

The continent of cancer

Allan Wilson

It was a cold spring afternoon more than 2 years ago when the call came. Before my wife said anything I could hear her crying.

“Josh has cancer.”

The words landed like a fist against my chest.

“The doctor said it’s 99% certain. It’s above his right knee. We have to go to the Children’s Hospital tomorrow.”

“How is he?”

“He cried a bit. He’s okay now.”

For 6 weeks our only child had been complaining of a sore knee. Today he was hit hard in floor hockey at school and collapsed in pain.

“We’ll be home soon.”

I hung up the phone and tried to let the information settle. How could this be? Josh was always so healthy, and until a few minutes ago all we were worried about was a sore knee. How could the best thing about us — a wonderful, intelligent, funny, vibrant young man of 14 — be hit with a deadly disease? What did we do wrong?

I had to sit down. There was a tightening across my chest. I was having trouble breathing. Eventually I came to the overpowering realization of any frightened parent: I would do anything for my child. I would cut off my hands if that would help.

And so began the longest and hardest journey of our lives.

It did not end well. In January we buried our son, the victim of bone cancer, osteogenic sarcoma. Whatever I, or my wife Sandy, or the doctors and nurses could do, it was not enough. Chemotherapy and surgery only slowed the inevitable.

Now I realize how that phone call — a singularly stunning moment like no other before in my life — took us instantly and irrevocably to another place. It is a harsh and unforgiving landscape where survival is possible but chancy, and where even the light and the sky seem different, as if permeated by fear and dread. We were immigrants on the continent of cancer, and never again would we get back to the old world.

In a few days we were in a room at the Children’s Hospital facing brutal choices. The doctors and nurses and counsellors were very kind, brilliant in their patience and anticipation, helping us adjust to the mental landscape. But their message amounted only to this: we will poison your son with chemotherapy, then cut up or cut off his right leg. He will stay in the hospital almost all the time for the next 10 to 12 months. He will be bald, very sick, will have to endure years of physiotherapy and will possibly end up sterile.

With all that he may have a chance of surviving 5 years. Sign here, please.

With little thought we deferred to their wisdom; we agreed to chemotherapy immediately and faced the choice of what to do about the 16 cm tumour. The choices were upper-thigh amputation, total knee replacement, and something called the Van Nes rotationplasty. The first was the simplest: an hour of chopping and then back to chemo in a few weeks. The second choice, the knee replacement, meant ending up with a leg that looked normal from the outside but had little flexibility and gave the feeling of limping on steel. The third involved amputation with most arteries and nerves intact, while the lower leg was turned backward and reattached at the upper thigh so that the reversed ankle became a bendable knee joint. A prosthesis would be added below that, offering flexibility, some athletic participation and, eventually, no limp.

My wife and I felt our son should make the decision. He chose the 11 hour, 5-doctor surgery to get the Van Nes. Even a year later, under his clothes, it was functional but still inelegant.

The operation and his recovery preoccupied us until September of that year, when Josh was strong enough to resume chemotherapy. I went back to teaching while Sandy stayed with him in the hospital in Calgary. I would visit and relieve her on weekends. He was responding acceptably, the scans were good and the fear was diminishing. We knew we could never leave this terrain of tension, but perhaps only once a day would fear grip us. The rest of the time we dealt with a routine of his treatment and comfort.

In February we sat in the oncologist’s office and listened.

“We can see no more evidence of tumours. He is ... cured.”

There was some hesitation in that sentence, not because the doctor had specific knowledge he wasn’t telling us, but because he feared, as he did with all patients, that the cancer would come back. When he said the word “cured” I felt both relieved and wary: “cured” meant only that their instruments couldn’t see into every single cell, just down to 1 mm. Perhaps we could be survivors in this new land, this place where fear was like bad weather that could settle over you in half a day.

In 3 months the cancer returned, proving that it had never gone away, one part per million resisting chemotherapy and hiding microscopically from medical imaging until it manifested itself as 2 tumours in the diaphragm. They wouldn’t tell Sandy until I arrived at the hospital in the afternoon, so I knew it was not good news. I remember dri-

ving home to pack, going into Josh's bedroom to get something and then collapsing on his bed in violent sobs, an image of his gravestone forming up before my closed eyes. That evening we again made the instant decision: a different and stronger chemotherapy. We lost almost all optimism. Two months later it was 6 tumours, and they decided to operate. The procedure was abandoned after an hour: in addition to 6 tumours on the scans there were now dozens of tiny ones on the heart and lungs.

Terminal diagnosis. Estimated survival between 1 and 4 months. We were waiting in a small room when the oncologist and the social worker came in to tell us. I felt like I has been cut in half; instantly I half cried, half yelled, "*But I love him so much!*" There was an incredible sense of being unable to breathe, as with the first call 15 months before, only much more intense. Now Sandy and I were going to lose him, and we would be stuck forever on this continent, locked in, without his friendship and love to comfort us.

There were other choices, chemotherapy protocols that would not save him, might add a few months, but would undoubtedly make him sick and even possibly shorten his time. There were choices on the Internet to sift through, but these fell into 2 categories: scientific research studies that crept along at glacial speed, and fraudulence.

Although I wanted to take the experimental route, we agreed that Josh should make the decision. He put it off, first until he recovered from the surgery, then until we returned from 10 days in London and Paris, and then until he found a better painkiller. It became clear he didn't want any more treatment but was pretending to stall out of respect for my feelings.

By the first week of September he had found an effective

pain medication, and a few weeks later steroids brought back comfort and appetite. He was able to have friends over, go for short walks during an extraordinarily warm fall, go to movies, laugh at the new season of TV shows. He had a wonderful 16th birthday on November 7, riding in a fire truck and driving three CPR engines across Lethbridge's High Level Bridge and then returning home to host a party with his friends and a keg of beer. We did have a Christmas, and then we watched the year 2000 come around. We were able to grow together in tenderness. One of his best gifts to us was to say, "We all did our best."

In the end his heart gave out, an engine pushed beyond its endurance not only by the 8 rounds of chemotherapy, steroids and narcotic painkillers but also by the tumours calcifying in his right lung. Our son was right about declining more chemotherapy. He might have died throwing up in an oncology ward instead of living 2 months beyond the doctor's prediction.

I remember looking out the window of his hospital room on that last morning, knowing it would only be a matter of hours, watching the glistening snow on the trees, seeing the brittle awkwardness of this new terrain stretching out before my wife and me. We knew we were going to be stuck forever in this place, that we would struggle on because our son wanted us to, forever haunted by that single phone call that banished us here, living with this sense of bewilderment muffling down upon us like snow in an unprotected, unfamiliar land.

Mr. Wilson is a teacher living in Lethbridge. His journal of his son's last 6 months, *Walking Upright Through Fire*, won an Alberta Arts Foundation Writer's Grant. Parts of this article were read by the writer on the CBC radio program *First Person Singular*.