



The Pain of Endometriosis

Doctors and scientists are still trying to understand this puzzling reproductive disease.

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McClatchy Newspapers

April 1, 2010

WALNUT CREEK, Calif. - Brie-Anne Paterson has suffered from chronic pelvic pain for more than half her life. She was the girl in gym class curled up on the locker room floor, crying and clutching her abdomen.

“I would just die the week of my period,” says Paterson, who lives in Tracy, Calif. “I’d be curled up in a ball and couldn’t get out of bed for a week.”

Paterson, 26, is one of approximately 5.5 million North American women suffering from endometriosis, a painful and puzzling reproductive disease that has no known cause or cure. Endometriosis is near impossible to diagnose without surgery because the symptoms – pelvic pain, difficult menstrual cycles and bowel problems – are common and lead to misdiagnoses. Even though Paterson had the disease from the age of 12, it took years of trial and error with seven doctors, including one who advised a hysterectomy at 22, to get effective treatment.

But that may be changing as sufferers tell their stories on the Web and the medical community responds with specialized outlets such as Kaiser Permanente’s Center for Pelvic Pain, which recently opened in Martinez, Calif. Also, the disease received national attention late last year when two professionals on the TV show “Dancing With the Stars” told millions of viewers that they suffer from endometriosis.

The disease occurs when endometrial tissue like that which lines the uterus is found outside the uterus and in other parts of the pelvic cavity and body. This misplaced tissue develops into growths that respond to the menstrual cycle in the same way that the tissue of the uterine lining does: Each month it builds up, breaks down, and sheds. Menstrual blood flows from the uterus and out of the

body through the vagina, but the blood and tissue shed from endometrial growths has no way of leaving. This results in internal bleeding and inflammation. In addition to inducing chronic pain, endometriosis can cause scar tissue, adhesions and infertility. Still, some women have no symptoms at all. A diagnostic laparoscopy, or surgery, is needed to locate the endometriosis, and, eventually to remove it.

Unfortunately, that is not a cure. Endometrial tissue has a 15 percent reoccurrence rate, according to Andrew Cook, a Los Gatos, Calif., surgeon and reproductive endocrinologist who specializes in pelvic pain disorders. “How well the disease is removed has a lot to do with that rate of reoccurrence,” says Cook, adding that he prefers cutting the tissue out over burning it, which is more common. The surgery is technical and very difficult. “This is worse than cancer from an operative perspective,” he says. “Endometrial tissue obliterates everything around it.”

Still, early detection is possible. Endometriosis is most likely genetic, and stress and a decreased immune system can make women more susceptible to the disease, says Jean Kayser, director of gynecology in the Department of Women’s Health at Kaiser in Walnut Creek, Calif.

Two theories persist on the cause. The retrograde menstruation theory suggests that during menstruation some of the menstrual tissue backs up through the fallopian tubes, implants in the abdomen, and grows. Another theory suggests that endometrial tissue is distributed from the uterus to other parts of the body through the blood or lymph systems, Kayser says.

There’s nothing that can be done to prevent endometriosis. Women who have symptoms can try to control the disease by having fewer periods, Kayser says, and that means rigorous and prolonged use of birth control pills or even Lupron, an injectable drug that stops the body’s production of certain hormones and puts women into early menopause. Cook, the surgeon, isn’t a fan of the latter. At the VitalCare Health Institute, where he treats women from 45 states and 10 countries, he favors comprehensive health care – adjusting diet and lifestyle – over treating women with drugs such as Lupron. “If I really did my job as a surgeon, there’s nothing to treat,” he says.

Paterson reduced her periods, and saw results. But her relief was temporary. She was diagnosed in 2005 and put on continuous oral contraceptives. When her pain returned, she was put on Lupron. Still, Paterson’s chronic pain continued. Finally, in 2006, she had a diagnostic laparoscopy. Endometrial tissue was found on her left kidney, bladder, colon and rectum.

“It was pretty advanced,” Paterson says. “It looked like black coffee grounds all over your organs.” She had surgery to remove everything. With weekly pelvic

floor physical therapy, she lives a mostly pain-free life. And, last March, she gave birth to her first child, Scott. “He’s my miracle baby,” Paterson says. “If you’re having trouble coping with endometriosis, don’t turn inward. Talk to somebody. I was horribly depressed. I wasn’t working. I wasn’t seeing my friends.”

Jessica Brooks of Concord, Calif., had a similar experience. The 28-year-old teacher was diagnosed with endometriosis at 19. Her maternal aunt and paternal cousin both had it, and miscarried. A year later, Brooks was approved for surgery. Surgeons discovered endometrial tissue growing all over her pelvic cavity, from her ovaries and bladder to her lower intestine and pelvic wall. “I’ve had a lot of digestive issues and bladder control issues,” says Brooks, adding that her endometriosis becomes aggravated whenever she is sick. “Fortunately I’m a middle school teacher and have a three-minute break every 45 minutes. “

Even after surgery, the endometriosis returned. To control it, Brooks had several rounds of monthly Lupron injections, which gave her severe mood swings. She also tried birth control pills. But she still suffers. These days, she has vaginal ultrasounds every time she visits her doctor to make sure the endometrial mass isn’t growing or spreading. The option for a second surgery is there, but Paterson is reluctant. More surgery means more scar tissue. And, she and her boyfriend of 10 years hope to have children one day. Yet they don’t want to feel rushed because of this disease.

“It’s a struggle,” she says. “I have nightmares about never being able to have children.”

Gabrielle Klein suffered through 14 years of heavy periods and debilitating abdominal pain. During that time, she saw four doctors who diagnosed Klein, now 33 and living in San Francisco, with gastrointestinal disorders including irritable bowel syndrome and candida, a yeast infection of the gut.

But Klein still had pain. And she knew better. A friend suggested she track her pain according to the lunar calendar. “After a few months I was able to prove that it was coming in a cyclic fashion a week before my period to midway through it,” she says. She turned to the Web, and read about her symptoms on the Endometriosis Resource Center site. After 2-1/2 years of trial and error, Klein walked into a doctor’s office at Stanford and said, “I’ve done my research and I think I have endometriosis.”

She was right, and the doctor performed a laparoscopy. Because she didn’t want to cause damage, however, the surgeon left what she called negligible amounts of the tissue on Klein’s urinary tract. The doctor put Klein on hormonal treatment to keep the tissue from regrowing. But, for the next two years, she continued to have severe pain for up to 14 days out of the month.

Finally, at an ERC support group in 2003, Klein met Cook and asked him to review her chart. He suggested a second surgery to remove the remaining endometriosis. Cook found the tissue covering the outside of Klein's uterus, ovaries and fallopian tube. It was on her spleen, gall bladder and growing on the outside of her bowels. Klein was in the early stages of appendicitis because the endometrial tissue was wrapping around her appendix. He removed everything. And Klein has been pain-free since.

"It's been a really long road, but I've been going in the right direction for a long time now," she says. Early education is vital, Klein says, because women don't really share experiences with their cycles and reproductive systems.

"It's something we keep close to the vest," she says. "But if you're popping six Advil a day and it's not cutting it, there might be something else wrong." These days, Klein feels little twinges of pain a few hours after she begins menstruating. That's it, she says, almost surprised. "It's been incredible for me to get my period and not know it's coming. It's a joy to have it just show up on me."

RESOURCES

[Endometriosis Association](#). This membership-based nonprofit organization is the oldest independent self-help organization about endometriosis. It has a network of chapters and support groups in 66 countries; funds international research on the disease; and has published two books, "Overcoming Endometriosis" and "The Endometriosis Sourcebook."

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