Endometriosis & You:
Putting Together the Pieces of a Puzzling Disease
An Educational Guide for Young Women
Presented in Alliance with the Endometriosis Foundation of America
This material is presented in partnership with, and supported by an unrestricted educational grant from, the Endometriosis Foundation of America (EFA). Studies have shown that symptoms of endometriosis often begin early in a young woman’s life. Through this ERC-EFA alliance, we strive to educate and advocate for early intervention among girls who may be faced with endometriosis - so that the daughters of tomorrow will not have to suffer in silence as so many women of today have.

**About the Endometriosis Foundation of America:** The EFA is a 501(c)3 non-profit organization founded by the international celebrity, Top Chef host and endometriosis advocate, Padma Lakshmi, and world-renowned gynecologic surgeon, Tamer Seckin, MD. The EFA seeks to provide hope to women suffering from the debilitating effects of endometriosis and associated diseases, and addresses societal prejudices and misinformation about the disease in the medical community. Learn more about the EFA’s important endeavors and efforts by visiting the Foundation online at [http://www.endofound.org](http://www.endofound.org). The ERC is grateful to the EFA for their support of this educational endeavor.

*Girl Talk* is a registered program of the Endometriosis Research Center. All materials contained herein © copyright Endometriosis Research Center & Women’s Hospital, Inc. except where otherwise specifically noted.

*Date of publication: July 2010. Revisions: August 2010. Disclaimer:* Material presented herein is offered for informational purposes only. It is not intended to offer or replace medical advice offered by your personal physicians or healthcare professionals. Additionally, the Endometriosis Research Center and the Endometriosis Foundation of America do not recommend or endorse any physicians, medications, organizations or treatment methods. Please consult your personal physician or other medical professional for treatments and diagnoses. The Endometriosis Research Center & Women’s Hospital is a 501 (c) 3 non-profit organization. A copy of the official registration and financial information may be obtained from the Division of Consumer Services by calling 1-800-435-7352 toll-free within the State of Florida. Registration does not imply endorsement, approval or recommendation by the State. Registration #SC-07844. Donations are received 100% by the ERC. *Cover model:* Gillian Doland. Image contributed from model’s personal portfolio. © copyright Gillian Doland. All rights reserved.
Think “Killer Cramps” are Normal? 
Think Again.

“I'm failing classes because I miss too much school. My teachers won't let me make up the work because they say that this is a normal part of womanhood and I need to get used to it. I wonder if they are right. Does every girl feel this way and I'm just a wimp that can't handle the pain??”

“I don't know of anyone else like me. I have to try all these treatments that my doctors throw at me for my period pain, and none of them help. I don't know what is normal and what to report to my doctor! My friends don't know how to act around me and my family thinks I make most of my pain up. I've already lost one friend who told me everything was in my head.”

Do you experience so much pain during or around ‘that time of the month’ that you are missing school, unable to attend academic or social functions, or even go about your normal routine? Do you have gastrointestinal upset during your period, such as nausea, vomiting, diarrhea or constipation? Do you experience bladder issues, such as painful urination, during your cycle? If you are sexually active, do you experience pain associated with sexual activity? Have any of your family members ever been diagnosed with endometriosis? If you’ve answered yes to any of these questions, you may have endometriosis. **Endometriosis is nothing to be embarrassed about.** Despite what the media, friends and even loved ones may tell us, “killer cramps” are never normal – they are our body's way of telling us something is wrong. Talk to your doctor about getting an accurate diagnosis for your pain and effective treatment. There is hope, and you don't have to suffer in silence. You are NOT alone. We are here to help you find the answers you need to live well in spite of endometriosis.
Endometriosis ("en-dough-mee-tree-oh-sis") is a painful and as-yet incurable reproductive disease affecting nearly 176 million women and girls around the world. Mistakenly, many people believe that endometriosis cannot affect teens or adolescents. Nothing could be further from the truth! Research has revealed that, among the young women studied, as many as 70% of teenagers with chronic pelvic pain went on to have endometriosis proven by laparoscopy. Other reports indicate that as many as 41% of patients experienced endometriosis pain as an adolescent. The illness can be quite disruptive and cause significant dysfunction, especially at a time in life when self-esteem, school attendance and performance, and social involvement are all critical. Many adolescents with endometriosis find themselves unable to attend or participate in classes, social functions, extracurricular activities, and sports due to significant pain and other symptoms of the disease.

**What is Endometriosis?** More than simply "painful periods," endometriosis is a leading cause of female infertility, chronic pelvic pain and pelvic surgery, and accounts for more than half of the 600,000 hysterectomies performed in the United States annually. Recent studies have even shown an elevated risk of other illnesses, including autoimmune disorders and certain cancers, in those with the disease. **Endometriosis is NOT contagious, nor is it an infection or sexually transmitted disease.**

Each month, the tissue that lines the uterus – the endometrium – breaks down, sheds and exits the body, resulting in the process of normal menstruation (**normal reproductive system shown below**):

With endometriosis, however, fragments of this tissue abnormally remain within the body, invading and implanting itself into other areas, most commonly the reproductive organs.

Though they cannot leave the body, these implants still respond to normal hormonal commands by breaking down and bleeding. The painful result is endometriosis; a disease characterized by internal bleeding, degeneration of blood and tissue, inflammation of surrounding areas, formation of fibrous bands known as adhesions, and scar tissue (**shown below**).

Depending on the location of the endometriosis, interference with bowels, bladder, intestines and other organs can occur. Less commonly, endometriosis can also been found in locations far from the pelvis, such as the skin, lungs - and even the brain. **Endometriosis does not discriminate on the basis of socio-economic status or ethnic background and has been diagnosed in females throughout every region of the globe.**
The Mother-Daughter Connection

Scientists and doctors still don’t really even know what causes endometriosis, but immune dysfunction and exposure to environmental toxicants are contributing factors. The disease is also hereditary: girls whose mothers have been diagnosed with endometriosis are nearly seven times more likely to have the disease themselves. An increased risk also remains among those who have relatives with endometriosis in their family. There is no way to prevent the disease, but being aware of signs and symptoms can lead to early diagnosis and treatment. While most women and girls do experience some minor discomfort during their periods due to the release of inflammatory hormones such as prostaglandins, menstrual pain that interrupts your life is not normal! The most important step a girl and her family can take when dealing with suspected endometriosis is to find a physician who truly understands and will work with her towards a diagnosis at the first sign of a possible problem and provide and effective, personalized treatments.

Symptoms of Endometriosis Include:

- debilitating period pain
- intermittent pelvic or abdominal pain at any time during cycle
- infertility, miscarriage or ectopic (tubal) pregnancy
- pain associated with sexual intercourse, if active
- allergies which tend to worsen around time of period
- family history of endometriosis
- gastrointestinal upset and discomfort during cycle, sometimes misdiagnosed as “irritable bowel syndrome”
- bladder pain or discomfort, particularly during period; may be misdiagnosed as a urinary tract infection or interstitial cystitis

Teens and young women may lack support and validation both at home and school; often told the pain is “in their head,” that they are “faking it,” that their debilitating cramps are “normal” and “a part of womanhood,” that they are merely suffering from “the curse,” or that they should just “grin and bear it.” Failure to acknowledge symptoms early in the disease process can lead to significant delays in diagnosis and treatment. Lack of support from family and loved ones can also add to the patient’s pain and fear. Studies have shown that endometriosis may have an even bigger impact on younger patients than older women. One study even discovered that in patients <22 years of age, the rate of disease recurrence was double that of older women (35% versus 19%). The study also revealed that endometriosis behaves differently in younger women; leading some scientists to believe it is a different form of disease altogether. Others feel that symptomatic, adolescent-onset Endometriosis is most often a lifelong problem that could progress to severe fibrotic disease if left untreated.
Endometriosis is treatable with the right help. With early intervention and effective therapies, the disease can be successfully managed. Endometriosis does not have to overtake your life. Don’t Feel Hopeless!

The good news is endometriosis CAN be effectively managed in many cases. Treatments typically range from surgical to medical, but there are a few surprisingly easy steps you can take on your own to help reduce some of the symptoms. Complementary therapies, lifestyle changes, certain diet and nutrition steps, exercise, limiting exposure to toxins as much as possible and much more can all lead to improved health overall.
Surgery is required to accurately and definitively diagnose endometriosis, though it may be suspected based on symptoms and diagnostic tests such as ultrasound or MRI.

Laparoscopic ("lap-a-rah-skopic") surgery is an outpatient procedure required to accurately diagnose and adequately treat the disease. This minimally invasive, 'same day surgery', in which you are put to sleep, will allow your doctor to look inside your pelvis to diagnose, take biopsies, and treat any endometriosis that may be present.

Surgical destruction of endometriosis can be done in many ways, ranging from the gold standard of excision to topical removal through laser vaporization. It is imperative that all disease is truly removed from all areas, as any endometriosis left behind will continue to cause pain and symptoms. Studies have shown that ineffective removal, such as vaporization, results in a 40-60% recurrence of disease within the first year following surgery. Talk to your doctor about what method they intend to use to diagnose and surgically treat you.

Anything less than a surgical, biopsy-confirmed diagnosis of endometriosis is considered uncertain. CT scans, MRIs, ultrasounds, pelvic exams and other diagnoses are often inaccurate and do not adequately detect the presence of disease.
Other Treatments

**Hysterectomy:** Endometriosis remains a leading cause of hysterectomy (removal of the uterus). It is not a cure for the disease, though some women have experienced relief following the procedure. **Hysterectomy is not an appropriate option for younger patients who wish to have children** later in life. Hysterectomy may sometimes include removal of one of both ovaries (oophorectomy) and/or fallopian tubes (salpingectomy).

**Medical Suppression:** Some patients experience temporary relief through the use of common hormonal agents and other medical therapies. These include (but are not limited to):

**GnRH (gonadotropin-releasing hormone) Agonists** - these are drugs, such as Lupron®, that are designed to temporarily suppress the disease by shutting down the "messenger" hormones sent from the pituitary gland to the ovaries. This stops the period, inducing a condition known as "medical menopause". Some patients experience positive results with GnRH treatments, others do not. As with any treatment, each case will vary. Though the medications can shrink the lesions of endometriosis, they do not have any impact on adhesions or scar tissue, which often play a part in the pain of the disease. Common side effects that have been reported by women undergoing treatment include hot flashes, headaches, insomnia, vaginal dryness, decreased libido, depression, mood swings, fatigue, acne, dizziness, nausea, short term memory loss, diarrhea, hair loss, anxiety, and bruising at injection site. Symptoms recur when the treatment is stopped.

**Aromatase inhibitors** - Aromatase inhibitors are drugs, like Letrozole®, that block estrogen synthesis. This in turns lowers the estrogen level and slows the growth of endometriosis temporarily. Side effects include hot flashes, joint pain, muscle aches, headache and fatigue. These side effects, especially the joint pain, can be quite prominent at times. The drug also puts patients at a greater risk of osteoporosis. Symptoms recur when the treatment is stopped.

**Danocrine®** - Danocrine® is a synthetic testosterone derivative that also works by temporarily suppressing hormones. However, expense and significant side effects have made its use far less common by most physicians today. Side effects range from acne, decreased breast size, deepening of the voice, weight gain, and more. Symptoms recur when the treatment is stopped.

**Depo-Provera®** (medroxyprogesterone acetate): these common injections are also used to quell symptoms temporarily, as are combination oral contraceptive pills like Alesse® or Lo-Ovral®. Seasonale®, which allows patients to limit their periods to just four times a year, is also a therapeutic option. Symptoms recur when the treatment is stopped. Like all drugs, they are not without potential side effects.

**Pain Medication:** Pain management options include non-steroidal anti-inflammatories (NSAIDs) such as Anaprox® or Toradol®. Stronger narcotics and anti-depressants are often used as well. You and your doctor can find the best pain relievers for your personal case after evaluating your situation together.

Your doctor will discuss all the available treatments and work with you to find one that fits into your lifestyle and provides relief for your specific case. If you do not feel as though your physician is adequately addressing your concerns, find one who will. Refer to our website at endocenter.org for more information on all the traditional, surgical and alternative treatments for endometriosis.
Complementary Therapies

Ranging from dietary measures to alternative therapies, there are a number of often effective and non-invasive means of managing symptoms. These include:

**Diet & Nutrition:** Eating a healthful diet of low refined carbohydrates and limiting caffeine, sugar, preservatives, additives, red meats and processed foods has been shown to be helpful in several patients. Dietary measures can be adopted as needed to suit a young woman’s active social and lifestyle to make the restrictions manageable.

**Naturopathy:** A healing method which is not a singular therapy, but rather includes combinations of fasting, vitamin and mineral therapy, color therapy, colonics, hydrotherapy, herbs, breathing exercises, physical exercise, massage, joint manipulation, and acupuncture, among others.

**Osteopathy:** Pain may be relieved by correcting structural problems through the manipulation of muscles, ligaments and bones.

**Chiropractic:** Differs from osteopathic treatment in that chiropractors believe pain can be relieved by correcting dislocations (subluxations) in the musculoskeletal system alone. Areas concentrated on include primarily the lumbar spine and the thoracic spine area, which also has beneficial effects on the immune system, long thought to be involved in the basis of endometriosis.

**Acupuncture:** The insertion of thin needles at various points in the skin. This is said to bring relief by restoring the balance and “Ch’I” – the “energy flow” of our bodies. Some researchers believe that acupuncture also releases endorphins, a natural painkiller produced by the body.

**Exercise:** Exercise is a demonstrated stress reliever, pain reducer and depression fighter because it stimulates the release of endorphins (natural painkillers).

**Aromatherapy:** Use of essential oils extracted from plants. Some oils have been found to have anti-viral, anti-fungal and even anti-bacterial properties. Effective oils for endometriosis include sage, cypress, fennel, bergamot and geranium.

**Herbs:** Trained herbalists believe this treatment works because of the impact selected remedies have on excess levels of estrogen, suggested to be linked to the flare of endometriosis pain. Herbs said to be helpful in relieving endometriosis include Blue Cohosh, Cranberry, Plantain, St. John’s Wort, Peppermint, Valerian, Dong Quai, False Unicorn, Evening Primrose Oil, Chasteberry/Vitex, Black Cohosh, Uva Ursi, Couchgrass, Red Raspberry, Yam, and White Willow.

Of course, you will need to consult a licensed professional as to dosing, regimens and other information on any therapy or treatment you may try.
Overall, the goal of all endometriosis treatment is to relieve pain, control disease progression and preserve fertility. Early diagnosis and effective treatments can make a positive difference in improving one's quality of life and will enable you to successfully manage - and live well in spite of! - the disease. Some helpful tips include:

• Make sure you are getting enough restful sleep at night.
• Eat healthy meals and nutritious snacks each day.
• Light exercise - when you can - may bring relief.
• Do the things you enjoy when you feel well enough to do them!
• Stay in touch with your friends in person, by phone, or online so you don’t feel “disconnected”.
• Keep up with schoolwork, so you won’t get overwhelmed or fall behind.
• Learn when you can push yourself - and when you can’t.

Try to reduce your exposure to toxic substances, such as dioxin, as much as possible. These pollutants are associated with endometriosis and countless other healthcare risks. Reducing exposure may not prevent endometriosis, but it can be very helpful in potentially alleviating symptoms. Endocrine disruptors – substances which act by imitating our natural hormones and altering, magnifying or blocking the normal function of those hormones - are found in many of our everyday products, including plastic bottles, metal food cans, detergents, flame retardants, food, toys, cosmetics, and pesticides. Unfortunately, endocrine disrupting agents are pervasive in our environments; identification and limitation of exposure to risky dietary and consumer products can help minimize the negative and risky effects.

Above all else...talk about it!

Endometriosis is nothing to be ashamed of. The more people in your life who understand the disease, the better equipped they will be to help and support you.
Support is perhaps the most important piece of the puzzle that is endometriosis. By talking with others who understand, it can help girls who may be dealing with the disease to not feel so alone.

The Endometriosis Research Center was founded because of the limited research, support and education that exist; one of our goals is to create enough awareness to ensure that women, teens, adolescents and their loved ones never have to feel like they are single-handedly battling the illness, all alone. Founded by Executive Director Michelle E. Marvel in early 1997, the ERC strives to improve the quality of life for women and girls of all ages with endometriosis and their loved ones through our extensive programs and outreach efforts. For information on treatments, resources, coping techniques and much more, please visit us online at http://www.endocenter.org, join us on Facebook at http://www.facebook.com/EndoResCenter or call us toll free within the United States at (800) 239-7280.
Helpful Resources
The ERC bookstore, featuring several leading publications on the disease:
http://www.endocenter.org/educationalmaterials.htm

Dr. Robert Albee & Dr. Ken Sinervo of the Center for Endometriosis Care – a specialty treatment center located in Atlanta, GA
http://www.centerforendo.com/articles/teenagers.htm

Dr. Tamer Seckin – a specialty treatment center located in NYC, NY
http://www.drseckin.com

The Endometriosis Foundation of America – a charitable endeavor launched in 2009 by celebrity Padma Lakshmi and gynecologic surgeon Tamer Seckin, MD
http://www.endofound.org

Jennifer Ritchie-Goodline, Psy.D. – Dr. Ritchie-Goodline is an ERC Advisory Board Member in private practice who provides a focus, in part, on endometriosis and women’s health issues
http://www.drjenniferritchiegoodline.com

Girls for a Change – a wonderful non-profit foundation focused on the empowerment of teen girls to create and lead social change
http://www.girlsforachange.org/

Dr. David Redwine – a specialty treatment center located in Bend, OR
http://www.endometriosissurgeon.com

Dr. Martin Robbins – a specialty treatment center located in Scarborough, ME
http://www.endoexcision.com

The Center for Treatment & Study of Endometriosis – a specialty research and treatment facility at SUNY Downstate Medical Center in NYC
http://www.downstate.edu/obgyn/endometriosis.html

Endometriosis.org – a global platform for all things endometriosis
http://www.endometriosis.org

The World Endometriosis Research Foundation – a global research organization focused on collaborative studies across international centers
http://www.endometriosisfoundation.org

Connect with Kids – a multi-media education company focused on helping educators and parents teach life skills, prevention, character, health and wellness to today’s children

The World Endometriosis Society – a professional society founded to promote the exchange of clinical experience, scientific thought, and investigation among doctors, scientists and other qualified individuals interested in advancing the field of endometriosis
http://www.endometriosis.ca

Leigh Layton – a personal life coach who successfully overcame endometriosis and is helping others to focus on fulfillment, balance and process in their own lives
http://www.thelifegardener.net