

The Downs and Ups of Caregiving

Jo Horne, Survival Guide for Family Caregivers

Caregiving is one of those tough experiences in life that is hard to explain to anyone who has never been there. Through the years I have learned so much that I never knew or understood until I become a caregiver:

I never knew regret until one day I realized I had missed the opportunity to really get to know my stroke-ridden father's thoughts and feelings about aging and his life.

I never knew frustration until I ran into a national health care system that penalized rather than rewarded efforts to give care outside of an institution.

I never knew anger until time and again all my best efforts to make life easier and more rewarding for my parents were rejected...mostly by them...mostly out of fear of losing independence, which is what they lost anyway.

I never knew desertion until I realized that, one by one, others were distancing themselves from the "situation."

I never knew shame until the day I admitted out loud that, the way things were going, it might be better if my parents died.

I never knew stress until I felt my parents turning to me to make it all better again and again and again.

I never knew sadness until the day I first cleaned up after my father's incontinence, and he was embarrassed and so was I, and all I could think to do was to chatter away so neither of us would cry.

I never knew heartbreak until the first time I realized that my father no longer comprehended that I lived away from "home."

I never knew defeat until the weeks and months and years passed and nothing I did could truly improve conditions for long.

I never knew guilt until I began to be torn between my parents' needs and my own.

But also, I never knew strength until the day I realized I had been giving care for five years and had not yet broken.

I never knew self-respect until the day someone said, "Whose approval are you seeking by going on with this; what are you getting out of it?" I knew that the answer to that

question had nothing to do with doing something for personal gain; it had to do with doing something because it was right.

I never knew faith until I prayed at odd times about insane things and got answers.

I never knew courage until the first day I spoke up for people who could not speak up for themselves.

And, I never really had the slightest understanding of what it took to be a survivor in even the most basic sense until I became a caregiver.