

Surgical Treatment of Endometriosis

Patient Information Leaflet



A member of the medical or nursing team may have suggested that you undergo surgery for endometriosis. This leaflet aims to help you understand the planned surgical procedure and the associated benefits and risks. This type of surgery is usually performed while you are asleep (general anaesthesia). As with any other treatment, all of the alternative treatment options including “doing nothing” should have been explained to you along with the pros and cons, to enable you to make an informed decision.

Laparoscopy and Treatment

Laparoscopy (‘keyhole surgery’) in gynaecology is a technique in which a thin telescope is inserted into the abdomen to inspect the pelvic organs. An approximately 5 - 10mm cut is made within or under the belly button or below your left rib cage and your abdomen is filled with gas. This distension allows the surgeon to inspect the pelvic organs to investigate possible reasons for your symptoms such as endometriosis, adhesions (scar tissue) and other possible causes of your symptoms. Another small approximately 5mm incision is made close to the pubic hairline or on the side.

A further one or two (rarely three) incisions may be made to allow further investigation and possibly treatment to the affected areas. The surgeon would then for example either remove (excise) or burn out (ablation/diathermy) the affected areas, divide adhesions or drain and/or remove cysts.

You may be required to use hormonal medication or gonadotrophin releasing hormone analogue injections (GnRH) prior to or after surgery. If the tissue is very vascular (rich in blood vessels), or organs are very stuck together, your surgery may entail partial treatment followed by medication and then a second planned procedure (see below). In rare cases surgery will be undertaken in two stages to optimise complete removal of disease and to minimise unnecessary complications/organ injuries.

Minor Surgery

Minor surgery will involve inspection of the pelvic and abdominal cavity. It may also include:

- Burning or cutting out superficial areas of endometriosis.
- Division and removal of scar tissue (adhesions).
- Opening, drainage and possibly removal of a cyst filled with clear fluid called endometriotic fluid. These cysts are known as an endometrioma or chocolate cyst.
- Removal of one or both fallopian tubes filled with clear fluid or blood (hydro-/haematosalpinges)

Major Surgery

Depending on the extent of disease, more extensive surgery may be necessary. Endometriosis is a sticky disease and adhesions may form between organs. These will be divided to restore the anatomy. Important organs such as ureters (tubes that transport urine from the kidneys to the bladder), nerves and bowel will be preserved before the excision of any deep infiltrating endometriosis from the affected organs. This is outlined further under the section “Deep Infiltrating Endometriosis”.

General surgical considerations

- If drainage or the removal of an endometrioma (ovarian surgery) is necessary, care will be taken to preserve as much normal ovarian tissue as possible and reconstruct the ovary where required.

Studies have shown that ovarian surgery can reduce the ovarian reserve of eggs. However, drainage of cysts without removal may lead to recurrence of the cyst which will eventually impact on the fresh ovarian tissues.

Sometimes this only becomes apparent during planned minor surgery which may require the surgeon to stop the procedure. Further investigations will then be performed and discussed with you. This may require further consent for another surgery in the future.

- You may have a catheter (tube in the bladder) overnight.
- You may also have a PCA (patient-controlled analgesia) overnight where you have the control of pain relief medication which you may administer yourself by pressing a button.
- You may also have drain (tube) coming out of the abdomen to help drain the collected fluid/blood inside.
- You may be asked to see your doctor/nurse to remove the sutures (stitches) stitches after one week although most skin sutures dissolve on their own after a few weeks. Please ask your surgeon or nurse before you are discharged home which type of sutures were used.
- You may be discharged on the day of surgery. However, the duration of your stay may depend on the extent of endometriosis/treatment and your recovery. Often the patients who had surgery for severe endometriosis may be discharged on day 1-2.

General Surgical Risks

Specific risks listed below will be discussed in detail by the members of the surgical team when you sign the consent form for the operation.

The risk of a major complication of laparoscopic surgery in general is 1 - 2 in 1000 but may be up to 7 in 100 if the disease is more widespread or involving organs such as the bowel*.

**Byrne D et al, BMJ Open 2018:8.*

As with all surgery the associated risks may include:

- Infection, bleeding, thrombosis (clots in veins) and scarring/adhesion formation.
- Damage to internal organs such as bladder, ureters, blood vessels, nerves, and bowel (1-2/100).
- Surgery in the pelvis may result in delay in return of bladder function. Occasionally, in the short term and very rarely in the long-term you may need to self-catheterise to empty your bladder.
- If the ureters are involved, then a stent (tube) may be passed via a telescope before and during endometriosis surgery. The stent will be removed as a day case usually 6 weeks later.
- If the ureter is cut or injured, then it is possible that an incision will be required in the abdomen to re-join it.
- Bowel damage can result in severe infection and formation of an abscess. This may require draining with a small tube; occasionally it will require further laparoscopic or open surgery to correct the problem. Sometimes this may result in temporary stoma (1-2/100).
- Endometriosis involving the bowel may require removing part of it. Sometimes, this requires a temporary stoma, which means the end of the bowel will come out at the abdominal wall. A bag that collects faeces would then be applied. After a few months the bowel is usually reconnected in the abdomen, requiring another procedure by the surgeons.

- Delayed complications include bowel leakage, haematoma (collection of blood in the abdomen) or formation of a fistula (passageway between two hollow organs or the outside) that can occur after the procedure (1-2/100). In addition, if a piece of bowel has had to be removed then there may be changes to the way the bowels work in the future. These changes usually resolve over a period of weeks to months.
- Loss of a tube or ovary due to bleeding.
- No or little improvement in pain.

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 bleeding. If you experience sudden or increasing pain at home, develop a fever after your discharge from hospital, have vomiting or feel increasingly unwell, please seek medical advice immediately. You can contact the Gynaecology ward within 72 hours of discharge. Any follow up care will be outlined on your discharge summary when you leave the ward.

You can always contact the endometriosis pathway co-ordinator if you are unsure about any aspect of your on-going management.

Deep Infiltrating Endometriosis

Your doctor may suggest that surgery to treat superficial endometriosis is all that is required. However, if the disease is deep, additional surgical treatments may be undertaken at the same time. Your doctor will advise you about this before your surgery and may involve the following:

- More widespread excision of diseased tissue involving organs such as the bladder, bowel or ureters and nerves.
- Releasing adhesions and removing the tissue affected by endometriosis around the back and the side of the uterus (womb), around the bladder and ureters and the space between the rectum (end portion of the large bowel) and the vagina (recto-vaginal endometriosis).
- Freeing up the ureters to be able to remove endometriosis tissue.
- Removal of endometriosis tissue from the bowel or possibly removal of parts of bowel (shaving bowel endometriosis) or creating a small hole in the bowel wall during shaving process (discoid resection) or possibly removal of parts of bowel (re-anastomosis of bowel).

Bladder Disease

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

- A cystoscopy (inspecting the bladder with a thin tube that has a light and camera on the end, known as a scope) may be undertaken.
- The bladder may need to be opened to remove endometriosis and may need to remove a small part of the bladder.
- A tube called a catheter may be retained inside the bladder and the bladder will be rested for about 14 days. An x-ray following the administration of a fluid which will show up on the x-ray (contrast) will also be taken to make sure the bladder has healed properly.
- These procedures are sometimes done as a joint case with the assistance of a urologist, who is a specialist in surgery of the urinary system, especially when the endometriosis is affecting a specific area of bladder or is close to the insertion of the ureters.
- If the ureter is cut or injured, then it is possible that an incision will be required in the abdomen to repair it.

Ureter Disease

If endometriosis is found involving and/or compressing one or both of your ureters (tubes that transports the urine from your kidneys to the bladder) (ureters) we may need to insert a thin tube (stent) into them to minimise the risk of long-term damage of the kidneys and improve the flow of urine. These stents are only temporary and can be removed during a short outpatient procedure a few weeks after your surgery.

Bowel Disease

The bowel may have endometriosis, or it may be closely attached (tethered) to surrounding organs or structures. The surgical treatment may involve dissecting the bowel free and assessing the degree of involvement.

At times, nothing more needs to be done, however, 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 re-joined.

- These procedures are sometimes done as a joint surgery together with the bowel surgeons.
- Generally, shaving of bowel endometriosis is performed by an accredited gynaecologist in an accredited endometriosis centre.
- The surgery may require an additional 3cm cut in or above the pubic hairline.
- Occasionally, if a piece of bowel needs to be removed and the bowel join is very low (near the anus) or the operation has been technically difficult, then a stoma bag is required. This effectively diverts faeces into a bag on the abdomen or stomach, thus protecting the join lower down in the bowel 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 two to three days.
- In very rare cases you may be asked to take a medicine (this is referred to as bowel prep) the day before surgery to clean out your bowels. Alternatively, you may receive a bowel enema on the day of surgery. This will help with the surgery and may reduce the risk of complications if the bowel is significantly involved.

Endometriosis in upper abdomen (liver and diaphragm)

- These procedures are usually undertaken together with the surgeons who specialise in the surgery of the gastrointestinal organs and with, or without thoracic surgeons who specialise in surgery of the chest depending on the extent and location of the disease.

Endometriosis in the front wall of the abdomen

- These types of endometriotic nodules can be found close to or within scars of the abdomen caused by previous surgeries (e.g., Caesarean section, laparoscopy and midline laparotomy etc.)
- These procedures are sometimes done together with plastic surgeons who specialise in reconstruction or cosmetic surgery depending on the extent and location of the nodule.

Research

As you may have experienced many aspects of endometriosis remain unknown. In Oxford we have been very active in undertaking research into the diagnosis, causes and development of new treatment options for endometriosis. Therefore, you may be asked if you are interested in taking part in any on-going research studies to improve our knowledge of the condition. If you are happy to hear more about these studies, a member of the clinical and/or research team will give you more information. You will then have sufficient time to decide about taking part or not. Taking part in such a study is entirely voluntary and your decision will not have any impact on your clinical management. You can withdraw your consent at any time.

For more information on our research:

www.wrh.ox.ac.uk/research/endometriosis-care

Further Information about Endometriosis

If you would like to learn more about endometriosis please have a look at the relevant websites listed below. In addition, your medical, nursing or research team would be happy to answer your questions.

- www.wrh.ox.ac.uk/research/endometriosis-care
- www.bsge.org.uk/centre/category/accredited-centres/
- www.endometriosis-uk.org
- www.eshre.eu/Guideline/Endometriosis
- www.rcog.org.uk/for-the-public/browse-our-patient-information/endometriosis/
- www.fertilitynetworkuk.org
- www.pelvicpain.org

Endometriosis UK Patient Support Group

If you would like to be involved in the Oxford Endometriosis Patient Support Group you can sign up to the local group by using the following link:

www.endometriosis-uk.org/new-support-group-member

Or feel free to contact the group by email:

OxfordGroup@endometriosis-uk.org

Contacts:

Endometriosis secretary Patient Pathway Co-ordinator and Endometriosis MDT co-ordinator:

Tel: 01865 231571

Email: ouh.gynaesecjr@nhs.net

Endometriosis nursing team:

Email: Endonurse@ouh.nhs.uk

Gynaecology Surgery Waiting List Office:

Tel: 01865 223245

Gynaecology Ward: (Women's Centre, John Radcliffe Hospital)

Tel: 01865 222001

Gynaecology Research Office (Nurses):

Tel: 01865 572258

Email: gynaereseearchoxford@wrh.ox.ac.uk

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

Grateful recognition of the contribution from the Oxford Endometriosis Support group

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Oxford University Hospitals NHS Foundation Trust
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