

PAS 1365:2015

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



Leading the fight
against dementia

**Alzheimer's
Society**

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Foreword

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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.¹⁾

¹⁾ For more information on the recognition process see 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.²⁾

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.



²⁾ 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 process³⁾ 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.

³⁾ See www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2136 [1].

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.

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. ⁴⁾ 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. ⁵⁾ 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].

⁴⁾ www.alzheimers.org.uk/aboutdfc

⁵⁾ See 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