

Patient information factsheet

Surgery for severe endometriosis

We have given you this factsheet because you have been diagnosed with a severe form of endometriosis and need keyhole (laparoscopic) surgery.

This factsheet includes details on what endometriosis is, what the surgery for severe endometriosis involves and the possible risks of having the surgery. We hope it will help to answer some of the questions you may have. If you have any further questions or concerns, please contact us using the details at the end of this factsheet.

How is this different to surgery I may have had in the past?

You may have had keyhole surgery to treat endometriosis before. However, it is important to understand that this operation is more complex than the operations you may have had previously. This is because surgery for severe endometriosis carries greater risks of accidental injury to the bowel and other organs in your tummy. Your doctor will discuss this with you before you give your consent.

What is endometriosis?

Endometriosis is a condition where tissue, similar to the lining of the womb (endometrium), starts to grow in other places in the body, such as the ovaries and fallopian tubes. This tissue can cause inflammation, pain and the formation of scar tissue. It is a common condition and affects one in ten women and those assigned female at birth during their reproductive years. It may have a significant effect on your physical health, emotional wellbeing and daily life, but there are treatments that can help.

What are the symptoms of endometriosis?

Symptoms of endometriosis can include:

- pelvic pain (may be worse at certain times in your menstrual cycle)
- heavy, painful periods
- pain during or after sex
- difficulty getting pregnant
- bowel symptoms (pain when going to the toilet, or recurring constipation, diarrhoea or bleeding)
- bladder symptoms (pain when peeing or blood in pee)

Some women may experience several of the symptoms above, while others may have no symptoms at all.

How is severe endometriosis different?

When endometriosis is severe, it affects more areas within the pelvis and tummy, such as the ovaries, womb, bladder and bowel. The spread of scar tissue causes organs to stick together and this can cause debilitating symptoms.

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Women with severe endometriosis are more likely to experience painful symptoms and may find it difficult to manage these with medication and pain relief alone. If your symptoms are severe, surgery may be the only option available as a further treatment.

What does surgery for severe endometriosis involve?

The surgery involves:

- releasing the ovaries and removing any cysts (endometriomas)
- identifying and releasing the ureters (tubes that carry pee from the kidneys to the bladder) from any tissue affected by endometriosis
- separating areas in the pelvis that have become stuck together
- cutting away tissue affected by endometriosis around the back and the side of the womb, the space between the vagina and rectum (back passage), the bowel wall itself, the ureter and the bladder

If endometriosis affects your vagina, a small part of the top of your vagina may need to be removed.

Bowel endometriosis

If endometriosis affects your bowel, a specialist gynaecologist will perform the surgery. They may be assisted by a bowel surgeon.

We will cut your bowel free from any areas it is stuck to and assess your symptoms and how deeply the endometriosis has grown into your bowel. We may then need to remove the endometriosis tissue by:

- 'shaving' it from the outer surface of your bowel
- removing a small disc of bowel wall (discoid resection) and closing the hole
- removing a section of bowel (segmental resection) and joining the ends together with metal staples

Before your operation

We will discuss with you the potential risk of needing a temporary stoma (where the bowel is diverted through an opening in the skin into a discrete bag). This will allow your bowel to heal. If we think you will need a stoma, we will offer you an appointment to see one of the stoma nurses before your operation.

You should eat a low fibre diet for four to five days before your operation to reduce the amount of poo in your bowel. This diet includes:

- white bread
- refined (non-wholegrain) breakfast cereals, such as cornflakes
- white rice
- refined pasta and noodles
- cooked vegetables (but not the peel, seeds or stalks)
- lean meat
- fish
- eggs

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You will need to take a bowel preparation solution (a laxative medication) the night before and morning of your surgery to help empty your bowel. This can be done at home or in the hospital depending on the time of your operation. We will discuss bowel preparation with you in more detail at your pre-assessment appointment (this is an appointment before your surgery to check that you are well enough to go ahead with the surgery).

Bladder endometriosis

If endometriosis affects your bladder or is blocking your ureter, a bladder surgeon (urologist) may help the specialist gynaecologist perform the surgery.

We will look inside your bladder with a telescope (cystoscopy). We may need to insert small plastic tubes (stents) into the ureters to help with the surgery. We will either remove these immediately after your surgery or we may need to leave these in for about six weeks.

If the ureter is affected by endometriosis, we may need to remove a small section of ureter and, depending on the severity of the condition, re-join or divert the ends into the bladder.

We may also need to remove a small piece of your bladder. This is called a partial cystectomy. Once this small piece has been removed, we will close your bladder with dissolvable stitches.

You will need to have a urinary catheter for two weeks after the operation to allow your bladder to heal. We will explain how to look after this at home and we will invite you back to the ward to remove it. You will need a follow-up x-ray of your bladder at Southampton General Hospital to check things have healed. After a partial cystectomy, you may not be able to hold as much pee before needing to empty your bladder and may need to pee more often.

What are the risks?

There are risks with any surgery and general anaesthetic, but this type of surgery is more complex and has some specific risks. These risks include:

- unexpected bowel injury (1/150)
- unexpected bladder injury (1/250)
- ureter injury (1/200)
- blood vessel injury (1/500)
- stoma (an opening on the surface of the tummy) formation (1/350)
- bowel fistula (abnormal connection between the bowel and another organ)
 - 1/500 if disease shaved
 - 1/100 if segmental resection
- bowel leak
 - 1/500 if disease shaved
 - 1/50 if segmental resection
- fertility issues

If we have to remove a piece of your bowel, you may find changes in the way your bowel works. These changes include:

- needing to go to the toilet more often
- needing to rush to the toilet
- finding it difficult to empty your bowel completely
- incontinence (problems controlling your bowel)

It usually takes a few months for your bowel function to improve.

Extensive surgery in your pelvis may mean that your bladder does not work properly for a period of time. In the short term, you may need to self-catheterise (insert a small tube into your bladder to help it empty) until your bladder works normally again. It is very rare that this will be a long-term solution.

General risks of surgery with anaesthetic

- Infection or abscess (a build-up of pus) formation
- Loss of blood needing blood transfusion
- Blood clots in the leg or lung
- Scarring
- Pain
- Laparoscopic site bruising or hernia (when an internal part of the body pushes through a weakness in the muscle or surrounding tissue wall)

Complications

Sometimes complications and organ injuries may not be obvious at the time of surgery and may become clear a few days afterwards.

Contact us or your GP for advice immediately if you:

- do not feel well
- have a temperature (38°C or above)
- have a lot of tummy or back pain

If there is a serious complication with your surgery, you may need a second operation to help the situation.

In an emergency, go to your nearest emergency department.

How should I prepare for surgery?

It is important to be as healthy as possible for your operation, as this will reduce your risk of complications and improve your healing process after the operation. Things that you can do to help include:

- stopping smoking
- maintaining a healthy diet
- exercising on a regular basis (even if this is only walking)

We advise purchasing a supply of paracetamol and ibuprofen before you have your operation in case you need it when you return home.

What to expect after surgery

Length of stay

Most people will stay in hospital for two nights, but if your operation was not possible by keyhole surgery or was particularly complicated you may need to stay for longer.

After-effects of anaesthesia

For the first 24 hours after your operation you may feel sleepy and your judgement may be impaired, so it is important not to make any big decisions during this time. Most modern anaesthetics are short-lasting and any side effects will usually pass within 24 hours.

Catheter

Sometimes we may insert a catheter (plastic tube) into your bladder during surgery. This is to keep your bladder empty during your operation. If this is the case, we will remove the catheter the following morning unless we have operated on the bladder, in which case it may stay in for longer.

Scars

If you have a keyhole surgery, you will usually have four small scars (5mm to 10mm in size) on your tummy. One of these will be in your belly button. Sometimes one of these scars will be larger if the bowel is operated on.

If you have an open surgery, you will have a longer scar on your tummy, which may be along your bikini line or vertically below your belly button.

Stitches and dressings

We will close your cuts with stitches or glue. Glue and some stitches will dissolve by themselves. Your other stitches may need to be removed. This will usually be done by the practice nurse at your GP surgery seven days after your operation. We will give you a letter before you leave the ward to take to your GP to arrange this.

We will cover your cuts with a dressing. You should be able to take this off about 48 hours after your operation to have a wash or shower.

Vaginal bleeding

It is very common to have some vaginal bleeding for a few days after your operation. This is because we temporarily place an instrument inside your womb during the operation.

Pain and discomfort

You may feel pain in your tummy for several days after the operation, particularly around the scars. This is part of the normal healing process. You may also have pain in your shoulders, which is normal for 24 to 48 hours. We will offer you regular pain relief medication, such as paracetamol and ibuprofen, with the option of something stronger if needed. Taking regular pain relief medication will help you to feel more comfortable after your operation, get out of bed sooner, stand up straight and be able to walk around more easily. Moving around will help speed up your recovery and reduce the risk of blood clots forming in your legs and lungs.

Eating and drinking

We will encourage you to drink water immediately after your operation in the recovery area, unless your surgeon tells you otherwise. We will offer you something light to eat on your return to the ward if you feel hungry.

Washing and showering

You should be able to have a shower the day after your operation. Your dressing may come off in the shower. It is important to keep your wounds clean and dry to ensure they heal well. You may be more comfortable wearing loose clothing for a week or so after the operation.

Avoiding blood clots

Having surgery may increase your risk of blood clots (venous thromboembolism). However, other factors may also increase this risk, such as diabetes, obesity, smoking and previous deep vein thrombosis (DVT).

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To reduce the risk of blood clots, we will offer you calf compression stockings after the operation to wear until you are fully mobile. We will also give you an injection (low molecular weight heparin) each day while you are in hospital to thin your blood slightly.

You can also reduce your risk of blood clots yourself by moving as much as you can after your operation, staying well hydrated and performing small exercises while sitting (moving your foot up and down as quickly as you can for 30 seconds on each side).

Recovery

It may take up to four to six weeks for you to recover from the operation. You may feel very tired during this time, so it is important that you rest. It may take up to six months to see any improvement in your symptoms.

Side effects

If you experience any of the following side effects in the days or weeks after the operation, you should contact your GP or call us for advice. We may need you to come back to the ward to be seen by one of our doctors. If you are very concerned and can't wait, please visit the emergency department.

- Burning or stinging sensation when you pee. This may be due to a urinary tract infection, which we can treat with antibiotics.
- Worsening redness or pain around the scars. This may be due to a wound infection, which we can treat with antibiotics.
- Tummy pain that is getting worse. Contact us immediately if you also have a fever (a high temperature of 38°C or above), loss of appetite or vomiting.
- Swelling, redness or pain in your calf. This may be a sign of a blood clot.

Getting back to normal

Activities and exercise

You will be able to return to your normal daily activities as soon as you're home. If things feel too much, then do a little less for a few days. It is important not to lift anything heavy for six weeks or so. Your body will tell you how much to exercise, but we recommend starting with some gentle walking in the first few days, which you can then gradually build up to your normal level of activity.

Driving

You should not drive for at least 48 hours after your operation. It is important that you do not drive until you feel confident to do so. You should be able to look over your shoulder and perform an emergency stop without causing any pain. This usually takes a few weeks. You should contact your insurance company to check their conditions for driving after an operation.

Work

Your return to work will depend on the sort of job that you do and how physically strenuous it is. Most people need four to six weeks off work. If you need a sick note, please ask us before you leave the ward.

Sexual activity

It is best to avoid sex for eight weeks after surgery to allow your body time to heal.

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Contact us

The Princess Anne Hospital is a nationally accredited (BSGE) endometriosis treatment centre and you may have been referred here from another local hospital for this reason.

Bramshaw ward

Telephone: **023 8120 6035** (24-hour line)

Endometriosis clinical nurse specialist

Email: **EndometriosisPAH@uhs.nhs.uk**

Useful links

Royal College of Obstetricians and Gynaecologists (RCOG) patient information leaflets

- Laparoscopy - recovering well
www.rcog.org.uk/for-the-public/browse-our-patient-information/laparoscopy-recovering-well
- Endometriosis
www.rcog.org.uk/for-the-public/browse-our-patient-information/endometriosis

Endometriosis UK

www.endometriosis-uk.org

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