

Virtual Mentor

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PERSONAL NARRATIVE

Through the Patient's Eyes: On The Road

Gay Madsen Jervey

Bad news can be delivered in many ways at a doctor's office. Whether it is announced in an offhand careless manner by a busy practitioner or (as in my case) in hushed tones of compassion, the result is often the same. You, the patient, are pole-axed. Numb and dumb. When my GP told me I had leukemia, I sat there staring at him. His consideration was notable, but for a few days it just didn't sink in. Not me, no way. I was never sick. Never mind that my husband had taken me to the doctor for lethargy so profound I had difficulty getting out of bed.

And so my journey to a new land began.

A cruel reality of the road, so to speak, is the public perception that all serious diseases are now curable or treatable. There have been great advances in cancer treatment, to be sure, but, for many cancers, treatment is only a holding action, and, for some, treatment is more toxic than the disease. Thus, for many of us, the initial bad news is rapidly followed by an excruciatingly disappointed expectation of being cured.

Because I live in a small community I often saw people I knew, liked, or loved visibly losing their grasp on life. One acquaintance, a feisty and slightly raffish Vietnam vet, had lymphoma. He lasted quite some time, but one day he was gone. He will appear again in this story.

I go through the stages people usually do, the stages common among those grieving for lost loved ones or lost selves. The feelings I experience after the first shock recedes, fear and despair, have a sickening intensity I can share only with my husband, and he holds me as I cry for the years I am going to lose. At other times I push him away and find any human contact too abrasive.

One of my worst fears has to do with how I will die. Because I am very curious, as everyone must be in these circumstances, I inform myself from books and the Internet. Liver and kidney failure often accompany leukemia in its acute stage. Less than a year before, my father and I had nursed my mother through liver failure. It is ugly, painful, humiliating, frightening, sad. At one point during this six-month period I became convinced that life is a sadistic joke being played by a monstrous cruel deity.

The major drug I take is interferon. It is a natural substance, but people with hepatitis, AIDS, or blood cancers have to take it in nearly toxic amounts. Most folks have some trouble tolerating it in high dosages. Interferon can make you feel like you have the flu -- fever, aches, general malaise, and lethargy. But I am also taking an antidepressant, which hides all the bad feelings under a rock inside my head.

As a result of the treatment, my hair started falling out. For women and men, rapid loss of hair from head, eyelids, legs, arms, and pubis possesses far more impact than the bald fact of its absence. As you watch your body beginning to ditch its hairy cargo, you know you are in big, scary trouble. But at an even deeper gut level, like Samson, you are losing your human power. There's a good reason that prisoners, quislings or collaborators have their heads shorn (aside from lice, that is).

About 6 months into my journey, I rebelled. My joints were so painful I couldn't write or walk easily and I gained so much weight I disgusted myself. My oncologist, a caring and exceptional person, allowed me a "recess." I was glad and became quite active again, able to walk and even run.

As an aside, the varieties of "weirdness" that drugs, friends, "healers," and hospitals can offer are too numerous to mention. A kooky friend takes me to a shaman healer who pronounces that I am "cured." Please! Because I claim to be a scientist, wouldn't you think I would know better? Nah. People like this shaman can prey upon not only an individual's gullibility but the incredible human knack for self-deception. Boy, I want to be well again.

So after a month of deceptive freedom, I had another bone marrow extraction. My leukemic stem cells had shot up to 100% again from a pre-recess low of 10%. I was back where I started. On Interferon again, I rebelled against going back on the antidepressant. I feared addiction would be the next stop on my trip. I decided to go on without it, only to find a life-threatening curve in the road ahead.

A strange and important thing occurred and I have a responsibility to explain it. Oddly, the warnings about interferon causing suicidal thinking did not impress me. I was West Texas tough, thank you, and by gritting my teeth could endure anything. I started running again and my blood work showed improvement. I reported in to my oncologist and he was pleased, I was pleased.

But drugs and the mind are tricky and sly. I hoarded old tranquilizers for weeks as if I knew what I would do next. Immediately after my good checkup, a couple of squabbles set off a series of reactions in my mind that were emotional and severely sad. I drank five glasses of wine. A mistake. I was thrown into a black place with sharp cutting edges. Every thought brought terrible, terrible pain. It was time to go. I took every pill I remembered I had. By some great good fortune, my husband woke and stopped me before I downed a large bottle of Tylenol for dessert. Ironically, he saved me from death by liver damage, the thing I most feared.

We all approach serious medical conditions in ways that differ according to our personalities. Some yield, others fight, some worship their doctors, others hate their doctors. Some are like me. There is no single right way through illness, just as there is no single right way to God.

My way is to hang in there. My father, whom I am very like, wrote to me each week when I left home for school. He always closed with admonitions to "hang in there." And I do. A boss I had long ago said in reference to my work, "Gay, if you can't be smart, you'd better be lucky." I am lucky. I have a husband who loves me as I love him; I have family and friends who support me, and a church with a thoughtful congregation. I receive joy every day from people, plants, animals, all living things.

When I first drafted this article, I didn't know whether I would be accepted into a new drug trial program. The drug (formerly called STI571 and now named "Glivec") was developed by Dr. Brian Drucker of Oregon Health Sciences University and Novartis Laboratories. It was designed specifically for the kind of leukemia that I have (CML). Results to date from clinical trials have been spectacularly good and side effects are minimal. I am starting on this program April 5, and FDA approval should come late this year. Another vista appears ahead.

My friend Bob the Vietnam vet cheered everyone in the oncology waiting room with rude jokes and obnoxious, outrageous remarks. It is hard to get people to laugh in that place, but he did. He made everyone an offer: if they couldn't stand his jokes, they could buy joke insurance. Now Bob is in another place and I am taking over as Minister of Bad Jokes. If we meet some day, I will offer you joke insurance.

Gay Madsen Jervey contributed to this issue of Virtual Mentor.

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