UNDERSTANDING ENDOMETRIOSIS

Patient information to assist informed consent

Endometriosis is a condition where tissue similar to the endometrium (that lines the inside of the uterus) also grows outside the uterus. These growths or "patches" occur most often in the pelvis and lower abdomen.

Endometriosis is dependant on the female sex hormone oestrogen. Oestrogen controls many functions during the menstrual cycle, and promotes the growth of patches of endometriosis.

The most common sites for patches are the:

- ovaries, uterus and fallopian tubes
- uterosacral ligaments
- inside walls of the pelvis over the ureters (the tubes running from the kidneys to the bladder)
- pouch of Douglas
- surface of the rectum and, less commonly, the large and small intestine and appendix
- bladder
- vagina.

Rarely, patches can occur in the upper abdomen, diaphragm, lungs, nasal passages, pharynx, a Caesarean-section scar, umbilicus (belly button) or elsewhere in the body.

The appearance of patches can vary widely. Depending on how and where they have developed, the patches may be black, brown, bluish, white, red, clear or yellow-brown.

The body's reaction to patches can vary from no reaction at all to the growth of scar tissue around them. More extensive scar tissue, called adhesions, can also develop around the pelvic organs.

Endometriosis is common, occurring in about one in 10 women between the ages of 12 and 50. However, not all have symptoms. A woman is more likely to develop endometriosis if her mother or a sister has it.

Endometriosis usually becomes inactive or less active after menopause. However, it may persist or regrow in women taking hormone replacement therapy.

Patches of endometriosis can be found in women who have no pain and are fertile. For example, they are found in up to four women in 10 having a laparoscopy for tubal ligation.

Types of endometriosis

❖ **Endometrial implants** – these are small patches, usually one to two millimetres across, or smaller.

❖ **Endometrial nodules** – these are of various sizes but usually are at least two to three millimetres across. Uncommonly, one may grow to four centimetres across.

❖ **Endometriomas** – These are cysts in an ovary that can grow to 10 centimetres, or more, across. They are typically dark brown due to the presence of old blood in them and are often called chocolate cysts.

❖ **Adenomyosis** – Endometriosis in the wall of the uterus is called adenomyosis. A troublesome non-cancerous tumour (adenomyoma) may be present.

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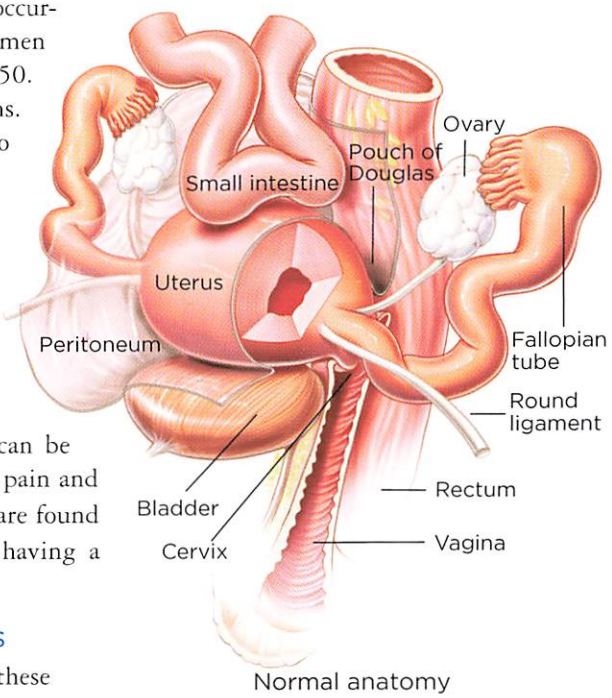
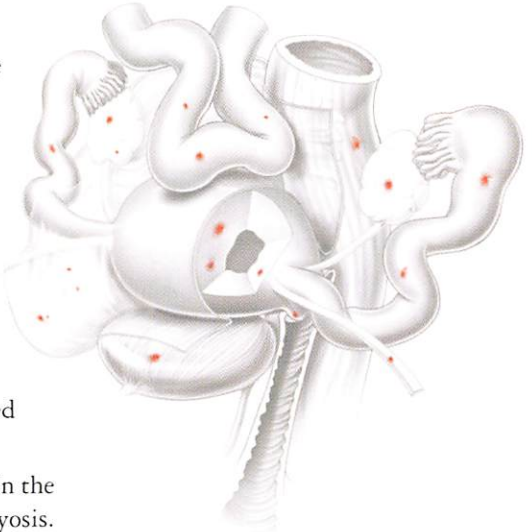


Normal anatomy



Common sites of patches

IMPORTANT: FILL IN ALL DETAILS ON THE STICKER BELOW

Dear Doctor: When you discuss this pamphlet with your patient, remove this sticker, and put it on the patient's medical history or card. This will remind you and the patient that this pamphlet has been provided. Some doctors ask their patients to sign the sticker to confirm receipt of the pamphlet.

TALK TO YOUR DOCTOR

This pamphlet is intended to provide general information. It is not a substitute for advice from your doctor and does not contain all facts about endometriosis. This information will change with time due to clinical research and new therapies. If you are not sure about terms used in this pamphlet, or related matters, ask your doctor. Read this pamphlet carefully, and save it for reference. Write down questions you want to ask. Your doctor will be pleased to answer them. Seek the opinion of another doctor if you are uncertain about the advice you are given. Use this pamphlet only in consultation with your doctor.

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Degrees of endometriosis

❖ **Mild** – Mild endometriosis appears as small patches scattered around the pelvic cavity, with no scarring.

❖ **Moderate** – Moderate endometriosis appears as larger patches or patches that are more widely spread. They may be attached to the ovaries, fallopian tubes, uterosacral ligaments and the pouch of Douglas. Small cysts may be present. They are often associated with significant scarring.

When endometriosis occurs on an ovary, a large cyst (called an endometrioma) may form over time.

❖ **Severe** – In severe endometriosis, most of the organs in the pelvic cavity are affected by numerous and large patches and severe scarring. The uterus, ovaries, fallopian tubes, bowel, bladder, uterosacral ligaments and the pouch of Douglas are often held down by adhesions.

Some doctors classify endometriosis as being in Stage I, Stage II, Stage III or Stage IV, as described by the American Society of Reproductive Medicine.

Causes of endometriosis

The causes of endometriosis are not fully understood and are a matter of ongoing debate. It may be related to the flow of menstrual blood back through the fallopian tubes and into the pelvis. This is called "retrograde" menstrual flow, which occurs to some degree in most women.

However, retrograde flow alone does not cause endometriosis. A small degree of retrograde flow occurs in about nine women out of 10. The immune systems of most women remove the live endometrial cells that are within the menstrual blood.

Women with moderate to severe endometriosis may have an immune system that is less capable of destroying endometrial cells or cannot keep up with clearing the larger amount of cells that may occur in women having heavier or longer periods.

Another theory proposes that some women have cells in their pelvis that are pre-destined from birth to turn into endometriosis when oestrogen levels rise during puberty. Other environmental, immunological, racial and genetic factors have been implicated but are not fully understood at present.

Symptoms of endometriosis

Pain is the most common symptom. It may occur on one side or both sides of the abdomen, around the abdomen, deep inside the pelvic cavity, in the lower back, or in the rectum. While pain during menstruation is common, the pain of endometriosis is often different.

Endometriosis may be indicated by pain that is prolonged or gets worse as menstruation continues. The pain can be severe enough to interfere with work and social activities during a period.

Pain during and after intercourse is a common symptom. It is felt deep in the pelvis and tends to be worse if intercourse occurs just before or after a period. It may be more severe during deep intercourse or if sexual activity is vigorous. Discomfort may last for several hours. This pain is probably caused by active endometriosis pressure on adhesions (scar tissue) and can often be reproduced during a gentle vaginal examination by a doctor.

If patches have attached to the bladder, a woman may have pain when passing urine, a frequent need to urinate, blood in the urine, or aching in the bladder area.

Other important causes of pelvic and abdominal pain also need to be considered and may include:

- bowel-related causes, for example, irritable bowel syndrome and constipation
- bladder conditions, such as interstitial cystitis
- hormonal causes, for example, prostaglandins and other substances that are released during the menstrual cycle.

Fatigue occurs differently among patients. Most commonly, it occurs throughout the month or around the time of menstruation.

Other symptoms include changes in bowel habits, bloating or nausea. These may worsen during menstruation.

Some women with endometriosis have no symptoms even when they have severe endometriosis. Conversely, a mild case can cause intense pain and other symptoms. It is unclear how endometriosis causes pain and why some women are affected more than others.

Sometimes it may only be diagnosed when tests for conditions such as infertility are carried out. There is often a poor correlation between the visual extent of endometriosis and a woman's symptoms.

Infertility

Although mild endometriosis is not a major cause of infertility, about three or four women in 10 who have endometriosis have difficulty becoming pregnant.

It is not clear why endometriosis affects fertility. Research suggests that women with endometriosis have eggs and embryos that may be less viable.

Endometriosis appears to cause infertility because the patches may release substances that:

- decrease sperm movement
- affect normal embryo development
- adversely affect the development of the placenta
- decrease the ability of the fallopian tube to capture the egg from the ovary after ovulation.

Moderate or severe endometriosis may also cause adhesions to form around a fallopian tube and ovary. Patches and adhesions can cause fallopian tubes to become narrowed, blocked or damaged. If the fallopian tubes do not function properly, then fertilisation is difficult.

Pregnancy

Pregnancy may improve the symptoms of endometriosis but does not cure it. During pregnancy, a woman has no periods, so pain from endometriosis may stop or be much less.

A woman may find that her symptoms improve after the baby is born and periods return. Doctors are uncertain why this happens in some women and not others.

Some women with endometriosis may be at higher risk of complications during pregnancy. Discuss this further with your doctor.

After menopause

Endometriosis typically improves after menopause because oestrogen production declines greatly.

However, hormone therapy taken after menopause can cause endometriosis to persist or grow. The result may be recurring symptoms of endometriosis.

Clinical research

The understanding of endometriosis has improved significantly over the years due to research. Your doctor may ask if you would like to be involved in a clinical trial. Participation is entirely voluntary, and you would be under no obligation to be involved.

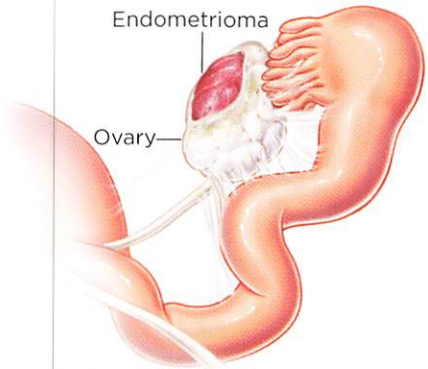
Diagnosis of endometriosis

The diagnosis of endometriosis can be difficult. Some women have had symptoms for many years before the diagnosis was made. Diagnosis is usually based on:

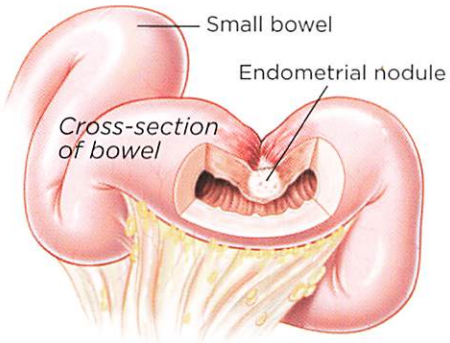
- a woman's symptoms
- a physical examination of the pelvic cavity
- ultrasound imaging, which may provide evidence of endometriotic cysts, adhesions, or nodules
- an examination of the inside of the abdomen and pelvic cavity using an instrument called a laparoscope, during a procedure called laparoscopy.

The examination of a tissue sample (usually obtained during laparoscopy) is the only way of diagnosing endometriosis for certain.

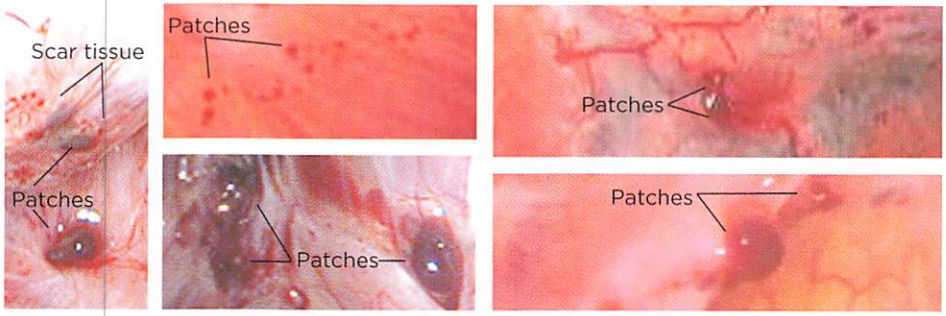
In addition to diagnosis, the doctor may be able to carry out treatment by using the laparoscope, as described in the section "Surgical treatment" on page 4.



Endometrioma on an ovary



Endometrial nodule in the wall of the small bowel



These photographs taken during laparoscopy show that the appearance of patches can vary widely.

Treatment for endometriosis

Treatment for endometriosis may stop the progress of the disease. Several treatments are available. The choice of treatment should be decided by a woman and her doctor together. Choice of treatments will depend on:

- the severity of the symptoms
- how much endometriosis was found during diagnostic laparoscopy
- the age of the woman
- plans to become pregnant.

Studies have estimated that, of every 100 women (with mild or no symptoms) who do not have treatment:

- endometriosis will get worse in 50
- it will remain unchanged in 25
- it will shrink or disappear in 25.

Some women with mild endometriosis are not greatly troubled by symptoms, and treatment may not be needed. If symptoms are chronic or severe, then a variety of treatments may be required, including:

- surgical treatment
- hormonal therapies
- combinations of the above treatments.

All of the following treatments have risks, benefits and limitations.

HORMONAL TREATMENT

Hormonal therapies are particularly effective in treating the pain associated with endometriosis. In cases of severe endometriosis, hormonal therapies usually do not work as well.

They may be used on their own, or in combination with surgical treatment. Hormones have the advantage of treating small lesions that surgery may miss.

As with all medicines and natural remedies, hormonal therapies have possible side effects. Side effects for the medicines are different and vary from woman to woman, and medicine to medicine. While side effects may be minor in some women, other women may want to stop treatment because of unpleasant or serious side effects. Some women find a gradual return of symptoms some months after treatment stops.

Treatment with the contraceptive pill

The contraceptive pill can help to relieve the pain of endometriosis. This is especially so if the tablets are taken continually for several months so that a period does not occur. This method is not suitable for women who are trying to become pregnant, as the contraceptive pill prevents pregnancy.

Treatment with a progestagen

Taken every day, progestagens usually help to relieve symptoms. Side effects are usually minor, but the pills may cause irregular bleeding, weight gain, tiredness and depression in some women. Progestagens can also be given as an injection once every 12 weeks. As with the contraceptive pill, progestagens are not suitable for women who want to become pregnant. After a woman stops having progestagen injections, the effects may take several months to wear off, and pregnancy may not be possible during that time.

Treatment with other medicines

Other medicines have been effective in treating endometriosis, including:

- gestrinone or danazol. These work by stopping periods. Side effects may include weight gain, increased hair growth, skin rash and, rarely, voice change.
- gonadotropin-releasing hormone (GnRH) agonists, for example, goserelin or naferelin. GnRH agonists prevent the release of oestrogen from the ovaries and suppress menstruation. This usually reduces the pain associated with endometriosis and the number and size of patches. As GnRH agonists cause oestrogen in the body to fall to very low levels, the side effects can be similar to symptoms of menopause and post-menopause, which may include:
  - a small loss of bone density
  - changes in libido
  - hot flushes and night sweats
  - vaginal dryness
  - decreased breast size
  - mood changes
  - muscle pains.

Add-back therapy: Most women taking a GnRH agonist have at least one or two side effects. These side effects may be reduced by "add-back therapy". During add-back therapy, a woman takes a small amount of oestrogen and progesterone. Add-back therapy does not appear to decrease the effectiveness of GnRH agonists, but it is effective in relieving side effects.

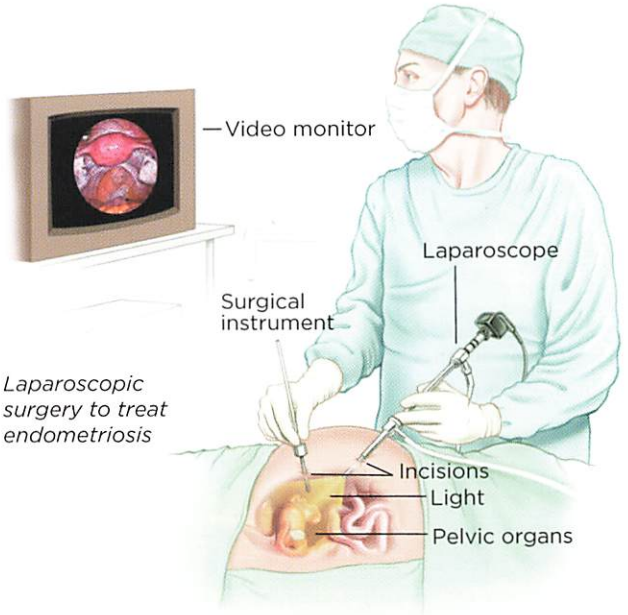
Your doctor or pharmacist can provide more information on medications.

Surgical treatment

Laparoscopy

Surgery can be effective for women who have mild, moderate or severe endometriosis. The aim of laparoscopic surgery is to remove patches, cysts and adhesions. It may be helpful in reducing pain and improving fertility.

Most endometriosis can be treated laparoscopically without the need to remove pelvic organs such as the ovaries or uterus. The surgeon can also repair damage caused by endometriosis. Surgery may be combined with hormone treatment. See the patient education pamphlet "Laparoscopic treatment of endometriosis – patient information to assist informed consent", available from your doctor.



Laparoscopic surgery to treat endometriosis

Laparotomy (open surgery)

In some cases of severe endometriosis, a laparotomy may be necessary. The advantage of a laparotomy is that the large incision may be helpful for the surgeon if the disease is severe or a bowel resection is needed. A laparotomy is major surgery.

Hysterectomy

In severe cases of long-term and painful endometriosis in older patients, the woman may choose to have her uterus removed (hysterectomy). This is only done in women who are not planning any further pregnancies. One or both ovaries and fallopian tubes may also have to be removed to:

- improve treatment of the endometriosis
- remove endometriosis involving the ovaries
- eliminate the source of oestrogen (ovaries)
- treat the pain from adhesions constricting the ovaries.

A hysterectomy is not usually recommended unless other treatments have failed. See the patient education pamphlet "Hysterectomy – patient information to assist informed consent", available from your doctor. If a hysterectomy is undertaken, all visible patches must also be removed.

Pain and periods

Periods should not stop you from doing your daily activities. If pain or heavy bleeding is limiting your daily activities, discuss this with your doctor. Your doctor may recommend medication.

Medication for pain relief, such as non-steroidal anti-inflammatory drugs (NSAIDs) and paracetamol, is most effective when taken before the pain becomes bad, and when taken regularly.

If you are still in pain despite taking medication for pain relief, tell your doctor. You may need to discuss hormone therapy.

If pain is still interfering with your daily activities despite taking hormonal therapy, tell your doctor. You may need to see a gynaecologist with an interest in endometriosis for further investigation.

Endometriosis and mental health

Endometriosis can have a large impact on a woman's emotional wellbeing. Support groups and organisations exist that can provide a forum for women to share their experiences.

Some women also find seeing a counsellor or psychologist to be helpful. You may want to ask your doctor for more information.

GLOSSARY OF TERMS

adhesions – scar tissue that can cause reproductive and other pelvic organs to stick together abnormally; severe adhesions can upset normal function

cysts – fluid-filled, bubble-shaped swellings

endometrium – the lining of the uterus

fallopian tube – the tube that carries the egg from the ovary to the uterus and where fertilisation takes place

hormones – substances produced by glands that assist the body in its functions; some give female traits to women and others give male traits to men

hysterectomy – removal of the uterus

infertility – difficulty in becoming pregnant

laparoscopy – looking into the abdomen and pelvic cavity with a thin telescope

laparotomy – surgery of the abdomen with a longer incision than laparoscopic incisions

menopause – when periods stop due to ovarian failure or the depletion of eggs

menstruation – monthly periods

oestrogen – the female sex hormone that controls many functions during the menstrual cycle, and which promotes the growth of patches of endometriosis

ovary – female organ that stores and releases eggs

patches – clusters of endometrium that become attached inside the abdomen

pelvic cavity – the area in the lower abdomen around the uterus

pouch of Douglas – the fold of tissue between the back wall of the upper vagina below the uterus and the large bowel

progesterone – a female hormone that is present in the second half of the menstrual cycle and during pregnancy.

Costs of treatment

Ask your doctor to advise you about coverage by public healthcare, private health insurance and out-of-pocket costs. You may want to ask for an estimate that lists the likely costs. Ask which costs can be claimed on private health insurance. As the course of actual treatment may differ from the proposed treatment, the final account may vary from the estimate. It is best to discuss costs with your doctor before treatment starts rather than afterwards.

Your doctor

"Understanding endometriosis" has been reviewed by obstetricians and gynaecologists in Australia and New Zealand

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