You Are In The Process Of Dying

Last year I sat by my wife's side and held her hand as she died on the day of her choosing

By Don Ayre



In Canada, we generally don't like to talk about death. Even our medical profession is reluctant. And rightly so: Doctors are committed to preserving life, and we wouldn't want it otherwise. But death is a part of life, and assistance in dying is increasingly being recognized as a medical option for terminally ill patients.

It was only a few years ago—in February 2015—that the Supreme Court of Canada ruled it would no longer be a criminal offence in Canada for physicians to assist a person with ending their life, in certain circumstances. On June 17, 2016, the federal government followed up by passing legislation

that details the circumstances in which someone may be deemed eligible.

Each province is responding differently. In Manitoba, specialized professionals, including a doctor, a social worker and a nurse, provide this service under the Winnipeg Health Authority. This centralized team, known as Medical Assistance in Dying (MAID), provides a referral source for medical practitioners who recognize assistance in dying is a medical service beyond the scope of their present practice or who won't participate for reasons of conscience. My wife, Jean, was one of the first 100 patients in Manitoba to use the services of MAID to die with dignity.

In February of 2018, I had taken Jean to the emergency department of our local hospital in a wheelchair, as she was having trouble breathing and too weak to use her walker. The triage nurse took Jean's vital signs, admitted her right away to a private room and hooked her up to oxygen. "The doctor will be here shortly," she said. Jean and I held hands when she left. A young doctor appeared almost immediately. He smiled and introduced himself as he quickly examined Jean. "I want to consult with one of my colleagues," he said. He returned with another doctor, who also examined Jean. The two physicians looked at one another knowingly. Then the first doctor began:

"You are in the process of dying. There are four options: You can keep on going from doctor's office to doctor's office and from hospital to hospital. But obviously, that's not working. You can come into Comfort Care here—and we are arranging that now. Alternatively, you might be able to go home into Palliative Care, once we get your pain and heart medications balanced. It will take some trial and error with close supervision and observation on our part, both here in the hospital and at home, however. A fourth option is Medical Assistance in Dying."

Now it was our turn to look at one another knowingly. Jean and I had talked about this eventuality for some months. We just couldn't understand why

none of the medical people we'd seen weren't as open about it as we were. They were always offering hope.

Jean smiled and looked at the two doctors: "Don and I can relate to what you're saying. We're in our 80s and we know that we're on the back nine of life. I'm close enough to the 18th hole that I can see the clubhouse. We're content with that. So what you call Comfort Care makes sense. But I want to know more about Medical Assistance in Dying also."

We'd known Jean's medical prognosis was critical for almost 25 years, when a cardiologist had discovered Jean's heart murmur was not caused by a childhood illness, but by a hole in her heart from birth. He offered that he could add another five years to her life by open heart surgery, but she felt she knew her own body. The operation to repair her heart, back then, would have been risky and, besides, her heart was managing to function, even though it was slightly enlarged from overwork. Instead Jean opted to see a heart specialist, who prescribed medications to support her heart in its day-to-day work. He agreed to monitor her progress on an ongoing basis. Jean was proud that she had already enjoyed life for an additional 25 years, rather than just the five predicted by the surgeon. But now the past was catching up with us. Her heart was failing.

To make things more complicated, Jean had developed hip problems and was in line for a hip replacement, then ultimately disqualified by the anesthesiologist. Over the years, her heart had become increasingly enlarged. "While the surgeon is doing his work, it's my job to keep you alive on the table," the anesthesiologist had said. "From your records, I can almost guarantee that you'll have a stroke. I'm recommending that you try pain management instead."

To manage Jean's pain, we'd gone from one specialist's office to another. My wife even tried medical marijuana. Nothing had a lasting effect, and her

heart was getting weaker.

Now we had to deal with the inevitable. The second doctor left the room, while the first doctor remained with us to explain the options. He regarded what he was offering as a continuum service, depending on how far along Jean was in the process of dying and how well she responded to medical interventions along the way.

"For now, Comfort Care will give doctors the opportunity of monitoring Jean's medications and the nurses the chance to build her up. She will also be referred to physiotherapy to get her walking again," said the young doctor, who arranged to have Jean admitted into a private room in Comfort Care. We did not think that she would be coming home. This doctor also said he'd make a referral to the MAID team.

Our feelings were, of course, mixed, but Jean took advantage of her private room to invite family and friends and inform them. The room was filled with flowers, and I was able to be there from morning to night without the inconvenience of hospital hours.

Three of our granddaughters were already in Winnipeg, but two of our grandchildren flew in, one from British Columbia, with our youngest great granddaughter, and the other, from Houston, Texas. When our grandchildren were all assembled, Jean discussed the situation openly and distributed her jewellery to each of them, explaining the significance of her choice for each piece.

In Comfort Care, the doctors and nurses carefully administered Jean's

medication for her heart and for her pain, expertly balancing the two. And while in hospital, we received counselling as well and were referred to a volunteer from "Dignity Therapy." The volunteer interviewed Jean about her life, and afterward we received a transcript of the interview. Jean was proud of it and distributed copies to family and friends. A local doctor had discovered that terminally ill patients had benefited from this process. As it happened, Jean rallied. She became strong enough to walk with her walker again and was overjoyed when the nurses said she could be released from the hospital into Palliative Care at home.

Palliative Care no longer has to happen in a hospital setting. Instead, professional assistance, medical equipment and training for the husband or wife of the patient can be provided at home. In our situation, a nurse visited two or three times a week to monitor Jean's medications, and we had round-the-clock access to medical advice by phone. Jean would be transported back to hospital and admitted back into Comfort Care, in case of an emergency.

The services of the Palliative Care staff were focused on the whole person, tending to physical, mental, emotional and spiritual needs. Although on oxygen 24 hours a day and highly medicated, Jean was enthusiastic. She used her nine months of Palliative Care to write her own obituary, plan her celebration of life and visit daily with friends and family. Most important, Jean and I had time to reflect on our lives together and prepare ourselves. Jean would say: "We can't be greedy. Don. We've had a wonderful life together. Our two boys are successful. We have five beautiful granddaughters and four wonderful great grandchildren. What more can we ask?"

Medical Assistance in Dying can be seen as the next step in the continuum of services for patients who are terminally ill. But it is very new—and very revolutionary. And because it's so new, it's not always known to doctors and

patients, nor accepted. Fortunately, the young doctor had already referred us to the MAID team back at the time of Jean's admission to Comfort Care.

We had three interviews with the MAID team, all within the first week of that hospital stay. Jean's first interview was more or less an explanation of how the service would be made available to us, if Jean qualified. We asked that our two sons, Ramon and Anthony, be present for the second interview.

Not surprisingly, our sons came prepared to argue in favour of their mother living longer. But as it played out, the MAID team only confirmed what our sons had already suspected: Their mother was terminally ill and, even with her medication, in excruciating pain. The third interview happened only a few days later. Again, by our request, our sons were present when we learned Jean qualified for assisted dying. It was now up to her to choose where and when.

Jean spent three weeks in the hospital and nine months at home, before the time came to decide. All along, we had agreed Jean would take the lead, with my full support.

On December 18, 2017, two doctors visited at the request of the Palliative Care nurse. They said they could adjust Jean's pain medication. They also said Jean's heart was failing rapidly.

The next day, we talked at breakfast and Jean phoned the coordinator of the MAID team to meet with our sons and us the following day. We were all familiar with one another by now, and the doctor heading up the MAID team hugged Jean, when we got there, and said: "We were surprised and pleased, of course, that we hadn't heard from you sooner." Jean smiled and responded: "It's time."

We settled quickly on December 23, 2017, at 10 a.m., as the date and time when the procedure would be administered. Jean and I wanted it to happen

in our apartment, which meant we didn't have to book a special hospital room. Jean gave our sons a list of 15 people she wanted invited. A few days earlier, she had had a friend bring a selection of new clothing for the occasion. She chose a red top with long sleeves, black slacks, and red earrings to match the top.

On December 23, 2017, Jean sat in her favourite chair in our apartment. The 15 invited family members and friends were present, along with the MAID team. She urged everyone to reflect on the happy time we had all had together and to be grateful. She assured them she was at peace within herself and felt fulfilled. There were tears of course, but also much laughter and happiness, just as Jean had wanted. Jean called each person forward, to speak with them individually. I sat beside her and held her left hand. Our sons sat on the other side of her and held her right hand. The doctor who was to administer the drugs sat on a small stool behind Jean. Jean had asked our granddaughter, Jessica, to sing her favorite song, "Smile"—the Steven Tyler rendition. Jessica sang it a capella.

Finally, it was my turn for a few private moments with Jean. We had already spent the past few days preparing one another, but what happened in Jean's final moments was completely spontaneous. We leaned toward each other to touch foreheads. Jean began the mantra we had written for ourselves some years earlier. It had carried us for the past few years, and we had repeated it together nightly:

"Look for beauty in all things," Jean said.

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"Give from the heart," she continued.

"And be grateful for life itself." I said.

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Then we smiled at one another, even though by that point it was very hard. The doctor from MAID asked Jean again—by way of a legal requirement, as much as a part of the process—whether she still wanted the assistance in dying. Jean said "yes," quietly but firmly. Then we said our last words. The MAID doctor waited and then introduced the drugs into the IV, hidden by the long sleeves of Jean's top—a sedative, an anesthetic and a muscle relaxant. Jean fell asleep, then into a coma and then finally, her heart stopped.

It's been a little more than a year since my wife chose to surround herself with family and loving friends at home and be medically assisted in the process of her dying, and less than a year since our family spoke of Jean with affection to the large crowd at her Celebration of Life at the First Unitarian Universalist Church of Winnipeg. Afterwards, there was the jolting shock of losing a loved one, followed by a period of calm. Then, we began talking among ourselves as a family.

This experience opened up the whole discussion around dying with dignity for us. Through Jean's example, we realized it was alright to talk about death, because it is an inevitable part of life. We saw how important it was to understand end-of-life care options. And we saw how a person who has purpose and is intentional about life can be the same way in death. Jean chose dignity, not victimhood at the fate of a medical process that is often very linear and often misunderstood. In the timing and the details, she was guided by her own sense of peacefulness.

My eldest son, Ramon, has since said a better way to describe what the MAID team provided was a "liberation." Those of us who accompanied Jean in her last months and on her last day agree that it's much more fitting than the very clinical sounding Medical Assistance in Dying.

Over the past year, we all have been questioned by friends and acquaintances, even by medical professionals. How did we find out about MAID? How did we learn Jean qualified? How did we support her? How did we feel afterwards? Almost always, there is an awkwardness. There is a lack of experiential knowledge out of there, of course, and a constant search for the right words to communicate freely. That's why, even though it's still so raw after one year, I write to share our experiences more broadly.

As Canadians, we don't like to talk about death. Yet Canada is one of the first countries to offer medical assistance in dying to patients who are terminally ill and suffering. People need to talk to understand it's a new way of valuing life. The conversation is only just beginning.

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