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Interstitial Cystitis- Patient Information

What is interstitial cystitis?

Interstitial cystitis is a chronic bladder problem. Thousands of Australian women have interstitial cystitis. Most (about 90%) of them are women. People with interstitial cystitis have a bladder wall that is inflamed and irritated (red and sore). This inflammation can scar the bladder or make it stiff. A stiff bladder can't expand as urine fills it. There may be pinpoint bleeding from the walls of the bladder. A few people get sores in the bladder lining.

People with interstitial cystitis may have many of the following symptoms:

- An urgent need to urinate, both in the daytime and during the night
- Frequent need to urinate. Women with severe cases of IC may urinate as many as 60 times a day.
- Pressure, pain and tenderness around the bladder, pelvis and perineum (the area between the anus and vagina). This pain and pressure may increase as the bladder fills and decrease as it empties in urination.
- A bladder that won't hold as much urine as it did before
- Pain during sexual intercourse

The symptoms of IC vary from case to case and even in the same individual. In many women, the symptoms get worse before their menstrual period. Stress may also make the symptoms worse, but it doesn't cause them.

What causes interstitial cystitis?

We don't yet know what causes interstitial cystitis. We do know that infections with bacteria or viruses don't cause it. It might be caused by a defect in the lining of the bladder. Normally, the lining protects the bladder wall from the toxic effects of urine. In about 70 percent of people with interstitial cystitis, the protective layer of the bladder is "leaky." This may let urine irritate the bladder wall, causing interstitial cystitis.

Other possible causes may be an increase of histamine-producing cells in the bladder wall or an autoimmune response (when antibodies are made that act against a part of the body).

How does my doctor know I have interstitial cystitis?

You may have interstitial cystitis if any of the following occur:

- You have to urinate often or urgently
- You have pelvic or bladder pain
- A doctor finds bladder wall inflammation, pinpoint bleeding or ulcers during an exam with a special scope (called a cystoscope) that looks inside your bladder
- Your doctor has ruled out other diseases such as urinary tract infections, vaginal infections, bladder cancer, sexually transmitted diseases. Diagnostic tests that help identify other conditions include urinalysis, urine culture, cystoscopy, biopsy of the bladder wall, distension of the bladder under anaesthesia, urine cytology.

How is interstitial cystitis treated?

Because the causes of IC are unknown, current treatments are aimed at relieving symptoms. One or a combination of treatments helps most people for variable periods. As researchers learn more about IC, the list of potential treatments will change, so patients should discuss their options with a doctor.

Most people feel better after trying one or more of the following treatments:

- **Diet.** Your doctor may tell you to change what you eat. You may need to avoid alcohol, acidic foods and tobacco.
- **Bladder distension.** Sometimes people feel better after having a bladder distension. Under anaesthesia, a doctor overfills your bladder with fluid. This stretches the walls of the bladder. Doctors don't know why distension helps. It may make your bladder be able to hold more urine. It may also interfere with pain signals sent by nerves in the bladder.
- **Medicine.** Your doctor may have you take an oral medicine called pentosan polysulfate (brand name: Elmiron). This medicine helps to protect the lining of the bladder wall from the toxic parts of urine. Elmiron is not on the PBS and is expensive. It helps about 40% of patients after 6 months of therapy. Another medicine that may help is amitriptyline (brand name: Endep). It blocks pain and reduces bladder spasms. This medicine can make you sleepy, so it's usually taken at bedtime.
- **Bladder instillation.** During a bladder instillation, a catheter (a thin tube) is used to fill your bladder with a liquid medicine. You hold the medicine inside your bladder for a few seconds to 15 minutes. Then the liquid drains out through the catheter. Treatments are given every one to two weeks for six to eight weeks. The treatment can be repeated as needed. The substances used include:
 - Dimethyl sulfoxide or DMSO (Rimso-50), a chemical solvent from wood pulp which has several uses in medicine. It is known to reduce inflammation and block pain in about a third of IC patients. It is a potent destroyer of free radicals that damage cells. It has the side-effect of leaving patients smelling of garlic that may last up to 72 hours after treatment.
 - Heparin, an anti-coagulant which is sometimes mixed with DMSO.
 - Steroids mixed with DMSO.

Difficult Cases

An extremely small minority of patients are not helped with regular treatments and require surgery. Many approaches and techniques are used, each of which has its own advantages and complications that should be discussed with a surgeon. Surgery should be considered only if all available treatments have failed and the pain is disabling. Most doctors are reluctant to operate because the outcome is unpredictable--some people still have symptoms after surgery.

What else can I do to help my symptoms?

- **Diet -** Alcohol, tomatoes, spices, chocolate, caffeine, citrus drinks, artificial sweeteners and acidic foods may irritate your bladder. That makes your symptoms worse. Try removing these foods from your diet for a couple of weeks. Then try eating one food at a time to see if it makes your symptoms worse.
- **Smoking -** Many people with interstitial cystitis find that smoking makes their symptoms worse. Because smoking is also a main cause of bladder cancer, people with interstitial cystitis have another good reason to quit smoking.
- **Bladder training -** Many people can train their bladder to urinate less often. You can train your bladder by going to the bathroom at scheduled times and using relaxation techniques. After a while, you try to make the time you can wait longer. Your physiotherapist can help you with bladder training and relaxation techniques.

- Physical therapy and biofeedback - People with interstitial cystitis may have painful spasms of the pelvic floor muscles. If you have muscle spasms, you can learn exercises to help strengthen and relax your pelvic floor muscles.
- TENS (this stands for "transcutaneous electrical nerve stimulation"). You can use a TENS machine to put mild electrical pulses into your body through special wires. You would do this at least two times a day. You might do it for a few minutes, or you might do it for a longer time. Some doctors think that electric pulses increase blood flow to the bladder. The increased blood flow strengthens the muscles that help control the bladder. It also releases hormones that block pain. TENS is not expensive.

Where can I get more information about interstitial cystitis?

The support of family, friends and other people with interstitial cystitis is very important to help you cope with this problem. People who learn about interstitial cystitis and participate in their own care do better than people who don't.

People with interstitial cystitis can get more information on this disease from these groups:

Interstitial Cystitis Support Group of Australia

Chairman: Alice Terry P.O. Box 767, Kingswood 2747 NSW Australia

<http://www.users.bigpond.net.au/ICSG/>

Interstitial Cystitis Support Group Mercy Hospital for Women

163 Studley Road Heidelberg, Victoria Australia

Phone : (03) 8458 4890

Contact: Christine Murray

Websites for further information:

Interstitial Cystitis Network (Australia)

<http://www.icnaustralia.com/>

Interstitial Cystitis Association

<http://www.ichelp.org/>

This handout provides a general overview on this topic and may not apply to everyone. To find out if this handout applies to you and to get more information on this subject, talk to your doctor.