

# Understanding endometriosis

All you need to know



# 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 one of Australia's leading and most trusted women's health organisations. Our work is built on four pillars: education and knowledge exchange; clinical care; research; and policy. We aim to translate the latest scientific and medical evidence to help inspire positive change in women and girls by improving their physical health and wellbeing.

Jean Hailes for Women's Health takes a broad and inclusive approach to the topic of women's health. This booklet generally uses the terms 'women and girls'. These terms are intended to include women with diverse sexualities, intersex women, and women with a transgender experience.

Jean Hailes for Women's Health gratefully acknowledges the support of the Australian Government.

This project is funded by the Victorian Government.



# Contents

<b>Glossary</b> .....	<b>2</b>
What do these words mean? .....	2
<b>Introduction</b> .....	<b>5</b>
What is endometriosis? .....	5
What causes endometriosis? .....	6
Where is endometriosis found? .....	7
What are the signs and symptoms? .....	8
<b>Diagnosis &amp; management</b> .....	<b>9</b>
Diagnosis .....	9
Stages of endometriosis .....	10
Managing endometriosis .....	10
Management options .....	11
Fertility .....	12
Things you can do .....	12
<b>Living with endometriosis</b> .....	<b>14</b>
Learning to manage .....	14
You're not alone .....	15
Endometriosis and future health .....	15
<b>Support and resources</b> .....	<b>16</b>

# Glossary

## What do these words mean?

You will see the below words and terms often throughout this booklet. We've provided meanings for each of them here, in case you need more help to understand them.

**Anxiety** – when fears or thoughts that are chronic (constant) and upsetting interfere with daily life

**Cells** – the basic unit/building block of any living thing. The average human body is made up of about 37 trillion cells

**Cyst** – an abnormal lump or sac that forms in or on the body

**Depression** – this is more than just a low mood or sadness. A person with depression may feel extremely sad, dejected and unmotivated. It can be a serious mental illness

**Diagnosis** – identifying/determining the cause of an illness or other health problem by examining the symptoms, signs and investigations

**Fallopian tubes** – the tubes that lead from each ovary through which an egg can travel to the uterus

**Fertility** – the ability to fall pregnant and produce a child

**Hormones** – the body's chemical messengers. Hormones tell the body what to do and when, such as releasing an egg from an ovary, or starting or stopping a period

**Infertility** – when you have had 12 months of unprotected sexual intercourse and have not become pregnant

**Inflammation** – heat, redness or swelling created by the body's attempt to heal itself in response to something harmful, such as an injury, disease or infection

**Ligaments** – strong bands of tissue that hold bones or organs in place in the body

**Lesion** – an abnormal spot or area on the body caused by illness or injury

**Nodule** – a small lump or growth

**Oestrogen** – one of the main female hormones, oestrogen controls the female reproductive system, making it important in puberty, periods and pregnancy. It is also important for bone strength. Men also have oestrogen, but not as much as women

**Ovaries/ovary** – a small round organ of a woman's reproductive system containing eggs. Women have two ovaries. Women who get periods usually release an egg from one of their ovaries every month

**Period** – also called menstruation, this is a girl or woman's monthly bleed. During a period, the lining of the uterus (womb) leaves the body through the vagina. If there is a pregnancy, the period will not happen, as the uterus will keep its lining

**Sign** – the presence of the condition or illness such as a skin rash, or being able to feel a lump or an abnormality on examination

**Symptom** – a physical or mental experience or feeling that shows the presence of a condition or disease. Examples of symptoms include a headache, or any change to a bodily function (such as your period) that is not normal for you

**Tissue** – groups of cells that combine to make up all the different parts of the body, such as flesh, nerves and muscles

**Uterus** – the womb.



# Introduction

## What is endometriosis?

Endometriosis – pronounced '*end-o-me-tree-oh-sis*', but commonly called 'endo' – is a progressive, chronic condition in which cells similar to those in the lining of the uterus, called the endometrium, are found in other parts of the body. It most commonly occurs in the pelvis and can affect a woman's reproductive organs. Studies suggest that endometriosis affects one 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 this cycle, leading to growth that bleeds at the time of your period.

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, so they 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?

Endometriosis is not infectious – you cannot catch it or give it to anyone else – and is not a cancer. No one knows what causes it, but there are many theories being researched worldwide. These include:

- **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 through 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:

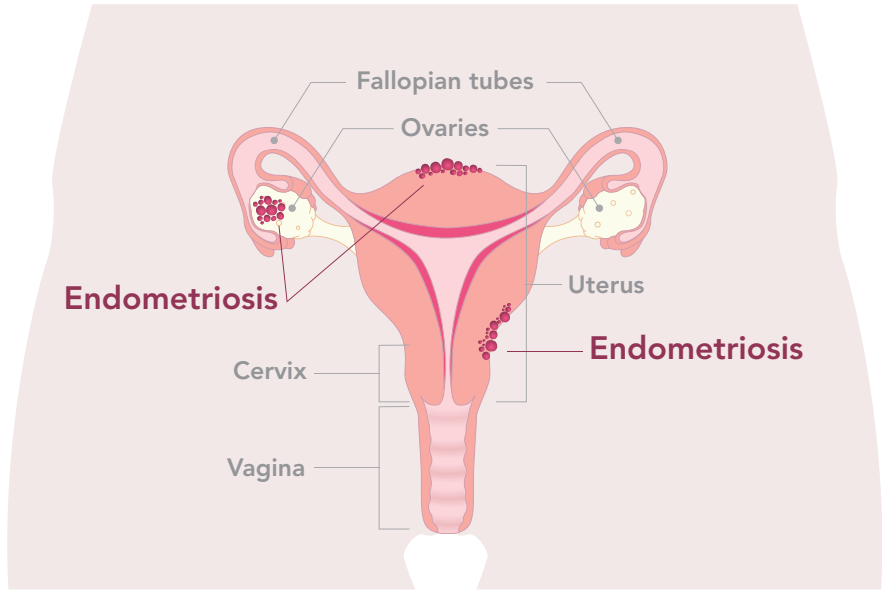
- immune problems (an altered immune response to endometrial cells)
- endometrial cells moving through your blood or lymphatic system
- metaplasia (cells changing their function)
- environmental causes (the effects and interactions between genetic and environmental factors, such as smoking, body weight and diet).



## 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 be found in other areas including:

- between your rectum and uterus (Pouch of Douglas)
- on your bowel and bladder
- in abdominal surgery scars
- on organs outside the pelvic area (in very rare cases).

## What are the signs and symptoms?

Endometriosis can cause a wide range of symptoms, which vary from person to person. Some have many symptoms, where severe pain occurs, while others have no symptoms.

The severity of the symptoms may not reflect the severity of the condition. Some of the symptoms of endometriosis are period pain, pelvic pain, painful sex and infertility.

### Pain:

- period pain that isn't relieved by pain medication such as paracetamol or anti-inflammatories (period pain medications)
- pain during sex, or while going to the toilet
- 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.

### 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.

### 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 & management

## Diagnosis

Diagnosing endometriosis is not easy, due to the varied symptoms, and can take a long time; the average time from first symptoms to diagnosis is seven years.

Your doctor will take a full history and ask lots of questions about any bleeding, pain or other symptoms you may have experienced. You will usually have a physical examination and may also need an internal examination – where your doctor will feel inside your pelvis and vagina with their fingers – 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 you. Download the Jean Hailes 'Pain and symptom diary' at [www.jh.today/tool6](http://www.jh.today/tool6)
- Ultrasound does not usually detect small or superficial patches of endometriosis. A specialist gynaecological ultrasound may detect larger areas of endometriosis related cysts or scarring if they are present.
- The **only** way to get a diagnosis of endometriosis is by having a laparoscopy (keyhole surgery). During the operation, a small telescope is inserted into your pelvis via a small incision, usually in your belly button. Areas of endometriosis can be seen to make the diagnosis. They can then be vaporised (cells destroyed with electrical energy) or excised (cut away) to treat the disease.

## Stages of endometriosis

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

Endometriosis may be classified as minimal (stage 1), mild (stage 2), moderate (stage 3) or severe (stage 4).

These classifications help to describe the amount of endometriosis and scarring present. However, they have limitations, as the level of endometriosis present does not always relate to the severity of symptoms. A woman with stage 1 endometriosis could be in just as much pain, or more, as a woman with stage 4 endometriosis.

## Managing endometriosis

There is no cure for endometriosis, but there are various ways to manage it. It is not true that pregnancy can cure endometriosis; it might offer some relief from symptoms, but they tend to return after a pregnancy.

Your doctor will discuss with you which management options are best for you and answer any questions you have. They will take into account your age, the severity of your symptoms, your fertility status and your individual circumstances. Endometriosis is usually treated by a multidisciplinary team, which means your doctor will work together with other health professionals.



## Management options

### Pain relief

Non-steroidal anti-inflammatory drugs (NSAIDs) may help, and are contained in period pain medication. If your pain is not manageable, discuss this with your doctor.

### Hormonal therapy

The aim of hormonal therapy is to reduce your symptoms by suppressing the growth of endometrial cells and stopping any bleeding (including the period). There are a wide range of treatments available and your doctor can advise which may suit you best.

Your therapy may be tablets, an implant, an injection, or an intrauterine device (IUD). The combined oral contraceptive pill (COCP) 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.

### Surgery

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

One surgical option is a laparoscopy. This is usually done by keyhole surgery, which requires small incisions to be made in your lower belly. Another option is a laparotomy, which is an open operation requiring a larger cut in your lower belly. This may be performed if endometriosis is severe, or if a laparoscopy is not an option.

Hysterectomy – the removal of the uterus – is rarely recommended. It is considered only in severe, recurrent cases that haven't responded to treatment or other surgery.

## Fertility

It is important to know that most women with endometriosis will become pregnant without any medical assistance. About 30% of women with endometriosis have trouble getting pregnant. For women diagnosed with moderate and severe endometriosis (stage 3/4), who want to become pregnant, about 75% will be able to do so; of these women, about 66% will fall pregnant naturally and the rest will do so with the help of IVF.

If you are thinking of trying to get pregnant, talk to your doctor about how endometriosis might affect your fertility.

## 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. They can help you reduce your pelvic pain symptoms by assessing the nature of your pain and teaching you gentle stretches and exercises. You can ask your doctor for a referral to a pelvic floor physiotherapist.

### 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 that stimulate core muscles, such as pilates, can help, 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 from your doctor for 10 sessions per year, which will reduce the costs of your visits. 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, a healthy diet is important for overall wellbeing. This 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 help 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 is a wide range of therapies, such as naturopathy, acupuncture, yoga and herbal medicine, that may help you cope better with endometriosis. Despite the popular use of natural and complementary therapies in endometriosis – often for the management of pain and inflammation – there is a lack of good-quality research evidence in the area. This is an emerging area, so evidence may change over time.

Visit [www.jh.today/endo](http://www.jh.today/endo) for more information on endometriosis & natural therapies and a list of associations for registered therapists.

# Living with endometriosis

## Learning to manage

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 the condition has 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, 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 with close family members, friends or your partner can be difficult, 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 people with endometriosis and share your story.

Visit [www.jh.today/endo](http://www.jh.today/endo) for more information, or [jeanhailes.org.au/endowise](http://jeanhailes.org.au/endowise) for videos of other women in Australia sharing their own experiences of living with 'endo'.

## 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.

If you are thinking of trying to get pregnant, 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.

With certain types of endometriosis, there is a very small increase in the chance of developing ovarian cancer. Discuss your risk with your doctor.



# Support and resources

At [jeanhailes.org.au](http://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.

For family and partners: see our factsheet 'How you can support women diagnosed with endometriosis'.

Several endometriosis support networks in Australia can be found under 'Related resources' at [www.jh.today/endo3](http://www.jh.today/endo3).

You can also visit the Better Health Channel, [www.jh.today/BHCendo](http://www.jh.today/BHCendo), for more information.

# Jean Hailes for Women's Health

Jean Hailes for Women's Health provides high-quality, trusted information, to assist you to make decisions about your health. We use the latest research to develop our website and resources on a range of topics, including:

- bladder and bowel
- bone health
- breast health
- cardiovascular health
- endometriosis
- fertility and pregnancy
- health checks
- healthy living
- Indigenous health
- menopause
- mental and emotional health
- natural therapies and supplements
- polycystic ovary syndrome (PCOS)
- periods
- sex and sexual health
- vulva, vagina, ovaries and uterus.

## Visit [jeanhailes.org.au](http://jeanhailes.org.au) to:

- Subscribe to our free magazine and email updates.
- Enjoy videos, podcasts and recipes.
- Be inspired to improve your health.



### **For further information contact**

Jean Hailes for Women's Health  
PO Box 3367  
East Melbourne VIC 3002

**Toll free** 1800 JEAN HAILES (532 642)

**Email** [education@jeanhailes.org.au](mailto:education@jeanhailes.org.au)

**Website** [jeanhailes.org.au](http://jeanhailes.org.au)

---

**Disclaimer** This booklet is designed to be informative and educational. Jean Hailes for Women's Health does not accept any liability to any person for the information or advice which is provided in this booklet or incorporated into it by reference. Information is provided on the basis that all persons reading this booklet undertake responsibility for assessing the relevance and accuracy of its content.

© Jean Hailes for Women's Health 2016

This work is copyright. Apart from any use permitted under the Copyright Act 1968, no part may be reproduced by any process without written permission from Jean Hailes for Women's Health. Requests and inquiries concerning reproduction and rights should be addressed to Jean Hailes for Women's Health using the contact information provided above.

Updated June 2019