

Battling a disease and bureaucrats

By RON CORBETT

Last Updated: 23rd June 2009, 9:42am

Lisa Nancarrow is 34, a federal civil servant working for the Canada Border Services Agency. She is a well-spoken, thoughtful woman who does not like to bring attention to herself.

Which is why she is quick to apologize when she starts to cry. She had promised herself she wasn't going to do that. She's fighting this thing. Not breaking down and crying about it.

Even though it's difficult, telling a stranger what it feels like to be told you are dying. At the age of 34. To be told you are dying. Imagine.

"I refused to hear it," says Nancarrow, of a recent medical appointment. "When the doctor tried to refer me, I said 'Whoa, I'm only 34. I am NOT going to a palliative-care doctor. What are my other options?'"

That fighting spirit will stand Nancarrow well in the months ahead, not only as she battles a disease called neurofibromatosis, but also while she battles the bureaucrats at the Ontario Health Insurance Plan.

It is a tossup which battle will tax her more. And in these days of million-dollar consultancy fees for eHealth Ontario — this is a story that should anger you.

* * *

In 1993, at the age of 17, during a routine medical check-up, Lisa Nancarrow was told a lump had been detected in her stomach. Later that year, the teenager was told she had neurofibromatosis.

She read about the disease with an almost detached curiosity. She had no symptoms, was feeling fine in fact, and the words almost washed over her — genetic nerve disease, tumours, Schwann cells, NF.

The part she remembered was what the doctor told her — we can treat this. We will monitor the non-cancerous tumours growing in your stomach, and we will remove them — "de-bulk" was the phrase used — if they ever become a problem.

Now, go and enjoy your life. That was the medical advice. And that's what she did.

For 15 years, not a problem. And then in the winter of 2007, the strangest thing occurred: Lisa Nancarrow finally got a symptom.

* * *

It started as a pain in her stomach. Months later, following a CT scan, she was told the NF tumours had grown larger, were beginning to push her stomach to one side, were slowly beginning to encase her organs.

What happened next was almost surreal, like watching a train wreck with no way of stopping it. Nancarrow was referred to surgical specialists in Toronto, who told her they could not operate. It was too dangerous.

She was referred to oncologists, who told her radiation was not an option. It was too dangerous.

It took more than a year, going from doctor to doctor, before the shocking truth emerged — there were no treatment options for her.

“I was stunned,” she remembers. “I had been told for years that the tumours could be removed if there was ever a problem. Now they were encasing my organs, and everyone was saying there was nothing they could do.”

Today, Lisa Nancarrow is starving. She has lost 40 pounds in the last year. Drinks meal supplements because she has trouble swallowing. Doctors have told her this is now a life-limiting illness.

Six months ago she learned about an NF clinical drug trial at the Mayo Clinic in the United States. She applied and was accepted into the program.

A few weeks later, OHIP told her they wouldn't pay for it.

* * *

I am sitting in Craig Nancarrow's house. His family — mom and dad, wife, young child, sister Lisa — have gathered for supper.

And I wonder, as I sit there with them, how this family can keep from being angry every minute of every day. How they can keep from feeling set up.

“The doctors told Lisa the OHIP claim would be a no-brainer,” remembers her mother, Janet. “There is no other treatment option for her. We were all shocked when they rejected it.”

OHIP has told the family the drug trial is “experimental” and will not be covered. Among those arguing for the treatment is Erick Poulin, surgeon-in-chief at the Ottawa Hospital, General Campus, but it has all fallen on deaf ears. OHIP has rejected an appeal as well.

Which leaves the Nancarrow family paying for their daughter's treatment. One trip to the Mayo Clinic is \$7,000. The family is there today. And will need to make dozens of trips in the next two years.

A family paying for their dying daughter's medical treatment, while eHealth consultants are billing Ontario taxpayers for tea and muffins. It's shameful.

I ask the family if they have contacted Lisa's local MPP. Lisa says yes, months ago.

"We spoke to someone in his office, and he was to get back to us," she says, then throws up her arms in a 'still waiting' gesture.

The local MPP might want to take another look at this file. Lisa Nancarrow lives in Ottawa south. Her MPP is Ontario Premier Dalton McGuinty.

Ron Corbett: Unscripted can be heard on 580 CFRA Monday to Friday between 8 p.m.-10 p.m. You can contact Ron at Unscripted@CFRA.com.