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# Interstitial cystitis/painful bladder syndrome

*Synonyms: bladder pain syndrome, hypersensitive bladder syndrome, trigonitis*

Painful bladder syndrome (PBS) is a chronic condition of unknown cause. The common symptoms include urinary urgency, frequency, nocturia and suprapubic or pelvic pain without any known aetiological factor. The term 'interstitial cystitis' is usually reserved for patients with typical cystoscopic features.

PBS is the occurrence of persistent or recurrent pain perceived in the urinary bladder region, accompanied by at least one other symptom, such as pain worsening with bladder filling and daytime and/or night-time urinary frequency. There is no proven infection or other obvious local pathology. It is often associated with negative cognitive, behavioural, sexual or emotional consequences, as well as with symptoms suggestive of lower urinary tract and sexual dysfunction.

The American Urological Association, European Association of Urology and International Consultation on Incontinence have published symptom-based diagnostic criteria for PBS. All include the symptoms of pain related to the bladder, at least one other urinary symptom, absence of identifiable causes and minimum duration of symptoms of six weeks to six months <sup>[1]</sup>.

## Epidemiology

- PBS is a diagnosis of exclusion with no definitive diagnostic test. Therefore it is difficult to estimate prevalence, which can be dependent on whether symptoms are clinician-assigned or patient-reported. A large American study found prevalence rates of 2.3–6.5% <sup>[1]</sup>.

- PBS is between two and five times more common in women than men. However, many women are often reluctant to seek treatment<sup>[2]</sup> .
- The average age at diagnosis is 40 years<sup>[3]</sup> .
- This condition can occur in any age, including childhood.

## Aetiology

- This condition has a multi-factorial aetiology including epithelial dysfunction, subclinical infection, mast cell and vascular abnormalities, neurogenic inflammation, autoimmune phenomena and up-regulation of sensory nerves in the bladder<sup>[4]</sup> .
- It is thought that there is injury or dysfunction of the glycosaminoglycan layer that covers the urothelium. This injury can be caused by bacterial cystitis, childbirth, pelvic surgery or urological instrumentation.
- These factors provoke sensory nerve activation, neurogenic inflammation, pain and fibrosis<sup>[5]</sup> .
- Changes in the somatosensory grey matter occur which may have an important role in pain sensitivity as well as affective and sensory aspects of interstitial cystitis (IC)<sup>[6]</sup> .

## Presentation

Symptoms vary widely in severity and nature but the onset of symptoms is often acute and may be sudden.

- Recurrent symptoms similar to urinary tract infections (urgency, frequency, dysuria), lower abdominal pain, pressure in the bladder and/or pelvis, and dyspareunia.

- Characteristics of the pain include:
  - Pain, pressure or discomfort perceived to be related to the bladder, increasing with increasing bladder content.
  - Located suprapubically, sometimes radiating to the groins, vagina, rectum or sacrum.
  - Relieved by voiding but soon returns.
  - Aggravated by food or drink.
- In women the symptoms are often worse during menstruation.
- There is wide variation in symptoms between individuals and in any one individual over time.
- Examination may be normal apart from suprapubic tenderness.
- The severity of the symptoms often bears little correlation with the clinical findings.
- Trials of antibiotic treatment do not cure the condition.

## Associated disorders

- An association has been reported between PBS and non-bladder syndromes such as [fibromyalgia](#), [chronic fatigue syndrome](#), [irritable bowel syndrome](#), [vulvodynia](#), [depression](#), [panic disorders](#), [migraine](#), [sicca syndrome](#), [temporomandibular joint disorder](#), [asthma](#) and [systemic lupus erythematosus](#)<sup>[7]</sup> .

## Differential diagnosis

Other causes of urinary frequency, urgency of micturition and pelvic pain, including:

- Infection or other inflammatory conditions – eg, [recurrent urinary tract infection](#), urethral diverticulum, infected [Bartholin's gland](#), [tuberculous](#), [bacterial or viral vaginosis](#), [schistosomiasis](#).

- Gynaecological – eg, pelvic malignancy, [uterine fibroids](#), [endometriosis](#), mittelschmerz (ovulation pain), [pelvic inflammatory disease](#), genital atrophy, [overactive bladder](#).
- Urological – eg, [bladder cancer](#), radiation cystitis, overflow incontinence, [chronic pelvic pain syndrome](#), bladder outlet obstruction, [urolithiasis](#), [urethritis](#), [chronic prostatitis](#), [prostate cancer](#).
- Neurological – eg, [detrusor overactivity](#), [Parkinson's disease](#), lumbosacral disc disease, [spinal stenosis](#), [spinal tumour](#), [multiple sclerosis](#), cerebrovascular disease.
- Others include [irritable bowel syndrome](#), gastrointestinal neoplasm, [diverticulitis](#) and adhesions from previous surgery.

## Investigations

The diagnosis and management of this syndrome may be difficult in some patients<sup>[5]</sup>. The diagnosis of IC/PBS is usually based on a thorough assessment and exclusion of other causes.

A bladder diary (frequency volume chart) should be completed. A food diary may also be useful, to identify if specific foods cause a flare-up of symptoms. A bladder diary (frequency volume chart) should be completed. A food diary may also be useful, to identify if specific foods cause a flare-up of symptoms<sup>[1]</sup>.

- Urinalysis and midstream urine for urine cultures: rule out urinary tract infection, including tuberculosis.
- Cervical swabs for herpes and chlamydia.
- Urodynamic studies: there are no specific findings but pain with bladder filling that reproduces the symptoms is very supportive of a diagnosis of IC/PBS.
- Most cases need cystoscopy to exclude bladder cancer. Hunner's ulcers (reddened mucosal areas often associated with small vessels radiating towards a central scar, sometimes covered by a small clot or fibrin deposit) may be seen in 10–50%.
- Men should have urethral swabs and prostatic secretion cultures (for chronic prostatitis).

- Investigations such as cystoscopy, hydro-distension and biopsy are often used for diagnosing IC/PBS in paediatric patients, as eliciting clinical symptoms can be difficult and unreliable<sup>[8]</sup> .

## Management

There are few clinical urogynaecological conditions that cause greater frustration than IC/PBS. This is due to its chronicity, serious impairment of quality of life, diagnostic difficulties and unsatisfactory treatment<sup>[5]</sup> . Management is often difficult and only partially effective. Early diagnosis, support and management are very important.

- A comprehensive assessment of patients is required to identify treatment options that are tailored to the needs of individual patients<sup>[9]</sup> .
- Multimodal behavioural, physical and psychological techniques should always be considered alongside oral or invasive treatments of IC/PBS<sup>[7]</sup> .
- Treatment is mainly symptomatic and supportive.
- This condition usually warrants a multidisciplinary approach for optimum outcome.
- The following are important to consider regarding managing these patients<sup>[10]</sup> :
  - Self-awareness of the condition.
  - Immediate urine culture test.
  - Specifying the location of pain.
  - The type of urinary incontinence.
  - Helpful dietary control.
  - Complementary and alternative medicine may be considered.
  - Finding an expert early is ideal but not always possible.

Initial conservative management includes<sup>[1]</sup> :

- Dietary modification can be beneficial and avoidance of caffeine, alcohol, and acidic foods and drinks should be considered.

- Stress management may be recommended and regular exercise can be beneficial.
- Analgesia for pelvic or bladder pain.

## **Non-drug**

- Behavioural therapy: biofeedback, pelvic floor exercises and bladder training programmes may be effective.
- Diet: certain foods and drinks such as alcohol, tomatoes, spices, chocolate, caffeinated and citrus drinks and acidic foods may contribute to bladder irritation and inflammation. Many patients find benefit in keeping a food diary to try to assess which foods exacerbate and worsen their symptoms.
- Some people report a reduction in symptoms following distension of the bladder during diagnostic cystoscopy. There is belief that distending the bladder causes the nerve cells to be stretched and thus less sensitive for a time.
- Transcutaneous electrical nerve stimulation (TENS) can help in conjunction with other therapies.

## **Drugs** <sup>[7]</sup>

### **Oral medications**

- Analgesics should be used preferably in collaboration with a pain clinic.
- There is no good evidence for corticosteroids, duloxetine or prostaglandins and they are not recommended for long-term treatment.
- Oral amitriptyline or cimetidine may be considered when initial conservative treatments have failed. Cimetidine is not licensed to treat PBS and should only be commenced by a specialist <sup>[1]</sup> .

- Oral pentosan-polysulfate sodium is recommended by the National Institute for Health and Care Excellence (NICE) as an option for treating bladder pain syndrome with glomerulations or Hunner's lesions in adults with urinary urgency and frequency, and moderate to severe pain, only if<sup>[11]</sup> :
  - Their condition has not responded to an adequate trial of standard oral treatments.
  - It is not offered in combination with bladder instillations.
  - Any previous treatment with bladder instillations was not stopped because of lack of response.
  - It is used in secondary care.
- Oxybutynin or gabapentin might be considered for some patients.
- Oral treatment with ciclosporin has been shown to be a beneficial therapeutic strategy for some patients with PBS<sup>[3]</sup> . However, adverse effects are significant and should be carefully considered.

### **Intravesical drugs**

- It is recommended that intravesical lidocaine can be administered prior to more invasive methods. Intravesical heparin is also sometimes used.
- Intravesical hyaluronic acid or intravesical chondroitin sulfate is also sometimes used and can be considered before more invasive measures<sup>[12]</sup> .
- Intravesical injection of botulinum toxin A may be effective, but not for all patients<sup>[1]</sup> <sup>[9]</sup> .
- However, intravesical therapy with BCG is not recommended, nor is intravesical therapy with Clorpactin®.
- Bladder distension is also not recommended as a treatment.

### **Surgical**

All ablative organ surgery should be the last resort for experienced and knowledgeable surgeons only<sup>[7]</sup> .

Major surgery (subtotal cystectomy and bladder augmentation or supravvesical urinary diversion with intact bladder) is associated with good symptom relief in strictly selected patients with disabling IC/PBS, where conservative treatment has failed<sup>[13]</sup> .

When all other treatment options fail to relieve disabling symptoms, surgical removal of the diseased bladder is the ultimate option, for which three major techniques are common: supratrigonal (trigone-sparing) cystectomy, subtrigonal cystectomy and radical cystectomy including excision of the urethra.

## Prognosis

- The prognosis is very variable. The condition can:
  - Have complete resolution of symptoms within months.
  - Follow a waxing and waning course.
  - Be completely asymptomatic with intermittent flares.
  - Follow a chronically progressive course of increasing symptoms over several years.
- Some people do recover spontaneously but individuals may have the condition for many years and there may be spontaneous resolution only to return days or months later.
- Short-term (up to one year) cure rates range from 50% to 75% for non-invasive or minimally invasive therapies but repeat administration of a therapeutic agent is required. Although definitive surgical intervention is associated with greater long-term cure rates ( $\geq 80\%$ ), significant short-term and long-term adverse effects occur more frequently<sup>[14]</sup> .
- IC/PBS can have a significant and even profound effect on self-esteem, sexual function and quality of life<sup>[2]</sup> .

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## Further reading

- [Suspected cancer: recognition and referral](#); NICE guideline (2015 - last updated October 2023)



- [Guidelines on Chronic Pelvic Pain](#); European Association of Urology (2020)

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