Interstitial Cystitis/Painful Bladder Syndrome

What is interstitial cystitis/painful bladder syndrome?

Interstitial cystitis/painful bladder syndrome (IC/PBS) is a chronic condition (symptoms persist for more than 6 weeks over 3 months) that causes pain or discomfort attributed to the bladder. It is associated with a sudden desire to pass urine (urgency) as well as having to urinate very often (frequency). Women are affected more often than men. Some women find that their symptoms are worse around the time of menstruation, when they are more stressed than usual, or when eating certain foods (triggers). Some of the symptoms are listed below.

- Urgency – during the day or night
- Frequency – sometimes up to 20x per day, as well as multiple voids overnight
- Pressure/pain around the bladder area – this gets worse as your bladder fills up and improves when you empty your bladder
- Your bladder may not hold a lot of urine
- Pain with intercourse.

What are the causes of IC/PBS?

While the underlying cause of IC/PBS is not well understood, it is believed that a defect in the protective layer of the bladder lining results in inflammation of the underlying bladder tissue. This causes pain and irritation. Other changes include an increase in histamine (due to inflammation) and an increase in certain types of pain nerve cells in the bladder wall. There is some evidence to suggest that an auto-immune response, where the body forms antibodies against certain types of cells, also contributes to the condition.

How do we diagnose IC?

You will have some or all of the above symptoms. Your gynaecologist will do tests to rule out other diseases which may cause similar symptoms. These may include tests for bladder or vaginal infections, bladder cancers or endometriosis. Your gynaecologist may also perform a test called a cystoscopy, which involves placing a small camera into your bladder to evaluate the appearance of the bladder wall. At the time of cystoscopy, the bladder is filled with saline and inspected for particular features such as bleeding spots (petechiae) or splitting of the bladder wall lining (fissures). If women suffer from the above symptoms, but we cannot identify these changes within the bladder, the condition is called painful bladder syndrome (PBS). If these features are present at cystoscopy, a diagnosis of interstitial cystitis (IC) is made (a subset of PBS)

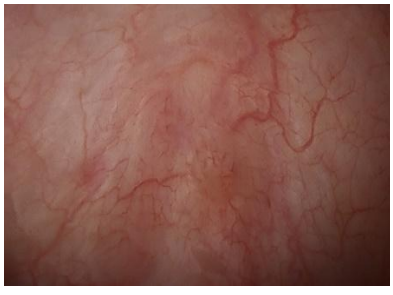

Fig 1: Normal Bladder

Fig 2: Bladder with IC (petechiae)

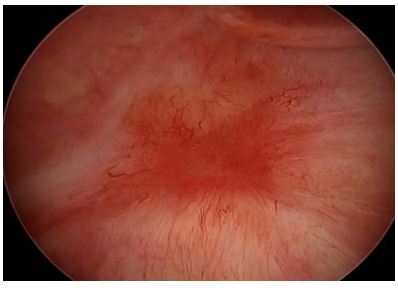

Fig 3: Bladder with IC (ulcer)

How do we treat IC?

Because we do not know the exact cause of IC, there is no one treatment that works for everyone. You and your gynaecologist may need to try several different therapies to find one that improves your symptoms.

A first-line approach is often physiotherapy and behavioural modification. This includes passing urine at specific times (timed voiding), bladder training and managing your fluid intake. It is also beneficial to identify specific 'triggers' and try to reduce these. Foods and drinks that are most bothersome include:

- Alcohol
- Coffee
- Citrus (juice/fruit)
- Cranberry juice
- Chilli peppers
- Carbonated (fizzy) drinks
- Spicy foods
- Tomatoes

As part of the cystoscopy, your gynaecologist may offer bladder distension. This means stretching the bladder wall while you are under anaesthetic. We don't know why this improves symptoms, but approximately one-third of women will get relief from with this procedure.

Medications for IC can be divided into oral medications (tablets) and instillations (solutions placed into the bladder). Medications that are available in New Zealand differ from those available in Australia, so be sure to check with your gynaecologist. Tablets that have been used include:

- Anti-inflammatories (such as ibuprofen)
- Medications that relieve neuropathic (nerve-related) pain, such as gabapentin and amitriptyline
- Anti-histaminics (such as cimetidine)
- Anticholinergics (such as oxybutynin, solifenacin or darifenacin) that relieve the urgency and frequency associated with IC
- Elmiron (pentosan polysulfate) passes into the bladder via the kidneys and coats the defects in the bladder wall. Elmiron is not funded on the PBS and you need to take it for at least 4 months to know if it will improve your symptoms

Instillations include DMSO (dimethyl sulphoxide) and hyaluronic acid. These are placed into the bladder with the help of a small catheter. The solution is left in the bladder for a maximum of 60 minutes (as long as you can tolerate it) and is then passed into the toilet. Women have one instillation per week for 6–8 weeks (this may vary between gynaecologists). Botox injections to the bladder have been shown to have a similar effect as bladder instillations, but are not currently funded for treatment of IC/PBS. Very rarely, surgery to bypass the bladder may be discussed – but this is an absolute last resort.

More information

There are several websites where you can find useful information and IC groups in your area. Joining a support group on social media may also be helpful.

http://www.ugsa.org – Information sheets on *Bladder retraining* and *Pelvic Floor Muscle Training*
http://www.painful-bladder.org
http://www.ichelp.org/wp-content/uploads/2015/07/food-list.pdf
(a helpful tool to evaluate food and drink 'triggers')