Interstitial cystitis (IC) is a severe and chronic pain syndrome that affects the bladder. It is also referred to as ‘painful bladder syndrome’. The vast majority of IC sufferers are Caucasian women. It is thought that many cases of chronic pelvic pain are due to IC.

Symptoms
Symptoms of IC include:
- frequent urination—including having to get up to go to the toilet during the night
- an urgent need to urinate
- pain (abdominal, urethral, vaginal or perineal).

Other characteristics of IC that may be present are a scarred or stiff bladder, glomerulations, (pin point bleeding), and ulcers (Hunner’s ulcers) and lesions in the bladder. The symptoms can be debilitating with many women unable to work full time and/or suffering from related mental and emotional health issues.

Women with IC generally experience pain when their bladder fills and find relief (temporarily) from this pain when they urinate. However, as the pain returns as soon as the bladder begins to fill again, women find themselves urinating very frequently to relieve the pain. Typically, a woman with IC will go to the toilet 16 times a day, but some sufferers go up to 40 times. As a consequence, they may suffer the effects of sleep deprivation. Women’s symptoms may be exacerbated with sexual activity and premenstrually.

Diagnosis
It is common for IC to be initially diagnosed as bacterial cystitis. However, women with IC do not have bacteria in their urine and therefore do not respond to antibiotic therapy. Unfortunately, the diagnosis of IC often takes time as other possible causes are usually excluded first. On average it takes 3-7 years and 3-5 different practitioners before IC is diagnosed.

There is no single diagnostic test for IC. A thorough medical history, pelvic examination and urine studies are all important in the diagnosis of IC.

Upon a pelvic examination, 95% of IC sufferers will report tenderness at the base of the bladder. A cystoscopy with distention may also be performed; under general anaesthesia a long thin viewing device (cystoscope) is inserted through the urethra into the bladder. The bladder is then filled to high pressure with fluid or gas (distention).

The medical community has differing opinions on the suitability of other diagnostic tools for IC such as urodynamics, potassium sensitivity test (PST), questionnaire based scales (eg. Pelvic Pain and Urgency/Frequency) and biopsy of the bladder wall (to rule out bladder cancer). A number of clinical markers are currently being investigated.

Causes
The exact causes of IC are unknown, with a number of theories being investigated. Patients who suffer with IC appear to have an increased risk of having conditions such as endometriosis, irritable bowel syndrome (IBS) and migraines.

It is thought that the symptoms of IC may be caused by several types of abnormalities in the bladder. These abnormalities may relate to the bladder surface, to the blood supply to the bladder or to microorganisms present in the bladder.

Some theories suggest that the immune system may play a role in some women with IC. Inflammation of the bladder may result from autoimmunity (where the body attacks its own healthy cells) or from the release of histamine from elevated numbers of mast cells in the bladder.

Treatment
The general aim of treatment is to help people manage their symptoms. Treatment recommendations are difficult due to the lack of good quality clinical trials. They will also depend on what is thought to potentially be causing symptoms to occur. As each woman’s case is different, preferred treatments will vary from woman to woman.

For some women the symptoms will stop after some time with the disease appearing to heal itself. Conservative treatment options are often explored initially, with dietary changes being the most common. While diet is not a cause of IC, many women report that particular foods and fluids seem to exacerbate the symptoms. Foods often reported as aggravating symptoms include chilli, coffee, chocolate, carbonated drinks, citrus fruits, tomatoes and products containing artificial sweeteners. Women may find it helpful to keep a diary, recording what they eat and drink along with symptoms, to determine if there are particular foods/drinks they should avoid.

Drinking enough water (1.5 – 2 litres per day) is an important aspect of managing the symptoms of IC. Because women with IC experience pain when the bladder fills it is tempting to reduce the amount of water consumed. However, not drinking enough...
water can result in reduced bladder capacity as well as concentration of noxious agents in urine, which can worsen symptoms.

Smoking is also thought to exacerbate symptoms so quitting can be helpful. Some women find techniques to relax their pelvic floor including warm baths and massage are helpful in relieving symptoms. Physical therapy to relax pelvic floor muscles can be beneficial. Myofascial release involves a physical therapist slowly massaging and stretching the pelvic floor muscles.

Bladder training may be helpful for those who have found a level of pain relief. It involves urinating to a schedule and gradually increasing the length of time between toilet visits. Techniques like pelvic floor contraction, distraction and breathing exercises are used to resist the urge to urinate before the scheduled time. A bladder diary can assist people to keep a track of their progress.

Participating in regular exercise may also assist, with low impact activities such as walking, yoga, swimming and cycling the most suitable.

While there is limited research on the use of complementary and alternative therapies in the treatment of IC, women report they are beneficial. Therapies with a focus on pain and stress relief may be most relevant. Women interested in using complementary and/or alternative therapies should consult a qualified practitioner.

Oral medications used to treat IC symptoms include those to coat the bladder surface, antihistamines and immunosuppressants as well as non-steroidal anti-inflammatory medications, muscle relaxants and antidepressants to reduce pain.

Following bladder distention for diagnostic purposes it was found that some women reported a decrease in symptoms. This has led to bladder distention being used as a treatment option. Bladder instillation involves filling the bladder with a solution and retaining it for a specific length of time before expelling it. The solution most commonly used is dimethyl sulfoxide (DMSO), either alone or with other substances. Other solutions for use in bladder instillation are being investigated.

Transcutaneous Electrical Nerve Stimulation (TENS) is a treatment used to reduce pain by desensitising nerves. It involves sending small electrical pulses through electrodes placed on the skin and/or through devices inserted into the vagina.

Surgery is reserved for cases where all other treatment options have failed and in which the symptoms experienced are severe and disabling. Surgical treatments include the injection of steroids into the bladder, laser removal of bladder ulcers, bladder augmentation (plastic or reconstructive procedure on the bladder) and urinary diversion (creation of a new urine storage pouch) with or without the removal of the bladder. Sacral nerve stimulation, a variation of TENS, involving the surgical implantation of a permanent electrode, is also currently under investigation.

Support

People who suffer from IC may also benefit from joining a support group. A support group can provide people with opportunities to share information and management strategies as well as reduce feelings of isolation. There are a number of online support forums available to women (see Further reading section).

Further reading

Interstitial Cystitis Association (US)
www.ichelp.org

Interstitial Cystitis Network (US)
www.ic-network.com

International Painful Bladder Foundation
www.painful-bladder.org

For help understanding this fact sheet call the Health Information Line on 3839 9988 (in Brisbane) or 1800 017 676 (toll free outside Brisbane)

This is one of a series of women’s health information fact sheets available at www.womhealth.org.au. A full list of references is available from Women’s Health or on the website.