

# Chapter 7

## *If You Don't Laugh... You'll Cry*

Unfortunately, this pregnancy wasn't working out to be any easier than the previous three. I had some trouble carrying this baby, and I had to wear a brace for a while, to help hold the baby in place. As time for delivery approached, the doctor told me he wanted to take the baby a little sooner than originally planned. That was fine with me.

When my baby finally was born, I was so excited that I literally started to scream. It was a girl!

When she came out, the doctors realized that the cord was wrapped so tightly around her neck, that she couldn't breathe. They quickly cut the cord from off her neck and, after some stimulation, she finally started to cry. I breathed a sigh of relief. They brought her over for me to see for just a moment, then handed her to Lee and whisked both of them out the door.

They told me again, and this time quite forcefully, that this baby *needed* to be our last baby. It was simply too hard on me. They strongly recommended that I allow them to tie my tubes. With my consent, they did.

When they were finished, I asked for my baby. To my chagrin, they told me that wouldn't be possible. She was in Intensive Care. "Take me to her," I said.

They wheeled me into the ICU, and there was my little baby girl, lying in an incubator, with tubes everywhere. She weighed a scant five pounds two ounces, which was very tiny for my babies, and she was very sick.

During the course of her birth, when the cord had gotten wrapped around her neck, she'd inhaled a lot of fluids into her lungs. On top of that, doctors informed us that for some unknown reason, she had an excessive amount of acid in her blood, which would require a total blood transfusion.

Immediately, visions and memories of baby Josh started flooding through my mind. I refused to accept that this could happen to us again. I started praying so hard that she'd get better, and I told myself that I needed to demonstrate my faith in God, if I expected Him to honor our prayers.

Lee called my Father and asked him to come in and help give our baby a blessing. This was the first time that he'd ever actually given a blessing himself, and

he did such a good job. Her head was so tiny that they could only get two fingers from both hands on top of her head. Lee trembled and cried as he gave our little girl a blessing. But when he was finished, I knew she would be all right. We named her Jenny Marie.

Jenny stayed in the ICU for about four weeks. We went to the hospital every day to visit her. Friends and family really helped us out by bringing in food, taking care of the boys, and doing whatever they could to ease our burdens. Finally, we were allowed to bring her home.

Our medical bills were still mounting. It seemed like we would never see the end of them, and, yet, that didn't seem to matter anymore. We just paid them the best we could. Somehow, it seemed like they were getting easier to pay. All that mattered to me was that we were a family, and we were finally home, together.

With Jenny home, I felt like things might finally settle down. The boys seemed to be developing just fine, and with Jenny there, I really felt like we were complete. There was one thing however that started to cause us some concern.

When Jeremy was about two years old, he began walking into walls and tripping over things. At first we thought he was just goofing around, but before long, I was convinced that this was something serious. I took him to the doctors, and they determined that he was having trouble seeing things. They fitted him with little bifocal glasses and he started doing much better. But, I couldn't help but wonder what a two-year-old was doing needing bifocals?

About the time he started kindergarten, my aunt noticed that he was running just like I had run when I was little, and I began to worry, wondering if I'd passed on this disease or whatever it was, to my children. Just the thought that it might be a possibility horrified me. I began working evenings to help pay off some of the medical bills we'd run up. I worked nights, so I could be with the kids during the day, and Lee worked during the day so he could be with them at night.

I spoke to my pediatrician and told him what was happening with Jeremy, how he was walking and running, and they agreed that something must be wrong. They referred me to one neurologist after another in an effort to help me try and figure out what might be wrong with him. I started to relive through him the nightmare I'd lived as a child. We were constantly going to visit different doctors, but none of them could identify any specific problems with Jeremy.

I was determined that I wasn't going to give up searching until I found out what was wrong with my son. I didn't want him to have to go through the same

kinds of things I'd gone through as a child, wondering all the time if there actually *was* something wrong, or if I was just crazy.

After going to five different neurologists, the last one said, "I'm going to refer you to the neuromuscular clinic at the University Hospital, I believe they can help." I took Jeremy in to visit with them. They told me that they wanted to do a muscle biopsy. This would require removing a small piece of muscle tissue from his leg, and doing some tests on it. They said they would have to keep him in the hospital for about three days.

I felt horrible, thinking of my little boy having to go through this procedure and the fear *he must have felt* being taken away from me and Lee. But I needed to know, for him as well as for me, so I agreed. I knew that the truth would better help him understand and cope with this burden he'd apparently inherited from me.

We went to the hospital, and they did the biopsy. Things went well, and almost immediately he was back to his happy, cheerful self. Before long, he had all the nurses and doctors wrapped around his little pinkie.

Since this was a "*learning*" university, there were constantly new doctors and interns coming in and out of his room to interview and examine him. I left him to go downstairs for some food and something to drink, and while I was out, a young intern came in to visit him. He looked at Jeremy, who was six years old by now, and asked, "So, how do you feel about having a terminal illness? Do you understand what that means?"

I returned just in time to overhear his questions and said, "Excuse me... would you come out in the hall with me?" I told Jeremy I'd be right back, and I accompanied this young intern out into the hallway.

"What on earth are you talking about?" I asked. "What do you mean terminal? I'm not asking What it means... I know what it means, but the doctor has said nothing about a terminal illness to me."

"I'm sorry, I thought you knew that muscular dystrophy was terminal." He responded.

I could see that he had spoken out of turn, and he felt terrible. He thought we knew the biopsy results, and in his ignorance, he'd just divulged this bad news to my little boy and to me. Thank heavens Jeremy was too little to understand exactly what that meant.

When Lee came to visit, the intern called our primary care physician in to speak with us because of the way this had all been handled. He sat us down,

apologized, and asked if he could take a biopsy of me as well. He'd seen me Walk, and heard the things I'd said about my childhood, and he wanted to see if I also had muscular dystrophy. He told us it was hereditary, the gene was usually passed from father to daughter, or from mother to son, but that it was extremely rare for both the mother and the son to actually develop the disease at the same time.

I agreed to have a biopsy done on me. When it was over, I couldn't believe how painful it had been. It made me feel just awful for Jeremy, realizing the pain he must have felt. The doctors came back with the lab tests and informed me that I too had *muscular dystrophy*.

I felt some really strange and conflicting emotions come over me when they told me I had MD. I started to cry. I was horrified that I'd given this disease to my little boy, and now he'd have to go through all the same trials I'd gone through in life. I felt frustration, anger, sadness and relief, all at the same time. I knew now that I hadn't been crazy, that I really had been sick all those years, and just being able to put a name on it seemed to make it at least a little easier to deal with. But, I was so frustrated that no one had ever been able to tell me what my problem was, and now, because of my lack of knowledge, I had to deal with the fact that I had given this terrible disease to my little boy.

The news came as a crushing blow to me. Not so much because I knew that I had this awful disease, but because I knew that I had given it to my own son. How does one cope with the knowledge that they have essentially passed on a death sentence to someone they love so much?

However, that was all water under the bridge now. All we could do was look to the future, and figure out how we could make the best of a bad situation.

I wanted to learn all I could about the Muscular Dystrophy Association, and find out what, if anything, they could do to help us. Soon we were both very involved with it. I wanted to do anything I could to raise awareness of the disease, as well as raise money that could potentially help find a cure for it and maybe for us. Because of Jeremy's wonderful personality, it wasn't long before he was chosen to be the Poster Child for our State chapter of MDA.

I wanted people to understand that even children with disabilities can be wonderful, useful, productive members of society and can contribute so much to this world. I remember one experience that illustrates what I'm talking about.

One day, I took Jeremy shopping at the mall. He was about six or seven at the time, and I walked around the mall pushing his little wheelchair. It had become

difficult for him to walk long distances, so we got him a wheelchair to help out. He really enjoyed going to places where there were lots of people.

I stopped at a store and told Jeremy that there was something inside I needed to get. He told me that he didn't want to go in but would rather just sit by the entrance and watch the people walking by. He loved being around people and watch them enjoy life.

When I was finished with my purchase, I walked out of the store, and saw something that really disturbed me. Jeremy was sitting there in his wheelchair when a little boy came over to speak with him. He, apparently, had never seen a wheelchair before, nor had he seen a little boy who looked the way Jeremy looked. He was obviously interested in Jeremy's situation and began asking all sorts of questions.

"What is that chair? Why are you in that? Can't you walk?"... just simple honest questions that a child might ask. That's when it happened. This boy's mother came rushing over to her little boy, grabbed him by the arm and said, "You leave that little boy alone. Come on." Then she proceeded to escort him away as if he'd just gotten a glimpse of a freak show or something. Maybe she was afraid her child might catch whatever it was this little boy had.

She started walking right towards me, and I couldn't help myself. I stopped her and asked her if she would mind bringing her little boy back to Jeremy and let him finish his conversation with him. You see, I believe that understanding is the first step towards compassion. I told her it was difficult for me to watch what had just happened because I didn't want little children to be afraid of my little boy. I asked her if she was aware, that by her actions, she was teaching her son to be afraid of speaking to disabled children. I told her it was difficult for me to have a disabled child, but it was much harder to have a son that no one wanted to talk to or be around just because he was different.

I'll admit I was a bit nervous speaking to this woman this way, I didn't want to offend or embarrass her, but I felt it was important for her son and my son, as well as society in general, to learn to be more understanding.

She agreed to let her son go back and speak with Jeremy. He went back but was a bit reluctant to talk now. Jeremy sensed his discomfort and spoke up to ease the tension. "It's OK," said Jeremy. "It's just a wheelchair. I have to ride in it 'cause I get real tired when I walk. My legs don't work good like yours do, but that's all right. Other than that, I feel normal. I feel just like you in every other way."

Well, the little boy asked a few more questions, and then Jeremy asked him if he'd like to have a little ride in the wheelchair, so he'd know what it was like.

As I watched this interaction between these two little boys, I had a thought. What better way could there be to teach little children that it's all right to associate with those who are different... whether it's a disability, a handicap, maybe they speak a different language, or possibly they have a different skin color, whatever it might be, what better way to teach them love, understanding and tolerance than to have them interact with someone who is different than themselves?

I wondered how I could help other little children have some interaction with Jeremy and help them become more understanding. Such interactions could remove some of the stigmas attached to those who are "different," so that Jeremy and others like him could have a better experience growing up than I'd had.

I called the Muscular Dystrophy Association, telling them of my mall encounter. I told them about an idea I had to visit pre-schools and kindergarten classes in order to educate the little children while they were still small and impressionable. They thought it was a great idea.

So, we began visiting pre-schools and kindergarten classes, and it was very interesting. We were told that the children would need to bring a note from their parents giving them permission to speak with us and meet Jeremy. Some people were worried that parents might be offended by our teaching their children about people who were different. They felt that some parents might think that should be their job.

Well, the program met with great success and very few people ever voiced any concerns about what we were doing. We visited a lot of groups, and I think we did a lot of good. Jeremy would sing one of his songs, and then the little children would talk to him, ask questions, and even ride around in his wheelchair. I think we helped take down a lot of mental and social barriers.

One lady was so impressed with the program, that she asked if she could have the children organize "Hop-a-thons." The kids would hop like a bunny or a frog, as many times as they could, and people would pledge so many pennies or nickels for each hop, and then donate the money to the MDA. It was a lot of fun.

For a year, we traveled all around, doing everything we could for the organization. The MDA asked us if we'd consider being the Poster Child for one more year, but Jeremy was not excited about the thoughts of another year of speaking. I spoke with Jeremy and we came up with an idea. I told them that we

would do it for another year, if we could sing songs for our presentations. Jeremy loved to sing, as did I, and I believe that music is a national language and that singing could help us convey our message and true feelings better. . .they agreed.

I got special permission from Michael Mclean to modify a few of the words from his song "You're Not Alone." In fact, he even made suggestions for some of the word changes, to make it even more personalized for our situation.

One night we were scheduled to sing at the game half-time show of our States hockey team, Jeremy was now seven years old. I remember looking out through the curtains of the Events Center and seeing all those thousands of people sitting there as they introduced us. I was terrified! Jeremy looked up at me, took me by the hand, and said, "Mom, you don't have to be scared. You just follow me. Everything will be OK."

We went out and sang "You're Not Alone," and the reaction from the crowd was incredible - a standing ovation! That song had such an impact on people, and especially in the context of this shared tragedy between me and Jeremy. We were the hit of the halftime show. That song coupled with Jeremy's great personality, opened up many doors, many hearts, and helped raise not only an awareness of the disease, but lots of money for a good cause.

When our second year with MDA was over, Jerry Lewis sent Jeremy a watch with his picture on it, and some other nice autographed memorabilia, along with an invitation to become the National Poster Child for MDA. It was tempting, but the other children were getting older, and I really needed to be home with them. I'd been gone a lot with Jeremy, and we'd grown close, but I felt we needed to come home and be a whole family once again.

Reluctantly I turned down Jerry's offer, and we both returned home.