Autumn 2019

CSI NEWS

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**

In September we wrote to Charlotte Church to thank her for an article she wrote for The Guardian newspaper reflecting on how the real experience of palliative care for many families is a very positive one. Palliative care is a medical specialty that is not well-known, and often misunderstood in society today.

Many people do not know about palliative care specialists – multi-professional teams of doctors, nurses, psychologists and social workers, and due to a skills shortage within the specialty are often not able to access palliative care.

In this edition of CSI News you can read about the many ways Cicely Saunders International is working with palliative care researchers, clinicians, hospices, patients and policymakers to take forward Dame Cicely's mission to ensure high quality palliative care is available to everyone who needs it, wherever they are cared for.

We want people get the right services, at the right time, in the right place. We want people's preferences to be heard, recorded, shared and acted upon. We want people to receive support from health and care professionals who can deliver care with expertise and compassion; and we want people to be informed about the treatment and care available to them, their condition, and how this might affect them over time.

Demographic change means this work becomes ever more urgent: CSI research shows that palliative care need in the UK alone is set to rise by 42% by 2040 and globally is set to double by the year 2060. We thank our many supporters, funders and collaborators who are working hard to meet this challenge.

Gareth Williams
Trustee, Cicely Saunders International

RESEARCH NEWS:

Letter to BMJ: Assisted dying: we need universal access to palliative care first

The British Medical Journal has published a letter from Dr Simon Etkind about the BMA's recent decision to poll its members on assisted dying.

The proposer of the motion stated that 'even if everyone had access to the best hospice care, at least 5,000 people a year would die in unrelieved pain.' But access to palliative and hospice care is far from universal; an estimated 92,000 people in England who might benefit from palliative care currently die without access to it.

This is a moving target; need for palliative care is set to rise 42% by 2040 in England and Wales, meaning that if service provision doesn't change, tens of thousands more people will miss out on high quality care at the end of their lives.

Further, the funding of palliative care services remains limited and inconsistent, with hospices receiving only one third of their income from the NHS and needing to raise one billion pounds a year from charitable donations to cover running costs.

The inequity of care provision at the end of life is neglected in the debate about assisted dying. Surely any consideration of a change in stance towards assisted dying should have as a prerequisite a demand for universal access to palliative care?

Etkind SN. Assisted dying: we need universal access to palliative care first.
Bmj. 2019;366:l4743. 10.1136/bmj.l4743.

RESEARCH NEWS:

IPOS: A major step forward

Few measures capture the complex symptoms and concerns of people receiving palliative care. Researchers at the Cicely Saunders Institute developed a measure to capture this information.

The measure is based on the POS (Palliative care Outcome Scale) and is called the Integrated Palliative Care Outcome Scale (IPOS). Latest research published in Palliative Medicine, has evaluated the measure, by testing its validity, reliability and responsiveness to change.

The Research showed that IPOS can pinpoint accurately patients with unstable or deteriorating status, versus stable patients. The measure shows good internal consistency and reliability and accurately records response to change over time. This represents a major step forward internationally for palliative care outcome measurement.

Murtagh FE, Ramsenthaler C, Firth A, Groeneveld EI, Lovell N, Simon ST, Denzel J, Guo P, Bernhardt F, Schildmann E, van Oorschot B, Hodiamont F, Streitwieser S, Higginson IJ, Bausewein C.
A brief, patient- and proxy-reported outcome measure in advanced illness: Validity, reliability and responsiveness of the Integrated Palliative care Outcome Scale (IPOS).
Palliat Med. 2019:269216319854264. 10.1177/0269216319854264.

RESEARCH NEWS:

Holistic services for people with advanced lung disease – what do patients think?

Breathlessness is a common and distressing symptom of many advanced diseases, affecting around 2 million people in the UK. Breathlessness increases with disease progression and often becomes chronic or refractory.

Breathlessness-triggered services that integrate holistic assessment and specialist palliative care input as part of a multiprofessional approach have been developed for this group, offering tailored interventions to support self-management and reduce distress.

Researchers at the Cicely Saunders Institute have published research in NIHR journal Health Services and Delivery Research showing that holistic services are highly valued by patients and improve distress caused by breathlessness and depression.

Not only did patients report less distress they also reported better mastery of their breathlessness. This was irrespective of their precise lung diagnosis, how well or badly their lungs functioned, and what phase of illness they were experiencing and the level of their general health.

Patients highlighted the need for improved access to person-centred, multiprofessional breathlessness services and support for informal carers.

Maddocks M, Brighton LJ, Farquhar M, Booth S, Miller S, Klass L, Tunnard I, Yi D, Gao W, Bajwah S, Man W D & Higginson I J. **Holistic services for people with advanced disease and chronic or refractory breathlessness: a mixed-methods evidence synthesis.** Health Serv Deliv Res 2019;7(22) https://doi.org/10.3310/hsdr07220

> *"We don't always know how to talk to each other about dying and grief because we can't find the right language."*
>
> **Kimberley St John**

The second conversation

MSc alumna Kimberley St John is a palliative care nurse at Guy's and St Thomas' NHS Trust. She is leading an initiative called 'Let's Talk – Transforming End of Life Care Conversations', an education initiative for patients, carers, staff and the public.

High quality end of life care discussions allow patients to make informed decisions. Conversely poorly handled conversations are a common source of complaints and cause unnecessary distress. Some healthcare professionals lack confidence when it comes to talking to patients about resuscitation and dying.

In partnership with the Royal College of Physicians, Guy's and St Thomas's NHS Trust has developed a training tool for junior doctors called The Second Conversation. A junior doctor observes an end of life care conversation between a senior doctor and patient/caregiver, then follows up with a second conversation with the patient/caregiver and later reflects back on the experience with a senior colleague.

The latest published results of an evaluation of The Second Conversation are that it appears to be of most value to foundation doctors, and works well on wards where patient stay is longer. Benefits include flexibility and its positive impact on the confidence and skills of junior doctors.

If the benefit to patients and caregivers is confirmed then there would be a strong argument to make The Second Conversation part of routine practice.

Kimberley also teamed up with VAULT festival, an annual arts event in London to curate a programme of plays about death and how we cope with it. Says Kimberley: *"I hosted a panel discussion with comedian Cariad Lloyd, journalist Erica Buist and Kristin Hellenga, founder of the charity CoppaFeel, who is living with stage four breast cancer. We had a really positive response to the events. The festival has created a ripple effect and people are still carrying on their conversations about death and grief.*

"We have developed four short films about planning ahead, including CPR. People learn most of what they know about CPR from TV which often portrays it unrealistically. These videos aim to educate and will encourage dialogue about end of life care, helping to normalise what is a difficult conversation for patients in the last year of their life."

Mathew R, Weil A, Sleeman KE, Bristowe K, Shukla P, Schiff R, Flanders L, Leonard P, Minton O, Wakefield D, St John K, Carey I. **The Second Conversation project: -Improving training in end of life care communication among junior doctors.** Future Healthc J. 2019;6(2):129-36. 10.7861/futurehosp.6-2-129.

RESEARCH NEWS:

End-stage kidney disease

For older adults with multiple medical conditions, the burden of dialysis for end stage kidney disease (ESKD) outweighs the limited benefits.

Instead a patient's healthcare team continues care without dialysis or a kidney transplant and focuses on quality of life and symptom control.

Common symptoms in conservatively managed ESKD include fatigue, anorexia, nausea and vomiting, pain and pruritis. The disease is associated with biographical disruption and a loss of sense of self. But little is known about patients' own perceptions of their illness.

Researchers at the Cicely Saunders Institute decided to explore older adult patients' experience and interviewed 20 older adults from three renal units in the UK. The patients described the invisibility and intangibility of kidney disease. They described a spectre-like presence, sapping their energy and holding them down. It was hard to differentiate symptoms of the illness from characteristics of aging. Not being able to identify the symptoms that were the result of kidney disease adversely affected their wellbeing and sense of self.

Researchers concluded that clinical services need to recognise the illness experience, alongside more traditional symptom-led approaches to deliver the best patient care. Recognizing the invisibility, intangibility and disconnectedness that patients feel could be achieved by improved clinical assessment, communication and education, and peer and professional support.

Bristowe K, Selman LE, Higginson IJ, Murtagh FEM. **Invisible and intangible illness: a qualitative interview study of patients' experiences and understandings of conservatively managed end-stage kidney disease.** Ann Palliat Med. 2019. 10.21037/apm.2018.12.06.

RESEARCH NEWS:

What impact do cultural aspects have on patients' decisions about palliative care?

Advance care planning is widely adapted to support decision-making in advanced diseases. However, the concept of advance care planning is largely derived from Western countries.

There has been little research about advance care planning in non-Western cultures. Researchers based at the Cicely Saunders Institute decided to explore advance care planning from the perspective of advanced cancer patients, families and healthcare professionals in northern Taiwan.

The researchers identified various decision-making trajectories, and discovered that cultural factors, in particular filial piety, combined with a lack of staff skills in communication affected decision-making. Opinions from families are highly influential, and patients often lack information on palliative care options. Strategies to facilitate decision-making require staff confidence in end-of-life discussions, and working with patients and their families while respecting the influence of filial piety.

Lin CP, Evans CJ, Koffman J, Sheu SJ, Hsu SH, Harding R. **What influences patients' decisions regarding palliative care in advance care planning discussions? Perspectives from a qualitative study conducted with advanced cancer patients, families and healthcare professionals.** Palliat Med. 2019:269216319866641. 10.1177/0269216319866641

CONGRATULATIONS:

CLAHRC South London now national lead for palliative/end of life care and mental health

The Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South London has won a bid to the National Institute of Health Research (NIHR) for £9 million over the next five years.

It will become the Applied Research Collaboration (ARC) South London, one of 15 ARCs undertaking research in public health and primary care. ARC South London and ARC East of England will be National Leads in Palliative and End of Life Care and Mental Health.

Institute Director Professor Irene Higginson said: *"I am delighted by this news … NIHR's support will drive the use of outcome measures in routine practice. This will help staff make better decisions, understand clusters and treat multimorbidity effectively. This will benefit people with serious and advanced illness and allow researchers to develop and evaluate improved care and therapies. The work will lead to innovative models of care. It will improve access to cost-effective, high-quality palliative and end of life care."*

Marion Sumerfield, patient representative, said: *"Cicely Saunders Institute's research is vitally important to ensure people at the end of life (and their families) are offered the best clinical support and compassionate understanding when they need it most. I am so glad that this bid has been secured in order that their work can continue."*

NEWS:

New palliative and end of life care website

Public Health England's National End of Life Intelligence Network has a new palliative and end of life care website presence on the government website gov.uk. These new pages bring together data, intelligence and reports onto one collection page.
https://bit.ly/2lKy7AK

The website includes a new Resource Directory to support professionals working in palliative and end of life care. The reports include information on policy and guidance, place of care, commissioning and contracting, and education and training.

NEoLCIN welcomes feedback and suggestions about the new website – please email neolcin@phe.gov.uk.

GLOBAL NEWS:

Advanced qualitative research workshop

In July Dr Ping Guo and Professor Richard Harding were guest speakers at an advanced qualitative research workshop run by colleagues at King Hussein Cancer Center (KHCC) in Amman, Jordan.

The workshop was part of the collaboration between the Cicely Saunders Institute and the Center for Palliative & Cancer Care in Conflict (CPCCC) at KHCC. More than 50 multidisciplinary healthcare professionals and medical students were invited from KHCC, Al-Basheer Hospital and Jordan University.

The workshop discussed outcome measures, qualitative data analysis, and Integrated Palliative Care Outcome Scale (IPOS) adaptation and validation. The training was followed by a meeting with the NCD Unit, cancer registry and death registry at Jordan Ministry of Health to discuss current and future research projects.

NEWS:

The best job I've ever done

MSc alumna Rebecca Tiberini and other friends and colleagues from St Christopher's Hospice feature in a video promoting careers in palliative care on twitter.
https://twitter.com/i/status/1169645363428392960

This is part of an initiative by Hospice UK promoting their jobs search facility
https://bit.ly/2rRiDeo
and on Twitter via **#hospicejobs**

NEWS:

Future projections of palliative care need in Scotland

Cicely Saunders International PhD training fellows Anna Bone and Simon Noah Etkind have been collaborating with a team from the University of Edinburgh to conduct projections of palliative care need in Scotland, funded by Marie Curie.

The findings replicate and build on existing Cicely Saunders Institute research and show that as in England and Wales, palliative care need is expected to grow in Scotland up to 2040.

Anna and Simon presented their data to clinicians, researchers and policymakers in Edinburgh as part of a knowledge exchange event and co-facilitated a consultation to generate recommendations for future care services. The team hope that the event will lead to new approaches to meet the need for more palliative care in the future.

MEDIA WATCH:

Thank you

Cicely Saunders International has written to Charlotte Church to thank her for an article she wrote for the Guardian published online 26 August 2019 about her family's recent experience of palliative care.

Church described palliative care as the 'ultimate in wellbeing practices' that meant her grandmother's death was 'a moment of peace'.

Read the full article:
https://bit.ly/2NAuB7l

NEWS:

Patient and Public Involvement

The latest edition of the Institute's Patient and Public Involvement newsletter is out now, and includes workshop and conference news, information about a new online forum and a new PPI group for breathlessness.

Congratulations also to PPI member Margaret Ogdon who won the 'Putting Patients and Carers First Award' at the NIHR South London awards.

For a copy of the newsletter please contact **csi.ppi@kcl.ac.uk**

"Having stopped working a few years ago due to my health, I felt devalued and I try to seek ways to change this. Having the opportunity to be part of a group such as this can only be empowering as I discover something positive from having this condition. If my condition and the experiences connected to it can be of benefit to someone else, I am empowered!"

Breathlessness PPI member

CICELY SAUNDERS INTERNATIONAL ANNUAL LECTURE 2019:

Got quality? – The urgent need to focus on quality and not solely costs

Monday 7 October 2019, 17.00 – 18.30
Cicely Saunders Institute
Bessemer Road, London SE5 9PJ

Speaker
Professor Joan Teno, Professor of Medicine at Oregon Health & Science University, Adjunct Professor of Health Systems, Policy, and Practice (Brown School of Public Health)

In 2018, Dr Teno was named one of the visionaries in hospice and palliative care. Throughout her career, she has been one of the leaders in defining and operationalising how we measure the quality of care for those who are dying through bereaved family member surveys and use of administrative data.

To register please email **csi.events@kcl.ac.uk**

EVENT:

Michal Galazka International Study Day

Speakers including Professor Sir David Spiegelhalter, Professor Irene Higginson and Professor Richard Harding will present on the use of data in formulating healthcare policy and how data can be used to address healthcare challenges in the 21st century.

Monday 7 October 2019
10.00 – 15.00
Cicely Saunders Institute
Bessemer Road
London SE5 9PJ

To register please email
csi.events@kcl.ac.uk

Sandwich lunch will be provided.

EVENT:

ON EDGE: The Sound of Anxiety

Can you hear anxiety? Take part in a live experiment and find out if it's possible to identify the cause of breathlessness from audio recordings of people breathing. The findings from this study will help researchers Natasha Lovell and Simon Etkind from the Cicely Saunders Institute understand the links between breathlessness and anxiety and could improve how breathlessness is treated in the future.

Monday 12 October 2019
13.00 – 17.00
Exhibition Gallery, First Floor, Science Gallery London, Great Maze Pond, London, SE1 9GU

EVENT:

Let's Talk About Death – But Why?

Is there a 'right time' to talk about death? What would it mean to society if we had spoken about death earlier? Arthur Rank Hospice hosts a thought-provoking and unique evening with Dr Katherine Sleeman, NIHR Clinician Scientist, Cicely Saunders Institute sharing insights, expertise and latest research on the importance of palliative care and what this means to society.

Wednesday 12 November 2019
18.00 – 21.00
Arthur Rank Hospice Charity
Cherry Hinton Road
Shelford Bottom
Cambridge CB22 3FB

http://bit.ly/2m1HDQ1

Speaker
Dr Katherine Sleeman,
NIHR Clinician Scientist,
King's College London

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Thank you for your support...