

FACT SHEET

INTERSTITIAL CYSTITIS/BLADDER PAIN SYNDROME (IC/BPS), HYPERSENSITIVE BLADDER (HSB), HUNNER LESION (HL).

What is it?

Chronic pain, pressure or discomfort in the urinary bladder, associated with lower urinary tract symptoms such as an urgent need to urinate (painful urgency), a frequent need to urinate (frequency) day and night, in the absence of infection or other identifiable causes.

Who gets it?

Mainly women (approx. 80-90%), men (approx. 10-20% but may be higher), but it can also affect children and adolescents. Found in all countries and all races. Prevalence is still unclear.

Symptoms:

Symptoms can vary from mild to extremely debilitating and include pain, burning, stabbing, pressure, discomfort or other unpleasant sensation in and around the bladder. Typically in many patients this may increase as the bladder fills and be at least partly alleviated when the bladder is emptied. Pain may be suprapubic, pelvic, in the lower back, groin or thighs; in women in the vagina and vulva, in men in the penis, testicles, scrotum and perineum; both male and females may have pain in the urethra and rectum. Pain during sexual intercourse may be experienced by both men and women. Typical symptoms are frequent urination day and night and an urgent need to urinate due to overwhelming increasing pain, pressure, discomfort or other unpleasant sensation. Spontaneous flares and remission of symptoms form a characteristic feature in many patients.

Associated disorders:

In some patients, IC/BPS may be accompanied by one or more other disorders, for example: allergy/hypersensitivity, drug/chemical intolerance, irritable bowel syndrome, vulvodynia, fibromyalgia, chronic fatigue syndrome, systemic autoimmune diseases such as Sjögren's syndrome, systemic lupus erythematosus and rheumatoid arthritis. This means that a multidisciplinary approach is essential.

Cause:

Despite much research and many different theories, the cause is still unknown. While the symptoms may be exacerbated by stress or overexertion, IC/BPS is not a psychosomatic disorder.

Diagnosis:

After checking for urine infection (stix + culture), pelvic cancer (vaginal and rectal exam), scars or lower back deformities, the primary care physician should refer patients with symptoms suggestive of IC/BPS to a urologist or urogynaecologist, preferably one with experience in this field, for further evaluation. Since there is as yet no specific test that can diagnose IC/BPS, diagnosis is primarily based on symptoms + exclusion with investigations aimed at ruling out other identifiable disorders which could be the cause of the symptoms, including damage or injury elsewhere in the pelvic floor. Cystoscopy with hydrodistension will reveal whether Hunner lesion (formerly known as Hunner's ulcer) is present. Hunner lesion disease occurs in some 10-50% of the patients and requires a different treatment approach to the non-lesion type. Investigations for IC/BPS vary from country to country but may include a detailed medical history, physical examination, urinalysis, urine culture, cytology if indicated, ultrasound & imaging, urodynamics if indicated, cystoscopy, hydrodistension under anaesthesia, biopsy.

Treatment:

Since at the present time no cure is available for this disease, treatment is aimed at alleviating the symptoms. Treatment is highly individual and no medication exists that is equally effective in all IC/BPS patients. While many different treatments are used for IC/BPS, few are evidence-based, many are used off-label and some are experimental. Certain treatments are reserved for Hunner lesion disease and can be very effective. Non-reimbursement can present a problems in many countries.

Treatment may include dietary and behavioural modification, stress reduction, physical therapy, oral drugs, intravesical instillations or injections, hydrodistension, neuromodulation/electrical stimulation, laser/electrocoagulation/resection (for Hunner lesion), and as a last resort surgical diversion with/without cystectomy. Patients with severe, intractable pain may need referral to a pain specialist for pain management. Complementary and alternative management therapies include biofeedback, hypnotherapy, trigger-point therapy, myofascial pain therapy, pelvic floor re-education, acupuncture, herbal supplements.

DIET MODIFICATION
The effect of food items on the IC bladder is highly individual but foods best avoided include:
Food/drink containing caffeine
Citrus fruit and juices
Other acidic food such as tomatoes, vinegar etc.
Artificial sweeteners
Alcoholic drinks
Carbonated drinks/soda
Highly spiced food

Impact on patient:

IC/BPS can have a major impact on the social, psychological, occupational, domestic, physical and sexual life of the patient and greatly affect quality of 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?” This kind of situation can make a patient afraid to leave the safety of their home. IC/BPS can have a big impact on sexual relationships since sexual intercourse may be painful and sometimes impossible for both male and female patients. Some patients will find it easier to cope with their IC/BPS than others, and the support or lack of it from their home environment may play a significant role in the ability to cope. IC/BPS patients also need a great deal of time, understanding, empathy and support from their doctor. The impact of IC/BPS, including sleep deprivation, can make patients feel tired, stressed, anxious, helpless and depressed. The health provider’s role in providing empathy, understanding and emotional support for these patients should not be underestimated.

Patient support groups

Patient support groups play an important role not only in providing information but also emotional support. Patient-to-patient counselling is invaluable since only another patient truly understands what IC/BPS is actually like, but in some cases professional counselling is essential such as in the case of suicidal patients.

Useful websites:

IPBF: www.painful-bladder.org

Contact and further information: info@painful-bladder.org

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