Midland Metropolitan Endometriosis Centre

Information and advice for patients

Gynaecology

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What is Endometriosis?

Endometriosis is a medical condition in which "endometrium like tissue" (lining of the womb) grows outside of it. This endometrial tissue can attach to other in the abdomen and pelvis, such as the ovaries, fallopian tubes, and intestines.

Endometrial tissue still acts as it normally would inside the uterus, thickening and breaking down each month in response to hormonal signals. However, since this tissue has no way to exit the body, it can cause inflammation, pain, and the formation of scar tissue.

What are the symptoms?

Symptoms vary from person to person. The amount of endometriosis present may not correspond to the severity of the symptoms. For example, you may have a small amount of endometriosis present, but have severe symptoms. The opposite is also true.

Typical symptoms include:

- ✓ Painful periods (Dysmenorrhoea)
- ✓ Painful intercourse (Dyspareunia)
- ✓ Chronic pelvic pain (Pain which has been going on for a long time, over 3 months)
- ✓ Painful bowel movements (Dyschezia)
- ✓ Pain on passing urine (Dysuria)
- ✓ Cyclical or premenstrual symptoms with or without abnormal bleeding and pain
- ✓ Chronic fatigue
- ✓ Infertility
- ✓ Pain in caesarean/surgical scars or a cyclical lump
- ✓ Back, leg or chest pain
- ✓ Family history

When should you see a specialist?

Referral may be indicated if:

- ✓ There is uncertainty of a diagnosis.
- ✓ A woman wishes for a referral.
- ✓ If there are fertility problems, you need a fertility specialist referral.
- ✓ If more complex/severe endometriosis is suspected (Like ovarian endometriosis cysts).
- ✓ If further medical or surgical management is required.
- ✓ Unsuccessful treatment with the GP in managing your symptoms

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The latest facts and figures about endometriosis:

- **1 in 10** women of reproductive age in the UK suffer from endometriosis.[1]
- 10% of women worldwide have endometriosis - that's **176 million worldwide**.[1]
- The prevalence of endometriosis in women with infertility be as high as to 30–50%.[2]
- Endometriosis is the second most common gynaecological condition in the UK.[3]
- Endometriosis affects **1.5 million women**, a similar number of women affected by diabetes.[4]
- On average it takes **7.5 years** from onset of symptoms to get a diagnosis.[5]
- Endometriosis costs the UK economy **£8.2bn** a year in treatment, loss of work and healthcare costs.[6]
- The cause of endometriosis is unknown and there is no definite cure.

Fertility

Should this be your main concern, your GP should do a referral to fertility services. The surgical treatment of Ovarian Endometrioma has an associated decrease of ovarian reserve and a small possibility of losing the ovary. If fertility is your main concern, you should have fertility assessment before surgery.

Current recommendation is to surgically treat mild to moderate endometriosis because improves the chances of spontaneous pregnancy, although consideration should be given to ovarian reserve.

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What to expect at the hospital/specialist centre?

You may see a general Gynaecologist, or if you are referred to an Endometriosis Centre, a Gynaecologist with a special interest in Endometriosis and/or an endometriosis Clinical Nurse Specialist (CNS).

What to expect when you see the clinician (Doctor or CNS):

- The consultation is likely to last approximately 30 minutes for a new patient
- They will take a history – ask about you your symptoms, the reason you have come to the clinic, including some intimate questions regarding any pain with intercourse
- They may wish to examine you – this will likely include an intimate examination, including a speculum / internal examination (similar to a smear test)
- You may be asked to complete a quality-of-life questionnaire
- You may have an ultrasound scan on the day, or have one requested if not already done
- You may be offered medication to help treat your symptoms
- You may be offered an operation, commonly a laparoscopy (key hole surgery to treat any endometriosis)
- Although some patients may prefer to see and be treated by a member of their own gender, our Trust does not offer this choice. A female chaperone is always present for any form of examination.

Consultations will be an opportunity for you to ask questions, which we encourage. We would recommend writing any questions down before you attend, so you can ensure all your concerns can be addressed.

Investigations

- An **ultrasound** scan is often arranged. This usually involves inserting an internal probe, gently inside the vagina. This will look at the womb and ovaries to look for anything that might be contributing to your symptoms. A female chaperone will always be present for this procedure.
- **Pelvic MRI (Magnetic Resonance Imaging)**, an MRI scan can be useful to for any deep endometriosis or adhesions affecting the bowel, bladder, or ureter. This is a much specialised test and only few patients need it.

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Treatment options

Pain killers:

Paracetamol & Non-steroidal anti-inflammatories (NSAIDS, e.g. Ibuprofen)
These can be used together, especially around the time of your period. If you are trying to conceive, NSAIDs are not recommended as they can interfere with ovulation.

Hormonal Treatments:

The aim of hormonal treatment is to stop or reduce the growth of womb lining tissue (endometrium), wherever it is located. This should help to reduce bleeding and pain.

However, not all women will experience amenorrhoea (no bleeding), and pain may persist.

**A summary table of contraindications and side effects to each type of hormonal treatment is seen below, (this list is not exhaustive).

Combined Oral Contraceptive Pill (COCP)

This may be taken in different ways:

a) As per package description, 21 days with 7 days break – Period may remain painful.
b) Tricycling – One tablet daily for three months and then 1 week's break, in which you will usually have a withdrawal bleed or 'mini period'- Usually more effective in pain control
c) Or continuous until breakthrough bleed occurs - take one tablet a day continuously without a break until bleeding happens for TWO days, then take 1 weeks' break and re-start the process again) Potentially the best for pain control. The benefit would be to have fewer periods and reduced symptoms.

Fertility may take up to three months to return to normal after stopping this type of treatment. Examples of the COCP include Microgynon©,
Rigevidon©, Yasmin©

Further Info: **www.nhs.uk/conditions/contraception/combined-contraceptive-pill/**

Endometriosis trends to recur after surgical treatment (10% per year). When acceptable we often combine surgical treatment with medical treatment (e.g. the progesterone only pill, hormonal coil) to prolong the benefits of surgery.

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Progesterone only contraceptive pill or the mini pill (POP)

This tablet is usually taken daily at the same time, and without a break between packets. Some patients do not have periods; others may experience irregular bleeding or persistent spotting. Fertility returns to normal immediately after stopping treatment. e.g. Cerazette©, Noriday©.

Further Info: **www.nhs.uk/conditions/contraception/the-pill-progestogen-only/**

Depo-Provera (The Depo injection)

This is a progesterone injection given every 12 weeks and also acts as contraception. You should be mindful that return to normal fertility may take up to one year.

Further Info: **www.nhs.uk/conditions/contraception/contraceptive-injection/**

Nexplanon (The Implant)

This is a small implant around the size of a hairpin, which is inserted into your upper arm. It works for three years, and also acts as contraception. Fertility returns to normal immediately after removal. Implant insertion and removal requires specific training, and is usually done by a Family Planning team, or other suitably qualified healthcare professional.

Further Info: **www.nhs.uk/conditions/contraception/contraceptive-implant/**

Levonorgestrel intrauterine system (IUS, also known as the hormonal coil)

This is a small plastic device that is carefully inserted into the womb and works for 5 years. It works by releasing a very small dose of progesterone hormone every day. It also acts as an effective form of reversible contraception.

Further Info: **www.nhs.uk/conditions/contraception/ius-intrauterine-system/**

Dienogest

Dienogest is a hormonal medication that can be used in the treatment of endometriosis. It makes the lining of the womb shrink. Dienogest is a tablet similar to the progesteroneonly-pill (the 'mini-pill'); **however it cannot be used as contraception**. Therefore, it is recommended that barrier contraception (e.g. condoms) is used while you are taking Dienogest. If you are diabetic you should monitor your blood sugars closely while taking Dienogest. This is because Dienogest can affect your ability to regulate your glucose levels.

You may stop having periods while taking Dienogest. For most women, menstrual cycles will return to normal within 2 months of stopping treatment with Dienogest.

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Gonadotrophin releasing Hormone analogue Analogues (GnRHa)

This is a medication that is usually given as an injection. It is designed to temporarily 'turn off' your ovaries, and suppress the hormones that cause endometriosis to grow. The treatment is licensed for up to 6 months, and reversible.

Your gynaecologist may discuss its use beyond 6 months (out-of-license); your doctor will recommend giving 'add back' Hormone Replacement Therapy (HRT).

The most common side effects are hot flushes, night sweats, insomnia, decreased libido, headaches, mood swings, vaginal dryness, decreased breast size, increased breast size, acne, muscle pains, dizziness, and depression. These menopausal-type symptoms usually disappear soon after treatment ceases.

Further Info: **www.endometriosis.org/treatments/gnrh/**

**Hormonal treatment summary table of contraindications

Treatment	Contraindications
Combined oral contraceptive pill (COCP)	• Body Mass Index above 35 • Taking certain antibiotics* • Epilepsy medications or St John's Wort • Smoker and age over 35 • Stopped smoking in the last year and are aged over 35 • Previous history of blood clots in legs or lungs • Poorly controlled hypertension • History of heart disease or stroke • Recent major surgery • Known thrombogenic disorder • Current or previous breast cancer • Liver disease • Migraines with aura • Systemic lupus erythematosus (SLE) with positive antibodies
Progesterone only contraceptive pill (POP)	• History of, or current breast cancer • Acute porphyria • Cautions: - Severe liver disease - Undiagnosed vaginal bleeding - Taking certain medications (i.e. for tuberculosis, HIV/AIDS or to control seizures.)

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Progesterone injectable	• Undiagnosed vaginal bleeding • History of /current breast cancer • Multiple risk factors for cardiovascular disease, such as: - Smoking - Diabetes - Hypertension - Obesity - Dyslipidaemias • Vascular disease • Heart disease • Severe liver disease
Levonorgestrel releasing intrauterine system	• History of OR current breast cancer • History of OR severe liver disease
Nexplanon Implant	• History of OR current breast cancer • History of OR acute porphyria
GnRH Analogues	• Undiagnosed vaginal bleeding
Dienogest	• Heart disease • Arterial disease • Severe liver disease • History or current blood clots in legs and lungs (VTE) • Diabetes with vascular involvement

Non-pharmacological treatments

✓ **Lifestyle interventions**

✓ **Acupuncture**
There has been limited research into acupuncture, however based on these data sets; no recommendation can be made for its use.

✓ **Exercise**
There is insufficient literature of its benefit for relieving endometriosis-related pain. However, exercise and activity are considered part of a healthy lifestyle in general.

✓ **Nutrition**
There is no particularly diet that can be recommended, but there is some evidence that diets which suit the individual patients are beneficial.

✓ **Mindfulness and Cognitive Behavioural Therapy**
There is a growing body of evidence supporting Mindfulness and Cognitive Behavioural therapy to improve chronic pain. These therapies can improve physical functioning, pain intensity and depression.

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✓ **Transcutaneous Electrical Nerve Stimulator machines (TENS)**
A TENS machine uses small electrodes attached to the skin and sends electrical impulses to the body. It is not painful, but may feel ticklish to some patients. It works by blocking the pain signals to the brain. There are no current studies which show if it works for endometriosis specifically, however there is currently a large amount of research looking into this. TENS may not be used in certain situations such as those with pacemakers or electrical implants, epilepsy, certain heart conditions or in early pregnancy.

✓ **Physiotherapy**
A physiotherapy assessment and treatment can be very beneficial helping to understand what exercises can be done, and how to do them in a safe manner despite your endometriosis related pain.

✓ **Pelvic Floor Physiotherapy**
Sometimes pelvic pain is partially related to problems with your pelvic floor muscles. A specialised pelvic floor therapy directed by a specialised physiotherapist can be very useful.

Surgical treatment

This is usually offered when it is required because of fertility advice, functional need or pain management. We have moved away from surgery as a diagnostic method.

Key terms:	
Peritoneum	Thin layer of tissue covering the internal organs.
Peritonectomy	Partial removal of the peritoneum.
Ureters	The tubes which drain your urine from the kidney, into the bladder.
Ureterolysis	Mobilisation of the ureters from adjacent tissues, adhesions, etc.
Ovarian cyst	Fluid-filled sac that develops on an ovary.
Cystectomy	Removal of the cyst.
Adhesion	Scar tissue.
Adhesiolysis	Removal of scar tissue.
Salpingectomy	Removal of a fallopian tube.
Oophorectomy	Removal of an ovary.

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If you are offered surgery

Often this will be a Laparoscopy (Keyhole surgery). This is an operation in which gas is used to inflate the abdomen and a small camera (1cm wide), is inserted into the abdomen, usually via the bellybutton. This allows the surgeon to inspect the pelvic organs in great detail and to diagnose endometriosis. Additional small cuts are made to the skin, around 0.5cm in size, to allow the surgeon to insert instruments to perform the keyhole surgery. The surgeon would then remove the affected areas or occasionally cauterise (burn) the affected areas.

On occasions open surgery might be needed. This is done via a larger cut through on the tummy wall, it can be done low transverse ('bikini line') or in the midline (usually from the belly button downwards). Surgery for endometriosis can be variable in its complexity. Surgery for severe endometriosis is often very complex, and sometimes requires input from different specialties, Colorectal (bowel) and Urology (Kidneys).

If at the time of your surgery, if you need minor treatment this might involve:

- Inspection and removal of the endometriosis tissue (From peritoneal biopsy to pelvic side wall peritonectomy).
- Adhesions (scar tissue) might be divided or removed.
- An Endometrioma or 'chocolate cyst' (cyst filled with endometriotic fluid) will be opened stripped or ablated. Care will be taken to preserve as much normal ovarian tissue as possible, and reconstruct the ovary where required. Usually, these cysts are diagnosed on scan prior to your surgery and will be discussed pre-operatively.
- You might have a catheter (tube in the bladder) should you need to stay overnight.
- You may have a PCA (patient-controlled analgesia) overnight where you have control over the pain relief medication which you may administer yourself by pressing a button.
- Usually, you would be discharged the same or the following day, depending on how you recover in terms of pain, nausea and the effects of the general anaesthetic.

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If there is 'major disease' or severe Endometriosis, surgery might involve:

- Cutting away the endometriosis affecting multiple sites.
- Releasing ovaries that are 'stuck' due to adhesions/scar tissue.
- Releasing scar tissue between different organs like the ovaries, fallopian tubes, uterus, bladder, bowel, pelvic walls, etc.
- Urological procedures, such as temporary stenting, or repair of any injury to the bladder or urine pipes. A small number of patients may require further Urological procedures, such as ureteric re-implantation or reconstructive surgery.
- Bowel Adhesiolysis / Shaving / Discoid Resection to remove endometriosis. A small number of patients may need to have part of their bowel removed and the healthy bowel reconnected (anastomosis). An even smaller number of patients might need a temporary procedure to disconnect the bowel, called a Stoma.

Bladder disease

If severe endometriosis affects the bladder, or is found close to the bladder, then:

- A cystoscopy (inspecting inside the bladder with a camera) may be performed.
- The bladder may need to be operated on to remove any endometriosis.
- A catheter (a small plastic tube) may be put inside the bladder and the bladder will be rested for about 14 days.
- You will be advised by your consultant how long the catheter might be needed for.

Ureteric disease

If severe endometriosis affects the ureters (urine pipes), then:

- Stenting may be required to protect the ureter(s) and make surgery safer. A stent is a fine plastic tube that is carefully passed inside the ureter, to help urine drain from the kidneys to the bladder. Stents can be left in place for several weeks, and can usually be removed via an Outpatient cystoscopy (camera test).
- The ureter may need to be cut and stitched together again to remove any scarred or narrowed areas caused by endometriosis. A stent would usually be left in place to help the ureter heal.

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Bowel disease

Endometriosis may sometimes involve the bowel. If disease is found on the bowel:

- We may need to separate the bowel from any scar tissue that has formed around it.
- We may need to remove the superficial layer covering the bowel to remove endometriosis (Shaving).
- We may need to cut a small hole into the bowel to remove endometriosis, and then sew the hole back together (discoid resection).
- If there is deep endometriosis, we may need to remove a small section of the bowel and then re-join it together (resection and anastomosis).
- Sometimes, a stoma bag is required to safely complete the surgery. Normally this is a temporary measure. It would usually be left for a few months, with a second procedure performed later to re-join the bowel inside.

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Surgical risks

The risk of a major complication from laparoscopy only is about 1-2 per 1,000. The risk from the major laparoscopic surgery for endometriosis is up to 1 in 10, due to the complexity of the disease and its effects on pelvic tissues. The risks listed below will be discussed in detail by the members of the surgical team when you sign the consent form for the operation.

Risks may include:

- Damage to bladder and uterus.
- If the ureters are involved, then a stent (tube) is passed via a telescope. This is removed as a day case usually 6 weeks later.
- If the ureter is cut, then it is possible that a cut will be required in the abdomen to rejoin it.
- Extensive surgery in the pelvis may result in delay in return of bladder function. Occasionally you may need to self-catheterise in the short term and very rarely in the long-term.
- Damage to the bowel. This can usually be identified and repaired immediately. If a section of bowel has to be removed and the normal ends joined together (an anastomosis), there is a risk of having a leak from a join, leading to an abscess. This may require draining with a small tube; occasionally it will require a larger cut in the abdomen to correct the problem.
- Damage to nerves and blood vessels.
- Infection.
- Risk of delayed complications (occurring after 2 weeks following the procedure), including bowel leak, infection and haematoma (collection of blood in the abdomen). In addition, if a piece of bowel has had to be removed, there may be changes to the way the bowels work in future. These changes usually resolve over a period of weeks to months.
- Risk of a fistula. This is an abnormal connection between two structures that are normally separate. A fistula can affect the bowel (or other structures such as the bladder or ureters) and the vagina, for example.
- Loss of a tube, ovary, or rarely the womb, due to bleeding or damage during surgery.
- Risk of adhesion formation after surgery.
- Loss of ovarian function due to endometriosis and treatment to the ovary.
- Risk of chronic pain, similar to or different from previous symptoms.

If any significant complications occur, a laparotomy (open surgery through a larger cut) may need to be undertaken to repair any injuries or to stop bleeding.

Once discharged from the hospital, if you experience any sudden or severe pain, are vomiting or feel unwell, please seek medical advice immediately. If you find you are unable to pass urine, please attend A&E urgently as you maybe in urinary retention.

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What happens after surgery?

Endometriosis trends to recur after surgical treatment (10% per year). When acceptable we often combine surgical treatment with medical treatment (e.g. the progesterone only pill) to prolong the benefits of surgery.

Where surgery is carried out for pain, it is important to appreciate that although we expect the operation to result in an improvement, in some situations pain will remain. Further investigations and treatment may be required, and input from a specialist Pain Management Team might be recommended. In some cases, patients choose to undergo a hysterectomy for pain if their symptoms are severe and they have completed their family. However, even this may not always cure their pain.

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Contact Email swbh.endometriosis@nhs.net

Quality of Life Questionnaire

The 'Quality of Life Questionnaire' has been designed to help your clinician understand your concerns regarding your condition and to help support any plans for the most appropriate treatments.

Please be assured that the information you provide will be kept confidential, in accordance with the 'UK Data Protection Act 2018' and 'UK GDPR' and automatically entered within your medical record together with the results of your clinical examination and any tests that you may have.

The questionnaire may also help you to formulate your thoughts on your symptoms and the way in which they can affect your quality of life.

Your clinician may request you to complete the 'Quality of Life Questionnaire' as part of your treatment plan, if so please complete the questionnaire by scanning the QR link or following the https e-link included below with your smart device. Where possible please complete within 24 hours of your appointment and enter a valid email address so that further questionnaires may be sent to you in future so that your clinician may monitor your progress. It is important that you answer all of the questions.

'Quality of Life Questionnaire'
e-link and QR Code

https://forms.office.com/r/s01H2YsKau

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The findings and results of any surgical intervention that you may have will be recorded and assessed, as will your responses from follow up questionnaires. The anonymous information collected on all patients may be used for research and study into the treatment of endometriosis, and may be published in medical journals or presented at medical scientific meetings.

Further information can be provided upon request to *swbh.endometriosis@nhs.net* or found at *www.bsge.org.uk* (British Society for Gynaecological Endoscopy).

Should you require any further information or assistance then please do not hesitate to contact use at *swbh.endometriosis@nhs.net*.

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Wellbeing Support Link

LiveWell with pain

Online Support Tool
www.livewellwithpain.co.uk

The Pain toolkit

Online Support Tool
www.paintoolkit.org

RETRAIN PAIN FOUNDATION

Online Support Tool
www.retrainpain.org

SandwellHealthyMinds

Sandwell Healthy Minds - Self Referral
Esteem Teams / Psychotherapy / CBT
www.sandwellhealthyminds.nhs.uk
0121 612 6650

NHS Birmingham and Solihull Mental Health NHS Foundation Trust

Sandwell Healthy Minds - Self Referral
Esteem Teams / Psychotherapy / CBT
www.bsmhft.nhs.uk/ourservices/birmingham-healthy-minds
0121 301 2525

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Other Resources:

NHS Overview – Endometriosis	www.nhs.uk/conditions/ endometriosis/
Endometriosis UK	www.endometriosis-uk.org
British Society for Gynaecological Endoscopy (BSGE)	www.bsge.org.uk
British Society for Gynaecological Endoscopy (BSGE) Endometriosis Centres	www.bsge.org.uk/centres
Royal College of Obstetricians & Gynaecologists (RCOG)	www.rcog.org.uk
Royal College of Obstetricians & Gynaecologists (RCOG) - Endometriosis patient information leaflet	https://www.rcog.org.uk/globalassets/documents/patients/patient-informationleaflets/gynaecology/pi-endometriosis.pdf
Royal College of Obstetricians & Gynaecologists (RCOG) - Recovering well from gynaecological procedures	www.rcog.org.uk/for-the-public/browse-allpatient-information-leaflets/recovering-wellfrom-gynaecological-procedures/
Royal College of Obstetricians & Gynaecologists (RCOG) - Laparoscopy – recovering well patient information leaflet	www.rcog.org.uk/for-the-public/browse-allpatient-information-leaflets/recovering-wellfrom-gynaecological-procedures/
European Society of Human Reproduction and Embryology (ESHRE)	www.eshre.eu
The Royal College of Nursing (RCN)	www.rcn.org.uk

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Incorporating City, Sandwell and Rowley Regis Hospitals

ML7203
Issue Date: July 2023
Review Date: July 2026