Some of
The
Writing
Part of
on the
Wind's Wall

Dialogues about
'Medical Assistance in Dying'

Appetizer Edition

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Out beyond ideas of rightdoing and wrongdoing,
There is a field. I’ll meet you there.

— Jelaluddin Rumi (1207-1273)

In a field
I am the absence
of field.
This is
always the case.

— Mark Strand (1934-2014)

I put my lips to the place a tube went into
the back of one hand.
The kiss—as if it knew what I did not yet—both full and formal.

As one would kiss the ring of a cardinal, or the rim
of that cold iron bell, whose speech can mean “Great joy,”
or—equally—“The city is burning. Come.”

— Jane Hirshfield (1953-)

A DOCTOR ASSISTING SUICIDE[1] was punishable in Canada with up to 14 years in prison —and for providing active euthanasia[2], a minimum of 25—on February 5, 2015.

But the next day, the Supreme Court unanimously struck down the criminal laws "unjustifiably infringing" on "the rights to life, liberty, and security of the person" "to the extent that [those criminal laws] prohibit physician-assisted death" for a "competent," "clearly consenting," "grievously," "irremediably," "intolerably suffering" "adult," suspending the ruling's effect for one year to allow Parliament time to amend the legislation and otherwise develop a regulatory framework for assisted dying.

On June 17, 2016, Parliament passed Bill C-14, amending the Criminal Code to allow two types of medically assisted death, self-

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[1] the act of providing a person who wants to die a death-causing drug (usually potable pentobarbital).

[2] the oral or intravenous administration of a lethal agent (usually injected rocuronium) contrasted with "passive euthanasia," the withdrawal of life-giving care (such as antibiotics, fluids, or the electricity powering a ventilator).

administered (previously called ‘assisted suicide’) and provider-administered (previously called ‘active euthanasia’), to people who meet a set of eligibility criteria[3] including, in a departure from the Supreme Court ruling, “natural death has become reasonably foreseeable.”

Informed by the Superior Court of Québec’s September 11, 2019 decision declaring this departure noncompliant with the Canadian Charter of Rights and Freedoms, Parliament on February 24, 2020 introduced and on March 17, 2021 passed Bill C-7 repealing the “reasonable foreseeability of natural death” requirement, allowing access to medical assistance in dying to people who might otherwise live naturally for decades albeit in a state of intolerable suffering. Bill C-7 also excluded from eligibility people with

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[3] An eligible person must at that time have been all of the following: 18 years of age or older; capable of making decisions about their health; eligible for government-funded health services; without influence upon their voluntary request; informed of the means available to relieve their suffering; and diagnosed with a “grievous and irremediable” medical condition (not including ‘mental illness’).

mental illness as their sole underlying medical condition. Meant to be automatically repealed in March 2023, this exclusion was on February 2, 2023 extended to March 17, 2024 and, on February 1, 2024 deferred again to March 17, 2027.

From a legal perspective, that's where we are today: from *Carter* setting out eligibility criteria for medical assistance in dying to Parliament narrowing eligibility criteria with the addition of the "natural death has become reasonably foreseeable" criterion to the repeal of that criterion to a twice-deferred delay on lifting the exclusion of people with mental illness as their sole underlying medical condition.

IN 2016, medically assisted deaths accounted for 0.6% of deaths in Canada.

In 2023, 4.7%.

What follows are words from five of the people in London, Ontario, Canada affected.

"DEATH HAS ALWAYS BEEN a foot or two behind me. As somebody with muscular dystrophy, I will likely not live as long as most, but must I live amidst a culture that insists that my life is tough; that my life is suffering; that it's hard to be me; that it's brave to merely leave my house? What type of consequence do such ableist assumptions have on people—particularly when people are born into all sorts of different circumstances?

"A lot of my personality, identity, and perspectives on disability I *directly* attribute to my parents and the way that I was raised, because my parents raised me with the belief that I was different in a way that many people are different: lots of people have different things about them that make them not the same as everyone else, and that it's *that* kind of *difference* that makes the world interesting.

"While there are things that I physically cannot do, there are things that I can cognitively do. Part of my pathway in navigating my world was about learning how to adapt, how to do the things that I'm able to do, the things that I like to do.

There are a lot of people that don't necessarily have that; and there is also a brutal reality that living with a disability is brutally expensive because of the way that we've set up our world. And so, when we started moving forward with MAiD 20, 30 years ago, I had really conflicting feelings because I could understand suffering as something that people might concede. ‘If I had no other option, I would want at least one choice, one opportunity to relieve the suffering.’

“But I knew that that’s not exactly the conversation we were going to end up having. If you look at every other instance in which we have offered disabled people either the opportunity to live on their own and suffer—and it's kind of a neoliberal, do-it-yourself, pull yourself up by your bootstraps approach—or give them a way out, obviously people are going to start to choose what may appear to be an act of mercy. But, in actuality, in my humblest of opinions, we are provided an out for a government system, a financial system, an ideological, moral, and ethical system that says, ‘You disabled people shouldn't be here.’ And I think the history of disability is a history of the non-disabled saying, ‘You shouldn’t live. You shouldn't be here. And we will get rid of you by any means necessary.’”

Jeff Preston has spent his life dedicated to advocating for himself and others with disabilities. He holds a PhD in Media Studies from Western University, where he is an Associate Professor of Disability Studies at King’s University College.

"FINDING THE BEAUTY of, the value in suffering is an individual thing. I won't stop you from finding that value or beauty, but who are you to impose the search upon somebody else? If the argument is, 'I'm able to find the beauty in my suffering, therefore you also have to find the beauty in your suffering,' that's where I get off the bus. If one reads the *Carter* decision, one would notice a disability-view in it. A lot of people didn't understand the law prior to *Carter*. The fact is, suicide isn't illegal—only asking somebody else to do it for you was. The argument in *Carter* was: somebody unwell might not want to end their own life because they have value and beauty in their life left, but they *will* want to end their own life at the point where they don't feel they have that value any longer—the rub being that, by the time they get to the point they no longer feel they have value and beauty in their life, they may no longer have the *physical ability* to end their own life. Now they're in a disabled position, deprived of liberty. Therefore we shouldn't force someone to end their life, sooner than they would want to, for fear of eventually not being able to.

"I know Jeff Preston. He's a great guy, by the way. If I were to phrase Dr. Preston's viewpoint for you as I understand him: Societally, we may as Canadians begin to devalue the life of those with disability, and there may be social pressure or expectation that *these* people chose to end their life, so why wouldn't you also choose that? I understand the argument, and I feel that if we get to the point where social pressure can be shown to be causing real harm, I'm all for the conversation to say, 'Have we gone too far?' But fear of some future dystopian state where, all of a sudden, the disabled person is told, 'You ought to end your life'? There are so many uncertain futures that we could, out of fear, make very cautious decisions about today—and in some sense we should, when it comes to things like environmentalism. We should be cautious about the way we treat the environment, but the question is, 'To what degree is our manipulation of the environment imposing some harm on others?' Preventing some from undergoing a medically assisted death is imposing a harm that I can’t support.”

Robert Sibbald is the Director of Health at the Office of Health Ethics at the London Health Sciences Centre, Adjunct Professor at Western University, and co-director of the Canadian Unit of the International Network of the UNESCO Chair of Bioethics.

"ROGER WAS TERMINAL: he was getting close to death and was in pain. We told our kids but we didn't make a date at that point in time (in early December). When they were all home for Christmas, that's when we confirmed it was going to happen and announced the date: January 7.

"The social worker and assessors came in. They understood Roger was clear of mind, although he would get his years mixed up in terms of saying it was 1919 instead of 2019 at one point. But that was just a sign of, you know, his *advanced years *laughs** though he wasn't all that advanced in years. His mother had died in the summer before he did, and she was 102. He was only 74 which, on both sides of his family, was the youngest that any of them had died: Most of them were in their 90s or over 100. It wasn't fair as far as I was concerned: Why didn't he get half of his mother's years, you know? Share the wealth? But no, she hung onto them. He had said he didn't want to die before his mom, and he went downhill quickly after his mom died.

"But I've gotten off track. One of them

asked Roger, ‘Tell me a little bit about your life.’ At this point you had to prove that you were lucid. So, he talked a little bit about his life and we filled in some things and so on. And then he said, ‘Okay, well, I think it's time.’ But then we kept talking. The woman would be just ready to give him something, *and then we would talk*. She'd come back; there was a little lull—*and then we would talk again*. So finally, he said, ‘Okay, everybody shut up: time to go.’ That’s the way that it happened.

“And we all said goodbye. It was the most peaceful thing I've ever experienced. There was one tiny flutter of his left eye, and that was it: He was gone. Of course then we all broke down. We waited a month for his celebration of life, which was a very smart thing to do, because we had our shit to get back together. By then we could talk without crying.

“I haven't really cried, but he's still with me. He’s just sitting over there saying, ‘What the hell are you saying about me *now?’* When I do something stupid, he's right there, saying, ‘What the hell are you doing?’ And I say, ‘Yes, dear, yes, dear, *shut up.’* At night I tend to have the TV on a little loud and I can see him come out of the bedroom and blinking his eyes, ‘Can you *turn that down* a little?’ ‘No, dear, you're dead,’ I said.”

Sheri Knott is a lifelong educator and travel enthusiast who retired as the principal of Fanshawe College (Oxford County) in 2008. Her late husband Roger received medical assistance in dying in 2019.

"BEFORE EACH CASE, I think about what I would want if I was the patient or family member, trying really hard to put myself in their shoes. I try to adapt my approach to individual needs but in general, I go see the patient and do an assessment to see whether or not they meet criteria. Usually the medical side of it is pretty clear: 'Hi. How are you? I'm glad you came. I'm requesting MAiD because I have terminal cancer.' Pretty much tick, right? I also need to assess that they are free of coercion and have had access to all available treatments and palliative care options. Once I've confirmed that they meet criteria, I explain to them what I'm doing and why I'm doing it. I talk about what meds will be given, what those meds do. I describe what it will be like for them. I say very clearly, 'At this point, you will lose consciousness.' Then I describe what everyone else in the room will see. I reassure them, 'I'm going to explain this again on the day of the procedure.' Then I ask everyone in the room if they have any questions. You read the room and watch family reactions. I tell them that it's usually surprisingly fast, a matter of minutes—sometimes less—so that they're as prepared as possible.

"No one taught me how to do this. The closest thing that helped me prepare for this was the withdrawal of life support in the ICU, but that's very different. You withdraw the life support, the machines that are keeping them alive. Their disease kills them. Most of those patients without those machines and the medications would die. MAiD patients often drive themselves in. They walk in. They had breakfast.

"What I hadn't prepared myself for was *after*. I didn't think that would be tough, but then suddenly, there you are sitting in a person's bedroom. They're dead because of some things you did. You're standing with their spouse; and then you wonder, *Is this person going to hate me? Are they angry with me?* Usually, they are grateful. But I've learned that my duty is to the patient. If doing right by the patient is in conflict with what the family wants, then I'm okay with that. That said, I try to support both and try to make it as positive an experience as I can. Sometimes that includes offering for families to leave, because some family members just can’t witness it. We go get them once the patient has died. Some don’t want to come back; they want to say their goodbyes right before and leave. I’ve had family members crawl into bed during the procedure. Someone kissed their loved one as they died. If I can throw some humour in: there was an incredible case with a young couple and *chuckles* right before she died the man put his arm around her and said, ‘One last time?’ And put his hand down her top. Everybody got a good laugh out of that, including the patient. That one surprised me. I had a former professional baseball player who had old radio recordings of baseball games playing in the background. People’s cats and dogs climb into bed with them.”

Ian Ball is an Associate Professor at Western University, a trauma physician with the London Health Sciences Centre Trauma Program, and the Critical Care Medicine lead for Southwestern Ontario.

"I SLOWLY STARTED TO REALIZE he was trying to let go of things, or he was still trying to hold onto things, either way. Then something clicked: *I can help him through this*. We'd be laying there and I'd feel panic coming on and I'd be like, 'It's okay, honey. It's okay, baby. Let go of that. Where you're going, you don't need that. Whatever it is, just let go of it.' He instantly would calm. This went on for hours, *hours* of me meditating with him, trying to keep him calm as he was going through the waves. At one point, I felt like I couldn't keep going. I sat up in the bed thinking, *I want to escape. I want to run away as fast as I can.* As quickly as that came was as quickly as that dissipated, and I returned to talking to him again, working through a process of counting, breathing, or reminiscing: 'Remember when it was just the two of us sat in a field full of dandelions? When it was just a *sea* of yellow everywhere? It was like the flowers were planted there just for us, just for *us*. A field full of yellow. Do you remember? I was sitting straddling you cross-legged and you were cross-legged behind me and we sat there for probably about eight hours, crying and loving each other. Do you remember I told you "no matter what happens, I will be there with you, holding your hand to the Gate?" Go there. Let go of whatever's trying to hold on. Go to that peaceful place.'

"Finally, it just—A calm happened. I could feel like he was still there but not necessarily in his body anymore. And I, too, had a calming. Something happened to me as well. I was laying in the bed on his chest; the family was all around the bed. I felt like he had blessed my life immensely. As I'm laying there, I lifted my head and said, 'I love you. I sure am going to miss you.' And he left his body. I sat up. I felt his presence go through me. I looked up at his son and he said, 'I felt it too, Bev.' My sister-in-law, she said, 'When he left his body, you and Caleb *glowed.'*

"Then I went back to his place and I stayed there for a month, packing his things, crying and smelling everything, just absorbing him. The day he died, I called my girlfriend in Texas. She'd only met Tony once. I told her that he passed away.

She's a medium; and she said, 'Yep, Tony's coming through clear to me right now.' She said, 'You need to go and find a coin. It's in a box.' So I had all these boxes lined up on the floor and I couldn't find this coin. Tony's telling her to tell me where to look. *And then I saw it*. I saw it and I saw Tony right in front of me. *Right in front of me* like he was clear as day. Maybe transparent but clear as day. I gave him this coin the day we went and sat in the field full of daisies. I gave him it to him to let him know that I'd always be with him—and *he gave it back to me when he died*."

Beverley Isabelle East is a certified sound healer, wellness intuitive, Yoga instructor, and Meditation teacher who provided a month of round-the-clock hospice care to the late love of her life, Tony.

THIS IS 4.7% of *The Writing on the Wind's Wall: Dialogues about 'Medical Assistance in Dying,'* a gathering of words from people in London, Ontario including Jeff, Robert, Sheri, Ian, and Beverley, as well as a Member of Parliament, a psychiatrist, differing Anglican priests, a death-doula, a son, a hospice-provider, a non-profit opponent, a retiree living with dementia, and a MAiD recipient facilitated in dialogue with his widow by a medium, agnostically transcribed by Londoner Kevin Andrew Heslop in honour of his late father, Kevin William Heslop, and his late grandmother, Fern Doreen Heslop—who together dedicated a century of community service to the people of London, Ontario.

This is for them, for you, for us.