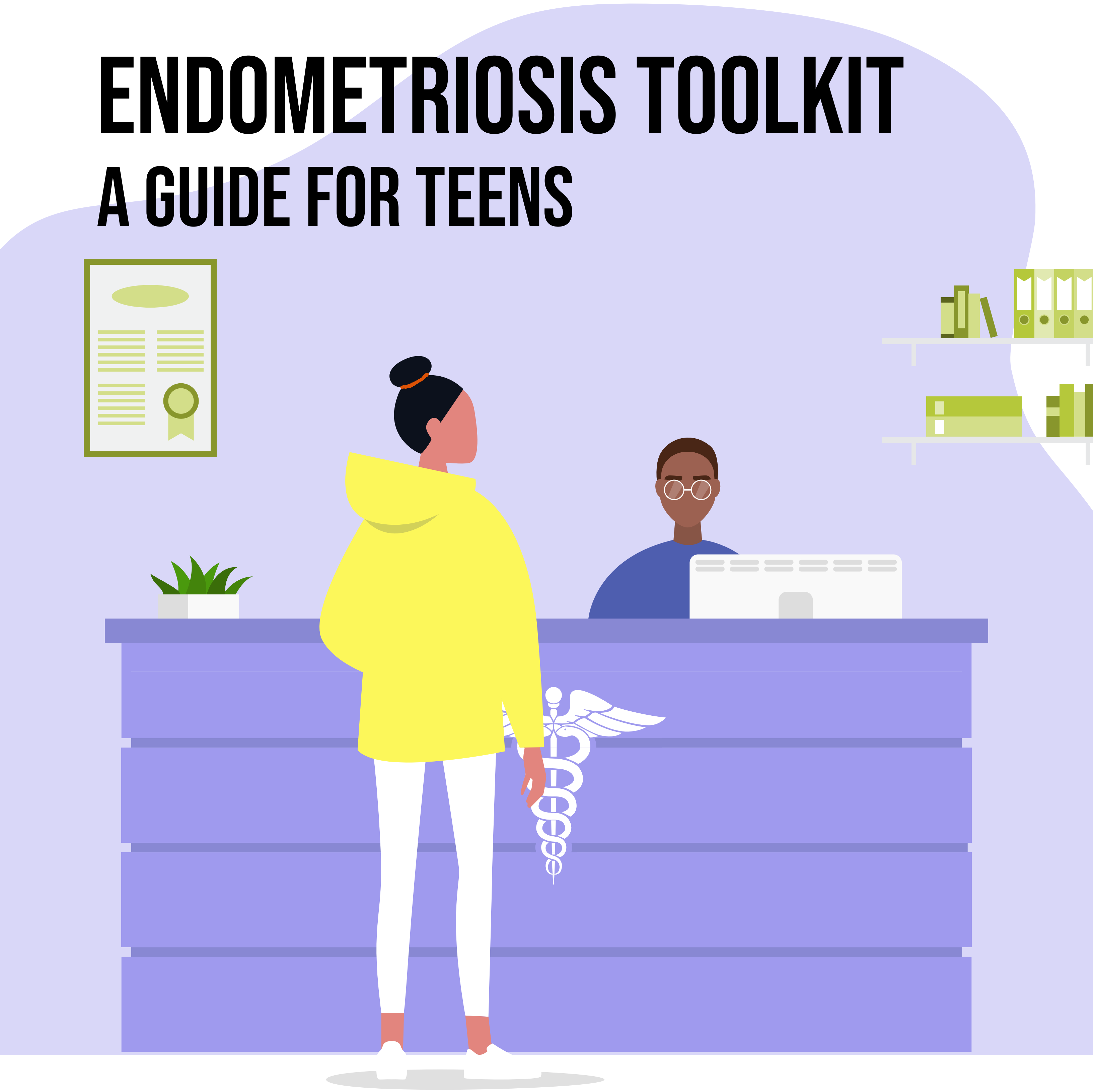
ENDOMETRIOSIS TOOLKIT

A GUIDE FOR TEENS



Society for
Women's Health
Research

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 for more information.

SWHR'S ENDOMETRIOSIS PROGRAM

SWHR Science Programs identify research gaps and address unmet needs in diseases and conditions that exclusively, disproportionately, or differently affect women. The Endometriosis Program was launched in 2018 to highlight the impacts of endometriosis on women's health and promote science-based health care policies to improve uterine health outcomes for women across the lifespan. The Program engages health care providers, researchers, patients, advocates, and health care policy decision-makers to explore strategies to address knowledge gaps, disease disparities, and relevant policies that present barriers to equitable and quality care for women living with endometriosis.

SWHR acknowledges that there are valued groups of people that may benefit from our materials who do not identify as women. We encourage those who identify differently to engage with us and our content.

SWHR extends our sincere thanks to the following sponsor for their support of this educational work.

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UNDERSTANDING YOUR PELVIC PAIN

Are you experiencing the following symptoms?

- Painful periods
- Pelvic or lower back pain between periods
- Pain with bowel movements or urination
- Heavy menstrual bleeding
- Irregular periods or bleeding between periods

Many girls have irregular cycles and experience unusual pains during the first two years of their period before they become more regular (every 4–5 weeks). However, if your periods are so painful that you are missing school and social events, or your pain medication isn't working well, it is important to talk to a trusted adult or your health care provider about your experience.

One potential cause for frequent and severe pain during and between periods is **endometriosis**—a chronic gynecological disease in which tissue that resembles the lining of the uterus (the **endometrium**) grows outside the uterus where it does not belong. These lesions most often cause pelvic pain and/or irregular menstrual bleeding. People with endometriosis are also more likely to experience trouble sleeping, migraine, irritable bowel syndrome, and fatigue.

Endometriosis Affects...

individuals of all races and ethnicities.

190 MILLION	6.5 MILLION
women worldwide	**women and girls ages 15–44 in the U.S.**

Endometriosis is not uncommon in girls, ages 10–19 years old. In fact, it is the cause of chronic pelvic pain for 64% of teens during their periods.[1] Because endometriosis is a condition that progresses over time, many people do not know they have it until their symptoms become severe.

2 out of 3

people diagnosed with endometriosis said they experienced symptoms as an adolescent.[2]

Tracking your periods every month (dates, symptoms, and flow) and when you experience pain can help you determine what is normal for you. You can use a calendar, write it down in a notebook, or use an app.

Check out this list of resources to help keep track of your periods from the Menstrual Health and Stigma section of SWHR's Endometriosis Toolkit.

You should note activities or things that seem to trigger or help to reduce pain. Consider:

- Foods
- Exercise or activities
- Sleep (hours and time of day)
- Stress

Remember: You do not have to manage your endometriosis alone.
Talk with people you trust about getting the care and support you need.

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[1] https://doi.org/10.1016/j.jpag.2020.07.011 | [2] https://doi.org/10.4293/jsls.2015.00019

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DIAGNOSING & TREATING ENDOMETRIOSIS IN TEENS

Solving a health concern starts with sharing your pain and experiences with someone (a family member or trusted adult) who can help connect you to the right health care providers.

Diagnosing Endometriosis

During your medical appointment, the health care provider may ask you questions about:

- **Your symptoms** – what are they and how bothersome they are
- **Your pain** – how bad does it get and where do you feel it
- **Your family history** – whether women in your family have had similar symptoms or were diagnosed with a gynecologic condition

The doctor may also perform a physical exam of your abdominal area and order an imaging test (ultrasound or MRI).

The traditional method to diagnose endometriosis is by **laparoscopy**—a surgical procedure that allows the doctor to view the organs inside your abdomen and collect tissue samples. However, most experts agree that your doctor can use the description of your symptoms, family history, physical exam, and imaging test results to presumptively diagnose and begin treatment for endometriosis.

Treating Endometriosis

While there is no cure for endometriosis, there are many options to help manage your symptoms and address bothersome lesions that have formed outside of the uterus. Treatment options include:

- **Pain Relief Medications** (over the counter or prescription) to reduce pain and inflammation
- **Hormone Therapies** to help relieve symptoms and reduce the growth of endometriosis lesions
- **Complementary Medicine Approaches** to manage symptoms and pain (e.g., heating pads, yoga, exercise, nutrition, meditation, and pelvic floor physical therapy)
- **Surgery** to treat or remove endometriosis lesions or surrounding tissue that has been affected by endometriosis

Your treatment plan may include a combination of approaches and will likely change over time. This plan should take into account your age, the severity of your symptoms, the progression of your disease, your lifestyle and activity levels, and your long-term family planning goals.

**Not all types of treatment will work well for every person.
Try to be patient with yourself while you discover a regimen that works well for you.**

Building Your Health Care Team

Your treatment plan may also require building a health care team from a variety of places and specialties. Some examples include:

LOCATIONS

- School health center
- Doctor's office
- Urgent care center
- Emergency room

HEALTH CARE PROVIDERS

- Doctor (MD, DO)
- Nurse practitioner
- Physician assistant
- Psychologist
- Physical therapist

MEDICAL SPECIALTIES

- Primary care
- Pediatrics
- Gynecology
- Gastroenterology
- Physical therapy
- Radiology
- Mental health
- Urology

LET'S TALK ENDOMETRIOSIS

Being an informed patient prepares you to make good decisions for your health. It is helpful to write down a list of questions before going to your medical appointments. These questions may vary depending on where you are in your journey to address your symptoms and the type of provider you are seeing.

Your health care provider might be a pediatrician, school nurse, urgent care or emergency room doctor, or gynecologist. Each provider can and should help you to better understand your body and your health before you leave.

A Health Visit Worksheet is provided in the SWHR Endometriosis Toolkit: A Guide for Teens for you to fill out and take with you when you visit your health care provider.

Initial Evaluation

- How can I know if what I am experiencing is endometriosis?
- What other conditions cause similar symptoms to what I am experiencing?
- Is there strong enough evidence based on my medical history and symptoms to diagnose endometriosis?
- Would additional testing be helpful to confirm or rule out endometriosis?
- Could any of my current medications make my symptoms better or worse?
- What are the different treatment options available for someone with endometriosis at my age? What are the risks and benefits of each of those treatments?
- What individual or combination of treatments would you recommend for my specific situation?

Ongoing Treatment

- What type of changes can I expect based on my treatment plan? When should I expect to see improvement in my symptoms?
- What additional activities or treatments can I do at home to help manage my symptoms?
- If your symptoms are not improving to your satisfaction or are getting worse: What are some other treatments we should begin to consider?
- What are things I need to consider about my endometriosis as I get older?
- What resources can you give me to help me educate my family, friends, and school about endometriosis?

Conversations with Your Family

Genetics can be a factor that increases risk for developing endometriosis. Looking into the medical history of your female relatives on both sides of your family might give insight into your symptoms and whether they could be associated with endometriosis. Talking to your mother, sisters, cousins, aunts, or grandmothers might also provide support throughout your health care journey.

Consider discussing the following topics:

- At what age did your family member's periods start?
- Does your family member experience frequent pelvic pain and/or irregular periods?
- Has anyone in the family been diagnosed with endometriosis or uterine fibroids?
- How does your family member manage their period or endometriosis symptoms?

HEALTH VISIT WORKSHEET FOR TEENS

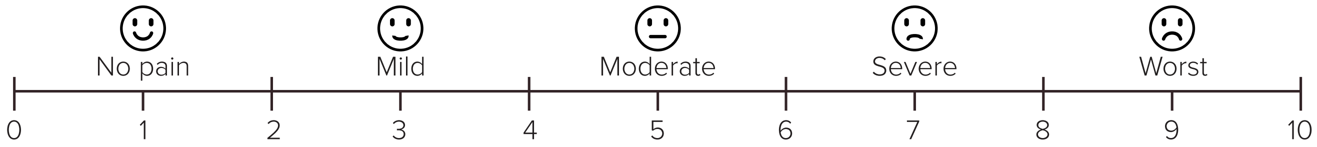
This worksheet can help you prepare for consultations with your health care provider. You do not have to answer every question.

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

Describe how your symptoms affect your day-to-day activities (e.g., school, home life, social activities, focus, etc.).

What makes the symptoms worse (triggers)?

What makes the symptoms better?



Indicate your pain level in the following situations:

On an okay day:

On a really terrible day:

During your period:

What do you usually do to manage the pain?

How often do you experience pain at a level of **5 or higher**?

Once a month

Once a week

2–3 days a week

4+ days a week

Goal for today's visit:

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

Period Tracker:

Age of first menstrual cycle:

Current age:

Average length of period (days):

Menstrual cycle length (days):

(from the start of one period to the start of the next)

Notes from doctor/next steps:

Medical History Worksheet

Have you received a previous diagnosis for endometriosis or a gynecologic issue?

No Yes

If yes, describe:

Previous urgent care/emergency room visits, gynecologic surgeries, tests, and treatments:

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

Family history of gynecologic or menstrual symptoms (mother, sister, aunt, grandmother, cousin):

Endometriosis
Uterine fibroids
Chronic pelvic pain
Adenomyosis
Polycystic ovarian syndrome (PCOS)
Undiagnosed symptoms:

Notes:

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	Last Visit

REFERENCES & RESOURCES

In-text Citations

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2. Dun EC, Kho KA, Morozov VV, Kearney S, Zurawin JL, Nezhat CH. Endometriosis in Adolescents. JSLS. 2015 Apr-Jun;19(2):e2015.00019

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Educational Resources

- Below the Belt: The Last Health Taboo (documentary): https://www.pbs.org/show/below-belt-last-health-taboo/
- Endometriosis Foundation of America ENPOWR Project: https://www.endofound.org/enpowr
- National Institute of Child Health and Human Development (NIH/NICHD): Endometriosis: https://www.nichd.nih.gov/health/topics/endometriosis
- SWHR Endometriosis Toolkit: A Patient Empowerment Guide: https://swhr.org/swhr_resource/endometriosis-toolkit-a-patient-empowerment-guide/

Support Organizations

- Endo Black: https://www.endoblack.org/
- Endometriosis Association: https://endometriosisassn.org/
- Endometriosis Foundation of America: https://www.endofound.org/
- National Latina Institute for Reproductive Justice: https://www.latinainstitute.org/
- The Endometriosis Coalition: https://www.theendo.co/

NOTES

ACKNOWLEDGEMENTS

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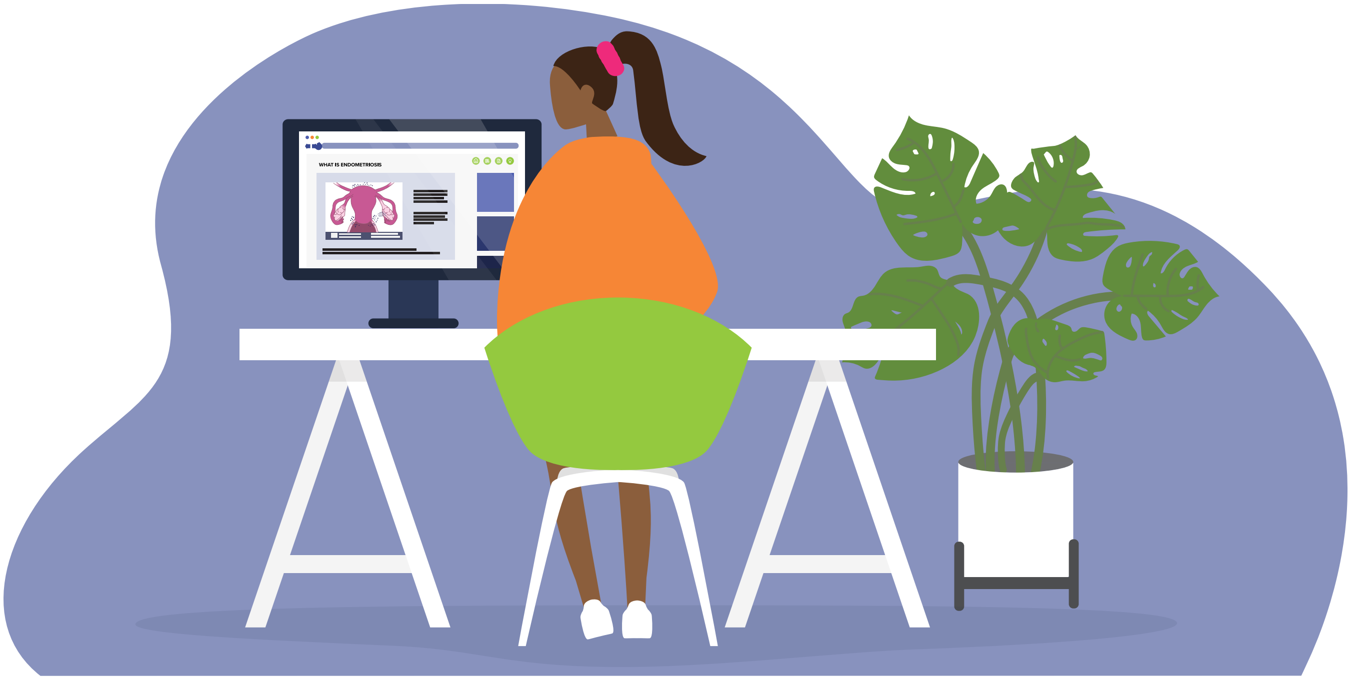

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