

IC Healthcare Team

Successfully managing interstitial cystitis (IC) usually requires multimodal therapy. Patients' bladder symptoms and pain are usually treated with multiple oral therapies as well as bladder instillations and, rarely, surgery. IC patients may also have other, possibly associated, conditions, such as allergies, irritable bowel syndrome (IBS), pelvic floor dysfunction (PFD), fibromyalgia, endometriosis, vulvodynia, and others. In addition, patients may be suffering socially and psychologically because of their disease.

Optimal management of this wide range of therapies and conditions calls for a multidisciplinary team approach. Nurse practitioners, who are often the primary healthcare providers, educators, and coaches for IC patients, can also play a crucial role in helping patients build and coordinate that team.

Providers for an IC Healthcare Team

What are the types of providers your IC patients may need on their healthcare team and the types of care they can provide?

Nurse practitioner, physician assistant: Nurse practitioners and physician assistants are often frontline providers of IC care. They play important roles in educating patients about their disease, coaching patients on self care, advocating for effective care, coordinating the care of different providers on the team, and even recognizing the signs and symptoms in undiagnosed cases.

Urologist: Because IC remains a diagnosis of exclusion and because these specialists are most familiar with IC presentations, diagnosis and therapy, especially surgical therapy, require their expertise. Often, urologists and their staff are the primary providers of IC care. Among the surgical diagnostic techniques and treatments urologists provide for IC are:



- Cystoscopy and hydrodistention with the patient under anesthesia, a procedure that is no longer universally considered necessary for diagnosis but is needed to exclude other conditions that may produce similar symptoms, such as bladder cancer
- Ablation of Hunner's patches with fulguration or laser
- Neuromodulation used to treat urgency and frequency by delivering electrical impulses to nerves, such as the pudendal or sacral nerves, or to the spinal cord with an implantable pulse generator
- Cystectomy, cystoplasty, and urinary diversion

Gynecologist or urogynecologist: Gynecologists may be the first to recognize that a woman's symptoms may be IC and provide a diagnosis. In addition, IC may occur together with endometriosis or vulvodynia, or the patient's IC symptoms may be affected by the menstrual cycle or menopause. A gynecologist or urogynecologist, especially one with an interest in pelvic pain, will be trained to treat and manage these conditions and symptoms.

Primary care practitioner: Although IC may be diagnosed by surgical specialists, the most widely used IC therapies are medical, so they can often be managed by primary care in consultation with the specialist. In addition, the patient's primary care provider may know more about the patient's other conditions and the needs and limitations that those bring to her healthcare.

Dietitian: Meal planning can be a challenge for IC patients who have many food and beverage triggers for IC flares. Dietitians can help them design a healthy diet despite these limitations and direct patients to helpful resources, such as IC-friendly cookbooks.

Physical therapist: Evidence is growing that physical therapy for pelvic floor dysfunction can ease pain and other IC symptoms. Patients should be referred to a physical therapist trained in techniques specifically designed for patients with pelvic pain.

Pain management specialist: Severe, chronic pain may require multiple analgesic medications or scheduled drugs that a patient's primary IC care provider may not have the expertise to adjust or manage. Also, some pain management specialists have special expertise in sleep disorders, which IC patients often have.

Psychologist, psychiatrist, or clinical social worker: Because IC can have profound social and emotional consequences, a psychologist or psychiatrist may be able to help patients cope with the effects of this often debilitating condition. IC care providers who give referrals should make it clear that patients are being referred for this reason, not because IC is a psychologic or psychiatric diagnosis. Mental health professionals with experience in multidisciplinary pain management, cognitive behavioral therapy, health psychology, rehabilitation psychology, or family or couples therapy may be especially helpful.

Sexologist or sexual medicine specialist: IC can profoundly affect sexual function. Adequate pain and symptom control are the first line of treatment for IC patients' sexual dysfunction, but patients and partners may need additional help from specialists with expertise in sexuality. Sexologists are often psychologists with specific training to help with sexual function. Some states license sex therapists, often as an extension of mental health counseling or marriage and family counseling or of a psychology/psychiatry license. Sexual medicine specialists may be physicians or other healthcare providers with special expertise in treating sexual dysfunction.

Gastroenterologist: IBS is one of the most common conditions associated with IC. Especially when IBS is severe and chronic, a gastroenterologist with expertise in IBS can design and adjust therapy.

Rheumatologist: Fibromyalgia is one of the more common comorbid conditions with IC. Rheumatologists, especially those with a special interest in fibromyalgia, will be able to rule out other similar conditions and be prepared to manage fibromyalgia symptoms.

Coordinating the IC Healthcare Team

An IC healthcare team needs coordination to identify the patient's needs for services and support that the primary IC care provider cannot provide, facilitate communication among all the patient's healthcare providers, educate the secondary providers about IC, and prevent orders for opposing or duplicate therapies. It can be challenging for patients with chronic disease to navigate the healthcare system, to identify all the healthcare services and support they may need, and to inform and educate their secondary IC care providers about IC and their specific needs and limitations. As frontline providers and coordinators of care in medical practices, nurse practitioners are the best prepared members of an IC patient's healthcare team to play this role and help patients do this. In addition to playing a key role as primary care providers, nurse practitioners help to accomplish treatment goals by:

- Developing "medical summaries" for patients to take to secondary providers, which may include a brief history, a list of current medications and medication allergies and sensitivities, and general information about IC
- Building knowledge about the providers in their communities with the expertise described above so you can help with referrals
- Following up with the patient's secondary providers on their treatments and outcomes
- Coaching patients on how to communicate with other providers and to obtain information other members of the healthcare team may need
- Managing community support groups



ICA **About the ICA**

Conquering IC. Changing Lives.

The Interstitial Cystitis Association (ICA) provides advocacy, research funding, and education to ensure early diagnosis with optimal care with dignity for people affected by IC.

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