

INTERSTITIAL CYSTITIS INFORMATION CENTER
1706 BRIERY ROAD **FARMVILLE, VA 23901-2556**
"Providing Hope for a Healthier Future"

"PAIN MANAGEMENT FOR IC - HOW TO GET THE HELP YOU NEED"
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When we have IC, we are often in severe pain. We can go to Pain Centers, see doctors who specialize in pain, but in the scheme of things, it is up to us to learn how to truly manage our pain. Many times we have more pain because we've gone beyond the limits our pain puts upon us. IC is a painful disease. Period. If anyone tells you this is not so, they have not experienced it themselves and therefore do not know of what they speak. IC can give chronic pain--chronic meaning you have it most of the time and may only be free of it a few hours or days at a time, if at all.

What exactly is pain? By definition, it is "a sensation in which a person experiences discomfort, distress or suffering due to provocation of sensory nerves." --Taber's Medical Dictionary. Thus, in order to have pain, a sensory nerve or nerves have to be involved. Sensory means to have feeling and for IC patients, that feeling begins as acute and then becomes chronic.

However, pain is always subjective; each person sees pain according to his own experiences with pain itself. Usually pain is not caused by a single factor but by many things such as:

- the actual pain signal your brain receives
- what expectations you place on yourself or others place on you
- you yourself--who you are and how you've been taught to treat pain
- your level of self-esteem
- how you are able to function with pain and at what level
- changes in the temperature of your surroundings
- possibly barometric pressure changes
- hormonal problems
- thyroid changes
- other previous lifetime traumas you've experienced
- your unique genetic background with which you are born

How does pain happen to us in the first place? Our bodies have everything they need to keep us healthy--where do we go wrong? Our houses, if you will, our bodies in actuality, no longer can keep the "bad guys" (ill health) out and our bodies crumble under immune dysfunction or "leaky guts.". If we were in good health, our immune systems could withstand the invasion of the "bad guys." But as we are pummeled over and over again, we develop an inability to withstand the environment around and in us. Every organ can become suppressed. We can develop blood pressure irregularities, sugar cravings, allergies of all kinds and the body gets to the point where the "camel's back" can't take anymore put upon it. Thus we become ill structurally, chemically and emotionally--all of which leads us to STRESS.

Stress affects the body in many ways. You need to acknowledge it as no one can escape stress in her life. Just living is stressful even if you are not ill! Eating the wrong foods to satisfy
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cravings causes great stress to the body. Did you know that one (1) teaspoon of sugar will suppress your white blood cell activity by 15% or to put it another way, for three or four hours? Did you know that sinus and ear infections are usually related to yeast problems? Sugar, white flour, and yes, even milk, can cause yeast. Did you know that milk, for most of us, is difficult to absorb and that we are the only mammals beyond infancy to continue to drink milk with many of us later developing lactic intolerance? We don't need milk; calcium from other food or supplement sources, yes, but we don't need milk itself as adults.

Yeast symptoms can be the same as IC symptoms, and it is often difficult to tell the difference even if a blood test is taken. Sometimes a simple surgical procedure can go wrong and a medication that is supposed to help us can make us much sicker. Lest we forget, medical personnel can make mistakes and "do us more harm than good," contrary to their Hippocratic Oath. Whatever, things can get worse instead of better and before we know it, we are chronically ill with seemingly no end in sight.

If we have become immune deficient, then we need antioxidants for immune protection to keep us strong so our houses/bodies won't fall ill. We can no longer count on our food supplies to provide these for us because of pollutants all around us. Allergy shots may help some as they give protection against the food/chemical poisons our bodies constantly come up against. If we can no longer handle stress, good or bad, the adrenals are probably not working properly and can't produce the anti-inflammatory responses needed to keep us well. We may develop a "leaky gut" which further allows the "bad guys" to get through to places where they harm us in our intestines and bladders.

Then if we don't digest our food properly, the liver gets involved and becomes congested. What does this mean to us as IC patients? Everything, because the liver filters all that goes through our bodies. The liver can't work as it should and can't do its processing. We fall ill. Usually illness attacks our weakest organ/s. For the IC patient, it's the bladder. Later, if we continue not to do well or get better, other organs become involved and we develop fibromyalgia, CFIDS, or other such diseases or syndromes.

How can we prevent this from happening? Well, if you already have IC and/or the other problems mentioned above, we are left with the dilemma of first, how to get rid of the pain and second, how to get rid of the IC? Or is it the other way around? Do we need to get rid of the IC and then the pain that goes with it? We all have choices and each person must decide for him/herself what they need to do.

If you choose to try and get rid of the pain because it is relentless and you can't even think about how to get rid of the IC, then you start with the pain. First, you must be able to

describe the pain to medical personnel with the right words. That's the hard part--the right words. Here are some you might find helpful:

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*pulsing, throbbing, pounding, shooting, boring, drilling, stabbing, sharp, cutting, pinching, cramping, pulling, wrenching, burning, searing, tingling, itchy, stinging, aching, heavy, tender, exhausting, sickening, frightful, terrifying, vicious, wretched, miserable, intense, unbearable, piercing, drawing, squeezing, tearing, agonizing, torturing.

* taken from the McGill Pain Questionnaire--there are many more but these probably fit the IC patient best.

Once you can describe your pain, a doctor may be able to help you with various pain medications. Treatment for pain, thankfully, for enlightened doctors today, is a bit better than a few years ago. Cancer doctors have learned that if their patients are given the pain medications they need and don't have to beg for them, then their patients cannot only get on with feeling better in most instances, but they can also concentrate harder on getting better or over their cancer entirely. In February, 2000, at a meeting of the American Academy of Emergency Medicine (AAEM), results of a large study done in the 1980s was discussed. The results pointed to the fact that only four patients became addicted out of 12,000 treated with opiates for pain. "It's just not a problem for more than 99 percent of people," said Henry Farkas, MD, MPH, and Medical Director of the Northern Chesapeake Hospice and a staff physician at Union Hospital in Elkton, MD. "Even patients with a history of drug abuse who legitimately need pain treatment can be given opioids," he said. "Then there are patients who need pain medication but are so afraid of becoming addicted that they refuse drugs....I assure them thatI know how to treat pain without opiates but it will not be as effective....But I also assure them that...if they want to try the stronger medication, it will not make them an addict, it will only make them feel better...and we take it from there."

Learn to accurately describe your pain and find a pain doctor or Pain Center who will listen to you and understand your demand for better pain medications. They are out there though it may not be easy to find the right doctor or the right combination of pain medications for you. Be persistent and ASK for what you think you need. DON'T GIVE UP--you are the one going through the pain and some time back, Dr. Daniel Brookoff, oncology specialist and a friend of IC patients, once said that he never met an IC patient who became addicted to pain medications. IC patients are happy if they achieve freedom from most of their pain at least some of the time.

Another idea to help you with your pain is to make a "pain plan" yourself, or in conjunction with your doctor. You can put it on a 3x5 card and place it on your bathroom mirror if necessary and put a copy in your billfold as well. You decide what steps need to be taken to

help get you out of a pain situation because when you are in severe pain, you cannot think clearly. If you have a plan and certain steps to follow such as 1,2, 3, then you can look at the card and do the things it tells you to do to help your pain. This really works and gives you a sense of some control over your pain. And you never wait until the pain totally overcomes you to take something; do something to start you on your way out of pain when you first notice the pain beginning. It may keep you from getting yourself into severe pain which we all want to avoid.

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When and if the pain subsides, you too can then concentrate on getting rid of the IC itself. Today, there are myriads of noninvasive treatments and therapies to help you do this. Some may only help you to achieve control of your IC but that in itself is good.. Others may help rid you entirely of IC. Diet, correct antibiotics for the correct pathogen that may be found on broth culture, nutritional supplements known to help IC, stress reduction techniques, certain herbs, thyroid supplementation for some, allergy shots, chiropractic adjustments, physical therapy, massage therapy, acupuncture, yoga - all or any one of these may play a part in healing your bladder.

JUST REMEMBER. Whatever you choose, it probably won't be easy. You've heard these words before but this is a reminder that nothing is usually achieved, no matter how easy it looks to someone else, without hard work and perseverance. I believe you can do it. **GO FOR IT!**

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