Summer 2024

CSINEWS

news from cicely saunders international

Cicely Saunders International
Better care at the end of life



Commitment to openness, openness to challenge and the absolute priority of patients' own view on what they need.

Dame Cicely Saunders

Welcome to the summer edition of CSI News.

Palliative care is about helping you to live. But one in four people in the UK don't know much about palliative and end-of-life care or haven't heard of it. For some groups in society the statistics are even more troubling.

Thoughtful, expert end-of-life care is an essential right for every individual. But high-quality palliative care is much more than that. It is about enabling individuals – young and old – to live their lives better. This affects millions of people every day. That is why the need for ongoing palliative care research, education and training is so pressing.

Tackling public misunderstanding about what palliative care is, and how palliative care can help when people are living with serious illness is urgent, and that's why we are fundraising for a new policy centre at the Cicely Saunders Institute – a 'one-stop shop' to gather and share reliable information about palliative care and empower people to get the support they need.

The new Centre will also teach evidence-based methods to healthcare workers, helping them to gain the skills, knowledge and confidence needed to provide good palliative care, and it will work with policymakers to improve how palliative care services are delivered.

We rely entirely on your generosity to continue this work.

Thank you for your support.



Gareth Williams
Trustee

65 per cent of adults are worried about access to palliative care

A YouGov survey commissioned by the Cicely Saunders Institute found that 65 per cent of people in the UK are worried about getting care at the end of their lives, and 41 per cent think the NHS does not spend enough on this kind of care.

The survey asked 2,164 adults in the UK about what they know and think about palliative and end-of-life care. The results were shared before a UK Parliamentarians' debate about assisted suicide/ assisted dying.

Results from the survey showed that nearly one in four people (24 per cent) in the UK don't know much about palliative and end-of-life care, or haven't heard of it. There are differences in knowledge between white people and people from ethnic minority groups.



The survey found that 22 per cent of people from ethnic minority groups haven't heard of end-of-life care, compared to four per cent of white people. Also, 18 per cent of people from ethnic minority groups think end-of-life care means giving people medicines to shorten their lives, compared to five per cent of white people.

As UK MPs may debate the issue in the next parliament, experts say it's very important for people to learn more about palliative and end-of-life care.

The survey also showed that almost one in three people from ethnic minority groups (30 per cent) don't trust healthcare professionals to give good care at the end of life, compared to 17 per cent of white people.

Professor Katherine Sleeman, Laing Galazka Professor of Palliative Care at the Cicely Saunders Institute, said: *"The fact that 65 per cent of UK adults say they are worried about access to palliative and end-of-life care should be a wake-up call for current and future governments. This is especially important given the large increase in palliative care need that is projected over the next decade.*

"The shocking gap in the public's understanding of palliative and end-of-life care also needs to be addressed as the assisted dying debate gathers pace. It is highly concerning that many people believe that palliative care involves giving patients medicines in order to shorten their lives. Over 100,000 people in the UK die each year needing palliative care but do not receive it, and inequalities in accessing care, including among people from ethnic minority groups, are common. It is essential that we address the disparities that create additional barriers for people to access the care that they need. This includes an urgent need to improve death literacy among the public."

Dr Sabrina Bajwah, Clinical Senior Lecturer at King's College London said, *"We already know that ethnic minority patients are more likely to experience distress at the end of life. It is concerning to note that nearly one-third of respondents from ethnic minority groups lack trust in healthcare professionals' ability to deliver high-quality end-of-life care. With our population becoming increasingly diverse, it is imperative that we promptly address this inequality by enhancing palliative care and end-of-life services to effectively cater to the needs of these patients and their families."*



Dementia Journeys at Science Gallery London

Dementia Journeys: Towards Better End of Life Dementia Care, an exhibition at the Science Gallery London presented stories of people who have cared for loved ones dying with dementia, alongside Empowering Better End of Life Dementia Care (EMBED-Care) research findings, to highlight the ways in which palliative care for people with dementia should be improved.

Through portraits, cartoons and poetry, Dementia Journeys showed the experiences of three women – Tia, Fran and Keiko. Tia cared for her Nan, Cherry, until the end of her life, Fran cared for both of her parents, Bob and Pat, who were diagnosed around the same time and died 14 months apart, and Keiko continues to care for Javed, her husband of 46 years, who remains mobile but is no longer able to speak or smile.

By bringing these women's lived experiences together with research insights and artistic interventions, Dementia Journeys highlighted the complexity of needs experienced by people with dementia, and the significant and difficult role carers play to ensure comfort and dignity for people with dementia. The exhibition also invited visitors to consider their own wishes and priorities regarding end-of life care and our collective hopes for people living and dying with dementia.



The concept for Dementia Journeys emerged from **Empowering Better End of Life Dementia Care (EMBED-Care)** – a six-year research programme, the largest of its kind, jointly led by Professor Liz Sampson at University College London and Professor Catherine Evans at the Cicely Saunders Institute at King's. It has brought together clinicians, researchers, policy makers, patients, and families to catalyse a step-change in palliative care for people with dementia. The aim of Dementia Journeys is to spark public discussions around dementia, and engage millions of people in the conversation, by combining art, science and lived experience.



More about EMBED-Care

Dementia is the most common cause of death in the UK. By 2040 it's estimated that annually 220,000 people will die with dementia, with many experiencing distressing symptoms like pain and agitation. Access to good care for people with dementia towards the end of life is highly unequal.

Professor Katherine Sleeman, EMBED-Care's public and policy engagement lead said: *"Both death and dementia are taboo subjects in our society. And yet, dementia is the leading cause of death, and the number of people dying with dementia is anticipated to increase several times over the next decades. Palliative care can improve physical comfort as well as psychological, spiritual, and social concerns for people with dementia. But only half of the public know that palliative care is relevant for people with dementia.*

"This exhibition shines a light on caring for someone with dementia near the end of life. Shown through the eyes of three inspirational – but ordinary – women, we want our exhibition to spark conversations about the importance of good care towards the end of life and generate a groundswell of public support for improving dementia care."



Dr Mary Baines (1932–2020)

The biography of physician Dr Mary Baines has been published in the Oxford Dictionary of National Biography.

In 1969 Dr Baines was the driving force behind the establishment of St Christopher's (Hospice) home care service, a pioneering approach that cared for patients in their own familiar surroundings, and an approach that is now replicated worldwide.

Dr Baines carried out pioneering research at the hospice, published textbooks and spoke at conferences about hospice and palliative care, devoting much time to supporting training for hospices in Eastern Europe and Africa. Some of the techniques she developed, for example to manage bowel obstruction, are still in use today.

To read the full entry please visit:
https://bit.ly/3RSwLjy

SELF-BREATHE: an individualised approach to managing breathlessness



Chronic breathlessness affects two million people in the UK and 75 million people worldwide. The symptoms may persist even after the best treatment for the underlying condition, like cancer, lung disease, or heart failure.

Chronic breathlessness is hard to treat because it has complex causes and effects. How well treatments work can vary based on the individual person's characteristics, specific condition, and how the breathlessness presents itself.

Understanding complex chronic breathlessness is important for managing it well. Researchers at the Cicely Saunders Institute wanted to find out how patients feel about their illness and how they deal with living with severe breathing problems.

They studied data from a randomised controlled trial called SELF-BREATHE, for people with chronic breathlessness. They found that how patients think about their breathlessness and their emotional reactions to it were linked to more severe breathlessness, more distress, less ability to manage their symptoms on their own, and a lower quality of life.

The researchers concluded that helping patients change how they think about their illness and how they respond to breathlessness might reduce their symptoms and improve their quality of life.

Reilly CC, Higginson IJ, Chalder T. **Illness perceptions, cognitive and behavioural responses to chronic breathlessness in individuals living with advanced respiratory disease: an observational study.** ERJ Open Res. 2024 Apr 29;10(2):00874-2023. doi: 10.1183/23120541.00874-2023. PMID: 38686180; PMCID: PMC11057503.



Improving palliative care for children and their families: adapting the C-POS for non-verbal children

Researchers at the Cicely Saunders Institute are working to improve the C-POS tool, which measures the well-being of children with serious illnesses.

The team conducted a study with children aged five to 17 and their parents from 14 sites in the UK. They aimed to see if the C-POS tool was understandable, comprehensive, relevant, and acceptable. They found that the C-POS questions were generally good, but they made some adjustments to include non-verbal children. For example, they added options for children to express their feelings in different ways, rather than just describing them.

They also simplified some terms, like changing 'living life to the fullest' to something easier to understand.

Parents mentioned that filling out the C-POS can be distressing, but they believe it is important.

In conclusion, the researchers improved the C-POS tool, making it more inclusive for non-verbal children and acceptable for use in everyday practice.

Coombes L, Braybrook D, Harðardóttir D, Scott HM, Bristowe K, Ellis-Smith C, Fraser LK, Downing J, Bluebond-Langner M, Murtagh FE, Harding R. **Cognitive testing of the Children's Palliative Outcome Scale (C-POS) with children, young people and their parents/carers.** Palliat Med. 2024 Jun;38(6):644-659. doi: 10.1177/02692163241248735. Epub 2024 May 6. PMID: 38708863; PMCID: PMC11158001.

VISITORS:

Maison Medicale Jeanne Garnier

In June we were delighted to welcome visitors from Maison Medicale Jeanne Garnier, a palliative care centre in Paris.



The centre has six palliative care in-patient units looking after approximately 1,200 patients. Their mobile team works in four partner hospitals caring for around 1,000 patients. They have a research and education programme with 540 trainees, with an additional 75 trainees in community services and nursing homes.

The visitors included clinical health professionals from the main hospice unit, and GPs working in practices in the community – Lyn Silove, Isabelle Lesage, Emmanuelle Quillet, Anne de la Tour, Emmanuel Bagaragaza, Julia Revnic, Sophie Chretien, David Guigou and Elie Fabre.

As part of a wider visit to hospices in the UK, the visitors met with Professor Catherine Evans, Dr Lisa Brighton, Dr Mev Hocaoglu, CSI Trustee Professor Sir Cyril Chantler and Administrative Director Sian Best to discuss recent developments in clinical care, training and research.

VISITORS:

Dr Juan Esteban Correa-Morales

In April we welcomed Dr Juan Esteban Correa-Morales on a three-month internship to the Cicely Saunders Institute.

He writes: *"I am a palliative care consultant from Colombia who was inspired to pursue this field by the book 'Beyond the Horizon' by Dame Cicely Saunders. Following the book's title, I embarked on the adventure of crossing many horizons to visit the institute that carries her legacy and stands as a beacon of cutting-edge research.*

"Colombia is a middle-income country in South America with 0.4 specialised services per 100,000 inhabitants. The country is currently part of a trial of the Lancet Commission Essential Medication package and has created the Latin American Observatory of Palliative Care as it implements its public health palliative care strategy 2022–2026.

"I am immensely grateful for the wonderful time I have had at the Cicely Saunders Institute, where I have been deeply impressed by the research being conducted and the institute's unwavering commitment to inclusion. The person-centred approach, combined with a supportive and collaborative environment, make it a unique and inspiring place to work and learn.

"I finish this brief three-month internship wanting to replicate in my country the CSI's standard of excellence in clinical care, research, and community engagement.

"I hope my experience at the Institute will lead me to better contribute to these initiatives, develop novel solutions to the country's geographical disparity challenge, and drive forward the palliative care agenda in Colombia."

Juan Esteban Correa-Morales
Palliative Care Consultant and Researcher
at the Colombian Observatory of Palliative Care

EVENTS ROUND UP:

Pint of Science



Pint of Science is an annual worldwide science festival which brings researchers to a local pub/cafe/ space to share their research with the public.

Dr Annabel Farnood and Dr Emel Yorganci from the **Empowering Better Dementia End of Life (EMBED-Care) research programme took** part in the Brainstorming Dementia series of the Pint of Science Festival at a pub in Chelsea, London.

In their talk titled *You, me and dementia: Why dementia should be everybody's business!* the researchers engaged with the audience about how palliative care improves the lives of people with dementia.

UPCOMING EVENT: CS INTERNATIONAL LECTURE 2024

Timely Integration of Oncology and Palliative Care: A Rapidly Evolving Paradigm

Date: Tuesday 1 October 2024, 16.00
Location: Online
Speaker: Dr David Hui
Registration:
eventbrite.co.uk/e/cicely-saunders-international-annual-lecture-2024-tickets-883263323377

Dr David Hui holds the Dallas Fort Worth Living Legend Professorship at the University of Texas MD Anderson Cancer Center, Houston, USA.

This lecture will highlight research about the effectiveness of integrating palliative care early alongside curative treatment, as currently recommended by oncology guidelines in the United States. The lecture is aimed at oncologists and palliative care specialists and non-specialists in all clinical settings.



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…