Parkinson's Disease: A Journey of Strength & Hope

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VIRGINIA CHAPTER

Strength in optimism. Hope in progress.



PARKINSON'S 101

What is Parkinson's Disease?

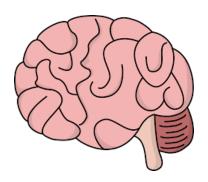
Neurodegeneration of dopaminergic neurons.
 Loss of Dopamine, key neurotransmitter in movement and balance.

Common Symptoms: Motor and Non-motor

- Shakiness/tremors, shuffle-walking, pillrolling, rigidity & slowness
- Depression, fatigue, constipation, sleep disorders, dementia
- Impacts daily functioning and quality of life









NON-MOTOR SYMPTOMS OF PARKINSON'S DISEASE

Note: Each person with PD has a different set of non-motor symptoms. Some have none.

Non-motor symptoms

NEUROPSYCHIATRIC

- Depression
- Anxiety
- Sleep disorders
- Cognitive impairment and dementia
- Apathy

SENSORY

- Visual disturbances
- Loss of smell
- Pain

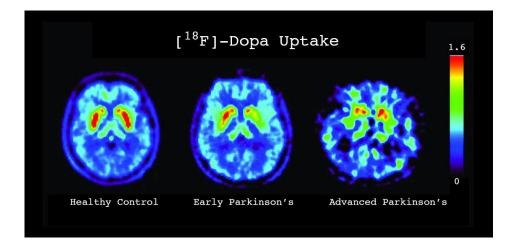
AUTONOMIC

- Orthostatic hypotension
- Constipation
- Urinary dysfunction
- Sexual dysfunction



HOW IS PARKINSON'S DISEASE **DIAGNOSED?**

- Not an actual test to diagnose PD
- Thorough case history
- Neurological exam
- CT,MRI, and blood test to rule out other disorders
 - Patient presents 2 of 4 cardinal symptoms (tremor, rigidity, slow movement, balance problems
- Positive reaction to medication
- DAT Scan
- A movement disorder specialist is a neurologist with additional training in Parkinson's disease and other movement disorders. This type of doctor typically has extensive knowledge of Parkinson's therapies and ongoing research.





PARKINSON'S 101

- How is Parkinson's different from Alzheimer's?
 - Dementia is an overlapping symptom between diagnoses
 - Parkinson's is the second-most common neurodegenerative disease after Alzheimer's disease.
 - Manifests in the brain similarly but presents with different symptoms and level of functioning.
 - Alzheimer's: language, memory to at or before diagnosis
 - PD induced dementia: hallucinations, delusions, paranoia







PARKINSON'S 101

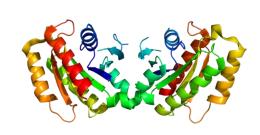
What Causes Parkinson's?

- Largely unknown: Leading theories but starts via degeneration of dopamine producing neurons (asymptomatic):
- Environmental Herbicides & pesticides, Agent Orange & head injuries
- **Genetic** Mutation in LRRK2 gene and/or mutations in proteins that make dopamine (rare). More likely if mutation gene and environmental factor
- Age highest risk factor Older you are higher risk for developing. Average onset 60 -65
- PD incidence estimates are higher in men compared to women at all ages.

Is Parkinson's a problem for Virginians?

- United States nearly 1 million people living with; 90,000 new diagnoses/year
- Yes! Southern and more rural states have higher rates. Under diagnosed









- Medication: People with PD have diminished levels of dopamine and many drugs either replenish dopamine or mimic the action.
- Medications may relieve or decrease motor/non-motor symptoms
- There are no medications available that protect neurons from degenerating
- Rehab Therapy
- Physical Therapy- for improving balance, walking and strength
- Speech Therapy- for speech and swallowing difficulties
 - LSVT LOUD is an effective speech treatment for people with Parkinson's disease (PD) and other neurological conditions.
- Occupational Therapy- for improving fine motor skills and independent living



MANAGING PD





AMERICAN PARKINSON DISEASE ASSOCIATION
Strength in optimism. Hope in progress.

- Exercise: Encourage residents to participate in daily activity
- Slows progression of PD symptoms
- The Center for Disease Control recommendations: 150
 minutes of moderate intensity or 75 minutes of vigorous
 intensity exercise/week for all older adults
- Being sedentary and de-conditioned can increase stiffness, stooped posture and poor endurance
- Popular methods of exercise with PD:
 - Boxing
 - Tai Chi
 - Zumba
 - Dance
- Nutrition: The MIND (variation of Mediterranean Diet) diet has been associated with a lower risk of Alzheimer's disease
- Lower risk and slower progression of Parkinson's Disease in the elderly.
- The Mediterranean diet has shown both heart and brain health benefits

DIVERSITY IN PARKINSON'S DISEASE

- One <u>study</u>, published in the *Journal of Cross-Cultural Gerontology*, found Black, Hispanic, and Asian adults were more likely than their white counterparts to regard Parkinson's symptoms as normal signs of aging.
- A study published in the journal Parkinsonism & Related Disorders found that Black patients were four years older than white patients at the time of their Parkinson's diagnosis.
- With Parkinson's Disease you can still have a great quality of life



YOU AND YOUR HEALTHCARE TEAM

Diagnosis and
Medical Management:
Movement disorders
specialist

Rehabilitation services: PT, OT, speech therapy

Psycho-social support: psychiatrist, social worker, psychologist



General health:
Primary care
physician, subspecialists, nursing,
nutritionist

Exercise and wellness:
Tai chi, yoga, boxing, dance, etc.

How to Support Your Loved One During the Holiday Season?



How to Support Your Loved One During the Holiday Season?



- Adjust Your Expectations
- Holidays often come with <u>high expectations</u> that lead to disappointment and stress.
- Letting go of the illusion of a "perfect" holiday and <u>flexibility</u> can help you keep expectations realistic and focus on what's most important about the holidays.
- Focus on gratitude!
- Make gift shopping simple with gift cards or consider a "Secret Santa", white elephant-style gift exchange where you purchase a gift for just one person.
- Maintain routine! Exercise and movement can help you feel better.
 There are many online classes you can join from home, or get outside for a walk



How to Support Your Loved One During the Holiday Season?



- Take time for yourself. Whether it's to squeeze in your own doctor appointments, a phone call to an old friend, to get some exercise, or just have some quiet alone time to read a book, it is important to find a little time for YOU.
- Incorporate self care-self-care is anything that recharges your batteries mentally, emotionally, or physically

For care partners

- If you have plans that include going to dinner or to a performance with your person with PD, call ahead to ask for seats on the aisle or near the front of the restaurant.
- When going out to a social event, set a code word.
- The code word could mean they need to leave, need a break to rest, etc. Ask them their expectations and boundaries in advance.



HOW TO SUPPORT YOUR LOVED ONE DURING THE HOLIDAY SEASON?

If traveling

- Try to bring some of your own snacks. Airports and planes have highly processed, overly salted foods that are high in saturated fats.
- Double check medications to make sure you have more than enough for the trip – PACK EXTRA!
- Keep an updated list of medications with dosages, schedule, allergies, insurance card, doctor's contact information, etc.
- Use a phone alarm or alarm watch to remind you to take your medications
- Allow extra time for transitions, your morning routine, eating, etc. to allow for you to feel comfortable and not rushed throughout your holiday events.
- **Find support.** You don't have to go it alone. APDA can help you find a support group near you, or you can join



APDA VIRGINIA – WHAT WE DO



Support





Research

-- APDA Virginia

Resources



Education



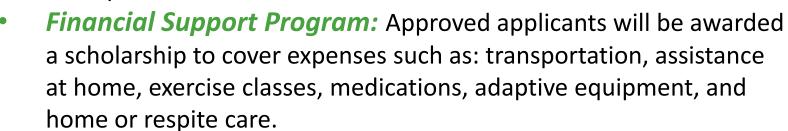




Strength in optimism. Hope in progress.

SUPPORT - PROGRAMS

- **Support Groups:** Develop support groups, assist support group facilitators and support more than 30 groups.
- PRESS Program: An 8-week programs designed for individuals
 diagnosed with PD in the last 5 years, covers post-diagnosis topics
 related to chronic illness mgmt to help feel empowered, in control,
 and optimistic.



Connecting Through Art: This program encourages PD
participants and their caregivers to socialize as they participate and
share in a painting art activity.







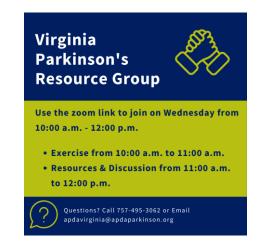


EDUCATION

- Virtual Education: In addition to publication hard copies, we offer online education through our website, Facebook posts, and coming soon regular YouTube and webinar series events
- Wellness Webinar Series: Online education presentation series featuring experts in the field for patients, family members, and caregivers – highlight state & national resources
- Conference In-person
- In Service Presentations: Parkinson's education to community & providers



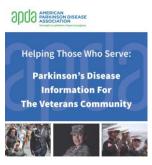


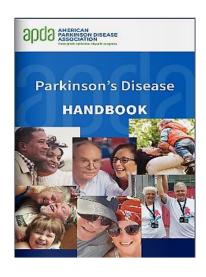




RESOURCES

- Literature: More than 40 Complimentary literature with information on nutrition, medications, and more, available in English or Spanish. Publications available to order free to the public.
- Referrals: Answering questions and offering a sympathetic ear. Referrals to healthcare providers, support groups, exercise classes, and other community resources.
 Build community through resource distribution and connection.
 - Build online community resource directory – one stop PD shop





	o Be Avoided C ution in Parkin	
This medication list is not intended to nedication.	be complete and additional brand n	ames may be found for each
liscuss your particular situation with aking without first seeking advice fro topped suddenly.	y need to take one of these medication your physician and do not stop any norm your physician. Most medications we medications at home, one of these	nedication that you are currently should be tapered off and not
n the hospital to advise which med Medications to be avoided of Zelapar ^a), Rasaglline (Azilec	r used with caution in combin	
Medication Type	Medication Name	Trade Name*
Narcotics/Analgesics	. ,	
Narcotics/Analgesics	Medication Name	
Narcotics/Analgesics	Medication Name Meperidine	Trade Name*
Narcotics/Analgesics (see note below)	Medication Name Meperidine Tramadol	Trade Name*
	Medication Name Meperidine Tramadol Methadone	Trade Name* Ultram Dolophine
Narcotics,(Analgesics (see note below) Antidepressants (see note below)	Medication Name Meperidine Tramadol Methadone St. John's Wort	Trade Name* Ultram Dolophine Several Brands
Narcotica/Analgesics (see note below) Antidepressants (see note below) Muscle Relaxants Cough Suppressants	Medication Name Mapperkline Tramadol Methadone St. John's Wort Cyclobenzaprine	Trade Name* Ultram Dossphine Several Brands Flexarii Robitsusin products, other brands- found as an ingredient in various cough and cold medications Sudfeld products, other brands-
Narrotics(Nas)penics (use note below) Antidepressants (use note below) Muscle Relaxants Cough Suppressants Decongretants/Stimulants Medications that inhibit Monoamine	Medication Name Medication Name Medication Name Transdol Methodone St. John's Wort Cyclobenzaprise Destroesborphan Passdoephedrise Phenylopinise	Trade Name* Ultram Dolophine Several Brands Flaveril Robbitusin products, other brands-found as an ingredient in various cough and cold medications. Suddled products, other brands-found on the cough and cold medications.
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OPTIMISM WALK 2024

- Optimism Walk: Annual walk event showcasing resources with a health fair, celebrate community and come together to support those who have PD, promote PD education and bring awareness to PD.
 Funding received goes to continues chapter services supporting clients.
- Sponsorship & Vendor Information available!







HOW CAN APDA SUPPORT YOU?

AMERICAN PARKINSON DISEASE ASSOCIATION
Strength in optimism. Hope in progress.

- Mission: Every day, we provide the support, education, and research that will help everyone impacted by Parkinson's disease live life to the fullest.
- Our goal is to work with community partners to share awareness of Parkinson's Disease
- If you have <u>ANY</u> questions call us!
 - One stop shop for PD questions
 - On Going Virtual/ In-Person Educational Programs
 - Finding a Support Group
 - Weekly newsletter
- Can send you Parkinson's Disease material- free of cost!
- Attend Community Events
- Connect Parkinson's Disease family/friends to APDA!



QUESTIONS? THANK YOU!

Connect with us!

Website:

https://www.apdaparkinson.org/community/virginia/

Email: apdavirginia@apdaparkinson.org

Facebook: facebook.com/apdava



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<u>Parkinson's Disease in African Americans: A Review of the Current Literature - PMC (nih.gov)</u>

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4134410/

Bringing more diversity to Parkinson's disease research | UCLA Health

