



More Than **Medicine**

At Magee, cancer patients get the most cutting-edge tests and treatments. But that's not all.

—By Anna Dubrovsky

When Anna Squilla was diagnosed with invasive breast cancer at age 47, she couldn't help wondering where she'd gone wrong.

She ate healthy, forgoing sweets. She exercised regularly. She'd even built a career helping other people get healthier as a personal trainer.

"I kept saying, 'I do everything right. Why is this happening to me?'" she recalls. "My husband looked at me the day I was diagnosed and said: 'You should have had the cake.'"

The first person she called was a UPMC executive whose wife she trained. "Look," she told him, "I just got diagnosed with cancer. I don't know where to start, where to go, what to do." He promised to put her in touch with a patient navigator at Magee-Womens Hospital of UPMC.

Squilla had never heard of patient navigators. In May 2008, when her gynecologist discovered her cancer, Magee's patient navigation program was only a few months old. It was one of many initiatives born of a series of discussions between hospital management and patients. "One of the things the patients told us was: 'Even though it's great at Magee because everybody's here — I can see my surgeon, I can see my oncologist, I can get my radiation all in one building — it's still a little difficult to go through that journey. I've got questions along the way,'" recalls Judy Herstine, administrator of Magee's Women's Cancer Program. "That's when we started the patient navigation program." Karen Cooper, a licensed clinical social worker who had worked at the hospital for more than a decade, was hired as the first navigator.

Squilla, who underwent a bilateral mastectomy and reconstructive surgery, credits her gynecologist, oncologist, and surgeons with saving her life. But she reserves her highest praise for Cooper.

"When I got the cancer diagnosis, I was just so floored," she says. "It was like a two-by-four had hit me on the head. I had questions, but I didn't really know what they were at that point. You're so stunned. The first question you think of is, 'Oh my God, am I going to live?' You don't think about what tests you're going to need. From the second they introduced me to the

patient navigator, she just took control."

"I kept saying, 'I do everything right. Why is this happening to me?'"

— Anna Squilla, breast cancer survivor and volunteer

Cooper gave her names of oncologists and surgical oncologists, scheduled appointments, and even accompanied her to appointments when Squilla's husband, a self-employed contractor, couldn't be away from work.

Magee, which celebrates its 100th anniversary this year, is on the cutting edge of cancer care and research. But medicine isn't its only priority. Cancer patients have multifaceted needs and concerns, and the hospital addresses them with a variety of innovative programs, from patient

navigation to fertility counseling to a center dedicated to survivors' issues. "There's no better place to go," Squilla insists.

One of the reasons Magee can offer a broad spectrum of support services is that it specializes in women's cancers. The number of cancer patients treated at Magee has more than doubled over the past decade to about 2,700 a year. Of those, about 1,300 have breast cancer and 700 have a gynecologic cancer. "There's a specialization here that you don't see at other places," Herstine says. "We are afforded the ability to really focus on the kinds of services women with breast and gynecologic cancers need."

Magee's ability to provide those services hinges on support from philanthropic organizations and individual donors. Grants from the Pittsburgh chapter of Susan G. Komen for the Cure made it possible for the hospital to hire patient navigators, whose

services are free. The National Ovarian Cancer Coalition funds educational workshops and other services for ovarian cancer patients. It's thanks to generous donors that Magee can offer patients free nutrition counseling. Another donor-created fund pays for staff to receive training in end-of-life care.

And then there's support of the non-monetary variety. Squilla and other former patients donate their time to help current patients. "We have a lot of peer-to-peer support, which you may not see in other places," Herstine says.

A Shoulder to Lean On

As licensed social workers, Magee's four navigators are adept at helping women manage the intense emotions that are part and parcel of the cancer experience. But with about a thousand appointments a month, they can provide only so much counseling. When a woman needs more, navigators may refer her to a psychologist at Magee who specializes in cancer patients or a therapist in her community. They may point her to support groups in the region. In some cases, they match her with a former patient, someone who knows the challenges of cancer all too well.

"We talk about everything," says Squilla, who mentors newly diagnosed women by phone. "It's a great place for people to put their fears. I'm as honest as I can be while being conscious of the fact that these people are as terrified as I was."

Squilla's story never fails to inspire. She has regained full range of motion, has never experienced lymphedema, and was back to work eight weeks after her surgery. Sometimes women echo her initial sentiment: "You did everything right, and you still got sick," they say. Squilla tells them she's glad she passed up the cake. "The reason I'm doing so well now is because I did everything right."

Pat Williams, another patient turned volunteer, also counsels women by phone. But on Wednesday mornings, she can be found on the third floor of Magee, seated in a corner where women wait for biopsy procedures. She introduces herself as a cancer survivor and volunteer and offers to answer questions or just chat. "It can be a tense little corner because emotions run pretty darn high," she says. "There are a lot of tears, a lot of hugs, and a lot of laughing."

Williams, who was treated for lobular cancer in 1999, assures every patient she meets that they're in the best hands. "I really try to convey that because I think if you have confidence in your doctors and the hospital staff, it helps tremendously in going through this ordeal and in your healing. And I mean it from the bottom of my heart. I know I couldn't have had better care or treatment anywhere else."

Some women need emotional support not during diagnosis or treatment but afterward, says Cooper, the patient navigator. "They put so much energy into treatment; it takes everything they have. And then when it's over, they will absolutely fall

apart. The reason is that they've been through so much, and they haven't processed it all." Frequent hospital visits have become their normal, and suddenly they have to adjust to a new normal.

That's where Magee's LiveWell Survivorship Program comes in. Started in 2009, it's dedicated to helping survivors of breast and gynecologic cancers adjust to life after cancer, prevent

"There are a lot of tears, a lot of hugs, and a lot of laughing."

— Pat Williams,
breast cancer survivor
and volunteer

and manage the side effects of treatment, and monitor for recurrences. Twice a year, it hosts a free workshop on issues specific to cancer survivorship. The next workshop will take place in September and will include presentations on sleep deprivation, cancer and the environment, treatment burnout, and the latest research. In addition to medical experts, participants will hear from a panel of survivors.

For details on the LiveWell Survivorship Workshop and other upcoming events, see page 20.

“You never know exactly when they’re going to need support. We want to make sure we’re there when they do.”

– Karen Cooper, oncology patient navigator

Finances, Fertility, and Other Worries

Cancer doesn’t just take a physical and emotional toll. It also takes a financial toll. In this time of economic turmoil, many patients are unemployed or underemployed and uninsured. Even those with insurance can find themselves in serious financial straits as travel and parking expenses, copayments, child care costs, and incidentals such as wigs add up.

Magee’s navigators help uninsured women with breast or cervical cancer apply for free treatment through the state Department of Public Welfare. They also help cash-strapped patients apply for financial assistance from a variety of foundations. Funding from cancer advocacy groups makes it possible for Magee to provide patients with assistance in the form of Giant Eagle gift cards, gas gift cards, bus tickets, and vouchers for cab or van transportation.

Thanks to funding from A Glimmer of Hope Foundation, Magee is in the process of putting together an information packet geared toward breast cancer patients under the age of 45. The number of younger patients has grown in recent years; Magee treated about 200 new breast cancer patients under 45 last year. Many younger patients are interested in genetic counseling and testing, which is available at Magee. Some are concerned about their future fertility, which chemotherapy and some hormonal therapies can jeopardize. Magee’s Center for Fertility and Reproductive Endocrinology is a leader in fertility preservation services such as embryo cryopreservation, and researchers at the affiliated Magee-Womens Research Institute are developing ever more advanced solutions.

Magee has also witnessed a growing hunger for complementary therapies and nutrition counseling. Acupuncture is available at the hospital. Navigators refer patients to the Center for Integrative Medicine at UPMC Shadyside or individual

practitioners for other complementary therapies. A \$25,000 pledge from a local family affected by cancer allowed Magee to launch a nutrition program earlier this year. Services include one-on-one counseling, monthly “Ask the Nutritionist” sessions, and cooking demonstrations.

“The cancer journey can be long, and patients have a variety of ups and downs during that time,” Cooper says. “You never know exactly when they’re going to need support. We want to make sure we’re there when they do.”



For more on A Glimmer of Hope Foundation, started by a local jewelry designer who lost a close friend to breast cancer, see page 18.

Cancer doesn’t just take a physical and emotional toll. It also takes a financial toll.