WHAT IS ENDOMETRIOSIS?

Endometriosis is a puzzling hormonal and immune disease affecting girls and women from as young as eight to postmenopause. 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 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 growths are in the abdomen—including 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 the bladder, vagina, cervix, or vulva (external genitals). They have also been found outside the abdomen, but this is uncommon.

It is possible, though relatively rare, for endo lesions to become cancers. In addition, researchers have 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, thyroid, and other 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 to ignore symptoms.

Like the lining of the uterus, the growths of endometriosis usually respond to the hormones of the menstrual cycle. They build up during 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.

The Association has been building the energy of those affected by endo for over three decades. The Association provides a wide range 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; a catalog of educational DVDs, brochures, booklets, and newsletters. For a free information packet, including our “Materials to Help You” catalog, call, write, fax, or e-mail the Association, or click on the red button “Free Information Packet” on our homepage.

If you have 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. plus $1.50 for U.S. shipping and handling charges.

(Do not: Above the listed postage rates are for shipping within the U.S. Please contact us for international rates.)
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 other disorders, including allergies, asthma, eczema, and certain autoimmune diseases. Infertility affects about 20-40% 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 associated with endo.

HOW THE ENDO ASSOCIATION CAN HELP

Endo is without question one of the most puzzling longstanding, troublesome diseases affecting women and girls. More is being learned about it all the time, 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 didn’t have the same access to 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 past that endo more often affected less-educated women. Now we know that this myth was wrong. 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 women with endo about their actual experiences with the disorder soon learns otherwise. While some women’s lives are relatively unaffected by it, too many others have had experiences so severe that physical, emotional stress, have at times been unable to work or carry on regular 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 ENDO ASSOCIATION CAN HELP

The Endometriosis Association is a self-help organization of women and families with endo, doctors and scientists, and others interested in endometriosis, offering mutual support and help to those affected by endo, educating the public and medical community about the disease, offering support and conducting research related to endo. Those affected by the disease help each other by ending the feeling of being alone, sharing with others who understand, and helping others understand how different they are. The association is an international organization with headquarters in Milwaukee, Wisconsin, (USA), members