

## **BLADDER PAIN SYNDROME AND INTERSTITIAL CYSTITIS**

Bladder pain syndrome (BPS) is a chronic pain syndrome and usually is part of other pain syndromes including Persistent Pelvic Pain (PPP). Interstitial cystitis (IC) is a subgroup of BPS and is treated in the same way.

Our understanding of persistent pain has changed due to a better understanding of pain science. It is important for people with long term pain to understand that there is often no cure for persistent pain however there is much that the person themselves can do to understand and manage their pain.

### **Understand that long term pain does NOT mean damage to your body.**

To learn more about long term pain management throughout the body:

[tamethebeast.org.au](http://tamethebeast.org.au) has many excellent resources to help you learn how to manage pain.

Endless rounds of tests, presentations to the Emergency Department and multiple surgeries and specialists will not help your pain in the long term. Putting you back in control with simple measures is an important step to your health and wellbeing.

For many women, PPP begins with period pain that has worsened over time and developed other symptoms such as pain with sex, pain with bowel action or irritable bowel symptoms (bloating and tenderness), burning over the vulva area (vulvodynia) and other pelvic and back pain, headaches and migraine and is associated with generalised pain syndromes (chronic fatigue, fibromyalgia and Sjogren's syndrome).

Because the bladder, vagina and uterus, bowel and pelvic floor muscles are all very close together, it is difficult for you to locate the painful area exactly and the nerves from all these areas can give similar signals to the brain. Once these areas are up regulated and over stimulated, the pain can set in and the nerve pathways are set up to "high alert" all the time. Learning to understand how this happens and how you can teach the nerves and muscles to calm down is one of most important part of managing PPP.

The Pelvic Pain Foundation has an excellent website to help you understand your pain and the importance of managing all your pain symptoms:

[www.pelvicpain.org.au](http://www.pelvicpain.org.au)

Because BPS/IC is usually part of PPP, you often need a team of health professionals to help manage the pain long term, these include:

1. A GP with an interest in women's health and pelvic pain who can coordinate your other health professionals
2. A pain physician who will help you understand how your pain started and set up these long term patterns and how to change them.
3. A pelvic floor physiotherapist who will help you manage the pain in your pelvic floor muscle (this is NOT pelvic floor exercises and is in fact the opposite of this). To start gentle stretches for your pelvic floor visit [www.pelvicpain.org.au](http://www.pelvicpain.org.au)
4. A psychologist who can help with previous trauma which contributes to PPP. Trauma can include shame about your body, periods or sexuality and sexual abuse and harassment. Understanding how to deal with past traumas, helps you to manage your pain today.

5. A general gynaecologist to manage your periods and other pelvic pain. This may require a laparoscopy (operation to look inside your tummy) to look for causes of pain. You will also need to try to reduce periods and period pain which your GP or gynaecologist can help with.
6. Please note Dr Higgs does not routinely see women with pelvic pain. If your treating gynaecologist or pain physician has a specific reason for you to see Dr Higgs, you will require a referral from them outlining your current treatment plan and goals and how your specialist feels Dr Higgs will be of assistance. Please note that a referral without these specific details will be rejected. In the meantime, ensure that you have tried the simple measures suggested below.

### **What are the symptoms of BPS/IC?**

Bladder pain: This is mainly when the bladder is full. The pain may improve with urination. Pain may be felt in the lower abdomen, vagina or urethra. Sexual intercourse often will worsen the pain.

Urinary frequency: The feeling of needing to urinate frequently due to pain rather than having a full bladder.

Urgency: The feeling of being “desperate” to pass urine or unable to delay urination due to pain symptoms.

Nocturia: Needing to get up from sleep to pass urine more than 2 times per night.

### **How is it diagnosed?**

There is no definite test which makes the diagnosis and your individual condition needs to be assessed before a diagnosis is made.

- A urine sample to exclude urinary infection.
- A physical examination to determine if your bladder is a site of pain. Commonly other painful sites are found within the pelvis. Usually the pelvic floor muscle is tender and this can be found with gentle examination of the muscles surrounding the vagina.
- Bladder diary to measure urinary voids and exclude other causes of frequent urination.
- Ultrasound of the pelvis and kidneys and bladder to exclude other causes of pain.
- A cystoscopy with distension of the bladder is NOT necessary to diagnose BPS but may be done in combination with a laparoscopy (look inside your abdomen to check for other causes of pelvic pain)

### **How is it treated?**

Mostly simple measures can be used to help manage your pain. Different treatments work for different people. A range of treatments may need to be tried or a combination of treatments may be best for you.

Water: Drinking enough water each day (about 2 litres per day) is important to ensure that the urine is dilute and not irritating. This may help symptoms. Try to slowly increase the amount of water you drink.

Dietary changes: Some women find certain foods can worsen their symptoms. A trial of eliminating certain foods may be worthwhile.

Suggestions include avoiding:

- Acidic foods such as citrus fruits, tomatoes and cranberries and Vitamin C
- Caffeine and chocolate
- Fizzy drinks
- Alcohol (especially red wine)
- Artificial sweeteners

Bladder first aid:

If you have a flare of bladder symptoms, have your doctor check for a Urine Infection with the urine sample sent to the laboratory.

In the meantime try:

Drinking 500mls of water with

- 1 teaspoon of bicarbonate of soda OR
- a sachet of Ural

Then drink 250mls of water every hour for the next few hours.

Physiotherapy: A recent study of many different treatments for BPS found that pelvic floor physiotherapy was the most effective treatment for the symptom of bladder pain.[1] Physiotherapy with a specialist pelvic floor physiotherapist can also be helpful to relieve trigger points in the pelvis that may be worsening pelvic pain. Many women with bladder pain have pelvic floor spasm which continues to cause pain even if their bladder pain is treated. It is essential to try to address all of the areas generating pain in the pelvis.

Central sensitisation: Understanding how long term and persistent pain makes you feel generally unwell. Symptoms such as fatigue, poor sleep, nausea, anxiety, depression, sweating and dizziness are part of PPP. Management of these symptoms help you to manage your pain. Learning how to have a good night's sleep, taking regular exercise and keeping active can help. Talk to your GP, psychologist or pain physician about resources to help you and see the resources at the end of this information sheet.

Medications:

- Simple analgesia. Paracetamol and non steroidal anti inflammatory medications (asprin type medications) are useful for pain relief.
- Avoid opioid type medications when possible (codeine and related pain killers) and only use for a short time when necessary. Long term, these medications actually change the nerves and increase pain symptoms (hyperalgesia).
- Amitriptyline (Endep) is an anti depressant that can improve pain symptoms and also suppress the urgency symptoms. It is usually started at a low dose (5mg) and slowly increased by 5mg every 3 days to a dose that helps the pain without causing drowsiness (aim for 10-25mg).
- Medications to reduce bladder frequency such as Oxybutynin, Solifenacin and/or Mirabegron. See patient information on Overactive Bladder.

### **What else can I do?**

Support groups are an important part of managing a chronic condition. They let you know that you are not alone and supply a lot of useful information. More information can be found at these websites:

<https://www.pelvicpain.org.au>  
[www.tamethebeast.org.au](http://www.tamethebeast.org.au)  
[www.ichelp.org](http://www.ichelp.org)  
[www.painful-bladder.org](http://www.painful-bladder.org)  
<https://www.ugsa.com.au/patient-resources/>

### **References:**

1. Imamura M, Scott NW, Wallace SA, Ogah JA, Ford AA, Dubos YA, Brazzelli M. Interventions for treating people with symptoms of bladder pain syndrome: a network meta-analysis. Cochrane Database of Systematic Reviews 2020, Issue 7. Art. No.: CD013325. DOI: [10.1002/14651858.CD013325.pub2](https://doi.org/10.1002/14651858.CD013325.pub2).