

We have to listen to the details of symptoms and bring constant attention to changing needs. We are concerned both to relieve suffering and that our patients should maintain their own character and style to the end.

This quote from **Dame Cicely Saunders**, in 1988, demonstrates the holistic, multi dimensional nature of palliative care and how important it is that care is patient-centred. Modern healthcare research is catching up with these ideas, integrating mind and body into treatment across many specialties. But there is much work to do to ensure that these treatments reach all patients, wherever they are cared for, and wherever they live.

Palliative care is internationally recognised under the human right to health. Despite this, the World Health Organization estimates that only 14% of those needing palliative care at the end of life actually receive it.

At Cicely Saunders International our mission is to support research to improve the care and treatment of all patients with progressive illness and to make high-quality palliative care available to everyone who needs it – be it in hospice, hospital or home. There is no other charity specifically concerned with carrying out work to identify and promote best practice in palliative care.

In June we launched our Centre for Global Health Palliative Care. We partner with individuals and organisations around the world to build research capacity, generate evidence, inform policy and deliver education. We support teams overseas to discover the answers to locally-relevant questions. We are working hard as a Collaborating Centre of the World Health Organization to ensure that up-to-date technical guidance translates quickly into practice and that evaluation of services is being supported.

In this newsletter we report on our Michal Galazka study day, and pay tribute to Michal Galazka, a pioneer of international hospice education and friend and collaborator of Dame Cicely Saunders. Here at the Cicely Saunders Institute we will continue Michal's international work to translate Dame Cicely's vision into action.



Professor Richard Harding
Herbert Dunhill Chair & Director of the Centre for Global Health

Investigating emergency admissions to hospital

A&E attendance for people with dementia is common and increasing



New research supported by Cicely Saunders International and published in August 2017 has found that A&E attendance for people with dementia is common and increasing.

For people who are approaching the end of life, attending A&E can be distressing. It is also often unnecessary and can be prevented. In recent years, there has been a drop in the number of people with dementia dying in hospital, seen as demonstrating better end of life care. But over three quarters of people with dementia were seen in A&E in their last year of life. This has also been increasing over time.

Sometimes people with dementia do need to be admitted to hospital, but admissions can also lead to deterioration, with an increased risk of infections, bedsores and distress.

In the study, the researchers identified people who had dementia and who had died over a five year period (2008–13).

The research team's main findings include:

- Out of 4,867 people with dementia who had died, 78.6% had at least one A&E attendance during their last year of life.
- A&E attendance became more common the closer people were to death, with just under half (44.5%) having an A&E attendance in their last month of life, and a fifth of people with dementia attending A&E in their last week of life.
- People living in a care home had fewer A&E attendances, which may be because plans were put in place to avoid this.

Lead author, Dr Katherine Sleeman from the Cicely Saunders Institute said: "Recognition of the need to improve end of life for people with dementia has been increasing. This includes enabling them to be cared for in their home or a care home. However, our results show a worrying increase in the reliance on emergency care. In light of the current pressures on the health service, our ageing population and the associated increase in deaths from dementia, there is an urgent need to look at ways we can provide better support for care in the community."

Read the full paper here <http://bit.ly/2vZyyb6>

Publication details: Sleeman KE, Perera G, Stewart R, Higginson IJ. Predictors of emergency department attendance by people with dementia in their last year of life: Retrospective cohort study using linked clinical and administrative data. *Alzheimer's & Dementia* (2017) 1-8. DOI: 10.1016/j.jalz.2017.06.2267

Hinohara Lecture

In July 2017 Professor Higginson spoke at the 12th Asia Pacific Hospice Conference in Singapore where she gave the Hinohara Lecture, named in honour of the physician Shigeaki Hinohara who died in July 2017 at the age of 105. Professor Higginson met Dr Hinohara in 1996.

Professor Higginson's lecture *Greater than the Sum of Its Parts* looked ahead to the development of palliative care in the next 50 years.

Professor Higginson described the philosophical roots of palliative care, the multi-professional nature of modern palliative care, and the multi-dimensional nature of the specialty, incorporating Mind and Body, as described by the founder of the modern hospice movement, Dame Cicely Saunders.



Read further details of the lecture on our website
<http://bit.ly/2fXljTy>

Open House London

We are pleased to announce that the Cicely Saunders Institute will be taking part in this year's Open House London, the capital's largest annual festival of architecture and design.

The Cicely Saunders Institute will be open to visitors on Saturday 16th September.

Open House London showcases good building design and provides a great opportunity for local people to find out more about buildings in London. Come along on the day and hear about our building, its construction, and the work that we do.

Several of our researchers will be on hand to answer your questions, and you will also be able to explore the Institute, see the view over central London from our roof garden, and have a curated tour of the artworks in the building led by the original artists.

There will be plenty of resources to hand, including the chance to find out more at the Macmillan information centre on the ground floor. For those who are interested in becoming more involved, you'll be able to find out more about our patient and public involvement in research, or sign up to our email list.

The Institute, on Bessemer Road, London SE5 9PJ (next to King's College Hospital) will be open from 1pm – 5pm on Saturday 16th September.

You can read more about Open House London on their website www.openhouselondon.org.uk

Contact sian.best@cicelysaundersinternational.org for further details of Open House at the Cicely Saunders Institute.



Tribute to Michal Galazka

In June the Cicely Saunders Institute held an all-day workshop entitled Palliative Care in 20 years time: Future Predictions and Global Challenges. Speakers presented the latest research on future needs for palliative care, and the challenges ahead.

This international study day was also a celebration of the life of Michal Galazka, a pioneer of international hospice education, and friend and collaborator of Dame Cicely Saunders. The event included tributes from friends, family and colleagues.

Michal Galazka was born in Scotland and emigrated to the United States with his family when he was 11 years old. He graduated from Harvard and went on to found a non-profit organization called the Hospice Education Institute, with a humble beginning out of his garage, which went on to become a multi-million dollar organisation, recognised and highly regarded around the world.

Michal Galazka chatting with HRH Princess Royal at the official opening of the Cicely Saunders Institute, May 2010



You can see a podcast of the study day on the Institute's YouTube channel www.youtube.com/CSIKCL

His daughter Taylor Heyl said:

Michal's constant curiosity and thirst for knowledge earned him several advanced degrees and carried him around the globe many times, but it was his empathy for and understanding of people that really defined him. He spent significant time and effort in linking people together across cultures and around the world and in giving valuable information about health care that brought comfort and empowerment to dying people and their families. I can remember from an early age, hearing him give advice on his "Hospice Link" phone line at the Hospice Education Institute. When he received a call on this line, I knew it would be hours before Michal would be available, and I came to deeply respect his intent listening skills and remarkable patience and kindness to strangers in need.

One of Michal's favourite sayings was "A life well lived includes a death well planned". He was single-minded in his attempt to show people how to live a good life and die in the way that they wanted to.

Avril Jackson, (retired) Manager of the Hospice Information Service at St Christopher's.

I remember Michal for his attention to detail, his warmth and incredible sense of welcome and hospitality, his unerring ability to remember names and faces, his humour, his good judgement, and his willingness to go the extra mile to help with an information enquiry on behalf of a patient, family or fellow information provider.

I first met Michal in 1985 when he brought a large group of healthcare professionals to visit St Christopher's Hospice. At the time I was the information officer for the Hospice Information Service at St Christopher's and the conference organiser so was much involved in coordinating the group's visit. The annual Hospice Education Institute visit, or 'Michal Galazka Day' as it was fondly known, became a highlight in St Christopher's education programme bringing people from across the world to experience palliative care in a UK hospice setting.

Michal would meticulously plan each visit, providing a summary of participants' experience and interests so that we could try to cover their needs. And with efficiency, there was great warmth and charm as he took the trouble to personally introduce the members of his group, never stumbling on a name.

As an information provider himself, as well as an educationalist, Michal was very aware of the value of forging international links and allowed time in the visit for me to talk to the group. Many of the contacts forged through the visits of the Hospice Education Institute enabled us develop links with new palliative care teams worldwide.

Professor Robin Downie writes: It is a great tribute to Michal that he saw the huge benefits to palliative care coming not only from talks by experienced practitioners and hospice visits but also from discussion among students from many cultural backgrounds. His organising and business skills made the sessions possible and his genial presence sent us away inspired. It was a great privilege to know him. He will be much missed.

Above: Professor Irene Higginson, Director of the Cicely Saunders Institute, Mr John McGrath, Chairman Cicely Saunders International and Professor Colin Murray Parkes

Below: Avril Jackson (centre) with Dr Simon Etkind and Lara Klass, from the Cicely Saunders Institute



Student's research on carers wins Cicely Saunders Prize for Academic Excellence 2017



Congratulations to MSc student Maja de Brito who has won the Cicely Saunders Prize for Academic Excellence in Palliative Care. The prize is awarded to MSc students who have achieved high marks in their Research Study Projects and impressed a panel of external judges.

Maja explains the aims of her research:

'Governments are investing more and more in home palliative care for various reasons. However, home care is only possible if family members are prepared to take on the responsibility. Although carers have been studied before, we still know little about their experiences of providing care in the home setting with the support of a specialised palliative home care team.

I took advantage of existing data from a study on the preferences of patients and carers for home palliative care to respond to this aim. In this preliminary work, I looked at the experiences of 12 purposely selected carers with different sociodemographic backgrounds from the North of Portugal that participated in the primary study.

My analysis found providing care in the home setting with the support of a specialised team can be an isolating experience (described by carers as "being locked" inside their home). The specialised home care team is crucial.

Caregiving is so full of challenges that the team is often not able to address all of the patient and carer needs.

The most surprising finding in this study was the openness of the carers to discuss their own need for support, especially psychosocial support. They were very clear that family carers should be considered as "the unit of care" together with the patients. This specific finding challenges one of the key assumptions of the international literature on family carers. Namely, that carers are often ambivalent about being considered as the recipients of care in addition to being providers of care, which makes it difficult to deliver interventions targeted at supporting family carers.

My MSc Research Study Project reported on the preliminary results only and the final model of family carers' experiences in providing care in the home setting. The recommendations for clinical practice, research, and policy based on these findings are currently in development.

The study was funded by the Calouste Gulbenkian Foundation. A special thank you to all family carers and the home palliative care teams who participated in the study'.

GLOBAL HEALTH:

Latest Spotlight booklet now available

The Cicely Saunders Institute has produced the latest in its 'Spotlight' series. The booklet looks at global health challenges in palliative care, and details our work in capacity

building, education and training as a World Health Organization Collaborating Centre for Palliative Care and Older People.

If you would like a copy sent to you in the post, please contact sian.best@cicelysaundersinternational.org
The spotlight series of booklets can be viewed online at <http://bit.ly/2whbZS7>

Cicely Saunders International Annual Lecture 2017

Integrating the Existential and Psychosocial into Palliative Medicine: Hope, Value and Meaning for Patients, Families and Care Teams

Wednesday 4th October 5:00 – 6:00pm

Cicely Saunders Institute, Bessemer Road, London SE5 9PJ

This year's lecture will be given by Professor David Kissane MD, Head of Psychiatry for Monash University, Australia and Chairman of the Department of Psychiatry and Behavioural Sciences, Memorial Sloan-Kettering Cancer Center, New York. Professor Kissane is an academic psychiatrist, psycho-oncology researcher and palliative care physician. He has made seminal contributions to the development of Psycho-Oncology and Palliative Medicine and has contributed significantly to the use of support groups in cancer care. He developed a model of family-centred care in both palliative care and bereavement, researched the state of demoralization as a form of existential distress, and built a comprehensive communication skills training program.

The event is free to attend. Please contact Lara Klass csi.events@kcl.ac.uk for further information.



Graduation 2017



Graduating students and staff from the Cicely Saunders Institute gathered in July at the Barbican, London to celebrate this year's successful completion of studies for 23 students.

The MSc (and associated Postgraduate Certificate and Diploma) in Palliative Care at King's College London is taught at the Cicely Saunders Institute and St Christopher's Hospice. The multi-professional research and evidence-based course attracts doctors, nurses, and other health and social care professionals including dietitians, social workers, physiotherapists among others, who work in palliative or end of life care, not only from the United Kingdom but also internationally.

The programme provides training in research methods and statistics, biology and management of symptoms, psychosocial, cultural, ethical and spiritual issues and service organisation. Since the programme was established over 500 students have graduated from the programme. Cicely Saunders International is currently funding a number of scholarships for MSc students.

Email: mscpallcare@kcl.ac.uk

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
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