Endometriosis and the Bowel

Introduction

This leaflet covers endometriosis and the bowel. It provides information for those diagnosed or undergoing investigations for endometriosis on the bowel. Medical terms are in italics.

What causes bowel endometriosis?

Endometriosis can affect the surface of the bowel (*superficial endometriosis*) or penetrate into the bowel wall (*deep endometriosis*). Deep endometriosis tends to cause formation of small lumps called 'nodules' which contain endometriosis and scar tissue.

Nodules between the rectum and vagina (*Recto-vaginal nodules)* are thought to start superficially on the surface and progress to deep infiltrating disease, growing through the wall of the bowel. There are lots of theories, but the exact cause of bowel endometriosis is not known.

What are the main symptoms of bowel endometriosis?

Symptoms of bowel endometriosis are pain on opening the bowels, sometimes described as severe as "a bread-knife up the bottom" (*dyschezia*), and deep pelvic pain with sex (*dyspareunia*). Symptoms may include abdominal bloating, diarrhoea, or constipation, particularly during periods. Less commonly, there can be rectal bleeding during a period.

The level of pain experienced will vary for each individual, from no or mild pain, to pain so severe that you cannot get to work or carry out your normal daily activities. It is common to already have received a diagnosis of irritable bowel syndrome, and endometriosis and irritable bowel syndrome can occur together. The difference between these is that symptoms of bowel endometriosis vary with the menstrual cycle; they are worse in the days before a period and during menstruation. It can be helpful to keep a note of your symptoms to see if they vary at different times of the month - Endometriosis UK offers a free pain and symptom diary that you can get from our website www.endometriosis-uk.org.

How is bowel endometriosis diagnosed?

Your doctor will ask you questions about your symptoms and examine you. This may involve a vaginal examination.

You may also be sent for an ultrasound scan, and/or listed for a laparoscopy (a keyhole operation to look inside your pelvic area). An MRI scan may be helpful if you are thought to have deep endometriosis inside the bowel wall. Occasionally an endoscopy to look inside the bowel with a small camera (*flexible sigmoidoscopy*) may be carried out. However, it may not be possible to know the extent of how the bowel is affected by endometriosis until a laparoscopy.

What are the treatment options for bowel endometriosis?

Treatment options include medical or complementary therapies to treat symptoms, and surgery to remove the endometriosis. It may also be appropriate to simply monitor symptoms, this may be recommended if you have mild symptoms or no symptoms.

What are the medical treatments?

Medical treatments offered include painkillers (*analgesics*) and/or anti-inflammatory drugs. Opiate-based painkillers such as codeine can be constipating which can make bowel symptoms worse. The use of stool softeners and/or laxatives may be recommended to help symptoms of constipation and painful bowel movements.

Beyond these, medical treatment can include stopping the hormonal menstrual cycle, using hormones called progestagens, contraceptives like the Pill or Mirena, or using medicines called gonadotrophin releasing agonists that bring on temporary menopause symptoms

Current evidence suggests that there is no difference in terms of pain relief between these - all approaches appear equally effective and may provide benefit for up to six months following the end of treatment. Medical and hormonal treatments can have side effects, and may not be suitable for everyone, it's important to discuss with your doctor or nurse to choose the most suitable option for you.

Complementary therapies

Complementary therapies such as acupuncture and dietary changes may have some benefit in treating bowel symptoms although the degree of benefit experienced is highly individual. Complementary therapies are not scientifically proven to treat endometriosis.

Surgery for Bowel Endometriosis

What happens during surgery for bowel endometriosis?

The aim of surgery is generally to remove as much of the endometriosis as possible, by cutting it out. In the majority of cases, surgery can be carried out *laparoscopically* (keyhole), or sometimes via open surgery, depending on the complexity of the surgery. Laparoscopic surgery can reduce adhesions and recovery time.

When bowel endometriosis is identified, surgery should be carried out within a specialised endometriosis centre, as detailed in the NICE Guideline on Endometriosis. Your operation may require two or more surgeons depending on the extent of the endometriosis. Usually this will include a gynaecologist with experience of this type of surgery, a bowel surgeon and, in some cases, a urologist.

There are three main options for surgery:

- The segment or section of the bowel containing the endometriosis can be removed. The bowel is then re-joined together (*re-anastomosis*).
- For smaller areas of endometriosis, a disc of the affected tissue can be cut away followed by closure of the hole in the bowel.
- The endometriosis or nodule can be 'shaved' off the bowel leaving it intact.

With bowel surgery there is a possibility that a temporary colostomy will be needed. This is a procedure where a section of the bowel is attached to an artificial opening on the

tummy wall. This opening is known as a stoma. A stoma bag stuck to the skin of your tummy collects faeces. If it is thought that you might need a stoma, your surgeon will arrange for you to talk this through with a specialist nurse. Stomas are usually reversible and allow recovery time for the bowel to heal following surgery. Reversal of stoma requires a further operation where the bowel is joined back together and the site where the stoma was is closed, this usually takes place 3-12 months following initial surgery.

This type of surgery is complex and may take several hours. It may not be possible to perform the operation by laparoscopy; and an open operation *or laparotomy* (a procedure involving a bigger incision in the abdominal wall to gain access to the bowel) may be needed.

Of those who undergo surgery for bowel endometriosis, about one in ten have complications. These can include stitches not healing properly when the bowel is joined together, resulting in a leak in the bowel. Similarly, after shaving a nodule, the 'weakened' bowel wall could leak. If complications occur, these may require a second operation as an emergency, and you may need a temporary stoma while the bowel heals.

There can be other, short-term complications, including a high temperature, infection in the stitches, and a chest or urine infection, which can be treated with antibiotics. Antibiotics may be given routinely to try and prevent infection, and you will be prescribed TED stockings and injections to thin the blood (low-molecular weight heparin), to try and prevent a *venous thromboembolism* (a deep vein blood clot) or *pulmonary embolus* (a blockage of an artery in the lungs). There may be temporary difficulty emptying your bladder after the operation, which usually returns to normal with time and recovery.

What can I expect after my operation?

You can expect to feel sore. You will have been given painkillers before you wake up and can have more in recovery until you are comfortable enough to go back to the ward. Your anaesthetist may discuss patient controlled analgesia (PCA) or an epidural with you, , to help manage pain immediately after your operation. A PCA connects with the drip in your arm, and you have a button to press which delivers a set amount of painkiller. This is pre-set to prevent you from having too much. You can start drinking water immediately after your operation and build up to eating. If you feel sick or do vomit after the operation, the nurses will administer anti-sickness medication to help reduce this.

In some cases, you may be transferred to a high dependency unit (HDU) for a short time – this means that you can be monitored intensively. You can expect to have a urinary catheter (a thin tube inserted into the urethra (the tube through which urine passes) or through a hole in the abdomen, to the bladder, allowing urine to flow through it and into a drainage bag), for 24 hours and possibly for a few days after your operation.

It is not uncommon for your bowels not to work for up to seven days after the operation. You may be prescribed a gentle laxative to help get your bowels moving. Drinking plenty of water also helps. You should avoid straining to go to the toilet.

When can I go home from the hospital? When will I feel back to normal?

Recovery time, both in hospital and at home, varies from one person to another. Don't try and compare yourself to how others are recovering. After laparoscopic bowel surgery,

it is usual to go home after 3 - 6 days, and after open bowel surgery (*laparotomy*) it is usual to go home after 7 – 12 days.

By the time you go home you will be able to get up and about. You may be taking regular painkillers for the first few weeks. You can gradually return to normal daily activities. A gentle walk every day is beneficial; try and do a little bit more every day, but stop if you feel pain. You can go back to driving when you have stopped taking strong painkillers (which might make you drowsy), and can comfortably sit in the car seat and turn to look in the mirror and do an emergency stop.

How much time you will need to be off work depends on the type of work that you do. You can expect to be off work for at least four weeks after major bowel surgery. It may take six months before you feel fully back to normal.

Bowel function may be altered following this type of surgery, particularly with a full resection (*re-anastomosis*). This does improve over time although you may need to watch your diet to see which foods aggravate or improve the situation. Some patients may benefit from the advice and support of a nutritionist. It is important to discuss any concerns with your consultant.

After going home, you should seek medical help if you have any of the following:

- Swelling or redness of any wound
- Bleeding, discharge or a foul smell from any wound
- Nausea, vomiting or loss of appetite
- A high temperature (more than 38°C or 100°F)
- Not passed flatus (wind from your bottom or your stoma if you have one) for more than 48 hours and have abdominal pain
- Abdominal pain that is getting worse.

Does bowel endometriosis have to be treated? What are the risks of not having treatment?

Whether or not bowel endometriosis requires treatment depends on your particular case, your symptoms and how severe they are. Your doctor is there to try and help you and explain the treatment choices. The final decision is yours.

References:

- ESHRE Guideline and Information for women with endometriosis. https://www.eshre.eu/Guidelines-and-Legal/Guidelines/Endometriosis-guideline.aspx
- NICE Guideline, Endometriosis: diagnosis and management - https://www.nice.org.uk/guidance/ng73

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Feedback:

If you have any comments about this leaflet, please contact us at admin@endometriosis-uk.org

Support:

If you'd like to find out more about Endometriosis UK support services, please visit our website.

www.endometriosis-uk.org

Helpline: 0808 808 2227