

# From pioneer days to implementation: lessons to be learnt

**Mary Baines** reflects on the pioneering days of palliative care, when she worked with Cicely Saunders at St Christopher's Hospice, in an article reproducing the talk she gave in Lisbon last May at the 12th Congress of the European Association for Palliative Care

I want to start by showing you this photograph of Cicely Saunders, and I am grateful to Avril Jackson, previously of the Hospice Information Service,\* for it. I like it because of her smile and because it shows her still at work – in fact giving prizes to hospice staff – though it was taken in 2001 when she was 83, just four years before her death.

Cicely Saunders in 2001, four years before her death



Cicely Saunders was, of course, the founder of St Christopher's Hospice in London and she is generally recognised as the founder of the palliative care movement.

She trained as a nurse, then as a social worker, and it was then that she met David Tasma, a young Polish Jew, who was dying of cancer. It was through her friendship with him that God called her to devote her life to improving the care of the dying – a most neglected group. She then trained in medicine and that was where I met her – we were contemporaries at medical school.

I wish, for your sake, that she could have given this talk on pioneering days. But this talk will be full of what she taught me and countless others. It is dedicated to her, Dame Cicely Saunders – an honour given by Her Majesty the Queen – the founder of our specialty and my dear friend.

## The beginning

When Cicely Saunders opened St Christopher's in 1967 she brought together, for the first time in the world, a large number of patients with terminal illness and staff who were committed to discover and then teach the best ways of caring for them. Previously

these patients would have been scattered – in various hospital wards or at home. There were a few hospices, mostly opened around 1900. The patients in them received excellent nursing and spiritual care but there was minimal medical input, for it was generally believed that the doctor's role was to cure. These patients were, of course, incurable.

I was a medical student at St Thomas's Hospital in London in the same year as Cicely Saunders. She was much older than the rest of us, having been a nurse and a social worker. When St Christopher's opened, I was working as a part-time general practitioner. Cicely asked me to join her on the staff and, very fearfully, I did. Medical friends said it was professional suicide.

I found myself entering a branch of medicine with no books or conferences. Symptom control was contained in a single sheet entitled *Drugs most commonly used at St Christopher's Hospice*, which was given to all staff. Yet, I suggest, this sheet contains the single most

important advance in end-of-life care that has ever been made. It comes, of course, from Cicely herself. To understand its importance, we have to go back to medical practice in the 1950s and 1960s, when it was generally believed that strong opioids were only effective when given by injection and that tolerance and addiction would inevitably occur if they were given regularly. So, in practice, patients were given injections of morphine but only when their pain became unbearable.

### **The revolution in symptom control**

Cicely Saunders had seen the value of regular oral morphine in a small London home for the dying that she often visited. After qualifying, she obtained a research scholarship to study pain control in terminal illness and she went to St Joseph's Hospice, where she was allowed to put her ideas into practice. She was permitted only four patients to start with because of the fear that regular giving caused addiction! But, to the surprise and delight of the staff, these patients became painfree and remained alert. So the practice of giving a strong opioid by mouth, regularly and in adequate doses became accepted at the hospice. When Cicely Saunders left St Joseph's, she had carefully documented records of over 1,000 patients dying of cancer – quite a series. The first research project in what was to become palliative care.<sup>1</sup>

The strong opioid used at St Christopher's at the beginning and listed in the hospice's symptom control leaflet is diamorphine or heroin, because it was widely believed to be superior to morphine, giving better pain control with fewer side-effects. Cicely Saunders herself said 'Diamorphine does the greatest good to the greatest number'. But she also knew that this was only her impression and had never been researched. And so she invited Robert Twycross to join St Christopher's as a research fellow to conduct studies into many aspects of pain control, including a comparison between morphine and diamorphine given orally.

Because of the strongly held belief that diamorphine was the better drug, the only ethical way to proceed was to do a pilot study first. Half the patients were given morphine and half diamorphine, and people like me were asked to guess which drug they were on. Not surprisingly, everyone who had good pain control with minimal side-effects we guessed

to be on diamorphine. Those who were sick and drowsy we judged to be on morphine. In fact, we were right 50% of the time! The trial was then started with 700 patients entering over two years. On completion, when the data were analysed, they showed that there was no significant difference between them.<sup>2</sup> Cicely Saunders' impression was wrong. Of course, we too have impressions but, like her, we should be keen to have them tested out – even if we too are proved wrong.

If you had joined our ward round in the early years, you would have found that the most common word used was 'why'. 'Why is this patient having this particular pain?'; 'Why has his breathlessness suddenly become much worse?'; and, relating to my own special interest, 'Why has this patient with proven intestinal obstruction stopped vomiting?'. This last question was fascinating. We admitted many patients who had had an 'open and close' operation for intestinal obstruction and nothing could be done. We treated them simply, with a combination of analgesics, anti-emetics and antispasmodics with no nasogastric tube, and the vomiting either stopped or was reduced to once a day with no nausea. In addition, sometimes, after weeks, the bowels opened. Why was this? What was happening? It had never been described before.

Fortunately, when St Christopher's was designed, Cicely Saunders included a post-mortem room and we had a senior pathologist, Richard Carter, from the Royal Marsden Hospital, who came to perform limited symptom-directed post-mortems. Some of you here today attended them. I wonder if you, like me, remember that they mostly seemed to happen on a Saturday morning! The first 63 autopsies were written up in the first edition of the journal *Palliative Medicine*.<sup>3</sup> Eighteen autopsies were in connection with our study of patients with malignant intestinal obstruction and, in each case, the obstruction was confirmed, with 14 patients showing it at multiple sites. This study, with 40 patients, was published in *The Lancet* in 1985.<sup>4</sup> [It included the 18 autopsied patients and 22 on which it was not possible or not appropriate to conduct post-mortems.]

I hope that, if I joined your ward round next week, I would often hear the question 'why?'. The hospice's symptom control leaflet has grown into the *Oxford Textbook of Palliative*

**So the practice of giving a strong opioid by mouth, regularly and in adequate doses became accepted at the hospice**



Mary Baines worked for many years alongside Cicely Saunders at St Christopher's Hospice; she was one of the founders of the first UK palliative home care service

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*Medicine* and countless other publications, but there is so much more to be learnt, not only on symptom control but on all the other aspects of palliative care.

### **Total pain**

I said that the regular giving of drugs to control pain was the most important advance in end-of-life care, but close to it – or even first – is, surely, the inspired concept of ‘total pain’ having physical, emotional, social and spiritual components. This came, of course, from Cicely herself and she first wrote about it in 1964, having learnt it at the bedsides of the dying patients she cared for.<sup>5</sup> This was revolutionary at that time, when the severity of pain was generally measured by the somatic injury that caused it. But this concept of total pain (or total suffering) gives us a wider approach and a framework to our understanding and care for patients at the end

of life. The physical component usually needs treatment with appropriate drugs, given regularly. Helping the emotional and social components of pain involves recognising and treating anxiety and depression when they are present, and spending time with patients and families, encouraging them to talk and ask questions, and giving kind but truthful answers. Spiritual pain may be due to guilt about the past or a fear of what happens after death. It was explored with all patients on admission by asking about the importance (or not) of faith, so that spiritual anxieties could be addressed.

Time will not allow me to mention all the dimensions of total pain that were studied in the pioneer days but I will highlight just two.

One important early study conducted by Professor John Hinton compared the experience of care of patients in the radiotherapy ward of a teaching hospital with those who were receiving hospice care either as an inpatient or at home, looking especially at levels of anxiety and depression.<sup>6</sup>

Perhaps the best known of early studies are the work and writings of Colin Murray Parkes on bereavement. He had met Cicely Saunders before St Christopher's opened and she invited him to start a bereavement service from the beginning. Colin developed an assessment card to be filled in after death by the staff member who knew the family best. This gave details of the ‘key person’ – the one thought to be most affected by the death. Those who scored high were visited at home by a specially trained bereavement visitor.

The effectiveness of this service, which was the first in palliative care, was written up in 1981 and it is considered by Colin to be his most important piece of work.<sup>7</sup> It showed that bereavement support reduced the risk in the ‘high-risk’ group to about that of the ‘low-risk’ group – a major reduction in symptoms of anxiety and the consumption of alcohol and drugs. Two early evaluations of palliative care looked at anxiety, depression and bereavement. How do you, in 2011, evaluate the care you give?

But for all the advances and research in this field, it is so important that we do not become people who just go round patients with questionnaires and boxes to tick. We need to remember daily the words of Cicely Saunders. ‘I have tried to sum up the demands of this work we are planning 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 just to be there.”<sup>8</sup>

### **Adapting home care**

Until 1969 St Christopher’s was purely an inpatient unit as were the other older hospices. Patients were admitted and, with very few exceptions, remained there until they died. For the few who went home there was no follow-up. Then an incident occurred that led to the founding of the first domiciliary service.

A woman in her 50s with severe pain from bone metastases due to breast cancer surprised us all by wanting to go home once the pain was controlled. We tried to make careful plans, I phoned the general practitioner, and the drugs, including a moderate dose of diamorphine, were given to her. But ten days later she was readmitted in agony because the doctor had reduced and then stopped the opioid, feeling that it would otherwise turn his patient into an addict. Of course, the pain had returned. Sadly, this story does not have a happy ending. Her pain was easy to control but she had lost her nerve and did not want to go home again. She remained an inpatient until she died.

However, it was this incident that prompted Cicely Saunders to say ‘We must start hospice care at home now’. She looked around the hospice to find staff who had worked in the community – a field in which she had no experience. She chose Barbara McNulty, a nurse, and me, and she told us to start a domiciliary service.

The way forward was far from clear. There were no other palliative care services at home to guide us and we felt it was very important to get it right. We needed our service to fit in with the UK pattern of care in the community. So we decided to spend some months going round those already working there and asking them if they wanted a hospice home care team and, if so, what form they wanted it to take. The answers came back, the majority welcomed the hospice going out into the community, but the general practitioners wanted to remain in charge of patients at home and the district nurses wanted to continue the practical nursing that was

needed. They wanted a 24-hour service with doctors and nurses in the team.<sup>9</sup>

And so the first home care service was born in October 1969, a model for the UK. This format has remained virtually unchanged at St Christopher’s and, in 2010, no less than 1,800 new patients were visited and 48% of deaths occurred at home. This model was right for us but may well not be right for you. You need to design your service to fit in with the needs and resources in your country.

Let me give you two examples that I know well, focusing on how they coped with a common problem.

The Communist years in Romania left an appalling legacy, with many sick children in derelict orphanages and virtually no treatment for older people unable to return to productive work. But, in 1991, just over a year after the fall of Ceaucescu, an appeal to start hospice home care in Brasov was launched by Graham Perolls and others. A senior oncologist came to the UK for training and, on his return, an English nurse joined him and immediately began to train Romanian nurses. There were no community nurses, so the team had to do the care themselves or teach the family. In spite of this, they offered a 24-hour service. At the start there was no oral morphine and the prescribing of morphine injections was so restricted and complicated that few received them. But the hospice team, with outside experts, worked tirelessly to change things and, in 2007, the government approved a law to allow all doctors to prescribe morphine, with no maximum dose.<sup>10</sup>

In Uganda, hospice care at home was started in 1993 by Anne Merriman. Before agreeing to launch it, she insisted that oral morphine must be available and local doctors were amazed at the difference that this made. But hospice could only cover a fraction of those who needed help, so an approach to the government was made to permit specially trained nurses to prescribe and deliver morphine, essential in rural areas where there are no doctors. In 2003, the law allowing this was passed and, at present, over two thirds of the 108 districts in Uganda have morphine-prescribing nurses working in them.<sup>11</sup>

Two examples of how palliative care at home has tackled a specific local need. How can your service or the one you are planning serve your community better? This is a challenge to us all.

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## Palliative care reaching out

There is no doubt that Cicely Saunders did not found St Christopher's purely to care for patients in south-east London. Her aim was to change the world's view of dying and this aim was shared by those of us who worked with her. There were many ways in which this could be achieved.

Even before St Christopher's opened, Cicely Saunders was lecturing in the United States. An eight-week tour in 1963 followed by annual visits inspired many people and was one of the factors leading to the formation of the American hospice movement. She and others went on to lecture widely in the UK and abroad and, from the start, we welcomed visitors. They came to see what we did and went home, not to copy it but to apply it to their own circumstances. These visits are always costly to staff but there are ways to minimise this, such as the monthly 'Friday visit' at St Christopher's, when individuals are combined in a group for talks and a tour.

But we also have visitors who come for a longer time. In 1973, Balfour Mount, a urological surgeon from Canada, visited. He went back and founded a unit in his hospital, the Royal Victoria Hospital in Montreal, and he gave the name 'Palliative Care' to our specialty. Then, Gustavo de Simone from Argentina came to a hospice conference and was persuaded to stay on for a further two weeks of clinical work. He had come across our first textbook of palliative care in a remote part of Patagonia and had decided to come and see the work for himself. He went back and founded Pallium and became one of the leaders of palliative care in South America.

But 'reaching out' is not just a matter of geography. One of the things that pleases me most about the modern hospice movement in the UK is its increasing involvement with different patient groups; for example, those in care homes and those with dementia.

Perhaps the hardest groups to reach, especially at the beginning, were our own professional colleagues. Even speaking about pain control in the early days was fraught with difficulties. I well remember being asked to talk on the use of opioids at a conference on the management of cancer pain. In the question time at the end, I was attacked by both anaesthetists and neurosurgeons! Looking back, I wondered if this was because they could see that, if drugs

were successful, there would be less demand for nerve blocks and percutaneous cordotomies. An outstanding exception to this was the late Vittorio Ventafridda from Milan. I remember him telling me that the use of nerve blocks for cancer pain in his clinic had fallen from 83% to 14%. But he was pleased because his concern was for the well-being of his patients, not the take-up of his specialty. A remarkable leader.

How are you going to 'reach out'? Perhaps by offering palliative care to a new group of patients, those with intractable cardiac failure or advanced multiple sclerosis. Perhaps by making a link with those trying to establish a palliative care service in one of the 119 countries without one or in one of the countries where the work is very difficult. Perhaps by seeking an invitation to speak to nursing or medical students at your local hospital, or writing an article in one of your professional journals. And there are hundreds more ways that I hope and pray you will explore during this conference. For the need for 'reaching out' is as relevant today as when we started 44 years ago. It makes me want to turn the clock back all those years and join you and start all over again!

**\* Avril Jackson was until recently International Information Manager at the Hospice Information Service run by Help the Hospices and St Christopher's Hospice.**

### Declaration of interest

The author declares that there is no conflict of interest.

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**The references in this article can be obtained from the librarian at St Christopher's Hospice. To contact her, please send an email to: [d.brady@stchristophers.org.uk](mailto:d.brady@stchristophers.org.uk)**

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