

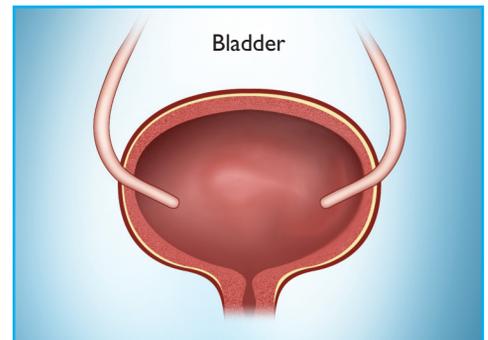
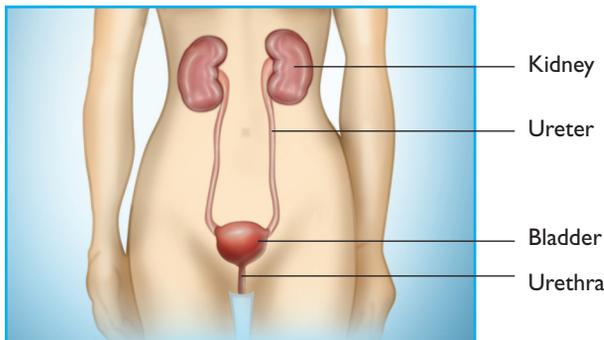
What to do if your doctor says you have interstitial cystitis

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First things first – what is the bladder?

Your bladder stores urine, produced by your kidneys, until you decide the time is right to empty it. Think of your bladder as a muscular balloon, or sac that gradually stretches as it fills. The muscular part comes into play when you go to the bathroom and want to completely empty your bladder. The sac is lined on the inside with a special layer of cells that prevent your urine from penetrating the bladder walls. In addition to the lining cells, there are nerves, blood vessels and connective tissue (layers of cells that support the structure of the bladder) that make up the bladder wall to make it thick.

You may be surprised to learn that the bladder is located much lower than it feels. The bladder is behind and below the pubic bone (the bone you can feel at the front of your body at the lowest part of your belly).



What is interstitial cystitis?

Interstitial cystitis (or IC) is a chronic, non-life threatening condition of the bladder. When you have IC, you tend to go to the bathroom a lot during the day and night and also have pain in your bladder. We don't know very much about IC. It can be called different names.

The other names of IC

- Painful bladder syndrome
- Detrusor mastocytosis
- Urethral syndrome
- Urethritis
- Chronic pelvic pain syndrome

There is no definitive test to confirm that you have IC. Your diagnosis will be based on suspicion and exclusion. A diagnosis of exclusion means that all other possible conditions, with similar symptoms, will be ruled out before your IC diagnosis can be confirmed. You may have your symptoms for 3 to 5 years before a correct diagnosis is made.

Who gets IC?

- Most people with IC are women
- You can have IC at any age (although it's rare in children and your chance of developing it drops off after your mid-50s)
- Estimates of how many people have IC vary from: 1.8 to 3.5 per 10,000 adult women to as high as 2.8% of Canadian women (which means there may be as many as 420,000 women with the disease in Canada)

What does NOT affect your chance of having IC?

- Numbers of sexual partners
- Race
- Ethnicity
- Marital status
- Education
- Household size

How do you get IC?

We still don't know what causes IC but we are still working on finding out. There is a weak link between IC and other diseases, including chronic fatigue syndrome and fibromyalgia.

How is IC diagnosed?

We diagnose IC by noting your symptoms and ruling out other diseases.

Symptoms of IC

- Pain
- Frequent urinating day and night
- Urgency
- Pain during sex

What are the symptoms?

1. Pain

The most common symptom is bladder pain; this doesn't mean burning when you urinate, but true bladder pain. You may feel it as pressure, but it's still pain. The pain, often in the lower abdomen or pelvis, may be constant, may occur when you drink, at the end of voiding or anywhere in between. If there no pain at all, then it's unlikely that you have IC.

2. Frequency and waking to urinate at night

The other major clue is frequent day and night urinating. In these cases, you would feel relieved of pain when you go to the bathroom, but the pain would not be completely gone. You may not wake up a lot during the night to go to the bathroom (also called nocturia), but you will wake up because your bladder wakes you up (not because you are already up and have to go to the bathroom). Dysuria, or burning when you urinate, is rarely associated with IC. Incontinence (or the involuntary loss of urine) is also rarely linked to IC.

3. Urgency

Urgency, or the need to rush to the toilet, is a tricky one.

Are you experiencing a sudden, irresistible urge to go to the bathroom? If so, you likely have an irritable or “unstable” bladder. In this case, urgency is not a symptom caused by IC.

Yet, if your “urgency” is really more of an extreme need to empty your bladder due to the increase in pain that occurs as the bladder fills, then you likely have IC. Your urologist will need to clearly understand what you mean when you say you have “urgency.” True urgency can be disturbing and inconvenient, but, fortunately, you have many treatment options.

If you have a constant sense of pressure/pain, burning, and have little relief after you go to the bathroom, you probably do not have bladder instability, but an infection. If you do have an infection, you may also have blood in your urine. Although blood in the urine, either seen or detected by testing, is not a symptom of IC, it is a very important finding and needs to be investigated thoroughly: from the top of the kidneys down to the end of the urethra (the opening where the urine comes out of the body).

4. Pain during sex

The most common symptom that is missed, either because your urologist didn't ask you about or because you didn't bring it up, is dyspareunia (or painful sexual intercourse).

What are the tests?

After we've noted your symptoms, the next step is to get some tests done to exclude other conditions that can cause the same, or similar, symptoms.

1. Urine tests: Urinalysis, urine culture, urine cytology

After a physical exam (including a vaginal exam in women and a rectal exam in men), the first and most important thing to do is to test your urine. A test called a **urinalysis** will detect blood in the urine and the possibility of an infection.

A **urine culture** (a test used to find and identify germs) will detect any infection and, if you have an infection, the test will detect the type of bacteria growing and determine the right antibiotic. IC cannot be diagnosed when you also have a bacterial, fungal, parasitic, sexually transmitted, or any other form of urinary tract infection.

If a cystoscopy (visual inspection of the bladder) is not going to be done, then several urine specimens should be sent for **cytology**. Cytology is the microscopic inspection of urine to detect abnormal cells. Abnormal cells may be a sign of bladder cancer; your doctor will have to thoroughly evaluate your cells to rule out bladder cancer.

2. Looking at the bladder: The merits of cystoscopy

The question of whether to perform a cystoscopy is controversial. There are some urologists who think that one is unnecessary if you have provided your doctor with a good history, physical exam and if your other test were negative. Other urologists feel that a bladder exam should be done with a local anesthetic (so you are awake during the procedure). I disagree, here's why:

1. A cystoscopy under local anesthetic is better than not looking at all, but, in some patients with IC, it can be painful when performed with only local anesthesia.
2. IC can only be diagnosed by excluding other disease, so a thorough exam is needed. Unless you look at the bladder, how can you be sure that nothing is being missed?
3. Your bladder capacity should also be measured; if the bladder has scarred down to less than 300 cc (normal is 800 to 1200 cc under general anesthetic), medicine will not help and you may need surgery. To check the true capacity of your bladder, you should be under general anesthesia. Even people with normal bladders, filled to the halfway point while awake, experience severe bladder pain. In a patient with IC filling the bladder, even slightly, is severely painful, so no realistic estimate of true bladder capacity is possible if you would be under local anesthesia.
4. The final reason you should be filling your bladder completely, draining it, and then looking again is that we may notice changes in the lining of the bladder. The changes are not seen in 100% of patients, but, if seen, they are another piece of IC puzzle.

3. Tests to avoid

a. Ultrasound

X-rays (including CAT scans) and ultrasound are not required to diagnose IC, unless the initial history or tests show something else brewing. A pelvic ultrasound (which means you would have to drink a lot to fill your bladder) is cruel and unusual punishment if you have severe pain trying to hold your urine.

b. Urodynamic studies

Urodynamic (bladder pressure and flow) studies are not needed for same reasons. These tests add nothing to the management of IC and the tests can be excruciating.

c. Potassium sensitivity test

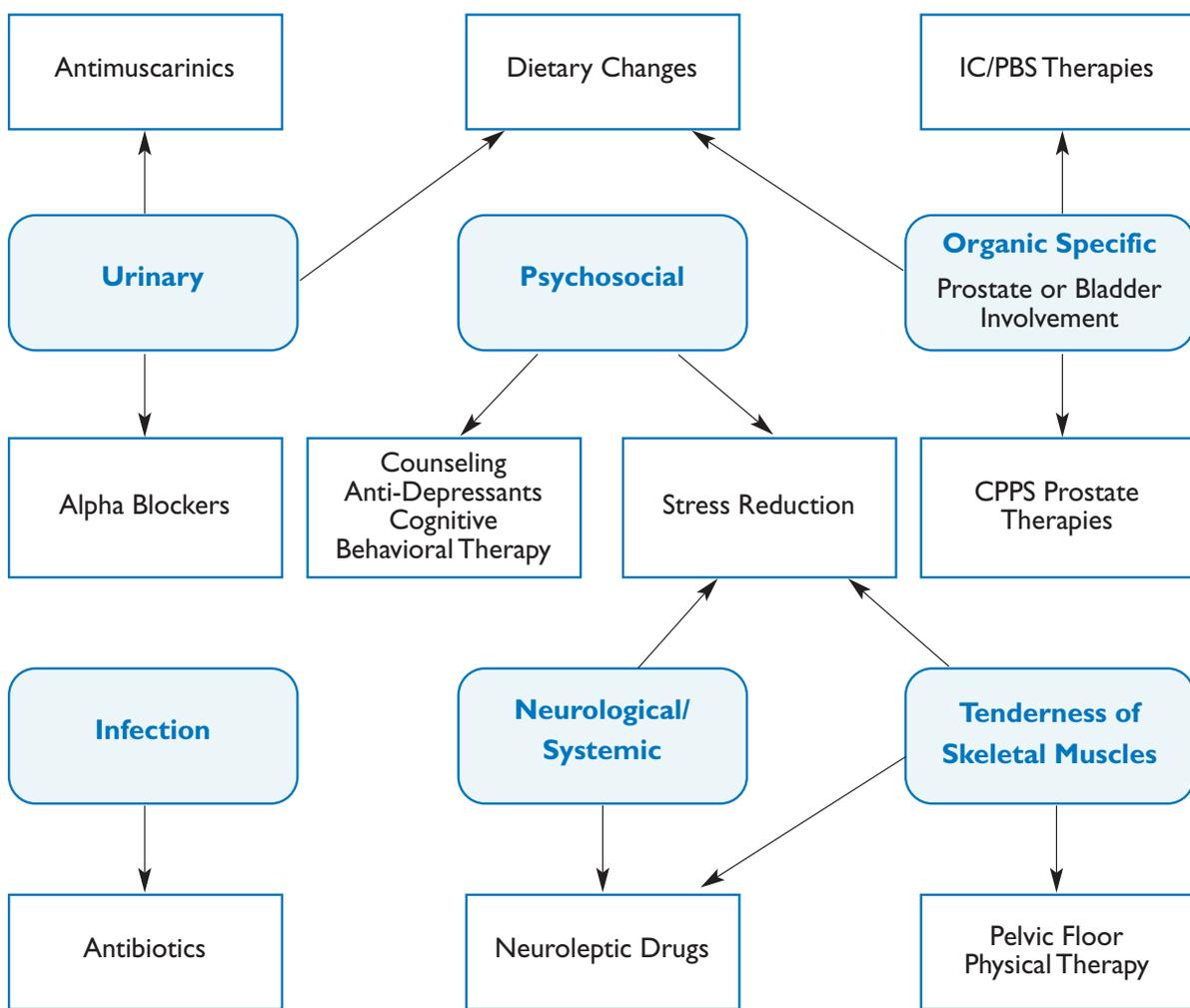
In this test a potassium solution is trickled into the bladder in the belief that patients with IC have an abnormal, leaky, lining of the bladder that would allow the potassium to irritate the nerve endings under the bladder lining. We believed this would cause much more pain in people with IC than in people with normal bladders. This was not the case – too many people with normal bladders also feel pain with this test. Also, we found that too many with IC don't report their severe pain in hopes that the test will be somehow beneficial.

d. Bladder biopsy

A biopsy may need to be taken if something abnormal (not linked with IC) is seen in the bladder. A biopsy, though, does not help in making the IC diagnosis and so should not be done.

A little pause is needed here before we dive into treatment. Let's look at ways we classify IC patients.

In 2009, doctors came up with a system to help classify IC patients and tailor treatment. The UPOINT system was born – U: urinary; P: psychosocial; O: organ specific; I: infection; N: neurologic/systemic, and T: tenderness of skeletal muscles. Take a look at the figure below; you'll see that each domain leads to treatment options. This isn't a complete list of all the available treatments associated with each of the UPOINT categories – this is just an example to help illustrate its usefulness. The beauty of this approach is that treatment is tailored to your specific needs. It is an exciting new way to holistically look at IC.



How can my IC be treated?

Generally, it's best to get the maximum response with the minimum inconvenience or discomfort, so let's start with conservative options.

Simple lifestyle, non-drug options

- Apply heat or cold just over the bladder, between your legs.
- Limit drinks, like coffee, alcohol, soft drinks, that irritate your bladder.
- Try to see if there are some foods that irritate your bladder through the process of elimination.
- Read “A Taste of the Good Life: A Cookbook for an Interstitial Cystitis Diet” by Beverley Laumann – many patients find it useful.
- Visit <http://www.ic-network.com/support/> for support and networking tools (there are branches in BC, Ontario and Quebec).
- Try stress management techniques.
- Try pelvic physical therapy (pelvic floor strengthening exercises, such as Kegel exercises, are NOT recommended because this often makes the symptoms worse).

When conservative therapy doesn't help, the next step is to move on to oral medications. These may be either over-the-counter (such as Quercetin, L-glutamine, or Calcium Glycerophosphate which has to be ordered from the United States), or by prescription.

Oral medications

Amitriptyline: This is a common first choice. Low dose amitriptyline can affect the nerves in your bladder and help with the pain and frequency of your urination. It can also help you sleep.

Cimetidine: Most commonly used to prevent stomach ulcers and heartburn.

Hydroxyzine: An antihistamine; no clear reason why this would help as IC is not caused by an allergic reaction.

Pentosan polysulfate: Also known as Elmiron, this helps repair the lining of the bladder. In some patients, the bladder lining is damaged.

If we really understood IC, most of you would have been cured or have your symptoms relieved – this unfortunately is not the case. Some of you may need bladder treatments. The idea behind bladder treatments is that medication can be introduced directly into your bladder, through a catheter. The direct exposure to the medication may work better than medications taken orally.

Treatment details of medications placed in the bladder

- Rimso and Heparin are common.
- Lidocaine, a local anaesthetic, is occasionally added to the mixture.
- Does not require general anaesthetic.
- Takes only about 5 minutes.
- The mixture is held in the bladder for about 1 hour (or as long as possible) before it is expelled by urinating.
- Six treatments are given, weekly or every other week, and outcome is checked to see if the treatment worked.
- The main drawback: 24 hours of smelling slightly garlicky. You won't notice the smell yourself, but your family and friends certainly may.
- If Rimso and Heparin fail to do the trick, try Cystistat or Uracyst. Both of these use a chemical from cartilage called hyaluronic acid to heal and soothe the bladder lining.
- Chlorpactin treatments (either 0.2 or 0.4%) are another option.
- Chlorpactin is kept in the bladder for 10 minutes; it can be very irritating, so this is done under general anaesthesia.
- Chlorpactin treatments are once/month for three months and then you are reassessed. Some patients do really well and don't need anything else; others may need repeat treatments to keep their IC symptoms at bay.

Avoid these bladder treatments:

High Pressure Hydrodistension, BCG, Resiniferatoxin, Antibiotics, Steroids, Botox

1. High pressure hydrodistension

This is an older treatment, done under general anaesthesia. In this treatment, the bladder was filled to capacity (under high pressure) and then kept swollen for at least 10 minutes, then the bladder is drained. This surgery is no longer popular because, although some patients did get some relief, the relief was short-lived. The main problem was that the bladder expansion may scar the bladder and make it small and functionally useless. Other complications include bladder rupture and infection.

2. BCG (or Bacille Calmette-Guerin) treatments

BCG treatment (Bacille Calmette-Guerin) is very useful for certain types of bladder cancer, but it has no effect on IC.

3. Resiniferatoxin

Resiniferatoxin is similar to the stuff that makes chili peppers hot. It causes lots of side effects, but no improvement in symptoms.

4. Antibiotics and steroids

Long-term antibiotic use in patients with negative cultures before the IC diagnosis and long-term steroid use can cause very serious complications.

5. Botox

Botox (or Botulinum Toxin A) can be injected into the bladder. I have found this to be excellent in my patients with an overactive bladder, but have not had success with my IC patients. Botox relaxes the bladder muscle so that urgency and urinary frequency diminish; however, it does not relieve pain. Patients with IC have frequency because of the pain and discomfort they feel as their bladder fills. My patients treated with Botox voided much less often, but had much, much more pain because they couldn't empty their bladders as often as their symptoms dictated. Since the effect of Botox lasts, on average, eight to nine months, these patients were very unhappy with it.

Surgery

1. Neurostimulators

Neurostimulation involves implanting a device to stimulate the nerves at the base of the spine with a small electric current. Some patients respond well to this, but neurostimulators are expensive and rarely available. There is only one centre in Ontario that does this procedure and the centre's budget only allows for a limited number of implantations per year. The waiting list is very long.

2. Open surgery

If all other treatments have failed and your symptoms are so severe that life is unbearable, then you may have to consider major surgery. There is no going back once this decision is made.

With surgery, your bladder is removed with your urine being diverted into either a loop of bowel (or a ileal conduit) that drains into a bag on the lower belly, or into a pouch of bowel that has an opening to the skin where a tube, called a catheter, is inserted by you, every 3 to 4 hours, to drain the urine in the pouch. Your surgeon may try to save your bladder by changing the flow of urine to the ileal conduit or the pouch, and leave the bladder in place. Sometimes part of your bladder is removed and a pouch of bowel is attached to what's left of the bladder, so that you drain the pouch through your own urethra (the normal tube that we urinate through).

Unfortunately, pain may persist even after the entire bladder is removed, and pain is more likely to persist if parts of the bladder are left behind. This is a major problem if a pouch is placed in the pelvis because it is then impossible to know if the pain is from the leftover bladder/urethra or from the pouch. Sometimes, the pelvic pouch has to be replaced with an ileal conduit (which is another long and difficult operation).

The removal of your bladder and creation of an ileal conduit often takes six hours and involves a hospital stay of about five to 10 days. In my experience, patients who have surgery are also very run down and have practically no reserves left. This prolongs their recovery significantly. I warn every one of them that it will take them three to six months to get back to a new kind of normal after surgery.

Despite all of the possible problems associated with removing someone's bladder, if it comes to it, these patients are often the most grateful patients because their lives are so much better compared to what it was like before the surgery, and, really, most of them had no life because their bladders had crippled them. This option should not be taken lightly.

What does the future hold for people with IC?

This may all seem a little overwhelming and even a little depressing. Don't be discouraged! It is important to look at the bigger picture.

1. Very few patients ever experience symptoms so severe that they need their bladders removed.
2. It is most likely that your symptoms will not get worse after your IC diagnosis is confirmed.
3. IC does not damage your kidneys or any other organ
4. IC does not cause death.
5. At least 10% of patients may develop spontaneous remission of their symptoms.
6. Most patients experience significant pain relief with lifestyle changes (listed earlier in the paper).

A final word

Just because we don't know what causes IC and don't have a cure yet, this doesn't mean that you are being ignored. There are many fine dedicated researchers who are passionately devoted to solving the puzzles of this disease. There have been many clinical trials in the past five years. I am confident that significant advances will be made within our lifetimes.