The Painful Bladder
(Interstitial Cystitis/Painful Bladder Syndrome)

There is a condition that predominantly affects women and presents with recurrent bouts of pelvic discomfort or pain that may or may not be associated with the uncomfortable need to urinate. The symptoms tend to come and go and usually slowly progress at which time medical attention is sought. After the initial evaluation the diagnosis of a urinary tract infection may be made and a prescription for antibiotics offered. The symptoms may or may not resolve only to resurface again another day. This uncomfortable and bothersome development can be rather typical of the beginning stages of Interstitial Cystitis or Painful Bladder Syndrome (IC/PBS).

The “classic” findings of IC/PBS are a combination of pelvic or bladder pain or discomfort with or without discomfort associated with the urge to urinate. Other symptoms may include painful intercourse, frequent daytime voiding more than 8 times and a need to get up and void frequently at night. Most women do not have all the classic symptoms particularly in the early stages of the disease. To make the diagnosis even more difficult symptoms are typically episodic in the early stages. This explains why the diagnosis is frequently missed in the early stages and may take the fourth or fifth visit for your provider to see enough signs and/or symptoms to put it all together.

The cause of IC/PBS has yet to be identified and there has never been a clear definition of the disorder. In the early 19th century, doctors were curious about a certain painful bladder condition that did not seem to have an identifiable cause. In 1887 Dr. Skene coined the term “Interstitial Cystitis” for this condition. In 1987 the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) put together a list of exclusion criteria to go along with urinary urgency and painful bladder symptoms to help the researchers investigate this disease. Eventually this criterion was found to be too complex and exclusive for clinical use. In 2002 the International Continence Society developed the definition that is commonly used today: “Painful bladder syndrome is the complaint of suprapubic pain related to bladder filling, accompanied by other symptoms such as increased daytime and nighttime frequency, in the absence of proven urinary infection or other obvious pathology”

The mean time from the start of symptoms until it becomes more obvious is generally 3 to 5 years. Some will start with pain symptoms while others start with urgency symptoms. IC/PBS is more common in women by a ratio of 10 to 1. The mean age of symptom onset is usually in the mid 40’s. Some studies have suggested up to 85% of women who see their gynecologist for pelvic pain have IC/PBS in addition to or in lieu of other gynecologic conditions. The pain associated with IC/PBS seems to arise from more that just the bladder. The pelvic floor muscles and
vaginal opening are frequently involved but it is unclear if these symptoms are the result of the disorder or part of another overall chronic pain disorder.

Unfortunately there are no reliable or definitive tests available to accurately diagnose IC/PBS. There are two popular screening questionnaires available to help decide if further investigation for IC/PBS is required. Some simple office testing although controversial can help differentiate your symptoms between a possible bladder source and a non-bladder source. Your provider can help explain the different options available and the rationale for their use. Your provider may suggest a cystoscopy (looking into your bladder with a telescope) to further evaluate your bladder. Other causes of your symptoms can mimic or cloud the IC/PBS diagnosis and will need to be investigated. Further recommendations will depend upon your symptoms and physical findings.

While there is no cure, there are treatment strategies that can allow you to live a normal life and minimize your discomfort. Treatment usually starts with lifestyle modifications and can be very effective at minimizing flares of symptoms. Regular exercise and other stress reduction techniques can be effective. Certain foods are more likely to bother patients with IC/PBS. Foods that are acidic or high in potassium seem to be the most problematic. Acidic foods include sodas (pop), citrus juices, cranberry juice (cranberry tablets are OK) alcoholic beverages and tomato based sauces. Foods high in potassium include avocados, bananas, chocolate and oranges. Diet drinks and foods with artificial sweeteners containing aspartame and saccharin sometimes make the symptoms worse. Hot peppers and spicy foods can be a problem for some. Some foods are a problem when raw but do not pose a problem when cooked. So there can be great variation as to which foods tend to irritate the bladder. It is best for you to keep a journal or follow an “elimination diet” to find your own personal trigger foods.

Medical therapies follow a trial and error process since the cause of IC/PBS is largely unknown. One approach is to help correct the “leaky bladder membrane” theory. This can be done with oral medication or instillation of different medication “cocktails” into your urinary bladder multiple times over a period of several weeks. They both have shown success at decreasing the discomfort and helping the disease to go into remission. Another approach is to control the immune system disorder theory with the use of antihistamines. A third approach is to control a suspected pain reception pathway disorder with different medications used to treat chronic pain. Occasionally your provider will add two or more medications or treatments in order to optimally control your symptoms. Some of these medications can have troublesome side effects and these should be discussed with your provider.

If lifestyle modifications and medical treatments cannot bring relief there are alternative treatments that may be effective. A cystoscopy may not only be diagnostic but it can also be a treatment when it is performed with hydrodilation. The exact mechanism is unknown but stretching the bladder under anesthesia
seems to give prolonged relief of symptoms. If your disease is refractory to hydrodilation, you may get relief with newer more invasive options available and can be discussed with your provider.

Even though there is currently no cure for IC/PBS effective treatment strategies are available. It is important to start treatments early in the disease process since they are more successful at keeping your symptoms under control. Today's treatments can be very successful at controlling your disease allowing you to live a more normal life. Further information including a list of IC friendly foods can be found at the website of the Interstitial Cystitis Association @ www.ichelp.org.