



Adventures

ALS Adventures is a periodic account of life's experiences by a person living with the disease.
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Under the Knife! November 7, 2005

"Count from 10 backwards." Ten, nine, ei I was out! Those surgery docs, they've got it down pat! Goin' under the knife ... an experience everyone should have ... at least once!

And just to be safe ... in big black letters I wrote on one leg, "**not this leg**" ... and on the other leg I wrote, "**not this leg either!**" (You've read those stories where someone goes in for surgery and they remove the wrong leg or something. I was taking no chances!)

But I did have one real concern. You may recall that I can no longer sleep on my back because saliva accumulates, drains down my throat, and I choke. So before surgery we were telling EVERYONE not to lay me on my back during recovery. I mean we told the anesthesiologist, the surgeon, every nurse we could find, the clerk in admitting, we even flagged down people on the sidewalk. **DON'T LEAVE ME IN RECOVERY LAYING ON MY BACK ... I WILL DIE!**

Here's sort of what the feeding tube doc said about the procedure. They'll run a camera and flash light down my throat and into my stomach. They'll look around for the perfect spot. Put the flash light against the inside of my stomach so the light kind of shines through so they can see it from the outside. "X" marks the spot. They punch the hole right there, about the size of .38 caliber slug.

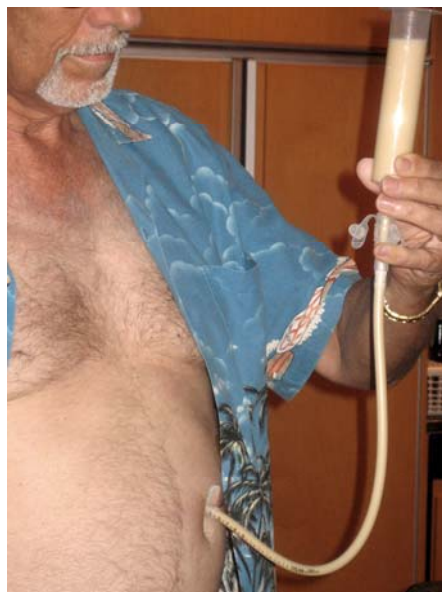
Got the picture? So far so good. Now they insert the feeding tube. (Oh yeah, now that we're all part of the 'in crowd' I'll call it a PEG.)

Twenty minutes ... it's all over!

Upon awakening, I saw Susan fussing over me. I thought for a moment ... they left me on my back in recovery and I died ... Susan was an angel there to take my hand. Not so fast! Susan was holding my hand and a small teddy bear ... I had survived! (Ahhh ... touching scene, don't you think?)

Not long after, Mike Butler, my best friend and business partner, showed up and wanted to update me on some project. What the ... ? I was all doped up, no idea what I agreed to. (When he shows up driving that new Mercedes, he'll say ... "we talked it over!")

Next, I observed an 18-inch long opaque rubber tube about three-eighths of an inch in diameter protruding out of my belly. It is located on the left side about 2 inches below my rib cage. Right where it enters is a little plastic bar that resembles a big wing nut. The doc had told me that I'll need to twist that bar. **WHAT?! TWIST IT!?! I'M NOT TOUCHIN' IT ... CREEPY! I'VE CHANGED MY MIND!**



See that little bar where the tube enters my belly. That has to be twisted.

The PEG doc said that although the procedure is simple enough to be completed as an outpatient, he liked to

keep his ALS patients overnight. That way they can monitor stuff, and he assured us that I would be discharged first thing the next morning, right after the nurse teaches us about the care and feeding of a PEG. (Sounds almost cute and cuddly, huh ... Just wait!)

The second day would be good. They would teach us everything we would ever need to know. I'll have breakfast and get my morning meds through the tube! Sounded good to us, obviously we're in good hands!

Wrong again ... PEG tube breath! (Did you catch it? A little Johnny Carson humor there, for those old enough to remember a Johnny Carson routine.)

It was on day two in the hospital that things went down the tube. Oops! Not a good analogy! But you get the picture, day two was not the better of the two.

Have you ever been trying to resolve some problem and in exasperation declared, it had "fallen through the crack"? Well, in our case, we fell through the hospital floor. Day 2 found us floundering in the Limited Stay Unit (LSU) in Hospital Hell!

First off, the nurse had little or no knowledge about ALS. She wondered why I was still there in her LSU on the second day. "It was only a PEG, for crying out loud!" (As she resumed exploring the internet.)

Wait! What about the meds-in-the-tube thing ... and breakfast-in-the-tube ... and the care-and-feeding thing ... and day two was supposed to be ... *good!*

Remember that New Orleans mayor in the Katrina aftermath? "Where's the friggin' Calvary!?" (His words not mine.) Well, that's kind of how we felt. Lots of staff visitors, we pleaded for relief ... none came.

Susan's usually ready for about any challenge when it comes to my ALS. But she had been there all night, chas-

ing pain meds and unplugging and replugging all the monitoring stuff, once an hour so I could go pee ... generally earning her very own nursing stripes.

The discharge orders had been written at 8 A.M. Around noon-thirty, my 'Case Manager' strolled in and proclaimed, "We're working on it." WHAT? CASE MANAGER? Did I go on welfare or something overnight?! (Michael was his name ... easy one to remember.) Michael soon learned what Susan thought of their LSU services. And I think he was most impressed when he heard what she thought about his 'managing' skills!

That's when it hit her. The ALS Association! They *used to have* a great nurse! She resigned from the association last month, but Susan still had her home phone number! And her parting words ... "Everyone should feel free to call." (I could already imagine. The Calvary's coming!!)

That's when Michael-the-case-manager rushed back into my room. "Janelle, 'Your Nurse' (My nurse?) just called, she's mad! She has taken responsibility for your *immediate discharge*. Here, take this box of supplies and sign this. The wheelchair nurse is right here." (So that's it, she's the "wheelchair nurse!" That's why she had time to surf the net!)

We went home. Janelle, 'My Nurse' showed up with her husband in tow. (Just in case there were any of those pesky LSU nurses nosing around. He looked like he could be the bouncer, if he wanted to.)

Check this out. Feeding with the PEG is a snap ... boring ... but a snap. Taking meds is pretty easy, too. After only two or three feedings, we're pros.

In the box of supplies from the hospital was a large syringe. (The syringe without its plunger looks like a small turkey baster.) We use the housing like a funnel ... simply pour in my

"baby formula." The plunger isn't used. (Looks like I will be fed formula for the rest of my life. They won't really let us put real food down that little tube. Ugh.)



Meal Time

Look at the picture, "Meal Time". See the tube leading up to the syringe housing? That rubber tube, it slips onto the tip of the syringe. Friction holds it there ... or it's supposed to! Um ... that's when it happened. Our first "experience."

I was having lunch. Susan had just filled that syringe for the second time. The tube, it slipped off the tip of the syringe and a stream of formula started pouring onto the dining room floor. LOOK OUT! It was splattering on our shoes!

Then I realized the tube connected to my stomach was hanging down ... it too was pouring onto the floor! WHOA! I bent over to grab the tube! (Think about it. When I bent over, my internal organs squeezed my stomach.) Now picture this. The end of the tube, with the extra pressure, started gushing out my stomach contents. In fact, the end of the tube started whipping about like an unattended fire hose might do!

Geez ... what a mess! My first experience throwing up with the PEG. (Come to think of it, if I ever have the real urge to up-chuck ... with the PEG it might be fun!)

I had all the regular monthly check-ups this month. I'm still passing their tests, but I'm realizing you have to be

damned near wheelchair bound before you fail their tests. So passing is no big whoop!

Fact is my arms, legs and neck are showing signs of weakening. I know it, Susan knows it, and at times, we pretend that the weakness must be from the loss of weight or maybe even remnants of that cold I had in September. Whatever ... I can't stand it!

When we finally decided to get the PEG, the clinic folks expressed lots of concern for how we might interpret that decision. That is, they wanted us to think of it as a mechanism for improving the quality of life and not ... proof that the disease is progressing.

Know what? That's a broad leap of faith! Yes, we want to give it the best spin we can. And we want to keep our spirits up. But you know what else? If the ALS weren't progressing, I wouldn't be needing that damned PEG!

Our challenge ... stay focused on all the good things in our life. That new grandbaby is sooo good for our spirits! Thanksgiving will be here soon. Then Christmas, and then a brand new year to celebrate!

And I think we're going to try to squeeze in there somewhere, a couple of weeks at our place Up North in St Ignace on Lake Huron. The frost is on the punkin' back there. We can hold hands, stroll through the woods and kick up some autumn leaves. Think about it. A roaring fire in the fireplace, a few candles and some soft music ... maybe we'll even pop open a bottle of Pinot!



Test run before our trip Up North