



*ALS Adventures is a periodic account of life's experiences by a person living with the disease.*  
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### Issue 13

## Grown-ups don't fight, do they? December 12, 2005

I've decided, we forget our physical limitations when emotions cause us to spring into action. I think that explains those stories we've all heard about some mother having superhuman strength and literally picking up a car when her kids are trapped.

Today, I sometimes forget my limitations. Mentally I'm ready to tackle most anything, just as I would have before ALS. You know, totally forgetting about reality. The other thing I've noticed is that since my ALS diagnosis, I seem to be less patient when things don't go quite like I expect. This next incident illustrates both points.

Fist fight ... not me! Grown-ups don't fight ... kids do ... grown-ups don't. And me, not since, I was in the Air Force, some 40 years ago.

Susan and I decided one lazy Sunday afternoon about three weeks ago, that we'd take a short stroll and have a snack. (I can do a milkshake and some soups, so we still go out even if I only pretend to eat.) We chose a little diner on Main Street, Seal Beach, where we could sit in the open patio area next to the sidewalk. Great spot for a leisurely bite along with a little people watching.

Just as we were being served a young guy, maybe 19 or 20 sat down on a bench right next to us with a cigarette. Now California prohibits smoking in restaurants, but the sidewalk is public property so legally, smoking is permitted on that bench right next to us.

However, Susan is not willing to accept OUR ambiance being disrupted by some insensitive punk trying to learn to smoke ... even if it is legally allowed! She politely asked him not to smoke there. Without a word, he obligingly got up and moved. Susan glanced at me with a rather smug look and we proceeded to eat.

So far so good. But wait ... there's more.

A few minutes passed when he returned with a buddy, plopped himself back down on that bench and promptly lit up. Susan this time demanded that he leave, but this time he defiantly turned to her and said, "NO!"

That's when I forgot all about my weak arms and legs, I forgot I can't talk, I forgot I get winded walking up one flight of stairs. I forgot that I have a brand new feeding tube poking out of my belly that's not fully healed. I was seeing red! That punk pimply faced jerk with his cap pointed off to one side, and his pants drooping so his belt line was somewhere close to his private parts, he's NOT going to tell my Susan NO! And that brazen tone in his voice definitely had to go. A sassy no to Susan means he's got ME to deal with!

I tore up from our table, back toward the inside of the diner and around the handrail then out to the sidewalk! (Yeah, getting there was a bit of a circuitous route but that's how the diner was laid out.) It was on that trip and the quick turn around that handrail that I felt a small pain from my not-yet-healed feeding tube. That pain brought reality rushing back!

But I was already in motion ... there was no turning back! (And Susan was right on my heels. She didn't have time to ponder the situation, I was headed into battle and she was going, too!)

Now, picture this. I'm standing in front of our antagonist, who was still seated and defiantly puffing away. His buddy was positioned off to one side. (I could see him out of the corner of my eye.)

It's about now that I'm starting to size up the situation. I'm thinking, this young guy still thinks like a kid. I'll bet he fights like a kid too and if he moves on me it's likely to be a football tackle in my mid-section, his shoulder will make a direct hit on my feeding tube ... and that's going to hurt! (OUCH!) Then I wondered about his buddy, was he there to watch or to help. Hmmm ... my thoughts ... don't blink first!

Then I thought, again ... WHAT AM I DOING HERE, I MUST BE CRAZY! That's when I decided, if this escalates to the next level, I'll have to get the upper hand, and fast! I'll have to hurt him

quick and hopefully scare his buddy ...  
OR I MIGHT BE IN REAL TROUBLE!

... SILENCE ... We were glaring at each other. (Can't you just imagine the setting.)

Then Susan broke the ice. (She's good at that.) She made another demand that he, or his cigarette must go. To which he responded that I hadn't asked him nicely. WHAT?! Susan quickly let him know that I can't talk. (There, that told him! Wonder what he thought about that. I think I know ... I sensed it, "Who does this grey haired 60 year old mute fart think he's trying to intimidate?")

Susan then reached over, in bold indifference broke off his lit cigarette, and threw it on the sidewalk! Okay ... here we go!

Know what he did? He reached in his pocket and pulled out a pack of Camels. (I thought right then. This guy's not a fighter. He's as worried he'll get hurt as I am!)

Next, he offered me a cigarette! What? He's offering me a cigarette! This is a peace offering! Know what, I took it! Yes I did!

The scenario reminded me of a little comic routine I used to perform years ago when someone offered me a cigarette. I would take it with thanks and then slowly peel away the paper and take tidbits of tobacco and toss it all around. When the person who gave me the cigarette exclaimed "WHAT THE ..." I would simply explain that he smoked his cigarettes for fun and relaxation. I destroyed mine for the same reasons. (You're right, they quickly stopped offering.)

So here we were. I'm holding a cigarette ... we've got a rather tense situation ... and I'm reminiscing in my mind about fooling with my buddies who smoked. (Maybe it's the ALS stimulating strange thoughts ... who knows!)

Guess what I did. Yep, I destroyed the cigarette, a little bit over here, a little bit over there. No explanation, I just did it. His response ... he looked over at his buddy with a rather perplexed expression on his face, then back at me and said, "If you guys go back inside, I'll leave."

Whew!



**We returned to the scene of the altercation just for this picture. Susan suggested I bring boxing gloves, just in case. Hmmm ... I d'know, maybe a baseball bat.**

This month's ALS progression has not been kind. You may recall last month I said that the monthly clinical strength tests were a joke ... that you needed to almost be wheelchair bound to not pass them. Well guess what ... I spoke too soon! My arms and legs did not fare very well this time. It makes us concerned that the progression is much faster than we thought. Bummer!

Nevertheless, the ALS is progressing slow enough that we muster up hope and we pray at each level, that it has gone into remission. As you might expect, this past month, we've been in the throws of acknowledging our new level. In addition to coping with diminishing strength, we've been focused on learning how our daily routines are affected because of the feeding tube.

I'm still walking without an aid ... for now anyway. But I can no longer put on my pants while standing up. (Yeah, that's a big deal only to me.) We've learned that I need to consume eight cans of formula daily in order to gain weight. That means a 'feeding' about every two hours, kind of like the grandbaby's feeding schedule. I'm up seven or eight pounds. It's working!

So if it's working, why do I hate it so much. I'll tell you why. No, it's not uncomfortable or anything like that. It's that taking in nourishment is no fun. I still smell yummy food cooking. (Thanksgiving ... wonderful aromas!) Food still looks good. Food commercials that I used to ignore have become

"Must See TV". Everything looks good. I'm kind of like that old geezer admiring a pretty young lady. That sort of describes me and food ... look but don't touch.

Prior to the tube, we went out for most evening meals. This month, most meals have been eaten at home. Something light for Susan, a dish of ice cream for me. (Yes, I can still coax down creamy things with minimal choking.) But now Susan is losing weight. That's not good ... she's already pretty small. We've got more work to do.

And another thing. That tube hanging down. I haven't figured out what to do with it. I tried coiling it up and taping it to my side. That was cumbersome. I tried letting it poke out of my shirt with the end stuffed into my shirt pocket. That made me look like a bad high school science fair project. So now, I let it droop down and I stick the end into a belt loop. Not perfect, but it works as long as I wear my shirt-tail out.

But think about it. It just hangs there looking goofy when I take a shower. And imagine how awkward it is to go hang out on a nude beach. There's got to be a better idea.

With that thought, (about the better idea, not the nude beach), I sent an e-mail to Don. Don is a fellow PALS (Person with ALS). Don and his wife Patty reside in Texas and he has been diagnosed with the same type ALS that I have. (Bulbar ALS, it affects the throat and speech first, then progresses onto the arms, legs and lungs.) It hit him in the throat just like me. In fact, when we met last March, Don's ALS accent sounded just like me talking. I was in total shock and awe when I first heard him speak. (And you thought *shock and awe* referred to a first strike in one of our modern wars.)

Don still goes to work even though his ALS accent is a bit of a challenge. You see, Don is the Chief of Police in a small Texas town. You can understand why his accent might be problematic for a Police Chief. He's running a stake out.

Then he presses the bullhorn button and says, "You're surrounded, come out with your hands up!" His crack sharp shooters, SWAT team and regulars all look at each other. What'd he say? "We surrender; someone ought to stand up?" GET SOMEBODY ELSE ON THAT BULLHORN! Think about it. Being a criminal in Don's town might be fun, or at least have its funny moments. (Then again, I'm not sure that giggling at the Police Chief's ALS accent would be a very good idea. We've all heard about those Texas cops!)

Anyway, Don's encouragement is what convinced me to go ahead and get the tube. He got his a couple of months before me. I figured he must be frustrated with that umbilical cord/feeding tube hanging down by now ... wonder what he's up to.

He's on it. He had his feeding tube replaced with a *button*. He calls it a Mickey, like in Mickey Mouse. The tube is gone, replaced by a plastic receptacle/button thing. Now when it's time to feed, he plugs the tube into that receptacle. No dangling tube to deal with. And he can tuck in his shirt. (Police Chiefs have to look sharp you know.)

So yes, we're going to look into it.

What's next? Christmas is what's next. So here's wishing all of you a sensational Merry Christmas and a prosperous, healthy and happy New Year!

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