Summer 2023

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. I am delighted to report a busy and successful 2023 so far.

In May we had our biennial review and visit from CSI's International Scientific Expert Panel (our first in-person meeting since 2018) and we have been working with national and international stakeholders and policymakers to change the way services are organised and delivered. You can read more in this newsletter.

We've come a long way since Irene Higginson, Dick Giordano and I agreed with Dame Cicely Saunders that we should establish the charity Cicely Saunders International and carry on the research that she had started at St Christopher's Hospice. After more than 20 years as Chair of CS International I'm now passing the baton to fellow trustee Kate Kirk, Dame Cicely's niece. I'm stepping down secure in the knowledge that with a new Chair and a fine group of trustees alongside her the future is bright.

But there is still much to do to make sure that everyone can access the care they need, when they need it. We rely entirely on the generosity of our supporters. Please consider making a one-off donation, or joining Friends of Cicely Saunders to make a regular donation, and help us continue our work.

Thank you for your support.

John McGrath
Chair, Cicely Saunders International

"We are delighted to have presented our policy brief to key policymakers in Parliament. Too often people with dementia encounter barriers to accessing high-quality care and support towards the end of life. We hope that our recommendations can be used to inspire and drive improvements in care for the near-million people in the UK today, from diagnosis to the end of life."
Dr Lesley Williamson, PhD Fellow at the Cicely Saunders Institute

Four ways to improve end-of-life care for people with dementia

Efforts to improve the quality of end-of-life care for people with dementia are urgently needed. CS International's programme Palliative Care for Older People is funding research at the Cicely Saunders Institute into how patients with dementia and their families can be supported better with dementia-focussed palliative care.

Dementia is the leading cause of death in the UK today. Most people with dementia will attend the emergency department at least once in their last year of life and spend an average 20 per cent of their last six months of life in a hospital bed. The number of people dying with palliative care needs is expected to more than double over the next two decades.

To coincide with Dementia Action Week, researchers and academics from the Cicely Saunders Institute went to Parliament to present a new policy briefing: **A Right to be Heard: Better palliative and end-of-life care for people with dementia**.

Informed by the latest evidence, the briefing includes four calls to action for policy makers:

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

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

Better-B: public participation working group

Researchers based at the Cicely Saunders Institute are investigating how results from the BETTER-B study will be presented and disseminated to patients, their caregivers and the wider public.

BETTER-B stands for Better Treatments for Breathlessness in Palliative and End of Life Care. The team surveyed doctors about their current practice and how they are using existing guidelines. The survey suggests there are wide variations in how breathlessness is managed. People are receiving different levels of care based on where they are treated and the disease that they have. Some people may be seen by a respiratory specialist, while others may be treated by palliative care specialists. There is also a need for better treatments to manage the condition.

The team then moved on to testing an antidepressant called mirtazapine to see the effect on a person's breathlessness and quality of life.

Data collection in the trial completed at the end of June 2023. At the end of the study, the team will produce new European guidance for respiratory and palliative care specialists. This will provide expert-led advice to professionals on how to best manage breathlessness.

The team are currently discussing with people with a lived experience of breathlessness (or caring for someone with breathlessness) to find out what formats they should use to make the results most accessible, how the dissemination plan should be implemented, and how to increase its reach, particularly to underserved/underrepresented groups.

Please contact us if you would like to participate, or if you have questions about the project – **admin@cicelysaundersinternational.org**

Hospital- and home-based palliative care in Vietnam: better care for patients

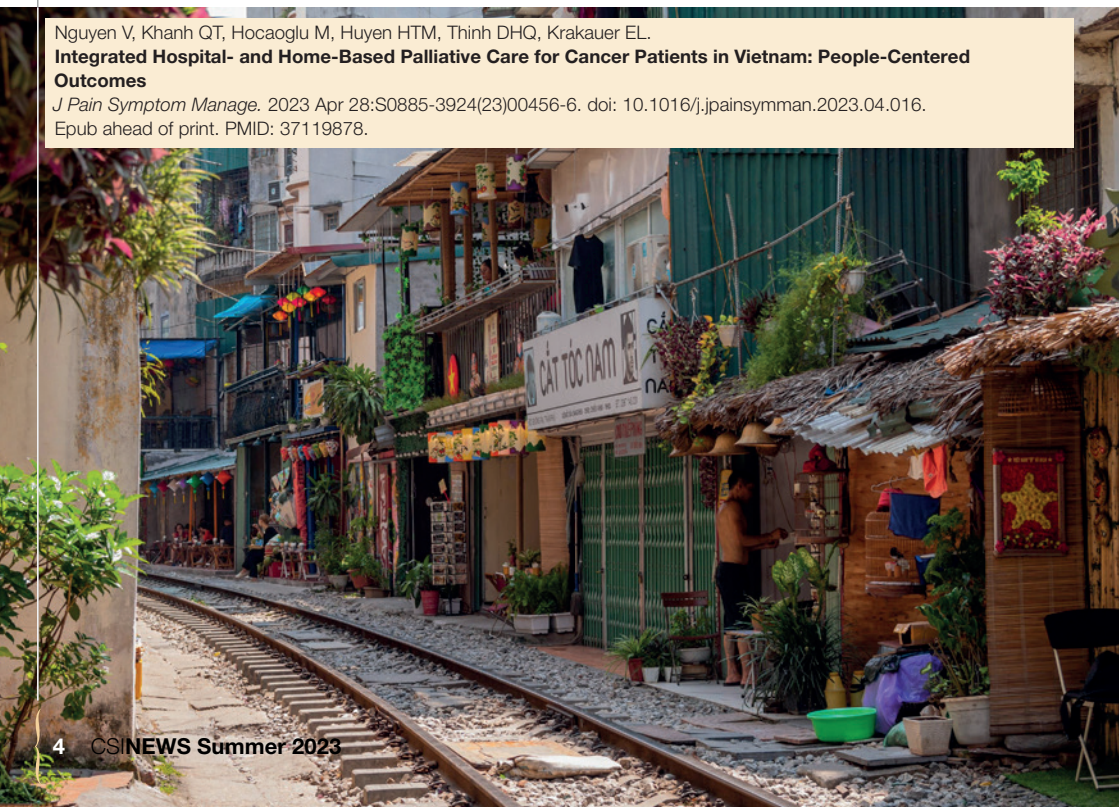
Hospital-based palliative care linked to palliative home care is rarely accessible in low- and middle-income countries. Researchers set out to study people-centred outcomes of a palliative home care team based at a major cancer centre in Vietnam.

The palliative home care team, consisting of at least one physician and one nurse, provided home palliative care when needed by patients of the cancer centre who lived within 10 kilometres. A linguistically validated version of the Palliative care Outcome Scale (POS) was integrated into standard clinical data collection.

Results showed that there was great demand for palliative home care. From baseline to follow-up, there was significant improvement in pain regardless of the baseline severity of pain and significant improvement in breathlessness, nausea/vomiting, diarrhoea, depression and worries about the illness.

The researchers concluded that the integration of hospital- and home-based palliative care for cancer patients is feasible and improves people-centred outcomes at low cost in Vietnam. The research was developed via the Globalcare and Fellowships programme, funded by CS International and The Atlantic Philanthropies.

Nguyen V, Khanh QT, Hocaoglu M, Huyen HTM, Thinh DHQ, Krakauer EL.
Integrated Hospital- and Home-Based Palliative Care for Cancer Patients in Vietnam: People-Centered Outcomes
J Pain Symptom Manage. 2023 Apr 28:S0885-3924(23)00456-6. doi: 10.1016/j.jpainsymman.2023.04.016. Epub ahead of print. PMID: 37119878.



The CovPall study

Although many people recover from COVID-19, some have very severe symptoms, and are supported by the palliative care teams. During the pandemic palliative care services and hospices rapidly changed how they worked to support existing patients who do not have COVID-19, and those with COVID-19 who have severe symptoms or are dying.

The CovPall study captures how palliative care and hospice services have changed, how their staff, volunteers and others have adapted what they do, and their challenges and innovations during the pandemic, from a total of 458 palliative care services of which 277 were from the UK. The study captures symptoms and problems, treatments and therapies that are used, and what seems to work best.

Palliative care services supported people during the COVID pandemic and developed 'frugal innovations' to care for more people. Palliative care can control symptoms in persons severely ill with COVID with symptoms such as breathlessness, cough, pain, anxiety, confusion/delirium, agitation, fever, sore/dry mouth, and nausea significantly reduced between first and last assessment during palliative care.

The study identifies that breathlessness, agitation and more than one pre-existing health condition are potential triggers to prioritise future referrals and timely care.

Sarah Perman, Director of Health and Care Integration at Hertfordshire County Council said: *"The CovPall findings demonstrate the essential role that palliative care services played during the pandemic. This has important implications for health and care partners working in Integrated Care Systems – not just for planning for future pandemics but for thinking about improvements to every day service provision. With the increasing demand for palliative care as people live longer and with more complex needs, these findings point to the importance of making sure that the role of palliative care is understood by managers, clinicians and the public, and that services support equitable access and early referral."*

CONFERENCE NEWS:

EAPC World Congress

The theme of this year's Congress was Equity and Diversity.

The EAPC task force for improving palliative care for LGBT+ people presented the English language version of recommendations for health and social care practitioners, organisations and policy makers. Co-ordinator Dr Debbie Braybrook said:

"We are looking forward to working with partners across 16 countries to develop translations for use in other languages."

Other EAPC sessions included presentations of UK data from the Children's Palliative Care study, and a session on identifying and meeting the needs of minority ethnic patients and families. Smriti Rana from Pallium India delivered a powerful talk which honed in on the problems of framing palliative care delivered in the global south through knowledge and resources developed in the global north.

CONGRATULATIONS:

Dr Sabrina Bajwah

Congratulations to Dr Sabrina Bajwah who has been awarded the King's Changemaker Award for her work to challenge structural racism in palliative care.

The award celebrates a King's graduate who uses their knowledge with purpose to challenge the status quo and shift traditional norms to address challenges in society.

A King's double alumna and Clinical Senior Lecturer at the Cicely Saunders Institute, Sabrina's work is challenging structural racism in palliative care, and changing the way medical professionals work to provide equitable care for ethnically diverse patients. During the first wave of COVID-19, she worked with companies to quickly produce translations of key advice into 25 languages.

Sabrina's research showed that UK-wide policies during COVID-19 negatively impacted people from ethnically diverse groups at the end of their lives. Her research found a lack of understanding by healthcare providers about the difference between equal and equitable care, which can lead to distress and inequality in outcomes.

"Even if the changes that we bring about are small, they are important. Lots of small changes will snowball, and each day we will move a little bit closer to equity."
Dr Sabrina Bajwah

CONGRATULATIONS:

Yok Sakharang

Congratulations to PhD student Yok Sakharang who has won the King's 'Spring on Campus' Photo Competition.

Yok is a PhD student at the Cicely Saunders Institute and her photo (above) features students on a sunny day at the Denmark Hill campus with flowering cherry trees in full bloom.

"I really enjoyed taking photos for this competition, the flowers were lovely and my friends and I had a great time."
Yok Sakharang

EVENTS ROUNDUP:

Reminding patients they matter

On 22 May, Professor Harvey Chochinov gave the 2023 Cicely Saunders International Annual Lecture online.

2,800 people registered to attend the lecture, entitled 'Intensive Caring: Reminding Patients They Matter'. Referencing his early work with Dame Cicely Saunders in the 1990s, Professor Chochinov's lecture explored the concept of putting patients at the centre of their care and the complexities around ensuring that patients are truly 'seen' by healthcare professionals.

"Hard-edged studies demonstrate that abandonment, the absence of someone who cares, is strongly connected to a patient's desire for death and that being present is protection against suicidal ideation in young adults with cancer, for example."

Professor Harvey Chochinov in the 1990s with Dame Cicely Saunders in her office at St Christopher's Hospice.

Professor Chochinov also highlighted the limitations of the 'golden rule' when a clinicians' own point of view/subjective assessment interferes with delivering goals of care based on the patient's own wishes.

Dr Harvey Max Chochinov is a distinguished professor of psychiatry at the University of Manitoba and a Senior Scientist at CancerCare Manitoba Research Institute.

His research in palliative care has resulted in more than 300 career publications, broaching diverse topics such as depression, quality-of-life, suicide, vulnerability, spirituality, and existential distress. He has also led a large program of research on dignity within the healthcare setting, which includes the development and study of Dignity Therapy. He is a member of CS International's panel of scientific experts.

The lecture is available on the Institute's YouTube channel.

EVENTS ROUNDUP:

Inaugural lectures

On 28 June, Professor Catherine Evans and Professor Katherine Sleeman gave their inaugural lectures at the Cicely Saunders Institute.

The event was an opportunity for colleagues, friends and supporters to come together and celebrate their personal journeys in academia, their research achievements so far, and hear about the impact of their research on clinical practice.

In their lectures, both Professor Sleeman and Catherine Evans acknowledged the importance of research funding in their early careers from CS International.

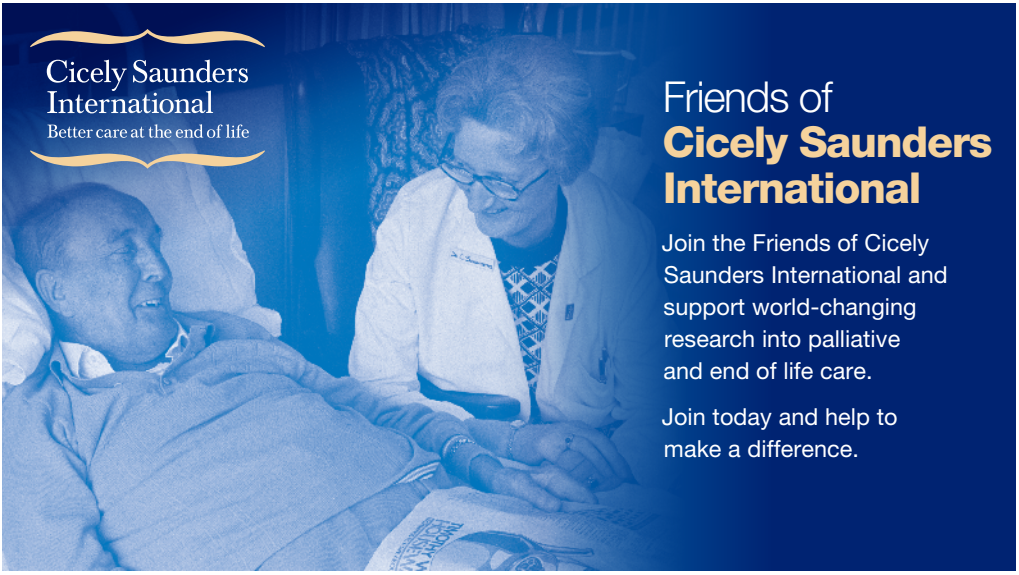
EVENT NEWS:

Science Museum Lates

Date: Thursday 27 July 2023, 18.30 – 22.00

Explore the power of play and its potential to change minds, improve wellbeing and boost your brain at an evening that celebrates 75 years of the NHS.

The **EMBED-Care** (Empowering Better End of Life Dementia Care) team from the Cicely Saunders Institute will have a stand called 'The D words' featuring a card game, quiz and a wishing tree to make you think about what matters. This event is for ages 18 and over. The doors will open at 18.45 and last entry is 21.15. It's free but please register to attend. **sciencemuseum.org.uk/see-and-do/science-museum/gaming-lates**



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