

**PAS 1365:2015**

# Code of practice for the recognition of dementia-friendly communities in England



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# Foreword

This PAS was sponsored by Alzheimer's Society, with funding from the Department of Health. Its development was facilitated by BSI Standards and it was published under the licence from The British Standards Institution. It came into effect on 30 June 2015.

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- Life Story network CIC
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- Local Dementia Action Alliance
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- London Fire Brigade
- Mental Health Foundation
- Public Health England
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The PAS process enables a code of practice to be rapidly developed in order to fulfil an immediate need in industry. A PAS can be considered for further development as a British Standard, or constitute part of the UK input into the development of a European or International Standard.

## Use of this document

As a code of practice, this PAS takes the form of guidance and recommendations. It should not be quoted as if it were a specification and particular care should be taken to ensure that claims of compliance are not misleading.

Any user claiming compliance with this PAS is expected to be able to justify any course of action that deviates from its recommendations.

Alzheimer's Society has introduced a recognition process for communities to support those that are working towards becoming dementia-friendly, which sets out seven criteria for communities to follow. Stakeholders across the dementia sector are keen to ensure that communities and organizations treat this recognition process as a continuous improvement pathway for lasting change and on-going sustainability to embed dementia friendliness into society. This PAS is designed to support the development of dementia-friendly communities that are part of Alzheimer's Society's recognition process or other forms of recognition.<sup>1)</sup>

<sup>1)</sup> For more information on the recognition process see [www.alzheimers.org.uk/dfcrecognition](http://www.alzheimers.org.uk/dfcrecognition)

## Presentational conventions

The provisions of this standard are presented in roman (i.e. upright) type. Its recommendations are expressed in sentences in which the principal auxiliary verb is “should”.

*Commentary, explanation and general informative material is presented in italic type, and does not constitute a normative element.*

The word “should” is used to express recommendations of this standard. The word “may” is used in the text to express permissibility, e.g. as an alternative to the primary recommendation of the clause. The word “can” is used to express possibility, e.g. a consequence of an action or an event.

Notes and commentaries are provided throughout the text of this standard. Notes give references and additional information that are important but do not form part of the recommendations. Commentaries give background information.

Spelling conforms to The Shorter Oxford English Dictionary. If a word has more than one spelling, the first spelling in the dictionary is used.<sup>2)</sup>

## Contractual and legal considerations

This publication does not purport to include all the necessary provisions of a contract. Users are responsible for its correct application.

**Compliance with a PAS cannot confer immunity from legal obligations.**



<sup>2)</sup> OXFORD UNIVERSITY PRESS. *Shorter Oxford English Dictionary*. Sixth edition. Oxford: Oxford University Press, 2007.



# 0 Introduction

## 0.1 About this PAS

Dementia-friendly communities are geographic areas where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia-friendly community people are aware of and understand dementia, and people with dementia feel included and involved, and have choice and control over their day-to-day lives. A dementia-friendly community is made up of individuals, businesses, organizations, services, and faith communities that support the needs of people with dementia.

The aim of dementia-friendly communities is to improve the quality of life for people with dementia wherever they live. In local communities, it is evident that small changes are making a real difference, however, these changes within communities are unique to those communities and the process may take a number of years to develop. Alzheimer's Society (AS) has been assigned by government to take the lead in driving the concept of dementia-friendly communities forward. To support this continuous development, Alzheimer's Society developed the foundation stage recognition process<sup>3)</sup> to ensure that communities are able to work towards a common set of criteria in the journey towards becoming dementia-friendly.

The framework set out in this PAS builds directly on the existing foundation stage recognition process for dementia-friendly communities and consideration of other good practices occurring within local initiatives in England. Through discussion with experts, which included people with dementia and carers, this PAS sign-posts users to the core *areas for action* and additional resources so that local communities can continue on their journey towards becoming dementia-friendly. It is expected that all communities considering themselves to be 'working to become dementia friendly' follow the recommendations in this PAS to choose which areas for action to focus on as communities develop. As further evidence becomes available in the future, the process contained within this PAS will also evolve.

### Foundation criteria for dementia friendly communities' recognition process

Alzheimer's Society has developed a national recognition process for dementia-friendly communities. 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:

- 1) ensuring the right local structure is in place to maintain a sustainable dementia-friendly community;
- 2) identifying a person to take responsibility for driving forward the work to support a community to become dementia-friendly;
- 3) having a plan in place to raise awareness about dementia in key organizations and businesses within the community that support people with dementia;
- 4) developing a strong voice for people with dementia living in communities;
- 5) raising the profile of the work to increase reach and awareness to different groups in the community;
- 6) focusing plans on a number of key areas that have been identified locally; and
- 7) 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 which they can give to organizations 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.

In some geographic areas of England, other symbols are used to support and promote dementia awareness. Where these have been chosen as symbols for a particular location, they may sit alongside the 'working to become dementia-friendly' symbol, thereby contributing to overall efforts to create greater dementia awareness and therefore better support and understanding for people with dementia.

<sup>3)</sup> See [www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=2136](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2136) [1].

## 0.2 Policy background

Currently in the UK, an estimated 850,000 people are living with dementia, of which over 40,000 are below 65 years of age. The number of people with dementia is expected to grow to one million by 2025 [1]. In England, the National Dementia Strategy (2009) [2] introduced a plan for addressing the impact of increasing numbers of people with dementia and strategies to improve diagnosis, care and support. The National Dementia Declaration (2010) [3] set out to maintain positive momentum to eliminate stigma by encouraging individuals, organizations and businesses to support seven outcomes that people with dementia would like to see in their lives:

- 1) I have personal choice and control or influence over decisions about me;
- 2) I know that services are designed around me and my needs;
- 3) I have support that helps me live my life;
- 4) I have the knowledge and know-how to get what I need;
- 5) I live in an enabling and supportive environment where I feel valued and understood;
- 6) I have a sense of belonging and of being a valued part of family, community and civic life; and
- 7) I know there is research going on which delivers a better life for me now and hope for the future.

In order to enhance and sustain the efforts of the National Dementia Strategy (2009) [2] and build on the priority of the National Dementia Declaration (2010) [3] which places people with dementia first; the Prime Minister's Challenge on Dementia (2012) [4] established three key areas which included improvements in health and care, creating dementia-friendly communities and better research. Membership of the Dementia Friendly Communities Champion Group includes public, private and voluntary sector organizations. Through the leadership of the Champion Group, ten sector-based task and finish groups were established to take action in individual sectors. Each group has produced an output, often in the form of a charter, to guide other similar organizations on steps they can make to become dementia friendly. <sup>4)</sup> The Prime Minister's Challenge on Dementia 2020 [4a] carries on this commitment with an ambition to see over half of people living in areas that have been recognized as dementia-friendly communities by 2020 and all businesses encouraged and supported to become dementia friendly, with all industry sectors developing Dementia Friendly Charters and working with business leaders to make individual

commitment. <sup>5)</sup> With dementia-friendly communities at the forefront of the policy agenda, people with dementia in England are encouraged to live as independently as possible with choice and control, while eliminating the stigma that surrounds dementia and thereby reducing social isolation. People with dementia report feeling marginalized and stigmatized by others, including losing friends, and not feeling comfortable telling people about their diagnosis [5], [6]. Underpinning dementia-friendly communities is increasing knowledge and awareness which may help alleviate many misunderstandings about dementia by people with dementia themselves and within society as a whole.

Among the most recent evidence supporting dementia-friendly communities is found in Building Dementia-friendly Communities: A priority for everyone (2013) [7]. This report provides information for how well people with dementia are living in their communities, how active they are and what barriers they face. A variety of solutions and examples are provided in the report that also underlie the *areas for action* in this PAS, such as increasing awareness and understanding, improving transport, housing, businesses, and physical environments to support people with dementia. To date, work towards building dementia-friendly communities builds on several other initiatives, policies and legislation such as the Age Friendly Cities (2007) [8], Mental Capacity Act (2005) [9] and the Equality Act (2010) [10].

Age Friendly Cities (2007) [8] taps into the potential that older people represent and creates an environment accessible and inclusive of their needs. It does this by adapting its structures and services to support individuals with varying needs and capabilities [8]. Although dementia is not specifically addressed, the largest risk factor for dementia is age and the prevalence of dementia significantly increases with age [11] therefore, people with dementia are likely to benefit from the Age Friendly Cities initiative [8]. People with dementia are also affected by the Mental Capacity Act (2005) [9]. Under the Mental Capacity Act, a person is presumed to be able to make their own decisions "unless all practical steps to help him (or her) to make a decision have been taken without success" [9].

<sup>4)</sup> [www.alzheimers.org.uk/aboutdfc](http://www.alzheimers.org.uk/aboutdfc)

<sup>5)</sup> See [www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020](http://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020)

Under the Equality Act (2010) [10] most people with dementia would be considered disabled, as the condition progresses over time. The Equality Act (2010) [10] combines several previous discrimination laws into one Act. It includes provisions for age discrimination as well as ensuring that all public bodies, under the Equality Duty (2011) [12], consider all citizens when carrying out their work in shaping policy, in delivering services and in relation to their own employees. The implications of this means that service providers, including businesses, cannot unfairly discriminate against disabled persons in the provision of services. Participation in dementia-friendly initiatives assists businesses, government, voluntary organizations and community citizens to comply with a variety of policies and laws. The collaborative nature of working towards a common purpose for the inclusion of people with dementia benefits everyone and alleviates some stresses of an increasing population of people with dementia and also benefits other people with lifelong disabilities.





# 1 Scope

This PAS provides recommendations for those involved in developing a dementia-friendly community, what areas of a community to consider and what changes to expect as a result. People with dementia and carers are an integral part of each stage of the process.

It covers:

- how to develop a dementia-friendly community by engaging community stakeholders;
- *areas for action* within the community that are meaningful to people with dementia;

**NOTE** Areas for action include, but are not limited to:

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

- opportunities for promotion, information sharing and awareness raising, during the development process, and as major accomplishments are completed;
- what to expect as a result of developing a dementia-friendly community.

**NOTE** *Although the process of becoming a dementia-friendly community continues to evolve over time.*

It is for use by participants engaged in a stakeholder engagement process.

**NOTE 1** *Stakeholders may include representatives from the community, and representatives from small and large shops, businesses and industries, local and regional governments, educational institutions, community services such as fire, police, libraries, museums, and the voluntary and faith sectors.*

It does not cover a specific checklist of what to do.

**NOTE 2** *Each community stakeholder group is encouraged to embark on the development process to determine their own aims and priorities considering the needs from the perspectives of people with dementia living in the target community.*

## 2 Terms and definitions

For the purposes of this PAS, the following terms and definitions apply.

### 2.1 dementia

group of symptoms that indicate a progressive cognitive decline which includes problems with memory, thinking, reasoning, language and judgement

**NOTE** *Typically caused by diseases or conditions such as Alzheimer's disease, vascular dementia, fronto-temporal dementia, Lewy body dementia, primary progressive aphasia or other related types of dementia. It may last an average of 8 years and a person can live up to 20 years, with many of these years with early symptoms of forgetfulness, disorientation, difficulty managing*

*complex tasks like inability to drive, cope with money or missed appointments. As individuals progress, they experience more difficulty with their own daily care needs and require assistance with tasks such as eating, getting dressed and bathing and eventually require full care. However, some people find they can live well with dementia and discover satisfying new interests, relationships and roles throughout the condition.*

### 2.2 person with dementia

individual with dementia who has the right to be treated with dignity and respect and included as an active, participating citizen within a community

**NOTE 1** *Diagnosis rates remain variable; therefore not every person in the community with dementia will have a formal diagnosis and may or may not know they have dementia.*

**NOTE 2** *Engaging with people with dementia requires empathy, understanding, compassion and support.*

### 2.3 carer

person(s) supporting a person with dementia on a day-to-day basis in an unpaid or non-professional capacity

**NOTE 1** *For example, a family member or a close friend.*

**NOTE 2** *Whether the person with dementia lives at home or in a care setting, carers are usually responsible for their well-being when a person with dementia can no longer take care of him or herself. Carers assist people with dementia with their daily tasks and help them to stay included in society. Carers can feel isolated and require support and inclusion just as much as the person with dementia.*

**NOTE 3** *Many organizations also provide paid professional carers who may visit people living with dementia.*

### 2.4 community

geographic boundaries established by each stakeholder group

### 2.5 dementia-friendly community

geographic area where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia-friendly community people are aware of and understand dementia, and people with dementia feel included and involved, and have choice and control over their day-to-day lives

**NOTE** *A dementia-friendly community is a community made up of dementia-friendly individuals, businesses, organizations, services, and faith communities that support the needs of people with dementia.*



## 2.6 inclusion

involving, incorporating and serving people with dementia and carers

**NOTE** Based on the perspective of business, organization, government or individual role, the inclusion of people with dementia may be different. The following are examples:

- the inclusion of people with dementia in a retail shop may include how employees engage with customers that have dementia;
- an industry that develops clothing for people with dementia and makes clothing that is more dementia-friendly with press studs instead of buttons;
- an organization that provides social activities that include people with dementia;
- a bank that makes financial processes easier for a person with dementia to retain control of their finances as long as possible and minimizes confusion with having to remember pass codes and the use of bank machines.

## 2.7 dementia awareness

basic understanding about what dementia is and how to effectively interact with and support a person with dementia

**NOTE** An example of a dementia awareness programme is *Dementia Friends*, a programme run by Alzheimer's Society.<sup>6)</sup>

## 2.8 dementia education and training

formal learning or skills development, which provide a person with the knowledge, skills and value base about dementia, relevant to undertaking their specific job or role

## 2.9 community stakeholders

participants within a community invested and engaged personally or on behalf of an organization or business to carry out the dementia-friendly community implementation plan as determined by the stakeholder engagement process

**NOTE** Stakeholders are users of this PAS (see Clause 1) and include people with dementia, carers, community organizations, businesses, government, and community citizens.

## 2.10 stakeholder engagement process

process of developing a dementia-friendly community, inspiring and connecting activists and champions, setting priorities within a community, promoting and monitoring the success of the community's efforts

**NOTE** An example of a stakeholder engagement process is the *Dementia Action Alliances across England* which is described in Clause 4.

## 2.11 BAME (Black, Asian and Minority Ethnic) population

population from all ethnic groups with the exception of White British

## 2.12 media

means of communication such as community newsletters and publications, newspapers, television, radio and the internet that provide information to the general public

## 2.13 LGBT (Lesbian, Gay, Bisexual, Transgender) population

population described by their sexual orientation or gender identity

## 2.14 planning

participatory process between a community and local government in order to have the needs of community citizens met

**NOTE** This includes the provisions of programmes, services and housing provided by local councils or authorities.

## 2.15 local Dementia Action Alliance

brings together regional and local members to improve the lives of people with dementia in their area

**NOTE 1** They are seen as the local vehicle to develop dementia-friendly communities.

**NOTE 2** A Local Alliance may be established at any level, be it a village, city, county or even a region. They can overlap geographically and member organizations are encouraged to participate in more than one.

<sup>6)</sup> For more information see [www.dementiafriends.org.uk](http://www.dementiafriends.org.uk)

## 3 The building blocks of a dementia-friendly community

### 3.1 The importance of 'people', 'place' and 'process'

People lie at the heart of what it means to be dementia-friendly. Dementia-friendly communities should consider from the viewpoint of someone with dementia how 'people', 'place' and 'process' supports them. On the subject of people, considerations include how to interact, communicate and support people with dementia and also provide support to carers. With regards to place, physical spaces should be easy to navigate and accessible for people with dementia. Attention should be paid to aspects of an environment that may help people with dementia or cause them difficulties. When consideration is made to public and private spaces, people with dementia are able to enjoy a more meaningful and inclusive life. Processes, such as systems, organizations and infrastructures are important to consider as these can help enable or provide barriers to ensuring people and places are successful in supporting people with dementia.

**NOTE** For more information on the importance of people and place as building blocks, see *Creating a Dementia-Friendly York (2012) [13]*.

People, place and process may be different depending on the context, such as a rural compared to an urban community. Considerations include the size and scope of the community. In a rural community, its strengths may include a small network of people and places to coordinate. In an urban community, perhaps there are more resources available, however deciding where to begin and how many stakeholders to engage can become complex. Regardless of the setting between rural and urban, each dementia-friendly community is unique and its aim is to support people with dementia living within its boundaries. Keeping the focus on people with dementia as the primary drivers of where change needs to happen is the key to being a successful community.

#### Plymouth Dementia Action Alliance

Plymouth City Council (P.C.C.) and Plymouth Dementia Action Alliance (P.D.A.A) have been working to make Plymouth a more dementia-friendly place since 2011. By 2015, it is predicted that 3,166 individuals in Plymouth will be living with dementia, rising to 3,667 by 2020. Two-thirds of people with dementia live independently within the community.

The P.D.A.A is an alliance of businesses and organizations from across the city who are working together to improve the experiences of people living with dementia and their carers so ensuring that they are included in all aspects of community life and that their decisions and choices are respected. The P.D.A.A. and P.C.C. have developed a toolkit which includes a range of useful information on training opportunities, details of useful contacts and other resources, and simple ways that all organizations in Plymouth can become more dementia-friendly.

The P.D.A.A's innovative work is mirrored in the range and diversity of the Dementia Friendly City Programme. By linking people with dementia into the development and planning processes within the city of Plymouth, they have influenced the physical, social, health and leisure environment which will have an impact for years to come on the lives of individuals with dementia and their carers. To further support this ethos, Plymouth University and P.C.C. have held a National Dementia conference in the city for the past three years. This conference has now become a diary date in the dementia conference programme in England.

The work of the P.D.A.A. has been successful by using awareness-raising events. By raising awareness and changing the culture of organizations, the P.D.A.A. has created sustainable improvements in the quality of life for people with dementia. These organizations include libraries, schools, the NHS, fire service, solicitors, Dartmoor Search and Rescue, dentists, Plymouth University, Local Authority, domiciliary care agencies, City Bus, First Bus, taxi firms, Plymouth Argyle Football Club, Plymouth Raiders Basket Ball Team, voluntary and private health and social care organizations, GP surgeries, police, housing associations, marine industries, veterans associations and businesses across Plymouth. The P.D.A.A. has created sustainable improvements in the quality of life for people with dementia. The P.D.A.A aims to continue to ensure that all support services are truly accessible to people with dementia. The result of this work is a menu of support to people with dementia covering early intervention, information and advice, low-level support and opportunities to get involved in all aspects of the life in the city.<sup>7)</sup>

<sup>7)</sup> [www.dementiaaction.org.uk/local\\_alliances/1961\\_plymouth\\_dementia\\_action\\_alliance](http://www.dementiaaction.org.uk/local_alliances/1961_plymouth_dementia_action_alliance)



### 3.2 Areas for action

*Areas for action* are the key areas within a community identified by people with dementia to be important. In some *areas for action*, people with dementia need to be included and supported and in other areas, systems and infrastructures may need attention to reduce barriers to access. As members of the stakeholder group, people with dementia can guide local priorities through the stakeholder engagement process as given in Clause 5. There are 8 *areas for action* as described individually (see Clauses 6 to 13). These areas are not exhaustive or all-inclusive and may have overlapping priorities with regards to people with dementia. This is a consolidation of key areas identified in current good practice within England.

The areas are a good place to start or to continue working towards becoming a dementia-friendly community and include:

- arts, culture, leisure and recreation;
- businesses and shops;
- children, young people and students;
- community, voluntary, faith groups and organizations;
- fire and police;
- health and social care;
- housing; and
- transport.

When reviewing the 8 areas, a useful way to think about the actions is through that of 'people', 'place' and 'process' within each area, and the responsibilities of a stakeholder to re-design spaces or create new services, infrastructures, laws, or policies that support clients, customers or employees that have dementia or are caring for someone with dementia. Stakeholders' responsibilities include encouraging increased awareness of dementia in its people and allowing better access to its space by individuals with dementia.

Furthermore, local authorities have a number of key duties under the Localism Act (2011) [14] and the Care Act (2014) [15] to promote the wellbeing of their local communities and have responsibility for services including social care, public health, housing and planning. Local authorities can be actively involved in the development of dementia-friendly communities<sup>8)</sup> and promote the engagement of people with dementia with recreation, leisure and cultural activities. Although local authorities have much responsibility in helping dementia-friendly communities to succeed, they cannot

<sup>8)</sup> For more information see [Developing dementia-friendly communities: Learning and guidance for Local Authorities \(2012\)](#).

do it alone. The stakeholder process encourages collaboration between all sectors within a community.

### 3.3 Recognizing a dementia-friendly community

Aspects of dementia-friendly communities may be visible or invisible, for example, a dementia-friendly fire or police service may have received training and have become prepared to serve people with dementia. However, these types of services are often invisible until a person with dementia uses the service.

In contrast, a dementia-friendly shop or business such as a supermarket may have widened its aisles, provided customer service training on dementia for its employees and included easier to read signage. These elements of dementia friendliness are more visible as a person with dementia is likely to visit a supermarket several times per week.

Communities embarking on the dementia-friendly community process are likely in different stages in the process of becoming dementia-friendly. Each community will choose its own *areas for action* to work on and some of these will be more visible than others. Clause 15.1 outlines the national foundation stage recognition process developed by Alzheimer's Society through consensus with various stakeholders. This recognition process forms the basis of measuring progress until future outcomes are more visible.

### 3.4 Measuring progress

The process of developing, maintaining and sustaining a dementia-friendly community is on-going. From year to year, people with dementia can assist in identifying areas for improvement of the local community. Not all areas can be focused on at one time. This PAS is intended to support a long-term development process. Recognizing and communicating accomplishments is an important task along the journey to becoming dementia-friendly. It is expected that users of this PAS will make progress over time in the 8 *areas for action*, plus other areas that they might identify.

The key determinant for working towards success is to ask the members of the stakeholder group, including people with dementia:

- Are people with dementia in your community understood, respected and supported, and confident they can contribute to community life?
- Do they feel included and involved, and have choice and control over their day-to-day lives?



## 4 Who should be involved

### 4.1 Stakeholders

A stakeholder group should drive the dementia-friendly communities' process.

The stakeholder group should consider two perspectives when working towards becoming a dementia-friendly community:

- a) people with dementia and their carers; and
- b) other key stakeholders, such as individuals, businesses, organizations, services, and faith communities, engaged in the process of becoming dementia-friendly.

**NOTE 1** People living with dementia and carers play three roles:

- a) they are the motivation for the development of a dementia-friendly community;
- b) key stakeholders at the table helping to drive forward the progress; and
- c) end users who help determine whether progress has been made.

**NOTE 2** For more information on previous views of people with dementia, see *Dementia Capable Communities: The views of people with dementia and their supporters. Executive summary and recommendations or full report (2011) [16]* and *Finding out what a dementia-friendly community means to people with dementia and carers: Toolkit for engaging people with dementia and carers (2012) [17]*.

### 4.2 People with dementia and carers

The stakeholder group should include individuals with dementia and carers.

**NOTE** Involving multiple people with dementia and carers can provide a well-rounded discussion of the needs and barriers people face and not reflect only one person's experience. Ensure participation by people with dementia is not tokenistic, but seen as a meaningful contribution by a community's citizens. The perspectives of people with dementia and their carers may differ. Ensuring both people living with dementia and carers are listened to ensures both viewpoints are heard and included.

Considerations should be made for the participation of people with dementia, such as:

- a) time of day for involvement in meetings;
- b) pace of the meetings;

- c) preparation documents available to the person with dementia prior to the meeting to allow the person time to prepare in a format that works for the individual;

- d) transport issues; and

- e) carer involvement, as needed.

**NOTE 1** For more information on how to involve people with dementia in stakeholder engagement, see *Choosing a dementia-friendly meeting space (2013) [18]* and *Collecting the views of people with dementia (2013) [19]*.

**NOTE 2** Involving the carer may enhance the participation of a person with dementia. Some carers assist the person to prepare ahead of time, provide transport, have unique perspectives on the situation and require dementia-friendly communities to support them in their caring role. Ensure the carer's schedule is also valued and appreciated in supporting the person with dementia to participate in the stakeholder group.

People with dementia should be integral to the process of developing a dementia-friendly community as individual insights and experiences provide first-hand experience of the everyday challenges faced.



### Joy (person living with dementia)

My husband and I were passionate about helping our local town to set out on the journey to become a dementia-friendly community. Having spoken to a good number of people with dementia and their carers and families, we realized there were lots of areas that we could look at. The main issue that stood out for many people was that of the small shops in the town centre. So we set out to visit every shop in the town asking them if they would be interested in finding out more. We had a fantastic response. It goes without saying that it is essential to have people living with dementia involved at every stage of the awareness journey, as they are best positioned to be able to identify the needs. We found that a personal approach worked really well. Shop keepers were more likely to come on board if someone had taken the time to explain things and answer their questions. Yes, this is time consuming, but it pays off in the long run because you've built up relationships with the businesses.

We didn't have the literature that is presently available, so we printed our own. We were very careful to produce good quality leaflets as we felt this would enhance our awareness message. We gave the shops time to read the information booklet before going back to enquire if all their staff had been informed. This gave us the opportunity to invite them to join the local Dementia Action Alliance. Larger establishments were given letters outlining the Dementia Action Alliance's position.

This is only a small representation of how we did things. Would we do things differently were we embarking on this again? Yes, we would. We would do more local research. We would offer Dementia Friends' awareness sessions sooner in the process. We would investigate how to engage better with the larger shops. Examples being, the post office, the chemists, the dentists, and the superstores.

We were a bit naive in the early days, and our passion ruled over being practical. **Becoming a dementia-friendly community is a journey, just as living with the disease is.** I'm not sure if we will ever arrive as there will always be follow up visits and new areas to address. But living well with dementia is about enjoying the journey on the days you can.

### 4.3 Other key stakeholders

The stakeholder group should include representatives from the community and from the private, public and voluntary sectors.

*NOTE See Clauses 6 to 13 for recommendations on types of stakeholder entities.*

Each stakeholder should consider the following benefits of their business or organization becoming dementia-friendly:

- a) improving customer, client or citizen relations through increased knowledge about the needs of people with dementia and how to provide products or services that can help improve the experience of living in the community;
- b) providing support for employees with dementia especially:
  - employees who wish to remain in the workforce;
  - employees who need help with a new work role adapted to their abilities;
  - employees who may need assistance stopping work and corresponding with appropriate support and referrals.
- c) providing support to employees who may be caring for a person with dementia through policies and practices such as:
  - flexible working arrangements;
  - support and referrals to organizations that can assist the carer.

*NOTE For more information about issues for employees, see Tips for employers who want to be more dementia-friendly (2013) [20] and Creating a dementia-friendly workplace: A guide for employees (2015) [21].*

- d) providing volunteer opportunities to enable people more flexibility and choice over their participation whilst contributing to meaningful activities.

*NOTE For more information on sample policies, see Supporting employees who are caring for someone with dementia [22].*

## 5 How to develop a dementia-friendly community

### 5.1 Stakeholder process

The process of developing a dementia-friendly community should include conducting stakeholder engagement and setting priorities for how a community can become dementia-friendly.

The following actions should be carried out for successful stakeholder engagement when developing a dementia-friendly community:

- a) create a local structure or stakeholder group;  
***NOTE** Stakeholders are the users of this PAS and include people with dementia, carers, community organizations, businesses, government and community citizens.*
- b) include people with dementia as the primary contributors;  
***NOTE** For more information on how to involve people with dementia in stakeholder engagement, see *Choosing a dementia-friendly meeting space* [18] and *Collecting the views of people with dementia* [19].*
- c) include people with dementia and carers alongside other stakeholders from private, public and voluntary sectors;
- d) identify a chair or rotating chair to keep the group on task and moving forward; and
- e) define aims, objectives and timescales for the stakeholder group based on the feedback of people with dementia.

***NOTE** For further information see *Building dementia-friendly communities: a priority for everyone* (2013) [7]; *Dementia-friendly Yorkshire: First Steps on the Journey* (2014) [23] and *Creating a Local Dementia Action Alliance: a guide to getting started* (2015) [24].*

### Yorkshire and Humber Dementia Action Alliance

From improving signage in public toilets to ensuring that front-line ambulance crew have a greater understanding of the communications difficulties often faced by people with dementia – the Dementia Action Alliance has begun to make Yorkshire & Humber a more dementia-friendly region.

Members from the private, public and voluntary sectors, from emergency services to high street retailers, acute hospitals to taxi operators, have made a significant commitment to change the way they respond to the needs of people with dementia.

Perhaps even more significant is the work undertaken by the regional alliance to encourage and support the development of Local Dementia Action Alliances in cities, towns and districts across the region.

Member organizations have also been responsible for an on-going programme of training. Between 30,000 and 40,000 people have already received comprehensive training to help them enable people with dementia to continue to contribute to family and community life.<sup>9)</sup>

### 5.2 Use of language<sup>9)</sup>

The stakeholder group should use positive language when engaged in discussions about people with dementia both within the stakeholder meetings and externally when promoting a dementia-friendly community.

<sup>9)</sup> [www.dementiaaction.org.uk/local\\_alliances/1639\\_yorkshire\\_humber\\_dementia\\_action\\_alliance](http://www.dementiaaction.org.uk/local_alliances/1639_yorkshire_humber_dementia_action_alliance)

The stakeholder group should use and encourage others to use positive terms which include:

- always using the person's own name when referring to an individual noting preference on use of first or surname;
- a person or people living with dementia;
- a person or people with dementia;
- a person or people affected by dementia;
- as experienced by people with dementia.

The stakeholder group should not use and encourage others, including the media, not to use the following examples:

- the demented;
- victims;
- sufferers;
- the afflicted;
- dementia patients.

People living with dementia should be respected by using language that maintains personhood. <sup>10)</sup>

### 5.3 Geographical boundaries

The stakeholder group should determine its own geographic boundaries and investigate if nearby cities, towns or villages are already working towards the process of becoming dementia-friendly to coordinate possible efforts.

The stakeholder group should identify and include any individual stakeholders who may be part of a larger dementia-friendly business or organization and work with their national partners to involve them locally.

**NOTE** For example, a restaurant, retail or supermarket chain, a national bank or communications provider may be in the process of becoming a dementia-friendly organization. The local affiliates would make good members in the stakeholder group.

### 5.4 Equal opportunity

**NOTE 1** Attention is drawn to the Equality Act (2010) [10] and protected characteristics for stakeholder groups looking to develop a dementia-friendly community.

<sup>10)</sup> For more information on language see <http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>.

The stakeholder group should be formed and encourage inclusion of people with dementia in the community irrespective of the following characteristics:

- age;
- disability;
- race/ethnicity;
- religion or belief;
- sex;
- gender reassignment;
- sexual orientation;
- marriage and civil partnership.

The stakeholder group should recognize health inequalities are also associated with characteristics such as:

- 1) socio-economic status;
- 2) geography;
- 3) seldom heard/vulnerable groups;
- 4) mental health;
- 5) long-term or acute medical conditions.

The stakeholder group should pay particular attention to local diverse populations affected by dementia, such as black, Asian and minority ethnic (BAME); lesbian, gay, bisexual, transgender (LGBT) and other populations that may traditionally be more likely to be excluded from support and service. The stakeholder group should have representation from these populations. The stakeholder group should seek to consider and respond to the specific need of these populations.

When becoming a dementia-friendly community that is inclusive of such populations, the stakeholder group should consider the following factors:

- a) avoid making well-meaning assumptions about any specific cultural, ethnic or identity group;
- b) understand that there may be differences in the stigma, discrimination and language regarding dementia and the care and support of people with dementia;
- c) involve representatives of minority communities in all co-production and monitoring activities of developing a dementia-friendly community;
- d) educate all people within a community, regardless of race, culture, identity or religion about locally available support including health and social care;
- e) promote the use of culturally appropriate awareness materials, assessment tools and information about dementia.

**NOTE 2** For more information on BAME populations, see *Black and minority ethnic communities and dementia: Where are we now? (2013) [25]* and *Dementia Does Not Discriminate the experience of people with dementia from black, Asian and minority ethnic communities (2013) [26]*.

### Connecting Communities Project

The Connecting Communities Project is a three year pilot project, run by Alzheimer's Society, working across 8 London boroughs to raise awareness of dementia for black, Asian and minority ethnic groups (BAME). The original targets included enabling 1,950 people from BAME communities to receive accessible information about dementia; know how to and appreciate the benefits of getting a diagnosis and be able to access local services. Within the first 16 months the programme reached well over 4,000 people showing that there is a clear appetite for people to learn more about this condition and engage with learning more about dementia. The project team works closely with many local leaders from diverse communities to ensure information about dementia, reducing risk and how to get a diagnosis is conveyed in a meaningful way. As the project develops the learning will be shared both to enhance the Alzheimer's Society's approach to dementia and BAME groups as well as externally through a variety of media.<sup>11)</sup>

## 5.5 Environment and design

All aspects of the environment including internal and external spaces, both built and natural, contribute to the physical context of a dementia-friendly community. Well-designed environments have the power to stimulate, refresh, remind and give pleasure to people with dementia and other disabilities. The stakeholder group should identify and build on their local assets and resources that can help people with dementia live a better quality of life.

**NOTE 1** Local assets can include natural resources such as water sources, woods, or moors or built environments such as cathedrals, museums, libraries and parks.

The stakeholder group should pay particular attention to those spaces that contribute to the risk of:

- falls;
- confusion or disorientation;
- getting into difficulties;
- embarrassment;
- any consequential stress responses that arise;
- inhibiting independence.

**NOTE 2** Attention is drawn to the Equality Act 2010 [10].

**NOTE 3** See BS 8300, BS 9266 and BIP 2228.

The stakeholder group should demonstrate understanding of the physical, sensory and neurological challenges experienced by people with dementia, by looking at ways to solve specific problems encountered with the following activities:

- a) travelling from one space or place to another;
- b) finding the way to and around familiar and unfamiliar locations;
- c) participating in every day tasks such as shopping, parking, or posting a letter.

The stakeholder group should ensure that environments are accessible and adaptable for people with physical and sensory needs, as well as being aware of how the sensory environment can affect people with dementia.

Public places and spaces should accommodate people with dementia and their carers.

Public places and spaces should be:

- a) easily accessible and approachable;
- b) navigated easily externally and internally.

Public places and spaces should have:

- 1) wide pathways/corridors and even surfaces without confusing patterns or reflections;
- 2) positive sights, sounds and smells without causing sensory stress or confusion;
- 3) available seating, shade and shelter from the weather;
- 4) available and accessible activities; and
- 5) available and accessible receptions, toilets, restaurants, entertainment spaces, and workplaces.

**NOTE** For more information on designing public places and spaces see *Designing Outdoor Spaces for People with Dementia (2012) [27]*; *Landscape Design for Dementia Care (2013) [28]*; and the *Dementia Green Care Handbook of Therapeutic Design and Practice (2013) [29]*.

<sup>11)</sup> [www.alzheimers.org.uk/connectingcommunities](http://www.alzheimers.org.uk/connectingcommunities)



The stakeholder group should encourage organizations to include people with dementia into their disability access policies.

**NOTE 4** *Good design and understanding from a facilities management perspective can help prevent and reduce challenges for people with dementia and those that support them.*

## Environment and design

### Mina

Mina loves to shop, but her dementia symptoms make her feel overwhelmed in crowded spaces and sometimes she is unable to find her way around a store. One time she got lost while trying to locate the toilet and was unable to remember how to get back to the ladies department.

Possible design improvements may include for example, the widening of aisles, places to sit down and rest, colour coding and easy to read signage that is located at lower eyesight lines and uses images rather than words to make it easier to find the toilets and other departments within a store.

### Joseph

Joseph has dementia and experiences perception issues, as well as confusion about everyday objects, for example, Joseph finds it hard to see a white toilet when it blends into a white wall and a white floor, which means that sometimes Joseph urinates outside of the toilet. Joseph may also use planters as a receptacle for urinating as an alternative to using a toilet.

Possible design improvements may include, for example, using different coloured tiles to differentiate the floor and the wall from the toilet, making sure there is colour contrast between the toilet seat, handrails and sanitary ware, better signage and directions to the toilet.

### Sally

Sally has dementia and sometimes experiences hallucinations. One time, while in hospital, she thought a standing lamp in the corner of her room was a person staring at her and she was frightened. When the nurse came in, the solution was to medicate Sally unnecessarily.

Possible environment improvements may include identifying possible causes for Sally's hallucinations and removing the cause. Do not assume there isn't a reason for it and blame the dementia automatically. Increased medications may cause Sally to experience unwelcome side-effects and reduce her autonomy and dignity.



## 6 Areas for action: Arts, culture, leisure and recreation

### 6.1 Process

The stakeholder group should ensure the identification, development and maintenance of meaningful activities specifically designed for individuals and groups of people with dementia and how other activities can be adapted for the enjoyment of people with dementia.

**NOTE 1** *Activities may be offered in formal or informal ways through private, public, voluntary, civic, or charity organizations, faith communities, schools, libraries, parks, museums, etc.*

These meaningful activities should promote:

- a) people's sense of worth, being a valued member of society, and maintaining their identity;  
**NOTE** *Meaningful activity does not mean a supervisory service where people are contained and looked after.*
- b) inclusion and participation by people with dementia in the general community with and without their carers;
- c) appropriate adaptations for people with dementia regardless of symptom severity;
- d) opportunities for carers to socialize with and without the person with dementia;
- e) education, counseling and support to people with dementia, carers and the general public.

**NOTE 2** *For more information and ideas on offering services and programmes for people with dementia, see the following: Dementia Green Care Handbook of Therapeutic Design and Practice [29]; Developing Support Groups for People with Early Stage Alzheimer's Disease (1995) [30]; A Guide to Setting Up a Memory Café (2011) [31]; The MoMA Alzheimer's Project: Making Art Accessible to People with Dementia - A Guide for Museums [32]; Reawakening the Mind: Arts interventions to re-energise and inspire people in the early stages of dementia and their carers (2013) [33].*

### 6.2 People

Staff working in arts, culture, leisure and recreation services such as leisure centres, libraries, adult education, and contact centres should be aware of the range of services and provide information about what help is available and how to access it.

Staff leading group activities such as museum, gallery, leisure or recreation staff should have specific skills in their delivery area to support people with dementia in enjoying meaningful activities.

Staff leading group activities should be able to adapt activities to the specific and individual needs of people with dementia, as necessary.

**NOTE 1** *People that run social programmes for people with dementia may locate awareness or training through contacting their local dementia or ageing organization.*

**NOTE 2** *Several universities also offer qualifications specific to dementia studies.*

**NOTE 3** *Educational workshops may be helpful to train sports and leisure employees to be more dementia-friendly. Services can be easily adapted and sports clubs such as bowls, tennis, swimming, golf and cricket can be inclusive of people with dementia to help people maintain an active lifestyle.*

### 6.3 Place

Libraries, museums, theatres, music and dance halls may provide opportunities for people with dementia who have either never visited before or lost the confidence to visit them. They offer ideas, support and culture in a local venue. They are typically welcoming places with supportive staff and can incorporate dementia programmes into disability programmes.

Arts, cultural education, peer support groups, art therapy and appreciation, and reminiscence and recreation may be offered.

Venues should, wherever reasonably possible, remove or reduce physical, sensory, or attitudinal barriers so that all aspects of spaces, and activities are as accessible as possible for all visitors.

Physical settings for activities should be consistent with 5.5.

Considerations should be made for adaptations to the space to help aid in the accessibility of meaningful activities.

### The Mede and Seaward House: Respite and holiday care for people with dementia

The Mede and Seaward House is a holiday home for people with dementia and their carers to enjoy time together. Activities such as cognitive stimulation therapy, yoga, gardening and art therapy are delivered to both people with dementia and their carers. The programme is facilitated through volunteers, support staff and partnerships with other providers.

If carers have a holiday with support in place they feel more able to cope with their loved ones at home. The Mede and Seaward House is a unique dementia-friendly business with good feedback and repeat bookings which aims to grow both locally and regionally.<sup>12)</sup>

### House of Memories: A museum initiative

House of Memories was created by National Museums Liverpool in 2012, as dementia awareness training for health, social care and housing providers. The aim was to introduce the care sector to new skills and memory activities that promote the need for compassion, respect and dignity in care – to achieve better health and wellbeing, and support for people living with dementia, their carers and families. To date, the programme has trained more than 4,500 participants in Liverpool, Bury, Salford, Sunderland, Newcastle, Nottingham, Leicester and Birmingham.

The success of the programme encouraged National Museums Liverpool to develop new initiatives including a digital app developed by people living with dementia as a memory resource; an intergenerational programme for children and grandparents; regular drop-in events for older museum visitors; and a free loan service designed to encourage people living with dementia to talk about objects, memorabilia and photographs relating to their past.<sup>13)</sup>

### Sporting Memories

Sporting Memories Network has created city and county-wide partnerships to embed inclusive, accessible, community-based projects that tap into the passion of sport to promote physical and mental wellbeing of people living with dementia. Sporting memories activities take place in care homes, day centres, libraries, museums, sports clubs, sports stadiums and pubs.<sup>14)</sup>

Participants are encouraged to record their sporting histories and their memories can be shared with fans across the UK, helping to trigger more memories in groups across the country.

The network has worked with high profile Premiership, Football League, Rugby and Cricket clubs to stage intergenerational 'memories games' to raise awareness of dementia and to encourage fans living with dementia to continue being engaged with their favourite clubs. Each club's match-day programme has featured information about dementia and Dementia Friends, reaching thousands of ordinary sports fans of all ages, with the games attracting high levels of media coverage.



<sup>12)</sup> [www.themede.org/](http://www.themede.org/)

<sup>13)</sup> [www.liverpoolmuseums.org.uk/learning/projects/house-of-memories](http://www.liverpoolmuseums.org.uk/learning/projects/house-of-memories)

<sup>14)</sup> [www.sportingmemories.org](http://www.sportingmemories.org)

## 7 Businesses and shops

### 7.1 Process

Business and shop owners should consider how working towards becoming dementia-friendly might help improve the reputation and social responsibility of the business, increase and maintain the employee and customer base, and produce cost savings by understanding employee and customer needs.

**NOTE 1** *From an economic perspective the cost of dementia to the UK economy is over £26bn.* <sup>15)</sup>

Business and shop owners should not discriminate against people because of race, ethnicity, religion, gender, sexual orientation or disability. Dementia is a disability that affects a person's cognitive abilities, but not their rights to participate in society.

**NOTE 2** *Attention is drawn the Equality Act (2010) [10] for businesses and shop owners for understanding obligations under this Act.*

### 7.2 People

Business and shop owners should provide appropriate awareness and education to customer-facing staff.

This should include:

- a) information about how dementia affects people;  
**NOTE** *Symptoms include memory loss, communication problems, difficulties with thinking things through and planning, confusion about time or place, sight and vision problems, unusual behaviour or responses or restlessness or disorientation.*
- b) advice on customer service skills including offering understanding and reassurance, communicating clearly and being aware of the environment;
- c) advice on how to help people with dementia with practical support;
- d) tips and suggestions to deal with a difficult situation.

**NOTE 1** *It is not possible to identify people with dementia because of any physical characteristics. A person might look lost or confused or perhaps act inappropriately, such as straightening items on shelves. It is important attention is not drawn to the person's condition, but additional help and assistance is offered,*

*as needed. It is important that dementia-friendly employees show patience, kindness, willingness to help, and being non-judgmental and understanding. This is good customer service practice and may be included in induction training.*

**NOTE 2** *For more information on specific skills, see How to help people with dementia: A guide for customer-facing staff (2014) [34].*

**NOTE 3** *For the banking industry, see Dementia-friendly financial services: A charter for improving the customer experience of people living with dementia when dealing with financial service organisations (2014) [35].*

**NOTE 4** *For the general inclusion of businesses becoming dementia-friendly, see Dementia Action Alliance's Guidance for businesses (2013) [36].*

### 7.3 Place

Physical settings for activities should be consistent with 5.5.

Considerations should be made for adaptations to the space to help aid in the accessibility and independence of people with dementia.

#### BT

BT is a supporter of dementia-friendly communities. Its 74,000 employees have the opportunity to register and become Dementia Friends through Alzheimer's Society.

Inclusive Design is embedded at the forefront of all products, processes and services – actively involving people with disabilities within the development stages (e.g. the nuisance calls' phone that enables vulnerable customers block up to 100% of nuisance calls).

BT sought insight into helping customers with dementia and their carers, and introduced a Power of Attorney (PoA) process making it easier to register a PoA and deal with BT on behalf of someone else.

Through a Carers Network, BT actively supports employees by removing any stigma around caring responsibilities, encouraging employees to tap into a wealth of resource and subject matter expertise available, and, at a practical level, supporting flexible working.

<sup>15)</sup> More information can be found on the economic costs of dementia at [www.cebr.com/reports/the-rising-costs-of-dementia](http://www.cebr.com/reports/the-rising-costs-of-dementia).



## 8 Children, young people and students

### 8.1 Process

To create a 'dementia-friendly generation', schools, colleges, universities and youth groups should be encouraged to include dementia awareness in the classroom, lecture hall or through relevant activities.

Schools and colleges should encourage teachers to include dementia within the curriculum, particularly within Personal, Social, Health, and Economic education (PHSE) and citizenship subject areas.

Developers of dementia-friendly curriculums should consider the following components:

- a) good public health messages around the prevention of dementia, such as good nutrition, exercise and brain health;
- b) information about caring for someone with dementia such as a grandparent, parent or other relative;
- c) meeting a person with dementia to help dispel myths, and promote living a fulfilled life with dementia;
- d) undertake activities with the older generation, such as creating memory boxes, to improve intergenerational relationships and understanding;
- e) an understanding of how young people can be involved in their community and support people with dementia to live well in a community.

**NOTE** *Alzheimer's Society have a number of resources for teachers and can provide support and guidance for anyone wishing to engage young people with dementia.* <sup>16)</sup> See also *Dementia information for children, teenagers and young adults (2015) [37]*.

### 8.2 People

Young people should be encouraged to get involved in supporting people with dementia, through interactions with people with dementia in youth groups, school programmes, volunteering, and intergenerational projects.

### 8.3 Place

Young people should be aware of how the environment affects people with dementia and compensate by having conversations with people with dementia in quiet places with few distractions and minimizing chaotic environments.

#### Primary Schools

##### Bernard Gilpin Primary School

As one of the pioneer schools in the Prime Minister's Challenge on Dementia, Bernard Gilpin Primary School teaches children to learn about the brain, dementia and its effects. People living with dementia have given talks at the school about how they cope with the disease and how the children can support them to live well. Year 5 held a parliamentary style debate about Dementia-Friendly Communities, chaired by the local MP and televised by ITV Tyne Tees. The school has opened "The Living Room – a place to enjoy spending time with others", an accessible area of the school for the community activities which include: Singing for the Brain, dementia café, dance and an intergenerational choir where children and people with dementia sing together. The primary school has more plans for intergenerational learning in other curriculum areas designed to enhance their dementia-friendly community. <sup>17)</sup>

##### Dixons Allerton Academy

A small group of students was initially interested in volunteering at a local care home. Wonderful intergenerational relationships blossomed between the students and residents. Together they worked on art activities and memory place mats. A set of memory place mats were designed and professionally made for *Meri Yaadain* (Asian Dementia support) which has led to the Academy to consider starting a social enterprise to make memory mats available to others.

The students educate the whole school about dementia including the creation of a short film and animations aimed at young people. School houses will begin new programmes such as running a pop-up memory café and inviting the elderly into their school to allow more students to experience special intergenerational relationships. <sup>18)</sup>

<sup>16)</sup> See [www.alzheimers.org.uk/youngpeople](http://www.alzheimers.org.uk/youngpeople)

<sup>17)</sup> [www.bernardgilpin.com](http://www.bernardgilpin.com)

<sup>18)</sup> [www.dixonsaa.com/](http://www.dixonsaa.com/)



## Higher Education

### Stoke Damerel Community College

As a pioneer school for the Prime Minister's Challenge on Dementia, Stoke Damerel Community College took a unique approach to dementia education, placing it across the curriculum into as many subjects as possible, endeavouring to work in partnership with the community and local and national organizations. There has been an emphasis placed on creative processes and outcomes, intergenerational contact and active learning. Subject leaders have been actively engaged in determining the shape of dementia education in their own subjects. The programme has resulted in raising awareness and understanding of dementia among both students and staff, and in engaging students in the curriculum, offering them new experiences and leadership opportunities. The programme has potential for replication and growth such as partnering with local primary schools to develop dementia education for younger students.<sup>19)</sup>

### Salford Institute for Dementia at University of Salford

Salford Institute for Dementia aims to improve the lives of people with dementia through the creation, development and dissemination of knowledge about living well with dementia. This includes enhancing understanding of the role of the built environment, technology and the performing arts by engaging directly with people affected by dementia in the definition of its priorities, design of its projects, dissemination and implementation strategies; working with colleagues across the University towards ensuring that dementia is included in undergraduate and postgraduate degree curricula across the university, as appropriate; and through relationships with partners in the public, private and third sectors.

Engagement with people with dementia is a core feature of the Institute's work, through regular participation in the Institute's meetings and in specific projects. The Institute plays a central role in the Salford Dementia Action Alliance, of which a university Pro Vice Chancellor is the Chair. The Institute leads the university's work to become a dementia-friendly university, including encouraging staff and students to become Dementia Friends and Dementia Friends Champions and ensuring that support is in place for staff and students affected by dementia.<sup>20)</sup>

<sup>19)</sup> [www.sdcc.net/](http://www.sdcc.net/)

<sup>20)</sup> [www.salford.ac.uk/salford-institute-for-dementia](http://www.salford.ac.uk/salford-institute-for-dementia)

## 9 Community, voluntary, faith groups and organizations

### 9.1 Process

Community, voluntary, faith groups and organizations should consider ways of demonstrating:

- putting the person first (and the dementia second), recognizing the personhood, rights and citizenship of people first and foremost;
- recognition of the person's source of identity (e.g. place, culture, history and community);
- the meaningful involvement of people with dementia in the governance, management and key decision-making processes of the organization, where people with other health conditions and disabilities are involved in these activities.

Community, voluntary, faith groups and organizations should consider providing services such as volunteer visitors, drivers, respite, and peer support programmes and dementia cafes for people with dementia and their carers.

**NOTE 1** *The purpose of self-help groups or peer groups is for either people with dementia or carers, or both together, to meet with, share and support one another. Groups exist throughout England. Groups may meet weekly, biweekly or monthly; the important factor being routine and consistency. Groups are typically facilitated by a paid individual who works for a local social care organization.*

*An average number of participants in a self-help or peer group is between 8-15. For groups with people with dementia, sometimes smaller numbers are better so everyone gets a chance to participate. The group's aims can be developed within the group and may focus on advice and support for each other about how to cope with dementia or group action to support greater awareness in the community.*

**NOTE 2** *A dementia café is a community setting where people with dementia and carers can come together socially. It is different than a peer group or self-help group as its primary goal may not be to discuss dementia, but rather to encourage social interaction and provide stimulating activities. Groups meet weekly or monthly in community-based settings such as churches or leisure centres. A social and welcoming atmosphere usually involves coffee and cake and encourages people meeting each other and activities such as arts, singing, reminiscence, and quizzes can keep the group engaged and interacting. The purpose is for people with dementia and carers not*

*to be isolated at home alone and enjoy each other's company.*

*Cafes are run by a number of different sources including Alzheimer's Society, other charities, local health and social care organizations and local councils. Additional staff and volunteers are useful depending on the size of the group. In many groups, both carers and people with dementia take on voluntary roles to greet others, and plan activities. Specialized groups can be created for people with younger onset dementia. More information can be found in *A Guide to Setting Up a Memory Café* (2011) [31].*

Community, voluntary, faith groups and organizations should consider ways in which they can use their influence in communities to support and encourage other organizations to become more dementia-friendly through community forums, inter-faith groups, work with schools, etc.

### 9.2 People

Community, voluntary, and faith organizations should consider raising awareness about dementia among their staff, users, volunteers, congregations and members, with a focus on the active inclusion and participation of people with dementia;

- a) as active citizens and members of their community and the organizations they participate in;
- b) to make decisions as much as possible about their own lives, and to be given the appropriate support wherever necessary to make their own choices.

**NOTE** *Attention is drawn to the Mental Capacity Act (2005) [9].*

### 9.3 Place

Community, voluntary, faith groups and organizations should consider ways that the physical environment of the buildings and facilities that their activities take place in are as accessible as possible for people with dementia (see 5.5).

Community, voluntary and faith organizations should consider having policies and practices that are inclusive of people with dementia and their carers, such as:

- a) reaching out to welcome people with dementia and their carers in all activities;
- b) activities that are sensitive to the needs of people with dementia, such as participation without the over-stimulation of crowds, or other alternative opportunities where appropriate, that allow people with dementia to participate in a quieter environment;
- c) home visits to people with dementia, where appropriate, so activities can be maintained;
- d) the recognition of carer stress so that help and support can be provided;
- e) referrals for supportive services.

## Dementia Cafés

### Sheffield Central Dementia Café

The Sheffield Central Dementia Café, run by Alzheimer's Society, has been running for 9 years. It takes place monthly on Fridays, 10am – 12:30pm, in the upstairs hall of a local church in Sheffield city centre which is accessible by a lift where a number of large tables are set out around the hall. There are generally four members of staff including a dementia support manager along with three dementia support workers, one of whom is responsible for organising the Dementia Café. In addition, there are a number of both regular and casual volunteers. Volunteers are briefed by staff at the start of the session.

The average number of service users attending the Café is 64, with a high of 130 at one point (during Dementia Awareness Week) and a low of 18 because of heavy snow. The Sheffield Central Dementia Café had previously had an even greater number of service users than this but four smaller community cafés were set up in the area demonstrating the need and popularity of these types of programmes.

### Swaffham Dementia Café

The Swaffham Dementia Café takes place monthly on Wednesdays, 10am – 12pm at a location in the town centre. An average of 26 service-users attend the Swaffham Dementia Café, with an average ratio of 12 people with dementia to 14 carers.

Service users sit around one large table that runs the length of the room, on which activities such as quizzes, word searches and reminiscence books are laid out. This layout is based on feedback from service users about activities they would like at the Dementia Café.

The first half an hour is spent welcoming and talking to service users. Staff and volunteers make efforts to help service users get to know each other. A member of staff then gives a talk which includes notices for that week and upcoming activities in the local area. Service users are also encouraged to provide suggestions to staff at any time about how they would like the Dementia Café to be run, before handing over to an external speaker. Activities sometimes take place at the Swaffham Dementia Café, such as gardening or crafts. Staff explained that they would like to run more activities at the Café sessions, such as music or singing, but are constrained by lack of funding.<sup>21)</sup>

### Lost Chord

Lost Chord is an innovative charity that brings music into dementia cafés. Music gives people with dementia a vehicle through which they can continue to communicate. The evidence of the power of music in unlocking memories is striking and undeniable. People with dementia can experience a sense of achievement. Especially with hard to reach individuals, music seems to reach into their very souls unlocking the door behind which a frightened, intimidated and humiliated person hides from the world. Through music, song and dance, carers often find the person they once knew and thought they had lost.<sup>22)</sup>

<sup>21)</sup> These examples were adapted with permission from Dementia Café evaluation report Alzheimer's Society internal report, January 2014.

<sup>22)</sup> [www.lost-chord.org.uk](http://www.lost-chord.org.uk)

## Faith-based Services

### Dementia-Friendly Gurudwaras

The Dementia-Friendly Gurudwaras Project is a local initiative in Bradford spear-headed by Sikh healthcare professionals. The project is focused on establishing the baseline understanding of dementia within the Sikh Community in Bradford through surveys and questionnaires, tackling the stigma and the lack of knowledge about dementia and its implications through the use of tailored workshops, courses, lectures and physical and virtual information portals both in English and Punjabi; modifying the environment at the Gurudwara to make it easier for people with dementia to interact and liaise with other organizations and dementia groups to share ideas and learn from each other while reassessing the impact of the project to guide future interventions.<sup>23)</sup>

### Kendal Parish Church

Kendal Parish Church seeks to promote the inclusion of people with dementia and their carers in all aspects of parish life, for example by encouraging attendance at services by those able to attend and offering a ministry, including Holy Communion, to those now resident in care homes. A number of members of the congregation are Dementia Friends, and one is a Dementia Friends Champion. The Church is active in support of the Kendal Dementia Action Alliance, and is closely involved in discussion of ways in which the Churches in Cumbria more generally may become dementia-friendly.<sup>24)</sup>

## Dementia Support South Lincolnshire

Dementia Support South Lincolnshire, supports around 200 families in south Lincolnshire through one-to-one advice, information, and emotional support from a memory health care worker. Peer support is provided at monthly meetings where members can share experiences or take part in an activity. A monthly pub lunch is facilitated for a group of younger people with dementia.

A fortnightly day club, Square Hole Club, occurs for younger members or those in the early stages of the illness. The name came from a member who was frustrated that day care services were not geared towards younger people. *'I feel like a square peg being forced into round hole'* he said.<sup>25)</sup>



<sup>23)</sup> <http://dementiafriendlygurudwaras.com/>

<sup>24)</sup> [www.kendalparishchurch.co.uk](http://www.kendalparishchurch.co.uk)

<sup>25)</sup> <http://dementiasupportsouthlincs.co.uk/>

## 10 Emergency services

### 10.1 Process

When new customer-related policies and processes are created, consideration should be given to how people with dementia might be affected by those, as part of the equality impact assessment process.

Processes should be in place to support staff who develop dementia and those who care for someone with dementia.

Provisions for routine safety visits by emergency services should be encouraged and may help spot signs of dementia.

Preparation and planning for the safety of people with dementia should be made before disasters such as flooding, major power outages, severe heat or cold or other national disasters.

**NOTE** Attention is also drawn to the Equality Act (2010) [10].

### 10.2 People

Emergency services staff should receive familiarization and training to a level appropriate to their role, in order to ensure:

- a) appropriate communication with people with dementia and their family carer;
- b) understanding of any risks which they may be able to reduce or remove in conjunction with the individual, specific to their area of expertise for example, fire risk.

**NOTE 1** In England, there is an appointed dementia representative in each police force.

**NOTE 2** For more information see the Chief Fire Officers Association Dementia Pledge (2012) [38].<sup>26)</sup>

**NOTE 3** If each of these agencies is not already educated about dementia, they may work with the local Alzheimer's Society or ageing organization to obtain dementia awareness.

Health and social care staff should be trained to recognize that people with dementia may be at risk of fire if they have difficulties with cooking, short term memory, or dexterity (in relation to smoking, lighters for cigarettes or cookers).

Staff should be made aware to contact their emergency services for free advice if they identify such concerns.

### 10.3 Place

Facilities open to the public should be considered for accessibility, which would include how the design might impact upon people with dementia (see 5.5).

#### Lily

Lily was 98 and had been diagnosed with dementia. She needed a high level of care but found it hard to settle in her care placements so had been allowed to return home to the flat she had lived in for 40 years. The decision to allow Lily to live at home was based on an assessment of her care needs but this did not include consideration of fire risk. The care package put in place by Lily's local authority to support her move home was supplemented by a night time carer paid for by her family. Lily had a very unsettled first night back in her home becoming confused and disoriented shortly after her family left in the early evening. She made a number of attempts to leave her flat and tampered with the controls on her cooker which prompted her carer to disconnect it from the power supply. Twelve minutes after Lily's carer left in the morning after her first night at home, the Brigade were called to a fire at Lily's flat.

#### Greater Manchester Fire & Rescue Service (GMFRS): Salford Borough HQ

Salford/Trafford Community Safety Team has devised partnership agreements with AGE UK, Alzheimer's Society, Adult Social Care, City West Housing, Salix Housing and Salford Royal Foundation Trust. By working closely with the above agencies reciprocal training occurs in that each agency is trained in fire safety and fire staff have training on dementia awareness. This ensures that when fire staff visit people with dementia they understand and relate to that person better. All the above agencies refer people with dementia to the fire service for a person-centred home safety check which gives the client and carer bespoke advice on how to reduce their risk of fire, escape routes and the installation of ten year smoke alarms in their properties. There is little doubt this initiative improves the life of people with dementia and certainly reduces their fear of fire.<sup>27)</sup>

<sup>26)</sup> [www.cfoa.org.uk/14241](http://www.cfoa.org.uk/14241)

<sup>27)</sup> [www.manchesterfire.gov.uk/my\\_area/salford.aspx](http://www.manchesterfire.gov.uk/my_area/salford.aspx)



# 11 Health and social care

**NOTE** For more information see, *Dementia-friendly health and social care environments (2015) [39]*. <sup>28)</sup>

## 11.1 Process

Health and social care services should provide quality care and support for people with dementia. This includes:

- a) ensuring timely diagnosis of dementia;  
**NOTE** For more information see, *Benefits of a timely diagnosis: A report for consideration in primary care (2014) [40]*.
- b) signposting people with dementia and their carers to appropriate and available post-diagnosis support, including personalized information to help them understand and manage their condition;
- c) ensuring that care in all settings, whether at home, in care homes or in hospital, is sensitive to the needs of people with dementia, such as the need for support with personal care, nutrition or at mealtimes;
- d) co-ordinated end of life care;
- e) seamless, integrated care with health, social care, supported housing providers, police, fire and rescue, where appropriate;
- f) ensuring overall clinical leadership on dementia.

## 11.2 People

Leaders within health and social care services should ensure the following:

- a) all health and social care staff, including but not limited to, general practitioners and medical specialists, nurses, care workers, qualified professionals and support staff have training in dementia care, with more appropriate further training for staff working directly with people with dementia;

**NOTE 1** The *Common core principles for supporting people with dementia (2011) [41]*, produced jointly by *Skills for Care* and *Skills for Health*, can be used to support workforce development for staff working with people with dementia in any health or social care setting.

**NOTE 2** For example, specialist training may include delirium as 25% of hospital beds are used by patients with dementia; 20% of hospital admissions include delirium as a primary presenting symptom; 20% will

develop delirium after admission; Delirium and dementia are not the same and delirium needs to be recognized and treated by clinicians as a separate and distinct condition. See *Delirium and dementia (2013) [42]*.

- b) all health and social care staff provide support to families and carers of people with dementia;
- c) all health and social care staff liaise with appropriate sectors such as fire and police, supported housing and residential providers and other businesses, voluntary and community-based organizations, where applicable.

## 11.3 Place

Leaders within health and social care services should consider how the physical environment (see 5.5) can be made more dementia-friendly.

**NOTE 1** For more information regarding design in care environments, see the *King's Fund dementia-friendly design documents: Developing Supportive Design for People with Dementia. The Enhancing the Healing Environment (EHE) Programme and accompanying Assessment Tool Bibliography (2009-2012) [43]*; *EHE environmental assessment tools are available as follows:*

- *Is your ward dementia friendly?*
- *Is your hospital dementia friendly?*
- *Is your care home dementia friendly?*
- *Is your health centre dementia friendly?*

See also, *Developing supportive design for people with dementia: Overarching design principles [44]*; and *the Alzheimer's Society Guide to the Dementia Care Environment (2010) [45]*.

**NOTE 2** Attention is drawn to the *NICE Clinical Guidance #42 [46]*; *House of Commons Committee of Public Accounts: Improving Services and Support for People with Dementia, (2008) [47]*. The care of people with dementia in acute hospital settings. Evidence-based practice, innovation, collaboration: a resource pack for staff (2012) [48].

**NOTE 3** Also see the following documents for more information on hospital design: *Enabling Independence - Living well with dementia (2013) [49]*; *The right care: creating dementia-friendly hospitals (2015) [50]* and *The role of lighting in promoting well-being and recovery within healthcare (2010) [51]*.

**NOTE 4** See [www.dementiaaction.org.uk/dkit](http://www.dementiaaction.org.uk/dkit) for an example of how hospital workers can know and understand a person with dementia. Care homes can sign

<sup>28)</sup> [www.gov.uk/government/publications/dementia-friendly-health-and-social-care-environments-hbn-08-02](http://www.gov.uk/government/publications/dementia-friendly-health-and-social-care-environments-hbn-08-02)

up to the Dementia Care and Support Compact [www.dementiaaction.org.uk/dementiacompact](http://www.dementiaaction.org.uk/dementiacompact) and hospitals can sign up to the Dementia-Friendly Hospital Charter.

### Royal Free – My Discharge project

Royal Free London NHS Foundation Trust applied to the Health Foundation for financial support in implementing a specialist discharge service for patients with dementia who are admitted to the Royal Free.

The project offered:

- A bespoke, personalized service working in partnership with patients, carers and the community;
- Signposting patients and carers to national and local services;
- Co-ordination and development of a community based infrastructure to ensure long-term support;
- Flexible follow up and management post discharge to support the transfer of care;
- 1:1 training and support to carers and family on the patients' care needs.

It is developed in partnership with the patient, the carer and the multidisciplinary hospital team in order to improve the quality of discharge planning for patients admitted from their own home.

One hundred patients with dementia were seen in the first 9 months. All came from their own homes and were keen to return home, however faced challenges due to the complexity of their dementia and concerns of family and community services.

The impact of the project can be seen through significant outcomes such as:

- Reduced length of stay by 2.6 days;
- 26% reduction in re-attendances to A&E;
- 85% patients supported to return home directly from hospital;
- 34% of the 100 patients were at risk of permanent placement and were instead supported home;
- 100% of carers acknowledged the effectiveness of the personalized approach;
- Cost saving estimated at £48,708.40. <sup>29)</sup>

<sup>29)</sup> [www.health.org.uk/areas-of-work/programmes/shine-twelve/related-projects/royal-free-london-nhs-foundation-trust](http://www.health.org.uk/areas-of-work/programmes/shine-twelve/related-projects/royal-free-london-nhs-foundation-trust)

### St Catherine's Hospice

St Catherine's Hospice is a charitably-funded organization which is also commissioned by the NHS and provides specialist palliative care and end of life care to people with life limiting conditions in West Sussex and East Surrey. St Catherine's also provides end of life education services. Historically, most people who were referred had a cancerous condition. More recently, people with multiple co-morbidities (which increasingly includes dementia) have also been accessing services. Patients may also be cared for by loved ones who themselves have dementia.

Through experience of caring for these groups, St. Catherine's recognized the need to enhance their knowledge and understanding of dementia at end of life in order to improve the quality of the end of life care. A specialist training course was developed to prepare staff and others to provide end of life care for people with dementia. A 5 day course is available. As well as helping to educate their own staff, St. Catherine's targeted the course at care home staff because national data suggests that 75%+ of people in care homes have dementia and only 8% of people with dementia die at home. This data confirmed that more was needed to ensure that local people with dementia had real choices when considering end of life care.

St. Catherine's also contributes to other initiatives such as Surrey Dementia Local Implementation Group, the development of the West Sussex County Council Dementia Strategy and the development of the Sussex Integrated Dementia Care and End of Life Pathway. Expanding their participation in other initiatives helps to provide people with equality of access to appropriate care throughout an illness including at end of life. <sup>30)</sup>

<sup>30)</sup> [www.stch.org.uk/default.asp](http://www.stch.org.uk/default.asp)

## 12 Housing

### 12.1 Process

Housing can include private owned or rented homes, mainstream social housing (council or housing association managed), specialist or supported housing such as extra care housing and care homes with the overall aim to enable an individual with dementia to have independent, inclusive and non-discriminatory housing. The following housing provisions should be considered:

- a) adaptations, built environment and design (see 5.5);
- b) assistive technologies, including telecare;
- c) access to outdoor spaces (see 5.5);
- d) support of family and paid carers in private homes;
- e) training of all staff in the housing sector appropriate to the settings in which they work and their roles;
- f) maintenance of tenancy if a person with dementia is temporarily admitted to care.



### 12.2 People

Housing provision for people with dementia should recognize that these individuals may need living environments which support their independence and emotional well-being, their community and family ties, and which reduce safety risks.

Housing officers, scheme managers and support workers should support people with dementia and their carers to live well and where appropriate, in coordination with health and social care providers, and police, fire and rescue officers.

### 12.3 Place

Considerations should be made for adaptations and tools that might assist in maintaining independence, emotional well-being, connection to others and safety such as:

- a) assistive devices and technology;  
*NOTE For example, telecare, walking sticks and frames, GPS, oven and hob safety switches.*
- b) spaces that accommodate accessibility and social needs;
- c) ensuring sprinkler, smoke and carbon monoxide alarms are in working order.

**NOTE 1** Local fire and rescue service may be contacted for free advice.

**NOTE 2** For more information see, *Improving the Design of Housing to Assist People with Dementia* (2013) [52]; *Enabling Independence – Living well with dementia* (2013) [49]; *Assistive technology as a means of supporting people with dementia: A Review* (2012) [53] and *Dementia-friendly technology charter* (2014) [54].<sup>31)</sup>

**NOTE 3** See <http://laskara.dlf.org.uk/> for use of technologies to assist daily independence.

**NOTE 4** For more information see, *Making a Start: Dementia – Skilling the General Needs Housing Workforce* (2014) [55], *Dementia: Finding Housing Solutions* [56] and *Housing Call to Action* (2015) [57].

<sup>31)</sup> See [www.alzheimers.org.uk/technologycharter](http://www.alzheimers.org.uk/technologycharter)

### Rose's story: Assistive devices and technology provide help at home <sup>32)</sup>

Rose has dementia and at times her recall is very poor. She recently moved into a new flat in an extra care building in Hull, which she loves. During the day staff are around to support Rose in her new surroundings. But during the night the building is not staffed, which has led to a few issues. Rose has woken up during the night and become disorientated. This has led to her walking down corridors, sometimes knocking on the doors of neighbours, and one time she left the building.

Rose agrees to have a bed sensor and door sensor fitted in her flat. Because she doesn't have any close family members, an arrangement is set up with Hull City Council that it's out of hours care team will respond to any alerts triggered by the sensors.

The sensor on the door sends an alert to the out of hours' team if Rose leaves her flat between 10pm and 7am and doesn't return within five minutes. In addition, within the same hours, if Rose leaves her bed and doesn't return within 15 minutes, an alert is also sent, which may indicate a fall.

So far, the out of hours team has been called out seven times in four months. This has provided reassurance to Rose and prevented her from disturbing other residents or leaving her building at unsocial hours. If this solution had not been implemented, there was a real possibility that Rose would have been placed into 24-hour care.

### Beeches Manor Wokingham: Dementia housing with care

In 2009 Wokingham Borough Council proposed the flagship in their strategy for housing for older people and put out a tender for a dementia housing development. The strategy was a direct response to the government publications: Lifetime Homes, Lifetime Neighbourhoods and a National Strategy for Housing in an Ageing Society<sup>33)</sup>. The latter of which had the objective of creating choice for older people currently restricted to the options of traditional sheltered housing or nursing or residential institutions. This need is further reinforced in 'Living Well with Dementia, a National Dementia Strategy'<sup>34)</sup>, which highlights the need for early intervention. All of the publications have been further emphasised in the coalition government's Dementia Challenge<sup>35)</sup>.

The aim of the project is to deliver a dementia focused housing scheme that will provide both quality and choice for older people. The facilities, care and support services available aims to make the scheme a home for life, with the key objectives and principles being:

- a flagship development of excellent quality, design and build;
- the units are 100% social-rented accommodation and subject to full nomination rights for the Council;
- a scheme that promotes and meets a range of environmental and sustainability issues through the use of innovative design and build solutions;
- able to demonstrate value for money and financial strength;
- able to contribute to the values and objectives set out in Wokingham's Housing Strategy for Older People;
- able to deliver a model that shows effective housing related support including social activities and excellent housing management services.

<sup>33)</sup> Department for Communities and Local Government, Lifetime Homes, Lifetime Neighbourhoods (2008).

<sup>34)</sup> Department of Health, Living Well With Dementia – a National Dementia Strategy (2009).

<sup>35)</sup> Department of Health, Prime Minister's challenge on dementia (2012).

<sup>32)</sup> Taken from [www.alzheimers.org.uk/technologycharter](http://www.alzheimers.org.uk/technologycharter)



# 13 Transport

## 13.1 Process

Subject to regulatory constraints and regions where bus and rail transport is available, interior design of buses and trains and design of bus and rail stops and stations should facilitate ease of access and egress.

Airports should include people with dementia into disability policies and consideration given to all sectors within an airport where knowledge of dementia may be useful such as information desks, security, airlines, baggage claim and retail.

## 13.2 People

Customer-facing employees should be trained to be dementia-friendly.

People with dementia should be encouraged to carry assistance cards, as well as, identification and carer's emergency contact details.

**NOTE 1** Assistance cards are designed to assist people with hidden disabilities to discreetly alert the personnel or officials that the individual may need assistance. This allows staff to assist accordingly using their dementia awareness training.

**NOTE 2** A Safe Journey Card, and the Journey Assistance Cards perform the same function.

## 13.3 Place

Seating and shelter should be provided at major stops and stations.

Where supporting technology is available, there should be appropriate audio-visual announcements of stops.

Signage should be clearly visible and understandable.

Maps and guides should be easy to read and navigate.

**NOTE 1** For more information on issues experienced by people with dementia in accessing transport, see series of videos by Alzheimer's Society that appear on Youtube.<sup>36)</sup>

Alternatives to bus and train transport in all areas; including areas where public transport services do not exist, the following should be considered:

- volunteers as drivers;

**NOTE 1** For example, neighbours, friends, and community volunteers can provide a service to people with dementia who are no longer able to drive on their own.

**NOTE 2** Volunteer driver programmes may be developed and sustained by faith communities or local ageing organizations.

**NOTE 3** Maintaining regular activities and outings helps the person with dementia remain an active part of their community and to maintain their health and wellbeing.

- dementia-friendly taxi services.

**NOTE 1** For example, a dementia-friendly taxi driver may provide extra services such as knocking on the door to remind the person with dementia of their arrival time and assist the person with dementia at their destination with finding the correct address or office rather than dropping them outside.

**NOTE 2** A dementia-friendly taxi company may assign the same drivers to their regular customers with dementia to make the person feel safe and confident that someone knows them and ensures they make it back home safely.

<sup>36)</sup> First UK Bus: [www.youtube.com/watch?v=XFKG503UNGo](http://www.youtube.com/watch?v=XFKG503UNGo); and Travelling when you have dementia: Mary's story [www.youtube.com/watch?v=ua4lqiuD2ss](http://www.youtube.com/watch?v=ua4lqiuD2ss). These videos can also be accessed at Youtube.com and searching for 'Alzheimer's Society transport'.

## Liverpool Dementia Action Alliance (DAA)

Following consultation with local people with dementia and their carers, Liverpool DAA's transport working group brought the transport sector together to explore how it can improve the experience of passengers with dementia. Personalized training is being provided to Virgin Trains to improve the understanding of staff about dementia so that they can respond more appropriately to passengers with dementia who may be lost or confused. Other providers are now taking up the offer of training. Joint work with British Transport Police and the local authority is exploring the idea of a place of safety as a more appropriate response for people who are lost than conveyance to A&E or a police station. Merseytravel, the local passenger transport executive, is considering how to capture emergency contact details for holders of concessionary travel passes and how it might amend its concessionary scheme for people who are eligible for a travel pass but cannot use it without assistance on the journey, to include a travelling companion such as a family carer or friend.<sup>37)</sup>

## First Bus

First Bus is one of Britain's largest bus operators carrying around 2.3 million people every day for school, work and leisure. One aim has been to actively improve how people living with disabilities and health conditions are served, including how to make services more accessible to people with dementia. In partnership with Alzheimer's Society, a 2.5 hour training module was produced for their 13,500 drivers that forms part of the annual Driver Certificate of Professional Competence. The objective is to raise awareness of dementia, so that drivers are equipped to help someone experiencing difficulties while travelling. In addition, a Safe Journey Card is another flexible, low tech solution for people with dementia to privately let drivers know if they need extra assistance.<sup>38)</sup>



<sup>37)</sup> [www.dementiaaction.org.uk/local\\_alliances/3012\\_liverpool\\_dementia\\_action\\_alliance](http://www.dementiaaction.org.uk/local_alliances/3012_liverpool_dementia_action_alliance)

<sup>38)</sup> See [www.firstgroup.com/ukbus/assets/pdfs/Safe\\_Journey\\_Card.pdf](http://www.firstgroup.com/ukbus/assets/pdfs/Safe_Journey_Card.pdf)

# 14 How to promote a dementia-friendly community

## 14.1 Awareness raising and education

Dementia awareness is a basic understanding about what dementia is and how to effectively interact with and support a person with dementia. The stakeholder group should work to increase dementia awareness throughout the community to individuals, groups, organizations and businesses.

**NOTE** An example of a dementia awareness programme is *Dementia Friends*, a programme run by Alzheimer's Society.<sup>39)</sup>

### Dementia Friends: Andy Jones

Andy is aged 55 years and has a diagnosis of young onset dementia. He became a Dementia-Friends Champion in Summer 2013 and has since created 33 Dementia Friends. Andy explained that, as a direct result of becoming a Champion, he and two acquaintances went on to create a Local Dementia Action Alliance (LDAA). The LDAA now has 16 key members and they are involved in a wide range of activities such as delivering Dementia Friends Information Sessions, posting topical dementia research and good news stories on their website, and doing radio interviews. They also encouraged their local NHS Trust to do a dementia-friendliness audit, resulting in the Trust changing their signage and layout. Andy feels that their work to help people living with dementia is having a positive effect.

Andy retired from paid work a year ago and feels that being part of Dementia Friends and the LDAA has given him a real sense of purpose; he is pleased and proud of what he is achieving. Andy says: *"Dementia Friends led me to more interest and passion to do something, the programme is wonderful. It is raising awareness which is great. The idea is based on your networks – it is a word of mouth movement."*

Dementia education and training is formal learning or skills development, which provide a person with the knowledge, skills and value base about dementia, relevant to undertaking their specific job or role. The stakeholder group should encourage dementia education and training within applicable sectors,

especially for workers that have the direct possibility of interaction with people with dementia.

### The Life Story Network project (LSN) – "Your Community Matters"

Building on a one year project with the residential, home care and housing sectors, 'Your Community Matters' has grown into a broader programme of community engagement. This aims to increase the capacity and capability of communities by raising awareness and understanding of dementia and its impact on individuals and giving people practical ways of responding positively. Narrative approaches are used to ensure that care and support adapt to the unique biographies of individuals within trusted relationships; this helps people stay connected within their communities and supports those communities to understand dementia better and be inclusive of people living with dementia. Family carers and people with dementia work alongside LSN staff as co-trainers and as members of the advisory group to shape the project, which operates under the umbrella of the Liverpool Dementia Action Alliance.<sup>40)</sup>

## 14.2 Promotion and sharing information

The stakeholder group should promote the work they are undertaking to become more dementia-friendly.

Promotional activity efforts should include:

- a) awareness-raising and education about dementia;
- b) what to achieve and by when;
- c) developing a relationship with the media to disseminate awareness and education.

The stakeholder group should identify a key person or several key people to be responsible for promoting the work of the local dementia-friendly community.

<sup>39)</sup> For more information, see [www.dementiafriends.org](http://www.dementiafriends.org).

<sup>40)</sup> [www.lifestorynetwork.org.uk](http://www.lifestorynetwork.org.uk)

Promotion should include how the local community process was started, where it is now, where it is headed and how people in the community can recognize that the community is dementia-friendly.



### 14.3 Media

The stakeholder group should discourage the media using negative representations of people with dementia as 'victims' and 'sufferers' and discourage use of fear producing images such as isolated people with dementia primarily in the later stages or at the end of life.

**NOTE 1** *Although occasionally appropriate based on the story line, there are now many positive images and examples of people with dementia from the earliest symptoms through to end of life that are available to help change the stigma of dementia.*

The stakeholder group should encourage the media to represent people with dementia positively interacting and engaging with other people and activities in a number of ways to show the possibilities and abilities of people with dementia.

People with dementia should be included in media events to promote the dementia-friendly community, where appropriate and where they have the desire and ability, and be given any necessary assistance to enable them to make the most of these opportunities and to have a successful experience.

**NOTE 2** *For more information on challenges people with dementia face in public speaking and ethical issues with public speaking, see How to involve people with dementia in speaking roles for your organization [58].*

### BBC Radio Devon working to make Devon, a rural community, more dementia-friendly

In January 2014, BBC Radio Devon announced it would spend the year helping to make Devon more dementia-friendly. It was explained that a "dementia-friendly" place was somewhere people with dementia and their carers feel understood, respected, included, valued and supported. Simply stating this aim on air was significant, it required radio DJ's to explain what the phrase *dementia-friendly* meant, to consider how much understanding, respect and support existed, and to ask what needed to be done to improve the situation.

BBC Radio Devon's efforts were particularly relevant as Devon is one of England's biggest rural counties. Although the geography can be difficult and some local services are limited, radio has the power to transcend these issues and reach into even the most isolated of homes. BBC Radio Devon helped make Devon more dementia-friendly through:

- Broadcasting material that raises awareness about, and reduces the stigma surrounding dementia;
- Making BBC Radio Devon itself more dementia-friendly;
- Investigating ways to make radio output itself, the mechanics of broadcasting, more dementia-friendly.

#### Raising awareness; reducing stigma

The station investigated and challenged individuals' and organizations' attitudes and actions towards those with dementia and their carers, and reflected on things being done locally that may help. The emphasis was on the fact that although they can't 'improve dementia' itself, that individually and collectively the station, its listeners, employers and organizations can dramatically improve people's experiences. Target coverage was across all output, from breakfast shows to mid-morning, lunch and drive, request shows and special documentaries.

#### Making BBC Radio Devon itself more dementia-friendly

The station held a highly successful Dementia Friends' awareness session for staff. Guidance was given to staff who answer calls to on-air programmes, as they sometimes get repeat calls from people who are confused or agitated, and who might be living with dementia. A range of experts were consulted for their views on the appropriate actions regarding programmes and policies. This has also involved exploring the current guidance to all wider BBC staff. <sup>41)</sup>

<sup>41)</sup> [www.bbc.co.uk/programmes/p01vwnqx](http://www.bbc.co.uk/programmes/p01vwnqx)



# 15 Measurement and evaluation

## 15.1 The recognition process

Since each dementia-friendly community is unique, each stakeholder group should consider how it will conduct measurement and evaluation to match its overall aim to be recognized as a dementia-friendly community.

### Recognition process (overview)

If signed up to the Alzheimer's Society Recognition Process, the following should be assessed:

- ensure the right local structure is in place to maintain a sustainable dementia-friendly community;
- identify a person or people (e.g. chair, local leader, key contact) responsible for driving forward the work to support your community to become dementia-friendly and ensure that individuals, organizations, and businesses are meeting their stated commitments;
- establish a plan to raise awareness about dementia in key organizations and businesses within the community that support people with dementia;
- ensure a strong voice of and for people with dementia and carers living in the community;

**NOTE** The stakeholder group has been established and represents individuals, organizations and businesses representative of the community.

**NOTE** Ensure the dementia-friendly community has focused on areas that people with dementia feel is most important.

- raise the profile of your work (e.g. increased reach and awareness to different groups in the community and through different approaches such as leaflets, awareness and education events, radio, and newspaper);
- identify a number of areas for action are being worked towards;
- develop a system to update the progress of your community after six months and one year.

**NOTE** It is suggested to begin with two or three areas for action and work towards adding more.

**NOTE 1** The recognition process has been developed by Alzheimer's Society through a steering group process and provides a good foundation in which to begin measuring progress. Once a community has demonstrated how the criteria is met, it is issued with a symbol which may be given to organizations and businesses in the community that wish to be part of the dementia-friendly communities' initiative and have stated what the actions are towards becoming dementia-friendly. Alzheimer's Society conducts an annual review and renewal process to ensure recognition standards are maintained.

**NOTE 2** In some geographic areas of England, other symbols are used to support and promote dementia awareness. Where these have been chosen as symbols for a particular location, they may sit alongside the 'working to become dementia-friendly' symbol, thereby contributing to overall efforts to create greater dementia awareness and therefore better support and understanding for people affected by dementia.

Local stakeholder groups should be accountable for the distribution and monitoring of a recognition symbol to organizations and businesses.

**NOTE 3** At the present time, recognition symbols are used in England for both awareness-raising by groups and as tools to recognize when an organization is working towards becoming dementia-friendly.

## 15.2 Other ways to measure output

The stakeholder group should develop an action plan and use the action plan to measure its own progress at specific intervals in time.

The stakeholder group should include people living with dementia and carers as an integral part of measuring a dementia-friendly community.

**NOTE** One cannot claim a community is "dementia-friendly" without including, or fully evidencing how attempts have been made to include people living with dementia as a full contributing member of the stakeholder process, both in development and measurement.

The stakeholder group should consider the following outputs when measuring its progress:

- a) How many awareness raising events, or information and education programmes have been completed;
- b) How many organizations within the community are working towards becoming dementia-friendly;
- c) How many of the *areas for action* (see Clauses 6 to 13) are being actively addressed.

### Creative outputs from Redditch

A DEEP (Dementia Engagement and Empowerment Project) peer group in Redditch notes some successes in measuring their progress in providing awareness about their group such as:

- The making of a DVD to demonstrate what peer support for people with dementia looks like and provide education to the greater community;
- Developing a Facebook page to show photographs of their work and their achievements;
- Attending the Redditch Dementia Café to seek ideas from other people living with dementia;
- Taking part in a Leisure & Wellbeing Group for people living with dementia based at a leisure centre in Redditch and encouraging other communities to set up a similar group at their local leisure centre. For example, a similar group, inspired by Redditch was formed in Pershore;
- Undertaking other projects to help people with dementia to access community activities such as a summer project to work with a local garden centre to set up a monthly gardening club for people with dementia.

This single peer group in Redditch can measure their success by their excellent use of social media, involving and sharing with other people with dementia outside their group, and connecting people with dementia to local businesses and organizations that may not have otherwise provided support to people with dementia. <sup>42)</sup>

### 15.3 Dementia-friendly as experienced by people living with dementia

The stakeholder group should consider the National Dementia Declaration 'I' Statements as a tool to measure progress:

- 1) I have personal choice and control or influence over decisions about me;
- 2) I know that services are designed around me and my needs;
- 3) I have support that helps me live my life;
- 4) I have the knowledge and know-how to get what I need;
- 5) I live in an enabling and supportive environment where I feel valued and understood;
- 6) I have a sense of belonging and of being a valued part of family, community and civic life;
- 7) I know there is research going on which delivers a better life for me now and hope for the future.

The stakeholder group should consider mystery shopping as one method of measuring progress and to help organizations and businesses improve their services and environments.

***NOTE** Encouraging the use of secret shopping as a positive tool helps build collaborations and understanding between customers and organizations or businesses. Where applicable, bringing attention to possible statutory regulations that impact people with disabilities is important.*

The stakeholder group should consider conducting walking tours of the community with people with dementia to experience possible barriers first hand.

<sup>42)</sup> [www.dementiaaction.org.uk/local\\_alliances/3141\\_redditch\\_and\\_bromsgrove\\_dementia\\_action\\_alliance](http://www.dementiaaction.org.uk/local_alliances/3141_redditch_and_bromsgrove_dementia_action_alliance)

## Walking the patch

*Adapted with permission from Developing dementia-friendly communities: Learning and guidance for local authorities (2012).*

Walking the patch is an effective way to find out how people with dementia experience their local environment. Ideally, a person with dementia should be taken to their favourite or most frequented places one-on-one to minimize distractions and to offer the full attention of the guide.

**Where to go?** Favourite or most frequented places might include supermarkets, restaurants, pubs, gymnasiums, railway stations, and leisure facilities. A leisurely walk on a high street or park can also be useful to learn how the person with dementia experiences these places.

**When to go?** Visit during less busy periods to help reduce the person with dementia's stress level and ensure the guide can focus on what they person is saying and experiencing.

**How to go?** Keep the activity informal to elicit enjoyable conversation with the person with dementia. Clearly explain the purpose of the activity and collect information such as:

What are you looking at?

How did you choose between this way and that way?

Can you see that notice?

What do you think it means?

Make mental notes of how well they are navigating the environment, the usefulness of navigation aids such as signs, or formal or informal aids, and how are the interactions with those they encounter.

A common example is a person with dementia's experience in the supermarket. There may be anxiety when the person enters the checkout lane. They might worry about not being able to count their money or worry about customers in the lane behind them becoming impatient. Once an experience is collected, it is important for the stakeholder group to consider how to approach the business or organization, what kind of training is needed, and what possible solutions might exist to ease the anxiety of the person with dementia.

## 15.4 Evaluating the bigger picture

The stakeholder group should have the aim of dispelling stigma and myths about dementia.

Although becoming dementia-friendly is an evolving, long-term process, in order to maintain momentum and be recognized as a dementia-friendly community, targets should be set by the stakeholder group.

Targets that should be used to evaluate the bigger picture and to possibly reduce stigma may include:

- a) evaluating the experiences of people with dementia and carers to assess if they feel attitudes from the general public have changed;
- b) evaluating the attitudes of the community to assess whether they feel more positively towards people with dementia;
- c) evaluating how meaningfully people with dementia are involved as:
  - volunteers;
  - committee members;
  - public spokespersons.

**NOTE** Peer-reviewed evidence-based tools do not currently exist to assess and evaluate dementia-friendly communities. Alzheimer's Society conducts a regular survey in England and publishes the results in a report and public opinion surveys are being carried out by local authorities.

## 15.5 Revisiting the definition

The stakeholder group should revisit the definition of what it means to be dementia-friendly (see 2.5) and assess if this aim has been achieved or is on its way to being achieved. Key points included in the definition include:

- Do people with dementia feel more understood, respected and supported, and confident they can contribute to community life;
- Are people aware of and more understanding about dementia;
- Do people with dementia feel more included and involved, and have choice and control over their day-to-day lives.

The stakeholder group should evaluate the following whilst working to become a dementia-friendly community:

- a) what is working;
- b) what is not working;
- c) where are the barriers;
- d) what is being learned that would be helpful in continuing to grow the dementia-friendly community.

<sup>43)</sup> See [www.innovationsindementia.org.uk/DementiaFriendlyCommunities/DementiaFriendlyCommunities\\_engagement.pdf](http://www.innovationsindementia.org.uk/DementiaFriendlyCommunities/DementiaFriendlyCommunities_engagement.pdf)

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