In Focus: Dame Cicely Saunders

"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

Dame Cicely Saunders - The Management of Terminal Disease: Volume 1

Pioneer of the Modern Hospice Movement

Welcome to our 'In Focus' series of short exhibitions. This series aims to shine a light on those who have continued the work and pioneering spirit of Florence Nightingale by making a great contribution to nursing and the medical world.

In this instalment, we look at Dame Cicely Saunders, known across the world as the driving force behind the modern hospice movement.

Dame Cicely used her vast experience as a nurse, almoner and then a doctor, alongside her religious beliefs to improve the lives of patients and their families who were living with terminal illness. Starting as a student nurse at the Nightingale Training School, she built up a wealth of knowledge about pain, and caring for the terminally ill. Throughout her studies, paid work and voluntary commitments, her focus was always on the patients and relieving their symptoms. This eventually led to her becoming a world-renowned expert on the 'end-of-life' care. She helped to spread her knowledge by inviting people from across the globe to see the hospice she had set up, bringing together her life's work.

Portrait of Dame Cicely Saunders, by Marian Bohusz-Szyszko, her husband. Used with permission from St Christopher's Hospice.

Here we celebrate the life and work of this incredible person, 20 years on from her death.

Early Life

Cicely Mary Strode Saunders was born on 22 June 1918 to Gordon and Chrissie Saunders, in Barnet, North London, and was the oldest of three children.

Cicely Saunders as a child. Used with permission from St Christopher's Hospice.

The family was affluent and able to move home several times during Saunders' early life. These houses had large gardens in which Saunders and her brothers spent large amounts of time playing tennis or cricket with their father, or building bonfires and burning leaves.

After going through kindergarten, Saunders joined the local private school, travelling by horse and carriage every day. She then moved on to a boarding school on the Sussex coast, where her aunt was the school matron. While she enjoyed her time with her aunt, she was not as academically successful as her father would have liked, so the family decided to move her to Roedean, a private boarding school for girls, near Brighton in Sussex. Saunders was shy and did not like being away from home but slowly those around her began to see a change. She began to thrive.

Cicely Saunders and her family. KCL Archives.

By 1936, she was a Prefect, Head of House and was elected as the Secretary of the School Mission – a charitable programme that supported a new school for local impoverished children.

Roedean had been set up with a goal of preparing young women to enter the women's colleges at Oxford and Cambridge Universities, to which Saunders soon applied. Saunders arrived at the Society for Home Students (later St Anne's College) Oxford in 1938 and embarked on her studies of Philosophy, Politics and Economics, with a view that she would become a secretary to a politician. Free time was filled with Scottish Country dancing, choir and friends.

The following year, the Second World War broke out. Saunders wanted to do something to help the war effort, so decided to leave her life in Oxford and train as a nurse. By early 1940, Saunders had applied to St Thomas' Hospital in London to train at the Nightingale Training School.

Cicely Saunders: Nightingale Nurse

Dame Cicely Saunders in nursing uniform. Used with permission from St Christopher's Hospice.

Saunders started at the Preliminary Training School (PTS) of the Nightingale Training School in 1940, which at that time was based near Guildford, Surrey. Conditions were basic at the PTS and she did not earn a very good wage. As well as learning all of the required nursing skills, Saunders learnt domestic skills that were also part of the job.

Among her small 'set' of around 20 trainees, Saunders was starting to find herself and felt that she was building a career for life and not just for the duration of the war. She got on with her peers and was elected as the 'Set Representative' when they moved onto the next part of their training. She soon became a respected nurse amongst her patients too.

It was during the second year of training that the reality of the role really started to sink in with Saunders. She was nursing very sick patients, including children, and had to learn how to talk sensitively to the patients' families.

Saunders also learned about the physicality of nursing. She had suffered with back troubles from her youth and slipped a disc early in her training. Any free time was spent resting, and she had to take some time out of her training to recover.

Despite this, Saunders completed her training with good results across the board. She was later advised by an orthopaedic surgeon to give up her nursing career for her own future health. Dame Cicely Saunders' Nightingale badge. Used with permission from St Christopher's Hospice.

An Alternative Path: Almoner Saunders

Looking to her future, Saunders decided to train as an almoner under the Institute of Almoners. She worked in the community and with the local hospitals. It was in this role that she came across her first cancer patients. Following a brief time out for back surgery, Saunders completed her almoner training in 1947. She soon started working at St Thomas' alongside a surgeon, accompanying him on rounds and working with his patients in the community.

What is an Almoner?

Before the National Health Service (NHS) was founded in 1948, patients would have to pay towards their care at the point of service. Almoners assessed patients to decide how much they were able to contribute to their care. Once the NHS was formed, patients no longer had to pay towards their care, so the role of an almoner evolved into a welfare role, monitoring the social and psychological effects that were affecting the patients. This role would evolve over time to become medical social work. Today medical social workers work under the NHS, assisting patients during their treatments as well as helping them with ongoing care.

Saunders' First Patient

Across her training, Saunders had worked with many terminally ill patients. This led her to believe that this was her calling in life. Medical advances in the mid-twentieth century brought cures and improved treatments. This was not the case for all illnesses though. Saunders started to see examples of patients with incurable illnesses being left behind or forgotten.

One patient that Saunders met at St Thomas' Hospital in 1947 would be the starting point of her life's calling.

David Tasma, Saunders' first patient. KCL Archives

Ela Majer 'David' Tasma was a Polish immigrant living in London who had been diagnosed with terminal cancer. During his time in London, David had got to know many of his neighbours but did not have any family or close friends around him. After David had been discharged from St Thomas' Hospital, Saunders kept in touch with him. She quickly began to visit him, even though she was risking her job by visiting a previous patient. She knew that David appreciated her company and honesty about his prognosis, as well as bringing him comfort in his final weeks. In his will, David left Saunders a small amount of money with the instruction that "I will be a window in your home", referencing Saunders' early ideas on setting up a home for the terminally ill. This episode was a key part of her life's mission and is what drove her throughout.

Not long after her encounter with David, Saunders started volunteering at St Luke's Hospital in Bayswater. It was here that she observed their practice of routinely giving patients medication to prevent pain, rather than in reaction to their pain.

Another Change: Doctor Saunders

Her experiences from St Luke's and other hospitals led to Saunders considering a return to nursing to take up a role at St Columba's, another home for the terminally ill in London. On discussing this with a close colleague, they concluded that Saunders would not be able to make effective change to the care of the terminally ill as a nurse, as it is doctors who made the clinical decisions and were in overall control of care. If Saunders trained as a doctor, she could be at the forefront of changes to terminal care. Saunders decided that this was the way forward and in 1951, entered the St Thomas' Hospital Medical School.

Following the completion of her medical training in 1957, Saunders secured a grant to enable her to study terminal care and work as a research fellow. Her work took her to St Joseph's Hospice in Hackney, London, a home for the terminally ill run by Catholic nuns. Here, Saunders helped make improvements by setting up a system for making notes on

patients and she also introduced the concept of medication to prevent pain like she had witnessed at St Luke's. Saunders would continue her work at St Joseph's until 1965.

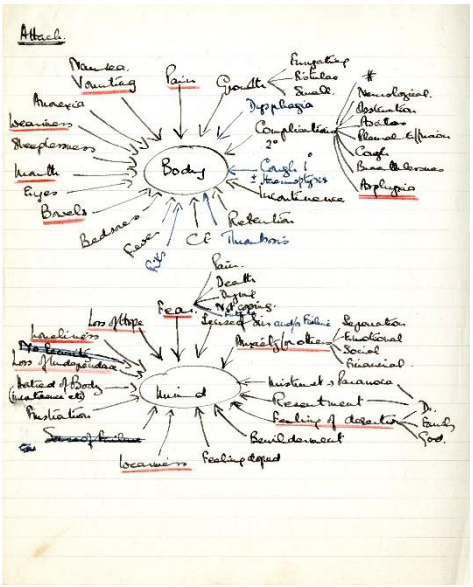
Total Pain

At a time before formal cancer diagnostics, Saunders could see that the side effects caused by cancer and subsequent treatments were not being managed well and were barely talked about. She witnessed various interventions by doctors and the use of large doses of opiates, but nobody was discussing these practices.

This led her to make precise medical notes about her patients and her work, knowing that the information would be useful for future medical papers and presentations to help improve the field of terminal care. She would also keep notes of all the latest publications on terminal care that were being published.

She wrote her first of many papers in 1958. This was comprised of a few short articles that were published in the Nursing Times. These looked at different areas surrounding terminal care, such as mental pain, nursing the terminally ill, whether a patient should know that they are dying, and euthanasia, something which she was against, feeling that suffering could be relieved or at least lessened. Her views on this very much reflected her religious beliefs.

Much of Saunders' work was based on her ideas of relieving a patient's pain and her theory of 'total pain'. Her theory put forward the idea that a patient could experience spiritual, social and emotional suffering, in addition to the physical pain caused by their illness. She began to realise that to help with all these aspects of suffering an understanding of the patient's full story would be needed, and that could only be gained by sensitive talking and listening to them and those that know them best.



Saunders' notes on 'total pain'. KCL Archives.

Start of the Modern Hospice movement

By 1959, Saunders had decided that her path in life was to use all her expertise and knowledge to open her own hospice for the dying. She put together what she called 'The Scheme', a document that outlined her plans for St Christopher's Hospice, a name put forward by one of her patients.

Over the next few years, she would continue to work on this, improving her plan and setting it in motion. When St Christopher's opened a decade later, it would be the first modern hospice in the world.

Her religious standpoint was a crucial part of her plans. While St Christopher's would not be a religious institution like St Joseph's was, the home would run on Christian values.

Saunders' first book was published in 1978 – The Management of Terminal Malignant Disease. The book had many contributors from across the field, many of whom had some involvement with St Christopher's over the years. She would continue to write papers and present at conferences, promoting her ideas on end-of-life care.

By the early 1980s, terms such as the 'hospice movement' and 'palliative care' were starting to be circulated as accepted terms. 'Palliative care' became a specialism for medical professionals at this time.

Saunders used various media appearances to broadcast her ideas and work in end-of-life care to wider audiences. This included a 1980 documentary on the BBC, called 'In Light of Experience' and 'Desert Island Discs' in 1994.

Marian Bohusz-Szyszko

Marian Bohusz-Szyszko (1901-1995) was a Polish artist living and working in London. Saunders first came across Bohusz-Szyszko in 1963, when she visited an art gallery displaying a number of his paintings. The spiritual imagery in his paintings appealed to Saunders and she purchased the first of many paintings, for the chapel at St Christopher's. Dame Cicely Saunders and Marian Bohusz-Szyszko in the late 1980s. Used with permission from St Christopher's Hospice.

Dame Cicely Saunders and Marian Bohusz-Szykzko in the late 1980s. Used with permission from St Christopher's Hospice.

Not long after, Saunders met Bohusz-Szyszko in person. She formed a close friendship with him and encouraged him in his work. This eventually led to them forming a relationship. Bohusz-Szyszko was already married and as a practicing Catholic, did not believe in divorce.

Eventually, Saunders and Bohusz-Szyszko married in 1980, as Bohusz-Szyszko's first wife had passed away a couple of years beforehand. They lived just around the corner from St Christopher's Hospice. Marian Bohusz-Szyszko passed away in 1995, aged 94, at St Christopher's following a long illness.

Hospice Founder

In order to set up St Christopher's, Saunders knew that she must secure the perfect location and have a building designed and built, which would cost time and money. She spoke to colleagues in the medical and religious fields to gather varied insights into her plans. Throughout the 1960s, a small group of Saunders' colleagues and supporters started to shape St Christopher's.

By 1964, £330,000 had been raised towards building and the acquisition of a site in Sydenham, south-east London. The foundation stone was laid in July 1965 and St Christopher's Hospice opened in 1967.

Saunders and Lord Thurlow, the Chair of the Board of St Christopher's at the start of construction work. Used with kind permission of the Saunders family.

A report Saunders put together following the opening of St Christopher's noted that it had 54 inpatients beds, an outpatient clinic and sixteen beds for the use of staff and their families. She also emphasized the community nature of the hospice. She wanted the family members of both patients and staff to be involved. A patient's family would play a crucial role in

their care and they would receive support during the patient's time at the hospice and after their passing. The hospice would also provide education on terminal care.

Saunders wanted St Christopher's to be a community where family members, inclduing children and pets, were welcome. Copyright photograph by Derek Bayes.

Over the following years, St Christopher's expanded, with new wards opening and a domiciliary service started in 1969. Domiciliary means within the home, so St Christopher's staff looked after patients in their own homes, building a relationship and a sense of community.

In the same year, a new study centre was built, and a formal training and induction scheme was put in place for students and staff. While the first patients had been exclusively cancer patients, over the years, St Christopher's slowly started taking in patients with other conditions, such as Motor Neurone and Parkinson's Disease.

Saunders was Medical Director of St Christopher's from 1967 to 1985, when she stepped down from this role and became Chair of the Board. She was still involved with the day to day running of St Christopher's and struggled to relinquish the control that she once had. Saunders remained as Chair until 2000 and continued to visit every day.

St Christopher's and Palliative Care Today

St Christopher's is considered to be one of the first modern hospices and there are now many hospices like it across the country and the world. The focus on community is still strong at St Christopher's as they continue to support patients and their families. St Christopher's CARE(Centre for Awareness and Response to End of Life Care) Saunders and Lord Thurlow, the Chair of the Board of St Christopher's, at the start of construction work. Used with the kind permission of the Saunders family. Saunders wanted St Christopher's to be a community where family members, including children and pets, were welcome. Today, St Christopher's has 35 beds and cares for over 1200 people in the local community within their own homes.

Modern day palliative care helps many people across the world to manage their symptoms, enabling them to have good quality of life during terminal illness. While many hospices in the UK do receive a small amount of funding from the National Health Service (NHS), many are registered charities who rely on donations for their income. St Christopher's Hospice alone have a fundraising target of nearly £17 million each year. Campaigns such as National Hospice Week and This is Hospice Care, are helping to raise the profile of the need for support for hospices.

Hospice UK is a national organisation that aims to promote and protect hospice care. You can use their website to search for your local hospice - https://www.hospiceuk.org/.

Recognition

Saunders received great recognition for her work. In 1980, she was made a Dame of the British Empire in the Queen's New Years Honours List. In 1989, she was awarded the Order of Merit and became the second nurse to have been presented with this award, the first being Florence Nightingale. She wrote hundreds of papers and articles, many publications and received countless honorary degrees and awards for her work.

Dame Cicely Saunders with Queen Elizabeth II. Used with permission from St Christopher's.

Saunders continued to work throughout her life. Despite having stepped down as Medical Director and CEO of St Christopher's Hospice, looking after her ill husband and suffering with her own health problems, she was determined to carry on. Throughout the 1990s, she continued to publish many articles and papers on terminal care, travelled across the world for conferences, spoke at engagements and kept up with the latest publications in the field.

Saunders continued working and spending her days at St Christopher's well into her eighties, but it was obvious to all her friends and colleagues that Saunders was slowing down.

Cicely: The Patient

Dame Cicely Saunders. Used with permission from St Christopher's.

In 2002, Saunders was diagnosed with breast cancer. The disease that she had been working with for her whole life was now affecting her. Slowly the disease started to spread to her hip and then her pelvis. Knowing the disease as she did, she felt calm about her prognosis and was thankful for the time that it would give her to sort her affairs.

Following several stays in hospital, Saunders realised that she could no longer live at home, despite having a carer to assist her. In February 2005, she packed up her belongings and made the short trip to St Christopher's, where she had decided to spend the last months of her life.

Dame Cicely Saunders passed away on 14th July 2005, aged 87, in St Christopher's Hospice, a place she had dedicated her whole to life to. Her ashes, alongside her husband Marian's, are interred in the garden at St Christopher's.

Saunders led a remarkable life and contributed so much to the care of the dying. Her legacy lives on in the Cicely Saunders Institute, St Christopher's Hospice and across the world in all palliative care work.

"I have been a nurse, I have been a social worker, and I have been a doctor, but the hardest thing of all is learning to be a patient".

Our thanks go to St Christopher's Hospice, the Dame Cicely Saunders Society, the Dame Cicely Saunders Institute and Kings College London Archives for their help, and support of this exhibition.