

IPBF

Interstitial Cystitis

**(Painful Bladder Syndrome, Bladder Pain Syndrome,
Hypersensitive Bladder Syndrome)**

What is it?

How is it diagnosed?

How is it treated?

How do you cope with it?

www.painful-bladder.org

International Painful Bladder Foundation

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Interstitial Cystitis (IC)

(Painful Bladder Syndrome, Bladder Pain Syndrome, Hypersensitive Bladder Syndrome)

- ❖ **If you have had pain, irritation or discomfort in your bladder for more than three months and need to go to the toilet more frequently than usual day and night, but your family doctor says that there is no infection to be seen in the urine and treatment with antibiotics has had no effect on the symptoms, what is wrong with your bladder?**

- ❖ **Maybe you have interstitial cystitis...?**

Interstitial cystitis (IC), also known as painful bladder syndrome (PBS), bladder pain syndrome (BPS) and hypersensitive bladder syndrome (HBS) in different parts of the world, is a chronic, urinary bladder disorder of unknown cause, with symptoms of pain, irritation, pressure or discomfort in or around the bladder and usually accompanied by a frequent and often urgent need to urinate day and night. It may occur alone or accompanied by other disorders or other chronic pain syndromes including irritable bowel syndrome, fibromyalgia, vulvodynia, allergies/hypersensitivities or autoimmune diseases such as Sjögren's syndrome.

While the symptoms may resemble bacterial cystitis, there is no infection to be seen in the urine and tests reveal no identifiable disorder that could account for the symptoms. Since there are a number of other disorders that can cause similar symptoms, it is important for these to be ruled out. In order for this to be done, you need to be referred to a urologist or urogynaecologist.

Symptoms:

The typical symptoms are **pain or discomfort, urgency and frequency**. These symptoms and their combinations vary greatly from person to person, and even in one person they can vary from day to day or week to week. Spontaneous flares and remission of symptoms are a characteristic feature of IC in many patients.

- **pain:**

The pain may be experienced as discomfort or tenderness, or a burning sensation in the bladder, in the form of spasms in or around the bladder, or stabbing or burning vaginal pain. It may also be felt throughout the pelvic floor, including the lower bowel system. The pain may be felt in the groin and thighs. In women there may be pain in the vagina, in men pain in the penis, scrotum and perineum, while both may have pain in the urethra. The pain may be constant or intermittent. In some patients the pain may be very severe. Other patients, particularly in the early stages, may have urgency and frequency without a clear pain sensation. What they may experience, however, is a feeling of discomfort, pressure or fullness, even when there is little urine in the bladder. The pain of IC usually increases as the bladder fills and is relieved when the bladder is emptied. Both men and women may experience pain with sexual intercourse. Women may feel a worsening of the symptoms around the time of menstruation.

- **urinary urgency:**

Urinary urgency in IC is an urgent or compelling need to find a toilet due to increasing pain or discomfort that becomes impossible to tolerate any longer, and may in some patients be accompanied by an increasing feeling of malaise. Some patients find that having to postpone urination leads to retention or difficulty in getting the urine flow started.

- **frequency:**

Frequency is the need to urinate more frequently than usual, day and night. In some patients this frequency may be very severe with a need to urinate up to 60 times a day. The amount of urine passed may be small. Frequency is by no means always related to bladder size. While some patients have a form of IC with a shrunken bladder which has a scarred stiff wall and a small capacity under anaesthesia, IC patients with a normal-sized bladder may also have severe frequency and pass small amounts of urine at a time.

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How does it start?

The symptoms may begin spontaneously for no apparent reason, or sometimes following an operation, particularly after hysterectomy or other gynaecological surgery, after childbirth or following a bacterial infection of the bladder or repeated infections. The symptoms may start suddenly and severely, but they may also begin almost imperceptibly with perhaps more frequent urination than usual and develop slowly over many years.

What causes it?

Despite considerable research into many different aspects of IC, the cause is still unknown. There are many different theories, but no answers have as yet been found. While many patients experience exacerbation of their IC symptoms due to stress of either an emotional or physical nature, it is important to emphasize that there is no evidence that stress is a cause of IC. Patients can rest assured that IC is a recognized medical condition and not a psychosomatic disorder.

Who is affected?

It is a bladder condition that is predominantly found in women (80-90%). Approximately 10-20% of IC patients are men who may in the past have been incorrectly diagnosed as having non-bacterial prostatitis (inflammation of the prostate gland) or prostatodynia (pain in the prostate gland). IC is also found in children. It is found in all countries around the world and in all races. The exact prevalence is unknown and it is probably being under-diagnosed in many countries.

Is there a cure?

So far there is no cure for IC. Treatment is therefore aimed at alleviating the patient's symptoms and improving quality of life.

Diagnosis

Since there are still no diagnostic tests specifically for IC, diagnosis is made on the basis of symptoms and exclusion of all other identifiable possible causes of these symptoms. The diagnostic procedures used may vary from country to country, but may include: medical history, physical examination, urine and other laboratory tests, imaging (x-rays, ultrasound etc), cystoscopy, hydrodistension and biopsy.

- tests and imaging

Urine tests (urinalysis) and cultures are taken to determine whether any bacterial infection is present. Other laboratory tests and imaging are carried out to exclude other identifiable disorders or diseases that could cause similar symptoms. These will vary in different parts of the world but are aimed at eliminating all other possibilities. For example: urinary tract infections, kidney or bladder stones, bladder cancer, vaginal infections, sexually transmitted infections, radiation cystitis (caused by radiation therapy after cancer), chemical cystitis (caused by drugs), eosinophilic cystitis, endometriosis (in women), prostatitis (in men), schistosomiasis and tuberculosis in countries where these are endemic, neurologic disorders including pudendal nerve entrapment, and low count bacterial infections that may be missed by dipstick testing. However, the diagnosis of another disorder does not necessarily exclude the presence of IC as well. A patient may have one or more of these other disorders in addition to IC.

- cystoscopy

Cystoscopy with hydrodistension (distending the bladder with water beyond its normal capacity) under general anaesthetic is an investigation used to take a close look at the inside of the bladder. Following hydrodistension, pinpoint bleedings (glomerulations or petechiae) may be visible in some patients. Once considered a hallmark of IC, it is now known that these are not seen in all IC patients. In some patients so-called "Hunner's ulcers" (lesions, patches) may be visible following hydrodistension. This is the so-called "Classic IC" subtype. Cystoscopy is sometimes performed without hydrodistension to rule out the possibility of stones, cancer, lesions etc. in the bladder. In this case, only a small amount of water is instilled into the bladder, just enough to allow the bladder wall to be clearly seen.

- biopsy

Biopsy involves taking a minimum of three small samples of tissue from different levels in the bladder wall at several different sites following the hydrodistension. These samples may reveal an increase in mast cells in the bladder urothelium (bladder lining) and detrusor muscle in the bladder wall. Mast cells play a role in

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allergic and inflammatory reactions in the body's tissues. The biopsy can also be useful to exclude the possibility of other causes of the symptoms.

Even if the results of the cystoscopy and biopsy are normal, this does not necessarily mean that the patient does not have IC. Some patients may show no abnormalities, while nevertheless displaying all the symptoms of IC.

- anaesthetic challenge test

Instillation of an anaesthetic solution into the bladder, such as lidocaine with sodium bicarbonate, is sometimes carried out to identify the bladder as the source of the pain since this solution will anaesthetize the bladder only. If the pain is located elsewhere, it will still be felt.

Treatment

At the present time, no medication exists that is equally effective in all IC patients. Treatment is highly individual and has to be tailored to each patient and to the severity of the different symptoms.

Treatment may include:

Dietary changes, lifestyle modifications, oral drugs, bladder instillations or injections, bladder distension, neuromodulation/electrostimulation, laser/electrocoagulation/resection and various other forms of surgery. Patients with severe pain that does not respond to treatment may need referral to a pain consultant.

- diet

Many patients will soon discover from their own experience that certain foods and beverages appear to worsen their bladder symptoms. Every patient is different, but by eliminating items known to cause irritation based on their own experience, a patient can at least avoid unnecessary exacerbation of the bladder symptoms. Patients with milder IC may even find that changes in diet are the only treatment they need. Foods and beverages that may cause irritation in some patients are: food/drink containing caffeine, citrus fruit and juices, other acidic food such as tomatoes, vinegar etc., artificial sweeteners, alcoholic drinks, carbonated drinks, highly spiced food especially food containing hot pepper.

- oral drugs

Oral drugs include tricyclic antidepressants (used for pain reduction and to aid sleep), antihistamines, antispasmodics, anti-inflammatories, analgesics, for severe pain opioid analgesics, pentosan polysulfate sodium, anticonvulsants (for pain treatment). Experimental oral drugs include cyclosporine A, suplatast tosilate, liposomes.

- intravesical/intramural treatment

Intravesical treatment includes heparin, pentosan polysulfate sodium, sodium hyaluronate, DMSO, oxybutynin, alkalized lidocaine, chondroitin sulfate, corticosteroids. Botulinum toxin A intramural injections (into the bladder wall) are still experimental but may be helpful for some patients.

- bladder hydrodistension, used as a diagnostic technique, but also as a therapy in selected patients.

- neuromodulation/electrostimulation works by reconditioning the nerves that control bladder function. It can help prevent unwanted contractions of the bladder and restore normal function.

- laser, electrocoagulation or resection, used for patients with the Hunner's ulcer (lesion, patch) subtype to seal bleeding patches or cracks or remove lesions.

- surgery, as a last resort option.

- pain clinic referral, particularly when strong opioid treatment is needed.

- lifestyle modifications

IC patients often feel more comfortable in loose clothing and especially cotton underwear not synthetic. No perfumed products should be used near the urogenital area, no perfumed soap, no bubble bath, no feminine hygiene products. They should also take care about the type of washing agent they use for their underwear

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since washing agents and fabric softeners containing perfume and harsh chemicals can cause irritation. Patients should also pay attention to hygiene to avoid infection. Women should wipe from front to back, change sanitary towels, tampons or panty liners frequently. In order to limit the need to urinate during the night, it is advisable to restrict drinking for about 4 hours before going to bed. The same applies to going on a journey. However, if you restrict your drinking at certain times, make sure you drink sufficiently at some other time of the day. Too little fluid intake can cause urine concentration and more pain in some patients. Since constipation can exacerbate symptoms by causing pressure in the pelvic floor, it is essential to ensure that the diet contains sufficient fibre, in addition to drinking enough fluid and taking adequate exercise in some form.

- stress reduction

Patients soon learn that the symptoms of IC can be exacerbated by physical or emotional stress. They consequently need to learn to pace themselves and try to avoid situations which make them physically or emotionally exhausted. Relaxation of any kind can help in reducing stress, including yoga, Tai Chi, meditation, breathing exercises (slow diaphragmatic breathing), regular exercise, walking (even short distances), swimming, warm baths, hydrotherapy, guided imagery. However, in order to achieve optimum results from relaxation therapy, every endeavour should be made to bring the symptoms – and particularly the pain aspect – under control through medical therapy.

Impact on life

IC can have a major impact on the social, psychological, occupational, domestic, physical and sexual life of the patient and affect a patient's quality of life and the structure of their life. The frequent need to urinate can form an obstacle to work, travel, visiting friends, or simply going shopping. When outside their home, the IC patient's life is dominated by the question "where am I going to find the next toilet?" Before every outing, the patient will carefully plan a network of toilets. This kind of situation can make a patient afraid to leave the safety of their home and thereby become isolated from the world around them. The frequent need to urinate may make it difficult for some patients to carry on working or they may be forced to change to a different type of job where they do have the possibility of frequent access to toilets. Work in some jobs becomes impossible when you have to keep running to the toilet. It is nevertheless important to try and maintain as normal a lifestyle as possible and to try to develop new interests to replace activities you are no longer able to undertake. IC makes patients feel that they have lost control over their life. The aim should be to regain some feeling of being in control again.

IC and related disorders

Surveys and studies have indicated that some IC patients also suffer from one or more non-bladder disorders including gastrointestinal disorders (irritable bowel syndrome or inflammatory bowel disease), chronic fatigue, pain in joints and muscles, vulvodynia, endometriosis, fibromyalgia, allergies/hypersensitivities (including medicine intolerance). IC is associated more frequently than normal with Sjögren's syndrome, systemic lupus erythematosus, rheumatoid arthritis and thyroid disorders.

Further information:

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The IPBF is a non-profit voluntary umbrella organization active worldwide that promotes knowledge and awareness of interstitial cystitis, painful bladder syndrome/bladder pain syndrome and associated disorders among patients, patient support groups, health professionals and the general public worldwide. The IPBF promotes the interests of IC patients around the globe

The IPBF is a non-profit voluntary foundation with fiscal charitable status registered at the Chamber of Commerce Rotterdam, Netherlands under number: 24382693.

The IPBF does not engage in the practice of medicine. It is not a medical authority nor does it claim to have medical knowledge. The IPBF advises patients to consult their own physician before undergoing any course of treatment or medication.

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