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Occupational Therapy Approach to
Assessment and Intervention in
Atypical Parkinsonian Disorders

Julia Wood MOT,
OTR/L

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Learning Outcomes

- 1) Describe the impact of symptoms on the daily function and participation of people with Atypical Parkinsonism.
- 2) Identify and list appropriate screening and outcome measures to create a person-centered approach to the evaluation and treatment of people with Atypical Parkinsonian Disorders.
- 3) Design occupation-based, task-oriented treatment strategies to address the participation challenges for people living with Atypical Parkinsonism.

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Condition Overview & Symptom Presentation

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Parkinsonism defined

Refers to a “constellation” of symptoms:

Rest tremor

Muscle rigidity

Akinesia and / or bradykinesia

Postural instability

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What is an Atypical Parkinsonism?

- Overlapping features with PD
- More rapid functional decline and disease progression than PD
- Standard therapies for PD provide only partial benefit with increased side effects
- Complex symptom presentation that responds best to multidisciplinary approach



(McFarland & Hess, 2017)

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Progressive Supranuclear Palsy

- 5-6% of people with Parkinsonism
- Estimated prevalence of 5 per 100,000 people
- Incidence is 5.3 per 100,000 men and women between ages 50-99.
- Average age of onset is between 63 and 66 years
- Mean survival 5 to 9 years from disease onset

(Golbe, 2014; McFarland & Hess, 2017)

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Progressive Supranuclear Palsy

- Symptom presentation:
 - Early gait and postural instability
 - Unexplained falls
 - Gaze palsy
 - Axial rigidity
 - Bradykinesia
 - Dysarthric speech
 - Progressive dementia

(Golbe, 2014; McFarland & Hess, 2017)

PSP—Movement Changes

- Early gait dysfunction and falls that often lead to injury
- Freezing of gait
- Reckless turns
- Lack of insight into postural instability
- “Rocket” sign in transfer

(Golbe, 2014; McFarland & Hess, 2017)

PSP—Visual Symptoms

- Blurred vision
- Photosensitivity
- Diplopia
- Difficulty reading (impaired down gaze and convergence insufficiency)
- Slowed saccades
- Square wave jerks
- Blepharospasm and eye lid apraxia

(Golbe, 2014; McFarland & Hess, 2017)

PSP— Mood & Cognitive Symptoms

Mood changes:

- Apathy more than depression
- Disinhibition
- Anxiety, irritability, agitation
- Pseudobulbar affect

Cognitive changes:

- Slowed processing
- Decreased verbal fluency
- Executive dysfunction
- Impulsivity

(Golbe, 2014; McFarland & Hess, 2017)

Multiple System Atrophy (MSA)

- Prevalence 3.4 to 4.9 cases per 100,000
- Median age of onset 58 years
- Mean survival 6 to 10 years
- Two phenotypes: MSA-P, MSA-C

(Golbe, 2014; McFarland & Hess, 2017)

MSA- Symptom Presentation

- Orthostatic hypotension
- Urogenital dysfunction
- Pseudobulbar affect
- Dystonia
- Early dysarthria & dysphonia
- Gait and postural instability
- Rapid progression
- Sleep disturbance
- Cognitive dysfunction/dementia

(McFarland & Hess, 2017)

Corticobasal Syndrome

- Actual incidence and prevalence is unknown
- Estimated 1 in 100,000, but may be over estimation
- Onset occurs in mid 60's
- Mean survival approximately 7 years from diagnosis

(Chahine, 2014; McFarland & Hess, 2017)

CBD- Symptom Presentation

- Marked asymmetric hand dysfunction
- Bradykinesia, tremor, rigidity
- Limb dystonia resulting in contracture
- Myoclonus
- Alien limb phenomenon & ideomotor apraxia
- Limb, hand, gait or speech apraxia
- Language deficits, dysarthria, dysphagia
- Gait abnormality, postural instability & falls
- Dementia (with later progression); semantic memory preserved

(McFarland & Hess, 2017)

Dementia with Lewy Bodies

The second most common form of dementia after AD

Clinical criteria include:

- with dementia
- Mental Status fluctuations
- Recurrent visual hallucinations

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Additional Features of DLB

- Gait instability
- Falls
- Orthostatic hypotension
- Rem behavioral disorder (RBD)
- Depression
- Delusions/paranoia (psychosis)
- Neuroleptic sensitivity

(McFarland & Hess, 2017)

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Impact of Symptoms on Function

- Decreased mobility/impaired functional mobility
- Falls/injury risk
- Decreased ADL/IADL function
- Impaired vision
- Micrographia
- Risk of aspiration
- Decreased occupational participation
- Increased need for assist and supervision

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Points to Remember

- Atypical parkinsonisms are not managed well with medication or surgical treatment like in PD
- Those with atypical parkinsonism progress rapidly through the disease process
- Symptoms and presentations can vary greatly
- Compensatory strategies may need to be implemented earlier (vs. restorative treatment methods used in idiopathic PD)

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Points to Remember

- Begin therapy as early in the diagnosis as possible
- Patients need to be followed more regularly due to the rate of progression and functional decline
- Help patient and family establish their care team early on for better management of rapidly progressing symptoms

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Screening & Assessment

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Semi-structured interview

Client-centered measure of perceived performance and satisfaction over time

PwP chooses five most important activities to target

Helpful in collaborative goal setting—client prioritizes and rates

Can be used to address the care partner

Established validity and reliability

(Law, Baptiste, Carswell, McColl, Poltjako, & Pollock, 2005)

Canadian Occupational Performance Measure (COPM)

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Performance Assessment of Self-Care Skills (PASS)

- 26 tasks in four different domains
 - Functional mobility, ADL & IADL (physical & cognitive)
 - Each subtask is rated for independence, safety, and adequacy on a scale from 0-3.
 - A higher score indicates greater independence, safety, or adequacy.
- Level of assistance needed and frequency of prompts
- Frequency of prompts and types of assistance are recorded to aid in intervention planning
- Therapist may administer only those tasks deemed relevant to client
- Therapist may use PASS template to develop new PASS items

(Chisholm, Toto, Raina, Holm, & Rogers, 2014)

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A simple to administer tool for assessing self care and mobility activities of daily living.

Widely used in geriatric assessment settings.

Reliability, validity and overall utility are rated as good to excellent.

Information is gained from observation, self report or informant report.

Barthel
Index

(Mahoney & Barthel, 1965)

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- 89 photographs of individuals performing activities
- Promotes choosing client centered interventions, based on client interests
- Measures changes in participation
- Guides discussion about current and prior interests and perceived roles
- Includes 20 instrumental activities, 35 low-physical-demand leisure activities, 17 high-physical-demand leisure activities, and 17 social activities

Activity Card
Sort, 2nd
Edition (ACS)

(Baum & Edwards,
2008)

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Five time sit to stand test

- Use a straight back chair with a solid seat that is 16" high. Ask participant to sit on the chair with arms folded across their chest.
- "Stand up and sit down as quickly as possible 5 times, keeping your arms folded across your chest."
- Quick and easy to administer

(Duncan, Leddy, & Earhart 2011)

Intervention Strategies
for ADLs and IADLs

OT & PT Collaboration

“A collaborative approach between OT and PT is successful when both disciplines focus on complementary, different aspects in both the assessment and interventions, while being aware of the instructions and strategies used by each other”

(Radder, Sturkenboom, Nimwegen, Keus, Bloem & de Vries, 2017)

Select activities and tools for therapy from daily life

Collaborate with client to select meaningful functional tasks

Analyze person and environmental aspects of task performance

Structure practice of the task and provide feedback to facilitate motor learning

Develop optimal movement patterns for task performance

Task-oriented Approach

(Almhdawi, 2016)

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Research Article

Effectiveness of an Inpatient Movement Disorders Program for Patients with Atypical Parkinsonism

Anna D. Hohler,^{1,2} Jyeming M. Tsao,¹ Douglas I. Katz,^{1,2} T. Joy DiPiero,^{1,2}
Christina L. Hehl,² Alissa Leonard,² Valerie Allen,² Maura Gardner,² Heidi Phenix,²
Marie Saint-Hilaire,^{1,2} and Terry Ellis^{2,3}

- Patients received physical, occupational, and speech therapy for 3 hours/day, 5 to 7 days/week.
- Interventions included functional training, range of motion, flexibility, strengthening exercises, gait training and speech exercises
- Scores were analyzed for the FIM, Timed Up and Go test, Two-minute Walk Test, Berg Balance Scale and Finger Tapping Test.
- All showed significant improvement on discharge ($P > .001$).
- Clinically significant improvements in total FIM score were evident in 74% of the patients.

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**Compensation for Cognitive Changes/
Dementia**

- | | |
|--|---|
| <ul style="list-style-type: none"> ▪ Establish familiar, simplified routines ▪ Break tasks into smaller more manageable steps ▪ Store things in consistent, predictable places ▪ Simplify instructions & cues ▪ Allow extra time for the individual to respond to prompting | <ul style="list-style-type: none"> ▪ Facilitate gradual transitions (music) ▪ Coach frequent re-orientation when needed ▪ Maintain a highly visible calendar (refrigerator) ▪ Decrease clutter/ distractions ▪ Create and maintain an activity box ▪ Train care partners in cueing strategies |
|--|---|

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Compensation for Visual Changes



- Downward head tilt for scanning environment
- Tinted glasses or brimmed hat for light sensitivity
- Improve light/visual contrast within the home
- Bring reading/objects to eye level (book stand)
- Recommend consultation with (neuro)ophthalmologist for diplopia (prism)
- Blepharospasms (inability to open eyelid) – physical assist
- Teach visual scanning exercises

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Fatigue Management

- Physical/cognitive fatigue
- Create a routine to make most of energy/medication cycles
- Alternate activities with rest
- Pace day—rest before times of general fatigue
- Modify/simplify activities to maximize energy
- Organize home and work spaces to conserve energy
- Prevent de-conditioning

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Fall Prevention

- Seated position for ADL's when possible
- Use of "power stance" for standing tasks
- Gait belt for safety
- Reinforce use of walker in all tasks when recommended by PT
- Tub transfer bench and toilet frame for safety
- Home modifications/evaluation to decrease falls risk
- Use of wheelchair for home function when needed

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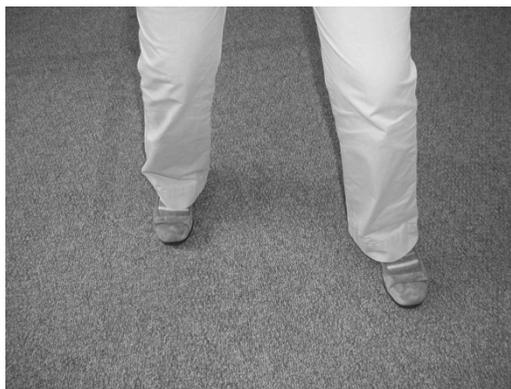
Functional Mobility Strategies

- Return to sitting
 - Practice complete turn in front of chair – NOT reaching before turning
- Side steps (to avoid stepping backwards in those with more frequent posterior falls)
- Turning without pivoting

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Staggered
"Power
Stance"



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Freeze break strategies

When you find yourself in a freeze, remember the 4 S's.....

- **Stop**- steady yourself and take a deep breath
- **Stand Tall**- arrange your center of gravity over your feet
- **Shift**- weight side to side until you can lift a foot and take a...
- **Step**- take a big step

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Video Courtesy of H. Cianci

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Toileting

- Toilet frame with raised seat (colored tape for marking)
- Marching turns in tight spaces— support walker use
- Men- sit or use urinal
- Moist wipes /bidet
- Velcro/magnetic adaptation for pants
- Trunk rotation exercises
- Clothing with easy access
- Incontinence pads/products
- Bedside commode/urinal for nighttime



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Showering/Bathing

- Avoid sliding glass doors
- Non-skid surface/non-slip mats
- Shower chair with back /tub transfer bench
- Hand held shower
- Wash mitt/soap in a nylon
- Long handled sponge
- Temperate water to prevent fatigue
- Terry cloth robe for assist to dry



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Dressing

- Sit to dress—arm chair
- Supervision/assist for safety when necessary
- Clothing set-up for assist
- Adaptive fasteners – MagnaReady, Tommy Hilfiger, Zappos
- Foot stool, long handled shoe horn , elastic laces, positioning (beware of cognitive load!)

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Self Feeding

- Raise food closer to line of vision—rotate plate
- Train in transfer close to table
- Utilize dishes with contrasting colors
- Stabilize dishes with non-slip material (dycem, shelf liner)
- Plate guard
- Bendable utensils, deep bowled spoon, universal design knife
- Train in resting fork/spoon between bites for pacing (supervision/reminders if needed)
- Promote quiet environment/limit distractions
- Consult with Speech Language Pathologist



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Urban OT Legend

...."contrary to the traditional belief about the advantages of weighted utensils, our results demonstrate the benefits of using lightweight or normal-weight utensils.

To facilitate high-velocity and smooth arm movement for people with Parkinson's disease, a lightweight utensil seems to be more appropriate than a weighted one."

(Ma et al, 2009)

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Raised plate
with dycem,
plate guard,
bendable
fork & nosey
cup



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Hygiene and Grooming

- Sit for safety
- Wide based stance/'power stance'
- Electric toothbrush
- Electric razor
- Magnified mirror
- Suction denture brush
- Suction nail clippers
- Support arms on table or vanity
- Sit to apply makeup/build up handles to brushes
- Build up handles on brush or comb
- Blow dryer stand



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Aids for Reading

- Ultra Optix line magnifier- gathers light, magnifies, eye on line
- Magnifiers
- Increased lighting
- Large print books
- Books on tape
- Easel/book stand to bring materials to eye level

Adaptations & aids for reading

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Help clients stay connected!

- Connection was a prevailing concern in QOL
- Subthemes of affected social life
- Communication impairment
- Perception of stigma
- Impact on relationships
- In neurological disorders, it has been shown that individuals who have wider social networks and better support tend to have better outcomes

(Wiblin, Durcan, Lee & Brittain, 2017)

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Adapted leisure pursuits

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Case Study:

Meet “Ellen”

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Occupational Profile

- 62-year-old female diagnosed with MSA 2 years ago
 - Lives alone in single level apartment close to adult children
 - Strengths:
 - Motivated to continue to live independently
 - Supportive family
 - Good insight (with education) into deficits
- ✓ Treatment plan: 2 days per week of PT, OT for 12 weeks

Participation Challenges

- Frequent falls with minor injuries
- Extreme fatigue
- Difficulty t/o ADLs due to bradykinesia and fear of falling

Ellen's Goals:

- Reduce falls and continue to live independently
- Reduce and manage fatigue to improve participation in meal prep activities

Client-Centered Intervention

Falls prevention:

- Collaboration with PT to support use of rollator at all times (bathroom & kitchen)
- Recommendation and training in use of tub transfer bench and toilet frame
- Training in freeze break strategies to support turns in kitchen and bathroom
- Education and training for family in cueing strategies
- Training in side stepping and power stance for kitchen and bathroom mobility

Client-Centered Intervention

Fatigue Management

- Education in balance of rest and activity
- Collaboration with Ellen to create daily routine with nap in bed at consistent time
- Education in sleep hygiene strategies

Client-Centered Intervention

ADLs & IADLs

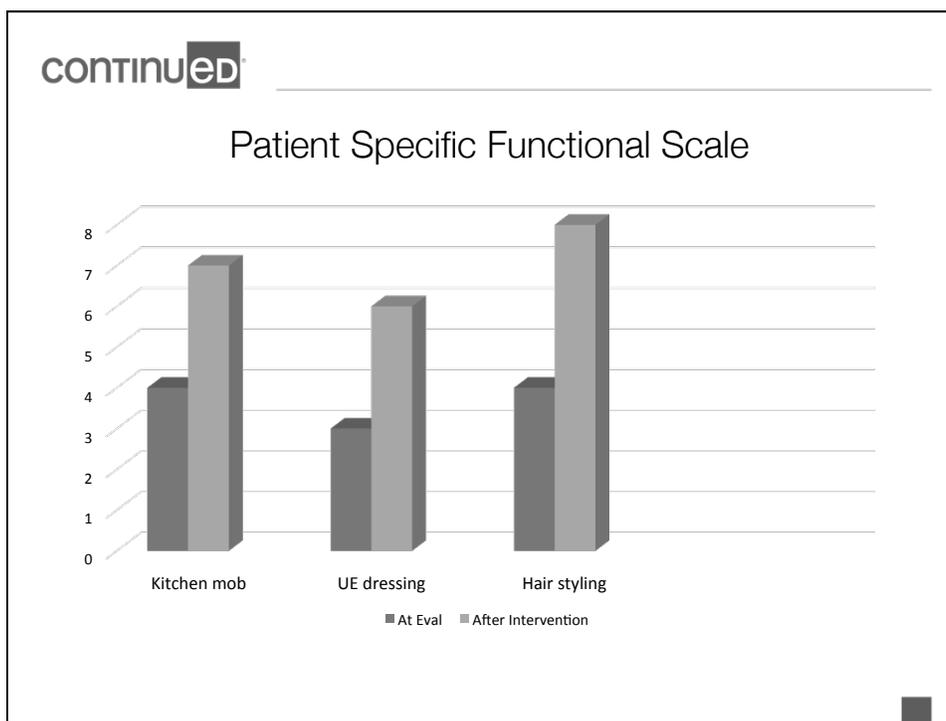
- Training in seated dressing strategies with use of rollator to gather clothing and arm chair for support
- Training in use of large amplitude grasp and movements to support donning clothing
- Recommendation for seated positioning for grooming and blow dryer stand for hair styling

Patient Specific Functional Scale (PSFS)

- 
- Individuals rate their perceived ability to complete a self-selected activity on an 11-point scale
 - "0" represents "unable to perform"
 - "10" represents "able to perform at prior level"
 - Individuals select a rating 0 to 10 that best describes their current level of ability on each activity selected
 - Selected as a distal outcome measure of improved participation and task completion

Ellen selected the following activities:

- Kitchen mobility 4/10, upper body dressing 3/10, styling hair 4/10.

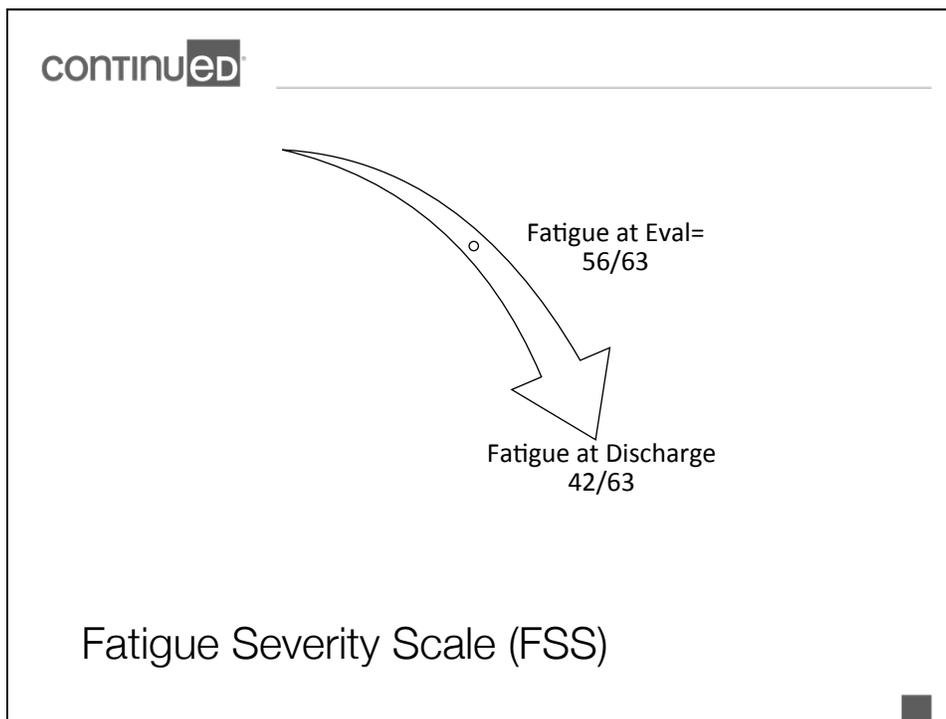


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Fatigue Severity Scale (FSS)

- A 9-item self report questionnaire
- Measures the severity of fatigue and its impact on an individual's activities and lifestyle
- The items are scored on a 7-point scale with 1 = strongly disagree and 7= strongly agree.
- The minimum score = 9 and maximum score possible = 63. Higher the score suggests greater fatigue severity.
- Selected in this case as a proximal outcome to measure if fatigue management strategies decreased fatigue for Ellen.

"I want to feel like doing more—I just stay in bed all day". --Ellen



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Summary

- The atypicals progress at a faster rate than PD and often need more therapy in a shorter period of time
- Begin a multidisciplinary approach to care soon after the diagnosis
- Compensatory strategies may need to be implemented earlier (vs. restorative treatment methods used in idiopathic PD)
- Utilize a task oriented, client-centered approach to assessment and intervention
- Always focus on FUNCTION to support participation!

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Resources for Clinicians & Families

curePSP®

UNLOCKING THE SECRETS OF BRAIN DISEASE™

https://www.psp.org/wp-content/uploads/2016/08/ALLIED-HEALTH-BROCHURE_web.pdf

alzheimer's 
association™

Lewy
Body
Dementia
Association, Inc. 

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Questions?

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