



Experience

Expérience

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This is the second of 2 articles; the first appeared in the June 16 issue.

CMAJ 1998;158:1748-50

Dead tired

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Before I was diagnosed with cancer I thought I knew a lot about sickness and health. In my practice as a general internist and palliative care physician I had prided myself on being a sensitive and empathetic physician, open to patients' concerns and always willing to take the time to listen. Besides, my credentials as a *patient* were impressive. I had lived with diabetes for over 30 years, and this was complicated by complete and permanent loss of eyesight when I was 27. When I was in my early forties, cardiac complications arose. I'd had 5 angiograms and 3 balloon angioplasties. I had been admitted to the cardiac intensive care unit on 3 occasions, and each time I thought it the most frightening place I had ever been.

And so, before the spring of 1996, when my long-standing fibrocystic disease transformed into an aggressive breast carcinoma, I thought I knew how it felt to be sick, tired, discouraged and scared. I thought I knew how to adapt to physical disability and limitations on energy and endurance. But I didn't know what it was like to have cancer. Quite apart from the surreal horrors of therapy, I was astonished to discover how little I had understood of what my own patients experienced.

"What did he say?"

Although for years I had taught seminars on breaking bad news and anticipating patient responses such as shock, disbelief, disorganization and difficulty understanding, I was unprepared for my own reaction to the diagnosis of cancer. At first I was simply stunned. Then the clinician in me took over, and I began to discuss the situation as if it were a third person who was in difficulty. Having sent hundreds of patients for a metastatic survey, I knew what tests had been discussed. Without my clinical experience I would have been lost.

Nonetheless, throughout treatment I had difficulty thinking clearly and rationally, and I was unable to concentrate sufficiently to read properly or follow in-depth conversations. I also had trouble retaining information and instructions from my doctors. Knowing how to access the system helped me to compensate. I could casually drop by to pick up forgotten requisitions. I could phone the radiology department to ask whether my studies had been booked and could book them myself if necessary. I knew what a CT scanner looked like and that bone scans and ultrasounds were not painful. The technology and terminology being used around me was familiar. Whenever I needed help, I knew who to ask and how to find them. Admissions were directly to the floor, bypassing long waits in the emergency room.

On the other hand, I knew the significance of what was and what was not being said to me. I knew that accounts of people in my position who lived for 10 years after diagnosis were anecdotal and by no means the norm. I carried the memory of women suffering terribly from local recurrence, breathlessness and pathologic fractures. Would I end up paralysed from spinal cord compression? I feared becoming helpless and dependent. In my practice of medicine I had tried thousands of times to sound encouraging while talking to patients and their families — while privately feeling a sense of foreboding on their behalf. And so I took little comfort from my colleagues' reassurances that all was not lost. The recollection of the misery and despair I had witnessed over the years far outweighed my memories of patients who resumed relatively normal lifestyles for prolonged periods.



Bad hair days: a whole new definition

Overnight I was catapulted from the position of one who orders and administers medications to that of a terrified and quivering recipient. The oncology clinic, which I had once thought to be so well designed for patient comfort, felt like foreign territory and was the last place I wanted to be. Five months of chemotherapy were like one enormous bout of the worst flu I could ever imagine. Although vomiting was prevented by medications, I felt queasy for 2 weeks out of every 4-week cycle. For 4 days after each injection the nausea was worst. The thought of eating was repulsive. Paradoxically, the best remedy was a small amount of “comfort food” such as pasta or bread and butter. I had several strong aversions: a veteran coffee drinker, I was sent reeling by the mere smell of coffee. I could manage tea, but only if it was weak and not too hot. Alcohol had no appeal; a white wine spritzer on ice was my best social effort. And although I always felt full after a few bites of a meal, I still managed to gain 5 pounds during chemotherapy. I thought that at the very least I should have shed a few pounds for my misery. I was grateful to the clinic nurses who reassured me that most women undergoing my treatment gained rather than lost weight. I was told to expect diarrhea. Quite the opposite was true. My whole body seemed to go on strike in response to the chemical onslaught. Everything worked slowly, if at all.

Although I was never in complete denial of the diagnosis, I had small anxiety attacks each time I went for an epirubicin injection. I wanted desperately to ask the doctors to double-check my pathology report to be absolutely certain that the injections were required.

How many times had I said to patients, “Don’t worry, your hair will grow back after chemo” or “There are some really excellent wigs available. No one would ever know it’s not your own hair.” I had secretly found it a little strange that in the face of a potentially life-threatening disease, patients would worry about losing their hair. I had no idea how devastating it is to lose all your hair. You feel literally naked. To compound matters, the hair loss occurs when you are feeling sick, tired, nauseated and psychologically fragile. The chest has been grossly disfigured, and younger women find themselves suddenly menopausal. The combined effect is overwhelming, leaving you feeling like an extraterrestrial. Some wigs look good, but they all feel weird; you know you’re bald even if the average person on the street doesn’t. Wearing a hat all the time is tedious and makes you feel like you’re carrying a banner proclaiming to the world that you have cancer.

Chemo was followed by surgery. Although I had explained to countless women the less aggressive nature of the current surgical approach compared with the muti-

lating procedures used in the past, the phrase “modified radical mastectomy” now seemed like a contradiction in terms. I took little comfort in knowing that it was merely my breast that was to be removed. Major panic arose in the operating room amphitheatre. Would I insult my surgical colleague by asking him to check the report just once more to ensure the biopsy specimens were correctly labelled and that we really had to proceed? Even at the postoperative follow-up visit, a small part of me was surprised to hear that the tissue removed was actually malignant.

My reaction to radiotherapy was another surprise. Lying on a table waiting for radiation beams to blaze at me sent chills through my core. And yet it seemed so innocuous. Every day a team of technicians shone lights on me for 15 minutes. Was this really a treatment? After the rigours of chemo and surgery, it seemed as if the radiotherapists were letting me off lightly. Yet I felt worse and worse as the therapy progressed. Was I becoming a chronic invalid?

Not just tired

The fatigue of cancer is unlike any fatigue I have ever known, not only in its severity and longevity but in its effect on my mood and spirits. In my university days I had been an avid swimmer and jogger. I knew well the exhaustion, exhilaration and then relaxation that follow profound physical exertion. Cancer fatigue is neither exhilarating nor relaxing. My muscles were soft and flabby; I felt old and decrepit. Nothing seemed to stem the tide of this deterioration. I walked as much as I could, but on some days this was not very far. During medical school and residency training, I had experienced the fatigue of being awake for sometimes 30 or 36 hours straight. This fatigue was not exhilarating or relaxing but it did respond to a hot bath and a good night’s sleep. Fatigue from cancer does not. I would sleep 3 or 4 hours during the day and then wake up feeling tired and unable to climb out of bed. Sleep was never refreshing.

During chemotherapy, I felt well only for the last 3 or 4 days of each cycle. I often felt as if I had just run a marathon, despite the fact that I had been sleeping all day. I was anemic, and although erythropoietin and occasional transfusions helped slightly, the next round of chemo soon reduced me to a snail’s pace. It had never taken me more than a week or 2 to bounce back from any medical problem. But the cumulative effect of repeated cycles of chemotherapy gradually wore me down. I had expected to be able to work more during chemotherapy and was discouraged to realize that I was no longer working efficiently. It took me hours to accomplish what used to take only minutes. I was accustomed to having boundless en-



ergy, and it was extremely depressing to be worn out by the slightest exertion. I was forced to plan each day carefully to make sure that I didn't overdo it.

I thought I'd be able to bounce back from surgery after 2 or 3 weeks. What I didn't factor in was that my body had just been put through a full course of gruelling chemotherapy and that I had required transfusions of both platelets and packed cells simply to allow the surgery to proceed. Nor did I arrive at my target for recuperation before radiotherapy began. It seemed extraordinary to feel more and more tired with each treatment. By the last week the technicians had to help me sit up after the session, and the walk back to the car was like a marathon.

Mind over matter?

I don't think I ever came to grips with the extent to which cancer impeded my engagement with life. I tried desperately to keep some semblance of normalcy. I took season's tickets to a chamber music series. I slept on the afternoon of the recitals but each time was desperately disappointed by my overwhelming fatigue by the second half of the performance. I used to enjoy evening concerts and plays after a full day's work. Now, even activities designed for pleasure were exhausting.

By believing that I could simply legislate myself to be better I did not make things any easier for myself. During active treatment I didn't have the energy to try to will myself better. But as soon as the treatments had finished, I set up a mental agenda for healing and recovery. One month of resting with gradually increasing activities ought to do it, I thought. It would be important to walk as much as possible to regain muscle tone. I was also anxious to resume my academic activities. It seemed an eternity since I had thought about medicine as it related to patients other than myself. During my fifth month of treatment, I had been asked to give presentations at McGill University the following February. McGill was my alma mater; many of my friends and colleagues there had been worried about me, and I thought how wonderful it would be to go back and present grand rounds. I knew that the preparation would be a lot of work, but since I had lots of time it never occurred to me to cancel or postpone. Not until it was too late. I had great difficulty focusing on my subject. The trip to Montreal, which I had never found tiring before, was exhausting. There was a major snow storm on the day of my presentation that made transportation difficult. I arrived early at the hospital to visit with friends, but by the time of the talk I could hardly stand on my feet. I was bedridden for 4 days after my folly.

I had also agreed to do some teaching at the University of Toronto. I really enjoy undergraduate teaching and thought this would be a perfect re-entry to the academic

world. The course was 2 hours, 3 times each week. Because I had taught the course before, I anticipated no difficulty in preparing. But for the 2 weeks I tried to teach I spent weekends and non-teaching days in bed. I was shattered — but I had to acknowledge that this was not a good use of my energy or time. I wept on the phone asking to be replaced.

A challenge

Treatment for breast cancer takes a full year out of your life. There is no way to circumvent this fact. I tried to force my recovery with schedules and frameworks that were unattainable. Setting unrealistic goals only made me feel worse, both physically and emotionally. My healing occurred more quickly after I gave up the notion that I could legislate the return of energy and health. Letting go of that notion and giving myself over to the pursuit of rest and relaxation and to pampering myself with good music, fresh flowers and other treats was the best medicine. Telling myself that I must get back to my former activities as quickly as possible was not the right thing.

More than a year has passed since my nightmare summer of 1996. Now that I am feeling and thinking like a physician again, my mind often returns to the fatigue of cancer and its treatment. Does the chemical onslaught of chemotherapy, which attacks cells whether they are malignant or not, induce compensatory metabolic changes? Is there some sort of "sick euthyroid" state that preserves body mass and energy? Could there be some sort of uncoupling process at a muscle mitochondrion level? I am neither a biochemist nor a molecular biologist and do not have the capacity to begin addressing these issues. My contribution to the work in this field must take the form of a challenge to my colleagues in oncology and palliative medicine. Cancer-related fatigue is a definite and discrete phenomenon that significantly impairs the quality of life of cancer patients. As a profession we have taken this symptom too lightly, assuming that our patients are complaining of the kind of tiredness that everyone feels from time to time and that they could, with a few minor adjustments, soldier on. The fatigue that one feels with cancer is different; it is unique to the disease itself. Prescribing an afternoon nap or an extra hour of sleep at night is insufficient. We have made enormous strides in treating cancer pain and chemotherapy-induced vomiting. But this is only the beginning of symptom management. Fatigue is experienced by most cancer patients. We must turn our attention to delineating the cause, pathophysiology and treatment of this pervasive and depressing symptom, which perhaps does more than any other to stand in the way of the optimism of cancer patients that they will one day be well again. ?