
REPORT

CREATING A DEMENTIA- FRIENDLY YORK

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This report considers how York can become a more dementia-friendly city. While York is responding positively in many ways to the needs of people with dementia, there is still much to do to make sure that people can live well with dementia.

Our work – a combination of research and development – has focused on what happens to people before and after they are given a diagnosis of dementia. This report:

- features real lives, accounts of lived experiences, and thoughts on how York compares to other places and what it might do to become increasingly dementia-friendly;
- draws on the experiences of life in York for people who are trying to live as well and as normally as possible despite their dementia, and occasionally *because* of their dementia; and
- puts forward some ideas on how York can build on the things that work well for people with dementia and overcome the things that work less well based on ‘the Four Cornerstones’ of place, people, resources and networks.

The report is timely in that it coincides with national interest in local communities sustaining their populations regardless of their needs, illnesses or conditions, and follows the implementation of the National Dementia Strategy and the Prime Minister’s own personal challenge to create more dementia-friendly communities.

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EXECUTIVE SUMMARY

This report is the culmination of a year's investigation into what it would take to make the City of York a good place to live for people with dementia and their carers who are trying to carry on with their lives as normally as possible. The city is responding positively in many ways to the needs of people with dementia, but there is still much to do to make sure that people can live well with dementia.

Our work – a combination of research and development – has focused on what happens to people before and after they are given a diagnosis of dementia. This report features real lives, accounts of lived experiences, and thoughts on how York compares to other places and what it might do to become increasingly dementia-friendly.

Context and focus

While not a consequence of ageing, the prevalence of dementia is increasing as people live longer and the proportion of older people in the population has risen. The work on dementia-friendly communities has grown out of national and international research and policy development in age-friendly communities, but also crucially from the voices of people with dementia and their carers, which are beginning to be heard. A movement has begun that has been boosted by Prime Minister David Cameron's personal challenge, in which *Dementia Without Walls* is cited, and this report is therefore timely.

The Joseph Rowntree Foundation, with its roots and continuing presence in York, wanted to set up a local project alongside national work to listen to people with dementia, and this project has created an opportunity for local partners in all sectors to consider how they can make the city more dementia-friendly. The focus is on people's lives in the round, looking at the services and facilities which make for a good quality of life, of which health and social care are only one feature. We have therefore tended to concentrate on and talk to people in earlier-stage dementia who are living at

home in the community. We have captured some views from people living in residential and nursing homes, and in hospital, but it has been more difficult or potentially intrusive to connect with single people living alone and with people from groups with other specific characteristics, such as lesbian, gay, bisexual and transgender, or people from minority ethnic groups. We have a sense of the complex isolation of some of these groups, and further work could reveal the strengths and weaknesses of their support networks.

What do we mean by dementia-friendly?

A dementia-friendly community has been described by people with dementia in this project and in others to which we have contributed¹ as one that enables them to:

- find their way around and feel safe in their locality, community or city
- access the local facilities that they are used to (such as banks, shops, cafés, cinemas and post offices, as well as health and social care services)
- maintain the social networks that make them feel still part of their community.

The concept is based on inclusion and an 'assets-based' approach – building on what people can still do and the contributions they can still make – rather than on a 'deficit model' which applies a definition of equality that compensates people for the things that they can't do.

What we discovered about York

In general, we found that York is well-placed to position itself as a dementia-friendly community. It already has many strengths and a willingness to work on the areas which would make life even better for people with dementia and their carers and families.

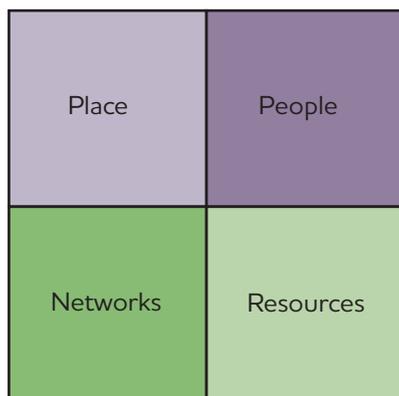
Some of the key strengths of the city are:

- human scale
- historic resonance
- friendly people
- hospitality culture from a tourist city
- a 'bounty' of cultural, leisure and spiritual resources
- good range of housing and neighbourhoods offering quality lifestyles
- choice of transport options.

Some of the things which people felt could make York even more dementia-friendly were:

- better awareness and understanding of dementia
- a more consistent and supportive response from GPs and health and social care professionals
- improved customer service, especially in larger and more 'corporate' companies where technology and speed are prioritised
- a slower pace of life generally, using quiet and green spaces better
- welcoming people with dementia to use all the facilities that the city has on offer.

Figure 1: The Four Cornerstones model



The Four Cornerstones model

Our analysis of previous and parallel work, supported by our findings in York, led us to propose a model for realising a dementia-friendly community. With the voices of people at the heart of the process, we believe that communities need to consider four ‘cornerstones’ to test the extent of their dementia friendliness.

These are:

Place – how do the physical environment, housing, neighbourhood and transport support people with dementia?

People – how do carers, families, friends, neighbours, health and social care professionals (especially GPs) and the wider community respond to and support people with dementia?

Resources – are there sufficient services and facilities for people with dementia and are these appropriate to their needs and supportive of their capabilities? How well can people use the ordinary resources of the community?

Networks – do those who support people with dementia communicate, collaborate and plan together sufficiently well to provide the best support and to use people’s own ‘assets’ well?

Priorities and opportunities

We captured many suggestions and bright ideas for making York a more dementia-friendly city, and we were able to test the resonance of these at a sounding board event in May, which was attended by many of the people who worked with us on the project.

Our task has been to make some high-level and practical recommendations for things that we believe should be done and those which we think are opportunities to grasp early. Grouped under the Four Cornerstones our key recommendations are:

Place

- Include people with dementia in planning and developing the city, including suburban areas and outlying villages. Make places as easy as possible to move around and enjoy, with uncluttered, legible signage and clear access to local facilities.
- Take a strategic view on the transport needs of people with dementia to support independence and quality of life. Transport is an important issue

for people with dementia; early in their illness, some people may lose their ability or confidence to drive, and need to use public transport more, or use other support in getting around.

- Make good use of York's historic character and green spaces and quiet places to benefit people with dementia. York's history has real meaning for people with dementia and the opportunity of a moment of calm in a park or by the river is good for all of us.
- When thinking about the housing needs of people with dementia, consider people at all stages of a dementia life and with different needs. Think about how people can be helped to stay at home with adjustments to the home, as well as support, and about the kind of environment which will promote their well-being.

People

- Listen to people with dementia and their carers and recognise and attend to their sometimes differing needs.
- Target information so that it addresses the different concerns of those who support people with dementia and the wider community, e.g. health and social care professionals, GPs, carers, shopkeepers, schools, families and the general public. Awareness raising should challenge stereotyping and promote positive images of what people with dementia can do as well as telling the truth about its effects.
- Provide training at different levels, which is easily accessible and affordable, and aimed at people who provide services in the wider community – e.g. in banks, libraries and shops – as well as health and social care professionals and carers.
- Improve the consistency of support from GPs and advice and contact with health and social care professionals. GPs are a critical link for people with dementia pre-diagnosis and throughout their dementia lives, yet practice varies widely in terms of attitude and skill in making referrals or accessing the wider resources of the city, such as leisure facilities.

Resources

- Consider how people with dementia can help to identify dementia-friendly services and resources in the city.
- Offer good support to businesses that want to serve people with dementia through networking, publicity and targeted training.
- Capture the benefits of York's culture, leisure and spiritual resources for people with dementia.
- Engage the tourism industry in York and capture its benefits. This sector and its visitor welcome are real opportunities for people with dementia, including residents.
- Consider the needs of people with dementia in reconfiguring and developing new services, and involve them in the process.
- Make dementia a central and shared concern of health and social care reform.
- Consider how new technology can improve the lives of people with dementia.

Networks

- Encourage people with dementia and carers, together and separately, to network and share experience.
- Spread good practice in neighbourhood and cross-agency networking.

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- Consider how corporate responsibility within the city for creating a dementia-friendly community can be signalled and used to ensure that change happens.
 - Create a York Dementia Action Alliance where partners can commit to action within their own organisations and support this movement.

For each recommendation we have included 'opportunities and bright ideas' to enable people to make a start now.

A collaborative effort

Over the course of the year-long project we worked with well over a hundred people in York, across North Yorkshire, the UK and beyond. A core group of colleagues from the public, voluntary and private sectors supported our work on a regular basis and we had invaluable insight and encouragement from the Project Advisory Group. Our finest support, however, came from people with dementia themselves and the carers and families that supported them. Hella's story, which appears at the beginning of the report, is one example which represents all the people involved in York's *Dementia Without Walls* project. People spoke freely to us and we agreed not to attribute comments and quotes to specific individuals. Throughout this report any comments and views are anonymised to respect this promise.

Hella's Story

We met Hella in January 2012 at the York Older People's Assembly Event at the Quaker Meeting House in Friargate, York. This was an important event for *Dementia Without Walls* and attracted about 90 people to hear about this project and another JRF project on Loneliness. The audience had a lot to contribute about their understanding of dementia and thoughts about what might make York more dementia-friendly.



Hella Reissmann

Towards the end of the discussion, a woman stood up and said, 'I am not sure I am in the right place. I have dementia.' With encouragement that she was in the right place, she talked about her experience of having dementia following a stroke and how it was affecting her life.

Hella was 84 at the time we met her, living in a lovely two-bedroomed first-floor flat which she had chosen for its space, its convenient location on good bus routes and its view overlooking the street. A very bright woman who had brought up five children and had a successful nursing career, Hella wasn't planning a quiet old age when she moved to this flat in retirement and chose a block which had a mix of ages.

Her stroke had left Hella needing to use a stick and with vascular dementia, which she found increasingly troublesome. She told us that she had felt it really hit home when her bridge partner had said she couldn't play with her any more. She expressed a great deal of frustration at her forgetfulness and her awareness of how much she repeated the same things, yet she led an intellectually stimulating life. Having come to England from Germany to train as a nurse after the war, Hella now taught German to a small U3A group in her flat. She gained obvious pleasure not only from the social contact, but also from the confidence she felt in planning lessons and passing on skills to others.

Managing daily living required ingenuity to overcome the barriers of mobility and dementia. Hella shopped at the local supermarket, catching the bus there and, laden with shopping, a taxi back. She found bus and taxi services frequent, helpful and good value. At the supermarket, she had worked out which staff were particularly helpful and made a beeline for them if she needed help. She and her friends had favourite cafés and restaurants in York, which they chose because the staff were particularly kind and patient. Hella was involved in many areas of York life from adult education to community affairs, debating challenging topics such as euthanasia and getting involved in the management committee of her block of flats. She regretted the impact that dementia had on her ability to concentrate and this affected her enjoyment of reading and listening to music and radio. She was slightly coy about enjoying 'those soaps', which she found watchable because they went over the story line again and again.

Hella was intrigued by *Dementia Without Walls* and wanted to be involved in the project. She was up for trying new sports and activities at the EngAge event in February, but since it was held in half-term, she had the pleasure of a visit from her family, and seeing grandchildren would be much more fun than indoor croquet. We agreed to visit her another time.

Sadly, soon after this, Hella had a fall and was in hospital for some weeks. When we saw her in the rehabilitation unit, she was preparing for an assessment in her flat, to see if she could manage on her own. What she seemed to fear most was the loss of quality of life in the round – managing to make a cup of tea and a sandwich weren't going to be enough for Hella, and she was quite right.

Hella didn't return home – she had another stroke and died before this could happen. We were sad to lose a friend of *Dementia Without Walls*, but greatly privileged to have met her. She shared so many things with us that her story resonates through the project, and she made an enormous contribution to our understanding of what makes a dementia-friendly city.

Hella's story represents all the people with dementia and their carers and families who have helped us. Whatever their circumstances, they have made a contribution by sharing their experience and the project would not be what it has been without them.

1 INTRODUCTION: THE DEMENTIA-FRIENDLY COMMUNITY

Over recent years more people with dementia have become visible and their voices have got stronger in speaking out about their experiences of the services and treatment they receive. They are increasingly confident in describing the kinds of lives they want to continue to live. In this project, people have been very candid about their experiences, their wishes and their ideas for how their lives could be better at their various stages of dementia and the different circumstances in which they live.

Amid the growing numbers of older people in the UK, the significant number with dementia have started to contribute to the creation of government policy and to local practice that will improve their experiences of health, social care and community services. They speak of others' behaviour towards them and how they feel about trying to live their lives as normally as possible.

The time has come for communities to respond by becoming more tolerant of and friendly towards their citizens who have dementia, and who care for those with dementia.

How a city like York can become more dementia-friendly is the subject of this report and the year-long project *Dementia Without Walls*. In this work, we have been guided in our definition of dementia-friendly by what people have told us about their experiences and the ways in which they would feel safer, freer and more comfortable to continue to live the life they choose for as long as possible.

What do we mean by a dementia-friendly community?

The definition of the word ‘community’ is problematic and in this paper we have used it both thematically (e.g. ethnic or spiritual group, specific interest group, club or society) and geographically to reflect the various domains of people’s lives. People with dementia in this project and in others that members of AESOP Consortium² (an organisation that advises local health and social care systems on reform) have been involved with³ have described a dementia-friendly community as one that enables them to:

- find their way around and feel safe in their locality/community/city
- access the local facilities that they are used to (such as banks, shops, cafés, cinemas and post offices, as well as health and social care services)
- maintain their social networks so they feel they still belong in the community.

Furthermore, a society or community that acts consciously to ensure that people with dementia (along with all its citizens) are respected, empowered, engaged and embraced into the whole is one that can claim to be, or is becoming, a dementia-friendly community. We have reflected that there are similar movements for communities currently to become generally more ‘age-friendly’, just as more recently they consciously became more ‘child-friendly’ and ‘wheelchair-friendly’. Dementia is covered by disabilities discrimination legislation⁴ (though awareness of this is poor), and therefore there are some legal imperatives too for places, organisations and groups to take the needs of people with dementia into account.

Communities that aspire to become dementia-friendly are likely also to be those that constantly strive to build social capital and community capacity for all their local populations of residents, workers and visitors and, in doing so, value the contribution that each makes. This may be summarised by the phrase ‘an assets-based approach’, that is, one that builds on what people can still do, as opposed to a ‘deficit-model’ that focuses on what people can no longer do and somehow ‘reduces’ them because they cannot contribute to society more fully. Appreciating the whole person – in line with Kitwood’s (1997) development of the notion of personhood – and their valuable individual contribution to the citizenry of a place, community or society is an aim of this project and of the whole of Joseph Rowntree Foundation’s programme of work on dementia and society.

Community development progresses this aim; civic engagement and increased social capital are its outputs. Mutual gain for everyone is the outcome.

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Where has the concept come from?

Growing awareness of the demographic changes in the population as the proportion of older people and the prevalence of dementia increase has prompted research and policy development in both age-friendly and dementia-friendly communities.

In 2011, the Department of Health convened a ‘Think Tank’ of experts, including people with dementia and family carers, to explore the concept of dementia-capable communities. In preparation it commissioned Innovations in Dementia to work with people with dementia to find out what makes

a good community for people with dementia to live in and what can be done to make this happen.⁵ They found that the things that make the most difference are:

- the physical environment
- local facilities
- support services
- social networks
- local groups.

People with dementia suggested that things could be made better by:

- increasing people's awareness of dementia
- having more local groups for people with dementia and their carers
- providing more information, and more accessible information, about local services and facilities
- making local facilities more accessible for people with dementia.

Innovations in Dementia, in association with the authors of this report, has since produced a toolkit to support work at a local level to develop dementia-friendly communities.⁶

The City of York has become conscious of the need to become a more dementia-friendly city for its residents and for the many visitors and tourists who are part of the lifeblood and economy of the city. York is not alone in this quest; other places and organisations have been gradually moving to a point where they can claim to have become dementia-friendly.

For some years Manchester⁷ has been developing its 'offer' for older people under the 'Valuing Older People – A Great Place to Grow Older' strapline and has more recently published a ten-year strategy. The city has now joined the age-friendly city movement driven by the World Health Organisation.⁸

In Plymouth, the university is a key partner alongside the council and health partners in helping the city to become a dementia-friendly community, and the Torbay area, with its large population of retirees, has also become a focus for dementia-friendly work.⁹

Other places developing dementia-friendly approaches include – to name but a few – Bradford, Leeds, Wakefield, Calderdale, Sheffield and Hampshire. In the latter two, members of the York *Dementia Without Walls* team have recently worked as Associates of Innovations in Dementia to produce guidance for local authorities (Local Government Association, 2012).

In Scotland,¹⁰ there is growing activism among people with dementia to redefine the kind of community in which they want to live. The University of Stirling Dementia Centre¹¹ is a leading authority on design for dementia living and has done much research on ways in which the lives of people with dementia, and those who care for them, can be improved.

The National Dementia Vision for Wales (2011) is subtitled 'Dementia Supportive Communities' and states that 'Our ambition must be to ensure that people at whatever stage of the condition are given the best chance to live well and to be as active a part of family and community life as they can'.

Liverpool Hope University is itself working towards becoming a dementia-friendly organisation and held a week of awareness-raising activities in January 2012 (Eley, 2012).

Around the world, dementia-friendly initiatives can be found on every continent. In the United States there is an emphasis on customer services and lobbying by people with dementia. When news of our project reached

the USA, we were contacted by an organisation in Denver that specialises in a moderated form of croquet for people with dementia, Jiminy Wicket.

In Japan, where the population is ageing faster than in the UK, innovative ways to create dementia-friendly communities include holding a lunch club in the street.¹²

In Perth in Australia, the city's approach includes raising awareness and involving the whole community in developing the concept of dementia-friendly.

In Europe, Bruges is leading the way in an expanding movement of towns and cities that are championing the dementia-friendly approach, which include Nantes in France and Ansbach in Germany. Bruges' knotted red handkerchief logo signifying *dementievriendelijkBrugge* (dementia-friendly Bruges) is being taken up by other organisations and countries and they welcome others using the logo too, to increase its chances of becoming a universally recognisable emblem (see Figure 5 on page 41).¹³

2 BACKGROUND: WHY DO DEMENTIA-FRIENDLY COMMUNITIES MATTER?

While dementia is not an inevitable consequence of old age, nonetheless the prevalence of dementia increases with an ageing population. Creating dementia-friendly communities is a way of optimising our response to people with dementia and using all resources – ours and theirs – to enhance their quality of life.

The national policy context

In March 2012, the British Prime Minister David Cameron issued a challenge to the wider community to deliver major improvements in dementia care and research by 2015 (Department of Health, 2012). He made a personal pledge to ensure that “we will go further and faster on dementia – making life better for people with dementia and their carers and supporting the research that will ultimately help us slow, stop and even prevent the condition.” In his challenge, key commitment no. 6 sets the target of 20 cities, towns and villages signed up to become more dementia-friendly by 2015; and in commitment no. 7, Mr Cameron seeks support from leading businesses to examine how they and others could play a part in this task, and in raising awareness of dementia. The dementia-friendly communities workstream is taking the first of these key commitments forward, and we are pleased that the Prime Minister’s Challenge cited *Dementia Without Walls* as an exemplar project.

When launched in 2009, the title of *Living well with dementia: a National Dementia Strategy* (Department of Health, 2009), was chosen in response

to the feedback from people with dementia during the consultation process that, although the diagnosis is devastating, there is plenty that can be done to support people and enable them and their carers to live fulfilling lives. The strategy's focus was primarily on improving mainstream, generic and specialist services for people with dementia and their carers. It places great emphasis on the importance of early diagnosis and providing information, advice and support at this stage to enable people to remain engaged, active and healthy and to plan for their futures. For most people this engagement will come from social inclusivity and community networks including voluntary groups and sources other than health and social care information, services and treatment.

The growing numbers of people with dementia

The most elder-rich period of human history is upon us. How we regard and make use of this windfall of elders will define the world in which we live.

– Thomas, 2004, pp. 307–8

All statutory agencies should be familiar with the public health and demographic changes occurring over the next generation, including a doubling of the numbers of people with dementia over the next 30 years and a shrinking of the working population to support those in later life. By 2019, 38 per cent of the population will be aged over 50, and by 2029 this will have risen to 40 per cent (Audit Commission, 2008). Children born today have greater than a 25 per cent chance of living to be 100 years old, whereas children born in the year of the inauguration of the NHS, in 1948, had a 10 per cent chance of reaching 100.

The value of independence and interdependence

The people we met told us that the most distressing part of their illness is that, after a lifetime of autonomy and self-determination, they find themselves having to rely increasingly on others.

Even when they recognise that they need help, they are sensitive to the complexity of nuance and understanding which can be felt on both sides. There are ways that help can be offered, when requested, that do not come over as condescending or dogmatic. Good customer care and straightforward approaches such as 'How can I help?' work better than 'Do you know what you want?' or 'What can I do for you?' or people assuming control over decisions and choices as if the views of the person with dementia don't matter anymore. Although such assumptions are generally meant kindly (see references to 'benign collusion' in Chapter 5), it can lead to the person with dementia feeling powerless as well as anxious about what will happen to them in the future.

The wish to remain connected to communities

Highest on the list of difficulties for people with dementia are the everyday community activities that everyone else takes for granted, such as withdrawing money at the bank, paying bills, shopping and using public transport. Trying to carry on daily life as before becomes more difficult and

problematic for people. As a result they start to feel disconnected from their old groups, friends, activities and places.

The interconnectedness of community life

We know from research and people's personal accounts that receiving a diagnosis of dementia is a major life event. Fear and ignorance of dementia among family and friends, as well as the general population, may mean that others respond negatively. We heard several accounts from people with dementia of how some friends melt away, even crossing the road to avoid personal contact, because they do not know what to say or how to behave when confronted with the illness. In turn, after diagnosis, people may become depressed and withdrawn, creating a vicious spiral in which they lose social connections and feel increasingly isolated. For many carers, their own distress, panic and frustration boil over into reactions varying from resignation to disappointment all the way through to rage. For many, this is effectively perceived as their 'death sentence', too – an end to all their plans and pictures of what their old age would be like.

Many report the necessity to make new friends, commonly from the dementia community, as they begin to lose friends and connections in their old walks of life. Whether or not people are abandoned by friends and associates, or *feel* as if they have been abandoned, the effect is still the same. People's networks break down and their sense of isolation intensifies.

The need to create inclusive local communities

Older people are fellow citizens who should be able to participate in local communities and benefit from universal services to the same extent as other age groups. Scrutinising local mainstream and universal services through an age-proofing lens benefits not only older people but also many other groups – younger people, families with children, wheelchair users and other disabled groups (Audit Commission, 2008). Older people should have a stake in how universal services such as transport, parks and gardens, refuse collection and leisure services are planned and organised.

The World Health Organisation initiative on Age-Friendly Cities¹⁴ provides an international network of good practice in these areas and opportunities to connect the growing number of places interested in dementia-friendly communities to this work. For example, in Manchester we saw how long-term involvement of older people in planning the development of the city at urban and neighbourhood levels improved the physical and environmental access for older people, raised their confidence and empowered them to become involved in decision-making.

Through better use of space and the increased use of technology, more older people are able to participate more fully in society. The *Independent*¹⁵ features in its reporting the impact of ageing on city life in the future, signalling the growth of environmental gerontology.

The economic arguments

This project took place at a time when the economic climate had driven significant cuts in public sector spending that have impacted on commissioners' abilities to fund services adequately or to invest in future

service provision. It has also coincided with the formation of different health commissioning arrangements; the Clinical Commissioning Groups (CCGs) and the Health & Wellbeing Boards, both still in their transitional infancy, are too new to have had much impact yet.

There are two ways of looking at this. Firstly, the 'dementia community' may be a source of custom and revenue; and, secondly, there may be savings to the cost of providing statutory services for members of the dementia community who seek or have been assessed as needing support.

The growing elderly population is a source of spending power that has been overlooked in the past in favour of younger people with apparently more cash to spend. Increasingly organisations have woken up to the demographic imperatives and have recognised the value of courting the 'silver pound'.

Insurance needs

The insurance sector has recognised that older people need assurances of health and economic well-being in their later years and the financial freedoms to enjoy them. Major insurer Aviva is engaged in discussions about how this applies to people with dementia and their families.

Many older people, in their retirement years, wish to continue to be consumers of the things they enjoy but a dementia diagnosis may mean that they begin to withdraw from leisure or recreational activities because they perceive that they will not be welcome.

While we would in no way want to advocate that people with dementia are targeted as a lucrative market, it is true to say that with a little bit of thought, empathy and planning, businesses could make themselves more dementia-aware and more dementia-tolerant and they may reap the reward in increased or sustained custom from this community.

Many older people, in their retirement years, wish to continue to be consumers of the things they enjoy but a dementia diagnosis may mean that they begin to withdraw from leisure or recreational activities because they perceive that they will not be welcome.

Good practice: the Edeka supermarket

The Edeka supermarket in Germany rebranded itself in 2008 as the Neukauf 50+ store, offering easy-to-manoeuvre shopping carts, magnifying glasses attached to fixtures, lower shelving units, a rest area with newspapers and a blood-pressure monitor, as well as a range heavily focused on the needs of the 'golden generation'. Shop assistants were hand-picked for their friendly attitudes and patience, and given further training to hone their customer service skills. In addition, families like using the store because the wider aisles enable them to get prams round the store more easily. See www.igd.com/index.asp?id=1&fid=1&sid=7&tid=10&cid=870

Adeg: helping senior citizens

In Austria, 'to please and accommodate senior citizens', the Adeg chain incorporated everything from reduced-glare lighting and slip-proof flooring to wider aisles, reduced-height shelving, smaller packaging and easier-to-navigate parking spaces. Nearly all of its employees are 50+. See www.springwise.com/retail/supermarkets_for_seniors

Tesco has sponsored dementia as its major national cause through the Alzheimer's Society, and other supermarkets attract custom because of their 'user-friendly' approaches that include responding more sensitively to people with dementia. In this project, people with dementia and their families told us that they will travel longer distances if necessary to do their shopping where they are certain of friendly staff who will provide the necessary advice and help, where parking is straightforward and where the layout of the store makes it easy to find their way around.

A major incentive for businesses to become more dementia-friendly, therefore, is the increase in numbers of people with dementia over the next twenty years and in their purchasing power. As more public sector services will be squeezed, private purchase of services may acquire an even larger share of the market than is currently the case.

If people are not welcomed into activities or organisations, the loss is not only felt by the commercial sector. Reduced use of leisure and community activities may hasten the onset of dependency on the statutory services, especially if loneliness or depression follows on from a withdrawal from 'normal' life.

Web resources in Edinburgh

In Edinburgh, a search on 'dementia' on the library website leads to information about leisure opportunities and community groups. This was refreshed in Dementia Awareness Week but remains on the website as a permanent resource. It can feel better to search for support through a culture or leisure link than through a health and social care source. See <http://yourlibrary.edinburgh.gov.uk/blogs/2011/05/dementia-awareness-week-6-10-june-2011>

Even with retirement ages moving into the late sixties, many of us will have twenty or more years of old age and increasing frailty, both physical and mental. How well the community can support people with dementia through shared cultural and leisure facilities, and encourage active participation, will be one measure of a dementia-friendly community.

In summary, therefore, our starting points for this project were as follows:

- Dementia is a national and international priority, given the changing demography and its implications for health and social care, for communities and for individuals.
- People with dementia and their families want to remain independent for as long as possible, to stay connected with their neighbourhoods and networks, to continue to do the things they enjoy and to contribute to community life.
- Supporting people to live well with their dementia, as active citizens, has benefits for businesses, health and social care as well as for the individuals themselves.

3 YORK DEMENTIA WITHOUT WALLS PROJECT

Trajectories in the York area show the number of people with dementia is increasing, and across North Yorkshire and the York area there is a forecast increase in prevalence of 68 per cent between 2008 and 2025, with major implications for services, costs and the quality of care.

The local context

Numbers recorded in York's Joint Strategic Needs Assessment (JSNA),¹⁶ published in April 2012, predict that the known number of people with dementia 65+ would rise from 2,304 in 2009 to 2,708 by 2015 and to nearly 4,000 by 2030. The City of York Council has the second-highest level of hospital patients discharged from hospital direct to residential homes and the highest rate of delayed transfers from hospital to residential care in the region. The area as a whole has high expenditure on secondary and continuing care and lower ratios of community health professionals, such as district nurses and health visitors, than the rest of Yorkshire and the Humber, so there is already pressure across clinical, residential and community settings. The projected increase in numbers indicates that, without careful planning, there could be a serious negative impact on the quality of life for people living with dementia (and their families) unless alternative models of care and support are developed.

The JSNA highlights the challenges arising from the growth of the population over 85 years of age, and makes some specific recommendations in terms of identifying physical and mental health needs, preventing admission to hospital and providing support in the community. The newly established Health and Wellbeing Board, led by the City of York Council, shares responsibilities with partners for the promotion of health and well-being and for oversight of appropriate services in the community and has a key contribution to make in promoting a dementia-friendly city.

Although numbers of older people from minority ethnic groups in York are low, evidence from our work suggests that they are represented in greater proportion in their local communities, which are often relatively self-contained and where more expectation falls on families to provide the support they need. Not only do those families find it difficult to ask for help, but also there is anecdotal evidence that suggests the statutory agencies make a general assumption that the care needs of older people, including those with dementia, are being met by their families and/or the wider minority ethnic community. Older people within other minority groups, such as gay, lesbian, bisexual and transgender groups, may not have children or close or regular contact with biological family members; they tend to live alone and have fewer social networks to support them in illness. It is not known how many members of these reticent communities may also have dementia.

How the project came about

This project was commissioned by JRF as part of its one-year scoping programme 'Dementia and Society', 2011–12.¹⁷ The York strand of this programme was based on a growing recognition at a local level of the pressures and challenges on services trying to support people with dementia and their families in the city. Meetings between the Joseph Rowntree Housing Trust (JRHT) and local service provider, The Retreat, had confirmed the will for a collaborative approach to forward planning, and a shared vision of:

- enabling people with dementia to stay in their home (or where they want to be) for as long as possible – in good environments, with minimal dislocations
- supporting relationships, reducing stigma and isolation, minimising 'professionalisation'; validating, informing and supporting carers as partners.

Discussions between JRHT and the City of York had also confirmed support for a scoping/mapping exercise to assist with forward planning in the York area. JRF commissioned the AESOP Consortium to carry out an independent scoping review and assessment of the current experiences of local people with dementia, which would seek to highlight as far as possible the different needs, expectations, perspectives and experiences of different stakeholders. The work would also set this local evidence in the context of what is known (nationally and internationally) about effective or promising approaches. The aim was that the review would help in informing the planning of providers (such as JRHT, The Retreat and others), the local commissioners (including the emerging GP clinical commissioning group) and other key players such as third-sector and private organisations. This is particularly relevant at a time of organisational change among health partners and in a climate more conducive to repositioning dementia services as central to the statutory agencies' investment and commissioning strategies.

Reflecting on the characteristics of a medieval walled city, and mindful that walls can provide insurmountable obstacles, AESOP Consortium coined the title *Dementia Without Walls* to name the project. The title deliberately alludes to the name of York's Strategic Partnership 'Without Walls', and its challenge is to consider how those divisive walls can be dismantled

both within and between the organisations that professionally, socially and commercially touch the lives of people affected by dementia.

Dementia Without Walls has challenged people and organisations to think about how the city can become more 'dementia-friendly'. Though not a service review or a strategic plan, the project has focused on being a catalyst for collaboration between agencies across the whole system to make York more dementia-friendly. We have considered not only health and social care services but have also looked at how housing and everyday amenities such as shopping, leisure and transport must adapt to meet the needs of those living with dementia. In doing so, we have referenced examples of current practice locally, nationally and internationally but we have found that some sectors remain relatively unaware of the impact of dementia on the local population and on their regular customer base. For example, a survey conducted as part of our information gathering, to all the banks, building societies and post offices, on the way they have identified and acted upon training needs for their staff to deal with the commonly reported difficulties of people with dementia in accessing money, drew a nil response.

At a local level, we have been included in consultations over reviews of elderly person's services, we participated in a dementia mapping exercise and joined a Dementia Network of professionals and clinicians working to implement policy and improve practice. We have attended forums and assemblies where ageing and dementia were central themes. We have visited many establishments and talked to a whole range of staff involved in providing dementia care services. We thank colleagues in health and local government and other statutory and voluntary bodies for their warm reception of the project and its aims, and for their insights and contributions.

People with dementia and their families have been at the heart of the study, however, and some of their stories about how they have identified the barriers to be overcome, or indeed have inspired us with how they have broken some of them down, are featured in this report. We include references to the many occasions we shared with them – walks, meetings, singing sessions, leisure activities, filming opportunities and more formal interviews and consultations. We thank them for their cooperation and the permission they have given us to 'tell it how it is'.

Aims of the project

The aims of the *Dementia Without Walls* project included:

- enlisting the help of people with dementia in identifying the factors that determine whether York is, or can become, a dementia-friendly city and, in drawing from their engagement, making recommendations about how barriers to achieving this can be overcome. This has been achieved by working alongside people with dementia, supporting them to describe to us and show us those facilities and services that are most important to them. We have met with a variety of groups introduced to us by clinicians and by local organisations. Members of the public responded to local media coverage of the project (including a call from the group in Denver, Colorado, offering insight into how games, such as a simplified version of croquet, can be modified to appeal to people with dementia).
- raising the aspirations of people with dementia and their carers about how services in York could change by identifying practical exemplars locally, nationally and internationally. This has been achieved by sharing the stories and experiences of people with dementia among a wide range

of organisations, groups and individuals. We have walked the city with them to understand the issues they face and to appreciate why they still want to enjoy the many activities that York offers its residents and its visitors. Many of the stories we have heard reflect on the roles of health and social care, which we have shared in settings across the city's service delivery. Many have also reflected what life is like in the wider community and we have shared these insights with businesses and other organisations which come in contact with people with dementia.

- being both realistic and ambitious about what might be achievable, particularly in the economic climate at the time of the research. By setting aspirations in the context of resource availability and service capacity, and engaging professionals, decision-makers and other stakeholders, we aim to describe a realistic and realisable vision of what can be accomplished. But while there is no doubt a compelling business and resource case for a dementia-friendly community, there is also an overriding moral case – one that recognises the worth of all York's citizens, particularly those who are elderly and affected by dementia, and that affirms their rights as citizens to have access to all the aspects of their normal lives that they have previously enjoyed.

Our approach

Our starting point was to make contact with existing forums (to publicise the project and enlist support) and with key individuals and organisations in the city that could put us in touch with people with dementia and their carers. A significant event for us was the City of York Older People's Assembly, where we met Hella (see page 8), and first garnered some ideas on what needed to happen to make York more dementia-friendly.

While it has been invaluable to meet and discuss these issues with care professionals across health and social care, it was even more essential to get the stories directly from people with dementia and, to a lesser extent, their family carers. Early discussions revealed that it was the daily attrition of trying to carry on and cope with dementia that bothered people more than their regular but infrequent contacts with health and social care professionals. It became evident that a wider range of partners and players needed to be involved.

To support the project, we established a cross-sector operational group involving health and social care, the voluntary sector, leisure services and other interested parties. We also attracted people through the networking of the group who were interested in, committed to, or already engaged in improving awareness and responses to dementia. During the course of the project we produced a series of newsletters that were distributed to a mailing list of more than 80 individuals and organisations locally and nationally. We regularly made use of social networking (such as LinkedIn and Twitter) to actively promote our news, ideas and contacts. We also used local radio and printed media to advertise the project and to attract contributions.

In engaging with wider public sector and statutory partners, as well as those from more commercial sectors, it became immediately apparent that there were already examples of innovative ways of working with clients or customers who may have dementia. Far from this being the 'purview' of the health and social care systems, other organisations in the City of York, for example the British Transport Police and the City of York Council's Leisure Services, had already recognised that they had a role to play in supporting people with dementia and many have found refreshingly direct and creative ways of working with them.

Early discussions revealed that it was the daily attrition of trying to carry on and cope with dementia that bothered people more than their regular but infrequent contacts with health and social care professionals.

Sounding board event, 24 May 2012

At the conclusion of our fact finding, we held a 'sounding board' event and invited all those who had contributed to the project to hear our findings and give us feedback. We chose the Hospitium in the Museum Gardens as a pleasant venue with good accessibility and were blessed with a rare



James Douglas and Anne Murray at the sounding board, May 2012

glorious summer day. A wide range of people – carers and people with dementia, staff from health care, housing and leisure, singers from Singing for the Brain, transport police, lawyers, a theatre group and voluntary groups – brought enormous amounts of energy, enthusiasm and ideas.

Chaired by JRF Trustee Dianne Willcocks, the day began with Julia Unwin, JRF Chief Executive, calling for York to lead the way on dementia and reminding us that, over its 800 years of history, York has always been able to adapt and grow to meet the changing needs of its citizens. Chief Executive of the City of York Council, Kersten England, committed to working with others to build a dementia-friendly city – calling our project 'hugely ground-breaking'.

We heard the testimony of people with dementia. James travels on his own to photograph interesting places and look at steam trains; if he loses his way, he finds a friendly person to ask for help. On video, Dennis talks about the friendliness of local people in his area. He is pleased and surprised that children are not frightened of him even though he has dementia. Jenny doesn't speak, but she smiles, looks directly at you and contributes enormously.

Bright ideas came thick and fast – one group suggested an annual 'Go Slow' day in York (with emails and mobile phones banned) to give people with dementia time to explore the city without the pressures of modern living. People built on this and proposed a quiet green route into the city centre, following the river. We heard about the progress some participants have already made – Fiona had just got an award for her work on dementia with her colleagues in the British Transport Police. Cath, a local GP, intends to train all her reception staff about dementia.

We asked people what was already good about York and what could be better for people with dementia. Some of the good things people identified were green spaces, friendly people, leisure facilities and tourism expertise. On the other hand, some barriers were identified, including not enough family-friendly loos, people's fear of dementia, rushed service in shops, and services not being joined up.

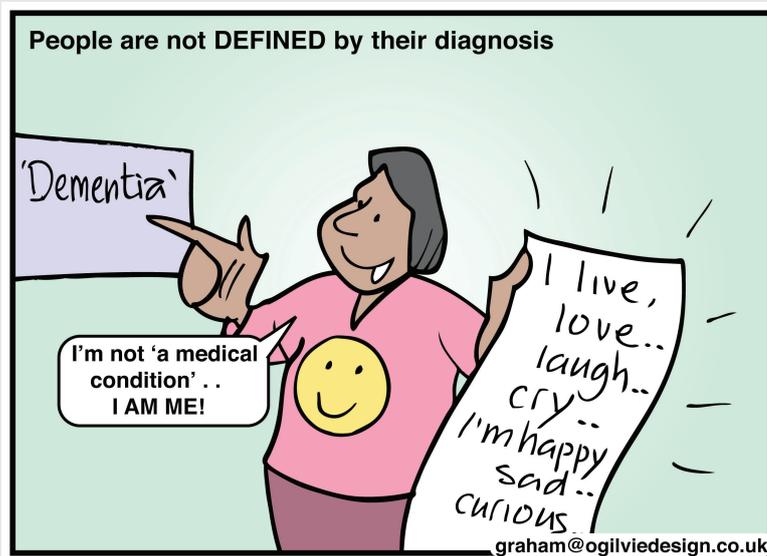
We were privileged to have Graham Ogilvie at the sounding board event. Graham is an artist who has the astounding ability to capture in real time the issues being highlighted at events.

Figure 2: ... life continues!



Graham came with some flipcharts prepared with cartoons depicting issues we had identified throughout the *Dementia Without Walls* project. Participants had the opportunity to say what they thought about these and to give some initial feedback on how dementia-friendly York is. Graham listened attentively to speakers and eavesdropped on conversations to pick out gems to turn into visual comments that make a powerful impact.

Figure 3: People are not DEFINED by their diagnosis



Within days, he had selected his best images, coloured them up and sent them back to us.

Originally conceived as a finale event, the sounding board became an integral part of the project and a significant influence on the shape and content of this report.

4 OUR OBSERVATIONS AND FINDINGS

As we have illustrated, there have already been some initiatives that improve the life of people with dementia, and these need to be built on. There are some aspects of York life, however, which operate as barriers, and by removing them, we believe it is possible for York to achieve a more dementia-friendly status.

What is good about York for people with dementia

In York, people with dementia told us they felt the city was mostly:

- a place where they were able to **live as well and as 'normally' as they wanted** though there were some geographical variations – some parts of the city and its suburbs and surrounding villages were better served than others.
- a community that **does not put obstacles in the way** or make more difficult the attempts of people with dementia to maintain their usual activities and normal networks. Naturally there are exceptions and we acknowledge that in the main we were engaging with people who were outgoing or well-networked and therefore easy to meet; there are others who are harder to reach who may not be so positive.
- a community – whether geographic or themed – that **does not judge or marginalise** people with dementia.

When we tested our ideas with a sounding board of people who had been involved in the project, they also told us:

- Yorkshire is a friendly place and York is a particularly friendly city. The city's emphasis on tourism means we are used to being helpful to people looking lost or confused. We are used to tourists and take pride in the city – it is mostly litter-free.

- There is a good range and diversity of resources that need skilling up and wiring together; examples are the EngAge day for discovering new activities and the Memory Bank,¹⁸ which uses film footage of historical/cultural York for reminiscence.
- If you have to go into a shop and are taking time, in general people are tolerant and positive – but sometimes you may see a little frustration creeping in.
- Smaller local communities outside the city centre are already very supportive: the Acomb Time-Banking Project is about giving time to help one another; Huntington is dementia-friendly – it is small, people know each other, the cul-de-sacs are helpful and shopkeepers are friendly.
- There are lots of quiet and green places, such as parks and gardens, available in the city.
- Cycle paths provide good routes around the city (but these need reconciling with the conflicting needs of pedestrians).
- There is good intergenerational work between care homes and schools, for example, where information and knowledge about information technology is shared, but more is always needed.
- People told us that ‘We all have a personal stake in this – becoming more dementia-friendly gives us optimism and in York we feel we’re pushing on an open door’.

And what is not so good

People with dementia in York told us they felt the city:

- **didn’t always actively support** people to achieve their relatively modest ambitions or seek to dismantle barriers and facilitate the easy assimilation of people with dementia into mainstream community life.
- **didn’t always make sure that giving the diagnosis of dementia was done well** – people’s stories abounded of how insensitively their diagnosis was given, or the extent to which access to support ‘depended on the lottery of which Community Psychiatric Nurse (CPN) you had’.
- **didn’t recognise that early diagnosis only really works if there is a network of services** and connections to support people with dementia.

Areas of concern

Conversations with local people with dementia and their carers indicate two main areas of concern. The first is the inconsistency around health and social care services that are offered; and the second relates to the daily attrition of everyday living, when simple tasks such as catching a bus or paying a bill are difficult, and are sometimes made harder by the organisations involved.

Inconsistency of health and social care services

Getting a referral in the first place or any support following diagnosis should not depend on who your GP is. People report their GPs making casually dismissive comments such as that ‘there’s no point getting a diagnosis; nothing can be done’, or (at the point of diagnosis) that ‘it’s just a feature of living longer and getting older’. Nor should access to local services be the accidental product of which CPN you are allocated or how you relate to the consultant. It is true that services in the community that support people with

dementia and their carers vary considerably from place to place, but often, medical staff are ignorant of what services exist, and of the value they may have.

Normal everyday living

Managing money, paying bills and buying goods and services are becoming increasingly reliant on information technology and subject to stringent security measures; just think how many passwords, pin numbers and registration codes we require, even for telephone enquiries about accounts. For people with dementia, this can mean that carrying out everyday activities becomes increasingly frustrating and may lead them to withdraw from such activities. Everyday shopping, using public transport, booking tickets for the theatre and negotiating queues at multiplex cinemas can all prove bewildering and take the fun out of activities that people previously enjoyed.

Other barriers preventing York from being more dementia-friendly

The experiences of people who attended the sounding board, and others who we have met during the course of the year, reiterated that what was mostly good or bad about their lives in York related to how they interacted with or were treated by others.

Interacting with other people around the city

People often don't like to admit they have dementia, or to ask for help. They may need to be helped to find a way of telling people they have dementia and, because of it, they need extra time or to be given some specific support. To others, they may come across as defensive, withdrawn, or 'odd' and the response from others can be variable in consequence.

Conversely, it's not easy for people to know how to help their customers or colleagues who may or may not have dementia, or to always get their approaches right. For example, how would an untrained shop worker know if a customer has dementia? There's a skill in being able to ask about dementia or enabling the person with dementia to feel comfortable, safe and included.



Jenny Neal being interviewed by
BBC Radio York

Lack of confidence in dealing with dementia may lead to:

- insecurity. 'What will they do – will they get agitated and upset?' 'How should I react – should I actually use the words and ask them if they have dementia?'
- avoidance. 'Is it best to avoid the issue and spare embarrassment?'
- exclusion. 'They shouldn't come here. It would save difficulties for everyone else.'
- impatience. Some staff show a lack of patience, e.g. when a customer is slow trying to input a PIN number at a shop till.

The changing pattern of life leads to self-exclusion from certain elements of social life, such as trips and holidays.

I will never be able to go abroad again!

Associated with this is the physical environment itself. York is a busy city with crowds and congestion. One challenge is how to equip people to be safe:

- Buses – signage, routes, timetables and bus stops need to be easy to understand.
- Better use of simple technology can help, such as visual and electronic reminder systems or information provision.

Local development frameworks should be revisited to make things age-friendly: planners need to be more in tune with what people want. When facilities are upgraded they should include dementia-friendly features such as signage and tackle the following feedback: 'there aren't enough family-friendly loos'; the 'bobbles in the pavements by crossings are a hindrance'; and 'there aren't enough public places to sit'. For example, it would be good to turn Parliament Square back into a 'piazza'.

Interacting with the professionals

Health professionals need to be more positive about living with a diagnosis – it's mixed at the moment. They need to balance realism with hope, and they need to join up referrals.

- People don't want to be referred or go straight to the Alzheimer's Society (though when they eventually do, many are impressed with the support and information they're given).
- They want the health and social care professionals to help them understand more about what is on offer within the statutory agencies and also how they can access services, facilities and activities in the community.
- The medical questionnaire for leisure centres doesn't include dementia – would it help if it did? Would people actually admit to it?
- Not all pharmacists fill medication compliance aids – is this because of lack of funding, time, or inclination to be collaborative with the other agencies?

Relationships among the professionals

Good communications between agencies is important and needs to flow from the outcomes identified for each individual who has been diagnosed

Health professionals need to be more positive about living with a diagnosis – it's mixed at the moment. They need to balance realism with hope, and they need to join up referrals.

with dementia. Collaborative working between and within organisations can be patchy and people sometimes have felt that they've fallen between two disciplines. For instance, we learnt that not all colleagues in different council departments routinely talk to each other even though they may be located in close proximity.

Support for carers

More activities for carers with the person with dementia are needed, but also separately – they have their own life! Some participants at the sounding board event suggested that a Carers' Card indicating the person's role and any special needs, such as closer parking, or access to adapted lavatories, is a promising initiative, and the York Mental Health Partnership Board endorses such practical support for carers (JSNA¹⁹).

*Remember the person, not just who they were, but who they are now.
We need a society that accepts people for who they are and values their
unique contribution.*

What else we've learnt from this project

Many people want to try to carry on as normally as possible, for as long as possible, and they will persevere so long as they do not have to overcome additional obstacles or burdens. People have told us that their request to everyone they encounter, especially those in the statutory agencies is, "If you can't do anything positive, at least do nothing that makes life worse!"

We were told that many people 'give up' soon after getting their diagnosis because they are fearful of the reaction from strangers and there are too many difficulties put in their way. They may also give up because of the negative and insensitive way in which they were given their diagnosis and the lack of advice, information and support made available to them. People with dementia need to feel confident that it is appropriate, expected and desirable to remain engaged and active.

While most welcomed the diagnosis as bringing an end to uncertainty and fear about what was wrong with them, some people were angry that their lives were only perceived and interpreted by others in terms of their diagnosis, thus limiting their choices and aspirations and reducing them to being one kind of person (i.e. a person with dementia). Peter Ashley, an Alzheimer's Society ambassador who has dementia, reminds us often of Professor Tom Kitwood's words that: "When you've met one person with dementia, you've met one person with dementia."

We have also learnt that the most valued help and support often come from other people living with dementia, or from local community support groups, rather than from the statutory agencies. It was heart-warming to notice the networking and the amount of information being exchanged in the tea breaks at many of the group and social events that we attended.

Many people are more focused on life at home and find it hard to think about the broader community, particularly people with more pronounced dementia. They were very ready to 'blame' their dementia for their restricted lives. It is not uncommon for people to believe that the fault lies with them and their illness rather than to challenge the accessibility of services.

The material we gathered from people's experiences was rich and in the next chapter we have organised the issues into the four main structural

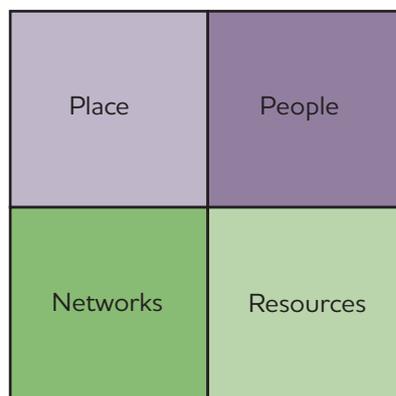
People with dementia need to feel confident that it is appropriate, expected and desirable to remain engaged and active.

supports or 'cornerstones' that underpin a dementia-friendly community. This analysis will help us to describe what needs to be done to make York more dementia-friendly.

5 YORK AND THE FOUR CORNERSTONES OF A DEMENTIA-FRIENDLY COMMUNITY

We have identified four requirements for a dementia-friendly community, which we refer to as ‘cornerstones’. While we will focus in this report on illustrating how the cornerstones apply in York, the idea has also been developed in our work with Innovations in Dementia in Sheffield and Hampshire (Local Government Association, 2012), and we have confidence that the concept would apply elsewhere.

Figure 4: The Four Cornerstones model



The Place Cornerstone

Walking the city

Going out and about with people with dementia is an illuminating way of finding out how their level of ability or disability will directly affect their experience of the neighbourhood, town or city environment. Visual impediments such as blocked, obliterated or unclear signage can hamper someone with dementia finding their way around, especially if they are in an unfamiliar place. The work of Burton, *et al.* (2004) explored the characteristics of dementia-friendly outdoor environments and has been picked up by local authorities as part of their strategic planning role, although the research team cannot as yet identify places which they would define as 'dementia-friendly'. While not directly focused on dementia, the recent Guardian Roundtable²⁰ on the future of urban living gave some indication of what we might expect by 2050 when the numbers of people with dementia will have grown substantially. Both urban allotments and plasma-screen noticeboards could be helpful additions to enhance the quality of our dementia lives.

In York we have found that while many people think of the city centre as very significant to their experience of living in York, most consider their village or neighbourhood the most important in supporting them through their experience of dementia.

People are proud of the historic resonance of York and its association with particular industries and landmarks which remind them of their past – the Minster, the City Walls, the Railway, Rowntree/Nestlé, the Racecourse and the River Ouse, for example. There is a familiarity in the city streets which people who have lived in York for a long time retain even as their short-term memory changes.

We also heard people expressing some concern about how quickly things change in York – shops, factories and housing estates changing ownership, closing down or expanding. We heard support for the idea of trying to retain some links to the past by landmarking, signposting or otherwise recognising the changes.

Memory Bank

The York-led initiative, Memory Bank, led by the Yorkshire Film Archive, has developed a commercial product that packages six themed films from the 1950s and 1960s to help prompt memories and aid reminiscence. While not specific to York, the DVDs are compiled from film donated from across the regions, and have been trialled in residential care homes in York, showing that the unbidden memory is often a reliable prompt to conversation and social engagement.

Everybody recognised the need for change and development, but there was a sense of wanting to retain something of the past and to keep memories of the city intact.

Part of people's appreciation of what made their local neighbourhoods more supportive of and welcoming to people with dementia was the feeling that they were less subject to the rate of change felt in the city centre. We do not know if this is true objectively, but people felt and appreciated greater continuity and stability in their local communities.

Some areas of York were named as particularly dementia-friendly, and these included Acomb, Huntington, Wigginton and Dunnington. Reasons for singling out these places included the convenience of local shopping, the layout of estates in cul-de-sacs, the village atmosphere and the friendliness of the community. Other places, such as Woodthorpe or Clifton, were cited as less dementia-friendly as people felt they had fewer ‘resources’ – perhaps health or social care facilities or infrequent bus services. It is important to strike the balance between how people feel about their communities, and some kind of objective view about how well resourced they are. Our report reflects a range of views, which may need wider testing.

Transport and access

Getting to, from and around the place where you live is an essential part of daily living. For people with dementia this can be a challenge as they become unable to drive and find public transport more difficult. Losing their way is both a fear and a reality for people with dementia, their carers and families, and this can reduce the confidence people need to continue to move around and enjoy the city and their local neighbourhood.

We found some good and less positive things about transport in York. As a railway city, York is very well served by trains, which can take people to every part of the country. Innovations in Dementia helped us to make a short film with some people with dementia and their spouses which illustrates how it feels to plan a journey from York Station.

The city of York is well served by buses, but some villages – such as Haxby and Wigginton – seem to be better served than places such as Copmanthorpe or Rawcliffe for instance, while other small villages have infrequent services. Park and Ride Services and buses to the university mean people have more choices in certain parts of the city. Generally, people value the bus services, but some find the numbering and colour coding of services confusing.

York is a city that people can walk into from the inner suburbs, with no major dual carriageways or ring roads in their way.

Cycling and walking are popular ways to get into and move around the city and there is a great deal of public support for the Cycle City initiative. Not all cyclists are courteous to pedestrians, however, sometimes shooting through red lights and cycling on pathways.

I used to be an architect and I still teach a watercolour painting class. I also like to go to the gym to keep fit. I feel my medication does help, and I am confident about cycling locally. I do still drive, but I stick to places I know well.

The council’s moves to create cycleways and to separate cyclists and pedestrians have mixed reviews and can create confusion for many of us, not just those with dementia.

Street scene and signage

Traffic and street signage are a distinct challenge in York because the management of road traffic has become increasingly complex, and the need of visitors and residents for orientation has to be met around the twisting streets of a medieval city. Proliferating signs, competing with one another for attention, are difficult for people with dementia to decode and remember, as they might be for the population as a whole. The goal is street signage which is clear and readable without making the city look less beautiful.

Losing their way is both a fear and a reality for people with dementia, their carers and families, and this can reduce the confidence people need to continue to move around and enjoy the city and their local neighbourhood.

Improving the Streetscape

During the course of our research we learnt of the initiative 'Improving the Streetscape' led by Professor Sir Ron Cooke, Chair of York Civic Trust, into the 'decluttering of York' and the promotion of clarity and legibility of signage. More information can be found at the York Civic Trust website: www.yorkcivictrust.co.uk

Our general observation about buildings and places is that they are dementia-friendly if buildings and signs reflect their purpose and their message. We suggest that the style of buildings should reflect their function as far as possible in terms of scale, positioning and material and that York should welcome excellent and innovative design (but wackiness can be unfriendly for people with dementia).

We also suggest that people will enjoy shopping in the city more if shops distinguish themselves clearly. We would encourage the use of symbols to signify different types of shops, as observed in Belgium.

In Bruges, a city that has many physical and historical similarities to York, we observed distinct differences. Firstly, there is almost total separation of the tourist and commercial aspects in the centre of Bruges, compared to the centre of York where they coexist equally. In Bruges, therefore, the centre of the town has stayed very faithful to its heritage associations and signage is discreet and subtle.

The people of Bruges have not allowed the cityscape to become overly modernised or commercialised so as not to compromise its great historical significance. This did mean that finding facilities such as an ATM was difficult – the sign for it was small and obscurely sited – but at the same time the city's canals, bell-towers, churches and squares are an unchanging point of orientation.

Housing

Good housing has a huge impact on people's experience of place. It is the first thing we think of in terms of 'where we live'. Most of the people working with us on the project were living in their own homes in the community, although some were living in residential care. We recognised the importance of managing the home environment to support people with dementia, especially as symptoms progress.

When I bought this flat for my retirement I wanted it to be convenient, but well connected and not full of older people. It's up one flight of stairs, but then all on one level with a good view of the street below, so that I can see what is going on. There are five buses which go into town and to Fulford, so I can do my shopping and go into York to have lunch with my friend. My friend lives in Clifton and doesn't have such good buses.

Early in the project, as a 'seeing-is-believing' visit, a group of us visited Stirling University's Dementia Services Development Centre,²¹ which demonstrates a wide range of aids to living and home adaptations that can make daily life and caring simpler and more pleasant.

We found, however, that few people with dementia and their carers who spoke to us raised the issue of housing and we think that there are a number of reasons for this, including:

- The people we spoke to appeared to be well housed – we found it difficult to identify and contact people with dementia who might be homeless or living in poor housing.
- Some people had made early decisions about retirement housing before their dementia was diagnosed, and were appropriately supported in their homes.
- Some people preferred to remain in familiar surroundings after diagnosis, even if there were aspects of their housing which might become a problem for them in older age.
- People in residential homes had sometimes experienced a ‘crisis’ at home, which had resulted in admission to care.

Hartrigg Oaks and Auden House

Hartrigg Oaks is an established retirement community in New Earswick opened by the Joseph Rowntree Housing Trust in 1998. It has 152 independent bungalows and 42 rooms in a care home providing seamless care for residents over 60. Communal facilities include a large restaurant and lounge, arts and crafts facilities and a fitness/therapy suite with pool. The lively community organises a full range of activities and trips.

Auden House is a new development by York Housing Association of 41 two-bedroom flats for people over 55. They provide a high-quality option for people who need some support and want to enjoy the benefit of communal facilities, such as an Internet café and laundry. Some facilities are open to the wider community, and there is an emphasis on resident involvement in planning events and activities.

We also found that early suggestions for ‘seeing is believing’ visits to innovative examples of sheltered or extra-care housing or residential care were not of great interest to the people with dementia we met living in their own homes. They may have felt these not to be relevant, or preferred not to think about their future needs in this way.

For housing, social care and health professionals, however, housing was seen to be an important issue and we spent some time talking about good housing solutions in the cross-sector group (see Chapter 3), citing positive examples in York such as Hartrigg Oaks²² and Auden House,²³ as well as contributing to discussion in the Elderly Persons’ Homes Wider Reference Group about re-provision of residential care for people with dementia in York.²⁴

Appropriate design is vital to improve the environment and help people with dementia to make sense of their landscape. There is a lot of interest in design for dementia, although it has tended to focus on the institutional needs of people in hospital or care settings. There are some innovative moves to use technology to support people at home, and the Design Council has recently run a national competition for ideas.²⁵

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.

In summary, some of the most important things that make a **place** dementia-friendly are its human scale, environmental quality and accessibility. We might ask ourselves these questions:

- Can people relate well to the place and find their way around and does it have meaning for them?
- Is it uncluttered and tidy and does it have a good balance of green quiet space to provide a retreat from city bustle?
- Can you get around it and in and out of it easily and safely?
- Do you have a good place to live in which you feel safe, secure and comfortable?

If the answers to these questions are 'yes', the place would be dementia-friendly as well as a good place for all of us to live.

The People Cornerstone

What do people in the community know, think and feel about dementia? Do they have a positive and supportive attitude towards people with dementia?

We found that a community was defined as dementia-friendly (or unfriendly) as much by its people as by the place. Important people in the community included close and wider family; friends and neighbours; professional, voluntary and family carers; and GPs and other key individuals, such as priests, community elders, chemists and local shopkeepers.

The needs of carers

What people wanted from those closest to them was an understanding of their needs, but also support to live as full a life as possible with dementia. While our focus in this report is on people with dementia, we are clear that a dementia-friendly community needs to recognise and support the role and contribution of family carers.

My husband organised for a group of eight friends to play canasta, quite a few years ago now. We enjoyed it and were quite good – we used to make the rules harder. When he got dementia, he couldn't remember how to play, so we had to give it up. But we still do other things together – like come here to the Harmony Café. In our village there is a feeling that we will all look after one another as we grow older and become affected by these things.

These are some of the important observations we have made about carers developed from the things people have told us:

- **Carers are not all the same, and not all are in the same position to care:** Carers' needs are likely to be different from the needs of the people with dementia; and they are entitled to assessments in their own right from the statutory services – which they don't often get. They often find 'no quarter given' in the commercial world.
- **Carers' needs and wants can be addressed without taking anything away from the focus on people with dementia, but achieving this is not necessarily without challenge:** especially where resources are tight and have to be targeted and prioritised to those who have had a diagnosis.

- **A carer is still caring when a person with dementia lives in a residential setting or is in hospital:** this applies also to the wider family and friendship network which is or should also be part of the caring circle, no matter where the person with dementia resides.
- **Carers may also be affected themselves by ageing:** Carers may be older themselves, and they tell us that their own health considerations affect their ability to care. In addition, their economic well-being can be prejudiced by their caring role e.g. by expenses and loss of earnings.
- **People without carers often have no one to champion them:** People with dementia living alone, without much family or friendship support, are very isolated and often not reached by services until there is a crisis.

Attitudes of others

We identified a wide range of experiences in relation to people's attitudes towards those with dementia. Some people had expert support and advice from their GPs; others felt that they were offered little more than negative messages at the point of diagnosis. We were shocked to hear from one person that their GP had told her and her husband at the point of his diagnosis that "That's it then, there's nothing that can be done." The emerging Vale of York Clinical Commissioning Group (VOYCCG) has a particular opportunity to raise awareness of dementia and share good practice among GPs as to how best to provide support personally, within the family and within the community.

A sense of hopelessness and fear about dementia prevails in our society; indeed the various forms of dementia are both physically and mentally challenging, especially in their later stages. It seems that dementia is the 'current taboo' and in some ways has replaced cancer as the disease we don't mention and that people are ashamed to say they have. More optimistically, however, attitudes can change, and over the past 20 years we have seen our communities become more child-friendly, more positive about disabled people and more supportive of those with learning disabilities and mental health problems. We suggest that this means that better awareness and a positive attitude towards dementia are entirely possible.

Maintaining independence

James likes to go off on his own with his camera as he has always done – he enjoys travelling and he is happy to chat to people, including asking for help when he needs it. His wife appears sanguine about his outings and, knowing how important this activity is to her husband, supports his interests, despite any misgivings about his safety she may feel.



We met people with dementia who were retaining high levels of skill in areas of their lives that had always been strong – for example, people with dementia teaching art classes and language classes, enjoying photography, literature and going to the gym. We also found people trying and enjoying new skills, such as sports and leisure activities, gardening, walking and cookery.

Helping people with dementia contribute

At a general level we have formed the view that a dementia-friendly city requires us to be more aware of dementia, to talk about it, and to recognise not only what people with dementia need, but also what they can contribute. We met people with dementia who were retaining high levels of skill in areas of their lives that had always been strong – for example, people with dementia teaching art classes and language classes, enjoying photography, literature and going to the gym. We also found people trying and enjoying new skills, such as sports and leisure activities, gardening, walking and cookery. One man told us that he found it fascinating that his wife was losing skills in some areas but gaining them in others, and people found new interests sometimes as a result of a change in their personality.

Singing for the Brain, run by the Alzheimer's Society in Selby and York, and the Harmony Café run by York University students, offered people with dementia and their carers the opportunity to demonstrate the ability to sing and respond to music. People without speech were able to join in with familiar songs. We found that people who had little spoken communication could contribute significantly through facial expression, gesture and touch.

The positive support of carers, family, neighbours and the wider community is therefore an essential 'People Cornerstone' of a dementia-friendly community. The testimony of Derek, living in a residential home, that the young families and children in his neighbourhood were not afraid to talk to him despite his Alzheimer's, shows how much human contact and kindness mean. We think that better awareness about dementia, particularly in developing understanding between generations, will help to make the whole community friendlier.

We also heard about and experienced some of the challenges people face in encountering low levels of awareness and understanding, as well as practical barriers between people. Some examples include:

- A generally inclusive and positive group aimed at older people was very wary of contact with *Dementia Without Walls* since they assumed we wanted to know which of their members had dementia and saw this as highly confidential information.
- We were made aware of some of the challenges people face in dealing with cultural and language issues. People with dementia sometimes lose English as their second language and this can be difficult in some care situations. Cross-cultural attitudes to dementia also need to be better understood.

- One gentleman, caring for his wife who could be violent, found that neither his children, his GP nor his priest were prepared to acknowledge the situation in which he found himself after almost 60 years of marriage.

We heard a range of views about the role of faith groups – some offering constant support and encouragement, others failing to recognise the changing needs of people with dementia in their congregations.

My wife was a regular attendee at church; she played the organ for many years. Now she doesn't go because she is humiliated that she can't remember when to stand up or sit down.

Many people with dementia may have past or current experience of spiritual practice, or be drawn to it in later life. Churches and faith groups, which usually have a physical as well as spiritual presence at the heart of most communities, have a genuine opportunity to be dementia-friendly.

Elders from BME communities and other minority groups

In York, the number of people from BME communities is growing rapidly, with a much higher proportion of older people than the general population. Such communities are still very self-contained with a very low awareness of dementia; in some communities it is regarded with huge suspicion and stigma. There is much work to be done to raise awareness and improve support to people feeling isolated because of language or culture. People with dementia who are also gay, lesbian, bisexual or transgender face additional difficulties of feeling marginalised or 'invisible' to the statutory agencies. We found it hard to get to know many people in these groups; many are wary of the statutory agencies and too many enquiries into their lifestyles, and others don't join groups or interact with other sections of the dementia community.

I accompanied my partner to see the GP, but when I explained what was going on with her, the GP asked me to leave because she didn't acknowledge our relationship.

Reaching out to people with dementia and carers

It is essential to hear directly from people with dementia and their carers about what works well and what doesn't.

Our project has demonstrated that people with dementia, and especially their carers, are keen to engage with others about their circumstances in their quest for more support, easier access or greater choice. People like to be sociable and generally don't rush to shut themselves away because of their dementia but it is clear, too, that they flourish best where other people understand what they are going through. Groups led by people with dementia were highly valued and provided the opportunity for sharing the ups and downs of life with dementia and learning from each other, including coping strategies, dos and don'ts, and information about amenities and services.

People with dementia and their carers don't understand some of the preoccupation with jargon about dementia – they don't always know the terminology to use, or realise that expressing anger and frustration may be interpreted negatively by some care services.

Groups led by people with dementia were highly valued and provided the opportunity for sharing the ups and downs of life with dementia and learning from each other, including coping strategies, dos and don'ts, and information about amenities and services.

We don't know which is the politically correct way to put things; we don't know the language, we just know how it is.

Among people who are experiencing the same disappointments and distress, and who are also dealing with the disease and its consequences, people can relax and not pretend to be coping if they are not. User-led and peer-based activities consequently often seem to provide more valuable support than any of the symptoms-management, task-based, measured and monitored care that the statutory agencies dispense.

In York we formed the impression that people are considered to be friendly and supportive on the whole. We think that our experience as a tourist city makes us used to helping people but, sometimes, poor attitudes and unfriendliness persist. At its broadest level, the People Cornerstone requires us all to develop a better understanding of dementia and to make mutual support a part of our daily lives.

I go about on my scooter and people talk to me. I was quite surprised that the mums talk to me and even the kids. They let the kids come over and talk – they don't seem frightened. It's good, yes, friendly.

The Resources Cornerstone

What services and facilities support people with dementia in York? What are the city's resources and how dementia-friendly are they?

The focus of *Dementia Without Walls* is on York as a dementia-friendly city, taking a holistic view and not just focusing on health and social care. The reason, therefore, that we consider one of the four cornerstones to be 'Resources' is because we are thinking beyond health, social care and other public sector services to the shops, businesses, facilities and assets that the whole city offers.

Good customer service

It is in considering the city's resources that we are focusing most closely on the role that good customer service plays in supporting people with dementia, on the inclusion of people with dementia in ordinary rather than specialist services, in helping people with dementia to maintain or indeed extend their quality of life through dementia and in also thinking about the changing shape of specialist services for people with dementia.

When we asked people what it means to live in a dementia-friendly community, many of them thought first about how they manage and are treated when undertaking everyday tasks. People often told us that shopping, remembering a PIN number, finding the right things in the supermarket and negotiating with banks and insurance companies in person and online were the things that caused them difficulty and which worried them the most.

We found examples of good and poor customer service in York and people identified for us the places they frequently used or avoided. Some supermarkets were better than others in spotting the need for patience at the checkout or in noticing someone losing their way or becoming confused. With a general move towards speeding up the checkout process and moving customers through quickly, for example with the introduction of self check-out points, patient service is even more valued.

People chose to frequent cafés and restaurants where service was attentive, patient or friendly and where there was no feeling of being

rushed. Easy-to-use facilities, particularly family-friendly toilets which can be observed from a distance and where there is no back way out, were a comfort for carers and people with dementia who feared taking a wrong turning and losing their way.

In addition to the accessibility of transport, which we discuss in the Place section, the service provided by bus drivers and train and station staff is crucial in providing the confidence and support for people to use services. Frequency alone is not enough.

York has a good range of shops, restaurants, hairdressers and other commercial facilities which people visit regularly. Our conversations throughout the project often led us to consider the benefits of training and accreditation systems which might mean that dementia-friendly locations – businesses, hotels and tourist guides etc – could be identified by a window sticker or a badge for staff. A scheme like this operates in Bruges, which has been working towards being a dementia-friendly community for more than two years; the sign in local windows is a knotted handkerchief signifying to those who may be forgetful that they will receive an empathetic reception. It also reminds staff within not to forget their dementia-awareness training.

People had a sense that customer service was reasonably good in York, again linked to the tourist industry, and this was seen as a foundation on which the city could promote itself as dementia-friendly – a positive attribute which could attract more visitors. The notion of ‘dementia tourism’ has been floated whereby the city could market its hotels, shops, restaurants and tourist attractions through customer or independently rated reviews.

Inclusion

The city’s resources are only of benefit to people with dementia if they know about them and are able to use them without fear of criticism or ridicule. An important focus of *Dementia Without Walls* is, as the name suggests, to challenge and remove the barriers to inclusion in York.

We found that one area which people with dementia and those close to them particularly noticed was the way in which early symptoms were seen as a reason to exclude people from hobbies, sports and activities.

This is a real personal blow at a time when somebody’s confidence is being eroded and can be the trigger point for people to retreat from community life, sometimes almost becoming institutionalised in their own homes. We observed opposing perspectives on this delicate issue – as one woman told us, “I realised my dementia had become a problem when my bridge partner said she would no longer play with me.” On the other hand, one sporting association was mindful of the sensitivity required: “Yes, we do have a problem with somebody with dementia and we are wondering how

Figure 5: The logo signifying a dementia-friendly location in Bruges



to tell him that he needs to review his membership. Lovely man, but he can't play by the rules any more."

As previously mentioned, the project was supported from an early stage by a cross-sector working group of public, voluntary and private sector colleagues. This group helped to identify people for us to speak to and involve and they also contributed many bright ideas and sound observations.

Of particular significance in relation to the resources of the city was the example shown by staff managing leisure services in York, and the way they have on board the challenge to include people with dementia in the activities offered to people over 50 as well as to the general population. City of York Council clearly recognises the health and well-being benefits of promoting leisure and cultural involvement to people over 50, and *Dementia Without Walls* has provided a focus for extending this approach to people with dementia.

In February we were invited by Paul Ramskill, Leisure Services Manager, to participate in an EngAge event at Energise Leisure Centre and we introduced the inventors of 'Jiminy Wicket', a simplified form of croquet, as well as enabling somebody with dementia to take part in other adapted sports and activities. There are many existing activities such as Health Walks, Guided Cycle Rides and Adult Education Classes that people with dementia could do. In a dementia-friendly city we might want to make sure that these are flagged up and appropriately promoted.

Maintaining and extending quality of life

The resources of a dementia-friendly city can do much to ensure that it isn't 'all over' at the point of diagnosis. But if people are to benefit from the opportunities that early diagnosis can bring, the resources have to be in place and well used.

We need to build on our shared knowledge about what the city can offer to people with dementia, and build their confidence to use those resources. This might involve publishing better information, sharing it and promoting it across sectors. For example, it might be useful for GPs to know what activities are on offer which are particularly suitable, beneficial or adapted for people with dementia.

We found that some people discovered a lot of useful information about the city's resources and others were generally out of the loop. This seemed to be about whom they happened to have met, rather than what they might need or want. As part of our desk research we found that in Edinburgh, for example, entering the word 'dementia' into the council's library search system led to a range of resources and publications of interest and use to people with dementia. We cannot currently do the same thing in York's database, and this might be an easy and discreet step to opening up the city's resources to people with dementia.

Specialist dementia services

Whilst the *Dementia Without Walls* team has worked most closely with people in early-stage dementia living in the community and has not concentrated on specialist dementia services, we have collaborated with colleagues in a number of ways during the course of the project.

We have contributed to the City of York Council Review of Elderly Persons' Homes and have laid particular emphasis on the need to think about people, their lives and where they will live rather than use the language of 'bed spaces'. We think there is more opportunity to work closely with health services in this area, particularly York Hospitals Trust and Leeds and York Partnership Foundation Trust as well as VOYCCG. We noted with some

surprise that York has not invested in memory clinics and instead offers other forms of consultations with consultants and practitioners.

We have also worked with North Yorkshire and York Primary Care Trust (PCT) and VOYCCG on the mapping of the dementia pathway, exploring the issues people face at each stage of their 'dementia journey'. The conclusion of the exercise indicated an increasing array of services and responses but there is still work to be done in making consistent the response people get from GPs and psycho-geriatricians when being referred and receiving a diagnosis. A useful resource will be the recent All-Party Parliamentary Group Report *Unlocking Dementia* (July 2012), which makes nine recommendations advocating measures that would improve the lives of people with dementia through early diagnosis, the way it is done, the training that medical staff need and better information, services and treatment.

Representatives of the Alzheimer's Society are closely involved in *Dementia Without Walls* and there are growing linkages to the national and regional work on Dementia Action Alliances. We have seen people benefit from current Alzheimer's Society services in Selby and York and use the Society as a rich source of information and support.

Singing for the Brain and New Age Kurling are two local activities which give particular pleasure and confidence to people with dementia and their carers. The next phase of development for the Alzheimer's Society will be to put more emphasis on peer support, for which they have recruited a new development worker to link people with dementia with similar interests and experiences and their carers, and also on better information, advice and support to access community resources.

The Alzheimer's Society faces a continuing challenge to reach its potential audience. For some the name Alzheimer's is a barrier, particularly for those with other forms of dementia.²⁶ Some people do not like being 'labelled' while for others a medical diagnosis and a clinical name for a disease are helpful. There is a benefit in a dedicated resource to support people with dementia, but it needs to lead to wider inclusion in society, not separation from it.

The Networks Cornerstone

How do the people and organisations involved with people with dementia work together to ensure the right things happen at the right time? Who provides the safety net? How do people find their way through the maze of life with dementia?

Networks is a harder cornerstone to describe than the others, but what we mean is the way that people work together to support people with dementia. This may be professional to professional; across sectors; or between professionals and people with dementia and their families. At its core, communication and sharing are the essential ingredients of a network.

Connecting with health and social care services

As we have said already, at diagnosis there is a tendency for people with dementia to become the 'property' of health and social care. What services people access might depend on who they meet, what that person knows about, what is available and whether they think it appropriate to refer.

Some points of access – GPs, social care professionals, health care workers, voluntary organisations, families and friends – have better networks than others, or just different ones which might take people in different directions. Making the networks as clear and free flowing as possible would

allow people to make better choices about what resources they can access if any at all.

Different communities also seem better networked than others, either because they are smaller or longer established, or because they have a different demographic make-up. Some places have stronger identities; to take Acomb as an example, people may look for services, facilities and information that relates to Acomb and find public sector workers or volunteers with an Acomb focus who all know one another well. We think a dementia-friendly community needs services and resources to be joined up or connected, so that people with dementia can find their way through easily, are well supported and not literally or metaphorically lost.

Such joining up needs to happen throughout the city, at every level. Strategically, partners need to work together to make sure that the resources that are tied up in hospitals can be better used in community settings; care can be personalised; leisure, exercise and nutrition can keep people healthier and confident for longer; people can return home after a crisis; and carers can be supported to care.

At a community level we identified the need for some support to help with the 'wiring together' of what are sometimes complex patterns of social, health and community support. Community Facilitators and Care Navigators employed by the city of York have an understanding of and a role in this, but most people navigating their way through a complex maze of services and resources need some kind of map or brokerage.

It is important for professionals, clinicians, practitioners and family members to resist the temptation to make decisions for people with dementia, especially those at more advanced stages of the illness, in the interests of protecting them from the confusion and hazards of the everyday world. We observed some instances where such care was not taken. We met a woman whose admission to a care home was arranged for her by well-meaning relatives and clinicians, in what we came to recognise as a 'benign collusion' of people acting in her best interests. She was pleasant and appeared content, but was clearly aware of and unhappy about the fact that she had been given no say in where she went to live.

To some extent Networks are as much the mortar as a separate cornerstone; through the effectiveness of their internal communication and collaboration, they draw from the benefits of place, using people to tailor and deliver the right resources and services. The features of good networks are collaboration, shared objectives and a lack of territorialism. A dementia-friendly community is not one that separates, pigeonholes and competes, but one that coordinates, includes and shares what it has to offer.

The review of services locally, the creation of a Health and Wellbeing Board and the newly established Vale of York Clinical Commissioning Group all provide opportunities to influence the health and social care agenda by sharing the learning from *Dementia Without Walls*. Such bodies have a leadership role in promoting York as a dementia-friendly city; it is inevitable that other sectors will look to health and social care for direction and guidance. Becoming a dementia-friendly city should be on the agenda of the Health and Wellbeing Board, given its responsibilities for the whole population.

Strategic partnerships to support broader approaches

While the role of health and social care is critical to good dementia care, these statutory agencies may learn much from other partners in the system whose formal role is not to treat or intervene in dementia but whose

Strategically, partners need to work together to make sure that the resources that are tied up in hospitals can be better used in community settings; care can be personalised; leisure, exercise and nutrition can keep people healthier and confident for longer; people can return home after a crisis; and carers can be supported to care.

experience has led them to develop methods of responding to it sensitively and effectively.

Leisure departments in local councils take the view that everyone who comes through their turnstiles is a bona fide customer and, apart from age-related concessions and occasionally the installation of specialist equipment for people with physical disabilities, do little else to differentiate one 'condition' from another. They are expert at helping people improve their stamina, fitness and ability levels within their own limitations and at making this an enjoyable experience. In the City of York, there is very strong leadership at Leisure and Recreation.

Planning and housing colleagues already use their training and skills to implement the research that exists on the sort of accommodation, lighting, décor and street scene that make a more conducive and healing environment but this is an iterative process where continual learning and experience need to be applied.

Statutory partners can learn a lot from external agencies such as transport, voluntary services and sports clubs. The police have everyday experience of responding to the needs of people with dementia who may get into difficulties, yet they receive little training on how to do so.

Transport police and rail service

We discovered a well-developed, if informal, protocol existed between British Transport Police and East Coast rail service in York. As an open station, trains stopping at York often attract people who are unsure of where they're going, sometimes have no tickets or are on the wrong train. East Coast staff are trained in how to deal with such situations and have a duty of care to de-train the person where they can be safe. British Transport Police, on the other hand, has a duty of care to help people get back home, and more powers to assist, but the two services work in collaboration to ensure that anyone lost or confused is given appropriate help.

In developing the Four Cornerstones model we recognise that different communities will start from different points, as will people with dementia themselves. At various times, Place, People, Resources or Networks might be critical factors in different ways, and the solutions that people need will vary. We do believe, however, that any community that genuinely aspires to becoming dementia-friendly must address all four of the cornerstones.

6 PRIORITIES AND OPPORTUNITIES

York has already proven that it is aware of the need to become more dementia-friendly and the project has highlighted many opportunities to further its reputation and effectiveness.

There is broad recognition that more needs to be done, and that the pace of change needs to be brisk.

At many points during our investigations, this view was reinforced by those agencies that were already tackling the impact of dementia on their families, customers, organisations, interest groups and communities. In anticipation of a greater impact of dementia on their activities, they were well aware of the urgency of the situation.

This is an important moment in time for York, and – in spite of the extremely difficult financial climate – there are many new opportunities to seize. We have therefore identified what we consider to be the key strategic opportunities that partners in the city now need to take.

We have grouped them under the Four Cornerstones so it will be important to consider issues under each heading, not just one or two. To illustrate each opportunity we have picked out examples of what we already know to be happening or offered ‘bright ideas’ which have been generated within the project or learnt from elsewhere.

Cornerstone 1: Place

Priority 1a: planning

Consider and highlight the current and future needs of people with dementia in planning and developing the city, including suburban areas and outlying villages. Make places as easy as possible to understand, move around and enjoy, with clear signage and good access to local facilities.

Opportunities and bright ideas

- There is an opportunity to connect thinking on how the city feels for people with dementia to the work on legibility sponsored by Professor Sir Ron Cook. This is a real opportunity to capture the benefits of a clearly signed and legible city for residents, visitors and people with dementia in an inclusive way.
- The City of York already has an Equality Officer working in this area and a Cabinet Member who champions inclusion – they are well placed to help planners and city management colleagues to broaden their remit to consider how they can develop dementia-friendly communities.
- There are more resources on the physical aspects of dementia-friendly communities than most other aspects – particularly through the work of Warwick University on Lifetime Neighbourhoods (Burton, *et al.*, 2004) and recent work published on Dementia-friendly Communities (Local Government Association, 2012). These resources can inform York's work on 'Place'.
- Other local authorities, such as Sheffield City Council, are leading work in planning policy and strategy for people with dementia, which could usefully inform York's work.

Priority 1b: transport

Take a strategic view on the transport needs of people with dementia to support independence and quality of life. Transport is an important issue for people with dementia; early in their illness, some people may lose their ability or confidence to drive and need to use public transport more, or require other support in getting around.

Opportunities and bright ideas

- British Transport Police officers in York have recognised that they meet people with dementia who need their help, and have undergone training supported by an officer who is effectively a 'dementia champion'. They have offered to arrange a guided train trip for a group of people with dementia and their carers to improve confidence in travelling.
- The council's leisure services have a guided cycling initiative which could help people with dementia to continue or restart cycling if their confidence is low (we met a person with dementia who regularly cycled in York, which is a Cycling City).

Priority 1c: green spaces

Make good use of York's historic character and green spaces and quiet places to benefit people with dementia. York's history has real meaning for people with dementia and the opportunity of a moment of calm in a park or by the river is good for everyone.

Opportunities and bright ideas

- The York Walk, which includes information on the history of the city, supported by Explore York, has particular resonance for people with dementia, and could be promoted more directly.
- Developing and signposting a quiet or slow route around the city or by the river could appeal both to residents and tourists with dementia.
- Promotion of the Yorkshire Memory Bank resources could build on people's delight in York's history.

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- The city could run an annual ‘Slow-down Day’ (perhaps as part of the over-50s festival) with quiet and unhurried activities, and peaceful places for reflection and social contact.

Priority 1d: housing

When thinking about the housing needs of people with dementia, consider people at all stages of a dementia life and with different needs. Think about how people can be helped to stay at home with adjustments to the home, as well as support, and about the kind of environment which will promote their well-being.

Opportunities and bright ideas

- Many people may be well housed but need specific adjustments (such as colour contrast or glass-fronted kitchen cupboards) which could help to avoid an early move to residential care. Stirling University has a rich resource of advice and equipment which can help people in their own homes as well as in care settings. A new GeniusYork initiative to provide advice to older and vulnerable people about daily living could exploit the expertise that Stirling holds.
- People with dementia may not want to consider moving and it can be challenging to move at a late stage. Encouraging awareness in the general population about planning for housing in older age might help people to prepare better. Groups such as York Older People’s Assembly may have a contribution to make here.
- The Design Council is a member of the national Dementia-friendly Champions Group and is very willing to share its expertise on dementia design, signage and planning, for example.

Cornerstone 2: People

Priority 2a: Listening

Listen to people with dementia and their carers and recognise and attend to their sometimes differing needs.

Opportunities and bright ideas

- People in early-stage dementia may be invisible to policy-makers because they may not identify themselves, may be undiagnosed or not yet in the ‘system’ of health and social care. This is a group that has both the experience of dementia and the ability to reflect on it, which can change our attitudes and approach. Policy-makers and commissioners need to connect with them and their carers.
- The new Development Workers in the local Alzheimer’s Society and in Dementia Forward will have the opportunity to build peer support for people with dementia and their carers. This has the potential to strengthen voices and generate new ideas.
- We found it difficult to engage with people with dementia who were living alone, who came from black or minority ethnic groups or who were lesbian, gay, bisexual or transgendered. We are concerned that these groups experience the dual impact of isolation and discrimination and we stress the importance of the inclusion of people with dementia across the whole community.

Priority 2b: targeting information

Target information so that it addresses the different concerns of those that support people with dementia and the wider community, e.g. health and social care professionals, GPs, carers, shopkeepers, schools, families and the general public. Awareness raising should challenge stereotyping and promote positive images of what people with dementia can do as well as telling the truth about its effects.

Opportunities and bright ideas

- GCSE Drama pupils at Joseph Rowntree School in York have developed a piece of theatre about people with dementia, which they performed at the Joseph Rowntree Housing Trust AGM in September. To prepare, they spent time with a person with dementia and his wife to deepen their understanding of how he sees the world. This idea could be promoted to other local schools.
- Manchester's commitment to an Age-Friendly City over the past 10 years has had a real influence on challenging stereotypes about older people. Their status as active and influential citizens has increased, and published images show strength and character rather than dependency.

Priority 2c: training

Provide training at different levels, which is easily accessible and affordable, and aimed at people who provide services in the wider community – e.g. banks, libraries and shops – as well as health and social care professionals and carers.

Opportunities and bright ideas

- The Social Care Institute for Excellence's e-learning Open Programme for Dementia²⁷ is a widely praised resource which can be used for free and is aimed at a general audience. In York a local health trust has made this a requirement for its staff to complete as part of their personal development and appraisal. The programme should be promoted widely.
- JRF/JRHT has a specialist Dementia Nurse Manager who supports staff working in housing and residential care with training, and this has been developed into packages of training which are now being delivered to other organisations.
- A need has been identified for national work using volunteers to educate the public about dementia. Once this develops, a local link with York Cares would be worth exploring.
- The Ageing Studies course in York, which is to be delivered by Keele University, will have a specific session on York as a dementia-friendly community (January 2013).

Priority 2d: consistency

Improve the consistency of support from GPs and advice and contact with health and social care professionals. GPs are a critical link for people with dementia pre-diagnosis and throughout their dementia lives, yet practice varies widely in terms of attitude and skill in making referrals or accessing the wider resources of the city, such as leisure facilities.

Opportunities and bright ideas

- The Vale of York Clinical Commissioning Group (VOYCCG) has a new leadership opportunity to monitor and improve health services in York for people with dementia. As a representative body for GPs, it is ideally placed to ensure consistently high-quality services from GPs for people with dementia.
- At the *Dementia Without Walls* sounding board event, the Lead GP for mental health and dementia within VOYCCG committed to provide training for her receptionists. This is an initial step which will raise awareness in her practice and could be rolled out across the CCG.
- There are established models of social prescribing, for example in Mental Health and Chronic Obstructive Pulmonary Disease (COPD), where GPs refer for exercise, leisure and cultural activity. This model could be extended for people with dementia.
- The Department of Health is planning a major TV and media awareness-raising campaign through Autumn/Winter 2012, which will encourage people with concerns to go to their GP. York could build on this to raise the awareness of local GPs.

Cornerstone 3: Resources

Priority 3a: identify services

Consider how people with dementia can help to identify dementia-friendly services and resources in the city.

Opportunities and bright ideas

- There is wide interest in some kind of scheme for a symbol or even accreditation over the longer term. Examples of this can be found emerging in other places such as Torbay and there are established schemes in Europe, such as those in Bruges, which has adopted the red handkerchief symbol.
- People at our sounding board event thought a 'Trip Advisor'-style website might be useful, and other ideas have included awards voted for by people with dementia.
- Services and businesses could adopt the 'walking the patch' concept tested out in the project.

Priority 3b: support for business

Support businesses that want to serve people with dementia well through networking, publicity and targeted training.

Opportunities and bright ideas

- Alongside an accreditation or symbol scheme, promotional support for dementia-friendly businesses could be an incentive for businesses to participate. Local business networks have been difficult to engage so far, but might respond if it is clear how such initiatives add value for them. The national Dementia-friendly Champions offer an obvious route into connecting with their local branches. Lloyds Banking Group, Nationwide Building Society and Aviva, as part of the Dementia-friendly Champions Group, are looking at how the financial services industry can make life

easier for people with dementia and their carers/attorneys. In due course these solutions can be publicised and adopted in York.

- In Bruges, local businesses have become involved in the dementia-friendly city programme and are collaborating in the making of a film about how people with dementia are treated in local shops and communities.
- Local businesses that particularly value their customers with dementia could become 'safe havens' in a crowded city, with a quiet space and the expertise to reassure and refer on in a crisis. Major flagship stores such as Marks and Spencer and Boots would make good landmark sites for this.

Priority 3c: identify resources

Capture the benefits of York's culture, leisure and spiritual resources for people with dementia.

Opportunities and bright ideas

- There has been very positive engagement by City of York Leisure Services staff in the York *Dementia Without Walls* project and this should be supported and developed. One example was the support for a person with dementia to participate in the EngAge event at Energise in February 2012, where she tried out new and adapted games and group exercise, including 'Jiminy Wicket' and New-Age Kurling.
- York has a very good web resource of community activities, Yortime, but it is not currently possible to search it for dementia-friendly resources. If this were possible, people might have the confidence to go along and join in ordinary leisure and cultural events.
- We met people with dementia who continued to enjoy many leisure and cultural interests including reading, painting and sport. Some had negative experiences of either feeling or actually being excluded from clubs and societies, however, and there is work to do here to encourage a more inclusive approach.
- Some of York's high profile cultural facilities – its theatres, galleries, cinemas and places of worship for example – could take a leading role in welcoming people with dementia.
- We found some excellent practice in supporting people with dementia and their carers through music and singing, including Alzheimer's Singing for the Brain and York University Students' Harmony Café. We liked the fact that people were actively involved and not just spectators. We heard about schemes in other areas which encourage people with dementia to write, act and paint and these could be encouraged in York, in adult learning and in care settings.

Priority 3d: tourist industry

Engage the tourism industry in York and capture its benefits. York's tourism industry and the visitor welcome are real opportunities for people with dementia, including residents.

Opportunities and bright ideas

- York has a range of people who provide guided tours and way-finding services for tourists. Their services can also assist people with dementia and it may be simple to improve their understanding of what people with dementia might need. A link with Torbay Dementia Action Alliance would be useful.²⁸

- Existing websites promoting hotels, B+Bs, restaurants and shops to tourists could be searchable for particularly dementia-friendly providers.
- Links could be made with specialist providers such as Dementia Adventure www.dementiaadventure.co.uk.

Priority 3e: inclusion

Consider the needs of people with dementia in reconfiguring and developing new services – include and involve people with dementia.

Opportunities and bright ideas

- People with dementia and their carers have been able to work with professionals from North Yorkshire and York PCT and the VOYCCG to map out the health ‘dementia pathway’. The NHS reforms need to ensure that this commitment to involve people continues.
- City of York Council’s Elderly Persons’ Homes Review works with a forum of people including health and social care professionals, voluntary organisations, York Older People’s Assembly, Alzheimer’s Society, AgeUK and older people and carers to help the council to consider how to develop new services. There are further opportunities to involve people with dementia directly in this work.
- Talk to people where they are – at home, in social settings – as well as bringing them into meetings or special events.
- JRF’s continuing support of the national empowerment initiative, DEEP (Dementia Engagement and Empowerment Project), offers an opportunity to develop a user-led network or group in York – working with Innovations in Dementia, the local Alzheimer’s Society branch and the council’s Independent Living initiative.

Priority 3f: health and social care reform

Make dementia a central and shared concern of health and social care reform.

Opportunities and bright ideas

- Dementia is a major concern of all health and social care providers, yet there is scope for more collaborative thinking and working together in this area. Health providers have not been sufficiently involved in the City of York Council’s Elderly Persons’ Home Review, and it could be better linked to the North Yorkshire and York PCT review of health spending.
- Some people get ‘stuck’ in hospital, residential and nursing care after a crisis at home. Small investments in anticipating and preventing crises, in supporting carers better and in supporting a move back home could save large amounts of money which could be reinvested in community facilities. Health and Social Care partners need to work in a more focused way with voluntary organisations, carers and people with dementia to change this.
- In Sheffield the Health and Care Trust and the Hospital Trust are working together in a local community to explore how community resources can reduce isolation for people with dementia and prevent crises occurring. At a recent community event an isolated woman with dementia came with her care worker to enquire about social care support but left with an inspiring list of clubs and societies to join.

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- People with dementia need to have their quality of life considered, as we all do, not just their basic needs. This will help them to use their own 'assets' better.

Priority 3g: new technology

Consider how new technology can make the lives of people with dementia better.

Opportunities and bright ideas

- York has an innovation scheme – GeniusYork – which is considering how technology can help older and vulnerable people. This has the potential to look at the specific needs of people with dementia, in terms of memory loss, confusion and disorientation. It could link to and learn from the winners of the national Design Centre Challenge innovation competition. The scheme could also support local innovations/ideas such as My Home Helper, based on Kevin Marsch's experience of caring for his mother; this remotely controlled computer screen can remind a person of events each day as well as providing links to family photographs and social networking sites.
- In Sheffield we heard about Respond and Reassure, a messaging service offered to older and vulnerable tenants by South Yorkshire Housing Service that can be pre-programmed with messages in different languages to remind people about appointments or taking medication.
- At our sounding board people suggested there might be scope for a mobile Dementia app specific to the needs of people in York. This is something that could be developed with students or local technology companies.

Cornerstone 4: Networks

Priority 4a: share experience

Encourage people with dementia and carers, together and separately, to network and share experience.

Opportunities and bright ideas

- We met with the York Older People's Assembly in January at a 'watershed' moment when around 90 people came to hear about this project and the JRF Loneliness Project. Many people had experiences, views and ideas to share and there is a rich source of expertise to exploit here.
- Recently agreed funding for the Alzheimer's Society in York, and for Dementia Forward, for Community Development and Peer Support is a welcome boost to the capacity of people with dementia and their carers, who benefit greatly from sharing their own experiences, knowledge and skills.
- Encouraging and enabling people with dementia to network by sharing interests and skills is positive and again draws on the assets that people have. We met people giving language lessons through the U3A, leading watercolour classes and sharing gardening skills.

Priority 4b: good practice

Spread good practice through neighbourhood and cross-agency networking.

Opportunities and bright ideas

- York has an emerging approach to Neighbourhood support which is benefiting from the work of Neighbourhood Facilitators who tap into and encourage the capacity which exists in communities. The Acomb Time-Banking Project, where people share time to help each other and exchange skills, would seem to offer one good opportunity for people with dementia and carers.
- In Shiregreen in Sheffield a Public Health Manager has been the catalyst for engaging people from the housing, health and leisure services, the police force and local businesses in planning how to make the area more dementia-friendly.
- Leeds has been recognised nationally for its comprehensive approach to neighbourhood coordination for older people. We were struck by the range of types of support available, the level of community and voluntary sector leadership, and real integration of people with dementia with the rest of the community.
- JRF's current programme on Neighbourhood Approaches to Loneliness²⁹ has two sites in York (and two in Bradford). Given that loneliness and disconnection are key risks for people with dementia (amongst others), there is great potential for initiatives advancing dementia care to link to and learn from this programme.

Priority 4c: corporate responsibility

Consider how corporate responsibility within the city for creating a dementia-friendly community can be signalled and used to ensure that change happens.

Opportunities and bright ideas

- At our sounding board event the Chief Executive of City of York Council, Kersten England, committed to making sure that all the council's services become dementia-friendly. Directors are already actively considering how they can respond to the challenge across all departments. The council is now well placed to encourage partners to join it in declaring the aspiration for York to become a dementia-friendly city.
- The newly formed Health and Wellbeing Board for York has the evidence from its Joint Strategic Needs Assessment that dementia is a high priority for the city. It needs to take on the responsibility for tracking improvements in outcomes for people with dementia in all aspects of their lives. In particular it should ensure that the changes to health and social care services deliver benefits for people with dementia and their carers.
- York's Local Strategic Partnership, Without Walls, has the opportunity to champion the idea of a dementia-friendly York and to encourage and engage all sectors, including the business community, to work towards making it a reality.

Priority 4d: create an alliance

Create a York Dementia Action Alliance where partners can commit to action within their own organisations and support this movement.

Opportunities and bright ideas

- A local Dementia Action Alliance (DAA) would enable the focus to be maintained on a dementia-friendly York and allow all interested partners to work collectively towards achieving that goal. The cross-sector and project advisory groups already established by this project provide a good starting point of enthusiastic and engaged local partners – though partners will need to decide on leadership and administrative arrangements. As the Yorkshire and Humberside Regional DAA establishes itself, it is hoped that it will be in a position to support this more local development.
- The City of York Council's Corporate Leadership Group of senior officers has already begun to identify ways in which each part of the council can contribute to making York a dementia-friendly city. An immediate opportunity is to look at the new Customer Service Centre through the eyes of people with dementia, and to ask people with dementia how it can best serve their needs.
- The Joseph Rowntree Foundation with the Joseph Rowntree Housing Trust has made its own commitment to becoming a dementia-friendly organisation by looking at its services and employment and corporate policies to ensure that employees with dementia and carers are not disadvantaged and are actively supported. It is hoping to work with other major employers in the city.

Conclusion

This is an extensive list of opportunities and ideas, but it is not exhaustive. Other ideas can be found in the body of the report; we believe those listed here represent the most important opportunities and some of the immediate ideas for building on early work and progressing this important agenda. Now it requires the leaders of York to engage with the people who have contributed to this report and ensure that the positive things they have told us become embedded in normal York life, and that their more negative experiences are eradicated in the future.

The forthcoming report of the Prime Minister's Challenge Group on Dementia Friendly Communities (expected October 2012) will include many other ideas and examples of practical initiatives which York will be able to draw on and link in with (and to which York has contributed through JRF). It is also intended that these will be brought together on a new national website.

We also hope that many other ideas will emerge in response to the idea of the dementia-friendly community; everyone has a part to play and there is no set blueprint. The dementia-friendly community is a relatively new concept and there is much to be done to make it a reality – in York as elsewhere. We hope this report has shown what can and should be done in many arenas, and that most of these solutions are not costly or resource-intensive. If York is to become a truly dementia-friendly city, it is essential that the person with dementia is valued for who they are now rather than constantly regretting what has been lost. We also need to fully recognise the

carers and families who support the people with dementia in York, involving them in diagnosis and decision-making, and understanding their different points of view and needs.

Finally, we want to stress that this transformation of York into a dementia-friendly city can only come about in full partnership with people with dementia themselves, their families and supporters.

We acknowledge the considerable input of a great many people, individuals, groups and organisations, many of whom are listed at the end of this document, for the great help and support they have provided to us at all stages of our work.

NOTES

- 1 See for example Local Government Association, 2012: *Developing dementia-friendly communities: Learning and guidance for local authorities*, www.repod.org.uk/downloads/dfc.pdf
- 2 AESOP Consortium comprises former members of the Department of Health's National Older People and Dementia team and, for this project, involved Janet Crampton and Ruth Eley, plus their associate, Janet Dean.
- 3 See Local Government Association 2012: *Developing dementia-friendly communities: Learning and guidance for local authorities*, www.local.gov.uk/web/guest/ageing-well/what-makes/-/journal_content/56/10171/3489459/ARTICLE-TEMPLATE
- 4 The Disability Discrimination Act 2005 amends the 1995 Act and includes the rights of people with dementia. See www.legislation.gov.uk/ukpga/2005/13/introduction
- 5 Dementia Capable Communities – the views of people with dementia and their supporters. See www.innovationsindementia.org.uk/DementiaCapableCommunities_fullreportFeb2011.pdf
- 6 See www.innovationsindementia.org.uk/DementiaFriendlyCommunities/DementiaFriendlyCommunities_ToolkitIntroduction.pdf
- 7 See www.manchester.gov.uk/downloads/file/11912/summary_manchester_a_great_place_to_grow_older_2010-2020
- 8 See www.manchester.gov.uk/news/article/6098/manchester_declares_itself_an_age-friendly_city and www.who.int/ageing/age_friendly_cities_process/en/index.html
- 9 See www.plymouth.ac.uk/pages/view.asp?page=36006
- 10 See, for example, the work of the Scottish Dementia Working Group, a national campaigning group run by people with dementia: www.sdwg.org.uk
- 11 Stirling University's Dementia Services Development Centre has a range of publications available: www.dementiashop.co.uk/taxonomy/term/11
- 12 See www.ninchisho100.net/english/campaign02.html
- 13 The 'knotted handkerchief' solidarity logo is downloadable at www.dementievriendelijkBrugge.be/index.aspx
- 14 See www.who.int/ageing/age_friendly_cities_process/en/index.html
- 15 See www.independent.co.uk/news/science/streets-ahead-a-revolution-in-urban-planning-2024234.html
- 16 <http://democracy.york.gov.uk/documents/s56034/Annex%20A%20-%20York%20JSNA%20Online%20Only.pdf>
- 17 For further information about the Dementia and Society programme see www.jrf.org.uk/work
- 18 For further information see www.yorkshirefilmarchive.com/content/memory-bank

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- 19 <http://democracy.york.gov.uk/documents/s56034/Annex%20A%20-%20York%20JSNA%20Online%20Only.pdf>
 - 20 See www.guardian.co.uk/what-future-urban-living/guardian-roundtable-ideas-for-urban-development?INTCMP=SRCH&goback=.gde_988747_member_81394826
 - 21 Stirling University's Dementia Services Development Centre has a range of publications available: www.dementiashop.co.uk/taxonomy/term/11
 - 22 Hartrigg Oaks is a retirement community run by the Joseph Rowntree Housing Trust. For further information, see www.jrht.org.uk
 - 23 Auden House is a housing scheme run by York Housing Association. See www.yorkha.org.uk
 - 24 The Housing Learning and Improvement Network (LIN) has some good resources for use in commissioning, adapting and designing new housing for people with dementia: www.housinglin.org.uk/Topics/browse/HousingandDementia
 - 25 The Design Council's programme 'Living Well with Dementia' supported the development of five innovative design solutions to improve the quality of life for people with dementia. Further details at www.designcouncil.org.uk/our-work/challenges/Health/Living-well-with-dementia
 - 26 For example, vascular or Lewi-Bodies dementia, Pick's Disease, or diseases such as Parkinson's which may develop into dementia at a later stage.
 - 27 See www.scie.org.uk/publications/elearning/dementia
 - 28 See www.torcom.org.uk/groups/torbay-dementia-action-alliance
 - 29 See www.jrf.org.uk/work/workarea/neighbourhood-approaches-loneliness

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- Audit Commission (2008) *Don't stop me now: Preparing for an ageing population*. Available at: www.audit-commission.gov.uk/SiteCollectionDocuments/AuditCommissionReports/NationalStudies/DontStopMeNow17July08REP.pdf
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- Welsh Assembly Government (2011) *Alzheimer's Society: Leading the fight against dementia*. Available at: <http://wales.gov.uk/docs/dhss/publications/110302dementiaen.pdf>
- World Health Organisation (2007) *Global Age-friendly Cities: a Guide*. Available at: www.who.int/ageing/publications/Global_age_friendly_cities_Guide_English.pdf

APPENDIX: ADDITIONAL RESOURCES

Further reading

All websites accessed 28 August 2012 unless otherwise stated.

Contracting and commissioning

Challis, D., et al., (2011) *Community support services for people with dementia: The relative costs and benefits of specialist and generic domiciliary care services*. Manchester: Personal Social Services Research Unit, Manchester University. Available at: www.medicine.manchester.ac.uk/pssru/research/ServiceArrangementsandIntegration/CommunitySupportServicesforPeoplewithDementia/CommunitySupportServicesProjectOutline.pdf

Dementia Services Development Centre Wales, based at the University of Bangor, has produced a series of guides and publications on managing dementia, funding and resourcing dementia care services, and training and supporting staff who provide dementia services (available at www.bangor.ac.uk/imscar/dsdc/stopress.php.en). DSDC Wales also has recently announced the introduction of a dedicated training website at www.dementiatrainingwales.co.uk

Department of Health (2010) *Commissioning for personalisation: a framework for local authority commissioners*. London: Department of Health. Available at: www.dhcarenetworks.org.uk/_library/Commissioning_for_Personalisation_-_A_Framework_for_Local_Authority_Commissioners.pdf

This framework refocuses existing and emerging perspectives on commissioning for health and well-being through the lens of personalisation.

Department of Health (2010) *Contracting for personalised outcomes: learning from emerging practice*. London: Department of Health. Available at: www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/Personalisation_advice/CFPO.pdf

Contracting for personalised outcomes draws on learning from six local authorities which had begun to reshape their contracts, processes, range of budget holding options and relationships with the provider market to ensure that personalised services are available for everyone with care and support needs.

Department of Health (2010) *Extra Care Housing and Dementia Commissioning Checklist*. London: Department of Health. Available at: www.housinglin.org.uk/Topics/browse/HousingandDementia/Commissioning/?parent=5048&child=7950

This checklist is designed to help stakeholders commission Extra Care schemes which meet the needs and aspirations of people with dementia and their families.

Department of Health (2010) *Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy*. London: Department of Health. Available at: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_119828.pdf

This document presents the Department's revised implementation plan for 'Living well with dementia: a National Dementia Strategy', which was published in February 2009.

Department of Health (2009) *Transforming community services: enabling new patterns of provision*. London: Department of Health. Available at: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093196.pdf

Enabling guidance intended to help health providers moving their relationship with their commissioners to one which considers the best way to meet the future needs of patients and local communities.

Department of Health (2009) *Working together for change: using person-centred information for commissioning*. London: Department of Health. Available at: www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/Personalisation_advice/WTFc_Final.pdf

Describes a method for collating and analysing person-centred information for use in strategic commissioning.

PSSRU (2009) *Community support for people with dementia and their carers*. Manchester: University of Manchester. Available at: www.medicine.manchester.ac.uk/pssru/research/ServiceArrangementsandIntegration/CommunitySupportServicesforPeoplewithDementia/DPM245-3.pdf

The purpose of this paper is to assist commissioners in ensuring that homecare for people with dementia is appropriate to their needs and/or supporting the needs of their carers.

South West Dementia Partnership (2010) *Dementia Quality Mark*. Bridgwater: South West Dementia Partnership. Available at: www.dementiapartnerships.org.uk/wp-content/uploads/dementia_quality_mark.pdf

The Dementia Quality Mark (DQM) aims to reassure people choosing a service that the care given meets the needs of people with dementia. The DQM also sets standards to which those providing services can aspire.

South West Dementia Partnership (2010) *Dementia Quality Mark – Quality assurance tools*. Bridgwater: South West Dementia Partnership. Available at: www.dementiapartnerships.org.uk/wp-content/uploads/dementia_quality_mark.pdf

These tools are based on person-centred theories and the observational methodologies developed from them.

South West Dementia Partnership (2010) *Improving care in care homes in the South West – Self-assessment tool for commissioners*. Bridgwater: South West Dementia Partnership. Available at: www.dementiapartnerships.org.uk/wp-content/uploads/dementia_quality_mark.pdf

This self-assessment tool will help commissioners to reflect on what they should or could do to improve care for people with dementia.

Education and training

Commission for Social Care Inspection (2008) *See me, not just the dementia: understanding people's experiences of living in a care home*. London: Commission for Social Care Inspection. Available at: www.bjf.org.uk/web/documents/resources/seemenotjustthedementia.pdf

This report looks at the experiences of people with dementia living in care homes in England, with a particular focus on whether their care offers dignity and respect.

Eden Alternative Training (www.eden-alternative.co.uk/Eden%20Training.htm)

A training organisation operating on principles of 'The seeds of the Eden Alternative are planted in people's hearts. It is, after all, with our hearts, rather than our eyes, that we see what is essential in this world' (Dr Bill Thomas – The Art of Building a Human Habitat).

Four Seasons Health Care, training for care home staff.

Pearl Programme, reviewing the (over)use of anti-psychotic medication. See www.guardian.co.uk/society/2010/nov/02/dementia-training-care-staff-antipsychotics

Merevale House Residential Home Ltd (2010) *Developing Coexistence – Merevale Approach*. Available at: <https://groups.its-services.org.uk/download/attachments/29688019/Developing+Coexistence+-+Merevale+Approach.pdf>

Developing a philosophy of active coexistence.

National Mental Health Development Unit (2011) *Let's Respect* toolkit for care homes. London: National Mental Health Development Unit.

A practical service improvement guide for the delivery of services for depression, delirium and dementia.

NHS Stoke (2010) *Understanding Dementia Training*.

A training session dispelling myths about dementia, and dementia care.

NHS Worcestershire (2010) *Worcestershire residential service standards*.

A toolkit to record and monitor service standards.

Northumberland, Tyne and Wear NHS Trust (2010) Newcastle Challenging Behaviour Service.

PowerPoint presentation on staff perspective in managing challenging behaviours.

Powys PCT (2010) VIPS tool and VIPS toolkit.

A values-based framework that asserts the absolute value of all human lives regardless of age or cognitive ability.

End of life care

Clinical Knowledge Summary service (2009) *Clinical Knowledge Summary: Managing end-of-life problems*. London: Clinical Knowledge Summary service. Available at: www.cks.nhs.uk/dementia/management/scenario_managing_end_of_life_problems#

This summary covers the principles of palliative care, and reviews the management of some common problems in palliative care.

Department of Health (2010) *End of Life Care Strategy: quality markers and measures for end of life care*. Available at: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_101684.pdf

The end-of-life care-quality markers provide detailed structure and process markers and measures which will be relevant for end-of-life care for people with dementia.

Gold Standards Framework for End of Life

A systematic evidence-based approach optimizing care for patients coming to the end of their lives – see www.goldstandardsframework.org.uk

Marie Curie Cancer Care (2009) *End of Life Care for People with Dementia*. London: Marie Curie Cancer Care. Available at: www.mariecurie.org.uk/Documents/HEALTHCARE-PROFESSIONALS/Innovation/project-report-0210.pdf

This project aimed to identify the major barriers for dementia patients and their carers in accessing good quality end-of-life care. The research findings suggest cost-effective ways of enabling improvements.

Marie Curie Palliative Care Institute (2009) *The Liverpool Care Pathway (LCP) for the Dying Patient*. Liverpool: Marie Curie Palliative Care Institute.

The Liverpool Care Pathway (LCP) is an integrated care pathway that is used at the bedside to ease the dying in the last hours and days of life. See www.liv.ac.uk/mcpicil/liverpool-care-pathway

National Council for Palliative Care (2010) *Priorities for dementia care within the end of life care strategy's quality markers and measures for commissioners*. London: National Council for Palliative Care. Available at: www.ncpc.org.uk/sites/default/files/EndofLifeQualityMarkersForDementia_0.pdf

This brief guide outlines some of the priorities for achieving high-quality care for dementia sufferers at the end of life.

National End of Life Care Programme (2009) *Planning for your future care – A guide*. London: National End of Life Care Programme. Available at: www.endoflifecareforadults.nhs.uk/assets/downloads/EoLC_Planning_for_your_future_care_FINAL_010212.pdf

This booklet provides a simple explanation about advanced care planning and the different options open to people.

World Health Organisation (2004) *Better Palliative Care for Older People*. Copenhagen: World Health Organisation. Available at: www.euro.who.int/__data/assets/pdf_file/0009/98235/E82933.pdf

This promotes better end-of-life care by incorporating palliative care into serious progressive degenerative illness within ageing policies.

Living at home

Alzheimer's Society (2010) *Living alone*. London: Alzheimer's Society. Available at: http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=107

This factsheet looks at how a person with dementia can be supported to live alone.

Alzheimer's Society (2010) *Managing alright – Living alone with dementia at 92*. London: Alzheimer's Society. Available at: <http://alzheimers.org.uk/rosegowler>

This video features Rose who is 92 and lives with dementia on her own in a flat in the London borough of Tower Hamlets. With the support of family, carers and the Alzheimer's Society, Rose has lived on her own since her husband died 30 years ago. In this film Rose, her daughter Sue, and her carer Elizabeth talk about how Rose manages.

Department of Health and Social Care Institute for Excellence (2009) *Advance care planning learning pack*. London: Department of Health. This website provides access to a free learning pack on advanced care planning. Registration is required but it is free.

Person-centred care

Bradford Dementia Group Good Practice Guides (2008) *Remembering Yesterday, Caring Today: Reminiscence in Dementia Care – A Guide to Good Practice*. Bradford: Bradford Dementia Group

This practical guide is designed to give those who care for people with dementia a clear sense of how reminiscence can be used to greatly improve their quality of life.

Kitwood, T. (1997) *Dementia reconsidered: the person comes first*. Buckingham: Open University Press

This well-known book was among the first that sets the person with dementia at the centre of support planning.

May, D., et al. (2009) *Enriched care planning for people with dementia*. London: Jessica Kingsley Publications

This book presents a complete practical framework for whole person assessment, care planning and review of persons with dementia or signs of dementia (including those with learning disabilities) who are in need of, or already receiving, health and/or social support.

Royal College of Nursing has produced a series of guides responding to the National Dementia Strategy on living well with dementia in a variety of settings, and practical information for practitioners on working with or providing services to people with dementia – see www.rcn.org.uk/development/publications

Shirley, L. (2008) *Developing new service provision for challenging behaviour in older people's care settings*. PSIGE newsletter 105, 28–53. This (subscription) newsletter refers to the challenges of dementia as well as other behavioural problems and posits ideas on how to engage with and stimulate people with dementia.

South West Dementia Partnership (2010) *Person centred support plan for people with dementia*. Bridgwater: South West Dementia Partnership. Available at: www.dementiapartnerships.org.uk/wp-content/uploads/person_centred_dementia_support_plan_A4.pdf

The person-centred support plan aims to enable and support the person living with dementia in a care home to be as self-reliant and in control as they can be.

Research

Centre for Policy on Ageing (2010) *Ageism and age discrimination in mental health care in the United Kingdom: a review from the literature*. London: Centre for Policy on Ageing.

This review is one of four reviews of ageism and age discrimination in health and social care.

Housing our Ageing Population Panel for Innovation (2010) *The Housing our Ageing Population Panel for Innovation (HAPPI) report*. London: Homes and Communities Agency. Available at: www.housinglin.org.uk/_library/Resources/Housing/Support_materials/Other_reports_and_guidance/Happi_Final_Report.pdf

HAPPI has gathered good practice from across Europe and put together new and creative proposals to help ensure that future housing will create sustainable and inclusive homes and neighbourhoods which our ageing population want and can afford to live in.

Joseph Rowntree Foundation (2009) *Extra Care Housing and People with Dementia: A Scoping Review of the Literature 1998–2008*. York: Joseph Rowntree Foundation. Available at: www.housinglin.org.uk/Topics/browse/HousingExtraCare/Evaluation/?parent=3664&child=5844&

This literature review identifies recent published and grey literature relating to people with dementia living in extra-care housing.

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Jo Roberts and her husband Stuart

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Janet Dean has worked across the public sector in local government, health and higher education for more than 30 years and is known nationally for her work in housing, and for her understanding of the wider context of public service delivery. She co-owns the Dean Knight Partnership, a York-based consultancy. She was Chair of Sheffield Homes from 2009-2012, and is currently a Non-Executive Director in the NHS, a governor and member of the Board of Sheffield Hallam University and Chair of Compass UK, a drug and alcohol treatment charity. Between 1991 and 2005 Janet was twice Chair of the York Branch of the Alzheimer's Society.

Ruth Eley was the former National Programme Lead for the Department of Health's Older People & Dementia Branch and drafted significant sections of the Commissioning Pack on Dementia. For the *Dementia Without Walls* project, Ruth has provided the quality assurance and monitored the development of this project against other dementia-friendly initiatives. As an Associate of Innovations in Dementia, and along with Janet Dean and Janet Crampton, Ruth contributed to the LGA work on developing dementia-friendly communities, and project-led a similar initiative at Liverpool Hope University. Ruth has wide experience of local government and working across the interface with health, and the voluntary sector. She is a Director of the Life Story Network CIC which has just completed an education and training project, funded by the Department of Health, aimed at health and social care staff working with people with dementia and their carers. She is a resident of the North West and a Trustee of the Parkhaven Trust, a Merseyside charity that provides day, residential and outreach support for people with dementia and people with learning disabilities.

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