

Guiding women through diagnosis



“There really isn’t a right or wrong reaction to a breast cancer diagnosis.” – Robin Lally, associate professor of nursing at the University at Buffalo who is developing the CaringGuidance After Breast Cancer Diagnosis program Sharon Cantillon/Buffalo News

By [Scott Scanlon](#) | News Refresh Editor on October 11, 2014 - 7:07 AM

The first few days after a woman is diagnosed with breast cancer can be a whirlwind. What kinds of treatments should they consider? What will the next few months look like? How should they feel? The medical profession has gotten pretty good on the treatment side questions. The emotional ones? That often can be another story. Robin Lally aims to change that.

Lally – a University at Buffalo associate professor of nursing and researcher, who also works with Roswell Park Cancer Institute – is in the process of developing the Caring Guidance After Breast Cancer Diagnosis program. “Our main goal is really distress reduction,” she said. “Distress covers your thoughts and your emotions and your behaviors.”

Lally, 49, who lives on Grand Island with her husband, Brian, is a Minnesota native who once worked as a clinical nurse specialist at the Jane Brattain Breast Center, outside Minneapolis-St. Paul. She came to UB in 2006 and is leading other researchers in the School of Nursing, on the South Campus, in the online Caring Guidance effort.

The American Cancer Society, Community Foundation for Greater Buffalo and the Foundation of New York State Nurses is helping cover the cost of the 2½-year effort, which will conclude next year. After that, Lally and UB hope to offer the Internet-based program to a wider audience. “There’s plenty of support groups and coping strategies out there, but nothing that really addresses specific issues that women have right after they’re diagnosed,” Lally said.

How can a woman participate in this research now? They can call or email me (at 829-2137 or rmlally@buffalo.edu). You have to have been diagnosed within the last two or three months. It takes a couple minutes, we do a quick screening. ... They get a \$25 Amazon gift card every time they return their packets to us, up to \$100.

What was your nursing job like in Minnesota? The job was 95 percent psychology and about 5 percent oncology. We were dealing with all of the womens’ initial distress. We were the ones calling in the women and saying, ‘I’m sorry, your biopsy results did come back positive and you have breast cancer.’ We would do that sometimes three or four times a day, and we’d trade off so we didn’t have to do it every day. That was difficult.

Talk about the Caring Guidance program.

It’s all about reducing stress and depression and anxiety in multiple ways. Some women really crave information, so there’s a lot of information in the program. Others want to see that other women have survived. That gives them strength and validation. So the program has six survivors who tell their whole story. I interviewed them specifically about certain aspects of their thoughts, about their coping and their anxiety. So there’s advice from people who have lived through it. It’s Internet-based, rather than a book or pamphlet, because the idea is to get it to women as soon after diagnosis as possible. They have access 24/7.

I’ve done interviews with women in Minnesota and then interviewed 26 women here. They would say, ‘I don’t think I’m acting normally. My family says I’m either too happy or I’m too sad, or a lot of this and that.’ There was a lot of reflection going on. There isn’t really a right or wrong reaction to a breast cancer diagnosis. Some women cry a lot, some don’t cry at all, or will wait and cry a couple months from now. The program is a lot of validation. We didn’t just sit here in Wende Hall and make it up. The whole program was developed with the input of survivors and experts: several psychologists, nurses, advanced practice nurses that work in breast centers.

So the program can help serve as a guide?

We say it’s information, support and guidance because it can help to guide some of the thought processes away from those thoughts that are going to be very distressful. Not that we’re going to fix it, but offer strategies about thinking about things in different ways.

We have tried not to make it too physiological because you can get that elsewhere. If you click on the National Cancer Institute or the American Cancer Society, you can learn all about breast cancer cells and types of surgeries. We do submit some facts, and questions and answers, and we start with four myths and facts, things that lead to distress and can trip women up. The stats tell us only about 10 percent of women get any psychological care, for all sorts of reasons. When you're treated for cancer, you're seeing surgeons and oncologists, people who care about you but who don't have the time or expertise to talk about all these other things. 'I'm feeling guilty.' 'I don't know how to talk to my children about this.' That's not something your surgeon or oncologist is necessarily going to talk with you about.

What do you recommend to women who are dealing with this distress?

Part of the reason this doesn't get addressed is that women don't bring it up, for all kinds of reasons. Talk to your health care provider. Ask about the resources that their clinics have. A lot have psychologists, social workers, chaplains, and sometimes women, are afraid to access those services.