NHS
University Hospitals Sussex
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Severe Endometriosis

Department of gynaecology

Patient information

This leaflet includes details on what endometriosis is, how severe endometriosis is different, what surgery for severe endometriosis involves, the possible risks of having the surgery and what to expect after surgery. This information is for you if you have been suspected or diagnosed to have severe endometriosis. It may also be helpful if you are the partner or relative or caring for someone with severe endometriosis.

What is endometriosis?

Endometriosis is a condition where tissue similar to the inner lining of the womb (endometrium) is found elsewhere, usually in the pelvis around the womb, ovaries and fallopian tubes. This tissue can cause inflammation, pain and the formation of scar tissue. It is a common condition, affecting around 1 in 10 women, usually in their reproductive years. It can be a long-term condition that can have a significant impact on your daily activities, general physical health and emotional wellbeing.

What are the symptoms of endometriosis?

Classical symptoms of endometriosis include:

- Painful periods, sometimes periods can be irregular or heavy
- Chronic pelvic pain, occurring when a woman is not menstruating
- Pain during or after sex
- Fertility problems or difficulty getting pregnant
- Fatigue
- Pain in lower back or the tops of your legs.
- Bowel symptoms (periodic bloating, painful bowel movements, recurring constipation, diarrhoea or cyclical bleeding)
- Bladder symptoms (Painful urination or cyclical pain when passing urine, cyclical blood in urine)

- Cyclical shoulder pain
- Cyclical cough or any other cyclical symptom
- nodules which enlarge during your period eg in an old scar or belly-button.

Some women with endometriosis do not experience any symptom, whereas others report multiple symptoms at the same time. Also, it is important to note that your symptoms do not necessarily correlate with the stage of disease.

How is severe endometriosis different?

When endometriosis is severe, it affects more areas within the pelvis and abdomen, such as the ovaries, womb, bladder and bowel. Adhesions develop when scar tissue attaches separate structures or organs together, causing debilitating symptoms.

How is severe endometriosis diagnosed?

You may be suspected to have severe endometriosis based on certain symptoms, clinical examination, imaging or it may have been detected during previous surgery. Based on this, you will be referred to an endometriosis specialist centre where a specialist team that usually comprise of a gynaecologist, a bowel surgeon, a urologists, a radiologist and specialists in pain management will discuss further diagnosis and treatment options with you.

During clinical examination the doctor looks for tenderness, nodules or swelling of the vaginal wall especially in the deepest point of the vagina between the back of the uterus and the rectum by inspection using the speculum and by palpation using his/her fingers. This may also give considerable information regarding deep endometriosis or endometriosis of the ovaries.

You may also have a transvaginal ultrasound to aid in the diagnosis of ovarian endometrioma or deep endometriosis.

In women suspected to have severe endometriosis, there can be lesions in other organs and/or adhesions.

Your specialist may request an MRI scan to assess the extent of the disease and/or additional imaging for assessment of the ureters, bladder and bowel involvement in preparation for further management.

How is severe endometriosis managed?

While medicine and pain relief are usually the first line treatment, you may find it difficult to manage severe endometriosis symptoms with these measures alone and surgery may be offered as further treatment. Prior to any surgery your case will be discussed in an endometriosis multidisciplinary team (MDT) meeting where all the specialists involved will review your case and plan management,

What does surgery for severe endometriosis involve?

With the aim of safely removing as much visible disease as one can, the surgery recommended usually involves:

- removing any ovarian endometriotic cysts (endometriomas) and/or releasing the ovaries that may be stuck to the pelvic wall, uterus or to each other
- dividing adhesions, i.e., scar tissue that causes different structures to be stuck together
- identifying the ureters (tubes that carry urine from the kidneys to the bladder) and freeing them by dissecting any endometriotic tissue around them.

- removing any tissue affected by endometriosis around the back and the side of the womb, the ureter and the bladder, the space between the vagina and rectum (back passage) or the bowel wall itself. A small part of the top of your vagina may also need to be removed if endometriosis affects your vagina.

Bowel endometriosis

If endometriosis affects your bowel, a specialist gynaecologist will perform the surgery, who may be assisted by a bowel surgeon. Your bowel will be freed from any areas it is stuck to and endometriosis tissue that has grown into your bowel will need to be removed. This can be achieved in the following ways:

- **shaving** - lesions involving the superficial surface of the bowel are 'shaved' off the bowel
- **discoid resection** - small 'disc' of bowel wall is removed and the defect is sutured
- **segmental resection** - a segment/section of bowel is removed and the ends are joined together with metal staples.

Type of surgery performed depends on area of bowel involved and extent of involvement. There is a potential risk of needing a temporary stoma to allow your bowel to heal. A stoma is a diversion of the bowel into a separate bag through an opening in the skin. You may be advised to modify your diet to include low-fiber foods for few days before surgery. You may also need to have an enema to empty your bowel before operation.

If a portion of your bowel has been removed, you may notice changes in your bowel movements such as needing to go on more occasions compared to prior to surgery, often feeling the need to rush to the toilet, incontinence due to problems controlling your bowel movement and difficulty in emptying your bowels completely. It usually takes a few months for your bowel function to improve.

Bladder endometriosis

A bladder surgeon (urologist) may help the specialist gynaecologist during the surgery if endometriosis affects your bladder and/or ureter/s.

If endometriosis is involving your bladder, you may need a cystoscopy – which means looking inside your bladder with a telescope and a partial cystectomy, meaning removal of a small portion of your bladder. The bladder defect is then closed with sutures and you will need to have a urinary catheter for a few weeks to allow your bladder to heal post-surgery. You may notice that you are needing to pass urine more frequently and not able to hold as much urine before needing to go as compared to before surgery. If your ureter is affected by endometriosis, you may need stenting (insertion of small plastic tubes into the ureters) and excision of ureteral lesions.

What are the risks of surgery for severe endometriosis?

Surgery for severe endometriosis is more complex and can be associated with complications with a higher risk of injury to organs as follows:

- unanticipated bowel injury (1/150)
- ureteric injury (1/200)
- unforeseen bladder injury (1/250)
- injury to blood vessel/s (1/500)
- stoma formation (1/350)
- bowel fistula (abnormal connection between the bowel and another organ)
  - 1/500 if disease shaved
  - 1/100 if segmental resection

- bowel leak
  - 1/500 if disease shaved
  - 1/50 if segmental resection
- issues with fertility
- early menopause and long-term consequences due to that

General risks of surgery include;

- Bleeding
- Infection or abscess formation
- Loss of blood requiring blood transfusion
- Blood clots in the leg or lung
- Scarring
- Pain
- Laparoscopic site bruising or hernia
- Anaesthetic risks

Not all complications and organ injuries are detected at the time of surgery and these may present over the course of the next few days. It is important that you seek medical advice if you do not feel well, have fever or if you have a lot of pain. There is a risk of you needing a second operation in order to fix a missed serious complication during the primary surgery.

What to expect after surgery?

Usual length of stay in hospital:

This is variable and completely depends upon the extent and complexity of surgery performed. If you have had a relatively simple, straightforward procedure as part of an operative laparoscopy, you may be able to go home on the same day, though you may be asked to stay in hospital overnight. Most people will stay in the hospital for a couple of nights, but if you underwent

open surgery or your surgery was particularly complicated, then you may need to stay for longer. It is advisable that you are not alone when you go home and that someone can stay with you overnight.

After-effects of general anaesthesia:

During the first 24 hours you may feel more sleepy than usual and your decision making may be impaired, hence it is safer to have an adult with you during this time and you should refrain from driving or making any important judgements. You should not have any after-effects for more than a day after your surgery.

Catheter:

You may have a catheter inserted into your bladder during surgery. This can be removed on mobilization the following morning unless there has been a surgery on the bladder, in which case it may stay in for longer.

Scars:

You will usually have three to four small scars (5mm to 10mm in size) on your abdomen if you have had a key-hole surgery. One of these scars will be in your belly button. One of these scars may be bigger if the bowel has been operated on.

Alternatively, if you underwent an open surgery, you will have a longer scar on your abdomen, which may be vertically below your belly button or along your bikini line.

Stitches and dressings:

Your cuts will be closed with stitches. These are usually absorbable sutures. You will have water-resistant dressings covering your cuts and stitches. You should be able to take these off about 2-3 days after your operation to have a wash or shower.

Vaginal bleeding:

It is very common to have some vaginal bleeding for a few days after your operation, most likely because there may be a temporary instrument placed inside your womb during the operation.

Pain and discomfort:

You may feel some pain and discomfort in your abdomen for first few days after the surgery, particularly around the scars. You may also have pain in your shoulders, which is a common side effect of the operation and is normal for 24 to 48 hours. You should take regular pain relief, such as paracetamol and ibuprofen, with the option of something stronger if needed. Taking regular pain relief will help you to feel more comfortable after your operation, get out of bed sooner, stand up straight and be able to walk around more easily. Moving around will help speed up your recovery and reduce the risk of blood clots forming in your legs and lungs. Sometimes painkillers that contain codeine or dihydrocodeine can make you sleepy, slightly sick and constipated.

Eating and drinking:

You are encouraged to drink water immediately after your operation in the recovery area, unless your surgeon tells you otherwise. You can eat something light on your return to the ward. If the bowel has been operated upon, eating may be prohibited for a while.

Washing and showering:

You should be able to have a shower the day after your operation. Keeping scars clean and dry helps healing.

Avoiding blood clots:

There is a small risk of blood clots forming in the veins in your legs and pelvis (deep vein thrombosis) after any operation. Other factors may also increase this risk, such as diabetes, obesity, smoking and previous deep vein thrombosis (DVT). These clots can travel to

the lungs (pulmonary embolism), which could be life threatening.

You can reduce your risk of blood clots yourself by being as mobile as you can and as early as you can after your operation, staying well hydrated and performing small exercises while sitting (moving your foot up and down as quickly as you can for 30 seconds on each side).

You may be given graduated compression stockings after the operation to wear until you are up and mobile. You may also be given an injection (low molecular weight heparin) each day while you are in hospital to thin your blood which may need to be continued on discharge for variable duration of time.

Recovery:

It may take you up to four weeks to recover from the operation. You may feel very tired during this time, so it is important that you rest. It may take up to six months to see any improvement in your symptoms.

Side effects:

If you experience any of the following side effects in the days or weeks after the operation, you should call the hospital or contact your GP for advice. We may need you to come back to the ward to be seen by one of our doctors. If you are very concerned and can't wait, please visit the emergency department.

- Burning or stinging sensation when you pass urine. 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.
- Abdominal pain that is increasing, especially when associated with fever, loss of appetite or vomiting.
- Swelling, redness or pain in your calf. This may be a sign of a blood clot.

Getting back to normal

Activities and exercise

You will be able to return to your normal daily activities as soon as you are home. If things feel too much, then do a little less for a few days. It is important not to lift anything heavy for six weeks or so. Your body will tell you how much to exercise, but we recommend starting with some gentle walking in the first few days and then building up.

Most women should be able to walk slowly and steadily for 30-60 minutes by the middle of the first week, and will be back to their previous activity levels by the second week. Swimming is an ideal exercise and, if you have had no additional procedure, you can start as soon as you feel comfortable. If you have had other procedures with the laparoscopy, you may need to avoid contact sports and power sports for a few more weeks.

Driving

You should not drive for at least 48 hours after your operation. It is important that you do not drive until you feel confident to do so. You should be able to look over your shoulder and perform an emergency stop without causing any pain. This usually takes a few weeks. You should contact your insurance company to check their conditions for driving after an operation.

Work

Your return to work will depend on the extent of procedure, kind of job that you do and how physically strenuous it is. If you have a procedure as part of an operative laparoscopy, such as removal of an ovarian cyst, you can expect to return two to three weeks after your operation. Most people with more extensive surgery need four to six weeks off work. If you require a sick note, please ask us before you leave the ward.

Sexual activity

It is best to avoid sex for six weeks after surgery to allow your body time to heal.

Sussex Endometriosis Centre

Sussex Endometriosis Centre (SEC), Princess Royal Hospital, Haywards Heath is a nationally accredited (BSGE) endometriosis treatment centre and you may have been referred here from another local hospital for this reason.

Following referral to SEC, you will be offered an outpatient appointment where you will be seen by Miss Rebecca Mallick, specialist gynaecologist and/or Ms Rebecca Bystry, endometriosis specialist nurse.

Further imaging such as a detailed gynaecological US scan or MRI scan may be arranged and your case will be discussed in the monthly endometriosis MDT meeting. You will be sent a copy of the endometriosis MDT meeting outcome and plans finalized following this.

Following surgery you will be reviewed by the endometriosis specialist nurse after 2-4 weeks and reviewed in clinic by the specialist gynaecologist in 3 months. Follow up continues via our patient initiated follow-up pathway (PIFU) for 2 years.

Our endometriosis specialist nurse can be contacted via email – **uhsussex.endometriosis.nurse@nhs.net.**

Full details of the team members of the Sussex Endometriosis Centre can be found here - **https://www.bsge.org.uk/centre/**

Useful links

RCOG patient information leaflet: Endometriosis

www.rcog.org.uk/globalassets/documents/patients/patient-information-leaflets/gynaecology/ pi-endometriosis.pdf

Royal College of Obstetricians and Gynaecologists (RCOG) patient information leaflet: Recovering well: Information for you after a laparoscopy

www.rcog.org.uk/en/patients/patient-leaflets/laparoscopy

University Hospital Southampton NHS foundation trust patient information factsheet: Surgery for severe endometriosis.

www.uhs.nhs.uk/Media/UHS-website-2019/Patientinformation/Surgery/Surgery-for-severe-endometriosis-patient-information.pdf

ESHRE Information for women with endometriosis Version 2022.
www.eshre.eu/-/media/sitecore-files/Guidelines/Endometriosis/ESHRE-ENDOMETRIOSIS-patient-Guideline_21032022.pdf?la=en&hash=79017723C4058B492626F8A02B10BC3590BAEEC5

This leaflet is intended for patients receiving care in Brighton & Hove or Haywards Heath

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