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What is Endometriosis?

Endometriosis is a puzzling hormonal and immune disease affecting girls and women from as young as eight to post menopause. The name comes from the word endometrium, which is the tissue that lines the inside of the uterus and builds up and sheds each month in the menstrual cycle. In "endo," as this disease is called for short, tissue like the endometrium is found outside the uterus in other areas of the body. In these locations outside the uterus, the endometrial tissue develops into what are called "nodules," "tumors," "lesions," "implants," or "growths." These growths can cause pain, infertility, and other problems.

The most common locations of endometrial growths are in the abdomen—involving the ovaries, fallopian tubes, ligaments supporting the uterus, area between the vagina and the rectum, outer surface of the uterus, and lining of the pelvic cavity. Sometimes the growths are also found in abdominal surgery scars, on the intestines, in the rectum, or on the bladder, vagina, cervix, and vulva (external genitals). Endometrial growths have also been found outside the abdomen, but these are uncommon.

It is possible, though relatively rare, for endo lesions to become cancerous. In addition, recent research has indicated women and girls with endo and their families are at greater risk for cancer, particularly ovarian and breast cancer, as well as melanoma, non-Hodgkin's lymphoma, brain, and thyroid cancers. They and their families are also at risk for certain autoimmune diseases, such as multiple sclerosis and rheumatoid arthritis, in which the immune system attacks the body's own tissues. Because of these risks and the life-disrupting nature of endo in many cases, women and girls are encouraged not to ignore symptoms.

Like the lining of the uterus, endometrial growths usually respond to the hor-

mones of the menstrual cycle. They build up tissue each month and break down. The result is internal bleeding, degeneration of the blood and tissue shed from the growths, inflammation of the surrounding areas, and formation of scar tissue (adhesions). Other complications can be rupture of cysts (which can spread endo to new areas), intestinal bleeding or obstruction (if the growths are in or near the intestines), interference with bladder function (if the growths are on or in the bladder), and other problems. Symptoms seem to worsen with time, though cycles of remission and recurrence are the pattern in some cases.

"Taking charge of your own health is the most important step in coping with endo."

Symptoms

The most common symptoms of endo are pain before and during periods (usually worse than "normal" menstrual cramps), pain during or after sexual activity, fatigue, infertility, and heavy bleeding. Other symptoms may include painful bowel movements with periods, lower back pain with periods, and diarrhea and/or constipation and other intestinal upset with periods. Many women with endo also experience a range of immune disorders, including allergies, asthma, eczema, and certain autoimmune diseases. Infertility affects about 30-40% of women with endo and is a common result with progression of the disease.

The amount of pain is not necessarily related to the extent or size of the growths. Tiny growths (called "petechial") have been found to be more active in producing prostaglandins, which may explain the significant symptoms that often seem to occur with small implants. Prostaglandins are substances produced throughout

the body, involved in numerous functions, and thought to cause many of the symptoms of endo.

Theories About the Cause of Endometriosis

The cause of endo is not known with certainty, but a number of theories have been advanced. One theory is the retrograde menstruation or transtubal migration theory. According to this theory, during menstruation some of the menstrual tissue backs up through the fallopian tubes, implants in the abdomen, and grows. Research shows most, if not all, women experience some menstrual tissue backup, so experts believe that an immune system problem and/or hormonal problem allows this tissue to take root and grow in women who develop endo. Another theory suggests that the endometrial tissue is distributed from the uterus to other parts of the body through the lymph or blood. A genetic theory suggests that certain families may have predisposing factors for the disease. Research spearheaded by the Association since 1992 has shown that environmental toxins such as dioxin and PCBs, which act like hormones in the body and damage the immune system, can cause endometriosis.

Another theory suggests that remnants of tissue from when the woman was an embryo may later develop into endo or that some adult tissues retain the ability they had in the embryo stage to transform into reproductive tissue under certain circumstances. Surgical transplantation has also been cited as a cause in cases where endo is found in abdominal surgery scars. However, endo has also been found in such scars when direct accidental implantation seems unlikely.

Diagnosis

Diagnosis of endo is generally considered uncertain until proven by laparos-

copy. Laparoscopy is a surgical procedure done under anesthesia. The patient's abdomen is distended with carbon dioxide gas to make the organs easier to see, and a laparoscope (a tube with a light in it) is inserted into a tiny incision in the abdomen. By moving the laparoscope around the abdomen, the surgeon can check the condition of the abdominal organs and see the endometrial implants, if the surgeon is careful and thorough.

A doctor can sometimes feel endometrial implants during a pelvic examination, and symptoms will often indicate endo, but it is not good practice to treat this disease without confirmation of the diagnosis. (Ovarian cancer, for instance, sometimes has the same symptoms.) A laparoscopy also indicates the locations, extent, and size of the growths and may help the doctor and patient make better-informed long-range decisions about treatment and pregnancy.

Treatment

Treatment for endo has varied over the years, but no sure cure has yet been found. Hysterectomy and removal of the ovaries has been considered a "definitive" cure, but research by the Association and others has found such a high rate of continuation/recurrence that women need to be aware of steps they can take to protect themselves. (Please see *The Endometriosis Sourcebook* and the chapter on menopause and endo in *Endometriosis: The Complete Reference for Taking Charge of Your Health* for more information.) Painkillers are usually prescribed for the pain of endo. Treatment with hormones aims to stop ovulation for as long as possible and can sometimes force the disease into remission during the time of treatment and sometimes for months or years afterward. Hormonal treatments include oral contraceptives, progesterone drugs, a testosterone derivative (danazol), and GnRH drugs (gonadotropin-releasing hormone drugs). New drugs are being tested. With all hormonal treatments, side effects are a problem for some women.

Because pregnancy often causes a temporary remission of symptoms and because it is believed that infertility is more likely the longer the disease is present, women with endo are often advised not to postpone pregnancy. However, there are numerous problems with the "prescription" of pregnancy to treat endo. The woman might not yet have made a deci-

sion about childbearing, certainly one of the most important decisions in life. She might not have critical elements in place to allow for childbearing and child rearing (partner, financial means, etc.). She may already be infertile.

Other factors may also make the pregnancy decision and experience harder. Women with endo may have higher rates of tubal pregnancy and miscarriage, and one study has found they have more difficult pregnancies and labors. Research also shows there are family links in endo, increasing the risk of endometriosis and related health problems in the children of women with the disease.

Conservative surgery, either major or through the laparoscope, involving removal or destruction of the growths, is also done and can relieve symptoms and allow pregnancy to occur in some cases. As with other treatments, however, recurrences are common. Surgery through the laparoscope (called operative laparoscopy) has rapidly replaced major open abdominal surgery. In operative laparoscopy, surgery

A survey of 4,000 women with endo found some of these treatments to be the most successful of all the treatments they had tried. See our books for more information.

Learning About Endometriosis

Endo is without question one of the most puzzling diseases affecting women and girls. More is being learned about it as time goes on, and this knowledge is dispelling some of the assumptions of the past. One of these past assumptions was that nonwhite women did not generally get endo. This has now been shown to be untrue. Often nonwhite women were not getting the kind of medical care to have endo diagnosed.

Another myth about endo is that very young women do not get it—an idea that probably arose because formerly teenagers and younger women endured menstrual pain (often one of the early symptoms) in silence and did not get diagnosed until the disease progressed to unbearable proportions. It was also believed in the

“A survey of 4,000 women with endo found some of these complementary treatments to be the most successful of all the treatments they had tried.”

is carried out through the laparoscope using laser, electrosurgical equipment, or small surgical instruments. Radical surgery, involving hysterectomy (removal of the uterus) and removal of all growths and the ovaries (to prevent further hormonal stimulation), may become necessary in cases of longstanding, troublesome disease.

Menopause also is believed to end the activity of mild or moderate endo, although little research has been done in postmenopausal women. Even after radical surgery or menopause, however, a severe case can be reactivated by estrogen replacement therapy or continued hormone production. Some authorities suggest no estrogen be given for a short time after hysterectomy and removal of the ovaries for endo.

Many complementary treatments, including nutritional approaches, immunotherapy, traditional Chinese medicine, allergy management techniques, and others, are being used by women with endo.

past that endo more often affected well-educated women. Now we know that this notion developed because well-educated women were those getting better medical care and were more often persistent enough to obtain explanations for their symptoms.

Another assumption sometimes made about endo is that it is not a serious disease because it is not a killer like cancer, for instance. However, anyone who has talked with many women with endo about their actual experiences with the disease soon learns otherwise. While some women's lives are relatively unaffected by it, too many others have suffered severe pain, emotional stress, have at times been unable to work or carry on normal activities, and have experienced financial and relationship problems because of the disease. Perhaps someday soon we will understand this perplexing disease and end all the myths, pain, and frustration that go with it!

How the Endometriosis Association Can Help

The Endometriosis Association is a self-help organization of women and families with endo, doctors and scientists, and others interested in exchanging information about the disease, offering mutual support and help to those affected by endo, educating the public and medical community about the disease, and promoting research related to endo. Those affected by the disease help each other by ending the feeling of being alone, sharing

Taking charge of your own health is the most important step in coping with endo.

with others who understand what one is going through, counteracting the lack of information and the misinformation about endo, and learning from each other.

The Association is an international organization with headquarters in Milwaukee, Wisconsin (USA), members in numerous countries, and chapters and activities worldwide. Elected officers guide the Association, with help and suggestions from an advisory board of medical professionals and others. The Association, founded in Milwaukee in 1980 by Mary Lou Ballweg and Carolyn Keith, was the first group in

the world dedicated to helping women with endo.

The Support Program provides a wide range of services to help girls, women, and their families. These services include support groups, counseling/crisis call help, assistance finding knowledgeable doctors, a prescription drug savings plan, networking, and other help. At the local group level, meetings and activities are planned according to each group's wishes. Usually some meetings are planned to allow informal sharing of information and support. Other meetings offer speakers and presentations on various aspects of the disease. Group activities also may include fundraising and outreach into the community to teach about endo.

The Education Program provides a wide range of literature, books, CDs, DVDs, and other educational items to help individuals and the public learn about the disease. Members of the Association receive a popular newsletter covering the latest treatment and research news, as well as Association activities. The Association also provides ongoing help to the media and medical community to aid in the dissemination of accurate information about endometriosis.

The Association's Research/Translational Medicine Program includes maintaining the world's largest database on

the disease, major research partnerships with Vanderbilt University School of Medicine, and the U.S. National Institutes of Health, and funding of promising research worldwide. The Association also serves as a clearinghouse for information on the disease and conducts programs to alert healthcare providers about the latest research and clinical findings on endo.

Donations to help continue the work of the Endometriosis Association are very much needed and appreciated.

To become a member, please visit the sign-up page at www.endo-online.org/membership_cart.html

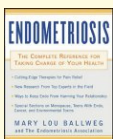
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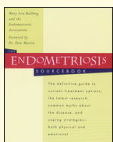
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How You Can Get More Information

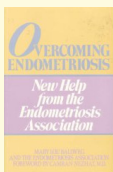
Contact us—we're here to help! We also invite you to join and be part of our mission to cure and prevent this disease.



A wide variety of informative, accurate, and highly acclaimed literature on endo and related health problems is available to you through the Association. Resources include our third book, **Endometriosis: The Complete Reference for Taking Charge of Your Health**. It is available from the Association for \$17.95 U.S./C, plus shipping & handling (\$4.95 U.S. or \$8.95 C), or from your local or online bookstore.



The Endometriosis Sourcebook, our second book, is almost 500 pages of authoritative information on endo (now in its seventh printing). It is available from the Association for \$15.95 U.S./C, plus shipping & handling (\$5 U.S. or \$9 C), or from your local or online bookstore.



Our first book, **Overcoming Endometriosis**, in its tenth printing, is available from the Association for \$14.95 U.S./C, plus shipping & handling (\$4.95 U.S. or \$5.95 C).

The Association also has available educational CDs and DVDs of speeches by leading experts on the disease, as well as booklets, kits, and newsletters. For a free information packet, including our "Materials to Help You" catalog, call, write, fax, or e-mail the Association.

If you have not been diagnosed with endo but wonder if you might have it, you can order the Association's Diagnostic Kit, **"How Can I Tell if I Have Endometriosis?"** Send \$4.75 U.S./\$5.75 Canadian, plus \$4.95 U.S./\$2.75 Canadian for shipping and handling charges.