

LEARNING TO LIVE AGAIN

Survivors of cancer wait in a limbo of uncertainty: 'Not knowing whether I would live or die,' says the author, 'seemed worse than the idea of dying.'

By Joel Solkoff

On May 5, 1976, with the filing of Tissue Examination S 76-1606, at age 28 I became one of 7,200 Americans who had new cases of Hodgkin's disease that year.

Hodgkin's is a form of cancer of the lymphatic system. In 1950, according to statistics published in Radiologic Technology, the chances of surviving all stages of the disease was 6 percent. The medical literature now refers to it as "a disease once considered fatal." Today, the odds of surviving Stage I, the mildest of the four stages, are estimated at 80 percent.

In a society in which cancer is the second largest cause of death and in which there is increased concern for the dying, the problems of those who survive cancer have been largely ignored. Until recently, the fear of death associated with cancer was so pervasive that the medical and social-service community even neglected those cured patients who, as a result of their treatment, have to live with practical physical problems.

Each year, there are about 675,000 new cancer patients in the United States, and one-third of them will be cured. Two million Americans have already been cured of cancer. An additional 333,000, who have been treated and whose life span may be unaffected by the disease, are waiting until they too fit the American Cancer Society's statistical definition of cure — five years without symptoms, in most forms of cancer. I don't yet know for certain whether I have been "cured," although it now seems likely.

Those of us who have undergone apparently successful

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Joel Solkoff prepares to leave his apartment in Washington, D.C. "I'm still O.K., though the balances have shifted a bit."

treatments are probably the most ignored class of cancer patients. We're neglected when we're treated and we're neglected after the treatment is over. We do not need the rehabilitation programs of former cancer patients who must learn to live without a leg, become adjusted to a voice box, or deal with the trauma of losing a breast. Ours are the problems of surviving a disease which most people assume is fatal. They are the emotional problems of never having met someone who's survived, of worrying alone that the lumps will return and

of knowing no one who understands. For us, there are no special public or privately funded programs, and physicians interfere with our efforts to find one another.

I didn't realize how lonely a group we were until a year ago when I wrote an article for the New York Times op-ed page describing my experience with Hodgkin's disease. It was an emotional piece, written when the first clumps of hair were beginning to fall out and when my belly was still oozing pus because of a run-of-the-mill wound infection following a routine exploratory operation.

Every day I felt weaker, thinking constantly of how little energy I had and feeling frustrated with the inadequacies of my body. It was impossible not to convey the sense of my own fear, because I was frightened when I wrote the piece. However, the message and the sense of understanding were clear. I would get over it. The hair would come back. Someday, perhaps, I would be cured.

The article had evoked two sets of contradictory responses. The first response was from people, especially family, for whom I'd forever be "the one who has cancer." My father, who had difficulty remembering the name of the disease, read the article — which another relative had sent to him — and asked about the spleen, which was routinely removed in the exploratory surgery. "That organ they took out? Do you need it?" A cousin, whom I had not seen in years, sent me a certified check for \$100. For my family, who mean well and love me, I will always be that person at death's door — the one who is asked, "How are you?" in a tone which is noticeably different.

The second set of responses was from people who had survived cancer. They wrote to establish contact with someone else who had been through an experience similar to theirs. A woman from Minnesota, who had been cured of Hodgkin's disease, told me that she knew of no one who had not died from it. She said that it made her feel less frightened to know that there was someone out there she could write to, someone who was alive. A lawyer from New Jersey said that he had been through a similar experience, that he had "resumed normal living," but he knew no one else who had been successfully treated. A friend of a friend, who had read my article, was due for a routine six-month checkup. She had also had Hodgkin's disease and had apparently been cured, but she was afraid the tumors would come back. They hadn't returned, but she was frightened. She had never talked to anyone about it before. She wanted to talk to someone who had survived cancer treatment.

The article had made me into a one-person support group, and I suddenly realized that there are a large number of us who have no place to

turn. I certainly didn't want to make a career out of being a former cancer patient, and there was my fear. But there are some life questions like, Should I get married? Should I have children? Doctors — some of whom know nothing of cancer or know nothing of emotions — answer these questions incorrectly or insensitively. (One Ohio physician, who apparently had not read the literature and did not know how favorable his patient's chances were, told her that she should abandon her plans to get married because it was unfair to her prospective spouse. She went to a competent physician and was treated. The Hodgkin's disease has not returned in seven years, and she is now married and has a child.) The mortality statistics prove that many of us are no less likely to live a normal life-span than anyone else, and yet insurance companies or their agents often discriminate against us.

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For me, the issue of cancer came in one of those series of black-comedy skits which seem to mark important events. I had a lump, about the size of a golf ball, under my right arm. The lump did not hurt and it was not noticeable. It was just there. After a number of weeks, I started thinking that maybe I ought to have someone look at it. I called my doctor and asked his secretary for the name of a physician who specialized in lumps. "Lumps?" she asked. I explained that I had a lump under my arm and didn't know what kind of doctor to see about it. She thought, decided on an internist, and gave me a couple of names from her book. I picked one.

I am in the internist's fancy office in an exclusive apartment-house complex in northwest Washington, looking at the potted plants in the waiting room. Immediately, I say to myself, "I can't afford this." The lump will probably be nothing at all. This visit is bound to cost me \$100, by the time they're done with the blood tests. This is a waste of money. And, if it is really expensive, will my insurance cover this?

I go in to see the doctor, who turns out to be not much older than I am. After examining me, he orders a battery of lab tests and X-rays. I explain to him, quite firmly, that I want

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him to keep costs down, that I'm not sure that my insurance will pay for it. He asks how I was referred to him, and I tell him. He says that I'm lucky, that, as it happens his office specializes in hematology, which means: "Lumps are our bag." He also explains that the tests are important, that I can't tell him how to practice medicine, that if it turns out that I can't afford to pay for them then we can worry about it at some point in the future and, if necessary, he'll go without the money.

He explains that cutting it out is the only way to find out what the lump is. So, terrified, I agree to meet a surgeon. He picks up the phone and calls one, who, as it turns out, is in his office and can see me right away. Because it is Friday, the internist tells me to run so I can catch the surgeon and then explains, as I am half out the door, that it doesn't mean anything serious, that it's best to do things quickly and that I shouldn't be alarmed.

The surgeon is also not much older than I. He has colorful modern lithographs in the waiting room. He feels the lump, decides that cutting it out will not be a problem, assures me that it won't be too painful, and sends me back to the internist, who tells me the options. It may be nothing at all, he says, "just some fatty tissue." On the other hand, he adds, it may be serious. I explain that I am extremely busy and as soon as I get around to it, I'll make an appointment for the surgery. He tells me, quite firmly, not to wait too long. I tell him, quite firmly, that I have an article to write.

It is late Friday afternoon and I'm terrified. I need a drink badly. I call up Julie and we meet.

By the following Friday, I am in the outpatient waiting room at George Washington University Medical Center. Julie has come to be with me, which helps calm me down because I'm nervous and jumpy. I've never had an operation before and I know that my threshold for pain is extremely low. The only thing I want to know is: Will it hurt? For how long?

The surgeon is very quick, and it's soon over. Now, all I need to know is what the lump is. Awake during the operation, I asked the doctor, as he was cutting it out, if he could tell and I suspected that he knew and wasn't telling me. But being on an operating table is no time for penetrating

questions. So I leave the hospital, tell my friend I'm all right, walk some slides of my lump to the internist's office a few blocks away, take a cab to Mike Palm's on Capitol Hill for lunch, and walk home to bed. Next week, I'll know.

It was a hard weekend. Thanks to anesthetics, operations don't hurt when they're happening. They hurt after the anesthetic wears off and there's no one around. That weekend, I was convinced that I had cancer and was going to die. By Sunday, I had called Julie and told her I never wanted to see her again. Since I love her, I figured that the best thing to do was break off the relationship and die without bothering her. It's called playing the martyr.

On Tuesday morning, I'm again in the internist's office and he tells me how lucky I am. It's toxoplasmosis, a disease which comes from eating steak tartare or playing with cats. It's nothing to worry about. It will go away by itself, and he does another blood test just to make sure.

On Wednesday, I am at the U.S. Department of Agriculture researching an article. For a couple of years, I had been writing about Earl Butz's food policy, and I badly wanted an exclusive interview with the Secretary of Agriculture. There I am at the Department when I learn that the Secretary will see me at 3:30 that afternoon. I run home to get a tape recorder, and while there decide to play back the messages on my telephone answering machine. My doctor's nurse has called twice and then the internist and specialist in hematology gets on to say that it is very important that I come to his office at 3:30 that afternoon. I call back to say that 3:30 is out of the question. The nurse puts the doctor on. The doctor asks why I can't come in at 3:30. I say, "Because I have to see Earl Butz at 3:30 and he's more important than you are. What do you want to tell me?"

He says, "I can't tell you over the phone."

I say, "Why can't you tell me over the phone?"

He says, "Because I just can't tell you over the phone. Call me when you are done. I'll be in the office late so I can talk to you."

That's how I found out that I had cancer.

While I was interviewing Butz, I kept thinking, "You're going to live and I'm not. I hate you. It's not fair."

So, I sauntered into the internist's office, tape recorder in

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He was embarrassed, even though Hodgkin's disease is difficult to diagnose and he had done a considerable amount of sleuthing among the city's pathologists to arrive at a clear diagnosis. Because of the importance of early detection, his efforts had certainly increased my life chances. However, he couldn't tell me what my chances were until I went through a series of tests to determine the location of my cancer and how far it had spread.

The things I especially didn't like about the situation were:

(1) The uncertainty. If he could tell me with any certainty that I would definitely die in two years or that I would definitely live, it would be easier to deal with. Not knowing whether I would live or die seemed, at the time, even worse than the idea of dying. I was not in the mood for an existential crisis. I had been through one in high school — when Kierkegaard was in fashion — and would have preferred delaying the next one until I was 65 or 70.

(2) More pain. In order to get a bone-marrow sample, he would have to take a needle, pierce my hip bone and pull out the stuff. In addition, there would be major surgery. They would open up my belly, remove my spleen and generally look around, and sew me back up. That would hurt and I'd have to be in the hospital for a week to 10 days.

(3) Scientific illiteracy. I had a disease of the lymphatic system, but I didn't know what the lymphatic

system was. I am a person who has difficulty believing things unless I see them in print. The popular publications and even the medical textbooks were out of date and the journal articles — discussions on MOPP versus the 3-and-2 technique for total nodal irradiation — were incomprehensible.

Certainly it would have helped if I could have talked to someone who had been through what I was about to go through. I asked the internist to let me talk to another of his Hodgkin's disease patients who had been cured, but he refused, on grounds of confidentiality.

Then there was the reaction of my friends and family. I wanted to talk about how I was feeling, what was going to happen. But I also knew that it would be difficult knowing whom to tell and how to tell it. My friend Andy said that he was glad that I told him because he always likes to know what's happening and he would have been angry had he heard it from anyone else. He then proceeded to tell me, for an hour and a half, why I was lucky not to have multiple sclerosis. After much hesitancy, I told my mother, making it very clear that I would be in charge.

My mother and I had been very close. It had, in fact, only been within that year that I had been able to get enough distance on my relationship with my mother to tell her that my goals in life were different from her goals for my life. Since it had taken me 28 years to feel free enough to do that, I was not about to give up that freedom simply because I had cancer.

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I checked into the hospital, where I was examined thoroughly and questioned endlessly about symptoms I didn't have. Finally, they removed my spleen.

When I awoke from the operation, the pain was terrible. The nurse screamed at me that I was full of morphine and should shut up. The operation had meant good news. My spleen was normal and so were my lymph nodes. It meant that the statistics for cure were heavily in my favor.

But the rest was the worst. I had always had plenty of energy, and I refused to believe, after I left the hospital, that my body would be too weak for it to do what I wanted it to do. Then, the radiation treatments began. They would — assuming that I follow the statistics — cure me. However, in the process, the high-energy X-ray beam kills everything that it hits, normal cells as well as cancer cells. The therapy does not hurt and it is quick. Lying under the enormous machine, one has no sensation as the therapist leaves the room and turns on the linear accelerator for less than three minutes.

However, each day, as the rays killed more cells, I felt weaker and more nauseated. For the first time in my life, I didn't want to eat and had to force myself in order to keep my body in strong enough condition to withstand more radiation. Later, my skin burned and the hair on the back of my head began falling out in huge clumps. Hailing a taxicab or waiting for a bus was so exhausting that I wanted to cry with frustration. But I wanted no help from anyone, thank you. I could not control myself, get enough

energy together, so I constantly worried about energy, worried about asking Julie for help. And then, because it was so difficult asking for help, I became angry at her or anyone else I asked to help me.

The radiation therapy was totally impersonal. I rarely saw a physician unless I got really angry and insisted upon seeing one. Day in and day out for five days a week for 16 weeks, I went through this process and was never asked how I was doing emotionally.

Then, all I was told was that for every six months for the rest of my life I would have to go for a checkup. The checkups are notably boring and routine. I'm no longer an interesting patient and am treated like anyone else coming in for a physical examination.

Now that my hair has grown back and I look and physically feel as healthy as anyone else, I believe that we "cured" cancer patients are in need of both emotional support and practical information. For the first time, last September, a national conference, sponsored by the American Cancer Society, discussed the problems of cancer patients who live, focusing on those patients who provide us with a resource for dealing with our problems, such as those who have physical problems and who must learn to live with disabilities. These patients have pioneered the way for those of us trying to deal with our fear of death without suffering from societal discrimination.

The most frightening part of the cancer experience is the isolation — the feeling that I am alone and the fear that I will not survive. The best time for us cancer patients to make contact is while we



The author with his friend Julie Dillingham. Convinced he was going to die, he once told her he never wanted to see her again. "It's called playing the martyr," he says.

are in the hospital, when talking to a healthy person who has survived would be most welcome. What I wouldn't have given when I was recovering from my operation or when my hair was falling out to have met someone with energy who had been through the same thing! Yet doctors make it difficult for us adult patients without long-term physical disabilities to meet one another. In isolated places, on an ad hoc basis, concerned hospital social workers, radiotherapists and nurses are beginning to express an interest in helping us. While I was writing this, a technician who operated the machine for my radiation therapy called. She said she was thinking of starting a group of Hodgkin's disease patients so that those who are currently being treated can talk to those who have physically recovered.

There is no body of literature on the emotional problems of adult cancer survivors. This is because only within the past decade has it become clear both to patients and to medical professionals that some of the more than 100 types of cancer are completely curable and many more are put into states of remission where life expectancy is unaffected.

According to Dr. Paul S. Weisberg, associate professor of psychiatry at George Washington University School of Medicine, those in my situation deal with the experience in four basic emotional styles:

(1) "Counter-phobic defense." This is characterized by the patient who says, "I'm not afraid of this." The patient's response is shallow and he or she projects fear of death on others. Since so much energy is involved in denial, emotional support programs would be meaningless. The patient's response would be, "I don't need this; there's nothing wrong with me."

(2) "Displacement of anxiety." It's not the cancer that's worrying, but the bus driver who won't stop. Cancer makes it clear that there are some things — such as the length of one's life — which the individual cannot control. There is an externalization of fate in an attempt to regain control. So, the patient who exhibits an otherwise well-organized personality reacts to that loss of control by an occasional irrational act — like the time when I broke the window of a bus with my fist.

(3) "Amorphous anxiety." This is characterized by vivid dreams of death and pain. The patient describes a vague sense of disquiet. The individual is anxious but says that he or she is uncertain as to the cause, citing some self-fulfilling prophecy of bad fortune. These and "displacement-anxiety" patients would benefit from professional counseling which would help them to arrive at the next style:

(4) The "correct" style. The patient's response is: "I am who I am." The individual recognizes that he or she is not exactly the

same person as a result of the terror of confronting the issue of death. The patient will always be more aware of the malfunctions of the body and expresses the understanding: "I'm still O.K., even though the balances have shifted a bit."

In "The Looking Glass War," John Le Carré's spy says to himself, "Nothing ever bridged the gulf between the man who went and the man who stayed behind." Cancer has given me a sense of myself that I didn't have. A friend told me: "Having cancer was the best thing that ever happened to you," and my friend was right. I have been to a place where I couldn't control what happened to me, how much pain I felt, how much energy I would have. I didn't want to go there, and if I could avoid doing it again, I would. But all of us must deal with that same "emotional scar," that fear of death. I will, as we all will at some point, die. The cancer has made it easier for me to understand that life here on earth is limited and that I should make the best use of my time while I'm here.

I recently saw a videotape of a 23-year-old black girl who died of Hodgkin's disease last year. The interviewer asked her what she thought of her impending death. She said, "Right now, I'm having more trouble living than dying." Perhaps, after all, it isn't even the fear of death which is at issue. Perhaps, what we are all really afraid of is learning how to live. ■