Understanding endometriosis
About Jean Hailes

Founded in 1992 in honour of an extraordinary medical practitioner, Dr Jean Hailes, Jean Hailes for Women’s Health reflects the enduring legacy that Jean made to women’s health. She had a far-sighted vision to improve the quality of women’s lives and give them practical information based on the best available evidence. She is credited with being the pioneer of menopause management in Australia.

Today, Jean Hailes is Australia’s leading and most trusted women’s health organisation, combining clinical care, evidence-based research and practical education for women and health professionals. We aim to translate the latest scientific and medical evidence in order to inspire positive change in women by improving their physical health and wellbeing.

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What is endometriosis?

Endometriosis, pronounced end-o-me-tree-oh-sis (or just endo) is a progressive, chronic condition where cells similar to those that line the uterus (the endometrium) are found in other parts of the body. Studies suggest that endometriosis affects 1 in 10 women of reproductive age, with an estimated 176 million women worldwide having the condition.

During your menstrual cycle, hormones are released that cause the lining of the uterus to thicken in preparation for a fertilised egg. If no egg arrives, the lining of the uterus breaks away causing menstrual bleeding (the period). Endometrial cells, no matter where they are, still respond to the cyclic hormones, leading to growth that bleeds at the time of your period.

What happens?

Endometrial cells found outside the uterus grow to form lesions or patches that bleed and leak fluid in response to your hormones at the time of the period. This leads to inflammation and scarring. These patches found outside the uterus cannot pass out of your body and remain in your pelvic cavity, on organs and other surfaces. On your ovaries, cysts called endometriomas can develop over time. These are sometimes called ‘chocolate cysts’ because of the darkish material they contain. On other surfaces the patches can form nodules.
What causes endometriosis?

No one knows what causes endometriosis, but there are many theories being researched worldwide. Endometriosis is not infectious, it is not sexually transmitted and it is not a cancer.

- **Family history:** women who have close relatives with endometriosis are up to 7-10 times more likely to develop it.

- **Retrograde (backwards) menstruation:** during menstruation, blood flows out of the vagina but can also flow backwards along the fallopian tubes into the pelvis. This is called retrograde menstruation. In most cases, the blood simply gets absorbed by your body without any issues. In endometriosis, the cells that remain start to grow and multiply, which can cause a wide range of symptoms.

- **Other theories being investigated are:** immune dysfunction, endometrial cell transport via your blood or lymphatic system, metaplasia (cells changing their function) and environmental causes.
Where is endometriosis found?

The most common sites for endometriosis are:
- your ovaries and fallopian tubes
- the lining of your abdominal cavity (peritoneum)
- the outside of your uterus and the ligaments that hold it in place (uterosacral ligaments)

In addition to the sites in the diagram above, endometriosis can also be found in other areas including:
- between your rectum and uterus (Pouch of Douglas)
- on your bowel, bladder, intestines and rectum
- in abdominal surgery scars
- on organs outside the pelvic cavity, in very rare cases
What are the signs and symptoms?

Endometriosis can cause a wide range of symptoms. The severity of the symptoms may not reflect the severity of the condition. Due to the varied symptoms, endometriosis can take a long time to diagnose (the average time to diagnosis is seven years). Some of the symptoms of endometriosis are period pain, painful sex and infertility.

Bleeding:
- heavy menstrual bleeding that may contain clots (thickened blood, ranging in size from small to large)
- bleeding/spotting in between periods, including premenstrual and after sex
- having blood in your urine or from the bowel

Pelvic pain:
- period pain that isn’t relieved by pain medication such as paracetamol or anti-inflammatories (period pain medications)
- pain during sex, passing a bowel movement or passing urine
- pain before, during or after your period
- ovulation pain
- severe abdominal or pelvic pain
- pain in the legs or lower back
- pain that gets worse over time
- severe pain that means you can’t participate in work, school or sporting activities

Other symptoms:
- irritable bowel syndrome (IBS) type symptoms – constipation, diarrhoea and bloating
- lethargy, extreme tiredness and feeling faint
- depression, anxiety, mood swings and irritability
- inability to get pregnant
Diagnosis

- Unfortunately, diagnosing endometriosis is not easy. Your doctor will take a full history and ask lots of questions about any bleeding, pain or other symptoms you may have been experiencing. You will usually have a physical examination and may also need an internal examination if you are or have been sexually active. The examination may detect painful areas within your pelvis.
- It’s very helpful if you keep a diary of your period for at least three months, recording all the signs and symptoms you experience and how they affect your quality of life (to download the Jean Hailes pain and symptom diary go to jeanhailes.org.au/health-a-z/periods/period-pain).
- A vaginal ultrasound will only detect large patches of endometriosis or nodules at the back of the uterus, on the bowel, or bladder and endometriomas. Most patches are not detected by ultrasound.
- The only way to get a diagnosis of endometriosis is by having an operation called a laparoscopy. During the operation a small telescope is inserted into your pelvis, via a small incision near your belly button. Your doctor can use this procedure to both diagnose and treat your endometriosis.
Different experiences of endometriosis

Some gynaecologists may talk to you about the different levels or stages of endometriosis.

Previously, endometriosis was classified into stages including:

- **Mild**: a few lesions found on or around the pelvic organs
- **Moderate**: quite a number of lesions in the pelvic area with some attached to other organs by adhesions (bands of tissue binding tissue/organs together)
- **Severe**: larger and thicker lesions (called nodules) with a greater number of adhesions, causing organs to stick to other tissues or organs

These classifications have limitations. While one woman may have only a few lesions, she may experience severe pain, another woman can have many lesions and not have as severe pain.

Managing endometriosis

There is no actual cure for endometriosis but there are various ways of managing the condition. The myth that pregnancy can cure endometriosis is untrue; it may offer some relief from symptoms but they tend to return again.

Your doctor will advise which management options are best for you, taking into account your age, the severity of your symptoms, your fertility status and your individual circumstances. Endometriosis is usually treated by a multidisciplinary team – that means that your doctor will work together with a number of other health professionals.
Management options

Surgery
The aim of surgery is to reduce your symptoms by removing as many endometriotic patches as possible, along with any nodules, cysts, endometriomas (chocolate cysts) and adhesions. This may also help improve your fertility. Your surgeon will also attempt to repair any damage caused by the condition.

The procedure, called a laparoscopy, is usually done by key-hole surgery that involves small incisions on your lower abdomen. It is sometimes done by laparotomy; this requires a larger incision and is a major operation. Hysterectomy is the removal of your uterus and is only considered in severe, recurrent cases that haven’t responded to treatment or other surgery.

Hormonal therapy
The aim of hormonal therapy is to reduce your symptoms by suppressing the endometriosis. There are a wide range of treatments available and your doctor can advise which suits you best. You may be given tablets, an implant, an injection or an intrauterine device (IUD). The oral contraceptive pill (OCP) is often used to treat the symptoms of endometriosis. Your doctor may recommend this even if you are not sexually active or seeking a contraceptive.

Pain relief
Non-steroidal anti-inflammatories (NSAIDs) may help and are contained in period pain medication. If your pain is not manageable, discuss this with your doctor.
Things you can do

Pelvic floor physiotherapy
A pelvic floor physiotherapist has a special interest in pelvic floor dysfunction, pelvic pain and bladder and bowel problems. Visiting a pelvic floor physiotherapist can help to reduce your pelvic pain symptoms.

Exercise
Accredited exercise physiologists are specially trained to assess your state of health and provide exercises you can enjoy, that won’t cause pain. Avoiding exercises such as pilates that stimulate core muscles may be helpful, because activating tight or sore pelvic floor muscles can make the pain worse.

Emotional support/counselling
Sometimes you may need to talk to someone about what you are going through. Ask your doctor to refer you to a pain clinic, an experienced pain psychologist or counsellor. You may be able to get a mental health plan for 10 sessions per year that will reduce the costs of your visit. There are also endometriosis support networks online where you can connect with other women with endometriosis.

Nutrition
While there is no direct evidence that nutrition influences endometriosis it is important to overall wellbeing. A healthy diet includes lots of plant-based foods (fruits and vegetables, nuts, seeds, legumes) and fish. Fish oils (omega-3 fatty acids) in dark fish, such as tuna, may help with pain relief. Getting enough magnesium, vitamins B1 and B6, and consuming a low-fat vegetarian diet may also reduce pain. If you experience bowel symptoms, learning what foods may trigger these can be helpful for some women.
Keeping a food diary is the best way to track how your diet affects you. If you find you are sensitive to certain food types, ask your doctor to refer you to a dietitian with experience in this area.

**Complementary therapies**
There are a wide range of therapies such as naturopathy, acupuncture, yoga and herbal medicine that may help you cope better with endometriosis. Visit jeanhale.org.au for a list of associations for registered therapists.
Living with endometriosis

Living with endometriosis or any other chronic condition can be difficult. Women with endometriosis are at risk of becoming depressed or anxious due to the impact on their quality of life. It’s perfectly normal to feel anger, disbelief, shock, frustration, fear, numbness, sadness, anxiety or even relief when you are diagnosed with endometriosis.

If you are worried about how you are coping with endometriosis ask your doctor to refer you to a pain clinic, psychologist or counsellor. They are specially trained to help people deal with pain and can teach you methods to cope better.

Learning how to relax and look after yourself are key to managing this condition successfully. Finding a local yoga or meditation class may help you to learn relaxation techniques to reduce your stress levels and anxiety. Making lifestyle changes may help relieve some of your symptoms and improve your sense of wellbeing.

Exercise reduces oestrogen levels in your body, helps to reduce inflammation and prompts your body to release endorphins. These are your body’s natural feel-good hormones and help you feel less pain while boosting your mood. Just 10 minutes of exercise (that gets you out of breath) is enough to start the process. Find an exercise that suits you and doesn’t cause you any pain and aim to do at least 30 minutes each day.

Getting a good night’s sleep is also essential for wellbeing, so try to avoid caffeine or heavy meals late at night.
You’re not alone

Talking about endometriosis can be difficult with close family members, friends or your partner, but it’s good to know you are not alone. Finding a support network can help you to reach out and make contact with other women with endometriosis and share your story. Visit jeanhailes.org.au for more information.

Endometriosis and future health

Endometriosis is a chronic condition that will require ongoing management. It is important to develop a good relationship with your doctor and healthcare team.

It’s estimated that 30% of women with endometriosis may have trouble becoming pregnant. Surgery to remove endometrial cells can increase the likelihood of pregnancy. If you are thinking of starting a family talk with your doctor about how endometriosis might affect your fertility. Ask your doctor to refer you to a fertility specialist to discuss your options.

There is a very small increase in the chance of developing ovarian cancer with endometriosis. If you are worried discuss your risk with your doctor.

Support and resources

At jeanhailes.org.au you will find further, more detailed information on endometriosis symptoms, diagnosis, management, fertility, emotions, relationships and sex. The website also has a range of resources for women including a pain diary to take to your doctor, webinars discussing the condition and links to find further information. Several endometriosis support networks in Australia can be found via jeanhailes.org.au/health-a-z/endometriosis.