

Living with Cancer

John Wilson writes of his life as a survivor, living with GIST cancer

I didn't like people saying that I was battling with cancer, so I told my family, "When I die, don't say that dad *battled* cancer; tell them that I *lived with* cancer." This is my story of how I discovered I had cancer and how I have been living with it for the last 15 years.

In the late 1990's, I started to have vague but persistent symptoms of discomfort, and even occasional twinges of mild pain, in the lower abdomen and groin. I also noticed that my stamina was not as great as it once was, but I put it down to ageing and not having enough cardio-vascular exercise. I had always tried to keep physically fit, but due to a knee injury I had stopped my daily jog, though I still walked a lot.

I don't recall when I first went to my family doctor, but he took me seriously, and over several months put me through a number of blood tests (including for PSA), a heart check, cystoscopy and sigmoidoscopy; but everything came back normal. "According to all these results, you are a very healthy male for your age. I know you are not imagining things, so we will have to keep monitoring your situation."

In 2001, my wife and I travelled to the remote province of Papua in Indonesian (formerly Dutch New Guinea) where, for twenty years, we had been missionaries, involved in literacy and Bible translation. The complete Bible in the Yali language had been published the previous year, and there were plans to make a documentary video about the Yali people and their story surrounding this first Bible in one of the 230 languages in the province.

The Yali people live in isolated valleys in the interior highlands, and there are no means of transport, except small single-engine aircraft; there are no doctors, grocery stores or hardware stores nearby; no modern conveniences—the only electricity was supplied to our house by a small diesel generator. For two weeks, every day, I was involved in the outdoor filming, and every evening, the producer had me orally translate all the interviews into English, so that she could write a script and do the editing. It was a tiring process.

One night, I woke up with acute abdominal pain. That day, we had been filming the spectacular mountain scenery from a helicopter. The camera person was beside the pilot in the front and I was seated behind the pilot, facing backwards, so I had to twist awkwardly around to talk to him to give directions. At one point I felt what I thought was a strain of my abdominal muscles, but now, in the middle of a dark, sleepless night, I wondered if it might be more sinister. However, when day came, I was caught up once again in the interesting round of video interviews, translating and editing.

When the work was done and the film crew left, I had another job to do. I had to fly to another mountain village location to help in a week-long seminar for church leaders. But one morning, when I got up, I collapsed on the floor with excruciating pain. I didn't know what to do with myself and I wasn't sure if anyone else was awake yet, but I called out as loud as I could. My colleague in the adjacent room heard me, got up and came to see me. Immediately, he saw that I needed urgent medical help, but

there was no phone or radio, so he called another colleague who had a trail bike, and asked him to ride to the nearest town where the mission aviation agency had pilots and planes, and where he could use a radio to talk to a doctor.

In the late afternoon, a mission plane landed. The doctor suspected peritonitis, and I was to be flown to a mining company hospital. I underwent an x-ray, abdominal ultrasound and blood tests. Meanwhile my medical insurance company was contacted, and after a week without diagnosis and continuing decline, it was determined that I should be evacuated to a hospital at Darwin in northern Australia. In the morning I was taken by ambulance to the airport where an executive jet hired by Australia's flying doctor service waited. The nurse and doctor on board, my wife and I were the only passengers. In Darwin, I was transferred to an ambulance for the short drive to the hospital.

After another battery of exams, the surgeon came to me. "We have no indications from the tests as to what we are dealing with, and nothing shows on the scans which would justify surgery; but we could do a laparoscopy, and if we find anything we could operate right away."

A few hours later, I came to, back in the two-bed ward, with tubes sticking out of me, and through the haze of my eyes I made out my wife standing beside the doctor. "We found a tumour," he explained, "It was quite large, and I had to do a resection of the small intestine. However, I am confident we got everything." Later he explained that the tumour had been sent to a pathology lab in Perth and the results were back. It was a "low grade sarcoma" and there was "little chance of metastasis". By the time I was released to make the long journey home, I was 20 kg lighter than I had been when I left Canada.

When I returned home, I immediately visited my doctor and told him the story. It puzzled me that it had taken so long to diagnose the cancer despite all the tests I had undergone in the previous years. He agreed with me, but assured me that he would be much more alert to the possibility of cancer even when none of the usual indicators are present. He made an appointment for me to see an oncologist at Princess Margaret Hospital. This oncologist was also intrigued by my case, because of the story of diagnosis, the size of the tumour and where it had been found. "The tumour must have been growing several years, and I imagine you had felt considerable discomfort for a while." He referred me to the Credit Valley Hospital for monitoring, but again affirmed that the chances of metastasis were small.

Two years later, in July 2003, I sat in the waiting room at Credit Valley following a regular follow-up CT scan, and I was thinking, "I feel pretty good." I was ushered into an examination booth where a young doctor asked some innocuous questions about how I was feeling. Then she explained, "We have looked at your scan, and it appears that the cancer has returned, and there are two, maybe three new tumours."

I was shocked. My wife and I had plans to take up a new assignment based in Singapore - the airline tickets had already been ordered. These were the first things that popped into my head! The enormity of this news for my health had not yet sunk in.

"Are you all right, Mr Wilson?" the doctor asked me kindly. "Yes, but it is a shock, because we had plans to move to Singapore, and now I need to cancel everything."

As well as working at Credit Valley, this young doctor was also in residence at Mt Sinai, where she worked with one of Canada's top oncologists, Dr Martin Blackstein, and thanks to her intervention, the following Tuesday, I was at his regular clinic. He informed me that earlier that year a drug called Gleevec had been approved by Health Canada, and that it could be beneficial in my case.

I had also been given an appointment with a surgeon at Sunnybrook, who after looking at the MRI declared that because of the complexity of the location and nature of the tumours, he declined to perform any surgery and sent me back to Mt Sinai. And so I started to take Gleevec.

But the financial cost, as readers will know, is very high. My private insurance would not cover the ongoing expense, but I had been tipped off to apply to the Ontario government's Trillium program. This is where it would have been good to have had some support from people who knew the ropes; but I had to do it alone—asking questions, making phone calls and doing research on the internet. When you are facing cancer and have so much on your mind, the last thing in the world that you want to be doing is worrying about finances and filling in forms. It took me weeks to find out that the manufacturer would provide financial assistance. Nevertheless, I was glad I was in Canada, with access to a splendid public healthcare system.

I was surprised by the number of well-meaning (but poorly informed) people who gave me advice about cures for cancer and "amazing diets" which would lead to recovery; or suggestions that I should *not* take all these "foreign chemicals" into my body. I thanked each one for their concern, and explained that there are multiple kinds of cancers and treatments, and I was confident that Dr Blackstein knew more about GIST than any of these people.

There are, of course, side effects to the drug, which I am sure vary from person to person. I experienced a lot of nausea. Then there was swelling of my arms and legs, and especially in the morning, puffiness of the eyes; occasional cramps and nerve pains in the arms, legs, hands and feet; but most of this abated—or maybe I just got used to it through the years.

More seriously, my haemoglobin count started to slide. About two years ago, Dr Blackstein printed out a graph of the blood results from the beginning of treatment to the present, and it looked like the financial chart of a failing company, zig-zagging down the page from left to right. He suggested I should get my family doctor to request an appointment with a haematologist. Fortunately, my doctor had noticed the downward drift too and had already asked me if I felt shortness of breath and a decline in energy. "Well, now that you mention it, I have, but I thought this was just part of the aging process!"

Soon I had an appointment to see a haematologist. One year ago, I was started on Eprex—a synthetic hormone which stimulates the bone marrow to produce red blood cells. I later learned it was called "the athlete's dope", and I learned why, because the results were quite dramatic, and it was like a new lease of life.

During all these years, I have been very thankful for the love and support of my close-knit family and the prayers of people around the world. My faith was, and is a great source of strength, and many of my

friends have kept on praying for me. The emotional and spiritual support is surely one of the key elements for maintaining hope, giving vision and stimulating vitality.

I also stayed active in the local church and, to the surprise of my oncologist, I also made occasional teaching visits to Indonesia and other parts of South East Asia. The first time, which was after one year of treatment, I asked his permission, and he simply responded: "You know the risks involved, and what medical facilities are available wherever you go. It is your choice!" In the ensuing years, at my regular check-ups, he would always ask, "Do you have another trip planned?" or, "When you go next to Indonesia can you bring me back some good coffee?"

On my last visit before he retired, he shared some statistics for all the patients he had treated since Gleevec was approved, and how I was one of the few who had not required second-stage drugs. When I started on Gleevec, my life expectancy was said to be 2 years, but now 15 years had passed. Not for the first time he said, "You are amazing, John!"

Of course, I am not amazing; what is amazing is that with Gleevec and God's grace I have lived a full, active and effective life with GIST cancer. And one of the things that thrills me most is that my oldest grand-daughter, who was only 6 years old when I first got cancer, will graduate this year with an honours degree, and I am still here to celebrate with her!

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