

# CREATING A DEMENTIA-FRIENDLY YORK

## What's the Issue?

For many people with dementia, the battle is not just about getting a diagnosis and support from the health and social care system, but about the everyday things we all take for granted – having control over daily life, spending time with friends and family and enjoying hobbies. These are made difficult by a lack of understanding about dementia in our communities.

While dementia is not a consequence of old age, it is more common in older people. In York, this is a particular challenge because there is a relatively higher older population already, so the number of people with dementia is set to grow.

Communities that are dementia-friendly have more opportunity to support people in the early stages of dementia, maintaining and boosting their confidence and their ability to manage everyday life. The York Dementia Without Walls project shows how many of the resources and services in a place can be harnessed for the benefit of people with dementia.

## Ways Forward

- What is good for people with dementia is good for everybody. Places and neighbourhoods that provide good housing, transport and facilities will not only be more dementia-friendly, but will also make life easier for everyone.
- Training for people at all levels and in all sectors should be easy to access and well promoted. This should enable people who provide everyday services (e.g. banks, shops, transport and leisure) to understand better what people with dementia need.
- York's bounty of leisure, cultural and spiritual resources can help people with dementia to live richer, fuller lives. This might require some adaptation.
- Health and social care services will need to change over time to ensure there is enough support for people living in the community. People with dementia should be central to helping to plan for this.

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OCTOBER 2012

# BACKGROUND

As part of its Dementia and society programme of work, the Joseph Rowntree Foundation (JRF) is supporting both national and local projects. York Dementia Without Walls is a local project which considers what aspects of York are already 'dementia-friendly' and how it can become more so.

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## Why are dementia-friendly communities important?

Most people already know somebody who has dementia, either a member of their family, someone in their neighbourhood or in their professional and social networks. As the 'baby boomers' live longer, more of them will experience dementia – though not always in old age as early-onset dementia can affect people in their forties. Over the next 30 years, the prevalence of dementia is set to double from about 750,000 to around 1.5m.

The pressures caused by the escalating costs of healthcare and social care are increasingly understood by the general population. It will be a challenge for the future to afford institutional solutions for a growing number of older people, some with dementia. While some people will spend time in hospital, nursing home or residential care, many people with dementia live at home: in their communities, alone or supported by family and carers. The more people with dementia can remain engaged with their communities, using their skills and retaining their confidence, the better their quality of life will be.

In March 2012, David Cameron set out his Prime Minister's Challenge on Dementia, recognising the need to build on the National Dementia Strategy. One commitment sets a target that 20 cities, towns and villages sign up to become more dementia-friendly by 2015. The Prime Minister highlighted the York Dementia Without Walls project as a first-wave exemplar in what is becoming a movement across the country and is now formally championed by the Alzheimer's Society nationally.

## York Dementia Without Walls: putting people with dementia at its heart

York Dementia Without Walls is an 'action research' project – which means that its approach is to talk to, listen to and observe people with dementia and their carers in a variety of settings and situations. An underlying premise of its work is that people with dementia have a contribution to make to society. Rather than constantly being seen as dependent, there might be an 'interdependency' to discover where people with dementia are naturally included and valued as essential to strong and diverse communities.

The project drew on existing networks and resources in York, so that the ideas about a dementia-friendly city were generated in the context of mainstream services. A cross-sector working group was established that met bi-monthly, and this acted as a source of inspiration and a route through which to contact people with dementia directly.

JRF had suggested that a programme of 'seeing is believing' visits with people with dementia could contribute to the development of what makes a place dementia-friendly. 'Walking the patch' and looking outside the city at best practice were both important, but understandably there was little interest from people with early-stage dementia in looking at residential facilities or specialist housing. There were richer sources of understanding to mine in talking and listening to people's experiences, and in testing findings and concepts at a sounding board event with people who had contributed to the project in a variety of ways.

## The Four Cornerstones of dementia-friendly communities

The involvement of the AESOP Consortium ([www.aesopconsortium.co.uk](http://www.aesopconsortium.co.uk)) and Innovations in Dementia ([www.innovationsindementia.org.uk](http://www.innovationsindementia.org.uk)) in the Local Government Association (LGA) Ageing Well Programmes in Sheffield and Hampshire provided the opportunity to compare what was being said about York with these two other areas. In these three very different communities it was possible to see that a dementia-friendly community was a dynamic concept in which people with dementia were acting and reacting with their community both environmentally and personally. From this, the 'Four Cornerstones' model emerged (see full report), which Innovations in Dementia has adapted as four of its five themes in the LGA work.

The name Dementia Without Walls derives from the name of York's Local Strategic Partnership, Without Walls, who kindly granted permission to use it. York is a walled city, protecting and containing its population; at the same time the walls can be obstacles and barriers to empathetic response to the needs of that population. Communities can create barriers for people with dementia, and dementia-friendly communities help people to take the barriers down. The Four Cornerstones model extends the metaphor to suggest that a dementia-friendly community needs some essential building blocks or 'cornerstones'.

The evidence from the project suggests that these cornerstones are place, people, resources and networks.

### Place

*'We moved from a large house in Heworth to a bungalow in Wigginton as our retirement plan. We find that Wigginton is very convenient, everything is to hand and we can walk to the shops. It is a friendly place and we enjoy living there.'*

Place covers everything from a person's home, to the feel of the neighbourhood, to the ability to get in and out of, and around, the city. The resources available from the University of Stirling Dementia Research Centre on aids to daily living, the work done on Lifetime Neighbourhoods and, more recently, on Dementia-friendly Communities by the University of Warwick, and the experience of Manchester as one of the World Health Organisation's Age-Friendly Cities, combined with the daily experiences of people with dementia in York all shaped the project's view of the importance of place.

A sample of the key project findings about **place**:

- A good place to live is a pre-requisite of a dementia-friendly community.
- Some of the negative effects of dementia can be reduced if attention is paid to the quality of a person's environment.
- Some places in York are recognised as having characteristics that support people with dementia better than others, and this understanding can be shared across the city.
- The historic resonance of York is positive for people with dementia, and a slower pace of change could be helpful.

British Transport Police colleagues worked with the project to improve their understanding of dementia, and have offered to support people with dementia and their families in building confidence to travel safely by rail.

## People

*'I would like support from the people around me – my GP, vicar, my family – but they don't know what to do or say.'*

People with dementia rely on others, to varying degrees, throughout their dementia lives. The critical people are partners, families, carers, neighbours, everyday service providers (such as shopkeepers, the milkman), as well as health and social care workers (and particularly GPs). What the people around them know about dementia, their attitudes to it, what they say and how they act, are critical to making people feel confident or otherwise. Carers are crucial for many people with dementia, and most care is provided within the family by a spouse or children or other close family member. It is important to provide support for carers to enable them to care, but also to recognise that they sometimes have a different view of the world from the person for whom they are caring.

The role of GPs is central to supporting people with dementia through early diagnosis and advice, not just about the long-term prognosis and care options, but also about staying well and engaged through the earlier stages. GPs' new lead in clinical commissioning through the NHS reforms means that their understanding and knowledge of dementia is even more important for the future. As a result of attending the project's sounding board event, the Vale of York Clinical Commissioning Group's lead GP on mental health and dementia recognised the value of training receptionists in her practice. This shows the immediate impact key people can have in creating dementia-friendly communities.

A sample of the key project findings about **people**:

- Increasing awareness of dementia and changing our attitude towards it can help to remove the stigma many people feel. This may help people to talk about their experience, to engage more in society and to ask for the help they need.
- Supporting carers and the families of people with dementia is essential to supporting people themselves.
- A consistent approach and response to diagnosis by GPs, and better signposting would increase confidence and support people in the community for longer.

GCSE Drama pupils at Joseph Rowntree School in York developed a piece of theatre about people with dementia which they performed at the Joseph Rowntree Housing Trust annual meeting in September. To prepare they spent time with a person with dementia and his wife to deepen their understanding of how they see the world.

## Resources

*'There are a couple of places we go to have lunch in York – we chose them because the staff were friendly and helpful.'*

One of the project's key observations is that people with dementia can feel they become the 'property' of health and social care. What seemed to happen to a number of people was that, following diagnosis, they had little support unless they engaged with the Alzheimer's Society or other groups. York does not have a memory service, and its resources tend to be targeted at those in the later stages of dementia. Community health and community-based social care services feel less visible to many people.

The project provided the opportunity to consider how York's wider resource base including the services outside health and social care provided by City of York Council, other public services, the voluntary and community sector and the private sector could support people with dementia. York has

a rich offering of shops, restaurants, leisure and cultural facilities and all these play a role in making the city more or less dementia-friendly.

From an early stage in the project people with dementia talked about the importance of good customer service, demonstrating that what is good for people with dementia is good for us all.

City of York Leisure services shared a number of opportunities and ideas for helping people with dementia to get involved in active leisure, such as Health Walks and guided cycle rides. At the EngAge event held at the Energise leisure centre in the city, the project supported demonstrations of adapted games, like Jiminy Wicket (a version of croquet), and enabled a person with dementia to try out new sports and fitness routines.

Whilst the project did focus more on people in early stage dementia and considered the resources of the City as a whole, good health and social care services provided up to the end of people's lives are equally important resources in a dementia-friendly community. During the project the NHS reforms were articulated and are currently being shaped and implemented, enabling GPs in the Vale of York to lead commissioning, and the City of York Council has undertaken a review of its Elderly Persons' Homes. At the same time North Yorkshire and York Primary Care Trust is undertaking a spending review of health services; York Hospitals Foundation Trust has completed the acquisition of Scarborough Hospital and also runs a range of community hospitals in and around York; and the Leeds and York Partnership Foundation Trust is now the provider of community mental health and learning disability services in York. All these organisations have major contributions to make to the future of health and social care services for people with dementia. A new Health and Wellbeing Board has been established which will have responsibility for overseeing health and care outcomes, and promoting wellbeing generally.

A further contextual issue for the project was concern about public sector funding, not only in the future but also in the present. This combined with some thinking about the opportunities that new technology might offer. At the sounding board event a number of suggestions were made about the need for simpler technology and equipment and about the possibility of a dementia mobile phone app or even a York Dementia app. A local entrepreneur whose mother had dementia contacted the project. He had set up a computer screen programmed to help her to remember daily events which also used family photographs and Facebook to support her social contacts. Simple technologies, such as pre-recorded and pre-programmed recorded messages, are already being used successfully in other areas, for example by South Yorkshire Housing Association.

A sample of the key project findings about **resources**:

- The welcoming approach of a tourist city can be exploited as a potential benefit for people with dementia.
- People with dementia benefit from the best of what we all need from local services – good customer service, patience and kindness.
- York is well placed to use its rich cultural and leisure facilities to engage and support people with dementia in the community.
- There is an opportunity with the NHS reforms and the City of York Council review of Elderly Persons' Homes to improve commissioning and delivery of services for dementia.
- Creative use of technology could expand the resources available for people with dementia in York.

York's innovation scheme – GeniusYork – is considering how technology can help older and vulnerable people. This has the potential to think about the specific needs of people with dementia, in terms of memory loss, confusion and disorientation.

## Networks

*'To keep individuals at the heart, agencies must work together (even when it's a bit strained) – the end justifies the means'. PCT Manager*

This is a slightly more elusive concept, but within the project there was a sense that a dementia-friendly community benefits from the 'glue' which holds things together.

The importance of networks emerged in a number of ways. From the point of view of people with dementia, the networks in their local community could be a vital part of their experience of whether York is or is not a dementia-friendly community. Generally, people felt that York was friendly and potentially dementia-friendly, but some places worked better than others, not just on a physical level but because of who knew what and how people interacted.

Another area where networks are important is in navigating around the health and social care and voluntary service systems. The GP often provides the first link, and people experienced significant differences in how and when they were referred to other services, or were told about local resources. If you happen to meet a series of informed and helpful people, you may experience networks working well to refer you on to more support, but this experience isn't consistent or guaranteed across the city.

A third level, not particularly visible to people with dementia but apparent within the project, is the need for good networking, coordination and collaboration amongst people involved in planning the future for people with dementia, at the highest strategic levels and also within neighbourhoods.

A sample of the key project findings about **networks**:

- Strengthening and building networks of dementia champions at neighbourhood level will optimise the impact of resources for people with dementia in the community.
- Networks of people with shared interests – like the York Older People's Assembly – are a good source of information and support, and provide opportunities to influence.
- There is a particular opportunity in York for the Health and Wellbeing Board to promote and monitor progress in creating a dementia-friendly city.
- A York Dementia Action Alliance could be the focus for wider and sustained business and community engagement in a dementia-friendly city.

The Joseph Rowntree Foundation with the Joseph Rowntree Housing Trust has made its own commitment to becoming a dementia friendly organisation, by looking not only at its services but also at its role as an employer.

## Conclusion

These proposals distil many ideas generated by the people who were involved in York Dementia Without Walls.

**Recognise that what is good for people with dementia is good for everybody by:**

- Planning for their needs in the development of housing, transport and local facilities.
- Expecting good customer service, patience and kindness as the way we treat people in York.

**Increase awareness** of dementia by:

- Talking about it more.
- Producing more and better information that can be used by a range of people, e.g. carers, GPs, local shopkeepers, teachers in schools.

**Change our attitude** towards dementia by:

- Challenging stereotypes and prejudices directly and by using positive images of older people and people with dementia.
- Focusing on what people with dementia can do rather than what they can't.
- Assuming that people with dementia will be included rather than excluded.

**Provide training** for people at all levels and in all sectors by:

- Developing ladders of training so that people can acquire the right detail of knowledge for their needs.
- Using online training resources that are currently available to make access easy and affordable.

**Encourage people with dementia** to use York's wealth of leisure, cultural and spiritual resources by:

- Promoting them as dementia-friendly and exploring how they could be rated as such by people with dementia.
- Adapting them or relaxing the 'rules' – this could apply as much to religious practice as to sports.

**Grasp current opportunities** to prepare for the future needs of people with dementia by:

- Responding to the Joint Strategic Needs Assessment and making sure that reform and reorganisation of health and social care has dementia at its core.
- Involving people with dementia in planning for their futures.
- Exploiting the potential of technology to improve the lives of people with dementia.

## References

The following references are good sources of information nationally and locally and will lead to a wide range of other resources.

'Living Well With Dementia: a National Dementia Strategy', 2009: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_094058](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058)

The Prime Minister's Challenge on Dementia, published in March 2012 builds on the National Dementia Strategy: [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_133170](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_133170)

The Dementia Portal is a useful source of references about dementia: <http://dementia.dh.gov.uk/>

The LGA has published a toolkit which helps local authorities to think about how to make their communities more dementia friendly: [http://www.local.gov.uk/web/guest/ageing-well/-/journal\\_content/56/10171/3511211/ARTICLE-TEMPLATE](http://www.local.gov.uk/web/guest/ageing-well/-/journal_content/56/10171/3511211/ARTICLE-TEMPLATE)

NHS Reforms – the Health and Social Care Act Explained: <http://healthandcare.dh.gov.uk/act-factsheets>

Outcome of the Design Council competition to help people live well with dementia: <http://www.designcouncil.org.uk/about-us/media-centre/revealed-new-designs-to-help-people-live-well-with-dementia/>

Stirling University's Dementia Services Development Centre has a range of publications available at <http://www.dementiashop.co.uk/taxonomy/term/11>

The Housing Learning and Improvement Network (LIN) has some good resources for use in commissioning, adapting and designing new housing for people with dementia: <http://www.housinglin.org.uk/Topics/browse/HousingandDementia/>

Manchester Age Friendly Strategy: [http://www.manchester.gov.uk/downloads/file/11912/summary\\_manchester\\_a\\_great\\_place\\_to\\_grow\\_older\\_2010-2020](http://www.manchester.gov.uk/downloads/file/11912/summary_manchester_a_great_place_to_grow_older_2010-2020)

The Social Care Institute for Excellence Dementia Gateway e-learning resource: <http://www.scie.org.uk/publications/dementia/resources/elearning.asp>

Alzheimer's Society newsletter resource on aspects of dementia-friendly communities: <http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200241>

iD Innovations in Dementia has good resources on their website: [http://www.innovationsindementia.org.uk/projects\\_communities.htm#communities](http://www.innovationsindementia.org.uk/projects_communities.htm#communities)

'Health and Well Being in York: Joint Strategic Needs Assessment' (JSNA) 2012 <http://www.york.gov.uk/content/socialcare/healthandwellbeinginyork2012.pdf>

City of York Review of Elderly Persons' Homes: [http://www.york.gov.uk/health/Services\\_for\\_older\\_people/eph](http://www.york.gov.uk/health/Services_for_older_people/eph)

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## About this paper

This paper looks at how the York Dementia Without Walls project has worked with local people with dementia to listen to their ideas about what would improve their lives. The project also considered experiences from other places to find out what can help to create a dementia-friendly city.

## FOR FURTHER INFORMATION

This summary is part of JRF's research and development programme. The views are those of the authors and not necessarily those of the JRF.

The main report, **Creating a dementia-friendly York** by Janet Crampton, Janet Dean and Ruth Eley, is available as a free download at [www.jrf.org.uk](http://www.jrf.org.uk)

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Other formats available  
ISSN 0958-3084  
ISBN 978 1 85935 940 2

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Ref: 2819