Management of Endometriosis: Information and Decision Aid

This leaflet provides information about endometriosis and its management options, including the benefits and risks. If you have any further questions or concerns, please speak to a doctor or nurse caring for you.

What is endometriosis and why have I got it?

Endometriosis is a condition where tissue like the inner lining of the womb (endometrium) is found elsewhere, usually in the pelvis. It is a very common condition, affecting around 1 in 10 women.

The exact cause of endometriosis is not known but it is dependent on hormones. This means that, just like the endometrium which responds to hormonal changes resulting in a period, the endometrial-like tissue located outside the womb also bleeds. This bleeding can cause pain, inflammation and scarring.

Endometriosis may be found:

- on the ovaries, where it can form cysts (often referred to as endometrioma or ‘chocolate cysts’)
- in the peritoneum (the lining of the pelvis and abdomen)
- in or on the fallopian tubes
- on, behind or around the womb
- in the area between the vagina and the rectum.
- Endometriosis can also occur within the muscle wall of the womb (adenomyosis) and occasionally on the bowel and /

or bladder.

What are the symptoms?

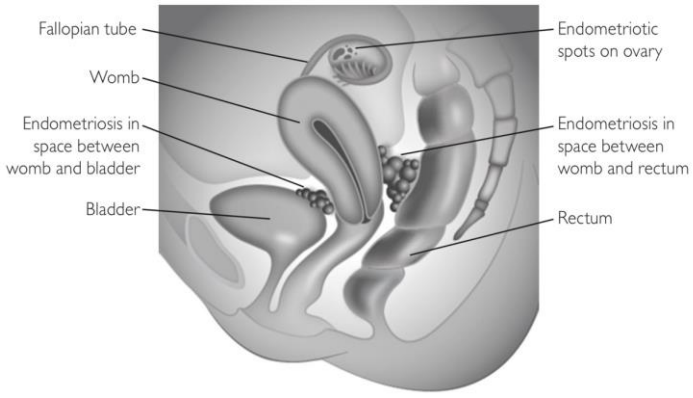
Common symptoms include pelvic pain and painful, heavy periods. It can cause pain during or after sex and can lead to fertility problems. You may also have pain related to your bowels, bladder, lower back or the tops of your legs and experience long-term fatigue.

Can you identify endometriosis on scans?

A transvaginal ultrasound scan may show whether there is adenomyosis, an endometriotic cyst in the ovaries or deep infiltrating endometriosis. It may also suggest adhesions (“sticky” areas of tissue that can cause organs to fuse together) in the pelvis. An MRI scan may be recommended to assess deep endometriosis involving the bowel or bladder. However, neither ultrasound nor MRI can identify superficial endometriosis.

What treatments are available?

There's no cure for endometriosis and it can be difficult to treat. Treatment aims to ease symptoms, so the condition does not interfere with your daily life. Support from self-help groups, such as Endometriosis UK, can be very useful if you are learning how to manage the condition.



Pain-relieving medications

These can range from simple analgesia such as paracetamol, ibuprofen or mefenamic acid, to stronger medications such as codeine and tramadol. In more severe situations, you may be referred to a specialist pain management team.

Hormone treatments

These treatments, some of which are also contraceptive, allow the endometriosis to shrink by decreasing hormonal stimulation. They also either temporarily stop your periods or make your periods lighter and less painful. They include:

- the combined oral contraceptive pill, which can be given continuously without the normal pill-free break.
- progestogens, including the mini pill (such as dienogest, desogestrel or norethisterone), Mirena® coil, injection or implant.

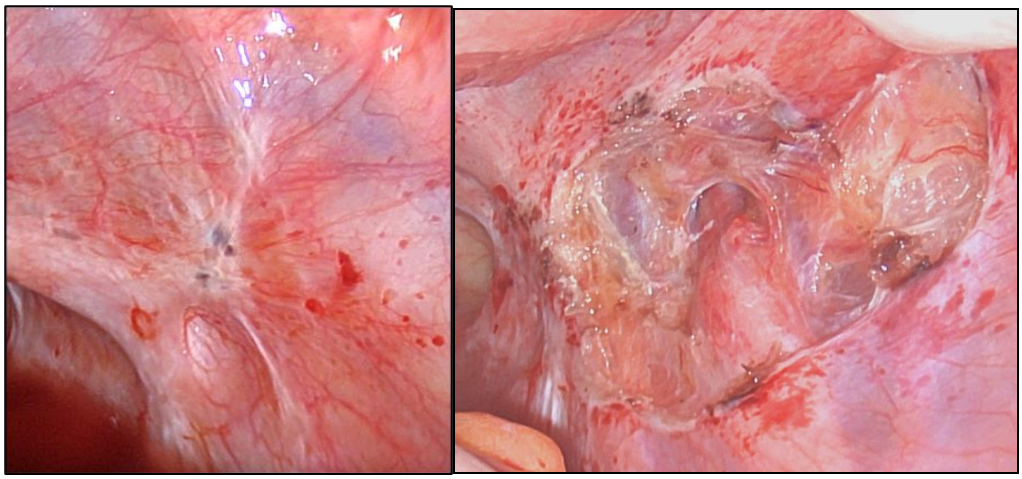
Common side effects include mood changes, nausea, breast tenderness, headaches and acne.

- GnRHa (gonadotrophin-releasing hormone analogues), which are given as monthly injections. They are very effective but can cause menopausal symptoms, such as hot flushes, whilst you are on treatment.

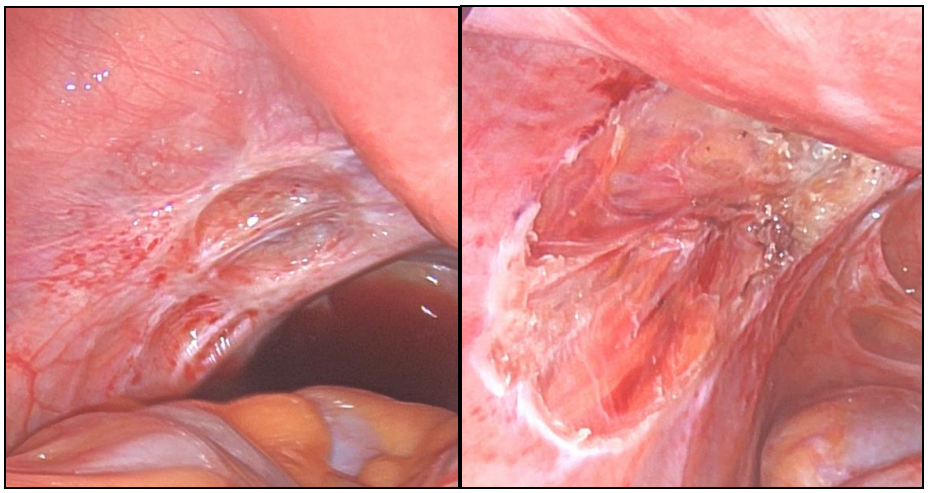
If you decide to try hormone treatment, you will need to give the kind you choose time to work (usually three to six months) but if it does not suit you or you do not feel it is helping, you can try a different kind if you wish. You can stop treatment at any time.

Surgery

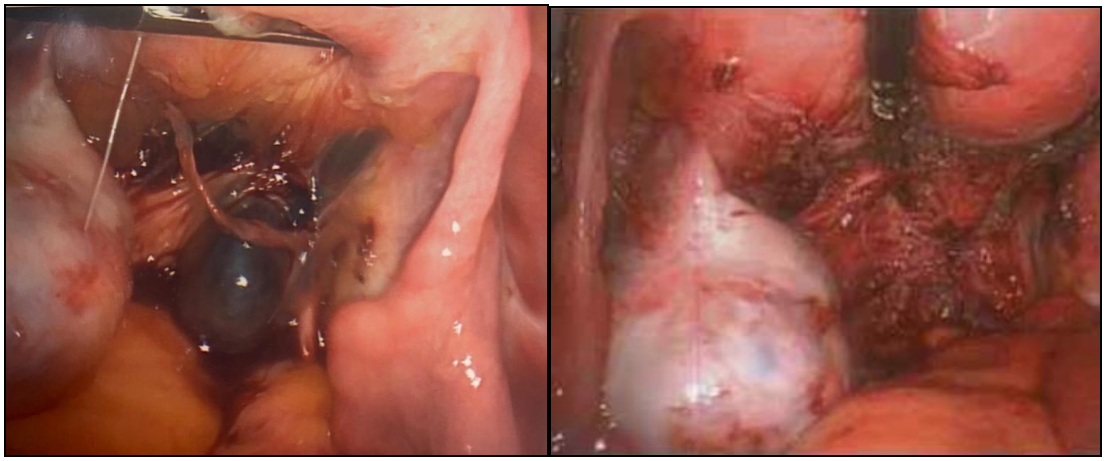
You may be offered a laparoscopy (keyhole surgery). Surgery can provide a definite diagnosis and remove or destroy areas of endometriosis and / or adhesions, as illustrated by the laparoscopic images below.



Laparoscopic images of superficial endometriosis before and after excision.



Laparoscopic images of scarring (due to previous endometriosis) before and after excision.



Laparoscopic images of severe endometriosis before and after excision.

If you have adenomyosis and do not desire future fertility, a hysterectomy (removing the womb) may be performed. If you have severe endometriosis involving the bowel or bladder, other surgeons such urology and colorectal specialists may be involved or you will be referred to an endometriosis specialist centre.

Success rates vary and you may need further surgery. Pain may persist or recur after surgery in some patients and it is difficult to predict who will benefit the most from having a surgery. Evidence suggests that laparoscopic excision of endometriosis can significantly improve symptoms and quality of life especially in women with moderate to severe endometriosis. Hormone treatment might be used after surgery to help get better, longer lasting results.

What are the risks of surgery?

All types of surgery carry a risk of complications. The more common complications are not usually serious and can include infection or minor bleeding. A negative laparoscopy may be encountered in 14% of cases, where there is an absence of

endometriosis or other pathology and we do not identify a structural cause for the symptoms.

Surgery to remove an endometriotic cyst is likely to have a negative impact on ovarian reserve and, if appropriate, fertility treatment options can be discussed.

The overall risk of serious complications from laparoscopy is approximately 2 in 1,000 women. This includes:

- Damage to an organ, such as bowel, bladder, ureters, uterus or major blood vessels which would require immediate repair by laparoscopy or laparotomy (open surgery is uncommon)
- A blood clot in the leg or lungs.

If a bowel injury is encountered, a section of bowel may need to be removed and a temporary stoma may be needed. This is where the bowel is diverted through a hole in the abdomen and waste products are collected in a bag. This may then be reversed after a few months.

What can I do to reduce the risk of complications?

There are some simple steps that you can take to reduce the risk of complications, including improving your diet, stopping smoking and drinking alcohol plus increasing your activity levels. Our prehabilitation service at St George's Hospital can support you in improving your health and wellbeing during the time you are waiting for your surgery. More resources are available at www.stgeorges.nhs.uk/service/prehabilitation.

Should I have a laparoscopy if my scans do not show evidence of endometriosis?

A laparoscopy can diagnose and treat superficial peritoneal endometriosis which may not be identified on scan.

Alternatively, empirical hormone treatments may be recommended by your clinician. If hormone treatment is unsuccessful or inappropriate, then the option of laparoscopy can be considered again. There is no evidence of superiority of either approach. Empirical hormone treatment may be preferred by women who want to avoid the risks of having a surgery. We can discuss the pros and cons of all treatment options to help you to make an informed decision about your treatment plan.

Asking for your consent

It is important that you feel involved in decisions about your care. Before having a laparoscopic surgery for diagnosis and treatment of endometriosis, you will be asked to sign a consent form to say that you agree to have the treatment and understand what it involves. You can withdraw your consent at any time, even if you have said ‘yes’ previously. If you would like more details about our consent process, please ask for a copy of our policy.

What happens during a laparoscopic surgery for management of endometriosis?

Laparoscopy is performed under general anaesthesia, i.e. you will be asleep throughout the procedure. The surgery involves passing a small telescope into your abdomen, usually through your navel, and inflating your abdomen with carbon dioxide gas so that we can see clearly your pelvic organs. We then make two or three further small incisions (usually less than 1cm in size each) on your abdomen to pass fine instruments into the pelvis. We aim to excise as much endometriosis as we can safely. We may use energy devices to ablate (destroy) endometriosis and divide and free adhesions within the pelvis. The length of the procedure will depend on how severe the endometriosis is and can range between one to three hours.

Will I feel any pain?

You can expect pain and discomfort in your lower abdomen for at least the first few days after your operation. You may also have some pain in your shoulder tip. You will be given regular pain relief medication. There will always be stronger medication prescribed on your medication chart which you can request from your attending nurse during your stay.

Sometimes painkillers that contain codeine or dihydrocodeine can make you sleepy, slightly sick and constipated. If you do need to take these medications, try to eat extra fruit and fibre to reduce the chances of becoming constipated.

Following your operation your bowel may temporarily slow down, causing air or ‘wind’ to be trapped. This can cause some pain or discomfort until it is passed. Getting out of bed and walking around will help. Peppermint water or chewing gum may also ease your discomfort.

What happens after my surgery?

You may or may not stay overnight depending on the extent of surgery. You may have a catheter coming from the bladder. This will be removed either at the end of the procedure or in the morning after the operation.

You may have a drip in your arm to provide you with fluids and when you can drink again, the drip will be removed. You can eat light food when you feel like it, unless advised otherwise.

We will see you before going home to explain what was found during the operation.

What do I need to do after I go home?

You should be able to have a shower and remove any dressings the day after your operation. Do not worry about

getting your scars wet – just ensure that you pat them dry with clean disposable tissues or let them dry in the air. Keeping scars clean and dry helps healing.

You will have between two and four small scars on different parts of your abdomen. We use dissolvable sutures, so you do not need to worry about the removing of any stitches. These will fall off by two weeks but if they remain, you can get them removed from your GP surgery.

You can expect to have some vaginal bleeding for one to two weeks after your operation. If there are any emergencies like increasing abdominal pain, heavy or smelly bleeding, fever, red and sore wounds or feeling unwell, please come to A&E with a copy of your discharge summary.

It can take one to two weeks for the wound to heal and we recommend you take time off work for this period.

Will I have a follow-up appointment?

You will receive a letter for a follow-up appointment in clinic. If you do not receive this, please contact our secretary via vanisha.gohil@stgeorges.nhs.uk

Contact us

If you have any questions or concerns about your care or treatment, please contact us on STGEM@stgeorges.nhs.uk (Monday to Friday, 9am to 5pm).

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

Additional services

Patient Advice and Liaison Service (PALS)

PALS can offer you advice and information when you have comments or concerns about our services or care. You can contact the PALS team on the advisory telephone line Monday, Tuesday, Thursday and Friday from 2pm to 5pm.

A Walk-in service is available:
Monday, Tuesday and Thursday between 10am and 4pm
Friday between 10am and 2pm.

Please contact PALS in advance to check if there are any changes to opening times.

The Walk-in and Advisory telephone services are closed on Wednesdays.

PALS is based within the hospital in the ground floor main corridor between Grosvenor and Lanesborough Wing.

Tel: 020 8725 2453 **Email:** pals@stgeorges.nhs.uk

NHS Choices

NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health. **Web:** www.nhs.uk

NHS 111

You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.
Tel: 111