Vulval Pain Society

Bladder Pain Syndrome (BPS)

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What is bladder pain syndrome (BPS)?

BPS is a collective term that includes Interstitial Cystitis (IC) and Painful Bladder Syndrome (PBS). It is a chronic condition of the bladder and is the cause of pain in more than 30% of females with chronic pelvic pain. Men are ten times less likely to have BPS compared to females, but management principles are common to both genders.

BPS is defined as *'the complaint of suprapubic pain related to bladder filling, accompanied by other symptoms, such as an increased daytime and night-time frequency, in the absence of a proven urinary tract infection or other obvious pathology'.*

IC is defined the same as PBS whilst including *'typical cystoscopic and/or histological features'.*[1]

As a result, the pelvic floor muscles become hypertonic and results in voiding dysfunction. These patients may also have the following conditions at the same time: endometriosis, vulvodynia, fibromyalgia, irritable bowel syndrome, chronic fatigue syndrome etc. At any one moment one of these conditions will be predominant so a comprehensive but flexible approach is needed.

Where is bladder pain felt?

Patients with BPS get pain as the bladder fills and the pain/discomfort is felt in the lower abdomen, urethra or the perineal area.

What is the cause of BPS?

This remains elusive but possible causes include previous urinary tract infections, glycosaminoglycan (GAG) layer defects, previous pelvic surgery, increased hypersensitivity of the bladder nerves or increased mast cell activation releasing histamine.

Why is it so difficult to diagnose?

This is because the diagnosis is made once all other diseases are excluded. These include infection, systemic autoimmune disease, cancer, or a structural abnormality of the genitourinary tract. This is the reason why diagnosis of BPS is often delayed. Another issue is the mis(use) of antibiotics for suspected urinary tract infections (cystitis) resulting in a global problem of antibiotic-resistant bacteria. So, this is why antibiotic stewardship is vital. In most cases a simple dipstick testing of a urine sample is sufficient. In complex cases a midstream urine sample should be sent to the laboratory for microscopy and culture. Only if the urine specimen confirms the presence of disease-producing bacteria should a course of antibiotics that the bacteria are sensitive to be prescribed by the doctor.

What are the symptoms of BPS?

The commonest ones are urgency, frequency and suprapubic pain/discomfort. The pain is related to bladder filling and can involve other remote sites such as the urethra, vulva, vagina or rectum. The pain is often described as a feeling of 'pressure'.

What can trigger BPS?

The most common triggers are in foods and drinks. These include coffee, tea, fizzy drinks, beer, red and white wine, champagne, grapefruit, lemons, oranges, pineapple, tomatoes, hot peppers, spicy foods, horse radish, vinegar, monosodium glutamate and sugar substitutes.

What foods and drinks are less of a problem?

Not surprisingly water! The others include milk, bananas, blueberries, melons, pears, raisins, broccoli, Brussels sprouts, cabbage, carrots, cauliflower, celery, cucumber, mushrooms, horseradish, potatoes, chicken, eggs, turkey, beef, pork, lamb, shrimp, tuna, salmon, oats, rice and popcorn.

What happens when you are referred to a urology team?

A member of the team will take a full history, perform an examination, test your urine and may arrange for you to have further investigations depending on the individual case. The commonest are a bladder diary, urodynamics and cystoscopy. Common urodynamic findings in BPS include a feeling of urgency and a reduced bladder capacity (less than 350 ml). Cystoscopy allows a systematic inspection of the bladder and urethra to exclude other causes of bladder problems as discussed earlier.

How is BPS best managed?

It is best managed by adopting several different options that include behavioural, dietary, interventions, use of drugs and last of all surgery.

1. Conservative measures: These are the fundamental options that must be in place before contemplating surgery. These include patient education, identifying trigger factors and avoiding them. So, stick to foods and drinks that are not bothersome for you. Often this will mean following an elimination diet with advice from a dietitian. Another error is restricting your fluid intake. The body needs to pass a certain amount of urine to get rid of waste matter. If you fail to drink that amount, then your urine becomes more concentrated and acidic making bladder pain worse! So, try and keep the colour of urine straw-coloured especially during hot weather when it is easy to become dehydrated. Try and improve your sleep patterns, but don't rely on sleeping tablets as they give a chemically-induced sleep rather than a refreshing night's sleep. Often, we use low doses of amitriptyline taken early in the evening to improve sleep, reduce the need to get up at night to pass urine and reduce bladder pain. Regular exercise is important for the heart but don't forget your pelvic floor exercises to try and relax your muscles as opposed to tightening the pelvic floor muscles like after childbirth or when you have urinary incontinence. Avoid getting constipated; yet another reason for drinking adequate amounts of water every day. Remember that stress can impact on your bladder pain so adopting relaxing strategies or mindfulness can be helpful. Sexual health is also important; do not be afraid to raise sexual issues with a member of the team when you feel comfortable to do so no matter how embarrassing it may seem to you. Avoid wearing tights or tight-fitting clothes and use cotton or silk underwear.
2. Oral medications: There is a trend to avoid the long-term use of strong opioids (morphine, fentanyl). They can cause constipation, a reduction in your immunity and development of tolerance and increase the risk of dementia and infertility. A

short course of anti-inflammatories such as ibuprofen or naproxen may be indicated. More commonly co-analgesics may be prescribed and these need to be taken for several weeks and the dose titrated to response. These include antidepressants (amitriptyline, duloxetine) or anticonvulsants (gabapentin or pregabalin). Women on anticonvulsants must not get pregnant as these drugs can cause cleft palate in the offspring. In addition, these drugs must not be stopped abruptly as they can cause fits or withdrawal symptoms. The side-effects like sedation will dictate your own safety and that of others when driving. Other drugs that have shown benefit include pentosan polysulphate, H2-receptor antagonist (cimetidine) and antihistamine (hydroxyzine).

3. Intravesical therapy: For this treatment the bladder needs to be emptied by inserting a urinary catheter (unless there is one in place) and then a mixture of drugs is instilled and left in the bladder for a certain amount of time. The urinary catheter is removed immediately after the instillation. The bladder is then emptied by going to the toilet. These may have to be repeated and only done if the discomfort or urgency is improved. The drugs used vary from team to team. These include local anaesthetic, heparin, hyaluronic acid and chondroitin sulphate. The last three drugs are GAG-like drugs. The GAG layer is the innermost lining of the bladder wall. If bits of the GAG layer are lost the acid of the urine irritates the bladder nerves resulting in pain/discomfort. So, the GAG-like drugs 'repaint' the inner layer thus providing a barrier against the urine stimulating the bladder nerves.

4. Surgery: These measures are considered when the above have not been effective. They include the injection of Botox to the bladder muscles thus reducing the pain on bladder filling. Other procedures include hydrodistension, resection or diathermy of lesions found on cystoscopy, sacral neuromodulation, cystoplasty, urinary diversion or even cystectomy. Only your urologist can advise you which surgery is appropriate for your condition. You need to understand the benefits and risks of

anaesthesia and surgery in the short and long-term. As a rule, surgery can make pain worse, so every effort is taken to reduce your stress levels, adopting relaxation techniques and choosing the appropriate anaesthetic and pain techniques to reduce the risk of persistent post-operative pain.

Do complementary therapies work for BPS?

Bearing in mind that any treatment may work for some people for some of the time, complementary options that have been shown to be effective include acupuncture, relaxation techniques and especially physiotherapy targeting the pelvic floor muscles which become tense in BPS. So give these treatments a go, but don't try and do too many at a time otherwise it will become difficult to work out what works for you. Do be careful with treatments offered on the internet or in chat rooms as they may be harmful to you and often cost a lot of money. So, discuss this with a member of the urology team.

Where can I get reliable information on BPS from?

Your best bet is to ask a member of the urology team for advice. We have found the following sites to be useful:

- https://www.nhs.uk/.conditions/interstitial-cystitis
- https://www.painful-bladder.org

Is there a cure for BPS?

The symptoms may reduce over time but there is no single treatment that can cure BPS. This is why we emphasise the need for taking several different approaches to help your quality of life in terms of your physical, psychological, sexual, professional and social state.

What do I do if I am having a flare-up?

Ideally you and your urology team will have a plan on what you should do in case of a flare-up. This will depend on the treatments you are already on. It may mean an increase in a dose or frequency of a drug, reducing stress (which makes pain worse) by adopting psychological strategies such as meditation, mindfulness or even simple breathing exercises to relax and calm you.

What about sex, getting pregnant or reaching the menopause?

Just because you have BPS does not mean that you will be spared from life events such as sexual health, pregnancy or menopause. Each has to be considered on its own merit by discussion with a urology team member. It is unlikely that they have not had to deal with these problems with other patients. Sometimes a referral to psychosexual counselling or to Relate for marital problems may be needed.

So, what are our top 10 tips for patients with BPS?

1. Drink at least 2 litres of water a day
2. Avoid obvious triggers
3. Do not smoke
4. Keep your weight within normal limits
5. Use the bathroom every 3-4 hours and soon after intercourse
6. Take time to fully empty your bladder by adopting a relaxed position on the toilet seat
7. Wipe front to back after using the toilet
8. Wear loose-fitting clothes and cotton underwear
9. Exercise for cardiac reasons and practise your pelvic floor exercises regularly
10. Never give up or lose hope!

Finally, we would like to thank our patients with BPS who have shared their journey with us. We have learnt from each other and hope that their quality of life has improved as a result of this shared experience.

This article first appeared in a 2019 newsletter produced by UK charity Bladder Health UK and is reproduced here with their kind permission. For more information about bladder pain syndrome and other bladder problems, please visit the Bladder Health UK website at https://www.bladderhealthuk.org/.

Addendum

The following information is a new supplement to the article reproduced above.

There are three non-antibiotic products that have been used in bladder pain patients. Before you try any of them do check with your GP or specialist that they are appropriate for you.

1. Vitamin C: In doses of 0.5 g to 1.0 g per day orally
2. Methenamine hippurate: 1 g twice a day orally. It works by acidifying the urine and prevents bacteria from replicating (so it is bacteriostatic) but it is not a treatment for urinary tract infections. It is safe and effective in patients with recurrent urinary tract infections (by reducing the number of infections) and in those with long term indwelling bladder catheters.
3. D-mannose: The dose is 2 g a day orally for prophylaxis or 1 g three times a day for two weeks in the presence of a urinary tract infection. It works quickly and its mechanism of action is to prevent the *E. coli* (the commonest bacteria in urinary tract infections) from adhering to the bladder wall, so that they get washed out by the urine during bladder emptying. It is a simple sugar and can cause kidney damage, so diabetics and those with kidney problems should take further advice from their GP. Common side-effects are abdominal bloating, loose stools or diarrhoea.

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15 September 2021

References

1. Baranowski A, Fall M, Gajewski J, Nordling J, Nyberg L, Ratner V, Rosamilia A, Ueda T. Painful bladder syndrome (including interstitial cystitis). *Incontinence* 2005 Jun; 2:1457.