Interstitial cystitis/painful bladder syndrome (IC/PBS) is a chronic condition characterized by pelvic pain, urinary urgency, and urinary frequency. IC/PBS significantly affects quality of life. Even though people with IC/PBS can appear healthy, many have to curtail work and leisure activities and have difficulty sleeping and maintaining sexual intimacy.¹⁻³ There is no cure for IC/PBS, but there are therapies that can relieve debilitating symptoms.

**Risk Factors for IC/PBS**

The only definitive risk factor for IC/PBS is female gender: significantly more women than men have this disease.⁴⁻⁵ In the United States, it is estimated that more than one million women and more than 80,000 men in the United States have IC/PBS. However, IC/PBS may be underdiagnosed in men because some men are misclassified as having chronic prostatitis.⁶ Other possible risk factors include heredity and previous urinary tract infection.⁷⁻⁸

**Causes of IC/PBS**

The exact cause of IC/PBS is unknown, but research has shown bladder damage may trigger this condition. In patients with IC/PBS, researchers have found specific pathologies, including abnormalities of the bladder surface mucin, changes in the nerve function within the bladder wall, and change in substances secreted by the urothelial surface, such as antiproliferative factor.⁹⁻¹⁰ Researchers are studying conditions that seem to occur more frequently in people who have IC/PBS than in the general population: allergies, sensitive skin, irritable bowel syndrome, vulvar pain syndrome (vulvodynia), pelvic floor muscle spasm, and endometriosis.¹¹

**Symptoms of IC/PBS**

Symptoms of IC/PBS can vary in severity and frequency, and include:¹²

- Pelvic pain, pressure, or discomfort
- “Persistent urge” to void or urinary frequency typically associated with these sensations
- Absence of infection or other pathology

Pelvic pain, sometimes described as pressure or discomfort, is the defining symptom. As bladder fills, pain increases; as bladder empties, pain often diminishes.⁷ The pain, in turn, can increase the feeling of urgency, which is usually relieved by voiding.

Women who have IC/PBS urinate as many as 10 to 50 times in 24 hours and suffer from nocturia and dyspareunia, especially perimenstrually.⁵⁻¹³ Men also have problems with nocturia and dyspareunia.

**Diagnosis of IC/PBS**

People with IC/PBS may suffer needlessly—for an average of 5 to 7 years—before they receive an accurate diagnosis. The condition is difficult to diagnose: biological markers have not yet been confirmed, and it mimics other conditions. Recent studies have focused on identifying biological markers.

The general approach to diagnosing IC/PBS is empirical. First, other conditions are excluded, e.g., urinary tract infection, overactive bladder, bladder carcinoma, and drug effects of cyclophosphamide, aspirin, NSAIDs, and allopurinol.⁹ Then, patients with characteristic signs and symptoms are treated for presumed IC/PBS.⁹

In the United States, clinicians generally use six tools for a basic diagnostic assessment:

- History (voiding symptoms, pelvic pain or discomfort, urinary frequency and urgency, and nocturia)
- Physical exam (pelvic exam in women and digital rectal exam in men)
- Urinalysis
- Urine culture
- Cytology (when indicated)⁹

Other tests that may be performed are cystoscopy with hydrodistention under anesthesia, “potassium sensitivity test” (to identify worsening symptoms caused by the potassium solution irritating the bladder wall), and an “anesthetic challenge” (to identify improvement in symptoms after intravesical instillation of an anesthetic).¹⁴⁻¹⁵

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**Impact of IC/PBS on Quality of Life (QoL)**¹⁻³

- Pain, urinary urgency, and urinary frequency
- Limitations on sexual intimacy
- Curtailed activities
- Sleep deprivation
- Reduced ability to work
- Reduced QoL

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What You Need to Know is a publication of the Association of Reproductive Health Professionals (ARHP) for health care professionals, educators, and researchers working in the field of reproductive health.
During the diagnostic stage, consider IC/PBS in the following scenarios:6,16

- Patient treated for overactive bladder continues to experience persistent urge with associated suprapubic/pelvic discomfort or pain.
- Patient does not respond to empiric antibiotics for “recurrent urinary tract infection,” especially if bacterial cystitis is not present and the patient has mounting discomfort with bladder filling.
- Female patient continues to have pelvic pain or discomfort after therapy for endometriosis (medical and/or surgical), especially if she has urinary frequency or change in pain or discomfort with bladder filling and emptying.
- Male patient has been treated for “prostatitis” with therapies such as antibiotics and alpha blockers but continues to have pelvic pain or discomfort perceived to be associated with the bladder and possibly irritative voiding symptoms.

Management of IC/PBS

Primary care providers vary in their treatment approach of IC/PBS, but many focus on diet and self-help strategies and oral therapy before trying other therapies. Surgery is rarely done.

- **Oral therapy.** Commonly used oral agents are pentosan polysulfate sodium (PPS; Elmiron®), the only oral therapy approved by the U.S. Food and Drug Administration (FDA) for use in IC/PBS; amitriptyline; and hydroxyzine (Atarax®, Vistaril®).9

Other therapies used for IC/PBS are:

- **Intravesical therapy.** This therapy involves instilling a single agent or “cocktail” of agents into the bladder. It is generally used as second-line treatment or in conjunction with oral therapy or other types of conservative treatment. Dimethylsulfoxide (DMSO; RIMSO®-50) is the only intravesical therapy that has FDA approval for use in IC/PBS.

- **Hydrodistention.** While patient is under anesthesia, the urologist performs a cystoscopic exam and distends the bladder with sterile water for 1-2 minutes.

Primary care providers may want to consider referring patients to specialists if symptoms do not respond to oral therapies, diagnosis is in doubt, or they are uncomfortable treating the condition or lack the time to do it.

Counseling Patients

Health care professionals should acknowledge the challenges of living with IC/PBS, reassure patients that the condition can be diagnosed despite the absence of specific markers, explore treatment options, and support diet and self-help strategies.12,17

With the diet strategy, patients remove potential trigger and reintroduce them one at a time.

Some substances that may trigger symptoms17

- Coffee and tea
- Other caffeinated drinks
- Soda
- Alcoholic drinks
- Citrus fruits and drinks
- Artificial sweeteners
- Spicy foods
- Tomatoes
- Food additives and preservatives

For a complete list, visit www.icahelp.org/diet

ARHP and ICA have a patient fact sheet that includes self-help strategies at www.arhp.org/healthmatters/icpbs.cfm.