

How to Talk About *Death* and *Dying*

BY Christina Frangou ILLUSTRATIONS BY Sonia Roy

My surgical resident husband sat on the edge of a bed at Foothills Medical Centre, wearing a blue-and-white patient gown, an IV tube in his arm. He'd grown thinner in the last month, though he was not yet as thin as he would become.

I rested my head on his shoulder. Our oncologist had just left the room after telling us the cancer found in my 36-year-old husband's kidney and lungs a few weeks earlier had taken hold of his liver, too, causing a blood clot to block the main vessel carrying blood to the liver from his intestines. A devastating diagnosis piled onto an already devastating diagnosis.

We felt exhausted. We'd arrived at the hospital by ambulance near midnight after my husband, Spencer McLean, was seized with pain at home. We felt stunned; we were supposed to fly to Ottawa the next afternoon where he would write his last exam to be certified as an orthopaedic surgeon.

Instead, we were here. Spencer broke the silence.

"I'm dying," he said. His voice broke on "dying."

"I know," I replied. I'd monitored him like a bodyguard for the last two weeks and knew I was losing more of him every hour.

That exchange started an honest, tearful and hard conversation about life and death. In the days following, we talked about what Spencer wanted in his last months, however many he had. His list was characteristically unselfish: spend as much time with me as possible, take care of his student loans, travel to the mountains, earn his fellowship in the Royal College of Surgeons of Canada, and, perhaps, if he had a miracle response to therapy, he could operate again. How contrary from the goals of two months before: a fellowship in California, a baby in the next year, a vacation to Chamonix.

Now we discussed medical goals so specific, they verged on macabre. Spencer didn't fear death, but feared how it might come. He worried that he was at very high risk of dying of a blood clot to the lungs. He feared it would be violent for him and frightening for me. He wanted to maintain his independence to the end. He did not want dramatic interventions to prolong his life.

Until that day, we'd never had a serious conversation about dying. We lived blissfully inattentive to those questions that become critical when death is suddenly overhead: what is a good death? what can you accomplish in the time you have left? what scares you most? We'd talked flippantly about death, and obliquely. We believed we'd have plenty of time. Suddenly we didn't.

As a culture, we are slowly starting to change the way we talk about death and dying. Led by advocates for advance-care planning and writers like *The New Yorker's* Atul Gawande and Oliver Sacks, a growing number of people argue we should not put off these uncomfortable conversations about dying. Just as we plan for and talk about a baby's birth, we ought to do the same for dying. It is, after all, something we will all experience.

Dr. Paul Kalanithi, a neurosurgical resident at Stanford diagnosed — like Spencer — with cancer at the tail of his residency, wrote a book about mortality, *When Breath Becomes Air*, in the 22 months he survived after his diagnosis. (A *New York Times* book reviewer said of Kalanithi, which was also true of Spencer: "By the time he was ready to enjoy a life outside the operating room, what he needed to learn was how to die.")

This paragraph from Kalanithi's book stays with me:

"I began to realize that coming face to face with my own mortality, in a sense, had changed both nothing and everything. Before my cancer was diagnosed, I knew that someday I would die, but I didn't know when. After the diagnosis, I knew that someday I would die, but I didn't know when. But now I knew it acutely. The problem wasn't really a scientific one. The fact of death is unsettling. Yet there is no other way to live."

No one relishes conversations about dying and death. Only 45 per cent of Canadians have talked to their family members about their end-of-life preferences, according to a 2014 Harris/Decima poll. The most common reasons that people gave for not discussing death: not wanting to upset family members, fear of dying, feeling so healthy that talking about dying seems pointless and being "creeped out" by the conversation.

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Our resistance to the inevitable is, in many ways, a credit to the success of medicine. We've medicalized the process of dying. A century ago, death typically occurred suddenly, caused by infections, accidents and childbirth. Today, people rarely die suddenly; we die slowly, little by little. As people age, most will acquire a serious progressive illness that slowly erodes their ability to live well. The medical literature describes three trajectories for patients with chronic illness: cancer, organ failure and the dwindling of capacity that comes with increased frailty. For each trajectory, medicine has become exceptionally good at holding off death. Even cancer — an illness once so quickly fatal that patients were not even informed of their diagnosis — has been transformed into a chronic condition for many. My 36-year-old husband with his 42-day survival is an extreme outlier on the wrong side of the curve.

As death became medicalized, it moved from homes into hospitals. In Canada, 70 per cent of the population receives their end-of-life care in hospital, with as many as 15 per cent of people admitted to the intensive care unit on their final hospitalization.

Dr. Chip Doig, head of critical care at the University of Calgary, talks to patients and their families every day about death. One in five patients admitted to the ICU will die; it is a serious and sickly place. Even after 20 years practising this kind of medicine, Doig finds conversations about dying are difficult, humbling and never standard.

"No two conversations are ever the same because I don't think I've met two people or two families that are ever the same," says Doig in a soft, circumspect style. "I think you have to approach this with a fair amount of humility.

"I do talk about 'dying.' I don't talk about 'passing on' or 'moving on' or use euphemisms. Sometimes people [talk of] 'life support.' I hope life is more than just the machines of the ICU or the heart rate on the monitor ... Sometimes, the language I use is not that we're prolonging life but we're delaying death."

Death, Doig says, "at certain times has become almost a frightful topic, but death is a part of life — a very intimate part of a family or social group. I don't think we should be afraid of those discussions because we're afraid of our own mortality."

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On that first afternoon after Spencer told me he was dying, we met our palliative care doctor, Dr. Brad Hunter. He's a man with an innate ability to be simultaneously serious and cheerful, to move from tears to laughter in one sentence. On particularly tough days, he'd ask us which of his wildly colourful ties we'd like to see the next morning. Options might include the Beatles or the Blackhawks.

In our initial meeting, he told us something we'd later repeat to each other *ad nauseum*. He was sorry we'd been forced onto this path — unfortunately, that was out of everyone's control. What we could control was the way we walked along it. That last part became our family motto for the spring of 2013.

Hunter told us his own story, which made us all cry. He was working as a journalist in 1978 when a drunk driver killed his fiancée, a medical student. That was a big motivator for why he chose to go into medicine and palliative care.

"I don't usually tell people and I don't make a big deal out of it," he said. "But it was obvious to me that you were pretty deeply in love, that you were soulmates. I could feel that. I thought [my story] has some relevance and purpose. Maybe it would help you to know that this happened to me 35 years ago and I'm still here."

Over coffee recently, I asked Hunter how he manages to bring people comfort in a very difficult conversation.

"I've been in those shoes and I know what a struggle it is," he answered. "I know everybody is different. You have to go at their own rate and what are they ready for.

"I try to approach it from the aspect of 'where are they; what do they want to know?' This is their journey, this is their struggle. I'm just another resource. I'm not here to lead your life or make your decisions. I'm here to help."

He described an exercise from a book by Dr. David Kuhl called *What Dying People Want* that medical resi-

dents go through when they arrive on the palliative care service. It's designed to help them empathize with their patients. Residents draw a horizontal line across a piece of paper. The left edge of the paper represents their birth; the right, their death. They make an X on the line to mark where they believe they are in their life course. They write the significant highlights in their lives to date on the side before the X and their long-term goals on the other. Then they're asked to move the X to the end of the line, indicating they've been given a terminal diagnosis with weeks to live.

"That changes your outlook dramatically," said Hunter. "Are you angry? Shocked? Surprised? Pissed? Bitter? What emotions are you feeling?"



"Now you get a sense of what our patients go through. They're no different than you. One minute, you're healthy and happy and you've got plans; the next minute, you're terminally ill."

We discussed the concept of a good death, this seemingly oxymoronic idea that there are goals to be achieved in the way a person dies. Hunter believes a good death is subjective but said there are constants for everyone.

"I have never yet had a family say to me, 'Doc, he was a mean son-of-a-bitch; can you make him suffer?' Never happens," Hunter said. "They always say, 'We don't want him to have any pain.' I get that."

Hunter said that, from the medical perspective, a good death is about achieving a balance between managing symptoms, eliminating pain and controlling agitation, but supporting some interaction between the patient and their loved ones. A good death also includes leaving with a sense of satisfaction about one's death — bringing life to a conclusion. A good death happens in steps, a series of events where things slow down.

"It's like shifting the gears," Hunter said. "You're gearing down as your body moves toward shutting down.

"I always tell people the ears are the last to go. They can still hear you. They can still hear your voice and know that you're present, even though they can't respond. I think a good death to me is knowing that you've had a full life, for however long that life is. You can have a full life in 20 years. You can have a full life in 60 years, 80 years. It's not how long, it's the quality of the time you have."

I told Hunter his words in hospital helped me then, and after Spencer died. I asked for advice on what people should say to someone who is losing or has lost a loved one.

"I don't think it's important what you say. It's more important that you be there," he said. "Just a hand on the shoulder to say, 'I'm sorry. Is there anything I can do for you?'"

"And bring the food. When you're at the bedside hour after hour, you're waiting for the inevitable, you don't look after yourself. Those small things are appreciated."

Hunter added grieving doesn't peak the day of the funeral and disappear thereafter. Grieving goes on for months, years. People need ongoing support. It's been nearly three years since Spencer died, and I agree.

Calgary has been one of the leaders in the province in its approach to advance-care planning. In 2008, the Calgary zone of Alberta Health Services (AHS) adopted a policy designed to encourage patients, families and health-care providers to discuss end-of-life care. Researchers and health-care providers established a program to get adults talking about what health-care treatments they would want, or not want, if they became ill or injured and could no longer speak for themselves.

They established "goals of care" designations — a system of medical orders that allows health-care providers to quickly communicate about the overall focus of care. The goals divide into three broad categories: medical care, comfort care and resuscitative care.



“Putting off trying to plan in the end doesn’t help yourself and doesn’t help those who love you to have peace of mind.” –Dr. Jessica Simon

The program is not just for the elderly and infirm, says Bev Berg, a social worker and manager of advance-care planning and goals of care and the grief support program for the Calgary zone of AHS. “Many of the most contentious circumstances in the courts, particularly in the U.S., involved women in their 20s who hadn’t had those conversations,” she says. “The younger we do that, the better it is.”

Based on the positive response to the program in Calgary, it was rolled out across the province. Surveys show it has led to a marked increase in Albertans talking about their wishes with their loved ones. According to a study accepted for publication in *BMJ Supportive and Palliative Care*, between 2007 and 2013, the percentage of Albertans who recognize the definition of advance-care planning increased by 25 per cent and those with a written personal directive grew by 16 per cent. Today, around 60 per cent of Albertans surveyed said they have talked to a family member or close friend about advance-care planning and close to 40 per cent have a personal directive where they have documented who they would want to speak for them.

Dr. Jessica Simon, the physician consultant to AHS on advance-care planning, is a palliative care doctor who championed the movement to talk about end-of-life care in Alberta. In her own family, she has witnessed angst from confusion over someone’s end-of-life care. Her grandfather experienced a series of small strokes that ended in a large stroke, leaving him unable to speak and to move. Doctors told his children he wasn’t expected to survive, but there were still medical decisions to be made.

“His children struggled to provide guidance to the physicians because they’d never had a conversation with their father around what he would want at that part of his life,” says Simon. “He was a lawyer. He had all of his documentations in place, but the absence of those conversations made it very hard for them to feel they were doing the right thing. I know, 20 years on, my mom still wonders: did they make the right decisions?”

Studies show advance-care planning benefits everyone involved — patients, their loved ones and their health-care team. It’s associated with an improved quality of life of patients, with a decrease in surrogate/family member distress, a

reduced use of life-sustaining procedures prior to death, increased use of hospice and care that agrees with patient wishes. It has also been shown to improve grieving outcomes among the bereaved.

In a randomized study of dialysis patients and their surrogates (the people responsible for making medical decisions when the patient is no longer able), the surrogates of patients who died had less depression, less anxiety and less post-traumatic stress if they’d had an in-depth discussion of advance-care planning with the patient.

Simon stresses that advance-care planning should not be confused with the debate around physician-assisted dying. The latter is applicable to very, very few Canadians, she says, adding what’s important is people make preparations for the inevitable.

“Death is a part of life. It’s okay to prepare for that, just as we prepare for everything else in our lives,” says Simon. “We need to do a little bit of preparation to make sure that we have the best quality of life in that period.”



S pencer did receive his fellowship in the Royal College of Surgeons of Canada. We made one afternoon trip to the mountains. We sat and watched the sun.

On the morning of June 23, 2013, as the city of Calgary was under floodwaters, Spencer told me he wasn’t going to take any more of his medications. I told him he didn’t have to. He asked me not to leave his side, not to run home for my daily shower or go downstairs for lunch. I didn’t. Over the next 24 hours, doctors and nurses came in and out, always making sure his pain was controlled.

He died the next afternoon — peacefully, quietly and surrounded by family.

What you should know

Advance-care planning helps you think about, talk about and document your wishes for health care if you become incapable of consenting to or refusing treatment or other care. There are five steps to advance-care planning: think about what you’d want, learn about your own health, choose someone to make decisions on your behalf, communicate to them your wishes and desires and outline your plan in a legal document called a personal directive.

Things you should ask

- What are your values, wishes and goals for your health care? What is important to you?
- Do you have beliefs that influence your health-care wishes?
- Are there conditions under which you do or don’t want a certain treatment?
- Where would you want to receive care?
- Who would you want to make the decisions for you if you are no longer able to communicate? 🗣️



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