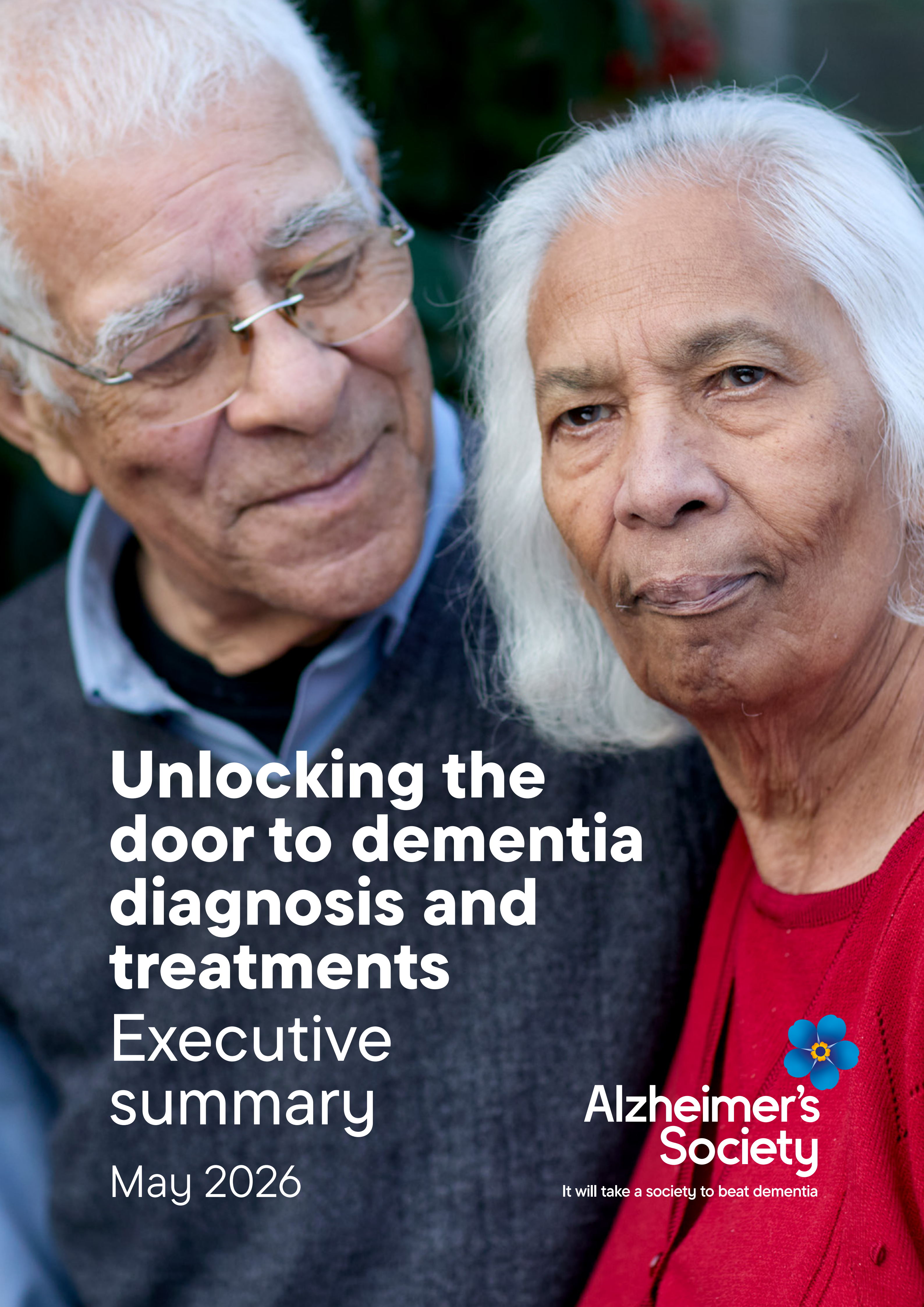


Unlocking the door to dementia diagnosis and treatments

Executive summary

May 2026

Alzheimer's Society

It will take a society to beat dementia

> **“The problem is because they take so long to diagnose, people are missing out on the opportunity to take the drugs and get the benefits out of them.”**
>
> Person living with dementia

1. Call to action

Around **one million people in the UK have dementia**.[1] By 2040, that number will **rise to 1.4 million**.[2] Yet the systems designed to diagnose and support people are struggling to keep pace, with delays, inequalities and missed opportunities far too common. Too many people have a poor experience, wait too long for a diagnosis and receive less treatment and support than clinical guidance says they should.

Everyone with dementia has the right to an early and accurate diagnosis and the best available treatments, including both drug and non-drug interventions. But the door to diagnosis and treatment is too often locked, and both individuals and our health and care systems are paying the price of inaction.

Alzheimer's Society's two new **Unlocking the Door** reports lay out a stark reality — and a clear programme of reform for England, Wales and Northern Ireland.[3] This executive summary sets out the clear opportunity for change, key recommendations, and evidence from the two reports.

2. The opportunity for change

Across both diagnosis and treatment, we see the same underlying challenges:

- **Unwarranted variation and inequalities in access and delivery**
- **Gaps in national guidance and standards**
- **Workforce constraints and capacity challenges**
- **Limited data on variation and outcomes**
- **Insufficient follow-up and a lack of continuity in care**

These issues are not inevitable. They are a result of a lack of investment and prioritisation. By contrast, we have seen improved outcomes in other conditions, including cancer, stroke and heart disease, through:

- **Clear national targets**
- **Structured clinical pathways**
- **Workforce investment**
- **Better use of data**
- **Consistent follow-up and accountability for services**

Dementia has not benefited from the same level of system focus and ambition as these other serious conditions. With rising demand for services, this focus is urgently needed. If we do nothing, the pressures on services and practitioners will only increase, and more people living with dementia will be left without the answers and treatments they need.

The costs of inaction are striking:

- **The cost of dementia in the UK is estimated to be £42bn in 2024, rising to £90bn by 2040 if nothing changes.[4]**
- **The costs of dementia rise significantly as the condition progresses.[5]**

However, these substantial increases in costs – to people living with dementia, health services and wider society - are not inevitable.

This is a key moment for dementia. Not only is there the chance to improve systems for people living with dementia now, but also to ensure readiness for new innovation. New diagnostic tools are emerging which can speed up and improve the accuracy of diagnosis. Disease-modifying treatments that can slow progression of Alzheimer's disease have been proved to be safe and effective. National governments and health systems need to improve diagnosis and treatment now, and in doing so, lay the groundwork for a better future.

> **This is a key moment for dementia. Not only is there the chance to improve systems for people living with dementia now, but also to ensure readiness for new innovation**

3. Our recommendations: a programme of reform

Together, our two reports set out a coherent programme of reform across diagnosis and treatment. These reforms are designed to:

- **Ensure diagnosis is early and accurate**
- **Support consistent access to effective dementia drugs and non-drug interventions**
- **Reduce inequalities and unwarranted regional variation**
- **Strengthen systems' readiness for future innovation in diagnosis and treatments**
- **Deliver better outcomes for people living with dementia and their families**

These reforms are achievable. They mirror successful initiatives that have been taken in other major conditions. Dementia, as the UK's biggest killer, warrants the same level of ambition.

People living with dementia deserve an open door to diagnosis and treatment. We owe it to them – and to future generations – to unlock it.

Clear targets to set national ambition and local accountability

- To drive progress and accountability within and across England, Wales and Northern Ireland, national governments must introduce:
  - A national goal to diagnose more people at an early stage of dementia.
  - A target on diagnostic accuracy, ensuring more diagnoses are biomarker supported. All diagnostic services should have access to the infrastructure needed to achieve this: including all imaging biomarkers (e.g. CT, MRI and PET scanning), CSF testing (lumbar puncture), and increasingly in the future, blood biomarker testing.
  - An 18-week referral to diagnosis target for dementia diagnosis, including care plan and treatment initiation as appropriate, with a long-term goal to enshrine this into elective waiting time targets for each nation.
  - New, more ambitious national diagnosis rate targets.
  - A commitment to make cognitive stimulation therapy (CST) available to everyone with a dementia diagnosis.
- Services, providers and relevant local bodies (ICBs, HSC Trusts and Health Boards) must work together to set appropriate localised targets, based on local population need, to support progress towards these new national targets.

Strengthen clinical guidance and standardise pathways

Clinical guidance from NICE must be updated to better inform and support clinical practice, together with national standards set by governments on collaboration between primary and secondary care.

- NICE must update national guidance to:
  - Embed structured mild cognitive impairment (MCI) identification and follow-up, including offering patients a review every 12 months (where non-neurodegenerative causes have been ruled out), and ultimately developing a new MCI guideline.
  - Help standardise the pathway for diagnosis and treatment, including improving consistency in referral, diagnosis, access to clinical trials and post-diagnostic care.
  - Emphasise persistence with dementia drugs where beneficial, including during transitions (such as from hospital or moving to a care home).
- National governments must set national standards to improve collaboration between primary and secondary care. These must include minimum standards for referrals between services, with templates for use in primary care which include clear prompts for triage, follow-up and referral.
- The UK Government's commitment to a Single National Formulary in England is a welcome development that could improve consistency in access to dementia drugs. Meaningful consultation with people living with dementia must be included in its development.

Invest in and support the workforce

Despite examples of good practice and the hard work of teams of expert professionals, workforce capacity is stretched while dementia prevalence and need for support are increasing.

- National governments and health systems must:
  - Undertake comprehensive workforce mapping across diagnosis and treatment pathways.
  - Invest in workforce expansion in line with the findings of that mapping, including in diagnostic services, specialist and community roles, and delivery of interventions such as CST.
  - Work with medical colleges, charities and local providers to improve training for frontline practitioners, including primary care professionals, on diagnosis, prescribing and management of dementia drugs, and the value of CST.

> **You are just released into the wild.**
> Person living with dementia

Strengthen data and monitoring

Without high-quality, consistent data, it is not possible to understand variation, track progress or target improvement effectively. Strengthening data systems is therefore fundamental to delivering more accurate and equitable diagnosis and treatment across all populations.

- National governments must:
  - Review diagnostic codes used by frontline services to check their suitability for capturing and communicating dementia diagnoses accurately, and update accordingly.
  - Dementia diagnosis data must be published routinely across England, Wales and Northern Ireland, collected as part of a unified dementia registry. The registry should have the capability to link to existing datasets whilst also recording dementia specific information such as methods of diagnosis and results (including biomarkers) and access to treatments. The registry should also consider how it could record appropriate data on unpaid carers and on people's experiences of the diagnostic pathway.
  - Use national and local data to monitor and address inequalities and regional variation in access to both diagnosis and dementia drug and non-drug interventions.

Build system readiness for innovation

Dementia care is on the cusp of being transformed by significant emerging technologies. National governments and health and care systems must act now to ensure they are ready to adopt innovation safely, equitably and at scale. To do this, they must:

- Invest in additional system preparedness planning, including identifying necessary staffing, infrastructure and equipment required. This must be informed by learnings from international comparators already implementing disease-modifying treatments (DMTs) and horizon scanning of the most promising DMTs in the research pipeline. It must also include a focus on preparing for new diagnostic technologies including blood biomarkers.

> The important thing for us was to get Mum on medication as soon as possible. She should've been on medication four months earlier, then it would've been better, but because of the ways things are, that didn't happen.

Family of person living with dementia

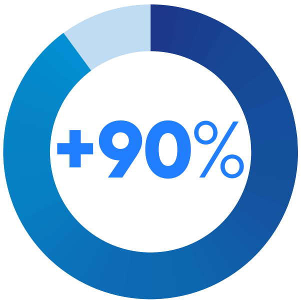
4. Our evidence

4.1 The value of early and accurate diagnosis

Dementia diagnosis benefits people with the condition, families and carers and health and care systems. More than 90% of people with lived experience of dementia (including people living with dementia, unpaid carers, and those close to them) surveyed by Alzheimer's Society saw a benefit to getting a dementia diagnosis.[6]

Diagnosis helps people understand changes in behaviour and cognition, reducing uncertainty and emotional strain.[7,8] When diagnosis happens early, people with dementia report greater independence and reduced anxiety.[9] Over half say that "just knowing" brings clarity and restores a sense of control.[10] A prompt diagnosis opens the door to treatment (dementia drugs and non-drug interventions) and can also provide opportunities for people living with dementia to access clinical trials and research.[11]

What's more, the earlier a diagnosis is made, the better chance this gives people living with dementia and their families to plan for the future and make essential financial and legal arrangements.[12,13] Diagnosis also means families and carers have the opportunity to access carer support, education, peer networks and respite services, helping address their anxiety and stress.[14]



More than 90% of people with lived experience of dementia surveyed by Alzheimer's Society saw a benefit to getting a dementia diagnosis.

> **Over half say that "just knowing" brings clarity and restores a sense of control**

Health and care systems also benefit. Early diagnosis supports safer care and access to treatments, reducing the chance of emergency or unnecessary hospital admissions and offering the potential for substantial cost savings to healthcare systems.[15, 16]

The first disease-modifying treatments were last year approved as safe by the medicines regulator (although not approved by NICE for use on the NHS) and more are now on the horizon, with 130 Alzheimer's disease drugs in clinical trials, over 30 of which are in late stage trials.[17] These work best at an early stage of the condition, so early and accurate diagnosis will be vital for access.

Yet despite the benefits that diagnosis currently brings, and further benefits that will emerge with new diagnostics and treatments, our Unlocking the Door to Diagnosis report finds significant issues across diagnostic pathways.

4.2 The diagnosis pathway

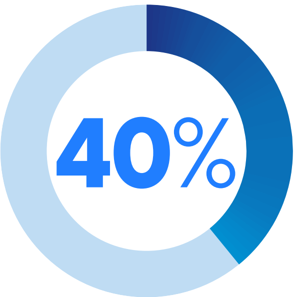
Delays, inequalities and missed opportunities

Currently, more than one in three people living with dementia in the UK do not have a diagnosis, and across England, Wales and Northern Ireland diagnosis is often late, inconsistent and inequitable. [18]

On average, it currently takes 3.5 years from symptom onset to diagnosis.[19] Waiting times from referral to diagnosis are on the rise: in England, the average wait time from referral to diagnosis has risen to 22 weeks.[20] In Wales, many health boards have average waiting times well above the current 12-week referral to diagnosis target.[21]

Inequalities are also evident, with waiting times for diagnosis varying significantly between regions and groups, with deprivation, rurality, and ethnicity all correlated with longer wait times.[22,23,24] People living with young onset dementia are also waiting longer for a diagnosis.[25]

People's poor experiences of diagnosis are reflected in our lived experience survey.



Two in five said the length of the diagnosis process delayed access to support they needed

Only around three in ten respondents reported a positive experience of the diagnosis process (31%), and more than half described the process as stressful (54%).[26] The top issues making the diagnosis process difficult were long waiting times to see a healthcare professional (52%) and seeing lots of different healthcare professionals (41%).[27] Two in five said the length of the diagnosis process delayed access to support they needed (40%).[28]

> **“He [someone from the mental health team] just gave me a letter, there was no consultation with anyone. No sit down with a doctor. It was there we go and that was it … I just wanted to die, disappear.**
>
> Person living with dementia”

Why diagnosis is falling short

Key drivers of these delays, inequalities and missed opportunities include:

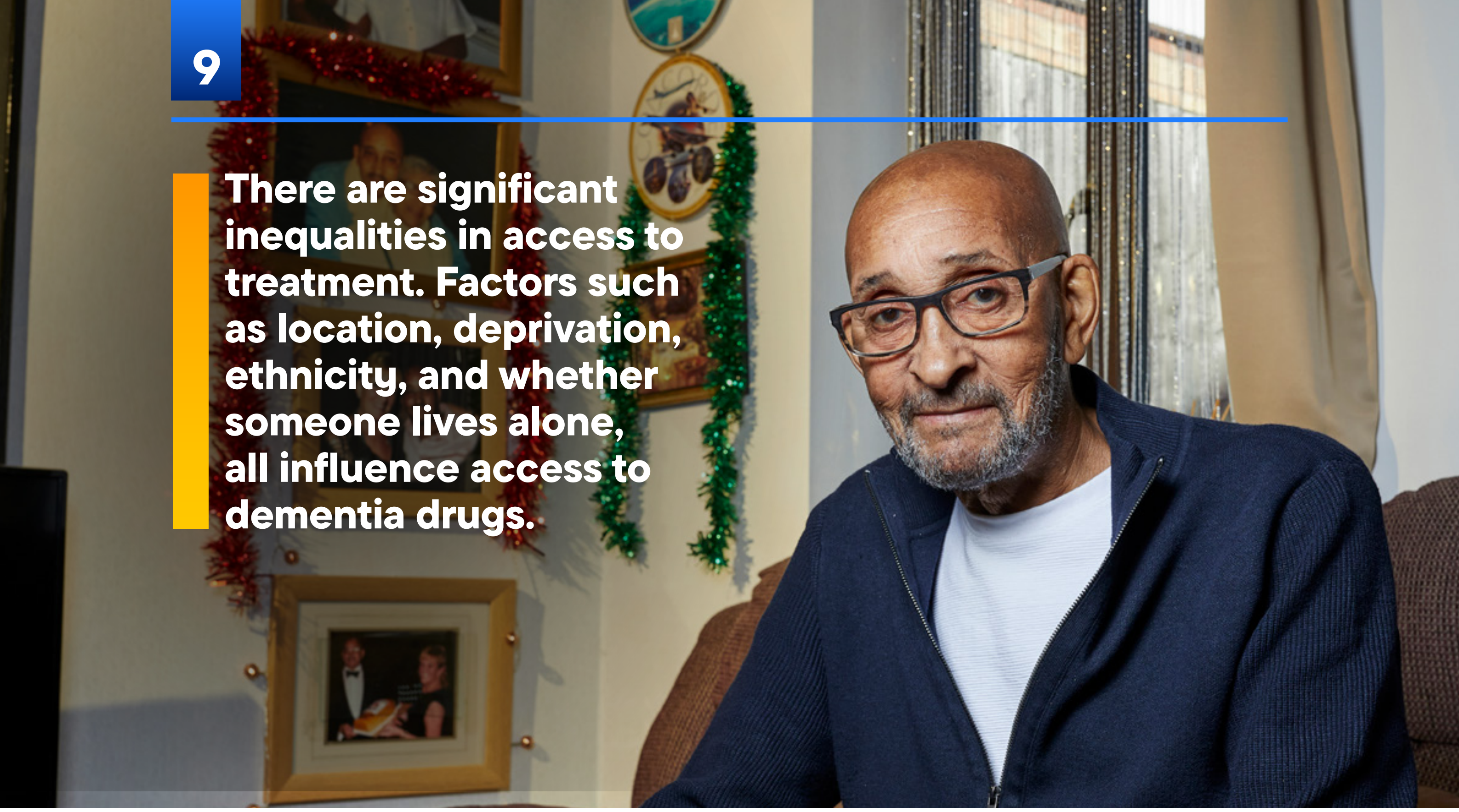
- **A lack of public and primary care practitioner awareness of the benefits of diagnosis:** in a recent survey, four in five GPs said they often encounter patients with signs of dementia who are reluctant to discuss it, and one in five GPs said they do not feel confident diagnosing dementia (although this is not unexpected given the majority of diagnoses currently take place at Memory Assessment Services). [29, 30]
- **A lack of national guidance to support a consistent approach to follow up for people diagnosed with MCI,** meaning opportunities for early dementia diagnosis risk being lost.
- **Service variation and inconsistent referral processes.[31,32]**
- **Workforce pressures, with capacity constraints and rising demand in specialist services.[33]**
- **Limited diagnostic infrastructure.[34]**
- **Inconsistent diagnostic coding used between primary and secondary care.[35]**

If diagnosis is the door to effective treatment and support, then too often this is locked. We argue access to treatment and support must follow.

4.3 Access to dementia drugs and non-drug interventions: inequalities and underuse

NICE recommends both dementia drugs and non-drug interventions for dementia. These have demonstrated benefits. Acetylcholinesterase inhibitors (AChEIs) and memantine can help reduce symptom severity, improve cognition, help people to be able to carry out everyday activities, reduce the impact on carers and on the healthcare system and potentially delay care home admission. [36, 37] Long-term use of AChEIs is also strongly associated with a reduction in mortality.[38, 39]

Cognitive stimulation therapy (CST), a non-drug intervention, has also been shown



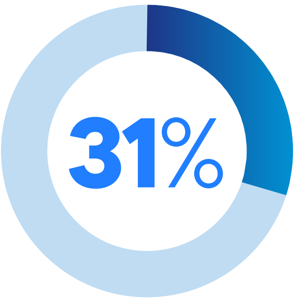
There are significant inequalities in access to treatment. Factors such as location, deprivation, ethnicity, and whether someone lives alone, all influence access to dementia drugs.

to provide short-term benefits in memory and thinking skills for people with mild or moderate dementia, as well as improvements in communication, social interaction, quality of life and mood. [40, 41, 42]

However, our Unlocking the Door to Treatment report has found that access to both dementia drugs and non-drug interventions is inconsistent and inequitable:

Over a third of those with dementia who responded to our lived experience survey had not been offered a non-drug treatment after diagnosis. One in five had not been offered a drug treatment.[43]

Many people with dementia may not be getting the full benefit from dementia drugs because they stop taking them relatively early, with only around half of people remaining on medication one year after initiation.[44] Even fewer were still taking the medication after two years.[45] Potential reasons for this reported by clinicians include care transitions (with poor communication between services leading to treatment interruption), and the fact that dementia, as a progressive neurological condition, makes it harder for a person to manage their medication routine (which may be exacerbated for people living alone).[46]



Only 31% of people diagnosed with dementia were offered CST from memory assessment services in England in 2023/24.

There are significant inequalities in access to treatment. Factors such as location,[47,48] deprivation,[49,50,51] ethnicity,[52,53] and whether someone lives alone, all influence access to dementia drugs.[54]

For CST only 31% of people diagnosed were offered CST from memory assessment services in England in 2023/24.[55]

Interviews we conducted with people with lived experience identified that take-up of some interventions is held back due to stigma of the condition, lack of awareness of non-drug interventions, cultural or language barriers, and/or lack of public transport or carer support to attend sessions.

Overall, it is clear that too many people are missing out from the benefits offered by dementia drugs and non-drug interventions.

4. Conclusion

Too often, the door to accessing to dementia diagnosis, treatments and interventions is locked.

As well as being clinically beneficial and empowering for people living with dementia, early diagnosis and effective treatment are also cost effective, reducing pressures on health and care systems. Failing to invest in earlier diagnosis and better treatment availability is a false economy, as well as a failure to support patients the way they deserve.

The changes we recommend, including ambitious national targets, updated national guidance, and a sustainable workforce, mirror successful initiatives in other conditions. They should be mutually reinforcing elements of a reformed system and are designed to deliver earlier, more accurate and equitable diagnosis and to improve access to existing and new treatments for one of the most challenging health conditions of our time.

This change is vital for people living with dementia. If diagnosis does not improve, people miss treatment and have less chance to benefit from this support and plan for the future. If treatment access does not improve, diagnosis becomes a dead end. Families face avoidable distress. Health and care systems across England, Wales and Northern Ireland then must absorb preventable costs arising from preventable crises.

Together, these reports provide a coherent set of reforms to diagnose earlier, treat better and prepare for the future. There are currently national plans on dementia in development in England and Wales, and a dementia pathway still to be fully implemented in Northern Ireland. Governments must act now. We owe it to people living with dementia now – and to future generations – to unlock the door to diagnosis and treatment.

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Quotes throughout this document are taken from lived experience engagement work conducted as part of the development of our **Unlocking the Door to Treatment** report.

At Alzheimer's Society, we bring people together to end the devastation of dementia. We give vital support to those who need it, fund groundbreaking research and campaign to make dementia the priority it should be.

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