

Hello, I'm in pain here

By Bob Strupat

Albert Einstein took years to formulate his theory of special relativity. But after just one night on the surgical ward at St. Michael's, I could have tipped him to this immutable fact about the space-time continuum: *It will take at least 10 hours to get from 7 p.m. to 9 p.m. whenever the observer is confined to a hospital bed in a room with nothing but a large clock on the wall!*

After three operations within the last year I've learned some other astonishing things about hospitals, health care and human nature.

For instance, food never comes when you're hungry but always comes as soon as you have a visitor; nurses can sense from a distance when you're falling asleep and will immediately return to take your blood pressure and heart rate; tape will always be applied to your hairiest parts; within five seconds of learning you have cancer, whoever you are talking to will tell you about someone you don't know who also has cancer...or has died from cancer; when you're sick, you have a duty to meet the needs of the healthy, so never question the motives of visitors.

In addition to the surgery, I've endured six months of chemotherapy, undergone dozens of X-rays and CT scans, and popped so many pain pills...well, let's just say that if I had sold them on the street instead of swallowing them, I'd be able to buy Saskatchewan.

Statistically, 95 per cent of people in my condition will be dead within five years, and they told me that a year ago. Actually, oncologists don't speak that way, preferring to talk about a "cure rate" of 5 per cent – still, what are odds for if not to defy?

How I got into this mess

I put off having a colonoscopy for years by declaring that nobody was going to send a television crew up *my* ass! It seemed funny at the time...but laughing right now is quite painful and truly to be avoided.

It turned out to be no big deal, certainly far less stressful than the four hours it was necessary to spend the night before ingesting and expelling an astonishing volume of stuff they accurately call a “colon flusher.”

During the procedure, there was a monitor so I could see the inside of my digestive track, but I was soon lost in pleasant reverie thanks to the pain killer/tranquilizer concoction I had been given. Employing the latest medical terminology, the doctor had advised that I would soon be feeling “loopy,” and he wasn’t far off.

He immediately identified a tumour and diagnosed cancer – biopsy to follow but no doubt about it. That this was bad news hardly registered with loopy me, but it gave my wife, Karen, quite a shock.

Had I co-operated five years earlier, I probably would have had little more than some polyps that could have been snipped out during the colonoscopy. Instead, I am now a stage four cancer patient, which is when the disease has spread to distant organs and the odds for survival plummet from somewhere in the vicinity of total to somewhere in the vicinity of none at all.

The first operation

I had my colon operation within the month. It was early spring and thanks to my Florida tan, doctors, nurses and visitors never tired of saying, “You’re looking good!” but I couldn’t help taking that to mean, “You’re occupying a bed that some sick person needs.”

The surgery itself was a non-event. After being wheeled into the operating room, I awoke in the recovery room unaware that any time had elapsed. But it was soon enough apparent that something had taken place – the recovery room is a temporary nut house, with people shouting, hallucinating and otherwise behaving in the honest belief that the nurses are trying to kill them.

The incision went from just below the bellybutton to just above a place where no knife should ever venture. The surgeon took my precious abdominal rectus muscles and stretched them beyond reason to get access to the colon. These things normally don’t get sufficient credit, but it appears that they are indispensable to movement of any kind.

When I was delivered to my room and was transferred from the gurney to the bed, I found that I was plugged into a surprising number of devices, including an intravenous drip for essential fluids, a drip for anti-nausea medicine, a catheter and collection bag, oxygen, and a morphine dispensing machine with a button on a cord that I could press to give myself a measured dose of pain relief.

All of this was attached to a four-wheeled coat-rack-like IV pole, holding the promise of access to exotic places...a process that started the very next morning when I was naively thinking I deserved a little rest.

They apparently like you to perambulate without delay (the nurse told me it was “good to perambulate”) even if only a few steps at a time.

At first, I was certain I would never get from lying down to sitting up, and even if I did, my feet would never actually touch the ground; and if they did, I’d never be able to walk more than a few yards, and if I did, I wouldn’t be able to return; and even if I did all of that, I’d never be able to get back into bed, and certainly not lying down.

That’s when I remembered the Universal Post-Op Prayer from something I’d seen taped on a hospital wall, which runs along these lines: “Oh Lord, I’ve been good today and haven’t asked for much recently, but when I get out of bed I’m really going to need Your help.”

A nurse, an orderly and the mechanized folding bed combined to get me sitting up. Fashioned out with two of those open-back gowns, one frontward and one backward, I was eased to the floor.

With one finger working the morphine machine like the Morse code operator on the Titanic, I walked (OK, I shuffled) about a dozen steps toward the nursing station before declaring the perambulation a success and anxiously heading back.

In retrospect, I admit to a certain sense of accomplishment at going for that stroll just one day after surgery, but it totally wiped me out and I slept like a baby for the rest of the night.

In the days that followed I went further and further, until I could make a complete circuit of the ward with the help of my wife, trailing tubes and hanging on to the IV pole for dear life. Before long, I could make the trip on my own.

God bless the morphine machine. The drug is placed inside the dispenser under lock and key. Somehow it is regulated so that you can't give yourself too much or use it too frequently, but it provides immediate relief and a sense that you are exerting some control over your own treatment.

It also has a very loud alarm when the battery is getting weak. Mine went off once as I reached the furthest point on my daily journey. I tried to hurry back to the nursing station for repairs but people were peering out from every room as I shuffled past their doors beeping like a reversing cement truck.

I wanted to tell them the medical system was failing us all, but you can't get very assertive while wearing a floral patterned gown.

Then one morning they took the morphine dispenser away. I cried. Maybe it was because I was finally experiencing a realistic pain level, or maybe it was because the second bit of bad news had arrived.

A pre-op chest X-ray had revealed a "lesion" on the left lung, so they wheeled me downstairs and did a biopsy by sticking a long needle through my side, guided by the CT scanner, and snipped a piece for testing.

It was another tumour. It had spread from the colon; and I didn't need a doctor to tell me that there are a lot of other organs in between that could even now be incubating more tumours.

In about a week I was ready to go home. Trouble is, after colon surgery they won't let you out until you pass some gas, a self-test to ensure the plumbing is correctly hooked up. But when the only hospital food one can actually swallow is Jell-O, this can take days. When I finally let one go, I called home so the whole family could celebrate!

On leaving, I was told – seriously – not to lift anything heavy.

The second operation

Within a month I was preparing for lung surgery at Sunnybrook, where the pre-op process includes some reassuring pamphlets. But here's a notice they should add in future: If you ever have a choice between constipation from pain medication or constipation from swallowing a bowling ball, go with the bowling ball.

This incision went right around my entire side, leaving the appearance of something akin to a giant gill. They took out the whole lower lobe of the left lung, which is probably why today I engage in heavy breathing even when I'm not having any fun.

First stop after the recovery room was the intensive care unit, where it's one nurse per patient for the most attention you're likely to get in this lifetime.

One morning I was being washed up and the nurse was attending to my private parts when a supervisor toting a clipboard poked through the privacy curtains to ask, "How are you enjoying the service?"

"Better than I get at home," is what I should have said. But for once I kept quiet, and all three of us savoured the improbability of the moment.

It turned out that during the first operation I had developed a reaction to morphine, so this time they gave me a morphine derivative and delivered it by way on an epidural. This meant constant and total pain relief. The question was always "On a scale of 1 to 10, how much pain are you feeling?" and my answer was always, "Zero."

That certainly changed when they disconnected the epidural and changed again when they sent me home with a bottle of pills, but aside from more people telling me, "You're looking good," I had a pretty easy stay in hospital.

With lung surgery, for reasons I've so far been reluctant to learn, they put two hoses through your side to drain fluid for the first several days. The tubes are flexible but the part inside the chest is rigid and you can't help but lie in bed and wonder about how they are going to get them out of there.

Well, they *yank* them out. You turn on your side, you take a deep breath, you hear a swoosh and they're gone. No pain, at least not physically.

When I was ready to leave this time, my surgeon pronounced me a suitable "candidate for chemotherapy." You'd think a person wouldn't want to hear that, but being a candidate for anything sounded pretty good to me.

The chemo phase

After six weeks to recuperate from the operations and three days after my daughter walked me down the aisle at her wedding, I began six months of chemotherapy at the Toronto-Sunnybrook Regional Cancer Centre under the care of a medical oncologist who has about twice as many patients as seems sensible.

In my case, chemo meant daily injections for one week of each month. There was plenty of waiting involved and a blood test at the start of each month that added hours to that day's schedule, but the actual injection took only a few minutes.

The chemo drug for colon cancer, fluorouracil, turned out to be relatively mild and the dreaded side effects in my case amounted only to some nausea and some diarrhea for a couple of days each month in the week following the injections.

That's not to say I enjoyed it. To this day can't get my head around the notion that it's medicine and not something chosen randomly from vats at the local chemical refinery.

Chemotherapy may or may not zap all your cancer cells, but it seldom misses a healthy blood cell. When too many white blood cells are killed, you lose your ability to fight infection; when too many red blood cells are killed, the heart doesn't get enough oxygen, you become anemic and you have no energy.

At the height of my chemo treatments, I could do a grand total of one pushup. I could heft one shovel of snow. I could walk upstairs but I couldn't talk on the phone until I rested. I felt more like 89 than 59.

Each month, the week of injections seemed to arrive faster and last longer than the previous round. No sooner would the side effects pass and some feeling of normalcy would return, then I'd be facing another session. Before long, the nurses could hardly find a vein in either hand and their tapping to find a suitable target caused me more discomfort than the operations did.

And then one day it was over. My energy level slowly came back, I could taste food again, and I was thinking it hadn't been so bad.

But a couple of months later another blood test indicated another tumour. A CT scan found it in the upper lobe of my left lung. It wasn't there at the time of the first lung operation, so that meant it grew during chemo, proof that looking good was no valid indication of my true condition.

The third operation

I headed again to Florida for some pre-op conditioning and a fresh tan. Our sister-in-law Carol joined Karen and me for bicycle riding, swimming (20 laps a day, but I had to catch my breath after every two).

As for the operation – been there, done that. Still, there's always the unexpected, and it came courtesy of the severe acute respiratory syndrome crisis. Because various parts of various Toronto hospitals were shut down or understaffed due to SARS, Sunnybrook's intensive care unit was full.

My surgery was too serious just to send me to a ward but not such a priority to get me into ICU in place of some accident victim, so they assigned me to 24 hours in the recovery room, where they don't have beds but simply hold patients on their gurneys until they are stable enough to go somewhere else, usually within a couple of hours.

After the last of the raving patients had quieted down enough to be shipped out, I spent the night in a large room that not only had no other patients, but no other beds, kind of like a warehouse waiting for its next delivery.

No one said as much, but it was obvious the recovery room nurses didn't care to have overnight guests. Still, they scrounged a bed and, despite the mental and physical trauma of getting me into it, the stay wasn't too bad.

Once I got to the ward, the regular routine resumed and my wife spent most days bringing me things and taking things away. If Karen promised to come at 9 a.m. and showed up 10 minutes late, I would be complaining – even if she stayed until 9 p.m. – because when you're in a place where day and night are indistinguishable, every scheduled event takes on enormous significance.

I even looked forward to the 10 p.m. nurse with her shot of blood-thinning warfarin. I'd been pricked by more needles than a spinster's pin cushion, but I knew that when she left I could watch some TV without interruption.

You might recognize warfarin as common rat poison. There's nothing in my family history that called for a rodenticide, it's just the medicine of choice to prevent post-operative clots that could lead to strokes.

This time, the surgeon was able to remove the tumour and leave most of the lung lobe, good news when you're beginning to run out of parts.

Meanwhile, my sister-in-law was diagnosed with lung cancer that had spread to such an extent that there was little treatment they could offer. She spent most of the two months following Florida in hospital or at home with oxygen support.

I was ready for release in just under a week. The surgeon finally yanked the tubes out and sent me down for an X-ray to ensure that the lung wasn't leaking.

Unfortunately, the X-ray technician told me with some agitation that I should tell my doctor right away that the lung wasn't fully inflated and the tubes might have to go back in. I have no idea how the tubes go back in, and I sure didn't want to find out.

By the time I was wheeled back upstairs, my doctor had gone and the duty doctor never got around to assuring me that I wasn't about to stop breathing. I didn't get much sleep that night, expecting any minute to be told I was being sent somewhere for re-tubing!

Looking back...and ahead

Recovering from surgery is now old hat to me. I rely on the pain pills, expect to be frequently out of breath, and try to get on with my family and professional life.

But already a blood test has indicated another tumour and a CT scan has found it in the liver. Within days I'll be having a seven-hour operation where they will remove about 40 per cent of that organ, my gall bladder and who knows what else.

I am also mourning Carol, who died before I had a chance to offer her the support she provided me during my earlier operations. Whatever lies ahead now has a new poignancy to it, and I am giving the disease, and the odds-makers, renewed respect.

Nevertheless, I'm taking the view that as long as I'm alive, I'm not dead; and if I'm not dead, I might as well get on with living.

With that in mind, let me leave you with some hard-earned medical advice: When you're about to get a needle, inhale. If you want any sympathy, don't go to Florida and get a tan just before surgery. If your spouse doesn't have the patience of a saint, hire a real saint to sit with you, because you're going to be frustrated and irritable. Bring your own slippers to the hospital, because the paper ones won't stay fully on but also won't come fully off.

And, most importantly – remember that whenever the bad news isn't as bad as it could have been, that's good news.

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Update:

The day this article was published in the Toronto Star (Oct. 31, 2003), I was having an operation to remove half my liver. In the next two years I had two more operations, including removal of my entire left lung. Subsequent annual CT scans did not reveal any more tumors. In mid-2011 I was discharged as a cancer patient!