

I'm Frank Ferris, here to talk with you about a most important concept: total pain. Dame Cicely Saunders, who developed a career in medicine specifically to focus on pain management, early in her career developed the concept of total pain back in 1964. She said, "You matter because you are you, and you matter to the end of your life." And she said, "We need to explore the whole experience of what's causing patients total pain."

Her idea was pain isn't just the physiological input-- but that's a part of it, the physical symptoms we experience—but pain also comes from our psychological and emotional reactions or problems to what's going on around us. Is it part of our disease process related to our relationships? Or is it about life and what's happened to us in life? Maybe life hasn't been that easy. Maybe I haven't had the life I hoped for.

She said, "There's more, there's also our social concerns." Am I safe? Do I have family around me? What about my relationships? Are they in turmoil? Is that adding to my stress?

And finally, I'm approaching the end of my life. I'm living with an advancing illness. What about my spiritual, my existential questions or, potentially, even distress? Are these actually the drivers of what's causing me pain? It's not just the inputs that are coming physiologically from my somatosensory system.

In EPEC, we had a chance for a lovely conversation with Dame Cicely Saunders talking about total pain. I'd like to share that with you now.

Dame Cicely Saunders: Well, I had a funny career in that I was nursing during the war, training, hurt my back and had to stop and became a medical social worker. And during the time as a social worker, I realized how much a patient was part of his whole family and how important home was.

But in the first ward I took over, there was a Polish Jew of 40 years who had an inoperable cancer. I was virtually his only visitor for the two months he was there before he died. And we talked together about somewhere that would have helped him rather better than the very busy surgical ward where he was, because he both needed better symptom control, although he didn't have a particularly severe pain problem. But most of all, he needed to sort out who he was, dying at the age of 40, and coming from the Warsaw ghetto, of course, leaving nobody behind, and feeling he'd made no impression on the world for ever having lived in it.

But, as we were talking, he said he would leave me something in his will, he had an insurance. And he said, "I'll be a window in your home." And the idea of openness to everybody who might come, an openness to every future challenge, really stems from that gift which was, I think, the founding gift of the whole hospice movement, made by David Tasma who thought his name would never mean anything to

anybody. That was really the founding, [St. Christopher's] didn't have a name. The home was just a dream, a castle in the air.

I immediately started going as a nurse volunteer in the evenings to one of the early homes to which I had been sending dying patients, as their social worker. And it was there that I found the regular giving of oral morphine, balanced to the patient's need, given regularly on a four-hour basis, and giving patients much better pain control than I'd ever seen before in my years as a nurse or in hospital, where people had to earn their morphine by having pain first. But here, it was constant control of a constant pain.

And I realized that this was a terribly important discovery, which was really obvious in many ways, but simply wasn't being used because there were the two big fears: that if you started pain-killing drugs too soon, they would lose their effect when you really needed them; and also, that patients would become drug dependent. And instead of the pressure of pain, it would be the pressure of longing for the drug. And those were sort of two myths that needed to be dealt with. And after I'd been a volunteer for about three years, I said to the surgeon I was working for, "I'll have to go back and nurse somehow. I must get to these people."

And it was he 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." So, I started medical school at the age of 33, not having done science before, with the idea of doing something about pain.

I think that those two old myths of drug dependence and tolerance have still not really been dealt with, in spite of all the proofs that we now have, the studies that have been made, they haven't got across. I think a major reason is because medical students in a teaching hospital largely see acute pain-- post-operative, post-trauma, post-burn, whatever-- and acute pain is an event and it's got a built-in meaning.

But, of course, patients dying of cancer and other diseases as well, have a chronic pain, a continual pain, and to treat it as if it's an acute event, but it's really a situation in which the patient is held, is completely illogical. You need to give your drugs regularly, you need to give them balanced to the patient, there's no standard dose, and you need to be alert to the whole person, who has the sort of total pain that I recognized when I started in St. Josephs and described back in the early 60s as total pain, with its physical, psychological, social, and spiritual components-- a whole experience for the patient.

I think it's isolation that people fear most of all when they're dying. It's becoming less than a person. It's not still being Mr. A or Mrs. B, who is part of a family, has had a job, has their responsibilities, their role in the world. I think people fear pain, but even more than that they fear dependence, not being in control of what is happening.

And I think palliative care aims to give the patient as much control as they can have in the rest of their lives, by covering, as much as you can, of the pain and the other symptoms, and leaving them the freedom to go on being themselves.

And I think a physician, in his training, is made to look very much at systems and symptoms and ways of coping with them, and less at the patient as a whole person. One is brought up to diagnose and to deal with and hopefully to cure, and it seems to get forgotten that 100% of our patients are in fact going to die eventually.

So often you meet patients who still say that a doctor has said, "There is nothing more I can do." And we don't like staying in situations in which we feel that there is nothing to do. There is a body of knowledge, there is plenty to do. When we look at the whole spectrum of the needs that a person, as part of his family or her family, may have at the end of life, we can be very daunted and feel, "I can't possibly cope with that. I'm a simple doctor. I know how to deal with physical things and that's what I should be doing."

But we're not here on our own. We should be very much part of a team, the nurses, the physiotherapists-- everybody who is involved with this patient is part of the team. And to be able to share is enormously important in this work. If you think, "It's only I who understand this patient and can deal with it," that's a dangerous position to be in. And it may not only be the patient, it may be the family. It may be the child of the family that needs to ask the question to the doctor. And it's very important that when we're thinking of the whole family, we don't leave the children out, because it may make a big difference to the whole of the rest of their lives how they handle the death of a parent or a grandparent or a sibling.

I think the physician has to look at his own sense of meaning of life, and that has to be an involvement at the real depth of what it means to be human. What we're looking at, I think, is the whole area of spirituality, which is much wider than a purely religious practice. It is, I think, the search for meaning, the look at one's own most important values, the feeling of looking beyond yourself and of somehow belonging to something more than you are, be it maybe only your own family network.

But there is something about knowing who you are and looking back on your life and coming to terms with it and being able to lay it down with some degree of quietness, which I think is much deeper than just psychological, and it's something to which I would give the title "spiritual." And I think that is part of man. And to leave that on one side and only look at the body and the physical side is to short-change people. People are more important than just that. And even if you think they leave nothing behind themselves but the memories of those who knew them, it's very important that they should be good memories.

I'm often asked, "What is the first thing you really want to say to somebody going into medicine or moving into palliative care? What is the major commitment?" And I'm sure the answer is simply, "Listen to your patients. They'll tell you. They'll tell you what they need. They'll tell you who they are and what they can achieve."

I think a lot of people over the years have gone into medicine and have perhaps felt hesitant at saying at their interview, "I want to help people." Because it may sound sentimental. But actually, the drive is to make bad things better. It's not new what we're doing. We're picking up a lot of things which are our inheritance. There aren't too many original ideas in the world. You pick up one thing here, another there, pain control here, home care. It's like putting it into a kaleidoscope, and you give it a shake and it comes down in the new pattern. But it's things that are part of being human, and part of being a professional, part of just being a person.

Frank Ferris: So, Dame Cicely Saunders beautifully encapsulates the ideas of total pain. And I'd like to share a patient's story. I met Sarah several years ago, an African American woman. When I saw her, just 43 years of age, she had metastatic colorectal cancer, very significant sacral plexus destruction, and my team within the hospice had been really working hard to control her pain over about six weeks when I took over her care. They had used all of the major opioids and co-analgesics, and she was still reporting 6 out of 10 pain. And she was curled up in a ball in the fetal position rocking when I came in to see her.

She'd had side-effects, drowsiness, and confusion with the medications. They had just not done what anybody hoped for. So, I said to our team, "Let's stand back. First of all, give me a total summary over a timeline of the medications we have given to her. But also, let's explore her life story." And I found it was profound.

When I first did my evaluation, I went into the room, and I touched her, and I kept my hand on her shoulder. She was lying in bed. And over the course of our I'm going to say approximately 45-minute evaluation, I felt her relax into my hand.

I got the story that, in fact, she had a very complex personal history. She had been born out of wedlock. She'd worked on the street. She'd been incarcerated in prison. She was following the pattern modeled by her mother. She had a father, but he hadn't owned her. And she had three sisters, and they hadn't owned her. It was profound.

The next day, having given her a wonderful Comfort Cub, and seeing her quickly grab this Comfort Cub, I went to her bedside and was surprised she actually wasn't in bed. Although her pain score was still 6 out of 10, she was sitting up out on one of our patios, smiling. We had begun to touch her.

What I'll tell you as her story evolves, she continues to constantly hold one of these wonderful teddy bears. She never lets anybody take it out of her hands. We worked closely with her family to actually create some reconciliations. Finally, her father said, "You are my daughter." And her sisters, all three of them, one by one said, "You are our sister." And about an hour after the last reconciliation, she died quietly in our hospice, still clutching her cub.

To me, the story, which was developed by a whole team, really exemplifies total pain. It's not just about the medications, it's not about the physiological inputs, it's about our persona and who we perceive we are as people.

She had been suffering all her life. She was young. She hadn't had the opportunity for the life she wanted. In fact, she had had no attachments. And the teddy bear was the first attachment. It was a bonding experience for her. And over the course of her story, she became attached to her family. And when she finally had a relationship, she let go, and she slipped away onto the next step of her existence.

You and I need to think about total pain in all of our patients and their families. Is it the physical, the psychological, the social, the spiritual? As Dame Cicely Saunders says, we need to help them be whole persons. Even in the face of advancing illness, we need to address their total pain and help them through this process have the capacity to be whole people and realize their full potential.

It's so incapacitating. You can see it requires a complex team to manage it. How do we build those teams in all those settings where we see patients in fact have significant pain? We need to think about it broadly through our healthcare system. I look forward to helping facilitate great stories with our patients and their families.