

Undiagnosed by physicians, was Jalene a hypochondriac or medical misfit?

Medical Misfit: Doctor, Why Can't You Diagnose Me?

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Medical Misfit

Preface

In the beginning none of my illnesses appeared to be life-threatening; however, because they weren't easy to diagnose and often experienced by only a small percentage of the population, I frequently found myself on a medical merry-go-round that nearly destroyed me physically and emotionally. Cheated of good health for years at a time, I felt betrayed by my body as well as the medical profession.

Today, in looking back, I realize that I must take some responsibility for my lost years. As a quiet, reserved person, I blindly followed my doctors' instructions, even when my body was crying, "foul." I didn't ask enough questions, challenge the treatment when I continued to get worse, or do research to try to find some answers on my own. In the back of my mind, I would think of my mother who had annoyed every physician she ever visited with her endless list of symptoms and complaints. I didn't want the medical profession to feel about me as I believed they must have felt about her. *Was she a hypochondriac?* I don't know; however, now that I'm older and have more experience in living, I find myself wishing that I had shown her more understanding.

I am writing this book for you—my readers—hoping that you draw from my experiences and listen to what your bodies are telling you. If your healthcare professionals tell you that your symptoms are all in your head, run for the door and don't look back. Be suspicious when a physician gives you medicine month after month without a definite diagnosis. Before agreeing to surgery, do not hesitate to ask for a second or third opinion. When you are referred to a specialist, be appreciative of your doctor's willingness to acknowledge his or her own limitations. Remember that a doctor usually has many patients; however, you have only one life!

Don't be afraid to approach your physician with information regarding your condition that you may have discovered through

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research of your own. This could relate to new medical procedures, alternative medicines, special diets or health supplements. Ask questions, find answers, and keep reminding yourself over and over that it's your life. Don't be a blind follower, believing that physicians are "little gods."

Any physician who behaves inappropriately toward you in a verbal, physical or sexual way should be reported so that future patients are spared this abuse. If you fail to do this, the experience will haunt you the rest of your life!

Remember that physicians are human beings who took an oath to provide you with the best medical care possible. In their humanness, they will make mistakes; however, such mistakes will be less frequent when you participate actively in your own healthcare. Insist on a verbal partnership with your healthcare provider! There are many physicians who truly care about their patients and want to help them get well or, at least, experience a better quality of life. Find one and then spread the word!

Introduction

Dr. William Lloyd sat behind his desk, his face void of any readable clues as he scanned some papers in my medical file. Though I was seated in a plush, comfortable-looking chair, I sat on the very edge, trying to push back haunting memories of other first-time visits with physicians. Finally, he peered over his glasses, speaking in an abrupt tone that did nothing to put me at ease. “I have no idea why you’re here...you were previously Ralph Steel’s patient.”

Trying to maintain my composure, I replied, “Dr. Austin Shasta at Riverside Diagnostic Hospital told me that I should see you for follow-up care. As far as Dr. Steel...well, I only saw him one time.” My voice sounded pathetically weak; my mind and body were both exhausted from battling a strange health problem for nearly two years. I had just about lost faith that I would ever recover.

“When Dr. Steel admitted you to Community Hospital, weren’t all your tests normal?”

“Not really. I had a high white count and a urinary tract infection. Dr. Steel brought in a specialist—Dr. David Shasta—who sent me to his brother Austin at Riverside Diagnostic Hospital for further testing. That’s where I finally got a conclusive diagnosis.”

He was brusque with me. “Neither Dr. Steel nor I accept the diagnosis—we’ve never heard of such a thing.”

I struggled for control. “You’re challenging the validity of Austin Shasta’s diagnosis—a physician with his reputation?”

Sighing, he brushed back a lock of gray hair from his forehead. “Lady, after studying your medical records, I’m convinced that there’s nothing wrong with you. You’ve seen at least five other doctors, and I don’t think any of them would buy into this bizarre ‘big city’ diagnosis.”

As I searched his face, realization set in. “You and Dr. Steel...the two of you know one another...you’re friends.”

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With a wry smile, he replied. “He’s my cousin, but it doesn’t change the fact that nothing is physically wrong with you.”

All I wanted to do was leave the room and run into the arms of my husband who was in the waiting room, praying that this would work out. Obviously, Dr. Steel had gotten to this man and, in order to protect himself, told a convincing story. Or, even worse, he had told Dr. Lloyd the truth, and the two of them were trying to protect his reputation by discrediting me. I stared at him. “So you can’t help me?”

His cold eyes locked into mine. “Lady, it’s like this; you’ll either get better or you’ll die. Personally, I think you need a psychiatrist.”

His heartless words penetrated my acquired victim mentality and smoldering emotions. I felt a quickening in my spirit as my thoughts rebelled. *No more*, I told myself, *enough is enough! It’s time to fight back*. Sitting up straight, I looked boldly into his eyes. Though my 105-pound-body might be physically exhausted, long overdue anger filled me with resolve. “You may be correct,” I said. “Perhaps I should see a psychiatrist—someone to help me understand how you, as a physician, could speak in such a cruel manner to a patient. And,” I continued, “how your cousin could sink to the level of sexually hitting upon a patient in desperate need of help! One day I hope I can forgive both of you.” He paled as I turned to run out the office door.

The next day I called Dr. Thomas Young, a local psychiatrist, and in the days and weeks ahead explained to him what had brought me to the point where I was willing to see him. This kind doctor, after several sessions, quickly reassured me that I was mentally sound but had been emotionally struck down by a series of medical mishaps that could have been prevented. The following story of my medical history is one that I shared with him and now with you.

Chapter Five

Against All Odds

My husband and I sat across from the short, slightly overweight, and red-haired Dr. James with our hands entwined. “Did you find out anything that would explain her condition?” Jack asked.

“Yes, I know exactly what is wrong; however, before I explain, I’d like to apologize.”

“Apologize?” we both echoed.

“Yes, I made an assumption about Jalene’s problem that isn’t true.” His eyes locked into mine. “Your pain has nothing to do with ‘stress,’ although the severity of the condition could certainly play havoc with your nerves.”

“Severity of my condition,” I repeated with alarm. “What’s wrong with me?”

“Let me begin by saying that it isn’t a life-threatening illness; however, it isn’t something you can take a pill for and expect an instant recovery.”

With obvious impatience, Jack repeated my question. “Doctor, please, just give us the bottom line. What’s wrong with her?”

“Your wife has a severely ulcerated bladder. The word ‘grotesque’ is the only way I know how to describe it.” Again, looking at me, he said, “Jalene, your entire bladder is inflamed and ulcerated; the condition is worse than any I’ve ever seen or read about. I honestly don’t know how you are able to walk—the pain has to be excruciating!”

“It is,” I replied, as relief slowly started to replace my build-up of anxiety. At least he’d found something wrong with me, and that was a beginning. “What...what can we do?”

“The first thing is to modify your diet. Until I say otherwise, I want you to cut out all acidic foods. We have to make it easier for the ulcers and your bladder to heal.”

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“I was eating lots of tomatoes just prior to the onset of this illness. Did this cause the problem?”

“No, but it certainly didn’t help! Before you leave, I’ll give you a list of foods that you should avoid. You’ll learn very quickly what does and doesn’t bother you.”

“What about medications?”

“I’m prescribing a liquid medicine that you’ll need to take after each meal and at bedtime. You mix it in a little water and drink it down. Some people don’t like the taste, but it usually does the trick. It’s an old-fashioned remedy—with ingredients that your pharmacist won’t have on hand so be sure and tell him that you’re going to be using lots of this medicine for a long time. In addition to this, you’ll need to come to my office once a week so that I can inject medication directly into your bladder. At the same time I will be stretching the bladder by filling it with more and more liquid during each visit. As you make progress, we’ll lengthen the time between visits to every two weeks, then once a month and...well, let’s just wait and see.”

Hanging onto his every word, I leaned forward in my chair. “How fast will I get better? Will I finally be able to enjoy my baby boy again?”

“You should get some immediate relief, but the healing is a process...and you may have flare-ups throughout your life. As you make progress, the ulcers will heal, the scabs will fall off and then, just like when you skin your knee, new scabs will form. This will be going on for a very long time. Just when you think you are totally well, you’ll have another attack, and of course there’s more danger of an infection right after the scabs fall off.”

Jack looked toward me with sympathy. “This doesn’t sound like it’s going to be a picnic for my wife!”

“It won’t be,” he said honestly. “But at least she has a diagnosis; Jalene has to be in horrific pain, and relief is long overdue! Unless you say otherwise, I won’t contact Dr. Ford concerning this diagnosis. I know that there aren’t many physicians in your small town.”

Jack’s face turned red, and he spoke loudly. “Hell, no, that isn’t what I want. I want him to know that he messed up. My wife has suffered—our whole family has suffered.”

I was shocked by my husband's outburst but expressed my agreement. "Dr. Ford needs to know in case he has another patient with my symptoms."

"To be fair to Dr. Ford, I have to tell you that he couldn't have diagnosed this! It's a very rare condition. Only a very small percentage of the population is affected by this disease. And, as I said earlier, your case is the worst I have ever seen or read about. I hate to repeat myself, but the word "grotesque" is the only adjective I can think of to describe your bladder, and believe me I'm going to follow your case very carefully. I intend to write a paper on it."

I shook my head back and forth. "Dr. Ford could have referred me to a specialist. My husband and I asked him to do this, but he refused."

"Yes," my husband agreed. "We're not letting him off the hook that easily."

Dr. James chose not to respond to our comments but did emphasize that I'd soon be feeling much better. Then he wrote the prescription, gave me a list of offending foods, and stood to usher us out of the office. The two men shook hands and the doctor turned toward me, offering yet another apology. "Jalene, I'm truly sorry for initially being so abrupt with you."

I extended my hand to him and replied, "It's okay. I'm grateful to finally know what's wrong. Thank you."

Although individuals react differently to different foods, the following are some items from Dr. James's list that persons with this problem should avoid:

- Aged canned, cured, processed or smoked meats and fish
- Aged cheeses
- Alcohol
- Apricots
- Artificial sweeteners
- Ascorbic Acid and Citric Acid

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- Aspirin
- Berries
- Caffeine
- Carbonated Beverages
- Cherries
- Chocolate
- Citrus Fruits - Oranges, Grapefruit, Lemons, Limes
- Coffee
- Cold and Allergy Medications containing Ephedrine or Pseudoephedrine
- Cranberry Juice
- Dried Figs
- Fava Beans
- Ketchup
- Lima Beans
- Mayonnaise
- Megadoses of Vitamin Supplements
- Mustard
- Onions
- Peaches
- Pickles
- Pineapple
- Processed Meats
- Rye and Sourdough Bread
- Spiced Foods
- Sugar – (honey may be used)
- Tea
- Tomatoes
- Vinegar

A lot of years have passed since that first meeting with Dr. James. Today, there is a name for the condition that caused me so much pain. It is referred to as interstitial cystitis (IC). Spending time at the library and, later, doing research on the Internet, I learned that there are two

types of interstitial cystitis: one is non-ulcerative IC and the other is classic IC which presents symptoms that are much more severe. The latter is the kind I had—my bladder was terribly ulcerated. Though persons with interstitial cystitis are more prone to bladder infection, unfortunately, the attempt to try and come up with an accurate diagnosis usually does not occur until the patient has been treated for numerous, ongoing infections with the symptoms persisting and becoming worse. When kidney stones or other problems with the kidneys are ruled out, the patient is finally sent to see that all-important urologist. Today, it takes a patient anywhere from three to five years to get a diagnosis, and that same patient usually sees an average of five doctors during this time. Because of my extreme back pain caused by the “grotesque” ulcerated bladder, I finally bypassed my possessive family doctor and went directly to a competent specialist. The treatment for my condition lasted for years, and even today, I occasionally have problems—especially when I don’t watch my diet. Ninety-five percent of patients with this disease don’t have ulcers but do have urinary urgency and frequency, as well as pelvic and back pain. The disease is not caused by stress, but it can be a chronic and debilitating problem.

I still can’t believe that, against all odds, I came down with a disease that didn’t even have a name at the time. My body, throughout the years, has seemed determined to challenge doctors by giving me illnesses and symptoms that don’t fit a textbook diagnosis. I don’t get sick often but, when I do, I literally lose months or years of my life. As we all get older, our years on earth become more precious which is one reason I’m writing this book. But wait, I’m getting ahead of myself. I still have lots of background to cover.

When I told my psychiatrist about being diagnosed with an ulcerated bladder, he agreed that it was very rare. He questioned me about the prescription that I had been given. “Do you remember what it was?”

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“No, but I do remember that right in the beginning my pharmacist had some difficulty in getting it. Then he kept it on hand all the time just for me. Throughout the next few years I must have taken gallons of the stuff. It was light green in color and I think was supposed to have sandalwood oil and some other ingredient in it. I know one thing—it was a miracle medicine. Even after I stopped getting the bladder injections, I had to continue with the medicine or I would start having pain in my side, especially my right side. But, as the years passed and my attacks became less frequent, I didn’t get the medicine refilled. The drugstore closed down, and my doctor passed away. When Dr. James died, I felt as though I had lost a best friend. He had seen me through a rough period of my life. You don’t forget someone who gives you relief from the kind of pain I was having.”

“Did you go back to Dr Ford?”

“Absolutely not, but I did call and tell him about my ulcerated bladder! Although he had very little to say, it was a sweet moment for me. Within a few months Jack made an appointment to have a physical with a general practitioner who had just set up a new practice in our town; however, other than an obstetrician, I didn’t see anyone except Dr. James for several years. Even though I had times when my bladder acted up, the pain and discomfort was nothing compared to what I had endured when my bladder was so severely ulcerated.”

“And you had a pediatrician for Tommy!”

“Yes for Tommy and his little sister Ann who was born nineteen months after I was finally diagnosed with the bladder problem. Dr. James referred me to an obstetrician who delivered Ann without any complications. Life was wonderful and stayed that way for seven more years.”

Narrowing his eyes, he said, “I assume that’s when you became ill again.”

“Yes, I climbed back on the medical merry-go-round, and the experiences were devastating.”

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