

## Home for the Holidays

January 3, 2006

The way I like to sing it here in sunny southern California ... "I'm dreaming of a *bright* Christmas, just like the ones ..." you know the tune, sing right along. Um, didja' say it politically correct this year? Not "Christmas," but "Nondenominational Winter Holiday" ... and if you changed it, go ask Larry-the-Cable-Guy his feelings about the whole thing ... and hang on to your John Deere cap!

It's rare, but it happened. All the kids and their special someone, gathered under one roof at the same time. Fantastic aromas to savor and an equally great looking spread to anticipate. The two Vegans in the group (you have to say 'Vegan' while holding up your right hand forming a four finger "V" ... the way Spock would do it on Star Trek), they also found their pallets soothed. And me, my nostrils took in the scent of roasted prime rib, and my mouth took in ... um ... I can eat anything I want these days ... so long as it's ice cream!

Grandbaby Hannah, she stole the show. In addition, I realized how much baby Hannah and her Granddaddy really have in common. For one thing, I'm sixty years older than her, to the day. (Remember, she was born on my birthday about three months ago.)

Now she's learning to hold up her little head. It flops over but she catches it and holds it steady for brief periods. Me, with a weak neck, I'm doing the same thing ... head dips, I catch it and hold steady for a while. Hannah drools and smiles about it... I drool and giggle about it. She's on

a liquid diet, (think boob tube) ... I'm on a liquid diet, (think feeding tube). She can only make cooing sounds, no real words. That's me, grunts groans and moans, no real words. (Only those close to me can decipher the sounds.) Her little legs are getting strong and she's trying to stand. My little legs are getting weak ... I'm trying to remain standing. The parallels are uncanny!!!

Susan and I got a special Christmas present. We named him *Blacky*. Check out the picture.



**Blacky, one eye still asleep, just waking up from a long winter's nap.**

Blacky goes to work with us each day. He often sleeps curled up beside my printer. He gets along great with our little "Alpha" dog. Actually, it's Alpha cat meets Alpha dog. Guess which one rules. Blacky is about 14 weeks old.

Son Jason, our Artist (remember the one who had the MoMA exhibit), he seemed interested in talking about death. Yes, I know, a strange topic for a Christmas Eve discussion, but death has become part of our ALS life in a bizarre sort of way.

So is death really a big deal to me? Well, YES! Duh! It's a VERY big deal. And I'm going to talk a little about it here. (I promise, it's not morbid.) I'll just touch on the light conversation we had while sitting around the ole' Christmas tree.

In addition, because the diagnosis date was just two days before Christmas, the Christmas season

seems to have become a time to reflect on the prognosis. Somehow, that makes Jason's interest in sharing views on death somewhat fitting.

No, I haven't given up and I don't think I'm on my death bed. I still expect to beat the odds ... relax!

It's interesting for me to reflect on the day the neurologist proclaimed my ALS diagnosis (one year ago, December 23). After a brief examination, he said as he popped back into the exam room, "I have good news and bad news. The good news ... I know what you have. The bad news ... you won't like it." What? Is this guy for real? Then he spit it out. Funny way to issue a death sentence, wouldn't you say.

I have to tell you though, it's different having a doctor look you in the eye and tell you that you're going to die. I already knew I was going to die, that's not news. Then again, prior to that day, there was no timetable assigned. I just knew it would happen one day ... a loooong time from now.

We all know our days on this earth are numbered. We know we're going to die someday, and we generally don't think much about it, at least I never did. But with the grim statistics assigned to ALS victims, Susan and I have tried to face facts. Most ALS patients live another two or three years following diagnosis. Some make it to the five-year mark, and precious few make it to ten.

But you know what? I'm not worried about being dead. I'm convinced that there are good things on the other side. I *believe* and I have faith. Things on the other side will be okay.

But think about it. There are a multitude of ways to get to the other side that simply sound horrible. Many that seem a lot worse than withering away with ALS. But those horrible scenarios are not what I'm facing. I'm dying one silly little neuron at a

time. Each day a little bit more of me is dead. Weird thought, huh.

It's mostly the crossing over that concerns me though. It's the process of dying that is scary. When my lungs finally give out, will it feel like I'm smothering? Will it be pneumonia that causes the end? Will that hurt? Maybe I'll choke on something and that will be the end. I don't like to choke. I wouldn't want to die that way. The way I understand it, my body will simply shrivel up, all voluntary muscles will cease to function, and finally my lungs will shut down. Creepy!

And remember, through all this the mind stays alert, the brain remains fully functional, so I'll be aware of everything. Doesn't that sound frightening ... It does to me! I'm a puss. When the time comes, I want to skip the dying part ... and just be dead!

I read somewhere about death being very similar to birth. The unborn is all snug and cozy inside the womb, and then WHAM, it's time to be born. Its familiar environment is warm and comfortable and now it's being pushed out and the crossing over, the birthing process, is traumatizing.

But life on the outside of the womb is much more fulfilling, and growing up is full of excitement. In short, life after birth is much better than life before birth.

Death is portrayed in the same light. No way do we want to cross over, or die. We fight with everything we have to remain healthy; we resist death with all our might. Kind of like the infant not wanting to leave the womb. But consider this. If death really is similar to birth, and things will be much better on the other side, then there is no reason to fear being dead. But like that baby in the womb, I'll resist the inevitable. I'll hold on to life for as many precious moments as possible. And when I'm on the other side, I'll likely have forgotten all about the crossover ... just like the newborn quickly forgets about the birthing process.

Several years ago, in a lighthearted conversation with my older brother, he commented that he would like to be buried in a red coffin. Guess he likes red.

Hmmm ... must run in the family ... I like red, too. Red cars, red hair, red shoes ... if it's red, sign me up! In fact, Susan knows that she has my undivided attention when she wears red. Doesn't matter, red underthings, red overthings, if she's wearing red anything, I'm bound to be around. (Not perverted ... g'me a break!)

So is it really illogical for me to want a red coffin, too. Okay, so brother Bill thought of it first, but looks like I might be the first one to take that red coffin for a spin around the block. (And besides, he can have it after I'm done. Moreover, think of the money he'll save ... a little red touch up paint and clean satin sheets ... what the heck!)

I figure the coffin should be the cheapest metal one they make. Our son Dave can toss it in the back of his pick-up and run it over to Earl Scheib for their \$99 special red paint.

I'm not saying this to be funny either. I mean it; I want a shiny red coffin. Let the record show that I have requested a red coffin. And I hope it makes everyone who attends the service laugh out loud! And know too that I'll be looking down with a big grin on my face! Picture the scene ... who will be able to deliver the eulogy with a straight face!

Okay, it's settled. I get the red coffin. But not real soon, I'm willing to put that off a bit.

And besides, I don't have time for death. I've got things to do, places to go, and people to see.

Even so, I'm not so anxious about places I've not yet seen, or adventures I've not yet taken. I am anxious about dying.

Everyday when muscles twitch, every night when it's difficult rolling over in bed, each time I look for something to hold onto when I stand, it's a never-ending stream of reminders.

And as I lose arm and hand functions, someone will have to wipe my ass. Think about it, is that a depressing thought or what!!

And finally on a much more positive note, I had another visit to the ALS dental doc. I'm happy to report that she is working hard to help me keep talking (mumbling) for as long as possible.

I was about ready to accept spoken English defeat. The palatal lift device had served its purpose and extended my speaking ability by several months. But frankly, it was no longer helpful.

Dr. Roumanas to the rescue, she went to work on my device. (Hold on ... mind out of the gutter please!) She has added more plastic stuff to the palatal lift; it's now nearly an inch thick! It has become a real mouthful. But it's working again. Not great, but it helps for sure. I'm happy getting an extension on mumble time. At this stage, I'll take any advantage I can get.



**There she is, the ALS Dental doc. She's being all proud that she's improved my "mumble" capability one more time!!**

*Readers who want to learn more about ALS can log onto the ALS Association's web site ... [www.alsa.org](http://www.alsa.org).*