Health News from NPR

A Good Life And A Good Death: What Is Palliative Care?

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Palliative care is a growing specialty that provides comfort care and that teaches patients and doctors how to talk about patients' goals for life with serious disease and how to prepare for a good ending.
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"He will not die on your watch."

That's what the family of a patient told Sunita Puri when she was a resident in internal medicine. They were chilling words for the young doctor as she took over the care of a very sick man on the overnight shift.

To Puri, the patient, who had widespread metastatic liver cancer, appeared to be dying. She tried to talk with the family about forgoing heroic measures, to let him have peace in his last hours. But they were adamant.

"Do everything," they told her. Hours after admitting him to the intensive care unit, she was overseeing chest compressions to revive him after his heart stopped. "I was blinking back tears," she recalls. The man died that night.

Few people would say they want to die while undergoing painful last-minute resuscitation or while hooked up to machines in a hospital. Yet it's the death many Americans end up with. Now a palliative care doctor at the University of Southern California, Puri is fighting for an alternative.

In her new book, *That Good Night: Life and Medicine in the Eleventh Hour*, Puri writes about how palliative care specialists are working to change medicine from within — teaching other doctors how to talk to patients about their hopes and fears, not just their disease and treatment. Palliative care, she says, gives doctors, patients and their families a new vocabulary with which to talk about the way life's goals can shift when you have a serious illness and how to plan for a good final chapter.
We spoke with Puri about the field of palliative care and what patients need to know.

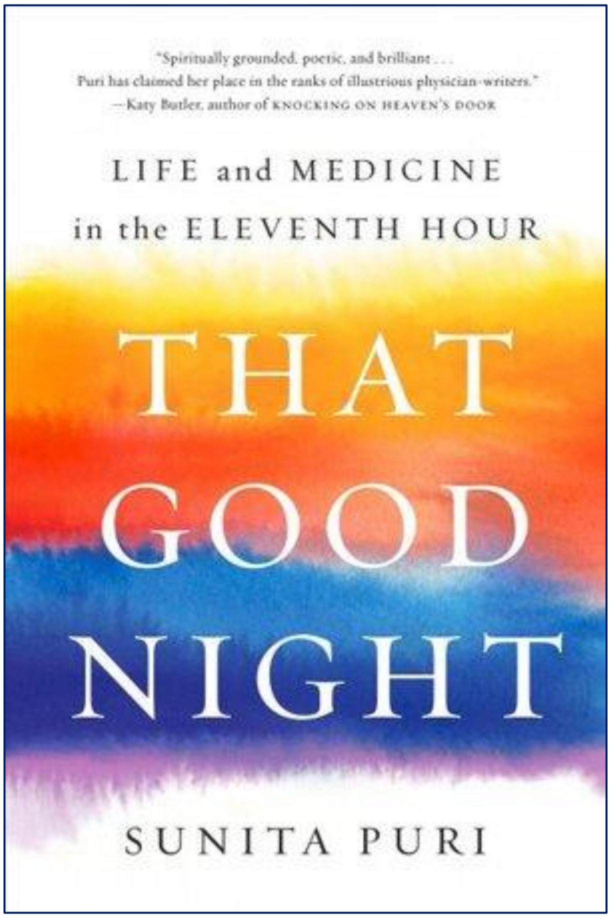
This interview has been edited for clarity and length.
What is palliative care, and how is it different from hospice?
Palliative care is attending to the physical, emotional and spiritual suffering of patients and families who are dealing with a serious illness. Hospice is a type of palliative care that we provide in the last six months of life. And I would say hospice is even distinct from end-of-life care, which is really the care of patients in the last days and hours of their lives.

In our country, hospice is overwhelmingly provided in a patient's home or in a nursing home, whereas palliative care is available at any stage of an illness. And so we can see people in the hospital; we can see people in clinics when they come to see their oncologist or their cardiologist. With palliative care, you can have us on your team just right alongside care like chemotherapy or dialysis — we're meant to attend to your quality of life. And in an ideal circumstance, we will be there when you decide to transition to hospice.

How common is it now to have palliative care specialists available?
There's actually very few of us, and many of us are concentrated in the big cities. So in rural areas or in nonacademic teaching hospitals, there's definitely a shortage of palliative care docs around the country. Our presence and the need for us is growing though. So for example, the American Society of Clinical Oncology now has a recommendation that at the time of diagnosis of a serious illness, palliative care should be involved. Patients with a serious illness can ask for

a consultation with the palliative care team if their other care providers don't bring it up, either in a hospital or a clinic setting.

We have studies that show that for patients with, for example, metastatic lung cancer, if they got palliative care right alongside their cancer treatment — as opposed to just getting cancer treatment alone — the patients actually lived longer and had better quality-of-life scores.



That Good Night

Life and Medicine in the Eleventh Hour

by Sunita Puri

Hardcover, 301 pages

What other advantages does palliative care offer?

I think the emotional and spiritual aspects of it are actually some of the most important supports that we can offer our patients.

One thing my patients tell me a lot is, "Thank you for listening." And I think there is something about our field — focused on being silent and listening to people — that is deeply therapeutic for the vast majority of my patients. To say, "I'm going to be with you through this whole journey, no matter what the outcome with your treatment, and work with your other doctors to make sure we're all on the same page about what therapies may or may not actually be helpful to you in the way that you define helpful." I think there's something pretty magical about that.

You wrote that when you found palliative care, you were finally able to become the kind of doctor you wanted to be. What did you mean by that?
I grew up the daughter of an anesthesiologist — she was always my first model for what a doctor should be. My mother is very technically skilled, but she is also deeply devoted to the idea that every human being is kind of an embodiment of the divine who she felt she was in service to. So, she really had this beautiful intertwining in her practice of being very scientific but also being very spiritual — being able to take people to the operating room and control their physiology to get them through an operation but also understanding that the body and nature has its limits.

And that's what I wanted to be: somebody with the technical and scientific command of medicine but who understood that every human life is different from the other. In my medical training, there were so much focus on the technical and scientific aspects. But as I was learning those things, I was not also learning how to talk with someone who has a serious diagnosis. How do you explain to them how their life might change? How do you ask, if this is not something that we can cure, "What would be really important to you in the time that you have?" And this language was not given to me in medical training.

When people get a diagnosis like cancer, they sometimes talk about "being a fighter" or "fighting the disease." Why do you find that kind of language problematic?
When we think of disease as a battle to fight, you kind of divide people into winners and losers — which is not a mentality I think benefits them.

What's dangerous is that when we're talking about a fight, if someone chooses not to "continue to fight," then people will often tell me, "I feel like I'm giving up." I have to reframe that for them to say, "You may be a fighter, but your body cannot fight this anymore. Can you hear that distinction between you and the natural limits of your body?" I have found that to be incredibly potent because people can see that this isn't a personal thing.

You know, you did not deserve to get this horrible bout of heart failure, and your not "beating it" is not your fault.

What are the consequences for doctors and for the patient's treatment of using this kind of language?
I think people feel an obligation, if they identify as a fighter, to keep trying any and every treatment offered to them — sometimes without a full appreciation of the risks of those treatments or whether those treatments might keep them in a place they don't want to be, like an intensive care unit, instead of having the opportunity to go home. I think that sort of "fight or give up" mentality is such a toxic binary. And I've seen people suffer tremendously because they felt that if they said no to therapy, that they would be letting other people around them down.

From my perspective, when I was in my residency, when I heard those words, I then felt obligated to offer anything and everything to the patient or family — even when I knew that certain treatments were not going to help them but could very well hurt them. So I think hearing those words almost put a stop to any real in-depth conversation about what someone is hoping for and what realistically we as physicians can offer them to fulfill those hopes.

I still regret the ways that I offered therapies to patients that I knew would not be in their best interest. But I didn't know how to talk about another way when I was in my training.

What kind of therapies might be harmful or not be in their best interest?
Being in a clinical trial is one example of a therapy people often feel they need to take but may not truly be in their best interests if it, for example, requires them to uproot their life and go elsewhere. Or if it has side effects that we may not really know about, because part of the trial is to figure out what the toxicities are.

And the other scenario I've seen is people in the ICU with an overwhelming infection or a set of post-surgical complications, and they're suffering one complication after another, especially if they're elderly. And we can keep trying to manipulate their physiology, using very powerful medications and machines, but we're not always as attentive to what someone's life would actually look like if we were successful in reversing some of the problems that they're going through.

So when a palliative care team is involved and you have these kinds of difficult discussions early on in a serious diagnosis, what can a good outcome look like for the patient?
The advantage of getting to know people and their family early on when they first get a diagnosis is that we can really help them through their treatment. To think about and articulate what's most important for them if a specific treatment doesn't work or if it takes a huge toll on their quality of life. And when we can have those discussions, then a happy ending might be that they have their pain, their shortness of breath, their nausea, all of those things exquisitely well controlled. And they decide on their own terms when to transition, for example, to hospice.

When I was a hospice doctor, I think the best situations were when people were still able to be themselves and participate as much in living as they could — even though their bodies were failing. They could still be cognitively intact. Their symptoms were well controlled. They were in a place they wanted to be in. They were living their lives on their own terms for however long they had. And that to me is what a good ending can look like.

Even other doctors don't always understand what palliative care is or embrace it. What do you think the obstacle is?
I think doing what we do in our field is a little bit of the rejection of our culture's idea of what medicine exists to do. I think the public thinks of doctors as heroes that can beat diseases and

extend lives. And in many important ways we are heroes. Surgery is safer. Childbirth is safer. We've eliminated certain infectious diseases almost entirely because of vaccines. But I think we are not good at knowing what to do when we can't fix a problem.

For patients who have a terminal diagnosis, what advice would you give about how to decide whether or not to opt for some of the more extreme life-sustaining measures, like going on a ventilator or a feeding tube?
In planning ahead, I always encourage people to think about the quality of life that they value. What are the things that they would be OK not doing? And what are the things that if they couldn't do them would make their life extremely difficult — maybe even not worth living? And if people can think about their values and their goals in broad strokes, the broad strokes can help inform the more specific question about CPR or a ventilator.

I encourage families to really look to their doctors to guide them. And to say, if there's a question about going on a ventilator, "Is this for a reversible condition, as far as you can tell, doctor? Or am I taking a gamble, a big enough gamble that he may be stuck on the ventilator forever, and then I would have to make the decision to stop? Tell me more about that." I think being able to ask your doctor openly and not feel alone in making some of these weighty decisions is extremely important. So there are those two components of it: thinking yourself, "What is the sort of life I value? What would be a life that would be too hard for me to live even with the help of medicine?" And to talk to your doctor, even if you're healthy right now, because you want to prepare for the storm.