

Cicely Saunders International

Better care at the end of life

Newsletter

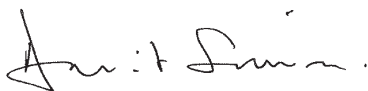
Issue 6, Summer 2010

This reflection comes from a newly retired Trustee of Cicely Saunders International after six years of office. I want to look back briefly in admiration to salute all those who contributed to the hard work that culminated in the opening of the new Institute on the King's Denmark Hill campus on 5th May 2010. What a wonderful day. To see Cicely's dream become reality and to enjoy the enthusiasm of staff, patients, academic colleagues and sponsors was remarkable. Trustees' hearts are not renowned for singing. I promise mine did.

But that was then and now you who are privileged to work with CSI must seize the opportunity and use the enthusiasms to great effect. I joined the Project in September 2001, inspired by Cicely herself to help realise a future where the end of life was better researched, better staffed and better organised.

The twinning of a concept of dignity and a better informed service for an aging population remains a real challenge worldwide. The fact that CSI has a clear international dimension and can contribute significantly to worldwide research excellence in its field is to my mind another element of inspiration for all who will work in the new Institute.

To create new options for care through research will be both a continuing passion and a driver for the Institute. It will lead I hope to an ever-growing reputation for quality and practical support for all that Cicely Saunders dared to dream.



Lord Simon of Highbury

Trustee (retired) of Cicely Saunders International

Official Opening of the Cicely Saunders Institute

After several years of fundraising and an 18-month construction period, the Cicely Saunders Institute of Palliative Care was officially opened by HRH The Princess Royal, Chancellor of the University of London, on 5 May 2010. Just over one hundred guests joined staff working in the Institute to celebrate the launch of the world's first institute of research in palliative care.

HRH was given a guided tour of the building by the Principal of King's College London, Professor Rick Trainor and Professor Irene Higginson, Director of the Institute and Scientific Director of CSI, and heard about the research that is being undertaken, as well as meeting staff, students, donors, patients and their carers.



In welcoming HRH and guests to the opening of the Cicely Saunders Institute, Lord Douro, Chairman of King's College Council, thanked HRH for officially opening the building and the interest she took in King's College London. He noted that: *'Over ten million pounds has been raised almost entirely from philanthropic organisations. We are immensely grateful to all those who gave so generously to the appeal and we admire them for their support for this pioneering Institute.'*

At the end of the tour HRH unveiled a plaque and gave a short speech in which she praised the Institute which she said would be *'much appreciated by many'*, and would *'have an important part to play in the future'*. She said

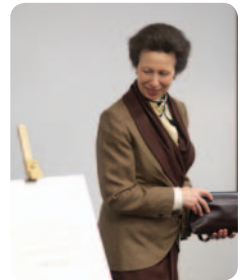
a huge degree of thanks was owed to those who had made the Institute possible and for what it would achieve in the future.

The Institute embraces the objectives and philosophy of palliative and hospice care. John McGrath, Chairman of Cicely Saunders International, spoke at the opening of the Institute: *'Today, we are moving a step forward in the historic journey that Dame Cicely started over sixty years ago. Cicely is recognized the world over as the founder of the modern hospice movement. ... Our challenge is to ensure that we fulfil Cicely's mission which in her words is "to ensure that patients and families feel they matter, even at the end of life".'*

The Institute will facilitate closer cooperation between academics and clinicians in palliative care and related disciplines from a wide range of local, national and international organisations, ensuring academic developments in research and education directly translate to clinical care quickly to benefit patients and families. Working within the Cicely Saunders Institute is the well-established multidisciplinary clinical palliative care team at King's College Hospital NHS Foundation Trust. Now that the team is based within the Institute, collaboration with their academic colleagues is proving to have most beneficial results.

It will also provide opportunities to train healthcare professionals from the UK and overseas, thereby increasing the skill base and disseminating knowledge.

The building, designed by architects Loates-Taylor Shannon, has already won a BREEAM award for its environmental features. It is a



light, landscaped space with a welcoming ambience; an open and integrated building, promoting interaction and communication. Open plan offices are arranged around a light infused central atrium and there are also quiet, reflective spaces. A programme of innovative art works and installations by artists Caroline McCarthy and Tanya Kovats, which were commissioned by the Contemporary Art Society, are featured in the building. Staff working in the Institute use words such as 'calm', 'energising' and 'inspirational' to describe the atmosphere. We would also add 'buzzing' especially when the numbers increase with the influx of students.

It comprises 1,800 sqm of floor space on three floors plus a roof garden. It will house around 100 researchers, academics, clinicians, rising to over 200 with students, patients and carers. There are lecture rooms, meeting facilities, office and research space as well as a Macmillan Information and Support Centre on the ground floor.

Work at the Institute is already having an impact. On the following page, you will find information about one such project. There will be many more.

Now that the Institute is up and running, we are turning our fundraising efforts to supporting a body of work which will incorporate education, research and dissemination of its findings, identification



of variations in care and its improvement. Professor Higginson: *'The next challenge is to deliver the vision that Dame Cicely Saunders set us in the Institute. The need for palliative care is growing in all countries, and far outstrips supply. We will be working with others to try and discover better treatments, better care, and better support for patients and families, and to spread the best in practice.'*

Our partners in the Cicely Saunders Institute, King's College London and King's College Hospital, are part of King's Health Partners. King's Health Partners Academic Health Sciences Centre (AHSC) is a pioneering global collaboration between one of the world's leading research-led universities and three of London's most successful NHS Foundation Trusts. Being a part of this collaboration will be an important factor in ensuring that research findings and the other work of the Institute will be spread quickly where it is most needed.

'We will promote collaboration and integration of research, teaching, and clinical activities on a scale never before achieved. This will include user involvement to promote evidence-based practice, and research and teaching driven by the needs of patients, families and clinical concerns.'

'We will enhance palliative care worldwide and seek to influence the lives of an estimated one billion people within 10 years of opening. Our aim is to improve the way that dying people are cared for and make a decent quality of life attainable, even at the end of life.'



Irene Higginson OBE, Director of the Cicely Saunders Institute of Palliative Care, Professor of Palliative Care at King's explains the vision behind the Institute

Spiritual care for Black and minority ethnic groups: launch of recommendations

At the opening of the Cicely Saunders Institute on 5th May, CSI and the Department of Palliative Care, Policy and Rehabilitation were delighted to launch the report *Spiritual care recommendations for people from Black and minority ethnic groups receiving palliative care in the UK*. The recommendations are authored by Lucy Selman, Richard Harding, Irene Higginson and colleagues working in chaplaincy, palliative care and public health, with a Foreword by Archbishop Emeritus Desmond Tutu.

The population served by the NHS has changed significantly with the rise in the number of immigrants to the UK over the previous decade. The Black and minority ethnic population experiences a high burden of disease, including cancer, organ failure and HIV infection. It is therefore a group with considerable need for palliative care, which integrates the spiritual aspects of patient care alongside the physical and psychosocial.

Health policy in the UK states that spiritual care should be available to all patients receiving palliative care, recognising that spirituality and religion often play a key role in patients' experience of serious illness. Spirituality can be understood as relating to a search for existential meaning that is sometimes, but not always, expressed through religion. Many patients report becoming more religious or more spiritual following a diagnosis of an

incurable condition, and religious faith and spiritual belief are important coping resources for many. Often patients wish to discuss their spiritual beliefs with their physicians, and may need spiritual support.

Until now there has been little work addressing spiritual care for Black and minority ethnic populations, despite evidence suggesting that some groups have a strong reliance on spiritual belief and practice. In particular, there is little guidance for palliative care services on how to meet the spiritual and cultural needs of people from different cultural groups.

The recommendations aim to fill this gap in policy guidance. They combine three subjects identified by the National Institute for Clinical Excellence as research priorities in palliative care – spiritual support, making services more sensitive to cultural differences, and improving care for underserved groups – hence adding to and building on Department of Health work in these key areas. As Tutu writes in his Foreword, these recommendations are an important step towards meeting the spiritual care needs of a diverse population, including the large numbers of Africans living with incurable, progressive disease in the UK. Adopting and implementing the recommendations will, we hope, lead to a future in which services can meet the cultural and spiritual needs of all patients and families, regardless of ethnicity.

'Living with incurable progressive disease such as advanced cancer and HIV infection has implications far beyond the physical dimension. The experience of illness can have a profound effect on one's spiritual well being, leading to times of crisis as well as opportunities for growth. It is imperative that healthcare services recognise the spiritual aspects of illness, and are tailored to support people spiritually as well as physically. This becomes even more essential in the context of palliative care, which aims to provide what Dame Cicely Saunders described as 'total care' for patient and family.'

† Archbishop Emeritus Desmond Tutu



Benny / Goai of Oryx Media

■ As part of her art project 'Light for Cicely' on display at the Institute, Caroline McCarthy has produced a hardback book containing the images and accompanying words of all those who contributed. If you aren't familiar with the project, you can read more about it at www.light-for-cicely.net. Family, friends, colleagues and supporters – from Poland, Italy, Norway, Uganda, Pakistan, Ireland, India, the USA and Canada, as well as from the UK – contributed to the project. Their response indicates Cicely Saunders' impact, and indeed continued influence, both at home and internationally. The book is now for sale (£38.50 plus p&p) and all profits will be put to the work of Cicely Saunders International. If you would like to buy a copy please contact Brenda Ferns on 020 7848 5580 or brenda.ferns@btinternet.com.

■ Developments in the Breathlessness programme

Benzodiazepines for the relief of breathlessness in advanced diseases in adults

Breathlessness is a common and distressing symptom in advanced cancer and other diseases at the end of life. Benzodiazepines, a group of sedating drugs that are mainly used for sleep disturbance and anxiety, are widely used for the relief of breathlessness. Dr Steffen Simon, a visiting research fellow in the Department of Palliative Care, Policy and Rehabilitation, King's College London published a Cochrane Review with other colleagues from the department assessing the effectiveness of benzodiazepines

to relieve breathlessness in adults with advanced disease. Data from seven studies were included in the review. The authors concluded that there is no evidence for a beneficial effect of benzodiazepines in the relief of breathlessness in adults with advanced disease. The review supports the use of benzodiazepines only if other first-line treatments, such as opioids and non-drug treatments, have failed.

This review was part of the Masters thesis of Dr Simon and he received the Help the Hospices Prize and the Award of the Department of Health Cochrane Review Incentive Scheme.

Simon ST, Higginson IJ, Booth S, Harding R, Bausewein C. Benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant diseases in adults. Cochrane Database of Systematic Reviews 2010, Issue 1. Art. No.: CD007354. DOI: 10.1002/14651858.CD007354.pub2.

Prof Irene Higginson and Dr Claudia Bausewein in close collaboration with Prof John Moxham and Dr Caroline Jolley (both Respiratory Medicine, King's College Hospital) won funding from the Research for Patient Benefit Programme (National Institute of Health Research) to set up a Breathlessness Support Service at King's College Hospital. The service will be evaluated in a randomised controlled trial from the time of opening. Charles Reilly, a physiotherapist with research background, has been recruited for the researcher post and will start in July.

Please contact Brenda Ferns, Administrator, on 020 7848 5580 or brenda.ferns@btinternet.com if you do not wish to receive future copies of this newsletter.

The newsletter is also available on our website – www.cicelysaundersinternational.org

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: **Brenda Ferns, Cicely Saunders International, Cicely Saunders Institute, Bessemer Road, London SE5 9PJ**, Tel: 020 7848 5580 or email: brenda.ferns@btinternet.com.

Making a Gift to Cicely Saunders International

(Mr/Mrs/Miss/Other) _____ Name _____

Address _____

_____ Post code _____

I would like to make a donation to Cicely Saunders International and enclose a cheque for £ _____
or

Please pay Cicely Saunders International £ _____ each month/year *(delete as appropriate)*

Starting on _____ *(please make this date one month from now)*

Until further notice and debit my account number

Bank sort code

Signature _____

To the Manager *(bank name)* _____

Address _____

_____ Post code _____

Please pay to HSBC, 60 Queen Victoria Street, London EC4N 4TR.

Sort Code **40-05-30**. For the credit of Cicely Saunders International, Account No **62126702**

I am a UK tax payer and I wish Cicely Saunders International to reclaim tax on this donation and all future donations I make to the charity or until further notice.

Thank you for your gift. All donations will be acknowledged unless you tick here.

Cicely Saunders International is a registered charity, No. 1087195.

THANK YOU VERY MUCH FOR YOUR SUPPORT