My doctor diagnosed me with interstitial cystitis, but I am having considerable difficulties. Do you have any advice?

Interstitial cystitis (IC) is a chronic inflammation of the bladder that is poorly understood. Study of its epidemiology, or patterns, has given some insight, but the essential question about cause has not been identified. For example, people who have a family history of IC are at greater risk for developing the disorder, and even people who were bed wetters past the age of 5 years have a greater possibility of having it. IC occurs much more commonly in women. It is characterized by bladder problems of urinary urgency, frequency, and pain in the lower abdomen. Many people are diagnosed initially as having a recurrent urinary tract infection, but such a diagnosis requires a urine culture, not just a positive dipstick. So if cultures are not done, the true diagnosis can be missed.

Newer understanding of the condition is leading doctors to believe it is a more common problem than was earlier thought to be the case. As many as 200 of a 1,000-patient group may have a degree of the disorder. It is often associated with other symptoms such as irritable bowel syndrome, or a condition in women called vulvodynia (or pain). It is believed that the longer a person has pain, urgency, frequency, and bladder dysfunction, the harder it is to get cured.

A mechanism exists by which chronic pain sensitizes the nerves in the spinal cord to increase in number and activity, and there may be a spillover of sensitivity into other organs in the area, causing irritability and pain. About 80 percent of patients with interstitial cystitis develop an irritability of the pelvic muscles, called the pelvic slings, or levator ani muscles. These may become spastic, resulting in chronic pelvic tenderness, and can interfere with sexual function. The muscles may be palpably tense and felt by a doctor as tight bands. The longer a patient goes untreated, the more difficult it is to get a good response.

Many persons benefit from dietary and fluid changes. Spicy, acidic, and heavy citrus intakes may irritate the bladder. Caffeine and coffee irritate the bladder of many with this syndrome. Some people reduce their fluid intake in a desire to cut down on the number of times they void, but this may result in an increased concentration of irritating substances in the urine.

A urinary diary will permit documentation of how many times a person actually voids in 24 hours (which is normally about eight times on average).
Management of IC is not always easy because it takes patience and discipline. The first step is to modify the diet and regulate water intake. A diet that is more alkaline, such as a vegetarian diet, may well be helpful.

It is also important to have your doctor be certain of the diagnosis. He or she may wish to perform some tests, which may involve a questionnaire, the instillation of potassium chloride into the bladder, or even an anesthetic solution. Cystoscopy used to be the gold standard test; but while it can confirm classic cases, it may miss the early ones—which respond best to treatment.

Treatment aims at preventing the up-regulation of the pain pathways, and so avoids a widening of the discomfort zone. This often uses a medication called amitriptyline in low doses. Another medication helps make the bladder wall less permeable to irritants, but this medication, Elmiron (pentosan polysulfate), may take weeks to work. Muscle-relaxing medications may be used to relax the pelvic sling muscles, and in this area massage or even electrical stimulation at high frequency has often reduced the pelvic pain and discomfort dramatically. A team approach of gynecologists, urologists, physical therapists, dieticians, and nurse practitioners is often required to give the best results.

Allan R. Handysides, M.B., Ch.B., F.R.C.P. (c), is director of the General Conference Health Ministries Department; Peter N. Landless, M.B., B.Ch., M.Med., F.C.P.(SA), F.A.C.C., is ICPA executive director and associate director of Health Ministries.

While this column is provided as a service to our readers, Drs. Landless and Handysides unfortunately cannot enter into personal and private communication with our readers. We recommend that you consult with your personal physician on all matters of your health.