Interstitial Cystitis/Bladder Pain Syndrome/Painful Bladder Syndrome

What is it?
Interstitial Cystitis (IC) is a chronic pelvic pain condition that may affect up to 5 in 1000 people. Women are 10 times more likely to be affected than men. Because IC symptoms are very much like some other conditions such as urinary tract infection, many IC sufferers can be misdiagnosed for many years.

The cause of IC is not known but it is believed that a particular event (such as infection, surgery or trauma) may cause bladder inflammation (cystitis) and this cystitis, in turn, leads to thinning of the protective layer within the bladder that lies in contact with the urine (urothelium). Thinning of the urothelium allows urine to cause further inflammation. Nerves in the bladder then stimulate nerve messages to the spinal cord which leads to further stimulation of nerves in the bladder, including pain nerves that are usually dormant. This upregulation or wind-up process causes further and further inflammation even when the original cause is no longer present.

What are the symptoms?
The commonest symptoms of IC are pain, urinary urgency and urinary frequency. Bladder pain is often worse with bladder filling and relieved with bladder emptying. Incontinence is uncommon. IC sufferers often experience flare-ups triggered by certain food or drink, sexual activity, menstruation or emotional stress. Common dietary triggers are caffeine, alcohol, acidic food, spicy food, tomatoes, strawberries or chocolate but many potential triggers exist.
IC often occurs in people with Irritable Bowel Syndrome, vulvodynia, endometriosis, fibromyalgia and autoimmune conditions such as lupus and Sjogren’s syndrome.

**What tests will I need?**
There is no specific test that will diagnose IC. It is a diagnosis of exclusion, which means that other bladder disorders have to be ruled out first. If IC is suspected, urine will be tested to check for infection and the possibility of cancer.

Cystoscopy and hydrodistension may be done to determine if the bladder has the characteristics of IC. Cystoscopy is a procedure to inspect the bladder with the use of a telescope. Hydrodistension is a process to fill the bladder with fluid to its full volume under general anaesthetic. Patients with IC may have smaller bladder volumes, bleeding of the bladder lining or bladder ulcers. A biopsy of the bladder may be done at the time of cystoscopy. If these tests are positive, then they are suggestive of IC, but not always diagnostic. Sometimes, a urodynamics test may be done to rule out other bladder diagnoses, which can have symptoms overlapping with that of IC.

**What are the treatments?**
IC cannot be cured, and treatments are aimed at controlling the symptoms, especially during flare ups. Often, a multi-disciplinary team is required (pain specialists, pelvic floor physiotherapist etc). There is no single best treatment option for IC. Sometimes it involves a bit of trial and error to find the best one for each individual patient. The treatment of IC depends on the individual’s preferences and response to various therapies but can be broadly be considered as behavioural, medication or procedural.
**Behavioural**
- Avoidance of triggers
- Pelvic floor relaxation
  - Yoga, tai chi, Pilates
  - Pelvic floor physiotherapy
- Meditation
- Counselling
- Support groups

**Medication**
- Tablets
  - Endep (Amitriptyline)
  - Lyrica (Pregabalin)
  - Neurontin (Gabapentin)
  - Elmiron (Pentosan)
  - Intravesical (placement of fluid into the bladder)
  - DMSO (Dimethyl Sulfoxide)
  - iAluril
  - Heparin
  - Lignocaine
  - Clorpactin

**Procedures/Surgery**
- Cystoscopy and hydrodistension
- Cystoscopy and fulguration of Hunner’s ulcers
- Botox bladder injection
- Neuromodulation
- Substitution cystoplasty
- Diversion
What are the success rates of treatments?
About 45% of patients who undergo education and behaviour change have a moderate to marked improvement to their symptoms.

Most medications lead to about 50-60% improvement.

Cystoscopy and hydrodistension leads to an improvement in about 65% of patients.

Cystoscopy and fulguration of bladder ulcers is an effective treatment and about 80% of patients find their pain is improved with this.

Botox treatment and neuromodulation each lead to improvement in about 70% of patients.