Health
Western Sydney
Local Health District

Women's & Newborn Health
Westmead Hospital

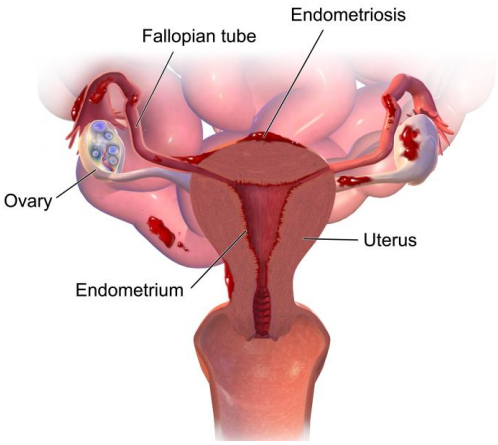
Fact sheet
Endometriosis

womensnewbornhealth.com.au

Endometriosis is a common but puzzling condition which may cause problems such as pain and infertility (difficulty falling pregnant). Up to 10% of women have endometriosis. Many of these women have no problems at all while other women have their lives significantly affected by it.

Endometriosis is caused by the lining inside the cavity of the uterus, called the endometrium, unexpectedly growing outside the uterus. This leads to endometriosis deposits or nodules (lumps) around the pelvis (lower tummy inside). Most commonly, these nodules are found on the fallopian tubes, ovaries, ligaments holding up the uterus and nearby organs like the bladder and bowel.

During the menstrual period, the endometriosis nodules bleed, just as the lining of the uterus does, but the blood is trapped inside the nodule. This leads to swelling and scar tissue build up (called inflammation). Over time, this can pull the organs around the uterus into an unusual shape or position and can make them 'stick together' rather than remaining smoothly separate. This combination of scarring, swelling, pulling and sticking together of tissues and organs can cause pain and infertility.



Why does endometriosis develop?
The bottom line is that no one really knows. There are a few theories (ideas) but none of these has given us a definite answer yet – which makes it hard to work on prevention. Endometriosis does not seem to be the result of diet or lifestyle. However, it does seem to be partly genetic (runs in families). It is also more common in women who start their periods at a younger age, have shorter menstrual cycles (less than 25 days) and who haven't had children.

What are the symptoms of endometriosis?
Many of the symptoms caused by endometriosis can also be caused by other conditions.

- For example, severe pain on the first day of the period is common in normal teenagers and young women without endometriosis.
  - Such pain usually improves after good doses of pain medication such as ibuprofen and is almost always quite a lot better on the second day of the period.
  - The period pain with endometriosis, however, often continues for more days of the period and may be less likely to improve with pain killers.

Many of the symptoms listed below may also be caused by conditions other than endometriosis - if you have these symptoms, your GP and gynaecologist will try and work out what is going on.

In addition, some women with endometriosis have no symptoms at all and don't even know it is there until it is found when they have a laparoscopy (or occasionally an ultrasound) for another reason. In these cases, the endometriosis often doesn't need treatment since it is not causing any problems for the woman.

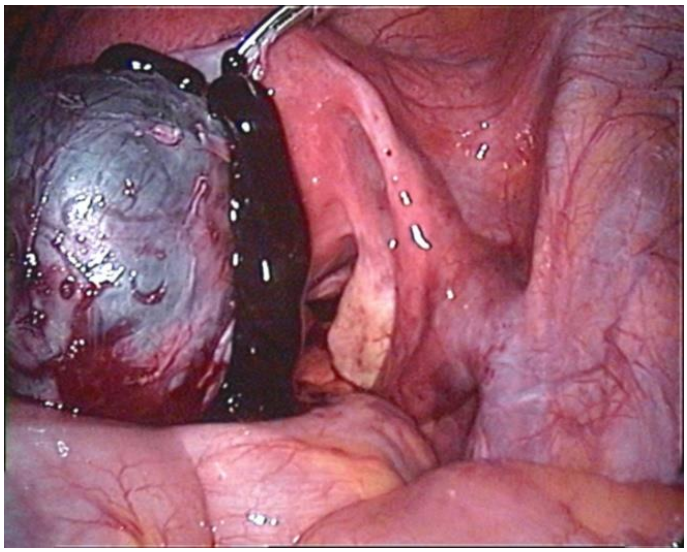
Endometriosis symptoms:

- Pain is a common symptom of endometriosis and can take different forms including:
  - severe period pain
  - pain at ovulation (release of the egg in the middle of the cycle) or other pain in between your periods
  - pain with sex - this pain is usually felt deep inside
  - pain with passing urine or having the urge to pass urine often; rarely there may be blood in the urine
  - pain with opening your bowels or passing wind; sometimes endometriosis causes constipation (difficulty opening the bowels)
  - feeling bloated or swollen in the abdomen (tummy).
- Bleeding problems can occur and include:
  - heavy and painful periods or periods that are longer than normal
  - spotting for a few days before the period or at ovulation.
- Fertility problems (difficulty falling pregnant).
  - Between 30-50% of women who have fertility problems are found to have endometriosis. This does not mean the endometriosis is definitely causing the fertility problem, as there are many other causes for difficulty falling pregnant. However, it could be part of the problem.
  - At the same time, two-thirds of women with endometriosis fall pregnant without difficulty while only one-third has difficulty.
- Endometriosis can rarely cause a lump to form in a caesarean or laparoscopy scar

How do I know if I have endometriosis?

If you think you may have symptoms of endometriosis, it is worthwhile speaking to your GP about them. Your GP may try simple treatments, send you for an ultrasound or other tests, or refer you to a specialist gynaecologist or the hospital clinic. If your period problems are causing you to take time off work or school and don't get better with simple treatments then you probably should be investigated (checked out) for endometriosis.

- **Blood Tests** – there are no blood tests to diagnose endometriosis.
- **Ultrasound** – is usually not a great test for mild or moderate endometriosis because an ultrasound mostly can't see small lesions and scars around the pelvis. It can sometimes see larger areas of scar tissue or nodules. It is also useful in finding cysts on the ovaries caused by endometriosis. These cysts are called endometriomas or 'chocolate cysts' (see photo) because they are full of dark blood.
- **Laparoscopy** (key-hole surgery) - this is the best way to diagnose endometriosis. Your gynaecologist uses a thin telescope to look inside the pelvis at the uterus, ligaments, ovaries and tubes. If endometriosis is found during a laparoscopy it can often also be treated at the same time. Treatments include cutting the endometriosis out or lightly burning it away (diathermy). Sometimes bigger surgery is needed as discussed below. [*see also laparoscopy fact sheet*]



What can be done for endometriosis?
The best treatment for you will depend on:

- what sort of symptoms you have and how bad they are
- the severity of your endometriosis
- whether you want to fall pregnant soon
- whether the endometriosis is causing fertility problems.

Can I wait and see if my symptoms go away?
If your symptoms are mild and the endometriosis is not severe, then you do not have to have treatment.

Endometriosis often improves with pregnancy although it may come back after you stop breastfeeding.

Endometriosis nearly always improves after menopause (the time when menstrual periods stop – usually around age 50).

However, if your pain is concerning you, or getting worse, or you are having difficulty falling pregnant, then treatment is probably a good idea.

What treatments are available?
Treatments that are used for endometriosis can involve either medication or surgery.

Medication for endometriosis
Painkillers like ibuprofen are often helpful for period pain. If possible, ibuprofen should be started the day before your period begins and continued throughout your period.

Apart from painkillers, the other medication treatment choices for endometriosis are contraceptive - so you probably won't want to use them if you are planning a pregnancy now.

Otherwise they are quite popular.

They include the oral contraceptive pill and hormones called progestins.

The oral contraceptive pill (OCP)

- The OCP contains two hormones, an estrogen and a progestin.
- It is often helpful in treating pain and may slow the growth of endometriosis
- Often the pill is taken continuously, skipping the sugar pills
  - This usually stops your period altogether; without a period, your pain is less and the bleeding from the endometrial spots and nodules inside should also be less
  - However, some women experience spotting if they take the pill continuously. A good compromise is to run 3 packs of the pill together and only take the sugar pills after the third pack. This gives you a period every 9 weeks. It is considered quite safe and is called tri-cycling the pill.

Progestin Therapy

- A progestin is one of the hormones in the OCP without the other one (the estrogen).
- Progestin therapy may slow the growth of endometriosis spots and nodules, prevent scarring and reduce pain.
- Progestin therapy can be
  - given by mouth as tablets *or*
  - attached to an IUCD (intrauterine contraceptive device) that is put inside the uterus. This is called a Mirena®. It can be left inside the uterus for up to 5 years before needing to be replaced.
- Many women have no problems with either progestin tablets or the Mirena® but some women feel bloated, have irregular spotting, or feel moody on the tablets, these women often have fewer side effects with the Mirena®.

Other hormones

There are other medications which can be used to treat endometriosis but they can have important side effects. If you need these treatments, your gynaecologist will discuss the advantages and disadvantages with you.

Surgery for endometriosis

- Surgery for endometriosis is usually done as laparoscopic (key-hole) surgery.
- This surgery cuts away or burns (diathermy) the endometriosis nodules and scar tissue and tries to make your pelvis more normal.
- If you have endometriomas (chocolate cysts) in your ovaries, these can also be removed.

This type of surgery is often helpful for pain and infertility.

- About 60-80% of women will find their pain gets better after surgery to remove endometriosis.
  - However, about half will find their symptoms come back over the next 5 -10 years.
  - Some women are given medication after their surgery, like the OCP or a progestin, to try and reduce the chance the endometriosis will return and to help manage the pain.
- If you have fertility problems, surgery often improves the chance of both natural pregnancy and success with IVF.
  - However, in rare situations, surgery can reduce fertility. It is important to carefully discuss the planned operation with your gynaecologist so that you know exactly what your options are and what you feel comfortable with.
- If your endometriosis is found to be very severe and is affecting other organs like the bladder or bowel you might need quite complicated surgery involving several surgeons. We have teams that specialise in this kind of surgery who can care for you.
- Some women who have severe endometriosis and who no longer wish to have children may want to think about a hysterectomy (removal of the uterus) as treatment.
  - If you are having a hysterectomy for endometriosis, one thing you will need to consider is whether you wish to have your ovaries removed at the same time or not.
  - Removing the ovaries reduces the chance of endometriosis coming back but does bring on menopause. This can cause hot flushes and other symptoms but these can generally be managed with low dose hormone treatment. *[See hysterectomy fact sheet]*

Can endometriosis cause cancer?
There may be a very small increase in cancer of the ovary in women with endometriosis but the overall risk remains very low. Women with endometriosis do not need any increased check-ups or treatments to look for or prevent ovarian cancer.

Is there anything else I should consider?
Endometriosis can be distressing and frustrating, so you need to be aware of how it is affecting you and try to take steps to manage it. Many women find that a healthy diet, regular exercise and enough rest help them cope with their symptoms (and their worries).

There is no scientific evidence that any particular vitamins, minerals, 'immune modulators', special diets or supplements have any benefit in treating pain or fertility problems due to endometriosis.

Joining a well-run endometriosis support group can be helpful, particularly speaking with other women who are experiencing the same problems you are. Emotional support is important. If you wish to speak with a counsellor please ask our staff or your GP about a referral.

Conclusion:
Endometriosis is a common and somewhat puzzling condition than can present with a broad mix of symptoms. Because of this and because it can mostly only be diagnosed by surgery (laparoscopy), reaching the diagnosis often takes a while, which can be distressing and frustrating.

Nothing exists at the moment to prevent endometriosis but a number of treatments are available that are very helpful for pain and fertility problems.

Please talk with your gynaecologist about your symptoms and your specific problems so that you can work out a treatment plan together that will best suit your needs.

Women in their 30s with fertility problems related to endometriosis should not delay speaking with their gynaecologist about it. Fertility treatments like IVF can be less successful for women aged over 35 years.

We welcome further feedback on this brochure as a way of continually improving our service.

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Attributes

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