

A GUIDE TO SIGNS AND SYMPTOMS OF ENDOMETRIOSIS

A RESOURCE SERIES FOR TRANS AND GENDER DIVERSE FOLKS

A note on language...

This resource uses non-gendered, accessible, and medically accurate language to describe bodies and experiences. This includes terms like uterus, menstruation or period.

We recognise that language is deeply personal and is always growing and changing. If these terms don't feel right for you, we encourage you to use - and ask others to use - words that feel more comfortable and affirm your gender.

Endometriosis (also known as endo) impacts bodies in diverse ways. Most symptoms are related to painful menstruation, but symptoms can occur in people who don't have a menstrual cycle or in between periods. Symptoms can also occur throughout the body.

This guide will introduce

- common endo symptoms
- an overview of extra-pelvic endo
- the ways that testosterone can impact endo symptoms and menstruation
- what is 'normal' menstruation and when to seek help

Signs and symptoms of endometriosis include:

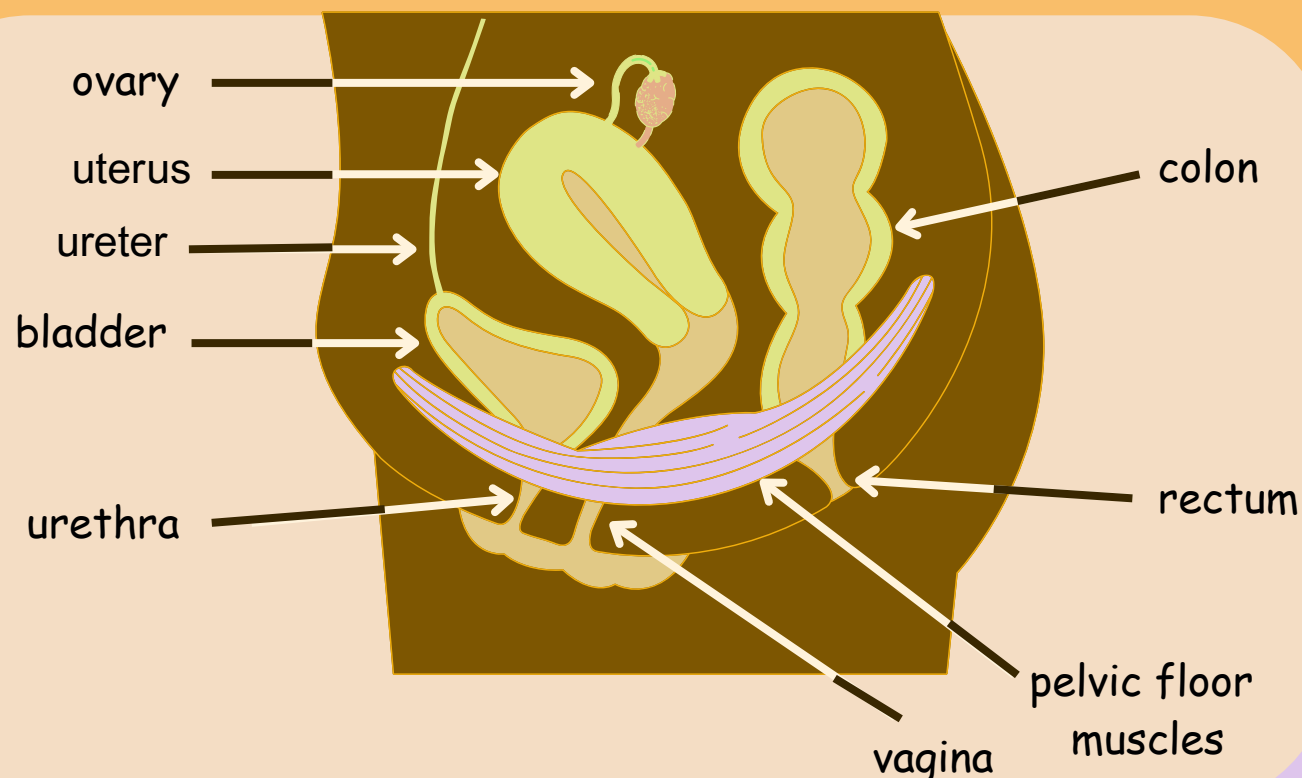
- Pelvic pain
- Painful menstruation
- Heavy menstruation
- Pain with peeing
- Pain with bowel movements
- Digestion problems like bloating, diarrhoea or constipation
- Lower back pain
- Fatigue
- Headache or migraine
- Mood changes e.g. anxiety, depression
- Nausea
- Painful rectal bleeding
- Blood in urine
- Pain with the insertion of a tampon or cup
- Pain during before or after sexual activity
- Swelling and pain of abdominal/belly scars (often worse during menstruation)
- Sciatic nerve pain (pain in the lower back, buttocks and down the leg)
- Other pain that travels down the legs, often at the time of menstruation
- Chest pain, shoulder tip pain or shortness of breath (often worse during menstruation)
- Difficulty conceiving (i.e. becoming pregnant)

Pelvic Endometriosis

Endo usually happens in the pelvis. This is the area between the belly button and the legs.

It often impacts the ovaries, fallopian tubes, and tissue between the vagina and rectum. It can also affect the pelvic lining and supportive structures like ligaments.

Sometimes, it involves the end of the bowel (the colon and rectum). Less often, it is found on the bladder or ureters, the tubes that connect the kidneys to the bladder.



Extra Pelvic Endometriosis

Endo can happen anywhere in the body. It has been found in almost all organs.

For instance, chest pain, shoulder pain, or shortness of breath may indicate endo in the chest area, like the lungs or diaphragm. Endo outside the pelvic cavity seems less common, but we lack research on how often it occurs. Recognizing and diagnosing endo outside the pelvis is also challenging.

Symptoms of extra pelvic endo are often worse during menstruation, but not always. For those with a menstrual cycle, keeping track of symptoms like stomach issues or rib pain can help. Note if they worsen during menstruation or in the days before, and take that information to a health care provider.

Whole body symptoms may relate to the immune response to lesions in the pelvic cavity or other health conditions. For example, while some digestive problems can be due to lesions on the bowel, this can also indicate irritable bowel syndrome, which often occurs alongside endo.

To read more about extra-pelvic endo, click [here](#) or scan the QR code.



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They centre lived experience and aim to provide you with up-to-date information, share collective knowledge, and help you to find community and relevant resources.

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How can testosterone impact menstruation?

The impact of testosterone on menstruation varies from person to person. In those who were menstruating before starting testosterone, it's common for menstruation to stop. This happens for around 80% of people.

Menstruation often stops within the first 6 months of using testosterone. Periods may get lighter over time and turn into spotting before stopping completely.

For others, menstruation can continue for longer. If stopping menstruation is the goal, it might take more time and may require changing the form, dose or timing of testosterone with a doctor's help. Some people may need further hormonal suppression like an IUD or oral contraceptive, alongside testosterone, to fully stop menstruation. To read more about safe ways to not menstruate click [here](#).



If menstruation stops while on testosterone, it can return at a later date, even without changes to the testosterone dose. It's important to see a doctor to get any unexpected bleeding checked out.

If someone is taking testosterone and not menstruating, but still experiences pelvic pain, this is also a reason to visit the doctor.

How can testosterone impact pelvic pain & endometriosis?

Pelvic pain while on testosterone can have a number of causes such as:

- endometriosis
- dryness and thinning of the genital tissues (known as atrophy)
- urinary tract infections
- increased tension in the pelvic floor muscles
- adenomyosis: a condition where tissue similar to the lining of the uterus is found inside the muscular wall of the uterus

Recent research suggests that pelvic pain while on testosterone is often related to increased tension in the pelvic floor muscles.

You can read more about pelvic pain on testosterone and what can be done about it by scanning the QR codes or clicking the titles below.



[Pelvic Pain on Testosterone: What's Going On and What Can Help](#)



[Genital Changes, Periods, and Pelvic Pain in People Using Testosterone](#)

Pelvic floor tension and endometriosis can co-exist.

Pelvic floor muscles are commonly impacted by endo and can tighten in an effort to guard the area. This is why pelvic floor physiotherapy is often used as a management tool.



Unfortunately we have limited research on the ways that testosterone impacts endometriosis symptoms.

What the research suggests is that trans people on testosterone have similar symptoms to cisgender women with endo, but often struggle to access the same supports.

Do symptoms improve or resolve on testosterone?

Endo is called an "oestrogen dependent" condition. This means oestrogen doesn't cause it, but it does boost lesion growth. Many believe testosterone will make endo symptoms disappear. While symptoms lessen for many, this isn't always true!

When someone takes testosterone, oestrogen levels drop significantly. However, they may still be slightly above the average range for cisgender males. This doesn't usually impact gender affirmation, but may contribute to endo symptoms.

In those with endo, the uterus lining (endometrium) and lesions can create their own source of oestrogen. An enzyme called aromatase turns testosterone to oestrogen which may contribute to symptoms.

Certain medications can reduce levels of aromatase to lower local oestrogen production.

Does testosterone use change the management approach?

Management options for endo are the same for trans and gender diverse folk on testosterone and cis women. Management approaches should take gender into account and avoid triggering or worsening dysphoria.

They often include hormonal suppression, surgery, and allied health care such as pelvic floor physio.

Testosterone can even be protective against the side effects of some therapies (GnRH agonists).

To read more about different management approaches, [click here](#) or **scan the QR code.**



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What is 'normal' menstruation & when should I seek help?

What does 'normal' menstruation feel like?

Mild discomfort on the first two days of the menstrual cycle is likely 'normal.'

Mild discomfort means that there is minimal impact on day to day life and it can be easily managed with over the counter pain medication (like ibuprofen and paracetamol) or with self-care strategies like a heat pack.

Pain that falls into these three categories may need to be investigated:

- Pain that lasts longer than the first two days of menstruation
- Pain that happens outside of menstruation
- Pain that disrupts someone's ability to go to work or school, sleep, eat, move, or feel okay in their body.

If you find yourself avoiding activities, planning around flare-ups, or feeling physically or emotionally drained by recurring pain, it's time to seek support.

Is spotting 'normal'?

Around one third of people who menstruate experience some spotting.

Spotting is simply really light bleeding outside of menstruation and might look like a few drops of often lighter pink or brown coloured blood.

Spotting is common and can be completely normal at the start or end of menstruation and when going through big hormonal changes. This can include perimenopause, starting hormonal suppression (e.g. the pill or an IUD) and starting testosterone.

Spotting should be checked out by a doctor when it happens regularly between menstruation, when spotting doesn't turn into 'normal' menstruation and when spotting occurs regularly after sex.

Still not sure if your menstruation is normal?

You can do a 5 question quiz by clicking [here](#) or scanning the QR code below



What is a 'normal' amount of blood loss?

The average amount of blood lost during menstruation is between 30-40mLs (this isn't much blood, it's less than 3 tablespoons). This typically occurs over 2-7 days.

Passing small clots during menstruation can also be 'normal.' Small clots are pea-sized or smaller.

Blood loss over 80mL during menstruation is a reason to visit the doctor.

For those who use a menstrual cup this might be easy to measure, but for those who don't, the following are also signs of heavy menstruation:

- Menstruation lasting for over 7 days
- Needing to change a pad or tampon more than every 2 hours, or often bleeding through a regular sized pad or tampon.
- Feeling tired, dizzy or short of breath in combination with the above. (This can be a sign of iron deficiency which can be caused by heavy menstruation.)

Passing large clots is more common with heavy menstruation. Large clots are those bigger than a bottle cap or \$1 coin. This can be a sign of an underlying health condition and is a reason to visit the doctor.



What is a 'normal' cycle length?

Menstruation often occurs monthly, but 'normal' can be anywhere from every 21 to 35 days (for those not taking testosterone or hormonal suppression).

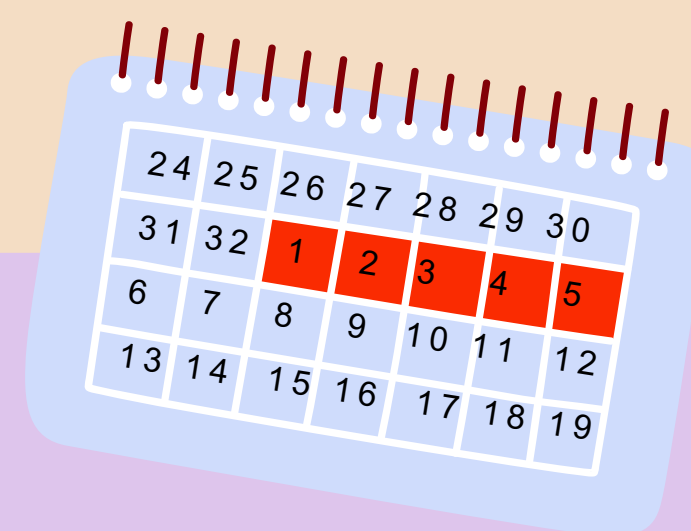
It's ok if this number varies month to month (this is pretty common during the first few years after menstruation starts).

It may be time to visit the doctor if:

- a) the time between menstruation is regularly more than 35 days, and
- b) menstrual cycles began more than 3 years ago

Longer menstrual cycles can be a sign of polycystic ovarian syndrome (PCOS).

It's fairly common for endometriosis and PCOS to occur together.



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Understanding endometriosis pain: beyond pain scales

Endo pain is complex, often misunderstood, and can be difficult to measure.

For many people, especially those who are neurodivergent or struggle with interoception, standard 1-10 pain scales can feel abstract, inaccessible, or disconnected from the real experience of pain.

Pain is deeply personal and two people with the same condition may describe their pain very differently. Our cultural background might impact how we respond to or talk about pain.

Describing pain

Instead of rating pain with numbers, some people find it helpful to describe:

- What the pain feels like (e.g. burning, pulsing, stabbing, cramping).
- What the pain stops you from doing (e.g. "I can't focus on conversation," "I have to lie down," "I haven't eaten all day").
- How it affects your brain or mood (e.g. "I feel like I'm shutting down," "I'm struggling to find words or speak" "I'm overstimulated and can't manage anything else").

Recognising that pain is more than a number can make space for more compassionate, tailored care. Everyone deserves to have their pain believed and understood, especially in systems that have often overlooked or dismissed certain bodies and identities.

Pain science

The nervous system, which includes the brain, spinal cord and nerves, plays a key role in pelvic pain.

A sensitised nervous system can raise pain levels. This is known as central sensitisation.

This may explain why people with a history of PTSD have higher rates of pelvic pain - the brain is on high alert and is amplifying the body's danger message.

Research shows that endo can exist without pain. There's no clear link between pain level and lesion size.

Some folks find it comforting to learn that pain doesn't always mean their endo is getting worse or that their body is damaged (but sometimes it does).

Understanding how pain science works helps some people to better manage their pelvic pain.

Pain scale alternatives

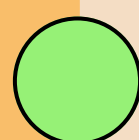
Pain scales can be helpful to tracking pain, knowing when to access help for pain and to communicating pain.

Many people, especially neurodivergent folks, find traditional 1-10 pain scales hard to interpret or communicate.

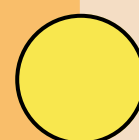
Alternative pain scales exist! Here are two alternatives that some folks find helpful:

The Mankoski Pain Scale offers more detailed descriptions for each level of pain (e.g. "can be ignored" vs. "interferes with concentration" vs. "unable to speak or move").

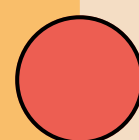
The Traffic Light Scale (green/yellow/red) helps communicate how pain impacts day to day life, not just how "bad" it is. For example:



Green: manageable, able to do most activities.



Yellow: uncomfortable, struggling with tasks, need support.



Red: overwhelming, unable to do day to day tasks, need immediate help.

This scale is often also used as a pacing tool for chronic pain i.e. red is stop, yellow is proceed with caution and green is go. (this scale can be tweaked to suit each persons needs, i.e. you can define what each colour means to you)

Click [here](#) or scan the QR code to see these pain scales and more



My introduction to pain science felt like gaslighting. Pain science shouldn't imply that pain is "all in your head," rather it describes how the brain increases levels of pain in an attempt to keep us safe.

Some folks find that understanding pain science helps them to better cope with endometriosis pain.

Pain science education can be helpful to managing pelvic pain and is best used alongside other management approaches.

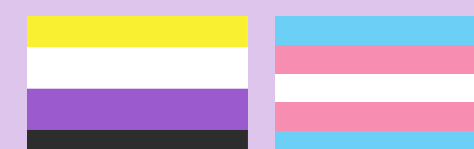


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These references can be helpful additional reading but may use less accessible language and often do **not** use gender inclusive language.

All Qr codes and links within the resource will take you to carefully selected web pages which use correct and inclusive language.