

ONE FAMILY'S EXPERIENCE WITH MEDICAL ASSISTANCE IN DYING

The end came with a smile.

The 78-year-old patient, diagnosed two years earlier with advanced lung cancer and told two months prior that it had metastasized to his brain, was in palliative care at Princess Margaret Cancer Centre, surrounded by his loving family, when medical assistance in dying (MAID) was administered.

He was asked by his physician to tell a joke. Midway toward the punchline, he passed away.

"He had a beautiful end to a wonderful life," says his daughter. "I'm grateful for that."

The woman, who asked that her name not be used, spoke to *UHN News* about her father's decision to request MAID, what the days leading up to his death and the final moments were like. She's decided to speak out in hopes of answering the questions on the minds of many people – patients, families, medical staff, the public – about what the process is like since Bill C-14, which allows Canadians with terminal illnesses to choose to die with the assistance of a physician, took effect in June of last year.

"People are curious," she says, noting that she'd love to tell her family's story more publicly, without anonymity, but feels public opinion is so polarized on MAID that a backlash would ensue.

"I hope I can help people move from a very rigid stance to being open and understanding at all times. So, that's why I'm sharing," says the woman, whose two siblings also supported their dad's decision.

"It's important to be able to talk and express and share the experience with others."

'It's a very emotional, stressful journey'

Make no mistake, she says, it's not easy. In addition to the deep sadness of knowing her dad was in steady decline and so close to death, there was the anxiety of managing his expectations – once he asked for MAID, he was ready to die rather than go through the required 10-day reflection period – and the unease for the entire family of not knowing how his final days would play out.

"This is not all rah-rah-rah, let's exercise your rights," she says. "It's a very emotional, stressful journey with its ups and downs. But there are beautiful moments and you have to be willing to embrace them."

Dr. Madeline Li, a psychiatrist in the Department of Supportive Care at Princess Margaret Cancer Centre and an architect of UHN's MAID framework, acknowledges the black and white nature of

public discourse – strong opinions in favor and opposed with little middle ground – on the subject of medical assistance in death as federal legislation was being drafted and put into effect. However, Dr. Li, who conducts separate debriefs with families, caregivers and UHN staff after MAID has been administered, says the reality for most families is not as straightforward as that. "The common theme is that it's more grey than black and white," she says of caregivers and families.

"It's important for them to talk about how they respected the way their loved one wanted to die and the comfort that brings," Dr. Li says. "But they also talk about how hard it is to know that this person chose to leave them, made a conscious decision to die and not spend more time with them. "That can be painful and is something people must balance with the respect for final wishes. More often, the difficulty is in just how new this is, as well as the usual grief over the death of a loved one no matter how it occurs."

'Time for debate is over, this is now a patient's right'

UHN began receiving requests for MAID in March 2016, after it had been decriminalized but before Bill C-14 became law. In the first year, March 8, 2016 to March 8, 2017, there were 74 MAID inquiries at UHN, says an article, co-authored by Dr. Li and published in the *New England Journal of Medicine*. A total of 29 of those inquiries proceeded to assessment, 25 were approved and 19 received MAID.

"I did not come at this from a position of either advocacy or opposition," Dr. Li says. "The issue is that the time for debate is over, this is now a patient's right and we have an obligation as an institution to provide it.

"And, if we're going to do it, we want to be sure we do it in a way that is safe for patients and supports staff who may have a conscientious objection. That was our motivation in developing our framework."

UHN's MAID framework consists of three teams – clinical, assessment and intervention – and includes a 10-day reflection period for the patient following the request. Death is by injection of intravenous drugs in the hospital. A multidisciplinary quality committee provides oversight, reports metrics annually to the medical advisory committee, and stewards data for use in quality assessment and research.

"We know that the bulk of MAID requests are on the basis of psychological suffering," says Dr. Li, noting that the public expectation was that pain would be the primary motivator. "I think there's just a kind of patient who wants MAID, who is actually going to be helped by MAID because there isn't

either time, or they're not able to explore death and dying in a way that will relieve their psychological distress.

"I've been surprised by how therapeutic it is for some patients and how powerfully it relieves their psychological distress."

That was the case for the 78-year-old man with end stage cancer, according to his daughter.

'He didn't look back and he wasn't going to change his mind'

"He kept saying: 'It's my time. There's nothing more that can be done.' He was very clear," she says, noting that he'd watched both his parents and his former wife die of cancer, and feared his final days would be spent suffering.

"He was always very clear. He didn't look back and he wasn't going to change his mind. "The thing he was most upset about was that he had to wait 10 days after requesting MAID."

While her dad may not have wanted the reflection period, she says it was vital to the family. She admits, even though he made clear on several occasions that he supported MAID, to being "stunned" when her dad called the family together in his hospital room one afternoon and calmly told them his decision.

After two independent assessments, a date for the intervention was set.

"It's so strange to think you're planning someone's death, that you know now the day that someone's going to pass," she says. "It's so surgical, so completely foreign to think he was going to die this day.

"I couldn't, emotionally, get my head around it. I wanted to support my dad," she says, speaking slowly, putting thought into every word. "I understand the legislation. I'm in support of it but when it's your dad, it's suddenly very difficult to have to reconcile.

"I wished he wasn't going to die but I knew he was dying, likely in a couple of weeks, without a doubt. He had a life-threatening illness that was not being treated, they couldn't treat it. And it was irreversible. He was in a steady state of decline but it's hard when it's your family member."

A wonderful night of music and memories

With her dad's death set for a Monday, the focus became on saying goodbye. He loved Saturday nights, music and dancing, so on his final Saturday night she brought her iPad to his hospital room. They played his old favorites from the 1950s and '60s, including Guy Lombardo and His Royal

Canadians, and reminisced about when he was a boy, his parents and dancing with her mom. She also fed him chocolate cake, something he'd been unable to eat over the past decade or more due to his diabetes.

"He was so happy that night listening to music and remembering happy times," she says. "It was all about focusing on the quality. He was coherent right to the end."

On the Monday, two members of the intervention team, who had been in regular contact throughout the MAID process explaining it, answering questions and offering support, were in the room. With the family gathered around his bedside, holding hands, the doctor who gave him the injection asked her dad to tell a joke "and midway through he went to sleep.

"He didn't want any music or readings, just wanted those he loved most around him. My dad loved to tell jokes, he was really good at telling them. And he loved to laugh. It was so him.

"He was ready to embrace this. He wasn't scared. He was very brave. He was really ready to die. "I thought I was going to be distraught when he went but it was just such an amazing moment," she says. "He was so peaceful. He just drifted away. The team at UHN was incredible."

These days, she admits she's grieving with the loss of her dad. And that, she says, would be the case no matter how the end came. But she's also "very proud" of what he did in taking control of his death as he had always done with his life, refusing to wait for what he felt would be "a very different ending.

"This is what he wanted," she says. "And, knowing this is what he wanted, that's the right thing."