Spring 2026

CS|NEWS

news from cicely saunders international

Cicely Saunders International
Better care at the end of life

It's very much part of our philosophy that the patient and family are one unit. We want to help the group as a whole, because it's the family who has to live on afterwards.

Dame Cicely Saunders

Welcome to our spring newsletter.

The debate around the Terminally Ill Adults (End of Life) Bill has raised strong and passionate feelings on both sides of the argument. Whatever the outcome, one fact is undeniable. It has shone a bright light on the substantial deficiencies in the later life/end-of-life care for the many people whose ailments and diseases cause them and their families great discomfort and distress. Why in this modern age can this be allowed?

In September 1963, Dame Cicely Saunders wrote *"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."*

There are many in the broad medical community trying to live this pledge, which should be everyone's right. But the resources being allocated to enable a universal palliative care system are visibly and alarmingly lacking. Even our hospices, which play such a vital role in this area are having to reduce beds and lay off staff because of insufficient funding. And they primarily support end-of-life care and not the wider community need for effective and stress relieving later life care.

The Government has committed to ensuring every person has access to high quality palliative care and end-of-life care through delivery of a Modern Service Framework. But it has made no commitments on the resources that will be necessary to achieve this promise. We must harness the momentum for change that has been stimulated by the Terminally Ill Adults Bill to press Government and all the relevant agencies to work together to deliver the resources and system that will ensure the right palliative and end-of-life care for all who need it as a matter of social urgency. That is what Dame Cicely expected of us.

Gareth Williams
Trustee

PARLIAMENT NEWS:

The future of palliative care

MPs warn palliative care system is ‘unsustainable’ as demand set to surge.

MPs from across the political spectrum have warned that palliative and end-of-life care in England is failing patients and families, during a Commons debate on 5 March 2026. The debate, led by Labour MP Rachael Maskell, drew on findings from the Independent Palliative Care Commission and exposed widespread agreement that current provision is unequal, underfunded and ill-prepared for rising demand.

More than 100,000 people who needed specialist palliative care last year received none, MPs were told. Access varies sharply across Integrated Care Boards, with hospice funding ranging from just 23p to £10.33 per person. Many areas continue to lack consistent out-of-hours or round-the-clock support.

Demand for palliative care is expected to rise by 42 per cent over the next decade, driven by an ageing population and increasingly complex health needs. Nearly half of patients attend A&E in their final three months of life, often due to crises that MPs said could be avoided with better community care.

The debate also highlighted the sector’s reliance on charitable fundraising, with hospices typically receiving only 20–30 per cent core NHS funding, alongside mounting workforce shortages.

Responding for the Government, ministers pledged to publish a Modern Service Framework later in 2026 and confirmed new funding for adult and children’s hospices, while acknowledging ongoing challenges around staffing, commissioning and long-term sustainability.

You can read the debate in full in Hansard on the UK Parliament website: **http://bit.ly/4ccarKT**

Should Assisted Dying be considered a ‘treatment’?

New research from the Cicely Saunders Institute and colleagues at King’s College London asks whether Assisted Dying, whereby an individual is helped by a medical professional to end their own life, should be considered a ‘treatment’.

The research, published in the *International Journal of Law and Psychiatry*, highlights how, if Assisted Dying is classified as a treatment, complex ethical and legal implications arise for the UK Government’s role over patient health.

The UK Parliament is currently debating the Terminally Ill Adults (End of Life) Bill with a view to putting forward legislation about Assisted Dying. The Bill is silent about whether AD is a treatment. Researchers in this study wanted to analyse how the Assisted Dying decision has been characterised in other jurisdictions where it has been legalised or is making progress in parliaments.

Having looked at the evidence from 30 jurisdictions in the world where Assisted Dying laws are in place, the researchers advocated framing Assisted Dying as a choice to end one’s own life, and not as a treatment decision.

“If Parliament does not make clear that the provision of a lethal substance is not a treatment, the parameters of care for all terminally ill people – irrespective of whether they might wish its provision – will be irrecoverably changed.”
Alex Ruck Keene KC, Professor of Practice, The Dickson Poon School of Law at King’s College London

“Psychiatrists have roles in Assisted Dying laws to assess mental capacity. In the UK, they will need to be clear about ‘what’ they are assessing mental capacity for. A treatment decision is not the same thing as a decision to end one’s own life.”
Professor Gareth Owen, Professor of Psychological Medicine, Ethics and Law at King’s College London

“The question of whether Assisted Dying is considered a treatment may appear to be of only academic interest, but it has profound real-world implications. Ambiguity on this question in the Terminally Ill Adults Bill introduces potential risks for both the patients who might consider assisted death, and the professionals who care for them. Parliamentarians must address this question.”
Katherine Sleeman, Professor of Palliative Care at King’s College London

Gareth S Owen, Maria Koniarz, Alex Ruck Keene
Is assisted dying a treatment?
International Journal of Law and Psychiatry
DOI10.1016/j.ijlp.2026.102196

Almost one in three people in England die without the basic care they need

This is the first major study in over a decade to estimate unmet palliative care need among people at the end of life.

Findings show that almost one in three people each year die with unaddressed symptoms and concerns, in pain or distress and with little or no access to GP support, despite evidence that the right care would help them. Without action to improve care, the situation will get worse; unmet palliative care need is expected to rise by 21 per cent over the next 25 years. This means that by 2050, over 212,000 people each year in England could die without the care they need.

The UK government has committed to publishing a Palliative and End of Life Care Modern Service Framework in 2026. But in the meantime people are continuing to live without the support they need at the end of their life. Jo from Leicestershire struggled to secure night care for her husband when he was terminally ill: *"It was constant phone calls, just trying to get things sorted for my husband. I was desperate for some night-time support, scared, exhausted and completely drained, knowing I still had to care for him the next day. He wanted to die at home and I fought for that. But fighting to make it happen safely, all the time, was utterly exhausting."*

Professor Fliss Murtagh, Professor of Palliative Care at Hull York Medical School, Director of the Wolfson Palliative Care Research Centre said: *"These findings are a stark warning that our systems are not meeting the needs of a growing older population as they reach the end of their lives. What we see from the evidence is not just gaps in care but system-wide limitations that repeatedly fail people in their final months."*

Matthew Reed, Chief Executive of Marie Curie, said: *"The evidence is clear. Hundreds of thousands of people are reaching the end of their lives without basic palliative care, causing pain and distress that is totally avoidable – and the situation is getting worse. The Modern Service Framework is a critical opportunity to fix this, but only if it delivers guaranteed 24/7 palliative care in every community, backed by proper funding."*

Bone AE, Diggle M, Johansson T et al.
Coproducing a conceptual understanding of unmet palliative care needs: stakeholder workshops using modified nominal group technique
BMC Palliat Care 25, 30 (2026)

NEWS:

Specialist palliative care can save the NHS up to £8,000 per person and improves quality of life

A new study published in March by researchers at the National Institute for Health and Research (NIHR) Policy Research Unit in Palliative and End of Life Care, considered two modes of care: for those living at home and for those in acute hospital settings.

By combining the best available evidence from other research and government statistics, researchers estimated the cost savings from reducing unplanned hospital care. Quality of life was measured by assessing five dimensions of patient health: mobility, self-care, usual activities, pain and anxiety or depression.

Specialist palliative care refers to care for those with more complex needs at the end of their life whose care cannot be delivered by a primary or core healthcare team. It requires a workforce with specialist skills who are experienced in delivering palliative care as their main role.

In 2022 in England, specialist palliative care supported over 20,000 people to die outside of hospital which saved approximately 1.5m hospital bed days and reduced healthcare expenditures by £817m.

Many people are missing out on receiving quality palliative care – if any at all – and there are growing needs for increased palliative care from hospices, community teams and in hospitals. This new study shows the value and cost-effectiveness of specialist palliative care at helping to solve key system problems in the NHS.

Peter May, Senior Lecturer in Health Economics at King's College London and lead author on the paper said: *"Previous studies showed that specialist palliative care supports people with serious illness to be at home. This is the first study to estimate the economic impact for England. About half of people who might benefit from specialist palliative care receive it, and this is highly cost-effective for both patients and the NHS. We must now turn our attention to understanding how and why people who might benefit do not yet receive palliative care."*

Professor Fliss Murtagh at Hull York Medical School, University of Hull said: *"Many people may be reluctant to ask for palliative care, believing that it might accelerate their decline or impose additional pressure on the health service. The reverse is true. This study shows good quality care in appropriate settings can improve their quality of life, lessen symptoms and other concerns, and reduce NHS pressures – everyone with serious medical illness should be asking for it."*

May P, Nikram E, Murtagh FEM.
Specialist palliative care improves patient experience, reduces bed days and saves money: An economic modelling study of home- and hospital-based care
Palliative Medicine
Published online 4 March 2026. doi 10.1177/0269216326142375

NEWS:

For people with dementia seeing the same GP can save the NHS money

Better continuity of care with GPs for people with dementia who are in their final year of life can save the NHS money, according to research from academics at the Cicely Saunders Institute.

The study, published in the British Journal of General Practice, used data from adults with a diagnosis of dementia who died in England between 2009 and 2018. Researchers found that people with better continuity of care with their GP cost the NHS less in their last 12 months of life than those with worse continuity of care.

Results from this large population-based cohort study suggest that increasing the level of continuity of care could result in an average total cost reduction of between £1,319 and £2,875 per person in the last 12 months of life.

When people with dementia receive better continuity of care from their GP, this reduces both GP practice costs and hospital costs due to fewer unplanned hospital admissions. Most people with dementia and their families prefer to avoid hospital admissions if possible, so, improving the continuity of primary care can both improve individual care and lower costs for the system overall.

The paper recommends that people with dementia who are in the last year of their life are prioritised to have appointments with the same GP. This approach could reduce unnecessary hospital admissions and costs by improving communication, identifying patients' needs and ensuring a more person-centred approach to dementia end-of-life care.

In the context of the NHS's recent 10-year plan, the cost of implementing this recommendation might not be significant, as higher continuity of care was associated with lower GP practice costs. The 10-year plan proposes a shift in focus from sickness to prevention; the benefit for dementia patients approaching the end of their life of seeing the same doctor is that subtle changes in their condition are much more noticeable.

Professor Katherine Sleeman said *"Unplanned hospital admissions are very common for people with dementia in their last months of life, and most people with dementia and their families would prefer to avoid hospital admission if possible. Improving continuity of primary care – seeing the same GP each time it's needed – has potential to improve care for people with dementia near the end of life and reduce overall costs for the NHS through reducing acute hospital use. These data add to the literature demonstrating the benefits of primary care continuity for both patients and the wider healthcare system."*

Leniz J, May P, Gulliford M, Sleeman KE.
Continuity of primary care and end-of-life care costs in dementia: a retrospective cohort study
Br J Gen Pract. 2026 Jan 12:BJGP.2025.0218. doi: 10.3399/BJGP.2025.0218. Epub ahead of print. PMID: 41136237.

NEWS:

COPD and the importance of social connection

People living with chronic obstructive pulmonary disease (COPD) often face social isolation and loneliness. These have a major impact on health and wellbeing, yet they are often overlooked in respiratory care.

Researchers based at the Cicely Saunders Institute explored how social connection affects the lives of people with COPD, and how it influences their health and daily functioning. They interviewed 19 people living with COPD, aged between 58 and 88 years, most of whom had severe breathing difficulties. Using a detailed analysis of these interviews, they identified three key themes.

Social connection plays an important role in managing COPD. Feeling connected gave them motivation and emotional strength.

Breathlessness and fatigue limited people's ability to leave home or take part in activities. This led to frustration, anxiety, and embarrassment. At the same time, a lack of public understanding about COPD made people feel judged or misunderstood, further increasing withdrawal from social life.

Loneliness often made symptoms feel worse, creating a cycle that was difficult to break.

Supporting people with COPD to stay socially connected should be a key part of care. Taking a whole-person, biopsychosocial approach may improve not only social wellbeing, but also physical and mental health outcomes.

Brighton LJ, Bristowe K, Evans C, Farquhar M, Man WD, Ogden M, Phillips A, Maddocks M, Chilcot J.
Social connection and living with severe chronic obstructive pulmonary disease: A qualitative analysis
J Health Psychol. 2026 Jan. 25:13591053251412948.
doi: 10.1177/13591053251412948.
Epub ahead of print. PMID: 41581205.

NEWS:

Financial stress affects pain at the end of life

A national study of people who died in England and Wales found that individuals in poorer financial circumstances were more likely to experience severe or overwhelming pain in their final week of life.

Whether the patient had access to care or not did not affect this association. But there was evidence that place of care (care setting) may influence this association.

The findings emphasise the need for continued improvement in palliative and end of life care.

Healthcare staff may benefit from additional training and support to hold sensitive conversations about financial concerns. Recognising and addressing financial stress as part of a holistic assessment can help ensure care meets each patient's wider needs.

Further research is needed to understand how socioeconomic factors, healthcare access, care setting, and pain management interact. This will support the development of more effective and equitable palliative care services.

Correa-Morales JE, Johansson T, Curtis T, Murtagh FEM, Davies JM, Sleeman KE.
Financial status and pain in the last week of life: Insights from a nationally representative mortality follow-back survey in England and Wales
J Pain. 2025 Dec 19;40:105642. doi: 10.1016/j.jpain.2025.105642. Online ahead of print. PMID: 41422847.

Palliative Care for children: 'We are running on the fumes of goodwill'

Researchers at the Cicely Saunders Institute and Hull-York Medical School and Leeds NHS Trust have published the results of a study of healthcare professionals views about palliative care services for children. Although end-of-life care for children has improved in recent years, there are still major inequalities in how 24/7 care is funded and provided. As a result, many families do not get the support they need.

This study explored the views of healthcare professionals who provide 24/7 paediatric palliative care and what they would want from a new service.

A total of 53 professionals took part, including doctors, nurses, managers, and allied health staff. Three main themes emerged. First, professionals were working in a fragmented system with poor coordination between services, making it difficult to provide consistent 24/7 care. Second, families often had limited choice about where and how care was delivered, mainly because community nursing and specialist support were unevenly available. Third, professionals paid a personal cost for making the system work, often going beyond their roles, feeling underprepared, and sacrificing their own wellbeing. Overall, healthcare professionals worked hard to deliver care in families' preferred settings, but their efforts were restricted by gaps in local services. Many relied on personal commitment and goodwill to cover system failures, which placed emotional and physical strain on them.

The study concludes that providing 24/7 end-of-life care in such an unequal system is not sustainable. It causes moral distress for professionals and hides deeper problems in how services are organised. To fix this, healthcare organisations need to work together to create fairer, better-coordinated services that do not rely on staff overextending themselves.

Barrett L, Fraser L, Ziegler L, Jarvis S, Picton S, Hackett J.
'We are running on the fumes of goodwill' Professionals' experiences of delivering 24/7 end-of-life care to children and their families: a qualitative study
BMC Palliat Care. 2025 Dec 3;25(1):9. doi: 10.1186/s12904-025-01958-1. PMID: 41339868.

NEWS:

Ethnic inequality in place of death

Most people prefer not to die in hospital, yet it remains the most common place of death in England and Wales. Previous research shows that people from ethnic minority backgrounds are less likely to access specialist palliative care and more likely to use emergency hospital services at the end of life. However, it has been hard to study ethnic differences in where people die because ethnicity is not usually recorded on death certificates.

This study used high-quality self-reported ethnicity data from the national Census, linked to death records for a one per cent sample of the population who died between 2011 and 2017. Researchers looked at whether people died in hospital compared to other places (home, hospice, or care home) and explored whether differences were explained by age, location, social factors, or cause of death.

The study included 34,230 people. The rate of death in hospital was about 48 per cent higher for Bangladeshi men and was also higher for Pakistani and Indian men and women.

The findings show clear ethnic inequalities in place of death that have not previously been described for England. This raises important questions about whether these differences reflect inequities in access to care, or differences in needs or preferences. Improving the quality of ethnicity data in health records and understanding the experiences and needs of ethnic minority communities are key steps toward fairer end-of-life care.

Davies JM, Chua KC, Maddocks M, Murtagh FEM, Sleeman KE.
Ethnic inequality in place of death: Analysis using 'gold standard' self-reported ethnicity data from the Census Longitudinal Study
Palliat Med. 2025 Dec 4:2692163251395455. doi: 10.1177/02692163251395455. Online ahead of print.
PMID: 41342480. No abstract available.

CONGRATULATIONS:

Professor Julia Verne MBE

Professor Julia Verne, Visiting Professor of Public Health at the Cicely Saunders Institute (CSI), has been awarded an MBE for Services to End of Life Care and Public Health.

Professor Verne strongly advocates for a holistic approach to caring for people at the end of life. She has collaborated with colleagues at the Cicely Saunders Institute for over 10 years, drawing on her expertise as a consultant in Public Health Medicine and previous national roles, including clinical lead for the National End of Life Care National Intelligence Network and the Department for Health and Social Care's Clinical Epidemiology lead.

Professor Verne has a special interest in end-of-life care for people dying from liver disease and has collaborated with liver disease experts at the Roger Williams Institute of Liver Studies at King's and King's College Hospital. She shares her wealth of expertise teaching on the MSc in Palliative Care at King's College London.

In 2025 Professor Verne started voluntary work as an Honorary Assistant Chaplain at King's College Hospital where she offers comfort and support to patients and families of faith and no faith as they face often significant worries and fear related to their health and wellbeing.

TRIBUTE:

Kay Glendinning MBE, 1935–2025

In December we were sad to learn of the death of Kay Glendinning MBE, former trustee of Cicely Saunders International. Kay was the great niece of Herbert E Dunhill, founder of the Dunhill Medical Trust (now The Vivensa Foundation) and had over 30 years experience as a Trustee, Administrator and Director at Dunhill.

Kay joined Cicely Saunders International as a Trustee in 2020 bringing a wealth of experience from her other charitable involvements, and a keen interest in the sustainability of health and care services and interest in palliative care for older people and other disadvantaged groups.

She served as a Governor, Director, Trustee, Chairman and non-Executive Director of a wide range of trusts, hospitals and research institutes – including serving as a Governor of Guy's Hospital, member of the Council at King Edward VII Hospital in Midhurst, a Non-Executive Director of the Portsmouth Hospital NHS Trust, a Director of Northwick Park Institute for Medical Research and a Trustee of Breakthrough (Breast Cancer) Research Charity.

She was an Honorary Fellow of University College, Oxford and served as an Honorary Fellow of both UMDS Guy's & St Thomas' Hospital and the RMPS Hammersmith Hospital. She was a founder trustee of St Wilfrid's Hospice in Chichester and its patron.

Professor Irene Higginson, Scientific Director of Cicely Saunders International said: *"Kay was such a force in transforming health and care, and such an advocate for improving care through research and supporting new ideas, innovation, evidence, as well as capacity building, and services.*

It was a privilege to know her and benefit from her wisdom, and work with her on many significant initiatives at CSI, Guys and beyond, which have benefited care, treatment and services for older people and in palliative care."

NEWS:

One in three people are missing out on benefits during the last year of their lives

For the first time, the ONS has published data showing whether people with chronic illnesses are receiving all the benefits they are entitled to during their final year of life.

The new data shows that 34 per cent of people who died from a chronic illness did not claim the non-means tested disability benefits they were entitled to under the 'Special Rules for End of Life'.

"Having a terminal illness puts pressure on household finances – benefits go some way to alleviate that – but one in three people are missing out on the non-means tested support available to them, worth between £110 and £187 each week. Not everyone will need financial support, but in the most deprived areas, after we adjusted for other factors, 34 per cent of people did not claim the benefits they were entitled to. This suggests that lack of need for support is not the only factor driving the take-up deficit."
Dr Joanna Davies, Research Fellow
from the Cicely Saunders Institute

The research reveals wide variation in take-up by condition which was lowest for HIV (41 per cent), liver disease (42 per cent) and heart failure (54 per cent), and highest for dementia (85 per cent) and neurological conditions (90 per cent).

Take-up rates also varied between local authorities, with the lowest take up in Wokingham (53 per cent) and the highest in Merthyr Tydfil (78 per cent). When other factors are accounted for, the analysis shows that 34 per cent of people in the most deprived areas are not claiming the benefits they are entitled to.

Healthcare professionals provide access to these benefits under 'The Special Rule for End of Life' by completing an SR1 form. Dr Davies explains that they *"do a fantastic job speaking to their patients about finances and providing this support. However, we need to raise awareness of this support and think about how the completion of SR1 forms could be incorporated into existing processes such as digital advance care planning or palliative care registers.*

"The DWP are clear that 'There are no negative consequences for the clinician or patient if a patient who claims under the Special Rules lives longer than expected' – this is an important message because we know that some healthcare professionals worry about this.

"Our recent review of take-up initiatives for severely disabled people and those with serious, life-limiting illness found a real lack of proactive take-up work among stretched Local Authorities and voluntary and community groups. Proactive initiatives could improve take-up and should focus on the diagnosis groups and geographical areas with the lowest levels of take-up indicated in our study."

This analysis was completed as part of a wider project on benefit take-up towards the end of life led by King's College London and funded by end of life charity Marie Curie. The full report will be released later in April.

GLOBAL NEWS:

Improving home-based palliative care in India

People living with advanced cancer often experience a wide range of physical, emotional, and practical challenges, especially when receiving care at home. This study explored whether a Hindi version of a short questionnaire, called the Integrated Palliative Care Outcome Scale (IPOS), can help patients clearly share how they are feeling and what support they need.

Researchers worked with people receiving home-based palliative care in India and asked them to complete the questionnaire. The results showed that patients found the questions easy to understand and relevant to their experiences. The tool reliably captured important issues such as pain, discomfort, anxiety, and communication concerns.

By using this Hindi version of IPOS, healthcare teams can better understand patients' needs, respond more quickly to problems, and improve the quality of care. This research supports the use of patient voices to guide compassionate, person-centred palliative care in diverse communities.

Bhardwaj T, Chambers RL, Watson H, Rajvanshi A, Sharma R, et al. (2026)
Evaluating the measurement properties of the Hindi Integrated Palliative Care Outcome Scale (IPOS) in advanced cancer patients receiving home-based palliative care in India
PLOS Global Public Health 6(4): e0006189. https://doi.org/10.1371/journal.pgph.0006189

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