Talking About Living With Those Who Are Dying

Palliative care physician Justin Sanders '00 brings compassion and clarity to the seriously ill.

At age 21, during midterms at Haverford, **Justin Sanders '00** received a call that changed his life. A childhood friend who had been suffering from a serious illness was close to death. He flew across the country and was with her for the final hours of her life. Sanders, who already had planned on going to medical school, became fairly certain he would specialize in palliative care.

He traveled the world after graduating, including time at a hospice in Calcutta, helping feed, bathe, and give medicines to patients. "It was very routine in some ways and taught me that caring for the dying is like caring for the living," says the art history major. "You're trying to help them get as much out of life as possible."

Now married and the father of two, Sanders earned his medical degree at the University of Vermont, followed by a master's in medical anthropology, and completed a palliative care fellowship at Harvard. Formerly an attending physician in the Psychosocial Oncology and Palliative Care department at Boston's Dana-Farber Cancer Institute and the Brigham and Women's Hospital, he recently accepted a position in Montreal, as chair of Palliative Care McGill, an interdisciplinary network of clinicians, educators, researchers, allied-health professionals, volunteers, and support staff working together across five teaching hospitals. Sanders spoke with journalist Anne Stein about palliative care's open-hearted, human-centered approach to terminal illness and death.

Anne Stein: What is palliative care?

Justin Sanders: It's specialized medical care focused on quality of life for people with serious illness. It's appropriate for people at all stages of serious illness. Serious illness is a health condition that carries a high risk of mortality and either negatively impacts daily functioning and quality of life or excessively strains caregivers. [Palliative care] grew out of the late 1960s hospice movement that started in the United Kingdom.

AS: Is palliative care's main focus on death and dying?

JS: People have this strong association between palliative care and dying, but it's really about enhancing the quality of life throughout the course of a serious illness. It's a subtle but important distinction. Palliative care strives to ensure that the treatments people get align with what matters most to them. We'll ask, "What are your most important goals?"

Palliative care reflects the notion that people have priorities in life besides living longer. Medical care typically operates as if that's not the case Medicine doesn't generally act that way, so, in some sense, palliative care is about humanizing medical care. Palliative care aims to help people live the lives they want to live. If someone wants to be with their grandchildren, for example, we may get them out of the hospital and home with hospice care.

AS: What do you say to patients when you're first called in to talk about palliative care?

JS: All of our focus is on how we can improve their life, managing symptoms and anxieties, up to the very end. We ask the patient what they know and understand about their prognosis. We talk about what we expect to happen over the course of their illness, including—if it's important to them to know—how much time they might have.

We ask, "What abilities are so important that you can't imagine living without them?" "What are you willing or not willing to go through to live longer?" If clinicians model these serious conversations well, families can go home and carry on those conversations with their loved ones in a way that makes a real difference in their care.

We ask what they are most worried about. A lot

PHOTO: VINCENT BOUSSEREZ

"Palliative care reflects the notion that people have priorities in life besides living longer," says Justin Sanders.

of physicians are afraid to ask that because often they can't address those worries, but to be able to say out loud what you are worried about is profoundly therapeutic. If you are able to engage in difficult conversations with people, if you are able to sit with that and respond to their emotion and sit in silence, it sends a message about what you are willing to do as a doctor, which is to go to difficult places with them. They are worried about being abandoned. Our field shows people that we will be caring for them until the very end. As a result, we develop strong relationships quickly with patients and families.

AS: Do you experience grief or sadness when a patient dies?
JS: Oh yes, absolutely! I was always resistant to this idea about never getting emotionally involved with patients. I've never believed that, not before medical school and not now. Our willingness to connect and engage with families gives my work so much meaning. It's an antidote to burnout, and it makes me more effective as a healer.

AS: How do you process grief?
JS: The palliative care team does a weekly "remembrance." Someone reads a poem or book passage that has meaning to them, then we read the names of the people who died in the last week or two. That can be 10 to 20 patients. Then we reminisce, tell stories about what it was like to work with family. We cry. We grieve openly, and it's an incredibly healing and very powerful thing to be a part of. It's something all of medicine could benefit from.

AS: Is there a particular personality that goes into palliative care?
JS: We have a reputation for walking calmly into a crisis. Comfort with uncertainty would also describe people who do our work. You need to make decisions, even when you don't know the outcome. And you have to help other people cope with uncertainty.

AS: How has the pandemic affected your palliative care team and healthcare workers in general?
JS: We are at risk of a tsunami of grief in medicine because of the pandemic. The hardest thing for all of us is that we rely on families very much to be present with people in the hospital. That was impossible during the pandemic, and we all experienced a lot of moral distress about that. Holding up an iPad with a person who's going to die while their family members erupt in tears and you feel helpless to do anything about it is not an easy experience. God bless the nurses who do it all the time. The isolation for families and patients was profound. That's what a lot of us will wrestle with.

—A. S.

My Death

During Labor Day weekend in 1995, **Tem Horwitz '66** *went into anaphylactic shock in the middle of the night. As his panicked wife, Susan, drove him to the hospital from their remote home in the dunes above Lake Michigan, ten miles from the nearest town, Horwitz had a near-death experience.*

After it happened, when what he had felt and witnessed was still fresh in his mind, Horwitz wrote down an account of the experience and its aftermath and eventually turned his notes into a short book, titled My Death: Reflections on My Journey Into Non-Being, *published in 1996. Here are some excerpts from the book.*

As I sat there, my body struggling to breathe, I watched the dashboard in front of me lose its definition. The lights lost their brightness. Everything turned a dark gray, and then black. My body began to feel very heavy. I could feel the weight in the middle of my back. I let everything settle down into my center, not struggling with this feeling of heaviness. I responded weakly to Susan, partly because of the physical state that I was in but largely because I was totally absorbed in the process of dying. My head felt huge and heavy, like a boulder. I felt my body toppling. I could not tell in which direction I was falling.

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Sounds. There was only one sound component of this experience. At what I take to have been one of the stages of my biological death, there was a tremendous roar that came out of nowhere. It felt like I was hearing my body from the inside,