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Cicely Saunders International
Better care at the end of life

KING'S College LONDON

A RIGHT TO BE HEARD

Better palliative and end-of-life care for people affected by dementia

May 2023

"Mum had a right for her voice to be heard, but it wasn't"

- BEREAVED CAREGIVER

Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation

The Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, at King's College London, is a world-leading palliative care institute, integrating research, education, and clinical care. It is one of a handful of centres across the world dedicated to delivering high quality palliative and end of life care research.

Cicely Saunders International

Cicely Saunders International has a mission to promote research to improve the care and treatment of all patients with progressive illness and to make high-quality palliative care available to everyone who needs it – be it in hospice, hospital or home. There is no other charity specifically concerned with carrying out work to identify and promote best practice in palliative care.

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"One of the paramedics said to me,
'it's just not worth my job not to take you in',
and I said, 'isn't it worth his life and his quality of life?'
And he sort of just looked at me and said
'Sorry, I understand but he's going to have to go in'.
And off we went for another eight-hour stint.
You know, in A&E."

– BEREAVED CAREGIVER[1]

Key message

Dementia is a progressive neurodegenerative condition affecting approximately 944,000 people in the UK,[2] and around 700,000 caregivers.[3] **It is the leading cause of death in the UK today**.[4] By 2040, the number of people dying with dementia is expected to more than double.[5]

The **Five Year Forward View** specifies a focus on dementia diagnosis and post-diagnostic support to reduce crises and avoid unnecessary hospitalisations.[6] The **NHS Long Term Plan** stipulates personalised care to improve the quality of end-of-life care, helping to reduce avoidable hospitalisations and enable people to die in their preferred place of death.[7]

However, the quality of end-of-life care for people with dementia remains **variable**. Most will experience unnecessary emergency hospitalisation,[8] which is often very distressing and can be detrimental overall.[1]

Recent high quality evidence identifies ways to improve care for people with dementia approaching the end of their lives. Based on this evidence, we outline **four calls to action**, with policy recommendations:

1. Prioritise dementia as a life-limiting condition
2. Ensure equitable access to integrated palliative dementia care
3. Optimise investment in integrated end-of-life care closer to home
4. Invest in palliative dementia care research

A note on palliative and end-of-life care

Palliative care is the active total care of patients and their families by a multi-professional team when the patient's disease is incurable.[9] It aims to improve quality of life and is provided through person-centred and integrated health care.[10] It has been found to be clinically and cost-effective in other conditions.[11] Although a flexible, needs-based palliative care approach is advocated for people with dementia,[12] it is often either adopted when death is imminent or not at all.[13]

The end of life is defined by NHS England as the last year of life.[14] Therefore, end-of-life care is the care and support of people who are thought to be in their last year of life.

Recommendations

1. Prioritise dementia as a life-limiting condition

- Public health campaigns to challenge stigma by educating the public and improving understanding of dementia as a life-limiting condition.
- Health and social care staff training to reiterate dementia as a life-limiting condition and embed dementia palliative and end-of-life care into core competencies.

2. Ensure equitable access to integrated palliative dementia care

- Dementia Care Pathway to include access to an integrated palliative care approach, at any stage of dementia.
- Integrated Care Boards to consider dementia in fulfilling their legal duty to respond to palliative and end-of-life care needs of the local population.

3. Optimise investment in integrated end-of-life care closer to home

- Local integration of primary, community and urgent care services to prioritise equitable access to timely and responsive medical and nursing expertise closer to home.
- Integrated Care Systems to consider joint workforce planning and development to ensure continuity and competency to meet the needs of people with dementia approaching the end of life.

4. Invest in palliative dementia care research

- National data providers to expand routine data collection to include palliative and end-of-life care outcomes that are meaningful to people with dementia, to monitor quality and address inequalities.
- Government to commit to additional funding for research and innovation to improve the quality of end-of-life care and reduce inequalities among people with dementia.

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Introduction

There are 944,000 people living with dementia in the UK.[2] It is the leading cause of death in the UK today.[4] By 2040, the number of people dying with dementia will more than double.[5]

The Five Year Forward View specifies a focus on dementia diagnosis and post-diagnostic support to reduce crises and avoid unnecessary hospital admissions.[6] The NHS Long Term Plan stipulates personalised care to improve the quality of end-of-life care, helping to reduce avoidable hospital admissions and enable people to die in their preferred place of death.[7]

Yet most people who are dying with dementia still make unnecessary trips to hospital and continue to receive variable quality of end-of-life care.

DEMENTIA IS THE LEADING CAUSE OF DEATH IN THE UK[4]

MORE THAN x2 PEOPLE DYING WITH DEMENTIA BY 2040[5]

1 IN 4 HOSPITAL PATIENTS OVER 65 HAVE DEMENTIA[15]

The quality end-of-life care among people with dementia is variable.

Although most people with dementia prefer to remain living in their usual place of residence,[16] many experience prolonged hospital stays, especially towards the end of their life.

In a study using routine data on 19,221 people with dementia, **rates and lengths of unplanned hospital admissions** remained relatively low and short in the months after diagnosis but **dramatically increased as people with dementia approached the end of life.**[8]

An England-wide study using routine data on 74,486 decedents with dementia found that **83% attended the emergency department** at least once in the **last year of life**. Almost a quarter of all attendances in the last year of life took place in the **final month before death** (Figure 1).[17]

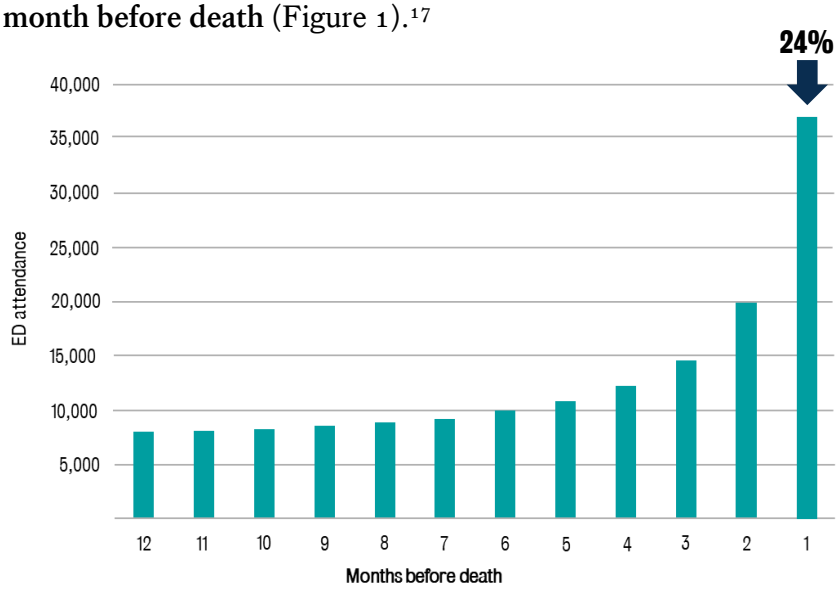


Figure 1: The number of emergency department attendances in the last year of life among people with dementia (*n*=154,508 ED attendances)[17]

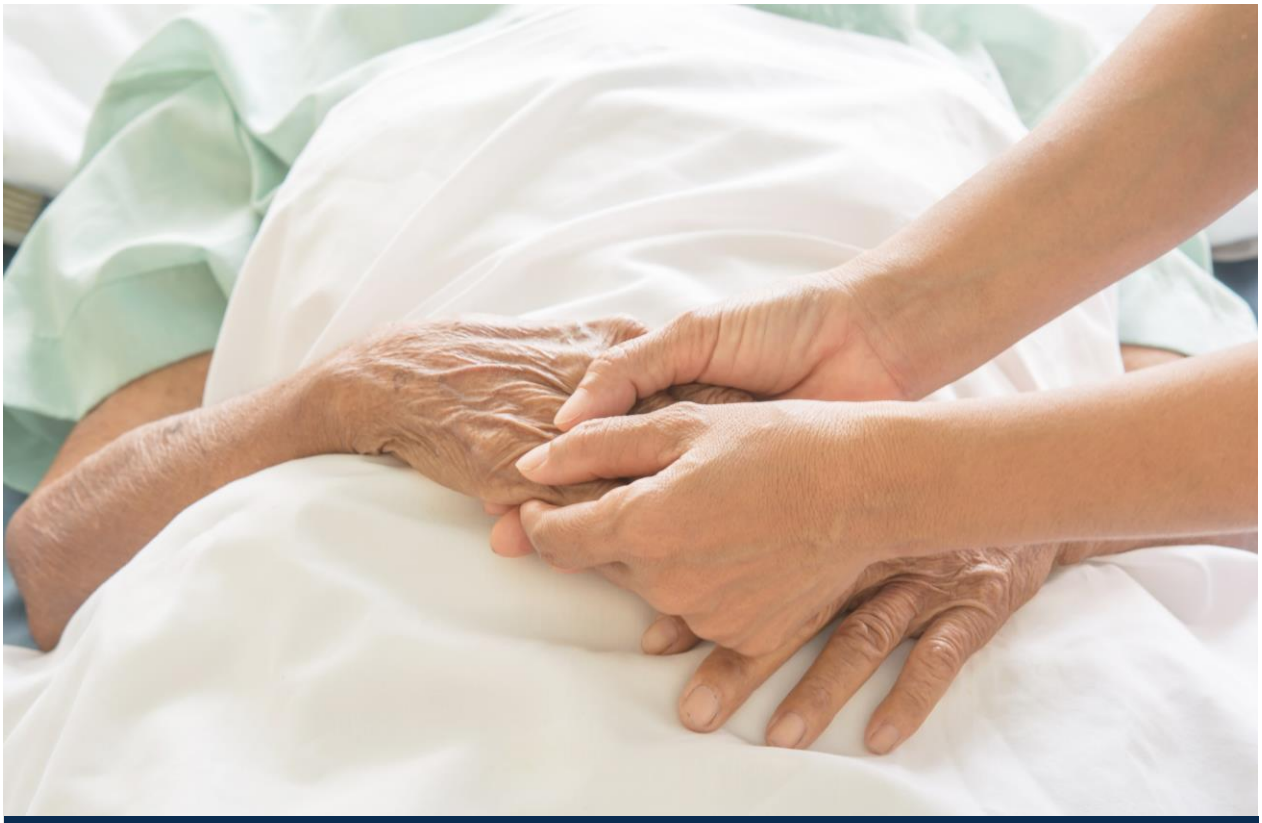
> *"We need to have hospital at home, if you like, simply because you go in the hospital, you don't come out at the same level as you were when you went in. I have seen it with so, so many of my friends. Just the noise, the lack of routine, lack of knowledge, lack of understanding, makes it just an alien environment. And that's why I simply won't go in anymore."*
>
> – PERSON WITH DEMENTIA[1]

Costs of healthcare increase towards the end of life.

A systematic review showed that the **total direct cost of care increases towards the end of life** among people with dementia.[18]

The costs of healthcare towards the end of life are **largely driven by hospitalisation**. In a study of 146 decedents with dementia in London and the South East, the average cost of care in the last three months of life was £31,224.70. Adjusted total costs were higher among those who went to hospital than those who did not **(£33,239.20 vs £21,522.00).**[19]

> *"I suppose, you know, if you're caring for someone at home, you don't have the expertise that they've got and it's no good ringing 111, I think; you go through so many hoops and you don't really get anywhere, and she ends up being taken to A&E anyway."*
>
> – BEREAVED CAREGIVER[1]



We are calling for

BETTER PALLIATIVE AND END-OF-LIFE CARE FOR PEOPLE AFFECTED BY DEMENTIA

Dementia is frequently not recognised as a life-limiting condition nor considered suitable for palliative care. Too often people affected by dementia have limited access to support in the community and experience high hospital use and a high burden of suffering. They deserve better.

Informed by latest evidence, we are making **four calls to action**:

1. Prioritise dementia as a life-limiting condition
2. Ensure equitable access to integrated palliative dementia care
3. Optimise investment in community and primary care closer to home
4. Invest in palliative dementia care research

CALL 1: Prioritise dementia as a life-limiting condition

There is persistent misunderstanding around dementia, in the health and social care sector and wider society.

While there has been an increased effort to improve dementia awareness, there are many misconceptions about dementia that persist.

Public health initiatives must educate the public about dementia as a life-limiting condition. This may help to increase equity of access to care, improving patient outcomes and experience, and pressures on the health and social care system.

58%
OF THE PUBLIC DO NOT KNOW DEMENTIA IS A TERMINAL CONDITION[20]

94%
DO NOT KNOW DEMENTIA IS THE LEADING CAUSE OF DEATH[20]

Dementia continues to be misunderstood.

Despite being a neurodegenerative condition and currently without curative treatment, there is general misunderstanding that dementia is a life-limiting condition.

In a survey of 2,133 adults across the UK, a **YouGov poll** conducted in 2022 by the **EMBED-Care** research team showed that:

- 94% did not know that dementia was the leading cause of death in England.
- 49% did not know that palliative care can benefit people with dementia.
- 92% had never heard of dementia specialist nurses, Admiral Nurses (see Figure 2).[20]

> *" it is not given the seriousness that I think that the disease should have."*
>
> – PERSON WITH DEMENTIA[1]

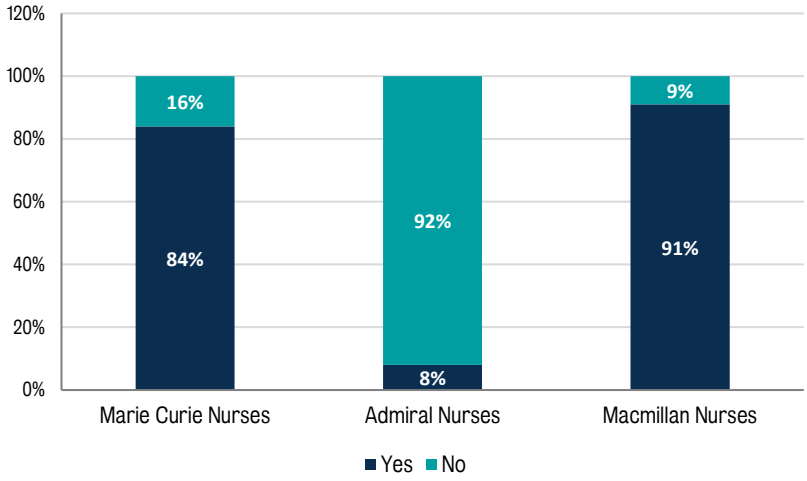


Figure 2: Percentage of YouGov poll responses to question: "Before taking this survey, which of the following had you ever heard of?" (n=2,133)

Preconceptions about dementia may influence access to community care.

A qualitative study of 37 people affected by dementia identified a deeply ingrained **societal bias towards dementia**, reminiscent of the **stigmatisation of mental illness**.[1]

Analyses suggested this bias was reflected in the health and care system, which fails to legitimise dementia as a life-limiting condition, risking diagnostic overshadowing and limited clinical workups.[1]

The study found that the changing needs of people with dementia were at odds with the **structural, legal, and cultural constraints** of the health and care system. Subsequent barriers to accessing community care support meant that the **emergency department became the path of least resistance**.[1]

> *" But they never say the word dementia. Because dementia to them is Uncle Fred disappearing into the asylum and never coming out. So, it's that stigma..."*
>
> – PERSON WITH DEMENTIA[1]

> *"You're relying on triple 1 and they don't want to know if it's dementia because there's nothing they can do... they've got other calls to make, and they know they're going to get stuck and they can't do anything. So, we end up, the last thing is an ambulance to A&E."*
>
> – BEREAVED CAREGIVER[1]

There is a lack of parity of esteem between dementia and other life-limiting conditions.

The qualitative study also found that participants affected by dementia repeatedly identified a **lack of parity** between dementia and other life-limiting conditions, noting an absence of clinical oversight and specialist support after diagnosis. Unlike other conditions, dementia was described as not sitting neatly in the health and social care system.[1]

Participants affected by dementia described feeling that they were not taken seriously by health and social care professionals. They described often feeling **unheard** and **passed off** in a system that routinely equates dementia with old age and poor quality of life.[1]

> *"Dementia is like a hot potato; no-one wants to hold onto it and handle it."*
>
> – PERSON WITH DEMENTIA[1]

> *" I had eight phone call conversations expressing why I want you to come and see my dad. If this was another illness; if I was saying, 'Look, my dad's passing blood', you'd be there."*
>
> – CURRENT CAREGIVER[1]

Strong leadership and staff training could help to better prioritise dementia as a life-limiting condition.

It is essential that people affected by dementia do not feel written off. Therefore, there must be a top-down **cultural shift** that cultivates respect for dementia as a life-limiting condition, and as with any life-limiting condition, worthy of specialist support from diagnosis to the end of life.

The development and delivery of dementia training for health and care staff is supported by the Dementia Training Standards Framework. A 2019 audit of training packages showed that few addressed the subject end-of-life care (36%), and of those that did, less than half (48%) delivered the end-of-life care learning outcomes listed in the Framework.[21] For a life-limiting condition that can present with unique end-of-life care challenges, and for which prognosis is difficult to assess, the minimum content of staff training requires urgent redress.

> *" He started these sorts of behaviours... they were more to do with the fact that he had an infection and, you know, that was undiagnosed. But if somebody had been an expert, they might have discovered that – and listened to what I was saying."*
>
> – BEREAVED CAREGIVER[1]

Recommendations

- Public health campaigns to challenge stigma by educating the public and improving understanding of dementia as a life-limiting condition.
- Health and social care staff training to reiterate dementia as a life-limiting condition and embed dementia palliative and end-of-life care into core competencies.

CALL 2: Ensure equitable access to integrated palliative dementia care

There is urgent need to improve access and availability of palliative and end of life care for people with dementia.

While palliative care needs in England and Wales are expected to increase, the **greatest increase is projected to be among people with dementia.**[5] Despite this, there are persistent barriers to accessing palliative care for people with dementia.

DEMENTIA HAS THE HIGHEST INCREASE IN SERIOUS HEALTH-RELATED SUFFERING[22]

OVER 3X INCREASE IN PALLIATIVE CARE NEEDS AMONG PEOPLE WITH DEMENTIA BY 2040[5]

The quality of end-of-life care among people with dementia is variable.

Evidence indicates unwanted variations in end-of-life care access and outcomes among people with dementia.

Most people with dementia would prefer to die at home or in a care home.[16] However, in an England-wide study of 388,899 decedents with dementia, findings showed that **dying at home** was more likely for **women, people who had cancer** as the underlying cause of death, and those living in more **affluent areas**.[23]

Another England-wide study of 74,486 decedents with dementia found **regional variation** in emergency department visits in the last year of life; these were less common among people with higher **socioeconomic position**, and more common among people of **South Asian ethnicity** (Figure 3).[17]

> *"But somewhere in this triangle you need to listen to his views because this is what he doesn't want. He doesn't want to be put in the back of an ambulance and be taken away and potentially die in an A&E resuscitation unit."*
>
> – CURRENT CAREGIVER[1]

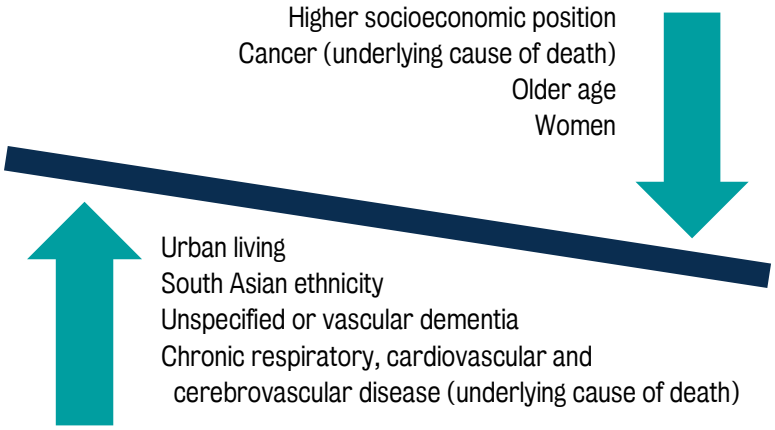


Figure 3: Factors associated with emergency department visits among people with dementia in the last year of life.[17]

Palliative care can improve the quality of end-of-life care among people affected by dementia.

There is increasing evidence that **community palliative care can reduce emergency department attendance** among people with dementia approaching the end of life.[24]

Using data from 365 primary care practices in West London, a study showed that **only one third** (33.6%) of people with dementia who had died had had palliative care needs identified in primary care. However, this group were found to have had a **lower risk of multiple hospitalisations** in the last three months of life.[25] This emphasises the importance of **integrated primary and community care** in meeting the palliative care needs of people with dementia.

> *" I was really pushed to the limit, I must confess, but I felt able to phone [hospice]... there was a nurse at the end of the phone to talk to. That, that, was really good. That was very helpful."*
>
> – BEREAVED CAREGIVER[1]

An integrated palliative care approach can help improve quality of life as well as quality towards the end-of-life.

Although there are evident benefits to improving the quality of end-of-life care, a palliative care approach can also help support people with life-limiting illnesses to live as well as possible.[9] The approach can therefore be beneficial when provided early (Figure 4).

A palliative care approach focuses on person-centredness, quality of life and dignity, autonomy, needs-based care, coordination and continuity of care.[26] These are fundamental to supporting people affected with dementia, at any stage of the condition.[12] However, there is inequity of access for people with dementia.[13]

Figure 4: Early palliative care input in the dementia trajectory, alongside any life-prolonging interventions

Integrated working is vital for good palliative care.

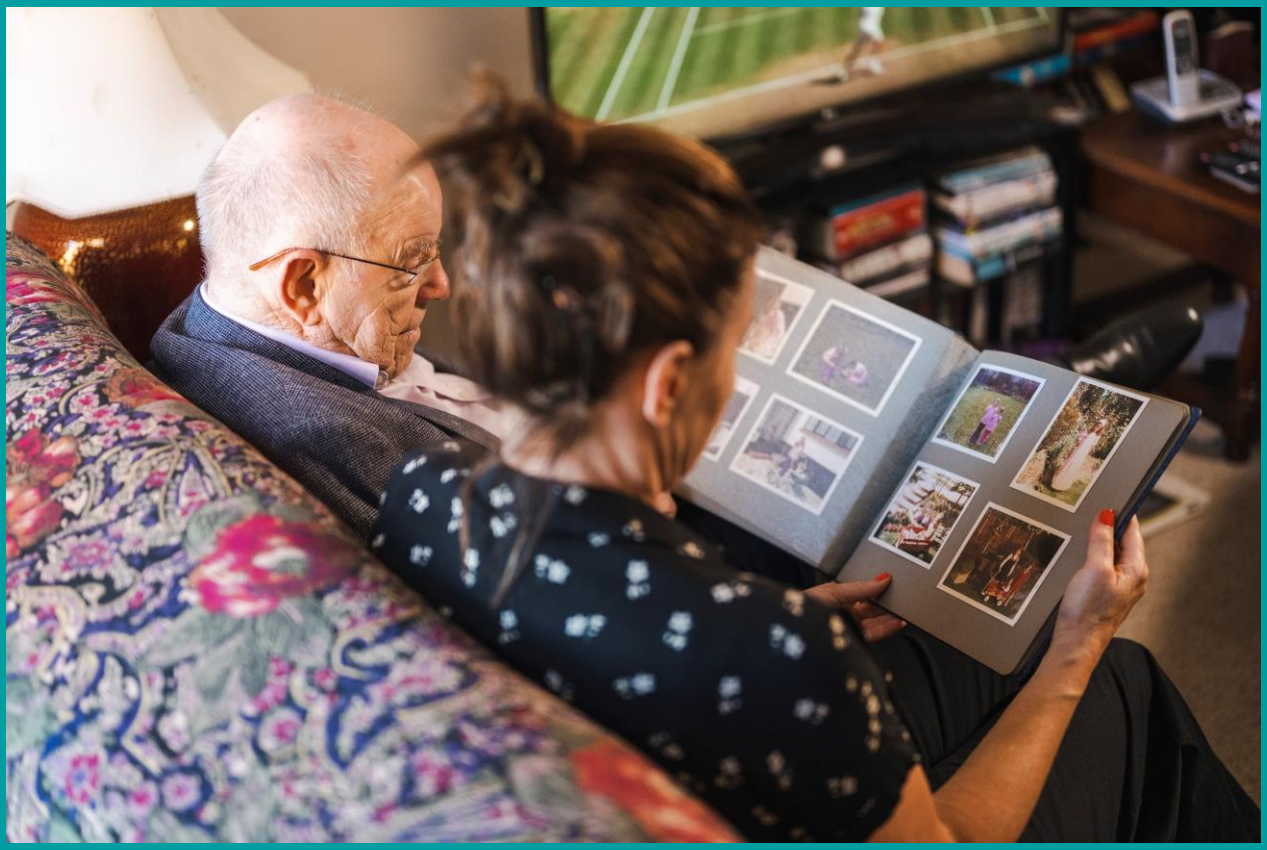
Continuous, integrated care provided by a multidisciplinary team is needed to help achieve good palliative care for people with dementia.[27] As identified in a review of equality in hospice care by Hospice UK, exemplar initiatives involved dementia expertise and integrated primary and community care.[28]

Given the rising proportion of people living with dementia, there is urgent need for system strengthening across health and social care. Greater **integrated working** and a **dementia policy focus** is needed to further support innovative practice and shared learning. Therefore, any attempt to address palliative care needs must include people with dementia.

> *"I was trying to keep him at home, and I'd spoken to the doctor to see could we get some palliative care for him, he sort of poo-pooed it and brushed it off..."*
>
> – BEREAVED CAREGIVER[1]

Recommendations

- Dementia Care Pathway to include access to an integrated palliative care approach, at any stage of dementia.
- Integrated Care Boards to consider dementia in fulfilling their legal duty to respond to palliative and end-of-life care needs of the local population.



CALL 3: Optimise investment in integrated end-of-life care closer to home

Access to timely and responsive clinical care is variable for people affected by dementia.

Most people with dementia want to die in a care home or their own home.[16] Currently, 58% of people with dementia die in care homes.[30]

It is essential that integrated primary and community care receives the investment needed to ensure high-quality end-of-life care is available closer to home.

OVER A THIRD OF PEOPLE WITH DEMENTIA LIVE IN A CARE HOME[29]

MOST PEOPLE WITH DEMENTIA WANT TO DIE IN A CARE HOME OR AT HOME[15]

Care homes are an essential setting for palliative and end-of-life care...

Care home residence among people with dementia may improve the quality of end-of-life care and reduce secondary care use and associated costs.

In an England-wide study of 388,899 decedents with dementia, findings showed that living in areas with greater number of care home beds was associated with **lower likelihood of hospital death.**[23]

A systematic review showed high-strength evidence that care home residence is associated with **lower likelihood of attending the emergency department** among people with dementia approaching the end of life.[24]

Furthermore, a study using routine data from a London mental health provider looked at early and late hospital transitions among 8,880 people with dementia (early: multiple admissions in the last three months of life; late: any admission in the last three days). It found that living in a care home was associated with **fewer early and late hospital transitions**.[31]

Health economic analyses show that care home costs can substitute hospital and informal care costs in people with dementia. A study of formal and informal care costs in the last three months of life among 146 decedents found that care home residents with dementia had **lower total costs** compared to people at home, **even considering the cost of the care home.**[19]

> *"There was a lot of things that we couldn't do without district nurse input. So, I think, like, administering end-of-life drugs and things like that. We have a lot of input from the community matrons, which was so helpful to us."*
>
> – RESIDENTIAL HOME STAFF[32]

...but rely on strong cross-sector collaboration.

Palliative and end-of-life care in the care home setting is determined by several factors, including **consistent and sufficient staffing and competency**.[33] For residents with dementia, it also requires staff to build **close care relationships** to help recognise and respond to individual palliative care needs.[34] Fundamentally, it relies on **strong interdisciplinary working.**[34]

A qualitative interview study showed that caregivers viewed transfers of care home residents to the emergency department partly because of **limited staff knowledge** and **access to timely and responsive clinical care**.[1]

> *"The nursing home obviously they had nurses on staff so therefore they can deal with medical issues provided the visiting GPs, visiting doctors were happy with the nursing that was going on there. But you don't in residential care."*
>
> – BEREAVED CAREGIVER[1]

A national survey of care home staff, followed by qualitative interviews, found that **relationship-centred care** was essential to providing high-quality palliative and end-of-life care in care homes.[32] Fundamental to maintaining this was:

- Integration with external healthcare systems
- Digital inclusion
- A supported workforce[32]

The critical need for **integrated primary and community care** reiterates the need to optimise its investment to ensure high-quality care is available and accessible closer to home.

Continuity is key to improving quality end-of-life care.

In a nationwide study of dementia decedents, living in an area with **more nursing home beds** was associated with fewer emergency department visits in the last year of life. No association was found with residential home beds.[17] This suggests that **readily accessible clinically trained staff, who know the individual** with dementia, can help to reduce unnecessary hospitalisations towards the end of life.

Nationally representative data on 33,714 decedents with dementia showed that better **continuity of primary care** was associated with a lower risk of multiple hospital admissions. This was particularly relevant for those with multiple long-term conditions.[35]

This evidence suggests that **continuity of care** and **timely and responsive access to clinical expertise** are key components of quality palliative and end-of-life care for people with dementia, which must be **equitably accessible** whether the person lives in a care home or their own home. This relies on a **strong cross-sector, assets-based, coordinated approach.**

> *"Agency staff were employed, though these rarely turned up. This all impacted end-of-life care—the ability to closely monitor residents and react appropriately... The home was using staff who were not familiar with the residents, unlike our own staff who knew their plans for end of life and would respond to palliative concerns."*
>
> – RESIDENTIAL HOME STAFF[32]

Recommendations

- Local integration of primary, community and urgent care services to prioritise equitable access to timely and responsive medical and nursing expertise closer to home.
- Integrated Care Systems to consider joint workforce planning and development to ensure continuity and competency to meet the needs of people with dementia approaching the end of life.

CALL 4: Invest in palliative dementia care research

While individuals continue to be diagnosed with dementia, there will be a need for palliative and end-of-life care. People with dementia have increasingly complex and unpredictable care needs as the condition progresses. End-of-life care can therefore present unique challenges for patients and families, staff, the wider system and society.

Access to high-quality evidence is needed to respond to these challenges and inform clinical, commissioning and policy decisions. Investment in high-quality research is therefore **essential.**

ONE DEMENTIA RESEARCHER FOR EVERY FOUR CANCER RESEARCHERS[36]

IN 2019 DEMENTIA RECEIVED

5X LESS FUNDING THAN CANCER RESEARCH[2]

Reducing inequalities and inequities in palliative and end-of-life care among people with dementia is critical.

> *"There is a saying that middle class people do much better out of the NHS than working class people."*
>
> – CURRENT CAREGIVER[1]

Everyone has the right to high-quality end-of-life care, though evidence indicates there are prevailing inequalities.[37-39] Since reducing inequalities in access and outcomes is the **duty of Integrated Care Boards,**[40] and fair access to palliative and end-of-life care is a key ambition of the **national framework** for local action,[41] there is urgent need to invest in research to better **identify and address these inequalities**.

Palliative and end-of-life care inequalities have been related to a wide variety of factors including differences in ethnicity, socioeconomic position, diagnosis and geographical location.[39] Among people with dementia, observations are similar and likely to be influenced, in part, by prognostic uncertainty. As presented earlier, hospitalisations are fewer among people with higher **socioeconomic position**,[17, 31] greater among those of minority ethnicity, specifically **South Asian** ethnicity,[17] and with unwanted **geographical variation** across different areas of the country.[17]

How these factors intersect is unclear, though interest in exploring and understanding the influence of **intersectionality** in palliative and end-of-life care research is growing.[42] This must include people affected by dementia to reduce unjust variations in access and outcome and **achieve truly personalised care**. This will require more comprehensive routine data collection and innovative methods of analysis.

Expansion of routinely collected data is urgently needed to monitor and improve the quality of end-of-life care.

> *" I am very hopeful that your research will lead to improvements for people, because, God, they're desperately needed."*
>
> – BEREAVED CAREGIVER[1]

There is huge potential in using **routinely collected data** to improve care for people with life-limiting conditions and their families, with minimal data collection burden.[43] However, the **data is limited**. Palliative care and voluntary services are not routinely monitored, and health and social care data are not integrated.

Robust **quality indicators used in routine data are vital** to improve quality of care.[44] However, a systematic review found that out of 976 quality indicators for end-of-life care for older people and people with dementia, just under one third (32%) were robust and less than a quarter (23%) were measurable using routinely collected data.[44] This is a **missed opportunity.**

Investment in end-of-life dementia research and innovation is essential to facilitate effective, equitable and cost-efficient practice.

It is recognised that palliative and end-of-life care for people with dementia demands a **shift from reactive care** based on uncertain prognosis**, to responsive care based on need.**[45]

The **EMBED Care programme** aims to promote this "step change" to enable delivery of timely person-centred care, identify unmet needs and improve outcomes towards the end of life for people affected by dementia.[45]

As part of this programme, a systematic review found that use of **patient-reported outcome measures** enable shared decision-making, by facilitating collaborative working between families and practitioners.[46] Ways to incorporate the measurement of outcomes into an eHealth intervention are being explored, with recommendations for implementation.[47] This will prioritise what each individual values most to ensure the **right services** are available in the **right place** at the **right time**.[45]

We must **bolster research innovation** with more funding to drive forward this step change in improving end-of-life care for people with dementia, and in doing so, increase system-wide efficiencies.

> *"You are listening to people with dementia… you are taking the time to listen; they should do exactly the same. May be on a bigger scale, but they need to put funding in place so that people like you and the people that do this research are asked what your opinions are because you talk to the people at the chalk face. They need to start listening."*
>
> – PERSON WITH DEMENTIA[1]

"People with dementia in the driving seat of research".[48]

There is strong appetite to involve people affected by dementia in research.[48] Efforts to facilitate this include the development of the Dementia Enquirers Gold Standards for Co-Research and Ethical Research,[49, 50] and evidence-informed guidelines to involve people with impaired capacity nearing the end of life.[51] Investment must support the **involvement of people affected by dementia** to ensure evidence-based care reflects what is most important to them.

Recommendations

- National data providers to expand routine data collection to include palliative and end-of-life care outcomes that are meaningful to people with dementia, to monitor quality and address inequalities.
- Government to commit to additional funding for research and innovation to improve quality end-of-life care and reduce inequalities among people with dementia.

Next steps

People affected by dementia have a right to be heard. Evidence shows us that this right is not always upheld – in clinical practice, in health and social care strategic priorities, or in wider society.

Our evidence-based recommendations aim to counter this and help to ensure people with dementia who are approaching the end of their lives receive the support and respect they deserve.

Next steps towards better palliative and end-of-life care for people affected by dementia will rely on **greater investment, strong leadership,** and **strong collaboration** between people affected by dementia, researchers, clinicians, commissioners and Government.

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