

Painful Bladder Syndrome

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What is Painful Bladder Syndrome?

Painful Bladder Syndrome (PBS) is a condition where the sufferer has a collection of symptoms that have been lasting for more than three months including:

- Pain – this can be in the bladder area (lower part of your tummy) or in the vagina.
- Urinary urgency and frequency – can occur just during the day or at night as well. Usually, women will have pain as their bladder fills so will need to empty it more often than non-PBS sufferers.
- Pain on sexual intercourse.
- Stinging or burning passing urine.

Over the years, PBS has had a range of names including Interstitial cystitis, Hypersensitive bladder and Hunner's lesion disease. It is also often mixed up in the diagnosis of recurrent UTI's because many of the symptoms overlap.

Pain symptoms in particular may fluctuate on a day-to-day basis with many women describing having "good and bad days".

Overall, we feel that PBS is much more descriptive of the actual symptoms women are suffering with.

What causes it?

We do not know the actual cause of PBS and it is often unique to each person as to what the contributory factors are. Some women can have it start after [childbirth](#), a bad [urine infection](#), [menopause](#), [surgery](#) and others it can start gradually over a period of time.

Whilst stress can worsen symptoms, there is no evidence currently that it is caused by stress. The impact of psychological wellbeing, however, is well known to be an important part of the treatment of any chronic medical condition, so whilst PBS is not a psycho-somatic condition, it is important to look at the person as a whole and treat their physical and mental wellbeing at the same time.

One theory is that the lining of the bladder, which has a protective layer called the "GAG layer", may be weak or not effective which can cause the bladder to be extra sensitive and prone to causing pain and infections.

How is it diagnosed?

PBS is diagnosed on a combination of history (what you tell us your symptoms are) and ruling out any other physical causes (such as cancers and bladder stones etc) There are two different types recognised – those with a “Hunner’s lesion” and those without. Other tests include:

- Urine specimens (to rule out infections).
- Cystoscopy and bladder biopsy – to look at the bladder and see if there are any Hunner’s lesions, signs of chronic infection or cystitis (which can be caused by chemicals, drugs such as ketamine, radiation).
- Kidney ultrasound examination.
- Vaginal swabs to rule out an infection.
- An anaesthetic challenge test – here some local anaesthetic is put into the bladder to see if it improves the pain. If the pain does improve, then it is likely to be a painful bladder, if not, then we need to look for another cause of the pain.
- Even if the results of the cystoscopy and biopsy are normal, this does not mean that you do not have PBS. Some women may show no abnormalities, while still having all the symptoms of PBS.

What can be done to treat it?

The mainstay of treatment is making the correct diagnosis, excluding any other cause for the pain and then treating the symptoms:

- Diet – sometimes women can be sensitive to particular food types, but it is important to know the common irritants, such as caffeine, citrus, tomatoes and artificial sweeteners (for example). Trying short exclusion diets with a bladder and pain diary can be helpful in determining which (if any) foods are making things worse.
- Self-help techniques – CBT and stress reduction all contribute to the overall management.
- Physiotherapy – RCOG guidance shows that physiotherapy has a good effect on the symptoms of PBS and should be used early in the treatment pathway.
- Avoiding the use of highly perfumed products.

- Careful choice of washing products (for clothes).
- Good fluid intake as per UTI guidance but avoiding fluids in the evening to reduce nocturia.
- Regular changing of sanitary pads/tampons, wiping front-to-back etc.
- Medication – some nerve-based painkillers (pregabalin or amitriptyline) can be of good benefit but can cause drowsiness.
- Bladder instillations – help to replace the bladders protective layer and reduce pain.
- Botox – helps to reduce the sensation of the bladder filling, relax the bladder muscle and allow more urine to be stored before needing to empty the bladder. 1 in 10 women will need to perform self-catheterisation after this.
- Neuromodulation – can be an alternative to Botox and aims to reset the nerves to reduce pain and allow the bladder to fill more easily.
- Larger operations – reserved for women who are fit enough to undergo such large and drastic surgery and who have exhausted all other options. These operations are only performed in a few centres countrywide so a referral will need to be made.

Pain specialists

For some women, none of the treatments are effective and they still suffer badly with pain. For these women, they will have tried most (if not all) of the treatments that can be offered specifically for bladder problems. In this instance they are better cared for by the chronic pain team as they have a better set-up to manage women holistically and look after their psychological wellbeing as well as physical.

Support organisations and information

The International Painful Bladder Foundation - www.painful-bladder.org


RCOG green top guidance - <https://www.rcog.org.uk/guidance/browse-all-guidance/green-top-guidelines/management-of-bladder-pain-syndrome-green-top-guideline-no-70/>

IUGA leaflets - <https://www.yourpelvicfloor.org/leaflets/>

BSUG Patient leaflets - <https://bsug.org.uk/pages/for-patients/bsug-patient-information-leaflets/154>

Useful contact numbers:

- **Urogynaecology Clinical Co-Ordinator**
Monday to Friday (excl. BH) - **0151 676 5619**
- **Day Surgery Unit St Helens Hospital (Sanderson Suite)**
8am-9pm Monday to Friday – **01744 64 6089**
- **Pre-assessment Clinic - 01744 64 6395**
9am-5pm Monday to Friday
- **Surgical Assessment Unit - 0151 430 1637**
after 9pm, weekends and bank holidays
- **Outpatients Department, St Helens Hospital**
9am-5pm Monday to Friday – **01744 64631 / 6300**
- **Main Switchboard – 0151 426 1600**



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