

## **Alzheimer's Society briefing – Waiting times for referral to memory assessment services – 5 July**

Full question: to ask Her Majesty's Government what is the national average waiting time for a referral to a memory service following a suspected dementia diagnosis; and how this has changed since January 2020.

For more information contact Laura Mullaney at [laura.mullaney@alzheimers.org.uk](mailto:laura.mullaney@alzheimers.org.uk).

This briefing includes:

- 1. Suggested questions**
- 2. Prime Minister's Challenge on Dementia**
- 3. Dementia Strategy and diagnosis**
- 4. Memory assessment services and dementia**

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### **1. Suggested questions**

- Can my noble Friend assure me that the Government is doing all it can to ensure people with dementia are able to access a timely diagnosis, and will he update the House on his Government's £17m diagnosis recovery fund?
- Does my noble Friend agree with me that early diagnosis is vital to ensuring people with dementia can access the financial, legal, emotional and care support that they need to live well with dementia for as long as possible?

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### **2. Prime Minister's Challenge on Dementia**

There are an estimated 850,000 people living with dementia in England.<sup>1</sup> It is estimated that 14% live with mild dementia, 28% live with moderate dementia and 58% have a severe form of the condition.<sup>2</sup>

The Prime Minister's Challenge on Dementia, established in 2012 under David Cameron's premiership, set out a range of priorities designed to make 'a real difference to the lives of people with dementia' and set the target of two-thirds of people with dementia receiving diagnosis and post-diagnostic support by March 2015.<sup>3</sup> This target was met in July 2016 but diagnosis has since been significantly affected by Covid-19 which brought about significant changes in the delivery of health and care. Remote GP service provision made spotting the signs of dementia harder, non-urgent primary care was deprioritised including medication reviews and over 75s health checks which can help identify dementia and, crucially, there has been a wide local variation in whether memory services have been open or closed and providing assessments in person or remotely.

The Challenge's 2015 update set the ambition of a national average of six weeks from GP referral to initial assessment by memory services, and that 'no one should be waiting several months for an initial assessment of dementia'.<sup>4</sup> No further targets have since been set.

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### **3. Dementia Strategy 2021**

The Department for Health and Social Care is consulting on a Dementia Strategy at present, designed to "boost dementia awareness, diagnosis, care, support and research in England".<sup>5</sup> This is an opportunity to draw together all strands of the Government's dementia activity to form a strategy with a clear timeline, which must recognise the substantial impact that the pandemic has had on people affected by dementia, and ensure that people with dementia can be supported to recover from the effects of the pandemic.

Alzheimer's Society welcomes the opportunity to feed into the Strategy. However, we are concerned by a lack of concrete ambitions in the current iteration. It must urgently address the impact of Covid-19 on people affected by dementia with a clear, timetabled strategy supported with sufficient resource to succeed.

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<sup>1</sup> Wittenberg et al. Projections of Older People with Dementia and Costs of Dementia Care in the United Kingdom, 2019-2040 (2019).

<sup>2</sup> Ibid.

<sup>3</sup> Gov.uk 'Prime Minister's Challenge on dementia' 2012 <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia> [Accessed 140621].

<sup>4</sup> Gov.uk 'Prime Minister's Challenge on dementia 2020' 2015 [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/414344/pm-dementia2020.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf).

<sup>5</sup> HC Deb 27<sup>th</sup> May 2021 Vol 696 Col 583.

#### 4. Memory assessment services and diagnosing dementia

##### *Benefits of diagnosis*

Diagnosing dementia helps people to access important sources of support, and information. It also enables the delivery of essential care and treatment; including emotional, legal, and financial support too. A long period without a diagnosis can also lead to an acceleration in greater levels of need, creating more pressure on health and care services over time<sup>6</sup> as an earlier diagnosis can ensure support mechanisms are put in place early to prevent premature deterioration. Diagnosis also helps people to manage their symptoms through providing important knowledge and certainty.

Interruption to the diagnostic process risks creating a significant cohort who will live without an early, timely or accurate diagnosis – or even any diagnosis at all. This has implications for future medication, care plans, interventions and opportunities for research<sup>7</sup>.

##### *National Memory Clinic Audit – waiting times*

There is limited assessment of memory service performance, which means that services are often left to rely on ad hoc audits.<sup>8</sup> The most recent national audit of memory clinics took place in 2019, and was carried out by the Dementia Clinical Network at NHSE&I. The mean waiting time from referral to diagnosis was 13 weeks, but there was significant variance with some services providing a diagnosis within 3 weeks and others taking up to 34 weeks.<sup>9</sup> Overall, just 26% of patients were diagnosed within the Government's target timeframe.

The Royal College of Psychiatrists is carrying out a further audit, with explicit focus on Covid. This audit will track referral times; however, it is unlikely to report back for several months. In the interim, there is a lack of data available on waiting times; an update from the Minister on how memory assessment services are performing in the light of the pandemic is welcome.

##### *Impact of the pandemic on diagnosis rates*

Prior to the pandemic, national dementia diagnosis levels had remained steadily above the Prime Minister's Challenge ambition since July 2016. In February 2020, the diagnosis rate was 67.6%. By February 2021, this had dropped to 61.1%, well below an already modest target<sup>10</sup>. This was due to a number of factors. There has been significant fear of developing Covid-19 or burdening the NHS, particularly amongst older people who are more likely to develop dementia. At the peak of the pandemic, there was also significant variability in whether memory assessment services were open or closed and what services they were providing; we know, for instance, that some were not taking on new caseloads<sup>11</sup>.

While the rate has now climbed to 61.7% as of April 2021, there is still a backlog of assessments, which will worsen waiting times in some local areas. There is also a variety of provision across different local areas, with some memory assessment services now holding more appointments face to face whilst others are not. Virtual assessments have kept memory services running; however, it takes longer to prepare and conduct virtual assessments. Moreover, in the absence of a full and comprehensive assessment, more people may be receiving 'unspecified dementia' diagnoses, preventing the better management of symptoms which can come from a specific diagnosis.

The Government announced a £17m fund to recover dementia diagnosis rates at the CSR in March 2021; we welcome this fund and hope to hear details on how it will be spent in the coming weeks.

<sup>6</sup> Alzheimer's Society 2020 'From Diagnosis to End of Life' [https://www.alzheimers.org.uk/sites/default/files/2020-10/pathway\\_report\\_full\\_final.pdf](https://www.alzheimers.org.uk/sites/default/files/2020-10/pathway_report_full_final.pdf).

<sup>7</sup> Ibid.

<sup>8</sup> Ibid.

<sup>9</sup> NHSE&I National Memory Service Audit 2019 <https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2020/04/The-2019-national-memory-service-audit.pdf> [Accessed 11 June 2021].

<sup>10</sup> NHS Digital Recorded Dementia Diagnoses 2021 <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/april-2021>.

<sup>11</sup> Alzheimer's Society August 2020 'How coronavirus is affecting dementia treatment and diagnosis' <https://www.alzheimers.org.uk/news/2020-08-10/coronavirus-affecting-dementia-assessment-diagnosis>.