

Dementia without Walls

Programme activity and progress

Last updated: November 2014

How can we help the UK to become a good place for those of us who have dementia to live, and live well?

We believe we need to challenge attitudes, understanding and behaviours around dementia which reinforce stigma, isolation and exclusion. We need to inspire local communities, organisations and businesses to become more aware and understanding of dementia, and more inclusive. And we need to support the collective engagement of people with dementia, so their voice is heard more clearly in this debate, and so they have more confidence and capacity to influence attitudes, policies and practice.

Our programme Dementia without Walls (July 2012 – Dec 2015) includes three main strands:

- Strand 1 - Empowering people with dementia
- Strand 2 - Dementia-friendly communities
- Strand 3 - Thinking differently about dementia

This update summarises ongoing and new work in the first two and a half years of the Programme (from July 2012 – November 2014).

Strand 1: Empowering people with dementia

This first strand builds on the Dementia Empowerment and Engagement Project ([DEEP](#)) which ran for one year until summer 2012. Led by Mental Health Foundation (MHF) with Innovations in Dementia (iD), DEEP mapped UK activity and, in spring 2012, brought together dozens of people with dementia at two ground-breaking events in London and Stockport to develop ideas.

Phase 2 of DEEP (*Innovations in Dementia: Oct 2012 – Sep 2015*) is building on the findings of this scoping project that:

- the collective voice of people with dementia is at a relatively early stage.

- groups are at different stages on their journeys and many (completely understandably) prioritise peer support, and local rather than national action
- but user-led groups are growing in number and confidence
- and they ask for support in capacity-building, networking and learning from each other so they can increase their influence over attitudes, policy and services.

In response to these findings, JRF is now investing in supporting the growth of a stronger collective voice of people with dementia across the UK. Our current project is exploring the question “How can people with dementia better connect with and support each other, so their experiences can shape policy, practice and attitudes?” Our goal is to influence the development of a collective voice of people with dementia through investing in emerging and established groups.

We have commissioned iD to lead on delivering this strand of the programme. The project also involves MHF, Alzheimer’s Society, and people with dementia as formal (paid) Associates. In October 2013, we welcomed Comic Relief as our funding partner.

DEEP2 is:

- Supporting the more established and ambitious groups in sharing their knowledge and expertise, building capacity around the UK
- Demonstrating the value of supporting user-led networks to actual and potential funders by collecting evidence of the impact of this on policy and practice
- Building capacity in groups that are at an earlier stage and in parts of the country where no genuinely user-led groups have been identified.

JRF and Comic Relief are providing grant-funding to cover: staff costs of iD, fees for the Associates and administrative support; costs related to involvement (travel, venues, supporters); communication channels (physical meetings, web, video-conferencing, news bulletins etc); regional and annual conventions of people with dementia from the groups; costs related to administrative and other practical support and advice (which will be provided by MHF). An independent evaluation is being carried out by Brightpurpose.

The outcomes we are aiming for are:

1. A stronger collective voice of people with dementia, with more confidence and capacity to influence attitudes, policies and provision
2. Empowered individuals within groups who feel more confident and aware of engagement and influencing opportunities, and what they can achieve
3. Empowered groups who are having influence at a local, regional or national level

For up to date information on DEEP’s activities, resources and member groups, see their [website](#).

Since the start of the programme we have:

- supported the DEEP network to grow in size (from 12 to over 40 groups across the UK), in visibility and in influence

- through DEEP: provided seed funding for various small projects led by people with dementia; produced a set of guidelines and resources; and set up the Dementia Voices website
- enabled DEEP groups to influence many key bodies such as the House of Lords; PHE; SCIE; NHS London; Pan London DAA etc. The East Kent group had an interview on You and Yours (weekly audience 3.5 million)
- supported the emergence of new involvement groups in specific areas including York, Bradford and Northern Ireland – all now linked into DEEP
- encouraged event organisers such as Hawker, the Alzheimer's Show and the DAA to include and support people with dementia well
- supported EFID, Alzheimer's Society and GeniusYork! to involve people with dementia in assessing award applications
- involved people with dementia in our internal project e.g. assessing award applications; selecting and educating film makers; commenting on design issues; planning the Five Senses Garden at Homestead Park and the rose garden at Hartrigg Oaks
- made a film of a dementia activist (Trevor Jarvis) influencing change

In 2015 we will be:

- publishing a report on DEEP, plus a film of a member group, to be launched at an event planned by and with people with dementia
- supporting Comic Relief to showcase DEEP appropriately for their 2015 Red Nose campaign

Strand 2: Dementia-friendly communities

Being dementia-friendly is about recognising that people with dementia want to carry on living their lives. This requires businesses, organisations, statutory agencies to think of the person first, as a citizen, member, participant, client, customer in their own right but with particular needs because of their dementia. Whilst the role of health and social care is important, and needs to be integrated, formal services are neither the whole picture nor always the most important part. It is also about recognising that people want to stay connected to natural supports locally. This is not easy. It is about a fundamental reshaping of the relationship between individuals, the community and the state. Because of this it is incredibly challenging and takes us well beyond services.

Our work in this strand builds on and extends beyond the scoping project we funded in York – [York Dementia without Walls](#). We have identified four key outcome areas for this strand of work.

1. Becoming a dementia-friendly employer (JRF/HT)

We see this as a cornerstone of our commitment to making York dementia-friendly, and an excellent opportunity to influence other employers and businesses through 'being the change we want to see in the world'. We aim to achieve awareness and understanding of dementia across every part of JRF/JRHT (not just care services) to:

- demonstrate what it can mean to become an organisation that is 'dementia-friendly' - that is informed, and that recognises and addresses the impact of dementia on staff their families and residents
- demonstrate how this contributes to making York dementia-friendly
- demonstrate the value of such an approach to other organisations across the UK (potentially partnering and influencing some of the big companies who are signed up to the DAA or as Dementia Challenge Champions).

This will require involving people with dementia and their families (staff or residents) in planning and delivering the initiative, and learning from and potentially collaborating with other employers who are trying something similar. We have recruited a community development manager, Katherine Blaker, to support this work.

In the Autumn of 2014 we held a 'roadshow', visiting all our settings across Yorkshire and meeting with over 200 colleagues. We talked about dementia and listened to people's experiences – as service providers or as family carers – and also to their worries about getting dementia in the future. Since then we have:

- trained several Dementia Champions and numerous Dementia Friends
- allocated grants to over twenty York based dementia-friendly projects, and shared the learning between them
- involved people with dementia in many aspects of our internal project
- influenced design and physical environment in JRHT and Bradford through a bespoke 2-day course from the University of Stirling
- refurbished the Folk Hall in New Earswick along dementia-friendly principles
- made dementia-friendly changes at our London office, and worked with other tenant organisations and the building manager to make the whole building dementia-friendly
- played an active role (through our HR department) in producing a national toolkit for employers, as part of the PM Champions Group
- held events at Hartfields to raise awareness of Lasting Power of Attorney
- placed dementia information boxes in 17 JRF/HT settings
- made a film about JRF/HT becoming dementia-friendly, focusing on our role as a housing association

In 2015 we will be:

- repeating the Stirling design training in Hartlepool, and hosting a new course on design of public buildings, in York
- delivering dementia-friendly awareness sessions across our housing services, and to Directors and Trustees, and agreeing training needs/plans for specific teams
- delivering Virtual Dementia Tour™ experiential sessions to colleagues, mainly in our care services

- influencing design and physical environment in planning for New Earswick, at our London office, and Derwenthorpe
- promoting access to our Admiral Nurse
- developing our library resources
- creating dementia friendly outdoor spaces at Hartrigg Oaks, Homestead Park and Plaxton Court
- supporting colleagues in JRHT to become actively involved in their local DAAS (e.g. York; Hartlepool) and to connect with other HAs which are working to be dementia friendly
- carrying out an online survey of all staff to assess impact and change
- publishing an independent evaluation of JRF/HT's project
- setting up an intranet page on the new website to bring together learning and resources which can support dementia-friendly JRHT
- maintaining an active role in EFID

2. Supporting York's aspiration to become a dementia-friendly city

We are supporting the evolution of the York *Dementia Without Walls* project. We do not see ourselves as leading or driving this agenda – but as playing a principal supporting role. We are already:

- Providing small grants (25K per year) to local groups in York who wish to play their part in making York or their local community more 'dementia-friendly' (via a stream within the JRF York Grants Committee). People with dementia and carers are involved in commenting on these applications.
- Supporting [GeniUS! York](#) with their dementia challenge
- Bringing together people from museums and art galleries to work on local initiatives
- Working with other member organisations of businesses through York Cares

We are also:

- Providing on the ground support with networking, sharing learning, co-ordinating and building relationships, and community development
- Using social media and local media
- Using our relationships with influential local figures
- Organising a programme of small events and meetings to help share learning
- Engaging in partnership activities with a range of private, public, community groups
- Funding York CVS to provide secretariat functions to the York Dementia Action Alliance.

3. Contributing to Bradford's ambitions around becoming dementia-friendly

We have commissioned the Alzheimer's Society to continue their work in dementia-friendly communities in Bradford (*Alzheimer's Society: April 2013 – March 2015*). This is a funding partnership with Bradford Council.

We have commissioned Janet Dean and QA Research to carry out independent evaluations of both projects in York and Bradford. These will be available in early 2015.

4. Supporting other communities across the UK to become dementia-friendly

Early in 2014, we published twenty case studies and photographs to reflect dementia friendly work across Yorkshire. These were extremely well received.

In 2014/15 we will also be producing three short films on the theme of dementia- friendly communities.

We have now commissioned projects in each jurisdiction on the theme of dementia-friendly communities. These include:

- DEED: a dementia-friendly project in Derry-Londonderry (*The Old Library Trust: Jan 2014 – July 2015*)
- Workshops and a DVD aimed at the deaf and hard-of-hearing communities in Northern Ireland (*Alzheimer's Society and BDA: Jan 2014 - Sep 2015*)
- A survey of public attitudes to dementia in Scotland, funded with the Life Changes Trust (*Scotcen: Jan 2014- Dec 2015*)
- Supporting a new network for dementia in Wales (*Public Health Wales: July 2014- June 2016*)
- *An evaluation of Dementia friendly Communities CIC in East Sutherland, Scotland*

We have also:

- played an active role in the local, regional and national DAAs, on the PM's Champions Group, and on its working group on employers and dementia
- joined and played an active role in EFID (European Foundations' Initiative on Dementia), part funded their European awards, and specifically helped them to develop the involvement of people with dementia in EFID
- presented at numerous events, including conferences of CIH, LGA, Community Care, UK Dementia Congress, Dementia Action Alliance, RTPI, Housing LIN, Hawker, Alzheimer Europe and Alzheimer's Society
- demonstrated the importance and value of people with dementia being at the start and the heart of DFCs
- specifically influenced the development of DFCs in many locations such as Swansea, Hampshire, Inverclyde
- influenced the Alzheimer's Society's recognition process and standards for DFCs
- shared our learning across the UK and with interested parties from Norway, Belgium, France, Italy, Spain, Canada and Germany
- made a film of a couple affected by dementia (Peter and Avril Jones) 'living well' in their local DFC, Haxby
- supported York University students to make a film about York Station (this has been picked up by the British Transport Police E&D unit and promoted nationally)

We are also playing an active role supporting the national and regional DAAs, and on the Prime Minister's Challenge Champions Group. We have sponsored significant events such as the DAA annual conference and the UK Dementia Congress, and in June 2014 we supported Hawker's dementia friendly communities conference in Leeds.

Finally, we host a [resource hub](#) , a portal for links to the most useful information and resources on dementia friendly communities.

In 2015 we will be:

- publishing independent evaluations of DFCs in York, Bradford and East Sutherland, and a summary report from Derry-Londonderry
- supporting the LGA to embed its Call to Action to Local Authorities; providing evidence-based content for several planned LGA outputs; and helping them to become the 'go-to' for Councils/councillors wanting to become dementia-friendly communities
- linking into DH re the new 'Dementia Vision' (successor to the National Strategy) (and linking them with DEEP)
- serving on Public Health England's Dementia Governance Board, and specifically advising on their remit to promote DFCs and their commitment to equity and diversity
- supporting the development and promotion of evidence-based dementia-friendly design standards through links with town planners and architects
- supporting and advising the second Hawker UK dementia friendly communities conference (June 2015)
- supporting DEEP and the Bradford FIT group to produce a DEEP guide on involving people with dementia in dementia friendly communities

Strand 3: Thinking (and talking) differently about dementia

We want to support the development of conceptual thinking around dementia for research as well as policy and practice.

We have commissioned the Mental Health Foundation (*MHF: Jan 2014-Oct 2015*) to set up an Inquiry into 'Dementia - what is truth'. This Inquiry is investigating ways of reframing our understanding of some of the most challenging and distressing symptoms of dementia - confusion, disorientation, and "delusions" - usually experienced by people with more advanced dementia. For the individual with dementia these experiences may appear to be very meaningful and responding to them purely as symptoms of an illness can be unhelpful or even harmful to the person. Can dementia be reconceptualised to enable responses which are more supportive, therapeutic, and possibly even empowering for people with dementia? The Mental Health Foundation (MHF) is conducting an 18 month UK Inquiry involving a panel of experts, including people with dementia and carers, that will consider evidence from a literature review, online survey, oral hearings, and site visits.

We have also commissioned a project which, uniquely, is exploring the experience and impact of dementia from the perspective of women (*Innovations in Dementia: Jan 2014-Oct 2015*).

We have also commissioned a Viewpoint on Positive risk taking (PRT). This is based on the idea that the process of measuring risk involves balancing the positive benefits from taking risks against the negative effects of attempting to avoid risk altogether. While recognising that negative consequences of risk still have to be managed appropriately, PRT also conceptualises risks as providing opportunities for learning and enabling people to make their own decisions, exercise choice and build upon a person's strengths and abilities rather than focusing on their deficits. This Viewpoint 'think piece' examines the practical implications and opportunities associated with the principles and practice of positive risk-taking (PRT) for the development of dementia friendly communities (DFCs) and the empowerment of people living with dementia. (*Mental Health Foundation: Jan 2014- April 2014*)

We have joined [EFID](#) (European Foundations Initiative on Dementia), a network of six Foundations (including JRF) which share our commitment to reframing dementia and to supporting the development of dementia-friendly communities.

Since the start of the programme we have also:

- joint funded a module in the Scottish Social Attitudes survey, to explore public attitudes to dementia
- highlighted and addressed diversity and marginalisation issues relating to faith, ethnicity and culture; gender; sexual identity; learning disability; and deafness
- supported a new DEEP guide on language. The BBC used these guidelines in their major dementia week in October 2014

In 2015 we will be:

- publishing reports on:
 - the MHF Enquiry 'Dementia – what is truth?'
 - Women and dementia
- helping to promote the findings of the Scottish Social Attitudes survey module on public attitudes to dementia
- co-hosting a round table with MHF and iD, to explore if and how clarifying legal definitions of disability could secure the rights of people living with dementia.
- disseminating our key messages through a coordinated social media campaign with our key partners
- launching a Call to Action on Dementia Words Matter through the national DAA, with an accompanying short film.

General information about the programme

Engagement and influencing

Partnership working is a key part of our approach (formal and informal). We have positioned ourselves as part of a wider social movement, locating our contribution in the wider Dementia Action Alliance and equivalents across the UK.

We are developing a communications plan and a media strategy for and across the three strands. This will build on extensive existing contacts and expand these. We will consider bespoke audience research to identify the best methods of engaging and communicating, and seek to learn from others. Our own demonstration (as an employer) can be used to good effect throughout. The favourable external environment – in terms of growing awareness – means we are able to use alliances, online and social media networks, events, as well as traditional broadcast media and our own website. We do not propose to lead on engaging with the public; rather we hope to inform those who do.

We have also: arranged training for our communications staff so we lead the way in communicating about and with people with dementia; provided accessible findings for people with dementia (this will be a key area for us – where we hope to learn from best practice and push at the boundaries); created a web-page to support resource-sharing and development of a dementia-friendly York. We are receiving many invitations to share our work, sponsor or support others' events and comment on external developments.

Other ideas under discussion include sharing this with peers; developing strategic links with specific journals, events, online or social media outlets

Governance Arrangements

Rather than a single Programme Advisory Group, we draw people together on an 'as and when' basis. We are using our relationships with key partners in York and through the DAA and the PM Challenge Champions Group to keep connected. Many of our specific projects have individual advisory groups. We have set up (supported by iD, and linked to DEEP 2) an advisory sounding board of people who have dementia for the programme. We have also reviewed progress against outcomes and milestones in-depth with Trustees at Ageing Society Awaydays. And we held a 24 hour mid-programme event in September 2014 in which 5 of our advisors who are living with dementia were actively involved.

The programme requires a truly collaborative approach across JRF and JRHT. Strong working relationships have been forged through the programme scoping phase and an internal steering group ensures a fully joined-up approach

Equality and Diversity

Our review of equality and diversity has shown that members of different minority communities have very different and specific experiences, both of services and of wider public/community attitudes and understanding. The impacts of dementia are compounded by the additional challenges and discrimination experienced by people with multiple and/or sensory impairments; the frailties and losses of old age; learning disabilities; from BME communities; LGBT groups; women; younger and older people (e.g. of those diagnosed with dementia aged 40-60 years, many more are men than women). Attitudes to dementia are very influenced by our society's ignorance about, and negativity towards, both mental

illness and old age. Perceptions can be shaped by age, generation, and by culture, including cultures associated with ethnicity and religion.

While we did not propose a specific focus on a particular equality 'group', we have tried to ensure that, across the programme, those from a wide range of ages, groups and communities are included and that their voice is heard. We have established relationships with key organisations which can help us to understand and access people with different perspectives. We have also been alert to the relevance of place, and the additional impact of poverty on those affected by dementia.

We have contributed to PHE's new commissioners' guide on Equity and Dementia.

Involving people with direct experience

Involving and working alongside people with dementia is central to this programme. In the scoping programme, our projects modelled good practice by supporting people with dementia to help plan and participate in the mapping activities and events. In this programme, we have strengthened this commitment and commissioned project teams who demonstrate a real understanding of how to involve people with dementia.

As well as the DEEP 2 partnership, we have commissioned support from Innovations in Dementia to embed the links between DEEP 2 and our programme by supporting a small advisory sounding board, comprising people with dementia, to work with us on specific issues e.g. film-making and grants assessment. This has helped ensure that we are genuinely informed by people with dementia as we go through, and be part of our governance for the programme.

Programme Timetable

The programme runs from July 2012 to December 2015, with the bulk of the project activity being commissioned in 2012 and 2013, and a rolling programme of engagement and communications.

For more information on 'Dementia without Walls', visit our [webpage](#)

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