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Physical Therapy Management of People with Advanced Parkinson Disease

Katy Hendron, PT, DPT, NCS
Boston University

Learning Objectives

The participant will be able to identify:

• Common motor complications in advanced Parkinson Disease.

• Treatment strategies for people in the later stages of Parkinson disease.

• Common functional limitations of people in the later stages of Parkinson disease.

• Outcome measures to implement within PT practice.
Presentation Goals

• Overview of Parkinson disease
• Defining “advanced Parkinson disease”
• Physical therapy management and treatment approaches for people living with advanced Parkinson disease
• Case study example

Parkinson Disease Epidemiology

• 1 million people (USA) live with PD (est 3-4 million undiagnosed)
• 60,000 are diagnosed annually

Predictions:
• Worldwide, the number of people living with PD will double from 4 million in 2005 to 9 million in 2030 (people > age 50 most populated nations)
• Neurodegenerative diseases are projected to surpass cancer as the second most common cause of death among the elderly by the year 2040

http://www.apdaparkinson.org
Dorey et al. 2007
Lang AE, Lozano AM 1998
Epidemiology

- Slightly more predominant in males
- Mean age of onset: early to mid 60’s
  - 5-10% of people have symptoms < 45 = Young Onset
- PD occurs throughout the world in all ethnic groups
  - Lowest incidence is among Asian and African people
  - Highest incidence is among Caucasians

Tanner, C. M., & Aston, D. A. 2000
Willis et al 2010

In PD, the neurons that control movement slowly lose their ability to make and send dopamine to the next neuron

Lang AE and Lozano AM 1998
# Stages of Parkinson Disease

**Modified Hoehn and Yahr**

<table>
<thead>
<tr>
<th>Stage</th>
<th>Signs and Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No signs of disease</td>
</tr>
<tr>
<td>1</td>
<td>Unilateral symptoms only</td>
</tr>
<tr>
<td>1.5</td>
<td>Unilateral and axial involvement</td>
</tr>
<tr>
<td>2</td>
<td>Bilateral symptoms. No balance impairment</td>
</tr>
<tr>
<td>2.5</td>
<td>Mild bilateral disease with recovery on pull test.</td>
</tr>
<tr>
<td>4</td>
<td>Severe disability, but still able to walk or stand unassisted.</td>
</tr>
<tr>
<td>5</td>
<td>Needing a wheelchair or bedridden unless assisted.</td>
</tr>
</tbody>
</table>

## Non-Motor Complications

<table>
<thead>
<tr>
<th>X</th>
<th>X</th>
</tr>
</thead>
<tbody>
<tr>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>X</td>
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</tr>
</tbody>
</table>

## Motor Complications

<table>
<thead>
<tr>
<th>X</th>
<th>X</th>
</tr>
</thead>
</table>
Pathophysiology – Motor Symptoms

• Tremor
• Bradykinesia
• Rigidity
• Gait changes (e.g. Freezing, acceleration)
• Postural instability
• Dystonia
• Hypophonia

Pathophysiology – Non-Motor Symptoms

• Dementia
• Autonomic dysfunction
• Fatigue
• Psychosis and hallucinations
• Sleep disorder
• Sensation Changes
• Behavioral Changes
Pharmacological Management

- Dopaminergic therapy (e.g. levodopa, extended-release, Rytary)
- Dopamine agonist
- MAO-B inhibitors
- COMT inhibitor
- Amantadine
- “Rescue” drugs (Apomorphine)
- Anticholinergics
- Duodopa

<table>
<thead>
<tr>
<th>Drug class</th>
<th>Examples</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dopaminergic therapy</td>
<td>Levodopa, ropinirole, pramipexole</td>
<td>Most effective, improves disability, prolongs capacity to perform instrumental activities of daily living</td>
<td>Motor complications: dyskinesia, dyskinesia, confusion, psychosis, sedation</td>
</tr>
<tr>
<td>Dopamine agonists</td>
<td>Pramipexole (Mirapex), ropinirole (Requip)</td>
<td>Can be used as monotherapy in early disease or added to levodopa for treatment of motor complications</td>
<td>All: dopaminergic adverse effects (nausea, vomiting, orthostatic hypotension), neuropsychiatric adverse effects (hallucinations, psychosis, impulse control disorder), excessive daytime sleepiness (e.g., pulmonary fibrosis, cardiac valve fibrosis, atrial fibrillation)</td>
</tr>
<tr>
<td>MAO-B inhibitors</td>
<td>Selegiline (Eldepryl), rasagiline (Azilect)</td>
<td>Can be used as monotherapy in early disease or to treat motor complications in late disease</td>
<td>Amphetamine and methamphetamine metabolites may cause adverse effects, risk of serotonin syndrome</td>
</tr>
<tr>
<td>Catechol O-methyltransferase (COMT) inhibitor</td>
<td>Entacapone (Comtan), tolcapone (Tasmar)</td>
<td>Used to treat motor complications; no titration, decreased off-time, mild improvement in activities of daily living and quality-of-life scores</td>
<td>Dopaminergic adverse effects, discoloration of urine, tolcapone associated with explosive diarrhea and fatal liver toxicity</td>
</tr>
<tr>
<td>Injectable dopamine agonist</td>
<td>Apomorphine (Apokyn)</td>
<td>Reduces off time in late disease</td>
<td>Requires initiation in hospital, regular subcutaneous injections</td>
</tr>
<tr>
<td>N-methyl-D-aspartate receptor inhibitor</td>
<td>Amantadine</td>
<td>Treatment of dyskinesia in late disease</td>
<td>Cognitive adverse effects, bardo reticulans, edema, development of tolerance, potential for withdrawal</td>
</tr>
<tr>
<td>Anticholinergics</td>
<td>Benztropine, trihexyphenidyl</td>
<td>Useful for the treatment of tremor in patients younger than 60 years without cognitive impairment</td>
<td>Use limited by anticholinergic adverse effects</td>
</tr>
</tbody>
</table>

Note: Medications are listed in approximate descending order of preference for use. Pergolide is not available in the United States.

*---“Off time” is a complication of Parkinson disease in which the medications used to control the disease become less effective over time, resulting in a gradual or abrupt recurrence of symptoms.
Surgical Management – Deep Brain Stimulation (DBS)

[Diagram of surgical components]

https://www.ucdmc.ucdavis.edu

Defining ‘advanced PD’
Defining ‘advanced PD’

- **Research Definition:**
  - Patients in Hoehn & Yahr stage 4-5
  - Increasing disease burden
    - Motor complications (Levodopa resistant symptoms)
    - Non-motor symptoms

- **Functional Definition:** Loss of independence and diminished quality of life

<table>
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<th>Stage</th>
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Giugni and Olan 2014
Defining ‘advanced PD’

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</table>

Advanced PD ✴ Older age

---

**Fig. 1.** Clinical course of Parkinson’s disease. RBD: Resting behavior disorder; FOG: Freezing of gait.
Motor Complications

Reduction in therapeutic window of medications leading to “On / off” times

“Off” times
- Insufficient level of levodopa
- Regular and predictable decline in response 2-4 hours after levodopa dose
- Most common motor fluctuation

“On” with dyskinesias
- Increased levels of dopamine (too much)
- Dyskinesias during peak dose
Management of Motor Complications

- Medications
  - Dopaminergic therapy (e.g. levodopa)
  - Adjunctive medications (reduce motor fluctuations and dyskinesias)
- DBS
- Duodopa
- “Rescue” drugs (Apomorphine)

For community dwelling people, NMS related to caregiver burden.
In nursing homes, patients typically display multiple types of NMS lending to complexity.
Cognitive Impairment

- Memory
- Bradyphrenia
- Attention
- Executive function
- Dual task / prioritization
- Visuospatial skills

http://www.mocatest.org/

Autonomic Dysfunction

- Gastrointestinal - constipation
- Incontinence – urgency, frequency, nocturia
- Slowed gastric emptying
- Dysphagia
- Sexual dysfunction
- Orthostatic Hypotension
- Thermoregulatory dysfunction / hyperhidrosis
Orthostatic Hypotension

• Drop in blood pressure >20 mmHg SBP or >10 mmHg DBP with a position change.

• Symptoms:
  • lightheadedness
  • dizziness
  • weakness
  • difficulty thinking
  • headache
  • feeling faint
  • nausea
  • pain (commonly in neck)

• Many people with PD are asymptomatic.

Freeman et al 2011.
Ziemssen and Reichmann. 2010

Sleep Disorder

• REM sleep behavior disorder
• Sleep fragmentation (frequent awakenings)
• Vivid dreams

Gershonik O 2016
Heflevi Y 2016
Sensation Changes

- Pain
  - Musculoskeletal
  - Neurogenic
- Olfactory changes
- Vision problems
  - Reduced contrast sensitivity
  - Reduced color discrimination
  - Convergence insufficiency (double vision)
  - Blurry vision
  - Dry eye

Behavioral Changes

- Depression
- Anxiety
- Apathy
Other Non-Motor Symptoms

- Fatigue
- Psychosis
- Hallucinations
  - Most predictive of nursing home placement

Physical Therapy Treatment
• Multisystem diseases (Parkinson disease) benefit from a **multidisciplinary team**!
• Experts in PD from different health care professions
• Models:
  • Inpatient Rehab
  • Outpatient rehab centers
  • Home care / Assisted Living
  • Community rehabilitation (e.g. exercise classes, support groups)
Physical Therapy Goals

• Maximize functional independence
• Perform fall risk assessment / fall prevention
• Provide equipment / aide recommendations
• Provide caregiver training
• Keep people with advanced PD engaged in physical activity and exercise!

Physical Therapy Exam

• Medical History
• Functional assessment (on and off, if possible)
• Patient and caregiver identify areas of difficulty during IADLs/ADLs
• Medication schedule and adherence
• Fall risk assessment
Functional Training

- **Movement Strategy Training**
  - Break down movement into distant steps versus continuous motion
  - Develop strategies for ‘on’ and ‘off’ times
  - Cognitive deficits may impact independence with use
  - Caregiver training to provide guidance

---

**Functional Training - Example**

**Movement – Standing up from a chair**

<table>
<thead>
<tr>
<th>Verbal Cue</th>
<th>Visual Cue</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) “Scoot to edge of seat”</td>
<td></td>
</tr>
<tr>
<td>2) “Tuck your feet under”</td>
<td></td>
</tr>
<tr>
<td>3) “Bend forward (nose over toes)”</td>
<td></td>
</tr>
<tr>
<td>4) “Push up to stand”</td>
<td></td>
</tr>
</tbody>
</table>
People with PD benefit from practicing skills in their everyday environments.

Blocked practice may be more beneficial than random practice.

Implementing Movement Strategies

• Practice, practice, practice
• Location may impact performance
  • Clinic versus home
• Caregivers are critical
  • Provide reminders
  • Improve safety
Gait in Advanced Parkinson Disease

- High variability in ability levels
  - On/off times
  - Level of assistance required
- Characteristics:
  - Shuffled gait with flexed posture
  - Variable speeds
  - Difficulty dual tasking
- Freezing of gait

Freezing of Gait

Episodic inability to generate stepping.

- Can occur at any point in their disease.
- Associated with cognitive deficits (executive function, set-shifting)
- May not occur in advanced PD.

<table>
<thead>
<tr>
<th>Freezing Trigger</th>
<th>Functional Example</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gait Initiation</td>
<td>First step</td>
</tr>
<tr>
<td>Turns</td>
<td>Transfers</td>
</tr>
<tr>
<td>Narrow spaces</td>
<td>Doorways</td>
</tr>
<tr>
<td>Time pressure</td>
<td>Elevator doors</td>
</tr>
<tr>
<td>Crowds</td>
<td>Public spaces</td>
</tr>
<tr>
<td>Dual tasks</td>
<td>Talking while walking</td>
</tr>
</tbody>
</table>

Nonnekes et al 2015
Freezing of Gait Management

• Cuing Strategies
• Education with patient and caregivers
• Medication management (“off” times)
• Environmental changes

Freezing of Gait – Cuing Strategies

• Auditory cuing:
  • Caregiver providing cues (‘Stop.’)
  • Metronome
• Visual cues:
  • Vertical lines
  • Laser light
• Other strategies:
  • Weight shifting prior to start walking.
  • Wide turns (to avoid pivot turns)
Freezing of Gait - Patient and Caregiver Education

• Recognize freezing
• Safe physical assistance during a freeze
• Impact of cognitive deficits
• Fall risk
• Medication management (“off” times)
• Environmental changes
  • Remove patterned rugs
  • De-clutter space

Exercise Recommendations
## Physical Activity in Advanced PD

- Reduced participation in daily activities.
  - Mobility deficits – dependence on caregiver
  - Behavioral (apathy, depression)
  - Autonomic Dysfunction
  - Freezing of gait
  - Fear of falls

## Physical Activity Recommendations

- Walking short distances frequently during the day.
  - Small bouts of walking can add up
Physical Activity Recommendations

• Focus on reducing sedentary time.
  • Standing up for 1-2 minutes every hour seated.

Physical Activity Recommendations

• If safe, reduce use of lift equipment to allow participation in functional activities.
## Exercise Recommendations in Advanced PD

- Exercise modifications for safe participation:
  - Use different positions (supine, seated)
  - Avoid quick position changes with autonomic dysfunction (squat = up and down)
  - Reduce use of equipment - bodyweight exercises

## Exercise Recommendations in Advanced PD

- Incorporate exercises that support functional training
  - Squat → Transfers
  - Bridging → Bed mobility
Exercise Recommendations in Advanced PD

- Keep movements simple
- Caregiver supervision for safety as needed

Falls Risk Assessment

- Biomechanical Constraints
- Gait Stability
- Sensory Orientation
- Anticipatory Postural Response
- Stability Limits
- Anticipatory Postural Response
Other Fall Risk Factors

- History of falls
- Greater disease severity
- Longer disease duration
- Cognitive deficits
- Decreased physical activity*
- Environment

Age and gender are not associated with fall risk in PD.

*Can also lead to decreased fall risk.

Orthostatic Hypotension Testing

- Change in blood pressure taken in two back-to-back positions
- Person remains in each position for 3 min before vitals taken.

- Positive test if any present:
  - > 20 mmHg SBP drop
  - > 10 mmHg DBP drop
  - Symptomatic
  - Unable to tolerate full test due to symptoms

Canning CG et al 2014
Freeman et al 2011.
Ziemssen and Reichmann. 2010
Orthostatic Hypotension Testing

Example:
Supine (3 minutes) → Sitting (3 min)

<table>
<thead>
<tr>
<th>Position</th>
<th>Vitals</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supine</td>
<td>BP 125/80, HR 75</td>
<td>none</td>
</tr>
<tr>
<td>Sitting</td>
<td>BP 90/72, HR 95</td>
<td>none</td>
</tr>
</tbody>
</table>

Freeman et al 2011.
Ziemssen and Reichmann. 2010

Orthostatic Hypotension Management

- Medication adjustments
  - Levodopa medication can reduce blood pressure
  - Adjustments to cardiac medications controlling blood pressure
  - Fludrocortisone
- Dietary – adding salt to diet
- Hydration!
- Compression stockings (legs) or abdominal binder

*Check with healthcare team

Freeman et al 2011.
Ziemssen and Reichmann. 2010
Precautions with Orthostatic Hypotension

- Allow extra time when transitioning to a more gravity dependent position.
  - Stay seated for 1-2 minutes before standing up from bed.
- Avoid prolonged static positions.
- Monitor vitals during mobility (delayed OH).
- Speak to health team regarding safety concerns and decreased activity tolerance.

Skin Integrity in Advanced PD

- People with advanced PD are at high risk for skin breakdown and pressure ulcers.
  - Increased sedentary behavior
  - Difficult to reposition or change position independently for pressure relief
  - Incontinence or hyperhidrosis creates moisture making skin more susceptible.

Beitz JM 2013
Skin Integrity Management

- Strategies to provide pressure relief and reduce risk of skin breakdown:
  - Encourage activity throughout the day
  - Monitor areas prone to dampness – change wet clothing
  - Develop turning or repositioning schedule
  - Use of equipment to facilitate ease of repositioning

Beitz JM 2013

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Assistive Device Selection

- Requires individual assessment
- Cognitive deficits may impact safe use, even under supervision

<table>
<thead>
<tr>
<th>Bilateral devices</th>
<th>Unilateral devices</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>U-Step</strong></td>
<td><strong>Rolling walker</strong></td>
</tr>
<tr>
<td>- Reverse brakes</td>
<td>- No brakes</td>
</tr>
<tr>
<td>- Heavy frame</td>
<td>- Lightweight</td>
</tr>
<tr>
<td>- High maneuverability</td>
<td>- Decreased maneuverability</td>
</tr>
<tr>
<td>- Seat</td>
<td></td>
</tr>
</tbody>
</table>

http://www.ustep.com
http://www.invacare.com

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Wheelchair Devices

**Manual**
- Patient able to propel.
- Lightweight frames availability
- Custom seat and back support
- Specialty cushion
- Moderate ease of transport (e.g. lift in/out of car)

**Transport Chair**
- Patient able to propel with lower extremities.
- Lightweight
- Easy transport
- Part-time use during the day

**Tilt-in-Space Chair**
- Patient unable to propel.
- Able to recline back (good for people with low blood pressure)
- Difficult to transport

[Image of manual wheelchair, transport chair, and tilt-in-space chair]

http://www.sunrisemedical.com/

Transfer Devices

**Lift equipment**
- Dependent transfers
- Decrease physical assistance required by caregivers

**Hydraulic**
- Semi-recumbent to upright seated position

**Manual**
- Standing position

**Hydraulic Standing Lift**

[Images of hydraulic lift, manual lift, and hydraulic standing lift]

http://www.invacare.com
Beds

Adjustable head and leg position
• Comfort
• Management of blood pressure

Seated position possible
• Reduces risk of aspiration

Mattress options
• Inner-spring
• Foam
• Alternating pressure

Improve participation with rolling or getting in/out of bed.

http://www.invacare.com

APTA - PD EDGE

Recommendations for patients with Parkinson disease:

<table>
<thead>
<tr>
<th>Highly recommended measures:</th>
<th>Recommended Measures for Specific Constructs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body Structure and Function</td>
<td>Freezing of Gait</td>
</tr>
<tr>
<td>MDS–UPDRS revision* – part 3</td>
<td>Freezing of Gait questionnaire</td>
</tr>
<tr>
<td>MDS–UPDRS – part 1</td>
<td>Fatigue</td>
</tr>
<tr>
<td>Activity</td>
<td>Parkinson's Fatigue Scale</td>
</tr>
<tr>
<td>6 minute walk</td>
<td>Fear of falling</td>
</tr>
<tr>
<td>10 meter walk</td>
<td>ABC scale</td>
</tr>
<tr>
<td>Mini BESTest</td>
<td>Dual Task</td>
</tr>
<tr>
<td>MDS–UPDRS – part 2</td>
<td>Timed Up and Go cognitive</td>
</tr>
<tr>
<td>Participation</td>
<td></td>
</tr>
<tr>
<td>PDQ–8 or PDQ–39</td>
<td></td>
</tr>
</tbody>
</table>

All measures in the highly recommended category are also recommended for use in research and students learn to administer.* recommend students exposed

http://www.invacare.com
# APTA - PD EDGE

## Description

<table>
<thead>
<tr>
<th></th>
<th>Highly Recommend</th>
<th>Recommend</th>
<th>Reasonable to use, but limited study in target group</th>
<th>Do not Recommend</th>
</tr>
</thead>
</table>
| **4** | *excellent psychometrics in target population (e.g. valid and reliable with available data to guide interpretation) AND*  
*excellent clinical utility (e.g. administration is ≤ 20 minutes, requires equipment typically found in the clinic, no copyright payment required, easy to score)* | *good psychometrics (may lack information about reliability, validity, or available data to guide interpretation) in target population AND*  
*good clinical utility (e.g. administration/scoring > 20 minutes, may require additional equipment to purchase or construct)* | *good or excellent psychometric data demonstrated in at least one population*, but insufficient study in target population to support a stronger recommendation (does not have any negative psychometric data)  
*good clinical utility (e.g. administration/scoring > 20 minutes, may require additional equipment to purchase or construct) No negative psychometric data.* | *poor psychometrics (inadequate reliability or validity) OR*  
*limited clinical utility (extensive testing time, unusual or expensive equipment, ongoing costs to administer, etc.)* |
| **3** | | | | |
| **2** | | | |
| **1** | | | |

---

**PD EDGE Task Force Recommendations by Disease Stage**

<table>
<thead>
<tr>
<th>Disease Stage Rating</th>
<th>Recommanded (3 or 4)</th>
<th>Reasonable to recommend (2)</th>
<th>Do not recommend (1)</th>
</tr>
</thead>
</table>
| Hoehn & Yahr IV     | Body Structure and Function  
Brief Test  
MD’s UPDRS section*  
Mini BEST*  
Mini Mental Status Exam (MMSE)  
Minimal Cognitive Assessment (MCA)*  
Parkinson’s Fatigue Scale  
Perfusor Pag Rod Test  
Push/Reach Test  
Sit to stand, 5 repetitions*  | Body Structure and Function  
Clinical Test of Sensory Integration and Balance  
Fatigue Severity Scale  
Functional Axial Rotation  
Multidimensional  
Rapid Staging Test—timed (max. of 30 mins)  
State—Loss Mental Status Examination  
Timed up to stand, reps completed in 30 sec second timed stop—stand  
Trunk Impairment Scale  
Unified Dyskinesia Rating Score  | Body Structure and Function  
Functional Independence Measure (FIM)  
Functional tests  
Movement Out Effacy Scale  
Self-Efficacy Exercise Scale  
Dyskinesia Rating Scale  
Unified Parkinson’s Activity Scale  
Timed Up and Go Backwards  |

---

**Activity**  
2 minute walk test  
4 Minute walk test  
360 degree Turn Test  
6 block peg test*  
BEST*  
Dynamic Gait Index  
Five squares step test  
Freeing of Gait Questionnaire  
Functional Gait Assessment*  

---

**Activity**  
Functional Independence Measure (FIM)  
Functional tests  
Movement Out Effacy Scale  
Self-Efficacy Exercise Scale  
Dyskinesia Rating Scale  
Unified Parkinson’s Activity Scale  
Timed Up and Go Backwards  

---

**Activity**  
Berg Balance Scale  
Fall Efficacy Scale - Modified  
OPTIMAL (APTA)  
Profile PD  
Single Leg Stance  
Steps—Walking Time  
Tandem Test (SWT)  
Timed Up and Go  
Timed Up and Go Backwards

---

http://www.neuropt.org/professional-resources/neurology-section-outcome-measures-recommendations/parkinson-disease
Caregiver perspective

Table 3 Caregiver experiences of health and social care

<table>
<thead>
<tr>
<th>Item</th>
<th>PD</th>
<th>n (%)</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not have a care assessment but would have liked one</td>
<td>154 (30)</td>
<td>NS</td>
<td></td>
</tr>
<tr>
<td>No/ not enough opportunity to discuss amount of caring w/ a health</td>
<td>523 (73)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>or social professional</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not involved in care planning as much as the caregiver would like</td>
<td>324 (44)</td>
<td>NS</td>
<td></td>
</tr>
<tr>
<td>Caring experiences not valued enough by health and social services</td>
<td>243 (33)</td>
<td>&lt;0.001</td>
<td></td>
</tr>
<tr>
<td>Not been able to take a break from caring</td>
<td>96 (13)</td>
<td>NS</td>
<td></td>
</tr>
<tr>
<td>Did not receive all the necessary equipment from health and social</td>
<td>114 (16)</td>
<td>NS</td>
<td></td>
</tr>
<tr>
<td>services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have not had enough help from health and social services with</td>
<td>138 (19)</td>
<td>0.002</td>
<td></td>
</tr>
<tr>
<td>personal care of the patient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have not had enough help from health and social services with</td>
<td>163 (23)</td>
<td>NS</td>
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</tr>
<tr>
<td>household duties</td>
<td></td>
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<tr>
<td>Have not had enough help from health and social services with health care</td>
<td>109 (16)</td>
<td>NS</td>
<td></td>
</tr>
<tr>
<td>Have not had enough help from health and social services with</td>
<td>163 (23)</td>
<td>&lt;0.001</td>
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<tr>
<td>physical care</td>
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<td></td>
<td></td>
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<tr>
<td>Do not receive financial support from health and social services,</td>
<td>125 (17)</td>
<td>0.023</td>
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<tr>
<td>but would like some</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Had difficulty in obtaining financial support from health and social services</td>
<td>116 (16)</td>
<td>&lt;0.001</td>
<td></td>
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</tbody>
</table>

Peters et al 2013
Palliative Care

USA Hospice Referral Criteria

Dementia
1. Stage 3 or higher on the Functional Assessment Staging Test AND
2. One or more of the following in the past year: aspiration pneumonia, pseudobulbar palsy, septicemia, stage 3 or 4 pressure ulcers, recurrent fevers, other conditions suggesting limited prognosis, or inability to maintain sufficient fluid/caloric intake in the past 6 months (10% weight loss or albumin <2.5 g/dL)

Stroke or coma
1. Palliative Performance Scale score <40 % AND
2. Poor nutritional status with inability to maintain sufficient fluid/caloric intake (10% weight loss in 6 months, 7.5% weight loss in 3 months, serum albumin <2.5 g/dL, or pulmonary aspiration resistant to speech therapy interventions)

Other neurologic disease (ALS, PD, muscular dystrophy, amyotrophic lateral sclerosis, or multiple sclerosis)
1. Critically impaired breathing including dyspnea at rest, vital capacity <30 %, O2 need at rest, AND refusal of artificial ventilation OR
2. Rapid disease progression (to bed-bound state, unintelligible speech, need for parenteral diet, and/or major assistance needed for ADLs) with either of the following:
   A. Critical nutrition impairment in the prior year (inability to maintain sufficient fluid/caloric intake, continuing weight loss, dehydration, AND refusal of artificial feeding methods) OR
   B. Life-threatening complications in the prior year (tumor aspiration pneumonia, pseudonephritis, sepsis, recurrent fever, OR stage 3 or 4 pressure ulcers)

Genetic criteria
1. Terminal condition (can be multiple conditions) AND
2. Rapid decline over past 3-6 months as evidenced by progression of disease signs, symptoms, and test results; decline in Palliative Performance Scale ≤40 % and involuntary weight loss >10% and/or albumin <2.5 g/dL.

Attendees:
- PD was 13th most common diagnosis
- Patients may be referred based on other diagnostic categories

Miyasaki and Kluger 2015

Case Study

74
Meet Sarah

- 68 year old female
- PMH:
  - PD - diagnosed at age 50 (1998)
  - Anxiety
  - Depression
- PSH
  - DBS surgery 2009 (battery replacement 2014, lead replacement 2016)
  - Bilateral hip replacement (R 2008, L 2010)
- Osteoporosis
- Breast cancer 2003, s/p radiation
- L knee injury (2 years ago)

Meet Sarah

- Lives with spouse (full-time caregiver)
- First floor apartment (5 stairs to enter)
- Retired 15 years – children’s author
- Completed graduate level education
- Falls: 1 x per month
  - Backwards while standing
  - Forward reaching from her wheelchair
- Near falls: Daily
  - Reaching when standing up (spouse assist with balance)
Meet Sarah

• Recent history:
  • Significant decline in function over past year.
  • Unsuccessful DBS and medication adjustments
  • Neurologist recommended replacement of DBS leads.

• PT referral post-lead replacement

Meet Sarah

• PT Goals:
  1. Improve her walking.
  2. Establish home exercise program to improve endurance.
<table>
<thead>
<tr>
<th>Time</th>
<th>Carbidopa-Levodopa, 25/100 (# of pills)</th>
<th>Carbidopa-Levodopa CR 200 mg (# of pills)</th>
<th>Amantadine 100 mg</th>
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<tbody>
<tr>
<td>6:00am</td>
<td>1</td>
<td>1</td>
<td>x</td>
</tr>
<tr>
<td>7:00am</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8:00am</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>9:00am</td>
<td>1</td>
<td>0.5</td>
<td></td>
</tr>
<tr>
<td>10:00am</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11:00am</td>
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</tr>
<tr>
<td>12:00pm</td>
<td>1</td>
<td>1</td>
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<tr>
<td>1:00pm</td>
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<tr>
<td>2:00pm</td>
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<tr>
<td>3:00pm</td>
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<td>1</td>
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<td>4:00pm</td>
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<td>5:00pm</td>
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<tr>
<td>6:00pm</td>
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</tr>
<tr>
<td>7:00pm</td>
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<tr>
<td>10:00pm</td>
<td>1</td>
<td>0.5</td>
<td>x</td>
</tr>
</tbody>
</table>

Total: 6 pills (600 mg) 4.5 pills (900) 2 pills = 200 mg

<table>
<thead>
<tr>
<th>Activity</th>
<th>‘On’</th>
<th>‘Off’</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bed mobility</td>
<td>mod A</td>
<td>Max A</td>
</tr>
<tr>
<td>Transfers</td>
<td>stand-step with rolling walker, contact guard</td>
<td>Squat-pivot, max A</td>
</tr>
<tr>
<td>Sit to / from stand</td>
<td>Supervision up to rolling walker</td>
<td>Max A</td>
</tr>
<tr>
<td>Gait - Household - Community</td>
<td>- Rolling walker, close supervision, 20’</td>
<td>- Unable</td>
</tr>
<tr>
<td></td>
<td>- Rolling walker, contact guard, 20’</td>
<td>- Unable</td>
</tr>
<tr>
<td>Wheelchair - Household - Community</td>
<td>- Independent - Max A</td>
<td>- Dependent (transport chair vs manual WC)</td>
</tr>
<tr>
<td>Stairs</td>
<td>- Mod A</td>
<td>- Dependent (wheelchair bump)</td>
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</table>
### Outcome measures

<table>
<thead>
<tr>
<th>Outcome Measure</th>
<th>Score</th>
<th>Detail</th>
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<tbody>
<tr>
<td><strong>Participation</strong></td>
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<tr>
<td>- PDQ39</td>
<td>46%</td>
<td>Mobility 80%, ADLs 67%, Emotional Wellbeing 29%, Stigma 44%, Social Support 33%, Cognition 44%, Communication 67%, Bodily Discomfort 8%</td>
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<tr>
<td><strong>Activity</strong></td>
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<tr>
<td>- 2 Minute Walk Test</td>
<td>47 meters</td>
<td>Rolling walker</td>
</tr>
<tr>
<td>- 10 Meter Walk (comfortable)</td>
<td>0.51 m/s</td>
<td>Rolling walker</td>
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<tr>
<td><strong>Body Structure and Function</strong></td>
<td></td>
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<tr>
<td>- Berg Balance</td>
<td>31/56</td>
<td>- Pull Test = catch (no step), wheelchair</td>
</tr>
<tr>
<td>- UPDRS Part 1</td>
<td>21/52</td>
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<tr>
<td>- UPDRS Part 2</td>
<td>36/52</td>
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<tr>
<td>- UPDRS Part 3</td>
<td>37/54</td>
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<tr>
<td>- H&amp;Y</td>
<td>Stage 5</td>
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</tbody>
</table>

### PT Recommendations

**Goal #1: Improve her walking.**

- Ambulation (home): 2 bouts of walking, 18’ loop inside of home
- Activity levels: Stand up for 2 min after 1 hour sitting.
PT Recommendations

Goal #2: Establish home exercise program to improve endurance.

- Home Exercise Program – supervised
  - Supine
    - Bridging, 3 x 10
    - Clamshells, 3 x 10
    - Trunk rotation stretch, 3 sets each side
  - Seated
    - Sit to stand, 3 sets of 10 (throughout day)
    - Scapular retraction (focus on upright posture)
  - Standing (rolling walker)
    - Focus on achieving upright posture throughout day with transfers (5-10 sec pause)

Thank you!
References

- Dorsey et al. Projected number of people with PD in the most populous nations, 2005 through 2030. Neurology. 2007 Jan 30;68(5):322-3
- Pfeiffer RP. 2016 Non-motor symptoms in Parkinson’s disease.