

Leading the fight
against dementia

**Alzheimer's
Society**

A guide for councillors:

Transforming the quality of life for people
with dementia in the community



**Changing the lives of people with dementia:
a priority for everyone**

Dementia is the biggest health and social care challenge facing England today



There are over 685,000 people living with dementia across England, many of whom are not living well and can't access the vital care and support they need.

The average cost of a year's dementia care is £32,250 per patient, and it is estimated that dementia costs the English economy £22.1 billion annually. There is no doubt as to the tough challenge this poses. Whilst the population ages and demand for social care grows, we know that local authorities have reduced expenditure on adult social care by £4.6 billion since 2010.

With two-thirds of people living with the condition doing so in the local community, it is local authorities who hold the key to helping people with dementia live well in their community.

That is why Alzheimer's Society is calling on all local councils and communities across the country to support our vision to improve the lives of people affected by dementia and work towards building dementia friendly communities by 2020.

By prioritising the needs of people with dementia, not only can local authorities meet the needs of a significant proportion of its older population, but also provide services that respond to those with other long-term conditions.

Local councils can make a difference by:

- Ensuring dementia is a key feature in integrated health and social care plans, a priority within the Better Care Fund and Health and Wellbeing Board
- Delivering on the Care Act to ensure availability of the right support for people with dementia and their carers
- Proactively informing the population how to reduce their risk of developing dementia

With leadership from councils now, everyone with dementia in the future can have a better quality of life. Working together we can improve the lives of people affected by dementia and work towards making your community dementia friendly by 2020.

A handwritten signature in black ink that reads "Jeremy Hughes". The signature is written in a cursive, slightly slanted style.

Jeremy Hughes, CBE
Chief Executive, Alzheimer's Society

Dementia in the UK: key statistics

Estimated number of people living with dementia in UK:

850,000

£10.3 bn

is spent on social care costs (publicly and privately funded)

Estimated number of people under-65 living with dementia in the UK:

42,000

£11.6 bn

is contributed by the work of unpaid carers of people with dementia

The societal cost of dementia in the UK is estimated at an average cost per person of:

£32,250

Average dementia diagnosis rate in the UK (March 2015):

66.5%

Two thirds

of people with dementia live in the community

£4.3 bn

is spent on healthcare costs

The total cost of dementia in the UK is estimated at

£26.3 billion

per year (2012/13 prices)

Raising awareness and building dementia-friendly communities

- 1 in 10 people with dementia reported that they only left the house once a month (DFC August 2013)
- Nearly 70% of people with dementia feel lonely and trapped in their own homes, with limited or no social networks
- Less than half of people with dementia think their community has the services they need to help them live well with dementia

Around three quarters of people think that communities and society as a whole are not geared up to deal with dementia¹. For many of those living with dementia, having a good quality of life is a distant dream, with support for everyday things like shopping or participating in community unavailable.

But local authorities can really help to build dementia friendly communities.

Alzheimer’s Society Dementia Friendly Communities Programme focuses on improving inclusion and quality of life for people with dementia, with many areas across the country already taking action to become dementia friendly by setting up local forums or Dementia Action Alliances. These are made up of public, private and voluntary sector organisations who are taking action to become more dementia friendly.

Our Dementia Friends initiative continues to raise awareness of dementia and is leading the change in communities to become more dementia friendly. Working with local government, this programme is the biggest ever initiative to change people’s perceptions of dementia. It aims to transform the way the nation thinks, talks and acts about the condition.

What local authorities can do?

- Put forward a council motion to become a dementia friendly local authority.
- Help establish (or join) a local dementia forum or action alliance and play a leadership role in its development.
- Appoint a dementia lead within the council to ensure the needs of people with dementia are taken into account and lead the work around Dementia Friendly Communities.
- Through Alzheimer’s Society, offer regular Dementia Friends sessions to councillors, council staff and the wider community.
- Commit to council buildings becoming dementia-friendly.
- Work with transport providers to ensure transport is responsive and respectful to the needs of people with dementia.
- Work with local business and other organisations to enable them to play their part, a little understanding about dementia and its effects is the only way to create dementia friendly communities.
- Create a dementia friendly generation by rolling out dementia awareness resources for schools.

¹ Alzheimer’s Society. (2013). Building dementia-friendly communities: A priority for everyone



Public health and prevention: reducing the risk of dementia

- Dementia is the biggest health concern of the over 55s
- 64% of people don't know that regular exercise and physical activity could reduce the risk of developing dementia

Dementia represents a major public health challenge. It is anticipated that there will be over one million people with dementia in the UK by 2021 and over two million by 2051 if no action is taken and current trends continue.

At present there is no cure and limited effective treatments for dementia. However, a healthy diet, regular physical exercise, managing conditions like type 2 diabetes and high blood pressure and avoiding smoking and excessive drinking can reduce the risk of developing Alzheimer's disease and vascular dementia (UK Health Forum, 2014).

A clear message of 'What's good for your heart is good for your head' is needed throughout preventative public health interventions and campaigns to improve public understanding of how people can reduce their risk of developing dementia.

What local authorities can do?

- Run local awareness raising campaigns focusing on risk reduction. In addition any campaigns on physical exercise, alcohol, smoking or diet should include a clear message of 'What's good for your heart is good for your head'.
- Public health teams and other health partners to prioritise dementia as a public health challenge and plan activity accordingly.
- Make sure that Health and Wellbeing Boards include a plan for dementia in their health and wellbeing strategies.
- Support Alzheimer's Society's annual Dementia Awareness Week.

Getting the right support: delivering integrated, person-centred dementia care

- The cost of dementia in the UK is estimated at **£26.3 billion per year (2012/13 prices)**
- The average cost of dementia per person per year is **£32,250**
- **70% of people with dementia have a co-morbidity**

Nearly everyone living with dementia will require care and support from both the NHS and social care system as a result of dementia's combination of features of chronic neurological disease, mental illness and physical frailty that cross the boundaries of the health and social care system.

In recent years the diagnosis of people with dementia has doubled. This means more people are wanting to access information, advice and support to maintain independence and make more informed choices about their future life.

People with dementia have to navigate a complex web of services from multiple providers and in different care settings, without appropriate co-ordination or a holistic perspective. We know, just in health and social care, that people with dementia have to access around twenty different local bodies and agencies just to get the vital care they need.

Inaccessible services lead to worse outcomes for people with dementia and significant costs to the taxpayer.

Integrated health and social care: the opportunity for change

The current financial pressures and the increasing demand on adult social care are putting local authorities under a lot of strain, so the need for change is greater than ever. The commitment to deliver local integrated health and social care plans, alongside new models of care vanguards and the Better Care Fund open up a real opportunity to transform the experience of health and care for people with dementia.

It's essential that an integrated health social care pathway is in place to support people to live well with dementia. Without a diagnosis and the right support in the community, people with dementia often enter the health service at point of crisis, e.g. they end up in hospital following a fall, or are forced to enter a care home early.



What local authorities can do?

- Ensure that dementia features in the local integrated health and social care plan.
- Prioritise dementia in Better Care Fund plans and ensure that there is a focus on preventative care (community support), person centred care and joining up non-clinical care.
- Make information about local dementia services more accessible by embedding the free Dementia Connect database on the local authority website.
- Highlight dementia care as a key criteria for the success of local new models of care for older people.
- Work with the CCG to address variations in dementia diagnosis rates and post-diagnosis support across your area, including how to reach seldom heard groups.
- Ensure people with dementia, and their carers, are involved in both designing and commissioning integrated dementia health and social care services.

Alzheimer's Society estimates there are

289,000

people living with dementia undiagnosed in the UK

Dementia is the **biggest** health concern of the over 55s

To discuss what action you can take, please email stakeholderrelationsteam@alzheimers.org.uk and we will work with you to deliver the change people with dementia and their carers need.

You can also:

- Take forward a council motion to make your local authority dementia friendly
- Become a Dementia Friend
- Visit one of our local services and meet people affected by dementia in your area
- Help us to raise awareness of dementia on social media, don't forget to mention @alzheimerssoc



Useful links and websites of interest

www.alzheimers.org.uk/dementiafriendlycommunities

Free resources and guides about making communities more dementia friendly.

www.alzheimers.org.uk/dementiaconnect

Free online services directory for anyone affected by dementia in England, Wales and Northern Ireland. It can be embedded on other websites.

www.dementiaaction.org.uk

Information about Dementia Action Alliances.

www.dementiafriends.org.uk

Information about dementia awareness sessions.

www.dementiavoices.org.uk

The Dementia Engagement and Empowerment Project, resources about involving and consulting people with dementia.

www.dementiaaction.org.uk/dementiafriendlyschools

Dementia friendly school resources.

www.alzheimers.org.uk/training

Alzheimer's Society offers training and consultancy services.

Alzheimer's Society's Stakeholder Relations team can also provide resources and further information on how to take forward any of the actions suggested in this leaflet.

Please contact us at stakeholderrelationsteam@alzheimers.org.uk

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About Alzheimer's Society

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 3,000 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.

For more information about dementia and the support available, visit alzheimers.org.uk or call our National Dementia Helpline on **0300 222 1122**.

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