

CANCER IS not an easy word to say out loud, but acknowledgment is the first step in beginning to deal emotionally with diagnosis. (MCT)



Part I

Confronting cancer

Being diagnosed during Operation Protective Edge was a double whammy, going from surgery and radiation treatments to taking cover in a bomb shelter

• BATYA L. LUDMAN

How strange the way catastrophic events etch themselves into our personal memories. While we know, for example, what we were doing on 9/11, do we have a clue what we were doing the day before? The tragedies of this past summer – the murder of the three young boys and Operation Protective Edge – unfolded concomitantly with my own personal war, and enabled me to put my issues into perspective, as they paled in comparison to current events.

While still waiting to hear news of the youths, I learned I had invasive breast cancer. As I came home from surgery, the first siren sent me into our bomb shelter, and my last radiation session – just a few hours before Rosh Hashana – happened on the day the boys' murderers were caught and killed.

Although I'm a very private person, I feel it important to share my story. Cancer need not be shrouded in stigma,

shame or embarrassment, but should be addressed head-on.

A cancer diagnosis can be incredibly frightening, and each person's journey is individual, dependent on the diagnosis, prognosis, treatment regimen and a myriad of personal factors. Each person's response to learning their diagnosis and dealing with their treatment, and how and how well they cope, will reflect this. With its acute and chronic phases, cancer can serve as a prototype for other illnesses. I use the word "illness" with reservation, as I never felt ill; for those who do, that will color how they respond as well.

Diagnosis

It had been barely 48 hours since the news broke that the three boys had been kidnapped. My mind was elsewhere when I heard the doctor say, "We see a little focus right here," pointing to the ultrasound during my routine mammogram. "Focus" is a euphemism for the word "abnormality," which might be – I was told – a tumor, and which also sound-

ed more benign (no pun intended) than the word cancer. Somewhat stunned, I left this first appointment having had a breast exam, a mammogram, an ultrasound and a biopsy.

For many women, the process starts when they feel a lump, which is benign more often than not. Follow-up is important, but there is little need to worry until there is something to worry about.

I made the decision with my doctor that I would have any news delivered over the phone rather than go into the clinic. I was busy with my own patients when "the call" came in. It went to voice mail, I continued with my patients. The message asked for me to call him back, and I knew I needed to prepare myself psychologically for bad news.

When we spoke, my doctor confirmed my suspicion. I had cancer.

The week before, he had put his hand on my arm, looked me straight in the eye and said that regardless of what this was, it was caught early and I would be fine. I believed him.

Hearing that you have cancer is a defining moment. My life in just about every respect was about to change, at least temporarily. When we spoke on the phone, he used the “good news, bad news” approach, and I felt reassured in spite of hearing that I had cancer. Not easy words to say out loud, but acknowledging what is going on is an important first step. I recognized that I had suddenly and unexpectedly been thrust into the “one in eight” club.

This statistic means that in your lifetime you will know many people with breast cancer. Hopefully it won't be you, but if so, you, too, can learn not to be frightened, to live in the moment and to cope well. We can plan all we want, but life has a way of shuffling our priorities. You will need humor, patience and organizational skills. There are many surprises along the way, some initially scary, but as you learn more, you'll find it easier to put things into perspective.

Disclosing the news

Having cancer was now my “news,” and while I'd barely had time to absorb it myself and was feeling quite possessive of it, I had to decide how and with whom I wanted to share it.

I told my husband first, using the same “good news, bad news” approach the doctor had used with me. My husband was stoic, but as a physician, he knows too much and was a little too silent for my liking. I wondered why I needed to cheer him up, but our personality differences cause us to see things differently.

Next we told our children, who are all young adults, and our parents, and while difficult, it got a bit easier with each one. I learned to start with the ending first: “Look at me. I am okay and I will be fine,” followed by, “My mammogram was abnormal and....”

I was determined to be positive, because I knew that how I handled the news would influence how others coped with it. The war happening at the time helped me to put things in perspective. I refused to see this as a life-threatening situation.

I rehearsed not-yet-made phone calls to friends, telling them my news with humor, my best coping strategy: “By the way, did I tell you I had a touch of cancer?” If you can't find something funny or good in a situation, you're just not looking hard enough.

The joke was really on us a bit, though, as I am married to a cancer geneticist. He sees cancer day in and day out, which I knew explained his behavior. I was happily trying, and for the most part succeeding, not to be in denial, to be an informed but not overwhelmed consumer, reviewing only the information I determined to be relevant. Meanwhile, he offered me a choice of over 430 research articles on every imaginable topic related to breast cancer.

We ultimately agreed that he would outline in yellow what he felt I really needed to know, and when ready, I would read it. This worked great, and giving him this job freed me up to focus on what had to be done next.

Aside from immediate family, during

the 100 days from diagnosis until I finished treatment, I told very few people. As long as only we knew, I didn't have to answer questions for which I had no answers, while I was still trying to understand the diagnostic complexities and treatment options. This gave me a sense of control that I knew I needed for the moment.

Nonetheless, the time had come to tell a handful of close friends who I knew could be there unconditionally for me. Telling them was difficult and emotionally draining, and it took time, which I didn't have. I discovered that, at times, I was drying their tears and trying to reassure them that I would be okay, dealing with their feelings when I was still trying to figure out my own. Once I moved into “See me, I'm fine... and I need you to be strong,” we all did much better.

It was important for people to know that I was the same person as before my diagnosis and that I really was okay. I knew that my family and I would need logistical more than emotional support, compassion rather than pity, and that I needed to have my work and a life outside of cancer as much as I could.

Amid meeting with surgeons, medical and radiation oncologists, and going for multiple diagnostic procedures, surgery and treatment, I continued offering trauma counseling to others, running to the bomb shelter and dodging missiles while recuperating from surgery. The juxtaposition was surreal.

Disclosing your diagnosis is an immediate conversation-stopper. It becomes hard to complain or discuss mundane things when someone puts cancer in the sentence and “one-ups” you. Some people become uncomfortable hearing that word and don't know what to say – it's best to just acknowledge it. Others' eyes immediately gravitate to your breasts.

Telling others can be done in person, but sometimes it has to be done by phone, email or the like. Each has advantages and disadvantages, but the key is to disclose your diagnosis slowly and on your terms. The type of cancer, its characteristics and prognosis will impact how you tell others and how much you reveal. Plan out in advance what you want to say.

While never easy, it's often easiest to start with close family. Your children, more resilient than you think, will follow your lead. Give honest, age-appropriate information. You'll have to determine what your boss and colleagues need to know. Pick people who will be there for you unconditionally. You need to invest your emotional energy wisely. If you know someone who has “been there,” they can be an incredible resource. I had two such “bosom buddies,” and their supportive emails and tips were great.

Remember, though, that diagnoses, treatments and prognoses differ. Guard against irrelevant or incorrect information, and be careful surfing the Internet.

Let your medical team guide you.

Choosing your support team

When you first find out you have cancer, you are confronted with a huge

amount of information to absorb, and you may feel confusion, fear, anger, or other overwhelming emotions. Remember, you're new at this, and as with any journey, you may have false starts, fear getting lost and wonder if you'll make it. You just need to break down information into small manageable bits that you can handle in order to feel in control.

How you initially hear the news plays a role in how you cope. Through the years, I've heard horror stories from my patients with cancer and can only add that there are good doctors and bad doctors – those with empathy and those who have no time for your questions, those who make eye contact and put their hand on you to reassure you, and those who can't be bothered to get out from behind their desk or look up from the computer. Some offer shared decision-making, and others are paternalistic, wanting to make all the decisions. One doctor's first response was, “How awful!” and another said there were other patients waiting so I should look online for the answers to my questions (she was off my case, pronto!).

You have a right to have your questions answered and receive the support you need. Whether it is hand-holding or brutal honesty, you know what's important to enable you to stay calm. I interviewed several doctors before choosing my team. Make sure to get a second opinion if you have any questions. This is serious stuff; you need to understand your options.

In addition to physicians, you will interface with nurses, technicians, social workers and many others. Don't be afraid to ask for help. The system has idiosyncrasies, but generally works remarkably well. You and your family will need emotional and physical support both for the short term and the long haul. This is uncharted territory, and with it come lots of questions, paperwork and fatigue.

At times, things move too quickly, and at others, it is as if time stops. A designated note-taker accompanying you to your appointments frees you up to listen and can provide emotional support. You'll be overwhelmed with information and can read the notes at a calmer time. Organize your records in a binder and bring them with you everywhere.

People can be incredible with sincere offers to help. Sometimes people you least expect to be there for you amaze you, especially when they anticipate your needs before you even realize them.

I'll stop here. There's so much to absorb. Remember, I'm fine and you'll be able to cope, too. I'll continue with my journey in Part 2, sharing the tools I used to get through, coming out a bit battered, perhaps, but in many ways stronger. ■

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