

“It’s okay Dad, I get it.”

Spencer was diagnosed with a chronic disease in his 20’s. He was a nice young man from a good family. He was raised by his grandmother. He had two young children and a fiancée. He also had a whole lot of denial about his disease and he was not taking his medication properly. Over time, as he became more susceptible to diseases he would end up in the Intensive Care Unit (ICU). These hospital stays would take their toll on his body but he would always recover and leave the ICU, a little weaker and thinner. Most of the time, he would leave the hospital against medical advice. This went on for years. His fiancée took their children and left him. Spencer became so weak that he moved in with his grandmother so she could care for him.

Each time he had an admission to hospital, the doctors caring for him would discuss the fact that he could not be cured and he would never regain his previous quality of life. The doctors would ask him if he wanted to “change his code status”, to be a “No CPR”. As his health care professional, he and I would talk about his pain, about yet another admission to the ICU and the invasiveness of it all. He told me he always felt as if he was being pressured to die. He told me that he could not do that to his grandmother or his kids, to just leave them.

We discussed doing an advanced directive in part because Spencer wanted to designate his grandmother as his proxy. However, given the legislation in the province, his fiancée felt she should be his decision maker whenever Spencer was incapacitated. The health care team would sift through old notes, discuss current relationships and contact the hospital’s legal team who would advise that his next of kin was his mother. Spencer did not want his mother to act on his behalf so he designated his grandmother as his decision maker. At first, Spencer did not want to complete a My Voice booklet. He felt that he would recover and return home. I left the package with him to read. We revisited the topic regularly.

He returned to the ICU after his kidney’s failed. This was his longest stay in the ICU. He went down to 65 pounds and needed dialysis for his kidneys to work. It was clear from his physicians that he would not leave the hospital. An emergency meeting was held as Spencer had begun to bleed uncontrollably and lose consciousness. The family, including his grandmother held fast to the belief Spencer would recover, even if he needed the ICU again. Spencer did not seem so sure.

A few days passed and he asked to meet with me and the elder, privately. He had been reading the My Voice booklet. The three of us discussed the document, and Spencer felt that he should complete it now. He did not want to return to the ICU but felt that even his proxy would choose that for him if he lost capacity. He also wanted to end dialysis and stop the tube feeds. In short he had come to his end. He was clear in the fact that he did not want to disappoint his family. He was frightened to discuss this with his grandmother and his kids. He was worried that they would not understand what he had gone through in the ICU last time and what he was feeling now. We met as a group and discussed his wishes. It was a very long conversation. At first his family was upset that he had made these choices. The document was passed around the group for two days. Copies were given to his Grandmother as his proxy to show his family who could not attend the meetings.

Spencer was unable to speak for himself a few days later. He was no longer communicating. He would stare off into the distance. In his culture, it is believed that a person’s ancestors visit them at life’s end.

I was there when Spencer passed. His daughter, barely a teen asked her great-grandmother why the doctors’ were not helping her Dad anymore. Her great grandmother took out a folded, well-worn My Voice booklet. It was the one designating what Spencer wanted for his care at the end of his life. She took her great grandbaby into her lap and read the page out loud to the group at Spencer’s bedside, and then she asked me to explain to her great granddaughter that this is what her Dad wanted, this was his dignity. I did not speak a word.

His daughter simply took her Dad’s hand in her own, and said “It’s ok Dad, I get it.”