I was diagnosed with ankylosing spondylitis nearly 12 years ago, and like so many of us, I dealt with this diabolical disease for years before I ever heard about AS. I’ve had flares; we all have. For me, the paralyzing fatigue comes first. Followed by the aches and chills that feel like the beginning of the flu. As the pain builds, there’s really nothing in my arsenal to combat what’s coming next. It’s the worst, and my typical flare drives me to bed where I’ll lay for hours, or days, completely at the mercy of my own immune system. I’m now in far greater touch with my body, what sets off pain, and what doesn’t. I’ve developed a pretty good feel for what I need to do to keep my muscles and joints moving without inflicting damage. I see my doctors regularly, and I listen to what they tell me. After all these years I thought I’d come to understand the complexities of this affliction, and what I could expect on any given day, week, or month. I can always predict a flare long before it levels me. Or so I thought.

This story starts in Victoria, British Columbia. As a novelist I can work virtually anywhere and part of my annual migration is to depart the mountains of Montana, and travel to coastal Canada to avoid the early blizzards in the Rockies. I’d settled in, had been working for several weeks and was well into my daily routine. I work some, move about often, and stretch all the time to fight the inevitable stiffness. In the middle of the afternoon I try to get out of the condo and take a walk. My smart phone has me zeroed in on the 3,500 to 4,000 steps per day range that I’ve found to be optimal for me. Everything seemed stable and my overall pain levels were what I’d describe as normal.

One Friday evening, a day like any other, I fixed a salad for dinner, watched television, and then went to bed to read. I eventually switched off the light, rolled on my side and a sudden pain erupted in the left side of my chest. Startled, I moved to my back expecting relief, but my chest pain got worse. I got out of bed as the pain quickly became unrelenting. I travel with opioids that I rarely take, but I didn’t hesitate a second as I took them. I’ve suffered from chest pain before, and I’ve heard doctors use the word Costochondritis to describe the condition. My previous attacks were painful, linked to a flare, and seemed to be movement related. I’d never experienced anything like this out-of-the-blue attack. Nevertheless, out of habit, or just plain foolishness, I diagnosed what was happening to me as an AS event. It wouldn’t be the first miserable night I’d spent in pain. Maybe I momentarily considered other reasons for the pain, but the obvious enemy was AS; I’d been here before. As I continued to analyze and battle my situation, the pain only intensified.

I have a theory that AS patients, people who’ve sometimes spent years being misdiagnosed by others, are often hesitant to reach out for help. We’ve witnessed at times spectacular inaccuracy, or even perceived indifference within a broad range of the health care system. Taking the lessons learned from those experiences, there is a tendency for us to become more proactive than reactive. We are almost forced into the role, so we become our own doctors. I could feel the opiates enter my system, and while they were ineffective against the pain, the message I should have received was that I was now self-medicated. I had accomplished nothing except impair my own judgment as the pain grew worse.
“Maybe I momentarily considered other reasons for the pain, but the obvious enemy was AS; I’d been here before.”

It hurt to sit, and to lay down, so I slowly paced the condo trying different positions to ease what had turned into what I was now calling a “super-flare.” I drew water for a hot bath to try and find relief. In agony, I could hardly move in and out of the tub. The water did nothing, and the pain pills were in no way up to the job at hand. The next phase happened fast. With no warning, I bent over and completely emptied my stomach. I’d never before gotten physically sick from a flare, and I recalled a small fact I’d learned in my now ancient CPR training: People in life or death situations often vomit. Its nature’s triage, the body telling you you’re going to need all of your energy to stay alive, and it’s not the time to waste precious energy on digestion. Properly scared as well as confused, I managed to make one of the few correct decisions of the evening. I did what I should have done ninety minutes earlier. I called the front desk and told them I was having chest pains and that I needed an ambulance.

As quick as that I was no longer in control. I’d passed myself off to others. The landline rang and a calm female voice began asking questions. She asked about my meds, when this started, and what I’d been doing since the pain started. In the distance I could finally hear a siren. They were coming. Miserable, I made my way to the door and propped it open for my guests. The second they arrived it was all business, and within minutes I was on a gurney headed out of the building. There are no windows in the back of an ambulance, so of course I had no way to know exactly where I was being taken. At that point I’m not really sure I cared.

I was rolled from the ambulance down a hallway past a waiting area, and whisked into a curtain draped cubicle. I was tagged, vitals were taken, blood was drawn, and an IV started. I felt very detached, only an interested spectator at this point. The labs came back and they were able to rule out a heart attack. They shifted gears and a nurse hurried in and gave me two injections of some kind of nonsteroidal anti-inflammatory. The medicine was administered in two doses, ten minutes apart via my IV. She waited with me. Within minutes of receiving the second dose, the pain ebbed and was completely gone within thirty minutes. Free from the pain, and exhausted from both my mental and physical punishment, I fell asleep.

At some point they woke me up, took another round of vitals and I was released and taken to a small deserted lobby. It was still dark outside. The nurse pointed toward a direct dial phone on the wall and explained that it would connect me directly with a taxi service. The phone rang and the dispatcher informed me a cab would be sent to the Royal Jubilee Hospital. I hung up. At least I finally had a name for the place I’d been taken and my brain was starting to connect the lost dots. Wherever I was, I was so very grateful for the people who had treated me.

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As I waited for my ride, I began to sift through everything that had happened, and even more worrisome, what could have happened. I was relieved it had only been a flare, though a flare that reached new levels of pain - unwelcome news I’d ponder another time. I repeatedly chastised myself for being so hesitant to get help. What if it hadn’t been AS? It could have easily been something else. Just because we have this painful disease in no way exempts us from other afflictions. Being stubborn could have resulted in me being found in the condo, a sad casualty of having played both doctor and patient. Never again, I know enough to realize that pain and fear create instant anxiety, which does nothing but
impair judgment. Throw in some opioids and you’re compromised without a sound decision to be found. I wasted a lot of time before reaching out. Please don’t hesitate to call for help. There are people out there, first responders, waiting to assist - and I can testify to the fact that they’re pretty good at their jobs.

**Editor’s Note:** We’d like to echo Mr. Donlay and stress to our readers to please reach out for medical help when in doubt, or when something just doesn’t seem right. Trekmedics.org has an international directory of Emergency and Ambulance services, should you experience an emergency while traveling. Our thanks to Mr. Donlay for sharing his experience.

Philip Donlay learned to fly at age 17 and was first published at 18. In the aviation world, success came quickly. Whether flying a Saudi sheik, nighttime freight, or executives of a Fortune 500 company, Donlay logged over six million miles while traveling the globe to 40 countries on five continents. After decades of unexplained pain, Donlay was finally diagnosed with ankylosing spondylitis, which eventually grounded him. Unable to fly, he turned to his second passion, writing, and is a bestselling novelist with eight published books. When he steps out of the world of fiction writing, Donlay is quick to share his insight into the ongoing battle he wages with AS. Currently, he divides his time between Utah and the Pacific Northwest.

You can learn more about, and contact Donlay through his website, philipdonlay.com and through Facebook at facebook.com/AuthorPhilipDonlay. He loves hearing from readers and fellow spondylitis warriors. Look for additional stories from Donlay in the next few issues of Spondylitis Plus.