

Jerry Lewis, "If I Had Muscular Dystrophy," *Parade* magazine, September 2, 1990
(Emphasis and elision in original.)

What if the twist of fate we hear so much about really happened?

What if...when the gifts and the pains were being handed out, I was in the wrong line. [Two words illegible in old copy.]

I don't usually take the time to think about "what if." Oh yes, there's the expression: "There but for the grace of God go I" is used in a variety of contexts, but rarely do people take a solid look from the outside in and see themselves as other than they are.

So I decided, after 41 years of battling this curse that attacks children of all ages and does it with 40 different ways to make its point (there are 40 different neuromuscular diseases), I would put myself in that chair ... that steel imprisonment that long has been deemed the dystrophic child's plight.

Let's start with what, for most of us, is a simple number of tasks just to get into the mainstream of everyday living ... like brushing our teeth, taking a shower, cutting our toenails, filing our fingernails, combing our hair, shaving, using makeup. All of that isn't even the tip of the iceberg. Example: Bathrooms aren't built in normal homes to accommodate a wheelchair (oh, in some cases people with money will rebuild and makes things easier for the child and themselves). Just getting through the bathroom door isn't all that's involved. Space is needed for a chair to turn, or for a child to be carried and dealt with out of the chair. It's still only the early hours of the day and already I am beginning to feel trapped and suffocated trying to visit that bathroom.

Now it's time for breakfast. If I live in a one-floor dwelling, it's not all that tough getting from Point A to Point B. But there are situations where you have to be carried down a flight of stairs with the wheelchair right behind. Just the indignity of having to be carried (especially when you're 12 or 13) is devastating. I know that if I don't use that chair I will be carried ... So you learn to live with that, or at

least you make every effort to try to feel that "this, too, shall pass." Although the conscious mind works in many cases, the subconscious mind knows the truth and reacts on it ... So the pain never leaves.

I think: "If I don't work those wheels, I go nowhere unless I'm pushed." Now we're back to indignity again. All my life I've heard hostile vicious voices screaming, "Don't push!!!" And here I am, at the very mercy of the thing that annoys most people.

Then we have school. Some of the unafflicted children I'd like to forgive but I really can't. They're mean, cruel and just plain inhuman because they find pleasure in having "fun" at someone else's expense -- like locking the wheels of the wheelchair, or putting their hands over

the eyes of someone who might be the pusher that day, or spilling oil in my path when I'm going it alone. And what do I say to the kid who parks his motorcycle in the only handicapped parking spot that's available for my mom to pick me up each day? You say nothing, that's what you say. You do a lot of smiling, because that's the only defense you have got cruelty -- smiling and not letting them know they're getting to you.

Before continuing, I think it might help for the reader to understand that none of what I write is fantasy or assumption. I have lived with "my kids" for 41 years now, and I've seen it all, maybe with one exception -- getting into that chair. For a purpose so important as getting you to feel maybe a little of what this is all about, I decided to take this tack in this article.

Now ... back to indignity. Why do people always have to bend down or lean down to someone in a wheelchair? Why not take the picture vertically, so the one who's not in the chair can stand at full height and maintain some kind of courtesy to the one in the chair? I must not forget the family photographer (either on your birthday or a family get-together) who moves the wheelchair wherever and however he wants. He pushes, pulls, slides, twists and does every he can to take his Instamatic picture with what he will later call "great composition."

Most restaurants are out. They love to build booths. Every now and then, we run into a round table, and it's a joy! But, on the whole, eating comfortably on any table is tough. The chair arms hit the table and keep you far enough away so that 90 percent of the pasta winds up on your lap!

Taking a trip by plane presents exceptional problems. Great efforts are put forth by so many caring people! The ride through the airport is OK until the security search, when the chair won't fit through the entryway. Actually getting on the plane isn't all that bad. They store the wheelchair pretty well, but when it comes time to go to the lavatory, my dad has to carry me all the way from Row 39 to back near Row 78. It's a long, demeaning trip.

And what about the hotel we check into that has no ramps... and the theater we go to that has no ramps... and the building where my dentist is that has no ramps? Going to an NFL game is out of the question. Trying to see the Dodgers is rough, too. Oh they've made tremendous strides in the area of assisting the handicapped, but who wants to see a .300 hitter from so high up that I might get a nosebleed?

Hey, I'm one of the lucky ones. I can use my hands. I can wheel that chair if there isn't a pusher. But what about those who have no real use of their hands. For them there's additional indignities of being dressed, being fed, being everything they wouldn't have to be if only they had use of their hands.

Now I could get into [illegible] the therapies, or what I go through with examinations ... the probing, the sticking, the pinching, and on and on. But does anyone realize what it's like just being stared at? You know what I'm talking about. There's something in the back of the mind of every healthy, walking human being that seems to trigger the need to stare at someone in a wheelchair. Some stares are out of pity, something we really don't want or need. Some stares are "There but for the grace of God, go I." Some stares may indicate a hidden joy, joy that it isn't one of theirs in a wheelchair.

I have a little trouble with people in public places whispering. No, I'm not paranoid. It's just that being in a wheelchair makes you feel like everyone is whispering about you. I know there are many who couldn't care less and many who are so indifferent that it hurts -- not a great deal, but enough to notice.

I know the courage it takes to get on the court with other cripples and play wheelchair basketball, but I'm not as fortunate as they are, and I bet I'm in the majority. I'd like to play basketball like normal, healthy, vital, and energetic people. I really don't want the substitute. I just can't half-do anything -- either it's all the way, or forget it. That's a rough way to think in my position. When I sit back and think a little more rationally, I realize my life is half, so I must learn to do things halfway. I just have to learn to try to be good at being a half a person ... and get on with my life.

I may be a full human being in my heart and soul, yet I am still half a person, and I know I'll do well if I keep my priorities in order. You really cannot expect the outside world to assist you in more ways than they already do, and I'm most grateful for the help I receive. But I always have the feeling in the pit of my stomach that I want to scream out "Help!" Or,

"See what has happened to me!" Or, "Is anyone watching?" But those screams are usually muffled by the inner voice that tells me what to do and when, and tells me softly and strongly: "Be still ... Hush ... Drive quietly ... Try to make as few waves as possible."

I have never really found out why, when someone is dealt a bad hand, they immediately feel inferior and out of touch with the mainstream of life -- when in fact we're more productive, more educated and more apt to excel than most of the fortunate people who are either indifferent or just don't care. I wish they knew that one day they could find themselves just as I am ... a statistic that breathes and lives and hurts and tries to make it through life without bothering too many people along the way.

I guess what I'm trying to say is: We are always hearing about people who pray that they die with dignity. And I say: "Hey! How about us? Help us live with dignity."