Objectives

• Understand durable medical equipment appropriate for people with PSP/CBD/MSA
• Understand exercise principles for maintaining mobility and function
• Understand environmental and activity modifications to enhance safety within the home setting
• Understand when/how to enlist rehabilitation providers in helping to manage care along the continuum of these conditions

Financial Disclosures
• None

Conflicts of Interest
• None
Durable Medical Equipment (DME)

- Utilized to improve your safety, mobility, and independence or to improve caregivers safety and ease while assisting you

- Requires an evaluation by neurologic-based physical and/or occupational therapists to assess which DME is best for you and your current needs

- Symptoms will progress so DME needs will also change and need to be re-evaluated
DME Along the Spectrum

**Mild Falls Risk**
- Less restrictive gait aid, such as a cane or trekking pole
- Falls prevention and education

**Moderate Falls Risk**
- Walker
- Transfer devices to aid in bed mobility, sit to stands, pivoting
- Caregiver training to improve safety with transfers and mobility as needed

**Severe Falls Risk**
- Wheelchair or powered mobility
- Mechanical lift systems
- Standers
- Caregiver training

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**Canes**

- Different grip styles
- Different tips

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Trekking Poles
• Also known as “walking or hiking sticks”

Different tips available:
• Baskets – best for snow or soft ground
• Steel tips – provides largest amount of traction (i.e. ice)
• Rubber tips – best for general walking over grass/asphalt

Three Wheeled Walkers

Things to consider:
• Smaller
• Easier to fit in smaller spaces
• Narrow base of support
• TIPPY = turning concerns!
• Difficulty walking within the frame of the walker = postural concerns!

Four Wheeled Walkers
• Also known as “rollators”
• Many styles and features based on brand
• Things to consider:
  • Larger increased turning radius
  • Easier to move stability
    • “It gets away from me!”
  • Centralized versus off-set handle positioning
  • Stationary versus swing away backrest
  • Wheel size – 5” or 8”
Four Wheeled Walkers

Some have the capacity to transform into a transport wheelchair.

U-Step Walker™

- Coined as the walker for Parkinson’s disease as designed to address common symptoms of this condition, specifically unsteadiness, poor postural control, small and shuffling steps.
- Things to consider:
  - Large
  - Heavy

Walkers

<table>
<thead>
<tr>
<th>Standard Walker</th>
<th>Front Wheeled Walker</th>
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To reduce friction from rubber tips and improve ease of moving, add:
- Plastic caps or skis
- Tennis balls

Stationary versus Swivel Wheels
Other Walker Styles

Walking Frame  Platform Walker  Hemi-Walker

Gait Aid Add-Ons

• Mobilaser™
  • Laser attachment that emits a red line across your path
  • Used as a visual cue to increase stride length and episodes of freezing of gait
  • Attachable on canes or walkers
  • Requires training

Transfer Devices

Transfer Pole  Pivot Disc  Bed Rail

Stationary Versus Travel
Standers

- Not a transfer device
- Used for physical well-being benefits of standing
  - Weightbearing = strengthen bones and muscles
  - Upright posture = improve respiratory health and dietary health (swallow)
  - Prevention of joint contractures = Sustained stretching of muscles that become stiff when sitting

Mechanical Lift Systems

- Devices used for dependent transfers
- When should I transition?
  - If assisted transfers become too unsafe for both parties
  - Things to consider:
    - Strength - how much can you assist your loved one?
    - Severity of orthostatic hypotension?
    - Severity of unsteadiness and postural control
    - Fall frequency and ability to perform floor transfer
    - Health of the carer
    - Injury prevention

Sit-to-Stand Lift

- Assists in sit to stands from bed, toilet, wheelchair
  - Can facilitate toileting and dressing
- Assists in transporting between rooms
- Promotes participation
- Things to consider:
  - Joint pain
  - Ability to maintain grasp
  - Sling style
Full Body Sling Lifts

- Moveable versus overhead

Powered Scooter

- Appropriate if still safely walking within the home or short distances with or without gait aid but cannot tolerate longer distances
- Things to consider:
  - Vision
  - Muscle stiffness
  - Postural control
  - Coverage – usually out-of-pocket if only for community use
Wheelchair
• Requires consultations with a physician and wheelchair seating specialist to assess what your current and future wheelchair, cushion, and specialized features needs
  • Need prescription and letter of medical necessity
• Things to consider:
  • Home needs to be wheelchair accessible
  • Insurance coverage – depending on insurer
  • Covers new piece of equipment every 5 years
  • Coverage for in-home wheelchair use

Exercise is Medicine: Finding the Evidence in the Benefits of Exercise in PSP/CBD/MSA
Melanie Brennan, PT, DPT
CEO/Founder Exercisabilities
Rochester, MN

Melanie Brennan, P.T., D.P.T.
• The value of exercise for PSP/CBD/MSA
• Barriers to exercise and rehabilitation
• Community options for exercise and rehab
• Home-based exercise
"If we had a pill that contained all the benefits of exercise, it would be the most widely prescribed drug in the world"… Ronald M. Davis, M.D. President AMA

Regular physical activity at the correct intensity:
• Reduces the risk of heart disease by 40%.
• Lowers the risk of stroke by 27%.
• Reduces the incidence of diabetes by almost 50%.
• Reduces the incidence of high blood pressure by almost 50%.
• Can reduce mortality and the risk of recurrent breast cancer by almost 50%.
• Can lower the risk of colon cancer by over 60%.
• Can reduce the risk of developing of Alzheimer's disease one-third.
• Can decrease depression as effectively as Prozac or behavioral therapy.

The ultimate brain workout
Different physical exercises can bring specific mental gains, from improving memory to dealing with cravings or reducing stress.

Evidence for Exercise and PSP/CBD/MSA
• Implication of Tau and Thalamus is the focus on recent studies - Tauopathy
• Gait impairment in PSP/CBD/MSA
• Evidence not yet conclusive on identifying the mechanism of how exercise improves Tauopathies
• Research indicated outcomes specific to PSP/CBD/MSA – Very focused on treadmill training
Finding the Evidence: The Benefits of Exercise for PSP/CBD/MSA

1. The disease is different, so the exercise prescription should be different.

OR

2. The diseases effect the same area of the brain with similar symptoms/presentations, so the same exercise prescription works for both.

Benefits of Evidence-Based Exercise for PD

- Exercise and neuroplasticity
- Examples of exercise intervention in the research for PD
  - Locomotor training body weight supported treadmill training (BWSTT)
  - Standard treadmill training
  - Vibration therapy
  - Group disease specific exercise classes (PWR!, Big and Loud, Tai Chi, specialized yoga, Rock Steady / Knockout Parkinson’s Boxing)
- Intensity matters
  - The Effect of Exercise Training in Improving Motor Performance and Corticobulbar Excitability in People With Early Parkinson’s Disease. Fisher et al
  - Findings: Higher level of MET expenditure (13.5) had best outcomes (BWSTT) as compared to standard 45 minute therapy session

Barriers to Exercise

- Motivation in the setting of symptoms (depression, anxiety and dementia)
- Difficulty participating – safety, movement initiation, follow commands, frustration, needs assist to meet intensity recommendation, special equipment
- Cost of programs – insurance does not always cover costs long term
- Access and transportation
- Availability of skilled clinicians or trainers in PSP/CBD/MSA or PD (TRUST)
- Availability of appropriate classes, accessible equipment, specialized facility
- Overwhelmed caregivers – can be tough to find time to exercise
- Lack of referral or recommendation to exercise and where from medical team
What is Available in Your Local Community?

- Group exercise
  - Classes focused on PD will likely benefit people with PSP/CBD/MSA when the individual with PSP/CBD/MSA are at a functional level to follow in a group
  - PWR! – seated or standing levels available
  - Boxing for Parkinson’s (Rock Steady Knockout Parkinson’s)
  - Tai chi
  - Specialized yoga
  - Big and Loud

- The individual’s ability to safely participate in any program should be assessed by a physical therapist, therapeutic recreation specialist or adaptive fitness trainer

- Individualized rehabilitation - PT and OT who understand and are current in treatments for PSP/CBD/MSA

- Medical fitness – exercise therapy delivered by skilled exercise specialists one on one

Community Based Organization-Medical Center Partnership Example:
ExercisAbilities in Rochester, MN

- A multidisciplinary non-profit rehabilitation and medical fitness facility
- Offers community-based long-term approach to wellness and fitness in the setting of acute or chronic disease
- Offers PD specific group classes in PWR! and Boxing
- Offers aquatic physical therapy and exercise at a local warm pool
- Offers physical therapy, occupational therapy, therapeutic recreation and exercise therapy (exercise physiologists) with knowledge of PD

- An accessible, SAFE environment
- Work with each client as an individual
- Applies evidence based research to all levels of care
- Works closely with referring medical team to assure best approach for each individual over time

National Center on Health Physical Activity and Disability
Conclusion on Exercise and Leisure Activities

- Evidence is now overwhelming on the health burden of physical inactivity.
- The benefits of exercise in the treatment and prevention of chronic disease cannot be denied.
- We cannot continue to ignore this evidence when formulating treatment plans for patients or in education of family/caregivers.
- No patient should leave a doctor’s office without an assessment of his/her physical activity and proper prescription of an exercise program, a referral to a physical therapist if any physical or cognitive concerns exist or a certified fitness professional who is specialized in specific health conditions that need addressed.
Home Modifications: The Dos and the Do Nots

Sarah Dahlhauser, OTR/L, OTD

Shower Modifications
Shower Modifications

Toilet Modifications

Visual Modifications

- Bright tape around grab bars or rails
- Utilize proper lighting throughout the home
- Avoid cluttered areas and cluttered work spaces
"He/She used to love………"

- Adaptive hunting, golfing, fishing, farming, arts, gardening
- Maintaining physical fitness and participation in beloved recreational activities is important.
- Being prepared to adapt to a body that works differently will likely be necessary
- Google search any one of these subjects as a good start
Durable medical equipment prescription

- May require a face to face meeting with office note including specific statements about patients needs

Driving

Driving assessment

- Acute-recoverable vs chronic and progressive
- Reaction to stimuli
- Maintenance of upright posture
- Arm and leg movement difficulties
- Anticipation
- Attention/focus
Driving Assessment

- Formal on the road driving assessment and training for individuals with disability is possible and may include modifications to car

Driving

- Patient/Family responsibility
  - Do I have to disclose a new medical problem to the state?
  - To insurance?
  - Anyone can report a concern for at-risk driver to the state DVS. You may need to provide your name address and phone number but if you are family, the information kept confidential. DVS contacts driver and requests formal assessment

- MD responsibility
  - Policies vary state by state; almost all are voluntary not mandated
  - When mandated, typically for seizures and dementia
  - Physicians will weigh the risks and benefits of driving on a case by case basis
  - Office note can reflect a recommendation of discontinuing driving
  - Could send a formal letter to DVS

Driving

A Guide For People Living With PSP, CBS, and Other Atypical Parkinsonian Disorders

Be Safe, Not Sorry
Disability

• Being unable to work
• Wage replacement and medical insurance coverage
• Short term and long term through employer
• Social security disability
Social Security Disability

- Monthly cash payments and medical coverage (via Medicare) to individuals who qualify and who are unable to work for one year or more because of disability
- Must have worked in jobs covered by SS
- Must meet definition of Disability
  - Compassionate Allowances Conditions

Home Health

- Homebound: Requires a severe and/or taxing effort to leave home.
- HCP ordered—needs to follow a care plan:
  - need skilled nursing/therapy services on an intermittent basis
  - care needs must be predictable and finite
- Complex home treatments: wound care, enteral feedings, IV meds
- Need for RN, home health aide, social services, PT, OT, SPT
- Need oversight of medical health including medications.
- Been in/out of hospital/care facility; upon hospital D/C are less independent
- Have a recent decline in functional status
Take away points

• Adaptation and resiliency are helpful

• There will be times when you begin to struggle with an activity-recreation, personal care, fitness. Rehab providers know how to assist you.

“Do not let what you cannot do interfere with what you can do” coach John Wooden
Resources

- APTA.org – search “Find a PT Directory”
- ADED.net – search “CDRS Provider”
- Social Security
  https://www.ssa.gov/planners/disability/
- Aging in Place

References

- Resources to consider to help remind of these concepts: Posts to CurePSP YouTube channel
  - https://www.youtube.com/watch?v=4V4-1VGIz24 A webinar with speaker Richard VandenDolder, OTR/L—Occupational Therapy for PSP/CBD/MSA
  - https://www.youtube.com/watch?v=TdY3QSt5SPU A webinar with speaker Maria Walde-Douglas, DPT—Physical Therapy for PSP/CBD/MSA
  - https://www.youtube.com/watch?v=0kz8ZgJHDVM A video with speaker Joellyn Fox, DPT—Methods to Improve Everyday Life

Thank you!

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