

A Personal Journey with PLS

These slides will automatically advance.

This slideshow is about 5 minutes long.

Press 'ESC' to exit before the end.

	•	1999	Numbness on Top of Left Foot When Walking for Extended Periods; Incontinence Starting Must Be the Shoes – Bought New Shoes
	•	Spring 2000	When Jogging With My Sister She Noticed My Left Foot Was Dropping Made an Appointment With Orthopedic Sports DR – Referral to Neurologist
		2000	Too Pleasant – Personality Changes – Can't Stop Smiling Lost My Bitchy Quality – Inappropriate & Uncontrollable Laughing and Crying
P		2001/2002	Limping More; Falling When Slightly Bumped
R	•	April 2001	Extreme Pain in Right Shoulder - Not PLS, but from falling Neurologist Prescribes Painkillers; June 2001 X-rays Show Calcium on Damaged Rotator Cuff – Cortisone Followed by 12 Months of PT
		July 2001	Unsteady When Walking - Start Using a Cane
O	•	April 2002	Falling More Often; Can't Keep up When Walking With Others - 4 Wheel Walker With Seat
G	•	June 2002	Can't Get up When I Fall – Signed up for a Lifeline Type Service
G	•	July 2002	Can't Step Over the Bathtub Side - Bought a Shower Seat; Swivel Bather
R	•	Sept 2002	Can't Clean Floors, Reach Baseboards, Bend Low or Pick up Things I Drop Without Falling Hired Cleaning Service and Got a Reacher / Grabber
Ε	•	Oct 2002	Difficulty Getting Out of Chairs and up From Toilet Seat Assist; 3 in 1 Commode; Uplift Chair From La-z-boy
	•	2003	Falling More With Walker; Can't Keep up With Others Using the Walker; Broken Nose
S	•	April 2003	Manual Wheelchair for Going Out. Use Walker at Home.
	•	Sept 2003	Hands and Arms Moving Slower and Less Dexterity - Gave up Driving Car
S	•	Oct 2003	Shallow Breathing - Start Using Bipap; Stacked Breath Exercise, the VEST
-	•	2003/2004	Speech Slurred Progressing to Unrecognizable Speech Whiteboard; Retractable Markers; Talking Computer With EZ Keys; Botox Injections
- 1		March 2004	Choking on Water and Thin Liquids – PEG Gastric Tube Implanted
		May 2004	Severe Spasticity - Can't Transfer Myself – Intrathecal Baclofen Pump Implanted
O	•	June 2004	Takes 2 to 3 Hours to Shower, Dress; Can't Get Legs Into Tub Even While Seated. Hire Caregiver to Assist
N	•	Aug 2004	Exhaustion From Wheeling Myself Around; Falling When Transferring Alone Permobil Power Wheelchair

Early Adaptation Saves Energy and Bruises

Swivel Bather





Reacher



Clothing Adapted for Wheelchair User

Seat Assist





Pivot Disc Transfer Disc

Remain Mobile







Involve Friends & Family

Winds



Hearing "I'd be mad if I were you" from family, Let me be MAD

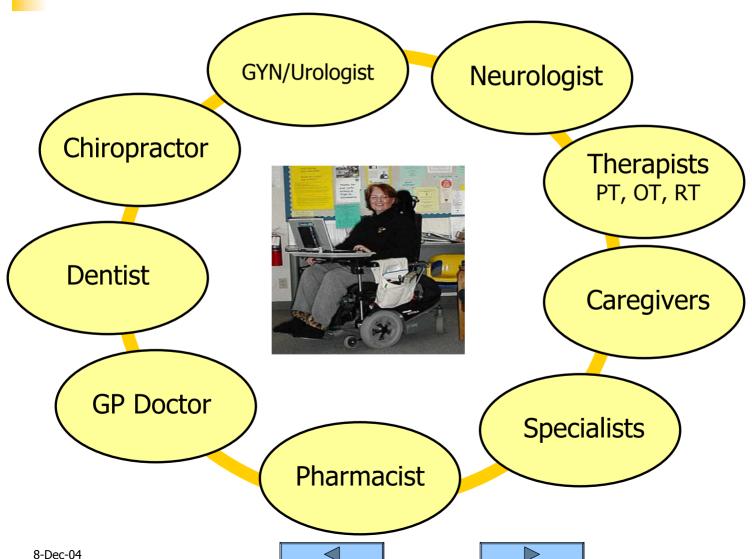


Being Involved Keeps ME ALIVE



Keep Everyone Informed about EVERTHING

You are the only ONE who knows what each Health Care Provider is Advocating, Prescribing, Exercising,





Today, I still live alone and make it work with the help of many people. My sister is my main support and does countless daily small things for me. Today she made a call to schedule a plumber, a repairman for the washer and filled out an application for a service dog. Later she'll stop by after work and make sure I'm all set for dinner.

I endeavor to get out in my community despite my physical limitations. I use a motorized power wheelchair, and a talking computer to help others hear me loudly and clearly either on the phone or in person. In December 2004, my neurologist and I spoke to about 25 other neurologists. I used my computer to speak my words. Much of this presentation was included in that session.

My hairdresser and dentist both like my reclining wheelchair. I remain in the chair and tilt for a shampoo or a dental cleaning. I use the Internet to most shopping. When I need to go out, someone drives me in my wheelchair accessible van or I schedule Paratransit.

I also motor around the neighborhood. I usually take my sister's dog, a 3-year-old Lab, off leash. He understands me when I say come, sit, down or when I honk the little horn on my wheelchair, it means come.