

Breast cancer diagnosis ‘is a whirlwind’

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Most of the one in eight women in the U.S. who get breast cancer don't die of the disease.

But the instant response of many to the diagnosis mirrors that of long-time state employee Vanda Ragans last summer.

“It's like someone handing you your death certificate and saying, ‘Sign it,’ and that you are agreeing to die soon,” the 55-year-old Department of Revenue worker said. “It's like making a deal, like you are finishing up on buying a house or something, but it is death.”

Dr. Jeannine Silberman, a medical oncologist and psychiatrist with Tallahassee Memorial HealthCare's Cancer Center, said there are as many reactions to a breast cancer diagnosis as there are women who receive one. But the prospect of death almost always looms.

“The big elephant in the room is concern with your own mortality,” Silberman said. “Their minds tend to wander to the worst-case scenario.”

One of her approaches to ease the fear is to provide statistics on the many positive outcomes that come from early detection and improved treatment options.

“Patients indicate how much or how little they want to know,” she said. “There is a lot of data that can be a comfort.”

Fellow TMH Cancer Center radiation oncologist Dr. Shelileah Newman said newly diagnosed breast cancer patients often are in a head spin.

“When you are first diagnosed, it is a whirlwind, everything goes into warp speed,” said Newman. “I give them a hug and tell them to breathe, because the first thing you need to do is to sort of reset yourself, and breathe.”

Health care experts say it's important that patients have time to digest and understand information about their particular case.

“Even when you want someone to tell you what to do, at the end of the day you are the one that lives with the results,” said Capital Health Care's Chief Medical Officer Dr. Nancy Van Vessem. “No one really knows your values like you.”

For most women the main question, after the type and stage of cancer they have has been determined by a biopsy and other tests, is whether to have a mastectomy or a partial breast-

preserving lumpectomy. The small percentage of women with more advanced and rare cancers have fewer and more complex choices.

“You have to tailor it to the patient,” Newman said. “There is no way to have a one-size-fits-all approach these days.”

Newman said misconceptions linger. Some people think the cancer will spread if the tumor is cut. Others believe treatment can be worse than doing nothing.

“I’ve had women who have very significant disease who will refuse chemotherapy because their hair will fall out,” Newman said. “In the end, I will always respect their decision. I may not agree with it, but it’s their body and their choice. But you can still see some extremes.”

The biggest challenge is to get survivors to continue with screening and follow up after the initial cancer is gone, Newman said. TMH has implemented a survivorship program that has helped.

“The most important thing after therapy is to make sure it doesn’t ever come back, but if it did, God forbid, we are there to get it early, attack it and get you cured,” Newman said.

TMH clinical geneticist Dr. Lea Kristin Parsley said thanks to treatment advances that allow particular cancer cells to be targeted, cure rates are significantly higher than they were 20 or 30 years ago.

“A lot of people think breast cancer is a death sentence, but the treatments have come a long way,” Parsley said.

Ragans credits her surgeon, Capital Regional Medical Center’s Dr. Kathy Langston, with helping her chart her course and quickly put breast cancer behind her.

Less than two weeks after a biopsy proved she had a type of non-invasive “in situ” cancer in the duct of one breast, Ragans and her husband Lyle were sitting in Langston’s office. The doctor spent more than two hours by Ragans’ estimate going over all the treatment options, drawing pictures of what a lumpectomy looks like, discussing hormone and radiation therapies and weighing the merits of completely removing one breast or two.

“She said, ‘If you had your pick of cancer you got the best kind because it is totally isolated,’ ” Ragans recalled. “Dr. Langston was the saint who pulled me through it. She was totally positive and gave me the strength and made me believe that the cancer would be gone after surgery and so far she has been right.”

Health care experts say people with breast cancer should take their time and get all the information they can before deciding what course of treatment to pursue.

“Somebody needs to sit down and make sure people understand their unique characteristics,” said CHP’s Van Vesse. “Some women are like, ‘I want a mastectomy, I want this sucker off,’ and some women say, ‘I really want to keep my breast.’ That individual comes in with her own set of values and you have to understand those values and put it together with the actual disease. You need to let some of the panic wear off before you make some of these decisions.”

TMH's Cancer Center emphasizes a "patient-centered" approach to breast cancer and other cancer treatment. The hospital employs "patient navigators" for newly diagnosed cancer patients and survivors who work to explain complicated treatment options, help meet basic care needs and provide emotional support.

"What we are there for is to reduce any barriers they may have," said navigator Dreama Taylor. "They are overwhelmed, medical terminology is new and it's just helpful to have a consistent contact person that they can call at diagnosis, when they are being treated with radiation or chemotherapy or if they have surgery, just someone to call."

Silberman said a patient-centered approach allows the medical team to treat the whole patient, not just the cancer that has brought them into care.

"The pros to getting to know a patient is getting to know their values, educate them on the options, then make decisions collaboratively," she said. "It is their life. Quality of life is not an insignificant thing."

Like most women who get breast cancer, Ragans had no symptoms when the tumor was detected. Since she was adopted, she didn't know if the disease ran in her family. (A subsequent genetic test showed she did not have the most common inherited cancer syndrome.)

In the end, Ragans swiftly decided she wanted both breasts removed and opted for reconstruction. Three weeks after she was diagnosed that's what happened.

"I had made my mind up as soon as I was told I had cancer, 'Just get it out of me,'" she said.

Lyle Ragans concedes now he had second thoughts about his wife's choice of treatment, but he kept his thoughts to himself. It was, he said, her call. His role was to be there for support.

"Vanda always thinks the worst. I knew I had to be strong for her," said Ragans, who owns his own landscaping business and was with his wife every step of the way during her diagnosis and treatment. "I took it as a way to be a better husband and father. It could have gone another way."

Ragans acknowledges her decision would not suit everyone. Her double mastectomy was a more old-school approach. The most common treatment for the type and stage of cancer she had is a breast-conserving lumpectomy followed by targeted radiation.

"You can't go by someone else's choice," she said.

Ragans is a decisive person, the no-nonsense mother of two sons, one grown and one 17, and a grandmother of three. She could not endure the uncertainty that the cancer may have come back. She said she has faith in modern technology and doctors, particularly Langston who so impressed her.

"Why would you want to settle for something that's always going to ride on you for the rest of your life? You would worry every time you got your mammogram that the cancer is back, and believe me,

no one wants to hear they have cancer,” she said. “I have always moved forward and never want to look back.”

Genetic testing

Women with a pervasive family history of breast cancer, particularly before the age of 50, should talk to their doctor about genetic testing.

TMH clinical geneticist Lea Kristin Parsley said about 10 percent of breast cancers are linked to inherited cancer syndromes, most commonly from BRCA 1 and BRCA 2 genes. Women with those gene mutations have an 80 percent chance of developing breast cancer. Men also can have BRCA 1 or BRCA 2, making them more prone to developing either breast or prostate cancer.

“We can be empowered by knowledge,” said Parsley, who counsels patients before a test to ensure they are mentally prepared for the results. “If you take the right steps, you can catch things earlier and you may never have metastasized cancer. You may live a very long life.”

The test costs \$3,400 and is paid for by most insurance companies, Parsley said, but not by Florida Medicaid. The company that does the testing, Myriad, offers payment options. Screening recommendations for women who have the BRCA 1 or BRCA 2 mutation include annual mammograms and MRIs beginning at 25, twice yearly clinical breast exams and additional screening for ovarian cancer and other tests.

Beyond increased surveillance, women with the gene face the choice of having a prophylactic mastectomy, which reduces their risk of breast cancer by 90 percent.

“Most women we counsel before the test are mentally prepared when they come back in for the result. It’s really tough choices and you don’t want to order the test lightly,” Parsley said. “By taking the test you are empowering yourself for your children and siblings. It doesn’t just affect you.”