

Med Life with Dr. Horton



# On patient-centred care at the end of life

Jillian Horton MD

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This is an excerpt from a longer podcast. You can listen to the full interview here: [cmaj.ca/medlife](http://cmaj.ca/medlife)

DR. LUCY KALANITHI is an internist and clinical assistant professor of medicine at the Stanford University School of Medicine with special interests in end-of-life care, physician wellness and caregiving. She is the widow of Dr. Paul Kalanithi, author of the No. 1 New York Times bestselling memoir *When Breath Becomes Air*.

The interview was conducted by Dr. Jillian Horton, director of the Alan Klass Health Humanities Program at the Max Rady College of Medicine, University of Manitoba, Winnipeg. She hosts *Med Life with Dr. Horton on CMAJ Podcasts*.

**Jillian Horton:** You advocate for culture change around end-of-life care. What's the problem with end-of-life care now, as you see it?

**Lucy Kalanithi:** I became interested in management of end-of-life care during my residency when I worked in intensive care units and was often trying to talk with families about how to choose wisely, how to proceed with a really ill family member. I began to feel unsure that we were doing the right thing for patients, partly because we lacked the language or cultural permission to be able to face up to mortality and the limitations of modern medicine.

**JH:** I'm wondering how your life experience has affected how you experience the death of your own patients?

**LK:** I think my personal experience in bereavement and my life as a physician reflect into each other, so things I learned as a caregiver and widow help me as a physician, and vice versa.

**JH:** For anyone who hasn't read your husband Paul's memoir, could you tell us about him?

**LK:** Paul was a neurosurgeon at Stanford. Toward the end of his residency, he started to develop a set of ominous symptoms and, ultimately, in the course of a few months was diagnosed with stage 4 lung cancer. He lived for almost 2 years after the diagnosis during which he wrote the manuscript for *When Breath Becomes Air*. We had a baby during that time, and he died in early 2015. The book came out in January 2016. It was on bestseller lists worldwide for more than a year. And it followed Atul Gawande's book, *Being Mortal*, which is about ageing and dying, and how those interact with our medical system. I think there's a yearning for this kind of a reflection.

**JH:** How do we better equip our residents and colleagues to feel more capable having end-of-life conversations?

**LK:** In the 1950s, the usual model for the physician–patient relationship was paternalistic. The next model was like a physician providing a menu: “Here are different options and which one would you like to choose?” The most recent idea is based on values first. It's almost like a pastoral role. What's important to the patient? What are they trying to accomplish today? What kinds of things are most meaningful to *them*? And then the physician can say, “Here are the options, here are the risks and benefits, and *here's* the one I recommend based on who *you* are.” I think that's a really beautiful way to do it. It's not us telling people what to do, and it's not us just throwing a menu at them and sitting there. That role — as an interpreter and guide — is one that makes sense to me.

**JH:** How do you make the case that these skills need to be regarded as core competencies and are not “soft” skills?

**LK:** Substantial research supports that skillful communication and decision-making with a patient has direct impact on quality of care. It's always useful to be able to make a moral case and a business case. And there's a great deal of research and real educational formulations available for clinicians. One that I like is the *Serious Illness Conversation Guide*, which came out of Ariadne Labs and Harvard Medical School. I also love VitalTalk, which is a series of workshops and online videos.

**JH:** You call it “Paul's book.” But you wrote the epilogue. It is your book, too.

**LK:** To me, it's so clearly Paul's book. In the immediate months after he died, I worked with the publisher to approve the edits and supplement some of it with additional writing that Paul had done in other settings. I chose the cover and then ended up doing a book tour at the time it came out. As a physician who's interested in health care values, my voice is part of it. I didn't think I would become a public speaker and that's been a part of my own contribution to medicine in a way that I didn't expect.