

UNDERSTANDING Interstitial Cystitis/ Painful Bladder Syndrome



PHOTO: Shutterstock. Models in photo are being depicted for illustrative purposes only.

When you have a condition that affects nearly every aspect of your life, as interstitial cystitis/painful bladder syndrome (IC/PBS) does, all you want to know is what's causing your symptoms and how you can relieve them. Unfortunately, we don't fully understand the cause of IC/PBS, and we don't yet have the cure, but there are treatments that can bring you relief.

IC/PBS is a chronic condition in which the bladder becomes overly sensitive, resulting in pain, pressure, or discomfort in the bladder and pelvic area, along with a strong need to urinate and to do so frequently, often day and night. **Although estimates vary, more than 1.3 million Americans are known to have IC/PBS, but some studies suggest that millions more may have symptoms as well.**

Recognizing the Symptoms of IC/PBS

The symptoms of IC/PBS differ from person to person and can even vary in the same person from day to day. The 3 main symptoms are:

- **Pelvic pain, discomfort, or pressure.** This pain is usually experienced as coming from the lower abdomen, below the belly button, or between the hip bones. It may also be felt in the area of the vagina. For many patients, the pain gets worse as the bladder fills with urine and is relieved when the bladder empties.
- **Urinary frequency.** People with IC/PBS feel as though they have to urinate often during the day, and many get up during the night to urinate as well.
- **Urinary urgency.** This is the feeling that you have to urinate immediately and that "holding it" for more than a few minutes would be uncomfortable or painful. Sometimes even after you have just gone, you feel like you need to go again.

The symptoms of IC/PBS can affect your quality of life. The pain may make it difficult to do what you need to at work or at home. You may not want to leave the house for fear that you won't be able to find a bathroom when you need to. Because certain foods, sexual activity, or stress can prompt or aggravate symptoms, it can be difficult to eat out or plan meals, maintain a satisfying sexual relationship, or meet daily challenges. For some, living with a chronic condition like IC/PBS may even lead to depression.

What Causes IC/PBS?

Experts don't know exactly what causes IC/PBS. Research suggests some possible theories. One main theory is that the bladder lining may have structural or molecular changes, which may cause abnormally enhanced permeability of irritating solutes, leading to sensory nerve activation and tissue damage. This may lead to symptoms of urgency, frequency, and pelvic pain.

Other research shows an increased number of mast cells in bladder epithelial tissue in patients with IC/PBS, indicating an inflammatory process. In addition, because people with IC/PBS seem to have allergies and autoimmune conditions more often than usual, it is thought that some immune system abnormalities might be involved. It may be that a combination of these causes results in IC/PBS.

Although the exact causes remain unknown, researchers are working hard to uncover the underlying cause(s). But one thing is known for certain: IC/PBS is a very real condition, and it is *not* "all in your head."

Diagnosing IC/PBS

Although there is increasing awareness of IC/PBS, the condition often goes undiagnosed for a long time. In one survey, about 1 of every 3 women who had been diagnosed with IC said that it had taken more than 3 years to receive an accurate diagnosis and that they had to see 3 or 4 healthcare professionals before one of them correctly identified the condition. **One reason for this delayed diagnosis is that the symptoms of IC/PBS often**

resemble those of other conditions, including urinary tract infection and overactive bladder. Many women with IC/PBS also have other conditions, such as irritable bowel syndrome, endometriosis, or fibromyalgia, so doctors treating these other conditions may not think about the bladder as a source of the pain.

There is no one test that will identify IC/PBS, so the key to diagnosing it is to see whether you have typical symptoms and then rule out, or exclude, other health problems that might be causing your symptoms. Your clinician bases the diagnosis on the results of a physical examination and on your description of your symptoms in your own words and on questionnaires. Any or all of the following may be part of making your diagnosis:

- **Patient History/Physical Examination.** Your healthcare professional asks you questions and examines you for signs of health problems.
- **Pain and Urgency/Frequency Patient Symptom Scale (PUF).** This self-scoring questionnaire is a checklist that helps show your healthcare professional whether you have pain, urgency, and frequency and how much it bothers you. If your physical exam suggests IC/PBS and your PUF score is 10 or higher, the diagnosis of IC/PBS is more likely. See page 11 for an example of this kind of questionnaire.
- **O'Leary-Sant IC Symptom and Problem Indexes.** This questionnaire assesses how severe your symptoms are and how much of a problem they cause.
- **Urinalysis and Urine Culture.** Urine should be sterile. If bac-

*But one thing is known for certain: IC/PBS is a **very real condition**, and it is not "all in your head."*

teria and white blood cells are found in your urine, it indicates that an infection of the urinary tract may be present. A bacterial infection can be treated with an antibiotic. If your urine is sterile for weeks or months but your symptoms of pain and urinary frequency and urgency persist, your healthcare professional may consider a diagnosis of IC/PBS.

- **Cystoscopy.** For this test, your clinician uses a device called a cystoscope—a thin tube with a tiny camera—to see inside the bladder. Further testing may include filling the bladder with liquid to stretch it out, called hydrodistention, to get a better look at the bladder wall. Cystoscopy with hydrodistention is usually done in the hospital when you are under general anesthesia ("put to sleep"). This test can show any



PHOTO: Shutterstock. Model in photo is being depicted for illustrative purposes only.

abnormalities, such as bleeding in the bladder. It is often done as an outpatient procedure.

- **Intravesical Anesthetic Challenge Test.** Some healthcare professionals have found this test useful for detecting whether your bladder is the source of your pain. An anesthetic (numbing) solution is placed into the bladder through a catheter (a flexible hollow tube that is guided through the urinary tract opening into the bladder). The pain often quickly and dramatically decreases in people whose bladder is the source of pain.
- **Potassium Sensitivity Test.** Clinicians do not commonly use this method. In this test, sterile water is first placed into the bladder through a catheter, and the patient is asked to rate his or her pain or urgency on a scale from 0 to 5 to get a baseline score. Then the water is drained out, and potassium chloride is placed into the bladder. Patients whose bladder is the source of their pain usually report an increase in their pain score.
- **Biopsy.** A biopsy is a tissue sample that your clinician looks at under a microscope. The tissue sample may be removed during your cystoscopy. This test helps rule out the very rare possibility of bladder cancer.

Treatment Options

There is currently no cure for IC/PBS. But there are treatments that may help reduce symptoms.

Conclusion

Answers may seem slow in coming, but this is a time of great hope for patients with IC/PBS. Investment in research has

Management Options to Discuss With Your Healthcare Professional

Pentosan Polysulfate Sodium (ELMIRON®). This is the only FDA-approved oral (taken by mouth) prescription medication used to treat the pain and discomfort of IC/PBS. ELMIRON® is a capsule that is taken 3 times a day. It is not known exactly how ELMIRON® works, but it is not a pain medication like aspirin or acetaminophen and therefore must be taken continuously for relief as prescribed by your doctor.

ELMIRON® may take a while to work, so it is important to stay on therapy. You can read more about this treatment in the next article in the issue, "What to Expect From Your Treatment With ELMIRON® for IC/PBS."

Be sure to talk with your healthcare professional to see if ELMIRON® is right for you. ELMIRON® is a weak blood thinner (anticoagulant), which may increase bleeding. Tell your healthcare professional if you will be undergoing surgery or if you are taking or will begin taking anticoagulant therapy such as warfarin sodium, heparin, high doses of aspirin, or anti-inflammatory drugs such as ibuprofen.

If you have a known hypersensitivity to ELMIRON® or similar drugs, you should not take it. Tell your healthcare professional if you are pregnant, plan on becoming pregnant, or if you have any liver problems. If you are undergoing surgery, talk to your healthcare professional about when to discontinue ELMIRON® prior to surgery.

The most common side effects of ELMIRON® are hair loss, diarrhea, nausea, blood in the stool, headache, rash, upset stomach, abnormal liver function tests, dizziness, and bruising. Hair loss, when it occurred, was almost always limited to a single area of the scalp. Tell your healthcare professional about any side effect that bothers you or doesn't go away. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088. Please read the information in the ELMIRON® patient leaflet in the back of this magazine and discuss it with your healthcare professional. See the full Product Information for ELMIRON® in the back of this magazine.

Physical Therapy. Perform pelvic floor muscle relaxation exercises and practice a scheduled voiding pattern.

Lifestyle Changes. Some lifestyle modifications you can make that may help manage symptoms are:

- **Bladder training:** Practice scheduled voiding patterns
- **Dietary changes:** Avoid spicy or acidic foods and beverages containing caffeine and alcohol
- **Gentle exercise:** Walking, yoga, and low-impact aerobics may be beneficial
- **Stress-reduction and relaxation techniques:** Try controlled breathing exercises, warm baths with baking soda, and applying warm or cold compresses on the lower abdomen.

Be sure to discuss lifestyle tips and techniques, such as diet and exercise, with your healthcare professional.

increased over the past couple of decades, and scientists are learning more and more about this painful condition. Medical professionals are becoming increasingly aware of IC/PBS and are able to diagnose

it more quickly and more accurately. And while there is still no cure, treatment may help reduce or relieve the symptoms of IC/PBS.

Work in partnership with your healthcare professional to find relief.

The IC-Smart Diet

Many people with interstitial cystitis (IC) find that simple changes in their diet can help to control IC symptoms and avoid IC flare-ups. Typically, avoiding foods high in acid and potassium, as well as beverages containing caffeine and alcohol, is a good idea. This helpful guide can help you make "IC-Smart" meal choices. Keep it handy for easy reference when dining out or when preparing meals at home.



Fruits

Allowable:

Blueberries, melons (except cantaloupe) and pears



Avoid:

All other fruits and juices



Meats/Fish

Allowable: Poultry, fish and some meats (except those listed below)



Avoid: Aged, canned, cured, processed or smoked meats/fish; anchovies; caviar; chicken livers; corned beef; and meats that contain nitrates or nitrites



Nuts

Allowable:

Almonds, cashews and pine nuts



Avoid:

Most other nuts



Vegetables

Allowable:

Homegrown tomatoes and some vegetables (except those listed below)



Avoid: Store-bought tomatoes, onions, tofu, soybeans, lima beans and fava beans



Beverages

Allowable:

Bottled or spring water; decaffeinated, acid-free coffee or tea; some herbal teas; flat soda



Avoid: Alcoholic beverages, including beer and wine; carbonated drinks, such as soda; coffee and tea; and fruit juices, especially citrus and cranberry



Milk/Dairy

Allowable: Milk, American cheese, cottage cheese, frozen yogurt and white chocolate



Avoid: Yogurt, sour cream, aged cheeses and chocolate



Seasonings

Allowable:

Garlic and some other seasonings (except those listed below)



Avoid: Mayonnaise, miso, soy sauce, salad dressing, vinegar and spicy foods (especially Chinese, Mexican, Indian and Thai foods)



Carbohydrates/Grains

Allowable: Pasta, rice, potatoes and some breads (except those listed below)



Avoid:

Rye and sourdough breads



Preservatives

Avoid:

Benzyl alcohol, citric acid, monosodium glutamate (MSG), aspartame (NutraSweet^{®*}), saccharin and foods containing preservatives, artificial ingredients/colors

*NutraSweet is a registered trademark of NutraSweet Property Holdings, Inc.

Dining Out: The IC-Smart Way

Call ahead

Before making plans to eat at a restaurant, it's a good idea to call ahead and ask about the menu. This will enable you to enjoy your meal and feel good afterward, too!

When ordering your meal

- Ask questions
 - Ask your waiter what spices are used in particular dishes
 - If you are unsure of an ingredient, ask what it is
- Modify your selection
 - It's your meal—don't be afraid to specify how you would like it prepared
 - When ordering a salad, tell the waiter **no** tomatoes or onions
 - Substitute a plain baked potato for a spicy rice combination
 - Ask for salad dressings and other possible "trigger" items to be served "on the side"
- Be careful with ethnic foods
 - Many ethnic foods contain spices that you may be unfamiliar with
- Know your "IC-Smart" menu choices
 - Most restaurants offer plain (not marinated) steak and chicken
 - Some chain restaurant foods may contain preservatives when sold in the grocery store

If you experience an IC flare-up

- Drink lots of water
 - This will help dilute the urine in your bladder
- Ask your waiter for one teaspoon of baking soda in a glass of water
 - This will help prevent acids in the urine from irritating the bladder

NOTE: Baking soda has high salt content, so patients with heart conditions, high blood pressure or other medical conditions affected by the intake of salt should consult their doctor first.