

Building Your Care Team and Support Network

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Who Doesn't Want to Feel "In Control?"

- ▶ "The worst day of this disease was the day of diagnosis. The best day was the day that we as a family understood that we could find ways to handle it. We needed a sense of control, and some power."
 - People can "do something" in many realms, with many different people, and from many different perspectives.

Objectives of Presentation

- ▶ “We cannot direct the wind, but we can adjust our sails.” (Chinese Proverb)



- Why and how to build your core team
- How to integrate care over time
- How to expand your care network as needed (or before)

Why and How to Build Your Core Team

Why Team Care

- ▶ Disease complexity: Movement disorders are more than “disorders of movement.”
- ▶ PSP affects the individual and the family.
Why:
 - Chronic – The disease and its demands continue over long period of time.
 - Progressive – Symptoms increase over time.
 - Multiple areas of functioning are affected.
- ▶ One discipline can't address all of the needs.
- ▶ Each case is different and progresses differently.

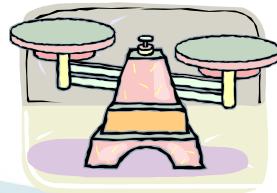
Why Team Care (cont'd)

- ▶ Therefore, people with PSP and other Parkinson's-plus disorders must be treated holistically; and effects on the family must be addressed.
- ▶ Medical management: first line of defense; physician's domain.
- ▶ Many other healthcare disciplines, kinds of interventions, and support and support programs play a significant part in treatment and management.

Patients and Families

You want your care team to view patients and families as:

- ▶ Essential and respected partners in their care.
- ▶ Part of ongoing decision-making.
- ▶ Collaborators in the development of a continuous care plan.

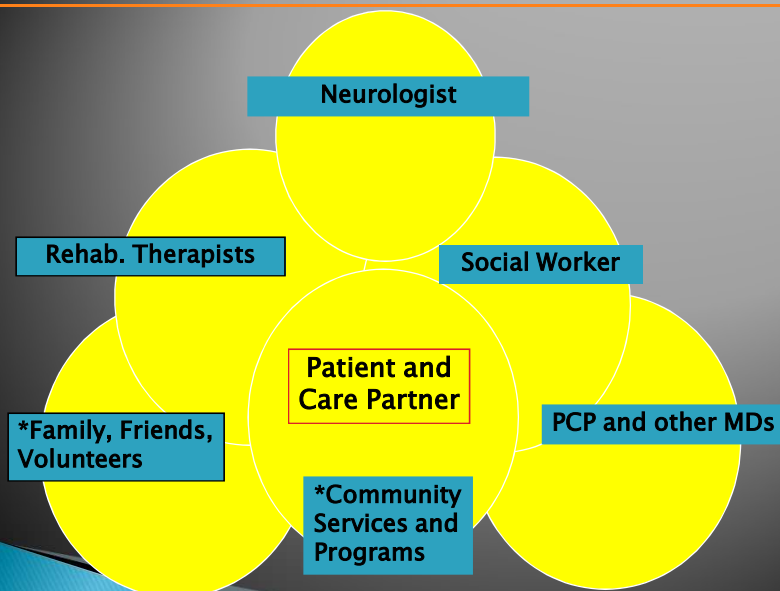


Goals of Your Care Team

- ▶ To deliver, over time, the right blend of clinical care, information and education, emotional support, and programs designed to improve quality of life.
- ▶ To provide care in a coordinated, seamless manner – across settings, professional disciplines, and time.

Integrating Care Over Time

Your Team/Your Network



The Professional Healthcare Team

- ▶ Patient and care partner
- ▶ Movement Disorders Neurologist (Specialist)
- ▶ Clinical Nurse
- ▶ Primary Care Provider (PCP)
- ▶ Physical Therapist (PT)
- ▶ Speech and Language Pathologist (SLP)
- ▶ Nutritionist/Dietician
- ▶ Social Worker (MSW)
- ▶ Occupational Therapist (OT)
- ▶ Pharmacist
- ▶ Psychiatrist, Neuropsychologist
- ▶ Neuro-ophthalmologist



Social Worker's Role

- ▶ Coordinate care among the various healthcare providers, community agencies, family members, etc.
- ▶ Provide Information and Referral re: community resources and concrete services
- ▶ Educate patients and families re: living with specific symptoms and life changes
- ▶ Assess and counsel re: reactions to and coping with diagnoses, family conflict, role changes, caregiving
- ▶ Plan and conduct support groups and educational programs

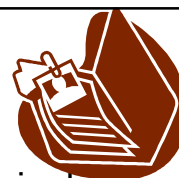
Becoming a Partner in Your Care

- ▶ Learn about each team member's role.
- ▶ Find out how to access their services.
- ▶ Acquire their contact information.
- ▶ Become educated about your disease and its management.
- ▶ Ask questions.
- ▶ Encourage family or friends to accompany you to your medical and therapy appointments and support group.
- ▶ Establish communication with your team.



Your Neurologist Visit

- ▶ Bring a list of all current medications, including dosages and times you take them.
- ▶ Inform neurologist of health and family changes, or hospitalizations, since last visit.
- ▶ Write down – and bring – your questions and health concerns.
- ▶ Ask for explanations of medical terms, medication changes, recommendations, etc.
- ▶ Ask for referrals, e.g. rehab therapist, social worker, classes.



Your Neurologist Visit (cont'd)

- ▶ Request the person who accompanies you to take notes and ask questions.
- ▶ Provide your neurologist with the contact info of your PCP.
- ▶ Before leaving the appointment, make sure you understand the plan: medication schedule and changes, potential side effects, referrals, date of return visit.



Expanding Your Care Network

Non-Health Care Members of Your Support Team

- ▶ Care Partner
- ▶ Family members
- ▶ Friends and neighbors
- ▶ Exercise teachers and trainers
- ▶ Support Group
- ▶ Array of classes: Creative arts, dance, yoga, music, Tai Chi, PD classes and conferences
- ▶ Community Interests: Clubs, service and advocacy organizations
- ▶ Volunteers, clergy
- ▶ Community and respite services
- ▶ Legal services

Caregiver Organizations

- ▶ National Family Caregivers Association – 800/896-3650 www.nfca.org
- ▶ Family Caregiver Alliance www.caregiver.org
- ▶ National Alliance for Caregiving – National Center on Caregiving – 301/718-8444 www.caregiving.org
- ▶ CurePSP

Why Join a Support Group?

- ▶ To better understand the disease
- ▶ To discuss reactions to diagnosis
- ▶ To talk about how to share diagnosis with family, friends, workplace
- ▶ To find ways to cope with feelings
- ▶ To discuss changes in the family
- ▶ To plan for the future, including Advance Directives, insurance issues, home care, respite
- ▶ To build and extend your network

Support Groups Offer:

- ▶ Commonality among members
- ▶ Safe atmosphere, comfort, consolation
- ▶ Education and information about the disease and resources
- ▶ Opportunity to learn ways to adjust to diagnosis, including practical pointers
- ▶ Reduction in feeling stigmatized
- ▶ Socialization and friendships
- ▶ Ability to connect outside of group
- ▶ *Feeling understood

Exercise Resources

- ▶ National Institute on Aging:
www.nia.nih.gov/exercisebook
- ▶ Sit and Be Fit: www.sitandbenefit.com
- ▶ American Physical Therapy Association:
www.apta.org
- ▶ *The Falls Prevention* Videos and Workbook
- ▶ *Smart Moves*
- ▶ *Motivating Moves*
- ▶ Hospitals, rehab centers, park districts
- ▶ Lee Silverman Voice Treatment Foundation:
www.lsvt.org

The Need for Legal Services

- ▶ Advance Directives
- ▶ Disability www.nationaldisabilitylawyer.com
- ▶ Guardianship
- ▶ Legal Advocates for People with Disabilities:
888/332-8066
- ▶ Volunteer legal services

Resources for Advance Directives

- ▶ Your State Medical Society
- ▶ Commission on Aging with Dignity:
www.agingwithdignity.org
 - Five Wishes
- ▶ Family Caregiver Alliance: www.caregiver.org

Make a “Vial of Life” for Yourself

- ▶ Date
- ▶ Your Name, Address, Phone Number
- ▶ Medications/Dosages/Frequency or Times
- ▶ Drug Allergies
- ▶ Medical Conditions
- ▶ Surgeries (including year)
- ▶ Blood Type
- ▶ Power of Attorney for Healthcare
- ▶ 2 Emergency Contacts–Name, phone number



Thank you.

- ▶ CurePSP
- ▶ All the patients and families with whom I am privileged to work.

- ▶ Questions and comments?
- ▶ Contact: Diane Breslow
dbreslow11@icloud.com