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Fact sheet

# Endometriosis

## What is endometriosis?

Endometriosis occurs when cells similar to those that line the uterus (or endometrium) are found in other parts of the body, usually the pelvic cavity.

These cells may stick to organs such as the ovaries, fallopian tubes, peritoneal lining, bowel or bladder, where they may grow to form patches, plaques, lesions or cysts.

These cells, although they are not in the uterus, are still responsive to the female reproductive hormone oestrogen and as a result, may bleed during menstruation, causing inflammation, internal bleeding and scar tissue.

Symptoms of endometriosis can include severe pelvic pain, back pain, heavy menstrual bleeding, bladder problems, nausea, bowel problems and infertility.

## Endometriosis myths dispelled

- Severe period pain is not normal. Women who experience pain so severe that they are missing work, school or other activities, or pain that can't be treated with painkillers or anti-inflammatory medication, should contact their GP.
- Endometriosis does not only cause pain during menstruation. Pain and symptoms may occur at all stages of the menstrual cycle.
- Hysterectomy is not a cure for endometriosis. Despite common belief, endometriosis, if already seeded in the peritoneal cavity prior to hysterectomy, can continue to grow and present problems.
- Pregnancy is not a cure for endometriosis. Women of all reproductive ages can get endometriosis, regardless of whether or not they've had children. Endometriosis symptoms may appear to improve during pregnancy due to higher progesterone levels, but many women experience recurrence within a few years.
- Endometriosis does not only affect the reproductive organs. In rare cases, lesions have even been discovered in women on the heart, knee and brain.

## What are the symptoms of endometriosis?

Endometriosis symptoms may include.

- Painful periods
- Ovulation pain
- Pain with sex
- Reduced fertility
- Pelvic pain
- Pain in the lower back and thighs
- Bowel symptoms (constipation or diarrhoea)
- Bladder symptoms (more frequent urination at different times of the cycle)
- Nausea and lethargy
- Premenstrual syndrome (PMS)

Symptoms may vary from woman to woman. The stage of endometriosis does not always correlate with severity of symptoms. Women with mild endometriosis may experience severe pain and symptoms, while some women with severe endometriosis may experience no symptoms, but present with infertility.

## What causes endometriosis?

It is not known what causes endometriosis, however there are a number of hypotheses.

**Family history:** Women with a close relative (such as a mother or sister) who has endometriosis are more likely to have the condition. Endometriosis risk genes have been identified but their role is not yet fully understood.

**Retrograde (backwards) menstruation:** When a woman menstruates, endometrial tissue is shed and leaves the body in menstrual fluid via the vagina. In most women, menstrual fluid also flows backwards through the fallopian tubes and out into the pelvic cavity. It is not fully understood why some women develop endometriosis lesions on nearby organs or the peritoneal lining while most others do not.

**Altered immunity:** One theory is that the immune system of women with endometriosis fails to clear the endometrial cells shed into the pelvic cavity during menstruation. In most women, these 'backflushed' endometrial cells are removed by various immune mechanisms, but this may not occur in women with endometriosis.

## Diagnosis

Endometriosis is usually diagnosed through laparoscopy, although some forms of endometriosis can be diagnosed with transvaginal ultrasound or MRI. Laparoscopy is a keyhole procedure where small incisions are made in the abdomen to investigate the presence of endometrial tissue in the pelvic cavity, using a light and telescope. The endometriosis tissue is sent off for pathology testing to confirm disease.

There is currently no early or non-surgical diagnostic test that detects all types of endometriosis.

## Treatment may include

**Laparoscopy:** Keyhole surgery performed to remove any lesions, cysts and patches of endometriosis to reduce pain, repair damage and improve fertility.

**Hormone treatment:** Hormone treatments such as the contraceptive pill or progestin-based implants like an intra-uterine device may be prescribed to stop all bleeding and the growth of endometrial cells.

**Hysterectomy:** In extreme cases of recurrent disease where other treatments have not worked, a woman may undergo a part or total hysterectomy with removal of both ovaries.

**Medication:** Anti-inflammatory medications or painkillers are sometimes used to manage pain and symptoms.

## Endometriosis facts

- Endometriosis affects an estimated one in 10 women, or 176 million women worldwide.
- Women with endometriosis can wait 7 to 10 years to receive a diagnosis. This may be because symptoms are non-specific and endometriosis is generally only diagnosed through surgery.
- There is no cure for endometriosis.
- While diagnosis is usually made via a keyhole procedure called a laparoscopy, ultrasound and MRI may be used to diagnose certain types of endometriosis.
- Around one third of women with endometriosis will experience infertility as a result of the condition.
- Women with endometriosis have a slightly increased risk of developing ovarian cancer.
- Annually, endometriosis is estimated to cost Australian society around \$5 billion in lost productivity, and around \$2.5 billion in direct healthcare costs.
- In Australia and globally, endometriosis research receives significantly less funding than research into other chronic conditions that affect a similar number of women and have a comparable morbidity rate.

## What is being done to help women with endometriosis?

Research is being conducted across the world to better understand the cause of endometriosis, to offer early non-invasive diagnosis and treatment options for women with endometriosis.

Currently, researchers at Hudson Institute are investigating

- Why endometriosis occurs in some women and not others
- What causes endometriosis
- Developing an early, non-invasive diagnostic test for endometriosis
- Preventing disease recurrence in women who have undergone surgery for endometriosis
- Better non-surgical treatments for endometriosis
- The relationship between endometriosis and infertility
- Detecting endometriosis in girls before symptoms appear
- Understanding innate immune responses in endometriosis

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