# Alzheimer's Society Briefing – General Debate on Lord Darzi's Independent Investigation into NHS Performance – Monday 7 October 2024

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



### Suggested interventions

- "Lord Darzi's investigation highlights a need to focus far more on primary and community care. However, recent Alzheimer's Society research found that just 1.4% of total spend on dementia is for diagnosis and treatment. Early diagnosis and treatment can reduce the cost of dementia care by up to £45,000 per patient. Will the Government commit to increased investment in early dementia diagnosis and treatment, to prevent significantly higher costs further down the line?'
- As noted by Lord Darzi, dementia diagnosis rates have yet to recover to their pre-pandemic levels. In addition, the present NHS diagnosis rate target of 66.7% still means that one third of the population with dementia does not receive a diagnosis. Does the Minister agree with me that this target is not nearly ambitious enough and must be amended for the future, so that everyone living with dementia deserves to know what is wrong with them, and get access to the care and support a diagnosis brings?
- Lord Darzi's investigation notes that 'as society continues to age, there is an important challenge to improve both the quality and quantity of care for people with dementia.' Can the Minister provide assurances that improvements to the care of people living with dementia will be included in the Government's 10-Year Plan for the NHS?'

#### 2. What does the Darzi Report say about dementia?

- "As society continues to age, there is an important challenge to improve both the quality and quantity of care for people with dementia."1
- The number of people aged over 65 in the UK is increasing, and older people are forming a larger proportion of the total population.
- The UK has a substantially higher rate of death due to dementia than comparable countries, despite having lower prevalence of the condition.
- Dementia diagnosis rates have not improved in recent years. The current rate of around 65% is still below pre-pandemic levels of around 68%.
- Darzi quotes Alzheimer's Society: "There are high levels of unwarranted variation in access to diagnosis and treatment for dementia, [and] insufficient adherence to clinical guidelines."

### 3. Background information

Dementia is the UK's biggest killer according to the ONS.<sup>2</sup> With prevalence projected to rise from around 1 million in 2024 to 1.4 million people living with dementia by 2040, and the cost of dementia to the UK rising from £42billion to £90 billion in the same period,<sup>3</sup> the condition will become an even greater challenge for the health and social care system. The NHS needs to be more ambitious on dementia.

<sup>&</sup>lt;sup>1</sup> Lord Darzi of Denham (2024), <u>Independent Investigation of the National Health Service in England, pg.49.</u>
<sup>2</sup> Office for National Statistics (2022), <u>Death registration summary statistics, England and Wales - Office for</u>
<sup>3</sup> Alzheimer's Society and Carnall Farrar (2024), <u>The economic impact of dementia - module 1, pg.11.</u> e for National Statistics.

- The central failing of the NHS in relation to dementia is the failure to diagnose enough people, and diagnose them sufficiently early or accurately.
- Early diagnosis and treatment reduce unplanned hospital admissions and delay admissions to residential social care. However, spending on dementia diagnosis and treatment is equivalent to just 1.4% of all healthcare spending on dementia.<sup>5</sup>
  - o Those with undiagnosed dementia attend A&E more than those with a dementia diagnosis, regardless of severity. These patients may not have the information, receive the care they need, or make the lifestyle changes required to avoid A&E.6
  - o Diagnosing dementia patients at an early stage and treating them effectively can result in cost savings of up to £44,887 per person compared with no treatment, due to resultant delayed care home admission.<sup>7</sup>

#### Diagnosis

- More than 1 in 3 people living with dementia in England are undiagnosed.8 below even the frankly unambitious target of 66.7%. Ministers should adopt a new, more ambitious target and produce a plan for delivery.
- There is significant regional variation in diagnosis rates. In England, diagnosis rates vary across upper-tier local authority areas by more than 40%. Government should work to reduce barriers to diagnosis through better training for healthcare professionals, improved quality and quantity of dementia data collection, and public awareness campaigns.

#### Social Care

- 70% of residents of older age care homes in England have dementia, 10 and 60% of those receiving care in their own homes across the UK.11
- Only 45% care staff are currently recorded as having any level of training in dementia.<sup>12</sup> We need to see a long-term social care workforce strategy, with social care staff required to undertake dementia training mapped to the Dementia Training Standards Framework. This call is reflected in Skills for Care's 2024 workforce strategy.<sup>13</sup>
- Someone with dementia spends an average of £100,000 on their care over their lifetime.<sup>14</sup> We need a sustainable funding model for quality personalised care, which pools the risk of care costs and is centred on achieving affordable care for everyone living with dementia.

## New Treatments for Dementia

Recent research breakthroughs mean there are now drugs for the first time that appear to slow the progression of early-stage Alzheimer's disease. One such drug (lecanemab) was approved by the MHRA, but rejected by NICE, meaning it will not be available on the NHS. This was due to its cost, particularly in relation to the modest clinical benefits of this treatment, with NICE's draft guidance stating that experts highlighted how significant

<sup>4</sup> Department of Health and Social Care (2023). Chief Medical Officer's annual report 2023: health in an ageing society, pg.145; and Livingston, G. et al (2024). Lancet Commission on dementia prevention, intervention and

<sup>5</sup> Alzheimer's Society and Carnall Farrar (2024). The economic impact of dementia - module 1. pg.11

Alzheimer's Society and Carnall Farrar (2024). The economic impact of dementia – module 2.pg.31 Alzheimer's Society and Carnall Farrar (2024). The economic impact of dementia – module 4. pg.18

NHS England (2024). Primary Care Dementia Data

Wittenberg et al. (2019) The Costs of Dementia in England, International Journal of Geriatric Psychiatry, 34(7), pp.1095-1103.

Wittenberg et a. (2019) The Costs of Dementia and Homecare: Driving Quality and Innovation, pg.8.

1 WKHCA/Homecare Association (2015) Dementia and Homecare: Driving Quality and Innovation, pg.8.

2 Skills for Care (2023). The state of the adult social care sector and workforce in England.

3 Skills for Care (2024). A Workforce Strategy for Adult Social Care in England.

4 Alzheimer's Society (2018). Dementia – the true cost: Fixing the care crisis

changes to the existing diagnostic pathway would be needed to deliver lecanemab on the NHS. Two more drugs are already being appraised by regulators, with dozens more in the pipeline.

- Tens of thousands of people in the UK could benefit from these new drugs, however the system is not yet ready to deliver them due to lack of early and accurate diagnosis.
- We therefore need to see health systems across the UK publish plans on how they will
  deliver new treatments if approved, which must include investment in the diagnostic
  infrastructure and workforce needed to identify patients who could be eligible for new
  treatments if approved.