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Lymphedema Program at YRMC Helps Breast Cancer Survivors Cope with the Aftermath

Susan G. Komen for the Cure Grant Reaches Low & Middle Income Women

Diane Bauer and Jeanne Hines have a powerful bond, even though they have never met. The two Quad City residents are breast cancer survivors who struggle with lymphedema. Both women have found relief through The Lymphedema Management Program at Yavapai Regional Medical Center (YRMC).

“Unless you have experienced lymphedema,” said Bauer, “it’s hard to understand its impact.”

Lymphedema is a side effect of cancer treatment that approximately 25 percent of breast cancer survivors experience. Its first signs may be as inconsequential as a heavy feeling in an extremity, a ring that seems tight, or even a watchband that doesn’t rest properly on the wrist. Initially, the swelling subsides at night but within weeks or months it becomes chronic and more intense. For some with lymphedema, the affected area can expand to several times its normal size. Lymphedema can limit mobility and affect how people feel about themselves.

“My arm began to get larger, especially the upper arm, and it was painful,” recalled Hines. “It felt like it was tearing on the inside. My hand began to swell, too. We called it my fat baby hand because it was chubby like an infant’s hand.”

That was in 2001, several years after Hines had undergone treatment for breast cancer. Bauer’s initial experience with lymphedema was different, but the results were similar. Her arm began to swell “fast and huge” when she began radiation therapy for breast cancer in April.

“I had never heard of lymphedema,” Bauer said. “I learned that it was something that could be treated but that it would always be with me, which is sad.”

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Today, both women work every day to control their lymphedema. Thanks to The Lymphedema Management Program at YRMC—and a grant from Susan G. Komen Phoenix Affiliate—they have the knowledge and tools necessary to control their lymphedema. The tools are custom compression bandages and garments that are provided through a grant that YRMC received from Susan G. Komen Phoenix Affiliate this year. The grant targets low and middle-income women suffering from breast cancer-related lymphedema.

A Phased Approach to Treating Lymphedema

Donna Hannah, OTR/L, CLT-LANA, leads The Lymphedema Management Program at YRMC. Hannah is the only lymphedema therapist serving Yavapai County and one of eight in Arizona. Hannah—an occupational therapist who is certified by the Lymphology Association of North America (LANA)—has reached the highest level of accreditation in this specialized area. She sees firsthand the impact of lymphedema on breast cancer survivors.

“At first, they wonder if their cancer has returned and the whole experience of breast cancer tumbles back on them,” she said. “In the beginning, we talk about how lymphedema is a chronic condition, but one that can be controlled. Once they understand they can control lymphedema, we get to work.”

That work includes two major treatment phases, which typically last a total of four to six weeks or 16-20 visits. During the first phase, Hannah evaluates the patient’s condition and develops an individualized treatment plan. Plans may incorporate:

- **Manual Lymph Drainage (MLD)**—Lymphedema patients undergo intense manual lymphatic drainage, which Hannah teaches them so they can continue the practice after their treatment concludes. MLD is a massage technique that helps open working lymph nodes so they can help drain the affected areas. According to the *Journal of the National Cancer Institute*, combined with other therapies, MLD can reduce fluid up to 73 percent in breast cancer patients.
- **Compression Therapy**—Bandaging the affected area after an MLD session also reduces lymphedema swelling. Hannah instructs women on how to apply short-stretch compression bandages during the first phase of treatment.
- **Exercises**—Hannah works with patients on exercises that promote lymphatic flow and reduce swelling.
- **Skin Care**—Keeping the skin clean and moisturized and preventing trauma, such as cuts and scrapes, can lessen the chances of skin infection that can cause lymphedema to get out of control.

According to both Bauer and Hines, Hannah goes beyond the mechanics of treating lymphedema to help support and encourage patients.

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“Donna has so much training and experience,” Hines said. “She’s also incredibly compassionate. She helped calm me when I needed it.”

Hannah is committed to educating patients about lymphedema so they can recognize it and seek early treatment. Lymphedema, for example, has stages:

- **Stage I**—The area (arm, hand or leg) is swollen and feels heavy. Pressing on the swollen area may leave a dent.
- **Stage II**—The limb is swollen and feels spongy. A condition called tissue fibrosis may develop and cause the limb to feel hard. Pressing on the swollen area does not leave a dent in this stage of lymphedema.
- **Stage III**—In this advanced stage, the swollen extremity may drain lymphatic fluid, in addition to the other symptoms outlined in the earlier stage.

“I work with patients to set goals,” Hannah said. “One patient with advanced lymphedema said, ‘I have not been able to reach over my head for 20 years. I want to be able to screw in a light bulb.’ We got her there.”

During the second treatment phase, treatment in the clinic is less frequent as patients are now more independent and capable of in-home maintenance, such as self-administered MLD and exercise. They also graduate from using only compression bandages to wearing a compression garment during the day. For some patients, Hannah may recommend separate day and night-time compression garments. Ideally, these are custom-made for the patient.

“By phase two, patients should be getting back to their normal activities,” she said. “If they like to make pottery or lift weights, we ramp up slowly to monitor what their systems will take.”

Support from Susan G. Komen Phoenix Affiliate

For patients like Bauer and Hines, the Susan G. Komen Phoenix Affiliate grant provides customized bandages and garments, which health insurance typically does not cover. Customized garments can cost as much as \$1,200. Hines, for example, has a customized sleeve (\$200), a nighttime garment (\$700) and a compression glove (\$150) for a total cost of \$1,050.

“When you live with lymphedema, infections are very scary. I am so grateful that Susan G. Komen has allowed me to get the garments I need to stay healthy and avoid infection. I never could have afforded to buy customized bandages and garments,” Hines said.

The Susan G. Komen Phoenix Affiliate grant will help approximately 18 patients purchase customized garments and also allow YRMC to purchase educational materials on lymphedema.

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“YRMC is very committed to building awareness about lymphedema and encouraging early treatment,” said Peter Brennan, director of philanthropy at YRMC. “With the support of Susan G. Komen Phoenix Affiliate, we know we can make a difference to women struggling with lymphedema.”

YRMC’s Lymphedema Support Group

Hannah founded a Lymphedema Support Group to provide information and allow lymphedema patients to learn from one another. Support group members range in age from 40 to over 70, but the common bond is their commitment to managing their lymphedema.

The approximately 20 regular attendees at the monthly Lymphedema Support Group meetings hear presentations from medical experts: genetic oncologists, dietitians and other healthcare professionals. They also spend time sharing information.

“Those women will take a new support group member by the hand and tell her to listen to Donna and work hard,” Hannah said. “They understand what it feels like and know what needs to be done to control it.”

Lymphedema management is a way of life for both Bauer and Hines. When asked what advice she would give breast cancer survivors in the community experiencing the early signs of lymphedema, Bauer said, “Run, don’t walk, to your doctor and get a referral to The Lymphedema Management Program at YRMC.”

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