

Painful bladder syndrome/Interstitial Cystitis (PBS/IC) ADAPTED FROM IUGA H/O

Painful bladder syndrome and interstitial cystitis (PBS/IC) are conditions characterised by pelvic pain and urinary storage symptoms (eg, urinary urgency or the strong desire to pass urine and frequency, or going to the toilet often). **Pain** is the driving symptom leading to the increased need to empty the bladder. Bladder Pain Syndrome is the name suggested to include both IC and PBS

It is very important to realise that PBS/IC is a condition or group of conditions that are still poorly defined, and inflammation is an important feature in only a small number (<20%) of patients. This group is considered to have interstitial cystitis (IC) or a special type of chronic inflammation of the bladder, whereas PBS refers to pain felt in the bladder region. People with IC have a bladder wall that is inflamed, red and sore. This inflammation can scar the bladder or make it stiff. A stiff bladder can't expand as urine fills it. There may be pinpoint bleeding from the walls of the bladder. A few people get sores or ulcers in the bladder lining.

American Urological Association guidelines recently provided a modified definition for the diagnosis and treatment of PBS/IC: "An unpleasant sensation (pain, pressure, discomfort) perceived to be related to the urinary bladder, associated with lower urinary tract symptom(s) of more than 6 weeks duration, in the absence of infection or other identifiable causes". This describes symptoms. To diagnose actual IC however, a cystoscopy (look in the bladder) is required.

What causes PBS/IC?

There is no general agreement about the cause of PBS/IC and many theories have been proposed including involvement of inflammatory cells or "mast" cells that release histamine, a chemical involved in inflammation, or having a lining of the bladder which allows some of the urine to permeate or "leak" into the surface as normally the lining protects the bladder wall from the toxic effects of urine (think of what nappy rash looks like). In about 70 percent of people with IC, the protective layer of the bladder is "leaky". This may let urine irritate the bladder wall, causing IC. There may be problems with function of the local nerves, pelvic floor muscle function and tension, an autoimmune condition (when antibodies are made that act against a part of the body) or the possibility of an as yet unidentified infective cause.

The lack of clear reason for PBS/IC to develop and the troublesome symptoms it causes make it a very frustrating condition for patients to understand and manage. Treatment and management approaches vary widely because the condition is complex, we don't have a definite way to diagnose it and the cause is not understood. There are also different groups of symptoms in different patients depending on what is the dominant symptom or source of pain, this is sometimes called the "phenotype".

What are the features of PBS/IC?

The condition for most patients has a relatively quick onset, which is unusual for a chronic condition. Most patients can tell you the day symptoms began. Symptoms will not usually progress but will often reach their final stage rapidly and continue without significant change in the future. The most common age of onset is around 40 years old but 30% of patients are less than 30 years old. About half of patients will experience spontaneous remission for anywhere between a short period of a month and much longer, even up to years. Patients with PBS/IC are 10-12 times more likely to have had childhood bladder problems than the unaffected population and are twice as likely to report a history of urinary tract infection.

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There are many associations with PBS/IC, these include allergies, irritable bowel syndrome, fibromyalgia, some autoimmune conditions, migraine and chronic fatigue.

Symptoms in PBS/IC may include frequent need to urinate, both in the daytime and during the night driven by pain, women with severe cases of IC may urinate as many as 60 times a day. Pressure, pain and tenderness around the bladder, pelvis and perineum (the area between the anus and vagina) may be a feature. 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 did before and pain during sexual intercourse may be symptoms. The symptoms of IC vary from case to case and even in the same individual. In many women, the symptoms get worse before their menstrual period. Stress may also make the symptoms worse, but stress does not cause them.

How is PBS/IC diagnosed? How do I know I have it?

You may have PBS/IC if you have symptoms of urinating often or urgently in the response to a feeling of pain or pressure that is different to the usual desire to void, pelvic or bladder pain, finding bladder wall inflammation, pinpoint bleeding or ulcers during an exam with a special telescope (called a cystoscopy) that looks inside your bladder. Your doctor has had to also rule out other diseases such as urinary tract infections, vaginal infections, bladder cancer or sexually transmitted diseases. Diagnostic tests that help identify other conditions include urinalysis leaking often for a wide variety of potential organisms (bugs) that may be involved, urine culture, cystoscopy, biopsy of the bladder wall, distension of the bladder under anaesthesia and urine cytology.

How is PBS/IC treated?

There are many different types of behavioural, dietary, pharmacologic (drug), and surgical treatments that have been used. The Interstitial Cystitis Data Base study reported on more than 180 different treatment modalities, which is why if you search using the Internet there can be both a baffling **quantity** and very varying **quality** of unfiltered information available. Hopefully this document will give you a good starting point and cover most of the information you will need to manage your condition better. *If you use the Internet, be sure to question what you are reading and where it came from before reaching conclusions about your diagnosis or treatment.*

Because the causes of PBS/IC are unknown, current treatments are aimed at relieving symptoms. One or a combination of treatments helps most people for variable periods. As researchers learn more about IC, the list of potential treatments will change, so patients should discuss their options with a doctor.

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Most people feel better after trying one or more of the following treatments:

1. Diet:

Your doctor may tell you to change what you eat. You may need to avoid alcohol, acidic foods and tobacco. Common bladder irritants begin with "C", eg: citrus, chocolate, caffeine, curry/spice.

2. Physiotherapy

Many patients with PBS/IC have tight and tender muscles and connective tissue in the pelvis, lower abdomen, thighs, groin, and buttocks. Tight muscles and connective tissue can be diagnosed during a physical examination. Physiotherapy may be recommended to decrease tightness in these muscles. PT can decrease bladder or pelvic pain as well as urinary urgency and frequency. This type of physio is quite different from that intended to treat a knee injury or back pain, which usually works to increase muscle strength.

With pelvic floor physiotherapy, you lie flat as the physio works on your body to manually "release" the tightness, tender points, trigger points, and restricted movement of the connective tissues and muscles. This includes the muscles and tissues of the vagina or rectum, abdomen, hips, thighs, and lower back. Physiotherapists perform this type of treatment must be specially trained in pelvic soft tissue manipulation and rehabilitation.

Several small studies have demonstrated the benefit of physiotherapy for tight and tender pelvic muscles associated with painful bladder syndrome/interstitial cystitis. One study reported that 70 percent of interstitial cystitis patients who were treated with manual physical therapy to the pelvic floor tissues for 12 to 15 visits experienced moderate to marked improvement.

3. Bladder distension:

Sometimes people feel better after having a bladder distension or hydrodilatation. Under anaesthesia, a doctor overfills your bladder with fluid. This stretches the walls of the bladder. Doctors don't know why distension helps. It may make your bladder be able to hold more urine. It may also interfere with pain signals sent by nerves in the bladder.

Bladder distention can however cause an upswing in pain that may prolong or delay improvement so this needs to be balanced and discussed when choosing this treatment.

4. Medication: Medications are recommended when conservative treatment fails or symptoms are severe.

1. Amitriptyline (brand name: Endep it blocks pain and reduces bladder spasms. This medicine can make you sleepy, so it's usually taken at bedtime).

Amytriptyline is an old style tricyclic antidepressant but in small doses such as recommended here, it reduces the abnormal signals that occur in chronic pain.

2. Pentosan polysulfate (brand name: Elmiron)

Pentosan helps to protect the lining of the bladder wall from the toxic parts of urine. Pentosan is not on the PBS and is expensive. It helps about 40% of patients.

3. Other Medications

Some patients find antihistamines helpful. Diazepam pessaries may help with pelvic floor spasm.

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5. Bladder instillation:

This is a treatment into the bladder in an attempt to be soothing, reduce inflammation and alter bladder lining. During a bladder instillation, a catheter (a thin tube) is used to fill your bladder with a liquid medicine. You hold the medicine inside your bladder for a few seconds to 15 minutes. Then the liquid drains out through the catheter, or you pass it into the toilet normally. Treatments are given every one to two weeks for six to eight weeks. The treatment can be repeated as needed. The substances used include a mixture of local anaesthetic, steroids and heparin that reduce inflammation and that may help the lining of the bladder. iAlurial is a premixed agent that alters the GAG layer or the complex lining of the bladder working on the theory there is “leak” altering bladder. Dimethyl sulfoxide or DMSO (Rimso-50), a chemical solvent from wood pulp which has several uses in medicine. It is known to reduce inflammation and block pain in about a third of IC patients. A further agent, Clorpactin can be given under anesthesia as an instillation for pain. For instillations to be effective you generally need to have a reduced capacity to store urine and some inflammatory changes on inspection or cystoscopy.

Difficult Cases

An extremely small minority of patients are not helped with regular treatments and require surgery. Many approaches and techniques are used, each of which has its own advantages and complications that should be discussed.

Surgery should be considered only if **all** available treatments have failed and the pain is disabling.

Most doctors are reluctant to operate because the outcome is unpredictable and some people still have symptoms after surgery.

What else can I do to help my symptoms?

- 1. Diet** – As mentioned above, alcohol, tomatoes, spices, chocolate, caffeine, citrus drinks, artificial sweeteners and acidic foods may irritate your bladder. That makes your symptoms worse. Try removing these foods from your diet for a couple of weeks. Then try eating one food at a time to see if it makes your symptoms worse.
- 2. Smoking** - Many people with interstitial cystitis find that smoking makes their symptoms worse. Smoking causes Bladder Cancer, which is not related to PBS/IC, but it is good advice to avoid smoking regardless.
- 3. Bladder training** - Many people can train their bladder to urinate less often. You can train your bladder by going to the bathroom at scheduled times and using relaxation techniques. After a while, you try to make the time you can wait longer. Your physiotherapist can help you with bladder training and relaxation techniques.
- 4. Physical therapy and biofeedback** - People with interstitial cystitis may have painful spasms of the pelvic floor muscles. If you have muscle spasms, you can learn exercises to help strengthen and **relax** your pelvic floor muscles.

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5. TENS (this stands for "transcutaneous electrical nerve stimulation")

You can use a TENS machine to put mild electrical pulses into your body through special wires. You would do this at least two times a day. You might do it for a few minutes, or you might do it for a longer time. Some doctors think that electric pulses increase blood flow to the bladder. The increased blood flow strengthens the muscles that help control the bladder. It also releases hormones that block pain. TENS is not expensive. Acupuncture may also work similarly.

6. Supportive therapy and psychology

Whilst stress is not known to cause PBS/IC, it can be worsened by stress, anxiety, depression, and other psychological factors. In addition, living with pain can cause difficulties in relationships, at work or school, and with general day to day living. Psychosocial support can be helpful in dealing with these issues.

Psychosocial support is not recommended because a person with painful bladder syndrome/interstitial cystitis is "crazy" or "difficult". Rather, it is recommended to address the stress, anger, or frustration that can develop as a result of frequent or chronic pain. Depression is common in people with chronic pain, and can interfere with the success of any treatment regimen. Therefore, evaluation and treatment of depression is recommended, if needed. Relaxation techniques can also relieve musculoskeletal tension, and may include meditation, progressive muscle relaxation, self-hypnosis, or biofeedback. I work with particular psychologists who I recommend and are experienced in seeing patients with PBS/IC. There is good information on the Biopsychosocial model of care by Professor Curtin Nickel on the following website: www.wmhp.com.au/blog/10-tips-managing-ic-pbs-professor-curtis-nickel.

Where can I get more information about interstitial cystitis?

The support of family, friends and other people with interstitial cystitis is very important to help you cope with this problem. People who learn about PBS/IC and participate in their own care do better than people who don't. Support groups exist in Australia can be accessed via most large hospital urology or urogynaecology departments. Please discuss this with the urology nurses if you would like more information.

Please remember that only a minority of patients will have true interstitial cystitis and most with PBS respond well to physiotherapy and lifestyle changes, occasionally requiring a bladder instillation or medication. Treatment of your condition is "multidisciplinary". It requires coordination between your Urologist, Physiotherapist, General Medical Practitioner and other practitioners. No one professional can provide total care.

Websites for further information: (including some of the information contained in this document)

Interstitial Cystitis Network (Australia) <http://www.icnaustralia.com/>

Interstitial Cystitis Association <http://www.ichelp.org/>

Up to Date <http://www.uptodate.com/contents/patient-information-treatment-of-painful-bladder-syndrome-and-interstitial-cystitis>