



Conquering IC.
Changing Lives.

WE'VE GOT GUIDELINES!

AUA Makes It Official

The first-ever American Urological Association (AUA) clinical guidelines for IC are now official. They will be a huge boon, helping to end the all-too-common misdiagnosis, underdiagnosis, mistreatment, and undertreatment, especially undertreatment of pain.

Arm yourself with these guidelines to get the best possible treatment. “When you’re diagnosed with IC or you think you have it, show the guidelines to your doctor and discuss the different options. That’s patient empowerment, and that’s important,” said ICA Medical Advisory Board Co-Chair Philip M. Hanno, MD.

The multidisciplinary team that developed the guidelines included ICA Executive Director Barbara Gordon, who made sure IC patients’ voice was heard. Thanks to her input, the guidelines include these important points: The potassium sensitivity test is not useful. Pain control is essential at every step of the treatment process, including using opioids when they’re needed. Men get IC, too—more than we used to think. Diet and other self-care techniques are important.

You can read the final guidelines and watch a webinar on the AUA website. Go to www.auanet.org. Click on “Policies, Guidelines, & Quality” and look for “Interstitial Cystitis/Bladder Pain Syndrome.”

Flexible Guidelines to Fit You

“Final” doesn’t mean the guidelines are set in stone. AUA will update them periodically, and they have plenty of flexibility built in. They make the point that *your preferences are key*.

Guiding the final version are the same principles that guided the preliminary version we reported on in the Summer 2010 *ICA Update*: For most patients, the diagnosis can be based on symptoms, not painful or invasive tests. Treatment should start with the gentlest therapies and step up to stronger stuff as needed. Major surgery remains the last resort.

What’s changed are the number of steps (now six) and the place of two treatments: Neuromodulation was bumped

down from a third-line to a fourth-line treatment and cyclosporine from a third-line to a fifth-line treatment.

Here are the key points for you from the guidelines:

Diagnostic Principles

- Start with a careful history, physical exam, and lab tests to rule in symptoms and rule out conditions that might be confused with IC.
 - Pain is the hallmark symptom, including pressure and discomfort—especially pain that worsens with specific food or drink or as your bladder fills and gets better with urination.
 - The potassium sensitivity test is **NOT** a useful diagnostic tool. Plus, it can hurt and trigger a severe symptom flare.
 - Urodynamic findings aren’t consistent in IC, and the tests can be very uncomfortable.
- Measure voiding and pain from the start so you and your doctor can see if treatment is working.
- Cystoscopy and/or urodynamics are **NOT** necessary for most patients. Use them only when the diagnosis is in doubt and the symptoms are complicated.
 - “Complicated” includes incontinence/overactive bladder, gastrointestinal problems, blood or protein in the urine, and gynecologic problems.
 - Any test should help identify and rule out another condition. Cystoscopy can rule out stones, urethral diverticula, or bladder cancer and rule in Hunner’s lesions.

Treatment Principles

- Start with the least invasive treatments and step up when they don’t control symptoms or improve quality of life. Surgery, other than to “burn” off Hunner’s lesions, is the last resort.
- The treatment to start with depends on your symptoms, how bad they are, the doctor’s judgment, and your preferences.
- Consider multiple, simultaneous treatments (multimodal therapy).
- Tracking how your symptoms change with treatment is critical. When a treatment isn’t working, stop!
 - How long to give a treatment will be between you and your doctor. *Speak up* if you think a therapy isn’t working! There are a lot of options today.
- Control pain! You and your doctor should keep an eye on pain and consider referrals to specialists and multidisciplinary approaches if your current treatment isn’t working.
- If you try a lot of treatments that don’t make you feel better, maybe you don’t have IC. Look at what else could be wrong.

Treatment Steps

First-line Treatments

- Get educated.
 - Learn what we do and don't know about IC and treatment benefits and risks. (Go to www.ichelp.org/!)
 - No one treatment works for everyone. It can take trial and error and treatment combinations to get your IC under control.
- Start self care and “behavioral modifications” as soon as you can, such as:
 - Adjust fluid intake. Increase or decrease depending on your situation.
 - Apply heat or cold over the bladder or between the legs.
 - Avoid diet triggers. Use an elimination diet to figure those out.
 - Try over-the-counter products: **neutraceuticals**, calcium glycerophosphates (**Prelief**), Pyridium (phenazopyridine).
 - Treat trigger points and hypersensitive areas.
 - Practice meditation or guided imagery.
 - Relax the pelvic floor muscles.
 - Modify or **STOP** Kegels, sexual intercourse, tight clothes, constipation.
- Manage stress.
 - Plus, get help for troubles that prompt flare-ups or make pain worse, such as irritable bowel syndrome (IBS), endometriosis, recurrent vaginitis/vestibulitis, menstrual cycle flare-ups, panic attacks, depression.

Second-line Treatments

- Appropriate physical therapy
 - That's therapy to help resolve pelvic floor, abdominal, and/or hip muscle trigger points, lengthen contracted muscles, and release painful scars and connective tissue restrictions. It's not Kegels.
- Pain management, including drugs, stress management, and manual therapy
 - Patients may need opioid painkillers. The guidelines outline how to manage them.
 - Combinations of drugs and drugs combined with complementary therapy, such as physical therapy, may ease pain better than one type of drug.
- Oral medications: Pregabalin, cimetidine (Tagamet), hydroxyzine (Vistaril, Atarax), or (Elmiron) or CystoProtek or Desert Harvest Aloe Vera.
 - This list is in alphabetical order. All got an evidence grade of B, except hydroxyzine, which got a C.
- Bladder instillation medications: DMSO, heparin, lidocaine
 - This list is in alphabetical order. Lidocaine Patch 5% got an evidence grade of B. The others got a C.

- If you use DMSO, hold it for only 15 to 20 minutes. Holding it longer can be very painful. Take care when DMSO is part of a cocktail, since it can enhance absorption of the other drugs, so toxicity is a risk.

Third-line Treatments

- Cystoscopy under anesthesia with short-duration (less than 10 minutes), low-pressure (60 to 80 cm of water) hydrodistention.
- Ask about how to reduce pain after hydrodistention, such as anesthetic instillation during the procedure.
- Treating Hunner's lesions can offer big relief. They can be taken off with electrodes or laser or injected with the steroid triamcinolone (Kenalog).

Fourth-line Treatments

- Neurostimulation—when other treatments haven't helped enough or you and your doctor agree your symptoms justify it.
 - Neurostimulation is for frequency/urgency. It is much less effective, and maybe not at all, for pain.

Fifth-line Treatments

- Cyclosporine (an immunosuppressant)—when other treatments haven't helped enough or you and your doctor agree your symptoms justify it.
 - The risk of side effects is high, so work with a healthcare professional experienced with this drug.
- Botulinum toxin A (Botox) injections into the bladder muscle—when other treatments haven't helped enough or you and your doctor agree your symptoms justify it.
 - Side effects can be difficult, including painful urination and retention that may require you to catheterize yourself for a long time.
 - This isn't the same treatment as Botox injection into the pelvic floor, which is used experimentally for pelvic floor dysfunction

Sixth-line Treatment

- Major surgery (bladder removal or enlargement or urinary diversion) only when **EVERYTHING** else has failed

Don't Use These Treatments

Long-term oral antibiotics, Bacillus Calmette-Guerin (BCG) instillation, resiniferatoxin instillation, high-pressure and long-duration hydrodistention, long-term oral steroids



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Did this article help you? Do you plan to use the information here? Let us know at takingaction@ichelp.org.