

Endometriosis

What is endometriosis?

Endometriosis is a progressive, chronic condition in which cells similar to those in the lining of the uterus – called the endometrium – grow in other parts of the body. It most commonly occurs in the pelvis and can affect a woman's reproductive organs. Studies suggest that endometriosis affects one in 10 women of reproductive age, with an estimated 176 million women worldwide having the condition.

The endometrial tissue cells may:

- be found on organs, usually in the pelvis
- start to grow and form patches or nodules on pelvic organs or on the peritoneum (the inside lining of the abdomen and pelvis)
- have the same cyclical/menstrual changes outside the uterus as inside the uterus
- may bleed at the same time as your period (menstruation).

What causes endometriosis?

We don't really know what causes endometriosis, and possible associations can vary, but may include:

- a family history of endometriosis – ie, a close relative with the condition
- retrograde (backwards) menstruation – during a period, menstrual blood flows out of the vagina, but also backwards along the fallopian tubes into the pelvis. In most women, the blood containing this tissue gets absorbed or broken down and causes no symptoms. In women with endometriosis, this tissue can implant and start to grow
- metaplasia – the change of normal pelvic tissue into endometriosis
- having the first period before 11 years of age
- the type of period – heavy bleeding, lasting longer than five days; regularly fewer than 27 days between periods
- low body weight.



Signs & symptoms

The symptoms of endometriosis vary from woman to woman. Some have many symptoms, where severe pain occurs, while others have no symptoms. The severity of symptoms may not reflect the severity of the condition.

Pain

Pain is one of the biggest symptoms. This can be pain immediately before and during your period and/or during or after sex. Pain can be felt in the abdomen, back or pelvis, with a bowel movement, passing wind or urine, or when you ovulate.

Heavy bleeding

Heavy bleeding can occur with or without clots. Bleeding may be irregular, continue for a long time, or you may have spotting before your menstrual period.

Bladder and bowel problems

Bladder and bowel problems may occur, eg, constipation or diarrhoea, feeling the need to urinate more frequently at different times in your menstrual period, and bloating.

Other symptoms you may experience include extreme tiredness, lethargy, feeling faint, depression, anxiety, mood swings, irritability and an inability to get pregnant.

What you can do

If you think you have endometriosis, see your doctor. They may refer you to a gynaecologist. Don't delay, as early diagnosis and treatment may reduce the severity of the disease. Many women do not get a correct diagnosis for up to 7-10 years, often because the symptoms can be different between women and can change over time.

Diagnosing endometriosis

A laparoscopy (keyhole surgery) is the only way to diagnose endometriosis. A thin tube (telescope) with a light (laparoscope) is inserted into the abdomen through a small cut in the belly button, to allow the gynaecologist to see if there is any endometrial tissue within the pelvis. Some of the tissue might be removed and examined to confirm a diagnosis.

Managing & treating endometriosis

The right treatment will depend on your symptoms, the severity of the condition and whether you are trying to become pregnant, or may want to have children in the future.

There is no direct evidence that lifestyle affects endometriosis; however, it is important to remain as healthy as possible.

- **Gentle activity** – this can help to ease pain. Aim for 30 minutes of physical activity on most days of the week.
- **Having enough quality sleep every night** – this will help your immune system to work at its best.
- **Finding ways to manage stress** – try gentle yoga techniques, relaxation exercises or mindfulness.
- **Managing the pain** – this may involve medication such as anti-inflammatory drugs or pain-relief medication. Speak to your doctor about medication.

- **Hormone therapy** – such as the combined oral contraceptive pill or progestins, which may be given as tablets, an implant and injection or intrauterine device (IUD). This may help to reduce pain and the severity of endometriosis by suppressing the growth of endometrial cells and stopping any bleeding, including your period.
- **Surgery** – if recommended, this aims to diagnose and remove as many patches of endometriosis, cysts, nodules, endometriomas (chocolate cysts) and adhesions as possible, to repair any damage caused and possibly improve fertility. More radical surgery – though rarely recommended – may include removal of the uterus (hysterectomy), tubes and ovaries (salpingo-oophorectomy), or sections of other affected organs, such as the bladder or bowel.

When recurrent endometriosis is at its worst, it may lead to chronic pelvic pain, reducing your quality of life. Living with endometriosis can be difficult and can affect your emotional health. Seek help from your doctor, a counsellor or a support group if you are worried about how to cope with endometriosis. You are not alone.

Endometriosis & fertility

Most women with endometriosis will become pregnant without any medical assistance. About 30% of women with endometriosis have trouble getting pregnant. There are treatments available to help increase your chances of getting pregnant. If you are thinking of trying to get pregnant, talk with your doctor about how endometriosis might affect your fertility.

Severe period pain is not normal. If the pain is so severe that you are missing school, work or other activities, please get help.

For more information go to jeanhailes.org.au/health-a-z/endometriosis

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This fact sheet is designed to be informative and educational. It is not intended to provide specific medical advice or replace advice from your medical practitioner.

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Jean Hailes for Women's Health takes a broad and inclusive approach to the topic of women's health. This fact sheet generally uses the terms 'women' and 'girls'. These terms are intended to include women with diverse sexualities, intersex women, and women with a transgender experience.

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