Winter 2023

CSINEWS

news from cicely saunders international

Cicely Saunders International
Better care at the end of life

How people die remains in the memories of those who live on… we must enable the patient to live until they die, and the family to go on living afterwards.

Dame Cicely Saunders

I am delighted to introduce this latest newsletter from Cicely Saunders International as Chair of Trustees. John McGrath stepped down in July, after 22 years of outstanding service, and the Cicely Saunders Institute is merely one of many testaments to his drive and commitment in furthering the cause of palliative care and upholding the legacy of Dame Cicely Saunders.

You could say that Cicely Saunders International and the Institute are well-placed, globally recognised and delivering over and above initial expectations. Indeed, when you read the stories in this newsletter, which cover only a few of the many successes and advances, you might think that we're coasting comfortably.

This is very much not the case. We know that palliative care needs will rise dramatically in the next 20 years, we know that many groups in society cannot access the care they need, and we know that the concept of palliative care is still poorly understood.

There is plenty more work to do. Thank you for your support.

Kate Kirk
Chair, Cicely Saunders International

Cicely Saunders International welcomes new life president and chair

After 22 years at the helm of Cicely Saunders International, John McGrath has stepped down as Chair and Trustee to become a Life President of the charity, alongside former Trustee Christopher Saunders. The charity's new Chair is Trustee Kate Kirk, a niece of Dame Cicely Saunders.

In 2001, palliative care pioneer Dame Cicely Saunders recognised that treatments for those with terminal or life-limiting conditions were being introduced with little evidence of their effectiveness. She also knew that there was a major lack of clinical training in specialist palliative care. Dame Cicely and a group including John McGrath, the late Sir Richard Giordano, Sir David Walker and Sir David Simon came together and created the Cicely Saunders Foundation, a palliative care charity now known as Cicely Saunders International.

John McGrath became Chair of the new charity in 2001 and started fundraising for palliative care research and training. He was in the process of stepping down from senior management positions in business and brought with him a wealth of experience from roles such as Director of ITV plc, Chair of The Boots Company and Group Chief Executive of Diageo plc. He was introduced to palliative care by his colleague at Grand Metropolitan, Richard Giordano, who met Cicely Saunders in the 1970s when he was raising funds for Calvary Hospice in New York.

Initially, the research funded by the charity focused on the management of breathlessness, a particularly distressing yet often neglected symptom, and home-based palliative care. It quickly became clear that what was really needed was a research institute that would transform palliative care by acting as a hub for integrating research-based evidence into clinical practice and service delivery. Ten million pounds was raised and the Cicely Saunders Institute of Palliative Care was established in partnership with King's College London. The Institute, situated in the grounds of King's College Hospital, was officially opened by Her Royal Highness Princess Anne in May 2010. It is the world's first purpose-built centre for palliative care integrating research with clinical care and education, and is a designated WHO Collaborating Centre.

Cicely Saunders International continues to fund research and training in all aspects of palliative care. The charity works closely with the Institute to support its development, assisted by a panel of international scientific experts. The Institute provides training to people across the UK and internationally in palliative care, building much needed capacity and skills, as well as building the evidence needed to improve not only care, but also related health policy.

John said: *"I met Cicely in 2000, and after just an hour chatting with her, I committed to help carry on her amazing work into the future. 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 Cicely Saunders 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."*

Professor Irene Higginson, Scientific Director of Cicely Saunders International said: *"John McGrath's dynamic management was pivotal during the fundraising stage for the Cicely Saunders Institute. He skilfully led the partnership with King's College London and ensured the construction of the Institute was finished on time and on budget. Many colleagues in my team have benefited, and continue to benefit enormously, from his wise counsel and his unceasing commitment to the work being carried out in palliative care. I believe that he demonstrates superbly the value of lending business acumen to the voluntary sector."*

Kate Kirk, new Chair of Cicely Saunders International said: *"Without John McGrath's involvement in Cicely Saunders International, without his drive and commitment, the Institute might well not have come into existence and certainly would not have made the outstanding progress of the last ten years. Because of his passion and dedication, the Institute has grown from a cold start to a position where its contributions to the way palliative care is viewed and carried out are recognised around the world. But we cannot afford to relax. We must use the firm foundations that John and others with his vision have created to build towards a world where high quality palliative care is available to all who need it."*

ISEP Chair awarded Fellowship of King's College London

Professor Eduardo Bruera MD FAAHPM has been awarded a Fellowship of King's in recognition of his exceptional fundraising for King's Cicely Saunders Institute and for the continuous academic and strategic leadership he has provided to the King's community.

Professor Bruera is recognised across the globe as a world leader in palliative care and his work has been cited more than 50,000 times. He is Chair of the International Scientific Expert Panel for Cicely Saunders International and Chair of the **Department of Palliative, Rehabilitation and Integrative Medicine** at the University of Texas MD Anderson Cancer Center.

Professor Eduardo Bruera (seen here on the left, on a visit to the Institute) said: *"I am delighted to have received a Fellowship of King's. As a close friend and collaborator of Dame Cicely Saunders, I supported the initial fundraising for the Cicely Saunders Institute at King's College London. Now that the Institute has been established for over a decade, I am honoured to continue to shape its future direction and to mentor researchers who become the palliative care leaders of the future."*

Professor Bruera's work on cancer cachexia has opened new lines of treatment and his work on pain management has increased the availability of pain medicines for those who need them. He pioneered and built a spring loaded syringe driver for use in countries where batteries were scarce and was one of the first to research treatments for breathlessness in cancer.

Through his collaborations with both the World Health Organization and the Pan American Health Organization, Professor Bruera has contributed to the development of palliative care around the world. The Edmonton Symptom Assessment Scale (ESAS) he developed is now used across the globe and has been translated into more than twenty languages. Training others has defined Professor Bruera's career. Over the years, he has trained hundreds of physicians who are currently practising palliative care and oncology around the world.

"Professor Bruera is one of the most important people globally in palliative care. In addition to this immense contribution to the field of palliative care internationally, Professor Bruera has devoted time over his career to guiding and advising the development of the world's first purpose-built Institute of Palliative Care – the Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation – at King's College London."
Professor Irene Higginson, Scientific Director, Cicely Saunders International

£25m funding to tackle health and social care issues

The National Institute for Health and Care Research (NIHR) has awarded King's College London £25m to tackle important long-standing and emerging health and social care issues.

The award is part of an £100 million funding boost to 20 new Policy Research Units (PRUs) across England, funded by the NIHR's Policy Research Programme. It includes a new PRU for palliative and end of life care at the Cicely Saunders Institute.

Each unit will bring together a multidisciplinary team of researchers to create a critical mass of leading experts with the ability to work dynamically with policy teams to address key research questions. The PRU researchers will respond to policy research needs and develop research programmes that provide evidence for current and emerging research priorities.

Professor Katherine Sleeman, Laing Galazka Professor in Palliative Care, who was awarded £3m to lead the PRU for palliative and end of life care, said: *"We are delighted to have been awarded an NIHR Policy Research Unit for palliative and end of life care. Our Policy Research Unit will support policy makers to improve care, and reduce inequalities, for children and adults affected by life-limiting illnesses, and their families and carers. Too many people die without having received the care and support they need to live as well as possible until the end of life. We hope our Policy Research Unit will catalyse a step-change in care for those affected by dying, death and bereavement."*

Professor Lucy Chappell, Chief Scientific Advisor DHSC and Chief Executive of NIHR, said: *"In the NIHR, we have a range of ways to make sure that health and care research benefits patients and the public. The NIHR's new Policy Research Units are designed to provide strong evaluation of policy. This helps government and related organisations to be able to act on the latest evidence when making decisions about health and social care that could impact us all.*

"We are funding Policy Research Units across a range of key areas of policy ranging from cancer screening to social care. Several new topics will expand the ability of the units to help address the major healthcare challenges that we are facing, including improving reproductive health, tackling addiction as well as dementia and neurodegeneration."

Survival and critical care for patients with dementia

Critical care admissions for people with dementia are increasing for those in their last year of life. A study led by the Cicely Saunders Institute has found that whilst critical care admissions for people with dementia are going down, they are increasing during the last year of life.

The study included people with dementia identified from South London and Maudsley NHS Foundation Trust, which covers four South London boroughs (Southwark, Lambeth, Croydon, Lewisham). The researchers found that whilst the number of people with dementia admitted to critical care units has decreased over the years, there is a small increase in admissions for people with dementia in the last year of life. This study does not compare these trends with critical care admissions data for people without dementia in their last year of life.

Critical care admissions can be lifesaving, but a significant proportion of patients admitted to critical care will die in hospital. The one-year survival of people with dementia following a critical care admission is 48 per cent, which is similar to that observed in general older populations. Careful consideration of care needs, a multidisciplinary approach and communicating with the patient and their families about preferences and end-of-life wishes are all vital for care planning during critical care admissions.

In the first study of its kind, the Empowering Better End of Life Care (EMBED-Care) team at King's College London and University College London were able to track critical care admissions of people with dementia in South London by linking data from the South London and Maudsley's Clinical Record Interactive Search (CRIS) with national hospital records.

Emel Yorganci, lead author and ESRC PhD Training Fellow at King's College London said:

"As the number of people living and dying with dementia is increasing, understanding how we can provide high-quality, equitable care to people with dementia until the end of their lives must be a priority. Having access to data can give an insight into care experiences of people with dementia and help to shape and improve the quality of the care they receive.

"Better quality, nationwide data on the use and quality of dementia healthcare is an important next step to provide evidence that can inform service planning for people with dementia and improve their care."

Yorganci E, Sleeman KE, Sampson EL, Stewart R, The EMBED-Care Programme,
Survival and critical care use among people with dementia in a large English cohort
Age and Ageing. Volume 52, Issue 9, September 2023, afad157, https://doi.org/10.1093/ageing/afad157

Improving the quality of life for care home residents with chronic diseases

When nearing the end of their life, care home residents with chronic diseases can often find themselves in and out of hospital. This affects their quality of life and is distressing for both them and their families.

Integrated palliative care is a coordinated strategy that brings together all the people involved in caring for a person towards the end of their life. This model of care can help keep older people comfortable and out of hospital; however, UK care homes often don't have the processes or systems in place to support this model of care for their residents with chronic conditions.

People with chronic conditions can end up in hospital as they near their end of life because their symptoms become harder to control. Once there, it can be much harder for them to recover enough to return to their care home. The researchers wanted to understand how to improve care for this vulnerable group of people as they move towards the end of their lives. So the ICPP project was born.

Researcher Dr Anna Bone said: *"We were just about to start our project when the COVID-19 pandemic hit. This really shone a light on the struggles and pressure care homes can face. We seized this opportunity to collect timely insights about how they were coping and the level of care they were able to provide during this time. This crucial data was passed to NHS Improvement to advise them about what additional support care homes urgently needed.*

Researcher Dr Clare Ellis-Smith said: *"Integrated palliative care can help care staff feel more supported and enable them to provide improved end-of-life care for residents. If we get the principles for an ICPP right, we can meet people's needs better. For example, we can pick up distress and worsening physical symptoms much earlier which can reduce avoidable hospital admissions.*

Proper integrated palliative care can also help care staff feel more supported and enable them to provide improved end-of-life care for residents.

"All of these improvements in the provision of care have huge positive impacts on an individual's quality of life. With the right support, we can help make someone's final years much more comfortable. This is ultimately what we want to achieve with our ICPP.

"Our economic modelling also showed that implementing ICPP could save the NHS money when the objectives of integrated care are achieved, as fewer people are admitted to hospitals."

This work was funded by the Dunhill Medical Trust and Cicely Saunders International.

Bayly J, Bone AE, Ellis-Smith C, Tunnard I, Yaqub S, Yi D, Nkhoma KB, Cook A, Combes S, Bajwah S, Harding R, Nicholson C, Normand C, Ahuja S, Turrillas P, Kizawa Y, Morita T, Nishiyama N, Tsuneto S, Ong P, Higginson IJ, Evans CJ, Maddocks M. **Common elements of service delivery models that optimise quality of life and health service use among older people with advanced progressive conditions: a tertiary systematic review.** *BMJ Open. 2021 Dec 1;11(12):e048417. doi: 10.1136/bmjopen-2020-048417. PMID: 34853100; PMCID: PMC8638152.*

OBITUARY:

Tribute to 'The Invisible Philanthropist' Chuck Feeney

Cicely Saunders International pays tribute to the Irish-American philanthropist Chuck Feeney who has died in San Francisco aged 92.

JIM WILSON/NEW YORK TIMES/REDUX/EYEVINE

Charles F Feeney was a pioneer of duty-free shops and an investor in technology start-ups who gave away nearly all of his $8 billion fortune to charity, much of it anonymously. He was born in New Jersey in 1931 and after serving as a radio operator in the Korean War and attending Cornell University, formed a partnership with fellow Cornell alumnus Robert Miller in 1960 to sell duty free items at Mediterranean ports to US military personnel returning home to the United States. The company they founded, Duty Free Shoppers, went on to become a multi million dollar global business, investing in hotels, retail and clothing.

In 1982 Chuck Feeney decided to give his personal fortune away during his lifetime and established a group of foundations by transferring his personal stake in DFS (estimated to be in the region of USD $500 million) to start what became The Atlantic Philanthropies.

The Atlantic Philanthropies donated a total of USD $16,287,455 for the Institute, its capacity building programmes and an endowed professorship in palliative care.

John McGrath, Life President of Cicely Saunders International said: *"I met Chuck in 1994, on business; standing in his office he was in crumpled chinos, and a Hawaiian T-shirt – a unlikely billionaire. However, he was an extraordinary human being. He was determined to give away all his assets during his lifetime. And he was extremely thorough in his analysis of who and which project he should support. Over several years in the early 2000s, he gave Cicely Saunders International over £10 million but believe me we really had to work for it because he looked into every possible detail and pushed us to ensure that the project was great value for money. The world will miss him."*

Kate Kirk, Chair of Cicely Saunders International said: *"Although I never met Chuck, every time I go into the Cicely Saunders Institute I see his legacy – in the building, in talking to the researchers, in the culture of sharing and generosity. He touched, inspired and supported the work of Cicely Saunders International and the Institute in so many ways, and we will continue to honour his memory in everything we do."*

Here I Stand

On 06 November Professor Katherine Sleeman joined Dr Rachel Clarke and Amber Jeffrey to speak at a lecture hosted by St-Martin-in-the-Fields entitled *Here I stand: Death & Dying*.

The lecture was part of this year's St Martin-in-the-Fields Autumn Lecture Series, inspired by the celebrated words of Martin Luther, to investigate those things in which we believe deeply – and for which we would be prepared to make a stand.

As well as a live audience, the lecture was live-streamed online and covered issues such as how we approach death, dying and the loss of those we love. **The lecture is also available to watch online on demand until 31 December 2023.**

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Welcoming Professor Mette Neergaard and her colleagues

On 01 November Cicely Saunders Institute welcomed Professor Mette Neergaard and colleagues from Aarhus University Hospital, Denmark during their visit to the UK. Professor Neergaard is professor and senior consultant in palliative medicine. Her colleagues included doctors, nurses, a psychologist, social work and physiotherapist.

Their Specialist Palliative Care Unit is based at Aarhus University Hospital, the largest and highest internationally-ranked hospital in Denmark and one of the largest in Europe:**en.auh.dk**.

The Unit is a multi-disciplinary, specialist palliative care team and provides specialist outreach services in patients' homes, care homes and hospitals. Doctors on the team also do rounds at the local hospices. The team includes nurses, physicians, a psychologist, social worker, physiotherapist, chaplain and administrator. The team also carries out research, development work and education. The service is for all patients with a need for specialist palliative care, ie all diagnoses and patients of all ages.

Celebrating Professor Lorna Fraser and Professor Matthew Maddocks

On 01 November families, friends and colleagues gathered at the Cicely Saunders Institute for the inaugural lectures of Professor Lorna Fraser and Professor Matthew Maddocks. The lectures were a fascinating account of their academic journeys in research so far and their contributions to the field of palliative care and their plans for the future.

Professor Lorna Fraser – A Tale of an Accidental Academic

Lorna Fraser joined King's College London as Professor of Palliative Care and Child Health in November 2022. Her background is in clinical paediatrics and her research focuses on children and young people. She was the founding director of the highly successful Martin House Research Centre a multi-disciplinary centre for research on the care and support of children and young people with life-limiting conditions, their families and the workforce that care for them. Her work has influenced national service specifications, children's palliative care funding, and vaccine prioritisation for children with COVID.

In 2018 Lorna was awarded the postdoctoral researcher award by the European Association of Palliative Care.

Professor Matthew Maddocks – Horizons

Matthew is an academic physiotherapist and Professor of Health Services Research and Rehabilitation. He completed his PhD on the role of exercise for people with cancer cachexia, and has held National Institute for Health and Care Research post-doctoral, clinical trials and career development fellowships.

His team undertakes applied clinical and health services research to advance rehabilitation and palliative care for people living with serious illness. This includes better management of complex symptoms such as breathlessness, fatigue, weakness, and timely multi-professional care for syndromes including cachexia, sarcopenia and frailty.

The inaugural lectures are available to view on the Institute's YouTube channel **@CSIKCL**

EVENTS ROUNDUP:

Michal Galazka Study Day 2023

Out-of-hours care for people with advanced illness

For people living at home with advanced illness, deterioration in health, severe symptoms and new problems can happen at any time, day or night. Therefore, at all times, people with advanced illness and their carers need to be able to access high-quality care that is accessible, integrated and safe. When care is not available, patients and carers may have no choice but to go to the Emergency Department.

This year's Michal Galazka Study Day presented recent research into out of hours care. Discussion focused on understanding the challenges and exploring potential solutions, to enable people to get the right care, at the right time, in the right place. Speakers included Professor Katherine Sleeman, Dr Alice Firth, Inez Gaczkowska and Dr Sarah Yardley. The panel discussion was chaired by Professor Gerry McGivern and panel members included Dr Emma Hall, from St Christopher's Hospice and Kate Heaps, Chief Executive of Greenwich & Bexley Community Hospice. Professor Catherine Evans thanked everyone for a highly stimulating and relevant discussion about the importance of skilled practitioners, and systems that enable deteriorating patients to remain in their usual place of care, being supported to live life well at home, and die peacefully.

For information about events at the Cicely Saunders Institute please email **csi.events@kcl.ac.uk**

UPCOMING EVENT:

Better Treatments for Refractory Breathlessness (BETTER-B) Conference

Join us for the BETTER-B Conference, an exciting online event, dedicated to exploring treatment options for refractory breathlessness.

Date: Monday 04 December 2023, 13:30 GMT

This conference brings together experts, researchers, people affected by breathlessness, policy makers, the public and healthcare professionals from around the world.

Through engaging presentations and interactive discussions, discover the treatment options for refractory breathlessness, a distressing symptom that affects individuals with various respiratory conditions, as well as the ethical aspects of carrying out an international, multi-centre, randomised controlled trial of a drug for this condition.

Don't miss this unique opportunity to connect with leading experts in the field. Whether you're a healthcare professional, researcher, policy maker, person affected by breathlessness or simply interested in the topic, this conference is a must-attend event.

Register now at **Eventbrite** to secure your spot and be part of the BETTER-B Conference.

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...