

Dementia without Walls – reflections from people with dementia on how people with dementia have been involved

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People with dementia have been involved in different ways in all the work funded by JRF as part of the Dementia without Walls programme. Here ten of them share their thoughts and experiences of being involved in 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:

- Looking at 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.

How people with dementia were involved

People with dementia and cognitive problems have been involved in all of these projects in different ways:

- Individuals have been asked their opinions.
- People have been part of panels of experts.
- People have been invited to speak or contribute in conferences and events.
- Groups of people with dementia have been asked to comment on projects or grant applications collectively.
- People have been involved in making films and photo exhibitions of positive images

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

This paper brings together the thoughts of ten of the many people with dementia who were involved in this work in different ways.

What motivates us to get involved?

“It makes you feel better that you’ve done something good”

The most important motivator is to make a difference. We want people to understand what dementia is and what it’s like to live with dementia.

It might seem obvious, but we also want to enjoy what we do. Having fun is very important to us.

We want to put something back into our communities. We want things to be better for everyone – not just people with dementia. This is especially true of the work we do around dementia friendly communities.

We also like to feel useful, valued, listened to and taken seriously. It is particularly good to continue to use skills that you have acquired throughout your life.

Sometimes when we’re involved in different projects it’s easier to forget that we’ve got dementia – it takes your mind off it.

Taking part and being appreciated boosts your confidence. We are a voice for people who are not able to be involved in the same way – maybe because of their personality, maybe because they haven’t come to terms with their dementia diagnosis or haven’t got the right support.

Making connections

“You might be brought together for a project, but it’s so much more than that, the bonding is much deeper, beyond words”

It is important for us to be able to get together with other people with dementia who are doing similar things, to find out what they’ve been doing, get support from them and learn from each other. You might be brought together for a specific project, but for us it’s more than that, the bonding is much deeper (for example when women with dementia were brought together for the women’s experiences of dementia project).

We also like working with different people and enjoy learning new things and meeting new people. People who were part of the Truth Inquiry liked to hear the expert witnesses talk; people involved in the rights and disability meeting enjoyed meeting people with physical disabilities; and others like to go to conferences and meetings where there are interesting

presentations. It's nice to be able to take learning from an event back to our local groups and communities.

We want to have an impact

"It's great to see the impact our voices have on other people – either other people with dementia or others"

It's important to know that you are influencing something or someone or you've accomplished something good.

In particular, it gives you a boost when organisations or people act on what you say or if you're part of a process that makes a decision (for example being part of the JRF York Committee grant making process). The best part is when you're told 'this is what you said, and this is what we've done'.

It's good to be asked for ideas, not just opinions, and it makes a big difference to see your ideas acted upon.

"It's good to think that you've changed attitudes – but the next step is positive change and improvement"

We want to change attitudes about dementia. Telling our personal experiences is important and we want to make a real impression of the people we come across. We hope that what we do and say inspires others to bring about change and results in positive changes and improvements. We want people to act on what they hear us say.

We also think we can encourage other people with dementia and their families to 'open up'.

It is important that we are asked to contribute to meetings to which the 'right' people are invited – so that we can have an influence and not feel we are wasting our time.

Some things we find frustrating

"It's worse being asked your opinion and then ignored than not being asked at all."

There is sometimes a conflict between the lived experience and the needs of professionals. The most frustrating thing is when an organisation asks for our opinions and then seems to ignore what we say (for example when

JRF involved some of us in interviewing a film-maker or when City of York Council asked our opinions about signage).

“It feels like they are ignoring us or think we’re not capable, that it was just a token gesture – you think, ‘What the point?’”

It’s also really difficult when you go to meetings and professionals talk over your head or in jargon. This makes it difficult to participate. There needs to be a balance between using simple English and not being patronising.

When asked to speak at conferences, it is important that people with dementia are given a good spot in the agenda – this means that they are heard by more people and sets the tone for how important their involvement is. It is also important that we feel at our best when we talk – which for many of us is earlier in the day.

Communication and feedback

“What happens to all the flip chart notes?”

It’s really good to be involved in a project from the beginning to the end. It’s important to know what happens next after any meeting. When you’ve been to a meeting and had a good discussion, it is important to know where those discussions lead and what happens next.

It’s annoying when there is a lack of communication about what’s happening in a project. This is especially true for complicated projects which involve lots of different people. For example, after the event in York on women and dementia, we didn’t hear much about what was happening with the project after that.

In the same way, it is important that we are told the key aims or objectives of any project or meeting we are involved with, and of any impact the work has had.

People with dementia who have contributed should always be sent summaries of any reports, documents or findings from the project. It was particularly nice to be taken back around the Folk Hall in York after the changes we suggested had been made. Including photos to jog our memories can help.

Being appreciated and treated as equals

“A simple thing - like getting a thank you letter saying what happens next - makes you feel appreciated and not just a number.”

Little things like being thanked can make a big difference. A thank you can make a bad experience better.

We want to feel truly an equal part of a project - working in partnership, learning together and exchanging views. People with dementia involved in the Truth Inquiry felt they were contributing to the panel as equals with the professors and other professionals involved. Open and honest communication is important, with no hidden agendas.

The language work felt like a good campaign because it came from what people with dementia have been saying.

Those attending events where people with dementia are participating need to value the opinions of people with dementia – “At one of the workshops at the women’s experiences of dementia event I felt that some delegates were shouting me down”.

Some things that make it easier for us

“People asking us to take part in projects etc. need to understand that we have to put in twice the amount of effort as someone without dementia.”

It is important that it is made as easy as possible for us to get involved. When being involved becomes challenging, it’s time to change how we are involved. The impact and interest has to be worth the effort.

Communication is vital. We understand that professionals have a job to do, but when something isn’t working, it’s important to have someone you can tell. For example, at the beginning of the Truth Inquiry project, some people with dementia found the process difficult, and so adaptations were made to the structure of the meetings (for example people with dementia were asked their opinions first). It’s important that arrangements are flexible and can be changed if possible.

Practical arrangements also help, and being well looked after makes all the difference to our experience.

- A full day meeting can be tiring.

- Keeping to time is important – it’s frustrating when things run over time.
- Asking people with dementia to speak at the beginning of a day helps with nerves, and people are often more alert earlier in the day.
- Equipment such as microphones should work.
- Food, drinks, acoustics, temperature and feel of the room are important.
- Being with people you know and trust helps.
- Being given time to take part fully is essential.

People asking us to take part in projects also need to be aware that we (or our carers) might have personal or health issues that mean we are not always able to take part. We need to live a balanced life and cannot always take part in everything even if we want to. It’s important that we are able to say ‘no’ on a particular occasion and know that we will still be invited to take part in the future.

Having a supporter at a meeting can help us to contribute – they can write notes for us, remind us about a point we want to make, tell us where we are on the agenda and highlight important items in documents.

Supporting us to make our contribution as effective as possible

“It’s important to use the life skills you have”

Different people enjoy different ways of being involved. Some like to get involved in big national projects. Others like to make a difference locally. We need to be selective in what we do so that we can enjoy our lives and make an impact.

All involvement needs to be tailored to the individual and their strengths, skills and interests – for example some people are happy writing and delivering a full presentation, others might like a Q&A or interview format when presenting. It’s also sometimes good to work as a team presenting with professionals.

Projects need to suit us and our interests, and our ability to take part in terms of health, time or travel. Some of us have past experience in our work that enables us to take on specific roles. Sometimes we take on a project just because we trust the person (for example JRF or Innovations

in Dementia staff) who asks us to take part – because we trust that we will enjoy the process.

For the Truth Inquiry, Daphne was a co-chair, which set the tone for how people with dementia were involved in the project. However, other people might find the role too difficult and even Daphne (who has much experience of chairing in her professional life) does find it more difficult to keep track of things.

It's important for us to feel at ease and part of something – contributing to the York Committee grant-making process made the people with dementia involved feel part of the community and part of JRF. A project like the Truth Inquiry that was made up of a number of regular meetings can be easier to understand than one-off meetings (such as those organised for the project on women and dementia or the rights and disability work).

For many, a balance between larger meetings involving different people including professionals, and smaller specialist sessions for just people with dementia and their supporters is a good idea. It's good to have a separate workshop just for people with dementia within a larger meeting (for example at the event on women and dementia).

Sometimes it is good to be able to visit a place, walk around and see something – rather than just sitting around talking. This is especially true when thinking about the design of buildings such as the JRF Folk Hall.

What we contribute

“We're more than our emotional stories”

Powerful though our personal stories are, we need the full spectrum of contributions. Sometimes it would be helpful to have support to contribute more than just our personal stories. We need information about what a project or meeting is about so that we can contribute fully and effectively. Guidance could be given to help people to talk more broadly outside 'my story' to focus on the topic under discussion, or a structure given of how to present. This could be challenging for some people, but for others it could be very helpful. Of course, there is a balance between supporting someone and putting words into their mouth. Not everyone has a background that means they are confident making presentations. It's important that we hear a range of perspectives.

Many of us have been involved in making films – for example the film for the Co-op in Bradford or films about dementia-friendly York. Films can be useful as they can get our messages out to the whole world. A film can capture us living our everyday lives.

Difficult topics

“Having support just to check ‘are you OK?’ is welcome”

Sometimes we are involved in projects where difficult topics are discussed or we hear from people who we don’t agree with. It is important that projects cover a wide range of views and that people are given a chance to have their say.

People organising meetings need to be aware of challenging topics which might be emotional for some people with dementia. Having support just to check ‘are you OK?’ is welcome, and it’s good to be able to talk things through with someone. It can be a long journey home thinking about topics which may have provoked negative feelings.

Involving family carers

“Sometimes carers can take over without meaning to”

Carers can be helpful supporters when we are taking part in projects, as they often know what the person wants to say. However, sometimes it is easier for the person with dementia to talk if their carer is not present, and the other way round.

Some projects have worked well when they split the carers and people with dementia into two groups and then get back together to discuss things afterwards.

Some of us feel that when we’re with a family member, people talk to them and not us. The views of carers are important but they mustn’t detract for our voices.

Being part of a group

“At the beginning it’s all about ‘me’ – later on it’s all about ‘us’”

People with dementia speaking together is very powerful. Being part of a group means we can support each other, so it increases people’s

confidence. With other people with dementia you can say what you want to say because you have a shared experience. In a group of other people with dementia, we feel relaxed and can have a laugh, you can learn and share things and help each other.

Being part of a group of people talking about something feels good – the more people involved the better, so you can hear different views and come to a decision together. We all contribute our ideas and then come to a consensus or agree to disagree.

“The legacy of these projects is bigger than what’s written down, it’s about what’s in the hearts of the people with dementia who were involved”

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.

