



What is Painful Bladder (PBS) or Interstitial Cystitis (IC)?

Interstitial Cystitis (IC) is a chronic inflammation of the bladder wall, which can also be diagnosed as Painful Bladder Syndrome (PBS) or Bladder Pain Syndrome (BPS). It is a disorder with symptoms of mild to severe bladder pain and an urgent and/or frequent need to urinate.

How common is IC/PBS?

There is an estimated 400,000 people in UK with IC/PBS, of whom 90% are females and 10% are males.

What causes IC?

The cause of IC/PBS is not yet known. Research continues to find the cause. Indications suggest the condition could be due to a defective bladder lining, or an autoimmune disorder. Normally, the lining protects the bladder wall from the toxic effects of urine. In about 70% of the people who have interstitial cystitis, the protective layer of the bladder is "leaky." This may let urine irritate the bladder wall, causing interstitial cystitis. Other possible causes may be an increase of histamine-producing cells in the bladder wall or an autoimmune response (when antibodies are made that act against a part of the body). IC/PBS may resemble a bacterial bladder infection, however short term antibiotics are not effective.

What are the main symptoms of IC/PBS?

People who have interstitial cystitis may have the following symptoms:

- An urgent need to urinate, (yet you may pass only very small amounts of urine each time) and increased frequency both in the daytime and during the night
- Pressure, pain and tenderness around the bladder, pelvis and perineum (the area between the anus and vagina). This pain and pressure may increase as the bladder fills and decrease as it empties in urination.
- A bladder that won't hold as much urine as it used to
- Pain during sexual intercourse

How can IC/PBS affect an individual's life?

Many IC/PBS patients find that their life revolves around knowing where the nearest toilet is known as "Toilet mapping". This can be very restricting. Going out of the house require thought and planning. Some severe sufferers of IC/PBS can find themselves virtually housebound. This leads to social isolation and depression. Interrupted sleep pattern due to frequency and urgency of urination throughout the night and pain causes tiredness and poor performance. Constant pain especially after sex can affect relationship. These issues are not easy to talk about so patients feel quite helpless about it.

How is IC diagnosed?

IC is diagnosed by elimination. If the symptoms are suggestive of IC, diagnostic tests such as Urodynamics (bladder pressure studies) or Cystoscopy (looking inside the bladder with telescope) are performed to rule out other similar conditions like overactive bladder. Repeated midstream urine samples might be checked to rule out bacterial cystitis. It can take time to obtain a correct diagnosis as symptoms of IC/PBS can be similar to other conditions.

Painful Bladder Flares

Patients suffering from IC have periods when symptoms are not bothersome and they can have almost normal life that alternate with periods when symptoms are bothersome or even severe. These periods are called "flares". It is not always clear why flares develop. There are triggers that worsen symptoms. The potential triggers are

- Bladder infections
- Gastrointestinal problems
- Activities, such as sex and prolonged sitting
- Certain Foods and beverages, including alcohol and coffee

Aggravating conditions such as bladder infections and yeast infections can worsen IC symptoms. Patients should see a healthcare provider to be evaluated and treated promptly for such conditions to avoid flare ups.

Pain in other areas due to conditions like Crohn's disease, Ulcerative Colitis, diverticulitis, irritable bowel syndrome, painful menstrual periods or endometriosis should be treated vigorously as these conditions can increase bladder sensitivity. More than one healthcare provider or specialist is often needed for people who have multiple medical conditions.

If you are able to identify foods or drinks that aggravate bladder pain or urinary urgency or frequency, it is reasonable to avoid these items during a symptom flare. However, it is not clear that these items should be avoided at other times. Some practitioners strongly

recommend a highly restrictive "interstitial cystitis diet", although its benefit has never been studied. (You can follow diet advice given by interstitial cystitis network, www.ic-network.com)

How is IC treated?

As yet there is no cure for IC, so treatment approaches are designed to control symptoms. Each patient has his or her own unique subset of bothersome symptoms. Many a times you need specialist team to design therapies to alleviate each of your symptoms. Most people feel better after trying one or more of the following treatments:

- **Diet.** Your doctor may tell you to change what you eat. You may need to avoid alcohol, acidic foods and tobacco.
- **Bladder distention.** Under anesthesia, a doctor overfills your bladder with gas or fluid. This stretches the walls of the bladder. It is unexplained why distension helps. It may make your bladder be able to hold more urine. It may also interfere with the pain signals sent by nerves in the bladder.
- **Bladder instillation for Interstitial Cystitis** (also called a bladder wash or bath), a procedure in which the bladder is filled with a therapeutic solution (usually containing a combination of agents) that is retained in the bladder for varying periods of time, from a few seconds to 15 minutes, before it is released through urination. Doctors use treatments that are thought to either coat and protect the bladder or suppress inflammation. This can be done by a clinician or you can learn to self-administer the treatment at home. The treatment schedule varies but it can be for a single dose every month to up to three times a week or only with flare ups. The medicines used include Cystistat ([sodium hyaluronate](#)) and Uracyst ([chondroitin](#)). They are believed to replace the deficient GAG layer on the bladder wall.
- **Medications for Interstitial Cystitis** such as Elmiron (the first oral medication approved specifically for IC). Elmiron may reduce bladder discomfort and pain in some people with IC and may work by repairing the damaged bladder lining. Another oral medicine used to treat interstitial cystitis is an antihistamine called hydroxyzine. This medicine reduces the amount of histamine that is made in the bladder wall. Another medicine that may help is amitriptyline. It blocks pain and reduces bladder spasms. This medicine can make you sleepy, so it is usually taken at bedtime. Your doctor may also suggest that you take an over-the-counter pain medicine to ease pain.
- **Transcutaneous posterior tibial nerve stimulation for Interstitial Cystitis** in which doctors send mild electric pulses to a nerve in the foot through a small acupuncture needle. These pulses may work by increasing blood flow to the bladder, strengthening pelvic muscles that help control the bladder, and triggering the release of hormones that block pain.
- **Bladder training for Interstitial Cystitis** is a therapeutic technique where you void at designated times and use relaxation techniques and distractions to help keep to the schedule. Gradually, the patient tries to lengthen the time between the scheduled voids.

A typical bladder training protocol involves avoiding an urge and learning to urinate "by the clock". This is used throughout the day, but is not used while sleeping. As an example, if you currently void every 30 minutes, you will first try to urinate only once every 45 minutes during the daytime, whether you feel the need to urinate or not. You should not urinate more frequently than every 45 minutes, if possible. This voiding goal is continued for a full week or until you are comfortable with this interval. Once you are comfortable voiding every 45 minutes, you can increase your time interval by 15 to 30 minutes every week. In this example, you would urinate every 60 minutes for the second week, every 90 minutes for the third week, every 2 hours for the fourth week, and every 2.5 hours for the fifth week.

- **Interstim for Interstitial Cystitis** is a small pacemaker that sends impulses to the sacral nerve, which controls the bladder. Some patients with IC find that it helps relieve their frequency, but it is usually reserved for those who have not responded to other treatments. Doctors implant the pacemaker in two stages. During the first stage (an outpatient procedure) they insert a small lead or wire into the tailbone. The lead is connected to an external battery that delivers a small electrical impulse, and is worn for two to four weeks. If the patient improves during this time, urologists insert a small generator for the bladder into the upper buttock region. If the device is not helpful during the first stage, doctors remove the device at the second operation.
- **Diet modification to treat Interstitial Cystitis** may help alleviate symptoms because alcohol, tomatoes, spices, chocolate, caffeinated and citrus beverages, and high-acid foods can contribute to bladder inflammation, some physicians and patients believe. Although there is no scientific evidence linking diet to IC, eliminating these substances from the diet helps some people with IC.
- **Smoking cessation to treat for Interstitial Cystitis** is important because the chemicals in cigarette smoke can concentrate in the urine and irritate the bladder wall.
- **Exercise to treat Interstitial Cystitis** can help relieve IC symptoms in some people or even hasten remission.
- **Alternative therapy can help** to cope with chronic pain. Psychosocial support (psychotherapy) can be helpful in dealing with issues like stress, anxiety and depression associated with this long term condition. Relaxation techniques can relieve musculoskeletal tension, and may include meditation, progressive muscle relaxation, self-hypnosis, or biofeedback. Many patients with IC have tight and tender muscles and connective tissue in the pelvis, lower abdomen, thighs, groin, and buttocks. Pelvic floor physical therapy (PT) may be recommended to decrease tightness in these muscles. It can decrease bladder or pelvic pain as well as urinary urgency and frequency. This type of Physiotherapy is specialised requiring therapist specially trained in pelvic soft tissue manipulation and rehabilitation. Several small studies have demonstrated the benefit of PT for tight and tender pelvic muscles associated with IC. It is performed weekly for at least 12 weeks. You will also be given stretching exercises to perform at home. Most people begin to see improvement after six to eight sessions.

Treatment of painful bladder often depends upon a clinician's preferences and experience in treating the disorder and availability of different options rather than upon scientific studies because the cause of this condition is not clear. A number of treatments are available for PBS/IC, many of which are effective for at least some patients. Most patients with PBS/IC need to try more than one treatment, sometimes in combination, to find the one(s) that provides the greatest relief.