

1

How I Became a Take-Charge Patient

*“Listen to the patient. He is telling you
the diagnosis.”*

SIR WILLIAM OSLER, FATHER OF MODERN MEDICINE

It was the first week of January 2010. I was working on my new book, *The Take-Charge Patient*, wrapping up six months of interviews with physicians, nurses, pharmacists, patients and more. I was excited by the information I had learned from my research, from esteemed medical professionals and patients from all over the country.

I knew I was onto something with my new book. I remember telling a friend that the writing was going so well that I thought that I might have the first draft completed in six months.

Little did I know that within two weeks I would develop debilitating pelvic pain that would last for over a year and that my life would be severely compromised in ways I could never have imagined. Unbeknownst to me that first week of January, I would end up using every strategy in my new book and living every single chapter to become a take-charge patient.

During those sixteen months, I saw twelve doctors, many of differing specialties, plus three alternative medicine practitioners, in an effort to figure out what was wrong with me and end my pain. I was given eleven diagnoses, was prescribed twenty-two medications, and endured fifteen

procedures and surgeries. The pain was simply indescribable. A few times I wondered just how much more I could take.

It was the third week of January. I was recovering from a nasty chest cold. I rose out of bed one morning, still coughing as I had the night before. I don't remember exactly when the pelvic pain began that day. Pain has a way of muddling our thoughts and memories. I do remember feeling pain in that area during my dance class, wondering at the time what it was, brushing it off to a possible bladder infection.

Days later I was in my gynecologist's office, undergoing tests. This began the onslaught of misdiagnoses, multiple antibiotics, tests, procedures, injections and surgeries.

My journey began with a misdiagnosis of interstitial cystitis (IC), a lifelong condition for which there is no cure. After doing research and discovering that I did not have two of the five major symptoms, I started to doubt the diagnosis.

It wasn't easy doubting a physician I'd known and liked for many years. I wanted to believe her, partly because she has education, training and a medical degree but also because I trusted her. To test out her theory, I did abide by the IC diet that withheld acid-producing foods and liquids. Nothing reduced my pain.

After two weeks of experimenting with the IC diet, I went to a urologist for a second opinion. He rejected my gynecologist's diagnosis of IC and offered his own, plus multiple rounds of antibiotics and some pain medication. After three months of painful exams, bladder procedures and tests, I was no better off than I was in January. The pain persisted and grew worse, stifling my participation in family outings, dance classes, work and more.

I sought a third opinion from another urologist. He did an exam and a set of tests and found nothing to warrant antibiotics. He instructed me to stop taking the antibiotics I'd been given and to eat a macrobiotic diet. This was the third conflicting medical opinion. Which was I to choose?

Frustrated that all three physicians had disagreed with one another, I became my own medical detective in search of a diagnosis. I sought more opinions from other specialists. The first was a highly respected gynecologist who specializes in fibroids because I wanted to find out if fibroids were the cause of my problem. They weren't.

I then consulted with my internist whom I'd known for twenty years. I asked his advice. He talked to the other specialists I'd seen and reviewed their theories. He explained that I had differing opinions from very respected doctors. Still no accurate diagnosis.

The pain wore on and my drive increased to find a correct diagnosis that would end my pain. I soon realized that I had been using many of the strategies in my own book. I was becoming a take-charge patient. For each medical encounter, I arrived prepared with copies of my medical records, list of medications, health summary, test results, lists of doctors I'd seen and what they had diagnosed me with. I kept a notebook with me at all times and recorded my symptoms, when they occurred and what made them worse or better. I researched every doctor I saw, every diagnosis, each treatment plan, every medication, and I discussed my findings with my husband and close friends, fishing for information and ideas as we talked.

By August of 2010, I was unable to complete a dance class without pain erupting with terrific force, unable to sit at my desk for more than a half hour before pain gripped me from beneath, tugging and twisting my insides. I continued as my own advocate, with the help of my husband and a couple of close friends.

Since I had no success with traditional doctors, I decided to try the alternative medicine route. I figured two highly respected acupuncturists/Chinese herbalists would be able to help me. After ingesting smelly teas and enduring hours of needles stuck in my arms, legs and face, I still was no closer to relief from the pain or to a diagnosis.

By November of 2010, I began losing steam. I was worn down, discouraged and fatigued by ongoing pain. I was becoming isolated; I avoided friends, turned down all social invitations and missed out on time with my family. My ability to work slowed. My dance classes were a thing of the past and my afternoons were spent lying down after a day of trying to forge on.

It's funny how chronic pain has a way of absorbing your life. At first you summon your energy to get multiple opinions to find an answer, do your own research, and discuss your findings with loved ones. Every effort is channeled into presenting yourself to doctors as a patient who is professional and worthy of respect—one to be taken seriously. But when every treatment,

test, procedure, medication and diagnosis fails, you are left with yourself and your body. Chronic pain is a lonely business. The sense of isolation and loneliness I felt was simply indescribable. The fear that I would never get better was with me most of the time, draining my energy, my hope and my confidence in doctors.

I now only discussed my medical condition with my husband and a couple of close friends. To the rest of the world, I pretended I was fine. I faked it to most, not wanting outside interference or having to explain one more time why I wasn't getting better.

It was at this time that a good friend of mine, who is very medically savvy, became much more involved in helping me. She agreed to be my advocate and offered continuous support and encouragement. F. researched my symptoms, possible diagnoses and current diagnoses I'd been given by physicians. We discussed everything we both uncovered on a regular basis. We brainstormed possible steps for me to take. F. grew more and more invested in helping me find the right doctor and the right tests to determine what was causing me such pain. She accompanied me to some appointments with new doctors and we discussed what had transpired in the office visits.

In this book and in my last, I have written about the importance of enlisting a loved one to be a patient's advocate. The impact of just how important that really is hit me when I realized I could no longer handle everything myself. My husband comforted me and discussed my symptoms with me—he listened to me ad nauseam when I shared ideas. He even came up with ideas of his own. F. and I shared research and ideas, brainstorming regularly. Another close friend offered consistent support and comfort. I can never thank my husband and F. and my other friends enough for their faith that I was going to get better and find the reason for my chronic pelvic pain. I had a good support system.

One day, F. brought up the fact that I'd had four abdominal surgeries over my lifetime and suggested that adhesions or scar tissue could be the cause of my pain. She suggested that I consult a surgeon. I did.

After faxing my medical records and health summary to the surgeon who had performed one of my surgeries, we talked on the phone. He said he didn't believe there was any chance that there could be complications

such as adhesions. He said he would be happy to see me in an office visit and recommended that I see a gastroenterologist.

I did take his suggestion and made an appointment for an overdue colonoscopy in hopes that something might be uncovered with that test. But I just didn't buy this surgeon's opinion that no complications could have arisen after four abdominal surgeries. F. and I discussed which medical professional to see next.

We asked ourselves which tests could determine adhesions, scar tissue or other issues that might have resulted from my C-section, belly button hernia repair from my pregnancy, gall bladder surgery and abdominal liposuction some twenty years ago. Who better to ask these questions of than a radiologist who specializes in imaging tests?

I called a radiologist I knew. After faxing my medical records, including test results, health summary, health history, list of doctors I'd seen and my previous diagnoses, I asked him which tests could reveal any aftereffects of my four abdominal surgeries. I explained my medical condition and the idea of adhesions or scar tissue as possible causes of my pain. This doctor said, "There is no test that can reveal scar tissue, adhesions or what you are looking for. Stick to the doctors you're working with. They know what they are doing." There was no point in explaining that I was simply looking for a clue to my next step, not going behind any doctor's back.

I thought a lot about what this radiologist had said. A couple of other doctors I'd seen for second opinions had also suggested that I stick with the doctor I was working with. I realized then that some doctors are in close-knit communities and watch each other's backs, protecting each other even at the expense of the patient. I've heard from other medical professionals that this kind of loyalty is based on friendships, mutual referrals and a sense of protectiveness of one another. Perhaps fear of being sued also factors into the equation.

I still didn't give up. I knew persistence was key to finding the right doctor, the right diagnosis and the right treatment plan. With the support of my husband, my medically savvy friend, F., and a couple of other close friends, I pushed forward.

One day my husband came home and shared a suggestion from a friend of his. "M. said you should go see the urogynecologist his wife sees." The next day F. suggested the very same doctor.

By the time I entered Dr. R.'s office in December of 2010, almost a year after my pain began, I was weak, vulnerable and exhausted. I presented this doctor with ten pages of my health history. Seated at her desk, she read every word. After a few pages she motioned to my health history and records and said, "This is very helpful. Thank you."

As she read, I thought about the upcoming holidays. I dreaded them. We had family coming in from out of town and a ski vacation planned. I knew I was not up for either.

Still reading, Dr. R. said, "You poor thing." Her empathy meant more to me than I could possibly express. I suspected she knew what kind of pain I'd been experiencing. I thought about the painful urological procedures I'd undergone, how after they were over I'd left the urologist's office only to slide into my car, call my husband and cry while still in the medical building parking lot.

This was the first time a doctor other than my internist had expressed empathy. Kind, caring and smart, Dr. R. reassured me that she would help me. She said it might take time but that she would do everything she could. I could have hugged her.

The holidays passed and I missed my family's ski trip, avoided all holiday parties, and while family visited us, I spent a lot of time in bed. I went through with the colonoscopy in early January and was disappointed when the results yielded nothing. No one wants something to be wrong unless she's suffered with ongoing pain or discomfort with no diagnosis or cure.

Around the middle of January, Dr. R. ordered tests, including a pelvic ultrasound, to rule out serious medical issues. One friend said to me, "You mean to tell me you haven't had a pelvic ultrasound yet with all the doctors you've seen?" At least Dr. R. was on top of things. She prescribed non-narcotic pain medications and asked me to report in to her. She returned my phone calls and emails. When she asked me to do something, I did it. When I brought up questions and shared the research I'd done, she listened and discussed what I had found. When I asked her if endometriosis could be causing the pain, she did tests to find out. She didn't brush me off—she respected me as her patient.

Even though Dr. R. was the medical expert, we had a collaborative working relationship. Our doctor-patient relationship was based on trust.

I knew she was an excellent doctor and I suspect she knew I was a credible reporter on my body.

On my third office visit with her, she tried something new. She asked me to bear with her for a moment while she pressed on trigger points in my pelvic region. She asked which were tender or painful. She said, "Let's try something." She injected an anesthetic into my pelvic nerves and then asked me to engage in the activities that brought on the most pain. I raced to my office and sat at my desk.

There was no pain.

I called Dr. R.'s office and her staff was almost as giddy as I was.

This began two and a half months of biweekly injections of an anesthetic and steroid into my pelvic nerves. As painful as these injections were, most of the time they were successful. Some numbed the pain for a few days, others not at all. But they gave me hope for a cure. Dr. R. gave me hope. She was the first doctor who thought outside of her specialty, who thought outside of the box. For the first time in a year, I had many days when I was actually able to sit at my desk for short periods of time and get through part of a dance class.

But it didn't last.

Dr. R. told me I needed to see a specialist who could do more for me, someone who specialized in treating this kind of pelvic pain. The thought of seeing yet another doctor when I had hinged my hopes on her was simply unthinkable. Dr. R. explained that the injections were not eradicating my pain in a permanent way as she had hoped.

My hope plummeted. Back to square one. I didn't want to see another doctor, especially after finally finding one who really wanted to help me, who used her own time to do research on my case and who talked to other doctors about my medical condition and possible treatments.

Accompanied by my medically savvy friend, I then saw a pelvic pain specialist. Even though I had researched him ahead of time and found impressive credentials, I was suspect from the onset. He rented an exam room in a big medical practice and required payment in cash.

Dr. A. was not interested in my medical history, list of medications or health summary. He didn't look me in the eye. He rushed through the first five minutes of my office visit and asked me to get up on the exam table.

He asked his nurse to prepare some sort of injection. He then focused on locating trigger points. He whipped out a syringe and needle the length of a ruler. I had to stop him. I said, "Wait please." I asked him what he thought my diagnosis was, asked him what his treatment plan was, and what he was about to do. He took the time to explain but I could tell he was not used to patients like me.

After his explanation, he gave me injections and told me to come back at the same time next week. He handed me a prescription for pain medication without knowing which medications I was already taking. I never filled it.

I gave Dr. A. another chance only because I was desperate. His credentials were good, so I held on to false hope and made excuses for his behavior. The next time I saw him, he did not remember where he had last injected me and when I showed him, he asked me why he had injected me so high up on my abdomen. Maybe it was because I was so tired, in pain, and not thinking clearly, but I allowed him to inject me again. Nothing he did relieved my pain. Not only was I out a sizeable amount of cash, but I was also no better off. I never went back.

My next step was to see a highly respected neurologist. I did my usual research on this doctor before I saw him, called a couple of doctors I'd interviewed for this book and asked for their opinions about him. Each comment was more glowing than the last. Dr. Z. believed my pelvic pain originated in my lower back. He said he could perform a surgical procedure that would relieve the pain.

What Dr. Z. explained made sense to me at the time. But when I arrived at the surgery center, I had a bad feeling. Parked outside of the surgery center at 6 o'clock on a Wednesday morning, my anxiety mounted. I started an argument with my husband, all because I was so nervous and couldn't put my finger on the source of my worry. I went ahead with the procedure. I was anesthetized and then awakened while needles in my lower back were electrically stimulated to elicit a response in my pelvic region and then steroids were injected. The procedure didn't work.

This was the end of the line for me.

I plunged into depression. After seeing so many doctors plus three alternative medicine professionals, trying so many medications and just about everything else, I had had enough. I thought about all the people

who cope with some form of chronic pain with no understanding of its root cause—only treatment for the symptoms. I was terrified that this was going to be my future.

In early May of 2011, I was researching “hiatal hernia” for a good friend of mine who had just been diagnosed with it. As I searched on the internet, I spotted an article in a highly respected newspaper. The headline read, “In women, hernias can be hidden agony.” I knew my friend had been dealing with some discomfort so I began reading. The third line talked about pelvic pain. It was a story about a woman who had agonizing pelvic pain and the root cause was hidden hernias with fat protruding through the holes, pressing on nerves.

My heart raced as I read the article. The woman described was just like me with the same symptoms. My instinct told me that this was my problem. I just knew it. I read that article twice and discovered that the surgeon, who specialized in hernias, was located in Los Angeles at a major teaching hospital that was affiliated with a highly respected medical school.

My hands shook as I called the surgeon’s office and made an appointment.

I called my medically savvy friend, my husband and a couple of other friends and sent them the link to the article. Whether they believed it or not, each person supported me and my conviction that this was, in fact, it.

Dr. T. was lovely. During my examination, she told me she thought I had hernias and ordered a high-resolution dynamic MRI.

The MRI showed that I had a muscle tear at my C-section site, an inguinal hernia, and a belly-button hernia. I was elated when Dr. T. gave me the results. I hoped this would be the end to sixteen long months of pelvic pain.

Until I interviewed ministers, rabbis and other religious professionals for a chapter in this book, I had no idea what they offered to people who have medical problems, surgeries, hospitalizations and more. I had been calling our church’s prayer line for many months, asking them to pray for an accurate diagnosis, a treatment plan and the right doctor to execute both. This time I called and asked for prayer for my surgery and its success. I then received a call from our minister and associate minister, both offering their support and a visit after my surgery. Then I received phone calls from our church deacons to see if I needed anything, such as meals. I was so touched

by all of their gestures. I thought back to my chapter about how religious institutions help people in medical need. Again, I was living out one of my book's chapters and realizing its value.

I had surgery two weeks later to repair the muscle tear and the hernias. My surgeon explained that in addition to the muscle tear, I also had an inguinal hernia with a nerve that passed through the hole and got pinched every time I exercised, walked, sat in a chair, rode in a car or hunched over. This had caused the excruciating pain.

Thankfully, the surgery was successful and I am now pain free.

To say that I am grateful to Dr. T. is an understatement. She gave me my life back. She is exactly the kind of doctor I recommend in this book if you need a highly trained specialist. She was

- affiliated with a highly respected medical school;
- very experienced with the kind of surgery I was about to have;
- nice and caring.

The fact that she performed my surgery on a Saturday morning because she was leaving the country shortly thereafter tells you a lot about her.

I am also very grateful to Dr. R., my urogynecologist, who took such good care of me and showed me exactly what a doctor-patient relationship should be, just as I describe it in this book. She taught me by example and experience what every single doctor I interviewed for this book told me:

Find a doctor:

- who you like;
- who you can talk to and who listens to you;
- who you can collaborate with in a partnership;
- who respects you;
- who will reach out to other physicians for more information, putting ego aside;
- who returns phone calls;
- who is invested in your health and well-being.

I now have my life back. I consider myself to be incredibly lucky and now well versed in my own strategies. I've implemented them, tried them out firsthand and realize their value.

A take-charge patient needs the strategies in this book, but she also needs persistence. Persistence is the key to finding solutions to both simple and complex medical issues. Even if you are healthy, you need persistence to get the kind of medical care you deserve. I hope this book helps every single one of you.