

The Patient's Perspective on the Burden of Disease in Ankylosing Spondylitis



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KEYWORDS

- Ankylosing spondylitis • axSpA • Patient perspective • Nontraditional therapies
- Exercise

KEY POINTS

- A patient's 50-year perspective of living with ankylosing spondylitis.
- Traditional and nontraditional treatments of ankylosing spondylitis.
- Challenges to receiving a diagnosis of ankylosing spondylitis.
- Physical and emotional outcomes after receiving a diagnosis of ankylosing spondylitis.
- Importance of exercise for ankylosing spondylitis patients.

When Dr Michael Weisman asked me to contribute an essay for this collection, I was flattered, but I also reminded him that I am not a doctor and I have not done any medical research. He laughed, and said, "I know that!" He requested I write something personal about my experiences as an ankylosing spondylitis (AS) patient, and that is what I have tried to do. Going back over my 51 years with AS, I see that I have had a lot of adventures—some good, some bad, some funny, and a few creepy, depressing, scary, uplifting, and even inspiring. Nothing I write here is meant to be critical of the doctors or treatments I have had. Some doctors and treatments were better than others, though. I have hardly been perfect, either. As an AS patient, I have at times been dubious, gullible, optimistic, sad, scared, and stubborn.

I was 13 when I first started having back problems. My family lived in Topanga Canyon, California. My mom was a bit of a hippie. Taking me to what she called a regular doctor was not her cup of tea, so she took me to visit what would be the first of many chiropractors. The adjustments gave me some relief but not enough. I still woke up nearly every night with my lower back in spasms. I was stiff. I may have been moderately athletic in elementary school—I was a fast runner and I was not bad at playing first base—but these things hurt my body too much now that I was in junior high. Complaining did not get me anywhere. My mother was a magical thinker.

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If I had a sore throat, it was because I was swallowing my emotions and therefore my words. If my back hurt, it was because I did not want to bear the weight of my responsibilities, like taking out the trash or doing my homework.

There came a day when my mom realized that my visits to the chiropractor were not helping me all that much, whereas at the same time I was not getting any closer to what she saw as the deeper emotional source of my physical issues. She broke down and took me to a regular doctor. The pediatrician bent me this way and that. Although I was only 13, I could no longer touch my toes. Once the examination was done, the doctor announced with something like awe, “You have the back of a 90-year-old man” (“man,” not even a woman), This was followed by, “You will never be able to bear children.” The doctor gave me a list of don’ts: Don’t go horseback riding. Don’t jog or run. Don’t do any sports that would have a jarring impact on my spine. I was not prescribed painkillers, which was a good thing, but I also was not prescribed any other type of medication or physical therapy. This was 1968. Was he unable to make a diagnosis because he was not accustomed to seeing arthritic diseases in his pediatric practice, because I was a girl (when the common wisdom at the time was that AS was a man’s disease), or because my mom seemed so flakey, and, by extension, I must have been flakey too? I do not know. What I do know is that the source of my problems remained a mystery, and my prognosis seemed, even at that age, rather grim.

Spring ahead to 1974. I was 19, going to college but living at home. I had gotten stiffer, and I continued to wake up in the middle of the night with my lower back muscles in spasms. We lived in an old, funky, 2-story cabin. To get from my bedroom to the main part of the house, I had to walk outside. One morning I awoke in terrible pain. I hobbled outside, wound my way upstairs, entered the house, and fainted on the kitchen floor. The pediatrician, whom I was still seeing, announced that I had lumbago and sciatica. He said I should stay in bed, which I did for the next 6 weeks. I lay on my back with my legs propped up on pillows. Not moving, I now know, was the worst thing I could have done.

My mother was desperate. She became convinced I would spend the rest of my life as an invalid. (There was a part of me—still a teenager, remember—that was rather enchanted by the idea, thinking of all the invalids in literature: Camille, Clara in *Heidi*, Pollyanna, Beth in *Little Women*, and Colin in *The Secret Garden*.) My mother may have been flighty in some ways, but she also has a PhD, was a single mother supporting my sister and me through her writing and teaching as an English professor, and was a woman who never gave up through all the hardships in her life, of which there were many. She wrangled every person she could think of to see what, if any, treatments might help me. I was caravanned down to Orange County to have electromagnetic field therapy. I was driven out to the desert to soak in hot springs and mud baths to draw out toxins. I was taken to a new set of chiropractors. Some crystals may have passed over me once or twice. I returned to my pediatrician, who only repeated what he had said years before—that I would never be able to bear children. This time he added that I would never be able to walk without a limp. Bottom line: nothing helped. I was flat on my back in bed, hopeless.

One night while out to dinner, my mother overheard a couple at the next table talking about an acupuncturist—recently arrived in the United States—who was introducing the ancient technique at a local university medical school and secretly giving treatments at his home. (This was still 1974. In 1976, California became the eighth state to license acupuncture.) My mom leaned over and asked how to reach this Chinese doctor, whom I will call Dr Yee. The diner outlined an elaborate system of calling a number, letting it ring so many times, hanging up, calling back, letting it ring another

specific number of times, and then calling back again. My mother followed the instructions and got an appointment.

I could barely walk. I mean, barely. I had already been in bed, except for visits to various traditional and nontraditional doctors, for 6 weeks. My mother drove me to a tract house in the San Fernando Valley. She stayed in the living room, while Dr Yee's pretty, young wife led me to their baby's bedroom, outfitted with a crib, changing table, and twin bed. I was told to take off all my clothes and lay on the bed. (Because acupuncture was not practiced in the state, no one—apart from that man in the restaurant—had any experience with it. Neither my mother nor I questioned the fully naked request.) Dr Yee came in, spoke to me for a few minutes, and then brought out the longest needles I had ever seen. The deepest one went several inches into my hip. Dr Yee left me alone. Laying there, not moving and hoping there would not be an earthquake, I felt something I had not felt in weeks, no, years. It was a total absence of pain. The doctor returned, pulled out the needles, and left me to get dressed. I walked out of that house without a limp.

The relief did not last, however, and I returned twice a week for treatments. I improved so quickly that I was able to attend classes again. I started driving again too. One day when I arrived at the house, Mrs Yee and the baby were out. This time Dr Yee led me to the master bedroom, where I was told to take off all my clothes, as usual. And, as usual, once I was settled, Dr Yee came in and inserted the needles. Later, after he pulled them out, he sat on the edge of the bed. I remember this so clearly: the big mirror on the ceiling, his matching white patent leather belt and shoes, and the earnest look on his face. "Now that I have cured you," he said, "I must have sex with you."

I was stark naked, on the man's marital bed, but somehow I had the wherewithal to say, "We don't do things like that in this country!"

As a 19 year old, I talked my way back into my clothes and out the door. He began calling me at home. Would I like to take a ride in his Citroën? (No.) Would I like to have lunch? (No.) Did I want him to heal me? (Yes.) My mother came up with a solution: she asked one of her students, a Vietnam veteran who had served in the Marines, to accompany me to all future acupuncture appointments.

Now I know that this episode was my first major flare-up, but I had no such knowledge then, because I still did not have a diagnosis. Life went on. I continued my college work. I went to parties and discos. My dad—an anthropology professor—got a new job, which came with good insurance benefits. Although I had not lived with him since I was 3 years old, he put me on his policy and got me in to see an orthopedist at Kaiser Permanente. The doctor confirmed things I already knew: I had the back of an old man, and I would never be able to bear children, because he could see on my radiographs that my sacroiliac bones were fused. He came up with a treatment plan, which included a stretching routine and regular sit-ups. I was religious about my physical therapy, which seemed to help, especially if I did my exercises at night just before bed. I was still to follow that initial list of don'ts, however: no horseback riding, running, jogging, etc.

After 2 years in college, I left to travel around Europe for a few years. I came home, graduated, started writing, drifted away from doing my exercises and stretches, and began to get tighter and stiffer. When I met my future husband, I was 25 years old and I could just barely touch my knees. I was in unrelenting, low-grade pain, but I had lived with it so long that I did not think much about it. The constant inflammation took a toll on my body, though. When I got married, I weighed 44.4kg. (It was not until years later that my husband would confide that when we married he expected that I would 1 day end up an invalid—in a wheelchair if I was lucky, bedridden if I was

not.) I am happy to say that I gave birth to 2 children. I am not going to say it was a walk in the park, but, thankfully, all the dire predictions failed to occur. After my second son was born, I was exhausted, achy, and unable to sleep because my back hurt so much. I went to my general practitioner. I listed my complaints. He looked at me and not unkindly said, "What do you expect? You're a mother with young children." I felt slightly vindicated when the bloodwork he had ordered came back and revealed that my thyroid levels were low. He suspected Hashimoto disease. I have been on thyroid medications ever since, which improved some symptoms but did not ease my aching back.

That is how things remained for another 5 years or so. Then there came a night when my husband and I were at a dinner party. Just as when my mother had overheard someone talking about the acupuncturist, on this night I eavesdropped on a conversation about a doctor who seemed to perform miracles on people with back and neck pain. I made an appointment. A new round of radiographs were taken, and, finally, I got my diagnosis. The way the doctor explained it, there had recently been 2 young men who had died in motorcycle accidents. Radiographs showed that their sacroiliac joints were fused. Their deaths, and this discovery, led to a way to diagnose AS.

Just now, having looked up the history of AS, I must doubt the veracity of this story, but at the time it made sense to me. It also made sense when the doctor said that on average it took much longer for women than for men to be diagnosed. In the 1970s, as I understand it, it took men 3 years to 4 years to receive a diagnosis, whereas for women the average was 10 years. I was in my mid-30s. In my case, it had taken approximately 20 years. I was prescribed Indocin, as well as physical and occupational therapy, and given a pamphlet suggesting I might struggle with the diagnosis and that I could benefit from joining a support group. On the one hand, I was relieved. I could finally put a name to the pain I had suffered. AS was not something in my head or some mysterious way my body was trying to communicate, as my mother had always told me. The Indocin worked amazingly well. (In the coming years, I would also try Celebrex, Mobic, and Vioxx, all of which produced side effects while not working as well for me as Indocin did.) On the flip side, after all the years of uncertainty, I did indeed struggle with the diagnosis. The word, *disease*, did not sit well with me. Instead of trying to deal with my feelings, I told my husband I was not the type of person who joined support groups. I went ahead with the physical therapy and occupational therapy—some techniques of which I use to this day.

When this doctor retired, I was at long last referred to a rheumatologist. He was horrified that I had been on a nonsteroidal anti-inflammatory drug (NSAID) for 20 years. I did not react well when he gave me a stern lecture, informing me that I had been taking Indocin for far too long and that, although I had never had a reaction to the drug, if I ever did, I probably would have a stomach hemorrhage and die. "You'll never get to the hospital in time," he warned. This should have scared me. This should have inspired me to consider other medications. Instead, I was so mad that I immediately looked for another rheumatologist. Let me note for the record that I have not always been the best patient. But you could also look at this another way: in all the years I had been taking Indocin, not a single doctor, including my personal physician, had ever mentioned anything about side effects that might include stomach hemorrhage, let alone death. And, unless he had a better idea, I needed that Indocin.

My second rheumatologist prescribed lansoprazole to protect my stomach from potential NSAID damage. She spoke to me about the new biologics, which sounded promising. But when I heard that I would have to give myself a shot...forget that! She also mentioned that Cedars-Sinai Medical Center here in Los Angeles was looking

for AS patients willing to participate in a national clinical study. In Los Angeles, the study was being overseen by Dr Weisman. Would I be interested in finding out more about it? Absolutely! By this time, I knew of Dr Weisman's reputation but had been told he was not accepting new patients. If I joined the study, he would see me, if only for a few minutes, every time I came in to have my blood drawn, have radiographs, or have measurements taken.

My participation was not entirely self-motivated. After my own adventures and misadventures, and after all the information and misinformation I had received over the years, I wanted to be a part of something that might create new ways to diagnose the disease, possibly change perceptions of who might get it, and look at the differences between how the disease presents in men and women (or if these differences are more a function of gender biases). Most important, I hoped that by participating in the study, I could be part of a cure, at best, and better understanding of the disease, at least, in case my children, grandchildren, or great-grandchildren should find themselves with back pain and stiffness as they entered puberty. I am proud to say that when additional studies came up, I prevailed on my parents and my sons to participate along with me. They all did.

I am a writer by profession. I go on the road for 6 weeks to 12 weeks a year on extensive—and grueling—book tours. On a typical day, I fly to a new city, speak at a lunch event, speak at an evening event, maybe do an interview or 2, shake lots of hands, sign piles of book, and get plenty of impromptu hugs from fans. In other words, I am in an environment of high stress, not enough rest, with a heightened exposure to germs. In 2011, when my novel *Dreams of Joy* was published, it debuted at number 1 on *The New York Times* bestseller list. When something like that happens, the publisher doubles down. My tour was extended. I did even more events. I was in Raleigh, North Carolina, when I developed a cough. By the time I got to Atlanta, I was very sick. But everyone was relying on me, so I kept traveling. Whenever I flew back to Los Angeles, I would see my personal physician. I was prescribed antibiotics and different medications to help with the cough. I continued to travel hard and put out a lot of energy doing events. I lost weight. I started to have pain in what felt like every joint. My knees, wrists, and fingers were swollen, hot, and pink. My hips, neck, and back felt like they were on fire. It hurt to sit. It hurt to lay down. It hurt to move. I was exhausted.

When the tour ended, I saw my rheumatologist. My bloodwork showed a high level of inflammation. Actually, all my bloodwork looked bad. She did more tests. We tried all the usual treatments, plus cortisone injections. I did not improve. If anything, I got worse. I developed the symptoms and markers for Reynaud disease. My rheumatologist was sure that 1 or more new autoimmune diseases were emerging—Sjögren syndrome, rheumatoid arthritis, lupus, or rhupeus. I was told it might take as long as 5 years to get a conclusive diagnosis.

If I have learned anything over all these years, it is that I need to be proactive about my care. It is important to try different treatments. It is important to get second opinions and sometimes third opinions. It also is important for a patient to keep his or her own medical records. (Now these can be accessed more easily online, but in the past I had to request copies of test results.) The next time I had an appointment for the AS study, I brought the file I had kept for the previous 20 years with me. When Dr Weisman came in for his usual quick visit, I asked him to look at my file and inquired if he would consider taking me on as a patient. He said yes to both. He told me not to worry. Those other diseases were not on my horizon. I was, however, having a serious flare-up of my AS.

It was through Dr Weisman's encouragement that I finally agreed to take Enbrel. He said it might take months before I felt a difference. For me, relief from my symptoms

was immediate, and I kick myself to this day for being so resistant to giving myself a shot, which turned out to not be a big deal after all. For someone like me, who travels a lot, there are challenges to having to take a medication that requires refrigeration. I realize that now some of these requirements have been relaxed; nevertheless, patients must be careful with how they handle delivery and storage of this drug. (It cannot, for example, be delivered to your front door and wait all day in the sun for you to come home. Believe me, no patient wants to pay the out-of-pocket replacement cost for a single injection, let alone a box of 4 injections.) This refrigeration requirement has led to some interesting experiences. I have been invited to store my medicine in hotel kitchens and bar refrigerators across the country as well as in South America and Asia. I have had conversations with chefs, bartenders, maitres d's, general managers, and hostesses. I have been given sneak peeks of what is coming up on dinner menus and been treated more than once to the house cocktail.

It has been a long and circuitous route. I still do not sleep very well, and many nights I can be found sleeping seated on the couch with my back and neck supported by pillows. The fatigue I feel—from lack of sleep, too much stress, and a daunting workload—may or may not be worse than what other AS patients experience. I feel fortunate compared with people like my father's cousin, who did not receive a diagnosis of AS until a few years ago, when she was 85 years old. She had lived in pain for the vast majority of her life, not knowing why.

I try to cover all bases in my care. I watch what I eat to avoid—or at least cut down on—foods known to cause inflammation, and I try to rest for an hour in the late afternoon before resuming work. I do not dwell on the ways the disease can manifest in the eyes, bowel, or heart, but that does not mean I do not watch out for symptoms. I now have an ophthalmologist and a cardiologist. I am my mother's daughter, so I also have a naturopath, chiropractor, acupuncturist, and Chinese traditional medicine doctor. (I would not go—or pay the money—if I was not helped by their treatments to some extent.) A few years ago, I started working privately with a Pilates instructor, who said the goal should be for me to touch my toes within 2 years. Although I thought the idea was far-fetched, I agreed to try. I not only met the goal of touching my toes but also, on a good day, I can get my palms flat on the floor. Now, in addition to hiking, tennis, and Pilates, I have added yoga. My current goal is to keep being able to touch my toes until the day I die. (So much for a back like a 90-year-old man!)

Now, when I learn of someone who has been diagnosed with AS, I always offer to talk to them. Usually, they are upset to have a disease. They are scared, having looked up various outcomes on the Internet. They ask me a variety of questions: Will I end up bent over like a pretzel, or will my case be mild? Will I be able to work? Will I be able to travel? Will I be able to take care of my family? Will I be able to rock climb, skydive, garden, knit, or golf? I cannot give them definitive answers. I can only share what I have learned from my own experiences. Try different treatments, because you never know what will work for you or help you, even if it is for a short time, even if it is only from the placebo effect. Trust your doctors but be willing to move on—and up—to new ones if, and when, you can. Remember doctors can be wrong. They are only human, after all. Understand that every new physician you see—whether a gynecologist or neurologist—will doubt your diagnosis, as still happens to me to 30 years after finally receiving mine. (These days it is easier to prove to a new physician with the results from an antinuclear antibody or HLA-B27 test.) Keep your freezer stocked with ice-packs and bags of frozen peas to reduce inflammation but know that sometimes only a heating pad will give you relief. Most important, remember that although the disease is now a part of you, it does not define you. Try to look at AS as an adventure, with

plenty of twists, turns, and discoveries along the way. And always remember to thank the people who help you—whether physical therapists, yoga instructors, nutritionists, or rheumatologists—for their insights, patience, persistence, and encouragement. Then thank your body, flaws and all, for getting you through another day.

DISCLOSURE

The author has nothing to disclose.