

# Helping Your Daughter Manage Endometriosis

*A Collection of Resources for Parents/Guardians*





## **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, Francie Mandel, LICSW, Kendrin Sonnevile, ScD, RD, LDN, and Amanda Kohn, BFA, designer/illustrator.

Special thanks to Dr. S. Jean Emans for her valuable edits, and Vicki Burke RN, BSN, for her contributions.

The team is especially grateful to Dr. Marc R. Laufer for his guidance and most of all for his commitment to supporting parents of teens with endometriosis.



# Helping Your Daughter Manage Endometriosis

Your daughter has been diagnosed with endometriosis. 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. This collection of resources will help you as a parent/guardian understand endometriosis, teach your daughter ways to cope with chronic pelvic pain and painful periods, and help her deal with the challenges of going to school and maintaining friendships.

## **HOW TO USE THIS RESOURCE BOOK:**

Finding information in this book 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, "Endometriosis and Teens" explains what endometriosis is and how it's diagnosed, and "Frequently Asked Questions" answers common questions parents/guardians often ask. There are also detailed guides that explain different types of hormonal therapy used to treat endometriosis.



# Table of Contents

|   |    |
|---|----|
| <b>ENDOMETRIOSIS AND TEENS:</b> An introduction to endometriosis that answers the most commonly asked questions about symptoms, causes, and available treatments.   | 1  |
| <b>FREQUENTLY ASKED QUESTIONS (FAQ'S) ABOUT ENDOMETRIOSIS:</b> A collection of parents' most frequently asked questions about endo.   | 5  |
| <b>TREATMENT OPTIONS:</b> A guide about various treatment options for teens with endometriosis.   | 11 |
| <b>CONTINUOUS ORAL CONTRACEPTIVE PILLS (OCP'S) FOR THE TREATMENT OF ENDOMETRIOSIS:</b> A guide about continuous oral contraceptive pills; why they are often prescribed for teens with endometriosis, including the benefits and possible side effects. | 13 |
| <b>HOW TO TAKE CONTINUOUS ORAL CONTRACEPTIVE PILLS:</b> A guide that reviews how continuous oral contraceptive pills should be taken with pointers on how to support your daughter with this treatment plan.  | 17 |
| <b>PROGESTIN–ONLY HORMONAL THERAPY FOR THE TREATMENT OF ENDOMETRIOSIS:</b> A guide about different progestin–only hormonal treatments: Norethindrone acetate and medroxyprogesterone acetate, including the benefits and side effects of each.          | 21 |
| <b>LEUPROLIDE ACETATE WITH ADD–BACK:</b> A guide about a type of gonadotropin–releasing hormone agonist (GnRH agonist) used to treat endometriosis.   | 23 |
| <b>CALCIUM AND TEENS:</b> A guide that discusses the importance of calcium during the teen years and how adequate calcium intake can prevent or lower the risk of osteoporosis.   | 27 |
| <b>DXA SCAN:</b> A guide that explains about a type of diagnostic test (DXA scan) that measures bone density.   | 33 |
| <b>HELPING YOUR DAUGHTER COPE WITH ENDOMETRIOSIS PAIN:</b> A unique guide with helpful advice on how you can help your daughter to manage pain caused from endometriosis.   | 35 |
| <b>PAIN TREATMENT SERVICES AT BOSTON CHILDREN'S HOSPITAL:</b> Information about the multi–disciplinary Pain Treatment Clinic at Boston Children's Hospital.   | 41 |

|  |    |
|--|----|
| <b>ENDOMETRIOSIS, NUTRITION, AND EXERCISE:</b> A guide that explains the important role of nutrition and fitness in maintaining overall health with specific strategies that can help improve your daughter’s endo symptoms. | 43 |
| <b>ENDOMETRIOSIS &amp; SCHOOL CONCERNS:</b> A guide that offers parents both advice and strategies when girls miss school due to endometriosis.  | 47 |
| <b>ENDOMETRIOSIS &amp; COLLEGE PLANNING:</b> Tips on how to help your daughter prepare for college while dealing with chronic pelvic pain caused by endometriosis.   | 53 |
| <b>YOUR DAUGHTER’S MEDICATION LIST:</b> A tool you can use to keep a record of your daughter’s medication.   | 59 |
| <b>GLOSSARY OF ENDOMETRIOSIS TERMS:</b> A collection of endometriosis terms that are used throughout this book.  | 61 |
| <b>EVALUATING HEALTH INFORMATION:</b> A unique guide that provides helpful information when searching for medical information online.  | 65 |
| <b>ADDITIONAL ENDOMETRIOSIS RESOURCES:</b> A collection of recommended resources for parents, including chats, discussion boards, websites, and books about endometriosis.   | 67 |

# Endometriosis and Teens

The best thing you can do to understand your daughter's diagnosis is to learn all you can about endometriosis. It's helpful for both you and your daughter to maintain an ongoing list of questions for your daughter's GYN team. The doctors, nurses, and social workers will assist you and your daughter in understanding her diagnosis and the treatment options at all stages of her treatment.

## What is endometriosis?

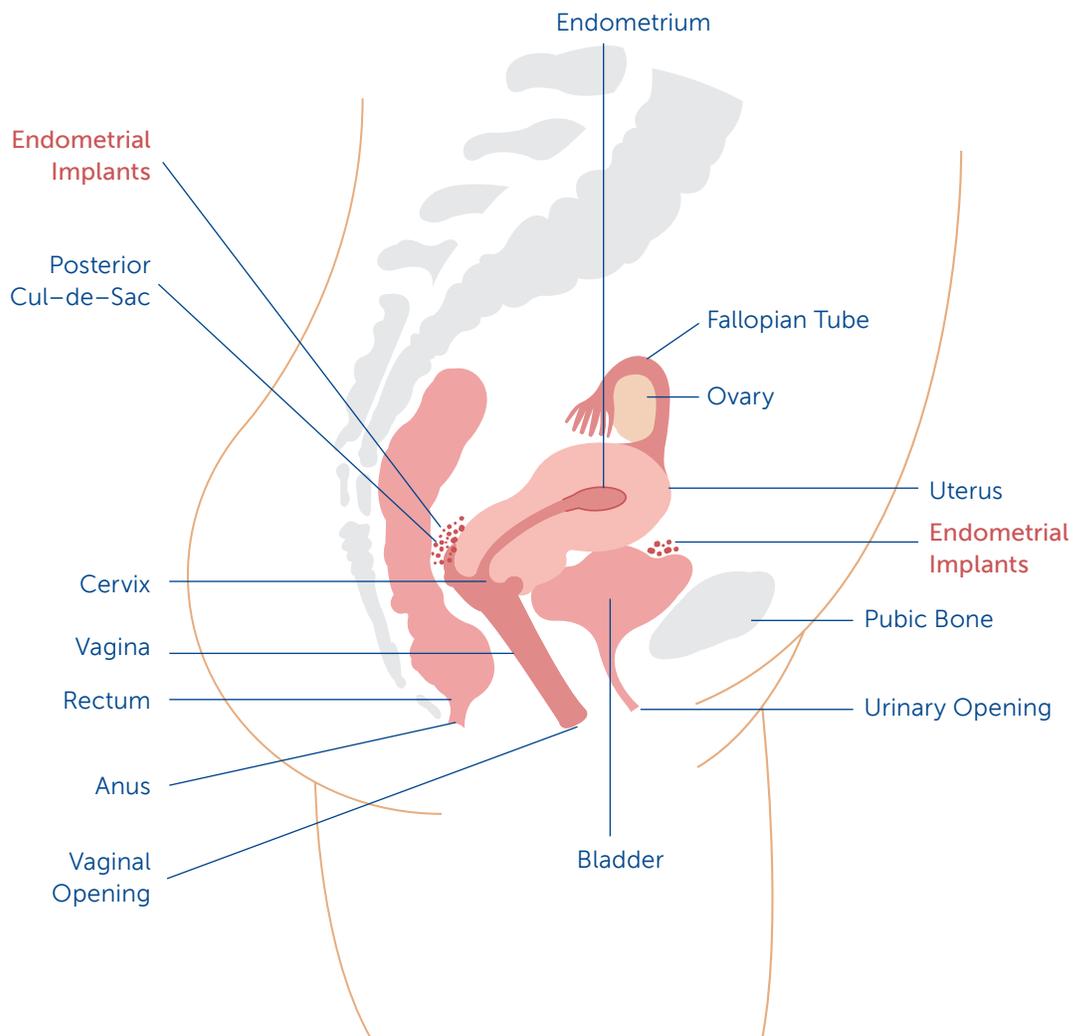
Endometriosis, pronounced, "end-o-me-tree-o-sis" can affect girls of all ages. It is a condition that occurs when tissue similar to the inside lining of the uterus is found outside of its normal location. Endometrial implants can be found on the ovaries, fallopian tubes, and ligaments that support the 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 on the next page.)

## 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 a period. The pain may occur at regular times in the menstrual 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 girls may have. Some girls may have pain with exercise, sex, and/or after a pelvic exam, others do not. Although not as common, some girls may have painful or frequent urination, diarrhea or constipation with pelvic pain. It's important to remember that some girls 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.

### **IMPORTANT FACTS 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 no or mild to moderate menstrual cramps one or two days a month. If your daughter is absent from school because of pelvic pain or menstrual cramps, tell her 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 daughter's pain makes her feel at all disadvantaged compared to other young women or young men her age, this is NOT normal.** Your daughter should not "normalize" her symptoms. If your daughter doesn't feel like she's as equally capable as other teens her age (*because of pelvic pain*), she should tell her gynecologist.



# Frequently Asked Questions (FAQs) about Endometriosis

## **Why is there no cure for endometriosis?**

Although medical researchers have been working for years to identify a cure for endometriosis, as of right now, there is no cure. This is because the exact cause remains unknown. The good news is that researchers around the world are investigating factors that might explain why one woman gets endo and another woman does not, such as: whether exposure to certain environmental agents cause endo, and if the immune system reacts a certain way to make a woman more at risk. Researchers have also been working on identifying a “gene” that would help recognize women more likely to be diagnosed with endo. Some doctors claim that they can “cure” endometriosis with surgery. This is NOT true as they cannot see the microscopic disease that is present and therefore they cannot remove all of the disease. Until a cure for endometriosis is discovered, there are effective treatments to control pain caused from endo, and preserve fertility.

## **How do I deal with the fact that there is no cure for my daughter’s endo?**

It’s normal to feel frustrated, angry, sad, or other emotions when you know that nothing can be done at this time to cure your daughter’s endo. You may find it reassuring to know that there are treatments to control her symptoms and prevent her endo from getting worse. Research is always moving ahead and the possibility of a cure could very well be in the near future.

## **How common is endometriosis among teen girls?**

We know that it is not uncommon for young women to have endometriosis. If endometriosis runs in the family, a young woman may be more likely to have it than someone else with no family history. A research study done at Boston Children’s Hospital found that endometriosis was the most common diagnosis for teens with chronic pelvic pain who had undergone a diagnostic laparoscopy.

### **How often will the gynecologist see my daughter?**

Many factors influence how often your daughter will be followed by her GYN team: the type of medication she is prescribed, how well she responds to treatment, and whether or not she has other gynecological issues. If your daughter is being treated for her pain with birth control pills, she will probably need to return about 3 months after she starts her pills. Typically, if your daughter is on Lupron Depot®, she will need to return for her shot either once a month or every three months depending on the prescribed dose. She may return earlier if she is experiencing side effects or she feels that her endo symptoms are not improving. When she is doing well and is happy with her medical treatment, she will need to have an annual appointment for a GYN check-up and to obtain a prescription refill.

### **How do I help my daughter comply with her treatment plan?**

Your daughter's compliance with her treatment plan relies on a good balance between assuming responsibility for her treatment, and your support. Support may include your assistance with the practical parts of her treatment plan, such as filling prescriptions, communicating with schools and providing transportation to appointments. Asking adolescents to assume increasing amounts of responsibility can be stressful, but it is a necessary part of growing up. Honest communication with your daughter about taking increased responsibility for her health care encourages her to be compliant with her medical treatment.

### **If my daughter goes on birth control pills for her endometriosis, am I giving her permission to have sex?**

No. If your daughter is offered birth control pills for the treatment of her endometriosis, it is because birth control pills are effective in reducing pelvic pain. The treatment will not change your daughter's values about sexually activity. This is a good opportunity, however, to talk to your daughter about your concerns and expectations.

### **How can I help my daughter live with endometriosis without it interfering with school and social activities?**

One of the primary goals of your daughter's treatment is to successfully manage her pain. The goal of her treatment plan should be to reduce the symptoms that interfere with her education, activities, and social life.

## How can I help my daughter maintain consistent school attendance?

Some young women with endometriosis experience an unusually high number of school absences due to chronic pelvic pain. Pain management is key when treating endometriosis so that your daughter can attend school and participate in social activities. If her pain is particularly bad in the morning, you may choose to give her the option of going to school late rather than being absent for the entire day. In rare cases when school absences are high, it may be necessary to work with the school system to arrange for a home tutor. It is important to communicate about extended school absences with your daughter's gynecologist.

## When should I let my daughter stay home from school (because of endo pain)?

There may be times when, despite the best of treatment plans and efforts, your daughter feels that the pain from her endometriosis is intolerable and requires her to stay home. It would be most helpful if the criteria for staying out of school or other activities were established BEFORE the situation arises. For example, if your expectations are clear about her school attendance, class work, and homework, it will be easier for her to take responsibility when she is absent from school due to her endometriosis. If you feel your daughter is falling behind in her classes and/or homework due to frequent absences, or that her pain interferes with completing assignments, make an appointment with her school counselor or advisor before she falls too far behind. Health care providers may be able to help by advocating for necessary support services so that your daughter can have a successful school year.

*If your daughter is experiencing sleep difficulties, disinterest in social activities, decreased appetite and/or change in weight, she may be depressed. It is important to make an appointment with her health care provider to discuss options for an evaluation with a mental health counselor, social worker, or psychologist.*

## **Are there any alternative or complementary treatments that will help my daughter?**

Complementary and alternative medicine or “CAM” therapies have become popular in the last decade. Although there is limited data that supports the effectiveness of herbs, acupuncture, and other forms of CAM therapy in the treatment of endometriosis, new research studies are underway to determine if in fact these therapies are helpful. Pain Treatment Centers in major hospitals will evaluate young women with endometriosis and often recommend CAM therapies in addition to traditional medical treatment. If you choose to explore options on your own, make sure that the CAM provider is a licensed professional and inform all of your daughter’s health care providers what herbs or therapies the CAM practitioner prescribes.

## **How will the endometriosis affect my daughter’s sexuality?**

Every gynecological condition by definition focuses on the reproductive system and this necessitates conversations about sexuality. This often makes young women and their parents uncomfortable. Young women with endometriosis may have more intense feelings about their sexuality because of all the medical attention they receive to this part of their body. As a parent, you can use this opportunity to have honest discussions with your daughter about sex and the choices she will make.

## **How will the endometriosis affect my daughter’s fertility in the future?**

Early treatment is important in the relief of pain but also in the prevention of the natural progression of endometriosis that in some cases may cause infertility. Infertility commonly results when endometriosis causes changes in the pelvic organs and/or the fallopian tubes. Since endometriosis is a chronic (life–long) disease, it’s important for your daughter to have early treatment to preserve her fertility. Your daughter should be followed for her endometriosis throughout her childbearing years.

## **Why does my daughter need to have surgery and medicine for her 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 her doctor combines medical and surgical therapy to treat this disease.

*A study done by Dr. Marc Laufer and colleagues at Boston Children's Hospital and published in the Journal of Pediatric and Adolescent Gynecology (2009) 22:257–263 concluded that there is supporting evidence that standard combined surgical–medical management in adolescents does in fact retard disease progression.*

### **Will my daughter ever need another laparoscopy?**

The need for another laparoscopy depends on many factors, such as when her last procedure was, if she's having a problem with pain control while taking medication, and if her gynecologist feels it's necessary to check to see if her endometriosis has grown. If she does require another laparoscopy in the future, the endometriosis lesions will be removed and/or destroyed. The goal is always to lower her pain and preserve her fertility,

In an earlier 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 my daughter need to have her uterus and/or ovaries removed because she has endometriosis?**

**No.** She will NOT need to have her uterus and/or ovaries removed (hysterectomy). All treatment will be aimed at relieving pain and preserving her ability to have children someday.

### **Will my daughter be able to get pregnant?**

Not being able to get pregnant (infertility) can result if endometriosis causes changes to your daughter's pelvic organs, including her fallopian tubes and ovaries. With early treatment, endometriosis should not interfere with her ability to become pregnant (when she is ready).

### **Should my daughter get pregnant to cure her endo?**

No. There is no cure for endometriosis at this time. Some women who are pregnant may experience less endo-related symptoms during their pregnancy while others may have no change or a worsening of symptoms. For women who have an improvement with their symptoms (while they are pregnant), the effects are usually temporary.

### **How long does my daughter need to be followed for her endo?**

Endometriosis is a chronic condition that requires long-term medical treatment and follow-up, especially during her childbearing years. Many factors affect how often she will need to be seen by her gynecologist, such as whether or not she is responding to treatment. Since there is no cure for endometriosis at this time, she will need to be on medication. Therefore, follow-up visits with her gynecologist will need to be made periodically. Refills for prescription medications (for endometriosis) are provided at this time.

*Your daughter may be followed here at Boston Children's Hospital until she's 22 years old. Before she turns 23, she'll need to see an adult endometriosis specialist. If she would like, she 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.*

### **If I have another daughter, should she get checked for endometriosis?**

Women are more likely to develop endometriosis if a close female relative from their mom or dad's side has it. Likewise, if one daughter has been diagnosed with endometriosis, and your other daughter(s) has painful periods and pelvic pain at other times during her menstrual cycle that interferes with school and social activities, it is a good idea that she has a gynecological evaluation.

# Treatment Options

When an evaluation suggests endometriosis, it is likely that your daughter will be scheduled for a diagnostic laparoscopy. When a definitive diagnosis of endometriosis has been made, treatment falls into the following categories.

**OBSERVATION:** After a complete evaluation and before beginning therapy, your daughter's gynecologist may decide to have her keep track of her symptoms and try mild pain medicine.

**MEDICAL SUPPRESSION:** Hormonal treatment such as birth control pills either taken cyclically or continuously are felt to relieve symptoms in 8 out of 10 patients. Another medication called a GnRH agonist, such as Lupron Depot®, works by shutting off hormones made by the ovaries and temporarily stopping periods. The use of GnRH agonist therapy lowers the body's estrogen level. This medicine has been approved by the Food and Drug Administration to be used for 6 months at a time. If used for over 6 months, studies have found it can cause loss of bone density. It is recommended that "add-back" hormone therapy be utilized to decrease this risk.

**SURGERY:** At the time of laparoscopy, a special instrument is used to cauterize the endometriosis. After this procedure, many teens find relief from symptoms but some teens may experience pain again over time.

**LIFESTYLE CHANGES:** Dealing with chronic pelvic pain can be challenging for many teens. Exercise often helps to relieve or lessen pelvic pain and menstrual cramps. Eating well and getting enough rest also helps the body to manage pain. Practicing relaxation techniques such as yoga and meditation help to ease pain too.

**PAIN TREATMENT SERVICES:** Many health care providers are associated with programs that provide treatment and support for patients with acute and chronic pain. Teens may be offered an evaluation for services such as biofeedback, physical therapy, TENS (transcutaneous electrical nerve stimulation), and exercise programs.

**COMPLEMENTARY MEDICINE:** Acupuncture, herbal remedies, homeopathy and healing touch are among popular "alternative approaches" to medical treatment. Many of these therapies can be helpful and are used in addition to traditional medical treatment. Not every alternative approach has been proven to be safe and effective as

research studies are limited. Before experimenting with any alternative therapy, check with your daughter's health care provider.

*While there is no cure for endometriosis, your daughter can be treated with surgery and medication to keep the endometriosis from getting worse and possibly affecting her future fertility.*

# Continuous Hormonal Pills (OCPs) 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 your daughter's pain by stopping her 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 preventing 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 progestin 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 contains all active hormone pills and the 28-day pack which contains 3 weeks of active hormone pills and 1 week of inactive (placebo) pills.

## How do I know if hormonal pills are right for my daughter?

Not everyone should take hormonal pills. Your daughter will be asked questions about her medical history, such as whether she or anyone in your family has a history of **blood clots**. In addition, your daughter will not be given a prescription for estrogen pills if she has **certain types of migraine headaches (*with aura*)**. There are different doses of hormones in different hormonal pills. Her gynecologist may prescribe a progestin-only pill if there is a medical reason why she should not take estrogen. **Please tell your daughter's gynecologist if your daughter suffers from migraine headaches or if anyone in your family has been treated for blood clots or stroke.**

## Are there other medical benefits to taking hormonal pills?

Yes. If your daughter is prescribed hormonal pills continuously (no inactive pills), then she probably won't have a period. Hormonal pills will also lower her chance of getting endometrial (lining of the uterus) cancer and ovarian cancer, ovarian cysts, certain breast lumps, and may protect her from osteoporosis. Hormonal treatment may also improve acne, if she has it.

## What is the difference between "active" and "inactive" hormonal pills?

Active pills contain hormone medicine. If your daughter's 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 her pill pack. The inactive pills are in the last row of the 28-day pill pack and DO NOT contain hormone medicine. If her 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 she is using a 21-day pill pack, **all** the pills are active. If she is prescribed continuous hormonal treatment for endometriosis, she 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 your daughter is prescribed the **28-day pill pack**, she will take 1 active pill a day for 3 weeks (3 complete rows) and then start her next pill pack immediately. She will not take the last row of inactive pills; rather she will just throw them away. If she is prescribed the **21-day pill pack**; when she finishes the entire pack (3 rows), she will start her next pill

pack the next day. Your daughter should not skip any days between pill packs. Most likely she will not have a period while she is taking the Pill continuously, but some girls may have breakthrough bleeding. It is important to remind your daughter to take her hormone pills at the **exact same time each day**, not necessarily when she gets up or at bedtime since this may vary on a daily basis.

### **What are the side effects of hormonal pills?**

Most women and teens have no side effects when taking hormonal pills, but some may. 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. Your daughter 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 your daughter takes her hormone pills at exactly the same time every day to keep her hormone levels in balance. This will lower the chance of having breakthrough bleeding.

**NAUSEA:** Your daughter may feel queasy or nauseous at times, but this may go away if she takes the Pill with a meal or a snack. If the nausea doesn't go away, her gynecologist may prescribe a pill with less estrogen.

**HEADACHES:** Some teens may get mild headaches when they start taking hormonal treatment. Although headaches usually happen because of stress or other reasons, be sure to let your daughter's GYN team know if her 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, the type of Pill she is taking may need to be changed.

**ACNE:** Usually hormonal treatment helps to improve acne, but some teens may get acne from a particular hormonal pill.

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

*Tip: Suggest that your daughter set her cell phone alarm as a reminder to take her pill at exactly the same time every day. If she is even 20 minutes late she may bleed or have pain.*

**OTHER SIDE EFFECTS:** Your daughter's breasts may feel tender or swollen, her appetite may increase, and/or she may 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, her gynecologist may switch her to a different hormonal pill or talk to her about other types of treatment.

# How to Take Continuous Oral Contraceptive Pills

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

The GYN team will explain to your daughter how to use the Pill pack. She will be told to start taking the Pill on a Sunday, on the first day of her menstrual period, or on the day of her appointment with her gynecologist.

1. She should take 1 Pill at the same time each day until she finishes the pack. The best time is ½ an hour after a full meal. She may feel mildly nauseous during the first month, but this usually goes away.
2. **After completing a 21–day pack, she should immediately start a new package of pills the next day.**

**PLEASE REMIND YOUR DAUGHTER:** to take her Pill at exactly 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 tell her to take the Pill when she wakes up or before she goes to sleep, as those times will likely vary on school nights and weekends.

*Young women have shared creative ways to remember to take their Pill such as writing a reminder on a calendar, or setting a cell phone alarm, which ensures that they take their pill at a consistent time each day. Try to think of a special way that your daughter can remember to take her Pill.*

## What if my daughter forgets to take one or more hormonal pills?

- If she misses 1 or 2 active (hormone) pills in a row, she should take the pill(s) as soon as possible and then continue taking 1 pill each day. She can take 2 pills on the same day (one at the moment she remembers and the other at the regular time) or even 2 at the same time.
- If she misses 3 or more active (hormone) pills in a row, she should take all 3 hormone pills as soon as possible and then continue taking 1 pill each day.
- **If your daughter is sexually active and does not use condoms**, she should call the GYN team to find out if she should also take emergency contraception (EC). She should use condoms for the next 7 days.
- Note: If she is taking very low dose hormone pills with just 20ug of ethinyl estradiol and misses 2 pills, she should follow the instructions for missing 3 or more pills.



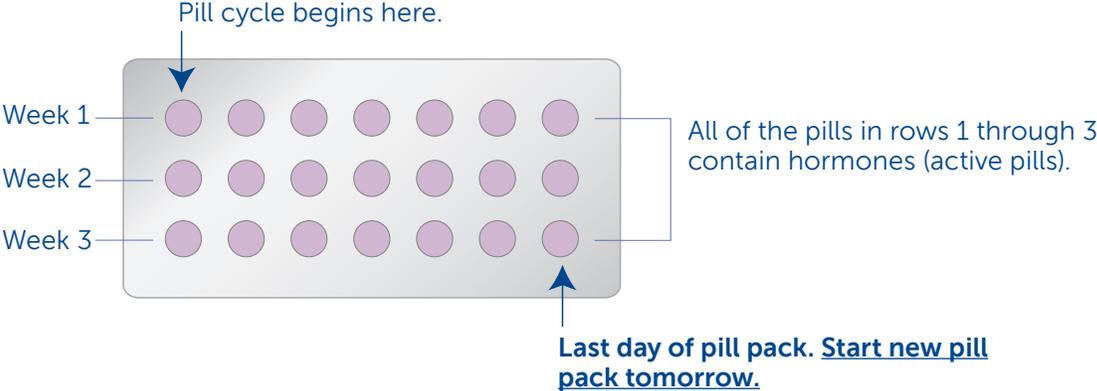
Your daughter may have breakthrough bleeding (spotting) if she forgets to take her Pill on time; some women/teens are so sensitive that they will bleed if they take their Pill just 20 minutes late. If she misses pills she may get an extra menstrual period.

## What if my daughter complains about the oral contraceptive pills that she was prescribed?

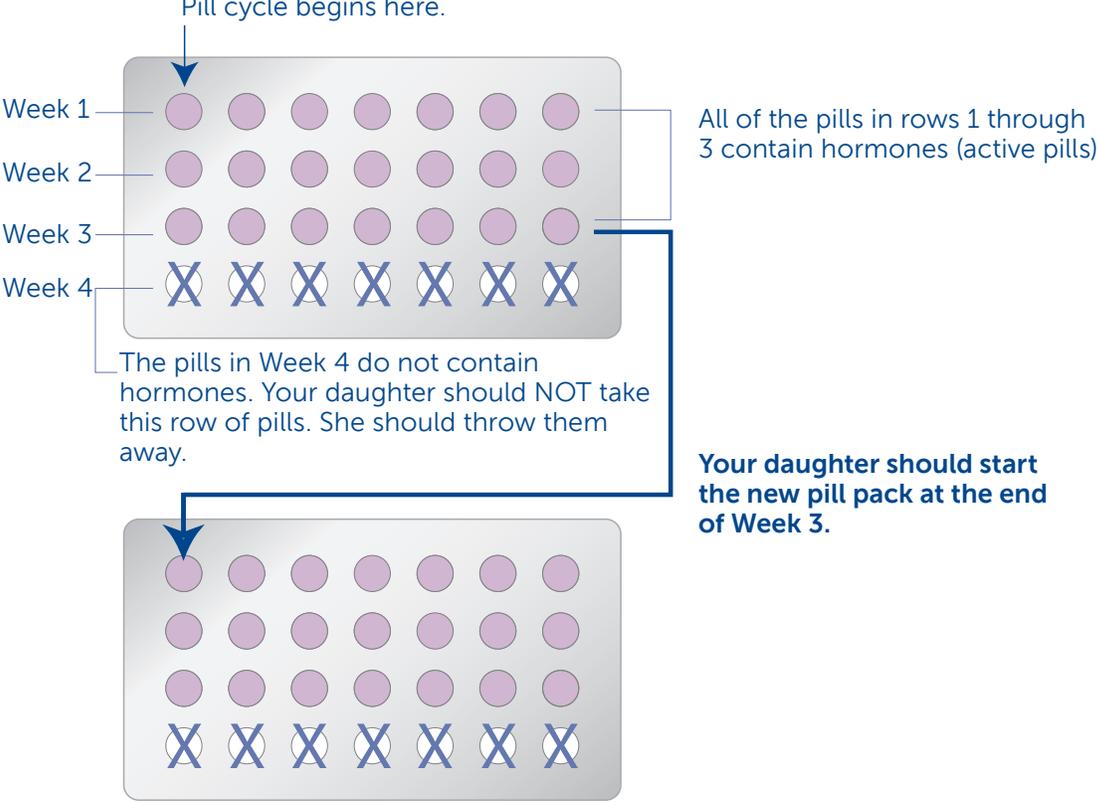
If your daughter is not happy with the Pill that she is taking and the effects they have on her body, please encourage her to talk to the GYN team. She should NOT just give up and stop taking the Pills. Most likely her gynecologist will be able to give her a prescription for a different type of oral contraceptive pill or another type of hormonal medication. There are many types of hormonal pills and they affect people differently. Your daughter may like some, but not others. Be prepared that she might need to try a few different types of hormonal pills until she finds the one that works best for her.

*Hormonal pills (also called oral contraceptive pills) can be a very effective treatment for endometriosis. Encourage your daughter to ask questions about the Pill before she considers taking it.*

**21 DAY PILL PACK**



**28 DAY PILL PACK**





# Progestin–Only Hormonal Therapy for the Treatment of Endometriosis

If your daughter is unable to take estrogen or if she does not respond to combination (estrogen and progesterone) pills, her gynecologist may prescribe a progestin–only hormonal pill such as norethindrone acetate (Aygestin®, Nor–QD®, or Camilla®) or medroxyprogesterone acetate (Depo–Provera®). These medicines stop a woman’s body from ovulating and the endometriosis from growing. Most teens will not have a period. Taking synthetic (man–made) progestin medication in this form is very similar to the natural progesterone that is made by a woman’s body after ovulation and during pregnancy.

## **Are there any reasons why my daughter might not be able to take progestin–only hormone therapy?**

There are certain circumstances when progestin–only hormone therapy may not be prescribed. The GYN team should be informed if your daughter is currently being treated (or has been treated in the past) for any other medical condition(s) in addition to endometriosis. Progestin–only hormone therapy is never prescribed while a woman is pregnant, or if she has severe liver disease.

## **Are there any side effects we should be aware of?**

Most teens and young women have little or no side effects while taking progestin–only medication. Possible side effects can include breakthrough bleeding or spotting, changes in weight, acne, breast enlargement, feeling bloated, headache/migraines, nausea or vomiting. There is a possibility of bone density loss (thinning of the bones) with Depo–Provera®. Hormone medications can affect people differently. Some teens/women will have irregular bleeding while taking progestin–only hormone therapy, especially during the first 6 months of treatment. Breakthrough bleeding is less common with long–term use.

### How is norethindrone acetate taken?

Norethindrone acetate is a pill that comes in a bottle (not pill pack) and is taken orally.

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

### How is Nor-QD® or Camilla® taken?

These progestin-only medications come in a pill pack like regular birth control pills. There are 28 active hormone pills in each pack. The dose is very low (.35 milligrams/day).

### 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 the menstrual cycle. A routine urine pregnancy test is typically done prior to starting the medicine. **The next injection is scheduled within 11–13 weeks.**

*In addition to being as effective as other hormone therapies that treat endo, progestin-only hormonal therapy protects against pregnancy but NOT sexually transmitted infections (STIs). We tell young women who are sexually active to always use condoms.*

# 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 progestin or progestin alone. Your daughter must take add-back therapy if she is prescribed leuprolide acetate (see below).

## How does leuprolide acetate work?

This medication works by shutting off hormones made by your daughter's ovaries, so her estrogen (one of the hormones that causes her body to have periods) level is lowered. After her first injection, her estrogen level will rise before it goes down. This is called an "estrogen surge". Because of this rise in estrogen, she may have an increase in her endo symptoms for a few days. After the estrogen surge, her estrogen levels will go down. This temporarily stops her period. Without periods endometriosis symptoms usually go away.

## How is leuprolide acetate given?

Leuprolide acetate is an injection. It is very important that your daughter gets her injection on time. Missed doses can cause breakthrough bleeding and the return of pain.

## How long can my daughter stay on leuprolide acetate with add-back?

Leuprolide acetate alone is usually prescribed for 6 months (1 injection every 3 months). However, when it is taken with add-back, a patient can almost always stay on it longer. After a few months of treatment your daughter will be scheduled for a follow-up appointment with her gynecologist to see if the medicine is helping her. This appointment also gives your daughter's gynecologist a chance to ask her about her pelvic pain and any other symptoms she may be having. If her symptoms are better, her gynecologist may suggest that she continue taking the medicine.

*After the second month of treatment, we expect that your daughter's period will stop. However, she may have a light period or spotting during treatment. If the bleeding continues or is heavier, call the GYN office at 617-355-7648, and ask to speak with a nurse. It is important that she has her injections on time and takes her medications as prescribed.*

### **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, your daughter will most likely NOT experience these side effects. If she does have symptoms, they will likely be mild.**

### **What is "add-back" therapy?**

Add-back is a pill that contains a small amount of estrogen and progestin, or progestin-only that is taken every day. Since hormones are important to keep her bones healthy, low levels of hormones can lower your daughter's bone density and put her at risk for osteoporosis (thinning of the bones). The goal of add-back therapy is to give her body back just enough hormone(s) to protect her bones and control any unwanted side effects such as hot flashes and vaginal dryness that are common when taking leuprolide acetate alone. Your daughter's gynecologist will decide on how much add-back medicine she will need, and give her a prescription. Add-back is either: Aygestin® 5mg/daily, Prempro® 0.625/2.5mg/daily, or Prempro® 0.62/5mg/daily.

### **When do the effects of leuprolide acetate go away?**

Effects will decrease after your daughter stops taking the medicine. Her period will return within 4 to 8 weeks after her last injection. If bone density loss occurred, it may recover partially or completely.

### **Can my daughter 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 there is a family history of osteoporosis. Osteoporosis causes our bones to become fragile and break more

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

### **What is bone density?**

Bone density is a measurement of how solid and strong our bones are. Bones need to be strong and solid so they do not break easily. The adolescent and young adult years are important for bone development. Weak bones during the teenage years may negatively impact bone health later in life. Our bones need lots of nutrients, especially calcium and vitamin D. It is also important that your daughter eat a well–balanced diet, take a vitamin D supplement, and include foods high in calcium. See page 27 for more information about calcium.

### **When will my daughter be scheduled for a bone density test?**

After your daughter has been on leuprolide acetate for approximately 6–9 months, your daughter’s gynecologist will order a DXA test. This is a simple test that measures how dense (or thick) her bones are and if her bones are losing bone mass. If the DXA scan is normal and she is told to continue on the medicine, she will be scheduled for a DXA test every 2 years. See page 33 for more information about the DXA scan.

### **Is there anything my daughter can do to prevent bone loss?**

Yes. Your daughter will likely be instructed to take a calcium supplement (the daily recommendation for most teens is 1300 milligrams). Calcium works closely with vitamin D to build and maintain bone density. In addition to taking calcium, your daughter should take 600–1000 milligrams of vitamin D every day as well.

She can also reduce her chances of preventing bone loss by:

- Participating in a form of \*weight bearing exercise every day
- Eating calcium–rich foods
- Avoiding the consumption of large amounts of alcohol
- Not smoking

\*Weight bearing or aerobic exercise involves doing an activity that supports your weight, such as walking, running, dancing, soccer, basketball, etc.

## Is it possible for a young woman to get pregnant while on leuprolide acetate?

Although this medication works by preventing ovulation, there is a rare chance that pregnancy could occur if a young woman has unprotected sex. We recommend that young women who are sexually active use a non-hormonal birth control method such as condoms while on this medication.

*It's important to remember that all medications affect people differently. If your daughter experiences side effects, have her talk with a member of the GYN team. It usually takes 2–3 menstrual cycles to see an improvement in symptoms and for a young woman's body to get used to this medicine. In the meantime, your daughter can help her body feel better by eating well and getting plenty of rest and exercise.*

# Calcium and Teens

Calcium is a mineral that gives strength to your bones. Calcium is also necessary for many of the body's functions, such as blood clotting and nerve and muscle function. During the teenage years (particularly ages 11–15), your daughter's bones are developing quickly and are storing calcium so that her skeleton will be strong later in life. Nearly half of all bone is formed during these years. It's important that your daughter gets plenty of calcium in her 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: the 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 my daughter's 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 your daughter cannot change (such as her race and the fact that she's female), but there are some she can! She should eat a healthy diet, get some exercise, and not smoke!

### **How much calcium does my daughter 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 my daughter eats?**

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. The table on page 31 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 did 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 my daughter is lactose intolerant?**

If your daughter is lactose intolerant and can't drink milk, there are plenty of other ways she can 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 my daughter get more calcium in her diet?

Here are some meal ideas to increase calcium in your daughter's diet:

### **BREAKFAST:**

- Cereal with milk
- Milk instead of water when making oatmeal
- Drink calcium–fortified orange juice
- Breakfast smoothie with a cup of milk or yogurt and a handful of frozen fruit
- Slice of cheese with a bagel or English muffin. Most cheeses, except for cream cheese, are high in calcium.

### **LUNCH:**

- Milk instead of soda at school or chocolate or strawberry milk
- Yogurt with a sandwich
- Add cheese to a sandwich

### **SNACKS:**

- Coffee–flavored drinks or milk–rich latte (decaf is best)
- Cereal bars or energy bars that contain calcium. Check the label to see if calcium is listed.
- Hot cocoa with milk instead of water
- Broccoli dipped in a veggie dip made with plain yogurt
- Cheese sticks or almonds
- Yogurt or pudding as an after–school snack

### **DINNER:**

- Macaroni and cheese made with milk, or chowder–style soups
- Prepare canned tomato soup with milk instead of water

- Tofu or edamame to stir fries or soups
- Beans (legumes)
- Lasagna or other pasta dishes with ricotta cheese
- Thin–crust pizza with vegetables
- Pudding made with milk or frozen yogurt for dessert

### What if my daughter just can't get enough calcium in her diet?

It's best for your daughter to try to meet her 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 she doesn't like dairy foods or calcium fortified juice or soymilk, she 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 for your daughter, keep the following things in mind:

- Most calcium supplements have between 200 and 500 milligrams of calcium. Remember, her goal is 1,300 milligrams of calcium per day.
- If she has to take more than one supplement per day, it is best to take them at different times of the day because **the body can only absorb about 500 milligrams of calcium at a time.**
- She shouldn't count on getting all of her 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 the 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 a dietitian or health care provider will be able to support her with recommendations on what supplement will best suit her needs.

| <b>FOOD</b> | <b>SERVING</b> | <b>MILLIGRAMS OF CALCIUM</b> |
|-------------|----------------|------------------------------|
|-------------|----------------|------------------------------|

**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?

It's the most widely used method to measure bone density—how dense or thick a person's bones are and if they've lost bone mass. If your daughter has been on Lupron (Leuprolide acetate) and add-back for 6–8 months and her pain has improved, her gynecologist may discuss the possibility of continuing the medicine at her 6 month follow-up visit. She will then be scheduled for a DXA scan to check her bone density. The scan should be scheduled before her next Lupron 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 help my daughter prepare for the DXA scan?

Your daughter should:

- Eat normally, but she should not take calcium supplements, vitamins, or TUMS® the morning of the scan.
- Wear comfortable clothing without metal buttons, snaps, or zippers, as metal interferes with this test. If the clothing she wears to the appointment with interfere with the scan, she will be given a hospital gown to wear.
- Remove any jewelry and all piercings (if possible).

## What will happen at the DXA appointment?

When your daughter arrives for her test, the technologist will ask her to fill out a short medical history form. and then she will have her height and weight measured. If she's 12 or older, she'll need to provide a urine sample. You should be aware that ALL patients who have started their period will receive a routine pregnancy test. The technician will ask your daughter questions about her medical history and explain the procedure.

### **What happens during the DXA scan?**

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

### **Should I be concerned about the amount of radiation my daughter 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 she would be exposed to if she took an international flight.

### **When will we get the results of my daughter's DXA?**

- The results will not be available on the same day as your daughter's DXA scan.
- 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 the Gynecology practice here at Boston Children's Hospital
- Your daughter's gynecologist will review the results with you and your daughter at her next appointment.
- A follow-up DXA scan will be done every 1-2 years as needed.

# Helping Your Daughter Cope with Endometriosis Pain

Even though everyone experiences pain differently, it can be helpful for you as a parent/guardian to think about the pain in two ways: the physical pain your daughter experiences and how it impacts both her life and that of the entire family. Your daughter's physical pain may include ongoing pelvic pain, painful periods, and less often, bowel and bladder problems.

How this pain impacts her 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). Her chronic pain can take a toll on family members and other important people in her life, causing added tension and stress. For all of these reasons and more, both you and your daughter may feel frustrated because her health feels out of your control.

Take a moment to remind your daughter to check out the "Coping with Endo Pain" guide in her booklet (page 51).

She should be able to:

1. Identify her physical pain symptoms
2. Identify how her pain impacts her life and that of your family

It is not unusual for one family member's physical issues to dominate the family system, particularly around the time of diagnosis AND when there is chronic pain. It is important for parents to consider developing their own strategies for remaining calm in the face of stress due to a child's illness.

**STRESS–RELIEVING TECHNIQUES:** Learning to manage life stress is important under any circumstance, but it is essential when you are living with someone who experiences chronic pain. Many young women with endometriosis feel overwhelmed with managing both their pain and their stress. You may feel overwhelmed at times, too.

You can encourage your daughter to effectively manage her stress by helping her incorporate the following techniques into her daily life. You may also want to try these techniques to help manage stress.

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

- Exercising
- Sleeping 8–9 hours each night
- Taking naps when needed
- Meditate daily
- Eating 3 healthy meals a day with nutritious snacks in between
- Doing things she enjoys when she feels well
- Staying in touch with her friends in person, by phone, or online
- Keeping up with her schoolwork (so she doesn't feel overwhelmed or get behind)
- Learning yoga
- Learning when to push herself and when not to
- Keeping to routines as much as possible
- Planning ahead with her for unexpected "flair-ups" of pain
- Talking to a counselor

Write down any additional things that you have tried to encourage your daughter to do that have been successful.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_
4. \_\_\_\_\_

We hope that your daughter will develop her own personalized list of things to do when she is experiencing a pain flare-up. Her list may 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 TV show, movie, or listening to music. It's important that this be HER list of techniques that she finds useful and accessible when she needs it!

**MANAGING PELVIC PAIN AT SCHOOL:** Does your daughter's endometriosis pain get in the way of plans to attend school or her ability to stay for a full day? Does her academic performance sometime suffer due to absences, missed assignments or difficulty keeping focused? It is not uncommon for families to experience tension due to poor school attendance and performance issues. Dealing with pelvic pain in a school setting can be very stressful, for both you and your daughter, particularly if teachers and school nurses are not familiar with endometriosis and are unaware of the pain your daughter must cope with on most days.

**Below are some of the realities of being a parent of a teen with chronic pelvic pain. Also included are suggestions on how to help her deal with the symptoms of endometriosis while at school.** *Note that ALL of the tips depend on being prepared.*

- **KNOW HER PAIN TOLERANCE THRESHOLD:** Your daughter's pain will likely be mild some days and severe on others. Encourage her to use the "Pain and Symptom Tracker" (page 11 in her booklet) to track both pelvic pain and any related discomfort she experiences each month.
- **TALK WITH YOUR DAUGHTER** about what she can tolerate in school and what she simply cannot manage. This is best done during a pain-free time when you are both calm and are thinking clearly.
- **URGE HER TO COMMUNICATE WITH CLOSE FRIENDS** about what it's like to have endometriosis, why she sometimes misses school or activities, and how they can be supportive.
- **WITH YOUR DAUGHTER, IDENTIFY AN ADULT CONTACT PERSON AT SCHOOL.** For example, you or she can ask the school nurse, a favorite teacher, or class aide to be a "point person" she can go to for support.

Choose someone with whom you both feel comfortable sharing your daughter's endometriosis history, and who can be supportive and available during the school day.

- **SHARE INFORMATION ABOUT ENDOMETRIOSIS ONLY WITH YOUR DAUGHTER'S PERMISSION** with the contact person, as well as teachers, school nurse, coaches, and friends. Those around your daughter are likely to be more understanding and supportive if they know what endometriosis is, and how it impacts her life.
- **MAKE A PLAN FOR PAIN AT SCHOOL.** Encourage your daughter to talk with the school nurse and find out if there is a place at school where she can lie down if she has severe pain.
- **URGE YOUR DAUGHTER TO IDENTIFY A PERSON IN EACH CLASS** (friend or teacher) who will e-mail her the homework assignment if she misses class.
- **MAKE SURE YOUR DAUGHTER HAS ENOUGH TIME IN THE MORNING TO GET READY FOR SCHOOL.** She may need to wake up earlier than her friends or siblings to get ready, especially if she is having pain.
- **DON'T ASSUME THAT EVERY DAY YOUR DAUGHTER WAKES UP WITH PAIN MEANS THAT SHE HAS TO STAY HOME FROM SCHOOL OR THAT THE DAY IS "LOST TO PAIN".** She should go to school every day even if she has some pain in the morning. It may be that her pain will get better or go away once she gets moving and is distracted. If her pain becomes unmanageable later in the day, she will have the option of getting dismissed.
- **MAINTAINING A HEALTHY LIFESTYLE IS ESSENTIAL FOR ALL TEENAGERS.** Your daughter should eat nutritious meals and healthy snacks and get at least 8–9 hours of sleep every night. She should also try to do some kind of physical activity every day, regardless of the pain. Activities could include, walking, riding her bike, dancing, playing a sport, etc.
- **DO YOUR BEST TO HELP YOUR DAUGHTER STAY ON TOP OF HER SCHOOLWORK.** If she needs extra help with a particular subject(s), she should talk with her teacher before the school work piles up. If she has to be absent from school for more than a week, you can look into arranging a home tutor.
- **IT IS NECESSARY FOR YOUR DAUGHTER TO KEEP IN TOUCH WITH HER FRIENDS.** Even when she is absent from school, she should try to talk to at least one friend every day either on the phone, via text messages, e-mail, or on a social networking site. She will feel less isolated and it will be easier for her when she returns to school.

- **BE PROACTIVE:** Encourage your daughter to make a list of things she can do to manage her pelvic pain at school. Offer your help with any tasks that would benefit from adult assistance.

**MANAGING ACTIVITIES, FRIENDSHIPS, AND CHRONIC PAIN:** As a parent or guardian you are aware that living with chronic pain can impact all areas of a person's life, even those areas that are typically fun and enjoyable. Your daughter's pain from endometriosis can sometimes get in the way of being able to do things with friends both on a daily basis and for special events. Her friends, family, coaches and teachers may appear frustrated and discouraged when her pain causes her to decline social invitations or when she appears to avoid activities. Your daughter may even worry about canceling plans too many times with her friends or not being a "good friend". One technique that other parents find helpful is to plan strategies that your daughter can use to deal with unexpected pain in social situations. **Here are some thoughts and advice from parents of girls with endometriosis:**

- **Encourage your daughter to 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 for her to be home.
- **Make sure her close friends, coaches or activity directors understand that her pain is a real medical condition.** Educate them with information about endometriosis.
- **Is there an activity your daughter really wants to do but is scared about fulfilling the requirements or keeping the commitment?** Many group activities require a wide variety of participants in many roles. She can explore the options with the group leader, explaining that she wants to be involved in any way that she can handle.
- **Plan ahead.** Does your daughter have an event coming up that feels more stressful than fun? She can go back to her personalized list of coping strategies in anticipation of pain.
- **If she does have to cancel with friends or family, or either of you realize she can't participate in an activity as planned, try to take it in stride:** explain promptly, offer alternative options, and help her to take care of the pain. Her friends, family, and others will respect her more for being honest rather than not showing up without an explanation.

### **COMPLEMENTARY 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 complementary treatments to traditional treatment helps manage their pelvic pain more effectively.

- **YOGA** involves a series of poses and gentle stretches. There are many different kinds of yoga. You and your daughter can explore yoga classes at your local YWCA, health center, and yoga studio. 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 releases 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 THERAPY** is another complementary practice which some girls with pelvic pain find helpful. There are several kinds of massage therapies available. Massage treatments are often combined with gentle heat.

*Learning how to cope with pelvic pain can feel like an overwhelming task at first for both you and your daughter. However, the more strategies and techniques you both learn, the easier it will become. Having the support of important people in your daughter's life will have a significant impact on how she manages her pain. When she learns how to take charge of her pain, rather than allowing it to take charge of her, she will have the confidence to live her 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 that 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 daughter's first visit to the clinic:** Each new patient is seen in the clinic for an initial evaluation. Every patient is evaluated by a doctor, physical therapist, and a psychologist. After each clinician meets with your daughter, they talk together and then make a Pain Management Plan that is designed just for her. You will be involved with the evaluation and your daughter's treatment 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 daughter's pain management plan is either provided through the clinic, or she may be referred to specialists closer to your home. Regular follow-up visits with the doctor will be scheduled to monitor her progress. Your daughter's plan, including the type of recommended therapy, will be adjusted as necessary.

**Things you will need for your daughter's 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 her first appointment.
- A pair of shorts for her to wear to physical therapy
- Insurance co-pay for each discipline

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

# Endometriosis, Nutrition, and Exercise

You may be wondering if there is anything in addition to taking medication that your daughter can do to feel better. Since healthy nutrition and exercise play an important role in maintaining overall health, choosing foods that are high in vitamins and minerals, and exercising each day will help keep her body healthy.

## 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 is limited research on whether certain foods can help improve endometriosis symptoms. Some young women with endometriosis say they feel better when they eat a healthy diet, and some experts believe that eating certain foods can help endometriosis symptoms by lowering estrogen and reducing inflammation.

*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 daughter's endometriosis symptoms.*

## **CONSIDER MAKING CHANGES THAT CAN IMPROVE YOUR DAUGHTER'S HEALTH AND YOUR OVERALL HEALTH TOO:**

- 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 that my daughter is getting all of the nutrients she needs?**

Your daughter should aim to eat a balanced diet with lots of fruits and vegetables, whole grains, plant-based protein, lean meats, and healthy fats. Eating a well balanced diet can help her get the vitamins, minerals, and other nutrients she needs to keep her immune system and body healthy. You can help your daughter achieve this goal by stocking the fridge with lots of fruits and vegetables and keeping healthy snacks made with whole grains in the cupboards. Choose meats that are lean and include chicken, fish, tofu, and nuts for protein.

### **Should my daughter take a vitamin supplement?**

If your daughter eats three balanced meals a day along with healthy snacks, she is probably getting most vitamins and minerals through the food she eats. If she isn't eating foods from all of the food groups on a regular basis, she may benefit from taking a daily multivitamin (to make up for any of the vitamins or minerals she isn't getting in her diet). Encourage your daughter to talk to her health care provider to see if she should take a multivitamin or other dietary supplement(s).

### **Does my daughter need to take extra calcium and vitamin D?**

Some endometriosis medications work by lowering estrogen levels. If your daughter is on an estrogen-lowering medication for more than 6 months, she may be at risk of developing osteoporosis (brittle bones). Either of you can ask her gynecologist or her primary care provider if she should take calcium and vitamin D supplements to help protect her 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 show 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 exert an estrogen-like action in the body.

**It's always best to talk with the GYN team before your daughter decides to take any over-the-counter herbs or dietary supplements.**

## What information should I pay attention to on food labels when I'm grocery shopping?

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, vegetables, and meats) and has important information about portion size and nutrient content.

## Will exercise make my daughter's endometriosis symptoms worse?

Probably not. In fact, exercise may actually improve her endometriosis symptoms. Daily exercise (about 60 minutes each day is recommended for teens) such as walking, swimming, dancing, and other cardio activities will help her to maintain a healthy weight and give her energy. It's a good idea for your daughter to check with her gynecologist 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. Encourage your daughter to communicate with her health care providers and ask questions about the right amount and type of exercise that's best for her.

- **Exercise releases endorphins.** When we exercise, our brain releases "feel good" chemicals called endorphins. These naturally occurring hormones work similarly to pain relievers to lower pain. It only takes about ten minutes of moderate exercise (any exercise that makes you sweat or breathe hard) for our bodies 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 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 everyone's overall health which may help endometriosis symptoms. Consider buying and preparing organic or plant-based foods that are high in fiber and omega-3 fats and are also low in saturated and trans fats. Remind your daughter to balance healthy eating with exercise she enjoys. Even if her endometriosis symptoms don't decrease as much as you both would like, eating a healthy diet has plenty of other health benefits!*

# Endometriosis and School Concerns

Your daughter spends a big part of her day in school where she needs support and guidance to deal with intermittent pain, fatigue, school absences, and other issues associated with endometriosis. As a parent you can be a strong advocate for your daughter.

Adolescence is a challenging time for teens and for their parents. Both teens and their parents have described “feeling like they are on an emotional roller coaster”. Combine adolescence with a chronic illness and the results can seem overwhelming. For parents it is especially hard to watch a daughter experience emotional and physical discomfort due to a medical problem. You probably want to do whatever it takes to fix the situation quickly; however, this is not always possible.

## How can I help my daughter deal with her endometriosis?

From the beginning, you should encourage your daughter to take part in her treatment plan so she can learn to manage her health care needs, such as communicating with her health care providers (HCP’s) and keeping track of her pain and periods. She can also be involved with making medical appointments and getting prescriptions filled. By learning to advocate for herself as well as how to effectively interact with her HCP’s, your daughter will be better equipped to transition into adulthood. Your daughter’s health care team can help her work towards this goal. If available, a social worker or counselor specially trained to help girls cope with chronic illnesses can be of great support.

*It can be useful to think about school challenges as either short term or long term dilemmas. Short term problems might include factors that interrupt her school day such as doctor appointments, episodes of acute pain, and occasional school absences due to pelvic pain. Long term issues include extended school absences due to chronic and severe pain, chronic fatigue, surgery, and recovery. These issues, and possible solutions, can be addressed well in advance with your daughter’s school.*

## **FIRST, CONSIDER THE FOLLOWING QUESTIONS:**

### **Is there a way to predict when my daughter will have acute pain?**

There may or may not be a pattern to your daughter's pelvic pain and there often is no predictability to when it will come or when it will cease. In fact, a young woman could be fine and suddenly have an acute bout of pelvic pain. This may inhibit your daughter's ability to participate in sports or other activities, or her perception that she can participate. Acute pain is also likely to affect her academic performance. Evaluation of sudden or acute pelvic pain often requires a medical consultation and diagnostic tests to rule out other possible reasons for her pain (such as appendicitis or pelvic inflammatory disease), even if she has an active diagnosis of endometriosis.

### **How can I advocate for my daughter at school?**

The most important thing you can do to advocate for your daughter, (along with her help) is to develop an "endometriosis education plan" for her teachers, school nurse, coaches, and other important adults in her school. The more accurate information her school faculty has, the more they will comprehend the diagnosis of endometriosis and how it affects her specifically. Any student with endometriosis should be evaluated on an individual basis so that specific needs can be addressed. As a parent you can encourage your daughter to take an active role in her education. When your daughter has a chronic illness this includes considering both academic AND medical issues that impact her school experience.

*Some families find it helpful to follow a yearly timeline based on the typical school calendar. If your daughter is diagnosed during the school year, you and she can adjust these meetings accordingly.*

## **BEFORE SCHOOL BEGINS: SCHEDULE A MEETING WITH SCHOOL STAFF**

Many parents contact their daughter's school and make an appointment to meet with their daughter's guidance counselor and school nurse prior to the beginning of the school year. If you are unable to make an appointment before school begins, try to schedule the meeting within a couple of weeks after school starts. Some parents and daughters decide that it's better to wait until after school starts so the faculty has the benefit of meeting your daughter first to help them identify her needs and/or challenges. Your daughter should be given the opportunity to participate in all of these meetings (phone calls, e-mails) so that she can express any concerns she may have. It is essential for her to feel a part of the discussion, which is, after all, about her body.

Sometimes, parental involvement may be perceived by school staff as overprotection. You are not being overprotective. You are simply advocating for your daughter and educating the adults who have the most contact with her during the day about the challenges she faces with endometriosis. Your goal should be to foster a spirit of collaboration between your family and your daughter's school so that she is able to thrive academically. Keep in mind that it takes time for some accommodations to be made; therefore it's best to address your daughter's needs as soon as possible in the school year and update the plan as things change, or at least once a year.

### **What can my daughter and I do to prepare for a meeting with school staff?**

In preparation for the initial meeting at your daughter's school, we encourage both you and she to put together packets for the school staff with information about endometriosis. The initial information you provide should be concise and to the point so that the staff can have time to read it and understand the essential facts about endometriosis, such as the guides from [youngwomenshealth.org](http://youngwomenshealth.org). These guides are intended for educational purposes. You may want to add additional information for the school nurse, such as a list of your daughter's current medications. Find out what the state regulations are regarding students carrying and/or taking medications during the school day. Other information, such as medical history and names/numbers of health care providers, should be shared only with your daughter's permission and only if you both feel it's necessary.

### **What are the goals of the initial school meeting?**

Your job at the meeting is to advocate for your daughter and establish credibility with the staff. If your daughter doesn't look ill, teachers may assume she is fine and not understand why provisions are necessary. You'll need to discuss the symptoms of endometriosis including the sudden onset of pain and the side effects of her treatment. Be clear that symptoms of endometriosis manifest themselves in different ways with each young woman. Response to treatment is also variable.

**A plan to address missed schoolwork should be established** in the event your daughter is absent from school due to her endometriosis. It is often helpful for your daughter to have a "point person" in each class who will automatically contact her with homework assignments if she misses class. Both you and your daughter should keep in mind that every student must complete a certain amount of school work. Every effort should be made so that she doesn't fall behind. Since teens with endometriosis often experience times of pain and fatigue, keeping up with school work can be challenging and requires good communication and cooperation from everyone involved.

**Plan a follow-up meeting mid-fall or after the first report card.** At this time both you and the school will have a good idea how well your daughter is doing academically and if there are any areas in which she needs help. The number of her absences will also be recorded, as well as “late days”. If necessary, a home tutor can be discussed. Your daughter should be encouraged to share her perception of the school year thus far: what has worked, what has not been helpful, and any other input. It’s important that she feels empowered to advocate for herself. She may feel more comfortable writing down her concerns and sharing them with both you and her teachers on paper; regardless, her input is essential.

**Check in with the team again at the end of the school year.** Discuss your daughter’s school year and consider her grades, school absences, visits to the nurse’s office for pain management concerns and any other issues that have come up throughout the school year. This is also a good time to reflect on the successes and put a preliminary plan in place for next year with any anticipated modifications. If your daughter has an IEP (Individual Education Plan) or a 504 plan, you both may want to consider including input from representatives of these plans.

**Below are some examples of school interventions contributed by mothers of teens with endometriosis.** Remember that the best advocacy you can provide for your daughter is based on her needs, so use the following information only as a guideline.

- Assignments could be modified during periods of frequent absences.
- A folder with her homework assignments could be kept in the office so a parent could pick it up at the end of a school day.
- Time could be extended for class work and make-up work.
- Extra time could be given to get to class. The distance between classes may be a factor.
- Assignments could be given out the day before her medical appointments so that she can complete the work ahead of time.
- Your daughter’s school schedule could be adjusted to give her study or rest periods during the day and still meet academic requirements.
- Homeroom could be reassigned so that it is closer to her classes and her locker.
- Keeping an extra set of books at home will reduce her daily backpack load.

- A home tutor could help her keep up with missed work so that she is not overwhelmed when she returns to school. Some schools have peer tutors, such as National Merit Scholars, who can be very helpful in “keeping up”.
- Your daughter should have unlimited access to the nurses office. Teachers should be sensitive to any complaint and have her go to the nurse office for a consultation.
- An Individual Education Plan (IEP) could be implemented according to federal/ state regulations. The Individuals with Disabilities Education Act (1975) mandates that anyone who is physically challenged be given an appropriate public education under the least restrictive circumstances. This is a federal law that provides for accommodations. If your daughter qualifies for a 504 plan it is important to have this in place BEFORE she goes to college, as these accommodations will extend into her college years. You can get information about the requirements from the school’s Special Education department.

*Good communication and frequent updates between you, your daughter, and the school system is essential to ensure your daughter’s academic success.*

### **What should I do if my daughter refuses to go to school (on any given day or several days in a row)?**

Despite the best laid plans, there are going to be some days when your daughter feels that she is unable to go to school due to pelvic pain, fatigue, or both, and you are questioning her decision. There are several things you can do to both anticipate days like this and deal with them as they come up. It is essential to determine beforehand, when your daughter is feeling comfortable and calm, the criteria for staying home. Have a conversation with your daughter about both tolerable and intolerable levels of pain. Discuss what things she can do to manage the pain in school and remind her of her support system. If you both operate on the assumption that she must go to school every day, even for part of the day, it will be easier to make an infrequent adjustment. Make sure she is getting up early enough every day to get ready for school, have breakfast and take her medication before she decides that her pain is intolerable. Sometimes it is useful to discuss the academic consequences of missing a given day (for example: having to reschedule a test, missing a deadline, creating an overflow of homework) and a compromise can be reached. Ultimately, you, she and the school need to develop a balance between responding to both her academic responsibilities and her endometriosis.

### **Is it normal to feel overwhelmed sometimes?**

Yes! Having a teen with a chronic illness can be exhausting even if you have total cooperation with school staff, family, friends, and your daughter!

### **Other parents of teens with endometriosis share your concerns and offer the following tips:**

1. Take care of yourself first. The more calm perspective you have on the situation, the better for everyone.
2. Take walks or exercise to clear your mind.
3. Listen to relaxation material and/or take a yoga class.
4. Enjoy time with your friends and family.
5. Use a journal to record your thoughts and feelings.
6. Talk with other parents of daughters with endometriosis.
7. Spend time with your daughter that is NOT focused on endometriosis.

# Endometriosis and College Planning

Planning for the day when your daughter goes off to college is a time filled with mixed emotions. As a parent you probably know that college life will open new doors as well as many opportunities for your daughter and it is also a time in her life when she will be growing personally. Her job will be to learn how to take care of herself and live independently. It can be difficult for both of you while she is learning how to manage her life, since she may be making decisions on her own for the first time. For your daughter, college is a chance to make new friends, try new activities, learn new things, and set up a home away from home. For you, it is a time of adjustment and letting go. Allowing your daughter to advocate for herself and problem solve may be a tall order if you have been managing most aspects of her life, including her health issues. However, it is likely that she has gradually taken on more responsibility during the last few years.

*There are many things to consider when helping your daughter plan for college. If she has endometriosis, and is planning on living away at school, there are additional things to consider. **We hope that the following information will answer your questions and offer helpful advice.***

## Should my daughter know about her health insurance coverage?

Yes. It is important that your daughter know exactly what kind of health insurance coverage she has. For example, some insurance policies will only provide coverage until a child is 18 or 19 years old. Other policies may continue to provide coverage beyond this age, if the child is a full-time student. Tell your daughter how long she will be covered and give her the contact information along with an insurance card. You or she can check with the admissions department at her college to see if she needs to buy an additional "student insurance policy" while she is a student. If you know she isn't covered by your family's insurance plan while at college, make sure she signs up for a special "student insurance policy".

Most insurance companies require a student to complete a form every year documenting that they are a full time student. If they don't complete the form, the insurance company may not cover your medical bills. **Complete the form!**

*Before your daughter leaves for college, or as soon as possible, ask your insurance company to send you a summary of your family's benefits. You both should know the answers to the following questions:*

1. How long will my daughter have insurance coverage? (For example, up to what age is she covered? Does she 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 she contact the insurance company within a certain amount of time if she requires emergency services?
4. Is there a waiting period for certain services?
5. How much is the co-pay for general medical, specialty, and urgent care appointments?

*If you're unable to find the answers by checking your insurance policy, encourage your daughter to call the insurance company and talk with a representative. Remind her to write her answers down someplace in her agenda or a notebook that she'll be taking to college.*

### **What does my daughter need to know about the health services at college?**

She will need to find out:

- When the Health Center is open
- What kind of services are provided
- Who she can talk to if she has any issues related to her endometriosis
- How to reach someone if she has 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, she should get the name and number before she needs it.)

- If someone at the Health Center can administer her Lupron Depot® injections (if applicable)

*Your daughter should know the location of the closest hospital to her college in the event of an emergency, or if she needs more care than her college Health Center can provide. She should also find out what kinds of services are offered, and if students are transferred to another hospital if more specialized care is needed.*

**Is there anything my daughter should do (because she has endometriosis) before she leaves for college?**

1. **Tell her to make an appointment with her gynecologist 1–2 months before she leaves for college.**
2. **Encourage her to keep at least a 1 month record of her pain and symptoms** (pages 12–13 in her endo resource booklet) and bring it with her to her appointment.
3. **Stress that it is very important that she tell her gynecologist** about her concerns, her symptoms, what helps to relieve her pain and what makes it worse.
4. **Suggest that she talk to the GYN team about a plan** for when she experiences pain or other symptoms while away from home. (This will give her control and comfort).
5. **Be sure to have your daughter get her prescriptions filled** with enough refills to last until she returns for a follow-up appointment. It is also a good idea to get the name and number of a pharmacy near her college campus.
6. **Have her schedule follow-up visits with her gynecologist ahead of time** so she can be seen during semester breaks.
7. **Help her request a copy of any recent operative notes from the medical records department** (if she has had surgery for endometriosis) from the hospital where she has been treated. Advise her to put the reports in a notebook/binder and bring it with her to college with other important papers and/or ask the Health Center at school to keep a copy on file.

**Should my daughter find a gynecologist near her college?**

If your daughter will be attending a college that is far away from home, you and she may decide that having a local health care provider or a gynecologist is best for her.

It is a good idea to schedule an appointment with her new gynecologist before she starts classes so she can establish a relationship. She can help the communication among all of her health care providers involved in her care by providing each of them with a list of all of her medical providers, and a brief description of their roles in her 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 she is taking and any side effects or allergic reactions she has had in the past. Creating a timeline of when her symptoms began, date of surgeries, etc., is also very helpful.

*It may take a little while until your daughter feels completely comfortable making her needs known since she will also be adjusting to college life. As she works with her new health care providers, she will soon learn how to advocate for herself so she can help coordinate her care.*

### **Should my daughter talk with her professors about having endo?**

Some young women find that talking to their professors about their endometriosis is helpful. Your daughter may feel awkward at first about approaching her professors. However, most college faculty appreciate students who come to them early on in the semester if there might be a problem that could potentially affect learning. If she finds her courses challenging because of pain from endometriosis, she should definitely speak with her professor(s) again. The longer she waits, the more overwhelmed she may become. You can explain to her that she does not have to give detailed information about her medical condition unless she wants to. She can simply explain that she has a “chronic disease with chronic pain”. Since endometriosis affects approximately 5 million women and girls, she may find that her professor is familiar with it.

### **Is there anyone else my daughter should talk to about her endo?**

It can be helpful to have 1–2 designated people at your daughter’s college Health Center as her “liaisons” – one person to whom she can go to if she needs medical assistance and another person who can offer her emotional support. These people should be capable of offering your daughter guidance if her pain interferes with her academics.

### **What are some ways to help my daughter deal with her college workload?**

Learning to use the course syllabus can be helpful for your daughter in dealing with her college workload. The syllabus keeps her informed about what is expected of her for each class, and allows her to plan her course work accordingly. An agenda can also help your daughter manage her time and plan ahead so she won't fall behind if she becomes ill. Recording lectures and then taking notes later can help if she has trouble concentrating in class. If she can't make it to class, she might be able to ask a friend to take notes or record the lecture for her. Most colleges also have Resource Centers that provide a variety of services to help students deal with heavy workloads.

### **Are there any special services on college campuses that help students with chronic illnesses?**

You and your daughter can check the college website to see if her 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. If she has a 504 plan, it will help her access special services.

*Learning to plan ahead particularly when dealing with a chronic illness will help your daughter to effectively advocate for herself and be aware of special services before she needs them, so she can make the most of her college experience.*



# Your Daughter's Medication List

Your daughter should be aware of the medications she is taking, how much and how often she should take them, as well as the benefit and potential side effects of any medication she is prescribed. Please encourage your daughter to fill in her Medication List located in the back of her booklet (page 69). She should also include over-the-counter medication she takes on a regular basis. If you would like, you can also keep a record of her medications below.

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

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

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

Medication \_\_\_\_\_  
Dosage \_\_\_\_\_  
Prescribed By \_\_\_\_\_  
Date Started \_\_\_\_\_ Date Stopped & Why \_\_\_\_\_  
Reason for Taking \_\_\_\_\_  
Side Effects (if any) \_\_\_\_\_

Medication \_\_\_\_\_  
Dosage \_\_\_\_\_  
Prescribed By \_\_\_\_\_  
Date Started \_\_\_\_\_ Date Stopped & Why \_\_\_\_\_  
Reason for Taking \_\_\_\_\_  
Side Effects (if any) \_\_\_\_\_

Medication \_\_\_\_\_  
Dosage \_\_\_\_\_  
Prescribed By \_\_\_\_\_  
Date Started \_\_\_\_\_ Date Stopped & Why \_\_\_\_\_  
Reason for Taking \_\_\_\_\_  
Side Effects (if any) \_\_\_\_\_

Medication \_\_\_\_\_  
Dosage \_\_\_\_\_  
Prescribed By \_\_\_\_\_  
Date Started \_\_\_\_\_ Date Stopped & Why \_\_\_\_\_  
Reason for Taking \_\_\_\_\_  
Side Effects (if any) \_\_\_\_\_

# 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 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.



# Evaluating Health Information

Books, magazines, and the internet are three major sources of information about health, but just because the information is published doesn't mean that it's reliable. Sometimes a book or website that looks trustworthy is based on opinions rather than facts, and sometimes the information is just plain wrong.

**QUESTION THE SOURCE OF THE INFORMATION** – Here are some questions to help you decide if the information is biased:

- Who created the information? Are they trying to promote a product, idea, or agenda?
- Is there a valid contact or an “About Us” information page on the website?
- Is there advertising presented along with the information? Is a variety of information presented, or just one point of view?
- Is the information from a medical or health–related organization? If not, what is the author or organization’s motivation for publishing health information?

**EVALUATE THE RELIABILITY OF THE INFORMATION** – Other things to consider:

- Is it easy to find out who created the information? The author and/or organization should be clearly identified, and contact information should be available. Is the site professionally managed and reviewed by experts in the field?
- Is the information up–to–date? Look for the date of the most recent publication. Health information and treatments change all the time, so old information may no longer be accurate.
- Who is the information created for? Content should be age–appropriate. For example, if intended for teens, it should be teen–friendly and written at an appropriate reading level.
- Does the site have sponsors? All sponsorship, advertising, or commercial interests should be clearly stated.

- Does the site credit sources? Statements such as “from my own experience” reflect the opinion of an individual rather than established facts from research.

**DON'T BE FOOLED BY WEBSITE CLAIMS** – Be alert to websites that credit themselves as the only source of the information or if the site blatantly discredits other sources of information.

**USE COMMON SENSE** – If the information appears unprofessional, it probably is. Compare the information you find on a website with information from other reputable sites.

**CHECK OUT WEBSITES** – It's important to take the time to check out a website before recommending it to your daughter. In the long run, it's good to know if the advice you are giving your daughter is reliable. Information published by medical societies, health care organizations (.org), the government (.gov), or nonprofit organizations are usually good sources of information.

# Additional Resources

## ONLINE CHATS FOR TEENS

### **The Center for Young Women’s Health**

[www.youngwomenshealth.org/chat.html](http://www.youngwomenshealth.org/chat.html)

Chats are held monthly for young women (ages 13 to 22) who have been diagnosed with endometriosis. The chats are moderated by a nurse specialist. Check the schedule and encourage your daughter to 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](http://www.youngwomenshealth.org)

Our website [youngwomenshealth.org](http://youngwomenshealth.org) is a trusted source of health information written by medical professionals and updated on a regular basis. It is an award winning website featuring health guides, quizzes, and online chats. 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**

[www.endometriosisasn.org](http://www.endometriosisasn.org)

USA Phone Number(s): 414–355–2200

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**

[www.endocenter.org](http://www.endocenter.org)

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

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, thus 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.

*Please let us know about any online support groups or information that you've found helpful so that we can share additional resources with other parents/guardians.*

Last Updated March 12, 2015



