

Leading the fight  
against dementia

**Alzheimer's  
Society**

The  
**DEMENTIA  
MANIFESTO**  
— for —  
**LONDON**

**Less than half  
of people with  
dementia feel  
part of their  
community.**





Dementia is the biggest health and social care challenge facing London today. It's the most feared health condition for people over the age of 55<sup>1</sup> – but affects all ages.

There are 70,000 people across London living with dementia, and even more friends and family affected by the condition. Many of these people are not living well. They are isolated and can't access the vital care and support they need and deserve.

This manifesto explains how local authorities can make our communities more dementia-friendly and transform the lives of people with dementia.

Alzheimer's Society is calling on local councils and communities across the city to support the vision of a dementia-friendly London. There are three key ideas running through *The Dementia Manifesto for London*. We want every person with dementia in the city to:

1. Get a timely diagnosis and appropriate post-diagnosis support.
2. Receive the best quality care and support.
3. Feel part of a dementia-friendly community and have choice and control over their own lives.

<sup>1</sup>'Public Awareness of Dementia', Alzheimer's Society 2008.

We know that improving the lives of people with dementia in London requires a tailored response because the city has some unique challenges, including:

- A postcode lottery of dementia care and support. Neighbouring boroughs can have wildly differing services, diagnosis levels and memory clinic waiting times.
- Most of the 25,000 people from black and minority ethnic communities who have dementia in the UK are living in London. This number is likely to rise faster than other groups of people in the future and there tends to be lower awareness of dementia in these communities. People are also far less likely to have a diagnosis or access the support they need.<sup>2</sup>
- Older people in London are more isolated than those from other areas of the UK, despite the city having the densest population in the country.<sup>3</sup>
- People with dementia occupy a quarter of all London's hospital beds<sup>4</sup>. More support is needed for them to maintain their independence in the community.

With action from London boroughs now, everyone with dementia in the future can have better quality of life.



**Kate Moore**  
**Operations Director, Greater London Alzheimer's Society**

<sup>2</sup>'Dementia does not discriminate', Report produced by the All-Party Parliamentary Group on dementia, July 2013.

<sup>3</sup>'Social isolation among older Londoners', Institute of Public Policy Research, October 2011.

<sup>4</sup>'Cost of Care', Alzheimer's Society, 2009.

# Timely diagnosis and better post-diagnosis support

Only 48% of people with dementia in England currently have a diagnosis. Across London boroughs, this figure varies from 33% to 63%. People are getting the diagnosis they need too late. Assessment and diagnosis of dementia soon after someone has experienced symptoms is essential. It means they, and their carers, can access the care and support they need. Working closely with Clinical Commissioning Groups, local authorities can help to provide a more integrated package of care and support.

- Late diagnosis can be due to people delaying seeking help. Getting a diagnosis can also take a long time, even once concerns have been raised with health professionals.
- Many people with dementia, and their carers, say they feel abandoned after a diagnosis, with no ongoing support to help them cope. They can often feel anxious and unsure about the future.

## Our vision

Clinical Commissioning Groups have committed to increasing the number of people diagnosed with dementia to at least 66 % by 2015. To help achieve this aim, care homes and general hospitals, as well as primary care and memory services, need to establish a diagnosis pathway for people with suspected dementia.

Appropriate, comprehensive and person-centered post-diagnosis support will meet the needs of local people, especially those living in the community. Priority must be given to commissioning support services that focus on ensuring people with dementia and their carers can access personally tailored information plus practical and emotional support. Access to peer support services and activities, such as support groups and dementia cafes, should also be provided.

## How local authorities can help:

- Make dementia a health priority and prioritise integrating dementia support with health and social care services.
- Work with professionals and service providers to develop good referral pathways for people with suspected dementia.
- Ensure there is a package of support for people with dementia as soon as they are diagnosed.
- Commit to ensuring that people with a diagnosis and their carers have access to a dementia adviser, a named contact for people with dementia, or equivalent, as well as our post-diagnosis pack, The Dementia Guide.
- Ask GP surgeries, libraries, schools and community centres to display dementia advice material, such as our leaflet Worried About Your Memory, to encourage people to seek help if they suspect someone may have memory problems.
- Work with black and minority ethnic communities to raise awareness of dementia, to increase diagnosis rates and access to services.

‘I always feel better in myself after the Dementia Adviser has left. Because after discussing things with her, her explaining, her help and understanding makes me feel better in myself that day.’

Person living with dementia





‘I would shout it from the rooftops:  
a diagnosis is essential. And you  
need it as soon as possible.’

Wife and carer





# Providing quality care for people affected by dementia

People with dementia deserve the best quality of care possible. Yet they tell us that it's difficult to get the support they need to remain independent. Their carers are often left to struggle alone. Lack of support at home means people with dementia are often admitted to hospital in an emergency. They stay there longer than necessary or go into a care home much earlier. Local authorities can help people with dementia to live well by providing quality and integrated health and care services.

- Nearly 70 % of people with dementia feel lonely and trapped in their own homes, with limited or no social networks, and are unable to live well.
- Less than half (42 %) of people with dementia think their community has the services they need to help them live well with dementia.

## Our vision

We believe everyone with dementia should have access to a range of high quality services that address their individual needs. In having some choice over what support they get, people with dementia can achieve their own goals.

Care must be provided by staff who have had relevant training in dementia and are sufficiently rewarded and supported. This reflects the high level of skills required to support people with dementia to maximise their quality of life.

It's important that carers have access to support, such as short breaks. Such services help them maintain their own health and wellbeing, which is so vital when they are caring for someone with dementia.

## How local authorities can help:

- Ensure information is accessible to all residents affected by dementia so they can make informed decisions about care.
- Increase specific training for staff working with people with dementia and ensure they have access to appropriate support.
- Work with local hospitals to deliver home from hospital services for people with dementia and reduce the chances of them being unnecessarily readmitted.
- Ensure people with dementia, and their carers, are involved in both designing and commissioning dementia health and social care services.
- Develop more integrated and high quality health and social care for people with dementia, using money from the £3.8 billion Better Care Fund.

‘Alzheimer’s Society Dementia Cafés and Singing for the Brain sessions have been such a big help to us. Meeting other carers where everyone was in the same boat meant that you could talk freely and people understood.’

David Thomas McGrail, husband and carer

# Building a dementia-friendly London

**Around three quarters of people think that communities and society as a whole are not geared up to deal with dementia.<sup>5</sup> For many of those living with dementia, having a good quality of life is a distant dream. Support with everyday things like shopping or participating in their community is not available. Local authorities can help to build dementia-friendly communities which will ensure people with dementia live well. Together we can create the world's first dementia-friendly capital city.**

- Two thirds of people with dementia live in their own homes in the community.
- A third of people with dementia live on their own.
- Less than half of people with dementia feel part of their community.

## Our vision

In dementia-friendly communities people living with the condition have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them.

These communities are aware of dementia. They are also supportive of people living with the condition and their carers. The result is a community that is more inclusive, improves the ability of people with dementia to remain independent, and gives them more choice and control over their own lives.

<sup>5</sup>'Building dementia-friendly communities: A priority for everyone', Alzheimer's Society, August 2013.

## How local authorities can help:

- Increase awareness and understanding of dementia by making our Dementia Friends sessions available to staff and the wider community. Dementia Friends might help someone find the right bus or spread the word about dementia on social media.
- Appoint a dementia lead to ensure the needs of people with dementia are taken into account throughout their borough.
- Commit to becoming dementia-friendly by helping to establish a local dementia action alliance in their borough. The alliance brings together organisations, from bus companies to care providers, to improve the lives of people with dementia in the local area.
- Play an active part in the pan-London Dementia Action Alliance – an initiative that asks members to come up with three actions they will take to make life better for people with dementia.
- Offer specific and appropriate activities, including existing leisure and entertainment choices to meet the needs of people with dementia.
- Work with Transport for London, and others, to ensure transport is consistent, reliable, responsive and respectful to the needs of people with dementia.

‘My wife Yvonne gives me a list of what I need to get or do that day. I take it to the newsagent or the bank and they tick things off for me when they’re done.’

Derek, a person living with dementia in Havering

**Meeting London's  
dementia challenge  
isn't just for national  
government and the  
NHS – it is local action  
that will make the  
biggest change.**





In London boroughs, the number of people living with dementia who have a diagnosis varies from 33 % to 63 % .

To find out more about Alzheimer's disease or any other form of dementia, visit [alzheimers.org.uk](http://alzheimers.org.uk) or call the Alzheimer's Society National Dementia Helpline on 0300 222 1122.

For questions about this manifesto and the recommendations inside, please email [ChangeLondon@alzheimers.org.uk](mailto:ChangeLondon@alzheimers.org.uk) or call **020 7423 1033**.

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