

Surgery for severe endometriosis

The aim of this leaflet is to answer any questions you may have about surgery for severe endometriosis. It explains the benefits, risks and alternatives of the procedure as well as what you can expect when you come to hospital.

You may have had laparoscopies (keyhole surgery) to treat endometriosis before. However, it is important to understand that this operation is more complex and difficult than the operations you may have had previously. It carries greater risks of accidental bowel injury and injury to other organs in your abdomen than your previous laparoscopies (see page 4 for more information about risks).

Please take time to understand what the surgery is going to involve. If you do not understand any of the information we give you, or if you have any other questions or concerns, please speak to a doctor or nurse caring for you.

What is endometriosis?

Endometriosis is caused by tissues that normally line the womb (uterus) growing in other areas of your body. It causes inflammation of your pelvis and can lead to organs in your pelvis and tummy sticking together. It can affect a range of organs, including:

- ovaries
- fallopian tubes
- bowel
- bladder.

Endometriosis is a non-cancerous condition that gets worse over time.

What are the symptoms of endometriosis?

Endometriosis can cause:

- pelvic pain
- painful periods
- bowel symptoms, such as painful bowel movements, diarrhoea and/or constipation
- urinary symptoms, for example frequency and pain during urination
- cysts – fluid-filled sacs that grow in the ovaries and may be felt as a lump in the abdomen when they are large.

What treatments are there available for endometriosis?

Medicine is the first line of treatment for endometriosis, but it does not work for everyone. Some people need surgery to remove endometriosis for long-term improvement in pain and bowel-related symptoms.

Surgery is also needed when:

- there are cysts in the ovary
- medicines used for the treatment of endometriosis cause side effects.

In most patients, this surgery is performed by laparoscopy (keyhole surgery). However, some patients need open surgery through a cut along the bikini line, or an up and down cut below the belly button.

Open surgery is performed by two specialists (a gynaecologist and a bowel surgeon) and carried out under general anaesthetic.

What does surgery for severe endometriosis involve?

The surgery for severe endometriosis involves:

- cutting away the tissue affected by endometriosis
- releasing the ovaries and removing cysts when they are present
- identifying the ureters (tubes that carry urine from the kidneys to the bladder) and freeing them so that endometriosis tissue around the ureters can be removed
- removing the tissue affected by endometriosis around the back and the side of the womb, and around the bladder, ureter and the space between the back passage and the vagina.

Bladder endometriosis

If severe endometriosis affects your bladder or is found close to your bladder, the gynaecologist will perform the surgery with a bladder surgeon (urologist).

Firstly, they may inspect your bladder with a telescope (cystoscopy). They will then:

- insert stents (fine tubes) into your ureters to allow for easy identification during surgery
- open your bladder to remove the endometriosis
- pass a catheter (fine tube to drain urine) into your bladder, which may need to be left in place for up to 10 to 14 days (although it is usually needed for a much shorter time).
The consultants will advise you how long you need the catheter for after the operation.

Bowel endometriosis

If endometriosis affects your bowel, the gynaecologist will perform the surgery with a bowel surgeon.

The surgery involves cutting your bowel free and assessing if the endometriosis is growing on your bowel, or how deeply it has grown into your bowel. Sometimes, nothing more needs to be done. However, depending on how the endometriosis has developed, the surgeon may decide that it needs to be cut away. If this is the case, the surgery team may need to:

- remove the outer surface layer of your bowel
- take out a small disc of bowel and sew up the resulting hole.

If the development of endometriosis is more extensive, the team may have to remove a small section of the bowel and rejoin it with metal staples. To do this, the surgeon will have to make an additional 3cm cut in the pubic hairline so he/she can remove the bowel section and staple it.

Occasionally, if the bowel join is very low (near the anus) or the operation has been technically difficult, you will need a temporary colostomy. Colostomy is where the end of the healthy bowel is brought out through a small cut on the tummy and a bag is used to collect the faeces. This is called a stoma, and it protects the stapled ends of the bowel and helps with the healing process.

The colostomy is usually closed after three months. You will need to undergo a smaller second operation for this and stay in hospital for about four to five days afterwards.

Ovarian endometriosis

If endometriosis only affects your ovaries, the surgery is carried out by a gynaecologist. If it affects your bowel too, a bowel surgeon will be involved.

The ovaries are often affected by endometriosis and the endometriosis can either be on or inside the ovary. Endometriosis within the ovary forms cysts. Usually the gynaecologist will remove the cysts safely without removing the ovary. But your ovary may have to be removed if:

- the cyst is large and has damaged the ovary
- there is bleeding from the ovary that cannot be stopped after the cyst is removed.

As your fallopian tube may also be damaged in these cases, it may need to be removed at the same time as the ovary. If you do not wish to have your ovaries removed, even if they are affected by endometriosis, please tell the doctor. If you do not want the ovaries and fallopian tubes removed under any circumstances, the surgeon may decide not to operate on you.

If an ovary affected by endometriosis is left in your pelvis, there may not be any improvement in your symptoms. You may also need further operations in the future for persistent pain, which carry greater risks of complications.

How can I prepare for the surgery?

You will need to attend a pre-assessment appointment at the McNair Centre at Guy's Hospital.

Before you come in for your operation, there are some things you can do to reduce the risk of complications. We recommend that you:

- cut down or give up smoking
- maintain a healthy diet
- maintain some form of exercise if you can
- try to lose weight if you know that you are overweight.

You will be sent information about how to prepare for your hospital stay with your admission letter.

You will also have an appointment with the endometriosis nurse specialist who will ask you about your symptoms and how they affect your life. He/she will also answer any questions or discuss any concerns you may have before the surgery.

Why should I have the surgery?

Whether or not this surgery is the right choice for you will have been discussed during your clinic appointment. The aim of the surgery is to significantly improve the symptoms associated with severe endometriosis and it is usually successful in 70 to 80 out of 100 patients.

What are the risks of surgery for severe endometriosis?

There are risks associated with any surgery and general anaesthetic. For more information about anaesthesia and the side effects and complications, please see our leaflet, **Having an anaesthetic**.

The risks listed below will be discussed in detail by the members of the surgical team when you are asked to sign the consent form for your operation.

Damage to the bladder and ureters:

- If your bladder is injured during the operation, your surgery team will repair it through keyhole or open surgery. A catheter to drain urine will be left inside your bladder and the bladder will be rested for about 10 to 14 days.
- If your ureters are involved, the surgeon will insert a stent (tube) into the ureters via a telescope (if the ureter is cut, it is possible that the surgeon may need to make a larger skin cut through which he/she can rejoin it). The stent is removed as a day procedure (you will not need to stay in hospital overnight) six weeks later.
- Extensive surgery in your pelvis may mean that your bladder does not work properly for a longer period of time. Occasionally, in the short-term, you may need to self-catheterise (insert a small tube into the bladder to help it empty) until your bladder works normally again. It is very rare that this is necessary in the long-term.

Damage to the bowel:

- As the bowel is often firmly stuck to the back of the womb, it can get damaged when it is detached. This can lead to a hole in your bowel, which can be stitched using keyhole surgery. However, in some cases the surgeon needs to make a larger cut in the skin, through which he/she can repair the injury. If the injury is large and particularly if it affects the lower end of your bowel (close to the anus), you will need a stoma (as described on page 3).
- When bowel ends are joined together with staples, sometimes there can be a leak from the join, which leads to an abscess. This may need to be drained with a small tube. Occasionally, the surgeon may need to make a larger cut in the skin, through which he/she can correct the problem.
- In addition, if a piece of your bowel has had to be removed, there may be changes to the way your bowel works in the future. It usually takes a period of weeks to months for your bowel to work normally again.

Other risks during surgery include:

- bleeding from a damaged blood vessel
- damage to your nerves
- infection
- blood clots in your legs (deep vein thrombosis also known as DVT)
- loss of a fallopian tube and/or ovary due to bleeding.

Delayed risks arising a few days or weeks after surgery include:

- haematoma (collection of blood in the abdomen) that can occur up to two weeks after the procedure
- a fistula (abnormal connection between the bowel or other organ and the vagina) that can develop in one to two out of every 100 patients
- internal scar tissue.

Giving my consent (permission)

We want to involve you in decisions about your care and treatment. If you decide to go ahead, you will be asked to sign a consent form. This states that you agree to have the treatment and you understand what it involves.

You should receive the leaflet, **Helping you decide: our consent policy**, which gives you more information. If you do not, please ask a member of staff caring for you for a copy.

What happens after surgery?

Following surgery you will be in hospital for two to five days, depending on whether the operation is completed by keyhole or open technique. If the surgery involves operation on the bowel, you may stay in hospital for a longer period.

After leaving hospital the recovery period is normally four to six weeks. You will need to take time off work.

You will also need to take regular medicines to prevent the build up of new endometriosis, unless you are actively trying to become pregnant.

Is there anything I need to look out for at home?

Recovery is specific to you as an individual and very much depends on the extent of surgery you have. Your doctor or nurse will talk to you about things to look out for at home before leaving hospital but if you have any concerns, please contact us.

Please go to your local A&E department immediately if you experience any of the following problems:

- **bleeding and/or pain at the site of the wound**
- **redness, swelling or oozing around the wound site**
- **fever (temperature higher than 37.5°C).**

Contact us

If you have any questions or concerns about your surgery, please:

- contact or visit your GP
- call the gynaecology ward for advice on 020 7188 2703 or 020 7188 2697
- call the endometriosis specialist nurse on 020 7188 3692
- call NHS 111 and speak to a specially trained nurse
- go to your nearest A&E department or call 999 in the event of an emergency.

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

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Patient Advice and Liaison Service (PALS)

To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

e: 020 7188 8801 at St Thomas' **t:** 020 7188 8803 at Guy's **e:** pals@gstt.nhs.uk

Language Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.

t: 020 7188 8815 **fax:** 020 7188 5953

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Become a member of your local hospitals, and help shape our future

Membership is free and it is completely up to you how much you get involved. To become a member of our Foundation Trust, you need to be 18 years of age or over, live in Lambeth, Southwark, Lewisham, Wandsworth or Westminster or have been a patient at either hospital in the last five years. To join:

t: 0848 143 4017 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk

Leaflet number: 2609/ VER3

Date published: August 2014

Review date: August 2017