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**Heads Up
May 1, 2006**

Heads up, means everything's okay, or we've got approval to proceed, or pay attention, something important is about to unfold. My dad used to say, "Hold your head up, shoulders back, wear your hat with the bill pointed in the direction you're going." Simple advice, but advice I never forgot.

Maybe his simple guidance is one reason a recent symptom has affected my spirits so much, perhaps more than any other symptom to date. All of a sudden, I can no longer hold my head up. All of a sudden I have a real bout of depression brewing. Kind of ironic, wouldn't you say ... when I put on my cap, the bill points down. Damn-it!

Our trip to the right coast in the box (motor home, remember) got interrupted. After we cleared Texas, we decided that the road trip was being harder on me than we anticipated. Climbing the 4 steps into the box became a routine of Susan literally pulling me up/in.

Destination Florida Keys, a spot I'll see in a future life, got replaced with a trek north to our place in St Ignace, MI. We figured we would go to our second home on the UP (Upper Peninsula) and rest, relax, and enjoy the tranquility.

3900 miles ... we pulled into our drive ... Susan drove them all. Didn't hurt herself ... the box ... or anybody else (a successful trip).

So my condition seemed to be worsening. And now, during the last few days of our road trip, I was having difficulty holding my head up.

Susan strapped on my head brace. (No ... although I suspect it would look good on her, she strapped it on me.) With the brace, my chin rests in a support and my head is held up. It's a goofy look, but it works.

But a weak neck was not the only symptom getting worse. My legs too have lost strength. Here's what happened. (A little potty talk ... be prepared.)

Soon after we arrived in St Ignace, I had to go to the bathroom. This was to be a private moment, number two, you know, a moment that warranted ... a closed door.

Here's the setting (as viewed while sitting on the throne). The bathroom is laid out with the toilet facing the door. It has a built in lavatory to the left and a tub/shower on the right.

So there I sat. Productive effort ... the paperwork finished ... I was ready to stand up, flush down, buckle up ... wash hands and emerge.

Stand up ... hmmm. I suddenly realized the toilet is one of those low profile jobs. I can't get my legs to lift me. Ah, I'll hold onto the lavatory cabinet on my left.

I try. But wait! My left arm ... that's my weakest arm ... too late! I'm committed! I'm up far enough that I have slid over so my right butt cheek is precariously perched on the left edge of the toilet seat! I managed to get my left elbow hooked over and into the lavatory. I'm hanging on, trying not to fall down between the toilet and the lavatory cabinet. (Can you picture that? Rather not, huh.)

PANIC!! I started pounding on the lavatory cabinet with my right hand. (Can't shout, remember.) I wanted Susan's attention. Private moment or not ... I needed her!

Susan, knowing this was a private moment, cautiously cracked the door. "You okay?" OKAY?! ... I'M STILL POUNDING! She saw my precarious predicament. Tried to lift me ... Can't! I'm too heavy! She did manage to get me centered back onto the pot. She flushed! Whew!

No, I'm not still sitting there! We figured it out. Susan's next trip was to the hospital to borrow one of those portable commode seats that sits over the toilet. It's higher and has handrails to push off from.

So with weak arms and neck, Susan has started helping me dry off after a shower. She now dries and brushes my hair, too. (Shouldn't give up her day job!)

My barber back in Seal Beach, Victoria, she wouldn't approve. Victoria works in a salon. Not a barber shop ... it's a salon. You see, I have a problem going to a salon to get my hair cut. I'm just not a "metro-sexual" kind of guy. (Too much red neck below my hair line, I guess.)

And I don't care if other guys do it ... NOT ME! So I beat the system. I visit the *salon* to get my hair cut before 8 a.m. That's well before the other stylists show up and all that "jabbering" starts. You know, that girl talk chatter stuff. I don't want a facial, and I don't want my nails done, and I don't care about who's dating who, or why ... just a hair cut!

But Victoria does a good job ... has now for a number of years. So Susan doesn't get to man the shears ... not yet anyway!



That's Victoria, all proud that she has made me look debonair.

Choking ... and the trach. Another trip to the ER. Three times in as many weeks. This time resulted in another ambulance ride. 40 miles. Here's the low-down.

The choking became intense. Most severe at nighttime, and mostly due to phlegm that I could not cough up. (I'm not talking about thick phlegm like when you have a cold. This is the clear lung stuff that a normal person handles many times each day with a simple clearing of the throat, or a light cough.) And another thing. Who decided how to spell phlegm? Shouldn't it be ... "flem"????

Anyway, when I went to bed, the choking started. Couldn't lie down. Finally I put on the head brace and tried to catch some ZZZs ... while sitting up. Susan sat up with me ... watching. For two nights we struggled, with neither of us getting a nickel's worth of sleep.

On the third night ... off to the ER.

One thing occurred to me when we first discovered our second home location a few years back. I thought about the hospital facilities in a small rural village. The services might be marginal. Did we care? NO. Susan and I were in pretty good health, so why worry. Besides, lots of people live the rural life and survive without a big city hospital.

So the St Ignace ER is about a half mile from our home. We were surprised and very pleased with the ER staff, their attitude and attentiveness.

And get this. When we walked in, I was ready for a tracheotomy! WOW! Not a light decision! Did you watch that episode of ER a few months back? Remember James Woods getting a trach? Gruesome. That's the mental picture I had as I suggested a tracheotomy. Not a light decision.

We have read, watched videos, talked, and prayed. We know how ALS progresses. Each new phase is dreaded, but each new phase is anticipated. And I decided when this ALS stuff became prominent in our life months ago, that Susan's instructions were that I was not to get a tracheotomy if I were totally paralyzed. But if I were still walking, still using my hands and I was not totally depressed, if needed, I'd do it.

But as dutiful as the St Ignace ER staff was, they felt a procedure as serious as a tracheotomy should be performed at a hospital where there was a team of specialists to add insight and advice. Hence the 40 mile, 1:00 am ambulance ride.

But the hospital we were headed toward was in a town not large enough to support an airport. Certainly not a large facility like in the big city. What are we racing into!!? I was anxious!

And think about it ... I expected a diversity of skill and attitudes among the nurses and doctors. I expected to find the duds spread among the diamonds. And reflecting back on our big city hospital experience when I got the feeding tube, I just knew we were headed into a hospital hell. After all, we were headed to Petoskey, a beautiful Lake Michigan resort city, no big city hospital anywhere in sight!

Guess what. We did not encounter a single dud. Excellence was the operative word. We were there for a full week. We could not find anyone or anything less than excellent. What a pleasant surprise.

But the procedure was not without its trying moments. For one thing, as we rotated through the team of specialist, they were all in agreement. The neurologist, although he agreed, suggested that I was entering the final stages of my disease. He said I had a choice of the tracheotomy ... or I could go to hospice.

Whoa! Hospice! Hospice means I have given up! It means, go to bed, take drugs, and ... wait to die!

I'll have to make that decision soon enough, but not today. I checked, I'm still wearing my red ALS wrist band that says, "NEVER GIVE UP." (But hearing that word ... hospice ... Susan and I held each other and cried.)

But the decision was made. No turning back. Less than 12 hours after rolling in, the team of doctors agreed, Susan and I agreed, the surgical team was standing by ... let's do it! (Or should I say ... heads up ... it's a go!)

I was in ICU. Fifteen minutes, it's all over. I was awake, I think, through the whole procedure. They punched a hole in my throat just below my Adam's apple ... about the size of your pointer finger.

Fifteen minutes! I remember the doctors huddling over me. The only words or word, I remember is the surgeon saying "PERFECT." I liked that word!

Here's what I think is amazing. I felt no pain. Not during the procedure, not during recovery and not since the operation. (When I got the feeding tube last October everyone suggested it was no big deal. Well I'm here to tell you it was a big deal, it hurt for at least 2 weeks after.)

But the trach ... I have felt absolutely no pain ... amazing. That's not to suggest however, that this has not been one hell of an ordeal.

Frankly, as I laid there in the recovery process (they had a ventilator connected to my brand new trach), semi-awake, and

feeling like I had a brick lying on my throat, I had lots of time to think. I considered that I might die right there. I prayed a lot, and I had detailed thoughts about my family, and the activities that consume their lives. I thought about one of our projects back at work and how I needed to tell everyone my opinion. Then I thought again... if I die ... they'll figure it out without me. I felt sad.

Back to reality. Susan needed to learn trach care. How to disassemble, clean and reassemble that plastic gizmo that now permanently resides in my neck. She has to learn how to thread a small tube down through the trach and suction my lungs (if I can't cough up the phlegm on my own). Scary stuff for her ... scary stuff for me.

Susan stayed in my room 24-7. Right by my side. (They dredged up a recliner chair. That became her bed.)

Susan was stressed. (You think?!) She called for daughter, Cori, Jesse and baby Hannah to fly out from California for support. They performed chores, brought Susan fresh clothes and food.

The hospital discharged us with an arm load of supplies and a ventilator. I was to use it at night. All of a sudden ... we're on our own! Scary! We tried to get a nurse to come in to help. Area is too rural ... none available!

Decision time. We better get back to California where we can get in-home support.

Son David and Girlfriend Catalina to the rescue. They are flying out from CA to pack us up and take us home.

Funny, Dave is the youngest. For many years, I always figured I would be the one to rescue one of the kids if they were ever in need. Never ... ever ... occurred to me that one day I might need rescuing. Seasons change ...

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