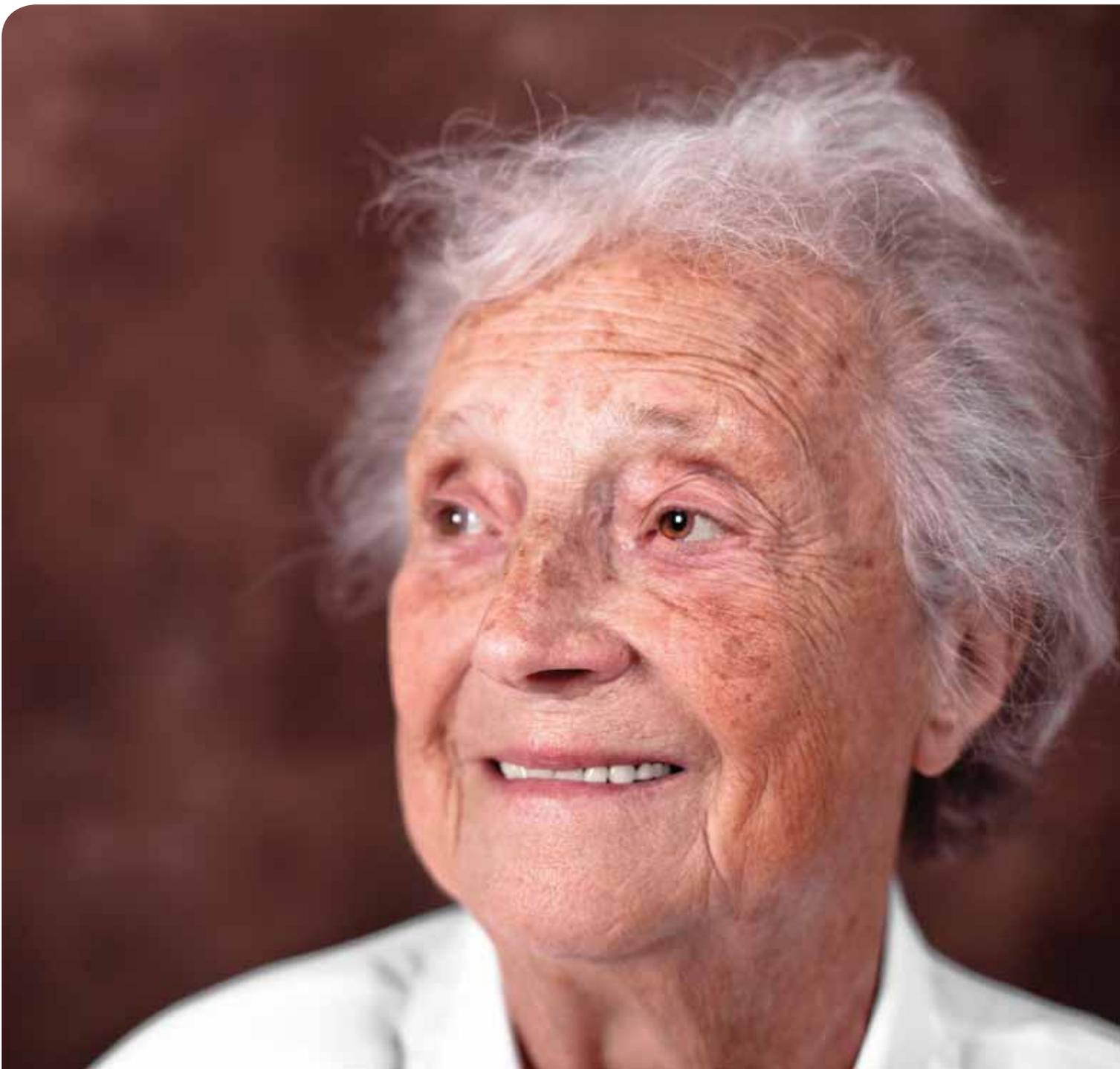


Developing dementia- friendly communities

Learning and guidance for local authorities





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Introduction

The Ageing Well programme, which ran from 2010-2012, was designed to support councils to prepare for an ageing society. The number of people with dementia is expected to increase over the next 20 years, especially those with mild to moderate dementia, so creating dementia-friendly communities that support and sustain people in their homes, neighbourhoods and social networks is an important element of the work that councils will need to do to address the ageing agenda.

The Ageing Well programme commissioned Innovations in Dementia to work with two councils who had expressed an interest in the work – Sheffield City Council and Hampshire County Council. The work was designed to explore what developing a dementia-friendly community might mean in practice for local government and what steps a council would need to take to begin to bring it into being. This publication attempts to provide a definition for dementia-friendly communities and sets out the learning from the work in the two pilot councils. The work has been grounded in detailed engagement with people with dementia and therefore responds to what they have told us has to be in place to help them live well with their dementia.

The Ageing Well programme was delivered by the Local Government Association with funding from the Department for Work and Pensions. Visit the Ageing Well website www.local.gov.uk/ageing-well for more information on dementia-friendly communities and other topics to help councils improve their areas for older people.

Innovations in Dementia is a community interest company which works nationally with people with dementia, partner organisations and professionals with the aim of developing and testing projects that will enhance the lives of people with dementia. Outcomes from such projects will influence approaches to dementia care and support in order that they are more creative, positive and enabling.

About the project

Dementia is an issue which is gaining greater prominence within discussions about ageing and public services. With the rapidly ageing population it is clear that the incidence of people with dementia is increasing. The National Dementia Strategy provides a framework for re-engineering health and social care services for those people with dementia who require specialist services. The work on dementia-friendly communities is designed to complement that strategy rather than stray into its territory (there is therefore little reference within this publication to health and social care services). Developing dementia-friendly communities focuses on supporting the wellbeing of those people with mild to moderate cognitive impairment in the early stages of dementia who are trying to live normal lives in the community. This is part of the essential work that councils need to be doing to prepare for an ageing society. However, councils should also be mindful of how communities can become more inclusive of people with more complex needs in the later stages of dementia.

Given the innovative nature of this work, the Ageing Well programme worked with only two sites. One was a large rural county (Hampshire) and the other was a major multi-cultural city (Sheffield). They represent two very different populations, geographies, histories and political environments and as a consequence adopted different approaches. This diversity helped test out ways of working in very different contexts, meaning that a wide range of local authorities, regardless of their make-up and population profiles, should be able to extract learning and ideas which are relevant to their particular areas. The timescale for completion of the project was approximately six months, so decisions had to be made quickly about where and how to get started, and this guide reflects early developmental work. There is no pretence that this document sets out a blueprint. Rather, we hope that it will provide food for thought and an inspiration to others to take the agenda much further forward.

A positive agenda

Developing dementia-friendly communities is a challenging agenda, particularly in the current financial climate. It is however a very important element of councils' preparations for an ageing society.

Work in Hampshire and in Sheffield, as well as parallel work being undertaken in York (the Dementia Without Walls Project sponsored by the Joseph Rowntree Foundation) and at Liverpool Hope University, suggests a clear correlation between people continuing to feel valued and included, and staying healthier and more positive about their lives and their dementia. All confirm that people will continue to do the things they have always enjoyed if they are welcomed and encouraged. Equally, they will stop attending or being involved if they are felt to be a nuisance or the atmosphere is in any way discouraging.

People who provide universal and non-specialist services and activities or proprietors of businesses that people with dementia have used in the past (and would want to continue to do so), find that awareness training for their staff increases their understanding of people's needs and the effect of dementia on their behaviour has several benefits:

- it potentially improves the customer experience, ensuring the continued attendance or patronage of the person with dementia
- it allows staff to feel they are doing a better job of meeting their customers' needs
- it provides their staff with insights into dementia that may help them in their personal lives as well as their work role.



What do we mean by dementia-friendly?

Defining the concept

The concept of dementia-friendly communities is an emerging one and there is not yet an extensive body of literature. Definitions from national and international attempts to explore the concept's dimensions include descriptions put forward by people with dementia and their carers.

A dementia-friendly community may be defined as being a place:

- in which it is possible for the greatest number of people with dementia to live a good life
- where people with dementia are enabled to live as independently as possible and to continue to be part of their community
- where they are met with understanding and given support where necessary.

People with dementia describe a dementia-friendly community as one that enables them to:

- find their way around and be safe
- access the local facilities that they are used to and where they are known (such as banks, shops, cafes, cinemas and post offices)
- maintain their social networks so they feel they continue to belong.

It is a place where the society or community acts consciously to ensure that people with dementia (along with all its citizens) are respected, empowered, engaged and embraced into the whole. To be dementia-friendly, a community addresses the needs and aspirations of people with dementia across several domains.

What people with dementia say is important

As part of the work of developing dementia-friendly communities it is important to hear the voice of people with dementia.

People told us about the things which make a difference in a dementia-capable community:

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

People told us that they kept in touch with their local communities:

- through local groups
- through the use of local facilities
- through walking
- through the use of support services.

People told us they had stopped doing some things in their community because:

- their dementia had progressed and they were worried about their ability to cope
- they were concerned that people didn't understand or know about dementia.

People told us that they would like to be able to:

- pursue hobbies and interests
- simply go out more
- make more use of local facilities
- help others in their community by volunteering.

People told us that one-to-one informal support was the key to helping them do these things.

People told us that a community could become more dementia-capable by:

- increasing its awareness of dementia
- supporting local groups for people with dementia and carers
- providing more information, and more accessible information about local services and facilities
- thinking about how local mainstream services and facilities can be made more accessible for people with dementia.

...And they told us that in order to do this:

- communities need knowledgeable input, not least from people with dementia
- there needs to be continued media attention and public awareness campaigns
- dementia needs to be normalised

- communities need more funding for supporting people with dementia
- communities should make better use of existing resources
- organisations should work together more effectively.

A detailed report on the views of people with dementia is available at Appendix 2.

Other relevant initiatives

Age-friendly cities

There is a developing interest in age-friendly cities. However when the World Health Organisation published its guide in 2007¹ no specific reference was made to meeting the needs of people with dementia in any of its work. That having been said, the main domains and elements set out in the Checklist of Essential Features of Age-friendly-cities (http://www.who.int/ageing/publications/Age_friendly_cities_checklist.pdf) are equally important to people with dementia:

- outdoor spaces and buildings
- transport
- housing
- social participation
- respect and social inclusion
- civic participation and employment
- information
- health and social care services.

They provide a useful framework for councils interested in developing dementia-friendly communities. Working through the criteria with dementia in mind is very instructive about what issues need to be addressed.

¹ Global age-friendly cities – a guide, WHO 2007

Department of Health

In 2011 the Department of Health (DH) convened a think tank on dementia and the Big Society to consider how communities could become more inclusive of people with dementia. To provide a baseline for the event, the DH commissioned Innovations in Dementia to work with people in a small town, a rural area and an urban district to find out how they would define a dementia-capable community.²

At the Department of Health's Big Society event, people told us that what they wanted was to carry on doing the same things they had always done – use the local shops, pubs, meet their friends – the “stuff of life”.

Their report sets out five key aspects that are important to people with dementia, none of which should be viewed in isolation:

- **The physical environment:** there is a lot that can be done to make the physical environment easier for people with dementia by making signage and directional information simple, clear and uncluttered, and by improving lighting and use of colour contrast.
- **Local facilities:** being able to access shops, banks, transport and leisure facilities as well as mainstream services supporting health, housing and social care needs and the universal services to which everyone is entitled.

- **Local groups:** being members of groups gives people with dementia the means and confidence to be part of the wider community³.
- **Social networks:** social isolation and exclusion from mainstream activities disadvantage people with dementia.
- **Support services:** are critical from the point of diagnosis onwards.



² Their report is available at <http://www.innovationsindementia.org.uk/projects.communities.htm>

³ The LGA-funded project in Sheffield acknowledges the diverse and complex communities in the city and its surrounding areas and intends to draw out some of the multi-cultural and historical characteristics of social life in the Sheffield area.

Why does it matter?

Ageing population

All local authorities are familiar with the 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 cent⁴. A significant proportion of this elderly population will have dementia – one in five over the age of 65.

Independence and inter-dependence

People with dementia, and their carers, increasingly require help to cope. In order to support people effectively councils need to broaden their focus beyond traditional health and social care responses to include a much wider range of services and functions which are important to people in their everyday lives (see next section).

People with dementia tell us that one of the most distressing parts of their experience is their increased reliance on others when they have been used to some freedom and self-determination. When they seek help, it is more effective when they feel that help is offered by staff who understand their difficulties and who are not patronising or controlling. Specifying services for people that are either purchased by local authorities, or funded through grant aid, need to take account of these qualitative aspects of service delivery.

“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.”

What Are Old People For? How Elders Will Save the World, William H. Thomas, MD, copyright 2004

⁴ (Audit Commission, 2007)

Better outcomes in offering help to people with dementia can be achieved when contract specifications require that:

- Practical support is seen as friendly and helpful, to boost confidence in the person with dementia and slow down any withdrawal from situations that have become untenable.
- Staff awareness of dementia is recognised as insufficient and rectified; staff also need some help in understanding what issues dementia creates and how best to respond. Many well-meaning people remain ignorant about the illness and what it means in terms of its progression and potentially fluctuating symptoms.
- People receiving services are empowered to retain a measure of independence and self-determination by the provision of training or encouragement to participate in user-led groups, where peer support can flourish with the help of the statutory agencies and voluntary sectors.
- Commissioners give real meaning to hearing people's voices by responding to what has been said and by embedding user consultation and feedback into their considerations of service design and service improvement. Projects such as Educate⁵ in Stockport offer a model for local authorities to consider. See below.

- Service providers are required to encourage people with dementia to give feedback on their views of services or activities in ways that do not rely on written or online customer survey forms, and that those views are reflected in future service delivery.
- Groups and activities are routinely reviewed in light of customer feedback and people who use them are regularly consulted.

EDUCATE (Early Dementia Users Co-operative Aiming To Educate) was set up to give people with dementia a voice through involvement in training, or speaking to others about their experiences of having dementia. EDUCATE was part of a two year multi-agency project to set up peer support for people with dementia.

Organisations involved in the project included NHS Stockport, Pennine Care NHS Foundation Trust, Stockport Council's Adult Social Care, Age Concern and the Alzheimer's Society.

Councillor John Pantall, executive member for Adults and Health at Stockport Council said: "People with dementia can often be stigmatised. The EDUCATE project will give people with early dementia a chance to challenge some of the negativity and despair around these diseases. It will also be an opportunity for them to influence the help and support available in Stockport."

⁵ Early Dementia User's Co-operative Aiming To Educate looks to give people with dementia a voice through involvement in training, or speaking to others about their experiences of having dementia – go to <http://www.stockport-pct.nhs.uk/NewsDetail.aspx?NewsID=67>

Everyday life

Conversations and surveys with people with dementia, and their carers, indicate that their main areas of concern relate to the practicalities of everyday living. Group work, especially with those living alone, reveals that it is the increasing inability to cope with the day-to-day activities that frustrates and depresses them, and leads them to withdraw from even trying. Banking, understanding insurance and finance, paying bills and dealing with the utility companies are amongst the first things that people feel unable to cope with. For others it may be shopping, or the frustration of getting to shops by public transport. Regular recreational activities – going to the cinema, a club or the leisure centre – can become irksome and less fun than they were. The general pace of life and the complexity of machines and electronic gadgets start to exclude those who cannot keep up, don't always follow instructions, or can no longer make sense of the rules.

Whilst local authorities may feel limited in how they can help their service users with dementia overcome such problems, they may have influence with local businesses and voluntary organisations about encouraging their services or activities to be more empathetic towards people with dementia. Discussions with the local Chamber of Commerce, for instance, can raise the issues that most concern people with dementia, and the council's economic regeneration teams perhaps need to understand that people with dementia, their carers and their families, are constituents whose commercial and recreational needs should be explicitly recognised.

Better outcomes for helping people cope with the everyday can be achieved when:

- Information about commissioned services, and those available provided by other organisations, is simple, explained clearly and presented colourfully, using strong contrast in colour and good lighting.
- Quality standards relate to how much contact time service users are given, and that staff deal with people patiently and are trained in the skills that enable them to recognise signs of dementia and to respond empathetically.
- Targets in contracts relate to the quality of services as well as the quantity of service.
- The use of assistive technology is encouraged. Simple aids such as personal GPS systems, pressure pads, intercom alarms and lights that come on if someone gets out of bed at night can make a big difference to safety for the person with dementia and peace of mind for family carers.

Inclusive communities and the localism agenda

The Audit Commission's publication *Don't stop me now*⁶ includes ways in which age-proofing local mainstream and universal services has benefits not only for older people but also for younger people, families with children, wheelchair users and other disabled groups. In building community capacity, an essential ingredient is the engagement with and involvement of older people in planning and designing services such as parks and gardens, leisure facilities, refuse collection and transport. Community groups need to be pro-active in encouraging people with dementia to participate. Local authorities have a role in supporting such groups and giving to grant-aid where possible or contracting specific dementia services from them. Such arrangements need to future-proof attendance so that the beneficial outcomes that people get from attending are not lost if people are made to feel unwelcome or that the service is not suitable for them.

The Ageing Well project learned that many people give up soon after getting their diagnosis because they are fearful of the reaction from strangers. They may also give up because of the negative and insensitive ways in which they were given their diagnosis and the lack of advice, information and support made available to them at the time.

Crucially, some of the most valuable help and support comes from other individuals or groups touched by dementia or community-based organisations that routinely deal with people with dementia, rather than from the statutory agencies. Such bespoke services are highly valued.

One of the most hurtful experiences occurs when clubs, societies or groups discourage a member who develops dementia from continuing to participate as they may no longer be able to play by the rules or are seen as troublesome. This may be out of fear or inexperience of how to help the individual concerned. Local authorities can provide some leadership on this issue. They also have a role in making available to the general public, and people working outside health and social care, topical information about issues surrounding dementia and what support is available. Local authority training units can offer basic awareness training in dementia to a wide variety of community partners.

Additionally, some concerns were noted that diagnosis becomes a label and a pigeon-hole and people have felt afraid or resentful that choices in their lives become circumscribed by being stereotyped in this way. It is not enough for a local authority or its NHS commissioning partners to provide health and social care services without acknowledging the whole person. For communities to be dementia-friendly, people with dementia need to feel confident that they will be welcomed and encouraged to remain engaged and active in all services and activities, wherever they are.

⁶ (Audit Commission, 2007)

The inter-connectivity of community life

Research and observation show that a diagnosis of dementia is one of life's major transitions. Negative responses are possible as people react in fear and ignorance of dementia, become depressed, lose income, lose social connection and feel increasingly detached from family, friends and neighbours. This may be even more marked for some people.

Evidence from the Ageing Well and Innovations in Dementia work suggests that older people from some ethnic minorities tend to live in relatively self-contained communities, and in those communities older people are represented in greater numbers than in the general population. The expectation by the community may be that families will care for their older people, including those who have dementia. This can make it difficult for families to ask for help, which in turn can lead to statutory agencies assuming that their needs are being met within their community and therefore do not require services.

“When you’ve met one person with dementia, you’ve met one person with dementia.”

Professor Tom Kitwood, a pioneer in the field of dementia

Better outcomes in keeping people connected can be achieved when local authorities ensure:

- Information on dementia services and activities is provided in a variety of formats, and is culturally sensitive, to help people with a diagnosis and members of their family cope better, knowing there are community services to support them.
- Staff working in council-provided services such as leisure, libraries, adult education, and contact centres are aware of a good range of services and can provide information about what help is available and how to access it. They do not assume that because someone has dementia, they will only need to be put in touch with social care.
- Councils recognise the particular issues facing younger people with dementia and seek to support people to avoid the loss of employment that can lead to reduced income and a consequent restriction on activity.
- People providing leisure activities are offered help in dealing with members who may be suffering the effects of social isolation or withdrawal from hobbies and pastimes because of their dementia; and also helped to consider how their attitudes, set-ups and signage can become more helpful to people who are becoming confused, or who may be unfamiliar with layouts.
- Leisure activities provide a route to other activities and foster an environment where people can meet and share information and experiences and they form their own networks and help each other.
- The built environment is reviewed – how lighting, colour, layout and shape affect people's cognitive ability to understand where they are and what they should be doing.

The economic argument

The business case for dementia-friendly communities starts with the knowledge that the proportion of people with dementia will rise sharply over the next 20 years at a time when public sector resources will continue to be under acute pressure. More of us, including those of us with dementia, will need to lead healthier and more active lives, drawing support from the wider community for as long as we can and delaying the need for support from intensive health and social care services.

Given the stringency of public funding for the statutory authorities, finding new money to invest in developing dementia-friendly communities is extremely unlikely but there are things local authorities can do within existing resources and processes.

In Hampshire and Sheffield, people with dementia and their carers could easily identify which supermarkets they preferred for consistency of layout, signs, staff attitude and available help, even though getting there might involve a longer bus journey.

What local authorities can do:

- Ensure people with dementia are consulted and involved in discussions about planned new developments or the redesign of existing public buildings, leisure complexes, hospitals or shopping centres. Incorporating dementia-friendly design features – such as signs, colour schemes and floorings – from the outset should not add to the overall cost of schemes.
- Take a lead in developing employment policies that include the needs of people with dementia and their carers; people frequently report that dementia does not get the same sympathetic response as cancer, for example, when requesting more flexible working hours or adjustments to working practices.
- Learn from each other about what works. Manchester is the first UK city to be accepted into the WHO's Global Network of Age-friendly Cities, based on work carried out as part of its Valuing Older People strategy and partnership. Much of what works for older people will work for people with dementia. York is exploring how to become a dementia-friendly city. Liverpool has declared 2013 to be the Year of Dementia as part of its Decade of Health and Wellbeing and the town of Torbay is establishing its own Dementia Action Alliance.

Access to private sector services can be just as important for people with dementia as it is for the rest of the population. It is therefore very important for councils who wish to develop dementia-friendly communities to engage with and seek to influence this sector's behaviour and encourage them to become more dementia-friendly.

There is no doubt that people with dementia and their families choose to shop and do business in those places that make them feel welcome and where support and assistance are readily offered, including travelling further if necessary. In Germany, a grocery chain has taken on board the issues of manoeuvrability of wheelchairs, customers with walkers and awkward shelving and launched Generation Markets that cater for older people. These supermarkets have better lighting, wider aisles, non-slip floors, larger price labels and smaller packages to make goods easier to handle. Magnifying glasses on chains hang from shelves and red help buttons are located around the stores. Although not dementia-specific, such initiatives are clearly beneficial to people living with dementia.

For more information, see Appendix 1c.

Better outcomes for people with dementia using private sector services can be achieved when local authorities use their influence to:

- Get organisations or local businesses to think about the desirability of keeping their existing customer base as they grow older, or by attracting new older customers.
- Help the business or activity to present themselves in ways that invite older participants, especially those with dementia, thereby increasing the range of services available to local populations.
- Improve the quality of signage and literature, by making style guides available or setting out quality standards on service delivery as part of service specifications. Customer experiences are paramount in shaping future services.
- Enable people to become active participants in the services/amenities/activities offered rather than passive recipients.

The national policy context

Until recently, dementia has been the domain of the NHS and social care. This framework does not replicate the efforts to improve services for people with dementia in these sectors but tries to point to the ways wider council services might respond. In March 2012 the Prime Minister launched his challenge to deliver major improvements in dementia care and research by 2015.⁷ Of the three key areas in the challenge, one is creating dementia-friendly communities. The Alzheimer's Society will take the lead, working with the Dementia Action Alliance, to create a formal dementia-friendly recognition process that will make villages, towns and cities accountable to people with dementia and their carers through local Dementia Action Alliances. Only those places that meet their criteria will be granted dementia-friendly community status. By 2015, the ambition is to have 20 cities, towns and villages signed up to become dementia-friendly. Other commitments in the Prime Minister's challenge under this topic include:

- support from leading businesses; several national organisations have already pledged to look at how they and others can play a part in creating a more dementia-friendly society and raising awareness of dementia

- awareness-raising campaign; a government-funded nationwide campaign to raise awareness about dementia, to be sustained until 2015
- a major event in the summer, bringing together UK leaders from industry, academia and the public sector.

The Prime Minister's challenge follows several key policy initiatives which provided the context and impetus for the announcement on dementia-friendly communities:

- The **National Dementia Strategy** (2009) (NDS) was titled Living Well with Dementia as a response to the feedback from people with dementia during the consultation process that although the diagnosis is devastating, there is lots that can be done to support people and enable them and their carers to live fulfilling lives. The strategy's focus was primarily about 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 very early stage to enable people to remain engaged, active and healthy and to plan for their futures. In 2010, this was supplemented by the DH publication Quality Outcomes for People with Dementia and references in the Prime Minister's launch of the Big Society in 2010 heralding "...a huge

⁷ Department of Health, 2012 www.dh.gov.uk/dementia

culture change... where people, in their everyday lives, in their homes, in their neighbourhoods, in their workplace...don't always turn to officials, local authorities or central government for answers to the problems they face..."

- The **Dementia Action Alliance**⁸ was launched in October 2010 to provide an impetus beyond government to support the implementation of the National Dementia Strategy. The Dementia Declaration includes the seven outcomes that people with dementia and family carers would like to see in their lives. In February 2012, 97 organisations had signed up as members, each with a published action plan detailing how they intend to improve the lives of people with dementia. Signatories include local authorities and non-health and social care organisations such as the Design Council. The Alzheimer's Society's pledge includes the intention to launch a project to define dementia-friendly communities, as detailed above. Already Yorkshire and Humber have developed a regional Dementia Action Alliance and several local authority areas are also considering such a move.

- The Department of Health's **Commissioning Pack for Dementia** (2011) includes inserts to generic contracts, together with information on documents and practical tools which may be of assistance to commissioners in developing a dementia-friendly community, an endorsement of the need to ensure that people with dementia can access the full range of services that support them in community living, not just those specialist services related to their diagnosis.
- Finally, the **NHS Operating Framework**⁹ requires the NHS to work with local authorities to fund and resource services appropriately for people with dementia, and to make sure that respect for the dignity and worth of a person with dementia is a requirement of all commissioned services.



8 www.dementiaactionalliance.org.uk

9 http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_131428.pdf

Making a start

As noted in the introduction, this guide does not suggest we now have the blueprint for what councils need to do to create dementia-friendly communities. However, this project has uncovered key steps including:

- reaching out and engaging with people with dementia
- adopting a strategic partnership approach
- supporting awareness-raising and training frontline staff
- focusing on particular areas or themes
- linking top down and bottom up approaches.

See Appendix 1a for more information.

Reaching out to and engaging with people with dementia

Inclusion in formal consultation processes is essential, but other less formal ways should also be used. Face-to-face meetings and consultations, with advance notice of questions to be discussed, and avoiding reliance on form filling or online surveys is also helpful.

In Hampshire, a workshop with key community organisations in the chosen localities was held to explore what was already known, identify potential groups of people with dementia and share ideas about how best to engage them and where to focus the activity. This was followed up with meetings with existing groups to explore the project and how people could help.

In Sheffield, meetings were held with the Sheffield Dementia Community Forum and with the Alzheimer's Society to consider what was good about living in the city and what mattered in being part of a community. In both localities this initial scoping led to specific activities to test what people said, for example visiting the leisure centre, going to the supermarket and buying a rail ticket.

Such projects have indicated that people with dementia, and especially their carers, welcome interest in their circumstances especially if it leads to more support, easier access or greater choice.

Groups convened and led by people with dementia are highly valued by them as offering opportunities for mutual support and social interaction, where other people empathise and there is mutuality about sharing information, tips, advice and experiences. Councils may wish to consider ways of supporting such groups.

Another powerful way of engaging with and understanding the issues faced by people with dementia is to walk the patch. As the title suggests, this means spending time with people with dementia on the streets, in cinemas and shops and anywhere else that people with dementia may want to go. The point of this is to try and see this world through the eyes of someone experiencing some level of cognitive impairment. Reporting this back to partners working to create dementia-friendly communities can be very powerful.

This simple activity has proved invaluable in the pilot areas. People's experience of the street-scene, or cityscape, varies intensely according to their level of ability or disability. So for example it can help to ensure that people such as town planners become aware of the visual obstacles or confusions that might affect someone with dementia finding their way around town (especially in an unfamiliar town).

People with dementia in Sheffield told us that the hardest thing for them in visiting the local leisure centre was getting through the door, feeling confident that it was a legitimate place for them to go to and that they would be welcomed and encouraged once inside.

This kind of work can generate a range of useful questions:

- Do the council's inclusion officers consider the ways in which the town is presented and how it can either encourage or deter people who have difficulties finding their way around?
- Do tourism officers consider how their amenities may attract or deter those who seek recreation but who may have dementia or be caring for or escorting someone who does?
- Have public transport providers seen through the eyes of someone with dementia how their information is displayed at shops or stations?

Adopting a strategic partnership approach

As strategic leaders, local authorities have a key role to play in influencing and encouraging their partners to consider the needs of people with dementia and their carers in the services that they provide, as well as a corporate responsibility within their own organisation and amongst their own staff for the services that all its citizens need to access at some point.

The Equality Act 2010 places a legal duty on organisations to make reasonable adjustments in their working practices, services and buildings so as not to discriminate and applies equally to people with dementia. It is a useful reminder to organisations of their obligations – and a powerful lever.

Examples of how the agenda can be taken forward in practical ways include:

- Leisure departments are expert at recognising individual limitations to do with age, inexperience or disability and helping people to build up from a low base to increase stamina or skill whilst enjoying the experience. They may need to give closer attention to how they attract people to try the facilities in the first place.
- Engagement of planning functions: in Sheffield, the full engagement of planning department staff means that the local development framework and planning policies are being reviewed to highlight the needs of people with dementia and planning staff are advising on practical changes that can be made to the environment at local level, including the streetscape, bus stops and lighting.
- Housing providers: pilot work in a specific Sheffield neighbourhood, Shiregreen, has involved the local social housing provider Sanctuary Homes, which has committed to supporting and maintaining the local network of professional and community groups interested in dementia. This will offer some sustainability after the pilot phase.
- Other statutory agencies also have many insights to offer. The police, transport, retail and voluntary services, for instance, have everyday experience of responding to the needs of people with dementia who may get in to difficulties, yet receive little training on how to do so. Councils can use strategic drivers such as the community safety plan, policing plan, health and wellbeing strategy and transport plan as well as strategies for older people and people with dementia as levers to reinforce their needs.

Better outcomes through strategic partnerships can be achieved when:

- There is strong civic leadership which encourages high standards to ensure services and amenities are accessible to everyone.
- Practical solutions (such as training) are offered as an effective way of achieving attitudinal changes that transform an unknowing service to one that is all-inclusive, regardless of the nature of the illness or the disability. Invoking disability discrimination legislation should be a last resort.
- Learning is shared on how other sectors have responded, benefiting from their good practice, recognising that dementia doesn't belong exclusively to health and social care and each agency or sector takes a more holistic view.
- Good practice occurs at every level and is recognised and endorsed by senior managers and lead councillors to encourage others and reinforce higher standards.

Supporting awareness-raising and training frontline staff

It is clear from the work in Hampshire and Sheffield that there is a need for basic awareness training about dementia for people working in frontline services, in all sectors. People with dementia tell us that the attitudes and behaviour of staff are just as important as the layout of buildings, signs and general access.

Most people with dementia live in communities and neighbourhoods and use generic and universal services; the proportion who use specialist mental health services is small. It follows therefore that most staff working in services such as housing, customer centres, leisure services, libraries, transport and adult education are going to meet people with dementia from time to time as customers and some basic knowledge and understanding about the condition would enable them to do their job better and provide a more satisfactory experience for the person with dementia.

As well as training their own staff, local authorities can offer advice and support to other organisations – such as retailers, bus companies, banks and post offices – that are keen to do better. Some of them will have regular customers, so recognising changes in behaviour and knowing how to respond would add to customer satisfaction.

Many of the techniques for responding to people with dementia are the basis of good customer care for all – respect, patience, clear and jargon-free communication, for example – but there are some particular things that staff need to know. Raising awareness of dementia in the workplace will also support staff who are carers of family members or friends with dementia.

Basic awareness training – what this might include:

- information about dementia – signs and symptoms, progression of the illness
- the impact on everyday life – things people might struggle to do
- recognising when things change for customers they see regularly
- understanding the emotional support needs of people with dementia and their carers
- how to communicate
- knowing when to ask for help from a colleague
- what help is available for people with dementia and how to refer them
- bespoke topics for particular staff groups, for example helping people using transport to make sure they're going in the right direction and have confidence that the bus will drop them where they need to be.

Please see Appendices 1d and 1e for more comprehensive information.

Focusing on particular areas or themes

Creating a dementia-friendly community cannot be undertaken all at once. It is therefore important to work out how to develop a phased programme which addresses one element at a time. The concept of dementia-friendly communities covers a wide range of facilities, activities, organisations and personnel. It is therefore important to adopt the right approach for your particular locality.

Geography may be an obvious place to start, but as experiences in Hampshire and Sheffield demonstrated this may not be straightforward. A small unitary authority may be able to take a borough-wide approach that includes all its citizens, whereas a large city or county authority includes many diverse and distinct communities within it.

Other options are to engage a particular sector as a starting point. Transport, for example, is consistently cited by older people and people with dementia as a crucial determinant of whether they can get out and about. Public transport is a good place to start, but many people prefer to use taxis and in more rural communities volunteer car schemes provide a valuable service.

Information about what is available is a universal service which can be provided in any location that people frequent – pubs, post offices, supermarkets, village shops, schools, mosques, churches and libraries.

Given what we know about the experience of dementia in BME communities, those councils with multi-cultural populations may want to focus on awareness-raising and improving information about dementia for them. Meeting with people on their own ground, rather than expecting them to come to you, is an important principle.

Building on what already exists and introducing the concept of being dementia-friendly into planned initiatives will make best use of resources. Local health promotion campaigns to encourage people to take up exercise can easily be adapted to get service providers to think about how accessible and welcoming their facilities are, as well as encouraging people with dementia and their carers to participate by targeting information at places and organisations where they meet up.

Intergenerational projects in schools can include information about dementia and help reduce from an early age the fear and stigma associated with the illness.

Wherever you start, it is important to make sure people with dementia are included in the planning and design of the dementia-friendly community initiative right from the beginning.

See Appendix 1a for more details.

Better outcomes can be achieved when:

- Faith groups, social clubs, sporting and leisure associations that often look out for their own are supported in their role. Sometimes, with a little seed-funding and encouragement, they can become very supportive of their members who have dementia or who care for someone with dementia.
- The huge role of family carers in continuing to look after their relative with dementia is recognised, and they are provided with back-up and support to help them continue in their caring role.
- Parish councils and town councils give some priority to dementia in the way that services are planned and budgets are allocated.
- Larger statutory authorities share information on valued practice happening in one part of their area with others.
- All organisations, however big or small, offer leadership in dementia services – by giving some precedence to ensuring that people with dementia and/or their carers are not excluded from what is on offer.

Linking top down and bottom up approaches

Developing a dementia-friendly community will require action at both a strategic and locality level. Work on both levels is equally important. In Liverpool, as part of the Dementia Awareness Campaign, Hope University students are talking to local shopkeepers and businesses to find out how much they know about dementia.

A postcard and poster are being developed with the message 'We're dementia aware – are you?' They include five top tips for making shopping easier for people with dementia, which it is hoped local shops and businesses will display. At the same time 2013 has been declared the Year of Dementia as part of Liverpool's Decade of Health and Well-Being – a strategic partnership involving all sectors. In Hampshire, the work on dementia-friendly communities was a natural next step to follow on from the high level strategic partnership developed over several years to tackle improvements in dementia-related services.

Better outcomes in joining up strategic approaches with those on the ground can be achieved when:

- People with dementia are encouraged to form their own support and self-help networks and they are supported to do so.
- The leadership in any organisation or agency promotes the importance of understanding and responding positively to people who may have dementia, and particularly to providing support to carers of people with dementia.
- Attention is given to relatively minor changes to transform a problematic activity into one which is accessible and fun.
- Even when greater change or larger investment is necessary, organisations are clear of the cost-benefits and can defend the investment of resources.

Toolkit and other resources

What follows is a distillation of the experience of the Ageing Well dementia-friendly communities project into a practical model and toolkit for others to use. It is not put forward as the prescription to developing dementia-friendly communities. Rather, it is offered as a starting point for others to take up and develop.

The voice of people with dementia

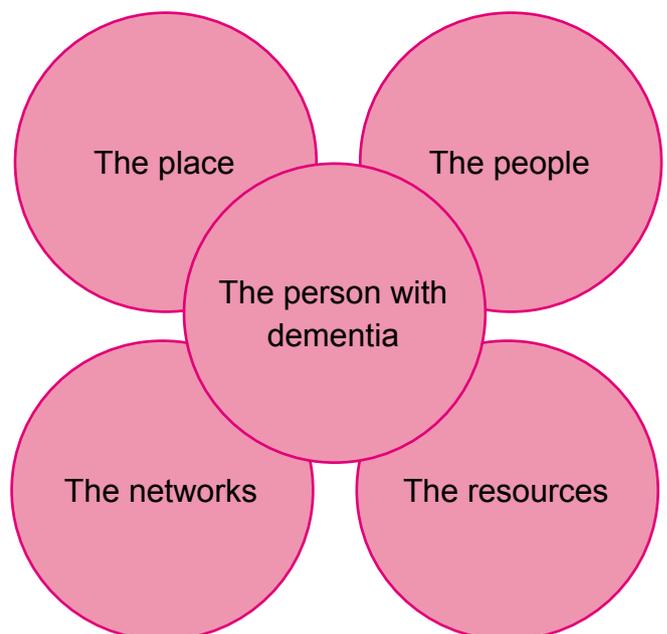
The voices of people with dementia and their carers should be at the start and the heart of the process of creating dementia-friendly communities. Dementia-friendly communities need to be responsive to what people want, but perhaps more importantly, people with dementia should have the right to have a sense of ownership, investment, responsibility and of connectedness to their own communities.

The tools can be found in the appendices.

A dementia-friendly community framework

While work across the two sites brought up some different issues, there were many common priorities identified as requiring attention. The following model synthesises these and provides a framework which we hope others may find helpful.

Overall there are five domains that should be addressed as part of developing a dementia-friendly community:



The person with dementia

In order for the person with dementia to remain, or become, active in their communities, they must feel motivated to do so, and have sufficient internal resources and resilience to enable them to connect.

It is widely recognised that many people become isolated following a diagnosis of dementia, and there is a strong tendency for people to withdraw into the relative safety and comfort of their own homes. There is also strong evidence that people with dementia who become isolated from their communities experience faster rates of cognitive decline.

“The review on promoting cognitive health and vitality (by Yevchak et al) clearly demonstrated the importance of older people maintaining social engagement, contacts and stimulation. Conversely, these authors found that older people with higher levels of perceived isolation and feelings of disconnection were twice as likely to experience more rapid cognitive decline in multiple-functional domains compared with “those individuals who perceived themselves to be supported by and connected to others.”

Keady et al: Neighbourhoods and dementia in the health and social care context: Reviews in Clinical gerontology 2012 22; 150-163 – referencing Yevchak AM, Loeb SJ, Fick DM. Promoting cognitive health and vitality: a review of clinical implications. Geriatric Nursing 2008; 29: 302–10

For some people with dementia and their carers engaged in this project, the notion of engaging in their communities or simply of going out were not seen as realistic options.

There was a strong focus on the dementia and other disabilities, and these were frequently cited as reasons why people had become so focused on life at home.

This mirrors earlier work (Department of Health 2011 Think Tank on dementia-friendly communities) which found that people with dementia and carers almost exclusively cited dementia as the sole barrier to community engagement, rather than external barriers such as unsympathetic attitudes, lack of support or environmental factors.

The message that ‘it is possible to live well with dementia’ is one which is often buried beneath the overwhelmingly negative messages coming from all directions.

This is not of course to deny the progressive nature of dementia, nor the impact it can have upon memory, cognition, the ability to function, and upon our lives and those of others.

But there are increasing numbers of people with dementia whose lives and voices are testament to the fact that while a diagnosis of dementia might be life-changing, it need not be life-ending.

The task at hand, therefore, is to think about how people with dementia can be supported in ways which enable people to, in the words of the National Dementia Strategy, ‘live well with dementia’.

Actions which have particular potential to strengthen and support the capacity of people with dementia to stay connected to their communities include:

- ongoing engagement and consultation in decisions which affect their lives
- post-diagnostic support – delivering post diagnostic support in a way which emphasises the potential to live well with dementia and maintain independence. Self-directed support has a significant role to play in raising the expectations of both people with dementia and their carers, as well as supporting their own motivation and resilience. The Think Again programme run by Avon and Wiltshire Mental Health Partnership NHS Trust is a good example of effective post-diagnostic support that goes beyond the simple provision of information.

See www.cot.co.uk/sites/default/files/ot_news/public/2-think-again.pdf

Supporting peer group development – encouraging and supporting access to and development of local peer support is an effective way of keeping both carers and people with dementia connected to, and engaged with, their local communities. Not only does peer support enable the sharing of knowledge and experience, but also represents engagement in the broader community.

People with dementia – what councils can do

- Ensure that statutory services across the board empower people to retain a sense of independence and self-determination and build resilience – ‘doing with’ as opposed to ‘doing for’. This approach needs to be adopted from the point of diagnosis.
- People with dementia should be encouraged and supported to participate in, or create, peer and self-help groups.
- Providing light-touch one-to-one support can be very effective. This should be a priority initiative, and should be promoted through community capacity building and or secured through the voluntary sector.
- Embed user consultation in processes designed to design, improve or commission services.
- Develop employment policies which are sympathetic to people with dementia and carers.
- Assess whether council information is as accessible as possible to people with dementia.

Case study: from a walk the patch session involving Innovations in Dementia

“Bert showed me where to park – immediately outside the range – which stands next to the main golf club building.

The driving range was clearly marked, however, there was no information about what to do next.

Bert told me that we needed to buy a ticket which we would then exchange for balls.

However, it was far from clear how or where we obtained our tickets.

We walked around the front and side of the main club building two times before trying a door to a part of the building that was displaying golfing items in a window.

At no point did we encounter any external signage to point us in the right direction. The shop was not marked as such – and we were a little unsure whether we should go in.

However, this was the shop, and the place from which we would get our tickets. The man behind the counter was very friendly, and Bert completed the transaction of 100 balls per person.”

The place

The physical environment, from streetscape down to individual shops and facilities within it, play a key role in determining the extent to which people with dementia will find their communities dementia-friendly.

People have told us that a physical environment which they can find their way around, in which they know where they are, and which makes them feel safe, is a huge advantage and an ideal gateway to their communities.

Place – what councils can do

- Review the built environment and involve people with dementia in planning of new developments or redesign. A toolkit listing environmental checklists is attached in the appendices.
- Encourage and support local businesses to become more dementia-friendly – see briefing note in the appendices.
- Talk to people with dementia about their experience of using ‘the place’ – see Engagement guidelines in the appendices.
- Support and encourage the piloting of ‘memory-aware’ high streets as outlined in the appendices.
- Improve signage and written information about services.

Case study: from Innovations in Dementia work in Hampshire

“While we were walking around, three different members of staff said “hello” to Jane, and I got the impression that she was a familiar face.

I asked Jane if she ever worried about not being able to find things. She told me that, no, because if she did, she could ask a member of staff for help.

I asked if she was confident that staff would help – “Oh yes” she replied. “They are very very helpful.”

The people

For most people with dementia what determined the dementia-friendliness of local facilities, over and above the elements of place, was the attitude of the people with whom they came in to contact.

People make communities friendly – those people whom a person with dementia might interact with in the course of everyday life – shop assistants, bus drivers, train conductors, the postman, the dustbin man, the library assistant, the gym instructor. These are not people providing care, but people who provide services to all of us.

In this category, we might also put family members or relatives who are not directly caring (some of them might be in close contact and live nearby, others not), neighbours, and a social network of friends and acquaintances from the community, at church, or at the social or sports club, and so on.

People are often willing to help, but the fear and stigma around dementia means that people are unsure of what to do for the best.

Awareness-raising and training have a substantial role to play in the creation of more dementia-friendly communities. It is important to see basic awareness-raising as the start of a positive continuum towards increasing dementia-friendliness:

- ▼ awareness of dementia and what it means
- ▼ not judging or stigmatising because of dementia
- ▼ understanding and empathetic towards my needs
- ▼ supportive of people with dementia and the decisions they want to make.

People – what councils can do

- Target training and awareness at those who are already on board, and then extend the use of awareness-raising and training tools to other providers and organisations who are not initially engaged (see toolkit). A toolkit for raising awareness of frontline private sector staff is also featured in the appendices.
- Develop awareness-raising event around themes – leisure/transport/housing.
- Develop pilots for ‘memory-aware’ high streets. A toolkit suggesting how this might be done is featured in the appendices.

Networks

Communities work through networking. By networks we mean the groups of people who have the capacity and the opportunity to contribute to making a community dementia-friendly.

These networks might be made up of a mixture of relatives, friends and neighbours, and of public and community service providers, as well as community leaders and local businesses. Examples of the kind of people who might be networked in a community are home care staff, housing officers, community police, local care providers, GPs, opticians, chiropodists, hairdressers, taxi firms and voluntary workers.

Sometimes these networks might be quite informal, at other times or in other places more formal.

The most important features of networks in dementia-friendly communities might be that they are:

- effective in sharing understanding of how well people with dementia are living in the community
- practical in helping to identify or create new solutions to problems which occur
- inclusive in that they cross organisational and sector boundaries and do not over professionalise
- discreet in that they understand how to respect confidentiality whilst creating a network of support.

Networks – what councils can do

- Work with people and their carers to identify those who might be networked.
- Use the local Dementia Action Alliance if there is one.

Resources

Much of the work around dementia-friendly communities is focused on engagement and working with organisations and individuals beyond those that would traditionally have a role in providing support for people with dementia.

However, if more people with dementia are to live in their communities for longer, we must recognise that the resources to support people must be in place. It is hard to imagine a dementia-friendly community where people are not well-housed, well-nourished, cared for, or enabled to stay as healthy as possible.

People with dementia, especially those in the very early stages, may be able to remain active in their communities with very little support from others.

However, as dementia progresses, people may need more support to stay engaged in their communities.

It is not just people in the later stages that benefit from support. This starts at the point of diagnosis, as the kind of support that people with dementia and their carers receive following a diagnosis is likely to be a key determining factor in their ability to live well, and remain active in their communities.

Case study: From Innovations in Dementia work

“In discussion with Bert’s wife Deanne – it seems that one reason why Bert became withdrawn was that he thought he would be getting gradually more impaired every day.

This came about when they asked me to explain the difference between Alzheimer’s disease and vascular dementia. I explained that one big difference was that they progress in different ways – with Alzheimer’s being more of a steady progression – and vascular dementia progressing in steps, often with long periods of stability.

I also pointed out the importance of maximising cardio-vascular health, not least in vascular dementia where anything that can be done to prevent further strokes can have very real benefit in terms of progression.

Her response: “Why weren’t we told that?” She wondered whether if Bert had known he wouldn’t necessarily be getting worse every day it may have given him a bit of a spur to keep active rather than simply withdrawing in to himself, withdrawing into the house.”

Resources – what councils can do

- Provide leadership and challenge to encourage civil society organisations to look after their own. For example, regular walking groups (whose membership is usually predominantly drawn from older people) could be encouraged to organise a buddy scheme from amongst their members to help support members who develop dementia to stay involved in their activities.
- Think about how community capacity can be stimulated to provide a range of support for people with dementia, for example:
 - activities at the local leisure centre in which people with dementia can take part – classes with carers, adapted games, supporting access to mainstream provision
 - leisure centres and facilities could be supported and encouraged to recruit existing members or users to buddy a person with dementia who wishes to continue an activity, or learn a new one
 - resources can be provided at the local library
 - adult education can be marketed for people with dementia, maintaining health, skills and learning capacity.
- An asset-based perspective can be promoted and sought to encourage and support people with dementia to make their contribution to civic society (ie through volunteering or intergenerational initiatives).
- Think about what resources can be made specifically available for people with dementia who live in the community in order to maximise their potential to stay connected to that community.

Examples might include:

- Post-diagnostic support, as we have seen, can have a significant impact on the ability of the person with dementia to live well. Experience of working with other groups of people with dementia who have received focused support following a diagnosis suggests that they experience better outcomes across a range of domains.
- Support to understand the implications of a diagnosis on a person's life and how to maximise the chances of living well with dementia could be of huge benefit.
- Delivering post-diagnostic support in a way which emphasises the potential to live well with dementia, and maintaining independence and self-directed support which has a significant role to play in raising the expectations of both people with dementia and their carers and supporting their ongoing engagement in their communities.
- Personalised budgets can be used for services provided across the community in the public, voluntary and private sectors, eg to give people a choice of transport options.
- Peer support groups have been identified as a major entry point into the community and place of safety within it for people with dementia, and for their carers in both project sites. The Alzheimer's Society has significant experience in providing this kind of support, most recently through Singing for the Brain (see page 32), and dementia cafés.

Being part of a support or social group gives people with dementia confidence to be part of the wider community.

Not only can these groups in themselves create both social networks and opportunities for engagement, but many see them as an important stepping stone to the wider community.

Case study: participants in Singing for the Brain, an Alzheimer's Society initiative in Hartney Whitney

“It's really good fun, obviously, but more importantly it gets us out of the house, and we get to be with others who share the same issues and problems.” (carer)

“I love it – it makes me feel we're not alone – and as I have always sung it's like I am helping the others with my loud voice – even if I do go out of tune.” (person with dementia)

One-to-one support has also been cited by participants as a service which would have a major impact on their ability to engage in their communities. Light touch support in the form of befriending or buddying schemes, or even less formal ways of engaging support could have a particular relevance for people in the earlier stages, but once established could serve to maintain the person's engagement in their community as their dementia progresses. This also offers the opportunity to engage volunteers from different backgrounds to support people with dementia in a wider range of activities than might have previously been on offer.

Ongoing consultation and engagement

Engaging people with dementia in decisions that affect their lives gives councils not only the chance to find out more about their issues and concerns, but can also engender a sense of ownership, and of agency – the feeling that what one says matters and makes a difference.

In terms of consultation around dementia-friendly communities, it also gives a clear view of where to start.

This framework is designed to be used with the tools in the appendices to help you create a dementia-friendly community.

This LGA guide and framework is designed to be used with the following tools which were developed by Innovations in Dementia as part of the work undertaken by the Ageing Well programme. These practical tools can be personalised where necessary and used to take this work forwards at a local level. The toolkit includes:

Appendix 1a: Finding out what a dementia-friendly community means to people with dementia and carers

A toolkit for engaging people with dementia and carers. We believe that the voices of people with dementia should be at the start and the heart of developing dementia-friendly communities. This toolkit is designed to help you find out from people with dementia and their carers what a dementia-friendly community means to them.

Appendix 1b: Checklist for dementia-friendly environments

A briefing note for organisations. There are many aspects of the physical environment that can make life easier for people with memory problems – this document outlines some very basic considerations as well as signposting to more detailed audit tools.

Appendix 1c: Why do we need to be dementia-friendly?

A briefing note for businesses. This document explains why it is important that local businesses think about becoming more dementia-friendly.

Appendix 1d: Dementia awareness-raising options for staff

A briefing note for businesses. People with dementia have told us that it is the attitude of those they meet that is the most important aspect of a dementia-friendly community. Raising awareness of dementia among staff is therefore crucial – and this document outlines a number of different awareness-raising options.

Appendix 1e: Help pack for customer-facing staff

A briefing note for businesses. During our research we were unable to find any awareness-raising materials written exclusively for customer-facing staff. This help pack is focused on helping staff to support customers with memory problems more effectively.

Appendix 1f: Thinking about a ‘memory aware’ high street scheme

A briefing note for organisations.

This document lays out recommendations for the development of a ‘memory aware’ high street scheme that puts people with dementia in control of how they want to be supported.

How do the tools work together?

The voices of people with dementia should be at the start and the heart of the process of developing dementia-friendly communities.

Appendix 1a – **Finding out what a dementia-friendly community means to people with dementia and carers** – should be used to find out what people's issues are at a local level.

What we learn from people with dementia and their carers then needs to be turned into action.

Appendix 1b – **Why do we need to be dementia-friendly?** – can be used to explain to providers why they need to act.

Depending upon the issues arising from the engagement of people with dementia and carers – we can then use appendices 1c, 1d, and 1e to support providers to understand **what** they need to do and **how**.

Finally – the development of a '**memory-aware**' **high street scheme** has the potential to create a structure within which people with dementia, their carers, organisations and local business can come together to create and sustain a high street at the heart of community which offers the best possible opportunity to live well with dementia.

Appendix 1a: Finding out what a dementia-friendly community means to people with dementia and carers

This is a guide for people working with people with dementia and their carers.

In particular it is for those who want to support people with dementia and their carers to have a say in building a more dementia-friendly community.

It includes notes to support you in finding out what is important to people with dementia about their communities, and what can be done to make them better places in which to live well with dementia.

There are guidelines for discussing the issues with people with dementia face-to-face, as well as a questionnaire for people who might prefer this approach, and are able to work alone.

You will also find a description of walking the patch – a way of finding out what it is really like for people with dementia out and about in their communities.

We have included findings from previous consultation work with people with dementia, to help you think about the various ways in which people with dementia in other areas are interacting with their communities, and the barriers they face.

It gives us a somewhere to start in developing dementia-friendly communities. If people with dementia tell us they all want to use the café in the garden centre – then we start there.

This guide is aimed at finding out what people think about their communities – it is not intended to be a comprehensive and exhaustive guide to consulting with people with dementia, so it includes links and suggestions for further reading.

Why talk to people with dementia and carers?

The idea of making our communities better places to live for people with dementia is something which engages the enthusiasm and interest of all sorts of people. Traders, leisure companies, transport providers, planners, service providers, health and social care organisations, charities are all potentially affected; all have a role to play in forming a vision about what a dementia-friendly community should look like.

The most important stakeholders in this process of course are people with dementia, and those who care for and support them.

“Nothing about us without us” is a slogan which carries great resonance for disability rights campaigners – and is one which is increasingly being articulated by people with dementia as well. The voices of people with dementia and their carers should be at the start and the heart of the process of creating dementia-friendly communities.

Dementia-friendly communities need to be responsive to what people want, but perhaps more importantly, people with dementia should have the right to have a sense of ownership, investment, responsibility and of connectedness to their own communities.

Why is it important for this work?

- People with dementia have a right to a say in decisions that affect their lives.
- Involving people with dementia sends an important message about the values inherent in the notion of dementia-friendly communities.
- It engenders a sense of ownership and investment.
- On a practical level it gives us a somewhere to start in developing dementia-friendly communities.

The voices of people with dementia and their carers should be at the start and the heart of the process of creating dementia-friendly communities.

Dementia-friendly communities need to be responsive to what people want, but perhaps more importantly, people with dementia should have the right to have a sense of ownership, investment, responsibility and of connectedness to their own communities.

You may like to get a feel for the responses we have had to these kinds of questions in other studies – you will find a summary of responses as Appendix 2.

Further reading:

The South West Dementia Partnership has produced a guide to engagement with people with dementia called What works. See

<http://www.southwestdementiapartnership.org.uk/2011/10/what-works-resource-pack/>

The Care Services Improvement Partnership has produced a toolkit - Strengthening the involvement of people with dementia toolkit. See

http://www.dhcarenetworks.org.uk/_library/Resources/Dementia/CSIPComment/strengthening-the-involvement-of-people-with-dementia.pdf/

Things to bear in mind before you start

- For some people the concept of dementia-friendly communities might be a difficult one to grasp. So make sure that YOU understand what this is all about so that you can in turn make it clear to participants.
- Find out whether there are any existing consultation processes or initiatives you might access.
- Are there conflicting needs between carers and people with dementia that you need to take into account (see below), which might influence how you carry out the work.
- Make sure that you have enough time, and staff or volunteers available to make this an enjoyable experience in which people feel they have the time and support to have their say in the way that best suits them.
- Make sure you tell participants what will happen next, and how they can stay involved, if they want to.

What are we trying to find out – and why?

At this stage of the process – we are interested in:

- the ways in which people with dementia engage in their communities
- what helps, and hinders this process
- what people have stopped doing since their diagnosis and why
- what new things people might like to be doing
- what can be done to help.
- Once we have identified the issues – we can begin to think about how we might begin to address them.

How can we go about finding out what people's issues are?

There are a number of ways you can go about talking to people with dementia and their carers, and these include:

- by talking to people one-to-one
- by talking to people in a group setting
- by asking people if they would like to fill out a questionnaire, either online, or on paper.
- by walking the patch with people with dementia – to get a feel for how they really experience getting out and about in their communities.

These are not mutually exclusive, some people might want to get involved in group work, as well as having a one-to-one. You might also want to offer a one-to-one conversation with people who seemed to have more to say during a group conversation.

There are lots of other ways to support people to express their views.

People respond to different approaches at different times in different ways. The communication needs of individuals, the person's background and interests, and their relationships with staff needed to be taken into account before identifying the most appropriate approach.

Talking to people one-to-one

Some people find it a lot easier to talk on a one-to-one basis. People with more advanced dementia will often have more particular needs with relation to communication, and may find group work more challenging, and may be sidelined by more vocal group members.

By working on a one-to-one basis we can provide a more person-centred approach that is more likely to meet their particular needs, and more likely to give us the information we need to move forwards.

Effective communication is the key to successful one-to-one discussions.

Don't forget that people with dementia have good days and bad days – if you are working regularly with someone, and they are having a bad day, you can always come back to the conversation another day.

Tip:

You may find that conversation veers away from the topic in hand – that's OK – and you will often find that you get some good results by allowing the conversation to take its course – it's more important that people feel relaxed and that their input is valued.

Group discussions

Some people may feel pressurised by one-to-one interviews and may worry about the impact of what they say. Group discussions can overcome this by generating a group rather than individual response. Hearing the views of others can also help people articulate their own thoughts.

Many people with dementia will be happy to work in a group – especially if it is an established group where people know and feel comfortable with each other.

You can use the questions and structure of the questionnaire on page 45, as the basis for your group discussion.

Don't feel too restrained by the questions or structure – you should think of these as guidelines for a conversation.

Further reading

The SCIE Open Dementia e-learning course has an excellent module on effective communication. <http://www.scie.org.uk/assets/elearning/dementia/dementia07/resource/flash/index.html>

Here's what people with dementia have said about running an effective meeting:

- Distribute easy to understand agendas before meetings. This gives us a chance to prepare and write down our thoughts.
- Meetings should be short, with only one or two agenda points. We get tired and find it difficult to concentrate after a while.
- It helps if you give us some ideas. But sometimes we will want to talk about things that are important to us.
- Slow down the pace of discussion to give people time to say what they want to say. Don't talk too much!
- It helps to take turns so that everyone can have their say, even if this is not in words
- Refreshments are essential. They help us to relax and make our journey worthwhile.
- Send us an easy to understand record of the meeting as soon as possible.
- Send us a reminder just before the next meeting.

Carers and people with dementia

You will be aware that people with dementia and their carers often have different, and sometimes conflicting needs and points of view, and this can influence the methods you use to seek their views.

Where people need space to articulate their own perspective, you might consider running two different sessions.

- one to consider the views of people with dementia
- one to consider carers' views.

People should feel free to go to either or both sessions, but you need to be clear about the issues under discussion. This can help if people with dementia or their carers feel anxious about being separated.

This will not guarantee there won't be any muddying of the waters between carers issues and those of people with dementia – but it can certainly help to keep things as clear as possible.

Tools for one-to-one work and group discussions

You can use the questions and structure of the questionnaire on page 45, as the basis for your conversations with people with dementia and carers.

Don't feel too restrained by the questions or structure – you should think of these as guidelines for a conversation.

You might also consider bringing along some pictures of commonly-used areas within the community – the shops, library, parks, bus or train stops, leisure centres and so on – these can be useful as:

- prompts for discussion, especially if people are struggling with direct questions
- reminders of the topic in hand – to help people to stay focused
- as props – some people feel more confident when they have a physical object they can handle and refer to.

Questionnaires

Some people prefer to work alone, and are able to fill out a questionnaire.

The questionnaire on page 45 is designed to help people to have their say on what a dementia-friendly community means to them.

It can be printed out after adding your contact details on the last page.

We have also uploaded a copy of the questionnaire to an online survey website called Survey Monkey.

The survey can be accessed <https://www.surveymonkey.com/s/TR9JCHR>

Walking the patch

This can be a very effective way of finding out more about how people with dementia experience their local environment.

It can also help to identify ways in which to support local facilities to become more dementia-friendly.

Arranging to go with them to visit these places can give us some really valuable insights into how people with dementia experience their environment.

While people in the early stages may need less support, and may be more active in their communities - it would be wrong to assume that people with more advanced dementia cannot enjoy the process and have nothing to offer.

Who should go?

It is tempting to assume that this activity is only suitable for people in the early stages of dementia. Certainly, people in the early stages may need less support, and may be more active in their communities.

However it would be wrong to assume that people with more advanced dementia cannot enjoy the process and have nothing to offer.

Much will depend on the activity you choose, the person's particular needs and preferences, and the level of support you have available to you.

It is best to do this on a one-to-one basis, as you will need to give your full attention to the person, and to their experience. If you have more than one person with dementia, you will need the same number of people to accompany them.

If carers want to come with you, that can be a big help, but bear in mind that the focus is very much on the person with dementia and their experience.

Where to go?

You may have already identified places in the community where people with dementia go, or have said they would like to go. This might include supermarkets, restaurants, pubs, gymnasiums, railway stations, and leisure facilities. If you have not identified specific venues, then a leisurely walk in a high street or park can be useful, not just to get a feel for how people find their way around, but can also serve to prompt people about particular places they might like to explore.

It can be really helpful to have a specific goal in mind. For instance to:

- buy a specific item in a shop
- find out the time of a particular bus or train, either at a train or bus station or by phone or online (we can walk the patch metaphorically as well as literally).

Remember:

- knowing the location of toilets can be a big help, for all concerned
- think about how the person will travel to and from the walk.

When to go?

You might want to think about going during less busy periods. This will reduce the stress on the person with dementia, and make it easier for you to focus on what they are telling you and experiencing.

The process

You should explain clearly to the person with dementia what this process is all about.

Depending upon the person you may need to remind them that you are just trying to find out what it is like for them to be out and about.

Try and keep it as informal as you can, and as enjoyable as possible for all concerned. Keep the whole exercise within 45 minutes if possible.

You should persuade the person to explain how they are making decisions as they navigate their way around. Get them to talk about what it is like for them.

Pay particular attention at key decision points, and use prompting questions where necessary like:

- what are you looking at?
- how did you choose between this way and that way?
- can you see that notice?
- what do you think it means?

Don't expect the person to explain every decision – you can learn a lot from observation. Make a mental note of how well they are navigating the environment, what use they are making of formal and informal aids to navigation, how are the interactions with those they encounter.

It's OK to reflect back what the person is telling you, or what you observe:

- did you find X difficult?
- it looked to me like you were struggling with XX
- you found XX useful didn't you?

Remember:

- you may need to reassure the person and point them in the right direction or assist with an activity (such as finding money)
- it should be an enjoyable experience – but be careful that the person doesn't get distressed.

After the walk

It can be helpful to have a conversation about the walk. Questions you might find helpful include:

- did they enjoy it?
- what did they enjoy most/least?

- what was helpful/unhelpful?
- what can be done to make it better?

From what the person has told you, and from your observations, it is possible that you might have some ideas together about how improvements can be made.

Walking the patch – issues to bear in mind

Safety

You should be conscious of the safety and support needs of people with dementia whilst you are out and about. Talk to them and their carers about safety issues, and whether the person needs any particular support whilst out and about,

As a service provider, you should apply your usual health and safety, and risk assessment procedures.

Consent

You should make sure that the person is able to consent. You should consider getting written consent if you are likely to use their words in any reporting that you do.

Agree with the person how you are going to record what they say, ie by writing it down, sound recording, photos, video recording, asking someone else to take notes. If the person is not happy with these, then you will have to make mental notes, and write it down as soon as you can after the walk.

A copy of Innovations in Dementia's ethical code of practice for involving people with dementia is available at www.innovationsindementia.org.uk

Approaching providers with what people tell you

Engaging with people with dementia is meaningless unless we do something with what we have learnt.

Depending upon what you learn, you may have information about:

- places in the community where people with dementia go
- places they would like to go
- things that help people to connect with their communities
- things that are a barrier to their communities
- things that people would like to do
- things that people have stopped doing, and why
- what might help people to stay connected, reconnect or make new connections.

Some of these things might be very general in nature like, for example, a lack of green spaces in urban areas. Or it might be something very specific, like a particularly helpful shopkeeper or a piece of poor or non-existent signage.

So a question to ask is: **if things are to move forwards who needs to know?**

If there are issues around outdoor areas and townscapes, then the planning department would be a good place to start.

For very specific issues – like signage in a building – then the manager is probably the best person to start with.

If there are issues that retail premises share in common – then the town or shopping centre manager, or traders association would be another option.

If there is a local Dementia Action Alliance, then this can be another very effective way of raising issues, especially those of a more general nature.

Another question to ask is: **what is the best approach to take?**

Your approach will depend upon the relationships that you have built up with providers of services and facilities.

In some instances an informal approach will work well, and in others, especially larger providers, it can pay to begin the approach in writing or by email.

You should introduce yourself, and let the provider know about your work in making your area more dementia-friendly.

Make sure you have the briefing note for businesses – Why do we need to be dementia-friendly – at hand, and ready to give to providers.

This will explain **why** they need to think about becoming more dementia-friendly.

You can go on to explain that you been talking to people with memory problems and their carers about their experiences – and that you feel that there is something that they should know about how they can make their service better.

This will help them to understand **what** their specific issues are so far as people with dementia and carers are concerned.

In our experience, what people have to say about their communities and the places within them are rarely wholly negative. There are usually positive comments to be made, very often about the attitude of staff that can outweigh, or at least sweeten potentially negative comments in other areas.

If there are positive things to say, then start there. Then you can move on to pointing out the areas where they might use some help.

This is where you can use some of the improvement tools to show providers **how** they can make changes for the better:

- Checklists for dementia-friendly environments (Appendix 1b) gives some basic guidance on things to consider in making indoor environments easier for people with dementia. It also provides links to more detailed audit tools if needed.
- Dementia awareness-raising options for staff (Appendix 1c) describes a range of options for raising awareness of dementia among staff.
- Help pack for customer-facing staff (Appendix 1d) is a basic awareness guide designed especially for customer-facing staff. It gives a very brief introduction to dementia, but focuses mainly on how to support customers who may be having problems.

Questionnaire

Why are we asking these questions?

We want to find out what people with memory problems do in **your** area, what facilities they use, and what helps or hinders them.

We want to find out more about what makes places easier to live for people with memory problems.

It would be a big help to us if you could let us know what you think by answering the questions in the **BLUE BOXES** below.

About you.

Tick the box that most applies to you:

I am a person with dementia or memory problems

I am the carer or friend of a person with dementia or memory problems – and am filling in this form on their behalf

I work with people with dementia or memory problems – and am filling in this form on their behalf

None of the above

I live in _____

We don't need to know your full address – just which part of town, or which village you live in.

When you are out in your local area – what sort of things do you do?

What helps you to do these things?

What makes it more difficult for you to do these things?

Are there things that you used to do, but have stopped doing?

If so, why have you stopped doing them?

What might help you to start doing them again?

Are there new things that you would like to be able to do in your community?

If so, what do you feel is stopping you?

What might help you to start doing them?

Finally – what do you think could be done to make your community more dementia-friendly?

If you would like someone to contact you about what you have said, or want to find out more about dementia-friendly communities, please write down your contact details here:

Once you have finished this form – please hand it to:

Or send it to:

If you would like to talk to someone about this form – please call

Thank you for your help.

Appendix 1b: Checklist for dementia-friendly environments

Environmental checklists

The Local Government Association Ageing Well guide to developing dementia-friendly communities talks about the importance the right environment plays for people with dementia.

There are a number of very thorough environmental checklists available free online.

These include:

Neighbourhoods for life – designing dementia-friendly outdoor environments produced by Oxford Institute for Sustainable Development

This is aimed primarily at designers and covers all scales from urban design to street furniture, on the criteria to consider in developing dementia-friendly urban areas. It also has much of interest to those thinking about the outside environment at any level.

<http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Design/?parent=5091&child=6988>

Dementia design checklist – design checks for people with dementia in healthcare premises Produced by NHS Scotland with the University of Stirling and Dementia Services Development Centre (DSDC) Stirling, this is aimed at healthcare facilities and is very thorough, but can also be applied to other indoor environments and those wanting to consider improvements on a smaller scale.

<http://www.dementiashop.co.uk/products/dementia-design-checklist>

Stirling University Dementia Services Development Centre produces a wide range of publications in the theme of design for dementia:

<http://www.dementiashop.co.uk/taxonomy/term/11>

Alzheimer’s Australia NSW dementia and age-friendly outdoor design checklist

This is contained within Building Dementia and Age-Friendly Neighbourhoods, produced by Alzheimer’s Australia NSW. It is a short checklist, some of which is quite localised in its priorities, but is relevant to those planning and designing new indoor and outdoor environments.

<http://www.fightdementia.org.au/common/files/NSW/DementiaFriendlyNeighbourhoodsWebVersion.pdf>

Checklist of essential features of age-friendly cities

The checklist was produced by the World Health Organisation.

Age-friendly environments have much in common with those for people with dementia. This is aimed at those working at a strategic level, and is intended as a tool for measuring dementia-friendliness across a wide variety of domains including housing and social inclusion.

http://www.who.int/ageing/publications/Age_friendly_cities_checklist.pdf

Small changes can make a big difference in the internal environment

The checklists above have much to offer those in a position to influence large-scale development, redevelopment or infill.

However, there are a number of changes that could be considered at much smaller scale and cost, especially in the indoor environment, that can have a major impact on improving accessibility for people with dementia:

Signage:

- signs should be clear, in bold typeface with good contrast between text and background
- there should be a contrast between the sign and the surface it is mounted on
- signs should be fixed to the doors they refer to – not on adjacent surfaces
- signs should be at eye level and well-lit
- the use of highly stylised or abstract

images or icons as representations on signage should be avoided

- think about placing signs at key decision points for someone who is trying to navigate your premises for the first time
- signs for toilets and exits are particularly important
- ensure that glass doors are clearly marked.

Lighting:

- entrances should be well-lit and make as much use of natural light as possible
- pools of bright light and deep shadows should be avoided.

Flooring

- avoid highly reflective and slippery floor surfaces
- changes in floor finish should be flush.

Seating

- in larger premises a seating area especially in areas where people are waiting can be a big help
- people with dementia prefer seating that looks like seating – so for example a wooden bench rather than an abstract metal Z-shaped bench.

Navigation

- research shows that people with dementia use landmarks to navigate their way around, both inside and outside. The more attractive and interesting the landmark (which could be a painting, or a plant) the easier it is to use as a landmark.

Appendix 1c: Why do we need to be dementia-friendly?

Why does my business need to be dementia-friendly?

Dementia currently affects some 800,000 people in the UK.

There are many forms of dementia, but they are all diseases of the brain which can cause:

- problems with memory
- problems with everyday tasks, like handling money
- problems with communication
- problems with perception.

It is progressive – in that it starts off with very mild symptoms and gets worse over time.

It affects everyone differently. No two people with dementia are the same.

Why do we need to know about dementia?

Increasingly, people with dementia are living for much longer in the community, and that will mean that increasingly, more and more of your customers, and potential customers will have dementia.

You probably already have some customers who have dementia.

You certainly have many potential customers who have dementia.

Making it easier for people with dementia to use your service, and supporting your staff to serve them more effectively has a number of very clear benefits:

- It will enable you to maintain your existing customers who might have, or be developing dementia. If they do not find it easy to use your business, they are likely to seek out another.
- It will enable you to attract new customers. There will be an increase in the numbers of people with dementia living independently. They will use the businesses which are easiest to use.
- Your business may have a community charter, or a community benefit component to your quality assurance programme. Making it easier for people with dementia to use your business will be a very big plus.
- It will help with compliance to the Equality Act 2010.
- Staff who are unsure how to best serve customers with dementia may be hesitant in helping, causing delays to themselves, the customer with dementia, and other customers.

How can I make things easier for people with dementia to use my business?

There are a number of things you can do fairly easily and cheaply in order to help people with dementia:

1. Ask people with dementia what it is like to use your business

You may already know people with dementia – if so, that is a great place to start.

People with dementia will often be able to tell you very directly which aspects of your business they find easy to use, and which present barriers to them.

For more information: If you don't know any people with dementia, then contact the Alzheimer's Society, who might be in position to arrange for people with dementia to visit and then let you know what they think.

2. Have a look around at your buildings and facilities – are they dementia-friendly?

There are often some very simple changes that can be made to create an environment which is much easier for people with dementia.

For more information – See Appendix 1b. This is not a prescriptive list, nor is it exhaustive, but it may give you a few ideas and some food for thought.

3. Check whether the information you provide about your business is dementia-friendly

At the very least you should make sure that you use plain English.

A design guide for businesses wanting to make their information dementia-friendly is available from Innovations in Dementia, see www.innovationsindementia.org.uk

4. Raise your awareness of dementia

People with dementia tell us repeatedly that it is the attitude of those they encounter in their communities which has the biggest impact on their lives in their community.

Our work has shown that those with good people skills or within organisations with a strong focus on customer care may already have many of the attributes or skills they need to be able to support people with dementia as customers.

However, a basic understanding of the impact of dementia and how to support people can make a huge difference both to the experience of the customer, and to that of the staff involved.

People living with dementia will encounter a range of people on a day-to-day basis as they go about their business.

They may experience a range of problems associated with dementia that have the potential to impact on their ability to interact with those they encounter. Similarly those they encounter may be unsure how and whether to help people who appear to be experiencing difficulties.

People with dementia all differ in the way they experience their dementia, but generally speaking in public situations people with dementia may have a range of difficulties, including:

- problems remembering what they are doing
- difficulties in communicating clearly
- problems handling money
- problems navigating in complex or confusing environments.

How staff respond to people who may be experiencing these kinds of problems makes the biggest difference.

For more information – see these other Innovations in Dementia documents:

- awareness-raising options for staff
- help pack for customer-facing staff.

Appendix 1d: Dementia awareness-raising options for staff

Awareness-raising resources

People living with dementia will encounter a range of people on a day-to-day basis as they go about their business.

They may experience a range of problems associated with dementia that have the potential to impact on their ability to interact with those they encounter. Similarly those they encounter may be unsure how and whether to help people who appear to be experiencing difficulties.

People with dementia all differ in the way they experience their dementia, but generally speaking in public situations, people with dementia may have a range of difficulties, including:

- problems remembering what they are doing
- difficulties in communicating clearly
- problems handling money
- problems navigating in complex or confusing environments.

How staff respond to people who may be experiencing these kinds of problem can make a real difference. People with dementia tell us repeatedly that it is the attitude of those they encounter in their communities which has the biggest impact on their lives in their community.

What do staff need to know?

Our work has shown that those with good people skills or within organisations with a strong focus on customer care may already have many of the attributes or skills they need to be able to support people with dementia as customers.

However, a basic understanding of the impact of dementia and how to support people can make a huge difference both to the experience of the customer, and to that of the staff involved.

This guide is aimed at staff whose role is not specifically to support people with dementia, but who may encounter people with dementia as customers on a day-to-day basis.

There will be some variation in the kind of knowledge that people will need, as they encounter people with dementia in different situations. The needs of people with dementia will differ from one encounter to the next, and the role of staff in respect to the person with dementia will differ according to the situation.

For example, the role of a police officer in this regard is going to be very different from that of a shop assistant.

It is important therefore to recognise that training and awareness-raising is at its best when it is designed for the audience in mind.

However, there are likely to be some similar themes and needs across all public-facing situations:

- why it matters
- how to recognise that people may be having problems
- how to respond to people who may be having problems
- how to communicate more effectively with people with memory problems
- what to do if someone needs help.

How much training do staff need?

This will depend upon the nature of the organisation they work for, and their role within it.

In a large retail organisation for example, a member of staff whose role is solely focused on customer care issues is likely to need a deeper level of understanding than a staff member who stacks shelves, or serves customers.

There are a range of existing training and awareness-raising options available to businesses and organisations that want to improve their customer service to people with dementia.

The options presented represent the best readily available training options ranging from full Alzheimer's Society dementia training or formal awareness-raising via the local Alzheimer's Society, through online self-training, to printed materials. These options are not mutually exclusive.

1. Face-to-face training from the national Alzheimer's Society.
2. Online training –via the SCIE e-learning Open Dementia Programme.

3. Printed materials – eg booklets from Alzheimer's Society.
4. Help pack for customer-facing staff.

1. Face-to-face dementia awareness training from the national Alzheimer's Society

Brief description

Offers an insight into the everyday experience of the person with dementia and looks at how the person may be affected physically by dementia, as well as the signs, symptoms, impact of and treatment of the disease.

Suitable for:

- staff who may come into regular or sustained contact with people with dementia
- organisations with a number of staff who can attend training at the same time.

Cost – one day course £1250 + VAT

https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1376

2. Online training – SCIE e-learning open dementia programme

Brief description

The open dementia e-learning programme is aimed at anyone who comes into contact with someone with dementia and provides a general introduction to the disease and the experience of living with dementia.

This programme is designed to be accessible to a wide audience and to make learning as enjoyable as possible and so allows users to fully interact with the content and includes video, audio and graphics to make the content come alive.

Suitable for:

- staff who may come into contact with people with dementia
- staff/organisations with internet access
- organisations with limited resources.

Cost : Free

Time commitment:

The whole course can be completed in between 2.5 and 3.5 hours and provides a very good grounding for people who want to know about dementia and how to support people who might be having problems.

However, there are some modules which might not be relevant for staff who only need to know the signs of dementia, and how to help.

For customer-facing staff who do not have a specific role in supporting people with dementia therefore, we would particularly recommend:

Module 1 – what it is and what it isn't (20 mins)

Module 5 – common difficulties and how to help (30-40 mins)

Module 7 – positive communication (20-30 mins)

<http://www.scie.org.uk/publications/elearning/dementia/index.asp>

3. Printed materials –from Alzheimer's Society

Brief description

A range of free information, including:

- Remember the person leaflet produced for Awareness Week 2011. This is an awareness-raising leaflet that encourages people to think about dementia.
- Ongoing information about dementia and what's going on locally via national and local newsletters and factsheets.

Suitable for:

- staff who may come into contact with people with dementia
- staff and organisations with little time or money to invest in training.

Cost: Free to download

More information

http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=41

4. Help pack for customer-facing staff

The Local Government Association and Innovations in Dementia have produced this pack which focuses on helping staff to support customers with memory problems more effectively. It is free and provides key information on dementia and dos and don'ts when dealing with people with dementia. See www.innovationsindementia.org.uk for more details.

Appendix 1e: Help pack for customer-facing staff

How to help customers with memory problems

This help sheet is designed to help you support customers who might have dementia.

What is dementia?

Dementia currently affects some 800,000 people in the UK.

There are many forms of dementia, but they are all diseases of the brain which can cause:

- problems with memory
- problems with everyday tasks, like handling money
- problems with communication
- problems with perception.

It is progressive – in that it starts off with very mild symptoms and gets worse over time.

It affects everyone differently. No two people with dementia are the same.

Why do I need to know this?

Lots of your customers may already have dementia.

Certainly, lots more of your customers will be developing dementia, and will want to carry on using your business.

This help-sheet has been written to give you some very basic information that can help you to provide great service to people with dementia.

What are people with dementia like?

Everyone experiences dementia in different ways.

What is a problem for one person, may not be for another, and vice-versa.

The image of a person with dementia you might have in your head is perhaps that of someone who is:

- very confused
- needs a lot of help
- lives in a care home
- can't communicate
- cannot control themselves.

If you have this image in your head, it would not be surprising, as that is the way people with dementia are often portrayed in the media.

Most people with dementia you will encounter will not resemble this stereotype at all.

They are more likely to have much less pronounced difficulties, be living independently, getting out and about, using shops and cafés, doing the same kind of things we all do. But they may just need a little more help to carry on doing these things as time goes by.

How can I spot a person with dementia?

You can't.

Most people with dementia are over 65, but some are younger.

Some people with dementia will tell you if they are having problems, and how you can help.

Some people carry a card which explains the problems they have and how you might help. There may be a memory-aware scheme in your area through which people with dementia can carry a card which explains how you can best help them.

You might also notice customers doing or saying things which suggest that they are having problems that might be caused by dementia.

These include:

- looking, or saying that they are a bit lost or confused
- they might appear to be searching for something they can't find
- they might be looking like they don't know what to do next
- they might appear to have problems handling or understanding their money, or how to use their card
- they might be finding self-service facilities hard to understand

- their speech might be hard to understand
- they might appear to have problems understanding what you are saying
- they might forget to pay for things they have picked up.

Of course, there are all sorts of reason why people might be having these problems that are nothing to do with dementia or memory problems.

Generally-speaking, the younger the person appears to be, the less likely it is to be dementia-related. But remember, younger people can have dementia too.

What can I do to help?

If you have good people skills and work for a business with a good culture of customer care, you already have much of what you need to provide great service to people with dementia.

Kindness, common sense, avoiding stress, using good communication skills and a smile go a very long way.

Let's look at what we can do to help if you see people having these kinds of problems.

What can I do if people are:

- looking, or saying that they are a bit lost or confused?
- appearing to be searching for something they can't find?
- looking like they don't know what to do next?

DO: approach them in a friendly open manner, and ask "can I help?"

It really is that simple, and for many people with dementia, this will be all they need, and they will be able to explain exactly how you can help.

DON'T: call to them from a distance.

Many people with dementia have also got hearing problems, or might have difficulty locating where the voice is coming from. It is also much less friendly than approaching someone directly.

What can I do if people are:

- appearing to have problems handling or understanding their money, or how to use their card?
- appearing to find self-service facilities hard to understand?

Again, simply asking if you can help can go a long way.

Also, **DO:**

- tell them to take their time – there's no hurry
- offer to pick out the right money if someone appears to be struggling to work out the coins or notes in their hand
- offer to run the items through self-service, or show them how to do it
- ask if they would like to sign for their purchase if they can't remember their PIN
- offer to keep their shopping to one side so that they can come back and collect it when they have remembered their PIN.

DON'T:

- attempt to hurry them
- let any impatience show, especially in the form of raised eyebrows, tutting, or exchanging knowing looks with other customers or staff.

What can I do if people are hard to understand?

Some people with dementia develop problems with their speech, and these can be made worse if they feel stressed or hurried.

DO:

- encourage them to take their time
- listen very carefully and make sure that you are communicating through your body language that you are listening and focused on them
- be conscious of their body language
- if you still don't understand, take a best guess and say something along the lines of "I'm finding it hard to understand you. Are you saying?"
- if this doesn't work, then ask them to point at what they want
- some people are still able to write so ask them if they can write it down.

What can I do if they appear to have problems understanding what I am saying?

Some people with dementia can develop problems with understanding what is said to them, especially if they feel stressed or hurried, or if there is a lot of background noise and distractions:

DO:

- take your time – speak clearly and not too quickly
- try to make only one point at a time
- say things more simply if you need to
- make sure you are at the same level as the person, and use good eye contact
- try saying things another way
- use sign language and gestures to reinforce what you are saying.

What can I do if someone appears to have forgotten to pay for something?

This is difficult. While someone may have forgotten to pay, they might equally be engaged in theft, and your safety is the most important thing.

If you know the person, and you know that they have dementia, then you can simply ask if you can help, and if they would like to pay. This will often be all you need to do.

Very rarely, people with dementia will not understand that they need to pay, or may feel that they shouldn't. In these cases, it is up to the discretion of the manager. Some businesses, if they know the person and their carer, have simply totted up the value of goods, and asked the carer to arrange for payment.

If you do not know the person, then your business' usual policy on theft should apply.

What if none of this works and I need help?

One approach is to ask the person if they would like to take a rest or a sit-down somewhere quiet – so long as you have that facility available. Quite often, after a break, people feel much better and are able to function more effectively.

Ask the person if there is anyone you can contact who might be able to help. If so, then call them.

If none of this works, and the person appears to need help, then you should call for your manager for help.

If you are the manager, or are working alone, then depending upon the nature of your business and location you could call:

- the disability support centre if you are in a large retail complex
- your community police officer, you should have their number on hand
- social services outreach
- if the person appears to be at risk, then the emergency services as a last resort.

Where can I get more information?

If you want to find out more about dementia, see the Innovations in Dementia document Awareness-raising for staff.

Appendix 1f: Thinking about a 'memory aware' high street scheme



The idea of a kitemark for shops and facilities that want to encourage customers with particular needs is not new. Schemes for people with learning

disabilities have already been developed in a number of locations, including Milton Keynes and Sheffield.

Developing such a scheme for people with dementia is a relatively new initiative. Plymouth was the first city to introduce the notion of shops and other businesses with dementia-friendly zones.

This has been developed under the auspices of the local Dementia Action Alliance and has already achieved considerable levels of buy-in from local businesses, with 400 local businesses signing up.

A Dementia Action Alliance may not have been set up as yet in your area, but this does not mean that steps cannot be taken to encourage the development of local dementia-friendly schemes.

However, it is important to establish a shared meaning about what this might mean, both for businesses signing up, and for people with dementia who might want to use it.

Developing a scheme without a mutual understanding of the implications of signing up risks both the participation and goodwill of businesses, and the trust of people with dementia for whom one poor experience might come to represent a loss of faith in the whole venture.

Essential characteristics of a dementia-friendly scheme

- It must be grounded in what people with dementia say they want.
- People say that the most important feature of a dementia-friendly community is the people that they encounter within it.

Building awareness of dementia at management level and crucially in customer facing staff must be seen as a priority.

- It must be grounded in what is possible and realistic from the perspective of local businesses.
- It must involve a commitment by businesses to, as a minimum requirement, provide awareness-raising for staff, using the Help pack for customer-facing staff as a baseline requirement.

In an ideal world, all staff would be highly trained and skilled in supporting people with dementia as customers. However, experience suggests it is unlikely that many businesses would sign up to this level of commitment.

However, experience also suggests that many businesses that operate effective customer care, either by accident or by design, already have many of the attributes and skills in place needed to become more dementia-friendly.

This suggests that, especially for staff who already employ good customer care, the level of additional training or support needed in order to extend their support to customers with dementia may be significantly lower than they expect.

- It must be owned by an organisation or alliance of organisations willing to support both businesses and people with dementia in its use.

Please note the use of the word owned rather than the word accredited. Whichever organisation has ownership of the scheme will need to be prepared to commit to a certain level of administrative, awareness-raising and promotional activity, but should avoid suggesting that buy-in by businesses implies any kind of accreditation. To do so would not only imply responsibility for the actions or omissions of participants, but users might also infer a degree of conformity to standards which go beyond the aspirational statements and awareness-raising we might reasonably expect businesses to accept.

In the future it may be possible to think about more formal standards, which would lend credibility to the idea of accredited kitemarking – but this a complex area not least because of the significant variation in the needs of people with dementia.

- It must involve businesses signing up to a charter, or dementia declaration that may be aspirational, but which commits them to reviewing the ways in which they support customers with dementia.

Elements of a memory aware scheme

1. Awareness-raising for staff

At the most basic level of awareness, staff should be aware of:

- how the help card scheme works
- how dementia might affect people using their business
- top tips for helping someone who might be struggling
- what to do if you need help or are concerned.

See the appendices for more information. Innovation in Dementia's guide Help pack for customer-facing staff should be regarded as a minimum requirement.

2. Help cards for people with dementia.

There are a number of help cards available for people with dementia to alert others to their condition.

The Alzheimer's Society produces a card which is widely used. This card, produced by Alzheimer's Scotland goes one step further in allowing the person with dementia to choose from a checklist of particular ways in which the person might help them.



This card, produced as part of the My Voice My Choice project run by Sheffield Learning Disabilities Partnership Board goes further still, and allows the person to personalise the card even further.



You can find out more about the scheme here:

<https://www.signpostsheffield.org.uk/my-voice/communication/card.html>

This level of personalisation has distinct advantages in that:

- it allows the person with dementia themselves to explain how their dementia affects them and determine how, (and whether) they want to be helped
- it gives the best possible instructions to the person reading the card, and means that the person with dementia is most likely to get the help they need, rather than help based on a more generic understanding of what works for most people with dementia.

An ideal card for people with dementia should allow the person to:

- choose versions which refer to either dementia, a specific form of dementia, or to more generic memory problems
- specify how the dementia might affect them
- specify how they want to be helped
- specify how they can best be understood
- specify how best to communicate with them.

Guidance should also be provided for the person with dementia and their carers on how to fill out the card, and how and where to use it.

3. Posters for participating businesses

Businesses which sign up to the scheme can be provided with a poster, or sticker, featuring the scheme logo which they can display in their window, as well as digital versions for use online and in other promotional materials.



4. Marketing the scheme

To businesses

Dementia Action Alliances provide an ideal platform for developing a memory aware scheme.

In the absence of an alliance, the scheme could be targeted initially at a small number of businesses known to be used by people with dementia.

Chambers of commerce and trading associations, town centre or shopping centre managers also provide a valuable route to local businesses.

It is important to make a clear business case for the scheme. For more information on making the business case see the Innovations in Dementia document Briefing note for businesses.

To people with dementia and their carers

One important feature of this scheme is that it puts people with dementia in control of determining how they describe their condition, how it affects them, and how they want to be helped.

Some people may need help to think about how best to articulate their needs, and guidance notes and one-to-one support could make this a lot easier.

Appendix 2 – Dementia-capable communities: The views of people with dementia and their supporters

Executive summary

People told us about the things which make the difference in a dementia-capable community:

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

People told us that they kept in touch with their communities:

- through local groups
- through the use of local facilities
- through walking
- through the use of support services.

People told us they had stopped doing some things in their community because:

- their dementia had progressed and they were worried about their ability to cope
- they were concerned that people didn't understand or know about dementia.

People told us that they would like to be able to:

- pursue hobbies and interests
- simply go out more
- make more use of facilities
- help others in their community by volunteering.

People told us that one-to-one informal support was the key to helping them do these things.

People told us that communities could become more dementia-capable by:

- increasing their awareness of dementia
- support local groups for people with dementia and carers
- provide more information, and more accessible information about local services and facilities
- think about how local mainstream services and facilities can be made more accessible for people with dementia.

And they told us that in order to do this:

- communities need knowledgeable input, not least from people with dementia
- there needs to be continued media attention and public awareness campaigns
- dementia needs to be normalised
- communities need more funding for supporting people with dementia
- communities should make better use of existing resources
- organisations should work together more effectively.

Comment and recommendations

Which aspects of a community make it a good place for people to live?

The physical environment

Our ability to maintain links to our community is closely linked to our ability to get around. Mobility and orientation for people with dementia can be severely hampered by the physical environment.

Good design and attention to orientation can make a significant difference to a person with dementia's ability to navigate their surroundings.

Guidance is available on environmental design, and there is potential for people with dementia to develop a role in advising and assessing access issues at a local level.

Recommendation: we build on the potential for people with dementia in advising on access issues.

Service providers have obligations to consider the needs of disabled people in the way in which they provide services. Similarly, building regulation also requires the needs of disabled people to be considered in matters of building and design.

Recommendation: service providers should be made aware that many people with dementia are considered disabled under the Equality Act 2010.

Recommendation: people with dementia and their supporters should be made aware of their potential rights under the Equality Act 2010, and supported to press for their rights if necessary.

Local facilities – especially shops and public transport

Most people with dementia said that it was the attitude of staff that made the biggest difference.

Many concerns were expressed about a lack of understanding of dementia, and many people said that this was stopping them from using local facilities.

Others reported very positive experiences of using local facilities, again usually linked to the attitude of staff.

People with dementia had three recommendations:

- staff should be made more aware of the needs of people with dementia – education, education, education!
- services and facilities could have someone responsible for making sure that everyone is included and able to participate
- a village champion for dementia.

Recommendation: we support and encourage the development of a role for people with dementia in raising awareness and training of staff.

Support services

Some had struggled to access or obtain support services.

For others it was the lack of more informal one-to-one support that was lacking, perhaps from a volunteer, buddy or befriending scheme. Most said that this kind of support would enable them to continue to maintain their links and be active and visible within their communities.

Recommendation: we consider the potential for further development of buddy schemes to support people with dementia in the community.

Social networks

Many people with dementia and carers report that family and friends drift away.

Long-established social networks can break down quickly and people with dementia and carers can find themselves having to negotiate a new set of relationships.

Some supporters expressed concern that people might be wary of help because they fear that things will escalate, and they will get 'roped in'.

A fear of escalation is one of the rationales for circles of support currently operating for people with other disabilities. The circle might include neighbours, friends, milkman, shopkeepers who volunteer to support the person but in a specific and limited way.

Recommendation: consideration is given to the applicability of circles of support to people with dementia.

Local groups

Many of the people with dementia who gave us their views are members of EDUCATE, or of a local group, like Singing for the Brain or a memory café.

So while it is not surprising that there is a lot of support and praise for local groups, there is no denying the impact that they have had on the people with dementia who gave us their views.

The phrases 'safe haven' and 'place of safety' were used frequently by both people with dementia and their supporters.

Others described the groups as a focus around which they could venture further into the community around them.

Others mentioned the feeling of mutual support and empowerment, as well as the ability to educate others about dementia.

It is clear that for many people with dementia and their supporters, local groups provide a very important anchor to their communities. However, while support groups for carers are common, groups for people with dementia are still the exception rather than the rule.

Recommendation: continued support and development of local support groups for both people with dementia and carers must be prioritised.

Barriers

With very few exceptions people with dementia said that they had stopped doing things in their community because of their dementia, and because they were very wary of the attitude and reaction of others.

The responses would suggest that thinking around a social model of dementia has had little impact on those who responded (a social model of dementia being one in which consideration is given to the effects of the physical and psycho-social environment as well as any individual impairment).

A social model of dementia has much to offer both in terms of campaigns to reduce stigma and raise awareness, and much needs to be done to enable people with dementia and their supporters to access the alternative perspective they provide.

Recommendation: organisations responsible for providing support and information to people with dementia and their supporters should ensure that the information they provide is informed by a social as well as a medical model of dementia.

Recommendation: public awareness campaigns should reflect a rights-based approach to dementia.

The most common response to the question 'what can a community do to make itself more accessible?' was to increase and improve awareness of dementia.

Recommendation: that we maintain and support awareness campaigns nationally and locally.

Recommendation: That we consider how we can support and encourage the development of a role for people with dementia in raising awareness of dementia.

Information

Many people with dementia said they found it hard to understand information produced for the general public, and that this presented a barrier to engagement with their communities.

Recommendation: that guidance is produced to enable service providers to produce information that is accessible to people with dementia.

Recommendation: the applicability of the Equality Act to people with dementia be investigated.

About the people with dementia who responded

This is not a representative sample.

People with more advanced dementia are unlikely to have been heavily represented, if at all, in the responses we received.

It is likely that most of the people with dementia that responded were in the earlier stages of dementia, and their comments must be understood in that light.

People with more advanced dementia are often excluded from consultations and research. However, with the right support and encouragement, people with more advanced dementia are able to have a say in the decisions which affect their lives.

Recommendation: That future consultations consider the need to allow the voice of a wider range of people with dementia, including those with more advanced dementia.

Innovations in Dementia

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