

Endometriosis: Guide for Trans and Gender Diverse People



Anyone who has, or has had, a uterus can develop endometriosis. This includes trans and gender diverse people, and all whose bodies or identities don't fit traditional medical assumptions.

Getting the right care for endometriosis can help you feel better and manage your symptoms. There are clinicians who are safe, respectful and inclusive, and who understand that endometriosis can affect people of all genders.

Getting care for endometriosis can take time. Some trans and gender diverse people find the process distressing and frustrating, especially if their doctor doesn't expect endometriosis because of their gender. It can also feel isolating, as many clinics and health services are labelled or designed as 'women's health' services.

This fact sheet covers ways to manage these challenges and how to find inclusive care. We use medical words in this fact sheet, such as uterus, vagina and menstruation. Some trans and gender diverse people use different words for their bodies.

Common symptoms

Endometriosis symptoms vary from person to person. Some people have mild or no symptoms, while others have severe pain that affects daily life. The amount of endometriosis does not always match the level of pain or symptoms.



Symptoms can include:

- pain with periods
- pain during or after sexual activity
- difficulty becoming pregnant
- pain affecting school, work or daily activities
- pelvic or stomach pain (not just during bleeding)
- pain when using the toilet or passing wind
- heavy bleeding or bleeding between periods
- bloating, nausea or bowel changes
- feeling very tired
- difficulty concentrating or sleeping due to pain

What is endometriosis?

Endometriosis is when tissue similar to the lining of the uterus grows outside it. It can affect many parts of the body and cause pain and other symptoms.

The causes of endometriosis are not fully understood. Sometimes, this tissue can develop in response to certain hormones in the body, especially oestrogen. Some people also notice changes with progesterone.



Managing endometriosis and gender-affirming care

Some ways of managing endometriosis can affect how you feel about your body and identity. There is no one way to manage endometriosis that works for everyone. Talk to your doctor about what is important to you so you receive care that supports your health and your well-being.

Hormone therapy

- Some trans people may choose to take hormones, including testosterone, as part of gender affirmation.
- Testosterone often stops ovulation and periods, which can improve some endometriosis symptoms.
- However, studies show that this varies. Some people still experience pain or other symptoms.
- You may want to talk to your doctor about breakthrough bleeding
- Some hormone treatments for endometriosis can affect how gender-affirming hormones work. If you take gender-affirming hormones, the dose or type of endometriosis treatment may need to be adjusted so it supports your symptoms, priorities and wellbeing. Talk to your doctor about your options.
- Always tell your healthcare team about all medicines or hormones you're taking so treatment can be coordinated safely.

Surgery

Surgery to remove the uterus (hysterectomy) stops periods, but may not cure endometriosis. This is because endometriosis tissue can grow outside the uterus.

Having surgery is a personal decision. You have the right to information about both gender-affirming and endometriosis-related options, and care that supports your gender identity.

Getting safe and respectful care

It's important to find health professionals you trust. You have the right to care that is safe, respectful and affirming. It's understandable to feel worried about seeing a doctor for endometriosis, especially if you've experienced discrimination before.

Who can help manage endometriosis pain

Endometriosis can cause ongoing pain. Different health professionals can help:

- Pelvic physiotherapists – help manage these symptoms through gentle exercises and techniques that improve muscle function, and support bladder and bowel comfort.
- Pain specialists – help manage long-term pain.
- Occupational therapists – help with fatigue, movement and daily activities.
- Psychologists and counsellors – support emotional wellbeing and help you cope with day-to-day challenges.



Looking ahead

You have a right to receive respectful, affirming health care. You know your body and your needs. Endometriosis is a long-term condition, but many people find ways to manage it well.

