

Alzheimer's Society briefing: House of Lords Question for Short Debate- plans to create parity of health and social care to address dementia



On **Thursday 18th January**, Baroness Browning will ask a question for short debate on *plans to create parity of health and social care to address dementia*. For more information about this briefing, please contact National Influencing Officer, Carlotta Rauch at carlotta.rauch@alzheimers.org.uk.

Dementia is the UK's biggest killer, and the country's largest health and social care challenge. With **1 in 3 people set to develop dementia in their lifetime**, it is more pressing than ever that dementia is made a political priority.

This briefing contains suggested questions to the Minister and key messaging for the debate on:

1. Health and Dementia Diagnosis
2. Social Care
3. Integration of Health and Social Care

1. Health and Dementia Diagnosis

Suggested questions to the Minister:

- “There are more than a quarter of a million people living with undiagnosed dementia in England alone. Part of the problem is a lack of magnetic resonance imaging (MRI) and computed tomography (CT) scanning capacity in the memory assessment pathway, and lack of positron emission tomography (PET) scanners for accurate diagnosis of dementia subtypes. We have one of the lowest per capita ratios of these scanners in the OECD – behind Russia, Slovakia, and Chile. **Can the noble Lord the Minister advise what steps the Government is taking to invest in diagnostic infrastructure for dementia?”**
- “With the Government's proposed reforms to the MHRA, cutting-edge medicines could be available in the UK much more quickly than previously. This includes drugs like lecanemab and donanemab – the first drugs which are proven to slow down the progression of Alzheimer's disease. This means the NHS must also be supported to prepare for this prospect. **Can the noble Lord the Minister provide details on what steps the Government is taking to prepare the NHS to deliver ground-breaking treatments such as those I mentioned for dementia?”**

Key messaging:

- **Dementia is the UK's biggest killer** according to the ONS, with **1 in 3 people set to develop dementia in their lifetimes**.
- **There are more than 900,000 people with dementia in the UK today**, which will rise to 1.6 million by 2040.
- **Dementia costs the UK economy £36.7bn per year. This will rise to £94.1bn by 2040.**
- More than a third of people with dementia in England and Northern Ireland do not have access to a diagnosis and the vital care and support it unlocks. In Wales around half of people living with dementia are undiagnosed.
- In January 2020, the dementia diagnosis rate in England was 67.6%. The rate fell during the pandemic and has been slow to recover. Addressing this needs to be an urgent system priority. **Alzheimer's Society have been calling on the Government to use the Major Conditions Strategy to put in place a funded plan to improve dementia diagnosis rates, not just to the national ambition of 66.7%, but further.**

- Getting a diagnosis can be daunting, but the sooner people receive one, the sooner they can plan for the future and gain access to treatment, care, and support. **91% of people Alzheimer's Society surveyed in 2022 said they benefitted from getting a dementia diagnosis.**
- **In the last 12 months, we have seen the announcement of two effective disease-modifying treatments for Alzheimer's disease, lecanemab and donanemab.** These drugs will be the first ever treatments for the underlying cause of dementia if, and when, they are approved and commissioned in this country.
- Currently, however, the UK is not able to benefit from these ground-breaking new treatments, with many people living with dementia either without a diagnosis, or without being told what subtype of dementia they have (e.g. a diagnosis of Alzheimer's disease rather than just dementia).
- Lecanemab and donanemab require an early diagnosis of Alzheimer's disease, including confirmation of the presence of amyloid proteins using a PET scan or cerebrospinal fluid test. **Only 2.2% of people receive these tests in the diagnosis process.**

2. Social Care

Suggested questions to the Minister:

- “With no current cure for dementia, quality social care is a lifeline for people living with the condition. However, too often, they do not get the personalised care they need. Good quality care requires the workforce to deliver it, backed by equal value and parity of funding with the NHS for resourcing, training and qualifications. The Government have rightly introduced a long-term workforce plan for the NHS. **Can the noble Lord the Minister advise when an equivalent long-term social care workforce strategy will be brought forward, to deliver the care people living with dementia need?”**
- “The financial impact of dementia is often devastating for those with the condition and their families, with an individual with dementia spending an average of £100,000 on care over their lifetime. We need to move towards a new way of approaching care for future generations; a system that funds social care on the same basis as the NHS by pooling costs and sharing risk. **Can the noble Lord the Minister advise what action the Government is taking to tackle the staggering care costs faced by individuals with dementia, and provide an update on plans for social care charging reform?”**

Key messaging:

- **Around 60% of people drawing on care at home in the UK have dementia and 70% of residents of older age care homes in England have dementia.**
- However, the current social care system is not set up adequately to meet the needs of people living with dementia.
- **An individual with dementia spends an average of around £100,000 on their care over their lifetime.** We need to move towards a new way of approaching care for future generations; a system that funds social care on the same basis as the NHS by sharing risk. We would also like to see long-term sustainable investment across the sector.
- There are 152,000 vacancies in the adult social care workforce in England, with 390,000 people leaving their care jobs annually. The Government must develop and deliver a **long-term plan for**

increasing investment in training and career development to help attract and retain staff, with **equal value and parity of funding with the NHS for resourcing, training, and qualifications.**

- The introduction of the first phase of the Care Workforce Pathway is a positive step towards improving career development in care, particularly the funding [announced by the Government](#) to increase access to training, including on dementia. Given the prevalence of dementia among people who draw on care, it is vital that as many care staff as possible can receive dementia-specific training.
- At the moment, only 45% of care staff in England are recorded as having any level of training in dementia, and training is not mandatory. **Alzheimer's Society would like to see a minimum mandatory level of training in dementia for all care staff, to Tier 2 of the [Dementia Training Standards Framework](#).**
- **We still need to see a comprehensive, long-term social care workforce strategy**, that delivers a trained workforce with knowledge of dementia-specific needs and the skills to provide personalised care.
- **Unpaid carers of people with dementia provide care to a value of £14.6bn a year across the UK, which is projected to increase to £35.7bn by 2040.** However, too often, they lack the support they need. We would like to see carers able to access a proper annual assessment of their needs and be supported to manage their own wellbeing through dementia-specific respite care.

3. Integration of health and social care

- The move towards better integration of health and social care across the UK presents a **unique opportunity** for people with dementia, as their care is normally split across multiple health and social care silos.
- As a complex condition crossing primary, secondary, community, acute and social care, this inevitably leads to a **lack of ownership of dementia within the health and care system**, creating variation in the quality and type of support people receive.
- Integrated Care Systems (ICSs) must reprioritise funding for dementia to ensure that it is focused on supporting timely diagnosis and support after diagnosis to reduce crises among people living with dementia that can be costly on a financial, social and individual basis.
- Alzheimer's Society wants dementia to be a declared a priority for every ICS in England with the following asks:
 - A named dementia lead, accountable for outcomes
 - A Dementia Steering Group for each ICS
 - A local dementia strategy for each ICS