

Afterword

This is not the story I would have chosen to tell. Had my cancer led to my death, this is not the memorial I would have preferred to leave behind, nor is the morose, self-centered woman I describe the mother I would want my children to remember. In short, this is a difficult story to own.

Certainly, I set out to write the truth about my cancer while I was still in its grip. I was passionate in my resistance to telling the story that other people seemed to want to hear—of lessons learned, of cancer as a transformative experience. But having told my story, I now find myself startled by its fierceness,

its raw and unrelenting character. I almost wish, when I read it over, that it left me with more of a feeling of transformation. There are other stories about breast cancer that would be easier to live with. Why, I wonder, couldn't I have written one of those? It's not my anger that I mind. I'm proud of my anger, at least when it's clean and direct, a response to injustice. But it's difficult to accept how mean spirited and lost I felt when I spoke from inside my illness.

Why am I surprised to find this angry Kathy Conway emerging from these pages when I know that I was angry during my cancer? Perhaps the experience of writing felt so good that I expected those good feelings to be reflected in the story. When I wrote, I felt creative, alive, still thinking, and productive—not deadened by the cancer or the chemicals. Somehow, writing transported me from that place of misery back to the ordinary world where I felt more like “myself.” But the writing that transformed the experience of cancer for me did not result in a book about a transformed person.

Sometimes I would like to tell the reader that the person in this book is not really me. I'd like to go back and add those times when I was funny, when I was loving to my husband and children and understanding to my friends. Such moments rarely made a mark on my experience of cancer, just as the generosity of friends and loving times with my family seemed to have so little effect on my essential misery. Those “good” aspects of myself or my relationships seemed to carry no weight. I had become the misery I felt.

This is not my first attempt at an afterword. I wrote another in which I assumed the role of an anthropologist back from the field, reflecting on the behavior of people I'd studied, people dealing with illness in sometimes strange but ultimately well-intentioned ways. I spoke then in another voice in order to leave behind a different version of myself: wiser, more magnanimous, more self-possessed. I was trying, in a way, to take it all back, to undo the fact that this book describes me as I actually felt and acted then.

When I began to write, I felt some urgency because I knew that once I was outside the experience I would forget what the illness and desolation really felt like—as I had after Hodgkin's disease. I recognized that the better I felt, the more I might talk as if breast cancer had been manageable; I might even begin to believe it.

I doubt that I could write this book today. I no longer feel as raw as I did then. I see now that, in my own way, I was like those women who appear in public without a wig or a prosthesis and say, "Look at me. I have no breast. I have no hair. You must see what breast cancer is." I was showing that breast cancer is also this: feeling so horrendous and beaten up that you can neither fight nor demand that the world pay attention; you can only get through it, barely and ignobly.

For me, hearing the diagnosis of cancer meant entering a closed circle inside of which I was separated from my ordinary life, my ordinary self, from the very people I loved. Inside that circle I felt like a creature from a different species or, more accurately, one of the possessed

characters in *Invasion of the Body Snatchers*. I looked the same, at least for a time, but my spirit had been taken away.

In my body, I had mindless, ruthless cells threatening to multiply ceaselessly and kill me. Even the chemicals intended to destroy them wreaked havoc. The most primitive emotions—terror, repulsion, blind hatred, and despair—seemed to overpower all positive or benign feelings. Only my anger at the threat to my life survived, and I held onto it for dear life.

Once I was inside that circle, my perspective changed: nothing seemed to matter much, except being sick. Activities that I had enjoyed disappeared from my life or lost their meaning. Friends who were generous (if sometimes insensitive) seemed only hurtful. The world outside felt unfamiliar and threatening in its normalcy; ordinary life like some idyllic state filled with innocent, fortunate people who did not have cancer.

I would have given anything to gain some distance from my cancer. But how could I, given that the cancer existed inside of me? My friends could. They could visit me, think of me, and then go about their business. They could still feel that they had control; that by eating carrots, avoiding stress, exercising, or meditating they could ward off cancer. I couldn't. The cancer was already in me. I was the threat, the one from whom they had to keep their distance.

People suggested at the time that I imagine myself somewhere else, at a beautiful place such as the beach, feeling healthy and calm; or in the future when cancer would

be gone. But I couldn't. I knew that I was in my doctor's office receiving chemotherapy. I knew I was nauseated. My imagination couldn't perform such tricks, couldn't overcome what I was feeling in my body or even conjure up a time when the circle would reopen. I simply couldn't conceive of a time without illness. It seemed presumptuous to think that I would ever be cured and have a future of good health to look forward to. Why should I be one of the fortunate ones?

I did have a healthy year after my chemo ended, when life again felt normal, my days free of the misery of illness, though never completely free of the threat of cancer. With some distance, I began to view my breast cancer less as a departure from my life than as a part of it. In December 1994, when the enlarged node removed from my clavicle was shown to contain some scattered lymphoma cells, I once again faced an array of diagnostic tests—a bone marrow biopsy, blood tests, CAT scans—in a search for the disease elsewhere in my body. For a while I struggled against despair, but my new coping mechanisms soon collapsed, and the angry person of this book reappeared. To my horror I found that, even if ordinary life no longer existed without cancer, cancer still didn't include ordinary life. With cancer, life once again lost its complexity.

My doctors discovered no further evidence of disease and so decided to hold off on chemo and monitor me closely. This was an aggressive lymphoma; were the cancer still present, I would probably have developed symptoms within months after the diagnosis. Chemotherapy is effective in treating this type of lymphoma and my doctors

believed that, if more cancer were found, the delay would not compromise the treatment's effectiveness. So far, no further cancer has been found.

Back in ordinary life again, I find that I view the experience of breast cancer differently, depending on where I am located in relation to it; and I understand that the emotional tasks that I face are different, depending on where I stand. When I wrote this book, cancer had taken over my life and I needed to tell the story of my ordeal. By the time I composed the ending, my view had begun to change: yes, breast cancer was miserable, but after the treatment I was returning to normal life. At that point I needed to bring the experience to an end, to end the book. Like my statement to Molly that cancer was over, completing my story was a way of willing the end, of drawing a line in the sand and saying, *No more*. This is the end of this experience with cancer. Of course, I knew that there can be no closure on this disease, but I needed to get on with life, as did my family.

During my illness I searched for narratives that would structure my experience and offer me a vision of the future in which breast cancer would end. I wanted to believe what my doctor said, that this was an acute episode, as was my Hodgkin's disease. I studied my diagnosis and statistical survival rates to find material with which to compose a story that had a future in which I would be healthy; and I tried to imagine the end of chemotherapy—I'll feel better in four days, in a week, when chemo ends, at Thanksgiving. None of this worked very well; I could believe in the end only when I felt healthy again.

When I am threatened once more by the possibility of having cancer, the experience looks as unmanageable and terrifying as ever. After my lymphoma diagnosis, I found this book and the portrait of the person I might again become unbearable. I could no longer see that cancer and its treatment could be a discrete episode in my life, only that it was a black hole into which I desperately feared being sucked, with no promise of escape.

At this remove from my illness, reassured by nineteen months of healthy life since the lymphoma diagnosis, I find that I can accept the story I have written—even my angry, whiney, critical self—because now I am the reader and she is the protagonist, the other, a character in the book. Although I can see her with all her faults, I do not completely identify her as me. I can even be compassionate and think that, of course, I was enraged, miserable, and self-centered; any behavior is understandable under those circumstances. Now I have the distance that so eluded me when I was sick.

This more benevolent attitude derives from the fact that back in ordinary life I have greater access to the loving and humorous parts of myself and can therefore tolerate even the more negative parts. Breast cancer has become only a piece of the quilt that is my life. I needed to be finished with it, to put a border around the experience. Inside that border are patterns that are familiar to my life, some interesting, some less appealing, and all the flaws that contributed to the creation of the piece. In looking at the piece as a part of the whole quilt, I can view it from different angles, in different light, in relation to all the other pieces.

My present task is to take this broader view, to regain a sense of the fullness of my life. My family helps me with this: they insist that I wasn't only angry when I was sick. David remembers vividly how demanding, unkind, and impossible I was, but, he jokes, even in healthy times I've been known to be difficult. He often reassures me that in the worst of moments I still managed to be loving to the children. Zach and Molly are rather matter-of-fact about the experience. They remember that I cried a lot and went to bed early, but cancer was simply part of their short lives. What else did they know? They had not lived long enough to realize that ordinary life is different from their experience in the past few years. I am their mother now, and I was their mother then, even with cancer. They loved me as I flailed about, trying not to drown, though they undoubtedly wished I'd learned to swim better.

The hard task for all of us is to integrate each of our experiences of cancer into who we are. I catch glimpses in David, Zach, and Molly, not to speak of myself, of the ways in which each of us has internalized some traumatic aspect of the experience, hardly modified by time.

For David, there is depression. Before my breast cancer, he had not known the feeling of waking up and dreading the day. Nor had he known the kind of anger he felt toward me during my illness. Now that these emotions are familiar to him they can easily be reawakened. Fortunately, he retains his sense of humor. He now jokes that, if I die, the next woman he dates will need to present a complete set of CAT scans first. I can't blame him.

He has a shorter fuse now and loses perspective more easily, perhaps because, like me, he lives with the knowl-

edge of illness and death as ever present possibilities. One evening in the week preceding my last CAT scan, he came home looking haggard and worried. When I asked what was wrong he listed the college's budget crisis, a looming deadline for his manuscript, a delay on the subway, and a mistake that the bank made in our account. I pointed out that not everything is a cancer diagnosis. Our experience, when we can call on it, does highlight the insignificance of many of life's problems.

And what is the legacy of my cancer experience for my children? When I allude to how upset and unavailable to them I was during my treatments, Zach and Molly look at me as if they don't have the faintest idea what I mean. Most likely they're not aware of the painful ways in which the experience affected them or they're aware only in ways that are, at their ages, inexpressible.

Zach coped with my illness by insisting, perhaps desperately, that everything would be fine, that I would get better and life would return to normal. He continues to cope in this way—maintaining that there are no problems, that he's not upset, downplaying the threat that cancer poses to his mother and to himself. One evening a while ago, I came through the door, cheerful but tired. Zach heard me sigh and said to me matter-of-factly, "Yeah, some days are hard: work, lymphoma, making dinner." He acknowledged the fact of cancer in my life, in our life, but he let me know by his tone that he wanted to keep the discussion light.

Because he has rarely spoken of this cancer experience, I wonder what he acknowledges to himself about it. When he learned that his friend's father had committed suicide,

Zach was stunned and shocked and without a way to cope. He wanted to lie down on our bed but needed our help to walk there. He kept saying that he wanted to put this out of his mind, but he couldn't. When we talked with him about our friend's depression, he made a connection to me and my depression when sick. He let me hold him and asked me over and over, "You're not depressed now, are you, Mom?" He, like David, tends to keep his feelings private, and only rarely do we get a glimpse of his worry. Most of the time he works hard in school, is busy with friends, talks on the phone behind closed doors.

Molly is different. The mountains and valleys of her emotional life form a landscape that we can view daily. She is always forthright: she wants my hair to grow longer; asks why my one breast is harder than the other; complains that I won't carry her book bag and violin as I did before I became protective of my arm.

She has always been intense, and for the most part her intensity serves her well: she is passionate about life—about learning, friendships, music. Her forthrightness and sense of outrage bode well for her future strength as a woman. But since my illness she possesses an intense rage. When tired and frustrated, she becomes a living embodiment of my more desperate moments during treatment; her anger escalates quickly into a fury that echoes my own. It's uncanny to hear how she took in my rage, which must have sounded terrifying to her, and made it part of herself. When she expresses her anger toward me, she feels guilty at the thought that she's hurt me, fearful that I am fragile as I was during my cancer. I am stronger now, but she still fears hurting me.

For me, there is still the profound terror I felt then in the middle of the night, when I awakened from dreams about dying and stared into the darkness. If I no longer cohabit with this fear, it remains frighteningly close to the surface, ready to emerge at the slightest provocation, whether it be speaking to my sister about her precarious health or simply feeling my lymph nodes and imagining them slightly swollen. Sometimes I feel momentarily afraid in just leaving the house, as if any change will be accompanied by a catastrophe.

My friend Laurie died last year. I miss her. The other women I described in the book have recovered, each in her own way living with the threat of a recurrence and the wounds left by her breast cancer. I imagine that these women feel a deeper sadness than they knew before, as I do. For me, that pain was expressed in wrenching sobs when I was sick. I've always been able to express my most painful and unnameable feelings through tears, but then my sobbing took on a different quality. It seemed meant neither to bring me comfort nor to be heard by anyone. It gave voice to the utterly inconsolable loneliness that I felt. I cry like that rarely now, only when fearful of serious illness in myself or people I love. But the background music of my life is more somber. I know how easily life can slip away, and the possibility of death is no longer remote. Ordinary life will never again be free of this awareness.

Perhaps for this reason I still keep myself at a slight distance from David, Zach, and Molly, sometimes refraining from expressing my love because to do so seems to bring pain along with it, a reminder of how afraid I am of losing them or of their losing me. This is the worst legacy

of my illness—that I sometimes avoid knowing how deeply attached I am to them.

So each of us carries the experience of cancer into our lives; some feelings rest more easily in us than others. The cancer caused real emotional damage, and each of us lives with that damage, much as I live with my lost breast, my less flexible arm, my scars. We cope well and not so well at the same time.

I still think of those scenes in nineteenth-century novels where the mother is dying in an upstairs bedroom. The doctor stops by and the loving family hovers at the bedside day and night. In my fantasy, the mother faces death calmly in the comfort of that love. Or does she?

I've always wondered what it was actually like for the woman in the bed. Was anyone really with her in her dying? Did she feel held in her family's love or totally alone, isolated in her own closed circle? Probably there were moments of each; moments alone, in fear or acceptance, and moments together. I wonder how I would face death if I knew it was really happening. I imagine that sometimes I would be strong and loving, sometimes terrified and furious. Why should the last days of my life, or anyone's, be different from the rest? I've heard that one's consciousness shuts down before one's body dies. I like that idea. It's nice to know that, when the mother in the bed finally faces her death, she may experience it and be protected from it at the same time.