



Whose life is it, anyway?

By Allyson Rowley

Medical assistance in dying elbowed its way into public consciousness in 2016, hitting the headlines and provoking heated debate.

For **Mary Valentich '63**, though, it's been a very personal journey

Above: Daniel Laurin and **Mary Valentich '63** hold a photo of Hanne Schafer.

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On February 29, 2016, **Mary Valentich '63** flew from Calgary to Vancouver with her friends Hanne Schafer and Hanne's husband, Daniel Laurin. They arrived in the late afternoon and went for dinner at a posh hotel. "We were friends, all together," says Valentich. The waiter came to take their order. "This is Hanne's last supper," said her husband.

And it was. At 7 o'clock that evening, Hanne Schafer became the first person outside Quebec to receive a court-approved, physician-assisted death. Diagnosed with Amyotrophic Lateral Sclerosis (ALS) in 2013, Schafer was now in constant pain, speechless, and confined to a wheel chair. A neck brace held her head, she ate and drank through a tube, and she required 24-hour assistance for all her bodily functions.

Fully awake and alert, she was frozen inside a body she could no longer control.

"Hanne did everything she could to fight the disease," says Valentich, a professor emerita in the Faculty of Social Work at the University of Calgary. She met her friend 38 years ago, soon after moving to Calgary. A psychologist, Hanne Schafer was attractive, articulate, gifted. After receiving the terrible news in the spring of 2013, she explored every possible option. She contacted medical authorities, attended symposia, reached out to the ALS Society, and scoured the internet for information about her condition, also known as Lou Gehrig's Disease.

But nothing could change the inevitable outcome. By June 2015, Schafer had made her decision.

"Hanne was very clear," says Valentich. "She took the lead and included all of us, to the extent that we wished, in her search." They discovered only Switzerland offered physician-assisted death to non-residents. But that would have meant an exhausting journey.

They learned of the possibility of a court-approved exemption in Canada, following the Supreme Court's landmark ruling of February 2015. Still, the road ahead was arduous – finding a lawyer, dealing with court postponements, locating willing physicians and pharmacists. "If there was an obstacle, we met it," says Valentich. Court approval was finally received on Thursday, February 25, and travel arrangements to Vancouver were made for the following Monday.

Even booking a funeral home close to the doctors' office was a challenge. "I had to reassure the funeral director I wasn't plotting a murder," Valentich recalls. Still able to type using a few fingers of her left hand, Schafer quipped that the phone conversation sounded "like a Monty Python skit."

While it's always been possible (and legal) to make the choice to withhold life-preserving treatments and procedures, the legalization of medically hastened death is a major paradigm shift in our society. And it's all the more challenging for the medical profession, with its time-honoured oath to "not play at God."

"There is nothing easy or straightforward about any of this for anybody," says Joshua Shadd, a physician and director

of the Division of Palliative Care in McMaster's Faculty of Health Sciences. He hopes the recent debates will help bring about "a more compassionate and well-informed conversation about how we as Canadians will look after one another at the end of life."

In his work as a palliative care physician, Shadd is very familiar with The Question that patients can sometimes ask. There are many reasons, he notes. Patients may be afraid of a possible future in which they have no control over their bodies, or they are worried about being a burden to their loved ones, or they are experiencing new symptoms, all of which can be addressed through good palliative care.

"My role is to understand the question behind the question," says Shadd.

And there are still more questions. How do we adapt medical school curricula? How do we ensure that a newly legal medical service is universally available, despite moral, religious and ethical objections of health care providers? And what about those whose suffering is unbearable, but whose natural death is not "reasonably foreseeable"?

These are some of the many questions that Lisa Schwartz tackles in her role as the Arnold L. Johnson Chair in Health Care Ethics at McMaster. "Medical assistance in death has to be seen as part of a spectrum of care," she says. "I'd want to know that you are choosing it with full knowledge of all the options."

Another big question is how we name it. Is it suicide, or is it assisted dying? Is it euthanasia or the right to die? Is it assisted or hastened death?

"The philosopher in me thinks that's one of our biggest problems. We don't know what to call it yet," says Schwartz, who co-leads sessions on the charged topic with McMaster's medical students. "I tell my students: What I wish for each and every one of us is the death of our choosing."

For Hanne Schafer, the choice was clear. "I'm satisfied with my life," she wrote in one of her many emails during her last months. On the way to Vancouver, her husband and her friend continued to ask if she had changed her mind. "She would glance at us lovingly with a half-smile and raise her thumb," recalls Valentich.

Since that day, Valentich has worked tirelessly, along with Schafer's husband, to fulfill Hanne's wish to make her story known. "Hanne made activists of all of us. She wanted to educate people about the legal and bureaucratic obstacles she faced at the end of her life," says Valentich.

"I so valued my friendship with her. I can't help but feel awestruck by someone who goes so bravely to her death." ■



“I’m satisfied with my life,”
Hanne Schafer wrote in
one of her last emails.