

# Interstitial Cystitis/Bladder Pain Syndrome Patient Guide



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## Bladder Health Committee

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## Tammy's Story



Tammy\* is a 38-year-old woman. She has suffered for many years with pain in her lower abdomen. As a child she was told that she had “lots of bladder infections” and was given antibiotics. Unfortunately, the medications didn’t help.

By the time Tammy was older and became sexually active, her pain had gotten worse. Her gynecologist said the pain was caused by “honeymoon cystitis” and it would get better. Later, she was diagnosed with another problem – overactive bladder (OAB). Even though she was taking medicines, she did not feel better.

Finally, she found a physician who realized that she did not have a problem with infections or overactive bladder. Her urologist said that she had a condition known as Interstitial Cystitis or Bladder Pain Syndrome, or IC/BPS.

While it took Tammy a long time to get properly diagnosed, once she did, she was very happy. Tammy said, “Having the diagnosis helped me understand what I could do to manage my pain and not to give up. Treatment and relief are possible!”

*\*Name has been changed*

## Introduction: Treatment and Relief are Possible

For many people, it takes months or even years before they get the Interstitial Cystitis (IC) or Bladder Pain Syndrome (BPS) diagnosis—a medical name for bladder pain and problems. Most of us may be diagnosed first, wrongly, with repeat **bladder infections**\*. You may have taken antibiotics over and over again, with little or no relief. You may also have been told you have “overactive bladder” and medications did nothing to relieve your symptoms.

The first step to feeling better is to learn as much as you can. Understand your symptoms and learn about the different treatment options. Some people feel better with

things they can do for themselves, like diet changes. Other people feel better after trying a few medical options to reduce stress and pain. A **urologist** is the specialist to help you create your own treatment plan.

However, treatment may not work quickly. Be patient. When you gain the power of information, work with your urologist, and try different options. You can find relief. You can regain your quality of life.

**\*All words that appear in blue are explained in the glossary.**

## How Does the Urinary Tract Work?

### FEMALE URINARY TRACT

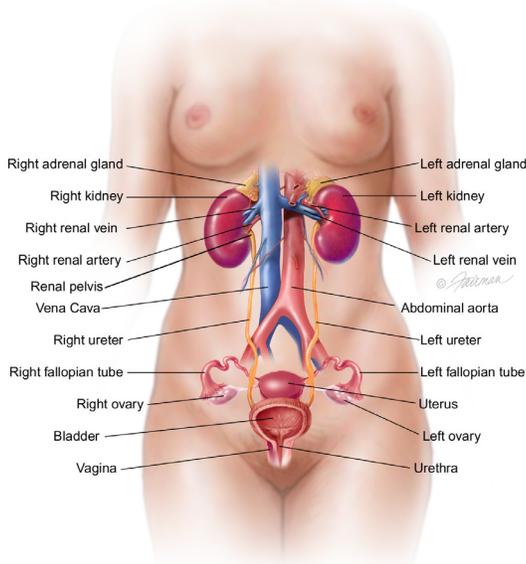


Image © 2016 Fairman Studios, LLC

### MALE URINARY TRACT

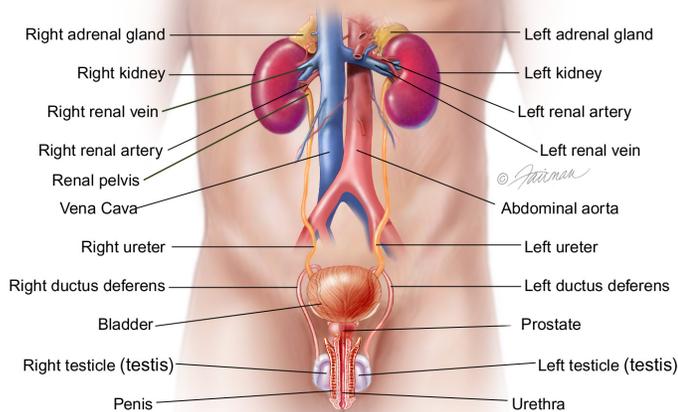


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The **bladder** and **kidneys** are part of the **urinary system**. These organs make, store and pass **urine**. When the urinary system is working, the kidneys make urine and move it into the balloon-shaped bladder. The bladder stores urine until you are ready to release it. If your bladder is working normally, you can hold urine for some time.

The bladder is relaxed when it is not full. It's held in place by pelvic muscles in the lower part of your **abdomen**. Nerve signals to your brain let you know when it is full and gives you the feeling that you need to release urine. Brain signals then tell the bladder muscles to squeeze (contract). This forces the urine out through your **urethra** (the tube that carries urine from your body). The sphincter muscles in the urethra stay closed to keep urine from leaking out. When you're ready to go to the bathroom, the sphincter muscles in the urethra open.

You should not feel pain during the urinary process.

### What Is Interstitial Cystitis or Bladder Pain Syndrome?

Interstitial Cystitis (IC) or Bladder Pain Syndrome (BPS) IC/BPS is an issue of long-term bladder pain. It may feel like a bladder infection, but it's not. It is a feeling of discomfort and pressure in the bladder area that lasts for 6 weeks or more with no infection or other clear cause. There may also be lower urinary tract symptoms like a regular, urgent need to urinate.

If you or a loved one has IC/BPS, it's important to learn how to control symptoms and relieve pain.

**You don't have to feel pain to have IC/BPS.**

**Some patients only describe an intense pressure in the bladder.**

## What Are the Symptoms of IC/BPS?

For some, IC/BPS symptoms come and go and may range in severity. For others, they persist. Some people with IC/BPS also have **irritable bowel syndrome**, **fibromyalgia** and other problems. Symptoms can make everyday life very difficult. These are the most common symptoms:

### PAIN

Pain (often with pressure) may be constant or may come and go. The pain can get worse as the bladder fills. Some patients feel discomfort in other areas as well, such as the urethra, lower abdomen or lower back. Women may feel pain in the vulva or the vagina. Men may feel the pain in the scrotum, testicle or penis. Both women and men with IC/BPS can have sexual problems as a result. Sex for women is painful because the bladder is right in front of the vagina. A man may have pain a day after having an **orgasm**.

### FREQUENCY

IC/BPS sometimes starts with urinary frequency. Frequency is the need to pass urine more often than normal. This can happen both day and night. The average person urinates no more than 7 times a day and does not have to get up at night more than once to use the bathroom.

### URGENCY

Some IC/BPS patients feel an urge to urinate that never goes away, even right after urinating. A patient may not notice this as a problem because it develops gradually. In other cases, the sense of urgency is much more dramatic, with symptoms occurring within days. It is unusual to experience urine leaks with this disorder. If you are leaking urine it might be a sign of another problem.

### IC/BPS CAN AFFECT YOUR LIFE

IC/BPS symptoms can get in the way of your social life, work life, exercise and sleep. IC/BPS can affect your relationships with your spouse, family and friends. Without treatment, IC/BPS symptoms make it tough to get through your day. It's hard to feel comfortable. Too little sleep from IC/BPS symptoms will leave you tired and unhappy. For some people with IC/BPS, eating can be an issue. Sometimes their symptoms get worse after a meal. It can also make you avoid intimacy because of the pain people experience during or after sex.

Overall, this condition can cause a great deal of distress. There's no proof that stress causes IC/BPS. However, it is well known that physical or mental stress can make IC/BPS symptoms worse.

### SYMPTOMS THAT MAY MEAN YOU HAVE IC/BPS

- Do you have pain or pressure in your lower abdomen or pelvic area?
- Do you urinate frequently?
- Do you have an urgent need to urinate day and night?
- Do some foods or drinks make your symptoms worse?
- Do you find that certain exercises make you feel worse?
- Do you have pain during or after sex?
- Do urine tests fail to show the signs of a bacterial infection?

Be sure to see your healthcare provider if you experience any of these symptoms.

## What Causes IC/BPS?

Experts don't know exactly what causes IC/BPS. There are many theories:

- A defect is in the bladder tissue. This defect may allow substances in the urine to weaken the tissues or cause ulcers (open sores).
- Something is in the urine that damages the bladder.
- A specific type of inflammatory cell, called a mast cell is detected in the bladder. This cell causes an allergic reaction that may lead to IC/BPS symptoms.
- Changes in the nerves that carry bladder sensations occur. This may cause pain with events that are not normally painful (such as bladder filling).
- The body's immune system attacks the bladder. This is similar to other autoimmune conditions.

No specific behaviors (such as smoking) are known to increase your risk of IC/BPS. Having a family member with this condition may increase your chance of getting it. Some people may be more likely to get IC/BPS after an injury to the bladder, such as an infection.

### What tests are there for IC/BPS?

Unfortunately, there is no medical test that says a person has or doesn't have IC/BPS. To make a diagnosis, your health care provider will decide whether or not the symptoms are typical of IC/BPS. Next, they'll need to rule out other health issues, like an infection, that might cause the same symptoms.

When it's diagnosed, IC/BPS is typically found to affect women 2 to 3 times more often than men. Data have shown the risk of IC/BPS increases with age. Four to 12 million people have IC/BPS. As many as 3 to 8 million women and 1 to 4 million men in the United States may have IC/BPS. However, these numbers do not tell the true rate of disease. That is because IC/BPS is often misdiagnosed in men and women. IC/BPS in men is often mistaken for another disorder, such as chronic **prostatitis or chronic pelvic pain syndrome**. In young women in their early 20's, IC/BPS is also commonly misdiagnosed.

Here are some ways to diagnose IC/BPS:

#### MEDICAL HISTORY

Your health care provider will ask you a number of questions, about:

- Symptoms you are having and for how long
- How symptoms are changing your life
- Current and past health problems
- Over-the-counter and prescription drugs you take
- Your diet, and how much/what kinds of liquids you drink during the day

#### PHYSICAL AND NEUROLOGICAL EXAM

In women, your doctor will want to examine your abdomen, organs in your pelvis and your **rectum**. In men, a physical exam will include your abdomen, **prostate** and rectum. For everyone, your health care provider may do a **neurological exam**. Patients with IC/BPS may have other mental health and/or **anxiety** problems that can affect their condition.

#### BASELINE PAIN AND VOIDING TESTS

Since pain is the number one symptom, your health care provider will conduct tests and ask you questions to learn your **baseline pain value**. The goal is to find pain location(s), intensity and characteristics, and to learn what

makes your pain better or worse. Your health care provider will also ask how often you urinate, which can lead to a different diagnosis.

#### OTHER TESTS

##### *Urine exam*

If a patient has the typical symptoms of IC/BPS and a urine exam shows no infection or blood, then IC/BPS should be suspected.

##### *Urodynamic Tests*

A **urodynamic test** involves filling and emptying the bladder with water through two small **catheters** (tubes used to fill and drain fluid from the body). This procedure measures bladder pressures as the bladder fills and empties. In patients with IC/BPS, bladders are sometimes small in capacity and may be painful when filling.

##### *Cystoscopy*

Using a special tool, your doctor looks inside the bladder. This test can rule out other problems such as cancer. The doctor can see actual ulcers (sores) through the cystoscope in some patients with IC/BPS. If a person has symptoms of IC/BPS and cystoscopy shows ulcers, then the diagnosis is fairly certain. Cystoscopy can be performed in the operating room. So, if bladder stones, tumors or ulcers are seen during cystoscopy, the doctor can take care of them right away. This test often includes a **biopsy**, which is when a small tissue sample is removed for diagnosis.

**Now that you have the correct diagnosis, you can learn what you can do for relief.**

## What are my options for IC/BPS treatment?

No single treatment works for all people. Treatment must be chosen and adjusted for everyone based on symptoms. The goal of treatment is to control your symptoms. A combination of lifestyle changes and medical options are tried until relief is found.

Most people can find ways to feel better, but it may take time. It can take weeks to months before symptoms improve.

IC/BPS treatment is often done in phases with careful monitoring. It is important to talk with your health care provider about how your treatment is working. Together, you'll find your best options. Even with successful treatment, IC/BPS may not be cured but may be in **remission**. Sticking with your treatment plan (even without symptoms) is usually recommended.

### There are 6 phases (or "lines") for IC/BPS treatment

#### FIRST LINE: LIFESTYLE CHANGES

Lifestyle changes, known as "behavioral therapy," are tried first. In behavioral therapy, you change the way you live day-to-day. This may include things you eat or drink, or practicing methods that may control symptoms. You may not get rid of all symptoms with lifestyle changes, but your symptoms may feel better after changing a few habits.

##### *Limiting Stress*

Emotional and mental stress can worsen IC/BPS symptoms. Patients are encouraged to learn coping skills to deal with family, work and/or past painful experiences. Professional counseling can be helpful to learn better strategies to cope with anxiety and pain.

##### *Limiting Certain Foods and Drinks*

Most (but not all) people with IC/BPS find that certain foods and drinks make symptoms worse:

- Citrus fruits
- Tomatoes
- Chocolate
- Coffee and caffeinated drinks
- Alcoholic drinks

- Spicy foods
- Some carbonated drinks

##### *Elimination Diet*

The list of foods that could aggravate symptoms is long, but not all foods affect all people. You'll have to find out how foods affect you. The clearest way is to try an "elimination diet" for 1 to 2 weeks. For this, you start by avoiding all foods that could irritate your bladder. (IC/BPS food lists are available from many sources. For more information on the elimination diet visit [www.ichelp.org](http://www.ichelp.org).)

If your symptoms improve with an IC/BPS elimination diet, this means that at least one food on the list causes your IC/BPS symptoms to get worse. The next step is to find out exactly which foods cause problems for you. After 1 to 2 weeks on the elimination diet, try eating 1 food at a time from the IC/BPS food list. If this food does not bother your bladder then this food is likely safe for you. In a few days you can try a second food from the list, and so on. In this way, you will add foods back into your diet one at a time. Your bladder symptoms will tell you what causes problems. Be sure to add only one new food at a time. If you eat a banana, strawberries and tomatoes in the same day, you won't know which of the foods caused a symptom flare-up.

#### SECOND LINE: PRESCRIPTION DRUGS AND PHYSICAL THERAPY

When lifestyle changes do not help enough, your health care provider may ask you to try appropriate physical therapy, prescription drugs, or a combination of the two.

Patients with IC/BPS often have tenderness and/or pain in the pelvic floor area, and sometimes manipulative physical therapy can reduce symptoms. There is evidence that physical therapy exercises to strengthen the pelvic floor muscles do not improve symptoms, and often make them worse, so activities such as **Kegel exercises** are not recommended for patients with IC/BPS. However, physical therapists trained to help with pelvic floor tenderness may offer relief through maneuvers that resolve trigger points in the abdominal and pelvic areas, lengthen muscle contractures, and release scarred or restricted tissue. A multimodal pain management approach using prescription drugs, stress management, and manual physical therapy are often beneficial at this phase.

The two types of prescription drugs that may be recommended are oral and intravesical drugs. There are

many types of oral drugs and the side effects range from drowsiness to upset stomach. Intravesical prescription drugs are placed directly into the bladder with a catheter.

### *Approved drugs:*

#### *Amitriptyline*

Amitriptyline (Vanatrip, Elavil, Endep) is a type of **antidepressant** which is commonly used to improve IC/BPS symptoms. It has **antihistamine** effects, decreases bladder spasms and slows the nerves that carry pain messages. It also helps with sleep. This oral drug is often used for chronic pain, like with cancer and nerve damage. The most common side effects are drowsiness, constipation and increased appetite.

#### *Oral Pentosan Polysulfate Sodium*

Pentosan Polysulfate Sodium (Elmiron) is an oral drug used to relieve pain. No one knows exactly how it works for IC/BPS. Many think it builds and restores the protective coating of the bladder tissue. It may also help decrease swelling. It often takes at least 3 to 6 months of treatment with this drug before you notice improvement. Possible side effects may include nausea, diarrhea and gastric distress, sometimes short-term hair loss.

#### *Heparin*

Heparin helps the bladder in similar ways as Pentosan Polysulfate Sodium. It is placed in the bladder with a catheter. It may be used daily. Heparin stays in the bladder only and does not affect the rest of the body. It is usually given with an anesthetic agent, like Lidocaine or Marcaine.

#### *Hydroxyzine and Cimetidine*

Hydroxyzine (Vistaril and Atarax) and Cimetidine (Tagamet) are antihistamines. An antihistamine may help treat IC/BPS if an allergic reaction is thought to be the cause of pain and symptoms. The main side effect is drowsiness. However, this may be helpful since patients can sleep better at night and get up less often to pass urine.

#### *Dimethyl Sulfoxide (DMSO)*

Dimethyl sulfoxide (DMSO) is placed directly in the bladder through a **catheter**. This is usually done once each week for 6 weeks. Some people use it on and off for maintenance. No one knows exactly how it helps. It may block swelling, decrease pain and remove "free radicals" that can damage tissue. Some health care providers combine it with other drugs, such as heparin or steroids (to reduce inflammation). The main side effect of DMSO is a garlic-like odor that lasts for a few hours. For some patients, it hurts to place DMSO in the bladder, but a local anesthetic helps.

### *Supplements and Herbal Medications*

You may or may not be using a supplement to help manage your IC/BPS. Knowing which supplement is best can be very confusing. There are a few that may help manage some of your symptoms, they include:

- Calcium glycerophosphate – helps to neutralize the acidity in your body. Acidic foods and beverages can cause IC/BPS symptoms to get worse. If you take this medicine, only use it when eating high acidic foods. Overuse of this can cause stomach problems and cause important nutrients your body needs to be absorbed properly.
- Osteoarthritis supplements – can help reduce the pain patients have. Examples of medicines include glucosamine and chondroitin.
- Quercetin complex – helps to reduce the inflammation caused by IC/BPS. It has also been found to reduce the pain and other urinary symptoms you may have.
- Aloe capsules – this is a relatively new pill that IC/BPS patients have been using to manage their condition. It may help some patients; however, more research is needed to find out its real benefits.

If you have IC/BPS you SHOULD NOT take Vitamin C, L-arginine and L-citrulline. These drugs can actually make your symptoms worse.

### **THIRD LINE: ULCER CAUTERIZATION**

#### *Cystoscopy with Hydrodistention*

Cystoscopy with hydrodistention in the operating room with anesthesia fills the bladder with water to stretch it to full capacity. Many patients will experience relief of bladder pain and frequency after the procedure. If ulcers are seen, they can be **cauterized** (burned off) with electricity or with a laser and sometimes are treated by a direct injection of steroids into the ulcer.

### **FOURTH LINE: NEUROMODULATION THERAPY AND INJECTIONS**

#### *Neuromodulation Therapy*

If other treatments don't help enough, more advanced therapies may help. You may be referred to a specialist/urologist who is an expert in IC/BPS. The specialist may offer **neuromodulation therapy**. This is a group of treatments that deliver harmless electrical impulses to nerves to change how they work.

## Injections

Injections of Botox® into bladder tissue is used to control symptoms. Small doses will paralyze muscles. When injected into the bladder muscle, it can relieve the pain of IC/BPS. Your health care provider should follow you closely to ensure that your bladder is working well after injections. A side effect can be urinary retention (incomplete emptying of the bladder). Botox can wear off and you may need another treatment 6 to 9 months after the first injection.

## FIFTH LINE: CYCLOSPORINE

### Cyclosporine

Cyclosporine (Neoral, Sandimmune, Restasis) is an oral drug used when other options don't help. It is an immune-suppressant. This means that it slows down the body's immune system. It is often used after an organ transplant. It can cause side effects that may be very serious, like kidney problems. It should only be considered when other safer options have failed to work.

## SIXTH LINE: SURGERY

### Surgery

Most patients do not require major surgery for this condition. Still, surgery can be an option when there are major bladder symptoms that haven't responded to other treatments. Surgeries range from minimally invasive to very invasive. There are lifelong changes after surgery that must be considered.

## AFTER TREATMENT

### Can IC/BPS Be Cured?

In some patients, IC/BPS symptoms slowly get better and even disappear with treatment. Many people find that symptoms come and go over the years. It is not known what causes pain to come back. Often, treatment is needed on and off, throughout a patient's life.

With pain management, most people find that they can live fully. You can try to prevent the return of symptoms by:

- Staying on your treatment plan even after remission
- Avoiding foods that may irritate the bladder
- Avoiding activities that may make IC/BPS worse
- Learning stress management



## GLOSSARY

### **ABDOMEN**

Also known as the belly. It is the part of the body that holds all of the organs between the chest and the pelvis.

### **ANTIDEPRESSANTS**

Medicine used to treat depression and related mental health problems.

### **ANTIHISTAMINE**

A drug that reverses the effects of histamine (a natural chemical that causes an allergic reaction).

### **ANXIETY**

Feelings of fear, dread and unease that happens as a reaction to stress.

### **BASELINE PAIN VALUE**

A number value that represents how someone feels pain. Usually on a scale of 1 to 10 (10=extreme pain). It is used for comparison.

### **BIOPSY**

A procedure to take out small bits of tissue (cores) for testing.

### **BLADDER**

The hollow, balloon-shaped organ in which urine is stored before it moves through the urethra.

### **BLADDER INFECTION**

Also called a Urinary Tract Infection (UTI). This is an infection caused by bacteria that makes its way up your urethra and into your bladder. It can cause frequent urination and pain with urination.

### **CATHETER**

A thin tube that is inserted through the urethra into the bladder to allow urine to drain or for performance of a procedure or test, such as insertion of a substance during a bladder x-ray.

### **CAUTERIZE**

To burn an ulcer (sore) with heat or a chemical substance to destroy abnormal tissue.

### **CHRONIC PELVIC PAIN**

A collection of conditions that can include spasms, bladder and/or rectal pain.

### **FIBROMYALGIA**

A condition of chronic pain in the muscles.

### **IRRITABLE BOWEL SYNDROME**

A chronic disorder that affects the large intestine (colon). It causes cramping, abdominal pain, bloating, gas, diarrhea and constipation.

### **KEGEL EXERCISES**

Exercises used to strengthen the muscles of the pelvic floor; often recommended to reduce incontinence and the symptoms of other urinary problems.

### **KIDNEYS**

Two large, bean-shaped structures that remove waste from the blood.

### **NEUROMODULATION THERAPY**

A group of treatments that deliver harmless electrical impulses to nerves in order to change how they work.

### **NEUROLOGICAL EXAM**

An evaluation of a person's nervous system. This includes motor and sensory skills, balance and coordination, mental status, reflexes and nerve function.

### **ORGASM**

A state of physical and emotional excitement. It occurs at the climax of sexual intercourse. In the male, it is linked to the ejaculation of semen.

### **PROSTATE**

Is a walnut-sized gland in men. It is located below the bladder in front of the rectum. The prostate provides seminal fluid to the ejaculate.

### **PROSTATITIS**

Inflammation or infection of the prostate. Chronic prostatitis means the prostate gets inflamed over and over again. Most common form is not from a bacteria or infecting organism.

### **RECTUM**

The lower part of the large intestine, ending in the anal opening.

### **REMISSION**

A decrease in or disappearance of signs and symptoms of a disease or condition.

### **URETHRA**

A thin tube that carries urine from the bladder out of the body (in men, it also carries semen, and it exits through the end of the penis).

## URINARY SYSTEM

The body's system for removing waste and extra fluid from the body. The organs in the urinary system are the kidneys, ureters, bladder and urethra. For normal health, all parts of the system must work together in the correct order.

## URINARY TRACT INFECTION

See Bladder Infection.

## URINE

A liquid, usually yellow in color, made by the kidneys and containing waste and water. Also known as pee.

## URODYNAMIC TEST

A series of tests that observe how well the urologic system collects, stores and releases urine.

## UROLOGIST

A doctor who specializes in the study, diagnosis and treatment of problems of the urinary tract.

# QUESTIONS TO ASK YOUR DOCTOR

- What treatment plan do you recommend for me and why?
- What can I do about my chronic pain?
- Will IC/BPS affect other parts of my body?
- Does drinking less water help?
- How can I avoid flare-ups?
- How are bladder spasms treated?
- Will an antidepressant help me?
- Where can I go for more information and support?
- Can I have IC/BPS and still be intimate?
- What is the long-term treatment plan for me?
- Will I ever be cured?

## Notes

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## ABOUT THE UROLOGY CARE FOUNDATION

The Urology Care Foundation is the world's leading urologic Foundation—and the official Foundation of the American Urological Association. We provide information for those actively managing their urologic health and those ready to make healthy changes in their lives. Our information is based on the American Urological Association resources and is reviewed by medical experts.

To learn more about different urologic issues, visit **UrologyHealth.org/UrologicConditions**. Go to **UrologyHealth.org/FindAUrologist** to find a doctor near you.

This information is not a tool for self-diagnosis or a substitute for professional medical advice. It is not to be used or relied on for that purpose. Please talk to your urologist or health care provider about your health concerns. Always consult a health care provider before you start or stop any treatments, including medications.

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