

## Endometriosis and the Bowel

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

### What causes bowel endometriosis?

Endometriosis can affect the bowel in the abdomen and pelvis. It can be on the surface of the bowel (*superficial*) or penetrate into the bowel wall (*deep endometriosis*). *Recto-vaginal nodules* probably 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, described by some women as “a bread-knife up the bottom” (*dyschezia*), and deep pelvic pain with sex (*dyspareunia*). Less common is rectal bleeding during a period. The pain may be so severe that you cannot get to work or carry out your normal daily activities.

It is common for a woman with bowel endometriosis to have been diagnosed with irritable bowel syndrome. Endometriosis and irritable bowel syndrome can occur together. The difference is that symptoms of bowel endometriosis vary with the menstrual or period cycle; they are worse in the days before a period and during menstruation. Try keeping 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](http://www.endometriosis-uk.org) or by contacting the office on 020 7222 2781.

### How is bowel endometriosis diagnosed?

Your doctor will ask you questions about your symptoms and examine you. This may involve a vaginal examination, ultrasound scan, and a day case procedure to look inside the bowel with a small camera (flexible *sigmoidoscopy*), and/or a laparoscopy (a keyhole operation to look inside your pelvic area). CT scan and MRI may be helpful if you are thought to have deep endometriosis inside the bowel wall. It may not be possible to know how badly the bowel is affected by endometriosis until your operation.

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### What are the treatment options for bowel endometriosis?

Treatment options include doing nothing, medical or complementary therapies to treat symptoms, and surgery. The 'do nothing' option may be appropriate if a woman has 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 are constipating which can make bowel symptoms worse.

Beyond these, treatment is centred on 'tricking' the body into thinking that you are pregnant - (e.g. by using hormones called progestagens or contraceptives like the Pill or Mirena), or that you are menopausal (using medicines like danazol or those called gonadotrophin releasing hormone agonists). Current evidence suggests that there is no difference in terms of pain relief between either strategy - all approaches appear equally effective and may provide benefit for up to six months following the end of treatment.

### Complementary therapies

Complementary therapies such as acupuncture 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.

### What happens during surgery for bowel endometriosis?

The aim of surgery is generally to cut out as much of the endometriosis as possible, balanced with individualised care. In the majority of cases, surgery can be carried out *laparoscopically* (keyhole), or via open surgery, depending on the surgeon. Laparoscopic surgery may reduce adhesions and recovery time.

There may be two or more surgeons present depending on the unit and 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 essentially three options for surgery:

- The segment or section of the bowel containing the endometriosis can be removed. The bowel is then re-joined (*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.

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- Alternatively the endometriosis or nodule can be 'shaved' off the bowel leaving it intact. This option may leave residual endometriosis.

Surgery should be tailored to the individual and their symptoms and needs. The majority of women (approximately 75%) can have conservative surgery, preserving their fertility. For some women, however, more extensive surgery (such as a hysterectomy in conjunction with removal of the endometriosis) is indicated.

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 to a specialist nurse.

This type of surgery is difficult and may take several hours. It may not be possible to perform the operation by laparoscopy; in 1 in 7 women, the operation is changed to *a laparotomy* (a procedure involving a bigger incision in the abdominal wall to gain access to the bowel).

About one in ten women have major complications; when the bowel is joined together the stitches may not heal properly resulting in a leak in the bowel. This may require a second operation as an emergency. You may need a temporary stoma while the bowel heals. Most complications are not serious and include 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 the TED stockings 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 are awake and can have more in recovery until you are comfortable enough to go back to the ward. Your anaesthetist may discuss an epidural or patient controlled analgesia (PCA) with you. A PCA connects with the drip in your arm, and you have a button to press which delivers a set amount of painkiller. There are presets that 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,

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the nurses will administer anti-sickness injections into the drip in your arm 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 4 – 7 days, and after open bowel surgery (*laparotomy*) it is usual to go home after 8 – 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 women may need to watch their 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

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- 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 the endometriosis is. Your doctor is there to try and help you and explain the treatment choices. The final decision is yours.

Without having treatment, your symptoms are likely to continue and may get worse over time. Research suggests that endometriosis may get better as well as worse over time. Endometriosis gets worse in about 50% of women and this may mean that deeply infiltrating endometriosis may penetrate through to the inside of the bowel.

### **Is there anything else I can read about endometriosis?**

The following information is reliable and available online and free of charge from the Royal College of Obstetricians & Gynaecologists (RCOG) website [www.rcog.org.uk](http://www.rcog.org.uk)

- Long-term pelvic pain: information for you. RCOG (December 2005)
- Endometriosis: what you need to know. RCOG (November 2007)
- Recovering well: Information for you after a laparoscopy RCOG (July 2010)
- Endometriosis, investigation and management. RCOG Green-top guideline number 24 (October 2006)
- Chronic pelvic pain, initial management. RCOG green-top guideline 41 (April 2005)

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