NHS
The Leeds Teaching Hospitals
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Deep infiltrating endometriosis

Information for patients

Leeds Centre for Women's Health

This leaflet is for patients with deep endometriosis whose symptoms, treatments and risks associated with surgery are often more complex and challenging than patients with milder endometriosis.

Please first read the information leaflet on **'endometriosis' (LN005669)** this is available by scanning the QR code or visiting the Trust website:

https://www.leedsth.nhs.uk/patients-visitors/patient-and-visitor-information/patient-information-leaflets/gynaecology-general-conditions

What is deep infiltrating endometriosis?

Deep infiltrating endometriosis is also sometimes called 'severe', 'stage 4', or 'advanced disease'. It refers to endometriosis that is deeper embedded in the abdomen and into structures in your pelvis and abdomen such as the bowel, bladder, nerves and blood vessels. The National Institute for Health and Care Excellence (NICE) in the UK defines deep endometriosis as a nodule at least 5mm below the peritoneum, which is a thin layer of tissue that lines the organs of the pelvis and abdomen as well as the abdominal wall.

Deep infiltrating endometriosis is more likely to cause significant symptoms usually associated to the structure that it is buried into. It can also be more difficult to treat surgically with an increased risk of injury to the structures mentioned.

Diagnosing deep endometriosis

Symptoms

Symptoms of endometriosis can vary, but the common symptoms are pelvic pain which can be constant or come and go. Commonly it is worse before or during periods, or during or after sex.

Endometriosis involving the bowel is more likely to cause pain on opening your bowels and bleeding from your back passage during your period. Endometriosis involving your bladder may be linked to pain on passing urine or visible blood in your urine during your period.

Examination

In clinic the doctor might offer an examination of your abdomen, internal pelvic examination and occasionally an examination of your back passage. These examinations can help understanding where you are experiencing your pain, identify the presence of endometriosis nodules at the top of the vagina and may help to understand whether there is scarring related to deep endometriosis affecting some of your pelvic structures such as your womb.

Ultrasound

You will be offered a pelvic ultrasound scan if you haven't had one already. Ultrasound scans investigate your pelvic organs including your womb and ovaries. A scan may identify features of endometriosis such as endometriomas which are benign cysts that develop in ovaries associated with endometriosis.

Further investigations

You may be offered further investigations particularly if surgery is being planned in order to get as much detail on the structures of your pelvis and abdomen and where the endometriosis and any scar tissue is possibly located.

- **Pelvic MRI scan**
  MRI stands for magnetic resonance imaging. An MRI is a type of scan that creates pictures using magnetism and radio waves. It does not use X rays. A pelvic MRI scan produces images (or pictures) from various angles in your pelvis and shows up soft tissues (such as your uterus, ovaries and bladder) very clearly. These images are then reviewed by an experienced radiologist to look for signs of disease and a report is generated.

  The test takes about 40 minutes where you will be asked to lay still on your back within a tube-like structure that is close to you but does not touch you.

- **Sigmoidoscopy**
  You may be offered a sigmoidoscopy if you are experiencing significant bowel symptoms or rectal bleeding. This is a tube inserted into the rectum to look at the internal aspects. It is performed while you are awake and only takes a few minutes to perform. Endometriosis invading through the bowel can be seen.

- **Cystoscopy**
  You may be offered a cystoscopy if you are experiencing significant bladder symptoms or blood in the urine . This is where a camera is inserted through the urethra (urine outflow tube) into your bladder. Sometimes a biopsy is taken of the bladder tissue. It is performed while you are awake and only takes a few minutes to perform.

- **Diagnostic laparoscopy**
  You might be offered a diagnostic laparoscopy. This is key-hole surgery performed under general anaesthetic (where you are put to sleep) aimed to investigate the cause of your symptoms. A camera and surgical instruments are placed through small holes in your abdomen to look into your abdomen and your abdominal and pelvic organs. If minor endometriosis is seen it can be treated at the same time.

  If needed you might be offered to have a sigmoidoscopy and/or cystoscopy at the same time as your diagnostic laparoscopy.

Multi-disciplinary meetings

If you are suspected to have deep endometriosis your care will be discussed at a multi-disciplinary meeting dedicated discussing patients with deep infiltrating endometriosis in order to offer the right and best treatment for you. The MDT includes specialist endometriosis gynaecology surgeons, nurses, radiologists, bowel surgeons, bladder surgeons and thoracic surgeons.

The team may also suggest additional tests to gain more information before offering surgery.

Alternative treatments to surgery

Those are extensively discussed in the endometriosis patient information leaflet. The standard treatments for endometriosis include lifestyle changes, pain relief medications, hormonal/contraceptives, basic laparoscopic surgery and occasionally Gonadotrophin releasing hormone (GNRH) injections.

Commonly patients have already tried all or the majority of these treatments without sufficient success prior to considering more extensive surgery. But if symptoms are adequately controlled using other treatments there may be no need to treat deep endometriosis with surgery.

Surgery

The management of deep disease is usually performed keyhole (laparoscopically). Your gynaecologist will discuss what operations can be performed for your endometriosis with the risks, benefits and recovery period will be explained to you. It may be necessary for bowel and/or bladder surgeons to meet with you prior to the surgery to make sure you are fully happy with the part of the operation they will be undertaking and the associated risks involved.

The planned operation is likely to be a RLEE (radical laparoscopic excision of endometriosis) plus removal of other causes of pain such as adhesions or ovarian cysts.

Depending on whether your family is complete and other factors, your surgeon may also discuss the option of having a hysterectomy (removal of the uterus) and the tubes and removal of the ovaries at the same time.

One stage surgery: This is when the surgeon plans to treat most, if not all your endometriosis in one operation. If you are known to have deep endometriosis before your surgery, there will have been a chance for you to understand the procedure and it's risks and benefits. Your surgeon will have had an opportunity to plan for the surgery including involving specialist surgeons where necessary such as colorectal surgeons (if you have bowel endometriosis) or urologists (if you have bladder endometriosis). This offers the best chance of safely removing as much endometriosis as possible during one operation.

Two stage approach: If you have a diagnostic laparoscopy, your surgeon may find deep endometriosis that was not suspected. If possible, your surgeon will treat as much of the endometriosis as is felt to be safe and reasonable.

You will be offered a follow up to review your symptoms and discuss further treatment if required. Sometimes the surgery performed after one operation is enough to improve your symptoms. However, if no endometriosis was treated or your symptoms are no better you might be offered a second procedure to treat the remaining endometriosis.

You might also be offered a two-stage approach if your surgeon knows that you have deep endometriosis but a procedure carries significant risk of injury of harm to you. In such a circumstance your surgeon might suggest treating some endometriosis but not all in a first operation.

For example, if you have a large endometrioma (chocolate cyst) as well as endometriosis affecting your bowel and it is known that surgery on your bowel carries significant risk, your surgeon might discuss the risks and benefits of removing the endometrioma and removing the bowel affected by endometriosis versus initially just removing the large endometrioma. It may be that it is reasonable to offer a less risky procedure that could still treat your symptoms. You would then be offered second surgery in a planned prepared fashion if the first surgery did not help your symptoms.

The benefits

Studies show that patients report significantly better pain and quality of life following surgery. On average patients reported their quality of life as 55/100 before the operation, improving to 80/100 after the operation and maintained at 2 years after the operation. Patients who had pain opening their bowels or during intercourse reported that this pain was 6/10 before surgery, reducing to 1/10 after.

Similar improvements were seen in patients with pelvic pain, period related pain and low back pain. It is important to remember that these are averages, some will have better results, some unfortunately will not see any improvement. We would usually recommend post operative hormonal therapy for example Mirena coil, Dienogest or GnRH analogues continuing for 6-12 months to help prevent recurrence of the disease.

The risks and complications

Endometriosis is an inflammatory condition of the pelvis which can cause the organs within your body to stick together and distort the normal anatomy. This leads to an increased risk of complications during surgery. Overall, risk of complication is 6.8% or 7 in 100 surgeries.

Broadly speaking at a standard operative laparoscopy, unexpected damage to the other organs in your body (bladder, bowel and ureter) is about 0.2% or 1 in 500. Endometriosis surgery doubles the risk of unexpected bladder and ureteric injury (0.4% 4 in 1000 or 1 in 250 and 0.5% or 1 in 200) and triples the risk of bowel injury (0.6% or 1 in 167).

Often with endometriosis surgery the organs are cut or partially removed on purpose (for example bowel surgery), especially if the endometriosis is known to involve them.

Damage to the bladder and ureters:

Bladder

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. After this time, you will have a cystogram (test where dye is injected through the catheter into the bladder) to check that the bladder has fully healed and will not leak through the closure. Once the cystogram has been performed you will be asked to attend the hospital where your catheter will be removed and you will undergo a "trial without catheter". If your cystogram demonstrates a bladder leak, we would usually leave the catheter for another week and repeat the process.

Ureter (tube that connects your kidney to your bladder)

If your ureters are affected by endometriosis, the surgeon may insert a stent (tube) into the ureters via a telescope to help prevent ureters from incidental damage. If the ureter is cut or damaged, the surgeon may need to perform a larger operation involving a skin cut through which they can repair the injury. The stent is removed six weeks later as a day procedure.

Other Bladder Problems

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:

Sometimes endometriosis involves the bowel. The part of bowel called rectum can often be firmly stuck to the back of the womb exposing it to damage 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 they 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 may need a stoma. Most stomas can be "reversed" (closed) within 3-6 months but occasionally they are permanent.

In some cases, the bowel surgery and stoma are part of the planned procedure.

The complications of bowel surgery include: leak from the join where the bowel was repaired (0.4% or 1 in 250), pelvic infection, abscess which need further surgery.

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:

- Conversion from keyhole (laparoscopic) to open Surgery 1% or 1 in 100.
- Bleeding from a damaged blood vessel 0.2% or 1 in 500.
- Damage to your nerves.
- Infection.
- Blood clots in your legs (deep vein thrombosis also known as DVT) and lungs (pulmonary embolus PE).
- Loss of a fallopian tube and/or ovary due to bleeding.
- Nerve injury. Various nerve injury can present with different complications. Nerve injury are uncommon and not well studied to provide an accurate risk. Some patients have developed difficulties with passing urine shortly after surgery which is often temporary; others have developed more permanent urinary symptoms many years after surgery, including the need to intermittent self catheterisation.

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 0.8% or 1 in 125.
- A fistula (abnormal connection between the bowel or other organ and the vagina) that can develop 0.5% or 1 in 250.
- Internal scar tissue.

Stoma

A stoma is a loop or piece of bowel brought to the skin surface of the abdomen emptying into a bag. There are two main type of stoma 1.) small bowel or ileostomy 2.) large bowel or colostomy. An ileostomy is usually performed during elective surgery to protect the internal closure of your bowel after bowel surgery. The decision to perform a stoma depends on where the piece of bowel is removed and how much is removed. A colostomy is more often performed as an emergency if there is a bowel leak.

If a stoma is considered preoperatively, you will have a discussion with a stoma nurse.

Please see the patient information leaflet entitled '**Dietary advice for your ileostomy' (LN004669)** for more information on what to eat and what will help when you have an ileostomy, this is available by scanning the QR code or visiting the Trust website:

https://www.leedsth.nhs.uk/patients-visitors/patient-information-resources/diet-and-nutrition

Proceeding with surgery

After discussion, if both yourself and your surgeons agree to proceed with planned surgery, a date will be set for the surgery and you may be asked to fill out baseline health questionnaires.

You will attend a pre-operative appointment where blood tests are taken and a final suitability for surgery and anaesthetics are checked. You may be provided with dietary advice and medications to take before the surgery to prepare your bowels to reduce the risk of injury and complications if injury occurs. On the day of surgery, prior to the procedure, you will again meet your surgeon to finalise your consent for surgery which would have been started in the gynaecology outpatients.

Some patients go home on the same day as the surgery, with the majority being discharged within 24 hours of the surgery. Patients recovery is variable, but you should feel better every day after surgery with a view to feeling 'normal' and resuming normal activities by 2 to 4 weeks.

Follow up will vary depending on the operation. If you were asked to fill out pre operative health questionnaires you will be asked to repeat these at 6, 12 and 24 months after surgery.

Further information and support

Endometriosis

- **National Institute for Health and Care Excellence (NICE) - Endometriosis: Diagnosis and Management:** www.nice.org.uk/guidance/ng73
- **National Institute for Health and Care Excellence (NICE) - Patient decision aid: Hormone treatments for endometriosis symptoms. What are my options:** www.nice.org.uk/guidance/ng73/resources/patient-decision-aid- hormone-treatment-for-endometriosis-symptoms-what-are-my-options-pdf- 4595573197
- **NHS conditions: Endometriosis:** www.nhs.uk/conditions/Endometriosis/Pages/Introduction.aspx
- **ESHRE: Information for women with endometriosis:** www.eshre.eu/Guidelines-and-Legal/Guidelines/Endometriosis-guideline/Patient-version.aspx
- **Endometriosis UK:** www.endometriosis-uk.org
- **British Society for Gynaecological Endoscopy:** http://bsge.org.uk/
- **RCOG Laparoscopy leaflet:** www.rcog.org.uk/en/patients/patient-leaflets/laparoscopy

Chronic Pelvic Pain - Information and Support

- www.pelvicpain.org.uk
- www.vulvalpainsociety.org

Emotional Wellbeing

- **Someone to listen**
  www.samaritans.org
- **Suicide Sanctuary**
  www.maytree.org.uk
- **British Infertility Counselling Association**
  www.bica.net
- **British Association of Counselling and Psychotherapy**
  www.bacp.co.uk

Bladder Symptoms

- http://bladderhealthuk.org/bladder-health-uk

Irritable Bowel Symptoms

- www.nhs.uk/Conditions/Irritable-bowel-syndrome
- www.theibsnetwork.org
- www.patient.info/health/irritable-bowel-syndrome-leaflet

Fertility

- **Human Fertilisation and Embryology Authority**
  www.hfea.gov.uk
- **British Infertility Counselling Association**
  www.bica.net
- **Fertility Advice, Support and Information**
  www.infertilitynetworkuk.com
- **Family Planning Association**
  www.fpa.org.uk

Menopause

- **www.menopausematters.co.uk**
- **www.womens-health-concern.org**

Contact us

The Gynaecology Acute Treatment Unit (GATU)

- **Level 2 Chancellor Wing, St James's University Hospital, Beckett Street, Leeds, LS9 7TF**
- **Telephone: 0113 206 5724 (24 hours)**
- **Email: LeedsTH-TR.ENDOMETRIOSIS@nhs.net**

What did you think of your care?

Scan the QR code or visit **bit.ly/nhsleedsfft**

Your views matter

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