

Remembering Dame Cicely Saunders

Remembering Cicely after 10 years

On 23 June 2015, 120 people gathered at St Christopher's to remember Dame Cicely Saunders to celebrate her life and many achievements ten years since she died at the hospice she founded.

Participants came from as far afield as the Shetland Isles and Uganda and ten renowned speakers shared some fascinating recollections of our founder, followed by an update on St Christopher's current direction delivered by our Joint Chief Executive Shaun O'Leary and Heather Richardson and a thanksgiving service presided over by Spiritual Care Lead Dr Andrew Goodhead and St Christopher's former Chaplain, Rev Len Lunn.

Speakers who were introduced by hospice trustee Dr Tyrrell Evans and led by Dr Mary Baines included Professor Irene Higginson, Dr Anne Merriman, Dr Colin Murray Parkes, Cicely's Goddaughter, Rosemary Burch and Drs Tom West and Gill Ford, both of whom trained as doctors alongside Cicely Saunders. Cicely's love of music was demonstrated by some fine playing of The Lark Ascending by Damian Falkowski, the violinist and family friend who played at her funeral and that of her husband.

A number of those in the audience have sent us their reflections on Remembering Cicely:

Dr Nigel Sykes, former Medical Director, St Christopher's

This was a unique gathering to remember a unique person. It was an event that covered a great span in time and also demonstrated the great breadth of Dame Cicely Saunders' influence. Here were people who had known Cicely as a medical student, had heard her developing ideas about a new and better way to care for dying people and had seen her determination to put those ideas into practice, even if to do so took twenty years (which it did). I found myself sitting alongside two other recently retired hospice medical directors, all feeling rather senior, but the freshly told recollections of Cicely went back to the year of our birth.

From the perspective of a doctor working in palliative care, here, in a way unlikely to be repeated, were gathered the physicians who had worked with Cicely Saunders to build the foundations of the service we now recognise as St Christopher's: Mary Baines, who set up the home care service, the first in Britain; Tom West, who worked alongside Dame Cicely as the hospice expanded and then succeeded her as Medical Director; Robert Twycross, who laid the foundations of the research that had been a part of the founding vision for St Christopher's; Gill Ford, who in addition to directing the hospice's education programme,



played an absolutely key role in gaining acceptance of palliative medicine as a specialty, an achievement that has greatly facilitated the spread of palliative care in hospitals and its entry into official policies; Colin Murray Parkes, involved in the St Christopher's project from even before the hospice opened, whose seminal work on psychological problems in bereavement is known worldwide but who also first showed that hospice care benefitted patients and families not only physically but emotionally too.

The afternoon was not just about how Cicely's vision brought St Christopher's into being. It also demonstrated just how far her influence has extended: beyond medicine into nursing and the whole multiprofessional team; beyond professionals, to be a greatly loved figure across her extended family; beyond her own country to be an inspiration to improve the care of the dying in Africa and across the globe; and beyond her own time to inspire through her original example the programmes of research needed in order to bring about continued improvements in palliative care.

Remembering Cicely was a very special event that in both speakers and audience brought together a rarely-assembled collection of people who knew and worked with her. All of them will have had their own memories stirred and, at the same time, learnt something new. Cicely herself should have felt honoured.

Dr Louis Heyse-Moore DM FRCP

Who could ever forget Cicely? I thought, as I sat in the audience listening to Dr Tom West, witty and pithy as ever; begin proceedings by remembering Cicely as a friend. Half an hour earlier I had walked the familiar

route to St Christopher's; but this was not quite the hospice I remembered. There had been change; rooms had morphed, contracted, expanded, moved, improved. Somewhat dizzy, I cautiously entered – to find I had stepped into the past. I met colleagues and friends whom I hadn't seen for twenty years; it was so moving. And when the remembering began, it was history relived: a gathering of the friends who had helped Cicely realise her dream.

No, I couldn't forget Cicely: compassionate, thoughtful, charismatic, scalpel sharp, vulnerable and with the single-minded tenacity you need to be midwife to a worldwide movement. I wondered how she did it. We were told: it was a vocation, literally. God put his hand on her shoulder and asked. Well, no wonder then.

Cicely is rightly famous for her achievements but it was the small stories that touched me most: her personal friendships, the memories of her god-daughter, her early years at medical school, walking in the Scottish Highlands, her love of the poetry of Gerard Manley Hopkins, her attention to detail in the care of her patients. And there was, too, the cost, the times of loneliness and grief: the three Poles she loved and lost.

Of course my own memories surfaced: Cicely leading the Christmas carol crocodile through darkened wards lit only by candles; students from the Yehudi Menuhin school playing Bach Partitas on the wards at her invitation; Cicely in tears in a seminar as she remembered her dead father.

So we came to her dying, the last scene in a long life. I wondered what it was like for the staff of St Christopher's to look after Cicely during her last illness; such a responsibility and such a privilege. They would have wanted to ensure that she had the best symptom control possible, that they were available to support her during times of fear or sadness, that her last wishes were met. Dr Mary Baines poignantly recalled going with Cicely to her flat to decide on giving away her clothes. One of Cicely's favourite sayings was 'Watch with me', the last service we can offer a dying person. Surely this is just what Cicely's carers, friends and family did during her last days and hours.

As Damian Falkowski played 'The Lark Ascending' by Vaughan Williams, chosen by Cicely for her funeral, and a beautiful metaphor for the journey of the soul to Paradise, I reflected, too, on the grief of all who worked at St Christopher's at the loss of its founder and their inspiration.

Stephen Spender wrote of 'The names of those who in their lives fought for life... And left the vivid air signed with their honour.' A good epitaph I think.

Ref: Spender, S. I Think Continually of Those in: J.B. Foreman (ed.) Collins Albatross Book of Verse. London: Collins, 1960: 621.

Dr David Oliver, Consultant in Palliative Medicine, Wisdom Hospice, Rochester and Honorary Reader, University of Kent

Listening to the talks about Dame Cicely brought back so many memories. I first came to St Christopher's as a student on my elective in 1978 and spent a month working on the wards as an auxiliary and having the opportunity to see everyone at work. Six years later I was back as registrar!

I have so many good memories of my two years at the hospice. The team was so welcoming and I had the wonderful opportunity to work closely with Mary Baines and Tom West, both showing the various aspects of care and medicine for patients and families, both in the hospice and at home. The Grand Rounds were always a time of anxiety as the registrar would be expected to present a patient with complex needs and we were always concerned as to the reaction of Dr Saunders. However, I can remember that after all the discussion, she would bring a clarity and reality to the deliberations, focussing clearly on the patient and family.

When I had moved to be consultant at the Wisdom Hospice in Rochester I would return at times for Grand Rounds, where we could bring our issues. On one occasion I discussed a man who was refusing to leave his house, but his symptoms were getting worse. There was discussion about the need for blood tests and investigations to elucidate the cause of these symptoms but at the end, Dr Saunders pointed out that if he was determined to stay at home, all we could do was treat according to our best judgement and investigations were never going to be a viable option.

I was also brought back to 1985 when several speakers talked of "the sherry". As a registrar on call on Sundays we were "summoned" to Dr Saunders' office for a glass of sherry before lunch. After a busy morning seeing patients and families a large sherry was certainly a challenge – and trying to remain sober and upright when leaving her office a further challenge!

Dame Cicely was always very supportive and when we were expecting our second child during my first year at the hospice she provided books for my wife to read, as she was in Kings' College Hospital for several weeks during a difficult pregnancy. When Tom was born she sent him, not the parents! a card. It was of a rainbow and inside was written "may you find your crock of gold".

It was a privilege to be at St Christopher's and work alongside Dame Cicely, who had such an impact on the care of the dying and modern medicine.

Richard Scheffer

Two words stand out from the recent day to remember the contribution of Dame Cicely: vision and leadership.

No-one who encountered Dame Cicely, no matter how peripherally, could not remember both her vision and her leadership. It was these qualities that time and again those reminding of us of their memories of Dame Cicely recalled – as a scientist, as a doctor, as “the boss”, but also as a friend, as a godmother, as an inspiration. And woven into the day was a constant reminder of another important quality – that of Dame Cicely's spirituality, her personal search for meaning and her expression of that through her faith.

I met Dame Cicely as a medical student in South Africa and, like all those present at this day of remembering, had being captured by her vision and excited by her leadership. We were a broad group that she influenced: nurses, doctors, social workers, chaplains, volunteers. All gathered to remember the woman and her remarkable effect, not just on our lives, but the countless numbers that each of us had cared for over our careers.

It is rare to be invited to a time of reflection on one's career and although the day was focussed on Dame Cicely, inevitably, being back at St. Christopher's, it became a time of reflection and remembering of one's own experience of learning from such a charismatic person, together with great people, who shared their skills and experience with us so freely and generously. It was not always an easy nor a pleasant experience. Learning to be with, and support, those who are dying and their loved ones, while retaining ones personal equilibrium is painful at times. Everyone present had a story of how Dame Cicely had cared for and supported them through a difficult experience.

Each person I spoke to at the end of the day seemed to have had a similar experience to mine. I had remembered not just the difficulties of learning and growing but especially the excitement of the experience of excellence of care at St Christopher's benefitting from Dame Cicely's vision and leadership.

A truly remarkable day. Thank you.

Dr Fiona Randall

'Although entitled 'Remembering Cicely', what impressed me most was that it was a day of giving thanks for her and all that she achieved, both directly and through the people she inspired by personal contact.

It was good to hear the different ways in which people knew her, each with their very personal insights into her character and great strengths. I recall how good it was to be together, especially at St Christopher's, with so many old friends. It was great to see Mary, Tom and others who taught us so much. It was also moving to be among that group of us for whom palliative medicine became a possible medical career simply because of the work of Dame Cicely. Many of us were the first generation of doctors who pursued 'palliative medicine' as a first choice of medical career, even though there was no such specialty when we went to St Christopher's to learn.

So what I will remember most from a personal perspective is a sense I felt, in the thanksgiving service on that day, of great thankfulness for what Dame Cicely gave me – the ability to follow a truly fulfilling medical career in the care of the dying, a career which used all of my 'talents' and energies, whilst rewarding so greatly at a human level. I also felt some sadness because of the thought that that group of people will probably not gather again, and it is likely that I will not see many of them again, since so many of us have retired.

Someone recently asked me if there is a 'memorial' to Dame Cicely. I explained that a physical memorial is not needed, for the real and living memorial is the work of the great many people she inspired, which work has changed patient care so very much for the better. And so many of those people gathered at St Christopher's this June to remember, be thankful, and to celebrate together.'

Tributes to Dame Cicely Saunders

A tribute to Dame Cicely – Dr Robert Twycross

Cicely Mary Strode Saunders 1918-2005

'I did not found hospice; hospice found me.'

I first met Cicely in 1963 in Bristol at a Student Christian Movement Conference. I was still a medical student; she was a qualified doctor in her mid 40s. It was truly a 'fate-full' meeting because it determined the direction of my future professional life. Things would have been very different for me if I'd never met Cicely. I therefore owe her a great debt of gratitude for what she did for me in 1963, and ever since. A small part of repaying her is the opportunity to honour her in your presence here today.

But no matter what she said, the obituaries were unanimous: Cicely Saunders was the Founder of the modern hospice (or palliative care) movement:

'She transformed the way we look at death and dying.'

'She transformed the care and treatment of the terminally ill.'

By her attitude, she conveyed a message to those she cared for:

'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.'

Cicely the person

So what was Cicely like as a person? One obituary stated that she was an awkward misfit in her early life – meaning, I think, during her senior school years. However, by the time she started training at St Thomas' Hospital, she was perceived very differently by her fellow student nurses. Her biographer writes:

'Cicely was happy – marvellously happy. For the first time she was the popular girl, the one whose opinion was sought, who had friends, who was successful. She slotted into nursing... like a book finding its right place on the shelf. Over 40 years later she still glows with warmth as she remembers the feeling that she had 'come home'... but, even so, her training was not all plain sailing. She had to fight a natural shyness and her ward reports are conflicting.'

Much more recently, one visiting professional described her surprise when she first met Cicely:

'I had somehow expected someone gentle, and was struck by her dynamism and force of character. This was clearly someone who had battled.'

And when someone observed a look of love and steel in Cicely's picture in the National Portrait Gallery, Cicely herself is reputed to have said:

'Love and steel, how kind. Anyone doing hospice work will need plenty of both.'

And certainly Cicely possessed both love and steel – compassion and determination.

How else could she have struggled to reverse her initial rejection by Oxford University? Coped as a student nurse with the limitations imposed by chronic back pain? Coped with the need to start all over again as a Social Work student? How else could she have coped with the need to go to Medical School because only as a doctor would she be listened to by doctors?

Then, in the early 1960s, Cicely suffered a series of bruising bereavements. First Antoni Michniewicz – the second Polish émigré in her life, then Mrs G – a very special patient with whom she had a mutually supportive friendship over many years – and then her father. Cicely was very much 'a wounded physician', and was thus enabled more readily to empathise with and support the patients and families who came under her care.

St Christopher's Hospice

The opening of St Christopher's Hospice in 1967 was a major milestone in Cicely's life, and was achieved with the help of a growing band of influential supporters, many of whom subsequently became members of the Hospice Council or the more informal Foundation group.

It was almost 20 years after her initial decision to build a special Home for people with terminal illness. People like David Tasma, a dying Polish émigré, who in 1948 had left Cicely £500 so that 'I can be a window in your Home'.

To describe the difference St Christopher's Hospice has made, and continues to make, to thousands of patients and families, let me quote from a letter by a grateful relative in 1972:

Dear Dr Saunders

I would like to write to you and attempt to express something of the gratitude and admiration that I feel for St. Christopher's. In saying this I realise that St Christopher's is not just a building, but a way of living – an attitude towards people, their life and their death – that is so remarkable. During those weeks which I spent with my father, and with you, it did seem very remarkable that the vision of one person, who had responded to a need, could be caught and sustained by so many others; so that the vision became a reality and the reality perpetuates itself creatively... The men and women at the Reception desk all greet you as if you belong and are welcome, the cleaners smile and look as if they enjoy playing their part in the scheme... The Nursing staff have all the qualities that nurses are supposed to have and something extra as well. I don't quite know what it is – perhaps it's a dimension of personality which is free to flow out when a nurse is trusted to motivate from within and is not oppressed by bossy hierarchies.

So how did this affect my father who was brought into the Hospice too ill and too weak to be much aware of his surroundings?... He benefited because St Christopher's is a happy place in spite of its sadness (perhaps joy is a more appropriate word because you can't experience joy without sadness). So those daily visits was marked by a feeling of serenity and calm as well as with humour and laughter, for which one is so grateful... And I think I came to know my father better during those visits, as a man and not just my father!

I have written more than I intended, but please accept it all as an attempt to say 'thank you' for so much that has been good.'

Cicely the professional

Cicely realised that it was necessary to combine patient care with teaching, advocacy, administration and research. And so she was soon appointing additional staff to share the load:

- patient care: Mary Baines, and later Tom West
- home care: Barbara McNulty
- staff support and bereavement support: Colin Murray Parkes
- advocacy in high places: Albertine Winner, and later Gill Ford
- research: Ron Weldon, and later me.

Although Cicely was a tireless ambassador for the cause, others joined her in the task:

- Eric Wilkes, Ronnie Fisher, the National Society for Cancer Relief (now Macmillan Cancer Relief), Thelma Bates, Derek Doyle, Prue Clench
- International: Florence Wald, and later Balfour Mount, followed by many others.

The cause was greatly helped in the 1980s when the World Health Organization adopted its Comprehensive Cancer Control Programme, which emphasised the need for both pain relief and palliative care.

Cicely was a gifted and inspirational teacher. She captured her audience's imagination and intellect with stories of actual patients, illustrated by slides. Her teaching model of 'total pain' took people, almost without effort, from a narrow physical outlook to a holistic approach, in which concern for the physical aspects of suffering was supplemented by and



integrated with concern for psychological, social and spiritual aspects. The unit of care became the family.

But this was clearly anchored in a scientific approach to the use of analgesics, other symptom relief drugs, and non-drug measures. In an article in the *British Medical Journal* 10 years ago, entitled *A personal therapeutic journey*, Cicely mentioned a handout she prepared to accompany her lectures: *Drugs most commonly used at St Joseph's and St Christopher's Hospice*. It was four pages and covered two sides of folded foolscap. It was later updated and expanded by Mary Baines, and remained a key handout for many years.

Now, the handout has been superseded by the 1244 pages of the *Oxford Textbook of Palliative Medicine*, and numerous other books – such as befits a full-blown medical specialty. But whether just four pages or 1244, the need for a thorough holistic evaluation of the patient remains essential. Cicely disparaged 'tender loving care'; she championed 'efficient loving care' in which attention to detail is the constant watchword.

Cicely's autobiography

Many of us have read Shirley du Boulay's biography of Cicely. I wonder how many have read Cicely's autobiography?

It is a slender volume entitled *Watch with me*, and contains five reflective articles written and delivered over a span of 40 years. The last talk, *Consider Him*, is dated 2003. In little over 10 pages, Cicely recounts the salient points on her pilgrimage through life, and tells again the constant inspiration of her faith. She quotes from a book by one of her favourite theologians:

'The crucified Jesus is the only accurate picture of God that the world has ever seen, and the hands that hold us in existence are pierced with unimaginable nails.'

She believed that, and I believe that. And, although she never paraded her Christian beliefs 'on her sleeve', she truly followed the Way of Jesus. Indeed, it is clear from her writings, and from her diaries, that her faith was a major, possibly the major, force in her life which sustained her through thick and thin. To ignore this would be to ignore a major source of her resilience and dedication. Cicely's personal watchword must surely have been: 'I am loved, therefore I am.'

Charisma versus routinization

It has been said that history alternates between charisma and routinization. In this context, charisma refers to the ability of exceptional individuals to act as a catalyst for social change, and acknowledges the impact of personality in bringing about radical innovation in

institutions and established beliefs. In relation to the evolution of hospice and palliative care, Cicely Saunders was without question the initial charismatic influence.

The question for us today is: Is palliative care in danger of moving from the creative and disruptive influence of charisma to the cosy ambience of routinization? I hope not.

Palliative care services, even in Britain, generally have not yet reached their full holistic potential. But movements tend to become monuments. So the best tribute we can give to Cicely is to make sure that hospice, that palliative care, remains a movement with momentum, and maintains an ongoing creative tension between charisma and routinization.

So, in summary:

Cicely was a friend, colleague, mentor, teacher or carer to hundreds, indeed to thousands. She was an inspiration to thousands, indeed to hundreds of thousands of nurses, doctors, and other health professionals in Britain and elsewhere.

Cicely didn't just talk the talk,
She walked the walk.

She stayed the course, and in doing so she changed the world,
And is changing it still.

Although physically she has left us, her vision lives on.

To honour Cicely, we too must not just talk the talk,
But, like her, we must walk the walk,
And stay the course, and continue the task of changing the world.

Fear of death is instinctive,
So the task is unending.

For each new generation, the same battles to fight and to win.

So may it please God to allow Cicely's mantle to fall on us collectively as we honour her as the founder of the modern hospice, as the founder of palliative care – and also as the one who was found by hospice.

A tribute to Dame Cicely – Dr Sam Klagsbrun MD

Individuals do matter! The bible is filled with examples of the power of individual people. Look at the impact Moses, Jeremiah, Job and Jesus had on the world they lived in and on untold generations thereafter. Where does such power come from?

There are two sources. The first is the power of personal example and the second is the power of teachings. Moses was both a leader by virtue of setting a personal example as well as by being a teacher. So was Jesus. I do not exaggerate when I say that it is precisely in

that mode that I think of Dame Cicely – both as an outstanding leader and as a superb teacher!

Our biblical ancestors did not start out planning to become leaders at the beginning of their journey. Moses certainly was not looking for that job – indeed, he argued vehemently against taking it on. Over time, he became a leader. Leaders become leaders because of the gradual accumulation of experiences in the positions they are in, which in turn begin to shape the impact of their leadership. The growing image of the leader captures the attention of an every-increasing audience, which gives leadership its power.

Thirty-five years ago when I first met Dame Cicely, she was already at that time making quite a mark. I was in awe of what she had created – not only at St Christopher's, but indeed of her influence, which was spreading throughout the world. What I saw in action on my first of 35 annual consultation visits was enormously powerful, precisely because of its utter simplicity! On my first day at St Christopher's, years ago, I followed Dr Saunders on Rounds, going to the bedside, watching her pull up a chair and sit so that she would be at eye level with the patient, rather than standing and looking down at the patient. I watched her smiling, reaching for the patient's hand, inquiring about the patient's feelings and symptoms, asking about family visits... taking time and sometimes simply sitting quietly at the bedside without even saying anything. I had literally never seen anyone in all my years of practice behave quite this way and take so much time with each and every patient. Here was a great teacher, teaching by personal example.

The lasting power of Dame Cicely's teachings had a lot to do with the uniqueness of her lectures. Dame Cicely's always let the patients do the teaching. Every lecture was based on slide presentations filled with the faces of the patients, each telling their own stories. Dr Cicely Saunders taught that it's the individual person that counts. It's the paying of attention to the individual's needs, symptoms, fears and pain, which matters. Teaching abstract theories and principles never have the power of the impact compared to that of the personal story. It's the translation of a particular person's needs into a broad system which explains the enormous power of Dame Cicely's impact on the world of medicine. I remember many years ago, inspired by my St Christopher's experience, launching a floating hospice team at St Luke's hospital in New York City, together with Rev Carlton Sweetser of blessed memory, a chaplain who had spent much time at St Christopher's. We went to the bedside of dying patients – wherever they were in the hospital. One day finishing rounds at the bedside of a particular patient who was in a semi-private room, as we were leaving, his room-mate in the

neighbouring bed yanked open the dividing curtain and yelled out at us, “Damm-it do you have to die around here to get this kind of attention?”

Cicely Saunders has left her mark in the medical world way beyond the world of hospice care. Because of St Christopher’s and Dame Cicely, the field of palliative care has been born. We live today in an era of enormous technological and scientific advances. However, all too often, it’s the entire patient who’s forgotten behind the newest symptoms, which are the centre of attention, rather than the patient.

It is most fitting to offer in our memorial for Dr Cicely Saunders her own words:

“I have tried to sum up the demands of this work... in the words ‘Watch with me.’ Our most important foundation for St Christopher’s is the hope that in watching, we should learn not only how to free patients from pain and distress, how to understand them and never let them down... but also how to be silent, how to listen and how to just be there.”

Dame Cicely – who we remember today – has taught us and shown us how to put the whole patient, the entire person back on centre stage – to the enormous benefit of all patients, families, and the entire field of medicine. We are deeply grateful and thankful! May her memory be for a blessing.

The Road to Gethsemane – a reading from the Service

From *The Stature of Waiting*, 1982
William Hubert Vanstone (1923-1999)

When a Christian believer is going through any distressing or disquieting experience, it can be a source of comfort and encouragement to him to remember

that the Lord Jesus ‘knows all about it’ – that He Himself went through the very same experience. So it may be that the thought of the handing over of Jesus – of His transition from action to passion can be of practical help to people who must face, or have already faced, a similar transition in their own lives. We have already stressed that the word ‘passion’ does not mean, exclusively or even primarily, ‘pain’ : it means dependence, exposure, waiting, being no longer in control of one’s own situation, being the object of what is done. So the passion of Jesus ‘connects’ not simply or even primarily with the human experience of pain : it connects with every experience of passing, suddenly or gradually into a more dependent phase or area of life-with going into hospital, with retiring or losing one’s job or having to wait upon the actions of other people and other factors beyond one’s control. If the thought of the passion of Jesus is helpful at all, then it may be helpful not only to the person who is bearing the ‘cross’ of pain but also to the person who feels that he is ‘on the sidelines’, that he has become useless or ineffective, that he is no longer making his mark in the world or his contribution to it. ‘To be handed over’ in ways such as these is particularly disquieting to a person who, by habit or temperament, has been exceptionally active and energetic or a notable achiever; and such a person may well find comfort in the thought that a similar pattern appears in the life of Jesus – that He also passed from activity and work and achievement into a final phase of waiting and dependence and passion.

Find out more

Dame Cicely Saunders Institute website:
<https://cicelysaundersinternational.org/>