



Interstitial Cystitis (IC)

Interstitial cystitis is a chronic, painful condition of your bladder. You and your doctor will work together to make a long-term treatment plan to control your symptoms.

What is interstitial cystitis?

- Interstitial cystitis (IC) is a painful, chronic condition of the bladder that may also cause pelvic pain.
- Doctors are not sure what causes it.
- It might be a defect in the lining of the bladder that is irritated by unknown substances in the urine.

How does my bladder work?

(See diagram: "The male and female urinary tracts")

- Urine is made by the kidneys and carried through the ureters to the bladder where it is held until you need to empty your bladder.
- When you urinate, the bladder muscle contracts to push the urine through its opening (the urethra).

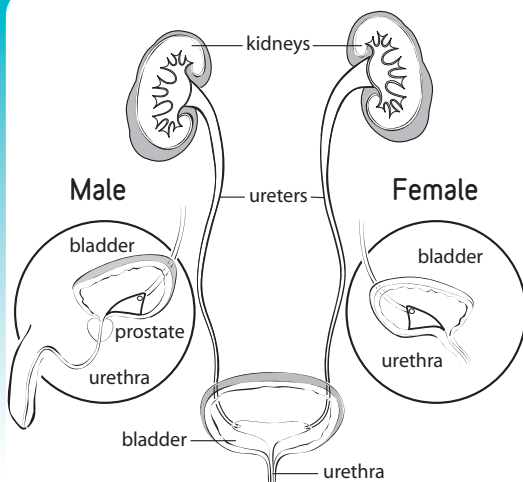
Who gets interstitial cystitis (IC)?

- IC is sometimes called "Painful Bladder Syndrome."
- Symptoms are like those of a urinary tract infection (UTI) except tests do not show infection, and antibiotics don't help.
- IC can affect anyone.
- Women (90% of cases) get IC much more often than men.
- In all cases, there is treatment but not yet a cure.

What are the symptoms of IC?

- There are different kinds of IC symptoms. They differ in the type of symptom, how long they last and how serious they are. Some are:
 - The need to urinate very often, both day and night,
 - A strong need to urinate that you can't control. With this need, you might feel increasing pain or pressure in your pelvis.
 - Burning or aching pain in your pelvis (including your bladder, urethra, vagina, testicles, or scrotum).
 - This pain is often worse before or after you urinate.
 - In some cases, the pain can also happen with sexual intercourse.
- Other symptoms may include general muscle aches in the body and depressed mood.
- In some people, other chronic illnesses and pain conditions like fibromyalgia or irritable bowel syndrome might affect IC.

The male and female urinary tracts



Interstitial Cystitis (IC)

How is IC diagnosed?

- Some diseases must be diagnosed by ruling out other conditions.
- Diagnosing in this way is like putting together the pieces of a puzzle. As more pieces are added, the picture slowly becomes more clear.
- In the same way, IC needs to rule out other diseases such as: urinary tract infection (UTI), sexually transmitted infection (STI), bladder cancer, and other disorders with similar symptoms.
- It is also common to use basic urine and blood tests to make a diagnosis.
- A thin tool like a small camera (cystoscope) can be passed through the urethra to inspect the lining of the bladder (process is cystoscopy) to rule out other problems.
- Rarely, specific red patches may be found in the bladder lining (called Hunner's ulcers) that can be treated during cystoscopy.
- To test for areas of bleeding in the lining (called "glomerulations"), the bladder can be gently filled with water at a controlled pressure (hydrodistension).
- Since the pressure from hydrodistension could be a very uncomfortable, an anesthetic is used.
- To make a diagnosis of IC, it is necessary to search for typical symptoms, to rule out other conditions and to look at the effect of treatment.
- Making a diagnosis this way requires patience.
- It is important to know that the symptoms of IC are real, not "in one's head."

How is IC treated?

- Once the diagnosis is clear, a complete treatment plan will help ease and control your symptoms.
- Treatment of IC is complicated and may need a combination of treatments that could include:
 - patient education (understanding the disease)
 - self-help (such as quitting smoking)
 - change in diet (see section "How will changing my diet help with IC?") or other
 - medication (see section "Are there medications to help with IC?")

- You may want to ask your doctor about other types of treatment that are less common or proven such as guided imagery or acupuncture.
- Surgery may be helpful in a few cases (see section "When is surgery used?").
- Although a cure may not be possible, you can get help with your symptoms.

How will changing my diet help with IC?

- It may be necessary to avoid some of the following as they may irritate the bladder.
 - acid and spicy foods
 - sparkling beverages (sodas)
 - caffeine (including chocolate)
 - other foods such as:
 - tomatoes
 - citrus fruits or beverages
 - alcohol
 - artificial sweeteners
- It will take patience to "zero in" on foods which may be causing pain.
- You may need to take out these foods from your diet.
- Then, one at a time, put them back into your diet to figure out which one(s) might be causing symptoms.

What kind of therapy might help with IC?

- Bladder training methods seem to help some people, such as:
 - Plan the times that you empty your bladder. For example, urinate every 30 minutes, whether you need to go or not. Little by little, wait longer between bathroom visits.
 - Try relaxation methods to increase the time between your need to urinate.
- Physiotherapy to strengthen your pelvic floor muscles can help relieve symptoms.
- A special machine to stimulate the nerves (with mild electrical pulses called a TENS machine) can help the bladder muscle relax to relieve symptoms.
- Self-help methods (such as physical activity and relaxation to reduce stress) may make your symptoms more reasonable.

Continued on next page

Are there medications to help IC?

- Although tricyclic antidepressants (such as amitriptyline) are usually used to treat depression, they can also help IC pain (at much lower doses).
 - They let the bladder relax
 - They let the bladder hold more urine
 - They decrease how often you need to urinate
 - They reduce the number of times you get up during the night to urinate because of the tranquilizing effect
- Pentosan polysulfate (like Elmiron™) is used to treat IC.
 - It must be used for several months before it works fully
 - In time, it may repair and keep healthy the coating that protects the bladder lining.
- Antihistamines, like hydroxyzine (like Atarax™), may be helpful, especially as they can be soothing and relaxing.
- In some cases, other types of prescription medications may improve IC symptoms, such as:
 - anticonvulsants (like gabapentin)
 - anti-inflammatory drugs (like ibuprofen)
 - narcotic pain killers (drugs with codeine or oxycodone)
 - bladder relaxants (like tolterodine or oxybutynin)
 - drugs to reduce acid in your urine
- New oral medications are still being created to help treat this difficult problem.

Are there medications that can be put right into the bladder?

- Medication can be put right into the bladder through a narrow tube passed through the urethra (called bladder instillation).
 - This helps some patients with IC by reducing the swelling and repairing the damaged coating that protects the bladder lining. Medications used for bladder instillation include:
 - DMSO (Rimso™)
 - Glycosaminoglycan (heparin or Cystistat™)
- Bladder instillations often start with weekly sessions and then occur less often.

When is surgery used?

- If nothing else has worked, major surgery may be considered for treatment of IC. These could include:
 - Making the bladder larger
 - Removing the bladder
 - Reroute urine away from the bladder (such as collecting urine in a bag on the outside of the body)
 - These procedures may have serious complications
 - You may not be able to do away with the pain

Research continues to find better treatment and a cure for IC and teach us more about IC.

IC is a painful, chronic condition of the bladder that physicians find difficult to diagnose. It is also difficult for patients to understand and deal with. Once diagnosed, you and your urologist can come up with a long-term treatment plan made just for you so that you can manage and control your symptoms.

This publication is produced by

Canadian **U**rological Association
The Voice of Urology in *Canada*



Association des **U**rologues du Canada
La voix de l'urologie au *Canada*

The information in the publication is not intended to convey medical advice or to substitute for direct consultation with a qualified medical practitioner. The Canadian Urological Association disclaims all liability and legal responsibility howsoever caused, including negligence, for the information contained in or referenced by this brochure.

© 2022. Canadian Urological Association. All rights reserved.

cua.org