

Dementia without Walls: Reflections on the programme from people with dementia

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The Dementia without Walls programme was made up of many different projects. This document brings together the reflections of ten people with dementia who were involved in different aspects of this work.

Introduction to Dementia without Walls

Dementia without Walls was the name given to a programme of projects and initiatives around the UK funded by the Joseph Rowntree Foundation between 2012 and 2015.

As well as strengthening the collective voice of people with dementia through the Dementia Engagement and Empowerment Project (DEEP) (see DEEP solutions accessible summary), the Dementia without Walls programme had two main strands of work in which people with dementia were involved:

- Supporting dementia friendly communities in different locations including York, Bradford, Derry-Londonderry and Sutherland.
- Projects to encourage us all to think differently about dementia, including truth telling with people with advanced dementia, positive risk-taking, rights and disability, and women's experiences of dementia.

Full reports and summaries of the projects are available from www.dementiawithoutwalls.org.uk

Here are some reflections about the programme from ten of the many people with dementia who have been involved:

"It's important to open people's eyes about dementia"

People with dementia must be included in discussions around dementia friendly communities, because only we know what it feels like to live with dementia in such a community. People with dementia are in a better place than most celebrities to spread the word about dementia.

"Doing it for ourselves"

People with dementia have a key role in making things better for other people with dementia:

Raising awareness

First and foremost, we can raise awareness of dementia. The easiest way is to tell people that we have dementia when we are out. It's not always obvious to other people that we have dementia, so if we want help we need to ask for it. We also need to reach out to more diverse communities

as for example we have tried to do in Bradford with LGBT and BAME communities.

Doing what we can

We can all make small changes – which can make a big difference. People need to contribute in ways that suit them.

Encouraging other people with dementia

We can encourage other people with dementia to get out of the house and take up some of the opportunities available to them. We can support other people with dementia not to get isolated. “We can say things to another person with dementia which people might not take from a professional.” Doing things for other people is important, such as the gardening projects in York which is something those involved with are proud of.

Fundraising

We can help to fundraise for services that support us. For example, Elaine is making greetings cards to sell and wants the proceeds to go to the DEEP group York Minds and Voices. Members of the Face it Together FIT group in Bradford help to run fundraising coffee mornings. We think that if we help ourselves, others will be more willing to give too.

Using our financial influence

We have some financial influence – for example, if we get treated well in a shop we should return there and tell other people so that they get more business. If we're not treated well we should take our custom elsewhere.

“We're not looking for special treatment”

We have the same rights as everyone, but if we can make a community dementia friendly it will become more accessible to many other groups as well.

Shops need to treat people well, whatever their disability. If you're spending money in a shop or business they should respect you. Good customer service should mean being patient. It's good to be included in consultations with other groups of disabled people. For example in Bradford we were involved in access issues for a new shopping centre.

It's our right to have good signage around the city – but this isn't just for us, the whole city would benefit.

Dementia awareness and understanding are important, but we're not special – lots of people would benefit from, for example, quiet places in town centres or slow lanes in the supermarket.

“There are too many assumptions made – and too many stereotypes around”

Many of the Dementia without Walls projects brought up issues around the attitudes of others and their assumptions about people with dementia.

We are all individuals and all have human rights – we want others to treat us as they would want to be treated.

People, including family, friends and professionals such as GPs, can be overprotective and stop us from doing things or getting involved. Dementia is a spectrum, you do not feel disabled by it straight away, but problems do creep up on you. People's attitudes can be disabling before you've lost the abilities. All we usually need is more time – just because it takes us an hour to do something and you five minutes, doesn't mean that you should do it! Positive risk taking means thinking about the worst thing that could happen and putting plans and strategies in place.

Language is powerful – if you see yourself as a 'sufferer' you will be one, and if others talk about you as a sufferer they will treat you as one.

It is important to remember that everyone with dementia is different. We might not like the idea of being told or telling lies, but the Dementia without Walls project about truth discussed ways of telling lies that can help certain situations. People with more advanced dementia may find it more difficult to understand 'the truth'. It is not possible to say that the truth is always good and a lie bad – or the other way round. It's difficult to know where to draw the line in terms of telling the whole truth, but it's also difficult to keep a lie going. The wellness of a person with dementia is paramount and telling the truth should fit with that, rather than being 'professionally correct'.

There are lots of assumptions made about people with dementia but also about women - women tend to be expected to be carers of those with dementia. Men are often seen as heroes for taking on caring roles, whereas for many women caring is seen as a duty. But at the same time, a

diagnosis of dementia does not take away a woman's nurturing nature – wanting to care.

Some specific ideas around support

“If there were two cafes I would choose the one with the dementia friendly sticker in the window”

The Dementia without Walls projects have covered many aspects of our lives.

There is a balance between us wanting to be treated in the same way as everyone else and asking for changes so that our lives are not made any harder.

It's great that JRF are supporting small organisations in places like York so that now there are lots of good things happening for people with dementia. But people don't always know about them and may need encouragement to take part.

There are stickers around in shop windows that say that the organisation is trying to be dementia friendly. They could be helpful because you feel more comfortable if you thought the people in the shop had been properly trained. Organisations should put into practice what the sticker is saying, and of course the attitude of the staff, knowing the place and trusting the staff are more important than any sticker.

Another idea is to have a 'safe place' for example in a café. It's a good idea to have somewhere where people could go in town if they felt confused or down. It's very important to have somewhere to be able to sit down in the centre of town.

Specific services for women might help those who feel intimidated or less likely to speak freely in a mixed group.

“I'm optimistic about the future – we do see that things are changing. It might never be perfect, but if we can help some people, that's a good thing”

About this paper

This paper has been written in the words of people with dementia and cognitive problems who have been involved in Dementia Without Walls. Nada visited all the authors in August and September 2015 and compiled this paper based on those conversations.