Summer 2022

CSINEWS

news from cicely saunders international

Cicely Saunders International
Better care at the end of life

Before making any attempt to consider what to teach others about the care of terminal illness, one must begin by looking at some of the things we must try and teach ourselves.

Dame Cicely Saunders

"How people die remains in the memory of those who live on," said Cicely Saunders. That quote is as relevant today as when first observed.

The Covid pandemic provides a stress test for health and care systems around the world. Thanks to research supported by Cicely Saunders International we know more about how to provide palliative care to relieve distressing symptoms and improve quality of life for people with conditions such as heart, lung or neurological diseases, cancer and Covid, at the same or lower costs to governments.

But there are unanswered questions about how best to improve symptoms and quality of life, and support families in better ways. There aren't enough people trained in palliative care, even to train others, and support is patchy.

Cicely Saunders International's **Action Plan for Better Palliative Care** provides an evidenced plan for improving care. We need your support to take the next steps. Please speak up for palliative care when you can. Please join Friends of Cicely Saunders International and consider making a regular donation to help continue this work. Thank you for your help in whatever way you are able to support us.

Professor Irene Higginson
Scientific Director, Cicely Saunders International

"I wanna live and not think about the future"

Listening to the voices of people with multiple sclerosis.

Researchers based at the Cicely Saunders Institute set out to investigate the understanding and relevance of advanced care planning (ACP) for people with multiple sclerosis (MS) and their families. The researchers conducted interviews with people living with MS and their families. This was followed by an ethical discussion group with five health professionals representing specialties working with people affected by MS and their families.

Three themes emerged from the interviews with people with MS and their families.

These were: planning for an uncertain future; perceived obstacles to engaging in ACP (including previous negative experiences, and uncertainty) and the importance of a trusting relationship with a health professional and being able to share information across services.

The researchers conclude there needs to be a whole system strategic approach, to share information about potential benefits of ACP with people with MS. They highlight the need for health professionals to be skilled and trained in engaging with ACP discussions. They also highlight the need for information to be shared in real-time across services.

Koffman J, Penfold C, Cottrell L, Farsides B, Evans CJ, Burman R et al.
"I wanna live and not think about the future" what place for advance care planning for people living with severe multiple sclerosis and their families? A qualitative study.
PLoS ONE. 2022 May 26;17(5):e0265861. https://doi.org/10.1371/journal.pone.0265861

Study highlights need for investment in better dementia end-of-life care

Dementia is the most common cause of death in the UK. By 2040, it is estimated that annually 220,000 people will die with dementia, with many experiencing symptoms like pain and agitation. Access to good care for people with dementia towards the end of life is currently highly unequal, and the experience of being admitted to a hospital can be upsetting for those living with the disease.

These findings, **published in Age & Ageing**, are part of the **Empowering Better End of Life Dementia Care Programme** which looked at the data of 19,221 people diagnosed with dementia aged over 50, across a 22-year period (1995–2017) in four South London boroughs.

There were over 54,000 unplanned hospital admissions recorded, which steeply increased for people towards the end of life with over one in three admissions (37.3 per cent) occurring in the last year of life, and many experiencing more than one admission. Although most people with dementia and their families prefer not spend time in the hospital towards the end of life, this study showed that people with dementia spent between 12-59 days in the hospital in the last year of life.

The study found that 38.1 per cent died in the hospital, which is similar to data across the UK, and of these around one in ten died on their first unplanned hospital admission after diagnosis.

"Hospital admissions can be detrimental to the person living with dementia and may be a consequence of poor community support. Understanding when unplanned hospital admissions are most likely to occur can help to inform where resources need to be invested to provide high-quality dementia care. Without adequate community focused dementia care services to manage the needs of people with dementia at the end of life, admission rates are likely to remain high".
Emel Yorganci, Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation

In the UK, those who make decisions about care and develop policy do not yet have sufficient information to deliver solutions to improve the care that focuses on the person and their needs or to plan future services, for which there will be increasing demand. The findings from this research demonstrate the need for improved community care and services for people with dementia who are approaching the end of life, and high-quality dementia end-of-life care in hospitals.

Yorganci E, Stewart R, Sampson EL, Sleeman KE.
Patterns of unplanned hospital admissions among people with dementia: from diagnosis to the end of life.
Age and Ageing, Volume 51, Issue 5, May 2022. https://doi.org/10.1093/ageing/afac098

Machine learning to identify changes in symptoms and phase of illness

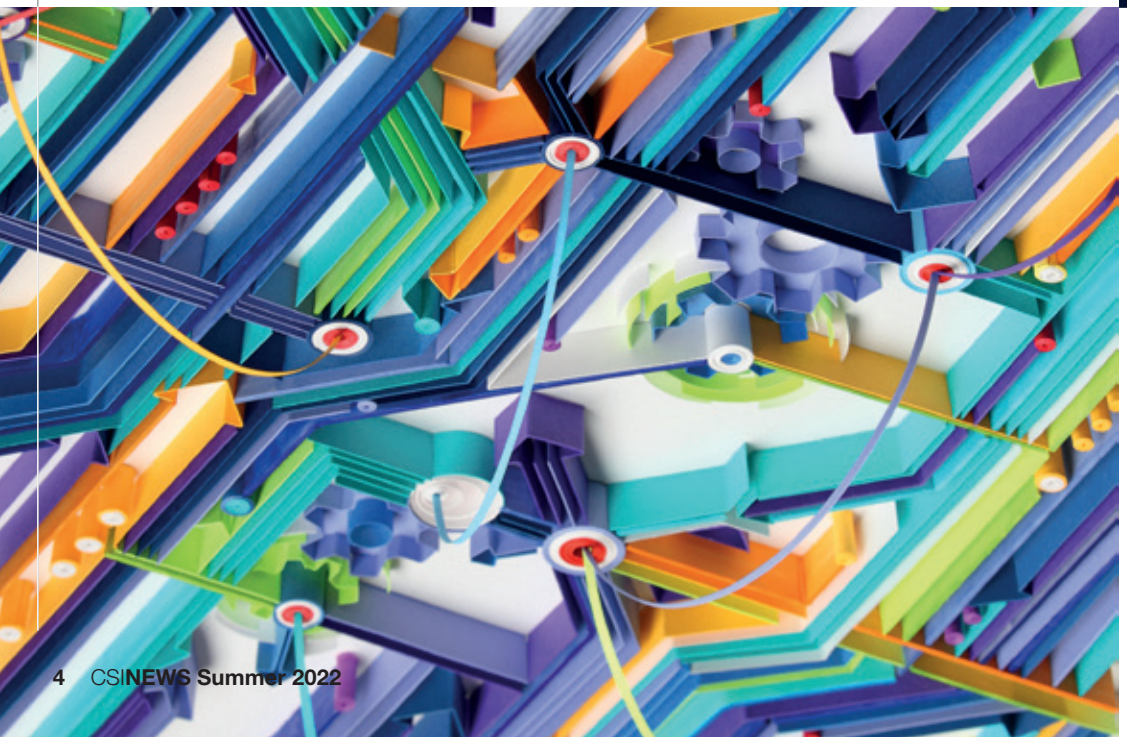
The growth of patient reported outcome measures data in palliative care provides an opportunity for machine learning to identify patterns signifying different phases of illness.

A study being carried out in New Zealand is exploring whether machine learning and network analysis can identify phases in patient palliative status through symptoms reported on the Integrated Palliative Care Outcome Scale (IPOS).

804 adult patients enrolled in a New Zealand palliative care service were analysed using a combination of statistical, machine-learning and network analysis techniques. Data from IPOS showed considerable variation with phase of illness. Six machine-learning techniques identified the most important variables for predicting possible transition between these phases.

These preliminary results, when coupled with the latest technological developments in mobile apps and wearable technology, could point the way to increased use of digital therapeutics in continuous palliative care monitoring.

Sandham MH, Hedgecock EA, Siegert RJ, Narayanan A, Hocaoglu MB, Higginson IJ.
Intelligent Palliative Care Based on Patient-Reported Outcome Measures.
Journal of pain and symptom management. 2022 May;63(5):747-757. https://doi.org/10.1016/j.jpainsymman.2021.11.008



Integrating palliative care and ICU

A recent article in *Intensive Care Medicine* has highlighted the need to develop a consensus and disseminate skills and training in order to provide high quality care in intensive care units (ICUs).

From the inception of the intensive care unit (ICU), end-of-life care has always been delivered in this setting due to the high severity of illness of the patients. But over time there has been an important distinction drawn between the primary palliative care that is provided by any clinician caring for a patient with life-threatening illness and the specialty palliative care provided by those with specialty training in palliative care.

The best approach for how patients' and families' palliative care needs are met and how primary and specialty palliative care are integrated will vary from ICU to ICU, but the functions of providing high-quality palliative care to critically ill patients and their families are universal.

The authors make three recommendations:
ICU clinicians, including physicians, nurses, and others, need training and experience in primary palliative care skills relevant in the ICU. Such skills include symptom assessment and management, parallel planning for diverse outcomes, communication with and support for critically ill patients and their families, and shared decision-making with patients and families that is inclusive of the interprofessional team.

It is important to implement efficient and effective ways to identify those patients and family members who would benefit most from specialty palliative care.

Curtis JR, Higginson IJ and White DB.
Integrating palliative care into the ICU: a lasting and developing legacy.
Intensive Care Med. (2022). https://doi.org/10.1007/s00134-022-06729-7

Congratulations to our MSC graduates

In May staff and students from the Cicely Saunders Institute gathered to celebrate 2022 graduation. The MSc in Palliative Care is a taught masters programme for doctors, nurses, and allied healthcare professionals.

The Palliative Care MSc enables palliative care professionals from a wide range of clinical backgrounds and career paths to synthesise their experience in the context of palliative care, develop their skills and knowledge, develop their careers and take the specialty forward.

Since the MSc course was established in 1998 students have included trainee doctors in palliative medicine, general practitioners (family doctors), doctors and nurses working in oncology, haematology, nephrology, cardiology, neurology and respiratory medicine. Other professions have included social workers, radiographers, psychologists, physiotherapists, pharmacists, music therapists and chaplains.

MSc students come from all over the world: UK, Europe, North and South America, Africa, Asia and Australasia. The international and multi-professional programme provides a rich learning environment, where students from all multiple professions and cultures are enabled and facilitated to share their experiences and support each other's learning through groupwork, seminars, online forums and classroom discussions. Thanks to newly refurbished AV facilities generously funded by the Garfield Weston Foundation in 2019, students can now attend remotely from wherever they are in the world.

Email: **mscpallcare@kcl.ac.uk**

NEWS:

REF2021: Cicely Saunders Institute demonstrates world-leading research

Research from the Cicely Saunders Institute of Palliative Care has topped UK rankings in the latest Research Excellence Framework results (REF2021) announced last month.

The REF is the **UK's system for assessing the quality of research** in higher education institutions.

The Institute included 16 members of staff (including five early career researchers), three impact case studies and 57 outputs, alongside submissions from colleagues in Nursing, Dentistry, Pharmacy and Life Course Sciences at King's College London. Out of the 89 submissions made by UK universities to UOA3 (Unit of Assessment 3) King's was first for overall research rated 4* (the highest possible mark), first for research outputs with 92.1% of outputs being rated 3* or 4*, first for impact rated 4* with 86.4% of impact case studies rated 4*, and first for Grade Point Average and Power*. King's UAO3 submission also received 100 per cent for environment, along with 12 other institutions.

"I am very proud of these results. They reflect the strength and interdisciplinary nature of the research that we conduct from Cicely Saunders Institute with our global partners. The impact case studies that we included in the submission speak to the very heart of 'cutting-edge research' as a goal within our Institute mission: to build new knowledge and discover new treatments through world-leading ethical and robust clinical, applied and health services research. We look forward to building on this excellent REF2021 result to continue our impact around the world."
Professor Richard Harding, Director Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, Director of the WHO Collaborating Centre on Palliative Care, Vice Dean (International), Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care.

REF 2021 Research Excellence Framework

The three impact case studies submitted to REF showed the enormous breadth of the Institute's research from **transforming breathlessness management** and specialist rehabilitation services, to **addressing the global need for palliative care**.

The Institute's rapid response to COVID included producing timely factsheets for people admitted to hospital, translated into 27 languages and downloaded >13,000 times in English and >1,000 times in other languages by patients, family members and hospitals across the NHS and globally.

The Institute's research on palliative care for people with multi-drug resistant tuberculosis was used by the World Health Organization to make recommendations on access to palliative and end of life care for all patients with multidrug-resistant tuberculosis in their End TB Strategy (2014).

The Institute also has an award-winning online **Patient & Public involvement Forum (PPI)**.

What Matters Most: delivering patient-centred care

Online conference 19 – 23 September 2022

This one week online conference includes presentations and discussions on using outcomes measurement to deliver patient centred care and connecting physical and mental health.

Key speakers include:

- Professor Jan Hazelzet, Emeritus Professor Healthcare Quality & Outcome, Erasmus MC who will deliver a session on patient-centred outcomes-based healthcare
- Ms Linetta Koppert, Consultant Surgical Oncologist, Erasmus MC who will deliver a session on successes and lessons learned from the outcomes journey since 2014
- Dr Sally Lewis, Director of the Welsh Value in Health Centre and National Clinical Lead for Value-Based and Prudent Healthcare, Wales who will deliver a session on embedding outcomes measurement in Wales.

KING'S HEALTH PARTNERS NHS

You can register **here**. There are 300 places available for each session and places are provided on a first come first served basis.

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...