

B.C. man receives assisted death after funding cut for in-home care

The family of a Canadian man who suffered from Amyotrophic Lateral Sclerosis (ALS) is urging the federal government to change the way it treats patients with the disease after he received a medically-assisted death following years of struggle to find adequate care.

Sean Tagert, 41, of Powell River, B.C. was diagnosed with ALS, also known as Lou Gehrig's Disease, in March 2013. In October 2017, he suffered cardiac arrest, and was subsequently placed on a ventilator. His illness robbed him of the ability to move his body, eat, or speak, and he communicated via an eye-gaze computer. His mental acuity was unaffected.

At that time, Tagert's doctors recommended 24-hour in-home care, which is typical for a person who uses a ventilator full time. Vancouver Coastal Health only initially offered 15.5 hours of care a day. Eventually, after much effort, they increased their offer to 20 hours a day – which still meant that Tagert had to pay \$263.50 each day for the remaining four hours of required care.

Tagert and his family continued to fight for coverage of a full day's care, to no avail.

"Hey everyone. I've been quiet lately because I'm just done, worn-out," wrote Tagert in a July 25 post on his Facebook page.

"So last Friday I officially submitted my Medically assisted death paperwork, with lawyers and doctors, everything in proper order. It's been over a month since I submitted my appeal to the Vancouver Coastal Health patient care quality department. They didn't even respond."

Tagert went on to explain that earlier in the day, two Vancouver Coastal Health officials came to his home, and had refused to talk to him when they realized he was recording the conversation. Eventually, they told his mother that they were there to cut his funding for care hours.

"Welcome to the great Canadian Healthcare system people," Tagert wrote.

On Aug. 6, he received a medically-assisted death and passed away. In Canada, patients over the age of 18 who have been diagnosed with a terminal illness are able to apply for Medical Assistance in Dying (MAiD). The lethal medication can either be self-administered, or, as it is in the vast majority of cases, administered by a doctor.

More than one in every 100 deaths in Canada is administered by a doctor, according to the latest national statistics on euthanasia and assisted suicide.

Euthanasia was legalized on Dec. 10, 2015.

In Alberta, under Covenant Health policy, witnessing and signing of legal documents and assessments of eligibility can take place on Covenant Health sites. Patients deemed eligible for MAID would still be transferred to other facilities

“We would ask, on Sean’s behalf, that the government recognize the serious problems in its treatment of ALS patients and their families, and find real solutions for those already suffering unimaginably,” reads a post on his Facebook page announcing his passing.

The post outlined the difficulties he endured to remain in his own home.

“Ensuring consistent care was a constant struggle and source of stress for Sean as a patient,” said the post.

“While he succeeded, with the help of many, in piecing together a suitable care facility in his own home (including an expensive saliva-suction machine, needed to prevent him from choking, obtained with the help of donations raised online), gaining the 24-hour care he required was extremely difficult, especially as the provincial government refused to fully fund home care.”

Going to a nursing home was not an option, said the post, as the facilities in his province “would have offered vastly inferior care while separating him from his family, and likely would have hastened his death.” Tagert had partial custody of his 11-year-old son, Aidan.

“Above all else Sean was devoted to his son,” said the post.

“Sean often said that Aidan was his reason for living, and had a close relationship with him right to the end.”

Since Tagert’s death, commentators and palliative care physicians have called for changes in the way the country’s health system handles patients with complicated health needs.

“No one should have to feel death is the only option due to lack of care,” Dr. Leonie Herx, a palliative care physician from Toronto, said on Twitter.

Herx pointed out the paradox that presently, Canadians have a “right” to medically-assisted dying, but not to palliative and disability care.

“We must do better for vulnerable Canadians,” she said.

The ALS Society of Canada was unavailable to comment specifically on Tagert’s case, but CNA was provided with a statement from CEO Tammy Moore saying “People living with ALS must have access to the appropriate personal care supports and palliative care to meet their needs.”