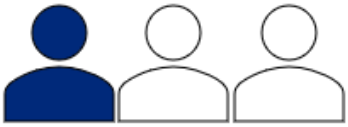
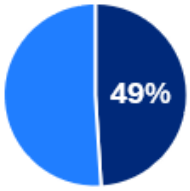
Section 1: A coordinated approach to dementia spending



With an estimated **1 in 3** people born today estimated to develop dementia in their lifetime.

For the past **10 years dementia has been the UK's biggest killer** using ONS methodology.

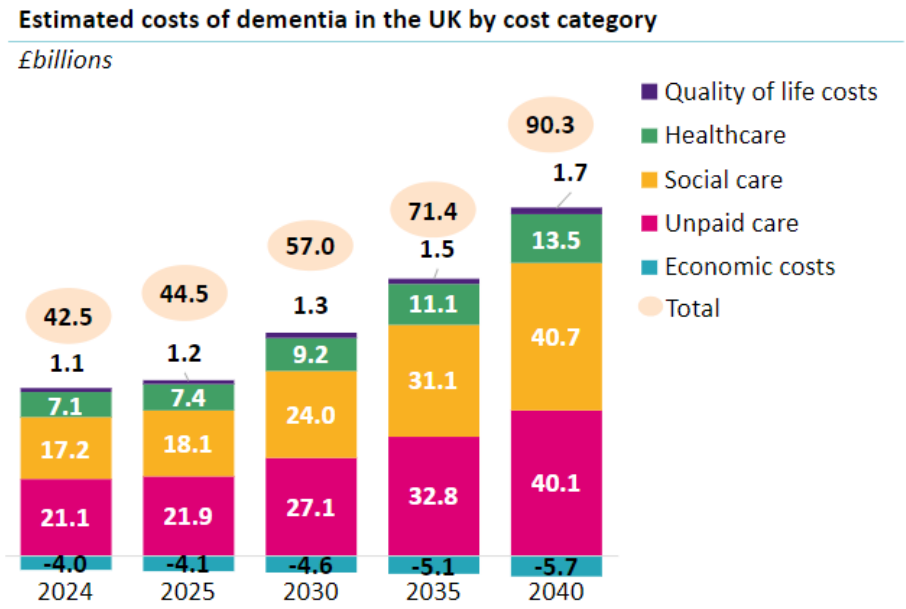


49% of UK adults report that **dementia is the health condition they fear getting the most in the future.**

Dementia has a significant and growing economic impact

Dementia is already the biggest killer in the UK, [1] but with prevalence rates projected to rise to 1.4 million by 2040,[2] the impact of this terminal disease will become an even greater burden for the health and social care system. The economic cost of dementia to the UK today is £42bn, and this is due to rise to £90bn by 2040.[3]

Figure 1



Source: Alzheimer's Society and Carnall Farrar (2024). The economic impact of dementia, Module 1, p.37.

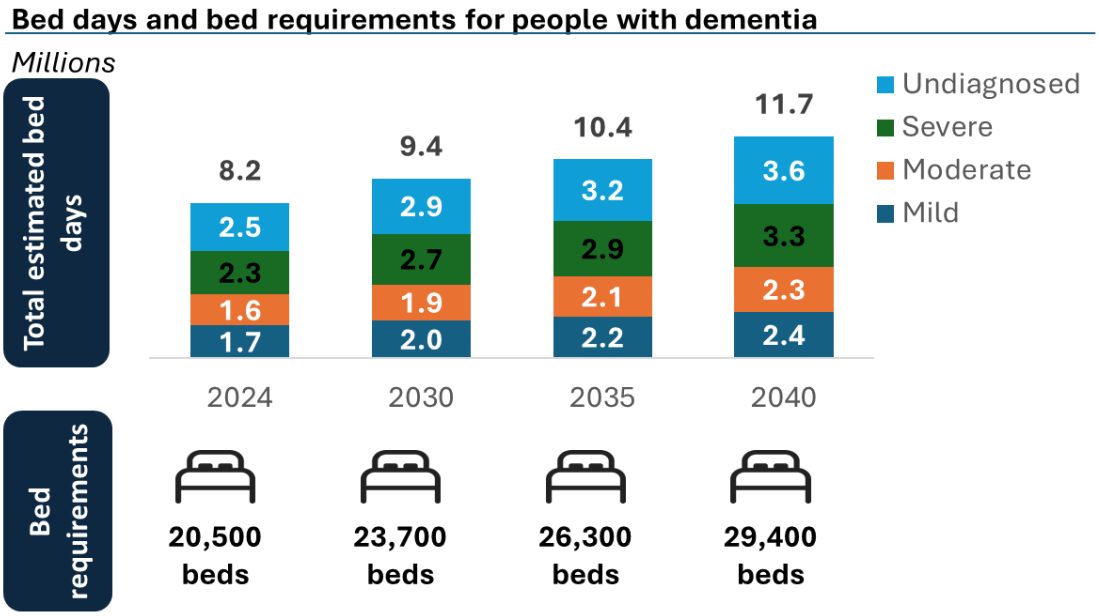
Dementia is a profound and growing whole-system challenge, and the health and social care system response to it is inadequate. More than a third of people with dementia are undiagnosed and the diagnosis process is slow and low-quality. Access to treatment, care and support following diagnosis is insufficient and there are high levels of unwarranted variation in access to diagnosis and care.

[1] **Office for National Statistics (2022).** Death registration summary statistics, England and Wales - Office for National Statistics.
[2] **Alzheimer's Society and Carnall Farrar (2024).** The economic impact of dementia – Module 1: Annual costs of dementia. P11.
[3] Ibid.

A recent report by the King's Fund highlights the need for a system-wide response to dementia,[4] yet currently this response is siloed. Dementia is categorised under mental health in NHS England and under adult social care in the Department of Health and Social Care. Fragmented ownership and leadership has resulted in dementia not receiving the focus or funding required nationally or locally.

Despite good evidence around their effectiveness, there is underinvestment in interventions such as early diagnosis, treatment and dementia training for the care workforce. As a result, dementia has a huge and costly impact on NHS services: one in six hospital beds today are occupied by dementia patients, who also visit the GP up to three times more per year than someone without dementia.[5] Without action, this impact will grow as prevalence increases: by 2040, there will 6.9 million additional primary care contacts associated with dementia, requiring an estimated 1.7 million more hours of primary care time.[6]

Figure 2

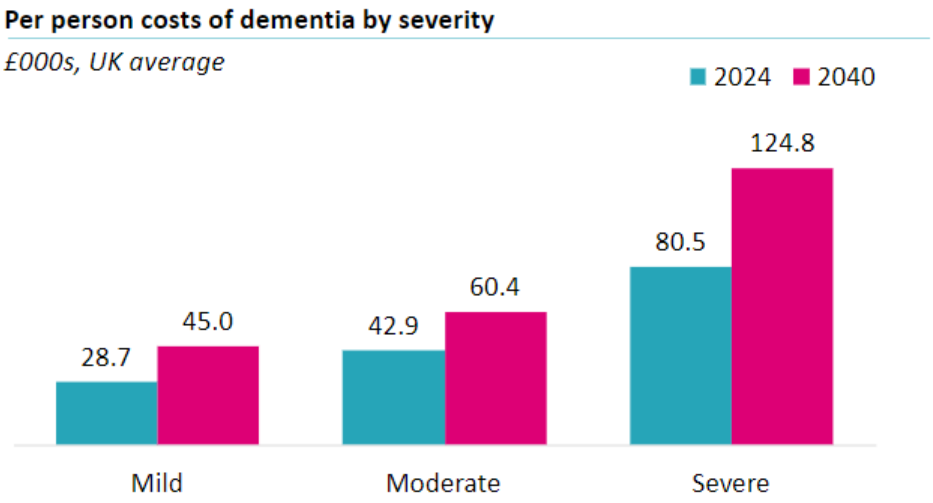


Source: Alzheimer's Society and Carnall Farrar (publication due Sept 2024). The economic impact of dementia, Module 2, p.12.

Dementia is a progressive condition and the cost associated with it grows significantly as severity increases. The average per person annual cost of mild dementia is £29,000: this increases to £81,000 for severe dementia. This illustrates how interventions that can slow the progression of symptoms have significant potential to be cost effective.

[4] **The King's Fund (2024).** The role of integrated care systems in improving dementia diagnosis.
[5] **Alzheimer's Society and Carnall Farrar (2024).** The economic impact of dementia – Module 2: Dementia's contribution to health metrics. P1. Publication due September 2024.
[6] Ibid.

Figure 3



Source: Alzheimer's Society and Carnall Farrar (2024) The economic impact of dementia, Module 1, p.40.

The current approach to dementia spending is reactive

Despite the huge costs of dementia, the UK spends a comparatively small amount on dementia diagnosis and treatment. Spending on diagnosis and treatment is the equivalent of just 1.4% of total healthcare spend on dementia,[7] despite the fact these interventions can reduce costs.[8] By contrast, a third of dementia healthcare costs are generated by unplanned hospital admissions.

Similarly, in social care, there is insufficient investment in the social care workforce. High-quality dementia training for care home staff is cost effective and reduces GP and hospital visits.[9] Training has the potential to reduce staff turnover, resulting in further benefit: Care England has estimated the costs of rehiring for providers at £3 billion each year.[10] This may understate the real cost from missed opportunities to improve patient discharge and the opportunity cost of not developing skills and supporting productivity in the care sector.

A new evidence base

This year, Alzheimer's Society has commissioned wide-ranging evidence, covered above and throughout this submission, that clearly demonstrates how taking action on diagnosis and utilising effective, evidence-based existing treatments can generate significant cost savings and economic benefits. Our economic impact work with Carnall Farrar, for example, is one of the largest UK studies of healthcare resource utilisation by patients with dementia, using a cohort of over 25,000 patients as well as a combination of modelling and expert opinion to identify real per-person healthcare costs incurred. We are therefore bringing significant new evidence to the table that government has not been able to consider in previous Budgets.

[7] **Alzheimer's Society and Carnall Farrar (2024).** The economic impact of dementia – Module 1: Annual costs of dementia. P11.
[8] **Jill Rasmussen (2019).** Alzheimer's Disease – Why We Need Early Diagnosis.
[9] **Ballard, C. et al. (2018).** Impact of person-centred care training and person-centred activities on quality of life, agitation, and antipsychotic use in people with dementia living in nursing homes: A cluster-randomised controlled trial.
[10] **Care England (2024).** Solving the annual £3bn recruitment and retention cost to adult social care providers.

A summary of our recommendations

The government has been clear about the value of shared visions and a long-term, preventative approach. Dementia is a challenge that perfectly matches that approach due to the whole-system nature of the condition, which affects all parts of the health and social care pathway. With new evidence from Alzheimer's Society highlighting the costs of dementia across society, the case for a new, evidence-based approach to dementia has never been stronger. There are therefore three critical areas for action, for which we have laid out detailed recommendations:

Invest in high-quality early diagnosis and treatment

- Bold, ambitious and achievable new diagnosis rate targets
- Improving the quality of diagnosis through dedicated funding
- A targeted awareness campaign to improve recognition of symptoms

Maximise the value of social care spending

- Ensuring all care workers receive dementia training

Data

- Improvements to the recording, collation and analysis of dementia data including greater use of secure data environments (SDEs)

Section 2: Invest in early diagnosis and treatment to improve quality of life and reduce system pressure and costs

In order to improve diagnosis and unlock potential resultant cost savings, investment is required to progress three key goals:

- **The introduction of bold, ambitious and achievable new diagnosis targets**
- **Improvements in quality of diagnosis**
- **A targeted awareness campaign to improve recognition of symptoms**

£17m was invested into dementia diagnosis in 2021/2, but this did not lead to a significant increase in diagnosis rates. We would welcome a conversation with the Treasury and Department of Health and Social Care to ascertain the appropriate level of investment required to achieve the goals listed above.

Context

Early diagnosis and effective treatment and support can help people live independently in their own homes for longer, helping to avoid unnecessary admission to care homes and hospitals.[11] However, spending on dementia diagnosis and treatment is equivalent to just 1.4% of all healthcare spending on dementia.[12]

[11] **Chief Medical Officer (2023).** Annual Report 2023: Health in an Ageing Society. P145.
[12] **Alzheimer's Society and Carnall Farrar (2024).** The economic impact of dementia – Module 1: Annual costs of dementia. P11.

More than a third of people with dementia in England are currently undiagnosed, with the latest available NHS data (July 2024) indicating a diagnosis rate of 65.2%.[13] There are variations in diagnosis rates linked to deprivation, rurality and ethnicity; the July 2024 NHS data highlights over 20% difference between the ICBs with the highest and lowest diagnosis rates.[14]

After diagnosis, large numbers of people lack access to existing interventions and treatments despite them being affordable, effective, and readily available. Only 31% of patients at memory assessment services were offered cognitive stimulation therapy despite it being recommended by NICE,[15] and it is estimated that only 6% of people with dementia are on NICE approved dementia treatment.[16] According to July 2024 data, 34.7% of people with a dementia diagnosis do not receive an annual care plan review.[17]

The government's manifesto noted the importance of transitioning towards a more preventative healthcare system, including moving care out of hospitals to address the challenges of an ageing population. In dementia, diagnosis will be a key part of achieving that. A lack of early diagnosis and intervention in dementia drives unnecessary hospital admissions and costs – the crucial factor delaying intervention is a lack of early diagnosis. This point has been recognised by experts and ministers. Driving higher dementia diagnosis rates will help to achieve the government's objectives.

"As we know, earlier diagnosis means better care and outcomes—it could not be simpler. The national target of two thirds is not good enough."

Andrew Gwynne MP, May 2024

"An early diagnosis [...] helps to avoid early or unnecessary admission to a care home or hospital, enhancing the quality of life for people with dementia and carers, and providing substantial savings on long-term care costs."

Chief Medical Officer, November 2023

"There are many things we can do in the health and care sector to support people if they do get a diagnosis, and importantly there is support for their families and carers too."

Amanda Pritchard, Chief Executive, NHS England, November 2023

Cost benefits of early dementia diagnosis and treatment

Earlier diagnosis and access to treatment and support can help people take control of their condition, live independently in their own home for longer, and maintain a good quality of life for themselves, their family and carers. It can allow carers time to adjust to changes in function, mood and personality and their transition to a caregiver role.

A lack of early diagnosis is associated with increased costs through higher rates of admission to hospitals and residential care, which disturbs efficient care management and ultimately worsens patient and carer quality of life. [18] A literature review has noted the

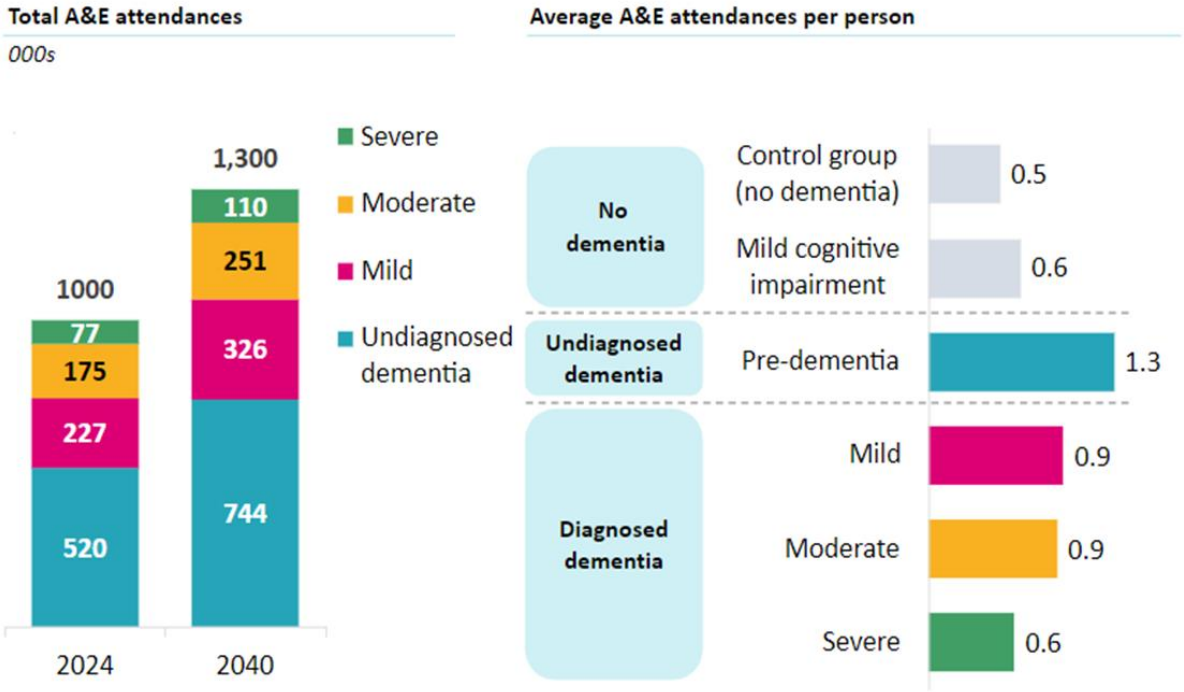
[13] **NHS Digital (2024).** Primary Care Dementia Data, July 2024.
[14] Ibid.
[15] **Royal College of Psychiatrists and HQIP (2024).** National Audit of Dementia: Spotlight Audit in Memory Assessment Services 2023/4. P5.
[16] **Alzheimer's Society and Carnall Farrar (2024).** The economic impact of dementia – Module 1: Annual costs of dementia. P14.
[17] **NHS Digital (2024).** Primary Care Dementia Data, July 2024.
[18] **Jill Rasmussen (2019).** Alzheimer's Disease – Why We Need Early Diagnosis.

substantial net savings diagnosis can provide,[19] and a recently published paper from the Lancet Commission on Dementia noted that early diagnosis and intervention leads to potential economic benefits from preventing unnecessary admissions to hospitals.[20]

Over 250,000 people in England currently live with undiagnosed dementia.[21] New evidence from Alzheimer's Society and Carnall Farrar shows how undiagnosed dementia increases the costs of the disease across the system.

- People with undiagnosed dementia attend A&E, on average, 1.5 times per year, which is more than people with diagnosis dementia of any level of severity, and three times as much as comparable patients without dementia.[22]
- Analysis of people in the two years prior to their diagnosis being recorded showed that pre-diagnosis, the average per person costs for A&E attendances and prescriptions are higher than the costs for people diagnosed with mild dementia.[23]

Figure 4



Source: Alzheimer's Society and Carnall Farrar (publication due Sept 2024). The economic impact of dementia, Module 2, p.31.

Early diagnosis allows for treatment with Acetylcholinesterase (AChE) inhibitors, used to slow cognitive decline for people with Alzheimer's disease and Lewy Body dementia. According to the Lancet Commission on dementia, AChE inhibitors are "cheap with relatively few side-effects; [they] attenuate cognitive deterioration to a modest extent,

[19] Ibid.
[20] **Livingston et al (2024).** Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission. P603.
[21] **NHS Digital (2024).** Primary Care Dementia Data, July 2024.
[22] **Alzheimer's Society and Carnall Farrar (2024).** The economic impact of dementia – Module 2: Dementia's contribution to health metrics. P10. Publication due September 2024.
[23] **Alzheimer's Society and Carnall Farrar (2024).** The economic impact of dementia – Module 1: Annual costs of dementia. P11.

with good evidence of a long-term effect."[24] However, analysis using real world patient data suggests that less than 6% of people with dementia are on NICE-approved dementia medications.[25]

We commissioned scenario modelling to assess potential savings to the system resulting from early diagnosis and treatment with AChE inhibitors. Though AChE inhibitors are not effective for everybody, this research modelled how, where they are effective, early diagnosis and treatment with these medications has the potential to create net cost savings ranging from £8,800 - £44,900 per person by delaying admission to care homes.[26]

Cost savings from earlier diagnosis and treatment are expected to be distributed across both individuals and the state, with people with dementia and their families each saving up to £10,000. Local authorities could save an estimated £38,000 for every person with dementia who can remain in their own home for longer.[27]

The scenario modelling did not include potential savings to the NHS that could be released due to reduce hospital admissions as a result of early diagnosis and effective treatment. It also did not model the effect of further effective post-diagnostic interventions such as cognitive stimulation therapy and memantine.

Recommendations

Bold, ambitious and achievable new diagnosis rate targets

NHS diagnosis rate target of 66.7% means that one third of the population with dementia does not receive a diagnosis. We therefore need to see NHS England setting bold and ambitious new targets for the future, with local systems collaborating and learning from one another by sharing good practice.

The current national diagnosis rate in England is at 65%, below the 66.7% target, but we expect the target to be met this year. Increasing the dementia diagnosis rate is realistic. In England, the existence of high-performing centres confirms this. For instance, South Yorkshire ICB has a high diagnosis rate of 75.6%.[28] International comparisons also show how higher rates of diagnosis nationwide could be achieved; Canada and South Korea are estimated to have dementia diagnosis rates of 83.7% and 73.6%, respectively.

As of 2024, diagnosis and treatment is currently a very small source of costs, with only 1.4% of all dementia healthcare costs spent on memory assessments and dementia-specific treatments.[29]. In short, we have a low rate of diagnosis, but we also have a low rate of spending on diagnosis.

[24] **Livingston et al (2024).** Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission. P573.
[25] **Alzheimer's Society and Carnall Farrar (2024).** The economic impact of dementia – Module 1: Annual costs of dementia. P14.
[26] **Alzheimer's Society and Carnall Farrar (2024).** The economic impact of dementia – Module 4: Impact of early diagnosis and treatment. P8. Publication due September 2024.
[27] **Alzheimer's Society and Carnall Farrar (2024).** The economic impact of dementia – Module 4: Impact of early diagnosis and treatment. P19. Publication due September 2024.
[28] **NHS Digital (2024).** Primary Care Dementia Data, July 2024.
[29] **Alzheimer's Society and Carnall Farrar (2024).** The economic impact of dementia – Module 1: Annual costs of dementia. P11.

There has been partial recovery in the dementia diagnosis rate since the COVID-19 pandemic. Along with a one-off post-pandemic investment in 2021/22 of £17 million, leveraging the dementia diagnosis rate target, including through guidance to ICBs seems to have been the main driver of progress on diagnosis so far. It stands to reason that progressively increasing the target, alongside investment and implementation support, will continue to improve dementia diagnosis rates. The King's Fund has catalogued a number of examples of good practice that investment could help scale.[30]

Improving the quality of dementia diagnosis

There is significant variation in the quality of diagnosis, including speed of diagnosis, accuracy and prompt referral into support services.

Time to diagnosis

Some treatments for dementia are most effective in the earlier stages of disease, but on average a dementia diagnosis takes 3.5 years from the onset of symptoms,[31] and, for about a third of those diagnosed, the diagnosis process takes up to 6 months.[32]

Waiting times are increasing: the average wait time from referral to diagnosis for a person with dementia has increased from 124 to 151 days between 2021 and 2023.[33]

There is also significant variation between services: 32 services assessed in the National Audit of Dementia had none of their patients receiving their diagnosis within 6 weeks of referral and there is significant variation in overall wait time for diagnosis, ranging from 44-347 days at service level.[34] Average wait times were longest in the most deprived areas, with consequences for existing health inequalities.[35]

Accuracy of diagnosis

Current treatments for Alzheimer's disease can delay cognitive decline, but their use requires patients to have a diagnosis of Alzheimer's specifically, not dementia in general. This involves either an MRI scan, a PET scan, a lumbar puncture or cognitive assessment. England has the lowest number of PET and MRI scanners and the second-lowest number of Alzheimer's disease specialists per capita among the G7 countries.[36]

Many memory assessment services experience challenges with brain scan capacity, and currently only 2.1% of patients at memory services receive specialist tests such as PET scans or CSF tests needed to detect the presence of amyloid in the brain.[37]

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[30] **The King's Fund (2024).** The role of integrated care systems in improving dementia diagnosis..
[31] **Aldus et al (2020).** Undiagnosed dementia in primary care: a record linkage study. P65.
[32] **Alzheimer's Society and Walnut (2024).** Personal Experiences of the Dementia Journey – The True Picture. Not yet published.
[33] **Royal College of Psychiatrists and HQIP (2024).** National Audit of Dementia: Spotlight Audit in Memory Assessment Services 2023/4. P4.
[34] **Royal College of Psychiatrists and HQIP (2024).** National Audit of Dementia: Spotlight Audit in Memory Assessment Services 2023/4. P16 and P4.
[35] **Royal College of Psychiatrists and HQIP (2024).** National Audit of Dementia: Spotlight Audit in Memory Assessment Services 2023/4. P11.
[36] **Mattke et al (2024).** Estimated investment need to increase England's capacity to diagnose eligibility for an Alzheimer's treatment to G7 average capacity levels. P1022.
[37] **Royal College of Psychiatrists and HQIP (2024).** National Audit of Dementia: Spotlight Audit in Memory Assessment Services 2023/4: Appendix Documents II-V. P30.

Unequal access to diagnostics can result in a dementia diagnosis that is insufficiently accurate. There is significant variation in diagnosis of Alzheimer's disease in memory assessment services: ranging from 90% of patients with AD in one service, to 6% of patients diagnosed with AD in another.[38] Reasons for this variation are unclear from the available data, but such a high level of variation suggests a serious lack of consistency in either service provision, record keeping or clinical practice.

Specialist tests such as PET scans and CSF tests will be a prerequisite for access to new disease modifying treatments. One has been licensed for use in the UK, though it was rejected by NICE for use on the NHS due to low cost-effectiveness.[39] There are currently 164 active Alzheimer's disease clinical trials,[40] and we expect that more cost-effective treatments will become available over the next two years. It's therefore vital that there is investment in the workforce and infrastructure needed to ensure more people get an early and accurate diagnosis.

Effective management and prompt referral to support

Only 31% of patients received an offer of Cognitive Stimulation Therapy from a memory assessment service, despite clear evidence of its cost effectiveness and it being recommended by NICE.[41] Some services offer 100% of their patients CST whilst others offered it to 0% of patients. Some services did not have the ability to refer for CST and 11 of those services who said they could offer CST had not offered it to any of the patients audited.

Dementia is a progressive disease and annual care plans are therefore essential to ensure that people with dementia receive the right level of treatment, care and support to meet their needs. More than a third (34.7%) of people with a recorded diagnosis of dementia in England did not receive a care plan or care plan review in the preceding 12 months.[42]

Funding decisions around dementia diagnosis are made at a locally by ICBs. However, the scale of the national challenge around dementia is such that we believe there is an argument for national dedicated funding to raise standards.

Initiate a targeted awareness campaign to increase understanding of symptoms

There is a clear case for a targeted awareness campaign for dementia symptoms to increase the rate of dementia diagnosis. Evidence shows that people who do not have substantial impairments in memory and orientation are much less likely to receive a diagnosis. This suggests a lack of both clinical and public awareness of non-memory symptoms of dementia.[43]

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[38] **Royal College of Psychiatrists and HQIP (2024).** National Audit of Dementia: Spotlight Audit in Memory Assessment Services 2023/4. P22.
[39] Lecanemab was approved by the MHRA for use in the UK. Whilst this is available for use in private clinics, it was not approved by NICE for use on the NHS due to poor cost effectiveness.
[40] **Jeffrey Cummings et al (2024).** Alzheimer's disease drug development pipeline: 2024.
[41] **Royal College of Psychiatrists and HQIP (2024).** National Audit of Dementia: Spotlight Audit in Memory Assessment Services 2023/4. P5.
[42] **NHS Digital (2024).** Primary Care Dementia Data, July 2024.
[43] **Aldus et al (2020).** Undiagnosed dementia in primary care: a record linkage study. PV.

A systematic review assessing barriers to dementia diagnosis highlighted how lack of knowledge contributes directly to delays in diagnosis, with people attributing cognitive decline to normal ageing. For some individuals, who did recognise symptoms, there was a feeling that "nothing could be done" due to a belief that there is no treatment for dementia.[44] Other barriers to seeking a diagnosis include a perception that other health worries have greater legitimacy for help seeking than dementia symptoms.[45]

There are several examples of public awareness raising campaigns targeted at increasing diagnosis. For example, the Department of Health and Social Care found that when Act FAST campaign adverts on stroke ran in 2012, public awareness of signs increased. In the two months after the adverts finished running, the NHS in England saw a 24 per cent rise in stroke related 999 calls, and a 16 per cent rise in stroke patients being seen quicker following the campaign in 2011.[46]

A public awareness campaign could build targeted messaging into current NHS resources, such as the NHS app, for which the previous government announced £430m funding to drive technological and digital transformation as part of the Spring Budget.[47] The use of targeted messaging within existing NHS resources could be aligned to the age group and demographic of app-users, including older people or groups with co-morbidities who are at increased risk of developing dementia.

There are also examples of Government working effectively with the third sector to design and deliver health awareness campaigns, not least the FAST campaign, which was designed based on research by Stroke Association. Alzheimer's Society stands ready to work with Government to design a campaign to drive improved awareness of dementia signs and symptoms.

Section 3: Maximise the value of social care spending

Our key call on social care is to ensure all care workers receive dementia training. As covered below, scaling up the NIDUS and WHELD training models would cost approximately £24m and £29.4m respectively, totalling £53.4m or £2,000 per care home in England, and £1,606 per home care agency.

Context

Getting social care right for people with dementia is vital. Insufficient capacity in adult social care continues to contribute to delays in discharging people from hospital, placing further pressures on the NHS.[48]

[44] **Parker et al (2020).** Persistent barriers and facilitators to seeking help for a dementia diagnosis: a systematic review of 30 years of the perspectives of carers and people with dementia.
[45] **Henley et al (2021).** 'We're happy as we are': the experience of living with possible undiagnosed dementia.
[46] **Department of Health and Social Care (2012).** Acting FAST proves it can save hundreds of lives.
[47] **HM Treasury (2024).** Spring Budget 2024.
[48] **Care Quality Commission (2023).** State of care report: the state of health care and social care in England 2022/2023. P8.

Through investment and prioritisation in the right areas, there is an opportunity to make significant progress in social care. The social care sector already adds almost £60 billion to the economy in England each year.[49] With the right investment and prioritisation, the social care system could contribute even more and better help alleviate pressure on NHS services.

The government's manifesto was clear on building toward a National Care Service. It also included a major spending commitment for a Fair Pay Agreement in the sector. This is a substantial and welcome spending commitment in the immediate term. To maximise the benefit of these reforms, we recommend a relatively small financial commitment to ensure all care staff undertake dementia training. Despite relatively low costs, this would deliver significant benefits to quality of life for people living with dementia, to local and national economies, and to the system as a whole through improved staff retention and higher quality care. If people get the right support at home, this can enable them to remain at home for longer reducing the need for more costly residential care.

The effectiveness of dementia training in social care

People with dementia make up around 60% of people drawing on care at home in the UK,[50] and 70% of residents of older age residential care in England.[51] It is therefore concerning that many social care staff lack the knowledge and skills to effectively support someone living with dementia.[52] Less than half (44%) of people living with dementia rate care staff's understanding of dementia positively, and two in five (39%) people say their care was not personalised.[53] Skills for Care data shows that only 45% of care staff in England undertake any kind of dementia training.[54] This is despite the fact that Care Quality Commission (CQC) regulations require providers to ensure that staff: "receive such appropriate support, training, professional development, supervision and appraisal as is necessary to enable them to carry out the duties they are employed to perform".[55]

There Government should therefore introduce a statutory duty for all care providers registered with the CQC to ensure their care staff undertake dementia training, with content mapped to the Dementia Training Standards Framework[56] as appropriate to their role. This should be accompanied by sufficient funding, following the precedent of the Oliver McGowan Mandatory Training (OMMT) on learning disability and autism, enacted in the Health and Care Act 2022.

[49] **Skills for Care (2023).** State of the Adult Social Care Sector in England. P11.
[50] **The Health and Care Champion Subgroup on Homecare (2015).** Dementia and Homecare: Driving Quality and Innovation. PVIII.
[51] **Wittenberg et al (2018).** The Costs of Dementia in England.
[52] **All-Party Parliamentary Group on Dementia** (2022). Workforce Matters: Putting people affected by dementia at the heart of care. P17.
[53] **All-Party Parliamentary Group on Dementia** (2022). Workforce Matters: Putting people affected by dementia at the heart of care. P17 and P26.
[54] **Skills for Care (2023).** The state of the adult social care sector and workforce in England. P141.
[55] **Care Quality Commission (2024).** Regulation 18: Staffing.
[56] **Skills for Health, Health Education England and Skills for Care (2015, updated in 2018).** Dementia Training Standards Framework.

The sector Workforce Strategy for Adult Social Care in England, published in July 2024, recommended that all care staff should undertake dementia training mapped to the Dementia Training Standards Framework. It would be simple and cost effective for Government to implement and fund this recommendation, following the OMMT precedent.

Two dementia training models for care workers demonstrate clear benefits: NIDUS-Professional for domiciliary care workers,[57] and WHELD for care workers in residential care and nursing homes.[58] Benefits include improved quality of life, reduced agitation, and, with respect to the WHELD intervention, reduced hospital and GP visits.[59] The WHELD training shows clear cost benefits: over the nine months of the study, the WHELD programme led to an average cost saving of £4,740 per care home, compared with usual care, equating to a cost saving of £2,000 per care home once the cost of delivering the training was taken into account.[60] This would equate to £29.4million cost savings to the Government if all CQC registered care homes were WHELD trained.

Both training interventions are well-evidenced, able to be scaled nationally, and have relatively low costs. We estimate that to scale the NIDUS-Professional intervention nationally for domiciliary care workers would cost approximately £24 million including staff reimbursement costs. To scale the WHELD intervention nationally would cost approximately £29.4million (i.e. £2,000 per care home for the 14,705 care homes in England as of August 2024).

As well as providing benefits for people with dementia and care staff, training also positively impacts staff retention - a significant benefit given the high turnover in adult social care and current vacancy rate of 8.3% (around three times the average for the economy).[61] Social care staff who receive regular training have a lower turnover rate (31.6%) than those who do not (40.6%),[62] with training being one of five key retention factors (along with higher pay, non-zero-hours contracts, full-time work, and relevant qualifications).[63]

Link skills to the Fair Pay Agreement

In addition to enacting a statutory duty as set out above, the Government could ensure that in the Fair Pay Agreement for care workers, pay levels agreed are linked to training standards, with all roles required to undertake dementia training. Linking pay to skills will ensure the Fair Pay Agreement delivers value for money. A Fair Pay Agreement linked to skills should also both reduce workforce turnover within the sector and see quality of care improved.

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[57] **Cooper et al (2024).** Feasibility and Acceptability of Nidus-Professional, a Training and Support Intervention for Homecare Workers Caring for Clients Living with Dementia: A Cluster-Randomised Feasibility Trial.
[58] **McDermid et al (2024).** Impact of the iWHELD Digital Person-Centered Care Program on Quality of Life, Agitation and Psychotropic Medications in People with Dementia Living in Nursing Homes during the COVID-19 Pandemic: A Randomized Controlled Trial.
[59] Ibid.
[60] **NIHR (2020).** The WHELD programme for people with dementia helps care home staff deliver person-centred care.
[61] **Skills for Care (2024).** A workforce strategy for adult social care in England. P7.
[62] **Skills for Care (2024).** A workforce strategy for adult social care in England. P21.
[63] Ibid.

A more skilled workforce not only can offer a higher quality of care and better outcomes for people living with dementia, but this will also mean a reduced burden on NHS acute, primary and community services. These measures to increase pay and skills will also be an important step to build the foundations for a National Care Service.[64]

Increasing the skills in the workforce is key to improving productivity and unlocking any benefits possible from digital transformation. Skills are vital for economic growth - the government's creation of the Skills England Programme reflects this and recognises that 'a third of productivity improvement over the last two decades explained by improvements to skills levels'[65]. Too often though – the role of skills and training in social care is overlooked. If the government is serious about the economic value of health and social care[66] - it will recognise increasing skills in the social care workforce is just as important for the economy as any other sector.

More generally, Government should implement relevant recommendations in the adult social care sector workforce strategy, published by Skills for Care in July 2024, to improve staff retention and long-term planning for a care workforce fit for the future.

Recommendations

We recommend that the Government ensure all care workers receive dementia training. There are two alternative ways in which this could be done:

- The introduction of a funded statutory duty for all care providers registered with the CQC to ensure their care staff undertake dementia training, with content mapped to the Dementia Training Standards Framework.[67]
- Link pay levels under the Fair Pay Agreement to training standards, with all roles required to undertake high quality dementia training, mapped to the Dementia Training Standards Framework.

Section 4: Investment in quality data to ensure the population health approach works for dementia

We understand the new government remains committed to the value of data to the healthcare system, and to the use of a federated data platform to guide the planning of services and interventions to support population health. To allow this to function properly within dementia, and ensure that this way of working is relevant to social care – the NHS's biggest partner in integration – quality data on dementia must be a focus.

There is a serious disconnect between the scale and urgency of dementia, as the biggest killer in the UK, and the relative paucity of data that exists around the condition. There is a significant inequality in data and evidence between dementia and other major disease areas. Dementia has been identified as one of the biggest killers in Independent

[64] **Wes Streeting (2022).** Our first step to a national care service will be paying carers a proper wage.
[65] **Department of Business Energy, Innovation and Skills (2024).** Skills England to transform opportunities and drive growth.
[66] **Jerome Smail, Nursing in Practice (2024).** Health and care sector can help boost economy, Streeting insists.
[67] **Skills for Health, Health Education England and Skills for Care (2015, updated in 2018).** Dementia Training Standards Framework.

Investigation of NHS Performance, led by Lord Dazi, alongside cancer, suicide and cardiovascular disease (CVD). CVD and cancer have effective audits, patient experience surveys, dashboards and data leadership. These are resources are lacking in dementia.

Improved data is a critical foundation for essential improvements in care, increasing understanding of the dementia pathway, improving service planning and aiding the priorisation of resources. Social care reform and improvements in diagnosis, which are both essential to reducing pressure on the health and social care system, are all dependent on real-time snapshots and future modelling, underpinned by better data. Data is key to identifying and implementing the levers required to delay system pressure resulting from severe dementia – pressure we know is there now and will apply with ever-growing intensity over the next 15 years.

Alzheimer's Society has commissioned research to bridge some of this gap, findings from this research, used throughout this submission, highlight inadequacies in the dementia pathway and the impact that dementia has on the healthcare system and economy. However, there remain significant limitations around evidence and data availability. Gathering this data to enable these improvements is essential to improving NHS performance and preparing the health and social care system for the increase in dementia prevalence that is forecast over the current Parliament and beyond.

Examples of the type of data and evidence required includes:

- Recording of disease severity and progression using a uniform severity measurement tool such as the Mini Mental State Examination
- Prescribing data highlighting the use of NICE-recommended medicines
- Diagnosis data – the recent audit of memory assessment services (MAS) found huge variance between services but was unable to determine reasons behind variation. Moreover, the audit only captures information around diagnosis that takes place in memory clinic setting; we have even less data around diagnosis that takes place in primary care, acute care and care homes.
- Social care provider data, allowing providers and policymakers to better track dementia patient journeys across multiple parts of the system. People living with dementia are the heaviest users of residential social care in particular and data improvements here are particularly critical.
- Research trial data to allow systems to better prepare for interventions and innovations of the future.
- Updated prevalence data. CFAS II is an epidemiological study which has served as a foundation for much other data and modelling on dementia. It is now several years old and many experts report there would be great value in acquiring up-to-date prevalence data. A study similar to CFAS II would cost around £4.5m to £5m today.

In order to address health inequalities linked to dementia, where relevant, all data should record protected characteristics and socio-economic status. A report commissioned by Alzheimer's Society from the Office of Health Economics identified a large number of health inequalities related to dementia including around location, deprivation,

socioeconomic status, age, culture, and ethnicity of people living with dementia with access to and experience of diagnosis and healthcare, A&E attendances and hospital admissions, inclusion in clinical trials, and drug prescribing. However, a major finding of the report was that improving the quality and availability of dementia data collection and publication is essential to improving the understanding of inequalities in dementia.[68]

Benefits of better data

Once acquired, better data can be embedded across other parts of the system. For example, it can be used by regulators to assess performance and will provide greater awareness within the NHS about performance variation, provide greater ability to intervene confidently. Improved data can also be aligned with dementia drug trial data to provide better real-world assessments of clinical impact and cost effectiveness of treatment impact. This will help to achieve the Government's ambition and manifesto commitment of putting Britain at the forefront of transforming treatment for dementia. Further, there is potential for commercialisation of this data, improving the cost effectiveness of this investment for Government.

Recommendations

The two main steps that the Government can take to procure necessary data are:
1. Improvements to record keeping in primary care, memory assessment services and care homes
2. Greater ability for researchers, policymakers and government to access high quality data through the opening up of more secure data environments (SDEs), building on Module 1 of Alzheimer's Society's work around the economic impact of dementia.

The former can be done in a way that is potentially relatively low cost, for example QOF and other incentive schemes could help to encourage better record keeping. The latter requires greater investment but also has significant benefits. The insight we've been able to extract from just a single SDE has helped to advance our understanding of the interactions between the condition of dementia and the health and social care system. Expanding to four further large local systems with SDE capability in England would require investment of £500k-£1m, depending on how effectively economies of scale could be designed into the process.

Improving dementia data is necessary if we are to see an evidence-based response to the UK's biggest killer. Alzheimer's Society is available and willing to be a partner to government to bring about these improvements through the work we have already done through a secure data environment, our expertise, our convening power and our understanding of the lived experience of people with dementia.

[68] **Office of Health Economics (2024).** Inequalities in Dementia: Unveiling the Evidence and Forging a Path Towards Greater Understanding. PV.