

Palliative care specialist explains how end-of-life conversations help families and patients alike

December 2 2015, by Marjorie Howard

In the late 1990s, Dawn M. Gross was headed for a prominent career in immunology. As a dual M.D./Ph.D. candidate at Tufts School of Medicine, she worked with scientists Allen Steere and Brigitte Huber and was the sole student researcher on a scientific breakthrough that identified the precise cause of an autoimmune reaction in the joints of patients with arthritis due to Lyme disease.

Then Gross' career took a sharp turn. During [medical school](#), she found herself drawn to patients undergoing bone marrow transplants, an arduous and risky procedure. The candid discussions she had with them led her to think about death and dying, and she found working with these patients immensely rewarding.

She decided to become a practicing physician after receiving her M.D. and Ph.D. in 2000. Now she is the attending physician in the palliative care service at the University of California, San Francisco School of Medicine and a member of the board of directors of the Zen Hospice Project. She is also working on a book about the end of life.

She has written extensively about death and dying, and urges her patients to have frank talks with family and friends about the issue. She's spreading the word. The *New York Times* published an essay of hers this summer in which she encouraged doctors to find out what their patients' end-of-life wishes are.

She spoke to Tufts Now about why she changed careers, and what she thinks people should do to prepare for their deaths.

Tufts Now: Why did you make the change from research scientist to physician?

Dawn Gross: I didn't envision myself being a practicing physician. I was going to be a scientist, a lab rat. I was very focused and very curious as a scientist, and as I was approaching my fourth year of medical school, I was looking for a match between my science background and my interest in medicine. My husband, who had already finished medical school and knew me well, introduced me to [bone marrow transplants](#), which are complicated and intense. The science was there, and it's an utterly amazing process involving immunology.

What was your experience during the transplant rotation?

It blew me away. I was with people who had the most profound courage I had ever seen in my life. For the most part, they seemed to be really aware of the life-threatening illness they had been diagnosed with, and they knew they were undergoing a risky procedure to treat it. And furthermore, they were in the hospital, isolated for a long time because of the nature of how transplants were done at that time. You would see the same people in the same room for weeks, if not months, at a time; they couldn't even leave their room and were in complete isolation.

How did this affect your career choice?

The level of trust and courage and the intensity of those relationships were unlike anything I had seen in medicine. I did not expect that. What surprised me, and what I can't really explain, is my gravitation toward

conversations I now realize are called "goals of care." I found myself becoming a black sheep in the field. I started to have conversations with my patients that I'd never seen anyone have.

What were you doing that was different from other physicians?

I would ask people why they wanted chemo or a transplant instead of assuming they did, and talk to them about what it meant, and make sure they really knew. With a transplant, you may never go home again. The way the immune system works is to recognize things that don't belong in your body. No matter how close the match, the body is good at picking up what's different. No matter how hard we try to quiet the immune system, the body can ultimately reject the transplant and kill you. So I became interested in people and how they make these choices. My colleagues weren't having these conversations.

Can you give an example of these conversations?

One husband and wife in particular clearly hadn't talked about it. The husband asked if it would be possible to have his wife, who was undergoing chemo, be admitted to the hospital when the time came for her to die, because he didn't want her to die at home. I looked at the wife and asked her in front of him, "Have you thought about where you would like to die?" He was shocked that I asked the question, and he tried to answer for her. But she said, "I want to die at home." They had never talked about it. It was an epiphany for me to watch this couple listen to each other for the first time, simply because I wasn't afraid to ask this question in front of them.

What else influenced your career change?

At the same time I was talking to people who were dying, my father was relapsing from cancer, and was entering the last six months of his life. I started to have conversations with him and he told me he didn't want any heroic measures taken. While he was in his last six months of life he taught me how to ask questions about what he needed versus what he wanted. He ultimately requested hospice from his primary care physician four days before he died. I still had not learned how to recognize that as an option and therefore had no ability to offer or suggest it even though I knew he was dying.

At the same time, I began to notice how much I actually—and unexpectedly—enjoyed being a clinician and particularly how much I liked having end-of-life conversations that can make a profound difference for people in the moment, which was very different from working in the lab on a question that will likely take years to resolve. It's a time when people are their most authentic. What's essential becomes paramount, and everything else falls away.

How are you getting the word out about that?

I'm writing a book about end-of-life care. It's a collection of true stories about patients I have been honored to care for as well as stories from the last six months of my father's life. I am also creating a live radio program as another way to invite people to engage in these conversations. Everyone has a unique life, and each story is a perspective that allows all of us to find resonance in our own lives, to see we are not alone here. These conversations may seem scary, but they give us our lives, the legacy we give to our families and those we love.

What do you want people to know?

There are ways to approach the end of life that don't have to be scary or

taboo. The legacy we leave people by not having conversations is damaging, creating a burden on families for the rest of their lives, wondering if they did the right thing, wondering if they should have done something else.

Having conversations with people when we are healthy and not in crisis is what gives life meaning. It's not about death at all; it's about what's extraordinary. What's amazing is when people start telling their stories, they are the deepest, richest, most gratifying stories.

What can people do who have trouble talking about end of life?

My favorite tool is a deck of cards called "Go Wish" that facilitates this conversation. The cards have simple phrases that ask people what they want, such as "to be with my family," "to maintain my sense of humor," "to have my finances in order." People then ask questions based on the cards. By being curious, we invite the stories of our lives to be shared. This isn't ultimately about what you want when you die, it is actually about what matters most while you are alive.

For example, one of my favorite cards is "to have family with me." But the next question would be, "Who is family? Do you want them in the house? In your room? Do you want them 24/7? Do you want everyone at once?" You get really specific, and, importantly, it's not a one-time thing that you write down and you're done. It's a lifelong [conversation](#) when we are well, because our priorities change. Your life is not static, so what matters changes.

I often tell [people](#) death is for the living. I never had anyone tell me how it went for them, but I sure as heck know how it went for those who are still here, and that's what they live with for the rest of their lives.

Provided by Tufts University

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