



Saint Mary's Managed Clinical Service  
Division of Gynaecology

## PATIENT INFORMATION LEAFLET

# SURGERY FOR SEVERE/COMPLEX ENDOMETRIOSIS

You have been given this leaflet as you may have a severe form of endometriosis and are listed for complex keyhole surgery (Laparoscopy). The aim of this leaflet is to give you some understanding of endometriosis and what to expect from surgery, during your stay in hospital and after surgery during the recovery period. The leaflet explains the potential risks associated with surgery for complex endometriosis.

You may have had keyhole surgery to treat or diagnose endometriosis in the past. Keyhole surgery for severe endometriosis is more complex and carries a greater risk of accidental injury to organs in your tummy. This will be discussed with you as part of the surgical planning and when you give your consent to undergo surgery.

Your keyhole surgery may be performed with a Robotic-Assisted approach. If you would like more information regarding Robotic Assisted Surgery, please read the following leaflet: **Robot-Assisted Gynaecology Surgery**.



Please scan the QR code or use the following link to access the above leaflet:  
<https://mft.nhs.uk/app/uploads/sites/4/2024/04/SMPIL-24-087-Robotic-Assisted-Surgery.pdf>

## WHAT IS ENDOMETRIOSIS?

Endometriosis is a non-cancerous condition which affects 1 in 10 women during their reproductive years. It occurs when tissue similar to the lining of the womb (endometrium), starts to grow in other places in the body, such as the ovaries, surrounding pelvic tissue (side walls of the pelvis, ligaments supporting the womb etc.). It unfortunately can get worse over time and is often difficult to predict progression of disease. Endometriosis can cause pain by inflammation, development of scar tissue or the trapping of nerves. It may have a major effect on your physical health, emotional and mental wellbeing. Medical and surgical treatment can help improve symptoms of endometriosis.

## WHAT ARE THE COMMON SYMPTOMS OF ENDOMETRIOSIS?

Symptoms of endometriosis can include:

- Lower abdominal / pelvic pain and low backache
- Heavy, painful periods – often since the start of your periods
- Pain during or after sex

- Infertility - Difficulty in getting pregnant
- Bowel symptoms especially around periods (pain when going to the toilet, constipation, loose stools or rectal bleeding)
- Bladder symptoms especially around periods (pain when peeing or blood in pee, symptoms suggestive of a urinary tract infection, increased frequency etc.)

The above symptoms do not have any direct link with the severity of endometriosis. Some individuals with severe endometriosis may have no symptoms. Some pain may not be caused by endometriosis; there may be other medical conditions that can mimic endometriosis pain

## WHAT IS SEVERE/COMPLEX ENDOMETRIOSIS?

Endometriosis is classed as severe / complex when it involves a large area within the pelvis and tummy (abdomen) and / or the disease is deep into the organs which can cause widespread scar tissue between organs that can cause them to stick to each other. Often the ovaries, womb, bladder and bowel (intestines) are involved in the disease.

Women with severe endometriosis are more likely to experience painful symptoms which can be unbearable. For some women, surgery may be the only option available to improve their symptoms and improve their quality of life. Up to 10% of women with severe pelvic endometriosis can have endometriosis outside of the pelvis such as on the appendix, intestines, diaphragm, in the chest cavity.

Endometriosis is staged depending on the severity of the disease from stage 1 to stage 4 (most severe form of the disease). Staging focuses on location, size and severity of the disease. Your healthcare professional will explain your staging with you.

Different stages of Endometriosis are shown below –

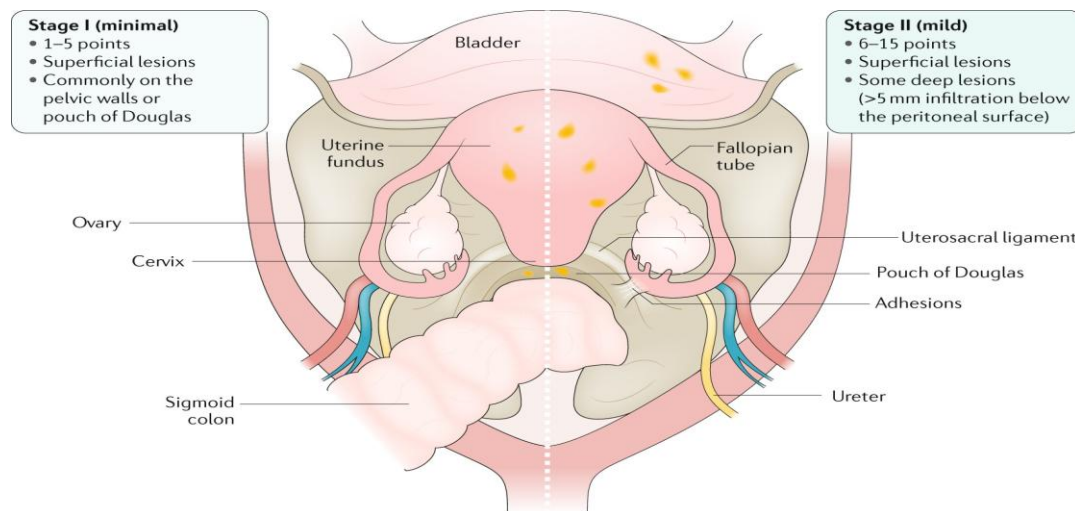
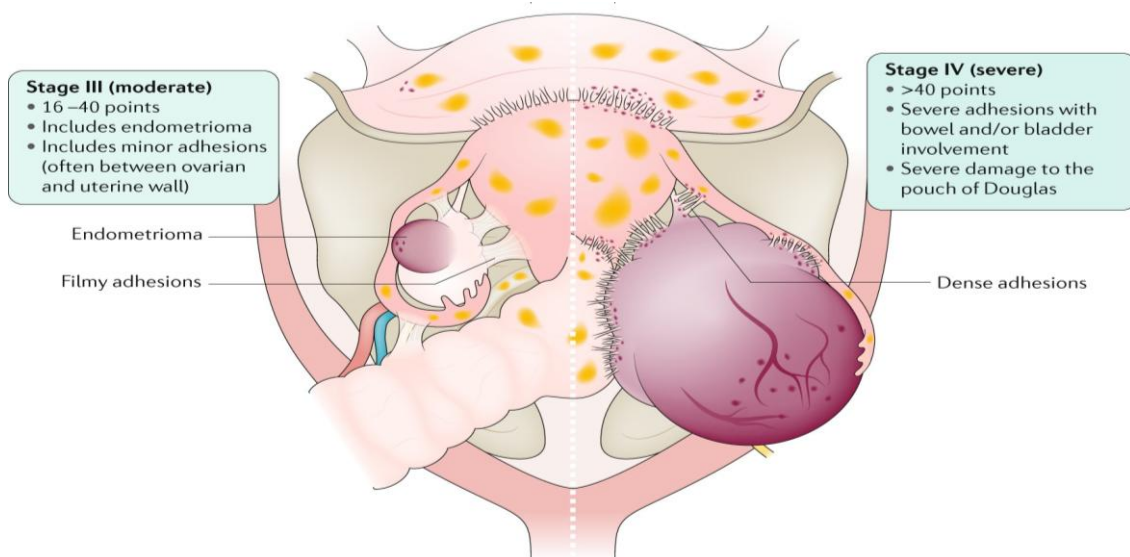


Image: Nature.com: Endometriosis. *Nature Reviews Disease Primers* volume 4, Article number: 9 (2018).



## WHAT DOES SURGERY FOR SEVERE ENDOMETRIOSIS INVOLVE?

Endometriosis causes significant distortion within the pelvis due to scar tissue and inflammation. The aim of surgery is to remove endometriosis by excision (cutting it away) to try returning the pelvis to “normal” appearance (anatomy).

This may involve:

- Vaginal examination under anaesthesia,
- Cystoscopy (camera in the bladder)
- Inserting stents (fine tubes) into the tubes connecting your kidneys to your bladder.
- Removing any scar tissue from the intestines (bowel), ovaries and fallopian tubes
- Removing any cysts
- Removing any scar tissue /endometriosis from the ureters (tubes that carry urine from the kidneys to the bladder).
- Removing tissue affected by endometriosis around any female reproductive organs, back passage (rectum), bowels and/or bladder
- If endometriosis affects your vagina, a small part of the top of your vagina may need to be removed.
- Removing endometriosis from outside of the pelvis if feasible.

## HOW CAN YOU PREPARE FOR SURGERY?

Ensuring you are in good health before surgery can improve surgery outcomes and reduce post-operative recovery. Things that you can do to help include:

- Maintaining a healthy weight (BMI). Surgery may only be offered if your Body Mass Index (BMI) is below 35. Further information can be found in our leaflet: *I want an operation and have a raised BMI. Why is this important?* You can access this online using the URL link at the end of this leaflet.
- Stop smoking
- Maintaining a well-balanced diet
- Exercising on a regular basis

In preparation for surgery, you may be prescribed GnRH agonist injections such as Prostag or Zoladex for 3-6 months prior to undergoing surgery. This medication is to alleviate your symptoms and suppress the growth endometriosis. You will also see the pre-operative team for general health assessment and investigations prior to the operation.

You will need to have an enema (a procedure in which liquid medication is administered into the back passage) on the morning of your surgery. This medication is to empty your bowel, prior to surgery incase endometriosis needs to be removed from your bowel. This can be done at home or in the hospital depending on the time of your operation.

## **SURGERY FOR ENDOMETRIOSIS INVOLVING BOWEL (INTESTINES)**

If endometriosis affects your bowel, a bowel surgeon may also be present for the procedure depending on the degree of bowel involvement. This may be determined based on pre-operative investigations and / or multi-disciplinary team discussion.

Your surgeon will attempt to separate your bowel from scar tissue and surrounding organs. Removal of endometriosis may occur through:

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

There is a potential risk of needing a temporary stoma (where the bowel is diverted through an opening in the skin into a discrete bag) to allow your bowel to heal after surgery. This decision is often made during the operation depending on the location of the disease and the extent of bowel resection. This is usually temporary and is reversed after a few months after confirming the healing of the stapled part of the bowel. The closure of the stoma is usually a smaller operative procedure.

If a section of the bowel is removed at surgery, an additional cut is made along the bikini line to facilitate this part of the operation. This is usually 2 inches long.

If we think you will require a stoma, we will discuss this with you, and you may be offered an appointment to see one of the specialist stoma nurses before your operation.

## **SURGERY FOR ENDOMETRIOSIS INVOLVING THE BLADDER**

If endometriosis is present in the bladder or is blocking your ureter (pipe that brings urine from the kidney to the bladder), a Urologist (surgeon who does operations on the urinary system) may help the specialist Gynaecologist perform the surgery.

The procedure involves looking inside your bladder with a telescope (cystoscopy) and small plastic tubes (stents) may be inserted into the ureters to help with the surgery. These will either removed immediately after your surgery or they may need to be left in for several weeks / months. If the ureter is affected by endometriosis, a small section of ureter may also need to be removed. The cut ends of the ureter can be re-joined or diverted into the bladder.

If the bladder is affected by endometriosis; the diseased part of your bladder may be removed (partial cystectomy). A urinary catheter (tube inserted into urethra and sits in the bladder) will be

inserted to help bladder heal and may need to stay in for 10-14 days. You will be discharged home with the catheter and return for an X-ray test to check if the bladder has healed. Once this is confirmed, the catheter will be removed.

Depending upon the amount of the bladder all that is removed, you may no longer be able to hold as much pee due to the decreased capacity of the bladder. This can improve over time.

## WHAT ARE THE RISKS OF SURGERY?

### General risks:

- Pain
- Bleeding requiring a blood transfusion, collection of blood in the tummy (Haematoma)
- Infection or abscess formation (collection of pus)
- Thrombosis - Blood clots in the leg or lung
- Scar tissue formation
- Bruising on the skin
- Hernia
- unexpected bowel injury (1-2 in 100)
- unexpected bladder injury (1 in 250)
- unexpected ureter injury (1-2 in 100)
- blood vessel injury (1 in 500)
- unexpected stoma formation (Bowel bag - an opening on the surface of the tummy): 1 in 100
- unexpected bowel fistula (abnormal connection between the bowel and another organ such as the vagina)
- 1 in 100 removal of a segment of the bowel (segmental resection)
- bowel leak with risk of severe infection in the tummy (peritonitis)
- fertility issues (decrease in the ovarian reserve of eggs if cysts removed from the ovary)

Complications can occur unexpectedly during the operation. However, sometimes complications may not be obvious during the operation and become obvious a few days or a few weeks after the operation. Symptoms to watch out for in the post-operative period for complications are:

- Raised temperature
- Feeling unwell
- Increasing tummy pain
- Increasing back pain
- Vomiting
- Unusual discharge through the vagina

If there is a complication after your surgery, you may require additional investigations, in-patient admission and surgery.

### Risks associated with removing part of bowel:

- Increased frequency of bowel movements
- Urgency – unable to hold and needing to rush to the toilet
- Incontinence of flatus or stool – inability to control your bowels
- Incomplete bowel emptying – difficulty in emptying your bowel completely.

Most of these symptoms resolve over time (usually a few months).

## **Risks associated with removing part of bladder:**

- Lack of sensation - Unable to feel the bladder when it is full
- Hesitancy and poor urinary stream
- Incomplete bladder emptying - Finding it difficult to empty the bladder completely
- Poor control of the bladder – Incontinence
- Needing to self-catheterise (inserting a tube into urethra to drain the bladder). This is often short term whilst the bladder heals.

## **WHAT TO EXPECT AFTER SURGERY**

### **Pain relief:**

You may feel pain in your tummy for several days after the operation. This is part of the normal healing process however a range of pain relief (analgesia) will be prescribed for you.

The Anaesthetist will discuss post-operative pain management with you on the day of your operation. You may be offered a spinal / epidural anaesthetic (needle in the back) along with a general anaesthetic to help with post operative pain. This may be particularly useful in patients who have chronic pelvic pain to achieve better pain relief in the first 24 hours after the operation.

Shoulder pain may occur within the first 24-48 hours after your operation due to the air that is used to inflate your tummy (abdomen) to assist in surgery. Taking regular pain relief, mobilisation and peppermint tea and help reduce this pain.

### **Urinary Catheter:**

A urinary catheter is inserted into your bladder during surgery. This is to keep your bladder empty during your operation and can be removed the following morning if your surgery has not involved removing part of the bladder.

If we have operated on the bladder, the catheter may stay in for longer. You may notice that the urine is pinkish (blood stained) after the operation if you have had stents inserted during the operation. This usually clears in 24-48 hours.

### **Vaginal Bleeding:**

You may experience some vaginal bleeding for a few days after your operation. Your first couple of periods after the operation may be different to what you have experienced prior to the operation. This will settle in a couple of months.

### **Eating and Drinking:**

You will be encouraged to drink water soon after your operation. You will also be offered a light meal on your return to the ward if you feel hungry. It is not uncommon to feel nauseous or to be sick after an Anaesthetic. Please ask the nurse for anti-sickness medication if you feel so.

### **Prevention of Blood Clots:**

Undergoing surgery increases your risk of blood clots in the legs and / or lungs (venous thromboembolism). Poor mobility, diabetes, being overweight, smoking and previous clots in the legs (DVT) or lungs (PE) increases the risk.

You will be required to wear anti-embolism stockings prior to the operation where a nurse will measure your calves for the correct size. If it is too tight, please inform the nurse looking after you. Please wear these stockings until you are fully mobile.

You will also be given an injection (low molecular weight heparin) each day while you are in hospital to thin your blood slightly. These injections may continue for 7 days after surgery, and your nurse will teach you how to do this at home after discharge.

The nursing staff on the ward will encourage you to mobilise as soon as this is feasible. This will help reduce the risk of blood clots and also aid your general recovery. Drinking adequate amount of fluids and moving your feet regularly when sitting will further reduce the risk.

### **Length of Stay:**

Most people will stay in hospital for between 1-3 nights. If your operation was complicated or required a large cut on the tummy, you may need to stay for longer.

### **Scars:**

Surgery for endometriosis is almost always done by keyhole. 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 up and down (sometimes extending above the belly button).

### **Stiches and Dressings:**

The cuts on your tummy will be closed with a dissolvable stitch and may also have surgical glue applied over the stiches. If your stiches need removal or if you have surgical staples on the skin, these will be removed in hospital or by the district nurse upon discharge home. A referral will be made to the district nursing team before discharge.

### **Washing and Showering:**

You should be able to have a shower 1 – 2 days after your operation. It is important to keep your wounds clean and dry to ensure they heal well.

## **RECOVERY AT HOME**

It may take you 2 – 6 weeks to recover from the operation. You may feel very tired during this time, so it is important to take adequate rest. If you require a sick note for work, please inform the nurse looking after you on the ward.

### **Concerns after Discharge:**

Contact details for our Emergency Departments can be found at the end of this leaflet.

If you have any concerns with your recovery, please contact the departments for advice. You may need to be seen by a doctor once we have discussed your symptoms with you.

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.

- Burning or stinging sensation when you wee. 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. Please contact us immediately if you also have a fever, loss of appetite or vomiting.
- Swelling, redness or pain in your calf. This may be a sign of a blood clot.

### **Exercise after Surgery:**

After undergoing complex surgery for endometriosis, your recovery will depend on the extent of surgery. Listen to what your body tells you. Start with walking in the first few days and then build up your distance.

Please avoid sexual intercourse and any heavy lifting for 6 weeks after your surgery.

### **Driving:**

You should not drive for at least 2 – 6 weeks after your operation.

Please check with your insurance company their conditions for driving after an operation. You should be able to look over your shoulder and perform an emergency stop without causing any pain.

### **Work:**


You will require between 2-6 weeks off work. If you require a sick note, please ask us before you leave the ward. Your return to work will depend on the nature of your job. It is important that you contact occupational therapy at your workplace especially if your job is physically demanding.

**If you require any further information or clarification, including clarification of terminology, please do not hesitate to talk to one of the doctors or nurses, who will be happy to discuss your concerns with you.**

## **CONTACT DETAILS**

- Endometriosis nurses:** Endometriosis.nurses@mft.nhs.uk
- Appointment queries:** 0161 276-60000 (please select option 1).
- <https://mft.nhs.uk/saint-marys/services/gynaecology/endometriosis/>

Please contact for any emergency advice within 4 weeks of your operation.

 **Emergency Gynaecology Unit (EGU)**  
 (0161) 291 2561 (24 hours)  
 EGU is located at Wythenshawe Hospital (enter via entrance 15)  
 The department operates a telephone triage service you must call and speak with a specially trained nurse before attending to plan your care  
***There are no emergency gynaecology services at Saint Mary's Hospital, Oxford Road***



## **Gynaecology Assessment Unit (GAU/G2)**

(0161) 720 2010 GAU Reception / (0161) 604 5130 GAU Nurses

Monday to Friday - 07.30 - 20.30

Saturday & Sunday - 08:30 – 16:30

**GAU is located at North Manchester Hospital (Ward G2, via Entrance 1 / main entrance).** To be seen in GAU a referral from your GP, Midwife, A&E or other health care professional is required. GAU is not a self-referral unit.