

Introduction to Parkinson's For the Newly Diagnosed

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A little about me..





Parkinson's 101



1. Receiving a Diagnosis
2. What is Parkinson's and who gets it?
3. How is PD diagnosed?
4. Parkinsonism vs Parkinson's Disease
5. Motor and Non-Motor Symptoms
6. How is Parkinson's Treated?
7. Importance of therapy and exercise

Receiving a Diagnosis of Parkinsons Disease

Hearing the words "You have Parkinson's" is life changing.

It can be the end of a long and frustrating journey of unexplained symptoms or can come as a complete shock.



Fig 2.

<https://www.prd-journal.com/article/S1353-8020%2823%2901005-2/fulltext>

The good news..

- There are countless ways to take action and make the best of your journey.
- Davis Phinney's "Every Victory Counts" book uses the analogy of thinking of your life as a designer would think of a project.
 - Your design plan is yours to make. Your disease does not define you. Build your way forward by reframing the problem and taking action consistently.
 - A good first step is to understand your disease.

What is Parkinson's and who gets it?



Cut section of the midbrain where a portion of the substantia nigra is visible



What is Parkinson's Disease

- A neuro-degenerative brain disorder with
 - Progressive loss of dopamine producing brain cells
 - Lewy Bodies (accumulation of abnormal alpha-synuclein) found in the substantia nigra neurons which leads to cell death
- Dopamine = is a neurotransmitter that helps regulate the body's movements.
 - Less dopamine = less fluidity to your movements.
- Rate of progression and symptoms will be different from one person to another.

Everyone has a different journey with Parkinson's Disease.

Who gets Parkinson's Disease?

PD is the 2nd most common neurodegenerative disease in the US.

Approx **1 million** people in the US are living with PD

Approx **90,000** people in the US are diagnosed each year

10 million people living with PD worldwide

Men are **1.5x more** likely than women.

Risk increases significantly with age however it is **NOT** just a disease for the elderly as 4% of patients are < 50 (YOPD)

What causes Parkinson's Disease?

Likely a combination of genetics,
environment and lifestyle.

Genetics

- **15%** of PD cases directly due to genetic cause.
- Abnormal genes have been identified but most are “**susceptibility genes**”.
- Typically, younger onset.
- PD GENERation

Environment

- **Toxins:** Pesticides and herbicides (paraquat)
- **Chemicals:** Solvents and PCBs
- Agent Orange
- Rural areas – well water

What causes Parkinson's Disease?

Lifestyle

- Higher Risk: ETOH, well-water, exposure to anesthesia, manganese, farming chemicals, head trauma.
- Protective: coffee/green tea, diet rich in vitamins, flavonoids (plant-based), EXERCISE

How do you diagnose Parkinson's Disease

Parkinson's is still a CLINICAL diagnosis.

History, medications, medical conditions, family history,
lifestyle factors.



Four Cardinal Symptoms of Parkinson's:

- 1) Slowness (Bradykinesia) **
- 2) Stiffness (Rigidity)
- 3) Resting Tremor
- 4) Postural Instability

Other clues include small handwriting, facial masking
and decreased arm swing.

Bradykinesia = "Slowed Movements"

The cardinal feature of PD.

- Spontaneous movements
- Facial expressions (animation/blinking)
- Repetitive hand movements (brushing teeth, buttoning, writing, whisking)
- Walking
- Speaking/Thinking
- Swallowing (Drooling)
- Micrographia

Commonly misinterpreted by patient as WEAKNESS, incoordination or clumsiness.

Tremor in PD

- Classically starts on one hand or leg
- Most pronounced at rest
- Difficult to treat and particularly bothersome especially when involving the dominant hand or affecting ability to sleep



NOT every case of PD will have tremor. Some PD patients have NO tremor at all.

Rigidity (Stiffness) in PD

- Again – typically involving one side of the body.
- Noticed with reaching across the body, standing up from seated or turning over in bed.
- This rigidity affects gait dynamics as well.
 - Stoop
 - Reduce arm swing
 - Shuffled steps
 - Freezing and festination
 - Postural instability
 - +/- Tremor



More Complex Motor Symptoms

- **Dystonia** – involuntary, excess muscle tone that results in posturing or spasms.

- Toe curling, foot inversion, reduced arm swing



- **Dyskinesia** – involuntary, "dance-like" movement that impacts most body parts. A side effect of levodopa.

- Higher risk in females.

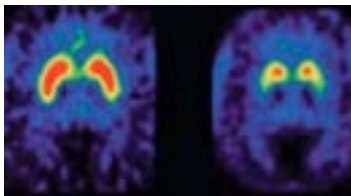
- NOT a reason to delay starting Sinemet.

What is the role of additional testing?

There are no definitive blood/CSF tests or brain scans that are confirmatory.

Tests such as blood work, MRI brain and DAT scans, ect can be used to support PD or rule out conditions that mimic PD but are NOT necessary for diagnosis.

DaT Scan – dopamine transporter study using a radioactive tracer. Most helpful in distinguishing PD from ET or DIP.



Syn-One Bx – identifies phosphorylated alpha-synuclein in cutaneous nerve fibers. Does not distinguish between synucleinopathies. Also tests for small fiber neuropathy and amyloidosis.

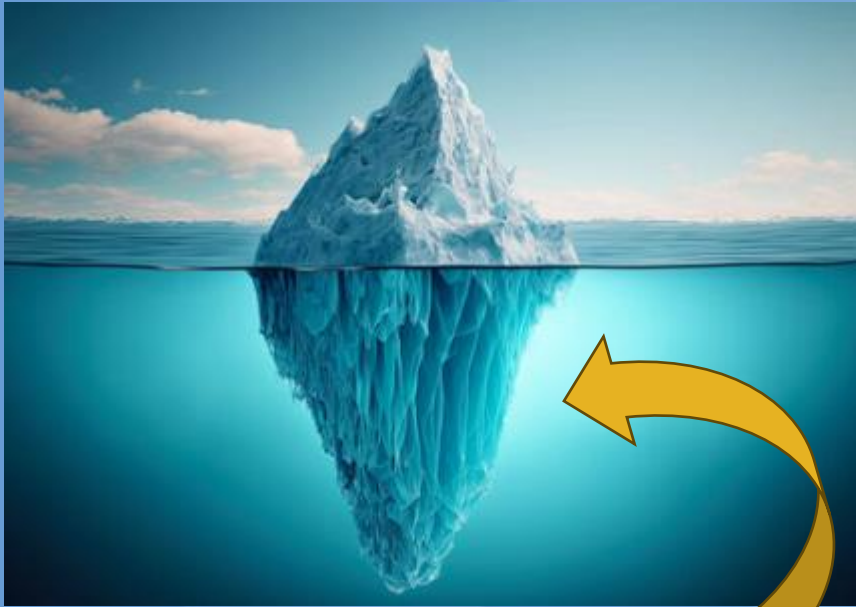
Alpha-Syn Seed Amplification Assay in CSF- used to detect prior to symptom onset.

What is Parkinsonism?



Parkinsonism = Umbrella Term

- Parkinsonism includes iPD, vascular parkinsonism, drug-induced parkinsonism, and the atypical parkinsonisms.
- Can be considered a clinical syndrome in which a person has some but not all of the Parkinson's motor symptoms.
- I personally utilize “parkinsonism” to label patients in their first 5-6 years until I have a better idea of their disease progression over time.



In a 2009 Study on PD and Non-Motor symptoms 98% of patients had non-motor symptoms with the average individual having 8 different non-motor symptoms.

These increase with disease duration and severity.

Non-Motor Symptoms

Non-Motor Symptoms of PD

- Anosmia **
- Constipation **
- Urinary dysfunction
- RBD/Active Dreams **
- RLS
- Mood changes *
- Hallucinations
- Cognitive changes
- Orthostasis
- Fatigue
- Sexual dysfunction
- Drooling
- Shortness of breath
- Sweating
- Pain
- Skin changes

**** = typically, a VERY early, pre-motor symptom.**

How is Parkinson's Treated

Treatment includes medication, lifestyle modifications and possibly surgery but..

First – Build your care team.

You are not alone.

- Movement Disorders Specialist
- Primary Care Provider
- PT/OT/ST
- Psychology/Psychiatry
- Nursing
- Family/Support
- Multi-disciplinary clinics are becoming more popular.



Parkinson's Disease Treatment Options

- **Disease-modifying Therapy**
 - Therapy that slows or reverts disease progression
 - **EXERCISE** is the **ONLY** disease modifying therapy in Parkinson's.
- **Symptomatic Treatment**
 - Improves the quality of life and treats symptoms but does not change underlying pathology.
 - Typically involves increasing the production of, decreasing the breakdown of or replacing dopamine. Surgical options as well.

Carbidopa/Levodopa (Sinemet)

- Gold standard treatment for > 50 years
- Absorbed in the small intestine, travels through the blood to the blood brain barrier.
- Your body converts it to dopamine by a natural enzyme. Carbidopa component prevents conversion peripherally.
- Most common side effects: nausea, low blood pressure, hallucinations and dyskinesias

Carbidopa/Levodopa (Sinemet)

- Protein Interaction: Not always an issue for everyone. If so can try dosing 30 minutes before or an hour after food. Discuss with your MD.
- There is no need to “reserve” levodopa because it loses its effectiveness. This is a myth. What is happening is disease progression, not lack of effectiveness.

As most of you know – there are other medication options outside of Levodopa however they all work on the dopamine system.



Exercise = Medicine

Exercise >>> Sinemet

I would argue that I medicate patients in order to maintain exercise. This is how important it is.

- Protective effect on the brain (slowing degeneration) and is also a great coping mechanism for living with PD.
- Can improve balance, mobility, depression, constipation and cognitive dysfunction.

Managing Non-Motor Symptoms Conservatively

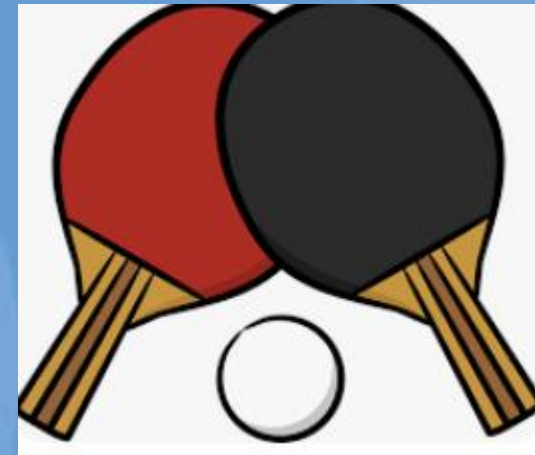
- Depression/Anxiety/Apathy - CBT, **exercise**, support
- Cognitive changes – **exercise**, sleep
- Dysautonomia – **exercise**, hydration
- Difficulties with Sleep – **exercise**, CBT
- Fatigue – **exercise**, hydration
- Constipation – **exercise**, hydration, plant-based diet

What is the best exercise?

- There is no one size fits all option. **Goal = 150 min/week of aerobic exercise.**
- Has to be something you enjoy.
- Mix it up (aerobics, stretching, strengthening)
- Use music. Use your voice.
- Try games – great for neuroplasticity and can involve your loved ones.

Types of Exercise Helpful in PD

- Running/walking (depending on fall risk)
- Biking (recumbent is a great option)
- Tai chi, yoga, Pilates, dance
- Weight training
- Swimming (great for NOH)



Importance of Neuro-Specific Therapy



LSVT BIG and **LSVT LOUD** focus on recalibrating your movements and voice projection to help feel more comfortable using stronger voices and big movements.

Locate an LSVT Certified Clinician


LSVT Certified Clinicians have attended LSVT Training and Certification courses and have passed a certification exam.

When is therapy necessary?

It is never too early.

Prehabilitation is just as important as rehabilitation.






Resources for Exercise at Home



Power for Parkinsons
@PowerforParkinsons · 28.2K subscribers · 1.4K videos
We are a non-profit organization offering FREE Parkinson's fitness classes in Austin, TX...more
powerforparkinsons.org/donate and 4 more links

Subscribe Join

Manage Your PD with Symptom-Focused Workouts

 <p>Parkinson's Rigidity Workout 3 videos</p> <p>Combat Stiffness & Rigidity Power for Parkinsons - Playlist View full playlist</p>	 <p>30 Minute PD Workout Minimize Shuffling 5 videos</p> <p>Overcome Shuffling & Improve Gait Power for Parkinsons - Playlist View full playlist</p>	 <p>6 HELPFUL PARKINSONS HAND EYE 5 videos</p> <p>Calm Tremors & Improve Hand Dexterity Power for Parkinsons - Playlist View full playlist</p>	 <p>Full Body Parkinson's Anxiety Stretch & Relief Breath 5 videos</p> <p>Ease Your Anxiety Power for Parkinsons - Playlist View full playlist</p>	 <p>20 Minutes Posture Exercises 5 videos</p> <p>Improve Posture Power for Parkinsons - Playlist View full playlist</p>
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PWR! is a 501(c)(3) helping people with Parkinson disease improve quality of life through research-driven exercise.



Virtual gym experience – similar to BIG

Includes YOPD program, Spanish speaking and symptom specific options.

Community Based Group Exercise Options for PD

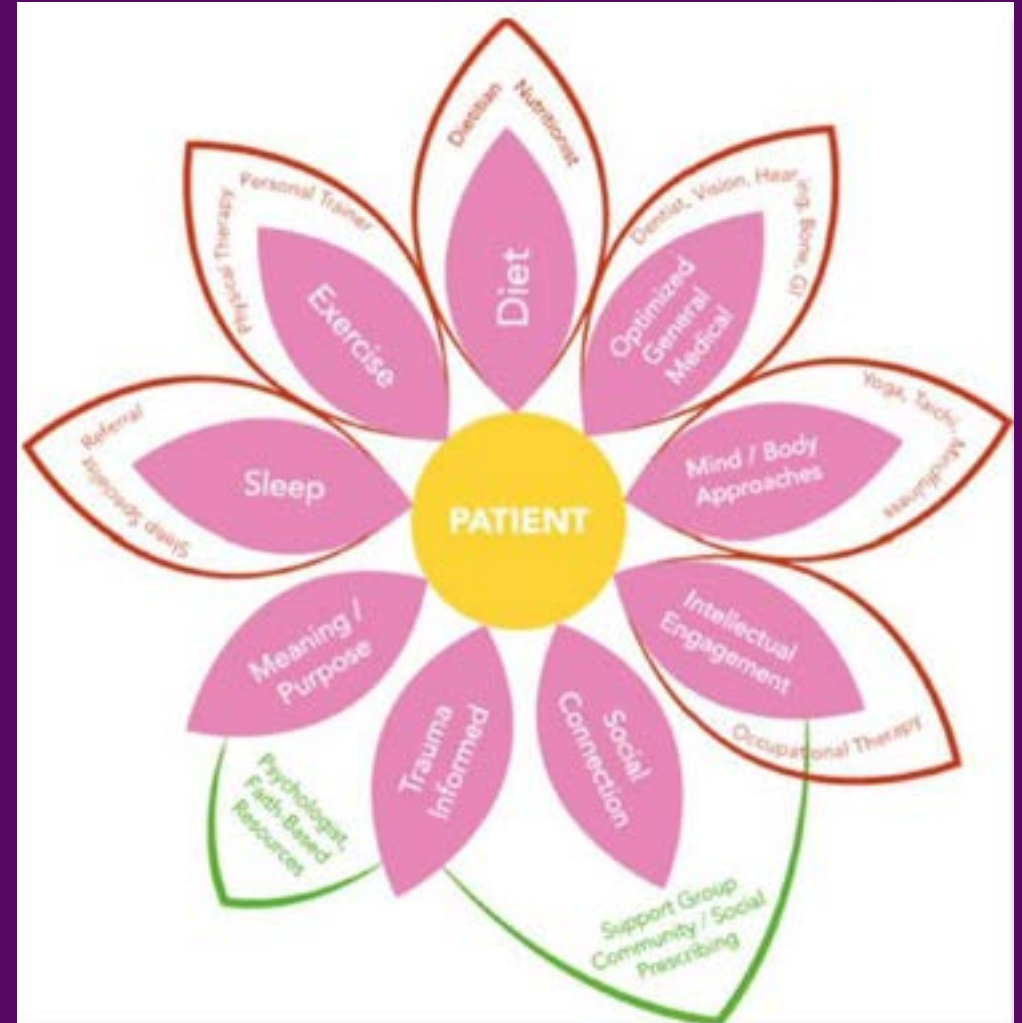


Exercising with others holds you accountable.

**A diagnosis of Parkinson's
Disease is life altering,
NOT life ending.**

Take Home Points:

- Exercise is medicine – take it every day.
- Prioritize your mental health.
- Know your team. Ask for help when needed.
- Keep living your life.





Questions?

References

- Subramanian I, Pushparatnam K, McDaniels B, Mathur S, Post B, Schrag A. Delivering the diagnosis of Parkinson's disease—setting the stage with hope and compassion. *Parkinsonism Relat Disord*. 2024 Jan;118:105926. doi: 10.1016/j.parkreldis.2023.105926. Epub 2023 Dec 21. PMID: 38129230.

Track 2 Breakout Sessions

1:40pm – 2:10pm

Ballroom

Advanced Technology: Wear It, Watch It, Work It
Brian Copeland, MD, University Medical Center-New Orleans
(New Orleans, LA)

Calcasieu

YOPD Meet and Greet
Anna Grill, Young Onset Parkinson's Network (Vienna, VA) and
Robert Cochrane, Yes, and...Exercise! (Walnut Creek, CA)

Barataria

So You Want to Be a Support Group Leader
Ben (B.J.) Bement, PMD Alliance (Baton Rouge, LA)