

About Interstitial Cystitis

Did you know? An estimated 3 to 8 million women and 1 to 4 million men in the USA have symptoms of interstitial cystitis.



You Are Not Alone!

Interstitial Cystitis (IC)
Bladder Pain Syndrome (BPS)
Painful Bladder Syndrome (PBS)
Hypersensitive Bladder Syndrome (HBS)
Ketamine Cystitis (KC)

Introduction

Welcome to the Interstitial Cystitis Network, a health education company dedicated to interstitial cystitis, overactive bladder, prostatitis and other pelvic pain disorders. Our mission is to present the best research, information, and support directly into the homes and offices of our users (patients, providers & IC researchers). In addition to our magazines and newsletters, the ICN offers patient support, guest lectures & videos through our award winning website and social networking services.

If you are newly diagnosed with interstitial cystitis, bladder pain syndrome, painful bladder syndrome, hypersensitive bladder syndrome or ketamine cystitis, we want you to be hopeful. There are many medications and other therapies that can help. Self-help strategies, if done daily, can also dramatically improve your condition. Your first task is to learn more about your condition. This brief, introductory guide will get you started and includes several lists of recommended readings, DVD's, CD's, etc. that you can purchase to learn more about this complex condition.

You can begin your healing now by simply modifying your diet to reduce foods that are well known to irritate a tender, irritated bladder, such as coffees, teas and sodas. Even one cup of coffee in the morning can create pain that will last throughout the day and night. Your daily goal should be to soothe, not irritate, your bladder.

We encourage you to be an active participant in your medical care. Do not sit at home and suffer in silence. Ask for help from your medical care providers. Be willing to change bad habits and/or addictions, such as caffeine, eating excessive junk food and smoking. Ketamine cystitis patients must stop using ketamine to avoid injuring their bladders further.

We hope that you will join a support group so that you can gain support and insight into how others successfully manage their symptoms. You can find a list of support groups on our website. If you don't have a support group available, you can participate in our on-line support activities, live support group chats and special events. You just need a computer and/or phone to participate.

Please share this information with your physicians, families, friends and support group members. There are still millions of others who are still suffering in silence, at home alone. They have no idea that there are new treatments or even basic diet information. There are physicians (especially primary care providers, family medicine & emergency room staff) who are unaware that IC is a legitimate disease. We must educate as many people as we can.

The future is filled with promise. Research is moving at a fast pace and many therapies are under development. If you have not talked with your physician recently about your bladder symptoms, we encourage you to do so immediately! There are new treatment options worth exploring. We wish you well!



Interstitial Cystitis Network

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What is IC/BPS?

Patients with interstitial cystitis experience “*an unpleasant sensation (pain, pressure, discomfort) perceived to be related to the urinary bladder*” that lasts longer than six weeks in the absence of infection or other identifiable causes. The symptoms can vary greatly between individuals and even for the same person throughout the month, including urinary frequency, urgency, nocturia, pressure and/or pelvic pain. People with severe cases of IC/BPS may urinate as many as 60 times a day.

Physicians may refer to IC with a variety of names, including: *bladder pain syndrome* (BPS), *hypersensitive bladder syndrome* (HBS), *urologic chronic pelvic pain syndrome* (UCPPS) or *chronic pelvic pain syndrome* (CPPS). In the United States, it is commonly referred to as IC/BPS. *Ketamine cystitis* can occur in patients who use the drug ketamine, either recreationally or in pain management clinics.

Pain levels can range from mild tenderness to intense, agonizing pain. Pain typically worsens as the bladder fills with urine and is then relieved after urination. Pain may also radiate to the lower back, upper legs, vulva and penis. In women, symptoms may fluctuate with the menstrual cycle, often flaring during ovulation and/or just before their periods. Men and women may experience discomfort during or after sexual relations.

When an IC bladder is closely examined during a *hydrodistention with cystoscopy*, physicians often find small, bleeding wounds, also known as *petechial hemorrhages* or *glomerulations*. About five to ten percent of patients may have larger, more painful wounds known as *Hunner's Lesions*. Ulceration is very common in ketamine cystitis. Some patients with mild IC may have bladders that appear normal during a cystoscopy.

In 2009, the **RAND Interstitial Cystitis**

Epidemiology (RICE) study estimated that 3.4 to 7.8 million women in the USA have symptoms of interstitial cystitis, much higher than was previously thought. Approximately 1 to 4 million men appear to have IC though the true rate has yet to be determined because men are often diagnosed *chronic prostatitis/chronic pelvic pain syndrome* (CP/CPPS) instead. IC can occur in children, adults and the elderly.

What causes IC?

The cause of IC remains a mystery for most patients. Some IC patients report that their symptoms began after a traumatic event, such as a fall, car accident, pelvic surgery (hysterectomy or ovarian cyst removal), childbirth or chemical exposure in a swimming pool. Others believe that their IC began after a severe UTI or as a result of another medical condition such as fibromyalgia. Some patients worry that their excessive drinking of sodas, coffees and/or alcohol was the cause of their IC. Pelvic floor muscle dysfunction, spinal cord trauma and bladder over-distention may also be contributing factors. In 2007, the first reports of ketamine cystitis appeared. A popular drug used by teens and young adults throughout the world, it has been proven to cause severe bladder ulceration and damage.



Researchers at the University of Maryland have also discovered a protein in the urine of IC patients, the *antiproliferative factor* (APF), which appears to block the normal growth of the cells that line the inside wall of the bladder. Thus, it may take longer for an IC patient to heal when their bladder is injured or irritated. Researchers are also exploring the role of heredity in IC. In some cases, IC has affected a mother and a daughter or two sisters, but it does not commonly run in families.

Diagnosis

A diagnosis of IC/BPS is based on clinical symptoms, including the presence of pain (usually occurring as the bladder fills with urine), frequency and/or urgency. A wide variety of tests are usually performed to rule out other conditions as well as to determine the integrity and health of the bladder wall.

In the 1990's, the gold standard diagnostic test was the *hydrodistention with cystoscopy*. This involved stretching the bladder with water to closely examine the bladder wall. The value of that test was placed into doubt when research by Waxman (1998) determined that it could produce false positive results. With the release of the **AUA Guidelines for IC/BPS**, diagnostic testing is now less invasive and traumatic. Urodynamics testing and/or hydrodistention are only performed if the diagnosis is doubtful. If performed, the hydrodistention should be low pressure and short duration rather than the more aggressive high pressure, long duration test.

Released in 2009, the **UPOINT System for the Clinical Phenotyping of Chronic Pelvic Pain** assesses patients in six specific areas, including urinary symptoms, bladder symptoms, infection, neurological symptoms, muscle tenderness and the presence of anxiety or depression. It then suggests a customized treatment plan.

Recommended Reading

- IC Survival Guide by Robert Moldwin – ICN Shop
- ICN Education Materials - <http://www.ic-network.com/>
- AUA Guidelines for IC/BPS
- UPOINT System - <http://www.upointmd.com/>

Treatments

The **AUA Guidelines For IC/BPS** revolutionized the care of patients in the USA by offering a simple six step treatment protocol. Patients are encouraged to begin with the easy, less risky interventions in Step One and then, as needed, proceed through the steps until relief is found. Treatments are organized with respect to risk of side effects and cost. Many patients manage their symptoms by just using Step One and Step Two strategies. Hunner's lesions may require prompt, direct treatment as found in Step Three.

Step One: First-Line Treatments

- Adequate water intake.
- Diet modification to avoid foods that trigger bladder irritation, such as: coffee, soda, citrus, cranberry, etc.
- Heat or cold packs over the bladder or perineum.
- Over-the-counter products: calcium glycerophosphate (Prelief®), phenazopyridine (Azo Urinary Pain Relief Tablets®) and supplements (CystoProtek®, CystaQ®, Desert Harvest Aloe®, Cysto Renew®).
- Meditation, guided imagery, pelvic floor relaxation and bladder training.
- Good stress management skills.

- Treatment of other sources of pain and discomfort, such as: constipation, IBS, endometriosis, panic, anxiety, depression and vulvodynia symptoms.
- Avoidance of activities which can worsen symptoms temporarily, such as: wearing tight clothing, sexual intercourse and Kegel exercises.

Step Two: Second-Line Treatments

- Pelvic Floor Physical Therapy - Physical therapy can reduce muscle tension and release tight muscle trigger points. Kegel exercises are NOT recommended because they increase muscle tension.
- Pain Management - The AUA suggests that pain be evaluated at every clinical appointment. They encourage the use of multimodal pain relieving modalities (i.e. physical therapy, urinary analgesics, narcotic and non-narcotic medication, as needed). Intractable pain or more complex presentations may require referral to outside pain specialists.
- Oral Medications - *Amitriptyline* (Elavil®), *Cimetidine* (Tagamet®), *Hydroxyzine* (Vistaril®, Atarax®), *Pentosan polysulfate* (Elmiron®)
- Bladder Instillations - *DMSO* (aka RIMSO-50®), *Heparin* and/or *Lidocaine* (aka Rescue Instillations).

Step Three: Third-Line Treatments

- Low pressure hydrodistention with cystoscopy
- Hunner's lesions should be treated with fulguration and/or triamcinolone injection.

Step Four: Fourth-Line Treatments

- Neuromodulation (tibial, sacral or pudendal) - The non-surgical, more affordable tibial method (Urgent PC®) is often attempted before the more invasive, costly surgical method (Interstim®).
- Botulinum Toxin (BTX-A) injections

Step Five: Fifth-Line Treatments

- Cyclosporine A

Step Six: Sixth-Line Treatments (Rare)

- Surgical intervention, such as urinary diversion, substitution cystoplasty or cystectomy.

Recommended Reading

- Exploring IC Treatments - <http://www.ic-network.com/treatments/>
- The Proactive Patient: Managing IC & Related Conditions by Gaye & Andrew Sandler
- IC Survival Guide by Robert Moldwin – ICN Shop
- Ending Female Pain by Isa Herrera – ICN Shop
- Heal Pelvic Pain by Amy Stein PT – ICN Shop

The Role of Diet

Diet modification is critical for patients struggling with bladder irritation and inflammation. Foods high in caffeine, acid, alcohol, and/or histamine can irritate the wounds in the bladder triggering IC flares, pain and discomfort. A comprehensive diet list, the **2012 IC/BPS Food List**, is available for download on our website. The foods below are the worst offenders and should be avoided for three to six months to give the bladder a chance to recover.



#1: Coffees and Teas

Coffee and tea are, regrettably, the worst bladder offenders. In a sensitive, wounded bladder, the acid, caffeine and tannins in regular & decaf coffees, teas and green teas can cause intense irritation and discomfort. In our experience, the patients who seem to struggle the most with IC pain are those who refuse to give up their coffee or tea. Even one cup of day scours the wounds in the bladder and can trigger long-term pain and discomfort.

If you are struggling with IC symptoms and/or a flare, the safest hot drinks are hot water or milk with sugar or honey! Tea lovers can try a simple herbal peppermint, chamomile or roasted carob based tea. Coffee is a well known bladder irritant. We strongly suggest avoiding all coffees when symptoms are active. You can find a variety of low acid coffees (**Simpatico®**, **Puroast®**) in the ICN Shop.

#2: Cranberry & Other Fruit Juices

Known as the ACID BOMB when it hits the bladder, cranberry juice is often the most surprising irritant for newly diagnosed patients. Sadly, well meaning family, friends and sales clerks often suggest cranberry juice to patients with bladder problems. Unfortunately, most

cranberry products trigger bladder symptoms and have no beneficial value for IC though cranberry has shown some effectiveness for patients struggling with e-coli based bladder infections. Citrus juices such as orange, grapefruit & lemonade will also be irritating to the bladder. If you are desperate for a juice, we recommend trying a baby pear or apple juice. Baby juices usually contain less citric acid than adult juices and seem to be more bladder friendly.

#3: Sodas, Energy Drinks or Vitamin Waters

Most soda drinks (i.e. colas, lemon lime drinks, orange drinks, etc.) are so high in acid and/or caffeine that they badly irritate the bladder. The worst appear to be diet sodas, which can be a quadruple whammy of acidic carbonation, citric and other acids, caffeine, and artificial sweeteners-- four well-known bladder irritants. Beware of energy drinks and vitamin waters as well.

#4: Tomato Products

Concentrated tomato products, such as soup, pasta sauce and juice, are simply too high in acid and are notorious for triggering bladder discomfort. If you're desperate for pasta, try using a pesto, clam or carbonara sauce instead. Pizza lovers can request a white sauce or the tomato sauce on the side.

#5: Multivitamins

Multivitamins that contain Vitamins C (Ascorbic Acid) and B6 are well known bladder irritants. A new lower acid multivitamin, MultiRight (www.multiright.com), has worked well for many patients. The best way to get your vitamins and to avoid irritating your bladder is to eat fresh vegetables, fruits and meats

#6: Beer, Wine & Spirits

Alcohol causes stinging when poured on a wound thus it should be no surprise that most alcohols bother IC patients. There are, however, some lower alcohol and acid varieties that might be more tolerable.

#7: Artificial Sugars

Both research studies and patient stories have confirmed that most artificial sweeteners (aspartame, saccharin, sucralose, etc.) appear to be bladder irritating, particularly aspartame (i.e. NutraSweet®).

Recommended Reading

- 20012 IC/BPS Food Guide – <http://www.ic-network.com/diet/>
- A Taste of the Good Life: A Cookbook for an IC Diet – ICN Shop
- Confident Choices: Customizing the IC Diet – ICN Shop
- Confident Choices: A Cookbook for IC and OAB

Understanding IC Flares

Interstitial cystitis patients often struggle with a sudden and dramatic worsening of their bladder symptoms, known as an *IC flare*. Lasting from hours to weeks, flares can be unpredictable, disruptive, frustrating and difficult to manage for both newly diagnosed and veteran IC patients. With time and experience, patients can learn the subtle differences between flare types and how to manage and prevent them. The most frequent types of flares occur when the bladder wall is irritated, when the pelvic floor muscles become tight or spasm and, for women, when hormone levels change.

Bladder Wall Flares

If the bladder wall is irritated or inflamed, even small amounts of urine can result in a desperate and painful need to urinate. For most IC patients, the first line of defense is to avoid those foods, beverages or drugs (i.e. ketamine) that are problematic. Drinking some water to dilute the urine or using **Prelief**® to reduce the acid in their urine may help. A bladder anesthetic, such as **Pyridium**® or **Azo Bladder Pain Relief Tablets**® may reduce bladder wall discomfort immediately though, for some patients, stronger pain management may be necessary.

Pelvic Floor Flares

Driving in a car, flying, exercising or enjoying intimacy may trigger pelvic floor and bladder spasms. Pelvic floor pain is lower in the belly, duller, more consistent and may have a burning quality to it. Some patients report that their bladder feels very heavy or that something is falling out of them. Where bladder wall flares hurt as the bladder fills with urine, pelvic floor flares and/or bladder spasms often hurt most after urination. Strategies to reduce muscle tension are ideal including: using a heating pad to relax muscles, a warm bath, a muscle relaxant, gentle stretching, and/or pain medication as needed. Bladder spasms can be treated with an antispasmodic medication. An **ICN Bladder Friendly Chair Cushion** can make sitting and driving much more comfortable.

Hormonal Flares

Women with IC quickly learn that their bladders are hormone sensitive. It's fairly normal to flare during ovulation and/or a couple of days before their period. Luckily, these flares are usually very short term and predictable. Post-menopausal women may struggle with vulvar, vaginal and bladder discomfort from dry or

atrophied skin. Women past the age of 30 or who have had a hysterectomy should have their gynecologist examine their vulva and vagina occasionally for signs of estrogen depletion. If present, a preservative free estrogen cream or vaginal insert may help.



Could a flare be a UTI?

Many IC patients have unnecessarily taken antibiotics for years only to discover they had interstitial cystitis rather than bacterial cystitis. It's important to remember that an IC flare and a UTI have very similar symptoms. Yet, IC patients can get occasional bladder infections. If you experience a burning sensation in the urethra during urination, see blood in your urine, experience fever, chills and/or low back pain, you may have a bladder infection. Please contact your physician immediately and request a urine culture. Some patients use a home UTI test kit, such as **Azo Test Strips**, to help them differentiate between an IC flare and a bladder infection.

Recommended Reading

- ICN Managing IC Flares - <http://www.ic-network.com/flares/>
- ICN Pain Resource Center - <http://www.ic-network.com/pain/>
- ICN Self Help Strategies - <http://www.ic-network.com/selfhelp/>
- Ending Female Pain by Isa Herrera PT - ICN Shop
- Heal Pelvic Pain by Amy Stein PT - ICN Shop

Five “Must Have” Resources For Newly Diagnosed Patients

As a newly diagnosed patient, your first goal is to gather information so that you can manage your IC symptoms, prevent IC flares and make informed decisions about what treatments, if any, you will try. The ICN offers a wide variety of resources that can help. Here are the most popular items purchased by newly diagnosed patients. Available at: www.icnsales.com, by phone (707)433-0413 or by mail.

[] \$16.99 - **The IC Survival Guide** by Robert Moldwin MD is an excellent resource to share with family or friends who don't understand IC. It covers IC diagnostic tests and treatments in depth and offers a superb section on pain management. It is THE BOOK you take to every doctor's appointment to credibility test and research proposed treatments.

[] \$12.50 - **ICN Guide to the IC Diet** discusses, in depth, foods to avoid and, more importantly, foods that you can enjoy without irritating your bladder. Includes our new alphabetized list of 250 foods, each broken down into "friendly," "try it" and "caution" categories. Patient success stories are shared and the three authors of the IC Cookbooks each offer their own insights!

[] \$10.00 - **ICN Guide to Managing Flares** offers a comprehensive discussion of the types of flares that IC patients struggle with and the most common strategies used to help manage and reduce them.

[] \$16.95 - **Heal Pelvic Pain** by Amy Stein MPT is the perfect book for men and women newly diagnosed with pelvic floor dysfunction. It offers readers a program of strengthening, stretching and relaxation exercises, massage techniques and self-care therapies for chronic pelvic pain without drugs or surgery.

[] \$25 (By E-mail) or \$50 (by Regular Mail to USA & Canada) - **IC Optimist Magazine Subscription** will help you stay informed about therapies, promising IC research, self-help tips & much more! These articles will help you, today, better control your IC.

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Your order can be placed on our secure website (www.icnsales.com) by phone (800)928-7496, fax (707)538-9444 and US Mail. We accept checks, money orders or credit cards. If you are paying by credit card, please provide the following information:

Credit Card: (Circle One) Visa - MC - Discover - AMEX
Name on Card: _____
Billing Address, City & Zip: _____
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Checks and money orders should be made out to the “IC Network.”
Please allow 3-4 weeks for the delivery of your order.

About The IC Network

Founded in 1995, the Interstitial Cystitis Network is a health education & publishing company that brings many of the best IC resources directly into the homes and offices of patients in need. We facilitate one of the largest urology support groups in the world where tens of thousands of patients have gathered, each day, to educate, encourage and support each other.

SUPPORT SERVICES - The ICN provides comprehensive patient support services in the USA and on the web. Join more than 30,000 other patients in the **ICN Support Forum** where you'll find more than one hundred forums dedicated to various IC topics. You can ask questions, correspond with other IC patients and receive comfort in knowing that you are not alone. We also offer a free patient education and support phone line. Wellness coaching is also available.

IC INFORMATION - The ICN was the top rated website dedicated to interstitial cystitis in studies conducted by Harvard Medical School (2011) and the University of London (2013). We offer a wide variety of patient educational materials to explore, as well as the latest industry news, IC clinical trials, physician & physical therapist listings, guest lecture transcripts, drug assistance programs, disability resources and much more. We offer more than twenty free videos on IC through **YouTube** that explain diet, treatments, self-help, traveling and much more! Don't forget to sign up for our free e-newsletter so that you can stay in touch with the latest IC news! You can also find the ICN on **Facebook** & **Twitter**.

IC RESOURCE MATERIALS – The **ICN Mail Order Center** offers a wide variety of books, audiotapes and CDs to help you learn about IC and its related conditions. We also carry a variety of products and food including: UTI test kits, bladder friendly chair cushions, heating pads, OTC supplements (i.e. Preliief, AZO Bladder Pain Relief Tablets, CystoProtek), low acid coffees & teas, IC friendly foods, Heather's Tummy Care IBS products and much more. See our full catalog at: www.icnsales.com.



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<http://www.ic-network.com>

<http://www.icawareness.com>

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