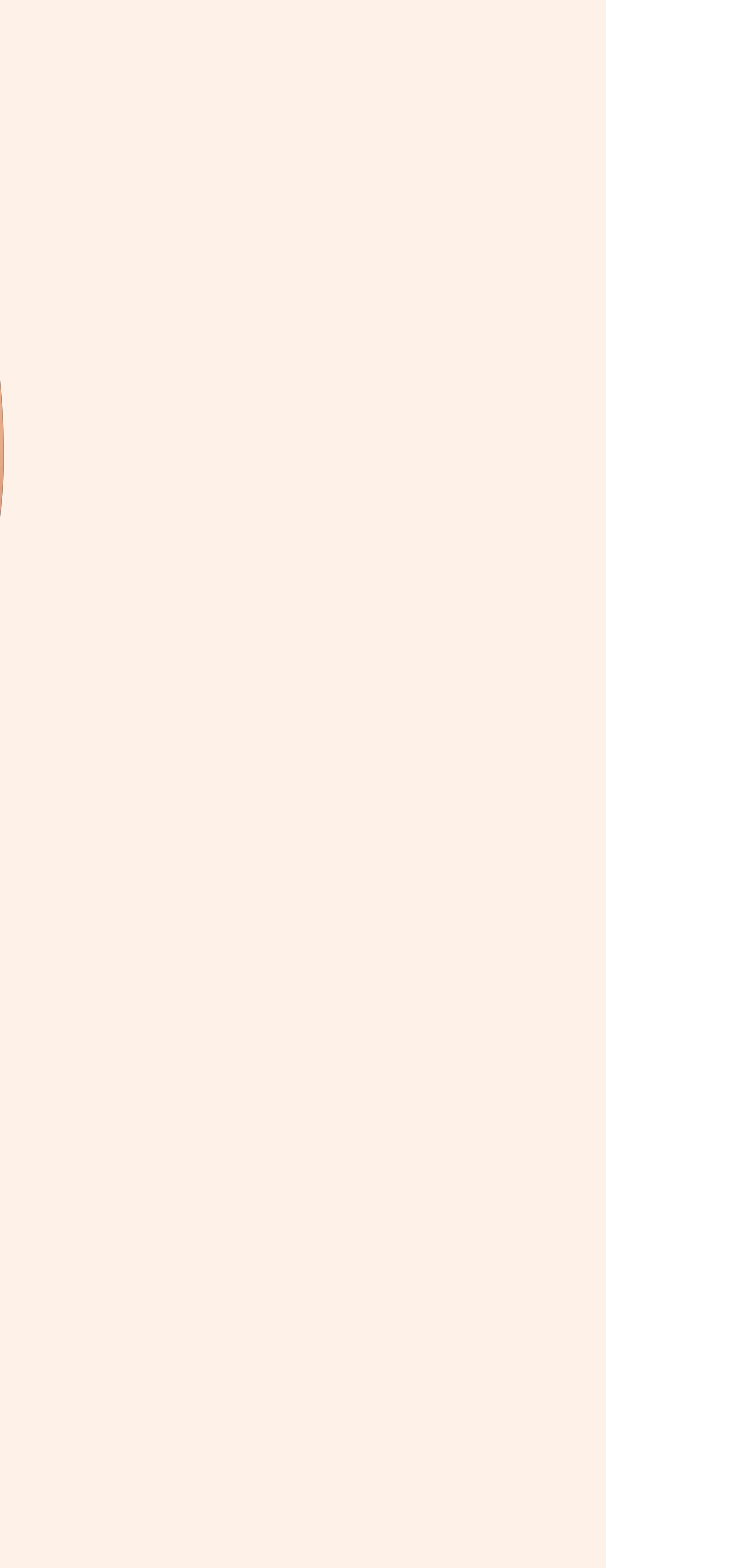




Understanding Endometriosis

and diagnosis criteria

Tempdrop®





What is endometriosis?

Endometriosis affects roughly 11% of women across the world. It's an incredibly common disorder, although it's not well-understood. Many of your patients may shorten it to "endo" for ease of speech.

Endometriosis is when endometrial lesions (tissue similar to that of the uterine lining) are found in other places throughout the body (outside of the uterus). These lesions have the potential to fuse together muscles, organs, and other things inside of the body that should not be fused together.

What causes endometriosis and what are its symptoms?

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).

While the exact cause of endometriosis remains unknown, we do know quite a bit about symptoms.

1. It often causes pain.

Some people experience excruciating pain constantly.

Others experience no pain (this is often called *silent endometriosis*). This pain is caused by the endometrial lesions adhering to places they shouldn't - most often the ovaries and fallopian tubes, but also possibly to other organs throughout the body. Common pain experienced by those with endometriosis include:

- intense period pain,
- pain during intercourse, and/or
- pain while using the toilet.

2. It can cause infertility.

One of the most invasive things people with endometriosis experience, other than pain, is infertility. The root cause of endometriosis-caused infertility is, again, the lesions. Lesions can grow and change, causing scar tissue and damage along ovaries and fallopian tubes. The best treatment for this type of infertility is surgical excision of the endometrial lesions by a specialist, but sometimes involvement of ovaries, fallopian tubes, and/or uterine can make infertility treatments or other options more viable, or a better option short term.

It's important to note that not all patients with endometriosis will struggle with infertility, or have endometriosis-caused infertility.

3. There are other symptoms.

While the largest and most universal symptoms are pain and infertility, there are other symptoms as well! These symptoms include (but are not limited to):

- Heavy menstruation,
- Nausea,
- Fatigue,
- Bloating,
- Constipation, and
- Diarrhea.





What are modern treatment options?

It's true that not all treatments are considered equal for endometriosis. However, few doctors specialize in endometriosis and it can be hard to dig through studies and reports to find the best way to treat patients.

We've summarized the top 6 ways we've found providers tend to treat endometriosis, and we've included the good and bad aspects of each.

Excision

Excision of endometriosis by a skilled, specially trained surgeon is the **gold standard** of treatment of the disorder. It's incredibly easy to miss tissue for those who aren't specially trained. Not all surgeons specializing in endometriosis are specialists in women's health (OB/Gyns). Many have other specialties and bring their extensive knowledge to the table, increasing the ability to find and remove the affected tissue, for example in areas like the bowels.

Excision also allows the surgeon (and/or their team) to confirm that the tissue was, in fact, an endometrial lesion through biopsy. Excision should be done by a specialist, so wait times can be long, as a result it may take time for patients to get the expert treatment they need.

Ablation

Ablation is the "burning" away of endometrial lesions by laser. It isn't as good as excision treatment since ablation may not be deep enough to reach the root, or base, of the endometrial lesion. This makes it highly likely that the lesion will continue to affect the patient's quality of life and/or regrow⁽¹⁾. Burning rather than removing can also make it difficult to remove disease on organs, since there is often a concern about causing damage to organs the lesions are found on.

Hysterectomy

Hysterectomy is generally considered an outdated treatment of endometriosis by specialists⁽²⁾. While a few people may gain relief, the main problem tends to be endometrial lesions outside of the uterus. Sometimes if the hysterectomy also includes ovaries, fallopian tubes, and/or cervix, the patient may find relief.

It's important to note that not all patients with endometriosis will struggle with infertility, or have endometriosis-caused infertility.

Pain Medication

Pain medications used to treat the symptom of pain from endometriosis are usually in the form of NSAIDs (non-steroidal anti-inflammatory drugs) ⁽³⁾. Some patients don't find relief using over-the-counter NSAIDs, and prescriptions may be necessary if this is the direction the provider and patient agree on. The downside of using NSAIDs for pain management is that they can cause stomach damage and pain, especially over long-term use.

Hormonal Treatment

Hormonal treatment of endometriosis (most often through birth control) has not proven to be very effective as it doesn't remove the cause of symptoms, rather it suppresses them. This means that often patients see a recurrence of symptoms as soon as they stop the treatment, or as soon as the treatment stops working effectively ⁽⁴⁾.

Treating pain and symptoms through micronized progesterone (or bio-identical progesterone) has shown promising results. It's important to note that it's micronized, as other forms of hormones have shown the possibility of endometriosis symptoms.

Note that hormonal treatments are generally seen as a short-term treatment option by specialists while waiting for the opportunity to treat the endometrial lesions directly.

Diet and Supplements

There isn't a specific diet or supplement that is known for helping to treat pain from endometriosis long term universally. Largely, the success of this type of treatment depends on the severity and location of the endometrial lesions. Often this sort of treatment takes a while to work out, and may be trial and error until patients find something that works for them (if they do). Most dietary changes focus on decreasing inflammation, as inflammation causes a lot of the symptoms experienced with endometriosis. Popular starting points include gluten free, dairy free, low FODMAP, autoimmune protocol, and anti-inflammatory diets.





Speaking with Endometriosis Patients

We believe that patients get the best care when healthcare is approached with **collaboration** between provider and patient.

1. Your patients have experienced their specific symptoms and have lived with those symptoms, making them an expert on their own bodies.
2. You have gone to school for many years, and have obtained specialized knowledge within certain topics.

Together, **you and your patient** have the knowledge about everything involved.

When you speak with your patients, make sure they feel heard. Two of the largest symptoms of endometriosis are pelvic pain (sometimes excruciating) and infertility. Both of these are incredibly difficult symptoms to live with, and many patients aren't diagnosed until 6+ years⁽⁵⁾ after the onset of symptoms - meaning these patients have often been living with these symptoms for years.

Address each concern they have fully before moving to the next. Provide studies and resources to help them better understand what you've discussed. One great resource is Tempdrop's patient-focused

endometriosis guide, which can be found on our resources page.

If you aren't an endometriosis expert specialist (completed a residency specifically for endometriosis, and did extensive research to remain up to date), we recommend referring your patient to a specialist. It can be incredibly hard to find and remove all of the tissue through excision if you aren't trained on where to look and how to properly remove it. Please consider using the resource <https://nancysnookendo.com/find-a-doctor/> to refer your patients on to a vetted, qualified expert specialist.

Asking for Data

While you should make sure your patients feel heard, you should also make sure the diagnosis is correct. The only way to diagnose endometriosis positively is through laparoscopic surgery. Specialists will use this opportunity to diagnose and treat through excision. However, collecting data from your patient can help with a **probable diagnosis**. When asking your patients to collect more data before their next appointment, we suggest the following.

1. Request that they keep a symptom journal.

2. Combine the symptom journal with a menstrual chart. Ideally, a chart where you can identify the different portions of the cycle such as the follicular phase, ovulation events and luteal phase. At the very least we recommend they should chart their bleeding patterns. We recommend using the Tempdrop sensor and charting app to help them easily identify where they are in their cycles and confirm ovulation.



If you are not your patient's last stop to receive a diagnosis and/or treatment, then encouraging them to collect data is incredibly important. It allows you and other doctors to see what those cumulative symptoms are telling both the patient and the medical professionals involved.

Sharing data about endometriosis

Many patients will want to know more about endometriosis, especially if they've never heard about it before. It's not uncommon for patients to forget specifics from their appointments if they're not taking notes. We recommend printing and sharing studies and publications so they can learn more at home.

One of the best educational resources for endometriosis is called Nancy's Nook Endometriosis Education. You can join the Facebook group as a provider, or check out the website <https://nancysnookendo.com/>(6). 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 endometriosis specialists and well-performed studies, which are available on the above linked website and group.

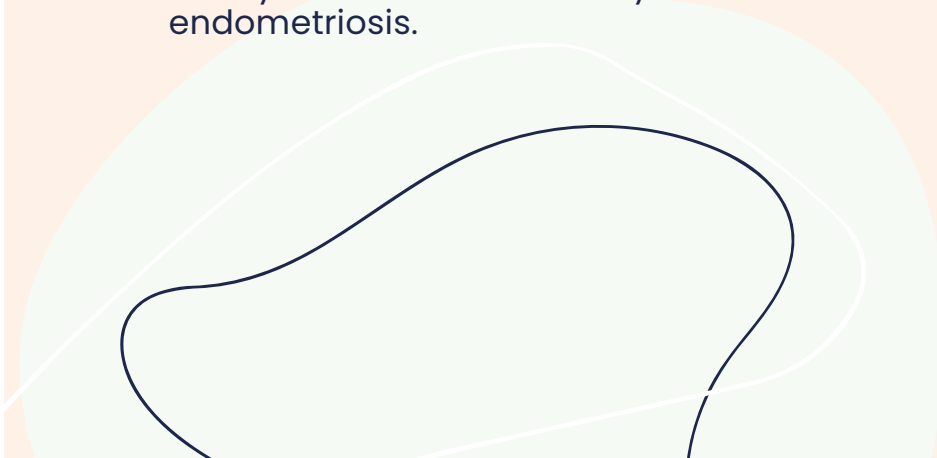
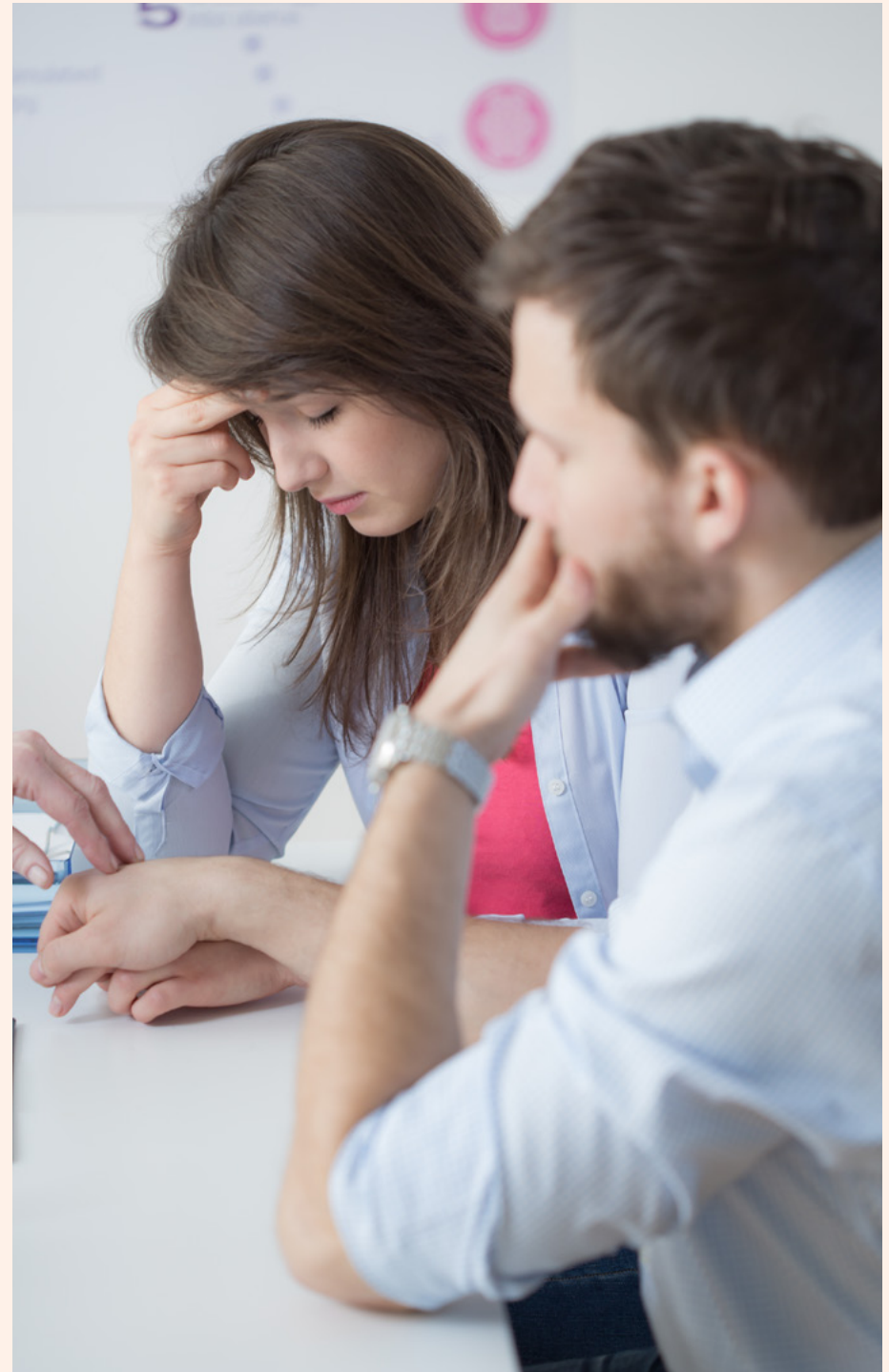
Tempdrop also has an online clinicians Group where you can ask questions and share best practices. You can also find more resources to share at the end of this guide.

Comorbidities & 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⁽⁷⁾ 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)⁽⁸⁾
- Infertility
- Uterine fibroids⁽⁸⁾
- Dyspareunia (painful sex)
- Interstitial cystitis (bladder pain and/or pressure)⁽⁹⁾
- Dysmenorrhoea (painful periods)
- Adenomyosis⁽¹⁰⁾
- Endometrial and/or uterine polyps⁽¹¹⁾

If your patient has any of these diagnoses already, it may be an indicator that you should consider endometriosis.





Questions to be prepared to answer

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?



Resources & 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.yumpu.com/en/document/read/37376957/endometriosis-the-case-for-surgical-excision-skin-allergy-news>
- <https://nancysnookendo.com/the-standard-of-care-is-not-sufficient/>
- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6464974/pdf/CD004753.pdf>
- <https://www.sciencedirect.com/science/article/pii/S0015028218302656>
- <https://www.speakendo.com/about-endometriosis/testing>
- <https://nancysnookendo.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:

- <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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