
Keri Phillips: Thanks for joining me for Rear Vision here on ABC Radio National. I'm Keri Phillips.

Cicely Saunders: What we set out to do was to teach skills of pain control, to teach skills in how families cope with this kind of problem, and to teach the public not to be so afraid. Then I think they find their own role, how they can be helpful, and start thinking about it differently.

Keri Phillips: That's the voice of Dame Cicely Saunders, founder of the approach to looking after people with terminal illnesses known as palliative, or hospice, care. Although modern palliative care only a short history, its practice has spread around the world.

Today on Rear Vision, we'll track its development first in Britain and then in North America and Australia, where the world's first professor in palliative care was appointed. It began in London in the 1950s, with the pioneering work of Dr Cicely Saunders, who was convinced that the needs of dying people were not being properly looked after. Professor David Clark is the Director of the International Observatory on End of Life Care at Lancaster University in the UK.

David Clark: She started off in the Second World War, studying the Social Sciences at Oxford University, but she wanted to make her contribution to the war effort, and she dropped her Social Science studies and trained as a nurse at St Thomas's Hospital, and it was there that she began to get interested in the problems of chronic pain, pain associated with cancer, and the wider difficulties being experienced by people with terminal illness. And after the war, she again re-trained as a social worker, what was called a medical almoner in those days, and developed a deeper interest in these issues, and particularly was moved by the care of a Polish émigré that she was involved with in 1948, who was dying alone and far from home in a London hospital.

She became more and more absorbed in the problems, and what she saw as the neglect of dying people in the modern British National Health Service, which was created in 1948, and in the mid-1950s she trained again as a doctor, and by 1957, by now in her early 40s, she was really getting very interested indeed, as someone who'd been a nurse, a social worker and trained as a doctor, in the care of dying people. And she studied this issue, she did research. She worked in one of Britain's few hospices for the care of the dying that existed at that time, St Joseph's in the East End of London. And then in 1967, after about a 10 year effort, she opened what we regard as the world's first modern hospice, at St Christopher's in South London.

Keri Phillips: Milton Lewis is a historian of medicine and public health and the author of 'Medicine and Care of the Dying: A Modern History'.

Milton Lewis: There's no doubt that she played an absolutely key role in developing the original ideas, particularly things like the notion of total pain. Pain of course, is a central problem for many dying people, and she had the idea that pain was not simply a physical thing, but it had a number of dimensions. It had certainly a physical dimension, it had a psychological dimension, and it had an emotional - it had for her, a spiritual dimension. She was a convinced evangelical Christian, and she believed it also had a spiritual dimension.

So she believed that if you addressed all those areas of a person's need in relation to the pain they were experiencing, you would free them from a major disability in coming to terms with their dying. There's even, if you like, a social dimension in that the emphasis was not only on the patient, but where applicable, on the family and friends, and so that it was an opportunity for example, to resolve unresolved issues between family members or with friends, or whatever, as is so often the case in that phase. So it had that dimension.

It was a very conscious effort on the part of the pioneers like Cicely Saunders, to provide these better conditions, because they were appalled by the often very cold, very unsatisfactory conditions under which people experienced death in normal, acute-care hospitals. People like Saunders and others said that it was the worst possible conditions under which to die, and that they wanted of course to try and provide the best possible conditions. So it was a reaction against what they saw as a failing on the part of modern medicine, for all its great strengths, for all its great capacities to provide therapies for a whole range of new diseases and conditions. It was failing heavily, they thought, in this area.

Keri Phillips: At first, palliative care was closely connected with cancer, itself emerging as a medical specialty in the period after the Second World War. So many of the big killers, the infections diseases, had been brought under control in the developed world, through antibiotics and vaccines. Cancer had become the next big medical challenge.

David Clark: There was a sense of fatalism that accompanied the diagnosis of cancer. It was a disease that wasn't spoken of, it was referred to in euphemistic terms, never named. It was seen as something about which very little could be done, especially when it was diagnosed in the late stages. So somebody with advanced cancer, was often told by their doctor or their hospital or their nurse, 'Now you must go home, there's nothing more we can do.' So there was a resistance that anything positive could be done about cancer. It was really analogous to the way in which we viewed the care of older people at that time. There was a sense with older people that they were really not amenable to very much in the way of positive interventions, that growing old was inevitable, that with old age came fragility and frailty, and this would have to be accepted as part of a person's lot.

Cancer was regarded in a similarly fatalistic way. And what Cicely did, which was I think quite remarkable, was to turn that around and say, 'You know, this is wrong. It isn't the case that there's nothing more we can do. There is in fact a huge amount we can do.'

Keri Phillips: Dr Joanne Lynn was a palliative care pioneer in the United States.

Joanne Lynn: It was just night and day compared to the way that the oncology was treating these patients at the time, which was mostly not to tell them that they were likely to die, to keep up the false image of hopefulness that somehow right around the corner there was going to be some big cure and to really pretty much ignore pain and the overall pain of coming to the end of your life misunderstood. Very few doctors had had much experience with anything other than fully aggressive efforts to stave off death, right up to the end. So at that time it seems that it was patients and families reacting to the suffering that that entailed, and the alienation, the isolation from your family. If you take a lot of chemotheraphy and you have no resistance to bacteria , then you're in isolation, you're off on a ventilator, people - not necessarily a lot of people - but a number of people started saying 'That's just not the way I want to be at the end. If I've got to have an end, then let's have it be more humane.' You know, cancer tends to kill us somewhat younger than heart disease or strokes or dementia. So very often these were people who were really in the heart of their family. Maybe it's a cruel observation but I think it is true that the pain of somebody at 88 who has no family left, is easier for the society to ignore. The pain of a 45-year-old dying of breast cancer in the midst of her school-aged children is pretty hard to take.

So I think that the fact that cancer so often causes pain, and often, not wholly, but often is striking people somewhat younger, made it quite a combination, and then when the hospice movement in Britain was able to show that essentially everybody could be at least comfortable. They weren't necessarily completely free of pain, and they weren't necessarily still awake. They might be pretty dozy, but you didn't have to be screaming in pain as you died of breast cancer. It was quite a revelation, and once people understood that, they wanted it.

Keri Phillips: So what exactly did palliative care involve? Professor Ian Maddocks was the Foundation Professor of Palliative Care at Flinders University in 1988, the first such post in the world.

Ian Maddocks: It's a bit like old-fashioned care. Before scientific medicine recognised all the very clever things that we can do nowadays, people used to do fairly simply things and comfort people. They thought they were doing some other special things, but most of the time they weren't working, and basically it was just care. So palliative care is now a specialist discipline, but it's still got some of that old-fashioned kind of care, where you depend upon good nursing as much as good medicine, where you depend upon family support as much as professional support. That kind of thing.

It's got characteristics that I think are becoming a little bit more recognised and more popular. I mean we're talking about words like 'patient centred', thinking about what does the patient actually want for themselves, rather than what does this pathology seem to need. Talking about words like 'holistic', a word invented by General Smuts, you know, talk about looking at comprehensively at the total needs of the patient. So we look at the physical needs, the emotional needs, and because partly of the long Christian tradition that impinges on this area, people like to talk about spiritual things as well. I mean what is the meaning of this whole experience for the patient, and how can you support them through it at that so-called spiritual level.

We use words like 'comprehensive', trying to encompass all the needs of the patient. 'Continuity', trying to follow the patient right through, so they don't miss out if they move from hospital to nursing home, or from hospital to hospice, or from hospital to home, or backwards and forwards. There is a team approach that tries to sustain them, wherever they are. And so there are familiar people, perhaps, that they can access when they need. And it's also family-centred as well as patient-centred, because the family often have a lot of difficulty looking after a dying patient.

Keri Phillips: Because cancer is a disease that can bring with it a lot of pain the key to the success of palliative care was pain management.

Ian Maddocks: Two-hundred years ago, you could pick up morphine anywhere. Towards the end of the 19th century, the drugs became a little bit controlled by the medical profession, and by the time I was a student 50 years ago, morphine was something that had very definite doses, it was always given by injection, and you could only have so much. And if your pain didn't get better, well, you couldn't have any more. And that was a bad understanding of pain. People were scared of pain, and it wasn't handled very well. Now the important breakthrough I think, was when Cicely Saunders promoted the understanding that oral morphine, in whatever dose was necessary, was going to be a good way of managing cancer pain, and being able to take a simple syrup of morphine and take as much as was necessary to control pain, was a quite different breakthrough, really. It's very simple; it's what people might have been doing in the 19th century, but now in the 1960s, they began to do it again, and began to get better control of pain. And in some ways, cancer pain is easy, compared with some of the other pains that people have, and there are some difficult pains, some associated with cancer, like nerve pains and so on, that require fairly sophisticated handling. But the pain that a solid cancer causes in the liver or the bone or something like that, is relatively easy to control in most cases if you have access to enough of the drugs, and you've got a patient that you can work with to get it right.

Joanne Lynn: The most striking thing is the rediscovery of something that actually had been known from quite a while ago, that there is no real upper limit to the use of opioid analgesics, the narcotic pain relievers. There had been a sense that you could only use a certain amount of morphine, and it turned out that pain is a tremendous antidote to morphine, so as pain got worse and worse, you can increase the morphine fairly safely. A person who has been on a particular dose of morphine and the pain gets worse and starts breaking through the dose that they've been taking, is ordinarily safe to double the dose, at any dose level. And that was just quite a revelation. There aren't very many drugs that behave that way. Either they have a ceiling effect, you know, there's no use really to take very much more than the standard dose of aspirin, you're not going to get any better pain relief. So there aren't very many drugs that you basically can just escalate to match the symptom, and it took a while to establish that and to show that even at very high doses, people were awake and talking and - they were very sick people, so they weren't in a sense doing fine, but they were comfortable, even at remarkable doses.

Keri Phillips: This is Rear Vision on ABC Radio National, with Keri Phillips. Today's program is a history of palliative care, and we're hearing from three pioneers in the field, Professor Ian Maddocks, Dr Joanne Lynn and Professor David Clark.

The principles and practices of palliative care spread through the English-speaking world fairly swiftly and grew strongly in Britain itself from the late 1960s.

David Clark: The concept of St Christopher's was something created outside of the National Health Service, so it was established as a legal entity of a charitable nature, serving a local community with its own systems of governance and trusteeship. And many other people, you know, the local communities around Britain, saw an opportunity to emulate this, and it set in train a great period of enthusiastic awareness raising, followed by fund-raising, followed by active planning and operationalising of local hospices. So that by the 1980s, we had 100 new hospices came into being during that decade. And most of these were in the voluntary and charitable sector.

The NHS didn't ignore things completely. And by the mid-1970s there was interest in these issues in the National Health Service, and we began to see hospitals building specialised palliative care units in the hospital grounds, modelled on the hospice principles, but organised and run within the National Health Service. But it is a particular feature of the development of hospices in Britain that they essentially began outside of the mainstream of the NHS, and I think the legacy of that has been seen just this year in Britain, when for the first time ever, our government has produced an end-of-life-care strategy for England. It's just for one of the countries of the UK, but it's still very, very important, and Scotland is working on the same kind of process at the moment.

Keri Phillips: Outside the UK, it was activists within medicine and especially the community, who spread the word. Mainstream medicine responded with indifference and sometimes resistance.

Ian Maddocks: I think Australia, we probably did better than some of the other places, both in terms of bringing palliative care into an academic standing, by establishing that first Chair, and then other Chairs that followed from other universities in Australia. We were pretty much in front. So I think the academic thing was one of the ways in which we pushed palliative care forward, and the other was government support. Because palliative care in many places, as a sort of community movement, grew by people raising money to build a hospice, or raising money to fund a home care program, that kind of thing. And a lot of it was done in a charitable way. But we were able in Australia to influence government and get specific funding for palliative care. It was coming in from the edges, it was strongly influenced by family perceptions, by nurse perceptions about what was necessary. Only a few special doctors began to recognise how important this might be, and there are interesting people in each State of Australia, who at various levels, some doctors, some nurses, some non-professionals, who took up this cause and said, 'We should do something more about this.' And each State did it to some extent in their own way.

It was to some extent a movement, rather than a professional-led process that engendered resistance; I don't think there was really resistance; people were a little bit bemused by it. 'What was this palliative care stuff and should it be part of medicine, because what did it really consist of?' And yet gradually it became recognised and gradually we were able to promote it, both at a political level and at a medical level and at a community level, and often it was the community level that was strongest. And it was the interest of nurses, who said, 'This is why I did nursing, because I wanted to look after people.' And nursing now in the big hospitals is so much looking at the computer and so much doing all the paperwork, and there isn't the same time to be with the patient.

Joanne Lynn: In the United States, there was pretty much just marginalisation of people who wanted to approach care this way. In Britain, it seemed to have been more well-accepted right from the start, although that may be the envy of somebody looking from across the water! But it doesn't seem as if it aroused the same degree of resistance. That doesn't mean everybody picked it up, an awful lot of the resistance to instituting palliative care has been to simply ignore it, and not to particularly say it's the wrong thing, or to fight against it, but just to fail to make something that's offered to patients, or to mention to patients that rather than one more surgery, or one more chemotherapy or a trip through the intensive care unit, they could take their chances with their illness, but live more fully, live more comfortably by staying home, by having good medications, by having lots of personal support. I think that, at least in the United States, there was much more a patient movement, a consumer movement, to take our bodies back, take back dying from the doctors, make it a more normal human event. And this was of course at the same time as we were moving a lot of childbirth to the home, or at least to natural childbirth, and having a great deal more consumer rights in everything, from buying cars to buying pills. It was run by church ladies out of basements and heavily volunteers. It was very much a seize back these important events from the doctors, and it was birth and death that are really part of the family life, so it was a sort of mood of the time to respect expertise less and insist upon more expertise being handed to the consumer or the patient, that they could run their own life.

Keri Phillips: Not surprisingly, given the Christian strand running through the palliative care movement, it's maintained a strong opposition to the idea of legalising euthanasia.

Ian Maddocks: There's a fairly strong Catholic move against any question of having the opportunity to perform euthanasia in any sense at all. But that's really to some extent irrelevant to what we do day to day because legally we know we can't do those sorts of things. But what we can do is provide good comfort care and we were able to get legislation in South Australia that said that if doctors are treating in a way that accelerates death but they're doing it for comfort, they're not going to be charged. The emphasis has to be that you're trying to help people die well not die quickly.

David Clark: I think it's fair to say that the relationship between the protagonists of palliative care and the protagonists of euthanasia, has generally been an adversarial one. There's a strong belief on the part of some people that euthanasia has no part to play in palliative care. And it's been interesting to see how, in the small number of places where legislation has been introduced, things have played out. For example, if you take the Dutch situation, euthanasia was decriminalised there for a long time, and it was only legalised within the last decade. It hasn't led to the huge explosion in numbers of euthanasia cases that many within the palliative care world predicted. Nor has it inhibited the development of palliative care in Holland, which is now after a rather slow start, progressing very successfully. In Belgium, some palliative care physicians responded to the legalisation of euthanasia, by developing the concept of what they call integrated palliative care, which allows euthanasia to be a part of palliative care. They have been largely condemned by their colleagues elsewhere in Europe, and are seen as stepping outside of the party line on this issue.

If you take the State of Oregon, it's very interesting again to see that where assisted dying has been legalised, the numbers of people availing themselves of it have remained fairly small and fairly constant over a decade or more, and we in fact know that many of those who do avail themselves of the legislation, also receive hospice care. So I think it's time for more dialogue between the two worlds of palliative care and the protagonists of euthanasia, because the loggerheads that they've been at over a number of years now, don't really help to advance the debate, and I don't think resonate very well with the feelings and the beliefs and the attitudes that exist within the wider society.

Keri Phillips: In the 1980s, the Medicare program in the US began funding, under certain conditions, what they call hospice care for the elderly. Today, in addition to hospice, which is mostly home-based, palliative care teams work within hospitals. Now more than two-thirds of all Americans have at least some use of hospice care before they die. So it's now not just cancer patients who are availing themselves of palliative care.

Joanne Lynn: When I was first starting to work in hospice in '78, it was very avant-garde; it was sort of the fringes of medicine. I think we've grown up and matured a good deal in understanding what people go through near death, and it's no longer thought of as strange or inexplicable for a person to want to be at home, to be willing to give up the chance to live an extra few days, in order to have the dying be the sort of thing that they thought that it was best for themselves and their families. Those were quite challenging ideas at one time. We're gradually coming to understand that there are different patterns as people live with fatal illness, that not everybody has a period of time when you can say, 'Oh, he's dying now', there's basically the course to death that has a person in fact getting very sick and having at least a few weeks, or maybe a few months in which it's clear that they're really on a decline. There's the course that a person has a known serious illness like a heart disease or emphysema and then has periods of time when they're terribly sick, and they get rescued a few times and then in one episode they can't get rescued. And then the third course is just really dwindling away, just having increasing loss of function, less and less able to get around and take care of yourself, and the small problems as you go, and then finally one of those small problems takes your life. And lots of countries and reformers are developing plans of care that tie to each of these populations.

David Clark: I think the other big challenge that palliative care is facing, particularly in the richer world but it's going to be a problem for most of the world in the decades to come, is that we live in an ageing world. The population is ageing, our lifetime experiences of health and illness are changing, and whereas in the past what we talked a lot about is palliative care for people with cancer, that was the driving force for a lot of the interest on the part of the founders. From there, we move to debate about 'Well how do we provide good palliative care for people who don't have cancer, who have other conditions that bring a heavy burden of symptoms and distress and avoidable suffering?' And there's been a lot of interest in recent years in how to address that.

What we're talking about now is how palliative care can respond to a situation where you have an ageing population, some of whose members will live well till very close to the end of their lives. This is what we all want, that's sometimes referred to as compressed morbidity. You know, dying whilst out at the Melbourne Races, or whilst playing cricket aged 102 or something. But of course some people will not experience that, and then they have quite a long period of time when they are battling with chronic illness, where they are perhaps receiving treatment for cancer at quite a late stage of their lives, and where they face other kinds of problems. They may face problems of poverty and social isolation, mental health problems, depression, loneliness, and so on. And where palliative care really scored in the early period of its development was coming in and responding to the fairly clear and fairly short trajectory of terminal cancer. What is going to be much more of a challenge in the future is responding to the longer, more erratic and less predictable trajectory. And how that is going to play out over time, as the world grows older and as the demand for good care grows, is really a massive challenge to us. Where will the carers come from who are skilled and able and willing to do this work? And what kind of care can we all expect as the century evolves, and as that great ageing population begins to grapple with some of these difficulties.

Keri Phillips: Professor David Clark, who's edited a volume of Cicely Saunders's letters and another of her writings, and intends to publish a biography based on his many interviews with her. She died of breast cancer in St Christopher's, the hospice she founded, in 2005.

We also heard today from Dr Joanne Lynn, Professor Ian Maddocks and the medical historian, Milton Lewis.

The technical producer for Rear Vision today is Jenny Parsonage. I'm Keri Phillips.