Cicely Saunders International
Better care at the end of life

KING'S College LONDON

Cicely Saunders Institute

Spotlight on Impact

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Thank you

We thank all our funders and key partners,
without whom our work would not be possible.

These include:

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Consolidated Contractors
Cancer Research UK
Department of Health & Social Care
Dinwoodie Charitable Company
(previously Dinwoodie Settlement)
Dr Robert Buckman Fund
Dunhill Medical Trust
Engineering and Physical Sciences
Research Council (EPSRC)
Economic and Social Research
Council (ESRC)
Garfield Weston Foundation
Guy's & St Thomas' Foundation
Health Data Research UK
Hospice UK
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NHS England
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Wolfson Foundation
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World Health Organization

Welcome

Professor Richard Harding Director, Cicely Saunders Institute
Professor Irene Higginson Scientific Director, Cicely Saunders International

Since the Cicely Saunders Institute (CSI) opened in 2010, we have made significant progress in expanding the evidence base for palliative care, educating future leaders and delivering high quality clinical care. This unique partnership between King's College London, Cicely Saunders International and King's Health Partners is enabling us to achieve sustained impact for patients and families facing life-limiting illness.

We are delighted to share with you some highlights from the last 12 years and to consider emerging health system challenges and new frontiers for palliative care. This booklet is co-produced with the independent charity Cicely Saunders International, who are committed to fundraising and supporting excellence in palliative care research.

The challenge

People with advanced illness who are approaching the end of life commonly have symptoms such as breathlessness, fatigue, pain and poor mobility, which can often be alleviated by palliative care. Globally, our research shows that palliative care needs will double over the next 40 years, so that by 2060, 48 million people will require palliative care each year. In the UK, it is estimated that 75% of us would benefit from palliative care before we die, and our research projects that needs will increase by up to 40% by 2040.

Much research, including from the CSI, shows that when people receive palliative care, they have improved symptoms and better quality of life. In addition, palliative care reduces reliance on emergency care and can reduce healthcare costs. However, access to palliative care is not equitable. Older people, people with dementia, people in lower socio-economic groups and in ethnic minority groups are less likely to receive high quality palliative care.

To meet these challenges, more research is needed: to understand patients and family needs, to understand access to care and inequalities, to develop and test innovative models of providing palliative care (including in people's homes) and to trial new treatments and therapies. Education is vital to ensure a skilled and knowledgeable workforce, and advocacy is needed to change national and local policies and protocols.

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Our research discovers better ways to care for our ageing population. We found that palliative care needs will almost double over the next 40 years.

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Spotlight on Impact

We are developing and testing better ways to relieve this common and distressing symptom.

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1 Management of breathlessness

Severe breathlessness in advanced illness is common and distressing, affecting 75 million people with lung and heart diseases, cancers and many other conditions worldwide. Our research has challenged inequities, and created a paradigm shift from a neglected and often invisible symptom to one that is widely recognised across multiple advanced diseases.

CSI teams discovered that non-drug interventions could be effective in reducing breathlessness and other symptoms in people with advanced disease.

These findings led to the development of short-term integrated holistic breathlessness support services to help patients self-manage their breathlessness at home.

The research has influenced numerous clinical services and policies nationally and internationally. Crucially it has transformed the lives of patients and their loved ones. One patient said *"I was in a very bad state before I came [to the service]. I was thinking that I was about to be dying…but now I know… I can handle this."* A family member described feeling more confident supporting a patient *"…that certainly helped me… you know, I can probably help him to calm down."*

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2 Home and community care

In many countries, people with advanced illness are not cared for, and do not die, where they wish, which is mostly at home. Cicely Saunders International research improved the evidence base on how to support patients and families to achieve a good death at home.

National and international studies shone light on ways to provide better care for people in the place of their choosing, how to support families, and how to ask about preferences and priorities. An international study on what people wanted from palliative care contributed to the development of home care services and, strikingly, a reversal in the UK trend (and in some other countries) of increasing hospital deaths.

However, if people are to be cared for where they wish, there will be pressure on services, particularly in care homes and community services. Considerable expansion of care home capacity and community health and social care services is needed to meet future increases in need. Research is needed to ensure an effective and high-quality infrastructure across care settings that supports people with advanced illness to be cared for and die peacefully and in comfort.

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We provided evidence on how to improve care at home so more people could die in the place of their choosing.

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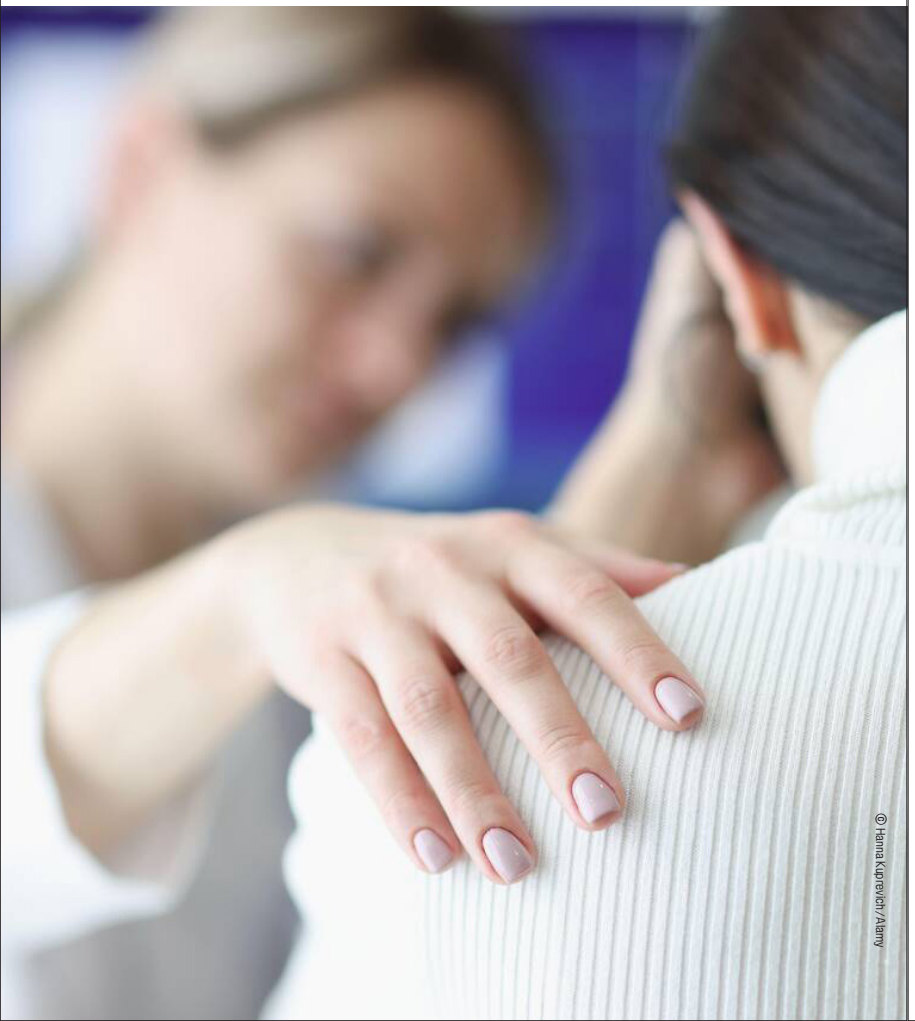
Spotlight on Impact

We developed the Palliative Care Outcome Scale (POS), one of the most widely used measures worldwide, to improve person-centred care.



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3 Person-centred care

The CSI has been at the forefront of person-centred outcome measurement in life-limiting and advanced illness as a proven way to put patients and families at the centre of their care.

The CSI-developed Palliative care Outcome Scale (POS) is one of the most widely used measures worldwide. It has been developed into a POS family of tools that have delivered long-lasting impact in the assessment and treatment of diverse populations. Versions of the POS are available to support clinical care, audit, research and training in different diseases. An integrated version (IPOS) brings together the original POS with a greater focus on symptoms.

POS tools reflect the core symptoms and concerns of patients and families, enabling patients to rapidly identify their main burdensome problems, and professionals to improve disease management and to set better standards of care. They are freely available in different languages, are adapted for different countries and cultures and for use in many diseases (see www.pos-pal.org) and there is a version of POS for use in health economic evaluations. An urgent future step is to develop and validate POS versions to help patients and families self-manage problems and decide when and how to call for help when they need it.

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4 Neurological rehabilitation

Acute health services get ever better at saving lives, which means more patients with severe neurological illness or injury are surviving. Some require lifelong care.

Together with the UK Rehabilitation Outcomes Collaborative, the CSI developed a robust toolset for real life settings to underpin the national clinical database for specialist rehabilitation. We developed and validated methods to evaluate the cost-efficiency of rehabilitation, and a robust set of clinical tools to identify and match rehabilitation programmes to individual patient needs, measure outcomes and demonstrate value for money. We found that specialist in-patient rehabilitation for profoundly disabled patients is highly cost-effective, with average net lifetime savings in care costs exceeding £670,000 per patient.

Our tools are now mandated to benchmark quality and outcomes for all NHS specialist rehabilitation services in England. This work transformed NHS commissioning and increased NHS funding and service capacity for this most vulnerable group, benefiting patients and their families. Our approach has been adopted internationally, including adaptation for the rehabilitation of patients following intensive care during the COVID-19 pandemic.

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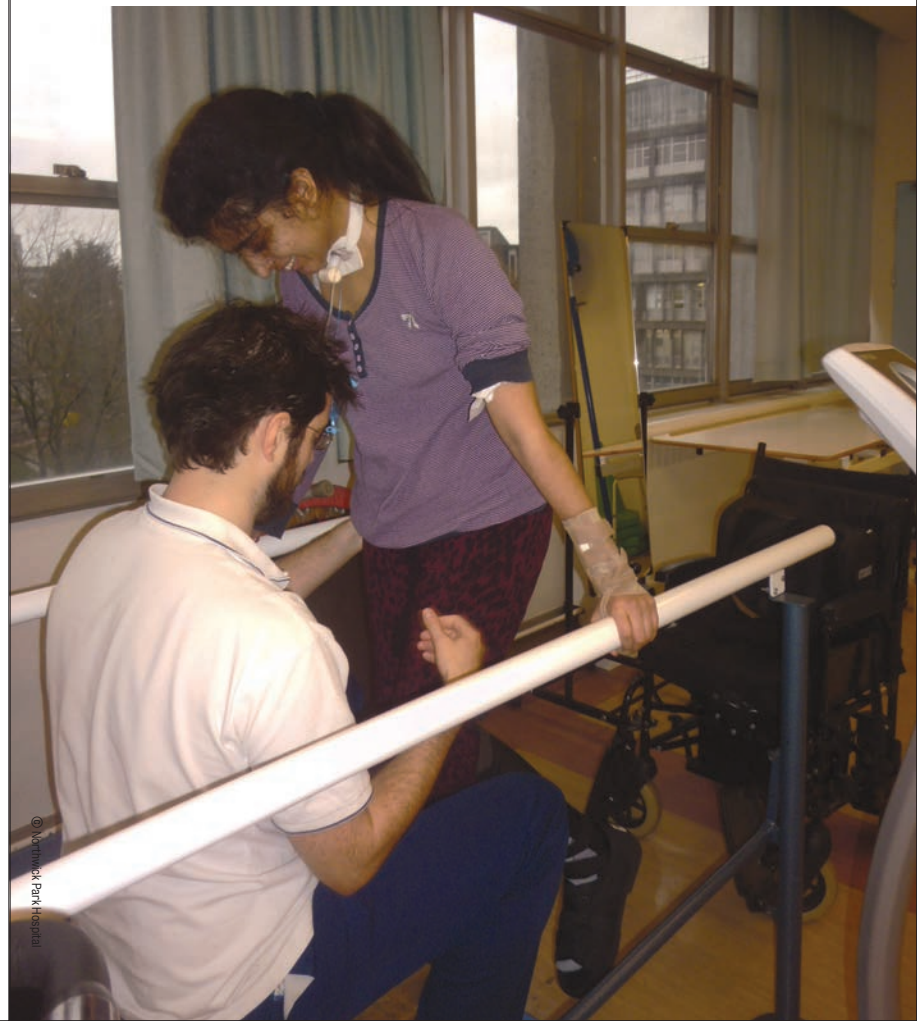
We found that the right rehabilitation for profoundly disabled patients can save hundreds of thousands of pounds in care costs for each patient.



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We led the development of national and international guidance on managing severe symptoms.

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5 COVID-19 pandemic

Our teams were at the centre of the COVID-19 response in palliative care, locally, nationally and internationally. Our clinical teams and clinical academics were at the frontline in providing care across our hospitals and in the community.

CSI research countered the common assumption that palliative care was not a priority, and demonstrated the need to manage severe symptoms and care for people who were dying. We led a team of multi-disciplinary experts to produce national and international guidance. Alongside this, evidence-based information sheets for patients and families affected by COVID-19 were produced, co-designed with the European Lung Foundation (a patient-led group). These were translated into 25 languages with local and global dissemination.

Supported by Cicely Saunders International and UK Research and Innovation we provided the first robust understanding of care and symptom management for people dying from COVID-19. We found that common symptoms can be managed by palliative care treatments. The research uncovered many innovations to improve care developed by palliative care services and these were quickly shared. We also identified challenges for services in providing care, in advance care planning, for volunteers, and especially for some groups in society, including minority ethnic groups. Additional projects looked at the response of care homes and palliative rehabilitation services. Findings fed directly into national clinical networks, government, and public understanding.

6 Policy impact

Our priority is that the research we do is used to improve care and benefit patients, families and wider society. Engaging policy makers at local, national and international levels is an important part of this.

CSI research has contributed to many important policy changes that have improved care for people approaching the end of life. A key moment was the May 2014 World Health Assembly resolution on palliative care requiring countries to include palliative care and research in their healthcare strategies. The needs assessment, and its evidence of palliative care effectiveness, used research from the CSI, and several members of the team were senior advisors to the World Health Organization on this.

Breathlessness research has changed clinical guidelines and policy documents internationally including the Global Initiative for Chronic Obstructive Lung Disease, the European Society for Medical Oncology and the American Society for Clinical Oncology.

In the UK, CSI research contributed to evidence that made palliative care mandatory in the 2022 Health and Care Act, and our evidence on models of care is recommended by the National Institute for Health and Care Excellence (NICE).

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We contributed evidence and advised the World Health Organization as it developed its 2014 resolution requiring countries to include palliative care and research in their healthcare strategies.

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Spotlight on Impact

We have built novel ways to engage with patients, their families and the wider community to help drive research priorities.

© Paul James / Tofunmi Awoniride

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7 Patient and public involvement

Involving patients, families and communities affected by serious illness in our research is central to improving care, treatment and outcomes in palliative care. It ensures that our research is focused on them so that we can best understand what is important to them and how we could improve people's experiences of palliative care and rehabilitation.

"The voices of patients and families are pivotal in ensuring care is patient centred. Sharing my experiences as a carer to help research has been cathartic and a privilege."

Margaret Ogden Public contributor, Cicely Saunders Institute

Over the past 12 years, we have continuously developed new initiatives to enable meaningful involvement in research for people affected by advanced illness. Our ambition is to expand, diversify, and increase the opportunities for, and impact of, public involvement across all aspects of our work at the CSI. We have built novel infrastructures including an online forum and interactive workshops for members of the public to drive research priorities. These activities are underpinned by the CSI's Public Involvement Strategy (2021-2023).

Capacity building

The CSI serves as an incubator to develop world leaders who can meet the urgent challenge of access to evidence-based palliative care, supported by local and global policy.

We achieve this through several routes. Our highly successful MSc and PhD programmes in palliative care are delivered to multi-professionals around the world using hybrid teaching methods. Under the guidance of our senior academic team, our post-doctoral fellows forge independence and develop academic skills that span disciplines from epidemiology to health economics, researching better care from birth to old age. We identify talent and nurture growth at all stages. We deliver a rich weekly educational programme, from clinical updates with our multi-professional clinical team to a well-attended Open Seminar series open to the public.

We have seen students and researchers from the CSI go on to independent careers at high-ranking institutions around the world, leading excellent clinical teams and taking professorial posts. Professor Claudia Bausewein, Director of the Department of Palliative Medicine, Munich University Hospital, Germany, said of her time at CSI *"...it allowed me to deepen my research skills and interests after completing my PhD at CSI... My time at KCL was one of the best of my professional career."*

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We have increased capacity for palliative care research, policy and delivery worldwide through our extensive education and training programmes.
PhD graduation ceremony at the Royal Festival Hall, August 2022.
Left to right: Anna Bone, Natasha Lovell, Jo Bayly, Cheng-Pei Lin, Simon Etkind.

Spotlight on Impact

Our global health programme has strong, sustained and impactful partnerships around the world including at this hostel facility in Uganda for children and young people living with cancer.

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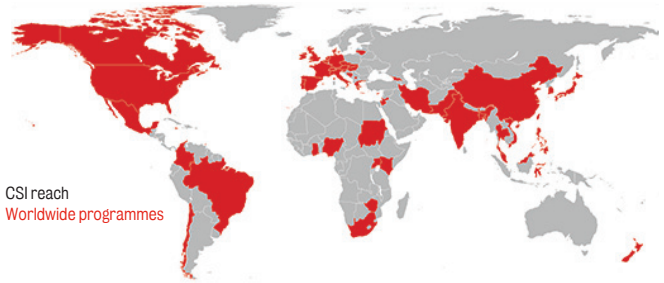
9 Global

Only around 14% of those who could benefit from palliative care actually receive it. Our global health programme has strong, sustained and impactful partnerships around the world. These partnerships are individually developed to offer a strategic package of research, education and leadership development. For example, the Buildcare Africa programme provided funding for MSc and PhD education alongside research project mentorship to answer local clinical challenges. This led to impactful scientific papers in new fields including African models of bereavement care, TB palliative care, and the world's first outcomes-focused programme of research for children.

Our patient-centred outcome tools for use in research and practice have underpinned the World Health Organization's six-region research programme to identify core quality indicators in palliative care. We led this in Belarus, Jamaica, Oman, Thailand, Vietnam and Zimbabwe, recruiting over 800 patients and their families. The data reveals which components of care are perceived as most useful, and which symptoms and concerns are most burdensome.



CSI reach
Worldwide programmes

Looking forward

The CSI has achieved much in its first 12 years, advancing knowledge and education and delivering high-quality care for patients and families. A growing body of evidence reveals the enormous societal need for more provision of, and better access to, high-quality, timely and effective palliative care. However, funding for clinical services, research and education is far below the required level for our current and future ageing population.

The need for more research, education and clinical care at the end of life is becoming more urgent. People at the end of life and those close to them face multiple and complex symptoms and problems. Increasing numbers of children survive with complex health needs, and adults live longer with multimorbidity. Health and social care services face increasing pressures to provide integrated, sustainable care for people with clinical uncertainty and palliative care needs.

Future healthcare will require new understanding to improve the reach and cost-effectiveness of palliative care across serious illnesses and for people of all ages. This includes better care and self-management of challenging symptoms, managing multimorbidity and frailty, providing services in the home and community, and reducing inequities relating to access and outcomes.

The CSI is uniquely positioned to tackle these societal challenges with transformative applied research that changes policy and practice.

We would be delighted to discuss with you our plans across research, education and care for the next 10 years.

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