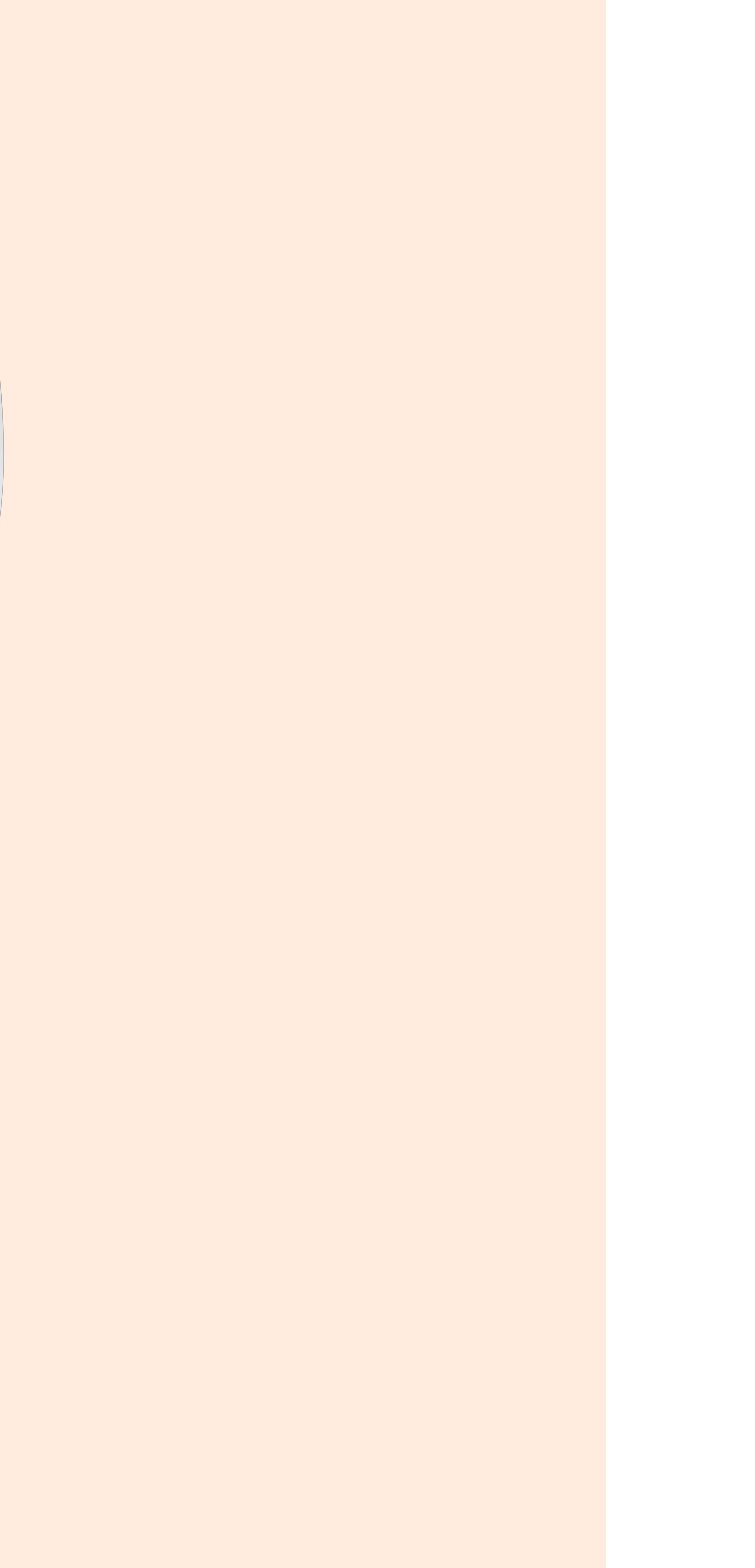




Your guide to understanding

Endometriosis & being diagnosed **Tempdrop**[®]





What is endometriosis?

Endometriosis is a disease affecting an estimated 11% of women across the world (although it's possible the numbers are actually higher). Many people shorten it to “endo” for ease of speech. Endometriosis is characterized by tissue similar to that which grows in the uterus (endometrial tissue) growing *outside* of the uterus.

These patches of endometrial-like tissue are called *endometrial lesions* and are most often found near the uterus, for example on the ovaries and fallopian tubes. However, they can also be found in other places as well, including the intestines, bowel, bladder, ligaments, and even other organs. While most often found in the abdominal cavity, these lesions can also be found outside of it.

As endometrial lesions grow and change, they tend to cause scar tissue and damage to the locations where they connect, which is often the root of infertility commonly found in those with the condition. The adhesions are also known to cause pain for many people, though some experience *silent endometriosis* in which they don't exhibit many, if any, symptoms.

What causes endometriosis?

Current research suggests that endometriosis is present at birth, rather than being a condition starting sometime after birth. That means it's likely either genetic or develops in utero (or a combination).





How to speak with your provider

Any time you go to see a provider, especially when you're seeking a diagnosis, you should be aware of how you communicate with them. We've seen plenty of suggestions from: "Remember, *you're* the one *hiring them!* You don't have to listen to what they say!" to "You should let them lead the conversation. After all, they have all of the information here."

At Tempdrop, we would like to suggest an approach that falls in between those two options:

1. You have experienced your specific symptoms and have lived with them, making you an expert on your own body.
2. Your provider has gone to school for many years, and has obtained specialized knowledge within certain topics.

Together, **you and your provider** are experts on everything regarding your concerns.

Note: Even if your provider isn't an expert on the concern you have, such as endometriosis, but you have to or choose to receive a referral from them, it's important to remember they're still your path to a specialist and they do have a lot of general knowledge.

Speaking to your provider in a way that indicates your own knowledge (having conducted at least some general research) while still being open to discussions is typically the best approach. One way to do this is to start with something like: "In the research I've done..." or "The data I've gathered about my own body tells me..." and then move on to your question.



Collecting data about your health & endometriosis

Gathering data yourself will often help to speed up the process of being taken seriously and receiving a diagnosis and effective treatment.

Remember: Getting an endometriosis diagnosis can take anywhere between 6-10 years⁽¹⁾, but gathering data independently may speed up the process.

If you're seeking a diagnosis, we suggest you collect data and conduct some basic research. (We've included some links at the end of this article to help you get started).

If you've received a diagnosis already (or have a provider who suspects endometriosis), it's still important to continue learning about the condition as long as it's affecting you, given that more data is becoming available regularly.



Collecting data about endometriosis

Not all doctors are well-educated on endometriosis, so it's important to make sure you have collected your own data and research concerning it. This will also help you during your appointment - see the suggestions on how to use this below!

Data to collect includes peer reviewed studies and publications with low personal bias. If you're not sure how to determine bias in a study (that's a whole skill itself!), look for information on how to use the Cochrane risk-to-bias tool, which can be found at <https://methods.cochrane.org/risk-bias-2>.

One of the best educational resources for endometriosis is called Nancy's Nook Endometriosis Education. You can join the [Facebook group](#), or check out the website <https://nancysnookendo.com/>⁽²⁾. The founder, Nancy Peterson, lived with severe endometriosis for many, many years. She is a nurse, and has been an endometriosis educator and advocate for a long time. She's spent many years creating worldwide lists of true endometriosis specialists and well-performed studies, which are available on the above linked website and group.

You can find more resources at the end of this guide.

Co-diagnosis & misdiagnosis

As with many other women's health issues, endometriosis shares symptoms with a number of other conditions. On top of this, laparoscopic surgery is the standard for diagnosis⁽³⁾ which may be difficult for some to receive for a variety of reasons.

The following is a list of common co-diagnoses (or comorbidities) and misdiagnoses for endometriosis (meaning symptoms may be caused by either or both):

- Irritable bowel syndrome (IBS)⁽⁴⁾
- Infertility
- Uterine fibroids⁽⁴⁾.
- Dyspareunia (painful sex)
- Interstitial cystitis (bladder pain and/or pressure)⁽⁵⁾
- Dysmenorrhoea (painful periods)
- Adenomyosis⁽⁶⁾
- Endometrial and/or uterine polyps⁽⁷⁾

If you have any of these diagnoses already, it may be important to bring them up to your provider when you speak to them.

Collecting data about your health

At Tempdrop, we're all about helping you understand your health. One of the best ways to do this is to chart your cycle using fertility awareness. For those of you who don't know, fertility awareness is essentially using your body's signs to interpret where you are in your cycle.

[Tempdrop](#) is revolutionary in that it has changed the charting world by making it easier and more reliable to chart your [basal body temperature](#). The overnight wearable basal body thermometer, with a full charting app attached to it, allows you to chart everything (more on that below) in one place! In the app, you can chart basal body temperature, cervical mucus, and any other symptoms you need to track in order to understand your cycle.



In addition, you can use the “Journal” tab in the app to add any symptoms you’d like that aren’t native to the app—but don’t worry, there are plenty that are just a simple click away from being recorded! When you use the Tempdrop device, you can also access your sleep patterns and sleep score through the premium app.

Since it is hard to get many providers to consider an endometriosis pre-diagnosis (a firm diagnosis can be done with surgery only), many providers will first evaluate you for likelihood of endometriosis and so it’s important to bring your own health data with you. For endometriosis, charting your cycles along with symptoms making you suspect endometriosis is a great starting point. The most common endometriosis symptoms include the following.

- Digestion and stomach problems
- Pain during menstruation
- Abdominal pain not associated with menstruation
- Pain during sex and/or when passing bowel movements
- Low back and/or leg pain
- Fatigue
- Infertility

There are other symptoms, as well, and not everyone with endometriosis has every symptom. If you experience any of these on a regular basis, charting them will provide more information to your providers. For example, the list includes pain associated with different parts of your cycle, which is easier to identify if you’re charting using fertility awareness. You can also chart symptoms along with your cycle charting—right in the Tempdrop app!



Provider Visits

Once you've done your research, the next step is to get a formal, accurate diagnosis. As with many other women's health issues, there are plenty of providers who don't fully understand endometriosis but continue to diagnose and treat it, often using outdated criteria and methods that may not actually get to the root cause. In addition, many of the symptoms overlap with other common women's health concerns, making it difficult to get the correct diagnosis. **This means it's incredibly important for you to do research and chart symptoms before seeing your provider.**

Finding a provider

While you may be tempted to go to your regular internist, family practitioner, or gynecologist, this isn't necessarily the best idea when it comes to endometriosis. This is because most standard providers don't know enough about endometriosis to diagnose and treat effectively. This lack of knowledge is one of the largest reasons the average time to receive a diagnosis for endometriosis is 6-10 years, and receiving effective treatment for it can take significantly longer.

Obviously in some health care systems, you'll need to receive a referral from your general practitioner before you can see an endometriosis specialist, so we've collected some suitable questions (see below)

to take to that doctor that will hopefully help you get a referral. If possible, when in these healthcare systems, you should try to get a private consultation (which may cost out-of-pocket) with an endometriosis specialist, who may be able to provide a letter to give to your GP explaining the importance of seeing a specialist.

When you call to schedule an appointment with your provider, it's useful to ask how long a standard appointment is. You may wish to ask for a longer appointment if possible.



Before the appointment

As we've already outlined, the benefits of preparing properly for an appointment with a provider is vital to getting answers and subsequent treatment. Using the research and data defined above will help you to prepare properly. In addition, arriving at your appointment prepared will indicate to your provider that you are serious, and that you have done your research and observations, making it much more likely for you to receive timely treatment. Here are some tips to help you get started:

- **Write down the symptoms you regularly experience:** Preferably take symptom charts with you if this is information you have readily available. With the Tempdrop app, you can export and share your full charting history directly with your provider. This means even at your appointment, you're only a few clicks away from sharing this data.
- **Gather your medical records (especially if this provider is new to you):** Taking all medical records in physical form or on your phone is also useful in case of computer and system difficulties while you're there.
- **Write out any questions you have that you would like answered:** You don't want to accidentally forget something in your appointment! We have a list of questions further down.
- **If you want a referral to another provider, bring that provider's information:** This is especially important in areas where you must receive a referral to a specialist, but oftentimes in other cases a referral will bump you up on the specialist's list as well. Depending on your current provider, it may also be useful to bring the specialist's bio, office

contact information, qualifications, and your written justification for the referral based on research.

- **Print off any information about endometriosis you feel is important:** Having a hard copy allows you to leave a copy for your provider if they want to look into it more. If you are seeing a general practitioner, it's very possible you've done more recent research than them.
- **Write out your agenda in priority order:** If you end up not having enough time, you will have covered the most important items to you. This agenda should include questions, requests, etc.

During the appointment

Often, provider visits are shorter than we would like as patients. However, this is commonly a function of the health care system rather than the specific provider or office. Therefore, prioritizing your appointment using your own personal priorities is often necessary.

- **Introduce yourself to your provider:** This can be a simple introduction of your name and what you've come in for. This is all in the chart, but hearing you say it will help them associate you with your charts.
- **Let your provider know what you've researched and brought with you:** The reality is that the majority of patients don't bring evidence, research, or much else with them. Being up front will help your provider be aware of the leg work you've already done, and will help them know where to start a discussion from their end.
- **Be 100% honest about your symptoms and concerns:** Don't exaggerate, but focus on what matters most to you.

- **Work through your agenda:** Be sure you're aware when the appointment is scheduled to end so you can stop a few minutes early if there are final items (like asking for a referral) that need to be addressed even if you don't get through everything else.
- **Communicate if you feel you aren't being heard:** Straightforward, simple sentences tend to work best for this. Consider the following:
 - "Can you explain the reasoning for this (test/prescription)?"
 - "I'm worried that we aren't communicating well. Here's why I feel that way..."
 - "Can you help me to understand point X."
- **Schedule a follow up appointment:** Especially if you haven't had time to address all of your concerns and questions. The follow up appointment may be with a specialist rather than this provider (see next point).
- **Ask how your provider will send their referral, if you're receiving one:** Will they call the provider you're being referred to? Do you need to follow up with this office or the one you're being referred to? How soon will the referral be sent?

If you're at an appointment with a provider who will be referring you to a specialist, here are some specific questions we've gathered to help you and your provider approach the problem from the same page.

- What background do you have in diagnosing and treating endometriosis?
- Are you willing to refer me to a specialist to get an accurate, correct diagnosis?
- Do you have studies providing evidence for the treatments you're familiar with?

Concluding the appointment

Believe it or not, how you end the appointment matters!

- **Ask what the next step is:** Even if you've discussed this during the appointment, it's good to clarify the next step right before your appointment ends to make sure everyone is on the same page.





Questions to ask your doctor – a guide

Here is a guide of questions you can use to speak to your doctor to ensure you get the correct testing, diagnosis and treatment plan carried out. This is just a guide for you to adapt for your personal needs accordingly. We also strongly recommend that you do additional personal research about the importance of the correct testing and the available treatments.

We have split the questions into sections to make it easier for you:

Testing

- Can you explain which test(s) treatment will be carried out/was carried out?
- Why wasn't X test carried out?
- Would additional testing might be beneficial?
- I would like to have laparoscopic surgery to confirm my diagnosis. Can you schedule that?

Diagnosis

- What is the basis for this diagnosis?
- Is my diagnosis on the basis of pain? If so, are there ways to rule out other root causes of the pain?

Treatment

- I've heard about X treatment? Would this be suitable for me?
- Do you feel that with X treatment my symptoms could be reduced?
- Can you explain the reasoning for this prescription?
- Are there any side effects I should be aware of with this treatment plan?
- Can you explain the reasoning for this treatment plan?
- How long should I trial this treatment before we look at other options if it isn't working?

If seeing a surgeon:

- How confident are you in removing all endometriosis present?
- What is your patients' recurrence rate for endometriosis?
- What tools and technology do you use for surgery?
- Did you complete a fellowship specifically for endometriosis excision?

General:

- Are you confident in diagnosing and treating endometriosis?
- Are there any other diagnoses that would explain my symptoms?
- Could my diet/medication be impacting the severity of my symptoms?

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Use code: [TEMPDROPFACEBOOK](#)





Resources and information

We know this is a lot of information to absorb, and it can be difficult to find current, quality information about endometriosis.

The following resources are the ones we directly used in this guide:

- <https://www.speakendo.com/about-endometriosis/testing>
- <https://nancysnookenendo.com/>
- <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD009591.pub2/full>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6235236/>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3015726/>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5694733/>
- <https://www.karger.com/Article/Abstract/487946>

Here is a starter list of other information and resources for the basis of your research:

- <https://methods.cochrane.org/risk-bias-2>
- <http://endopaedia.info/index.html>
- <https://www.tempdrop.com/blogs/blog/an-introduction-to-endometriosis-what-it-is-and-how-can-you-support-your-cycle>
- <https://www.tempdrop.com/blogs/blog/5-ways-to-support-endometriosis-with-nutrition>
- <https://www.tempdrop.com/blogs/blog/conceiving-with-endometriosis-increase-your-chances-for-a-baby-today>
- <https://www.endometriosis-uk.org/getting-diagnosed-endometriosis>
- <https://www.acog.org/womens-health/faqs/endometriosis>
- <https://cgf.cochrane.org/news/endometriosis-awareness-month-2021>

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