

Written evidence submitted by the Alzheimer's Society

Introduction

1. Covid-19 has led to dramatic change in how health services operate as well as a reduction in routine NHS activity. People with dementia – who rely heavily on NHS services both for accessing a diagnosis as well as the care and support received after – were worst hit by the pandemic. Over a quarter (27.5%) of people who died with Covid-19 from March to June 2020 had dementia. These 13,840 deaths during this time period made dementia the most common pre-existing condition in deaths involving Covid in England and Wales. The largest increase in excess non-covid deaths was also seen in people with dementia, with 5,049 excess deaths recorded between 4 January and 10th July 2021, (in addition to deaths attributed directly to Covid)¹.
2. This submission focuses on the impact of the pandemic on dementia diagnosis. A diagnosis of dementia is vital for people living with the condition. Not only does it provide an explanation for symptoms – with which some may be living with for years – but it is also essential to facilitating access to care and support that enables people to live well with dementia. An early diagnosis has many benefits such as enabling more time for the person and their family to plan for the future and aiding access to both pharmacological and non-pharmacological treatments, which may only be effective if provided earlier in the disease progression.
3. The pathway to diagnosis for many people experiencing symptoms is that they will access their GP, who will rule out reversible causes of cognitive decline through various tests. If dementia is still suspected, then a person will be referred to a specialist diagnostic service. Here, they will undergo further tests and will be provided with a diagnosis, if appropriate. Often, they will also be offered some form of post-diagnostic support, although this varies from service-to-service, depending on how memory services are commissioned.

Backlogs

4. There is a national ambition, set in 2013, to diagnose two-thirds of all people living with dementia, which was achieved in November 2015.² However, the pandemic caused significant

¹ Alzheimer's Society. (2021), Worst hit: dementia during coronavirus
<https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf>

² Alzheimer's Society. (2021). Increasing access to a dementia diagnosis: regional variation. Available at:
https://www.alzheimers.org.uk/sites/default/files/2021-09/regional_variations_increasing_access_to_diagnosis.pdf

disruption to dementia diagnoses, with the latest data showing a 5.5 percentage point drop from 67.4% in March 2020 to 61.9% in October 2021. The diagnosis rate dropped on each of the 12 consecutive months from March 2020 to February 2021, with just minimal increases in months March 2021 to July 2021³. The following months – August 2021 to October 2021 – has shown stagnation and a further decline⁴.

5. We estimate that there are around 33,000 people living with dementia who would have been diagnosed had the pandemic not happened.⁵ However, this is likely to be an underestimate, with people under 65 with dementia not recorded in official data.⁶ Due to the lack of available data, we are unsure as to how many of these 33,000 people are currently ‘within the system’ or are yet to reach out to their GP with concerns around symptoms. On a more local level, we estimate that it will require each GP practice in England, on average, to diagnose five people on their GP register.⁷
6. We know that Covid-19 has had a significant impact on dementia diagnoses, with the changes to delivery of healthcare at primary care level, the closure or part-closure of memory services and fears of infection by the public all contributing to the reduction of the national diagnosis rate.⁸ Our analysis of NHS Digital data shows that, in 2020, the average number of monthly GP assessments for dementia was 54% of 2019 levels, with referrals to memory services 58% of 2019 levels and memory service assessments 50% of 2019 levels.⁹ Currently, the average number of monthly GP assessments in 2021 is 61% of 2019 levels, with referrals at 81% of 2019 levels and memory service assessments just 49% of 2019 levels.
7. However, it is difficult to ascertain the size of the dementia diagnosis backlog since neither the Department of Health and Social Care nor NHS England routinely track referral and waiting time data. A freedom of information request submitted in October 2021 to both organizations found that neither held data on the current size of the backlog, nationally or at an integrated care system level.

³ NHS Digital. (2021). Recorded dementia diagnosis, October 2021. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/october-2021>

⁴ *ibid*

⁵ Methodology is based on the fact England had been consistently achieving the national ambition of two-thirds of all people with dementia to have a diagnosis before the pandemic and, had been for some time. 33,018 diagnoses are therefore needed to get back to the national target, a number which we attribute as an impact of the pandemic

⁶ NHS Digital. (2021). Recorded dementia diagnoses, October 2021. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses/october-2021>

⁷ This is calculated by dividing the numbers needed to reach the diagnosis rate target by the number of GP practices, which we’ve identified as 6,500. Although the number of GP practices in England is slightly higher, around 6,500 contributed to NHS Digital data publication in October 2021.

⁸ Alzheimer’s Society. (2021). Increasing access to a dementia diagnosis: regional variation. Available at: https://www.alzheimers.org.uk/sites/default/files/2021-09/regional_variations_increasing_access_to_diagnosis.pdf

⁹ Alzheimer’s Society. (2021). Increasing access to a dementia diagnosis: regional variation. Available at: https://www.alzheimers.org.uk/sites/default/files/2021-09/regional_variations_increasing_access_to_diagnosis.pdf

8. The average number of referrals pre-Covid (October 2018 to September 2019) was around 2,600 per month. In the 20 months from March 2020 to October 2021, there should have been around 52,000, yet the actual number of referrals was just 32,915, 63% of the expected number of referrals. Whilst it is positive that referrals now are reaching pre-Covid levels, we are concerned about the capacity of secondary care to manage these referrals. We estimate that there will be an extra 10,400 referrals for dementia assessment by February 2022.
9. The most recent publication (August 2021) of the Mental Health Services Dataset shows 117,195 open referrals to memory services, an increase of over 8,500 (7.5 per cent) since August the previous year¹⁰. This means that people are being referred into the services but there is a significant delay in being seen and assessed at these clinics. The data showed a small recovery in numbers in the autumn of 2020 but since January 2021 open referrals to memory services have risen every month. Calculating the average memory assessment output by memory services this year (2,265 assessments per month, January to October 2021), we estimate that it would take 4.3 years, or 51.7 months, to clear the current backlog. This calculation only stands if no new referrals were accepted, and memory services are only assessing referrals already in the system.
10. However, not all of the 117,195 who are currently waiting an assessment for dementia will have the condition. The latest national memory clinic audit found that, overall, 67% of patients referred to memory services were diagnosed with dementia.¹¹ This means that we estimate that 78,520 of these backlogged referrals may have dementia – meaning that even if the national diagnosis rate is recovered to 67 per cent there is much greater unmet need that has not been planned for. Some caution must be given to this estimate. Covid-19 specific considerations, such as those presenting with long Covid which may have a cognitive impact and may skew the appropriability of referrals.
11. Furthermore, this memory assessment backlog is not split regionally or into integrated care system footprints so we cannot understand where there is regional inequity of access. We do know that the diagnosis rate varies significantly. In October the variation in diagnosis rates between clinical commissioning groups ranged between 51% and 79%. We understand the Office for Health Disparities is currently developing data on dementia diagnosis rates based on ethnicity and welcome this commitment in helping to understand and therefore reduce health inequalities.
12. In March 2021, the Government announced £17m funding to boost capacity within memory assessment services to support improvements in the national diagnosis rate.¹² With a lack of routinely collected data by Department of Health and Social Care and NHS England, it is unclear

¹⁰ NHS Digital. (2021). Mental Health Services Dataset (MHSD). Available at: <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-sets/mental-health-services-data-set>

¹¹ NHS England (2020) The 2019 national memory service audit. Available at <https://www.england.nhs.uk/london/wpcontent/uploads/sites/8/2020/04/The-2019-national-memory-service-audit.pdf>

¹² Department of Health and Social Care press release (2021). Available at <https://www.gov.uk/government/news/mental-health-recovery-plan-backed-by-500-million>

how this funding was calculated. The £17m of additional money has now been allocated to ICSs and will be spent by the end of the March 2022.

13. One study found the cost of diagnosing people and offering a six-month follow-up varies between £1,600 and £2,500 per patient¹³, while a separate study found the average cost of diagnosis via a memory assessment service was £742 and £807 via a community mental health team¹⁴. Given the variation of diagnostic services at MAS clinics, we have estimated that funding of £46.6m¹⁵ is needed to return the diagnosis rate back to the national target of 67%. This is equivalent to a spend of £8.48m to increase the diagnosis rate by 1%. The calculation is based on our estimate that 33,018 people are living with dementia who would have been diagnosed had the pandemic not happened. This £46.6m figure does not cover associated costs at primary care level nor the fact the trajectory of the current recovery rate continues to fall, moving the national target further from reach. Nor does it take into account that the cost of recovering the diagnosis rate will almost certainly be higher as recovery will require increased agency/bank staff use and other overtime costs, plus inflationary pressures on MAS. Others have suggested the total cost of recovering the diagnosis rate to run into the hundreds of millions of pounds.¹⁶
14. The £46.6m also does not address the wider unmet need the memory clinic backlog data suggests exists. The £17m of current additional funding equates to just £145.06 per backlogged referral to memory clinics. Even if we just took the 78,520 referrals that are estimated to result in a diagnosis of dementia, the money assigned to each case is just £216.51. Using the same average cost of diagnosis, it would cost £110.9m to clear the 78,520 backlog entirely, which excludes the costs associated with auditing the waiting list and removing inappropriate referrals. While we recognise there will always be a backlog to access services, further data collection from MAS services is needed to understand what a reasonable backlog would look like.
15. In the October 2021 spending review a further £8bn was promised to help clear the elective backlog that has built up across the country in all health conditions. To date no monies from this fund has been allocated to the dementia backlog and we understand that it is unlikely this will happen. It is clear from the current diagnosis rate performance, the estimated time to recover the backlog and the cost of recovery that a further and urgent funding boost is needed to ensure that people living with the condition can access a diagnosis. Without a diagnosis and the care and support it facilitates, people are at risk of living with a complex condition unsupported for many years, increasing chances of crisis, such as emergency admissions, which have significant financial implications for the health system.

¹³ Mark Pennington et al (2018). The cost of diagnosis and early support in patients with cognitive decline. *International Journal of Geriatric Psychiatry*.33(1):5-13.

¹⁴ Judy Sasha Rubinsztein et al (2018). A memory clinic v traditional community mental health team service: comparison of costs and quality. Cambridge University Press. [A memory clinic v. traditional community mental health team service: comparison of costs and quality | BJPsych Bulletin | Cambridge Core](#)

¹⁵ $(\text{The average of study one } (\pounds 2050) \times \text{the average of study two } \pounds 774.50) / 2 = \pounds 1412.25$ cost per diagnosis.

¹⁶ UK Parliament Committees. (2021). Written evidence submitted by Alzheimer's Research UK (CBP0083). Available at: <https://committees.parliament.uk/writtenevidence/38818/pdf/>

16. There is large variation in the percentage of people diagnosed with dementia from service to service, with some services diagnosing as little as 22% of their patients with dementia.¹⁷ This obviously presents capacity challenges at secondary care level when inappropriate referrals take up valuable clinical time. Improved referral processes are needed at primary care level to improve timely access to dementia and to reduce the stress waiting for a diagnosis can bring to patients, especially those where the dementia is clearly advanced.
17. Given these costs, Alzheimer's Society is calling for a minimum of £70m over two years to tackle the backlog, ringfenced for dementia, although we are happy to work with NHS England to discuss specific costs. We estimate this would cover the costs of the backlog to secondary care and make allowances for increased primary care costs. It would also allow for NHS England to invest in much needed data collection from memory assessment services to understand regional and health inequality disparities, plus the sharing of innovative new practice. This reasonable investment will see a significant return on investment given we have previously reported the cost to the NHS of emergency admissions of people with dementia to alone cost over £280m (2017-18).¹⁸

Waiting times

18. Diagnostic waiting times are as equally concerning as the referral backlog. When demand for diagnostic services increases, so do waiting times, leaving more people waiting longer for a diagnosis.¹⁹ Historically, many memory services have been dogged with capacity limitations since their inception, with significant increases in referrals affecting waiting lists.²⁰ GPs have previously reported a lack of funding and capacity, as well as a lack of clinical and administrative staffing, at secondary care level as factors influencing access to a dementia diagnosis.²¹
19. In 2018, the National Collaborating Centre for Mental Health set a national goal to increase the number of people being diagnosed with dementia and starting treatment within six weeks of referral, a target that is in line with other health conditions.²² However, the last memory clinic

¹⁷ NHS England (2020) The 2019 national memory service audit. Available at <https://www.england.nhs.uk/london/wpcontent/uploads/sites/8/2020/04/The-2019-national-memory-service-audit.pdf>

¹⁸ Alzheimer's Society. (2020). Alzheimer's Society analysis of NHS England's Hospital Episode Statistics dataset 2012/13 to 2017/18. Available at: <https://www.alzheimers.org.uk/sites/default/files/2020-01/Hospital%20Admissions%202012-18%20for%20people%20with%20dementia%20Alzheimer%27s%20Society%202020.pdf>

¹⁹ Alzheimer's Society. (2021). Increasing access to a dementia diagnosis: regional variation. Available at: https://www.alzheimers.org.uk/sites/default/files/2021-09/regional_variations_increasing_access_to_diagnosis.pdf

²⁰ Foreman, P. et al. (2004). Multidisciplinary memory clinics: what is important to caregivers and clients? *International Journal of Geriatric Psychiatry*. 19(6):588-9

²¹ Chithiramohan, A. & Iliffe, S. (2016). Identifying barriers to diagnosing dementia following incentivisation and policy pressures: General practitioners' perspectives. *SAGE Publications*. 18(2):514-529

²² National Collaborating Center for Mental Health 2018. The Dementia Care Pathway. https://www.rcpsych.ac.uk/docs/default-source/improving-care/nccmh/nccmh-dementia-care-pathwayfull-implementation-guidance.pdf?sfvrsn=cdef189d_6

audit, taken before the pandemic, showed the mean waiting time from referral to diagnosis was 13 weeks and varied between services from three to 34 weeks (almost eight months). Overall, just over one quarter (26%) of patients were diagnosed within six weeks of referral, varying from 0% to 87% per service.²³

20. Whilst we know that many people were not previously receiving a diagnosis in a timely way, the pandemic has further exacerbated waiting times. A survey conducted by Alzheimer's Society in January 2021 (37 responses) for people diagnosed with dementia over the pandemic found that almost one third of people (30%) waited over five and a half months (24 weeks) for a diagnosis after being referred to a memory service. We know that rising waiting times is a significant issue for memory services with many reporting to us at the beginning of 2021 they were operating at capacity and that the backlog of appointments due to the pandemic worsened their position.
21. Anecdotally, throughout autumn 2021 we have heard that waiting times to diagnosis for some memory services are currently as high as nine months. This length of time is highly concerning given it leaves the potential for people and their families to be without care and support to help them manage the condition.
22. One memory assessment service based in North England told us that as of November 2021 their waiting time for assessment is nine months, with GP referrals now higher than pre-Covid. In October the service received 100 referrals compared to a pre-Covid monthly average of 90. Staff sickness and burnout from the pandemic means the team gets through even less than its average of 20 assessments per week, and now has a backlog of 700 people waiting to be seen. Another service operating in the South of England reported to us in the same month that they had a seven-month waiting list.
23. As of December 2021, two memory assessment services in the Home Counties have built up backlogs of 10-12 weeks. Both of these backlogs occurred as the services did not have the available resources to cope with increased referral numbers. As a result, one clinical commissioning group has suspended all screening for potential dementia at primary care level and its MAS is now classified as being in crisis.

Diagnostic capability and infrastructure

24. Scanning capacity is of particular concern regarding waiting times. Previously, the national memory clinic audit found that people, on average, waited five weeks for a brain scan, not including additional time for the scan report to be received, significantly impacting the ability of services to meet the six-week diagnosis waiting time target.²⁴

²³ NHS England (2020) The 2019 national memory service audit. Available at <https://www.england.nhs.uk/london/wpcontent/uploads/sites/8/2020/04/The-2019-national-memory-service-audit.pdf>

²⁴ NHS England (2020) The 2019 national memory service audit. Available at <https://www.england.nhs.uk/london/wpcontent/uploads/sites/8/2020/04/The-2019-national-memory-service-audit.pdf>

25. Memory services reported to us that routine brain scans were suspended over the pandemic, with emergency cases being prioritized. The prioritization of scans during Covid-19 has built up a backlog of people with dementia waiting for scans, which has subsequently impacted waiting times to diagnosis. During autumn 2021, we heard of waiting times for a brain scan is as high as six months in one area. In another area of England, we have heard there is currently a backlog of 2000 scans, with routine head computerized tomography (CT) scans stopped, and the local memory service is now expected to diagnose without the use of scans or, alternatively, people are being asked to pay £804 to have a scan.
26. Whilst not all people going through a dementia assessment require a brain scan to determine their diagnosis, it is particularly advantageous for people with atypical symptoms or those with rarer dementias. For instance, cases of individuals with Lewy body dementia (dementia with Lewy bodies and Parkinson's disease dementia) take twice as long to reach a diagnosis in comparison to those without Lewy body dementia and undergo more scans.²⁵
27. Guidance for memory services during the pandemic proposed that, in the absence of access to brain scans, services should offer a 'working diagnosis' of unspecified dementia.²⁶ While services recognized this change in dementia diagnosis was necessary during the pandemic, we are concerned that this diagnosis pathway will hinder the ability of services to deliver a subtype diagnosis. Without a subtype, some people may not be able to access specific interventions targeted at different types of dementia.
28. In our survey about dementia diagnosis to memory services (April 2021, 21 responses), we asked what could be done to improve diagnosis as a response to the pandemic. Whilst many spoke of a 'tsunami of referrals' and 'massive backlogs'; responses focused on reducing backlogs, increasing access to scanning infrastructure and increasing staffing capacity. It is paramount that an urgent funding injection is put into the system to enable services to cope with demand.

Staff capacity

29. Workforce, or the lack thereof, has also been suggested as a potential barrier to diagnosis. In most local diagnostic services, consultant-level clinicians are required to confirm dementia diagnoses and consultants can come from a range of professions including psychology, gerontology, psychiatry and neurology, amongst others.
30. There has been significant difficulty in increasing the psychiatric workforce over the past five years. The Five Year Forward View for Mental Health and NHS Long Term Plan both included indicative workforce requirements to deliver service ambitions and improve mental healthcare, but the requirements have not been met nor are they on track to be met. In the plan to deliver the *Five Year Forward View for Mental Health – Stepping forward to 2020/21: The mental health*

²⁵ Surendranathan, A. et al. (2020). Clinical diagnosis of Lewy body dementia. *Psych Open*. 6:1-8

²⁶ Yorkshire and the Humber Clinical Networks (2020) Memory Service Assessments: A New Way of Working. Available at <http://www.yhscn.nhs.uk/media/PDFs/mhdn/Dementia/Covid%2019/MAS/MSA%20-%20A%20New%20Way%20of%20Working%20revised%20Dec%202020.pdf>

workforce plan for England – there was a target to employ 570 more consultant psychiatrists by March 2021. By this date, only 209 (37%) posts were filled compared with March 2017 (the Government’s baseline date).²⁷ Furthermore, the NHS Long Term Plan is meant to build on the planned workforce set out in the Five Year Forward View. Yet as of June 2021, the NHS was almost 400 consultant psychiatrists behind the target for 2020/21, and therefore on course to miss the Long-Term Plan’s ask to reach this target by 2023/24.²⁸

31. When looking at old age psychiatry specifically, over the past year there has been a decrease in the number of consultant old age psychiatrists. For comparison, there were increases across three of the six specialties reported by NHS Digital: forensic, 3.7%; general, 3.1%; and child and adolescent, 0.7%. The other three specialties all had decreases in consultant numbers: learning disability, 1.8%; old age, 2.3%; and psychotherapy, 16.9%.²⁹ Similarly, The College for Radiology latest research also found there is a 1,313 WTE consultant radiologist shortfall.

December 2021

²⁷ NHS England. (2017). Stepping forward to 2020/21: The mental health workforce plan for England. Available at:

<https://www.hee.nhs.uk/sites/default/files/documents/Stepping%20forward%20to%202021%20-%20The%20mental%20health%20workforce%20plan%20for%20england.pdf>

²⁸ NHS England. (2021). NHS workforce stats. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-workforce-statistics>

²⁹ NHS England. (2021). NHS workforce stats. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/nhs-workforce-statistics>