JULIA ARGYROU
Endometriosis Centre

Epworth

Understanding Endometriosis
A Patient's Guide

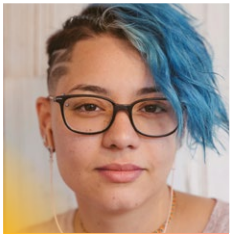
Second edition







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Contents

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A Patient's Guide
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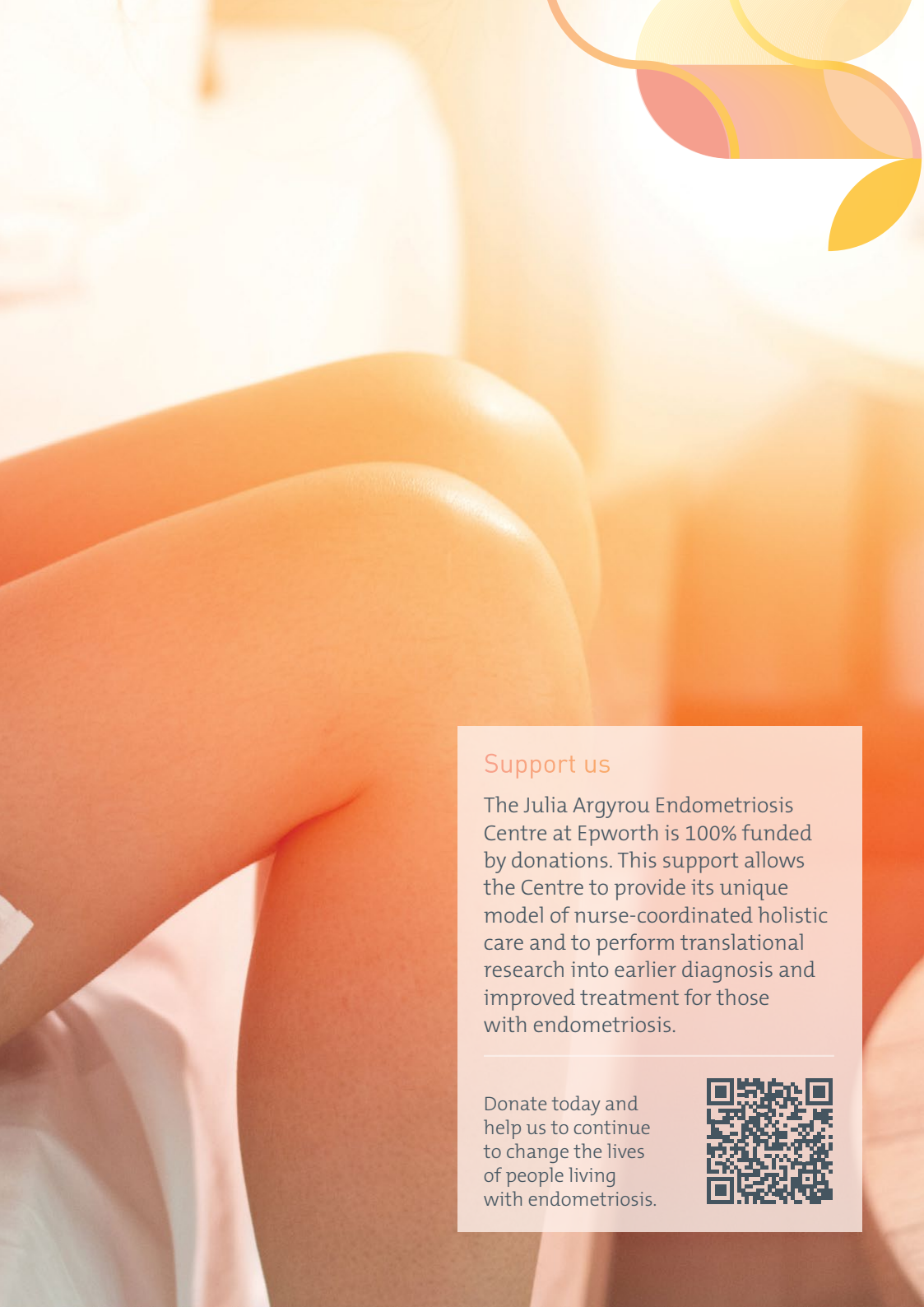
Note to reader:

All care has been taken to ensure the accuracy of the information within this booklet prior to publication. Please remember that information pertaining to endometriosis is constantly being updated by healthcare professionals and the research community. This guide is intended as an introduction to endometriosis. This handbook is not intended as a replacement for medical or professional advice. You must always consult with your healthcare professionals about any medical symptoms, questions or concerns that you may have. The Epworth Medical Foundation and the Julia Argyrou Endometriosis Centre at Epworth exclude themselves from liability for any injury, loss or damage incurred by the use of or reliance on the information provided in this booklet.



Support us

The Julia Argyrou Endometriosis Centre at Epworth is 100% funded by donations. This support allows the Centre to provide its unique model of nurse-coordinated holistic care and to perform translational research into earlier diagnosis and improved treatment for those with endometriosis.

Donate today and help us to continue to change the lives of people living with endometriosis.

Your guide to endometriosis

An endometriosis diagnosis may help explain some of the symptoms you have been experiencing, including pelvic pain, abnormal vaginal bleeding, infertility and other problems. It can also leave you feeling overwhelmed. Endometriosis is a dynamic condition. This can cause you to have a lot of questions.

We're here to help answer these questions.

Our endometriosis guide is a tool that will help you better understand endometriosis and the associated symptoms. It will provide you with a broad overview of endometriosis and how it may impact you and those close to you. Some of the topics we cover include diagnosis, treatment options, fertility impacts, and where to find support.

At the Julia Argyrou Endometriosis Centre at Epworth, we want you to be aware of all the options available to you. While endometriosis is a chronic condition, it can be managed. As endometriosis can have a widespread impact on those close to you, we recommend that you ask them to read this guide as well.

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Glossary

As you're reading through this booklet, you may find terms that you don't understand. While we have tried to keep the language free of complicated medical jargon, there are some terms that you will need to know. If we haven't explained them in the booklet, you can find the definition here if you need it.

ablation – the destruction of body tissue

adenomyosis – a condition where cells similar to those that line the uterus are found in the muscle wall of your uterus

adhesions – scar tissue that joins or attaches organs or tissues together

anatomical distortion – body parts twisted or pulled out of natural or normal shape and position

androgen – (e.g. testosterone) thought of as a 'male' sex hormone, but is produced naturally in females and is important in female puberty and reproductive health

central sensitisation – when the central nervous system undergoes structural, functional, and chemical changes that make it more sensitive to pain and other sensory stimuli

cystoscopy – a procedure where a doctor uses a thin, flexible tube with a small camera on the end to look inside the bladder

endometriosis lesions – endometrial-like tissue that is growing outside of the uterus

endometrium – tissue that lines the uterus

endometriomas – a cyst that forms because of endometrial-like tissue growing on the ovaries, also known as chocolate cysts

excision – the 'cutting out' or removal of tissue

dysmenorrhoea – pelvic pain that occurs at the time of your menstrual period, also known as period pain

fibroids – uterine fibroids (leiomyomas or myomas) are non-cancerous tumours of the muscle of the uterus

fistula – an abnormal connection/tract between two structures

flares – a term used to describe the symptoms experienced by people with endometriosis

frozen pelvis – when adhesions cause pelvic organs to stick together

fulguration – the process of destroying tissue by electricity

genetic predisposition – the increased chances of developing a particular disease or condition based on your genes

graded exposure – involves gradually increasing exposure to build up tolerance

heavy menstrual bleeding (menorrhagia) or prolonged menstrual bleeding, is defined as excessive menstrual bleeding that interferes with the physical, emotional, social and material quality of life

hormone – a substance that is created and released by the endocrine glands to control and regulate the actions of specific cells and organs in the body

hormone therapy – medication often used to treat endometriosis, which works by reducing the natural release of hormones and altering the relative amounts of hormones

infertile – unable to conceive a pregnancy

irritable bowel syndrome – a condition that affects the colon that causes a host of intestinal symptoms

IUD – short for intrauterine device, is a T-shaped contraceptive device that a doctor inserts into the uterus

laparoscopy – a minimally invasive surgical procedure that uses a telescope to examine inside the abdomen and pelvis. It can be used in the process of diagnosing endometriosis or therapeutically with an aim to improve symptoms

menarche – the onset of menstruation

menstrual cycle – a hormonal cycle that the body of people with female reproductive organs go through including ovulation and menstruation

multidisciplinary care – involves health professionals from different fields working together collaboratively with a patient concerning their care

neuropathic pain – damaged nerves send the 'wrong' signals to pain centres in your body, resulting in pain

occlusion – a complete or partial blockage

oestrogen – a sex hormone predominantly produced by the ovaries

ovarian reserve – the number of eggs you have in your ovaries

ovulation – the release of a mature egg from an ovary

osteoporosis – a condition where bone mineral density is reduced

period – the shedding of blood and endometrial tissues from the uterus that happens as part of your menstrual cycle

pelvic inflammatory disease – inflammation of the upper genital tract due to an infection in people with female reproductive organs

pelvic floor dysfunction – a condition that affects a person's ability to control or coordinate the pelvic floor muscles

placenta previa – a condition that occurs during pregnancy, where the placenta is low in the uterus, covering all or part of the cervix

pouch of Douglas – an area deep in the female pelvis between the rectum, cervix and upper vagina

pre-menopausal – haven't reached menopause yet

preterm birth – a preterm birth (also known as a premature birth) is a baby born before 37 weeks of pregnancy

preeclampsia – a complication that causes high blood pressure and protein in the urine during pregnancy

primary neurogenic inflammation – inflammation resulting from the release of various neuropeptides, chemokines, and cytokines from the peripheral endings of sensory nerves in response to tissue damage or painful stimuli

progesterone – a sex hormone mainly produced by the ovaries

progestogens – a synthetic version of the progesterone hormone

reproductive tract – located within the pelvis and containing the vulva, vagina, cervix, uterus, fallopian tubes and ovaries

uterine artery embolisation – a procedure causing occlusion of the uterine artery vessels that can be used to treat fibroids and other disorders of the uterus

uterosacral ligaments – major ligaments in the uterus that support and attach the cervix to the sacrum

vaporisation – the process of destroying tissue by laser

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About the Julia Argyrou Endometriosis Centre at Epworth

One of the major problems facing people living with symptoms of endometriosis is the delay before they receive a diagnosis. In Australia, in 2023, the average time between symptoms starting and a diagnosis was six to eight years.[1] We've come to believe that severe period pain is normal, and it's something that we should silently endure. This is not the case. If your period pain is stopping you from being able to participate in your normal, everyday activities, it should be investigated

In 2024, the Department of Health estimated that in Australia, one in seven women have endometriosis.[1] This number is likely higher as the numbers don't account for transgender and gender diverse people, nor do they account for people that remain undiagnosed.

Endometriosis can also be a progressive condition. It's likely to get worse over time without management or treatment. For some people, this means that your symptoms can worsen, impacting your quality of life. It can prevent you from participating in everyday activities. Activities that can include working, going to school, sports, and socialising. As a result, you may experience mental and social health issues. Additionally, the loss of productivity and the cost of treatment can lead to financial hardship.

At the Julia Argyrou Endometriosis Centre at Epworth, we know how important it is to provide outstanding clinical care.

We have a network of gynaecologists with a special interest in endometriosis and nurse coordinators who are able to liaise with other relevant health professionals. Multidisciplinary care is now considered essential in the management of chronic conditions.

We also understand the importance of your experience. Endometriosis is a chronic condition that can take a physical and emotional toll.

Having someone that can answer your questions is important. You can self-refer to the centre, and you will be able to book in to see our endometriosis nurse coordinators. We also have an endometriosis support group at Epworth. This group provides you with support, information and understanding. It's a place where you can ask questions and share your experience with other people with endometriosis.

Our centre also undertakes vital research. Endometriosis research has been historically very underfunded. It's hard to believe, considering the high cost of this condition to our economy and our health care system. We are running research studies and clinical trials to better understand endometriosis.

Our primary mission is to make sure our patients receive the very best care. We apply a holistic approach to patient care that encompasses all aspects of your treatment. At the Julia Argyrou Endometriosis Centre at Epworth, we strive to achieve better outcomes for people with endometriosis.

Julia's story

'Getting out of bed in the morning is a huge challenge. I feel crippled by pain, lethargic, and all my senses are saying 'stay in bed'. Once I push through the physical torment, the mental defiance begins. I start moving, and I get up.'

—Julia Argyrou.

Having lived with chronic endometriosis for most of her life, Julia Argyrou knows how debilitating this disease can be. Her battle with endometriosis started on the last day of Grade 6—the day she got her first, extremely heavy period.

Less than a year later, the pain began. When it became unbearable, Julia went to see the family GP, who told Julia that period pain was normal and prescribed the contraceptive pill.

Julia's doctor tried different contraceptive pills to find one that didn't cause her side effects, but none relieved her symptoms. Instead, the pill caused her to feel nauseous and led to the rare side effect of blood clotting and emergency visits to the hospital.

When she turned 21, Julia saw a gynaecologist and had her first laparoscopy, which confirmed that she had endometriosis.

It had taken many years, but Julia was relieved to finally have a diagnosis. It explained her chronic pain, and she felt vindicated. She could now explain to her employer, friends, and family that she wasn't making it up and there was a medical reason for her pain.

While there was some brief relief from the pain after the laparoscopy, it eventually returned and got worse over time.

By 2021, Julia had undergone 14 laparoscopies from the time she was diagnosed. The laparoscopies have caused extensive scar tissue and adhesions, but in her case, they have done little to help her pain. The only time Julia has been pain-free since Grade 6 was when she was pregnant and for the first few months after her hysterectomy.

After the birth of her last child, Julia encountered complications that led to internal haemorrhaging, and the doctor performed a hysterectomy. She was told that the hysterectomy would cure her endometriosis. For months after the hysterectomy, Julia was pain- free. So, when the pain returned, she was devastated.

Julia still suffers from back and pelvic pain caused by endometriosis and pain from ovarian cysts on her remaining ovary. She no longer seeks relief from symptoms with laparoscopic surgeries and does her best to manage the pain using medication.

'I hate taking medication. It makes me feel lethargic. I can't think or function properly, and I don't like how it makes me feel,' said Julia.

There are days when Julia's pain is so severe that it causes her to blackout. She no longer drives, as she has no idea when the pain will spike to a level that will cause her to blackout. She can't plan events in advance as she doesn't know the level of pain she will be experiencing on any given day.

'We have cancelled on people so many times for so many dinners and events that people just stop asking,' said Julia.

Julia said that endometriosis has had a significant impact on her life and on her family.

'Endometriosis changes you as a person,' says Julia. 'It impacts your children's lives, and it has an effect on your partner and your relationship. Your family are all going through it, not just you.'

Julia didn't want to discuss her endometriosis for a long time, but she realises that being silent about her experience wasn't helping her or those closest to her.

'... in many ways, talking about it has been beneficial to help people understand what I'm going through and raising awareness for others.

'Having three beautiful daughters, I'd never want them to go through this battle—especially now that they're around the age I was when I was diagnosed,' said Julia.

Realising it's time to do more to help herself and others with endometriosis—and with some family members showing signs of having the condition—has led Julia and her husband Michael to help establish the Julia Argyrou Endometriosis Centre at Epworth. Together, they hope the Centre will help other sufferers be diagnosed earlier, find effective pain management and invest in groundbreaking research to end this painful battle.

What is endometriosis?

Endometriosis is a chronic, systemic, inflammatory condition.

Endometriosis occurs when cells that are similar to the ones that line your uterus (endometrium) grow in other areas of your body.

The most common place where it grows is on the lining of the pelvic cavity, called the peritoneum. This may make it difficult to see with imaging, and many people with endometriosis will have a normal ultrasound or MRI in the early stages of the disease.

Endometriosis can cause a multitude of symptoms, including painful periods, pain when using the toilet, pain with intimacy and difficulty falling pregnant. In addition, many people also suffer from symptoms that are commonly associated with endometriosis, such as bloating, fatigue, gastrointestinal disturbance and abnormal uterine bleeding. Some people with endometriosis have minimal or no symptoms.

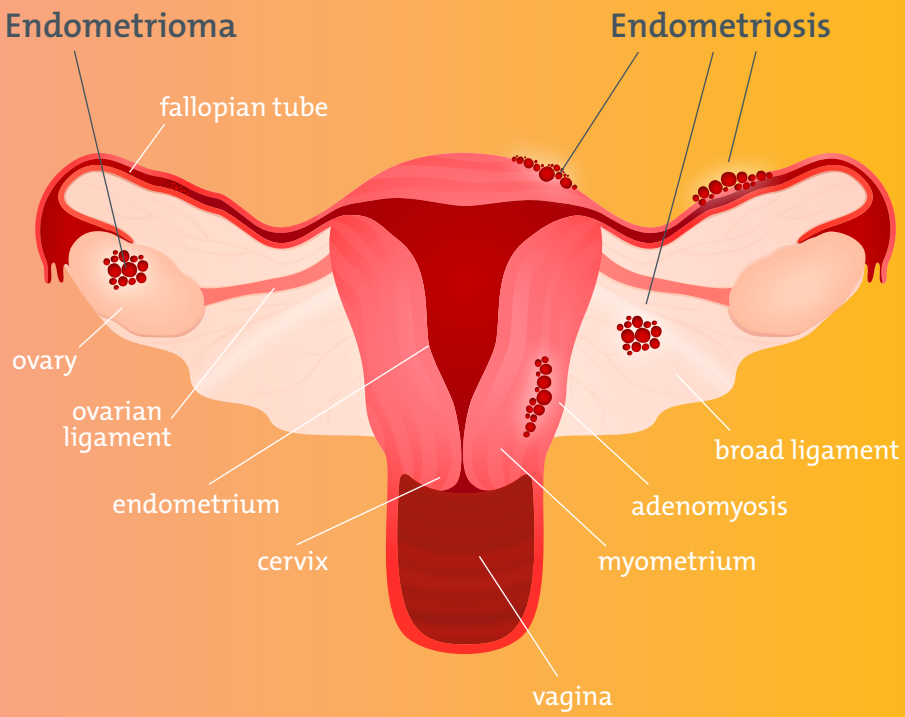
Endometriosis can grow on organs. The pelvic organs are most often affected including:

- ovaries (endometrioma)
- fallopian tubes
- the outer surface of the uterus
- pouch of Douglas
- ligaments that hold the uterus in place (for example, uterosacral ligaments).

Endometriosis can also occur on the bowel, bladder and vagina. Endometriosis will generally remain contained within your pelvis or abdomen. Although extremely rare, it can occur in other parts of your body, such as your heart, brain, and lungs.

Endometriosis is largely an oestrogen-dependent condition. The hormonal changes (including oestrogen production) during your menstrual cycle can cause lesions to grow, and symptoms to worsen. Lesions themselves are also able to produce oestrogen.

Inflammation and growth within lesions can lead to swelling and adhesions in the tissue around the lesions. As a result, scar tissue from adhesions can cause your organs and pelvic tissue to stick together.


Endometrioma
Endometriosis
fallopian tube
ovary
ovarian ligament
endometrium
cervix
vagina
broad ligament
adenomyosis
myometrium

What causes endometriosis?

The exact cause of endometriosis is still unknown. It is most likely that the cause of endometriosis is a combination of factors, including:

- retrograde (reverse) menstruation: the blood and endometrial cells and tissue that shed during your period travel through the fallopian tubes into the pelvic cavity instead of leaving your body
- genetic predisposition: if an immediate family member (mother or sister) has endometriosis, your risk increases
- endometrial-like cells travel through your blood or lymphatic system to other areas of your body
- an immune system issue fails to remove endometrial tissue that is found outside of the uterus
- environmental factors such as weight, diet, and alcohol consumption
- hormones that can change precursor cells into endometriosis lesions during puberty
- coelomic metaplasia: the transformation of normal peritoneal tissue into endometrial-like tissue.

Similarly, it is poorly understood why endometriosis causes severe symptoms in some people and minimal symptoms in others, and why some people respond better to some therapies than others.

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Who is most at risk of having endometriosis?

Certain risk factors may increase your chances of developing endometriosis. Most of these factors are outside your control, including:

- being born of a low birth weight
- family history of endometriosis
- starting your period at an early age (before 11)
- heavy periods that go for longer than seven days
- having your period more frequently (cycles that are less than 27 days long)
- reproductive tract abnormalities including conditions that prevent, block, or redirect the flow of your menstrual period.

Others may have a modifiable component, including:

- alcohol consumption
- low body weight (this can be highly variable from person to person and may not be modifiable for everyone).

While these factors make endometriosis more likely, anyone experiencing symptoms should consider endometriosis as a possible cause.

What are some common myths around endometriosis?

There are many myths associated with endometriosis. Science has debunked many of the myths that have led to the spread of misinformation about endometriosis. These myths have been partly responsible for the delays in diagnosis. We have included some of the myths around endometriosis below:

- **Chronic period pain is normal**
  FALSE – Having chronic or severe pelvic pain at any time during your menstrual cycle is not normal and can be a symptom of endometriosis
- **All people with endometriosis experience severe pain**
  FALSE – Some people never experience any pain with their endometriosis
- **The pain associated with endometriosis will depend on the severity of the endometriosis**
  FALSE – The severity of a person's endometriosis and the symptoms that they experience do not always correlate. Meaning, there is no association between the number of lesions and the pain or symptoms experienced
- **Pain for people with endometriosis only occurs during their period**
  FALSE – People with endometriosis can experience pain at any time
- **Having a hysterectomy will cure endometriosis**
  FALSE – Endometriosis can return after surgery, even if you have a hysterectomy
- **Having endometriosis means you can't have children**
  FALSE – Many people with endometriosis have no problems conceiving naturally. Other people with endometriosis can conceive after treatment or with the assistance of reproductive technology
- **Pregnancy cures endometriosis**
  FALSE – During pregnancy (and breastfeeding), the change in hormones can reduce symptoms for some people, but it won't cure endometriosis
- **Young people do not have endometriosis**
  FALSE – Endometriosis can affect people of any age. It's very common for people with endometriosis to start experiencing symptoms as a teenager, when they first start having periods, or sometimes even before then.
- **Endometriosis is caused by having too much oestrogen**
  FALSE – while endometriosis-associated lesions are influenced by hormones including oestrogen, peoples hormone levels change on a daily basis due to the complexity of the menstrual cycle (including oestrogen and progesterone).

What are the symptoms?

Symptoms of endometriosis will vary from person to person. Some people may experience symptoms as soon as they get their first period. Others may have no symptoms at all. The severity of your symptoms is not an indication of the extent or severity (or stage) of your endometriosis.

As endometriosis can be progressive, over time, your symptoms may get worse or change. Managing your endometriosis can help to reduce your symptoms and the impact this condition has on your life.

Symptoms that people with endometriosis may experience include:

Pain

- period pain (also called dysmenorrhoea)

- pelvic pain that occurs outside the time of your period

- ovulation pain (during the middle of the menstrual cycle)

- pain that radiates down to the legs, buttocks, and thighs

- pain during or after sex (dyspareunia)

- pain when using your bladder (dysuria) or bowels (dyschezia), particularly during your period.

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Menstrual and reproductive

- heavy menstrual bleeding (menorrhagia)

- irregular bleeding (including bleeding between periods)

- menstrual bleeding for longer than normal

- infertility.

Bladder, bowel and gut

- diarrhoea or constipation

- needing to urinate more often

- blood in your stool or urine (in rare cases)

- bloating

- nausea and vomiting.

Other

- fatigue, feeling tired or feeling lethargic

- difficulty concentrating or remembering things (brain fog)

- mood changes

- shoulder tip pain

- cyclical cough, haemoptysis (coughing up blood) or catamenial pneumothorax (collapsed lung that occurs repeatedly).

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How is endometriosis diagnosed?

People will often wait years before they receive an endometriosis diagnosis. In 2023, it was reported that the average delay in diagnosis was six to eight years.[1] This is from the onset of symptoms to a surgical diagnosis.

What causes the delay in diagnosis?

Many symptoms of endometriosis are normalised within society. This can mean that sometimes people do not recognise that their symptoms are not normal, are reluctant to seek care or are not referred to specialised care when they see their doctor. In addition, people are still experiencing a lack of validation and progression of specialised care when they do approach health care providers. This can be a significant barrier for people. This is especially true in younger people with this condition.

Another factor delaying diagnosis is the similarity of endometriosis symptoms to many other conditions. These can include irritable bowel syndrome, adenomyosis, endometrial polyps or pelvic inflammatory disease. As a result, people with endometriosis are often misdiagnosed.

Pain is never normal. It is important to make your GP aware of all of your symptoms, including pain. You should track any symptoms you experience during your menstrual cycle so you can provide your health care team with detailed information. There are multiple mobile phone apps that can help you track your menstrual cycle and symptoms.

You can also ask your GP to refer you to a gynaecologist who has a special interest in endometriosis. A gynaecologist will be able to investigate further.

Pelvic exam

With your permission, as part of your assessment, your doctor may perform an internal pelvic examination.

They will be examining for the size, positioning or mobility of your uterus (if you have one). They may also be able to feel ovarian cysts, scar tissue or other types of endometriosis lesions. Tenderness in particular areas can help identify lesions.

The vaginal examination may also detect whether your pelvic floor muscles are contributing to your pelvic pain and other pelvic floor symptoms.

Pelvic examination may also include a cervical screening test if you are due for one.

Imaging

Ultrasound

Ultrasound is an imaging procedure that can be used in the detection of endometriosis.

An ultrasound creates an image of your internal organs using sound waves. An ultrasound can show signs of endometriosis, including ovarian endometriosis cysts (or endometrioma), pelvic organs sticking together or thickened uterosacral ligaments.

The highest quality image is achieved when it is performed through the vagina. The transducer (probe) is placed inside the vagina. Using this method, detailed images can be taken of pelvic organs. However, it is your choice whether to have this imaging procedure or not, and you can request for the scan to be stopped at any time. Alternatively, useful information may be obtained by taking an image through your abdomen instead.

Identifying endometriosis by ultrasound is a highly skilled technique and not all ultrasound services are able to provide the detailed information required. Subtle signs of endometriosis may be missed, therefore, it is preferred that the scan is completed by somebody with experience in endometriosis.

An ultrasound alone is often not enough to confirm an endometriosis diagnosis. Importantly, a negative finding doesn't exclude endometriosis and will often highlight a need for further investigation.

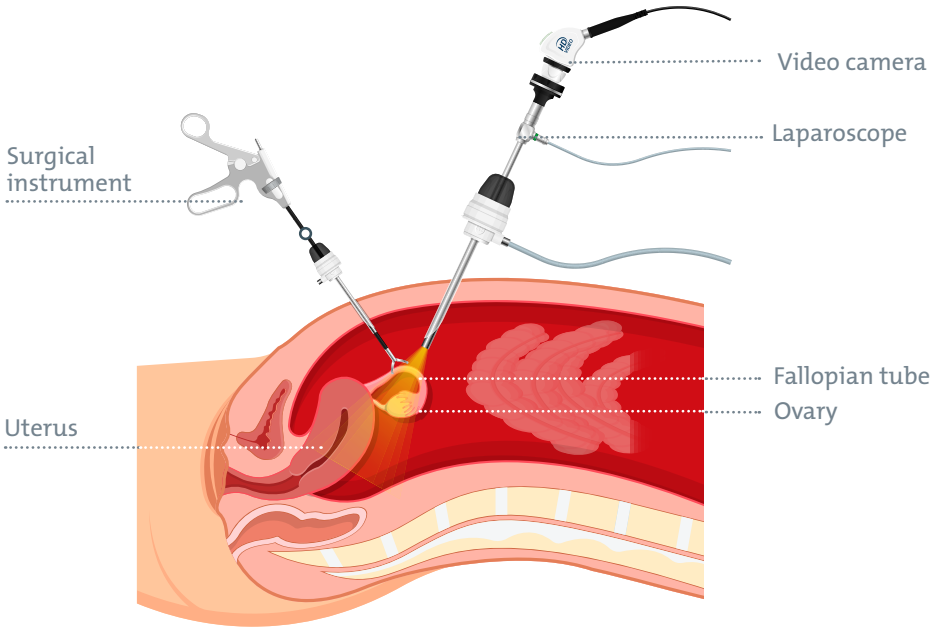
Magnetic resonance imaging (MRI)

MRI uses a magnetic field and radiofrequency waves to generate detailed, cross-sectional images of your organs and other tissues. While an MRI is not a first line investigation, it can sometimes help detect deep endometriosis, endometriosis on your ovaries (endometriomas), and lesions in your pelvis, or on your bowel and bladder. This can help in planning whether a bowel or bladder surgeon may need to assist the endometriosis surgeon for complex endometriosis

operations. MRI can be used in addition to an ultrasound, especially in patients who can't have a vaginal ultrasound, patients with bowel endometriosis, or where there is uncertainty about the findings on an ultrasound.

Laparoscopy

Laparoscopic surgery is a minimally invasive procedure that allows your surgeon to look inside your pelvic and abdominal cavities. Your specialist may recommend a laparoscopy if they suspect you have endometriosis, or to see if there is recurrence of endometriosis after previous surgery. Surgery is most commonly offered or recommended to assist in controlling symptoms or improving fertility. Most times, lesions suspicious for endometriosis will be removed and sent for examination under the microscope to confirm if the disease is present.



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The different stages of endometriosis

There are multiple staging systems for endometriosis. The most common is the revised American Society for Reproductive Medicine (rASRM) staging system.

The rASRM staging system comprises of four stages. It uses a points system to determine the severity of a person's endometriosis (as seen at the time of surgery). People are allocated to a stage based on the number of points scored. The number of points scored will depend on the size and location, as well as any anatomical distortion caused by the endometriosis and adhesions.

It's important to note that the level of pain or infertility experienced is not associated with this staging system. Someone with stage 4 endometriosis may experience little or no pain. Whereas someone with stage 1 endometriosis may have severe and chronic pelvic pain.

The rASRM stages and point classification for endometriosis.[2]

Stage 1 – Minimal (1-5 points)	› very few implants present › implants are not too deep in the pelvic and/or abdominal lining
Stage 2 – Mild (6-15 points)	› more implants than stage 1 › implants are a little deeper into the pelvic and/or abdominal lining than stage 1
Stage 3 – Moderate (16-40 points)	› many implants are present › implants are deep in the pelvic and/or abdominal lining › small cysts are growing on one or both ovaries › there are adhesions present
Stage 4 – Severe (greater than 40 points)	› many implants are present › implants are deep in the pelvic and/or abdominal lining › large cysts are growing on one or both ovaries › many thick adhesions are present

What are the treatment options for endometriosis?

There are many treatment options to help you manage your symptoms. It's a matter of finding a treatment that works for you. It is important to remember that endometriosis is only one of the possible causes of the symptoms associated with the disease. It is important to address other causes or associated conditions at the same time. Treatment is rarely one single therapy, and may need to address multiple pathways and associated conditions to achieve the best control of symptoms.

Your treatment plan will be unique to you. People with endometriosis can experience a variety of different symptoms. These can include pain, fatigue and infertility. As such, there is not a single treatment that will work for everyone. Often, people will need a combination of treatments to relieve their symptoms.

Our commitment is to provide patient centred care. Our team will work with you to develop a personalised care plan.

Making treatment decisions

The aim of treatment is to control your symptoms to allow you to live your life fully. Your doctor will guide you through any risks that may be relevant to you and how this can impact your treatment options.

Treatment also aims to ensure that your pelvic organs, such as the uterus, ovaries and bowel continue to function. Unfortunately, the treatments themselves may cause you to experience side effects. That an make finding the right treatment for you difficult. This highlights the need for seeing health professionals that specialise in endometriosis.

At the Julia Argyrou Endometriosis Centre at Epworth, our team specialises in endometriosis. They use the latest research and technology to achieve the best possible health outcomes. We also understand the importance of your involvement in your treatment decisions.

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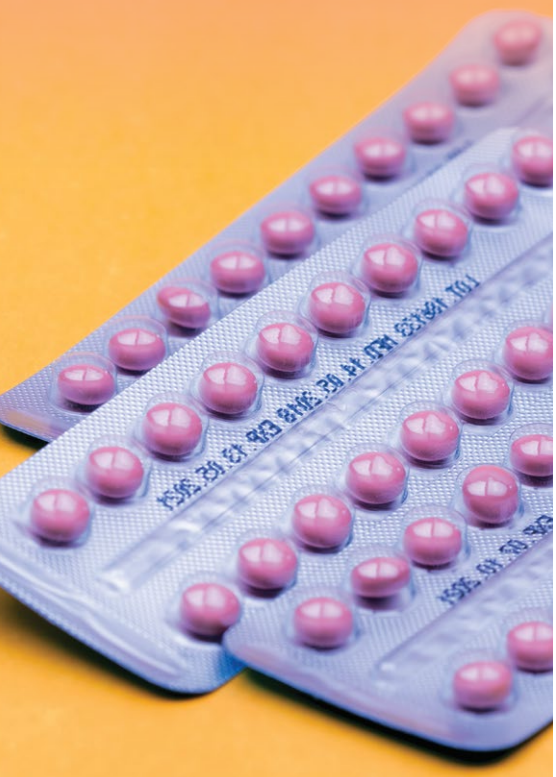
When making decisions about your treatment, make sure you discuss the options available with your medical team. This allows you to make an informed decision about your treatment pathway. Questions you could ask your doctor include:

- Why have you recommended this treatment?
- What is the aim of the treatment?
- Is there anything else I can do to help manage my symptoms?
- How will I know if the treatment is working?
- What are the risks with this treatment?
- What are the side effects of the treatment?
- Are there any alternatives?
- Do I need to be concerned about my fertility?
- What if the treatment doesn't work?
- What is the cost of treatment?
- What will happen if I do nothing?

The observation (watch and wait) approach

If you are not experiencing symptoms, your GP or gynaecologist may decide to monitor your condition without providing treatment. Treatment for endometriosis focuses on relieving your symptoms. If you're symptom free, or if your symptoms aren't bothering you, you may not need treatment at this time.

If you start to develop symptoms, or if your symptoms worsen or start to bother you, visit your GP or gynaecologist. You can discuss the treatment options that are available to you.



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Hormone therapy

Your ovaries produce hormones during your menstrual cycle. These hormones cause your endometrial tissue to thicken, break down and then shed (bleed). Endometrial-like tissue outside of the uterus (endometriosis lesions), may be responsive to cyclical changes in these hormone levels.

The aim of hormone therapy is to reduce symptoms. Some hormone treatments can stop the release of hormones from your ovaries by putting your body into a temporary menopause or pregnancy-like state. This is not a permanent change. Once you stop taking the hormones, your body will return to its normal menstrual cycle. You can use hormone therapy no matter what your stage of endometriosis, and it's often used in conjunction with other treatments.

Hormone treatments come in a variety of formats and therapies. Your doctor will be able to discuss these different options with you.

Combination contraceptive (birth control) pill (COCP)

This pill is a combination of oestrogen and progesterone. It stops ovulation. The pill often makes your period lighter and shorter, as well as sometimes allowing you to skip your period completely (at the recommendation of your doctor). This can help to improve symptoms or slow the progression of endometriosis.

You can take the COCP indefinitely unless you develop a medical reason that requires you to stop. You may find that you experience side effects until you find a pill that suits you. Speak to your doctor if you experience any health concerns while taking the contraceptive pill.

While many people have tried several contraceptive pills in the past, there are many options available which can be tailored to your needs by your doctor.

Progestogens

A progestogen is any hormone that has a progesterone action. A progestin is a synthetic hormone with progesterone action. You can take it as a pill, injection, implant or an IUD (intrauterine device). Progestogens have been shown to be successful in reducing symptoms in people with endometriosis. Progesterone stops and shrinks endometriosis lesions, and can reduce the associated inflammation and pain.

The IUD containing progesterone has the lowest dose in the blood stream and the least side effects.

Gonadotropin-releasing hormone (GnRH) analogues

GnRH analogues help to control your symptoms by putting your body into a temporary state of menopause. GnRH analogues stop the production of oestrogen and progesterone. This causes your endometriosis lesions to shrink in size. GnRH analogues are available as an injection, nasal spray or orally in a combination pill with menopausal hormonal agents.

GnRH analogues are most used in moderate to severe cases of endometriosis. Due to the strength of this treatment, it does have side effects. Inducing temporary menopause means you're likely to experience menopausal side effects. These include:

- hot flushes/night sweats
- vaginal dryness
- mood swings/depression
- decreased libido
- dry skin and hair
- muscle pains
- insomnia
- temporary loss of bone density.

There are medications you can take to reduce side effects.

GnRH analogues are often used before surgery to control severe symptoms, and in some situations, they can make surgery safer and easier.

Aromatase inhibitors

Aromatase is an enzyme that converts the hormone androgen into oestrogen. There are high levels of aromatase in endometriosis lesions. Higher aromatase activity in lesions can lead to higher levels of oestrogen, which can feed the endometriosis.

Aromatase inhibitors block the conversion of androgens into oestrogen. This helps stop the progression of endometriosis, which can help improve your symptoms.

Aromatase inhibitors are also often used as a treatment for breast cancer and infertility.

Surgery

Treating endometriosis with surgery

Surgery is sometimes recommended for the dual purpose of diagnosis and treatment of endometriosis. Surgery for the single purpose of diagnosis is no longer standard practice.

When you undergo surgery, the aim is to remove endometriosis and restore pelvic anatomy while maintaining the use of your pelvic organs (unless they are being removed). The goal of surgery should be clear from the outset.

Surgery is not always a cure, but it can offer relief from symptoms and improve fertility for many people. Surgery is generally considered safe, although there are some risks. Your specialist will have a discussion with you about the risks involved prior to surgery. You should also tell them what you hope to achieve from surgery.

Research highlights the importance of using specialists with experience and training in endometriosis surgery to perform your surgery.[3] Sometimes this might involve more than one specialist surgeon (for example, a gynaecologist and a colorectal surgeon). Specialists with the necessary skills and training will help reduce the risk of complications and also reduce the need

for multiple surgeries. The aim is to have as few surgical treatments of endometriosis in your life as possible, balancing the risks and benefits of surgery.

What surgeries are available to treat endometriosis?

Laparoscopy

Laparoscopic surgery is the most common surgical treatment for endometriosis. The aim of the surgery is to safely treat endometriosis, mostly by excising lesions. Sometimes adhesions will be removed to help with symptoms or to access endometriosis lesions.

At the start of the surgery, your surgeon will make a small incision (cut) in your abdomen. Your abdomen is then filled with carbon dioxide gas. This creates more room inside your abdomen so that your organs are visible. Your surgeon will then make several small incisions to your abdomen to insert a camera and other surgical instruments. The images from the camera appear on a small screen (like a TV). This enables your surgeon to see inside your abdomen and pelvis.

Your surgeon will then remove or destroy any visible endometriosis lesions. They can also remove endometriomas during this procedure, as well as other identified problems as discussed with your surgeon beforehand (e.g. adhesions, fallopian tubes or ovaries).

Your surgeon will either destroy (using ablation, fulguration, or vaporisation) lesions or cut them out (excision). Your surgeon will discuss the method they plan to use at the time of consultation.

A laparoscopy is a minimally invasive procedure, so your incisions are very small. This makes recovery time much quicker. All surgeries involve some level of risk. Risks can include:

- Infection in the abdominal wounds
- Bruising to your abdomen
- Pain in your shoulders when you wake up.

Serious complications are rare. These complications can include:

- Damage to other organs inside the abdomen
- Excessive bleeding
- Conversion to open surgery
- Perforation of the uterus.

Before any planned surgery your surgeon will discuss what the risks are for you.

Laparotomy

A laparotomy is a major abdominal surgical procedure. The size of the incision for a laparotomy is much larger than the incisions for a laparoscopy and are often made in the same place as a caesarean section incision. A larger incision means a longer recovery time. A laparotomy is only recommended if a person's endometriosis is not treatable via a laparoscopy. This is rare and more likely to be required if your surgeon has recommended surgery with another specialist present (for example, a urologist or colorectal surgeon).

Hysterectomy

A hysterectomy is the removal of the uterus. During a hysterectomy the fallopian tubes are usually removed, and often the cervix is removed as well. In some cases, one or both ovaries may also need to be removed. It's not uncommon for a person to have both adenomyosis and endometriosis, in this case a hysterectomy may be helpful in reducing symptoms. Endometriosis can return after surgery, even if you have a hysterectomy. If a hysterectomy is required, it is important that all endometriosis is also removed.

You need to be aware that this procedure is irreversible. You can't carry a child after this procedure. The advantages and disadvantages associated with this procedure need to be carefully considered and discussed with your specialist.

Oophorectomy

An oophorectomy is the removal of an ovary. This can be bilateral oophorectomy (removal of both ovaries) or a unilateral oophorectomy (removal of one ovary). It is known that if you are under the age of 66 you may benefit from hormones released from the ovaries, including a decreased risk of death. Ovary removal is an irreversible surgery. The risks and benefits of removing an ovary (or both ovaries) need to be discussed with your specialist.

Robotic surgery

Robotic surgery is a type of laparoscopic surgery that utilises a surgical robot. Some surgeons perform laparoscopic surgery using the robotic platform. However, studies to date have not shown the robotic platform to be superior. The choice to use a robot for your surgery will depend on your specialist.

Physical activity and exercise

Exercise, or physical activity, is a complementary treatment option for managing the symptoms of endometriosis. When we exercise, we increase the anti-inflammatory and antioxidant chemicals within our bodies.

As endometriosis is an inflammatory condition, anti-inflammatory and antioxidant chemicals can help to soothe inflammation. Exercise also helps to increase the blood flow to your stomach and pelvis. This can help to clear inflammatory by-products of inflammation. Exercise has also been found to reduce the pain response in many pain conditions. It's also great for good mental and physical health and wellbeing.

Everyone is different and is suited to and enjoys different types of exercise and physical activity. It is worthwhile finding a form which you enjoy and that suits you, so you can continue being active long term.

It's important when you first start exercising that you slowly build up the level and amount of exercise over time to reduce the risk of pain and injury. This is called graded exposure and is also an effective tool in helping to manage persistent (chronic) pain.

Many people find non-impact exercise (such as swimming, yoga or cycling) the most beneficial. If you're unsure how to approach exercise, an exercise physiologist or physiotherapist can provide you with an exercise plan, support and guidance to start exercising and being active in a way that suits you.

Pacing

Pacing is a strategy that encourages people with persistent (chronic) pain or fatigue to remain active while not over-exerting themselves. You should spend just enough time on an activity that you're able to enjoy it without pushing yourself to a point where you cause an increased level of pain or fatigue. It's about balancing activity with rest. Intentionally planning to rest in between times of increased activity can help you remain active. Pacing aims to avoid over and under activity, also known as boom-bust. Over time, you will build up how much you can do without worsening your symptoms.

Sleep

People with symptomatic endometriosis experience higher levels of sleep disturbances compared to those without endometriosis. Sleep, fatigue and pain are closely linked, and can impact quality of life. Improving the amount of sleep you get, your sleep pattern and the quality of your sleep can be beneficial. You can discuss any sleep issues with your GP.

Simple ways to improve your sleeping patterns include:

- get into a routine and try to get up and go to bed at the same time each day
- don't have screens in the bedroom
- spend time in natural light during the day
- avoid napping as it can make sleep harder at night
- limit your caffeine intake and don't have caffeine at all in the afternoon or evening
- reduce liquids in the evening if you find you are needing to wake multiple times overnight to empty your bladder
- avoid alcohol and smoking
- have a warm bath or shower before bed
- try meditation before bed
- ensure your bedroom is quiet and comfortable.

Pelvic health physiotherapy

The pelvic floor muscles are located at the bottom of the pelvis and they have several important functions such as supporting pelvic organs (bladder, bowel, uterus and vagina), bladder and bowel control (contract and relax when we use our bowels or empty our bladder), and sexual function. Pelvic floor dysfunction (PFD) involves the abnormal function of the pelvic floor muscles.

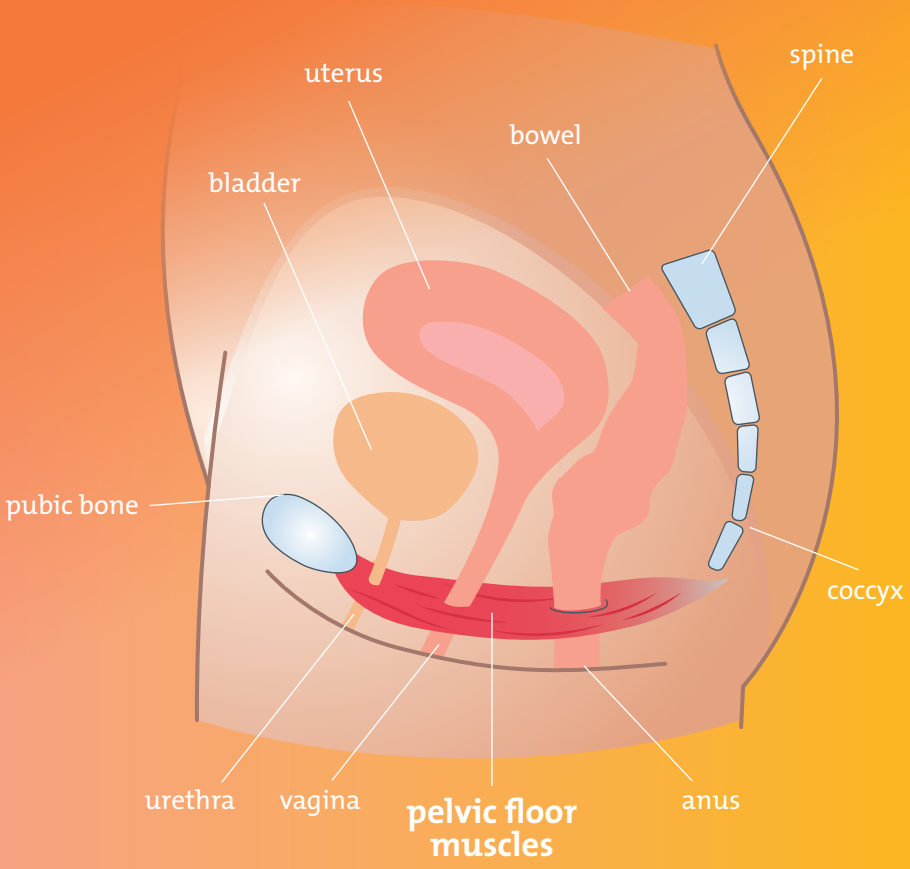
Insufficient pelvic floor muscle relaxation, coordination and/or strength can contribute to pelvic floor dysfunction. When someone experiences persistent or severe pelvic pain, it's common for the pelvic floor muscles to struggle to relax in response to this pain. Over time, the pelvic floor muscles can become painful too. Pelvic floor dysfunction includes issues such as:

- pain during and/or after sexual intercourse
- general pelvic pain which can spread to the back and/or down the legs
- incontinence
- frequently needing to go to the toilet
- constipation
- straining during a bowel movement.

Pelvic floor dysfunction is common in people with endometriosis.

A pelvic health physiotherapist or gynaecologist can assess your pelvic floor muscles and function. With your permission, the physiotherapist can complete an internal vaginal examination to assess your pelvic floor muscles. If you do not want an internal vaginal examination your physiotherapist will be able to provide you with other assessment options. Based on your individual symptoms and assessment they can provide you with an individualised treatment plan to improve your pelvic floor function, including contracting and relaxing your pelvic floor muscles optimally.

Pelvic health physiotherapy is a specialised area of physiotherapy. Our nurses may recommend you see a pelvic health physiotherapist to help you and your specific symptoms.


uterus
spine
bowel
bladder
pubic bone
coccyx
urethra
vagina
pelvic floor
muscles
anus

Nutrition

You can use nutrition to help manage symptoms related to endometriosis. The foods you eat are just one of many factors that can impact your symptoms. There are multiple dietary interventions which may be useful, and a therapeutic trial may determine which is the best for you. Some diets which have been helpful include the Mediterranean diet and anti-inflammatory diet.

Should I see a dietitian?

The nutritional information and support dieticians can provide can help you to better manage your endometriosis. A dietitian can provide personalised guidance regarding what diet and food would be most suitable and helpful for you.

You should see a dietician or your GP prior to eliminating any foods or trying any of the diets in the list below:

Gluten-free diet

Gluten is a protein found in wheat, rye, and barley. Some foods containing gluten include bread, beer, cakes, pies, cereals, and biscuits. In 2012, a research study found that 75% of people with endometriosis experienced a decrease in their symptoms when they cut gluten from their diet.[4]

FODMAP diet

FODMAPs are shortchain carbohydrates that are more difficult for the body to digest. FODMAP stands for fermentable, oligosaccharides, disaccharides, monosaccharides and polyols. Common FODMAPs include:

- some fruits and vegetables, sweeteners, and table sugar containing fructose
- dairy products containing lactose
- wheat products, fruit and vegetables containing fructans
- legumes containing galactans
- artificial sweeteners, fruit and vegetables and sugar alcohols containing polyols.

Some people with endometriosis experience improvements in their symptoms after following a low FODMAP diet.[5] Ensure you speak to a dietitian or your GP prior to eliminating food from your diet.

Support services

Psychologist or counsellor

People with endometriosis suffer both physically and mentally. Symptoms of persistent (chronic) pain (including persistent pain associated with endometriosis) and or infertility can negatively impact your quality of life, which may contribute to mental health conditions like anxiety and depression. This makes the multidisciplinary approach to endometriosis care a critical part of the management of the condition. A psychological consult is recommended to make sure you're receiving the emotional support you need. Psychologists can also help provide and support you with pain management strategies. Our endometriosis nurse coordinators or your GP can recommend suitably qualified professionals.

Support groups

Talking to others can help you feel less isolated in your endometriosis journey. At Epworth, we have a support group that is open to anyone with endometriosis. The Epworth Endometriosis Support Group meets regularly throughout the year, in person or online. The group provides support, information and a place where you can talk openly and ask questions about endometriosis.

Contact our Endometrioisis Nurse Coordinators at **EHEndonurse@epworth.org.au**

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Complementary therapies

You can use complementary therapies to help manage your endometriosis symptoms. You can also use them in conjunction with other treatments. Complementary therapies can also provide you with physical and emotional support.

Complementary therapies can include:

Yoga – uses specific yoga tools to help you with your physical and emotional wellbeing needs. Yoga tools can consist of postures, exercises and breathwork, to name a few. The benefits include reducing stress, lowering fatigue, improving sleep, improving your emotional wellbeing and physical functioning by enhancing your strength.

Massage – involves manipulation and rubbing of your muscles and soft tissue. People with endometriosis can use massage therapy to help reduce pain, anxiety, nausea, and depression.

Meditation – aims to calm you by developing your concentration and improving your focus. Improving your focus and concentration helps bring clarity and positivity. Meditation improves your emotional wellbeing by improving sleep and reducing stress and anxiety.

Mindfulness – Mindfulness is a technique you can learn that involves noticing or being conscious of what's happening in the present moment, with acceptance and without judgement. You might take notice and be aware of your mind, body or surroundings. Practising mindfulness can be helpful for managing worrisome or negative thoughts, and can be particularly helpful for people with persistent (chronic) pain.

Naturopathy – is a holistic approach to health and wellness that uses natural remedies to enable the body to heal itself. Natural healing is achieved by using therapies such as herbs, massage, acupuncture, exercise, nutritional counselling and lifestyle changes.

Acupuncture – a therapy that involves inserting thin needles in the skin in targeted areas of the body. It is thought that acupuncture can help to decrease persistent (chronic) pelvic pain, menstrual pain and improve peoples' quality of life.

Guided image therapy – a relaxation technique in which people focus on an image that makes them feel relaxed and happy. The purpose is to take a person's concentration away from what is upsetting them. It will teach them how to change their feelings by changing their focus. People with endometriosis can use this therapy to help with pain, fatigue and to reduce anxiety and stress.

Music therapy – uses music to help your physical, emotional, cognitive and social needs. It involves you participating in various activities, including listening to music or playing an instrument. Music therapy can help decrease your anxiety, depression, and pain. It can also help promote sleep and enhance people's quality of life.

Hypnotherapy – a guided relaxation technique where you are placed in a heightened state of awareness (also known as a trance). When in this state, you're more open to suggestion. This allows for changes in thoughts, sensations, perceptions, and behaviours.

Pain management

Many people with endometriosis experience pain. As a result, pain management is an essential part of care. Without effective pain management, you may notice an impact on your quality of life. Anyone experiencing pain should speak to their doctor.

It is important to determine the cause of pain first, to allow it to be treated directly. A thorough history and examination will help. Once the contributors or causes of pain have been established, these can be treated directly.

For more information and detail regarding pain management, please refer to our separate Pain Management Guide.

The International Association for the Study of Pain and Chronic Pain Australia provide the following definitions and explanations:

Pain: An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage.

Acute pain: pain that lasts less than six months.

Persistent (chronic) pain: pain that persists or recurs for longer than three to six months.

Persistent (chronic) pelvic pain: is cyclic or non-cyclic pelvic pain lasting for at least six months, with or without dysmenorrhea, dyspareunia, dysuria, and dyschezia.

Nociceptive pain: arises from actual or threatened damage to non-neural tissue and is due to the activation of nociceptors (nociceptors are sensory endings on nerves that can be excited or sensitised and signal potential tissue damage). Nociceptive pain can be thought of as pain associated with tissue injury or damage or even potential damage.

Neuropathic pain: is caused by a lesion or disease of the somatosensory nervous system – meaning any pain associated with injury or disease of nerve tissue.

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Nociplastic pain: is defined as pain that arises from altered nociception despite no clear evidence of actual or threatened tissue damage. This can cause the activation of peripheral nociceptors or evidence for disease of the somatosensory system (sensory nervous system) causing the pain. This type of pain may reflect changes in the way the nervous and immune systems function.

Central sensitisation: is defined as increased responsiveness of nociceptive neurons in the central nervous system to their normal or subthreshold afferent input.

The International Association for the Study of Pain

Chronic Pain Australia

Central sensitisation and endometriosis

When you repeatedly experience painful stimulation (for example, ongoing nociplastic pain), your peripheral nerves and central nervous system become more sensitive and receive 'pain' signals more easily. This often includes stimuli you did not previously find painful. Once this happens, your central nervous system starts to respond differently to pain. This means, you may still feel pain after the initial injury has healed. Often, when the nerves do respond to pain, the response is stronger and goes on for much longer. You may also feel pain, even if there is no painful stimuli. Central sensitisation is common in people with endometriosis, and can require multiple treatment methods to manage the condition.

What can I do to manage my pain?

The multidisciplinary pain management approach – building a toolbox

When approaching pain management, it's important that you have a toolbox of resources to help you manage pain. By learning and implementing skills to self-manage your pain, you can improve your pain experience and enjoyment of life.

You may need the expertise of different healthcare professionals to help you manage your pain and create your toolbox. Our endometriosis nurse coordinators or your GP can support you in creating a team of healthcare professionals who can help you.

These professions include:

- gynaecologists
- pain doctors
- pelvic health physiotherapists
- pain physiotherapists
- occupational therapists
- psychologists
- dietitians

We have listed some options that can help you manage the pain associated with endometriosis. It is important to note that hormonal therapies (see page 30) and surgery (see page 34), may also be useful in reducing your pain.

Lifestyle modifications

Making some simple lifestyle changes is one of the quickest and easiest ways that you can start to self-manage your pain. Some common lifestyle modifications that can improve your pain include nutrition changes (see page 42), optimising your sleep (see page 39), implementing pacing (see page 39) and completing regular exercise (see page 38).

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Pain psychology

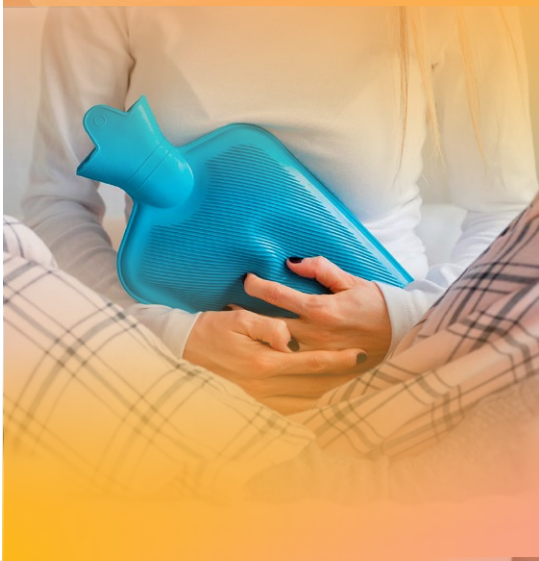
Psychologists play an important role in helping you to manage pain. As psychological and emotional factors contribute to pain, it can help to see someone who specialises in this field. By understanding the behaviours, thoughts, and emotions that contribute to your pain, you can help reduce the pain you're feeling and learn strategies to cope with it better.

Transcutaneous electrical nerve stimulation (TENS)

TENS therapy involves using low voltage electric current to help ease pain. A small, battery operated device provides electrical current that is delivered through electrodes. Electrodes are placed on your skin near the nerves where the pain is or the trigger points for your pain. The idea is to stimulate nerves to block the transmission of pain signals and alter your perception of pain.

Heat therapy

Applying heat to painful areas can give relief because it relaxes muscles and opens blood vessels. Helpful tools include a hot water bottle, heat pack and hot bath or shower.



Medications used for pain management

It's important to note that medicines are usually only effective for a limited time. Combining medicines with other non-drug treatments is essential for your pain management plan. Even with strong pain, starting with simple pain killers can help make managing pain easier. Taking pain killers before your pain becomes severe can help you get on top of things before pain escalates to an uncontrolled level.

Nonsteroidal anti-inflammatory drugs (NSAIDs)

The purpose of NSAIDs is to reduce pain and inflammation. They block enzymes that help to produce prostaglandins. Prostaglandins increase during your period and cause your uterus to contract. If your prostaglandins levels are too high, this can cause severe contractions and period cramps. NSAIDs are very effective in treating acute pain.

Paracetamol

Paracetamol is a simple and affordable pain relief option that is highly effective. When combined with NSAIDs it has an additive effect, and it's safe to take these together.

Neuropathic agents

Neuropathic agents are medicines that are used to help treat neuropathic pain. Medications for depression (such as Amitryptiline and Duloxetine) and epilepsy (such as Pregabalin) are usually the first choice for treating neuropathic pain. This is because of their effect on chemicals in the brain that send pain signals through the nervous system.

Medicinal Cannabis

Some people with persistent (chronic) pain use medicinal cannabis as a form of pain relief. To access medicinal cannabis you need to see a qualified medical practitioner for assessment, guidance and to obtain a prescription.

Opioids

Opioids are strong drugs that can provide relief from acute pain. Examples include Endone and Tapentadol. They work by binding to opioid receptors in cells located in your brain, spinal cord and other parts of the body. After attaching, they block pain signals to your brain and give you a sense of pleasure by increasing your dopamine levels. They also slow down some of your body's automatic functions, such as breathing and your heart rate. Due to the risk of addiction, opioids are only available by prescription. You should only use opioids for short term, acute pain relief. For this reason they are highly effective for surgical pain.

Long term opiate medication generally carries more risks than benefits. Opiates can make your pain worse by altering the receptors in the central nervous system. Higher doses are needed with time. This makes them unsuitable as a long-term treatment option for persistent (chronic) pain and endometriosis.

Other

There are other classes of medication which are often useful for people with endometriosis.

Interventional pain management

People with persistent and severe pain may require an interventional pain management strategy, led by a pain specialist. It is important that interventional pain management has a multidisciplinary approach. Potential interventions include Botox injections, ketamine/ lignocaine infusions, nerve blocks and sacral nerve stimulators. All of these interventions involve a hospital admission. Your pain specialist will always discuss the risks and benefits with you.

Endometriosis and fertility

How does endometriosis affect fertility?

Having endometriosis doesn't necessarily mean you can't have a baby. Many people with endometriosis have no problem conceiving and won't need medical help.

Unfortunately, some people with endometriosis do have trouble becoming pregnant. In 2024, research showed that the risk of infertility in women with endometriosis is between two and four times higher when compared with the general population.[6] There is a complex relationship between endometriosis and infertility.

Multiple reasons for infertility often exist, including:

- pelvic adhesions
- a decrease in the quality and quantity of eggs in people with endometriosis
- ovaries with endometriosis lesions (endometrioma) present, can have difficulty ovulating
- inflammation can impact ovulation and the development of endometrium
- pain can decrease the ability to have intercourse.

How will I know if I am fertile?

The only way to know is to try to conceive.

A blood test called AMH can assess egg number but not egg quality. Infertility can be female factor, or male factor, or both, and a comprehensive assessment of both partners is essential in understanding fertility.

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How can I improve my fertility?

To assess your ability to conceive, you may want to seek the advice of a fertility specialist, who can provide you with a list of different options to help. This may include surgery or assisted reproductive technologies (ART).

Lifestyle modifications

Some lifestyle factors can contribute to low fertility and should be addressed in conjunction with other treatments. Smoking and alcohol in excess both reduce the chances of conceiving. Healthy body weight is important for both conception and reducing pregnancy risks. Being active is also important.

Laparoscopic surgery

A laparoscopy offers a clear view of your reproductive organs. A surgeon can investigate your reproductive organs and pelvic cavity to see if there are any problems which may be affecting your ability to conceive. They can also remove endometriosis during this procedure. Endometriosis is known to reduce fertility, even if it's not causing any other symptoms. Removing endometriosis can improve your chances of conceiving. The patency of your fallopian tubes can also be assessed at the time of laparoscopy.

Assisted reproductive technologies (ART) procedures

Freezing eggs

Freezing your eggs is an option if you're concerned about your fertility but you're not ready to conceive. The procedure involves storing unfertilised eggs so you can use them when you're ready. To produce multiple eggs, you will self-administer a hormonal medication to stimulate your ovaries. The eggs are then removed from your ovaries. As with any medical procedure, there are side effects with freezing your eggs. These may include swollen and painful ovaries because of the stimulation. You can discuss any associated risks with your fertility specialist.

Intrauterine insemination (IUI)

IUI is a procedure that involves injecting sperm into the uterus close to the time of ovulation. IUI can take place during your natural menstrual cycle, or your ovaries can be stimulated to regulate ovulation.

In vitro fertilisation (IVF)

With IVF, the ovaries are stimulated to produce multiple eggs. The eggs are then collected and are fertilised by sperm in a laboratory to create an embryo. An embryo is then implanted into the uterus. The steps involved in the IVF process can take many months.

If more than one embryo has resulted from fertilisation, they are usually frozen. The extra embryos can be used at a later date if needed.

Endometriosis and pregnancy

Most people with endometriosis have normal, healthy pregnancies. They generally don't need extra monitoring during their pregnancy. But having endometriosis can increase the chance of some complications. These complications can include:

- Miscarriage
- Placenta previa
- Preeclampsia
- Preterm birth

For some individuals, pregnancy can make some of the symptoms of endometriosis improve or lessen. Symptoms rarely get worse during pregnancy.

If you suffer from persistent (chronic) pain prior to pregnancy, some pregnancy symptoms may be exacerbated for you. Having endometriosis doesn't mean that you can't have a normal pregnancy and deliver a healthy, full-term baby. As with any pregnancy, the key is to see your health care professional if you have any concerns or if any issues arise.

What other conditions are associated with endometriosis?

Adenomyosis

People with endometriosis often have adenomyosis as well. Both are conditions that involve endometrial-like tissue growing in areas it shouldn't. Yet, they are different conditions. Endometriosis involves tissue growing outside the uterus, whereas adenomyosis involves endometrial-like tissue growing in the muscle wall (or myometrium) of the uterus. With adenomyosis, the tissue in the uterus wall will continue to thicken, break down and bleed during your period. This can cause your uterus to become enlarged and painful. This is why some of the symptoms of adenomyosis overlap with those of endometriosis.

Symptoms can include:

- period pain
- pain before and after your period or around ovulation
- heavy menstrual bleeding.

Unlike endometriosis, adenomyosis often develops later in life. Pregnancies also increase the risk of developing adenomyosis.

Adenomyosis can be difficult to diagnose. It is often detectable on a high-quality ultrasound or MRI. The only way to make a definite diagnosis is a pathology test of the uterus after a hysterectomy.

Treatment for adenomyosis will depend on how severe your symptoms are. There are pharmacological treatment options that are highly effective at controlling adenomyosis symptoms. Unlike endometriosis, you can cure adenomyosis by having a hysterectomy.

Bladder pain syndrome

Endometriosis and bladder pain syndrome (also known as interstitial cystitis) are closely linked and share similar symptoms. People are often misdiagnosed with one for the other however it is also possible for someone to have both conditions.

People with endometriosis are thought to be more likely to develop bladder pain syndrome (BPS).

BPS is a chronic bladder condition that often causes persistent (chronic) pelvic pain, bladder pain and pressure, and sometimes an urgency to urinate, or the need to urinate more often. Those with pelvic floor dysfunction, bladder trauma, or persistent (chronic) pain conditions, are at a higher risk of developing BPS.

Diagnosis is based on symptoms and ruling out other causes.

Treatment of bladder pain syndrome involves various approaches tailored to the individual. Some treatment options can include:

- modifying your diet
- stress reduction
- pelvic health physiotherapy
- bladder distension (stretching of the bladder with water)
- surgery
- nerve stimulation
- oral medications (such as NSAIDs or prescription drugs).

Premenstrual dysphoric disorder (PMDD)

People with endometriosis can also have PMDD. However, there has not been a lot of research on people that have both conditions.

PMDD affects you in the lead up to your period and can cause severe emotional symptoms. The combination of the physical and emotional symptoms of both conditions around your period each month can cause a lot of distress. PMDD is a severe form of premenstrual syndrome (PMS). People will often experience a mix of physical and emotional symptoms 7 to 10 days before their period.

Symptoms will usually include:

- irritability or anger
- anxiety or panic attacks
- depression
- having trouble concentrating
- fatigue
- lack of energy
- sleeping issues
- changes in eating habits (binges/ cravings).

PMDD is thought to occur because of the drop in progesterone levels before your period. Another view is around the change in your serotonin levels during your period. Serotonin affects your sleeping habits, your mood and your hunger levels. PMDD symptoms disappear during pregnancy and stop permanently after menopause.

Treatment for PMDD aims to minimise the impact of your symptoms.

Treatments can include lifestyle changes such as:

- sleep hygiene
- exercise
- eating a diet low in salt and rich in leafy greens.

Your doctor may consider the following treatment options:

- Hormones which stop ovulation and stabilise the hormonal changes during the menstrual cycle.
- SSRIs (selective serotonin reuptake inhibitors) are antidepressants that can improve symptoms. SSRIs can be prescribed only for the luteal phase of the menstrual cycle (when symptoms are present) or continuously throughout the cycle.

Heavy menstrual bleeding

Heavy menstrual bleeding (or menorrhagia or prolonged menstrual bleeding) is a common symptom of endometriosis.

Heavy menstrual bleeding is defined by RANZCOG* as "excessive menstrual blood loss that interferes with the physical, emotional, social and material quality of life".

Treatments for heavy menstrual bleeding include surgical or non-surgical pathways, and will depend on the cause of the bleeding (for example, presence of polyps or fibroids), desire for children in the future, and desire for contraception.

Non-surgical treatments include:

- Hormone treatments that aim to reduce or stop your periods.
- Non-hormone treatments that aim to reduce blood flow and cramping.

Surgical treatments include:

- Hysteroscopy – a procedure that is used to examine the uterine lining and can be used to remove polyps or small fibroids.
- Endometrial ablation – a procedure that uses heat to destroy the endometrial lining of the uterus.
- Hysterectomy – a procedure that involves surgically removing the uterus.

*The Royal Australian and New Zealand College of Obstetricians and Gynaecologists

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Your treatment team at Epworth

Endometriosis affects people in different ways. It's important that you receive a personalised treatment plan that suits your specific symptoms. The team at the Julia Argyrou Endometriosis Centre at Epworth will work with you throughout your diagnosis and treatment.

As a specialised treatment centre, our team is here to support you throughout your journey. This means help is on hand when you need it. As part of our commitment to providing patients with centralised care, our endometriosis nurse coordinators can recommend and help you coordinate a multidisciplinary, holistic treatment plan for long term management of your endometriosis.

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Endometriosis
Centre

Epworth


Welcome
Cheryl

The multidisciplinary team at the Julia Argyrou Endometriosis Centre

You will likely be recommended to see a variety of different health professionals to help you receive holistic treatment for your endometriosis. Members of the multidisciplinary team may include people from the list below.

Endometriosis nurse coordinators	› Will oversee your treatment pathway at Epworth. This includes the planning and coordination of your care in collaboration with your treatment team. They're also available to answer your questions and are your first point of contact relating to your care at Epworth.
Gynaecologist	› The centre has a network of gynaecologists with a special interest in endometriosis. They will create a treatment pathway individualised to suit your specific diagnosis.
Women's or Pelvic Health GP	› A GP with a special interest in and sometimes additional qualifications in women's and/or pelvic health.
Colorectal surgeons	› Specialise in diagnosing and treating diseases and conditions relating to the colon, rectum, and anus.
Urologist	› Specialise in diagnosing and treating diseases of the urinary tract.
Medical imaging professionals	› Responsible for conducting different imaging tests needed to diagnose or treat your condition.
Pain specialist	› Will provide options for managing any ongoing pain. They will advise you on pain relief options to best manage your symptoms during treatment.

Nurses	› A variety of nurses will support you and your family through the different stages of your care.
Dietician	› Offers guidance and support in managing nutrition-related problems caused by your condition and/or its treatment.
Pelvic health physiotherapist	› Helps you to optimise the function of the pelvic floor muscles and treat a range of pelvic floor symptoms. Can also create a tailored exercise program and help manage fatigue and pain.
Exercise physiologists	› Specialise in exercise and movement to manage and prevent many health issues and conditions.
Social worker	› Provides practical support and advocates for the needs of you and those closest to you. Can also connect you with support groups.
Psychologist/ psychiatrist/ counsellor	› Provides ongoing emotional support, which can help with managing living with endometriosis. They can also perform pain psychology treatment.
Occupational therapist	› Can help with adaptation of daily activities (e.g. housework) to reduce pain and improve overall functioning and quality of life.

Endometriosis and teens

It's important that GPs consider endometriosis when teenagers present to them with symptoms.

Most people with endometriosis can track their symptoms back to their early teens. This is usually around the time they have their first period. However, it is not uncommon for periods to be irregular and/or mildly painful (pain lasting less than 2 days, which goes away with simple over the counter pain medication) for the first few years.

If you are a teenager you need to watch out for if your period becomes heavy or painful. Are you taking time off school, or are you struggling to take part in sports or other activities? If so, it's time for further investigation, a good place to start is visiting your GP. It was once thought to be rare for adolescents to have endometriosis. The normalisation of period pain and the belief that teenagers can't have endometriosis contributes to the long delay before diagnosis.

One of the greatest risk factors for teenagers when it comes to endometriosis is genetics. If your parent (or another immediate family member) has endometriosis, the chances of you developing the condition increases significantly. Awareness is important and watching for the signs can help save years of mismanagement of the condition. Endometriosis is often progressive and can cause physical, emotional and financial distress. Early diagnosis and management can lead to better outcomes for people with endometriosis. Are you not responding to medications? Are you suffering from persistent (chronic) pain that has lasted for three to six months? If you answered yes, then it's time to seek help.

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Clinical research and trials

The primary goal of a clinical trial or research study is to answer specific research questions. As a result, we will be able to find better ways to treat and diagnose endometriosis, and find a cure.

Clinical or scientific research can be:

- an observational study that involves collecting data on a disease's history to better understand it
- an interventional trial to determine whether an experimental treatment is safe and effective
- experiments performed in the laboratory using models of disease or analysis of human tissues to better understand the causes of a disease
- computer-based studies combining clinical information and biological and molecular data.

Scientific and clinical trials need volunteers to test research questions. Testing will determine if new treatments for endometriosis work and if there are side effects.

They're also an effective way for people to gain access to the latest treatment options. Participation leads to advances in research, better treatments, and better patient outcomes. When deciding if you want to take part in research or a clinical trial, you need to be aware of what is involved. You should also seek advice from your specialist before taking part. It is important to note that clinical trials are bound by Australian laws and regulations. All research is reviewed and approved by a Human Research Ethics Committee (HREC) and Epworth's Office for Research. Testing therapeutics (medicines and devices) requires the review and approval of the Therapeutics Goods Administration (TGA). These approvals and authorisations ensure that clinical trials are ethically and responsibly run. Participation in clinical research is entirely voluntary and confidential. Advancements in endometriosis diagnosis and treatment will happen as a direct result of scientific research and clinical trials.

The details of research projects and clinical trials currently being undertaken through the Julia Argyrou Endometriosis Centre at Epworth are available at **Epworth.org.au/juliaargyrouendocentre**.

Or for more information, please contact our research team on **03 9516 2434** or at **EHEndocentre@epworth.org.au**.

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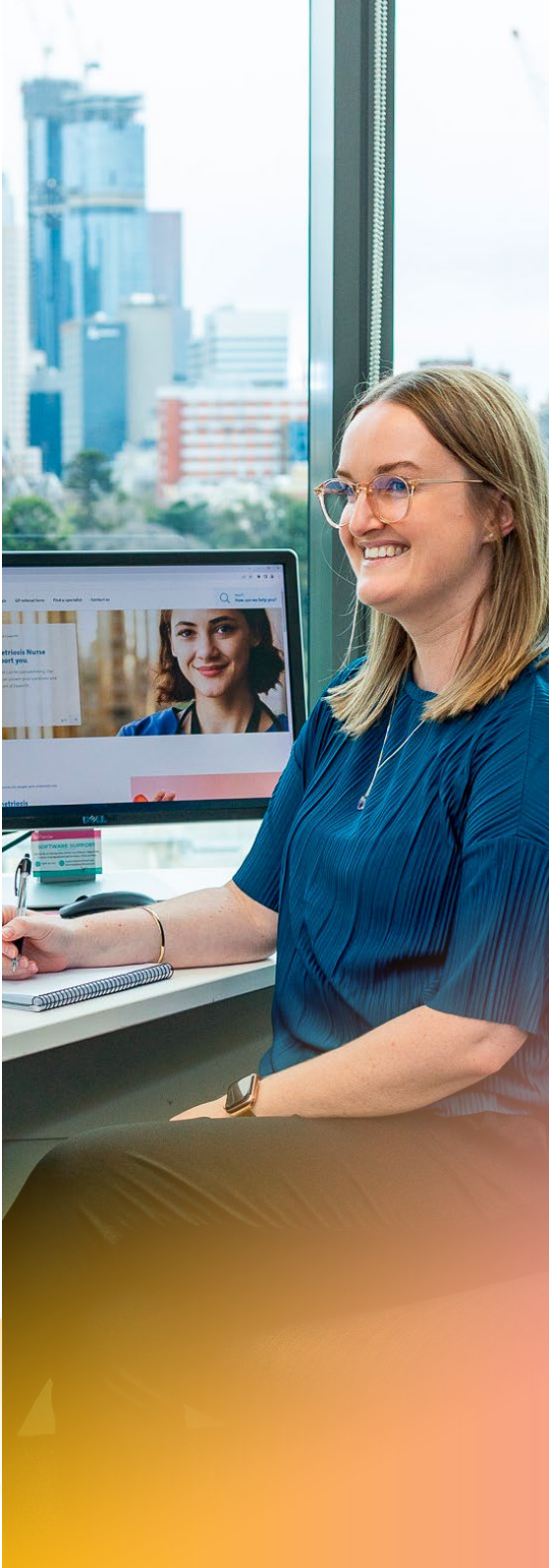

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