

The days that will still be mine

Jane Poulson, MD

I think I must have experienced the whole range of human emotions during the time I was being treated for an aggressive breast cancer that seemingly appeared from nowhere. It is an extraordinary and terrifying experience to cross the line from a philosophical grasp of the fact that no one lives forever to the realization that one has a life-threatening illness. Although I had expected and prepared myself for some of my feelings, I was frequently thrown for a loop by emotions that arose when I least expected to feel anything at all.

Shockwaves

There was anger. Even though I had exceeded recommended screening guidelines, this tumour presented out of the blue. I'd had regular radiologic and physical exams throughout the preceding 10 years. Everything had been fine, even at a routine visit 5 months earlier. Then, despite my diligence, a nasty inflammatory carcinoma suddenly appeared and dramatically put a stop to all normal activities. No one can satisfactorily answer for me the question of whether this tumour did "just appear" or whether it had been lurking for years. I tried to tell myself: "What difference does it make? You have a bad tumour now and all you can deal with is the present." It appeared at the worst possible time in my career. I had just joined the Department of Medicine at The Toronto Hospital and the University of Toronto. This was not a good way to begin new professional relationships, but when I think about it now I ask myself, "Is there any good time to get cancer?"

There was fear. As a general internist I had cared for many patients with cancer. I was fascinated by the disease itself and really liked my patients. However, I could not imagine being able to cope with having cancer myself. Eight years of experience in palliative care only served to heighten my fears. The Toronto Hospital had hired me to establish an academic program in palliative medicine and I had set up a clinic for symptom management only 6 months before my own diagnosis. My mind was flooded not with images of people dying peacefully with good symptom management but rather of patients with intolerable pain and global distress.

None of the conditions I have lived with — not juvenile diabetes, not blindness, not heart disease — has had the emotional impact of cancer. Although other diseases have potentially life-threatening consequences, cancer carries with it a unique terror. The diagnosis of heart disease was extremely distressing but it did not make my world crumble. Angiograms looking for blocked coronary arteries are relaxing compared with MRI scans looking for cancer. The metaphors that we use in talking about cancer are distinct; words like "battling," "struggling" and "courageous fight" do not constantly arise in the context of other diseases. A diagnosis of cancer changes one's life irrevocably and carries with it a lingering foreboding. Although the physician in me knew that heart disease, rather than breast cancer, is still the leading killer of women, the statistics held no comfort for me. I was able with time to reconcile myself to my heart disease and not carry the spectre of imminent doom with me constantly. But I continue to wake in the middle of the night with gripping fear at the thought of having cancer.

There was shock and denial. I walked around for weeks feeling certain that this was happening to someone else or was not happening at all. I kept checking my office voice mail, waiting for a call from my surgical colleague to say that there had been an error in the pathology report. Life became surreal, like a nightmare. I continued with my work, but all conversations, both professional and social, left



Experience

Expérience

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me feeling as if a thick layer of plexiglass divided me from the rest of the world. It seemed odd that people recognized me and interacted with me as they had always done. I felt that it must be written all over my face: "I have cancer." I used to be the doctor; now I was the patient.

Treatment

I was not surprised to feel fear, anger and apprehension on the days I visited the oncology clinic. What *did* surprise me was my enthusiasm to get there. I never slept well the night before an injection but always woke up early and jumped into the shower. Although I dreaded how the injections would make me feel, I never once refused to get into the car. In fact, I became rather irritable when traffic jams delayed our arrival.

Is it possible to feel positive emotions sitting in an oncology clinic? I was always comforted when I heard the familiar voices of favourite nurses or my doctor. Somehow I felt safe. Snuggling under a hand-made afghan in the treatment room made me feel comfortable and secure. "Just like a day at the spa," one nurse always quipped.

As I look back on my chemotherapy I realize that, as miserable as it was, it made me feel as if I were actively engaged in a war. I had a sense of being united with a team that was determined to kill my cancer. It was reassuring to be surrounded by knowledgeable, experienced practitioners supervising the administration of incredibly toxic drugs. Although distraught by total alopecia, including the loss of my eyelashes, I took some perverse comfort in thinking that if even the cells that made eyelashes and peach fuzz were affected by the chemo, surely the cancer could not survive. As my bone marrow flagged we started marrow growth factors. Severe anemia was reversed by transfusions of packed cells; thrombocytopenia was reversed with platelets. We seemed to have an endless arsenal of weapons to combat the cancer cells. I was in the fight of my life, with all guns blazing.

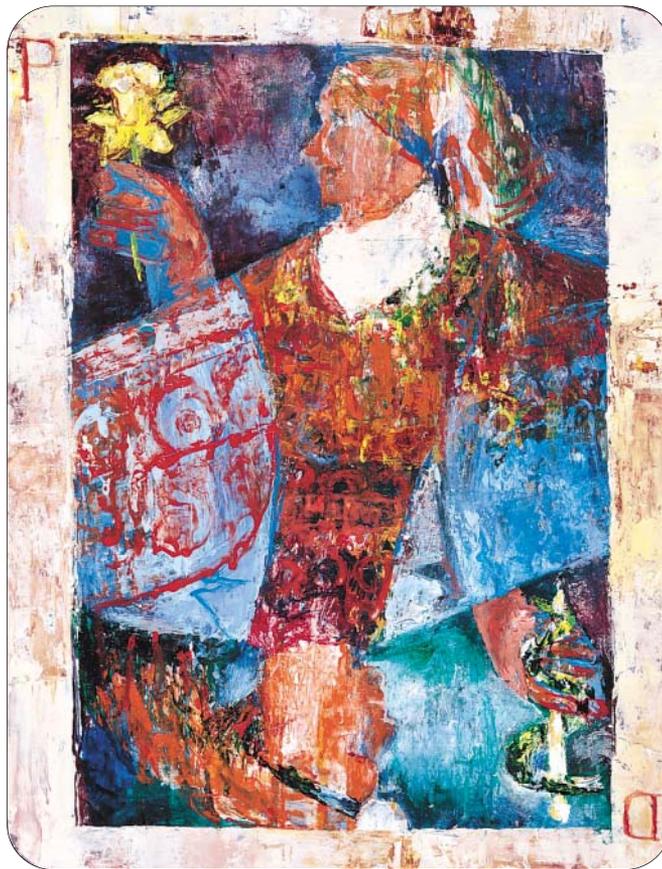
Friends and family who accompanied me remarked on my peaceful and calm countenance despite repeated setbacks. They said that I was a person of great courage and inner resources. I would like to think so. But at least part of my calm during those months came from satisfaction at what we were doing to my tumour. I could always be shored up with transfusions and antibiotics, but the tumour had no recourse.

Having had such a rough ride with chemotherapy, I wasn't prepared for my emotional reaction to the sudden discontinuation of therapy. The original plan had been to do chemo first and then operate. Surgery was to be followed by more chemotherapy.

However, the pathology reports after surgery were so discouraging that it was felt we should move directly to radiotherapy. Instead of being thrilled at avoiding more chemo, I pleaded for more of the dreaded poisons. When I was told firmly but kindly that chemotherapy was not working against the tumour I had a whole-body reaction. I went hot and cold; I had goose bumps and felt weak at the knees. I shook all over and was not at all certain that I could stand up and walk with dignity through the waiting room to the car. Although I understood that one could not go on treating cancer endlessly with chemotherapy, losing this avenue of treatment precipitated the most violent emotional response I had ever experienced.

I had to wait several weeks for the surgical site to heal before starting radiation. During that time I was relentlessly tormented by images of tumour cells flooding through my veins, each choosing a cosy spot in my liver or lungs to nest and raise a family. At last, we moved into the radiotherapy phase: 30 treatments administered daily, 5 days a week. I was more terrified of the radiation than I had been of the chemotherapy. Soon, however, I settled into the routine of daily treatments and weekly consultations. Once again, I developed a sense of certainty that radiotherapy would be successful in blasting this invader out of my body.

Fred Sebastian





Anticlimax

During treatments, I kept myself going with thoughts of how wonderful it would be when my life was no longer determined by doctors' appointments and hospital visits. I looked forward to feeling well again and resuming my regular activities. I expected some acknowledgement of the fact that I had graduated from therapy: a diploma of some sort, or anything concrete to let people know what I had been through. Instead I simply walked out of the hospital with an appointment card telling me to return in 3 months. A journal entry from that time captures my dismay and confusion.

I have just finished my 30th and last radiotherapy. For 8 months I have been sequentially poisoned, nauseated, anorexic, anemic, neutropenic, thrombocytopenic, febrile, infected, constipated and fatigued. . . . I do not have another doctor's appointment for 3 months: that is 90 days. Surely, this is the day I have been waiting for.

During chemotherapy, days were no longer called Monday, Tuesday or Wednesday, but day 1, 2, 8 or 12. Each day had its own significance. Days 1 and 8: injections. Days 4 and 11: stop ondansetron. Day 14: stop cyclophosphamide. Days 15 through 22: take filgrastim and watch for infections. Day 28: start over again with day 1. Surgery followed on the heels of chemotherapy. My days were now called post-op day 1, 2 or 10. Post-op day 8 brought the discouraging pathology report. . . . On post-op day 12, I began radiotherapy; before long my days were called radiation day 1, day 2, and so on. Christmas and New Year's had an additional significance, as no treatments were given on those days.

At the beginning, I felt as if radiation day 30 would never dawn. Now it has come and gone, and I am bemused by my strange lack of enthusiasm. I have kept myself going with positive images of waking up on the first day when there was no treatment to be given: day 1 of my life. Tonight I struggle with a more stark and frightening reality. My life has been irretrievably altered. I do not think or feel the same. What once seemed so important to me now seems irrelevant. I am beset with strange and unfamiliar feelings. I do not know myself or my life. My challenge now is to reclaim day 1 for my own and to move forward to claim all the days that will still be mine.

I was not prepared for the loneliness and sense of abandonment I experienced. After months of frequenting the hospital and dealing with experts in the field, it seemed inconceivable to spend 3 months without seeing any of the staff I had come to rely on to kill this tumour. The pathology reports suggested that we had failed to eradicate my tumour successfully. At any moment it could surface again somewhere else. I have had to let go of my image of full-scale battle. Now I think in terms of guerrilla warfare. Initially I felt protected by the big guns; now I feel as if I am standing alone in the middle of an arena — defenceless, and waiting to be shot. It all feels like a

grotesque game of hide and seek. We have used our biggest guns and failed in our attack. Should the cancer reappear, the arsenal available for battle will be less impressive.

I had been looking forward to redirecting all the energy I had funnelled into health concerns toward normal activities and enjoying my friends. Instead, I found it difficult to attach myself to the world as I knew it. None of my former interests seemed particularly relevant. I was consumed by the need to search for something precious and significant. Another journal entry captures my virtual panic:

Without realizing it, I have begun to seek the Holy Grail. I am searching for thoughts and activities that have meaning for me now. All my former activities seem like frivolous pastimes. I must leave them behind and focus my time and energy upon accomplishing whatever it is that I was always supposed to do with my life. I am frustrated, discouraged and depressed that I cannot discern what this task is. My body is exhausted and is begging me for time to rest and recuperate. I know now, however, that my time is finite; I don't wish to waste a single, precious moment simply recovering.

Strangely, everyone and everything else appears to be as it always was. It is only my interior world that has been smashed, irretrievably rearranged and then given back to me. How am I to fit a shattered and unrecognizable self into my old world? Connecting with old things and old people is complicated by the fact that my dramatic and radical transformation is not apparent to anyone else. I am still "the old Jane" to them. They have been waiting for 8 months for me to return to my teaching, my career and all the other signposts that the cancer was a self-contained nightmare and is now finished. . . . But I know that I can never return to my former space. The challenge before me is to acknowledge this fact, to meet and know this new person that I have become and to live differently in the world.

In the first 6 months after therapy, things I had always taken for granted caught me by surprise. Everyone appeared to live in and for the future. They spoke of holidays they were going to take the next year. My desk was covered with notices of meetings scheduled 2 years hence. I received a new credit card and realized with a chill that I could easily expire before this piece of plastic did. I had no dread of the future but, rather, a sense of a deep void as I regarded the horizon of my life.

There were practical concerns. Did it make any sense to buy a new winter coat if this were to be my last season? Why buy a party dress? Surely I could wear my old dress one more time.

My emotions were not all negative. The enormous support and positive reinforcement I received from loved ones sustained me from the moment of first diagnosis and carried me at times when I could not stand alone. My family and friends laughed with me and wept with me. Throughout the whole experience I felt loved. This gave me the ability to hope for the best and to go on liv-



ing in a fully engaged manner despite the nightmarish circumstances.

A different lens

Now I am more than a year past treatment. In a paradoxical way, I think I can say that I feel more alive now than ever before in my life. Another journal entry:

I see all that I do now through a different lens. . . . When you presume to have infinity before you the value of each person, each relationship, all knowledge you possess is diluted. My life is now concentrating before me. This the most painful yet most enriching experience of my life. I have found my Holy Grail: it is surrounding myself with my dear friends and family and enjoying sharing my fragile and precious time with them as I have never done before. I wonder wistfully why it took a disaster of such proportions before I could see so clearly what was truly important and uniquely mine.

I am now awaiting my fourth 3-month follow-up visit. The pathology reports notwithstanding, the disease has not behaved as predicted. I long to move forward, but feel restrained by the sword of Damocles hanging over my head. It is difficult to strike a balance between reasonable watchfulness for symptoms of return and excessive vigilance. I had never noticed before the dry cough brought on by low humidity in my home. I must actively remind myself that cancer patients can have coughs or minor aches and pains just as they did before the diagnosis. This departure from the expected course of the disease has also given me a period in which I have felt relatively well, and thus the chance to do things that I thought I would never be able to. My emotions are generally more muted than before; neither fear nor anger are quite so acute. My denial has been slightly reinforced. I continue to live largely in the present, although I am now beginning to plan some trips several months from now. I cannot think much beyond this point. I am delighted by my involvement with life, and I am living with a passion unlike any I have ever known. I know that I cannot ultimately sustain such intensity but, for the moment, I enjoy nature, friends, family, music, art, sleep and relaxation as I have never done. I have a new dog who is a delight. Should this period of grace continue, no doubt my emotions will continue to mute gradually as I take up more of the activities that once formed a framework for my life.

Cancer continues to permeate my consciousness when I least expect it, but it no longer dominates my existence. I cannot say that cancer has been a positive experience, but my enhanced appreciation of being alive has been a gift. I only wish that I had been able to connect with this passion within me in some different way. What I would like to say is this: Live fully every moment of your life. Do not wait for everything to be threatened before you realize the value of all you have. ?

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