MAVEN CENTRE
ADVANCED GYNAECOLOGY & WOMEN'S HEALTH

Suite 5.3, Level 5,
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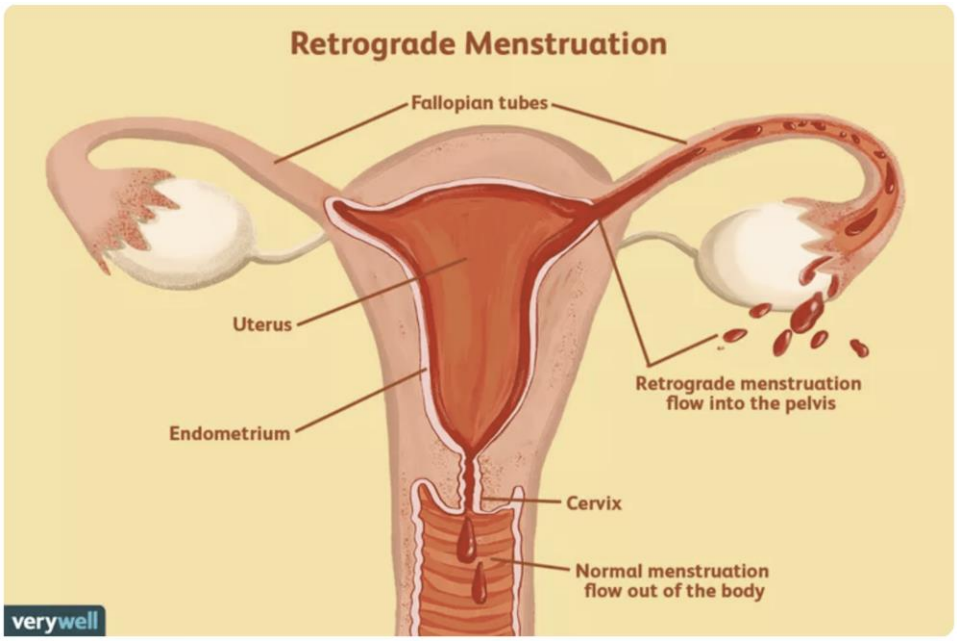
# Endometriosis: patient information

## What is endometriosis?

Endometriosis is a common condition, in which deposits of tissue that normally line the inside of the uterus (called the 'endometrium') are found elsewhere in the body (such as the Fallopian tubes, cervix, uterus, and on the ligaments in the pelvis). Up to 1 in 8 women of reproductive age have symptomatic endometriosis.

## What causes endometriosis?

The most widely-held theory is so-called 'retrograde menstruation'.




Periods are caused by the uterine lining (the 'endometrium') shedding every month, leading to vaginal bleeding. 'Retrograde menstruation' posits that in some women, some of the uterine lining goes 'upstream' in the wrong direction: through the Fallopian tubes, into the abdomen and pelvis. These endometrial cells may implant onto the: peritoneum (the clingwrap-like layer that lines the inside of the abdomen and pelvis); pelvic ligaments; bowel; bladder; and ovaries. These endometriotic deposits (or 'nodules') respond to the usual monthly hormonal fluctuations, causing local inflammation, pain, and slowly growing over time.

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What are the risk factors for endometriosis?

Retrograde menstruation is thought to occur in up to 90% of all women, yet most women don't develop endometriosis. Additional risk factors for endometriosis include:

- Family history
- Not having had children
- Heavy periods
- Early puberty (eg. prior to 11yo)
- Shorter menstrual cycles
- Late menopause (eg. after 60yo)

**How is endometriosis staged?**

There are four stages of endometriosis, from minimal to severe:

- Stage I (minimal) endometriosis = a few shallow deposits, minimal internal scarring
- Stage II (mild) endometriosis = endometriotic deposits that are more numerous and deeper than stage I +/- some associated internal scarring
- Stage III (moderate) endometriosis = many deep nodules, significant internal scarring, +/- endometriotic ovarian cysts
- Stage IV (severe) endometriosis = widespread deep nodules, thick bands of internal scarring between pelvic organs +/- large endometriotic ovarian cysts, bowel, or bladder endometriosis

Generally, there is a reasonable correlation between the severity of a patient's symptoms and the stage of their endometriosis. But this is not always the case.

**What symptoms can endometriosis cause?**

The most common symptoms of endometriosis are:

- Period pain: endometriosis is a very common cause of moderate – severe period pain
- Persistent pelvic pain: endometriosis can cause inflammation and internal scarring, causing pelvic organs to stick together. Endo can also cause the pelvic nerves to become overly sensitive (ie. 'central sensitisation'). Both internal scarring and 'central sensitisation' can cause persistent pelvic pain, lasting for more than six months.
- Painful insertive sex: especially deep, internal, and positional pain
- Bowel symptoms: eg. severe pain when defecating during your period, or predictable changes to your bowel habit depending on where you are in your menstrual cycle
- Bladder symptoms: eg. blood in your urine or pain with a full bladder during your period
- Subfertility

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**How is endometriosis diagnosed?**

If you have suggestive symptoms, it may be said that you have 'possible' or 'suspected' endo.

High quality ultrasound (especially a 'deeply infiltrative endometriosis' or DIE scan) is very good at diagnosing stage III or IV endometriosis. If bowel endometriosis is suspected, you may be asked to take laxatives prior to this ultrasound scan, so the bowel walls can be more easily seen. If signs of moderate or severe endometriosis are seen, it may be said that you have 'probable' endo.

Strictly speaking, the only way to diagnose endometriosis definitively is to undergo keyhole ('laparoscopic') surgery. A gynaecologist can perform keyhole surgery to look for and cut out any endometriotic nodules. These will then be sent off to the laboratory, where the specimens can be examined under the microscope, to confirm that it definitely was endometriosis.

**How is endometriosis managed?**

There are various approaches to managing endometriosis symptoms. Most women use a variety of approaches every month, and an even broader range of approaches during their life.

<u>Complementary medicine</u>

Complementary medicines are treatments tried alongside Western medicine and allied health. Benefits may include: reduced pain; improved mood; and improved general health and wellbeing. Examples of complementary medicine (in the endometriosis context) include:

- Acupuncture
- Mindfulness-based interventions: eg. deep-breathing exercises; guided imagery; hypnotherapy; and progressive relaxation
- Yoga

Using complementary medicine to self-manage pain flares improves patients' agency over their endometriosis symptoms. Complementary medicine can be used as part of a multidisciplinary, team-based approach to your endometriosis.

<u>Allied health</u>

The following allied health clinicians often help patients manage their endometriosis symptoms:

- Pelvic physiotherapist
- Dietician
- Clinical psychologist

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Medical management

Medications to manage endometriosis symptoms include:

- Pain relief (eg. paracetamol, naprogesic, and mefenamic acid)
- CBD oil: can be accessed using the Special Access Scheme, and an eligible prescriber
- Hormonal contraception: any medication that lightens your period may reduce period pain. While hormonal suppression can help with stage I or II endo, it cannot: shrink endometriotic ovarian cysts; dissolve internal scarring; treat pain with sex; nor persistent pelvic pain. Options include:
    - Combined oral contraceptive pill: on average, women with endometriosis find a 50% improvement in their period pain when on The Pill
    - Progesterone-only Pill: progesterone is thought to dampen down endometriosis; it also has anti-inflammatory properties. Approximately two-thirds of women with endo notice significantly improved period pain when taking progesterone-only contraception
    - Mirena intrauterine device
- GnRH analogues: in certain situations, your gynaecologist may recommend taking a 'GnRH analogue' medication for a few months. These are strong medications, that put you into a temporary menopause; they should help to reduce any endometriosis-related symptoms.

Surgical management

There are several reasons why your gynaecologist may suggest keyhole surgery, such as:

- Significant symptoms (e.g. severe period pain, despite trying the above management options)
- Excision of endometriotic ovarian cysts
- Separation (or 'division') of suspected internal scarring
- Subfertility, when endometriosis is thought to be a contributing factor
- A DIE ultrasound has shown signs of moderate to severe endo +/- bowel involvement

By excising these nodules, we hope to:

- Reduce ongoing irritation of the pelvic nerves
- Reduce pelvic inflammation
- Reduce the development and progression of internal scarring
- Improve your chances of falling pregnant

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Keyhole (or 'laparoscopic') surgery to remove endometriosis involves:

- A general anaesthetic
- 3 – 4 small (generally 5mm) scars on your tummy
- Panoramic photos of your abdominal and pelvic organs
- Systematic cutting out of any endometriosis, which is sent to the laboratory for analysis
- Separation ('division') of significant internal scarring
- Endometriotic ovarian cysts will be drained and / or removed

If endometriosis is found growing near your bowel, bladder or ureters, your surgeon may need to leave this severe endometriosis inside you for now, before performing additional investigations to guide further management. This may require the expertise of a colorectal or urological surgeon.

In some cases, a hysterectomy may be appropriate. This requires a comprehensive discussion with your gynaecologist, who can: help you to weigh up the risks and benefits; discuss your plans for children; and consider what you have tried previously to manage your endometriosis.

**Endometriosis and fertility**

There is significant overlap between 'endometriosis' and 'subfertility'. It is estimated that:

- 10% of the female population have endometriosis
- 25 – 50% of women with subfertility have endometriosis
- 30 – 50% of women with endometriosis are impacted by subfertility

However, subfertility is often multifactorial: endometriosis is only one of numerous possible causes for a couple's subfertility. In addition, there are several mechanisms by which endometriosis can reduce fertility.

Broadly speaking, the more severe your endometriosis is, the more likely it is that your fertility will be impaired. In addition, the more severe your endo is, the worse IVF outcomes tend to be.

If you have both endometriosis and subfertility, you may benefit from seeing a gynaecologist with expertise in both areas, such as Maven Centre's Dr Melissa Cameron. She can guide you as to whether keyhole surgery, IVF, or both are needed (and in what order).

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**Frequently asked questions (FAQs)**

Is there anything I can do to prevent endometriosis?

There are no known ways to definitively prevent endometriosis. You could consider the following, in order to decrease the risk of developing severe endometriosis:

- Having fewer periods: eg. by taking continuous hormonal pills, or having an IUD inserted
- Having lighter periods: eg. by taking the contraceptive pill, or tranexamic acid

How do I know whether or not I have endometriosis?

A good transvaginal ultrasound will see signs of moderate or severe endometriosis. However, mild endometriosis can only be diagnosed at keyhole surgery. Some women are happy to be labelled as having 'possible endometriosis', if their symptoms can be managed medically. Others prefer to undergo keyhole surgery, so that they know for sure whether or not they have endo.

Do any medicines slow the regrowth of endometriosis after keyhole surgery?

After surgery, the regrowth of endometriosis can be slowed by taking: a GnRH analogue; the contraceptive Pill; or using the Mirena intrauterine device. Hence, your gynaecologist may suggest that you go onto one of these hormonal treatments after your surgery.

How quickly does endometriosis grow back, after it's been cut out?

The rate of growth / re-growth is unique for everyone, so is very difficult to predict. It depends on a number of factors: your genetics, what kind of surgery you had (ablation or excision), whether or not all the visible endometriosis was able to be removed, and whether or not you use hormonal suppression after your operation.

Can any gynaecologist do keyhole surgery to cut out endometriosis?

While all gynaecologists are trained in performing basic laparoscopies, not all of them will have the skills to manage endometriosis surgically. Some gynaecologists (such as Maven Centre's Dr Sneha Parghi and Dr Alison Bryant-Smith) complete further training in advanced laparoscopic surgery, to enable them to manage severe and complex endometriosis.

*This pamphlet is a general overview of endometriosis, and may not apply to everyone.*
*If you have any further questions, please speak to your gynaecologist.*