

Volume 2 Issue 6

Report Card
June 1, 2006

Report cards, remember getting them years ago in grade school? Some of us were happy to see them. Me ... I usually felt like I could have skipped the whole ordeal, if you know what I mean ... I didn't become a good student until after I grew chin whiskers.

Now as events have unfolded, I feel like producing my own report card covering my condition. Or perhaps, I could grade the two hospitals I have recently had an opportunity to visit ... or maybe ... I should do both.

You may recall last month's episode ended with our youngest son David, making his way toward our second home on the Upper Peninsula of Michigan. It was a rescue mission to get us back to California where we could get in-home care and have access to the big city hospitals.

What an experience! My newly installed tracheostomy was about a week old. (It's a *tracheotomy* when you talk about the procedure ... it's a *tracheostomy* once it's done.) Anyway my body was weak from the ravages of ALS and from lying in bed for 10 days. Here's our trip home.

Susan put Dave and Catalina (Dave's girlfriend) to work with chores necessary for closing up the house. Then they packed boxes to be shipped, baggage to be

checked, and carry-on bags for traveling ... and Mia the dog, and Blacky the cat, they had their own carry-on containers, too.

We're running a little late. Anxiety is high. Dave's driving my pick-up. I'm riding shotgun. Susan insists that he need not obey the speed limit. (A little back-seat driving ... you think? Susan?)

First leg of the trip was on a prop-driven puddle jumper. You know, one of those small planes where they take your carry-on bag and check it at the gate because there just isn't room to squeeze it into the cabin. (They did let Blacky and Mia ride with the passengers.)

Ahh ... before we could board, they picked me, the suspicious looking dude slouched over in the airport courtesy wheelchair, for the "extended" strip search. Yeah, I know, shouldn't complain.

Anyway that first leg got us to Detroit. Pouring rain. Arrival gate, no less than 10 miles from the next departure gate. As planned, airport personnel met us at the gate with a wheelchair. They announced, "Here's the chair ... but we don't have a pusher." Susan opted for the pusher job. (Dave and Catalina had their hands full with carry-on stuff plus Mia and Blacky.) I think we may have looked like the gang that couldn't shoot straight, from Arkansas.

Huffin'-n-puffin' we found the departure gate. Dave and Catalina, they're hungry. That reminded Susan ... time for my feeding. (You may recall I receive all my nourishment through the feeding tube. An 8 oz can of Ensure every hour and a half or so.) That's when the fun began.

The device that plugs into my feeding tube ... it had been packed in one of the checked bags! (It's pouring rain, remember.) Susan's amped up on caffeine. Dave's plea to one of the Northwest Airline staff worked. A big burley guy splashed in from the flight line.

The plane was boarding ... those needing extra time were to board first. No ... not us! The flight line guy said, "Can't bring your checked bags up here ... you can't come onto the flight line ... I'll stand in the open with your bags and you wave when I pull out the thing you need." (It's raining, remember.)

Susan is standing at the big window waving her arms. (Hairdryer ... NO ... makeup bag ... NO ... underwear ... NOT!) Can't you picture it? Pouring rain, flight line guy's dragging everything out of our checked luggage ... remind you of an I Love Lucy escapade?! (Yes, she got it!)

They parked me by the boarding door ... everyone's on board except us. Then the ticket checker guy became impatient. He grabbed my wheelchair and raced me down the ramp! WAIT, I'm thinking, CAN'T GO WITHOUT SUSAN! Besides ... I must be hungry.

It's dark-thirty. We arrived in Los Angeles. I'm more than beat. Susan's frazzled. Dave's off to get his pick-up. He returned and announced that he lost his cell phone on the parking courtesy van! (Although considered, NO, we did NOT go find the van.)

At home, we were met by friends and neighbors, all there to help get

me up the stairs. (We live in a second level condo.) Whew ... made it!

Two days later ... I'm back in ICU ... this time I'm in one of our big city hospitals. (California docs got concerned about my shortness of breath and decided I needed to spend some time in their ICU, where they could assess the work done by those country-bumpkin docs back in Michigan.)

Sooo ... my opportunity to compare and contrast a MI community hospital against the CA big city facilities.

I'm here to announce ... there is no comparison! For me, the myth that we need to be near a big city to get the very best care, is just that ... a myth! The hospital in little ole' Petoskey, MI wins hands down!!!! I won't bore you with the gory details but simply stated, from technology to staff attentiveness, Petoskey gets an A+. Big ole' Long Beach barely gets a C!

There, my hospital report card ... and that sets aside... once and for all ... any notion that I need a big city hospital.

But wait! You say. (Did you say wait??) What about those stairs where you live in a second level condo? What are you doing about the stairs?

In January we launched an effort to install a lift. Not done yet ... maybe six more weeks.

So what the hell happened? It seems like only a couple of months ago we were running around in the motor home ... today I'm talking about wheelchairs and an elevator lift.

I don't know what happened. It seems like all of a sudden the walls came tumbling down.

We were on the road, remember? The choking got us to an ER in Santa Fe. Then my head flopped over, no longer able to hold it up. Then the legs gave way. Susan was literally pulling me up/into the motor home. Next the quick decision to get the trach. WOW ... what a month!!

If we are keeping score, the ALS bug may have won one.

So what's the status today? And do I really feel like making light of things in this ALS Adventures?

Good questions.

Report Card

Left arm ... F
Left hand ... C-
Left leg ... D-
Right arm ... C
Right hand ... B
Right leg ... C-
Neck ... F
Lungs ... D

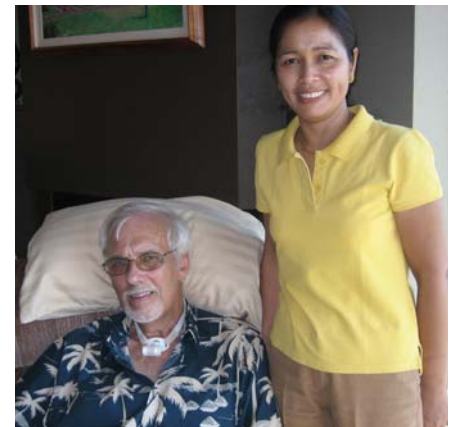
Yeah, okay, so what do all those letter grades mean? Well, for the most part it means my body is being overpowered by this stupid disease.

I now rely on a walker to shuffle along. A trek of 50 feet leaves me winded ... gasping for air. We have a wheelchair, loaned to us from the ALS Association loan closet. We are checking out one of those power jobs next week.

I'm on a ventilator at night for about four hours or so. Susan has learned trach care and knows how to "deep suction" my lungs should I become clogged up. (Horrible procedure to endure. Means running a small tube down through

the trach then down into the bowels of my lungs.) I now need care 24-7.

Enter Josie. She provides in-home care for me, to give Susan an opportunity to run errands, check in at the office and generally get a break. Two months ago I would not have forecast today's status.



Meet Josie. She's perfect. She has 16 years experience caring for ALS patients.

Otherwise ... I'm just fine. That's part of the problem. My mind still works as though my body were not restricted. I dream about doing things with a normal body. My "dream brain" does not recognize the disease.

I find myself thinking of adventures Susan and I could embark on. Even my "awake brain" seems to forget what we're dealing with.

What about writing these Adventure episodes? I do have my down moments. I decide I've written my last word. Then a new day comes, I feel better, and some things once again seem humorous.

So here's one more episode! Go figure.

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