



Dear Parkinson's Care Partner Training participant,

We received two beautiful pieces of writing from one of your care partner peers and because we believe they speak to the role of care partners so well, we asked if she would be open to sharing her work with all of you. Thankfully, she said yes.

**Reflection on Session #5 - Depression, Anxiety, Apathy, Loneliness, and Isolation  
by Susan Campanelli, Ed.D, RN**

141 people tried to communicate overwhelming feelings in 40 words or less and then put them into a 2 X 2 box. Cumulatively we have been with Parkinson's for hundreds of years. We know the disease. We know what we are saying is true and we understand, for some, it may be difficult to believe.

We have heard the platitudes and the hollow encouragements. We've endured endless stories about others with this disease. But each of us needs to be heard. Each of us deserve the opportunity to tell our story. Because to be heard gives the gift of dignity. When will someone listen to my story? Will my story become the next anecdote to explain the unexplainable or describe the indescribable?

The uniqueness of Parkinson's and the stigma of mental health combine to create an aura of unapproachability. The tremors, festinating gait, drooling, choking and constipation are inglorious. But these are only the visible signs of Parkinson's, and most often in our culture, these are considered repulsive, or at the least socially unacceptable.

Changes in the mind and in the mood of PWP can be overlooked by health care providers, ignored by family, and shunned by friends. The inability to speak clearly, or even loudly enough to be heard, is not well tolerated in our culture. The pace of grocery shopping, walking to the park, or taking laps at the YMCA are too fast for the PWP. The PWP is rushed at the checkout when they have to key-in membership codes, follow credit card directions, take receipts from cashiers and push a cartful of items to the door.

The visible clues of Parkinson's shift like the beach under a rising tide. Stepping up or down from a curb, navigating an uneven sidewalk, or getting in the car are all taken for granted until a PWP freezes and is unable to speak. Being the frozen object of abject staring intensifies the shame and embarrassment of the disease. Unfreezing may occur quickly, or proceed at a glacial pace. All the while, the PWP and the caregiver are stuck; just waiting for it to be over.

Freezing can be interpreted as tuning out or ignoring their surroundings. When in fact, the PWP could be silently screaming for support or assistance as they navigate a maze of confounding daily tasks. Everyday occurrences, brushing teeth, walking to the mailbox, changing channels on the remote control become a struggle. Patience is the only antidote. Good humor and laughter help release what little dopamine and serotonin are left in the brain of the PWP.

Humor, patience and grace are essential skills of any carepartner. These are regularly tested, success in these trials bring relief, while failure may cause guilt or shame. Carepartners know the symptoms of Parkinson's in their person sometimes better than their person. This intimacy can be the glue of a loving relationship. It can also cause a forest fire of emotions. The spark igniting the fire can come from a glance, a joke gone wrong, or misplaced sarcasm. Bringing the PWP back to reality may take hours.

The emotional, mental, and mood changes of Parkinson's can dwarf the physical symptoms. Remember, not all disabilities are visible.

### **A Caregivers Soliloquy**

by Susan Campanelli, Ed.D, RN

We are caregivers to People With Parkinsons  
We are seekers of  
Solace

We went to the Neurologist  
And received a diagnosis we didn't expect  
No one is like us

We search for someone who understands  
And just knows

Our struggle

We look for a way forward  
But our families avoid us  
We are isolated

We know aloneness  
And struggle with everyday tasks  
We are overwhelmed

We grieve today and we grieve for tomorrow  
Because we fear what's coming  
There are no answers

We may feel helpless  
Or anxious, because every moment is different  
Than the one before

We fear our own anxiety will win  
Or apathy and depression  
Will claim our souls

Parkinson's is chipping away at our person  
Every day  
At the cellular level

Parkinson's gnaws at our stamina  
And  
We fear that no one will notice