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From diagnosis to end of life:

The lived experiences of dementia care and support



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For a full list of thanks see the Appendix.

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Foreword

At Alzheimer's Society, we've long focused our campaigning efforts on social care – and with good reason. The social care system doesn't work for people with dementia. We will continue to demand political action until it does.

We also know that people affected by dementia face several other issues in managing the condition. We consistently hear about people meeting hurdles at various points of the dementia pathway. From diagnosis to death, people are navigating a system that is disjointed and that doesn't work as well for them as it does for people with other conditions. People living with dementia and their families are left to fight for the care they're entitled to, whether it meets their needs or not.

This must change. As the UK's leading dementia charity, we want to shine a light on the need to improve care across the dementia pathway. The number of people affected by dementia is rising. The number of carers and the burden on them is increasing. It's vital that local and national actors use the evidence and recommendations in this report to set a higher standard of care across the dementia pathway. Historical barriers in the provision and accessibility of high-quality care must be overcome. Research for a future cure for dementia continues, but this doesn't affect what needs to be done now: stop people with dementia falling through the gaps in the health and social care system and improve quality of life.

This report is grounded in the voices of people affected by dementia. It also considers the Dementia Statements, which reflect the things people with dementia have said are essential to their quality of life. The Dementia Statements are:

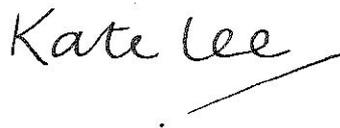
- 1** 'We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.'
- 2** 'We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.'
- 3** 'We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.'
- 4** 'We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.'
- 5** 'We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.'¹

This report benchmarks the experiences of people affected by dementia against current national policy. It identifies gaps in the care people are receiving, from pre-diagnosis to end of life. By doing this, it raises important questions about the current and future provision of dementia care.

The report highlights where previous Government commitments and ambitions have not been met. It also highlights where National Institute for Health and Care Excellence (NICE) evidence-based guidance fails to become a reality. While professionals and services strive for the best, the complexity of dementia leads to variation in practice and a debilitating lack of ownership.

This report calls on national and local governments, NHS England and local health systems to drive the changes urgently required to improve care and support for people living with dementia. We're calling for a prioritisation of dementia care, and ambition to deliver the scale of change needed.

Most of this report was written before the COVID-19 crisis. But we can't ignore the significant impact the pandemic has had on people affected by dementia. It has showcased their distinct needs, as well as their reliance on both health and social care. The report therefore also looks at the impact of COVID-19 on the dementia pathway. It serves as further evidence of the need for national leadership in order to build a more integrated pathway. We commit to working collaboratively with national and local stakeholders to deliver this, and we intend for this report to be used as a roadmap for how we get there. But it requires national leadership to coordinate and bring together the changes we so desperately need to see.



Kate Lee

Chief Executive



Executive summary

This report looks at four stages of NHS England's Well Pathway for Dementia – Diagnosing Well, Supporting Well, Living Well and Dying Well. As the report assesses the pathway from diagnosis to end of life, it doesn't focus on Preventing Well.

It explores in detail what NICE and the Government say people in England should be receiving at each stage, and therefore the care and support they say will enable people to live well with the condition. We benchmark this against the experiences of people affected by dementia.

Our research found that people aren't consistently receiving good quality, integrated care and support that enables them to live well. This report highlights a series of issues facing people across the dementia pathway, and the many accounts we heard where care is not providing what's needed. While there is good practice happening in parts of the country and significant progress has been made on improving dementia care and support over the years, there is still work to be done.

The following list summarises the main issues at each stage of the pathway:



Diagnosing well:

- People are being misdiagnosed, particularly younger people, or opportunities to identify dementia early are being missed. Referral processes can be confusing, with people feeling daunted about 'what comes next'.
- Variation between memory services and limited performance data can make the initiation of service improvement projects challenging.
- Delivery of a diagnosis, including a subtype and tailored information, is variable, and too often focuses on what people can no longer do, rather than what they can do.



Supporting well:

- Information provided at the point of diagnosis is not being delivered in the right way, if at all.
- People are struggling to access a care coordinator. This could significantly help people navigate the complexity of the health and social care system to get the right care and support.
- Care planning, including advance care planning, if undertaken, can be insufficient and dementia-specific needs are not considered. This is made worse by a lack of integration of care and support plans.
- The provision of post-diagnostic support interventions – those that exist from national guidance and based on clinical evidence – can be variable and inappropriate.



Living well

- People receive limited access to coordinated, proactive and ongoing care and support. Follow-up care is not the same for everyone living with dementia, and many people are left to manage their condition themselves.
- Many people receive most of their support from their primary informal carer, but carers are struggling to access support services for their own wellbeing.
- Hospital and care homes need to identify and accommodate dementia specific needs. They must ensure access to the right services at the right time.



Dying well:

- Dementia is a terminal condition, meaning those with the condition will live with it until death. Despite this, people often struggle to access palliative care, including end of life care.
- Advance decisions are sometimes ignored, meaning the interests of people and their wishes at end of life are not being fulfilled.

Dementia is a term that covers a range of different symptoms and diseases. Each of these will be different according to the subtype of dementia that someone has. One person with dementia will not experience their condition in the same way as another person with dementia. This means their progression through the pathway will also vary. This doesn't mean that people diagnosed with dementia should receive insufficient and disjointed care.

This report shows the need to drive change at various stages of the dementia pathway. It outlines the gaps in care and support. It identifies the actions that can be taken to provide more integrated and streamlined care, ensuring access to services. It also highlights many examples of good practice from across the country, so that these can be learned from and adapted to local contexts.



Introduction

There are currently 850,000 people living with dementia in the UK.² This is set to rise to 1.6 million by 2040.³ The scale and the need to prevent, diagnose, support, live and die well with dementia will only become greater.

Prevention is a critical part of the dementia pathway. With costs of care reaching nearly £35 billion,⁴ it's vital to take all actions possible to reduce cases of dementia. This must be done both by improving public awareness and understanding of the risks for developing dementia, and by ensuring that awareness-raising activity reaches a wide audience across society. However, this report doesn't cover dementia risk reduction. It assesses the dementia pathway from the point of experiencing symptoms onward, setting out what makes good care from pre-diagnosis to end of life.

Dementia is a progressive neurological condition. It occurs when the brain is damaged by diseases (such as Alzheimer's disease) or by a series of strokes. The symptoms of dementia can include memory loss and difficulties with thinking, problem-solving, language and physical function. The specific symptoms that someone experiences will depend on the parts of their brain that are damaged and the underlying cause of their dementia. The rate of progression will also vary from person to person.

Dementia causes complex cognitive and behavioural symptoms and is unpredictable. This means that the provision of appropriate care and support, across the entire dementia pathway, is also complex. This has led to significant variation in practice, with more focus on the early stages of the pathway, and less focus on the later stages, where people find it harder to access appropriate care and support.

Despite this, there are a range of policy documents and guidance that set a benchmark for what care people with dementia should expect:

- The National Institute for Health and Care Excellence (NICE) guidelines⁵ are evidence-based recommendations for health and care commissioners and providers in England. They set out what care and services are most suitable for people with specific conditions, including people with dementia. Guidelines ensure people receive care that's based on the best available clinical evidence. They also ensure health and social care professionals meet standards when delivering services.
- The Prime Minister's Challenge on Dementia 2020⁶ sets out more than 50 commitments that aim to make England the world-leader in dementia care, research and awareness by 2020. It includes priority actions across four themes: risk reduction, health and care, awareness and social action, and research. While this strategy is nearing its conclusion, it's important to reflect on whether those commitments have been achieved.
- The Department of Health and Social Care's 'Joint declaration on post-diagnostic dementia care and support'⁷ is a shared commitment between government, health, social care, the third sector and other relevant partners to deliver better quality post-diagnostic support for people affected by dementia.

Another key document is NHS England's 'Universal Personalised Care: Implementing the Comprehensive Model'.⁸ This outlines how the NHS in England will change the scale and delivery of personalised care. It's a whole-system approach that aims to integrate services around the person. It will therefore directly affect post-diagnostic support for anyone with dementia from diagnosis to end of life. However, this report doesn't include analysis of Universal Personalised Care. The transformative changes, though underway, aren't planned to be implemented until 2023/24. It will, therefore, be explored in a separate piece of work.

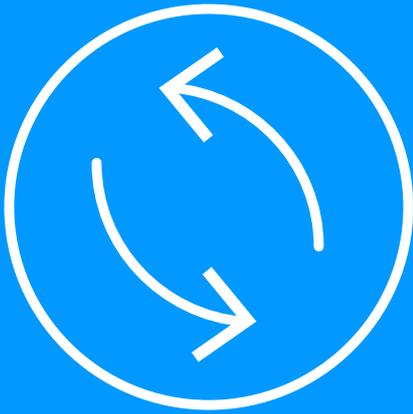
This report considers current provision of dementia care, but it was mostly researched and written before the COVID-19 crisis. It assesses whether the expected standards set out by NICE, the 2020 Challenge and the joint declaration are being met, and whether people are receiving effective care right now. It explores whether people with dementia are truly benefiting from health and care services in their current form. And it identifies the gaps in the system that need to improve. This has been carried out across the dementia pathway, using parts of NHS England's Well Pathway to structure the analysis.

Although a high-level dementia pathway has been developed, in practice it can't apply to everyone in the same way because individuals will have different needs. NHS England's Well Pathway provides a loose framework for the design of services and local pathways, but there is still confusion around what each section involves. Diagnosing Well and Dying Well are easier to classify, but the differences between Supporting Well and Living Well are less clear. In this report, we've taken Supporting Well to mean immediate support needs, up to around one year after diagnosis. Living Well covers the support a person may receive from around a year after diagnosis up to the point they reach the end of life.

Throughout this report, a consistent theme is a lack of clarity around roles and responsibilities within dementia care. NICE guidance has no statutory grounding, and despite clear policy advice from government, variation still exists and has proven difficult to tackle. The adoption of different and flexible approaches has led to good practice in some cases. But it has led to disjointed care in other cases, where people are falling through the gaps. This is made worse by a lack of integration between services, not only within health but also between the health and social care systems more widely. However, ambitions set out in the NHS Long Term Plan and the formation of Integrated Care Systems create an important opportunity to deliver integrated services that meet the needs of local populations. Dementia must be central to their decision-making.

NICE provides a clear framework for commissioners and professionals to use. But there's no data on whether guidance is followed, or whether people with dementia are receiving consistent, high-quality care over the course of the pathway. While variation is clearly shown in diagnosis rates, data isn't regularly collected across the rest of the dementia pathway. This makes it harder to identify what's happening at a local level and therefore harder to drive national quality improvements. We're therefore calling for a National Dementia Observatory that informs wider policy, research and implementation of high-quality, effective and evidence-based care and support.

The programme of work outlined in this report addresses these aims. Using information from speaking to people affected by dementia and health and care professionals, it sets out where change is needed and how to deliver high-quality dementia care across the pathway. But it needs renewed ownership, oversight and accountability from central and local governments.



What needs to change?

This report evidences the need for a streamlined dementia pathway. Local decision-makers, services and professionals are best placed to take ownership of developing dementia pathways, but these must be underpinned by clear roles and responsibilities at each stage.

The move towards Integrated Care Systems provides an important opportunity to assess how dementia care is being delivered at a local level. This includes reviewing how health and care providers are working together, and how NHS and local authority commissioning could be better aligned. Consideration and implementation of the local recommendations should be coordinated through Integrated Care Systems, where they're already in place.

This chapter provides a roadmap for action to improve dementia care from pre-diagnosis to end of life. It offers insight from people affected by dementia about what makes a good pathway and how meaningful change can be implemented.

First, effective local action must be underpinned by national action.

National recommendations

There is a clear role for national actors to take more responsibility in enabling good practice and supporting local actors to develop and implement clear local dementia pathways.

The Department of Health and Social Care should:

- work with NHS England and NHS Improvement to produce clear guidance on care coordination. This should include who can do it, what it involves and transition requirements if the care coordinator changes along the pathway. This should be supported by regular data collection and publication.
- review the NHS Continuing Healthcare process to ensure it's fit for purpose for people with dementia.
- clearly identify dementia as a terminal condition, and conduct a national review of capacity and access to palliative care in care home settings. This must include an audit of training for care home staff, as well as access to out-of-hours support.
- establish a National Dementia Observatory that brings together new and existing data. This must inform wider policy, research and implementation of high-quality, effective and evidence-based care and support.

The Care Quality Commission should:

- include end of life as a separate entity for inspection within care homes. Evidence of access to palliative care and personalised care and support planning should be reviewed.

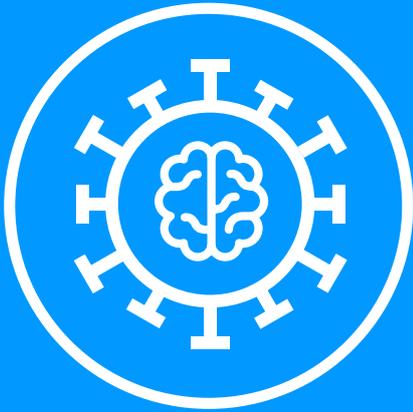
NHS England and NHS Improvement should:

- further recognise the growing challenge of dementia which requires solutions from health and care. The revised NHS Long Term Plan must make further progress on dementia care quality and outcomes.
- develop and publish good practice guidance for the commissioning of dementia assessment, diagnosis and ongoing post-diagnostic support.
- ensure that all memory services have access to picture archiving and communication systems, so that memory services can view brain scans.
- ensure that people with dementia have a single digital health and care record that's accessible to all health and care professionals involved in their care. This must include advance care planning.
- publish regular, accurate memory service data, including memory service waiting times. It should also commission an annual national memory service audit to measure performance and initiate service improvement projects.
- add further indicators for dementia on the Quality and Outcomes Framework to include:
 - identification of a main carer, and the number of carers offered annual access to relevant NICE-recommended carer interventions
 - the number of patients diagnosed with dementia given opportunities to participate in advance care planning discussions
 - the number of people with dementia added to the palliative care register, and who have been offered a personalised care planning discussion as a result.
- ensure that named clinical leads for care homes:
 - facilitate dementia assessment and diagnosis to ensure access to appropriate care within care home settings
 - identify people who need advance care planning.
- monitor and publish data on the implementation of The Enhanced Health in Care Homes model.

Local recommendations

While it's recognised that local pathways need some flexibility, there are considerations that must be factored into their development:

- Each Clinical Commissioning Group (CCG) should have a dedicated dementia lead. They should be responsible for ensuring the delivery of training to GPs on referral criteria, diagnosis and personalised care and support planning. Leads must have dedicated time to fulfil this role.
- To facilitate dementia diagnosis, particularly complex cases, there must be formalised arrangements that enable multidisciplinary team meetings between memory service clinicians, neurology and neuroradiology.
- 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.
- Memory services should all include dementia adviser services, with people automatically referred to the service unless they opt out. There must also be integration of dementia adviser services within primary care.
- All people 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.
- Evidence-based, post-diagnostic support interventions should be provided for people with dementia and their carers. These must be appropriate and tailored, considering age, ethnicity, religion, gender and sexual orientation.
- There should be clarity on where responsibility sits for the initiation of medicines and follow-up appointments for people with all types of dementia.
- People diagnosed with dementia should have access to follow-up opportunities to discuss their diagnosis and this should be embedded within the local pathway. For example, this could be delivered through follow up within primary care by a GP, specialist nurse, dementia adviser, or through memory services. There must be opportunities to step up care when more support is needed.
- Memory services should consider accepting referrals from sources other than primary care, including social services and patients and carers themselves. This would support access to timely specialist input, especially in urgent or crisis situations.
- There should be support for carers, which includes providing straightforward methods of booking overnight care in advance, and accessible lists of recommended local respite care services identified by local authorities.
- Appropriate post-diagnostic support interventions and social care services should be provided to ensure language, communication or cultural needs are met. This should consider projected future population trends and needs.
- There should be ongoing opportunities for people with dementia and carers to access support interventions following diagnosis.
- 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.
- Every health and social care professional involved in dementia care should be trained to at least Tier 2 of the NHS-backed Dementia Training Standards Framework. This must be accompanied by protected training time, targets for numbers of staff trained and training standards being a part of inspections by regulators.



COVID-19 and the dementia pathway

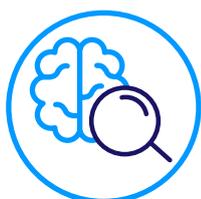
The third sector has provided significant support to people affected by dementia during the COVID-19 pandemic.

Both NHS England⁹ and the Department of Health and Social Care¹⁰ signpost people with dementia concerned about COVID-19 to charities including Alzheimer's Society.

Throughout the pandemic, our Dementia Connect support line has been extremely busy with calls regarding COVID-19. Our online forum, Talking Point, saw 1,113 new people join in March 2020 alone, with the COVID-19 thread having the most visits and engagement. Our frontline staff adapted to provide support to the people worst affected by the crisis. Other staff and volunteers worked to ease loneliness and isolation during COVID-19 through our Companion Calls – a service created in response to the pandemic.

This report highlights the disjointed nature of dementia care across the pathway, and we've seen the impact of this during the COVID-19 crisis. With increased risks of death and of declining physical and mental health, COVID-19 has further demonstrated a lack of coordination and leadership on dementia.

This chapter looks at the dementia pathway in the context of COVID-19. It assesses the short-term changes that have happened and the impact they've had on the lives of people affected by dementia. More research is needed to explore the issues outlined in this chapter, which must be a national priority. Age is the biggest risk factor for COVID-19 – 95% of people with dementia are over 65¹¹ and there are likely to be continued implications for how care and support are delivered to them. It's therefore critical that central and local governments and NHS England use the best evidence to ensure that people affected by dementia can access the services and support they need as we emerge from this pandemic.



Diagnosing well

Since February 2020, there has been a steady decline in dementia diagnosis rates which now fall below the national target.



This means that more people are living without a diagnosis of dementia. They are therefore unable to access emotional, practical, legal and financial advice, as well as vital support services and pharmacological and non-pharmacological interventions. A long period without a diagnosis can also lead to an acceleration in greater levels of need, creating more pressure on health and care services over time. A diagnosis is important to better enable people to manage their symptoms safely. It lets them consider any necessary adjustments they might need to make in the context of enforced restrictions caused by the pandemic.

COVID-19 is leading to more inequality in terms of accessing a diagnosis. The way people interact with GPs has changed, leading to reduced primary care referrals to memory services. There has been variation in the reopening and resuming of memory services after they've been deemed non-critical, with some reducing the number of appointments, some only supporting urgent and severe cases and some moving to virtual assessments and appointments. There's also a backlog of assessments, which will worsen already-long waiting times in some localities.

Memory services have adapted rapidly to new ways of working in the form of virtual assessments.¹⁷ There can be many benefits to virtual assessments, including not having to travel. However, there are also challenges with virtual assessments. Some services have questioned the validity of remote cognitive testing due to time lags in connectivity, an uncontrolled environment and other technology difficulties. There are also concerns that people over 70, a population at higher risk of dementia, will be deterred from face-to-face assessments due to continued social distancing and shielding measures. However, virtual assessments will not suit everyone and we need to ensure that in the long term we don't move to a 'virtual first' approach and make health inequalities worse.

Interruption to the diagnostic process risks creating a generation of people who will live without an early, timely or accurate diagnosis – or even any diagnosis at all. This has implications for future medication, care plans, interventions and opportunities for research.



Supporting well

COVID-19 has also affected the ability of memory services to deliver post-diagnostic support interventions. Efforts by some memory services to deliver post-diagnostic support remotely have been commendable, but new ways of working take time to establish. It's more important than ever to be considerate of people who can't use technology.

Memory services have reported an increase in support required for carers and people living with dementia because of increased isolation. This comes at a time when local authorities' duties under the Care Act have been reduced. The Coronavirus Act 2020¹⁸ introduced the Care Act easements. These let local authorities temporarily relax certain responsibilities if they're experiencing high levels of staff absence and service pressures because of the pandemic. For example, local authorities may no longer have to carry out detailed assessments of people's care and support needs, or prepare or review care and support plans. This puts people affected by dementia at further risk, when social care was already facing significant challenges in its ability to meet the level of demand for dementia care and support even before the pandemic.

People with dementia need additional consideration. Not meeting their needs by adopting the easements risks leading to an irreversible worsening of their condition. Also, their ability to do basic activities can change or decline quickly if their needs aren't met. It's vital that these arrangements do not become permanent.

The easements allow local authorities not to carry out financial assessments complying with previous Care Act requirements, but to charge people retrospectively for the care and support they receive during this period. Paying for care retrospectively is worrying, as people risk being asked to pay for unaffordable care homes they've been discharged to in a rush, or being forced to move for financial reasons, even if it's not in their best interest.

Another central part of post-diagnostic support is advance care planning. COVID-19 has highlighted the importance of timely advance care planning, which can improve provision of care for people who may be nearing end of life. Reports of services rushing to document end of life care wishes¹⁹ reinforce the need for these conversations to be embedded within the pathway as routine post-diagnostic support. They also highlight that this must be a person-centred process. Examples of bad practice include blanket approaches to Do Not Attempt Resuscitation forms. It's crucial that people who have had these inappropriately applied to their records can have them removed.



Living well

These are difficult times for people with dementia to live well.²⁰ Social distancing measures risk causing heightened need. People living with dementia at home are experiencing the interruption of daily routines, less social interaction and reduced access to support and services. This has had a negative impact on their cognitive function and quality of life.

COVID-19 has also had an impact on carers' quality of life. They're experiencing increasing isolation and inability to access respite care due to the closure of day centres and support groups. It's estimated that 60,800 people with severe dementia and 93,100 people with moderate dementia (who have care needs) live in the community and only have support from unpaid care.²¹ But respite provision – or short breaks – for carers has been significantly restricted during the pandemic. Since before COVID-19, non-professional carers were struggling to access the support they need, but the pandemic has meant they're faced with even more responsibility. Supporting carers, and easing the impact of the pandemic and of measures such as lockdown on them, must be a priority.

For people in care homes, the benefits of regular contact with family or loved ones is shown through the work of the Wellbeing and Health for people with Dementia (WHELD) programme. This research found that increasing social interaction improves the wellbeing of people living with dementia in care homes, based on a programme of daily interaction from trained staff combined with personalised care planning.²² Evidence also shows that failure to meet the needs of people with dementia for activities is associated with the progressive worsening of cognitive and functional deterioration. This results in them losing levels of autonomy and the ability to satisfy their own needs.²³

There are also issues around digital connectivity for older people at home and in care homes. This had an impact on the ability of people affected by dementia to maintain social relationships and support. The long-term impact of isolation and social distancing measures in the UK needs extensive research. But we know from European research that people with Alzheimer's disease and mild cognitive impairment have shown a worsening of symptoms after five weeks of lockdown.²⁴ Rehabilitation will be particularly important for people with dementia who have suffered cognitive, functional and neuropsychiatric decline as a result of measures taken to contain the pandemic which forced a change in routine and isolation from regular support systems.

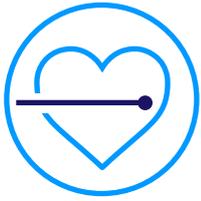
In care homes, people with dementia are experiencing interruption of normal routines, being unable to have visitors, and staff wearing PPE which can cause distress and result in communication and recognition difficulties. There are challenges of staff shortages, and difficulties in implementing prevention and infection control measures. An Alzheimer's Society survey of 105 care home managers, carried out between 30 April and 12 May 2020, revealed that:

58% didn't feel able to effectively isolate suspected COVID-19 residents

32% had taken in COVID-19 positive residents who were discharged from hospital

25% felt residents should have been admitted to hospital with COVID-19 but haven't been²⁵

More investigation is also needed to interpret data from April 2020 that shows an increase in the proportion of people with dementia being prescribed anti-psychotic drugs. For the last year this has remained steady at around 9.3-9.4%, but it increased to 9.7% in March and 10% in April.²⁶ These prescriptions should only be used as a last resort and kept under regular review.



Dying well

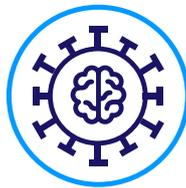
COVID-19 has highlighted the need for more collaboration with care homes.

It has demonstrated the stark differences between care homes' access to clinical support at end of life. Earlier action from NHS England to identify a named clinical lead for every care home may have supported earlier spotting of atypical and asymptomatic cases in care homes.

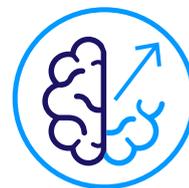
The lack of support for care homes, where 70% of residents have dementia,²⁷ is demonstrated by the number of deaths that happened in this setting. Analysis by the Health Foundation shows that deaths from any cause in care homes have increased by 220% since the start of the COVID-19 outbreak.²⁸ Office for National Statistics (ONS) data on care home residents from 2 March to 1 May shows that dementia was the most common main pre-existing condition found among deaths involving COVID-19.



Dementia was involved in 42.5% of deaths of care home residents involving COVID-19.²⁹



20% of people who died with COVID-19 in March and April in England and Wales had dementia as the main pre-existing condition.³⁰



There was a 52.2% increase in excess deaths of people with dementia not involving COVID-19, from 13 March to 1 May.³¹

A review of the data to better understand why people with dementia are dying at such a high rate, whether due to COVID-19 or another condition, is critical. Given the scale of the deaths, this review must also consider access and quality of end of life care during this time.

We must consider whether care homes were adequately resourced to support residents during the pandemic and whether this was what resulted in the high death rate. Given the significant emotional pressures facing care home staff, it's vital they're provided with support to continue in their roles, both now and in the future. With an increase in personal risk, more provision of difficult end of life care, staff shortages, and the psychological impact of working through the pandemic, there's a risk of further increasing the already high staff turnover rate in care homes.³²

Conclusion

From diagnosis to end of life, people affected by dementia have been disproportionately affected by the COVID-19 pandemic.

It has resulted in some positive developments, including better joined-up working between health and social care, and removing the debate over payment when a person is discharged from hospital. But it also shows that the solutions to some of these long-standing challenges are known and that their implementation has been stalled for other reasons. The evidence in this report must be used to inform future thinking about how we can improve the dementia pathway – both as we continue to respond to the pandemic but also as we emerge from it.



Diagnosing Well

What do we mean by diagnosing well?

Receiving a dementia diagnosis can be life-changing, and often leads to feelings of grief, loss, anger or helplessness. But a diagnosis is essential in supporting people to live well, even in the absence of a cure or drugs to slow the progression. It opens the door to emotional, practical, legal and financial advice and support.

In recent years there's been a significant effort to reduce waiting times for diagnoses and increasing diagnosis rates. This has led to increased rates of diagnosis, but there's been less focus on improving the experience and accuracy of a diagnosis.

This chapter considers the diagnostic process from initial identification of symptoms, whether in a GP surgery, hospital or care home, and the subsequent referral process. It also considers identification of a dementia subtype, as well the delivery of a diagnosis.

What are the benchmarks?

The following benchmarks have been used to assess what care people are receiving at this stage of the pathway:

- ‘People worried about possible dementia in themselves or someone they know can discuss their concerns and the options of seeking a diagnosis, with someone with knowledge and expertise.’ (NICE)³³
- People with suspected dementia are referred to a specialist dementia diagnostic service if reversible causes of cognitive decline have been investigated. (NICE)³⁴
- ‘By 2020, in every part of the country people with dementia [should have] equal access to diagnosis as for other conditions, with an expectation that the national average for an initial assessment should be six weeks following a referral from a GP (where clinically appropriate), and that no one should be waiting several months for an initial assessment of dementia.’ (Prime Minister’s Challenge on Dementia 2020)³⁵
- Diagnose a dementia subtype (if possible) if initial specialist assessment (including an appropriate neurological examination and cognitive testing) confirms cognitive decline and reversible causes have been ruled out. (NICE)³⁶
- ‘We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.’ (Dementia Statements)³⁷

Key questions and gaps between policy and practice

This research has identified the following key considerations at this stage of the dementia pathway:

- The benefits of a timely diagnosis and how to ensure people are diagnosed in the early stages of their condition.
- Current challenges in diagnosing, especially in younger people and ethnic minorities, and reducing misdiagnosis.
- The impact of GP consultation time and referral processes on effective diagnosis.
- The benefits of a subtype diagnosis, the barriers to doing this effectively, and whether people understand what their subtype means for their symptoms and prognosis.
- Case-finding – a strategy to actively search for people at risk of dementia – and diagnosis in hospitals and care homes, and the interaction between primary, secondary and social care at this point of the pathway.
- How to improve the diagnostic experience, particularly when delivering a diagnosis, to ensure people see their condition as positively as possible.

We begin to explore these questions in this chapter. It’s essential they are considered as part of the development of local dementia pathways.



‘My husband, Bob, used to work for BT and travelled to lots of different countries as part of his work. Now he has dementia, I’ve had to give up my job to care for Bob and I’ve now lost my sense of purpose. I have cared for my husband for the past six years.

Just getting a formal and verified diagnosis has been an incredible struggle. Not having a formal diagnosis has impacted on his subsequent treatment by healthcare professionals.

Bob was diagnosed with Parkinson’s disease when he was 57 in 2006. Due to a separate brain injury to his frontal lobe in 2001, healthcare professionals have struggled to identify a dementia subtype, recording it only as ‘dementia’. I used to work with people living with dementia, so I understand different dementias carry different symptoms. From his behaviours, he presented as having frontotemporal dementia, but this is due to his brain injury.

Getting a diagnosis was a heck of a battle. Because of his other conditions, he has been under different healthcare teams. The biggest problem is the lack of communication between different hospitals and wards and many multidisciplinary teams. To compound matters further, different hospitals use different computer systems, so computers don’t talk to each other even if all the hospitals are NHS.

The Parkinson’s consultant initially identified potential dementia in Bob. Over the years, he had six MRI scans, many CT scans and eventually a lumbar puncture. It was finally confirmed his dementia is mainly due to his brain injury.

However, at every hospital visit, each doctor had thought it was a different subtype – vascular dementia, alcohol-related dementia, Alzheimer’s disease and on one set of notes Parkinson’s dementia. But I knew from experience he was displaying frontotemporal behaviours and did not present as typical dementias.

In some wards, because he didn’t have a formal diagnosis, they treated him like he didn’t have dementia at all. In one hospital, he had nine urinary tract infections in just 12 weeks and ending up with a serious chest infection. Yet, because his dementia was not formally diagnosed, the occurrence of these infections was not linked to his dementia. A subtype would not only help us prepare for symptoms, but it would also make sure Bob gets the care and support he needs.

In some hospitals when he displayed some odd behaviours – not violent or aggressive, just behaviours that challenge – I would get called up by the hospital asking why he was acting odd. I would then have to continually explain that he did in fact have dementia. As a carer, you know the person’s character, you know how to manage behaviours and help and support the person. Everyone needs to be singing off the same sheet and carers need to be regarded as experts in caring for and knowing their person and be acknowledged and listened to.’

Julia, carer for Bob who is living with dementia

Identification of symptoms

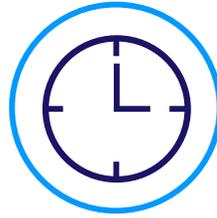
An early and timely diagnosis of dementia has many benefits. It can:



help caregivers to better understand a person's behaviour



provide an explanation of symptoms that are affecting a person's life



give people time to plan for medical and financial decisions



facilitate access to disability allowances and support groups³⁸

Identifying symptoms can be challenging, both for professionals and non-professionals. People with dementia may be experiencing symptoms for some time before contacting a healthcare professional. One study suggests that the average time between a person noticing symptoms and first talking to a friend or relative about this is one year.³⁹ It takes a further year and four months to first contact a healthcare professional to discuss these symptoms. A recently published paper suggests that the median time to diagnosis from first meeting clinical criteria is three years.⁴⁰

Dementia assessments can happen in different health and care settings, but people will often first visit a GP because of their symptoms. Sometimes it's difficult for GPs to identify dementia because some symptoms are typical of other conditions and illnesses. Analysis of primary care records has shown that people with non-memory loss symptoms may have to wait longer for a diagnosis.⁴¹ We heard from people affected by dementia that symptoms were sometimes misunderstood, leading to misdiagnoses and unnecessary delays.

Misdiagnosis is particularly common for younger people. Dementia may not be considered at first due to common misconceptions around dementia and ageing. It's known that around 42,000 people living with dementia are under the age of 65 in the UK, representing 5% of the 850,000 people with dementia.⁴² But the actual figure could be much higher because of difficulties diagnosing the condition, with an estimated 6-9% of all people with dementia under 65.⁴³

It's important GPs and other healthcare professionals consider possible dementia in people with non-cognitive symptoms. They should be especially vigilant when assessing people under the age of 65. Younger people told us about their experiences of being diagnosed as depressed or anxious, having relationship difficulties or suffering from the effects of stress. For women, symptoms were also sometimes wrongly attributed to menopause.

One person with dementia told us they were misdiagnosed with a mental health condition and were referred to six weeks' worth of counselling, where the dementia symptoms were seen as a result of repressed issues with a family member. In another case, a woman was misdiagnosed with epilepsy and was then prescribed the wrong medication for three years until she received the correct diagnosis of dementia.

'I was relieved to get a diagnosis of something. Throughout I was constantly being asked if I was or felt depressed or stressed and they [the GP] tried to get me to take anti-depressants.'

Person living with dementia

Another person with dementia told us that the onset of his symptoms began in 2011 and by 2012 he was made redundant. At the original GP appointment he was told to 'pull himself together,' and he was prevented from accessing specialist diagnostic services. His GP finally referred him to a memory clinic in 2016 and he was diagnosed a year later with Alzheimer's disease. However, by this time, he deteriorated rapidly and had no financial support in the five years since his redundancy.

GPs and other healthcare professionals are key in facilitating a referral to specialist diagnostic assessments which can lead to a timely diagnosis. Historically, however, research has found that older GPs were more confident in diagnosing and giving advice about dementia but were less likely to see an early diagnosis as beneficial.⁴⁴ Many GPs also reported they hadn't had sufficient basic and post-qualifying training in dementia, and that their overall knowledge of the condition was fairly low. More positively, a recent study surveying future GPs found these attitudes were changing. It found that GPs are now generally positive about their future role in caring for people with dementia, particularly around earlier diagnosis.⁴⁵ Training for GPs on referral criteria and diagnosis could further support appropriate referrals and help to avoid misdiagnoses. This could be carried out by a named dementia lead identified at CCG or Primary Care Network level. However, they must have dedicated time to fulfil this role.

Dementia assessment tools may also affect the timeliness of a diagnosis, as they can identify who needs referral for specialist assessment. National guidance recommends that a GP should take a history of the person's cognitive, behavioural and psychological symptoms from the person and, if possible, from someone who knows the person as well.⁴⁶ If dementia is still suspected, then brief cognitive testing should be used, such as The Mini-Mental State Examination (MMSE). The MMSE used to be the most commonly used assessment tool,⁴⁷ but recent NICE guidance doesn't provide a preferred method. A recent study found that the MMSE test has a dementia misclassification rate of 21%, mainly due to different biases such as age, education and ethnicity.⁴⁸ Professionals working at memory clinics also told us about the challenges involved in diagnosing dementia in people from ethnic minorities. These range from awareness, identification and access, through to assessment and diagnosis. They include concern about shame and stigma in the community, linked to negative views of psychiatry, belief that nothing could be done to help, and not viewing dementia as an illness. During assessments, challenges ranged from language, lack of familiarity with the concept of cognitive functions, and assessments seeming unrelated to needs.

One person told us they noticed symptoms of dementia in their husband because they replicated the symptoms they'd previously seen in their mother. After going to the GP, the husband correctly answered all the questions on the MMSE. They were accused of exaggerating the issue, despite his struggles with everyday tasks and a change in personality. Without a formal diagnosis, the carer increasingly struggled, leading to physical, emotional and mental exhaustion. Despite this, they felt as though they'd used up all options of support without a formal diagnosis.

The short consultation time GPs offer can also cause difficulties in assessing patients with suspected dementia. This can be made harder by the likelihood of comorbidities within older patients.⁴⁹ Dementia can affect a person in many ways, including their cognitive, mental, physical and emotional wellbeing. So it's difficult for a person to describe the impact of dementia symptoms on their life in a single 10-minute consultation. It's also difficult for GPs to fully understand the impact of symptoms on daily living. A large proportion of standard consultation time can be taken up carrying out just one of the brief cognitive tests. This leaves no time to discuss the sensitivities of a diagnosis.

Speaking with GPs, we found that it's good practice to spread an initial assessment of dementia across several appointments or to conduct longer appointments. Alternatively, other members of the primary care team could become involved in the diagnostic process. For example, a nurse could undertake a brief cognitive assessment screen in addition to taking a blood sample. This can ensure enough time is taken both to assess potential dementia and to have meaningful conversations with the patient.

Another opportunity to identify symptoms can arise in hospital. A person with possible dementia may be assessed by hospital staff if they've been admitted for a different reason. If a person is assessed in hospital for possible dementia, it's likely that opportunities to identify the condition have previously been missed. The most recent data, from February 2020, shows that 81.7% of patients who were aged 75 and over and were admitted as an emergency for more than 72 hours were initially identified or given case-finding for potential dementia.⁵⁰

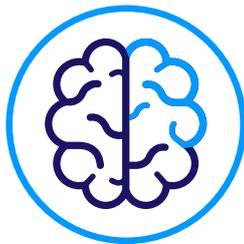
For people with dementia, the primary reason for admission into hospital is almost always due to other reasons than their dementia alone.⁵¹ For example, delirium, which people with dementia can be particularly susceptible to, can be a frequent cause of hospital admission and can contribute to falls and prolonged lengths of hospital stay.⁵² It's important that acute hospital trusts have in place effective and integrated pathways so that dementia screening is undertaken in instances of dementia-related hospital admission cases. The data may also suggest a need for additional or supplementary dementia-specific training within the acute setting for hospital staff, to identify links between reason for admission and potential dementia.

Referral process

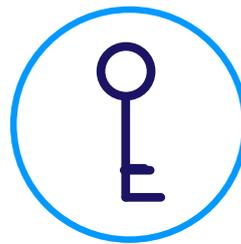
Referral to specialist diagnostic services can:



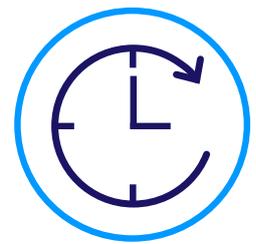
ensure that a diagnosis is timely and accurate



provide an opportunity to diagnose a dementia subtype



facilitate access to support and services, pharmacological and non-pharmacological interventions and explanation of symptoms



enable planning ahead while someone has mental capacity⁵³

All these things may be more effective when carried out earlier on in the dementia journey.⁵⁴ But people affected by dementia told us that the referral process can delay getting a timely diagnosis. It's important to recognise that diagnosis is a gateway to, and a key requirement of, disability entitlements.

A diagnosis also serves as a right to protection under the Equality Act 2010,⁵⁵ which identifies dementia as a protected characteristic. This means any delay in receiving a diagnosis can have significant financial implications.

There has been some progress on raising awareness of dementia and its symptoms. But it's not always possible to have an early diagnosis, partly because it often requires a person to actively seek medical help. However, a timely diagnosis should be a goal. This would improve the diagnostic part of the dementia pathway and ensure more streamlined access to services and support.

One person told us he managed to have a scan within two weeks of seeing his GP, and an appointment with the neurologist two weeks after that. However, it became clear to him that the timeliness was due to fears of a brain tumour, rather than suspected dementia, when he was told **'the good news is that it isn't a brain tumour, but the bad news is it's Alzheimer's.'**

People with dementia told us that the lack of information and clarity about the referral process was unhelpful. This can be made worse by the lack of communication, or differences in the use of information communication systems, between healthcare settings. This is because GP surgeries are part of primary care, and specialist diagnostic services are usually within a secondary mental health setting. If GPs fail to fully explain why they're referring the person to a specialist memory clinic, this can make the assessment and referral feel disjointed, at a time when a person already feels confused and scared. One woman told us she only found out her referral was due to suspected dementia when she was included in a referral letter from the GP to the memory service.

We heard that additional written information on the referral process can help address questions and concerns, as well as help people feel more comfortable about 'what comes next'. All communication needs to be clear, personalised and non-clinical. People told us that a smooth referral process sets the tone for the rest of their pathway. When referrals are delayed, we heard that people often don't know who to contact and feel at risk of 'slipping off the radar'. This is made worse by the complexity of the healthcare system.

Care home residents with possible dementia may be more advanced in their condition, and a referral may not be appropriate. A poll of 1,013 GPs commissioned by Alzheimer's Society found that one-third (33%) of GPs would be less likely to diagnose someone or refer them to a specialist diagnostic clinic if the person is living in a care home.⁵⁶

NICE guidance says the diagnosis of dementia should be made by a specialist, but this can be a professional outside of secondary care if they have the necessary skills and expertise.⁵⁷ Services and healthcare professionals should recognise a person's right to a diagnosis regardless of where they're living, or how advanced their dementia is. The Diagnosing Advanced Dementia Mandate (DiADeM)⁵⁸ can be a useful tool to support GPs in diagnosing people living with advanced dementia in a care home setting. People with advanced dementia, their families and staff caring for them still benefit from a formal diagnosis. It enables them to access appropriate care for their needs, and prompts staff to consider Mental Capacity Act issues where relevant. Named clinical leads for care homes should facilitate dementia assessment and diagnosis and be supported with training and time to conduct assessments. This would not only lead to better care but would also support national efforts to improve diagnosis rates.

Making a diagnosis

There is limited data on memory service performance, so regular assessment of variation relies on ad hoc audits. The National Collaborating Centre for Mental Health's Dementia Care Pathway⁵⁹ recommended an increase in the number of people being diagnosed and starting treatment within six weeks of referral. The 2019 national memory service audit data shows that the mean waiting time from referral to diagnosis was 13 weeks, but it varied across services from three to 34 weeks. Overall, just over a quarter of patients (26%) were diagnosed within six weeks of referral.⁶⁰

One person who eventually received a dementia diagnosis told us they initially assumed they'd been cleared when they didn't hear anything for four months after their scan. Regular audits of memory service data and performance would support the initiation of service improvement projects, leading to a higher standard of care at this stage of the pathway.

Appropriate staffing of memory services is essential to delivering a high-quality diagnosis. Formal arrangements must be made to facilitate multidisciplinary meetings between memory service clinicians, neurology and neuroradiology to promote joint working and facilitate clinical case discussions. There must also be timely access via a multidisciplinary team or good referral pathways to psychiatrists, psychologists, occupational therapists, social workers, dementia advisers and linguists and interpreters. Integrating a social worker within the memory service can be beneficial because it creates a clear referral pathway. This reduces the time it takes someone to access support and it upskills the social worker on dementia. In addition, occupational therapists are crucial to conduct functional assessments, which is even more important for non-English speaking people.

A significant part of the diagnostic process, which can also improve people's experiences, is the delivery of the diagnosis. Being given a dementia diagnosis is a life-changing event. A diagnosis should therefore be delivered to a person sensitively, face-to-face and framed as positively as possible. But we heard from people with dementia that their diagnosis was given insensitively, with the conversation focused on what they can no longer do, rather than what they can do. We heard that the delivery of a person's diagnosis sets the tone for how they view their subsequent pathway, and the condition itself.

A review of studies found that offering hope during the delivery of a dementia diagnosis was considered beneficial by clinicians, patients and carers.⁶¹ For patients, it signalled that things could be done. For clinicians, it offered a constructive way for patients and carers to move on and felt necessary when delivering bad news.

'It's so daunting when you get that diagnosis and think 'what's life going to be like now?'... It's getting that message across, to get out there – your life isn't over.'

Person living with dementia

A study from 2018 found many people were dissatisfied and disempowered by the way their diagnosis had been communicated to them.⁶² One of the reasons for this was that they were told insensitively, for example by letter, or with little time or emotional support to digest the news. Messaging accompanying the diagnosis also tended to reinforce negative views and stigma around dementia – a challenge sometimes described as ‘Prescribed Disengagement’.

One person told us his diagnosis involved a pat on the shoulder and the message: **‘you’ve got a little bit of dementia.’**

We heard from people affected by dementia that being given an opportunity to see a brain scan was useful. Scans show people how dementia is affecting their brain, helping explain their behaviour and how they may be feeling. This aligns with a recent study which found that visual information helped people process their diagnoses and was identified as valuable by patients and carers.⁶³ There must also be timely communication of new diagnoses to the appropriate GP – for example, it’s faster to use email rather than post letters.

‘There is something in the human psyche that makes us think/hope “this is not happening to me” but when I saw the brain scan it was something tangible that I could make sense of – and see just what was causing our life-changing problems.’

Person living with dementia

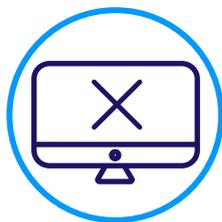
Diagnosing a subtype

Improving diagnosis rates and ways to diagnose subtypes will enhance our understanding of the causes of dementia. This will lead to the development of new treatments, which will be a significant part of the dementia pathway in the future. But while work is carried out on future tests that can ensure accuracy, it’s crucial we use what we have today to give people as much information as possible about their type of dementia.

Dementia is a broad term and describes different conditions affecting the brain. The specific symptoms that someone with dementia experiences will depend on the parts of the brain that are affected, but also the condition that’s causing the dementia.

It’s recommended in national guidance to diagnose a subtype. This can affect future medication, care plans, interventions and opportunities to engage in, or benefit from, research. All these things can affect a person’s ability to live well with dementia. So it’s vital that people are informed about the type of dementia they have, and that the information they receive afterward is tailored to their diagnosis.

We heard from some diagnostic services that they're unable to view brain scans, because they don't have access to picture archiving and communication systems (PACS).



60% of services nationally reported they were unable to view brain images they had requested.⁶⁴

This may be the result of community mental health trusts – where most memory clinics are – not having the same IT systems as acute hospital trusts, where most brain scans are undertaken. We heard it's good practice for diagnostic services to have joint working arrangements with acute trusts to access PACS if they don't have access themselves.

We also heard from memory services that the provision of additional information supplied from radiology departments, where brain scans are undertaken, can vary. Brain scans should be accompanied by information on why a particular dementia diagnosis is suspected. This can enable diagnostic services to deliver the correct diagnosis and reduce the chance of a misdiagnosis with specialist input.

We heard that some people diagnosed with dementia want to know what type of dementia they have. There were positive stories about the difference this can make to their wellbeing in terms of understanding symptoms. But for this to happen, it's essential to make sure that people receive tailored information on their subtype. In 2019, an audit of specialist diagnostic services found that, on average, 6% of patients over the age of 65, and 9% of patients under the age of 65, were diagnosed with 'unspecified dementia'. It also found that this varied between 0% and 50% across services.⁶⁵ Tailored information enables people to better understand the impact their dementia subtype can have. It therefore supports the development of strategies to enable them to live well. It also enables more effective planning for future care by health and social care professionals together with the person affected. A recent study noted the importance of care providers to consider varying needs across different dementia subtypes, particularly the complex needs of people with Parkinson's disease dementia and dementia with Lewy bodies.⁶⁶

Despite this, we heard that the provision of tailored subtype information is variable. People described their diagnostic experience as very basic, with no information given and a lack of explanation about their diagnosis. One person told us the doctor 'couldn't get me in and out quick enough' and he said he felt like getting up and walking out halfway through the appointment.

It's also important that the subtype diagnosis is shared across all relevant healthcare systems. This ensures continuity of care and provides all professionals involved in a person's care with the same information to inform and support clinical and non-clinical decision-making.

Research is critical to improving practice within the dementia diagnostic process. Despite national guidelines for diagnosis and management of dementia, we often heard people express frustrations with the diagnostic process and with the limited post-diagnostic support. The COGNISANCE programme is an international project funded and promoted by Alzheimer's Society. It's run in partnership with people with dementia, family care partners and healthcare professionals in Australia, Canada, the Netherlands, the UK and Poland. It aims to design and deliver toolkits and campaigns to improve the dementia diagnostic process and post-diagnostic support.

What is good practice?

Primary care:

- ✓ **Ensuring there's enough time to assess potential dementia and engage in meaningful conversations with the patient at primary care level.** This can be done either through staggering an initial assessment of dementia across several appointments or conducting longer appointments. Alternatively, other members of the primary care team can become involved in the diagnostic process to overcome the barrier of securing enough time with a GP. For example, a nurse could carry out a brief cognitive assessment screen in addition to taking bloods, or a specially trained healthcare assistant could carry out initial assessments.
- ✓ **Rolling out training for primary care on referral criteria and diagnosis and management of dementia.** In Stockport, Named Dementia Specialist Link Nurses from the memory service are attached to each GP practice and offer bespoke training.
- ✓ **Supporting GPs with the diagnosis and management of dementia.** For example, as part of the Integrated Care Communities model in North Cumbria, a pilot is taking place in which a nurse-grade Memory Link worker is based in a GP surgery one day a week. The worker screens and reviews patients identified at the practice with existing or suspected dementia. They can make fast-track referrals to the Memory and Later Life Service (MLLS), with the GP offering triage of more complex cases. This pilot is a partnership between MLLS and primary care, resulting from consultation with people living with dementia and their families. It aims to improve access to MLLS and free up GP time.
- ✓ **Using Yorkshire and Humber Dementia Clinical Network's Diagnosis of Advanced Dementia Mandate in Care Homes (DiADeM) tool.** This supports GPs in diagnosing dementia for people living with advanced dementia in a care home setting.

Secondary care:

- ✓ **Ensuring clear, personalised and non-clinical referral communications.** For example, the South of Tyne and Wear Memory Protection Service ensures all patients are copied into jargon-free referral letters between services.
- ✓ **Ensuring the GP is copied into all correspondence.** Timely communication of a new diagnosis to the GP is particularly important so that they're aware before the patient or family contact them. For example, quicker methods of communication such as email could be used.
- ✓ **Running an open referral system, accepting referrals directly from sources other than primary care, including hospitals, social services, patients and carers themselves.** This should include ensuring ongoing patient access to the service in the event of concern about their condition, as well as referrals in and out of GPs. For example, at Wigan Later Life and Memory Service people can be referred back for a review by their GP as the dementia progresses. Patients and their family members can also recontact the service directly if they need to.
- ✓ **Ensuring access, or timely referral, to psychiatrists, psychologists, occupational therapists, social workers, dementia advisers, as well as linguists and interpreters.** All of these professionals can add value during the diagnosis process and ensure a smoother diagnostic pathway.
- ✓ **Integration of a social worker within the memory clinic.** For example, at Tower Hamlets Memory Clinic a social worker from the local authority is seconded to the memory service. This ensures timely access to social care at any point of the diagnostic pathway, reducing the time taken between diagnosing someone and waiting for social service involvement. It also enables the social worker to upskill themselves clinically around dementia through working with memory clinic staff.

- ✓ **Adopting service-level agreements with acute hospital trusts to ensure timely access to scanning equipment within radiology departments and subsequent reporting.** It's also good practice for memory clinics to have access to picture archiving and communication systems to ensure they can view brain images they've requested. Ensuring patient access to viewing brain scans can also be a helpful aid to explain how dementia is affecting their brain.
- ✓ **Providing tailored post-diagnostic support according to dementia subtypes, enabling people with dementia and their families to understand what their subtype means for their symptoms and prognosis.** One example is Stockport Memory Assessment Service, which offers information groups on Alzheimer's disease, vascular dementia and dementia with Lewy bodies.
- ✓ **Good working relationships between memory services and commissioners.** For example, Stockport Memory Assessment Service meets with the local commissioner on a quarterly basis to discuss progress and developments within the clinic.
- ✓ **Delivering a diagnosis positively, focusing on what the person can do, not only what they can no longer do.** Early support and possible interventions should be discussed.
- ✓ **Ensuring that measures of success include patient and carer reported outcomes and assessments of a 'good' diagnosis.**
- ✓ **Ensuring appropriate case-finding of dementia for dementia-related hospital admission cases, such as delirium, using effective and appropriate pathways.** For example, Cumbria's 'Reach Out' Delirium service actively seeks out patients at risk of delirium following admission. This includes those with new or suspected dementia. The team will contact family or carers for background details and arrange diagnostic assessment with the local memory service. This enables appropriate diagnosis to be taken forward once the person leaves hospital. The service is also able to link in all patients living with dementia with any additional or enhanced support needed from local memory services or third sector partners.
- ✓ **Assessment of case-finding data and appropriate training for staff to support them in identifying links between reason for admission and potential dementia.**



Supporting Well

What do we mean by supporting well?

Initial post-diagnostic support is vital to ensure that people can come to terms with their diagnosis and that they're better able to manage their condition. Given the variety of symptoms that people can experience, post-diagnostic support is essential to facilitate access to services.

This chapter looks at a person's immediate support needs, up to approximately one year after diagnosis. It looks at information access, care coordination and care planning, as well as post-diagnostic support interventions.

What are the benchmarks?

The following benchmarks have been used to assess what care people are receiving at this stage of the pathway:

- At diagnosis, offer the person and their family members or carers oral and written information that explains:
 - what their dementia subtype is and the changes to expect as the condition progresses
 - which health and social care teams will be involved in their care and how to contact them
 - how dementia affects driving and the need to notify the Driver and Vehicle Licensing Agency of their diagnosis
 - their legal rights and responsibilities
 - their right to reasonable adjustments under the Equality Act 2010
 - how to contact local support groups, online forums, national charities, financial and legal advice services, and advocacy services. (NICE)⁶⁷
- 'Increased numbers of people with dementia participating in research, with 25 per cent of people diagnosed with dementia registered on Join Dementia Research and 10 per cent participating in research, up from the current baseline of 4.5 per cent.' (Prime Minister's Challenge on Dementia 2020)⁶⁸
- 'We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.' (Dementia Statements)⁶⁹
- 'We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.' (Dementia Statements)⁷⁰
- 'Adults with dementia have a single named practitioner to coordinate their care.' (NICE)⁷¹
- 'Adults with dementia are given the opportunity to discuss advance care planning at diagnosis and at each health and social care review.' (NICE)⁷²
- People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care, that identifies a named care coordinator and addresses their individual needs. (NICE)⁷³
- 'All people with a diagnosis of dementia being given the opportunity for advance care planning early in the course of their illness, including plans for end of life.' (Prime Minister's Challenge on Dementia 2020)⁷⁴
- 'People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.' (NICE)⁷⁵
- 'Access to holistic, integrated and effective post-diagnostic support is available for all, which takes into account age, ethnicity, diagnosis and co-morbidities.' (Department of Health and Social Care)⁷⁶
- 'We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.' (Dementia Statements)⁷⁷
- 'We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.' (Dementia Statements)⁷⁸

Key questions and gaps between policy and practice

This research has identified the following key considerations at this stage of the dementia pathway:

- How to make sure people are receiving the right information in the right way at the right time, and how to combat information overload, lack of information or misinformation.
- The impact of commissioning memory clinics as diagnostic services only, and the bearing this has on providing opportunities for follow-up.
- Who performs the role of care coordinator, what it involves, as well as access and availability.
- The role of commissioners in understanding local provision of services.
- The integration of dementia advisers within the pathway.
- The distinction between care plans by GPs and local authorities and the lack of integration between different services and the impact this has on subsequent referrals and coordination of care.
- Whether people have care plans and are aware they have them.
- The different follow up trajectories depending on medication prescriptions and the different role of GPs and memory clinics in terms of care planning.
- How integrated advance care planning is within post-diagnostic support, and the barriers to doing this effectively, including training and local levels of responsibility.
- Access to post-diagnostic support interventions that help people with dementia maintain cognitive function, independence and wellbeing, as well as the appropriateness of these and the point of intervention within the pathway.

We begin to explore these questions in this chapter. It's essential they are considered as part of the development of local dementia pathways.



‘My husband, Atherton, is a gentle and intelligent man. In his spare time, he used to write poetry and even had some published. He was interested in astronomy, the arts and was incredibly well-read. Before his diagnosis, we had plans to volunteer overseas in our retirement.

Atherton was a haematologist before retiring six years ago. I think he knew something wasn’t right when he was still working, which is why he retired at 62, saying ‘I want to retire now before I start making mistakes’. His mental flexibility diminished, and it was clear there was a major problem. Initially, his GP thought it was depression, but Atherton knew in his heart of hearts that it was something deeper.

After a lengthy process, he finally received his diagnosis in 2016. When the diagnosis was given, we walked out with absolutely nothing apart from the instruction 'to see the GP and he'll sort out your medication'. We never even had a leaflet about dementia, let alone signposting to any services.

The only support my husband and I had were things I had to discover and instigate myself. People with dementia and their loved ones should not have to fight for the care and assistance to which they are entitled. We were given a life-changing diagnosis, then left to our own devices to navigate the complexity of the health and social care system.

No care plan was discussed or put in place. For us, there was no dementia pathway. I felt like I was walking through candy floss – everywhere I turned for help I met a sticky end.

In one instance, I asked about a respite break at a care home. They refused to help saying they only offered respite to those who attended their day centre. I didn't even know they offered day care. The centre is just seven minutes' walk from our home and on the same site as my husband's GP, who had never suggested it to us. I can't help but feel that had a care plan been in place, his needs could have been identified and we would have had better access to services.

Furthermore, when we found support services and groups, they simply weren't geared towards younger people with dementia. My husband grew up on Led Zeppelin and Queen, but local singing groups assumed everyone wanted to sing along with Vera Lynn. Services need to understand that younger people with dementia have different needs and different life experiences.

What would have been useful would have been a named person to help guide us through the dementia journey; one who knew what support was available – just someone to make something happen.'

Deborah, wife of Atherton who is living with dementia



Information in the right way

We heard about variation in the amount of information people received upon diagnosis. It's important for services to recognise that when a person is diagnosed, they may experience feelings of confusion, uncertainty and insecurity. The emotional impact must be managed first. Information given afterward must then provide clarity and understanding to a person's situation, while giving them advice on how they can live well with dementia.

Speaking with people affected by dementia, we found that this often isn't the case. One group said they all received visits from professionals initially after their diagnosis but didn't know which organisations they represented. One person said: 'they all left lots of books and paper, but I haven't even looked at it, so I don't know who they were from.' Another person said they 'were given a large pile of information and leaflets from the memory service. Some of it was helpful for my carer... [but] it was overwhelming for me.' Feelings of being overwhelmed by the amount of information received post-diagnosis were common among the people we spoke to. Despite this, we heard that Dementia Connect – Alzheimer's Society's support service – is beneficial in terms of information provision. It also provides a consistent offer of support, aiming to make sure that no one faces their journey alone.

There are crucial bits of information that people want and need after receiving their diagnosis. This inevitably varies according to the individual, but an opportunity to discuss the diagnosis in more depth and ask questions at their own pace should be an integral part of the diagnostic process. A recent Dutch study found that while clinicians often provided information on the results of diagnostic testing, they rarely invited questions or checked understanding.⁷⁹

We heard about the need to manage the flow of information at this stage of the pathway. Trying to address everything at the point of diagnosis, where many people already feel overwhelmed, is often counterproductive. This aligns with a recent literature review which found follow-up sessions beneficial for both clinicians and carers.⁸⁰ Careful consideration must be given to which systems, providers, or clinicians are responsible for the delivery of this support. One piece of recent research suggests that primary care provider-led case management partnership models of post-diagnostic support offered the most promise, with impact on neuropsychiatric symptoms, caregiver burden, distress and mastery, and healthcare costs.⁸¹

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. People can be discharged from memory clinics and be left alone to come to terms with their diagnosis. Clear local consistent pathways are essential to offer people 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 could support an integrated pathway. 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.

People told us they didn't receive enough information about financial matters. People said they only found out about the financial support available to them by speaking with people in similar positions in local support groups. Dementia affects all aspects of a person's life including their ability to work.

If diagnosed with dementia, a person and their carer may be eligible for financial support. Financial assistance to continue daily living activities can significantly improve quality of life. It's vital that a person is fully aware of financial entitlements at the point of diagnosis. It's insufficient for healthcare professionals to simply recommend that someone 'gets their affairs in order', as we've often heard. The social security system is very difficult to navigate. There was a consensus for more information on financial matters, how dementia affects working and a comprehensive list of what benefits are available to a person with dementia during the diagnostic process.

People with dementia should also be given information about research opportunities. We heard that involvement in research can ease some of the impact of receiving a dementia diagnosis and can help people feel like they're doing something worthwhile. It's therefore important for people to be made aware of these opportunities and given choice and support to get involved. The 2019 national memory service audit, which analysed results from 85 services and 3,978 patients, revealed that only 36% of people were asked for consent to contact them for research.⁸² More work must be done to ensure research opportunities are embedded in the pathway as routine.

'What I do now will not help me, but I take great pride that it will help people in the future.'

Person living with dementia

It's also important that clinicians are providing correct information. Too often we've heard that the wrong information and advice was given around the suitability to drive for people diagnosed with dementia. We heard in one example that a person who drove professionally, usually driving around 60 to 70 thousand miles annually, had been told by his GP: 'I would hand over your driving license before I tell the DVLA.'

Care coordination and access to a dementia adviser service

The provision of post-diagnostic dementia care is highly varied across the country. It's fragmented due to the range of providers involved. An integrated pathway of care is needed to ensure gaps in provision are avoided and that everyone diagnosed with dementia has access to post-diagnostic care.⁸³

Because of 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 for the person and the care they receive can often feel disjointed. But access to a range of professionals can be very beneficial. It can mean that specialists are able to support with specific symptoms.

An Alzheimer's Society survey from 2015 found that 73% of GPs agreed it's confusing for people with dementia and their carers to navigate the health and social care system.⁸⁴ While information can go some way to ease this, more proactive person-centred support in the form of a care coordinator can be beneficial. Identification of a care coordinator must happen toward the beginning of the pathway, either by a memory clinic or by primary care during a follow-up appointment.

‘When my mother was treated for other conditions, I didn’t need to know things like the difference between primary and secondary care. However, with dementia, that all changed.’

Family member of a person with dementia

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.⁸⁵ 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.⁸⁶ 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.

However, unpublished data from Improving the Experience of Dementia and Enhancing Active Life (IDEAL) study shows that 68% of people with dementia don’t have access to a care coordinator.⁸⁷

There’s also a lack of clarity around the role, specifically who does it and what it involves. People living with dementia and their carers may not know who their care coordinator is. Professionals may not know that they’re the named care coordinator. It’s therefore difficult to find out how far people are receiving proper coordinated care, or even access to appropriate services that would help them. There must be national guidance on care coordination for people with dementia, including who can do it, what the role involves and transition requirements if the care coordinator changes along the pathway. While not dementia-specific, it is promising that the contract specification for Primary Care Networks includes the role of care coordinators.⁸⁸

The care coordinator role was only recommended in the updated 2018 NICE guidance. But dementia advisers – a recommendation of the 2009 English National Dementia Strategy – are already working in many parts of the country and may undertake some elements of care coordination for people living with dementia. These roles are locally-based and support those with dementia from the point of diagnosis. A benefit of this service is that they act as a single identifiable point of contact that has knowledge of, and direct access to, a range of available local services.⁸⁹ Speaking with people affected by dementia, access to a dementia adviser has been described as ‘life-changing.’ They’ve helped people come to terms with their diagnosis and enabled access to services which are appropriate for their care needs.

Dementia advisers may also provide additional and valuable post-diagnostic support services, particularly early intervention provision. For example, in a 2016 survey by Alzheimer’s Society, 73% of commissioners reported that dementia advisers run support groups for people with dementia in their area, as well as carer support groups (67%), carer education groups (60%) and education groups for people with dementia (46%).⁹⁰

However, access to a dementia adviser-type service can be patchy. Data from 2016 revealed that 75% of CCGs and local authorities commissioned Alzheimer’s Society to deliver this service. But only 91% of commissioners (81 out of 89) say there’s a dementia adviser or similar service in their area.⁹¹ Also, this doesn’t necessarily mean there’s capacity for that service to be offered to everyone in their area who’s been diagnosed with dementia.

Almost a fifth (17%) of commissioners don't know exactly how many dementia advisers are commissioned within their area. Most (68%) don't know what the average caseload of a dementia adviser in their area is. Of those commissioners who could estimate a caseload figure, the average caseload of a dementia adviser is 126, with the North of England having the highest caseload (186) and London having the lowest (88).⁹² This data doesn't factor in the extent of the role carried out in practice locally. But it does highlight that more work needs to be done to consider availability and access.

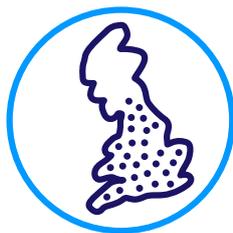
'What I think I really want is someone who I get to know in the months ahead who I can talk to when I have concerns, who listens to me and knows me and can help me.'

Person living with dementia

'We need someone who is our own helper who we can trust. Someone that I don't feel anxious about. When all these people came round after I had been told [my diagnosis], I ended up feeling unhappy because it was really pressurised. I want to get to know someone and they get to know me, so that I can relax and talk to them about my worries.'

Person living with dementia

The 2019 national memory service audit found that almost 20% of people who'd received a dementia diagnosis had not been offered any form of dementia adviser-type service via a memory service.⁹³ We heard that where dementia adviser services are co-located within diagnostic services, this increased the number of service users being recruited at the point of diagnosis. We also heard that automatic referral with an 'opt out' system for a dementia adviser service can work well. Professionals and people affected by dementia told us that integration of dementia advisers within specialist diagnostic services helps to create a seamless pathway at the diagnostic stage. It's also important to consider how to integrate this service within other settings which people with dementia may encounter later in the pathway, including primary care.



The number of people with dementia in England is set to increase to **1,046,100 by 2030**.⁹⁴

It's important commissioners fully understand the dementia adviser services in their area, and who is locally responsible for delivering a care coordinator service to everyone who needs it. It's also important to consider what combination of professionals provide the best model of post-diagnostic support.

This is something that PriDem, one of Alzheimer's Society's three Centres of Excellence, is doing. PriDem is a project led by Newcastle University, in collaboration with University College London and London School of Economics. It's examining post-diagnostic dementia support with the aim of developing and co-designing evidence-based, primary care-led models of support for people with dementia and their families. PriDem works with a group of people affected by dementia, professionals and practitioners. It will develop, translate and disseminate findings from the research into practical outputs including resources and commissioning guidance and future cost projections.

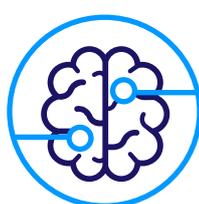
Care planning

The product of personalised care and support planning is a written plan. This details what matters to an individual, what care and support needs a person has and what mechanisms should be put in place to help mitigate care and support needs.⁹⁵ It should be developed by both the individual and a health or social care professional.

It should include:



a review of the diagnosis



identification of new symptoms



what matters to the person enabling them to live well



treatment and support



a carer's review



evaluation of additional risk factors



a medication review



advance care planning⁹⁶

Last, and most important, the professional should provide a copy of the plan to the person and their family members or carers.⁹⁷

Usually, a care plan will be started by a health or social care professional during the diagnostic process at a specialist diagnostic service. After some time, the care of an individual will be referred to the person's GP. The GP will then have oversight and responsibility for reviewing that person's care plan on a regular basis, including the management of any comorbidities.

However, often a person can stay with the diagnostic service for longer if their medication requires follow-up from the memory clinic. This means there are two different trajectories in terms of immediate follow-up involving the GP and the memory clinic, which makes dementia pathways even more complex.

The distinction between care plans that fall under the remit of a GP and care plans that fall under the remit of the local council can also be confusing for people with dementia. Council-level data of social care plan reviews shows that only 45% of people with dementia using social care had a planned review in 2018.⁹⁸

Uncertainty over who should do what in dementia care is a key barrier preventing people from accessing the consistent care they need. This confusion may also be made worse by the timing of a diagnosis. Where a person is diagnosed late in their pathway, they may need immediate social service support whereas people diagnosed early may not immediately need local authority support. There must be more integration of care and support plans between different services involved in a person's care.

Care plans can bring many benefits, but we've been concerned about how regularly we receive reports that people don't have one. Care plans should be individualised, tailored to the person's needs and preferences, and goal-oriented.

Data from the 2020 GP Patient Survey shows that only 64% of people with dementia have an agreed plan with a healthcare professional from their GP practice to manage their condition.⁹⁹ Of those we spoke to who did have one, one person told us it took four years to get his care plan.

We also know that some people who may have a care plan are unaware they have one. This is particularly concerning given that care plans should be drafted in consultation with the person they relate to. Almost one in 10 (9%) people responding to the 2020 GP Patient Survey said that they don't know if they have a care plan in place.¹⁰⁰ This shows clear failings in quality and co-production requirements.

NICE guidance recommends that every person with dementia should be given a written copy of their care plan. Data from 2020 suggests that under half (46%) of people with dementia have been given or offered a written or printed copy of their care plan. 40% of people say they haven't and 14% say they don't know.¹⁰¹

We heard from people with dementia that having a written copy of their care plan allows them to understand what care and support they're entitled to. It offers them something tangible to use when taking control of their own care and liaising with others about what they need in order to live well. To ensure continuity of care, health and care professionals should also have access to the same care plan, so that they're aware of the person's needs and what interventions have already been provided. This is particularly pertinent for people with dementia who will need to access a range of services and professionals, such as occupational therapists, speech and language therapists, GPs, social workers, psychologists and mental health nurses.

However, we know this isn't happening. People with dementia told us they're too often explaining their story multiple times to different healthcare professionals. This leads to frustration both from the person affected by dementia and the professional. This is particularly inappropriate for people with dementia, who may struggle to remember their own medical professional history or to communicate it effectively. Professionals told us they have to try to piece together disjointed information about the person, which can lead to 'scattergun' referrals. Untimely or inappropriate referrals can cause significant disruption to someone's pathway that could have been avoided. They can also provide an impersonal experience of care that doesn't account for a person's needs. Everyone with dementia should have a single digital health and care record that's accessible to all health and care professionals involved in their care, which includes advance care planning. This would help overcome these barriers and deliver more integrated care.

Initiation of advance care planning

NICE guidance says healthcare professionals should offer early and ongoing opportunities for people living with dementia and the people involved in their care to discuss advance care plans. These discussions should include the benefits of planning ahead, Lasting Power of Attorney, advance statements about wishes, preferences, beliefs and values regarding future care, advance decisions to refuse treatment and preferences for place of care and death. People should also be made aware that they'll be given chances to review and change any advance statements and decisions they've made, and that this should happen at each care review.¹⁰²

Advance care planning is therefore a means of improving care for people who may be nearing the end of life by enabling better planning and provision of care.¹⁰³ This is an integral part of the pathway, but it isn't happening as standard.

Dementia is a progressive condition that affects mental capacity. Early and ongoing conversations around advance care planning must take place before a lack of capacity prevents a person from documenting what care they'd like at end of life. To achieve this, healthcare professionals should support people in the early stages of dementia to make as many decisions as possible about their future wishes.

Discussing end of life is a difficult and sensitive topic. We heard mixed responses about people's willingness to talk about what they would like at the end of life.

'End of life is a thing you don't talk about.'

Person living with dementia

'It's a good thing [talking about end of life]. I'd like to, but my son doesn't, he doesn't want to talk about it.'

Person living with dementia

A 2019 study by Alzheimer's Society and West Yorkshire and Harrogate Health and Care Partnership found that almost half of people with dementia and their carers (48%) said they would find discussions around advance care planning 'very difficult' or 'difficult'. Only 34% would find these discussions 'easy' or 'very easy'.¹⁰⁴ While all healthcare professionals involved in the care of a person with dementia should discuss future wishes with them, there are mixed views on when these conversations should happen:

- 27% of people with dementia and their carers said diagnosis was the right time to engage in advance care planning conversations
- 53% said that some time after diagnosis, when a person's health is stable, is the right time
- a further 18% said these conversations should happen after a deterioration of health
- 1% said discussions should happen when a person is in the last weeks of life
- just 11% said that conversations should happen at all the stages above.¹⁰⁵

Aside from family members (78%), the study found that people would be most comfortable having an advance care planning conversation with:



a GP (40%)



a palliative care doctor or nurse (28%)



a social worker (15%)



a dementia adviser (39%)



a memory clinic staff member (23%)



a nurse practitioner (14%)



an Admiral Nurse (25%)



a professional carer (19%)



a hospital doctor (8%)¹⁰⁶

GPs are key within advance care planning, as they traditionally hold a long-term relationship with a patient. One study found that almost 83% of GPs strongly or moderately agreed that it's their role to initiate advance care planning. 40% believed this should happen at diagnosis.¹⁰⁷ However, other studies suggest that GPs feel advance care planning is outside their professional remit.¹⁰⁸ A cause of this may be that GPs are used to providing reactive care, whereas advance care planning requires forward preparation and so initiating conversations may prove to be more difficult.¹⁰⁹

A high proportion of Admiral Nurses and memory clinic staff also thought that advance care planning was part of their role.^{110,111} The study also found that 77% of care homes agree that advance care planning conversations should happen before care home admission. But just 13% reported that these conversations often happen at that time. They reported that it sometimes (69%), rarely (15%) or never (3%) happens.¹¹²

Despite this, and national guidance on advance care planning,¹¹³ we heard from some professionals that they aren't comfortable or trained to have those conversations. Also, people who have no contact with healthcare services after a diagnosis – who have effectively 'fallen off' the pathway – struggle to access opportunities for advance care planning until a crisis, such as a hospital or care home admission, when it may be too late. Despite this, advance care planning should also be happening at those transition points. It's also essential that named clinical leads for care homes identify people who don't have an advance care plan and initiate the process.

To ensure early, necessary and repeated conversations, there must be a more prominent role for advance care planning within post-diagnostic support. There must be clear levels of responsibility outlined at a local level.

This will avoid the mentality one person described as **'if it's everyone's responsibility, it's no one's responsibility.'**

Access to interventions

Currently, there is no cure for dementia. But there are interventions that can help people with dementia maintain cognitive function, independence and wellbeing. These interventions come in two forms – pharmacological and non-pharmacological. Both can support people to manage symptoms, or progression, of dementia.

For non-pharmacological management, NICE recommends that healthcare professionals offer a range of activities tailored to the person's preferences.¹¹⁴ For people with mild to moderate dementia, healthcare professionals should offer Cognitive Stimulation Therapy (CST) and Group Reminiscence Therapy and should consider Cognitive Rehabilitation or Occupational Therapy. Education and support groups, post-diagnostic counselling and Life Story work can also help a person come to terms with their condition.

We heard from people with dementia that these interventions are beneficial, not just for cognitive function but also for their general wellbeing. However, essential to this is the provision of appropriate interventions that are tailored to the person's preferences. But we heard about a lack of access to age-appropriate support groups, particularly for people with young-onset dementia. One person said it was one of the worst experiences she'd ever had, as the choice of activities wasn't tailored to her preferences. She didn't feel included and the other members were unable to understand how she could get there alone. She had already moved from Scotland to England to access more age-appropriate support, but she still described feeling out of her depth.

This lack of appropriateness can cause barriers for people from many groups, including people from Black, Asian and Minority Ethnic (BAME) communities, men, and people from the Lesbian, Gay, Bisexual and Transgender (LGBT) community. It's vital that we look at how to make activities and services more inclusive. People from BAME communities may face additional barriers relating to language and culture. For example, some older BAME people may be less likely to speak English or use English as their dementia progresses. The provision of interventions must be reviewed and made more appropriate and tailored. It must consider age, ethnicity, gender and sexual orientation, and reflect the diversity of our society.

A 2020 study surveying dementia commissioners revealed that few areas reported providing dementia health services specifically for BAME populations.¹¹⁵

We heard from people with dementia that the condition meant there were things they can no longer do, and so access to group activities was extremely beneficial. People told us about the value of peer support groups and meeting others who are also living with dementia. They said it 'really helped us come to terms with what was happening' and it provided a space for 'having someone there who knows what it's like'.

We heard positive stories of people sharing experiences and learning how to live well with dementia: **'it's difficult but it's not impossible'**.

Despite the benefit of these services, we know that people aren't being offered them as standard, or they're struggling to access them. We know that post-diagnostic support interventions aren't universally available and vary in their duration and content.

In 2020, a fifth (20%) of people said that, in the last 12 months, they hadn't had enough support from local services or organisations to help them manage their condition.¹¹⁶ In some cases, people told us they were taking responsibility for setting up local support groups in the absence of formal support services.

Unpublished data from the IDEAL study shows that 70% of people with dementia and 71% of carers haven't taken part in any intervention to help with their condition.¹¹⁷

The 2019 national memory service audit shows that 25% of services were unable to refer to another service for CST.¹¹⁸ However, group activities aren't suited to everyone. The 2019 audit shows that in total, 46% of people were offered CST but almost half (46%) declined it.¹¹⁹ Despite this, it's one of only a few post-diagnostic support interventions recognised within national guidance. Therefore, the opportunity to access these interventions, at an appropriate time and accompanied by clinical recommendation acknowledging its benefit, is essential. It's worth noting that service design and commissioning priorities may explain the lack of provision and access of post-diagnostic support interventions. For example, some services are commissioned solely as a diagnostic service and so may not have sufficient workforce, budget or resources to provide different post-diagnostic support interventions.¹²⁰

We heard much about the benefits of cognitive rehabilitation, which aims to improve a person's ability to carry out daily living tasks and other meaningful activities. This is particularly beneficial in the earlier stages of dementia. It helps manage memory impairment more effectively and improve quality of life for both people with dementia and family carers.¹²¹ It involves working with healthcare professionals to set personally relevant goals and developing strategies to reach them. These strategies may include techniques for learning new information, maintaining attention, concentration and stress management. It's valuable for people at all stages of dementia, although in different ways.

Occupational therapists are one professional group that can provide cognitive rehabilitation and help support functional ability. After speaking with professionals and people affected by dementia, it became clear that occupational therapy can significantly improve quality of life. We heard positive stories about occupational therapists providing information and tips on memory and supporting independent living.

Losing the ability to do day-to-day tasks can have a negative impact on a person's mental health. One person with dementia told us that 'occupational therapists saved my life when I would have been happy to drink and eat myself to death.'

He described being unable to tie his shoelaces and receiving advice from his consultant to buy Velcro shoes. Instead, his occupational therapist gave him a frame to practice doing his shoelaces, which made a significant difference to his independence and mental health.

A key issue, however, is the point of intervention. It's beneficial that occupational therapists can be accessed via a range of health and care settings. But we heard it's most beneficial for them to be embedded within the diagnostic pathway for dementia. This is to intervene early and take on a preventative role in order to sustain everyday living. Too often referrals come as a result of crisis, when people aren't as receptive to support. This doesn't prevent occupational therapists being used at other stages – they can also maximise recovery after a fall, for example.¹²² But the challenge is ensuring that services are able to implement cognitive rehabilitation to support people living in the community to prevent problems.

Other Allied Health Professionals (AHPs) that are important for people with dementia in terms of offering rehabilitation are physiotherapists, dieticians, speech and language therapists and podiatrists. AHP leadership on dementia, and enhanced dementia awareness for AHPs, are critical to ensure people can access these therapeutic services but also realise the contribution they can make in developing supportive self-management strategies.

What is good practice?

- ✓ **Actively promoting research participation.** For example, in Stockport research is embedded within post-diagnostic support groups, with time dedicated to discussing research and why people should sign up. They aim to find creative ways to increase participation, such as through attending research days within the trust.
- ✓ **Ensuring people diagnosed with dementia have access to follow-up opportunities to discuss their diagnosis and that this is embedded within the local pathway.** For example, a one-month follow-up in primary care for all dementias, or for memory services to follow-up with people diagnosed with all dementias (depending on local pathways). At Camden Memory Service, if a person is diagnosed with dementia, they will be reviewed at home every six months by a named practitioner in the team for ongoing monitoring and to offer support, advice and signposting. This also has the benefit of being one point of contact for all patients with dementia in the borough.
- ✓ **Ensuring that every person with dementia has a named care coordinator and knows how to contact them for consistent and proactive follow-up care and support.** The care coordinator role may be filled by one of a range of professionals, such as an admiral nurse, GP, dementia navigator or social worker. It may change as the person with dementia's needs and their family's needs change. In Bristol, the GP provides care coordination, but the Dementia Wellbeing Service ensures each GP and person living with dementia also benefits from the support of a named Dementia Navigator and named Dementia Practitioner – these are linked to each GP practice across the city. The Dementia Navigator and Dementia Practitioner provide additional support to GPs to identify and support people with memory problems and possible dementia, as well as supporting the person with dementia. Every person with dementia has a named Dementia Navigator and knows how to contact them for consistent and proactive follow-up care and support. The Navigator can liaise with a range of professionals, including their Dementia Practitioner colleagues in the service or external partners such as an admiral nurse, GP or social worker.
- ✓ **Locating dementia advisers within memory services and primary care.** For example, in Merton, the dementia adviser sits in the memory clinic to provide more information and arrange a follow-up home visit. In Cambridgeshire, every month a specialist Dementia Support Worker or Manager works in GP surgeries and sees patients referred to them by GPs – both people living with dementia and carers. This enables GPs to focus on health-related issues during appointments, while the Dementia Support Worker or Manager provide support for all other issues.

- ✓ **Listening to feedback from people affected by dementia to influence service improvements and ensure a needs-led approach.** For example Dorset CCG completed an extensive consultation process in 2019. They worked with voluntary organisations, people living with dementia and their carers to co-design various options and choose a way forward. Another example is the DEEP group in Wigan, who have influenced the following service improvements:
 - An ‘Under One Roof’ event which takes place at local venues several times a year, attended by agencies such as Alzheimer’s Society, Wigan Later Life and Memory Service, Citizens Advice and the Carers Centre.
 - Additional information being included in the post-diagnosis course, such as details of the Herbert Protocol, and the CEA card which gets carers free cinema tickets.
- ✓ **Developing a local support offer that recognises the diversity of people living with dementia.** It should consider how ethnicity, religion, gender, age, sexual orientation and any disabilities might shape interests and needs. For example, Touchstone BME Dementia Service in Leeds has provided specialist support since 2012 to people from ethnic minorities living with dementia or memory problems and to their carers. It’s commissioned by the CCG. It supports people to access mainstream services and provides case work to address the lack of culturally appropriate post-diagnostic support. It also provides pre-diagnostic support, including raising awareness of dementia in different languages and making links with communities and faith groups. The Bristol Dementia Wellbeing Service also has an inclusive practice. It works with local communities through its Community Development Coordinators, such as the Deaf community and Somali community, to raise awareness of dementia and highlight issues communities may face in accessing or receiving services. These include the need to adapt cognitive testing so that it’s more appropriate for specific communities, and ensuring interpreters are booked for appointments.
- ✓ **Developing local advance care planning initiatives.** For example, West Yorkshire and Harrogate Health and Care Partnership are currently piloting a resource which has been coproduced by people with dementia and carers. Aimed at anyone living with a long-term condition, it has been designed to support people to start conversations with friends and family about their future wishes for care. This project is part of a wider workstream which also aims to upskill staff working across health, social care and the voluntary sector to start timely conversations with people who are living with dementia about their future wishes for care.
- ✓ **Implementing technological solutions to enable the sharing of care plans.** For example, Coordinate My Care is an NHS digital service currently available across London. It’s funded by the London CCGs and has supported over 100,000 patients. It holds patient care plans electronically. These plans can be completed by a patient with their healthcare professional.



Living Well

What do we mean by living well?

Living as well as possible with dementia is an aspiration for many people. But policy, literature and guidance aren't always clear about what this means in practice, both for people with dementia and for the professionals who support them.

This chapter looks at the period following initial post-diagnostic support – we take this to be around a year after diagnosis onwards. It covers consistency of follow-up, care coordination and care plan reviews. It also looks at support for carers, assessment of need as someone's dementia progresses and the impact increasing care needs have on health and care services.

What are the benchmarks?

The following benchmarks have been used to assess what care people are receiving at this stage of the pathway:

- ‘People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change.’ (NICE)¹²³
- People diagnosed with dementia meet a named coordinator of care¹²⁴ and should be reviewed every 12 months. (NICE)¹²⁵
- Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs. (NICE)¹²⁶
- ‘Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.’ (NICE)¹²⁷
- ‘Health, physical and emotional needs of families and carers are fully recognised, and their views are taken into account, especially at times of change.’ (Department of Health and Social Care)¹²⁸
- ‘We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.’ (Dementia Statements)¹²⁹
- ‘We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.’ (Dementia Statements)¹³⁰

Key questions and gaps between policy and practice

This research has identified the following key considerations at this stage of the dementia pathway:

- How to tackle variation in practice for how people with dementia are consistently supported throughout the dementia pathway.
- The role of GPs in supporting someone with a progressive condition, changing needs and varying symptoms, and where responsibility sits within primary or secondary care to ensure access to services.
- Care plan reviews and how far they deliver on expectations for how a person’s condition is progressing, particularly considering comorbidities.
- How to initiate more proactive provision of interventions throughout the pathway, for both people living with dementia and their carers.
- How to effectively support carers, both in terms of support they’re eligible for, but also formal support for the people they care for, considering cultural, practical and financial considerations and needs.
- How best to care for people with severe dementia. This includes preventing hospital admissions and ensuring subsequent care meets clinical and personal needs and changes in residence are handled effectively.

We begin to explore these questions within this chapter. It’s essential they are considered as part of the development of local dementia pathways.

Consistency of follow-up

In a 2016 survey of GPs, 70% cited the lack of accessible local services as the main barrier to support for people with dementia. Only 50% thought their patients with dementia get enough support from the NHS and 67% thought their patients get enough support from social services.¹³¹

Dementia is a progressive condition, meaning that people's needs will change. Proactive and consistent follow-up is therefore essential to ensure people's needs are regularly assessed and appropriate support is put in place.¹³² But there's much variation in practice across the country for how people with dementia are supported throughout the dementia pathway.

Guidance says that every person with dementia should have a review of their care needs within the first 12 months of their diagnosis and every 12 months thereafter, unless agreed otherwise between the person and healthcare professional.¹³³ While NICE recommend a named coordinator of care to review people's needs every 12 months, the Prime Minister's Challenge on Dementia 2020 recommends that a GP takes on this role.¹³⁴

In cases where the GP has acted as the care coordinator, we heard from people with dementia that contact with their GP can vary a lot. The level of support received from GPs also depends on their knowledge of dementia.

One person said that when he was referred back to his GP, his GP 'answered [my] questions as best he could but didn't have the level of knowledge to answer them all.'

We know that care plan reviews aren't happening consistently or as regularly as required. One person said that since their diagnosis of Alzheimer's disease three years ago at a memory clinic, they've had no appointments or contact with their GP about their condition. The 2020 GP Patient Survey found that under half of people with dementia (47%) said they've had a conversation with a healthcare professional from their GP practice to discuss what's important to them when managing their condition, 40% haven't, and 12% didn't know.¹³⁵

Public Health England data shows a more positive assessment of the number of reviews of care plans: on average, for 2018/19, 78% of people in England had their care plan reviewed in the last 12 months.¹³⁶ However, there's much regional variation, with average scores ranging from:

31.7%  **92.5%**¹³⁷

While it's important that care plans are regularly reviewed at least every 12 months, it's also vital that these reviews are done meaningfully. The review of dementia care plans is an indicator under the Quality and Outcomes Framework (QOF), a voluntary reward and incentive programme.¹³⁸ But recent research found no evidence that the QOF influences integration or coordination of care, holistic care, self-care or patient experience.¹³⁹

Our research suggests care plan reviews are not matching people's expectations. We consistently heard from people with dementia that they want to know if their dementia is progressing and cited that as an outcome they'd value. The Prime Minister's Challenge on Dementia 2020 identifies GPs to take on the leading role for the healthcare of people with dementia. Therefore, future service design should consider how primary care can be enabled to provide more appropriate and integrated care necessary for people living with the condition. Or it should consider where responsibility for dementia lies in terms of primary or secondary care. Proper oversight of a person's care is essential to enable access to timely specialist input when required.

One person with dementia told us her GP went through the list of her comorbidities, asked how her dementia was, and moved on. She felt her comorbidities made this a tick box exercise, rather than a meaningful activity which assessed the progression of her dementia. People with dementia told us they wanted to understand and monitor how their dementia was progressing.

'They sent me a care plan, but it was just a summary of my review meeting. That's not what a care plan is. [A] care plan should be about what is next, not what has just happened.'

Person living with dementia

We also heard from people with dementia that when they had a review of their care plan with their GP, it has focused on their physical and pharmacological needs. There was little emphasis on their dementia-specific needs. One person said their mother's GP 'simply continued to prescribe medication and had no further input into her care.' But figures from NHS England show that less than a quarter (23.1%) of people with a diagnosis of dementia at 31 January 2020 had had their medication reviewed by a GP in the previous 12 months.¹⁴⁰

Reviewing prescribed medication allows professionals to track any improvements from pharmacological interventions but also to identify any side-effects. This is particularly relevant for people with comorbidities. A review of studies found that higher levels of comorbidity were linked to an increased risk of inappropriate prescribing for people living with dementia, with the rate ranging from 14% to 64%. It's estimated that there's a 31% rate for potentially inappropriate prescribing within the community and 42% in a nursing or care home setting.¹⁴¹ Given that 77% of people living with dementia also have one or more other health conditions, with 22% having three or more and 8% having four or more,¹⁴² it's critical that GPs understand the impact of a person's medication and that this is regularly reviewed.

'Since my wife's diagnosis, the GP has concerned himself with physical issues alone but, when I request referrals, has referred us to the local care team. In turn, the care team have then made referrals to Occupational Therapy and Speech and Language Therapy, as well as completing needs assessments.'

Carer for a person with dementia

Because dementia is a complex condition, people encounter a range of different services and professionals that can provide support for the different symptoms they may be experiencing. But the route of access to these is also complex. A lack of ownership means that people are falling through the gaps and are not receiving the support they need from the professionals they need it from.

This inconsistency of follow-up is also shown by therapeutic interventions coming to an end. Within a dementia pathway, few non-pharmacological interventions are provided or designed for after the initial diagnosis, or they're harder for people to access once they've been discharged from the memory service. There isn't enough provision to refer to, or enough activities suitable, for later in the condition when more specialist support is needed. This is especially true for people without carers or for carers needing a break. Initiating more opportunities within the pathway would help ensure that people who might have declined the offer during the initial post-diagnostic support meeting, or people who are in crisis, can access these. Regular reviews in primary care, and open referral systems within memory services, would support continued access to specialist input and proactive provision of post-diagnostic support interventions, especially in urgent or crisis situations.

Cognitive Stimulation Therapy (CST), for example, is usually provided over a series of weekly sessions, with people left with little or no support soon after they end. We heard frustrations from people with dementia that when interventions finish, such as CST or other group activities, people are left alone to maintain contact with other people with dementia that groups had connected them to. One carer told us that referral to temporary interventions, such as a set number of counselling sessions, is unhelpful. While it may be effective for some people, it's important to explore different options to best support the individual.

We heard from people that this was where the pathway suddenly dropped away. After receiving their diagnosis and initial support interventions, they felt there was nothing more that could be done for them. People told us that more proactive provision of interventions and support would enhance their ability to live well.

Supporting carers

In 2014, it was estimated that around 700,000 people were providing informal or unpaid care to the 850,000 people living with dementia in the UK.¹⁴³ Further estimates echo this.¹⁴⁴ Data from 2018/19 revealed that 35.3% of carers were caring for someone with dementia.¹⁴⁵ Four in 10 carers (40%) provide over 100 hours of care a week, and 61.2% provide more than 35 hours per week.¹⁴⁶

Caring for someone with dementia can put a huge strain on a person's physical and mental health and on their general wellbeing. So that they can care effectively for people with dementia, as well as look after themselves, support for carers is essential.

'I feel tremendous guilt when I can't cope. Sometimes I react and it doesn't help. I feel numb, hurt, sad, angry, resentful of my loss of freedom then tremendously guilty and selfish.'

Carer for a person with dementia

When asked about living well, one focus group told us that receiving support from their carers is the only reason they can live well. In a 2015 survey of GPs, 64% reported that not having a carer to navigate the system was a barrier to someone with dementia getting the support they need.¹⁴⁷ Supporting carers is, therefore, a crucial part of the dementia pathway.

NICE recommend several measures to support carers, including psychoeducation and skills training, and the provision of services that enable them to support people with dementia. These services should be tailored to individual needs and preferences and be available when needed.

Data published in 2020 shows that over a quarter of memory services (26%) were unable to provide or refer on to carer psychoeducation training. In the services that were able to refer on, in 45% of cases it was deemed inappropriate, and 27% declined the service.¹⁴⁸ It's important to consider the timing of these interventions, as many carers may not be ready for it straight after diagnosis. There needs to be a range of routes available to access these programmes, such as the Strategies for Relatives (START) intervention, to ensure proactive provision and access to interventions. Services should also do more to outline the importance and benefit of doing this training. For most people living with dementia, their primary carer will be their main source of support.

NICE also recommend that services and professionals should advise carers about their right to a carer's assessment and an assessment of their need for short breaks and other respite care. Despite this, an Alzheimer's Society study revealed that the most common concern amongst carers is the lack of support to know how to access help and information.¹⁴⁹ We heard many carers are often left to research local respite care services themselves, and they told us that an accessible list of recommended places would be preferable.

Respite care enables a carer to take a break, offering them time to look after their own physical and mental health. It also gives them a chance to catch up on activities they may have missed due to their caring responsibilities, such as getting their prescription or seeing friends and family. The proportion of adult carers of people living with dementia who have had as much social contact as they would like has decreased from 41% in 2012/13 to 36% in 2016/17.¹⁵⁰ This suggests that more needs to be done to support carers to improve their own quality of life.

The Care Act 2014 gives people who care for someone with dementia a legal right to a carer's assessment.¹⁵¹ This in turn should lead to the creation of a support plan to help ease some of the challenges the carer may be facing. The plan may include adaptations and aids to help care, or arrangements for carer visits and respite care.¹⁵² However, we heard of issues regarding provision, access, type and quality of carer support. While we heard from some carers that they want respite care, others told us that more practical support, and less written information, would be helpful.

Carers' assessments are the gateway to accessing support. But we know that carers of people with dementia consistently aren't receiving an assessment of their needs. One research study suggests that just 39% of carers for people with dementia living in the community had received a carer's assessment.¹⁵³

A 2020 report by Alzheimer's Society had similar findings. Only 39% of respondents said they had a carer's assessment, 8% were unsure and 53% hadn't had an assessment.

For the 53% who hadn't had an assessment, this was due to:



not having been offered one (47%)



not being aware of carer's assessments (16%)



being told they were not eligible for one (4%)



other reasons (22%)¹⁵⁴

Services working directly with people with dementia and their carers, as well as local authorities, must do more to identify carers so that appropriate support can be put in place. Not only are carers' assessments a legal requirement, but they can have a significant impact on a person's ability to continue in their caring role if they wish to do so. This can be more cost-effective, and it can also enable people with dementia to stay at home for longer – something we know many people affected by dementia prefer.

Carers' assessments are critical to set out how needs are met, but councils may charge for this support. Unfortunately, this reflects the social care system more generally, where people affected by dementia typically spend £100,000 on their own care.¹⁵⁵ Ending the artificial divide between free healthcare and means-tested social care would enable better integration between systems. It would remove the question of who pays for care that can delay people receiving the care they need. It's long been something that Alzheimer's Society has called for through its Fix Dementia Care campaign.

Formal support for people with dementia can support informal carers to continue in their role. Despite this, paying for care and enduring financial assessments can deter people from seeking support. We also heard that carers felt disengaged with asking for support, because they know the support put in place won't be there when it's really needed.

One carer asked,

'Am I meant to just leave my wife sitting in soiled clothes until 11am when the care workers come around?'

Dementia requires different types of care around incontinence, nutrition, dressing, hygiene and more. But we heard that the quality of caring by local authority carers can be inconsistent. Some informal carers describe the assistance provided by formal care workers as a lifeline, but others report frustration in the support provided. High staff turnover rates amongst care workers – 30% in 2018/19¹⁵⁶ – can also mean that carers of people living with dementia struggle to build a rapport with the care worker. This may have an impact on the continuity and level of care that can be provided.

Another issue we heard about is the lack of culturally appropriate care. A recent research study which explored the experiences of South Asian carers of people with dementia receiving health or social care supported our findings.¹⁵⁷ For people to receive personalised care, local authorities must consider the provision of culturally appropriate services and the ability of different communities to access them.



‘It’s never been easy finding support for my Mum that takes cultural differences into account. She needs female care staff and they ideally need to speak Punjabi as Mum is resorting to her native tongue as the condition progresses.

It’s been a struggle from the beginning. Persuading the authority that Mum needed support was an ordeal. It was quite evident that Mum wasn’t bathing or brushing her teeth, she was wearing the same clothes for weeks, not eating properly and not taking her diabetic medication. They finally agreed to pay for three 15-minute homecare visits via their preferred agency for two weeks to determine if that was actually the case. However, the quality of care was just awful. One of the carers found Mum holding a pan that was on fire, while suffering from a serious UTI, and as a result Mum ended up in hospital on the psychiatric ward.

I decided to take responsibility for arranging care for Mum myself as the council were unable to help in sourcing Punjabi-speaking caregivers. Arranging that really shouldn't be as traumatic as it has been. I have searched for Punjabi-speaking professional carers, with Alzheimer's experience, for the past three years to no avail. The ladies I found had very little or no experience, so I had to train, educate and manage them constantly. This presented so many challenges in that so many ladies have come and gone over the past three years, only one has stuck by Mum.

I've been managing Mum's care for over three years from my home in the North West – 200 miles from Mum's home in the South East as well as visiting every week. I ended up leaving my job three years ago to coordinate Mum's care as advocating for Mum was taking up so much time – it is a full-time job in itself. I am constantly having to search for culturally appropriate carers, speak to the council, and get different healthcare professionals and services to speak to each other. It all became too much and I had what I would describe as a nervous breakdown.

After the lengthy and gruelling process of justifying the need for funding from Adult Social Care, I had no choice but to opt for direct payments from the council as they weren't aware of Punjabi-speaking carers. The initial funding wasn't enough, so I had to fight for more. We were advised the direct payments awarded were at the top end but we still had to top up significantly to ensure Mum had 24-hour care as she couldn't be left on her own at all. I was continually told by adult social services that Mum would never be eligible for Continuing Healthcare funding, so I never broached the subject.

With no income, I can barely afford to top up Mum's care anymore. However, I promised Mum years ago that I wouldn't move her into a care home, and I'm doing everything I can to keep that promise. She knows every nook and cranny of her home and Mum gets distressed in a different environment, even when she has stayed with me or my Sister. I'm also very worried that most care homes wouldn't give Mum the culturally appropriate care she needs. Why, in a society like ours, am I having to seek culturally appropriate care for my Mum? And why do I have to pay extra for it?

Managing Mum's care has been challenging on all fronts over the past three years, but the COVID-19 pandemic has escalated it to an excruciating level. Mum was hospitalised with sepsis and was admitted to the local community hospital mid-May 2020. I have always stayed with Mum for the duration of her many hospital admissions (numerous UTIs, pneumonia and sepsis) – advocating for Mum was essential as so much information was lost in translation between the professionals, often leading to mistakes. Thankfully I was present to ensure this was avoided but I couldn't this time due to coronavirus. I received so much misinformation and no face-to-face with Mum, despite being advised they had iPads. When Mum was finally discharged it was quite clear she was traumatised. The consultant notified us that Mum will not benefit from another hospital admission and that she is at the end stage as she is aspirating. He has recommended palliative care at home.

While trying to come to terms with this emotionally, I find myself, yet again, fighting for the right care so that Mum's end of life can be as comfortable as possible in her home.'

Jag, daughter and carer for a person living with dementia



Advanced care

Research published in 2020 shows that the number of people with severe dementia across the UK is projected to more than double by 2040. Among the current population of people with dementia, 14% have mild dementia, 28% have moderate dementia, and 58% have severe dementia.¹⁵⁸ With a high proportion of people living with severe dementia, we must be able to support their needs.

While a person can live well with dementia, there will come a time where decisions regarding more advanced care will need to be taken. In some cases, this may be more support at home, but other cases may involve taking a decision to move into a care home. We heard this can often follow a hospital admission and is a significant point in a person's pathway. Despite this, we heard that care in both hospitals and care homes can be variable.

It's well known that hospital admissions are best avoided for people with dementia. However:



Over half of people with a diagnosis of dementia in 2018/19 were admitted to hospital.¹⁵⁹



Emergency admissions in the six years to 2017/18 found 379,000 cases where dementia had been recorded on admission.



This is a rise of 100,000 admissions since 2012/13.¹⁶⁰

Poor integrated working between health and care services or a lack of appropriate care provided in the community are often cited as reasons behind hospital admissions for people with dementia.

Hospitalisation can have a negative effect on people's health, cognition and wellbeing. On hospital admission, older people with dementia are at higher risk of death, long lengths of stay and nursing home admission, as well as higher risk of delirium, dehydration, falls, reduction in nutritional status and decline in physical and cognitive function.¹⁶¹ So it's particularly worrying that in 2017/18, 40,000 admissions of people with dementia — around one in 10 of all admissions — were for 28 days or longer.¹⁶²

We also heard that people had received inappropriate care while in hospital — often it didn't consider dementia-specific needs. A hospital stay can increase the likelihood of behaviours that challenge, while reasons for admissions such as delirium and urinary tract infections may also increase agitation and aggression. This can lead to the increased prescription of psychotropic medicines in hospital.

A recent audit found an estimated 6% of all inpatients with dementia were given a new prescription during their time in hospital, but just 57% of new prescriptions had the reasons for their need recorded.¹⁶³ It's important that a clear understanding of a person's needs is sought before pharmacological interventions are used. By doing this, better care can be provided and the risk of any side-effects from pharmacological interventions can be reduced. It's also important that inpatient hospital prescriptions are reviewed on discharge to ensure they're still appropriate. Currently, one-fifth (20%) of new prescriptions during admission weren't reviewed at discharge.¹⁶⁴

A person's needs must be appropriately assessed, and proper care implemented, so that a hospital stay doesn't impact on the rest of their pathway outside of a hospital setting. The discharge process is equally important. A delayed discharge can have a negative impact on a person living with dementia. It extends the time a person spends in an unfamiliar and unsuitable environment and increases the risk of preventable complications or infections. Discharge planning processes should happen at the point of admission, and any reasons for delayed discharges should be addressed quickly.

Both health and social care services must work together effectively to ensure that people with dementia don't spend more time in hospital than clinically necessary. In 2019, around 16% of people with dementia in hospital had a change of residence after discharge. Of these, 77% went from their own home or carers' home to a nursing or residential care facility.¹⁶⁵ How far different health and care services communicate with each other has a significant impact on a person's discharge experience. One person whose mother was in hospital said she wasn't kept properly informed about when her mother was to be discharged or given enough help about where to go. She made six to seven phone calls every day for over a week to get the information she needed.

'This is the hardest thing about the health and social care system, nothing is joined up and you never know who the right person is to call.'

Family member of a person with dementia

Involving the person with dementia and their family in the discharge process and keeping them fully informed may also improve a person's hospital and discharge experience. Crucially, it can allow families enough time to look for different care arrangements if a person's needs have changed. However, data shows that 28% of people with dementia in hospital received fewer than 24 hours' notice of discharge in 2019.¹⁶⁶

NHS Continuing Healthcare (CHC) assessments were identified as a big issue when we spoke to people affected by dementia about the discharge process. CHC is a financial care package for people with long-term complex health needs who require social care. This is arranged and funded solely by the NHS.¹⁶⁷

One person told us that their mother was bed-bound in hospital for a month. She could no longer walk, eat, drink or use the toilet for herself. During her hospital stay she was assessed for CHC and awarded a six-to-eight-week care package. But on reassessment, it was judged she didn't meet the criteria and so she was now ineligible for funding – even though her care needs hadn't changed.

Another person told us their mother had been in hospital for eight weeks and subsequently lost the ability to walk, eat and drink. She had been in hospital for this long due to the costs of a nursing home suitable for her needs, and because the NHS and the care home couldn't negotiate the cost of this care.

People affected by dementia told us that CHC assessments aren't fit for purpose and can be very lengthy. Too often, people with clear high care needs aren't receiving appropriate funding. This is affecting the extent to which they can receive care outside of hospital. Also, when CHC assessments are carried out during the discharge process, disagreements between health and care services can often increase the time a person spends in hospital. This can have negative effects on their condition. The Government should urgently review the CHC process and how it's serving people with dementia.

For some people, care needs may be best facilitated in a care or nursing home. This is to ensure people can continue to live well by providing the necessary health and social care for their needs. We heard that this can be an extremely difficult decision for families, but often they're left with no other option.

It's critical that nursing and care homes are suitable for people living with dementia. Public Health England data from 2019 shows that a quarter (27%) of residential care home and nursing home beds, suitable for a person over 65 with dementia, were found to be inadequate or needing improvement. However, this has improved from 31.4% in 2018 and 40.3% in 2017.¹⁶⁸ It's also essential that all care home staff are trained to Tier 2 of the NHS-backed Dementia Training Standards Framework to provide good quality care to people with the condition.

Time spent in care and nursing homes is a large part of the dementia pathway for many people. People in care homes will often need to receive more advanced and specialised care. It's important these services, and local authorities commissioning them, understand the particular clinical and personal care needs of people with dementia and put in place the most appropriate support. This should include regular assessments of residents with dementia. It should also include the appropriate use of assessment information to ensure additional care needs can be identified and support measures put in place. Electronic access to patient notes and care plans can also support more integrated care.

Care home staff should be supported by clinical input and quick access to advice and support where necessary to support residents and improve care, but also to reduce hospital admissions. The provision of Care Home Liaison support is vital to assess needs and develop effective management plans via a multidisciplinary team that has dementia training. They can also provide effective opportunities to provide support, education and training to care home staff. But this isn't commissioned everywhere, so people can struggle to access the services they need. Recognition of the value of Allied Health Professionals within care homes is also critical to support health, care and wellbeing.

What is good practice?

- ✓ **Ensuring people with dementia have opportunities to access continued specialist support.** For example, Stockport Memory Assessment Service offers a monthly clinical drop-in for discharged patients to see the nurses in person or over the telephone.
- ✓ **Offering telephone helplines so that people can easily get in touch for advice, information or help in a crisis.** In Bristol, the Dementia Wellbeing Service runs an Access Point and staff on the helpline have access to information about people with dementia on their caseload. They can easily get a picture of each person's unique situation and existing support.
- ✓ **Psychology input for patients and carers, and the development of robust structures to enable the provision of regular opportunities for carers to access psychoeducation and skills training – they shouldn't just be part of the initial post-diagnostic support offer at the memory service.** For example, Camden Memory Service have a dedicated Assistant Psychologist who offers the START intervention. It's available at any time for any informal carers experiencing increased stress, anxiety or depression associated with caring. The practitioners who review patients on a six-monthly basis can identify carers' stress. They can provide basic psychological strategies at every review or they can signpost to local services. Patients, carers and GPs can also contact named workers if the patient or carer is struggling, or if they've noticed changes before the review is due. This allows for an intervention before a crisis occurs. The Psychology team also offer CST and Carers' CST in cases where English isn't the patient's first language, as well as individualised patient and carer psychology interventions when needed.

- ✓ **Embedding support for carers within services.** For example, the Bristol Dementia Wellbeing Service helps carers access support. This includes carrying out Integrated Carers Assessments on behalf of the local authority, enabling them access to vital respite funds or alternative provision that supports them in their caring role. It provides opportunities for carers to access psychoeducational counselling and has commissioned both specialist individual and couples' counselling.
- ✓ **Enabling access to timely specialist input by adopting a 'step up/down' model.** For example, integration of specialist nurses within primary or secondary care to incorporate clinical skills and knowledge. In Camden where the memory service provides ongoing support, people can be reviewed by an assistant practitioner but can be stepped up to a nurse when additional support is needed. Or they can access the Home Treatment Team for intensive short-term support to avoid hospital admission or in times of crisis. Another example is in Doncaster where a pilot was undertaken to improve post-diagnostic care and support through providing an integrated service delivered by Admiral Nurses and Dementia Advisers using a case management system. This has proven to be successful and has now developed into a well-established service. Referrals undergo a robust triage process, and get allocated to Admiral Nurses if they are assessed as 'intensive' (meaning they have high or complex levels of need), or allocated to Dementia Advisers if they are assessed as 'maintaining' (meaning they are helped to access support and other appropriate services). If a referral comes into the service that is not appropriate for either of these, consent is gained from the carer to refer on to other appropriate agencies within the local area. This integrated structure provides continuity of care. It enables families to be seamlessly transferred between the caseloads of the Dementia Advisers and Admiral Nurses as appropriate, and enables close working with other providers in the post-diagnostic pathway.
- ✓ **Upskilling care home staff and ensuring appropriate outreach to care homes.** For example, Cumbria's Care Home Education and Support Service (CHESS) aims to improve and support the ability of care homes to understand and manage dementia and mental health needs and reduce unnecessary hospital admissions. The team includes a community mental health nurse and dementia specialist support workers. The service has three elements:
 - A rolling programme of education on dementia and mental health experiences for care home staff, offered to all care homes free of charge and for up to three staff per care home
 - A practical outreach service to provide mental health assessment, specialist interventions and support
 - Outreach support to ease the transition from inpatient unit to care home.
- ✓ **Clinical input and quick access to advice and support from a multidisciplinary team working within care homes, to ensure people with dementia can access the right services at the right time and benefit from fast-track referrals.** For example, Care Homes Assessment Teams in Enfield is an integrated, multidisciplinary mental and physical health team. It includes community matrons, geriatricians, a consultant psychiatrist and mental health nurses, occupational therapy, a phlebotomist and pharmacists. It also works closely with primary care, frailty networks and a tissue viability service.
- ✓ **Recognising the value of Allied Health Professionals when considering the makeup of staffing across services.** For example, ongoing access to occupational therapists can review the environment, physiotherapists can help with strength and balance exercises, and speech and language therapists can support with communication, eating, drinking and swallowing. Dieticians and podiatrists are equally important. In Camden, there's a dedicated dementia specialist occupational therapist within the memory service who can be deployed to any person with dementia for a review if they need it.



Dying Well

What do we mean by dying well?

Everyone diagnosed with dementia will have the condition at the end of their life. Dementia is a life-limiting condition and can be the primary cause of, or a significant factor contributing to, a person's death.

This chapter looks at the care people receive at the end of life, including access to palliative care and advance decisions. It also looks at where people with dementia are dying, which is a frequently-used quality marker.

What are the benchmarks?

The following benchmarks have been used to assess what care people are receiving at this stage of the pathway:

- 'People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.' (NICE)¹⁶⁹
- 'All people with dementia and their carers receiving coordinated, compassionate and person-centred care towards and at the end of life, including access to high quality palliative care from health and social care staff trained in dementia and end of life, as well as bereavement support for carers.' (Prime Minister's Challenge on Dementia 2020)¹⁷⁰
- 'We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.' (Dementia Statements)¹⁷¹

Key questions and gaps between policy and practice

This research has identified the following key considerations at this stage of the dementia pathway:

- Access to palliative care and how to overcome the barriers to this in light of increasing need.
- How palliative care needs are assessed and delivered across the range of health and care settings people with dementia may be living in.
- How to ensure access to the right services that meets need, rather than default hospitalisations.
- How to manage hospitalisations and instead increase comfort and quality of life.
- How to ensure people with dementia have a good end of life regardless of place of death.
- Whether advance decisions are considered and issues surrounding mental capacity at end of life.

We begin to explore these questions within this chapter. It is essential they are considered as part of the development of local dementia pathways.



‘My mother, Dorothy, last lived independently in October 2017. She spent a total of seven months in hospital and a further seven months in two care homes, one a residential home, the other a nursing home, before sadly passing away in January 2019.

During this time, there were a total of 101 NHS and local authority staff involved with her case, and this does not include all the acute hospital staff and care home staff who cared for her in her last year of life. Despite the involvement of these staff, Mum failed to get a sufficient end of life care package.

In October 2017, she had two emergency hospital admissions in nine days due to suspected sepsis and falls. She was still in hospital in December 2017, when a doctor assessed her as frail and in decline, writing that she was likely to be in the last weeks and months of her life, and advised that palliative care would be reasonable. However, neither the doctor nor any other clinician developed a palliative care plan for my mother. After this, she proceeded to have three recurrent chest infections while in a temporary placement in a residential care home, before another hospital admission in 2018 where she was diagnosed with pneumonia.

This hospitalisation lasted four months, before my mother was discharged to a nursing home for end of life care. The hospital consultant requested that end of life care planning be carried out in the discharge letter to the GP and nursing home. However, I found out GPs are not duty-bound to follow up on hospital requests and as such, failed to instigate any appropriate palliative and end of life support for Mum.

When she was discharged to the nursing home where she was supposed to be receiving end of life care, she had a chest infection and experienced breathing problems. She was also routinely refusing food, liquids, personal care and medication. According to nursing home records, it was clear that she was not consuming enough food and fluids to sustain life and even a hospital-prescribed food supplement regime was not complied with.

In the 13 months from December 2017, when she was first identified for palliative needs, right up until her death, absolutely nothing was done to provide Mum with the palliative care and support she required. If a palliative care plan had been delivered, I am certain she would not have gone back into hospital and there would have been less involvement from ambulance, A&E doctors and hospital staff, which were at times completely avoidable.

I think if our family had received the support we needed from Mum's GP and social services at the time it was urgently required, it would have been possible for Mum to live in her own home for longer and perhaps end her life there, which is what she wanted. I believe the fact that she was not supported to do this by health and social care professionals hastened her cognitive decline and increased her anger and unhappiness about her situation. I remember Mum telling her social worker in September 2018 – 'so far everyone who's meant to have helped has done harm.'

Mum wanted to die at home. I really deliberated when Mum was in hospital and care homes whether it was in her best interests to get her home and provide her with an end of life care package there. However, the risks outweighed the benefits – I could never be sure she would get the right package of care so that she would not suffer unnecessarily in her last weeks and months. It saddens me that despite being in a nursing home at the end of her life, she still didn't have a palliative care plan to deliver appropriate end of life care.'

Daphne, daughter and attorney for Dorothy who was living with dementia



Care at the end of life

Dementia was the leading cause of death in 2018, accounting for 12.7% of all registered deaths.¹⁷²

More than ever, there's a need to ensure people with dementia can access the right palliative and end of life care to enable them to die well. With much of the focus on living well, this part of the dementia pathway is often overlooked. This has resulted in a significant gap between what people are experiencing and what is optimistically phrased 'dying well' within dementia health policy.

Palliative care includes treatment, care and support for people who have a serious, life-limiting condition, where a cure or a reversal isn't possible. End of life care – treatment, care and support for people nearing the end of their life – is an important part of palliative care.¹⁷³ It aims to enable a person to live as comfortably as possible in the time they have left.

NICE guidance says that people living with dementia should be offered flexible needs-based palliative care that considers how unpredictable progression can be from the point of diagnosis.¹⁷⁴ For those who are approaching end of life, healthcare professionals should use an anticipatory healthcare planning process. They must involve the person and their family members and carers as far as possible. It's important to note that while end of life care is normally thought to be within the last year of life, the timeframe can be difficult to estimate for people with dementia.

According to the law and to national guidance, healthcare professionals should use best-interest decision-making principles if the person doesn't have capacity to make decisions about their care, and if there's no legal proxy with the authority to make the decision (for example an attorney acting under a Lasting Power of Attorney for health and welfare). If advanced decisions to refuse treatment are in place, professionals must follow one that is valid and applicable to the situation. They should also encourage people living with dementia to eat and drink, taking into account their nutritional needs. They should consider using a speech and language therapist if there are concerns about a person's safety when eating and drinking.

The Prime Minister's Challenge on Dementia 2020 says that all people with dementia should be able to access high quality palliative care. But the evidence we collected shows that people affected by dementia can struggle to access these services, particularly at end of life.

People with advanced dementia who are nearing the end of life will have complex needs. They typically have a high level of symptoms, leading to frequent hospital admissions and in turn high health and social care costs. Some people with dementia are unable to communicate their symptoms and wishes at end of life, which can affect how far professionals can manage those symptoms. Given average life expectancy in care homes, there should be more oversight and regulation of this aspect of care by the Care Quality Commission.

Family involvement, autonomy and individuality, realistic expectations and living in the present are considered important aspects of end of life care by people living with dementia and their carers, alongside compassionate care and information availability when making decisions.¹⁷⁵ Supporting carers is essential at this point in the pathway, as well as acknowledging their strengths in spotting the signs of pain, infection or deterioration.

Further evidence found timely planning discussions, coordination of care, effective working relationships with primary care, managing hospitalisations and continuing care after death were seen as required for the delivery of good end of life care for people living with dementia by staff, people with dementia and family carers.¹⁷⁶ 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.¹⁷⁷ They also had the highest number of emergency admissions in the last year of life across all conditions.

Hospital admissions can be stressful for people with dementia and contradict the aim of comfort and quality of life during their last year of life. Also, transitions between care settings can have limited clinical benefit for patients with advanced cognitive and functional impairment, and transitions among patients with advanced dementia are often avoidable.¹⁷⁸ This means that more resources should be targeted towards reducing hospital admissions and increasing comfort and quality of life in their place of residence. This includes upskilling and increasing the confidence and judgment of care home staff to manage hospitalisations. Better integration between primary, community and secondary care via multidisciplinary teams would be essential to support this.

Complex needs and symptoms, including pain and severe agitation, require intervention and multidisciplinary working. However, one research study highlights the current mismatch between services and need at end of life. Most participants received visits from primary care and emergency paramedics but had little input from geriatric or mental health care professionals.¹⁷⁹ The same study also revealed the lack of advance care planning, with fewer than 40% having an advance care plan in place.

There are several barriers to receiving good quality end of life care. These include a lack of staff skills, difficulty in communicating, pain and symptom management, a lack of coordinated care, a lack of commissioning guidance and policy levers, and above all a lack of awareness that dementia is a terminal condition. Commissioning structures aren't conducive to integrated care. Different services (and therefore commissioning costs) are involved, such as acute trusts, local authorities, charities and general practice at the end of life, but at the same time there's a lack of shared accountability. The future direction of Integrated Care Systems will hopefully bring shared planning and delivery, formalised arrangements, collective responsibility and shared accountability. But local authorities need to be integrated too.

Another reason that people with dementia may struggle to access end of life care is difficulty in identifying when a person might be in their last year of life.¹⁸⁰ But the impact of poor access to these services is significant. It can result in worse outcomes in terms of pain and symptom control, and of quality and experience of care.¹⁸¹ Identifying pain in people living with dementia can be challenging, even using clinical assessment tools. Even when it is identified, people with dementia may receive less pain relief than for those with other conditions such as cancer.¹⁸² Access to services should be based on need, not prognosis.

People affected by dementia told us they struggled to access end of life care through general practice, community nurses and hospitals. The reasons they were given include:

- the person isn't nearing the end of their life, they just have 'good days and bad days'
- Alzheimer's disease is a mental illness not a physical condition (this is incorrect)
- it isn't their responsibility
- the person already has carers coming to the home
- there isn't enough funding.

There must be regular data collection at primary care level. It should document the number of people with dementia added to the palliative care register, and who have been offered a personalised care planning discussion as a result.

We know there are significant benefits to palliative care. One person told us about their battle to get palliative care for their mother and described the ‘revolving door’ as a ‘nerve-wracking time’. She had to explain to different healthcare professionals why she was going back to hospital. She said that once palliative care was in place, she was ‘looked after beautifully’. We also heard that partnerships with hospices can provide good outcomes due to their expertise. Provision of out-of-hours advice to care homes was also highly valued.

Need for these services is going to increase. It’s vital to start a national conversation about dying with dementia. By 2040, annual deaths in England and Wales are projected to rise by 25.4%. If the trend of age and sex-specific proportions of people with palliative care needs remains the same as between 2006 and 2014, the number of people requiring palliative care will increase by 42.4%.¹⁸³ Disease-specific projections show that dementia is proportionally the biggest cause of increased need.

To date, there’s been a strong policy focus on place of death. Preferred place of death is a commonly used quality marker. Across all conditions, the number of people dying in hospitals is declining. This has led to the number of deaths in care homes increasing. Care homes are key to reducing the number of people with dementia who die in hospital, so more must be done to ensure end of life care is improved in care home and nursing home settings. Nearly three-fifths of people aged 65 and over who died with a mention of dementia died in care homes.¹⁸⁴ Given the average life expectancy of people in care homes, there must be a bigger role for regulation of end of life care within care homes.

If trends are sustained, by 2040, the annual numbers of people dying at home and in care homes will almost double. However, if there’s no expansion of capacity and end of life care training for staff in care homes and in home care services, the trend in declining hospital deaths will likely reverse by 2023.¹⁸⁵

This is particularly concerning given that almost six in 10 (58.8%) people with dementia express a wish to die in a care home and 39% express a wish to die in their own home. However, despite 39% expressing a wish to die at home, just 8% of people over 65 with dementia died at home.¹⁸⁶ This is significantly lower compared to all deaths for people aged over 65 (21%).¹⁸⁷ There must be a national review of capacity and access to end of life care in care home settings. This must include an audit of training for care home staff, as well as access to out-of-hours support.

Further data from Public Health England shows that, on average in England, over 69.1% of people over 65 with dementia died in their usual place of residence in the 2017/18 reporting period.¹⁸⁸ However, this varies according to region from:



Good advance care planning should include where a person wishes to die. But this depends on whether a person has had these conversations and whether their wishes have been noted in a shareable care plan. Clear limits of treatment and records updated close to death can enable a person’s preference to be met.

Where people die is influenced by what care options are available locally. Good quality, community-based end of life care can increase the chance of death in a person's usual place of residence.¹⁸⁹ But people with dementia have symptoms that often aren't effectively addressed earlier in their pathway. This means the dying phase in a person's dementia journey may often go unrecognised.¹⁹⁰

It's vital that advance care planning conversations are undertaken to ensure a person's wishes on place of death are identified and documented, so that people have the best chance to die in a place of their choosing.

Advance care planning

Advance care planning enables people with dementia to plan ahead and can support healthcare professionals and families to carry out the wishes of a person at the end of their life.

This is particularly important because many people may not have the capacity to make these decisions when they're in the last months, weeks or days of their life. This reinforces the need for professionals to discuss end of life care at every stage of a person's pathway and enable opportunities for revisions if a person changes their mind.

It can involve making an advance decision, which allows someone to decide about specific treatments they don't want to receive in the future. It can also involve making an advance statement, which allows someone to express their wishes about future care options. For example, they can say where they wish to live and which type of care and support they wish to receive, and express other wishes such as food preferences. Lasting powers of attorney (LPAs) are another way to plan ahead. An LPA is a legal document that lets a person appoint one or more people to help make decisions or make decisions on their behalf, at times when they cannot make their own decisions due to a lack of mental capacity.¹⁹¹ Some people may limit their attorneys to make decisions about specific things, such as sustaining treatment. It's also important to consider that there may be situations where healthcare professionals will overrule someone's previous wishes and preferences if they believe it's in the best interests of the person.

One person, whose mother was in a care home, said that staff found her unconscious and sent her to hospital. But they didn't tell the paramedics or the hospital staff of her wishes, set out in her LPA, that she wanted her attorney to make decisions about life-sustaining treatment. Staff therefore gave her medication which contradicted the wishes she'd set out in her LPA.

Despite the importance of this legal document, we heard from some families of people with dementia that their advance decisions haven't been taken into account by healthcare professionals. If someone lacks mental capacity to make a decision, an attempt should still be made to find out their wishes. Their past, present and future preferences should be considered. For example, if someone has made an advance statement this must be considered by the decision-maker. We heard about cases where this doesn't happen, and the decision is simply taken by the healthcare professional.

It's essential that healthcare professionals providing care to people with dementia in the last stages of life have access to a person's advance decisions. They must adhere to the wishes of the attorney with authority to act, if one has been appointed.

What is good practice?

- ✓ **Commissioning specific services for people with advanced dementia.** One example is Services for Adults with Advanced Dementia in Oxleas NHS Foundation Trust. This is a community-based service for people who have dementia, are living at home and are thought to be in their last year of life. It's funded through the Better Care Fund and aims to coordinate care, support carers and help people remain in their homes for longer. They provide a detailed, person-centred assessment of the care that someone needs, conducted by the care coordinator together with the consultant psychiatrist and the person and their family, to establish a care plan. This includes looking at what the carer needs in terms of respite and support. The service visits the person with dementia, supports the carer, liaises with other services and advocates for them. Plans are regularly reviewed, and carers continue to be supported after bereavement if necessary.
- ✓ **Ensuring family involvement at end of life.** For example, Services for Adults with Advanced Dementia in Oxleas NHS Foundation Trust supports people in their own homes, supporting carers and acknowledging their strengths in spotting the signs of pain, infection or deterioration. Although this is a 9am to 5pm Monday to Friday service, access to out-of-hours services is rarely needed, probably due to the detailed anticipatory care planning.
- ✓ **Developing partnerships between care homes and hospices, where there's extensive experience in palliative and end of life care.** For example, Wigan & Leigh Hospice provide a service called Hospice In Your Care Home, which sees the hospice work with care homes in the borough. The service provides: support to care home staff to understand the principles of palliative and end of life care, a formal education programme and bespoke training, additional support at short notice if needed, support for the development of advance care plans, and additional support for those important to the person who is dying.
- ✓ **Ensuring care homes have access to electronic patient notes and care plans.** For example, in Enfield care homes have been supported in providing training for staff in information governance and GDPR. This allows the care homes to access notes and care plans. Care plans are shared across care homes, the community teams and secondary care. Requests not to attempt resuscitation (if appropriate) are signed off by the nurse prescriber, the geriatrician or the GP. This can prevent inappropriate ambulance trips to hospital.
- ✓ **Upskilling and increasing the confidence and judgement of care home staff to manage hospitalisations.** For example, the Care Homes Assessment Teams in Enfield have upskilled care home staff in assessment and provided access to support and advice. This enables them to make better and more confident decisions about when to seek hospital support for people in their care. They provide education and follow-up on-the-job training to care homes to manage their resident's needs safely and holistically. They also provide emergency rapid response to deteriorating patients, medically supporting residents to not be admitted to hospital, where possible. This has led to a reduction in A&E attendances and admissions, people dying in their preferred place, patients stopping or reducing their medication usage, and better management of their mental health conditions.
- ✓ **Ensuring that measures of success include patient- and carer-reported outcomes and assessments of quality of life and a 'good death'.** This must include ongoing carer support after death and access to specialist bereavement services if needed.



Conclusion

From diagnosis to death, people with dementia face challenges in accessing effective care and support. From speaking to people across the country, this report identifies key issues across the dementia pathway.

Each gap identified in the pathway is as important as the next. Each type of support can affect the rest of a person's pathway, both positively and negatively.

We know that people struggle to access a timely and high-quality diagnosis, as well as get a subtype diagnosis. This can affect the information they receive, their understanding of their condition and their ability to plan for their future care.

We know that access to follow-up care, therapies and care coordinators is inconsistent across the country. People are left to fight for the care they're entitled to, or they're simply left unsupported.

We know that informal carers, who are cited as one of the only reasons people with dementia are able to live well, are left without support and often reach crisis.

We know that hospitals and care homes can be a large part of a person's pathway, but people still struggle to access the appropriate care for their level of need.

To die well with dementia is to have comfort and quality at the end of life. But we know that people with dementia struggle to access appropriate palliative and end of life support.

A recurring theme at each stage of the pathway is the sense of disjointed, fragmented care.

Health and social care both have a role to play in improving the dementia pathway. They must ensure that people are receiving consistent care from diagnosis to death, and that no one is left behind.

Appendix: Methodology

The information in this report, including reference to policies and Government status on issues, is correct at the time of writing (June 2020).

National guidance

We identified and analysed national guidance and legislation relevant to the dementia pathway. We used this as a benchmark against what people affected by dementia had told us about their own pathway.

The guidance used was 'Dementia: assessment, management and support for people living with dementia and their carers 2018' (NICE guideline [NG97]). The legislation used was the Care Act 2014.

We also used older NICE guidance on dementia (2010, 2013). While some quality statements regarding dementia care were no longer considered a national priority, we included them based on experiences at a local level.

Literature review

We undertook a thorough literature review of existing pathways, standards and datasets for people with dementia.

Focus groups

From November 2018 to April 2019, we ran a series of focus groups with people affected by dementia to explore their experiences of care and support in England. In total, we engaged with nine focus groups, and spoke to over 75 people with dementia and carers of people with dementia. Due to the coronavirus pandemic and timing restrictions, we had to halt further engagement we'd planned with people affected by dementia.

Engagement with healthcare professionals

To supplement our understanding of issues within the dementia pathway, we contacted a range of health and care professionals. These included General Practitioners, geriatricians, nurse practitioners, occupational therapists, neurologists, psychiatrists and dementia advisers.

From 30 January to 30 February 2020, we ran an online survey targeted at healthcare professionals. We asked the following questions:

- In what area of dementia care do you provide care and support?
- What type of health care and support service do you work in?
- What is your job title?
- Please describe your day-to-day role in providing care and support for people affected by dementia.
- What challenges exist within your service and job role specifically that impact the provision of effective, timely and person-centred care and support to people affected by dementia?
- What do you think would help improve the provision of effective, timely and person-centred care and support to people affected by dementia in the service you work, and your job role specifically?
- Do you consider the service in which you work best practice? If so, why do you think this?

The survey had 64 responses, although not every respondent answered every question.

External commissioning

We commissioned Imogen Blood & Associates to support with the identification of good practice examples between January and March 2020. Their methods included an online search and literature review, approaching 31 services, interviewing 17 professionals from eight different services, and interviewing four people living with dementia and eight family carers.

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