

INTERSTITIAL CYSTITIS/BLADDER PAIN SYNDROME

Patient Fact Sheet

Introduction

You have been told by your clinician that you have a condition commonly known as interstitial cystitis or “IC.” The new term for this is bladder pain syndrome (BPS) or IC/BPS since a syndrome of symptoms are often present for at least 6 weeks. Many women and men with IC/BPS have frequent urinary urge to empty the bladder much more than the average of 8 times in a day, and can urinate small amounts up to 50 times in a 24 hour period. IC/BPS is not caused by bacteria so isn’t helped by taking antibiotics. Current research shows there may be 2 sub-classes of IC/BPS—one group having true ulcers or Hunner’s lesions, in their bladder accounting for about 10-15% of those with IC/BPS, and the other group with symptoms often related to pelvic floor muscle spasms and nerve upregulation leading to the syndrome of symptoms present. This 2nd group comprises 85% of the population diagnosed with IC/BPS. Often the ulcerative type occurs in those over 40 years of age, while the second, larger group is comprised of younger people who become symptomatic. It is important that you know which group you fit into so that appropriate treatments may be ordered.

The symptoms that you might notice include

- The feeling that the bladder needs to be emptied soon, even after just voiding—this is called “urge”.
- Emptying the bladder as often as every 10-20 minutes—this is called “frequency”.
- Urinating frequently but only very small amounts of urine even if fluid intake is adequate (at least 48 oz/day)
- Waking up more than 2 times per night with a strong need to empty the bladder.
- Dull to sharp to burning sensations/discomfort/pain over the bladder and into the genitalia (private area of the body)
- Your symptoms may be worse after eating spicy, acidic foods, some wines and caffeine.
- Your symptoms may worsen with exercise, or with environmental allergy flares.

Signs that your healthcare provider may find on examination

- Blood in the urine seen through a microscope.
- Small areas of bleeding or ulcers in the bladder wall seen when looking at the bladder through a scope (cystoscopy)
- Small bladder capacity as determined by a voiding diary, ultrasound, or other testing. The normal adult bladder holds about 500-700 ml, with people often feeling an urge to urinate after about 2 cups of fluid intake.
- Pain during an exam when the pelvic floor muscles (levator muscles) are touched in different areas.

Treatment

Treatment should target the type of IC/BPS that you have.

For the 85% of people with pelvic floor muscle spasms and nerve upregulation along with their bladder pain:

- Pelvic floor physical therapy to release the muscle spasms is a first line of therapy (no Kegels).
- Guided imagery, gentle yoga, relaxation techniques/heat/cold, and stress reduction are key.

For both groups of IC/BPS:

- Medications are available to alleviate the symptoms.
- Bladder instillations of various medicines may help down-regulate the nerves to help alleviate pain.
- IC/BPS diet recommendations can be found at the following two websites: www.ic-network.com and www.ichelp.org
- Psychological support for dealing with pain/relationship/work issues can help.

For those with ulcerative IC/BPS (10-15% of those diagnosed):

- Medications to heal the bladder lining may be helpful—they can take 6 months to work.
- Outpatient surgery to correct the ulcerative areas of the bladder can be helpful if done by an expert in the field.

Prevention:

Researchers are still working on this. Drink adequate fluids, limit stress, and be aware of pelvic muscle tension or pain early on to get early treatment.

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