



Getting a diagnosis

This factsheet is for anyone seeking a diagnosis of endometriosis. It explains how endometriosis is diagnosed and the scans and tests you may have. Included in this factsheet is advice on how to get the best out of your GP appointment, how to prepare for an endometriosis consultation, and how to get a second opinion.

Where to start?

The first step to getting a diagnosis is to visit your GP. A GP cannot diagnose endometriosis for certain, but they can offer you treatment to help with your symptoms. Your GP can also give you a referral to a gynaecologist to investigate your symptoms further.

How is endometriosis diagnosed?

The only way to be certain you have endometriosis is to have an operation called a laparoscopy, and a biopsy. This is known as a definitive diagnosis. During a laparoscopy the surgeon will use a small camera called a laparoscope to look inside your abdomen (tummy) for signs of endometriosis. The surgeon will then take a small sample of tissue for analysis. This is known as a biopsy.

Endometriosis does show up on some scans. However as not all endometriosis shows up on scans you can still have endometriosis and have a negative scan result.

Your endometriosis may be on your ovaries, fallopian tubes and other pelvic organs like the bowel or bladder. In rare cases, endometriosis can also be found outside the pelvis, such as the in the chest.

There are four different types of endometriosis and it's possible to have more than one type. The different types refer to the location, amount and depth of endometrial lesions. You may be diagnosed with:

Peritoneal (superficial) endometriosis - is found mainly on the pelvic peritoneum – a thin film that lines the inner surface of the pelvis and surrounds the pelvic organs.

Ovarian endometriosis (endometrioma) – is when endometriosis cysts are found in the ovaries.

Deep endometriosis - is found in locations such as the bladder, bowel and recto-vaginal septum (tissue separating the vagina and the rectum). The lesions of endometriosis are at a deeper level invading the pelvic peritoneum.

- is when endometriosis is found outside of the pelvis, such as the thorax (chest) and caesarean scars.

Other scans and tests

Endometriosis symptoms can vary from person to person. They can also vary depending on where the endometriosis is in your body. You may have tests and scans to look for other conditions or take a closer look at affected parts of your body such as the bladder or bowel.

Endometriosis does not show up on all scans. You can still have endometriosis and have a negative scan result.

The test and scans you may have include:

Clinical investigation - your doctor will ask you questions about your symptoms and examine you. They may feel your tummy or ask to examine your vagina

Urine sample - testing your pee to look for infection

Ultrasound scan - uses high frequency sound waves to make images of inside the body.

Trans-vaginal ultrasound - this test uses ultrasound technology to look more closely at your internal organs. A probe is placed inside your vaginal and transmits images to a computer.

Magnetic resonance imaging scan (MRI) uses magnetic fields and radio waves to make images of the inside of the body. An MRI Scan can be helpful to look for deep endometriosis affecting organs such as the bladder or bowel.

What will happen at the appointment?

Your GP will ask you questions about your symptoms. They may also perform a clinical investigation which will involve feeling your tummy and may ask to examine your vagina.

Remember you can always take someone with you to the appointment or ask for a chaperone when having an examination. If you don't feel comfortable being examined you can refuse it.

Our [consultation questionnaire](#) gives examples of the types of questions your GP might ask. You can fill this in beforehand to help you answer questions in your appointment.

Explaining your symptoms

Symptoms vary from person to person, some may have severe and debilitating symptoms, others may have no symptoms at all. Symptoms are not always related to the location, amount or the type of endometriosis. It's also important to know that endometriosis symptoms can also be symptoms of other health conditions. We recommend that you speak to a doctor if your symptoms are interfering with day-to-day life.

Common symptoms include:

- Pelvic pain
- Painful periods that interfere with everyday life
- Heavy menstrual bleeding
- Pain during or after sex
- Painful bowel movements/when having a poo
- Pain when urinating/peeing

- Difficulty getting pregnant – up to 70% of those with endometriosis will be able to get pregnant naturally
- Fatigue, with one or more of the above symptoms

Many with endometriosis also experience significant bloating around the time of a period. However, bloating can also be common for those without endometriosis and bloating that does not go away can be a symptom of other health conditions.

Having endometriosis can significantly impact mental health and wellbeing.

With treatment, many of these issues can be addressed, and the symptoms of endometriosis made more manageable. The main ways to manage and treat endometriosis are, pain management, hormone treatments and surgery. Sometimes it can take time to find a treatment that suits you and response to treatment can vary, please keep speaking to your doctor.

Our [symptom checker](#) is designed to check for common endometriosis symptoms and support you in seeking medical advice and our [pain and symptoms diary](#) allows you to record how your symptoms are affecting your everyday life. It is important that you share as much information as possible about your symptoms with your doctor.

How can my GP help?

Your GP can check you for infections and arrange for you to have a scans and tests to investigate your symptoms. They may look for or try to rule out other conditions such as polycystic ovary syndrome (PCOS), Heavy menstrual bleeding (HMB), irritable bowel syndrome (IBS) or fibroids. Your GP can help with symptom management including prescribing painkillers. They may also start treatment with the pill or other hormone treatments.

If your symptoms do not improve with treatment, you can ask for a referral to a gynaecologist or an endometriosis specialist.

How do I get a referral?

You can ask your GP for a referral to an endometriosis specialist centre. Use this list of [endometriosis treatment centres](#) to find a centre near you.

The referral pathway for endometriosis is outlined in the National Institute for Health and Care Excellence guidelines for endometriosis. These are evidence-based recommendations for health and care in England. These guidelines have been adapted for use in Scotland and Wales.

The guidelines show how care should be managed if endometriosis is suspected or confirmed. They list the signs and symptoms that show there is a medical reason to be referred to a specialist, such as a gynaecologist.

Referral to gynaecology

Gynaecologists specialise in the treatment of health conditions affecting women or those assigned female at birth. In England and Wales Your GP will refer you if:

- initial treatment is not effective, is not tolerated or is contraindicated, **or**
- you have symptoms of endometriosis which have a detrimental impact on activities of daily living, **or**
- you have persistent or recurrent symptoms of endometriosis, **or**
- you have pelvic signs of endometriosis, but deep endometriosis is not suspected.

Additional investigations, such as ultrasound and referral to gynaecology (if necessary), should happen alongside each other and in combination with initial treatment to prevent delays in diagnosis and access to treatment.

In Scotland you will be first treated by your GP who will aim to manage your pain with medication such as paracetamol or non-steroidal anti-inflammatory drugs (NSAIDs). You may be given pain relief alone or in combination with hormonal treatment.

If after 6 months your symptoms do not improve with treatment because it does not provide adequate pain relief or is not effective, not tolerated, or is not appropriate, you will be referred to gynaecology.

In Wales your GP will refer to endometriosis nurse specialist or specialist counsellor for support and advice. Your GP will also treat you for a period of 3 months with pain with medication such as paracetamol or non-steroidal anti-inflammatory drugs (NSAIDs).

You may be given pain relief alone or in combination with hormonal treatment. After 3 months you will be referred to gynaecology if your symptoms do not improve with treatment because it does not provide adequate pain relief or is not effective, not tolerated, or is not appropriate, you will be referred to gynaecology.

Referral to an endometriosis specialist centre

Endometriosis specialist centres are gynaecology teams that have been accredited by the British Society for Gynaecological Endoscopy. They hold specialist expertise in the treatment and care of endometriosis. You will be referred to an endometriosis specialist centre if you have:

- endometrioma (ovarian endometriosis). Or
- deep endometriosis involving the bowel, bladder or ureter, or
- endometriosis outside the pelvis - this is rare but can occur in places like the chest or other areas of the body

Young women or people aged 17 and under with suspected or confirmed endometriosis should be referred to a paediatric and adolescent gynaecology service or specialist endometriosis service (endometriosis centre) for further investigation and management.

Use this list of endometriosis treatment centres to [find a centre near you](#).

How can I prepare for my appointment with the consultant?

In your consultation your doctor will ask you about your symptoms and suggest scans and tests and possible treatment options. Read through the information you prepared for your GP and update it if necessary. This will help you share important information to your doctor. Our [consultation questionnaire](#) gives examples of the types of questions your doctor might ask. You can fill this in beforehand to help you answer questions in your appointment.

Think about the questions you want to ask before the appointment. You can write them down questions as well as listen to the doctor. Some questions you may want to ask include:

- What do you think is causing the symptoms?
- What scans and tests will I have?
- What will you be looking for?
- Will you want me to have a laparoscopy?

- How can I control my symptoms?
- What treatments do you suggest and why?
- Do you think my fertility is affected?
- Are there any other options that I need to consider?

You can take notes during your consultation to help you remember what was discussed. You can also bring someone with you for support and take notes so you can concentrate on talking to your consultant.

Getting a second opinion

If you are finding it difficult to manage your symptoms you can talk to your GP. If you are not happy with the treatment they offer, you can ask to see another GP. This could be a GP in the same surgery, or you can change to a different practice. You can also ask your GP for a referral to a gynaecologist.

If you want a second opinion after your specialist consultation, ask your GP to refer you to another gynaecologist or endometriosis specialist.

How we can help

Seeking a diagnosis of endometriosis can be a daunting experience. If you're finding things difficult, we're here to help. Our trained volunteers, all with personal experience of endometriosis, can offer you the help you need to understand your condition and take control. We offer:

Quality information and advice on endometriosis

Emotional and practical support through our network of support groups, helpline, webchat, and online forum

Visit www.endometriosis-uk.org/get-support or Helpline: 0808 808 2227

Further information on endometriosis

[NHS England](#)

[NHS Inform Scotland](#)

Tell us what you think

You can give us feedback on all our publications by contacting us on information@endometriosis-uk.org

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