

Turning Darkness Into Light ~ My Story of Living with Cancer

By Sara Schreiber

(I received a diagnosis of multiple myeloma, an incurable form of bone marrow blood cancer, in September 2004. One month later I began chemotherapy and have continued off and on until December 2006 when I decided, due to debilitating side effects, that I would never again have chemotherapy. For the past year I have tried alternative therapies-vitamin C infusions, anthroposophical medicines, Japanese Ki healing, herbs, vitamins, a healing diet, prayer, and love. I continue to have my blood monitored regularly and to meet with my cancer doctor at the University of Michigan Cancer Center to check on the progress of the multiple myeloma. My crucial "M-protein" number is about the same as when I quit chemo. I feel better than at any time since the diagnosis, and am writing a book titled "Turning Darkness into Light" about my experiences with cancer and what I've learned from this experience. The following are excerpts from the manuscript.)

Writing has to do with darkness, and a desire, perhaps a compulsion, to enter it, and with luck, to illuminate it, and bring something back out into the light.

- Margaret Atwood

I am hoping to delay my death... I have been told the (death) train is on its way. And when it arrives, I will have no choice but to leave on it. So I live in hope that the train will be late. I am in no hurry to leave. Hope is my modus operandi.

I have cancer. I live with it. But I am not cancer. I refuse to be defined by it. And yet it has become a gateway to experiences I did not choose. Those experiences have given me insights I would not otherwise have had. My life has become a private war for survival. But paradoxically the private war also takes me out of myself as new challenges destroy my illusion of self-sufficiency. It has always been difficult for me to accept help from others. Now I am forced to do so.

I am hoping to delay my death. Yes, I know the old adage. "Everyone is going to die." But here is a major difference between folks with incurable cancer (or some other similarly grim diagnosis) and folks without it. Those receiving such news learn that the death train, the one that is bound for glory, as the song says, is on its way. Others will someday board the same train of course, but they haven't been told that their train is on its way. I have been told the train is on its way. And when it arrives, I will have no choice but to leave on it. So I live in hope that the train will be late. I am in no hurry to leave. Hope is my modus operandi. But my hope is in conflict with my new reality, so possibilities have become less certain articles of faith than they were before. Yet I believe in possibilities.

When I was first diagnosed, I was embarrassed and afraid. I indulged in magical thinking. Like every other crisis that had come my way as an adult I instinctively responded in ways formed in my childhood. In other words, I regressed. (I'm told that this is not unusual.) I did not allow myself to think that I

had really had cancer, let alone a cancer that had no cure. I had to find a reason for this invasive outbreak. As a child I developed the illusion of omnipotence in order to avoid the burden of blame and abuse. So I myself must be responsible for my cancer. At some point I sensed that these feelings of helplessness, omnipotence, and guilt were all too familiar.

My maternal orthodox Jewish grandmother raised me. She and my grandfather adopted me after my mother died giving birth to me. I was my mother's first child. My mother was a talented concert pianist and was revered by my grandmother. My grandmother wanted me to play the piano. But it soon became evident that I could only play the radio.

Each of my birthdays was therefore the anniversary of my mother's death. My grandmother would remind me repeatedly that I killed my mother. She did this especially when I was argumentative or tried to assert myself or ask questions about sex. I managed to make her angry much of the time. It is not something I consciously tried to do. I was determined to escape the pervasive blame that she managed to inflict on me. It took me many years of therapy to disassociate myself from this experience. She would look up at the ceiling and talk to her invisible god in guttural Yiddish and say: "Kookshun vas ze gattuned tzu mine tauchter ('Look what she did to my daughter.')." "Kook shun Gott, mine touchier geschtarbin from der. ('Look God, my daughter died because of her.')." "Kook shun! ('Look!')." She would glare at me with eyes afire. Then my grandmother would point her finger at me in case her god didn't know for sure where I was. Once more in guttural soul-wracking Yiddish "She

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is a murderer! Look what she has done!" When a fire bolt did not immediately come through the ceiling I began breathing again. Not until I was older did I understand my grandmother's agony. But as a child I soon learned how to look away and hope that this god who lived in the ceiling of every room in our small house would forgive me for killing my mother. The echoes of her accusations are still lodged somewhere in my soul.

was the perpetrator of my mother's death and of my own cancer. I was the cause of my family's anguish when I was a child. And the family I have now is anguished because of my cancer. At some level I feel responsible for both families. My first response to my guilt over having cancer and to my helplessness was to become numb.

I stayed numb for some time after the diagnosis. When friends and family asked what multiple myeloma is my husband, Richard, would explain the



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Turning Darkness
Into Light
(continued)

Photo by Ruth Schekter



Sara Schreiber and her husband, Richard Gull, a recently retired philosophy professor.

disease to them. I was unwilling to put myself in this picture. I was disconnected from his words. I sat still and observed him explain details about the disease I had. I went to doctor appointments as if in a trance.

Then I had an awakening. Kathy has been my dear friend for a long time. She is a nurse and educator. I gave her the results of my blood tests and the cancer doctor's (Dr J.'s) reports. I wanted a prognosis. None had so far been forthcoming. Kathy, of course, could not ethically give me one but I wanted to know what the literature indicated about the survival of multiple myeloma patients. "Are you sure you want me to do this, Sara?" "Please" I said. She called two days later and her voice sounded very sad. "What is it Kathy?" I asked. "Sara," she replied, "Multiple myeloma is a bone-marrow blood cancer that, as of now, gives one on average three years to live." She sounded worried. But her words brought me back to reality. I was ready to declare a war for my survival. There was no alternative but to look closely at this death sentence and begin a new way of living. There was no choice. It was time. I began my education. I had to face the facts. I had to face me.

I asked my three children, Jan, Scott, and Rachel to come to our home in Ann Arbor and meet. I wanted to begin preparing them for my death. We first discussed how to divide my personal possessions. Since I don't have many possessions this did not take

My birthday is December 21, the winter solstice. Is this just a coincidence? My birth brought a death. For me, my birthday and my mother's death are forever conjoined. My birthday always has an air of sadness... "It is the darkest day and yet the one promising a rebirth of the light."

long. Instead of possessions my children wanted me to write something meaningful from me to them. I was surprised. So the idea of this book was born.

I also wanted to know how my children felt about my treatment options. Should I have chemotherapy or seek alternatives? My family was adamant about my having "proven therapies." I never understood what was proved in individual cases. It felt as if the "proof" was evidenced by the result of the many studies, which was less relevant to individuals. Nevertheless, I valued the opinion of Richard and my children. So I complied. I agreed to begin chemotherapy. They compromised by assuring me that if chemotherapy didn't work, they would agree to support my choice of alternative therapies.

The first encounter with this new side of my life meant taking steroids and Thalomid. I had an unexpected and frightening reaction to the steroids. I had several psychotic episodes. I tried not to inflict my outburst on Richard, so I closed our bedroom door to

escape. It didn't help. Our home just isn't that big. Dr. J. took the steroids away and suggested a new treatment called Velcade. That meant going to the hospital twice a week for infusions, three to four hours each time.

One reason these infusions are so lengthy is that since Velcade is a poison (it says so on the label) it must be preceded and followed by infusions of saline solution. The infusions were administered in a large room in which 20 to 25 other patients received chemotherapy or other prescribed infusions. Velcade lowers the blood's platelet and hemoglobin counts. With platelets constantly on the decrease, platelet infusions were necessary. And low hemoglobin sometimes required more blood transfusions. My depleted blood brought weakness and shortness of breath. I was taken to the emergency room three times after Velcade treatments. I was often sick to my stomach with dry heaves. I kept feeling more and more disconnected from my former self. My energy was depleted and it became an effort to eat or get myself dressed each morning.

Another side effect was pervasive dizziness and physical disorientation. Late afternoon in December, as I was about to sit down, I missed the chair and fell on my left hip. I was in excruciating pain and knew immediately that something was fractured or broken. I was taken to the emergency room at University of Michigan Hospital. Two days later my fractured femur was repaired surgically by means of a titanium screw. This was the beginning of my bionic woman identity.

In June 2006 Dr. J. suggested a new cancer treatment--Revlimid-- that had recently been approved for multiple myeloma. Revlimid is taken orally and thus requires no infusions. By this time I had recovered from the fractured femur of 2004. I was sailing along for three months with high hopes until I again began having dizzy spells that affected my balance. I fell again on

my left side at the end of August 2006. This time my leg was broken. A rod was surgically inserted. My bionic woman status was enhanced. It's a challenge going through an airport. I carry a little card now so that when I beep they won't search me for hidden weapons. The two injuries to my left leg in less than two years left me with a slower, uncertain gait. Recovery was slow. I was more dependent on others than ever before. I couldn't drive. My freedom was circumscribed. I was depressed.

Someone I loved once gave me
a box full of darkness
It took me years to understand
that this, too, was a gift

- Mary Oliver

My husband Richard is a philosophy professor. During my recovery from the falls, he was teaching full-time and was on several university committees. I was alone most of the time with our two cats. Regurgitating on bad chemo days, I felt a special connection with the cats. After the last fall my California daughter, Jan, decided we needed help and put an ad on Craig's List. She flew in again and she and

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Richard interviewed possible helpers. Companions? Aides? The concept was new to me.

Patti was the first one we interviewed. She has remained number one ever since. Patti and I instantly became pals. With Patti I've surrendered some of my

fear of dependence and not struggled against it, which has been my usual mode of being. I now realize that one challenge of illness is relinquishing the illusion that strength of will can bring back my ability to do what I used to do. I now need help doing things I previously did myself. My energy and strength have declined. Since the beginning Richard has done his best as a caretaker but recovery from the second fall



Photo by Ruth Schekter

“never.” “What if the multiple myeloma comes back with a vengeance?” “You might at least try chemo off and on again some time in the future.” I listened and said nothing.

For the past eight months, Patti and I have driven to Sterling Heights, Michigan to the dojo of a respected Japanese healer whom we call Sensi. The treatment is hands-on. I sit in a chair opposite Sensi. His warm hands work on me for about 10-15 minutes, and then I go to the spot where his assistants continue the treatment. Sensi is able to feel the areas of distress and connect his energy to them. He often emits whistling or hissing sounds. This is part of the Ki healing. He speaks little English. When I indicate an area of concern to him he will often say, ‘Don’t worry, I fix.’ His spirit always lifts mine. Sensi’s healing is a much more effective treatment for my depression than Cymbalta which I took for a while after the diagnosis but no longer need.

Sensi came to the United States from Japan twenty-three years ago. I heard from other clients that Sensi was able to heal his own daughter of brain cancer many years ago. But he makes no promises about cancer cures. After a treatment with Sensi I feel stronger. I wish I had skipped chemo and come to Sensi and other alternative healers first. In retrospect, I feel that I compromised by subjecting myself to chemotherapy. I wish I had not deserted my faith in alternative healing. At the point of the compromise, my willfulness failed me.

These days small things, like certain looks from another, can break my heart. My emotional defenses have been weakened. For example when we recently applied for new health insurance, the benefits man was friendly until I told him I have cancer. His lips immediately tightened; he turned and looked at his computer. I felt that he saw me as an untouchable. Larger things, like people dying in an unnecessary war, enrage me so much that I cannot watch news reports or talk objectively about it. I am more than ever before empathetic to the plight of others. I feel a strong connection, real or imagined, to other people waiting for tests or appointments in the Cancer Center. Though these silent interactions are situational, reciprocal looks affirm a mutual recognition of membership in a dark waiting club.

Sometimes when I wait my turn in the hospital I think about what else I could be doing if I did not have this enervating cancer. I could be planning trips to Italy or Peru with Richard, teaching psychodrama, or volunteering for the Obama campaign. But these are my fantasies. And yet there is wisdom in recognizing the reality of my circumscribed possibilities. Chogyam Trungpa has written:

Disappointment is a good sign of basic Intelligence. It cannot be compared to anything else. It is so sharp, precise, obvious and direct. Then we begin to see that our expectations are irrelevant compared with the reality of the situation we are facing.

For me, planning now involves a large dose of folly, and yet disappointment is a source of wisdom. Love is not love if it cannot withstand disappointment. Disappointment can seal a marriage—or end

it. My expectations are overwhelmed by the reality of my situation. There is an old Yiddish proverb: “Mann tracht und Gott lacht.” (“Man plans and God laughs.”) I feel the truth of this more intensely than before my diagnosis. Before, I was filled with plans.

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Life’s possibilities abounded. Now, I stop myself from connecting to a tomorrow or to an outcome. The present is more real, while expectations about the future are less so. I am acutely aware of feeling my breath, especially when I pray. Waking up each morning, moving my limbs, looking at the morning sky, seeing and talking with my husband, spending time with my grandchildren, are simple joys that fill me with gratitude. But this is not a simple way to live; it is an uneasy balance between wishing for future possibilities and hoping that God is not laughing. Each moment has become precious. I experience holiness in others. I am grateful that I am not alone. My California daughter Jan calls at least twice every day. Each conversation ends with her saying to me “I love you. Walk mindfully, Mom.” That is not only good advice for her mother the klutz, it is a mantra for how I now need to be.

My need to overcome childhood adversity made me willful. It is my grandmother to whom I owe this. In her rage over her daughters’ death, she tried to annihilate me. She inadvertently taught me how to survive. From the darkness of my childhood came a will to find the light. I thank her and I bless her for this. I pray that if, as some believe, my grandmother gets a return trip through life, she can live it without bitterness and fill it with health, happiness, and laughter.

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Sara Schreiber will hold a workshop on living with cancer, and turning darkness into light, on January 12 from 9:30 am to 2:30 pm, lunch included, at Steiner Stone School House. \$80. A few scholarships are available. For more information, call 734-662-1450.

required more time and energy than he had.

Two months after Patti came on board I fell again. Luckily nothing fractured but I had a painful bruise on my tailbone. The pain medication the hospital prescribed gave me hallucinations. I thought I was in a hospital in Iowa. I was sure that Richard was involved with an old girlfriend from Iowa he had once told me about. Another day I was sure that I was close to an ocean and kept begging the nurses to take me out to the water just outside my window. When I made requests like “Please take me outside to the beach,” the nurses would smile at me and nod. I told Richard that Nancy Pelosi, Carl Levin and Debbie Stabenow had come to visit me. Of course they didn’t. After I came home I was unable to drive. The effects of chemo continued to make me dizzy. My sense of balance was impaired. There was still a kind of fog in my head known in the vernacular as “chemo-brain.” I was grateful to have Patti in my life.

Dr. J. and I agreed to stop the new regimen of chemotherapy in December 2006. Now it was time to do it my way. “You’re so sensitive to all of these drugs,” said Dr. J. He felt that I had achieved “partial remission,” so medically a hiatus from chemo for as long as this plateau continued was justified, even though the disease was still “smoldering.” But he did not abandon me nor I him. I have continued weekly blood tests and Dr. J and I meet monthly to discuss my progress. I decided that I had given chemo a try. Now it was time to do it my way. I had fulfilled my end of the compromise with my family. I knew they would support me in my pursuit of alternative healing. They did support my decision, but they wanted me to treat the alternatives as a trial. My position was that I would never do chemo again. Richard, my primary physician, and my therapist said to never say