- Local facilities
- Support services
- Social networks
- Local groups

**The physical environment**

The importance of being outdoors was a strong theme, with parks and communal areas being of particular importance:

> *“somewhere you can see life going on and be part of it” (person with dementia from a rural area)*

The layout of the built environment was also stressed by a number of people:

> *“Our physical community is a nice and safe area with interesting things to look at out the windows. We have lived here a long time, all the neighbours know us as do the merchants in the local high street.  My husband remembers his way around and can go to the shops and barber etc on his own” (supporter from a suburb)*
> *“It’s not too busy. There are long term buildings such as the bank, library, supermarket, and church which make for good prompts”  (supporter from a suburb)*

### Local facilities

Shops were a strong theme across all communities, with most people saying that it was the staff that made the main difference and in particular the importance of good communication skills:

> *"If you tell people that you are struggling and why – they are generally very helpful" (person with dementia from a small town)*

A number of respondents said that staff in the local supermarket had been very helpful and understanding, with one person with dementia from an urban area describing Sainsbury's as "my local shop"

In rural areas, pubs and the post office were of particular importance:

> *"The pub was the centre of the village, and as long as Dad could go there he felt connected to what was going on" (supporter from a rural area)*

In urban areas – public transport came in for praise, and again the attitude of staff was seen as particularly important.

### Support services

The positive role of support services in the community was mentioned frequently by all communities, although this featured less strongly in suburban areas:

> *"Yes the area in which I leave [sic] has many different facilities and services for people with dementia and enables them to remain as independent as possible whilst living in the community" (supporter from urban area)*

Mental health teams and the NHS were most frequently mentioned support service.

No-one mentioned their GP.

### Social networks

The importance of friends, family and neighbours as well as the broader community were cited across all communities:

> *"Friendly neighbourhood - I think people would help out if needed, rather than ostracize anyone with dementia" . (person with dementia from a suburb)*

Being known to those in ones area is seen as central across all communities

> *"Clearly identified community within an urban conurbation[sic] - urban village - people living within such areas for most of there lives"  (supporter from an urban area)*

**Local groups**

Many of the respondents were already part of a local group such as Singing for the Brain (Alzheimer's Society),  a local memory café, the EDUCATE group in Stockport or a walking group – so perhaps unsurprisingly membership of a local group was viewed as very important across all communities.

Words like "safe haven" and "place of safety" were frequently used to describe local groups:

> *"The local groups for people with dementia – Singing for the Brain and the memory Cafes are very important – it helps me to stay connected and gives me a safe haven giving me the confidence from which to venture further" (person with dementia from a rural area)*

There was a strong sense that local groups provide not just support and activity, but a sense of mutual support and engagement:

> *"those people touched by dementia are engaged in mutual support and friendship" (person with dementia from a rural area)*
>
> *"There is a group [of]  professionals that organises the dementia group, including outreach visits to interested parties, where we can explain about the problems living with dementia to the general public. The group also gives mutual support reducing feelings of isolation" (person with dementia from an urban area))*

All EDUCATE members put their confidence down to attending the EDUCATE group. One member described the importance of the group: he said it was like many things in life – it's easier to do things when motivated by the group, being able to share experiences and get mutual support (he gave the example of slimming clubs).

Two other respondents who were not members of EDUCATE mentioned the opportunity for people with dementia to volunteer with support from local groups.

## What makes my community a difficult place to live for people with dementia?

> *"not all agree with a philosophy of family and looking after each other, and consider dementia patients a nuisance" (supporter from a suburb)*

As with the previous question responses fell into 5 main categories, all of which were common across the different types of communities.

- The physical environment
- Local facilities
- Support services
- Social networks
- Local groups

**The physical environment**

Geographical isolation was a strong feature for many in rural areas, particularly with regard to facilities and services.

> *"Remote and no public transport, at least 6 miles from any doctor's surgery, no groups except church which is a long way outside village centre requiring transport and off a busy road" (person with dementia from a rural area)*

In urban areas – poor signage and difficulty navigating the environment, as well as the impersonal nature of some urban and suburban environments were mentioned:

> *"The main shopping area is a triangle shape which makes it long and difficult to figure out which direction you are in" (supporter from a suburb)*

For those in small towns – the only negative reference to the physical environment was:

> *"No obvious carers' groups or information service signposted within the town showing carers where to go for early info, advice or services." (supporter from a small town)*

For others, concerns around the physical environment were closer to home:

> *"There are many small things - one that comes to mind is that our housing estate has put a gate between the houses and the river walkway for security reasons. My husband cannot operate the lock - so he can no longer easily reach the riverside to walk on his own" (supporter from a suburb)*

### Local facilities

Again shops, shopping and transport were a strong theme across all communities.

Some felt that the demise of the corner shop has been bad for people with dementia, with supermarkets coming in for criticism from some for being too impersonal, and difficult to navigate.

> *"every time I go in they have moved stuff around and I always assume that it's my fault for not remembering" (person with dementia from a rural area)*

Other sited problems with confusion around payment, especially the use of pin numbers:

> *"Shops – I can't handle it because I am always forgetting my pin number – well not always but I am worried in case I inconvenience anyone coming in behind me." (person with dementia from a rural area)*

Public transport was seen as problematic, either because there is very little of it (rural areas), that it was difficult to navigate (urban), or that staff were unhelpful.

The attitude of those working in retail and transport seems for most to be the major factor.

> *I asked a member of staff at the bus station to write down the time of my bus for me and he refused – pointing at a timetable which of course I don't understand – who does though? (person with dementia from an urban area)*
>
> *"It is so important to give us time, and not make us feel bad if we are taking time to find our money or pack our bags – it makes all the difference" (person with dementia from a small town)*

### Support services

Poor experience of support services was reported by all communities, but especially by those in urban and small town environments.

The problems associated with support services were focused around:

- Access:

  *“it’s hard to access services unless you know the ropes” (supporter from urban area)*

  *“With the council – everything seems to be done on-line and if you can’t handle that then you are excluded – you can rarely find anyone to talk to and when you do, they always seem to have to tell you to talk to someone else – I think they call it silo working or something” (person with dementia from a rural area)*

- Lack of services, especially day services and services for people in the earlier stages of dementia:

  *“…we are having trouble finding activities which are appropriate for someone with early Alzheimer’s. Ramblers groups and things like U3A are too difficult in various ways - and day centres are too dull and are depressing for him while he is still quite well. We are lucky to have good friends who help, and to supplement that I organise and pay for people to exercise with him, take him to museums etc. As AD is being diagnosed earlier it is important for the community to provide (not all for free) activities which are stimulating and keep the person with dementia as well as possible” (supporter from suburban area)*

- Problems with understanding of dementia by those working in services

- Lack of joint working between support services.

**Social networks**

Social isolation was reported as a difficulty, across the communities.

In urban areas, several people made reference to the sense of loss of community:

> *“It isn't very 'neighbourly', everyone keeps themselves to themselves.” (person with dementia from urban area)*

People in rural areas talked about the changes that have taken place in their communities, especially the loss of younger people and the influx of people moving in who don’t or can’t participate in community life to the same extent:

> *“In the past If you have lived in a small village for a long time you are probably going to be OK as everyone knows you and can help keep an eye out you know? – but if you have recently moved down like I have – then people don’t know you and seem to want to keep themselves to themselves……(person with dementia from rural area)*

> *" of course lots of new people have moved in and we don't know them –and many of them aren't even around a lot of the time working in London I suppose so it has changed really" (person with dementia from rural area)*

The "drifting away" of family and friends following a diagnosis of dementia was reported by a number of people.

> *"family and friends disappear" (supporter from urban area)*

One carer mentioned the fear of driving new people away by appearing too needy:

> *"They would be worried about getting sucked in. They start with one little way of helping and must work that more and more will be piled on them. Carers get so stressed I'm sure this must happen"*

## Local groups

The lack of the kind of opportunities afforded by local groups was mentioned by a number of participants in rural and suburban areas.

One participant expressed a concern that the facilitation and involvement of a "professional" in the local group could be lost:

> *"Removing the professional support would undermine the group." (urban)*

The EDUCATE group in particular were very conscious of the role of the professional as an essential enabler.

## What do you do that keeps you in touch and involved with your local community?

We limited these responses to people with dementia and those responding on their behalf. Therefore all the responses below are attributed to people with dementia, unless indicated otherwise.

> *"Walks to the local shops/village, community events such as fetes, open gardens, church visits, community coming into us - such as school visits, garden fetes and jumble sales, volunteer visitors, local clergy, choirs and entertainers coming in, local and international news board in the home" (small town)*

This response, from someone with dementia living in a care home illustrates that people are engaged in a variety of different ways within their communities, and that for her, the care home and the community were not necessarily two separate entities.

The ways in which people continued their involvement with their communities fell into 4 broad and to some extent, overlapping areas:

- Through local groups
- Through the use of local facilities
- Through walking
- Through the use of support services

### Through local groups

This was by far the most common way for people with dementia who responded to stay connected to their communities

Singing for the Brain (Alzheimer's Society), memory cafes, and other support groups  accounted for more than half of all responses to this question.

This is unsurprising, given that many respondents came to take part through groups, but it is clear that people value the support and opportunities for engagement from local groups very strongly indeed.

> *"The local groups for people with dementia – Singing for the Brain and the memory Cafes are very important – it helps me to stay connected and gives me a safe haven giving me the confidence from which to venture further" (rural)*

Many people across all communities said that their local group played a very significant role in keeping them connected with their communities.

### Through the use of local facilities

Shops, the church, the pub, and the gym were the most commonly cited local facilities that people with dementia used. Shops were the most commonly mentioned.

Local facilities were very strongly cited for both urban and small town communities, the pub and post office being particularly relevant for those in rural areas.  Those living in suburban communities, made no mention of local facilities.

### Through walking

Many people in all communities felt that walking provided them with an important connection to their community. There were a number of references to walking groups (urban), but for most people this was an activity they did alone or with friends and family.

### Through the use of support services

A small number of people mentioned day care facilities as one way in which they kept in touch with their community.

## Is there anything you have stopped doing in your local areas since you developed dementia?

## If so, can you say why?

## What could be done to help you start to do those things again?

There were a wide range of activities which people had stopped doing since they developed dementia across all communities. These included driving, spending time with friends, hobbies such as golf and badminton, and using the library.
Only one activity was mentioned more than once - shopping.

**Reasons why people stopped doing things.**

Responses fell into two main areas.

- The progression of dementia – people had been advised to stop driving, and one person felt that they were no longer able to read well enough to use the library. Many had some concern about abilities – some people were concerned that they would get lost, especially when going shopping:

  > *"I'm not always able to remember how to get home" (person with dementia - urban)*

- Concern about lack of understanding of dementia:

  > *"I don't take my husband out much myself as people don't understand the illness" (supporter - urban)*

**What could be done to help you start doing these things again?**

The need for low level 1-1 support by a volunteer or "buddy", was cited by all respondents:

> *" More volunteers, or befriending services. Someone to come with me would be a huge help" (person with dementia - urban)*
>
> *"Yes - loss of memory, self-esteem and confidence means social networks and friendships are non-existent. A buddy/friendship scheme where I could be accompanied by someone who knows me and understands the difficulties (without any stigma) would help address this and take pressure off the immediate family who care most of the time" (person with dementia - small town)*

## Is there anything you would like to be doing in your community that you are not doing at the moment?

## What is stopping you from doing the things you would like to do?

## What could be done to help you to start doing these things?

> *"In my opinion as a professional working with people with dementia - the greatest thing lacking is a companion (someone the person with dementia can know and trust) to assist with attending events, going to the park, accessing the shops and community centre. It is the fear of being seen as having dementia, and of becoming confused that stops a lot of people with dementia from going out. They want someone they know and trust and they need to build up their activity gradually and to a level which is not too overwhelming" (supporter - suburban)*

> *"Many of our members had stopped doing things, but becoming part of EDUCATE helped them to start doing things again, and things they hadn't ever dreamed of doing before" (EDUCATE member – person with dementia*)

There was a wide variety of responses to these questions, some very specific, others very general. There was little variation between the communities. Responses to the question "what would you like to be doing" fell within four broad areas:

**To pursue hobbies and interests**

Responses varied from participating in arts and music, to swimming and golf.

The barriers to participation were split roughly equally between "dementia" and "lack of support" – especially informal 1-1 support.

One respondent talked about members of the golf club that take her husband to play golf, but was wary of relying too much on friends and family as she worries that they might drift away is she becomes over-reliant.

Improvements to support were seen by all as the best way to help them:

> *"To prevent me getting confused and lost and to take pressure off my husband who is 80 as well" (person with dementia - small town)*

**Simply “going out”**

Many respondents gave a very general response to this question – simply “going out” – while others talked of going out as part of a group.

The perceived barriers were again evenly split between “dementia” and “lack of support”

Again – improvements in levels of support were seen by most as the best way to help.

**To make more use of local facilities**

Respondents wanted to make more use of facilities ranging from the library, local shops and cafes.

The perceived barriers to these more specific activities were slightly biased towards “dementia”

> *“I don’t use the library any more – I can’t follow the plot” (person with dementia - rural)*

However “lack of support” again featured heavily:

> *“I have stopped using the library because they have introduced self-checkout and and I’m worried what will happen if I get it wrong – or if I can’t keep track of when my books are meant to be returned – they don’t stamp it in the front of the book like they used to – I’d need someone to help with that” (person with dementia - rural)*
> Cost was also a barrier for one respondent:
>
> *“ We cannot afford £20 per hour for a trip to the shops !” (person with dementia - urban)*

Again – improvements in levels of support were seen by most as the best way to help.

**Volunteering**

Several people with dementia mentioned that they would like to be able to volunteer to help others:

> *“I’d like to be making people more aware of this illness” (person with dementia - urban)*

> *"Possibly more work in a charity, where I can help others less fortunate than myself" (person with dementia - small town)*

The main barrier expressed around volunteering work was lack of opportunity:

> *" I need to find the right environment to get involved, where there is no pressure to do things too fast" (person with dementia - small town)*

In reply to the question "what could help" the overwhelming response was "more support" – not highly intensive, but mostly informal support of a low-level 1-1 "befriending" nature, especially for people in the earlier stages of dementia.

## Imagine a community that is perfect for people with dementia:

> *“Light and airy, clean and fresh, support available in an unobtrusive way if and when needed, quiet areas as well as stimulating areas, the outside coming in with greenery, foliage - plenty of things to do alone or in groups - gardening areas, pets - a utopia of love, positive regard and encouragement”. (person with dementia - urban)*

> *“An integrated society where people with dementia live in "normal" home like situations throughout their lives with support to continue to engaging in everyday community activities.*
>
> *People would understand about dementia and the problems it creates and how to resolve those problems as they arise or even prevent them in the first place. The facilities should be as ordinary as they are for everyone else but the support to use them should be personalised” (supporter of person with dementia- small town)*

**What would it physically look like?**

Responses from people with dementia are *italicised.*

Non-italicised responses are from supporters of people with dementia

People said it would:

- *be bright, clean, user friendly, different colours,*
- be accessible to disabled people
- *have clear signage and good orientation materials*
- *be well signed in the right colours and fonts*
- *have campus-style living*
- *be “individual accommodation in countryside but with access to town and amenities and near to family and friends”*
- *communities would be more involved in the life of care homes and visa versa*

**What sort of facilities would there be?**

People said there would be

- *Groups like Singing for the Brain and the memory cafes:*

  *"Yes – you need an organisation like this that can be a focus for people, especially now that things aren't so sociable"*

- Church
- *Good transport*
- *Sitting services*
- *Respite care for carers*
- *Befriending schemes*
- A nice day centre with good care and caring staff
- A drop in where the carer could leave the person with dementia – possibly staffed by carers on rota basis
- *"Possibly more facilities where we could have dementia cafes alongside discussion areas involving all illness".*
- Social events, movies, sports
- Facilities would include places for people with dementia to regularly meet to have a cup of tea
- *Somewhere for like-minded people to be*
- To be in very small groups getting attention rather than sitting in larger groups getting little or no personal attention.
- *There would be more 1-1 support*
- A welcoming, patient corner store in close proximity for everyone
- *a café where you can get a coffee that doesn't cost four pounds.*

**What would the people be like?**

People said:

- *there would be a mix of ages*
- *people would be friendly and understanding*
- they would have a strong neighbourhood ethos
- *"they would be proactive in engaging with me".*
- people would be supportive but not smothering
- *"equality would be uniformed throughout*"
- *people would better understand dementia, the stigma would have been removed.*
- *people would be more knowledgeable about dementia.*
- all public sales staff would be trained in dementia

These responses were evenly spread through the different communities.

## What do you think could be done by the community itself to make it be better for people with dementia?

## ……and what sort of help would your community need to become more dementia friendly?

> *“The community needs to "own" its local unmet needs in relation to dementia- for each community this may be different- in a small village there may be several residents with dementia who will have shared needs and individual needs which will be able to be met in different ways- local people will come up with local solutions” (supporter of person with dementia – urban)*
>
> *“everyone has a connection to dementia” (person with dementia - urban)*

Most of the responses to this question across all communities fell into 4 main categories.

People said that communities could:

- Improve their awareness of dementia
- Support local groups for people with dementia and carers
- Provide more information, and more accessible information about local services and facilities
- Think about how local mainstream services and facilities can be made more accessible for people with dementia.

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**Increasing its awareness of dementia**

This was by far the most common response, and was directed at the community at large, as well as providers of both support services and mainstream facilities:

> *“more education - the word dementia is a sentence of stupidity in some people’s minds” (person with dementia - urban)*

In order to make this happen, it was suggested that communities need:

- *“Input from local organisations with the knowledge”*
- *“Substantial public awareness programme”*
- *“More media attention on dementia will help people to understand and cease being afraid of it.”*

> *“Information and links to learning sent as leaflets into people's homes, at the library, on the web and TV.  A campaign that gives people awareness and simple ways to help (just like the stroke campaign - knowing the signs and knowing how to respond). (supporter of person with dementia – small town)*

It was also suggested by a significant number of people that a greater presence of people with dementia in the community, and more contact between people with dementia and their broader community would also raise awareness, and would serve to help “normalise” dementia:

> *“Make activities and services for people with 'memory loss' a very normal function of the community and not just part of specialist mental health services. Make information higher profile at all health centres with telecare equipment displayed in all health centre foyers so that it is in people's faces routinely. The rule not the exception.” (supporter of person with dementia - urban)*
>
> *“Provide plenty of activities and trips and make the community aware of dementia” (supporter of person with dementia- small town)*
>
> *““Dementia is to be celebrated, not hidden and ignored. It can make different values known and practiced - such as breaking people's conceptions about social rights and wrongs, getting more in tune and responding to all our communication (not just words!), and pushing us to be more connected as people and a community” (supporter of person with dementia - urban)*
>
> *Encourage schools to send pupils visit and work as carers in the holidays” (person with dementia - urban)*
>
> *“more links between community and care homes” (person with dementia - urban)*

**Support local groups for people with dementia and carers**

The significance of local groups such as the Memory Cafes and Singing for the Brain as a “safe haven” for people with dementia cannot be overestimated. Many respondents felt that the community must continue to support these groups, and could do more:

> *“Yes – you need an organisation like this that can be a focus for people, especially now that things aren’t so sociable” (person with dementia -rural)*
>
> *“ there must be a café where you can get a coffee that doesn’t cost four pounds?” (person with dementia - rural)*

In order for this to happen, people said that:

- communities needed more funding
- others suggested being creative in making use of existing resources:

  *"Open up the community centre for a day at least so the spouse/main carer could take the dementia sufferer and spend a little time in the company of others in similar situation so the ones doing the caring could also have a chance to discuss things with other parties." (supporter of person with dementia - suburban)*

  *"this café has been a great success, but it does feel a little out of the way, being in the council offices, and people have asked whether we could meet somewhere a bit more "normal" – so we asked around and lots of cafes in town seem to be more than happy to have us, so there's a thought" (memory café organiser)*

**Provide more and better information about services**

There was a strong feeling that many people simply aren't aware of the facilities and support that is available, and communities aren't doing enough to get the information out in accessible formats to the people that need it.

Here's an exchange that took place at a memory café in a rural area

Person with dementia 1: *"I have stopped using the library because they have introduced self-checkout and I'm worried what will happen if I get it wrong – or if I can't keep track of when my books are meant to be returned – they don't stamp it in the front of the book like they used to"*

Person with dementia 2*: "they have always got people to help you if you can't work out the machines, and they'll put a reminder card in the front of your book for you if you ask"*

Some people felt that where information is provided, it was often in formats which were not easily accessible to people with dementia:

> *"With the council – everything seems to be done on-line and if you cant handle that then you are excluded – you can rarely find anyone to talk to and when you do, they always seem to have to tell you to talk to someone else – I think they call it silo working or something - and when you do get paper copies the forms are too complicated" (person with dementia – rural area)*
> *"I find it really hard to understand bus and train timetables, and I have asked for easy to read versions and been told no on a number of occasions. My*

> *daughter has set up an i-telephone (iphone) for me and that has a thing that tells you about trains, but busses are still hard" (person with dementia – small town)*
>
> *"If I can't get into the library because I use a wheelchair, then I would have the right to ask for help, like a ramp. But if I struggle to use the library because I can't understand the information about the new system then I am stuck. Isn't it the same thing?" (person with dementia - urban)*

In order for this to happen people said:

*"People who write information for the public need to be more aware of plain English, and the needs of a wider range of people. If we make information easier to understand for people with dementia, it will be easier for everyone else" (supporter – small town)*

The importance of organisations working together was stressed, especially around the provision of information:

> *"We need more direct links between the charities and other organisations so that everyone works together" (person with dementia -urban)*
>
> *"We need full support from the frontline charities who claim to be working for people with dementia, so that all the relevant information is in one spot" (person with dementia - urban)*

**Think about how local mainstream services and facilities can be made more accessible for people with dementia**

People felt that there was a lot that could be done to make existing services and facilities better for people with dementia:

- "*Staff should be made more aware of the needs of people with dementia" (person with dementia - urban)*
- *Education, education, education!!! (person with dementia - urban)*
- *Services and facilities could have someone responsible for making sure that everyone is included and able to participate. (supporter - suburban)*
- *A village champion for dementia (supporter – rural*)

In order to make this happen, again, funding for training was mentioned, and other people saw a solution a little closer to home:

> *"I spend a lot of my time raising awareness about dementia, giving talks. If you want to find out how to fix your plumbing you call a plumber. If you want to find out how to make your service better for people with dementia, who better to ask than people with dementia?"*
> *(person with dementia - urban)*

## Comment and recommendations

### Which aspects of a community make it a good place for people to live?

### The physical environment

Our ability to maintain links to our community is closely linked to our ability to get around. Mobility and orientation for people with dementia can be severely hampered by the physical environment.

Good design and attention to orientation can make a significant difference to a person with dementias ability to navigate their surroundings.

Guidance is available on environmental design, and there is potential for people with dementia to develop a role in advising and assessing access issues at a local level.

**Recommendation:** That we build on the potential for people with dementia in advising on access issues.

Service providers have obligations to consider the needs of disabled people in the way in which they provide services. Similarly, building regulation also requires the needs of disabled people to be considered in matters of building and design.

**Recommendation:** Service providers should be made aware that many people with dementia are considered “disabled” under The Equality Act 2010

**Recommendation**: People with dementia and their supporters should be made aware of their potential rights under the Equality Act 2010, and supported to press for their rights if necessary.

### Local facilities - especially shops and public transport.

Most people with dementia said that it was the attitude of staff that made the biggest difference.

Many concerns were expressed about a lack of understanding of dementia, and many people said that this was stopping them from using local facilities.

Others reported very positive experiences of using local facilities, again usually linked to the attitude of staff.

People with dementia had three recommendations:

- “Staff should be made more aware of the needs of people with dementia”
  “Education education education!!!
- Services and facilities could have someone responsible for making sure that everyone is included and able to participate.
- A village champion for dementia

**Recommendation:** That we support and encourage the development of a role for people with dementia in raising awareness and training of staff.

## Support services

Some had struggled to access or obtain support services

For others it is the lack of more informal 1-1 support that was lacking, perhaps from a volunteer “buddy” or befriending scheme. Most said that this kind of support would enable them to continue to maintain their links and be active and visible within their communities.

**Recommendation:** That we consider the potential for further development of “buddy” schemes to support people with dementia in the community.

## Social networks

Many people with dementia and carers report that family and friends “drift away”.

Long established social networks can break down quite quickly and people with dementia and carers can find themselves having to negotiate a new set of relationships.

Some supporters expressed concern that people might be wary of helping because they fear that things will escalate, and they will get “roped in”.

A fear of escalation is one of the rationales for “circles of support” currently operating for people with other disabilities. The circle might include neighbours, friends, milkman, shopkeeper, who volunteer to support the person but in a specific and limited way.

**Recommendations:** That consideration be given to the applicability of “circles of support” to people with dementia.

## Local groups

Many of the people with dementia who gave us their views are members of EDUCATE, or of a local group, like Singing for the Brain or a memory café.

So while it is not surprising that there is a lot of support and praise for local groups, there is no denying the impact that they have had on the people with dementia who gave us their views.

The phrases “safe haven” and “place of safety” were used frequently by both people with dementia and their supporters.

Others described the groups as a focus around which they could venture further into the community around them.

Others mentioned the feeling of mutual support and empowerment, as well as the ability to educate others about dementia.

It is clear that for many people with dementia and their supporters, local groups provide a very important anchor to their communities. However, while support groups for carers are common, groups for people with dementia are still the exception rather than the rule.

**Recommendation:** The continued support and development of local support groups for both people with dementia and carers must be prioritised.

## Barriers

With very few exceptions people with dementia said that they had stopped doing things in their community because of their dementia, and because they were wary of the attitude and reaction of others.

The responses would suggest that thinking around a social model of dementia has had little impact on those who responded. (a social model of dementia being one in which consideration is given to the effects of the physical and psycho-social environment as well as any individual impairment)

A social model of dementia has much to offer both in terms of campaigns to reduce stigma and raise awareness, and much needs to be done to enable people with dementia and their supporters to access the alternative perspective they provide.

**Recommendation:** Organisations responsible for providing support and information to people with dementia and their supporters should ensure that the information they provide is informed by a social as well as a medical model of dementia.

**Recommendation**: Public awareness campaigns should reflect a rights-based approach to dementia.

The most common response to the question “what can a community do to make itself more accessible?” was - “to increase and improve awareness of dementia”

**Recommendation:** That we maintain and support awareness campaigns nationally and locally.

**Recommendation:** That we consider how can we support and encourage the development of a role for people with dementia in raising awareness of dementia.

## Information

Many people with dementia said they found it hard to understand information produced for the general public, and that this presented a barrier to engagement with their communities.

**Recommendation:** That guidance is produced to enable service providers to produce information which is accessible people with dementia.

**Recommendation:** That the applicability of the Equality Act 2010 to people with dementia be investigated.

## About the people with dementia who responded

This is not a representative sample!

People with more advanced dementia are unlikely to have been heavily represented, if at all, in the responses we received.

It is likely that most of the people with dementia that responded were in the earlier stages of dementia – and their comments must be understood in that light.

People with more advanced dementia are often excluded from consultations and research. However, with the right support and encouragement, people with more advanced dementia are able to have a say in the decisions which affect their lives.

**Recommendation:** That future consultations consider the need to allow the voice of a wider range of people with dementia, including those with more advanced dementia.

**Appendix 1**

Innovations in Dementia

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# Report

Memory Cafe Network Event

17th November 2010

Dementia friendly community workshop notes

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**If you were to design a 'dementia friendly community' what would you make sure existed? (think about the environment, facilities, people, attitudes).**

- Central area containing the facilities, with clusters of property surrounding – a real centre to the community
- Facilities within walking distance
- Opportunities for communication between people and generations
- Step-free wherever possible
- Simplified directions and signposting
- Less stigma about dementia; more awareness about how memory problems affect the person and how they see themselves
- A more friendly and safer community (for everyone); a more inclusive community
- Time for relationships to develop
- Dementia to be 'normalised'
- Familiarity – don't keep making 'improvements'
- A post office, pub, library
- School education projects about dementia
- Communal areas
- Education for all businesses/staff
- A feeling of pride about approaches to people with dementia
- Fairly small and compact
- Somewhere where everyone is welcome – where you could ask for help – a 'help centre'
- Local shops
- Good public transport
- Where people say 'hello' and are friendly
- Easily accessible toilets

**What are the things a community can do for itself?**

- Raise awareness of dementia
- Distribute SOS cards
- Set up memory cafes
- Create a ‘safe haven’ in doctors surgeries; other safe havens
- Think about how to support younger people with dementia
- Generate a feeling of community spirit – know your neighbours and keep a watch for them
- Accepting people with dementia as valuable citizens with things to offer
- Lunch clubs, cafes, links with schools
- Social events
- Volunteer helping
- Taking responsibility – find a good leader
- Community champions
- Approach Chamber of Commerce to help shops become more dementia friendly
- Promoting awareness via trade associations
- Promoting inclusive events for all
- Show that its OK to be honest and ask questions about dementia

**What would a community need to become more dementia friendly?**

- Educated town planners who understand the needs of people with dementia
- Integration between age groups
- Education at all levels
- Acknowledging that people with dementia have rights to inclusion in community life
- Parish council support
- More community centres
- Break large communities into smaller ones
- Develop links with schools
- Money for training
- Ideas about what works well in other places
- Help for developing a vision for improvements in relation to dementia
- Everyone taking responsibility and ownership
- Highlighting the commercial value of dementia friendly communities

Rachael Litherland
Director
30 November 2010

## Appendix 2

## Out and about………

Four people from the Stockport group volunteered to take me with them in their community to show me aspects of their lives.

These sessions took place on Wednesday 12th January and Wednesday 19th January 2011.

None of these activities were particularly close to their houses: all required a car journey.

The people involved were:

- Graham (and his wife Ann) who took me around Sainsbury's in Hazel Grove with them.
- Sue who took me to her local library.
- Jenny (and her husband Les) who took me to the pub for lunch.
- Elaine who showed me her local gym.

Graham is 79 and has Alzheimer's disease
Sue is in her 50s and has Alzheimer's disease.
Jenny is early sixties and has Alzheimer's disease.
Elaine is in her 50s and has Alzheimer's disease.

### Why Graham loves Sainsbury's

To Graham and his wife Ann the huge Sainsbury's at Hazel Grove in Stockport is their 'corner shop'.
They go there regularly: shop and have a coffee and a cake in the café.

Graham says, 'I feel comfortable here; if I flaked out in the middle of the place, I know I wouldn't be on my own'.

Graham makes it his business to say hello to everyone and to be cheerful. He tells how he went up the security guard at the entrance ever visit and said hello and now the man recognises Graham and says hello first.

Graham knows his way around the café and the shop. He recognises the uniforms of staff and uses their badges to call the staff by their names.

He remembers when he did have a 'funny turn' in the shop. A first-aider was there immediately, making sure he was OK and guiding him to the café where he was sure Ann would find them. He was reassured by the uniform and the badge.

He makes use of all the services Sainsbury's offers: he points out the big 'customer services' sign, 'They're always busy and you have to wait. The service varies because of the person you get and the ease of the question'. He explains that there is a 'captain' behind the till who walks up and down to help with any queries from the cashiers. Graham will stop that person and ask for help.

He tells of when the butchers counter didn't have a specific item – and instead of waving him away they made sure that another member of staff took him to the correct aisle. He says that being taken to the correct place (rather than being given instructions) is helpful and common-place – as long as they're not busy.

In the café, Graham knows where everything is. Everything is visible and the people are friendly. But he does find the noise in the café area difficult.

**Sue's trip to the library**

Sue said she was nervous of going to the library and would I go with her. The library is some distance from her home, so we got a taxi.

The first problem was finding the entrance. There appeared to be three: Sue had expected to be dropped off at the car park at the back, the taxi dropped us at the main entrance of an old impressive building, but eventually we spotted a modern building with ramped access at the corner of the old building.

Inside the door, Sue stopped at a large notice board. She said she was interested in finding a local walking group. She noticed a poster for a over 50s fitness group – but said she wasn't old enough..

Inside the library the first thing that greets visitors are the machines to take out books. These looked daunting.
Sue found it difficult to orientate herself.
The labels on the shelves were small – although all the shelving was low.

We found the large print books that Sue though might help her with reading and concentration. Sue picked a few out – but said she didn't know what to do next. She would have to ask – but wasn't very keen to. The staff were busy and Sue was nervous.

Sue found the DVD and CD collections and was very interested – although she didn't know which ones they had seen. She wondered if there was a charge for renting discs and so decided to ask a librarian.

When Sue is nervous she finds it difficult to find the right words. Eventually she explained that she has Alzheimer's disease. The librarian was kind and helpful. Unfortunately, Sue library card didn't work and a new one had to be made. This entailed questions about address, date of birth etc that were daunting for Sue. Later of Sue said that this was her worst moment in the library. There was a lot of information to take in: how long she could have books for, how long for DVDs, the costs of renting DVDs. However the librarian explained that there were no fines or costs for Sue as she had a 'special card' because of Sue's Alzheimer's disease. Sue said she would have to write things down to remember. I asked if there was a leaflet that might help – but no. Eventually Sue found some paper and a pen, but as she was nervous found it difficult to write. At no point did the librarian offer to write for Sue. The librarian showed Sue how the machines worked. The demonstration was very quick and not explained well – but Sue said she would have to ask every time (that seemed to be the case with many library users at the time).

Outside we talked about the visit – what was good and what was bad. Sue explained it was all about confidence. She hoped that now people in there 'knew her' she wouldn't worry about asking for help.

She also explained that the visit wasn't really about going to the library at all. She felt the need to 'get out of the house' and explained that when she was first diagnosed she didn't go out – but spent the whole time cleaning.  She is also worried about her weight – she felt she needed to walk more. In an ideal world she would have some friends or belong to a group that would walk down to the library with her.

**Lunch at the pub with Jenny**

Jenny's husband Les enjoys a quiet drink and a visit to the pub. Jenny enjoys it too. But Jenny's dementia has changed her perception and spatial awareness significantly. She finds it cannot put her coat on without help and finds it difficult to get in and out of the car.

Les explains that they used to go to a favourite pub by bus so that he could have a drink. But the buses were busy. One day Jenny was sitting next to a man who wanted to get off the bus. Jenny couldn't understand what was going on or that he needed her to let him passed. The man was not rude – but Jenny got flustered and upset. So they haven't been on the bus since.

They take me to a pub they have known for year – they explain that they used to go there with Jenny's parents.

The staff are pleasant, and Les is in charge getting drinks and sorting out the menu. Jenny's spatial awareness problems mean she has difficulty using cutlery. Les suggests that she has a sandwich – and Jenny asks for chips with it.

They say they are lucky to live in Stockport and tell me about a number of day clubs, drop-ins and services that they attend. They particularly mention the Ada Kay centre which has a drop-in run by the local Alzheimer's Society.

Jenny says the staff there are crazy – 'they're on my side!'

They both say how important people are to them. Some support workers have clicked with Jenny straight away – others haven't.
They can name those staff who 'go the extra mile'.
Les also mentions needing to trust the staff and the need for people who do what they say they're going to do.

They like groups, but find they can get monotonous and can be cliquey.

Les feels that Jenny could do with a female 'friend' to have a one-to-one relationship with. Someone in whom Jenny could confide.

Jenny mentions the Educate group (the 'chat shows'). She feels it's a bit like going to work.

Les feels that there are almost too many services offering similar things – for example Age Concern offering walking and singing activities that are already available via the Alzheimer's Society. He thinks there is a lack of real respite services.

Jenny likes to walk around talking to people – so they are both happier in groups for people with dementia, where people understand Jenny.
Jenny explains she is a 'people person'. She says if someone is on their own she will look after them 'whether they like it or not!'.

Jenny goes to the hairdressers twice a week. She enjoys it and knows her hairdresser. Les thinks it's important for Jenny to keep doing things. He know how easy it would be for her to stop.

Les talks a bit about community spirit – people talking to each other in the street and helping out – he thinks people are too busy now.
But Les and Jenny are the sort of couple who do help their neighbours. Les gets called upon to help people with DIY etc and they have neighbours keys in case of emergency. He thinks that sort of attitude has to be 'within you'.

They have some bad stories to tell: the young mother in a lift who said they should have taken the stairs, the couple staring at Les as he cut Jenny's food up. Les has taken to explaining to people that Jenny has Alzheimer's disease.

They have had different reactions from their family. Their daughter is there for them: being with her mother every Friday so Les can nip to the pub for a break. One son is has not seemed to fully accept the situation. Even the grandchildren have different reactions.

Les feels that doctors don't have time for individual patients and so there should be practice nurses who have more time.

He knows the dementia is frustrating for Jenny. Jenny explains – 'sometimes I swear!'

**Elaine loves going to the gym**
Elaine is very young to have dementia. She is still very active and still drives ('to places I know').

She is worried about giving up things she likes to do.

She joined the gym quite recently. Her gym membership is part of the Paris programme (Physical Activity Referral in Stockport) – and she has been referred to the gym by her doctor.

A support worker from Stockport went along with her to the induction programme – but she feels she can do it on her own.

She puts her confidence in using the gym down to two things: firstly she has been going to gyms for years and so knows how they operate. Secondly the gym has a 'key' that helps her to keep track of what she is doing.

One problem with the gym is there are two electronic systems – there is a swipe card to let you in and a key system to log equipment usage. Elaine has difficult with the swipe card, but the staff let us in. She doesn't know which way round to hold the card.

Elaine thinks the key system is wonderful and allows her to use the gym well. As long are she remembers to ‘log into’ the system it works well. When she forgets the equipment doesn’t recognise her – in the past people have reminder her to go to log in.

Each piece of equipment has a large scrolling display that recognises the user from the key. The key also sets the pace of the machine, how long to use it, etc.

Although under the Paris scheme Elaine has lots of paperwork eg forms to fill in about her progress, attendance at the gym etc, Elaine has not completed most of it – and prefers to rely on the key.

At the end of each session the scrolling displays indicates the next piece of equipment to be used.

Elaine finds the displays easy – she has no problem finding the ‘stop’ and ‘pause’ buttons on the tread mill.

She is slightly confused about how the key works with each piece of equipment. The cycling machine appears only to recognise her once she starts to cycle.

She is most happy about the chest press equipment counting the number of ‘presses’ she has completed. She finds it difficult to keep track of the number of exercises she has done without it. For example when she does floor exercises, she needs to concentrate more to count herself.

She admits that the system might be difficult if someone was unfamiliar with the names of the different pieces of equipment – but she is always willing to ask
“I must make mistakes, but I don’t care – I just ask again!’

Innovations in Dementia CIC
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