# Alzheimer's Society Briefing – Lords Oral Question – Improving and Futureproofing the Dementia Diagnosis System – 4 September 2023



On 4<sup>th</sup> September, Lord Weir of Ballyholme will ask an oral question on Alzheimer's Society's new report 'Improving access to a timely and accurate diagnosis of dementia in England, Wales and Northern Ireland', on ways to improve and future proof the system for dementia diagnosis.

For more information about this briefing, please contact National Influencing Officer, Lewis Scott at lewis.scott@alzheimers.org.uk

### 1. Suggested interventions

- "My Lords, the national ambition for the dementia diagnosis rate is for two-thirds of the estimated number of people with dementia to have a formal diagnosis. This was achieved before the pandemic, but the national dementia diagnosis rate has since fallen and is currently at just 63.5%. By what date does the Minister estimate that this rate will return to the national ambition, and will the Government consider a more ambitious target thereafter?"
- "My Lords, NHS England's own statistics estimate that there are more than a quarter of a million people in England who have dementia but do not have a formal diagnosis. What is the Government doing to rectify this situation and to ensure that these people are receiving the care and support they need and deserve?"
- "My Lords, I'm sure many in this House are excited about the prospect of the new treatments for Alzheimer's disease that have been recently announced, and with good reason. But further innovations will require healthy clinical trial infrastructure and the participation of people with dementia. What steps is the Government taking to increase the number of pharmaceutical clinical trials for dementia in this country, and to make it easier for people with dementia to know about and take part in those trials?"

## 2. Alzheimer's Society Diagnosis Consensus Statement

- Alzheimer's Society published its report, <u>Improving access to a timely and accurate</u> diagnosis of dementia in England, Wales and Northern Ireland in May 2023.
- The report is based on original research involving focus groups of senior stakeholders in all three nations including clinicians, civil servants, academics, and people living with dementia.
- The report includes a consensus statement signed by 27 dementia experts setting out recommendations to improve and future-proof the dementia diagnosis system.

#### 3. Findings and Recommendations

#### Workforce

- Dementia is a complicated syndrome which can be caused by more than 100 different conditions. People with dementia require care from many specialisms, but currently there is a lack of joined-up thinking and there is no service centrally responsible or accountable for the care of people with dementia.
- Workforce planning must take account of the complex nature of dementia and that prevalence will increase due to our ageing population.

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 Healthcare workers are not routinely trained to recognise dementia symptoms, and should be trained to an appropriate level on the Dementia Training Standards Framework. GPs should be trained to differentiate between subtypes of dementia and have knowledge of the different treatment pathways for different dementias.

### Health inequalities

- There is unwarranted variation in dementia diagnosis rates across the UK but the reasons for this variation are under-explored. Action must be taken to level up the diagnosis pathway across the country.
  - o The APPG on Dementia will publish a report on this point on 19<sup>th</sup> September. The Minister would be more than welcome to attend the launch event.
- Culturally relevant assessment tools and interpreters should be introduced and made widely available, and co-production of local diagnosis pathways should reflect the local population.
- There is a lack of understanding in the general public about the symptoms and prognosis of dementia. An annual diagnosis public messaging campaign should be developed to educate, and overcome stigma.

# Financial and System Pressures

- Dementia pathways across the three nations are routinely underfunded, with commissioning arrangements often disincentivising an increase in diagnosis rates.
   National health systems should invest in dementia care to help prevent costly dementia crises.
- Patients are routinely discharged from memory services at the point of diagnosis which can cause distress. Peri-diagnostic support should be integrated into the pathway so that diagnosis is the beginning not the end of support.

## Future-proofing the diagnosis system

- Health systems must ensure equitable access to scans for memory assessment services.
  All diagnoses of dementia should be delivered with information on the person's specific dementia subtype.
- National health systems should plan for the introduction of blood-based biomarkers to ensure people developing dementia benefit from new treatments.
- Health systems must commit to ensuring that the advent of new treatments for Alzheimer's disease specifically does not divert resources away from diagnosing and supporting those with other subtypes of dementia. Diagnosis remains important in accessing timely care and support.