

Alzheimer's Society briefing - King's Speech debates on Science and Research

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 born today set to develop dementia in their lifetimes, it is more pressing than ever that dementia is made a political priority. Dementia research has the potential to revolutionise how people with dementia are diagnosed, supported, and cared for, and is instrumental in working towards a cure.

Briefing contents:

- Suggested interventions
- Key messaging

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Suggested interventions

- *“Blood biomarkers and other exciting new technologies that will transform the way people with dementia are diagnosed 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?”*
 - *“The Government’s announcement to double spending on dementia research to £160 million a year by 2024 is welcome, but investment needs to lead to increased participation of people living with dementia in clinical studies in order to get the best possible outcomes. How are Government addressing associated barriers and inequalities to accessing clinical trials by those living with dementia?”*
 - *“Currently only a small amount of people living with dementia are registered to the Join Dementia Research (JDR) database which means that the vast majority of people being diagnosed with dementia aren’t participating in research. What steps will the Government take to improve involvement in JDR?”*
 - *“The Government’s announcement to double funding into dementia research to £160 million a year by 2024 was greatly welcomed. Given we are only a matter of weeks away from 2024, could the Government confirm a timeline for when they plan to deliver this funding?”*
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Key messaging

1. The massive and growing challenge dementia poses to us all, and the economy
 - 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 solving it, including recent developments

- **Dementia is one of the biggest health challenges facing the world today, which means increasing research funding and capacity is essential.**
- Recent successful drug trials have shown hope of a future where we can treat and possibly prevent the diseases that cause 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. More needs to be done as a matter of urgency so that progress isn't stalled

- **The failure to recruit volunteers to participate in dementia clinical studies** is acknowledged to be one of the biggest barriers to dementia research. The Government's recent investment in research needs to lead to increased participation and diversity of people living with dementia, by addressing the associated barriers and inequalities so that disease modifying treatments work for all.
- In the last 12 months, we have seen two effective disease-modifying treatments for Alzheimer's disease, lecanemab and donanemab, announced. These drugs 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 in this country.
- However it remains to be seen whether people living with dementia in the UK will be able to access these life-changing drugs of the future. There are sizeable barriers standing in the way of our health and social care system being ready to deliver disease-modifying treatments to patients, including:
 - **Lack of workforce capacity** to deliver disease-modifying treatments. Memory services currently 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 additional information, it will be impossible to determine an individual's suitability for a disease-modifying treatment.
 - **Lack of access to PET scanners and cerebro-spinal fluid testing** for people with dementia symptoms. Lecanemab and donanemab cannot be prescribed unless there is evidence of amyloid protein in the brain.