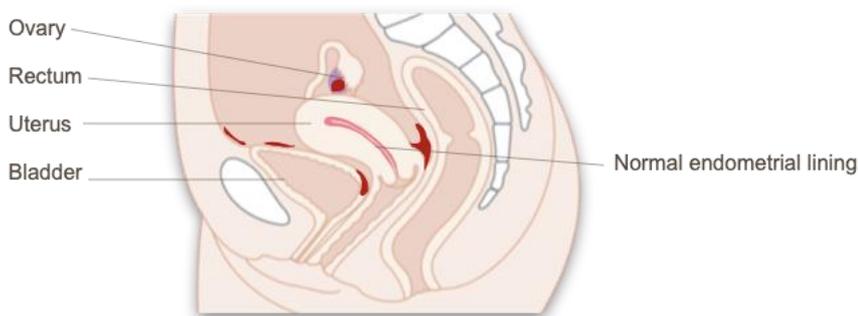


Surgery for Complex Endometriosis

An information leaflet for you about your operation and recovering well after surgery

What is endometriosis?

Endometriosis is a condition that affects 1 in 10 women and up to 50% of women with pelvic pain, discomfort or infertility. It is described as the finding of endometrium-like tissue that is normally found in the lining of the uterus or womb (endometrium) being abnormally located in areas other than the uterus, such as on the ovaries, bladder, ureter (tube from the kidney to the bladder), bowel or rectum.



What is laparoscopy?

Laparoscopy is a procedure to look inside the abdomen using a telescope. A laparoscope is a thin telescope with a light which is passed into the abdomen through a small incision (cut) in the skin, often referred to as a port. The laparoscope lights up and magnifies the structures inside the abdomen. It is connected to a television monitor allowing the surgeon to see clearly inside the abdomen.

A laparoscopy may be done to find the cause of your symptoms (such as painful periods or pain during intercourse) or to see a specific area within the abdomen or pelvis.

In addition to simply looking inside, the surgeon can use fine instruments to perform operations. These are also passed into the abdomen through three or four small incisions in the skin. These instruments are used to cut, trim, take a biopsy, or repair organs inside the abdomen.

How is it done?

The abdominal skin surface is cleaned. Under general anaesthetic the surgeon makes a small incision (cut) about 1-2 centimetres long near to the navel (belly button). Carbon dioxide gas is introduced through the incision to slightly distend (make larger) the abdominal wall.

This makes it easier to see the internal organs with the laparoscope, which is gently pushed through the incision into the abdominal cavity. The surgeon views the end of these instruments through the laparoscope and manipulates them to perform the required procedure.

If any endometriosis is seen, a further 1-3 incisions are made to allow treatment in the affected areas. The surgeon will then either burn out or remove (cut out) the affected areas.

You may be required to have medications before surgery to ease your symptoms until your operation. If you have a large cyst of endometriosis on an ovary, your surgery may require partial surgical treatment, followed by medication and a second planned procedure. In other words, your surgery will be undertaken in two stages to optimise complete removal of the disease.

BSGE (British Society of Gynaecological Endoscopy)

Norwich Endometriosis Centre is one of 63 centres in the UK accredited by the British Society of Gynaecological Endoscopy. We perform joint laparoscopies, sometimes with gynaecologists and colorectal/urological surgeons.

As a BSGE accredited Endometriosis Centre, we are required to collect questionnaire data about our patients. The data is anonymised and relates to the symptoms you experience, the surgery you may have and any changes in your quality of life as a result.

You may also be asked to complete an Endometriosis Health Profile (EHP – 30).

We will ask your permission before any information is shared and you have the right to decline. If you decline to complete these questionnaires it will have no effect on the care you receive.

Currently we are sending the questionnaires out via email, and we will ask for your email address, however paper copies are available if preferred.

Surgical Consent

By law we must obtain your written consent before any operation. We will explain all the risks, benefits and alternatives before you to sign the consent form. If you are unsure about any aspect of your proposed procedure or treatment, please ask us to explain again.

Identification wristbands

Wristbands are used to identify hospital inpatients. When you are in hospital it is essential that you are given and wear your wristband, which carries your name, date of birth, NHS number and hospital number. This ensures that staff can identify you correctly and give you the right care.

Your photographic records

As part of your treatment, a photographic record may be made, such as X-ray(s), clinical photographs or digital images, which will be kept confidentially in your health records and seen only by people involved in your care or quality checking. They are also extremely important for

teaching or medical research so we may ask for your written consent to use your images, in which case your personal details will be removed so you cannot be identified.

Your NHS Number.

When you attend hospital, you will be asked for your NHS number and other information, such as your address. Please be patient with this procedure - it is to ensure our records are kept up to date and to protect your safety. If you do not know your NHS number, please don't worry, you will still receive care.

Minor surgery

Although 1 in 10 women suffer with endometriosis, a small number of these require minor surgery that involves inspection and burning or cutting away the endometriosis tissue or spots. This is achieved via a laparoscope and can include:

- Dividing or removing adhesions (scar tissue)
- Treating an endometrioma or chocolate cyst (cyst filled with endometriotic fluid) This involves opening and draining the cyst then burning or stripping out the cavity. Care is taken to preserve as much normal ovarian tissue as possible and to reconstruct the ovary where required. This will usually significantly reduce pain in the majority (70 out of 100) women, although 30 out of 100 women will not get improvement in pain and 10-30 in 100 may get a recurrence of the cyst in the future. Stripping out the cyst seems to reduce the chance of recurrence, although it carries a small risk (less than 5 in 100) of the ovary failing to function in the future.

Major surgery

Sometimes the endometriosis is more advanced (1 in 100 women) and hence the complication rate is a little higher. Extensive surgery is usually achieved through a laparoscope, though a slightly longer duration of stay may be needed.

Major surgery often involves:

- Cutting away the tissue affected by endometriosis.
- Releasing ovaries
- Releasing adhesions and removing the tissue affected by endometriosis around the back and the side of the uterus, around the bladder and ureter and the space between the rectum and the vagina.
- Dissecting the ureter (tube that carries urine from the kidney to the bladder) to be able to remove endometriosis tissue and possibly inserting a tube (stent) into the ureter for six weeks or so, then removing it as a day case procedure under local anaesthetic.

Bladder disease

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

- a cystoscopy (inspecting the bladder with a scope) may be carried out.
- the bladder may need to be opened to remove the endometriosis.
- a catheter may be retained inside the bladder and the bladder rested for about 14 days.
- the consultants will advise you how long the catheter is required.

Bowel disease (rectovaginal endometriosis)

Your consultant should be able to tell you if this is likely to apply to you: often if you pass blood via your rectum during your periods, have pain passing your motions during your periods or if felt during an internal examination or seen on an MRI scan.

The bowel may sometimes be involved with endometriosis. The surgical treatment involves cutting the bowel free and assessing the degree of endometriosis. Sometimes nothing more need be done but at other times the endometriosis may need to be cut away. This may require taking off the surface layer of the bowel or taking out a small disc of bowel and sewing up the resulting hole.

Sometimes, if the involvement is extensive, a small section of the bowel needs to be removed and the bowel rejoined. These procedures are done with the bowel surgeons. The surgery may require an additional 3 cm cut in the pubic hairline or in the umbilicus (tummy button).

Occasionally, if the bowel join is very low (near the anus) or the operation has been technically difficult, a stoma bag is required (ileostomy/colostomy). This effectively diverts the faeces into a bag on the abdomen or stomach, thus protecting the join lower down, allowing it to heal. The stoma bag is usually left for three months and then requires a smaller operation to return the bowel into the abdomen. This usually requires a hospital stay of 2-3 days. Rarely, leakage of bowel fluid at the site where the bowel was stitched or stapled back together may occur. The risk of this is 4-8 in 100.

Bowel preparation

Before surgery you will be asked to stick to a low residue diet (mainly starchy foods, such as potatoes, bread and/or rice) and to avoid fibre. You may be given either an oral preparation or an enema the day before surgery to clean out your bowels. This will help with the surgery and may reduce the risk of complications if the bowel is involved.

Surgical risks

The risk of a major complication from a laparoscopy is only about 1-2 per 1,000. The risk from the most major type of laparoscopic surgery for endometriosis is up to 1 in 10. All the risks listed below will be discussed in detail by the surgical team before you are asked to sign the consent form for the operation. The risks include:

- Adhesion formation (where organs can stick together and sometimes cause pain or discomfort)
- Possible damage to bladder and ureter, needing a stent (tube) passed via a telescope. This is usually removed as a day case six weeks later. If the ureter is cut, it is possible that a cut will be required in the abdomen to rejoin it.
- loss of a tube or ovary due to bleeding
- A delay the return of bladder function or bladder irritability. Occasionally, you may need to self-catheterise in the short term and very rarely in the long term.
- A delay (or overactivity) of normal bowel function
- Damage to the bowel. This can be in the form of a leak from the join, resulting in an abscess. This may require draining with a small tube.
- Risk of a fistula (abnormal connection between the bowel or other organ and the vagina)
- Risk of recurrence of endometriosis or pelvic pain.

The risk of delayed complications that can occur up to two weeks after the procedure include bowel leak (following either cutting a disc-shape out of the bowel, or cutting a whole segment of bowel out and rejoining the two cut-ends) up to 4-8 in 100 and if this happens the mortality rate is estimated to be 3 in 100); ileus (bowel is temporarily paralysed, leading to distension and vomiting) - the risk is 5-10 in 100; haematoma (collection of blood in the abdomen) is 2-5 in 100. In addition, if a piece of bowel has had to be removed there may be changes to the way the bowels work in the future.

You may become either more constipated or the opposite may occur and, very rarely, you may become incontinent. These changes usually resolve over a period of weeks or months.

If any of these complications occur, a laparotomy (open surgery through a larger cut) may need to be undertaken to correct the damage or to stop the bleeding.

Other complications that can sometimes happen include:

- collapse of small areas of the lungs, which increases the risk of chest infection and may need antibiotics and physiotherapy
- clots in the legs/deep vein thrombosis (DVT) with pain and swelling. Rarely, part of this clot may break off and go to the lungs (pulmonary embolism [PE]), which is more serious and can be fatal.
- people who are obese are at increased risk of wound and chest infections, thrombosis (blood clots) or heart and lung and circulatory complications
- the procedure or subsequent complications can be fatal. The risk of death from a normal laparoscopy for minor endometriosis is 1 in 10,000 (similar to that of driving your car).

Recovering from your operation

After your operation the nursing staff will watch you closely until you have recovered from the anaesthetic. You may even be cared for in the intensive care unit immediately following your surgery, although this is rare.

The recovery period after bowel surgery varies. It usually involves a stay in the hospital of 3-10 days in uncomplicated cases.

Immediately after your operation, the following are usually in place for your care and wellbeing:

- Intravenous fluids via a cannula (fine plastic tube) in your arm to keep you hydrated until you can drink enough. You may also be given medication via this tube.
- A catheter (plastic tube) draining urine from your bladder into a collection bag so we can accurately measure the amount.
- A pelvic drain – a tube which comes out through your abdomen to allow any residual fluid or blood to drain.
- A PCA (patient-controlled analgesia) overnight where you have the control of pain relief medication which you administer yourself by pressing a button usually, you will be discharged the following day, but the duration of stay depends on the extent of endometriosis.

These are removed as soon as possible after your operation, depending on your condition and rate of recovery. You will be discouraged from spending long periods of time in bed and given the help you need to carry out your daily hygiene, dietary and exercise routines until you gradually become stronger and more independent.

Sometimes people feel sick after an operation, especially after a general anaesthetic and might vomit. If you feel sick, please tell a nurse. You may feel a little sore around the abdominal incisions and may have some pain in your shoulder tip. This is caused by the gas which had been pumped inside, irritating the diaphragm, which has the same nerve supply as the shoulder tip. This pain gradually eases, particularly once you are up and moving around.



Eating and Drinking: Straight after the procedure, you will be able to drink fluids when you are ready. Your doctor will discuss with you when you will be able to eat.

Once you can eat and drink you may have a reduced appetite. It is important to choose small amounts at more frequent intervals at first.

Meals can be supplemented with nourishing soups and snacks, and with high-energy drinks. The body will use a lot of calories during the healing process.



Your lungs and blood supply: It is likely that you will be wearing elastic (anti-embolism) stockings. These are tight-fitting stockings that are used to reduce the risk of blood clots forming in your legs.

It is very important after surgery that you start moving as soon as possible. This helps to prevent blood clots forming in your legs and possibly going to your lungs, which could be fatal.

You might be prescribed anti-clotting injections for one week following your surgery to reduce the risk of a blood clot. You will be shown how to give these to yourself before you go home.

You need to do your deep breathing exercises. Take 10 deep breaths every hour during the day for the first week to prevent secretions collecting in the lungs because if this happens you may develop a chest infection.

Avoid smoking after surgery because this increases your risk of a chest infection. Coughing is painful after abdominal surgery.



Exercise: Expect to feel tired for some time after surgery. You need to take things easy and gradually return to normal activities and work as you feel able. The time taken to recover from surgery is variable and depends on you as a person and the type of operation you have had. In most cases, this should take no longer than 2-6 months.



Driving: Check with your insurance company about whether there are any exclusions to your driving. This includes being under the influence of some pain medication. Ensure you can do an emergency stop and wear a seat belt before you drive.

On your discharge we advise you not to drive for four weeks but you must check with your insurance company. You will need somebody to collect you from hospital and accompany you home.



Work and resuming normal activities: You may experience more tiredness than normal because of the anaesthetic. Everyone recovers at a different rate, so when you are ready to return to work will depend on whether your surgery was minor or major, the type of work you do, the number of hours you work and how you get to and from work. Usually, you can resume normal activities including beginning gentle work within two weeks after your operation if you feel well.

If you have a physical job or are on your feet for long periods of time you will need a 'Fitness for work' certificate which we can give you before you leave the ward – make sure you ask before you are discharged. Generally, this is for six weeks, but you may require 12 weeks off.



Vaginal Bleeding: You may experience some vaginal bleeding for one to two weeks following the procedure. We advise the use of sanitary towels rather than tampons. You should refrain from swimming until the bleeding has stopped.

The first day or so the bleeding may be like a heavy period, but this will lessen overtime, and you may even have a brown discharge before it stops completely.

You may have a 'gush' of blood about ten days after the procedure; this is not uncommon and is part of the natural healing process.

If you are concerned about the bleeding because it has not settled, or you have a fever and flu like symptoms you should contact either your GP, Cley Ward or the Endometriosis Nurse (Please see the numbers below) for advice.



Wound Care: Your wound sites may have been closed by glue, or you may have a dressing covering the areas, these are usually removed the following day. You are advised to keep the wound area clean and dry, but you are able bath or shower. If the wound becomes red, hot to touch, or you experience swelling or oozing you should contact your GP or telephone Cley ward (please see numbers below) for advice.



Pain: Initially you may have a PCA, this is usually removed the following day and you will be given regular oral pain relief whilst in hospital. If you have had a laparoscopy, you may experience some soreness around the wound sites and may feel bloated due to the gas used during the operation. This gas can also create pressure on the abdominal nerve that is connected to the shoulder area and may make your shoulders ache. This discomfort may last up to a week.

Commonly following laparoscopy women can experience "wind" pain which causes pain in the abdomen and shoulders. We recommend that you move around to ease this and sometimes peppermint tea can help alleviate the pain. Simple painkillers such as paracetamol or ibuprofen may help relieve your pain, please take as instructed on the packaging. If your pain is not relieved by taking this medication regularly or the pain becomes distressing, please contact your GP or telephone Cley ward (please see numbers below) for advice.



Bowels: We recommend you drink plenty of fluids and eat lots of fresh fruit and vegetables to ensure that you do not become constipated following the surgery. If your procedure has involved bowel surgery you may be discharged with laxatives, we recommend you take these as directed.

 **Sexual intercourse:** We recommend that you wait four to six weeks before you have sexual intercourse, this is to ensure that you have healed internally and to prevent infection. You may find that your vagina is drier than before the surgery and may find the use of a vaginal lubricant beneficial; these can be purchased from most supermarkets and pharmacies.

 **Contraception:** Depending upon the type of surgery you have had and whether you are to manage your condition with hormones, it may be advisable to continue using your current form of contraception. Your doctor/nurse will discuss this with you and will give personal advice if your surgery was performed for subfertility.

 **Check-ups and results:** You will be given information about the results of your surgery after the operation. Usually, a letter is sent with the results as soon as these are available. A clinic appointment is not usually booked for routine follow-up after surgery; however, we may arrange a telephone clinic or face to face follow-up for you. However, if you feel you need to talk to someone, please contact the specialist nurse in the first instance, on the telephone number below

Further Questions

If you have any further questions, please see the numbers below:

- Your GP surgery.
- Cley Gynaecology Ward - 24 hours (For urgent advice post-surgery i.e., bleeding/pain) 01603 287242
- Endometriosis Nurse – Answerphone only. Please leave a message and the nurse will contact you within 2 working days (not urgent advice) 01603 286303.

We aim to provide the best care for every patient. So, we would like your feedback on the quality of the care you have received from the Hospital. Please visit: <http://ratenhs.uk/IQu9vx> Or scan QR code:

