



remarks

"I Don't Share Recipes"... Among Other Things One woman's journey seeking treatment for her breast cancer carries a message for physicians: Patients need their caregivers to work together.

BY LENORA FINN PARADIS, PhD



Debra sat across from me. Her tan cap barely concealed her hairless scalp and neck. Dressed in a beige short-sleeve top and white shorts, she was prepared for the heat of the Texas summer. Debra smiled at me. I told her I liked her cap. "I have quite a collection. It's much more comfortable than a wig," she said.

As cancer patients are prone to do, we became intimate quickly. Waiting to have our blood drawn at the Cancer Center in Arlington, Texas, we talked about our experiences in detail. Debra had discovered her breast cancer 18 months earlier. She had eight positive nodes, but was ER negative. She had had a radical mas-

tectomy, completed two rounds of chemotherapy, 33 sessions of radiation, and two more rounds of chemo. Ignoring her concerns about aches and pains, her doctor opted for x-rays rather than CT scans. Irritated by the continued aches, she decided to get a second opinion. Now, her cancer had spread to her head, lungs, hip, and shoulder.

Debra confided, "I wish I had done some patient research. I just took whomever the hospital gave me and thought that they would have my interests at heart...I was wrong, now I'm

here. But I'll be OK. I'm 39, I have two small kids and I can beat this..."

Perhaps I'll be luckier than Debra. I did my research first, but the journey was an interesting one and not without pitfalls.

I was diagnosed with cancer in early November of 1999. I remember feeling disassociated from the diagnosis. My surgeon was more concerned about my prognosis than I was. He was the one who told me my lymph nodes were positive and that he was "sorry." I told him not to worry, things would be fine. I

didn't quite understand the severity of my prognosis. I remember asking my hospital-assigned oncologist if I could schedule the chemotherapy so I had hair for my New Year's party. She didn't see a problem. "Your hair will probably be in for a few days after the first of the year, but after that you'll lose it," she said. Ever the optimist, I thought that was great. It wasn't until months later that I was able to really read my chart and understand the magnitude and possible outcome of my situation. But I'm getting ahead of the story.

Quick decisions

Everything happened so quickly. I found a lump, called my obstetrician and had a mammogram within hours. The results showed something, probably a cyst, in the breast. The lump grew within days and I called my physician

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again. She suggested I see a surgeon. Together, we called 10 different surgeons to see who could see me the quickest. Her first choice doctor had an appointment available in one week because of a cancellation. The others only had openings weeks later. I was lucky. After performing a biopsy and viewing the lump in my breast on ultrasound, the surgeon told me it was probably malignant. He gave me his first available surgery date five days later. It was less than three weeks from the time I found the lump until I had surgery. Growth was rapid. My cancer grew from one to three centimeters and went from Stage I to IIb in that time.

My cancer was lobular, and I was ER and HER 2 positive. From my hospital-assigned oncologist I learned that my chance of being in remission and alive in five years was 50 percent. I still did not internalize the situation. My friends were calling in panic and I was telling them, "Don't worry. Things will be OK." I realized that I needed to read about my disease. I needed facts. Luckily, I had four weeks between the time I had my surgery and the time my chemo was to commence to conduct my own research.

I started with cancer patients. I gravitated toward those who had information and were similarly situated. Patients without positive nodes were eliminated immediately. Someone with four or more nodes was of interest, but a woman with eight or more nodes was definitely in my sphere of influence—particularly if that woman was ER positive. I met several women with leukemia who were very helpful as I considered stem cell transplant as an option.

The literature and videotapes from the hospital were of little use. My assigned oncologist was too busy to deal with me and was not particularly interested in my outcome. I decided to find someone else. My cousin, a dermatologist in Michigan, suggested I call Sloan Kettering. The wait for a medical visit was eight weeks—too long.

One of the cancer patients I spoke to suggested Duke; another friend suggested the Arlington Clinic, founded by several physicians from M.D. Anderson in Houston; a third suggested the Block Institute in Chicago. I decided to visit each one. Fortunately, all three centers were able to schedule a visit quickly. Ironically, Sloan Kettering called back after two weeks to tell me they had an opening. I decided three other opinions would be satisfactory.

No consensus

I knew I'd made the right decision by seeking other opinions. My hospital-assigned oncologist had given me a 15-minute consult during my first visit. When I saw my physician at Duke, he spent more than two hours with me. He recommended I become part of a study which would randomly assign me to either stem cell or dose dense treatment groups. I decided I wanted more control over my treatment and did not elect the Duke option. When he told me that dose dense and stem cell showed similar outcomes, I questioned the efficacy of doing stem cell procedure. He felt I should participate in the study so that other women could benefit. In my own selfish way, I didn't want to be part of an experiment.

My husband and I next headed for the Block Institute in Chicago. That physician's approach is holistic and focuses on supplements, diet, exercise, and building the body's natural defense system. He does use chemotherapy, but only in conjunction with supplements. He felt stem cell was too aggressive, and recommended a three-drug chemotherapy regimen followed by radiation. He believes that the drugs operate best when the circadian rhythms are considered as part of the therapeutic approach. His patients use a pump over a period of several days. He has a bi-lumin port inserted and uses supplementation in tandem with chemo. He believes the supplements enhance the chemo and keep the immune

system from being depleted.

Now I had received two opinions and two very different approaches to treating my disease. Both physicians spoke of "curing" my cancer and thought my odds were very good. I felt better daily and believed that I was doing the right thing by talking to other doctors.

My time was running out as I went to the Arlington Cancer Center. My physician there insisted I be on tamoxifen immediately. During my two-and-a-half-hour appointment, (he recommended that I tape his discussion of his treatment approach and then call back if I had questions), he discussed his philosophy of cross-resistant chemotherapy over a period of several days. He recommended that I receive six rounds of a three-drug chemotherapy cocktail over a four-day period so the body better tolerated it and to better kill cellular activity. He would follow this with two more series' of drugs. Radiation would follow.

At this point the only thing the doctors agreed on was that I should receive chemotherapy over an extended period of time.

When I returned home, I decided to contact a naturopath. Trained in acupuncture, naturopathy, and Chinese herbal medicine, this doctor believed in building my immune system and foregoing any chemo or radiation. While I liked this approach, something in the back of my mind told me that I did need chemo, but I also needed to change my diet and build my immune system.

I called each doctor and asked if he would participate in a conference call with the others. I requested 30 to 45 minutes of time and told them I'd pay for the phone time. I wanted them to discuss the merits of the different approaches to my situation. I told each of them that I was confused because the recommendations were so diverse and that no two physicians agreed. Worse, I felt if I kept going I might end up with six

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to eight different opinions. The physicians refused. One told me that I could not expect them to talk—“after all,” he said, “it would be like one chef sharing his special recipe with another chef.” I never considered myself a dish, but apparently I was.

I opted for treatment at the Arlington Cancer Center. The physician there was the most positive, flexible, and made the most sense to me. He agreed to provide a protocol for another doctor to follow. Living in Louisville, it made it very difficult to go to Texas every time I needed a treatment so I found a local oncologist who would work with the Arlington doctor's formula. This oncologist was young, conservative, and willing to try something a bit different. We followed the protocol. I hired a naturopath for supplementation advice, to which my local oncologist reluctantly agreed and I also worked with nutritionists at the Block Institute where the focus was on immune enhancement. Thus, I had a loosely knit “team.” None of them spoke to one another, were particularly in agreement, or had any curiosity about the respective actions of the others on my “team.” I became the link, faxing information between practitioners so that they all knew what I was doing.

Everything moved along reasonably well until my fifth treatment. My chemo port became infected and I spent five days in the hospital with strong antibiotics. With my port removed and my white blood count at seven, I felt like a failure. My local oncologist wanted to have another port inserted and continue. I felt this was dangerous, given my mental and physical state—not to mention an open hole in my chest that was one and a half inches across, a half inch wide, and almost as deep.

The doctor in Arlington recommended starting radiation and then returning to chemo. After a week of healing, I began my radiation process. I became friends with my radiologist and told him that I was going back for more chemo after radiation. He did

not feel this was a good idea given the fact that by now my scans were negative. He said “talk to your oncologist, but I think you should wait until you have a reoccurrence, if it does happen.”

Radiation progressed uneventfully. I had PET, CT, Chest scans, constant blood monitoring, biofeedback analysis, and dark field analysis by my naturopath, among other things. All tests showed I was in good shape with no evidence of cancer metastasis. I went back to Arlington.

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Again a disagreement. The doctor in Arlington recommended a three-month course of chemotherapy with new drugs. He said the treatment would be preventive and give me the cross resistance he felt was critical. My local oncologist now was of another opinion. He saw no reason to treat a disease he could not see and recommended I monitor the situation. My chiropractor and naturopath agreed with the latter physician. I asked my local oncologist to please talk with the doctor in Arlington—he agreed.

The physician in Arlington felt strongly that I needed “preventive chemo.” I meditated for several days to come to a decision. My gut feeling was to continue building my immune system and forego any additional chemotherapy. The critical point came when I spoke to a cancer patient in England. She told me that she was receiving tamoxifen and radiation but had received no chemotherapy. She had three positive lymph nodes. Her doctors had told her that chemotherapy was “reserved” for reoccurrence. I decided that I should

wait for a reoccurrence—which hopefully never materializes—before I receive any more drugs.

At this point, I'm trying to learn about better nutrition and supplementation. I'm also trying to learn about new treatments and studies for breast cancer.

I know I am not alone in struggling to coordinate all aspects of my treatment. Other patients I have spoken with have expressed the same frustration and confusion. Somehow, physicians and other practitioners need to talk to each other. Patients are not diners to be treated to special recipes. They are human, and as such, need to be examined and diagnosed according to their uniqueness. Having a second or third opinion is crucial to long-term survival. I learned a long time ago that two heads are better than one. It sounds trite, but sometimes the best solutions are the most simple.

Finally, I was able to have my naturopath, oncologist, and nutritionist talk to each other. I agreed to pay for a phone visit which lasted about 10 minutes. None of them felt comfortable, but I was glad that some contact had been established. Perhaps we can arrange a second conference and accomplish more...but I'm not holding my breath. ■

Dr. Lenora Finn Paradis lives in Louisville, Kentucky. Her cancer is currently in remission. She is working to create a Center for Healing for cancer patients with several local physicians, nutritionists, counselors, psychiatrists, dieticians, and others. She hopes to have a holistic center where cancer patients can work with traditional practitioners using complementary therapeutic approaches.

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