

# Interstitial Cystitis

## What is interstitial cystitis (IC)?

IC is a chronic inflammatory condition of the bladder wall, which frequently goes undiagnosed. Although the cause is unknown and no treatment is uniformly effective for everyone, many treatments are available and the vast majority of patients obtain relief.

## What are the symptoms of IC?

Symptoms include bladder pain, urinary urgency, day and night frequency (up to 60 times per day), suprapubic (lower abdominal) or perineal (area between the vagina and anus), pain and pressure, and painful sexual intercourse. Women's symptoms often get worse during menstruation.

## Are there different types of IC?

Most IC experts agree that IC appears to be a multifactorial syndrome rather than a single disease and may have more than one cause. The cause(s) and symptoms of IC may vary from patient to patient. There are currently considered to be two types of IC:

1. Non-ulcerative IC
2. Ulcerative IC (Hunner's patches or ulcers)

Many researchers and clinicians have questioned the usefulness of this classification, since the vast majority (about 90%) of cases do not involve ulcers, and their presence or absence does not influence treatment options.

## How do I know if I have IC?

You may suspect IC if:

- You feel unexplained pain and pressure in the urethra, the vagina, the area above the pubic bone, the inside of the thighs, the lower abdomen, the lower back, or the groin area, in any combination.
- You urinate frequently (normally, people urinate an average of 6-7 times per day, IC patients average about

16 times per day, and some urinate as often as 60 times per day)

- You are unable to hold a lot of urine
- You wake more than once a night to urinate
- You may feel the urge to urinate, sometimes even after you've emptied your bladder
- Your symptoms flare up with sexual intercourse, menstruation, certain foods, allergies, or stress
- Your symptoms come and go

Because IC symptoms are similar to those of other disorders of the urinary system and because there is no definitive test to identify IC, doctors must rule out other conditions before considering a diagnosis of interstitial cystitis.

### **How common is IC, and whom does it affect?**

Originally, IC was thought to be a rare disease affecting mostly post-menopausal women. Now, it is clear that IC can affect any age group, and men and children as well. A recent study found that the prevalence of interstitial cystitis in the U.S. is over 700,000. More than 90% of those affected are women.

### **How is IC treated?**

At this time there is no cure for IC nor is there an effective treatment which works for everyone. However, a vast majority of IC patients are helped by one or more of the following treatments:

#### **Oral Medications:**

**Elmiron®:** Elmiron received FDA approval in 1996. It is the only oral medication approved specifically for use in IC. It is believed to work by repairing a thin or damaged bladder lining.

**Antidepressants:** Tricyclic antidepressants such as Elavil® (amitriptyline) have been shown to help with both the pain and frequency of IC. In IC, these medications are used for their anti-pain properties, not as treatment for depression.

**Other Oral Medications:** These include anti-inflammatory agents, antispasmodics, bladder analgesics, antihistamines, and muscle relaxants.

## **Bladder Instillations:**

**Bladder Distention:** The bladder is stretched by filling it with water under general anesthesia. This is also a diagnostic procedure for IC.

**Intravesicle Therapy:** The bladder is filled with a solution that must be held for varying times, usually 10-30 minutes, before being emptied.

## **Other Treatments:**

**Diet:** Eliminating certain foods (acidic, spicy) may decrease the severity of IC symptoms. Also, drinking coffee or tea, and alcoholic beverages may aggravate IC.

**Smoking:** Many patients feel that smoking makes their symptoms worse. Because smoking is the major known cause of bladder cancer, one of the best things smokers can do for their bladder is to quit.

**Self-Help:** Self-help techniques can improve the quality of life and reduce the incidence and severity of flare-ups. These include changes in diet, stress reduction, visualization, biofeedback, bladder retraining and exercise, among others.

## **Electronic Nerve Stimulators:**

*Transcutaneous Electrical Nerve Stimulation (TENS):* This device, which is worn externally, relieves bladder pain in some people.

*Sacral Nerve Stimulation Implants:* These surgically implanted devices are approved for use in treating urinary incontinence, urgency and frequency.

**Surgery:** For a small minority of patients whose symptoms are severe and who do not respond to other IC treatments, bladder surgery may be considered.

## **Where can I get more information?**

*Interstitial Cystitis Association (ICA)*  
Phone: 1-800-HELP-ICA (1-800-435-7422)  
Web site: [www.ichelp.com](http://www.ichelp.com)

*Interstitial Cystitis Network*

Phone: 1-707-538-9442

Web site: [www.ic-network.com](http://www.ic-network.com)

*National Bladder Foundation*

Phone: 1-877-BLADDER (1-877-252-3337)

Web site: [www.bladder.org](http://www.bladder.org)

## **Potassium Sensitivity Testing**

This test is designed to help your healthcare provider determine if you have a condition called interstitial cystitis. Interstitial cystitis (IC) is a breakdown in the lining of the bladder wall. Symptoms include bladder pain, urinary urgency, urinary frequency (sometimes urinating up to 60 times/day in severe cases), suprapubic (lower abdominal) or perineal (area between the vagina and anus) pain and pressure, and painful intercourse. It is also associated with other conditions like migraine headaches, irritable bowel syndrome, fibromyalgia, and vulvodynia.

### **Procedure:**

- You will be asked to empty your bladder and provide a urine sample (to be tested for a UTI)
- You will be directed to a room and instructed to undress from the waist down
- The nurse will come in and ask you whether you are having any pain or urgency before the test is started
- Pain and urgency will be evaluated on a "0-5" scale. "0" meaning no pain or urgency, and "5" meaning severe pain or urgency. Pain and urgency are to be evaluated separately
- For purposes of establishing a baseline, before the start of the test any pain or urgency that you are having will be considered "0"
- You will be asked to put your feet in the stirrups and lay back (just like for a pap smear)
- The nurse will insert a small (pediatric) tube into the bladder
- The first solution will be infused over 2-3 minutes. During that time the nurse will ask you to grade your pain and urgency.
- That solution will then be drained and the second solution will be infused over 2-3 minutes. During that time, the nurse will again ask you to grade your pain and urgency.

- You may be asked to empty your bladder into a commode or the solution may be drained through the tube at the nurse's discretion.
- After the 2 solutions have been infused, you will be asked which one was worse (which caused more pain and urgency). If one was worse, was the difference mild, moderate, or severe.
- At the end of the test your bladder may be washed by instilling a solution of sterile water and a separate medication solution may be instilled. You will be asked to hold the 2<sup>nd</sup> solution for at least 20 minutes before emptying your bladder.

This test along with your physical exam and complaints of symptoms will assist your physician in determining if you have IC.