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# Treatment options for deep endometriosis

Department of Gynaecology

Information for Patients

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## What is deep endometriosis?

Endometriosis is not a cancer. It is also not a pre-cancerous condition. It is very unlikely to be life-threatening.

In some people, it can grow deeper into the pelvis. This may affect organs such as the bowel, bladder, ovaries, or tissues around the womb. This can cause:

- pain,
- heavy bleeding,
- painful periods,
- painful sex,
- sometimes problems having a baby (fertility problems),
- bowel symptoms: pain when opening the bowels, constipation, diarrhoea, bloating, or bleeding from the back passage, especially around periods.
- bladder symptoms: pain when passing pee, needing to pee often, bladder pressure, or blood in the pee, especially around periods.

Endometriosis is different for each person. In some people it stays stable for years, while in others it may progress. The treatment we use is based on your symptoms, imaging findings such as ultrasound /MRI, examination findings, and your wishes about having a baby.

## Diagnosing deep endometriosis

We diagnose deep endometriosis by looking at your symptoms, imaging scans and examination findings. In clinic, the doctor may offer a tummy (abdominal) examination, internal pelvic examination and sometimes a rectal examination. This can help identify tenderness, reduced mobility of pelvic organs or lumps (nodules) at the top of the vagina, which may suggest deep endometriosis.

We often do a transvaginal ultrasound scan. This gives the best view of the pelvis. Ultrasound can identify ovarian endometriotic cysts, called endometriomas, and other signs that may suggest deep endometriosis.

If symptoms, examination or ultrasound findings suggest deep endometriosis, we may arrange for more tests before planning treatment. These tests may include:

- **MRI scan**

An MRI scan is a detailed scan of the pelvis. You will lie on a bed while a ring-shaped scanner takes images of the pelvis and internal organs. MRI does not use radiation. The scanner does not touch you, but it takes several pictures for around 40 minutes to build a detailed image. MRI can help identify deep endometriosis, involvement of other organs, and adhesions or scarring between pelvic organs.

- **Sigmoidoscopy**

We may offer a sigmoidoscopy if you have bowel symptoms or rectal bleeding. A small camera is passed into the back passage to look at the lower bowel. This can help identify bowel endometriosis or other causes of bowel pain and bleeding. We do this test while you are awake and only takes a few minutes.

- **Cystoscopy**

We may offer cystoscopy if you have bladder symptoms or blood in the pee (urine). We pass a small camera through the urethra into the bladder to look for bladder endometriosis or other causes of symptoms. We do this test while you are awake and only takes a few minutes.

- **Multidisciplinary team meetings**

We may have talks with the multidisciplinary team in a meeting. This includes specialist gynaecologists, radiologists, bowel surgeons, bladder surgeons and specialist nurses. The team reviews the findings and recommends the best treatment options.

## Medical treatment

Hormonal treatments can help reduce pain and may slow it down. This does not remove endometriosis. Symptoms can come back when treatment is stopped. Common medical options include:

- **GnRH antagonist such as Ryego / Linzagolix**

This is a tablet you take daily. It lowers ovarian hormone activity. Ryeqo contains a small amount of hormone “add-back” treatment to reduce menopause-like side effects. With Linzagolix, there is add-back option. This means we can give hormone replacement therapy (HRT) as needed.

Possible side effects: hot flushes, mood changes, irregular bleeding, and reduced bone density. You may need a bone density scan if treatment is continued longer term. You will need to use a reliable non-hormonal contraception for the first month.

- **GnRH agonist injections such as Zoladex, Prostap or Decapeptyl**

These are injections. They switch off the ovaries for a short period of time. They create a reversible menopause-like state.

They are often used for 6 to 12 months with hormone add-back treatment. They can improve symptoms, but symptoms may return after stopping treatment.

- **Dienogest**

This is a daily progesterone-type tablet that can reduce endometriosis activity.

Possible side effects: irregular bleeding, headaches, acne, weight changes, and mood changes.

- **Levonorgestrel coil (LNG-IUS)**

This is a hormone-releasing coil placed inside the womb. It can reduce bleeding and period pain. It also acts as contraception.

You may get irregular bleeding in the first few months. Many patients later have very light periods or no periods.

## Surgical treatment

In surgery we can remove visible endometriosis. This helps to improve symptoms and restore normal pelvic anatomy where possible.

The type of surgery needed depends on where the endometriosis is found and how deeply it is affecting the tissues around it. We often do a keyhole surgery (either as laparoscopy or robot assisted) whenever possible.

In selected patients, we may offer robotic surgery. This is a keyhole surgery. Here the surgeon uses a robotic system to control very precise instruments through small cuts in the tummy (abdomen).

Robotic surgery is not needed for every patient. It depends on:

- how complex and where your endometriosis is,
- if bowel or bladder surgery may be needed,
- previous surgery or scarring,
- your body weight and what is safest and bests for you.

If endometriosis is close to or involving the bowel, your surgery may include a gynaecology surgeon and a bowel surgeon.

# Bowel endometriosis

Your MRI may suggest that endometriosis or scarring is affecting the lower part of the large bowel. MRI is very helpful, but it cannot always show exactly how deep it goes. Because of this, we can only make a decision for the type of bowel surgery you need during the surgery. You may be asked to give consent for more than 1 possible bowel procedure before surgery. This is so that the surgical team can safely choose the best option during the surgery.

# Possible bowel procedures

### Bowel shaving

In this surgery we remove endometriosis from the surface of the bowel or from the outer muscle layer. We do this without opening the inside of the bowel.

This is often suitable when endometriosis is on the surface or not deeply entering the bowel wall.

The risk of making a hole in the bowel is low, around 1 in 100. If this happens, it is often repaired during the same surgery. The chance of bowel endometriosis returning in the longer term is around 10 in 100.

### Disc excision

- In this surgery we remove a small disc-shaped area of the bowel wall where the endometriosis is.
- We do this if there is a deeper lump (nodule) of endometriosis, often less than 3cm. We do this when we do not to remove a longer section of bowel.
- You often do not need a stoma.
- There is a small risk of bleeding or leakage from the bowel repair site. This happens in around 1 to 6 in 100 of patient. You may need more treatment if this happens.

### Segmental bowel resection

- In this surgery we remove a short section of bowel affected by endometriosis. We then join the healthy ends back together.
- We may need to do this if the endometriosis is bigger, deeper, or involves more than 1 area of bowel.
- In some cases, we may need to use a stoma to protect the bowel join while it heals. A stoma is when poo is moved into a bag outside the tummy instead of passing the normal way. This is often for a short while. You can go back to normal without the stoma around 6 to 9 months later.
- Risks include infection, bleeding, bowel leak, abscess, bowel function changes, and symptoms coming back.

## Is a stoma always needed?

No. A stoma is not always needed after bowel surgery. The chance of needing it is low.

A stoma is only needed for a short while if the bowel join needs extra protection while it heals. We make this decision during the surgery based on your safety.

## After the surgery

**Symptom improvement:**

- Many patients notice a big improvement in pelvic pain, period pain, and heavy bleeding after surgery.
- However, surgery does not mean a complete cure for pain. Some symptoms, especially bloating, fatigue, constipation, urgency, or incomplete bowel emptying, may not fully improve.
- Some patients with long-standing pelvic pain may also need support from a specialist pain clinic.

**Activity and recovery:**

You should avoid:

- heavy lifting,
- strenuous exercise,
- vaginal sex for 6 weeks,

This gives time to your tissues to heal properly.

## Risks and complications

Keyhole surgery for endometriosis is safe, but it is still a major surgery. Possible risks include:

- bleeding,
- infection,
- pelvic abscess,
- internal scar tissue,
- injury to the bladder, bowel, or ureters,
- blood clots in the legs or lungs,
- need to change to open surgery,
- need for blood transfusion,
- readmission to hospital,
- very rarely, serious complications including death,

The risk of complications is higher when deep endometriosis involves the bowel, bladder, ureters, or pelvic sidewall.

## Specific risks in deep endometriosis surgery

Possible risks include:

| Possible complication | Possible risk |
|---|---|
| Blood clots in the legs or lungs | 4 in 1,000 patients |
| Pelvic infection or abscess | 2 in 1,000 patients |
| Blood transfusion | 1 to 1.5 in 100 patients |
| Bladder injury | 1.3 in 100 patients |
| Ureter injury | 1.1 in 100 patients |
| Bowel injury during shaving | 1 in 100 patients |
| Conversion to open surgery | 3 to 4 in 100 patients |
| Fistula involving bowel or urinary tract | 7 in 1,000 patients |
| Bowel leak after bowel resection | 1.5 to 6 in 100 patients |

## Sexual activity after hysterectomy

If you have a hysterectomy, the top of the vagina is closed with stitches. The risk of this area opening is very low. Please give time for proper healing. Avoid vaginal sex for 6 weeks.

## Your eggs and having a baby

If you need surgery on an ovary, for example to remove a endometriosis cyst, there is a chance that some healthy ovarian tissue may be affected. This can reduce the egg supply. This can make it harder for you to get pregnant.

We try to reduce this risk by using careful surgical techniques, limiting heat energy where possible, and using fine dissolvable stitches when we can.

Surgery for severe endometriosis may improve fertility in some patients. However, it cannot be promised that you will get pregnant or have baby.

## Removing or keeping your ovaries

This is your choice. It depends on your age, symptoms, your wishes to have a baby, severity of disease, and long-term health.

**Keeping the ovaries**

- Your body will keep making natural hormones. This helps protect bone, heart, brain, and general health.
- You do not get instant menopause.
- Because the ovaries keep making oestrogen, there is a higher chance that endometriosis symptoms may return.

**Removing the ovaries**

- Reduces oestrogen levels and may lower the chance of endometriosis coming back.
- We may talk about HRT but it is not suitable for everyone.
- The decision to have this will only be made after speaking with you.
- Can cause instant and permanent menopause. This can cause:
  - hot flushes,
  - mood changes,
  - vaginal dryness,
  - reduced bone density,
  - possible long-term heart,
  - bone health risks,

## Expected outcomes

Most patients with severe endometriosis have an improvement in pain and quality of life after surgery. However, it is important to understand that:

- Surgery may not completely remove all pain.
- Bowel symptoms may not fully improve.
- Bloating and fatigue often do not improve by a lot.
- Symptoms can sometimes worsen.
- You may need more treatment.
- Sometimes the disease is more advanced than expected from MRI.
- In some cases, we may need to do surgery in stages.
- You may still struggle to get pregnant.

## Hospital stay

Your hospital stay depends on the type of surgery you have.

You may stay for:

- Bowel shaving: 1 to 2 nights
- Disc excision or bowel resection: 3 to 4 nights

Your recovery depends on the complexity of the surgery and how you feel afterwards.

**Time off work**

Most patients need around 6 to 8 weeks off work after surgery.

This depends on the type of operation, your job, and how your recovery progresses.

We can give you a letter for your employer if needed.

## Travel after surgery

We do not advise long-haul travel for at least 4 weeks after major pelvic or abdominal surgery. This is because there is an increased risk of blood clots.

If travel is unavoidable, please speak to your surgical team. You may be advised to use:

- compression stockings,
- regular walking and leg exercises,
- good hydration,
- blood-thinning injections, such as Clexane, in some cases.

## Your treatment

We understand that decisions about endometriosis treatment can feel overwhelming.

We will talk about your treatment plan with you carefully, taking into account your symptoms, scan findings, fertility wishes, and personal priorities.

Health information and support is available at www.nhs.uk or call 111 for non-emergency medical advice
Visit www.uhleicester.nhs.uk for maps and information about visiting Leicester's Hospitals.
To give feedback about this information sheet, contact uhl-tr.informationforpatientsmailbox@nhs.net

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