

Spring 2018

# CSINEWS

news from cicely saunders international

Cicely Saunders  
International  
Better care at the end of life



**It seems that each time this newsletter comes around, it needs to be twice as long as the previous one to fit everything in. But that is the point, isn't it? As Cicely said so eloquently, learning is the key to improvement, and the more we can learn about the many complexities of palliative care, the more we can do to improve that care for patients and their families. Researchers associated with and supported by Cicely Saunders International are at the forefront of this work.**

I was particularly struck by the assessment of St Christopher's Hospice reported in this newsletter, and the understanding that each care setting creates its own 'lifeworld'.

Cicely was often invited to set up a new 'St Christopher's' in other locations, but each time she refused. She knew that only those local to a place can truly understand what is needed and what will work best in that location. People were always welcome to come to St Christopher's to learn, but then they had to take that learning away and mould it to suit their own situation.

Just like the notion of patient-centred care, in fact – and we're delighted that the CSI Patient and Public Involvement forum has been recognised with a prestigious innovation award. Bringing in patients' voices can only make research better and more relevant to the people it is ultimately intended to serve, and continuing to innovate is the way we can honour Cicely's legacy and take it forward into the future.



**Kate Kirk**

Trustee, Cicely Saunders International

*We need to go on learning so that in 10 years time we are doing things better than we are now.*

**Dame Cicely Saunders** in later life, when she established a research foundation, Cicely Saunders Foundation (later Cicely Saunders International).

# "Keep All Thee 'Til the End"

## *A sort of homecoming*



Image: © Photograph of St Christopher's Hospice by Derek Bayes

**Researchers from the Cicely Saunders Institute, King's College London and the Institute for Health and Care Research and University of Maastricht, the Netherlands have published research identifying the important elements for creating a hospice setting.**

The researchers were interested to find out what set St Christopher's Hospice apart from hospital care of the dying at the time the hospice was created. They systematically analysed archive material from 1953 to 1980 from the Cicely Saunders Archives at King's College London. Five themes emerged – home/homelike; community; consideration of others; link with the outside world and privacy. What emerged from their research was that in contrast to acute care, hospices formulate their own lifeworld to support and engage patients. Lifeworlds are culture-sensitive and this underlines the need for variation in design and organisation of hospices around the world.

*"This time, that can be so hard or so dreary, will be changed into one of peace, security and meaning – a sort of homecoming"*

St Christopher's was intended as a place that would provide specialist care to those suffering from incurable illnesses with sensitivity to the needs of patients and families. Cicely Saunders' early work had explored the idea of 'total pain' – that pain is not only a physiological experience but also has spiritual, psychological and social dimensions. St Christopher's Hospice was developed after careful consideration of this philosophy and led to a different way of dying, a philosophy that spread and became the bedrock of a new medical specialty – palliative care – that could be adapted to different environments. The research shows that St Christopher's was quite different to the hospitals of the time. It was a 'home from home' and the physical environment was vital. For healthcare professionals it is important to consider the impact of physical space and organisation on patients and families since these can have an important impact on their experiences.

West E, Onwuteaka-Philipsen B, Philipsen H, Higginson IJ, Pasman HRW. 1 "Keep All Thee 'Til the End": Reclaiming the Lifeworld for Patients in the Hospice Setting. *Journal of Death & Dying*. 0(0) 1–14. 2017. DOI: 10.1177/0030222817697040

# Improving junior doctors' skills and confidence

**The Second Conversation project is a novel teaching intervention currently being piloted in three London NHS Trusts.**

Dr Katherine Sleeman, NIHR Clinician Scientist at the Cicely Saunders Institute has won funding from Royal Marsden Partners to evaluate the intervention aimed at improving junior doctors' skills and confidence in conducting end of life conversations.

The dramatic increase in the older population and the multiple health and other problems of ageing will put great pressure on healthcare providers in the future, and many more people will need palliative care and support to help them live as well as possible until they die.

Advance care planning, personalised to patients' needs and priorities, is the cornerstone of good end of life care. However, inadequate clinician communication skills and a reluctance to initiate conversations about death can lead to the failure of end of life care planning, and is frequently the focus of NHS complaints.

Improving junior doctors' skills in end of life communication helps ensure patients' preferences and priorities are met, while improving satisfaction for doctors.

Dr Katherine Sleeman said "I am delighted to have won funding from Royal Marsden Partners to evaluate the Second Conversation model of improving junior doctors' communication skills. Isolated educational programmes may be effective, but often lack sustainability and reach. Through built-in observation, experiential learning, feedback and reflection, the Second Conversation model offers a practical means of improving doctors' skills in end of life communication at an early stage in their careers.

Our research will explore in more depth the acceptability of the Second Conversation with patients, carers, and staff, and examine its effectiveness. Most excitingly, the Second Conversation project has the potential to be implemented at scale, and within a short time frame, leading to benefits for patients, carers and the NHS."





FEATURE:

# A day in the life of a Community Palliative Care CNS *Clinical Nurse Specialist*

**Emma Thomas, Palliative Care Matron, Guy's Hospital explains the role of community palliative care nurses and how her team supports patients in the community.**

Clinical Nurse Specialists work Monday to Friday 9am to 5pm and provide an out-of-hours advice line for patients, relatives and healthcare professionals in Southwark, Lambeth and Lewisham.

Our day starts with a triage and handover meeting with the multi-professional palliative care team (consultants, doctors, nurses, social workers) to discuss patients who have been identified as rapidly changing/deteriorating.

These patients may have been seen by or had contact with the Pal@home service overnight. We discuss new referrals and pass them to the relevant CNS.

Patients with any life-limiting condition can be referred: cancer, heart failure, COPD, MND, MS, dementia are the most common conditions. Referrals are sent through by GPs, hospital teams, Specialist Nurses and local hospices.

There are approximately 65-70 GP surgeries connected to the community palliative care team at Guy's and St Thomas's Hospitals.

Each CNS has a caseload of around 30 to 50 at any one time, and during a typical day, will visit between two and six patients, either in their own homes or in a care/nursing home. A first assessment with a new patient takes between 1-2 hours.

The CNS will meet the patient and their family to identify what the current issues are for them, allowing the patients and those close to them to discuss their thoughts and feelings about their illness and give them the space to achieve this.

We discuss plans for their care including their preferred place of care.

The CNS will liaise with GPs regarding changes to the patient's care and medication advice and can contact local hospices to request admission for symptom control if this is where the patient has chosen as their preferred place of care.

We also teach new staff, and provide teaching support to colleagues in other specialties such as heart failure and respiratory services. The CNS team is closely supported by a team of medical staff, specialist social workers, and administrative staff.

#### ARTICLE:

## What is Pal@Home?

**Louise Gunn, Matron Pal@home service, Guy's and St Thomas' NHS Foundation Trust explains.**

Patients who are coming to the end of their lives or are facing a serious illness can get quicker expert nursing care at home thanks to a night-time nursing service run by Guy's and St Thomas' NHS Foundation Trust.

Pal@home is a rapid response, 'out of core hours' community nursing service for palliative and end of life patients (EoL). It has been developed to support patients and carers at a crucial time of life in their usual place of residence.

The pal@home service takes planned and unplanned referrals through the night – visiting patients in their homes in Lambeth and Southwark. Patients are prioritised through the night with the aim of seeing patients as quickly as possible according to their needs.

The focus of pal@home is to improve the patients' and carers' experience through the twin goals of avoiding unnecessary hospital admissions and where an admission is necessary, to support the patient's rapid discharge from hospital to receive all necessary care in the environment of their own home.

Referrals to the service come from GPs, Community Nursing teams, the End of Life Care Team and Specialist Palliative Care teams (hospital and inpatient settings). Patients known to Guys and St Thomas's Specialist Palliative Care Team can refer themselves directly to the service overnight if support is required. The pal@home service also covers urgent District Nursing calls until 11pm.

Guy's and St Thomas pal@home service runs from 8pm to 8am seven days a week.





# Centenary Celebrations 2018

Cicely Saunders  
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The Cicely Saunders Institute will be hosting a series of events in 2018 celebrating the centenary of Cicely Saunders.

The events will include seminars, workshops, music, film and talks.

Contact [csi.events@kcl.ac.uk](mailto:csi.events@kcl.ac.uk) for more details and follow us on Twitter @cicelysaunders1 and @csi\_kcl #Cicely100

Celebrating in partnership with



## EVENT NEWS:

MICHAL GALAZKA INTERNATIONAL STUDY DAY

## New Frontiers, New Technologies

**Monday 9th July 2018**  
**Cicely Saunders Institute**

The day will include the latest research on the use of technology in healthcare, particularly the implications of new technology, including wearables, the global aspects of technology in different locations, and the opportunities for big data and outreach presented by technology.

Speakers will include Professor Irene Higginson, Professor David Currow, Professor Jackie Sturt, Dr Gao Wei, Eve Namisango, Professor Matthew Hotopf, Professor Richard Dobson and Professor Bridget Johnston.

For further information please contact [csi.events@kcl.ac.uk](mailto:csi.events@kcl.ac.uk) or register via <http://bit.ly/2o0QgYe>

## EVENT NEWS:

ANNUAL LECTURE 2018

## Improving end of life care: lessons learnt, what now, what next?

**Tuesday 10th July 2018**  
**Cicely Saunders Institute**

This year's Cicely Saunders Annual Lecture will be given by Rabbi Baroness Julia Neuberger DBE, Senior Rabbi at West London Synagogue. Baroness Neuberger chaired Camden & Islington Community Health Services Trust and was CEO of the King's Fund. She chaired the Review of the Liverpool Care Pathway for Dying Patients, published in July 2013. She is also an author and broadcaster who is particularly interested in refugees and asylum seekers, mental health, housing and homelessness, and health inequalities.

If you would like to attend please contact [csi.events@kcl.ac.uk](mailto:csi.events@kcl.ac.uk)

# Innovation Award for Patient and Public Involvement



**On 2 February 2018, stakeholders from across the South London National Institute for Health Research (NIHR) Clinical Research Network (CRN) gathered for their annual meeting at St Thomas' Hall, London.**

There was a 'marketplace' of stalls for networking with colleagues including INVOLVE, the Biomedical Research Council at Guy's at St Thomas, and the Collaboration for Leadership in Applied Health Research and Care (CLAHRC).

The team who developed the Cicely Saunders Institute online forum for Patient and Public Involvement ([www.csipublicinvolvement.co.uk](http://www.csipublicinvolvement.co.uk)) won the Innovation Award.

The forum now has around 90 members, including researchers, patients, carers, and members of the public. Dialogue within this online forum has led to improved research proposals, materials, and involvement of PPI members in research at the Institute.

PPI members Sylvia Bailey and Pam Smith were also commended for their contributions to the Strategy Group at the Cicely Saunders Institute. They co-authored the Institute's first PPI Strategy 2017-2020 and assisted with the design and implementation of public engagement events.

## IN THE MEDIA:

### **BBC ONLINE – THE NEED FOR PALLIATIVE CARE**

Dr Katherine Sleeman, NIHR Clinician Scientist at the Cicely Saunders Institute has written an article for BBC Online about the growing need for palliative care globally. In the first three days, the article had been viewed nearly 700,000 times.

Research suggests that palliative care can significantly improve quality of life - with people experiencing fewer physical symptoms and reduced rates of depression. They also have a greater chance of dying outside hospital.

[bbc.co.uk/news/health-43159823](http://bbc.co.uk/news/health-43159823)

# Supporting Cicely Saunders International

Cicely Saunders International relies entirely upon the charitable support of foundations, companies and generous individuals to carry out its programme of world-class research and education. We would like to thank our past and current donors and would also like to encourage new donors to support our work. If you want to make a donation by cheque or a regular commitment by standing order, please complete this form and return it to:

Sian Best, Cicely Saunders International, Cicely Saunders Institute, Bessemer Road, London SE5 9PJ  
Telephone: **020 7848 5580** or email: **sian.best@cicelysaundersinternational.org**

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