

# Building dementia-friendly communities: A priority for everyone

Executive summary



This booklet contains the executive summary of the Alzheimer's Society report **Building dementia-friendly communities: A priority for everyone**.

The full report can be read online at [alzheimers.org.uk/buildingdfcs](http://alzheimers.org.uk/buildingdfcs)

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**Target audiences** Overall, the report aims to provide guidance to areas that are looking to become dementia friendly or to provide extra evidence for those already committed to becoming dementia friendly. It puts the views of people with dementia at the centre of the work, and offers relevant insights to central and local governments, the health and social care sector, wider public services, business and community stakeholders alike.

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**Authors** Geraldine Green, Senior Policy Officer and Louise Lakey, Policy Manager, Alzheimer's Society

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**Contact** Alzheimer's Society's Public Policy team can be contacted on 020 7423 3500 or at [ppa@alzheimers.org.uk](mailto:ppa@alzheimers.org.uk)

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**Web** [alzheimers.org.uk/dementiafriendlycommunities](http://alzheimers.org.uk/dementiafriendlycommunities)

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## Executive summary

### Introduction

Across England, Wales and Northern Ireland close to half a million people with dementia are living in the community and a third of those are living on their own (Alzheimer's Society, 2013c; Miranda-Costillo, 2010). For many, the idea of living well and having a good quality of life is still a distant dream. But change is underway and across communities we are starting to see small changes that are building to make a real difference.

Towns, cities and villages across the country are now seeing what they need to do to become dementia friendly, recognising the need to act and change in order to better support people with dementia. From Preston to Plymouth, Newcastle to Norwich, communities are setting out on a journey to transform the experiences of people with dementia and their carers.

Alzheimer's Society has been at the forefront of the creation of dementia-friendly communities. Working with governments and others, such as fellow members of the Dementia Action Alliance, we are supporting communities who want to become dementia friendly.

In order for dementia-friendly communities to succeed, the views and opinions of people with dementia and their carers must be at the heart of any considerations or decisions. This report provides evidence of dementia-friendly communities from the perspective of people affected by dementia. It explores the barriers that people face in their community, how they would like to be engaged in their local area and the support they need to empower them to do so.

Overall, the report aims to provide guidance to areas that are looking to become dementia friendly and to provide extra evidence for those already committed to becoming dementia friendly.

The report collates new and existing evidence from people with dementia and their carers with examples of projects that are making a difference for people with dementia. It uses this information to develop a definition of a dementia-friendly community and lay out 10 areas of focus for communities working to become dementia friendly.

This report acts as a useful source for those involved in the development of essential frameworks, systems and further guidance on creating dementia-friendly communities. It puts the views of people with dementia at the centre of the work, and offers relevant insights to central and local governments, the health and social care sector, wider public services, business and community stakeholders alike.

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### Key findings and statistics

The report firstly explores new evidence from people with dementia: their experiences of living in their community and the changes that they would like to see in place. Findings summarised below include the results from Alzheimer's Society 'DFCsurvey', to which over 500 people with dementia responded, and the invaluable evidence provided in interviews with people with dementia and their carers. It also includes results from a poll of over 2,200 UK adults conducted by YouGov.

#### **While there are some excellent examples of communities gearing up for dementia, many people with dementia do not feel supported and a part of their local area.**

- Less than half of the respondents to the DFCsurvey think their area is geared up to help them live well with dementia (42%).
- Less than half feel a part of the community (47%). Results become considerably lower the more advanced the person's dementia is.
- People from seldom heard communities expressed complex issues around feeling part of their community. Stigma was particularly highlighted by people with dementia and carers.
- More than half of UK adults surveyed in the YouGov poll feel that the inclusion of people with dementia in the community is fairly bad or very bad (59%).
- Nearly three quarters (73%) of UK adults surveyed in the YouGov poll do not think that society is geared up to deal with dementia.

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

- 35% of people with dementia said that they only go out once a week or less and 10% said once a month or less.
  - 9% of people with dementia said they had had to stop doing all of the things they used to do.
  - People said that they had to give up activities such as getting out of the house (28%), shopping (23%), exercise (22%) and using transport (16%).
  - Shopping was identified as the most common activity that people with dementia do in their local area (79%), followed by socialising (72%), eating out (69%) and leisure activities (55%) such as going to the park, library or cinema.
  - 63% of people with dementia did not want to try new things, and the underlying issues of confidence, worry and fear must be overcome in a dementia-friendly community.
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**People with dementia currently feel that they can't or don't know how to contribute to their local community. There is an overriding sense of low expectations and low self-belief.**

- Two thirds of people with dementia (66%) do not feel they can make a contribution to their community. Despite wanting to do more, people feel restricted by their condition or health and hold low expectations about being able to contribute.
- Some people with dementia feel they can contribute by being personable, such as offering company and good conversation or socialising with others (10%), by volunteering (8%), sharing their skills (6%) or being involved in groups (4%).

**The YouGov poll of UK adults shows that there is significant goodwill in the community to help people with dementia live well and a positive perception of the concept of dementia-friendly communities. Communities can utilise the recognition from the general public about the positive contributions that becoming dementia friendly can bring.**

- Only 3% of UK adults think that people with dementia don't have anything to offer their communities.
- 47% of people think that dementia-friendly areas would be nicer places for everyone to live.
- 33% of people think that shops and local businesses would benefit in areas where people with dementia were supported to be more involved in their local community.
- 74% of UK adults think supporting people with dementia to be part of the community would help to reduce stigma.
- 40% of UK adults said that everyone has a role to play in supporting people with dementia.

**While people with dementia face barriers to engaging with their community, it is possible to make changes that can make their day-to-day lives much better.**

- People face psychological and emotional barriers to being able to do more in their community, alongside physical issues. The most common barriers are:
    - a lack of confidence (69%)
    - being worried about becoming confused (68%)
    - being worried about getting lost (60%)
    - mobility issues (59%) and physical health issues (59%)
    - not wanting to be a burden to others (44%)
    - lack of appropriate transport (33%).
  - The YouGov poll found that UK adults think that the barriers that people with dementia face are due to issues such as stigma or lack of understanding about dementia from the general public (65%), a lack of formal and informal support from others to carry out the activities they want to (57%) and a lack of appropriate activities for people with dementia to do (53%).
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**To help support them to live well in their local area, people with dementia and their carers want a range of support.**

- One third of people (35%) would like more care, support and services to do things in the community, including more opportunities to participate and help to attend activities through a befriender.
- 14% of people wanted better or more transport.
- 10% wanted improved health – related either to their dementia or another condition.
- Many people also mentioned that information should be readily available to help people make decisions about their day-to-day lives and the activities they engage in.

### **What is a dementia-friendly community?**

The report collates the new evidence, existing evidence and examples of work being undertaken to provide a definition of a dementia-friendly community. This definition gives the essence of what a dementia-friendly community is striving for, which is underpinned by 10 key areas of focus.

**A dementia-friendly community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them.**

To achieve this, communities working to become dementia friendly should focus on the following 10 key areas:

#### **1 Involvement of people with dementia**

Shape communities around the needs and aspirations of people living with dementia alongside the views of their carers. Each community will have its own diverse populations and focus must include understanding demographic variation, the needs of people with dementia from seldom heard communities, and the impact of the geography, eg rural versus urban locations.

#### **2 Challenge stigma and build understanding**

Work to break down the stigma of dementia, including in seldom heard communities, and increase awareness and understanding of dementia.

#### **3 Accessible community activities**

Offer organised activities that are specific and appropriate to the needs of people with dementia. Also ensure that existing leisure services and entertainment activities are more inclusive of people with dementia.

#### **4 Acknowledge potential**

Ensure that people with dementia themselves acknowledge the positive contribution they can make to their communities. Build on the goodwill in the general public to make communities dementia friendly.

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**5 Ensure an early diagnosis**

Ensure access to early diagnosis and post-diagnostic support. Have health and social care services that are integrated and delivering person-centred care for people with dementia in all settings.

**6 Practical support to enable engagement in community life**

Deliver a befriending service that includes practical support to ensure people with dementia can engage in community life as well as offering emotional support.

**7 Community-based solutions**

Support people with dementia in whatever care setting they live, from maintaining independence in their own home to inclusive, high-quality care homes. Community-based solutions to housing can prevent people from unnecessarily accessing healthcare and support people to live longer in their own homes.

**8 Consistent and reliable travel options**

Ensure that people with dementia can be confident that transport will be consistent, reliable and responsive and respectful to their needs.

**9 Easy-to-navigate environments**

Ensure that the physical environment is accessible and easy to navigate for people with dementia.

**10 Respectful and responsive businesses and services**

Promote awareness of dementia in all shops, businesses and services so all staff demonstrate understanding and know how to recognise symptoms. Encourage organisations to establish strategies that help people with dementia utilise their business.

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# Dementia-friendly communities





## Making the economic case for dementia-friendly communities

The rationale for creating dementia-friendly communities comes from the voices and experiences of people living with and affected by the condition. It is about ensuring that people with dementia are empowered to live well, and exert choice and control in their lives. Importantly, it recognises the impact that dementia has on relationships and people's confidence to engage in daily tasks and activities. These all have a profound impact on a person's quality of life, affecting not only the individual but also their carers and loved ones. Dementia-friendly communities seek to address this. Improving the wellbeing of every individual with dementia is of paramount importance in this work.

It is also suggested that there is an economic case for creating dementia-friendly communities. When making an economic cost-benefit analysis, quality-of-life indicators are very difficult to quantify and measure. Yet, even in the early stages of developing dementia-friendly communities, there are clear economic benefits to be realised, particularly within health and social care. Supporting people to live independently and safely in their own homes will lead to less time needed in costly residential or hospital care.

A dementia-friendly community should be a place where there is increased awareness that dementia is a disease that touches the lives of many, and so requires community-based solutions. Greater awareness will, in turn, support better diagnosis rates and joined-up working by health and social care providers. A dementia-friendly community will be a place where people with dementia and their carers are given assistance at home earlier, reducing the risk of comorbidities or falls, fractures or urinary tract infections, and helping reduce stress and fatigue in their carers. This will mean that the person with dementia could require fewer hospitalisations and remain in their own home for longer.

To put it into figures, a year living in the community with dementia (excluding the initial memory services assessment) is estimated to cost £24,128. This includes the cost of an integrated health and social care package, together with respite, therapies and medication. A year in residential care costs an average of £35,424. Therefore, for every person who is able to live at home rather than in residential care there is a saving of £11,296 per year or £941 per month. Therefore, if just 5% of admissions to residential care were to be delayed for one year as a result of dementia-friendly communities, there would be a net saving of £55 million per annum across England, Wales and Northern Ireland.

For further details and the methodology behind these costs see sections 1.4.4, Making the case for dementia-friendly communities: the individual health and social care pathway, 6.2, Appropriate care and support, and Appendix A: Economic case (for an infographic).

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**Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.**

If you have any concerns about Alzheimer's disease or any other form of dementia, visit [alzheimers.org.uk](https://www.alzheimers.org.uk) or call the **Alzheimer's Society National Dementia Helpline** on **0300 222 11 22** (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)

**Alzheimer's Society**

Devon House  
58 St Katharine's Way  
London E1W 1LB

T **020 7423 3500**

F **020 7423 3501**

E [info@alzheimers.org.uk](mailto:info@alzheimers.org.uk)  
[alzheimers.org.uk](https://www.alzheimers.org.uk)