

60 Plus column – for March 26, 2007

A Personal Journey Through Parkinson's

By Sarah Lemnah

The story of each person's journey with Parkinson's disease is as unique as the individual. Most people associate Parkinson's with Michael J Fox, his tremors and his difficulty speaking have put a public face on a disease that is rarely talked about. Over 1 million Americans are diagnosed with Parkinson's, over 1500 in Vermont alone. What causes Parkinson's is unknown and though medical advances have helped treat the symptoms there is no cure for this chronic and progressive disease. According to Mike O'Connor, President of the American Parkinson Disease Association Vermont Chapter with Parkinson's, "there is a natural progression but everyone is different, how it advances or how long it takes is individually different."

Most Parkinson's patients are over 60 years old. Many people with Parkinson's have the disease for years before diagnosis. Symptoms range from tremors, rigidity, Bradykinesia-slow movement, and impaired balance. Many others experience depression, sleep abnormalities, difficulty swallowing, and sometimes dementia or mood changes. Parkinson Disease is a progressive degenerative neurological disorder of the brain caused by the death of cells that produce dopamine, a chemical that transmits brain signals involved in motor skills

For Vivian Branschofsky she first noticed she couldn't wave her hand and her foot dragged. After her diagnosis it took a while to get over the shock but as she says "once you get over the shock of it you realize you are going to be living with this disease and not dieing of it like a lot of diseases."

For O'Connor his business use to take him around the world and now he stays pretty close to Vermont and home because the traveling is tiring and he never knows when he will have a good day or a bad one. According to O'Connor his "handwriting is sometimes illegible, there are days when I seem fine, my right side is the most troublesome, and I do not swing my right arm when walking." He was somewhat relieved when he got the diagnosis and he knew what he was dealing with, but it took some time for the reality to set in. "Reality set in three months later, I knew something was

seriously wrong and realized this is where I'm going, dealing with something that will make life tough."

For people living with Parkinson's there is always that fine line of balancing the symptoms of the disease with the side effects of the medication. Without the medication their symptoms make living almost impossible and the pain unbearable but with the medications there are times when serious complications may occur, even the smallest adjustments in medications can cause huge reactions. Cassie Blanchard found out the hard way that sometimes when her meds were adjusted even slightly they can cause a difference. One day she was stiff and went to take a bath when she froze. As Cassie tells it "I always hold onto the pole when I get in the tub and I went down and I couldn't get back up, and I thought oh my god I can't get myself back up, I was pulling my head back up and yelling for my husband who had to pull me out of the tub. For this busy mother of three who suffers from early onset Parkinson's she has to balance the symptoms with being a Mom. Her youngest daughter has admitted that "she has cried before saying it is not fair, that she only knows her as Parkinson Mommy."

For many people living with Parkinson's they start to retreat. On bad days they stay home or they are not able to get out especially if they are older and live in small towns. So people do not see what challenges this disease presents. As Branschofsky says "one of the problems with Parkinson's is you tend to disappear, you don't go out and do as many things anymore because it is too hard, and you may feel embarrassed, for example if you have difficulty feeding yourself ." Blanchard knows "it's hard when you get looked at and criticized for doing the best you can, with a disease you don't want."

Parkinson's does not affect just the person diagnosed but their circle of family and friends who love and care for them. For Susan Werntgen her world changed when her husband Ralph was diagnosed. She questions why she didn't figure out what was happening with her husband, especially when he experienced psychological problems caused by the Parkinson's medications. "Parkinson's has taken over our life, my husband can't drive, he is homebound, life really narrows, my children have seen their dad deteriorate, a huge loss- you lose your partner, he is not the same person," according to Werntgen.

Support groups help those living and caring for those with Parkinson's. According to Werntgen for caregivers "there is a lot of isolation, meeting

with other caregivers helps knowing you are not the only person going through these challenges.”

For these four individuals they know a sense of humor is as required as the medicine cases that are never far from their side. It is not just about finding a cure it is about improving the quality of life and helping people know they are not alone.

Governor James Douglas will proclaim March 31 as Parkinson’s Awareness Day at the Cortina Inn in Killington. O’Connor, Blanchard, Branschofsky, and Werntgen will be in attendance to meet with people living with Parkinson’s and support care givers.

Sarah Lemnah writes on senior issues for the Champlain Valley Agency on Aging, a private, non-profit United Way organization. For more information on services for seniors call the Senior HelpLine at 1-800-642-5119

SIDEBAR INFO

American Parkinson Disease Association
Annual Awareness Day
March 31, 2007
Cortina Inn,
Killington, VT

Information on Parkinson’s or to find a support group near you
888-763-3366
www.parkinsonsvt.org