endometriosis uk

Endometriosis and the Bladder

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

How does endometriosis on the bladder occur? Can other parts of the urinary system be involved?

Endometriosis affecting the bladder is uncommon. It can be superficial (just on the outer surface of the bladder) or deeper, inside the bladder wall creating a nodule, or in the bladder lining. Endometriosis can affect the *ureter* (the tube from the kidney to the bladder). Endometriosis only truly infiltrates the ureter itself in 0.5-2% of cases. The ureter runs down the side of the pelvis and can be compressed or pinched by an endometriotic nodule. There are lots of theories, but the exact cause of bladder endometriosis is not known.

What are the main symptoms of endometriosis on the bladder?

Symptoms of endometriosis vary with the menstrual or period cycle. They are worst in the days before a period and during menstruation. Women may experience bladder irritation or *urgency* (wanting to pass urine). Some women experience pain when the bladder is full. If there is endometriosis affecting the lining of the bladder then blood can be seen in the urine (*haematuria*) at the time of the period.

In rare cases, where there is significant endometriosis compressing the ureter, loin pain in the area of the kidney may be experienced. An ultrasound scan can determine if there is any back pressure on the kidney.

How is bladder endometriosis diagnosed?

Your doctor will ask you questions about your symptoms and examine you. This may involve a vaginal examination, ultrasound scan, a urine sample to test for infection and an operation to look inside the bladder with a small camera (*cystoscopy*) combined with laparoscopy (an operation to look inside your abdomen). CT and/or MRI may be helpful if you are thought to have deep endometriosis inside the bladder muscle.

What are the treatment choices for bladder endometriosis?

Symptoms can be controlled by medical treatment (hormones and anti-hormones - please refer to our factsheet on treatments for more information on medical treatments). Some women have found that complementary therapies have helped their symptoms, but these are not proven scientifically and the degree of benefit experienced is highly individual. An operation is the usual way of treating bladder endometriosis.

What happens during an operation for bladder endometriosis?

An operation can confirm a diagnosis of bladder endometriosis and/or can surgically treat bladder endometriosis. Whether bladder endometriosis can be treated at the time of diagnosis depends on where it is and how bad it is. Before your operation your surgeon will discuss your specific operation with you.

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Superficial endometriosis on the outside of the bladder can be vaporised with a laser, burned with diathermy or excised (cut out). Endometriosis inside the bladder may indicate deeply infiltrating endometriosis within the bladder wall, but can be burned by diathermy or vaporised by laser. Deeper infiltrating endometriosis may require cutting out (*excision*) of the nodule or the affected section of your bladder. You may need 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 a few days after the operation and an X-ray (*cystogram*) to check that the bladder has healed.

During bladder surgery, the *ureters* (muscular tubes that drive urine to the bladder from the kidneys) may be stented. *Ureteric stents* are narrow silicone tubes, which are inserted into the *ureters* during the operation and are removed before you wake up or are kept for a few weeks after an operation. They make it easier to remove endometriosis by transforming the ureter from a soft tube into a semi-rigid tube. *Ureteric stents* often result in blood stained urine (*haematuria*) and can cause mild kidney discomfort which can be treated with simple painkillers. Urgency and frequency of passing urine are common as the stents can tickle the sensitive base of the bladder. Urinary infections can occur but are easily treated with antibiotics or with removal of the stents if appropriate. The stents are removed through your urethra (the hole/tube through which urine leaves the body) and doesn't necessarily require a general anaesthetic. It feels a bit uncomfortable during and afterwards, but isn't painful.

Does endometriosis on the bladder have to be treated? What happens if I don't have treatment?

Whether or not bladder 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. You may want to discuss your treatment options with other women with endometriosis. You can do this through Endometriosis UK's helpline, message-board or Facebook group. You could also join your local support group.

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 bladder. Endometriosis affecting the ureters and resulting in back pressure on the kidneys should be treated to prevent kidney damage.

What can I expect after the operation?

You can expect to have a urinary catheter after surgery for bladder endometriosis. Most commonly the catheter is put in through the urethra, but can be put in through the lower tummy just above the pubic bone (*suprapubic catheter*). You may need a catheter for 24 hours or a few days. How long you need a catheter will depend on your particular operation. Your surgeon will advise you.

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Most women are able to pass urine normally when the catheter is removed. Occasionally it can be difficult to pass urine and the catheter may need to be put back in. This is just a temporary set-back and not expected to give any long-term problems.
If the catheter needs to be kept in for a few days, you may be able to go home with the catheter still in. You may bath and shower as normal with the catheter in. It is important to drink plenty of fluids to prevent bladder infections while you have the catheter. Signs of infection are a high temperature and flu-like symptoms. If you don't feel well you should phone the ward or contact your GP.

When 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.

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

- 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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