



ALS Adventures is a periodic account of life's experiences by a person living with the disease.
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On the Road Again April 1, 2006

"On the road again", can't you just hear Willie belting out those words. I can. And in my mind's ear I'm whaling right along with him. Interesting, I think I sound just like him, too.

This sounds-like-Willie phenomenon happens to me every time we load up the old motor home (we call it the "Box," remember) and head out.

After our successful test run to San Francisco last month, we're now headed to the right coast. Susan loaded the box, coaxed me into the passenger seat, and on the second day of spring, we sprung ... headed east.

She packed enough of my feeding formula to last a month. When I approached the box to board, she still had the basement doors open. For a moment I thought I was climbing onto an Ensure delivery truck. Do the math. 8 cans per day times 30 days ... that's 240 cans ... that's also 10 cases. Geez, is there room for anything else?

Some time ago, Susan and I had a heart to heart talk about camping. She said she really liked camping, and was ready to hit the ole' camp trail any time I wanted. (Wow, music to my ears ... unlimited camping, hiking, etc, etc. You get the picture.) Then she went on ... "So long as I can take two hot showers each day, wash my hair, be warm and dry, sleep in a king size bed, and have TV to fall asleep watching" ... and oh yes, she wanted fresh clean towels each day, too.

That sort of set the stage back in '02 for us to purchase the "box." And since its purchase we have added satellite internet so we can stay connected to the office and the world, even as we are perched on the north rim of the Grand Canyon. Technology gave us the freedom to roam, and feel not far from home. It's

the greatest! (And this episode of ALS Adventures is coming to you via satellite ... direct to you from the "box.")

About every 5-600 miles we stop for fuel. And since we are about 55 feet long including the toad (tow vehicle) not any old gas station will do. So we usually look for the big truck stops and we pull in right along with all the big rigs.

On our first stop for fuel, Susan pulled in with the big guys. Filling the box with diesel is about the same as filling your car at a gas station ... well almost.

First, the nozzles are bigger at a truck stop. For Susan it's a job for two hands. Second, everything's dirty. I mean truckers with oily, greasy hands service their trucks, and not once do they stop to wipe down the nozzle handle when they're through. Even the long handled window washer squeegee. It's dirty, too.

So what happened? Not much. (Remember, Susan's doing all the man-jobs ... from hooking up the poop chute and hitching up the toad, to fueling and checking the oil, she's doing it all.)

Anyway I hobbled out to watch/coach the fueling process and we immediately had the attention of the nearby truckers. There were snickers when Susan grabbed the nozzle and screeched "eeuu". More smiles when the fuel hose brushed against her jeans and left a big black smudge. Her comment, as she's trying to wipe it clean, "Damn-it, now I have to change jeans." (I used to get those smudges; the jeans were good for a couple more days.)

Then one driver sauntered by me and laughed as he inquired how I got Susan so well trained. "I saw her drive in ... she's pumpin' the fuel ... now she's washin' the windshields! How'd you do it?" (If he only knew!)

We got a late start leaving Southern CA. It was dark and we were about 40 miles from home when I had a choking spell. (Guess that's why I'm not driving.) The next day ... a couple more choking spells. Susan called our family doc and he told her if this keeps up go to the ER.

800 miles into our trip we arrived in Santa Fe, New Mexico. Another choking spell, we're headed for the ER. Six hours later, several X-Rays and a bunch

of blood work, the ER doc said, "It's just part of the disease, sorry."

Sorry, I guess! I hate the choking ... this disease sucks!

The next morning we're off for some sightseeing. Maybe 10-15 miles out we stopped to fuel up the Jeep. With a tear in my eye I told Susan we couldn't go on. You see, the Jeep is a rough ride. Short wheel base, tight suspension, off road tires, it's a rough, noisy ride. My weak body was getting beat up. I could not take it all day ... sad. ☹

And I needed help getting in. The Jeep simply is not built to haul around someone in my condition.

Lately, I've become aware how people enter and exit their vehicles. Have you noticed? You know, these days, we all wear jeans and tennis shoes. We get in to drive our cars right foot first, then the butt slides in followed by the left foot. Pretty smooth.

But think about how a shapely young lady wearing heels and a tight skirt does it. She backs in, cute butt hits the seat first then both legs swivel in under the wheel.

Well guess what. I can't pick up my legs to enter the car like a normal person. I'm doing it like the shapely young lady. My cute little butt hits the seat first, and then I grab one leg at a time and lift them inside the car.

The Jeep seats are positioned so that process just can't happen; I needed Susan's help to get in.

So what do we do? The Jeep, as much as I loved it, is not serving our needs. Susan suggested we go trade it in on something that works. I said we can't do that, we're a long way from home! A few hours later we are the proud owners of a '06 Chrysler PT Cruiser. We did it! Traded that '02 Jeep Wrangler straight across for the new PT Cruiser. No cash, even trade.

The dealership was top notch. Our salesman, Ken, put up with my type-n-talk method of communication. And I parked my suction machine on the table ... he had to watch as I cleared saliva every few minutes. Overall, a good experience. If you're ever in Santa Fe, NM

and get to hankering for a new car, give us a call, we can point you in the right direction.

But don't get me wrong. The PT Cruiser is not nearly as much car as the Jeep Wrangler. We gave up our 'macho' car. We gave up much more car than we got. But the PT has a surprisingly smooth ride. Plenty of front seat room. My cute butt easily hits the seat first. It's low to the ground ... easier for me to lift my legs into position. It's small enough to be a great toad ... the motor home won't even know it's back there. In short, it's perfect!



Ken, the car salesman, stayed past closing time to close the deal.

Okay, new car's ready, we're going to try that sightseeing ride. (The one we didn't complete in the Jeep.) About two hours into our sightseeing jaunt we discovered a small Army Corps of Engineers lake. Big sign said "View Overlook." Sounds like we are invited to take a look-see, wouldn't you think? Wrong canyon breath!

Not very impressed ... we decided to leave. Not so fast! The gate's locked! What? Can you believe this? We're in the middle of left arm pit somewhere and we are locked in the Army Corps lake viewing area. Locked in! There's no way out (If we still had the Jeep, we could have crawled out of there. Who cares if the gate's locked?! But that new PT Cruiser ... it's not going to crawl anywhere! Hmmm.)

I'm taking inventory. I have two cans of Ensure left. (Susan and I can share.) We have half a tank of fuel. (We can stay warm) And we have a couple of jackets. (In case we have to go pee.) No, silly, we wouldn't pee on the jackets. We would need jackets to go to the

restroom. We CAN make it through the night, I think.

Ah-ha, cell phones still work. (Thank goodness!) Who should we call? 411 told us there is *no* Police Department, and *no* sheriff. We settled for the fire department. (It was actually a voluntary firemen's home phone.) He said he knows people. He'll try to find the guy. He did!



Abiquiu Lake, NM...we're on the inside looking out! Where's the Jeep when you need it?

Blacky the cat is in the news again. We took him to the vet to be neutered. No big deal, right? Everyone gets their pets fixed, it's a routine procedure.

Um ... except when Blacky stretched out to endure the dastardly deed, the vet noticed he was endowed with only one ball. What, one ball? So what, whack it off and send him home. Nooo! The vet said "We have to go in." Go in? Now the poor guy has a 2 inch incision in his belly. (Calmed him down, though.) Check out the pic. The guys in our office are calling him "Cone Head." "Not funny," says Blacky!



"My name is Blacky, thank you ... not Cone Head"

I had a new experience at Wal-Mart. We took that new PT Cruiser to replenish supplies. Wal-Mart is a big store and my

walking ... well it's just a struggle. Left leg is so weak I can just barely lift it to clear a standard 7 inch step. (We avoid stairs these days.) And the thought of hobbling all over Wal-Mart was a bit much.

As we entered the store I spotted one of those battery-operated riding shopping carts. We asked and that happy greeter you always see as you enter, she was obliging as she got me settled in. What fun! That thing zoomed along faster than Susan walks. It turns on a dime, and maneuvers nicely in tight aisles. If I had a cowboy hat ... I would have been waving it in the air and hollering YA-HOO ... if I could holler.

I have avoided the discussions about getting a wheelchair. The focus of ALS doctors and support staff is to equip the ALS patient with whatever they may need, before they need it, so it's ready when the day comes.

Well there's a problem with that. Every time I get something so it will be ready when I need it ... I end up needing it. I want that to stop. If I don't get a wheelchair, then maybe I won't need it! Clever, huh?



Linda, one of the UCLA docs (an ALS expert). She pushes to get meds and machines before they're actually needed.

Fact is I got on that riding shopping cart without a second thought. I wasn't embarrassed, I wasn't ashamed. I was happy for the relief from that walking task!

We did our shopping. I hobbled out of that store not exhausted. It's a nice service they provide. And I guess it's time we started a serious talk about a wheelchair. Damn-it!

Readers who want to learn more about ALS can log onto the ALS Association's website ... www.alsa.org.