



Challenges of Parkinson Disease and the Caregiver Perspective
Rozena Davis, MS, APRN-CNP, FNP

Center for Parkinson Disease and other Movement Disorders
The Ohio State University Wexner Medical Center

Caregiving

- Who is a caregiver?
- Some one who provides care or emotional and physical support, for someone who needs it.
- The need can be due to a medical condition or other disability.
- A care partner

Caregiving statistics

From the National Alliance for Caregiving and AARP report “Caregiving in the US 2020” we find that

- More than 1 in 5 adults are unpaid family caregivers
- The 2020 update reveals an increase in the number of family caregivers in the United States of 9.5 million from 2015 to 2020. (from 43.5 million to 53 million)
- 39% of caregivers are men, 61% women
- 24% of caregivers report caring for more than one person (up from 18% in 2015)

“There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver.”

— Rosalyn Carter

What are some of the challenges people with Parkinson disease may face?

Mobility deficits: falls, freezing of gait, postural instability

Cognitive decline, mental health issues: Mild cognitive impairment, dementia, depression, anxiety, apathy

Medical treatments: Transportation to appointments, organization of medications

Speech and Swallowing difficulties: Changes to quality of speech, communication problems, choking

Bowel and Bladder issues: constipation, overactive bladder, urgency, frequency, incontinence

Physical Risk Factors for Falls

- Advanced age
- History of previous falls
- Weakness or pain
- Balance issues
- Problems with walking
- Poor vision
- Orthostatic hypotension
- Bowel and bladder dysfunction
- Chronic medical conditions
- Fear of falling
- Cognitive decline
- Taking many medications

Internationally, falls and fractures are the reason for about 75% of the total hospitalizations in patients with Parkinson disease. (Appeadu M, Gupta V., 2021)

Cognitive & mental health

Mild cognitive impairment, dementia

Mild cognitive impairment affects approximately 20–50% of people with PD, and longitudinal studies reveal dementia in up to 80% of PD. (Goldman, et al 2018)

Depression, anxiety, apathy

Speech and swallowing

- Softer voice, changes in speech
 - can cause people with Parkinson disease to avoid conversation and withdraw socially
 - Can create issues when conversing with caregivers as they may not be able to hear to understand what is being said.
- Problems with swallowing
 - can make people want to avoid eating in public due to embarrassment, again lessening social interactions
 - Can make it harder for the person to get adequate nutrition due to fear of choking
 - Can lead to aspiration and pneumonia

Medical treatment

Managing multiple medical appointments as well as medications

- Transportation to appointments
- Coordination of appointments
- organization of medications

Other physical problems

Bowel and bladder issues

- Constipation, bowel incontinence
- overactive bladder, urgency, frequency, urinary incontinence
- Poor hydration due to fear of needing to urinate more

How can caregivers help?

Mobility deficits

- Encourage therapy and physical activities, help with falls prevention

Cognitive decline & communication problems

- Help with memory strategies, encourage activities

Managing multiple medical appointments as well as medications

- Transportation to appointments, organization of medications

Swallowing difficulties, bowel and bladder issues

- Encourage safe swallowing strategies, be supportive of measures to help constipation and urinary problems

What do caregivers want to know?

- What can we expect as the disease progresses?
- How can the I help with medical appointments?
 - transportation, moral support, historian, note taker, ask questions, pay attention to information about starting new medications or therapies (are there side effects that I should call to report?).
 - Know what medications patient is taking and how they are reacting to the medication
 - Have a release of information on file. Consider mychart proxy.

Who do we call?

- **When do we call to report symptoms? Who do we call?**
 - Is this a medical emergency? Seek emergent help
 - Is this a slowly progressive worsening of symptoms? Is it related to PD symptoms? If so, contact your neurology office. If not related to PD symptoms, contact primary care or other relevant specialty office.
- **What is normal and what is not?**
 - Is this a sudden change?
 - Was there some other recent change you can correlate this with? New medication started? Possible infection? Exacerbation of other health issue?

Possible medication side effects

Compulsive behaviors	Insomnia	Excessive daytime sleepiness
Shopping, gambling	Dizziness	sleep attacks
Sexual urges	Leg discoloration/rash	discoloration of urine
eating	Blurry vision	diarrhea
confusion	hallucinations	constipation
nausea	Dry mouth	Urinary retention

Burden of care

“...caregiver burden is a broad, multidimensional construct that reflects the unique experience of caregiving for individuals from different backgrounds with differing levels of resilience and resources facing distinctive illness-specific symptoms.”(LoMonaco, et al 2021)

“Greater difficulties with mobility, emotional well-being, and nonmotor symptoms were unique predictors of reduced caregiver QOL.” (Henry, et al 2020)

“Researchers and clinicians should collaborate to incorporate the assessment and tailoring of training and supportive interventions to provide the necessary support for caregivers across the U.S.” (Mollica, et al 2020)



Thank you for your interest and time to watch this presentation

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