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## What is Painful Bladder Syndrome and interstitial cystitis?

Painful bladder syndrome is a chronic inflammation of the bladder wall causing pain related to the bladder filling, accompanied by other symptoms, such as increased daytime and night-time frequency **in the absence of bacterial infection.**

Patients who have been diagnosed with Interstitial Cystitis suffer the same symptoms as those with a bacterial infection, but also have typical changes to the bladder wall seen on cystoscopy (camera examination of the bladder) and typical histological (microscopic features seen under microscope at the laboratory) findings.

## What causes Painful Bladder Syndrome?

We are not completely sure what causes the syndrome, but the most accepted theory is that there is a deficiency in the bladder wall lining called the GAG (glycoaminoglycan) layer. This layer is thought to protect the bladder from absorbing harmful substances in the urine, which would otherwise cause a chronic inflammation.

## What is the treatment?

Cystistat or IAurilil is a derivative of hyaluronic acid, which occurs naturally in the fluids of the eyes, the joints and is a major constituent of the bladder lining (or GAG layer).

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### Further Information

We endeavour to provide an excellent service at all times, but should you have any concerns please, in the first instance, raise these with the Matron, Senior Nurse or Manager on duty.

If they cannot resolve your concern, please contact our Patient Experience Team on 01932 723553 or email [asp-tr.patient.advice@nhs.net](mailto:asp-tr.patient.advice@nhs.net). If you remain concerned, the team can also advise upon how to make a formal complaint.

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- Laser cauterisations (burning off) of Hunner's ulcers, if you have them.

## Further information

If you would like any further information on Painful Bladder Syndrome or Interstitial Cystitis, please ask your nurse or contact

- Cystitis and Overactive Bladder Foundation  
[www.cobfoundation.org](http://www.cobfoundation.org)
- International Painful Bladder Foundation  
[www.painful-bladder.org](http://www.painful-bladder.org)

## What does it do?

Either solution temporarily replaces the deficient GAG layer of the bladder wall, which helps to relieve the symptoms of pain, frequency and urgency.

## What does the treatment involve?

The treatment involves an outpatient visit only. You will need to pass urine before the procedure so that your urine can be tested for infection.

A catheter (small plastic tube) is placed into your bladder via your urethra (water pipe) and any remaining urine is drained away. If you have a very sensitive urethra, a small amount of anaesthetic gel will be inserted before the catheter is inserted.

The solution (in 50 mls) is instilled into your bladder via the catheter, which is then removed. This procedure lasts only a few minutes. You will need to hold the fluid in your bladder for a minimum of 30 minutes.

## How often will I need this treatment?

For an initial course you will be seen weekly for four weeks and then 4 monthly for four months.

## **When will I notice an improvement in my symptoms?**

Results may not be apparent for 4-5 doses; however symptom improvement will vary for individual patients. Some patients benefit from maintenance doses, which could be monthly, two monthly or three monthly depending on your response to the medication.

## **What are the side effects of this treatment?**

Hyaluronic acid is a naturally occurring substance found in our bodies. The treatment is usually well tolerated and causes few, if any, adverse reactions. Occasionally patients will experience localised irritation as a result of the catheterisation itself. This usually clears within 24 hours. You are encouraged to drink plenty of fluids after you have passed the solution, to decrease the effects of possible irritation.

## **Are there any alternative treatments?**

Diet is thought to be a large factor contributing to the symptoms of Painful Bladder Syndrome and Interstitial Cystitis. There are many types of foods and fluids to avoid, but each case is individual and it is often a case of trial by elimination as to what foods affect you. Typically, acidic food and drinks should be avoided, such as orange juice. Alcohol and smoking can also have adverse effects and are best avoided. As pain is a major feature of your condition, you can investigate different methods of pain management and try out different self-help strategies.

There are some drugs taken orally, which may help. They include antihistamines, antidepressants and antispasmodics.

Bladder training programs aim to teach you to stretch your bladder so that it holds more urine. These programs involve, following a schedule suggesting designated times to go to the toilet and increasing the times between each void.

There are other types of drugs, which can be instilled into the bladder in the same way as that described above. The most commonly used drug is DMSO.

Surgical intervention can be a drastic step and is only considered in a minority of very severe cases where all other treatments have failed.

Different types of surgery include:

- the formation of a urostomy - an opening in your abdominal wall for your urine to be diverted away from your bladder into a bag, which will need to be emptied regularly.
- a cystoplasty - a piece of your bowel is removed. The bladder is then cut open to enable the piece of bowel to be attached to increase its capacity.
- the removal of your own bladder, which is replaced with a newly formed bladder made from your bowel