



Living With Cancer

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New Internationalist, August 1989.
Photographs by Gregory Guest.

When I woke up in the recovery room in November 1978 my doctor was waiting to tell me the results of the biopsy. It couldn't happen to me; I was just 37 years old. But it had — I had breast cancer. My feelings ricocheted all over the place. I was afraid, angry, grateful and sad all at the same time. I remember thinking: "I've been a caring person, how could this happen to me? It's not fair, it's so arbitrary." I cried, wailed and curled up into a ball but I also continued to work — it seemed like my sanity depended on returning to "normal" as quickly as possible. A month of radiation treatments began a long series of checkups, more biopsies and finally surgeries. My last surgery was in 1983 — a lymphectomy; afterwards I was put on a hormone blocker. Last summer, I was nearing the famous "five year" marker which meant that statistically I had a much better chance of surviving. Then I had a bonescan and they discovered bone cancer in two places. I was put on another hormone blocker and given more radiation. I had the summer to put my life into a new framework: "The best we can do is slow it down," they said.

excursions

get into a "war" with my cancer, I can only interpret myself winning if my cancer "loses" or is "defeated." This kind of either/or thinking reduces all experience to win or lose. A person like myself with a "terminal" cancer has automatically lost.

We do need a language of resistance in our struggles with chronic illness, but it needs to be a language free of militarism. I found it wonderfully healing to spend quiet time in nature — a form of resistance perhaps but hardly a battle. Even supposedly alternative language can be infuriating. The "new age" philosophy of illness is a good example. At first, I would go out and buy these latest self-help books only to find the basic message was: "You made yourself sick so you can heal yourself." So simple but so damaging. It fits all too well with mass media messages that bombard us daily: problems are individual, not social. We're kept disorganised with a simplistic presentation of blame and responsibility.

I began to think about how I got cancer.

I read and asked around. There were many possible explanations — heredity (my grandmother died very young from breast cancer), occupational hazards (for the previous 20 years I had made silk screen prints using highly toxic paints and clean-up solutions), poor diet, lack of exercise, too much stress, birth control pills and many more. Often I read that one or another of these factors was the primary cause. I found this completely immobilising so gradually I developed a map, a kind of ecology of possible causes. This allowed me to deal with those dimensions that I had some control over. I didn't feel like I needed to have a "scientific map" but could elaborate my own open map so that as my experience grew I could alter it.

By the time cancer was diagnosed I had an excellent relationship with my doctor. He trusted me as an expert on my aches, pains and feelings; I trusted him because he was able to tell me what he didn't know as well as what he did. He also knew how to cry. Most doctors see surgery as a response to unhealth, he told me. So advice from a surgeon must be seen from this critical vantage point. He was open to my exploring alternative health support (like massage therapy) and would ask me whether they were having any effect. It was important to me to understand the limits of medical knowledge and to recognise the intuitive as a legitimate part of making decisions.

Writing this is difficult. It brings up complex and contradictory memories. But it does add both a clarity and simplicity that wasn't there at the time. Perhaps this article should be written by my husband and daughters who know what happens when someone you love gets cancer. Or by my friends who've shared my fears, anger, frustration and even the small moments of beauty that have come from trying to make sense of cancer.

I have resisted putting words on paper for fear of getting back on an emotional roller coaster. Also because what has helped me to understand and live more calmly with cancer may not work as a "prescription" for others. The sense of loss of control is so great with this illness, that it is a time to be very careful about issues of power and control. While waiting in clinics and hospital corridors I have found that many people are not as enthusiastic as me for knowledge about their illness and for playing an active role in their health care. Death is such a responsibility that I hesitate to project my keenness to be clearer, to understand better, onto others who share my illness. I write not to prescribe but to describe and wonder aloud about some difficult times.

For me there is irony in the act of reflecting on cancer since I'm the kind of person who might easily have left these thoughts until five minutes before death. I too frequently gallop into new projects without sufficient time for contemplation. But in trying to make sense of cancer I think it is important to speak out in a straightforward manner. The knowledge gained from coming to terms with this disease too easily remains in the hands of medical professionals. So I stumble for words to speak of problems, responses, speculation, small rearrangements.

As a visual artist and teacher

I use many kinds of language. For me the meaning of words changes with time and place. How we use words indicates our values and priorities. I have found most writing about cancer disempowers those of us who have the disease. One example is the use of militaristic or war-like metaphors. Phrases like "fight," "beat" and "win the war" are commonplace. But if I

When I shifted from Princess

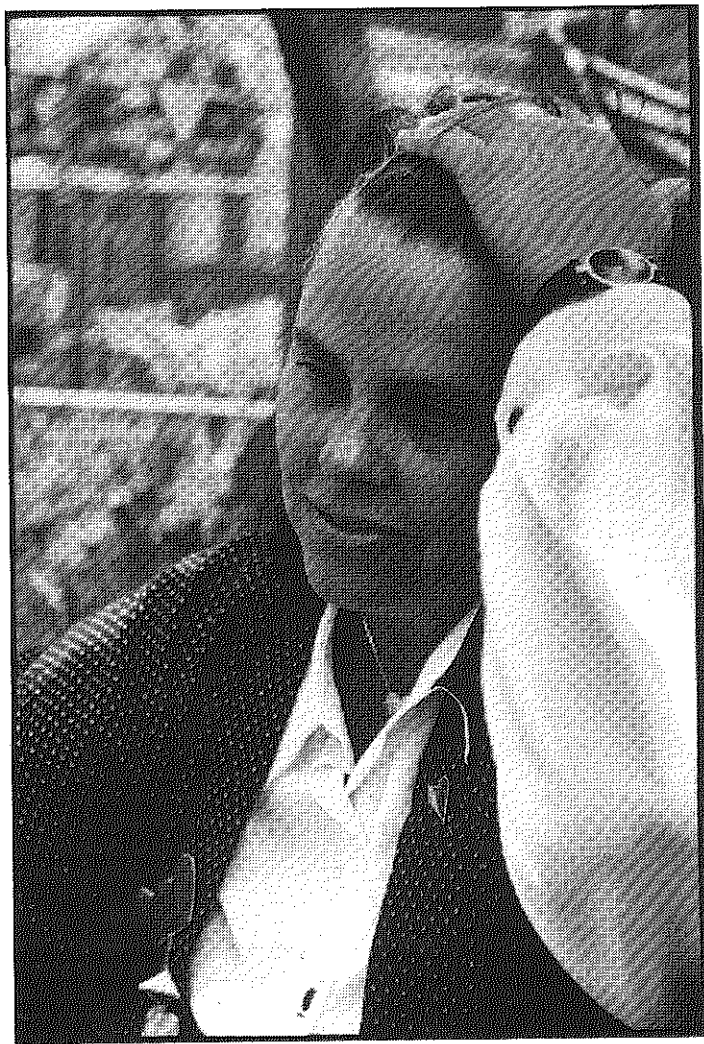
Margaret Hospital to the Sunnybrook cancer clinic a doctor introduced herself as the head of my team of seven different specialists. She then gave me a physical exam. The usual response of a new doctor was to admire my many incisions and scars and ask which surgical artist had given me this or that wonderful piece of handiwork. She said simple: "I can see that you have been through a lot." In a simple sentence she affirmed that I had a history and was not merely an example of her peers' technical skills. I told her that she had a lot to teach her colleagues.

Last summer I wanted my bone-scan results quickly because I needed to spend time with my oldest child who was going off to university. Most doctors wouldn't have bothered trying to speed up the bureaucracy. Fewer still would trust that I was the best judge of when I needed to know something. She told me over the telephone which wasn't easy for either of us. It gave me an extra week to let my daughter know how serious it was this time.

In the first five years, I had four surgeries.

Whenever I asked the experts what the odds of survival were for different cancers, they would at first answer ambiguously. As I insisted they would get more precise. Later I learned this was called "staging," a way of finding out what patients really wanted to know. Some doctors withhold information based on whether or not they think you can handle it. I would say you should lose those characters fast. If they can't trust you, how can you ever trust them?

I needed to know as much as possible so I could get the most out of the time I have left. It doesn't mean that I wasn't overwhelmed and anguished when I heard cancer had returned. But knowledge and understanding helped liberate me from self-destructive fear, anger and sadness. These feelings are always close by. But now I have learned to treat them as reminders of my current agenda — to figure my way as creatively and peacefully as possible through the last part of my life.



You can read my face like a book.

If I am happy, worried or frightened you know immediately. We told the children in as calm a way as possible and tried to keep open the lines of communication on the subject. I would get extremely tense and agitated before routine check-ups. I learned to tell the children the reason for my short temper. It was important that they "felt in the know" as much as any of us. My daughters (now 21 and 18) both realise the transition from a parent-child relationship to more of an adult friendship has happened earlier with us than with most families. They feel good about giving support. Instead of feeling powerless in all this my daughters feel they have some control over events.

Family and friends make all the difference. I was surprised, delighted, shocked and often healed by how they reacted. My husband ditched his jeans and dressed in a three-piece suit to look like a doctor so he could sneak into the hospital at 7:00 am to bring me capuccino and the newspaper. Another friend called me at home and asked, "How are you feeling?" "Terrible," I replied, "I'm depressed." "Good," she said, "I though you were going to avoid this part." I burst out laughing. For me, irreverent stories and fumbling attempts to connect were far better than never responding for fear of doing "the wrong thing." A

few people told me about their friends' ills (back pains for example) as a way of connecting. As much as I appreciated their concern I always wanted to say: "Hey, wait a minute, this disease is life threatening. I'm afraid I'm going to die too soon." Even now friends I only see every few years will call to say hello and find out the latest news. In moments of crisis I find it healing to know my friends are not denying my most recent diagnosis of cancer.

I'm afraid. I fear my cancer will isolate me socially.

People with the best intentions will treat me as incompetent and exclude me. I fear people will feel sorry for me and patronise me — denying the energy and intelligence I bring to this current phase of my life. Recently, a person I considered a close friend did just that. He told me he was close to me because he felt sorry for me and that I was naive to think otherwise. I felt betrayed and angry to be treated in such a cold and clinical fashion. It is one thing to feel sad. But if you feel sorry for me you distance yourself from my pain in a way that denies my status as an actor in my own life. Friends like this are toxic and I will resist being any one's social work project or charity case.

Last summer, during my bone-

scan test I could tell by the way the technician responded that something had shown up. He went out of the room and when he reappeared he said: "You look a lot younger than you are. Do you have any children?" I said, "you checked my file." To which he replied: "Yes." I was pretty sure that they had indeed identified some cancer.

That same day I went to my massage therapist. I decided this was a unique moment in my life when I could look into my psyche. When I am very frightened I sometimes have the courage to face or to see the unseeable. So as my friend did his work I decided to let go and see what images would surface. The first image was very surprising to me. There was field of wild carrot (white flowers composed of many smaller white flowers) surrounded by pine trees. Strolling through the field was a huge grizzly bear. He looked strong, confident and curious as he moved through the field of flowers. At one point he stopped and picked a handful of flowers which I knew symbolised my essence, even as the whole field was me too. Then, in my flower form I made him sneeze and laugh and I flew back into the ground except for one small white flower which landed on his shoulder. Together we strolled away.

The next day bone cancer was confirmed. Almost immediately my husband and I (we have been separate for four years but are still fine friends) began to look for a cottage or a place for me to be still. I sometimes feel my cells vibrating from too much work or not enough sleep and I imagine that I can see them all jangled and in motion. I told Chuck that I had a recurring dream that I needed to spend the last part of my life on a lake surrounded by trees with a beach. This became a guide for us. We found an island we liked called Cranberry Island and Chuck had a cottage built. The day after we bought the property we went to look at it again and much to my delight in the middle of the cranberry bog was a large patch of white flowers. The lake is called Kahshe which I later found out means "healing waters." I am keeping my eye out for the grizzly. ■

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