

against the ODDS

Millions of women live with benign uterine fibroids. Cyndi Bunge was shocked to learn that hers were hiding a rare and deadly cancer

BY NANCY ROSS-FLANIGAN



The symptoms that sent Cyndi Bunge searching for a gynecologist soon after she and her family settled in a new town in December 2001 did not scare her. She simply saw them as signs that the time had come to deal with a nagging problem that so many women face: an increasingly troublesome uterine fibroid.

"My periods had gotten very heavy and long—up to ten days," recalls the 43-year-old mother of three. "And then my clothes started not to fit. I had to buy elastic-

for several days between periods. She remembered her mom putting up with similar symptoms for years, and she assumed she was traveling the same path: She'd have a hysterectomy, spend a few days in the hospital, enjoy six weeks of respite from heavy housework and then carry on.

But the road Bunge was about to travel would be far different from her mother's—and, for that matter, from the experience of most women with fibroids. Surgery would reveal an uncommon and

her that they never turn cancerous, and that's technically true. But sarcoma, a cancer of soft tissue, can develop in the muscular uterine wall and invade—or simply masquerade as—a benign fibroid.

Because uterine leiomyosarcoma (ULMS) is found in fewer than one in 160,000 women (typically in their mid-forties to fifties), no one had prepared Bunge

ered two days after her hysterectomy. Not only did she have cancer, but she had a rare and stealthy kind, which had been lurking inside for who knows how long.

"The doctor came into my hospital room and told me that they had found a sarcoma," Bunge recalls. She understood that "sarcoma" meant cancer, but how bad was it? "Her comment was, 'People *do* survive this,' which to me indicated that most people don't. In twenty-five years of exams, not one doctor ever mentioned that uterine fibroids could contain cancer."

On and off that afternoon, Bunge wept as her husband, Marty, held her. He was usually affable and upbeat, and tried to stay positive for her sake. Besides, he told himself, "Cancer is something you can beat. We'll just get it treated, and it'll go

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waist pants." She'd had the fibroid (also called a leiomyoma) for ten years, and her doctor back in Forest City, Iowa, had always assured her it was a harmless nuisance—even when, a couple of years earlier, Bunge had suffered killer cramps

obstinate cancer growing in the original fibroid and in several more that had developed over the previous year. Everything Bunge had read about fibroids—lumps of muscle and fibrous tissue that grow within the wall of the uterus—had reassured

for the diagnosis. It's also impossible to detect without extracting the mass of tissue, so doctors tend not to look for signs of it until after fibroids are removed for another reason.

Bunge was blindsided by the news her doctor deliv-

away." It wasn't until a sympathetic nurse brought in information she had found online that the family began to understand the grim reality.

"I remember coming home that night and going on the Internet," says Marty. "You look at the survival statistics, and it's kind of scary." Only half the women whose cancer is found and removed at an early stage survive five years; for more advanced stages, the survival rate is as low as zero. Bunge's cancer was rated Stage II, meaning that it was confined to the uterus and cervix. The Bunges hoped for the best, but couldn't help imagining the worst.

A NEW START

Life was supposed to change after the Bunges left Forest City, but not like this. After selling the newspaper businesses they had owned for 14 years, they had moved 200 miles southeast to Williamsburg. With brick streets, a town square and a population of 2,600, Williamsburg is the kind of place where the whole town turns out for high school football games. As the family settled into a bright ranch house overlooking a golf course, Bunge spent her days unpacking and reassuring teenagers Aaron and Allison and preschooler Angela that they'd soon feel at home.

But Bunge's cancer diagnosis swept in unexpectedly, rearranging priorities, flattening hopes and splintering the Bunges' dreams of security and a new beginning.

"Life had been so stressful, with us selling the businesses and Marty looking for a job," says Bunge. "After the move, we were thinking that maybe now we'd have a year where everything went okay. Then this happened."

A DISEASE NO ONE KNOWS

Any cancer diagnosis can be overwhelming. Suddenly, you have so much to absorb, so many decisions to make, so little time to waste. Having an uncommon cancer only adds to the confusion, as information can be harder to find and interpret. "There's no national awareness day for my cancer," says Bunge. "I can't pick up a pamphlet explaining it."

The regional hospital where she had the hysterectomy sent her home with little more than

right move, I felt like I wasn't trying to help myself," Bunge remembers. "I wanted to figure out if radiation was my best choice or if I should consider chemo or something else. I also thought there might be a possibility of more surgery to remove my ovaries," which she had opted to leave in during her hysterectomy. Overshadowing it all was the nagging fear that no matter what she did, it wouldn't be enough to keep the cancer away.

Unfortunately, Bunge didn't



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a handful of general brochures on dealing with cancer and a referral to the University of Iowa. But Bunge's appointment with an oncologist at the university was three weeks away, and she was eager to find out all she could. Searching the Web became a daily ritual, as automatic as pouring a cup of coffee. "I'd get the kids going for the day and then spend entire mornings online," she says. "It was depressing."

Questions and concerns kept her brain buzzing even after she switched off the computer. "If I wasn't doing something to determine the

find the clear-cut answers and reassurance she was hoping for. What information she did ferret out usually combined ULMS with other uterine sarcomas or other leiomyosarcomas, which can develop in the smooth muscle of the blood vessels or gastrointestinal tract. "You read horrible things, but they're all lumped together, so you don't know what's what," she says. When she managed to find specifics, Bunge was dismayed to learn that "Statistics are based on a small number of cases, research is limited and much of the news is not encouraging."

What Bunge did learn is that ULMS is a formidable foe, defying the most powerful weapons in medicine's anticancer arsenal. Chemotherapy has not proved effective against this type of cancer, and while radiation treatments to the pelvis halve the risk of recurrence in that area, they don't keep the cancer from spreading or improve survival rates. Some doctors and patient groups advise postponing further treatment until there are signs of a recurrence, yet others recommend radiation right after surgery. Trying to reconcile the conflicting opinions was overwhelming, Bunge says.

The dearth of unambiguous information often takes an emotional toll on people with rare and intractable cancers, says Patrice Rancour, a mental-health clinical nurse specialist at Ohio State University who helps patients and their families cope with the stresses of cancer diagnosis and treatment. "They express feelings of frustration and anger toward the healthcare establishment for not having gotten a leg up on their problem," notes Rancour. "They feel abandoned."

A friend of Bunge's brother, a research oncologist, recommended that she seek out a second opinion from William McGuire, M.D., a medical oncologist specializing in women's cancers at Franklin Square Hospital in Baltimore. McGuire explained that ULMS is persistent, reappearing time and time again, either in the pelvis or in the lungs, liver or other organs. And when it recurs, it often comes back "angrier" than before. After consulting with McGuire, as well as with her medical team at the University of Iowa, Bunge chose

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radiation. "Otherwise, I would have felt I was just sitting there, waiting for it to come back," she says.

Further surgery to remove her ovaries turned out not to be necessary, though there was confusion on that matter, too. First, doctors said the decision would hinge on the results of a hormone receptor test, which indicates whether tumor growth is influenced by hormones such as estrogen and progesterone. Her results were positive, but because she had opted for radiation, which shuts down hormone production in her ovaries, the surgery wouldn't be needed, her doctors said. Later, Bunge learned that ULMS tumors aren't sensitive to hormones, so most experts say removing the ovaries is unnecessary. It was just one more example of the kind of fuzziness she was learning to live with.

By contrast, the predictability of her daily radiation routine was almost a relief. Every weekday morning for six weeks, Bunge made the 30-mile drive to Iowa City for treatments. She and Marty tried to keep family life as normal as they could, cheering at Aaron's baseball games, taking the kids camping, even indulging in a few extravagances, like a roomy new hot tub on the deck. There were bright moments, like the time Marty, hearing despair in his wife's voice over the phone, waited for her at an interstate on-ramp just to give her a hug. Or the morning of Bunge's last treatment, when a limo—another Marty surprise—was waiting outside the house to take her to the hospital. But in between were dark times when sadness and fear obliterated any optimism she had been able to muster.

Bunge stood little chance of meeting other women with ULMS in her small town, but she did connect with some in an online leiomyosarcoma support group. But instead of providing solace, the interactions began to feed her fears. "People would talk about having pains and finding out their cancer had spread, so things started going through my mind about every little pain I was feeling." And there was bickering—almost to the point of nastiness—about the pros and cons of radiation. "I got to feeling that it wasn't so supportive," says Bunge. She stopped participating in the chats so often. ►

A NUISANCE, OR SOMETHING MORE?

FIBROIDS OCCUR IN AT LEAST ONE IN EVERY FOUR WOMEN. BUT ULMS IS VERY RARE, AFFECTING ONE IN ABOUT 160,000.

GROWTH RATE: "If a woman develops signs of a fibroid, and within three to six months it's rapidly growing, we have to be suspicious that a more aggressive process is going on," says Christine Pellegrino, M.D., of Montefiore Medical Center in New York City.

PELVIC PAIN AND BLADDER OR BOWEL CHANGES: These symptoms are no cause for panic, but too many women shrug them off, assuming they're just part of having fibroids, says Lois Ramondetta, M.D., an assistant professor at M.D. Anderson Cancer Center and the University of Texas in Houston. If symptoms persist, it's time to consider surgery, adds McGuire. That could mean a simple laparoscopy—an exploratory procedure—but often a hysterectomy is needed to rule out ULMS.

PELVIC RADIATION: Radiation can cause cancer as well as treat it, and women who have had radiation to the pelvic area (for ovarian, cervical or bladder cancer, for example) are at slightly increased risk for developing ULMS, says Pellegrino.

REMEMBER: Most cases occur for no apparent reason. While ULMS can develop in a fibroid, having a fibroid does not increase your cancer risk.

Watching daughter Angela and her playmates in the park one day, Bunge couldn't even feign the carefree, goofy attitude her kids love about her. "I just sat and stared and tried not to cry. I was afraid that Angela would never remember me if I died."

Hospital visits were stressful, too. Bunge found herself having to fight for the kind of follow-up care she thought she should have. Her doctors recommended pelvic exams and chest X rays every three months; Bunge felt quarterly CT scans—in addition to exams and X rays—would increase the chance of catching a recurrence early. But early detection doesn't improve the survival rate for recurrences of ULMS, so Bunge's radiation oncologist, Geraldine Jacobson, M.D., wasn't convinced the treatment was worth the extra radiation exposure. They settled on CTs every six months.

Last October, Bunge's research took her to M.D. Anderson Cancer Center in Houston, where a group of physicians

specialize in treating sarcomas. Her oncologist there agreed that more frequent CT scans are valuable; they decided Bunge would have six-month checkups at M.D. Anderson, with checkups and scans at the University of Iowa in between.

Traveling far for medical care isn't unusual for people with rare cancers, says mental-health nurse Rancour, and that only adds to the stress. "It's an emotional, financial and physical drain."

So far at least, the travel hasn't put the family in a bind. "I guess we're pretty lucky," says Bunge. "We have really good insurance, and the doctors down there are on our network, so financially, it's mainly the flights and the hotels. This is not how we planned on spending our money, but we can do it." To Bunge, the peace of mind is well worth the cost. "Everybody there just does sarcomas. I think it makes a huge difference."

THE BATTLE CONTINUES

Bunge remained cancer-free for 18 months, but as this story goes to press she's starting a round of chemotherapy at the University of Iowa: Doctors recently discovered that two small spots on her lungs have grown over the past few months, and a third one has appeared.

Because ULMS is so rare, there haven't been a lot of clinical trials using chemo to treat it, and many consider the drugs a last resort. But Bunge's doctors at M.D. Anderson say they've had a 60 percent success rate using the combination of drugs that they're giving her.

"I am praying to achieve remission, but am told that even if I do, I will have another recurrence," Bunge says. "Such is the case with leiomyosarcoma. I try not to dwell on anything beyond getting through chemo; most of the time, I feel amazingly calm. I'm not doomed yet."

Now she's telling other women to make sure their doctors don't dismiss their complaints. "Fibroids are very common, and you don't want to freak people out, but you have to be cautious and aware of things that change in your body. I just never dreamed my symptoms could be so serious." ■

Nancy Ross-Flanigan, a three-time cancer survivor, has written for Health and Fitness.