Staying on Your Feet At Home and in the Community

With Parkinson's Disease

Meet Maria and Sidney

Maria Allen, PT is a physical therapist with over 40 years of experience. She has been providing Parkinson-specialized therapy for the last 12 years in outpatient, home health, and wellness settings. She also teaches physical and occupational therapy PWR!Moves certification workshops monthly for Parkinson Wellness Recovery.

Sidney Collin is a biomedical engineer, the founder of De Oro Devices and the developer of the NexStride device. She has a passion for helping people with Parkinson's disease and other mobility issues live better lives. She is on the board of the Capital Area Parkinson's Society and runs a PD support group in Austin, TX.

Introduction

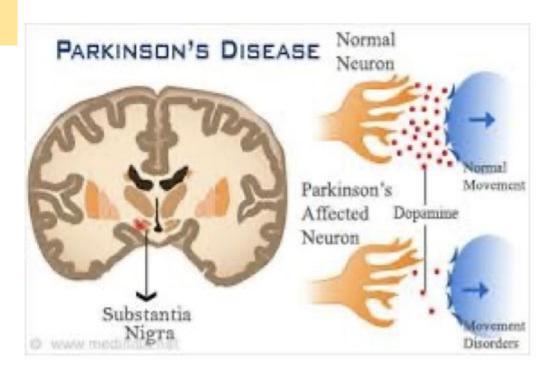
The research is strong in both human and animal studies pointing to the benefits of exercise and activity for reducing the motor symptoms of Parkinson's Disease and helping to maintain a good quality of life over time. But sometimes it is quite a challenge to stay on your feet and remain active when you have Parkinson's Disease. Let's talk about some of the challenges including:

- 1. Motor symptoms stiffness/rigidity, bradykinesia/movement problems, incoordination, imbalance, postural changes, festenation and freezing of gait, dystonia
- 2. Non-motor symptoms autonomic dysfunction, pain, executive function problems including initiation, motivation, dual-task, motor and cognitive set switching
- Emotional and psychological symptoms apathy, anxiety, depression, fear of falling and fear avoidance behavior.
- 4. Barriers stigma, access to PD specialized therapy and group exercise, transportation, financial burden.

Let's talk about ways to manage some of these challenges and creatively problem-solve how to "Stay on Your Feet" for the best quality of life!

What is Parkinson's Disease?

- Progressive neurodegenerative disease involving the Basal Ganglia
- Loss of dopamine-producing nerve cells
- Dopamine helps regulate the body's movement
- 50-60% cell death at diagnosis, cell death proceeds diagnosis by 5-6 years



How does Parkinson Disease affect your Brain?

Alphasynuclein - protein found throughout our bodies

Dopamine - neurotransmitter

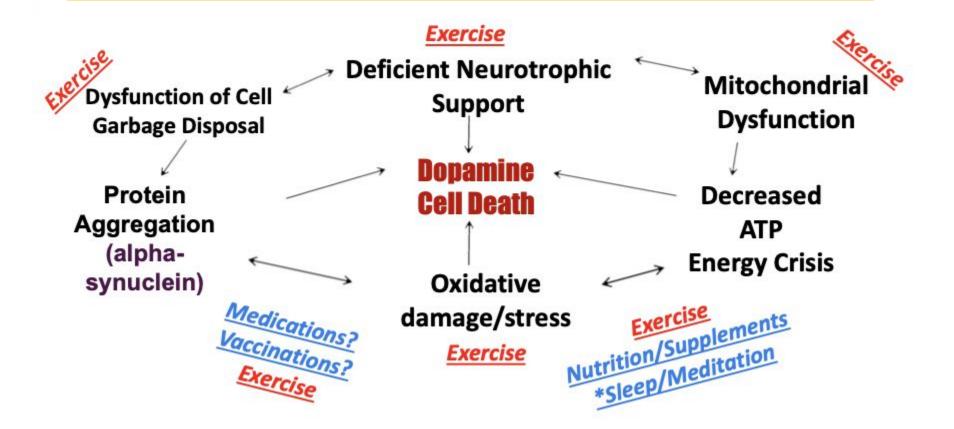
Basal Ganglia Pathways -

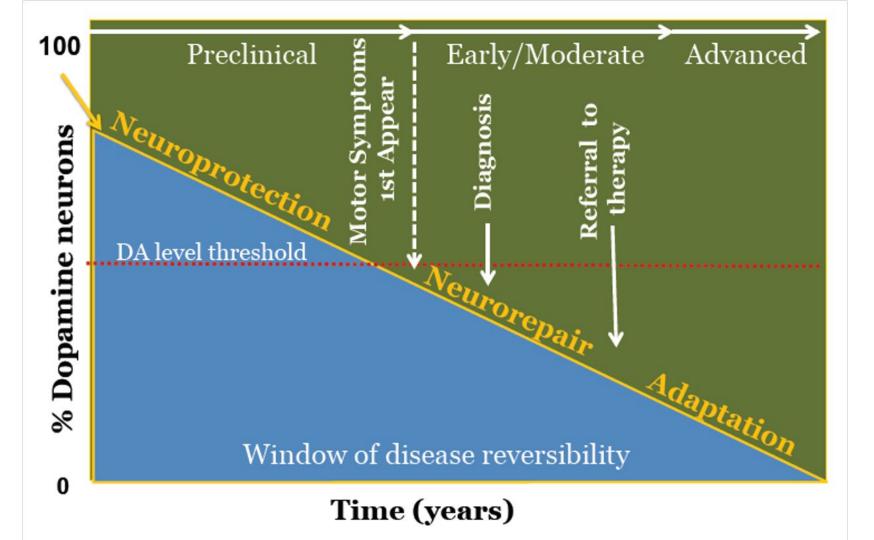
Sensory-Motor - goal based and automatic/habitual movement

Cognitive - executive function

Emotional - motivation and reward

Many Mechanisms Contribute to Cell Death





General Exercise benefits

Optimizes the dopaminergic system

Prevents cardiovascular complications

Reduces risk of osteoporosis

Improves cognition, memory

Reduces depression, reduces fatigue

Improves sleep

Improves drug efficiency

Reduces constipation

Motor and Sensory Symptoms in PD

- Bradykinesia
 - Speed and/or amplitude dysregulation across motor systems
 - Slow, small movements and postural responses
 - Habitual, every day movements are most impaired
- Rigidity
 - Co-contraction flexors>extensors
 - Loss of spinal mobility/axial mobility
 - Pain
- Tremor
- Impaired sensory integration
 - Inconsistent, inefficient, unreliable movement sequencing
- Incoordination
- Postural instability (later in disease process)

How do motor symptoms affect walking and activity?

Flexed posture affects balance, increases fall risk

Slower reactions affect ability to catch your balance, increases fall risk

Freezing of gait increases falls, adds stigma, reduces ability to be out in the community, perform ADL's safely

Rigidity causes pain, dystonia causes foot and ankle problems

Loss of vigorous steps, decrease in overall activity level, decrease in overall fitness level

Reduced participation in the things you enjoy, reduced quality of life

How do you manage motor symptoms?

Exercise

Therapy

Modify the environment

Use compensatory strategies - add external cueing, assistive devices

Optimize your medication

Reduce stress, improve sleep, improve your social connections

Research on Exercise/Activity

Aerobics and Skilled Training

Intensity beyond self-selected

Treadmill Studies

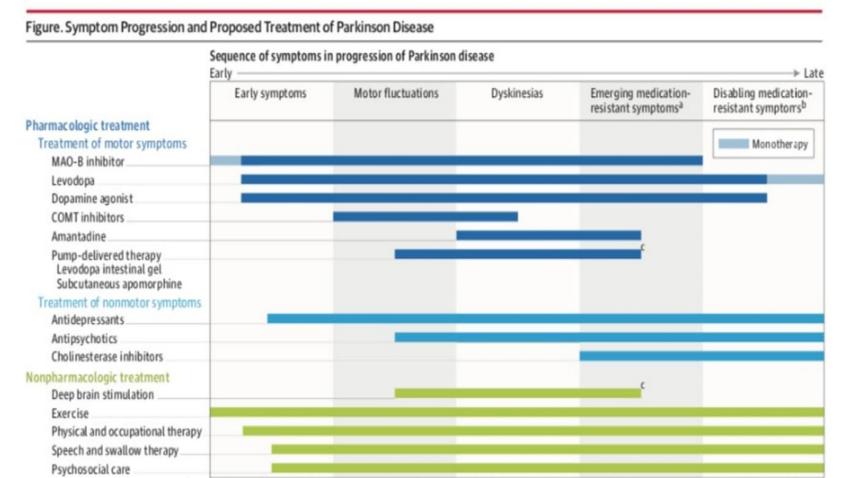
Cycling Studies

Park in Shape

Strengthening

High Intensity Interval Training

Dance

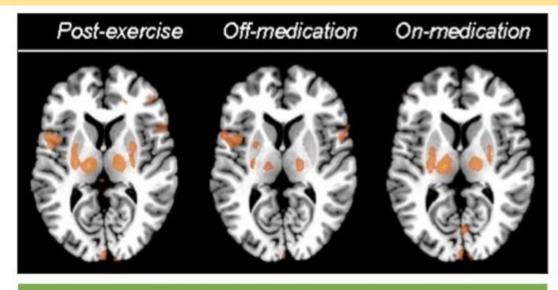


Dr. Michael Okun, JAMA online Management of Parkinson Disease in 2017 Personalized Approaches for PatientSpecific Needs

PD Brains on Exercise!

Subcortical fMRI activation during UE force tracking task

Acute 3-h post exercise N=9 averaged



Aerobics + Skill = helps brain do more with less -----forced "rate" pedaling on a tandem----

Cortical and motor responses to acute forced exercise in Parkinson's disease.

Jay L. Alberts, Michael Phllips, Mark J. Lowe, Anneke Frankemolle, Anil Thota, Erik B. Beall, Mary Feldman, Anwar Ahmed, Angela L. Ridgel. Parkinsonism Rel Disord 2016;24:56-62

Early is best, but It is never too late to start exercising!

Change in QUALITY OF LIFE ON PDQ-39 Score From Baseline

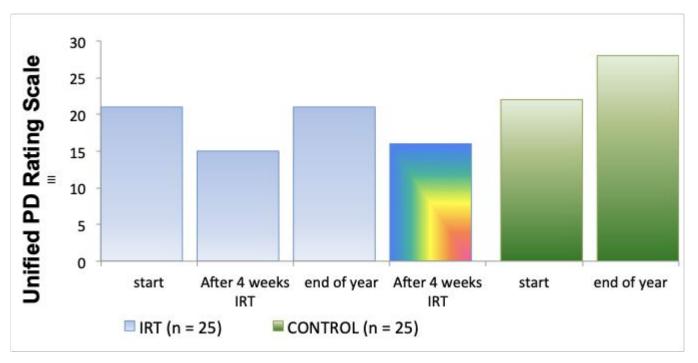
"Do you exercise at least 2.5 hours/week?"

Reported Exercise: Baseline/1-yr/2-yr	1 – YEAR PDQ-39	2 – YEAR PDQ-39
YES / YES / YES	0	1.8
NO / YES / YES	0.7	1.3
NO / NO / YES	2.4	3.5
NO/NO/NO	3.4	6.2

- Database of 3000 patients who started exercising at different times
- No matter when patients started exercise, they could benefit!
- Indirect evidence of neuroprotection

www.parkinson.org

Research on Therapy bouts- PT/OT/SP



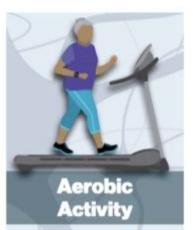
Disease Progression in Parkinsonian Patients: A Randomized Controlled Trial With 1-Year Follow-up. Giuseppe Frazzitta, MD et al. Neurorehabi Neural Repair, Aug 15, 2011

Parkinson's Exercise Recommendations

Parkinson's is a progressive disease of the nervous system marked by tremor, stiffness, slow movement and balance problems.

Exercise and physical activity can improve many motor and non-motor Parkinson's symptoms:

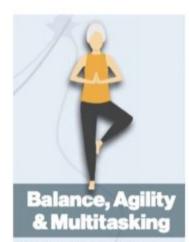




3 days/week for at least 30 mins per session of continuous or intermittent at moderate to vigorous intensity

TYPE: Continuous, rhythmic activities such as brisk walking, running, cycling, swimming, aerobics class

considerations: Safety concerns due to risks of freezing of gait, low blood pressure, blunted heart rate response. Supervision may be required.



2-3 days/week with daily integration if possible

TYPE: Multi-directional stepping, weight shifting, dynamic balance activities, large movements, multitasking such as yoga, tai chi, dance, boxing

considerations: Safety concerns with cognitive and balance problems. Hold on to something stable as needed. Supervision may be required.



2-3 non-consecutive days/ week for at least 30 mins per session of 10-15 reps for major muscle groups; resistance,

TYPE: Major muscle groups of upper/lower extremities such as using weight machines, resistance bands, light/moderate handheld weights or body weight

speed or power focus

CONSIDERATIONS: Muscle stiffness or postural instability may hinder full range of motion.



Stretching

>2-3 days/week with daily being most effective

TYPE: Sustained stretching with deep breathing or dynamic stretching before exercise

CONSIDERATIONS:

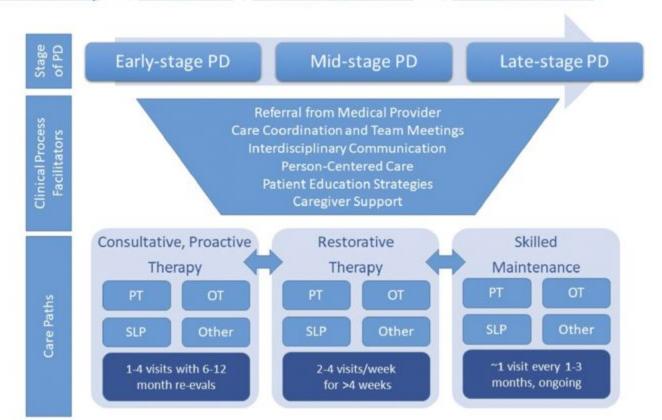
May require adaptations for flexed posture, osteoporosis and pain.

Exercise Guidelines – Parkinson's Foundation



Frameworks for Parkinson's Disease Rehabilitation Addressing When, What, and How

Miriam R Rafferty 123, Ella Nettnin 4, Jennifer G Goldman 456, Jillian MacDonald 4



Non-Motor Symptoms - Cognition

Executive dysfunction

- Attention sustained and divided
- Working memory simple tasks
- Set-switching both cognitive and motor responding to rule changes
- •Response inhibition/response selection prioritization
- Reduced self-awareness safety

Emotional and psychological symptoms

Emotional dysfunction

- •Apathy 20-40%
- Depression 40-50%
- Anxiety 69% (precede diagnosis in 30% of PWP)

Dementia

Non-Motor **Symptoms** - the rest of the iceberg

Parkinson's

what people see tremors

what people don't see



"The Non-Motor Revolution" anxiety
bladder issues
central pain
cognitive issues
constipation
depression
difficulty sleeping
fatigue
involuntary movement

loss of smell muscle spasms restlessness sciatica sexual dysfunction skin cancer slowed movement speech changes stiff muscles

How do non-motor symptoms affect walking and activity?

Executive function problems are part of Freezing of gait

Reduced self awareness and prioritization problems reduce safety and independence, lack of vigorous activity

Autonomic dysfunction - blood pressure issues limit ability to stand and walk

Urinary issues often reduce sleep for both the PwP and the Carepartner

Depression, apathy, fatigue, daytime sleepiness - less active

Anxiety, fear of falling, result in fear avoidance behavior - less active

How do emotional and psychological symptoms affect walking and activity?

Stigma

Fear of falling

Fear Avoidance Behavior

Anxiety

Lack of motivation, decreased, initiation, apathy

Reduced self-awareness, safety awareness, poor decision making

How do you manage all of these non-motor symptoms?

Wellness - Primary Care Provider

Specialists - gastroenterologist, pelvic floor specialists, dietician,

Speech Therapy - Cognitive assess and therapy

Social Worker, Psychologist, Psychiatrist

Life Coach, spiritual counselor

EXERCISE!

How do you manage psychological and emotional symptoms?

Exercise

Sleep

Healthy diet

Yoga, meditation, breathwork, mind-body focus

Counseling/therapy

Medications

Social networks, social support - Build your team!

Traditional Healthcare Professionals

Wellness Professionals

Physician/Neurologist Nurse PT OT ST Social Worker Dietician **Psychologist**

Psychiatrist

P W P **Exercise professionals Nutritionist Art/Music Therapist** Counselor/Life Coach Massage Therapist

Barriers to "staying on your feet"

Access to PD -specialized providers:

Movement Disorder Neurologists

PD-specialized Therapist - PT, OT, ST

PD-specialized Exercise professionals

Mental health, carepartner support

Cost -

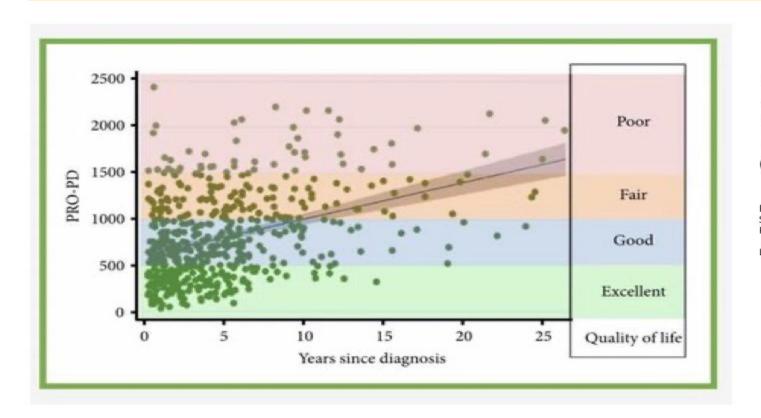
Insurance limitations, co-pays, lack of funding for wellness and fitness programs

Transportation

How do we address these barriers?

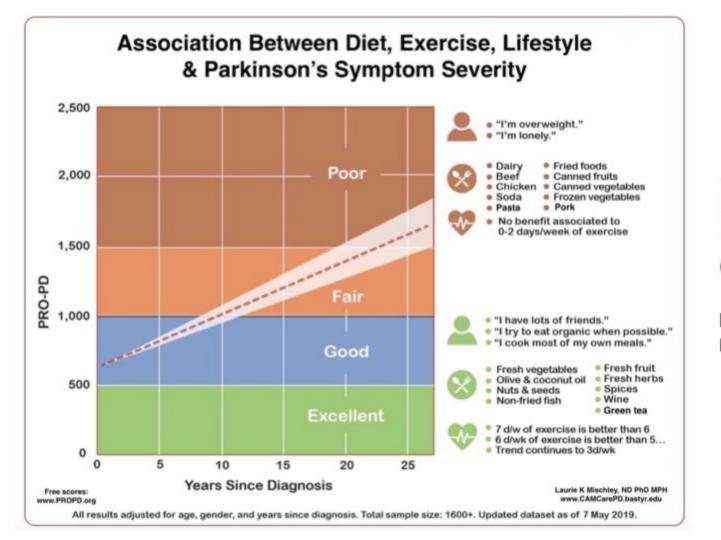
- Seek out PD specialized physicians and health care providers
- Join a local support group, or online education and support
- Take advantage of telemedicine
- Find PD specialized exercise groups
- Search for low cost or free programs, programs with grants or scholarships
- Prioritize your exercise and fitness, prevention is always less expensive
- Find a buddy, or a group to walk or exercise with

What else can you do?



Dr. Laurie Mischley CAMCarePD

Role of Diet and Nutritional Supplements in Parkinson's Disease Progression Laurie K. Mischley,1 Richard C. Lau,2 and Rachel D. Bennett1

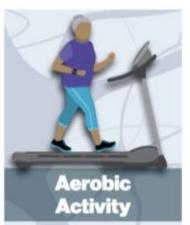


Dr. Laurie Mischley CAMCarePD

https://livinghealthywith parkinsons.com/

Summary

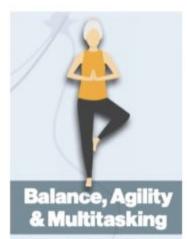




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See a physical therapist specializing in Parkinson's for full functional evaluation and recommendations.

Safety first: Exercise during on periods, when taking medication. If not safe to exercise on your own, have someone with you. It's important to **modify and progress** your exercise routine over time.

Participate in **150 minutes** of moderate-to-vigorous exercise per week.





Helpline: 800.473.4636/Parkinson.org