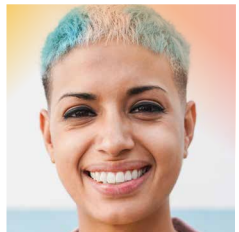


# Endometriosis Patient Guide



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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.



## Your guide to endometriosis

An endometriosis diagnosis can help explain your symptoms, including severe pelvic pain, abnormal vaginal bleeding, infertility and other problems. It can also leave you feeling upset and emotional. Endometriosis is a complicated 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. It will provide you with a broad overview of endometriosis and how it may impact you and those closest to you. Some of the topics we cover include diagnosis, treatment options, fertility, and support. We recommend that you get those closest to you to read this guide. This condition is likely to impact them as well.

At the Julia Argyrou Endometriosis Centre at Epworth, we want you to be aware of the options available to you. While endometriosis is a chronic condition, it can be managed. We can show you how. We also want those close to you to understand endometriosis. This will help them to be able to support you better. This is a big step towards helping to improve your quality of life.

*This guide is not a replacement for medical advice. Please discuss any matters affecting your health immediately with your healthcare professionals.*

JULIA ARGYROU  
**Endometriosis  
Centre**



## 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 speak, there are some terms that you will need to know. If we haven't explained them in the booklet, you can easily find the definition here if you need it.

**ablation** – the destruction of body tissue

**adhesions** – tissues that have attached 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

**endometrial implants** – 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

**excision** – the cutting out of abnormal body tissue using a scalpel or other cutting instruments

**dysmenorrhoea** – painful periods

**fistula** – an abnormal connection/tract between two structures

**frozen pelvis** – when adhesions cause pelvic organs to stick together and become fixed

**fulguration** – the process of destroying by electricity

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

**Graded exposure** - involves gradually increasing exposure to certain activities to build up tolerance

**hormones** – 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

**infertile** – unable to conceive children

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

**laparoscopy** – a minimally invasive procedure that uses a telescope to examine inside the abdomen and pelvis

**lesions** – areas of abnormal tissue growth

**menstrual cycle** – a hormonal cycle that the body of people with female reproductive organs go through in preparation for pregnancy

**interdisciplinary care** (also referred to as multidisciplinary care) – involves health professionals from different fields working together collaboratively with a patient concerning their care

**occlusion** – a complete or partial blockage

**oestrogen** – a sex hormone predominantly produced by the ovaries

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

**ovulation** – the release of a mature egg from an ovary

**osteoporosis** – a condition where bone is thin

**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

**Pouch of Douglas** - area between your rectum, cervix and upper vagina

**pre-menopausal** – haven't reached menopause yet

**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** – 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



## About the Julia Argyrou Endometriosis Centre at Epworth

**Endometriosis is a chronic condition, which at times can be debilitating. In Australia, the Department of Health estimates that one in nine women have endometriosis.<sup>1</sup> This number is likely higher as the numbers don't account for transgender and gender diverse people. Nor do they account for misdiagnosis or 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. It also accounts for thousands of hospitalisations each year. 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.

One of the major problems facing patients is the delay before they receive a diagnosis. The average time between symptoms starting and a diagnosis is seven years. This often means a patient is in the later stages of the condition, making managing it much harder. This can be partly attributed to the conditioning we've received around period pain.

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.

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

It's necessary to achieve better outcomes for patients with endometriosis. Our interdisciplinary approach means we have a network of experienced endometriosis specialists. Our team includes gynaecologists, pain specialists, physiotherapists, psychologists and other allied health specialists. Interdisciplinary care is now considered essential in the management of chronic conditions. During treatment, you will have full access to the healthcare professionals needed for your care. You will also receive a personalised treatment plan suited to your individual diagnosis.

We also understand the importance of the patient experience. Endometriosis is a chronic condition that takes a physical and emotional toll.

Having someone that can answer your questions is important. After your referral to the centre, you will have access to our endometriosis nurse coordinator. We also have an endometriosis support group at Epworth Freemasons. 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.

And the final, but one of the most critical components of our centre is research. To date, endometriosis research has been very underfunded. It's hard to believe, considering the high cost of this condition to our economy and our health care system. We will be running research studies and clinical trials to better understand endometriosis.

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**The goal is to improve diagnosis methods and treatment options.**

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. This will help us to improve your quality of life. At the Julia Argyrou Endometriosis Centre at Epworth, we will achieve better outcomes for endometriosis patients.

## 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 gynecologist and had her first laparoscopy, which confirmed that she had endometriosis.

It had taken seven 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.

In total, Julia has had 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 the 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 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 occurs when cells that are similar to the ones that line your uterus start growing in other areas of your body. These growths are also known as endometrial implants or lesions. Endometriosis is most commonly found on the lining of the abdominal cavity, called the peritoneum.**

Endometriosis can implant on any organ. The pelvic organs (listed below) are the sites most often affected.

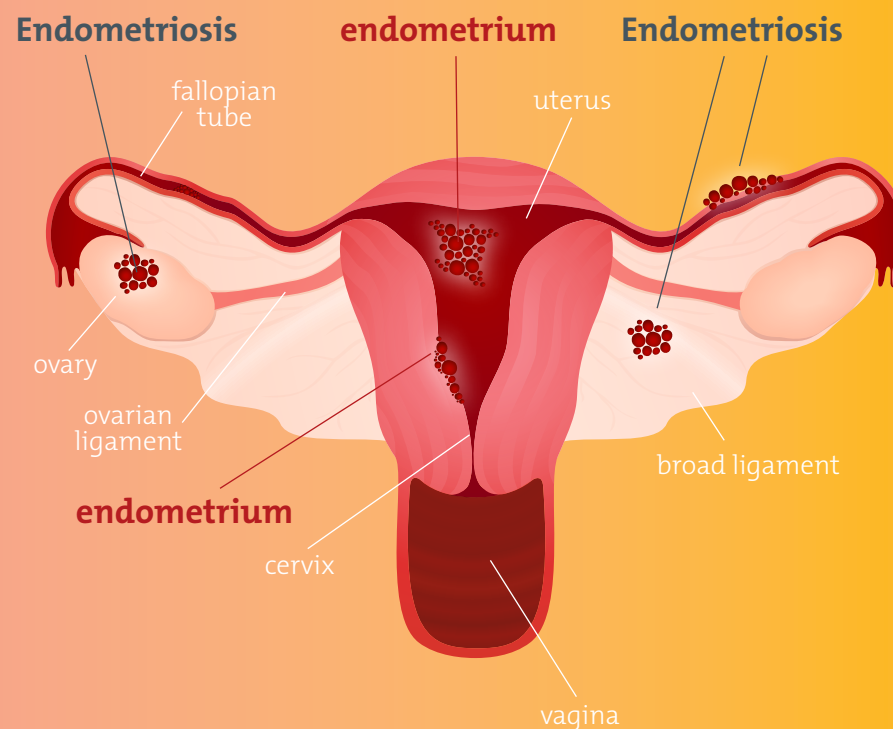
- > Ovaries (can develop into cysts called endometrioma)
- > fallopian tubes
- > the outer lining of the uterus
- > Pouch of Douglas (area between your rectum, cervix and upper vagina)
- > ligaments that hold the uterus in place (uterosacral ligaments).

Endometriosis can also occur on the bowel, bladder and vagina. In some cases, parts of these organs may need to be removed during surgery.

Endometriosis will generally remain contained within your pelvis or abdominal cavity. Although rare, it can occur in other parts of your body, such as your heart, brain, and lungs.

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

The production of oestrogen can cause the lesions to become inflamed. Inflammation can lead to swelling and adhesions in the tissue around the implants. As a result, scar tissue from adhesions can cause your organs and pelvic tissue to stick together.





## What causes endometriosis?

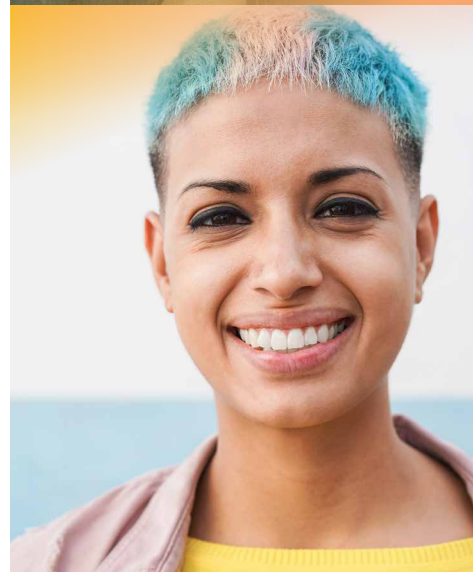
The exact cause of endometriosis is still unknown. Possible explanations for the condition include:

- > genetic predisposition: if an immediate family member (mother or sister) has endometriosis, your risk increases
- > retrograde (reverse) menstruation: blood and endometrial tissue shed during your period travels through the fallopian tubes into the pelvic cavity instead of leaving your body.

Other possible causes that are being looked at include:

- > endometrial cells travelling through your blood or lymphatic system to other areas of your body<sup>2</sup>
- > an immune system issue that prevents your body from being able to destroy endometrial tissue found outside of the uterus
- > environmental factors such as weight, diet, and alcohol consumption
- > endometrial cells attaching themselves to a surgical incision after surgery
- > hormones that can change precursor cells into endometrial-like cell implants during puberty<sup>3</sup>
- > coelomic metaplasia: the transformation of normal peritoneal tissue into endometrial-like tissue.

It's most likely that the cause of endometriosis is a combination of the above factors. This makes it harder to prevent.



## What are the symptoms?

Symptoms for 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 of your endometriosis. We are all different, and our body's reaction to endometriosis will be different from person to person.

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

Symptoms that endometriosis patients may experience include:

- > period pain (also called dysmenorrhoea)
- > infertility
- > ovulation pain (during the middle of the menstrual cycle) can include pain in the legs, buttocks, and thighs
- > pelvic pain that occurs outside of your period

- > pain during or after sex (dyspareunia)
- > pain when using your bladder (dysuria) or bowels (dyschezia), usually during your period
- > heavy vaginal bleeding
- > irregular bleeding (including bleeding between periods)
- > bleeding for longer than normal
- > bloating
- > feeling tired and lethargic
- > diarrhoea or constipation
- > needing to urinate more often
- > blood in your stool or urine (in rare cases)
- > mental health problems (such as anxiety or depression)
- > nausea and vomiting
- > difficulty concentrating or remembering things (brain fog).





## Who is most at risk of having endometriosis?

The exact cause of endometriosis is still not known. However, certain risk factors may increase your chances of developing endometriosis. These risk factors include:

- > starting your period at an early age (before 11)
- > family history of endometriosis
- > heavy periods that go for longer than seven days
- > having your period more frequently (less than 27 days)
- > reproductive tract abnormalities
- > any condition that prevents, blocks, or redirects the flow of your period
- > oestrogen levels that are higher than normal
- > not having any children
- > alcohol consumption
- > low body weight.

While these factors make endometriosis more likely, anyone experiencing symptoms should consider endometriosis as a possible cause. People can have endometriosis and experience no symptoms at all.

## What are some common myths around endometriosis?

There are many myths associated with endometriosis. Science has exposed 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 patients with endometriosis experience severe pain

**FALSE** – Some patients never experience any pain with their endometriosis

### > The pain associated with endometriosis will depend on the severity of the endometriosis

**FALSE** – People with mild (Stage 1 and 2) endometriosis can experience more pain than advanced (stage 3 and 4) endometriosis

### > Pain for patients with endometriosis only occurs during their period

**FALSE** – Patients with endometriosis can experience pain at any time

### > Having a hysterectomy will cure endometriosis

**FALSE** – Endometriosis can return after excision, 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 patients with endometriosis can conceive after surgery or with the assistance of reproductive technology

### > Pregnancy cures endometriosis

**FALSE** – During pregnancy, the change in hormones can reduce symptoms for some people, but it won't cure endometriosis.



## How is endometriosis diagnosed?

**Patients will often wait years before they receive an endometriosis diagnosis. Studies have shown that the average delay in diagnosis is seven years. This is from the onset of symptoms to a surgical diagnosis.**

What causes the delay in diagnosis? Many symptoms of endometriosis are normalised in the community, meaning patients do not seek care, or are not referred to specialist care when they see their doctor. This is especially true in younger people with the 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 your symptoms. You should track any symptoms you experience during your menstrual cycle so you can provide your GP with detailed information. You can also ask your GP to refer you to a gynaecologist that specialises in endometriosis. A gynaecologist will be able to investigate further.

### Pelvic exam

With your permission, your doctor will perform a pelvic examination. When conducting a pelvic exam to look for endometriosis, your doctor will manually feel the inside of your pelvis through the vagina. They will be feeling 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. Although hard to find during a pelvic exam, the presence of lesions can indicate that you have endometriosis.

Pelvic examination may also include a cervical screening test if you are due for one. It may also detect any abnormality in the muscles of the pelvic floor which can be a cause of pain in patients with and without endometriosis.



## Imaging and visualisation

### Ultrasound

An ultrasound is the best imaging procedure for the detection of endometriosis. A high-quality image is achieved when a transducer (probe) is gently placed inside the vagina. Using this method, detailed images can be taken of pelvic organs. If you can't have a vaginal ultrasound, useful information can be obtained by taking an image through your abdomen instead.

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

Identifying endometriosis by ultrasound is a highly skilled technique and not all ultrasound services are able to provide the detailed information required. Signs of endometriosis may be missed and patients may be asked to repeat their scan with a specialist gynaecological ultrasound service.

An ultrasound alone is often not enough to confirm an endometriosis diagnosis. Importantly, it 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. An MRI can sometimes help detect deep endometriosis, cysts on your ovaries, and lesions on your pelvis, bowel, and bladder. This can help in planning whether a bowel or bladder surgeon may need to assist the specialist 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.

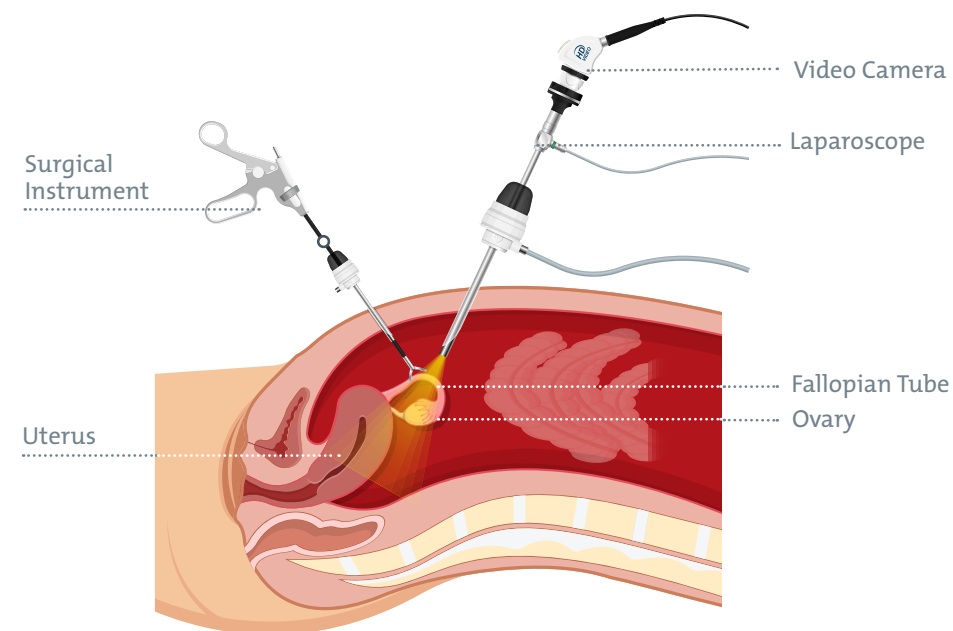


### Laparoscopy

Laparoscopic surgery is a minimally invasive procedure that allows your surgeon to look inside your pelvic and abdominal cavities. Your specialist is likely to recommend a laparoscopy if they suspect you have endometriosis, or to see if there is recurrence of endometriosis after previous surgery.

Other tests can help lead to an endometriosis diagnosis. However, a laparoscopy is currently the only way to positively confirm that endometriosis is present. It also allows your specialist to see inside your pelvic and abdominal cavity to determine the stage of your endometriosis.

Samples of tissue removed will be examined by a pathologist to confirm the tissue is endometriosis.





## The different stages of endometriosis

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

Staging allows specialists to determine the extent of endometriosis in a patient. Staging can help determine the best treatment options for patients. It's important to remember that staging isn't an indication of the severity of your symptoms. Staging is used to determine how difficult the surgery is likely to be, and ensure you have the right surgeon performing your surgery.

The American Society for Reproductive Medicine (ASRM) developed the staging system, and it comprises four stages. It uses a points system to determine the severity of a patient's endometriosis. Patients 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.

It's important to note that pain is not associated with this staging system. A patient with stage 4 endometriosis may experience little or no pain. Whereas a patient with stage 1 endometriosis may have severe and chronic pelvic pain.

The ASRM stages and point classification for endometriosis.<sup>4</sup>

<b>Stage 1 – Minimal</b> (1-5 points)	<ul style="list-style-type: none"><li>&gt; very few implants present</li><li>&gt; implants are not too deep in the pelvic and/or abdominal lining</li></ul>
<b>Stage 2 – Mild</b> (6-15 points)	<ul style="list-style-type: none"><li>&gt; more implants than stage 1</li><li>&gt; implants are a little deeper into the pelvic and/or abdominal lining than stage 1</li></ul>
<b>Stage 3 – Moderate</b> (16-40 points)	<ul style="list-style-type: none"><li>&gt; many implants are present</li><li>&gt; implants are deep in the pelvic and/or abdominal lining</li><li>&gt; small cysts are growing on one or both ovaries</li><li>&gt; there are adhesions present</li></ul>
<b>Stage 4 – Severe</b> (40 points and over)	<ul style="list-style-type: none"><li>&gt; many implants are present</li><li>&gt; implants are deep in the pelvic and/or abdominal lining</li><li>&gt; large cysts are growing on one or both ovaries</li><li>&gt; many thick adhesions are present</li></ul>

## What are the treatment options for endometriosis?

**Although there is no cure for endometriosis right now, treatment will help you to manage your symptoms. It's a matter of finding a treatment that works for you.**

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

Our commitment is to provide patient-centred care. Our interdisciplinary team will work with you to develop a personalised care plan. The severity of your symptoms and the stage of your endometriosis will determine your care plan.

### Making treatment decisions

The aim of treatment is to control your symptoms to allow you to live your life fully. Treatment also aims to ensure that your pelvic organs, such as the uterus and ovaries, continue to function. Unfortunately, the treatments themselves may cause you to experience side effects. That can make finding the right treatment for you difficult. This highlights the need for seeing health professionals that specialise in endometriosis.

At the Julia Argyrou Centre for Endometriosis at Epworth, our team are endometriosis specialists. 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.

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 to ask your doctor should include:

- > What is the aim of the treatment?
- > How will I know if the treatment is working?
- > Are there any risks with this treatment?
- > What are the potential side effects of the treatment?
- > Will the treatment improve my quality of life?
- > What will happen if I do nothing?
- > Are there any alternatives?
- > Do I need to be concerned about my fertility?
- > Will this improve my fertility?
- > What if the treatment doesn't work?
- > What is your approach to pain relief?
- > Is there anything else I can do to help manage my symptoms?
- > What is the cost of treatment?

### 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, visit your gynaecologist. You can discuss the treatment options that are available to you.



## Hormone therapy

Your ovaries produce hormones during your menstrual cycle. These hormones cause your endometrial tissue to thicken, break down and then bleed. This is normal for endometrial tissue inside the uterus. For endometrial-like tissue outside of the uterus, changes in hormone levels can lead to pain and inflammation around lesions.

Although it's not a cure, the aim of hormone therapy is to alleviate symptoms. This is achieved by stopping ovulation (which stops your menstrual cycle), or altering the balance to a more 'progestogenic' endometriosis by balancing out oestrogen. This means having a higher level of progesterone may help to suppress endometriosis.

Some hormone treatments can stop the release of hormones from your ovaries by putting your body into a temporary menopause or pregnancy-like state. The type of hormone therapy you are taking will determine which 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.

## Combined oral contraceptive pill (COCP)

This pill is a combination of synthetic oestrogen and progesterone. It stops ovulation by changing the hormone levels produced by your ovaries. The pill often makes your period lighter and shorter as it thins the lining of your uterus. This can help to improve symptoms or slow the progression of endometriosis.

The pill may be prescribed after surgery to slow the recurrence of endometriosis. Your specialist may suggest you skip the seven days of sugar pills. Skipping the sugar pills is safe to do and can stop your period completely and be more effective in treating symptoms.

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.

## Progestogens

Progestogen is a synthetic version of the hormone progesterone. You can take it as a pill, injection, implant or an IUD. Progestogen has shown to be successful in reducing symptoms in people with endometriosis. Progesterone stops and shrinks the growth of endometrial tissue and reduces inflammation. The IUD containing progesterone has the lowest dose in the blood stream and the least side effects.

The dosages prescribed to patients with endometriosis often stops their period altogether. After stopping treatment, it can take months before your period returns. You may experience side effects until you find the progestogen that suits you. Speak to your doctor if you experience any health concerns while taking progestogen.



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### Gonadotropin-releasing hormone (GnRH) analogues

GnRH analogues help to control your period by putting your body into a temporary state of menopause. GnRH stops the production of oestrogen and progesterone. Without oestrogen and progesterone, your endometriosis is unable to grow. This causes your endometrial implants to shrink in size. GnRH analogues are available as an injection or a nasal spray.

GnRH analogues are most used in moderate to severe cases of endometriosis. Due to the strength of this treatment, it does have side effects. Some patients are unable to tolerate the side effects. There are medications you can take to help reduce side effects. Inducing temporary menopause means you're likely to experience menopausal side effects. These include:

- > hot flashes/night sweats
- > vaginal dryness
- > mood swings/depression
- > decreased libido
- > dry skin and hair
- > muscle pains

- > insomnia
- > temporary loss of bone density.

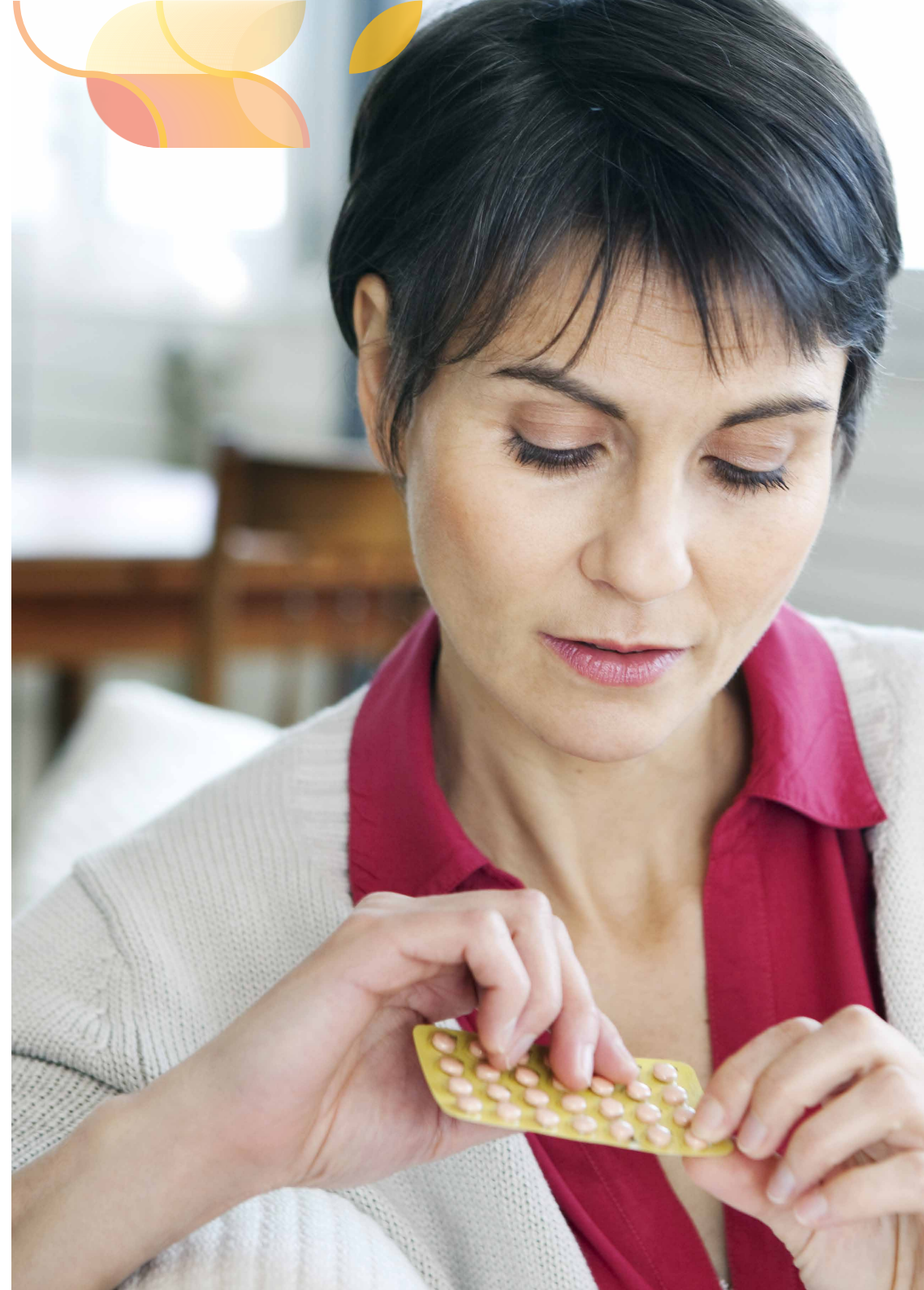
GnRH analogues are often used before surgery to control severe symptoms, and in some situations, they can make surgery safer and easier. They are used after surgery to reduce recurrence of endometriosis.

### Aromatase inhibitors

Aromatase is an enzyme that converts the hormone androgen into oestrogen. Studies have shown there are high levels of aromatase in endometrial implants.<sup>5</sup> When the aromatase in your implants converts to oestrogen, this can feed your endometriosis.

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

Aromatase inhibitors are often used as a treatment for breast cancer and infertility. This doesn't mean that they are chemotherapy drugs. As a treatment for endometriosis, it's still considered a new treatment. Ongoing research is underway to assess its success as an endometriosis treatment.





## Surgery

### Treating endometriosis with surgery

**Surgery is sometimes recommended for the diagnosis and treatment of endometriosis.**

When you undergo surgery, the aim is to remove endometriosis while maintaining the use of your pelvic organs (unless they are being removed).

Surgery is not a cure, but it can offer relief from symptoms and improve fertility for many patients. 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 endometriosis specialists to perform your surgery.<sup>6</sup> Using specialists with the necessary skills and training will help reduce the risk of complications. It can also reduce the need for multiple surgeries.

### 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 the inside of your abdomen and pelvis.

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

Your surgeon will either destroy (using ablation, fulguration, or vaporisation) implants or cut them out (excision). Your surgeon will discuss the method they plan to use at the time of consultation. In general, excision results in less recurrence of endometriosis compared to ablation.

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:

- > perforation of the uterus
- > damage to other organs inside the abdomen
- > excessive bleeding.



### 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 for a patient. A laparotomy is only recommended if a patient'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).

A laparotomy involves your surgeon making a 10-20 centimetre incision into your abdomen. They cut through your skin and the layers below so they can see inside the abdomen and pelvis. They will then remove the endometrial implants or other endometriosis-related issues.

A laparotomy has more risks associated with it than a laparoscopy. This is a result of the size of the incision and the longer recovery time.

### 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 rare cases, one or both ovaries may also need to be removed.

Patients may choose to have a hysterectomy once their family is complete, and if other treatments have been unsuccessful. It's not uncommon for patients that have both adenomyosis and endometriosis to require a hysterectomy.

Hysterectomies have proven to be effective in treating chronic endometriosis pain. One study showed reoperation-free rates of 96 per cent, 87 per cent and 77 per cent at the two, five and seven-year mark.<sup>7</sup> It's important to note that a hysterectomy won't cure your endometriosis. It means you may have fewer symptoms after this procedure and may not need further surgery.

Patients 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 women under the age of 66 benefit from hormones released from the ovaries, including a decreased risk of death. Ovary removal is radical and irreversible surgery. The risks and benefits of removing an ovary 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.

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## Pain management

Many patients with endometriosis experience pain. As a result, pain management is an essential part of patient care. Without effective pain management, you will notice an impact on your quality of life. Anyone experiencing pain should speak to their doctor. Pain is not normal. Patients with endometriosis will often experience either acute pain or chronic pain.

**Acute pain:** pain that happens after tissue has been damaged. This pain will ease once the tissue has healed and there is no more stimulation to your pain nerves.

**Chronic pain:** pain that continues for more than 3-6 months after damaged tissue has healed. There is still stimulation to your pain nerves after damaged tissue has healed as your body has become used to pain. This type of pain is more difficult to treat.

### What is central sensitisation?

When the nerves of your central nervous system repeatedly experience painful stimulation, they become more sensitive. Once this happens, your central nervous system starts to respond differently to pain as it's in a state of high reactivity. This means that your nerves receive pain signals easily, including stimuli not usually considered painful. As a result, you may still feel pain after the initial injury has healed. Your nerves now react to stimulation that they wouldn't have previously. You may also feel pain, even if there is no painful stimulation. Central sensitisation is common in patients with endometriosis, and requires multiple treatment methods to manage the condition. Your specialist will be able to recommend appropriate treatments after your diagnosis.

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## What can I do to manage my pain?

We have listed some options that can help you manage the pain associated with endometriosis.

### Analgesics (pain killers)

#### Nonsteroidal anti-inflammatory drugs (NSAIDs)

The purpose of NSAIDs is to reduce pain and inflammation. They block enzymes that help to produce prostaglandins. Prostaglandins occur 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. 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.

#### Opioids

Opioids are strong drugs that can provide relief from acute pain. 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 their strength, and the risk of addiction, opioids are only available by prescription. You should only use opioids for short term, acute pain relief. You should not use them for long term pain relief, as they can make your pain worse by altering the receptors in the central nervous system. This makes them unsuitable as a long-term treatment option for chronic pain.

## Exercise

**Exercise is an emerging treatment option for endometriosis. When we exercise, we increase the anti-inflammatory and antioxidant markers within our bodies.**

As endometriosis is an inflammatory condition, these markers 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 can also help to reduce oestrogen levels, which is the hormone that stimulates endometriosis.

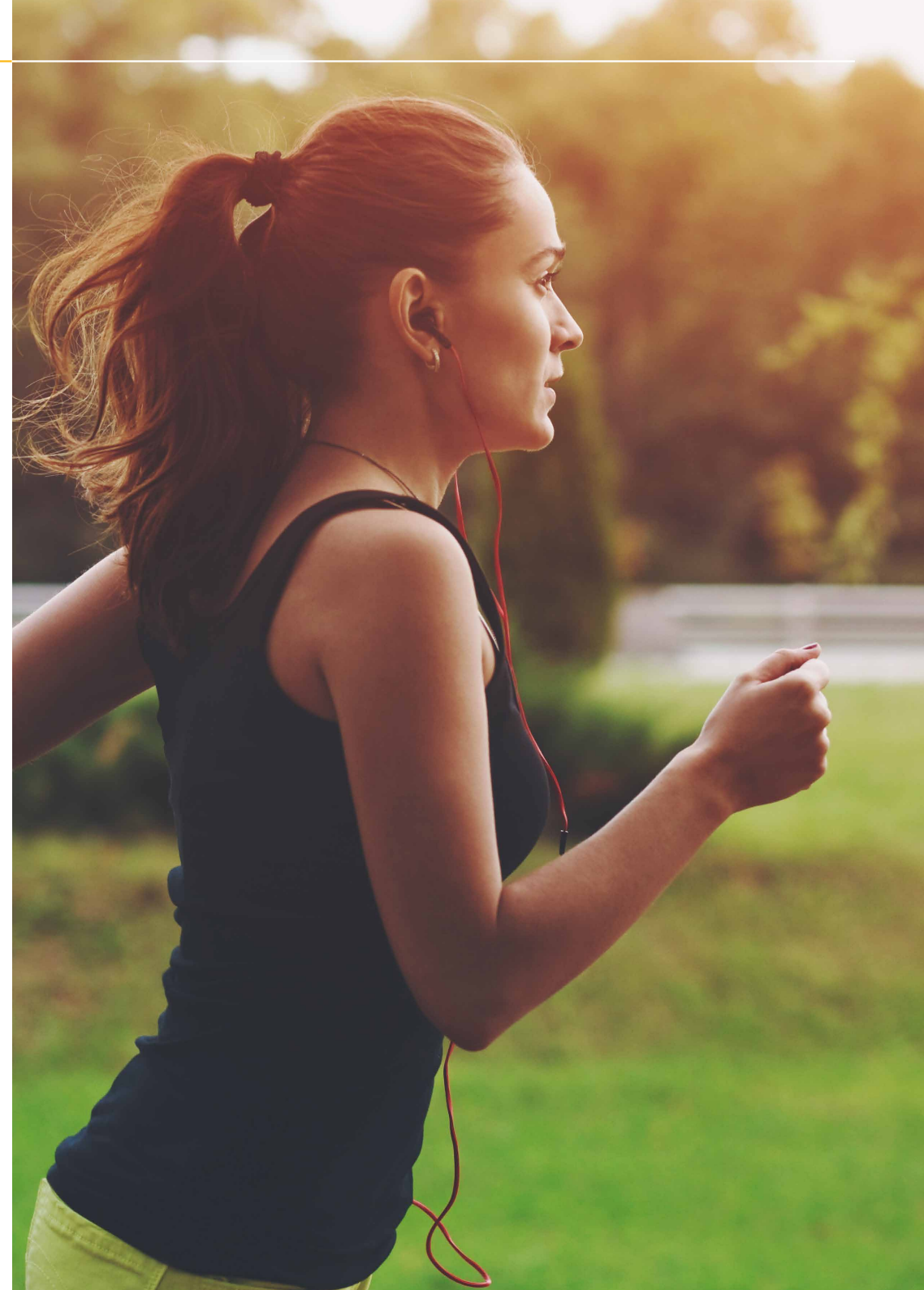
Exercise has also been found to reduce the pain response in many pain conditions. It's also great for your cardiovascular and mental health.

You can experience pain from exercise if you don't find an exercise that best suits you or if you don't prepare your body for exercise. Your body can respond by tightening the muscles in the pelvic area in anticipation of pain.

Many people find non-impact exercise the most beneficial, including swimming and cycling. If you're unsure how to approach exercise, our exercise physiologists can provide you with exercises to loosen and lengthen these muscles. They can also provide you with an exercise plan tailored to your personal needs.

It's important that 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 an effective tool in helping to manage chronic pain.



## Pelvic floor physical therapy

**Pelvic floor dysfunction (PFD) is when you are unable to properly control your pelvic floor muscles. Your pelvic floor muscles are at the bottom of your pelvis.**

They act as a bowl to support your pelvic organs, including the bladder, rectum and uterus. The pelvic floor muscles contract and relax when we use our bowels, empty our bladder, have sex and give birth. If these are unable to tighten or relax when needed, they can't do their job correctly. This can lead to issues such as:

- > pain during sex that can often last for hours
- > 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.

PFD is common in people with endometriosis. You may experience severe pelvic pain because of your endometrial implants. It is common for your pelvic muscles to tighten in response to this pain. Pelvic pain will often continue after your treatment for endometriosis. Pain can persist due to scarring or prolonged muscle tightness and overactivity.

A pelvic floor physiotherapist will provide you with an assessment of your pelvic floor muscles. Based on the results, they will provide you with a strategy to relax muscle tightness in your pelvis and restore elasticity to tissue.

Pelvic floor physical therapy is a specialised area of physiotherapy. Our pelvic floor physiotherapists have the training needed to help you improve your pelvic floor function.





## Nutrition

**You can use nutrition to help control symptoms related to endometriosis.**

**One of the common issues that patients with endometriosis experience is bowel irritation.**

**Some of the symptoms may include:**

- > bloating
- > diarrhoea or constipation
- > pain when using your bowels
- > excessive wind
- > cramping in your bowel.

This may be caused by your endometriosis, or an overlap in diagnoses of IBS or food intolerances. To help ease your bowel issues, you may want to look at the foods you're eating. Certain types of food can make your symptoms worse. To help work out the foods that may be upsetting you, you may want to keep a food journal. You can note down the foods that you have eaten as well as any symptoms you have experienced. You will need to keep the food journal going for at least three months as it may take some time before any patterns emerge.

### Should I see a dietitian?

A dietitian can help you manage any food issues related to your symptoms. A dietitian can create a personalised diet plan and provide you with nutritional information and support. This can help you to better manage your endometriosis.

There are specific diets that you can look at to help relieve your symptoms. These are not calorie-counting diets. These are diets that eliminate known inflammatory foods. These diets have proven beneficial for patients with endometriosis:

**Gluten-free diet**—gluten is a protein found in wheat, rye, and barley. A gluten-free diet involves removing gluten from your diet completely. Some foods containing gluten include bread, beer, cakes, pies, cereals, and cookies. One study found that 75% of people with endometriosis experienced a large decrease in their symptoms when they cut gluten from their diet.<sup>8</sup>

**FODMAP diet**—FODMAPs are short-chain carbohydrates that are hard for the body to digest. FODMAP stands for fermentable, oligosaccharides, disaccharides, monosaccharides and polyols. Common FODMAPs include:

- > fruits, 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.

Not everyone is intolerant to FODMAPS. Most people are only intolerant to one or two. By using a process of elimination, you can work out which FODMAPS are causing your symptoms. They seem to trigger symptoms in people with IBS and other gut-related conditions. This includes people with endometriosis. Some endometriosis patients are seeing a big improvement in their symptoms after following a low FODMAP diet.<sup>9</sup>



## Support services

### Psychologist or counsellor

People with endometriosis suffer both physically and mentally. Symptoms can impact your quality of life, leading to anxiety and depression. Studies have shown the significant impact of chronic pain on mental health. However, a recent study has shown that symptoms other than pelvic pain can also impact the mental health of people with endometriosis.<sup>10</sup> This makes the interdisciplinary approach to endometriosis 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.

Our qualified counsellors and psychologists are available to help you as part of our interdisciplinary care model. Our specialists are ready to support you.

### Pain management program

Chronic, debilitating pain can be a complication of endometriosis. We offer a pain management program that will provide you with the tools you need to help you manage your pain. This can help you to improve your quality of life.

You will be fully supported by a team of pain management specialists throughout your time in our pain management program. These specialists include:

- > pain doctors
- > physiotherapists
- > occupational therapists
- > psychologists
- > dietitians.

There are many facets to treating pain. You need the expertise of different specialists to make sure your pain is managed effectively.

### 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 Freemasons Endometriosis Support Group meets bi-monthly, in person or online. The group provides support, information and a place where you can talk openly and ask questions about endometriosis.

Contact our Endometriosis Nurse Coordinator at [EHEndonurse@epworth.org.au](mailto:EHEndonurse@epworth.org.au)





## 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 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. The purpose is to improve your health and/or your wellbeing. Patients 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 reducing stress and anxiety and improving sleep.

**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.

**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. Endometriosis patients 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 the quality of life.

**Hypnotherapy** – a guided relaxation technique. You're 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. It can help you reduce your pain by relaxing you and drawing your attention away from the pain.

## Endometriosis and infertility

### How does endometriosis affect fertility?

Having endometriosis doesn't 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 or are infertile. Previous estimates place this number at 30-50 per cent of people with endometriosis.<sup>11</sup>

There is a complex relationship between endometriosis and infertility. Multiple reasons for infertility often exist, including:

- > pelvic adhesions and scar tissue can cause organs and ligaments to stick together—this can lead to blockages preventing sperm/egg contact and other fertilisation issues
- > a decrease in the quality and quantity of eggs in people with endometriosis<sup>12</sup>
- > ovaries with endometrial implants can fail to ovulate, stopping the release of eggs
- > inflammation can cause the release of molecules called cytokines that repel sperm
- > pain with intercourse can lead to decreased ability to have intercourse.



## How can I improve my fertility?

After assessing your reproductive capabilities, our reproductive specialists can provide you with a list of different options to help you conceive. 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. Ideal body weight is important for both conception and pregnancy risks. If you need support to reach a healthy body weight we can help. Smoking and alcohol excess both reduce the chances of conceiving. Being active is also important for fertility.

### Laparoscopic surgery

A laparoscopy offers a clear view of your reproductive organs. A surgeon can investigate to see if you have problems which may impact your fertility. They can also remove endometriosis using 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. This happens under sedation using an ultrasound-guided probe with a needle attached. It's a short procedure that only requires you to rest for what's left of the day once you've had the procedure.

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 washed sperm into the uterus right before you're due to ovulate. IUI can happen during your natural menstrual cycle, or your ovaries can be stimulated to regulate ovulation. Washing sperm involves getting the most concentrated and mobile sperm from the semen sample.

The aim is to get the sperm as close to the egg as possible. The closer the sperm is to the egg, the easier it is for the sperm to fertilise the egg. By injecting the sperm, it doesn't have as far to travel as it does after ejaculation. IUI is sometimes used before moving onto other fertility treatments, such as IVF. This is because of its lower cost and simplicity.

#### In vitro fertilisation (IVF)

IVF is a process where fertilisation of the egg and sperm occurs outside of the body. The fertilised egg is then implanted into the uterus. The process involves stimulating the ovaries to produce multiple eggs. Egg collection involves using an ultrasound-guided probe with a needle attached. The eggs are then fertilised by sperm in a laboratory to create an embryo. An embryo is then implanted into the uterus. If more than one embryo has resulted from fertilisation, they are usually frozen. You can use the extra embryos 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. Pregnancies are usually low risk. But having endometriosis can increase the chance of some complications. These complications can include:**

**Placenta previa:** A condition that occurs when the placenta is low in the uterus, covering all or part of the cervix.

**Miscarriage:** A miscarriage is the loss of an embryo or fetus before the twentieth week of pregnancy (after this it's a stillbirth). Miscarriages are a common occurrence, with one in five pregnancies resulting in miscarriage.<sup>13</sup> Some studies have shown an increased risk of miscarriage in people with specific types of endometriosis.<sup>14</sup>

**Preterm birth:** A preterm birth (also known as a premature birth) is a baby born before 37 weeks of pregnancy.

**Preeclampsia:** A complication during pregnancy that causes high blood pressure and protein in the urine. If your doctor believes you are at high risk of developing preeclampsia, aspirin and calcium supplementation during the pregnancy can decrease these risks.

Pregnancy often makes your endometriosis symptoms improve or disappear altogether. This is because progesterone levels increase during pregnancy.

Symptoms rarely get worse during pregnancy as your uterus expands. If you suffer from 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.



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## What other conditions are associated with endometriosis?

Endometriosis can also be the cause of or associated with other conditions. We have included some information on these conditions in our patient guide.

### Adenomyosis

Patients 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 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, putting pressure on your lower abdomen. 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
- > heavy 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 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 are closely linked and share similar symptoms. Bladder pain syndrome was previously (and sometimes still is) referred to as interstitial cystitis. Patients have often been misdiagnosed with one condition when they had the other. It's also not uncommon for patients to have both conditions. Research suggests that people with endometriosis have four times the risk of developing bladder pain syndrome.<sup>15</sup>

This is a chronic bladder condition that often causes chronic pelvic pain, bladder pressure and bladder pain. You may also experience an urgency to urinate and a need to urinate a lot more often. Some patients are at higher risk of developing bladder pain syndrome, including those with pelvic floor dysfunction, bladder trauma and chronic pain conditions.

Bladder pain syndrome is diagnosed based on patient history and by excluding other possible causes of the symptoms. Your GP, gynaecologist, urologist or pain specialist can make this diagnosis. A urine test will be needed to exclude infection, and often a cystoscopy (camera inside the bladder).

Treatment of bladder pain syndrome involves many different aspects. Some of the ways to treat it include:

- > modifying your diet
- > stress reduction
- > pelvic 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 patients that have both conditions. PMDD and endometriosis affect you differently around period time. 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). Patients will often experience a mix of physical and emotional symptoms seven to 10 days before their period. Unlike depression, the symptoms go away as soon as your period starts. 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)
- > bloating
- > breast tenderness.

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.

Diagnosis involves your doctor looking at your medical history and assessing your symptoms. You should keep track of your symptoms in a diary. Having symptom-free periods during your period and ovulation is an indicator that you have PMDD. Other disorders, such as depression, don't stop during your period or ovulation.

There is no cure for PMDD. 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.

High dose Vitamin B6 has also been proven to be helpful. Other treatments can include medications to stop the hormonal cycle, such as the pill, and antidepressants which can be used just at the time before your period.

Talking to your friends and family about this condition may help them to support you better.



## Polycystic ovary syndrome (PCOS)

**Endometriosis and PCOS are very different, but they are both common conditions and share similar symptoms. It's also possible to have both conditions at the same time. Research has shown that if you have PCOS, you're at a higher risk of developing endometriosis.<sup>16</sup>**

PCOS affects eight to 13 per cent of women globally.<sup>17</sup> It's a hormonal condition resulting from higher-than-normal levels of male hormones (androgen). As a result, your ovaries develop many tiny fluid sacs (follicles) that often fail to reach maturity. If these follicles fail to reach maturity, they are unable to produce eggs for fertilisation. These tiny fluid sacs are also known as cysts and are how the condition obtained its name ('polycystic' means 'many cysts').

Although it's not known what causes the condition, genetics is considered a risk factor. You have a 50% chance of developing PCOS if your mother, aunt or sister has the condition. Hormones and lifestyle can also be a risk factor for PCOS.

An ultrasound alone showing polycystic ovaries is not enough to confirm a PCOS diagnosis. For a definitive diagnosis, you need to have at least two out of three of the following symptoms:

- > irregular or absent periods
- > symptoms of or blood tests showing excess androgen levels
- > polycystic ovaries on ultrasound.

Treatment involves long term management of the condition as there is no cure. The recommended treatment will depend on your symptoms. Patients with PCOS will benefit from maintaining a healthy body weight, as polycystic ovarian syndrome predisposes to the development of impaired glucose tolerance or diabetes.

PCOS also increases the chances of developing anxiety and depression, making it important that you watch out for any mood or behavioural changes.

Treatments for PCOS can include:

- > hormone therapy
- > lifestyle modifications (balanced diet and exercise – losing weight can help improve the condition)
- > assisted reproductive treatments to help you conceive.



## 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. It also means reduced wait times for diagnosis, treatment and/or surgery to ensure we achieve the best possible patient outcomes.

As part of our commitment to providing patients with centralised care, we have an interdisciplinary team in place. They will work together on all aspects of your care. But what is an interdisciplinary team? It's a group of health professionals that specialise in a particular disease or condition. They meet regularly to develop and manage a treatment plan for you based on your needs.





## The interdisciplinary team at the Julia Argyrou Endometriosis Centre at Epworth

You will meet a variety of health professionals during your treatment. Members of the interdisciplinary team will include people from the list of health professionals below.

<b>Endometriosis nurse coordinator</b>	<ul style="list-style-type: none"> <li>&gt; 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.</li> </ul>
<b>Gynaecologists</b>	<ul style="list-style-type: none"> <li>&gt; The centre has a network of credentialed endometriosis specialist gynaecologists. They will create a treatment pathway individualised to suit your specific diagnosis.</li> </ul>
<b>Colorectal surgeons</b>	<ul style="list-style-type: none"> <li>&gt; Specialise in diagnosing and treating diseases and conditions relating to the gastrointestinal tract.</li> </ul>
<b>Urologists</b>	<ul style="list-style-type: none"> <li>&gt; Specialise in diagnosing and treating diseases of the urinary system.</li> </ul>
<b>Medical imaging specialists</b>	<ul style="list-style-type: none"> <li>&gt; (or radiographers/radiologists/sonographers) Responsible for conducting different imaging tests needed to diagnose or treat your condition.</li> </ul>
<b>Pain physician</b>	<ul style="list-style-type: none"> <li>&gt; Will provide options for managing any ongoing pain. They will advise you on pain relief options to best manage your symptoms during treatment.</li> </ul>
<b>Nurses</b>	<ul style="list-style-type: none"> <li>&gt; A variety of nurses will support you and your family through the different stages of your care.</li> </ul>
<b>Dietician</b>	<ul style="list-style-type: none"> <li>&gt; Offers guidance and support in managing nutrition-related problems caused by your condition and/or its treatment.</li> </ul>
<b>Pelvic physiotherapist</b>	<ul style="list-style-type: none"> <li>&gt; Helps you to increase and optimise function of the pelvic floor muscles. Can also create a tailored exercise program and help manage fatigue and pain.</li> </ul>
<b>Exercise physiologists</b>	<ul style="list-style-type: none"> <li>&gt; Specialise in exercise and movement to manage and prevent many health issues and conditions.</li> </ul>
<b>Social worker</b>	<ul style="list-style-type: none"> <li>&gt; Provides practical support and advocates for the needs of you and those closest to you. Can also connect you with support groups.</li> </ul>
<b>Psychologist/psychiatrist/counsellor</b>	<ul style="list-style-type: none"> <li>&gt; Provides emotional support after your diagnosis and during treatment. They can also perform pain psychology treatment.</li> </ul>
<b>Clinical research coordinator</b>	<ul style="list-style-type: none"> <li>&gt; Can help you enrol in a research study and organise your research assessments, should you choose to participate.</li> </ul>

## 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 for the first few years. What you need to watch out for in your teen is if their period becomes heavy or painful. Are they taking time off school, or they can't take part in sports or other activities? Then it's time for further investigation.

It was once thought to be rare for adolescents to have endometriosis. This isn't the case now. A 2017 study showed that up to 80% of teens with chronic pelvic pain (that wasn't responding to medication) had endometriosis.<sup>18</sup> The normalisation of period pain and the belief that teens can't have endometriosis contribute to the long delay before diagnosis.

One of the greatest risk factors for teens when it comes to endometriosis is genetics. If a mother (or another immediate family member) has endometriosis, the chances for teens to develop the condition increase significantly. Awareness is important and watching for the signs can help save your teen years of mismanagement of the condition. Endometriosis is often progressive and can cause physical, emotional and financial distress. Early diagnosis and management lead to better outcomes for patients.

Is your teen not responding to medications? Are they suffering from chronic pain that has lasted for three to six months? If you answered yes, then it's time to come and see one of the gynaecologists at our centre that specialises in endometriosis.

By getting a definitive diagnosis, your teen can start early treatment. This will help to manage their symptoms and prevent the progression of the condition. This means they can begin to lead a normal teenage life again.



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## Scientific and 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 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.

Scientific research can be:

- 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.

The main aim of clinical research is to see if discoveries made during the research phase are better than the current treatment options.

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 patients to gain access to the latest treatment options. Participation leads to advances in research, better treatments, and better patient outcomes. 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](http://Epworth.org.au/juliaargyrouendocentre).

When deciding if you want to take part in research or a clinical trial, you need to be aware of 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 a Research Governance Office. 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.

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## Clinical registries

**A clinical registry is a database that collects health information from patients. The data collected comes from patients with the same or similar conditions to endometriosis. Registries collect data from patients over a set time and track their care. The types of information collected can include risk factors, response to treatment and outcomes.**

Clinical registries benefit the wider research and healthcare community. Data sharing and collaboration across endometriosis centres and research laboratories will help to drive research findings from the laboratory into practice to benefit patients.

Clinical registries may also assess the quality of care patients are receiving. As with clinical trials, clinical registries need to pass a reviewal and approval process by an HREC and a Research Governance Office. You do not have to share your data with clinical registries. Any information you share will have identifying information removed and remain confidential.

For more information, please contact our research team on **03 9516 2434** or at **[EHEndocentre@epworth.org.au](mailto:EHEndocentre@epworth.org.au)**.



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