AN INTRO TO PELVIC PAIN & 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.

What is endometriosis?

Endometriosis (also known as endo) is a condition where **tissue similar to the lining of the uterus grows outside of the uterus.** These are called endometriosis lesions.

A close relative of endometriosis is adenomyosis. In this condition, tissue similar to the lining of the uterus grows inside the muscle wall of the uterus. While this resource will focus on endo, it's important to know that endo and adenomyosis often occur together.

Endo is an inflammatory condition impacted by (but not caused by) the hormone oestrogen. Inflammation is the body's response to a threat, in this case lesions.

Painful periods are one of the most common symptoms of endo, but high levels of inflammation impact the whole body and many people with endo report whole-body symptoms like fatigue or gut issues.

Endo is often found in the pelvic cavity, but can also occur in other parts of the body such as inside the chest or lungs. This can contribute to a variety of symptoms that go beyond pelvic pain (see signs and symptoms in the box below).

This is why a whole-body approach can be helpful to understanding and managing the condition.

What is pelvic pain?

Pelvic pain is pain felt in the lower abdomen (below the belly button and above the legs).

The pelvic cavity contains organs including the uterus and ovaries, the large bowel and the bladder.

Some common examples of pelvic pain are:

- pain during, in-between or in the complete absence of menstruation
- pain during, before or after sexual activity
- pain with the insertion of a tampon or cup

For those who menstruate, pelvic pain is often intensified during this time and can significantly interfere with day-to-day life.

Endometriosis is a common cause of chronic pelvic pain. Other causes can include irritable bowel syndrome (IBS), bladder pain syndrome, pelvic inflammatory disease and pelvic floor issues. This resource will focus on endometriosis.

What is menstruation?

Menstruation is a medical term used to describe the release of blood and tissue from the lining of the uterus. This is also referred to as a period. This is one phase of the menstrual cycle.

Many trans and gender diverse people may not menstruate due to gender-affirming hormones, or use of hormonal suppression (also known as hormonal contraceptives), but endo can still be present and can cause symptoms.

Signs and symptoms of endometriosis include:

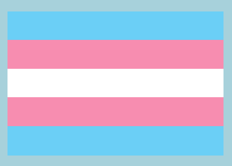
(symptoms may be worse around menstruation)

- painful and/or heavy menstruation
- pelvic pain in-between or in the absence of menstruation
- pain with peeing
- pain with bowel movements
- pain that travels down the legs
- stomach problems like bloating, diarrhoea or constipation
- nausea
- lower back pain
- fatigue
- sciatic nerve pain (pain in the lower back, buttocks and down the leg).
- headache or migraine
- mood changes e.g. anxiety, depression
- painful rectal bleeding
- blood in urine
- swelling and pain of abdominal scars
- chest pain, shoulder tip pain or shortness of breath
- pain with the insertion of a tampon or cup
- pain during, before or after sexual activity
- difficulty conceiving (i.e. becoming pregnant)

These resources have been co-designed by trans and gender diverse people with endometriosis.
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.

What does co-designed mean? This means that we recruited trans and gender diverse folk with endometriosis and facilitated an online space where they were actively involved in making decisions about the contents and wording of these resources.

The development of these resources was generously funded by Endometriosis Australia.



Who can have endometriosis?

Endo can impact anyone of any gender.

Around 1 in 7 cisgender women and around to **1 in 11 trans men and non-binary folk presumed female at birth (PFAB) may have endo.**

We also have some reports of endo in trans women, cisgender men and intersex folk (of any gender).

Can I have endometriosis if I don’t have a uterus?

Yes, many folks experience symptoms of endo after a hysterectomy (a procedure that surgically removes the uterus). While hysterectomy is commonly used to manage endo, it is not a cure.

Can I have endometriosis if I’m on testosterone or do not have a period?

Yes, many trans and gender diverse individuals may not menstruate due to gender-affirming hormones, or use of hormonal suppression (like the pill or an IUD), but endo can still be present and can cause symptoms.

While pelvic pain is often worse around menstruation, some have pelvic pain throughout the month and endo symptoms can reach far beyond the pelvis.

Am I too young or old to have endometriosis?

Endo is often diagnosed in someone’s 20's or 30's, but symptoms often start much earlier. Many people with endo struggle with painful or heavy menstruation from their very first period. In rarer cases, endo has also been found before the first period.

Sometimes endo symptoms can continue on into perimenopause and menopause. While many find relief from symptoms with menopause, around 4 in 100 people with endo report symptoms continuing on or coming back.

Any level of pain that stops you from enjoying or being part of every day activities should be looked into, regardless of age, gender or menstrual status.

The impact of endometriosis

Currently endo has no cure.
It can affect daily life in many ways, including chronic pain, fatigue, digestive issues, and difficulties with concentration, movement, or mental health.

These symptoms can make everyday tasks—like working, studying, socialising, exercising, or simply getting out of bed—feel exhausting or even impossible at times.
Managing flare-ups, attending medical appointments, and navigating stigma or disbelief can also take an emotional toll.

Although this condition is deeply challenging, with the right information, care and community support, many people with endo find ways to live full and meaningful lives.

Navigating endometriosis as a trans person comes with added challenges. Still, many find hope in connecting to community and in sharing collective knowledge.

Scan the QR codes or click on the resource titles to learn more

A guide to signs and symptoms of endometriosis

Resource contents

- Signs and symptoms
- Pelvic and extra pelvic endometriosis
- Impacts of testosterone
- Defining normal menstruation and when to seek help
- Understanding endometriosis pain: beyond pain scales

Management strategies used for pelvic pain & endometriosis

Resource contents

- A whole body approach to management
- Understanding hormonal suppression
- Pain medications
- Allied health, complementary therapies and self care
- Surgical management
- Looking after mental wellbeing
- Neurodivergence and co-occurring health conditions
- Community support and wellbeing resources

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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.

References

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