

Painful Bladder Syndrome/Interstitial Cystitis

Information for patients



Leeds Centre for
Women's Health

Welcome to the Department of Urogynaecology

Your consultant has referred you to have a course of bladder instillation treatments to help treat your painful bladder or interstitial cystitis.

This leaflet will help explain the following:

- What is painful bladder syndrome and interstitial cystitis?
- What is bladder instillation and what happens during treatment?
- The risks and benefits of bladder instillation and alternatives to treatment?

What is Painful Bladder Syndrome (PBS) / interstitial cystitis?

Painful bladder syndrome and interstitial cystitis are considered the same condition and are diagnosed due to symptoms that you have described and often after a cystoscopy investigation which is a camera test looking into the bladder.

Painful bladder syndrome is a chronic (long lasting) inflammation (irritation) of the bladder wall. It is more common in women than men and can occur at any age.

The symptoms of PBS include:

- Pain and burning on passing urine but no evidence of a urinary infection
- Reduced bladder capacity
- Pain or bladder filling

- Urgency (sudden sensation to urinate) and frequency (urinating very often through day and night)
- Pain in the lower abdomen

What causes painful bladder syndrome?

The exact cause is unknown however research has suggested there may be damage to the lining of the bladder wall known as Glycosaminoglycan (GAG).

What is bladder instillation?

In a healthy bladder there is a natural barrier made from a chemical called Glycosaminoglycan (GAG) which protects the bladder wall from the chemicals in urine. If the GAG layer is damaged the chemicals in the urine can cause irritation to the bladder wall which causes pain, urgency and frequency symptoms. Bladder instillation involves reforming this GAG layer with drug treatments that are passed through a catheter into the bladder.

We use two types of bladder instillation treatments in combination over a course to help relieve your symptoms:

1. **Hyacyst** is used as the first treatment which contains a GAG chemical called sodium hyaluronate which is a liquid that helps replenish and repair the GAG protective layer of your bladder. It is used first at a dose of 40mg and may be increased up to 120mg and then you may be switched onto the next instillation.
2. **iAluril** which contains 2 natural GAGs; hyaluric acid and chondritin sulfate may then be used for the rest of your treatment visits or instead of Hyacyst.

What to expect on the day of bladder instillation treatment

The procedure is performed in the outpatient department by a specialist nurse.

Firstly you will be asked to remove your lower garments and asked to lie on a couch and cover your legs with a sheet. A catheter (small plastic tube) will be inserted into the urethra which is the tube that allows urine to pass from the bladder to the outside when you urinate. Any urine in your bladder will be emptied through the catheter. The bladder instillation liquid is then passed through the catheter into your bladder and the catheter is then removed.

The bladder instillation liquid needs to be held in the bladder for at least 30minutes, once it cannot be held anymore your bladder can be emptied by urinating normally.

Following the treatment you do not need to stay in hospital to wait to pass urine, you can return to work or daily activities straight afterwards. Some patients can be taught to self-administrate the bladder instillation at home.

Is the procedure painful?

Bladder instillation is a relatively painless and routine procedure. The insertion of a catheter can be uncomfortable for some people and a small amount of numbing gel is placed into the urethra before passing the catheter to reduce any discomfort.

How often are the treatments?

Treatment is often started once a week for five weeks followed by two treatments in a month, increased to two treatments across two months and finally once every three months. If response to treatment occurs then the treatment may be continued for two years with bladder instillations every three months.

How effective is bladder instillation?

Studies have shown that bladder instillation can improve the most distressing symptoms in approximately 70% of patients. Improvement of symptoms may not be noticed until five doses, however this varies for each patient. It is important that you still attend every treatment even if there is no initial benefit.

What are the side-effects?

Bladder instillation is a straight forward and often well tolerated procedure. Insertion of catheter can cause irritation and there is small risk of a urinary infection.

Irritation from the bladder instillation chemicals is rare as they are chemicals which are found naturally in your body however if you do experience any side-effects please discuss this with your nurse or doctor and between you a decision can be made whether to continue the treatment or to stop.

Who cannot have bladder instillation treatment?

There are a few patients who should not have bladder instillation therefore if you have any of the listed conditions please discuss this with the nurse or doctor:

- Pregnancy and breast feeding
- Underlying liver, kidney or blood conditions

Useful Tips

Preparing for your bladder instillation:

- Visit the toilet a few minutes before your bladder instillation to help ensure the bladder is empty before the procedure
- Minimise your fluid intake six hours before the instillation as this can help you hold the bladder installation fluid for half an hour after the procedure. You may still take sips or small amounts of fluid
- If you take diuretics (water tablets) please consult your doctor or nurse before the instillation
- Eat normally before the treatment
- If you suspect you have a urinary infection or are pregnant contact the clinic for advise immediately

Alternative methods to help with bladder pain syndrome

Diet

Most, but not all people with painful bladder syndrome find that certain foods can cause a flare up of symptoms, therefore try keeping a food and drink diary to identify any triggers.

Please read the diet advice leaflet that will be given to you before your treatment as it will give you useful information about diet triggers.

Common causes:

- Citrus fruit; lemons, limes, oranges
- Caffeine; tea/coffee
- Chocolate
- Spicy food
- Alcohol

Lifestyle and self-help:

Relaxation and mediation has been shown to help with some symptoms as well as gentle exercise such as walking. Patients are often inclined to cut down fluid intake due to the symptoms of painful bladder however this can make your urine more concentrated and irritate the bladder more making your symptoms worse, therefore is important to maintain a balanced fluid intake and drink normally.

Advice on treating urinary infections:

If you think you may have symptoms of a urine infection take a urine sample to your GP for testing. If the sample is positive of an infection your GP will treat it, if negative then rest and be reassured there is no infection, make sure you drink plenty of fluids and take painkillers for your symptoms.

Where can I find more information and support?

For more information or support about painful bladder syndrome or for your symptoms you can contact the Cystitis and Overactive Bladder Foundation a patient support group.

Helpline: 01217 020 820
www.cobfoundation.org

If you have any questions about painful bladder or bladder instillation please speak to one of the nurse specialists in the department.

What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft
Your views matter



© The Leeds Teaching Hospitals NHS Trust • 4th edition (Ver 1)
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Produced by: Medical Illustration Services • MID code: 20230919_013/MH

LN004225
Publication date
09/2023
Review date
09/2026