

John C. Liebeskind History of Pain Collection

**Oral History Interview
with
Cicely Saunders**

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Biographical Sketch

Cicely Saunders was born in England in 1918. She attended Roedean School and St. Anne's College, Oxford, before completing nursing training at St. Thomas's Hospital Nightingale School in 1944. Forced to leave her nursing post for health reasons, she returned to St. Anne's to earn a degree in public administration and was certified in medical social work in 1947. An experience with a dying patient drew her to lifelong work in hospice care, and she began medical school at St Thomas' in 1951 while working as a volunteer at St. Joseph's Hospice. After earning a Bachelor of Medicine in 1957, Ms. Saunders practiced at St. Joseph's, but her goal was to found a hospice that would combine teaching and research with patient care. Her efforts bore fruit with the opening of St. Christopher's Hospice in South London in 1967. She served as medical Director of St. Christopher's from 1967 to 1985, and since then has held the position of Chairman. She was made a Dame of the British Empire in 1980 for her innovative work with the dying, and received the order of Merit in 1989. She is also a Fellow of the Royal College of Physicians.

Interview History

Dame Cicely Saunders was interviewed by John Liebeskind in her office at St. Christopher's Hospice in London on August 11, 1993. The interview lasted approximately 1.5 hours. The transcript was audit-edited Marcia Meldrum and reviewed by Dame Cicely prior to its accession by the History of Pain Collection. The tape and transcript are in the public domain, by agreement with the oral author. The original recording, consisting of two (2) 90-minute audiotapes, is in the Library holdings and is available under the regulations governing the use of permanent noncurrent records. Records relating to the interview are located in the offices of the History & Special Collections Division.

Topical Outline (Scope and Content Note)

The interview is organized as a loose chronology with several topical digressions. The conversation begins with Dame Cicely's early training and her encounter in 1947 with David Tasma, the patient who inspired her ideas of hospice care. It moves on to discuss her decisions to enter nursing and then medicine; her family's attitude and her Christian vocation; the history of hospice; the origins and founding of St. Christopher's; Dame Cicely's principles of hospice care and patient management; hospice in other countries; her marriage and daily life. Major topics of interest include pain medication for dying patients; the importance of education in hospice; the lack of acceptance of hospice in the United States; and the work of Robert Twycross and Vittorio Ventafridda in establishing WHO (World Health Organization) guidelines for hospice care.

Access to the Interview

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Citation Information

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Related Materials in the *John C. Liebeskind History of Pain Collection*

The reader is referred to the following related materials: oral history interview with Kathleen Foley; oral history interview with Russell Portenoy; oral history interview with Mark Swerdlow.

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Cicely Saunders, DM

Palliative Medicine Specialist

CICELY SAUNDERS INTERVIEW

TAPE ONE, SIDE ONE

JOHN LIEBESKIND: I'll just note for the record that it's the eleventh of August and we are in the office of Dame Cicely Saunders, whom I ignorantly referred to in my letter as Dame Saunders [Saunders laughs] -- someone said that would be like calling him Sir [Charles] Sherrington. I apologize.

CICELY SAUNDERS: That's all right, lots of people do it. And quite honestly, I sometimes do it myself, when I'm ringing up a shop on an order or something like that.

LIEBESKIND: Well, we're not used to referring to people we don't know by their first names, so I think that's the problem, but anyway. Well, I wanted to acknowledge at the outset that although my interest and focus is on the subject of pain, I of course recognize that your purview in the hospice work and so forth is more than simply pain management, it's the management of the whole individual, and I'm very interested in your comments from the broader standpoint. I don't want you to feel that you have to only talk about the subject of pain, or your work in relation to the field of pain. I thought we might begin by just having you identify as you can, what early factors there were in your life and your family and school and university that directed you towards the work that you've done. What could you identify there?

SAUNDERS: Well, I think I had a rather conflicted family and I was pretty unhappy at school; and I was used to being rather unpopular and rather left out, right until I started nursing, when I just fitted like a book into a shelf and was completely happy, and I think it was a feeling of concern for the underdog in a way. I remember, when I finally did become Head of the House at school, I had a concern for people who weren't finding it easy, and when I went up to Oxford, that had been put in the background. I had thought of doing nursing, but [my] family didn't want me to, and I was reading philosophy, politics and economics, which obviously gave me a fairly broad view. But I only had four terms or semesters, I suppose, before war [World War II] broke out and I came down and went nursing and trained as a nurse. But --

LIEBESKIND: That means you left Ox -- you left the university?

SAUNDERS: I left university and went and trained as a nurse at St. Thomas' Hospital. And I had trouble with my back, which I've had all my life anyway; I've had a lot of lying on my back and a lot of remedial exercises and all the rest of it. Anyway, my back finally completely packed up, but I had just got my R.N. So I went back to Oxford and got a war degree in a rather busy year and the diploma in public and social administration, which again gave me a concern for persons. And I had an absolutely wonderful tutor, who was one of the real founders of social work. She remained a great friend until she died in her 90's.

LIEBESKIND: What was her name?

SAUNDERS: Her name was Violet Butler [Christina Violet Butler (1884-1982) was the first female economics tutor at Oxford, and the author, in 1912, of *Social Conditions in Oxford*, the first social survey of the city]. She is a real name in Oxford. She was an Oxford figure -- she used to go about very dangerously on her bicycle, up to an advanced age. But she had the most wonderful, quirky sense of humor and realism about people, without idealizing them, yet with enormous feeling for what potential there could be in the most unlikely places and people. So I think all that was a background which was important, but I wanted to get back into hospital as soon as I could, and having had an operation on my back and a certain amount of time as a patient, I became a social worker, and started --

LIEBESKIND: Now you're both a nurse and a social worker.

SAUNDERS: Yes.

LIEBESKIND: Already multidisciplinary.

SAUNDERS: Yes, that's right; and I started in the cancer department, a particular cancer surgical department, of St. Thomas', back again, because I had already taken an interest in cancer patients, both when I was nursing and as a social work student. In the first ward I took over, there was a patient -- this by now is 1947 -- there was a young Pole, a Polish Jew originally from Warsaw, though not from the uprising in the ghetto [January-May 1943], he'd left before then -- aged 40, with an inoperable cancer. And I knew he had no relatives and very few friends. I followed him up in outpatient; so when he collapsed a few months later, his landlady got in touch with me while he was waiting to go to hospital and I went to see him, and then I followed him and visited him about twenty-five times during the two months that he was dying in a very busy surgical ward. And he was David Tasma, and he is really the founder of the modern hospice movement.

When David died [February 25, 1948], having quietly come back to the faith of his fathers, but not seen a rabbi or anything, he made me his executor and left me this legacy. He said, "I'll be a window in your home", and it turned out to be five hundred pounds. So that's why we have a commitment from the beginning to openness, openness to the world, openness of course to patients and their families, but openness among ourselves, and I didn't realize all of that to begin with, I just had the rather symbolic picture of a window.

But two other things he said, or one [thing] he said and one I knew about him, were equally important, sort of pillars of Hospice, and the first was, "I only want what is in your mind and in your heart." He wanted me to say something to comfort him and I was repeating Psalms, which I knew by heart; and then I said, "Well, shall I read something to you?" and that's how he used that phrase. But thinking about it afterwards, I realized or began to realize that it could mean everything we could offer of the mind, and that would mean research and constant inquiry and constant learning and increase in understanding, but it had to be given with the friendship of the heart. And then when he finally died, I had an absolute assurance -- keen evangelical Christian as I was at that time -- he's safe, it's all right, he had freedom of the spirit to find his own way, and I've never worried about anybody as to which way they found the end of their journey if they went safely. I could commit them in inner peace. And so the openness, the mind and heart

and the freedom of the spirit, were built in hospice [the hospice concept] in 1948, and then it took me nineteen years to build the home around the window.

LIEBESKIND: How did this man know so much? How did he have this appreciation? Was he himself a physician?

SAUNDERS: No, he was working as a waiter. His grandfather had been a rabbi, but he was, as he said, "I'm only an ordinary fellow." But he had a sensitivity -- he told me one or two books that he'd read, which were rather surprising -- and he had a sensitivity and that -- We discussed what would have helped him more than the very busy ward he was in, excellent though his ward sister was. But it was a fifty bed ward; it was huge, and she was certainly busy, and that's why he said, "I'll be a window in your home;" the idea of a home came out of conversations together. But I mean, he was obviously -- I mean, that's a very poetical thing to say, "I'll be a window." He was special, David. I was very fond of him.

So he was the beginning. But I didn't know what to do about it. I had become what we would call a committed Christian about three years before. And at that time, I said, "What do you want me to do?" and I was waiting to find out. So after David died, I was very out of work in the evenings, because I used to go and see him so often. And so I telephoned one of the then homes for the dying, to which as a social worker I had been transferring patients, and said, "Would you like a volunteer nurse?" and so I started volunteering in the evening at this home. And --

LIEBESKIND: This was the busman's holiday, after a day's work of nursing, you volunteer.

SAUNDERS: Well, I wasn't nursing, I was a social worker.

LIEBESKIND: That's right, okay.

SAUNDERS: And when they found I was a registered nurse, I used to find myself in charge in the evening, giving out the drugs and so on. And there I met the regular giving of oral morphine on a -- well, we only went up to 60 mg, which was of course a grain in those days -- but it was balanced to [the] patient's need. It was given orally usually, though [they] did go on to injections, but it was given regularly, it didn't wait for pain to happen, for the patients to earn their morphine. And although I had seen --

LIEBESKIND: This was quite enlightened then.

SAUNDERS: Yes. I had seen oral morphine in the Brompton cocktail mixture given, but I'd never seen it given in this way; and the then matron had arrived there as a ward sister in 1935, and she said it was in operation then, which of course was quite soon after the Brompton cocktail was in fact put together at the Brompton Hospital. But she said she thought it had been really done by the nurses or the matron herself, because it was a nurse's view of pain. Because a doctor will write up something for pain and come back tomorrow and see how it worked; whereas a nurse is up and down and beside the bed all day and wants to see a patient comfortable, not either stuporous or anxiously waiting for the next dose.

LIEBESKIND: I very much know what you're talking about. I do a little teaching of nurses at UCLA and in wandering around giving lectures here and there, speak to nursing groups fairly often, and they're the one group, as a group, that always know exactly what I'm talking about and the importance of the message. Sometimes that's not true for physicians or for other professional groups. You know, their attention is elsewhere. But nurses are always riveted by the discussion of the topic of pain. They really do understand it.

Well, let me understand a few things, because you went over several things quickly for me. So here in the evenings, doing this volunteer nursing work, you came upon -- I expected you to say horrendous conditions that made you realize something. But in fact you came upon very good conditions for pain management -- oral morphine titrated to the individual and so forth. Where did this come from? You attribute it to the nurses -- they had the authority to do that? Because in our country they don't, you see, and they get in trouble.

SAUNDERS: Well, I think the nurses -- they had three visiting doctors, local family doctors at the time I was there -- and I imagine that, when this regime started, a very strong matron, according to the matron I knew, had said, "Why don't we try this?" And if the doctors wrote up "pain to be given as needed, prn, you know -- sorry, *medication* to be given as needed," she said, "Well, it's needed to stop pain ever happening, let's give it regularly."

LIEBESKIND: Brilliant. Again, from the standpoint of my interest in tracing the history of ideas, is this just something that this particular matron came up with, do you know or was she -- was there a group that felt this way, that -- you see what I am saying?

SAUNDERS: Yes. The only other place I met it -- well, I met it twice -- was in, if you remember, [Walter] Modell [(1907-) of Cornell/New York Hospital, a leading American expert on pharmacology and clinical trials in the 1950s-70s] wrote a book on the control of symptoms back in the 1960s. Somebody who was working at, I think, New York Hospital, but it was in New York. He, in writing about pain -- I lent my copy to somebody else and never got it back, so I can't refer it -- but in writing about pain, he said that sometimes, in terminal pain, small regular doses seem to be a good way of controlling it. The other thing was the first time I gave a lecture in our Royal Society of Medicine here, which was in 1962, in the winter, from the work I had been doing at St. Joseph's since '58, by then. [The treatment of intractable pain in terminal cancer. *Proceedings of the Royal Society of Medicine* 56 (1963): 195-197.] A doctor from the London Hospital came up to me and said, "I knew regular giving worked, but I didn't know why before." So here and there were people who had got onto it.

LIEBESKIND: Just on their own, had stumbled onto it.

SAUNDERS: But really, it was simply wasn't published and there were other people writing to say that the best way to get addiction was to give drugs regularly.

LIEBESKIND: Right, that's right. So that was the counterforce.

SAUNDERS: So that was the counterforce. So I never said that I invented regular giving, but I did find it happening, virtually unannounced, and was able to exploit it. So when in due time,

having finished my medical training, I got a clinical research fellowship to look at pain management in terminal pain at St. Joseph's Hospice, which was desperately short of medical input and which were giving drugs on demand, or last thing at night, first thing in the morning, that sort of thing. I was able to, once I had been really accepted by the sisters, which didn't take very long, to institute, with the drugs they were using already, a regular schedule -- that was like waving a wand over the house. One of the sisters wrote to me not very long ago, saying, "I well remember those days and the change from pain-full to pain-free."

LIEBESKIND: Just a miracle, isn't it -- such a simple --

SAUNDERS: It's so simple, and in a way so obvious. But I mean, a lot of important ideas are sort of around, and ideas find people just as much as people find ideas.

LIEBESKIND: That's right. Yes, that's right. You mention medical training -- when did this come about?

SAUNDERS: Well, I started as a volunteer at St. Luke's, which had been founded as a home for the dying poor in 1893, but was then called St. Luke's Hospital and had forty-eight beds for patients with terminal malignancy. Anyway, I started there in '48 and I was working for a very, very interesting thoracic surgeon as his social worker, and I took over some of his medical secretary work and a job that combined the two. We were driving down to a hospital together where he had patients and I was going to catch up on the notes, and I said, "I'm going to have to go back and nurse somehow." And one of the other homes had said, what about trying to be a night sister and see how you can manage with your back? And it was he, Mr. Norman Barrett, who said, "Go and read medicine -- it's the doctors who desert the dying and there's so much more to be learned about pain and you'll only be frustrated if you don't do it properly and they won't listen to you." At that time, 1951, he said, "People have hardly looked at hormones and pain," and so on -- which was very farsighted. And he gave me some help to get into St. Thomas' medical school [in SE London], because I hadn't done science and here I was, by this time, age thirty-three. So I started from the beginning with physics, biology, and chemistry, at the age of thirty-three.

LIEBESKIND: Wonderful. [both laugh] That must have been a challenge.

SAUNDERS: It certainly was.

LIEBESKIND: Going back to another comment you made, you said that at the time that you were at Oxford and war broke out, you were studying philosophy, I think you said.

SAUNDERS: Philosophy, politics and economics. It was a mixed degree known as Modern Greats.

LIEBESKIND: Which college were you in at that time?

SAUNDERS: St. Anne's.

LIEBESKIND: St. Anne's -- my wife is an Oxford graduate from St. Hilda's, which I guess is a woman's college, is that right?

SAUNDERS: Yes. I think it's almost the only one that hasn't gone mixed.

LIEBESKIND: And you said that because of the war, or was it because of the war that you decided that --

SAUNDERS: Oh, definitely because of the war. I decided that this was no place for a girl to be in wartime, but it didn't seem to be sensible just to join the Red Cross. It seemed to be much more sensible to actually do a proper nursing training.

LIEBESKIND: Get some training. So you thought to go into nursing so that you could be available for the wounded and so forth, to work with the casualties.

SAUNDERS: Yes, but you know, well, I mean, it was just nursing generally. And for the first time in my life, I was the popular person. I plodded a bit because I used to have to rest a lot with my back and was a bit diffident to begin with. But I really loved it and there are some patients from those days that I still remember.

LIEBESKIND: This is where you really first --

SAUNDERS: When first I found where I was, and who I was.

LIEBESKIND: You said that your parents were not happy about that.

SAUNDERS: Well, my father said, you know -- he would have liked me to have done medicine then, but certainly I didn't want to do that. I said, "No, nursing it must be," and he said, "Okay, but you must do it properly, you must go to St. Thomas'."

LIEBESKIND: I suppose they saw this as leaving the University to do something else, and probably -- Were they concerned about that as well, that they had hoped that you would stay on at the University?

SAUNDERS: Well, I had had to work quite hard to get in because I spent my first year in the sixth form, or whatever grade it is in the States, doing music, and then I'd switched over. And so I had to work quite hard to get in and failed the first time and got in on the second go. But, no, they were quite good about it actually. And wartime did alter everything. It was much more reasonable to think of doing that.

LIEBESKIND: Yes, that changed everything. That's right. Good. Were there other people or circumstances from those early days that you would say -- I mean, what -- Do you feel it was just sort of your nature that, when you did find nursing, that this now clicked and you said, well, gosh, this is it; or were there formative experiences, would you say, that made it so, that nursing seemed so right for you when you did find it?

SAUNDERS: I don't know that I'm a particularly reflective person. I just got on with it.

LIEBESKIND: How about your finding your Christianity? You mentioned that. That was a bit later, then, was that right?

SAUNDERS: Well, I was searching hard all through the time I was nursing; and then at the time of the surrender of Japan [September 2, 1945], I went on holiday with a group of keen Christian friends and it sort of came -- fell into place and I made a very strong commitment. I've been traveling on ever since; I'm no longer particularly am evangelical, I'm certainly a Protestant with strong Catholic input. My husband's a Catholic. But I'm rather a liberal, I think. But it has been very much a vocation to do something about pain and eventually take up the word hospice, which of course is a very ancient Christian word, although it does turn up in the Hebrew at almost the same time.

LIEBESKIND: Really.

SAUNDERS: Yes. One of the people who's the medical director of a hospice in Israel wrote it out for me in Hebrew.

LIEBESKIND: That's interesting. What is the origin of the word? You said --

SAUNDERS: Well, you go back to the early years of the Christian era, and in Syria and in eastern Mediterranean there were a number of what they called *xenadochia* [as indicated by the name of Greek origin, these were originally lodgings for visitors or the poor, which arose under religious supervision in the 4th century of the Common Era], which were refuges which were meant to carry out what were known as the seven works of mercy, which were to feed the hungry, give drink to the thirsty, clothe the naked, welcome strangers, visit the sick, visit prisoners, and offer hospitality, of course. And Fabiola about the mid third century -- fourth century -- went to visit St. Jerome at Jerusalem and saw all this going on; and realized that in fact Christianity was spreading just as much by the care it was giving to the destitute as it was by its preaching, came back and opened the first, well, she used the Latin word, hospice, in the port of Rome, towards the end of the fourth century. [St. Fabiola of Rome, died about 399 CE] And that was obviously an impossible mix of patients, but very much a stopping place for travelers, for pilgrims. And the word *hospes* started by meaning "guest" but came to mean "host" as well.

LIEBESKIND: The word hospitality, is this all of the same?

SAUNDERS: All derived from there. And *hospitium* meant both the place where they met, but also the relationship between the two, which is a very important part of hospice later. After that a large number of hospices were opened up all over Europe as Christianity spread; and as various orders set up their places, they usually had a hospice, sometimes they called it an infirmary. They welcomed pilgrim travelers, but they also welcomed the sick locals and so on. But they were never specifically for the dying. Then most of those, or a great many, were closed at the Reformation; and certainly they were closed with the Dissolution of the Monasteries in this country in the reign of Henry VIII [1536-40, when Henry, having broken with the Pope and declared himself the Head of the English Church, appropriated most of the lands and wealth held

by the monastic orders]. And there was really nowhere for the sick poor, other than what then were put up as the Poor Law institutions [from 1597]. And there were a few hospices left who tended to become either almshouses for the elderly or travelers, like the St. Gotthard Pass hospice [in Switzerland].

The first person who ever used the word for care of the dying was a Madame Jeanne Garnier in France, who opened Hospice of the Dames de Calvaire in Lyons in 1842. And she opened about seven homes altogether. And one of them, the one in Bordeaux, has in fact turned into a modern palliative care unit. But the others have become very much the sort of rather long-stay chronic care, which has meant that hospice isn't such a very acceptable word in Europe, and palliative care unit is much more acceptable. The next person who picked up and used the word hospice for the dying, the next people, were the Order of the Irish Sisters of Charity, who opened Our Lady's Hospice just outside Dublin in 1879, but with no connection with the Dames de Calvaire. And that was the same order who opened St. Joseph's, which is where I worked from '58 to '65. So that's a rather long story of the word hospice and how it has gradually come to mean "for the end of life."

LIEBESKIND: In this little brochure which I was reading downstairs, it mentions that St. Christopher's is a Christian community, inspired by this Polish Jew, you said about '48.

SAUNDERS: Yes, with a Jewish visitor. Sam Klagsbrun, a Jewish psychiatrist from New York, is our visitor [Dr. Klagsbrun is Executive Director of the Four Winds Hospital in Katonah, NY, and a lecturer at Columbia University]. We had a Jewish chairman for a long time.

LIEBESKIND: So really, what -- ?

SAUNDERS: It's a very ecumenical foundation, but you can be a good atheist in the middle of St. Christopher's, as a member of staff, let alone of course a patient, and not be a second-class citizen. It's a community with a very small "c", and it's -- and a lot of people working here would say, yes, okay, there is a Christian foundation, but it doesn't bother me. But a high proportion of the really senior people have a Christian commitment.

LIEBESKIND: In fact, Pat Wall told me a little story about you in this respect. He said that, I think, the first time he came over -- he wanted to learn something about the hospice care movement and so forth, and you met him and welcomed him and said, "Services are at nine in the morning," or something. He said that was the last it was mentioned. His eyebrows raised, but that was the last it was mentioned. Well, so there's a whole history, then, of the use of the word and of hospice, hospices in all their different meanings, including the care for the dying. What's, well, let me ask it this way -- I was going to say, what's unique about the approach that you've brought to it? How does St. Christopher's work? What's the -- ?

SAUNDERS: Well, I mean, I never obviously said we were the first hospice [St. Christopher's opened in South London in 1967]. What I did say we were the first research and teaching hospice, and took the academic model of putting research and teaching together with care and put it into care for dying people, and that was new. But the idea of home care, care for the family and all the research and the teaching and the way we do it and all the rest of it, I picked

those ideas up around and they developed in my mind. Or I saw patients needing it, particularly when I started being able to discharge patients from St. Joseph's and I couldn't properly follow them up. And I think it's like putting things into a kaleidoscope and you give it a shake and it comes down in a new pattern. So when we started here, we started with thinking of the family as the unit of care. We started doing evaluative research from the beginning.

LIEBESKIND: Especially in relation to pain control?

SAUNDERS: We were looking at what the patterns of terminal care were, what the results of terminal care were, in the locality of two of our local boroughs, and a social psychiatrist set off to do this. I had a grant from the Department of Health to do something in the way of evaluation, to look and see how we were needed and what impact if any we were going to make; and then we did a ten-year study ten years later. We were also going to do drug studies -- it was very important to do the comparison between morphine and diamorphine [heroin], for a start, because I had been using diamorphine at St. Joseph's, I'd introduced it. And I had the clinical impression it was the better drug.

LIEBESKIND: This is heroin?

SAUNDERS: Heroin, yes. I did know we were getting better at everything. And also it's very important to test your own enthusiasms. And if you turn out to be wrong, it's ever so nice that you actually did it yourself. So I had a grant from our Department of Health waiting to do that, and we started both that and home care two years after we opened, in 1969. And of course we found out that there was no clinically observable difference [between morphine and heroin] with a double-blind crossover study.

LIEBESKIND: Right, wonderful. Now, just tracing that a little bit -- you mentioned the Brompton mixture.

SAUNDERS: Yes.

LIEBESKIND: I'm sorry to be ignorant about that -- I had always assumed that was part of your work. That was a separate --

SAUNDERS: No, no. The Brompton Chest Hospital in the early 1930's had a lot of people dying of tuberculosis. And one of the physicians, whose name I don't know -- Mr. Barrett told me this -- and the pharmacist put together a mixture which had morphine and heroin or sometimes both or either, cocaine, alcohol, and at one point they even put marijuana, although I don't think it works orally -- and honey to disguise the taste, and that was the Brompton cocktail. [*Ed. Note:* There were several versions of the Brompton cocktail in use by the 1950s. Its invention has been attributed to Brompton surgeons Arthur Tudor-Edwards and J.E.H. Roberts, but also to Clifford Hoyle ("Hoyle's mixture") of King's College Hospital.]

LIEBESKIND: A little something for everybody.

SAUNDERS: Yes, it was a little; and it was very much for people dying. And of course, some of them had extraordinarily sore throats, and whether that amount of cocaine that they put in was going to have much effect, we don't know, but it would end this coughing. But that's where it came from; that's why it was known as the Brompton cocktail. But one of the things was, we did a study on cocaine and found it really made no continuing difference, so that came out. We took the alcohol out, because some patients didn't like the bite of it. We used the syrup as a prochlorperazine [a phenothiazine used as a tranquilizer and antiemetic] syrup, rather than honey, and so we were left really with the active ingredient only, the oral morphine. So we never call it the Brompton cocktail now, and in fact we didn't call it that from early on.

LIEBESKIND: This study that you did that really showed that morphine was the active --

SAUNDERS: Well, that was done by Dr. Robert Twycross. We had another researcher here for the first year, from '69 to '70, and then sadly he died after a laminectomy [surgery to relieve back pain from spinal stenosis]. And I invited Robert Twycross to come and take his place. So he came up and carried on the work.

LIEBESKIND: Is he still working here?

SAUNDERS: No. No, he moved away from here in '77, I think it was, to be director of a new National Health Service Hospice, or a continuing care unit, they called it, at Oxford, where he still is, and he is Lecturer in Palliative Care at Oxford University, and runs the unit there [Twycross is now Consultant Physician and Reader Emeritus in Clinical Medicine at Michael Sobell House in Oxford]. And he's been around the world and very much involved with WHO [World Health Organization] and their cancer pain relief booklet [*Cancer Pain Relief*, 1986], which I'm sure you know.

LIEBESKIND: Yes, I do. I wanted to ask you about that. That was really the next thing I wanted to get into. I mean, it seems to me -- I'm part of the pain group, I belong to these various pain societies and so forth and go to their meetings. The reason I'm here is, I'm on my way to the World Congress of the International Association for the Study of Pain in Paris in a few weeks. And within the pain movement, I mean, you are an honorary member of the International Association, very deservedly -- within the pain movement and at these meetings, we hear a lot about the WHO program. But it seems to me that, as an idea, that that really derives very directly from the work that you've done here, and that --

SAUNDERS: Well, it derives from here via Robert Twycross, via Professor [Vittorio] Ventafridda [long-time WHO consultant on palliative care, Director of the WHO Collaborating Centre in Cancer Control and Palliative Care at the European Institute of Oncology of Milan] visiting here and then they were both involved with the committee who drew that booklet up. But it's funny, it's better to have the WHO in the medical literature; I mean, when other people start using your ideas as if they were their own, you've really won, although it may be quite difficult to stomach it.

LIEBESKIND: Exactly. There is a phrase for that, isn't there --whatever it is, something about copying someone else is the greatest form of flattery, or something like that. "Imitation is the

greatest form of flattery.” Okay. Now in mentioning Dr. Twycross, there must have been over the years quite a number of people who’ve come through here. You mentioned Dr. Ventafridda - - when was that, when was he here?

SAUNDERS: He visited here just before he set up his pain unit in Milan. He didn’t work here or anything. He came here for a day. And I remember taking him around and I remember -- and I frequently show this particular slide -- I took him into our then very small day center and a lady with very -- pretty high doses of mixture of drugs. I mean, she had deafferentation pain, which of course we all know is difficult and we’re learning more and need to -- anyway, as he saw her, she was drawing a beautiful blue line across the horizon of the landscape she was painting. And I was able to tell him the drugs she was on. And he was so impressed by seeing, here was the example of somebody in which one could really tackle pain as a totality, with all her -- she was quite young -- her social, psychological and other problems, as well as her purely physical pain. And I think Mrs. Hughes probably impressed him and got, you know, under his skin and thus into the WHO more than anything else.

LIEBESKIND: Have you kept up at all with that WHO group? Do you meet with them ever?

SAUNDERS: No, because when -- I was invited to go over when they were setting up that group [the WHO Expert Group on Cancer Pain Relief first met in Milan in 1982]. But I knew I wouldn’t be able to do that amount of traveling and said no; and anyway Dr. Twycross was going to be there and he had been here for about seven years, so he’d got it well under his belt.

But, I mean, I met up with various people. And Professor [Michael] Cousins [Professor of Anesthesiology at the Royal North Shore Hospital in Sydney, Australia] was here when he was President [of the International Association for the Study of Pain 1987-90], and you know, he spent a day, came into our clinical meeting, and so on. I think -- I mean, I take the journal [*Pain*] and I pass it on to our very bright new doctors -- I mean, I’m not, I didn’t do the research, Dr. Twycross did it. I’m not basically a researcher, although I did try very hard and had punchcards of eleven hundred patients from St. Joseph’s and was able to show lack of tolerance and that sort of thing. But that was sort of the groundwork for what we then knew needed to be done in detail. I’m much more the impresario for research.

And I’m not medical director [of St. Christopher’s], haven’t been for some years now. I’m only the chairman, but we have a very bright new young medical director who has got a real interest in research and we’ve got a very good research committee which includes Professor Wall. And we have a research forum and about twenty projects of smaller kinds going on around the house, as well as some work on breathlessness and dehydration and also the use of flecainide [used with local anesthetics, to treat refractory ventricular arrhythmias] and so on for intractable pain, or particularly neuropathic pain, of course.

LIEBESKIND: You mention this study on tolerance. I’m always puzzled by this field and I don’t understand, because it’s such an easy phenomenon to produce in a rat in a laboratory, just give repeated doses of morphine and you can show the tolerance. But I understand that clinically --

SAUNDERS: It doesn't happen.

LIEBESKIND: It doesn't happen that way. It does happen to some patients, is that right?

SAUNDERS: Depends on how you use it, and depends with --I mean, I remember having a meeting -- I was on the Medical Research Council for a while, and we had two or three pain meetings there, and some of them came down here. And somebody, oh gosh, I can't remember his name, some professor had been working on endorphins -- You'd know him, but I can't --

LIEBESKIND: [Hans] Kosterlitz [1903-96, discoverer with John Hughes of the first endogenous opioid in 1975], perhaps?

SAUNDERS: Yes; I'm not sure it wasn't. Anyway, when we were saying it won't cause tolerance, he would say, "I don't believe it. I didn't know it." And we said, "No, clinically, it is true." And if you look at the doses that you give, they just do not escalate, and where they do start going up, it's much more that new situations have occurred, there are fresh pains, more pain. But there are some -- It's iatrogenic if you produce tolerance, I think, by giving lots of doses. Particularly by giving bolus intravenous doses, you can produce tolerance like anything, like you do with rats, but if you use orally and regularly and prevent pain escalating, patients will reach their own optimum and plateau.

LIEBESKIND: I think research will follow clinical practice and finally figure this out. There is some research on it; [Ronald] Melzack has done some showing that, even with a rat, if you give a bolus injection, with pain, in the presence of a pathological pain condition with the rat or something, then you don't see the tolerance as clearly.

SAUNDERS: Well, I mean, pain itself is a strong antagonist to painkillers.

LIEBESKIND: Yeah, that's it. All right. So this Polish émigré died and you were really inspired at that time, but it took a number of years, you said, between what was it, '48?

SAUNDERS: He died in '48 and I just quietly went on as a volunteer in the evenings, reading around. At what stage I read [Alfred] Worcester [prominent Massachusetts physician 1855-1955], *The Care of the Aged, the Dying and the Dead* [Charles C. Thomas, 1935], I don't remember, but I think I was already a medical student. But it was not until 1951 that I thought, no, I really have to get back and get to the dying somehow. And then it was Mr. Barrett who said that was the most important thing, and my father, who'd wanted me to do medicine anyway, was delighted and said don't worry about money, and I never have.

LIEBESKIND: Is he a physician?

SAUNDERS: No, he was a chartered surveyor.

LIEBESKIND: Oh, yeah. Now, it took a while before you could achieve this and to get this place [St. Christopher's] and so forth. What were the processes? What did you have to fight?

What -- you needed money, you needed land, you needed commitment by other people -- that took a long time.

SAUNDERS: Well, I knew I had to do something, but I didn't quite know how to do it. But I knew it was just simply learning. And so then I arrived at St. Joseph's in October of '58, with a clinical research fellowship at St. Mary's Hospital Medical School in the department of pharmacology, where Professor [J. W.] Stewart was doing work on pain. And he had no access to patients and I had, and I could get access to patients in the hospices which I'd been visiting as a medical student. And I'd written about four patients in the hospital journal. My father used to play tennis with Professor Stewart, ran into him at Wimbledon, and they were having tea together and he said, "What's the family doing?" And he said, "Well, Cicely's reading medicine and she's interested in pain," -- "Oh, tell her to get in touch with me." So that's how I got a clinical research fellowship and was able to go to St. Joseph's in '58. In the summer of '59, God tapped me on the shoulder and said: Now you've got to get on with it, on a particular morning reading in June.

LIEBESKIND: This is reading of the Bible? [CHECKS TAPE]

SAUNDERS: Yes, on daily readings, and so I went off on a private retreat to sort of think and realized that I would never persuade people of an idea, unless it was clear in my own mind. Which it was, pretty clear by that time, because I'd already been listening to patients for seven years at St. Luke's and another year at St. Joseph's, by which time I was sort of in charge of patient care as a sort of general physician. So I wrote down a memorandum -- the need and the scheme -- and then that got rewritten and so on over the years, but basically remained what it is now -- and I started.

LIEBESKIND: Right. You had the essential skeleton at that time, is that what you're saying?

SAUNDERS: There was a skeleton of what we had to do. And somebody who, matter of fact was admitted to St. Christopher's yesterday, recovering from arthritis and endless hip operations, a member of our council, was in fact my boss at St. Thomas' [Miss Reed], when I was visiting with David, and she gave me very important introductions and I was able to go and tell the tale. By this time -- I went over to the States for the first time in '63 to have a look and met [Henry K.] Beecher (1904-76) and [Louis] Lasagna (1923-2003) [of the Anesthesia Research Unit at Massachusetts General Hospital] and one or two people like that -- Nelson [Nathan B.] Eddy [(1890-1973), Chief, Analgesics Section, Laboratory of Medicinal Chemistry at NIAMD, and long-time head of the NRC Committee on Drug Addiction and Narcotics], sort of the real doyens.

But between '59 and '63, I read and I thought and I talked and I met up with and a little pioneering group got together and we were registered as a charity in '61. And we got the land through the King's Fund -- it was a grant giving trust [The King's Fund, founded as the Prince of Wales Hospital Fund in 1897, is an independent health charity in the UK]. I couldn't do a big public fundraising thing, because nobody would really have known what I was talking about. Just, it's nuns and, you know, they've no idea of the potential. It was obviously essential to move out from the old charities and out from the Health Service in order to demonstrate what

really could be done. No way was it going to happen with either of them. And between '63, we got the land, and '64 --

LIEBESKIND: From the government? From the -- ?

SAUNDERS: No, from the King's Fund -- it's a grant-giving charity. And that's a fantastic story of coincidences and so on too, but I don't think you want all of that.

LIEBESKIND: I'm fascinated.

SAUNDERS: Well, I'll run it down briefly and say that the King's Fund used to go around visiting places they were supporting, which included St. Joseph's; and I got the job of helping to take them round, and said to one of them that I wanted to do something. And he said, "Well, how do you start?" And I said, "Well, I need a grant for the land." I'd already got the architect for St. Joseph's interested. And so he said, "Why don't you put in an appeal to the King's Fund?" So I drew up an appeal to the King's Fund and put it in, and my brother, who had followed on after my father as a chartered surveyor and estate agent, who was looking for sites. I knew it had to be southeast London.

LIEBESKIND: Why?

SAUNDERS: Because there wasn't anything, there was no home and there was a need; and also the King's Fund had fortunately done a study showing there was a need. Anyway, my brother found this site through a local agent and I came down and looked at it and I rang up the King's Fund and said, "Well, we've seen the site." He said, "How much is it?" I said, "It's twenty-seven thousand pounds." He said, "Well, you'd better put in a bid for it." So I did, with five hundred pounds in the bank. Anyway, the King's Fund committee, of which Miss Reed was a member -- the one who's just come in here --

CICELY SAUNDERS INTERVIEW

TAPE ONE, SIDE TWO

SAUNDERS: "Okay, we will put the project up to the main committee who can give grants of this size;" but they grilled me as to what I was going to do next and who I'd got on the steering committee and so on. And then I -- the architect hastily drew up drawings and we applied to the Town Planning Committee. And both the King's Fund and the planning people were meeting on the seventh of February in 1963. And in my daily reading in *Daily Light* [a Christian prayer and meditation guide], I turned over the page and it said, "Thou shall bless the Lord thy God for the good land which He hath given thee." And at five o'clock that afternoon, I had patients around the hospice praying for us like beavers. And the King's Fund rang up and said, "It's all right, Dr. Saunders, up to thirty thousand pounds to pay for the cost of purchase." So we got the land, so we could do things.

The town planners deferred us and they deferred us a second time; and they still -- we'd only just got the permission, we were negotiating and everything, when I went over for my first trip that I'd already got organized to the States. I got a fellowship because of having been a nurse. And I got something from the Ella Lyman Cabot Trust, whom I met through one of my brothers [the Massachusetts-based Ella Lyman Cabot Trust offers short-term grants to individuals for personally meaningful projects which may benefit others.]

LIEBESKIND: So you were really ready, you were poised, you knew how you wanted to do it, you had these ideas well in mind, and when this opportunity came up, this fellow from the King's trust and so forth, you were just ready to jump.

SAUNDERS: Well, there are two things there. "Chance favors the prepared mind," which is Pasteur, I think, isn't it -- but there's also, I mean, what I felt the Lord had said to me is that "I will give you the opportunities, you have to take them." So it is a phased project. Because to start out with an unknown charity, to raise -- well, it was half a million pounds at that time, which seemed huge in the 1960's, it wouldn't be now, and the money came in from grant-giving trusts. We started with only half the money given and promised, we ran out in the midst of a credit squeeze when we couldn't get a bridging loan -- we kept going somehow, the money came in, we never, we always managed to pay it off, and we opened without debt in the summer of '67.

LIEBESKIND: Did the Royal Family...I mean, I see that Princess --

SAUNDERS: The Princess Alexandra opened us. [Princess Alexandra (1936-) is Queen Elizabeth II's first cousin; she has a lifelong interest in medical issues and philanthropies].

LIEBESKIND: Were you able to get to them early on, reach them?

SAUNDERS: I'd got their...Lord [Francis] Thurlow [a senior British diplomat] had become our chairman of the then Council of Management and he persuaded the Princess, and she said she'd come. Which was an act of faith on her part, because we were very unknown.

LIEBESKIND: Had you written things down that were published, a book, important articles, that you could point to at that time?

SAUNDERS: Yes. I was asked to write a series of six articles on care of the dying in the *Nursing Times* in the summer of 1959. And that was printed as a booklet [*Care of the Dying*. Macmillan, 1960.] in the following year and had a very enthusiastic review in the *Lancet*, and sold about fifteen thousand copies. And I always had that to say, look, we need to develop this, this is what I was able to do so far, but this has got to go on. Then I'd talked to the Royal Society of Medicine, as I said, in 1963; I talked to a meeting and I was printed there and in the *Annals of the Royal College of Surgeons*; I'd been around the country lecturing -- not to raise money, but lecturing -- and I'd talked to the British Medical Association meeting and so on. I just started, and people started hearing that something funny was happening at St. Joseph's, and people started asking me, and that little original "Care of the Dying" was very important.

LIEBESKIND: So it's a gradual thing, it's a process.

SAUNDERS: It was just doing the work, and it was being able to take medical rounds to meet the patients at St. Joseph's, take charitable gentlemen to come and meet the patients at St. Joseph's, showing before and after slides or pictures and showing what could be done. But I remember lecturing in 1966, in Vienna, a pre-Congress colloquium; it was a gerontological congress. And there was a group there around a table, including an American -- they were all gerontologists, several Americans -- and one of the English saying, after I had shown the slides, that stopped those Americans right dead in their tracks. But one of them said, "But this is ridiculous -- these people aren't dying. Something should be done about it."

LIEBESKIND: That's marvelous! Turn them over to the American medical establishment, that'll take care of it. I suppose the general public thinks that great ideas and discoveries and new theories and so forth just immediately take hold, but they rarely do, do they? It seems like they most often have to be repeated and repeated and repeated, and they only sort of gradually --

SAUNDERS: Education is a terribly slow process.

LIEBESKIND: Yeah, very slow.

SAUNDERS: And changing public opinion is even slower.

LIEBESKIND: Yeah; I interviewed John Bonica. He was the first person that I interviewed. He talked about that and how he became persuaded that pain management -- thinking of chronic pain, back pain and so forth and so on -- that this needed to be approached in a multidisciplinary manner; and he started preaching that shortly after the Second World War and that it really has taken an awful long time and it's still a process which is only gradually being accepted. Well, education takes a long time. Because it's not just the transfer of information, it's not just putting

knowledge and ignorance in the same room together -- there are attitudes, aren't there, there are beliefs that act as impediments, I suppose, to understanding, to learning. What -- Do you see it that way? What do you see as the major impediments to convincing others? I mean, the hospice movement has been enormously successful, and it has gained widespread approval; but it's not all the way there, is it?

SAUNDERS: In the States it's much less medically respectable than it is over here. I mean, it hasn't been accepted by the great bulk of medicine in the States, I don't think, from what I keep hearing. And it doesn't have enough medical input. The first of the modern hospices there was with a doctor who went from here, after a joint appointment between here and St. Joseph's, to a group I'd been meeting with in Yale from '63 onwards; and Florence Wald, a nurse [b. 1916, Wald was Dean of the Yale School of Nursing 1958-1967], and Ira Goldenberg, [an oncology] surgeon [b. 1925], and Morris Wessler, pediatrician [opened the first modern US hospice in 1971]. And it had plenty of medical input then, but they [hospices] then got picked up with less and less medical input. But Bill Lamers in Marin [psychiatrist William Lamers, Jr, established Hospice of Marin (County, California, near San Francisco) in 1974] -- Of course, Elizabeth Kübler-Ross [1926-2004, Swiss-born University of Chicago psychiatrist who wrote the groundbreaking book on the stages of dying, *On Death and Dying*, in 1969] did a huge amount of public relations for the dying, but in a way hampered it by making stages and things which I think were on the whole a bit of a pity, and that also got up the noses of the medical establishment.

But the way it got over to America were three groups. First of all, there was the New Haven group [Wald and colleagues], which started home care with no backup beds. Then a chaplain came on a sabbatical from St. Luke's [Hospital], Amsterdam Avenue, New York; he was at Memorial Sloan-Kettering [Cancer Center in New York] when I went there in '63, and then he was at St. Luke's -- and he went back and they started the first hospital support team, a peripatetic team with no backup beds at the end of '74. And also in '74, Balfour [M.] Mount, a surgeon from Montreal, came over and he did a sabbatical here, and he went back and set up the first palliative care unit [at the Royal Victoria Hospital; Dr. Mount, b. 1940 and trained as a urologic surgeon, is currently Flanders Professor of Palliative Medicine at McGill]. It was he who put the word palliative care into the scene.

So those patterns, the independent hospice -- and there were others starting up in this country by that time, the home care team, the hospital support team, and the separate unit or ward in a -- and particularly it was important -- in a *teaching* hospital with Bal -- were established by '75. And then there was a terrific upsurge. Home care started really going like anything -- I mean, it was our home care team that very few others -- no others, except then later St. Joseph's took it up, and then the Cancer Relief Macmillan Fund spread Macmillan nurses all round the country. [The UK's Macmillan Cancer Relief Fund, a private charity founded by Douglas Macmillan in 1911, provides practical and supportive care to cancer patients; the first "Macmillan nurses" were funded in 1975.] Palliative care is a more accepted word worldwide than hospice, and I'm perfectly happy -- it doesn't worry me.

LIEBESKIND: A rose by any other name --

SAUNDERS: "What's in a name?", as I wrote in the first number of *Palliative Medicine*, which is our journal over here. But we have a hospice information service that is here and we're in touch with people who are --

LIEBESKIND: Yes, I read something about that in this booklet.

SAUNDERS: -- pioneering in about sixty countries. So we keep a hospice directory. There's the hospices in this country [shows the list]. But we also do an overseas directory -- I think it's - - (take that book to the other room) it's in -- as I say we've got contacts in sixty countries. Some of them are thriving, some of them are just trying.

LIEBESKIND: Is there an organization of hospices? If a hospice were to open in South Africa or Germany or wherever, how would you know about it? Would they contact you? Is there a --

SAUNDERS: They'd be quite likely to contact St. Christopher's --in fact, both those two countries have -- and we've been out lecturing in there and so on. It was a good multiracial hospice in Capetown for years now [St. Luke's Hospice founded 1980], with a doctor in charge [Christine Dare] who had actually trained here. In Germany -- we've had various people over from Germany, and there are quite a number of groups functioning, but it's quite difficult in the medical establishment there to really get going. There is an overseas -- I can't remember what it calls itself -- useful addresses at the back here -- at Oxford, with Robert Twycross involved [British Aid for Hospice Abroad] -- and they go out and do talks overseas or run conferences and so on, which is very useful. But a lot of people would get in touch with us actually as a start, which is why we happen to have -- I can't find the address, the proper name, but there is, most countries gradually turn up with a national hospice organization of some kind.

LIEBESKIND: And they certainly know about you.

SAUNDERS: I have slightly ambivalent thoughts about the American one.

LIEBESKIND: Please explain that.

SAUNDERS: The American hospice scene has been more a consumerist movement and more anti-technology and so on than we've been, and I think they drew up standards. They started a bit early and they kept saying Hospice has come of age when it really hadn't -- needed to get its act much more together. And although there are some excellent units in the States, and there are some very, very good people and some superb nurses, but it is much more nurse-run than doctor-run -- not that I'm against that per se, for heaven's sake, I'm a nurse anyway. But I think it has a -- I mean, I was talking to somebody quite high up in the -- the International Hospice Institute had a meeting in London and I talked to that, and Jo Magno is very involved with that. [Josefina B. Magno, a Philippine-born physician (1920-2003), organized the International Hospice Institute in the US in 1984; the organization has since been renamed the International Association of Hospice and Palliative Care.] And they were saying, you are constantly talking about research and continued learning; we never hear about research in Hospice in the States. And where there is research, it is much more likely to be psychosocial. I think clinical research isn't easy in our situation, I'm not disputing that, but it's very necessary.

LIEBESKIND: Exactly. You absolutely have to know the effect, you know, that you're producing.

SAUNDERS: And one of the things you have to look at is, what is meant to be received wisdom, like, we don't need oxygen for breathlessness, we have been looking at that -- like, we don't need to put up drips because dehydration is not a problem -- we've been looking at that. And you need to look at what is received wisdom and really look at it again.

LIEBESKIND: Yeah, exactly. Well, I think you are like your colleague, Professor [Patrick] Wall, in that respect. That was a theme that came up a lot as he and I talked about his research career and how he has never been one to receive wisdom very gladly. He said that you were the same in that respect, so he obviously admires that in you, a questioning mind.

SAUNDERS: I think what -- why St. Christopher's had such an impact is that it put together a spiritual concern with a good hard-nosed medical outlook and wanting to make real scientific foundations as well, in our case, a Christian foundation. But in a way we are a spiritual foundation in a much wider way. Spiritual is much wider than the purely religious, and our chaplain is particularly good and sensitive in talking that way. I was part of the National Hospice Council, giving evidence to the House of Lords Select Committee on medical ethics, and one of the members said, asked me, "When you started out, there was a strong spiritual component of hospice -- how do you teach ordinary doctors and nurses to approach spiritual issues?" So I was able to say, "Well, first of all, by pointing out that the purely religious, to which they may have no commitment, is not the same as the much wider spirit, and what people are asking for is not answers, but the response of listening, and while they make their own searches." And that's what we hope -- that we're still searching ourselves to know more, and therefore create a climate in which patients and families will make their own particular search.

LIEBESKIND: Yes, that's very well said. Going back to this issue of learning and the difficulty that people have in accepting things -- do you have a sense at all of what the factors are -- what are the components about the hospice movement that have been so difficult to accept? Why is it that -- ?

SAUNDERS: Well, I mean, Hospice does suffer from very quickly getting a halo from families because they've seen a patient change so completely. And Hospice, when media come and take films, they are amazed and they tend to get something which has rather got the halo effect. That makes people say, oh, well, hospice is elitist and that gets, you know, is counterproductive. Okay, it may be productive of a lot of public giving, and Hospice has an enormous amount of public giving. I mean, nearly two-thirds of all that runs the hospices in this country, all the teams and so on and all the buildings, just comes from public giving. The Health Service is saying about fifty-fifty, but we are nowhere near that.

But also -- I think that's one thing. I think another thing is that in a sense, particularly, I think family doctors and oncologists, feel that we're coming in on their preserves. "I've always looked after dying patients perfectly all right, who is this coming in telling us?" And oncologists who feel, like Walter Holland [a British public health physician], we should never give up. And

to give up is tantamount to maleficence. And to realize that there is a real alternative between voluntary euthanasia, physician-assisted suicide on the one side, and frenetic behaving as if the patient were still curable on the other. There is a way in the middle, and it is perfectly respectable, challenging medicine and nursing and all the other disciplines. I mean, we've got an excellent physio [physical therapy] department here, a fascinating occupational therapist and a very strong chaplaincy department, and they're all needed, but they're all part of it -- and holistic medicine, which is a phrase I don't like, but it's, I suppose, what we're talking about.

LIEBESKIND: Yeah. These terms get surplus meaning. Is there anything about the medical establishment, the way physicians are trained in this country as opposed to -- and I'm not a physician, so this not is a rhetorical question -- as opposed to the way they're taught in other countries, for example, the United States, that would make acceptance of this idea -- for example, you mention the kind of territoriality, a concern on the part of oncologists that, who are these people, you know, encroaching on my territory -- would that be less apt to happen in this country than in the States or in some other countries?

SAUNDERS: Well, oncology isn't quite as strong in this country as it is in some others. The oncologists in Australia are trying to take over palliative care totally themselves anyway as part of their thing. But I think, quite frankly, it was very important that I actually joined them [the physicians]. If I'd started out as a nurse and a social worker --

LIEBESKIND: You would have always been out there.

SAUNDERS: Yes. Whereas I knew, I mean, Mr. Barrett was absolutely right -- go and read medicine. He was absolutely spot on and I'm very grateful to him. And therefore, you see, the Joint Board for Higher Medical Training in this country has accepted Palliative Medicine as a specialty and we are a specialty, affiliated or whatever it is, with the Royal College of Physicians.

LIEBESKIND: Now, take someone like Dr. Kathleen Foley at the Memorial Sloan Kettering [Professor of Neurology and Director of the Project on Death in America]. She's considered an expert in pain management, especially the management of cancer pain. I don't know -- I assume there is not a hospice there, or that she is not working out of a hospice, but --

SAUNDERS: No -- I've met her on two or three occasions and a chap went from here to work with her, our second, no, our third research fellow, Declan Walsh. [Walsh established the Harry R. Horvitz Center for Palliative Medicine at the Cleveland Clinic in Ohio, in 1987-88.] And I read a lot of things that [Russell] Portenoy [now Professor of Pain Medicine and Palliative Care at Beth Israel Medical Center in New York] and the others have written and some of the things that she has done are absolutely superb. I think what is sad in America is that the pain lot and the hospice lot and even now a growing up palliative care lot, don't really meld.

LIEBESKIND: Right. Exactly so. That was my question.

SAUNDERS: Well, they don't. But what Kathleen Foley is doing is very important.

LIEBESKIND: Right. And you would see that as an important segment of a greater level, which is -- I understand.

SAUNDERS: Yes. If we've all got to give up the name hospice and use palliative care, as long as the work happens, you know, I don't mind.

LIEBESKIND: Exactly. Does hospice care always work? Are there patients who are problems?

SAUNDERS: Of course there are. That's what's being discussed by our doctors' clinical meeting at this moment, are the week's problems. Two wards -- there are four wards, one of them closed for rehabilitation at the moment -- have done their rounds by Wednesday morning, and on Wednesday morning the intractable problems, the new problems, or the problems that have been going along, are brought together to the whole doctors' meeting for a very brisk two-hour discussion. There are, usually, there are very complex problems and you will have somebody who has a young woman in her forties who has a family, who has deafferentation pain, who has myeloma, or multiple bone metastases and fractures; who is emotionally absolutely anguished because of leaving kids; her husband has gone off and left her; if she's got teenagers they are creating havoc; and it's that sort of problem that produces the intractable "pain." And it's that sort of problem that increasingly fills our beds as a tertiary referral center, or -- Because we have twice as many people at home as we have in.

LIEBESKIND: Is that right? Twice as many?

SAUNDERS: Oh yes. At least. [Comment from Dame Cicely on reviewing transcript in 1996: "Now five times!"]

LIEBESKIND: Do they get -- I mean, they get the same kind of attention, is that right? Either they've chosen to be at home, or they don't need to be here?

SAUNDERS: Well, most people want to be at home as long as possible. What brings them in is the longer they -- it goes on, the more exhausted their carers are and a lot of them are elderly, of course, and their carers are elderly, or they're daughters with families, and just social breakdown just as much as physical breakdown. But a lot of -- the better you are at home care, the shorter your median stay will be and the more complex will be the problems that come across from hospital; but a lot of people will come in for the end. Professor John Hinton [British psychiatrist, researchers on the care of the dying from the 1960s. *Quarterly Journal of Medicine* 32 (1963): 1-21.] followed every third patient in home care until he had a cohort of seventy-seven, and he found that nearly ninety percent of their time was spent at home and only ten percent of their time was spent in the hospice.

LIEBESKIND: I see. Very interesting, yeah. Are there certain problems that are common, that keep coming back again and again that you could cite?

SAUNDERS: Well, deafferentation pain, neuropathic pain --

LIEBESKIND: Yes, that's very stubborn.

SAUNDERS: -- pelvic pain with fistulae and things like that; and the controlling person who finds dependence almost intolerable and will create mayhem in all sorts of different ways. And it's usually when they produce our problems on a Wednesday morning, they've almost certainly got a terrible social background to them. We also take patients with ALS [amyotrophic lateral sclerosis], or motor neuron disease, and when we've got all the floor wards open we have up to eight -- only six at the moment -- and we take a certain number of patients with AIDS, but we're not tremendously asked for AIDS actually.

LIEBESKIND: Really. You would think that would come. That there would be a parallel movement, or something.

SAUNDERS: Well, they're the wrong age group, although we do have quite a lot of young patients, but we don't have many in their twenties, and an awful lot of them are. There are two specially AIDS hospices in London, Mildmay [Mission] and Lighthouse [both opened 1988], and most AIDS patients want to be at home with partner as long as possible anyway. But we've got a local hostel opening for drug users and we're likely to work together with them quite a lot, and of course drug users are *impossible* patients. It's all their visitors -- you have to have everything clamped to the floor because they just steal everything.

LIEBESKIND: Yeah, I see. [both laugh] You try and keep these places so friendly and open.

SAUNDERS: That's right, yes, and we get pilfering just the same as any other hospital.

LIEBESKIND: Not a police state. I saw a man walk in with a dog this morning.

SAUNDERS: Oh yes, that's common.

LIEBESKIND: Lovely. Amazing. Do you have thoughts about the use of opiates for other kinds of --

SAUNDERS: Well, I think that Kathy Foley has shown that that can be very possible on a long-term basis, yes I do. And I think what we are looking at with morphine for breathlessness -- I mean, people with endstage respiratory disease, some of their physicians are picking up and showing that you can use them. I think if you use opiates properly, they are very good drugs.

LIEBESKIND: Exactly. The intelligent use of drugs. I keep coming back to this -- I'm not sure if we've explored all -- I'm very interested in the impediment to change. In other words, why is it such a stubborn problem? I keep trying to ask people about this and whether it's drugs we're talking about -- well, let's focus on drugs. I mean, there's obviously a great fear on the part of patients, a fear on the part of physicians to prescribe opiate drugs; but when you tell them that they can be used intelligently, that there, if you just do this and keep your eyes open, you'd think they would learn, "oh, okay". No one wants their patients to suffer, no patient really wants to suffer.

SAUNDERS: Yes, but an awful lot of doctors don't bother. As you say, you start talking about pain to medical students, they're not so interested.

LIEBESKIND: No, they're not. A lot of them are not. Some are, but a lot are not. I keep wondering what that means.

SAUNDERS: Other people's suffering is awfully easy to bear. Unless you care, and caring is costly.

LIEBESKIND: Sometimes we joke and we say that what every surgeon should have as part of his training is surgery.

SAUNDERS: Oh, yes. Well.

LIEBESKIND: Did your own back condition, do you feel, and the surgery that you had, I guess, early in life. You were relatively young when you had this. Certainly that must have sensitized you.

SAUNDERS: Yes. I had one of the early laminectomies, actually. I've had a long -- I've had quite a considerable amount of pain. And it only just recently stopped being extremely painful to walk, because I had various injuries in my ankles, and I'm always getting painful tendons that just don't work, and every step has been painful. And getting up at night to help my husband on and off the commode, because he's ninety-two, has been almost intolerable, but that's better again. But I think what taught me much more was the pain of bereavement.

LIEBESKIND: You are referring to David?

SAUNDERS: David, and another Pole along the way, and Mrs. G., a patient who had Devic's disease and whom I visited for seven years, all through my medical student time, and was a close, close friend, and my father, who all three died within a year. And I got my bereavements quite muddled up. But -- And you know, an awful lot of patients you get very fond of. But no --

LIEBESKIND: How does that affect you?

SAUNDERS: Not now, because I'm not daily on the wards. But --

LIEBESKIND: But if not for yourself, if even for the people who work here, who spend their lives working with dying patients. Is that not a very difficult trip for them -- are they built differently, so that they can --?

SAUNDERS: They are ordinary caring people who are prepared to open themselves quite a lot. There are ways of finding rewards in seeing what patients achieve. If you see a family reconciled, if you see somebody become peaceful, if you see the purely effectiveness of your symptom control, these are all very rewarding. People like working in hospices. You never have trouble filling vacancies. There are plenty of people out there, I mean, who say, "I want to

come and learn and perhaps I'll go back;" but we have an awful lot who stay. We have a lot of young married nurses. We've run a nursery since the beginning.

LIEBESKIND: Yes, I saw that. That's -- What a wonderful thing to have in a place like this.

SAUNDERS: And we've got a nursing home wing for the elderly, with priority for our dependents that end.

LIEBESKIND: Do the children in the nursery, I assume, have some interaction with --

SAUNDERS: Not very much. But they do a little, yes.

LIEBESKIND: That must be very rewarding for some of the patients.

SAUNDERS: Not as much as they used to. We used to have them running all round the whole garden. Now they've got their own special place, which I quite see why our nursery coordinator - manager wants to do it that way, and I've accepted it, but --

LIEBESKIND: I think, if I were in my last days, I would like to hear the sound of children.

SAUNDERS: Well, people see their own children a lot. I mean, a lot of children visit. And we have, as you saw, those children's drawings in the front. And there's a special playbox and things in the family room, and there's a children's corner in every ward with books and puzzles and toys and so on.

LIEBESKIND: You said people want to work here, but I would think it might be that they would be afraid to work here, but once they come here, then they find they like it.

SAUNDERS: Well, they get here. They still get here.

LIEBESKIND: They still get here, so they must have heard.

SAUNDERS: They hear by word of mouth. I mean, there are some people locally -- oh, this lovely place, but you only die there, oh, how could you want to work there, it would be so depressing. But there are far more people who say, you've no idea, it's so alive. So we have open days and family fun days and things like that.

LIEBESKIND: I was just going to ask that. Open days, is that just for the community? They don't have to know anyone here to come in.

SAUNDERS: No, no.

LIEBESKIND: Just to see it, part of it.

SAUNDERS: Yes.

LIEBESKIND: Yeah, I can see where that would be very important. Pat [Wall] emphasized, again we talked a little bit about this, that St. Christopher's and really, I guess, all of these hospices, are kind of community-based and that that's an important part of it -- that some wealthy chap from up north country, whatever, just can't buy his way in.

SAUNDERS: Oh no, no.

LIEBESKIND: You have to be from the community, there's an admissions committee and so forth -- even Dame Cicely Saunders can't just admit someone here, it has to go through the committee. But that also, by being a community-based hospital, you're serving an educational function within the community.

SAUNDERS: Oh yes. And we teach. I'll give you our education program for next year. We teach schools, policemen on breaking bad news, schools and teachers, how to support bereaved children and loss and that sort of thing. We talk a lot in local church groups and wives' groups and all the rest of it. And we talk a lot in schools.

LIEBESKIND: Not just you, but there are other emissaries.

SAUNDERS: Oh, I don't do much of it now. I used to do a lot. I talked a lot in medical schools early on. I'm a bit of a pied piper in getting up and talking, because I'm an enthusiast and because there are always, in every audience of students, there are people who will -- "This is what I've been looking for, it's the first time I've really heard somebody talked about as a person." And we had a student group of the twelve (then) medical schools of London which ran for twenty-five years, and I was one of only two speakers, I think, who was constantly asked for by the students for the whole twenty-one years, until I finally said, "Now, this is enough. My call stops." I handed on to somebody else. I was pulled back for a multidisciplinary one and then for their twenty-fifth, and that was that; and that's their sort of logo thing, you see? [she shows logo]. So I mean it's been student demand. There are a lot of students who are not interested. But there are enough who are. And when we advertise for new young doctors we get plenty of response, and a very good caliber are our doctors here.

LIEBESKIND: When a medical student hears about this and becomes enthusiastic and wants to do this, what track does he follow? Is there one or several tracks?

SAUNDERS: Several tracks, but go and get a further degree, probably general medicine, probably your mentorship, possibly your mentorship [in] general practice, which you really need, you know. And don't think of coming and specializing, until you've got a good lot under your belt, because once you come in here or in any other hospice and start specializing, you'll never go back. Our current medical director has worked very hard across the board, including cardiology and so on, before he actually settled for specializing.

LIEBESKIND: So really you're saying that the individual has to be multidisciplinary in some sense, and to have a broad understanding.

SAUNDERS: Yes. If you want to then go and do some radiotherapy or some oncology, if you want to even do some neurology for that matter, but you know, you really want -- I mean, one of our registrars at the moment has been doing some chest physician -- he's got his mentorship, and he did a year with us, and he's now moving along. One has got a background in general practice and he's going back to that, but with an interest in the local hospice. A new girl is coming in, has just been finishing a thesis, but I can't remember what it's about. We've got a chap who is an orthopedic surgeon, and he's our director of studies and went to Hospice quite late in life. There are some who come across quite late. If you are a young one coming up through, you've got to get a good background in general medicine first.

LIEBESKIND: I think, in our country, just because of the sociology of medicine today, that wouldn't happen as readily, and I think what these chaps would do would be to just go right into anesthesiology or oncology or something of that sort, because they all specialize. That's a real problem. I see the wisdom of what you are suggesting. I think we're going to have to change our system to get back to having some general practice, general medicine specialties or people who have that kind of broad training, before they do something like this. Otherwise they have the blinders on, don't they?

SAUNDERS: But in the several hundred members of the Association of Palliative Medicine, there are people who come from a lot of backgrounds. And that does include the odd anesthetist and so on.

LIEBESKIND: That's right. In Britain today, are there enough hospices? Certainly not.

SAUNDERS: I think there are probably almost enough units -- I would like to see more hospital teams and I would like to see the home care teams with more often a full multidisciplinary backup. But I think as separate units around, we've got knocking two hundred -- that's probably pretty near enough. But you don't want to have a hospice in every next town, because no way are they all going to be supported. But I think it's terribly important that, wherever a patient is, there is somebody nearby who has some knowledge on basic symptom control, for a start. The hospital team, which is not an easy thing to do, is a very important work going forward. But they're being undercut by financial stringency at the moment. I'm very sad about that.

LIEBESKIND: Within your own district here in southeast London, is it, could it happen that a patient would have a need, but not be able to be helped by St. Christopher's because of the volume of work that you already have?

SAUNDERS: We currently take about two-thirds of suitable applications and have something to say to the other third, or maybe they were using us as insurance and didn't need us at the last minute. We look after roughly fifty percent of people dying of cancer in two of the local boroughs. And then we share with other teams in other boroughs. I think most people in this part of London, if their GPs are alert enough to ask for help soon enough, will get it.

LIEBESKIND: There's always that middleman, isn't there? That's so critical.

SAUNDERS: That's right. That's how you get into the -- And also there are families who say, "Well, I don't want him to go to St. Christopher's, he'll know then;" and they still do that, even though doctors are much more enlightened about sharing communication with patients, but a lot of families are still very protective.

LIEBESKIND: Is there one aspect of your work that you feel particularly proud of, or that gave you particular satisfaction?

SAUNDERS: Well, we've got a nice textbook which has come out in its third edition. If you look down the chapter titles, you'll see it's cut a pretty wide span. [They look at textbook; not clear what book this is; possibly *Living with Dying: A Guide for Palliative Care* (Oxford University Press).]

LIEBESKIND: Are these all people who are from here?

SAUNDERS: Nearly all have worked here or are here -- one or two who are elsewhere -- Frances Sheldon, for example, we know quite well but has never worked here. [Frances Sheldon, 1940-2004, social worker who taught and wrote extensively on the psychosocial needs of the dying.] And the [author of the] excellent chapter on anxiety and depression -- she's never worked here, but a lot of the others have.

LIEBESKIND: This fellow Tom West [Thomas West, OBE] is your medical director?

SAUNDERS: He was. He's retired.

LIEBESKIND: I saw his name. Yeah, that's marvelous. So this first came out when?

SAUNDERS: This has only just come out as a third edition. The first came out in '78.

LIEBESKIND: I see. It just keeps being updated and so forth.

SAUNDERS: Yeah, and the next time it won't be me anymore. Although it may be like *Brain*, you know, Saunders' Management, edited by so-and-so -- I don't think so. No, I think the fact is that we are a respectable part of medicine and hopefully that will get good reviews. The fact that there is now an *Oxford Textbook of Palliative Medicine* [third edition published by Oxford University Press in 2003] shows that something has happened.

The fact that a nurse the other day who is moving off to a more senior position -- and a girl that I've met quite a lot, because my husband is in a studio with a girl looking after him at the moment up at the top of the house. And just to the side of that is one of the wards. And the girl who was working on that ward was moving on. And I was just saying goodbye to her and saying, it's very exciting what job you're going to and so on and she said, "Yes, but in a way I'm sorry to be leaving here when such exciting things are happening." And that they should be saying that twenty-six years after, I think that's good. So I'm very proud of our new young team.

LIEBESKIND: Yes. You have a lot of contact with them? Do you come in daily?

SAUNDERS: Yes. I bring my husband in daily, because he's the artist who's done all the pictures and he's a Polish professor of art -- he's my third Pole [Marian Bohusz-Szyszko (1901-1995)]. He's pretty frail now at ninety-two and he falls, so I can't leave him; so he has care assistants with him and we've brought our Polish granddaughter over at the moment and she'll take over. I'll have to go up to say goodbye to my care assistant just before 12:00.

No, I am about. I'm chairman of the Council of Management. I've got fairly good antennae and I've got a brilliant personal assistant, who is on holiday at the moment, who is wonderful at picking up what I need to know. And I meet with the medical director every week, and we, you know, touch base.

LIEBESKIND: What does the future hold for you? Do you see yourself with additional projects coming up on the horizon?

SAUNDERS: Well, I still have to talk a bit against euthanasia and things like that. There was a biography and that's coming out again at the end of the year; and I've just had to write a chapter on euthanasia to go with it, which they wanted to sort of update it. I'm looking after my husband until I see him safely. And then I would like to put together a book on "beyond the horizon," looking at facing suffering and dying from a Christian point of view, although there are Jewish and other things in it.

LIEBESKIND: You have already done that book, you say?

SAUNDERS: Yes, I've got a little on it, a little book that I did. And -- But I would like perhaps to -- I don't know, I find writing interesting but difficult. But I'll probably go on writing. And I'm responding to what is asked of me, is really the simple thing, which is what I've always done. Or trying to.

LIEBESKIND: Do you have any suggestions for me about this interview process? How has this been? Do you feel I've gotten the essential points?

SAUNDERS: You knew what you were after, and therefore I think it's up to you to say whether you got what you wanted. But I think you've got me to talk a lot about how it happened, which to me is interesting. But I think the challenge now for us -- I did give the closing address for the European Association of Palliative Care -- dashed to Brussels and back in a day because I won't leave my husband. Well, I can't leave my husband, he's not leaveable. And the idea was "The History and Challenge", and a bit of the history -- David's three-prong thing -- and then the challenge to really -- symptom control for what? What do you hope you're going to enable the person to do at the end of their life? And I think that needs to be thought of as a constant challenge, because they are challenged to meet adversity and the achievement must be theirs, not ours. We are there as facilitators for what they can do. And I think it's trying to get it across the people, okay, you control pain, you control the other symptoms, you learn more about breathlessness and confusion, even more difficult. But what your ultimate aim is not just to see the pain gone, but to see a patient free of pain doing something.

LIEBESKIND: Right. Which as a psychologist, I take -- have a lot of sympathy with. I'm very interested in behavior, the study of behavior. Well, would you have any final suggestions about who else I should interview? Are there any people that you feel from the standpoint of --

SAUNDERS: Who else are you seeing over here?

LIEBESKIND: Well, that's it for now, I'm just seeing you and Pat on this trip. I'm going to be with all my colleagues at this pain meeting in Paris, but I don't think I'm going to try and use the tumult of that occasion to try and bring people off and interview them. I'm going to interview Melzack in Montreal.

SAUNDERS: Well, talk to Bal Mount while you are in Montreal too.

LIEBESKIND: Do you keep in touch with him?

SAUNDERS: Yes, oh yes, very much.

LIEBESKIND: Melzack speaks about him very fondly, he has done very important work there. I think what appeals to me so much about the Hospice Movement, and the way you've talked, is that it doesn't seem to have boundaries. It is the whole person and all aspects of a person at this time in their life, and what I find troubling about --

CICELY SAUNDERS INTERVIEW

TAPE TWO, SIDE ONE

SAUNDERS: But you have to see pain as a whole experience. I've quoted over and over again the person who gave me the concept of total pain, and that was a lady called Mrs. Hinson in 1963. And I said to her, "Tell me about your pain." Without any more prompting, she said, "Well, doctor, it began in my back, but now it seems that all of me is wrong." Talked about all her symptoms. "I could have cried for the pills and the injections, but I knew that I mustn't and it seemed as if nobody understood how I felt and that the world was against me. My husband and son were wonderful, but they were having to stay off work and lose their money, but it's so wonderful to begin to feel safe again." So she's talked about physical, psychological, social, and the spiritual need for safety, security, to be herself, and that's pain. So I've endlessly lectured, saying it's these areas, and tried to cover them. And that was thirty years ago.

LIEBESKIND: True, that's lovely. That's a wonderful example. So you've been guided by it ever since. I think we've gone through the questions that I have and I feel content with this interview, if you --

SAUNDERS: OK. Yes, I'm fine. Good.

LIEBESKIND: Wonderful. End of interview. Thank you so much.

END OF INTERVIEW