

## Talking to Bellybuttons

By Cindy Bittker

*In honor of my sister, Terry Elyse Bitker who in every aspect of her life advocated for those who are disabled, disenfranchised, and dismissed.*

My sister, Terry, had disabilities that were hard to put neatly into one diagnostic category. She had some health problems from birth, some she acquired along the way, and some were long-standing but unrecognized.

Terry's constellation of problems didn't have a diagnosis, didn't fit into an identifiable group, and didn't have a name. But she understood the difficulty I experience living with advancing Parkinson's disease in a world where very few people understand even without having the disease herself.



Terry's medical and health problems were not the greatest challenge in her life. They should have been, but they were not.

Her biggest challenge was finding a place she fit in, finding people like her.

She had mobility impairments that kept her mostly housebound and used an electric scooter to go out. The physical world is full of barriers when you can't stand up, walk, or go up stairs. It's nearly impossible to negotiate someone else's house. If you could enter, very rarely is there a bathroom that can accommodate the needs of a disabled person. I have similar limitations from PD and **when you are homebound, single and live on your own, it can be a very lonely life.** Nothing takes away your quality of life more than loneliness.

Terry longed for ways to re-engage her life, to socialize more, to go out more, to be with friends more.

She overcame developmental and educational obstacles. No one noticed that she was hearing impaired until the 4th grade but went on to graduate from Gallaudet College and also earned a Master's Degree in Social Work from the University of Maryland. I have learned a lot from my sister who said it "like it was" and in return developed life-long friendships.

Parkinson's Disease is not a disease for the self-conscious. Unlike my sister who demanded to be recognized with dignity, I remain self-conscious, often trying to hide the indignities of my disease.

It embarrasses me that I no longer can stand up for any length of time. I avoid parties and group meetings where there is a cocktail hour and people stand, mulling about the room.

I absolutely hate when I am sitting down and someone comes over to talk to me and STANDS in front of me. They don't know that I am unable to lift my head to look far up enough to see their face.

Thus, I get stuck talking to belly buttons.

I wish everybody would sit down whenever they talk to a person who is sitting down because they are unable to stand. No one wants to talk to belly buttons.

When talking to a belly button, I should speak up. Terry would.

My sister would not have made whispered requests, like I do - embarrassed, apologetic, as though I'm asking for a favor. Terry would have said it like it is. "I do not want to talk to your belly button. If you want to talk to me, sit down!"

You would have gotten that right, sister! And now, I will too.

Cindy Beth Bittker  
cindybittker@gmail.com