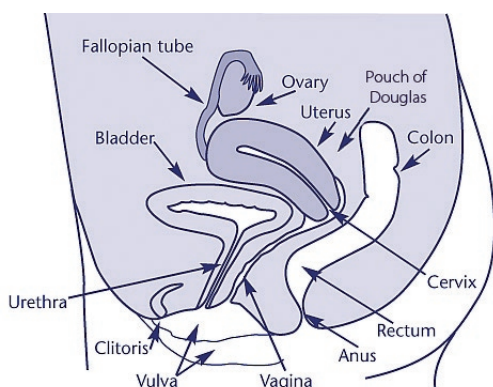


Endometriosis

Endometriosis is a condition where tissue similar to that which normally lines the uterus grows in other parts of the body. Studies suggest that it affects 5 – 10% of menstruating women in Australia.

The stray endometrial tissue is referred to as endometrial implants or endometrial lesions. Endometrial lesions are most commonly found in the pelvis, on the ovaries, on the ligaments that support the uterus and in the Pouch of Douglas (the area between the uterus and rectum). Other common sites include the surface of the uterus, fallopian tubes, bowel, cervix, vagina, vulva, ureters (the tubes connecting the kidney to the bladder) and bladder.

The condition is associated with severe pelvic and period pain, heavy periods and infertility, all of which can have a negative impact on the lives of affected women, their family and friends.



Pain is the most common symptom experienced by women with endometriosis. There are many ways that endometrial lesions can cause pain. Lesions cause irritation and inflammation to the tissue and organs that surround them. Scar tissue forming around the lesions can result in adhesions that stick the pelvic organs together. These adhesions can mean that the stuck together organs are unable to move freely, making movements such as ovulation, sexual intercourse or going to the toilet painful. Over time, the endometrial lesions on the ovaries may enlarge and form cysts. These cysts are called 'chocolate cysts' because they are filled with old blood which is chocolate-like in colour.

Symptoms

Endometriosis symptoms vary widely depending on the location of the implants in the body. They can include:

- Period pain (dysmenorrhoea)
- Pelvic and abdominal pain outside of menstruation
- Heavy periods (menorrhagia), clotting, long periods, irregular periods, premenstrual spotting.
- Ovulation pain
- Pain during sexual intercourse (dyspareunia)
- Bowel disturbances - including painful bowel motions, diarrhoea, constipation, bleeding from the bowel
- Difficulty in getting pregnant
- Painful urination
- Lower back, thigh and/or leg pain
- Premenstrual syndrome

The severity of symptoms is not necessarily related to the severity of the endometriosis; a woman with extensive endometriosis may have no symptoms at all while a woman with minimal endometriosis may have severe symptoms.

While women typically experience symptoms at the time of their period, because there are many different types of pain experienced by women with endometriosis, symptoms can occur at other times and can continue after menopause.

The anticipation of pain or discomfort, recurrence of symptoms following treatment and fertility problems can lead to feelings of depression, anxiety, anger, hopelessness and stress amongst sufferers.

Causes

While a number of theories exist the exact cause of endometriosis has not been established. The most popular theory is that of 'retrograde menstruation' where endometrial cells are pushed back up through the fallopian tubes into the pelvic cavity during a period, implanting on pelvic organs and the lining of the pelvis (peritoneum). However, it appears that most women have some degree of retrograde menstruation and yet not all develop endometriosis. It is therefore suggested that other factors such as a lowered immune response may also play a role.

Another theory suggests that the lining of the pelvis and abdomen can change under stimulation, possibly in response to inflammation or a rise in oestrogen levels (such as at puberty), to form endometrial implants.

Women's Health Queensland Wide Inc (Women's Health) is a not for profit, health promotion, information and education service for women and health professionals throughout Queensland.

Health Information Line

3839 9988 in Brisbane

1800 017 676 toll free outside Brisbane

Website

www.womhealth.org.au

Administration and library

07 3839 9962

Email

admin@womhealth.org.au

Other theories suggest that stray endometrial cells occur during the formation of the foetus or are spread through the body via the blood or lymphatic system or through gynaecological surgery. Current research is examining genetic influences in the development of endometriosis.

Risk factors

Women can develop endometriosis at any age. There are a number of factors that appear to increase the chances of developing the condition. These factors include:

- **Menstrual pattern** – The risk of developing endometriosis increases according to the number of periods a woman has experienced. An early onset of menarche (first period), short cycle length (under 28 days), long periods (more than seven days), regular periods and heavy periods are all associated with an increased risk.
- **Family history** – Women with a family history of endometriosis appear to be at increased risk of developing the condition. These women are also more likely to suffer severe endometriosis.
- **Reproductive history** - Because pregnancy and lactation reduce the number of periods a woman has (and the opportunities for retrograde menstruation), having no or few children increases a woman's risk of endometriosis.
- **Immune factors** - Women who suffer from endometriosis also appear to experience a higher incidence of autoimmune conditions such as rheumatoid arthritis, multiple sclerosis, allergies and asthma.
- **Obstruction in outflow of menstrual blood** – It is thought that an obstruction due to factors such as congenital abnormalities or a narrow cervix may increase the likelihood of retrograde menstruation and, therefore, endometriosis.
- **Environmental toxins** - Studies have suggested a link between dioxins and the risk of developing endometriosis. It is thought that dioxins may contribute to the development of endometriosis by mimicking the female hormone oestrogen and/or by compromising the immune system. Concerns have been expressed in the past regarding dioxin levels in rayon tampons. However, studies have found that women are exposed to higher levels of dioxin and dioxin-type substances through the food they eat than through tampon use.

Diagnosis

Endometriosis can take a long time to diagnose with the average length of time between the onset of symptoms and diagnosis being 7 years. There are several reasons for this. Women might consider their symptoms to be normal and delay reporting them to their doctor. Doctors may also initially attribute symptoms to other conditions such as pelvic inflammatory disease, fibroids, kidney stones, stomach ulcers, irritable bowel syndrome or cystitis. Delays in diagnosis can leave women feeling frustrated, angry or depressed.

It is recommended that any woman who has period pain severe enough to take time off from work or school, even if only occasionally, is investigated for endometriosis.

A doctor may be able to detect signs of endometriosis such as tenderness, a fixed uterus (due to adhesions) and enlarged ovaries during a pelvic examination. If enlarged ovaries or a mass in the pelvis is detected, a vaginal ultrasound (which uses a probe inserted into the vagina) may be performed.

Currently the only way to definitively diagnose endometriosis is through laparoscopy. Laparoscopy is a surgical procedure which involves inserting a long, thin telescope (laparoscope) into the

abdomen through an incision near the navel. Gas is pumped into the abdomen to separate the organs so the surgeon can look for signs of endometriosis. If endometriosis is present it is classified from stage 1 to 4 (mild to severe) according to its location and depth. If endometriosis is present it might also be removed at this time (refer to *Laparoscopy* section below).

Recent Australian research has shown that women with endometriosis have nerve fibres present in their endometrium. Taking a biopsy to test for the presence of these fibres may provide a less invasive diagnostic tool than laparoscopic surgery in the future.

Treatment options

There are a variety of treatment options available for women with endometriosis. The treatments chosen by women depend on a number of factors including the severity of symptoms, the location of implants, the woman's age and the outcome she wishes to achieve (ie. pain reduction, improved fertility).

A common misconception concerning endometriosis is that having a baby will cure the condition. While endometriosis is generally suppressed during pregnancy, some women actually experience a worsening of symptoms in the first few months of pregnancy. Most women who find their symptoms are relieved during pregnancy will have them return within five years. For some women symptoms return as soon as their periods start again.

DRUG TREATMENT

Medication used to treat endometriosis can treat hormone levels or simply provide pain relief. Because endometrial implants tend to recede during pregnancy and menopause the majority of hormonal treatments aim to mimic the hormonal state at these times. It is important to note that while drug treatments can shrink endometrial implants they have no effect on adhesions.

The medication chosen will depend on the individual woman's situation taking into account possible risks, benefits and side effects. These should be discussed with a doctor at length before commencing treatment. Endometriosis can return following drug therapy with women who suffer more severe endometriosis having a higher recurrence rate.

Nonsteroidal anti-inflammatory drugs (NSAIDs)

These drugs block the production of prostaglandins in the body. Prostaglandins have a number of functions, including making the uterus contract during periods to help with the shedding of the endometrium. These contractions can cause pain. It is thought that women with endometriosis may produce more prostaglandins than women without the condition. Because NSAIDs work by stopping the production of prostaglandins they are most effective when taken the day before a period is due. Women may need to try different types of NSAIDs to find one that is most effective for them. Common side effects of NSAIDs include nausea, vomiting, diarrhoea, stomach upsets and stomach ulcers. These can be reduced by taking the drugs with food or milk.

Combined oral contraceptive pill

The combined oral contraceptive pill (the pill) can be used by women to 'skip' periods, and therefore lessen the incidence of pain. It can reduce prostaglandin pain associated with periods. Because women on the pill have a "withdrawal bleed" rather than a true period the pill can help lighten bleeding and reduce the possibility of further endometrial implants occurring via retrograde menstruation. The pill types favoured for treating endometriosis have a higher progestogen to oestrogen ratio. The pill may be useful for adolescents and women with milder symptoms, particularly those who do not wish to take the other drugs available.

Progestogens

Progestogens act as anti-oestrogens, inhibiting the growth of endometrial implants. Progestogens are available as tablets, injections, an intra-uterine system (Mirena) or an implant (Implanon). Side effects differ for each delivery method but may include weight gain, fluid retention, nausea, breakthrough bleeding, depression and fatigue (less likely with the intra-uterine system). Research into a newer progestogen medication, dienogest, has indicated it to have potentially fewer side effects than other progestogen medications.

The Mirena IUCD (intrauterine contraceptive device) is a small plastic device that is inserted into the uterus and delivers progestogen medication. Because the progestogen doesn't reach the rest of the body the Mirena has fewer side effects than other progestogen delivery methods. The Mirena is effective in lightening periods and reducing period pain.

GnRH agonists

These drugs are a modified version of the naturally occurring Gonadotropin-releasing hormone (GnRH). GnRH agonists are administered by either injection or a nasal spray. They induce an artificial menopause by preventing the ovaries from producing the hormones oestrogen and progesterone. The lack of oestrogen causes the endometrial implants to degenerate.

Side effects of GnRH agonists include menopause-related symptoms, including a reduction in bone density. Although the effect of reduced bone density is largely reversible after finishing medication, to minimise risk, treatment is generally limited to a six month course. "Add back" hormone replacement therapy (HRT) is also commonly used at the same time as GnRH agonists to help overcome menopause-related symptoms.

GnRH agonists should not be taken during pregnancy or breastfeeding. However, studies have indicated that women who receive GnRH three to six months *before* commencing IVF treatment were four times more likely to fall pregnant. They were also more likely to carry the pregnancy through to full term.

Danazol and gestrinone

Danazol is a mild anabolic steroid that contains a weak form of testosterone. It works to suppress endometriosis by creating a menopause-like state. Most women who take danazol stop getting their period. Side effects include those related to a drop in oestrogen (vaginal dryness, hot flushes and night sweats) and those related to an increase in testosterone (weight gain, increased muscle strength, decreased breast size, acne or oily skin, increase in facial and body hair and voice changes).

Gestrinone is a steroid which also creates a menopause-like state. The side effects are similar to danazol, although gestrinone is reported to have fewer masculinising side effects. Danazol and gestrinone should not be taken during pregnancy or while breastfeeding.

SURGERY

Surgery plays a major role in both diagnosis and treatment of endometriosis. As with drug treatments, symptoms can reoccur. However, unlike most drug treatments, surgery can improve fertility.

Laparoscopy

The surgical removal of endometrial lesions and adhesions can be carried out using a range of instruments at the time of the diagnostic laparoscopy. As with any medical procedure, there are risks associated with surgery and anaesthetic. The most common side effect following laparoscopic surgery is pain and discomfort in the abdomen and shoulders. This pain can be felt for several days and is due to left over carbon dioxide gas pooling in the abdomen. Other possible side effects may include the development of adhesions and, rarely, damage

to pelvic structures. It is also possible that not all the endometriosis is visible to the surgeon and therefore will not be removed. Most women will be able to go home the same day they have the operation. They will generally take 5-7 days to feel better and will be able to return to work sometime in the second week.

Laparotomy

If a woman has extensive endometriosis or adhesions or laparoscopic surgery is difficult it might be necessary to make a larger cut in the abdomen. This is called a laparotomy. Women requiring a laparotomy will need 3-5 days in hospital and around 6 weeks to fully recover.

Hysterectomy

If a woman's symptoms persist despite drug and conservative surgical treatment a hysterectomy may be suggested (see the Women's Health *Hysterectomy* factsheet for more information). This type of surgery is usually only chosen in cases where all other forms of treatment have failed. Hysterectomy will involve removal of the uterus and all of the endometriosis. If the ovaries are unaffected they may be kept to avoid a surgically induced menopause. However, women who keep one or both of their ovaries may experience a recurrence of symptoms with some requiring further surgery. Women should discuss the pros and cons of keeping their ovaries at hysterectomy with their doctor.

HRT AFTER HYSTERECTOMY

Women who have both ovaries removed at hysterectomy are sometimes prescribed hormone replacement therapy (HRT) to help relieve menopausal symptoms. However, as HRT contains oestrogen it is thought that it may possibly lead to a return of the endometriosis. For this reason HRT is often recommended to be held off for several months after hysterectomy to help ensure that any possible remaining endometrial implants are minimised. Prolonged use (over 5 years) of combined HRT has been associated with additional health risks for some women. Women should therefore discuss the pros and cons as well as expected treatment length with their doctor before starting HRT.

COMPLEMENTARY THERAPIES

Many women report finding complementary therapies helpful in managing their endometriosis symptoms. There are a range of therapies available. Those most commonly used are herbal medicine, Traditional Chinese Medicine (TCM), aromatherapy, homeopathy, massage, yoga and meditation. Complementary therapies are used to assist in balancing hormone levels, relieving pain and reducing the feelings of stress and depression often associated with this condition.

It has been suggested that Chinese herbal medicine may provide relief from the symptoms of endometriosis comparable with the conventional drug treatments gestrinone and danazol. Women using Chinese herbal medicine compared to gestrinone also appear to suffer fewer side effects.

Women interested in using complementary therapies should consult a qualified practitioner who can properly advise them on a course of treatment. It is also important that women disclose any use of complementary therapies to their doctor as herbal and Traditional Chinese Medicines can interfere with conventional medications.

DIET AND EXERCISE

A balanced diet plays an important role in assisting recovery following surgery as well as combating the side effects of drug treatments. The many benefits of regular exercise include more stable hormone levels and an increased ability to deal with stress, pain and depression.

EMOTIONAL SUPPORT

In addition to the drug, surgical and complementary therapies available, women may find the services of a professional counsellor experienced in working with endometriosis helpful. A professional counsellor can help women address some of the issues associated with being diagnosed with the condition. Women may also consider joining a support group. Support groups can provide women and their families with information on endometriosis and coping strategies as well as contact with other people who are experiencing similar problems.

Endometriosis and fertility

There are many ways in which endometriosis can affect a woman's fertility. Scar tissue and adhesions might affect the movement of eggs and sperm or the ability of a fertilised egg to implant successfully. And of course some women may be avoiding regular sexual intercourse if it is painful.

Although endometriosis is associated with infertility (approximately one third of women being investigated for infertility are diagnosed with the condition), many women with endometriosis can, and do, fall pregnant easily. It is therefore important for women diagnosed with endometriosis to continue to use contraception if they are not seeking to fall pregnant.

Women having difficulty falling pregnant should discuss this with their doctor as there are a range of fertility assistance options available for women and their partners in this situation.

Further reading

QENDO

The Endometriosis Association (Qld) Inc
07 3321 4408 (messagebank service)
info@qendo.org.au
www.qendo.org.au

Endometriosis Care Centre of Australia (ECCA)
www.ecca.com.au



For help understanding this fact sheet or further information on endometriosis call the Health Information Line on 3839 9988 (within Brisbane) or 1800 017 676 (toll free outside Brisbane).

This is one of a series of women's health information factsheets available at www.womhealth.org.au.

A full list of references is available from Women's Health or on the website.

call our **Health Information Line**

A free information and referral service for Queensland women

3839 9988
1800 017 676
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Staffed by nurse/midwives

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