

A complicated grief: Living in the aftermath of a family member's death by MAID

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At his home in Lumby, B.C., Gary Hertgers holds a framed photo from 2000 of his sisters, twins Wilma and Jen Hertgers. Wilma received a medically assisted death this past January; Jen died of cancer in 2008.

Gary Hertgers learned that his sister, Wilma, had received a medically assisted death when her apartment manager called to say that her body was being carried out into the street.

“You mean, my sister is dead?” he asked.

“I thought you knew,” the manager said. “She told me the family knew.”

But, in fact, none of her immediate family knew that Ms. Hertgers had been approved for medical assistance in dying, let alone set a date. Not her 88-year-old mother, whom she called twice a day. Not her older brother, who lived one town over. And not Mr. Hertgers, 61, who had only that Friday, after driving

the four hours to Chilliwack, B.C., shared a pot of tea at Ms. Hertgers's kitchen table.

They'd chatted as usual, mostly about Ms. Hertgers's health; at 63, she experienced chronic pain, and wrestled with depression. She told him the location of her will. But she had done that before, so the clue didn't register. They parted with a hug. See you soon, he said.

Two days later, in the same apartment, someone said a prayer at her side while she died. At least, that's what Mr. Hertgers was later told by the doctor who delivered the fatal medication. The identity of that person is still a mystery, like many of the details around his sister's death.

When Canadians receive MAID, families and caregivers are often with them, providing comfort along the way. But the situation becomes much more fraught, ethically and emotionally, when patients don't want relatives and friends involved.

Under the law, a person's right to privacy limits the medical information that can be shared with a third party. Even caregivers can be excluded from MAID assessments and find out, only near the end, that a loved one has even applied. When they go looking for closure after the fact – to ensure a mistake didn't happen, to know their loved one died peacefully – the system can turn them away. This is devastating for families, creating aftershocks of complicated grief, as Mr. Hertgers can attest.

It is also a problem for a system promising to be rigorous and transparent. How can doctors and nurse practitioners make fully informed decisions in complex cases without gathering information from the people who know the patient as a person?

If death is really meant as a last resort, after all options have been explored, experts argue, then excluding a patient's social circle should be the exception.

"You feel like you're taken for granted, like the relationship you've built over all these years is superseded by someone who has known her a few months, that your care has been for naught," says Mr. Hertgers. "At the end of the day, did all that time and effort mean anything?"



Wilma Hertgers died without her brother knowing she had decided to receive MAID.
AARON HEMENS/THE GLOBE AND MAIL

The role of families, some experts say, needs to be clarified before MAID extends to patients with mental illness. In December, responding to concerns raised by doctors and health care organizations, the federal government announced it would ask Parliament to delay the MAID expansion, to allow more time to establish clear safeguards. Toronto's Centre for Addiction and Mental Health, the country's largest psychiatric teaching hospital, has suggested that should include more consultation with patients and their families.

The current law allows capable adults to receive an assisted death if they have an irremediable physical condition causing intolerable suffering that can't be relieved with care acceptable to the patient. Their death does not need to be "reasonably foreseeable." They may have a history of mental illness, but they are only eligible for their physical condition.

Cases that don't involve a terminal illness are already more controversial than those where a patient clearly faces an imminent or foreseeable death. But widening MAID eligibility, international research shows, will lead to younger patients potentially qualifying for an assisted death. Doctors may also disagree about their chances of recovery, particularly in cases of mental illness. MAID decisions are already emotionally complicated. But it's one thing to hold the hand of an elderly parent with terminal cancer who wants a better death. And quite another to say goodbye to a thirtysomething daughter with depression who may have decades yet to live.

In Ontario, for instance, a father learned this fall that his adult daughter was being assessed for MAID when she forwarded an e-mail from a B.C. doctor

proposing that she travel west to complete the process. By then a plane ticket had already been booked for November. Her parents, who had been caring for her since she was diagnosed with schizophrenia as a young woman, were distraught.

The father, whom The Globe and Mail is not identifying to protect his daughter's privacy and his relationship with her, says he'd watched, over many months, as MAID consumed his daughter's day; she pored over how-to information online.

His daughter's life is not easy, he conceded in an interview. Her mental illness causes fearsome bouts of anger, she spends most of her time alone, and she is plagued by delusions that she is rotting inside from a terminal physical illness.

But certainly, he didn't think she'd be eligible for an assisted death. While she has some physical health issues, he could not imagine they were serious enough to qualify for MAID. He'd also observed longer periods of stability now that his daughter is closely monitored by a clinical team in the community. Although he's not privy to the details of her care, beyond what she willingly shares, there were no indications that her doctors had deemed treatment futile.

So it was unfathomable, he says, that a physician was counselling his daughter, who suffers from psychosis, to travel alone halfway across the country. Or that two MAID assessors might approve her without insisting on input from her treating psychiatrist or family doctor. Yet the e-mail suggested an expeditious outcome: If she could get to B.C. – where ostensibly a physical illness might make her eligible – she could qualify within weeks.

The father doesn't know what illness his daughter used to apply, and was not privy to all the discussions with the MAID clinician. But in the end, the parents managed to persuade their daughter to cancel the plane ticket. A reprieve, the father says – for now. Their daughter insists she will be approved at some point. Her father fears that one day they'll find an empty room and a goodbye note, and learn she received an assisted death only when they have to bury her.

In the final decision, Canada's MAID law leans heavily toward patient autonomy. What counts as intolerable suffering is a subjective condition, only truly understood by the one who suffers – and even critics of the proposed expansion say that treatment is the patient's choice. But people are not only

individuals; they exist in relationships with others. Those human connections clearly factor into MAID decisions: According to Health Canada, 35 per cent of Canadians who received MAID in 2021 said feeling like a burden to family, friends and caregivers was among the reasons, and 17 per cent cited loneliness and isolation.

“It’s an impoverished view of autonomy,” says Christopher Lyon, who was given two days’ notice that his father was scheduled to receive an assisted death in July, 2021. “It separates us from our context.”

Before his father died, Dr. Lyon, an environmental social scientist, says his family tried to share what they consider to be important context for the MAID providers and assessors. When his father was first assessed for MAID, the family wrote up a detailed history of his physical ailments and mental health struggles, his alcohol use and personality quirks – and sent it to the office of the MAID co-ordinator. Dr. Lyon knew his father experienced bouts of depression, especially around negative events. Hospitalized after a fall, he now faced moving into an assisted-living apartment. He had been openly talking about suicide for months. The family expressed their opinion, however, that with time, social support and mental health care, their father would improve.

Even today, Dr. Lyon is not sure who read it. He doesn’t know the content of his father’s assessments, or what information was collected. He says the health authority has declined to release the full records, deeming it not to be in the “patient’s best interest.” A late-stage psychiatrist report that he has seen contained so many errors and omissions that he worries about what else was overlooked.

When the MAID provider phoned to give him 48 hours’ notice, it was the first time they had spoken. By then, Dr. Lyon and his family had been trying for weeks to find a solution to keep his 77-year-old father alive. They thought they had time; his chronic health conditions had qualified him for MAID as a non-terminal patient, which required a 90-day waiting period, and there was still a month to go. But his dad stopped eating a few days after moving, reluctantly, into the new apartment. He was admitted to hospital after another fall, and fast-tracked to receive an assisted death.

Dr. Lyon rushed to Victoria from Montreal, and on a sunny afternoon, he gathered at his father’s hospital bed with his two siblings, and his mother. He remembers that the MAID provider was running late. “We were just watching

the clock tick down until someone was going to come and kill him, which is, you know, an excruciating, unbearable thing to experience.” Arriving, Dr. Lyon recalls, she said, “I hear it’s someone’s birthday,” as if joining a party; by awful chance, the procedure had been scheduled on a family member’s birthday. “Get me the hell out of here,” his father declared, giving his consent. He was dead 20 minutes later. His son still has nightmares about it.

“It was like some sick, dystopian Black Mirror or Squid Game,” Dr. Lyon says. “You, family member, have 90 days to convince a doctor, whose name you don’t know and cannot directly contact, to save your father’s life.” To pass on important information the patient might conceal. To scramble when the date is unexpectedly moved up. To make sure, before the lethal injection, that all options have been fully explored. It felt, he said, that “if we want to save our loved one’s life, we are actually in competition with the assessors and providers.”

But families don’t have to be left on the sidelines. As other countries have shown, carefully crafted guidelines can find a consistent and valuable place for them.

In Belgium, one of only a few countries where psychiatric euthanasia is legal, the law explicitly allows doctors to set extra conditions for their assessments, including speaking to a patient’s social circle. With rare exceptions, involving families “has become the rule” included in all professional and ethical guidelines, says Joris Vandenberghe, a psychiatrist at the University of Leuven, who was part of the working group for the care standards created by the Flemish Psychiatric Association.

Involving family, he says, gives people a chance to say goodbye, and helps to ease the grief of those left behind. But he also describes family or significant others as “the single most recovery-promoting intervention.” He has seen it happen: The support of a loved one turns a patient who is seeking death back toward life.

Last year, the federal expert panel reporting to Parliament recommended that doctors could deny MAID requests if they felt the lack of family input prevented a full assessment. But it is still unclear how those recommendations will be implemented. The parliamentary committee studying the MAID expansion isn’t slated to report back until February.



Christie and Alicia Duncan of Mission, B.C., whose mother, Donna Duncan, had a medically assisted death last year. DARRYL DYCK/THE GLOBE AND MAIL



The Duncan sisters now have matching tattoos in their mother's honour. DARRYL DYCK/THE GLOBE AND MAIL

Christie Duncan, and her sister, Alicia, learned their mother, Donna, who lived near Abbotsford, B.C., was starting the MAID process when their mom's husband texted them a link to a support group in October, 2021.

Their mom's decline began after a car accident in early 2020, Christie says, and she was losing weight, without a clear diagnosis. But her daughters worried that the pandemic had made it hard to get treatment, and lockdowns had affected their mom's mental health.

When they found out a MAID date had been set, the sisters successfully appealed to the courts for a delay. A few days later, Donna was admitted to hospital after cutting her wrist – an event her daughters hoped would postpone their mom's assisted death indefinitely.

In the hospital, on Oct. 29, Christie says, “I hugged her goodbye, and I went home, thinking I will talk to my mom in the morning.” Donna was released a few hours later, and that night, her daughters received a text from her husband that their mom had received MAID, “as per her wishes.” (A police investigation, prompted after her daughters filed a complaint, did not find any evidence of criminality.)

Just like Dr. Lyon, however, Christie and Alicia have had trouble getting information about their mother’s MAID process, to resolve their own doubts about their mom’s case. In an October letter from the local health authority, their request for paperwork was denied, on a legal technicality, because it was not clear that they were acting “in the interest of the deceased.”

But who better to hold the system accountable than the loved ones left behind?

“Families normally should be considered advocates for patients,” says Trudo Lemmens, an expert in health law and policy at the University of Toronto, who has been an outspoken critic of the lack of safeguards in Canada’s assisted dying laws. “If they don’t have an opportunity to check that things were done right,” he asks, “how can we reassure the public that there is accountability, if we shield the system from scrutiny?”

Indeed, experts have been critical of the lack of transparency in Canada’s system. In the Netherlands, for instance, where euthanasia has been legal for 20 years, assisted dying cases are reviewed by independent regional panels, who then publish their findings of individual cases in detail – a level of oversight that doesn’t exist in Canada.

Rules around patient autonomy and privacy, Dr. Lemmens argues, need to be balanced against the reality that this is a state-delivered end-of-life procedure. “In the Canadian debate, I think this is too easily presented as another form of normal medical treatment.”

For Christie, who says she isn’t morally opposed to MAID, the anguish she feels might have been avoided if she’d had time to talk to her mom and understand her reasoning. “I could have wrapped my head around it.”

Instead, she and her sister are left with questions they can’t answer, frustrated by a system that won’t easily share information. “The hardest thing to wrap my head around is that my mom would never have chosen to leave her family,” Christie says. “The grieving process has been very hard.”



Photos of Donna Duncan at her daughter Alicia's home. DARRYL DYCK/THE GLOBE AND MAIL

Stefanie Green, president of the Canadian Association of MAID Providers and Assessors, says that primary caregivers “can be incredibly valuable,” and that without them, she concedes, “we may be missing some information that would be helpful in an assessment.” As well, research shows that when families participate in the process, it often makes grieving easier.

But relatives can also be a difficult presence – unwilling to accept the patient’s wishes, causing conflict, and even, in some cases, applying pressure on doctors’ decisions. Sometimes personal dynamics don’t create a respectful space for patients, Dr. Green says. Whatever the reasons, if someone tells their MAID provider not to include family or friends, she says, they are professionally required to follow their directions.

And so, that Sunday afternoon, Mr. Hertgers found himself on the phone with a doctor he didn’t know who had helped his sister die. She told him that after assessing his sister over seven months, she had administered an assisted death. “Did you know she had mental health issues?” he asked. Yes, the doctor said. At the time, he wrote down the doctor’s response to his questions on a sheet of paper: “I am protected by the laws of the land.”

Where do families fit into that law, he wants to know. His sister’s death devastated his elderly mother, who died in December. His attempts to get more information about his sister’s MAID assessment have been mostly fruitless. He has spoken to her family doctor, reached out to her pain specialist, attempted to contact the MAID provider again, called names he found in her sister’s address book – all trying to figure out how she qualified for MAID, and what the

family missed. “Did I do enough? Did we do enough? Could we have done more?” he asks.

He knows he should move on, and accept what he doesn’t know. But he is angry that the country’s MAID process decided his sister’s fate without hearing from all the people watching over her. Even if the family didn’t agree with her decision, even if they couldn’t stop her, he says, “we could have tried to grapple with it, and maybe given her some more peace.” And found some peace themselves. That chance is gone, he says. The guilt and the grief remain.



Gary Hertgers says he's upset with the MAID process and regrets that his family lost a chance to find peace with his sister's death. AARON HEMENS/THE GLOBE AND MAIL

<https://www.theglobeandmail.com/canada/article-maid-death-family-members-privacy/>

Erin, again, is a brave lady wading into this debate with these people. I’m not sure I can follow her lead here on all matters, but it is just more a matter of emphasis; she does an exceptional job of coming out the end of the analysis in the right place.

Why would Canadian authorities have not followed the North European/Belgian model more closely in matters of mental illness? Belgians and the Dutch have tested out “assisted dying” more thoroughly than anyone. This doesn’t mean we should copy them, but when they temper their “liberal” propensities with safeguards, we should pay very close attention.

Again, we have been let down. We need better than this from our “leaders.” TJB