Reflections

Lessons for us all
One doctor’s experience with a fatal illness

W. Paul Hooker, MD

Like many doctors, I have had the uncomfortable duty of informing a patient that he or she has a fatal illness. It is part of the job, and we must do it with compassion and composure. But, as doctors, who of us has not wondered how we would react to receiving such news?

My life changed instantly
Throughout the winter of 1998 and 1999, I was feeling unusually fatigued. By February I was starting to lose weight and could no longer attribute my fatigue to overwork. I had a blood test, but I fully expected the results to be normal. Unfortunately, the results were anything but normal. My white blood cell count was 64 000; there were myelocytes, metamyelocytes, promyelocytes, and myeloblasts. I had chronic myeloid leukemia (CML). My life changed in the time it took me to read my test results. I accepted it immediately without any of the denial or anger we see occasionally in our patients. I think this is a doctor’s reaction. We know the truth when we see it. We have been trained that way.

I drove home and told my wife. This was very difficult and extremely emotional. We had a good cry, which was a profound relief for both of us. I empathized with how she must feel: to contemplate seeing someone you love wither away and die; to have to say “goodbye”; to have to go on alone. We made the decision that I should retire. Faced with this disease, I found it remarkably easy to quit my family practice of 30 years.

I read all I could find on CML and developed a new understanding for some of my “tedious” patients who had to know everything about their diagnoses. I learned that CML is fatal. If I were an average patient, I could expect to live 3 to 4 years.

Feeling like a patient
The first time I felt like a patient and not a doctor was during my initial visit to the outpatient hematology clinic in the very old Heather Pavilion at Vancouver General Hospital in British Columbia. I knew none of the staff on the ward. I looked to my wife for reassurance that I was important to someone. We had a long wait in depressing surroundings reminiscent of pictures I had seen of the inside of a hospital in communist Albania. The furniture appeared to have been acquired at a rummage sale. Several emaciated and bald patients were watching a soap opera on television. They were receiving blood and medications through awkward-looking Hickman catheters protruding from their chests. For the first time since my diagnosis, I was afraid. Here was my future, and it looked pretty awful.

The hematologist struck me as someone trying to do the best possible job under grossly underfunded circumstances. We discussed the natural history of CML and my treatment options. He advised chemotherapy rather than a bone marrow transplant, because the transplant would be too risky for someone my age (54 at the time), and I lacked a matched sibling donor.

He escorted me to a small room where I lay down on a cot against a wall. Eight to 10 tubes of blood were withdrawn, mostly for research purposes. Then I rolled onto my side. While the resident did a painful job of the bone marrow biopsy, I stared at the large patches of old paint peeling off the wall. For distraction I tried to count the

Dr Hooker is a retired family physician living in Cranbrook, BC. His e-mail address is phooker@cintek.com.
layers of paint that showed how many times those old walls had been painted. I felt afraid and vulnerable. Afterward I related my experience to my wife. She was a big help, but I knew that, at some stage, I would have to go it alone.

Back home I went to the local hospital for weekly blood tests. I was always greeted with recognition and concern. I knew the hospital staff and my colleagues would do anything they could to help. This knowledge was very therapeutic.

My chemotherapy consisted of high-dose interferon plus cytosine arabinoside. Quality of life became a real issue. The side effects are like having constant influenza with nausea, anorexia, extreme lethargy, and depression. Over the next 10 months I lost 35 pounds. Despite this potent chemotherapy, I failed to achieve hematologic remission, and my white blood cell count started rising again. I could sense the frustration in my poor beleaguered oncologist’s voice over the telephone. It must be a tough job. I am desperate and know I am slowly dying. There is really nothing more he can offer.

Hope returns
I received an e-mail message from my nephew in California. On the front page of the Wall Street Journal was an article about a new and amazingly promising drug for CML. The principal investigator was a Dr Brian Druker at the Oregon Health Sciences University (OHSU) in Portland. The drug was called STI571. I called my oncologist in Vancouver again and, although he was pessimistic about new wonder drugs, he agreed to refer me to Dr Druker.

Two weeks later I was at OHSU. The facility, in contrast to our poorly maintained buildings in Canada, was modern and welcoming. Dr Druker and staff were courteous, efficient, and thorough. My white blood cell count was now 39 000, and results of my bone marrow chromosome test showed 97% of my stem cells were still positive for Philadelphia chromosomes. Obviously the interferon was not working. My insurance company refused to pay for any of my costs once I started receiving STI571. They would continue to cover my medical costs only if I continued my therapy with interferon in Canada.

Three weeks into the STI571 therapy, my white blood cell count fell to normal, just as Dr Druker had predicted. Better yet, for the first time in a year, there were no early forms in my peripheral blood. This was nothing short of miraculous. Now, 10 months into therapy, I remain in hematologic and cytogenetic remission. My bone marrow biopsies, however, still show quiescent CML. It is too early to say whether I will be cured. I might develop resistance to the drug.

Lessons learned
What have I learned from this experience and what are the lessons for us all?
1. Make sure you are well covered with life, disability, and overhead insurance. Do not assume you will live a long time, which is largely a function of luck and your genome at birth.
2. Maintain a good rapport with your colleagues and hospital staff. This is professionally a good policy, and should you ever need help, they will be there for you. They will be compassionate and willing to spend the extra time and effort. Comradeship among health professionals is important.
3. Be an advocate for yourself. Learn all that you can about your disease, and when necessary, be prepared to push the envelope. Do not feel guilty because you are taking up your physician’s time. He or she wants to help just as you would want to help your patients.
4. Enjoy your job, even enjoy working hard, but always leave time for family, friends, and hobbies.
5. Should you develop a fatal or serious disease, do not expect to go through the classic stages to eventual acceptance. You will probably accept the truth for what it is and immediately go into problem-solving mode. Expect to be frightened, however, as the dismal prognostic data will be evident, and you will be unable to convince yourself that you will be “the exception to the rule.”
6. Never diagnose yourself. Find a good compassionate doctor, and do not hesitate to talk to him or her if you have any concerns.
7. Never give up hope. Hope is what keeps you going. It is the one cure for depression. It is the one positive thing you can share with your loved ones. Do not hesitate to talk to your colleagues and loved ones should you be so unfortunate as to develop a fatal illness and you are afraid and lost. They want to help but might be reluctant to initiate the conversation. Talking about your feelings and fears will help tremendously. If you have no one to share this burden with, contact me. If I am still here, I would be happy to help. ...