

# Dementia friendly communities

Guidance for councils



# Foreword

Dementia is a condition that is increasingly common; it can have a profound impact on an individual and their family and friends. Traditionally, the focus for dementia care has been NHS treatments and care services delivered by local councils. Recently there has been a shift to a focus on how we can enable people who have been diagnosed with dementia to live as full a life as possible and encourage communities to work together to help people to stay healthier for longer. Councils have a key role in developing inclusive dementia friendly communities.

Many councils are already working in partnership with their local communities to develop innovative ways to enable people with dementia to take part in everyday activities and retain their independence for as long as they are able. Examples include developing dementia friendly streets, where as a result of simple adaptations and awareness raising among staff working in shops, shopping becomes easier for people with dementia

Simple changes to existing services, and awareness raising for those who come into day-to-day contact with people with dementia such as staff working in libraries or in leisure centres, also help people with dementia feel more confident and welcome in using council services.

This guidance outlines the important role of councils in supporting people with dementia by creating local dementia friendly communities and demonstrates how councils are making this happen through case study examples.

**Councillor Izzi Seccombe**  
**Chair LGA Community Wellbeing Board**

# 1. Introduction

A lot has changed since guidance on dementia friendly communities was first published by the Local Government Association (LGA) and Innovations in Dementia in May 2012.

Shortly before publication, the concept of dementia friendly communities was given a huge boost by the launch of the Prime Ministers Challenge on Dementia. Since the launch of the Challenge:

- more than 70 communities have committed to become dementia friendly
- leading businesses across retail, finance, leisure and transport sectors are developing ways to respond to the needs of people with dementia
- More than a million people have signed up to become Dementia Friends – and committed to take action to make their communities a better place for people with dementia.

At the same time there has been a rise of 17 per cent in diagnosis rates, against the backdrop of significant financial pressures on public services, including those for people with dementia.

There has also been a significant increase in the visibility of dementia in the public arena, both in terms of high-profile events such as the G8 Summit on Dementia, but also in the media and through sustained public awareness campaigning at national and local level.

The original guidance, and the tools it contained, have been widely used and adapted both in the UK and overseas, making a significant contribution to the creation of dementia friendly communities. However, a lot has been learned since its publication, and a refresh of the guidelines is now timely. With the introduction of health and wellbeing boards, the return of public health duties and powers, and an increased focus on prevention and information and advice in the Care Act, councils have an even stronger role to play in the creation of communities in which it is truly possible to live well with dementia.

This guidance looks at current best practice and learning in the creation of dementia friendly communities, how it fits within the broader policy landscape, and what actions councils can take, and are already taking.

# 2. About this guide

The purpose of this guide is to help councils play their part in developing communities where people can live well with dementia. It is about enabling people with dementia, their families, friends and carers to feel at home, supported, understood and that they matter.

It is about what local government can do to help make this a reality.

It builds on earlier guidelines produced by the LGA in 2012<sup>1</sup>, and is informed by good practice over the last three years and emerging evidence about what works well in supporting people with dementia and those that support them.

## Who is it for?

This guidance is for all those in local government who have a role in making our communities easier places in which to live well with dementia. It is aimed those who have a role in leading, planning, commissioning and delivering services – from housing, transport, advice and guidance, through to leisure services, cultural activities and supporting community development. It is aimed at leaders and members of health and wellbeing boards (HWB). It is aimed at those working with the newly refreshed public health duties, and those members and officers responsible for health and social care.

It is not intended to be prescriptive, rather, it hopes to inspire and inform those in local government to make a real difference in the lives of their constituents and local citizens, and to help create communities in which it is truly possible to live well with dementia.

## What is dementia?

The word 'dementia' does not describe a medical condition. It refers to a set of symptoms that occur when the brain is damaged by a disease like Alzheimer's, or by small strokes or conditions like Lewy-Body Dementia.

These symptoms may include:

- difficulties with memory
- difficulties with completing or initiating everyday tasks
- problems with communication
- difficulties with perception.

<sup>1</sup> Developing Dementia Friendly Communities – LGA and Innovations in Dementia May 2012.  
[www.local.gov.uk/c/document\\_library/get\\_file?uuid=b6401bb0-31a8-4d57-823b-1fde6a09290e&groupId=10180](http://www.local.gov.uk/c/document_library/get_file?uuid=b6401bb0-31a8-4d57-823b-1fde6a09290e&groupId=10180)

The conditions which cause dementia are usually progressive, with symptoms worsening over time. However it is important to note that:

- every experience of dementia is different – both in the presentation of symptoms, and the rate of progression
- while there is currently no cure for dementia, there is much that can be done to support people with dementia to live well.

# 3 What is a ‘dementia friendly community’?

The Alzheimer’s Society defines a dementia friendly community as:

“A city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia friendly community people will be aware of and understand dementia, and people with dementia will feel included and involved, and have choice and control over their day-to-day lives”<sup>2</sup>

People with dementia have described 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.

Dementia friendly communities are those in which people with dementia have the best possible opportunities to live well.

The idea that it is possible to ‘live well’ with dementia is one that presents a challenge to the orthodox view of dementia. The idea that a diagnosis of dementia is life-ending is deeply ingrained, but is increasingly being challenged as new visions for living well with dementia emerge.

The notion of ‘living well’ is difficult to pin down, and highly individual. However, research suggests that there are some common themes for people with dementia and common outcomes that we might expect to see from people living well with dementia.

In 2010 the National Dementia Declaration for England (Dementia Action Alliance, 2010)<sup>3</sup> laid out seven quality outcomes, as described by people with dementia and their carers that would indicate they were living well with dementia. These are:

- I have personal choice and control or influence over decisions about me
- I know that services are designed around me and my needs
- I have support that helps me live my life

<sup>2</sup> Building Dementia Friendly Communities – a Priority for Everyone – Alzheimer’s Society 2013  
[www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2283](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2283)

<sup>3</sup> [www.dementiaaction.org.uk/nationaldementiadeclaration](http://www.dementiaaction.org.uk/nationaldementiadeclaration)

- I have the knowledge and know-how to get what I need
- I live in an enabling and supportive environment where I feel valued and understood
- I have a sense of belonging and of being a valued part of family, community and civic life
- I know there is research going on which delivers a better life for me now and hope for the future.

These quality outcomes are important, not least because:

- the concept of dementia friendly communities represents, in part, a recognition that in order to make these aspirations a reality a community-wide response is required.
- arising as they are from the aspirations of people with dementia and their carers, they are amongst the most significant outcomes by which the success of dementia policy can be measured.

### **The Alzheimer's Society recognition process for dementia friendly communities**

In 2013 the Alzheimer's Society and Dementia Action Alliance (DAA) launched its recognition process for dementia friendly communities<sup>4</sup>, which outlined 10 characteristics of a dementia friendly community.

It suggests that becoming dementia friendly means:

- Shaping communities around the views of people with dementia and their carers
- Challenging stigma and building awareness
- Ensuring that activities include people with dementia
- Empowering people with dementia and recognising their contribution
- Ensuring early diagnosis, personalised and integrated care is the norm
- Befrienders helping people with dementia engage in community life
- Maintaining independence by delivering community- based solutions
- Appropriate transport
- Easy to navigate physical environments
- Businesses and services that respond to customers with dementia

It is clear that supporting the development of communities that model these key characteristics, which take action across these key 'areas of interest', will give people with dementia a better chance of 'living well' within the framework of the quality outcomes listed above.

<sup>4</sup> [www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2136](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2136)

The purpose of the recognition process is to show that the community in question has committed to becoming dementia friendly. Once a community has registered with the process, they may demonstrate how they meet the foundation criteria for ‘working to become dementia friendly’ by:

- ensuring the right local structure is in place to maintain a sustainable dementia friendly community
- identifying a person to take responsibility for driving forward the work to support a community to become dementia friendly
- having a plan in place to raise awareness about dementia in key organisations and businesses within the community that support people with dementia
- developing a strong voice for people with dementia living in communities
- raising the profile of the work to increase reach and awareness to different groups in the community
- focusing plans on a number of key areas that have been identified locally
- having in place a plan or system to update the progress of your community.

Once a community has demonstrated how they meet the criteria, they are issued with a symbol that they can give to organisations and businesses in their community that wish to be part of the dementia friendly communities’ initiative and have stated what their actions are towards becoming dementia friendly.

The British Standards Institution recently published it’s Publicly Available Specification (PAS) ‘Code of Practice for the recognition of dementia friendly communities in England” (2015).<sup>5</sup> This document, funded by the Department for Health provides additional guidance and recommendations to support communities taking part in the Alzheimer’s Society recognition process.

It also provides guidance and recommendation across specific ‘areas of action’ to focus on as dementia friendly communities develop, namely:

- arts, culture, leisure and recreation
- businesses and shops
- children, young people and students
- community, voluntary, faith groups and organisations
- emergency Services
- health and social care
- housing
- transport.

These will be of particular interest to officers and lead members with specific interests or duties in these areas.

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<sup>5</sup> <http://shop.bsigroup.com/ProductDetail/?pid=000000000030300514>

# 4. Why is dementia a key issue for councils?

There are currently estimated to be 850,000 people living with dementia in the UK. With projected numbers of people with dementia set to increase to 1 million by 2021 and 2 million by 2051, it is clear that a sustainable response to meeting the needs of people living with dementia is required.<sup>6</sup>

You can find details of the numbers of people with dementia in local authority areas, broken down by age and gender as well as projected figures to 2021 at the Alzheimer's Society website [www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=4](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=4)

## Dementia has a massive impact

Dementia has a huge impact on those with a diagnosis, those close to them, and society more generally:

- The Alzheimer's Society estimates that the cost of dementia to the UK economy is £26 Billion a year <sup>7</sup>, more than the cost of heart disease, stroke, or cancer.
- The Alzheimer's Society estimate that 25 percent of hospital beds at any given time are occupied by people with dementia<sup>8</sup> People with dementia also stay in hospital for longer and are more likely to be re-admitted than people with other conditions.
- People fear dementia more than any other disease. 39 percent of over 55s fear getting Alzheimer's the most, compared to 25 percent who worry most about cancer.<sup>9</sup>

## People with dementia want to live everyday lives.

Work with people with dementia reveals a strong desire to live well, to continue with 'the stuff of life' and stay connected to their interests, social networks and communities.

However, research by Innovations in Dementia<sup>10</sup> and Alzheimer's Society<sup>11</sup> suggests that people with dementia increasingly withdraw from everyday life.

6 Dementia UK: Update Second edition 2014 Alzheimers Society

7 Dementia 2014: Opportunity for Change - Alzheimer's Society 2014  
[www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=2317](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2317)

8 Counting the cost – Alzheimer's Society 2009  
[www.alzheimers.org.uk/site/scripts/download\\_info.php?downloadID=356](http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=356)

9 3. Prime Minister's Dementia Challenge – Department of Health 2012  
[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/215101/dh\\_133176.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215101/dh_133176.pdf)

10 Dementia Capable Communities – The views of people with dementia – Innovations in Dementia CIC 2011  
[www.innovationsindementia.org.uk/DementiaCapableCommunities\\_fullreportFeb2011.pdf](http://www.innovationsindementia.org.uk/DementiaCapableCommunities_fullreportFeb2011.pdf)

11 Building Dementia Friendly Communities – a Priority for Everyone – Alzheimer's Society 2013  
[www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2283](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2283)

“Many people with dementia are not able to take part in activities that they enjoyed before they developed the condition. Many feel constrained by the condition and are not confident to get out and engage in their area. There is more that the person with dementia would like to do but they need support to do so.”

### **Building Dementia Friendly Communities – a Priority for Everyone – Alzheimer’s Society 2013**

- Thirty-five per cent of people with dementia said that they only go out once a week or less and 10 per cent said once a month or less.
- Nine per cent of people with dementia said they had had to stop doing all of the things they used to do.
- People said that they had to give up activities such as getting out of the house (28 per cent), shopping (23 per cent), exercise (22 per cent) and using transport (16 per cent).
- Sixty-three per cent of people with dementia did not want to try new things and the underlying issues of confidence, worry and fear must be overcome in a dementia friendly community.<sup>12</sup>

(Building Dementia Friendly Communities – a priority for everyone – Alzheimer’s Society 2013).

Yet – enabling people with dementia to take part in ‘everyday activities’ – to meet up with friends, take part in sporting activities, enjoy green space, go shopping – is key not only to enabling them to live healthier and more fulfilling lives, but to reducing and delaying their dependence on expensive health and social care services.

## **So, what is the role of local councils?**

Local councils; as leaders, commissioners, planners, regulators and service providers have a key role in supporting, facilitating and leading the development of sustainable, responsive and community led approaches that enable people living with dementia to overcome these barriers and to live well in their communities for as long as possible.

Councils that look at dementia strategically and positively, working with key partners and communities locally, will help mitigate the pressures on their services, particularly health and social care, from growing demand, while also unlocking enormous potential from people living with dementia, their carers and the wider community.

Health and social care services alone cannot meet the challenge of dementia, nor do people with dementia aspire to spend their lives within it. Dementia requires a community response, and yet it is clear that communities are still not, by and large, set up as well as they could be to support people with dementia to live well.

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<sup>12</sup> Building Dementia Friendly Communities – a priority for everyone Alzheimer’s Society 2013

Many people with dementia feel that the support they need to participate in their community and to do the everyday things they want to do, for example, shopping, socialising or using public transport, is not available. Many do not feel that they are a part of their local communities. The creation of dementia friendly communities is an attempt to meet this need.

As the State of the Nation report on Dementia set out in 2013:

“Establishing dementia friendly communities has the potential to transform the lives of people with dementia in England. Two thirds of people with the condition live in the community, close to a third of whom live on their own. Health and care services, while fundamental, cannot alone ensure people with dementia live good quality lives. Support from wider communities, services and organisations is needed, utilising the untapped potential of communities to help people with dementia and their carers.”<sup>13</sup>

Enabling and supporting the development of dementia friendly communities provides councils and their partners with a vehicle to work in new ways with local communities and to support the development of more responsive services that enable people living with dementia to live well within their local communities for as long as they are able.

The central role of dementia friendly communities in enabling people with dementia to live better lives within their communities has been well documented and established. This has been most recently set out in the Prime Minister’s Challenge on Dementia 2020, in which dementia friendly communities sit at the heart of the vision for the challenge. For example, it sets out an ambition that by 2020:

- half of the population will live in areas recognised as dementia friendly
- all businesses will be encouraged to become dementia friendly
- national and local government will take a leadership role with all government departments and public sector organisations becoming dementia friendly and all tiers of local government becoming part of a dementia friendly alliance.

Councils, working in partnership with others, are well placed to deliver on this ambition. Through their public health responsibilities and their key role within health and wellbeing boards, lead members and officers can engage in and support the development of dementia friendly communities within their areas.

### **Health and wellbeing boards**

The 2012 Health and Social Care Act set out key health duties and responsibilities for councils. This recognises local government’s unique ability to:

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<sup>13</sup> [www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/262139/Dementia.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf)

- Shape ‘place’ around the needs of people, including those with dementia. The links between wellbeing and the environment in which people live, work, and play are well understood by councils, who wield considerable power in shaping ‘place’.
- Maximise preventative measures by influencing those factors that contribute to shaping people’s health and tackle health inequalities. The links between the conditions in which people are born, grow up, work and raise their families and health are well-documented. Many of these factors fall within the remit of councils and there is increasing evidence about links between health inequalities, lifestyle and dementia.

Health and wellbeing boards have a statutory responsibility to:

- produce a Joint Strategic Needs Assessment (JSNA) that gives a comprehensive analysis of the health and wellbeing needs and assets of the community
- produce a joint health and wellbeing strategy that identifies key priorities in respect of commissioning plans on health and wellbeing
- promote integration – health and wellbeing boards bring together the clinical, commissioning, professional, political and community leadership of an area to drive health improvement and promote better health outcomes.

A number of boards are actively prioritising dementia and dementia friendly communities. In a number of areas, the development of joint health and wellbeing strategies are also following a ‘person-centered’ or ‘life-centered’ approach. This would, for example, include dementia as part of a focus on the ‘later life agenda’.

## **Public health**

The transfer of public health from the NHS to local government in April 2013, was one of the most significant extensions of local government powers and duties in a generation, and offers a unique opportunity to promote the health and wellbeing of communities.

Dementia is a national public health priority, and as such, further serves to highlight the key role for councils in taking forward public health responses on dementia.

This includes promoting a healthy lifestyle to help potentially reduce the risk of developing dementia and work to actively promote access to sport, leisure activities and wider community facilities for those who have been diagnosed with dementia. Public health could incorporate dementia risk reduction work as a key outcome of core health improvement programmes for the whole population, such as work to reduce smoking and harmful drinking and to promote physical activity and programmes.

There is also a clear role for public health in the promotion of positive messages about living well with dementia as well as more general messages about prevention and brain health. This is supported by recent findings outlined in the Blackfriars Consensus on Promoting Brain Health<sup>14</sup>, which states that the evidence on dementia risk reduction is now sufficient to justify action to incorporate it into health policies and to broaden awareness about factors which can reduce the risk of developing dementia.

<sup>14</sup> Blackfriars Consensus on promoting brain health: Reducing risks for dementia in the population; PHE 2014

“It strengthens the case for action to create the physical and economic environments which will support people to lead healthier lives; for example, transport plans and investment that promote more walking and cycling as part of everyday life”  
(Paul Lincoln UK Health Forum CEO quoted in Public Health England press release 20 May 2014).

### **Social care**

The Care Act introduces a raft of new responsibilities for councils, many of which can be clearly linked to and supported by engagement in the creation of dementia friendly communities. One example of this would be the duty to promote people’s wellbeing and to prevent needs for care and support. Another example would be the duty to provide an information and advice service about care and support.

There is the opportunity for councils to extend the information provision and involve community groups to help support people with dementia. For example, in order to live well with dementia people will need information about health and social care, but will also need and benefit hugely from information about support in other areas of their lives as well, from benefits to leisure, transport, housing, employment issues and volunteering opportunities.

New duties around personalisation also provide opportunities to commission support services that allow people to engage the kind of support that suits them.

### **The Equality Act 2010**

The Equality Act 2010 defines disability as a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on a person’s ability to do normal daily activities. Under this definition many people with dementia fall within its scope and are protected under the Act against all forms of in both employment and the provision of goods and services.

### **A strategic approach to the development of dementia friendly communities**

The development of effective community-based responses to enable people living with dementia to live well within their communities is a cross-cutting issue for councils at ward level, district level, unitary level and county level. Councils can embrace and help deliver dementia friendly communities by working differently and in partnership with community organisations, across the whole of their areas of responsibility. For example:

- Planning officers can involve people with dementia in advising on new developments and make others aware of the issues that people with dementia face in accessing the built environment.
- Housing departments can make sure that housing staff understand how adaptations can enable people with dementia to stay independent in their own homes for longer.
- Transport providers can consider the needs of people living with dementia in the development of their services, so that they have the confidence to travel and can ask for help when required.

Local government has the power to shape these services:

- as leaders and influencers
- as commissioners
- as planners and regulators
- as service providers and employers.

# 5. A dementia friendly community framework.

In the first edition of these guidelines we outlined a model that synthesised the issues arising from our work across the two project sites.

The model was based on five domains, each of which needs to be considered when planning, developing, or assessing the dementia friendliness of any given community, organisation or process.

This model has since been successfully used in assessing more than 60 organisations and services at both national and local level since 2012.

It is easy to understand, and flexible enough to be used in a variety of settings.

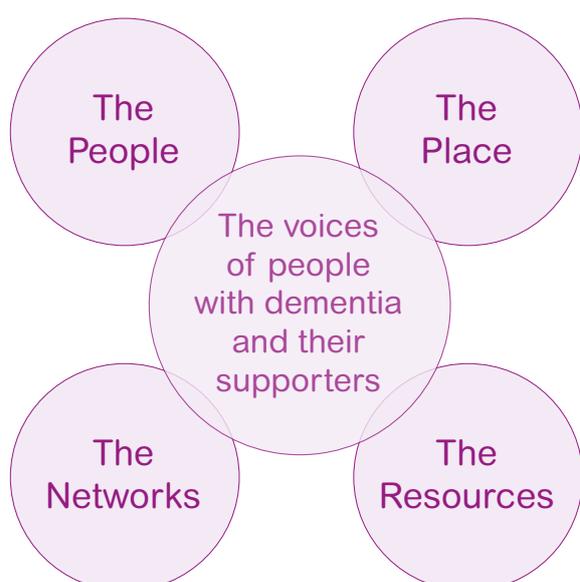
It is not intended to be prescriptive, but is offered as a starting point for others to take up and develop.

## Structure of the Framework Sections

Each of the following sections contains:

- the background to the issue
- key actions that councils can take to make this happen
- examples or case studies of existing practice

## The five domains



# A: The voices of people with dementia and their carers

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

Most people expect the right to have a say in the services they use and the kind of society in which they wish to live. In health and social care settings people with learning disabilities and people with mental health problems, for example, are routinely involved in shaping services and the development of strategies.

For people with dementia, however, this expectation is not yet the norm. For many years, carers were the proxy voice for people with dementia speaking on their behalf. People with dementia tended to be diagnosed at a late stage of their illness, with delivery of care being more of a priority than involvement. However, this is changing and people with dementia are increasingly demanding a say in the decisions that affect their lives.

## Consultation

User consultation should already be embedded in the processes of designing, improving or commissioning services.

### **What can councils do?**

- Take a look at the accessibility of the mainstream consultation and engagement processes you use. DEEP (Dementia Engagement and Empowerment Project) has produced a series of guides that will be of use here (see section on resources below).
- Ask whether there are ways people with dementia can be supported in mainstream engagement processes, for example through the provision of one to one support.
- Ask whether there is a need to set up a separate engagement process for people with dementia.
- When commissioning or licensing services – how do these services go about hearing what its users or customers want or think? User consultation will have a stronger role to play in some services than others, but there will be situations where councils feel justified in making it a determining factor in its decisions.

- Specifications for services for older people or people with dementia should include the need to involve people with dementia and their carers, both in the planning and the delivery of services.
- Make sure that you find out what other strategic partners know about local needs and issues, in particular those who work directly with people with dementia and their carers
- Consider joining forces to consult and engage on issues of common interest.
- Feeding back to people is crucial as it engenders a sense that people have been listened to, even if what they say cannot be acted upon.' Here's what you told us and here's what we did as a result' sends out a very powerful message not just about the validity of the engagement process, but about the values of the organisation and what it thinks of the value of what people say and who says it.

## Beyond consultation

Hearing the voice of people living with dementia is not just about consultation, which is often one-off and as such limits the ways in which people are involved in decisions, planning, and shaping the future.

### **What can councils do?**

- involving people is an ongoing process where people are supported to engage, connect, participate and influence at many points and in many ways
- involving people with dementia can feel hard to implement, especially when resources and time are in short supply. Often, individual staff members feel inspired to support involvement, but feel unconfident or unsupported to take initiatives forward without buy-in and support from above.

## Case study – Gateshead Dementia Action Alliance

A Dementia Friendly Communities Consultation is underway. A questionnaire has been designed and circulated throughout Gateshead's Dementia Action Alliance and sent out to Gateshead residents in receipt of services. It is also available on the council consultation portal. A number of consultation events have been set up and actors from Equal Arts will be delivering these sessions to assist in communicating with people with dementia, in order to get the best out of the sessions. The results of the consultation will be used to ensure that each dementia friendly community that is developed, as part of the Alzheimer's Society accreditation programme, is tailored to the needs of people with dementia in that area.

### Source – Dementia Action Alliance

- Statutory services across the board can be developed and delivered in ways which empower people to retain a sense of independence and self-determination and build resilience – 'doing with' as opposed to 'doing for'. The 'resources' section explores this area in more detail.

## Case study – AGE UK Coventry and Coventry City Council

Coventry City Council commissioned AGE UK Coventry to work with people with dementia on environmental audits of five day centres and residential care settings across the city. A small team of staff and volunteers visited each of the venues to engage with people with dementia using or living in these settings, to gather their views and ideas about their environment.

"For the people with dementia involved, there was a real sense that they saw the process as important and valuable and with each person it was clear that their contributions were considered. In one case, a day centre member telephoned the worker from Age UK Coventry on the day following their visit as he had thought of something else he wished to raise and didn't want it to be missed, a clear indication of the significance of the process for the individuals involved"

### Nichola Lavin – Age UK Coventry

### Age UK Living Life with Dementia 2014<sup>15</sup>

<sup>15</sup> Living Life With Dementia - AGE UK 2014 [www.ageuk.org.uk/Documents/EN-GB/For-professionals/Health-and-wellbeing/Living\\_life\\_with\\_dementia.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Health-and-wellbeing/Living_life_with_dementia.pdf?dtrk=true)

### Case study – Swindon Forget me Not Group (Avon and Wilshire MHP)

Members of the group were fully involved in the recruitment of a new member of staff. They were supported to draw up the person specification, elected interviewees from a shortlist prepared by the facilitator, and sat on the interview panel. Members who did not want to sit in on the interviews took part in activities with candidates, and then fed back their feelings to the interview panel. Crucially, they also made the final decision about which person got the job.

**Source DEEP Project Dementia Voices Website<sup>15</sup>**

- 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 it also provides significant opportunities for engagement in the broader community. See the ‘resources’ section for more.

### Case study - The Dementia Engagement & Empowerment Project (DEEP)

DEEP brings together groups of people with dementia from across the UK and supports them to try to change services and policies that affect the lives of people with dementia.

‘I often say I spend a third of my time on dementia activities, a third of my time doing ‘fun things’, and a third of my time recovering from the other two!

Towards the latter days of my career, occasionally I would consider the question, ‘What will I do when I retire?’ Never for one moment could I have anticipated how the last three years have unfurled. Looking back over this time, the biggest rewards have been to see a growing awareness within all sectors of dementia care that the person with a diagnosis can play a significant part in the services which we are to receive. It has been great to see a number of people who previously felt that there was no contribution they could make and nothing they could do to help themselves or others, grow to speaking in front of large and small audiences with passion and conviction, and a real desire to help to make things better for all. Some might say, “Once a teacher, always a teacher.”

**Keith Oliver reflects on his engagement with the DEEP network<sup>16</sup>**

- 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 may want to go. Seeing this world through the eyes of someone experiencing some level of cognitive impairment can be a revelatory experience.

<sup>16</sup> DEEP Webpage <http://dementivoices.org.uk>

<sup>17</sup> <http://dementivoices.org.uk/>

## More reading and resources

For more information about **DEEP** - the Dementia Engagement and Empowerment Project. Various guides to engaging with people with dementia can be found here.

<http://dementivoices.org.uk>

Exploring ways for Staff to Consult People with Dementia about Services – Kate Allen JRF 2003 – [www.jrf.org.uk/publications/exploring-ways-staff-consult-people-with-dementia-about-services](http://www.jrf.org.uk/publications/exploring-ways-staff-consult-people-with-dementia-about-services)

RIPFA – Practice Tool – Involving and Engaging People with Dementia

[www.ripfa.org.uk/publications-resources/professional-development/157-practice-tool-involving-and-engaging-people-with-dementia](http://www.ripfa.org.uk/publications-resources/professional-development/157-practice-tool-involving-and-engaging-people-with-dementia)

A guide to community-centred approaches for health and wellbeing – NHS England – Public Health England 2015

<https://www.gov.uk/government/publications/health-and-wellbeing-a-guide-to-community-centred-approaches>

# B: The place

The physical environment, from streetscape down to individual shops and facilities within it, as well as people's own homes, plays a key role in determining the extent to which people with dementia will find their communities dementia friendly.

In the work that informed the original version of these guidelines, people stated that a physical environment in 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.

## The Built Environment

Neighbourhoods that are designed to make it easy and enjoyable to go outdoors are a significant factor in determining whether people attain recommended levels of physical activity through walking (regardless of sensory or mobility impairment) and is, more generally, a significant predictor of health and life satisfaction.

People who live within a 10 minutes' walk of a local open space are twice as likely to achieve the recommended levels of healthy walking compared with those whose local open space is further away. Access to green space and to nature has been shown to have particular benefits for people with dementia, including better mood, memory and communication and improved concentration. (Greening Dementia - Dementia Adventure<sup>18</sup>)

Orientation, wayfinding, and familiarity all contribute to an accessible environment for people with dementia, as does a reduction in unnecessary clutter and potentially disorienting visual and auditory stimuli.

Unsurprisingly, environments that are viewed by people with dementia as accessible also tend to be easier and more pleasant for everyone else as well. Relatively small changes can make a significant difference to people with dementia, often at no or very little cost.

Many people living with dementia however find it difficult to negotiate public spaces and environments, making it more difficult for them to access social groups or cultural activities, keep fit or visit their local shops.

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<sup>18</sup> Greening Dementia – a literature review of the benefits and barriers facing individuals living with dementia in accessing the natural environment and local greenspace – Natural England 2013 <http://publications.naturalengland.org.uk/publication/6578292471627776>

A number of councils are addressing the issue of place 'head on' – reviewing issues as the height of kerbs, the availability of seating and toilets and the availability and accessibility of green spaces. This has benefits, not only for older people and people living with dementia, but for the wider community.

Many councils are also working in partnership with local businesses, to enable people living with dementia to be able to access local high streets and community amenities without fear of stigma or their needs not being understood. Such work includes the development of 'dementia friendly high streets', shopping areas where local shops and staff working in them are aware of the needs of people living with dementia and extra support that they may need to access their facilities and services.

### **What can councils do?**

Councils can have a significant impact on the accessibility of the built environment to people with dementia through their role in the design and maintenance of local place.

- Councils could conduct an audit of their customer-facing premises to ensure that they are as accessible as possible to people with dementia. A link to a basic audit tool from Innovations in Dementia and other more detailed resources are given below.
- Councils can encourage developers to consider how design can support dementia friendly communities in, for example:
  - the layout of roads and streetscape
  - the design of adequate and legible signage
  - the design of wider and pedestrian-only pavements with clearly-defined edges
  - the provision of more drop-off and pick-up points outside of public venues
  - the impact of good lighting
  - acoustics
  - the design and placement of seating
  - the design and provision of adequate toilets, including those with enough room for people who need support
  - the provision of more handrails at road crossings.
- Engage people with dementia in planning and reviewing the physical environment. New and existing development and planning projects could be considered through the lens of people with dementia to ensure spaces are accessible and inclusive.
- 'Walking the patch' with people with dementia can provide valuable insight for those with responsibility not just for planning but for services across the board. Ask people to explain how they make decisions about where to go and how clearly they understand the environment as you go.
- The design of green and natural spaces could also be considered – having pleasant safe and easily navigable outdoor spaces encourages people with dementia to get out and about and can have a significant impact on health and wellbeing.

- By taking a leading or supportive role in the local Dementia Action Alliance – councils have a great opportunity to share good practice with those partners who can make a real difference to the day to day experience of people with dementia. This includes businesses and organisations who form the ‘high street’. There is much that can be done to improve the physical environment of, for example shops – and of course these are the places where people with dementia are likely to be spending most of their time when they are out, rather than in health and care settings.

### Case study – Hampshire Dementia Friendly High Street

Dementia Friendly High Streets - we are working with local, regional and national shops, organisations and businesses to establish High Streets in which people with dementia will feel understood and accepted. Businesses participating in a Dementia Friendly High Street are entitled to display our Dementia Friendly Hampshire window sticker, which shows people with dementia and their carers that the business is working towards being dementia friendly.

Our first Dementia Friendly High Street was launched in Fareham on 27 November 2013. Since then we have launched 5 more Dementia Friendly High Streets - Lyndhurst; Fleet; Romsey; Alton; Winchester - and have supported local Dementia Action Groups to launch a further 2 - Lymington and Eastleigh. Planned launches for 2015 include Milford-on-Sea, Basingstoke and Andover.

#### **Source – Dementia Action Alliance**

- Councils could also consider the significant role that feeling safe plays in the perception of a dementia friendly community. The creation of safe neighbourhoods needs joint working across council departments, including housing, transportation, and planning, as well as with broader strategic partners.

## Case study – Protection from Doorstep Crime – North Yorkshire County Council Trading Standards

“Doorstep crime gangs increasingly target people with dementia,” warns Ruth Andrews. “It’s big business and well organised.”

Gangs specialise in, say, roofing or gardening but share information, grooming victims carefully. The stakes are high; offenders can take tens, even hundreds, of thousands of pounds from victims.

“Trading Standards wants to help people stay in their own home safely and confidently. That’s not just about the crime, it’s about seeing the whole person,” explains Ruth.

That’s why her 13-strong team has changed their emphasis from prosecution to safeguarding and protection. They’ve put victims in touch with befriending services, arranged family reconciliations, helped get locks changed and had surveyors safety-check homes.

“It’s very labour intensive. But it’s hugely rewarding,” says Ruth.

One challenge has been gathering evidence differently. Ruth’s team thinks constantly about imaginative ways to build a picture. People with dementia can’t always give written statements so the team captures what they can tell the court on video. This also helps the judge and jury understand the personal impact.

**Source – Dementia Friendly Yorkshire JFR 2014<sup>18</sup>**

## Transport

The Equalities Act places a legal duty upon transport providers to make ‘reasonable adjustments’<sup>19</sup> to enable people with disabilities use services, and while the provision of ramps and assistance for people with mobility and sensory problems is widely available, the needs of people with dementia is not often considered. Few service providers take cognitive impairment due to dementia into account when considering their duties under the act.

Many people with dementia are able to drive for some time after their diagnosis, but as dementia progresses many make the decision to stop driving. The loss of a driving licence is a significant blow for many people, not just in terms of convenience, but also in terms of the psychological impact. Passing a driving test for many is a rite of passage and marks transition into adulthood and independence. To lose it may feel like a reverse process, suggesting dependence upon others, loss of status and an activity that many will have found enjoyable and intricately tied up with their own identity. This is particularly hard on people in rural areas who might have very limited access to public transport.

<sup>19</sup> Dementia Friendly Yorkshire - first steps on the journey - JRF 2014 [www.jrf.org.uk/publications/dementia-friendly-yorkshire](http://www.jrf.org.uk/publications/dementia-friendly-yorkshire)

<sup>20</sup> <http://www.equalityhumanrights.com/private-and-public-sector-guidance/organisations-and-businesses/businesses/creating-reasonable-adjustments-disabled-people>

Further guidance around transport is included in the BSI Code of Practice<sup>2021</sup>.

### **What can councils do?**

- Design transport hubs and stops that are accessible to people with dementia.
- Service specifications could require that consideration be given to accessibility for people with dementia, including:
  - training for customer-facing transport staff (including taxi drivers)
  - clear signage and written information about services.
- Other things that people with dementia say can improve their experience of using public transport include:
  - staff that can be seen at key points in transport hubs
  - clear explanations and support to understand changes and disruptions.

### **Case study - York Station – Yorkshire and Humber DAA**

York has become the first UK railway station to attempt to become dementia friendly. In addition to training for all British Transport Police office, train operating company staff and even the staff running the coffee shop concessions, they have introduced a 'safe haven' room for people needing a quiet space to collect their thoughts – or to enable carers or family members to be contacted. They have gone one step further, by organising day trips to reassure people with dementia and carers that they can continue to use the railways with the support of knowledgeable and sympathetic staff.

#### **Source Dementia Action Alliance**

- Councils can encourage the development of one to one support in the form of volunteer drivers or transport 'companions'. Many people with dementia may only need support to gain confidence on a particular route, which they then may be able to use independently.
- Councils could take a lead in coordinating provision of community transport services between themselves and local partner organisations.

### **Case study - Reading Dementia Action Alliance**

One of the most notable achievements of Reading DAA to date is the collaboration with Reading Buses, who have committed to providing all new employees with Dementia Friends training sessions, with the ultimate aim for all staff to have attended a session. Drivers have been observed as being more considerate to elderly passengers, ensuring they have embarked on the correct bus regardless of a dementia diagnosis.

#### **Source Dementia Action Alliance**

21 Code of Practice for the recognition of dementia friendly communities in England. British Standards Institution 2015 [www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=279](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=279)

## Housing

People with dementia and their carers live in a range of housing including privately owned or rented homes, social housing, as well as supported housing such as extra care housing and care homes. Councils and their partners can help to ensure that housing supports people with dementia to live as independently as possible and engage with their local community.

### Case study – Connect Housing Association

Involvement with the Dementia Action Alliance has enabled Connect Housing to develop an internal Dementia Strategy detailing how it will be supporting current and future generations of tenants with dementia to live independently and well as part of their communities. Connect is a charitable housing and support provider operating in Leeds, Kirklees and parts of Calderdale and Wakefield, providing quality housing to people in over 700 properties specifically for older people. The organisation is already investing in a wide range of physical improvements to property and has supported about 70 staff to undergo dementia awareness sessions and other training.

Further guidance around housing is included in the BSI Code of Practice<sup>21</sup>.

### What can councils do?

- Support staff who are involved in housing to access training that enables them to respond to the needs of people with dementia in the settings in which they work - ie the training needs of people working in community housing are different from those in extra-care. Staff should be able to identify changes that can be made in people's homes to make them easier to live in with dementia.

### Case study – AGE UK Social Care

AGE UK Social Care staff including people from handy person services attended a training course in which they explored ways of making clients' homes easier to live in with dementia. The course included the basic principles of environmental design and audit considerations and practical examples of simple changes, including, for example, see-through doors on kitchen cupboards, placing high contrast covers over light switches to aid visibility, and replacing white toilet seats with black, again, to aid visibility.

<sup>21</sup> [www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2790](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2790)

- Encourage housing providers, people living with dementia and their carers to consider assistive technology such as aids and adaptations, both low and hi-tech which can help them remain independent for longer. Examples include:
  - flood detectors in bathrooms and kitchens to protect from over-running sinks and baths
  - infra-red detectors to turn on lights if someone leaves their bed – this can help to prevent falls as well as aiding navigation and orientation
  - blackout blinds in the bedroom can aid sleep as well as reducing confusing shadows and light pooling which might lead to disorientation
  - the ASK Sara website run by the Disabled Living Foundation has a wealth of information in this area.
- Encourage housing staff to work with fire and rescue services so that they are aware of fire safety issues, so that where appropriate joint working can take place to address specific needs (see case study ‘protection from doorstep crime’ on page 21).
- When the transition from mainstream to specialist housing is needed, support people with dementia to keep their links to their community by working with housing providers, the family and the person themselves.

## The importance of written and published information

Councils produce a great deal of information both on paper and online and there is much that can be done to make sure it is accessible. The DEEP project has produced some guidelines on writing for people with dementia, referenced below.

The biggest contribution to accessibility comes from the use of plain English – and the Plain English Campaign have a wealth of free information available at their website – see below.

### What can councils do?

- Highlight the importance of the basic principles of plain English and good design for those writing or designing. Ensure that information is written with the end-user in mind. Many professionals write well for other professionals but this doesn’t always translate well into materials for people with dementia.
- Consult with people with dementia about the accessibility of published materials. The DEEP project has produced guidance to consulting with people with dementia, linked below.
- Avoid language that stigmatises people with dementia as a group – words like ‘sufferers’ and ‘victims’ are viewed as exceptionally unhelpful when applied collectively to people with dementia. A guide to language is referenced below.

## **More reading and resources**

**How to do an audit** - basic audit checklists and resources for dementia friendly environments (Innovations in Dementia 2015)

<http://www.innovationsindementia.org.uk/HowToDoAnAudit.pdf>

**Neighbourhoods for life** – designing dementia friendly outdoor environments. Oxford Institute for Sustainable Development

This is aimed primarily at planners, designers and developers 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.

[www.dementiaaction.org.uk/assets/0000/8252/NfL-FL.pdf](http://www.dementiaaction.org.uk/assets/0000/8252/NfL-FL.pdf)

**Stirling University Dementia Services Development Centre** is arguably the centre of excellence for issues around the design and dementia. It produces a wide range of publications in the theme of design for dementia and also provides training and auditing services:

<http://dementia.stir.ac.uk>

The Virtual Care Home is an online resource from Stirling DSDS that demonstrates key features of dementia friendly design in a care home setting.

<http://dementia.stir.ac.uk/design/virtual-environments/virtual-care-home>

## **Alzheimer's Australia WA**

Alzheimer's Australia WA, in partnership with the NSW Dementia Training Study Centre at the University of Wollongong, have developed a national project focusing on translating research into practice in the area of enabling environments for people with dementia. There are lots of free resources here, including an audit tool for gardens.

[www.enablingenvironments.com.au/About.aspx](http://www.enablingenvironments.com.au/About.aspx)

## **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](http://www.who.int/ageing/publications/Age_friendly_cities_checklist.pdf)

## **Housing LIN**

Housing LIN have produced a comprehensive resource list around housing and dementia

[www.dementiaaction.org.uk/assets/0000/9077/Housing\\_LIN.pdf](http://www.dementiaaction.org.uk/assets/0000/9077/Housing_LIN.pdf)

### **The King's Fund – Developing supportive design for people with dementia**

To support clinical and care staff, managers and estates colleagues, The King's Fund has produced a range of resources to enable hospitals, care homes, primary care premises and specialist housing providers to become more dementia friendly

[www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia](http://www.kingsfund.org.uk/projects/enhancing-healing-environment/ehe-design-dementia)

### **Social Care Institute for Excellence (SCIE)**

SCIE have detailed online resources looking at dementia friendly design in every room. These resources have been mapped to specific Qualification and Credit Framework (QCF) units.

<http://www.scie.org.uk/publications/dementia/supporting-people-with-dementia/dementia-friendly-environments/index.asp>

**ASK Sara Website** – great for aids and equipment to support people with dementia

<http://asksara.dlf.org.uk/>

**DEEP guidelines** on writing dementia friendly information

<http://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing--information.pdf>

**DEEP guidelines** on consulting people with dementia about written information

<http://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Consulting-about-written-documents.pdf>

**DEEP guidelines “Dementia Words Matter”**

<http://dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>

### **Plain English Campaign**

link to free guides to writing in Plain English

<http://www.plainenglish.co.uk/free-guides.html>

# C: The people

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 collector, the library assistant, the gym instructor. These are not people providing care, but people who provide services to all of us.

Most people with dementia live in communities and neighbourhoods and use generic and universal services. Most staff working in services such as housing, customer centres, leisure services, libraries, transport and adult education are going to meet people with dementia as customers. Basic knowledge and understanding about the condition would enable them to do their job more effectively and provide a better experience for the person with dementia.

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

Awareness-raising and training have a crucial role to play in the creation of more dementia friendly communities. This is probably the most important feature of a dementia friendly community and the area where councils have the greatest potential to transform the lives of people with dementia.

Experience suggests that organisations and services with a strong ethos of customer care, and who recruit people with good communication skills, already have most of the attributes they need to provide a great service for people with dementia. All that is needed for many is just a little information.

At a basic level, especially for staff working in non-care services and settings, Dementia Friends is proving to be an effective way of delivering dementia awareness.

## **Dementia Friends**

Dementia Friends was developed by Alzheimer's Society under the Prime Minister's Challenge, and at the time of writing more than a million have attended information sessions and signed up as Dementia Friends. The Dementia Friends programme is the biggest ever initiative to change people's perceptions of dementia which helps people to understand a bit more about dementia and the little ways they can help.

It aims to transform the way the nation thinks, talks and acts about the condition.

Ways of becoming a Dementia Friend include attending an information session, learning a little bit more about what it is like to live with dementia and then turning that understanding into practical action that could help someone with dementia living in their community.

Local councils can actively support the roll out of Dementia Friends by promoting the training amongst council staff and members; by making space available for Dementia Friends training and by encouraging all staff to visit the Dementia Friends website and watch the short video on becoming a Dementia Friend. Further information on becoming a Dementia Friend is available at [www.dementiafriends.org.uk](http://www.dementiafriends.org.uk)

### **Dementia Friends Champions**

Dementia Friends Champions are volunteers trained by Alzheimer's Society to deliver Dementia Friends sessions in their workplaces and communities. In many councils, local members are choosing to become dementia champions and to take an active role training others to become Dementia Friends and in supporting their local areas to become dementia friendly.

Further information on becoming a dementia champion is available at [www.dementiafriends.org.uk](http://www.dementiafriends.org.uk)

### **Training all council staff about dementia**

Local councils commission and deliver core services that are necessary for all of us to live our daily lives well. These include libraries and leisure services, waste disposal services, council tax and other revenue services, advice and guidance services and welfare rights services, etc.

Ensuring that staff working within these services are aware of the potential needs of people living with dementia and their carers, can make a significant difference to their lives. It can also be cost effective for councils, as it can result in people with dementia living in their local communities for longer without requiring intensive health and social care support.

For some staff, accessing a Dementia Friends information session may be sufficient. However, for others and particularly those in customer facing roles, staff might benefit from additional training or support. We have set out below a few examples of areas where local councils may want to consider providing additional information or training for staff. For example for staff working in:

- **Welfare rights.** Training might be helpful to enable them to understand the variety of services and supports that can be accessed by people living with dementia and their carers. This will include occupational therapists, physiotherapists, social workers, GPs, Dementia Support workers. It is important that staff working in more generic advice roles are aware of these services so that they can make sure that the advice and guidance they offer takes these into account.
- **Waste disposal.** Training might be helpful on how to recognise the signs of dementia so that they can be responsive to the needs of people living with the condition.
- **Libraries.** Training or information might include the impact of dementia on reading, resources that are available on dementia and how they can make the library more accessible to people living with dementia.
- **Transport.** Drivers are trained to understand the impact of dementia, how this might affect someone while travelling and how to do their job in a way which makes the service more accessible to everyone:

## Case study Drivers for Change: Dementia friendly bus transport in Northumberland

Northumberland is developing a dementia awareness training package for local bus drivers for inclusion in the Certificate of Professional Competency.

The training development has identified that a more sustainable and effective process is to work in partnership with the existing providers of driver training to develop an enhanced package that focuses on awareness and practical measures to support passengers.

- **Tourist and visitor information.** Visitors with dementia who are unfamiliar with the environment may need additional support.

## Case study – Sam Farooq – Information Advisor – Visit York

“When my manager suggested dementia friendly training, I’m embarrassed to say I had to Google what dementia meant,” says Sam Farooq. The training gave Sam a real insight into what living with dementia involves. But she also realised she was already helping people with dementia day in, day out. “One lady came in every day with the same question,” she explains. “I wondered why she didn’t remember what I’d told her the day before. Now I think she was probably living with dementia.”

Around seven million people visit York each year. Whether they live locally or on the other side of the world, many pass through the visitor centre. “We’ll go the extra mile for anybody. It’s what we do,” says Sam. “That made switching to dementia friendly working easy.” The big difference is simply having more awareness, taking a little more time. “If someone comes in five times a day asking the same thing, it doesn’t matter,” says Sam. “I’d rather they felt safe and secure.” Sam tells how one lady came into the centre in distress, having completely forgotten why she was in York. Staff were able to reassure her, find her address in her handbag and arrange a taxi home. Sam is proud of the centre’s dementia friendly sticker. It impressed four Canadian visitors so much they came in just to say congratulations. “They gave me a huge hug,” she laughs. “I’d like to see the sticker across the whole city. On buses, in taxis, at the post office and the library, in schools.” To anyone thinking of making their workplace dementia friendly, Sam says: “Go for it. Don’t be embarrassed if you feel you know nothing. Go on a course, talk to other people, listen to their stories. There’s a lot of support out there.”

### **Dementia Friendly Yorkshire – first steps on the journey – JRF 2014**

The Social Care Institute of Excellence (SCIE) has produced an E-learning course called Open Dementia – it is a useful and flexible resource as a starting-point for further training and awareness- raising. It has seven modules, and each can be completed in about half an hour. It is free of charge, of very high quality, and focused chiefly on people with dementia living in the community.

The SCIE course has been used by more than 60 local Age UKs, who have been working to make their mainstream services accessible to people with dementia since 2012 – and feedback has been very positive.

To ensure that the SCIE course was relevant to specific roles, many AGE UKs produced a matrix to map volunteer and staff roles to specific elements of the course.

In this approach, staff who manage a particular team, service, or function within the organisation complete the whole course themselves. While they are becoming familiar with the material, they are also constructing their own ‘matrix’ linking specific parts of the course with specific roles within their team.

There will of course be staff who might benefit from some additional training, but the SCIE course provides a firm foundation of knowledge that should be suitable for most staff and volunteers working within mainstream services AGE UK 2014<sup>23</sup>

### **Addressing the needs of people with dementia from Black, Asian, Minority and Ethnic (BAME) communities through training and support.**

In the delivery of a dementia friendly community, it is important to remember the person behind the dementia, and that they will have their own unique set of circumstances like, for instance, being from a Black, Asian and Minority Ethnic community.

“Research into the barriers to social participation for all people from seldom-heard communities shows that many face additional pressures or difficulties. People from black, Asian and minority ethnic groups, for instance, may face problems around both accessing health services and engaging in activities, especially where people feel that practitioners do not have cultural competence, hold particular stereotypes, or make assumptions about the care that people want”<sup>24</sup>

### **Lesbian, Gay, bisexual and transgender (LGBT) people with dementia**

LGBT people with dementia and their carers often face particular challenges. For example they may feel out of place in traditional support groups or they may be worried about accessing services due to fears of homophobia. Many feel that they would be uncomfortable with care home staff or paid carers knowing their sexual orientation. The Alzheimer’s Society makes a number of recommendations for working positively with LGBT people with dementia<sup>25</sup>.

23 Making your services dementia friendly – a how to guide for local AGE UKs – Age UK 2014

24 Black and minority ethnic people with dementia and their access to support and services; Moriaty et al: SCIE 2014

25 [www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1100](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1100)

## **Younger people with dementia**

There are more than 40,000 younger people with dementia in the UK. Younger people with dementia may have different needs, and require some different support to older adults. The Alzheimer's Society have published a factsheet 'younger people with dementia' that looks at the types of dementia that younger people may have, some of the difficulties that they might experience and where support can be found.<sup>26</sup>

## **Councils as employers**

As employers, councils have a responsibility towards staff whose lives may be affected by dementia. There will not be any council who does not have staff or elected members who have close family members with dementia. It is almost certain that many, if not most councils will also have employees and elected members who have or are developing dementia.

Dementia increasingly affects younger people and older people are retiring later, this means that many people are still in work when they get the first symptoms of dementia or a diagnosis. Dementia affects each person differently so it is not possible to predict how long someone can keep working. Also an individual's ability to continue working is dependent on the nature of their work. Earlier diagnosis and medication are helping more people with dementia stay in work for longer. It is important to recognise that a person with dementia may not need to stop working: indeed it may be better for their well-being to carry on as long as they are able to do so.<sup>27</sup>

Under the Equality Act (2010) employers must avoid discrimination and make reasonable adjustments to make sure that people with dementia and their carers are not disadvantaged at work. Developing employment policies and practices that support people affected by dementia not only fulfils councils' duty as employers under the Equality Act 2010, but also communicates a powerful message about their commitment to creating a dementia friendly community.

Local councils can be one of the largest employers within an area. As such, they play an important role in supporting the needs of people living with dementia or who have caring responsibilities within their employment.

This might include:

- making sure that information about dementia and support is available to staff
- providing occupational health services for staff
- developing action plans to enable staff who have been diagnosed to continue in their role for as long as possible, as their dementia develops
- providing flexible working arrangements where appropriate to accommodate the caring responsibilities of employees with close family members with dementia
- developing clear exit strategies which might include volunteering opportunities to enable those leaving to maintain their connections with the organisation and their communities, continue to use their skills and knowledge and to maintain their self-esteem.

<sup>26</sup> [www.alzheimers.org.uk/site/scripts/download\\_info.php?downloadID=1104](http://www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=1104)

<sup>27</sup> [www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=355](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=355)

## Case study – Joseph Rowntree Foundation (JRF)

The Joseph Rowntree Foundation and Housing Trust employ around 750 people in Yorkshire. As part of their initiative to become a dementia friendly organisation, JRF has reviewed its HR policies and is promoting the role of its Admiral Nurse in supporting employees as well as residents. Information boxes have been placed in all 17 work settings, and a resource of books built up in the central library. A local solicitor has been providing pro bono information sessions open to all staff about the importance of Lasting Power of Attorney and wills. One third of all staff, including most Trustees and Directors, have become Dementia Friends, raising awareness of the condition in all parts of the organisation.

### What can councils do?

- Encourage and support all staff and elected members to engage with the Dementia Friends programme and to become Dementia Friends.
- Support key staff and elected members to become dementia champions – so they can train and support other members and officers to become dementia friends and to act as ambassadors and supporters of work to promote dementia friendly communities locally.
- Consider including Dementia Friends as part of basic induction for all customer facing staff.
- Support the rollout of Dementia Friends to partner organisations and the broader community by making premises available for session, or by running sessions in public spaces or as a part of larger events.
- Provide additional training or information on dementia for staff in customer facing roles who need more than basic awareness, including and going beyond those in health and social care.
- Take advantage of the existing good quality and free training resources – there is a great deal of existing high quality training online, including the SCIE open dementia course.
- Raise awareness about the specific issues facing people with dementia within Black and Minority Ethnic Communities.
- Take a lead in developing employment policies that include the needs of people with dementia and their carers.
- Include information about dementia and dementia support in newsletters, websites and on council noticeboards.

## **More reading and resources**

Dementia Friends at <https://www.dementiafriends.org.uk/>

SCIE Open Dementia E-learning course

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

How to help people with dementia - a guide for customer-facing staff - Alzheimer's Society <http://alzheimers.org.uk/customerfacing>

For more information on BAME populations, see Dementia Does Not Discriminate the experience of people with dementia from black, Asian and minority ethnic communities All Party Dementia Group

DEEP guidelines - Dementia Friendly Tips for Employers.

<http://dementiavoices.org.uk/resources/deep-guides/>

Employers Toolkit (Draft) Alzheimer's Society (2015)

Living with Dementia booklet; Employment. Alzheimer's Society. (2010)

[http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1016](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1016)

# D: The resources

This section looks at how resources can be deployed in services that have the greatest potential to support people with dementia and their carers engage with their communities.

Traditionally, support to people with dementia has focused on the later stages, through day centres, care homes and home care. Over the last 20 years the focus has shifted towards earlier support and this has accelerated, along with the demographic changes, improvements to diagnosis and the changing aspirations of people with dementia.

More recently still, an emphasis on prevention of dementia has become prominent in public health messages along with emerging evidence about the possibility of reducing specific risk factors for dementia.<sup>27</sup>

It is not just people in the later stages that benefit from support. This starts from before diagnosis and at the point of diagnosis. The provision of timely support enables people to maintain independence and avoid crisis admissions to healthcare. It also contributes towards the sustainability of dementia friendly communities.

The following three sections discuss important initiatives and services that have the potential to support the capacity and resilience of people with dementia and their carers:

- access to timely diagnosis
- appropriate post-diagnostic support
- services which support people to stay connected, such as accessible activities, peer groups and one to one support.

## Supporting people to access a timely diagnosis

Improving the rate of diagnosis has been a major focus of dementia policy from the Dementia Strategy onwards. Research suggested that attempts to improve diagnosis rates have achieved mixed results. In 2010/11, in England, less than half (42 per cent) of those estimated to have dementia were being diagnosed. The recent Prime Minister's Challenge on Dementia reports that this has risen by 17 percentage points to 59 per cent.

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<sup>27</sup> Blackfriars Consensus on promoting brain health: Reducing risks for dementia in the population; PHE 2014 [http://nhfshare.heartforum.org.uk/RMAssets/Reports/Blackfriars%20consensus%20%20\\_V18.pdf](http://nhfshare.heartforum.org.uk/RMAssets/Reports/Blackfriars%20consensus%20%20_V18.pdf)

Receiving a diagnosis of dementia can be devastating for individuals and their families. However, with the right support to enable people to understand the implications of a diagnosis and how to continue to live well, being diagnosed can bring huge benefits.

- it gives them a better chance of learning to live well and cope better with dementia
- it opens up appropriate treatments and support
- it enables people to plan ahead and make decisions about their future needs
- it can identify common treatable conditions that can mimic the effects of dementia, such as depression, constipation or infection.

It is also essential for the health and social care system because it makes it easier to plan for future care needs, avoid crisis admissions to hospital and use local resources better.

However, the best diagnosis services are of little use if people are unwilling to seek diagnosis, or don't know how to access it.

Stigma is a major barrier to diagnosis<sup>29</sup>. People are less likely to seek a diagnosis if they are unaware of the advantages of doing so, and there is strong evidence of a connection between awareness of dementia and take-up of diagnosis -so activities to raise awareness, in relation to both people with a potential to develop dementia and the wider public are likely to have a continued impact, particularly within black, Asian and minority ethnic communities for whom lack of awareness has been identified as a significant influence on poor rates of diagnosis<sup>30</sup>.

There is strong evidence to show the benefit of early diagnosis to individuals and families and also to the taxpayer. As long ago as 2009, an economic metric was published by the Department of Health, which demonstrated the financial benefits of early diagnosis in delaying admission to hospital and to care homes (Department of Health, 2009a)<sup>31</sup>.

## Appropriate post – diagnostic support.

Delivering immediate and appropriate post-diagnostic support in a way that emphasises the potential to live well with dementia 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.

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29 [www.mrc.ac.uk/news-events/news/social-stigma-around-dementia-hinders-diagnosis-care-and-research/](http://www.mrc.ac.uk/news-events/news/social-stigma-around-dementia-hinders-diagnosis-care-and-research/)

30 Dementia Does not Discriminate -The experiences of black, Asian and minority ethnic communities - House of Commons All Party Parliamentary Group on Dementia 2013

31 Unlocking Diagnosis – the key to improving the lives of people with dementia APGD 2012 – referencing Department of Health (2009a). The clinical and health economic case for early diagnosis and intervention services in dementia. Department of Health, London.

## Case study – The Think Again programme – Avon and Wiltshire MHP

The Think Again programme provides a post-diagnosis therapeutic group course for up to seven people with dementia and their carers which lasts for eight weeks. Each session lasts for two hours and covers a variety of issues including practical coping strategies, looking at the impact on the relationship, forward planning, and sessions with a psychiatrist. An exit strategy is agreed with ongoing support from local partners, including the Alzheimer's Society.

However, this level of support following diagnosis is far from the norm, with many people with dementia and carers reporting significant delays between diagnosis and the receipt of meaningful support, if at all<sup>32</sup>.

'You are fine at the moment – but come back when there is a problem' is a phrase which is often reported by people with dementia and carers<sup>33</sup>.

Ongoing support post-diagnosis has been identified as a significant challenge, if improvements in the diagnosis rate are to have meaning for those receiving the diagnosis.

“Improving diagnosis rates involves more than just improving numbers – it involves designing a diagnostic pathway that takes people from their first appointment with their GP through to the support they receive in the years following a diagnosis. This requires investment, joint working across health and social care, and leadership. Political commitments and top-down policy directives are starting to yield improvements, but must also be met with local services designed around the needs and voices of people with dementia”<sup>34</sup>.

However, there is currently a lack of clarity and strong evidence about what interventions work in post-diagnostic support, with the Alzheimer's Society also highlighting further inconsistencies:

“...at present there is no guidance on a minimum provision of support and it is unclear in England and Wales whether the responsibility for commissioning services lies with health or social care. As a result access to support after diagnosis is inconsistent.”

**(Alzheimer's Society 2014)**

The impact of a range of different post-diagnostic interventions is, in the words of

32 [http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=404](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=404)

33 <http://dementiapartnerships.com/wp-content/uploads/sites/2/dementia-review-final-report.pdf>

34 Dementia 2014: Opportunity for Change – Alzheimer's Society 2014  
[www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=2317](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2317)

the 2020 Challenge currently being ‘robustly tested’, and there is an acceptance that there needs to be significant improvement in the sharing of good practice in this area. However, the Prime Minister’s Challenge 2020 also challenges local commissioners to develop a better understanding of local needs, available services, and gaps in provision in order to develop appropriate commissioning strategies.

“People’s experience of living with dementia or caring is significantly determined by characteristics such as their ethnicity, age, pre-existing disabilities or whether they have a carer living with them. Local commissioners and providers need to continue to improve their understanding of the best ways to tailor post-diagnosis support services to diverse needs.”<sup>35</sup>

While giving little in terms of recommendation for specific forms of post-diagnostic support, the Challenge cites one to one support and peer group support as good examples of practical ways to support and maintain engagement.

It also highlights the role of Dementia Advisors or Navigators to support people to find and coordinate appropriate support, as well as the broader role of information and advice services to people with dementia and carers. Also cited is the need for access to psychological interventions for people with dementia and their carers. Access to counselling support for carers and people with dementia in particular have been very poor, which may seem surprising given the impact that dementia has in so many areas that counselling may seem ideally suited to address.

It is likely that these forms of post-diagnostic support will continue to be highly significant factors in supporting people with dementia to maintain resilience.

### **What can councils do?**

- Councils could review how they are enabling people living with dementia and their families and carers to access holistic, integrated and effective post-diagnostic support. It is important that people living with dementia, their families and carers are aware of what local services are available and how to access them, and that such services are based on evidence of what works.
- Psychosocial interventions have a key role to play, both immediately post-diagnosis and on an ongoing basis. Health and wellbeing boards could consider how services can be stimulated and supported to meet this need.
- Existing counselling and mainstream information services could be encouraged to consider their accessibility to people with dementia, and their awareness of issues affecting carers.
- Support from Dementia Advisors is crucially important for people with dementia and these initiatives could be encouraged and maintained.

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<sup>35</sup> Dementia 2014: Opportunity for Change – Alzheimer’s Society 2014 / [www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=2317](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2317)

- Councils have a key role to play in ensuring their staff have access to appropriate information and knowledge about dementia and, where relevant, understand what good quality post-diagnostic integrated care and support looks like.
- Good quality post-diagnostic support is not confined to health and social care, but includes a whole range of services that enable people to take a part in the lives of their communities and to live as fulfilling a life as possible.
- Public health could maintain focus on public health campaigns using resources such as Dementia Friends, as well as promoting key messages and actions to promote prevention and healthy living.

## Supporting people to stay connected

The most dementia friendly community in the world will be of little use if people with dementia are so discouraged and downhearted that they won't even leave the house. This is where the support and services people receive post-diagnosis are so important for building and maintaining resilience and social capital.

“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.’<sup>36</sup>

Systematic reviews have found evidence that participating in stimulating and social activities can reduce the risk of developing dementia. These activities can also help reduce depression and feelings of loneliness in people with dementia, increasing quality of life and self-confidence.<sup>37</sup>

People with dementia commonly express a desire to continue to live their lives and maintain their interests, activities, hobbies, and community connections. 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.

As research from the Alzheimer's Society (Building Dementia Friendly Communities 2013) highlights, many people with dementia withdraw from everyday life, and face significant barriers in maintaining their engagement.

36 Prime Minister's Challenge on Dementia 2020: Department of Health, Cabinet Office, Prime Minister's Office. [www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020](http://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020)

37 Dementia and Cognitive Decline – a review of the evidence - Sujita Ray and Dr Susan Davidson – pub AGE UK 2014 [www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Cognitive\\_decline\\_and\\_dementia\\_evidence\\_review\\_Age\\_UK.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/Cognitive_decline_and_dementia_evidence_review_Age_UK.pdf?dtrk=true)

“Many people with dementia are not able to take part in activities that they enjoyed before they developed the condition. Many feel constrained by the condition and are not confident to get out and engage in their area. There is more that the person with dementia would like to do but they need support to do so”.

### **Staying connected through dementia specific initiatives**

In many areas, local councils are working with voluntary organisations such as the Alzheimer’s Society and AGE UK to offer a variety of activities for people with dementia at a local level. These include activities such as ‘dementia cafe’s’ and ‘singing for the brain’.

Dementia cafe’s come in various shapes and sizes. Some cafes provide additional support and information from professionals, others do not. Some provide structured activity, others do not. What they all share in common is an opportunity for people with dementia and their carers to meet in mainstream community settings and enjoy company and the support of others

#### **Case study - Singing for the Brain – Hartney Whitney**

Singing for the Brain uses singing to bring together people with dementia and their carers with volunteers. There is a strong emphasis on fun, but the sessions are also structured to include activity which stimulates memory and cognition.

“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)

These services are well-used and very popular with people with dementia and their carers. For many they provide an important ‘way in’ to meeting other people in a similar situation and experience suggested that they can also provide a ‘safe haven’ from which to venture further into the community.

#### **Case study – Dementia cafe**

In one cafe visited by the author, people with dementia had started to venture to the pub next door, with initial support from a volunteer. This has become a regular part of the cafe session, with carers remaining in the cafe. A number of men with dementia have since started to meet in the pub informally, once they realised that they would be welcomed and felt comfortable.

**Source – Innovations in Dementia**

It is clear that for many people with dementia and their supporters, these services provide a very important anchor to their communities. However, although they are highly cost-effective, they are often insecurely funded.

Dementia cafe's and Singing for the Brain are widely adopted and well recognised ways of providing opportunities for peer support and activity for people with dementia and their carers. However, there is a huge range of imaginative approaches to providing activities targeted at people with dementia.

Many councils have been proactive in supporting the development of a range of approaches, often working together with local partners.

### Case study – Wolverhampton City Council and the Dementia Action Alliance

Thirty people with dementia took part in a project involving the city's Arts and Heritage Service in collaboration with the Grand Theatre, English Touring Opera, the Royal College of Music and Turtle Key Arts. The project was supported by a grant from Wolverhampton City Council and the use of facilities at the City Archives and Art Gallery. People with dementia worked with musicians and a writer, using objects from the museum collections to stimulate ideas for new songs. Participants were fully involved in writing the songs and performed them to a specially-invited audience of family and friends at the Grand Theatre. The project aimed at promoting the message that people can live well with dementia, enjoying new activities and new learning. Funding from the city council enabled the production of a booklet and CD so participants and their families could have a permanent reminder of their achievement.

#### Source – Dementia Action Alliance

It is easy to fall into making assumptions about what people want to do, but the range of activities being developed is a useful reminder that people with dementia are as varied in their interests and aspirations as everyone else.

“When I was younger, I was into punk music..... I don't do tea dances.” person with dementia in Scarborough (source DAA)

#### One to one support

This is where the potential for personalised one to one support is particularly relevant, and is one of the forms of post diagnostic support specifically mentioned in the 2020 Dementia Challenge.

One to one support has been consistently identified by people with dementia as key to engaging in their communities, dating from early work by Innovations in Dementia<sup>38</sup> Alzheimer's Society notes:

<sup>38</sup> Dementia Capable Communities – The views of people with dementia – Innovations in Dementia CIC 2011 [www.innovationsindementia.org.uk/DementiaCapableCommunities\\_fullreportFeb2011.pdf](http://www.innovationsindementia.org.uk/DementiaCapableCommunities_fullreportFeb2011.pdf)

One third of people (35 per cent) would like more care, support and services to do things in the community, including more opportunities to participate and help to attend activities through a befriender.

Alzheimer's Society 2013 <sup>39</sup>

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.

### Case study – My Day, My Way

My Day, My Way is a specialised 1 – 1 support service for those with a dementia living in the community. As part of the service we support individuals to remain independent in the community accessing local groups and activities. We use the life history of those that access the service to engage in meaningful activities, for example horse riding, swimming, craft clubs and exercise classes. All of our staff are trained with regards to dementia support and promote the ideals of a dementia friendly society at all the groups we attend, often signposting group organisers and attendees to Dementia Friends sessions.

**(Source - Dementia Action Alliance)**

### Peer group support and volunteering

Peer group support has also been identified by many people as playing a crucial role in building and maintaining community connectedness. Similar to one to one support, it is one of the few forms of post-diagnostic support specifically cited in the 2020 dementia challenge.

People with dementia engaging in the DEEP project report enormous benefits from being in the company of other people with dementia. Not least of these is the inspiration derived from seeing others living well, and renewed confidence to be part of the wider community.

Many people with dementia have spoken about the sense of loss of role that they experience upon diagnosis. Many feel that their life is over, that they have nothing to offer.

This is why opportunities to contribute and to maintain reciprocity are so important for people with dementia. Feeling that what they say matters is a very significant characteristic of a dementia friendly community.

<sup>39</sup> Building Dementia Friendly Communities – a Priority for Everyone – Alzheimers Society 2013  
[www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2283](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2283)

Many people with dementia also mention their need to give back to their communities, and many choose to volunteer to support other people with dementia, and have been actively involved in setting up support groups.

“Helping vulnerable groups of people to get out and get active in their communities is shown as the best way to have a huge positive impact on their overall wellbeing, according to a SCIE report into ageing (May 2012). Although existing campaigns encouraging better understanding of dementia and developing befriending groups will help to achieve this, the Council for Voluntary Service’s experience with various other groups of individuals with additional support needs shows that continued active involvement in community life and being able to make a contribution through volunteering is the most effective way of fostering a sense of belonging and value”

**(Council for Voluntary Service – Dementia Active Project Proposal).**

The DEEP project provides numerous examples of user-led initiatives. One such is Dementia Mentors – a support service which provides people with dementia to mentor those with a recent diagnosis:

**Case study – Maidstone Mentors – Kent and Medway Primary Trust, Alzheimer’s Society Maidstone Peer Support Group (Members of the DEEP network)**

Maidstone mentors provides volunteers with dementia to support and provide a listening ear to people recently diagnosed with dementia.:

“The idea for Maidstone Mentors came from Tom who attends Maidstone Peer Support group. Tom had previously reached out to his GP offering his phone number to be passed onto people who had been recently diagnosed so that he could listen to their worries and let them know that support is out there. He wanted to prevent anyone else feeling as alone as he had when he was diagnosed.”

**Staying connected through mainstream services and activities**

However, while activities specifically targeted at people with dementia are important, more significant and sustainable gains are likely to be made in ensuring that mainstream provision is as accessible as possible. Many people with dementia have argued for the importance of ‘normal’, of the ‘stuff of life’, and of wanting to maintain their everyday activities, rather than being channelled into ‘specialist’ provision.

This is at the core of the notion of dementia friendly communities. The more accessible mainstream services become, the less likely it will be that people with dementia will need or want specialist provision.

## Case study – AGE UK

Sixty local Age UK services across England are working to make their mainstream services accessible. Innovations in Dementia was commissioned to support them to audit their accessibility of their mainstream services to people with dementia.

Services have been opened up to people with dementia, by ensuring that staff and volunteers are aware of how to support people with dementia, and by making often small but highly impactful changes to the environments in which services are delivered. Recent research by AGE UK recognises that the unique potential of AGE UK in supporting people with dementia may lie in the fact that it is NOT a dementia specific organisation.

## Case study – Age UK Solihull

Since taking part in the first 'Including People With Dementia' project in late 2012/ early 2013, Age UK Solihull has taken a different approach to how it provides services for all older people their families and carers.

“At Age UK Solihull, over the past two years, we have shifted our ethos to recognise and understand dementia but not let it define the person. The view we take is simple – focus on the person and their needs, not a diagnosis or a label. All services provided by Age UK Solihull are now regularly assessed to ensure they are all accessible to all, irrespective of whether or not the individual has a mental or physical condition. Dementia specific services are not provided, indeed, recently the Carers Support Scheme, which was restricted to carers of those living with dementia, has been opened out to all carers of older people living with a long term condition. The aim is to ensure all services reflect the needs of the older population of Solihull and the illnesses they live with. We do not label, we are inclusive of all”

### **Age UK – Living Life with Dementia 2014**

Across the AGE UK network, and in other voluntary sector organisations, more and more people with dementia are being supported through mainstream services and activities. Services such as information and advice, leisure activities, basic help at home, and opportunities for social interaction are essential to people with dementia and their carers throughout the progression of dementia.

## **What can councils do?**

### **Dementia-specific activities**

- Consider how they can support the development and sustainability of popular and well used services such as Singing for the Brain and Dementia cafes. This could be through direct funding support, or by helping with access to premises, staff or equipment.

### **One to one support**

- Support the development of one to one support schemes for people with dementia that include opportunities for both practical support and engagement in the community.
- Encourage organisations to think differently about recruiting a broader range of volunteers with specific interests to support a broader range of people with dementia.

### **Peer group support and volunteering**

- Encourage and support the development of peer support groups for people with dementia – the DEEP project can offer further guidance.
- Encourage and support opportunities for mentoring and volunteering for people with dementia.
- Work with volunteer agencies to ensure that their services are accessible to and aware of the needs and potential of people with dementia as volunteers.

### **Stimulating Support through mainstream services and activities**

- Provide information about activities and facilities in accessible formats (see section on written and published material on page 25).
- Involve people with dementia in exploring the accessibility of existing services.
- Think about how the capacity of council services 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 in– 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
  - libraries can provide dementia specific resources and facilities specifically aimed at people living with dementia
  - highlight the importance of ongoing adult education for people with dementia to local adult education colleges – as accessing further education and learning can help maintain health, skills and learning capacity.
- Provide leadership and challenge to civil society organisations to look after their own members (for example, regular walking groups, whose membership is usually predominantly drawn from older people could be encouraged to organise a buddy scheme to help support members who develop dementia to stay involved in their activities)

- Help people providing leisure activities to consider how their people, set-ups and signage can become more helpful to members who are becoming confused, or who may be unfamiliar with layouts
- Through appropriate training and awareness-raising ensure that frontline staff do not inappropriately refer people with dementia seeking support from mainstream services and facilities to specialist provision
- When commissioning services, recognise the role that mainstream activities and services play in the lives of people with dementia – ultimately, it is in mainstream provision that people with dementia will spend most of their time and derive most of their benefit
- Encourage organisations to think differently about recruiting a broader range of volunteers with specific interests to support a broader range of people with dementia.

**Further reading:**

Unlocking Diagnosis – the key to improving the lives of people with dementia  
APGD 2012

**The British Psychological Society, with partners including DEEP, has produced a guide to psychosocial interventions in the early stages of dementia.**

**It is available here:**

[www.bps.org.uk/system/files/user-files/DCP%20Faculty%20for%20the%20Psychology%20of%20Older%20People%20\(FPoP\)/public/a\\_guide\\_to\\_psychosocial\\_interventions\\_in\\_dementia.pdf](http://www.bps.org.uk/system/files/user-files/DCP%20Faculty%20for%20the%20Psychology%20of%20Older%20People%20(FPoP)/public/a_guide_to_psychosocial_interventions_in_dementia.pdf)

# E: The networks

It takes a lot of organisations and individuals to make a community, and it is therefore important that a range of organisations are involved in creating dementia friendly communities.

Lots of other people and organisations are thinking about the need to become more dementia friendly, including many of your strategic partners. Working with and supporting them could be a valuable contribution to making the wider community more dementia friendly as well as getting support and learning to apply to your own services.

As strategic leaders, councils 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. There are various ways councils can support others to become dementia friendly. Councils are well placed to galvanise other organisations to work together, most likely through:

- health and wellbeing boards
- by becoming an active member of or leading the development of a local Dementia Action Alliance
- via their regulatory and licensing functions, examples of which can be seen in the domains 'the voice of people', 'the place' and 'the people'.

## Case study – Norfolk Health and Wellbeing Board

Norfolk have as one of their three priorities - Making Norfolk a better place for people with dementia and their carers - with clear actions focused upon:

- building an integrated approach – including a comprehensive dementia needs assessment to inform the JSNA to include the needs of BAME groups – and a review of transport
- promoting awareness of dementia – including supporting dementia friendly communities and ensuring that strategic partners staff and volunteers are required to have appropriate levels of awareness and training in dementia
- improving dementia care pathway- with a focus on co-production with people with dementia and their carers – timely diagnosis – effective post-diagnostic support – support for Dementia cafes – Admiral Nurses – and increased awareness and use of aids and adaptations in housing
- supporting Independent living - including support for information and advocacy services – support for carers – and focus on housing
- improving services for those unable to live independently.

Statutory members of health and wellbeing boards with remits of particular relevance to dementia friendly communities include:

- Director of public health – public health has an important role to play both in prevention, but also as a source of information about local demographics.
  - Director of adult social care – the lead officer for adult social care will be the source of much knowledge and expertise in supporting people with dementia and their carers.
  - Director of children’s social care – children’s social care could play an important role in communicating the impact of dementia on children, including children acting as carers for younger people with dementia, as well as providing education and support for children affected by dementia.
  - Healthwatch representative – has clear potential to ensure that the voice of people with dementia and their carers is heard clearly (whether or not people with dementia have been directly co-opted).
- They have a key ‘listening’ function, not just in the production of the JSNA, but also in the capacity to co-opt representatives of user and patient groups – including potentially people with dementia and their carers.
  - They have a statutory duty to promote integration such that all the relevant partner organisations work together to maximise the wellbeing of the local population.
  - They are the most important forum for local authorities to influence how healthcare is developed, commissioned and delivered.
  - They are responsible for producing the Joint Health and Wellbeing Strategies.

Local health and wellbeing boards will prioritise the areas their JSNAs have highlighted as being of particular concern locally. This may mean that dementia is not specifically highlighted within the strategy, nor that dementia is named as a priority. In many areas councils and their partners are providing strategic oversight and shared ownership of the commissioning and delivery of the range of services that people living with dementia and their carers need. This might include evidence-based and high quality clinical services through to community based services that promote wellbeing and enable people to stay connected. In many areas, such partnerships and strategic groups include:

- **Education** – as work with schools is key to help children understand more about dementia and to promote important intergenerational work.

### Case study – Dementia Diaries

The Social Innovation Lab Kent (SILK) is based within Kent County Council. SILK has co-produced the Dementia Diaries - a book aimed at young people – with a group of 20 young carers of people with dementia between the ages of seven and seventeen.

Read more here: <http://socialinnovation.typepad.com/files/journal-of-dementia-care-1.pdf>

- **Planning** – as we have seen in the section on ‘place’, planning officers can involve people with dementia to advise on new developments and ensure that others are aware of the issues that people with dementia face in accessing the built environment.
- **Housing** – Making sure that housing works well for people with dementia and that housing staff understand how adaptations can enable people to stay independent in their own homes for longer.
- **Transport** – working with partner organisations to take on board the needs of people with dementia.
- **Highways** – providing signage is clear and easily understood.
- **Environmental services** – providing instructions for recycling that are clear and easy to understand.
- **Leisure and culture services** – providing leisure and cultural services that are accessible, and frontline staff who are aware of how they can support people with dementia to use their facilities.

### Other statutory agencies

Other statutory agencies also have many insights to offer and contributions to make. The police and transport services, for instance, have everyday experience of responding to the needs of people with dementia who get into difficulties but receive little training on how to do so. Councils can use strategic drivers such as the community safety plan, policing plan, the health and wellbeing strategy and transport plan, as well as strategies for older people and people with dementia as levers to reinforce their needs.

Many police and fire and rescue services are already members of their local Dementia Action Alliance and are taking steps to ensure that people with dementia are properly supported.

Here, for example are the action points listed by Essex Police on their membership page of the Dementia Action Alliance:

- make frontline officers aware – Dementia Friends meetings
- have a look at the setup of our stations. Are they Dementia Friendly?
- have a point of contact at each station. Preferably a Dementia Friend
- have a person trained to train others within the police. Dementia Champion
- PCSO to attend a coffee meeting within their ward
- GPS trackers / Missing people – extend funding

interact with local stores within their ward.

### Case study – Kent Fire and Rescue Service and Kent County Council

Kent Fire and Rescue Service and Kent County Council have worked together to improve safety for people with dementia.

Eight of the fire service's team are now able to do the councils home safety assessment and give the go-ahead for a range of safety equipment to be installed. This includes monitored lifeline units, pendants, keysafes and smoke and heat detectors.

This helps people stay in their own homes for longer and gives peace of mind to their families.

Previously there could be significant delays in getting the equipment installed as fire officers identifying problems had to request a further assessment by the council. The cost savings to the council are significant – as the equipment costs a few hundred pounds versus thousands if someone has to go into residential care due to problems caused by a delay in getting the equipment fitted.

### Working with wider partnerships – Dementia Action Alliances

Local Dementia Action Alliances present a powerful way for local councils to work together with local partners in the creation of dementia friendly communities.

**“These local alliances or similar action groups bring together diverse stakeholders including bus companies, taxi firms, police, fire and rescue services, high streets, local authorities, charities, care providers and health trusts, faith groups and schools”**

**(Building Dementia Friendly Communities – Alzheimer's Society 2013).**

One of the main areas of activity for local Dementia Action Alliances has been around the process of building dementia friendly communities.

At the time of writing there were 138 Dementia Action Alliances working on action plans to create dementia friendly communities , and The Prime Minister's Dementia Challenge 2020 sets out a vision that all tiers of local government should become part of a local Dementia Action Alliance by 2020.

Many councils have already been very active in their local DAA's with some taking the lead role. Examples of this can be seen in the case studies throughout this document.

The role of councils in respect of their local DAA will vary according to local conditions. There is considerable scope for:

- Councils to take the lead in creating a local DAA if there is not one in existence. This does not mean that their leadership has to continue once the DAA has been set out but could involve the initial impetus and a small amount of initial input to get things up and running.

In some areas, councils have stepped in to provide leadership and direction if the local DAA appears to be faltering, through either lack of resources or lack of direction or support.

In other areas, councils have joined existing DAAs which already have strong leadership and have played their part accordingly.

Experience suggests there is a strong argument for leadership to come from, or be passed to other partners, not least because of the need to emphasis the role of partners from outside of health and social care in creating dementia friendly communities.

### **What can councils do?**

- set up a local DAA if there is not one in existence or join one if there is
- provide support to the local DAA if it needs it – but be conscious of the value of not taking over. DAAs have an important role in creating a shared and jointly owned vision across all partners
- sign up for the Alzheimer's Society Dementia Friendly Communities recognition process
- 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 the needs of people living with dementia
- support and encourage local businesses, community based and voluntary organisations to ensure that they are enabling people living with dementia to access their services and activities. This will include working with local faith groups, social clubs, sporting and leisure associations – to persuade them of the importance of making their services accessible to people living with dementia and actively promoting activities for them. This might involve minimum seed funding, to enable organisations to address the needs of members who have dementia or people with care for someone with dementia.

## **More reading and resources**

The website of the National Dementia Action Alliance <http://www.dementiaaction.org.uk>

The Alzheimer's Society Dementia Friendly Communities recognition process.  
<http://alzheimers.org.uk/recognitionprocess>

## **About the Author**

**Steve Milton** has worked in social care since 1987 as a researcher, writer, trainer, and service manager. He has worked in the dementia field since 1995. In 1996 he set up the Alzheimer's Society helpline, which he led until 2002. During that time the helpline provided support and information to over 150,000 people.

Steve leads Innovations in Dementia's work on dementia-friendly communities and disability rights.

Steve was awarded fellowship of the Royal Society for Arts in 2014 in recognition of his work on behalf of people with dementia.

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**Local Government Association**

Local Government House  
Smith Square  
London SW1P 3HZ

Telephone 020 7664 3000  
Fax 020 7664 3030  
Email [info@local.gov.uk](mailto:info@local.gov.uk)  
[www.local.gov.uk](http://www.local.gov.uk)

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