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THE CURRENT STATE OF DEMENTIA DIAGNOSIS AND CARE IN ENGLAND

Prepared by

CARE ENGLAND
The voice of care

Dementia Forward
Care and Support for Life

nightingale hammerson

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About Care England:
Care England is the largest and most diverse representative body for independent providers of adult social care in England. It is a registered charity that works collaboratively with its members, stakeholders, and the Government to implement the foundations of a sustainable future for adult social care. Care England represents small, medium, and large providers, including single care homes, small local groups, national providers, and not-for-profit voluntary organisations and aims to improve the quality of care and ensure the health and safety of both staff and residents in care settings and advocates for sustainable policies and practices that address the sector's workforce challenges.

About Dementia Forward:
Dementia Forward is the leading dementia charity for North Yorkshire and York. They provide support, advice and information to anybody affected by dementia across the county, and have developed a comprehensive range of services, including specialist support for people living with young onset dementia.

About Nightingale Hammerson:
A leading expert in Residential, Nursing, Respite, Dementia and Palliative Care, serving the Jewish community since 1840

Foreword

Dementia can affect every aspect of life, and as the leading cause of death in England, its impact stretches far beyond statistics, touching the lives of nearly one million people and their families. Yet, the care and support offered to those living with dementia, particularly those with young-onset dementia and those living alone, remains inconsistent and fragmented.

At Care England, we believe that everyone affected by dementia deserves more than just compassion, they deserve action. This report lays bare the realities faced by individuals, families, and care professionals on the frontline. It presents a sobering picture of delays in diagnosis, postcode lotteries in support, and a troubling lack of integration across health and social care services.

However, this report also offers hope. Through powerful case studies, staff testimonies, and evidence-based recommendations, it shows what good dementia care can, and should, look like. The voices captured here are clear: we must act earlier, train better, and integrate smarter. Importantly, we must listen to those who live with dementia, and to the care professionals who support them, day in and day out.

The removal of the dementia diagnosis rate target and the lack of a national strategy are not just policy oversights, they are missed opportunities to drive meaningful change. If we are serious about improving lives, we must urgently commit to a comprehensive, person-centred, and properly resourced dementia care pathway.

Together, we can create a system that no longer waits for crisis before stepping in, a system that offers clarity, dignity, and support at every stage of the journey.

M L Green

Professor Martin Green OBE
Chief Executive, Care England

Executive Summary

Dementia is the **leading cause of death** in the UK, responsible for 66,876 deaths in 2023, and the number of people living with the condition in England and Wales is projected to rise to 1.4 million by 2040. The associated economic burden is significant, with the total cost expected to more than double from £42 billion in 2024 to £90 billion by 2040. **Despite its scale, the current dementia care system remains fragmented, underfunded, and difficult to navigate, leaving many individuals and families unsupported.**

Major systemic issues persist, including stigma, lack of public awareness, inconsistent diagnosis processes, and poor integration between health and social care services. People with dementia, particularly those living alone or with complex needs, often experience long waits for diagnosis and inconsistent or poor post-diagnostic support, if any at all. Without timely intervention, individuals are at increased risk of avoidable calamities, **the lack of support pushes them to a crisis point,** leading to hospital admissions, abrupt moves into care, or mental health issues.

The removal of the NHS Dementia Diagnosis Rate Target in 2025 has further weakened accountability within the system. The absence of a national benchmark has created a leadership vacuum, reducing the urgency around early diagnosis and care coordination. Although a target alone did not directly improve dementia care, the process had meant that Health and Social Care Teams and people involved in regional dementia strategies had formed working groups. Although nearly half a million people in England had a recorded dementia diagnosis last year, the actual number of people living with dementia is much higher. Diagnosis rates vary by region by nearly 10 percentage points, in the South West, 61.2% of people aged over 65 estimated to have dementia had a recorded diagnosis, compared with 70.1% in the North West[1]. The targets focused people and could be used as an indicator to measure the success or failures of memory services. The situation is particularly dire for vulnerable groups such as those with learning disabilities, young-onset dementia, and individuals living alone.

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[1] CQC, Access to Health and Care Support, (2025)

In response to these systemic challenges, Care England, in partnership with Dementia Forward and care providers, conducted a national survey in January 2025. This initiative aimed to capture the experiences of people living with dementia, their families, and care staff. The findings highlight significant gaps and inequalities in the dementia care pathway and inform a set of urgent policy recommendations.

Key Findings

1

Delayed diagnosis

Nearly **one in three** wait **over a year** for a formal dementia diagnosis

Waiting times for memory clinics can exceed **two years.**

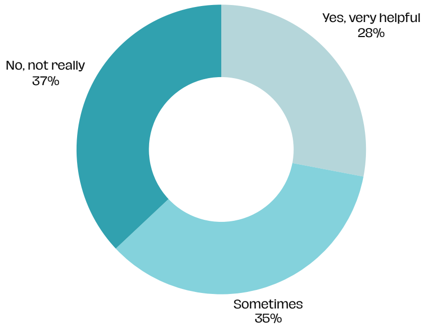
2

Inadequate Support

72% of individuals received **no signposting** to support while waiting for an appointment with a memory clinic

Only 28% of respondents found post-diagnosis support helpful.

Was the support and advice you received helpful?



3

Role of Care Staff

82% of residential care workers have supported diagnostic processes

70% face barriers accessing professional help for residents

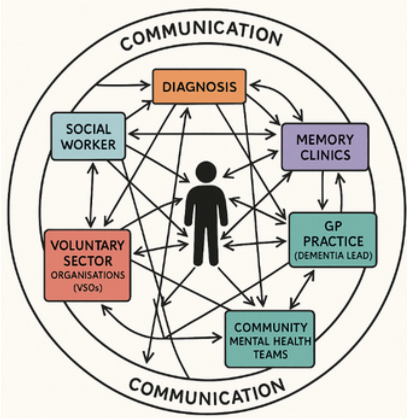
Recommendations

1

Diagnostic Pathway Standards

A national standardised diagnostic pathway must be established and adopted consistently across all regions. This should align with the recommendations of the NAD Memory Service Spotlight Audit, which calls for streamlined processes and better integration across services.

Tools such as the Diagnosing Advanced Dementia Mandate (DiADeM)[2] should be routinely used in care homes to reduce waiting times and promote timely diagnosis, especially for those with advanced needs.


Diangostic Pathway Standard

2

Diagnosis Accountability Framework

The government needs to reintroduce a national dementia diagnosis benchmark, not simply as a target, but as part of a Dementia Accountability Framework.

While the government should consider reinstating a dementia diagnosis target, this should not be seen solely as a numerical goal. Instead, it must be reframed to drive local accountability, reduce delays, and ensure access to post-diagnostic support, and facilitate a multidisciplinary approach.

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[2] *NHS, DiADeM Tool*, (2023)

3

Waiting Well Support Scheme

A nationally mandated standard of care must be established across every stage of the dementia care pathway - including the pre-diagnosis period.

Too often, individuals face long waits with little to no support before reaching a memory clinic. This creates a vacuum where symptoms worsen, families struggle, and individuals fall through the cracks. The ‘Waiting Well’ support scheme offers a model for structured, wrap-around care during this critical period, and must be implemented consistently nationwide.

4

Workforce Education for Care Workers

Provision and funding for national education as a minimum, for care providers to choose tailored workforce education specific to their needs. This workforce education should be a standardised base level of knowledge with the opportunity for more specialised, tailored education.

A blended learning approach, combining e-learning and workshops should be used to ensure practical and applicable skills.

5

Dementia Leads in Every GP Surgery

Every GP surgery should appoint a Dementia Lead responsible for:

- Promoting dementia awareness and education practice among staff.
- Supporting all those involved with information, planning and signposting to local support services.
- Liaising with specialists, community teams, and voluntary organisations.

The Dementia Lead will help maintain dementia as a visible and ongoing priority within dementia care.

Background

Dementia is the leading cause of death in the UK [3], claiming the lives of **66,876 people in 2023**. As a progressive condition, dementia causes gradual and irreversible damage to the brain, severely impairing essential functions *beyond memory loss* and ultimately leading to a significant decline in health and independence. The number of people living with dementia in England and Wales is projected to rise to **1.4 million by 2040**, underscoring the urgent need for effective care and support. In addition to the profound human impact, the economic burden is substantial—costing the UK **£42 billion in 2024, with projections reaching £90 billion by 2040** [4].

Despite the fact that almost everyone in the UK is likely to be effected by dementia, whether by developing it themselves, or via a family member or friend, there are **barriers within the dementia care pathway** - including stigma, lack of awareness and knowledge, and lack of integration between health and social care – that not only **hinder timely diagnosis, but also affect the quality of support** received by individuals living with dementia and their families.

Dementia Care Pathway Barriers

Early Symptoms

- ⚠ Stigma
- ⚠ Lack of Awareness
- ⚠ Isolation
- ⚠ Misdiagnosis

Diagnosis

- ⚠ Inconsistent Processes
- ⚠ Lack of Training
- ⚠ Delayed Access
- ⚠ Lack of Capacity

Access to Care

- ⚠ Environment/ Choice
- ⚠ Postcode Lottery
- ⚠ Option Limitations
- ⚠ Complex Funding

Long-Term Support

- ⚠ Location Dependent
- ⚠ Workforce Challenges
- ⚠ Not person-centred

⚠ **Throughout:** Lack of Integration, Funding, & Support for the Third Sector

[3] *Alzheimer's Society, Dementia is One of The Biggest Killers in the UK, (2021)*
[4] *Nuffield Trust, What Needs to Improve for Social Care to Better Support People with Dementia, (2024)*

Previous reports [5] have highlighted that those caring for individuals with dementia, those living with dementia and their friends and relatives often feel unheard and isolated - further exacerbated by a slow and stressful diagnostic process, which can delay much-needed support and resources. A streamlined and efficient dementia care pathway, with a focus on early diagnosis and continuous support, is critical to ensure those with dementia, their relatives and friends are not left to navigate these challenges alone, and it is vital to ensure early intervention of treatment and care, so the individual, their relatives and friends are well-supported throughout the whole process. Importantly, funding early intervention is likely to be significantly less costly than funding delays in assessment, diagnosis, and treatment, making a clear case for investment in timely support.

Without an early diagnosis, a person may not have access to support until they reach a crisis point - which should be avoided at all costs. The lack of integration between health and social care within the dementia care pathway, highlights the varying degrees of support and services available to those with dementia. If the process became more coherent, the postcode lottery of care and diagnosis may not be as apparent as we currently see.

This is particularly important given that many people living with dementia are doing so **alone** - it is estimated that around 120,000 people with dementia in the UK live by themselves [6]. Without someone close to them to notice the early signs, individuals may not recognise symptoms themselves – leading to increased isolation, especially as friends or social networks withdraw from contact. If the individual does not understand what is happening to them or why their connections are changing, they are far less likely to seek help or access appropriate treatment and support. It is vital that people living alone have support to navigate the dementia care system and connect with services and networks [7], this emphasises how much harder it is for individuals living alone to access support. There is a need for greater awareness for pre and post-diagnostic support for individuals living with dementia alone.

In January 2025, the Government scrapped the dementia diagnosis rate targets in the NHS Operational Planning Guidance 2025-26. Prior to this announcement, the target sat at 66.7% [8] - with no target timeline. Although the target alone did not help improve dementia care, it was the **only thing holding the NHS and government to account**, as the target kept focus on dementia diagnosis which aimed to identify those with dementia as soon as possible. The target meant that Health and Social Care Teams and people involved in regional dementia strategies had formed working groups. The targets focused people and could be used as an indicator to measure the effectiveness of memory services.

[5] *Alzheimer's Society, Personal Experiences of the Dementia Journey - The True Picture, (2024)*
[6] *Dementia UK, Living Alone with Dementia, (2024)*
[7] *NIHR - Dementia Researcher, Living Alone with Dementia: Addressing Hidden Inequalities, (2025)*
[8] *Alzheimer's Society, Our Response to the NHS Dementia Diagnosis Target Cuts, (2025)*

According to NHS England data [9], at the end of February 2025, 65.4% of patients aged 65 or over who are estimated to have dementia had a recorded diagnosis of dementia. This rate has gradually increased from 62.6% since October 2022.

However, the previous dementia diagnosis rate target of 66.7% has been removed from the NHS Operational Planning Guidance for 2025/26 [10]. This is a concerning step backward. Prioritising early intervention and improving support for both individuals with dementia, their relatives, and their carers, will help to ensure that the dementia care pathway can be an inclusive environment, providing adequate advice and support.

The target allowed for individuals to have a chance to receive the appropriate support and care in a timely manner; however, **the removal of the target means there is now nothing motivating NHS professionals to identify people living with dementia, and nothing holding them to account.** It raises larger concerns that there is carelessness from Government to adequately address the needs of those living with dementia.

As a result of the chronic barriers in dementia care and a lack of Government support, Care England alongside Dementia Forward and care providers leading the way in dementia care, joined together to assess the current needs of people living with dementia now. They launched a survey in January 2025, which aimed to gain the views of people living with dementia, their family and friends, as well as their care workers. The data collected from survey, outlined in this report, provides the evidence needed to address the gaps and opportunities in the dementia care pathway, ultimately making recommendations to Government of how they can support people living with dementia, their friends and family, and support staff – creating a better quality of life for those affected now.

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[9]NHS, Primary Care Dementia Data, (2025)
[10]CQC, Access to Health and Care Support, (2025)

Common Misconceptions

Dementia is an umbrella term used to describe a range of progressive neurological disorders that affect brain function. **It is not a single disease, but rather a collective term for various conditions that impact memory, thinking, behaviour, and the ability to perform everyday activities.**

There are over 100 types of dementia. Within this report, we are using the term dementia to describe all dementias. The most common dementias are: Alzheimer's disease, Lewy Body, vascular and fronto-temporal lobe and additionally, there are rarer forms such as progressive supranuclear palsy, Huntington's disease and Prion disease which each have a unique set of symptoms illustrating the importance of a specific diagnosis. Furthermore, individuals with learning disabilities, particularly those with Down's syndrome, are at an increased risk of developing dementia, as well as those with Parkinson's disease and alcohol-related dementia, which is a brain disorder caused by binge drinking over several years[11].

Dementia is progressive, leading to brain degeneration over a period of time, which severely impairs critical functions beyond memory loss, ultimately contributing to a person's decline in health and independence [12]. A diagnosis is important to identify a prognosis, potential treatment and care moving forward.

A common misconception is that dementia **always** results in memory loss. However, this is **not universally true across all types**. For instance, frontotemporal dementia primarily affects behaviour and personality, often without initially impairing memory.

This challenges the appropriateness of the term "memory clinic," which may mislead individuals into thinking memory loss is a prerequisite for diagnosis [13], and therefore delay initial contact with a GP to investigate symptoms.

[11] Alzheimer's Society, Types of Dementia
[12] Barchester, Common Myths Surrounding Dementia, (2017)
[13] Norton Healthcare, A person can Have Dementia Without Memory Loss, (2024)

Types of Dementia: Prevalence and Key Characteristics

Disease Type	Approx. % of all Cases	Core Symptoms
Alzheimer’s	60%	Memory loss, confusion, difficulty with language and problem-solving
Vascular Dementia	15%	Slowed thinking, poor concentration, stroke-related symptoms
Dementia with Lewy bodies	10%	Hallucinations, fluctuating attention, Parkinson’s-like movement issues
Mixed Dementia	10%	Combination of memory loss and executive/motor problems
Frontotemporal Dementia	2%	Personality and behaviour changes, language difficulties

While often associated with older adults, dementia can also affect younger individuals. Known as **young-onset dementia**, and sometimes referred to as early-onset dementia, this form typically arises in individuals between the ages of 30 and 65. In the UK, it is estimated that there is around **70,000 people living with young-onset dementia,** accounting for approximately 7.5% of the total population affected by the disease [14], because there is not a specific NHS coding for this cohort of people, data is unreliable and there is no designated funding, meaning that care is allocated to older peoples services, neglecting age appropriate support for this demographic. **To learn more about the challenges associated with young-onset dementia, read Care England and Dementia Forward’s report ‘Young Onset Dementia Current Struggles and Recommendations.’[15]**

While young-onset dementia affects adults under 65, there is a lesser-known condition, **childhood dementia**. This progressive brain disorder is caused by over 100 genetic conditions, and although the UK has no data on this, in Australia approximately 1 in 2,900 babies are born with the condition which causes childhood dementia. As with all dementias, childhood dementia is terminal, where 50% of children die by age 10, and 71% of children die before reaching their 18th birthday [16], highlighting a more urgent need for increased awareness and initiatives.

[14] Care England, Young Onset Dementia - Current Struggles & Recommendations, (2024)
[15] ibid.
[16] Childhood Dementia Initiative, State of Childhood Dementia in Australia 2024, (2024)

Dementia Diagnosis

GPs and Primary Care

As the demand for dementia diagnoses increases—particularly among frail, elderly, and housebound individuals—primary care settings are increasingly being seen as both accessible and appropriate locations for diagnosis. Not only can this approach offer a more comfortable and familiar setting for patients, but it can also help relieve pressure on overstretched specialist memory services.

However, there remain several persistent issues within GP and primary care practice that contribute to delays, inconsistent diagnosis, and fragmented post-diagnostic support. These include:

Limited awareness of local and community-based support services
GPs are well-placed to signpost individuals and families to dementia support, but many remain unaware of local resources or post-diagnostic pathways. This lack of knowledge reduces the likelihood of timely referrals and community engagement.

Insufficient involvement in care planning
Despite the progressive nature of dementia, **fewer than 40% of people with dementia received a care plan or review in 2023–24 [17].** GPs, though often under time pressure, should play a greater role in initiating and updating care plans to ensure coordinated support for individuals and their families.

Inconsistent or inaccurate coding of dementia in primary care records
Accurate coding is vital for understanding the prevalence of dementia and planning appropriate care and funding for support services. Yet this has been lacking, particularly in cases of young-onset dementia. There is now a call for retrospective coding to build a clearer picture of the true scale and nature of the condition.

Overlooked follow-up for Mild Cognitive Impairment (MCI)
Many people diagnosed with MCI are discharged without structured follow-up, despite a significant proportion going on to develop dementia. While charities like Dementia Forward help monitor some cases, formalised pathways within primary care are urgently needed.

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[17] The Rt Hon. Professor the Lord Darzi of Denham, Independent Investigation of the National Health Service in England, (2024)

Inadequate annual reviews for those not prescribed medication

People not on dementia medication may still receive annual reviews, but this alone is insufficient for managing a progressive condition. Regular check-ins and timely signposting to support services must be embedded into routine practice.

Lack of dedicated leadership on dementia within GP surgeries

As a GP, it is required to be knowledgeable of a wide range of topics, which may sometimes prevent them from signposting local support services which would help to promote a good post-diagnostic service. Therefore, we recommend that **within every GP surgery, there should be a designated trained dementia lead** – a clinical team member - to promote awareness and ensure dementia care remains a visible and ongoing priority within primary care. GPs should start to initiate conversations about cognitive health, provide clear information about age-related dementias, and serve as informed intermediaries between patients, carers, and specialist services.

A cultural reluctance to engage with dementia as a “treatable” condition

There remains a cultural hesitation among some GPs, who may see dementia as something they cannot "fix." This perception needs to shift toward a model of sustained support and management, focusing on helping individuals to live well with the condition and avoid crisis.

Current Dementia Pathway

The ideal dementia care pathway begins with early identification and timely diagnosis. Recognising symptoms and providing swift referral to specialist services ensures individuals receive accurate diagnoses and early access to care. The ideal pathway begins with a primary care visit, once symptoms have been noticed. This case study encompasses a positive pathway:

Tom visited his GP, where Dr Turner reviewed Tom's blood tests, medical records, and carried out a brief memory test, which Barbara, his wife, noticed Tom struggled with. The doctor suggested a referral to the memory clinic, but Tom was hesitant, not wanting to make a fuss. Dr Turner reassured him that the clinic ran sessions at the GP practice, making it feel like a regular appointment. Tom agreed.

Three weeks later, Tom saw Dr Fisher from the memory clinic. He conducted further memory tests and spoke with Barbara. Dr Fisher explained that Tom might be showing early signs of Alzheimer's disease and recommended a brain scan to rule out other causes. He also offered to introduce them to the practice's dementia advisor, which Tom accepted.

The brain scan confirmed early Alzheimer's, showing shrinkage in the hippocampus. A week later, Dr Fisher met with Tom and Barbara to confirm the diagnosis and introduce them to their dementia advisor, Kevin, for ongoing post-diagnostic support. After ensuring Tom understood the diagnosis, Dr Fisher prescribed donepezil, explaining that while there is no cure, treatment can help manage symptoms and potentially slow progression [18].

Once diagnosed, **the pathway should prioritise person-centred care, tailored to individual needs, preferences, and values, with the individual, their relatives and their carers actively involved in the planning process [19]**. Integrated and coordinated care is another essential feature of an ideal pathway. Collaboration between health services, social care, and voluntary organisations enables a seamless support system that addresses both medical and non-medical needs.

Unfortunately, this is not what the current system looks like. In reality, many people face delayed diagnoses, disjointed services, and insufficient post-diagnostic support.

[18] NHS England, Getting The Dementia Pathway Right: Tom and Barbara's Story, (2017)
[19] NICE, Dementia: Assessment, Management and Support for People Living with Dementia and Their Carers, (2018)

Current Dementia Diagnosis Timelines

A dementia diagnosis is crucial as **without it, individuals are unable to access the necessary care and medication to help manage and delay their condition.** Many individuals face symptoms of dementia while waiting for this diagnosis, **nearly 60% had symptoms for more than 9 months, and 30% took more than a year to diagnose**. Without early intervention and specific medication, individuals with Alzheimer's disease are denied access to some treatments which might delay progression.

With the current dementia care pathway, it is clear that individuals are not receiving a timely diagnosis, with **30% of survey respondents outlining that a dementia diagnosis took over a year (Figure 1).** The reality is, contradicting NHS guidance, which outlines that a dementia diagnosis helps people with dementia get the right treatment and support. It can also help them, and the people close to them, to prepare for the future [20]. However, the support and guidelines aren't as readily available as the NHS guidance assumes, which emphasises the need for a clearer, more coherent dementia care pathway which continues to signpost individuals to support. Future treatments that are coming through need to be applied early, making timely diagnosis even more important.

While waiting for a dementia diagnosis, individuals may still experience symptoms of dementia, such as confusion, difficulty concentrating as well as difficulty in carrying out familiar daily tasks [21]. Moreover, while waiting for a dementia diagnosis, individuals may be at risk financially, as a diagnosis should help to unlock support in order to plan for the future and access therapies and support groups [22].

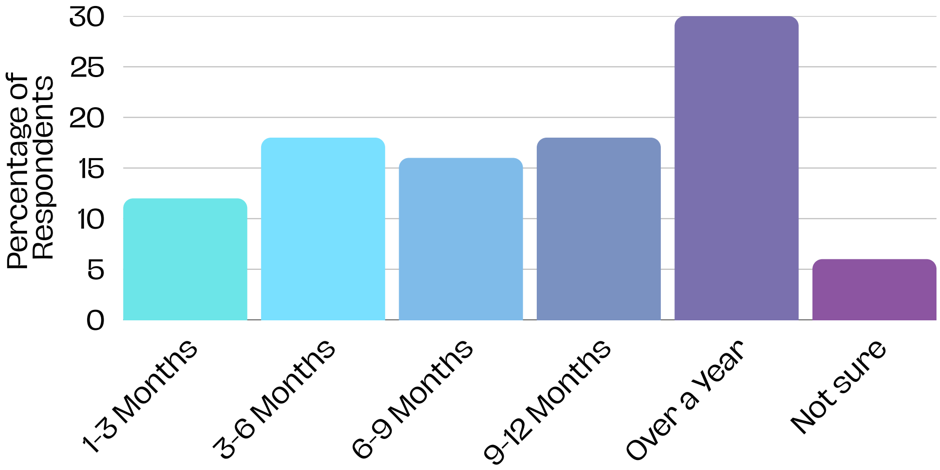

Figure 1: Time to Receive Diagnosis after first contact with GP, reported by percentage of respondents

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[20]NHS, Diagnosis - Alzheimer's Disease, (2024)
[21]NHS, Symptoms of Dementia, (2023)
[22]Alzheimer's Society, Benefits of Getting a Dementia Diagnosis, (2023)

According to Figure 1, **almost one-third of individuals risk receiving no support while awaiting a diagnosis.** During this time, their disease may worsen, leaving some of the most vulnerable people increasingly at risk. However, **early intervention is critical - not only for planning care but also for accessing treatments.** For example, medications such as memantine [23] can help slow the progression of early-stage Alzheimer's disease, but these treatments require a confirmed diagnosis. Moreover, the Diagnosing Advanced Dementia Mandate (DiADeM Tool) is a useful resource to help reduce waiting times, as it provides residents in care homes with a formal diagnosis - without the need for a memory clinic appointment - allowing them to have access to appropriate care and support. The initiative has indicated a positive effect on waiting times in a number of the trust sites. In one Trust, the average decreased from 36 weeks to 7 weeks wait time between February and December 2023 [24]. **Any delay in diagnosis can prevent individuals from accessing potentially life-enhancing medication, reducing their quality of life and independence.**

There is also a clear **postcode lottery in dementia diagnosis and care** [25], with referral times varying significantly across Integrated Care Boards (ICBs). Nationally, people face widespread delays, with some waiting over a year for diagnosis. The survey found that following referral to memory clinics, 29% of individuals waited 3 to 6 months, and 11% waited longer than 6 months (Figure 2). **The average waiting time from referral to diagnosis has increased from 124 days in 2021 to 151 days in 2023**. According to this report, these growing delays are driven by rising demand for diagnostic services, without a corresponding increase in staffing levels [26].

In cancer care, individuals are referred to a Clinical Nurse Specialist (CNS), a qualified nurse with expertise in a specific type of cancer, who provides personalised support, information, and guidance from the point of diagnosis throughout treatment and follow-up [27]. **A CNS is typically introduced as soon as someone begins testing or receives a diagnosis** [28]. In contrast, when individuals are diagnosed with dementia, **many are not signposted to any form of support** (Figure 4), and for those who are, the support is often reported as **inadequate** (Figure 6), a point we explore further later in this report.

[23] Alzheimer's Society, Medication for Dementia Symptoms.

[24] Royal College of Psychiatrists (2023/24) National Audit of Dementia Spotlight Audit in Memory Assessment Services national report, (2024)

[25] Alzheimer's Society, FOI Replies Reveal Postcode Lottery of Care, (2017)

[26] CQC, Access to Health and Care Support, (2025)

[27] Chelsea and Westminster NHS Foundation Trust, Colorectal Cancer Clinical Nurse Specialist

[28] Macmillan Cancer Support, Macmillan Nurses

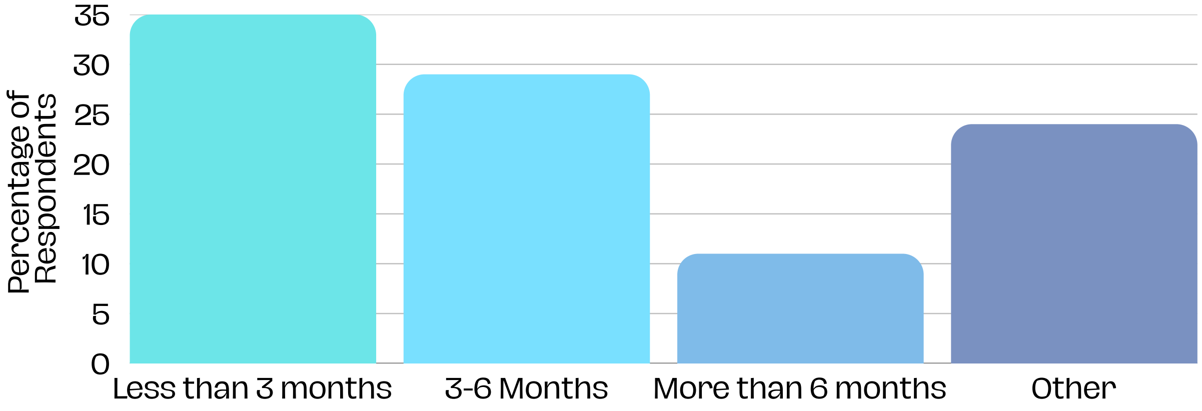

Figure 2: Waiting time for a Memory Clinic Appointment following referral, by percentage of respondents

The average waiting time from referral to dementia diagnosis has increased to 17.7 weeks - up from 13 weeks in 2019 - with current waiting times ranging anywhere from 0 to 104 weeks (two years) across the country. In comparison, the range in 2019 was between 3 and 34 weeks [29]. **This worsening trajectory, compounded by an ageing population and the projected rise in those needing care and support, points to a government failure to deliver timely and effective strategies to address the growing demand for dementia services.** As a result, inequities in access to diagnosis and care are deepening across regions—something unlikely to be resolved by scrapping the national dementia diagnosis target.

Ironically, while the government continues to promote prevention in its public health rhetoric, **it appears to have turned a blind eye to a foreseeable crisis.** Thousands remain undiagnosed and unsupported until they reach a crisis point - at which stage more intensive and expensive care is required. **Ultimately, the state will bear the greater cost,** forced to manage preventable emergencies that could have been avoided through earlier investment. **Prevention, it seems, is only a priority until it becomes politically or economically inconvenient.**

Investing in early intervention for dementia is far more cost-effective than managing the condition at crisis point. Dementia currently costs the UK economy approximately £42 billion annually [30], much of which stems from late-stage care and emergency use of health and social care services. Evidence from the Alzheimer's Society shows that **early diagnosis and personalised support can delay the need for residential care—saving up to £45,000 per person** [31].

[29] Alzheimer's Society, People with Dementia Face up to a Two Year Wait for Diagnosis, (2022)
[30] Alzheimer's Society, Reducing Dementia's Impact on Health and Social Care Through Early Diagnosis and Treatment, (2024)
[31] ibid.

Taking early action not only leads to better outcomes for individuals and families, but also helps ease long-term pressure on the NHS and the wider social care system.

Furthermore, it is essential to develop greater focus on the concept of 'waiting well' (Figure 3), developed by Dementia Forward. This model illustrates that while an individual's condition is progressing, they must have adequate access to support during the wait for a memory clinic referral or diagnosis. Without this, people are at greater risk of falling through the cracks and missing out on early help that could improve their long-term outcomes.

Pre-diagnosis – 1 week response	Ongoing support response
• Receive referral • Available helpline so individuals can receive supported if necessary • Weekly meetings to allocate referrals to a specific Dementia Support Adviser • Ensure a first home visit is arranged with the Adviser they were allocated	• Home visit made by support advisor – discuss forward planning with individual and family. • Signposting and onward referrals made • Provide ongoing support to individual • Ensure a helpline is established for individuals to have support when needed

Figure 3: 'Waiting Well' Pathway

For those with Young Onset Dementia (YOD), the path to diagnosis is even more complex, due to the difficulty of recognising symptoms that are often mistaken for other common conditions such as menopause, stress, or depression. This, combined with a lack of awareness that dementia can affect younger people, and a general reluctance to diagnose a terminal condition, means that diagnosis can take several years to complete. The forms of dementia most commonly seen in younger people often present with symptoms that affect behaviour, social skills, language, and visual processing—including issues with spatial awareness and object recognition. Younger individuals also tend to have higher physical energy levels, which necessitates more active, movement-based models of care [32].

Additionally, support **must go beyond clinical care to include practical and social interventions.** For those of working age, this includes ensuring that individuals with young-onset dementia are provided with reasonable workplace adjustments. Dementia is a recognised disability, and as a progressive illness, it requires ongoing review and accommodation. Workplace support might include changes to duties where possible, consistent communication with carers or spouses, and educational initiatives for colleagues and managers to better understand young-onset dementia.

[32] Alzheimer's Society, Reducing Dementia's Impact on Health and Social Care Through Early Diagnosis and Treatment (2024)

Support should also include a well-managed exit from the workplace, with appropriate support and signposting for the individual and their relatives. This should include access to financial and benefits advice to ensure families are fully supported during this difficult time. Currently, funding for young-onset dementia care presents a significant challenge, and there must be a clear acknowledgement that young-onset care will inevitably cost more due to its complexity, the age and activity level of those affected, and the longer duration of support required.

Importance of Care Staff in Securing Diagnosis

According to the data collected, residential care staff play a vital role in helping people living with dementia. **82% of staff reported to support people in securing a dementia diagnosis, and 89% of staff have helped to get individuals on the diagnostic pathway, starting the process to help secure a diagnosis of dementia.**

These figures highlight the essential role of the social care workforce in helping individuals along the dementia care pathway; however, the clear lack of resources, such as the lack of a post-diagnostic support service prevents timely support and advice to the individual, their relatives and friends.

The Alzheimer’s Society has called for mandatory training for the workforce, their report, ‘Because We’re Human Too’ outlines how mandatory dementia training is beneficial not only for the individual living with dementia, but also their relatives, friends and the staff which look after them. Dementia training provides greater awareness and understanding of dementia, enabling the care staff to liaise with prescribers to reduce inappropriate use of prescribing of antipsychotic and other psychotropic medications as well as promoting a better relationship between individuals and carers [33]. The sector needs to be provided with adequate funding for a mandatory, minimum training for paid carers across the sector, which will further help prevent a postcode lottery of varying levels of support from occurring.

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[33] Alzheimer's Society, Because We're Human Too: Why Dementia Training for Care Workers Matters, and How to Deliver It, (2024)

Mental Health and Dementia

Dementia can be accompanied by complex behavioural and psychological symptoms that often escalate into crisis situations, particularly when ongoing, personalised support is absent. When an individual with dementia experiences these symptoms without adequate support, they are at risk of being detained under the Mental Health Act. **There have been documented instances where police have responded to residents in crisis with excessive force, including the use of pepper spray, handcuffs, and detention in police cells.** These interventions are extremely distressing for the individual, their families and friends, and the staff responsible for their care.

The following case study illustrates some of the urgent concerns around dementia and mental health crises:

A care home colleague heard a female resident screaming, and immediately attended, where they found the male resident, with his hands around her throat and mouth.

Care home colleagues attempted to de-escalate the incident but couldn't and therefore called the Police to keep the female resident safe. Four police officers attended and despite the resident being 82 years old, and around 5ft tall, the police chose to pepper spray the male resident as he was attempting to strike them with a "Wet Floor" sign.

Additional care home colleagues (just starting their shift) arrived and supported the male resident, after being pepper sprayed. After this incident, 999 were called again and paramedics attended and supported both residents, who were both okay.

This case study reflects a broader systemic failure to protect the dignity and rights of individuals with dementia. It emphasises the urgent need for comprehensive, wrap-around support, which, if provided earlier, may have prevented such a distressing incident. The lack of appropriate, timely care and intervention leaves individuals vulnerable and can have traumatic consequences for all involved.

These events also erode trust, as families may wrongly place blame on care homes, when in reality, **such outcomes often result from chronic under-resourcing, delayed access to specialist support and lack of training for police.** Care homes must be supported by proactive input from GPs and community mental health teams, particularly in managing medication and behavioural symptoms. In some areas, **Care Home Liaison Teams** serve this role effectively and this could be expanded.

This issue is particularly acute for individuals with young-onset dementia, as their symptoms may be misunderstood or misdiagnosed. According to the National Audit Office, the NHS spent £12 billion on mental health services in England in 2021/22. The confusion around differentiating young-onset dementia from other conditions contributes to inappropriate responses, including sectioning, which may occur simply due to the lack of tailored long-term care solutions. For instance, the South West London and St George's Mental Health NHS Trust [34] informed CCHR that the daily cost for inpatient care on adult acute wards is £429. That equates to £3,003 per week. Under Section 3 of the Mental Health Act [35], individuals may be detained for up to six months, which would cost approximately £78,078 per person. When multiplied by the number of psychiatric beds in a facility, these costs rapidly escalate[36].

This financial burden underscores the importance of early, proactive support for people with dementia, not only to safeguard their wellbeing but to avoid expensive and traumatic crisis interventions.

People living alone with dementia are particularly vulnerable to mental health challenges. They are more likely to receive a delayed diagnosis, have less formal support, and are more frequently admitted early to residential care. Studies show that early treatment can delay care home admission by up to 21 months [37]. Individuals living alone also report higher levels of loneliness, isolation, and difficulty managing daily life [38], which heightens the need for targeted support and outreach to prevent them from falling through the cracks.

Finally, **misdiagnosis between depression and dementia remains a persistent issue**—especially among older adults in care settings, where both conditions are common. Many individuals visit outpatient clinics believing they have dementia, when their symptoms are attributable to depression [39]. Conversely, some depressed patients are mistakenly referred to dementia specialists due to overlapping symptoms [40]. **While NHS strategies to address this issue exist, there is a pressing need for more tailored guidance on mental health and dementia in care settings, to ensure accurate diagnosis and appropriate interventions.**

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[34] South West London and St George's Mental Health NHS Trust
[35] CCHR, How Much Does it Cost to be Detained on a Psychiatric Ward and 'Treated'?, (2017)
[36] Alzheimer's Society, Because We're Human Too: Why Dementia Training for Care Workers Matters, and How to Deliver It, (2024)
[37] Alzheimer's Society, The Economic Impact of Dementia, (2024)
[38] NIHR - Dementia Researcher, Living Alone with Dementia: Addressing Hidden Inequalities, (2025)
[39] Syuichi Tetsuka, Depression and Dementia in Older Adults: A Neuropsychological Review, (2021)
[40] ibid.

Risks and Consequences of a Delayed Diagnosis

There is great importance of receiving a **timely dementia diagnosis,** as without this, individuals are at risk of not receiving the appropriate care and support needed to help manage their condition and help improve their quality of life.

Planning for the future is vital for an individual with dementia, without having to worry about any potential consequences, including financial matters [41]. By having a timely diagnosis, **45% of cases of dementia could potentially be delayed or reduced,** which helps individuals manage their condition [42], at a reduced cost to the health and social care system.

Until the dementia care pathway is streamlined with reduced diagnosis pressures in primary care, an individual who has to wait for a prolonged time which could cause distress. There needs to be a greater focus on support for individuals, their relatives and friends to help them 'wait well', as support pre-diagnosis is just as important as support post-diagnosis. Any delay in referral can cause unnecessary distress and costs which could be avoided to both the individual and their family. While referral and waiting times can vary significantly across the UK due to the well-known postcode lottery, extended waits inevitably lead to increased anxiety and distress.

In January 2025, we saw the Health and Social Care Secretary, Wes Streeting MP remove the Dementia Diagnosis Rate Targets from the NHS Operational Planning Guidance 2025-26, and despite being in the Long-Term Conditions Strategy, there has been backwards progress. This emphasises how dementia is not on the government's priority list, even though dementia remains the leading cause of death in England [43], and as it currently stands, there is no dementia strategy in the country, which emphasises a staggering lack of focus on a devastating condition that affects nearly a million people in the UK.

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[41] Alzheimer's Disease International, Importance of a Timely Diagnosis

[42] Alzheimer's Disease International, Lancet Commission Identifies Two New Risk Factors for Dementia and Suggests 45% of Cases Could be Delayed or Reduced, (2024)

[43] Dementia Community, ONS Data Shows Dementia Remains the Leading Cause of Death in the UK, (2024)

Post- Diagnosis Support

Due to long waiting times and inadequate support, the quality of both pre- and post-diagnostic dementia care varies significantly. The absence of consistent, structured support leaves individuals at increased risk of reaching crisis point—placing avoidable strain on both the person living with dementia and NHS emergency services. Access to these services is highly dependent on geography, reflecting a persistent postcode lottery [44].

Given that dementia is the leading cause of death in the UK, it is deeply concerning that this terminal diagnosis is often delivered without any guaranteed post-diagnostic support. The lack of personalised, tailored care pathways leaves many individuals and their families feeling isolated and unprepared. **In the survey, 72% of respondents reported they were not signposted to any support, either pre or post-diagnosis, highlighting a widespread failure in early-stage dementia care.**

Only

1 in 4

signposted to support

[44] Alzheimer's Society, *Left to Cope Alone: The Unmet Support Needs After a Dementia Diagnosis*, (2022)

Without having access to this crucial support, there is a direct impact on the health and quality of life of people affected by dementia, which contributes to a negative impact on the wider health and care system [45] at an unnecessarily increased cost to society.

Having adequate support for all those involved on the dementia care pathway is vital to ensure individuals can remain at home for longer. This will keep the individual more comfortable and depending on how much their dementia has progressed, it will also save the government money. To ensure this saving, individuals need support from the first moment of visiting the GP.

The costs of dementia rise significantly as the condition progresses. **The annual, per person cost for mild dementia is £28,700 compared to £80,500 for severe dementia, driven by increasing need for more complex health, social and unpaid care.**

If we can increase the support given in the earlier stages of dementia, it could decrease the length of time for which people require more complex care and the total costs of dementia could be reduced. Spending on dementia diagnosis and treatment is equivalent to just 1.4% of total dementia healthcare costs [46]. Further, only 37% of respondents stating the support was sometimes helpful and 34% of respondents reported the support was not helpful to them.

This case study of Sam, who experiences Young Onset Dementia, illustrates what good support can look like

Their story is one of complexity, resilience, and connection. Through each stage of their journey, from initial diagnosis to long-term care, DF has been there, adapting, listening, and supporting a family navigating the many challenges of young onset dementia.

[45] Alzheimer's Society, Left to Cope Alone: The Unmet Support Needs After a Dementia Diagnosis, (2022)
[46] Alzheimer's Society, Paying for Dementia Care in England, (2023)

Case Study: Sam’s Support through Young Onset Dementia

Sam was just in his early 30s when his family began to notice the first signs that something wasn’t right. Subtle changes in memory and behaviour began to disrupt daily life. Concerned, his wife reached out for help, and that was the beginning of their connection with Dementia Forward(DF).

From the outset, Sam's diagnosis of young onset dementia (YOD) brought unique challenges that were very different from those typically faced by older individuals. Sam and his family needed age-appropriate support that could adapt as his condition evolved—and DF were uniquely positioned to provide this. Over the years, Sam’s needs - and those of his family - changed significantly. DF responded with tailored support that respected their situation.

The family faced many of the complex and emotionally challenging realities of dementia, including:

- Managing the needs of a toddler living in the same home as Sam
- Sam leaving the house and becoming lost
- A deep need for purposeful, meaningful activity to maintain quality of life
- Episodes of expressive behaviour and emotional distress
- Bereavement and heightened emotional strain within the family
- Complex financial challenges that required specialist advice and guidance

Throughout all of this, DF remained a constant, trusted support. They offered:

- Access to services specifically designed for those with young onset dementia, including weekly active well-being days with peers
- Bereavement support for the family
- Ongoing signposting and advice as new needs emerged
- Adjustments to transport and activities as Sam's mobility and preferences changed
- Invitations to social events to ensure the family remained connected and could build friendships with others in similar situations
- Education for professionals unfamiliar with young onset dementia
- Bespoke financial advice tailored to their situation
- Consultancy to develop a YOD-specific care provision
- Emotional support for Sam and his family throughout

Eventually, Sam’s condition progressed. He began expressing his frustration physically, using his strength and speed in ways that became difficult to manage safely at home. After being detained under the Mental Health Act and spending more than a year in hospital, he moved into full-time care.

Today, Sam is non-verbal and reliant on others for feeding and daily care. While his condition has changed dramatically, DF continue to stay closely connected with his wife, offering ongoing emotional and practical support.

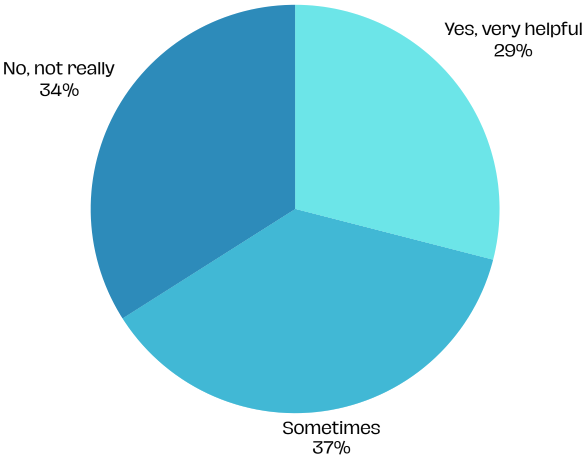


Figure 4: Helpfulness of support received, by percentage of respondents

From the survey, 37% of respondents outlined that the support they received was only sometimes helpful, emphasising that many individuals and their families are not being signposted to useful support. Without receiving helpful support, individuals may feel like they are slipping through the cracks, unsure of where to turn next, it is imperative that post-diagnostic support is firmly placed on the medical pathway.

After diagnosis, some individuals on the dementia care pathway may struggle to navigate the complexities of the system; the lack of signposting to support services may derive from an absence of a coordinated response between professionals and Memory Clinics. A majority of respondents, **58%, outlined that they did not feel they received the appropriate support at the right time, where 49% outlined after diagnosis, there was a lack of support, and 39% did not receive any advice on future planning.** In most cases, after getting a diagnosis, people receive a **discharge** letter, which can cause **huge distress** when people are living with a terminal illness.

Without this support, individuals and their families can feel overlooked, as there needs to be a direct focus on post-diagnosis support as a service, which offers a transparent pathway, where individuals with dementia can understand and recognise what support they are entitled to. Individuals with dementia, their friends and relatives want support with housing, finances, social clubs/activities, and the next steps of the care pathway: without this, all those involved are left at a dead-end.

Specifically for people with young-onset dementia, there is a need for a transparent pathway that they are able to understand, this would include:

- Post-diagnostic support throughout, with a named worker.
- A multi-disciplinary approach with health and social care working together.
- Age-appropriate respite and day-care to prolong the need for full time care.
- Age-appropriate full time care.
- Workforce training, specifically on young-onset dementia.

As a result of the lack of coordinated support, many individuals utilise charities such as Dementia Forward, Alzheimer's Society, Dementia UK and Age UK. The support these organisations provide is vital to emphasise what is needed for all those involved in the dementia care pathway, without this support, individuals are left waiting until they go into crisis. This support offered includes:

- Emotional support
- Understanding the dementia diagnosis
- Family education
- Finance, benefits & legal advice (including Power of Attorney)
- Onward, tailored, responsive individualised support.

Due to dementia being progressive, there needs to be regular check-ins and reviews to ensure the individual and their family are well-supported. This support is important to help the individual process their diagnosis, as well as preventing them from feeling isolated.

Bea's journey into care illustrates how creative practice, interdisciplinary collaboration, and a relationship-centred care approach[47] can shape a dignified and responsive dementia pathway.

[47] Nolan et al., Developing The Senses Framework, (2006)

Case Study: Bea: Creative and Relationship-Centred Pathways into Dementia Care

Background and Admission

Bea was already known to the care home as a volunteer. She is a vibrant, creative individual who sold handmade jewellery and wrote for the BBC. Over time, the team noticed moments of confusion and disorientation. Several months later, following a hospital admission for dehydration and delirium, Bea moved into the home. The hospital shared detailed notes, highlighting how delirium had exacerbated Bea's distress and that she experienced chronic back pain. This information supported a responsive care plan:

- The home was able to initiate antibiotics promptly.
- Bea was referred to physiotherapy, based on advice from hospital clinicians.
- Her seating was adjusted to reduce pain, which had been intensifying her distress and verbalised desire to "go home".

A Relationship-Centred Approach

On admission, a comprehensive "Home from Home" document and life story were created. This captured not only biographical data (e.g. names of Bea's parents), but relational meaning — including Bea's close bond with her father, which was emotionally significant and featured prominently in future reminiscence sessions.

This relational insight reflects the framework of relationship-centred care outlined by Nolan et al. (2006) [47], which emphasises mutuality, emotional investment, and interdependence between residents, care home team, families, and practitioners.

When Bea repeatedly expressed a wish to return home, particularly when in pain, the team referred her to a drama therapist. With written family consent and Bea's verbal assent, the therapist conducted a trial session and developed a holistic plan in collaboration with the care and activities teams.

Therapy focused on making Bea's room feel safe and familiar, co-creating artwork and gradually introducing changes to the space. Abrupt visual changes had triggered distress in the past. A sign bearing the name and number of Bea's former street was added to her door: a symbolic anchor that improved orientation. The Care Team was encouraged to engage with her creative work, reinforcing her identity and sense of contribution.

Clinical Input and Communication

Bea's GP played a crucial role in her ongoing dementia assessment. Aware that Bea was awaiting a new hearing aid, the GP used a Mino assistive hearing device during cognitive testing. This ensured Bea could fully hear and respond which is a critical consideration, given that undetected hearing loss can lead to diagnostic inaccuracies.

The GP also took a validation-based approach, avoiding confrontation or reality orientation during episodes of disorientation. Written records reflected this philosophy: rather than pathologising behaviours as "challenging" or "aggressive," (link to language booklet) the GP noted context, emotional triggers, and signs consistent with Alzheimer's disease. When drama therapy concluded, a structured handover was provided to the care team, ensuring creative and emotional continuity in Bea's daily care.

Professionals need greater training to better recognise the different types of dementia, for individuals, their friends and relatives to have the professional support and resources available to help manage their dementia, as currently we are taking a backward step in supporting all those involved in the dementia care pathway, due to the reversal of the diagnosis rate target.

Currently, care workers are providing quality care to those living with dementia, however, with better professional support and training, residential staff will be able to continue to provide effective support and care. Within care settings themselves, 95% of respondents outlined that they feel supported by the staff within the setting, and 86% of respondents feel staff in the care setting have a good understanding of caring for those with dementia.

> **95%** of respondents feel **supported** by the **staff** in the care setting

The staff in the settings feel confident to provide the care that is needed, however, 70% of staff said they have difficulty getting the right level of professional support for those they care for, and 82% of staff help individuals secure a dementia diagnosis. This professional support should consist of a minimum, mandatory dementia training which should look at embedding this into existing frameworks, such as NVQs, rather than introducing separate, time-intensive programs. This pragmatic approach could yield better uptake and integration across the workforce. Importantly, training should focus on enabling care staff to help individuals to live well with dementia, not just manage symptoms.

reach
BY NIGHTINGALE HAMMERSON
OUR EXPERTISE FOR YOU TO CARE AT HOME

Conclusion

The dementia care pathway in the UK faces significant challenges which hampers timely diagnosis and appropriate support for individuals living with dementia, their families, and care staff. The growing prevalence of dementia, coupled with the recent removal of diagnosis rate targets and the lack of a national dementia strategy, highlights a concerning gap in the system. Early diagnosis and post-diagnostic support, with coordinated care is needed to improve the quality of life for those affected. Delaying access to assessment, diagnosis, and treatment not only increases long-term strain on services, but also leads to higher overall costs, whereas early intervention offers a more sustainable and cost-effective approach.

This is especially critical for the growing number of people living alone with dementia, who may not recognise early symptoms themselves and risk becoming increasingly isolated without intervention. Without someone to advocate for them or notice behavioural changes, these individuals often slip through the cracks of an already fragmented system.

With the number of people living with dementia expected to nearly double by 2040, the need for a robust, integrated, and person-centred care pathway is undeniable. This report has highlighted the systemic gaps, regional disparities, and inconsistent post-diagnostic support that continue to leave individuals and their families navigating the dementia care pathway alone. For those living alone, this isolation is even more pronounced, as a lack of diagnosis means they may never receive the support needed to maintain independence, safety, and dignity. The removal of the dementia diagnosis rate targets and the absence of a national dementia strategy mark a concerning shift in government priorities, signalling a step backwards at a time when clear leadership and accountability are most needed. Delays in diagnosis, fragmented services, and lack of professional support across both health and social care sectors have created a postcode lottery that fails too many.

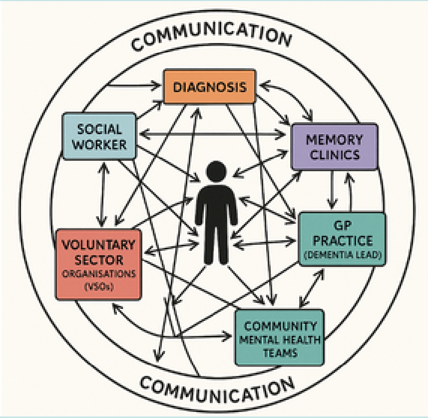
However, the solution can be attainable with the correct support and advice, as the voices of people living with dementia, their carers, and their relatives are clear: we need early diagnosis, timely and continuous support, more consistent training, and genuine integration of services. By acting on these recommendations and listening to those most affected, this can create a dementia care system that no longer waits for crisis before stepping in.

Recommendations

The following recommendations aim to address the gaps in diagnosis, care, and support, ensuring all those involved in the dementia care pathway, receive the timely and effective assistance they need. By focusing on early intervention, better integration of health and social care, and enhanced professional support, these recommendations seek to create a more cohesive and responsive system that can meet the growing demand for dementia care.

Recommendation 1: Implementation of Diagnostic Pathway Standards

A national standardised diagnostic pathway must be established and adopted consistently across all regions. This should align with the recommendations of the NAD Memory Service Spotlight Audit [48], which calls for streamlined processes and better integration across services. Tools such as the Diagnosing Advanced Dementia Mandate (DiADeM) should be routinely used in care homes to reduce waiting times and promote timely diagnosis, especially for those with advanced needs [49].



It needs to be understood that there should be consistencies across GPs, Social Perscribers, Memory Clinics, Social Workers, Community Mental Health Teams, Voluntary Sector Organisations, Domiciliary Care and Care Home workers.

This allows for individuals to see what they would be entitled to and offers accountability. Receiving a dementia diagnosis is a stressful time, which is highlighted in the diagram.

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[48] The Royal College of Psychiatrists, Dementia Audit: Memory Assessment Services, (2024)
[49] NHS, DiADeM Tool

Recommendation 2: Diagnosis Accountability Framework

The government needs to reintroduce a national dementia diagnosis benchmark, not simply as a target, but as part of a Dementia Accountability Framework.

While the government should consider reinstating a dementia diagnosis target, this should not be seen solely as a numerical goal. Instead, it must be reframed to drive local accountability, reduce delays, and ensure access to post-diagnostic support and facilitate a multidisciplinary approach.

As there are widespread delays in diagnosis, reintroducing a benchmark can serve as a necessary safeguard, helping to identify where individuals are falling through the cracks and prompting earlier intervention. However, a meaningful target must be accompanied by a nationally agreed definition of high-quality dementia care throughout the diagnostic process.

To ensure quality and consistency, the following elements should underpin the dementia diagnostic pathway:

- **Timely Access:** Individuals should receive a memory clinic appointment within three months of referral.
- **Continuity of Care:** A named dementia advisor should be introduced at the point of referral to support navigation of the system and reduce fragmentation.
- **Clear Communication:** The diagnosis should be delivered compassionately, with tailored information and support offered to both the individual and their family.
- **Access to Early Support**: Individuals and carers should be immediately signposted to relevant services and community resources.
- **Advanced Care Planning**: As dementia is a terminal illness, there must be timely discussions around end-of-life care planning. Individuals and their loved ones should have the opportunity to work with trained professionals to establish plans while the individual has capacity, ensuring that their wishes are understood, respected, and enacted.

These expectations should align with national guidance, such as the 2025/26 Neighbourhood Health Guidelines [50], where dementia should be a priority within local care planning.

By linking diagnosis targets to quality standards and personalised planning frameworks, ensures early diagnosis and coordinated care.

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[50] NHS, Neighbourhood Health Guidelines 2025/26, (March, 2025)

Recommendation 3: Waiting Well Support Scheme

A nationally mandated standard of care must be established across every stage of the dementia care pathway - including the pre-diagnosis period.

Too often, individuals face long waits with little to no support before reaching a memory clinic. This creates a vacuum where symptoms worsen, families struggle, and individuals fall through the cracks. As illustrated in Figure 3, the 'Waiting Well' support scheme offers a model for structured, wrap-around care during this critical period, and must be implemented consistently nationwide.

In addition, there needs to be integration of best practice models like Next Steps [51] into the 'Waiting Well' framework. Next Steps provide tailored guidance and support to people recently diagnosed with dementia, providing the wrap-around support which is needed during an individual's and their families journey on the dementia pathway.

Alongside the Next Steps guidance, **key components** of a national 'Waiting Well' standard should include:

- A dedicated Dementia Support Advisor assigned within one week of referral, offering a named point of contact for both the individual and their carers.
- Access to a helpline for reassurance, advice, and emotional support throughout the waiting period.
- Regular check-ins to monitor symptoms, flag deterioration, and update support needs, ensuring no one is left behind.
- Immediate signposting to local support groups, advice services, and financial planning resources. This support must be clearly communicated and visible, with a coherent system for referral.

For individuals with **Young Onset Dementia,** there is a need for a transparent pathway that they are able to understand, this would include:

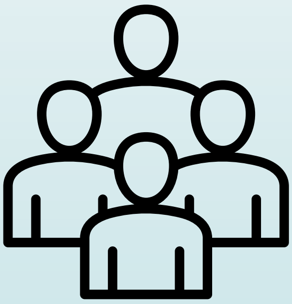
- Post-diagnostic support throughout, with a named worker.
- A multi-disciplinary approach with health and social care working together.
- Age-appropriate respite and day-care to prolong the need for full time care.
- Age-appropriate full time care.
- Workforce training, specifically on young-onset dementia.

Implementing a uniform national standard for the pre-diagnosis phase will help reduce distress, enable forward planning, and may lead to improved health outcomes. Without structured, wrap-around support, individuals, carers, and professionals alike are left to navigate uncertainty alone—with devastating human and financial consequences.

[51]Dementia Change Action Network, Next Steps, (2021)

Recommendation 4: Support for Workforce Education for Care Workers

Provision and funding for national education as a minimum, for care providers to choose tailored workforce education specific to their needs. This workforce education should be a standardised base level of knowledge with the opportunity for more specialised, tailored education.



A blended learning approach, combining e-learning and workshops should be used to ensure practical and applicable skills.

Recommendation 5: Have a Dementia Lead in Every GP Surgery

Every GP surgery should appoint a Dementia Lead responsible for:

- Promoting dementia awareness and education amongst practice staff.
- Supporting all those involved with information, planning and signposting to local support services.
- Liaising with specialists, community teams, and voluntary organisations.

The Dementia Lead will help maintain dementia as a visible and ongoing priority within dementia care.

Incorporating existing national guidance is essential, the 2025/26 Network Contract DES highlights the Enhanced Health in Care Homes (ECHC) model as a key part of integrated, place-based care. Primary Care Networks (PCNs) are expeted to deliver EHCH, which includes:

- Named clinical leads for care homes,
- Weekly mutidisciplinary team (MDT) meetings,
- Proactive support for long-term conditions, e.g. dementia [52].

Linking the Dementia Lead role to this structure can provide consistency and avoid duplication.

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[52] NHS, Network Contract DES, (April, 2025)

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