Summer 2026

CSINEWS

news from cicely saunders international

Cicely Saunders International
Better care at the end of life

You matter because you are you. You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also to live until you die.

Dame Cicely Saunders

Welcome to the summer edition of CSI News.

In 2023, Professor Harvey Chochinov delivered our Annual Lecture, *Intensive Caring: Reminding Patients They Matter*. He highlighted the Patient Dignity Question: "What do I need to know about you as a person to give you the best care possible?" The answer can be recorded alongside a patient's priorities, preferences, and key information to guide their care.

The challenge has always been where this information should be stored, who can access it, and how it can be shared across the many organisations involved in a person's care. For years, patients have complained about repeatedly telling their story and the resulting lack of continuity – particularly in palliative care, where support often comes from GPs, hospitals, hospices, community, social care, and voluntary services.

This may soon change. Legislation before Parliament proposes a digital Single Patient Record (SPR) as part of the NHS Ten-Year Plan. We have argued that the patient should determine who should have access to their SPR and the government should be a data processor on behalf of the patient and not the data controller (Times Letters 8 June, 2026). After more than 20 years of attempts, success will depend on patients retaining control over who can access their information. If achieved, the SPR could improve continuity, dignity, and person-centred care in the way Professor Chochinov envisaged.

Thank you for your support.

Professor Sir Cyril Chantler
Trustee

The Terminally Ill Adults (End of Life) Bill

The Terminally Ill Adults (End of Life) Bill ran out of parliamentary time at the House of Lords committee stage in the House of Lords in April 2026. The 2024–26 session of Parliament has prorogued and the Bill will make no further progress this session.

Supporters of the failed Bill have committed to re-introducing it as a Private Member's Bill in the new session of Parliament, and using the Parliament Act to ensure its passage through the Lords.

Professor Katherine Sleeman and colleagues from the Complex Life and Death Decisions research group at King's College London have written an article for *The House Magazine* arguing that the failure of the Terminally Ill Adults Bill demonstrates the inadequacy of using a Private Members bill for a change of such consequence.

"A Private Members Bill is not appropriate for legislation with significant, systemic impact… Campaigners have every right to seek to put matters on the agenda; they do not, however, have responsibility for, nor expertise in, making law".

The authors argue that further examination of the issue in Parliament requires a clear boundary between the role of campaigner and that of the legislator. They urge the House of Commons not to reintroduce the Bill as a Private Member's Bill but to consider alternative ways forward. This could include an independent review, drawing on work in Jersey and the Nuffield Trust Report in August 2025 to envisage how assisted dying might work in practice, outside of the NHS, not in conflict with palliative care and suicide prevention, as part of an informed national debate, considering safeguards, commission and delivery.

The new UK Prime Minister Andy Burnham has publicly said assisted dying should not be considered in England and Wales until palliative and social care funding is improved. Burnham said people must first have confidence in receiving proper end-of-life care. Although the Government is expected to remain neutral, his comments indicate he will not support the return of the proposed Bill.

www.politicshome.com/opinion/article/big-changes-need-made-assisted-dying-legislation-success-next-time

UK government publishes interim Modern Service Framework for palliative care

The UK Government has published an interim Modern Service Framework for palliative care. This sets out a vision for improving palliative and end of life care, so that people receive high-quality, consistent care when they need it.

At the moment access to palliative and end of life care is not consistent. People's experiences often depend on where they live, who they are, and why they are ill.

Hospices are a vital part of this care system, supporting thousands of people every year alongside NHS services. But rising demand, increasing costs and a broken funding model mean many hospices are facing difficult decisions about the services they can provide. Palliative care capacity within the NHS is limited too and not sufficient to meet the increasing need for palliative care.

Responding to the latest developments Professor Katherine Sleeman at the Cicely Saunders Institute said: *"The need to improve palliative and end-of-life care has never been more urgent. Our research shows that one in three people die with avoidable suffering. At the same time, stark inequalities in access and outcomes persist, while demographic change means demand for palliative care will grow substantially in the years ahead. The interim update on the Modern Service Framework is therefore a very positive step, particularly its emphasis on evidence, outcome measurement, and reducing inequalities. If we are to ensure that everyone receives high-quality care tailored to what matters most to them, these priorities must remain at the heart of the final Framework."*

Building capacity in palliative care

The BuildPall programme is a five-year capacity building programme funded by Cicely Saunders International. As the programme enters its final phase we reflect on its beginnings and how it has grown to date.

Between 2021 and 2040, palliative care needs are forecast to increase by 42 per cent. Current ways of providing palliative care need to change to meet this demand: building research and capacity are essential. In 2021, Cicely Saunders International provided funds from a generous private donor to start a five-year programme to do just that.

Led by Professors Richard Harding and Irene Higginson, the programme has identified and is developing future academic and clinical leaders in palliative care, and engaging them in research and evaluation of palliative care challenges.

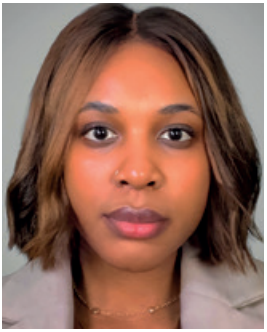
The programme is helping train healthcare professionals to deliver better palliative care across a range of settings, including hospitals, hospices and communities. The aim is to deliver earlier interventions backed by strong evidence.

With further funding from other charities via CS International and funders such as the Dinwoodie Charity, Wellcome Trust, NIHR, Dunhill Medical Trust (now Vivensa) and Dementia Research UK, the programme now supports 12 PhD training fellows working on a broad range of palliative care research, from dementia to breathlessness, frailty, palliative care for young adults, and support for carers. The programme also includes projects in Zimbabwe and Vietnam.

RESEARCH NEWS:

BuildPall fellows

Ruth Tebo joined the Cicely Saunders Institute in October 2024 as a Dunhill Medical Trust-Saunders Fellow. Her PhD focuses on adapting the Breathlessness Support Service into an AI-enabled telehealth prototype, combining a mobile app and clinician portal designed to improve accessibility and equity for adults living with chronic breathlessness.



Ruth trained as a nurse in Cameroon, specialising in geriatrics, and gained experience across community and facility-based care. She moved to the UK to complete an MSc in Computer Science, where she developed skills in software development, data-driven methods, and digital innovation.

Her PhD aims to develop an inclusive, user-centred digital tool that helps people monitor and manage breathlessness at home. Ruth's work integrates co-design with digital profiling, involving patients, carers, and clinicians to ensure the telehealth prototype reflects the realities of home-based breathlessness management. Her approach ensures that digital tools reflect the needs of people who have historically been marginalised or overlooked in technology-driven healthcare.

She has developed the first working prototype of the telehealth system and has begun AI-enabled profiling, applying modelling to identify patterns in A&E use and inform personalised approaches to breathlessness support. She is now preparing for user-testing and co-design phases with people living with breathlessness, carers, and clinicians.

Ruth's supervisors are Dr Sabrina Bajwah, Dr Crina-Daniela Grosan, and Dr Joanna Davies.

Sandra Dyer joined the Cicely Saunders Institute in February 2025 to begin her PhD, funded by the Vivensa Foundation (previously the Dunhill Medical Trust).

Sandra's doctoral research focuses on primary palliative care for older people living with advanced multiple health conditions in socio-economically deprived areas. Her work is deeply rooted in health equity, aiming to address how social determinants impact care for those with palliative care needs.

Sandra has spent most of her NHS career in general practice and community settings, caring for patients with long-term conditions. Sandra has a BSc in Community Nursing, an MSc in Advanced Nursing Practice and has an Independent Prescriber qualification.

Building clinical academic pathways

A core focus for Sandra is developing general practice/primary nursing, as well as advanced nursing roles. She is committed to ensuring the distinct value of nursing is fully recognised and used within healthcare, particularly when navigating complex multiple health conditions and palliative care.

Looking beyond her own PhD, Sandra wants to act as a role model in the field. She is passionate about developing research careers within general practice and primary care nursing, and hopes to support the effort to build clearer, more accessible clinical academic roles for nurses working in these settings.

RESEARCH NEWS:

Improving access to breathlessness support services

Breathlessness is a common and upsetting symptom for people with serious illnesses. It affects daily life, confidence and emotional well-being. Experts like Professor Abe Guz helped doctors understand that breathlessness is not only physical but also emotional, and that care should focus on both.

Research now shows that non-drug treatments, such as breathing exercises, handheld fans, pacing activities and relaxation techniques, can help people feel more in control.

Special Breathlessness Support Services combine medical, psychological and rehabilitation care to improve quality of life. However, access to these services is unequal. Many patients cannot get support because services depend on where they live or local funding. Educational materials can also be hard to understand for people with limited English or lower health literacy.

In an article published in the BMJ in April, palliative care experts Dr Sabrina Bajwah and Dr Natasha Lovell highlighted the results of a survey of Breathlessness Support Services in the UK and Republic of Ireland. The survey collected data on service delivery models, professionals involved, interventions offered, outcome measures used, patient demographics and resources provided to support equitable access to these services.

This national survey is the first to explain how Breathlessness Support Services (BSS) are provided across the UK and Republic of Ireland. The survey found that many services did not collect enough information about the people using them, making it difficult to know if support is fair and equal for everyone. The study shows that more BSS are needed. It also highlights the importance of collecting better information about patients, including their ethnicity, to make sure services are accessible to all patients.

Further recent research at the Cicely Saunders Institute highlights the how long term breathlessness is exacerbated b environmental factors such as poor air quality and other long term health conditions. The researchers suggest that a joined up public health approach is needed. Health services should work with housing and environmental agencies to reduce avoidable causes of breathlessness and improve support for patients.

Bajwah S, Lovell N. **Tow can we deliver equitable, evidence-based breathlessness care for all?** *BMJ Support Palliat Care.* 2026 Apr 17:spcare-2026-006244. doi: 10.1136/spcare-2026-006244. Epub ahead of print. PMID: 41997717.

Van der Linden S, Davies JM, Bajwah S, et al. **Breathlessness Support Services in the UK and Republic of Ireland: a survey** *BMJ Supportive & Palliative Care* 2026;**16:**494-498.

Reilly CC, Higginson IJ, Roach A, Chalder T, Bristowe K. **"Breathlessness stops me doing everything": exploring the impact of chronic breathlessness due to advanced respiratory disease and exacerbating factors – a qualitative study.** ERJ Open Res. 2026 Mar 16;12(2):00660-2025. doi: 10.1183/23120541.00660-2025. PMID: 41846694; PMCID: PMC12991001.

Palliative care in ICUs

Intensive care units (ICUs) are increasingly managing patients with greater clinical complexity and life-limiting conditions. Despite evidence on the effectiveness of palliative care integration models in the ICU setting, the specific characteristics for integration remain poorly articulated and insufficiently understood.

A recent systematic review of the evidence highlighted that early palliative care, integrated alongside active treatment and not just at the end of life, can significantly improve outcomes for both patients and their families.

In this study, published in International Journal of Nursing Studies Advances, the researchers set out to map the key characteristics of palliative care integration models in adult ICUs.

Looking at previous global evidence, the team identified literature from 10,000 sources on the integration of palliative care in ICU, to establish the key characteristics essential for integrating palliative care in ICU.

The characteristics they identified were:

- **Screening criteria:** using structured tools to identify patients who may benefit from early palliative care alongside ongoing treatment.
- **Embedded daily practices:** routines focused on symptom assessment, timely family meetings, and proactive palliative care evaluation of the needs of patients and families.
- **Education and training:** targeted programmes to strengthen ICU clinicians' understanding of palliative care.
- **Specialist palliative care collaboration:** joint rounding, embedded palliative nurse practitioners, and coordinated teamwork between ICU and specialist palliative care teams.

The scoping review can be used by clinicians, healthcare providers and policymakers to inform service development, implementation strategy, standardisation, and policy decisions.

A further study surveyed 105 ICU professionals and 48 palliative care specialists about palliative care in ICUs. Everyone who responded felt that palliative care was part of their normal work. Obstacles to integrating palliative care in the ICU included the availability of resources, leadership support and education.

King Y, May P, Whyte B, Tiernan E, Brady AM. **Key Characteristics of Palliative Care Integration in Intensive Care Units (ICUs): A Scoping Review.** Int J Nurs Stud Adv (2026). **https://doi.org/10.1016/j.ijnsa.2026.100535**

Meddick-Dyson SA, Finch T, Boland JW, Pearson M, Bradshaw A, Murtagh FEM. **Implementing Palliative Care in Intensive Care Units: Assessing Processes Using The Normalisation Process Theory NoMAD Instrument.** Implement Sci Commun (2026). **https://doi.org/10.1186/s43058-026-00945-8**

Global outcomes – New Zealand

On 6 May 2026, Associate Professor Margaret Sandham from Massey University, New Zealand, joined the team at the Cicely Saunders Institute to talk about her research developing culturally-appropriate health outcome measures for Māori people, including those in end-of-life care.

Margaret is a Registered Nurse and Clinical Psychologist, and has partnered with Māori researchers on this project.

The POS is widely used in New Zealand and can assess people's physical and psychological symptoms, as well as emotional, spiritual, information and support needs. The measures are widely used globally. To be useful, outcome measures must be accurate, honest and true to people's values.

The COSMIN standards state that understanding culture is an essential element of content validity. However, how this translates into outcome measure development, has not yet been described.

In New Zealand, much work is ongoing to improve equity for Māori people. Māori models of health and practices around death are different to those in Western culture with a strong focus on spirituality and family as part of health.

Margaret and her team undertook a systematic review to identify what health and wellbeing outcome measures were available to support Māori people. They found seven measures that used a Māori worldview and included Māori concepts. None met the strict COSMIN criteria and there were no outcome measures for end-of-life care.

Following on from this research, Margaret worked alongside Māori researchers Dr Melissa Carey and Dr Tess Moeke-Maxwell who were developing outcome measures for end-of-life care, lending psychometric knowledge to traditional Māori knowledge to develop measures that prioritised Māori health models. The first measure Nuku Manawa Rahi was a compassionate self-assessment tool, and the second was the Te Oro Ngākau Nui (The pathway to illumination and understanding) to support family who had a loved one considering medical assistance in dying.

Both research teams worked with Māori people to develop a tool from what Māori people said they needed. The research team were directed by feedback and developed a self-assessment tool from the domains identified from participant discussions. Both measures use Likert-type scales to open discussions between family and health providers, and are grounded in Māori world views and models of health.

Old wisdom, new technologies

Palliative care supports people living with a wide range of serious illnesses, helping them manage symptoms, stay independent, and improve their quality of life.

Experts say early access to palliative care makes a major difference — for patients, for families, and for carers. Research shows it can reduce emergency hospital admissions, improve emotional and physical wellbeing, and provide more coordinated, compassionate support.

But the sector faces growing pressure. Uneven access to services mean many people still struggle to receive the care they need. Healthcare leaders are now exploring how technology, including artificial intelligence (AI), could help ease the strain. AI tools may assist clinicians by identifying patients who could benefit from palliative care earlier and may cut down on time spent on paperwork.

But specialists stress that the heart of palliative care remains deeply human. Listening to patients' stories, understanding their fears and wishes, and helping them maintain dignity and control are central to good care.

The role of unpaid carers – often family members and friends – is also receiving greater attention. Carers provide vital emotional and practical support but can face significant stress and exhaustion themselves. Campaigners argue that better support, workplace protections, and recognition for carers are urgently needed.

As healthcare systems adapt to growing demand, experts believe the future of palliative care will depend on stronger teamwork, better support for carers, wider use of appropriate technology, with a continued focus on compassionate, person-centred care.

Ramjeawon N, Higginson IJ. **Old Wisdom, New Technologies: Sustaining Palliative Care.** J Palliat Med (2026). **https://doi.org/10.1177/1096621826144247**

Left to right:
Dr M Hocaoglu, Beverley A Manzar
and Kate Garraway.

Celebrating Excellence in Palliative and End-of-Life Care

The Palliative and End-of-Life Care Awards 2026 brought together professionals from health, social care, hospice and community settings to celebrate excellence, compassion and innovation in care.

Dr Mev Hocaoglu represented Cicely Saunders International at the event, where she presented the Workforce Development Award. The award recognises individuals and teams whose commitment to education, training, mentorship and staff development strengthens the quality and consistency of palliative and end-of-life care.

This year's recipients were Beverley A Manzar of Ebury Court Care Home and the End-of-Life Care Education Team at Somerset NHS Foundation Trust. Both were recognised for supporting colleagues, developing inclusive practice and helping patients, residents and families receive compassionate, person-centred care.

"It was a privilege to represent Cicely Saunders International and present an award that recognises the vital contribution of workforce development," said Dr Hocaoglu. *"Dame Cicely Saunders' words, 'You matter because you are you,' were reflected in the dedication of colleagues working to ensure that every person is treated with dignity, compassion and respect."*

Hosted by broadcaster Kate Garraway, the evening offered an important opportunity to celebrate outstanding practice and the skilled, supported workforce on which excellent palliative care depends across services and communities every day.

NEWS:

Public engagement event – Coin Street Neighbourhood Centre

On 13 July 2026, researchers and community partners hosted an afternoon celebrating public engagement in health and care research.

The informal drop-in event, at the Coin Street Neighbourhood Centre, South Bank, was organised by the Better Health & Care Hub in collaboration with the Centre for Translational Medicine, the Inclusive Research and Education Practices (IREP) Project, and King's Engaged Research Network. It invited members of the public to explore inspiring examples of collaboration and engagement.

Cicely Saunders International had a stall at the event focused on breathlessness (hosted by Mevhibe Hocaoglu, with support from Sam Cassidy). Among the presented work at the breathlessness stall, was 'Co-designing a framework to communicate patient-centred outcomes in palliative care: involving patients and the public to reframe understanding' and infographics produced after three workshops.

Mev talked with people about work exploring communication of patient-centred outcomes and patient-reported outcome measures. The work emphasises the critical role patients and members of the public play in communicating science, particularly when it is complex. This work was supported by Cicely Saunders International, and other funders.*

Mev also talked about findings from workshops held in June 2026 with people who live with breathlessness and those who had cared for people living with breathlessness. The purpose of the work was to understand daily challenges of breathlessness; to develop a tool that is easy for patients to complete and relevant to their challenges, and provide clinicians with easy to interpret information.

*Medical Research Foundation, Thomas Deane Trust, The Garfield Weston Foundation, Medical Research Council, National Institute for Health and Care Research, Policy Research Strand, and Applied Research Collaboration, South London, hosted at King's College Hospital NHS Foundation Trust.

RESEARCH NEWS:

Let's talk

Guy's and St Thomas' Hospital has launched two new films as part of its Let's Talk campaign encouraging people from all backgrounds to have conversations about end of life care.

The films are aimed at patients and staff. The film for patients encourages all of us to think about and share what's important to us if we become seriously unwell or approach the end of our life. The film for staff aims to help healthcare professionals have culturally sensitive conversations with patients and families about end of life care.

The films feature real life experiences and are available in a range of languages and accessibly formats. They build on existing films for patients, website information and easy-read resources.

Thanks to funding from GST charity the palliative and end of life care team has also introduced video playing devices and support packs across the trust's hospitals and in GP practices and care homes in Lambeth and Southwark. Collectively these materials can guide meaningful conversations.

Joanna Bate matron for palliative and end-of-life care said: *"We're thrilled to be able to offer these resources to patients and staff to support compassionate clear and timely conversations about end-of-life care. We hope they help everyone start the conversation."*

To learn more visit **guysandstthomas.nhs.uk/letstalk**

CONGRATULATIONS:

Professor Scott Murray

Professor Scott Murray has been awarded the Cicely Saunders International Award 2026 by the European Association of Palliative Care.

The Cicely Saunders International Award is awarded every two years to an individual who has made an outstanding contribution to palliative care, either in research, clinical practice or in organisation and policy.

Professor Scott Murray is Emeritus Professor of Primary Palliative Care at The University of Edinburgh. He is the Founder of the Primary Palliative Care Research Group at the Usher Institute, University of Edinburgh.

He continues to support the team in an advisory capacity for ongoing research projects. He maintains his longstanding interests in global palliative care through continued collaboration with colleagues in Africa and South East Asia.

The award was presented to Professor Murray at the EAPC Congress that took place in Prague 14–16 May 2026. Presenting the award Professor Irene Higginson said: *"This award is a well-deserved recognition of Scott's outstanding contributions to primary palliative care and to reducing inequities."*

Cicely Saunders International is a registered charity 1087195. It relies entirely on charitable support to carry out its programme of world class research and education. If you would like to make a donation please contact **sian.best@cicelysaundersinternational.org** or visit our website **cicelysaundersinternational.org**

Thank you for your support…