FREQUENTLY ASKED QUESTIONS

Interstitial Cystitis (Painful Bladder Syndrome)

Q: What is interstitial cystitis (IC)?
A: IC is a chronic bladder problem that can cause pain and other symptoms. People with IC can have an inflamed and irritated bladder. This can lead to:
- scarring and stiffening of the bladder
- less bladder capacity
- bleeding in the bladder

More than 700,000 Americans have IC. IC often shows up between the ages of 30 and 40. Women are ten times more likely to have IC than men. Some people with IC feel only mild discomfort and some have severe pain. Severe cases of IC can keep people from doing their daily tasks, such as going to work or school.

Q: What are the causes of IC?
A: No one knows what causes IC. Researchers are working to learn more about it and find treatments that will ease symptoms. Right now, there is no cure for IC.

Current research shows that a substance found in the urine of some people with IC may block the normal growth of the cells that line the inside wall of the bladder. Learning more about this substance may lead to a better understanding of the causes of IC.

It is thought that genes may play a role in some forms of IC. In a few cases, IC has affected a mother and daughter or two sisters. Still, it does not commonly run in families.

Q: What are some symptoms and signs of IC?
A: The symptoms of IC vary from person to person. Also, one person can have symptoms of IC that change over time. People with IC may have an inflamed and irritated bladder. They may have mild discomfort, pressure, tenderness, or intense pain in the bladder and pelvic area. The pelvic area is between your navel (belly button) and your thigh. Symptoms also may include feeling like you need to urinate right away, often, or both.

Pain may get better or worse as the bladder fills with urine or as it empties. Women’s symptoms often get worse during their periods. Pain during sex is common.
Q: How can I tell if I have IC?
A: Your doctor can tell if you have IC if you have the symptoms above and by ruling out other diseases with similar symptoms.

The first step in diagnosing IC is to rule out other health problems that may be causing the symptoms. Symptoms of urinary tract infections, bladder cancer, endometriosis, sexually transmitted diseases (STDs), and kidney stones can be the same as those caused by IC. Tests on your urine, bladder, and urinary tract may be done. These can include:

- **Urine culture.** Looking at urine under a microscope can show if you have germs that show you have a urinary tract infection or an STD. Your doctor will insert a catheter, which is a thin tube to drain urine. Or you may be asked to give a urine sample using the “clean catch” method. For a clean catch, you will wash the genital area before collecting urine midstream in a sterile container.

- **Cystoscopy with or without bladder distention.** Your doctor may use a device called a Cystoscope to see inside the bladder and rule out cancer. Further testing may include slowly stretching the bladder, called bladder distention, by filling it with liquid. This helps the doctor get a better look inside the bladder. This test can find bladder wall inflammation; bleeding or ulcers; a thick, stiff bladder wall; and total bladder capacity. This test is often done as an outpatient surgery.

- **biopsy.** A biopsy is a tissue sample that your doctor looks at under a microscope. Samples of the bladder and urethra may be removed during a cystoscopy. A biopsy helps your doctor rule out bladder cancer.

Q: Is there a cure for IC?
A: Doctors have not yet found a cure for IC. They cannot predict who will respond best to the different treatment options. Sometimes, symptoms may go away for no reason or after a change in diet or treatment plan. Even when symptoms do go away, they may return after days, weeks, months, or years.

Q: How is IC treated?
A: There are treatments available to help ease symptoms. Although many of these options are still being studied, they have shown to help some women feel better. Some of these include:

- **Bladder distention.** The doctor slowly stretches the bladder by filling it with liquid. Doctors are not sure why, but this test eases pain for some patients.

- **Bladder instillation** (a bladder wash or bath). The bladder is filled with a liquid that is held for different periods of time before being emptied. The only drug approved to date by the U.S. Food and Drug Administration (FDA) for use in bladder instillation is dimethyl sulfoxide. Other drugs for this use are being studied.

- **Oral medicines.** These medicines include a prescription medicine called pentosan polysulfate sodium (Elmiron®), which can help ease symptoms in some patients. **Because Elmiron has not been**
tested in pregnant women, it is not recommended for use during pregnancy, except in severe cases. Other oral medicines used include aspirin and ibuprofen, other stronger painkillers, antidepressants, and antihistamines.

- **Transcutaneous electrical nerve stimulation (TENS).** Wires send mild electric pulses to the bladder area. Scientists do not know exactly how TENS works, but it helps ease pain and urinary frequency in some people. Sacral nerve stimulation implants are being studied as another way to relieve IC symptoms.

- **Self-help strategies.** Bladder training, dietary changes, quitting smoking, reducing stress, and low-impact exercise have been shown to help some people.

- **Surgery.** If other treatments have failed and the pain is disabling, surgery may be an option. Surgery may or may not ease symptoms.

**Keep in mind, these treatments do not cure IC.** For some people, these treatments have helped ease their IC symptoms.

**Q:** How does diet affect IC?

**A:** There is no proof of a link between diet and IC. Still, some people think alcohol, tomatoes, spices, chocolate, caffeinated and citrus drinks, and high-acid foods may irritate the bladder. Others notice that their symptoms get worse after eating or drinking products made with artificial sweeteners. If you think certain foods or drinks may be making your symptoms worse, try avoiding them. You can start eating or drinking these products again one at a time to see if any affect your symptoms.

**Q:** I have IC and just found out I’m pregnant. Will it affect my baby?

**A:** Doctors do not have much information about pregnancy and IC. IC is not thought to affect fertility or the health of a fetus. Some women find that their IC symptoms get better during pregnancy. Others find their symptoms get worse.
For more information...

You can find out more about IC by contacting womenshealth.gov at 1-800-994-9662 or the following organizations:

**National Kidney and Urologic Diseases Information Clearinghouse**
- Phone Number(s): (800) 891-5390
- Internet Address: http://kidney.niddk.nih.gov/index.htm

**Interstitial Cystitis Association**
- Phone Number(s): (800) 435-7422
- Internet Address: www.ichelp.org

**American Urological Association Foundation**
- Phone: (866) 746-4282
- Internet Address: www.afud.org

All material contained in the FAQs is free of copyright restrictions, and may be copied, reproduced, or duplicated without permission of the Office on Women’s Health in the Department of Health and Human Services. Citation of the source is appreciated.

This FAQ was reviewed by:
- Debuene Chang, M.D.
- Program Director, Women’s Urology
- National Institute of Diabetes and Digestive and Kidney Diseases
- National Institutes of Health

March 2007