# Living Well with Parkinson's Disease

Adrienne M. Keener, MD WEST LA VA PADRECC & UCLA Movement Disorders

Disclosures: nothing to disclose

# Learning Objectives

1) Provide a holistic definition of wellness

- 2) Describe lifestyle interventions for people living with Parkinson's disease, including exercise, nutrition, sleep, mind/body approaches, and social connection.
- 3) Understand how lifestyle interventions can improve motor and non-motor symptoms, and in the case of exercise, slow down PD progression.

### Parkinson's Disease

- 2<sup>nd</sup> most common neurodegenerative disease next to Alzheimer disease
- Estimated to affect 1-2% of the population over
   65
- Affects men:women in a 2:1 ratio
- Mean age of onset 60
  - Young/Early onset PD <50</p>
  - Juvenile onset PD <18; rare</p>





#### What causes Parkinson's Disease?



#### FIGURE 2

Genetic, environmental, and epigenetic underpinnings of Parkinson's disease. Individual genetic background, environmental exposures (e.g., pesticides), and lifestyle-related factors (e.g., exercise, smoking, head trauma) influence PD risk. These factors may act directly or indirectly through modification of DNA methylation and/or DNA hydroxymethylation patterns, which in turn can influence the regulation of genes involved in neurodegenerative pathways. Head injury icon created by George E. Thomposon (thenounproject.com).

Purely genetic, biological or environmental Parkinson's is rare

Most Parkinson's cases are due to **the combination** of a genetic/biological predisposition and environmental exposures.

Schaffner SL, Kobor MS. *Front Genet*. 2022 Aug 19;13:971298.

## Parkinson's Disease Diagnosis

- PD is a CLINICAL diagnosis based on motor symptoms
- Bradykinesia (slowness)
- Rigidity (stiffness)
- Tremor
- At least 2 supportive criteria
  - Rest tremor of limb
  - Levodopa response
  - Levodopa-induced dyskinesias
  - Olfactory loss
  - No evidence of red flags/atypical parkinsonism



#### Other associated motor symptoms

- Hypophonia quiet or muffled voice
- Hypomimia masked facial expression
- Dysphagia trouble swallowing
- Micrographia small, cramped handwriting
- Postural changes stooping, camptocormia
- Festination shuffling gait
- Freezing of gait difficulty initiating walking



## Non-motor symptoms of PD

- Anosmia
- Sleep issues
  - REM sleep behavior disorder, fragmented sleep, altered sleep/wake cycle, daytime fatigue
- Autonomic dysfunction
  - Orthostatic hypotension, bladder dysfunction, constipation, erectile dysfunction, seborrhea, sweating, sialorrhea
- Psychiatric
  - Depression, anxiety, apathy, inability to make decisions, psychosis
- Cognitive
  - Bradyphrenia, "tip of the tongue" phenomenon, dementia (later)
- Sensory/Pain
  - Shoulder pain, paresthesias

#### Non-motor symptoms

- Average patient with PD experiences 7.8-11.9 NMS
- Prevalence of NMS increases with disease severity and duration
- Associated with increased morbidity and nursing home placement
- Multiple neurotransmitters involved beyond dopamine
- Risk factors:
  - Gender certain female, certain male
  - Older age
  - PIGD motor subtype
  - Higher daily levodopa dose

Kadastik-Eerme et al. Parkinson's Disease 2016

#### The Parkinson's Iceberg



Artist: Deborah Conn

- NMS are important not visible so you need to ask
  - MDS-UPDRS Part 1
  - PD NMSS
- NMS contribute significantly to QOL in PD
- NMS often predate motor symptoms, sometimes by decades
  - Clues to the diagnosis
  - Opportunities for early intervention?
  - Prodromal PD

#### Non-Motor Symptom assessment scale for Parkinson's Disease

Patient ID No:

Initials: \_\_\_\_\_

Age:

Symptoms assessed over the last month. Each symptom scored with respect to:

Severity: 0 = None, 1 = Mild: symptoms present but causes little distress or disturbance to patient; 2 = Moderate: some distress

or disturbance to patient; 3 = Severe: major source of distress or disturbance to patient.

Frequency: 1 = Rarely (<1/wk); 2 = Often (1/wk); 3 = Frequent (several times per week); 4 = Very Frequent (daily or all the time)

#### MDS UPDRS Score Sheet

Source of information	<ul> <li>Patient</li> <li>Caregiver</li> <li>Patient + Caregiver</li> </ul>
Cognitive impairment	
Hallucinations and psychosis	
Depressed mood	
Anxious mood	
Apathy	
Features of DDS	
Who is filling out questionnaire	<ul> <li>Patient</li> <li>Caregiver</li> <li>Patient + Caregiver</li> </ul>
Sleep problems	
Daytime sleepiness	
Pain and other sensations	
Urinary problems	
Constipation problems	
Light headedness on standing	
Fatigue	
	Source of information Source of information Cognitive impairment Hallucinations and psychosis Depressed mood Anxious mood Anxious mood Apathy Features of DDS Who is filling out questionnaire Sleep problems Daytime sleepiness Pain and other sensations Urinary problems Constipation problems Light headedness on standing Fatigue

#### 9 domains of the NMSS:

- Cardiovascular
- Sleep/fatigue
- Mood/Cognition
- Perceptual problems/hallucinations
- Attention/Memory
- Gastrointestinal tract
- Urinary
- Sexual function
- Misc. (pain, smell, sweating, weight change)



### **PD** Progression



#### Poewe et al. Nat Rev Dis Primers 2017

#### **1** The Parkinson's journey



**Figure 1.1** The stages of Parkinson's disease (PD). NMS, non-motor symptoms; REM, rapid eye movement.

Chaudhury & Fung. Fast Facts: Parkinson's Disease (4th Ed) 2016



#### Parkinson's Disease Treatment

- Non-pharmacologic treatment
  - Lifestyle Interventions
- Pharmacologic treatment is symptomatic, start when function is impaired
- No disease-modifying treatment....yet!
- Needs to be individualized. Considerations:
  - Age, Gender, Cultural Context
  - Symptoms and Severity
  - Comorbidities (pharmacologic: side effect profile)
  - Cost





(5)



Michele Tagliati, MD



# Beneficial Lifestyle Choices for People with Parkinson's Disease



#### What does it mean to be HEALTHY?

World Health Organization Constitution (1946) states:

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.



#### What is WELLNESS?

Definition: The active pursuit of activities, choices, and lifestyles that lead to a state of holistic health

- A conscious, self-directed, and evolving process
- Multidimensional and holistic, encompassing many facets of wellbeing.



# Shifting the Paradigm

#### **Wellness Continuum**



Source: Global Wellness Institute, adapted from Dr. Jack Travis

\*The continuum concept is adapted from Dr. Jack Travis' Illness-Wellness Continuum. Travis is one of the pioneers of the modern wellness movement in the late 1970s. "What's the matter with you?"

"What matters to you?"

VS

- What gives you purpose?
- What brings you meaning and joy?



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#### Wellness vs. Well-being

#### Wellness

#### Well-being & Happiness

- Multidimensional, dynamic, subjective, and personal
- Subject to historical and cultural differences and contexts
- Relates to intention, action, activities.
- Has a prominent physical dimension.
- Consumers associate it with healthy lifestyles, choices, and market offerings.
- Common usage in business/private industry context (e.g., wellness sector).
- Useful concept for measuring industry size and discussing business opportunities (e.g., wellness economy).

- Perception of a state of being.
- Has a prominent mental/emotional dimension.
- Citizens associate it with feelings of satisfaction and sense of fulfilment.
- Common usage in policy/government context (e.g., well-being budgeting).
- Useful for measuring individual/citizen welfare (e.g., Global Happiness Index) and for organizing policies and interventions.

Source: Global Wellness Institute



#### Lifestyle Interventions

- Exercise
- Nutrition
- Sleep
- Mind/body approaches
- Social connection

### Exercise is Critical to PD Management

- Neuroprotective in animal studies
- Improves motor symptoms, flexibility, core strength, gait and balance
- Improves non-motor symptoms
- No specific exercise plan yet recommended but should be tailored to interests and capabilities







# EXERCISE benefits PD at all stages



Bars indicate approximate periods of initiation and duration of each treatment except where noted. COMT indicates catechol-O-methyl transferase.

For the treatment of motor symptoms, drugs are usually added sequentially. Monoamine oxidase type B (MAO-B) inhibitor monotherapy may be started in the early symptom period followed by the addition of levodopa or a dopamine agonist. As symptoms progress, other drugs may be added and then discontinued as medication-resistant symptoms and adverse effects emerge. Levodopa may be continued through late stages of the disease as monotherapy.

Medication-resistant symptoms refer to symptoms resistant to medications for the treatment of motor symptoms.

<sup>a</sup> Gait dysfunction, soft speech (hypophonia), and memory and cognitive problems. <sup>b</sup> Dysphagia, falls, and memory and cognitive problems.

<sup>c</sup> Beyond this point, pump-delivered therapy and deep brain stimulation should not be initiated but may be continued if already prescribed.

### The Science of Exercise

**Experience-Dependent Neuroplasticity** 



Petzinger, Fisher et al, 2013

#### Most evidence for Disease-Modification



- Epidemiologic studies show that exercise reduces PD risk
- Furthermore, those with PD who exercise have slower disease progression
- Exercise has also been shown to reduce risk of cognitive decline



Animal studies have shown that exercise protects against DA cell loss, can alter dopaminergic synapses, modulate neuroinflammation, and stimulate growth factors (BDNF)

# Designing your Exercise Program

- Intensity: at least 30 mins, up to 60 mins
- Frequency: at least 2-3x/week, the more the better
- Groups / classes / exercise buddy accountability, social connection
- Vary your routine avoid boredom, challenge yourself
- Do something you love
- Get outdoors
- Components
  - Skill-based
  - Aerobic moderate intensity
  - Resistance
  - Balance / fall prevention
- Mind/body

Resistance Aerobic Skilled





### Exercise for Neuroplasticity



Goal-directed motor skill training

- Goal based practice to acquire a skill
- Learning through feedback
  - Challenge beyond
  - Motivate
  - Facilitate engagement of movement awareness
- Progressive
  - Change in environment

#### Skill-Based

- Tai Chi (Hackney & Earhart 2008)
- Tango Dancing (Hackney & Earhart 2010)
- Boxing (Combs et al., 2011)
- Amplitude Training (Farley et al., 2005)
- Treadmill Training (Fisher et al, 2008)
- Cycling (Ridgel et al., 2009; Tabak et al., 2013)













# QUESTIONS TO ASK ABOUT YOUR EXERCISE

- Am I acquiring a skill? Is it challenging, am I working hard?
- Is someone analyzing how I perform and providing feedback?
- Am I becoming aware of my movement?
- Am I continually being progressed vs. doing the same thing again and again?
- Is it fun, will it become a lifelong habit?
- Am I changing environments?
- Am I motivated to take my own control of the exercise and do it on my own?



Slide courtesy of Ali Elder, DPT re+ac

### Physical, Occupational, Speech Therapy

Best interventions to effectively target speech impairment, gait and balance impairment, freezing of gait

Helpful in jump-starting and designing home exercise regimen





LSVT LOUD has been documented to improve vocal loudness, breath support, voice quality, intonation, and speech articulation (Mahler et al., 2015). The goal is always healthy vocal loudness.

#### Nutrition

- Mediterranean diet fresh fruits and vegetables, olive oil, fish, lean protein, whole grains, nuts, seeds, legumes
- Variety/color
- Healthy fats
- Spices and herbs
- Avoid too much dairy, red meat



#### Mediterranean Diet



- Rich in antioxidants
  - Phytochemicals: curcumin, resveratrol, flavonoids
  - Berries, cruciferous vegetables
  - Spices: cinnamon, turmeric, ginger
- Healthy fats
  - Olive oil, avocados, coconut oil, eggs
- Omega-3 fatty acids
  - Fish, nuts, seeds (flax, chia), soybeans

### Nutrition: Motor & Non-motor symptoms

- Levodopa is an amino acid, competes with protein for absorption
  - take at least 30 min before or 1 hr after high-protein meals (meat, fish, eggs, dairy)
- Constipation
  - Fiber: whole grains, fresh fruit, leafy greens, seeds
  - Stay well-hydrated
  - Exercise
- Orthostatic hypotension
  - Drop in blood pressure upon standing
  - Can be part of PD, and also be a side effect of dopaminergic therapy
  - Contributes to fall risk
  - Eliminate offending meds when possible, compression stockings/abdominal binder, salt, hydration, frequent small meals, elevate head of bed at night



hydration by Mohammad Iqbal from the Noun Project



#### Nutrition

- Caffeine associated with reduced risk of PD
  - Evidence that it may also benefit motor symptoms
  - Don't drink too late in the day
  - Moderate alcohol intake associated with reduced risk of PD





# Sleep

- Detoxify and replenish
- Practice good SLEEP HYGIENE
  - Set a sleep schedule
  - Healthy sleeping environment (dark, cool, quiet, mattress?, humidifier?)
  - Avoid screen time for at least 1 hour
  - Avoid eating/drinking too close to bedtime (especially fatty/heavy foods and excessive alcohol)
  - No caffeine late in the day
  - Establish a bedtime ritual
  - Exercise!
- Morning sun, avoid daytime naps
- Wind down routine book, quite music, soothing tea, guided meditation



# Mind-Body Approaches













#### COVID-19 Pandemic & PD

Fig. 1



A concept map highlighting the key direct, indirect and drug therapy correlations between COVID-19 and PD patients

Elbeddini *et al. J Clin Mov Disord* 2020

#### THE BURDEN OF COVID-19 FOR PEOPLE WITH PARKINSON'S

The corona crisis has upset people's routines. This is challenging for everyone. And even more so for people with Parkinson's

extra

Social isolation

Stress

Physical inactivity

To counteract the downward

spiral, and set up new

home-bound routines, people

with Parkinson's can use a little help from their friends (and physicians)

Worsening symptoms Less cognitive flexibility

#### **Cognitive flexibility**

N.F

Cognitive flexibility is necessary to adapt in times of crises. It is powered by dopamine of which people with Parkinsons' have less than other people. Stress diminishes dopamine levels and a feeling of being in control even further

Researchers are curious how the corona pandemic will show in the data which are now being collected by following patients in time. Data are collected with wearable sensors and identification of biomarkers in bodily fluids. Analysis may give us hints about resilience in Parkinson's



Socialising online

Mindfullness Home based/on

Home based/online workout

This is the CC BY 4.0. visual interpretation of @Sparks4PD of the article by Bastiaan R. Bloem and R. Helmich. The Impact of the COVID-19 Pandemic on Parkinson's Disease: Hidden Sorrows and Emerging Opportunities. Journal of Parkinson's Disease 10 (2020) 351–354. https://doi.org/10.3233/JPD-202038

### Social Connection

- Even before the pandemic, the negative impact of social isolation on PD was known (Fleisher et al. Annals of Palliative Medicine)
- Exacerbated by the pandemic
- Access to care
- Impact on physical activity / exercise
- Impact on mental health
- Caregiver burden
- Resulted in worsened QOL
- Social prescribing!



Subramanian I, Farahnik J, Mischley LK. Synergy of pandemics-social isolation is associated with worsened Parkinson severity and quality of life. *NPJ Parkinsons Dis.* 2020

#### A Prescription for Wellness in Early PD: Just What the Doctor Ordered

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Bradley McDaniels, PhD<sup>1</sup>, Gregory M. Pontone, MD<sup>2,3</sup>, Adrienne M. Keener, MD<sup>4,5</sup>, and Indu Subramanian, MD<sup>4,5</sup>







The American Journal of Geriatric Psychiatry Available online 10 March 2023 In Press, Journal Pre-proof ⑦ What's this? 7



**Clinical Review Article** 

#### A Wellness Prescription for Parkinson's: Mid to Late-stage Disease

<u>Gregory M Pontone</u><sup>1</sup> ♀ ⊠, <u>Bradley McDaniels</u><sup>2</sup>, <u>Adrienne M Keener</u><sup>3 4</sup>, <u>Indu Subramanian</u><sup>3 4</sup>

#### Highlights

- What is the primary question addressed by this study? This review explores proactive, patient-centered strategies to promote psychosocial adaptation in Parkinson's disease
- What is the main finding of this study? Psychosocial adaptation strategies have improved quality of life in many chronic diseases and can be adapted for Parkinson's disease
- What is the meaning of the finding? To improve quality of life in Parkinson's disease we propose a "Wellness Prescription", a proactive strategy to adaptively cope with the progression of disease

# Holistic Care for PD



https://www.VA.gov/WholeHealth

Neurobiol. 2022

#### Multidisciplinary Care: The team is expanding



<sup>1</sup>Radder DLM, et al. Exp Rev Neurotherapies. 2019; 19(2): 145-157.

- Working collaboratively with health care providers, family, friends, ancillary support results in the best outcomes.
- Build your team
- Determine best individualized strategies for success in managing PD
- Communication is key

#### Individualized Care is essential



- No two people with PD are alike.
- Medication management is only one piece of the PD puzzle
- Effective management involves addressing wellness as a whole and consideration of the multitude of symptoms caused by or affected by PD.
- Each person responds best to their own <u>individualized</u> <u>regimen</u> of exercise, medications, daily routines and other therapies.



