Winter 2024

CSINEWS

news from cicely saunders international

Cicely Saunders International
Better care at the end of life

We have to listen to the details of symptoms, giving constant attention to changing needs. We are concerned both to relieve suffering and that our patients should maintain their own character and style to the end.

Dame Cicely Saunders

Welcome to the winter edition of CSI News. Research and developments continue across a range of areas, as you will read in this newsletter, but we are also mindful of the current situation in the UK and how we can contribute.

We welcome the UK government's recent commitment to enhancing community-based care, and urge that this includes enabling more people to receive palliative care in the comfort of their own homes and the community. Evidence generated through CSI's support shows that appropriately-funded timely palliative care alleviates distressing symptoms, and improves patient and family outcomes, without raising costs to the NHS, and can support care in the community, reducing unnecessary hospital admissions and easing the pressure on acute services.

CSI sees the consultation on NHS reform and the ongoing debate on assisted suicide and assisted dying as opportunities to elevate the conversation around palliative care and end-of-life services, stress the urgent need to advocate for universal palliative care access, and push for greater public understanding and investment in high-quality palliative care research, education and services.

We urge our friends and supporters to join us in raising awareness of the patchy access to palliative care across the UK and the need for well-funded, universally available services and the underpinning research that enables us to discover better ways of care. For more details, please see **Palliative Care Crisis: Statement from Cicely Saunders International** on our website.

Thank you for your support.

Kate Kirk
Trustee

Drugs prescribed off-label may do more harm than good

A new study from the Cicely Saunders Institute shows that off-label prescriptions of a common antidepressant do not help breathlessness in patients with respiratory disease – and may cause side effects.

Researchers warn prescribing medicines for a use which it has not been licensed could make things worse, even though the prescriber was trying to help.

The findings, presented at the ERS Congress in Vienna and published in **The Lancet Respiratory Medicine**, show the desperate need for options to treat the symptoms of severe breathlessness, as there are no drugs licensed for this in the UK or most other countries.

The severe breathlessness caused by chronic respiratory diseases greatly impacts a patient's quality of life as well as creating substantial clinical challenges and health care costs. Most patients with diseases like this have few options to help with their symptoms.

Ahead of the trial, researchers surveyed doctors in respiratory and palliative medicine and found doctors were often using off-label prescribing – where a clinician prescribes a medicine for use in a different way than that stated in its licence. Various off-label prescriptions were being used, including common anti-anxiety and anti-depressant drugs like benzodiazepines and SSRIs.

Mirtazapine, a common antidepressant, was one of the types of drugs being prescribed. Case series and early studies showed it had potential. However, in this international trial, the first large-scale study to be done, researchers found that mirtazapine does not improve breathlessness in patients with respiratory disease compared with a placebo. They also found that patients receiving mirtazapine had slightly more side effects and needed more care from hospitals and family members.

Chronic respiratory diseases affect 454.6 million people worldwide, with numbers predicted to increase with an aging population. Over 217 million people globally have Chronic Obstructive Pulmonary Disease (COPD) or Interstitial Lung Disease (ILD), both of which can cause severe breathlessness as they progress.

Off-label use can be as safe as on-label use if based on good evidence. It is often used when symptoms can't be controlled with licensed medicines, particularly in serious illnesses. This is common in severe breathlessness care, making proper evaluation of medicines vital. Off-label prescribing doesn't mean a doctor is making a mistake; it often happens when there are no other options to manage symptoms like breathlessness.

First author Professor Irene Higginson, Scientific Director of Cicely Saunders International, said:

"Breathlessness is a widespread issue in palliative care as a symptom of respiratory diseases, heart disease and some cancers. When severe, it's distressing for patients, as well as their caregivers, family and friends. It diminishes people's quality of life and often leads to considerable health and social care use, including emergency hospital admissions.

"Despite being a widespread issue we still don't have effective treatments available. As such, many doctors turn to off-label prescribing, trying to help their patients.

"Our earlier survey found that 19 per cent of respiratory and 11 per cent of palliative physicians frequently recommend antidepressants for severe breathlessness in COPD, so these medicines are already being used off-label. This new trial concludes that mirtazapine is not recommended for the treatment of breathlessness, that the use of unlicensed medicines should be approached with caution and that it's crucial to subject medicines in palliative care to rigorous trials.

"We need further research into potential therapies for severe breathlessness. In the meantime, we recommend clinicians use early identification and non-pharmacological approaches, such as those offered from breathlessness support services, to treat the symptom."

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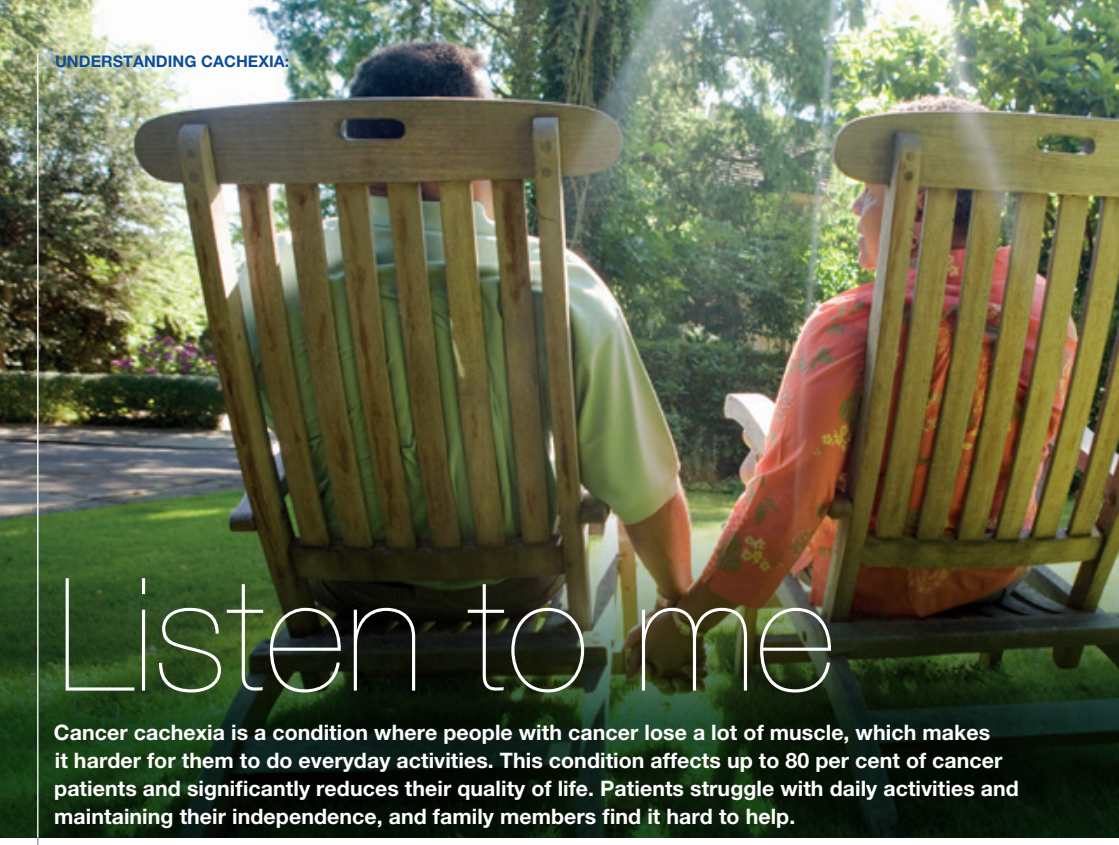
Find more **resources on managing breathlessness**. Further information on the BETTER-B programme is available **here**.



Listen to me

Cancer cachexia is a condition where people with cancer lose a lot of muscle, which makes it harder for them to do everyday activities. This condition affects up to 80 per cent of cancer patients and significantly reduces their quality of life. Patients struggle with daily activities and maintaining their independence, and family members find it hard to help.

Researchers based at the Cicely Saunders Institute decided to carry out a review of current experiences of cancer cachexia from the perspective of patients and unpaid/family carers, to find out how patients and families cope with severe weight loss and muscle wasting, and how this impacts on their daily activities and their independence. The review also looked at the clinical management of their cachexia from the viewpoint of patients and the family members who care for them.

The researchers found that patients with cancer cachexia face considerable challenges with everyday activities. They struggle to keep their independence and fulfil their usual family roles, and this leads to distress. Carers felt powerless to help and both patients and carers experience feelings of sadness, boredom, frustration and guilt.

Common themes that emerged from the studies included distress related to eating, misunderstandings about cachexia by both medical professionals and by wider society, and noticeable weight loss and other aspects of the condition leading to a loss of identity and social isolation. Many patients and carers feel that doctors don't acknowledge or manage cachexia well.

Both patients and their family carers value personalised, flexible care that includes carers in physical activities or exercises as well. They also appreciate opportunities to talk about cachexia, which improves their understanding of health, nutrition, and their relationship with food. Most studies so far have focused on physical activity or exercise as interventions. Patients and family carers value educational activities as well because they help improve their quality of life.

Bowers M, Higginson IJ, Maddocks M. **Patient and carer experiences of cancer cachexia and its management.** Curr Opin Support Palliat Care. 2024 Jul 9. doi: 10.1097/SPC.0000000000000710. Epub ahead of print. PMID: 38980806.

CHOICE AT THE END OF LIFE:

New research on people's preferences

The BuildCare research team at the Cicely Saunders Institute has published research on where people choose to be cared for. The latest study looks at where people prefer to die and where they actually die. Sometimes, what people want and what happens can be different, and this study tried to understand why.

The study used data from two surveys about people who received special care in the last three months of their lives in Ireland. It looked at why people might prefer to die at home or in a hospital and whether their wishes matched what actually happened.

The study was done in four different regions in Ireland, each with different levels of special care available. The study analysed combined data from two previous mortality follow-back surveys: the Economic Evaluation of Palliative Care in Ireland (EEPCI) and the Irish component of International Access, Rights, and Empowerment (IARE I) – part of the BuildCare programme funded by The Atlantic Philanthropies and Cicely Saunders International.

The average age of the people in the study was 77 years old. Half were men and half were women. About 19 per cent lived alone, and 64 per cent had cancer.

The data was collected from 2011 to 2015, with about 342–351 people in the study.

Around 51 per cent of people died where they wanted to. People who lived alone were less likely to want to die at home and less likely to actually die at home. But living alone in itself didn't affect whether their wishes matched what actually happened.

The study shows that it's important to look at both what people want and what actually happens. Sometimes, people choose based on what is possible, not just what they want. It also highlights the need for good community-based support – home care, making hospital discharge more straightforward, and management of complex conditions at home – so that people can be cared for in the place they prefer. Extending and offering meaningful choices to people enhances their quality of life and alleviates suffering.

Smith S, Brick A, Johnston B, Ryan K, McQuillan R, O'Hara S, May P, Droog E, Daveson B, Morrison RS, Higginson IJ, Normand C. **Place of Death for Adults Receiving Specialist Palliative Care in Their Last 3 Months of Life: Factors Associated With Preferred Place, Actual Place, and Place of Death Congruence.** J Palliat Care. 2024 Jul;39(3):184-193. doi: 10.1177/08258597241231042. Epub 2024 Feb 25. PMID: 38404130; PMCID: PMC11097611.

Assisted suicide/assisted dying debate at Bush House

In October Professor Katherine Sleeman, Laing Galazka Professor at the Cicely Saunders Institute spoke at an event organised by the Complex Life and Death Decisions group at the King's Policy Unit to examine the principles, practice and politics of assisted dying.

The discussion explored the complexity of how assisted dying might work in reality, the uncertainty in implementing this policy and the nuance in public opinion. Also discussed were issues around consent and how best to ensure patient safety.

In an opinion poll conducted by the King's Policy Unit in September, around two-thirds (63 per cent) of people in England and Wales say they want the current Parliament to make assisted dying legal for terminally ill adults in the next five years. 20 per cent say they do not want this to happen, while a further 17 per cent do not take a side or have an opinion.

The research also finds that support is virtually the same when the public are told key details of Lord Falconer's assisted dying bill, which are likely to be very similar to a parallel bill being introduced in the House of Commons by MP Kim Leadbeater. 66 per cent back the Lords bill when they know its core provisions.

However, the findings also reveal much of the public still have reservations about the risks of assisted dying, even if they are broadly supportive of its legalisation.

Read more about the survey here **cicelysaundersinternational.org/assisted-dying-two-thirds-of-public-back-legalisation-within-this-parliament-study-finds/**

Other speakers at the event included members of the UK parliament, Anna Dixon and Ben Spencer, legal experts Professor Alex Ruck Keene and Professor Gareth Owen and journalist Sonia Sodha.

Professor Katherine Sleeman, Laing Galazka Professor of Palliative Care, at the Cicely Saunders Institute said:

"While two thirds of people say they would want assisted dying legalised this parliament, 61 per cent of the public are concerned about people being pressured into having an assisted death, and 83 per cent of assisted dying supporters say poor palliative care is a reason for their support. With a Parliamentary vote on assisted dying imminent, it is critical that the debate considers the complexities involved in implementing this kind of reform. This includes the implications of legalising assisted dying in a context where many dying people struggle to access the care they need."

Read the full report here: **Assisted dying: principles, practice and politics**

NEWS:

Palliative Care Crisis: statement from Cicely Saunders International

Cicely Saunders International calls on friends and supporters to join us in raising awareness of the critical shortage and fragmented availability of palliative care across the UK, as well as the need for appropriately funded, universally accessible services to support people with serious illness and those important to them.

Critical gaps in access and provision

Access to palliative care remains highly patchy across the UK, with marked disparities based on geography, socio-economic status, health condition and the times that services are available. Rural communities and economically deprived areas are especially affected by this inequity, and individuals with non-cancer diagnoses are sometimes excluded from palliative care services despite facing similar or even more severe symptoms than those with cancer.

These gaps not only undermine patient choice and quality of life but also place additional strain on families and informal carers, who often assume caregiving responsibilities willingly, but with too little support or guidance. The fragmented access to palliative care also means that patients frequently face emergency admissions to manage symptoms that could have been addressed earlier through community-based palliative care.

Studies suggest that early palliative intervention even improves bereavement outcomes, helping to mitigate complex grief and supporting families through difficult times.

You can read the statement in full and download a pdf on our website here: **cicelysaundersinternational.org/palliative-care-crisis-statement-from-cicely-saunders-international/**

NEWS:

Help shape the future of the NHS: contribute to the new 10 Year Health Plan

Closing date: 02 Dec 2024

The UK's Health and Social Care Secretary, Rt Hon Wes Streeting MP, has launched the Change NHS website to start a discussion about the future of the NHS. The website invites everyone to share their views, experiences and ideas to help shape a new 10 Year Health Plan for England.

If you live in England, you can share your thoughts on how the NHS should evolve: **change.nhs.uk**

The consultation allows you to share your views as the UK Government prepares its 10 Year Health Plan, which will be published in spring 2025. The plan aims to:

- Shift care from hospitals to communities
- Expand digital healthcare and services
- Focus more on illness prevention, for example through wearable health technology.

Key reforms include:

- Creating neighbourhood health centres that integrate care under one roof.
- Developing a single, unified digital patient record accessible across all NHS services.

You can register your email when responding to the consultation to receive updates on the 10 Year Health Plan.

Naomi Takemura

Dr Naomi Takemura from Hong Kong University recently finished a three month visit to the Cicely Saunders Institute in London. She worked with researchers to share learning about the best ways to manage chronic breathlessness, including the online SELF-BREATHE programme. Now back in Hong Kong, she is focusing on making this programme suitable for a culturally diverse population, collaborating with Professor Matthew Maddocks, Dr Charles Reilly, local stakeholders, and patient groups.

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Doctor Takemura shared her thoughts on the experience:

"My time at the Cicely Saunders Institute has had a big impact on my work. I learned a lot from experts in palliative care and rehabilitation, which will help me in my future projects. The programme I worked on is important because it offers non-drug treatments that can help people from different cultural backgrounds. I believe this will lead to better care and outcomes for patients.

"To share what I've learned I plan to continue working with the Institute's research team on new projects. These partnerships will help our university improve its research and contribute to global progress in palliative care. I also want to add what I've learned to our current courses and create new ones. This way, our students will be better prepared to help people with chronic breathlessness. By doing this, we can improve our teaching, research, and collaboration with other departments, which will benefit our university and the field of palliative care."

GLOBAL NEWS:

Capacity-building in Vietnam

Earlier this year representatives from the Cicely Saunders Institute visited colleagues from the University of Medicine and Pharmacy (UMP) in Ho Chi Minh City, Vietnam in June to sign a Memorandum of Understanding between the two schools. Professor Richard Harding, Dr Anna Peeler, and Dr Duong Le Dai were welcomed by UMP faculty from the schools of nursing and medicine.

Collaborators from the Cicely Saunders Institute and UMP have been working together over the last six months to develop a joint grant proposal to facilitate cross-cultural learning between the two schools. With the goal of building nursing research capacity in the UK and Vietnam, the proposed grant will establish a cohort of PhD students from each of the schools to learn with and from each other through a series of online workshops focused on complex intervention development and scientific writing, a journal club, and visits to London and Ho Chi Minh City.

The visit included a ceremony to commemorate the signing of the Memorandum of Understanding, a tour of the UMP medical centre, focus group discussions with faculty and students at UMP, a visit to a Bhuddist temple, and plenty of delicious food!

Dr Peeler and Dr Duong are funded by Cicely Saunders International's Project BuildPall, a five-year capacity-building programme of research, training, education and dissemination.

OBITUARY:

Dr Robert Twycross 1941–2024

Dr Robert Twycross (seen here on left with ISEP member Professor Harvey Chochinov) was a pioneer in hospice and palliative care, leaving a profound legacy that has reshaped end-of-life care worldwide.

He trained in medicine at the University of Oxford and began his career in the 1970s at St Christopher's Hospice in London alongside Dame Cicely Saunders. His groundbreaking work focused on pain management and the alleviation of suffering, particularly for cancer patients. His research on the use of opioids for cancer pain set global standards for pain control, and he was a leading figure behind the World Health Organization's Cancer Pain Analgesic Ladder.

In addition to his clinical and research contributions, Dr Twycross was a passionate educator, training countless healthcare professionals in palliative care principles that extended beyond hospices into hospitals. His textbooks, lectures, and workshops became essential resources in the field.

Known for his empathy, intellectual rigour, and dedication to improving life for those with terminal illnesses, he shifted the focus of care to dignity, comfort and respect in a patient's final days. His impact on the hospice and palliative care movement will be felt for generations, and will continue to inspire caregivers worldwide.

Professor Irene Higginson, Scientific Director of CS International said:

"Robert's legacy is far reaching, he was a pioneering figure in hospice and palliative care. His work transformed the way patients at the end of life are cared for and his influence continues to resonate in palliative care practices worldwide today."

New Director at Cicely Saunders Institute

In September Professor Catherine Evans was appointed Director of the Cicely Saunders Institute, King's College London.

Professor Evans is a senior clinical academic in palliative care and nursing. She joined the CSI in 2010 as a post-doctoral fellow, pursuing a successful career as a clinical academic to her current position as Professor in Palliative Care. She is an Honorary Nurse Consultant with Sussex Community NHS Foundation Trust in a joint clinical academic post established in 2011 between the Trust and the CSI. She pursued her clinical academic career through personal fellowships from the National Institute of Health and Care Research (NIHR) Integrated Clinical and Practitioner Academic Programme, and was supported by Cicely Saunders International to build her research team.

Professor Evans has built a programme of research on community palliative care for older adults with multimorbidity, including dementia. She leads the Economic and Social Research Council (ESRC)/ NIHR national **EMPOWER Dementia Network+** – 'Empowering a meaningful life for all', addressing inequalities in dementia care for people needing support, with co-lead Dr Emma Wolverson, University of Hull. Her success built on a major £4.7 million research programme called 'Empowering Better End of Life Dementia Care' (**EMBED-Care**), led jointly with Professor Liz Sampson, UCL.

She is a Deputy-Director of the **King's Clinical Academic Training Office**; a pan-professional training hub for practitioners to follow clinical academic careers. She co-leads the **NIHR INSIGHT Programme for South London** for students and early career registrants to showcase and inspire them into the full range of research careers.

"It is a huge privilege to lead the highly successful, dynamic multidisciplinary team that forms the Cicely Saunders Institute. I have been part of this team for nearly 15 years; a journey that has enabled me to build a rewarding career as a clinical academic nurse. The appointment of Director is for me a fantastic opportunity to support and nurture others in their research careers in palliative care from across disciplines, specialties, settings and methodologies. I am excited about the year ahead working with amazing colleagues and team as we strive for all who require palliative care to receive it, nationally and internationally."
Professor Catherine Evans

"We are very much looking forward to working with Professor Evans as she takes up her new position as Director of the Cicely Saunders Institute. Her research record speaks for itself, and her leadership skills, especially in supporting young researchers, will further strengthen the Cicely Saunders Institute as a globally renowned centre of excellence."
Kate Kirk, Chair of Trustees, Cicely Saunders International

EVENTS ROUNDUP:

Better Futures for Health & Care

In September CS International and academic, clinical and other partners from across south London took part in a consultation exercise with *King's Better Futures for Health & Care*, a pioneering initiative using evidence-based community approaches to solve the global problems of health and care services.

The event focussed on people with the most complex illnesses and examined solutions based on examples of current practice that can be delivered at scale to deliver early impact. The aim was to identify key priorities for the initiative framed around a three-pronged approach – restructuring and expanding the careforce, implementing frugal innovations at scale and using citizen engagement to tackle the systemic problems that prevent people getting the right care.

The results of the consultation will be presented to UK Parliamentarians and policy-makers in November. The project has appointed a coordinator, and will be advertising for four research associates to work on the programme soon, and are seeking further partners.

Higginson IJ, Shand J, Glenn R, Boaz A, French C, Carvalho N'Djai A, Malone M, Wolfe I, Normand C, Hotopf M. **Reimagining Health and Care to Tackle the Rising Tide of Inequity, Multimorbidity, and Complex Conditions.** NEJM Catalyst. September 11, 202410.1056/CAT.24.0266 [doi] https://catalyst.nejm.org/doi/full/10.1056/CAT.24.0266

NEWS:

Triennial Report 2020–2023

The Cicely Saunders Institute of Palliative Care has published its latest Triennial Report (2020–23) highlighting a broad range of activities in ground-breaking research, education, training and clinical care.

If you would like a hard copy of the report please email us at **admin@cicelysaundersinternational.org**

'Making a difference in palliative care'; the Cicely Saunders Institute of Palliative Care, Policy, and Rehabilitation – Vision and Mission, and Triennial Report (2020–2023) https://cicelysaundersinternational.org/triennial-report-2020-2023/

EVENTS ROUNDUP:

Timely palliative care prevents suffering

On Tuesday 1 October the Institute was delighted to welcome Dr David Hui from MD Anderson in Texas to deliver the 2024 Cicely Saunders International lecture – *Integrating palliative care into oncology – what does the evidence show?*

Dr Hui's presentation outlined concepts of palliative care, working from the first principles of palliative care developed by Dame Cicely Saunders, Balfour Mount and other pioneers, and demonstrated how research evidence shows that palliative care not only treats suffering, but when delivered in a timely way it prevents suffering. Stigma around death and dying creates a negative feedback loop that results in late referrals followed by early death.

In contrast strong research evidence shows that earlier referrals disrupt this feedback loop and deliver more benefits, deliver more supportive and palliative care for patients, more opportunity to educate clinicians, more evidence for research and more opportunities to improve leadership and health systems. It therefore benefits not only individual patients and their families, but also healthcare professionals and the wider healthcare system.

Private insurance companies in USA now advocate for palliative care, as it avoids costly and potentially harmful interventions, and ground-breaking research in 2010 demonstrated how palliative care improves survival. Dr Hui concluded that effective supportive and palliative care should be timely, interdisciplinary, personalised and appropriate to the setting, whether virtual or in-person.

The lecture is available to watch now on the Institute's YouTube channel **Cicely Saunders International Annual Lecture 2024 – Dr David Hui – YouTube.**

Michal Galazka Study Day 2024, palliative care for children and young people: policy and practice

This year's Michal Galazka Study Day took place in early November at the Cicely Saunders Institute and online, and focused on palliative care for children.

The sessions looked at paediatric palliative care from the perspectives of children and their families, including siblings and the health and caregiving experiences of parents of children with a life-limiting condition.

Experts included Professor Lorna Fraser, Professor Katherine Sleeman and Dr Katherine Bristowe from the Cicely Saunders Institute, Professor Claire Cassidy, University of Strathclyde, Toby Porter, Chief Executive of Hospice UK, Zillah Bingley, Chief Executive Rainbow Trust, James Cooper, Together for Short Lives, Dr Emily Harrop, Association for Paediatric Palliative Medicine, Sophie Andrews, Noah's Ark Children's Hospice and Dr Liz Bendle, Evelina Children's Hospital.

The Michal Galazka Study Day is named in honour of Michal Galazka, a friend and collaborator of Cicely Saunders who established the Hospice Education Institute in the United States.

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