



Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

Elsevier hereby grants permission to make all its COVID-19-related research that is available on the COVID-19 resource centre - including this research content - immediately available in PubMed Central and other publicly funded repositories, such as the WHO COVID database with rights for unrestricted research re-use and analyses in any form or by any means with acknowledgement of the original source. These permissions are granted for free by Elsevier for as long as the COVID-19 resource centre remains active.



Profile

Irene Higginson: progress towards a better ending

Media coverage can drive change—so the note of exasperation in Irene Higginson's voice is understandable: "I wish there was as much attention paid to people who don't have proper access to palliative care as there has been to the assisted dying debate", she says. Higginson has a particular interest in the way we die; as Professor of Palliative Care and Policy at King's College London (KCL), London, UK, she is eager to advocate for her specialty. "UK hospices still rely for two-thirds of their funding on charitable donations", she explains. Of all the research spending on health care, no more than a quarter of 1% goes to palliative care. "And there are more professors of oncology in the Royal Marsden Hospital than there are professors of palliative care in the world", she says.

In view of this relative neglect, the creation of an institute for research in palliative care was a prospect that clinicians in the field viewed as a pipe dream. Higginson, however, set out to make it a reality. "Many people said she'd never be able to raise the money", says Sabrina Bajwah, a palliative care consultant at KCL. "Irene carried on regardless." And she succeeded. The Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, with Higginson as its Director, opened in 2010. It has become an international leader in research, and a fitting memorial to Dame Cicely, the woman whose forceful arguments established her branch of medicine as a discipline in its own right.

Now the advent of coronavirus disease 2019 (COVID-19) is generating a new raft of uncertainties. "The pandemic is going to change health care and societies in previously unimaginable ways, and palliative care is going to change also", says Higginson. "Sadly, so many people who are severely ill with it need palliative care to help relieve their symptoms, especially when they become sick enough to die. Such a surge of need has never existed in our history."

Higginson studied at the University of Nottingham Medical School, emerging in 1982 with no firm idea for the future. A book by Cicely Saunders and a job at St Joseph's Hospice in London sparked her interest in palliative care, on which she did a PhD. But because palliative care was not then recognised as a specialty, she did her specialist training in public health. "But I was more and more drawn to palliative care, so I kept it up, and eventually moved into it completely", she says. It was in 1996, after some public health jobs, that Higginson joined the medical school of KCL as Professor of Palliative Care and Policy, with a consultant post at St Christopher's Hospice. Professor Sir Robert Lechler, KCL Senior Vice President/Provost for Health, got to know Higginson when he joined KCL some 15 years ago. He saw from the outset that she had leadership talent. Her achievements, he thinks, stem from a combination of clarity of purpose, drive, determination, and persuasiveness. "She has a very clear mission", he adds.

In research, those successes began with the introduction of a more rigorous assessment of palliative care. "In the early days", Higginson explains, "you couldn't easily assess what was happening to people...so my first big contribution was trying to make palliative care more measurable". Her palliative care outcome scale is now used around the world. She moved on to questions of equity, where her public health experience came into its own. "Palliative care was really entirely for people with cancer, and yet three-quarters of deaths are not from cancer". Equally unfair, she felt, was the skewed distribution of care. "Older people were missing out...Very few people in poorer areas died at home...a lot did want to be at home, and I tried to look at what sort of services we might need to keep people at home." She has also worked on the symptoms associated with terminal illness, notably breathlessness. "Irene's research into breathlessness and how to intervene is world-leading", says Bajwah. "She demonstrated the effectiveness of intervention services."

Barbara Gomes, a psychologist who worked for years with Higginson before taking a research post in her native Portugal, talks of her mentor's international work for bodies including WHO and the EU: "She's always been committed to helping develop palliative care in other countries... She can bring people together and inspire them." In clinical work Higginson is equally determined. "She has an interest in patient empowerment...In helping patients' wishes and hopes to be met at the end of life", Gomes says.

Higginson is full of ideas for the future. Besides the better management of symptoms at the end of life, she talks of the role of new technologies and how good it would be if the value of friends or relatives caring for the terminally ill was recognised financially through "a carers' benefit... like a maternity benefit", she suggests. Less predictably, she foresees the value of a link between palliative care and rehabilitation. "Some symptoms like fatigue and breathlessness, and perhaps mood, are actually helped by muscle strengthening. The old way of managing fatigue was to lie down and have a rest." Although rehabilitation cannot restore everything that has been lost, it can minimise the decline in function at life's end.

In the meantime, there is still the calamity of COVID-19 to be negotiated. "Huge efforts have gone into working harder with what services we have", says Higginson. "The separateness of many independent hospices from the health-care system has meant that some have struggled to get the protective equipment needed to provide care... But I have been so impressed with how hospices and palliative care services have responded."

Geoff Watts



For the Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation see <https://www.kcl.ac.uk/cicelysaunders>