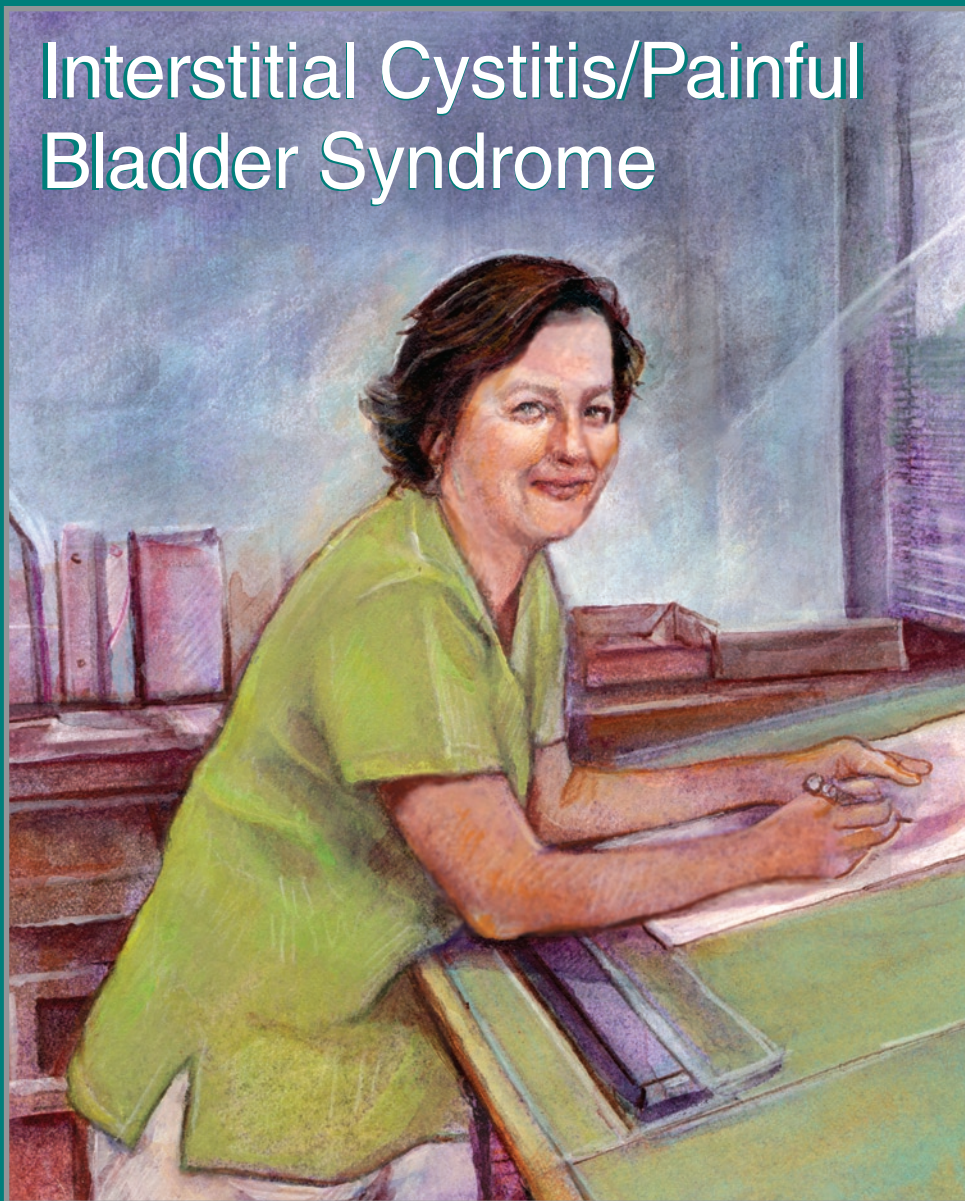


What I need to know about

Interstitial Cystitis/Painful Bladder Syndrome



U.S. Department
of Health and
Human Services

NATIONAL INSTITUTES OF HEALTH

NIDDK NATIONAL INSTITUTE OF
DIABETES AND DIGESTIVE
AND KIDNEY DISEASES

National Kidney and Urologic Diseases
Information Clearinghouse

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What is interstitial cystitis/painful bladder syndrome (IC/PBS)?

Interstitial cystitis*/painful bladder **syndrome** (IC/PBS) is one of several conditions that causes bladder pain and a need to urinate frequently and urgently. Some doctors have started using the term bladder pain syndrome (BPS) to describe this condition.

Your bladder is a balloon-shaped organ where your body holds urine. When you have a bladder problem, you may notice certain signs or symptoms.

*See page 16 for tips on how to say the words in **bold** type.

What are the signs of a bladder problem?

Signs of bladder problems include

- **Urgency.** The feeling that you need to go *right now!* Urgency is normal if you haven't been near a bathroom for a few hours or if you have been drinking a lot of fluids. But you may have a problem if you have strong urges before your bladder has had time to fill. All of a sudden, you feel a strong urge to go. At times, you may even have an accident because the urge strikes so quickly you don't have time to find a bathroom.
- **Frequency.** The feeling that you need to go much more often than anyone else. Doctors and nurses use the term **void**, which means to empty the bladder. Most people void between four and seven times a day. Drinking large amounts of fluid can cause more frequent voiding. Taking blood pressure medicines called **diuretics**, or water pills, can also cause more frequent voiding. If you void more than eight times a day, and you don't take diuretics or drink large amounts of fluid, it may be the sign of a problem.



- **Pain.** The feeling of more than discomfort when you need to go. Having a full bladder may be uncomfortable, but it should not be painful. You may have a problem if you feel burning or sharp pain in your bladder or **urethra**—the opening where urine leaves the body.

Some people may have pain without urgency or frequency. Others have urgency and frequency without pain.

What causes bladder problems?

Many different problems can cause urgency, frequency, and bladder pain. Just a few of them are

- infections
- bowel disorders
- **endometriosis**—tissue that normally lines the womb that appears in other places outside of the womb
- bladder cancer

Your doctor will ask you questions and run tests to find the cause of your bladder problems. Usually, the doctor will find that you have either an infection or an overactive bladder. But urgency, frequency, and pain are not always caused by infection.

Sometimes the cause is hard to find. If all the test results are normal and all other diseases are ruled out, your doctor may find that you have IC/PBS.

Who gets IC/PBS?

Both men and women can get IC/PBS, though twice as many women are affected as men. It can occur at any age, but it is most common in middle age.

People with IC/PBS rarely have bladder pain all the time. The pain usually comes and goes as the bladder fills and then empties. The pain may go away for weeks or months and then return. People with IC/PBS sometimes refer to an attack of bladder pain as a flare or flare-up. Stress may bring on a flare-up of symptoms in someone who has IC/PBS. But stress does not cause a person to get IC/PBS.

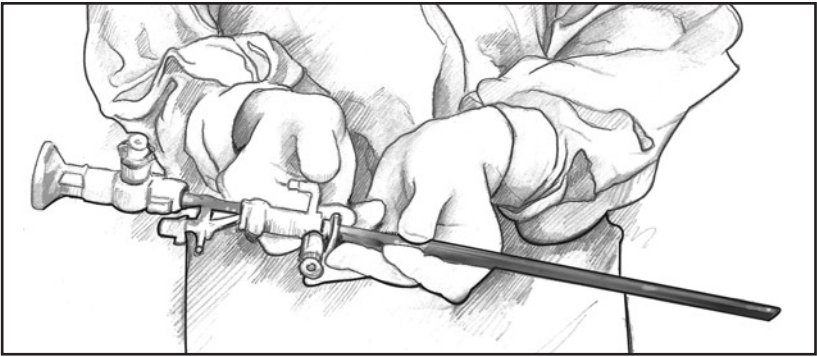
What tests will my doctor use for diagnosis of IC/PBS?

Finding the cause of bladder pain may require several tests.

Urine sample. At the doctor's office, you may be given a cup to take into the bathroom. A health professional will give you instructions for collecting urine in the cup. If you have a bladder infection, your urine will contain germs and maybe pus that can be seen with a microscope. The doctor can treat an infection by giving you **antibiotics**. If your urine is germ-free for weeks or months, but you still have bladder pain, the doctor may decide that you have IC/PBS.

Bladder exam with a scope. The doctor may do an exam to see the inside of your bladder using a **cystoscope**. The tip of this long, thin scope is guided gently up the urethra and into the bladder. The doctor can then see inside your bladder by looking through an eyepiece at the other end of the scope. The doctor may fill the bladder with a liquid. When the bladder is filled, the doctor can see the inner wall better. After the exam, you will release the liquid naturally through your urethra.

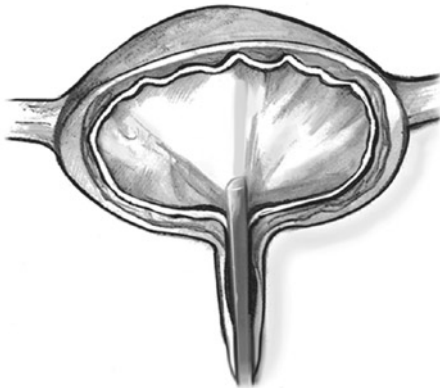




Cystoscope

Inside the Bladder

What does the doctor learn from looking inside your bladder? This exam can help the doctor make sure cancer is not in the bladder. If you have a bladder stone, the doctor can take it out through the cystoscope.

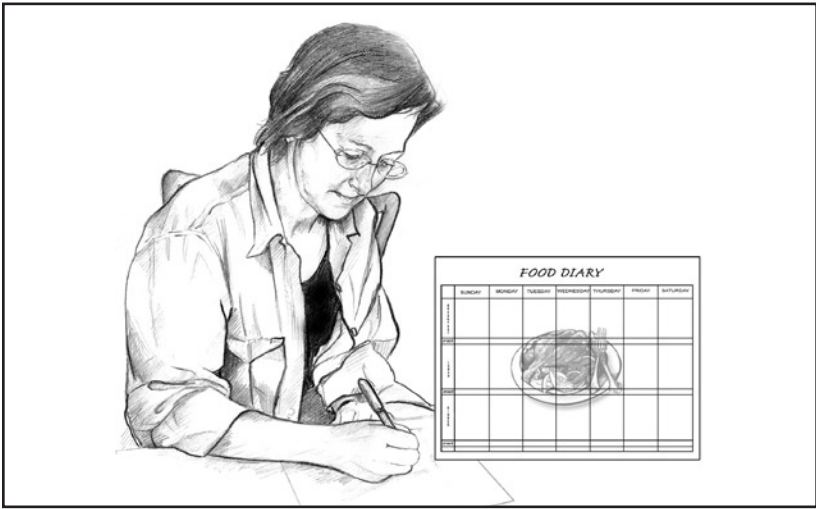


Symptom scale. Your doctor may ask you to fill out a form with a series of questions about how you feel. The symptom scale cannot be used to diagnose IC/PBS but may allow your doctor to better understand how you are responding to treatment.

While tests may aid your doctor in making a diagnosis of IC/PBS, a careful review of your symptoms and a physical exam in the office are generally the most important parts of the evaluation.

What treatments can help IC/PBS?

No one treatment for IC/PBS has been found that works for everyone. Your doctor or nurse will work with you to find a treatment plan that meets your special needs. The plan may include diet and lifestyle changes, bladder retraining, activity and exercise, physical therapy, and various types of medicines. You should expect some treatment failures along the way, but, with time, you and your doctor or nurse should find a treatment that gives you some relief and helps you cope with your disease.



Keeping a food diary might help you identify foods that cause flare-ups.

Diet and Lifestyle Changes

Some people with IC/PBS find that certain foods or drinks bring on their symptoms. Others find no link between symptoms and what they eat.

Learning what foods cause symptoms for you may require some trial and error. Keep a food diary and note the times you have bladder pain. The diary might reveal that your flare-ups always happen, for example, after you eat tomatoes or oranges.

Some doctors recommend taking an **antacid** medicine with meals. The medicine reduces the amount of acid that gets into the urine.

If you make changes to your diet, remember to eat a variety of healthy foods.

Bladder Retraining

Bladder retraining is a way to help your bladder hold more urine. People with bladder pain often get in the habit of using the bathroom as soon as they feel pain or urgency. They then feel the need to go before the bladder is really full. The body may get used to frequent voiding. Bladder retraining helps your bladder hold more urine before signaling the urge to urinate.

Keep a bladder diary to track how you are doing. Start by noting the times when you void. Note how much time goes by between voids. For example, you may find that you return to the bathroom every 40 minutes.

Try to stretch out the time between voids. If you usually void every 40 minutes, try to wait at least 50 minutes before you go to the bathroom.

If your bladder becomes painful, you may use the bathroom. But you may find that your first urge to use the bathroom goes away if you ignore it. Find ways to relax or distract yourself when the first urge strikes.

After a few days, you may be able to stretch the time out to 60 or 70 minutes, and you may find that the urge to urinate does not return as soon.

Activity

If you have IC/PBS, you may feel the last thing you want to do is exercise. But many people feel that easy activities like walking or gentle stretching exercises help relieve symptoms.

Physical Therapy

Your doctor or nurse may suggest pelvic exercises. The pelvic muscles hold the bladder in place and help control urination. The first step is to find the right muscle to squeeze. A doctor, nurse, or physical therapist can help you. One way to find the muscles is to imagine that you are trying to stop passing gas. Squeeze the muscles you would use. If you sense a “pulling” feeling, you have found the right muscles for pelvic exercises.

You may need exercises to strengthen those muscles so that it’s easier to hold in urine. Or you may need to learn to relax your pelvic muscles if tense muscles are part of your bladder pain.

Some physical therapists specialize in helping people with pelvic pain. Ask your doctor or nurse to help you find a professional trained in pelvic floor physical therapy.

Reducing Stress

Stress doesn't cause IC/PBS. But stress may trigger painful flare-ups in someone who has IC/PBS. Learning to reduce stress in your life by making time for relaxation every day may help control some symptoms of IC/PBS.

Oral Medicines

Pain pills like aspirin, **ibuprofen**, or **acetaminophen** can help control mild bladder pain. Advil and Motrin are examples of ibuprofen. Tylenol is an example of acetaminophen. Talk with your doctor if you feel you need a stronger pain medicine.

Your doctor may recommend a medicine, **pentosan polysulfate sodium**, sold as Elmiron, which is approved for treating the pain of IC/PBS. You may need to take this medicine for up to 6 months before you notice improvement. Elmiron does not work for everyone, but some people with IC/PBS have found relief taking it. You need a doctor's order for Elmiron. If you don't notice improvement of your symptoms in 6 months, this medicine is not likely to work.

Researchers are also looking at other kinds of medicines. Medicines that treat heartburn might help bladder symptoms by reducing the amount of acid made in the body. Muscle relaxants can keep the bladder from squeezing at the wrong time. Keeping the bladder muscle relaxed helps ease the symptoms of IC/PBS.

Bladder Stretching

The doctor may stretch the bladder by filling it with liquid. You will be given an **anesthetic** to prevent pain and help relax your bladder muscles. Some patients have said their symptoms were helped after this treatment.

Bladder Medicines

Many patients who have IC/PBS find relief after a treatment in which their bladders are filled with a liquid medicine. The doctor guides a tube into your bladder and slowly fills the bladder with a liquid that eases irritation of the bladder wall. The liquid may be a compound called DMSO or a solution that contains **heparin** and a pain medicine called **lidocaine**.

You will keep the liquid in your bladder for about 15 minutes and then release it. You can have this treatment once every week or every other week for 1 or 2 months. You may not feel any better until the third or fourth treatment.

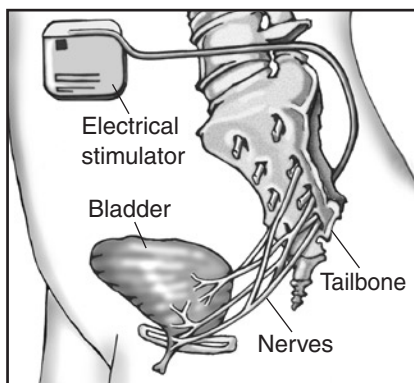
Nerve Stimulation

If you have tried diet changes, exercise, and medicines and nothing seems to help, you may wish to think about nerve stimulation. This treatment sends mild electrical pulses to the nerves that control the bladder.

At first, you may try a system that sends the pulses through electrodes placed on your skin. If this therapy works for you, you may consider having a device put in your body. The device delivers small pulses of electricity to the nerves around the bladder.

For some patients, nerve stimulation relieves bladder pain as well as urinary frequency and urgency. For others, the treatment relieves frequency and urgency but not pain. For still other patients, it does not work.

Scientists are not sure why nerve stimulation works. Some believe that the electrical pulses block the pain signals carried in the nerves. If your brain doesn't receive the nerve signal, you don't feel the pain. Others believe that the electricity releases **endorphins**, which are hormones that block pain naturally.



Implanted nerve stimulation device

Surgery

As a last resort, your doctor might suggest surgery to remove part or all of the bladder. Surgery does not cure the pain of IC/PBS in all cases, but if you have tried every other option and your pain is still unbearable, surgery might be considered.

Talk with your doctor and family about the possible benefits and side effects.

Points to Remember

- Bladder problems have many possible causes.
- Your doctor will need to do tests to find the cause of your bladder problems. If all the test results are normal, you may have IC/PBS.
- No one treatment option for IC/PBS works for everybody.
- Treatments for IC/PBS may include changing your diet and exercising.
- Medicines for IC/PBS may be taken by mouth or put directly into the bladder through a tube by a doctor.
- Nerve stimulation helps some people with IC/PBS.
- Surgery is a last resort for treating IC/PBS.

Hope through Research

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) sponsors programs aimed at understanding the causes of IC/PBS and finding treatments to relieve its effects. The NIDDK's Division of Kidney, Urologic, and Hematologic Diseases supports the Interstitial Cystitis Clinical Research Network. This network includes many universities and medical centers that work together to test new treatments for IC/PBS.

Participants in clinical trials can play a more active role in their own health care, gain access to new research treatments before they are widely available, and help others by contributing to medical research. For information about current studies, visit www.ClinicalTrials.gov.



Pronunciation Guide

acetaminophen (uh-SEE-tuh-MIH-nuh-fen)

anesthetic (AN-es-THET-ik)

antacid (ant-ASS-id)

antibiotics (AN-tee-by-OT-iks)

cystoscope (SISS-toh-skohp)

diuretics (DY-yoo-RET-iks)

endometriosis (EN-doh-MEE-tree-OH-siss)

endorphins (en-DOR-finz)

heparin (HEP-uh-rin)

ibuprofen (EYE-byoo-PROH-fen)

interstitial cystitis (IN-tur-STISH-uhl) (siss-TY-tiss)

lidocaine (LY-doh-kayn)

pentosan polysulfate sodium (PEN-toh-san)
(POL-ee-SUHL-fayt) (SOH-dee-uhm)

syndrome (SIN-droh-m)

urethra (yoo-REE-thruh)

void (voyd)

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