



Bladder endometriosis

This factsheet is for those who have suspected bladder endometriosis and those who have been recently diagnosed. It explains the symptoms of bladder endometriosis and how it is diagnosed and treated.

What is bladder endometriosis?

Endometriosis occurs when cells similar to the ones in the lining of the womb (uterus) are found elsewhere in the body. These cells can grow and change in response to hormones in the menstrual cycle, this can cause inflammation, pain and scar tissue.

Endometriosis is most commonly found on the lining of the pelvis (peritoneum) and may occur in the ovaries and involve other pelvic organs, like the bowel or bladder. Less commonly, endometriosis can also be found outside the pelvis, such as in the chest.

Bladder endometriosis can be superficial, this is when endometriosis is found on the outer surface of the bladder. Or it can be found deep inside the bladder wall. Rarely, endometriosis can affect the ureters. These are the tubes that carry pee from your kidney to the bladder.

Unfortunately, the cause of bladder endometriosis is unknown.

What are the symptoms?

Symptoms of endometriosis vary with the menstrual cycle. They are worst in the days before a period and during menstruation.

The most common symptoms for bladder endometriosis are:

- Needing to pee more often
- Pain when peeing
- Having an urgent need to pee
- Having trouble emptying your bladder when peeing
- Blood in your pee
- In rare cases you may have kidney pain

How is bladder endometriosis diagnosed?

Clinical investigation

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

Scans and tests

Urine sample - testing your pee to look for infection

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Cystoscopy - uses a small camera called a cystoscope to look inside your bladder

Laparoscopy - uses a small camera called a laparoscope to look inside your abdomen (tummy).

Ultrasound scan - uses high frequency sound waves to make images of inside the body. You may have an ultrasound to look at your kidneys and bladder.

Renogram – a scan that uses a radioactive dye and a special camera to better see how your kidneys and bladder are working.

Magnetic resonance imaging scan (MRI) uses magnetic fields and radio waves to make images of the inside of the body. An MRI Scan can be helpful to look for deep endometriosis affecting the bladder or ureters.

How is bladder endometriosis treated?

Bladder endometriosis is usually treated by surgery. Surgery can confirm your diagnosis and treat bladder endometriosis. Your surgeon will aim to remove any endometriosis that is visible to help improve your symptoms. Sometimes your endometriosis can not be treated at the same time as your diagnosis. This will depend on where the endometriosis and how it affects you. Your surgeon will talk to you about your surgery and discuss your options. The type of surgery you have will depend on your individual circumstances.

What happens during surgery?

Ureteral stents

Ureteric stents are narrow silicone tubes, which are placed into the ureters during surgery. They make it easier to remove endometriosis by turning the ureter from a soft tube into a semi-hard tube. They may be removed before you wake up or remain for a few weeks after your operation.

Ureteric stents can cause side effects including:

- Blood-stained pee
- Mild kidney pain, this can be treated with simple painkillers
- Having an urgent need to pee or to pee more often
- Urinary infections, these can be treated with antibiotics or with removal of the stents

The stents are removed through your urethra. This is the tube through which urine leaves the body. This procedure does not usually require a general anaesthetic and although it can feel uncomfortable is usually not painful.

Ureterolysis

This type of surgery is used to remove scar tissue and adhesions from around the ureter. It may be used during your surgery to reduce the risk of injury by giving the surgeon a clear view. It also frees the ureters from external pressure.

What happens after surgery?

After surgery you may need a urinary catheter. A thin tube will be put into your urethra. The catheter goes through to your bladder and allows pee to flow into a drainage bag. Usually you will have a catheter for 24 hours after your operation. You may have a catheter for 1 to 2 weeks after your operation.

The majority will be able to pee normally once 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.

In rare cases where the bladder does not empty fully following surgery, you may need to self-catheterise, and you will be taught how to do this. Again, if required this is usually a temporary part of the recovery process.

You can still leave hospital with a catheter in. You can have a bath and shower as normal. It is important to drink plenty of fluids to prevent bladder infections while you have the catheter.

At home

When you go home you should be able to get up and about gradually return to normal activities. You can expect to have pain which can be treated with painkillers for the first few weeks. You can resume driving when you have stopped taking strong painkillers that make you drowsy. You will need to sit comfortably in the car seat, can turn to look in the mirror and do an emergency stop.

You should look out for signs of complications. These will include:

Infection

Signs of infection include a high temperature and flu-like symptoms; Other signs of infection may include:

Urinary tract infection - peeing more frequently, pain when peeing, or strong-smelling pee

Wound infection – the wound site is hot to touch, red, swollen or has discharge

If you experience any of these symptoms following surgery, you should phone the ward or contact your GP.

Urinary retention

This means not being able to pee. If you feel like you need to pee but can't go to A&E

Pain and bleeding

Pain and bleeding are to be expected after surgery. If you are bleeding so much that you fill a sanitary pad in 30 minutes, or your pain is not controlled by your prescribed painkillers it could be a sign of infection or complications. If you're unsure contact the ward, you can also visit your GP. If you need emergency care, go to A&E.

Find out more about [complications post-surgery](#).

Symptoms Management

Everyone's case is different, and you may not need or want surgery to treat your bladder endometriosis. Your doctor will explain the treatment options available to you and the final decision to have surgery is yours.

Symptoms can be controlled by hormone treatments including contraceptive medication and medication that mimics the menopause. Find out more about [Hormone treatments for endometriosis](#) on our website.

The main symptom of endometriosis is pelvic pain and there are various pain relief and pain management options available. Find out more about [pain relief for endometriosis](#) on our website.

How we can help

Being diagnosed and living with endometriosis can be a daunting experience. If you're finding things difficult, we're here to help. Our trained volunteers, all with personal experience of endometriosis, can offer you the help you need to understand your condition and take control. We offer:

Quality information and advice on endometriosis, including a series of webinars

Emotional and practical support through our network of support groups, helpline, webchat and online forum

Visit www.endometriosis-uk.org/get-support or Helpline: 0808 808 2227

Tell us what you think

You can give us feedback on all our publications by contacting us on information@endometriosis-uk.org

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