Painful Bladder Syndrome/Interstitial Cystitis

Painful bladder syndrome (PBS) is a chronic, painful condition of the bladder of unknown origin. Although the symptoms may initially resemble a bladder infection, a urine culture is negative.

Interstitial cystitis (IC) is a painful bladder syndrome with inflammatory changes in the bladder. Further specification of these changes awaits more research, but includes cystoscopic findings (e.g. glomerulations, Hunner’s ulcer) and biopsy results (e.g. increased number of mast cells).

PBS/IC is found in all countries around the world, in all races and all age groups.

The characteristic symptoms are:
- Pain that increases as the bladder fills; voiding usually alleviates the pain and gives a sense of relief; lower abdominal (pelvic) pain, sometimes extending to the lower part of the back; pain may also be felt in the groin and thighs. In women, pain in the vagina. In men, pain in the penis, testicles, scrotum and perineum. Both sexes may have pain in the urethra.
- Pain with sexual activity.
- A constant, intense need to urinate.
- Frequent urination, including at night.

The pain may be experienced as a burning sensation in the bladder, in the form of spasms in or around the bladder, or stabbing vaginal pain, or a feeling of pressure on the bladder. It may be constant or intermittent. Pain may also spread throughout the pelvic floor and into the lower back.

The symptoms may begin spontaneously for no apparent reason at all, sometimes following an operation, particularly - in the case of women - after a hysterectomy or other gynaecological surgery, after childbirth or following a severe bacterial infection of the bladder.

It is a bladder condition that is mainly found in women (90%). Approximately 10% of PBS/IC patients are men who may in the past have been incorrectly diagnosed as having non-bacterial prostatitis (inflammation of the prostate gland) or prostatodynia (pain in the prostate gland).

Spontaneous flares and remission of symptoms are a characteristic feature of interstitial cystitis. Many women find that their symptoms are exacerbated just before menstruation and during the menopause.

Sexual intercourse may be painful for both male and female patients and for some even impossible.

Many patients experience exacerbation of their PBS/IC symptoms due to stress of either an emotional or physical nature. But it is important to emphasize that there is no evidence that stress is a cause of PBS/IC.

The constant need to urinate can form a major obstacle to work, travel, visiting friends, or simply going shopping. When outside the confines of the home, the PBS/IC patient's life is dominated by the question ‘where am I going to find the next toilet?’

Despite considerable research into many different aspects of PBS/IC, the cause is still unknown. It is gradually becoming accepted that PBS/IC may not have one single cause, but may in fact be a multi-factorial syndrome characterized by an inflammatory response of the bladder wall that could be based on a number of different factors such as allergic, immunological, neuro-vascular, bacterial or viral infection and even environmental factors. There are many different theories, but no answers have as yet been found.

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 PBS/IC patients.

Treatment may consist of oral drugs, bladder instillations, bladder distension, neuro/electro-stimulation, laser therapy or various forms of surgery.

In some patients, PBS/IC may be associated with pain in joints and muscles, fatigue, gastrointestinal disorders, fibromyalgia, allergies and medicine intolerance. PBS/IC occurs more frequently than normal in association with rheumatoid arthritis, systemic lupus erythematosus (SLE), Sjögren’s syndrome, and thyroid disorders.
The International Painful Bladder Foundation does not engage in the practice of medicine. It is not a medical authority nor does it claim to have medical knowledge. The IPBF advises patients to consult their own physician before undergoing any course of treatment or medication.

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