

Cystistat® for your interstitial cystitis

You have been asked to come into hospital to have a treatment called Cystistat® (hyaluronic acid). This leaflet explains:

- what this treatment involves
- why it has been recommended for you
- the risks, benefits and alternatives to this treatment
- what will happen after your treatment.

There are times when doctors advise patients to use a treatment in a different way to that specified by the manufacturer. You may find some of the information in this leaflet varies to the manufacturer's information provided with Cystistat®. If you have any questions or concerns, please do not hesitate to contact the urology team using the contact details on page 4 of this leaflet.

What is interstitial cystitis?

Interstitial cystitis is a **chronic** (long-term) **inflammation** (irritation) **of the bladder wall**. It affects women more than men, across all ages and ethnicities. Research suggests that causes of the condition include:

- non-bacterial infections in the bladder
- damage to the lining cells of the bladder
- irritants in the urine
- nerve disorders and/or autoimmune diseases.

Interstitial cystitis is not a stress-related disease but its symptoms can cause a lot of distress. They include:

- pain in the lower abdomen
- reduced bladder capacity – the amount of urine the bladder can hold is reduced
- urgency and frequency passing urine
- pain or burning on passing urine.

This leaflet describes Cystistat® treatment and does not explain interstitial cystitis in detail. If you would like more information on this condition, please contact the Cystitis and Overactive Bladder Foundation – please see page 3 for their details.

What is Cystistat® treatment?

Cystistat® is a clear, colourless, sterile solution that contains 40mg of sodium hyaluronate. This is a substance that naturally occurs in your body.

Cystistat® is used to treat interstitial cystitis and painful bladder disease. It is inserted into your bladder (bladder instillation) and works by coating the bladder lining with a protective layer, which helps to reduce symptoms of pain, urgency and frequency.

Please note that Cystistat® is **not a cure**, but provides a temporary relief from your symptoms.

How is the treatment given?

A nurse will pass a thin tube called a catheter through the urethra (a tube attached to the bladder that urine travels through before leaving your body) into your bladder. The catheter will be lubricated with a local anaesthetic gel to reduce any discomfort.

Any remaining urine will be drained away from your bladder and 50mls of Cystistat® solution will be passed through the catheter and into your bladder. This catheter will then be either removed from your bladder, or left in place until the treatment is finished about one hour later.

You will need to keep the solution in your bladder for a minimum of one hour, so if the catheter has been removed, you will be asked not to pass urine during that time. It is very important that you follow this guidance because Cystistat® may not work as well as it should if it does not stay in for the full hour.

If you are receiving the treatment for the first time, you will be asked to stay in the department until you pass the solution.

How do I prepare for the treatment?

Try not to drink a lot of fluids for four hours before the treatment – this will improve the effect of Cystistat® on your bladder lining.

You will be asked to pass urine before your treatment to empty the bladder and to test it for infection.

Giving my consent (permission)

We want to involve you in all the decisions about your care and treatment. If you decide to go ahead, you will be asked to give your consent verbally. This confirms that you agree to have the treatment and understand what it involves.

You may wish to read a copy of our leaflet, **Helping you decide: our consent policy**, which gives you more information. Please ask us for a copy if you have not received one.

How many treatments will I have?

You will be given one treatment each week for six weeks. After this time, treatments are usually given once a month until your symptoms resolve.

Don't be discouraged if the treatment does not work immediately, as you may need five or six treatments before your symptoms improve.

Are there any side effects?

There are no specific side effects noted for this treatment. However, the catheter insertion may cause minor discomfort and a temporary increase in urinary frequency and urgency.

Are there any alternatives?

There may be other treatment options – this depends on your individual circumstances. Alternatives may include oral (taken by mouth) medicines, including anti-inflammatory medicines, antispasmodics, antihistamines and muscle relaxants. These medicines have been found to be effective in controlling some symptoms of interstitial cystitis. Your consultant will discuss these with you in more detail if they are appropriate for you, although you may have already tried some of these without success.

Advice following your treatment

- Men should sit down on the toilet when passing the solution to avoid it splashing on their skin.
- If the solution does splash on your skin, wash it off immediately with warm soapy water.
- Do not have sexual intercourse for 24 hours after the treatment to prevent irritation.

Will I have a follow-up appointment?

At first, you will have a follow-up appointment with the consultant and if the treatment is successful, you will see the nurse specialist each month. If the treatment is not helping, alternative treatments will be discussed with you.

Useful sources of information

The Cystitis and Overactive Bladder Foundation is a charity that provides information and support to sufferers of bladder problems.

t: 01908 569196 w: www.cobfoundation.org

The Bladder and Bowel Foundation is the UK-wide charity for people with bladder and bowel control problems. It provides information and support services.

t: 0845 345 0165 w: www.bladderandbowelfoundation.org

Appointments at King's

We have teamed up with King's College Hospital in a partnership known as King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at King's. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.

Contact us

If you have any questions or concerns about the treatment, please contact the Urology Department on the numbers below for advice.

Call **020 7188 7632** or **020 7188 7636** to speak to one of the urology nurses, Monday to Friday, 9am to 5pm.

Alternatively, call the hospital switchboard on **020 7188 7188** and ask for the bleep desk. Ask the operator to bleep 1596 and wait for a response. This will connect you to one of the urology nurses.

Out of hours, please call **Aston Key Ward** on **020 7188 0709** or **Florence Ward** on **020 7188 8818**.

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.guysandstthomas.nhs.uk/leaflets

Pharmacy Medicines Helpline

If you have any questions or concerns about your medicines, please speak to the staff caring for you or call our helpline.

t: 020 7188 8748 9am to 5pm, Monday to Friday

Patient Advice and Liaison Service (PALS)

To make comments or raise concerns about the Trust's services, please contact PALS. Ask a member of staff to direct you to the PALS office or:

e: 020 7188 8801 at St Thomas' **t:** 020 7188 8803 at Guy's **e:** pals@gstt.nhs.uk

Language Support Services

If you need an interpreter or information about your care in a different language or format, please get in touch using the following contact details.

t: 020 7188 8815 **fax:** 020 7188 5953

NHS 111

Offers medical help and advice from fully trained advisers supported by experienced nurses and paramedics. Available over the phone 24 hours a day.

t: 111

NHS Choices

Provides online information and guidance on all aspects of health and healthcare, to help you make choices about your health.

w: www.nhs.uk

Become a member of your local hospitals, and help shape our future

Membership is free and it is completely up to you how much you get involved. To become a member of our Foundation Trust, you need to be 18 years of age or over, live in Lambeth, Southwark, Lewisham, Wandsworth or Westminster or have been a patient at either hospital in the last five years. To join:

t: 0848 143 4017 **e:** members@gstt.nhs.uk **w:** www.guysandstthomas.nhs.uk

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