

## **FACT SHEET**

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

**What is it?**

Chronic pain, pressure or discomfort perceived to be related to the urinary bladder, associated with lower urinary tract symptoms such as an urgent need to urinate (urgency), a frequent need to urinate (frequency) and with/without Hunner lesions, 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 very disabling and include pain, irritation, pressure or discomfort in and around the bladder. 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, in men in the penis, testicles, scrotum and perineum; both male and females may have pain in the urethra and rectum. Sexual pain may be experienced by both men and women. Typical symptoms are frequent urination day and night and/or an urgent need to void due to increasing pain, discomfort or irritation. 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, stress is not a cause of IC/BPS which 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. Cystoscopy with hydrodistension will reveal whether Hunner lesion (formerly known as Hunner's ulcer) is present. Often described as "Classic IC", this subtype occurs in some 10-50% of the patients and requires a different treatment approach to the non-lesion painful or hypersensitive bladder. Investigations for IC/BPS vary from country to country but may include: detailed medical history, physical examination, urinalysis, urine culture, cytology if indicated, ultrasound & imaging, urodynamics if indicated, cystoscopy, hydrodistension (under general 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 the Hunner lesion subtype and can be very effective.

Treatment may include: dietary and behavioural modification, stress reduction, physical therapy, oral drugs, intravesical instillations or injections, hydrodistension, air or balloon inflation, neuromodulation / electrical stimulation, laser/electrocoagulation/resection (for Hunner lesion), and as a very last resort surgical diversion with/without cystectomy. Patients with severe, intractable pain may need referral to a pain specialist for pain management.

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	

Complementary and alternative management therapies include: biofeedback, hypnotherapy, trigger-point therapy, myofascial pain therapy, pelvic floor re-education, acupuncture, herbal supplements.

**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 this ability to cope. IC/BPS patients also need a great deal of time and support from their doctor. The impact of IC/BPS, including sleep deprivation, can make patients feel tired, 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.

**Useful websites:**

- IPBF: [www.painful-bladder.org](http://www.painful-bladder.org)
- IPBF brochure: [http://www.painful-bladder.org/pdf/Diagnosis&Treatment\\_IPBF.pdf](http://www.painful-bladder.org/pdf/Diagnosis&Treatment_IPBF.pdf)
- NIDDK: <http://kidney.niddk.nih.gov/kudiseases/pubs/interstitialcystitis/>
- ESSIC: [www.essic.eu](http://www.essic.eu)

**Contact and further information:** [info@painful-bladder.org](mailto:info@painful-bladder.org)

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