



Lifeline

A Quarterly Publication of Y-ME National Breast Cancer Organization



Y-ME National
Breast Cancer
Organization™

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Communication Tips from Patients and Survivors

Discussing breast cancer can be tough, whether you've just been diagnosed, are going through treatment or are continuing life as a breast cancer survivor. However, there are conversations with your health care providers, family and friends that are too important to skip. Your relationships are key in helping you get the support you need and maintain control over your life. Here are some tips you can employ to make sure that you are effectively heard.

Tip #1: Be an informed patient.

"As a clinician and health care communication consultant, I'm very comfortable talking to just about anyone regarding medical issues," says Helen Osborne, M.Ed., OTR/L, of Health Literacy Consulting, who recently completed breast cancer treatment. "But when I was diagnosed with breast cancer, I was so overwhelmed that I could barely think, let alone talk to my doctor about it well."

JoEllen Gray, a retired independent insurance agent, agrees. "I remember being told the diagnosis was a surreal

experience," she says. "I was hearing the doctor's words, but I was thinking he had to be talking about someone else."

However, JoEllen says that she was lucky because she was informed early on by her general practitioner about the importance of clear communication. She was diagnosed in the early 1980s when it was common practice to perform a mastectomy immediately after a positive biopsy, without patient consultation. That was the experience of Ann Marcou, cofounder of Y-ME, in the late 1970s shortly before she began facilitating the support groups that evolved to become Y-ME.

"After being advised by the family doctor, I read consent forms very carefully," JoEllen says. "And I made it clear that if I was diagnosed with breast cancer, I wanted additional testing and time to consider all of my treatment options, not just jump into a mastectomy."

Both Helen and JoEllen say that their communications with health care providers improved after they learned about their options. Helen kept her own personal medical record, and

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wrote down questions for her doctors that she might have trouble remembering during an office visit. JoEllen gathered information from every available resource she could think of, including copies of clinical studies her daughter found at the college library, and discussed the information with her doctors.

Tip #2: Be honest.

You'll feel better about your decisions and the direction of your treatment if you can remain true to yourself. "I waded through an incredible amount of information about treatment options before deciding," says JoEllen. "My mother really pushed me to have a mastectomy before I was finished with the decision-making process, and I had to make it clear to her that I was going to do what was best for me. It was my body, my health at stake." After weighing her options, JoEllen made her own decision have the mastectomy.

JoEllen's surgeon informed her that she wouldn't need chemotherapy, but she decided to have it anyway. Twenty years later, she does not regret it. "Chemotherapy was my emotional insurance policy," she says. "I needed to know I had done everything I could do to keep the cancer from coming back."

As a breast cancer patient, the sheer number of people that you have to communicate with on a regular basis, from health care professionals and insurance providers to caring family and friends, can be mentally and physically exhausting.

Both during and after treatment, Helen prefers that breast cancer be treated as a life experience, instead of becoming incorporated into her every day life. She has created boundaries by respectfully asking family, friends and colleagues to refrain from discussing her experience with breast cancer during inconvenient times.

Tip #3: Build a communications vehicle.

As a breast cancer patient, the sheer number of people that you have to communicate with on a regular basis, from health care professionals and insurance providers to caring family and friends, can be mentally and physically exhausting. As a result, many patients seek the help of a trusted individual, or "point person," who can communicate for them during treatment.

This frees patients to devote their full attention to the things that matter most to them.

JoEllen says she depended heavily on her husband's support, particularly when chemotherapy affected her memory. "I could lose my memory in an instant," she says. "I could be driving and forget how I got there or where I was going; I'd forget that people had visited immediately after they left."

Other people wish to maintain control over communications themselves, and devise ways of managing the way they contact friends and family. Instead of fielding constant questions regarding her health, Helen opted to keep people updated by sending out periodic group e-mails.

Tip #4: Seek positive support.

Having a positive outlook is important to quality of life, but it is difficult to achieve and maintain on your own. After all, breast cancer is not good news, and surgery and treatment are not pleasant experiences.

"I really needed to talk openly to someone who knew first-hand what I was going through, explains JoEllen. "That kind of support was something that I had to go outside of my family for." She found that support in a local group of women called "Bosom Buddies," all of whom had survived breast cancer and met during monthly socials to talk about their experiences. Hearing about how other people coped with breast cancer, she says, helped her to believe that she could get through it too.

Through friendships she made in the group, JoEllen was able to explore issues that came up after her treatment was over, such as deciding whether to undergo reconstructive surgery. "I got to hear about other women's experiences," she says, "as well as see the results of the surgery. Ultimately, I decided that reconstruction wasn't for me. But femininity is an issue after mastectomy for a lot of women, and it was important for me to explore those thoughts."

Y-ME offers services for the patient and family members. Call the Hotline at 800-221-2141 for 24-hour support and information. You can also find local groups that provide support through your oncologist, hospital or clinic. Peer-to-peer support like JoEllen mentions is what Y-ME does best. Every Hotline peer counselor is a breast cancer survivor who has been trained. **Y**

Need help communicating with your health care team or loved ones? Speak with a Y-ME peer counselor who can talk to you about strategies for expressing your needs. Call us at 800-221-2141.