

Last year I woke up one morning and thought that I must be developing a bladder infection. I constantly felt like I had to pee and over the next few days the sensation built and nothing would make it stop. Two urine tests were negative for infection and my symptoms grew worse. In a short period of time, the skin in my vulva became inflamed and extremely painful. I also developed a searing, burning pain in my urethral area. I seemed to be acquiring new sources of pain daily and found myself dealing with nearly incapacitating inner thigh pain, shooting pains throughout my pelvis, burning in my vagina and bladder, low back pain, and more. I was not getting any sleep, I cried every day (and throughout most nights), and my pain was unremitting. I saw a variety of medical providers who were sympathetic, but unable to determine the cause of the pain or solve it. Late one night, I was desperately searching the internet in the hopes of finding someone in Maryland who might be able to help me. That is when I found Marci's website and read about the other women she had helped. I called the next morning to schedule my first visit. Thanks to Marci, I am now on the road to healing. My current diagnoses related to pelvic pain include interstitial cystitis (IC), vulvodynia, and pelvic floor dysfunction. Perhaps you have been diagnosed with or think you have one or more of these conditions and are looking for help and someone who understands. Marci is that person.

I still have a long road ahead of me, but I am making progress. I know how hard it is to find solutions to your pain. The ideas below have helped me and I hope they might also benefit you.

- **Do whatever Marci tells you to do!** She is incredibly knowledgeable and will guide you in the right direction. She can make suggestions about diet modifications to follow, complementary treatments to try, medical specialists to consult, self-help practices to do at home, and resources to explore. Follow every one of her instructions and suggestions. Give them each an honest try and then pick those that work best for you.
- **Make an appointment at the Center for Pelvic Medicine** (<http://centerforpelvicmedicine.com/>). Yes, it is a hike for those of us with pelvic pain to go to the Philadelphia area because sitting, especially in the car, is so challenging. However, the women at the Center for Pelvic Medicine know their stuff. If you have the time and resources, stay over in a nearby hotel and have someone drive you. Not having to travel there and back in the same day really helps with pain management.
- **Meditate daily.** Learn how to meditate and do this every single day. *You Are Not Your Pain: Using Mindfulness to Relieve Pain, Reduce Stress, and Restore Well-Being---An Eight-Week Program* (2015) by Vidyamala Burch and Danny Penman is a great way to start. The book has an easy-to-follow meditation plan and an accompanying CD of guided meditations. Each meditation is about 10 minutes – something that anybody can fit into a day. Meditation helps to center you, it can help to reduce the sensation of pain a bit, it helps to calm you before sleep, and it gives you some peace in the midst of stress.
- **Find additional healing modalities that work for you.** Daily meditation, stretching, and using heat (via a warm bath or an infrared lamp) have helped me. I also do gentle yoga regularly. (*Your Pace Yoga: Relieving Pelvic Pain* is a great DVD that Marci recommended and I love it.) In addition to the things you can do at home, find healing practitioners who can supplement the

work you do with Marci. Maybe acupuncture, tai chi, deep tissue massage, chiropractic care, or another treatment modality will benefit you. Marci can guide you as you explore options.

- **Be and have an advocate.** If a medical provider is not taking your pain seriously, is not listening to you, is out of ideas to help you, or does not have treatments that alleviate your pain in some way - find a new one! Take a trusted friend or family member with you to medical appointments and have that person in the room when the medical provider is speaking to you. Having another person there to take notes, ask questions, and clarify information is important. (It is also nice to have someone there to hold your hand during painful procedures or to laugh with while you are waiting.)
- **See a counselor regularly.** Having a chronic pain issue can be exhausting, isolating, and life-altering. Emotional support from a professional is crucial. Find a practitioner who fits your style and has experience working with those in life/health transitions and those dealing with pain.
- **Keep thorough records.** I keep a computerized, daily chart of medications, treatments, appointment reminders and symptoms. I also have a document of current medications that I print out and take to each medical appointment. Doctors appreciate having a quick reference sheet and the daily charting has been invaluable when I prepare for appointments.
- **Educate yourself.** Use reliable sources to learn more about your condition(s). For instance, the Interstitial Cystitis Association ([www.ichelp.org](http://www.ichelp.org)) has a wonderful website with lots of information.
- **Budget your time and money.** Having a chronic pain condition is expensive. To the degree possible, put your money toward investing in your health. It requires a lot of time to do the work at home, the treatments, the record keeping, etc. Put in the time every day to help yourself. Make yourself and your health a priority. There is no one secret that has helped me start feeling better – it is a combination of many things. Make the time to explore the options available, determine what is best for you, and do those things regularly.
- **Check your embarrassment at the door.** You will spend much of your time half naked at medical appointments and in treatments. Multiple people may be examining your nether regions, inserting catheters, using needles in places you never thought needles should be, stretching muscles you didn't know existed, and generally doing things that are probably not on your list of favorite activities. At first it may seem overwhelming and mortifying, but remember that the people involved are professionals and want to help you. People working in this field have seen it all and there is no need to be embarrassed.
- **Adopt a warrior mentality.** The treatments for pelvic pain are not for the faint of heart. It seems terribly unfair to go through so much more pain to fix the pain you are in, but you will learn which treatments work for you. Adopt the identity of a warrior and do whatever it takes to get better!