



The Dementia Engagement
and Empowerment Project

Involving people with dementia in creating dementia friendly communities

Key messages

- **Dementia friendly communities can only work if people with dementia and their carers are involved.**
- **There are many different ways in which people with dementia can take part in initiatives to make a community more dementia friendly.**
- **Many groups in the DEEP network are active in their communities.**

This guidance note is based on discussions by 15 people with dementia and 8 carers at a DEEP networking event in 2015. DEEP is a national network of involvement/influencing groups of people with dementia across the UK. 60 groups are currently part of the network.

The event was hosted by the Face it Together (FIT) group which is supported by the Alzheimer's Society in Bradford. They were joined by members of Shindig (from Sheffield) and Minds and Voices (from York). Carers had separate discussions about their experiences and views.



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www.bradford.gov.uk

What is a dementia friendly community?

A 'dementia friendly community' has been described as:

A city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia friendly community people will be aware of and understand dementia, and people with dementia will feel included and involved, and have choice over their day-to-day lives (Alzheimer's Society, www.alzheimers.org.uk, 2013). Communities also exist beyond geographical communities e.g. online groups and faith groups.

People with dementia have described a dementia friendly community as one that enables them to find their way around and be safe, access local facilities and maintain social networks (Dementia friendly communities Guidance for Councils, Local Government Association, 2015).

Why is it important to involve people with dementia in creating dementia friendly communities?

The main point that people make is:

“How can you know what ‘dementia friendly’ communities look and feel like without involving people with dementia (and carers)? We are the ones experiencing it. We are human beings with minds and voices.”

People with dementia said it is important to keep them involved because:

-  “It is good to know there are others in the same boat as you. That you are not alone.”
-  “It helps to be part of a group where dementia is understood and discussed.”
-  “Communities where you are understood and accepted make you want to carry on with the things you enjoy in life.”
-  “Knowing there is more understanding out there helps to keep life the same.”
-  “By being involved, we can show people that we still have a life. Dementia is not the end.”
-  “It challenges stigma and other people’s attitudes.”
-  “It gives me more confidence when people understand.”
-  “It is right to be involved.”
-  “It reminds me that I am an adult.”
-  “It helps me to find my voice.”
-  “It helps me to feel safe when I leave my house.”
-  “It makes me feel valued.”
- “It improves the way I feel about myself and about life.”

Carers said that it is important to involve people with dementia and carers because:

-  “You cannot know what people need unless you can understand their perspectives and difficulties.”
-  “Carers should be listened to because they save money.”
-  “It helps carers to be more open, and talk to people in the community about what support or understanding they need.”
-  “Carers are the frontline - they often come up with ideas and solutions that can be used.”

What kinds of things are DEEP groups doing to create dementia friendly communities?

Redditch and Bromsgrove Friends Together

The group meets to support members, to find ways of improving services and attitudes, and to make a better community for people with dementia. They are raising awareness about living with dementia with:

- local authorities
- police
- places of education
- transport
- local MPs
- businesses

Members of the group attend local Dementia Action Alliance meetings.

Face it Together (FIT) Bradford

From the outset members agreed they want to:

- Support each other and others to face their dementia together
- Raise awareness about dementia and what people with dementia can contribute to the wider community
- Be consulted about issues affecting their lives
- Have support to undertake campaigns that interest the group
- Be part of the Bradford Dementia Friendly work and feed into that work with their expertise gained through their lives and by being experts by experience of living with dementia

The group meets monthly and looks at topics including leisure activities, signage, awareness raising and power and control.

Several members of the group have taken part in consultations, or planning groups including for a new dementia crisis intervention team, a refurbishment

of a local hospital, and a consultation on how the council spends it reduced budget.

The group sits on all interview panels for new jobs at the Alzheimer's Society locally and members have also assisted with interview panels for senior NHS staff.

Members speak at public Dementia Action Alliance (DAA) meetings and local Dementia Friendly community meetings. Members are on the advisory groups for both these Bradford programmes.

EDUCATE Stockport

Members of EDUCATE have set up local drop in centres. These are places that people with dementia can find out information about dementia. They can also meet other people with dementia for support and social contact. People with dementia or people worried about dementia, have started to use these drop-ins as a 'safe' place to talk about dementia, and meet professionals. People are being supported who have not yet accessed more traditional dementia services.

What makes it difficult to get involved?

People had often experienced difficulties in terms of accessing local community life or helping to create dementia friendly communities:

-  "It can be difficult to get involved if you haven't got support."
-  "I can't always be bothered to get involved. It's a lot of work."
-  "There are not always visible signs of dementia. This means that people don't always know you might need support."
-  "The world is quite complicated, too fast, too frantic. Lots of technology is used. It is hard to keep up."
-  "Noise is distracting."
-  "Other people's negative attitudes can make you not want to stay involved. I've heard people tutting because I've been too slow. Tutting makes me more anxious and affects my speech. It has a snowball effect and goes from bad to worse."
-  "Not knowing other people with dementia can be hard."
-  "Feeling embarrassed about having dementia."
-  "I hate the word 'dementia'."
-  "It can be hard to keep up a momentum - being involved is tiring."
-  "A lack of transport."
-  "Inaccessible venues."
-  "The speed of conversation."
-  "If things don't go according to plan, it puts you off being involved the next time."

What approaches help people with dementia to be involved in creating dementia friendly communities?

These are some organised ways that people with dementia have been involved in local work to create dementia friendly communities.

Taking part in regular DEEP meetings

DEEP groups usually meet on a regular basis. This might be weekly or monthly. Meeting regularly helps people to keep up with progress on work. It ensures people feel supported and inspired to carry on being involved. It also gives people an opportunity to keep up to date locally around the creation of dementia friendly communities. DEEP groups are well supported, and work hard to make sure that all group members are well supported to stay involved. DEEP groups are a useful local resource for local people and organisations who want to become more dementia friendly.

See www.dementivoices.org.uk for a list of all DEEP groups.

DEEP groups can also make requests to local shops and businesses to work with them to help them become more dementia friendly.

Advisory panels and patient participation groups

These are local meetings, often on different pieces of work to develop dementia friendly communities. Including people with dementia makes sure that these groups are keeping people at the centre of their work. It sends out a strong message about the important role of people with dementia. With the right support, it can be a good way of people with dementia having a strong voice in local dementia friendly communities. See DEEP guidance “Involving people with dementia in advisory groups and panels”.

Walking the patch / dementia audits

This is a way of finding out how people with dementia experience their environment. For example, people might walk a particular route to a building or a park. They may try to plan and book a journey from a train station.

All the time the person is carrying out their task, they are explaining what their thought processes are. Prompt questions can help here e.g.

- What are you looking at?
- How did you choose between this way and that?
- Can you see that notice? What do you think it means?
- Is it easy to find the entrance to the building?

It is recommended that a 'walking the patch' exercise doesn't take any longer than 45 minutes. Some people have done a 'walk the patch' using video cameras to show the difficulties they have.

Speaking at community meetings and Dementia Action Alliances

People with dementia are often inspiring speakers, and can gain a lot of confidence from developing their skills in public speaking. Discussing what to say in a DEEP group can help the person feel they are speaking on behalf of people with dementia as well as from their own experience. To help support the speaker with dementia an interview style presentation can be helpful, where pre-agreed questions are asked. This aids the person to stay on track and means they do not have to face an audience on their own which can feel daunting. Participants at meetings about creating dementia friendly communities and organisations tell us that hearing the stories and views of people with dementia is inspiring and helps them see the value and urgency in making changes to become dementia friendly.

Working with schools and other youth groups

People with dementia say how important it is to educate children about dementia. They are likely to know family members or neighbours with dementia. Young people are also good at considering alternative ways of thinking about things, including dementia. Work in communities between young people and people with dementia has had very positive outcomes, from sharing games and music together to people with dementia running awareness sessions like the dementia friends programme. Young people are the next generation of doctors, bus drivers and shop assistants.

Mystery shopping

This is similar to walking the patch. Mystery shoppers will aim to buy something, order something, or behave in a certain way in a shop or a public building. They will then provide feedback about their experiences. This can be very useful for shops to know how best they can provide a supportive service to people with dementia.

In Bradford members of the FIT group and their carers have been to banks and other businesses. They had a task to undertake for example enquiring about a savings account. They were asked to gain a general impression of the premises and service provided. They were also asked how staff interacted with them both, and the degree to which they supported the person with dementia to take an active part in discussions.

Different types of consultation

People with dementia say it is best to offer different ways in which they can give their views. This might be in a small group setting or on a one-to-one basis. Group discussions can help people to feel more confident, gaining ideas from other people in the group. As one person said: *“There is safety in numbers.”*

Other people may find it easier to share their views in conversation with one other person.

The following items can help people be involved and express views:

- Post-it notes and pens.
- Flipchart.
- Name badges (in large, clear font).
- Agreed ground rules (for example, giving each person time to speak, always summarising the discussion before moving on to the next issue).
- Pictures or objects about the issues you are discussing.
- One-to-one support for some people to help them stay connected to the discussion and to help them communicate their perspective.
- A quiet room with no distractions - good lighting and acoustics, a hearing loop system if possible and no strongly patterned or reflective surfaces.
- A sound recorder to record the discussion, allowing you to facilitate better.
- Photographs from the discussion that you could include in any written minutes.
- Clear signage (temporary if necessary) to and from toilets, exits, lifts, etc.

From “Involving and engaging people with dementia” (RiPFA, 2015)

Making films

Films by people with dementia are a good way of raising awareness. People can tell their stories in their own words. Films can be viewed by lots of people, who might not otherwise get the chance to hear directly from people with dementia.

See <http://www.innovationsindementia.org.uk/Telling%20our%20stories.pdf> and www.dementiawithoutwalls.org.uk

Blogs and social media can also be a good way of people with dementia telling their stories. See: <http://dementiavoices.org.uk/resources/>

What ways of getting involved work best for people with dementia?

- Telling other people you have dementia. How can they help if they don't know? An identification card helps some people...something that says 'I have dementia.'
- Writing things down. It acts as a memory prompt and can be passed onto other people.
- It can be difficult for one person to 'speak out'. It can be helpful to have a spokesperson to do this on behalf of a group.
- Having a choice of things to get involved in. People with dementia should set their own priorities for what they think is important.
- Good hospitality is helpful - an accessible meeting place, good signage, accessible agendas and meeting notes, refreshments, and appropriate follow up information (about what happened after the meeting).
- Keep it simple.
- Being clear about why you are involved. Understanding your role and the contributions you can make.
- Opportunities to design services - not just comment on them.
- Don't overwhelm people with too much information. When people with dementia first start to get involved, they can often find that they are 'over-consulted'. This is because others are keen to find out the views of people with dementia. But it may be better for them to work through a DEEP group, rather than individual people with dementia.
- Make the most of people's skills and professions. People with dementia have a lot more to bring to discussions of dementia friendliness as well as their diagnosis.
- It can be helpful for people with dementia and carers to have some separate space for discussions. Their views may not be the same.
- Training helps people with dementia to become more confident e.g. at public speaking.

Dementia friendly communities - "Think Big!"

People with dementia are clear that they want a central role in the development of dementia friendly communities. They advise that DEEP groups should 'think big' about who they want to influence and how.

"Talk to commissioners. Talk to MPs. Write to the managing directors of large companies - ask them to change their policies and systems."

People recognise that there is an economic case for dementia friendly communities. People with dementia are more likely to use (and spend money) in businesses and shops which are dementia friendly.

People with dementia across the UK are involved in a lot of work to create dementia friendly communities. It is important that this day-to-day involvement is captured in some way.

Connecting to other people with dementia to create dementia friendly communities

People with dementia say that “*There is power in numbers*”. Involving more people with dementia will continue to encourage others to express their views and opinions. It also means that people with dementia feel more confident about telling others how best to involve them. There should be clear terms for involvement.

Involving people with dementia in DEEP groups helps people to get involved. Getting stories out into local media also helps.

These guidance notes were written in partnership with DEEP and the local Alzheimer’s Society office in Bradford. They were based on discussions at a DEEP networking event in 2015. This hosted by Bradford’s ‘Face It Together’ group which plays a vital role in strengthening the voices of people with dementia in Bradford’s Dementia Friendly Community Initiative.

This guide was created with help of 15 people with dementia and 8 carers who came together for a day in Bradford

DEEP guides aim to support the involvement of people with dementia. Some are aimed at DEEP groups, others at organisations wanting to work well with people with dementia. They have all been co-produced with people with dementia and will be updated regularly throughout the project. Suggestions for new guides are welcome – contact Rachael Litherland at Innovations in Dementia: email rachael@myid.org.uk or telephone 01392 420076.

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