

## **Mom Would Never Have Wanted It That Way**

Mom loved the simple things in life. She lived a very simple, uncomplicated life. It wasn't hard to please my Mom. We all know that.

All my Mom wanted to do was live her simple, enjoyable life, spreading love and good cheer whenever and wherever she could. In many ways I would call her a songbird.

She loved hummingbirds. She loved cooking, for herself and for the many, many others she cooked for in her lifetime. Cooking the wonderful things she came up with gave her some of her greatest joy, and to this day I compare ANYBODY else's cooking to my Mom's.

She loved balancing her checkbook and bank statements, always to the penny. Especially "getting" the troublesome ones. She got a special kick out of that.

She loved to eat, and play cards, and do her crossword puzzle and her jumble puzzle. She loved driving down to the grocery store to do her own shopping and always get the best deals, with never a thought to whether or not there were stairs involved. I'm 51, and even at 70, my Mom never looked a day over 56. Even at 80 this was true, and always with the energy to match. She was always going strong, and we all expected her to reach 90 easily.

A little over a year ago, Mom's simple life fell apart. She started stumbling for no apparent reason. Her legs wouldn't work right, first the right one and then the left also. Nobody could tell us what was wrong, despite doctor visit after doctor visit.

A very important scene from a not very important movie kept running through my mind after we had received the diagnosis of ALS in March. It was from Star Trek 2, The Wrath of Khan. Spock had just received a lethal dose of radiation, after saving the ship from destruction. Kirk tries to get to the chamber where Spock is breathing very heavily, and both Scotty and Bones grab him, and won't let him get any closer. Kirk says, "But he'll die!" Bones says, "Jim—he's dead already." After which Kirk and Spock proceed to have their last words in this world.

For this episode at least...

This scene is etched in my mind, never to go away now. That's exactly what happened to Mom, and I knew that just as soon as I heard about the diagnosis.

Mom loved to take walks. After awhile, Mom couldn't do that. Mom never would have wanted it that way.

Mom loved to do her bank statements. I always was impressed with how she considered this illness just a minor annoyance, and she sure wished she could get to her bank statements. It was irritating to her to not be able to do her bank statements, as if she could swat this illness away like an irritating insect. But she would then go on to other things to do.

After awhile she couldn't even sign her own name, depriving her of even the most basic of legal sovereignties. Mom would never have wanted it that way.

Mom loved to eat. Even when the disease would still allow her to do that, she still liked to at least use her own knife and fork.

After awhile, she couldn't do that either—and being the brave and proud person she always was, she wouldn't ask anyone to feed her. Our favorite phrase became, "Let me do that for you, Mom." And she was always gracious as she received the help she would not ask for.

Mom never would have wanted it that way.

Mom never lost her spirit, her famous Bea Jones spunk, her indomitable will to live. Even long after it was obvious that she would never use her hands again, she would still ask us to place the remote control of her bedroom TV—the room that would eventually become her whole world—in her hand, saying that she might just be able to work it this time.

No? Not this time, huh. Darn. Here, let me do it for you this time, Mom. And then we would put the remote back in her hand for her.

Mom never would have wanted it that way.

Mom liked to talk. Her words were always soothing, comforting, real, and always accurately indicative of how she saw things, and what was on her mind. The interactivensness with which we conversed was integral to our communications, for all of us. Her input was always invaluable and absolutely crucial to the communication process, with us, especially around her personal care and hygiene, later on. Mom was always a very fluent communicator.

One of the most heart-rending things that's ever happened to me was after her speech had been losing ground for weeks, getting harder and harder for us to understand. One day she very innocently said a sentence, one she obviously thought was as plain as the nose on your face, and quizzically looked at me for my response, as always. And I didn't know what to say. Nothing had come out but gibberish. The unthinkable had finally happened. Her speech had become completely unrecognizable. Her eyes were still speaking volumes, and her lips could still be read most of the time by the specialized caregiver--during those limited times when she was on duty--for another little while, but she could never speak again. And with Mom not having the patience for cue cards and pantomime and charades--no matter how much we offered her our patience on such things--communications between her and us all went steadily downhill from there.

Unfortunately, I've never heard of anyone who can eye-read, even tho Mom's eyes continued to speak volumes, every day, until very near the end.

The day had finally come when we could no longer say, "Let me do that for you, Mom."

Mom never would have wanted it that way.

Mom never liked to inconvenience people. If there were ever an instance where Mom had to either be the caregiver or be the care receiver, Mom's comfort zone was very deeply entrenched in being the caregiver. To be the receiver of the care made Mom feel like a fish out of water, and she simply did not know how to do it.

It was always intensely uncomfortable for her to have to ask for help. She would always rather be doing the giving than the receiving. She was just wired that way.

Within a short time after her diagnosis, her discomfort with being so far out of her comfort zone on this issue was max'd out when needing to ask for help became the rule rather than the exception, anymore. An itch on her nose became torture for her, because she steadfastly would not intentionally ask for help on something so apparently minor. Over and over, she would endure that torture rather than inconvenience my older brother Roger or Linda, his wife, who were already giving so much and so constantly already, sacrificing the ongoingness of their own lives to be there for Mom. I know this because she would tell me, during our daily phone conversations between Oregon and California.

Once when I had let it slip that I had felt just a little inconvenienced after a particularly trying set of circumstances caused by the disease, Mom broke down and cried over it. I had to apologize, and reassure her that it was not her that was inconveniencing us if indeed anybody at all was being inconvenienced—it was the disease that was doing the inconveniencing, not her. I told her about people I've known who would consciously go around purposefully inconveniencing other people, just for the cruel fun of it—they have psychological names for it, it's called covert hostility, and passive-aggressive tendencies—but that Mom just wasn't cut from that cloth, just wasn't wired that way.

I think she needed to hear that. I also assured her that when all was said and done, she was being inconvenienced VASTLY more than we ever would be, by this disease. No additional discussion was necessary.

Mom had to inconvenience people now—her life depended on it.

Mom would never have wanted it that way.

Mom was fastidious about certain things, and a very private person about other things, the same things we are all very private about. There came a time when all that went out the window. When she could no longer do the most simple, private things we all have to do every day, others had to do them for her. This was only halfway into the longer-than-a-year lifespan of the disease.

I know this was one of the most difficult things Mom ever had to allow to happen, even though she eventually made it look as if it were easy.

Mom never would have wanted it that way.

Amyotrophic Lateral Sclerosis is a mean, debilitating, debasing, horrible, vicious, evil, hideous disease. No depiction I have seen or read yet does justice to the actual extent of the unrelenting, inexorable carnage it wreaks on its victims. The simple explanation is that it slowly and steadily shuts down all the voluntary nerve pathways in its victim, making it impossible for him or her to move on their own, at first in small ways, and then eventually in any way, shape or form.

This description is much too kind, for this disease.

This disease begins by robbing its victim of his faith in the future; nay, of his hope of ever again having a future. All terminal diseases do this, of course.

It then moves on to completely decimating its victim's sovereignty in this life. First you lose the ability to sign your signature, destroying your personal legal sovereignty. Then you lose the ability to use your hands at all, making losing your personal legal sovereignty seem inconsequential by comparison.

It then robs the victim of his ability to communicate, and then tears his quality of life apart, eventually making life for the victim not worth living. This last thing I'm going to mention was something none of us saw coming.

Shortly before mom died, this disease caused my Mom's teeth to chatter occasionally. It was not bad at first—I kept asking Mom if she was cold, because it looked exactly like she was shivering.

As the weeks went by, this teeth chattering became more and more intense. After a few weeks it was happening all the time, and then it began to get stronger, causing Mom to be biting her tongue and cheeks. We knew this because there began to be blood in the saliva we had had to start suctioning from her mouth on a semi-constant basis. We were working on it all we could, and I once told her that every time I accidentally chomped down on my own tongue or cheek, it was 2 days before I was able to start to feel any relief. She gave me the agreed-upon sign for Yes—the single long slow blink. I knew that this teeth chomping would be horrible for her if it didn't stop soon. It was incomprehensible to me what would happen if it didn't stop at all. How would she be spending her days after that?

It didn't stop at all.

Pretty soon we were seeing pieces of tissue in with the blood that would come out when we would need to suction her mouth. We all discussed anything we could, to try to protect her tongue and cheeks from those powerful and uncontrollable teeth, and there was always something that would preclude us from being able to do anything. Her teeth would clamp shut whenever they were not chattering, such that we couldn't get anything inside her mouth; or we were afraid that she would swallow any flexible plastic guard we might put in, between her cheeks and her teeth, when she would yawn. We had to sit there and do nothing, as my Mom's mouth kept getting more and more torn up and mutilated inside, week after week after week, not to mention the way her breath started to smell bad from not being able to clean her teeth. Mom had always been very fastidious about brushing and flossing, and I knew even though she could no longer speak, that this alone was an unbearable situation for her.

To me the true meaning of the word "horror" is when you have to watch something terrible happen, and can't do a thing about it. Toward the end, we had to use both hands whenever this teeth-chattering would happen, to stop her jaws from chomping so horribly. The pain that was showing on her face was obvious to all of us, still there was nothing we could do. This uncontrollable teeth-chattering, with fixed, clamped-shut jaw at all other times, became a death grin I couldn't get out of my mind whenever I would think of Mom from the adjoining state in which I lived. Yet her eyes would continue to speak the volumes her mouth now could not, letting us all know that she was still alive, aware, sentient and conscious in there even though unable to speak, day after day and week after week experiencing this pain, unable to be healed from it and unable to be saved from it.

I know she forgives us, but at least at one time or another, I also believe she had to have repeated, over and over to herself--since she couldn't to us anymore, during all the countless hours she was awake during those days and weeks towards the end-- "Aren't they going to do something?"

The disease had won another horrible round, and had both Mom and us helpless on the ropes, while it continued to do its dirty work.

Fortunately there are drugs that could keep that teeth-chattering from happening, but they made Mom woozy, and robbed her of the ability to be awake and aware, which Mom prized above all. Many times, before her teeth had started chattering, when it was time for sleep I would ask her if she wanted painkillers as part of her evening medication regimen. Unless whatever pain might be involved was absolutely too much for her, she always, without fail, refused the painkillers. She wanted to be with us, awake and aware until her last moment of consciousness. We should all be so brave.

Mom did not die an easy death. Please remember these things next time someone casually mentions those 3 innocent-sounding words, ALS.

Mom's at peace now, and I am mostly at peace also, from the pain of not having been around when she finally started going inward and away from us. I was able to make a brief contact with her a few days before she died—her breathing changed, one last time, in response to my massaging her back and neck. This was a touch from me that she had grown quite fond of, in her involuntarily adopted capacity as an invalid, who never quite got off her back anymore, at all.

And this also let her know we were all around her in the end, that all of her family was now home again with her. She would want to have known that. She would never have wanted to die in some facility, tended by strangers. And we were not about to let that happen.

At Mom's funeral, after I and others had spoken about what Mom had been all about in this world, I said, "I'm going to say 'Aloha', Mom, which is neither Hello nor Good-bye, and is at the same time both Hello and Good-bye."

We played an incredible Celine Dion song called "Fly" upon Mom's leaving the church; then released a dove, which circled first this way, wide and strong, and then circled that way, wide and strong, and finally was gone.

"Aloha, Mom".

Bob Jones