

BLADDER HEALTH

# Painful Bladder

INTERSTITIAL CYSTITIS

AUA  
FOUNDATION  
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AMERICAN UROLOGICAL ASSOCIATION





## Don't Let Interstitial Cystitis Keep You from Enjoying Life.

### What Is Interstitial Cystitis?

Interstitial cystitis (IC) is a **chronic\*** bladder condition. Its symptoms are pain, pressure, or discomfort that seem to be coming from the bladder. Individuals with IC may have urinary frequency and/or an urge to urinate. The symptoms range from mild to severe. For some, they come and go; for others the symptoms are constant. IC is not an infection, but its symptoms can feel like those of a bladder infection. Women with IC may feel pain upon intercourse.

Interstitial cystitis is sometimes called bladder pain syndrome (BPS). It may be linked to irritable bowel syndrome, fibromyalgia, chronic fatigue syndrome, and other pain syndromes. The more severe cases of IC can have a devastating effect on both sufferers and their loved ones.

### Who Gets IC?

About 80 percent of people diagnosed with IC are women. However, the difference in rates of IC for men vs. women may not really be as high as we think, because some men diagnosed with **prostatitis** or similar conditions may really have IC. It is hard to know how

many people have IC, because doctors have different opinions about how exactly to diagnose this condition. Current research suggests that IC affects well over 1 million Americans.

### What Causes IC?

The kidneys make urine. It then flows down the ureters into the bladder. The bladder is a hollow, balloon-like organ made of mostly muscle. During urination, the bladder muscle contracts to squeeze out the urine through the **urethra** and out the body. The bladder and urethra have a lining called the epithelium. The epithelium forms a barrier between the urine and the bladder muscle. The epithelium also helps keep bacteria from sticking to the bladder and to prevent bladder infections.

There are no specific behaviors known to increase a person's risk for getting IC. Having a blood relative with IC may increase the risk of getting IC yourself.

Many researchers believe that IC is caused by one or more of the following:

- A defect in the bladder epithelium. This may allow irritating substances in the urine to penetrate into the bladder.
- A specific type of inflammatory cell called a mast cell. This cell releases histamine and other chemicals that promote IC symptoms in the bladder.

- Something in the urine that damages the bladder.
- Changes in the nerves that carry bladder sensations that are not normally painful, such as when the bladder is filling, to become painful.
- The body's immune system is attacking the bladder. This is similar to other **autoimmune** conditions.

Recent research shows that IC patients may have a substance in their urine that stops the growth of cells in the bladder epithelium. Therefore, they may be more likely to get IC after an injury to the bladder caused by an infection.

### What Are the Signs/Symptoms of IC?

The symptoms of IC vary for different patients. If you have IC, you may have urinary frequency, urgency, pain, pressure, or discomfort. These symptoms feel like they come from the bladder. Some IC patients may have all of these symptoms.

\*Bold words are defined in the Glossary.

Frequency is the need to urinate more often than normal. The average person urinates around seven times during the day. He or she does not have to get up at night to use the bathroom. An IC patient may have to urinate frequently both day and night. As frequency becomes more severe, it leads to urgency. Urgency to urinate is a common IC symptom. Some patients feel a constant urge that never goes away, even right after urinating.

IC patients may have bladder pain that gets worse as the bladder fills. Some IC patients feel the pain in other areas in addition to the bladder. They may also feel pain in the **urethra**, lower abdomen, lower back, or the **pelvic** or **perineal** area. Women may experience pain in the **vulva** or the vagina and men may feel the pain in the **scrotum**, **testicles**, or penis. The pain may be constant or may come and go.

Many IC patients can identify certain things that make their symptoms worse. For some, their symptoms are affected by certain foods, drinks or by physical or mental stress. For women, the symptoms may vary with the menstrual cycle. Both men and women with IC can experience sexual difficulties due to this condition.

## How Is IC Diagnosed?

IC is a disease that sometimes begins with urinary frequency. In other cases, the onset is much more dramatic with severe symptoms occurring within days, weeks or months. In many cases, the symptoms become **chronic**. In rare cases, the bladder will become smaller over time to the point where there is almost no capacity to store urine.

A medical history, physical exam and urine tests are needed to rule out other conditions that might be causing the symptoms of IC. Some doctors believe that IC is present if a patient has symptoms and no other cause for those symptoms is found. Other doctors believe that more tests are necessary to determine whether the patient has IC.

One test that doctors may use is simple office cystoscopy. In this test, the doctor looks inside the bladder with a special instrument. This can rule out other problems such as cancer. Some IC patients will have small areas of bleeding or actual ulcers the doctor can see these through the cystoscope. If a person has symptoms of IC and the cystoscopy shows bleeding or ulcers, the diagnosis is fairly certain.

A cystoscopy is done in the doctor's office. A more complex test is performed

in a hospital operating room, where a basic cystoscopic examination is followed by a stretching or distention of the bladder. This is done by adding water to the bladder. The doctor can see cracks in the bladder in more severe cases of IC.

The doctor may perform a bladder **biopsy**, which helps to rule out other bladder diseases. Urodynamics evaluation is another test that is done for some people who may have IC. This test involves filling the bladder with water through a small tube called a catheter. This measures bladder pressures as the bladder fills and empties.

Some IC patients may have a potassium sensitivity test. This medical test adds a potassium solution to the bladder. The same test is then performed with water. A person who has IC feels more pain and urgency with the potassium solution than with the water. Patients with normal bladders cannot tell the difference between the two solutions. This test can be painful, and is not a routine part of every evaluation.

At this time, there is no definite answer about the best way to diagnose IC. However, if a patient has typical symptoms and a negative urine examination that shows no infection or blood in the urine, then IC should be suspected.

## How is IC Treated?

No single treatment works for everyone with IC. Treatment must be chosen for each patient based on his or her symptoms. Patients usually try different treatments (or combinations of treatments) until symptom relief occurs.

Two treatments are approved by the United States Food and Drug Administration (FDA) to treat IC. Other treatments can help relieve the symptoms of IC. If you have IC, ask your health care provider about your treatment options.

None of the IC treatments works immediately. It may take weeks to months before symptoms improve. Even with successful treatment, the condition may not be cured; it is simply "in remission."

Most patients need to continue treatment or the symptoms may return. Some patients may have flare-ups of symptoms even during the treatments. In some patients, the symptoms gradually improve and even disappear.

There are some patients that do not respond to any IC therapy. However, with pain management, they can still have significant improvement in their quality of life. Pain management can include medications, acupuncture and other non-drug therapies.

Although most patients will find that their symptoms improve as they are treated for IC, not all patients will be completely symptom-free. Many patients still have to urinate more frequently than normal. They may have some degree of persistent discomfort. IC patients may have to avoid certain foods or activities that make symptoms worse.

## Can IC be Cured?

It is possible for IC symptoms to recur even if the disease has been in **remission** for a long time. It is not known what causes a recurrence.

Some things that patients do to try to prevent recurrence include: (1) staying on their medical treatments; (2) avoiding certain foods that may irritate the bladder; and (3) avoiding certain activities or stresses that may worsen IC. The specific foods or activities that affect IC are different for different patients.

## What Should IC Patients Eat?

Most, but not all, people with IC find that certain foods and beverages make their symptoms worse. There are four

food items that IC patients often find irritating to their bladders: citrus fruits, tomatoes, chocolate and coffee. All four of these items are rich in potassium. Other items that bother the bladder in many IC patients are alcoholic beverages, caffeinated beverages, spicy foods and some carbonated beverages. The list of foods that have been reported to affect IC is quite long, but not all foods affect all patients the same way.

The simplest way to find out whether any foods bother your bladder is to try an “elimination diet” for one to two weeks. On an elimination diet, you stop eating all of the foods that could irritate your bladder. IC food lists are available from many sources. If your bladder symptoms improve while you are on the elimination diet, this means that at least one of the foods was irritating your bladder.

The next step is to find out exactly which foods cause bladder problems for you. After one to two weeks on the elimination diet, try eating one food from the IC food list. If this food does not bother your bladder within 24 hours, this food is probably safe and can be added back into your regular diet. The next day, try eating a second food from the list, and so on. In this way, you will add the foods back into your diet one at a time and your

bladder symptoms will tell you if any food causes problems for you. Be sure to add only one new food to your diet each day. If a person eats a banana, strawberries and tomatoes all in the same day, and the IC symptoms get bad that evening, he or she will not know which of the three foods caused the symptoms to flare up.

## Glossary

**AUTOIMMUNE:** An autoimmune disorder is a condition that occurs when the immune system mistakenly attacks and destroys healthy body tissue.

**BIOPSY:** A procedure in which a tiny piece of a body part (tissue sample), such as the kidney or bladder, is removed (with a needle or during surgery) for examination under a microscope; to determine if cancer or other abnormal cells are present.

**CHRONIC:** A disease that is long-lasting or recurrent.

**PELVIC:** Relating to, involving or located in or near the pelvis.

**PERINEAL:** Related to the area between the anus and the scrotum in males and the area between the anus and the vagina in females.

**PROSTATITIS:** Inflammation or infection of the prostate. Chronic prostatitis means the prostate gets inflamed over and over again. The most common form of prostatitis is not associated with any known infecting organism.

**REMISSION:** Disappearance of the signs and symptoms of disease.

**SCROTUM:** Also referred to as the scrotal sac. The sac of tissue that hangs below the penis and contains the testicles.

**TESTICLE:** Also known as testis. Either of the paired, egg-shaped glands contained in a pouch (scrotum) below the penis. They produce sperm and the male hormone testosterone.

**URETHRA:** In males, this narrow tube carries urine from the bladder to the outside of the body and also serves as the channel through which semen is ejaculated. Extends from the bladder to the tip of the penis. In females, this short, narrow tube carries urine from the bladder to the outside of the body.

**VULVA:** The vulva is the external female genitalia. It includes the labia, clitoris, and the openings to the urethra and vagina.

# Where Can You Go for More Information about Interstitial Cystitis?

For more information about interstitial cystitis and other urologic conditions, please visit the AUA Foundation's website, [www.UrologyHealth.org](http://www.UrologyHealth.org) or call the Urology Health Line at 1-800-828-7866 for assistance in English and Spanish.

## ABOUT THE AUA FOUNDATION:

The AUA Foundation is the world's leading non-profit urologic health organization and the Official Foundation of the American Urological Association. Our mission is to promote health, provide hope and promise a future free from urologic diseases, including cancer.

**UROLOGY HEALTH SERIES:** Information based on current medical and scientific knowledge. This information is not a tool for self-diagnosis or a substitute for professional medical advice. It is not to be used or relied on for that purpose. Please see your urologist or other healthcare provider regarding any health concerns and always consult a healthcare professional before you start or stop any treatments, including medications.

Additional resources may be available.

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