

Intravesical (in the bladder) GAG layer replacement treatment for your chronic cystitis

This leaflet explains what this treatment involves, why it has been recommended for you, the risks, benefits and alternatives, and what will happen after your treatment. If you have any further questions, please speak to a doctor or nurse caring for you.

You have been asked to come into hospital to have a treatment involving the insertion of a chemical into your bladder to replenish its natural protective coating (the glycosaminoglycan, or GAG, layer).

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 iAluRil® or Cystistat®. If you have any questions or concerns, please do not hesitate to contact the urology team (contact details at the end of this leaflet).

What is chronic cystitis?

Chronic cystitis is a chronic (long-term) inflammation (irritation) of the bladder wall. It affects women more than men, across all ages and ethnicities. Causes of the condition include:

- recurring bacterial infections of the bladder
- non-bacterial infections in the bladder (interstitial cystitis/bladder pain syndrome)
- damage to the lining cells of the bladder due to treatments such as radiotherapy or Bacillus Calmette-Guérin (BCG)
- irritants in the urine
- nerve disorders and/or autoimmune diseases.

Chronic 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 intravesical GAG layer replacement treatment and does not explain the individual causes of chronic cystitis in detail. If you would like more information on this condition, please contact the Cystitis and Overactive Bladder Foundation (contact details at the end of this leaflet).

What is intravesical GAG layer replacement treatment?

iAluRil® and Cystistat® are clear, colourless, sterile solutions that contain sodium hyaluronate with or without chondroitin sulphate. These are substances that naturally occur in your body.

We insert iAluRil® or Cystistat® into your bladder (instillation) and they work by coating the bladder lining with a protective layer, which helps to reduce symptoms of pain, urgency and frequency.

Please note that this is not a cure, but may provide a temporary relief from your symptoms.

How is the treatment given?

A nurse will pass a catheter (thin tube) through the urethra (the tube attached to your 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 the chemical 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 the treatment 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 the treatment 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 decisions about your care and treatment. If you decide to go ahead, you will be asked to sign a consent form. This states that you agree to have the treatment and you understand what it involves.

If you would like more information about our consent process, please speak to a member of staff caring for you.

How many treatments will I have?

You will be given one treatment each week for four weeks, then every two weeks for two treatments (the frequency of treatments may be changed, depending on the cause of your cystitis). 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 and condition. Alternatives may include oral (taken by mouth) medicines, including anti-inflammatory medicines, antispasmodics, antihistamines and muscle relaxants. 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?

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 – a charity that provides information and support to sufferers of bladder problems.

t: 01908 569196 **w:** www.cobfoundation.org

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

t: 01926 357220 **w:** www.bladderandbowel.org

Contact us

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

Urology nurses, **t:** 020 7188 7632 or 020 7188 7636, Monday to Friday, 9am-5pm.

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

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

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit **w:** 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, Monday to Friday, 9am-5pm

Your comments and concerns

For advice, support or to raise a concern, contact our Patient Advice and Liaison Service (PALS). To make a complaint, contact the complaints department.

t: 020 7188 8801 (PALS) **e:** pals@gstt.nhs.uk

t: 020 7188 3514 (complaints) **e:** complaints2@gstt.nhs.uk

Language and accessible support services

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

t: 020 7188 8815

e: languagesupport@gstt.nhs.uk

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 website

Online information and guidance on all aspects of health and healthcare, to help you take control of your health and wellbeing.

w: www.nhs.uk

Get involved and have your say: become a member of the Trust

Members of Guy's and St Thomas' NHS Foundation Trust contribute to the organisation on a voluntary basis. We count on them for feedback, local knowledge and support. Membership is free and it is up to you how much you get involved. To find out more, please get in touch.

t: 0800 731 0319

e: members@gstt.nhs.uk

w: www.guysandstthomas.nhs.uk/membership

Was this leaflet useful?

We want to make sure the information you receive is helpful to you. If you have any comments about this leaflet, we would be happy to hear from you, fill in our simple online form, **w:** www.guysandstthomas.nhs.uk/leaflets, or **e:** patientinformationteam@gstt.nhs.uk

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