



diagnosis

One woman's agonizing wait for surgery

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It was the end of March 2006 and I was getting ready for a fabulous European cruise. The airline tickets were bought and special passes for the Uffizi Gallery in Florence were ordered. My husband and I were to go to spend more than a month visiting Iceland, Norway, Sweden, the Netherlands, Gibraltar, Sardinia and the Italian mainland. At age 59, I had already travelled a lot, but this would be the trip of a lifetime.

I decided to get a thorough medical checkup — I wanted clear sailing for my trip. I added a Pap smear to the mix. Since February, I had been having menstrual-like cramps and a clear odd discharge that contained square-shaped bubble-gum pink patches. I shrugged off these symptoms as related to my age and my history of yeast infections.

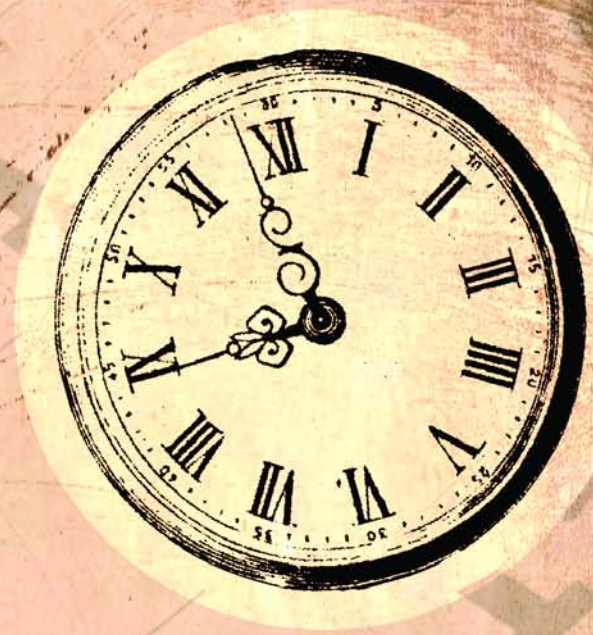
When several weeks had gone by since the Pap smear, I figured no news was good news. I didn't follow up too assertively on the test results, concentrating instead on getting ready for my wundertour.

FIRST STEPS

Then, out of the blue, in mid-May, my doctor's assistant phoned. "Do you have a gynecologist?" she wanted to know. The Pap smear — whose results, she admitted, had been buried for some time in the overflowing paperwork on her desk — had turned up abnormal cells. I needed to have a colposcopy, an imaging test to inspect the uterus, as soon as possible.

I wasn't too alarmed because I had a friend whose Pap-smear readings were often abnormal, yet further testing found nothing wrong. The assistant made an appointment for me to see a gynecologist in two weeks — in early June. No alarm bells were ringing yet, but as I look back, I realize that the clock had started to tick.

cancer



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The gynecologist was sympathetic and reassuring. He took a sample of tissue from my uterus and sent it off for analysis. The procedure was painful but quick, and the results would be available in two days. I wasn't worried — there was no history of cancer in my family — I just didn't want anything to mess up my cruise.

THUNDERSTRUCK

Two days later, the gynecologist phoned and delivered the staggering news as gently as he could: I had cancer of the uterus, and “everything would have to come out.” He promised to get back to me in a couple of days with an appointment to see a gynecologic surgeon. He got back in two hours. You want your doctor to be prompt but not that prompt! Still, I didn't panic — he was just being efficient, I told myself. I figured I had early-stage, garden-variety endometrial cancer, which has a generally good prognosis if caught in time. I could take my trip and have the hysterectomy later in the summer.

My appointment with the surgeon was not until the third week in June, a full two weeks away. The trickling sand in Father Time's hourglass was starting to speed up.

After several hours on a hard chair in the surgeon's overflowing waiting room, I finally got in to see him. He was the polar opposite of the kindly gynecologist. Gruff and unfriendly, he scanned my medical file in silence, then announced — with no softening of the blow — that I had a very aggressive form of uterine cancer with a poor prognosis (papillary serous carcinoma).

How soon can I have the surgery? was all I wanted to know. Possibly in three weeks, he said, but before surgery could even be scheduled, I needed to have a CT scan to determine the extent of the tumour. “If it's spread extensively,” he said, “there'd be no use operating on you. We'd just send you off to palliative care.” Hardly words I wanted to hear so early in the game.

On the heels of this terrible news, I underwent a comprehensive colposcopy and an unexpected cervical biopsy. Ouch! I was to cancel my trip, the surgeon said, writing *Emergency* in block letters on the requisition slip for the CT scan. If all went well, the surgery would be performed about two weeks after the CT results were in.

CARDIAC COMPLICATIONS

But there was a spanner in the works. In the fall of 2005, I had experienced severe shortness of breath. I was

prescribed an asthma inhaler at the hospital. The next day, my legs swelled up hugely, an edema possibly related to pulmonary edema and potential heart failure, although I did not know that at the time.

Even though I had fully recovered, the surgeon said I would have to undergo a battery of time-consuming cardiovascular tests before my operation could even be scheduled. The meter was turning over really fast now.

Leaving the surgeon's office, my husband and I went directly to a nearby hospital to book the CT scan. There, we both broke down sobbing. The terrifying knowledge that I had an aggressive cancer with a poor outcome had at last sunk in. And so many obstacles to surgery loomed on the horizon. To make matters worse, I researched my type of cancer on the Internet when I got home. Things did not bode well for me at all.

In all this, I never once asked, Why me? but rather, Why this kind of cancer? The risk factors for the less aggressive endometrial cancer I knew I had: I was post-menopausal, diabetic and overweight. But for the first time in my life, I had absolutely no appetite and I began to lose weight effortlessly.

My second appointment with the surgeon was not for another agonizing two weeks. By this time, it was the end of June, almost three months since I had had the Pap smear. The wait was painful and frightening, but the results of the CT scan were good. There were no signs that the cancer had spread beyond the uterus, and the cervical biopsy was clear.

The bad news was that there could well be some microscopic spread too small for the CT scan to pick up. And, again, any heart problems would have to be addressed before the operation. If all was well with my heart, I might still be able to have surgery in mid-July.

COPING

The cramping became much worse, particularly when I was physically active, and the discharge became bloody. I got it into my head that if I kept as still as possible, I could perhaps prevent the tumour from spreading. If only there were some medication that would halt its progress until the hysterectomy, I thought. I was obsessed with having this blackness cut out of me. Every minute seemed like an hour; every hour seemed like a day. I couldn't eat or sleep. I couldn't read or watch TV. I could only sit and contemplate my future. Outwardly,

wait-time counselling to get them operations will never happen

I may have been quiet, but I was screaming inside.

Patients facing life-saving surgeries need some kind of wait-time counselling to help get them through the dark days of fear and the feeling that their operations will never happen. I did contact the Canadian Cancer Society to see about finding a mentor, but with all the cardiac tests I was undergoing, we never managed to connect.

By now, my family doctor had referred me to a cardiologist for a workup — an exhaustive and exhausting battery of tests. I broke down in his office, crying that I didn't care if I died on the operating table — I had to have this tumour out ASAP. Of course, I was being irrational; doctors cannot perform surgery for early-stage cancer on a patient who might die of heart failure during an operation intended to wrest her life from the jaws of cancer.

The cardiologist was very caring and moved quickly to get me through the required tests. "You are my most important patient at the moment," he said, and his actions supported his words.

A week's worth of tests — several electrocardiograms, an echocardiogram, a chemical stress test, a breathing test and an angiogram — finally diagnosed me with cardiomyopathy. My heart was slightly enlarged, possibly because of a previous viral infection, and was not pumping enough oxygenated blood.

My heart's ejection fraction, the proportion of blood it pumps out of the filled left ventricle with each heartbeat, was just 25% (it should be at least 55%) and certainly not good enough to withstand a gruelling five-hour operation under general anaesthesia.

By now I was reeling. Two life-threatening diagnoses within a month. With my weak heart, was I ever going to have this tumour out? I imagined myself wasting away to a jumble of bones under a white hospital sheet. From all I had read, the only hope of surviving this cancer was timely surgery.

The cardiologist prescribed a drug to increase my ejection fraction and gave the go-ahead for the surgery. I am shy, but I very nearly leapt across the desk to give this reserved gentleman a hug.

So, finally, the surgery was scheduled for July 28 — about two weeks later than I had originally hoped, some



seven weeks after the gynecologist's diagnosis of cancer and four months after the Pap smear that had first raised the suspicion of cancer.

SHOULD I GO TO THE U.S.?

Meanwhile, realizing the aggressiveness of this cancer, my take-charge older sister had started checking for doctors in the U.S. who could perform the hysterectomy sooner than July 28. One cancer centre in Buffalo, N.Y., quoted us a price of \$30,000, but with my cardiac problems, travel and accommodation costs and the exchange rate at the time, it would have been more like \$50,000. I would have to have mortgaged my house, and I was willing to do this as long as I could have the surgery quickly. But with travel time and pre-op testing, going this route would have saved us only a week, so we soon abandoned that plan.

Frighteningly, all the U.S. doctors my sister contacted expressed deep concern at the type of cancer I had. They stressed that the chances for survival were reasonable only when the cancer was removed at stage 1. How that added to my heavy millstone of fear.

VISUALIZATION — BAD AND GOOD

I'm not sure how I got through the next few weeks, how I lived with the icy feeling that every minute the tumour cells were dividing and spreading. My mind raced between manic fear and beaten-down despondency. I had a lovely

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antique clock by my favourite chair. When it ran down, I refused to rewind it. As I sat looking into the black abyss, with every tick, I visualized the tumour cells metastasizing to distant sites such as my lungs and liver. A vivid imagination can be a bad thing at times, and mine is vivid.

I owe my psychological survival to my sister, who gave me touch therapy twice a day. This one-on-one contact calmed me down and seemed to mitigate the cramps. Every four days, she also gave me reflexology, a form of foot massage that some believe can boost the immune system. We also did an imaging exercise called clay tabling, a technique that helps you visualize your disease. This involved making a three-dimensional clay model of my reproductive system, including my conception of the tumour's appearance and its location. Then I performed on the model the steps that I thought would be performed in the operation. The second time I did this, I modelled some defensive white blood cells safely encasing the tumour and a few extras protecting the cervix. I've never been big on alternative medicine, but this imaging exercise was calming and empowering.

Perhaps it was the distraction — I have always loved to work with my hands — and the sense it gave me of taking control, but, remarkably, the bleeding would stop after these exercises. And as the pathologist's report would confirm after surgery, my cancer was very close to the spot I had imagined it to be in the clay model.

As the time of the operation approached, I had to fast for several days in preparation. I was absolutely starving and actually looking forward to being out cold under anaesthesia so I could be free of this gnawing hunger. Then, incredibly, the day before I was to enter the hospital, I got a phone call. My surgery had been cancelled and postponed until September as the surgeon had fallen seriously ill.

This time, I became uncharacteristically aggressive and demanded an immediate referral to a U.S. cancer facility. Luckily, that would not be necessary. Another surgeon volunteered, and I had my surgery on July 29, just one day later than scheduled. As I was wheeled toward the operating room, I greeted the prospect of

five hours of surgery with open arms and a big grin. But the operation was a massive one — afterwards I felt as though I'd been eviscerated in hand-to-hand combat with crude weapons on some ancient battlefield (my imagination again). The recuperation process would be long and hard, but I was free of this scourge and I was grateful.

The post-operative pathology report identified my cancer as clear-cell carcinoma with some evidence of papillary serous cancer as well (both very aggressive and quite rare). The stage was 1B, meaning that the tumour, though still contained within the uterus, had spread from the lining (endometrium) into the muscular wall (myometrium), but that less than half of the muscular tissue was affected. Fortunately, the malignancy had not invaded any lymph nodes. It had, however, started to creep toward a nearby node, its passport to colonizing other parts of the body — just as I had imagined it doing in the agonizing weeks before surgery. I had another reason to be grateful: my cancer surgeon — a wonderful young doctor — said that all seemed clear and I would not have to undergo chemotherapy or radiation.

Why did I develop this rare cancer? No reason, my surgeon said, other than sheer bad luck. There are no established risk factors for it.

For me, it had been a long, nail-biting wait from diagnosis to surgery, but I realize that many patients wait far longer than I did. I also realize that I was complicit in any delay since I had shrugged off the early-warning symptoms back in February and was only too happy not to follow up assertively on the results of my Pap smear.

As this article goes to press, I'm happy to say I've been cancer-free for more than two years, and the outlook for me is positive. I have rewound my antique clock to its rightful time. And I have vowed never again to ignore the signals my body sends me.

If you'd like detailed information about a specific cancer or a referral to a counsellor or peer-support group, call the Canadian Cancer Society at 1 888 939 3333 or go to www.cancer.ca. 