**ROLE OF THE NURSE IN LATE STAGE and End Stage PARKINSON’S DISEASE**

**Susan Heath, MSN, RN**

Selected slides complements of Joan Gardner, BSN, RN

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**Hoehn and Yahr Staging**

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
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<tbody>
<tr>
<td>I</td>
<td>Unilateral involvement</td>
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<tr>
<td>II</td>
<td>Bilateral or Axial involvement without balance impairment</td>
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</tbody>
</table>
| III   | Bilateral involvement  
Mild postural imbalance  
Patient leads independent |
| IV    | Bilateral involvement  
Postural instability  
Requires help with activities of daily living |
| V     | Fully developed disease  
Patient restricted to bed or chair |

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**Late Stage PD**


**FINDINGS:**
- Living with advanced Parkinson’s disease meant daily struggles with unpredictability where the disease gradually took over

**Themes:**
- The body sets the agenda
- Always a struggle to be “on”
- Living in dependence and compromise - being a burden
- Living with restrained space and changes in social life

**Conclusion:**
- Nurses need to be aware of the impact the disease has on the entire lifeworld, and how this may affect the way treatment is perceived.

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**Chronic Disease Management**

**Transitions**

- May need help to stay in the home
  - In-home care
  - Adult day care
  - Periodic respite
- May need to move to a new living environment
  - Assisted Living
  - Long Term Care/Skilled Nursing Facility about 40% (Hely et al, Mov Disord 2005 190-9)
- End of life care
  - Palliative Care
  - Hospice Care

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**Disclosures for Susan Heath**

- Paid Consultant and educator for Medtronic
- Consultant for AbbVie
### The Big Picture

**AAN Parkinson’s disease measures**

**All stages of Parkinson’s, annual assessments**

- Review of diagnosis
- Psychiatric disorders or disturbance
- Cognitive impairment dysfunction
- Autonomic dysfunction
- Sleep disturbances
- Falls
- Need for rehab therapies
- Safety issue counseling
- Medication-related motor complications
- Review of medical and surgical options

### Impact of Symptoms-Late Stage

**Increased motor symptoms and immobility**

- Increased dependence on caregiver

**More mid-line symptoms:**
  - Dysphagia, balance, gait issues

**Increased medication side effects**

- Medications may be withdrawn/schedules simplified

**Increased non-motor symptoms**

- Autonomic (OH, bladder, GI)
- Mood and/or behavior changes (apathy, depression, hallucinations, dementia)

### Transition to Advanced PD

**Late Stage PD**

- Increased caregiver burden
- Need to adjust to “a new normal”
- This adjustment may be more difficult for some
- Until acceptance of this “new normal” occurs, there will be multiple struggles and conflicts between:
  - Patient and family
  - Family and health care team
  - Multiple phone calls, etc.

### Clinical Assessment

**Late Stage PD**

**Beyond the physical problems**

- Look beyond the disability of the patient or the anxiety or uncertainty of the carepartner
- Include in care planning with individual choices respected (advanced directives)
- May have limited access to care due to disability
- May lack comprehensive care
- Psychosocial symptoms have as much effect as physical symptoms for the patient and family

- Medication effect/side effect/problems
- Autonomic Nervous System Challenges
- Swallowing and Nutritional Challenges
- Communication Challenges
- Immobility
- Behavioral and Personality Changes
- Cognitive Changes and Dementia
Clinical Assessment
Late Stage PD

- Medications become less effective
- Medications cause many unwanted cognitive side effects
- Dopamine agonists, amantadine, anticholinergics likely not tolerated and withdrawn
- However, studies show more QOL issues with the non-motor symptoms rather than the motor debilitation.

Medications

- Immediate release carbidopa/levodopa may be crushed if swallowing medications becomes difficult or unsafe
- Parcopa®, orally disintegrating tablets are available in IR formulations (Now available in generic)
- Liquid carbidopa-levodopa (Sinemet) is another option
  - Allows for giving smaller doses at more frequent intervals
  - Allows some patients to “fine tune” their individual dose responses to provide more “on” time during the day
  - Liquid carbidopa-levodopa is not available commercially and must be prepared each day

Refer to NPF Medication booklet for formula for Liquid carbidopa-levodopa

Late Stage PD - Bowel and Bladder Challenges

Increasing severity

- Toileting difficulties
  - Urinary Frequency → incontinence, need for diapers. Educate regarding principles of skin care.
  - Reduced ability to walk or wait for help to go to the bathroom
  - Dependence to physically move from the chair or bed to the bathroom without assistance
  - May need for a urethral or suprapubic catheter (versus diaper)
  - Constipation may become a serious problem
    - Can result in impaction, bloating, discomfort and pain


Late Stage PD - Autonomic Challenges

Orthostatic hypotension - symptomatic in 35% (Hely et al, Mov Disord 2005 190-9)

- Postprandial hypotension can result in fainting after a meal, especially if the meal is large
  - Offer small frequent meals throughout the day to avoid this effect
  - Often compounded by inadequate fluid intake

Dehydration

- May not be able to lift a glass
- May not able to obtain a beverage
- Offer smoothies, sorbets, fruit or other foods with a high water content

Late Stage PD - Swallowing Changes

Impaired swallowing-dysphagia - choking in 50% (Hely et al, Mov Disord 2005 190-9)

Dry mouth or excessive saliva, incoordination of the swallowing muscles, contribute to dysphagia

Swallowing changes may lead to aspiration in 15-56%

Aspirations may be completely silent

Swallowing problems may cause

- Pneumonia
- Weight loss (advanced stages)
- Insufficient medication intake
- Dehydration
- Death

Story: Keith – 30 yrs with PD


Late Stage PD - Swallowing Changes

Considerations for family education include:

- Strategies for difficulty in initiating the swallow
  - Ice chips or lemon ice may help initiate swallow
  - Carbonated beverages may be helpful
- Family instruction in the Heimlich
- Take advantage of “on” times for eating
- Upright positioning after meals
- Referral for formal swallow exam (Speech Therapy)
- Ask if they want a feeding tube for nutrition
Late Stage PD - Swallowing Changes

Referral to SLP/Video swallow to determine needs

- Necessary dietary/mealtime changes may include
  - Soft and easy to chew foods
  - Avoidance of foods with different textures (vegetable soup)
  - Mealtime assistance
  - Avoidance of the use of straws
  - Medications given in applesauce (not pudding or high protein foods)

Late Stage PD - Severe Swallowing or Weight Loss Problems

Discussion regarding patient wishes, advanced directives, including feeding tube placement (hopefully early in the disease)

Feeding Tubes:
- Will allow adequate nutrition and medication delivery
- Removes the ‘stress’ of eating
- Must respect patient / family choices

Oral Hygiene and Parkinson’s

Struthers Dental Care in PD project: Surveys were sent to 1,499 PD patients and carepartners seen at our center in the last 2 years.

- Survey questions included:
  - Since your diagnosis of PD, do you have more problems with your teeth and gums (dental health)?
  - Do your PD symptoms affect your ability to do mouth and teeth care (PD symptoms)?
  - Rate the health of your mouth and teeth, with 0 being poor and 10 being excellent
  - Do you have dry mouth (dry mouth)?
  - Do you have too much saliva (excess saliva)?
  - UPDRS-II (ADL) score within the last year was calculated
  - Used spouse as age-matched control group

Results: 890 surveys (61.5%) and 622 carepartner surveys received

- 25.4% felt that dental health was more of a problem since the PD diagnosis.
- 35.2% felt that their PD symptoms affected their ability to do mouth and teeth care.
- As ADL scores increased, dental health worsened.

Tips for caregivers
- Incorporate oral care into the daily routine and have a set process.
- Wash your hands before starting.
- Choose a place that is comfortable. The kitchen or dining room may be better than the bathroom.
- Make sure you have good light. Sit or stand where you can see all of the surfaces of the teeth.
- Use an electric or Sonic® toothbrush, alternating areas of the teeth when signaled by toothbrush.
- Brush the front, back and top of each tooth. Gently brush the tongue after you brush the teeth.
- Take the time needed (recommend 2 minutes total).
- Use an oral swab toothette (small sponge on a stick) soaked in non-alcohol mouthwash to clean teeth and gums between meals.
- Be patient and verbalize each step in the process.

Oral Hygiene and Parkinson’s

Conclusions
- PD patients rate their oral health significantly worse than their spouse.
- Despite similar frequency of dental check-ups and perceived health of mouth and teeth, carepartners had fewer urgent or unplanned dental care visits.
- There is a significantly higher rate of dry mouth, too much saliva, and the combination of dry mouth and too much saliva in the PWP as compared to spouses.

Frequency of Too Much Saliva and Dry Mouth: PWP vs Spouse

- Frequency of Too Much Saliva: PWP vs Spouse
- Frequency of Dry Mouth: PWP vs Spouse

Late Stage PD - Weight Loss Problems

Unplanned Weight Loss
- Unplanned weight loss and low body mass index are significant predictors of morbidity and mortality in older adults.
- Adequate nutrition bolsters bone strength and prevents loss of body mass.
- May not make good food choices that maintain bone strength and muscle mass (many “crave” sweets).

Failure to Thrive
- Despite adequate calories and nutrition, some may continue to lose weight.
- Weight loss is a side effect of levodopa.
TULIPS for better Parkinson’s Care

**People with Parkinson’s Need:**
- **T:** Time
- **U:** Understanding
- **L:** quality of Life
- **I:** Increased awareness
- **P:** Pills on Time
- **S:** Support

Late Stage PD

**Communication Challenges**

Speech in late stage PD patients is often severely affected
- It is often soft and unintelligible or garbled
- This problem can result in the inability of a patient to communicate to/with others
- This leads to frustration, alteration in dignity and a decrease in self-esteem

**Management Strategies**
- Ask “yes-no” question
- Give clear choices, avoiding open-ended questions
- Use alphabet boards or devises (iPADS : “text to speech”)
- Decrease background noise
- Referral to Speech Therapy

Late Stage PD

**Mobility**

*Increased Risk of Falls occur in (40-70%)*
- 23% sustain fractures

- Increased postural instability and gait disturbances
  - Increase the risk for falls and fractures
- The inability to maintain balance may progress to the inability to stand or walk without assistance
- A hip fracture is catastrophic, especially for the frail, with reduced rehab potential and longer rehab

**Pain**

- 62% of PD patients have chronic pain
- Despite the intensity of pain, few PD patients use analgesics to treat the pain
- Pain is often proportional to the degree of motor dysfunction and may take the form of muscle cramps, stiffness, radiculopathy or arthralgias
- Increased carepartner responsibility

**Pain**

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Late Stage PD

**Behavioral and Personality Changes - Psychosis**

25-30% of PD patients may experience illusions, hallucinations, or delusions

**Management Strategies**
- Medications to minimize symptoms
  - Quetiapine (Seroquel®)
  - Clozapine (Clozaril®)
- Attempt to refocus/redirection to another activity
- Educate family members and provide support

**Clinical Assessment**

Late Stage PD

**Impact of Immobility**

- Bradykinesia and rigidity cause marked slow movements and decreased ability to achieve full range of motion - may lead to contractures
- Increased need with Activities of Daily Living (ADL). May require total assistance. Try to accomplish ADL’s when “on”.
- Waking hours are spent in ADL’s, and meals, and rest, foregoing activities that foster quality of life


Late Stage PD - Cognitive Changes and Dementia

In late stage PD, cognitive decline is present in 84% (Hely et al, Mov Disord 2005 190-9).

**Dementia** - loss of previously acquired abilities of memory, judgment and abstract thinking as well as changes in personality (48% fulfill the criteria for dementia) (Hely et al, Mov Disord 2005 190-9).
- If occurs early in diagnosis, probably Lewy Body Dementia
- Recognize that clients can be adept at hiding limitations
- Family denial can occur

Death from Parkinson’s?

- Most literature, textbooks and physicians state PD is not cause of death
  - “one of the first things you are told... is that you are not likely to die from PD” (providers want to provide ‘hope’)
- Course of PD is relatively slow
  - Evidence for shortened life expectancy - risk of death 3.75 > than no PD within 6 yrs ( Willis AW, Arch Neurol, 2012.)
  - Terminal conditions such as pneumonia often cited rather than PD
  - Variability in symptoms, prognosis difficult (Carney, 2009)
  - In Cancer pts, no prognosis is given in 63% if asked, 37% don’t answer
  - Death certification data unreliable in PD in 53-57% (Pennington, S. 2010)
- Clear trajectory in late stage disease
  - In Goy, Carter et al. (2007) 47 pts had PD reported as primary cause of death; Kerrigan & Ormerod, (2010) Acceleration is foreseeable in PD.

CDC Leading Causes of Death (2006)

- PD #14 overall
- First appeared in top15 in 2003
- 19,000 deaths total (1/3 over 85) 0.8% overall

The Reality of the Last Years of Life: Death Is Not Predictable


How Do people die from PD?

What are symptoms EOL is near?

- Very few studies on how PD patients die
- Common clues:
  - Increased motor disability: falls and fractures
  - Dysphagia with aspiration and recurrent pneumonias
  - Recurrent urinary infections
  - Dementia, persistent hallucinations in absence of drugs
  - Weight loss may start 24-36 months before death (unpublished study Goy, 2010)
  - Medication reduction/simplification is predictive within last 6 months
    - (Risk/benefit changes - Goy, unpublished data, 5/10)
Death from Parkinson’s Disease?

Problem: Unspoken Truth

- Reluctance to talk about death and dying even if its obvious. Opportunities for preparation are lost.
- Majority of EOL care is still hospital-focused.
  - 27% of U.S. Medicare’s annual budget ($88 billion) goes to care for patients in their final year of life. 13% are admitted to hospice.
  - 58% of UK deaths occurred in an NHS hospital, 18% at home, 17% in residential care homes, and about 4% in hospices. (UK’s Dept. of Health’s EOL Care Strategy, 2008)
- World trend preference is to die at home, but rarely achieved.
  - Trend towards hospital admission at EOL
  - Majority PD pts die within 1-2 weeks of admission (Snell, 2009; McLennon et al., 2010)
- End-staged palliative care needs are unmet in PD patients/families last months of life.
  (Gay, Carter et al., 2008; Giles & Miyasaki, 2009;)

Common Practice of Palliative Care

What is Palliative Care?

- The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for pts and families regardless of the stage of the disease or the need for other therapies.
- It aims to guide/assist patients and families to make decisions and work toward goals in whatever time they have remaining.
  - Not the same as EOL or hospice care, not prognosis dependent.
  - Is not (necessarily) about dying, but living with the burden of disease.
  - Improves the way a patient/family feels and copes which improves QOL.
- Comprehensive palliative care services often require the expertise of a multidisciplinary team. (Giles & Miyasaki, 2009; Clinical Practice Guidelines for Quality Palliative Care, Second Edition, 2009)

Palliative Care Goal

Palliative Care is: Palliative Care is NOT:

- Excellent, evidence-based medical treatment to promote relief of suffering
- Vigorous care of pain and symptoms throughout illness
- Care that patients want at the same time as efforts to cure or prolong life
- Not “giving up” on a patient
- Not in place of curative or life-prolonging care
- Not the same as hospice
**Advanced Directives = Advanced Decision-Making**

- Health care directives and Health care proxies
  - Documents made in advance to clarify EOL wishes
    - Peg intubation? Antibiotics? Where do you want to spend final days?
    - Designate who can speak for you if and when unable.
  - Provides pre-emptive “crises” decision making
  - Makes sense to all, but most can’t handle discussion until needed.
    - Goy, Carter 2007: 15% of Caregivers were unable to state loved one’s goals of care, 48% of end-staged pts unable to make decisions.
    - Giles & Miyasaki 2009: “Wanting and not wanting to know”
    - Watson, H. et al. unpublished 2010: “Moderate-staged CG asked “when” good time to address EOL goals.” “Not now, sometime later, and providers should bring topic up.”

**Five Wishes**

- [www.agingwithdignity.org/five-wishes.php](http://www.agingwithdignity.org/five-wishes.php)
  - Who you want to make health care decisions for you when you can’t make them.
  - The kind of medical treatment you want or don’t want.
  - How comfortable you want to be.
  - How you want people to treat you.
  - What you want your loved ones to know.

**What Evidence is there on the challenges in Late-Stage PD?**

- There is a cumulative caregiver (CG) burden throughout trajectory of Parkinson’s Disease. (Carter, 1998)
  - The positive quality of the relationship, as perceived by the caregiving spouse, declines beginning at stage 2. (Carter, 1998)
  - CG burden is associated with depression, poor coping ability and sleep deprivation. (Carter, 1998; Cifu et al., 2006)
    - Many unprepared to cope with the stress of caregiving (average of 6-7 hrs/day)
    - Dissatisfied with information given about prognosis, treatment options, and overall communication from their health care providers (hospice enrollment made no difference.)

**Caregiver Burden: Relationships and Mental Strain**

- [www.agingwithdignity.org/five-wishes.php](http://www.agingwithdignity.org/five-wishes.php)
  - Bi-lingual *Five Wishes* is available in the following languages:
    - Albanian Arabic Bengali Chinese
    - Croatian French German
    - Gujarati Haitian Creole Hebrew Hindi Hmong Ilocano
    - Italian Japanese Korean Polish
    - Portuguese Russian Somali Spanish
    - Tagalog Urdu Vietnamese

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Caregiver Burden:
Coping Skills
• CG causes permanent atmosphere of stress with insecurities, tension and major frustration.
  – Most spouses do not allow themselves respite and become overwhelmed with ambivalent feelings.
  – They experience a kind of “hostility towards their spouse” and guilt and helplessness. (Dressen et al., 2007; Martinez-Martin et al., 2007)
• Negatively impacts burden and QOL for both pt and CG. (Martinez-Martin et al., 2007)

Caregiver Burden:
Physical Strain and Lack of Skills
• As disease advances, care requirements triple by H & Y stage 4/5. (Carter, 1998)
  – Caregiving is physically hard, especially for older carers, toileting, ambulating most difficult.
  – 1/3rd of CG’s unprepared for the stress and physical strain encountered with CG. (Goy, Carter et al., 2007)
• Lack of coping skills to manage stress, and a lack of physician contact/support at EOL. (Goy, Carter et al., 2008)
• Inadequate CG knowledge for caring. (Docherty, 2008; Roland, 2010)

Caregiver Burden:
Loss of Social Support
• The disease also leads to an impoverishment of couples’ social network, due to reduced autonomy and fear of other people’s way of looking at them. (Martinez-Martin, 2007)
• Increased symptoms/disease burden leads to decreased social networking/support.
• As disease progresses, CG’s describe experience of frequent “little (social) deaths” and “pre-death grieving”. (Roland et al., 2010, Carter et al. 2012, in press)

Caregiver Burden:
Placement and End-Of-Life Fears
• CG’s felt unprepared to manage emergencies, make medical decisions (Goy, Carter et al., 2007) and lacked skills and information to care for terminal stage of PD. (Hudson, 2009)
  – Significant safety concerns choking, falls, confusion. (Roland, 2010)
• CG overload were reasons to place pts in institutions months before death (McLennon, Habermann et al., 2010)
• In last months of life, palliative care needs were unmet in PD pts (Giles & Miyasaki, 2009; Goy, Carter, 2008) and most not referred to palliative specialists/hospice. (Hudson, 2006)

What are the Opportunities:
What is the Evidence to Meet these Challenges?
• Stay connected with skilled multidisciplinary team. (Hudson, 2010)
  Teams help to network with other disciplines & community services to optimize care. (Giles & Miyasaki, 2009)
  • Nursing care
  • Social work services
  • Respite care
  • Physician services
  • Counselling: dietary & pastoral
  • Home care
  • Pain control
  • Symptom management
  • Medical appliances
  • Physical & occupational therapy
  • Speech and language pathology services
• Nursing led Support Groups - cost effective way to provide counseling/support. (Edward & Sheets, 2002)
Educational Courses Help

• Studies have shown the usefulness of organizing a formal educational support program for spouses/CG’s. (Dressen et al., 2007; Martinez-Martin, 2007; A’Campo et al., 2010; Lorig 2008; Hendrix et al. 2011)

• Best published educational program described a series of separate classes for patients and their caregivers. (A’Campo et al., 2010; Lorig 2008; Hendrix 2011)
  – Classes focused on medical treatment, teaching needed physical care and coping skills to improve their quality of life.

• The aim was to help patients and caregivers adapt to changes in their life caused by Parkinson’s disease.

• Most valued sessions by the caregivers (n = 73) were ‘Stress management’ and ‘Caregivers’ challenge’.

Late Stage PD Care for the Caregiver

Skills building classes which provide hands on and concrete information that help with day to day cares are helpful and useful:
Topics may include (among others):
– Learning to Lift
– Creating a Safe Home Environment
– Changes in Thinking and Memory
– Changes in Swallowing
– Building a Support Network
Caregiver support groups offer education and support to help manage feelings of being helpless and lonely

Initiate the Conversation with Patients & Caregivers - Palliative Approach

• Health care decision-making difficult if caregiver is unclear about patient’s wishes/preferences. (POLST)
  – Less pressure to discuss issue before the need arises and while patient can (still) participate
  – More time to explore ‘ideal’ or goals of EOL care

• Effective communication skills are requisite in palliative care.
  – Involves collaborating with a team of individuals who care for patients and their families.
  – Whoever has the competence or the relationship initiates the conversation. (RN, MD, Social Worker, or Clergy)

Strategies for Introducing Topic:

“When the Conversation” (Back, Arnold, Quill, 2003)

• When providers and patients discuss life-threatening illness & only focus on hope, opportunities are lost to:
  – Address fears and concerns
  – Explore life closure needs

• Recommend “dual approach” of planning care that is responsive to a range of outcomes (”BIG PICTURE” discussions.)

• Family members or pts may be too anxious to bring topic up in front of their loved ones, but have fears and concerns.
  – One study of moderate staged caregiver gps asked “When” EOL care should be addressed?
  – Response was “Sometime, but not now.”
  – And “providers should be the one to initiate conversation.” (Watson et al., unpublished data 2010)

Useful Language for Hospice Discussions

(“I’m not ready for Hospice!” Casarett & Quill, 2007)

• Identify key decision makers: “Who in the family should be here to help you make decisions?”
• Assess understanding of prognosis: What have your doctors told you about your condition?
• Define pt’s goals for care: What do you hope for in the next months/year?
• Reframe goals: I wish we could guarantee that we could.......but...we can’t....
• Identify needs for care: It can be very difficult to care for a family member at home, have you thought about what kinds of help you might need?

Go Wish Cards

www.gowish.org/index.php

• Coda Alliance makes a “Go Wish Game”, helpful to bring up what’s important to a person and their family at their end of life.
• The card game starts the conversation with reviewing the deck and rank order topics: very important, somewhat important, or unimportant.
• It helps patients and family discuss difficult topics about EOL goals.
• Through this “game” patients and families learn how to best comfort their loved ones and learn what are patient’s priorities.
Other Recommendations

- **Telemedicine programs**
  Studies on chronic disease home mgt = Facilitates self-care, provides teaching on relevant topics, decreases hospital readmissions, increased provider contact via nurse-mediated monitoring. (DeToledo, et al., 2006; Helms, et al., 2007; Koizumi, et al., 2003; Selbert, et al., 2008)

- **Caregiver Clinics** (Orna Moore - Israel)
  – Acknowledge CG distress at every visit
  “How are you managing?” “What do you need?”

- **PD Palliative Care Clinics** (J. Miyasaki’s - Toronto; SFVA PADRECC)
  – Multidisciplinary team approach

Key Points - Take Home Messages

- **People die from Parkinson’s Disease, though prognostication is difficult.**
  - Promote honest discussion of prognosis and clarify goals of care.

- **Most Parkinson’s Disease patients and caregivers have unmet palliative care needs.**
  - Help to initiate advanced decision making goals.
  - Early initiation of the palliative care team approach.

- **Educational programs, support groups and continued Nursing contact can improve the patient’s and caregiver’s transition to EOL.**

Late Stage PD

- **Team Coordination**
  - Nurses are often the health professional most closely involved in the day-to-day care of late-stage Parkinson’s patients and may have the most contact with caregivers
  - Nurses may be the point person who coordinates the PD Interdisciplinary Team
  - Patients and family depend on the nurse to triage calls and respond promptly with answers to questions
  - Caregivers depend on nurses to advise and assist in the coordination of referrals

Questions?