

The Absolute Worst Thing

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Ever since kindergarten, I'd wait at the school bus stop with my best friend Chris Kelly. To kill the time we'd invent games. 'The absolute worst thing' was a real favorite. We'd dream up the worst situations we could think of and progressively build upon them until they were as dreadful as possible.

No matter how we tried to outdo it, the absolute worst we could come up with was always trumped by one particular scenario:

"What if you could still think and feel but you weren't able to move?"

We agreed—this was The Absolute Worst Thing.

That was about thirty years ago, and I still think it's the absolute worst thing.

I was diagnosed with Lou Gehrig's Disease (ALS) December 14, 2001—no problem remembering that date. The doctors who diagnosed me were careful to explain that this meant a death sentence. I was thirty-nine years old.

When they suggested one more blood test, since "maybe you're lucky and you just have AIDS," I knew that the absolute worst thing was for real, and it was happening to me. I knew things were going to get ugly, so I told my good friend (and recent girlfriend), Shannon, that she should run from me. Luckily for me she ignored sound advice and asked to get married instead.

We got married that March.

In the last two years, seven months, and eight days, this disease I'd never heard of has been busy kicking my ass. I've gathered way too much info on ALS (all of it depressing) and can rattle on about it. It boils down to this: ALS kills motor neurons, the signal pathways to voluntary muscles. Those are what you use for things you want to do, like petting the cat, rolling over in bed, holding your head up...you get the idea.

Those muscles are also used in breathing, something I do regularly, and very much hope to keep on doing.

I have bulbar onset ALS, whose symptoms include uncontrollable outbursts of laughter and weeping, sometimes both at once. Fortunately for me, most of my outbursts have been in the more socially acceptable form of laughter. The slightest humorous thought, or the dreaded heart-tug of a Spielberg moment, so popular in phone commercials, and I wave goodbye to self-composure. It makes it tough to act macho. It's not as bad as it was initially but I still cry in my oatmeal most mornings.

I miss being able to do everything I used to do. I thought I understood what I'd miss and could sort of stockpile experiences to keep from missing them too much. It worked better with some things than with others.

I knew that I'd miss fishing, so I did a butt-load of it. But how can you stock up on hugging your wife?

We have three cats I can no longer pet. Shannon, my wife, sometimes takes my hand and runs it over the fur of one that's nearby. The cats start purring and, usually, I end up sobbing.

Mosquito season has now become its own special form of torture. I watch the mosquitoes land on me. They walk about a bit searching for just the right spot to drill. I try to explain to whomever is around, what's happening. My voice is hard to understand in the best circumstances, but when you add frustration and impending doom, I'm reduced to undecipherable yowls. They only know I'm upset, but not why.

I know all too well there's nothing funny about ALS. It's stripped me of the use of my body and voice. It has been an endless source of frustration and humiliation.

But there's already enough depressing crap written about ALS. Laughter and denial are the tools that make living with this nightmare possible.

I credit my approach to dealing with ALS to the many hours I've spent stuck in highway traffic. When you find yourself in a traffic jam, you are faced with a choice. You can get all mad, flipping the finger to everyone, banging on the dashboard. Or you put on your favorite CD, rummage around for a roach, and sing along with the guitar solo.

Either way you're going to end up at the same place. ☹