

# Painful Bladder Syndrome and Interstitial Cystitis



**PAINFUL BLADDER AND INTERSTITIAL CYSTITIS OVERVIEW** — Painful bladder syndrome/interstitial cystitis (PBS/IC) is a disorder with symptoms of mild to severe bladder pain and an urgent and/or frequent need to urinate. 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.

**AVOIDING PAINFUL BLADDER FLARES** — Many people with PBS/IC have periods when symptoms are not bothersome that alternate with periods when symptoms are bothersome or even severe (called flares). It is not always clear why flares develop. However, the following triggers may worsen symptoms in some people:

- Certain conditions, such as bladder infections or gastrointestinal problems
- Certain activities, such as sex and prolonged sitting
- Foods and beverages, including alcohol and coffee

**Aggravating conditions** — Conditions such as bladder infections and yeast infections can worsen PBS/IC symptoms and should be evaluated and treated promptly. Because symptoms of these conditions are often similar to those of PBS/IC, most patients should see a healthcare provider to confirm their diagnosis, rather than simply self-treating based upon symptoms

Other disorders that cause pain should also be treated since pain in other areas probably increases bladder sensitivity. These disorders include inflammatory bowel disease (Crohn's disease, ulcerative colitis, diverticulitis), irritable bowel syndrome, painful menstrual periods, or endometriosis. More than one healthcare provider or specialist is often needed for people who have multiple medical conditions.

**Activities** — In some people, exercise or recreational activities (eg, riding a bicycle), sexual activity, or certain body positions (eg, prolonged sitting) can worsen bladder symptoms. Other activities, such as yoga, Pilates, walking, or working at a standing desk may be less bothersome.

**Foods and beverages** — 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.

**COPING WITH CHRONIC PAIN** — Painful bladder syndrome/interstitial cystitis 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. There are several types of psychosocial support:

Psychotherapy involves meeting with a psychologist, psychiatrist, or social worker to discuss emotional responses to living with chronic pain, treatment successes or failures, and/or personal relationships.

Group psychotherapy allows people to compare their experiences with PBS/IC, overcome the tendency to withdraw and become isolated in pain, and support one another's attempts at more effective management.

National support groups are also available, including the Interstitial Cystitis Association ([www.ichelp.org](http://www.ichelp.org)) and the Interstitial Cystitis Network ([www.ic-network.com](http://www.ic-network.com)).

Online or local support groups that deal with chronic pain may also be helpful, such as the American Chronic Pain Society ([www.theacpa.org](http://www.theacpa.org)) and the American Academy of Pain Management ([www.aapainmanage.org/links/Links.php](http://www.aapainmanage.org/links/Links.php)).

Relaxation techniques can relieve musculoskeletal tension, and may include meditation, progressive muscle relaxation, self-hypnosis, or biofeedback.

**BEHAVIORAL THERAPY FOR PAINFUL BLADDER** — Behavioral therapies are treatments that can improve bothersome symptoms through changes in behavior. For people with painful bladder syndrome/interstitial cystitis, one of the more bothersome symptoms is the need to frequently urinate. Behavioral therapies for urinary frequency work to slowly increase the time interval between voids, which increases the amount of urine the bladder can comfortably hold; this is called timed voiding.

A typical timed voiding protocol involves learning to urinate "by the clock" rather than voiding when there is an urge. 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. If 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.

Timed voiding is inexpensive and has no side effects. In one small study of patients with interstitial cystitis, timed voiding reduced symptoms of IC significantly.

**PHYSICAL THERAPY FOR PAINFUL BLADDER** — Many men and women with painful bladder syndrome/interstitial cystitis 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. Pelvic floor physical therapy (PT) 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 PT is quite different from physical therapy intended to treat a knee injury or back pain, which usually works to increase muscle strength. With pelvic floor PT, you lie flat as the physical therapist 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. Physical therapists who perform this type of PT must be 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 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 [6].

Pelvic floor PT is usually performed for one hour once per week 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. If you are not able to tolerate PT due to pain, a local anesthetic can be injected into the painful muscles before PT to reduce pain and allow the therapist to work more effectively.

#### **MEDICATIONS FOR PAINFUL BLADDER**

**Medications to repair bladder lining** — One of the theories regarding the cause of painful bladder syndrome/interstitial cystitis is that the lining of the bladder is damaged. Several treatments have been developed to repair this damage.

**Pentosan polysulfate sodium (Elmiron®)** — Pentosan polysulfate sodium (PPS) is an oral medication that was developed to repair the lining of the bladder in people with interstitial cystitis. However, some studies suggest that only a minority of patients improve as a result of taking the medication.

As an example, one study demonstrated that 38 percent of patients on pentosan polysulfate sodium achieved greater than 50 percent reduction in pain during three months of medication treatment [2]. However, another trial using this medication showed that it had no benefit over placebo pills (an inactive treatment) [3].

**Bladder instillations** — Some healthcare providers recommend a combination of medications, which are instilled into the bladder with a catheter, to reduce symptoms of pain. This can be done in a clinician's office, or you can learn to self-administer the treatment at home. The treatment may be used as a single "rescue" treatment when symptoms are severe, or as a regularly scheduled

treatment (eg, three times per week for two weeks). The medications are in a liquid form and are a small amount (about 15 mL or 0.5 ounces). You hold the liquid in the bladder for as long as possible, and then urinate normally.

The combination of medications may include lidocaine, heparin or pentosan polysulfate sodium, and sodium bicarbonate. It is believed that this combination helps to repair the bladder lining and decrease nerve sensitivity in the bladder. There are no controlled clinical trials of bladder instillations of any medications. In one small study, approximately 80 percent of patients had decreased pain for at least four hours after one treatment with heparin, sodium bicarbonate, and lidocaine [4]. In addition, some patients experience reduced pain for days or weeks after bladder installations.

Medications to decrease nerve pain — Another theory regarding the cause of painful bladder syndrome/interstitial cystitis is that the nerves of the bladder become hypersensitive. Several medications, previously used for other pain-related conditions, have been used to treat nerve hypersensitivity caused by PBS/IC.

Amitriptyline — Amitriptyline is an antidepressant that is commonly used to treat people with chronic pain problems. When used to treat pain, the dose of amitriptyline is typically much lower than that used for treating depression. It is believed that amitriptyline reduces pain perception when used in low doses, but the exact mechanism of its benefit is unknown. In the United States, amitriptyline is not approved for the treatment of pain caused by painful bladder syndrome/interstitial cystitis, although it is safe and effective for the treatment of other conditions.

A common side effect of amitriptyline is fatigue, especially during the first few weeks; this is not always an undesirable side effect since it can help improve sleep when taken in the evening. Other side effects may include dry mouth, weight gain, and a decrease in blood pressure after sitting or standing up. Amitriptyline is generally started at a low dose (5 to 10 mg) and increased gradually. The pain-relief benefit may not be seen for three or more weeks.

Gabapentin — Gabapentin (Neurontin®) is a medication that was initially developed to treat seizures and was later discovered to reduce some types of nerve-related pain. It is not clear how gabapentin works to decrease pain. Side effects of gabapentin may include feeling tired or dizzy. In the United States, gabapentin is not approved for the treatment of pain caused by PBS/IC, although it is approved for the treatment of other types of pain.

Other medications —The antihistamine hydroxyzine (Atarax®) was commonly used in the treatment of interstitial cystitis. Some patients have been found to have up regulation of mast cells and the hydroxyine inhibits the mast cells.

Unfortunately there is no good evidence for its efficacy, but many patients, especially those with “allergies” have found significant benefit.

One small study of women with interstitial cystitis involved the use of montelukast (Singulair®) for three months [5]. Montelukast was originally developed to treat asthma and seasonal allergies. After one month of montelukast treatment, the women had a significant decrease in 24-hour urinary frequency, nighttime voiding and pain, which persisted during the three months of treatment. No side effects were observed during treatment. However, this was a very small study and

further testing is needed before montelukast is recommended for treatment of IC. In the United States, montelukast is not approved for the treatment of PBS/IC, although it is approved for the treatment of asthma and nasal allergies.

**ELECTRICAL STIMULATION FOR PAINFUL BLADDER** — If all other treatments for painful bladder syndrome/interstitial cystitis fail to improve pain or cannot be tolerated, some clinicians will consider performing a surgical treatment called sacral nerve stimulation. This involves surgically implanting a small device, similar to a pacemaker, under the skin in the upper buttock.

This device, called an implanted pulse generator, is connected to a nerve in the lower back through an opening in the tailbone. The pulse generator sends a mild electrical pulse to the nerve; this pulse is thought to interrupt signals from the brain that trigger pain, urgency, and frequency in people with painful bladder syndrome/interstitial cystitis. Most patients can feel the electrical pulse, although it is not painful and usually becomes less noticeable over time.

The surgery is done in two stages, both of which are performed as a day surgery while you are under local anesthesia +/- sedation. During the first stage, a wire is connected to the nerve in the low back, then tunneled out of the skin and connected to a small device (about the size of a pager) that is worn on the waist. The wires are taped securely to the skin. If your symptoms improve while wearing the device over a period of days to one week, a permanent device is then surgically implanted under the skin of the upper buttock and the wires are secured under the skin. If your symptoms do not improve, the wires and device are removed.

Small trials of sacral nerve stimulation show that many people with painful bladder syndrome/interstitial cystitis improve significantly after the procedure [7]. However, the surgical procedure and device (called Interstim™) are expensive. Interstim™ is not approved by the US Food and Drug Administration for treatment of pain caused by painful bladder syndrome/interstitial cystitis, although it is approved for treatment of other bladder problems (eg, overactive bladder).

Risks of the procedure include the need for a subsequent surgery to reposition or remove the wire or pulse generator, infection, bleeding, and pain. Anyone who is considering sacral nerve stimulation should discuss the risks and benefits with a physician who is experienced and knowledgeable about all available treatments for painful bladder syndrome/interstitial cystitis.

**WHERE TO GET MORE INFORMATION** —A number of web sites have information about medical problems and treatments, although it can be difficult to know which sites are reputable. Information provided by the National Institutes of Health, national medical societies and some other well-established organizations are often reliable sources of information, although the frequency with which they are updated is variable.

National Library of Medicine  
([www.nlm.nih.gov/medlineplus/healthtopics.html](http://www.nlm.nih.gov/medlineplus/healthtopics.html))

National Institute of Diabetes and Digestive and Kidney Diseases  
(<http://kidney.niddk.nih.gov/kudiseases/pubs/interstitialcystitis/>)

United States Department of Health and Human Services  
([www.4woman.gov/faq/intcyst.htm](http://www.4woman.gov/faq/intcyst.htm))

Interstitial Cystitis Association  
([www.ichelp.org](http://www.ichelp.org))

Interstitial Cystitis Network  
([www.ic-network.com](http://www.ic-network.com))

European Society for the Study of Interstitial Cystitis  
([www.essic.eu](http://www.essic.eu))

International Painful Bladder Foundation  
[www.painful-bladder.org/index.html](http://www.painful-bladder.org/index.html)

## REFERENCES

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