

Planning for the Future

The program will begin shortly.

A few notes before we start:

- All attendees will be muted and off camera.
- Share a comment by using the **chat** box.
- Submit a question by using the **Q&A** feature.

- **Next webinar for Veterans: December 14th**
 - Veterans & Parkinson's: Planning for the Future
 - Register: [Parkinson.org/VetsPlanning](https://www.parkinson.org/VetsPlanning)



Better Lives. Together.



**Veteran's & Parkinson's:
Planning for the Future**

Better Lives. Together.

Our Mission



The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson's community.



We have everything you need to live better with Parkinson's.

Our Goals



To help our global community live better with Parkinson's, we pursue **three goals**:



Improve **care** for everyone with Parkinson's



Advance **research** toward a cure



Empower and educate our global **community**



Weekly programming that includes:

- Mindfulness Mondays
- Wellness Wednesdays
- Fitness Fridays
- Expert Briefings
- EP Salud en Casa

Better Lives. Together.

www.Parkinson.org/Veterans



FREQUENTLY ASKED QUESTIONS:
For Veterans With Parkinson's Disease and Their Care Partners

Managing Parkinson's

- Diet & Nutrition
- Emotional Well-Being
- Advice for the Newly Diagnosed
- Activities of Daily Living
- Dental Health
- Sexual Health
- Living Alone
- Veterans and Parkinson's Disease
 - Medical Care and Treatment
 - Agent Orange & Other Toxic Exposures
 - Veterans Benefits
 - Caring for a Veteran with Parkinson's
- Talking to Children About Parkinson's

In Your Area

Resources & Support

PD Library

Newly Diagnosed: Building a Better Life with Parkinson's

Legal / Financial / Insurance

My PD Story

Parkinson's Today Blog

For Caregivers

Parkinson's Foundation Online Courses

Veterans and Parkinson's Disease

[View](#) [Outline](#) [Revisions](#)



Over 110,000 veterans with Parkinson's disease (PD) receive care through the U.S. Department of Veterans Affairs (VA).

Most people with Parkinson's develop symptoms at 50 years of age or older. One million people in the U.S. live with Parkinson's today. This number will rise as our population ages, as will the number of veterans diagnosed with the disease. While living with Parkinson's can be challenging, an early diagnosis and beginning **treatment** can help people live well with Parkinson's.

Better Lives. Together.

Thank you



DON and LORRAINE FREEBERG FOUNDATION

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6

Upcoming Veterans Webinars



June 29

Resources
for Veterans
with
Parkinson's

August 31

Veterans &
Parkinson's:
Managing Anxiety,
Depression, &
Apathy

October 26

Veterans &
Parkinson's:
Planning for the
Future

December 14

Environmental
Exposures in
Veterans with
Parkinson's

Learn more and register to attend at:

www.Parkinson.org/Veterans

Better Lives. Together.

Veteran's & Parkinson's: Planning for the Future

Better Lives. Together.

Emily Hall, LCSW



- Southeast PADRECC Senior Social Worker
- Central Virginia VA System
- Richmond, VA

VETERANS AND PARKINSON'S: PLANNING FOR THE FUTURE

Emily Hall, LCSW

Richmond PADRECC

Central Virginia VA Healthcare System

October 26, 2023

Program Description

Advancing PD may bring the need for more planning to best address your care needs. In this session experts will discuss helpful tips on preparing for your future and making decisions regarding advanced care and treatments as a veteran living with Parkinson's.



Schedule

4:00PM EST	Parkinson's Foundation Introduction (Crista Ellis)
4:05PM EST	Part 1 – Veterans & Parkinson's: Planning for the Future (Emily Hall) <ul style="list-style-type: none">• Have a better understanding of how treatment plans may change with disease progression• Learn how to discuss advancing symptoms with the care team to best address needs/concerns
4:35PM EST	Q&A Session #1 (Moderated by Crista Ellis)
4:50PM EST	Part 2 – Veterans & Parkinson's: Planning for the Future (Emily Hall) <ul style="list-style-type: none">• Discuss various care options available and when to seek outside assistance for care needs• Understand the role of Palliative Care in long-term planning
5:15PM EST	Q&A Session #2 (Moderated by Crista Ellis)
5:30PM EST	Closing Remarks & Conclusion of Webinar (Crista Ellis)

DISCLOSURES

I have no disclosures!

Parkinson's Disease – Brief Overview

- 2nd Most Common Neurological Disease (after Alzheimer's)
- Affects Dopamine-producing neurons in a specific area of the brain (loss of dopamine)
- Age of onset
 - Common after 60 yrs.; risk increases with age
 - Mean onset – 60-70 yrs
 - Young onset (20-50 yrs.) 10-15%
- Men are more likely than women to develop PD
- 1 million people in the US have PD
 - 90K new cases each year
 - US Veterans – est. 110,000 living with PD
- Est. 10 million people worldwide
- Seems to result from a series of interactions from both environmental & genetic factors
 - <https://www.parkinson.org/understanding-parkinsons/causes/environmental-factors>
 - <https://www.parkinson.org/understanding-parkinsons/causes/genetics>



Motor Symptoms

Rest Tremor (worsens with stress, fatigue or anxiety)

Stiffness/Rigidity & Impairment of Fine Motor Movements

Slowness & Bradykinesia

Impaired Balance & Postural Reflexes Increasing Risk of Falls

Stooped Posture with Shuffling and/or Festinating Gait (start hesitation, freezing of gait and slow turning)

Non-Motor Symptoms

Depression

Anxiety

Apathy

Confusion, Memory Impairment, & Dementia

Psychosis

Urinary Frequency & Urgency

Constipation

Pain

Fatigue

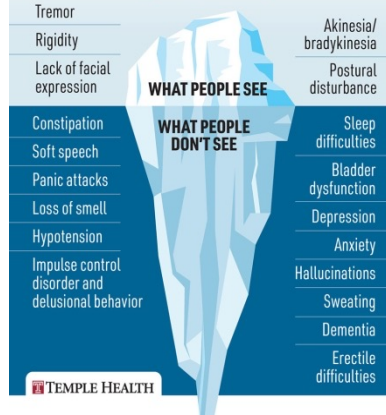
Swallowing Issues

Softening of Voice

Sialorrhea (excessive drooling)

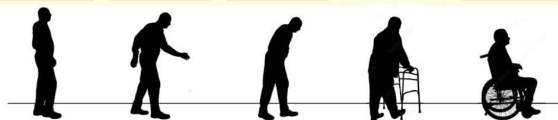
Increased Sweating & Impaired Thermoregulation

THE PARKINSON'S ICEBERG



HOEHN AND YAHR SCALE

STAGE 1	STAGE 2	STAGE 3	STAGE 4	STAGE 5
Only one side of the body is affected	Symptoms affect both sides of the body	Balance and stability become affected	Symptoms increase, however are able to stand and walk	Assistance is required for everyday activities



HOEHN & YAHR – 5 STAGES OF PD



Stage #1

Mild symptoms

Generally do not interfere with daily activities

Tremor & other movement symptoms occur on one side of the body only

Changes in posture, walking, and facial expressions



Stage #2

Symptoms start to worsen

Tremor, Rigidity, and Other Movement Symptoms Affect **both** sides of the body or the midline (such as the neck and the trunk)

Mobility Issues, Poor Posture may be observed

Person is able to live alone, but daily tasks may be more difficult and require increased time

Stage #3

Loss of Balance

Falls are more common

Motor symptoms continue to worsen

Functionally, PWP may be more restricted in their daily activities now but are still capable of having an independent life

Disability is Mild-Moderate Stage



Stage #4

Symptoms are fully developed & disabling

Still able to walk & stand without assistance, but may need cane/walker/rollator for safety

Needs significant help with activities of daily living

Unable to live alone safely



Stage #5

Most Advanced, Debilitating Stage

Stiffness in the legs make it nearly impossible to stand or walk

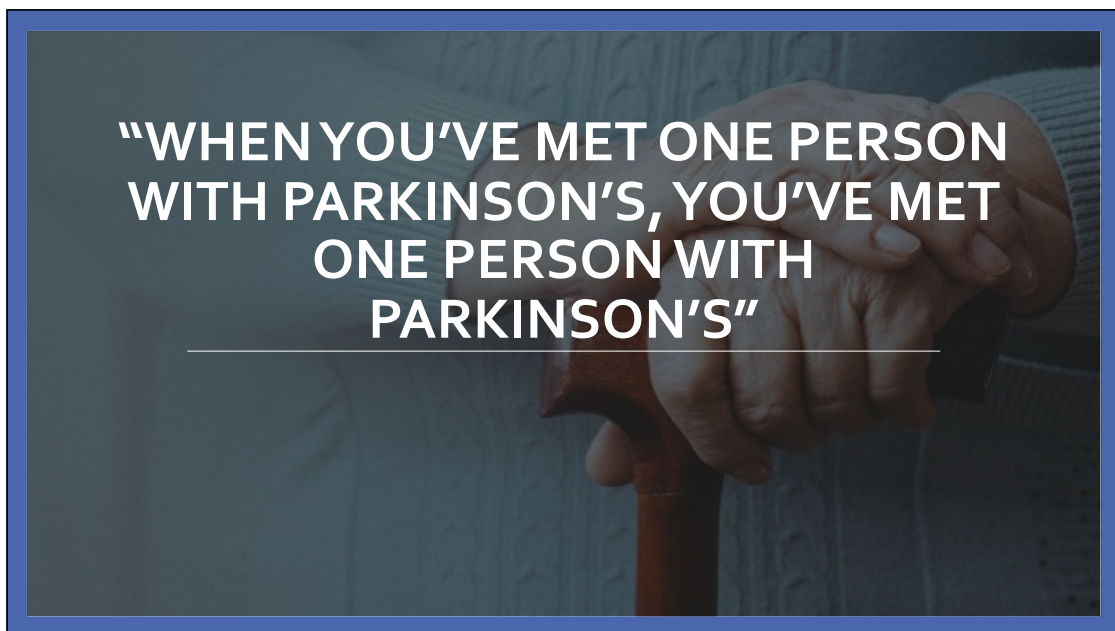
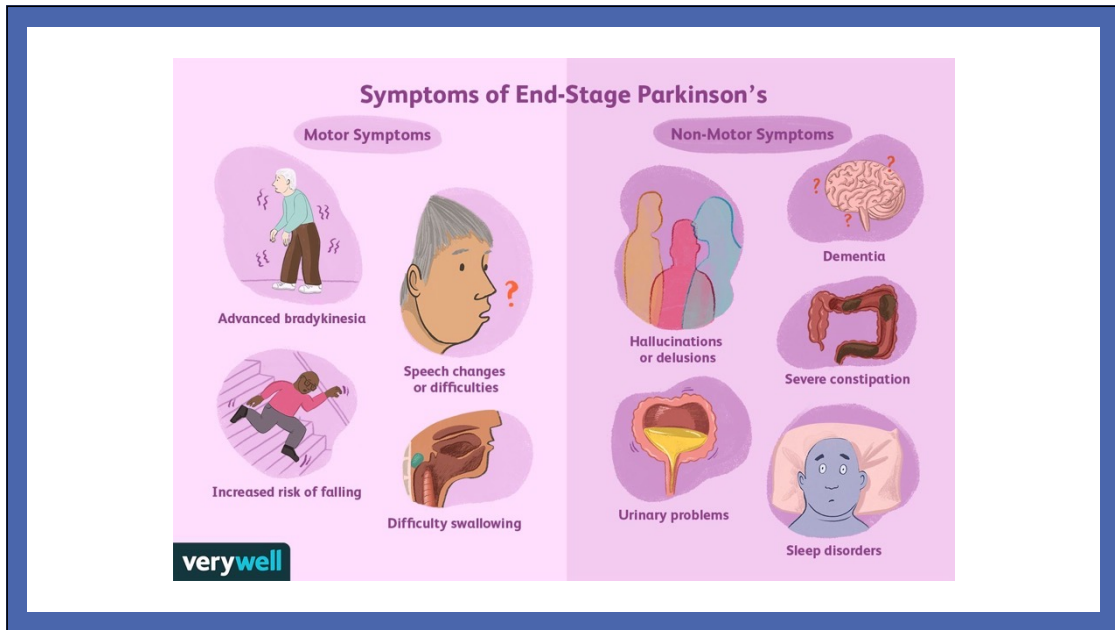
May be bedbound, wheelchair bound, or require a hoist lift for transfers

Require 24/7 care for all activities



What are Advance PD Symptoms?

- Limited Mobility, likely due to stiffness in legs
- Medications lose ability to work effectively – Symptoms progress
- Typically ~10 years after living with PD, but can occur much later
- May require a Rolling Walker, Wheelchair, or other Assistive Device for Mobility
- May have higher risk of falling
- May need assistance with daily activities (eating, bathing, dressing, grooming, toileting)
- May have a higher risk of Dementia or other Cognitive Problems
- Experiencing hallucinations or delusions
- May become bedbound (hospital bed, lift transfers)
- May need continuous nursing care





KEEPING THE BALANCE

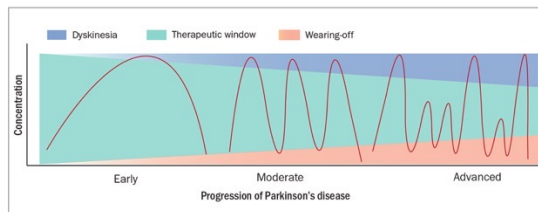


Figure 3. Therapeutic window of levodopa therapy in patients with Parkinson's disease. The therapeutic window narrows as disease progresses. Excessive levodopa concentrations may lead to levodopa-induced dyskinesias, whereas insufficient levodopa concentrations may lead to 'wearing-off phenomena'. Responses to levodopa are of shorter duration and become unpredictable and inconsistent.

Complexities Increasing...

- As your PD progresses, changes to your meds (dosages, timing, frequency, combination) may change – requiring more complexity to treat your symptoms
- Side effects from PD medications that didn't exist early on may develop over time



HIGH PILL BURDEN



How Do I Discuss These With My Provider?

- Bring notes to your appointments
- Ask questions. Don't be afraid to ask questions if you don't fully understand what your provider is saying
- Voice concerns
- Voice your goals, preferences, what matters most, and most bothersome symptoms
- Keep regular appointments with your provider
- Care Partner/Trusted Other Involvement for Input/Observations
- Contact your clinic if any significant changes occur:
 - Secure Messaging, Phone Calls, Appointments, Telehealth
- Utilize your Social Worker, Nurse, or Educator



What Does Quality of Life Mean to Me?

- Being able to travel
- Being able to go to exercise classes
- Being able to feel well-rested after sleep
- Being pain-free
- Being able to walk with my rollator
- Being able to spend time with my grandchildren
- Being able to dress myself in the morning
- Staying at home as long as possible



SO...
**WHAT ARE
MY OTHER
OPTIONS?**



Management of Psychosis

Psychosis: severe confusion, disordered thinking

Hallucinations: seeing things that aren't there

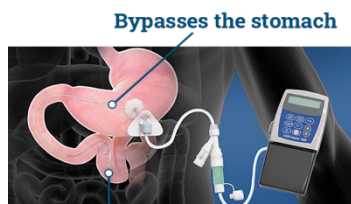
Delusions: believing things that aren't true

1st - Reduce/Adjust PD Medications (balancing act)

2nd – Prescribe an Antipsychotic (still balancing act)

It is important to report ANY of these to your team, even if they are NOT bothersome!

Duopa Therapy (Carbidopa/Levodopa)



Bypasses the stomach

Delivered in the intestine, where levodopa is mostly absorbed

<https://parkinsonsnewstoday.com/duodopa/>

Duopa
for Parkinson's disease

Duopa (carbidopa and levodopa) is an approved continuous intestinal gel infusion to reduce off episodes in people with Parkinson's disease.

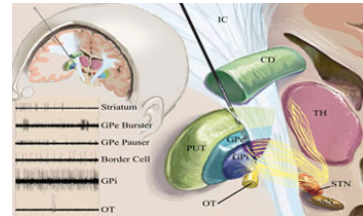
Administration: Administered over 16 hours via a tube surgically inserted into the small intestine.	Indications: Approved to treat motor fluctuations in people with advanced Parkinson's disease.
Side effects: May include device-related complications, nausea, depression, swelling in the hands and feet, hypertension, and more.	Contraindications: Not recommended for patients on nonselective monoamine oxidase inhibitors or with a major psychotic disorder.



<https://www.duopa.com/duopa-your-day>

Deep-Brain Stimulation (DBS) Surgery

- Surgical procedure used to treat a variety of disabling neurological symptoms associated with movement disorders such as Dystonia, Essential Tremor, and Parkinson's Disease.
 - Does NOT involve destructive of brain tissue
 - Effects are reversible and adjustable
- DBS administers a well-controlled electrical current into the target area(s) to help restore normal activity in the brain and increase controlled movement
 - Electrical impulses are generated from an implanted battery and then pass through the lead and into the target area.
 - Entire system is implanted under the skin.
- Typically will have series of evaluations prior to surgery
 - Ex: H&P, PAS, PT, SLP, MRI, CT scan, Neuropsych Testing



<https://www.parkinson.org/living-with-parkinsons/treatment/surgical-treatment-options/deep-brain-stimulation>

25

Q & A #1

4:35-4:50PM EST