Ankylosing Spondylitis brings change, and most of it is bad, or really bad, depending on your point of view. I’m not describing physical pain, as we all know far too well what that’s all about. What I’m talking about is psychological injury - the kind that injures your spirit.

I used to fly airplanes for a living. I’d been that kid at the airport fence, and told myself I would be a pilot one day. I worked hard to earn enough money to take flying lessons when I turned seventeen. I continued advancing my career until I was flying jets. I flew for many years until the fatigue and pain of what I would eventually learn was AS had taken its toll. The biologics didn’t work, and the drugs I needed in order to have any kind of quality of life ended my career. Not being able to fly was by far the worst damage this disease brought upon my life. For years my spirit recoiled from that loss as I slowly accepted and then adapted to the new realities of my world. AS is all about loss; as warriors, we’re about trying to adapt.

Not long ago I was staring at the yellow paint on the rear quarter panel of my beloved car. The car is black, the yellow wasn’t supposed to be there. Over the years, AS has made sure I can’t turn my neck very far in either direction, so backing up my car was becoming problematic. I never hit anything but concrete, and in the latest case, concrete painted yellow. There have been utility pole foundations, traffic barriers, and of course the inside of any parking garage is nothing but concrete. Any dash of black paint on a concrete wall could very well be my work. Someone less stubborn would have traded in the car for one of those do-everything models they make now. Not me, though I guess I should confess that my car and I have been together nearly fifteen years, it’s a sleek, road hugging, finely tuned, high performance European dream. I bought the car new, still wrapped in plastic, sitting on the transport truck at the dealership. That purchase predated my AS diagnosis. A little yellow paint is nothing; my car is literally the last part of my old life that I still possess. With its horsepower, stick shift, and handling, it allowed me, on occasion, to still experience a small part of how it felt to be a pilot. I love that car, everyday for fifteen years it made my spirit sing.
Over the years, that car never let me down - it signified a test of wills between me and the AS. I would adapt no matter what. When my left knee needed surgery, I taught myself to drive using only one foot. (It’s harder than it sounds.) My knee got better, and then I was forced to adapt how I shifted with a surgically repaired right shoulder. Though if I were being honest with myself, when I’m getting into my car, I grimace as I kind of lean down and blindly drop backwards into the seat. It’s not pretty. Climbing out of the car hurts, and I do make a straining noise that has, on occasion, turned heads in alarm. My left hip complains each time I push in the clutch, and it zings my shoulder when I have to put the car into reverse. The pain, coupled with my lack of ability to avoid concrete was making my driving experience difficult. Yet each time I thought about an upgrade, I dug in my heels on giving in to yet another AS loss, one that I feared would irreparably damage my spirit. Though somehow, that yellow paint had crawled into my psyche, and it was rattling around in there whispering for me to do something.

I had been procrastinating, I admit it, and after a great deal of deliberation, I finally found myself at a car dealership.

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I went straight for the brand new versions of what I’d been driving. With each sleek model I inspected, I realized I was still sitting in a hole, still making my reverse blind entry, and still emitting involuntary moans and groans upon climbing out. After trying on four or five cars I’d broken a sweat and was in pain. On the other side of the lot sat a row of SUVs. My spirit seemed to cry out, startled, and I got a little panicky. I sauntered toward the first model, and my eyes hurt from how ugly it was. Clearly, no engineer had ever bothered to put the thing in a wind tunnel. It reminded me of a platypus, the metal version. Still, I cracked open the door. I will admit I was a little peeved at how effortlessly I could slide behind the wheel. The salesman showed up with keys and convinced me to take it for a spin. I decided I should at least drive it before I walked away. As we began, I was shocked by how easy the camera made it to go in reverse. With all of the computer sights and sounds, I probably couldn’t hit anything if I tried. I then realized my growing annoyance at how effortless it was to drive, to change lanes, etc. I took these sensations as the Universe schooling me for waiting so long to do something smart. The power seat had ensured my comfort in three dimensions, right down to the millimeter. I sat up high and could see everywhere. Concrete far and wide must have breathed a sigh of relief as I brought us back to the dealership. The final slap in the face was when I discovered I could step out of the driver’s seat in complete silence. 

I had no choice, really, so I sat with the salesman and went over the options. A rear camera, heated, fully adjustable seats, an automatic transmission, and finally, the proximity alert system. I looked across the desk, and since there was no way he would understand that what I needed was the Ankylosing Spondylitis package - I mumbled something about the “Elderly Package.” He laughed. Me, not so much.

The day I turned over the keys to my high performance companion of fifteen years, was bittersweet. I had mixed emotions; I clearly wasn’t going to be cool anymore, and certainly there was no sex-appeal in my mechanized all-wheel drive platypus. A reality check did remind me that my gray hair and cane had probably already diluted any coolness I thought I still possessed. Painlessly, I climbed into my new ride. What surprised me most was that my spirit seemed unaffected. In fact, it was fine. This change, though AS induced, was perhaps not a bad thing. I finally understood that my ego was the part of me that wasn’t thrilled, but spirit beats ego any day. I hadn’t really lost anything. In fact, I may have gained. I began to consider all the places this new vehicle could take me that my old car couldn’t. It crossed my mind that maybe I should get a dog, SUVs were made for dogs. I could carry lots of stuff in the back, and if I wanted, I could probably still go fast, it would just take a lot longer, and wouldn’t be nearly as much fun. Though you want to know what fun is? It’s less pain. That’s fun. I used to pat my old car lovingly on the hood from time to time, but I only give the platypus an occasional nod. As I cruise around, I invariably switch on the seat heater regardless of the outside temperature because it makes my back feel better. I understand that having AS is a constant search for ways to adapt, and we do. Change is hard, but we do it, and we get a little better sometimes because we don’t quit trying. I guess that’s why we’re called warriors, and I’m a warrior in a metal platypus.