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1-800-994-9662

TDD: 1-888-220-5446

Interstitial Cystitis/ Bladder Pain Syndrome

Q: What is interstitial cystitis/bladder pain syndrome (IC/BPS)?

A: Interstitial cystitis (int-uhr-STISH-uhl siss-TYT-uhss) (IC), is a chronic pain condition that affects the bladder. Many experts now call it bladder pain syndrome (BPS). Symptoms of IC/BPS include:

- Pain or discomfort believed to be related to the bladder, which often gets worse as the bladder fills.
- Feeling like you need to urinate right away (urgency), often (frequency), or both. Most people urinate between 4 and 7 times a day. Yet with IC/BPS, the bladder may hold less urine. People with severe IC/BPS urinate as often as 30 times a day.
- Pain, pressure, or tenderness in the pelvic area and/or genitals.
- Pain during sexual intercourse, or pain during ejaculation for men.
- Ulcers and/or bleeding in the bladder.

The symptoms of IC/BPS vary from person to person and can change over time. Women's symptoms often get worse during their menstrual periods. Some people with IC/BPS feel only mild discomfort. Others have severe pain and symptoms.

IC/BPS can greatly affect a person's quality of life. Severe cases of IC/BPS can keep people from going to work or school and being socially active. It can affect a person's sex life and relationships. Living with a chronic condition can increase your risk of depression.

Q: Who gets IC/BPS?

A: More than 1.3 million Americans have IC/BPS, but some studies suggest that millions more may have symptoms of IC/BPS. About 8 in 10 people with IC/BPS are women, although more men might have IC/BPS than we think. Men who actually have IC/BPS may be diagnosed with conditions that have similar symptoms, such as some prostate conditions. Most people with IC/BPS are diagnosed in middle age, but it may be diagnosed in teenagers and senior citizens as well.

Q: What are the causes of IC/BPS?

A: No one knows what causes IC/BPS. The following factors may play a role in IC/BPS:

- A defect in the bladder wall that allows substances in the urine to irritate the bladder.
- A specific type of cell that releases histamine (HISS-tuh-meem) (chemical released during an allergic reaction) and other chemicals, which lead to symptoms of IC/BPS.
- Something in the urine that damages the bladder.
- Changes in the nerves that carry bladder sensations, making normal events, such as bladder filling, painful.
- The body's immune system attacks the bladder.



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It's hard to know if some of these factors actually cause IC/BPS or are part of the process that leads to IC/BPS. Also, the causes of IC/BPS in some people may be different than the causes in other people with IC/BPS. Studies of people who have IC/BPS suggest that it sometimes develops after an injury to the bladder, such as an infection. Genes also may play a role in some forms of IC/BPS. In some cases, IC/BPS affects both a mother and daughter or sisters. Still, IC/BPS does not commonly run in families.

Recently, researchers have identified a substance found almost only in the urine of people with IC/BPS. This substance appears to block the normal growth of the cells that line the wall of the bladder. Learning more about this substance might help researchers better understand the causes of IC/BPS and possible treatments.

Many women with IC/BPS have other conditions, such as irritable bowel syndrome and fibromyalgia (feye-broh-meye-AL-juh). Allergies also are common in people with IC/BPS. Learning about these conditions also might provide clues on the cause of IC/BPS.

Q: How can I tell if I have IC/BPS?

A: No single test can tell if you have IC/BPS, which can make it hard to diagnose. Your doctor will ask you lots of questions about your symptoms. Your doctor also will need to rule out other health problems that may be causing your symptoms, such as:

- Urinary tract infection (UTI)
- Bladder cancer
- Endometriosis (en-doh-mee-tree-OH-suhss)

- Sexually transmitted infections (STIs)
- Kidney stones

Some tests used to help rule out other health problems that can cause bladder pain include:

- **Urine test.** 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 your genital area before collecting urine midstream in a sterile container. Your urine will be looked at under a microscope or sent to a lab to see if you have germs that cause UTIs or STIs.
- **Cystoscopy with or without bladder distention.** Your doctor may use a cystoscope (SISS-tuh-skohp), which is a thin tube with a tiny camera, to see inside the bladder. 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. The doctor can look for signs of cancer, bladder stones, or other problems. It can show whether your bladder wall is swollen, thick, or stiff and can measure how much urine the bladder can hold. It can also find bleeding or ulcers in the bladder. This test is often done as an outpatient surgery.
- **Biopsy.** A biopsy is when a tissue sample is removed and looked at under a microscope. Samples of the bladder and urethra may be removed during cystoscopy. A biopsy helps your doctor rule out bladder cancer.

Researchers are working on developing new tests to help diagnose IC/BPS.



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Q: Is there a cure for IC/BPS?

A: Doctors have not yet found a cure for IC/BPS. 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. Even when symptoms do go away, they may return after days, weeks, months, or years.

Q: How is IC/BPS treated?

A: There are treatments available to help ease the symptoms of IC/BPS. Doctors usually start with a conservative approach, and progress to other therapies as needed. Although no one treatment helps everyone, over time many women are able to find a treatment plan that helps them to feel better. Some of these include:

Self-help strategies. Some people with IC/BPS find relief with self-care methods, such as:

- Bladder retraining — This helps the bladder hold more urine before signaling the urge to urinate.
- Dietary changes
- Wearing loose clothing
- Quitting smoking
- Reducing stress — Stress cannot cause IC/BPS, but it can trigger flare-ups.
- Pelvic exercises — A doctor or physical therapist can teach you how to do these.
- Low-impact physical activity, such as stretching and walking

Oral medicines. Several types of medicine might help with symptoms of IC/BPS. Over-the-counter pain relievers, such as aspirin and ibuprofen (eye-byoo-

PROH-fuhn), might help with mild bladder pain. Talk to your doctor if you feel you need stronger pain medicine.

A prescription medicine called pentosan (PEN-tuh-san) polysulfate (pol-ee-SUHL-fayt) sodium (Elmiron) can help ease symptoms in about one-third of patients. Because Elmiron has not been tested in pregnant women, it's not recommended for use during pregnancy, except in severe cases. Doctor's aren't sure how it works, but it may restore the inner surface of the bladder and protect the bladder wall from irritating substances. You may have to take this medicine for up to 6 months before you start to feel better. Other oral medicines for IC/BPS include:

- Amitriptyline (a-mee-TRIP-tih-leen), an antidepressant that can help increase bladder capacity and block pain
- Antihistamines

Bladder distention. The doctor slowly stretches the bladder by filling it with liquid. Doctors aren't sure why, but this procedure eases pain for some patients.

Bladder instillation (a bladder wash or bath). The bladder is filled with a liquid medicine that is held for different periods of time before being emptied. Treatments are given every week or 2 in about 6-or 8-week cycles. Some people are able to do this at home.

Nerve stimulation. Wires send mild electric pulses to the nerves that control the bladder. Scientists don't know exactly how nerve stimulation works, but it helps ease urgency and urinary frequency in 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.



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Keep in mind, these treatments do not cure IC/BPS. But, you may find that these treatments help to ease your IC/BPS symptoms. Researchers continue to study new treatments for IC/BPS. Talk to your doctor to find out if taking part in a clinical trial might be right for you.

Q: Can consuming certain foods and drinks bring on symptoms or make them worse?

A: Studies have not proven a link between diet and IC/BPS. Yet, some people find that their symptoms begin or get worse after consuming certain foods or drinks, such as:

- Alcohol
- Tomatoes
- Spices
- Chocolate
- Caffeinated and citrus drinks
- High-acid foods
- Artificial sweeteners

Keeping a food diary might reveal a link, if there is one, between certain foods or drinks and the onset of symptoms. Or, you can avoid foods or drinks you think might bring on your symptoms or make them worse. Then, you can start eating or drinking these products again one at a time to see if any affect your symptoms.

Some people with IC/BPS find no link between symptoms and what they eat.

If you decide to avoid certain foods or drinks, make sure that your meals are still well-balanced and healthy.

Q: Does IC/BPS affect pregnancy?

A: Doctors do not have much information about pregnancy and IC/BPS. IC/BPS is not thought to affect fertility or the health of the unborn baby. Some women find that their IC/BPS symptoms get better during pregnancy. Others find their symptoms get worse. If you are thinking about becoming pregnant, talk to your doctor about your IC/BPS and any medicines you might be using to treat IC/BPS or other conditions. Some medicines and treatments are not safe to use during pregnancy.

Q: I just found out I have IC/BPS. What else can I do to cope?

A: Learn as much as you can about IC/BPS and play an active role in your treatment and self-care. Adopt a healthy lifestyle, so you can feel your best. Try to live life as normally as possible. Reach out to loved ones and trusted friends for support. Think about joining a support group for people with IC/BPS, which can help you to cope with symptoms and stress. ■



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For more information

For more information about interstitial cystitis/bladder pain syndrome, call [womenshealth.gov](http://www.womenshealth.gov) at 800-994-9662 or contact the following organizations:

National Kidney and Urologic Diseases Information Clearinghouse

Phone Number: 800-891-5390

Internet Address: <http://kidney.niddk.nih.gov>

Interstitial Cystitis Association

Phone Number: 800-435-7422

Internet Address: www.ichelp.org

American Urological Association Foundation

Phone(s): 866-746-4282; 800-828-7866

Internet Address: <http://www.urologyhealth.org/auafhome.asp>

American Chronic Pain Association

Phone Number: 800-533-3231

Internet Address: <http://www.theacpa.org>

American Pain Foundation

Phone Number: 888-615-PAIN (7246)

Internet Address: <http://www.painfoundation.org>

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Content last updated April 14, 2010.