

Alzheimer's Society briefing – Westminster Hall Debate on New Treatments for Dementia

Dementia is the UK's biggest killer, and the largest health and social care challenge we face in this country. With one in three people set to develop dementia in their lifetimes, it is more pressing than ever that dementia is made a political priority. Recent scientific breakthroughs have seen in the development of novel drugs that target the underlying cause of Alzheimer's disease (the most common form of dementia). If approved for use by regulators these drugs could benefit thousands of people in the UK, however, in order for them to succeed the healthcare system must be made ready to deliver new dementia diagnostic technologies and treatments as they become available.

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Suggested questions to the Minister

- *“With the Government’s proposed reforms to the MHRA, we have the prospect that cutting-edge medicines like lecanemab and donanemab could be available in the UK more quickly than ever before. As such, the NHS will need to prepare to receive the first drugs proven to slow the progression of Alzheimer’s disease. **What steps is the Government taking to prepare the NHS to potentially deliver groundbreaking dementia treatments?**”*
 - *“Exciting new technologies that will transform the way people with dementia are diagnosed such as blood biomarkers are on the horizon. **What steps are being taken now to ensure that we’re ready for such technologies, and that those living with dementia across the UK will be able to access them?**”*
 - *“In England there are more than a quarter of a million people living with dementia who are undiagnosed. 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 position 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. **What steps is the Government taking to invest in diagnostic infrastructure for dementia?**”*
 - *“The Government’s announcement to double funding into dementia research to £160 million a year by 2024 was greatly welcomed. **Given we are now in 2024, could the Government confirm a timeline for when they plan to deliver this funding?**”*
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Key messaging

1. The seismic health and economic challenge posed by dementia

- Dementia is the UK's biggest killer, according to the ONS, with 1 in 3 people born today set to develop dementia in their lifetimes.
- There are more than 900,000 people with dementia in the UK today, rising to 1.6 million by 2040.

- Dementia costs the UK economy £36.7bn per year. This will rise to £94.1bn by 2040.

2. The role of research in treating dementia including recent developments

- Dementia is one of the biggest health challenges facing the world today, which means **increasing research funding and capacity is essential**.
- In the last 12 months, two effective disease-modifying treatments for Alzheimer's disease have been announced. **Lecanemab and donanemab will be the first ever treatments which target the underlying cause of Alzheimer's disease** (the most common form of dementia) if they are approved and commissioned by regulators in this country.
- These **novel drugs target and remove a protein called amyloid that builds up in our brain and is harmful to our brain cells**. The damage and eventual death of these brain cells is what leads to the development of dementia.
- Investing in the research, development, and the implementation of new diagnostic techniques will **support people living with dementia to receive an early and accurate diagnosis**, so they can access disease modifying treatments as and when they become available.

3. The barriers to our health and social care system delivering disease-modifying treatments

- **Lack of workforce capacity**. Memory services do not have the staff available to deliver timely appointments for the current waiting list, let alone meet the expected increased demands if disease-modifying treatments do become available.
- **Lack of sub-type diagnosis**. There are more than a hundred different diseases which cause dementia. Often people receive a general diagnosis of dementia, without a sub-type. Without this, it will be impossible to determine an individual's suitability for an Alzheimer's specific disease-modifying treatment.
- **Lack of access to PET scanners and cerebro-spinal fluid (CSF) testing** for people with dementia symptoms. The prescription of lecanemab and donanemab require a specific, early diagnosis of Alzheimer's disease and this can only be accurately determined via a PET scan or CSF test to prove that amyloid exists in the brain. Without accurate and readily available testing this will not be possible.

4. We need to see clear action on:

- **Diagnosis**: A transformational change to diagnostic infrastructure and workforce so that everyone with suspected Alzheimer's disease can access a test to confirm eligibility for treatment at an early stage in their disease progression. This requires a focus on both infrastructure and workforce with the necessary specialist skills required to identify eligible patients.
- **Involvement**: Meaningful involvement of people living with Alzheimer's disease must be central to these plans, with people living with dementia consulted from the start and on an ongoing basis, through the establishment of an oversight group.