IPBF

Interstitial Cystitis/Bladder Pain Syndrome, Hypersensitive Bladder, Hunner Lesion

What is it?
How is it diagnosed?
How is it treated?
How do you cope with it?

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- **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/bladder pain syndrome…?**

Interstitial cystitis/bladder pain syndrome (IC/BPS), also known as painful bladder syndrome (PBS) and hypersensitive bladder (HSB), is a chronic urinary bladder disorder, with or without Hunner lesions (formerly known as Hunner's ulcers), with symptoms of pain, irritation, pressure or discomfort related to the bladder and usually accompanied by a frequent and often urgent need to urinate day and night. Although the symptoms may resemble bacterial cystitis, there is no infection to be seen in the urine. While cystoscopy may reveal Hunner lesion to be present in some patients, in others no identifiable disorder can be seen to account for the symptoms.
Since there are a number of other disorders that can cause similar symptoms (confusable diseases), it is important for these to be ruled out. Referral to a urologist or urogynaecologist is necessary.

Symptoms:

The typical symptoms are **pain or pressure or discomfort, an urgent need to urinate (urgency) and a frequent need to urinate (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/BPS in many patients. Women may feel a worsening of the symptoms around the time of menstruation.

- pain:

The pain of IC/BPS usually increases as the bladder fills and is temporarily relieved when the bladder is emptied. The pain may be experienced as discomfort or tenderness, or a burning sensation in the bladder, or stabbing pain or spasms in or around the bladder, or stabbing pain. It may also be felt throughout the pelvic floor, including the lower bowel system, or 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 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.

- sexual pain

Both men and women may experience pain during sexual intercourse (dyspareunia).

- urinary urgency:

Urinary urgency in IC/BPS is an urgent or compelling overwhelming need to find a toilet due to increasing pain or discomfort that becomes impossible to tolerate any longer, accompanied by an increasing feeling of stress.

- 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/BPS with a shrunken bladder which has a scarred stiff wall, a small capacity under anaesthesia and lesions (known as Hunner lesion disease), IC/BPS patients with a normal-sized bladder may also have equally severe frequency and pass small amounts of urine at a time.

How does it start?
The symptoms may begin spontaneously for no apparent reason, or sometimes following an operation such as hysterectomy or other gynaecological or pelvic 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 a number of years.

What causes it?
Despite considerable research into many different aspects of IC/BPS, 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 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/BPS. Patients can rest assured that IC/BPS 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/BPS patients are men who may in the past have been incorrectly diagnosed as having non-bacterial prostatitis. IC/BPS is also found in children and adolescents. 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 due to lack of awareness.

Is there a cure?
So far there is no cure for IC/BPS. Treatment is therefore currently aimed at alleviating symptoms and improving quality of life.

Diagnosis
Since there are still no diagnostic tests specifically for IC/BPS, 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.
Hunner lesion is diagnosed by cystoscopy with hydrodistension. It is particularly important to know if lesions are present since these are treated differently to the non-lesion conditions.

- 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, including ketamine abuse), 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/BPS as well. A patient may have one or more of these other disorders in addition to IC/BPS.

- cystoscopy
Cystoscopy with hydrodistension (distending the bladder with water beyond its normal capacity, sometimes distension with balloon inflation) under general or regional anaesthetic is an investigation used to take a close look at the inside of the bladder. Following hydrodistension, pinpoint bleedings (glomerulations) may be visible in some patients. However, once considered a hallmark of IC/BPS, it is now known that these are not seen in all patients, are not specific to IC/BPS and cannot be considered diagnostic. In some patients, so-called Hunner lesions (formerly known as Hunner's ulcers) may be visible following hydrodistension. This is the so-called "Classic IC". 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. The biopsy can be useful to exclude the possibility of other causes of the symptoms. The biopsy can also further confirm Hunner lesion.

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

- 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 standard medication exists that is equally effective in all IC/BPS patients. Treatment is highly individual and has to be tailored to each patient and to the severity of the different symptoms, also taking into account any associated disorders (comorbidities). Every patient is different.

Treatment may include:
Dietary changes, behavioural modification, stress reduction, myofascial therapy, oral drugs, bladder instillations or injections, bladder distension, neuromodulation/electrostimulation, and various other forms of surgery including diversion with/without cystectomy. Patients with severe pain that does not respond to treatment may need referral to a pain consultant. Hunner lesions can be successfully treated surgically with laser, electrocoagulation, or resection.

- diet
Many patients will soon discover from their own experience that certain foods and beverages appear to worsen their bladder symptoms. While every patient is different, by eliminating items perceived to cause irritation based on their own experience, a patient can at least avoid unnecessary exacerbation of the bladder symptoms. Patients with milder IC/BPS may even find that changes in diet are the only treatment they need. Studies have shown that 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. Medicines and even food supplements (such as vitamin C) can also cause additional bladder irritation.

- **behavioural modification**

IC/BPS patients soon find that they often feel more comfortable in loose clothing and especially cotton underwear, not synthetic. No perfumed products should be used near the sensitive 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 since washing agents and fabric softeners containing perfume and harsh chemicals can cause irritation. Patients should also pay strict attention to hygiene to avoid infection. Women should wipe from front to back, and change sanitary pads, 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 if possible. The same applies to travel. However, if drinking is restricted at certain times, it is important to ensure sufficient fluid intake at some other time of the day. Too little fluid intake can cause urine concentration and more pain.

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/BPS 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.

- 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).

- intravesical/intramural treatment

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

- bladder hydrodistension, used as a diagnostic technique, but also as a therapy in selected patients. Distension is sometimes also performed with air inflation or balloon.

- 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 specifically for patients with Hunner lesion to seal bleeding patches or cracks or remove lesions. May need repeating from time to time.

- surgery, diversion with/without complete bladder removal (cystectomy) as a last resort option.

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

Impact on life

IC/BPS 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/BPS 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/BPS 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/BPS and associated disorders (comorbidities)

Surveys and studies have shown that some IC/BPS 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 and chemical intolerance). IC/BPS is associated more frequently than normal with Sjögren's syndrome, systemic lupus erythematosus, rheumatoid arthritis and thyroid disorders.
This means that a **multidisciplinary approach** is essential.

Further information:

International Painful Bladder Foundation (IPBF)
info@painful-bladder.org
Website: www.painful-bladder.org

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, hypersensitive bladder, chronic pelvic pain and associated disorders among patients, patient support groups, health professionals and the general public worldwide. The IPBF promotes the interests of IC/BPS patients around the globe
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Editorial address:
International Painful Bladder Foundation
Mahlerlaan 4
1411 HW Naarden,
The Netherlands
Tel/fax: +31-35-8879516
Email: ipbf@dds.nl

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