CONDITION

Interstitial cystitis

Interstitial cystitis is a long-term condition causing bladder pain, urinary urgency, and frequent urination without infection.

WHAT IT IS
Chronic bladder pain condition with urinary urgency and frequency

BODY SYSTEM
Urinary system

MAIN SYMPTOMS
Bladder pain, pelvic pressure, urgency, frequent urination

WHAT CAUSES IT
Unknown, likely involving bladder and pain-processing factors

HOW IT IS DIAGNOSED
Symptoms, urine testing, and exclusion of other causes

MAIN TREATMENT
Self-care, pelvic therapy, medicines, and bladder procedures

CAN IT BE CURED?
No, but symptoms can improve significantly

IS IT AN EMERGENCY?
Sometimes, with inability to urinate or severe bleeding

LONG-TERM OUTLOOK
Symptoms often fluctuate, with workable control possible

Overview

Interstitial cystitis is a long-term condition that causes pain, pressure, or discomfort around the bladder. It often also causes urinary urgency-the sudden need to urinate-and frequent urination.

It is also called bladder pain syndrome or interstitial cystitis/bladder pain syndrome, often shortened to IC/BPS. Despite the name, it is not usually caused by a bladder infection. Antibiotics like amoxicillin or doxycycline do not help unless a separate bacterial infection is present.

The symptoms can resemble a urinary tract infection, overactive bladder, endometriosis, or other pelvic conditions. This can make interstitial cystitis difficult to identify. There is no single test that confirms every case.

Symptoms may affect sleep, work, travel, exercise, relationships, and sexual activity. However, the severity differs greatly between people. Treatment usually combines several approaches and is adjusted over time according to which symptoms are most troublesome.

Symptoms

Pain, pressure, or discomfort linked to the bladder is the central symptom. It may be felt above the pubic bone, in the pelvis, or around the urethra, which is the tube that carries urine out of the body.

The discomfort may become stronger as the bladder fills and improve for a while after urination. Some people describe burning, aching, spasms, or a persistent feeling that they need to urinate.

Other possible symptoms include:

Symptoms often come and go. A period when they become worse is sometimes called a flare. Menstruation, sexual activity, stress, prolonged sitting, and certain foods or drinks may be linked to flares for some people, but triggers are individual.

Urinary leakage is not a defining feature of interstitial cystitis, although it can occur for other reasons. Fever, chills, cloudy or foul-smelling urine, or pain in the side of the back may suggest an infection or another condition rather than a typical flare.

- Urinating more often than usual, during the day or night
- A strong or difficult-to-ignore need to urinate
- Passing small amounts of urine many times
- Pain during or after sexual activity
- Pelvic floor pain or tenderness

Causes and risk factors

The exact cause is unknown. Interstitial cystitis is probably not one single process, and different factors may be important for different people.

Researchers have studied possible changes in the bladder lining, immune activity, inflammation, pelvic floor muscles, and the nerves that carry pain signals. The nervous system may become unusually sensitive, so ordinary bladder filling is experienced as painful or urgent. None of these explanations accounts for every case.

Some people have visible inflamed areas in the bladder called Hunner lesions. These are identified during cystoscopy, a procedure that uses a small camera to look inside the bladder. Many people with interstitial cystitis do not have these lesions.

The condition is diagnosed more often in women, but people of any sex can have it. It may occur alongside other persistent pain conditions, such as irritable bowel syndrome, fibromyalgia, migraine, or vulvodynia. Having one of these conditions does not mean you will develop interstitial cystitis.

It is not considered contagious, and you cannot pass it to a partner. It is not caused by poor hygiene. Evidence does not support one food, activity, or personal habit as the universal cause.

Diagnosis

There is no blood test, scan, or bladder biopsy that confirms all cases. Diagnosis is based on your symptoms and on checking for other possible causes. A commonly used clinical definition includes symptoms lasting longer than six weeks without infection or another clear explanation.

An assessment may include:

Depending on your symptoms, testing may also look for sexually transmitted infections, stones, endometriosis, prostate problems, overactive bladder, or other causes of pelvic pain. Blood in the urine may require a separate evaluation.

Cystoscopy is not necessary for every person. It may be recommended when the diagnosis remains uncertain, another bladder condition needs to be excluded, or Hunner lesions are suspected. A biopsy may be taken if an unusual area is seen, but biopsy findings alone do not diagnose interstitial cystitis.

Urodynamic testing measures how the bladder stores and releases urine. It may be useful in complicated cases, but there is no urodynamic pattern that proves someone has interstitial cystitis.

- A discussion of pain, urgency, urination patterns, and symptom duration
- A physical and pelvic examination
- Urine testing for infection and blood
- A bladder diary recording drinks, urination, pain, and urgency
- Measurement of urine left in the bladder after urination

Treatment and management

There is no single treatment that works for everyone. Management usually begins with education, symptom tracking, and lower-risk treatments. More than one approach may be used, and it can take time to find a helpful combination.

A bladder diary can help identify patterns without assuming that every symptom is caused by food or activity. If particular foods or drinks repeatedly worsen symptoms, a short, structured elimination and reintroduction may help identify personal triggers. Highly restrictive diets can cause nutritional problems and are not necessary for everyone.

Other self-management approaches may include heat or cold packs, comfortable clothing, planned rest during flares, and stress-management methods. These measures do not mean stress caused the condition. Stress can increase pain and urgency in many long-term conditions.

Some people benefit from bladder training, which gradually lengthens the time between bathroom visits. It should be adapted to what is tolerable rather than forcing you to hold urine through severe pain.

Pelvic floor physical therapy may help when the pelvic floor muscles are tight or tender. Treatment may involve manual techniques that relax muscles and address painful trigger points. Repeated strengthening exercises, often called Kegel exercises, can worsen symptoms when the muscles are already overactive, so assessment matters.

Medicines may be used to reduce pain, urgency, inflammation, or abnormal nerve signalling. Options include oral medicines and treatments placed directly into the bladder through a catheter. Benefits and side effects differ, and some medicines are used outside their original licensed purpose.

Pentosan polysulfate sodium is an oral medicine used specifically for bladder pain associated with interstitial cystitis in some countries. It has been linked to pigmentary changes in the retina, the light-sensitive tissue at the back of the eye. People considering or taking it should receive current advice about eye assessment and report visual changes.

Procedures may be considered when other treatments have not provided enough relief. Options can include gently stretching the bladder under anaesthesia, treating Hunner lesions, injecting botulinum toxin into the bladder, or using nerve stimulation. Some procedures can cause difficulty urinating or may require temporary self-catheterisation.

Major bladder surgery is rarely used. It is generally reserved for carefully selected people with severe, persistent symptoms after other options have failed, and it does not guarantee that pelvic pain will disappear.

Complications

Frequent urination and nighttime symptoms can disrupt sleep and contribute to fatigue. Pain and uncertainty about bathroom access may limit work, travel, exercise, or social activities.

Pelvic pain can also make sexual activity uncomfortable. Open communication, changes in position or timing, pelvic floor treatment, and sexual health support may help.

Persistent symptoms can affect mood and increase anxiety or low mood. This does not make the pain imaginary. Pain, sleep, stress, and mood can influence one another, so emotional support may be a useful part of treatment.

A small group of people develop a bladder that holds less urine because of long-term scarring or inflammation. This is not the usual outcome.

Interstitial cystitis is not considered a form of bladder cancer. However, new or unexplained blood in the urine still needs assessment because it can have other causes.

Prevention

There is no proven way to prevent interstitial cystitis because its cause is not known. It is not known to result from poor hygiene or a failure to follow a particular diet.

If you already have the condition, learning your own triggers may reduce some flares. This may involve tracking symptoms, treating pelvic floor problems, avoiding repeated use of antibiotics when tests do not show infection, and following a management plan. These steps manage symptoms; they do not guarantee that flares will stop.

Living with it and what to expect

Interstitial cystitis usually follows a long-term, fluctuating course. Symptoms may worsen for days or weeks and then settle. Some people have long periods with few symptoms, while others have more persistent pain or urgency.

The condition does not necessarily get steadily worse. Over months and years, many people learn which treatments, routines, and flare strategies are useful. Treatment may need to change if symptoms, health needs, or personal priorities change.

Regular follow-up is appropriate when symptoms are not controlled, treatment causes side effects, or the pattern changes. It is also reasonable to review treatments that no longer seem helpful rather than continuing them automatically.

Daily life can remain active and meaningful, although adjustments may be needed. Planning bathroom access, pacing activities, addressing sleep, and discussing workplace accommodations can reduce the condition's impact. Support for sexual health, mental health, and persistent pain may also be useful.

When to get medical help

Arrange a routine medical appointment if bladder pain, urgency, or frequent urination lasts several weeks, keeps returning, or affects sleep and daily activities. These symptoms have several possible causes, so an assessment is needed rather than assuming they are interstitial cystitis.

Seek prompt medical advice if you have:

Get urgent or emergency help if you cannot pass urine despite a painful, full bladder, have heavy urinary bleeding or blood clots, feel faint, or are seriously unwell with possible infection. These are not routine features of an interstitial cystitis flare.

- New or visible blood in your urine
- Pain or burning that is different from your usual symptoms
- Fever, chills, vomiting, or pain in your side or back
- New difficulty emptying your bladder
- A major or unexplained change in your urinary pattern

Common questions

Is interstitial cystitis the same as a urinary tract infection?

No. The symptoms can be similar, but interstitial cystitis is not usually caused by bacteria. A urinary tract infection can still occur at the same time, so new symptoms may need urine testing. Repeated antibiotics are unlikely to help when testing does not show an infection.

Can interstitial cystitis go away?

Symptoms may become mild or disappear for long periods, but there is no established cure. Some people achieve good control with treatment, while others continue to have flares or persistent symptoms.

What foods make interstitial cystitis worse?

There is no universal interstitial cystitis diet. Some people report symptoms after coffee,

alcohol, carbonated drinks, citrus, tomatoes, spicy foods, or artificial sweeteners. Others tolerate them without difficulty. A diary and careful reintroduction are more useful than permanently removing many foods at once.

Does interstitial cystitis cause bladder cancer?

Interstitial cystitis is not considered bladder cancer and is not known to turn into cancer. However, symptoms such as visible blood in the urine need proper evaluation rather than being attributed automatically to interstitial cystitis.

Can sex make symptoms worse?

Sexual activity can trigger pelvic pain or a temporary flare in some people, especially when pelvic floor muscles are tight or tender. Pelvic floor therapy, lubricant, position changes, and allowing recovery time may help. Persistent pain during sex deserves assessment.

Why do I feel like I need to urinate when my bladder is nearly empty?

The bladder, pelvic floor, and nerves may send urgency or pain signals before the bladder is full. Urinating may briefly reduce discomfort, which can lead to increasingly frequent bathroom visits. Bladder training or pelvic floor treatment may help in suitable cases.

Sources

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