Living with dementia

Dementia affects around 850,000 people in the UK. By 2025 this number will have reached one million. As the number of people with dementia increases it’s important that their local communities understand and support their needs. In a dementia-friendly community, individuals, local businesses and organizations work together to improve the quality of life for people with dementia. The creation of dementia-friendly communities is at the forefront of government policy and there is an ambition to see over half of people living in areas that have been recognized as dementia-friendly communities by 2020.

See link to website for Prime Minister’s Challenge on Dementia under Useful Information.

Dementia-friendly communities: the basics

What is PAS 1365?

PAS 1365 is a voluntary code of practice published by BSI that offers guidance for community stakeholder groups that want to create a dementia friendly environment. It was developed by a group of experts, including people with dementia and their carers.

It aims to help people living with dementia to feel included in their local communities, with choice and control over their day-to-day lives. It is not a specific checklist and each community should tailor their aims and priorities to meet local needs.

Dementia-friendly communities: the details

Setting up a stakeholder group

As a first step, the local community could establish a stakeholder group responsible for implementing the PAS. This might include representatives from: local shops and businesses, local authorities, schools, religious groups, fire services, police and libraries. It should always include people with dementia and their carers. They have firsthand experience of the challenges and can ensure that the needs of real people are addressed.

The stakeholder group should:

• Identify a chairperson to keep things moving forward
• Define the physical boundary of the ‘community’ – which villages and towns are included
• Seek to understand the needs of people living with dementia in the community and which services they are using
• Determine aims and objectives that are specific to their area and the people living there

“Increasing understanding, reducing barriers and encouraging independent living.”
Areas for action

PAS 1365 identifies eight ‘areas for action’ that should be considered when developing a plan for a dementia-friendly community. These are:

• 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
• transport

Different communities might focus on different priority areas. Within each of these areas the group should consider how community members with dementia might be supported by three elements - ‘people’, ‘place’ and ‘process’.

PEOPLE

How can people within the community best interact with, and support, people who have dementia?
For example, training for customer-facing employees.

PLACE

Are physical spaces such as shops, offices, museums and streets accessible and easy to navigate for people with dementia?
For example, wider aisles in shops, clear signage in public spaces or special events to encourage people with dementia to participate.

PROCESS

Do local systems, organizations and infrastructures facilitate people and places to be successful in supporting people with dementia?
For example, inclusion of topics in school curriculum, plans to help people with dementia in case of an emergency.

Measuring success

The journey towards a dementia-friendly community is expected to be an evolving process. The stakeholder group should identify ways to measure progress and regularly evaluate what is and isn’t working so that improvements can be made. For example, by seeking feedback from those with dementia, using ‘secret shopping’ to test local services, or accompanying people with dementia on community walking tours to learn about their experiences.

Promoting the scheme

The success of the scheme depends on raising awareness and increasing understanding within the local community. This can be achieved by talking to local people and promoting positive stories in the local media.

Where an organization has been awarded dementia-friendly status - for example by The Alzheimer’s Society’s “Working to become dementia-friendly” scheme - the relevant logo should be displayed to promote recognition.

“Living well with dementia is about enjoying the journey on the days you can.”
Frequently asked questions

Q. What is BSI?
A. BSI is the UK’s National Standards Body. It’s been developing standards for more than 100 years to make products and services safer and better for consumers. Standards set out good practice and guidelines for organizations to follow.

Q. Is it compulsory to comply with the PAS?
A. No, the PAS is a voluntary code of practice. It helps organizations by providing detailed guidance on how to achieve a better living environment for those members of society that are affected by dementia.

Q. If an organization doesn't follow the standard is it breaking the law?
A. No, it’s not a legal requirement to follow the standard. But if an organization claims to comply with the standard, then doesn’t, Trading Standards may be able to take action. Consumers can get in touch with their local Trading Standards via the Citizens Advice Consumer Helpline (see ‘Useful information’). Even if an organization doesn’t claim compliance, in the event of a serious complaint or incident, the standard could be used in a court of law to provide a benchmark of best practice.

Q. Where can I find a copy of PAS 1365?
A. PAS 1365 is available to buy from the BSI website (shop.bsigroup.com). Some libraries and universities can access reference copies of British Standards for you.

Useful information

BSI
For information about standards
0845 086 9001
bsigroup.com
For information about consumer-focused standards
bsigroup.com/consumers

Alzheimer’s Society
A charity aimed at improving the lives of people living with dementia.
Telephone: 020 7423 3500
Helpline: 0300 222 11 22
alzheimers.org.uk

Dementia UK
A charity offering help and support to people affected by dementia. Dementia UK provides Admiral Nurses, mental health professionals that specialise in dementia care.
Admiral Nursing DIRECT helpline: 0845 257 9406
dementiauk.org

Which?
For information about how best to support a relative with dementia, including finance and care options
which.co.uk/elderly-care

Prime Minister’s Challenge on Dementia