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The National Women's Health Information Center

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Frequently Asked Questions about Interstitial Cystitis

What is interstitial cystitis?

Interstitial cystitis (IC) is a chronic bladder condition that can cause pain and other symptoms. People with IC have an inflamed or irritated bladder wall. This *inflammation* can lead to:

- scarring and stiffening of the bladder;
- less bladder capacity (the bladder is able to hold less urine);
- pinpoint bleeding in the bladder lining.

In rare cases, ulcers form in the bladder lining.

Of the more than 700,000 Americans estimated to have IC, about 90 percent are women. Severe cases of IC can be very disabling.

What are the causes of interstitial cystitis?

No one knows what causes interstitial cystitis. Because IC varies so much in symptoms and severity, most researchers believe that it may actually be several diseases. One theory being studied is that IC is an *autoimmune* response following a bladder infection. Another theory is that there are substances in urine which are irritating to people with IC. Other theories are also being studied. Interstitial cystitis is different from urinary tract infections, which are caused by bacteria and can be treated with antibiotics. Studies have shown that antibiotics are not useful for treating IC.

What are some symptoms and signs of interstitial cystitis?

The symptoms of IC vary from person to person and even in the same person. People with IC may experience mild discomfort, pressure, tenderness, or intense pain in the bladder and surrounding pelvic area. Symptoms may include an urgent need to urinate (urgency), frequent need to urinate (frequency), or a combination of these symptoms. Pain may change in intensity as the bladder fills with urine or as it empties. Women's symptoms often get worse during their periods. Pain during sex is common.

Some people find that their bladders cannot hold much urine, which increases the frequency of urination. Yet some people with severe frequency have bladders that can hold a normal amount of urine. People with severe cases of IC may urinate as many as 60 times during a 24-hour period.

How is interstitial cystitis diagnosed?

The first step in diagnosing IC is to rule out other conditions that may be causing the symptoms. Other possible causes of the symptoms found in IC include urinary tract or vaginal infections, bladder cancer,

endometriosis, sexually transmitted diseases, and kidney stones. Various tests on the patient's urine, bladder and urinary tract may be done.

The most important test to confirm IC is a *cystoscopy* done under anesthesia. This test uses an instrument called a *cystoscope* to see inside the bladder. A liquid or gas is used to stretch the bladder. Anesthesia is required because stretching the bladder can be very painful for a person with IC. This test can detect bladder wall inflammation, pinpoint bleeding or ulcers, a thick, stiff bladder wall, and maximum bladder capacity.

Diagnosis of IC is based on:

- the presence of urinary urgency, urinary frequency, or bladder/pelvic pain;
- bladder wall inflammation, including pinpoint bleeding or ulcers, found by cystoscopy;
- the absence of other diseases that could cause the symptoms.

Is there a cure for interstitial cystitis?

Scientists have not yet found a cure for interstitial cystitis, nor can they predict who will respond best to which treatment. Symptoms may go away for no reason or at the same time as a change in diet or treatment. Even when symptoms go away, however, they may return after days, weeks, months, or years. Scientists do not know why. Because the causes of IC are unknown, treatments are aimed at relieving symptoms.

How is interstitial cystitis treated?

Treatments for IC include:

- Oral medicines, including *pentosan polysulfate sodium* (Elmiron), which the Food and Drug Administration (FDA) approved for IC treatment in 1996. (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, stronger painkillers, *antidepressants*, and *antihistamines*.
- Bladder instillation (a bladder wash or bath). During bladder instillation, the bladder is filled with a solution that is held for varying periods of time before being emptied. The only drug approved to date by the FDA for use in bladder instillation is *dimethyl sulfoxide* (DMSO). Other drugs for this use are being studied.
- *Transcutaneous electrical nerve stimulation (TENS)*, which delivers mild electric pulses to the bladder area. Scientists do not know exactly how TENS works, but it helps relieve pain and urinary frequency in some people. *Sacral nerve stimulation implants* are being studied as another way to relieve IC symptoms.
- Self-help strategies such as bladder training, dietary changes, stress reduction, and low-impact exercise.

- Surgery, considered a treatment of last resort. Surgery does not necessarily improve symptoms.

How does diet affect interstitial cystitis? Do artificial sweeteners make symptoms worse?

There is no scientific evidence linking diet to IC, but some people believe that alcohol, tomatoes, spices, chocolate, caffeinated and citrus beverages, and high-acid foods may add to bladder irritation and inflammation. Others notice that their symptoms get worse after eating or drinking products containing artificial sweeteners. If you believe certain foods or drinks make your symptoms worse, try avoiding those products. You can reintroduce them one at a time to see which, if any, affect symptoms. It is important, however, to maintain a well-balanced and varied diet.

I have interstitial cystitis and have just discovered I am pregnant. Will it affect my baby in any way?

Researchers have little information about pregnancy and IC, but believe that the disorder does not affect fertility or the health of the fetus. Some women find that their IC symptoms improve during pregnancy, while others' symptoms worsen.

For more information...

You can find out more about interstitial cystitis by contacting the National Women's Health Information Center (NWHIC) at 1-800-994-9662 or the following organizations:

National Institute of Diabetes and Digestive and Kidney Diseases

Phone Number(s): (301) 654-4415

Internet Address: www.niddk.nih.gov

Interstitial Cystitis Association

Phone Number(s): (301) 610-5300

Internet Address: www.ichelp.org

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