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

Neurologist

Rehab. Therapists

Social Worker

Patient and Care Partner

*Family, Friends, Volunteers

*Community Services and Programs

PCP and other MDs
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

- Family Caregiver Alliance www.caregiver.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.sitandbefit.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
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