

INTERSTITIAL CYSTITIS AND PAINFUL BLADDER SYNDROME

Bladder pain may be caused by a condition called interstitial cystitis (I.C). The cause of IC is unknown and although there are many theories, more research is required. Although it sometimes starts with a urinary infection, it is not contagious.

Most people with IC are women, and symptoms frequently start in the 20-30 year age group. It is a chronic condition which tends to fluctuate over time. Rarely do the symptoms completely resolve. The key is to try to control symptoms as best as possible and a number of treatments may need to be tried before the best individual treatment is found.

Some women will also experience pain with defecation, periods, sex and other pelvic and back pain. These areas may need to be investigated with other specialists such as gastroenterologists, colorectal surgeons and pain specialists. Often referral to a pain clinic is an important part of treatment.

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

<https://www.pelvicpain.org.au/an-intro-to-pelvic-pain/>

What are the symptoms?

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 or almost constantly, often without much urine being present in the 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 a diagnosis and your individual condition needs to be assessed before a diagnosis is made.

- A urine sample to exclude urinary infection.
- A physical examination.
- 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. This is usually done under general anaesthetic. A small medical telescope is passed through the urethra (the tube that passes urine from the bladder) and no incisions are required. Sterile fluid is

used to inflate the bladder and the inside of the bladder is then inspected. A biopsy may be taken.

How is it treated?

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.

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

Suggestions include avoiding:

- Citrus fruits
- Tomatoes and pineapples
- Spicy foods (eg curries)
- Alcohol (especially red wine)
- Artificial sweeteners

Physiotherapy: Pelvic floor physiotherapy for a number of symptoms including frequency and urgency by teaching bladder training techniques. Physiotherapy 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.

Stress management: Although IC is not caused by stress, the chronic nature of the disease impacts on day to day living and psychological health. Managing stress helps to control pain and is important to ensure that other treatments can be effective.

Natural therapies: Some benefit may be found from natural remedies available from a pharmacist.

- Slippery elm (in milk)
- Ural
- L-Arginine

Medications:

- Simple analgesia. Paracetamol and non steroidal anti inflammatory medications (asprin type medications) are useful for pain relief.
- 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).
- Pentosan polysulfate (Elmiron) is a drug specifically designed to repair the layer in the bladder which is believed to be damaged in IC. It cost about \$200 per month and is not available on PBS.
- Gabapentin or Pregabalin (Lyrica) are used in conditions with nerve pain such as IC. They may be able to modify the pain signals.

- Medications to reduce bladder frequency such as oxybutynin, solifenacin and/or mirabegron. See patient information on Overactive Bladder.

Bladder installation:

This involves putting medications directly into the bladder using a catheter.

- Heparin is an anticoagulant that has a similar structure to the bladder layer. It can be instilled 2-3 times per week.
- DMSO is a chemical solvent which is instilled in courses into the bladder. This requires a course over 8 weeks and is performed as an outpatient procedure (twice a week for 4 weeks then once a week for 4 weeks). The medication is put into the bladder via a small catheter. The medication is held in the bladder for 20 minutes then voided into the toilet. Women often notice a garlic odour the next day. Treatment can be successful in up to 70% of cases.
- Sodium Hyaluronate with Chondroitin sulphate is a new treatment available which has shown similar results to DMSO on initial studies. This treatment is over 3 months (weekly for the first month, then fortnightly for the second month, then monthly). The medication is put into the bladder via a small catheter and held in the bladder for as long as possible. Cost is approximately \$2000 for the 3 month course and is not claimable on Medicare or Private Health Funds currently.

Surgery:

This is not usually the first line of treatment..

- Sacral neuromodulation. A pace maker type of implant with electrodes into the pelvic nerves is implanted and may relieve pain.
- Urinary diversion. The bladder is bypassed and urine is collected into a bag on the outside of the body.
- Bladder removal.

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/an-intro-to-pelvic-pain/>
www.ichelp.org
www.painful-bladder.org
<https://www.ugsa.com.au/patient-resources/>