

*Palliative care is a combination of tough clinical science and personal attention to detail... With the whole family as the unit of care.*

**Dame Cicely Saunders** wrote these words over 30 years ago, and today they are more relevant than ever. The need for palliative care has never been greater, and is growing rapidly. In this newsletter you can read a summary of our latest published research on future predictions for palliative care published in BMC Medicine on 18th May.

**As a Trustee, I was privileged to hear an early presentation of some of the latest work from the team at Cicely Saunders International – on what the future might bring. I think all of us round the table that morning recognised the significance of what Simon Etkind and Anna Bone were describing.**

It's a truism now that we live in an ageing world, and that the number of people dying each year will rise, but what Simon, Anna and the team have shown is that palliative care needs will rise even more quickly as a result. As you will read in this newsletter, their paper, published recently in BMC Medicine, predicts that 25% more people will die each year by 2040, but that the number of people with chronic illnesses, dementia and other conditions requiring palliative care could rise by 42%.

The extensive media coverage of this research demonstrates the public interest in what could potentially be a major burden for the health system if issues around capacity, training and resources in specialist and non-specialist palliative care are not addressed.

But improving palliative care is a complex challenge, and CSI's response is equally complex, as this newsletter illustrates. Ground-breaking research, capacity building through our students, seminars and international projects, and our commitment to the End of Life Care Coalition and its important work in keeping palliative care high on the agenda in the UK's Department of Health, are just some of the ways we continue to put the case for better care at the end of life.



**Kate Kirk**  
Trustee, Cicely Saunders International

# At least 42% more people will need palliative care in England and Wales by 2040

The number of people requiring palliative care over the next 25 years is likely to increase substantially, requiring a shift in healthcare priorities in England and Wales, according to new research from the Cicely Saunders Institute published in the open access journal *BMC Medicine*.

By 2040, at least 160,000 more people each year are likely to have palliative care needs, including pain management of chronic illnesses and end-of-life care at hospitals, hospices, and at home. If all these people are to receive palliative care through the healthcare system, a significant increase in training and resources for both specialist and non-specialist care providers is needed immediately, according to the researchers.

The research was funded by The Atlantic Philanthropies via Cicely Saunders International. Dr Simon Noah Etkind, lead author from the Cicely Saunders Institute, King's College London, said: 'Current population and mortality trends in England and Wales suggest that 25% more people will die each year by 2040. In our research we found that if current trends continue, the estimated number of people who will require palliative care will grow by much more than this, due to a sharp increase in the number of people dying from chronic illnesses, particularly cancer and dementia. This, combined with an aging population means that we should expect that there will be 42% more people with palliative care needs by 2040.'

The projections also found that over half of all deaths will occur in people aged over 85 and that dementia deaths will almost quadruple by 2040.

Dr Etkind explained: 'We estimate that at least 85% of deaths in 2040 will require some form of palliative care and we can predict a shift towards dementia as a greater contributor to palliative care need.'

Professor Irene Higginson, Director of the Cicely Saunders Institute at King's College London and co-author of the paper, said: 'There is an urgent need to act now to transform health, social and palliative care services to meet the projected growth in palliative care need. More attention should be given to the needs of people and those close to them when facing progressive illness, particularly those dying from chronic and complex illnesses, and age related syndromes such as frailty and dementia. There is a need to support their families, who shoulder so much of the care. The way in which we provide health care, and palliative care will need to change. In advance of this we are testing new more integrated approaches, where people can have expert palliative care alongside their illnesses.'

The projections were based on data from the Office of National Statistics. This was used to estimate recent trends of deaths from chronic illnesses likely to require palliative care. These trends were then extrapolated to predict the number of people that would require palliative care through to 2040 accounting for population and demographic change.

## IN THE MEDIA: BMC MEDICINE

Our article in *BMC Medicine* on predictions for palliative care by 2040 was covered by national and international press including *The Times*, *Independent*, *Guardian*, *Sun*, *Sky News*, *Daily Express*, *Daily Mail* and *The Huffington Post*. Much of the coverage focussed on implications for care of people with dementia. <http://econ.st/2oVKFB4>

## Palliative Care in 20 Years Time: Future Predictions and Global Challenges

Speakers will include Professor Irene Higginson, Director of the Cicely Saunders Institute, and Dame Barbara Monroe, former Chief Executive of St Christopher's Hospice. The day will also include tributes to Michal Galazka, of the Hospice Education Institute from friends and former colleagues. Did you know or work with Michal and would you be interested in taking part? Contact [sian.best@cicelysaundersinternational.org](mailto:sian.best@cicelysaundersinternational.org)

## EAPC 2017

At the World Congress of the European Association for Palliative Care, researchers from the Cicely Saunders Institute and members of CS International's International Expert Panel presented the results of several research projects that have been funded by Cicely Saunders International and The Atlantic Philanthropies, including:

- Complexity, Economics and Health Policy – what we know and how can we plan
- Informal Care and Grief of Carers – the importance of carers and providing support for carers at all stages of care and in bereavement
- Future Predictions of palliative care needs in 2040 – what do the numbers say and how can we plan palliative care provision in the future
- Future projections on place of death, and implications for health and social care services

Contact [sian.best@cicelysaundersinternational.org](mailto:sian.best@cicelysaundersinternational.org) if you would like us to send you written summaries of the research or information about these research programmes.

## Does playing a wind instrument or singing improve respiratory function?

Researchers at the Cicely Saunders Institute are investigating possible new treatments for patients with breathlessness. They decided to look at whether singing or playing a wind instrument provides better symptom control. The study published in the Journal of Music Therapy did find a trend towards improved respiratory function. But only one study, on Parkinson's disease, had significant between-group differences.

Many long-term neurological conditions adversely affect respiratory function. Singing and playing wind instruments are relatively inexpensive interventions with potential for improving respiratory function. Researchers undertook a systematic review of published randomized controlled trials and observational studies examining singing or playing wind instruments to improve respiratory function in individuals with long-term neurological conditions.

68 full texts were reviewed and five studies included. These concerned 109 participants but were low-quality due to evidence of bias. However the positive trend in respiratory function following music therapy merits further investigation.

Ang K, Maddocks M, Xu H, Higginson I, The Effectiveness of Singing or Playing a Wind Instrument in Improving Respiratory Function in Patients with Long-Term Neurological Conditions: A Systematic Review. *J Music Ther* (2017) 54 (1): 108-131. <http://bit.ly/2sLL0ki>



# Dying at Home

Where people die is important to them and their families. Most people want to die at home, but most die in hospital.

Researchers at the CSI have looked at data for deaths from respiratory disease, a condition that in the advanced stages can lead to multiple hospitalisations.

London had the highest hospital deaths, and the South-West and South East Coast regions had lower hospital deaths than most other regions. Living in urban areas increased the chances of hospital death.

Lead author, Professor Irene Higginson said: 'Understanding which factors affect place of death is vital for planning service and improving care, especially given our ageing population, rising chronic diseases worldwide and the high costs of hospital admissions.

'Our results show that while the End of Life Care Strategy may have helped to move some deaths out of hospital for people with respiratory disease, it still misses important groups.

'It is therefore essential that future strategies for end of life and palliative care directly target those at highest risk, especially with multimorbidity, and in deprived areas and cities, and this may require different approaches.'

Read the full paper here: <http://bit.ly/2sSza3w>

**Publication details:**

Higginson IJ, Reilly C, Bajwah S, Maddocks M, Costantini M, Gao W on behalf of GuideCARE Project. Which patients with advanced respiratory disease die in hospital? A 14-year population-based study of trends and associated factors. BMC Medicine 2017 15:19 DOI: 10.1186/s12916-016-0776-2

# House of Lords

On 14th March 2017 CS International's ISEP member, Baroness Finlay of Llandaff spoke in the House of Lords and asked the government how they intend to ensure that Clinical Commissioners respect the undertakings made in Our Commitments to You for End of Life Care: The Government Response to the Review of Choice in End of Life Care.

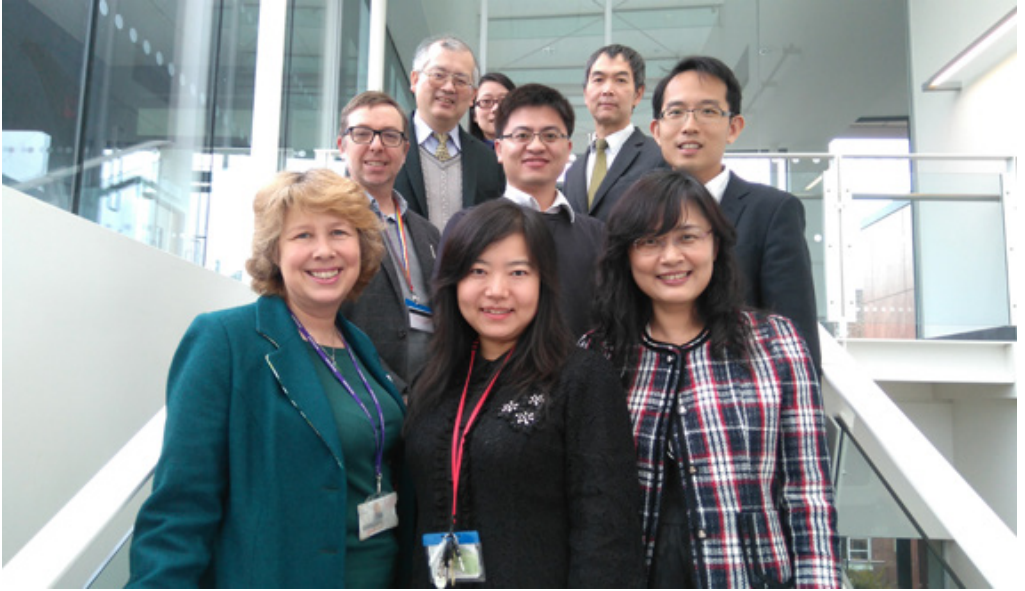
'Cicely Saunders founded the modern hospice movement 50 years ago, with activity underpinned by evidence. It was she who said:

***'You matter because you are you, and you matter to the last moment of your life. We will do all we can to help you, not only to die peacefully but to live until you die.'***

'Her scientific evidence showed that morphine, given regularly at the right dose at the right time, can safely get on top of pain. Sometimes, other effective interventions, ranging from expert use of modern sophisticated analgesics to nerve blocks, are needed. Acute breathlessness and acute anxiety can now be managed. Open, calm and honest conversations with patients about their illness, their needs and what lies ahead can transform their experience as death approaches... Two important randomised controlled studies of specialist palliative care input have shown that patients have a higher quality of life and better moods. Not only do they live better, but they also, surprisingly, live longer with good palliative care support, at no additional overall cost'.

You can read the debate in full at: <http://bit.ly/2sLNN0S>

# International Visitors



Visitors from Taipei City Hospital and Taipei Representative Office with Professor Irene Higginson, Dr Richard Harding and Dr Ping Guo

Visitors from Beijing Cancer Hospital, led by Professor Wei Liu Head of Palliative Care Centre and Day Care Centre, spent a week meeting with key members of the department and visiting some of the sites that we collaborate with, including St Christopher's Hospice.

'The Cicely Saunders Institute has an excellent reputation for palliative care and is very well-known in mainland China... We are looking forward to further collaboration with the Cicely Saunders Institute in the field of clinical medicine, teaching and scientific research,' (Professor Wei Liu, Beijing Cancer Hospital).

We also welcomed a group from the Taipei City Hospital in Taiwan, led by Deputy Superintendent Li-Lin Kuo, who were accompanied by representatives from the Science and Technology Division of the Taipei Representative Office in the United Kingdom; an institution which aims to promote bilateral trade, investment and technology cooperation between Taiwan and the UK.

'We all agreed that leadership training is the key to the future and the world. Many thanks to Professor Higginson and Dr Harding, for sharing their experience and wisdom, and to Dr Guo'. (Deputy Superintendent Li-Lin Kuo, Taipei City Hospital).

## Dame Cicely Saunders Centenary 2018

The Cicely Saunders Institute is preparing to celebrate Dame Cicely Saunders' centenary in 2018. Did you work with Dame Cicely? Do you have any personal memories or photographs you would like to share with researchers? We would love to hear from you! Contact [sian.best@cicelysaundersinternational.org](mailto:sian.best@cicelysaundersinternational.org)

# PhD Students at the Cicely Saunders Institute

## Dr Jen-Kuei Peng

Palliative care for Older People



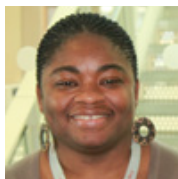
Jen-Kuei joined the Cicely Saunders Institute in October 2015.

His project is an analysis of healthcare for patients with end-stage liver disease and the effectiveness of palliative care services for these patients.

Jen-Kuei qualified in medicine from National Yang-Ming University in Taiwan in 2001 and then undertook training in family medicine and palliative medicine at National Taiwan University Hospital. In 2008, he also qualified in geriatric medicine and was awarded an MSc in preventive medicine at National Taiwan University. He is particularly interested in palliative care for non-cancer and palliative care for older people.

## Mary Abboah-Offei

Palliative care for HIV/AIDS in Africa



Mary qualified as a Registered General Nurse in 2006, worked full

time at the Surgical-Medical Emergency Unit of the Korle-Bu Teaching Hospital, in Ghana for about 4 years. While there, she also worked part-time as a Chemotherapy Nurse at the National Centre for Radiotherapy and Nuclear Medicine, in the same hospital.

*'After completing my MSc in 2014, I travelled back to Ghana, and became a nurse-lecturer in one of the private nursing schools, where I lectured in Basic Nursing and Medical Nursing. In 2016 I secured funding from the Ghana Education Trust Fund to fund my PhD at the Cicely Saunders Institute, King's College London. For my PhD, I will be developing a person-centered community model of palliative care that will improve outcomes for HIV/AIDS patients in Ghana.'*

## Eve Namisango

Palliative Care for Children in Africa

*'I am a BuildCARE Africa –PhD training fellow. I am currently the research manager at the African Palliative Care Association. [www.africanpalliativecare.org](http://www.africanpalliativecare.org) and coordinate the African Palliative Care Research Network.*

*'For my PhD, I am working on the Children's Palliative Care Outcome Scale for sub-Saharan Africa. My focus is on appraising the conceptual content of this measure and then assessing its psychometric and clinometric properties. I have an MSc in Palliative Care from King's College London, and an MSc in Clinical Epidemiology and Biostatistics from Makerere University. My PhD project is driven by passion for children living with life-limiting and life-threatening conditions, health outcomes research, palliative care and psychometrics'.*

Eve is supported by The BuildCare Africa Programme, funded by the Open Society Institute.

## IN THE MEDIA: BBC2

On 17th May, BBC2 screened a documentary called *A Time to Live*, a film 'about living, not dying' made by Sue Bourne featuring first-hand interviews of people living with terminal illness. Cicely Saunders Institute acted as academic consultants on the film. The film was funded by the Open University with support from the Wellcome Trust. The film is on BBC iPlayer [www.bbc.co.uk/programmes/b08r3xyv](http://www.bbc.co.uk/programmes/b08r3xyv)

# Athena SWAN Award



The Cicely Saunders Institute has won an Athena SWAN Silver award. The award recognises continued commitment in supporting gender equality and championing an inclusive working environment for all. Dr Katherine Bristowe, from the Cicely Saunders Institute said:

'We are delighted to have won a Silver Athena SWAN award. At the Cicely Saunders Institute we have embraced the principles of Athena SWAN since our inception in 1997. The guiding principles of Dame Cicely Saunders, this pioneering woman who put the person before their disease, are embedded within our culture and permeate all that we do'.

## Congratulations to Joanna Davies

Joanna Davies, PhD Research Training Fellow at the Cicely Saunders Institute has been awarded the Dame Cicely Saunders Award for Academic Excellence. The award is for her work as part of the Outcome Assessment and Complexity Collaborative (OACC). OACC is a research project led by Dr Fliss Murtagh and Professor Irene Higginson at the Cicely Saunders Institute.

The project implements routine collection of patient-centred outcomes data in hospices, hospitals, care homes and in the community. The research team uses this data to improve the quality of care for patients and families. Joanna has been recognised for her ongoing contribution at St Christopher's Hospice. She uses data analysis and feedback to engage clinical teams, understand the complexity of patients and evidence the care being delivered.

# MSc News



Caroline Quilty, MSc scholar, gave evidence to the All-Party Parliamentary Group (APPG) on Patient Safety's inquiry into Malnutrition in End of Life Care. The APPG will take around 18 months to complete its inquiry and issue its report and recommendations in 2018.

Caroline is a dietitian with 25 years' experience. In the early 2000s she set up a dietetic service at St Christopher's hospice in Sydenham. In 2013 she became a specialist palliative care dietitian for St Joseph's Hospice in East London. While at St Joseph's, Caroline became interested in developing her clinical skills and knowledge and heard about the MSc in Palliative Care at Cicely Saunders Institute, King's College London from colleagues who were very positive about the programme. She was awarded the Professor Rob Buckman Scholarship, via Cicely Saunders International.

Caroline writes: 'I was extremely fortunate to be awarded the Professor Rob Buckman scholarship which fully funded the programme and without which I would not have been able to accept a place on the MSc. As a dietitian what strikes me about working with patients in palliative care and their families is the importance of eating and drinking not just for the nutrition it provides but for the social and emotional impact it has: providing food is a way that we show love and care for each other.'

### IN THE MEDIA: THE ECONOMIST

The Economist covered palliative care extensively in its edition on 29th April 2017, quoting Dr Katherine Sleeman, Clinician Scientist at the Cicely Saunders Institute. The coverage included several articles and the results of an international survey on people's preferences and the importance of spirituality in four different countries. <http://econ.st/2oVKFB4>

# 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:

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