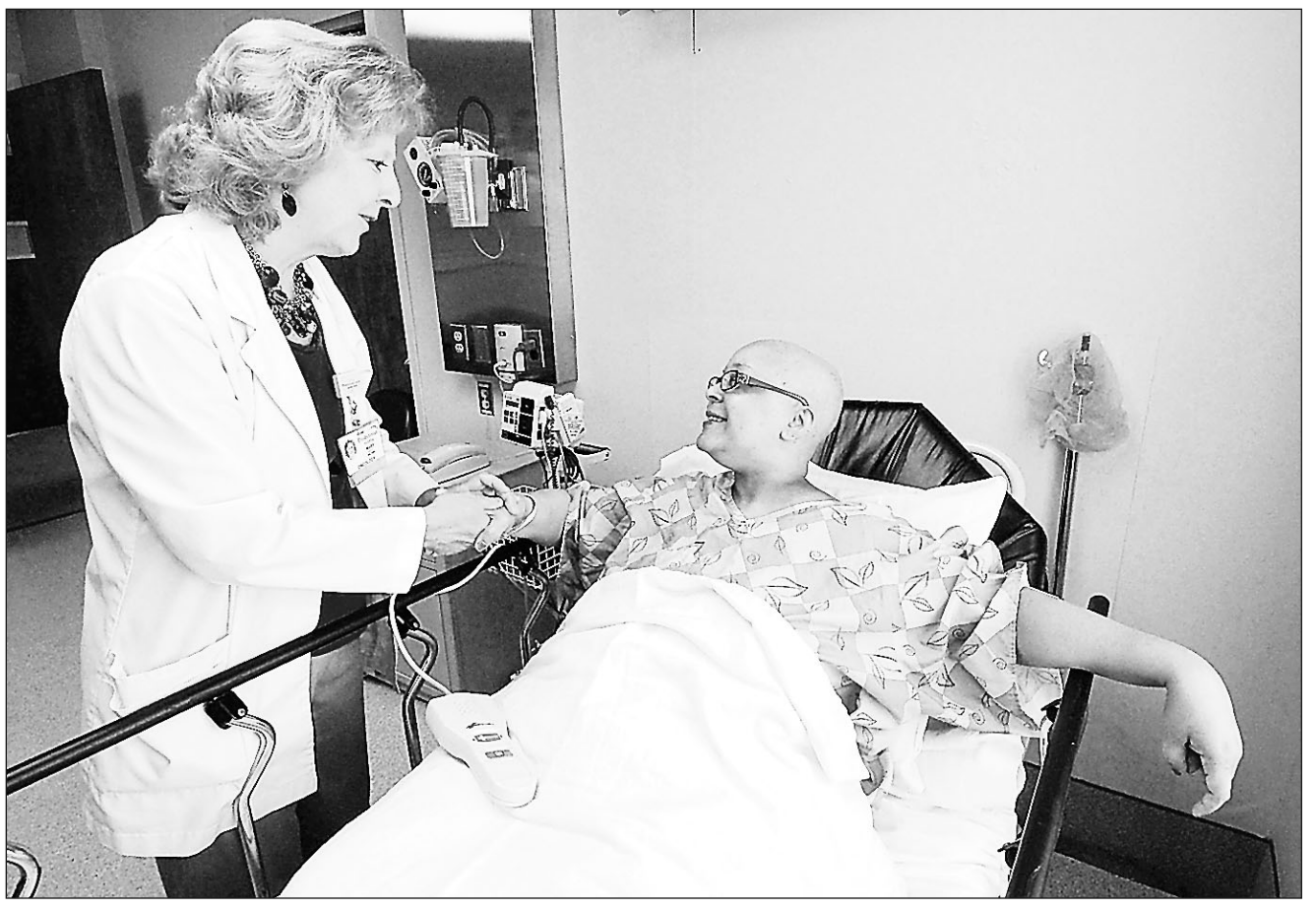
Guiding Lights For Patients

In Complex Medical World, New Nurses Can Be GPS For Breast Cancer Patients



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Mary Keefe, left, talks with patient Sue McKenzie as she prepares to undergo a double mastectomy at Presbyterian Hospital in Charlotte, N.C., recently. Keefe is a breast cancer nurse navigator helping patients make choices in treatments in tough times.

BY KAREN GARLOCH

CHARLOTTE, N.C. — An hour before surgery, as she lay waiting in a hospital bed, Sue McKenzie smiled with relief when nurse Mary Keefe walked into her room.

They held hands and talked through last-minute questions.

"You'll check on me Thursday and Friday if I'm here?" McKenzie asked hopefully.

"Oh, yeah," the nurse said.

Making sure breast-cancer patients get what they need is Keefe's job.

She's a pioneer in the growing health care field known as patient navigation.

With advances in cancer treatment, patients face far more complex decisions today than the past. As a result, hospitals across the country are hiring nurses or other professionals to help patients navigate their way through the medical system.

The job of a navigator is not only to explain breast cancer, answer questions and arrange doctors' appointments, but also to counsel patients through the terror of a cancer diagnosis, show them how they can survive it, and guide them through their journey.

There is no extra charge for the service. It's part of the health care package.

Barbara LiPira, vice president of oncology services at Presbyterian Cancer Center in Charlotte, N.C., said it's worth the cost. "It's more than a feel-good program," she said. "It's a better way to care for patients."

One of three breast-health navigators at Presbyterian, Keefe met McKenzie the day she was diagnosed. She was there when McKenzie had CT and bone scans before chemotherapy. And she'll be there as long as McKenzie wants to stay in touch.

Since 2006, Keefe has done this for hundreds of patients, some of whom have referred friends, sisters or mothers.

"We connect with them on day one, and we spend as much time as they need," Keefe said. "I tell them, 'I don't work for the doctors. I work for you first of all, as your educator, your supporter and your coordinator.'"

Patient navigation started in 1990 at Harlem Hospital Center in New York, where Dr. Harold Freeman hoped to reduce health disparities by improving access to cancer screening and reducing barriers faced by low-income, African-American women.

Many studies support the use of navigators, said Angelina Esparza of the American Cancer Society. "Patients really do feel that they are able to better cope with the diagnosis and the cancer.

"There are significant differences in outcomes in terms of stress, fatigue and quality of life. For many years, these psycho social needs were often overlooked."

Accrediting bodies for cancer programs — not just breast cancer — are making patient navigation a required standard. The Commission on Cancer will require accredited cancer centers to offer navigation services by 2015.

Navigators don't have to be nurses. Some programs use social workers or even lay leaders. Navigator is the buzzword today, but some hospitals use the term coordinator.

"The name changes but the job is the same," said Susan Postell, breast program nurse coordinator with Levine Cancer Institute at Carolinas Medical Center. "I think all nurses are navigators. I've been in this role for over 30 years.

"A lot of what I do is crisis intervention, explaining the disease, the name of the cancer and what it means, offering hope more than anything else," she said. "This is an intimidating place to come. Every new cancer patient needs that person they know they can call."

Keefe, 56, was one of the first official breast-health navigators in Charlotte. She was working as an oncology nurse at Presbyterian when the position was advertised in 2005.

"I thought 'What a great thing to do for people,'" Keefe said.

But doctors weren't convinced at first that navigators were needed.

"I was ambivalent about it," confessed Dr. Peter Turk, a Presbyterian surgical oncologist. "I didn't know if she had the ability to make an improvement in what we were doing."

Today, he's a believer.

When Turk meets patients who have worked with a navigator, "The discussion can be much more focused. ... By the time they come to see me, a lot of the emotion has calmed down. They are able to synthesize and make decisions."

Patients who haven't met with a navigator are "still very much like a deer in the headlights," Turk said. "At the end of the meeting, they don't remember a thing. All they hear is the word 'cancer.'"

Misty Burgie remembers the day, Oct. 30, 2008, when she got her breast-cancer diagnosis at Presbyterian Cancer Center.

Only 35, she had chosen not to meet with the radiologist who would give her the results of her biopsy.

"I opted for a phone call," Burgie said. "I was working full time. I didn't want to waste another trip downtown because I knew I didn't have breast cancer."

The news stunned her.

"I couldn't breathe," she said. "I remember thinking, 'This must be a misunderstanding. I'm 35 years old. There is no history of breast cancer in my family.' ... It felt as though I had been given a death sentence."

She got a call from Keefe within minutes.

"When I got off the phone, I thought, 'OK, I can get through this,'" Burgie said. "She just made it sound very do able."

When they met the next day, Keefe gave Burgie a 200-page book about breast cancer and showed her which parts to read and which parts she could ignore. "I knew absolutely nothing about breast cancer," Burgie said. "She helped put my mind at ease."

Before each of Burgie's surgeries, Keefe showed up to make sure she was OK. And earlier this year, when Burgie's mother was diagnosed with breast cancer, Keefe was again there to guide them through.

"It just brought instant peace knowing that my mom was going to be in such good hands," Burgie said.

Typically, Keefe spends each morning meeting one or more newly diagnosed patients. Instead of giving bad news over the phone, Presbyterian usually schedules initial appointments jointly with a radiologist and a navigator.

"Unless they absolutely refuse, we make them come in and sit down," Keefe said. "We've sat here for two hours with people who have lots of questions, and with tissues, whatever they need."

Keefe gives each patient a tote bag including a journal and a homemade pillow to elevate the arm after surgery. Mastectomy patients receive camisoles with pockets that hold post-surgical drains. Keefe also gives them lists of places that provide breast prostheses and wigs for those who'll need them.

Some centers make appointments for patients to meet their surgeons in two weeks or more. But Keefe and her colleagues make appointments within 48 hours. They also arrange appointments with multiple doctors on the same day.

"I can say, 'Let me work this out so you don't have to come into town but once,'" Keefe said. "I can say (to the doctor's scheduler), 'You've got to work her in.'"

On a recent morning, Keefe made rounds in the hospital, checking on patients. She walked quickly, and her phone rang loudly and often.

In addition to visiting Sue McKenzie, the surgical patient, Keefe stopped to see Joy Wells, a Charlotte woman finishing a radiation treatment.

They held hands as they sat to talk. Wells, 52, cheerfully pointed out that her hair is growing back, albeit gray, after chemotherapy.

"It's so good to see you," Wells said. "Thank you so much for helping me. I don't know what I would have done without you."

FYI: 10 Things To Know About Breast Cancer

BY KAREN GARLOCH

Check your expertise during Breast Cancer Awareness Month in October.

1. A lot of people talk about preventing breast cancer, but the correct term is risk reduction.

"We don't really know how to prevent breast cancer. We know how to reduce people's risks," said Judith Swasey, a nurse practitioner at the University of North Carolina- Chapel Hill's cancer hospital. The basics: Don't smoke, exercise a lot, watch your diet, annual screenings.

2. There has been lots of controversy in recent years over the usefulness of annual mammograms for some women. Some researchers suggest they aren't needed until women reach 50 and that it's OK for women not at high risk to have scans every other year.

But the American Cancer Society and many breast cancer centers continue to recommend annual mammograms starting at 40. The cancer society also recommends clinical breast exams by physicians annually, beginning at the same age as mammograms.

For those at high risk for breast cancer because of family history, annual screening should begin before age 40. For example, if you have a sister who developed breast cancer at 45, the recommendation is to start mammograms at 35.

Monthly self-exams have also been the subject of debate, but the cancer society recommends them for women starting in their 20s.

Mammograms are controversial partly because they produce both benefit and harm. Awareness and screening have led to more early detection. But critics say that some patients have been harmed by unneeded surgery, radiation and chemotherapy for small cancers that wouldn't have been found without mammography and wouldn't have caused problems.

3. Post-menopause weight gain is particularly dangerous when it comes to breast cancer risk. With extra body fat comes more estrogen, which can stimulate breast cancer growth. A normal body mass index is less than 30.

To calculate BMI, multiply your height in inches by that same number; divide that total into your weight in pounds; then multiply the total by 703. A person who is 5-feet-5 (65 inches) and weighs 150 pounds has a body mass index of 25. (Or Google "BMI calculator" for an online tool.)

4. Many studies have looked for a link between diet and breast cancer risk, but results are conflicting.

Experts say it's good advice to eat a diet high in fruits, vegetables and whole grains, and low in fat and red meat. "That's what I tell my patients," Swasey said. "Whatever diet is heart-healthy is probably the best one to follow."

5. Evidence is growing that regular exercise lowers the risk of breast cancer.

"It doesn't have to be high-intensity exercise," said Rachel Burns, dietitian with Levine Cancer Institute at Carolinas Medical Center. "It can be as easy as just walking, being physically active 30 minutes a day."

6. Avoid soy supplements, Burns said. Soy contains isoflavones, which can act like estrogen and stimulate the growth of certain types of breast cancer. Supplements usually contain more concentrated doses of isoflavones than whole forms of soy, such as soy milk, tofu or edamame, Burns said. "Three servings a day of those (whole) forms are OK."

7. Smoking hasn't been linked specifically to breast cancer risk, but a recent study of women at high risk for breast cancer found that, for those who smoked, the more they smoked and the longer they smoked, the more their risk increased, Swasey said.

8. MRI scans are not recommended as regular screening tools for the general population. But they are used, in addition to mammography, for screening high-risk patients and for diagnosis after mammograms that detect suspicious masses.

9. Women with dense breasts are at higher risk for breast cancer, and mammograms aren't as effective in detecting cancer in very dense breasts. Ask your doctor whether you have dense breasts and, if so, you might benefit from regular MRI scans or ultrasounds along with mammography.

10. Breast cancer risk goes up with age. The often-repeated statistic that "1 in 8" women will get breast cancer is calculated over a lifetime to age 95. The National Cancer Institute has created a Breast Cancer Risk Assessment Tool. Take the test at www.cancer.gov/bcrisktool.

OTHER KILLERS

Breast cancer gets a lot of attention, but heart disease is the No. 1 killer of women. One in three U.S. women die of heart disease compared with 1 in 30 who die of breast cancer, according to the American Heart Association.

Other gynecological cancers are harder to detect and treat. For example, 70 percent of women with ovarian cancer are diagnosed in the late stage of disease, when it's difficult to treat.

"There are 80,000 women who contract a gynecological cancer other than breast cancer annually," said Dr. James Hall, a gynecological oncologist with Levine Cancer Institute.

"I celebrate the fact that (breast cancer survivors) have done a wonderful job of educating the population and getting increased awareness. I just hope we can replicate that success." Learn more about breast cancer