



Living well with dementia: your thoughts

During Dementia Awareness Week 2015, we asked you to help us improve our awareness of dementia by sharing your answers to a few questions:

- 1 Can you share some examples of great work being done to support people living with dementia, by projects large or small?
- 2 Which models or types of projects respond best to local and regional differences across the UK?
- 3 How can we successfully involve people affected by dementia so their experiences and expertise shape projects and services?
- 4 What data is there that would help us understand what works, and what doesn't?
- 5 If you could do one thing to make a real difference for people living with dementia, what would it be?
- 6 If you had £10k, £100k, or £1m to help bring about change for people living with dementia, what would you do?

Most of the responses we received came from people working in voluntary and community sector organisations who deliver projects to support people living with dementia. They gave us plenty of interesting things to think about and we wanted to share the responses, so here goes...

Empathy, understanding and communication

Empathy, understanding and communication were important themes that came through in the responses. You wanted people to stop focusing so much on memory and stop correcting people's perception of reality. People should take the time and have the respect, compassion and willingness to reach out to someone with dementia in their world and learn to communicate with them through sensory language rather than just words. The understanding of sensory perception and the impact of smell, touch, taste, sight, and sound will be different for each person with dementia, and we should endeavour to look past the dementia to see these different people.

“Be with them in their moment, wherever they may be and whatever their reality or understanding of time and space”

PossAbilities using welcome values

Members of staff from across the organisation spend time observing an individual on four separate occasions and in different settings. The idea is to experience and feel what they do. At the observation stage it is not about intervening or changing things; just feeling as a human being. Staff then identify things that could make a big difference for that person during feedback and analysis sessions, before considering whether these could be applied across the organisation. This sort of approach can affect change and improve practice in areas beyond those covered by checklists and kitemarks.

Focus on person-centred support and individual needs

Many people talked about the importance of recognising the individual experiences of those with dementia. Dementia is very personal and can affect people in many different ways, so it follows that interventions should be personal and local, helping people to retain their individuality and personhood.

If we had £10k, we would...

...create 'biblets' about the lives of each of the people we support for use by them and their families. A biblett is a widget where you can embed film, pictures, words and music about anything. They are currently used for marketing books, but we think they could be really useful in helping people keep track of their lives.

Raising awareness and changing the image of dementia

Lots of people told us that they'd like to continue to help change the negative image of dementia – that a dementia diagnosis does not mean that a person's life has ended and that it is possible to adapt and to live well with dementia. There are plenty of examples of great work going on to raise awareness and improve people's understanding of dementia, such as [Dementia masterclasses](#) to influence politicians and the media, [Dementia Friends](#) and [Dementia Champions](#) who help raise awareness among the general public. [Dementia Cafés](#) help to create an environment where professionals and carers listen to people living with dementia and alter their understanding and perception of dementia as a result.

In particular, there are some simple concepts and knowledge about dementia that are little known and understood, but where a greater awareness could make a big difference. For example, as dementia affects different parts of the brain, it changes the way that it is wired and alters sensory perception. This might mean that something a person enjoyed in their younger days, such as a genre of music, may become irritating as these changes happen.

Nature Therapy CIC's pop up dementia theatre

Nature Therapy CIC worked with people with dementia and their carers to develop a pop-up dementia theatre to help communities become dementia friendly. Whilst most people generally understand that dementia impacts on memory and language, it is far less known that dementia also impacts on the senses. This is known as sensory deprivation because changes in the brain alter responses to smell, touch, taste, sight, and sound, and it can have a distressing impact on an individual. Sensory deprivation is known as white torture and evidence shows that deprivation can lead to hallucinations, agitation, aggression, poor sleep patterns, social isolation, withdrawal, and depression. Ultimately it can lead to hospitalisation and care homes.



Nature Therapy helps carers, family members, professionals, and the general public understand the importance of sensory experiences in improving the quality of life and well-being of someone with dementia. They do this through a hands-on, fun pop-up theatre, which also gives participants ideas on how to use the free resource of nature to create positive sensory experiences. The aim is to help people living with dementia feel less socially isolated. They are also seeing a decrease in compassion fatigue for carers as they learn to communicate through sensory experiences rather than language and memory alone.

Making services feel familiar

It was clear in the responses that making services and settings feel more home-like and relaxed, and less clinical and institutional could make a big difference. Home, identity, and transitions from home are very important and should be remembered, particularly at times of crisis, when a person with dementia often has little control or choice about where they would like to continue living. The importance of drawing on what is familiar and personal should always be recognised.

Maintaining independence for as long as possible through community approaches

Inclusive, whole community approaches where families, carers, professionals, and the wider community all understand the impact of dementia and what they can do to help can make a huge difference. For example, [Local Dementia Action Alliances](#) run by the Alzheimer's Society, help communities to become dementia friendly and to provide help and support in everyday places, such as at the supermarket or on the bus. There might be a specific bus pass for people with dementia so that staff know to take extra time and offer assistance if required, or the library might identify customers with dementia and not fine them for late return of books. We can also provide care in the community, through telecare or by taking therapies and services to people in their homes. Technology is being used in increasingly creative ways too. For example, GPS tracking technology that can give people with dementia freedom to roam independently, while at the same time giving their loved ones peace of mind.

BME Memory Café set up by Lost Chord, Alzheimer's Society, and the Ethnic Minority Alliance

This example highlights the importance of cultural differences when taking community approaches. Dementia has historically been quite hidden in black and minority ethnic (BME) communities, as there has tended to be more of a culture of shame associated with dementia and a desire to 'look after their own'. So this memory café is trying to target people from BME communities and challenge some of these beliefs to help people living with dementia.

If we had £100k, we would....

...make our dementia day centre intergenerational by creating a small day nursery on site. The effects of mixing young people with older people and those with dementia can be extraordinary, so we would like to create a space which has a degree of integration.

The environment – both built and natural

The Dementia Services Development Centre has handy online resources that explain how the environment can make a big difference for people with dementia. Good technology and design can help to make buildings and built-up environments beautiful as well as dementia-friendly so that they don't unnecessarily disable people with dementia. Getting people with dementia into nature and great outdoor environments can be really effective too. Organisations working in this area include the Sensory Trust, Thrive (who design dementia gardens and give social therapeutic horticulture training), Learning through Landscapes (who are currently piloting a garden design project), and Nature Therapy CIC (who are using pop up theatres to demonstrate how to use nature to create positive sensory experiences for people with dementia).



Nature Therapy CIC

If I had £1m (or more!)...

...I would create a Dementia Care Village modelled on those near Amsterdam.

Quality care

Responses emphasised the importance of great training, support and pay for those caring for people living with dementia in order to ensure continuity of care, the right expertise, and quality of care. This should go beyond specialised staff to appropriate awareness-raising and training for all those likely to have any contact with people living with dementia – as a first step towards whole organisations becoming dementia-friendly. With extra funding, a few people said that they would like to invest in the workforce – training, adequate staffing levels, and pay levels that recognise their skills.

The power of music

We received some really passionate responses about the power of music for people living with dementia. Musicians visiting residential homes and day centres to perform interactive music sessions have been able to stimulate some amazing responses from people with dementia. For example:

- People with dementia have spoken for the first time in a long time
- People who have been very unresponsive, and who are mostly unable to communicate through language, have expressed themselves through music and dance, singing all the words to a familiar song from the past
- People with violent or aggressive tendencies have been visibly calmed by music, without the need for antipsychotic drugs
- People who are very confused and unable to sit for any length of time have sat and listened for longer than anyone thought possible.

“To observe people who are withdrawn and isolated come out of their shell and engage by singing and dancing is tangible, powerful and emotional for all to see. Music has the ability to transform the lives of people with dementia where everything else fails!”



Lost Chord

Training sessions can also be offered to carers, family and volunteers to explain the effect that music can have on the brain and its importance in future care for people with dementia. Musical sessions themselves can be a great experience for carers to share with their loved ones too, helping them to visibly relax and enjoy the music together as a couple or companions, rather than as a carer and person with dementia.

Organisations working in this area include [Musical Moments](#) and [Lost Chord](#).

Look out for Lost Chord's research in partnership with Sheffield University in their new research unit 'Music and Wellbeing' – the results of the research will be disseminated across the sector in order to help shape the future care of people with dementia.

Putting people in the lead

The responses told us lots about ways to successfully involve people affected by dementia so their experiences and expertise shape projects and services – this really stood out for us as that's what [our new strategic framework](#) is all about. The value and importance placed on talking directly to people living with dementia came across strongly in the responses – while the benefits of using more formal and academic research methods was questioned, due to the nature of dementia.

A few people spoke about approaches that include as many people in the community as possible and engage with people at all levels; from people with dementia, to small community groups and projects, to people working on local strategies and national sharing of good practice. Approaches that work across the whole community and across generations can help to develop activities and services which work well in the wider community and are also dementia-friendly – fostering inclusion rather than creating 'dementia ghettos'.

These kinds of principles could be applied to lots of issues – not just dementia. But there are also quite specialist skills and research methods that are often required to successfully involve people with dementia in the development and delivery of projects and services. On one hand, early diagnosis and support can be really helpful so that people are able to contribute their expertise and experiences while they are able to communicate easily through language. But asking people with dementia questions can often cause anxiety – because to answer a question you have to be able to recall the answer and often they cannot. However, if you have researchers with the right skills, they can involve people with dementia long after others might think that they can't communicate. Sometimes carers can provide extra support here too. Methods might include anything from more traditional interviews for those earlier on in their dementia

journey, to observation and arts activities. Approaches like welcome values are an opportunity to step into the lives of people with dementia and understand their experience. Often it also creates a bond with a person, so that in lucid moments they can explain what their experiences and needs are.

It's also important to actively consult people with dementia along with their families and carers. Working creatively with carers and giving them the skills to involve people with dementia can improve their own relationships with loved ones and help us to understand more about people's experiences of dementia. Support and structured activities to help enhance communication with the person they care for can help to improve their understanding, empathy, kindness and compassion. For example, you could ask family and carers to record relevant parts of conversation and anecdotes over a period of a month or so to understand what people with dementia have enjoyed and benefitted from. Or use family members' memories of their loved ones to help design very personalised environments and services.

PossAbilities working with cartoonist Tony Husband

PossAbilities have been doing some really creative work with [Private Eye](#) cartoonist Tony Husband. Tony is the author of 'Take Care Son', the illustrated story of his dad's experience of dementia. He is creating a wall sized mural for PossAbilities' dementia day centre, based on the reminiscences of people that they support who have dementia.



Dementia engagement and empowerment project (DEEP)

DEEP brings together groups of people with dementia and enables them to influence services and behaviour. Through the Dementia Action Alliance they developed a 'call to action' called 'Words Matter', which aims to challenge and change inappropriate language used to describe people living with dementia. They also published a guide that made suggestions for alternative words that can be used instead.

The forget me nots in Kent

The forget me nots frequently give talks at conferences and have recently published a book called 'Welcome to Our World'. Groups like these have invaluable experience that we can learn from and can help us get insights into dementia.

The Big Ask at the DSDC

The Big Ask is a survey being hosted by the DSDC and is all about what people really think dementia means to them – anyone is welcome to take part online.

More examples of great work being done

These are just some examples of great work being done that you shared with us – a flavour of what's out there:

North East England and Cumbria Dementia Fund, DSDC

A three-year project to support family and informal carers throughout the North East of England and Cumbria. A programme of events gives practical information and help which draws on research and knowledge developed over the last 25 years. It provides an opportunity for carers to explore specific issues that matter to them, both with each other and with experts from DSDC. The training is delivered in a relaxed environment by experts who have both professional and personal experience of caring for a family member with dementia.

Dementia Festival of Ideas

A one-year project with a range of events to improve support for people living with dementia – a celebration of the most stimulating thinking, writing, and discussion on what dementia means in 2015.

TIDE, Life Story Network

Tide, 'Together in Dementia Everyday', is an involvement network that recognises family carers of people with dementia are experts by experience, experts that can play a significant role in supporting other carers, influencing policy and shaping improved responsive local commissioned services. The network, which follows on from the excellent legacy of the Dementia Action Alliance Carers Call to Action, will provide a development programme which has been designed by carers to pass on the necessary skills and confidence to other carers finding themselves in a similar situation, so they too can influence and represent their peers.

A Guide to Psychosocial Interventions in Early Stages of Dementia, The British Psychological Society

The BPS produced this guide in partnership with the Alzheimer's Society, Dementia Action Alliance, and DEEP. It aims to help when someone first receives a diagnosis of dementia, offering practical advice about coming to terms with a dementia diagnosis and information about the different support available.

To finish, a story from a Memory Café

RR attended a Memory Café after being signposted to our groups by the Memory Clinic. RR had been attending the Memory Clinic for 18 months before being diagnosed with early onset Alzheimer's disease. The couple were struggling with adjustment to the diagnosis, as RR had been a very independent and a successful businessman, and had always taken control of the family finances and decisions. Attending local groups had never been something that interested him. After attending the Rotherham memory cafés regularly, the couple have made a large number of friends. They always get actively involved with the concerts and activities – RR has even been known

to accompany the singers and they have supported him perform a solo on numerous occasions. He has also developed a closer relationship with another gentleman who has dementia, and they will often sit together, allowing their wives to chat and get support from one another. The two men have gone on to attend satellite day services at the same time, and this has made for a very smooth transition on both parts, allowing their wives valuable respite from their caring roles. RR and JR have both commented that their time at the café is invaluable because they are spending time with people in similar situations. RR can be himself when he is there. They see the café as a comfortable environment where they do not have to explain anything to anyone. They are enjoying their lives to the full with the support of others and will continue to do so for as long as possible.

And finally...

Thank you to everyone who took the time to respond to our survey! Given the wide range of things that we fund here at the Big Lottery Fund, it really is invaluable for us to get your insights into an area where you have such expertise. We'll be reflecting on what we've learnt from you and considering how this can inform our decisions about funding projects that support people living with dementia.