

# Your guide to Bladder Pain Syndrome (BPS)

This guide includes information about bladder pain syndrome (BPS), symptoms associated with this condition, ways you can care for yourself and an up-to-date overview of treatment options.

We hope that a lot of the questions you might have will be answered in this leaflet; however, everyone's experience is different, so don't be afraid to talk to your healthcare team.

## What is BPS?

Bladder pain syndrome (BPS), is sometimes called painful bladder syndrome (PBS) or interstitial cystitis (IN-ter-STISH-ul sis-TY-tis) (IC). It is a long-term, painful condition of the bladder that can affect men but is more common in women.

Everyone's bodies and bladders are different and so the symptoms of BPS can vary from person to person, but the most common signs are the almost constant feeling of pain and pressure in the bladder area.

## How common is BPS?

As there isn't a specific test for BPS, and the definition of the disease has changed over time, it is difficult to know how common it is. Some estimates suggest that:



**400,000**

people in the UK may be affected by BPS



BPS is more common in women; 90% of people with the condition are women in their 50s–60s

## What causes BPS?

Experts don't know exactly what causes BPS, but we do know that people with BPS seem to have the following in common:

- A defect in the lining of the inside of the bladder, which may allow irritating substances in the urine to enter the bladder wall and cause irritation. This can sometimes be triggered by a urinary tract infection
- The presence of more inflammatory cells in the bladder compared with those without BPS. These cells release histamine and other chemicals, making bladder sensations more intense
- Something in the urine that damages the bladder or prevents it from healing itself properly after injury
- Changes in the nerves that carry bladder sensations, which may mean you feel pain from sensations that should not normally feel painful (such as bladder filling)

## Are there risk factors for getting BPS?

There are no specific behaviours (such as smoking) that are known to increase your risk of getting BPS; however, there are a few things that might:

- Having a family member with BPS may increase your risk of getting it
- Patients with BPS may have a substance in their urine that inhibits the growth of cells in the bladder tissue, stopping the bladder from repairing itself effectively. So, some people may be more likely to get BPS after an injury to the bladder, such as an infection

# What are the symptoms of BPS?

Symptoms of BPS can feel quite similar to a bladder infection; however, unlike a bladder infection, BPS does not improve with antibiotics and no obvious infection can be identified. It is often described as a feeling of discomfort and pressure in the bladder area that lasts for 6 weeks or more.

## Diagnosis of BPS

Only a healthcare specialist can diagnose BPS. Your doctor will review your medical history, consider your symptoms, conduct a physical examination, and possibly perform additional tests.

This may seem like a lot of information to need before a diagnosis, but since there is no specific test for BPS and there are a number of conditions that may cause similar symptoms, this information will help your doctor to make the correct diagnosis and prescribe the treatment that you need.

In addition to taking a detailed medical history, some of the tests your healthcare team may perform, if you have not had them already, include:

- **Physical and neurological exam**

In women, the physical exam will likely include your abdomen, the organs in your pelvis, vagina and your rectum. In men, a physical exam will include your abdomen, prostate and rectum

- **Baseline pain assessment and bladder diary**

Your doctor will conduct tests and ask you to complete a series of questionnaires to find out your baseline pain value. This may include completion of a bladder diary, in which you will note the amount you drink and how often you pass urine. This will aid in the assessment of your bladder function

- **Voiding tests**

A voiding test will give your doctor an idea of how much urine your bladder can hold before you have the urge to pass urine and if your bladder doesn't empty fully when you do pass urine

- **Cystoscopy**

A special procedure to allow your doctor to look inside the bladder. Small samples of tissue may be taken for further testing during the cystoscopy

These symptoms can be debilitating, frustrating and unpredictable, often vary from person to person and can even change over time in the same individual. The most common symptoms of BPS to look out for are:

- **Pain:** Bladder pain that worsens as the bladder fills and does not ease after passing urine. Some patients feel pain in other areas in addition to the bladder, such as the urethra, lower abdomen, lower back or the pelvic region
- **Constant need to pass urine:** BPS sometimes starts with an increased need to pass urine more frequently than normal. The average person passes urine no more than 7 times a day and does not have to get up at night more than once to use the bathroom. A patient with BPS often has to pass urine more frequently both day and night
- **An urgent need to pass urine:** The constant urge to pass urine is a common BPS symptom. Some patients feel an urge that never goes away, even right after going to the toilet. In some cases, a patient may not notice this urge, or see it as a problem. In other cases, the onset is much more dramatic, with severe symptoms occurring within days, weeks or months

## Further tests

After performing some tests, your healthcare team may decide to refer you to a different hospital specialist, who may send you for further tests.

These could include:

- **A urodynamic evaluation**

This involves filling the bladder with water through a thin tube called a catheter. This measures bladder pressures as the bladder fills and empties

These tests not only give your doctor a good idea of what is going on inside your bladder, but they also give an indication of how severe your BPS may be.

# There are different types of BPS

Like all diseases, symptoms and how severe they are can vary from person to person. BPS is no different.

When performing a cystoscopy, your healthcare team will be looking at the health of your bladder lining and for signs of the following:

- **Tiny bleeds (glomerulations)**
- **Distinctive lesions/ulcers on the bladder wall (Hunner's lesions)**
- **More mast cells in the bladder lining than usual**

BPS with evidence of tiny bleeds or lesions/ulcers on the bladder wall is sometimes referred to as, interstitial cystitis/bladder pain syndrome, IC/BPS for short.

This type of BPS is quite rare. Estimates of the prevalence are approximately 1.8 per 10,000 people.

## Supportive therapies

Some people also find the following supportive therapies helpful:

- **Physiotherapy** – strengthening and massaging the pelvic floor muscles may help reduce any strain on your bladder
- **Bladder re-training** – where you gradually learn to be able to hold more urine in your bladder before needing to go to the toilet
- **Psychological therapy** – to help you cope with your symptoms and their impact on your life. For local psychological services (in England), visit: <https://www.nhs.uk/service-search/find-a-psychological-therapies-service/>

# Managing BPS

## Things you can do

It is natural to feel alone when you have symptoms that, at times, make it hard to live your life as normal. Following a few BPS lifestyle tips may help you to take back control. Things that may help improve your symptoms include:

- **Reducing stress**

Anything that helps you to relax, such as exercise or regular warm baths, may help reduce your symptoms, and recent evidence suggests that mindfulness-based techniques, such as meditation, can help.

- **Limiting certain foods and drinks**

You shouldn't make any drastic changes to your diet before seeking medical advice. However, avoiding certain foods or drinks, if you notice that they make your symptoms worse, may help. Many people report that acidic foods and drinks make their symptoms worse, which may include citrus fruits, tomatoes, chocolate, coffee, alcohol and carbonated drinks.

The list of foods that have been said to affect BPS is quite long, but not all foods affect all patients in the same way. Each patient must find out how foods affect his or her own bladder. The simplest way to find out whether any foods bother your bladder is to try an 'elimination diet'. Some patients have noted improvements after following a low histamine diet.

To find out more information, visit:

- [bladderhealthuk.org](http://bladderhealthuk.org)
- [histamineintolerance.org.uk](http://histamineintolerance.org.uk)

# Treatments for BPS

Although currently there is no cure for BPS and it can be difficult to treat, there are various treatments designed to alleviate symptoms and improve your quality of life. However, it is important to remember that no single treatment works for everyone. You may need to try several treatments to find one that works for you.

## Medicines

Your healthcare team might recommend several different medication types and combinations to help relieve your BPS symptoms. Some examples include:

### • Pain medications

- Over-the-counter painkillers – such as paracetamol and ibuprofen
- Stronger painkillers available on prescription – such as codeine
- Pain modulators, which alter how your body responds to pain – such as amitriptyline and gabapentin

### • Antihistamines

Hydroxyzine and cimetidine – prescription medicines that may help by blocking the effect of a substance called histamine on cells in the bladder.

### • Medicine to help repair the bladder lining

If your healthcare team has found evidence of tiny bleeds or lesions/ulcers on your bladder lining, they may suggest pentosan polysulfate sodium (elmiron®). This medicine, taken orally, may help to repair the bladder mucosal lining and over time may reduce the pain and need to go to the toilet so often.

### • Intravesical medication (instillations)

Rather than taking a pill, intravesical medications are given to you via a small tube called a catheter that is inserted directly into your bladder.

Intravesical medications are a combination of different drugs that might help BPS symptoms. The solution is left in the bladder for a certain period before being emptied. The combination your healthcare team use may vary across the country; common ones include:

- Sodium hyaluronate
- Chondroitin sulphate
- Chondroitin sulphate with sodium hyaluronate
- Lignocaine and sodium bicarbonate
- Heparin

## Surgery and other procedures

Surgery and other procedures may sometimes be an option if you have abnormal areas (lesions) in your bladder or if other treatments do not work.

Procedures that may be carried out include:

- **Cauterisation** – where ulcers inside the bladder are cauterised (burned off) using electricity or with a laser
- **Bladder distension** – where the bladder is stretched with fluid, which can aid diagnosis and may temporarily relieve your symptoms
- **Neuromodulation** – where an implant that stimulates your nerves with electricity is placed in your body to relieve pain and reduce sudden urges to pass urine
- **Augmentation surgery** – although not common, some centres may consider augmentation – making the bladder larger using part of the small intestine; this usually also includes removing any inflamed areas of the bladder

## Other resources

### You are not alone

A support network of family, friends and caregivers may help you through your treatment. In addition, patient advice groups can provide you with more information, help and support. Below is a list of websites for some support organisations that you and your caregivers may find helpful.

- <http://bladderhealthuk.org>
- <https://www.ic-network.com>
- <http://ichelp.org>
- <http://iuga.org>
- <https://www.histamineintolerance.org.uk>
- <https://cks.nice.org.uk/luts-in-men>