

# Policy Position Paper

## Living well with dementia (England)

March 2016

**Every person with dementia should be supported to live well and to continue participating in society. They and their carers should have access to good-quality care and support from diagnosis to the end of life, wherever they live and whatever their background.**

### Key issues

In 2014, around 850,000 people in the UK were estimated to have dementia (both diagnosed and undiagnosed), and some 670,000 people acted as primary carers for people with dementia<sup>1</sup>. These figures are likely to increase significantly as the UK's population ages, with the total number of people with dementia predicted to exceed 1 million by 2021<sup>2</sup>. Alzheimer's disease and other forms of dementia were the third leading cause of death in the UK in 2013<sup>3</sup>.

Despite a growing focus on improving dementia care and support, there are still important challenges facing people living with the condition and their carers, relating to the ability of health and care services to respond to their needs, and our society's capacity to enable people to live well with their condition in the community. In the absence of a treatment or cure, action to reduce people's risk of developing dementia, postpone its onset and/or mitigate its impact is also seen as vital.

While progress has been made in identifying more people with the condition – from 33 per cent of the estimated number of people living with the condition in England in 2009 to around 67 per cent in January 2016<sup>4,5</sup> – there remain wide variations in **diagnosis** rates<sup>6</sup>, as well as problems with misdiagnosis<sup>7</sup>. Too often, for those

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<sup>1</sup> Deloitte UK Centre for Health Solutions and Alzheimer's Society, *Dementia today and tomorrow - A new deal for people with dementia and their carers*, February 2015

<sup>2</sup> All-Party Parliamentary Group on Dementia, *The £20 billion question*, July 2011

<sup>3</sup> GBD 2013 Mortality and Causes of Death Collaborators, Global, regional, and national age–sex specific all-cause and cause-specific mortality for 240 causes of death, 1990–2013: a systematic analysis for the Global Burden of Disease Study 2013, *The Lancet*, 2015; 385: 117–71

<sup>4</sup> Deloitte UK Centre for Health Solutions and Alzheimer's Society, *Dementia today and tomorrow - A new deal for people with dementia and their carers*, February 2015

<sup>5</sup> Department of Health, *Prime Minister's Challenge on Dementia 2020 Implementation Plan*, March 2016

<sup>6</sup> Public Health England, *Dementia Profile – Diagnosing Well*, March 2016. Available at: <http://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia>

<sup>7</sup> Department of Health, *Dementia – A state of the nation report on dementia care and support in England*, 2013

diagnosed, access to emotional, practical and information support remains patchy<sup>8</sup>. Unlike Scotland<sup>9</sup>, there are no mandatory standards of **post-diagnosis support** in England. However, the Government published a Joint Declaration on Post-

Diagnosis Support in March 2016, committing themselves to working with partners to improve access to support following diagnosis<sup>10</sup>.

People living with dementia may receive care in a variety of settings as their condition progresses, but standards are inconsistent<sup>11</sup>. In **hospitals**, the extent to which wards have become dementia-friendly varies, and there are still negative consequences for people with dementia when they are admitted into acute care<sup>12,13</sup>. While many **care homes** offer excellent support, some are not doing enough to follow national guidelines and help people with dementia live well<sup>14</sup>. Finally, people with dementia are less likely to have advance care directives in place and have less access to, and receive poorer quality, **end of life care** than people with other conditions<sup>15</sup>.

At the moment, two thirds of people with dementia live in the **community**, one third of whom live on their own<sup>16</sup>. With the right support and services, people with dementia can lead fulfilling lives independently in their own homes. Essential to this is good access to everyday services such as banking, shops or transport for people with dementia and cognitive impairment and their carers. However, too often those services do not meet their needs<sup>17,18</sup>, and there are still examples of prejudice against dementia where people feel patronised or discriminated against<sup>19</sup>.

Finally, people's ability to remain independent often relies on support from a relative. Yet caring for someone with dementia can be distressing, and there is an urgent need for better help for carers, including emotional support and respite breaks<sup>20</sup>.

## Public policy proposals

- More communities should work to become dementia-friendly so that more people understand dementia, and those living with the condition can participate in society, access essential public and private services, and continue to work if they wish. The Government should take steps to share evidence of good practice impact assessments in this area.

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<sup>8</sup> All-Party Parliamentary Group on Dementia, *Building on the National Dementia Strategy: Change, progress and priorities*, 2014

<sup>9</sup> The Scottish Government, *Scotland's National Dementia Strategy 2013-16*, 2013

<sup>10</sup> Department of Health, *Joint Declaration on Post-Diagnostic Dementia Care and Support*, March 2016

<sup>11</sup> Alzheimer's Society, *Dementia 2014, Opportunity for Change*, 2014

<sup>12</sup> Care Quality Commission, *Cracks in the Pathway*, October 2014

<sup>13</sup> Alzheimer's Society, *Fix Dementia Care*, January 2016

<sup>14</sup> Care Quality Commission, *Cracks in the Pathway*, October 2014

<sup>15</sup> Marie Curie Cancer Care and Alzheimer's Society, *Living and dying with dementia in England: Barriers to care*, December 2014

<sup>16</sup> Department of Health, *Dementia – A state of the nation report on dementia care and support in England* 2013

<sup>17</sup> Alzheimer's Society, *Short Changed - Protecting people with dementia from financial abuse*, December 2011

<sup>18</sup> House of Commons Hansard, Transport Committee – Evidence from Alzheimer's Society, DAT16, January 2013.

Available at: <http://www.publications.parliament.uk/pa/cm201314/cmselect/cmtran/116/116we07.htm>

<sup>19</sup> House of Lords Select Committee on the Mental Capacity Act 2005, *Mental Capacity Act 2005: post-legislative scrutiny*, March 2014

<sup>20</sup> Carers' Trust, *A road less rocky: supporting carers of people with dementia*, 2013

- Public and private services should take steps to become dementia-friendly, including tackling discriminatory practices and stigma in the language they use around dementia, signing up to the 'Dementia Words Matter' Call to Action<sup>21</sup>. Banks and police services should ensure their systems and staff are better able to help people with dementia and their carers, and to prevent abuse.
- Public Health England and all local authorities should develop health promotion programmes to encourage people to recognise the risk factors and take action to delay and reduce the risk of cognitive decline and dementia.
- Health professionals should give advice on healthy living and brain health promotion activities, and refer people to support regardless of age.
- Health professionals should take full account of the whole of a person's physical health, mental health, social and environmental circumstances in order to ensure that people are supported when receiving a dementia diagnosis.
- Health professionals should offer practical and emotional support to people with dementia and their families whenever a diagnosis of dementia is made, including signposting to non-medical services which can support wellbeing and assist with planning around life choices, financial and legal matters.
- The Government should urgently establish, in partnership with voluntary sector organisations, a minimum standard of good-quality post-diagnosis support for people with dementia and their carers. This should complement the monitoring of levels of access to post-diagnosis support through the NHS Outcomes Framework, as is currently planned (indicator 2.6 ii)<sup>22</sup>.
- Clinical Commissioning Groups (CCGs) and local authorities should continue their efforts to better join up and integrate health and social care services, recognising the positive contribution of the voluntary sector. When commissioning services, they should acknowledge the role that mainstream services can play in the lives of people with dementia and their carers.
- Pre-registration training and revalidation of all health and social care professionals should include sufficient time devoted to the needs of people living with dementia, frailty and multiple long-term conditions. Levels of training should be regularly monitored, including through Care Quality Commission's inspections, and checked against Health Education England's Dementia Core Skills Education and Training Framework.
- Health and care professionals should take steps to enable people with dementia and their carers to exert control over their care and their lives throughout all stages of the condition, including advance care planning as soon as possible.
- Local authorities should measure their progress in implementing their duty under the Care Act 2014 to promote wellbeing. This should include protecting the rights of people with dementia to self-determination and maintaining a sense of identity, supporting them to live as active members of society with dignity and without fear of abuse and neglect, and providing independent advocacy.

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<sup>21</sup> Dementia Action Alliance & Dementia Engagement and Empowerment Project, Dementia Words Matter. Accessed on 29 May 2015 via: <http://www.dementiaaction.org.uk/dementiawords>

<sup>22</sup> Department of Health, *NHS Outcomes Framework 2015/16*, December 2014.

- Every person with dementia who wants to remain in their own home should have access to the help needed to do so. This should include consideration of how assistive technology and home adaptations can help.
- Local authorities should ensure that all carers of people with dementia are provided with information, advice and support to maintain a good quality of life, as specified under the Care Act 2014. This should include access to respite care and wellbeing services as well as signposting to relevant financial support.

*See also policy position papers on Health and Care Integration, Independence and Personalisation, Carers and Social Care Funding.*

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