

# Endometriosis Toolkit

A Patient Empowerment Guide



Society for  
Women's Health Research

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## About SWHR

The Society for Women's Health Research (SWHR®) is a nonprofit thought leader dedicated to promoting research on biological sex differences in disease and improving women's health through science, policy, and education. Founded in 1990 by a group of physicians, medical researchers, and health advocates, SWHR is correcting imbalances in health care for women by addressing unmet needs and research gaps in women's health. Thanks to SWHR's efforts, women are now routinely included in most major medical research studies and more scientists are considering sex as a variable in their research. Visit [www.swhr.org](http://www.swhr.org) for more information.

## About SWHR's Interdisciplinary Network on Endometriosis and Fibroids

SWHR's Interdisciplinary Science Networks identify knowledge gaps and opportunities to effect change for diseases and conditions that disproportionately or differently affect women. Launched in 2018, SWHR's Endometriosis and Fibroids Network is working to engage and educate patients, clinicians, and health care decision-makers about the burden of these diseases, which significantly impact women's lives.

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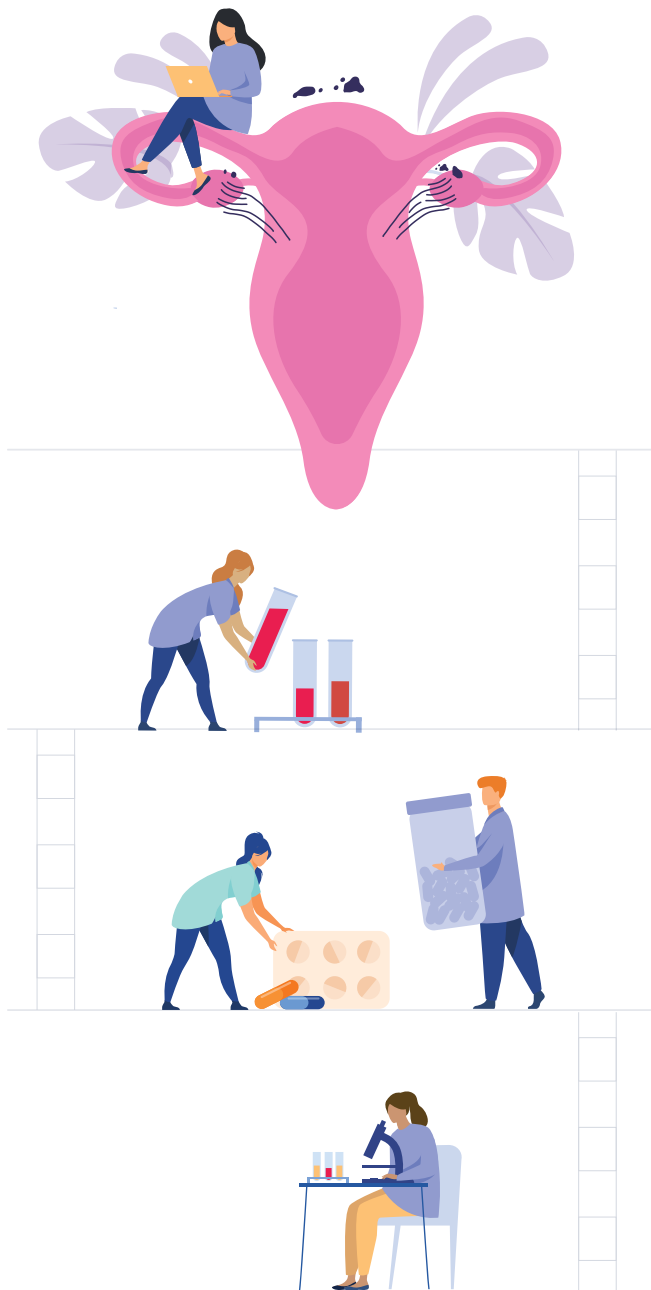
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# What Is Endometriosis?



**Endometriosis** is a common, chronic gynecological disease in which tissue that resembles the lining of the uterus (the **endometrium**) grows outside the uterus where it doesn't belong, leading to lesions, pelvic pain, and other symptoms.

These endometrial **lesions**, or **implants**, are usually found in the pelvic cavity – on the ovaries, fallopian tubes, bowel, or outer surface of the uterus. In some rare cases, endometriosis can spread beyond the pelvic organs. Like endometrial tissue, these lesions may thicken and bleed during the monthly **menstrual cycle**, which can cause swelling and pain, as the tissue has no way to leave the body and irritates the healthy tissue around it.

Women with endometriosis may also have bands of fibrous scar tissue inside the body called **adhesions**. Adhesions can cause pain that is distinct from the pain related to endometrial lesions. Adhesions are often formed after surgery but may also form as a result of local inflammation related to endometriosis.

## Common Symptoms

- Pelvic pain and pain between periods
- Lower back pain
- Pain during sex
- Infertility

## Other Associated Symptoms

- Heavy menstrual bleeding and bleeding between periods
- Rectal bleeding
- Gastrointestinal issues (constipation, diarrhea, nausea, and vomiting)
- Pain with bowel movements or urination
- Fatigue
- Nerve pain

## DISEASE BURDEN

**6.3 HRS**

lost in work productivity per week



**4.9 HRS**

lost in home productivity per week

There are physical, emotional, and financial burdens associated with endometriosis. SWHR's Endometriosis Toolkit is designed to help you overcome these challenges, so that you can advocate for your health and live well with endometriosis.

## Who Does Endometriosis Affect?

Endometriosis can develop in any girl or woman after the onset of their menstrual cycle. Although it is most commonly diagnosed in women in their 30s and 40s, endometriosis can begin in adolescence and can also affect women over 50 and postmenopausal women. Statistics about endometriosis are often underestimated because many women are not getting accurately diagnosed. The exact cause of endometriosis is still unknown, though researchers are studying many possible explanations.

### Endometriosis tends to occur in women who have:

- Relatives (mother, aunt, or sister) with endometriosis
- A medical condition that prevents menstrual blood flow from the body

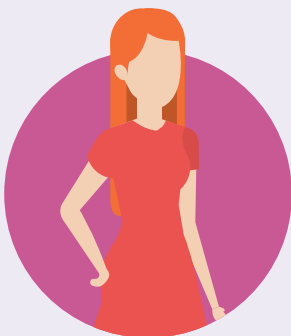
### Other indicators to look for:

- Your period started at an early age (11 or younger)
- Short monthly menstrual cycles (less than 27 days)
- Heavy periods that last more than 7 days

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# 200 MILLION WOMEN WORLDWIDE



17% OF ADOLESCENTS  
WITH PERIODS



10% OF REPRODUCTIVE-  
AGE WOMEN



5% OF ENDO PATIENTS  
ARE POSTMENOPAUSAL

## What Is a “Normal” Period?

During a woman’s reproductive years, she experiences a monthly discharge of blood and uterine lining, or **menses**, also known as a period. Globally, more than 800 million people are menstruating each day.

A “normal” period is not the same for every person. What’s normal for you might be different than for your friends or family members. **It is not normal, however, when your period-related symptoms cannot be managed with over-the-counter medications or when they significantly disrupt your life.**

Women with chronic pelvic pain and/or heavy menstrual bleeding are often unaware that their debilitating symptoms may be caused by gynecologic conditions such as **endometriosis**. The normalization of symptoms and the dismissal of pelvic pain as a supposedly inevitable part of the **menstrual cycle** can play significant roles in diagnosis and treatment delays for women with endometriosis. **Period symptoms can cause discomfort, but they should not be distressing.**

**EVEN  
YOUR “NORMAL”  
CAN CHANGE...**

It is not uncommon for your period to change over the years. For example, cycles are commonly longer and more irregular in younger women, but might become shorter and more consistent as you get older.



### A “NORMAL” PERIOD

- Occurs every 21 to 35 days
  - Lasts from 2 to 7 days
- Can be light or moderate flow (averaging no more than 1 soaked pad/tampon every 3 hours)



### “NORMAL” PERIOD SYMPTOMS

- Abdominal and/or lower back cramping
  - Bloating
- Sleep problems
- Food cravings
- Mood changes

## Keeping a Period Diary

Tracking your **menstrual cycle** is a good way to figure out what is “normal” for you. It can also give your health care provider a more complete picture of your symptoms, their severity, and their impact on your daily life.

### What to Track:

- ⦿ Start and end date
- ⦿ Flow – heaviness, changes from usual, how often you change menstrual products
- ⦿ Cramping/pelvic pain, including severity and impact on your ability to function
- ⦿ Irregular bleeding between periods
- ⦿ Late or missed periods
- ⦿ Gastrointestinal symptoms such as constipation or diarrhea, nausea, vomiting, or pain with urination or bowel movements
- ⦿ Mood and sleep issues

### Consult Your Doctor If You:

- ⦿ Miss a period (and you’re not pregnant)
- ⦿ Bleed for longer than 7 days
- ⦿ Have heavy bleeding (or go through more than one pad/tampon every hour or two)
- ⦿ Bleed in between periods
- ⦿ Experience abnormal or high levels of pain between periods or with sex. Everyone’s pain threshold is different and subjective, so it is important to recognize the changes in your own body.



### PERIOD TRACKING APPS

Clue



Eve



Flo



Period Tracker Period Calendar



Spot On

### ENDOMETRIOSIS APPS

Endo Empowered



EndoWheel



Flutter



MyEndometriosisTeam



MyFLO



Phendo

There are many health apps to choose from. The Federal Trade Commission provides **guidance to consumers** on how to select and use health apps while reducing privacy risks.

# Addressing the Stigma Around Menstruation



## Some people still refuse to say it: menstruation.

Societal and cultural **stigma** around menstruation can prevent women from voicing their concerns about life-disrupting, period-related symptoms, even to their health care provider. When stigma silences women, they are more likely to experience delays in diagnosis and treatment for gynecological disorders like endometriosis.

### 20% OF WOMEN

*do not feel comfortable talking about menstruation with health care providers*

### 64% OF TEENS

*believe society teaches people to be ashamed of their periods*

### 58% OF WOMEN

*have felt embarrassment because they were on their period*

### 10% OF MEN

*do not feel comfortable talking about menstruation with anyone*

## Overcoming Period Stigma

Stigma contributes to the negative and dismissive reactions that some people experience when they speak up about menstruation and their related symptoms.

### How can you help fight this stigma?

- Talk openly about periods with friends, family, and others
- Ditch the slang terms for menstruation
- Do not hide menstrual products
- Advocate for menstrual health education in schools
- Support menstrual movements like **National Period Day** and **Menstrual Hygiene Day**

## Help Fight Period Poverty

Period poverty refers to lack of access to safe, hygienic menstrual products, education, and waste management. Without these products, women may be forced to use the same sanitary product for a long period of time or to use an alternative product, such as paper towels, which is unsafe and can result in health problems.

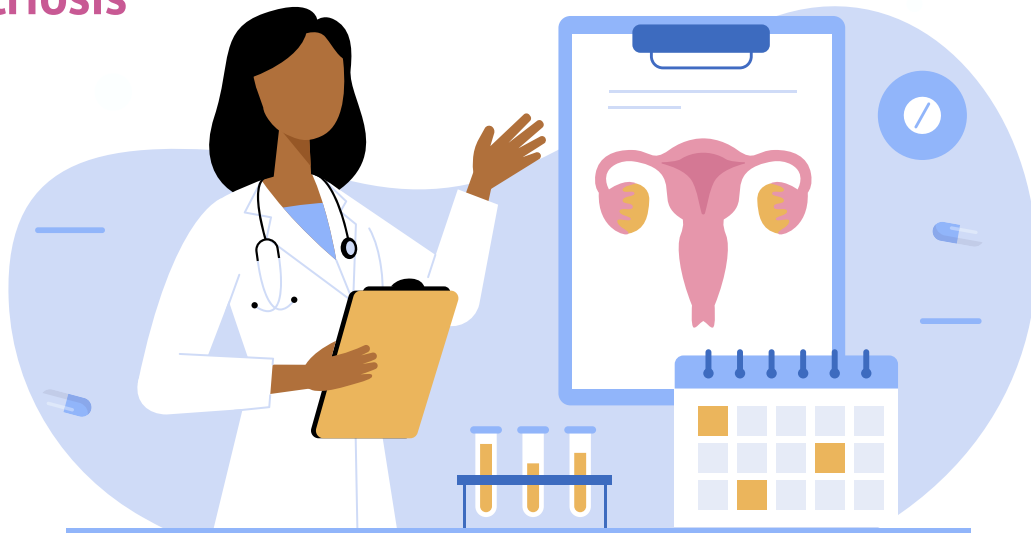
### How can you fight period poverty?

- Donate menstrual products to groups like **PERIOD, Alliance for Period Supplies**, or **I Support the Girls**
- Advocate for free menstrual products in places like schools, shelters, food banks, and prisons
- Support legislation that eliminates taxes on menstrual hygiene products

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**Being able to talk about your period and the symptoms you experience will help you and your doctor better understand your body and your health.**

# Diagnosing Endometriosis



Patients with **endometriosis** often face challenges on the path to diagnosis. Preparing in advance for your health care appointments and advocating for your own health may help you overcome potential hurdles.



**3 OUT OF 4 PEOPLE**  
*experience a misdiagnosis*



**3+ PHYSICIANS VISITED**  
*before endometriosis diagnosis*



**6.7 YEARS**  
*average delay in diagnosis*

Because of the **stigma** around menstruation, some women find it difficult or embarrassing to initiate conversations with their health care provider about period-related symptoms like pelvic pain and heavy bleeding. It is often only when the pain becomes severe or when infertility occurs that women consult their providers about a diagnosis and treatment.

**Open communication with your health care provider is the best way to ensure you get a timely diagnosis.**

## How Is Endometriosis Diagnosed?

Your health care provider will ask for you to describe your symptoms and may perform a **pelvic exam** and/or an imaging test, such as an **ultrasound** or **MRI**, to look for endometrial **lesions**. However, these methods are unlikely to find lesions unless they have developed into large cysts.

Traditionally, the primary method to diagnose endometriosis is through **laparoscopy**, a surgical procedure that allows the surgeon to view the organs inside your abdomen and collect tissue samples for pathological evaluation. However, most experts agree that a definitive diagnosis through laparoscopy is not necessary to treat presumed endometriosis with medical management.

## Surgical Stages of Endometriosis

The American Society of Reproductive Medicine classifies endometriosis into the following disease stages, based on the number, depth, and size of the **implants**.

**It is important to note that the disease stage does not necessarily reflect the severity of a person's symptoms or the impact on their quality of life.** For example, a person with stage 4 endometriosis may experience fewer life-disrupting symptoms than a person with stage 1.

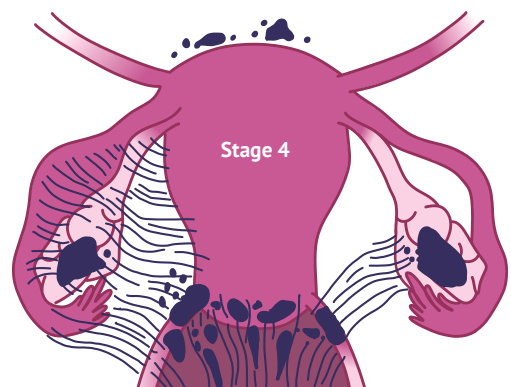
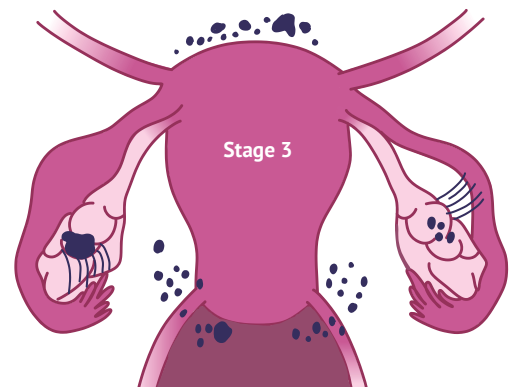
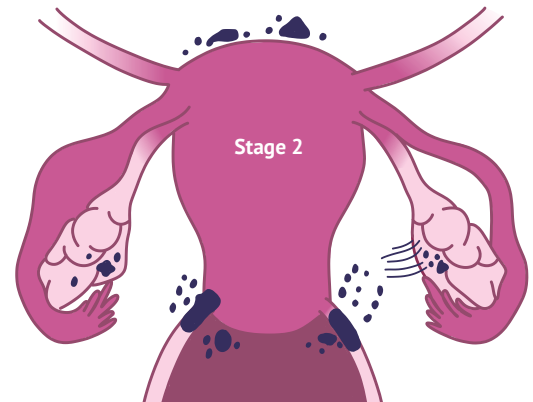
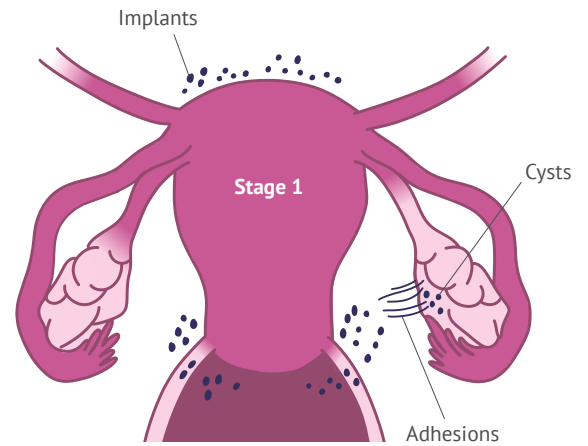
Each stage can present itself in so many variations that additional classification systems for endometriosis have been developed to describe lesion location, fertility index, and pain.



### What Is Adenomyosis?

Lesions can also occur in the muscle of the uterus (the myometrium), causing a related condition called **adenomyosis**, with some symptoms similar to endometriosis. Adenomyosis is not as well understood, but has been shown to also be present in up to 42% of women with endometriosis.

**Ask your doctor about evaluating your symptoms for the presence of adenomyosis too.**



## Talking With Your Health Care Provider

**Endometriosis and its symptoms can manifest differently for each individual. Make sure to communicate to your health care provider which aspects of your disease are most burdensome to you.**

Be graphic and descriptive about the frequency and severity of your pain. Give examples of activities that your pain prohibits you from doing and remedies you have tried to manage your symptoms. If you are uncomfortable verbalizing your experience, try to write it down in advance and share it with your provider.

### How to Prepare for Your Doctor Visit

To help your provider better understand your experience, consider bringing the following information to your appointment:



*A record of your menstrual cycle and related symptoms (such as in a journal or an app)*



*Your history of symptoms and, if applicable, past diagnoses or misdiagnoses*



*A record of past gynecological surgeries, tests, and treatments*



*A list of your current medications*



*Family history of endometriosis or undiagnosed symptoms*



*A support person (such as a spouse, family member, or friend) who can help you take notes and advocate for you*



*Names and contact info for other health care professionals who provide you with care*

## Questions to Ask Your Health Care Provider



**Researching and compiling a list of questions to ask your health care provider may help you to feel more prepared to engage in discussion around your diagnosis and treatment.**

Questions may vary depending on whether you are being evaluated for the first time or receiving ongoing treatment, as well as whether you are seeing your primary care physician, gynecologist, or other specialist.

- How can I know if what I am experiencing is endometriosis?
- What else could it be? What other conditions cause similar symptoms?
- Do I need to have a **laparoscopy** to fully diagnose what is going on with my body, or is there strong enough evidence based on my history and symptoms to start treatment?
- Would additional testing, like an **ultrasound** or **MRI**, be helpful in my case?
- Could any of my current medications make my endometriosis worse? (Have a list of medications and doses prepared to share with your provider.)
- What treatment options are available to me, and what are the risks and benefits of each of these treatments?
- Which treatment option or plan do you recommend that I try first? Why?
- What alternative treatments (e.g., acupuncture, yoga) might be worth trying?
- Are there any helpful strategies or practices I can do at home to assist with managing my symptoms?
- Would physical therapy for my **pelvic floor** potentially benefit me?
- What kind of surgical options are available? Can you recommend a skilled surgeon trained in minimally invasive procedures?
- Can you provide me with additional resources to learn more about endometriosis and similar diseases?
- Could you recommend resources to help me educate my family, friends, and employer about endometriosis?

**You can help foster clear communication with your doctor by asking direct and specific questions.** Don't be afraid to restate what your doctor has told you or to ask clarifying questions to ensure that you understand the answers.

## Treatments For Endometriosis

There is no cure for **endometriosis**, but there are many options to help you manage the symptoms of this chronic disease.

Treatment should take into account your age, the severity of your symptoms, and the progression of your disease, as well as your long-term family planning goals. Not all types of treatment will work well for every patient. Symptoms are likely to return if you decide to discontinue prescribed treatment.

### Non-Prescription Pain Relief Options

- Nonsteroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen or naproxen
- Heating pads, heat wraps, or a warm bath to help relax muscle tension and cramping
- Yoga, stretching, and regular low-impact exercises to help strengthen your pelvic area muscle groups
- Rest, relaxation, and meditation to help reduce stress
- Increased fiber in your diet (fruits, vegetables, beans, and lentils) to help minimize excess estrogen that can aggravate symptoms

### Prescription Pain Relievers

- Some high-dose NSAIDs require a medical prescription
- Muscle relaxants
- Antidepressants and **anticonvulsants**

#### DID YOU KNOW?

Antidepressants and anticonvulsants prescribed in small doses can help treat pain. Ask your doctor if this can help you manage your endometriosis symptoms.



### Hormone Therapies

These can be used to regulate your body's natural hormone production and/or function to help prevent new endometriosis **implants** and reduce pain and associated symptoms. As with any treatment, discuss potential side effects with your health care provider to determine the best option for you.

- **Hormonal contraceptives** (birth control pills, patches, vaginal rings) can make your periods lighter and shorter and may reduce pain associated with endometriosis.
- **Progestin therapies** (pills, contraceptive implants and injections, and IUDs with levonorgestrel) may reduce endometriosis pain by making periods lighter or stopping them altogether.
- **Gonadotropin-releasing hormones (GnRH) receptor agonists** (injections and nasal sprays) regulate estrogen levels to reduce endometriosis pain and bleeding and the size of endometriosis implants.
- **GnRH receptor antagonists** (pills and injections) control estrogen levels to reduce endometriosis pain.
- Danazol (synthetic androgen that can be taken orally or vaginally) can reduce pain by causing endometrial implants to shrink.

### Other Types of Treatment

- **Pelvic floor** physical therapy
- Transcutaneous electrical nerve stimulation (TENS) to treat pain in targeted areas
- Nerve blocks (local anesthetic injections) to target specific regions of pain at the nerve sources
- Muscle injections (e.g., botulinum toxin) to treat pelvic muscle spasms and pain
- **Cognitive behavioral therapy** to identify coping mechanisms to help reduce stress-aggravated pain

## Treatments (cont.)

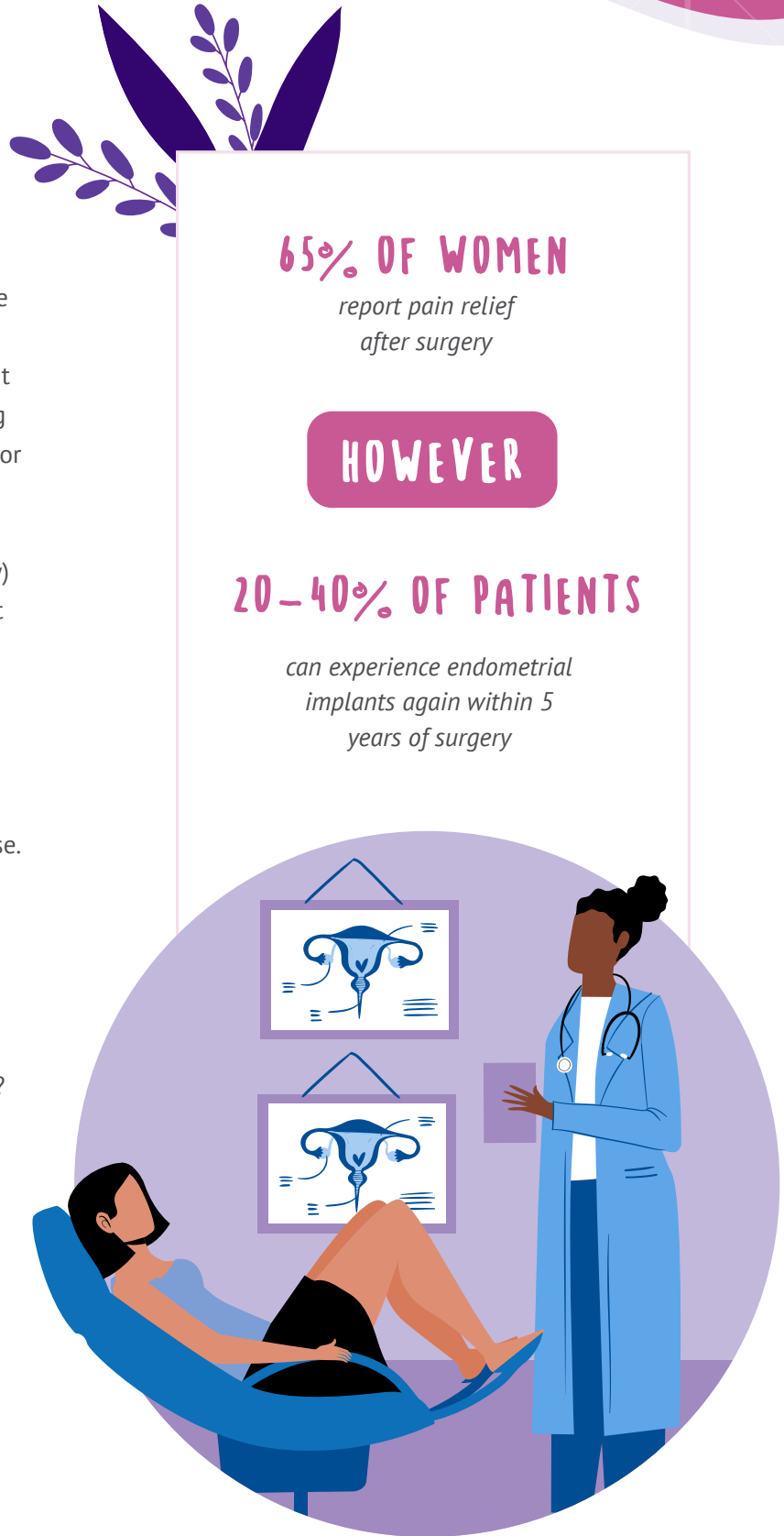
### Do I Need Surgery?

If your endometriosis symptoms are poorly controlled despite medication or other forms of treatment, surgery to remove areas of endometriosis growth and scar tissue may be helpful. For patients with moderate to severe symptoms, this type of surgery can be an appropriate but temporary fix, as pain is likely to return over time. Taking hormonal therapy after surgery, however, may eliminate or delay the return.

At one time, surgery to remove the uterus (hysterectomy) and/or ovaries (oophorectomy) was considered the most effective treatment for endometriosis. However, experts are moving away from this approach and focusing on less invasive treatment options, such as the medication, hormonal therapies, and other treatments previously mentioned. The surgical removal of your ovaries also depletes your body of estrogen and results in menopause.

### Before Committing to Surgery, Ask Your Provider:

1. What type of surgery do you recommend? Why?
2. How long will the surgery last? What is a reasonable expectation for recovery time?
3. What common complications might I have to anticipate?
4. What happens if my endometriosis pain persists after the procedure?
5. How will surgery affect my future chances of getting pregnant?



# Deciding on A Treatment Plan

## Things to consider when deciding your treatment plan:

- Your age
- Lifestyle and activity levels
- Symptom management
- Family planning goals
- Treatment efficacy and side effects
- Health insurance

When deciding on a treatment plan with your provider, your plan may incorporate a combination of approaches and may change over time. You should discuss with your provider(s) which treatments will address the endometriosis disease itself and which will address your symptoms, as well as your personal needs/goals for treatment now and in the future.

## Some other key topics to discuss include:

- How long you should wait before you can expect to experience positive results from your treatment
- Side effects of any medications and/or therapies, both physical (e.g., breakthrough bleeding, weight gain or loss) and emotional (e.g., changes in mood)
- Expectations for the frequency and severity of side effects, and how to handle them
- Recommended resources to help you understand your financial options for paying for treatment(s)



Do not hesitate to seek out a second opinion if you want another perspective on your diagnosis and/or treatment options.



It is also important to find out the details of your health insurance coverage for the treatment options you desire to pursue.

Ask your provider to outline what a follow-up plan for monitoring your health looks like – recovery time for any procedures, which specialists to consult, how often to schedule a visit, etc.

## Tracking Your Treatment

It is helpful to keep an accurate record or journal of your treatment activities and how each affects your symptoms and health. Share this information with your health care provider so that you can discuss any modifications to your plan that may be helpful or necessary moving forward.



## A Team Approach

A good primary care physician is important, but managing your endometriosis may benefit from the care of a multidisciplinary team. This might include specialists such as:

- Obstetrician-gynecologist (OB/GYN) for sexual health and fertility
- Endocrinologist for hormonal therapies
- Internal medicine practitioner or gastroenterologist for bowel and bladder problems, gastrointestinal health, and pain management
- Physical therapist for **pelvic floor** dysfunction and pain management
- Mental health professional for emotional health, sexual health, behavioral therapy, and coping skills
- Nutritionist or dietitian for nutritional counseling and health

# Endometriosis

## In Teens



**17%** OF ADOLESCENTS WITH PERIODS EXPERIENCE ENDOMETRIOSIS

**Endometriosis** is not uncommon in adolescents, ages 10–19 years old, and is the leading cause of severe pelvic pain during a girl’s period. At least two-thirds of adolescent girls with chronic pelvic pain unresponsive to hormonal therapies and pain relievers will eventually be diagnosed with endometriosis.

In the first two years after a girl gets her period, it is normal for her cycles to be irregular. After that, her cycle will usually become more regular, about every four to five weeks.

Tracking your periods will help you know if they are regular. You can use a calendar, write it down in a notebook, or use an app. More information on **Keeping a Period Diary** and a list of health apps are provided in the **Discussing Menstrual Health** section of SWHR’s Endometriosis Toolkit.

### When to Talk to Your Parents or Doctor

Many girls have cramps during the first few days of their periods. Mild discomfort can be normal, but if your periods are so painful that you are missing school and social events, and/or constantly taking pain medication with little to no relief, you may want to discuss the possibility of endometriosis with your doctor.

### Common symptoms in teens with endometriosis:

- Painful periods
- Abnormal or irregular menstrual bleeding
- Urinary frequency and urgency
- Nausea
- Gastrointestinal pain and bloating
- Constipation and/or diarrhea
- Trouble sleeping

A pediatrician may not be familiar with adolescent-onset endometriosis, so you may have to visit a gynecologist or other specialist to help you with diagnosing your condition. **A Doctor’s Visit Worksheet** is provided in SWHR’s Endometriosis Toolkit for you to fill out and take with you when you visit your health care provider.

**It is always good to discuss your experience and feelings with a trusted friend or family member. You don’t have to manage your endometriosis alone.**

**71%** OF TEENS FEEL SELF-CONSCIOUS DURING THEIR PERIOD

Some girls find it difficult explaining to friends and teachers why they miss school, sports, or other activities. If you feel embarrassed talking about your endometriosis or are concerned your condition is not being understood by teachers or coaches, ask your doctor to write a note so you don’t have to explain yourself. You can then work with them to be sure you don’t miss out on key assignments – or fun!

## Endometriosis And Fertility



Some women who experience issues with fertility may have **endometriosis**. There is no definitive reason as to why endometriosis is associated with slightly higher rates of infertility.

**60–70%**  
OF WOMEN WITH ENDOMETRIOSIS  
HAVE NO ENDO-RELATED ISSUES  
BECOMING PREGNANT

**It is possible that in patients with endometriosis:**

- Endometriosis tissue blocks or changes the shape of reproductive organs
- Chronic inflammation in the abdominal cavity hinders **embryo** implantation
- The layer of the uterine lining where the embryo implants does not function properly

The most important thing you can do while pursuing pregnancy is to have continued conversations with your doctor. You might have to adjust your treatment regimen or stop your medications for managing your endometriosis during this time. Your health care team can help you determine a plan for safe conception and a healthy pregnancy.

Treatment options to improve fertility include certain medications (such as clomiphene citrate) often paired with assisted reproduction methods (*in vitro* fertilization or **intrauterine insemination**).

### I'm Pregnant ... Now What?

Individuals with endometriosis who become pregnant should be carefully monitored by their OB/GYN. Most deliver healthy babies, but there is a higher rate of pregnancy complications, such as preterm birth.

For some people, pregnancy may temporarily lessen endometriosis symptoms, but this is not true for everyone. **Pregnancy should never be viewed as a treatment or cure for endometriosis.**

## Endometriosis And Menopause

Although menopause alleviates the symptoms of **endometriosis** for most women, some will continue to experience symptoms or even develop endometriosis after menopause.

### 5% OF ENDOMETRIOSIS PATIENTS ARE POSTMENOPAUSAL

As a woman gets older, her ovaries produce less of the hormone **estrogen** and her **menstrual cycle** begins to change and eventually stops, resulting in menopause. Menopause is the point in time 12 months after a woman's last menstrual cycle, typically in her late 40s or 50s.

This drop in estrogen typically results in relief from endometriosis symptoms. However, because the body still produces small amounts of estrogen, some women continue to have symptoms after menopause.



Surgical procedures that remove or damage your ovaries (e.g., oophorectomy or hysterectomy) can also result in the onset of menopause, regardless of age.

Hormone replacement therapy is commonly used to treat menopausal symptoms by supplementing the estrogen that the body has stopped making. However, this may reactivate pain and other endometriosis symptoms. In this case, your doctor may prescribe alternative hormonal therapies through oral contraceptives or an IUD to manage symptoms. Aromatase inhibitors are medications that can also provide symptom-relieving effects by blocking estrogen production.



Just like patients in any other life stage, the most important aspect to treating postmenopausal endometriosis is tracking symptoms and talking to a health care provider about any changes or pain experienced.

### Common symptoms in postmenopausal women

Pelvic  
pain

Gastrointestinal  
dysfunction

Ovarian  
cysts



Case studies have indicated that up to 19% of perimenopausal and postmenopausal women over 40 with unclear pelvic pain may have endometriosis.

There is thought to be a higher risk for malignancy in endometriosis that appears after menopause. If you experience abnormal symptoms after menopause, consult your doctor and discuss a treatment plan that is appropriate for your age and lifestyle.

## Wellness Tips For Endometriosis

Here are some strategies to help you maintain an active and healthy lifestyle along your journey with **endometriosis**.



### Exercise and Sports • LISTEN TO YOUR BODY.

Athletes often push their bodies to physical limits, but it is important to pay extra attention to changes and pain that might indicate an aggravation of your endometriosis symptoms. Low-intensity stretching exercises may help to relieve cramps and pain, so don't skip your warm up and cool down stretches. Be sure to give your body plenty of rest after long practices and events.



### Diet • SNACK WELL.

Healthy eating and drinking behaviors can reduce inflammation and manage nausea and bowel issues associated with endometriosis. Keep snacks in your desk or work bag so that you aren't skipping meals during a busy day. Think: fiber, fruits, veggies, and healthy fats. Make sure to drink plenty of water during the day, and reduce your caffeine and alcohol intake.



### Work and School • ASK FOR ACCOMMODATION.

In the United States, endometriosis is not classified as a disability, but that doesn't mean you cannot consider asking for reasonable accommodations at your school or workplace. Document and communicate your challenges, along with suggested ways that your employer or school can assist you in meeting their expectations for performance. Every environment is different, but accommodations might include a comfortable chair, scheduled breaks, adjusted or flexible hours, and/or remote work or attendance. Understand that this may require one or multiple conversations with your supervisor, institution, HR department, and even documentation from your doctor. On days that your symptoms are particularly difficult to manage, consider using sick or other appropriate leave.



**Prepare a handy survival kit with pads or tampons, pain medicine, and spare underwear.**

Keep one in your locker, car, work desk, and handbag, so you can access it in emergency situations.

## Wellness Tips (cont.)



### Travel • BE PREPARED.

Try to schedule travel during the less problematic times of your monthly cycle, and make sure you have enough medication to last the trip. Check for fitness center access to continue your stretching exercises and routine after a long drive or flight. Try to journal what you eat and drink that might be different from your normal regimen at home. Pack portable heat wraps or thermal pads to manage pain when you're on-the-go. Schedule enough time to rest and allow your body to recuperate after strenuous or high-intensity activities.



### Sexual Health • TALK ABOUT IT.

Remember, you did not cause your endometriosis and you have nothing to be ashamed about. Talk to your partner about how you are feeling physically and emotionally. Sit down together to figure out ways to make sex, intimacy, and even reproduction work better for both of you. To help with pain during or after sex, try taking a pain reliever one hour before intercourse. If pain, bleeding, or infertility continue to affect your sexual health and wellness, talk to a health care provider about your concerns. Consider taking your partner with you to your consultation, and hold them accountable if they aren't following through or listening to your issues.



### Rest and Relaxation • TAKE A BREAK.

Stress and anxiety can promote muscle tension and inflammation that can aggravate endometriosis symptoms and pain. Take mini breaks to stand or sit (depending on what you do all day) and keep your body limber. Schedule vacations or staycations during which you can recharge your body and mind.



### Community of Support • DON'T BE AFRAID TO ASK FOR HELP.

You don't have to battle endometriosis alone. Find a confidant (or two or three) that you can go to share your experiences and concerns. Ask them to hold you accountable for maintaining your health and wellness. You would be surprised how many individuals you already know that have also been impacted by endometriosis and are willing to be in your circle of support. You can expand your circle by exploring local or virtual support groups – ask your doctor or search online for additional resources.

## Glossary

- **Adenomyosis** – A medical condition in which tissue that normally lines the uterus (endometrial tissue) grows into the muscular wall of the uterus
- **Adhesions** – Bands of scar-like tissue that can cause pain for patients with endometriosis
- **Anticonvulsants** – A group of pharmacological agents used in the treatment of epileptic seizures that can also be used for management of nerve pain for patients with endometriosis
- **Cognitive behavioral therapy (CBT)** – A short-term treatment technique that helps individuals learn how to identify and change thought patterns that have a negative influence on their behavior and emotions
- **Embryo** – A fertilized egg in early stages of cellular division and development
- **Endometriosis** – A medical condition in which tissue similar to that which lines the uterus grows outside the uterus where it does not belong
- **Endometrium** – The mucous membrane lining the uterus, which thickens during the menstrual cycle in preparation for possible implantation of an embryo
- **Gonadotropin-releasing hormone (GnRH) agonists and antagonists** – Man-made versions of the naturally produced pituitary hormone GnRH that modifies its action in the body. Agonists initially produce a rise in GnRH (and an increase in estrogen levels), followed by a profound decrease. Antagonists directly inhibit GnRH without a rise in estrogen.
- **Hormonal contraceptive** – A type of birth control that uses hormones to prevent pregnancy. Hormonal contraceptives contain estrogen and progesterone, or progesterone only
- **Implant** – Endometrial growth outside of the uterus, usually found in the pelvis or abdomen
- **Intrauterine device (IUD)** – A contraceptive device fitted inside the uterus that physically prevents the implantation or fertilization of eggs
- **Intrauterine insemination (IUI)** – A fertility treatment that involves placing sperm inside a woman's uterus to facilitate fertilization
- **In vitro fertilization (IVF)** – A fertility treatment whereby an egg is fertilized by sperm in a test tube or elsewhere outside the body before being placed in the uterus
- **Laparoscopy** – A surgical procedure in which a fiber-optic instrument is inserted through the abdominal wall to view the organs in the abdomen or to permit a surgical procedure
- **Lesion** – Area of abnormal tissue that has suffered damage through injury or disease, such as a wound, ulcer, or abscess
- **Menses** – Vaginal bleeding resulting from the shedding of uterine lining as the ovum releases mature eggs, on average lasting 3–7 days; also known as menstruation
- **Menstrual cycle** – The monthly changes a woman's body goes through in preparation for the possibility of pregnancy. Each month, one of the ovaries releases an egg in a process called ovulation. At the same time, hormonal changes prepare the uterus for pregnancy. If and the egg isn't fertilized, menses occurs and the lining of the uterus sheds through the vagina
- **MRI (Magnetic Resonance Imaging)** – A medical imaging technique that uses a magnetic field and computer-generated radio waves to create detailed images of the organs and tissues in the body
- **Pelvic exam** – A physical exam of the vagina, cervix, uterus, fallopian tubes, ovaries, and rectum
- **Pelvic floor** – A base group of muscles that stretch like a hammock from the pubic bone (at the front) to the coccyx or tailbone (at the back) and from side to side
- **Progestin** – A synthetic form of the body's naturally-occurring hormone progesterone
- **Stigma** – A mark of disgrace (perceived or actualized) associated with a particular circumstance, quality, or person
- **Transcutaneous electrical nerve stimulation (tens) unit** – A device that sends small electrical currents to targeted body parts to relieve pain
- **Ultrasound** – An imaging method that uses high-frequency sound waves to produce images of structures within the body

## Toolkit Quick Links

### Period Tracking Apps

- **Clue**  
<https://helloclue.com>
- **Eve**  
<https://glowing.com/apps#eve>
- **Flo**  
<https://flo.health/>
- **Period Tracker**  
<https://apps.apple.com/us/app/period-tracker-period-calendar/id896501514>  
<https://play.google.com/store/apps/details?id=com.popularapp.periodcalendar>
- **Spot On**  
<https://www.plannedparenthood.org/get-care/spot-on-period-tracker>

### Endometriosis Apps

- **Endo Empowered**  
<https://apps.apple.com/ca/app/endo-empowered-by-melissa-m-turner/id1113833818>
- **EndoWheel**  
<https://apps.apple.com/us/app/endowheel/id1540917271>  
<https://play.google.com/store/apps/details?id=com.abbvie.endowheel>  
*This app was developed by SWHR's Endometriosis Toolkit sponsor, Abbvie.*
- **Flutter**  
<https://www.flutterhealth.com>
- **MyEndometriosisTeam**  
<https://www.myendometriosisteam.com/resources/myendometriosisteam-to-go-get-the-free-upgraded-mobile-app>
- **MyFLO**  
<https://myflotracker.com>
- **Phendo**  
<http://citizenendo.org/phendo>

### Federal Trade Commission: Guidance on Health Apps

- [https://www.ftc.gov/sites/default/files/u544718/flo\\_health\\_app\\_infographic\\_11022020\\_en\\_508\\_0.jpg](https://www.ftc.gov/sites/default/files/u544718/flo_health_app_infographic_11022020_en_508_0.jpg)

### Overcoming Period Stigma: Menstrual Movements

- **National Period Day**  
<https://www.everydayhealth.com/menstruation/national-period-day>
- **Menstrual Hygiene Day**  
<https://menstrualhygieneday.org>

### Help Fight Period Poverty: Advocacy Groups

- **PERIOD**  
<https://period.org>
- **Alliance for Period Supplies**  
<https://www.allianceforperiodsupplies.org>
- **I Support the Girls**  
<https://isupportthegirls.org>

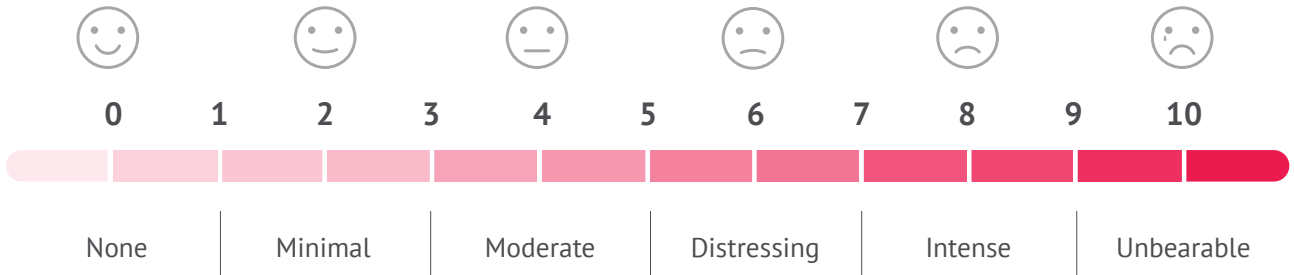
## Select References

1. Agarwal N, Subramanian A. (2020). Endometriosis – Morphology, Clinical Presentations and Molecular Pathology. *Journal of Laboratory Physicians*, 2(1):1.
2. As-Sanie S, Black R, Giudice LC, Valbrun TG, Gupta J, Jones B, Laufer MR, Milspaw AT, Missmer SA, Norman A, and Taylor RN, Wallace K, Williams Z, Yong PJ, and Nebel RA. (2019). Assessing Research Gaps and Unmet Needs in Endometriosis. *American Journal of Obstetrics and Gynecology*, 221(2):86-94.
3. Ballweg ML. (2004). Impact of Endometriosis on Women's Health: Comparative Historical Data Show that the Earlier the Onset, the More Severe the Disease. *Best Practice & Research: Clinical Obstetrics & Gynaecology*, 18(2):201-218.
4. Brigham and Women's Hospital. (2020). *Endometriosis Treatment Overview*. <http://www.brighamandwomens.org/obgyn/infertility-reproductive-surgery/endometriosis-treatment-overview> Accessed 1 Sep 2020.
5. Endometriosis.org. (2020). <http://endometriosis.org>. Accessed 18 Nov 2020.
6. Female Forward Together. (2020). *Stigma, Education, and Conversations*. <http://femaleforwardtogether.com> Accessed 2 Sep 2020.
7. Giudice LC. (2010). Clinical Practice: Endometriosis. *New England Journal of Medicine*, 362(25):2389-2398.
8. Health Essentials from Cleveland Clinic. (2019). *Can I Get Pregnant If I Have Endometriosis?* <http://health.clevelandclinic.org/can-i-get-pregnant-if-i-have-endometriosis> Accessed 1 Sep 2020.
9. Hussain S. (2020). *Four Stages of Endometriosis and What Are They?* <https://mygynae.co.uk/four-stages-of-endometriosis-and-what-are-they>. Accessed 2 Nov 2020.
10. Johns Hopkins Medicine. (2020). *Endometriosis*. <http://www.hopkinsmedicine.org/health/conditions-and-diseases/endometriosis>. Accessed 1 Sep 2020.
11. Kuhlmann AS, Bergquist EP, Danjoint D, and Wall LL. (2019). Unmet Menstrual Hygiene Needs Among Low-Income Women. *Obstetrics and Gynecology*, 133(2):238-244.
12. Mayo Clinic Editors. (2019). *Endometriosis*. <https://www.mayoclinic.org/diseases-conditions/endometriosis/symptoms-causes/syc-20354656>. Accessed 11 Nov 2020.
13. Nezhat C, Vang N, Tanaka PP, and Nezhat C. (2019). Optimal Management of Endometriosis and Pain. *Obstetrics and Gynecology*, 134(4):834-839.
14. Practice Committee of the American Society for Reproductive Medicine. (2012). Endometriosis and Infertility: A Committee Opinion. *Fertility and Sterility*, 98(3):591-598.
15. Tanbo T, Fedorcsak P. (2017). Endometriosis-associated Infertility: Aspects of Pathophysiological Mechanisms and Treatment Options. *Acta Obstetrica et Gynecologica Scandinavica*, 96(6):659-667.
16. U.S. Department of Health and Human Services Office on Women's Health. (2019). *Endometriosis*. [www.womenshealth.gov/a-z-topics/endometriosis](http://www.womenshealth.gov/a-z-topics/endometriosis). Accessed 2 Sep 2020.
17. Zullo F, Spagnolo E, Saccone G, Acunzo M, Xodo S, Ceccaroni M, and Berghella V. (2017). Endometriosis and Obstetrics Complications: A Systematic Review and Meta-analysis. *Fertility and Sterility*, 108(4):667-672.

# Doctor's Visit Worksheet

What symptoms have caused you to seek medical advice? When did they start? *(Try to be specific.)*

MM • YY		MM • YY
MM • YY		MM • YY



**Indicate pain level in the following situations:**

- During your period: \_\_\_\_\_
- During or after sex: \_\_\_\_\_
- On a moderate day: \_\_\_\_\_
- On a really difficult day: \_\_\_\_\_

**What do you typically do to manage pain?**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Describe how your symptoms affect your day-to-day living** *(work, school, home life, activities, etc.):*

\_\_\_\_\_

\_\_\_\_\_

**The reason for seeking time with your doctor:**

- Pain management
- Gain control over symptoms
- Identify a diagnosis
- Monitor disease progression
- Get a second opinion

**Describe your preferred qualities**

**in a health care provider:** *(Consider factors such as expertise, cost, age, gender, convenience, etc.)*

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Notes from doctor/ next steps:**

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Period Tracker**

- What age did your first menstrual cycle begin? \_\_\_\_\_
- How old are you now? \_\_\_\_\_
- How many days does your period last? \_\_\_\_\_
- How long is your menstrual cycle? \_\_\_\_\_  
*(from the start of one period to the start of the next)*

First day of your last period:

\_\_\_\_\_

Are you:

- Perimenopausal    Postmenopausal    I don't know

**Reproductive history** *(pregnancies, child births, infertility, etc.):*

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

**Medical history**

- Have you received any previous diagnosis for a gynecologic issue?    No    Yes \_\_\_\_\_
- Previous gynecological surgeries, tests, and treatments:

Procedure/Test/Treatment	Date	Notes (provider, results, etc.)

- Family history of endometriosis or undiagnosed menstrual symptoms *(grandmother, mother, aunt, sister):*

\_\_\_\_\_

\_\_\_\_\_

- Current medications *(include prescription and any over-the-counter meds you regularly take):*

Medication	Dose & Frequency	Notable Side Effects

- Your health care professional team:

Name	Specialty	Contact Info	Date of Last Visit