

MISSION

Increase awareness of progressive supranuclear palsy, corticobasal degeneration, and related brain diseases; fund research toward cure and prevention; educate healthcare professionals; and provide support, information and hope for affected persons and their families.

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BECAUSE HOPE MATTERS

The Bi-monthly Newsletter of CurePSP



THE ROLE OF HEALTHCARE PROFESSIONALS IN SYMPTOM MANAGEMENT

*Trish Caruana, MSW
 VP, Programs & Education*

Movement disorder specialists or general neurologists are most often the physicians who make the diagnosis of PSP, CBD, or other atypical parkinsonian diseases. While these physicians may prescribe medications to manage symptoms, other healthcare professionals can play a complimentary and essential role in helping people with the diseases.

Physical therapists, occupational therapists, and speech & language pathologists work closely with patients and families to maximize independence and improve quality of life. They teach practical techniques to address mobility, swallowing, safety concerns, and also help patients by recommending adaptive equipment.

If you would like more information about how these healthcare professions can help in managing the symptoms of PSP, CBD, or MSA, please contact:

Stefani Baca
 800-457-4777 x5668
baca@curepsp.org

UPCOMING EVENTS OPPORTUNITIES FOR LEARNING AND SUPPORT

WEBINARS

Speech and Swallowing in PSP, CBD, MSA, and Related Disorders
 Kristen Larsen, MA, CCC-SLP
Northwestern University, Communication Sciences and Disorders
 Thursday, October 27, 2011
 11:30am - 12:30pm EDT

Understanding and Supporting Loved Ones with Aphasia
 Ellayne Ganzfriend, MS, CCC-SLP
National Aphasia Association
 Tuesday, January 10, 2012
 1:00pm - 2:00pm EST

The Choking Problem and How to Help
 Barbara Sonies, Speech & Language Pathologist
University of Maryland
 Date TBD

SPECIAL EVENTS

Marine Corps Marathon, In Memory of Marla Louise Culp
 Sunday, October 30, 2011
 Washington, DC

FAMILY CONFERENCES

2012 Midwestern Family Conference
 Dallas, Texas
 Date TBD

ASSISTED CARE OPTIONS

Parkinson Center of Oregon at the Oregon Health & Science University and Vicki Wolff, MSW, LCSW

Making a decision as important as where you or a family member will live and who will provide the care that is needed requires time, financial planning, understanding of the available options, and support from family, friends, and professionals. Assisted care settings provide a wide range of medical and social services for people who need assistance with daily living tasks or monitored health care. The following information can help guide your initial steps to making an informed choice.

Independent Living Retirement Communities are for individuals 60 years and older who are able to live on their own, but want the convenience of meals, light housekeeping, activities, transportation, and security. This is an option for

adults who do not need any daily assistance with activities of living. These communities are not regulated or licensed by your state's Department of Human Services.

Continuing Care Retirement Communities (CCRC), also called Life Care Communities, offer several levels of care in one location: independent living, assisted living, and nursing home care. In general, many residents move in before needing assistance. When assistance is needed, residents move into a higher level of care on the same campus. Many communities require an entry fee plus monthly maintenance fees in exchange for a living unit, meals, and, eventually, care up to the

IN THIS ISSUE

Assisted Care Options.....2
Eating Recommendations...2
The Importance of Support Groups.....3
Ask the Experts.....3
Making a Difference.....3
Symptom Management.....4
Upcoming Events.....4



EATING RECCOMENDATIONS

Christine Robertson Roxberry, OTR/L
Dan Aaron Parkinson's Rehabilitation Center

Positioning and Posture are very important. Always sit in a firm, straight-back chair and close to the table. Use a pillow or a lumbar roll to help with improving posture, if necessary.

Elevate the height of your plate or bowl to decrease the distance between your food and your mouth. You can use a box, a few books, or whatever else works best for you.

Support and anchor your elbows on the table throughout the meal. This arm support may help to calm the tremor and cue you to sit tall, instead of leaning forward and down toward your food. Use your elbow as a lever when you are going to retrieve food from your plate.

Use a food guard on your plate to help with improving scooping and to decrease the tendency of you pushing food off of your plate. This often decreases frustration during meals. Before purchasing a food guard, be sure to measure your plates at home for the best fit.

Use a weighted utensil if you are having difficulty keeping food on your fork. Soup spoons are especially helpful - the deeper the bowl of the spoon, the better.

When out in the community, select foods that are successful for you. If out at a restaurant, request that your waiter or waitress bring your food pre-cut to decrease stress and anxiety about cutting difficulties. Decreasing stress and can assist with symptom control.

Consider using a non-spillable cup/thermos for liquids. However, if you are having swallowing problems please consult with a Speech and Language Pathologist.

Food Guards, weighted utensils, non-spillable cups/thermoses, and other items are available for purchase via the Sammons Preston Catalog or at www.pattersonmedical.com.

Continued from Page 1

nursing home level. CCRCs are required to register with the state and disclose specific information about the services they provide and their finances. Any nursing facility, residential care, or assisted living facility located on the campus of CCRC must be licensed by the state. Otherwise, the state's Department of Human Services does not regulate continuing care retirement communities.

Residential Care Facilities (RCF) are homes for six or more people who require minimal physical assistance and supervision with activities of daily living. They offer private and shared rooms, meals, medication monitoring, planned activities, and often transportation services. These facilities are not required to provide private bathrooms or kitchenettes. These settings are licensed and regulated by the state's Department of Human Services.

Assisted Living Facilities (ALF) are designed for those who want to live in a community setting and require, or expect to require, some assistance with daily activities. They offer private apartments with private bathrooms, small kitchenettes and full dining room services, housekeeping, assistance with personal care, medication administration, and call systems for emergency help. The amount of help provided depends on individual need. These settings are licensed and regulated by the state's Department of Human Services.

Adult Foster Care (AFH) are private homes with family-style living that provide room, board, and physical care 24 hours a day for up to five people. A wide variety of residents are served in adult foster homes, from those needing only room, board, and minimal personal assistance, to those residents needing full personal care and skilled nursing tasks. Residents typically have their own room and share the living and dining room areas with the other residents. All adult foster home providers and primary caregivers are required by the state to pass a criminal record check, complete a basic training course, and pass an exam. They must be physically and mentally able to provide care, and provide that care in a home that meets structural and safety requirements. Adult foster homes are inspected, monitored, and licensed by the state's Department of Human Services.

Nursing Homes (NH) provide

comprehensive care services in a single setting for individuals who require daily nursing care as well as other support services. Nursing facilities are most appropriate for people who need 24-hour medical oversight and a protective/structured setting. Most residents will share a room and space is limited, but residents are allowed to bring personal items to encourage a more home-like atmosphere. In addition, NHs must provide recreational activities for residents. Nursing facilities are licensed by the state's Department of Human Services and are required to meet both federal and state regulations.

Memory Care Units are facilities that specialize in the care of people with memory impairment. These facilities have additional regulations that are specifically intended to support individuals with dementia. Special services typically include secured grounds, trained staff, special architectural design, and therapeutic activities. Some memory care units are either free standing or connected to an assisted living facility or nursing home.

Deciding where to live as we or our family members age is a complex issue and it is important to be aware of all the different options available. It is advantageous to consider all levels of care before they are needed, as many programs have waitlists or limitations on how much care they can provide to someone with PSP. The costs associated with different levels of care can vary greatly. It is important to be aware of those costs and consult with a financial planner or elder law attorney regarding ways to pay for long term care.

For more information concerning assisted care and long term care options, planning, and costs, please visit www.longtermcare.gov (run by the U.S. Department of Health and Human Services), or contact them via phone at 1-202-619-0724.

This article was provided by the Parkinson Center of Oregon (PCO) at the Oregon Health & Science University (OHSU). Since 1979, PCO has been a leader in the battle against Parkinson's disease, offering a center of hope for people and families living with parkinsonisms. Their care model embraces comprehensive, patient-partnered, team care by experts in the field, who combine the latest innovations in care, education, and research to serve all touched by these diseases.



THE IMPORTANCE OF SUPPORT GROUPS

Trish Caruana, MSW
VP, Programs & Education

Support groups provide a sense of community:

- A safe atmosphere
- Empathy and the understanding support of others
- Education and up-to-date information about Atypical PD
- Comfort and consolation
- Socialization and bonding: Friends to turn to, both at the meetings and during difficult times between group meetings
- Discussion of coping techniques and practical information/resources
- Discussion of personal, emotional, and family issues
- Freedom from stigma
- Encouragement and hope

Support groups can be led by:

- Trained professional therapists such as social workers or counselors
- Peers: patients or caregivers
- Nurses

Structure of support group meetings:

- Topic-oriented, with a speaker
- Open discussion
- Question and Answer
- Time for socializing and one-to-one conversations

Reasons for joining a group:

- Better understand the disease and to discuss reactions to receiving the diagnosis
- Talk about when and how to share the diagnosis with family and friends, or at the workplace
- Find ways to cope with a myriad of

feelings, such as sadness, depression, anger, worries, frustration, and other feelings

- Plan for the future, including understanding advance directives, insurance issues, home care and housing options
- Talk about and find ways to cope with loss
- Discuss changes in the family, e.g. what it's like to be a carepartner for someone with Atypical Parkinson's Disease
- Find ways to build or maintain good communication with a carepartner or other family members about the impact of living with Atypical PD throughout the illness
- Learn about and access resources in your local community

One of our support groups opens each meeting by reading aloud this reflection:

In this circle may we give and receive love and find space to search, to listen, to understand.

Each one of us here brings a story: the story of our sorrow and joy, the story of our survival and growth, and the need for meaning and connection.

We are here to be with people who understand our struggle, our hurt, and our search – people who have had tears upon their cheeks and pain in their hearts.

This is a sacred place where we explore and express our feelings, share our humanity, and find strength and inspiration in each other.

Let us remember and respect that each one of us is at a different point in our journey: we can all learn from each other.

Although life remains a mystery, we have chosen to trust and love.

Let us find comfort and healing in what we believe and in our ability to affirm and care for each other.

ASK THE EXPERTS

Russell H. Swerdlow, MD
University of Kansas School of Medicine

The NIH recently ended the CoQ10 study in Parkinson's Disease due to a lack of evidence that it slowed progression of PD. Does this have any effect on how doctors evaluate CoQ10 for PSP/CBD/MSA?

Or is the treatment of mitochondrial dysfunction in PSP/CBD/MSA totally different than in PD?

The results of CoQ-PD studies do not indicate CoQ will or won't help in PSP, CBD, or MSA.

Efficacy (or lack of) in those diseases would need to be demonstrated in studies of subjects with those diseases. One might speculate still, though, that if it fails in one disease, the chances it might fail in the others becomes more likely.

In general, the "mitochondrial medicine" field is in its infancy. Those seeking to treat these diseases by treating mitochondria are still unsure what aspect of mitochondrial function to target. Hopefully, as soon as we come to better understand why mitochondria fail in some of these diseases, and what the consequences of this failure are, we will design more rational mitochondrial treatments.



MAKING A DIFFERENCE

Kathleen Matarazzo Specca
VP, Development & Public Relations

In past newsletters, I've provided information about organizing a special event in your area or coordinating a writing campaign to help raise awareness and funds for CurePSP. The Development Department has all the tools you will need to help you with your fundraiser. You'll even receive weekly progress reports to keep you posted and also help you reach your goal. Today, I'd like to remind you about how you can pay tribute to your loved one through a "Named Fund." Many of our families and volunteers find this option most gratifying.

A Named Fund provides donors with the opportunity to make gifts that will have a lasting impact while recognizing their family, or honoring or memorializing a loved one. Named Funds may be established through special events or a special family writing campaign, or even an annual donation. Many volunteers who participate in marathons, walkathons, dances, sporting events, and other activities have established a named fund such as: *The Jane Doe Family Fund, The Jane Doe Memorial Fund, and/or The Jane Doe Legacy Fund.*

A Named Fund requires an annual donation of at least \$1,000 to keep the fund active and recognized. Named Funds of \$1,000 or more receive recognition in the CurePSP Annual Report and may also receive recognition at a family conference, webinar, printed materials, and a research grant depending on the amount that is raised.

To learn more, please contact me at specca@curepsp.org or 800-457-4777, ext. 5672. I look forward to hearing from you.

