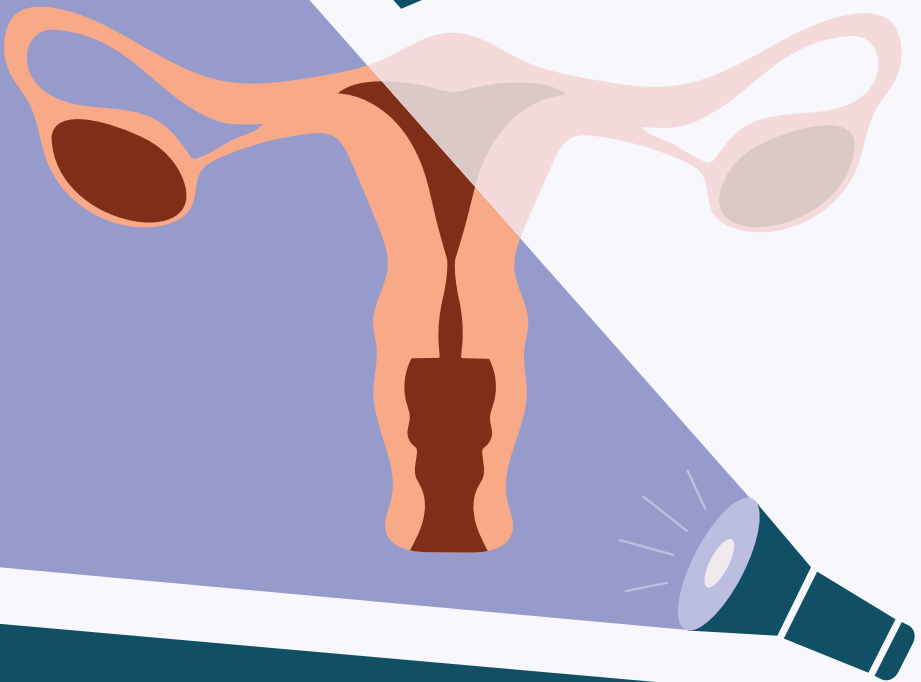


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Endometriosis and You

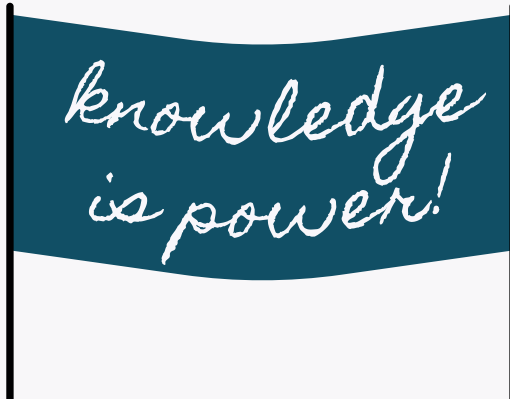


**A GUIDE TO DIAGNOSIS,
TREATMENT AND THE MENOPAUSE
IF YOU HAVE ENDOMETRIOSIS**

Endometriosis and You

A guide to diagnosis, treatment and the menopause if you have endometriosis

This booklet was written by Dr Louise Newson, menopause specialist, with contributions from Dr Catherine Taylor, GP and menopause specialist, and Vicki Shattock, who lives with endometriosis.



In the UK, around 1.5 million individuals are living with endometriosis, but many people know very little about the condition. Symptoms can be hard to live with but often improve with the right treatment, so it's really important to get a diagnosis and a management plan that's right for you. It can sometimes take a long time to get a diagnosis, and if you're entering the perimenopause or menopause, you might feel unsure about whether you can, or can't, take HRT.

In this booklet, we take you through the symptoms of endometriosis, the treatment options available, and what you need to know about the menopause and HRT.

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What is endometriosis?

Endometriosis is where cells very similar to the cells lining your womb are found in other areas of your body, which can often cause symptoms such as pain. The lining of your womb is called the endometrium. When similar cells are found elsewhere, this is endometriosis.

Patches of endometriosis are commonly found within your pelvis, for example, on your ovaries, fallopian tubes, on the outside of your womb, or on your bladder or bowel. In around 10% of cases, there are patches of endometriosis further away, such as on your lungs.

The lining of your womb responds to the hormones released from your ovaries during your menstrual cycle. The cells build up and cause thickening for half of the month, then there is a change in hormones and the lining of your womb sheds – this is your period.

The cells that line your womb have somewhere to go and can leave your body (a normal period), but the endometriosis cells lying elsewhere have nowhere to go, often causing pain and inflammation and over time, scar tissue can form.

Adenomyosis is where you have tissue similar to endometriosis inside the muscles of your womb. This is a separate but related condition.

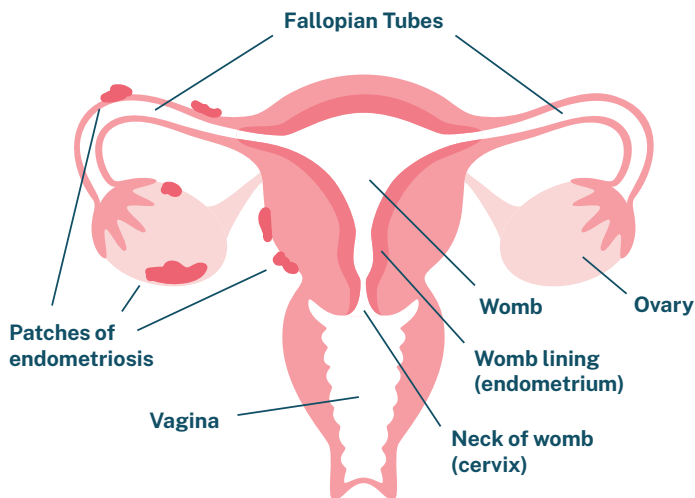
Endometriosis can be quite mild, with one or two small patches in one area of your body, or you might have lots of patches over different organs. These can be on the surface of your organs, known as superficial endometriosis, or they can go deep into your tissues, known as deep infiltrating endometriosis. Endometriosis can grow and spread over the years.

What causes endometriosis?

The exact cause isn't known, and it could be down to several factors at once, such as your genes, the environment, your immune system and inflammation. There's no way to prevent it and it's not caused by anything you have or haven't done.

Good to know:

Endometriosis is not an infection so you can't pass it on to anyone else, and it is not cancer.



What are the symptoms of endometriosis?

Symptoms vary, and no two individuals have exactly the same experience. Most people with endometriosis have heavy, painful periods from the time their periods start, and they tend to get worse over the years (unless they're taking the contraceptive pill which often eases the symptoms).

The symptoms tend to be linked to your menstrual cycle, coming on in the few days before and during your period, then calming down again. Some have symptoms throughout the month.

The main symptoms are:

- Painful, heavy periods
- Pain in your pelvis even between periods
- Pain during or after sex
- Pain when you pass urine and/or have a bowel movement
- Feeling very tired all the time (fatigue)
- Difficulty getting pregnant

There can be other symptoms too, such as irregular bleeding, pains in your back, chest or legs, and feeling low in mood.

Understand what's normal and what isn't

It's quite common to have some pain or aching around your pelvis during your period. It's **not** normal to have so much pain and bleeding that you have to miss work, or you can't get on with the things you like doing such as socialising or going to the gym. You shouldn't have to change your tampons or pads more than about every two hours, you shouldn't have a lot of pain elsewhere in your body, and you shouldn't feel sick or pass out during your periods. Not everyone with these symptoms will have endometriosis, but it does affect one in ten people who have periods.

If your periods are affecting your quality of life and your ability to do things, speak to your doctor.

Endometriosis is quite unusual in that the severity of the symptoms doesn't always match the extent of the disease. So, you might have only a few small patches of endometriosis but be in a lot of pain. Or, you might have very widespread endometriosis but have very few symptoms. Sometimes people only discover they have endometriosis when they're having tests for something else, for example, if they're trying to get pregnant.

Most individuals with endometriosis live a healthy and active life, but for some, it can have a major impact on their emotional and physical health. It can make you feel very tired and lacking in energy, you might feel down, frustrated and isolated, and the condition can sometimes cause infertility. The pain from endometriosis can, at times, stop you doing things and can affect work, your social life and your relationships. That's why it's important to be aware of it, to get a diagnosis and plan with your health professional of how to manage it.

Getting a diagnosis

There are a number of tests and scans your GP can request to find out if you might have endometriosis.

Laparoscopy

The gold standard route for a definitive diagnosis of endometriosis is with a laparoscopy. This is where a surgeon looks inside your pelvis using a thin, flexible tube with a light and a camera on the end (called a laparoscope) which they insert through small cuts in the skin of your abdomen. This is done under a general anaesthetic.

The surgeon might treat patches of endometriosis there and then, or they might do a biopsy, where they remove some tissue to be looked at under a microscope to give them further information.

A laparoscopy isn't a perfect test and it's possible to miss endometriosis (if the cells are microscopic or the surgeon is inexperienced) but at the moment it's the best tool available.

Other tests

It's unlikely that you will be referred for a laparoscopy straight away as it involves surgery and a general anaesthetic. There is no one simple way to get a diagnosis before that stage, but other tests can be useful for getting an idea of what's going on.

- Abdominal examination – where the doctor feels your tummy area
- Internal examination – where the doctor looks and sometimes feels inside your vagina
- Blood tests
- Ultrasound scan of the pelvis and abdomen
- CT or MRI scan

Scans can be enough to identify adenomyosis (endometriosis inside the walls of the womb), but further tests may be needed to confirm it.

Problems getting a diagnosis

It can take a long time to get a diagnosis – on average it takes around seven years – and there are a number of possible reasons why.

- The symptoms vary from person to person and can be quite general, such as feeling tired or depressed, so it's not obvious what's causing them.
- The symptoms can look like other conditions such as IBS (irritable bowel syndrome).
- Sometimes people have more than one condition at once, making a diagnosis more challenging.
- There is no simple test that makes diagnosis straightforward.
- There's an expectation and acceptance that periods can be heavy or painful, so it might not get mentioned and doctors might not investigate it.
- Most people either haven't heard of endometriosis or don't know much about it. Even GPs, who have very broad knowledge of a huge number of conditions, won't necessarily have specialist knowledge of endometriosis.

The pill is helpful for managing symptoms but....

If you have heavy or painful periods, your doctor might prescribe the oral contraceptive pill, which often makes your periods much lighter and less painful. This is a valid treatment for managing heavy periods, but on the flip side it can mask underlying endometriosis, meaning you might not know you have endometriosis until you stop taking the pill. It's helpful for you and your doctor to be aware of this.

If a diagnosis of endometriosis has already been made, or is suspected, the oral contraceptive pill can be a useful part of the treatment. Sometimes the pill is prescribed for a trial period of time to see if symptoms improve, if they do, it can indicate that there might be endometriosis present and your doctor might refer you for further investigations.

It's quite common to have to see multiple health professionals before you find out what's going on. Even gynaecologists can miss endometriosis if it's not their specialist area.

Unfortunately, sufferers are sometimes made to feel like 'it's all in your head' or 'you just have heavy periods'. This can be really stressful and impact on your mental health as well as eroding your trust in health professionals.

Most professionals really want to help. Make sure you're doing your part by keeping track of your symptoms and communicating them clearly, and find out as much as you can about endometriosis so you know the signs and treatment options available.

Tips for getting a diagnosis

Keep a pain and symptom diary. The more information you can give your doctor, the more likely they are to recognise what's going on. Keep a record of your periods and any symptoms you have. Be as detailed as possible, for example, note how heavy your periods are, if you have any pain, where in your body you felt it, how bad it was, and any other symptoms such as tiredness or bowel problems. You can download a pain and symptom diary from www.endometriosis-uk.org. If you're showing signs of perimenopause or menopause, you can also track all your hormone related symptoms and periods using the free balance menopause support app from www.balance-menopause.com/balance-app/.

Ask for a second opinion. If you feel you're not making progress with your GP or healthcare professional, you can ask for a second opinion. You should be able to see another GP or clinician in the same practice who may have a special interest in 'women's health'.

Ask to see a gynaecologist who specialises in endometriosis. If you or your GP wants you to see a specialist, ask if your GP knows of a gynaecologist with a special interest in endometriosis. You can find out about specialist centres and health professionals from the [British Society for Gynaecological Endoscopy](http://www.bsg.org.uk).

See a specialist privately. If you need more specialist care and you have the funds available, you can see a specialist gynaecologist privately. You may be able to have tests privately and still have treatment on the NHS, as the specialist can write to your GP advising a management plan.

Don't give up! It can be really frustrating and isolating having to go through various health professionals and push for tests, especially if you feel you're not being taken seriously. Don't give up. It's really important you find out what's going on and remember there are many doctors who do want to help.

"There's peace in getting a diagnosis, it means you and your doctor know that something is really there. Don't be confined to sitting at home every day. Play your part, do your research, keep a symptom diary and then push for answers, don't be pushed aside."

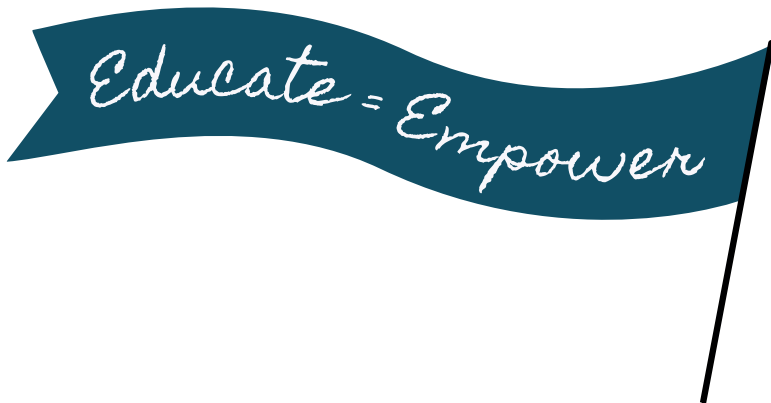
Vicki Shattock

Implications for fertility

Having endometriosis can cause fertility problems, although the reason why isn't always known. It affects fertility in 30-50% of the people diagnosed, but that also means that more than half *are* able to get pregnant without any medical help at all.

If endometriosis does affect your fertility, there are usually options and chances of pregnancy can improve after surgical treatment to the endometriosis by laparoscopy. IVF might also be an option for you if you don't manage to conceive naturally. This is something you can discuss further with your doctor and have a referral to a fertility clinic if necessary.

You can get more information and support about fertility from www.fertilitynetworkuk.org and www.fertilityfriends.co.uk



Treatments for endometriosis

Treatments generally aim to manage endometriosis and the associated symptoms, and they can make a big difference. Which treatments are suitable for you will depend on your age, whether you would like to become pregnant in the future, how extensive the endometriosis is, your symptoms, and how much they are affecting you.

You have the right to be involved in your treatment decisions

The treatments you have should be a joint decision between you and your health professionals. You don't have to have any treatments you don't want. Ask questions and make sure you know all your options – and their pros and cons – before you make any decisions. Take your time to think things through, there's usually no rush.

Different options are right for different people. You might have to try several options before you find what works for you, and this might change over time. Keep in touch with your health professionals about any changes in symptoms or side effects you're experiencing.

Treatments for endometriosis include:

- **pain relief**
- **treatments to control your hormones**
- **surgery.**

Pregnancy does not cure endometriosis.

Some individuals are told that getting pregnant will put an end to their symptoms. This might be true while you are pregnant because your hormones no longer go through a monthly cycle. But pregnancy does not get rid of the endometriosis and the symptoms usually come back after you give birth and your menstrual cycle starts again.

Pain relief

There are different options for pain relief depending on what you need.

- Painkillers such as paracetamol for mild pain.
- Ibuprofen and other NSAIDS (non-steroidal anti-inflammatory drugs). For these to work, it is best to start taking them a few days before you expect your period or pain to begin. (Bear in mind regular use of NSAIDs can affect your stomach so you may require additional medication to prevent this).
- Codeine-based pain killers for more severe pain. These can cause constipation so they might not be right for you if you have bowel symptoms, and they can become addictive if relied upon heavily.
- Antidepressants. While mostly used to treat depression, they can help to reduce pain as well.
- TENS machines (Transcutaneous Electrical Nerve Stimulator machines). These are small machines with electrodes you stick to your skin which send electrical impulses into your body to relieve pain. Speak to your doctor before trying one because they are not suitable for everyone.

Make yourself comfortable

You might find some simple ways to make yourself more comfortable and relaxed when you are in pain. Heat or warmth can help. Try using a hot water bottle, heated wheat bags, or a hot bath.

See a physiotherapist. There are physiotherapists who specialise in pelvic floor health. They can give you exercises and techniques to strengthen and relax the muscles in your pelvis, as your muscles can tense up when you're in pain.

Seeing a physiotherapist can help reduce pain and support your bladder and bowel problems, which can all help your mental health. It can also be very helpful after surgery (see page 11).

Visit a pain clinic. Some hospitals and trusts have pain clinics which specialise in supporting people with long-term pain. Ask your GP if they can refer you.

“Your emotions can impact your physical health, and in turn your physical health can impact your emotions. If you're in pain, your body can tense up. Try yoga, Pilates and breathing techniques to relax your mind and body, you don't always need to reach for the painkillers.”

Vicki Shattock

Treatments to control your hormones

Endometriosis cells respond to your hormones, so medicines to regulate your hormones can help with symptom control. In simple terms, the hormone estrogen causes the cells to grow in the lining of the uterus wall. It causes the same thickening to cells inside the deposits of endometriosis. The hormone progesterone (or a progestogen) prevents the womb lining from thickening and keeps the cells thin and healthy, if it's present in enough quantities.

The following treatments are for people who are still having regular periods and not yet showing signs of perimenopause. They all work to stop or minimise your periods and amount of bleeding and pain:

- Combined oral contraceptive pill (known as 'the pill') containing estrogen and a progestogen, often taken on a continuous or 3-monthly basis.
- Progestogens – Mirena Coil inserted into uterus, oral medication such as Medroxyprogesterone (Provera), Norethisterone (Primolut), Dydrogesterone (Duphaston) or Depo-Provera injection.
- GnRH analogues, examples include Prostag injection, Zoladex, Synarel, block all sex hormones in your body. They are often used with 'add-back estrogen' to prevent the onset of menopause symptoms.

All of these treatments work to suppress symptoms but do not stop the endometriosis tissue from occurring or growing.

There is a myth that if a temporary menopause caused by GnRH analogues suppresses your endometriosis symptoms, surgically removing your womb and/or ovaries might be a good option for you. This isn't necessarily true because, even if your symptoms are suppressed, the endometriosis could still be growing elsewhere, and surgery might not solve the problem.

Surgery

If your endometriosis is more severe and other treatments have not helped enough with your symptoms, you and your doctor might discuss surgery. Surgery is the only way to remove the endometriosis itself. It can be done to remove any patches of endometriosis, or remove the organ or part of the organ where they are growing.

Be aware that surgery will only stop the symptoms caused by the endometriosis tissue you have removed. It can be hard to find all the patches of endometriosis, and if there are any left inside your body, it's likely that you will still have symptoms. All surgery can have risks, so make sure you discuss these with your doctor.

Laparoscopy

Surgery can be done with a laparoscopy (keyhole surgery) and the surgeon will cut away the areas of endometriosis. This is the gold standard treatment and should be done by a BSGE (British Society for Gynaecological Endoscopy) accredited surgeon. Burning or lasering the tissue is another option and this removes the surface of the cells but can leave some endometriosis behind, which may continue to grow and cause further issues and need for repeat surgeries.

Surgery to remove your womb (hysterectomy)

If you have endometriosis on your womb (uterus), you might be offered surgery to remove your womb, known as a hysterectomy. Many people go into an early menopause within about five years of a hysterectomy if their ovaries are not removed. If your ovaries are also removed at the same time, then you will be menopausal straight after the surgery surgery (known as surgical menopause).

Surgery to remove your ovaries (oophorectomy)

If your endometriosis is affecting your ovaries, then they might be removed. This is called an oophorectomy. Because estrogen is made by the ovaries, this operation will cause a sudden menopause. This is also the case if your ovaries are removed as part of your hysterectomy, even if they were not affected by endometriosis.

Take your time to decide if you want surgery

A hysterectomy is not the right operation for everyone and it's not a decision to take lightly. Hysterectomy and oophorectomy are irreversible and mean you would not be able to get pregnant naturally and may go into menopause earlier. Consider all the options and discuss things fully with your GP or gynaecologist to make sure you're happy with your decision.

What is a surgical menopause?

This term usually means a menopause brought on by a surgical intervention and would usually be permanent, as your body won't start producing hormones again if the ovaries have been removed. (If menopause symptoms have started due to medication, it would usually be called an 'induced menopause' and may be temporary or permanent).

With a surgical menopause, symptoms often come on suddenly and these can have a significant impact on your quality of life. So even though your endometriosis symptoms may have stopped, you might have to deal with another group of unpleasant menopausal symptoms instead, if left untreated.

Having the right type and dose of hormone replacement therapy (HRT) is essential as we will explain. This can improve menopausal symptoms and protect your health in the future.



Menopause, HRT and endometriosis

The menopause is when your ovaries stop producing enough hormones and your periods stop. For many, this process happens slowly and naturally over many months or years as your periods begin to change – a time known as the perimenopause. The perimenopause often starts in your early to mid-40's and the average age of the menopause is 51 (when periods have stopped for over a year). In some cases, it can start much earlier, and it is wrong to say that anyone is “too young” for the menopause.

Some people find their endometriosis flares up during the perimenopause because hormones tend to fluctuate more widely before they then start to decline, and these fluctuations can last for several years. Luckily, endometriosis after the menopause (more than a year after your last period or after surgery involving removal of the ovaries) is very rare because of the drop in estrogen. Over time, your endometriosis symptoms should disappear (although you might still have symptoms if you have scarring).

What are the symptoms of the perimenopause and menopause?

Some peri/menopause symptoms can be common experiences if you're living a busy life, like tiredness or headaches, so it's good to know what to look out for and take a moment to consider the role hormones might be playing.

Like endometriosis, your peri/menopause will be unique to you. You may sail through it and hardly notice anything, or you may feel like a completely different person and battle with a range of symptoms on a daily basis. Most will fall somewhere in between. Here are some of the common changes:

- A change in your periods, including the frequency, pattern or flow
- Hot flushes
- Night sweats
- Mood changes
- Anxiety or worry
- Fatigue and poor sleep
- Brain fog or poor concentration
- Loss of interest in sex or relationships
- Joint pains and muscle aches
- Hair loss and skin dryness
- Worsening migraines and headaches

The free **'balance' menopause support app** is a useful source of information about symptoms and is brimming with practical advice on how to alleviate them, and you can use the app to track your symptoms to understand more about your hormones.

- Genital symptoms, including vaginal dryness and soreness.
- Urinary symptoms such as needing to wee more often, leakages of urine and symptoms which feel like cystitis.

Future consequences of the menopause

As well as being aware of menopausal symptoms, it's important to know that a reduction in your estrogen levels after your periods finish is a permanent state, and this raises your risks of health problems in the future. Your risk of osteoporosis (bone thinning) increases, as does the risk of heart disease, such as heart attacks and strokes, along with the risk of type 2 diabetes and dementia.

Living well

There's lots you can do to help manage the impact of the perimenopause and menopause, including eating healthily, avoiding too much alcohol and caffeine, staying active, managing stress levels, sleeping well and doing things you enjoy regularly. There's more information on this in the booklet titled 'Living well through your perimenopause and menopause' and on the balance app.

Unfortunately, even if you're doing all the right things, many of you will still have peri/menopausal symptoms, and a higher risk of certain diseases in the future.

Consider taking HRT

HRT replaces the hormones your body is no longer making, namely estrogen, progesterone and testosterone. It's the most effective treatment for menopausal symptoms, and it also lowers the risk of heart disease and osteoporosis in the future, as well as other conditions such as dementia and type 2 diabetes.

Because of misunderstandings around HRT amongst the public and health professionals, individuals aren't always offered the treatment that would benefit them. This is even more the case with endometriosis. You may have been told HRT isn't suitable for you when in most cases it is.

If you have endometriosis, it's really important that you have individualised care and advice, ideally from a doctor who specialises in the menopause. You might need higher or lower doses of estrogen or progesterone, as well as testosterone, and these should be tailored to your individual needs.

Types and ways of taking HRT

There are different types and doses of HRT and different ways of taking it:

Estrogen

Estrogen is available to take through your skin (transdermal) via a sticky patch you change twice a week, or a gel or spray that you apply every day. It also comes in tablet form but through the skin is better as there's no risk of blood clots. People in their 30s and 40s often need higher doses of estrogen than those in their 50s and 60s, especially after a surgical menopause.

Progesterone

As well as estrogen, if you still have your womb (and sometimes even if you don't) you will need to take a form of progesterone to keep your womb lining thin and healthy. This will also suppress the growth of any endometrial tissue elsewhere. The safest type of progesterone is micronised progesterone, known as Utrogestan in the UK. This is identical to the progesterone naturally made in your body and is derived from the yam vegetable – you might hear it called 'body identical' progesterone.

You can take it orally as a capsule daily, or you can insert the capsule into your vagina at night time on alternate nights. Another way of having progesterone is to use the Mirena coil which is inserted into your womb and releases a progestogen slowly. This stays in place for five years and is particularly useful if you are still having periods, as it can cause periods to stop. It is also ideal if you need contraception as it provides both contraception and the progesterone part of HRT for 5 years.

It is preferable to take progesterone every day because it will continue to suppress any endometrial tissue in the body.

Some progesterone pointers if you have endometriosis:

You can take progesterone after a hysterectomy, and you might need to. Doctors sometimes believe that you don't need to take progesterone after a hysterectomy because the role of progesterone is to protect the lining of the womb from estrogen. This makes sense for most people after a hysterectomy, but if you have endometriosis, you might have womb-like tissue (endometriosis) elsewhere in your body. This can cause symptoms if you take estrogen, so you might still need to take progesterone to protect the endometriosis tissue, even if you've had a hysterectomy. Ask your surgeon if all the endometriosis tissue was removed. If they're not sure, then it's safer to take progesterone as well.

If you had a subtotal hysterectomy (where your cervix is left in place), you might have some womb tissue remaining within the cervix. If there is remaining womb tissue, then you might need to take a progesterone on a long-term basis. You can do a test called a

‘progesterone challenge’ to see whether this is necessary. This is where you take estrogen on its own for a month, then you also take progesterone for two weeks, to see if you have any bleeding. Bleeding will show that you do have some womb tissue left in the cervix, and suggests you do need to take progesterone.

Remember it's your choice, some people like the effects of taking progesterone as it makes them feel calmer and helps sleep. Others don't respond so well to progesterone, and it can cause PMS-like symptoms such as bloating and low mood. If you have been advised to take progesterone, try using a body identical option (which you could use vaginally) or you could opt for the Mirena if you still have your womb.

You can usually have HRT if you have endometriosis. Many doctors are hesitant to give HRT to people with endometriosis because they're worried the estrogen will encourage the endometriosis tissue to grow, but for most this can be well controlled. The hormones are given in a managed and continuous dose rather than fluctuating throughout the month, and you can take progesterone to minimise any adverse effects on the endometriosis deposits.

Testosterone

Taking testosterone, in addition to estrogen and progesterone, often helps improve your energy levels, bone and muscle strength, concentration and clarity of thought, and your libido.

Testosterone comes as a cream or gel that you rub into your skin daily. Most GPs don't prescribe this yet for the menopause, as there isn't a licence for it to be used for this reason. You may need to obtain testosterone from a menopause specialist, and you may need to pay for it. Testosterone should only be provided via a doctor and your blood hormone levels should be checked after 3 months and then at least yearly after that.

Vaginal estrogen for genitourinary symptoms

If you have vaginal and/or urinary symptoms such as vaginal dryness or soreness, leaks of urine, needing to wee more frequently, or more infections like thrush or UTIs (urinary tract infections), you can use estrogen directly inside your vagina. It's available as a pessary (a small tablet you insert into your vagina), or as a cream or gel. Alternatively, you could use a flexible, silicon ring that is placed inside your vagina, which works for about 90 days, called an Estring.

Vaginal estrogen is very safe and can be taken long-term, alongside HRT, and it should not have adverse effects on endometriosis tissue in other areas of your body.

There is also another hormonal vaginal treatment called Intrarosa, a pessary that contains DHEA. This converts to both estrogen and testosterone and is also a safer option.

Are there any risks with HRT?

For the vast majority of people taking HRT, the benefits outweigh any risks.

Breast Cancer

It can be common for people to worry about breast cancer when taking HRT. Most types of HRT do not actually increase the risk of breast cancer. The only type that might have a very small risk is HRT containing both estrogen and the older, synthetic types of progestogen. And this is only if you're over 51 years. The risk is related to the type of progestogen in the HRT and not the estrogen. Taking micronised progesterone (the body identical progesterone) has **not** been shown in studies to have a statistically significant increased risk of breast cancer.

Even if you're over 51 years and take the synthetic type, such as combined HRT patches, the risk is very low. In fact, the risk is less than the increased risk if you drank a couple of glasses of wine each night or the risk of being overweight. And it's worth bearing in mind that this small risk has never been shown to increase the risk of death from breast cancer. The risk of breast cancer when using the Mirena Coil has been shown to be less than that of other synthetic progestogens.

If you've had a hysterectomy and are taking estrogen without a progestogen, you actually have a **lower** risk of developing breast cancer than someone who doesn't take HRT at all.

Blood clot

If you take estrogen as tablets, you have a small increased risk of developing a clot in your veins or of having a stroke, especially if you're very overweight, have had a clot or stroke in the past or are a smoker. Remember, there is no increased risk of clot if you take the estrogen through the skin in a patch, gel or spray.

Bottom Line

There is a lack of high-quality research exploring the effects of HRT in people with endometriosis in particular. It's possible that the estrogen could stimulate the tissue in some cases, but for most, once their endometriosis and menopausal symptoms are managed with HRT, the endometriosis doesn't come back and the benefits to their quality of life and future health far outweigh any risks.

Living with endometriosis and the menopause

Endometriosis can affect you in many ways. Throw the menopause into the mix, and you may feel overwhelmed, emotional and at a loss on some days. This is normal, just take each day at a time and think about ways you can help your emotions and wellbeing.

"As I live with both endometriosis and surgical menopause, I realise the detrimental impact this can have on your mental health, so it's vital to get as much support and guidance as possible and speak to people close to you about how it is affecting you."

Vicki Shattock

Wellbeing

Your mental health

The strain of trying to find out what's going on with your body, finding treatments that work for you, and issues around fertility can all make you feel anxious, confused, stressed or depressed, and lower your confidence and self-esteem. Talking to others, taking the right type of hormones and finding self-management strategies can really help.

Fatigue

Pain and other symptoms might mean you can't sleep well, and stress and worry can be tiring. Feeling very tired and low in energy can stop you doing the things you want to do and affect your work and quality of life. Treat your energy like a battery, you only have a certain amount. Prioritise the things you want to do and do those first, pace yourself, and make sure you have time to rest. Testosterone replacement can help energy levels if the struggle is ongoing.

Feeling isolated

If you're not feeling up to socialising, you've seen health professionals who don't seem to take you seriously, or you have friends, colleagues and loved ones who don't understand, endometriosis and/or the menopause can leave you feeling isolated. Talk to a trusted family member or friend and see page 21 for information on getting support.

Work and money

Pain and other symptoms can affect your ability to work. If you're employed and can't work for more than three days at a time, you may be entitled to Statutory Sick Pay (SSP) which

will be paid by your employer. You can also ask for flexible working conditions if you need days off only at certain times, for example, around your period. You may meet the criteria for a disability which means your employer has to make reasonable adjustments under the Equality Act so that you can continue working. Speak to your line manager, HR, or your Occupational Health team if your workplace has one, to discuss how endometriosis and the peri/menopause is affecting you at work

Sex and relationships

Living with endometriosis can put a strain on intimate relationships. Problems with work and money, socialising or simply doing everyday tasks, plus the stress of trying to find the right treatments or dealing with fertility issues or the menopause can all take their toll. No one wants to see their partner in pain and your partner might want to help but doesn't know how.

Endometriosis can also affect your sex life which can be frustrating for both of you. Sex can be painful or you may have long, painful periods, and your partner might be worried about hurting you. You might feel too tired or unwell, and both of you might feel guilty, either for expressing sexual needs or for not wanting to have sex.

While there is no magic solution, there are strategies you can try to strengthen your connection and communication with each other. For example, discuss ways your partner can support you practically and emotionally. This gives them a role in your life that they know will genuinely support you, such as discussing treatment decisions and coming to appointments with you.

Showing physical intimacy through touching, kissing and cuddling can reassure you both and bring you closer together. Communication is key. No one can know what another person is thinking or feeling, so talk to each other and let them know. Choose times when you have time and space, and if either of you feel too stressed, you can come back to the conversation later.

If you need some help understanding each other and finding ways forward, you can ask for a referral to a counsellor or therapist. Although it's not easy, coping with endometriosis and the perimenopause or menopause can make relationships stronger as you learn to communicate with each other. www.relate.org.uk is a good place to start for relationship support.

“You should be given a management plan including physiotherapy, mental health support and monitoring. Don't settle for just the painkillers. There is support available through the NHS. Do your own research, be your own advocate, and find out what's available.”

Vicki Shattock

Self-management

There are things you can do to manage the impact endometriosis has on your life.

Self-management courses

Self-management courses, known as Expert Patient Programmes, are courses led by patients who have become experts in managing their own conditions and can give you the tools to do the same. Find out more from [Self Management UK](#), or ask your GP about courses near you.

Complimentary therapies

Many people find complimentary therapies help with their symptoms, although there is not much research to back them up. It's always a good idea to see a registered, qualified practitioner, and let your healthcare professionals know about any you'd like to try in case therapies might interact with your medications, especially herbal remedies and supplements.

Some complimentary therapies include:

- acupuncture
- herbal remedies and homeopathy
- osteopathy
- reiki
- relaxation and stress management techniques
- reflexology
- yoga.

www.endometriosis-uk.org have more information about these therapies.

Dietary changes

Making changes to what you eat may help. You could ask to speak to a clinical nutritionist that has an interest in endometriosis for more advice.

Healthy choices

Take care of all aspects of your health. Avoid smoking and limit alcohol, try to get a good night's sleep and do things that make you feel better, such as yoga, outdoors activities, and other hobbies you find relaxing.

Acceptance

Rather than focussing on a cure, some people living with endometriosis find it helps to accept they have a condition and focus on managing it as well as they can. It's possible to feel optimistic about the future while accepting the present.

Find support

Around 1.5 million people in the UK are living with endometriosis so remember you're not alone and there are people who can support you. Culturally, we are not used to talking about periods, sex and sometimes even our emotions, but staying silent only adds to the feeling of isolation, hopelessness or embarrassment. Make sure you talk about what's going on for you so that you can feel understood, and it often helps reduce or dispel negative feelings.

Talk to your friends, family and partners. Talking to partners, friends and family can strengthen your relationships with them. Explain what's going on and how it's impacting you and if there's anything they can do to help. If you don't have friends or family you want to talk to, or they're not able to understand, there are professionals and support groups who are well placed to listen.

See a counsellor. Your GP should be able to refer you to a counsellor or therapist. There are different types of talking therapies that can help in different ways, including CBT (cognitive behavioural therapy). The British Association of Counselling and Psychotherapy is a good place to find a counsellor.

Find a support group, or start one. There are local support groups run by volunteers where you can meet other people affected by endometriosis. Talking to people who understand can be very helpful. You might be able to start one and support others too. Ask your GP, search online or visit www.endometriosis-uk.org who also have an online community.

your voice matters

Be your own advocate

It can feel unnatural or uncomfortable to ask for someone's time, attention and support. It can feel like you're somehow 'breaking the rules' by challenging an authority figure such as a health professional. It can be stressful knowing you might hear the word 'no'. Now is the time to change this. You have every right to ask for information, tests and treatment. This is your body and your health and no-one else has as vested an interest in it like you do. What you are asking for is legitimate and valid. If you are told 'no' or you're not getting the support you need, then you might need to try again or go elsewhere.

Make decisions about treatment with your doctor.

Guidelines from the General Medical Council and recommendations from NICE state how decisions should be made between a patient and doctor and specify that a shared decision making process should be used. This involves:

- encouraging the patient to take an active role in making decisions about their treatment
- taking into account what is most important to the patient, their expressed needs and priorities and treatment options are explained in light of these
- open discussion of the risks, benefits, and consequences of each treatment option, including doing nothing, with the acceptance that the patient's views can differ to the professional's
- allow time to answer questions and time to make decisions, making it clear that the patient can change their mind down the line
- come to a joint decision that is satisfactory to the patient

These conversations should include information about the various ways to take HRT and an explanation about how what's likely to happen if you do nothing, as well as the risks of any possible treatment. They should support you to come to a decision about what treatment you would like and respect your right to make that choice.



For better discussions with your doctor:

Do your own research and be prepared. Visit www.endometriosis-uk.org for more on endometriosis, a helpline and further places to get support. You can also view the medical guidelines on endometriosis from the National Institute for Health and Care Excellence. Read more about the menopause and HRT at www.balance-menopause.com and you may want to look at the [NICE guidelines](#) on managing menopause.

Keep a record of your symptoms to show a clear account of the range and severity and how they're affecting your daily life. You could use the [balance menopause support app](#) or complete the [Menopause Symptom Questionnaire](#) to do this. You can also use these tools to measure any improvement in your symptoms once you start a treatment. If you're considering systemic HRT or vaginal estrogen, learn about the options, find out the benefits and if there's any risks, and think what type you would prefer.

Plan the time you need to discuss matters adequately; you might want to ask for a double appointment or spread discussions out over separate appointments. Write comments or questions down if you're worried about forgetting in the moment.

Inform your doctor about what you are wanting to discuss prior to the appointment, this will ensure you get the most out of your consultation.

Know your rights as a patient. Doctors will be more likely to consider your views if you can show you are fully informed. Regarding your decision as 'unwise' is not enough of a reason for the doctor to refuse to prescribe the treatment for you, if you demonstrate you're fully aware of all the implications of that choice and have weighed up your decision carefully.

Be persistent but polite. If you do not get the desired outcome at the first appointment, try again another time. You can ask to see another doctor within your practice. Ask which member of the team has an interest in menopause or endometriosis and if there is no one with that interest, consider changing practices to one where there is. Ask if there is an NHS endometriosis and/or menopause specialist clinic in your area.

Find accredited endometriosis centres. [The British Society for Gynaecological Endoscopy \(BSGE\)](#) has information about accredited treatment centres where there are surgeons, gynaecologists and nurses who specialise in endometriosis. Specialist nurses can support you and your partner if you have severe or complex endometriosis.

Stay hopeful. Attitudes and awareness are changing among health professionals. The Royal College of Obstetricians and Gynaecologists are training more surgeons in laparoscopy, and patient groups are also making endometriosis better known.

“I didn’t set up a support group so that I could get support, but now that it’s there, I didn’t know how much I needed it. It’s so important to not feel alone. One in ten women have endometriosis and yet we don’t speak about it – you can be in a room full of women and no-one’s talking about it. Because there’s a lack of awareness, there’s a lack of support. We can change that.”


Vicki Shattock

Balance app and website

Free menopause support and information, including the balance app, films and podcasts at www.balance-menopause.com

 @balancemenopause

 @drlouisenewson

 menopause_doctor

 @balance-app

Endometriosis UK

www.endometriosis-uk.org

 @endometriosis.uk.org

 @EndometriosisUK

British Society for Gynaecological Endoscopy

Visit www.bsge.org.uk for a list of accredited endometriosis centres.

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