

Just for Me

Focusing on your unique experiences as a woman newly diagnosed with breast cancer



NEWS FOR THE NEWLY DIAGNOSED

Making Decisions About Surgery

By Janine E. Guglielmino

Beth McAbee was unconcerned when she went for her “just-because-I’m-40” mammogram in April 2008. She had always heard breast cancer was “something you felt,” and her breasts were as smooth and symmetrical as ever. Yet two weeks, several tests and a biopsy later, Beth learned she had ductal carcinoma in situ.

Beth, who lives in Atkinson, New Hampshire, visited a local surgeon. He advised her to have a lumpectomy and sentinel lymph node biopsy, followed by radiation. The surgery brought good news and bad: Her diagnosis was the same, but the surgeon hadn’t gotten clean margins.

“I am very small breasted, so I asked, ‘What if you don’t get clear margins [the second time]?’” Beth says. “He said, ‘You would get a mastectomy.’ So I asked, ‘Well, what if [the cancer] comes back later?’ He said, ‘You would get a mastectomy.’ So then I asked, ‘Well, why wouldn’t I just get a mastectomy now?’”

If you have DCIS or stage I-II breast cancer, you may face the same choice Beth did—whether to remove your entire breast (mastectomy) or only the cancer and a small rim of healthy tissue around it (lumpectomy, or breast-conserving surgery). The decision can be heart-wrenching, especially because it comes at a time of great stress and confusion. Here are ten tips to help you with decision-making.



Beth McAbee got a second opinion from a breast specialist while weighing her options.

Tip #1: Breast Cancer Is Not an Emergency

In general, surgery is not urgent (although it may feel that way). Many breast cancers grow slowly, and most doctors believe you can safely take between four and six weeks to weigh your options.

Thrown into the whirlwind of a diagnosis, **Nicole LeVere**, 34, of Salinas, California, decided on lumpectomy based on one conversation.

“My surgeon told me I had both options,” Nicole says. “She didn’t explain to me why, but I was just so overwhelmed at the time and relieved that I didn’t have to have a mastectomy that I didn’t question it.”

If you find you need more than six weeks to decide, you may be “looking for opinions and answers that do not really exist,” says **Monica Morrow, MD, FACS**, a surgical oncologist at Memorial Sloan-Kettering Cancer Center in New York. Talk with your healthcare team about a reasonable time frame.

Tip #2: You May Have a Choice

With early-stage breast cancers, you are likely to have a choice between lumpectomy and mastectomy. Some circumstances require mastectomy; surgery depends on the size, number and location of tumors; your breast size; and other treatments you might need.

“Your surgeon should discuss the treatment options with you, explain what is involved in each of them, and if you are



Nicole LeVere had the option of lumpectomy or mastectomy.

not a candidate for one of them, explain why you aren’t,” Dr. Morrow says. “[The surgeon] should explain what particular features about your case make one option preferable over another.”

Tip #3: Longer Survival Is the Goal

One of the most secure findings in medical literature is that “breast cancer survival is equivalent with lumpectomy-radiation and mastectomy,” Dr. Morrow says. Yet many women aren’t getting the message.

“The idea that a ‘bigger’ operation has to be a ‘better’ operation is hard to get rid of, no matter what you’re told,” Dr. Morrow says.

If your doctor suggests you have both surgical options, ask, “What is the risk of recurrence after lumpectomy? What is my personal risk of local recurrence after lumpectomy or mastectomy?” Your health-

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Talking with Children

In our last issue of *Just for Me* and on Facebook, we asked readers to respond to the question: How did you share your diagnosis with your children? One Facebook fan wrote:

I was diagnosed at age 40 with a triple-negative tumor in my left breast that included lymph node involvement. My treatment consisted of a lumpectomy followed by chemo and radiation. I'm now celebrating six years cancer-free, and my kids are now teenagers. At the time of my diagnosis, they were seven and ten. The advice from their school counselor was to tell the truth. So, my husband and I described the situation in simple terms...breast cancer. We explained the treatment process, and we kept them informed as we moved through the journey and provided assurance that Mom would get well. Now "breast" is a commonly accepted word in our vocabulary.

Terri Sterk
Johnston, Iowa

This issue's question:

How do you manage fatigue?

Send your answers
to editor@lbcc.org.

To become a "fan" of our page, go to the Facebook pages application and type in "Living Beyond Breast Cancer."

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care team probably won't be able to answer the question about risk of recurrence after mastectomy in detail until after your surgery, but the risk of recurrence after lumpectomy can usually be estimated fairly accurately before surgery, and opening the dialogue early never hurts.

Tip #4: Your Needs Are Important

With a lumpectomy, you will need daily radiation for up to seven weeks. Can you commit to the time and travel? Will other health problems impact your choices?

Does your exercise regimen, job or family responsibilities make one surgery preferable to another? How important is it to you to preserve your breast?

Finally, will a mastectomy lead to less anxiety for you in the long run? Even though the treatments have equivalent long-term survival rates, perhaps you still prefer to have your breast removed. Make sure you get the facts.

Tip #5: Your Diagnosis Is Unique

Just because your mother, sister or friend had one surgery does not mean the same surgery will work for you.

Sue Merrick, 59, of Las Cruces, New Mexico, was diagnosed with DCIS in May 2008. Her surgeon initially suggested lumpectomy and radiation. But when Sue's surgery failed to return cancer-free margins, her doctor recommended a different route.

"She suggested a bilateral mastectomy because of my [medical] history," Sue says. "My breasts remained dense, even

after menopause, and I had had seven biopsies, mostly on the opposite breast."

Sue needed a mastectomy because her risk for recurrence was higher than average. Nicole, on the other hand, could have a lumpectomy because removing her breast would provide no additional survival benefit.

Although mastectomy had not been Sue's first choice, she felt confident because she understood the unique nature of her diagnosis.

"Don't let anybody influence you," Sue says. "Make your own decision, and make it for your own reasons. When it's the right one, you will feel it in your gut."

Tip #6: Treatments Change

Treatment advances make today's therapies very different from what you might remember.

"All you have to do is look at a computer and how it is today versus how it was 15 years ago," Dr. Morrow says. "We have had the same technical advances in radiation [and surgery] as in computers."

Tip #7: Find a Surgeon You Trust

Women who went to high-volume breast surgeons tend to be more satisfied with their outcomes than those who see less experienced doctors, but you can still get excellent care from general surgeons in busy breast practices, Dr. Morrow says.

For her second opinion, Beth visited Dana-Farber Cancer Institute in Boston, because "breast is all they look at, and they know it inside and out." The doctors took her step-by-step

through her diagnosis and unfamiliar medical terms.

Whomever you choose, make sure your doctor is accessible, listens to your questions and provides clear answers.

Tip #8: Get a Second Opinion


If you have doubts, get a second opinion. If two surgeons give you the same answer, ask again why they recommend that particular surgery.

"We know that surgery is a driver of survival," Dr. Morrow says. "Failure to control the tumor locally with surgery, or not doing radiation, or insisting on lumpectomy when your doctor tells you it's medically inappropriate, gives you an increased risk of breast cancer death at fifteen years. There are choices for most people, but unfortunately not for everyone."

Tip #9: Breast Reconstruction Is Possible

If you have a lumpectomy followed by radiation but later need a mastectomy, you probably can have reconstruction. That you could not "is a common misimpression," Dr. Morrow says. If you aren't sure, ask your doctor before surgery.

Tip #10: Resources Can Help

Never underestimate the power of support. Call our Survivors' Helpline at (888) 753-LBCC (5222) to be matched with someone who made this decision. You also may order our free **Guide for the Newly Diagnosed** and **Guide to Understanding Treatment Decisions** for more information. 

Surviving with Uncertainty

By Bette Sorrento, for LBBC

In July 2008, a mammogram revealed a slight growth in a shadow in my left breast. The radiologist told me to “watch it” and check back in six months. But I’m a strong self-advocate, and my gut told me to follow up immediately.

I wanted definite answers. I made an appointment with a breast surgeon for the following week. I had a needle biopsy and then had the tumor removed for analysis.

Then the rough part began. I received the call from the surgeon, who said, “It is cancer”—the only time in my life when a “positive” result was not good. The rest is a blur. Before the news came, I had moved from New Jersey to Pennsylvania to be closer to my family. How would I find new doctors and get the treatment I needed?

Two days later, the surgeon handed me the pathology report (which I immediately wanted to give back). I felt like my life was not my own. I had entered

Living in a new location, I was on my own in finding an oncologist, radiologist and other healthcare providers. Thankfully, a survivor I met through a support group at The Wellness Community provided much needed medical contacts. I found an excellent oncologist who helped me understand the complex medical information I received. I soon learned that appointments, treatments and a new hormonal therapy medication would be part of my “new normal.”

I was doing diligent research on the Internet, seeking resources and information, but I was careful not to overwhelm myself with clinical details. On Living Beyond Breast Cancer’s Web site, lbbc.org, I found easy-to-understand information. I started to think, “It is not all bad news.”

As I gathered information, reports, papers and medical “stuff” were piling up. But I could not locate my pathology report when I was ready to read it. I

10 Things to Do Right Away When You’re Newly Diagnosed

1. Make a list of your doctors and their contact information.
2. Decide whether you want a second opinion.
3. Find out whether you can take time off from work should you want to do so.
4. Talk with your family and friends about your fears and concerns.
5. Think about what you need most right now.
6. Take good care of yourself.
7. Seek information about breast cancer from trusted sources.
8. Make necessary doctor’s appointments.
9. Keep track of your medical records. Make copies of everything you receive.
10. Get a notebook or journal to write down questions or other information.

A phone conversation with a survivor was my first personal connection to the people of this culture.



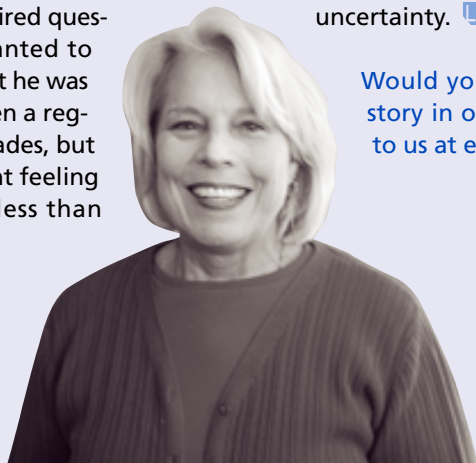
the “culture of cancer.” This would mean having to adjust to a new “fast track”: different emotions, new language, unfamiliar procedures and a change in lifestyle. I came to understand that this life-threatening diagnosis would require connections to like-minded people with unbelievable courage. A phone conversation with a survivor was my first personal connection to the people of this culture.

I met with my doctor after the second surgery (resection of margins and sentinel node biopsy). I fired questions at him, as I wanted to know more than what he was telling me. I have been a registered nurse for decades, but I left the appointment feeling adrift, as if I knew less than when I had come in.

decided to label my reports and information and keep them in a folder. I was regaining that “lost control.”

As I moved away from my diagnosis, I craved connection with others on the journey. Feeling somewhat alone, I continued attending support groups and meeting people who are cancer survivors. Talking with people who understand what I’m going through comforts me, and I am grateful for those who share their stories and listen to my own. My life is balanced with hope, gratitude and uncertainty. LBBC

Would you like to share your story in our next issue? Write to us at editor@lbbc.org.



*Did you find this list helpful? Read more in our **Guide for the Newly Diagnosed**, from which this list is excerpted. To get your free copy, visit our “Marketplace” at lbbc.org or call us at (610) 645-4567.*

When you are ready, we encourage you to call our Survivors' Helpline at (888) 753-LBBC (5222) for guidance, information and peer support. Our trained volunteers are here to listen and help you.

Managing Insomnia and Fatigue

LBBC's new *Guide to Understanding Insomnia and Fatigue* explains the symptoms and cancer-related causes of insomnia and fatigue, how to manage sleep issues and how to discuss them with a healthcare professional. Below we share an excerpt that lists a few practical ways to manage insomnia and fatigue. Order your free brochure at lbbc.org's "Marketplace" or by calling us at (610) 645-4567.

Improving Your Sleep

You can improve your sleeping patterns by changing your habits. Researchers have found that changing sleep habits is as effective at fighting chronic insomnia and lasts longer than using sleep medicines.

Make sleep a priority and set aside seven to nine hours for sleep each night. Use your bed for sleep and intimacy only; avoid working, eating or watching television in bed. Go to bed at the same time every night.

Start a routine to follow before bedtime. Allow yourself at least a half hour to wind down before going to bed, and go to bed only when you feel sleepy. Do not spend long amounts of time in bed not sleeping, because your body will associate the bed with tossing and turning rather than sleep. Instead, after 20 minutes of not sleeping, get out of bed and go to a restful place to relax and read with a dim light. Return to bed when you feel tired. Repeat this process as many times as you need. Make sure to get out of bed at the same time every day.

'Power' Napping

"Power naps" give you the boost you need to make it through the next important task or event. These naps of 30 minutes or less, taken early in the day, give you

rest but won't put you into a deep sleep, which can make it harder for you to fall asleep and stay asleep at night. After a power nap, you may feel groggy at first but better within the next half-hour. Set an alarm clock to control the length of naps.

Exercise

Regular, low-intensity exercise prevents and improves fatigue caused by treatment. Exercise also helps you sleep more soundly and can even improve your outlook.

Exercise need not cost much or take a lot of time. Start with a 20-minute walk each day. Walk as briskly as you can. By night, this small amount of exercise will help you to fall into a deep sleep and stay asleep.

Other types of exercise depend on your body and physical needs, so it's best to ask your healthcare provider before you start. Ask to be referred to a physical therapist or cancer rehabilitation program before treatment begins. A physical therapist, rehabilitation medicine specialist or a physiatrist specializing in people with cancer can help create a safe and effective exercise routine for you.

If you already exercise, try to keep your usual routine, if possible, during treatments. Once treatment begins, exercise at an intensity level that is comfortable for you. If you can, walk or exercise every day. When you cannot walk your usual 20 minutes, start with five or six minutes. When you feel ready, add a few minutes more. As you gain more energy, aim for a 20-minute walk several days a week. Finish walking two hours before bedtime so it doesn't prevent you from falling asleep at night.

Try not to go more than two days without exercise. When you feel very tired, try a slow exercise such as yoga or tai chi to relax your mind and move your body. [LBBC](http://lbbc.org)

