

## LINDA'S LIFE, IN HER OWN WORDS

"To try and explain the impact--on every area of my life--is too overwhelming to even think about. It's like setting up a giant set of dominos and saying "let 'er rip" For the rest of my life--confined to wheel chair--electric at that, to have any mobility--having only regained minimal use of my right hand. I have a feeding tube in my stomach, an indwelling catheter in my bladder (causing frequent infections requiring antibiotic therapy--often only-painful-inter muscular injections 1xshift x10 days is the only medication that work...and when the bacteria build up a resistance to that...???), using a portable computer to communicate--tedious is an understatement--time consuming--some can't see it, some are unable to read well--if at all, always aware of an under current of impatience, the physical and occupational therapy. Needing complete care in bathing, dressing--needing to be mechanically transferred by a lift and sling--bed to chair and vice versa. Relying someone to do everything for me--from watering my plants to making out an envelope, to combing my hair. The indignity of no privacy with personal hygiene ie.- having someone else changing a tampon to being given enemas every other day to evacuate my bowels--and again--relying on another -- who ever is assigned..whether you like them or not... whether they are good or marginal worker...you get who you get. I will never again know the luxury of an uninterrupted nights sleep...I have 12:00 midnight tube feeding, 1:00 am, 4:00 am, 6:30 am turns...because I need someone to change my position in bed. I have itches (endlessly) that are out of my reach. I like nights the most because sleep provides some escape, evenings come in second--because I can occupy my mind more and days are my least favorite--because I am forced to deal more with the full impact of my limitations. The list goes on and on...That doesn't begin to touch the emotional impact. That is--so far--beyond measurement.

People commonly believe a crisis tightens family bonds. In the short term that may be true; in the long term, all too often, the reverse is true. My daughter cannot deal with this situation. She lives with her father and step mother when not away at college. He makes it acceptable for her to feel justified in not coming. I rarely see her. It was tremendously painful to play the major role

in her life to suddenly be on the out skirts of everything that happened. To "hear" about her prom, to "hear" about her graduation, to hear about her first love in vague comments-long after the fact, to not even hear about getting college acceptance letters...I would keep expecting her to "come to terms with things"-only to realize that this is the way it is going to be ---"I" have to come to terms with things. The man I was involved with took a position out of state. My closest friend moved out of state. My mother and I had such a fragile relationship to begin with-now it is almost non-existent. My younger brother was the only family that visited on regular basis; he died three years ago in the spring. My life is totally devoid of any type of affection. I spend every holiday alone. I always feel like a burden. I never feel attractive. I spend most of my time alone. I basically an introvert [sic] prior to my stroke--now I feel [sic] it's a forced isolation; a like monk in a monastery who took vows of silence and solitude. [sic]

I try to imagine...what could be worse..? Well I suppose I could be like this and live in a third world country...that would be worse. I don't feel particularly sorry to hear if someone has a terminal illness. They have a way out. This is like a life sentence. No one can imagine what it is like to live this way...they can try...but there are too many facets one outside-could never even consider. I hear how "lucky" I am to have my cognition. However wonderful of "others" to project their opinions [sic]... when they can only have a very "one dimensional" view. I think "...you fools, you fools, you fools...You-can't know...it makes it harder." I see human nature from a vista few do. For the most part we are not so noble as we like to think.

My life is "imposed" on me-in a physical sense- and in an emotional--by some "challenging" my "will" to live (a sunset, a flower, a snowfall...touching-huh?...moxie[sic]..??)--but the "will" to live--if you can really live--is this really living? It's existing...I can tell you that. Am I supposed to "derive" something of worth from this? Is that a task I just haven't mastered yet? My life is today-and I imagine will always be--like walking a tight rope-everyday. Am seen as "deranged" or at the very least "maladapted" for speaking "my" truth? It's like the Proverb: Tell the Truth and Run. My way of seeing my life is wrong?? by others to don't waken to this...everyday.

It is like I had a bomb dropped in the middle of my life.

That does not begin to touch on how dehumanizing living in an institution is. Apart from the physical handicaps; it is like a mental bludgeoning to beat the psyche into a "herd mentality" until one's sense of self starts to fragment and shrivel.

As a nurse I would see families struggle to cope with tragedy; as much as I empathized, I still felt exempt. I no longer feel exempt."