

## 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?**

Mainly women (80-90%), men (10-20%) and children. Found in all countries and all races. Prevalence 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. There may be dyspareunia in both men and women. Frequency day and night and/or an urgency due to increasing pain/discomfort. Spontaneous flares and remission of symptoms are a characteristic feature of interstitial cystitis in many patients.

### **Associated disorders:**

In some patients, IC may be accompanied by one or more other disorders: such as: allergy/hypersensitivity (including drug 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.

### **Cause:**

Despite much research and many different theories, the cause is still unknown and the disease remains as enigmatic as ever. While the symptoms may be exacerbated by stress or over-exertion, stress is not a cause of IC 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 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 will reveal whether Hunner's ulcer (lesion) is present. This "Classic IC" variant requires a different therapeutic approach to the non-ulcer variant. 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, hydrodistension (under general anaesthesia), biopsy.

### **Treatment:**

No possibility has as yet been found of curing this disease, merely of alleviating the symptoms. Treatment is highly individual and no medication exists that is equally effective in all IC patients. 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 ulcer variant.

Treatment may include: dietary and lifestyle modification, stress management, oral drugs, intravesical instillations or injections, hydrodistension, neuromodulation / electrical stimulation, laser/electrocoagulation/resection (Hunner's ulcer/lesion), and as a very last resort surgery with 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 therapies include: biofeedback, hypnotherapy, trigger-point therapy, myofascial pain therapy, pelvic floor re-education, acupuncture, herbal supplements.

#### 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 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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