

The Wedding! September 10, 2005

“Her mother and I do.” That’s my line ... my big moment ... the line that six months ago when the engagement was announced, we all wondered if I would be able to deliver.

Six months ago. My ALS diagnosis was only three months new. We didn’t know how fast it was progressing. Would I be able to speak in six months? (My voice was already heavily slurred.) Would Alicia be able to take my arm? (You know, would I be able to hold it out for her.) And too, would I be in a wheelchair by then?

The docs had told us to make plans, set goals, be active, and watch my diet, think positive, and ... never give up.

Sounded easy enough. One of those goals six months ago ... on September 9, 2005 ... walk Alicia down that isle and deliver my line.

Alicia is the classic Type A personality. EVERYTHING is planned. Every ‘I’ is dotted twice and every ‘T’ is crossed at least three times. Nothing could go wrong. Nothing! Well ... almost nothing.

First event, meet the family. The rehearsal and subsequent dinner ... that’s our chance to check out Keith’s clan. What, did you think we would just assume they’re okay? No way, I want to meet them ... face-to-face!

They arrived from Mulberry, Indiana as planned and seemed nice enough ... but I was watching ... just in case. (Remember the movie, Meet The Parents ... “eyes on you.”) What is his mom REALLY like? How about his dad? When they weren’t looking my way, I had my eyes on them! Ummm ... cute sister ... okay, he comes from good stock!

So far, so good.

When we arrived at the Chapel, we learned that Alicia was, how should I say this ... a little anxious. Her stomach wasn’t as well organized as she was. (I’ll skip those details.) Nevertheless, she looked absolutely radiant. I asked if she was ready to “Run”. She tried to reassure me. Her mom, with a guarded giggle, seemed cool enough. Hummm ... why was I anxious???

I’ll tell you why. It occurred to me, what if when the preacher man asks, “who gives this woman,” rather than say my line, instead I say, “I changed my mind ... you can’t have her!” What would Alicia say? (Scream) DAAAAD! I could even imagine that terrified look. HOW COULD YOU! Don’t you think that would make the whole wedding experience more memorable!



A few moments before strolling down the isle ... my last ‘official’ Dad duty.

You’re right. I couldn’t do it! With the help of my trusted pallet lift, I delivered my line on queue. No guts ... Damn it!

But wait ... something did finally go astray. The limo, sparkling clean, it showed up on time, and ... broke down! (Secretly, I was delighted!) Ahhh ... too bad. Alternator belt broken? Looked like someone cut it? Couldn’t be!

Remember that ‘93 Vette that Susan and I bought from friends a few months back? It just happened to be close by. Washed and shined up. Top already removed. Tank full ... READY TO GO!



Back up plan ‘B’ underway

Weddings ... lots of hugs, lots of kisses, a few laughs, a few tears ... don't you just love them! I'm a lucky guy.

I had my monthly check up. The clinical trial doc did her routine exam for arm and leg strength. Arms and legs are still okay. My lung capacity has slipped some. We think that is because I had a little chest cold.

The clarity of my speech, or my enunciation, continues to diminish. I rely on the palatal lift device to improve my speech to where it was about three months ago. (And it wasn't that good even then!) I don't gag on it nearly as often. The ALS dental doc is still tweaking it. She's working on my "G" sounds. Interesting how she knows how to do that.

That chest cold. What an experience! All those fluids that develop with a cold ... yuck! When things in your throat don't work right, those fluids become a real challenge to manage. (I know, too much information.)

Eating, or should I say swallowing, causes us the most concern right now. I can no longer swallow as a natural reflex. I believe that every time I now swallow, it is because I think to do it. Often, it's even hard to initiate the swallow when I'm trying. That makes eating a struggle.

That's probably the reason I'm losing weight too. After working on a meal for a while, I get tired of fooling with it and I quit eat-

ing. I think I weigh less today than I did 35 years ago. Susan is learning to cook for the ALS patient, and she is taking every opportunity to shove more calories into every bite. We want to stop the weight loss.

I think the swallowing problem is also the root of the nighttime choking. When I am asleep, and with the swallow reflex not working, saliva accumulates and eventually starts to drain down my throat, choking me on the way. It's almost becoming routine. Sleep for an hour or two ... wake up choking ... sleep for another hour, wake up choking again. But it's the occasional 30-minute choking episode that is really disturbing.

The solution? (We'll put this one off for as long as possible.) The solution for the swallowing problem is to have a feeding tube inserted into my belly. Yep, they'll punch a hole in my stomach and insert a tube. It's done as an outpatient procedure, with local anesthesia, pretty routine for ALS patients.

I know, that sounds horrible. But think about it. I've already pretty much given up eating crumbly things like nuts, cake and tortilla chips. I've stopped having that scotch and soda before dinner; and that fine glass of Pinot Noir on a lazy sunny Sunday afternoon has been gone for months. Those things all cause terrible choking.

Can't you picture it? Susan and I would fix a cocktail. Then perform our ritualistic toast to our

health, each other, or some other worthy event, and take that first most meaningful and simultaneous sip. Except in my case, I would tip the glass and pour a bit into the funnel inserted in the feeding tube. What about taste? Yeah, I know, some sensations will be sacrificed.

Ugh you say. I don't know. No more coaxing me to eat my veggies; and broccoli (*SHIVER*), I could cut it into little pieces and stuff them in the tube then, with a rod shove them into my stomach. (Kind of like cleaning your gun barrel.) Furthermore, swallowing all those pills will be a breeze, and think of the dishes I won't dirty. See, it could even be good for the environment!

And occasionally we could create a little ambiance. Consider a real cozy setting, a few candles flickering in the darkness, some light music, a crackling fire in the fireplace, the sound of rain drops on the windowsill ... maybe a couple of glasses of vino, and then the magical toast. Sounds like fun, maybe even romantic ... maybe.

We're not there yet ... the feeding tube I mean. However, we're starting to think about it. Got to stop the weight loss! And the ALS progression ... we still think it's slow. I'm a lucky guy!

What's next? The baby is next. The other daughter Cori, she's expecting in early October. Are we ready to be grandparents? There's no turning back now!