

*A Quick Reference Guide
for Clinicians®*

Diagnosis and Management of Interstitial Cystitis/ Painful Bladder Syndrome

Contents

Using This Guide	1
Introduction to IC/PBS	3
Diagnosis	7
Diet and Self-Care	13
Oral Therapy	15
Treatment with Cystoscopy, Intravesical Therapy, or Surgery	19
Counseling Tips	22
Resources for Patients	25

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Using This Guide

Interstitial cystitis/painful bladder syndrome (IC/PBS) is a chronic debilitating condition characterized by pelvic pain, urinary urgency, and urinary frequency. The condition takes a significant toll on patients' quality of life. People who have IC/PBS suffer from a "silent affliction," often appearing healthy but experiencing unrelenting pain that requires frequent trips to the bathroom, both day and night. Although curing IC/PBS is not yet possible, the high toll that IC/PBS exacts can be mitigated with currently available therapy once the disease is diagnosed.

Unfortunately, people who have IC/PBS often suffer needlessly because of delays in diagnosis, misdiagnosis, and lack of awareness of the disorder. On average, patients experience a lag time of five to seven years before they receive a diagnosis of IC/PBS.

Primary care providers can play an essential role in reducing such suffering by identifying persons whose symptoms are consistent with IC/PBS, promptly diagnosing and treating the disorder, and referring patients to specialists as necessary. For this reason, it is important for primary care providers to be aware of IC/PBS and become familiar with the presentation and recommendations for diagnosis and management of IC/PBS.

This *Quick Reference Guide for Clinicians*® is designed to help health care providers more easily identify patients for whom a diagnosis of IC/PBS should be considered and, depending on their level of experience and comfort, begin the process of diagnosis and treatment, referring for specialty care when needed.

Considering the possibility that a patient's symptoms may represent IC/PBS is the crucial first step in uncovering previously undiagnosed and untreated IC/PBS. We hope this *Quick Reference Guide for Clinicians* allows health care providers to confidently take that first step, preventing unnecessary and prolonged suffering for the many people whose condition remains undiagnosed and therefore inadequately treated.

The following abbreviations are used throughout this document:

DMSO – dimethylsulfoxide

FDA – Food and Drug Administration

IC/PBS – interstitial cystitis/painful bladder syndrome

NSAIDs – nonsteroidal anti-inflammatory drugs

OAB – overactive bladder

PFD – pelvic floor dysfunction

PPS – pentosan polysulfate sodium

SSRIs – selective serotonin reuptake inhibitors

UTI – urinary tract infection

Introduction to Interstitial Cystitis/Painful Bladder Syndrome

Overview

- Interstitial cystitis/painful bladder syndrome (IC/PBS) is a chronic debilitating condition characterized by pelvic pain, urinary urgency, and urinary frequency.¹
- The type and severity of symptoms in IC/PBS can vary widely, which may lead to misdiagnosis or a delayed diagnosis.
- Experts estimate that the condition affects about 1.2 million women and 82,000 men in the United States, although these figures may significantly underestimate the true prevalence of the condition.²

Definition

- Clearly defining IC/PBS is difficult because the underlying pathology has not yet been elucidated, biological markers are not yet available, and the type and severity of symptoms can vary.
- Participants of an expert consensus meeting on IC/PBS convened by the Association of Reproductive Health Professionals (ARHP) and the Interstitial Cystitis Association (ICA) in February 2007 accepted the following as a definition for IC/PBS:

Pelvic pain, pressure, or discomfort related to the bladder, typically associated with persistent urge to void or urinary frequency, in the absence of infection or other pathology.

Symptoms

- Bladder pain (or pressure or discomfort)
 - A defining symptom.
 - Characteristic of IC/PBS: pain or discomfort often increases with bladder filling and may diminish during voiding.³
 - Bladder pain or discomfort is associated with a persistent urge to void, urinary frequency, or both.

- Urinary urgency
 - Often a progressive course of urgency that may be relieved by voiding.
 - Urgency is caused by increasing pain, unlike overactive bladder (OAB), in which urgency waxes and wanes and is due to concern about impending incontinence.³
 - *Persistence* of urgency often is useful in differentiating IC/PBS from acute urinary tract infection (UTI) or OAB.
- Urinary frequency
 - Common in IC/PBS, with voiding 10 to 15 times or more within 24 hours.
 - May be severe, with voiding more than once an hour.²
- Other symptoms
 - Nocturia is common and may cause sleep deprivation.
 - Dyspareunia is common in women with IC/PBS.⁴
 - Incontinence is uncommon.

Symptom presentation

- Variable presentation.
- Symptoms range from very severe, described as a sharp pain, to less severe, described as feeling similar to a persistent urinary tract infection.
- Symptoms can be intermittent or constant.
- Symptoms can wax and wane over time.
- Among women, symptoms may flare during the premenstrual week.⁴

Comorbid conditions

- Certain conditions are more common in patients with IC/PBS than in the general population.
- Some of these conditions have an immunologic or allergic basis.
- In late 2007, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) launched research opportunities

to better understand the relationship between IC/PBS and these comorbid conditions.

- Providers should be alert for the presence of such conditions in patients who have IC/PBS or who present with symptoms suggestive of IC/PBS.
- Identifying and treating these conditions can reduce or eliminate a secondary source of pain for patients who have IC/PBS.
- Comorbid conditions⁵⁻⁸
 - Allergies
 - Chronic fatigue syndrome
 - Endometriosis
 - Fibromyalgia
 - Inflammatory bowel disease
 - Irritable bowel syndrome
 - Migraine headaches
 - Pelvic floor dysfunction
 - Sensitive skin
 - Systemic lupus erythematosus
 - Vulvodynia

Pelvic floor dysfunction (PFD)⁶

- Common among patients with IC/PBS.
- Defined as myofascial dysfunction of the pelvic floor muscles (e.g., levator ani—the posterior portion of the pelvic floor muscle).
- A frequent cause of chronic pelvic pain.
- Common symptoms:
 - Constipation
 - Decreased force of urinary stream
 - Urinary hesitancy
 - Straining with urination
 - Sense of incomplete void

- Low-back pain
- Dyspareunia
- Tenderness of the levator ani muscle found on pelvic or rectal exam.
- Therapy directed at PFD may help reduce IC/PBS symptoms in patients.

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Diagnosis

Challenges of diagnosis

- Currently available diagnostic criteria, which were developed for research, have been shown to miss many patients with the condition.¹
- Techniques that are painful and invasive have been used for diagnosis, but some experts believe these to be inaccurate and unnecessary.²
- There are currently no biological markers for use in diagnosis.
- The diagnosis of IC/PBS remains one of exclusion.^{3,4}

Approach to diagnosis

- The general approach to diagnosis of IC/PBS tends to be empirical.
- Once other conditions are excluded, patients with characteristic signs and symptoms generally are treated for presumed IC/PBS.
- In certain circumstances, some clinicians may choose to evaluate further, with cystoscopy with hydrodistention under general anesthesia, urodynamic studies, or lidocaine instillation.
- Clinicians should especially consider IC/PBS in patients who may have been misdiagnosed with another condition.
- It is also important to identify any comorbid conditions, such as pelvic floor dysfunction, that may serve as “secondary pain generators,” exacerbating symptoms in patients who have IC/PBS.
- Bladder carcinoma and drug effects are rare but should be considered in patients with relevant findings, such as microhematuria on cystoscopy.
- Note that cyclophosphamide, aspirin, NSAIDs, and allopurinol are associated with a nonbacterial cystitis that resolves when the drugs are discontinued.⁴
- Two or more of these conditions can occur concurrently.

Differential diagnosis of IC/PBS

Bladder carcinoma

Drug effects: cyclophosphamide, aspirin, NSAIDs, allopurinol

Endometriosis

Overactive bladder

Radiation cystitis

Urinary tract infection

Avoid underdiagnosis by considering IC/PBS in:^{5,6}

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

Caveats for diagnosis

- Be wary of making a diagnosis of IC/PBS in patients who have OAB unless adequate treatment of involuntary detrusor contractions fails to resolve symptoms.
- Similarly, avoid making a diagnosis of IC/PBS in patients who have a history of recurrent UTI unless adequate antibiotic treatment fails to resolve symptoms.
- Be aware that although urgency is a common symptom of IC/PBS, it is also characteristic of OAB.

Components of basic assessment

- History
- Physical examination
- Urinalysis
- Urine culture
- Cystoscopy with hydrodistention under general anesthesia
- Cytology (when indicated)

History

- Elicit a detailed history of voiding symptoms, pelvic pain or discomfort, urinary frequency and urgency, and nocturia.
- Ask the patient to keep a voiding log for assessing urinary frequency.
- Use a variety of terms to query about bladder pain. Some patients who have IC/PBS do not complain of pelvic pain but, if asked, will admit to discomfort or pressure that is relieved by voiding.
- Ask about the timing and course of symptoms. A distinguishing characteristic of IC/PBS is progressive bladder pain or discomfort with increased bladder filling.

Physical exam

- Perform a pelvic exam in women and a digital rectal exam in men. Many patients who have IC/PBS have exquisite tenderness at the bladder neck, at the perineum between the anus and scrotum in men, and at the anterior vaginal wall near the urethral meatus in women.⁷
- Perform assessment of pelvic floor muscle strength and pelvic floor muscle tenderness.
- Evaluate for vaginal vault, introital, or vestibular pathology and periurethral or urethral lesions.

Urinalysis

- Assess for signs of infection.
- If hematuria is present, further work-up (e.g., cystoscopy with hydrodistention or urine cytology) is needed to rule out other pathology, such as renal stones or cancer.

Urine culture

- Assess for signs of infection.
- Recurrent UTI can cause symptoms similar to IC/PBS.

Cystoscopy with hydrodistention under general anesthesia

- Characteristic finding: diffuse glomerulations.
- Can have short-term therapeutic benefit in up to 50 percent of patients.⁴
- How procedure is performed:
 - With the patient under general anesthesia, the urologist performs a cystoscopic examination, obtains urine for cytology, and distends the bladder with sterile water for 1–2 minutes.
 - The bladder is emptied and then refilled to look for lesions or ulceration.
 - The urologist then distends the bladder again for 8 minutes. The bladder is then emptied again, at which time the urologist may take a biopsy specimen.

Cytology (when indicated)

- Send for urine cytology in patients who are at higher risk for bladder cancer.

Other intravesical diagnostic tests

- Lidocaine challenge.
 - Therapeutic technique that may be useful for diagnosis, though it is not yet validated.
 - Can help differentiate bladder from nonbladder sources of pain.
 - How procedure is performed:
 - Intravesical catheter is used to fill bladder with lidocaine, with a variable combination of heparin, gentamicin, triamcinolone, or other agents.
 - Patients are instructed to keep mixture in bladder for 30 minutes if possible before voiding.
 - Pain relief may last for days.

- Potassium chloride challenge (Parsons' test).
 - Tests for epithelial leakage or bladder sensitivity; not specific to IC/PBS.²
 - Not widely used by urologists in this country.
 - Some experts feel it may be helpful in the subset of patients who have minimal pain.
 - Test is positive if instillation elicits irritative voiding symptoms and/or pain.
 - How procedure is performed:
 - Intravesical catheter is used to fill bladder with potassium chloride (0.4 M solution, 400 meq/L).
 - After 5 minutes of retaining solution in the bladder, the patient rates his or her level of symptoms and pain.
 - A positive result is pain and re-creation or exacerbation of IC/PBS symptoms.
 - For more information, see http://drlowellparsons.org/uploads/PST_instr.doc.

Imaging studies

- Pelvic ultrasound.
 - Useful for assessing other causes of pelvic pain (which can coexist with IC/PBS and exacerbate symptoms), including ovarian cysts and uterine fibroids.⁸
 - Requires full bladder, which can be painful for patients who have IC/PBS. Vaginal probe is an alternative, although this option also may be painful.
- Intravenous pyelogram.
 - Useful for ruling out urinary system obstructions, such as kidney stones.
 - Requires intravenous injection of contrast material and X-ray.

Urodynamic studies

- Generally show normal function, with the exception of hypersensitivity and reduced bladder capacity.
- Can help assess bladder compliance: check for reproduction of symptoms with bladder filling and rule out detrusor overactivity.⁴
 - How procedure is performed:
 - Intravesical catheter is used to fill bladder with sterile water.
 - The urologist then asks the patient about sensations (first urge to void, discomfort) while measuring changes in pressure and volume.
 - The procedure can be painful for patients who have IC/PBS because of the need for catheterization and bladder filling.
- Pain on bladder filling and low volume at first sensation of fullness are characteristic of IC/PBS.⁸

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Diet and Self-Care

Diet

- Avoiding certain foods, beverages, vitamins, and additives may help control symptoms and avoid flare-ups.
- Not every patient is affected by all of these substances, and the degree of response varies from patient to patient.
- Working with a knowledgeable nutritionist on an elimination diet (removing potential trigger substances and then reintroducing them one at a time) may be helpful.
- Patients who are sensitive to a particular substance will notice symptoms 30 minutes to 6 hours after ingesting it.¹

Some substances that may trigger IC/PBS symptom flares:²

- Coffee
- Tea
- Soda
- Alcoholic beverages
- Caffeinated beverages
- Citrus fruits and juices
- Artificial sweeteners
- Spicy foods (e.g., hot peppers)
- Tomatoes
- Food additives and preservatives

This list was compiled from responses to a questionnaire by patients who have IC/PBS, published by Shorter and colleagues, supplemented by anecdotal reports from patients provided by expert committee members.

Self-care

- An important component of IC/PBS management
- Can help patients better manage symptoms
- Can help address secondary causes of pelvic pain that can exacerbate symptoms
- Encourages patients to take an active role in managing IC/PBS
- Randomized controlled data are not available, but faculty reviewers of this *Quick Reference Guide* believe that patients may find these strategies helpful.

Specific self-care strategies

- Gentle exercise, such as low-impact aerobics, walking, yoga, and Tai Chi
- Stress reduction techniques, such as relaxation techniques, meditation, visualization, self-hypnosis, massage, and psychotherapy
- Pain relief strategies, such as a warm sitz bath or use of a cold pack or hot water bottle on the perineum or suprapubically
- Comfortable and nonrestrictive clothing
- Alternative therapies, such as acupressure, acupuncture, and biofeedback
- Physical therapy—transvaginal massage using the Thiele technique, which has been shown to improve IC/PBS symptoms and decrease tone of pelvic floor muscles³
- Bladder retraining programs that include suppression of urgency—a protocol of progressive, small increases in the intervals between voiding with the goal of reducing urinary frequency (appropriate only for patients who are free of pain)
- Experimenting with different positions during sexual intercourse or using lubricants, if dyspareunia is an issue
- Controlled fluid intake—but not fluid restriction—may help patients (if symptoms increase when urine is concentrated, it is suggested that patients increase fluid intake, but not more than about 2 liters per 24 hours; some clinicians suggest that patients “drink to thirst”)

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Oral Therapy

The majority of agents used in the treatment of IC/PBS are not approved by the Food and Drug Administration (FDA) for this indication. Oral pentosan polysulfate sodium (PPS) and intravesical dimethylsulfoxide (DMSO) are the only FDA-approved agents. The majority of medications mentioned in this *Quick Reference Guide* have either shown efficacy in non-FDA-based clinical trials or are used in clinical practice by advisory committee members.

Approach to therapy

- The preferred approach to first-line therapy varies among clinicians, making construction of treatment algorithms for IC/PBS a challenge.
- Most clinicians knowledgeable about IC/PBS focus on self-care and oral therapy, adding intravesical therapy as needed.
- Surgery is an option of last resort for patients whose symptoms are unresponsive to primary forms of treatment, and is rarely performed.

Oral agents

- Oral therapy is a mainstay of IC/PBS management.
- The most commonly used oral agents (with the exception of use in clinical trials) are:¹
 - Amitriptyline
 - Hydroxyzine
 - Pentosan polysulfate sodium
- Other oral agents are sometimes used for symptomatic relief.

Amitriptyline

- Tricyclic antidepressant often used to treat IC/PBS.
- The dose used for IC/PBS is generally much lower than that used for depression.
- Modulates pain by decreasing reuptake of serotonin and norepinephrine in the central nervous system.²

- May help stabilize mast cells, reducing release of pro-inflammatory substances during allergic reactions.²
- May increase bladder capacity through beta-adrenergic receptors on the bladder.³
- Seems to be most effective for IC/PBS patients for whom pain is a significant component of their symptom complex.
- A randomized, placebo-controlled trial (N=50) found that treatment significantly reduced mean symptom score compared with placebo ($p = 0.005$).⁴
- Sedation can be a limiting side effect but can promote sleep if taken in the evening.
- Should be prescribed only by health care providers who are familiar with its side effect profile and use in IC/PBS.
- Typical doses of amitriptyline used for IC/PBS: start at 10 mg to 25 mg qhs; if needed, the dose can be slowly increased to 75 mg qhs, as tolerated.

Hydroxyzine (Atarax®, Vistaril®)

- Histamine H₁ antagonist.
- Inhibits mast cell degranulation, thus reducing histamine release, which has been implicated in the pathophysiology of IC/PBS.^{1,2}
- Open-label study found treatment reduced symptom scores by 55 percent on average in patients who have a history of allergies.⁵
- A subsequent randomized controlled trial found no reduction in global assessment scores compared with placebo.⁶
- May promote sleep and may act as a skeletal muscle relaxant, two actions that may help modify IC/PBS symptoms.
- Typical doses of hydroxyzine used for IC/PBS: started at 10 mg to 25 mg qhs; if needed, the dose can be slowly increased to 75 mg qhs, as tolerated.

Pentosan polysulfate sodium (PPS; Elmiron®)

- The only oral therapy approved by the FDA for IC/PBS (1996).
- PPS is a heparin analogue that has 1/15th the anticoagulation activity of heparin.²

- PPS is believed to repair the lining of the bladder, counteracting the increased permeability seen in IC/PBS.²
- In clinical trials, PPS was found to be beneficial in a minority of patients (overall improvement of greater than 25 percent in 32 percent of PPS-treated patients compared with 16 percent for placebo).^{7,8}
- A long-term, open-label study found that 42 percent to 62 percent of patients treated with PPS experienced moderate or better improvement in overall symptoms when the data are analyzed without the subjects who withdrew for lack of efficacy.⁹
- Can take 2 months or longer to be effective.
- Is generally well tolerated.

Other oral agents used in IC/PBS management^{1,2,11,12}

Some clinicians use these agents to treat IC/PBS; like many agents used for IC/PBS, they are not FDA-approved for this use

Oral Agent	Comment
Alpha blockers	Examples: doxazosin, terazosin
Anticonvulsants	Examples: gabapentin, pregabalin, carbamazepine.
Antihistamines other than hydroxyzine	Anecdotal reports exist of symptom improvement in some patients with loratadine or diphenhydramine
H ₂ antagonists	Example: cimetidine
Leukotriene inhibitors	Example: montelukast
Muscle relaxants	Can be an effective therapy for muscle spasticity syndromes like pelvic floor dysfunction
Opioids	Chronic narcotic therapy is sometimes used in patients who respond poorly to other therapies; referral for pain management can be helpful for some patients
Tricyclics other than amitriptyline	Examples: imipramine, nortriptyline, doxepin
Urinary anesthetics	Example: phenazopyridine

- Side effects include dyspepsia and reversible alopecia.
- Typical doses of PPS used for IC/PBS: 100 mg TID.

Other oral agents

- Specialists occasionally use other oral agents to treat IC/PBS symptoms.
- Clinical trial data are not available for these agents in treatment of IC/PBS.

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Treatment with Cystoscopy, Intravesical Therapy, or Surgery

Approach to therapy

- The preferred approach to first-line therapy varies among clinicians, making construction of treatment algorithms for IC/PBS a challenge.
- Most clinicians knowledgeable about IC/PBS focus on self-care and oral therapy, adding intravesical therapy as needed.
- Surgery is an option of last resort for patients whose symptoms are unresponsive to other forms of treatment, and is rarely performed.

Cystoscopy with Hydrodistention Under General Anesthesia

- A procedure often used to better identify bladder abnormalities commonly associated with IC/PBS.
- Can have short-term therapeutic benefit in up to 50 percent of patients.¹
- For a complete description of the procedure, see page 7.

Intravesical Therapy

Uses for intravesical therapy

- As a second-line treatment.
- In conjunction with oral therapy or other types of conservative therapies.

Agents used for intravesical therapy

- Dimethylsulfoxide (DMSO; RIMSO®-50)
 - The only intravesical therapy with FDA approval for use in IC/PBS (1978).
 - Appears to have anti-inflammatory, analgesic, and muscle-relaxant effects.
 - Often administered in the form of a “cocktail.”
 - Instilled in the bladder via catheter and for 15 minutes.
 - Treatment is repeated weekly for 6 to 8 weeks.

- Randomized controlled trials showed intravesical DMSO to have a 70 percent efficacy rate in reducing the symptoms of IC/PBS.^{2,3}
- Patients who respond often experience improvement for several months, perhaps as long as a year.
- Side effects include a garlic taste and body odor and discomfort caused by catheterization.
- Intravesical cocktail:
 - Randomized controlled data are not available for any cocktails.
 - Examples of typical cocktails:
 - Heparin, lidocaine, and sodium bicarbonate—demonstrated immediate and statistically significant symptom relief in an open study (n= 82).⁴
 - DMSO, a methylprednisolone, and heparin sulfate—demonstrated initial remission of symptoms in 92 percent of patients in an open study (n=25).⁵

How intravesical therapy is performed

- The therapeutic agent is introduced slowly into the bladder via urinary catheter.
- The agent is held in bladder for varying duration (usually 20 to 30 minutes), then voided.

Surgery

Indications for surgery

- Treatment of last resort, reserved for patients with severe symptoms that are unresponsive to other therapy.
- Some patients continue to experience pelvic pain even after the bladder is removed, possibly due to pelvic floor spasm or central nervous system-mediated pain.
- Goal is to increase the functional capacity of the bladder or to divert the urine stream.⁶

Surgical options

- Cystoscopic treatments: usually performed for the rare patient with the “classical” form of IC/PBS, which is associated with specific inflammatory lesions on the bladder wall.^{7,8}

- Bladder wall resection.
- Laser therapy ablation.
- Implantable nerve stimulators
 - Interstim is approved by the FDA for urinary frequency and urgency.
 - Less helpful for IC/PBS patients whose primary symptom is pain.
 - Two open, noncomparative studies found that a majority of IC/PBS patients whose condition was refractory to other treatment experienced at least 50 percent improvement in symptoms with implantation of the device.^{9,10}
- Radical surgery options
 - Urinary diversion with or without cystectomy (removal of bladder).
 - Augmentation cystoplasty, in which a portion of bowel is added to the bladder to increase bladder capacity.

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Counseling Tips

Acknowledging challenges

- Acknowledge the challenges of living with IC/PBS:
 - Unremitting pain
 - Living with an “invisible” chronic illness
 - Disruption of daily life by urgency, frequency, and nocturia
 - Delays in diagnosis due in part to a lack of familiarity with IC/PBS among providers
 - Delays in relief of symptoms (some IC/PBS treatments take months to be effective)
 - Sexual intimacy problems
 - Greater likelihood of having certain associated conditions (e.g., irritable bowel syndrome, fibromyalgia, allergies)
 - Living with side effects of medications
 - Dealing with the effects of chronic illness on family life or employment
 - Lack of full appreciation and validation of patient’s experience by family, coworkers, and friends, sometimes leading to a sense of isolation

Exploring IC/PBS diagnosis

- Reassure patients that it is possible to use a working diagnosis and to treat symptoms.
- Discuss the possibility of making a diagnosis without invasive techniques.
- Explain the importance of the medical history, symptom questionnaires, and a voiding history.
- When asking about pain in taking a history of symptoms, use a range of terms (some patients will deny pain yet affirm that they suffer from bladder discomfort or pressure).
- Ask patients to rate their pain (e.g., on a scale from 0 to 10).
- Discuss the need and timing of referral to a urologist or IC/PBS specialist.

- Encourage patients to ask questions and seek additional sources of information, such as the Interstitial Cystitis Association at (800) HELP ICA and www.ichelp.org.

Referring for Specialist's Care

- Referral to a specialist is recommended if:
 - Symptoms do not respond to oral therapies.
 - The diagnosis is in doubt.
 - The provider is uncomfortable treating IC/PBS or lacks the time to do so.
- Refer patients needing a specialist's care to a urologist, gynecologist, or urogynecologist who has experience diagnosing and treating IC/PBS.
- Inquire about the specialist's comfort and experience with IC/PBS before referring.
- Consider referral to a pain management clinic if appropriate urologic and gynecologic evaluations have been performed and interventions have not been sufficiently effective in relieving pain.

Exploring treatment options

- Explore available options with patients.
- Reassure patients that treatment can be tailored to suit their specific symptoms and needs.
- Explain the oral therapy options and ask about previous use of oral therapy for other conditions.
- Discuss potential drug-related side effects and methods for minimizing or avoiding them.
- List available intravesical therapy options and describe the procedure used for bladder instillation.
- Discuss the timing of referral to a urologist or IC/PBS specialist for treatment.
- Encourage patients to ask questions and seek additional sources of information and support.

Supporting dietary and self-care practices

Self-care is an essential component of IC/PBS treatment, helping patients to manage symptoms and providing them with a sense of control over the condition. Providers can support self-care in a number of ways.

- Supporting dietary practices
 - Describe the elimination diet.
 - Provide a list of possible trigger substances (see page 13).
 - Consider referral to registered dietitian who is knowledgeable about IC/PBS.
 - Explain that each patient is unique in terms of the foods and beverages that trigger symptoms, and that some patients' symptoms seem to be unaffected by diet.
- Supporting self-care practices
 - Encourage patients to avoid using fluid restriction to reduce urinary frequency, but instead use controlled fluid intake to manage symptoms.
 - Discuss options for stress reduction with patients, including meditation, yoga, massage therapy, progressive muscle relaxation, and support from other IC/PBS patients.
 - Recommend that patients try applying heat or cold to the perineum or suprapubically to reduce symptoms.
 - Recommend practices to minimize or prevent further discomfort, such as avoiding straining when moving bowels and treating constipation.
 - Discuss the impact of IC/PBS on sexuality.
 - Recommend that patients with dyspareunia experiment with various positions and use of vaginal lubricants.
 - Consider referral to physical therapy if pelvic floor dysfunction is present.

Resources for Patients

Support for IC/PBS: The Interstitial Cystitis Association (ICA)

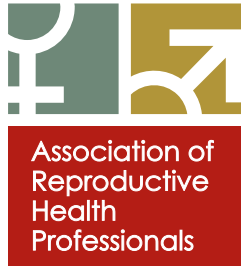
- Founded by a physician with IC/PBS.
- Goals: raise awareness about the condition, support patients with IC/PBS and their families, provide information about IC/PBS, raise funds for IC/PBS-related research, and work with Congress and the National Institutes of Health to ensure that funds are dedicated to study IC/PBS.
- Offers one-on-one support.
- Maintains an informational Web site, a registry of health care professionals with experience in IC/PBS diagnosis and management, and produces books, newsletters, and fact sheets about IC/PBS.
- Contact through www.ichelp.org or (800) HELP ICA

Support for IC/PBS-Associated Diseases

- IC/PBS is associated with a number of diseases, such as irritable bowel syndrome, fibromyalgia, and vulvodynia.
- Patients who have IC/PBS and associated diseases may find it helpful to contact organizations that can provide disease-specific education and support.

Organizations focused on IC/PBS-associated conditions

- The American Chronic Pain Foundation: www.theacpa.org
- The American Pain Foundation: www.painfoundation.org
- The Chronic Fatigue and Immune Dysfunction Syndrome Association of America: www.cfids.org
- Crohn's and Colitis Foundation of America: www.ccfa.org
- The Endometriosis Association: www.endometriosisassn.org
- International Foundation for Functional Gastrointestinal Disorders: www.iffgd.org
- The Lupus Foundation of America: www.lupus.org
- National Fibromyalgia Association: www.fmaware.org
- National Fibromyalgia Partnership: www.fmpartnership.org
- National Vulvodynia Association: www.nva.org



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The Interstitial Cystitis Association of America (ICA) is the authoritative source of IC/PBS information in the US. A national nonprofit organization, the ICA educates the public and the medical community about IC, offers support networks for people with IC, advocates for research funding and patient rights, and funds research aimed at finding effective treatments ultimately, a cure.

www.ichelp.org

