

A Canavan Dad's Viewpoint

By Ken Epstein

I've had these thoughts for a long time. Once, they actually did escape my mind during a situation when I was asked what it was like to be a Canavan Dad. I was asked to comment on what life was like and all that is attached, by an expectant family who was carrying a Canavan child. I answered honestly, pretty much in the same vein as to what follows.

From a Dad's point of view. My wife would say that this sucks. Yea I'd agree, but... There is not one word or single thought after seven years that would sum up what is in my head. Yes it sucks to be told, "... take her home and enjoy her for she will only live to be 4 or so years"... Yea that's what our neurologist said on our June 7th, 1999, 11:00 A.M. appointment. You all know what I mean, where you were when Challenger blew up or when 9-11 happened, or when you got your diagnosis. That was the death of my dreams, but I did not know it then. Seven years ago, I had it fairly good. We had a double income, and we were just 3 steps away from climbing out of the hole. I could see the edge and we had it all. I had hopes and dreams. Not just personally, but professionally too. I was at the cusp of looking for that next big thing. It was either going to be a vacation home, or investment property, or a boat ... but it was going to be something.

Then BOOM.

It wasn't like the catastrophic dam breaking, not at first; it was more like an internal pop. Nothing much at first, just a crack here, a leak there, but it foretold of a huge disaster. That was 7 years ago. Since 1999, I have held four positions and

had a 9-month unemployment stint. Has this affected my career? You tell me. I have had managers that have told me that if they heard any more about my child, her disability or her disease, I'll be put on disciplinary action. I have had managers that have been the single largest contributor at a fundraising event. I am also at the same basic career level that I was at on June 7, 1999. Watching your friends both professional and personal climb up the ladder is hard. Watching your wife lose her career is even harder. She had it all, and when she was climbing the ladder, I saw things for her were great!

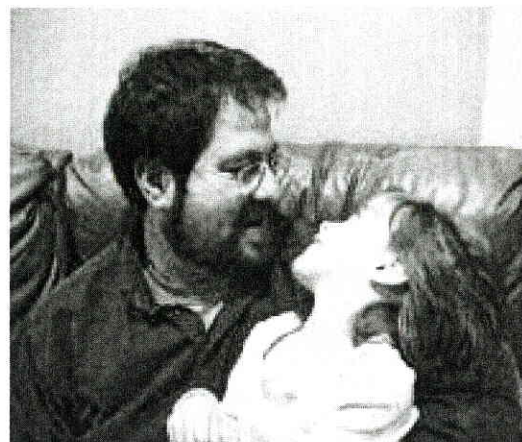
The crack in the dam gets bigger.

As the months go by, early intervention comes and goes, and things are still status quo. The 3-month maternity leave becomes 3 years, then 5, and finally at 6 years, we are finally at a point where Sherri was starting to think that she can go back to work. The first time, it's great, a position where she can work part-time, but would you know it, that's the year where the snow didn't stop and there were five no school days or delay days. When our daughter, Ray Ray, had a grand mal seizure, wouldn't you know it, the college where Sherri was employed misses the boat of family compassion and fires my wife.

The dam continues to leak the cracks get even bigger, and the rumbling starts.

Yes, I'm angry. Yes, I'm frustrated. Yes, I'm a lot of things but as a father how can I not stop. I'm the dad... the provider.

Someone once said or mentioned



"black thoughts"... wow, if that statement is not all encompassing. I have had black thoughts! About a lot of things! But they have always been, and will always be, just thoughts.

Another Canavan Dad once said, "I'm sorry to have to know you." Think about that for a second. "I'm sorry to have to know you." If we all did not have a child with this disease we all would not know each other. That in itself says a lot. How the world has gotten smaller and tighter, how we all need an organization to catch us all. So, "I'm sorry to have to know each and every one of you."

So what's it like being a dad with a child that has a disease like Canavan?

It's rough, it's humbling, it's great, it's awful, it's tiring, it's rewarding, it's frustrating; it's a lot of things that end in "-ing."

But mostly, it brings meaning to what matters most... family, friends, and our support network. It means being there for my family. It means being a real dad for my whole family. But it also means being there for each one, for all different reasons.