Winter 2025

CS|NEWS

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**

As always, this newsletter is packed with news of the internationally recognised work into many areas of palliative care supported by Cicely Saunders International.

We're also celebrating the continuing successes of our researchers in gaining important grants, fellowships and significant recognition for what they do so very well, both here in the UK and globally. This year's meeting of our International Scientific Expert Panel (ISEP) was extended over two days for the first time, giving staff in the Institute more opportunities to engage with world leaders in the field.

Given the quality and quantity of research supported by CSI in the Cicely Saunders Institute, it is no surprise that our representatives have been making important contributions as the Terminally Ill Adults (End of Life Bill) goes through Parliament.

Professors Irene Higginson and Catherine Evans sat on the Commission on Palliative and End-of-Life Care, as did Baroness Finlay of Llandaff, a member of ISEP. Other colleagues provided evidence in person and through written submissions, including Professor Katherine Sleeman, in her role as a member of the Complex Life and Death Decisions group at King's College London.

The complexity of the debate has not abated, but the message that patients do not have a true choice regarding assisted suicide if they do not have access to quality palliative care is cutting through. The work of Cicely Saunders International and the Cicely Saunders Institute at King's has never been more pressing.

Kate Kirk
Trustee

NEWS:

UK assisted dying legislation not fit for purpose

In September King's College London released a statement highlighting concerns from the King's Complex Life and Death Decisions (CLADD) Group about new assisted dying legislation now before Parliament. The proposed law would allow terminally ill adults in England and Wales to receive help to end their own lives. However, the experts argued that the Bill is not ready to be put into practice.

They say the Terminally Ill Adults (End of Life) Bill needs major changes to make it workable and to protect patients, healthcare staff, and society.

They recommended several amendments. These included compulsory palliative care assessments for anyone requesting an assisted death, clear instructions for professionals on how to respond if medical complications arise, and a strong reporting system to track how the law is working and ensure patient safety.

CLADD member Dr Katherine Sleeman, Professor of Palliative Care, stressed that assisted dying laws must recognise the vital role of palliative care. She warns that without proper care, some people might choose assisted dying not because their symptoms cannot be treated, but because they have not received the support they need.

"Without access to high-quality palliative care, there is a risk that individuals may decide to have an assisted death, not because their suffering is untreatable, but because they haven't had access to the care that they need."
Professor Katherine Sleeman

In November Professor Sleeman gave evidence to the House of Lords Select Committee on these concerns.

For a full version of this story please visit **cicelysaundersinternational.org/uk-assisted-dying-legislation-not-fit-for-purpose**

PARLIAMENT NEWS:

The Terminally Ill Adults (End of Life) Bill

The Bill passed its second Reading in the House of Lords on 12 and 19 September and the Lords Select Committee began to hear evidence on 22 October.

Members of the House of Lords began their detailed examination of the Terminally Ill Adults (End of Life) Bill, in committee stage on Friday 14 November. **parliament.uk/business/news/2025/nov-2025/terminally-ill-adults-end-of-life-bill-lords-committee-stage**

Amendments to the bill will aim to address a number of issues such as coercion, mental capacity, deprivation of liberty, assessment by multiprofessional palliative care teams and inclusion of patients suffering from military or industrial injury.

PARLIAMENT NEWS:

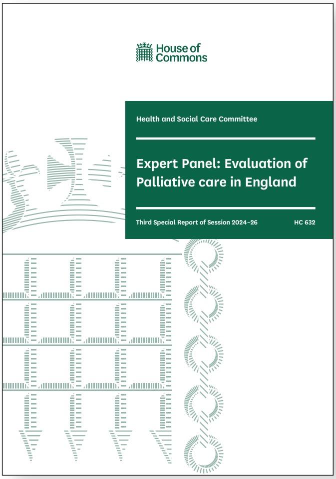
Palliative care under significant strain

The Health and Social Care Committee of the UK House of Commons has published its evaluation of palliative care and end of life care in England.

Undertaken by a panel of independent experts including Dr Sabrina Bajwah from the Cicely Saunders Institute, the report highlights workforce shortages, lack of training, inequitable access and 'significant strain in all settings'.

ICBs are poorly equipped to commission the right services and lack proper funding. People struggle to navigate the system and are unable to access the services they need. The report warns that current funding models and commissioning practices make the Government's ambition to shift more care into the community difficult to achieve.

Ministers will address issues raised in the report in a special tabled event in the House of Commons on 7 January.


House of Commons

Health and Social Care Committee

Expert Panel: Evaluation of Palliative care in England

Third Special Report of Session 2024–26 HC 632

See the full report here:
https://committees.parliament.uk/publications/50461/documents/273119/default/

PARLIAMENT NEWS:

UK Government announcement

On 24 November the Minister for Care, Stephen Kinnock MP announced that the UK Government will publish a palliative care and end of life care modern service framework in Spring 2026.

He said: *"This will be aligned with the ambitions set out in the recent 10-year health plan."*

He acknowledged the significant challenges currently facing the sector, including delays in early identification of palliative care needs, workforce challenges and gaps in provision that have led to a postcode lottery for patients and their families. He continued: *"We want a society where every person receives high-quality, compassionate care from diagnosis through to the end of life, and we recognise that access to high-quality, personalised palliative care and end-of-life care can make all the difference to patients and their loved ones."*

Commenting on the announcement, Dr Peter May, health economist at the Cicely Saunders Institute said: *"It's encouraging to hear that the Government is taking steps to improve palliative and end-of-life care. Our research conducted in 2025 shows that both hospital- and home-based palliative care in England are highly cost-effective, improving outcomes and saving hundreds of thousands of hospital bed days.*

"But there remains huge room for further gains – only half of people in England with palliative care needs currently receive it, and those who do receive palliative care often do so too late to maximise benefit.

"The Government plan to look at earlier identification of need, out-of-hours support and proactive home-based interventions is aligned with this evidence and has the potential to be 'win, win' for patients, families and the NHS."

RESEARCH NEWS:

Music therapy and dementia

Dementia is becoming more common worldwide, and many people are now cared for at home. Research shows that music can help manage dementia symptoms, but there is still a need for clearer guidance on which musical activities work best and why. The international HOMESIDE trial trains family caregivers to use music as part of everyday care for people living with dementia.

As part of this project, Dr Sarah Crabtree, a music therapist at the Cicely Saunders Institute, helped develop the *Music Therapy Triangle of Care Model*. This approach emphasises supporting both the person with dementia and their caregiver, encouraging them to use music together in a more collaborative and meaningful way.

The study found four major areas where music can make a difference: physical effects, behavioural and psychological improvements, cognitive stimulation, and stronger relationships.

For caregivers, who often face long and challenging days, sharing moments of connection with their loved one can be deeply meaningful. Using music at home not only supported the wellbeing of the person with dementia but also improved the caregiver's own wellbeing, helping strengthen their relationship and making daily caregiving feel more rewarding.

To find out more about the international study visit **homesidestudy.eu**

Crabtree S, Baker FA, Bukowska AA, Hsu MH, Kvamme T, McMahon K, … Tamplin J (2025). **Exploring the use of musical activities implemented in home-based dementia care as part of the HOMESIDE study.** *Arts & Health*, 1–18. **doi.org/10.1080/17533015.2025.2525334**

Review urges focus on low- and middle-income countries

A major international review has found large gaps in how countries measure the quality of palliative care for people with cancer. The study brought together experts from 10 countries and 13 institutions, who analysed 41 existing studies.

They discovered that most research focuses on patient outcome measures (POMs) such as pain control, symptom relief, and emotional well-being. However, quality indicators (QIs) which examine how palliative care services are organised and delivered, are far less developed. This problem is especially serious in low- and middle-income countries, even though these regions have the greatest need for palliative care. More than 90 per cent of current research comes from high-income settings.

Experts stress the need for person-centred care supported by clear, relevant, and consistent indicators. A separate WHO study, led by Professor Richard Harding, confirmed seven universal quality indicators – pain, worry, weakness, mobility, appetite, need for help, and peace – after testing them in six culturally diverse countries. These indicators proved reliable across different settings.

The review recommends creating a global, open-access repository of quality indicators and outcomes, increasing research in lower-income regions to develop suitable tools, and encouraging innovative, ethical research designs that better capture patient and caregiver experiences.

Dr Eve Namisango (African Palliative Care Association) said: *"The need for palliative care in low-middle income countries is high, the development of services must be underpinned by a person-centred approach and should be of high quality. Our study highlights an urgent need to invest in research on developing measures to assess and evaluate the process and structural aspects of the quality of care."*

Dr Mev Hocaoglu commented: *"Our review calls for globally relevant, person-centred indicators. The WHO study delivers the evidence that it is possible – and urgently necessary – to define and track quality based on what matters most to patients."*

Ng CPY, Hegyi M, Lewison G, Pastrana T, Namisango E, Cleary J, Hasties B, Kabisa E, Musau H, Spangenberg K, Ruiz P, Ali Z, Mallafre-Larrosa M, Polo A, Torode J, Aggarwal A, Sullivan R, Hocaoglu M. **Quality indicators and patient outcome measures for palliative care in cancer patients: a systematic review.** *Ecancermedicalscience.* 2025 Jun 20;19:1929. doi: 10.3332/ecancer.2025.1929. PMID: 40606950; PMCID: PMC12221262.

GLOBAL NEWS:

Using the IPOS-Dem to improve dementia care in China

Around 55 million people worldwide live with dementia, and most are in low- or middle-income countries. China has about 15 million cases, making up a quarter of the global total. People with dementia often have several long-term health problems and many symptoms that reduce their quality of life. Most die in hospitals, care homes, or at home, often without proper palliative care, which focuses on comfort and support.

Because many people with dementia cannot clearly express their needs, it can be difficult for carers to recognise their symptoms. To improve this, researchers developed the Integrated Palliative Care Outcome Scale for Dementia (IPOS-Dem). It is a short questionnaire completed by care staff to identify common symptoms and concerns, especially when the person cannot describe how they feel. IPOS-Dem is based on earlier palliative care tools and has already been used successfully in several European countries.

There is a strong need for a version that works well in China. Researchers translated and adapted the tool into Chinese with help from experts in medicine, language, and culture. They tested it with care workers in nursing homes. Most parts translated well, but some phrases – like ‘drowsiness,’ ‘difficulty communicating,’ and ‘at peace’ – were harder to express clearly. The study showed that adapting healthcare tools to different cultures is essential.

Chen L, Sleeman KE, Huang H, Mo Y, Bradshaw A, Ellis-Smith C.
Translation and cross-cultural adaptation of Integrated Palliative Care Outcome Scale for Dementia.
Palliative Medicine. 2025;0(0). **doi:10.1177/02692163251347826**

TRIBUTE:

Dr Balfour Mount 'Father of Palliative Care'

Dr Balfour Mount, who has died aged 86, was a global pioneer who in 1975 launched the world's first Palliative Care Unit and Service in Montreal, Canada.

In an **interview by Devon Phillips published in 2018**, Balfour Mount described how he learnt about Cicely Saunders and St Christopher's Hospice in London through the Elizabeth Kübler-Ross book, *On Death and Dying*, published in 1970. He resolved to contact Cicely Saunders, visit the hospice, and learn about the principles of hospice care and establish a similar service in Canada.

When he returned to Canada he set up a home care programme caring for around 100 patients in the community, an in-patient unit in the Royal Victoria Hospital, research and teaching programmes, and a bereavement support team. This new 'Palliative Care Service' was the first use of the term 'palliative care'.

The term palliative care was adopted worldwide to describe the new medical specialty, based on the principles of Cicely Saunders, and became the foundation of a worldwide movement.

Director of the Royal Victoria Hospital Palliative Care Service, Palliative Care McGill, and the McGill Programs in Integrated Whole Person Care, Dr Mount was the Eric M Flanders Emeritus Professor of Palliative Care at McGill University. In 1985, he was made a Member of the Order of Canada in recognition of 'having founded the first Palliative Care Service at Montreal's Royal Victoria Hospital.' In 2003, he was promoted to Officer in recognition of being 'the father of palliative care in North America.' In 1988, he was made an Officer of the National Order of Quebec.

Professor Irene Higginson, Scientific Director of Cicely Saunders International said: *"Balfour Mount was the first person in North America to found a full palliative care service—comprehensive, researched, taught—in Montreal. Cicely Saunders, whom he admired deeply and counted among his mentors, always spoke warmly of him. She recognised in him not just a kindred spirit, but someone who took the lessons from her research and education. He took the notion of 'total pain' that she developed and carried it forward, embedding compassion, dignity and whole-person care into medicine. Balfour made palliative care work in practice in Canada, and helped to spread the word about palliative care helping people to live well even in advanced illness, not only in Canada but across the world."*

Can antidepressants help manage breathlessness?

Breathlessness (trouble breathing) is a common and upsetting symptom for people receiving palliative or supportive care. When treatments aimed at the disease itself stop working, there are few approved medicines to help.

A review carried out by researchers based at the Cicely Saunders Institute, MD Anderson Cancer Centre in the US and Nicolaus Copernicus University, Poland concluded there's not enough strong evidence to support using antidepressants to treat breathlessness.

Dr Peter May who led an economic evaluation as part of the **BETTER-B trial** said: *"We found that mirtazapine has a significant negative effect on patient outcomes, is associated with increased use of healthcare and unpaid family care, has a very low probability of cost-effectiveness, and should not be prescribed.*

"We hope that our results dissuade prescribers from mirtazapine for breathlessness, thus sparing patients, families and systems the additional burden. Furthermore, we hope that we have highlighted more broadly the risks of prescribing off-label, repurposed medicines without a strong evidence base."

May P, Normand C, Oluyase AO. *et al*. **The cost of drug repurposing: parallel economic evaluation of mirtazapine for severe breathlessness in the multinational BETTER-B trial.** BMC Health Serv Res 25, 1442 (2025). **doi.org/10.1186/s12913-025-13605-9**

Higginson IJ, Bajwah S, Krajnik M, Jolley CJ, Hui D. **Recent advances in understanding the role of antidepressants to manage breathlessness in supportive and palliative care.** Curr Opin Support Palliat Care. 2025 Jun 1;19(2):83-94. doi: 10.1097/SPC.0000000000000761. Epub 2025 Apr 21. PMID: 40265531; PMCID: PMC12084019.

The future of palliative care

On 21 October the Cicely Saunders Institute welcomed Professor Lieve Van den Block to deliver this year's CS International Annual Lecture on the future of palliative care.

Professor Van den Block explored how a palliative care approach for older people living with frailty, dementia, and cancer can be integrated across disciplines and different care sectors. She highlighted that timely referral to palliative care is key to improving the experience and quality of care.

Palliative care's central question *'What matters most?'* reveals that meaningful activities, independence, mobility, respect, dignity, social connection, and continuity of care, all play a vital role – alongside meeting people's financial, emotional, and spiritual needs.

Professor Van den Block called for wide-reaching cultural and organisational change to achieve this vision. She also highlighted innovative developments around the world, including the growth of 'navigator' roles in different cultural settings. Navigators work closely with patients and families, building trust and understanding, and provide connection, advocacy, and support. Through training and mentorship, they help to promote empowerment and enhance quality of life for those receiving care. This integrative model of palliative care can transform healthcare systems in a sustainable way, including in low- and middle-income countries.

The lecture is available to watch on the Cicely Saunders Institute YouTube channel **Cicely Saunders International Annual Lecture 2025 – YouTube**

Below: Professor Van den Block (centre) with PhD students at the Cicely Saunders Institute.

INTRODUCING:

BuildPall Fellows

Ana Maksimovic joined the Cicely Saunders Institute in October 2024. Her PhD is part of the EMPOWER Dementia Network+, which brings together lived experts, researchers, health and social care professionals, and community partners.

Ana is an economist whose PhD research applies a health economic mode of thinking to decision-making in dementia care. She is interested in how people with dementia, family carers, and health and social care practitioners work together to make decisions. By combining her expertise in economics and engaging with people with lived experience, she aims to ensure that the voices of people living with dementia and their carers are heard and valued.

She recently presented at the 19th International Meeting on Behavioural Sciences Applied to Healthcare (BSAH) conference. This represents a key milestone in her PhD and career development, being her first opportunity to deliver a peer-reviewed abstract to an international audience of social scientists. She shared findings from her first paper, which identifies and synthesises the microeconomic insights that explain dynamics that underpin decision-making in dementia care and drive costs.

Ana Maksimovic

Flora Tarisai Dangwa joined the Cicely Saunders Institute in September 2024 and is leading an innovative qualitative study to better support people with serious illness and their families in rural and urban Zimbabwe.

Flora said *"I was inspired by my father, who died following a long and serious illness in Zimbabwe. I witnessed the inadequate and inequitable palliative care services available, despite palliative care being classified as an essential health service by the World Health Organization under Universal Health Coverage."*

Her motivation is to improve the lives of people living and dying with serious health-related suffering and to support their caregivers through research and generate evidence that can influence palliative care practice and policy.

Currently based in Zimbabwe for fieldwork, Flora aims to complete data collection within the next two years. Her short-term plans include piloting the Mutsa Study – meaning helping each other with compassion – to empower communities, enhance death literacy, and foster mutual support.

Looking ahead, Flora envisions continuing work on sustainable, community-based palliative care projects in low-resource settings and mentoring the next generation to engage in impactful, locally driven initiatives.

Flora with Rumbie Mutendera, MUTSA study community gatekeeper and advisor

CONGRATULATIONS:

APCA celebrates 20 years

In 2025 the African Palliative Care Association celebrates 20 years of advocating for palliative care across Africa. Its triennial conference in Gaborone, Botswana in October was attended by delegates from 40 countries across sub-Saharan Africa and by heads of government and health ministers.

APCA has been partnered with the Cicely Saunders Institute and Cicely Saunders International throughout their existence, beginning with the development of the **African Palliative Outcome Scale**, through the largest US government **Public Health Evaluation** and more recently the **Global Health and Palliative Care (GHAP) project**. This is an NIHR global health group focused on children's palliative care in Uganda, early integrated adult cancer palliative care in Zimbabwe and palliative rehabilitation in South Africa.

At the conference Professor Richard Harding received an award celebrating this 20 year partnership (above).

"I am delighted and proud to receive this award on behalf of King's to mark our 20 year research partnership. We have come so far, with so many brilliant African clinicians and scholars having graduated with an MSc or PhD (or both) in palliative care from the Cicely Saunders Institute at King's and having conducted many primary research studies across child, adult and older person's care. APCA is a very important partner for us, and together we have a strong track record of impactful research."

Professor Richard Harding, Executive Dean, Faculty of Nursing, Midwifery & Palliative Care

CONGRATULATIONS:

Dr Joanna Davies awarded prestigious King's Prize Fellowship

Dr Joanna Davies, a Research Fellow at the Cicely Saunders Institute, has been awarded a prestigious King's Prize Fellowship, given every two years to exceptional post-doctoral scientists.

This award will allow her to continue investigating why people experience different levels of hospital-based care in their final year of life, and how factors such as where they live, their ethnicity, and their gender shape these differences.

The number of deaths in England and Wales is rising and is expected to reach 635,000 a year by 2040. This makes it crucial that end-of-life care supports people's dignity and quality of life, while also helping the health and social care system manage increasing demand. Although most people prefer to avoid hospital in their final weeks and months, hospital use usually rises sharply before death. Many of these hospital visits could be avoided with stronger community support.

Evidence shows that people in more deprived areas have higher rates of emergency department visits, including at the end of life. Dr Davies' earlier work explored how ethnicity, deprivation and gender affect emergency visits in the last three months of life. Her new research will examine the causes of unnecessary variation and work with services to reduce these inequalities. She said:

"It's an honour to receive this King's Prize Fellowship to take the first steps in delivering a programme of cutting-edge data science and translational research using routine data to inform more equitable resource distribution and service delivery for people with advanced illness. This work is about bridging the gaps between research and practice by ensuring that our research is responsive to the needs of commissioners and service providers who are working to improve care for patients and families."

Executive Dean, Faculty of Nursing, Midwifery & Palliative Care

Professor Richard Harding has been appointed as Executive Dean for the Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care at King's from 1 December 2025.

Richard is the Herbert Dunhill Chair of Palliative Care & Rehabilitation and has a wealth of expertise in his field as well as extensive knowledge of both King's College London and the Faculty.

Richard previously held leadership roles as the Vice-Dean International in the Faculty and Director of the Cicely Saunders Institute. He also gained his PhD Public Health whilst studying at King's.

"I am delighted to lead the Faculty in response to the challenges and opportunities of modern healthcare. It is an honour to be Dean of a Faculty that bears the name of Florence Nightingale – a woman who was committed to data and evidence to inform care. I look forward to working with our teaching and research teams to provide the workforce and evidence for high quality nursing, midwifery and palliative care."
Richard Harding, Executive Dean,
Faculty of Nursing, Midwifery & Palliative Care

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