



LIVING WITH CANCER

“It was the best of care, it was the worst of care”

JAMES L. CONNORS

With apologies to Charles Dickens “it was the best of care, it was the worst of care.”

In May 2006, my company doctor called and said to go immediately to the Emergency Department of our local hospital for a blood transfusion. He said I was in imminent danger of having a fatal heart attack.

I had been feeling poorly. A few days previously at his request I had had blood drawn. He had just received the results, indicating my red blood count was dangerously low. He insisted I not drive. My wife had to do that, just in case.

That day I had several blood transfusions. I stayed in hospital and within 24 hours was diagnosed with metastatic colon cancer. Life as I knew it had changed.

A professional and corporate executive, age 50, with three university age children I now found myself traveling through the health system. My journey illustrates some of what is working well and not so well in cancer care.

Let’s turn the clock back a few months before May 2006. I had started to feel extremely tired. A walk-in clinic ordered blood tests and forwarded the results to my family doctor. He called to say I was “chronically anemic.”

I saw him and that’s when things started to go awry. There was no physical examination. He simply announced I had a stomach ulcer. He prescribed an ulcer medication, said he would book an “upper GI exam” several months down the road and opined the drug would likely clear up the ulcer by that time.

I knew I didn’t have a stomach ulcer. So I had the same blood results reviewed by my company doctor.

His approach was a universe apart. He looked at the results and said I didn’t have an ulcer. He examined me very thoroughly. He indicated my blood count raised

questions about the colon. I needed immediate referral for colonoscopy, CAT scan, etc. and he set those up.

He insisted I have more blood taken. In the following week, it was the results of my next blood test that prompted his fateful call to go immediately to the Emergency.

Subsequently, I suggested to the doctor who misdiagnosed an ulcer that he should have colleagues in his practice “peer-review” my file. I expressed fear that if uncorrected, his practice “may result in other individuals being similarly misdiagnosed when there is still time to successfully address their cancers.”

When he ignored my letters I wrote the College of Physicians and Surgeons. Making it clear I was not seeking disciplinary action, I only sought assurance that “knowledgeable medical professionals would look at this, and if there was merit to my concern” they address it with the doctor “so that his future care of others would be better than it seems to have been in my case.”

The College did as asked and “identified a number of areas of concern with the care provided” to me by my original doctor. They directed him to take actions including attending a program to “update his knowledge and develop an appropriate approach to the investigation of anemia.”

1. Doctors need to be more aware of cancer symptoms and, having identified those symptoms, be more timely and aggressive in referring patients for further investigation.

My company doctor, who took over as my family doctor, referred me to a surgeon who specializes in the colon. He had trained and practiced at the Mayo Clinic

before deciding to return home to Canada. This surgeon put me on his “emergency list.” He also told me that when he first returned home he was promised five surgery days every two weeks. But shortages of anesthetists and other cutbacks reduced this to three days every two weeks. His waiting list became huge, and he had to stop accepting referrals of complex cases from other provinces.

2. Resource constraints are preventing extremely competent specialists from being fully productive.

Let’s return again to when I was first diagnosed. It is the second day of my hospitalization. I was told I had colon cancer which spread to my liver. I’m now on a gurney about to be pushed through the donut hole of a CAT scan.

A doctor I had never met before suddenly loomed over me. Without any preliminaries she said. “I’m Dr. N——. I’ve looked at your scan. You have at best six to nine months so I’m not recommending surgery.”

Wow! Talk about a lack of bedside manner. And leave aside the fact that, as of the time of writing this, I have lived three times as long as her grim and off-the-cuff prognosis.

Of more importance was not letting what that doctor said deter me from seeking other doctors’ opinions and finding out that there were the other options (including the surgery she wasn’t “recommending”). These have kept me alive and generally well, in spite of my still having very serious cancer.

One should be very troubled by the question: “How many other folks, less assertive than me, would have just taken what she said as the final word, pursued no other treatment, given up, gone home, and made ready to die?”

3. Carelessly giving premature and incomplete information contributes to some cancer patients not seeking the care they need to significantly prolong their lives.

Let’s jump ahead few months. I have now had successful surgical removal of cancer from my colon, but I know the real fight is in my liver. I have a great oncologist. Several months into chemotherapy he recommended a targeted therapy, Avastin, which, while not a cure, might shrink the tumors and further sustain my life.

The trouble is that while the oncologists here and elsewhere have all agreed this drug should be included as standard medical care for patients with precisely my condition, it is very expensive (on average \$35,000). It is not funded by my province. Here’s the real kicker. If I

lived in BC, or in Quebec, or next door in Newfoundland and Labrador, the drug is provincially funded.

Fortunately I have the means to pay for this drug. So I began taking it at a private clinic, still under my oncologist’s care.

But I got angry as I became aware that in any given year, of about 100 Nova Scotians who should be taking and potentially benefiting from this drug, only a handful, for financial reasons, actually receive the drug.

This is the worst of two-tier health care. It starkly demonstrates the unfairness of a system that allows one standard for the wealthy and a lower standard for everyone else. Those who have the financial means to obtain the drug will probably live longer while those who do not will probably die sooner.

4. Canadians should not live or die of cancer by reason of their province of residence.

I responded reasonably well to chemotherapy. The tumors in my liver shrank to the point where a surgeon said, if I was prepared to be aggressive, he “might” be able to get it all.

But some annoying little spots were showing up in CAT scans of my lungs. A PET scan was required to determine if they were cancerous. We don’t have a PET scan in Nova Scotia. (One is under construction, thank goodness.)

The closest PET scan is in New Brunswick, a five hour drive away. But Nova Scotia, engaged in a silly bureaucratic disagreement, will not pay for PET scans in New Brunswick. Instead Nova Scotians must travel a far greater distance to Quebec where the government will pay for scans.

Travel costs (none of which government pays) were not an issue for me. But again, let’s think of all those Canadians, in tighter financial circumstances, who need this important test which would determine if they could undergo life-prolonging surgery, but cannot pay for it, or cannot access it much closer to home.

5. Inequitable access to cancer diagnostics means some Canadians will do without and suffer unnecessarily.

Then I encountered an example of how waiting times become much longer than necessary. The office of the surgeon who ordered my PET scan waits until the results have been received before contacting the patient to book the follow-up consultation.

A suggestion to medical booking staff: determine how long it usually takes to receive the report for each diagnostic test. Then book the follow-up appointment

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with the patient at the same time you book the patient's diagnostic test. This might shorten the time to the next doctor's visit by only two to three weeks, but it will make a huge difference for patients worrying about the progression of their disease.

6. Wait times can be shortened by better schedule management and doing so will make patients feel better.

Speaking of feeling better, here's a tale of two nurses. The day I was diagnosed with cancer, I was lying in my hospital room when an older nurse came in and introduced herself as just coming on midnight shift. She said she knew I had had some bad news. She offered that it might be a long night and if I was awake and needed someone to talk to or sit with, I should press the button and she would be there.

A few weeks later, I was just out of surgery. Once again alone in a hospital room, this time looking at pictures of my three beautiful children, I must have been feeling sorry for myself for another nurse appeared, sat down, and gave me a hug.

I don't recall the names of either nurse but they are the closest I have ever met to angels. God bless them.

The only other health professional who has asked about emotional or non-physical issues was my company doctor. People with cancer face practical issues that have nothing to do with their treatment options. They and their loved ones face tough decisions and experience a range of strong emotions. There may be economic pressures, sexual issues and certainly a whole host of other stresses with which to cope.

You cannot fully treat a cancer patient without being aware of the other non-medical stresses in the life of a

cancer patient and his family that may negatively affect the outcome of treatments.

7. Failure to address the emotional and practical issues confronting the cancer patient can negatively affect treatment of the whole person.

By nature I am not a critical person. I look for the positive in any situation. Likewise as we consider shortcomings in cancer care (including the criticisms I have made) it is important to view the big picture. An older oncologist told me that when he started practicing 40 years ago, 80 per cent of children with cancer died. Today, 80 per cent live.

There have been huge advances. I have nothing but praise for the vast majority of the professionals who serve in the front-lines. But as with any large system, especially one over-burdened and under-resourced by government, there are always opportunities for improvement. The foregoing, though anecdotal, is, I hope, illustrative of a few of those opportunities.

We face a cancer crisis in this country. At current rates, one of every four persons will die of cancer. To return to Dickens, one might say in the face of such an ominous future "it was the worst of times." But when we consider the array of resources and talents which we could potentially use to meet that challenge head on, surely we would want to be able to look back and say instead that "it was the best of times."

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