Confined to a Toronto nursing home bed 24 hours a day, Tommy Sec wants to die

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A rare disorder has confined a 42-year-old man to a bed in a Little Portugal nursing home normally used for patients nearly double his age. And now, To Phat Sec, who goes by Tommy, is waiting to die.

For the last four years, Sec has been a patient in various long-term care facilities in Toronto, where he’s lived since 2014 following complications from a surgical procedure. Bedridden for virtually every hour of the day due to his condition, Sec is fully dependent on the care of nursing home staff to feed and attend to his hygiene.

“I have a hard time ... living in this condition for the rest of my life. I can’t eat my favourite food. I can’t go to the washroom, can’t brush my teeth, can’t walk, can’t use my hand accurately like before,” said Sec last week during an in-person interview at Fairview Nursing Home. He communicated via the messaging service Skype as he is unable to speak.

While his cognitive abilities are intact, Sec is deaf and incapable of verbal conversation, which creates significant barriers for communication. His only option is a laptop, which he uses to type out messages with his left index finger, his only functioning digit.
“Some people don’t understand my strange way of communication,” said Sec. “Some take a long time to understand it at first contact.”

With no chance of improving his health and the prospect of living out the rest of his life bedridden with no ability to travel or even listen to music, Sec, who was born in Vietnam and lived near Montreal most of his life, says his only goal is to no longer be among the living.

“I would like to return to Quebec to be considered a candidate for euthanasia,” said Sec. “No goals in life equals wasting time.”

Sec has already applied to the federal government for the right to end his life. Euthanasia became legal in Canada with the passing of the Medical Assistance in Dying Act (MAID) in 2018.

Sec’s health took a turn for the worse in 2008 when he was officially diagnosed by Quebec doctors — where he lived with his family, Vietnamese immigrants, for much of his life — with neurofibromatosis type 2 (NF2), an extremely rare hereditary condition which manifests in noncancerous tumours growing on the nerves, inner ear and other areas.

As a result of NF2, Sec, who was already hard of hearing, became fully deaf. By 2013, he lost much of his ability to walk due to the emergence of more tumours. Hospitalized in Montreal, Sec underwent several surgeries. Even so, his health continued to deteriorate.

In 2014, Sec travelled to St. Michael’s Hospital in Toronto to undergo more surgery to remove a large tumour, a procedure so potentially dangerous that his doctors in Quebec refused to carry out the operation.

After the surgery, Sec suffered a massive stroke which resulted in paralysis of the entire right side of his body.
According to correspondence between Sec and his case officer, which was forwarded to our publication, he was informed of his eligibility for legally-assisted suicide in May. Sec’s caseworker declined to respond to our questions on the status of the MAID application citing patient privacy.

“He wants to change his situation,” said Lydia Sun, who along with Paul Nguyen has stayed in touch with Sec since profiling him for a feature story that appeared in Vietnamese and Cantonese language newspapers earlier this year. “I see he’s really trying, and he’s still fighting (for his right to die),” Sun said. “It’s a sad story. He’s young and he’s stuck in a nursing home.”

Sun admits to being unsure whether Sec is completely resolute in wanting to die. She points out Sec has demanded to be moved out of the nursing home, which he says he dislikes, into a private residence with a live-in caregiver. And he has taken steps to repair his relationship with his family in Quebec, particularly his teenage son with whom he has little contact.

Since their story was published, Sun says Sec has received more visitors from Vietnamese and Cantonese speaking communities, which has elevated his spirits.
“A lot of people from the community, they visited him and built a friendship,” said Sun. “He’s lonely and has no family in Toronto. So if a lot of people visit him, bring a small bowl of pho noodles (his favourite food), he will feel so happy.”

Simon Kim met Sec online through a Facebook discussion group for Toronto francophones a few months back. Since then, the Willowdale resident has messaged back and forth with Sec and visited him on occasion.

“Sometimes I’ll get messages from Tommy at 5 in the morning,” said Kim. “Just making small talk. He’s a very lonely guy.”

Despite opposing euthanasia for religious reasons, Kim supports his friend’s wishes.

“I don’t personally believe in it, but I believe there’s a reason our paths have crossed,” said Kim.

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