

Bladder Pain Syndrome Management- A Partnership in Care

Bladder pain syndrome (BPS) is a name given to a range of symptoms which are also called interstitial cystitis (IC) or painful bladder syndrome (PBS). There are an estimated 400,000 people in the UK who suffer with the condition, 90% of whom are female¹. There is no known cause and diagnosis is often only made once other bladder conditions are ruled out, so it can take years to be diagnosed.

This article will explain the science behind the condition whilst also highlighting how important it is that doctors and nurses explain your treatment choices and make sure your opinion is asked about them.

The condition

There are a range of symptoms that make up BPS/IC and not all patients will suffer from the same set of symptoms to the same degree. The main symptoms however, are:

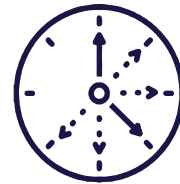


Pain



Urgency

(needing to wee suddenly)



Frequency

(needing to wee often)

Pain from BPS/IC can be felt in the lower tummy, pelvis, vagina and urethra (the tube that connects the bladder to the outside of the body). Some days might be better than others, but the pain is usually long-term.

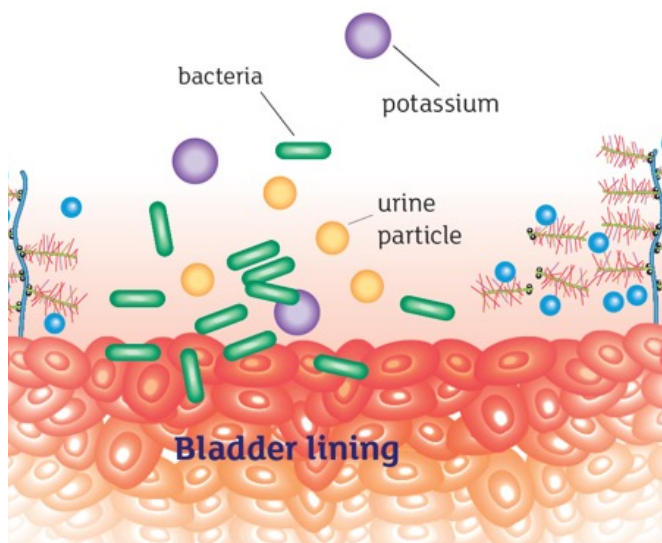
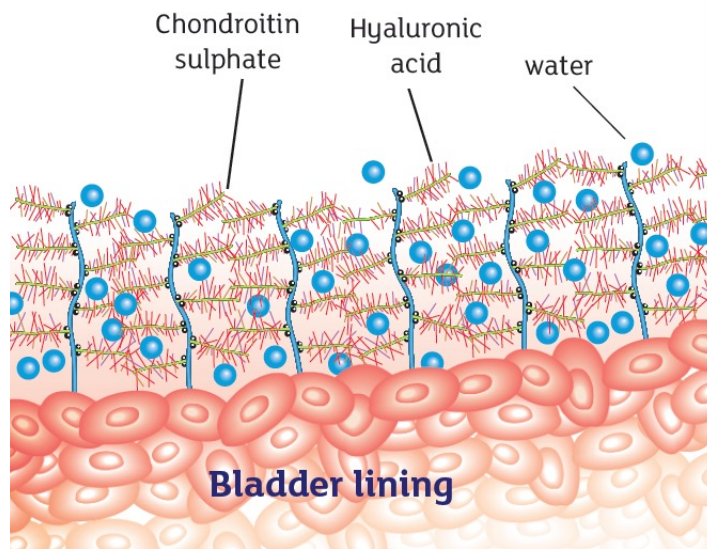
Needing to wee urgently is usually constant and the feeling of pressure and pain can be very uncomfortable. Sometimes, going to the toilet for a wee can occur up to 60 times over a 24hr period; including throughout the night. Often, only a very small amount of urine is being passed each time.

From being in constant pain, to not wanting to leave the house because of the need to be near a toilet; it's easy to see how having BPS/IC can take over your life. But, there are many treatment options and, in understanding why BPS/IC occurs, you will be able to be more involved in your treatment plan with your doctor/nurse.

The science

Although the exact cause of BPS/IC is not known, the changes that happen to the bladder lining as a result of the condition are.

The bladder lining is made of a coating known as the glycosaminoglycan (GAG) layer. Hyaluronic acid (HA) and chondroitin sulphate (CS) are the main elements that make up the GAG layer. HA acts as a building block and allows proteins to attach themselves; these act as branches which more GAG units can join to. CS is present in high amounts in a healthy GAG layer. Water attaches itself to CS to create a waterproof, protective coating to the inside of the bladder.



In certain bladder conditions, like BPS/IC, the GAG layer becomes damaged which means the bladder lining is unprotected. This can cause irritation and damage; resulting in pain. Nerve endings which are usually protected by the GAG layer may also become exposed; changing the signals sent to the brain about when to urinate; even a very small amount of urine in the bladder can feel like you're about to burst. The risk of infection is also higher.

Self-management

There are some things that you can do yourself to help with the symptoms of BPS/IC, including cutting out certain foods, keeping active and trying to reduce any stress. Find the best things that work for you and that fit into your lifestyle and routine; that way; you're more likely to keep going with them.

More details can be found on the iAluRil website: www.iAluRil.co.uk.

Treatment

A diagnosis of BPS/IC can be overwhelming but it is important to remember you are the one with the condition, so there should be a partnership between you and the doctors and nurses treating you. This is even more important now, with appointments sometimes likely to be over the phone or by video. There are a number of different options of treatment and all suitable ones should be discussed with you by your doctor/nurse.

This article will focus on bladder instillations; where medication is put directly (instilled) into your bladder to help repair the damaged GAG lining, but there are other treatment options such as oral medication, surgery and nerve stimulation.

Evidence and research

The professional bodies overseeing healthcare professionals require doctors and nurses to ‘provide effective treatment based on the best available evidence’². Your doctor/nurse should take into account the amount of evidence for a particular treatment and the quality of it. It is important to ask your clinician to explain what research has been done into a particular treatment and what the results mean.

Administration

Ask about how a treatment is administered into your bladder; will this require a trip to the hospital or clinic each time and how often will it need to be done? There are options that mean you can administer treatment yourself in the comfort of your own home; your nurse will be able to teach you how to do this if suitable. This could be with or without a catheter.

Key ingredients

Ask what the ingredients of the instillation are. Many will contain either hyaluronic acid (HA) or chondroitin sulphate (CS) but, as we know from a healthy GAG layer, both GAG elements are needed, so an option that contains both may be more effective³.

Extra ingredients

Are there any extra ingredients that have further benefits? The thickness of the liquid of the bladder instillation can change how effective it is. Calcium chloride makes the instillation thicker, so it sticks to your bladder wall better and for longer⁴. An instillation that contains calcium chloride also allows higher concentrations of both HA and CS to be used, making it more effective^{5,6}.

Your doctor or nurse should always check, but let them know if you have any allergies as some products contain ingredients which might not be suitable for you.

Top tips

- ✓ Do your research- learn about your options so you can raise any concerns or questions with your clinician.
- ✓ Be confident- remember you are the one being treated. If you don't feel like you know enough about something; ask.
- ✓ Talk to other patients- not one treatment will work for everyone and other sufferers will be able to let you know their experiences. Join a patient group for this.
- ✓ Write it down- take a notebook to jot down any important notes from your clinic or virtual appointments. Use this also as a reminder of questions that come to mind in-between appointments.

Patient stories and tips

Most people suffering from BPS/IC can feel isolated and alone, especially when the people surrounding them don't realise how life-changing this condition can be.

Whilst support from your friends, family and work colleagues is vital, support from fellow BPS/IC sufferers can really help you manage. It is important to feel connected and to share experiences of treatment and tips, so here, we are sharing some.

Samantha has been diagnosed with IC/BPS and retention

“...push and demand better health care if you are struggling to be listened to... no-one knows your body better than yourself.”

Anita suffers from IC/BPS and chronic cystitis

“Find a good urologist - someone that you can communicate well with and someone that allows you to be part of the decision-making process around your treatment.”

Further support

There is lots of support available to patients suffering from BPS/IC and the patient experiences above highlight just how important this is.

Bladder Health UK

Fact sheets, nutrition advice and dietary services, patient support line.

www.iAluRil.co.uk

Tip sheets, food diaries, self-administration videos, nurse support.

Bladder Matters

A social media community for patients suffering from a range of bladder conditions. Useful tips, relatable stories and background science.



@bladdermatters



Bladder Matters

iAluRil[®]
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| Sodium Hyaluronate
| Sodium Chondroitin Sulphate
| Calcium Chloride

1. <https://painuk.org/members/charities/cystitis-and-overactive-bladder-foundation-uk/> [Accessed April 2023] 2. Good Medical Practice guidance, GMC. Available at: <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice> [Accessed April 2023] 3. Tasdemir S et al. Intravesical Hyaluronic Acid and Chondroitin Sulfate Alone and in Combination for Urinary Tract Infection: Assessment of Protective Effects in a Rat Model. Int J Urol 2012; 19(12): 1108-1112 4. Stellavato, Antonietta et al. “Hyaluronic acid and chondroitin sulfate, alone or in combination, efficiently counteract induced bladder cell damage and inflammation.” ESSM Poster, Ljubljana 2019. 5. Horkay, Ferenc et al. “Chondroitin Sulfate in Solution: Effects of Mono- and Divalent Salts.” Macromolecules vol. 45,6(2012): 2882-2890. doi:10.1021/ma202693s 6. Zoppetti G, Puppini N, Pizzutti M. 2006 May 26; “Compositions comprising glycosaminoglycans of low viscosity and use of said composition in therapy of chronic cystitis” EP2034956B1.

