Cicely Saunders International sets out to make a major contribution in an area of universal need – researching and disseminating further evidence-based knowledge in a field that has an impact and importance worldwide.

Dame Cicely Saunders

In this edition of CSI News you can read about CS International’s latest research published in Lancet Global Health on the rapidly escalating need for palliative care across the world.

Tackling this steep rise in health-related suffering is an ethical and economic imperative. At the 2016 Cicely Saunders Annual Lecture I announced a plan to raise funds to establish a new senior role of Professor in Palliative Care. This has proved to be rather challenging, however I am delighted that thanks to generous pledges and donations from our funders we have nearly achieved our fundraising total to establish a permanent professorship in palliative care at the Cicely Saunders Institute.

The professorship will enable us to expand education and training programmes to sustain a skilled multi-professional workforce. It will enable us to develop our research programmes into scientifically tested treatments and new models of care, so that we can meet the challenges of modern healthcare in the 21st century.

John McGrath
Chairman and Trustee, Cicely Saunders International
Global burden of serious health-related suffering due to almost double by 2060

New CSI research findings published in The Lancet Global Health show that the number of people dying with palliative care needs is set to almost double over the next four decades. By 2060, an estimated 48 million people each year (47% of all deaths globally) will die with serious health-related suffering, an 87% increase compared to 2016. 83% of these people will be in low and middle-income countries.

Serious life-threatening and life-limiting illnesses place an enormous burden on society and health systems. For the first time CSI researchers have produced worldwide projections of the future need for palliative care based on serious health-related suffering, in order to help inform policies that alleviate suffering and prevent health systems weakening.

They modelled future estimates of suffering by World Bank income classification, WHO region, age, gender, and condition causing death.

The main findings included:

- Serious health-related suffering will increase most rapidly among older people (183% increase in those aged 70+ 2016–2060).
- The increase in serious health-related suffering will be driven by rises in cancer deaths (16 million people dying each year with serious health-related suffering by 2060, 109% increase 2016–2060). The condition with the highest proportional increase will be dementia (6 million people dying each year with serious health-related suffering by 2060, 264% increase 2016–2060).
- For other conditions the global burden of serious health-related suffering is expected to decline. For example, the number of people with HIV dying with serious health-related suffering worldwide is expected to reduce from over one million in 2016 to under 400,000 in 2060.
Dr Katherine Sleeman said: “Immediate global action to integrate palliative care into health systems is an ethical and economic imperative. “Palliative care can relieve suffering for patients and families, and save money for health systems and society... Our findings call for global policies to strengthen health care systems through providing essential drugs to relieve symptoms, staff training and public education, with a focus on the populations that will experience the fastest rise of suffering and need.”

Prof Richard Harding said: “Palliative care and the relief of suffering have been described as some of the most neglected dimensions of global health today. It is estimated that just 14% of the people who need palliative care globally receive it, most of whom are in high income countries.

“The increase in palliative care need that we have identified will place an enormous burden on already weak health systems, particularly in low and middle-income countries. There is growing evidence that investment in palliative care services can support patients and families, as well as take pressure off hospital services by keeping people pain-free at home for as long as they wish. Society has a duty to provide care for all to the last moments of life.”

Further information about the study is on the King’s College London website, www.kcl.ac.uk/palliative.

Sleeman KE, de Brito M, Etkind S, Nkhoma K, Guo P, Higginson IJ, Gomes B, Harding R.
The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions.
Low socioeconomic position associated with worse care at the end of life

In high income countries, people with a low socioeconomic position are more likely to receive poor quality end of life care and die in hospital, according to a CSI study published in PLOS Medicine.

Lower socioeconomic position (SEP) is a known risk factor for reduced life expectancy and earlier onset of diseases. In this study, researchers carried out a systematic review of studies that reported an association between any measure of SEP—including income, education, occupation, or housing—and healthcare received by adults in their last year of life. 209 studies were included in the review, including data on 142 outcomes in people from North America, Europe, Australia and Asia.

Compared to people living in the least deprived neighbourhoods, those living in the most deprived neighbourhoods were more likely to die in the hospital than at home, more likely to receive acute hospital based care in the last three months of life, and less likely to receive specialist palliative care.

The least educated people were also less likely to receive specialist palliative care. Specialist palliative care is known to reduce symptoms and improve well-being.

Lead author Joanna Davies from the Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation at King’s said: “These findings should stimulate widespread efforts to reduce socioeconomic inequality towards the end of life.

“We recommend that all research on care received towards the end of life should attempt to account for SEP; end of life care interventions should be analysed for their different effects across the social strata; and the planning and provision of end of life care services should consider SEP in local populations.”

Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis
Breathlessness study to relieve suffering and improve quality of life

A new international study launched in early 2019 is seeking to deliver a step change in the evidence-based treatment of severe breathlessness among people affected by respiratory diseases, especially chronic obstructive pulmonary disease (COPD) and interstitial lung disease (ILD).

Breathlessness is a debilitating and frightening symptom that currently effects an estimated 15 million people in Europe, with this figure set to increase in the future. The BETTER-B programme (BETter Treatments for Refractory and chronic Breathlessness) builds on an impressive international body of work from a consortium of EU partners to tackle the problem of breathlessness. These include studies into the effects of breathlessness on people’s lives, the different types of breathlessness experienced and into better treatments.

The programme is surveying doctors about their current practice and how they are using existing guidelines and conducting a randomised controlled trial of mirtazapine, a commonly used anti-depressant across five countries to determine its effectiveness in relieving breathlessness. The programme has launched a new website with the latest information on treatments for those affected by breathlessness and for doctors, nurses, physiotherapists and others caring for people affected by this condition. At the end of the programme, the consortium will produce a new European position statement for respiratory and palliative care specialists on breathlessness management.

Principal Investigator for BETTER-B, Professor Irene Higginson from the Cicely Saunders Institute said: “The Cicely Saunders Institute and our BETTER-B partners have built a large body of work in breathlessness, testing both medicines and non-pharmacological treatments. As a first step in treating breathlessness it is always important to try to control the underlying disease, and to use the many evidence-based non-pharmacological treatments. However, when these don’t work anymore and breathlessness gets worse, then there are too few options. In BETTER-B we want first to provide better information on what we already know does (and doesn’t) work, so that everyone can get the best from what we know now. At the same time we will test the new medicine. We have some preliminary evidence that this medicine, the antidepressant mirtazapine, may relieve breathlessness, even when people are not depressed. But now we need evidence from a properly conducted clinical trial.”

For further information on the BETTER-B study visit the website: https://betterbreathe.eu/
Congratulations: Dr Natasha Wiggins

Congratulations to Dr Natasha Wiggins, an MSc scholar funded by the Kirby Laing Foundation and Cicely Saunders International, for publishing the results of her MSc research project in the journal Age and Ageing.

This is the first study to compare preferred and actual place of death for people dying with dementia. Natasha’s research looked at 1047 adults with a diagnosis of dementia who died between December 2015 and March 2017, and were registered on Coordinate My Care. Coordinate My Care (CMC) is an electronic palliative care coordination system hosted by the Royal Marsden NHS Foundation Trust and is available to all patients with chronic illness living in London.

Information on preferred and actual place of death was available for 803 people. Preferred place of death was most commonly a) care homes or b) home and 83.7% died in their preferred location. Dying in the preferred place was more likely for those most functionally impaired and/or receiving symptomatic treatment only.

Enabling people with dementia to remain in their usual place of residence is considered an essential component of good care. Understanding preferences for place of death and the factors that influence achieving these could guide service development and lead to more people dying in their preferred place.

Wiggins N, Droney J, Mohammed K, Riley J, Sleeman KE.
Understanding the factors associated with patients with dementia achieving their preferred place of death: a retrospective cohort study. Age and Ageing 2019; 0: 1.7 Doi: 10.1093/ageing/afz015

Vietnam powers ahead in palliative care education

The University of Medicine and Pharmacy at Ho Chi Minh City (UMP) has implemented the recommendations of the World Health Organization (WHO) on palliative care education, thanks in part to funding by The Atlantic Philanthropies and Cicely Saunders International.

By 2022, all graduates of the medical school will have basic knowledge and skills in palliative care. The University has established one of the first academic departments of palliative care in the developing world and now offers basic, intermediate, and specialist education in palliative care, as recommended by the World Health Organization.

The faculty includes CSI’s alumni Bui Thi Thanh Huyen, MD, MSc, a paediatrician, and Le Dai Duong, MD, MSc, a geriatrician who completed their MSc in Palliative Care as part of the Cicely Saunders Institute’s Fellowships Consortium, funded by The Atlantic Philanthropies and Cicely Saunders International.

Palliative Care Bill gets second reading in the UK House of Lords

On 14 June 2019 the private members’ bill Access to Palliative Care Bill received its second reading in the House of Lords. The bill is sponsored by Baroness Finlay of Llandaff who is a member of CS International’s Scientific Expert Panel.

Members discussed a range of issues highlighted by the bill, including: training for palliative care specialists; palliative care for babies, children and for those with learning disabilities; and the responsibility of Clinical Commissioning Groups to identify, fund support and provide services to those with palliative care needs.

Introducing the bill, Lady Finlay quoted the words of Cicely Saunders that the way a person dies lives on in the memories of those left behind. Poor or non-existent services and clinical failings at the end of life have a devastating impact on society, particularly on child bereavement. After debate, the motion was agreed to, and the bill was committed to a Committee of the Whole House.

You can follow the progress of the bill via: services.parliament.uk/Bills/2017-19/accessstopalliativecare.html
EVENT NEWS:

Dr Katherine Sleeman

Many congratulations to Dr Katherine Sleeman, NIHR Clinician Scientist at the Cicely Saunders Institute who was given EAPC’s Women in Palliative Care award, an award that honours the contribution of women in palliative care.

The EAPC hopes that this award will bring more visibility to the achievements of women in research, advocacy, and leadership, and bring about more balanced gender representation in clinical, institutional and academic organisations.

Katherine said: “Thank you EAPC for this wonderful award and to the brilliant women and men who have supported and inspired me.”

CONGRATULATIONS:

Dr Katherine Sleeman

The Departure Lounge

CSI research features in The Departure Lounge, a free installation aimed at sparking a national conversation about death and dying from the Academy of Medical Sciences.

The pop up installation, modelled on an airport departure lounge, seeks to enable people to talk more openly about death and dying. Visitors can explore the space, share their thoughts and talk to guides staffing the space, who are a diverse mix of researchers and professionals with experience of death and dying.

The project also includes an interactive website, a digital campaign and workshops chaired by CSI Director Professor Irene Higginson and blogs from faculty members including Dr Katherine Sleeman. See more at: thedeparturelounge www.departure-lounge.org

The Departure Lounge was developed by the Academy of Medical Sciences with design agency The Liminal Space, to create an empowering space where the public can explore what having a ‘good death’ might mean now and in the future.

To extend the reach of the project, 30 flat pack versions of The Departure Lounge installation are available. These flat packs will be given to people interested in hosting events to spark conversations about death and dying across the UK. The flat pack is free and includes £250 in support costs for events using these materials. The flatpacks will be available from June 2019. If you are interested in taking this suitcase-sized flat pack version of The Departure Lounge into your community please register your interest via: www.research.net/flatpack
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 operationalizing 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

OPEN SEMINAR:
Using connected datasets to deliver systemwide insights: a matched analysis of health and social care costs at the end of life

A large proportion of acute care costs are known to occur at the end of life, although less is known for other care settings. This seminar will share the outputs of a recent study in Barking and Dagenham and look at the implications of using linked datasets to improve care and develop policy.

Wednesday 26 June 2019
16.00 – 17.00
Cicely Saunders Institute
Bessemer Road
London SE5 9PJ

Speaker
Jenny Shand,
Director and Executive Lead UCL Partners

OPEN SEMINAR:
What are the systems-level factors that contribute to overly aggressive, burdensome life-sustaining treatments near the end of life?

This talk will present an ongoing ethnographic study of high and low intensity hospitals in California (USA) that seeks to understand the systems-level factors that contribute to burdensome, overly aggressive care near the end of life in older adults.

Wednesday 24 July 2019
16.00 – 17.00
Cicely Saunders Institute
Bessemer Road
London SE5 9PJ

Speaker
Elizabeth Dzeng, MD, PhD, MPH,
Assistant Professor at UCSF, California USA

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.

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...