



# Interstitial Cystitis

# Interstitial Cystitis/ Bladder Pain Syndrome

Voices for PFD

AUGS

Interstitial cystitis/bladder pain syndrome (IC/BPS) is a condition with symptoms including burning, pressure, and pain in the bladder along with urgency and frequency.

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## About IC/BPS

IC/BPS occurs in three to seven percent of women, and can affect men as well. Though usually diagnosed among women in their 40s, younger and older women have IC/BPS, too. It can feel like a constant bladder infection. Symptoms may become severe (called a “flare”) for hours, days or weeks, and then disappear. Or, they may linger at a very low level during other times.

Individuals with IC/BPS may also have other health issues such as irritable bowel syndrome, fibromyalgia, chronic headaches, and vulvodynia. Depression and anxiety are also common among women with this condition.

The cause of IC/BPS is unknown. It is likely due to a combination of factors. IC/BPS runs in families and so may have a genetic factor. On cystoscopy, the doctor may see damage to the wall of the bladder. This may allow toxins from the urine to seep into the delicate layers of the bladder lining, causing the pain of IC/BPS. Other research found that nerves in and around the bladder of people with IC/BPS are hypersensitive. This may also contribute to IC/BPS pain. There may also be an allergic component.

## The IC/BPS Bladder

Symptoms of IC/BPS vary from woman to woman. However, most experience pain, pressure and discomfort as the bladder fills. In addition, chronic pain or pressure in the pelvis and perineum are common, including discomfort and pain during sexual intercourse. The severity of symptoms is variable.

### LEARN THE TERMS

#### **Interstitial cystitis/bladder pain syndrome (IC/BPS):**

Symptoms of bladder pain, pressure, and discomfort with urinary urgency and frequency, without any sign of infection or other cause.

**Perineum:** The tissue (skin and muscles) located between the vagina and the anus.

**Urinary urgency (“gotta go right now”):** Sudden, strong desire to pass urine, which is very difficult to defer.

**Urinary frequency (“gotta go often”):** Urinating eight or more times per day.

**Urethra:** Tube from the bladder to the outside of the body that urine passes through during urination.

**Cystoscopy:** A procedure using a camera to look at the inside of the urethra and bladder.

**Glomerulations:** Pinpoint sites of bleeding or ulcers on the inside of the bladder.

**Urodynamics:** A group of tests performed in the office using a machine to evaluate how well your bladder fills and empties.

## GLOMERULATIONS



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## HUNNER'S LESIONS



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Urinary urgency ("gotta go right now") and urinary frequency ("gotta go often") are common—both during the day and at night. Many women feel a constant need to empty their bladders to relieve the intensity of the pain. Women with IC/BPS rarely leak urine but go often to decrease pain. IC/BPS flares are common during the menstrual period. Flares also occur during times of emotional or physical stress. Some women note symptoms specifically in their urethra. For them, urinating can feel like pushing sharp pieces of glass into the tissue.

When cystoscopy is performed on women with IC/BPS, the bladder appears inflamed and irritated. Pinpoint sites of bleeding (glomerulations) can be seen on the bladder wall. A small number of women have a specific type of lesion, known as Hunner's lesion. Cracks in the lining of the bladder are also often visible.

## Diagnosis

To diagnose IC/BPS, your urologist or urogynecologist will review your medical history and symptoms. Your doctor will ask about your pattern and level of pain, as well as urinary symptoms. To help rule out other conditions, you may need some lab tests. Cystoscopy and urodynamics may be done depending on your symptoms, but are not required. Often you will be asked to keep a diary of your bladder symptoms, urinations, and fluid intake.

Women who are diagnosed with IC/BPS typically experience pain, burning, pressure, and discomfort in the bladder for more than six weeks with no other apparent cause. Some women go years with these symptoms before diagnosis.

## Treatments

Treatments depend on the severity of symptoms. Most women require more than one type of therapy to manage their pain and urinary symptoms. Right now, there is no cure for IC/BPS, but the symptoms can be treated and controlled.

**DIET:** Women with IC/BPS often find that certain foods and drinks irritate their symptoms. Identifying which items are bothersome to you and restricting or limiting them can help control symptoms. Food sensitivities can vary. However, there are foods and beverages that appear to trigger a flare among many women. Often women eliminate these foods and slowly add them back individually to determine which ones they can still eat safely. It's helpful to meet with a Registered Dietitian Nutritionist to identify individual trigger foods.

**STRESS MANAGEMENT:** For most women, stress can worsen IC/BPS symptoms. Find an activity that relaxes you. It might be meditation, yoga, hypnosis, acupuncture, or taking a walk. Whatever it is, schedule time so you can help manage stress.

## MOST BOthersome FOODS AND DRINKS

### FRUITS

Cranberry juice  
Grapefruits and grapefruit juice  
Lemon juice  
Oranges and orange juice  
Pineapples and pineapple juice

### VEGETABLES

Hot peppers  
Pickles  
Sauerkraut  
Tomatoes and tomato products

### CONDIMENTS

Chili  
Horseradish  
Salad dressings  
Vinegar

### DRINKS

Coffee (caffeinated and decaffeinated)  
Tea (caffeinated and some decaffeinated)  
Carbonated drinks (cola, non-cola, diet, caffeine-free)  
Beer  
Wine (red and white)  
Champagne

### OTHER FOODS

Chocolate  
Indian food  
Mexican food  
Thai food  
Spicy food

### ADDITIVES

MSG  
Artificial sweeteners

**PHYSICAL THERAPY:** A specially trained physical therapist (PT) can manually maneuver your pelvic area to help relieve pelvic pain. This therapy may loosen tight pelvic floor muscles and tissues. Women with IC/BPS should NOT do pelvic floor strengthening exercises (called "Kegel exercises") unless under the care of a PT. These exercises can worsen symptoms.

**MEDICINES:** Your provider may prescribe one or a combination of medicines. Pentosan polysulfate sodium (Elmiron™) is the only FDA-approved oral medicine for IC/BPS. It helps about one-third of women control their symptoms. Other drugs that help IC/BPS symptoms are: phenazopyridine, amitriptyline, cimetidine, or hydroxyzine.

**BLADDER INSTILLATIONS:** Some find it helpful to get medicine inserted directly into their bladders. A series of these instillations is usually done in the office. Treatments can be 1 to 2 times a week for 6 to 8 weeks.

**CYSTOSCOPY UNDER ANESTHESIA:** Stretching the bladder wall, called hydrodistension, can also be helpful. Because this can be painful, it is often performed as an outpatient surgery with general anesthesia. This procedure provides relief for some women. But, it often causes a flare immediately afterward.

**NEUROSTIMULATION:** Electrical stimulation devices can be placed outside of your body (TENS unit) or surgically implanted inside the body (called InterStim®). They send mild electrical pulses through the pelvic area. This can help relieve IC/BPS symptoms, especially the urinary symptoms.

**BOTULINUM TOXIN (BOTOX):** Botox can increase bladder capacity, which can help a patient with IC/BPS urinate less often. Under local anesthetic or sedation, your doctor uses a small camera and needle to inject Botox into the bladder wall. Typically, the injection needs to be repeated 1 to 2 times per year. A small number of women experience side effects, such as difficulty emptying the bladder or urinary tract infection.

**SURGERY:** This is reserved for extreme cases. Most women never need surgery. For women with Hunner's lesions, the area can be surgically treated with a laser. Very rarely, the bladder may be removed or enlarged surgically.

## Three Takeaways

- 1. Interstitial cystitis/bladder pain syndrome (IC/BPS) is a condition including bladder pain, pressure, and discomfort along with urinary urgency and frequency, without any sign of infection or other cause.**
- 2. Treatments often include diet changes, stress management, physical therapy, medicines, bladder instillations, cystoscopy under anesthesia, nerve stimulation, and Botox injections.**
- 3. A bladder diary can help provide more information about the link between diet and your bladder symptoms.**





Thank you!