

## Painful Bladder Syndrome/ Interstitial Cystitis

Painful bladder syndrome (PBS), also called Interstitial Cystitis (IC), is a chronic inflammatory condition of the bladder wall. Symptoms include pain when the bladder is filling, causing sudden strong urges to pass urine, often relieved after emptying the bladder. The degree of discomfort varies in each patient.

It is a chronic condition with unknown causes, research continues. People of any age and background can be affected, the majority of sufferers are aged between 20 and 50 years. The condition is more common in women than in men. PBS can have a significant impact on your lifestyle, work, emotional wellbeing and relationships. However, there are medications, treatment options and self-help suggestions that can help to manage the symptoms.

### Symptoms

When symptoms first occur PBS may appear very similar to a lower urinary tract infection but antibiotics have no effect.

Symptoms are different from person to person. You may experience some or all of the signs:

- Frequency- day and/or night frequency of urination
- Urgency- sudden strong urges to pass urine, may be accompanied by pain, pressure or spasms
- Pain or tenderness in the bladder area, in your abdomen, in the genital area which may include painful sexual intercourse, lower backache
- Symptoms can worsen for women before or during their menstrual period
- Fatigue

### Possible Causes

It is not clear exactly what causes PBS, generally it is believed there may be several causes.

- One theory is that PBS is an autoimmune response following a bladder infection. An infection and/or the body's defences damage the lining of the bladder, allowing urinary toxins to infiltrate the bladder wall and initiate an inflammatory reaction.
- Another theory is a deficient bladder wall lining called the Glycoaminoglycan (GAG) layer. The GAG layer is thought to protect the bladder wall from absorbing harmful substances in the urine. Defects in this layer expose the bladder wall tissue, causing chronic inflammation secondary to irritation of the bladder tissue and surrounding muscles and nerves.
- Onset can be sudden or gradual. Some patients are able to cite a certain event, such as a severe urinary tract infection or a traumatic event (i.e. pelvic fracture), as the initial trigger of their symptoms. Others are unable to remember how long their symptoms have been present as they slowly deteriorated over a long time. Pelvic

floor dysfunction frequently accompanies the symptoms of PBS. It is unknown if this is a result of the symptoms or possibly a contributing factor.

### **Investigations/ Tests**

There is no definitive diagnostic test, PBS is a diagnosis of exclusion. This means tests are done to eliminate other bladder conditions before PBS is diagnosed as the cause for your symptoms. Symptoms can be very similar to other conditions such as overactive bladder or urinary tract infections. As the tests may not show specific abnormalities, you may require monitoring for some time before a definite diagnosis is made.

The tests and diagnostic tools include:

- Urine tests- to look for infection or other problems
- Bladder diary- to chart your fluid intake (drinking pattern), how frequently you need to go to the toilet and the volume of urine passed on each visit to the toilet
- Ultrasound scan of your bladder and kidneys
- Urodynamics test- this is a complex test carried out in an outpatient setting, this will enable your consultant to see how your bladder responds to being filled and how it empties. There is a separate patient information leaflet for urodynamics which gives more details on the procedure
- A diagnostic cystoscopy- insertion of a small telescope into your bladder to inspect your bladder wall, small samples can be taken at the same time

### **Treatment**

Sadly there is no cure for PBS. Without treatment this bladder disorder can make day to day life very difficult. As you are unlikely to look unwell, family and friends may not understand the severity of your symptoms. The relationships with people close to you may be affected. The need to pass urine frequently at night and/or pain disrupts sleep, in the daytime you may find yourself planning activities around the availability of toilets. This can severely impact on your activities of daily life, leading to depression and isolation.

There are a number of treatments available, including lifestyle adaptations, exercises, medical treatments and alternative treatments to help you manage your symptoms and you may need to try a few before you find the combination that works for you.

- Diet: Certain foods can aggravate your symptoms, however the trigger foods are different for everybody. It is important you look out for the foods/drinks that upset you. Avoid alcohol, tomatoes, spicy foods, chocolate, acidic foods, artificial sweeteners, citrus drinks, caffeinated drinks, fizzy drinks, soy products and processed cheese. There may be other foods which trigger your symptoms. Try removing the suggested foods and drinks and reintroduce them one at a time. This may help to determine which foods or drinks worsen your symptoms. Drink plenty non-irritant fluids to dilute your urine.
- Smoking: Smoking can irritate your bladder. Coughing as a result from long term smoking puts pressure on your pelvic floor and abdominal muscles and may increase pain.

- **Stress:** Stress does not cause PBS but can reduce your ability to cope and manage your symptoms. Reducing your stress levels can improve your symptoms. Consider introduction of relaxation therapies, meditation, regular low impact exercise, which will help improve your psychological and physical wellbeing.
- **Medications:** Simple over-the-counter painkillers such as Ibuprofen and Paracetamol can relieve discomfort if it is mild. You may need other stronger painkillers that can be prescribed by your GP. Tricyclic Antidepressants such as amitriptyline may give some relief. There is also medication that helps to repair the mucin layer of the bladder which is thought to be damaged in patients with PBS. These options can be discussed with your GP or consultant.
- **Bladder instillations:** These are solutions instilled into the bladder through a small catheter and released when you visit the toilet to pass water. These solutions we use within this Trust help restore the GAG layer. Some patients experience improvement in their symptoms after a cycle of instillations.
- **Bladder distention:** This procedure is usually carried out under a short general anaesthetic, the bladder is filled and stretched with fluid. It can aid diagnosis and may temporarily relieve symptoms.
- **Botulinum Toxin injections (Botox):** Botox is injected into multiple sites of the bladder surface, aiming to relax the bladder wall and therefore relieve spasms and increase the volume of urine the bladder can hold. This can be done under a short general anaesthetic or with a local anaesthetic. The effects of Botulinum toxin may last up to 9-12 months. The treatment can be repeated when the symptoms reappear.
- **Physiotherapy:** Chronic pain can be caused by or cause pelvic floor muscle dysfunction. Our Women's Health physiotherapists are available to assess your pelvic floor function, teach appropriate techniques and exercises to help relieve symptoms and enable you to continue your treatment at home.
- **Complimentary therapies** can be used in combination with conventional medical treatments. They include acupuncture, acupressure, homeopathy, psychotherapy, biofeedback, herbal remedies, muscle relaxation, reflexology.
- **Surgical options:** Surgery is only considered in very few cases when other treatments have been ineffective and pain continues to be severe. A number of surgical treatments are available but you must be aware of potential risks, side effects, complications and potential benefits.

Coping with PBS can include significant changes to your lifestyle to enable symptom control and a life as 'normal' as possible. It may be helpful to keep a diary of your pain and symptom flares. It may help you with managing your life and can provide clear and concise details during reviews with health services. Triggers for symptom deterioration could be travel, sexual intercourse, lifting, certain exercises, alcohol and other drinks or foods. Your partner, family, friends may be worried by your symptoms. Be open about your condition, it enables them to support you. If long term pain control proves difficult you may benefit from a pain clinic referral (specialists for treatment of chronic pain).

Do not suffer in silence. Talk to someone who understands the nature of your condition, support groups for PBS sufferers are available. Health professionals can support with physical symptoms.

### **Prognosis**

The prognosis is variable from individual to individual. It's important to remember that it can often take weeks or months before you notice any improvements in your symptoms. This may be temporary and will require follow up or maintenance treatments at regular intervals. However by relieving significant symptoms you can improve your quality of life.

### **More information:**

<https://patient.info>

<https://bladderhealthuk.org>

### **Support:**

<https://bladderhealthuk.org>

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