



Patient Education Sheet

Interstitial Cystitis or Bladder Pain Syndrome

The SSF thanks the Interstitial Cystitis Association (ICA) for authoring this Patient Education Sheet.

Interstitial cystitis (also known as IC) is a chronic bladder condition that usually consists of recurring pelvic pain, pressure, or discomfort in the bladder and pelvic region, urinary frequency (needing to go often) and urgency (feeling a strong need to go). IC also may be referred to as painful bladder syndrome (PBS), bladder pain syndrome (BPS), and chronic pelvic pain (CPP). The exact cause is unknown, but researchers have identified different factors that may contribute to the development of the condition. About 25% of IC patients have a definite or probable diagnosis of Sjögren's, and as many as 14% of Sjögren's patients are estimated to have IC.

Some things you can do to control your IC include:

- Avoid or limit foods and beverages that may irritate the bladder, including coffee, tea, soda, alcohol, citrus juices, and cranberry juice. For some, spicy foods may be a problem as well as foods and beverages containing artificial sweeteners.
- Apply heat or cold over the bladder or between the legs to alleviate some pain.
- Modify or stop Kegel exercises which may make pelvic floor muscles even tighter.
- Avoid tight clothing to prevent further irritation and restricted blood flow to the pelvic region.
- Treat constipation. It can add pressure to the pelvic area and increase pain and discomfort.
- Develop healthy sleep habits as sleep is crucial for pain control.
- Adjust fluid intake. Increase or decrease depending on your situation.
- Retrain your bladder by learning to urinate on a set schedule and not when your bladder tells you.
- Find healthy ways to manage your stress since it may make IC symptoms worse.
- Find, in advance, the location of restrooms along your route when traveling.
- Get active! The health of your bladder depends on good blood flow to the area and on having flexible and strong muscles around your bladder and other pelvic organs to protect and support them.
- Quit smoking. Cigarettes may irritate the bladder and worsen pelvic and bladder pain.
- Take a trial and error approach to treatment as no one treatment works for everyone. A combination of treatments is often necessary to get your IC under control.
- Track how your symptoms change with treatment and speak with your healthcare provider if you think a therapy is not working.

Visit the Interstitial Cystitis Association website, www.ichelp.org, for the most up-to-date and accurate information about IC and to find knowledgeable healthcare providers.

For more information on Sjögren's, contact the Sjögren's Syndrome Foundation at:
6707 Democracy Blvd, Suite 325, Bethesda, MD 20817 • 800-475-6473 • www.sjogrens.org • ssf@sjogrens.org.

Clinicians: Please make multiple copies of this Patient Education Sheet and distribute to your patients.