

Interstitial Cystitis Network

A Health Education Company Dedicated to IC & Pelvic Pain Disorders - 707.538.9442 - <http://www.ic-network.com>



- **Interstitial Cystitis (IC) * USA**
- **Bladder Pain Syndrome (BPS) * Europe**
- **Hypersensitive Bladder Syndrome (HBS) * Japan**
- **Urologic Chronic Pelvic Pain Syndrome (UCPPS)**
- **Chronic Prostatitis/Chronic Pelvic Pain Syndrome (CP/CPPS)**

Introduction

Welcome to the Interstitial Cystitis Network, a health education company dedicated to interstitial cystitis, 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, on-line classes, guest lectures & videos through our award winning website and social networking services.

If you are newly diagnosed with interstitial cystitis, we want you to be hopeful. IC is treatable. 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 interstitial cystitis. 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. We strongly recommend that you take advantage of these extra resources.

You can begin your healing now by simply modifying your diet to reduce foods that are well known to irritate the 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. Create a partnership with your doctor as you both seek to understand and find a treatment for your IC. Be bold and ask questions. Take the time to track your progress by using a voiding or pain diary.

We hope that you will join a support group so that you can gain support and insight into how others successfully manage their IC. You'll find a list of support groups and international organizations on our website. If you don't have a support group available, you can participate in our on-line support activities. In addition to monthly live support group chats, we often have free lectures with many of the best IC clinicians and researchers in the world. 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 with IC 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. IC research is moving at a fast pace and many therapies are under development. If you haven't 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! - *Jill H. Osborne, ICN Founder*



Interstitial Cystitis Network

PO Box 2159, Healdsburg CA USA 95448
Patient Assistance: (707)538-9442
Fax: (707)538-9444
Mail Order Center: (707)433-0413
<http://www.ic-network.com>
<http://www.icawareness.com>
<http://www.icnsales.com>

Find us on Facebook, Twitter and YouTube

Disclaimer:

The ICN website and publications are for informational purposes only. The IC Network is not a medical authority nor do we provide any medical advice. Nothing contained in this publication should be considered medical advice and should not be relied upon as a substitute for consultation with a medical professional. We strongly recommend that you discuss your medical care and treatments with your personal medical care provider (i.e. physician). Only that medical professional can and should give you medical advice.

*What is IC Adapted from the 2010 AUA Guidelines for IC/BPS
Diagnosis & Treatment Sections Adapted From The NIH/NIDDK Guide
to IC/BPS*

Diet, Treatment & Flares Section Adapted From The ICN Website

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.

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. Women's symptoms may fluctuate with their 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 Ulcers*. Some patients with mild IC may have bladders that appear normal during a cystoscopy.

In 2009, the **RAND Interstitial Cystitis Epidemiology (RICE)** study provided astonishing new data on the prevalence of IC in the USA. This National Institutes of Health funded 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, teens, young adults and the elderly.

*There is nothing so moving, not even acts of love or hate,
as the discovery that one is not alone! – R. Ardrey*

What causes IC?

The cause of IC remains a mystery. In a 2000-2001 ICN Research Survey, we asked patients how they believed their IC began. Some IC patients reported 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 believed that their IC began after a severe UTI or as a result of another medical condition such as fibromyalgia. Some patients thought 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 overdistention may also be contributing factors.



Researchers at the University of Maryland have 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. Since then, clinicians in the USA have favored less invasive and more affordable tests such as the potassium sensitivity test or anesthetic challenge to determine if the bladder wall is damaged. If a hydrodistention is performed, it was suggested in the **2010 AUA Guidelines for IC/BPS** that it be low pressure and short duration rather than the more aggressive high pressure, long duration test.

Released in 2009, the new **UPOINT System for the Clinical Phenotyping of Chronic Pelvic Pain** is gaining considerable attention by clinicians. It assesses IC and pelvic pain 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 Patient Education Materials - <http://www.ic-network.com/patientlinks.html>
- 2010 AUA Guidelines for IC/BPS
- UPOINT System - <http://www.upointmd.com/>

Treatments

Most physicians and IC clinics utilize a multi-modal approach to therapy, offering therapies that can reduce discomfort and improve symptoms. For example, a newly diagnosed patient struggling with bladder pain and frequency might be given rescue instillations, a bladder coating, an antihistamine, physical therapy and, if needed, pain management.

A. Bladder Instillations

A bladder instillation is placed directly into the bladder via a small catheter. The medication is held for varying periods of time, from a few seconds to 15 minutes or more ("dwell time"), before being drained or voided. Some treatments are thought to coat and protect the bladder, while others are thought to suppress inflammation. Many physicians instill *bladder cocktails* that they believe work better than a single medication. The most common instillations used today are rescue instillations made with heparin or Elmiron, Uracyst, Cystistat and/or Rimso-50.

B. Oral Drugs

A variety of oral medications and food supplements are available, including:

- Bladder Coatings: Elmiron
- Antidepressants: Elavil, Imiprimine
- Antihistamines: Atarax, Vistaril
- Antispasmodics: Ditropan, Levsin, Urispas, Urised
- Muscle Relaxants: Valium, Flexeril
- Urinary Anesthetics: Urised, Pyridium
- OTC Supplements: CystaQ, Cystoprotek, Algonot

Bladder coatings are believed to help protect the bladder wall. Antidepressants and antihistamines can help to reduce mast cell induced inflammation and nerve discomfort. Antispasmodics are ideal for patients struggling with bladder spasms. Muscle relaxants can help reduce pelvic floor muscle tension. Urinary anesthetics may help reduce minor pain and discomfort originating from the bladder wall. *Quercetin* based OTC food supplements (i.e. **Cystoprotek, CystaQ**) have gained popularity in recent years, particularly with patients who cannot afford traditional medication or who wish to explore a more natural approach to treatment.

C. Pelvic Floor Rehabilitation

IC patients frequently struggle with unusually tight pelvic muscles and/or trigger points that may make it difficult to start their urine stream, sit for long periods of time or enjoy sexual relations. Many IC clinics now provide physical therapy to help patients control and reduce muscle tension.

D. Neuromodulation & Surgery

Neuromodulation and surgery are considered only after all other therapies & self-help strategies have been tried and failed. *Sacral neuromodulation* is a controversial therapy due to the potential risks, lack of published long-term data and difficulty in removing the device. A less invasive form of neuromodulation, *post-tibial nerve stimulation*, is also available. We encourage you to educate yourself and speak with other patients who have experienced neuromodulation to understand the potential risks and benefits. The IC Network offers several discussion forums for this purpose.

Recommended Reading

- Exploring IC Treatments - <http://www.ic-network.com/treatments/>
- 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, salt and/or potassium irritate the wounds in the bladder triggering IC flares, pain and discomfort. A comprehensive diet list, the **2009 IC/BPS Food Guide**, 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're struggling with IC symptoms and/or a flare, the safest hot drink is hot water with sugar or honey! Tea lovers can try a simple herbal peppermint, chamomile or roasted carob based tea. You can find a wide variety of no & low acid coffees (**Tyler's**, **Euromild & Puroast**), herbal coffees (**Pero**, **Cafix & Kaffree Roma**) 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 in an IC patient's diet. 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're 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 much 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. If you must have a soda, try a non-diet, usually non-caffeinated, root beer and load the cup with plenty of ice to dilute it! Beware of energy drinks or vitamin waters now being sold throughout the nation. Drinks that are high in Vitamin C or B, that use stimulants and/or citric acid can be badly irritating to the bladder. As a substitute, look for a low sodium mineral water, such as San Pellegrino.

#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. Yellow tomatoes seem to be less acidic than most of the red tomatoes. You can often find low acid tomato plants to grow in your annual vegetable garden.

#5: Multivitamins

Multivitamins that contain Vitamin C (Ascorbic Acid) and Vitamin B6 are well known bladder irritants. Other vitamins, such as Vitamin E and D, do not appear to irritate the bladder. The best way to get your vitamins and to avoid irritating your bladder is to eat fresh veggies and fruits rather than artificially manufactured vitamins. You can find a list of IC friendly fruits and veggies in the **2009 IC/BPS Food Guide**.

Recommended Reading

- 2009 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 in the bladder can result in a desperate and painful need to urinate. The first line of defense is to avoid those foods or beverages 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 help 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 vaginal burning quality to it. Some patients report that their bladder feels very heavy or that something is falling out of them. When 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 their 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. These can be purchased on-line at: www.icnsales.com, by phone (707)433-0413 or by mail.

[] \$13.99 - **The IC Survival Guide** by Robert Moldwin 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.

[] \$10.00 - **ICN Special Report on 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.

[] \$10.00 - **ICN Special Report on Managing Bladder Pain** will help you determine the many potential triggers for bladder pain and how it is treated. Learn how to prevent painful IC flares with this easy guide.

[] \$12.50 - **My Mom Has Interstitial Cystitis: A Painful Bladder Story** helps you educate your family and, particularly, young children about IC. Children are often silent victims in an IC household. They can see that their mom or dad is ill. They can be frightened by doctor's visits. They may worry, unnecessarily, that their parent is dying. This funny, lighthearted book educates them about IC, about doctors, about the bladder and offers ways that they can help at home.

[] \$30 (By E-mail) or \$60 (By Regular Mail) - **IC Optimist Magazine Subscription** will help you stay informed about therapies, promising IC research, IC patient events, clinical trials & much more! These articles will help you, today, better control your IC. More subscription types are available, including professional & gold subscriptions. Read more about them at: <http://www.icnsales.com>.

Order Summary

Total Items: _____
Subtotal: _____
Shipping: \$5.50 (except subscriptions, which have no shipping cost)
Amount Due: _____

Customer Details

Name: _____
Address: _____
City, State, Zip: _____
Daytime Phone: _____ Evening Phone: _____
E-mail: _____

Payment Details

Your order can be placed by phone (707)433-0413, 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: _____

Card Number: _____ Exp. Date: _____

Please detach this form and mail or fax to:

IC Network - P.O. Box 2159, Healdsburg CA 95448 --- (707)538-9444 (FAX)

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. We offer live IC support group meetings in our on-line chat room and “Meet the IC Expert” guest lectures that allow patients to interact with many of the best clinicians and researchers in the world. Join other patients in the **ICN Support Forum** and on Facebook 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.



IC INFORMATION - Our award winning website offers 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, low acid coffees & teas, IC friendly foods, Heather’s Tummy Care IBS products, the Very Private line of products and much more. See our full catalog at: <http://www.icnsales.com>.

Interstitial Cystitis Network

A Health Education Company dedicated to IC, BPS, HBS, PFD & CP/CPPS

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

<http://www.icawareness.com>

<http://www.icnsales.com>

PO Box 2159

Healdsburg, CA 95448 USA