

Female trouble

Debilitating periods, infertility—for years, doctors didn't know how to help women with endometriosis. Finally, new hope is here.

IMAGINE THE WORST PERIOD OF YOUR LIFE. ONE SO PAINFUL, you can barely stand up straight. Now imagine having it every single month while doctors tell you there's nothing wrong with you. Carrie Pauley doesn't have to imagine—she lived that nightmare for seven years. “I missed at least 4 days of work a month and sometimes spent 10 days in bed,” says Pauley, 35, who lives in Greenwich, Connecticut. “When I was in the hospital, they even sent a shrink to my room to see if I was making all this up.”

She wishes she had been. Pauley was finally diagnosed with endometriosis, a condition in which tissue that lines the uterus ends up scattered throughout the pelvic cavity. Stimulated by monthly hormonal changes, the misplaced cells engorge and bleed, inflaming surrounding areas and causing scar tissue to form. Over time, that scar tissue may even block the fallopian tubes or cover the ovaries. In fact, endometriosis is one of the leading causes of infertility, and some women may not even know they have it until they try to get pregnant. Though the disease affects roughly 1 in 10 women, it's believed to be highly underrecognized, partly because diagnosis requires a doctor to perform surgery in order to see the lesions. But soon stories like Pauley's may be a thing of the past. SELF went into the lab with leading researchers to give you an inside look at the new ways the disease is being diagnosed and treated. Some innovations could change millions of women's lives for the better.

Until recently, endometriosis was thought of as a purely gynecologic disorder. “But now we're looking at a disease that's

essentially being reclassified,” says Mary Lou Ballweg, president of the Endometriosis Association in Milwaukee. “Scientists are realizing that it's part of a much larger dysfunction of the body.” This fresh perspective has led to groundbreaking research, much of it looking at endometriosis as one sign of a hormonal system gone haywire. “We're focusing on understanding the relationship between the uterus and the endocrine and immune systems instead of the uterus alone,” says Kevin Osteen, Ph.D., director of the Women's Reproductive Health Research Center at Vanderbilt University in Nashville.

Connecting endometriosis to immunity has already helped doctors glean a better understanding of what may cause the illness. The long-accepted theory has been that a backflow of men-

strual fluid through the fallopian tubes and into the pelvic cavity triggers the illness, says David Olive, M.D., director of reproductive endocrinology at the University of Wisconsin at Madison. The problem with that theory, however, is that 90 percent of women have this backflow, called

retrograde menstruation, while only 8 to 10 percent get the disease. The immune system now appears to be the missing link, Dr. Olive says. In October, the National Institutes of Health (NIH) in Bethesda, Maryland, published results showing that women with endometriosis were much more likely than healthy women to have other immune-related conditions. The 3,680 endometriosis sufferers surveyed were 20 times more prone to lupus, about 6 times more likely to have hypothyroidism and about 3 times more likely to experience allergies. Researchers

If your sister has endometriosis, your risk is five times higher than average.

The latest endometriosis treatments may allow women to avoid a hysterectomy.

suspect that in the case of endometriosis, women may have an immune defect that allows the rogue cells to proliferate, says lead study author Ninet Sinai.

AN EASIER DIAGNOSIS IS ON THE WAY Thanks to a new tool called the MetrioTest, an endometrial biopsy and a blood sample may one day be all that's needed for diagnosis. The test, expected to debut in the United States next year, is 90 percent accurate and less invasive than surgical diagnosis, which is inconclusive at least 40 percent of the time.

Genetic research is also helping pinpoint women at risk. A study published earlier this year in *Human Reproduction* reported that a woman's chance of developing endometriosis is five times higher if her sister has the disease. Knowing this five years ago might have spared Sandra Pace, 25, more years of agony. "From the time I was 14, I thought my severe cramps were normal," says Pace, who lives in

Gretna, Louisiana. When Pace was 20, a sister was diagnosed with endometriosis; it was the first time she had heard of the illness. Pace asked her doctor if she could have it, too, but he told her she was clear after a physical exam. Her periods remained excruciating, so Pace continued her long-standing practice of taking 8 to 10 ibuprofen pills at a time for relief. Earlier this year, after another sister was diagnosed, Pace consulted an M.D. who did a laparoscopy (a procedure in which a camera is inserted into the abdominal cavity). The results? She had advanced endometriosis; most of the problem tissue was removed during the surgery.

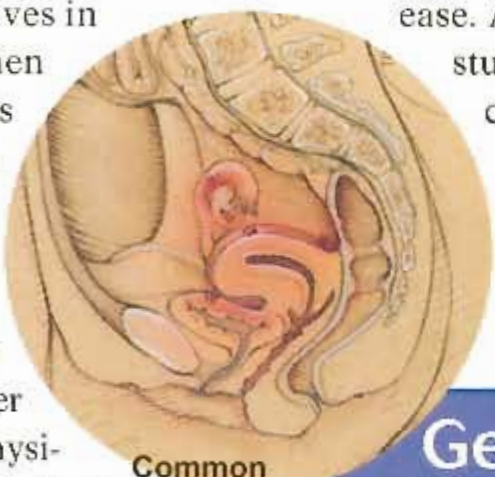
HOPE FOR A CURE So far, women with endometriosis have had few treatment choices and no cure. Even the most extreme option—hysterectomy—isn't guaranteed to end symptoms for good. Birth control pills reduce estrogen production and growth of the lesions; more potent medications, called GnRH agonists, stop periods altogether. The downside of these hormone therapies is that they trick the body into menopause and can cause hot flashes, vaginal dryness and bone loss.

Worse, when you stop taking them, the symptoms come back, says Harry Reich, M.D., who runs a treatment clinic in Wilkes-Barre, Pennsylvania.

Women with disabling cases can opt to have the lesions removed surgically, as Pace and Pauley did. But surgeons can easily miss some deposits and symptoms may recur. That's why hopes are so high for selective progesterone receptor modulators, which work in a way similar to the abortion pill mifepristone, says Dr. Olive. The NIH funded their development after several studies in the mid-1990s revealed that mifepristone reduced both the pain and size of endometriosis lesions without menopausal side effects. Though SPRMs don't appear to induce abortion, you can't take them if you're hoping to conceive.

That's where vitamins C and E may come in. Researchers at Emory University in Atlanta are studying the power of these antioxidants to relieve the pain of this disease. Although results of all these studies won't be available for a couple of years at least, endometriosis may no longer be the monthly curse in the future that it is today.

Melanie Haiken lives in San Francisco.



Common sites of endometriosis include the bladder, vagina and rectum.

Get tomorrow's treatments now

If you think you have endometriosis, visit a reproductive endocrinologist, who's much more likely to be up on the latest research and treatments than an ob/gyn is, says Mary Lou Ballweg, president of the Endometriosis Association in Milwaukee. If you're interested in joining a trial of new therapies, the association can help. "Often when researchers are recruiting for a clinical trial, they'll let us know," says Ballweg. To become an EA member, call 800-992-3636 or visit www.endometriosisassn.org; the cost is \$35 for one year. To find other studies, check out the databases at CenterWatch (www.centerwatch.com) and the National Institutes of Health (www.clinicaltrials.gov). It might take a little digging, but you may find the treatment that will bring you relief.

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