Winter 2020

CS|NEWS

news from cicely saunders international

Cicely Saunders International
Better care at the end of life

> *We must somehow give everything we can to these people that says you matter because you are you, everything to enable the patient to live up until he dies and the family to go on living afterwards.*
>
> **Dame Cicely Saunders**

As the 10-year anniversary of the Cicely Saunders Institute draws to a close, we can reflect on how far we have come during those ten years. Palliative care has now become a medical, social and economic model of care for those with life-limiting illnesses. Palliative care is evidence based – we have robust evidence that not only does it relieve suffering, it is cost-effective.

Furthermore we now have strong evidence that early integration of palliative care alongside curative treatment not only improves quality of life, it may actually prolong life. One of our key messages (derived from the work of Dame Cicely Saunders and many others in palliative care) is that palliative care is not about dying, it is about living well.

Who could have predicted that our 10th anniversary year would see the onset of a global pandemic of a new disease with a high mortality rate, and long-term, life-limiting effects for some survivors? COVID-19 has shown that every healthcare professional needs to know basic palliative care practices and communication skills, and every patient needs to know about their options for care when facing a serious life-limiting illness. Now more than ever we need to educate about symptom management, communication skills and psychological and spiritual care.

Thank you for your support.

Dr Kathleen Foley
Trustee

Support for bereaved children is urgently needed

The British Journal of Child Health has published a letter about the impact of COVID-19 on child bereavement urging all professionals and organisations providing care to dying patients to ensure that children's rights are recognised and protected.

The death of a parent for children is a life-altering experience. Although families may want to protect children by exclusion, not being involved in an age and developmentally appropriate way has been shown to have an adverse and long-lasting effect on children's health and wellbeing.

Restrictions on hospital visiting for the children of patients dying of COVID-19 may also combine with depression, fear and anxiety cause by separation from peers and a loss of school support during the pandemic.

The team called on the UK's Minister for Bereavement, Nadine Dorries, to ensure that children's voices are heard and that culturally competent, evidence-based services are urgently commissioned to meet the holistic needs of children when a parent is dying with COVID-19, to reduce the risks of long-term harm.

Dr Steve Marshall, Social worker at the Cicely Saunders Institute and co-author of the letter said:

"It is important that children and young people do not become invisible during the COVID-19 pandemic and that we do not overlook their needs when a parent is dying."

British Journal of Child Health
Steve Marshall, Andrew Rowland, Susan Higgins, Christina Woods, Lisa Jones, Sandeep Ranote, Iain Lawrie, Fiona Murphy
Letter published online:1 Sep 2020
https://doi.org/10.12968/chhe.2020.1.4.161

Action Plan for Palliative Care

Next month sees the launch of CS International's Action Plan for Palliative Care, a seven-point plan based on the Institute's own research, combined with independent reviews, surveys and reports. The Action Plan addresses longstanding challenges in palliative care and shows how to tackle the issues that prevent people getting the right care when and where they need it.

The Action Plan is part of CS International's campaign to make sure that people get the right care, in the right place, at the right time.

The Action Plan calls for:

- specialist palliative care to be integrated into all care settings;
- investment in community care services, so that patients are at the centre of care and their voices are heard;
- more palliative care training for all healthcare professionals, particularly in communication, and clinical management of complex symptoms.

"The COVID-19 pandemic has presented us with a unique opportunity to make palliative care more visible, and bring about change. I urge all our supporters to join us when we launch our Action Plan for Palliative Care."
John McGrath, Chairman and Trustee, Cicely Saunders International

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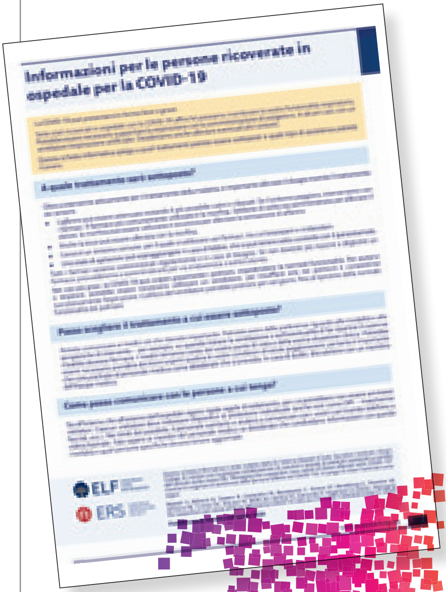
COVID-19 NEWS:

Important information for patients and families in different languages

Dr Sabrina Bajwah (Clinical Senior Lecturer, Cicely Saunders Institute) and a team of international respiratory and palliative care experts have developed factsheets jointly with patients and carers from across Europe to help manage the symptoms of COVID-19 in people admitted to hospital. The team worked with the European Lung Foundation to produce two versions of the factsheet – one directly for the patient and one for family and friends of the patient.

The factsheet explains what will happen once a person goes into hospital, how their symptoms will be managed and what will happen if they get put on a ventilator. The factsheet also explains the issues around contact and communication. This was drafted as part of an ERJ editorial highlighting the supportive care needs of COVID-19 patients.



Informazioni per le persone ricoverate in ospedale per la COVID-19

COVID-19 is affecting people from all over the world and appears to be having a worse impact on people from black and minority ethnic groups. Because of this, it is important that the information is accessible to as many people as possible. Thanks to many kind volunteers, the factsheet is available in 24 languages.

Family and friends can download these factsheets from the European Lung Foundation website so they can understand more about what might happen. Doctors can also download these factsheets and add information about local support services in their own hospitals. The factsheets are also downloadable from the CS International website: **https://bit.ly/2JrSoax**

Dr Bajwah said: *"At the height of the pandemic and recognising the disproportionate impact on the BAME community, we worked with the European Lung Foundation and PPI from across Europe to develop the factsheet and then translate it into 24 different languages. The non-English versions have been downloaded over 2,000 times by different patients, carers and institutions worldwide."*

Resistance training in advanced cancer

Resistance training is an effective way to increase muscle mass, but little is known about its role in preventing the loss of skeletal muscle mass and strength in people with advanced cancer.

Home is frequently the place of care and death preferred by cancer patients and researchers decided to investigate whether home would be a better training setting than hospital. The team decided to test if resistance training at home and in hospital is feasible and safe for patients with advanced cancer. Research participants were randomised into one of three groups: i) supervised at home, ii) supervised in hospital and iii) standard care with information leaflet.

The training programmes were similar, ran for 12 weeks for three sessions per week. The researchers found that patients doing the training at home stuck to the programme more than people training in hospital. The researchers concluded that resistance training is a safe intervention, and is more feasible at home than in hospital for patients with advanced cancer. There could be ways to increase adherence to the home intervention, and this could further improve its potential benefit.

Ribeiro C, Santos R, Correia P, Maddocks M, Gomes B.
Resistance training in advanced cancer: a phase II safety and feasibility trial – home versus hospital
BMJ Supportive & Palliative Care Published Online First: 13 August 2020. doi: 10.1136/bmjspcare-2020-002230

Cochrane Review: How effective is hospital-based palliative care?

Serious illness is often characterised by physical/psychological problems, family support needs, and high healthcare resource use. Hospital-based specialist palliative care (HSPC) has developed to assist in better meeting the needs of patients and their families and potentially reducing hospital care expenditure.

Collaborating with researchers in the UK and Europe, researchers based at the Cicely Saunders Institute carried out a systematic review of the evidence to establish the effectiveness and cost-effectiveness of hospital palliative care compared to usual care for adults with advanced illness and their unpaid caregivers/families.

Results suggest that when compared to usual care, HSPC may offer small benefits for patient's health related quality of life, their symptom burden and their satisfaction with care. It also increases the chances of patients dying in their preferred place (measured by home death).

While the researchers found no evidence that HSPC causes serious harms, the evidence was insufficient to draw strong conclusions. Although these are only small effect sizes, they may be clinically relevant at an advanced stage of disease with limited prognosis, and particularly for the person-centred outcomes important to many patients and families. More well-conducted studies are needed to study populations with non-malignant diseases and mixed diagnoses, and across different populations.

Bajwah S, Oluyase AO, Yi D, Gao W, Evans CJ, Grande G, Todd C, Costantini M, Murtagh FE, Higginson IJ.
The effectiveness and cost-effectiveness of hospital-based specialist palliative care for adults with advanced illness and their caregivers.
Cochrane Database Syst Rev. 2020 Sep 30;9:CD012780. doi: 10.1002/14651858.CD012780.pub2. PMID: 32996586.

New palliative care model shown to reduce costs without compromising on quality of care

Findings from a large-scale clinical trial testing a new palliative care model have shown that adding palliative care was viewed positively by patients and their carers while showing no difference in patient-reported outcomes when compared with standard care.

The trial – OPTCARE Neuro – aimed to investigate how effective short-term palliative care is and whether it represents good value for money. It is the world's largest palliative care intervention in patients severely affected by long-term neurological conditions such as multiple sclerosis, motor neurone disease and Parkinsons.

These conditions represent a major health, economic and societal burden and lead to substantial deterioration in quality of life. They require lifelong support from health and social care services, and often are an immense strain physically and emotionally on informal caregivers and family members.

The findings from OPTCARE Neuro provide the most robust evidence to date to support service and policy developments that improve palliative care provision for people with LTNCs in the UK or health care systems similar to the NHS.

The trial ran across six centres in the UK: London, Nottingham, Brighton and Hove, Liverpool, Cardiff and Ashford & St Peter's and was led and coordinated by the research team based at the Cicely Saunders Institute.

Data from 350 patients and 229 caregivers was analysed. Questionnaires from local health care professionals in palliative care and neurology also gathered information about their expectations and experiences of palliative care for this group of patients.

"Now that we know the benefits of this new palliative care model for patients with long-term neurological conditions and their unpaid carers, what we should do next is to test how best to implement it more widely so more people will benefit from it."
Professor Wei Gao,
Co-Chief Investigator and Trial Statistician

Gao W, Wilson R, Hepgul N, Yi D, Evans CE, Bajwah S, Crosby V, Wilcock A, Lindsay F, Byrne A, Young C, Groves K, Smith C, Burman R, Chaudhuri KR, Silber E, Higginson IJ, for the OPTCARE Neuro Trial Investigators.
Effect of Short-term Integrated Palliative Care on Patient-Reported Outcomes Among Patients Severely Affected With Long-term Neurological Conditions: A Randomized Clinical Trial
JAMA Netw Open. 2020;3(8):e2015061. doi:10.1001/jamanetworkopen.2020.15061

Preferences and experiences of Muslim patients and families

Researchers based at the Cicely Saunders Institute Centre for Global Health have carried out a study of the experiences and preferences of Muslim patients and families in Muslim-majority countries. There are an estimated 1.7 billion Muslims worldwide, largely living in low-and middle-income countries. Care for people with progressive illness should be person-centred and account for their cultural values and spiritual beliefs.

The research team carried out a systematic review of the published evidence, including grey literature. From an initial search of 5,098 papers they identified 30 papers. 98% of research participants in these studies were suffering from advanced cancer.

The researchers identified conflicts in diagnosis disclosure and total pain burden experienced by both patients and families. They conclude that to achieve palliative care for all, in line with the 'total pain' model, beliefs must be identified and understood in relation to decision-making processes and practices.

Abdullah R, Guo P, Harding R.
Preferences and experiences of Muslim patients and their families in Muslim-majority countries for end-of-life care: a systematic review and thematic analysis.
Pain Symptom Manage. 2020 Jul 10; doi: 10.1016/j.jpainsymman.2020.06.032. [Epub ahead of print] Review. PubMed PMID: 32659320.

CONGRATULATIONS:

Professor Sheila Payne

Congratulations to Professor Sheila Payne, who has been awarded the EAPC Cicely Saunders Research Award 2020. The award is sponsored by the EAPC and Cicely Saunders International, in recognition of Professor Payne's contribution to palliative care research.

The award was presented at the EAPC World Congress Online by Kate Kirk, trustee of Cicely Saunders International and niece of Dame Cicely Saunders.

In accepting the award Professor Payne reflected on her experience of meeting Dame Cicely Saunders as a young researcher, and seeing at first-hand Dame Cicely's multi-professional approach as a trained nurse, social worker and physician.

As a nurse and health psychologist herself, Professor Payne has made multidisciplinary team-working the foundation of her research career. In her lecture she reflected on the importance of achieving and communicating a shared vision within teams. She discussed what that means in different contexts and cultures, and how building teams could be compared to growing and nurturing trees, with tree trunks seen as two-way support, branches as different disciplines and the tree's leaves as individuals. Trees change and adapt, shed their leaves and renew them, and are resilient to many different environmental challenges, as multiprofessional teams must be.

CONGRATULATIONS:

Dr Mary Abboah-Offei

Many congratulations to CSI researcher Dr Mary Abboah-Offei who has won two awards at this year's EAPC Congress for her presentations of research into models of community care for people living with HIV/AIDS in Ghana.

Mary said: *"Findings from the systematic review led to the development of a community-based enhanced care intervention to improve person-centred outcomes for people living with HIV/AIDS. This was tested in a feasibility cluster trial and the results confirm feasibility and justify a definitive trial to test its effectiveness. The effectiveness of this intervention could contribute to the global targets set by the World Health Organization to deliver holistic and person-centred care for people living with HIV/AIDS to improve outcomes and their quality of life".*

Kimberley St John

Tributes have been paid to palliative care nurse Kimberley St John who died suddenly earlier this year. Nursing Times described Kim as ‘a passionate nurse who was building a reputation both nationally and internationally for her trailblazing work in the field of palliative care’.

Dr Natasha Lovell writes:

“Kim was known to many of us as Transforming End of Life Care Lead. However, she was first and foremost a palliative care specialist nurse who saw the individual in every patient, carer and colleague she encountered.

Kim inspired many across her clinical and academic career as she progressed through her Master’s degree in Palliative Care from King’s College London. Kim published her research study on the benefits of Namaste Care to make our hospitals dementia-friendly and improve care and outcomes for people living with dementia. She published this work in two scientific journals and pursued this work in her highly esteemed Darzi Fellowship. Her multiple successful projects have achieved national and international impact. Most recently, her innovative ‘Let’s Talk’ programme championed conversations about dying and grief, supporting people to think about the right treatment for them at the end of their lives.

Kim’s legacy in nursing, palliative care and dementia care will continue to benefit patients and families affected by advanced conditions”.

St John K, Koffman J.
Introducing Namaste Care to the hospital environment: a pilot study
Ann Palliat Med 2017;6(4):354-364 doi: 10.21037/apm.2017.06.27

St John K, Koffman J.
Acceptability of Namaste Care for patients with advanced dementia being cared for in an acute hospital
End of Life Journal 2015;0:1–13. doi:10.1136/eoljnl-2015-000013.

NEWS:

Michal Galazka International Seminar 2020: reclaiming the public understanding of dying

Due to the COVID-19 pandemic the annual Michal Galazka International Study Day was not able to take place as planned in 2020. However the Institute was delighted to welcome author and palliative care consultant Dr Kathryn Mannix to give an online seminar as part of the Michal Galazka International Global Fellowships Programme.

Dr Mannix has over 30 years experience as a palliative care consultant and has recently campaigned for better public understanding of dying. Her book about the way people live while they are dying, *With the End in Mind* (William Collins 2017) became a bestseller and was shortlisted for the Wellcome Book Prize in 2019.

In her talk Dr Mannix highlighted how the medicalisation of dying, combined with increasing life expectancy has meant that within only one or two generations, public understanding of the dying process has declined rapidly. Portrayals of dying in films and television give an unrealistic picture of the normal dying process, and euphemisms for dying continue to be used, such as 'passing on' and 'gone to a better place'. Misinformation, media distortion, trivialisation and lack of direct experience can also lead to people distrusting their own direct experience of observing the normal dying process, and not sharing their experience with others in the mistaken belief that it is atypical.

Dr Mannix emphasised that clear and skilled communication by healthcare professionals is of paramount importance, using phrases such as 'sick enough to die' gives patients and families a clear understanding of what might happen, and may give them additional valuable time to live every day as well as possible, while preparing for what might happen.

When she was a young medical student Dr Mannix met Dame Cicely Saunders and recalled Dr Saunders asking her how she thought she could make a difference to real people, a question that has stayed with her throughout her medical career, along with Dr Saunders' famous quotation: *"How people die remains in the memories of those who live on."*

NEWS:

CSI Annual Lecture

The Cicely Saunders International Annual Lecture is an annual event hosted by the Cicely Saunders Institute, King's College London. These lectures are a unique opportunity to learn from world-leading clinicians and scientists and are aimed at clinicians, healthcare researchers, health policymakers and palliative care funders.

This year's lecture was given online by international speakers Professor Irene Higginson, Professor Steven Pantilat and Dr Eve Namisango and reviewed the global role and response of palliative care to COVID-19 in the UK, USA and Africa. The learning and global insights for palliative care from the pandemic have been transformative. Dr Pantilat highlighted how the use of telemedicine was highly rated by patients, and protected staff, and it also enabled teams in different locations to support teams elsewhere. For example the team at UCSF in California were able to support a hospital in New York under severe strain from the pandemic. Dr Namisango highlighted the achievements and challenges for healthcare professionals in Africa and how MHealth is helping teams to continue to provide care in the midst of the pandemic, and how projects like Project ECHO are supporting healthcare professionals through knowledge. Professor Higginson said:

> *"In future surges we urgently need better integration of services, recognition of palliative care staff, and better access to medications for symptom control."*

Around 900 people attended the lecture. In his closing remarks CS International Chairman, John McGrath paid tribute to the many funders who have supported Cicely Saunders International and the Cicely Saunders Institute:

> *"2020 has presented us with a unique opportunity to make palliative care more visible, and bring about change. I urge all our supporters to join us when we launch our Action Plan for Palliative Care. I would also like to take this opportunity to pay tribute to the staff at the Institute and in particular the clinical team – young people in many cases – who in late March stepped into the frontline and took on heavy responsibilities with energy and a can-do spirit. Thank you."*

The lecture is available to view on YouTube at **www.youtube.com/watch?v=3d7BTw0LrMc**

Cicely Saunders International Annual Lecture 2020

'Palliative care in an era of COVID-19: Perspectives from three continents'

Thursday 5th November
4:00pm - 5:30pm
Hosted virtually via Microsoft Teams

'Perspectives on using telemedicine to support palliative care during the COVID-19 pandemic'
By Professor Steven Pantilat, Kates-Burnard and Hellman Distinguished Professor in Palliative Care, Inaugural Chief of the Division of Palliative Medicine, UCSF

'The impact of COVID-19 on palliative care in Africa: Challenges, opportunities and emerging innovations'
By Dr Eve Namisango, Programmes and Research Manager, African Palliative Care Association, Honorary Health Scientist at the College of Medicine, Makerere University

'Role and response of palliative care: findings from the multinational COVPALL study'
By Professor Irene Higginson, Vice Dean for Research, Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care and Director of Cicely Saunders Institute, King's College London

This event will be held virtually and is FREE to attend, register your place online:

CPD (1 credit) Royal College of Physicians

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csi.events@kcl.ac.uk
www.kcl.ac.uk/cicelysaunders

The cost of informal care

Findings from an international study into the costs and outcomes of informal end of life care have been published in *BMC Medicine.* The study found that in the UK, Ireland and the US, care provided by informal carers, meaning family and friends, accounted for more than half of total care costs in the last three months of life.

Researchers concluded that there was an urgent need in all three countries to improve community palliative care services and support people across the whole journey of care.

The study surveyed 767 carers in three countries about the last three months of life for the person they cared for. This is the first study of its kind and found:

- Costs to informal carers are larger than those to formal care services (health, social and voluntary combined) for people in the last three months of life.
- Poor quality home care was associated with greater burden to carers.
- If well supported informal carers can play an important role in providing care, and this can be done without detriment to them, providing that they are helped.
- Improving community palliative care and informal carer support should be a focus for future investment.

The study was led by researchers from the Cicely Saunders Institute at King's College London in collaboration with King's College Hospital Foundation Trust (UK), Trinity College Dublin (Ireland), Mater Misericordiae Hospital (Ireland), Beaumont Hospital (Ireland), University of Bristol (UK), University of California, San Francisco (USA) and Icahn School of Medicine at Mount Sinai (USA).

Professor Irene Higginson, who led the study, said: *"Family and friend carers do so much in helping people who need palliative care. Alongside being a wife, husband, partner, daughter, son, friend or other relation, our study shows the huge amount of practical help, advocacy, co-ordination and 'being there' that they provide. This costs more to society than do the formal care services, and when home care is of poor quality the burden on informal carers increases."*

Dr Steve Pantilat, from the University of California, San Francisco said: *"Family and friends provide tremendous help with the practical and emotional issues that people need as they approach the end of life. We know that this kind of help is priceless and unpaid. We learned that, if paid, the care provided by family and friends would cost more than all the formal care provided by the healthcare system. In addition, caregiving while seen as a privilege for many, also takes its toll on the caregiver. As a society we need to recognise and support these caregivers to keep them healthy and to allow them to continue to care for their loved ones. Palliative care services are among the ways that we can better support caregivers to improve the quality of life for them and the person they are caring for."*

Higginson IJ, Yi D. Johnston BM *et al.*
Associations between informal care costs, care quality, carer rewards, burden and subsequent grief: the international, access, rights and empowerment mortality follow-back study of the last 3 months of life (IARE I study).
BMC Med **18**, 344 (2020). https://doi.org/10.1186/s12916-020-01768-7

The IARE 1 study is part of the BuildCARE programme, funded by Cicely Saunders International and The Atlantic Philanthropies.

ONLINE EVENT: VIA ZOOM:

Academy of Medical Sciences: The Jean Shanks Lecture 2020

Thursday 3 December 2020, 17.00

Palliative care for the 21st century

Speaker: Professor Irene Higginson, Director, Cicely Saunders Institute and Vice Dean for Research, Faculty of Nursing, Midwifery and Palliative Care, King's College London

Incredible progress in public health and medical interventions during the 20th century have led to major advances in health and life expectancy. This lecture will consider the changing patterns of need, illnesses and symptoms, the role of technologies, as well as recent and likely future discoveries and advances in palliative care that could improve the lives of those affected by serious and/or progressive illnesses.

Watch later: **https://bit.ly/3acGJqJ**

OPEN SEMINAR: MICROSOFT TEAMS LIVE EVENT:

Clinical intuition or mathematical models – which are better for prognosticating?

Wednesday 27 January 2021, 16.00 – 17.00

Speaker: Professor Paddy Stone, Professor of Palliative and End of Life Care, UCL and Consultant in Palliative Medicine, UCLH

Numerous prognostic models and scoring systems have been developed for use in palliative care, but are any of them superior to clinical intuition? This lecture will review evidence regarding accuracy and usefulness of clinical predictions of survival. Paddy will present results from the Prognosis in Palliative Care Study II (PiPS2) study; including validation of PiPS; the Palliative Prognostic (PaP) score; the Palliative Prognostic Index (PPI); the Feliu Prognostic Nomogram; and the Palliative Performance Scale (PPS).

Register at **https://bit.ly/33bUDVQ**

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