

Tips for Patients with Interstitial Cystitis/ Bladder Pain Syndrome (IC/BPS)

Finding an HCP, Seeking a Diagnosis, and Pursuing Treatment

Many patients with interstitial cystitis/bladder pain syndrome (IC/BPS) report struggling to communicate with their healthcare providers (HCPs) about their condition. While many patients say they talk about their entire experience with IC/BPS, including its emotional, social, and psychological toll, many HCPs say they hear these issues as more of modest complaints. HCPs report hearing a greater emphasis on the physical symptoms of IC/BPS, including bladder pain and urinary symptoms. This provider-patient dynamic is not unique to IC/BPS. “As medicine grows more complicated, the gap between what patients say and what doctors hear – and vice versa – grows more significant,” says Danielle Ofri, M.D., author of *What Patients Say, What Doctors Hear*. How patients and their healthcare providers communicate is a critical element of effective medical care.

Finding an HCP

If you suspect you may have IC/BPS, but have not yet been diagnosed, talk to your primary care provider or visit a Urologist about your concerns. Because IC/BPS involves a process of ruling out other potential causes of your symptoms, it is often helpful to find an HCP who is familiar with IC/BPS. Click [here](#) to access the Interstitial Cystitis Association's healthcare provider registry.

Seeking a Diagnosis

Here are some tips for a productive dialogue:

- **Be prepared:** An HCP who suspects you are experiencing IC/BPS will want to hear about your symptoms—physical, emotional, psychological, and social. The key symptoms to an IC/BPS diagnosis are physical ones: bladder pain; other urinary symptoms that persist for more than six weeks; and the absence of infection or other identifiable causes. Before you see your provider, consider keeping a log or diary of your experience. Such a diary should document your experience with:
 - o Bladder pain (which can feel like pain, pressure or discomfort in your bladder). Note how severe your pain is and when during the day it is most severe
 - o Urinary frequency, or how often you need to go to the bathroom daily
 - o Urgency, or the feeling of a sudden, uncontrollable urge to go to the bathroom
 - o Nocturia, or how many times you wake up to go to the bathroom during the night
 - o Keep detailed notes on the foods and drinks you consume, and when
 - o Keep track of your stress levels, physical activities, or emotional states during a day, as these may correlate with increased pain levels, and suggest potential treatment approaches
 - o Bring information about any recent lab test results and medications you are taking. Often patients with IC/BPS are mistakenly diagnosed with urinary tract infections, while lab cultures are negative.

This information may be useful to your provider:

- **Be clear about what you want:** When your provider asks you how they can help you, be as clear as you can about your goal for this consultation. Perhaps you want to know if you have IC/BPS. Or, if you have already been diagnosed, you may want to discuss a change in your treatment approach.
- **Be responsive:** Your healthcare provider will likely ask questions to guide his or her assessment. Discuss your physical symptoms as well as the emotional, psychological, social, and quality of life impacts of your disease openly. Try to be as objective as you can.

Pursuing treatment

No single treatment approach works for all patients with IC/BPS, but there are options. Working with your provider will likely involve a combination of approaches to address your IC/BPS symptoms.

- **Ask informed questions:** You may want to read the American Urological Association guideline for IC/BPS. While an HCP has specific training that makes them the best judge of the right approach, some providers may not be familiar with the guideline. (Click [here](#) to access the guideline and [here](#) to download a .pdf of the IC/BPS treatment algorithm.) Asking about guideline-recommended treatment approaches, or clinical trials evaluating new medications that may be appropriate, can prompt a helpful discussion.
- **Multi-modal approach:** There is no one-size-fits-all treatment for IC/BPS. Most patients will require a multi-modal treatment approach. You and your HCP will likely need to try multiple therapies to find an approach that will best help you manage your symptoms.
- **Multi-disciplinary care team:** Be open to working with several HCPs, as it often takes more than one specialist to address the needs of the patient with IC/BPS. Your provider may engage a pain specialist, a psychiatrist or other mental health provider, and/or a pelvic floor physical therapist.

Ultimately, your HCP should be a partner who can help you find an approach to managing IC/BPS that works for you. Dr. Lenore Ackerman, M.D., a specialist in IC/BPS from Cedars-Sinai Medical Center in Los Angeles, says, “The most important thing is a validation that this is real for patients and a demonstration of the real commitment of us as medical professionals to do what we can to make things better while acknowledging the limitations of what we have to offer.” For most patients, she says finding the right approach to treatment can feel like a bit of an exploratory journey, making the partnership between patient and provider all the more important. “It’s very much a team effort.”