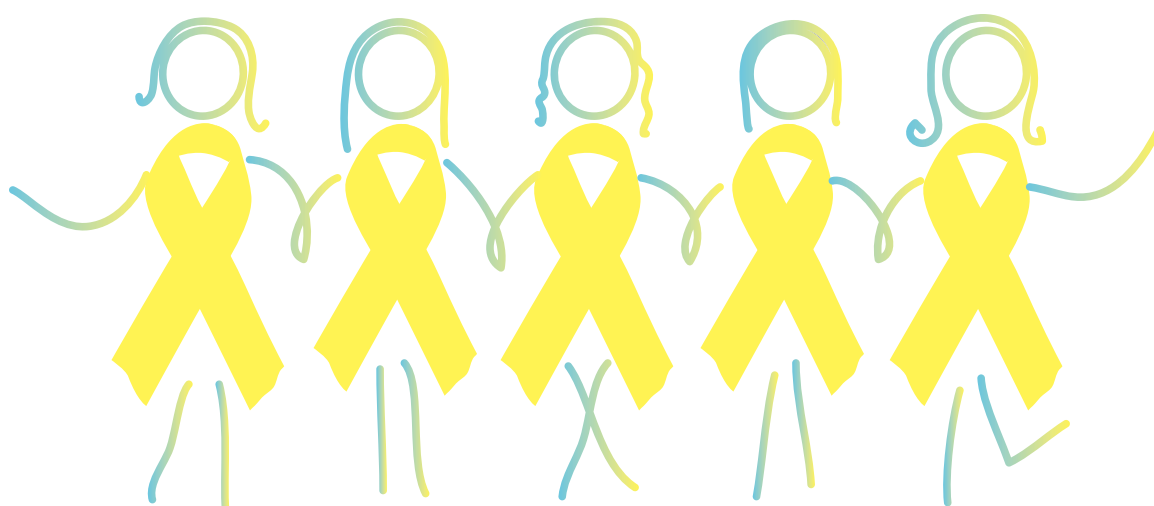


Managing Your Endometriosis

A Collection of Resources for Teens and Young Women with Endometriosis



IN APPRECIATION

The staff of the Center for Young Women's Health gratefully acknowledges the D'Orsi Family and The Boston Children's Hospital League for funding this project.

We would like to recognize our dedicated team of authors: Phaedra Thomas RN, BSN, Laura Clasby RN, MSN, CNOR, CPN, Francie Mandel, LICSW, Kendrin Sonnevile ScD, RD, LDN, and Anna Miller, BA, designer/illustrator.

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The team is especially grateful to Dr. Marc R. Laufer for his guidance, and most of all for his commitment to improving the lives of young women with endometriosis.

Managing Your Endometriosis

You have been diagnosed with endometriosis, and since there is a lot to learn about managing a chronic condition, the GYN team here at Boston Children's Hospital created this book especially for you. *"Managing Your Endometriosis"* will help you understand endometriosis, teach you ways to cope with chronic pelvic pain and painful periods, and help you deal with the challenges of going to school and maintaining friendships.

HOW TO USE THIS RESOURCE BOOKLET:

Finding information is easy. Check out the Table of Contents on the next page. Each section is listed along with a brief description of what's inside. For example; the Endometriosis Guide answers the most commonly asked questions about the causes, symptoms and available treatments; the Pain & Symptom Tracker offers tools to help you keep track of your pelvic pain and other discomforts; and the Coping with Endometriosis Pain guide will help you identify ways endometriosis impacts your life and strategies to effectively manage your pain. There are also detailed guides that explain different types of hormonal therapy used to treat endometriosis.

Learning about endometriosis, available treatments, and how to cope with pain will make a difference in improving the quality of your life.

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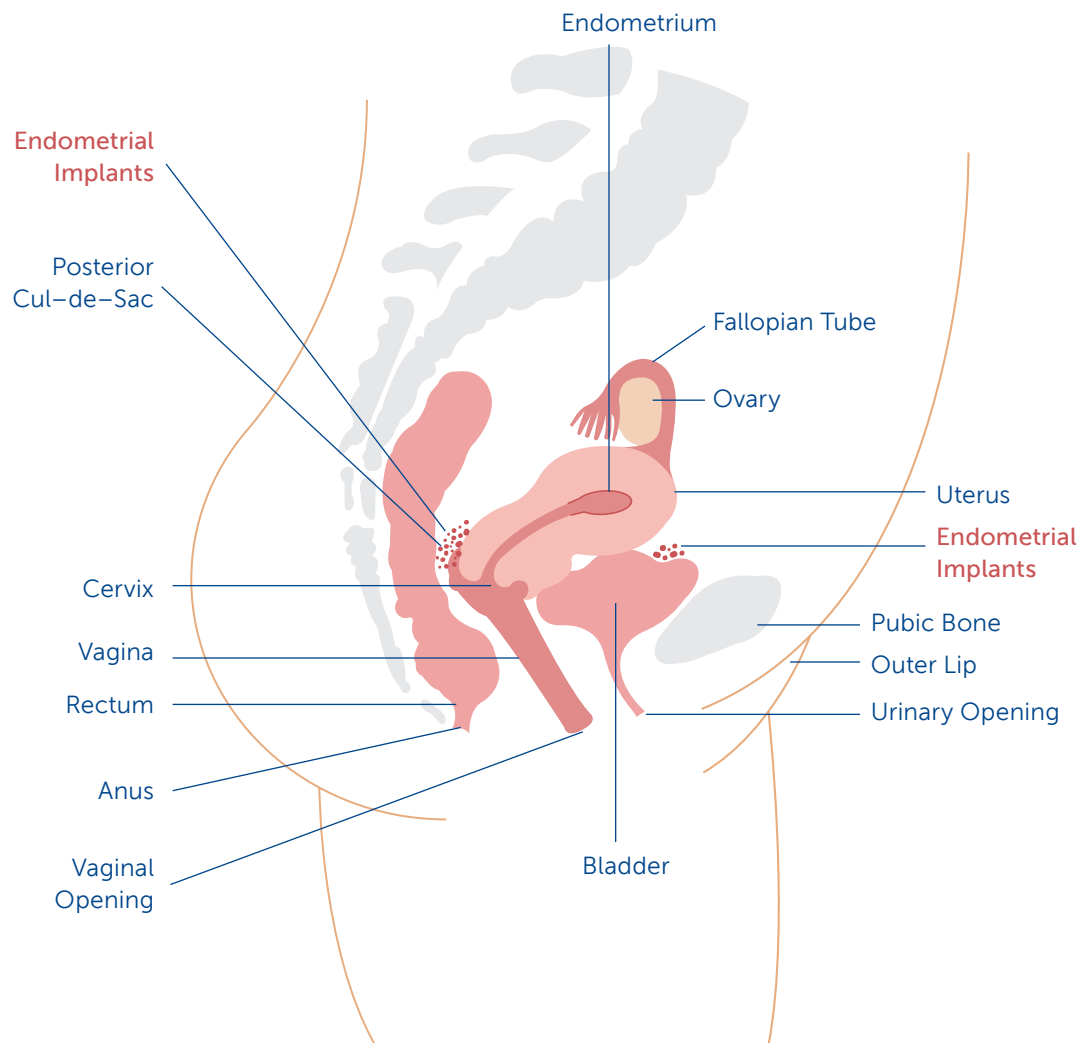
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Endometriosis

What is endometriosis?

Endometriosis, pronounced, “end-o-me-tree-o-sis” can affect girls of all ages. It is a condition that occurs when tissue similar to the inside lining of the uterus is found outside of its normal location. Endometrial implants can be found on the ovaries, fallopian tubes, and ligaments that support the uterus and tissue covering the bladder and rectum. The most common locations of endometrial implants in teens are in the cul-de-sac area (behind the uterus), and near the bladder. (See illustration below.)



What are the symptoms of endometriosis?

Endometriosis causes different symptoms in young women. Pelvic pain and/or severe period cramps are the most common symptoms. There can be pain before, during or after your period. The pain may occur at regular times in your cycle or it may occur at any time during the month. It is often referred to as “chronic” pelvic pain. The location of the endometrial implants and the way in which the lesions affect the pelvic organs contribute to the symptoms teens may have. Some teens may have pain with exercise, sex, and/or after a pelvic exam. Although not as common, some teens may have painful or frequent urination, diarrhea or constipation with pelvic pain. It’s important to remember that some teens have a lot of endometriosis and have very little pain, while others may have a small amount of endometriosis and severe pain.

What causes endometriosis?

Although we know that some young women may be slightly more likely to develop endometriosis because female relatives have it, the fact is we do not know the cause of this disease.

THE THREE MOST ACCEPTED THEORIES ARE:

- **Sampson’s Theory:** This theory explains that the flow of menstrual blood gets “backed up” causing some of the blood to flow in a reverse direction. This process causes blood containing endometrial tissue to attach to surfaces outside of the uterus.
- **Meyer’s Theory:** This theory proposes that specific cells called “metaplastic cells” change into endometrial cells and are actually present at birth.
- **Vascular Theory:** This theory suggests that the endometrial tissue “travels” through the body via blood vessels. It then reaches various tissues, implants, and then grows, causing pain.

How is endometriosis diagnosed?

The ONLY way to be 100% sure of this diagnosis is to have a procedure called a laparoscopy. There is no blood test, x-ray, ultrasound, or MRI that can diagnose endometriosis at this time. A laparoscopy allows your doctor to look inside your belly at your pelvic organs with a special lens to identify the endometriosis (implants). Other tests that may be ordered before a laparoscopy might include blood tests, vaginal cultures to check for infection, ultrasound or an MRI (to make sure it’s not something else).

Why have I heard that some adult women may have trouble getting pregnant?

If endometriosis is not found and treated, it can grow and damage the fallopian tubes and ovaries. This can make it more difficult to get pregnant. Studies done at Boston Children's Hospital have shown that if endo is found in teens and treated early, it does not tend to get worse over time.

Is there a cure for endometriosis?

While there is no cure for endometriosis, you can be treated with surgery and medicine to keep the endometriosis from getting worse and harming your future fertility. It is very helpful to use a Pain and Symptom Tracker (page 11) to record your pain for a while. Another method to locate and describe your pain is "Pain Mapping" (page 15). Make a copy of your Pain and Symptom Tracker and Pain Mapping worksheets, fill them out, and bring them with you to your appointments. These tools will help you explain your pain to your medical team.

WAYS TO HELP YOU DESCRIBE YOUR PELVIC PAIN:

- Type (sharp, dull, burning, aching, crampy)
- Location (where the pain is)
- Duration (how long the pain lasts)
- Intensity (on a scale of 1–10, how "bad" the pain is)

What kinds of treatment are available?

Once a diagnosis of endometriosis has been made, treatment falls into the following categories.

OBSERVATION: After an evaluation and before beginning hormonal therapy, you and your gynecology (GYN) team may decide to keep track of your symptoms and try mild pain medicine. This is usually the first step for girls with premenarcheal endometriosis (who are too young to have had their first period).

MEDICAL SUPPRESSION: Hormonal treatment such as birth control pills containing estrogen and progesterone taken continuously (to stop periods) relieves symptoms in many patients. A second treatment is progesterone medicine alone. This comes as a progestin-only birth control pill in a pill pack (Nor-QD® or Camilla®) or as a regular pill that comes in a bottle Norethindrone acetate (Aygestin®).

The dose of Aygestin® can be adjusted for your body to stop your pain and bleeding. Another type of medication is a GnRH agonist, such as Leuprolide acetate (Lupron–Depot®). This medicine works by shutting off hormones made by the ovaries and temporarily stops your period. The use of GnRH agonist therapy lowers your body’s estrogen level (one of the hormones that causes your body to have periods). We offer GnRH agonists with add–back therapy (see page 37).

SURGERY: Visible endometriosis will be destroyed at the time of laparoscopy. After this procedure, many teens find relief from symptoms. Most say that their pain is better, but not completely gone. Remember, there is no cure for endometriosis. Many teens may experience pain again.

LIFESTYLE CHANGES: Dealing with chronic pelvic pain can be challenging. Exercising often helps to relieve or lessen pelvic pain and menstrual cramps. Eating a balanced diet and getting enough rest also helps your body manage pain. Practicing relaxation techniques such as yoga and meditation help to ease pain too.

PAIN TREATMENT SERVICES: The GYN team works closely with other clinicians in the Pain Treatment Services program. If you do not have relief from your symptoms, your gynecologist may refer you for an evaluation. Following an evaluation, services such as biofeedback, physical therapy, acupuncture and exercise programs may be offered. An appointment with the Boston Children’s Hospital Pain Treatment Service can be arranged by calling: 617–355–6995. For more information, see page 59.

COMPLEMENTARY MEDICINE: Acupuncture, herbal remedies, homeopathy and healing touch are among popular “alternative approaches” to medical treatment. Many of these therapies can be helpful however, not every alternative approach has been scientifically proven to be safe and effective. Research studies are limited. Before experimenting with any alternative therapy, make sure that you are working with a licensed provider that has been referred to you.

What else do I need to know about endometriosis?

- Young women CAN suffer from symptoms of endometriosis. Medical studies have found this disease in teenagers and young children.
- Chronic pelvic pain is NOT normal. Most young women have none or mild to moderate menstrual cramps one or two days a month. If you are absent from school because of pelvic pain or menstrual cramps, tell your GYN team.

- Endometriosis occurs among women of ALL races.
- Endometriosis is NOT an STI (sexually transmitted infection).
- Getting pregnant does NOT cure this disease but may improve symptoms for some women. Some women with endometriosis who have had children continue to have pain.
- If your pain makes you feel at all disadvantaged compared to other young women or men, this is *not* normal. Don't "normalize" your symptoms. If you *don't* feel like you are equally capable as other young women your age (because of pelvic pain), you need to seek medical attention.

The goal of the treatment for endometriosis is aimed at relieving pain, controlling the progression of the endometriosis, and preserving fertility for future childbearing. Treatment can make a big difference in improving the quality of your life.

For girls who have been diagnosed with endometriosis:

The young women who attended our 9th Endometriosis Conference on October 24, 2015, were asked the question, "What would you say to a girl who was just diagnosed with endometriosis?" Below are their responses:



Frequently Asked Questions (FAQs) about Endometriosis

Why do I need to have surgery and medicine for my endo?

Endometriosis can only be diagnosed by laparoscopy. At the time of a laparoscopy, great care is taken to destroy any visible endo lesions (also called implants) and any adhesions. Some endometriosis isn't visible, yet it responds well to medication. That's why we combine medical and surgical therapy to treat this unpredictable disease. A study done at Boston Children's Hospital strongly suggests that combined surgical and medical management stops endometriosis from getting worse. This helps to preserve your fertility.

Will I ever need another laparoscopy?

Most girls will not require any more laparoscopic procedures in the future, but some may. This depends on many factors, such as when your last procedure was, if you are having a problem with pain control while taking medication, and if your gynecologist feels it is necessary to check to see if your endometriosis has grown. If your endometriosis has grown, the lesions will be removed and/or destroyed. The goal is to lower your pain and preserve your fertility.

- In a recent study at Boston Children's Hospital, Dr. Laufer and his colleagues were interested to find out if they would see more endometriosis at the time of a second laparoscopy (in young women with diagnosed endometriosis). **They found that endometriosis did not get worse (didn't grow) in patients who were treated with both surgery and medication.**

Will I need to have my uterus removed?

You will NOT need to have your uterus removed (hysterectomy). All treatment will be aimed at relieving your pain and preserving your ability to have children some day.

Will I be able to get pregnant?

Not being able to get pregnant (infertility) can result if endometriosis causes changes in your pelvic organs, including your fallopian tubes and ovaries. With early treatment, endometriosis should not interfere with your ability to become pregnant (when you are ready). Other factors besides endometriosis (such as sexually transmitted infections) can affect your fertility. It's important to take good care of your reproductive health by always practicing safe sex.

Should I get pregnant soon to cure my endo?

You may have heard that "pregnancy cures endometriosis". This is a myth. There is no cure for endometriosis. Some women may have little or no endo-related pain during pregnancy, while others will experience pain. Becoming a parent is a big decision and should never be used as a treatment for endo.

How long do I need to be followed for my endo?

Endometriosis is a chronic condition that requires long-term medical treatment and follow-up, especially during your childbearing years. Many factors affect how often you will need to be seen by your medical team, such as whether or not you are responding to the treatment. Since there is no cure for endometriosis, you will need to be on medication. Therefore, you will need to be checked and have your prescriptions refilled. For example: if your gynecologist gives you a prescription for medication to stop your period, you will need to schedule a follow-up appointment in approximately 3 months. During this visit, he/she will meet with you and ask if the medication is working to stop your periods and pain. If you are feeling well and your blood pressure is normal, you will be given a prescription for more refills. If you are on Leuprolide acetate (Lupron Depot®) you will need to return 2½ months after your first shot, then again every 3 months while you are on this treatment. If you have any problems or need questions answered in the meantime, you should contact the GYN nurse at: 617-355-7708.

You may be followed here at Boston Children's Hospital until you're 22 years old. Before you turn 23 years old, you'll need to see an adult endometriosis specialist. If you would like, you can see Dr. Laufer at the Brigham and Women's Hospital in his adult practice. The Brigham and Women's Hospital appointment line is: 617-732-4222.

Should my sisters and other family members get checked?

Women are more likely to develop endometriosis if a close female relative from their mom or dad's side has it. Likewise, if you have been diagnosed with endometriosis, and someone in your family (such as your sister, or cousin) has painful periods and pelvic pain at other times during her menstrual cycle that interfere with school and social activities, it is a good idea to suggest that they get evaluated. They can make an appointment with a pediatric adolescent gynecologist in our GYN practice who has experience treating teens with endometriosis.

My Pain & Symptom Tracker

Keeping track of pelvic pain, menstrual cramps, and other symptoms such as pain when you pass urine or when you have a bowel movement is important. Be sure to write down any symptoms you have, the number from 1–10 that describes the degree of pain, and where it is located. If you are taking continuous hormone pills and you do not have periods, you can use the chart to track any other symptoms, including breakthrough bleeding.

INSTRUCTIONS

- Be sure to check out the Sample Pain and Symptom Tracker and carefully read the keys at the bottom before you start filling out your own tracker.
- Make a few copies of My Pain and Symptom Tracker on page 13.
- Write the name of the month at the top of the page and begin tracking your pain and symptoms.
- To fill in the bleeding “Amount” row, look at the Blood Flow Amount Key at the bottom of the page to figure out which letter (S, L, N, or H) best describes your flow.
- Figure out which letter best describes the location of your pain (M, L, or R) by taking a look at the “Pelvic Pain Location Key” at the bottom of the page. Write it down in the Pelvic Pain “Location/Intensity” row. Then, decide which number best describes your pain (0 = no pain, 10 = the worst pain you have ever had) by looking at the Pelvic Pain Numerical Rating Scale at the bottom of the page. Write that number down in the same row. Example = M/5.
- If you don’t have any pain symptoms or breakthrough bleeding on any given day, just leave the box empty.
- Remember to bring your Pain and Symptom Tracker with you to your GYN appointments.

SAMPLE MONTHLY PAIN & SYMPTOM TRACKER

MONTH: JANUARY

| DATE | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | 31 |
|--------------------|---|---|---|---|---|---|-----|---------|---|-----|-----|-----|-----|-----|----|----|----|----|----|----|----|----|----|-----|-----|-----|----|----|----|-----|----|
| PELVIC PAIN | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| LOCATION/INTENSITY | | | | | | | M/4 | M/4 M/5 | | M/5 | M/6 | M/7 | M/7 | L/5 | | | | | | | | | | M/5 | M/5 | M/5 | | | | M/6 | |
| GI SYMPTOMS | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| PAINFUL BM | | | | | | | | | | | | | | | ✓ | | | | | | | | | | | | | | | | |
| CONSTIPATION | | | | | | | | | | | | | | | ✓ | | | | | | | | | | | | | | | | |
| NAUSEA | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| URINARY SYMPTOMS | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| PAIN | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| URGENCY | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| FREQUENCY | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| ACHES AND PAINS | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| LOWER BACKACHE | | | | | | | | | | | | | ✓ | | | | | | | | | | | | | | | | | | |
| BLEEDING | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| AMOUNT | | | | | | | | | | S | S | L | N | H | H | N | | | | | | | | | | | | | | | |
| PAIN MEDICATION | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| VOLTAREN 50MG | | | | | | | | | | | | ✓ | | ✓ | | | | | | | | | | | ✓ | ✓ | | | | | ✓ |

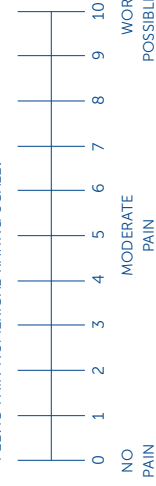
BLOOD FLOW AMOUNT KEY:

- S = SPOTTING (TINY AMOUNT OF FLOW ON YOUR UNDERWEAR OR PANTY SHIELD)
- L = LIGHT (1-3 TAMPONS OR PADS/DAY)
- N = NORMAL (4-6 TAMPONS OR PADS/DAY)
- H = HEAVY (MORE THAN 6 TAMPONS OR PADS/DAY)

PELVIC (LOWER ABDOMEN) PAIN LOCATION KEY:

- M = MIDDLE
- L = LEFT SIDE
- R = RIGHT SIDE

PELVIC PAIN NUMERICAL RATING SCALE:



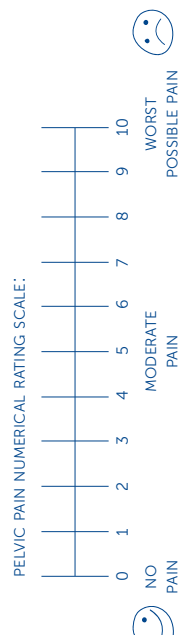
MY MONTHLY PAIN & SYMPTOM TRACKER

MONTH: _____

| DATE | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 | 26 | 27 | 28 | 29 | 30 | 31 | |
|--------------------|---|---|---|---|---|---|---|---|---|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|--|
| PELVIC PAIN | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| LOCATION/INTENSITY | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| GI SYMPTOMS | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| PAINFUL BM | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| CONSTIPATION | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| NAUSEA | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| URINARY SYMPTOMS | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| PAIN | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| URGENCY | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| FREQUENCY | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| ACHES AND PAINS | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
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| BLEEDING | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| AMOUNT | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
| PAIN MEDICATION | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | | |
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 M = MIDDLE
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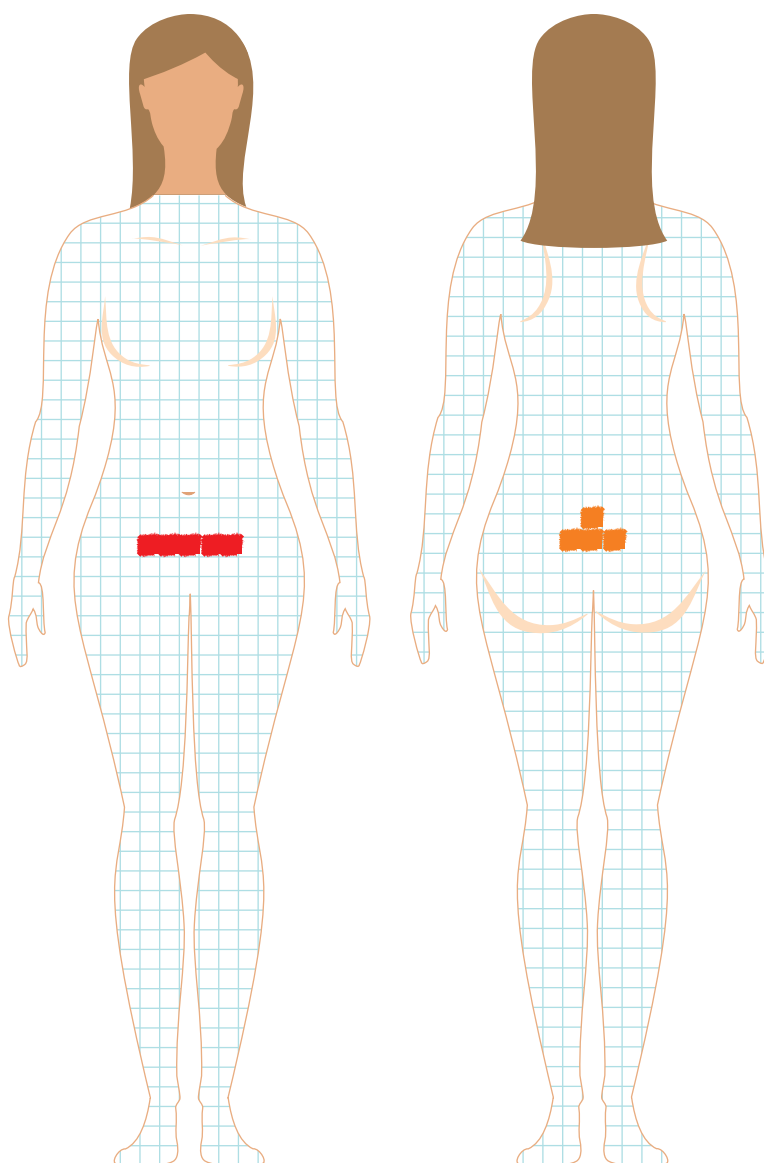


My Pain Mapping Worksheet

Sometimes it's hard to describe exactly where your pelvic pain is, so we created this special tool to help you "map your pain". Pain mapping using colored pencils or markers is a unique way to show your medical team the location of your pain. Simply color in the area where you have pain. You can create your own "key" using different colors. For example; you may use the color red to show the location of severe pain, while you may choose the color orange to indicate moderate pain—it's up to you, you're the artist. We've included a sample pain mapping worksheet on the next page to show you an example of how to map your pain.

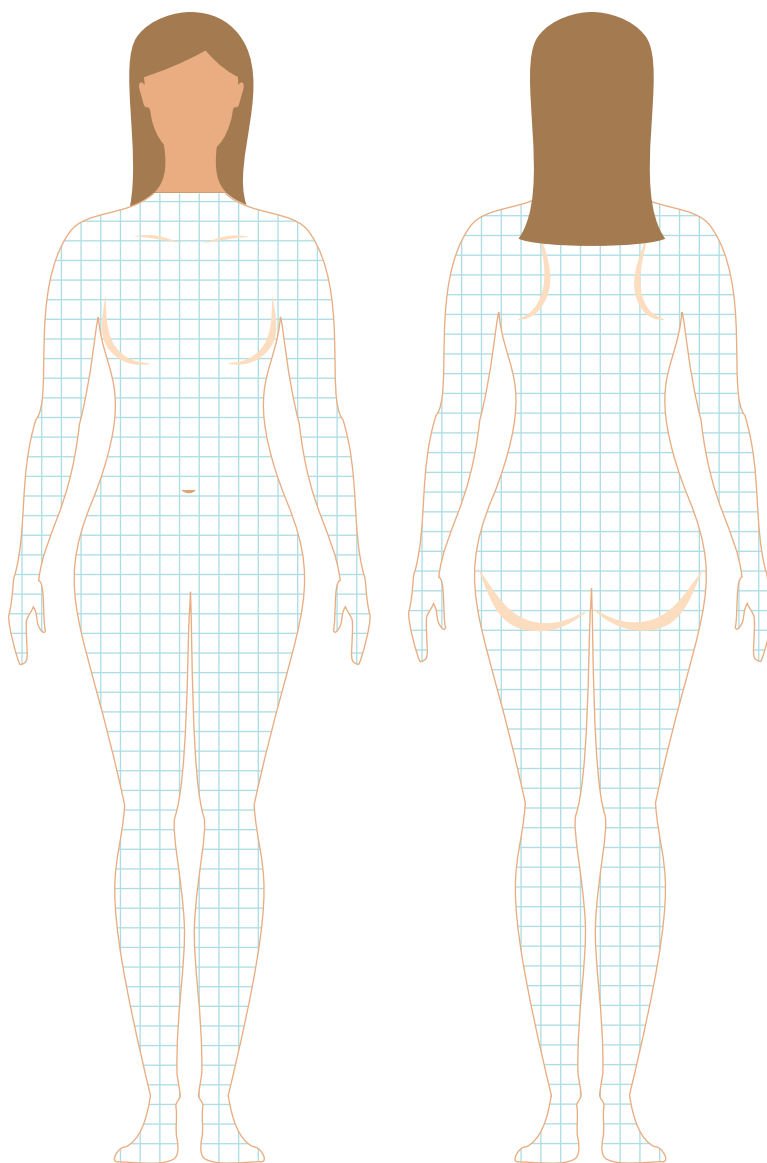
Sample Pain Mapping Worksheet

INSTRUCTIONS: Make a copy of this page, and color in the squares to show the location of your pain. (You may use different colored pencils/markers for different kinds of pain.) Bring your completed pain mapping worksheet with you to your follow-up appointments.



My Pain Mapping Worksheet

INSTRUCTIONS: Make a copy of this page, and color in the squares to show the location of your pain. (You may use different colored pencils/markers for different kinds of pain.) Bring your completed pain mapping worksheet with you to your follow-up appointments.



An Overview of Hormonal Treatment

There is no surgical cure for endometriosis, and if it is untreated it will grow, causing pain and lowering your chances of being able to become pregnant in the future. This is why you need to take medication. Treatment is aimed at controlling pain and preventing the endometriosis from getting worse. This guide was created to help you understand the different choices of hormonal treatment for endometriosis, as well as the benefits and possible side effects that are most commonly reported.

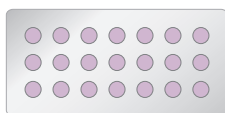
How do I know if hormone treatment is right for me?

Most young women can take hormone medicine, however, if you have certain medical conditions (such as a history of blood clots, high blood pressure, certain kinds of heart disease, hepatitis, severe migraines with visual changes or numbness over parts of your body, or if you smoke), hormonal therapy may not be an option for you. Be sure to tell your gynecologist if you have migraine headaches with loss of vision, flashing lights, numbness/tingling, or loss of speech. Also, it is very important to tell your GYN doctor if anyone in your family has ever had a blood clot or stroke.

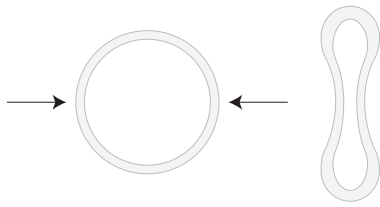
How does hormonal treatment work?

Hormonal treatment works by temporarily turning off your ovaries so you don't ovulate (make eggs). When you don't ovulate, you don't have regular periods. When you are prescribed hormonal treatment continuously, you will rarely have periods or not have them at all. Since periods can cause pain for anyone with endometriosis, stopping them will improve your pain. Hormonal treatments include the Pill, vaginal ring, an injection (once every 3 months), an IUD (which is placed in the uterus) or a hormonal implant that is inserted under the skin in your upper arm.

HORMONAL TREATMENT WITH COMBINED ESTROGEN AND PROGESTIN



Oral contraceptive pills (ocp's): OCP's contain the hormones estrogen and progesterone. The goal of the treatment is to stop your periods and pain. Teens with endometriosis will take them in a continuous fashion.



The vaginal ring: The vaginal ring is a small, thin, flexible rubber ring that fits inside the vagina. Once in place it releases a combination of estrogen and progestin (hormones). If you choose this method of hormonal treatment for your endo, you would insert the ring and leave it in place for 3 weeks. You would then take it out and replace it with a new one right away. (If you are sexually active, neither you nor your partner will be able to feel the ring when it is inserted properly.)

BENEFITS:

- ★ Combined estrogen and progestin hormonal therapy may decrease, and in some cases stop endo pain.
- ★ Most girls will only have 0–4 periods a year.
- ★ Some young women prefer using the vaginal ring or patch because they don't need to remember to take it every day.

POSSIBLE SIDE EFFECTS:

- Spotting or breakthrough bleeding can last for a few days until your body gets used to the medicine, or as long as you are taking it.
- Some girls may have heavier bleeding or a regular period.
- Breast tenderness, mood swings, headaches, nausea, cramps, bloating, and/or weight gain.
- There is some concern that the patch may release a higher dose of hormones than the pill, which can increase the risk of blood clots and/or stroke.
- Some girls who use the hormone patch may have skin irritation where the patch is worn.
- Some girls who use the vaginal ring may have vaginal irritation.
- Some girls may not have relief from their endometriosis pain.

PROGESTERONE–ONLY HORMONAL TREATMENT

Norethindrone acetate: Aygestin® (Norethindrone acetate) is a pill that contains only progesterone. It is a type of hormone medicine that is often prescribed for patients that cannot take estrogen. The dosage is 5–15mg per day, and can be individualized for each patient.

Medroxyprogesterone Acetate (Depo–Provera®): Medroxyprogesterone acetate is another type of medication that only contains the hormone progesterone. It is an injection that is given once every 3 months by the GYN nurse or your primary health care provider. Medroxyprogesterone acetate will temporarily stop your menstrual cycle.

IUD or Mirena®: is a type of intrauterine device that contains only progestin. The IUD is most often prescribed with combination OCP's (oral contraceptive pills) to reduce the size of lesions caused from endometriosis and lessen the amount of bleeding.

Implants: Hormonal implants such as Nexplanon® come in the shape of a tiny tube that is placed under the skin in the upper arm. The implant prevents pregnancy and reduces the size of lesions caused from endometriosis. It is effective for 3 years. The implant is about the size of a toothpick and made of a flexible plastic that contains a type of progestin hormone medicine called etonogestrel.

BENEFITS:

- Progesterone–only hormone therapy can be effective in treating symptoms of endometriosis.
- The Mirena® IUD lasts for 3-10 years
- The IUD plus oral contraceptive pills can lessen bleeding and pain from endo
- The Nexplanon® Implant lasts for 3 years

POSSIBLE SIDE EFFECTS:

- Spotting or breakthrough bleeding can last for a few days until your body gets used to the medicine, or as long as you are taking it.
- Bleeding or a regular period.
- Breast tenderness, nausea, bloating, weight gain, and/or hair thinning.
- Headaches, mood swings including depression, nervousness
- Bone density loss and increased risk of osteoporosis (thinning of your bones) when taken for a long time.
- Some girls may not have relief from their endometriosis pain.

HORMONAL TREATMENT WITH GnRH AGONISTS (GONADOTROPIN RELEASING HORMONE AGONISTS) AND ADD-BACK

The combination of GnRH agonists and hormonal add-back therapy is usually prescribed when other hormonal medicine does not work in relieving endo pain. The goal of GnRH agonists and add-back therapy is to stop the endometriosis from growing and lower the side effects of GnRH therapy alone. Add-back therapy can be a small amount of progesterone, or a combination of estrogen and progesterone.

GnRH agonists work by temporarily turning off your pituitary gland, which stops your ovaries from making estrogen and progesterone (so you won't have a period). Since all of the GnRH agonists lower estrogen levels, the possible side effects for all of the medicines in this group are the same symptoms that women often have during menopause. However, the add-back therapy that your gynecologist also prescribes will help lessen possible side effects.

Leuprolide Acetate (Lupron-Depot®): Leuprolide acetate is one type of GnRH agonist that is given as an intramuscular (in the muscle) injection (shot). It can be given either once a month or once every 3 months. Our GYN team prefers that you get the injection once every 3 months so you don't have to come in for appointments every month. Please make sure that the shot comes in the 3 month form (blue box).

Nafarelin Acetate: Nafarelin acetate (Synarel®) is another type of GnRH agonist that comes in the form of a nasal spray. The recommended dose is one puff in one nostril in the morning, then another puff in the other nostril at nighttime.

BENEFITS:

- ★ Low levels of estrogen cause your period to stop and endometriosis from growing.
- ★ Low levels of estrogen stop endo from growing so your fertility is preserved.

POSSIBLE SIDE EFFECTS:

- Bone density loss and higher risk of osteoporosis (thinning of your bones) when taken without add-back therapy.
- Side effects may include hot flashes, mood swings, vaginal dryness, bone and joint aches, hair loss, lack of interest in sex, and possible short-term memory loss.
- In many cases, teens and women may be able to stay on this treatment longer

than six months as long as their bone density is checked and is normal.

- Some girls may not have relief from their endometriosis pain.

Remember, all medicine affects each person differently. It usually takes about 2–3 months to see an improvement in symptoms and for your body to get used to any new medicine. Side effects will go away soon after the medication is stopped and your menstrual cycle returns. Deciding what treatment is best for you may take some time. Talk to your GYN team about any concerns or questions you might have. In the meantime, you can help your body feel better by eating well and getting exercise and sleeping 8-9 hours every night.

Continuous Hormonal Pills (OCP's) for the Treatment of Endometriosis

Combination hormonal treatment is very effective for treating endometriosis. Hormonal treatment doesn't "cure" endometriosis, but it may help with controlling pain by stopping your periods and preventing endometriosis from getting worse. **Hormonal treatment, also known as "oral contraceptives" or "birth control pills" are used for many reasons other than trying to prevent pregnancy.**

What exactly are hormonal pills?

Hormonal pills contain the hormones estrogen and progestin, which are similar to the hormones that are normally made by the ovaries. There is also another type of pill that contains only one hormone (progestin), and is called either the "progestin-only pill", or the "mini-pill".

Are there different kinds of hormonal pills?

Yes. There are many different hormonal pills that come in a lot of different packages. The shapes and colors of the packages may be different but there are just two categories of pills: **combined estrogen and progesterone pills** (these have both estrogen and progesterone hormone medicine in them), and **progestin-only pills** that contain just progesterone. Hormonal pills come in a 21-day pill pack or a 23, 24, or 28-day pill pack. The most common pill packs are the 21-day pack which contain all hormone pills and the 28-day pack contains 3 weeks of hormone pills and 1 week of inactive (placebo) pills.

How do I know if hormonal pills are right for me?

Not everyone should take hormonal pills. You will be asked questions about your medical history, such as whether you or anyone in your family has a history of blood clots. In addition, you won't be given estrogen pills if you have certain types of migraine headaches. There are different doses of hormones in different hormonal

pills. Your gynecologist may prescribe a progestin–only pill if there is a medical reason why you should not take estrogen. **Please tell the GYN team if you have migraine headaches or a family history of blood clots or strokes.**

Are there other medical benefits of taking hormonal pills?

Yes. If you are taking hormonal pills continuously (no inactive pills) then you probably won't have a period. Hormonal pills also lower your chance of getting endometrial (lining of the uterus) cancer and ovarian cancer, ovarian cysts, certain breast lumps, and may protect you from osteoporosis. Hormonal treatment may also improve acne.

What is the difference between “active” and “inactive” hormonal pills?

Active pills contain hormone medicine. If your pill pack is in the shape of a rectangle, the pills will be in 4 rows (7 pills in each row). The active pills are in the first 3 rows of your pill pack. The inactive pills are in the last row of the 28–day pill pack and DO NOT contain hormone medicine. If your pill pack is round, the pills will be in a circle. The active pills are the first 21 pills and the last 7 pills are the inactive ones, and are usually a different color.

If you are using a **21–day pill pack**, all the pills are active. When you are on continuous hormonal treatment for endometriosis, you will take an “active pill” every day in a continuous pattern.

What does “cyclic” use and “continuous” use mean?

Cyclic use means taking all the pills in the 28–day pack (21 active pills plus 7 inactive pills), then starting the next pack. This method results in periods and is not routinely used for the treatment of endometriosis.

Continuous use means taking active hormone pills every day without a break. If you are using the **28–day pill pack**, you will take 1 active pill a day for 3 weeks (3 complete rows) and then start your next pill pack. You will not take the last row of inactive pills; throw them away. If you are prescribed the **21–day pill pack**, finish the entire pack (3 rows) and then start your next pill pack the next day. Do not skip any days between pill packs. Most likely you will not have a period while you are taking the pill continuously, but some girls may have breakthrough bleeding (spotting).

What are the side effects of hormonal pills?

Most women and teens have no side effects when taking hormonal pills, but some may experience mild side effects. Each type of hormonal pill can affect each woman or teen differently.

Spotting: Breakthrough bleeding between periods may occur while taking the first three weeks of hormone pills, but this is not serious. This usually happens during the first two or three cycles. You should call the GYN team if the bleeding is heavier than a light flow, or lasts more than a few days. **It is very important that you take your hormone pills at exactly the same time to keep your hormone levels in balance.** This will lower the chance of having breakthrough bleeding.

Nausea: You may feel queasy or nauseous at times, but this may go away if you take the Pill with a meal or a snack. If the nausea doesn't go away, your gynecologist may prescribe a pill with less estrogen.

Headaches: Some teens may get mild headaches when they start taking hormonal medicine. Although headaches usually happen because of stress or other reasons, be sure to let your GYN team know if the headaches are severe or if they continue.

Mood Changes: Mood changes or mood swings can happen when taking hormonal treatment. Exercise and a healthy diet may help, but if they don't, you may need to change the type of pill you are taking.

Acne: Usually hormonal treatment helps cure acne, but some teens may get acne from a particular pill.

Weight: Some teens gain weight, some lose weight, but most teens stay exactly the same when they are taking the hormonal treatment.

TIP: *Set your cell phone alarm to remind you to take your pill at exactly the same time every day. If you are even 20 minutes late you may bleed or have pain.*

OTHER SIDE EFFECTS

Your breasts may feel tender or swollen, your appetite may increase, and/or you might feel bloated.

Most often, side effects go away within the first 3 to 4 months of taking the hormonal pill. If the side effects are severe or if they don't go away after three cycles, your gynecologist may switch you to a different hormonal pill or talk to you about other types of hormonal treatments for your endometriosis.

Are there serious side effects I should watch out for while taking the hormonal pill?

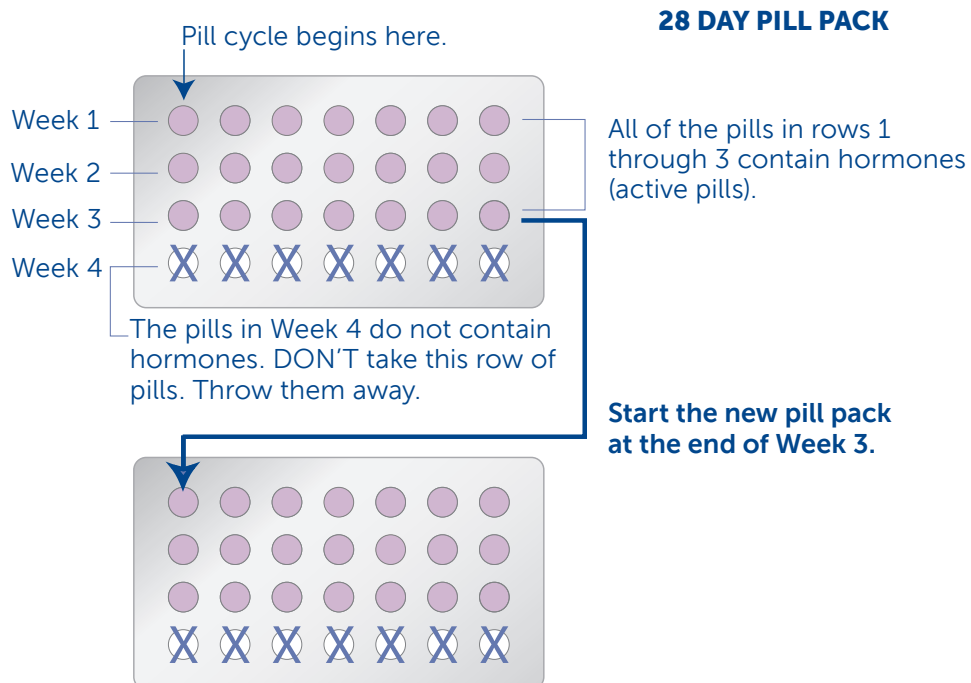
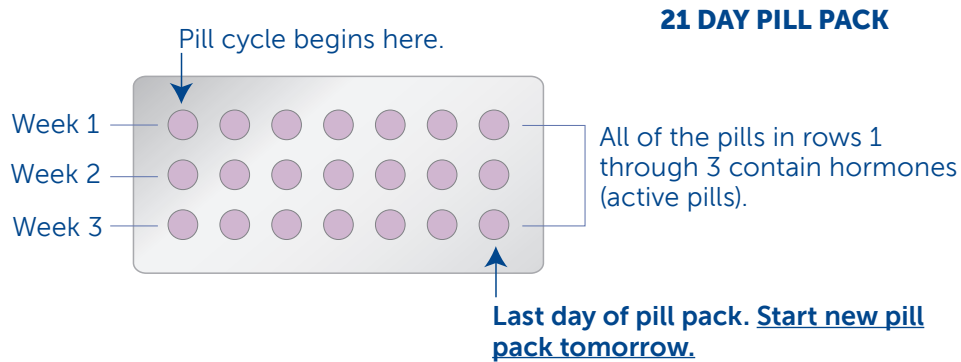
Most young women who take hormonal pills have few or no problems. However, if you have any of the following problems, go to the closest emergency room right away, and call the GYN office at: 617-355-7648.

- **A**bdominal pain (severe)
- **C**hest pain (severe), cough, shortness of breath
- **H**eadache (severe), dizziness, weakness, or numbness
- **E**ye problems (vision loss or blurring), speech problems
- **S**evere leg pain (calf or thigh)

Remember: **ACHES**

How to Take Continuous Oral Contraceptive Pills

Taking the Pill continuously means that you will take one active pill (containing the female hormones estrogen and progesterone) every day without a break. This will help keep the lining of your uterus very thin. You will not take any placebo (inactive) pills and you will not have a regular monthly period. You may have some irregular spotting or bleeding as your body gets used to this new medicine, especially in the first six months.



1. To take the oral contraceptive pill, follow the instructions on the package. The GYN team will also explain how to use your pill pack. You will be told to start taking the oral contraceptive pill on a Sunday, on the first day of your menstrual period, or on the day of your appointment with your gynecologist.
2. You should take 1 oral contraceptive pill at the same time each day until you finish the pack. The best time is ½ an hour after a full meal. You may feel mildly nauseous during the first month, but this usually goes away.
3. **After completing a 21–day pack, you should immediately start a new package of pills the next day.**

Do I need to take the hormonal pills at the same time every day?



Yes. Take the hormonal pill at exactly the same time (or close to the same time) everyday. A good time to take the Pill is at 6, 7, or 8pm every evening. It is not a good idea to take the Pill “when you wake up” or “before going to sleep”, as those times will vary on school nights and weekends.

What if I forget to take one or more hormonal pills?

- **If you miss 1 or 2 active (hormone) pills in a row**, take the pill(s) as soon as possible and then continue taking 1 pill each day. You may take 2 pills on the same day (*one at the moment you remember and the other at the regular time*) or even 2 at the same time.

Many teens find creative ways to remember to take the Pill such as writing a reminder on a calendar, or setting an alarm on their cell phone. Try to think of a special way to remember to take your pill.

- **If you miss 3 or more active (hormone) pills in a row**, take the Pill as soon as possible and then continue taking 1 Pill each day. If you missed the pills in the third week, finish all the active hormone pills in your current pack, and then start a new pack of pills.
- **If you are sexually active and missed 3 pills**, use condoms or do not have sex until you have taken active (hormone) pills for 7 days in a row.
- **If you are sexually active and have missed more than 2 pills**, talk to the GYN team about whether you should use emergency contraception.

- **Note:** If you are taking very low dose pills with just 20ug of ethinyl estradiol and miss 2 pills, you should **follow the instructions for missing 3 or more pills.**

You may have breakthrough bleeding (spotting) if you forget to take your pill on time; some women are so sensitive that they will bleed if they take their pill just 30 minutes late. If you miss pills you may get an extra menstrual period.

What if I'm not happy with the hormonal pills that I'm taking?

If you are not happy with the hormonal pills that you are taking and the effects they have on your body, talk to your GYN team. Don't just give up and stop taking the pills. Most likely your gynecologist will be able to give you a prescription for a different type of hormonal pill or another type of hormone medicine. There are many types of hormonal pills and they affect people differently. You may like some, but not others. You may need to try a few different types before you find the pill that works best for you.

*Hormonal pills can be an effective treatment for endometriosis. Ask questions before you decide to take the Pill and **if you have side effects, call the GYN team.***

Frequently Asked Questions (FAQs) about the Oral Contraceptive Pill and Endometriosis

Do I need a pelvic exam before going on the oral contraceptive pill?

No. Although it is important for teens to have checkups as part of their general health care, a pelvic exam is not needed for girls with endometriosis in order to start oral contraceptive pills.

Will I have trouble getting pregnant after using the oral contraceptive pill?

There is no change in fertility with the use of the oral contraceptive pill. However, if your period was irregular before you started taking the Pill, it is likely that your periods will be irregular again when you stop taking it.

Does the oral contraceptive pill cause birth defects?

No. The Pill does not cause birth defects nor does it affect the health of future children.

Does the oral contraceptive pill cause cancer?

No. The Pill actually protects against cancer of the ovaries and cancer of the lining of the uterus. A woman is half as likely to get cancer of the uterus or ovaries if she takes the Pill. Most experts believe that taking oral contraceptive pills does not cause any increased risk of developing breast cancer. Even girls with a family history of breast cancer can take the Pill.

How long can I be on oral contraceptives?

It is safe for you to be on the Pill for years, whether to regulate your menstrual cycle, treat your cramps, as hormone replacement, or birth control. It is important to be on hormonal treatment for endometriosis until you are ready to become pregnant, so that the disease does not progress.

Do I need to take a break from the Pill?

There is no medical reason that you need to take a “break” from the Pill.

Where does the blood go?

When you are on the Pill continuously, the lining of your uterus does not build up. Therefore, you don't get your period and there is no blood. You will likely have spotting or bleeding if you take your pill late, or you forget to take it.

Can I smoke if I'm taking the Pill?

It is NOT safe for you to smoke and take oral contraceptives. Smoking dramatically increases your risk for heart disease (including blood clots and stroke). The more you smoke, the higher the risk.

What if I am also using the oral contraceptive pill for birth control?

If you are also taking the oral contraceptive pill for birth control, you should know that oral contraceptive pills do not protect you from sexually transmitted diseases. Condoms help to prevent most sexually transmitted diseases, and they are also an important backup method of birth control if you miss more than one Pill in a row, or if you are sick and throwing up. All of these factors can lower the effectiveness of the Pill. Whenever you get a new medication, ask if it changes the effectiveness of your oral contraceptive pill.

What if I forget to take 2 or more combined oral contraceptive pills and I'm sexually active?

If you have had intercourse during the time you missed your pills (and you don't use condoms), talk to your GYN team about whether you should use emergency contraception. If you are 15 or older, you can buy “Plan B” without a prescription. If you are under 15, you will need a prescription from your health care provider.

How do I talk to my parents about taking the Pill?

If you are taking hormonal pills for the treatment of endometriosis, your parents may have some worries about you taking a pill that is also called the “birth control pill”. It’s best to talk openly with them about how the Pill will stop your periods and help lower your pelvic pain and other discomforts you may have. If your parents have concerns, have them read our health guide “Oral Contraceptive Pills and Teens: A Guide for Parents”. You can find it online at youngwomenshealth.org.

How do I talk to my friends about taking the Pill?

You may not want to tell your friends that you are taking hormonal pills for the treatment of endometriosis. Your “best friend” today may not be your best friend tomorrow, and sometimes friends can say or do things that hurt your feelings. Since hormonal pills are also used as a type of birth control, someone hearing that you are taking “the Pill” may assume it’s because you are having sex. When it comes down to it, you really don’t have to tell anyone except your GYN team about your medical treatment. Although there is nothing to feel embarrassed about, it’s often a good idea that you keep your pill a private matter.

The Pill does much more than prevent pregnancy. Adolescent girls and young women are frequently prescribed the oral contraceptive pill just for its medical benefits. It is a very safe and effective treatment for many types of medical problems besides endometriosis including; irregular menstrual periods, menstrual cramps, acne, and PMS.

Progesterone–Only Hormonal Therapy for the Treatment of Endometriosis

If you are unable to take estrogen or if you do not respond to combination (estrogen and progesterone) pills, your gynecologist may prescribe either Norethindrone acetate (Aygestin®, Nor-QD®, or Camilla®) or Medroxyprogesterone acetate (Depo-Provera®), different kinds of progesterone–only hormone medicine. These medicines stop your body from ovulating and your endometriosis from growing. Most teens will not have a period. Taking synthetic (man–made) progesterone medication in this form is very similar to the natural progesterone that is made by your body during pregnancy.

Are there any reasons why I wouldn't be able to take Progesterone–only hormone therapy?

Tell the GYN team if you have epilepsy (seizures), migraines, asthma, heart, or kidney problems. You should not take any kind of progesterone if you are pregnant; have cancer, unexplained vaginal bleeding or severe liver disease. You should also tell the team if you have diabetes, high blood pressure, high cholesterol or you have been diagnosed with depression in the past.

What are the side effects?

Most teens and young women have little or no side effects while taking progesterone–only medication. Possible side effects can include breakthrough bleeding or spotting, changes in weight, acne, breast enlargement, feeling bloated, headache/migraines, nausea or vomiting, and possible decrease in bone density (thinning of the bones).

Hormone medications can affect people differently. Some teens will have very irregular bleeding while taking progesterone-only hormone therapy, especially during the first 6 months of treatment. Breakthrough bleeding is less common the longer you are on hormonal therapy.

How is Norethindrone acetate taken?

Norethindrone acetate is a pill that you swallow.

Starting Aygestin®: Take 1-2 (5mg) tablet at the same time every day as prescribed by your health care provider. At Boston Children's Hospital, we currently recommend that you do not take more than 10mg of Aygestin®/day.

How is Nor-QD® or Camilla® taken?

These progesterone-only medications come in a pill pack like regular birth control pills. There are 28 active hormone pills in each pack.

How is Medroxyprogesterone acetate given?

Medroxyprogesterone acetate (Depo-Provera®) is an injection that is given in a muscle (in the buttocks, arm or thigh) every 3 months. The first shot is usually given within the first 5 days of your menstrual cycle (during your period). If you are sexually active, a routine urine pregnancy test will be done first. **The next shot needs to be scheduled within 11–13 weeks.**

In addition to being as effective as other hormone therapies that treat endometriosis, both medications protect against pregnancy but NOT sexually transmitted infections (STIs). Always use condoms if you are sexually active.

Leuprolide Acetate with Add–Back

Leuprolide acetate (Lupron Depot®) is a type of gonadotropin–releasing hormone agonist (GnRH agonist) medicine. GnRH agonist medications help to lower pelvic pain caused by endometriosis. Add–back therapy is the addition of a small amount of the hormones estrogen and progesterone or progesterone alone. ***You must take add–back therapy if you are prescribed Leuprolide acetate (see below).***

How does Leuprolide acetate work?

This medication works by shutting off hormones made by your ovaries, so your estrogen (one of the hormones that cause your body to have periods) level is lowered. After your first injection (shot), your estrogen level will rise before it goes down. This is called an “estrogen surge”. Because of this rise in estrogen, you may have an increase in your symptoms for a few weeks. After the estrogen surge, your estrogen levels will go down. This temporarily stops your period. When you do not have periods, endometriosis symptoms are usually relieved.

How is Leuprolide acetate given?

Leuprolide acetate is an injection. It is very important to get your injection on time. Missed doses can cause breakthrough bleeding and the return of pain.

How long can I take Leuprolide acetate with add–back ?

Leuprolide acetate alone is usually prescribed for 6 months (1 shot every 3 months). However, when you take it with add–back, you can almost always stay on it longer. After a few months of treatment you will have an appointment with your gynecologist to see if the medicine is helping you. This appointment also gives your doctor a chance to ask you about your pelvic pain and any other symptoms you may be having. If your symptoms are better, he may suggest that you continue taking the medicine.

What are the side effects of taking Leuprolide acetate?

Taking Leuprolide acetate alone lowers the estrogen level in the body, which typically causes side effects similar to menopause. These side effects may include: hot flashes, vaginal dryness, decreased interest in sex, moodiness, headaches, spotting, and change in bone density. **However, with the addition of “add-back” therapy, you will most likely NOT experience these side effects. If you do have symptoms, they are generally mild.**

After the second month of treatment, your period will likely stop. However, you may have a light period or spotting during treatment. It is important to get your injections on time and to stop treatment when recommended.

What is “Add-back” therapy?

Add-back is a pill that contains a small amount of estrogen and progesterone, or progesterone-only that is taken every day. Since hormones are important to keep your bones healthy, low levels of hormones can lower your bone density putting you at risk for osteoporosis (thinning of your bones). The goal of add-back therapy is to give your body back just enough hormone(s) to protect your bones and control any unwanted side effects such as hot flashes and vaginal dryness that are common when taking Leuprolide acetate alone. Your gynecologist will decide on how much add-back medicine you will need, and give you a prescription. Add-back is either: Aygestin® 5mg/daily, or Prempro® 0.625/2.5mg/daily.

When do the effects of Leuprolide acetate go away?

The effects of Leuprolide acetate will decrease after you stop taking the medicine. If you've been getting Lupron® every 3 months, your period will return within 4 to 8 months after your last shot. If you've been getting Lupron Depot® every month, your period will likely return 6–8 weeks after your last shot. Bone density loss may be partially or completely recovered. This means that your bones may or may not be as solid as they were before you started the medicine.

Can I take Leuprolide acetate forever?

Research has shown that long term use of Leuprolide acetate alone can cause bone density loss. Bone density loss is a big concern especially if you have a family history of osteoporosis. Osteoporosis causes your bones to become fragile and break more

easily. “Add–back” therapy can help prevent loss of bone density, which may allow you to stay on the medicine longer.

What is bone density?

Bone density is a measurement of how solid and strong your bones are. Bones need to be strong and solid so they do not break easily. Your teenage and young adult years are important for bone development. Weak bones during the teenage years may negatively impact your bone health later in life. Your bones need lots of nutrients, especially calcium and vitamin D. It is also important to eat a well–balanced diet and include foods high in calcium. See page 43 for more information about calcium.

When will I be scheduled for a bone density test?

After you have been on Leuprolide acetate for approximately 8 months, your gynecologist will order a DXA test. This is a simple test that measures how dense (or thick) your bones are and if your bones are thinning. If the DXA scan is normal and you continue on the medicine, you will need to repeat the DXA test every 2 years. See page 49 for more information about the DXA scan.

What can I do to prevent bone loss?

You will likely be told to take calcium supplements. Calcium works closely with vitamin D and magnesium to build and maintain bone density. If you take a calcium supplement, make sure it includes vitamin D and magnesium.

Can I get pregnant when I am on Leuprolide acetate?

Although this medication works by preventing ovulation (stops you from making eggs), there is a rare chance that you could become pregnant if you have unprotected sex. Thus, it is important to use a **non–hormonal birth control method** such as condoms while on this medication. The long term effects to an unborn baby whose mother was on Leuprolide acetate at the time of conception are unknown at this time, but it does not appear to cause birth defects.

Remember, all medication affects people differently. If you have side effects, talk with your GYN team. It usually takes 2–3 menstrual cycles to see an improvement in symptoms and for your body to get used to the medicine. In the meantime, you can help your body feel better by eating well and getting plenty of rest and exercise.

Leuprolide Acetate

Instructions

If your gynecologist has prescribed Leuprolide acetate (Lupron Depot®) to treat your endometriosis, please read the following important information.

- **Leuprolide acetate** (3 month formulation) is an injection (shot) that is given in the buttocks, arm or thigh every 3 months (12 weeks). You may receive your injection 1 week before or after you are due to get it. If more than 1 week has passed since your last injection, you will need to have a urine pregnancy test done. If it is negative, schedule an appointment to get your next injection in 10 days.
- **Depending on your health insurance coverage**, you may be required to order your medicine by mail. You will then need to bring it (and the box it came in) with you to our office. The GYN nurse will give you the injection.
- **Add-back therapy** is Norethindrone acetate (Aygestin®) or Medroxyprogesterone acetate (Prempro®). **It must be taken at the same time each day.**
- **Oral contraceptive pills:** If you are on oral contraceptive pills, continue the Pill for 3 weeks after your first injection. On the day you stop the Pill you will begin taking the add-back medication.
- **Calcium supplements:** While on Leuprolide acetate, it is important that you take a calcium supplement, as your body needs 1300 mg of calcium every day. Eating and drinking foods that are high in calcium is also important. See page 43 for more information about calcium.
- **Vitamin D:** It is recommended that teens take 10 mcg or 400 IU's of vitamin D every day. Vitamin D is a pill that can be taken with calcium.
- **Your first period on Leuprolide acetate:** Please be aware that you may have a heavy and painful period during the first 4–6 weeks after your first Lupron Depot® shot. After that, you will probably not have anymore vaginal bleeding as long as you **take the add-back therapy at the same time each day.**

- **In the event your Leuprolide acetate is given by a health care provider outside of our office:** If you received your last injection by a health care provider outside of our GYN practice, you must provide documentation of the date of the injection and who gave it to you—either via a letter or fax from the health care provider’s office. Our fax number is: 617–730–0186.
- **Appointments to get your follow–up injection:** Make sure you make your appointment on a day that your gynecologist sees patients.
- **6 month follow–up visit:** After 6–8 months on Leuprolide acetate and add–back, you and your gynecologist will talk about whether or not you can continue on the medicine. If you do continue, you will be scheduled for a DXA Scan.
- **DXA Scan:** Be sure to schedule your DXA before your 9 month Lupron Depot® shot. Your gynecologist will need to review the results before you can have your next shot. A follow–up DXA will be done every 1–2 years as needed. See page 49 for more information about the DXA scan.
- **Improvement in pain:** It usually takes about 2–3 months to see an improvement in symptoms (while on Leuprolide acetate and add–back therapy).
- **Questions & Concerns:** If you have any concerns about your treatment, please call the Gynecology Nurse at: 617–355–7708 or schedule a follow–up appointment with your gynecologist by calling: 617–355–7648.

Calcium and Teens

Calcium is a mineral that gives strength to your bones. Calcium is also necessary for many of your body's functions, such as blood clotting and nerve and muscle function. During the teenage years (particularly ages 11–15), your bones are developing quickly and are storing calcium so that your skeleton will be strong later in life. Nearly half of all bone is formed during these years. It's important that you get plenty of calcium in your diet because if the rest of the body doesn't get the calcium it needs, it takes calcium from the only source that it has: your bones. This can lead to brittle bones later in life and broken bones at any time. Unfortunately, only 12% of teen girls actually get enough calcium in their diet.

What is osteoporosis?

Osteoporosis is a bone disease that develops slowly and is usually caused by a combination of genetics and too little calcium in the diet. Osteoporosis is a disease in which bones become fragile and more likely to break. Osteoporosis can also lead to shortened height because of collapsing spinal bones and can cause a hunched back.

How do I know if I'm at risk?

Several factors can put a young person at risk for developing osteoporosis.

They include:

- Being white
- Being female
- Having irregular periods
- Doing little or no exercise
- Not getting enough calcium in your diet
- Being below a normal weight
- Having a family history of osteoporosis
- Smoking
- Drinking large amounts of alcohol

Osteoporosis can be prevented. There are some risk factors that you cannot change (such as your race and the fact that you're female), but there are some you can! Eat a healthy diet, get some exercise, and don't smoke!

How much calcium do I need?

Children and teenagers between the ages of 9 and 18 should aim for 1,300 milligrams per day, which is about 4 servings of high-calcium food or drinks. Each 8-ounce glass of milk (whether skim, 1%, 2%, or whole) and each cup of yogurt has about 300 milligrams of calcium. Adults 19 to 50 years of age should aim for 1,000 milligrams per day.

How do I know how much calcium is in the foods I eat?

For foods that contain calcium and have a nutrition facts label, there will be a % Daily Value (DV) listed next to the word calcium. To figure out how many milligrams of calcium a serving of food has, take the % DV, drop the % sign, and add a zero. Can you use the label to find out how much calcium is in one cup of skim milk? 30% means there is about 300mg of calcium per serving. The table on page 47 shows how much calcium is in some calcium-rich foods from different food groups.

What foods contain calcium?

You probably know that dairy foods such as milk and cheese are good sources of calcium, but do you know that tofu and beans contain calcium, too? Even if you don't drink milk or eat cheese, you can get the calcium you need from other foods. See the list of high-calcium foods at the end of this guide.

What if I'm lactose intolerant?

If you are lactose intolerant and can't drink milk, there are plenty of other ways to get enough calcium. These include eating foods high in calcium and drinking fortified soy milk, fortified juice, or Lactaid milk (the lactase enzyme that you are missing has been added into the milk). You may also take lactase enzyme tablets before eating dairy products to help digest the lactose sugar in the milk. Some people who are lactose intolerant can tolerate having small amounts of milk or other dairy products at a time.

How can I get more calcium in my diet?

Here are some ideas for how you can get more calcium in your breakfast, lunch, dinner, and snacks:

BREAKFAST:

- Have a bowl of cereal with milk.
- Use milk instead of water when making oatmeal.
- Drink calcium–fortified orange juice.
- Make a healthy breakfast smoothie with a cup of milk or yogurt and a handful of frozen fruit.
- Add a slice of cheese to your bagel or English muffin. Most cheeses, except for cream cheese, are high in calcium.

LUNCH:

- Choose milk instead of soda at school. If you don't like plain milk, try chocolate or strawberry milk.
- Pack a yogurt with your lunch.
- Add cheese to your sandwich.

SNACKS:

- If you like coffee–flavored drinks, try a milk–rich latte (decaf is best).
- Look for cereal bars or energy bars that contain calcium. Check the label to see if calcium is listed.
- Make hot cocoa with milk instead of water.
- Eat broccoli dipped in a veggie dip made with plain yogurt.
- Snack on cheese sticks or almonds.
- Have a yogurt or pudding as an after–school snack.

DINNER:

- Have macaroni and cheese made with milk, or chowder–style soups.
- Prepare canned tomato soup with milk instead of water.
- Add tofu or edamame to stir fries or soups.
- Include more beans (legumes) in your meals.
- Make lasagna or other pasta dishes with ricotta cheese.
- Eat thin–crust pizza with vegetables.
- Have pudding made with milk or frozen yogurt for dessert.

What if I just can't get enough calcium in my diet?

It's best to try to meet your calcium needs by having calcium–rich foods and drinks, but some teens find it hard to fit in 4 servings of high–calcium foods daily. If you don't like dairy foods or calcium fortified juice or soymilk, you may need a calcium supplement. Calcium carbonate (for example, Tums® or Viactiv®) and calcium citrate (for example, Citracal®) are good choices. When choosing a supplement, keep the following things in mind:

- Most calcium supplements have between 200 and 500 milligrams of calcium. Remember, your goal is 1,300 milligrams of per day.
- If you have to take more than one supplement per day, it's best to take them at different times of the day because your body can only absorb about 500 milligrams of calcium at a time.
- Don't count on getting all of your calcium from a multivitamin. Most basic multivitamin/mineral tablets have very little calcium in them.
- Look for a calcium supplement that has vitamin D added. Vitamin D helps your body absorb calcium.
- Avoid "oyster shell" or "natural source" calcium supplements. These may have lead or aluminum in them and are not recommended.
- Know that your dietitian or health care provider will be able to support you with recommendations on what supplement will best suit your needs.

| FOOD | SERVING | MILLIGRAMS OF CALCIUM |
|--------------------------------|-------------------|------------------------------|
| Dairy Products | | |
| Yogurt, low-fat | 1 cup | 338–448 |
| Ricotta cheese, part-skim | ½ cup | 335 |
| Milk (skim) | 1 cup | 299 |
| Fortified soy and rice milks | 1 cup | 301 |
| Milk (1%) | 1 cup | 305 |
| Milk (whole) | 1 cup | 276 |
| Ricotta cheese, whole | ½ cup | 255 |
| Swiss cheese | 1 ounce | 224 |
| Mozzarella cheese, part skim | 1 ounce | 222 |
| Cheddar cheese | 1 ounce | 204 |
| Muenster cheese | 1 ounce | 203 |
| American cheese | 1 ounce | 296 |
| Frozen yogurt | ½ cup | 103 |
| Ice cream | ½ cup | 84 |
| Pudding | 4 ounce container | 55 |
| Protein Foods | | |
| Canned sardines (with bones) | 3 ounces | 325 |
| Soybeans, cooked | 1 cup | 261 |
| Canned salmon (with bones) | 3 ounces | 212 |
| Nasoya Tofu Plus®, firm | 3 ounces | 201 |
| Kidney beans, canned | ½ cup | 44 |
| White beans, cooked | ½ cup | 80 |
| Crab, canned | 3 ounces | 90 |
| Clams, canned and drained | 3 ounces | 55 |
| Almonds | 1 oz (24 nuts) | 76 |
| Sesame seeds | 1 tablespoon | 88 |
| Vegetables | | |
| Collard greens, cooked | ½ cup | 134 |
| Spinach, cooked | ½ cup | 122 |
| Kale, cooked | ½ cup | 47 |
| Broccoli, cooked | ½ cup | 31 |
| Fruits | | |
| Calcium-fortified orange juice | 1 cup | 349 |
| Rhubarb, cooked | 1/2 cup | 174 |
| Dried figs | 1/3 cup | 72 |
| Orange | 1 | 66 |
| Cereals and Bars | | |
| Total Raisin Bran® Cereal | ½ cup | 500 |
| Cream of Wheat® Cereal | 1 cup | 303 |
| Basic 4® Cereal | 1 cup | 250 |
| Kix® Cereal | 1 ¼ cup | 171 |
| Luna® Bar | 1 bar | 425 |

U.S. Department of Agriculture, Agricultural Research Service. 2013. USDA National Nutrient Database for Standard Reference, Release 26.

DXA Scan

What is DXA scan?

DXA stands for “Dual–energy X–ray Absorptiometry”. It is the most widely used method to measure bone density–how dense or thick your bones are and if your bones are thinning. If you have been on Leuprolide acetate and add–back for 6–8 months and your pain has improved, your gynecologist may talk to you about continuing the medicine at your 6 month follow–up visit. You will then be scheduled for a DXA scan to check your bone density. The scan should be scheduled before your next Lupron Depot® shot is due.

Does a DXA scan hurt?

The test doesn’t hurt. There are no injections or medications to take. The machine is open and each scan takes about 5–10 minutes.

How should I prepare for the DXA scan?

- **Appointments should be scheduled at least 10–14 days after having any procedures that involve contrast materials** (for example a CT Scan with contrast dye).
- **You can eat normally, but you shouldn’t take calcium supplements, vitamins, or TUMS® the morning of the scan.**
- **Don’t wear clothes with metal buttons, snaps or zippers** as metal interferes with this test.
- **Remove jewelry and piercings.**

What happens when I get to my appointment?

The technician will ask you questions about your medical history and explain the procedure. You may need to pee into a cup, as a routine pregnancy test is done in most hospitals on all patients, but if it’s not, make sure to tell the technician performing the test if there’s a chance you’re pregnant. A machine shaped like an upside down “L” will slowly move back and forth over your stomach area to measure the bone density of your spine and hips, but will not touch your body. You will be asked to stay still and not talk during the entire scan, but you can breathe normally.

You should ask questions if you don't understand what's going on.

What happens during the DXA scan?

The technologist will help you onto the table where you will be asked to lie on your back with a pillow under your knees, and your arms by your side. Sometimes you may be asked to lie on your side or another position. A machine shaped like an upside down "L" will slowly move back and forth over your stomach area to measure the bone density of your spine and hip (the arm of the machine is about 12 inches away from your body as it scans). You will be asked to stay still and not talk during the entire scan. You should breathe normally.

Should I be concerned about the amount of radiation I will receive?

No. The amount of radiation is much lower than that of an x-ray. It is even less than the amount of radiation that you would be exposed to if you took an international flight.

When will I get the results of my DXA?

- You will not get the results on the same day as your DXA.
- The DXA scans must be carefully reviewed by the technologist and a doctor who specializes in bone health. This can take up to 2 weeks.
- The results will be sent to your gynecologist and he/she will review them with you in about 2 weeks over the phone, or at your next appointment.
- A follow-up DXA scan will be done every 1–2 years as needed.

Coping with Endometriosis Pain

If you are reading this guide, you probably already know about the challenges of living with the chronic pain of endometriosis. Even though everyone experiences pain differently, it can be helpful to think of your pain in two ways: the physical pain you have, and **how your pain impacts your life**.

Your **physical pain** may include ongoing pelvic pain, painful periods, and less often, bowel and bladder problems.

How your pain impacts your life may include challenges such as: isolation from friends due to unexpected bouts of physical pain, not being able to participate in sports or other activities (because of chronic pain and/or fatigue), and anxiety over school work because of absences. Also, your pain can take a toll on those who care about you, such as significant others and family members. This can cause added tension and stress. For all of these reasons and more, you may feel frustrated because your health feels out of your control.

Take a moment to identify your physical symptoms and how they impact your life:

MY PHYSICAL PAIN SYMPTOMS:

WAYS MY PAIN IMPACTS MY LIFE:

STRESS-RELIEVING TECHNIQUES

Learning to manage the stress in your life is important under any circumstances but it is essential when you are living with chronic pain. Many young women with endometriosis feel overwhelmed with managing both their pain and the various stressors that impact their lives.

Here are some examples of ways to manage the stress of chronic pain:

- Exercise
- Sleep 8–9 hours each night
- Take naps when you need them
- Meditate daily
- Eat 3 healthy meals a day with nutritious snacks in between
- Do things you enjoy when you feel well
- Stay in touch with your friends in person, by phone, or online
- Keep up with your schoolwork (so you don't feel overwhelmed or get behind)
- Practice yoga
- Learn when to push yourself and when not to
- Keep to routines as much as possible
- Plan ahead with your parents/caregivers for unexpected "flair-ups" of pain
- Talk to a counselor

What have you tried so far?

Check off the techniques that you have already tried.

Write down some things you would be willing to try in the future:

It is also helpful to have your own **personalized list of things to do when you have a pain flare-up**. Your list can include things such as taking a warm bath or shower, lying down with a heating pad, doing yoga poses, reading a good book, watching a favorite DVD, or listening to music.

Write your list below:

MANAGING YOUR PELVIC PAIN AT SCHOOL

Does your endometriosis pain get in the way with your plans to attend school or your ability to stay for a full day? Does your academic performance and grades sometime suffer due to absences, missed assignments or difficulty keeping focused? Perhaps you've also experienced tension with your family, and/or teachers due to poor school attendance and performance issues. Dealing with pelvic pain in a school setting can be very stressful, particularly if your teachers and school nurse are not aware of the pain you have to cope with most days.

Below are tips to help you manage the realities of being a student with chronic pelvic pain. Notice that all of the tips depend on BEING PREPARED.

- **Know your pain tolerance threshold:** Your pain will likely be mild some days, but other days it may be severe. Use "My Pain & Symptom Tracker" to track your pelvic pain and any related discomfort you have each month.
- **Talk with your parent(s) or guardian(s)** about what you can tolerate in school and what you cannot manage. This is best done at a pain-free time when you are calm and are thinking clearly.

- **Communicate with your close friends** about what it's like to have endometriosis, so they can understand why you sometimes miss school or activities, and be supportive.
- **Identify an adult contact person at school:** For example; you can ask a school nurse, favorite teacher or class aide to be your "point person" who you can go to for support. Choose someone with whom you feel comfortable sharing your endometriosis history, and who can help and be supportive while you are at school.
- **Share information about endometriosis** from *youngwomenshealth.org* with your contact person, teachers, school nurse, coaches, and friends. Those around you are likely to be more understanding and supportive if they know what endometriosis is, and how it impacts your life.
- **Make a plan for pain at school:** Talk with your school nurse and find out if there is a place at school where you can lie down if you are in pain. Listening to relaxing music may also help.
- **Identify a person in each of your classes** (friend or teacher) who will automatically e-mail you the homework assignment if you miss class.
- **Give yourself enough time in the morning to get ready for school.** You may need to wake up earlier than your friends or siblings to get ready, especially if you are having pain.
- **Do not assume that every day you wake up with pain means that you have to stay home from school or that the day is "lost to pain".** Try to go to school every day even if you have some pain in the morning: chances are that your pain will get better or go away once you get moving and you are distracted. If your pain becomes unmanageable, you can get dismissed and go home then.
- **Maintain a healthy lifestyle:** Eat nutritious meals and healthy snacks and get at least 8–9 hours of sleep every night. Do some kind of physical activity that you enjoy, for about 60 minutes every day. Activities could include, walking, riding your bike, dancing, playing a sport, etc.
- **Try not to fall behind in your schoolwork.** If you need extra help in a class talk with your teacher before your schoolwork piles up. If you have to be absent from school for more than a week, find out about having a home tutor.
- **Keep in touch with your friends:** Even when you are absent, talk to at least one of your friends every day either on the phone, via text messages, e-mail, or on a social networking site. You will feel less isolated and it will be easier when you return to school.

- **Be proactive:** Use the worksheet to make a list of things you can do to personally manage your pelvic pain at school.

In the space below, write down the ways you feel your endometriosis has affected your school life.

Now, make a list of the things you will try to do to improve the way you manage your pain at school. Be sure to include strategies that have worked.

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

Congratulations! You have taken a big step towards managing your endometriosis!

MANAGING ACTIVITIES, FRIENDSHIPS, AND CHRONIC PAIN

Living with chronic pain can impact all areas of a person's life, even those areas that are typically fun and enjoyable. Having pain from endometriosis can sometimes get in the way of being able to do things with your friends both on a daily basis and for

special events. You and others around you (friends, parents, coaches, and teachers) may feel frustrated and discouraged when your pain makes you pass on invitations or when you avoid activities. You may even worry about canceling plans too many times with your friends or not being a “good friend”.

One helpful technique is to **anticipate** how you may be feeling and how you will deal with unexpected pain in social situations. Here are some thoughts and advice from girls with endometriosis who try to rule the pain, not let the pain rule their lives:

- **Be in touch with at least one person outside of your family every day.**
- **Organize activities that can be held at your house** (such as craft parties, reading groups, board–game marathons, watching movies) if it is more comfortable to be home.
- **Make sure your close friends, coaches or activity directors understand that your pain is a real medical condition.** Educate them with information about endometriosis from *youngwomenshealth.org*.
- **Is there an activity you really want to do but are scared about fulfilling the requirements or keeping the commitment?** Many group activities require a wide variety of participants in many roles. Explore the options with the group leader, explaining that you want to be involved in a way that you can handle.
- **Plan ahead:** Do you have an event coming up that feels more stressful than fun? Go back to your personalized list of things you can do in anticipation of pain.
- **If you do have to cancel with friends or family,** or you realize you cannot participate in an activity as planned, try to take it in stride: explain promptly, offer alternative options, and take care of yourself. Your friends, family, and others will respect you more for being honest rather than not showing up without an explanation.

Below, make a list of things that you love to do, and try to do one thing each day!

COMPLIMENTARY AND ALTERNATIVE TREATMENT FOR PAIN MANAGEMENT

Some young women are helped by surgery, some by medication, and some with a combination of both. Many young women find that adding **alternative or complimentary** treatments to traditional treatment helps them manage their pelvic pain more effectively.

Yoga involves a series of poses and gentle stretches. There are many different kinds of yoga. You can explore yoga classes at your YMCA, health center and yoga studios. Many girls find it helpful to take yoga classes. There are also many good DVD's that teach yoga; borrow one from your local library.

Acupuncture is an Eastern Asian Medicine that involves the insertion of very fine needles into "acupuncture points" in the body. This is thought to stimulate the body's nervous system to release certain chemicals in the muscles, spinal cord, and brain, which in turn release other chemicals and hormones in the body that may help to improve pain and other discomforts. Acupuncture may be covered by your health insurance.

Massage is another complimentary practice which some girls with pelvic pain find helpful. There are several kinds of massage therapies available. Often massage treatments are combined with gentle heat.

Learning how to cope with your pelvic pain can feel like an overwhelming task at first. However, the more strategies and techniques you learn, the easier it will become. Having the support of important people in your life will also help you manage your pain. When you learn how to rule your pain, rather than allowing it to rule you, you will have the confidence to live your life to its fullest potential.

Pain Treatment Service at Boston Children's Hospital

Chronic pain associated with endometriosis can affect all aspects of a young woman's life, including her appetite, sleep, ability to concentrate, school work, and social life. When a young woman suffers from chronic pelvic pain and other symptoms, it is a challenge which affects the entire family. Due to the complexity of the problem, a multidisciplinary approach is needed to successfully treat most chronic pain.

The Pain Treatment Service is a multidisciplinary outpatient clinic that is dedicated to helping children, teens and young adults to manage their chronic pain. The Pain Treatment Service combines traditional and contemporary interventions to reduce pain, build coping skills, and improve functioning.

The Pain Treatment Staff includes anesthesiologists, neurologists, psychologists, pediatricians, pain medicine physicians, physical therapists, nurses, and administrative staff. The staff is affiliated with Boston Children's Hospital and Harvard Medical School. For an appointment and more information about the Pain Treatment Service, contact:

Tel.: 617-355-7040

Fax: 617-730-0199

The Pain Clinic is located at: 333 Longwood Avenue, 5th floor, Boston, MA 02115

YOUR FIRST VISIT TO THE CLINIC:

Each new patient is seen in the clinic for an initial evaluation. The clinics are held Monday-Friday. Every patient is evaluated by a doctor, physical therapist, and a psychologist. After each clinician meets with you, they talk together and then make a Pain Management Plan that is designed just for you. You and your family will be involved with this plan. **This evaluation is comprehensive and takes about 2-3 hours.**

PAIN MANAGEMENT PLANS

Each plan is uniquely tailored for each patient. Management plans usually include a combination of:

- Medication
- Psychotherapy
- Physical therapy
- Biofeedback
- Acupuncture
- School interventions
- Physical conditioning
- Regulation of diet and sleep
- Regulation of environmental and stress triggers

* Your pain management plan is either provided through the clinic, or you may be referred to specialists closer to your home. Regular follow-up visits with the doctor will be scheduled to monitor your progress. Your plan, including the type of recommended therapy, will be adjusted as necessary.

Things you will need for your first appointment:

- Referrals for each of the disciplines, if insurance requires pre-authorization
- Psychology Parent and Child forms which are e-mailed to you before your first appointment
- Insurance co-pay for each discipline

*If you have any questions, please call the Pain Treatment Service (Clinic) at:
617-355-7040*

Endometriosis, Nutrition, and Exercise

Is there a special diet for girls with endometriosis?

The good news is that we know that some foods can boost our immune system, which in turn protects our bodies from some illnesses and diseases. Unfortunately, there has been very little research done to figure out if eating certain foods can help improve endometriosis symptoms. Some young women with endometriosis say they feel better when they eat a nutritious diet and some experts believe that eating certain foods can help endometriosis symptoms by reducing inflammation and estrogen levels in the body.

Experts recommend eating plenty of fiber, fewer saturated fats, and more omega-3 fats for overall health. These are healthy changes to make even if they don't improve your endometriosis symptoms.

Consider making changes that can improve your overall health:

- **Eat a high fiber diet that** includes plenty of fruits, vegetables, beans, whole grains, and nuts
- **Limit saturated fat** by eating mostly plant-based foods, choosing low-fat dairy products, and selecting lean meats
- **Eat more sources of omega-3** fats such as fatty fish (salmon, mackerel, herring, and sardines), fish oil, canola oil, flaxseeds, walnuts, and pumpkin seeds
- **Choose organic** produce, meat, and milk when possible

How can I make sure I am getting all of the nutrients I need?

Eating a balanced diet with lots of fruits and vegetables, whole grains, plant-based protein, lean meats, and healthy fats can help you get all of the vitamins, minerals, and other nutrients you need to keep your immune system and body healthy.

Do I need to take a vitamin supplement?

If you eat three nutritious meals a day and healthy snacks which include a variety of fruits and vegetables, protein, dairy foods, and whole grains, you are probably getting enough of most vitamins and minerals through the food you eat. If you aren't getting in all of your food groups on a regular basis, you may want to consider taking a daily multivitamin so you will get the total amount of nutrients that your body needs. Talk to your health care provider to see if you should take a multivitamin or other dietary supplement.

Do I need to take extra calcium?

Some endometriosis medications work by lowering estrogen levels. If you are on an estrogen-lowering medication for more than 6 months, you may be at risk of developing osteoporosis (brittle bones). Ask your gynecologist or your primary care provider if you should take calcium and vitamin D supplements to help protect your bones.

What about other vitamins and herbs?

Some young women with endometriosis take other supplements such as vitamin E, zinc, selenium, B-complex vitamins, magnesium, essential oils (such as primrose, flax, and fish oils), and acidophilus, but there are no published scientific studies that prove that extra supplements improve endometriosis symptoms. It is important to remember that some herbs (such as ginseng) can actually interfere with medications that treat endometriosis because they contain plant-estrogen. It's always best to talk with your health care providers first before taking any over-the-counter herbs.

What information should I pay attention to on food labels?

It is always important to pay attention to food labels when grocery shopping. The more processed a food is, the less nutrient value it retains. Generally, everyone should try to eat as many unprocessed foods as possible and avoid foods with added artificial colors and preservatives. The Nutrition Facts Label is on most foods (except fresh foods such as fruits and vegetables) and has important information including portion size and what vitamins/minerals the food contains.

Will exercise make my endometriosis symptoms worse?

Probably not. In fact, exercise may actually improve endometriosis symptoms. Daily exercise (about 60 minutes each day) such as walking, swimming, dancing,

and other activities will help you to maintain a healthy weight and give you energy. It's a good idea to check with your health care provider or physical therapist to find out whether it's okay to participate in very active sports or other strenuous exercise. Occasionally very active exercise such as running and jumping may bring on or increase endometriosis symptoms or other medical conditions. Talk with your health care provider about the right amount and type of exercise that's best for you.

Can exercise improve my endometriosis symptoms?

There are a few reasons why exercise may help your endometriosis symptoms.

- **Exercise releases endorphins.** When we exercise, our brain releases "feel good" chemicals called endorphins. These naturally occurring hormones work like pain relievers to lower pain. It only takes about ten minutes of moderate exercise (any exercise that makes you sweat or breathe hard) for your body to start making these chemicals.
- **Exercise improves circulation.** Moderate exercise gets our heart pumping and improves the blood flow to our organs. Good blood flow is important because our blood carries oxygen and nutrients to important body systems.
- **Regular exercise lowers the amount of estrogen in the body.** Since the goal of endometriosis treatment is to lower estrogen levels, regular exercise may help improve endo symptoms.

Although nobody knows for sure what the best diet is for someone with endometriosis, healthy eating can improve your overall health, which may help your endometriosis symptoms. Consider selecting organic foods and eating foods that are high in fiber, plant-based foods, and omega-3 fats, and low in saturated and trans fats. Don't forget to balance healthy eating with exercise you enjoy. Even if your endometriosis symptoms don't decrease as much as you would like, eating a healthy diet has plenty of other health benefits!

Endometriosis & College Planning

Planning for college is a time filled with challenges and excitement. College life opens the door to personal growth and independence. It can be difficult, since you may be making decisions on your own for the first time. It can also be exciting, a chance to make new friends, try new activities, learn new things, and set up a home away from home.

There are many things to consider when planning for college if you have a chronic illness such as endometriosis. We hope that the following information will answer your questions and offer helpful hints.

Should I be concerned about my health insurance coverage?

Yes. It is important to know exactly what kind of health insurance coverage you have. For example, some insurance policies will only provide coverage until you are 18 or 19 years old. Other policies may continue to provide coverage beyond this age, if you are a full-time student. Ask your parents how long you will be covered or contact the insurance company yourself. You should check with the admissions department at your college if you need to buy an additional “student insurance policy” while you are a student there. If you aren’t covered by your parents’ insurance while at college, make sure you sign up for a special “student insurance policy”.

Before you leave for college, or as soon as possible, ask your insurance company to send you a summary of your benefits, or ask them the questions listed below.

1. How long can I expect to have insurance coverage? (For example, up to what age am I covered? Do I need to be a full time student to receive or “get” full coverage?)
2. Does the policy cover out-of-state emergency services?
3. Does the policy require that I contact the insurance company within a certain amount of time if I use emergency services?

4. Is there a waiting period for certain services?
5. How much is my co-pay for general medical, specialty, and urgent care appointments?

What do I need to know about the health services at college?

You will need to find out:

- When the Health Center is open
- What kind of services are provided
- Who you can talk to if you have any issues related to your endometriosis
- How to reach someone if you have concerns or questions
- If there is a health care provider at the Health Center that has experience in caring for young women with endometriosis. (If so, get the name and number before you need it.)

You should know the location of the closest hospital to your college in the event of an emergency, or if you need more care than your college Health Center can provide. Find out what types of services are offered, and if students are transferred to another hospital if more specialized care is needed.

What should I do before I leave for college?

1. **Make an appointment with your gynecologist *before* you leave for college.** Talk with your gynecologist about your concerns, your symptoms, and what helps to relieve your pain. Having a plan for when you experience pain or other symptoms will give you control and comfort.
2. **Be sure to have prescriptions filled** with enough refills to last until you return to your doctor for a follow-up visit.
3. **Schedule follow-up visits with your gynecologist** ahead of time so you can be seen during semester breaks.
4. **Ask for a copy of recent operative notes** (if you have had surgery for endometriosis) from the hospital where you were treated. Put them in a notebook and bring it with you to college with your important papers and/or ask the Health Center at school to keep a copy on file. You will need to request a copy of your medical records from the “Medical Records” department at the

hospital where you had your laparoscopy. You may have to do this in person, or you may be able to send or fax a letter.

Should I find a gynecologist near my college?

If you are going to a college that is far away from home, you may decide that having a local health care provider or a gynecologist is best for you. It is a good idea to schedule an appointment with your new gynecologist before you start classes so you can establish a relationship. You can help the communication among all doctors involved in your care by providing them with a list of all your medical providers, and a brief description of their roles in your health care. Include telephone numbers, fax numbers, addresses, and e-mail contact information, if appropriate. Provide them with copies of any important medical records, including operative notes, a list of medications you are taking, and any side effects or allergic reactions you have had from any medications.

It may take a while until you feel completely comfortable making your needs known since you're also adjusting to college life. As you work with your new health care providers, you'll soon learn how to express yourself so that you can help to coordinate your care.

Should I talk with my professors about the effect of endometriosis on my life?

Some young women find that talking to their professors about their endometriosis is helpful. You may feel awkward at first about approaching your professors. However, most college faculty appreciate students who talk to them early on in the semester if there might be a problem that could potentially affect learning. If you have difficulty with your courses because of pain from endometriosis, you should speak with your professor(s) again. The longer you wait, the more overwhelmed you may become. You don't have to give specific information unless you want to. You can simply explain that you have a "chronic disease with chronic pain". Since endometriosis affects approximately 5 million women and girls, you may find that your professor is familiar with it.

Is there anyone else I should talk to?

It can be helpful to have 1–2 designated people in your college Health Center as your "liaisons"— a person to whom you can go to when you need medical assistance and another person who can offer you emotional support. He/she may likely be able to

offer guidance if your pain interferes with your academics.

What are some ways to deal with my college workload?

Learning to use the course syllabus to your advantage can be helpful in dealing with your college workload. The syllabus lets you know what is expected of you for each class, and allows you to plan your course work accordingly. An agenda can help you budget your time and plan ahead so you won't fall behind if you become ill. Taping lectures and then taking notes later from the recorded lecture can help if you have trouble concentrating in class. You will need to make time for listening to taped lectures sometime after class. If you can't make it to class, ask a friend to tape the lecture for you. Most colleges also have resource centers that provide a variety of services to help students deal with heavy workloads.

What else should I know?

Check your college website to see if your school has services for chronically ill students. They may be able to offer help with note taking, extensions on tests or papers, and/or help with special dietary needs.

Please note that our office does not consider endometriosis to be a disability, therefore, we cannot authorize "disability services" for college students.

Planning ahead when you have a chronic illness helps you to advocate for yourself and be aware of services before you need them, so you can make the most of your college experience.

My Medication List

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|-----------------------|-------|--------------------|-------|
| Medication | _____ | | |
| Dosage | _____ | | |
| Prescribed By | _____ | | |
| Date Started | _____ | Date Stopped & Why | _____ |
| Reason for Taking | _____ | | |
| Side Effects (if any) | _____ | | |

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| Medication | _____ | | |
| Dosage | _____ | | |
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| Date Started | _____ | Date Stopped & Why | _____ |
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Glossary of Endometriosis Terms

ACTIVE HORMONE PILL: An oral contraceptive pill that contains estrogen, progesterone, or both.

ADD-BACK THERAPY: Hormonal therapy prescribed to help females with the side-effects of a class of medicine called GnRH agonists.

BLADDER: The organ that collects and stores urine.

BONE DENSITY: How solid and strong your bones are.

BREAKTHROUGH BLEEDING: Light vaginal bleeding or spotting that can happen during the first month on oral contraceptive pills (OCP's) or when switching to another kind of OCP, or when a pill is missed or late. Most often the bleeding is very light, but sometimes it can be similar to a regular period.

CHRONIC: A condition that continues for a long time.

DYSMENORRHEA: Pain with periods, menstrual cramps.

ENDOMETRIAL CELLS: Cells from the lining of the uterus.

ENDOMETRIAL LESIONS (IMPLANTS): Tissue from the lining of the uterus that sticks and grows outside of its normal location.

ENDOMETRIAL TISSUE: Tissue from the lining of the uterus.

ENDOMETRIOSIS: A condition that occurs when tissue similar to the lining of the uterus is found outside its normal location.

ESTROGEN: A female sex hormone.

GnRH-a AGONIST (GnRH-a): A category of medicine used to treat certain medical conditions such as endometriosis. This medicine works by lowering the body's level of the hormone estrogen. (In this book, we refer to the GnRH-a agonist as Leuprolide acetate, or Lupron-Depot®.)

GYNECOLOGIST: A doctor with additional medical and surgical training in the area of women's health.

HORMONE: A chemical messenger that is released by an organ or gland and then sent through the bloodstream to another part of the body.

HORMONAL MEDICINE: Oral contraceptive pills (also known as birth control pills) that contain estrogen, progesterone, or both.

IMMUNE SYSTEM: The immune system is the system in our body that protects against disease, infection, and foreign substances.

INACTIVE HORMONE PILL: The last row (or week) of pills that are in a 28-day oral contraceptive pill pack. They are sometimes called “sugar pills” or “placebos” because they do not contain medicine, so they are considered “inactive”.

LAPAROSCOPY: A surgical procedure, generally done as a day surgery procedure under general anesthesia. A small incision is made near the navel, and a lighted, thin tube is inserted to view the pelvic organs.

MENSTRUATION: The release of blood from the uterus.

MENSTRUAL CRAMPS: Pain in the lower abdomen during a period.

NAUSEA: Feeling like you are going to throw up.

OMEGA-3 FATTY ACIDS: Omega-3 fat is a “heart healthy” type of fat that your body needs. Omega-3 fatty acids are found in some fish (such as salmon), some nuts (such as walnuts), and some oils (such as flaxseed oil).

ORGANIC FOODS: Organic produce is grown without the use of pesticides, synthetic fertilizers, sewage sludge, genetically modified organisms, or ionizing radiation. Animals that produce meat, poultry, eggs, and dairy products do not take antibiotics or growth hormones.

OVARIES: Two tiny organs (or glands) that are located inside the lower belly area of a female. The ovaries make the female hormones estrogen and progesterone.

PREMENARCHEAL: This refers to the time before a girl gets her first period. “Pre” means before and “menarcheal” means menstrual period.

PELVIC ULTRASOUND: A test that uses sound waves to make a picture of the reproductive organs; ovaries, fallopian tubes, uterus, cervix, and bladder.

TRANS FAT: *Trans* fat is a “heart unhealthy” type of fat. It is made by companies that make processed foods by adding hydrogen to vegetable oil. Foods with *trans* fat will have the words “partially hydrogenated oil” in the ingredient list. *Trans* fat can be found in some margarines, fast foods, fried foods, and baked goods.

ULTRASOUND: A way to take pictures inside of body parts. Pictures taken by ultrasound are similar to x-ray photographs. However, when ultrasound is used, the images are made with sound waves instead of x-rays.

UTERUS: A female organ (also called a "womb") that sheds blood every month (a period), and also holds a baby while it develops inside its mother.

Additional Resources

ONLINE CHATS

The Center for Young Women’s Health

www.youngwomenshealth.org

Chats are held monthly for young women (aged 13 to 22) with a confirmed diagnosis of endometriosis. The chats are moderated by a nurse specialist. Check the schedule and register to participate in a free online chat with other girls who have endometriosis.

HELPFUL WEBSITES

The Center for Young Women’s Health

www.youngwomenshealth.org

Youngwomenshealth.org is an award winning website featuring health guides, quizzes, and online chats for girls with Endometriosis. The mission of the website is to help teen girls, their parents, teachers, and health care providers improve their understanding of normal health and development, as well as specific diseases and conditions.

Endo–Online The Voice of the Endometriosis Association

USA Phone Number(s): 414–355–2200 | Toll Free: 800–992–9696

www.endometriosisassn.org

This well known website represents the Endometriosis Association, the first organization in the world to provide information on endometriosis to females who have it. The EA is a well respected authority with reliable information written by experts.

Endometriosis Research Center

USA Phone Number(s): 561– 274–7442 | Toll Free: 800–239–7280

www.endocenter.org

The Endometriosis Research Center was founded in 1997 because of the limited research, support, education and awareness for endometriosis. The ERC strives to improve the quality of life for women and girls with endometriosis through their extensive programs and outreach efforts.

Every effort has been made to ensure that the URL's listed in the Helpful Websites section are as accurate and up-to-date as possible. We realize that the internet is constantly changing, and we can only guarantee that the links are accurate as of the date that this book was re-printed.

HELPFUL BOOKS

Ballweg, Mary Lou, and The Endometriosis Association. Endometriosis—The Complete Reference for Taking Charge of Your Health. McGraw–Hill, 2003.

Written by the founder of the Endometriosis Association and expert clinicians, this book is packed with information about managing symptoms, medications, and alternative treatments. It is primarily geared towards adult women, however there is a chapter on “Teen Endometriosis” that would be helpful for parents, family members and friends, as well as health care providers and educators who advocate for teens.

Mills, Dian Shepperson MA, and Vernon, Michael PhD HCLD. Endometriosis: A Key to Healing Through Nutrition. Thorsons, 2002.

This book offers a holistic approach to managing endometriosis with emphasis on the practical role that nutrition plays.

Phillips, Robert, and Motta, Glenda. Coping with Endometriosis: A Practical Guide. Avery, 2000.

This book addresses the psychological and emotional concerns related to endometriosis and offers practical ways to cope with chronic pain.

Last updated March 4, 2015

