



**DementiaUK**

Helping families face dementia

# **A better death:** fixing palliative and end of life care for dementia



## **A better death:** fixing palliative and end of life care for dementia

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# Forewords



**Dr Hilda Hayo, Chief Admiral Nurse and Chief Executive, Dementia UK**

Every day, millions of families across the UK face the emotional, physical and practical realities of dementia. Yet too often, they tell us they are left to navigate this journey alone. They are not always given the information they need to plan ahead, to understand the progression of dementia, or to feel confident that they will receive care that reflects the person's wishes and values. Despite the best efforts of many dedicated professionals, our health and social care systems are still failing to recognise dementia as the complex, life-limiting condition it is.

People living with dementia deserve better: better planning, better coordination and better access to specialist support from the moment of diagnosis through to the end of life. Families deserve to feel prepared. They deserve to understand what lies ahead. They deserve skilled professionals who will listen to them, guide them and stand by them through the most difficult conversations and decisions.

Dementia specialist Admiral Nurses already provide this lifeline for many families. Their expert knowledge, continuity of care and emotional support ensure that families affected by dementia feel prepared and supported. But access to Admiral Nurses remains inconsistent and unfairly distributed across the UK. At the very moment when families most need specialist support, many simply cannot access it.

This report offers clear recommendations and a roadmap for how we can deliver palliative and end of life care that is proactive and person-centred, so that no one faces dementia alone.



**Andrew Woodhead, person living with dementia**

I'm not afraid of the prospect that my life will inevitably end, because I know that I have the empathy, compassion, commitment and experience of the Dementia UK Admiral Nurses, there to support me to die peacefully, with respect and dignity. It is also comforting to know that my family will be an important priority for their care, too. Coping with bereavement can be hard, and Admiral Nurses can always give them emotional support and advice if they need it when I'm gone.



# Executive summary

Dementia is the leading cause of death in the UK and one of the defining health and social care challenges of our time. From the moment of diagnosis, people with dementia and their families face complex, often overwhelming decisions about care, support and planning for the future.

As dementia progresses from early to advanced stages, symptoms become increasingly challenging, including communication difficulties, disorientation, distress and physical changes. The life-limiting nature of dementia often means that there is a requirement to meet significant palliative care needs.<sup>i</sup>

As defined by the National Institute for Health and Care Excellence (NICE), palliative care aims to improve quality of life for people with life-limiting illness by managing pain and other distressing symptoms and addressing psychological, social and spiritual needs. End of life care forms part of this approach and focuses on the final stages of life (typically the last year).

Yet palliative and end of life care for people with dementia remains inconsistent and inadequate. Only a minority of people are supported to plan ahead, many experience unmanaged symptoms, and over a quarter die in hospital despite evidence that most would prefer to die at home. These gaps represent not only a failure of care, but a significant and avoidable burden on families and the health and care system. The Health and Social Care Committee's Expert Panel 2025 report on the state of palliative care in England found that up to a quarter of people in the UK die without receiving the end of life care they need, and noted that people with dementia are disproportionately affected.<sup>ii</sup>



## The national scale of dementia and palliative care need



It is estimated that just under **one million people** in the UK are living with dementia, although this could be substantially higher. <sup>iii</sup>



Up to **one in four** hospital beds is occupied by a person with dementia,<sup>vi</sup> and over a quarter of people with dementia die in hospital. <sup>vii</sup>



The number of people with dementia who will require palliative care is projected to double by 2040.<sup>ix</sup> The most conservative estimate suggests that **399,000** people living with dementia will have palliative care needs by 2040, but this could be as high as **676,000**.



Over **90,000** people die with dementia every year. <sup>iv</sup>



It is projected that more than **two million people** in the UK will have dementia by 2050. <sup>viii</sup>



By 2030 it is estimated that the cost of dementia care will be **£30 billion**, and in 2050 it will be approximately **£47 billion**. <sup>x</sup>



Just under **60%** of those living with dementia are in the advanced stages of the condition. <sup>v</sup>

## Headline findings from our research

### Of current carers and people living with dementia surveyed:

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#### Only 28%

have been supported by a professional to plan for future health and care needs.

#### Only 26%

reported that a professional explained to them the importance and benefits of an advance care plan (ACP).

### Of the people who cared for someone with dementia who has since died:

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#### 18%

noted that the person with dementia did not have any legal or health planning measures in place.

- Only 14% had an ACP in place
- Just under half (49%) had a lasting power of attorney (LPA) in place
- Only 45% had a Will in place

#### 46%

reported that health or social care professionals did not talk to them about what to expect when the person with dementia was approaching the end of their life.

#### 42%

ranked access to specialist dementia nurses as being the most useful/beneficial resource for people with dementia at the end of their life.

#### Only 12%

reported that they accessed a specialist dementia nurse during the end of life stage.

### Across the UK, people with dementia and their families are missing out on timely, compassionate and coordinated palliative and end of life care. The findings highlight:

- persistent gaps in early planning and conversations about future needs
- a lack of professional confidence and training
- limited access to specialist dementia nurses, such as Admiral Nurses
- an overreliance on crisis-driven, hospital-based care – much of which is avoidable

Our research shows a critical need for **comprehensive, person-centred palliative and end of life care** that starts at the point of diagnosis, is consistently reviewed, and is delivered by skilled professionals who understand the unique needs of people living with dementia.



# Key recommendations

Dementia UK is calling on governments across the UK to take urgent action to ensure that people with dementia are supported to plan ahead. Everyone should be supported to live and die in the place that best reflects their needs and preferences, with their symptoms well managed and their care coordinated around what matters most to them and their carers.

Findings and recommendations for this report were developed using a mixed-methods approach that combined qualitative and quantitative research, including with lived experience and clinical experts. Participants were consulted through interviews, qualitative surveys and focus groups, alongside two national YouGov surveys commissioned by Dementia UK (see Methodology and Appendix A).

This report sets out a series of recommendations for governments and health and care leaders with responsibility for commissioning, delivering and overseeing services. The recommendations are grouped into three areas that reflect the main themes emerging from the research and are intended to inform early action.



## Early and proactive planning ▶

**Recommendation 1:** recognise dementia as a life-limiting and palliative condition from the point of diagnosis.

**Recommendation 2:** ensure consistent, meaningful advance care planning that is an evolving process with timely, clear and proactive guidance for families.



## High-quality and person-centred end of life care ▶

**Recommendation 3:** invest in workforce training to improve awareness and management of symptoms experienced by people living with dementia at the end of life.

**Recommendation 4:** support families and carers through access to timely education, respite and emotional support.



## Dementia specialist expertise and a continuous point of contact ▶

**Recommendation 5:** ensure continuity of care is a priority by funding specialist dementia services, such as Admiral Nurses.

**Recommendation 6:** deliver integrated health and social care records to provide continuity of care through to end of life.

For the full set of recommendations, please see [page 36](#). ▶

Our vision is that no one should face dementia alone or without support. With clear policy leadership and sustained investment, people living with dementia can be supported from diagnosis through to the end of life, including dying in their preferred place. This requires a health and care system that recognises dementia as a life-limiting condition and is equipped with a skilled, confident workforce able to deliver high-quality, compassionate end of life care.



# Introduction: why this matters now

## Dementia is the leading cause of death in the UK

Dementia is a progressive, life-limiting condition with no cure and is the leading cause of death in the UK.<sup>xi</sup> Nearly one million people are currently living with dementia, and more than 90,000 people die with the condition every year.<sup>xii</sup>

The scale and severity of need is growing rapidly. Nearly 60% of people with dementia are in the advanced stages, where symptoms become more complex and consistent, and continual support becomes essential.<sup>xiii</sup>

Looking ahead, more than two million people are expected to be living with dementia by 2050. The number who will require palliative care is projected to double by 2040, and could be as high as 676,000.<sup>xiv</sup>

These figures underscore a critical reality: dementia brings profound and complex palliative care needs, especially in its later stages. Behind the statistics are thousands of families navigating uncertainty, distress and loss, and struggling to access the specialist support required to manage the condition with dignity and comfort.

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## What is palliative and end of life care?

Palliative care aims to improve the quality of life of individuals who have a life-limiting illness. The National Institute for Health and Care Excellence (NICE) guidelines set out that palliative care aims to provide relief from pain and other distressing symptoms, integrate the psychological, social and spiritual aspects of the person's care, and continue to offer a support system to help people to live as actively as possible until their death.

End of life care overlaps with this approach but focuses specifically on the final year of life, including the last days and weeks when death is imminent.

## Current system failures

The research identifies systemic failures across health and social care that prevent people with dementia from receiving timely, coordinated and high-quality palliative and end of life care.

- **Lack of early, proactive support:** people are rarely provided with proactive, structured support after diagnosis, often receiving no meaningful follow-up or guidance about progression or planning for end of life
- **Inconsistent delivery of advance care planning (ACP):** only 28% of people were supported by a professional to plan for future care, and ACP is often either absent or treated as a cursory exercise rather than a meaningful, evolving process
- **Fragmented and reactive care:** care is frequently uncoordinated, with families left to navigate complex services alone. Professionals often lack confidence in identifying deterioration or discussing end of life care, leading to missed opportunities for anticipatory support and crisis-driven hospital admissions
- **Poor symptom recognition and management:** distressing symptoms such as pain, breathlessness, agitation and swallowing difficulties are often under-recognised and inadequately managed, particularly when verbal communication is lost
- **High rates of unwanted hospitalisation:** over a quarter of people with dementia die in hospital, despite many wishing to die at home, and hospital environments frequently exacerbate distress at the end of life

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## The economic impact of system failings

There is clear evidence that gaps in palliative and end of life care carry a significant financial cost. NHS England has noted that the combined health and social care costs of dementia exceed those of cancer and coronary heart disease,<sup>xv</sup> reflecting the complexity of needs and the length of time people require support for.

A major driver of these costs is avoidable hospital-based admission at the end of life. Research shows that the mean total cost of care in the last three months of life for people with dementia is £31,224.<sup>xvi</sup> Costs are significantly higher when there is a transition to hospital: those with a hospital transition have mean costs of about £33,239, compared to £21,522 for those without; a difference of around £11,700. These figures highlight an avoidable financial cost to the system, one that could be reduced through proactive, coordinated and more accessible palliative support in the community.

Improving access to community-based dementia specialist palliative care can lead to substantial savings for local systems.

- A Derbyshire-wide Dementia Palliative Care Team, which included Admiral Nurses, delivered a **£367,000 reduction in non-elective inpatient costs in six months**<sup>xvii</sup>
- A Plymouth-based service saved an estimated **£790,000 in eight months** through reduced readmissions and improved discharge planning
- In North Central London, Admiral Nurse support delivered estimated savings of **£38,142 in supporting one family for three months**<sup>xviii</sup>

These figures demonstrate that specialist dementia care not only improves experiences and outcomes but also reduces avoidable financial pressures on health systems.

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## The impact of good palliative and end of life care

High quality palliative and end of life care does more than reduce avoidable costs; it transforms the experience of people with dementia and those who care for them. Our research shows that when support is timely, coordinated and tailored to the specific needs of the person with dementia, families experience profoundly better outcomes, including:

- **Better symptom management and comfort:** clinical experts describe how the right interventions can prevent unnecessary distress and ensure comfort-focused care, including effective pain relief, early recognition of decline and avoidance of uncomfortable interventions
- **Reduced crisis admissions and better alignment with preferences:** high-quality palliative care enables people to remain in their preferred place of care and reduces avoidable hospital admissions by addressing needs proactively and holistically
- **Improved experiences for families:** families supported early by specialist dementia professionals report feeling more confident, prepared and able to uphold the wishes of the person with dementia. Survey responses and lived experience accounts consistently highlight the emotional reassurance, guidance and continuity provided by skilled professionals such as Admiral Nurses
- **Better carer wellbeing outcomes:** emotional support, clear communication and preparation for end of life transitions help families cope with anticipatory grief and reduce feelings of guilt or distress after death

With the right investment and leadership, people with dementia can die with dignity, in their preferred setting, supported by skilled professionals who deliver compassionate care throughout the course of the condition.



## UK-wide policy context

Across the UK, there is an urgent need for strong and coherent national action on palliative and end of life care.

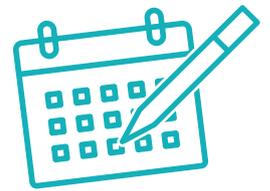
In England, the Government has committed to publishing Modern Service Frameworks for both palliative and end of life care,<sup>xx</sup> as well as dementia and frailty,<sup>xx</sup> in 2026. Alongside this, the Commission on Palliative and End of life Care, established in December 2024, examined gaps in provision and made recommendations for future policy in 2025.<sup>xxi</sup> The Health and Social Care Committee also commissioned an Expert Panel evaluation of palliative care in England, with findings published in November 2025. Both reports noted that people with dementia face pronounced inequalities of access and outcomes related to palliative and end of life care.

Scotland is implementing the new Palliative Care Matters for All (2025-30) plan. Wales is approaching the end of its Ambitions for Palliative and End of life Care (2021-26) programme. In Northern Ireland, stakeholders from across the palliative care sector are calling for a refresh of the 15-year-old 2010 Living Matters, Dying Matters strategy to reflect current needs and practice.

This is therefore a critical opportunity to ensure that the unique needs of people with dementia are fully recognised and embedded within national palliative and end of life policy.

Across all four nations of the UK, dementia must be central to these developments. National health and social care departments should lead efforts within every level of the health and care landscape to explicitly assess and plan for the palliative and end of life care needs of people with dementia, across community, acute, primary and social care settings. This includes ensuring that specialist dementia nursing is prioritised and sustainably funded, so that every family can access skilled, continuous and compassionate support throughout the course of the condition.





# Early and proactive planning

## Information and advice following diagnosis

“ It’s something about that control... Putting things in place which take away what could be pressure points and questions that the family might not know the answer to. ” Admiral Nurse

After diagnosis, people living with dementia and their families are often left without meaningful follow-up and frequently report that there is no further contact or guidance beyond the initial appointment when they are given the diagnosis.

Only 28% of respondents to the 2025 YouGov survey commissioned by Dementia UK of people who have been diagnosed with dementia or are currently caring for someone diagnosed with dementia reported that the carer or person living with dementia was supported by a professional to plan for future health and care needs.

Research has shown that people are often not made aware that dementia is a life-limiting, palliative condition.<sup>xxii</sup> **One study found that 94% of the public were unaware that dementia is the leading cause of death in the UK.** Only 42% recognised dementia as a terminal illness, while just 51% understood that palliative care can benefit those with dementia.<sup>xxiii</sup>

The experience of being told to prepare for the progression of dementia without help to understand what this means or how to access support can be demoralising and cause additional distress. A survey by Dementia Carers Count found that 71% of carers feel they do not receive enough support, and 76% have no arrangements in place for what happens if they cannot continue to care in the future.<sup>xxiv</sup> Similarly, people living with dementia described to us how a lack of support left them feeling overwhelmed.

Participants in both lived experience and professional focus groups noted that carers and people living with dementia are often forced to initiate conversations about future care needs themselves, without knowing how to do so, what to ask or who to turn to for help.



## Advance care planning (ACP)



**At the moment, what we're hearing is that families get absolutely no help at all. They're not getting any proactive advance care planning information.** » Admiral Nurse

The term 'advance care planning' applies in both England and Northern Ireland. It is known as 'future care planning' or 'advance and future care planning' in Wales, and 'anticipatory care planning' in Scotland. For ease, in this report we use advance care planning as an umbrella term for care planning in all four nations of the UK.

Advance care planning allows people with dementia to express their preferences for future care and treatment while they still have decision-making capacity. It provides a framework that supports individuals, families and health professionals to anticipate future needs and make informed decisions collaboratively.

Those who took part in our focus groups, from both professional and lived experience backgrounds, underscored that failure to provide comprehensive advance care planning is the most concerning, impactful omission when it comes to proactive support with palliative needs following diagnosis.

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**18%** of respondents to Dementia UK's commissioned YouGov survey noted that the person with dementia did not have any legal or health planning measures in place. Of all respondents:

- **Only 14%** had an advance care plan in place
- **Just under half (49%)** had a lasting power of attorney (LPA) in place
- **Only 45%** had a Will in place

**Only 26%** of people surveyed who have been diagnosed with dementia or are currently caring for someone diagnosed with dementia reported that a professional explained to them the importance and benefits of an advance care plan.

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According to the insights of clinical experts interviewed, good practice in carrying out advance care planning should involve:

- the use of legal tools such as LPA, advance decisions to refuse treatment (ADRT) and do not attempt cardiopulmonary resuscitation (DNACPR) orders
- a holistic approach to the needs of the person with dementia, their preferences and values, such as via an advance statement of wishes
- initiation early in the dementia journey, ideally immediately after diagnosis, revisited as the person's condition evolves



Research shows that timely and high-quality advance care plans can:<sup>xxv</sup>

- reduce crisis-driven decisions
- reduce inappropriate hospital admissions and over-treatment
- relieve family members of the burden of making uninformed decisions during emergencies
- minimise confusion and distress during periods of deterioration or at the end of life

In cases where advance care planning is well implemented, families report greater satisfaction with the care they and their families receive, and reduced challenges in decision-making and upholding care preferences. Of the Dementia UK YouGov survey respondents who have been diagnosed with dementia or are currently caring for someone diagnosed with dementia who had been supported to create an advance care plan, 78% reported they were satisfied or very satisfied with the support they received from the professional(s) in planning for future care needs. People with lived experience also noted that when an advance care plan is in place, it generates reassurance for the future:

“ **It is important to me that I die at home. I went to my GP, had a 30-minute appointment. Now it flashes up on my medical records, including [to] the ambulance service [...]** Plus, my wife has power of attorney, which is vital, as she can now show the document [...] This makes me feel doubly secure. » **Person living with dementia**

Despite the well-established benefits of advance care planning, our findings reveal a persistent gap between evidence and practice. People with lived experience and clinical experts consistently told us that ACP often does not take place at all for people with dementia, or is reduced to a brief, superficial exercise. Where ACP is initiated, it is frequently treated as a one-off task rather than an ongoing process that is revisited as needs change and capacity declines.

Participants identified several contributing factors. These included uncertainty among professionals about the appropriate timing for ACP, lack of clarity over who is responsible for initiating discussions, and reluctance to raise the subject for fear of causing distress. The result is that meaningful planning is often delayed or absent, leaving families unprepared and clinicians without clear guidance at critical points in the dementia journey.

Combined, these factors limit timely, meaningful planning for families affected by dementia:

“ **Advance care planning requires open and honest conversations with both the individual and their family members. However, there is a widespread societal fear around discussing end of life care, which often prevents these vital conversations from happening.** » **Admiral Nurse**

The failure to initiate, sustain and review advance care planning means that people living with dementia are not routinely empowered and supported to document their wishes and preferences for future care as their dementia progresses and before they lose the cognitive capacity to do so. Families therefore lack the knowledge or confidence to advocate, and care preferences may be missed without formal documentation.

**There is a critical need for system-level change to ensure advance care plans are created, accessible and adhered to.**

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## Regular reviews

Research shows that advance care planning cannot be a one-off conversation. It must be revisited regularly as dementia progresses, because a person's needs, abilities and preferences can change significantly over time. Yet our research highlights major barriers to accessing these ongoing reviews, leaving many families without the chance to update plans or express evolving wishes.

In England and Wales, annual reviews for people with dementia, while incentivised through the Quality and Outcomes Framework (QoF), are inconsistently carried out.<sup>xxvii</sup> Although publicly available data published by NHS England states that 68% of those with a recorded diagnosis of dementia on 31<sup>st</sup> of January 2026 received a care plan or care plan review in the preceding 12 months, other data sources contradict this estimate.<sup>xxviii</sup> For example, one survey found that only 25% of people with dementia had had an annual review in the past year.<sup>xxix</sup> The difference in estimates suggests that what GP practices count as annual reviews may not be the same as what a person with dementia or their family member might expect or need.

Qualitative research found that many people with dementia and their families were not aware that their annual review had taken place, as the review was cursory, whereas the expectation was that the review would be thorough and holistic.<sup>xxx</sup> People with dementia similarly noted that reviews did not meet the complexity of their needs:

 **[My only support is an] annual visit to a GP who has little or no specialist experience and is carrying out a 'tick box' exercise. [The GP is] very caring but unable to provide any realistic form of support.**   
Person living with dementia

Palliative care needs are unlikely to be addressed in light-touch reviews. One study found that only 34% of people with dementia who had died had palliative care needs identified in primary care.<sup>xxxi</sup>

A related problem is the lack of continuity of primary care clinicians. GPs, who are well placed within communities to be a consistent point of contact, are often seen on a rotational basis, whereby the person sees a different GP each time. Many people living with dementia report never seeing the same GP twice.<sup>xxxii</sup>

The absence of regular, structured contact with a known professional means that subtle signs of deterioration may go unnoticed, resulting in opportunities for anticipatory care being missed and needs escalating to a crisis point.

## Recommendations

### Recognise dementia as a life-limiting and palliative condition

#### ☑ National governments across the UK should:

- Require that future strategies for palliative and end of life care and/or dementia:
  - frame dementia as a complex neurological condition that requires specialist support
  - improve understanding of the palliative needs of people living with dementia

#### ☑ In England, the Government should additionally:

- Ensure that both the Modern Service Frameworks for frailty and dementia and for palliative and end of life care recognise the importance of addressing dementia as a life-limiting, palliative condition

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### Ensure consistent, meaningful advance care planning

#### ☑ National governments across the UK should:

- Introduce single patient records and care plans that explicitly include palliative and end of life care support for people living with dementia. Records should:
  - include key components of advance care planning
  - list the key professionals responsible for palliative and end of life care for the person with dementia
  - include a named primary care clinician and specialists
- Review existing datasets and develop new mechanisms to capture and report advance care planning activity reliably. Datasets should be designed to promote best practice and accountability, and enable local targeted interventions where gaps are identified

#### ☑ In England, the Government should additionally:

- Ensure that the planned changes to the NHS app outlined in the NHS 10-Year Health Plan explicitly include palliative and end of life care support for people living with dementia, including advance care planning and key professionals involved in care

#### ☑ Local health systems, integrated care boards (ICBs) and health boards should:

- Provide people with dementia and their carers with information and advice at the point of diagnosis to aid understanding about the progression of dementia and the importance of advance care planning, while the person still has capacity
- Establish local frameworks to ensure annual primary care dementia reviews are meaningful, consistent and include structured advance care planning conversations that revisit and update palliative and end of life care preferences
- Assign every person with dementia a named primary care clinician (such as a GP) with responsibility for annual reviews
- Provide families with support to understand and make decisions regarding legal tools such as lasting power of attorney (LPA), the practicalities of care planning and the person's end of life preferences



# Jenny's story

Mum was diagnosed with frontotemporal and vascular dementia in 2019 when she was only 69. Despite being a palliative care nurse myself, I still found it difficult to have certain conversations around Mum's care. I knew she didn't want to be resuscitated or have artificial feeding tubes, but I had to initiate that conversation with a healthcare professional to make sure her preferences were recorded before she lost mental capacity. I would have felt much more comfortable if someone had brought it up with Mum earlier in her illness.

I knew Dad needed support, but he had a 'stiff upper lip' attitude, which created a barrier to accepting any help. But Anne, the dementia specialist Admiral Nurse who we were referred to, would visit him and Mum at home; she made Dad feel at ease, and he was able to open up to her about how he was feeling.

Anne initiated a conversation with Dad about Mum's end of life care. She helped Dad to prepare for Mum's death by talking openly about it and left some leaflets for him to read and reflect on in his own time. Whilst it was difficult to have these conversations, we needed to be prepared.

I wish we'd had an Admiral Nurse involved throughout the whole dementia journey. Dad needed continuity and one person to coordinate and advise on Mum's care.

Full story at ["Our Admiral Nurse helped start end of life talks"](#) ▶





# High-quality and person-centred end of life care

## Reducing hospital admissions

People with dementia frequently experience avoidable, unwanted hospital admissions at the end of life. Hospital admissions for people with advanced dementia are often precipitated by crises such as aspiration pneumonia, dehydration or behavioural changes.<sup>xxxiii</sup>

These episodes are regularly underpinned by unmet physical or emotional needs that could have been addressed through proactive, community-based support; as such, these admissions are deemed preventable.

“**I would like to die in the house, to be honest. That’s why we have adapted the house – I’d like home.**”  
Person living with dementia

However, lengthy hospital stays and misalignment between care received at the end of life and individual preferences can be highly distressing for both the person living with dementia and family carers:

“**What I really wanted was to keep Charles at home, where he was happy. I promised him I’d care for him at home and that it was where he’d pass away. But he didn’t, and I feel that I let him down.**”  
Wife of a person who died with dementia<sup>1</sup>

Hospitals are rarely set up to deliver end of life dementia care, and the environments can be busy, disorienting and often unfamiliar, which can exacerbate confusion and distress at the end of life.<sup>xxxvi</sup>

In addition, over admittance into acute care during the end of life stage is extremely costly. A study in London and South-East England found that the average cost of care for people with dementia in the last three months of life was £31,225, but adjusted total costs were significantly higher among those who went into hospital than those who did not: £33,239 compared to £21,522. This cost difference is driven by in-hospital costs, intensive care, emergency room visits, ambulance services and outpatient hospital contacts.<sup>xxxvii</sup>

More than **one in four** people with dementia die in hospital.

**29%** of people with dementia received care in hospital during the final three months of life.

People with dementia spend **around 20%** of the last six months of life in hospital.<sup>xxxiv</sup>

The vast majority of people with dementia would prefer to die in their place of residence; either a care home (**59%**) or their own home (**39%**).<sup>xxxv</sup>

<sup>1</sup> Full story at [“My last years with Charles shouldn’t have been so stressful”](#)

## Factors behind preventable hospital stays

Clinical experts and people with lived experience described emergency and care home staff frequently defaulting to admission. This was often due to not being able to differentiate between sudden deterioration from an underlying cause that requires hospital treatment, and deterioration due to the person being near the end of life, where care at home may be more appropriate. Therefore, even where Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) forms and advance care plans are in place, care sometimes does not align with the person's documented wishes.

A lack of staff confidence and understanding of dementia contributes to missed opportunities for anticipatory planning and support to keep the person at home.

Within our focus groups and interviews we heard scenarios in which people living with dementia remained in hospital for extended periods, not due to medical necessity, but because of breakdowns in discharge pathways. A lack of timely assessment for fast-track NHS continuing healthcare (CHC) funding in England, or care homes refusing to readmit residents with behavioural changes, were among the most common barriers to timely discharge. In such cases, people living with dementia deteriorated further while awaiting placement, often acquiring additional health complications as a result.

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## Unnecessary interventions

Clinical experts within our research repeatedly highlighted concerns about unnecessary and overly uncomfortable treatments administered during hospital stays. They stated that interventions such as intravenous fluids and nasogastric feeding are sometimes pursued without meaningful consideration or understanding of the person's stage of illness, best interests or previously expressed wishes:

 **Unfortunately, decisions might get made like to do nasogastric feeding, which is not in that patient's best interests as [...] research tells us that the mortality rate does not decrease by giving someone nasogastric tube feeding at advanced stages of dementia.**  Admiral Nurse

It should be noted that whilst this report does not seek to review clinical decision-making out of context, research has found that nasogastric feeding, despite being commonly used, has limited evidence to suggest it improves survival time or quality of life for people with advanced dementia.<sup>xxxviii</sup>

Unnecessary interventions like these are likely the result of difficulty ascertaining or understanding when a person with dementia has entered the end of life stage, at which point interventions can prolong distress or delay access to comfort-based care whilst not bringing meaningful benefit to the person.

## Holistic and skilled symptom management

As people living with dementia approach the end of life, they may experience a range of complex symptoms, including pain, breathlessness, pressure sores and eating or swallowing problems, alongside deterioration in cognition and communication ability.<sup>xxxix</sup> Despite the high prevalence of such symptoms, clinical experts and people with lived experience within focus groups and interviews described widespread challenges in their recognition, assessment and management.

One person detailed failings in managing end of life symptoms:

“ **My mum was struggling to breathe; she didn’t really have anything to drink because she’d lost the swallowing mechanism. We had to continually call out the district nurses to administer pain relief, but they were reluctant to use a syringe driver, even though we got the out-of-hours doctor to approve it. The syringe driver would have eased the pain and her breathing difficulties, allowing her to have a dignified death.**

**There were so many missed opportunities to escalate Mum’s care. We were left feeling powerless and had to watch Mum slowly die in pain.** »

Daughter of a person who died with dementia

A central theme from the clinical experts interviewed was the under-recognition of distress in people with advanced dementia, particularly when they could no longer communicate verbally. Symptoms were often expressed through changes in behaviour, such as agitation, restlessness, aggression or withdrawal. It was reported that these symptoms were frequently misattributed solely to dementia. Professionals in focus groups noted that signs which would prompt urgent symptom management in people with other diagnoses, such as hallucinations or discomfort, were often dismissed in dementia as ‘just part of the condition’.

Misinterpretation of common symptoms often leads to under-treatment. Within our focus groups, pain in particular was cited as being poorly assessed, with clinical experts emphasising that hospital and care home staff often lacked the skills or tools to detect it in people with dementia who are unable to communicate verbally:

“ **Unfortunately, I still see cases where I go to see someone with dementia who has a pressure sore, and they’re not on any pain medication. And anyone with a pressure sore, there’s going to be an element of pain regardless.** » Admiral Nurse

Pain assessment tools, though widely available, are often not used consistently or effectively. Instead, clinical experts noted that staff tend to rely on basic physiological observations which fail to capture the nuanced and person-specific indicators of pain and distress.

The lack of awareness around end of life symptoms in a person with dementia can prevent implementation of comfort-based approaches, such as palliative care reviews, hydration care plans or skin integrity assessments. Admiral Nurses described having to repeatedly advocate for palliative care such as pain relief, even when signs of end of life were apparent.

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## Support for carers

A central concern voiced across focus groups and interviews was a lack of clear guidance or support for carers in understanding what to expect as dementia progresses. Many family members reported feeling unprepared for the reality of decline and death.

As noted previously, families likewise frequently lack knowledge about fast-track CHC funding, advance care planning and legal tools like lasting power of attorney early enough.<sup>xi</sup> Families often reached a crisis point before support was initiated, by which time the person was sometimes close to death and opportunities for holistic planning had been lost.

Carers interviewed found themselves in the position of having to advocate for care that reflected the wishes and best interests of the person with dementia. They described having to repeatedly advocate for palliative care recognition, fast-track CHC referrals or appropriate symptom relief in the face of professional hesitation. This advocacy role was made harder when professionals themselves lacked awareness of palliative dementia care or failed to initiate necessary conversations.

Often, carers serve as the only source of continuity in an otherwise fragmented care system. When no professional leads were in place and documentation was lacking, families were left relaying vital information between GPs, hospital teams, care homes and community services. This informal coordination role placed additional pressure on carers, who were often navigating these responsibilities while also managing their own grief and uncertainty. As one participant noted:

 **I had to advocate for [my grandmother]. All of that shouldn't be on carers. It shouldn't be down to relatives to carry that burden and fight with healthcare professionals. Professionals need to be trained and confident in recognising when enough is enough.**  Nurse Educator and granddaughter of a person with dementia

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## 46%

of respondents to the YouGov survey stated that professionals did not talk about what to expect towards the end of life.

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## Only 46%

of respondents said they were told when the person with dementia was approaching the end of life.

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## 71% of carers

(current and former) feel they do not receive enough support.

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## 76%

have no arrangements in place for what happens if they cannot care in the future.<sup>xi</sup>

Family carers of people with dementia often face significant loss and grief even before their relative dies, highlighting the need for timely support, information and interventions. Delayed recognition of palliative and end of life care needs can further intensify the emotional burden on carers and potentially lead to more complex grief responses.<sup>xiii</sup>

The absence of respite care or ongoing emotional support increases strain on carers. Carers Trust found that 68% of unpaid carers in the UK are unable to get a respite break from their caring role when needed, and under half (43%) said that in the last year, they had had an assessment, review or reassessment of their needs as an unpaid carer.<sup>xliii</sup> Many carers report exhaustion and loneliness as a result of providing round-the-clock care, especially in the advanced stages of dementia:

“**As Nan’s dementia progressed, she needed 24/7 care. Dad and I moved in to care for her... Nan would hallucinate and try to leave the house, as she didn’t feel like she was at home. She would often scream and cry in the middle of the night. I felt alone, and other parts of my life took a back seat. I lost contact with most of my friends because I couldn’t commit to making plans, and my career was at a standstill.**”  
Granddaughter of a person who died with dementia<sup>3</sup>

Without opportunities for respite, mental health support or even basic peer connection, carers described feeling on their own and unsupported by formal systems. This often left them feeling physically and emotionally depleted, with long-term consequences for their own wellbeing. Carers UK found that 42% of carers say their physical health has suffered as a result of caring, and 74% of carers are worried about the impact their caring role will have in the future.<sup>xliv</sup>

3 Full story at [▶ “My Admiral Nurse Liz was the first person I opened up to”](#)



## Recommendations

### Invest in workforce training to improve awareness and management of symptoms experienced by people with dementia at the end of life

#### ✓ National governments across the UK should:

- Require health and social care frontline staff to undertake dementia-specific palliative and end of life care training on the practical and communication skills required to recognise and respond to the complex needs of people living with dementia. This training should include awareness of the progression of dementia and core components of palliative care, such as advance care planning

#### ✓ In England, the Government should additionally:

- Set minimum standards for the provision of end of life care within community settings, tailored for people affected by dementia, within the Modern Service Frameworks for frailty and dementia and palliative and end of life care. These standards should be developed in line with pre-existing research, with input from clinicians with dementia expertise and people with lived experience

#### ✓ Local health systems, ICBs and health boards should:

- Provide training for health and care staff across primary, community, emergency, acute and care home settings to recognise and respond to the dying phase of dementia. This should include:
  - understanding common markers of the end of life phase, such as swallowing difficulties, weight loss, delirium and behavioural changes
  - using non-verbal symptom assessment tools and recognising how pain, breathlessness, terminal agitation and swallowing problems may present without verbal communication
  - early initiation of comfort measures such as anticipatory medications, hydration support and pressure area care
- Set, and regularly review, targets within local service frameworks to ensure improvements in the recognition of end of life care needs and a reduction in avoidable hospital admissions



## Support families and carers through providing access to timely education, respite and emotional support

### ☑ Local health systems, ICBs and health boards should:

- Implement systematic, proactive processes to identify unpaid carers of people living with dementia at the earliest possible stage
- Ensure carer identification triggers an automatic offer of support, supported by appropriate guidance and resourcing, to include:
  - information on how to prepare for the progression of dementia, including advice on legal tools, eg lasting power of attorney (LPA) and do not attempt cardiopulmonary resuscitation (DNACPR), and funding options such as NHS continuing healthcare (CHC)
  - regular, documented assessments of carer wellbeing, including their training needs, physical health and emotional support requirements, and their ability to continue caring
  - signposting to local peer support networks
  - support with anticipatory grief, such as through tailored counselling
  - support with accessing respite care



# Emma's story

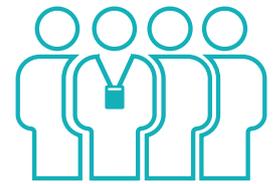
My mother, Nancy, passed away at the end of October 2019, after living with mixed dementia for about six years. In many ways, I'd already had periods of grieving, in some sense of the word, at various points over those years – when she suffered sharp deteriorations in her capabilities, for example, and again when she had to move into a care home. It was like repeatedly losing bits of my mother.

Linda, my Admiral Nurse, came to sit with me at my mother's bedside after she passed away. She talked to me about my mum, and I felt like I was sitting next to a supportive friend. It was a small thing but giving me that time was much appreciated. When she left, she told me that I was more than welcome to call and talk to her if I wanted or needed support. She, more than anyone, was able to understand how I was feeling.

I'm so grateful to have had the support of an Admiral Nurse, but not all of us are so fortunate. There needs to be more of them.

Full story at [“You have to allow yourself to feel whatever you're feeling”](#) ▶





# Dementia specialist expertise and a continuous point of contact

## Supporting palliative and end of life care for people with dementia

Experts who contributed to our research emphasised that advance care planning and end of life discussions are most effective when professionals feel confident talking sensitively about illness progression and future care. To achieve this, professionals require knowledge of the life-limiting, progressive nature of dementia and the common signs and symptoms that emerge as someone approaches the end of life.

However, our research found that many professionals lack the dementia-specific knowledge required to provide the high-quality, person-centred care needed. A recurring theme from clinical experts was a potential lack of awareness, or at least a lack of recognition, that dementia is a palliative, life-limiting condition, which undermines timely planning, symptom management and compassionate decision-making:

“ **There are still many, many GPs that wouldn't categorise it as a palliative illness, and that's something we hear all the time on the [Dementia UK] Helpline.** » Admiral Nurse

Similarly, clinical experts reported that professionals do not feel confident having conversations about the progression of dementia, and often encounter new challenges specific to advanced dementia that they are unfamiliar with:

“ **I've had countless examples where people shy away from end of life discussions. Staff often don't have the confidence to have those conversations, or they don't recognise that someone is entering that phase.** » Admiral Nurse

“ **Care staff, professionals, they're encountering things they've never seen before as well. So it's not just family members; it's staff, too.** » Admiral Nurse

Clinical experts in focus groups emphasised that while not every professional needs to be a palliative and end of life care specialist, key knowledge about the palliative and end of life care needs of people living with dementia is essential to deliver the person-centred care required. Generalist professionals within the health service (such as district nurses, care home staff and GPs) should understand the disease trajectory; be able to identify deterioration; interpret behavioural and physiological changes as potential indicators of distress or pain; and initiate appropriate symptom management.

“ **You need to have more education on how to have conversations with people and how to be confident in having those conversations.** ”  
Nurse Educator

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## Fragmentation of care

Palliative and end of life care for people living with dementia is too often fragmented. Families affected by dementia often lack a continuous point of contact throughout their care journey. As a result, clinicians may lack familiarity with the person’s history, understanding of the condition’s progression, communication needs or care preferences.

Clinical experts also stated that professionals often approach dementia through a task-oriented lens, focusing on the immediate clinical symptoms rather than considering the progressive and terminal nature of the condition:

“ **Health and social care professionals are all working within a curative model, unless they are specifically in hospice care. And it’s a very task-focused model. It’s dealing with this particular set of symptoms that is in front of us, and they don’t look at it holistically.** ” Admiral Nurse

In contrast, clinical experts emphasised that a key component of quality palliative and end of life care is considering the totality of a person’s wellbeing and needs, and ensuring that different elements of their care align:

“ **For some people, it may be that the primary diagnosis is dementia. But others may have dementia with comorbidities – like cancer, for example – and it’s about looking at them as a whole. That can be tricky.** ”  
Admiral Nurse

The absence of a continuous point of professional contact who assesses the individually holistically may mean that subtle signs of deterioration go unnoticed, and opportunities for additional support or anticipatory care are missed:

“ **Families and people living with dementia often have to navigate complex services alone. Additionally, families are frequently unaware of the support and services available to them.** ” Admiral Nurse



Research participants across professional and lived experience groups highlighted that continuous and holistic care is often lost at the precise moment when stability and familiarity are most needed. Poorly coordinated transitions of care, frequent in the later stages of dementia, can be disorienting and distressing.

A transition of care refers to any movement of a person between different care settings or providers, when their care responsibility, environment or team changes – for example, moving from a hospital back to their place of residence. Studies have found that poorly planned transitions of care can contribute to repeated hospital admissions and preventable deterioration.<sup>xiv</sup>

Research participants noted that the absence of integrated systems across healthcare providers, and the siloed nature of health and social care systems, prevent seamless sharing of vital advance care planning documentation between GPs, hospitals, ambulance services and care homes. Therefore, even when advance care planning documentation is completed, it is often lost or inaccessible during transitions of care.

For example, documents about care preferences may not be accessible on admission into hospital, and hospital-based assessments and decisions often fail to be communicated back to community services on discharge. As one clinical expert noted, this means the palliative and end of life care needs of the person with dementia may be noted in one setting, but this then does not transfer to another:

“ **They just get discharged home saying, ‘Yes, this person’s UTI is now being cleared up,’ but there’s nothing on there about, ‘Should be considered for palliative care’ on the discharge. It’s just not joined up at all. It’s so siloed.** ” Admiral Nurse

Research participants noted that the failure to address the person’s needs holistically and to provide continuity of support is a key factor behind fragmented transitions of care. When planning for a transition of care, such as discharge from hospital, wider needs should be considered and addressed:

“ **If somebody goes into a hospital, then rather than just discharging them home, we should be looking at the wider things. People just get discharged home because their UTI is now cleared up, but there’s nothing on considering their broader palliative care on the discharge.** ” Admiral Nurse



## Specialist dementia nursing

Both qualitative and quantitative findings demonstrate the vital difference that access to Admiral Nurses can make in decision-making and support for families affected by dementia, and for health and social care professionals.

Acting as consistent points of contact, Admiral Nurses offer sustained oversight, emotional support and practical guidance for families throughout the dementia journey:

 **Having that lead professional can really change the way that somebody dies and their palliative care experience. I know that everybody I supported [as an Admiral Nurse] received the best palliative care that they could ever ask for. And they died very comfortably. But it was extremely difficult and I put a lot of hours into making sure that happened.**  Admiral Nurse

Admiral Nurses enable meaningful, evolving conversations about advance care planning, the progression of dementia and support for family carers. By initiating sensitive discussions early and revisiting them as the condition progresses, Admiral Nurses empower families to make informed, person-centred decisions about future care. In a national Dementia UK survey, almost all professionals working alongside Admiral Nurses reported that the service had introduced or reinforced the importance of advance care planning for families.<sup>xlvi</sup>

Admiral Nurses can also bridge different health and social care systems, providing families with much-needed continuity. This can help to ensure that people with dementia experience fewer unnecessary and unwanted hospital admissions as their condition progresses.

For example, a Derbyshire-wide Dementia Palliative Care Team, which included Admiral Nursing, achieved a £367,000 reduction in non-elective inpatient costs over just six months,<sup>xlvii</sup> while a service in Plymouth saved an estimated £790,000 in eight months through reduced readmissions and improved discharge planning.

As dementia progresses, Admiral Nurses can help to promote personalisation of care, alignment with preferences and comfort-based interventions. At the end of life, Admiral Nurses can tailor care to the specific needs of people living with dementia during the final stages.

In addition to the support provided to families, Admiral Nurses provide expert training and advice to other health and social care professionals, greatly strengthening generalist provision of palliative and end of life dementia care.

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### 42%

of former carers said access to specialist dementia nurses was the most beneficial form of support at the end of life.

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### Only 12%

of former carers reported receiving support from a specialist dementia nurse during the person's final three months.

Admiral Nurses act as mentors and sources of expert advice for generalist staff, enhancing workforce confidence, reducing stress and promoting a culture of reflective, person-centred care. In a Dementia UK survey on Admiral Nurse services within primary care, all professionals reported that the service had improved case management or coordination, while three-quarters of carers said the service had enhanced the coordination of support from other health and social care professionals.<sup>5</sup>

However, despite their proven benefits, access to Admiral Nurse services remains highly variable across the UK. Many regions still lack specialist dementia support, leaving families without the skilled guidance and continuity of care that can make the difference between a supported and a distressing end of life experience. Sustainable, long-term funding is therefore essential to ensure equitable access to specialist dementia services nationwide.

While the NHS 10-Year Health Plan for England's ambition to expand community-based multidisciplinary care through Neighbourhood Health Centres is a positive step,<sup>xlviii</sup> it must ensure equity in access to dementia specialists within multidisciplinary teams (MDTs) if it is to improve end of life care for people living with dementia. Similarly, national frameworks for dementia care for Scotland, Wales and Northern Ireland would all benefit from a clearer commitment to embedding specialist dementia nursing within every community setting.

Equally, establishing a specialist dementia nursing service in every acute trust or local health board would provide consistent access to expert advice, improve discharge and care transitions and uphold person-centred care at every stage of the dementia journey.

<sup>5</sup> The survey was of 83 professionals (relating to nine primary care Admiral Nurse services) and 105 carers (relating to 18 primary care Admiral Nurse services).



## Impact of Admiral Nurse support \*



### **Lincolnshire Admiral Nurse service, hosted by St Barnabas Hospice**

- 90% of carers said the service provided emotional support
- 68% said it improved their ability to take better care of themselves
- 67% reported improved confidence, 71% reported improved ability to care for the person with dementia and 79% reported improved ability to influence or make decisions about care<sup>xlix</sup>

### **North Central London Admiral Nurse Service, hosted by the NCL Training Hub and Haringey GP Federation**

- 95% of health professionals surveyed felt the service improved advance care planning for families
- Estimated health system savings: £2,934 for supporting one family for one week and £38,142 for supporting a family for three months<sup>l</sup>

### **Western Devon Transitions of Care Admiral Nurse service, hosted by Livewell Southwest**

- There were no avoidable readmissions into hospital for those supported by the service
- One-third of referrals to the service were discharged within 48 hours of referral<sup>li</sup>

\* High-impact Admiral Nurse services are being lost despite clear improvements in outcomes, carer wellbeing, system efficiency and costs. The St Barnabas Hospice service closed in March 2025 due to financial pressures. The North Central London service closed in 2024 due to lack of sustainable long-term funding.



## Recommendations

### Increase access to specialist dementia nursing services, such as Admiral Nurses

#### ☑ National governments across the UK should:

- Embed specialist dementia nurses within care models to provide continuity of care for families and support the wider workforce to deliver high-quality palliative and end of life care. This should include:
  - providing sustainable and ringfenced funding to local health systems for specialist dementia nursing
  - requiring specialist dementia nurses within community health teams and acute care commissioning frameworks

#### ☑ In England, the Government should additionally:

- Publish dementia outcomes and guidance for incoming neighbourhood health teams, requiring ICBs to include dementia specialist roles within multi-disciplinary teams (MDTs) and to demonstrate that people with dementia and their families receive timely, specialist, community-based support

#### ☑ Local health systems, ICBs and health boards should:

- Commission specialist dementia nurses as core members of MDTs in community and incoming neighbourhood health teams in England
- Report annually on dementia specialist nurse provision against local population need within metrics focused on driving improvements in end of life and palliative care for people living with dementia

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### Deliver integrated health and social care records to provide continuity of care through to end of life

#### ☑ National governments across the UK should:

- Undertake a comprehensive review of the current state of integration across health and social care records, assessing interoperability, data-sharing capacity, digital infrastructure and workforce readiness across all care settings
- Following this review, fully fund and implement a national strategy to deliver robust, end-to-end integration of care record systems, aligned with wider national reforms intended to improve coordination of care such as the establishment of MDTs proposed under the NHS 10-Year Health Plan for England
- As part of this strategy, create and support the national implementation of shared clinical databases to enable continuity of care and shared ownership of palliative care through transitions between teams and care settings, supporting timely and safe discharge to a person's preferred place of death



# Neil's story

One morning, it appeared my dad was having another stroke, so we called 999. Luckily for us, we were told that the hospital had a specialist dementia nurse. When my dad was admitted to the same hospital 18 months earlier, we had to remind every single consultant who saw him that he had dementia, despite information in his medical notes. We didn't like to imagine what might have happened had we not been there to act as his advocates.

It's taken me a while to write this as I wanted to truly honour what our Admiral Nurse meant to us. I could tell you how the very first thing she did was to find out who my dad was and what mattered to him, not what was wrong with him, and how she made this the framework for his care.

I could write about all the practical help and advice our Admiral Nurse provided in helping us to understand what was happening and what was going to happen. I could tell you about the support she gave in finding a care home place. I could tell you about the honest, sensitive counsel she gave us about whether continued treatment was in my dad's best interests. And I could reflect on how doing all of the above must require such diplomacy, tact and expertise to win and sustain the trust and respect of patients and their families and hospital colleagues at all levels.

Our Admiral Nurse helped my dad have the best possible end to his life and helped to give us the strength we needed to be there for him.

Full story at [Neil's story](#) ▶



# Conclusion

Making proactive and person-centred palliative and end of life care available for everyone who needs it is achievable. The evidence in this report shows that when dementia is recognised early as a life-limiting condition, people gain the clarity and reassurance needed to plan for the future. From the point of diagnosis, individuals must be supported to understand how dementia progresses, engage in meaningful advance care planning and make informed decisions while they still have capacity.

High-quality palliative and end of life care also depends on skilled and confident professionals who can recognise deterioration, manage complex symptoms and deliver comfort-focused care. When challenges such as pain, breathlessness, agitation or swallowing difficulties are understood and addressed promptly, people experience less distress and a more dignified final stage of life.

Continuity of care is equally vital. Specialist dementia nurses provide a consistent point of contact, enable anticipatory care, coordinate complex transitions and offer emotional support to families. Their involvement leads to better symptom management, fewer avoidable hospital admissions and care that more closely reflects the person's wishes. Yet access to this expertise remains uneven across the UK, highlighting the need for sustainable, equitable investment.

**Improved palliative and end of life care for people with dementia must be proactive rather than reactive; coordinated rather than fragmented.**

Achieving this requires clear national commitments that recognise dementia as a palliative condition, expand access to specialist dementia roles and embed consistent standards of care across all settings.

The recommendations set out in this report will prevent crisis-driven decisions, reduce avoidable hospital admissions and ensure care aligns with personal preferences. This is not only the standard of care that people deserve; it also delivers meaningful savings for health and care systems.

Improving palliative and end of life care for people with dementia is both urgent and achievable. The evidence in this report demonstrates that when dementia is recognised as a life-limiting condition, and when people and families are supported by skilled professionals with access to specialist expertise, outcomes improve and avoidable pressures on the system are reduced.

The forthcoming Modern Service Framework for palliative and end of life care in England presents a critical opportunity to embed dementia as a core priority within national reform. Dementia UK calls on governments and system leaders across the UK to take decisive action to strengthen advance care planning, invest in workforce capability, expand access to specialist dementia nursing, and ensure continuity of care across settings. With clear leadership and sustained commitment, no one should face dementia unsupported at the end of life.



# Full list of recommendations

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## Recommendation 1:

### Recognise dementia as a life-limiting and palliative condition

**National governments across the UK should:**

- Require that future strategies for palliative and end of life care and/or dementia:
  - frame dementia as a complex neurological condition that requires specialist support
  - improve understanding of the palliative needs of people living with dementia

**In England, the Government should additionally:**

- Ensure that both the Modern Service Frameworks for frailty and dementia and for palliative and end of life care recognise the importance of addressing dementia as a life-limiting, palliative condition
- 

## Recommendation 2:

### Ensure consistent, meaningful advance care planning

**National governments across the UK should:**

- Introduce single patient records and care plans that explicitly include palliative and end of life care support for people living with dementia. Records should:
  - include key components of advance care planning
  - list the key professionals responsible for palliative and end of life care for the person with dementia
  - include a named primary care clinician and specialists
- Review existing datasets and develop new mechanisms to capture and report advance care planning activity reliably. Datasets should be designed to promote best practice, accountability and enable local targeted interventions where gaps are identified

**In England, the Government should additionally:**

- Ensure that the planned changes to the NHS app as outlined in the NHS 10-Year Health Plan explicitly include palliative and end of life care support for people living with dementia, including advance care planning and key professionals involved in care

**Local health systems, ICBs and health boards should:**

- Provide people with dementia and their carers with information and advice at the point of diagnosis to aid understanding about the progression of dementia and the importance of advance care planning, while the person still has capacity
- 



- Establish local frameworks to ensure annual primary care dementia reviews are meaningful, consistent and include structured advance care planning conversations that revisit and update palliative and end of life care preferences
  - Assign every person with dementia a named primary care clinician (such as a GP) with responsibility for annual reviews
  - Provide families with support to understand and make decisions regarding legal tools such as lasting power of attorney (LPA), the practicalities of care planning and the person's end of life preferences
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### **Recommendation 3:**

## **Invest in workforce training to improve awareness and management of symptoms experienced by people with dementia at the end of life**

### **☑ National governments across the UK should:**

- Require health and social care frontline staff to undertake dementia-specific palliative and end of life care training on the practical and communication skills required to recognise and respond to the complex needs of people living with dementia. This training should include awareness of the progression of dementia and core components of palliative care, such as advance care planning

### **☑ In England, the Government should additionally:**

- Set minimum standards for the provision of end of life care within community settings, tailored for people affected by dementia, within the Modern Service Frameworks for frailty and dementia and palliative and end of life care. These standards should be developed in line with pre-existing research, with input from clinicians with dementia expertise and people with lived experience

### **☑ Local health systems, ICBs and health boards should:**

- Provide training for health and care staff across primary, community, emergency, acute and care home settings to recognise and respond to the dying phase of dementia. This should include:
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  - using non-verbal symptom assessment tools and recognising how pain, breathlessness, terminal agitation and swallowing problems may present without verbal communication
  - early initiation of comfort measures such as anticipatory medications, hydration support and pressure area care
- Set, and regularly review, targets within local service frameworks to ensure improvements in the recognition of end of life care needs and a reduction in avoidable hospital admissions

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## Recommendation 4:

### Support families and carers through providing access to timely education, respite and emotional support

#### ☑ Local health systems, ICBs and health boards should:

- Implement systematic, proactive processes to identify unpaid carers of people living with dementia at the earliest possible stage.
- Ensure carer identification triggers an automatic offer of support, supported by appropriate guidance and resourcing, to include:
  - information on how to prepare for the progression of dementia, including advice on legal tools, eg lasting power of attorney (LPA) and do not attempt cardiopulmonary resuscitation (DNACPR), and funding options such as NHS continuing healthcare (CHC)
  - regular, documented assessments of carer wellbeing, including their training needs, physical health and emotional support requirements, and their ability to continue caring
  - signposting to local peer support networks
  - support with anticipatory grief, such as through tailored counselling
  - support with accessing respite care



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## Recommendation 5:

### Increase access to specialist dementia nursing services, such as Admiral Nurses

#### ☑ National governments across the UK should:

- Embed specialist dementia nurses within care models to provide continuity of care for families and support the wider workforce to deliver high-quality palliative and end of life care. This should include:
  - providing sustainable and ringfenced funding to local health systems for specialist dementia nursing
  - requiring specialist dementia nurses within community health teams and acute care commissioning frameworks.

#### ☑ In England, the Government should additionally:

- Publish dementia outcomes and guidance for incoming neighbourhood health teams, requiring ICBs to include dementia specialist roles within (MDTs) and to demonstrate that people with dementia and their families receive timely, specialist, community-based support

#### ☑ Local health systems, ICBs and health boards should:

- Commission specialist dementia nurses as core members of MDTs in community and incoming neighbourhood health teams in England
- Report annually on dementia specialist nurse provision against local population need within metrics focused on driving improvements in end of life and palliative care for people living with dementia

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## Recommendation 6:

### Deliver integrated health and social care records to provide continuity of care through to end of life

#### ☑ National governments across the UK should:

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- Following this review, fully fund and implement a national strategy to deliver robust, end-to-end integration of care record systems, aligned with wider national reforms intended to improve coordination of care such as the establishment of MDTs proposed under the NHS 10-Year Health Plan for England
- As part of this strategy, create and support the national implementation of shared clinical databases to enable continuity of care and shared ownership of palliative care through transitions between teams and care settings, supporting timely and safe discharge to a person's preferred place of death



## Acknowledgements

We would like to thank everyone who contributed to the development of this report.

We are particularly grateful to the people living with dementia and the family carers who shared their experiences and insights. Their contributions have been central to shaping recommendations that reflect the realities faced by families across the UK.

We also would like to thank the Admiral Nurses and other clinical experts who participated in interviews, focus groups and surveys. Their specialist knowledge and professional insight have strengthened the depth and credibility of this report.

We are grateful to YouGov for undertaking two national surveys on our behalf, providing important quantitative evidence to complement the lived experience and professional perspectives captured through qualitative research.

Lastly, we thank the members of the expert reference group for their guidance throughout the research process.

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### About this report

This report was authored by Amy Cotter, Policy Manager, Dementia UK.

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For further information please contact [📧 campaigns@dementiauk.org.uk](mailto:campaigns@dementiauk.org.uk)



## Methodology

Research for this report was conducted throughout summer 2025 using a flexible, mixed-methods approach designed to capture a wide range of perspectives on palliative and end of life care for people living with dementia.

The approach combined both breadth and depth of insight, engaging people with professional expertise, lived experience or both. This ensured that findings reflect not only the realities of practice, but also the experiences of those directly affected by dementia.

For the purposes of this report:

- ‘People with lived experience’ refers to individuals directly affected by dementia – either living with dementia themselves or caring for someone with the condition
- ‘Clinical experts’ refers to professionals who work with people affected by dementia in a clinical capacity. Most were current or former Admiral Nurses, with some additional expertise contributed by other dementia care specialists, such as Community Practice Teachers specialising in dementia care

An expert reference group comprising five clinical and research professionals provided ongoing input throughout the research process. This group advised on data collection methods and contributed specialist knowledge to enhance interpretation.

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## Research methods

**Desk-based research:** a review of existing literature and evidence on dementia, end of life care and palliative care provided contextual understanding and informed the study design. It also helped to triangulate findings from the primary research.

**Interviews:** interviews were conducted with people with lived experience of dementia and clinical experts to generate rich, qualitative insights.

- Interviews with clinical experts were semi-structured, allowing flexibility to explore individual areas of expertise
- Lived experience accounts were gathered through a mix of synchronous conversations (interviews or storytelling sessions) and asynchronous written submissions, enabling participation from those who preferred written input or had previously shared relevant insights



In total:

- Four semi-structured interviews were held with expert stakeholders
- Nine interviews or storytelling sessions were conducted with people with lived experience of dementia

**Focus groups:** two focus groups were convened, each involving Admiral Nurses, to facilitate peer discussion and reflection on clinical experience in dementia and end of life care.

**Surveys:** two types of survey were undertaken.

- A qualitative survey was distributed to Admiral Nurses who were unable to participate in interviews or focus groups. Ten nurses contributed in-depth written responses
- Dementia UK commissioned two surveys from YouGov to understand experiences of palliative and end of life care and advance care planning for people with dementia and their families. The surveys were carried out from August to September 2025
  - The first was a nationally representative omnibus survey of UK adults, with screening to include those diagnosed with dementia or caring for someone with dementia. It received 357 respondents affected by dementia in these ways
  - The second was a dedicated UK-wide survey of UK adults (6,473) with screening for those who had provided care for a person with dementia who has since died. It received 1,259 respondents who had provided such care
- Both surveys were conducted online using YouGov’s UK panel of over 2.5 million adults, with respondents selected at random and data weighted to reflect the profile of the target population. As with all sample-based research, findings are subject to the normal statistical limitations of survey data. For full details of the YouGov surveys, please see [Appendix A](#)

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## Strengths and limitations of our approach

This research design offered significant strengths by capturing diverse perspectives from people with lived experience and clinical experts through a range of different data collection techniques. The inclusion of multiple data sources (interviews, focus groups, surveys and desk-based research) also enhanced triangulation and validity of findings.

However, the approach also carried limitations. The sample sizes were relatively small, particularly for qualitative components, which may limit the generalisability of findings. Participation was voluntary, so the views captured may reflect those more engaged or confident in sharing their experiences.



### Appendix A: YouGov surveys

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#### Methodology

Dementia UK commissioned two surveys by YouGov. One was an omnibus survey, and the other was a dedicated survey on end of life care.

The omnibus survey aimed to explore experiences of advance care planning and support with palliative care from the point of diagnosis of both people with dementia and their carers.

The dedicated survey aimed to explore experiences of end of life care among carers of people with dementia.

The surveys were conducted using an online interview administered to members of the YouGov Plc UK panel of more than 2.5 million individuals who have agreed to take part in surveys.

The screening criteria for the two surveys differed slightly:

#### **Omnibus survey:**

All figures, unless otherwise stated, are from YouGov Plc. The total sample size was 8,708 adults, of whom 357 had been diagnosed with dementia or are currently caring for someone diagnosed with dementia. Fieldwork was undertaken between Monday 4<sup>th</sup> to Thursday 14<sup>th</sup> August 2025. The survey was carried out online. The figures have been weighted and are representative of all UK adults (aged 18+).

- UK adults aged 18+
- Additional screening: diagnosed with dementia or caring/had cared for someone with dementia

#### **End of life care survey:**

All figures, unless otherwise stated, are from YouGov Plc. The total sample size was 6,473 adults, of whom 1,259 had provided care for someone with dementia who had since died. Fieldwork was undertaken between Wednesday 3<sup>rd</sup> and Monday 8<sup>th</sup> September 2025. The survey was carried out online. The figures have been weighted and are representative of all UK adults (aged 18+).

- UK adults aged 18+
- Filtered for: those who have provided care for someone with dementia who has since died

The survey results were analysed by YouGov. While YouGov Plc makes every effort to provide representative information, all results are based on a sample and are therefore subject to statistical errors normally associated with sample-based information.



## Omnibus survey

Fieldwork was undertaken between Monday 4<sup>th</sup> and Thursday 14<sup>th</sup> August 2025.

Nationally representative sample of 8,708 UK adults, with 357 who have been diagnosed with dementia or who care for someone diagnosed with dementia.

Note: 301 respondents skipped Q1

**Q1.** For the following question, when we use the term ‘care for’ this includes anyone with dementia you look after or looked after or give any help or support to – this does not need to be full-time care, help or support. In which, if any, of the following ways have you been affected by dementia? (Please select all that apply).

Unweighted base	8,407
Base: all UK adults	8,346
I have been diagnosed with dementia	1%
I currently care for someone diagnosed with dementia	4%
I used to care for someone who was diagnosed with dementia	13%
None of these	78%
Don’t know/can’t recall	2%
Prefer not to say	3%

For the following question, if you currently care for more than one person with dementia, please answer based on the person who is closest to you.

**Q2a\_1.** Following a dementia diagnosis, were you/the person with dementia supported by a professional to plan for any future health and care needs (also known as advance care planning)?

Unweighted base	357
Base: all UK adults who have been diagnosed with dementia or are currently caring for someone diagnosed with dementia	352
Yes	28%
No	50%
Don’t know/can’t recall	16%
Prefer not to say	5%

**Q2a\_2.** Following diagnosis, did any professional explain the importance/benefit of having an advance care plan in place?

Unweighted base	357
Base: all UK adults who have been diagnosed with dementia or are currently caring for someone diagnosed with dementia	352
Yes	26%
No	46%
Don’t know/can’t recall	24%
Prefer not to say	4%

**Q4.** You said that you or someone you care for with dementia has received support to plan for any future health and care needs. Who supported you to plan for future care needs? (Please select all that apply).

Unweighted base	97
Base: all UK adults who have been diagnosed with dementia or are currently caring for someone diagnosed with dementia and who received support from professional with an advance care plan	
	100
A dementia specialist	36%
Another healthcare professional	44%
Another social care professional	39%
Other professional	4%
Don't know/can't recall	6%

**Q5.** Overall, how satisfied or unsatisfied were you with the support you/the person you care for received from the professional(s) in planning for future care needs?

Unweighted base	97
Base: all UK adults who have been diagnosed with dementia or are currently caring for someone diagnosed with dementia and who received support from professional with an advance care plan	
	100
Very satisfied	24%
Satisfied	54%
Neither satisfied nor unsatisfied	19%
Unsatisfied	3%
Very unsatisfied	1%
Don't know	-
Prefer not to say	-
Net: satisfied	78%
Net: unsatisfied	3%

## Dementia UK end of life care survey

Fieldwork was undertaken between Wednesday 3<sup>rd</sup> and Monday 8<sup>th</sup> September 2025.

Base of all UK adults who have provided care for someone with dementia who has since died: 1,240.

**QA.** Have you ever provided care for someone with dementia who has since died?

Unweighted base	6,473
Base: all UK adults	
	6,473
Yes, I have	19%
No, I have not	79%
Prefer not to say	2%

**Q1.** For the following questions, if you have looked after more than one person with dementia who has since died, please think about the person you most recently cared for. What was your relationship to the person with dementia?

Unweighted base	1,259
Base: all UK adults who provided care for someone with dementia who has since died	
	1,240
I was their spouse/partner	3%
I was their child	38%
I was their sibling	3%
I was another relative	31%
I was a friend/neighbour	6%
Other	19%

**Q2. What was the person with dementia's usual place of residence? (Please select the option that best applies, thinking about where they lived most of the time before any hospital stays or short-term changes in their living situation).**

Unweighted base	1,259
Base: all UK adults who provided care for someone with dementia who has since died	1,240
Their own home	54%
A residential care or nursing home (including sheltered housing)	35%
They lived with me in my home	6%
Other	3%
Don't know/can't recall	1%
Prefer not to say	1%

**Q3. Did the person with dementia only receive care in their usual place of residence in the last three months of their life? (Select all that apply).**

Unweighted base	1,259
Base: all UK adults who provided care for someone with dementia who has since died	1,240
Yes, they only received care in their usual place of residence	36%
No, they received some care and support in a hospital	18%
No, they received some care and support in a hospice (ie a special care service where people are cared for when towards the end of their life)	5%
No, they received some care and support in a residential care or nursing home	36%
Don't know/can't recall	3%
Prefer not to say	1%

**Q4. Did health or social care professionals talk to you and/or the person with dementia about what to expect when the person with dementia was approaching the end of their life (ie about symptoms that may arise etc)? (Please select the option that best applies).**

Unweighted base	1,259
Base: all UK adults who provided care for someone with dementia who has since died	1,240
Yes, they did	36%
No, they did not	46%
Prefer not to say	3%
Don't know/can't recall	15%

**Q5. Were you and/or the person with dementia told that the person living with dementia was approaching the end of their life? (Please select the one that best applies).**

Unweighted base	1,259
Base: all UK adults who provided care for someone with dementia who has since died	1,240
Yes, we were told this	46%
No, we were not told this	39%
Don't know/can't recall	12%
Prefer not to say	4%



**Q6.** Which, if any, of the following services did the person with dementia get care and support from in the last three months of their life? (Please select all that apply).

Unweighted base	1,259
Base: all UK adults who provided care for someone with dementia who has since died	1,240
A GP or doctor	39%
A hospital	29%
A community nurse (sometimes called a district nurse)	21%
A paid carer (sometimes called domiciliary care, home care, support worker, personal assistant)	34%
A community palliative care nurse (sometimes called a hospice nurse)	14%
Social worker	12%
Pharmacist	5%
Occupational therapist	6%
Physiotherapist	3%
Specialist dementia nurse	12%
Other	8%
Not applicable – they did not receive care and support from these services	12%
Prefer not to say	5%

**Q7.** Overall, how was your experience with the services that provided any care and support in the last three months of the life of the person with dementia?

Unweighted base	1,098
Base: all UK adults who provided care for someone with dementia who has since died and who received care from services in the last three months of their life	1,086
Very good	21%
Good	34%
Fair	24%
Poor	8%
Very poor	7%
Don't know	3%
Prefer not to say	3%
Net: good	55%
Net: poor	15%

**Q8.** In the last three months of their life, if the person with dementia needed a visit or support from a health or social care professional, were they able to get the support requested?

Unweighted base	1,098
Base: all UK adults who provided care for someone with dementia who has since died and who received care from services in the last three months of their life	1,086
Yes, always	32%
Yes, sometimes	34%
No	12%
Not applicable	8%
Don't know/can't recall	11%
Prefer not to say	4%
Net: yes	66%
Net: no	12%

**Q9.** Overall, when they received care and support, do you feel that the person with dementia was treated with respect and dignity by health or social care professionals? (Please select the option that best applies).

Unweighted base	1,098
Base: all UK adults who provided care for someone with dementia who has since died and who received care from services in the last the months of their life	1,086
Yes, always	47%
Yes, sometimes	33%
No	8%
Not applicable – they did not see health or social care professionals	4%
Prefer not to say	3%
Don't know	4%
Net: yes	81%
Net: no	8%

**Q10.** Which, if any, of the following legal or health planning measures did the person with dementia have in place? (Please select all that apply. If they did not have any legal or health planning measures in place, please select the 'Not applicable' option).

Unweighted base	1,259
Base: all UK adults who provided care for someone with dementia who has since died	1,240
Lasting power of attorney (LPA)	49%
Advance care plan (ACP)	14%
Writing a Will	45%
Other	2%
Don't know/not sure	14%
Not applicable – the person with dementia did not have any legal or health planning measures in place	18%
Prefer not to say	4%

Which, if any, of the following things do you think would be most useful or beneficial to people with dementia and their families at the end of their life? (Please rank in order of importance).

**Q11a\_1.** Information about what health and social care support is available at end of life.

Unweighted base	1,259
Base: all UK adults who provided care for someone with dementia who has since died	1,240
1	26%
2	29%
3	24%
4	12%
Don't know/can't say	9%

**Q11a\_2.** Information about local dementia support services or carer groups focused on supporting someone with dementia at the end of life.

Unweighted base	1,259
Base: all UK adults who provided care for someone with dementia who has since died	1,240
1	14%
2	19%
3	25%
4	34%
Don't know/can't say	9%



**Q11a\_3. Access to specialist dementia nurses.**

Unweighted base	1,259
Base: all UK adults who provided care for someone with dementia who has since died	1,240
1	39%
2	22%
3	18%
4	13%
Don't know/can't say	9%

**Q11a\_4. Information about legal and financial support that is available for end of life care.**

Unweighted base	1,259
Base: all UK adults who provided care for someone with dementia who has since died	1,240
1	13%
2	21%
3	25%
4	33%
Don't know/can't say	9%



## Appendix B: glossary of terms

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### Admiral Nurse

An Admiral Nurse is a specialist dementia nurse, supported and developed by Dementia UK, who is trained to provide expert, practical and emotional support to families affected by dementia. They work across a wide variety of settings, including on Dementia UK's Helpline and within health and social care host organisations such as hospitals.

Everyone can access support from an Admiral Nurse by calling Dementia UK's Helpline for free on **0800 888 6678** or emailing [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

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### Advance care planning

Advance care planning (ACP) is the process of thinking about, discussing and documenting preferences for future care. It involves recording values, goals and what matters most to the individual in terms of care and quality of life; and completing legal documents, such as a lasting power of attorney (LPA) for health and welfare.

It is known as 'future care planning' or 'advance and future care planning' in Wales, and 'anticipatory care planning' in Scotland.

### End of life care

End of life care, while often overlapping with palliative care, refers to care provided within the final 12 months of life.

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### Lasting power of attorney

Lasting power of attorney (LPA) is a legal document that allows an individual to appoint one or more trusted people (attorneys) to make decisions on their behalf if they lose the mental capacity to do so themselves.

LPA applies in England and Wales. The equivalent is enduring power of attorney (EPA) in Northern Ireland, and power of attorney (PoA) in Scotland.

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### Palliative care

Palliative care takes a comprehensive, person-centred approach to enhance quality of life for people facing life-limiting illnesses and their families from the point of diagnosis. It focuses on the early recognition and effective treatment of pain and other distressing symptoms – whether physical, emotional, social or spiritual – to alleviate suffering.



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NHS Digital further estimated in June 2024 that there are approximately 70,000 people whose condition began under the age of 65. NHS England >> RightCare dementia scenario. [online] [england.nhs.uk](https://england.nhs.uk). Available at: [england.nhs.uk/long-read/rightcare-dementia-scenario/](https://england.nhs.uk/long-read/rightcare-dementia-scenario/)

According to the most recent official strategy from the Scottish Government (2023), there are about 90,000 people in Scotland living with dementia: Scottish Government (2023). Dementia in Scotland: everyone's story. [online] Available at: [gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2023/05/new-dementia-strategy-scotland-everyones-story/documents/dementia-scotland-everyones-story/dementia-scotland-everyones-story/govscot%3Adocument/dementia-scotland-everyones-story.pdf](https://gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2023/05/new-dementia-strategy-scotland-everyones-story/documents/dementia-scotland-everyones-story/dementia-scotland-everyones-story/govscot%3Adocument/dementia-scotland-everyones-story.pdf)

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**If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.**

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**Open Monday-Friday, 9am-9pm**

**Saturday and Sunday, 9am-5pm**



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Dementia UK, 7<sup>th</sup> Floor, One Aldgate, London EC3N 1RE

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