

## **INTERSTITIAL CYSTITIS: PRIMARY CARE FACT SHEET**

*Also known as Painful Bladder Syndrome (PBS), Bladder Pain Syndrome (BPS), Hypersensitive Bladder Syndrome (HBS).*

### **Interstitial cystitis (IC): What is it?**

Chronic pain, pressure or discomfort perceived to be related to the urinary bladder, associated with lower urinary tract symptoms such as urgency and frequency, in the absence of infection or other identifiable causes.

### **Who gets IC?**

IC mainly occurs in women (80-90%), but also in men (10-20%) and children. IC is found in all countries and all races. The prevalence of IC is still unclear.

### **Symptoms:**

Symptoms can vary from mild to very disabling and include pain or irritation, pressure, discomfort or a sense of fullness in the bladder. This may increase as the bladder fills and be at least partly alleviated when the bladder is emptied. The 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. Both men and women may have pain with sexual intercourse. Frequency (day and night) and/or urgency due to increasing pain/discomfort are also typical. Spontaneous flares and remission of symptoms are a characteristic feature of interstitial cystitis in many patients. Approximately 5-10% of patients may develop the Hunner's ulcer variant (now known as Hunner's lesion) with inflammatory lesions in the bladder wall.

### **Associated disorders:**

In some patients, IC may be accompanied by one or more other disorders: such as: allergy (sometimes multiple allergies and medicine intolerance), other chronic pain syndromes such as irritable bowel syndrome, vulvodynia and fibromyalgia, systemic autoimmune diseases such as Sjögren's syndrome, systemic lupus erythematosus and rheumatoid arthritis. Chronic fatigue, migraine, muscle and joint pain also occur in some IC patients.

### **Cause:**

Despite much research and many different theories, the cause is still unknown and the disease remains as enigmatic as ever. Theories include changes in the bladder surface causing leakage of toxic elements in the urine through to the underlying layers, upregulation of nerves both centrally and peripherally, autoimmunity, allergy, an increase in mast cell activity, occult infection and many more. Therapeutic options are often based on these different theories. While the symptoms may be exacerbated by stress or over-exertion, stress is not a cause of IC and IC is not a psychosomatic disorder.

### **Referral and Investigations:**

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 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, 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 (stretching the bladder) will reveal whether Hunner's lesion is present. This variant requires a different therapeutic approach to non-lesion variants. Investigations for IC vary from country to country but may include: medical history, physical examination, urinalysis, urine culture, cytology if indicated, ultrasound & imaging, urodynamics if indicated, cystoscopy with/without hydrodistension (under general anaesthesia), biopsy.

### **Treatment:**

Although no cure for IC exists, therapeutic options are aimed at alleviating the symptoms and improving quality of life for the patient. Treatment is highly individual and is a question of finding a

treatment that suits an individual patient. While many different treatments are used for IC, few are evidence-based, many are used off-label and some are experimental. Certain treatments are reserved for the Hunner's lesion variant.

Treatment aimed at alleviating the symptoms of pain, urgency and frequency may include: dietary and lifestyle changes, stress management, coping strategies, oral drugs, intravesical instillations or injections, hydrodistension (under anaesthesia), neuromodulation / electrical stimulation, laser / fulguration therapy (for Hunner's lesion) and combinations of the above. Patients with severe, intractable pain may need referral to a pain specialist for pain management. In a small number of patients, urinary diversion with or without cystectomy may be necessary as a last resort.

Complementary therapies include: biofeedback, hypnotherapy, trigger-point therapy, myofascial pain therapy, pelvic floor re-education, acupuncture, herbal supplements, yoga, Tai Chi, guided imagery. These can sometimes help the pain through relaxation of body and mind.

**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 can have a major impact on the social, psychological, occupational, domestic, physical and sexual life of the patient and greatly affect quality of life and the structure of the structure of the patient's 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?" This kind of situation can make a patient afraid to leave the safety of their home. IC 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 than others. And the support or lack of it from their home environment may play a significant role in this ability to cope. IC patients need a great deal of time and support from their doctor. The impact of IC, including sleep deprivation, can make patients feel tired, anxious, helpless and depressed. The doctor's role in providing 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 is actually like, but in some cases professional counselling is essential, for example in the case of suicidal patients.

### **Useful sources of information:**

International Painful Bladder Foundation (IPBF): [www.painful-bladder.org](http://www.painful-bladder.org)  
IPBF 37-page brochure "Interstitial Cystitis: Diagnosis & Treatment": [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/>  
European Society for the Study of IC/PBS (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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