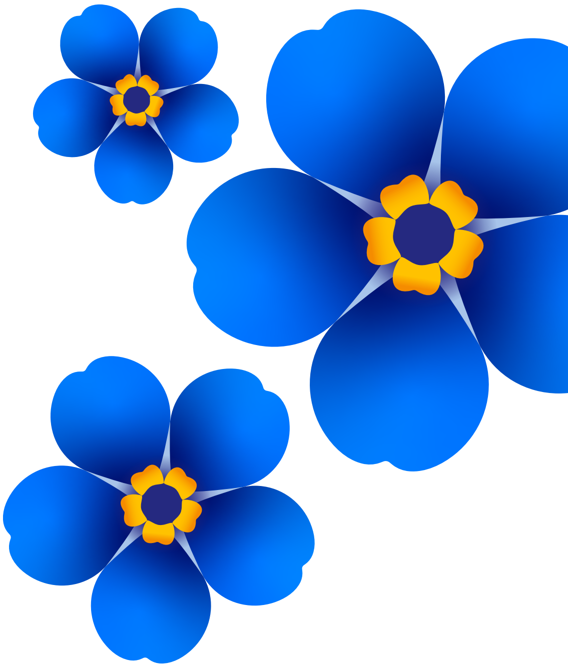
Local Dementia Strategy Recommendations

Alzheimer's Society

It will take a society to beat dementia

Contents



This document was last updated in June 2025. It is part of the **Alzheimer's Society Local Dementia Strategy Toolkit** produced by the Local Systems Influencing Team, with input from and informed by colleagues in our Policy, Research, Evidence and Dementia Services and Partnerships teams, as well as the voices of people living with dementia.

Introduction

This document has been designed to support Local Authorities, Integrated Care Systems (ICSs), and those with responsibility for developing dementia strategies, with guidance on what Alzheimer's Society would recommend is included in a local dementia strategy.

We believe that a well-defined, clear, and accessible dementia strategy should lay the foundations for shaping future support and services in every part of the country and, most importantly, improve the quality of care and support for people living with dementia in the specified local area.

This document includes recommendations that are linked to National Institute for Health and Care Excellence (NICE) guidelines, recommendations taken from previous Alzheimer's Society reports, as well as additional evidence-based recommendations developed as part of our policy and research work.

This body of work is informed by previous dementia strategy reviews carried out across the country, discussions with local authority and ICS leads, and from comments made by people living with dementia. It is also informed by specialist, deep dive research into the increasing challenges facing effective dementia diagnosis and accessible post-diagnostic support.

Within this document, you will find each of our recommendations along with supporting information and evidence. The recommendations included are set out to align with the structure of NHS England's Well Pathway for Dementia[1].

Alzheimer's Society stands ready to support local systems with designing and implementing their dementia strategies. If you would like us to support you with your local dementia strategy, please contact:
local@alzheimers.org.uk

1 in 3 people born today in the UK will develop dementia in their lifetime

Dementia costs the UK £42 billion today, rising to £90 billion by 2040

1 in 6 hospital beds in the UK is currently occupied by a person with dementia

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[1] NHS England. (2016). Well Dementia Pathway

01

Integrated Care System (ICS) wide recommendations

The following recommendations are to be used by Integrated Care Systems when developing dementia strategies that cover all or part of the ICS footprint.

1.1: Every ICS should have a dedicated Dementia Strategy Lead in post.

Each ICS should have a named individual as a dedicated ICS Dementia Lead. The Dementia Lead should be responsible for delivering dementia priorities for health and care services within the ICS footprint as identified by the Integrated Care Partnership (ICP) Integrated Care Strategy, and by the Integrated Care Board (ICB) Joint Forward Plan.

The Dementia Lead must be the accountable person for the implementation of either an ICS-wide dementia strategy, or the coordination of each dementia strategy developed at place level (see recommendation 2).

The ICS Dementia Lead will set and/or co-ordinate priorities for dementia planning and delivery to ensure there is consistent, high quality, comprehensive services across the entire ICS footprint.

We recommend publishing the ICS strategy to promote transparency and accountability for the plan.

The Dementia Lead role should also have accountability for the integrated work conducted at place level via place-based governance boards, local authorities, and in Primary Care Networks (PCNs).

A dementia strategy and action plan supports the development of an integrated dementia pathway.

1.2: All Integrated Care Systems should have a dedicated dementia strategy in place.

Every ICS should have either a dementia strategy developed by the ICS that covers the entire geographical footprint or should help each place within the footprint area to develop their own strategies.

A dementia strategy should outline what care and support people living with dementia can expect from services in the ICS, as well as explaining what steps are being taken to make the local area a fulfilling place to live with dementia. It should also provide clear timelines and targets for how and when services will be improved or developed.

If there is not a single ICS dementia strategy, the Dementia Lead should ensure that:

- commissioned services meet the same quality standard in different areas;
- reporting on quality and performance outcomes is standardised; and
- dementia pathways in each area offer a similar and comprehensive service.

1.3: Every Integrated Care System should have a dementia specific steering group.

Each ICS should set up a dementia-specific steering group bringing together local authority representatives, providers, third sector organisations and people living with dementia.

We believe that there are many dementia-specific challenges across the country that need to be addressed by dedicated dementia steering groups, such as variability in diagnosis rates, waiting times for referral and assessment, inconsistency of support and services, and the postcode lottery of care and support.

Dementia is the UK's biggest killer and has been the leading cause of death for the last 10 years[2]. As such, it is the greatest challenge to our health and social care system. It should therefore be given the recognition and attention it deserves and not be rolled into more generic ageing well or older people's mental health/mental health groups that won't adequately address dementia-specific needs.

Dementia steering groups can address specific issues in the area, bringing together local experts from across the ICS footprint to share learnings and co-produce solutions.

Some Integrated Care Systems have already set up dementia steering groups, and in some cases, these are chaired by the dementia lead for the ICS. We would recommend that Integrated Care Systems advertise these steering groups and dates of the meetings on their websites so that it is easy for people living with dementia, and relevant Voluntary, Community and Social Enterprise (VCSE) organisations to find them and become involved.

Dementia is the UK's biggest killer and has been the leading cause of death for the last 10 years.

1.4: Integrated Care Systems should improve data quality and reporting of dementia-specific data.

Robust dementia data is essential for identifying gaps, tracking progress, and improving services. Consistent collection and reporting provide the foundation for better understanding the dementia pathway, supporting effective service planning, and prioritising resources. High-quality data also helps ensure timely access to appropriate care and support, enabling people living with dementia to maintain a better quality of life.

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[2] **Alzheimer's Society (2021).** Dementia is the UK's leading cause of death | Alzheimer's Society

Data is also essential to address health inequalities. A report commissioned by Alzheimer's Society from the Office of Health Economics identified many health inequalities related to dementia including location, deprivation, socioeconomic status, age, culture, and ethnicity. These inequalities presented in access to and experience of diagnosis and healthcare, A&E attendances and hospital admissions, inclusion in clinical trials, and drug prescribing. 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. Accurate, timely and relevant data can help identify critical aspects of the dementia pathway, particularly in underserved communities.

Data is essential to address health inequalities.

Improvements could be achieved through ensuring that data cleaning exercises are carried out regularly and embedding quality data across all parts of the dementia pathway[3]. For example, by making sure that dementia diagnosis is coded consistently across primary and secondary care services. Some cases of dementia that are diagnosed in secondary care are not coded appropriately in primary care records. As a result, dementia cases are missing from data reporting, and local dementia prevalence is underrepresented.

To improve data quality and reporting of dementia-specific, ICSs should:

- **Improve record keeping in primary care, memory assessment services and care homes. Examples of the type of data and evidence to record include:**
  - Recording of disease severity and progression using a uniform severity measurement tool such as the Mini Mental State Examination (MMSE).
  - Prescribing data highlighting the use of NICE-recommended dementia medicines.
  - Diagnosis data, including waiting times for diagnosis.
  - Social care provider data, allowing providers and policymakers to better track dementia patient journeys across multiple parts of the system.
- **Ensure that, where relevant, all dementia data can be disaggregated by protected characteristics and socio-economic status. This will help address health inequalities linked to dementia.**
- **Ensure that there is greater ability for researchers, policymakers and Government to access high quality data through the opening of more secure data environments (SDEs).**

Improvements to record keeping can be done in a way that is potentially relatively low cost, for example the Quality and Outcomes Framework (QOF) and other incentive schemes could help to encourage better record keeping. Opening up SDEs requires greater investment but also has significant benefits both to the system and to people living with dementia.

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[3] NHS England. (2022). Coding GP Guide 2022

02

Pathway wide recommendations

These recommendations will apply to some or all the dementia pathway, or to the dementia strategy formulation process itself, and as such have been included in this stand-alone section for clarity.

2.1: Systems should work to improve dementia diagnosis and care by creating joined-up services through co-designed integration strategies, involving shared care plans, co-commissioning, and local partnerships.

People living with dementia continue to experience highly varied and fragmented care across the UK. They meet lots of different health and social care professionals that vary across different regions, which can be very confusing and the care they receive can often feel disjointed.

According to the 2024 Walnut survey commissioned by Alzheimer's Society, 24% of people living with dementia said seeing different health care professionals made it hard for them to get a diagnosis[4].

ICSs should ensure that services are more joined-up and better integrated across health, social care and the VCSE sector. ICSs should develop co-commissioning strategies that support practical mechanisms such as shared care plans, and improved information sharing for an integrated service that would ensure a seamless provision of care for people affected by dementia.

Local systems can ensure integration of services by working collaboratively with ADASS, LGA, DHSC, the Office for Health Improvement and Disparities and VCSE organisations like Alzheimer's Society to co-design plans and create appropriate information sharing agreements that would improve communication between relevant bodies providing key services for people living with dementia.

24%

Number of people living with dementia who said seeing different health care professionals made it hard for them to get a diagnosis

2.2: Local dementia strategies should be co-produced with people living with dementia, who should also be involved in monitoring their progress.

People living with dementia should be involved during any refresh, development or monitoring of a dementia strategy. Dementia strategy leads should seek to uphold the value of 'nothing about us, without us' by ensuring the dementia strategy is co-produced by people living with dementia. This can be at place level or higher if this is where the dementia strategy is being developed.

Co-production is a way to involve people living with dementia when producing or evaluating services or products for people with dementia. It is about individuals, communities, and organisations, taking the time to bring their knowledge and experience together to create opportunities for development and to solve problems[5].

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[4] Alzheimer's Society (2024). Personal Experiences of the Dementia Journey – The True Picture

[5] National Development Team for Inclusion. (2010). A guide to co-production with older people

Involving people living with dementia should not stop after the development phase, it should continue throughout the life cycle of the strategy. Involving people with a range of experiences of living with dementia on strategy programme boards will help to provide first-hand examples and greater insight into how the actions in the strategy are having an impact at various stages of the care pathway.

To gain better insight into the local dementia care pathway and the services that are provided along the pathway, use observations as part of any evidence gathering and follow people living with dementia during each stage of strategy development. This will allow for questions to be asked as issues come up during an observation, getting on the spot feedback as to why a certain part of the pathway is an issue.

By engaging with people living with dementia as mentioned above, the local dementia strategy will be much more in tune with local needs. To support you in this engagement we would encourage you to use Alzheimer's Society's Dementia Experience Toolkit, which provides guidance on how to measure the experience of people living with dementia when improving or creating services and products for people living with dementia[6]. The Alzheimer's Society's 'Commissioners' Guide to Involvement'[7] will also support you in this work.

Involving people living with dementia should not stop after the development phase, it should continue throughout the life cycle of the strategy.

2.3: A dementia strategy should be guided by the principles of the Dementia Statements.

The Dementia Statements aim to articulate the rights of people living with dementia and were developed with individuals with lived experience, including people with a diagnosis of dementia and carers as part of a rights-based approach. These statements should be used to shape any dementia strategy and, ideally, be referenced within it. For more information, see resources section of this document[8].

2.4: Systems should commit to ensuring dementia services are full accessible – both physically and culturally – at every stage of the dementia pathway, from diagnosis through to end-of-life care.

With diverse populations, a one-size-fits-all approach to provision and access to services is not appropriate. It is important for services to see the whole person and consider their unique needs and wishes to personalise their care. Services should consider potential barriers to care and work to improve the accessibility of support for the whole community.

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[6] Alzheimer's Society. Dementia Experience Toolkit

[7] Alzheimer's Society. (2024). A Commissioner's Guide to Involvement

[8] Alzheimer's Society. The Dementia Statements and rights-based approach

2.5: Every health and social care professional directly supporting people with dementia should be trained to at least Tier 2 of the NHS-backed Dementia Training Standards Framework.

To ensure that people living with dementia receive the standard of care they need from health and social care services, it is vital that staff are adequately trained in providing specialist dementia care services.

High-quality, evidence-informed dementia training and education for care staff can lead to positive impacts for people living with dementia and the staff delivering care. It can in turn, benefit the wider system by reducing hospital admissions or additional healthcare usage. It also has cost benefits for governments. For example, one recent evidence-based dementia training and education programme trialled in the UK, the well-being and health for people living with dementia, WHELD, showed cost savings of approximately £2,000 per care home per year to the wider health system (made through reductions in use of primary and hospital care). The new interventions for independence in dementia (NIDUS) is another example of well evidenced and impactful dementia training.

Current available evidence indicates five major components for the effective implementation of high-quality dementia training. These components include:

- **Evidence-based training design**
- **Effective delivery method**
- **Inclusive digital learning**
- **Support and accessibility**
- **Strong leadership**

These components only apply to the implementation of dementia training, not its content. Providers must ensure that the content of dementia training is mapped to their relevant national framework, namely the Dementia Training Standards Framework[9] in England, the Dementia Learning and Development Framework[10] in Northern Ireland, and the Good Work Framework in Wales[11]. The content of dementia training should be updated regularly to reflect the latest evidence and best practice guidance in dementia care.

More information on the delivery of high-quality, evidence-based dementia training, including the critical enablers and barriers to dementia training implementation, can be found in our report 'Because we're human too: Why dementia training for care workers matters, and how to deliver it'[12].

High-quality, evidence-informed dementia training and education for care staff can lead to positive impacts for people living with dementia and the staff delivering care.

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[9] Skills for Care. (2021). Dementia Training Standards Framework

[10] Health and Social Care. (2016). The Dementia Learning and Development Framework

[11] Social Care Wales. (2025). Dementia care and support learning and development implementation toolkit

[12] Alzheimer's Society. (2024). Why dementia training for care workers matters and how to deliver it

People living with dementia should be supported by a knowledgeable workforce who understand the complexities of dementia and are able to provide high-quality, personalised care. The Department for Health and Social Care supports the need for dementia training for staff caring for people with dementia and we recommend providers ringfence funding for training purposes[13]. The CQC has also highlighted dementia as a specific area of concern within it's 'The state of health care and adult social care in England' report and highlights the need for staff to have appropriate training to deliver dementia specific support.[14]

2.6: All services should ensure people living with dementia and their carers are given the opportunity to support dementia research.

Dementia is the most significant health and social care challenge we face today. By 2040, the number of people living with dementia in the UK is expected to rise by 43%, which is equivalent to just over two-fifths. Research provides us with hope by helping to uncover the causes of dementia, develop effective treatments, improve care, and ultimately work towards a cure. However, our understanding of dementia still falls behind that of other major conditions, such as cancer or heart disease — a gap that we urgently need to address.

The Prime Minister's Challenge on Dementia 2020 set an ambition to have 25% of people with a dementia diagnosis registered with Join Dementia Research. Join Dementia Research is written into NHS commissioning, NICE guidance and the MSNAP statement; however, only 2% of people living with dementia in England have registered on the site. The National Audit of Dementia conducted by the Royal College of Psychiatrists (2022) found that just 36% of patients were asked by Memory Assessment Services about being contacted for research.[15]

All services that work with people whose lives are affected by dementia across a patient's journey can play a vital role in ensuring people are given the opportunity to get involved in dementia research. It's only by increasing the number of volunteers registering to take part in dementia research through registration services like Join Dementia Research that research can make a difference to people's lives now and in the future.

Dementia is the most significant health and social care challenge we face today.

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[13] **Department of Health and Social Care. (2024).** Care workforce pathway for adult social care

[14] **CQC (2024).** The state of adult social care in England 2024

[15] **Royal College of Psychiatrists. (2022).** National Audit of Dementia - Memory Assessment Service Spotlight Audit 2021. London: Healthcare Quality Improvement Partnership.

03

Preventing well

The recommendations in this section refer to reducing the risks of people developing dementia.

3.1: Local Authorities and Integrated Care Systems should ensure their healthy living messaging references dementia, alongside heart disease and cancers, recognising that what is good for the heart is good for the head.

The Lancet reports that nearly half of all dementia cases worldwide could be prevented or delayed by addressing 14 modifiable risk factors such as hearing impairment, high cholesterol, depression, cardiovascular health, physical activity and other lifestyle factors[16]. Targeted preventative brain health messaging that encourages people to live a healthy lifestyle and to seek a dementia diagnosis can play an important role in helping reduce risk.

Brain health messaging should raise awareness of dementia risk factors and prevention. Regular exercise, mental stimulation, and maintaining a healthy weight can all help to reduce risk of developing dementia.

We also know that smoking and drinking too much can increase the chances of developing the condition, with smokers 50% more likely to develop dementia than non-smokers. Similarly, those with Type 2 diabetes, high blood pressure in middle age or obesity are at greater risk of developing the condition. Health checks and appointments at clinics for conditions recognised as comorbidities for dementia should share preventative messaging.

Quality statement one of the NICE quality standards for dementia points out that there is limited awareness amongst both the public and practitioners that the risk of developing some types of dementia can be reduced or delayed through lifestyle changes[17].

The APPG on Dementia's 2023 report reveals that data from the Office for Health Improvement and Disparities (OHID) shows between 20% – 27% of estimated variation in dementia diagnosis rates can be explained by the level of deprivation or rurality. This is supported by the 2024 report of the Office of Health Economics (OHE), which suggests that diagnosis rates were approximately between 5% and 8% lower in rural areas between 2018 and 2023. These reports indicate the importance of improving local efforts to improve access to dementia diagnosis. Localities should therefore focus on improving prevention messaging in areas with low dementia diagnosis rates, with an aim to tackle reluctance to seek a dementia diagnosis[18].

Using preventative messaging like 'brain health' may be particularly pertinent to younger audiences. One way of raising awareness is to use social prescribers to relay local public health messaging. Social

> Nearly half of all dementia cases worldwide could be prevented or delayed by addressing 14 modifiable risk factors.

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[16] **The Lancet. (2024).** Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission - The Lancet

[17] **National Institute for Health and Care Excellence. (2019).** Quality standards for dementia

[18] **Alzheimer's Society. (2023).** Raising the Barriers: An Action Plan to Tackle Regional Variation in Dementia Diagnosis in England

prescribers play an essential role within the community and may be particularly useful to reach communities with protected characteristics and in rural areas[19].

3.2: Health and Wellbeing Board members should support ongoing implementation of the NHS Health Checks and ensure they include dementia risk factors and how they relate to general health.

Ensuring implementation of the dementia component of the NHS Health Check programme will enable healthcare professionals to talk to their patients about how they can reduce their dementia risk, such as by their social life, keeping mentally and physically active and stopping smoking[20].

All adults aged between 40–74 without a pre-existing condition are eligible for a free NHS Health Check. Since 2018, risk factors for dementia and how to reduce risk have been explicitly included in these 20-minute appointments.

Research shows that awareness of the risks of dementia amongst those who attend a Health Check is higher than for those who do not.[21]

- 52% of adults name dementia as one of their top three health worries.
- 28% have no awareness of any of the risks factors and only 2% are aware of all the things they can do to reduce the risk.
- 60% of people think more information would improve the lives of those living with dementia, while half think a better understanding among the general public would be beneficial.
- 31% of people stated that fear of getting a diagnosis has directly prevented them from seeking help from professionals.
- 45% of dementia cases may be prevented by improved lifestyle choices which address 14 modifiable risk factors.

Implementation of the NHS Health Checks should be supported by:

- Ensuring health professionals who deliver the Health Checks have the tools and knowledge they need.
- Using latest guidance on best practice for Health Checks.
- Improving follow-up including access to appropriate support services to help reduce risk.

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[19] **Alzheimer's Society. (2023).** Improving access to a timely and accurate diagnosis of dementia in England, Wales and Northern Ireland

[20] **Alzheimer's Society. (2016).** Dementia risk now included as part of NHS Health Check

[21] **Alzheimer's Research UK. (2017).** Solutions Research, NHS Health Check 40-64 Dementia Pilot 2017

The same can be said for diagnosis of dementia, with new diagnoses more likely to be identified in those who attend an NHS Health Check than those that do not. However, we know that across the country, take-up of these important Health Checks is low. For the year 2022/23, 38.9% of eligible people invited attended an NHS Health Check in England.[22] This was down 1.6% from the year 2021/22.

To support health professionals who deliver the Health Checks, the Office for Health Improvement and Disparities has developed multiple training resources to support delivery of the dementia component[23]. The resources cover the three mandated components of dementia: general awareness, risk reduction, and signposting for more information on dementia.[24]

3.3 Systems should establish a preventative approach to reducing self-neglect among people living with dementia.

Up to a third of older adults can experience self-neglect and dementia is one of the biggest risk factors due to its effect on people's insight, decision-making capacity and ability to meet their own needs[25].

UK research reveals that most cases of self-neglect and/or hoarding in older adults present at 'crisis' or 'end stage'. One 2021 study interviewing safeguarding leads and managers from across 31 English local authorities echoed this concern - responses stressed the difficulty in addressing causes, given the late stage at which cases come to their attention[26].

Living alone with dementia and weak support networks for people living with dementia is consistently highlighted as a risk factor for self-neglect. Research suggests that 40% of people with dementia are living alone [27]. Those living alone are more likely to have experienced inequalities and have a high level of unmet needs, particularly concerning cognition, physical health, mobility, eyesight and hearing.

Research highlights that taking a preventative approach is crucial in properly identifying and responding to self-neglect cases in older adults. However, due to the complex nature of self-neglect and the influence of life history, medical and psychological factors and social resources, research highlights the need for a collaborative and preventative approach to identifying and addressing self-neglect risk.

40%
of people with dementia live alone

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22 Robson, John et al. British Journal of General Practice (2021). NHS Health Checks: an observational study of equity and outcomes 2009-2017

23 NHS Health Check. (2021). NHS Health Check

24 Public Health England. (2021). NHS Health Check - Dementia training.

25 Mingming Yu, et al. (2021). A systematic review of self-neglect and its risk factors among community-dwelling older adults. Aging Ment Health. 25(12):2179-2190.

26 Social Care Institute for Excellence. (2015). Self-neglect policy and practice: research messages for practitioners

27 National Institute for Health and Care Research (NIHR) Policy Research Unit. (2025). Living alone with dementia: a neglected inequality

To prevent cases of self-neglect amongst older adults from only reaching healthcare professionals at crisis point, people living with dementia should be provided with clear, accessible information about how the condition may affect their ability to meet daily needs. Early connection to appropriate support services and resources can empower people to manage changes more effectively and prevent issues from escalating.

Services should take a proactive approach to identifying individuals at increased risk of self-neglect—particularly those living alone—and engage with them early to build trusting, supportive relationships. Tailored support pathways and consistent, ongoing support can help mitigate risk while promoting independence and autonomy.

Mechanisms should be established to regularly check in with individuals at increased risk of self-neglect, ensuring that any emerging changes or concerns are identified and addressed promptly. Raising public awareness is also crucial to help communities recognise signs of self-neglect and potential risks, encouraging early intervention and support.

Liz Trout, person living with dementia.

04

Diagnosing well

The following recommendations will help to contribute towards ensuring that everyone who needs one receives an early and accurate dementia diagnosis.

4.1: Integrated Care Systems should identify primary care networks (PCN) and GP practices with lower dementia diagnosis rates and work with them to improve performance.

This may include identifying high care home resident populations and low diagnosis rates and work with practices to increase their performance. An early and accurate diagnosis provides huge benefits for the individual. A survey found that over 90% of people affected by dementia see a benefit to getting a dementia diagnosis; for 6 in 10 people affected by dementia, a key benefit is being able to receive the right care[28]. A dementia diagnosis is essential in unlocking access to the care, support, and treatment that can support individuals to manage the condition; as well as supporting better management of other conditions that may be impacted by their dementia. It can also enable care planning and empower people to set priorities, prepare for the future and embrace the here and now.

An early and accurate diagnosis, and subsequent earlier access to care, support and treatment, is not only beneficial for the individual, but for local systems too. Recent evidence suggests that savings of £8,800 to £44,900 per person could be made where nursing home admissions can be delayed through effective management and treatment of Alzheimer's disease[29]. Further benefits include offsetting health care utilisation; for example, undiagnosed people living with dementia attend A&E on average 1.5 times per year, which is more than people with a diagnosis for mild, moderate and severe dementia[30].

> An early diagnosis can delay admission to a care home and save up to £44,900 per person.

The priority for local systems should be supporting Primary Care Networks (PCNs) and GP Practices to ensure they are, at least, meeting the national ambition of 66.7% for dementia diagnosis with plans in place to ensure this is being driven forward.

4.2: Integrated Care Systems should have a system in place locally to monitor the time it takes for a dementia diagnosis to be made. Systems should ensure that people have an assessment and receive a diagnosis as early as possible in line with national guidance.

Our analysis of NHS Digital data shows that the number of people receiving an initial memory assessment and receiving a dementia assessment fell by 16% and 3.6% respectively between March 2024 and February 2025 compared with the same time period in 2023-2024[31]. During the same time period, memory clinic referrals also fell by 2.5%.

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[28] **Alzheimer's Society. (2024).** Personal Experiences of the Dementia Journey – The True Picture

[29] **Alzheimer's Society (2024).** The economic impact of dementia - Impact of early diagnosis and treatment

[30] **Alzheimer's Society. (2024).** The economic impact of dementia - Dementia's contribution to health metrics

[31] **NHS England. (2025).** Primary Care Dementia Data February 2025

A survey of people affected by dementia has found that approximately 30% of people had to wait over 6 months to get a diagnosis and that almost half (49%) agree that a quicker diagnosis would improve the lives of people living with dementia[32]. There is also research that has shown that those who do get a diagnosis live with dementia for an average of 3.5 years before receiving a diagnosis[33].

Considering that both waiting times are increasing and memory clinic referrals are falling, an emphasis on improving early and accurate diagnosis should be critical for local systems.

30% of people had to wait over six months to get a diagnosis.

4.3: Where appropriate, services should recognise and diagnose Mild Cognitive Impairment (MCI). This should be supported by a clear pathway to monitor, track, and support people with a diagnosis of MCI, enabling those who go on to develop dementia to receive an early dementia diagnosis.

Mild Cognitive Impairment is a condition in which someone has minor problems with their cognition, such as with memory or thinking.[34] These difficulties are worse than what would normally be expected for a healthy person of their age. However, the symptoms are not severe enough to interfere significantly with daily life and so are not defined as dementia. There are links between MCI and dementia; as with dementia, incidence of MCI increases with age.[35] It is thought that total prevalence of MCI in the UK is between 12% and 18%.[36] Research suggests that around 16% of people with MCI will go on to develop dementia[37], with some suggesting this may be as high as 20%.[38]

MCI is therefore a significant predictor of dementia[39], and it is important that services recognise MCI and diagnose this where appropriate.[40] When MCI diagnoses are given, these should be recorded and monitored to ensure that those who go on to develop dementia are provided with a

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32 Alzheimer's Society. (2024). Personal Experiences of the Dementia Journey – The True Picture

33 National Institute for Health and Care Research. (2020). Undiagnosed dementia in primary care: a record linkage study

34 Alzheimer's Society (2021). Mild Cognitive Impairment

35 Lu, Y. et al. (2021). Prevalence of mild cognitive impairment in community-dwelling Chinese populations aged over 55 years: a meta-analysis and systematic review. BMC Geriatrics. 55(2):79–91.

36 Richardson, C. et al. (2019). Two-decade change in prevalence of cognitive impairment in the UK. European Journal of Epidemiology. 34(3):1085–1092

37 Michaud, T.L. et al. (2017). The Risk of Incident Mild Cognitive Impairment and Progression to Dementia Considering Mild Cognitive Impairment Subtypes. Dementia and Geriatric Cognitive Disorders Extra. 7(1):15-29.

38 Public Health England (2015). Prevalence of dementia in population groups by protected characteristics A systematic review of the literature.

39 Tomaszewski, S.F. et al. (2009). Progression of Mild Cognitive Impairment to Dementia in Clinic- vs Community-Based Cohorts. Archives of Neurology. 66(9):1151-7.

40 Alzheimer's Society (2021). Regional variation: increasing access to a dementia diagnosis

dementia diagnosis and access to support as early as possible.[41]

Research suggests that neuropsychological testing can be useful in diagnosing MCI and tracking cognitive symptoms.[42] Services may benefit from using this tool to understand who is likely to develop dementia.[43]

We have also heard from health professionals that it is good practice that people with MCI diagnoses are assigned a code and have cognitive tests repeated at regular intervals, such as every six or 12 months.[44] Commissioners should recognise the impact of tracking these cases. It would likely increase services' caseloads, so it is important to consider whether tracking is carried out in primary or secondary care.[45]

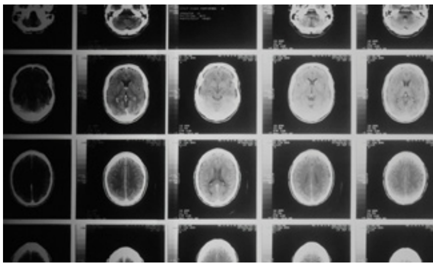
It may be beneficial for memory services to audit conversion rates from MCI to dementia. This may allow further understanding into MCI as a risk factor for dementia, which will help determine which patients are most in need of follow-up.[46]

4.4: Ensure consistent and equitable access to brain scans and cerebrospinal fluid (CSF) testing across all memory services to support early and accurate dementia diagnosis, including identification of dementia type.

Available data suggests that scanning levels remain relatively low, largely due to memory services struggling to access scanners[47]. The National Audit of Dementia's most recent Memory Services Spotlight Audit 2023 found that brain scans such as CT or MRI were requested for just 47% of patients; of those requested scans 94% were carried out. However, the proportion of patients who received a scan as part of their assessment varied widely across services, ranging from 0% to 90%.

Similarly, data from the 2021 audit indicated that this variation is likely driven by inconsistent access to scanners rather than clinical need. Beyond standard imaging, only 2.2% of patients in memory services receive specialist diagnostic tests, such as positron emission tomography (PET) scans or cerebrospinal fluid (CSF) tests via lumbar puncture.

A survey found that 91% of people would be willing to have a brain scan to make an early and accurate diagnosis. However, recent survey data from Alzheimer's Society found that when getting a diagnosis, only a quarter of people had seen a neurologist and less than four in ten people had a brain



In 2023 brain scans such as CT or MRI were requested for just 47% of patients.

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[41] Ibid.

[42] Nelson, A.P & O'Connor, M.G. (2008). Mild cognitive impairment: a neuropsychological perspective. CNS Spectrums. 13(1):56-64.

[43] NHS London Clinical Network (2020). The 2019 national memory service audit. London.

[44] Alzheimer's Society (2021). Regional variation: increasing access to a dementia diagnosis

[45] Ibid.

[46] Robinson, L. (2015). Dementia: timely diagnosis and early intervention. British Medical Journal.

[47] Royal College of Psychiatrists. (2023). Memory Services Spotlight Audit 2023: National Report Publication

scan[48]. Expanding access to these specialist tests would enable more people to receive an early and accurate diagnosis, including a diagnosis of dementia type. In the future, an early and accurate diagnosis will be particularly important for ensuring eligibility for new disease-modifying treatments, if or when they become available on the NHS.

4.5: To facilitate dementia diagnosis, particularly in complex cases, including young onset dementia, there must be formalised arrangements that enable multidisciplinary team meetings between memory service clinicians, neurology, and neuroradiology. Memory services must also have access to Picture Archiving and Communication Systems (PACS).

Waiting for neuroimaging investigations can be a key factor in the time it takes to receive a dementia diagnosis. A lack of access to PACS software, which allows memory services to view images and electronic scan reports, can also be a barrier. Nationally, over 60% of memory services report that they do not have access to PACS[49].

Many cases of dementia are diagnostically straightforward and often do not require neuroimaging examinations. However, in more complex cases of dementia such as younger people presenting with symptoms, or in cases of rarer types of dementia, providing a diagnosis, particularly a subtype, can prove more difficult. Access to PACS allows memory services to interpret brain images alongside a patient's clinical features. This, as well as memory services having joint working arrangements with neurology and neuroradiology enabling the facilitation of clinical case discussion, can help provide an accurate dementia diagnosis.

We recommend a clear pathway is set out with joint working arrangements in place to facilitate communication between clinicians within the diagnostic pathway. This will enable more timely and correct diagnoses being made.

In more complex cases of dementia such as younger people presenting with symptoms, or in cases of rarer types of dementia, providing a diagnosis, particularly a subtype, can prove more difficult.

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[48] Alzheimer's Society. (2024). Personal Experiences of the Dementia Journey – The True Picture

[49] NHS London Clinical Networks. (2019). The 2019 national memory service audit

4.6: Memory services should have clear referral pathways to enable access to psychiatrists, psychologists, occupational therapists, social workers and dementia advisers, as well as linguists and interpreters during the diagnostic process.

At the point of diagnosis, each person will be at a different stage of their condition. Some people are diagnosed early in their condition, whereas others might be diagnosed in the mid to later stages of dementia. This means every individual will have different and varying levels of health and social care needs at the point of reaching a memory service.

Given this variation, it is important that clear referral pathways are in place for memory services to access allied health professionals. This can help to mitigate any symptoms and impact a person may be experiencing at the point of diagnosis, helping to ensure access to the right services at the right time in their dementia journey.

Navigating the health and social care sector can be complex and confusing for people with dementia. Research shows that only three in ten agree that accessing support is easy and that almost a quarter (24%) were not given information on how to seek support following their diagnosis[50]. Yet identification of health and social care needs at point of diagnosis, with clear pathways to allied health professionals, clinicians, and support services, can enable people to access the right services, at the right time, for the right level of need. Some people, particularly younger people presenting with symptoms, may also benefit from pre-assessment counselling.

Navigating the health and social care sector can be complex and confusing for people with dementia.

4.7: Improving diagnostic pathways for ethnic and minority groups.

Ethnic and minority groups face additional barriers towards getting a dementia diagnosis. To support people from different ethnicities, culturally sensitive assessments Rowland Universal Dementia Assessment Scale (RUDAS), General Practitioner Assessment of Cognitive (GPCOG) and Mini-Cognitive Assessment Instrument (Mini-Cog), and employment of interpreters with high quality and accurate interpretation may be necessary. Admiral nurses and care navigators can also play a vital role in providing support to people at the point of diagnosis and into the community.

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[50] **Alzheimer's Society (2024).** Personal Experiences of the Dementia Journey – The True Picture

4.8: To support access to early specialist input, especially in urgent or crisis situations, memory services should consider accepting referrals from sources other than primary care and review non-standard referral pathways.

Referrals should be considered from sources including social services and patients and carers themselves. This, alongside reviewing non-standard pathways to diagnosis will help people access and receive a diagnosis in a timely and equitable way as with standard referral pathways.

Many people will access a memory service through their GP. However, symptoms can be recognised in other settings, such as acute hospital or social care, presenting themselves before attending any primary care setting. It is important to recognise that many older people in hospital or social care settings will possibly have dementia. Facilitating direct access from these services to specialist diagnostic services supports a timelier specialist input.

Whilst primary care is mainly seen as an enabler in the diagnostic pathway, it can also act as a barrier. It is important to recognise most GPs are generalist clinicians and in cases of atypical symptom presentation, dementia may not be the first clinical consideration. This can often lead to people attending their GP multiple times before a referral to secondary care.

Enabling direct access to specialist services from sources other than primary care, particularly in urgent or crisis situations, reduces the number of potential gatekeepers, therefore providing more timely access to a diagnosis. Speeding up the diagnostic process will allow people to better plan for their condition, as well as facilitate access to other support services sooner.

We go into more detail on this within our in-depth look at hospital and care home diagnosis report[51].

1 in 3 people with dementia do not have a diagnosis.

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[51] Alzheimer's Society. (2021). Hospitals and care homes: increasing access to a dementia diagnosis

05

Treating well

The following recommendations relate to treating the symptoms and progression of dementia both medically and holistically as well as preparing systems for future developments in the treatment or management landscape.

5.1: Systems should ensure that everyone diagnosed with dementia has timely access to the full range of effective, evidence-based treatments and personalised support, to improve quality of life and reduce avoidable health and care costs.

There is currently no available treatment that offers a cure for dementia. However, there are many approved medications and interventions recommended by the National Institute for Health and Care Excellence (NICE) that have shown many benefits for people living with dementia[52]. With the right care and support, people living with dementia can live as well as possible for as long as possible[53].

Dementia treatments and interventions include medications, regular reviews and personalised care that aim to address the different complex needs and symptoms of people living with dementia at each stage of the disease progression[54]. They aim to help manage medical symptoms and are usually combined with interventions to help to improve a person's quality of life. They also offer an opportunity to reduce the costs associated with dementia[55].

Early diagnosis allows some people to access existing symptomatic treatments which have been found to improve cognition and quality of life and can reduce unplanned emergency admission to hospital, and delay admissions to residential care.

There are two different types of drug-based treatments for the diseases that cause dementia: symptomatic and disease modifying. Symptomatic treatments such as Acetylcholinesterase (AChE) inhibitors and memantine aim to improve the daily symptoms of living with dementia, but they do not stop the disease from progressing and getting worse[56]. Treatments that can slow down the disease or modify its progression and are known as disease-modifying treatments (DMTs)[57]. There are not currently any DMTs for dementia available for use within the NHS, but there are now two DMTs for Alzheimer's disease which are MHRA approved (and available through private access, for those who are eligible)[58]. There are more DMTs for Alzheimer's disease in the research pipeline and it is likely that more will be submitted to regulators within the next few years.

There is currently no available treatment that offers a cure for dementia. However, there are many approved medications and interventions recommended by the National Institute for Health and Care Excellence.

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[52] National Institute for Health and Care Excellence. (2018). Dementia: assessment, management and support for people living with dementia and their carers.

[53] NHS. (2025). Living well with dementia.

[54] Dubois, B., et al. (2014). Advancing research diagnostic criteria for Alzheimer's disease: The IWG-2 criteria. The Lancet Neurology, 13(6), 614–629.

[55] Alzheimer's Society. (2024). The economic impact of dementia. p (10).

[56] Royal College of Psychiatrists. (2018). Alzheimer's: drug treatments.

[57] Livingston, G., et al. (2024). Dementia prevention, intervention, and care: 2024 report of the Lancet standing commission. The Lancet, 404(10452), 608.

[58] National Institute for Health and Care Excellence. (2025). Final draft guidance finds benefits of 2 Alzheimer's treatments remain too small to justify the additional cost to the NHS

Treatment with AchE inhibitors is used to reduce cognitive decline for people with Alzheimer's disease and Lewy Body dementia. AchE inhibitors can help delay the onset of severe dementia symptoms, enable patients to stay in their own homes for longer, avoid earlier admission to residential care settings, improve quality of life, and generate cost savings[59]. According to the Lancet Commission on dementia, AchE inhibitors are "cheap with relatively few side-effects; reduce cognitive decline to a modest extent, with good evidence of a long-term effect[60]. However, while estimates vary on the exact level of prescriptions of these treatments, it is thought that they are currently under-prescribed.

There are also a variety of non-drug related therapies available to people affected by dementia. They are often used to enhance the well-being and quality of life of individuals living with dementia. These therapies aim to engage and stimulate individuals, promote social interaction, and provide a sense of purpose. They include activities and support that improve learning, memory, mood and social engagement for both people living with dementia and their carers[61].

There are a variety of non-drug related therapies available to people affected by dementia.

5.2: Local system leaders should have agile plans in place for implementing Disease-Modifying Treatments (DMTs) and review the status of these plans on a regular basis, informed by all the relevant evidence, to ensure appropriate system readiness for any new treatments.

Recent breakthroughs in dementia research have led to the development of disease-modifying treatments (DMTs) that can slow the progression of mild or early-stage Alzheimer's disease. Two of these treatments, donanemab and lecanemab have now been approved for use in the UK by the Medicines and Healthcare products Regulatory Agency (MHRA)[62] [63]. However, the National Institute for Health and Care Excellence (NICE) did not recommend them for use in the NHS due to neither drug meeting NICE's cost-effectiveness thresholds[64].

However, with over 130 Alzheimer's disease drugs in clinical trials and over 30 of them in late-stage clinical trials, new treatments may be

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[59] NHS. (2024). Treatment: Alzheimer's disease.

[60] Dubois, B., et al. (2014). Advancing research diagnostic criteria for Alzheimer's disease: The IWG-2 criteria. The Lancet Neurology, 13(6), 614–629.

[61] Livingston, G., et al. (2024). Dementia prevention, intervention, and care: 2024 report of the Lancet standing commission. The Lancet, 404(10452), 610.

[62] Department of Health and Social Care. (2024). Donanemab licensed for early stages of Alzheimer's disease in adult patients who have one or no copies of apolipoprotein E4 gene

[63] Department of Health and Social Care. (2024). Lecanemab licensed for adult patients in the early stages of Alzheimer's disease.

[64] National Institute for Health and Care Excellence. (2025). Final draft guidance finds benefits of 2 Alzheimer's treatments remain too small to justify the additional cost to the NHS

submitted to regulators within the next few years. We can also expect that, like treatments for other conditions like cancer, dementia treatments will become safer, more effective and more affordable over time[65]. Local systems need to be ready for when these new DMTs become available. For example, we know that DMTs like lecanemab and donanemab require early dementia diagnosis and a confirmatory test such as a PET scan and lumbar puncture as requirements for eligibility. It is possible that future DMTs may require similar tests.

National and local healthcare leaders need to prioritise improvements in dementia diagnosis to increase the number of people with dementia who receive a diagnosis and who receive a diagnosis at an early stage of disease progression, in recognition that improving dementia diagnosis is vital to being ready for the DMTs of the future and will also deliver benefits for people living with dementia today.

National and local healthcare system leaders should have agile plans in place for implementing DMTs and should review the status of these plans on a regular basis, informed by all the relevant evidence, to ensure appropriate system readiness.

5.3: Integrated Care Systems (and health and wellbeing boards where appropriate) should regularly review the use and rates of anti-psychotic medication for the treatment of dementia and conduct reviews to ensure that medication use is appropriate.

Ninety percent of people with dementia experience behavioural and psychological symptoms (BPSD) such as aggression, agitation, loss of inhibitions and psychosis (delusions and hallucinations)[66]. These symptoms can be distressing for the person and their carers, as well as putting the person at risk.

People with dementia who experience BPSD are often, and sometimes inappropriately, prescribed antipsychotic drugs used to treat schizophrenia[67]. Antipsychotic drugs do reduce psychotic experiences such as delusion. However, they are also linked to serious side effects, have a moderate benefit, and do not address underlying causes of BPSD[68].

Between 2008 – 2011, the use of anti-psychotics for people with dementia reduced from 17% to 7%, stabilising at around 9.5% between 2018 - 2020. However, during the pandemic prescription rates increased to as high as

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[65] Cummings, J., et al. (2025). Alzheimer's disease drug development pipeline: 2025. Alzheimer's & Dementia: Translational Research & Clinical Interventions, 11(2), e70098.

[66] Seo S, Mattos M. (2021). Modifiable Risk Factors of Behavioral and Psychological Symptoms in People with Dementia. Innov Aging. 2021;5(Suppl 1):645.

[67] NHS England. (2022). Appropriate prescribing of antipsychotic medication in dementia

[68] Stroup TS., Gray N. (2018). Management of common adverse effects of antipsychotic medications. World Psychiatry. 2018;17(3):341-356.

10.1%.[69] It is important that medication reviews of people with dementia are regularly conducted, and any anti-psychotics are only prescribed as a last resort, after other non-pharmacological interventions have been explored, and where it is clinically necessary.

There are many non-pharmaceutical interventions to help those experiencing BPSD such as music therapy, reminiscence therapy and other cognitive stimulating activities[70]. Valuable insight can be gained from the treatment of depression where health clinicians are encouraged to use both non pharmaceutical and drug approaches.

Dr Sarah Ryan, Alzheimer's Society Dementia Research Leader Fellow

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[69] **NHS Digital. (2020).** Dementia diagnosis rate and prescription of antipsychotic medication to people with dementia

[70] **Li YQ, Yin ZH, Zhang XY, et al. (2022).** Non-pharmacological interventions for behavioral and psychological symptoms of dementia: A systematic review and network meta-analysis protocol. **Front Psychiatry. 2022;13:1039752.**

06

Supporting well

The following recommendations have been developed to shape a person’s care and support experience in the immediate 12 months following a dementia diagnosis.

6.1: People diagnosed with dementia must have access to follow-up opportunities to discuss their diagnosis and this should be embedded within the local pathway.

Support for this recommendation could take the form of ICSs committing to help memory assessment services to achieve the Memory Services National Accreditation Programme standard that states all people diagnosed with dementia should be offered a face-to-face post-diagnostic meeting.

Often, diagnostic services are commissioned to provide a diagnostic service only. This can lead to systematic pressure to discharge patients once the diagnosis has been delivered. It can therefore prevent services from offering follow-up opportunities for patients who may have questions about their diagnosis and its implications. This can represent a sticking point within the dementia pathway, resulting in people being discharged from memory clinics and left alone to come to terms with their diagnosis. Research has shown that almost a quarter of people (24%) were not given information on how to seek support following their diagnosis[71].

Clear, consistent local pathways are essential to offer individuals a chance to revisit their diagnosis, and to check how people are and what support they need. For example, a one-month follow-up in primary care by a GP, specialist nurse, dementia advisor or through memory services, could support an integrated pathway[72].

Consistent and ongoing models of care would address the current lack of post-diagnostic support, and particularly help people cope with changes in their family members' behaviour, ensuring that there are opportunities to step up care when more support is needed[73].

24%

of people were not given information on how to seek support following their diagnosis.

6.2: Everyone with a dementia diagnosis should have a named care coordinator.

For example, this could be allocated during the initial post-diagnostic support meeting with the memory service but could be reviewed within primary care.

Due to the progressive and unpredictable nature of dementia, people will encounter a range of services and will often meet lots of different health and social care professionals. This can be very confusing and emotionally draining for the person and the care they receive can often feel disjointed. While information can go some way to ease this, more proactive person-centred support in the form of a care coordinator would help a person living with dementia navigate this complex system[74].

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[71] Alzheimer's Society. (2024). Personal Experiences of the Dementia Journey – The True Picture

[72] Ibid.

[73] Ibid.

[74] Health Innovation. (2024). Opportunities and challenges to delivering a system-wide dementia care coordinator service

Identification of a care coordinator must happen towards the beginning of the pathway, either by a memory clinic or by primary care during a follow-up appointment.

Under NICE guidance, everyone diagnosed with dementia should have access to a named health or social care professional. This person is responsible for coordinating their care from the point of diagnosis to the end of life[75]. During the early stages of the condition, this may involve signposting to services. In later stages, it may involve coordinating all aspects of the person's health and social care.

The care coordinator role may be taken on by one of a variety of different health or social care professionals such as GPs, nurses, psychologists, occupational therapists, social workers, and others[76]. The benefit of a named care coordinator is that it may improve the continuity of care a person with dementia receives. This enables care to be more person-centred and integrated. Ideally, care coordinators should be culturally and linguistically matched to service users, but where impossible, they should be sensitive to their cultural background. Research has shown that only 13% of those surveyed were aware of care co-ordinators as a means of support[77].

Under NICE guidance, everyone diagnosed with dementia should have access to a named health or social care professional.

6.3 Integrated Care Systems should help PCNs to ensure all people living with dementia receive an annual care review.

As of May 2025, 75 per cent of people with dementia had received a review of their care plan in the previous 12 months[78]. In recognition of the importance care plans play in reducing crisis and pressure on acute trusts, ICSs should support primary care to ensure all people living with dementia receive a care plan review.

Local health systems should ensure that everyone has fair and equal access to a review. Currently, those receiving medication to treat symptoms of Alzheimer's Disease may have more contact time with specialists due to regular medication reviews. This may be exacerbated by new pharmaceutical treatments on the horizon.

To improve the quality and time spent on annual reviews, local health systems, such as integrated care systems, should undertake a multi-disciplinary team approach to annual reviews and stagger reviews throughout the calendar year. This will benefit people living with dementia as well as reducing system pressure on general practitioners.

Local Systems should ensure that people at risk of crises are offered care plan reviews more frequently if needed.

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[75] National Institute for Health and Care Excellence. (2019). Quality statement 4: Coordinating care

[76] Ibid.

[77] Alzheimer's Society. (2024). Personal Experiences of the Dementia Journey – The True Picture

[78] OHID (2025). Dementia Surveillance Factsheet - Care Plans

6.4: Evidence-based, post-diagnostic support interventions should be provided for people with dementia and their carers.

Self-report data found 50% of people living with dementia received or accessed support services after their diagnosis[79]. This was lower among people living with dementia who are older, female and have fewer educational qualifications. Additional targeted efforts should be made towards vulnerable groups to improve the efficacy of dementia support. Support interventions must be appropriate and tailored, considering age, ethnicity, religion, gender, language and sexual orientation.

Members of ethnic and minority groups often feel that services and groups are not culturally sensitive or meeting their needs. Services that do provide culturally appropriate care were either non-existent, geographically dispersed, or had long waiting lists. The structure of services, fears of institutional racism, as well as lack of trust were also listed as barriers to access. Particularly for paid care at home, caregivers felt anxious about letting a stranger into the house, experiencing racism, and experiencing professionals lack of cultural competence.

There is a lack of culturally appropriate dementia services.

To overcome this, services should provide interpreters, bilingual resources and create culturally sensitive outreach materials as standard. To improve the dissemination of dementia-related information, community groups should be engaged. Additionally, healthcare providers should be trained in the provision of culturally sensitive care.

Receiving a diagnosis can have a significant emotional and psychological impact on people diagnosed with dementia and their loved ones. Ongoing support is crucial to help manage this impact. Due to increasing demands on secondary care services, the World Alzheimer report 2016 advised shifting towards primary care led post diagnostic support.

For additional information, see the further information section at the end of this document.

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[79] Van Horik, J et al. (2023). International Journal of Geriatric Psychiatry | Wiley Online Library

07

Living well

The following recommendations support people living with dementia to live well in their community following the immediate 12 months post a diagnosis.

7.1: There should be effective assessment of, and appropriate support for, carers of people with dementia in place.

This should include providing straightforward methods of booking overnight care in advance, and accessible lists of recommended local respite care services identified by local authorities. Effectively supporting carers is important for the health of the carer and the person they are caring for. Caring for a person living with dementia can be exhausting for family or friends who are providing informal care. About 40% of family carers of people with dementia have clinically significant depression or anxiety.[80] A carer's psychological health can predict a breakdown in care. Almost half of family carers report moderate loneliness and nearly one fifth report severe loneliness.[81] Interventions promoting positive aspects of caregiving may increase carers beliefs about their competency and resilience.[82] As part of the engagement for our report, From diagnosis to end of life: The lived experiences of dementia care and support, one of the focus groups told us that receiving support from their carers is the only reason they can live well. Carers assessments should be undertaken to ensure appropriate support is provided to carers, facilitates short- and long-term planning, and so they can easily access respite care when needed.

Research as part of our The Fog of Support report[83], shows there is a lack of dementia-appropriate respite services available for carers when they need a short break. Dementia is a complex and progressive condition, requiring different types of care around incontinence, nutrition, dressing, hygiene and more. Couple this with a complex health and social care system and carers often find themselves having to be proactive in seeking support from local authorities, rather than local authorities seeking out carers and offering them a range of services.

Appropriate respite support for people affected by dementia needs to be made available and clearly advertised to those who might need it. The system for booking overnight care in advance needs to be as simple as possible, to ensure the process doesn't add to what is already a complex situation.

Where they do not already exist, local authorities should consider having a dedicated page on their website for people caring for someone with dementia that contains information on council tax exemption, carers rights and local support options.

Effectively supporting carers is important for the health of the carer and the person they are caring for.

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[80] **Livingston, Gill et al. (2020).** Clinical effectiveness of the START (STrAtegies for RelaTives) psychological intervention for family carers and the effects on the cost of care for people with dementia: 6-year follow-up of a randomised controlled trial. **British Journal of Psychiatry, 216(1), 35–42.**

[81] **Victor, C. et al. (2021).** The prevalence and predictors of loneliness in caregivers of people with dementia: findings from the IDEAL programme. **Aging & Mental Health, 25(7).**

[82] **Quinn, C. (2019).** Caregiver influences on 'living well' for people with dementia: Findings from the IDEAL study. **Aging and Mental Health, 24(9):1505-13.**

[83] **Alzheimer's Society. (2020).** The Fog of Support: An inquiry into the provision of respite care and carers assessments for people affected by dementia

7.2: When producing housing plans, local authorities should consider the specific housing needs of people living with dementia in their local area and dementia strategies should commit to addressing specific housing needs of people living with dementia.

Local housing plans should address any shortfall of dementia-ready, social and supported housing in the local area and should consider accessibility needs and adaptations to make houses dementia friendly. These plans could specifically include allocating a percentage to suitable sites, such as town centres, to dementia friendly housing, and researching and reporting on housing needs among people with dementia from ethnic minority communities and LGBT communities.

Additional points to consider include ensuring people affected by dementia receive timely housing information and advice, creating dementia grants which allocate home adaptations, helping people to secure living aids and assistive technology, and planning to prevent emergency admissions and postpone the need for more care in the home or a move into a residential care setting.

Dementia friendly housing reduces the risk of entering long-term care and accessible homes enable independent living which contributes to savings for the NHS and social care worth over £3,000 per year[84].

Local housing plans should address any shortfall of dementia-ready, social and supported housing in the local area.

7.3: Social care services should be provided ensuring that language, communication and cultural needs are met. This should consider projected future population trends and needs.

A person with any type of dementia can have problems with language. This is because dementia can damage the parts of the brain that control language. There may eventually come a time when the person can no longer communicate as they once did.

Language has been identified as a significant barrier for people from ethnic minority communities engaging with care services. A general practice record study from 2023 identified that continuity of care was lower for all Black ethnic groups and some Asian communities compared to their white British counterparts[85]. For example, some older people from ethnic minority communities may be less likely to speak English or use English as their dementia progresses. Instead, they may resort back to their first language.

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[84] Institute for Public Policy Research. (2024). Healthy places, prosperous lives

[85] Stafford, M. et al. (2023). Continuity of care in diverse ethnic groups: a general practice record study in England. British Journal of General Practice; e257-66.

All language and communication needs to be clear, personalised, and non-clinical. For people to receive personalised care, local authorities need to consider the provision of culturally appropriate services and the ability of different communities to access them.

The Rowland Universal Dementia Assessment Scale (RUDAS) is a brief cognitive screening tool crafted to reduce the impact of cultural learning and language diversity when evaluating initial cognitive functioning. This culturally sensitive test can be used without the support of an administrator.

Local authorities should strive to improve access for the Deaf/deaf community. Access to British Sign Language interpreters should be met and additional support should be accessible. The British Deaf Association has created a Deaf/deaf dementia toolkit which can be used by BSL users, their loved ones and staff who are supporting them[86].

It is of the utmost importance to remember that most Deaf/deaf people are born to hearing parents. Deaf/deaf people caring for their loved ones need access to healthcare information in BSL to understand what is happening and being discussed about their loved one.

7.4: There should be ongoing opportunities for people with dementia and carers to access support interventions following diagnosis.

Dementia is a progressive disease, with symptoms worsening over time. This can lead to changes in care needs of the person living with dementia, and support needs for carers. Therefore, people living with dementia should be able to easily access support interventions as soon as their needs or symptoms change. This can help people to live in the way that is important to them for longer.

7.5: Local multidisciplinary teams should be formed to assist local care homes. These teams should include (but not be limited to) palliative care teams, Allied Health Professionals, and wider support services such as dentistry.

Many people living with dementia will spend part of their pathway in nursing and care homes. It is therefore key that nursing and care homes are suitable for people living with dementia and can provide the more advanced and specialist care that their residents will often need. This can be achieved by forming local multidisciplinary teams that can provide clinical input and quick access to advice and support for care home staff, which will enable staff to help residents living with dementia access the care they need, at the right time and in the best place for them. With this support, care homes will be better equipped to avoid unnecessary hospital admissions.

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[86] British Deaf Association. (2019). Dementia Toolkit

7.6: Councils should work to ensure their local authority area is safe and welcoming for people living with dementia.

Too many people living with dementia feel society fails to understand the condition they live with, its impact or how to interact with them. That is why people with dementia sometimes feel they need to withdraw from their community as the condition progresses. Councils should use the social model of disability when working to ensure the community is safe and welcome for people living with dementia[87].

The report by the All-Party Parliamentary Group (APPG) on Dementia in June 2019, noted the work of councils and many other organisations in creating inclusive communities, highlighting the great work that councils like Wigan Borough Council have done, in making their borough more dementia friendly[88].

The latest APPG report on Dementia in October 2023 has built on this suggestion, emphasising the importance of dementia friendly rural communities. The report noted that parish councils provided a central community resource to develop dementia awareness, reduce stigma and signpost into the dementia pathway. This acts as a great enabler for rural communities to access a diagnosis and support.

Everyone, from governments and local shops to book clubs and churches, has a part to play in creating communities where people with dementia feel active, engaged, included, and valued.

Ways in which a council can help to create a dementia friendly area include:

- Listen to and engage with people living with dementia to understand their needs.
- Improve the accessibility of the physical environment, including housing, transport, natural and urban spaces.
- Co-produce new developments and services with people living with dementia.

The following points are important to consider when refreshing local carers strategies:

- A council's carers' strategy should include a specific focus on carers of people with dementia, detailing the support to them, including access to psychological support and practical training for unpaid carers.
- Carers of people with dementia are vital contributors to our health and social care system. Unpaid carers', or families and friends providing care to their loved ones, are providing care to a value of £162 billion per year in England and Wales. Yet many of them are struggling in silence, often dealing with myriad challenges including practical, financial, and emotional difficulties including stress, loneliness, and depression.

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[87] **Inclusion London. (2015).** The Social Model of Disability

[88] **Alzheimer's Society. (2019).** Hidden no more: Dementia and disability

7.7: Systems should ensure hospital discharge planning for people with dementia is person-centred, timely and begins at admission.

People with dementia can experience hospital discharges that are inappropriate, unsafe, and untimely. This can lead to significant challenges, both for people living with dementia and their families, as well as the wider health and social care system.

In 2018/19, 16% of people with dementia admitted to hospital had a change of residence after discharge. Of those who changed residence, 77% went from their own home or carer's home to a nursing or residential facility[89].

Further issues with hospital discharging include:

- **Inappropriate discharge:** just 39% of patients with dementia had a discharge plan initiated within 24 hours of admission[90] even though planning for discharge from point of admission helps ensure this happens in a safe and effective way.
- **Unsafe discharge:** people with dementia sometimes get sent home late at night, without appropriate clothing, and without the support they need to settle into their environment. This can be disorienting and sometimes leads to people being readmitted to hospital, especially when discharged without appropriate care and support in place[91].
- **Delayed discharge:** Upon admission, older people tend to have extended hospital stays and a higher likelihood of encountering delayed discharge[92].

Early dementia diagnosis can prevent unnecessary hospital admissions. A high-quality social care system can both reduce unplanned admissions and speed up appropriate hospital discharge.

Further, we believe discharge models should work for people with dementia. Discharge should occur following a holistic assessment at a place of the persons choosing to inform the appropriate onward care and support which should be arranged. This should happen in a timely manner and ensure the person is equipped with the right information and advice.

Early dementia diagnosis can prevent unnecessary hospital admissions. A high-quality social care system can both reduce unplanned admissions and speed up appropriate hospital discharge.

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[89] Royal College of Psychiatrists. (2019). National Audit of Dementia Care in General Hospitals 2018–2019

[90] Royal College of Psychiatrists. (2023). National Audit of Dementia Round 5 Report

[91] Alzheimer's Society. (2022). Improving hospital experiences for people affected by dementia.

[92] NHS England. (2023). Urgent and Emergency Care Daily Situation Reports 2022-2023

7.8: Systems should reduce unplanned hospital admissions and deterioration in hospital settings among people living with dementia by ensuring early diagnosis, proactive community-based support, and better management of avoidable health risks – recognising that the significant impact on patient outcomes and the high cost to the health and social care system.

Unplanned hospital admission can be distressing for people with dementia, resulting in higher societal costs compared to those without the condition[93]. Data from Public Health England shows that in 2017, people for whom dementia was an underlying or contributory cause of death spent the largest total number of days in hospital in their last year of life in comparison to all other conditions[94]. They also had the highest number of emergency admissions in the last year of life across all conditions. This means that more resources should be targeted towards reducing hospital admissions and increasing comfort and quality of life for people living with dementia, in their usual place of residence.

There is strong evidence that early diagnosis of dementia can help to avoid unnecessary admission to hospital, improving quality of life and providing substantial savings for the health care system[95].

People with dementia can become deconditioned and deteriorate in cognitive function while in hospital due to the unfamiliar environment which can cause disorientation, and lead to behavioural symptoms which complicate care[96].

People with dementia have a five-fold risk of developing delirium during a hospital admission, and the risk increases with the progression of dementia[97]. Delirium is associated with greater risks of longer admission, hospital acquired infections, admission to long term care, and death[98].

Compared to those without cognitive disorders, following admission, people living with dementia have a higher 30-day mortality rate (13.6% v 9.0%), one-year mortality rate (40% v 26%) and readmission rate (62.4% v 51.5%)[99].

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[93] Shepherd, H., et al. (2019). Hospitalisation rates and predictors in people with dementia: a systematic review and meta-analysis. BMC Med 17, 130

[94] Public Health England. (2020). Older people's hospital admissions in the last year of life.

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[96] Digby, R, Lee, S, Williams, A. (2018). The liminality of the patient with dementia in hospital. J Clin Nurs. 27: e70– e79).

[97] National Institute of Health and Care Excellence. (2023). Delirium: prevention, diagnosis and management in hospital and long-term care

[98] Davis, D. et al., & Epidemiological Clinicopathological Studies in Europe (EClipSE) Collaborative Members. (2017). Association of Delirium With Cognitive Decline in Late Life: A Neuropathologic Study of 3 Population-Based Cohort Studies. JAMA psychiatry, 74(3), 244–251)

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08

Dying well

The following recommendations relate to end-of-life care for people living with dementia.

8.1: Integrated Care Systems and Local Authorities should ensure all messaging clearly identifies dementia as a terminal condition to ensure access to palliative care.

We know that people living with dementia often struggle to access palliative care services towards the end of their life. This may be in part because dementia is often not recognised as a terminal condition or incorrectly categorised as a mental health condition. Some health and social care professionals therefore do not see dementia as a condition that would require palliative care, and do not include end-of-life care in care plans.

Dementia is a progressive condition for which there is currently no cure, this means people living with dementia will have dementia at the end of their lives. People living with dementia should have access to high-quality, flexible, needs-based palliative care that understands dementia as a complex progressive condition that can be unpredictable[100].

Integrated Care Systems and Local Authorities must ensure their messaging in relation to dementia identifies the condition as life-limiting and terminal. This will contribute to service providers across the pathway correctly acknowledging dementia as a terminal condition to allow for advance care planning and access to palliative care.

Dementia is a life-limiting and terminal condition.

8.2: Systems should ensure personalised, coordinated end-of-life care for people with dementia, supported by advance care planning and trained staff.

Approaching end-of-life can be a very sensitive and emotional time for people living with dementia, as well as wider family and friend. Everyone living with dementia should be entitled to holistic, personalised end-of-life care and support, in the setting of their choosing.

Health and care staff should be appropriately trained in dementia to enable them to effectively provide high-quality person-centred care. Commissioned palliative and end-of-life resources should be targeted towards reducing hospital admissions and increasing comfort and quality of life in the person's place of residence. The availability of domiciliary care is beneficial in allowing people living with dementia to remain at home for longer.

Planning for the end of life is important for anyone who has a life-limiting and/or terminal condition. For a person with dementia, it is important to have these conversations as early and as often as possible, while they can consider and make choices for themselves. Advance care planning should be discussed at diagnosis and at each health and social care review[101].

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[100] National Institute for Health and Care Excellence (2018). Recommendations | Dementia: assessment, management and support for people living with dementia and their carers | Guidance | NICE

[101] National Institute for Health and Care Excellence. (2019). Quality statement 3: Advance care planning

Discussions at each stage of the pathway will allow for revisions to be made to a care plan and ensure it is up to date reflecting the person living with dementia's current needs and wishes, particularly as their condition progresses. This will also allow for better personalised care as support should be individually tailored to the person living with dementia.

Health and social care staff should recognise dementia as a terminal, life-limiting condition and allow time in appointments for care planning conversations to ensure that individuals' care plans are regularly reviewed and include end-of-life plans including a note of where a person wishes to die. Everyone living with dementia should be entitled to holistic, personalised end-of-life care in the setting of their choosing. Advance care plans should be shareable and digitised so that they can be accessed by health professionals and care home staff involved in a person's care.

When discussing end-of-life care planning, professionals should make efforts to involve family and carers. These discussions will also provide opportunity to signpost carers to bereavement support, so they are aware of their options when they need it.

Dementia-specific palliative care must be provided.

8.3: Local Authorities should conduct an area review of capacity and access to high-quality palliative care. This must include an audit of training for staff working with people living with dementia at the end of life, as well as access to out-of-hours support.

Local Authorities should conduct a review of their area to determine whether there is sufficient availability of accessible palliative care services, and that staff are suitably trained to deliver high-quality end-of-life care to people living with dementia. Where it is identified that a service provider lacks suitable training to deliver dementia-specific palliative care, Local Authorities should encourage the development of partnerships between care homes, hospices, domiciliary care providers, etc, where there's extensive experience in palliative and end of life care. This will support staff learning and facilitate the sharing of good practice.

Councils should endeavour to audit access to out-of-hours support for palliative care, identifying the number of eligible residents and their access to on-call emergency support outside of normal working hours.

Further information

To hear more about our dementia pathway work, or to find out how we can provide additional support with the creation or refresh of a local dementia strategy, please email: **local@alzheimers.org.uk**

Additional resources:

- Reports and briefings
- Policy and influencing
- Dementia 100 Pathway Assessment Tool
- Dementia - Reducing Your Risk
- The Gold Standards Framework: Integrated Care Systems and local authorities may want to consider supporting providers to work towards Gold Standards Framework (GSF) accreditation as part of efforts to strengthen end-of-life care. GSF offers a structured approach to improving the quality and coordination of care, helping to reduce unnecessary hospital admissions and supporting people to die well in their place of residence.
- The Dementia Statements support the rights of people living with dementia to:

  – access an early and accurate diagnosis

  – access appropriate and compassionate care

  – be recognised as partners in care with the right to plan and make decisions about the future, including through co-production.

  The Dementia Statements can be applied when designing strategies and services for people living with dementia, helping to ensure that person-centred care and individual needs are met, including in local settings. They refer to the right for people living with dementia to be protected from discrimination or unfair cost, and for them to be accepted and included in local communities and not live in isolation.

  Including the Dementia Statements in a dementia strategy is a good way of ensuring the views of people living with dementia inform and shape a strategy, this should be in addition to co-production (see recommendation 2.2). The Dementia Statements reflect the things people living with dementia have said are essential to their quality of life[102].
- Additional information for recommendation 6.4 can be found within the Alzheimer's Society report, From Diagnosis to End of Life[103].

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[102] Alzheimer's Society. The Dementia Statements and rights-based approach

[103] Alzheimer's Society (2020). From Diagnosis to End of Life

It will take a society
to beat dementia.

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