Interstitial Cystitis (IC) / Painful Bladder Syndrome (PBS)

What is IC / PBS?
Interstitial cystitis is a condition that results in recurring discomfort or pain in the bladder and the surrounding pelvic area. Of the estimated 1 million Americans with IC, around 90 percent are women. Symptoms vary from case to case and even in the same individual. You may experience mild discomfort, pressure, tenderness, or intense pain in the bladder and pelvic area. Symptoms may include an urgent need to urinate (urgency), a frequent need to urinate (frequency), frequent nighttime urination (nocturia), or a combination of these symptoms. Pain may change in intensity as the bladder fills with urine or as it empties. Many women have pain with vaginal intercourse. Symptoms often get worse during menstruation. Symptoms may fluctuate in severity, but usually get worse with time if not treated.

What causes IC/PBS?
We do not know. Urine is essentially a very strong salt solution. Normally, the bladder is protected from irritation from urine by a lining, called the urothelium. In women with IC this mucosal layer is thin or leaky & urine irritates the nerve endings in the bladder wall. Many dietary substances can make the symptoms worse, particularly acidic things like citrus. IC is not associated with cancer & does not run in families. Once you have IC, you have it indefinitely, but the symptoms can be managed. Symptoms often improve after menopause.

How is IC / PBS diagnosed?
There is no single test for IC, & researchers & physicians often do not agree on how to diagnose it. Most doctors use a combination of patient symptoms, findings on exam, & bladder testing including:
- The presence of pain related to the bladder, usually accompanied by frequency and urgency
- Absence of other diseases that could cause the symptoms (infection, cancer)
- A urine test for blood & infection
- A bladder test for spasms (urodynamics, cystometrogram)
- Looking inside the bladder with a small cystoscope (cystoscopy)
- Placing a potassium solution in the bladder

What are the treatments for IC / PBS?
The goals of treatment for IC are to improve symptoms of pain, urgency, & frequency. Treatment usually involves a combination of behavioral & medical therapies. With time it is often possible to reduce or eliminate the medicines. While it may take up to 6 months to respond to treatment, women with milder forms of IC seem to respond faster. Treatment options include:

Diet- Many people find that eliminating acidic, spicy, and sugary foods, as well as dairy products from their diet helps to control symptoms. Don’t make too many changes at once. The Interstitial Cystitis Association (ICA) provides a list of foods that may be problematic:
- Beverages — hard liquor, beer, wine, carbonated drinks, coffee, tea, cranberry juice
- Carbohydrates and grains — rye and sourdough bread
- Condiments — seasonings, mayonnaise, miso, soy sauce, salad dressings, vinegar
- Dairy products — aged cheese, sour cream, yogurt, chocolate, milk
Fruits — apples, apricots, avocados, bananas, cantaloupes, citrus fruits, cranberries, grapes, nectarines, peaches, pineapples, plums, pomegranates, rhubarb, strawberries, fruit juices

Meats and fish — aged, canned, cured, processed, or smoked meats and fish, anchovies, caviar, chicken liver, corned beef, meats containing nitrates or nitrites (e.g., ham, bacon)

Nuts

Others substances — tobacco, caffeine, diet pills, junk food, cold and allergy medication containing ephedrine or pseudoephedrine, vitamins that contain fillers (especially aspartate)

Preservatives and additives — benzol alcohol, citric acid, monosodium glutamate, aspartame (Nutrasweet®), saccharine, artificial ingredients and colors

Vegetables — favabean, lima beans, onions, tomatoes

Most IC patients have the least amount of trouble with rice, potatoes, pasta, vegetables, and chicken. Foods from the above groups that may be tolerable include the following:

Beverages — decaffeinated and acid-free coffee and tea, certain herbal teas

Carbohydrates and grains — breads other than rye and sourdough, rice

Condiments — garlic

Dairy products — cottage cheese, white chocolate

Fruits — melon other than cantaloupe, pears

Nuts — almonds, cashews, pine nuts

Bladder training- voiding regularly & gradually increasing time between voids (handout available)

Bladder spasm medicines- increase the ability to hold urine & decrease urgency & frequency

Medicines that heal the bladder lining- Elmiron ® (pentosan polysulfate sodium) is the only oral medication approved by the Food and Drug Administration (FDA) for IC. It is thought to prevent irritating elements in the urine from affecting the cells that line the bladder. Elmiron helps to rebuild the epithelium by coating the bladder wall. Side effects include gastrointestinal discomfort and reversible hair loss, but these are uncommon.

Many other treatments have been used including distending or “stretching” the bladder, filling the bladder with various solutions, electrical stimulation either through the skin or by a device implanted in the lower back, herbs & patent medicines, physical therapy, acupuncture, Chinese medicine, or surgery. It is not clear whether these treatments are effective or long lasting.

Coping

The emotional support of family, friends, and other people with IC / PBS is very important in helping patients cope. Studies have found that patients who learn about the disorder and become involved in their own care do better than patients who do not. See the Interstitial Cystitis Association of America's website (www.ichelp.org).

Follow-up

The good news is that most women will respond to treatment. We will usually not have to repeat the bladder test, & we would like you to call when you have been on the medicines for a month to see how you are doing. We usually will not change the medicines at that point, but we may do so in another couple of months.

In 4 weeks please call the nurse as noted at 828.670.5665 (extension 313 or 315) & tell her how you are doing on the treatment.