

Building a Solid Doctor-Patient Relationship

How you interact with your doctor can have a major impact on how you are diagnosed and treated.

By Nicole Cozean, PT, DPT, WCS, CSCS

Having a trusting, positive relationship with your doctor is incredibly important in your journey with interstitial cystitis, but creating that doctor-patient connection can be a struggle. With the nature of the condition and the length of today's appointments, many patients don't feel *heard* by the medical community. The reality is that how you interact with your doctor can be an important factor in the quality of care you receive for IC.

IC is a complex and invisible condition. It's defined by pain or pressure and urinary symptoms "in the absence of infection or other identifiable causes." Because there are no conclusive diagnostic criteria, the condition may still be dismissed as "all in your head" or trivialized by practitioners who aren't familiar with IC.

Another challenge is that doctors often don't have much time with patients. Financially, they are incentivized to keep visits short and see more patients each day. Appointments now average 15-20 minutes per patient, with almost half of that time taken up with paperwork. With time so precious, having a clear goal for your visit, communicating well with your doctor, and preparing in advance can ensure you have a positive, meaningful visit.

We always recommend four major areas that our patients can focus on to have better interactions with their doctor:

1. Prepare for your appointment and bring the right paperwork.
2. Understand what you can—and can't—expect from your doctor.
3. Set clear goals for each appointment with your doctor.
4. Be prepared to speak the doctor's language.

Bring the *right* paperwork to your appointment

In a perfect world, doctors would communicate with each other seamlessly. Before your appointment, your doctor would have reviewed your entire file and spoken with your past practitioners about their results. Unfortunately, this is exceedingly rare in the real world.

For either an initial visit or a follow-up with a doctor, you need to be prepared with a succinct summary of the most important information. You want to give your doctor a snapshot of your condition without bringing binders full of old test results. The tools listed below can

12 MILLION
People in the US
have IC Symptoms.

On average,
patients see

3¹/₂ DOCTORS
about their symptoms.

Yet FEWER than **10%** receive a correct
IC Diagnosis.

ensure you bring the most pertinent information to your doctor's attention in the time that you have and help keep your visit focused on what matters to you. You can find printable templates at pelvicanxiety.com/the-ic-solution.

- **Symptom Log:** This is a detailed description of your primary symptoms and what you've experienced recently. It's great to keep this for a week prior to your appointment if possible, but even a few days is helpful. (Many of our patients keep this log continually to track their symptoms.) A detailed log builds credibility with the doctor, shows your primary symptoms, and gives important clues about what is contributing to them (the time of the day, food triggers, prolonged sitting, etc.).
- **Bladder Diary:** If you're experiencing urinary symptoms like urinary urgency, frequency, or waking at night to urinate, your doctor will likely ask you to go home and keep a bladder diary. This chronicles what you eat and drink throughout the day and when you go to the bathroom. Having this diary already completed when you arrive for your visit can provide the doctor specific and objective information about your bladder symptoms. Keeping the diary also guides you into talking about your urinary symptoms more scientifically. Instead of saying "I always have to go!" you can point to your bladder diary and show your doctor you went 14 times the previous day for an average of only five seconds each time.
- **One-Page Summary of Recent Tests:** Your doctor won't have time to look through your entire medical file, but a quick one-page summary of what tests and procedures you've had done within the last year is a great tool. It provides your medical history at a glance and helps keep the doctor from ordering duplicate tests.
- **One-Page Summary of Medications:** Include both medications that you're currently taking (at the top of the list) as well as ones that you've already tried. Make sure to list the reason that you stopped any

medications (side effects, drug interaction, etc.).

Documenting the reasons for stopping medications can provide important clues to your doctor about how your body responds to different medications and help them select the medication with the highest chance of success for you.

- **Summary of AUA Guidelines for IC:** The AUA Guidelines provide a snapshot of all the different treatments recommended by the American Urological Association. If you've been going to a doctor and only getting a single recommendation for treatment, you can use this summary to ask about whether you would be appropriate for other treatments. This is a great way to mention other treatment options in a way that your doctor will respect and take seriously. Doctors tend to discount—and, often, rightly so—when they hear "I heard online that..." or "when I Googled my condition..." from a patient. However, bringing it back to the professional guidelines means your questions will likely be much better received. (To access a copy of the AUA guidelines, visit www.ichelp.org/ic-treatment-guideline.)

Understand what you can—and can't—expect from your doctor

What is the doctor's role in treating IC? Understanding the role of your doctor in your IC journey is important in setting your expectations for your visit. We're generally conditioned to think of our doctor as the "fixer." We go into the office with a problem, the doctor prescribes a medication or does a procedure, and we get better.

But with IC, no single medical practitioner has a one-size-fits-all answer. In fact, many of the most powerful tools for treating IC symptoms are within your control—diet, stress reduction, stretching, and physical therapy. These are things that your doctor can teach you about, but can't do for you. Your doctor should be an integral part of your medical management. They can prescribe oral medication to

reduce pain and inflammation, which can be vital in breaking the cycle of dysfunction-inflammation-pain (the DIP Cycle) and improving quality of life. Urologists or urogynecologists also can perform bladder procedures like instillations, fulguration of Hunner's lesions (if present), and Botox to the bladder or pelvic floor. Muscle relaxants prescribed by your doctor can be an important complement to pelvic floor physical therapy.

Your doctor can provide important tools in your IC journey, but can't be expected to have all the answers. Keeping in mind that your doctor is a single (but crucial!) piece of the puzzle will help you hold realistic expectations for your visit.



Image courtesy of The Interstitial Cystitis Solution (FairWinds Press, 2016) by Nicole Cozean

Do your own research about your doctor. Finding the right doctor for you starts with doing your own research. We always tell patients that you need to find a doctor who *wants* to be working with patients like you. No doctor can specialize in everything, so look for a doctor who routinely deals with people with chronic pain or IC specifically.

Look at online reviews of the doctor—we can now be so much more informed about our medical practitioners. If you have another medical practitioner you trust, ask them if they know anyone who would be good; at PelvicSanity we frequently refer our patients to an appropriate local specialist. You can also use your local IC support group or the ICA Online Support Community (www.ichelp.org/onlinesupportcommunity) as a resource to find great doctors.

Don't be afraid to ask for a second opinion or change doctors. Remember that the patient-doctor relationship is a two-way street. If you don't feel comfortable with your doctor, either personally or with their knowledge of the condition, you can always look for a second opinion. With IC, your relationship with your doctor will likely be

a long-term one, so it's important to find someone you trust. The ICA website has a list of practitioners who have both the experience and the desire to treat patients with IC (www.ichelp.org/healthcareproviderregistry).

Set clear goals for each appointment with your doctor

"So how can I help you today?"

Many doctors begin their visit with that simple question, and it's not rhetorical. It's important to make sure that you have a clear goal in mind for your appointment.

If you only suspect that you have IC, your goal might be to get a clear diagnosis and understand more about the condition. If you're an IC veteran, you might be adjusting your medication to minimize side effects while maximizing the benefits. If you're in the middle of a flare, you may need additional help in managing pain. Or you might be looking for a referral to another practitioner if you need treatment for another condition—IBS, allergies, migraines—that is accompanying your IC.

Common goals for an appointment include:

- Getting a diagnosis and starting to understand the condition
- Starting oral medications to combat pain and inflammation
- Trying bladder instillations to determine whether they benefit your condition
- Fine-tuning your medication to maximize the benefits while minimizing side effects
- Dealing with the breakthrough pain of a flare
- Referral to another practitioner (physical therapist, acupuncturist, psychologist, or other specialist) for IC treatment or help with another co-existing condition.

If your goal is to receive a concrete diagnosis, either for the first time or from a new doctor, it can be important to understand what other causes your doctor is considering. That's because IC is a condition of exclusion, diagnosed "in the absence of any identifiable cause."

As most patients have experienced firsthand, the first suspect when you present with IC symptoms is a urinary tract infection (UTI). This is a logical first step, but if your test for bacteria is negative or inconclusive, you can waste months going through multiple antibiotic regimens for an infection that doesn't exist. Make sure you don't get stuck for too long in the medical purgatory of these "phantom UTIs." If you don't have a positive culture and antibiotics aren't helping the symptoms, ask your doctor to consider something other than a UTI—or find a doctor who will.

Many women report having their pain trivialized, or told to relax because it's "all in your head." Doctors also may suspect the presence of a sexually transmitted disease,

especially in younger men who present with pelvic pain and IC symptoms.

Another thing that a doctor may suspect when a patient comes in and reports extreme pain without a clear cause is drug-seeking behavior. The opioid epidemic in America has made both doctors and public health officials concerned about the amount of painkilling medications that are prescribed, and recent rule changes have made it more difficult for patients with IC to get access to opioid pain medication. This is a reason that having a trusting relationship with a doctor can be essential; they will know your condition and understand the importance of responsible pain management with IC.

Speak the doctor's language

Your doctor's perception of you is directly affected by how you present your symptoms. When we're in pain, it's often difficult to present information objectively, but that is what your doctor is trained to respond to. You're much more likely to be dismissed as exaggerating if you say

something like "it's the worst pain imaginable" than if you can more dispassionately state that "it's usually a 7 out of 10, but spikes higher after eating a trigger food or intercourse." The same goes for urinary symptoms—giving a specific number of times you go each day is far more effective than telling the doctor that you "always" feel the urge (even if that's completely true).

Another common temptation is to story-tell during your appointment. It's completely natural to want to share what you're going through with your doctor, and you may feel like personal stories or anecdotes can better illustrate what living with IC is like. But in most cases, your doctor has limited time and is focused on extracting the information they need to solve the puzzle quickly and accurately. Sharing a limitation caused by the condition can provide useful information, but try not to allow engage in too much storytelling with details that are relevant to you but not to your doctor.

The chart below offers some suggestions on how to discuss symptoms in ways your doctor are more likely to respond to.

	What you <i>want</i> to say	What your doctor will <i>respond</i> to
<i>How much does it hurt?</i>	It's the worst pain imaginable. On a scale of 1 to 10, it's an 11. I can't even think straight it hurts so badly. I cry every night.	My pain ranges from a 6 to an 8, depending on the time of day and trigger foods. Here's my symptom log for the last three days so you can see how it fluctuates.
<i>Where does it hurt?</i>	All over! No one can even touch me. My bladder feels like it's on fire!	My pain seems to be centered here, just a few inches below my belly button. It's burning in nature.
<i>How often do you have to use the bathroom?</i>	All the time—I'm always running to the bathroom, and I'm up all night too. I can't even function.	It ranges from 11-14 times each day, as you can see in my bladder diary from the last three days.
<i>What caused this recent flare?</i>	The pain just comes and goes at will—I have no idea, the pain is so bad all the time I just don't know anymore.	I'm not sure, but I did have to sit on a plane for several hours and wasn't eating as well as I usually do. I've seen that this can contribute to my pain.
<i>What helps your bladder pain?</i>	Nothing, it's always there. I feel terrible, my pain never changes.	In looking at my symptom log, it seems like heat and rest are my best help right now, but the relief is minimal at best.

Final Thoughts

Remember that there is a person behind that lab coat. There are great doctors and mediocre doctors, doctors who are fantastic listeners and those who are faster in jumping to conclusions. There are doctors who enjoy working with patients through a chronic condition and doctors who prefer the quick fix of an antibiotic or surgery. Ideally, your relationship with your doctor should feel like a partnership, where you feel comfortable sharing both your symptoms and ideas. There will always be trial and error in finding the right medications and dosage, so

having that sense of partnership is crucial. How you communicate with your doctor can help establish that relationship and make your doctor an invaluable ally throughout your IC journey.

—Nicole Cozean, PT, DPT, WCS, CSCS is owner of PelvicSanity in Orange County, California, a member of the ICA Board of Directors, and author of The Interstitial Cystitis Solution.