Young Onset Parkinson's Disease

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Aurora Health Care®

For your life.

Disclosures

- Consultancy fees from Abbvie (Duopa).

Outline

- Defining “Young Onset”
- Overview of Differences seen in Young Onset Parkinson Disease (YOPD)
- Genetics
- Motor symptoms
- Nonmotor Symptoms
- Treatments
- Social impact

YOPD = <40 or 50 at onset

YOPD: Young Onset 5%

MOPD: Middle Onset 55%

LOPD: Late Onset 40%

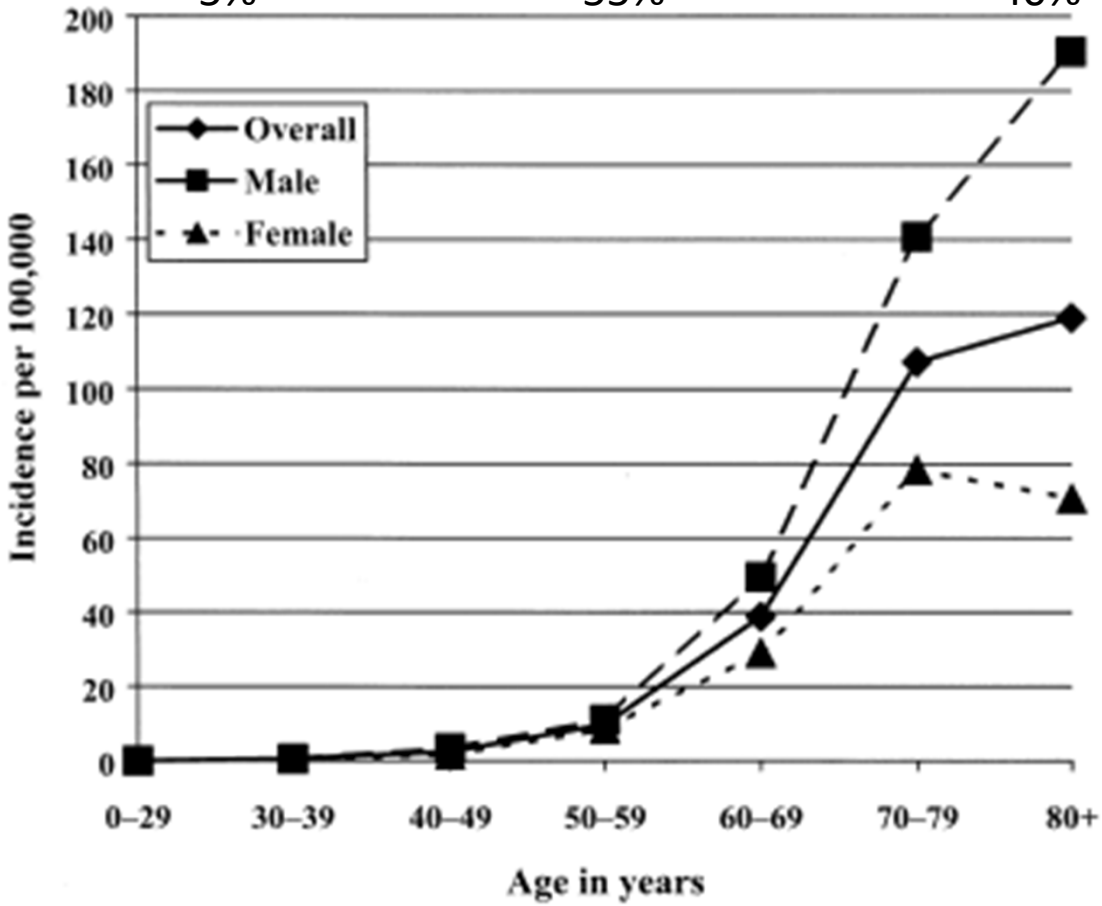
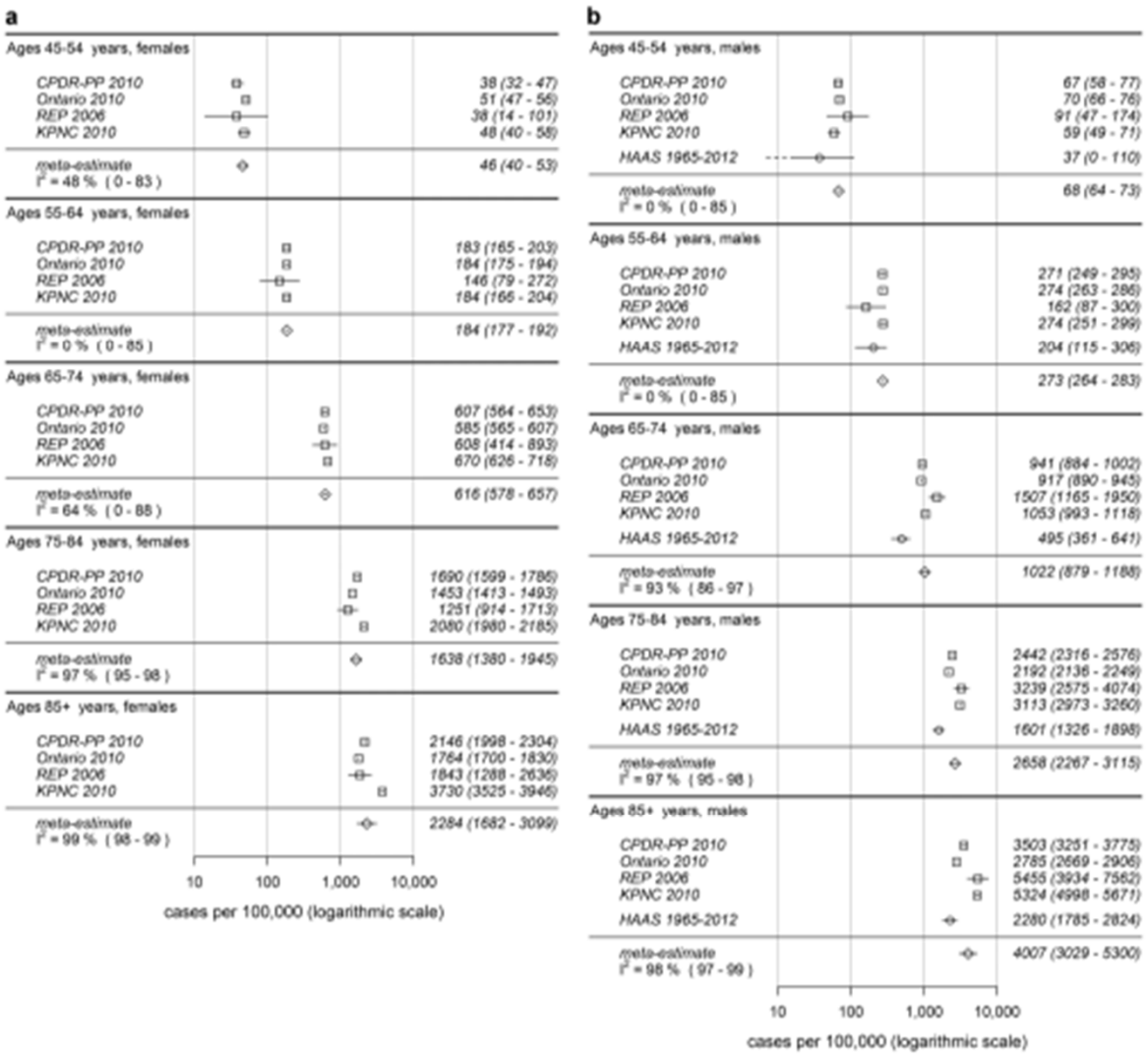


FIGURE 1. Incidence of Parkinson's disease by age and gender, Kaiser Permanente, 1994–1995.

Fig. 1

From: Prevalence of Parkinson's disease across North America



Prevalence of PD aged ≥45 years by age group and sex: **a** Females. **b** Males. HAAS Honolulu-Asia Aging Study, REP Rochester Epidemiology Project, CPDR-PP California Parkinson's disease Registry-Pilot Project, KPNC Kaiser Permanente Northern California Integrated Health Care System. In each row, the squares or diamonds are centered on the point estimate of the prevalence and whiskers represent 95% confidence intervals. Point estimates for HAAS are indicated by circles instead of squares because the meta-estimates exclude the HAAS study due to methodologic differences between this and the other studies

Prevalence of PD is about 1-1.5 million in US

Prevalence of PD increases with age

Marras, C., Beck, J.C., Bower, J.H. et al. Prevalence of Parkinson's disease across North America. npj Parkinson's Disease 4, 21 (2018). https://doi.org/10.1038/s41531-018-0058-0

Differences in YOPD

The Bright Side

- Slower Progression
  - Falls
  - Cognition
  - Swallowing
- Less comorbidity
- Greater longevity after diagnosis

The Dark Side

- Longer delay to diagnosis
- Higher rate of genetic cause
- Higher rate of motor fluctuations
- More disabling dyskinesia
- Greater loss of income/family/career impact
- Greater mental health burden
- Greater loss of life expectancy

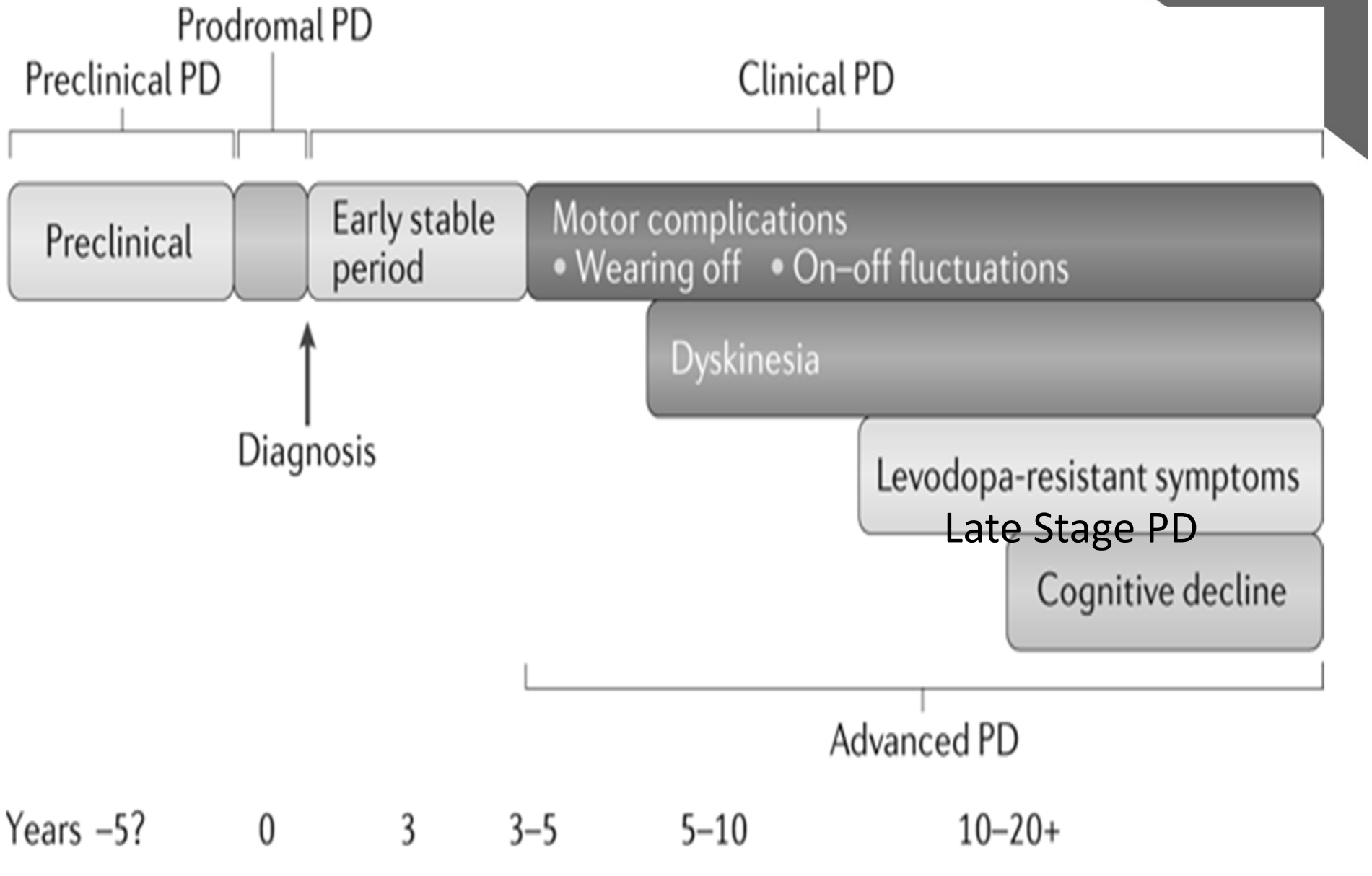
Table 2
Findings that are less frequent, less severe or delayed in YOPD compared to LOPD [180–188].

Disease progression
Gait disturbances, including freezing of gait
Falls
Dementia
Anxiety
Psychosis
Double vision
Gastrointestinal complaints (constipation, gastroparesis)
Urinary complaints
Impairment of taste and smell
Daytime sleepiness
REM sleep behavior disorders
Insomnia
Nightmares

Legend: YOPD: young onset Parkinson's disease; LOPD: late onset Parkinson's disease.

Mehanna et al Park Relat Disord 2019

How is PD staged?



Longevity

- ~78 years old for average american
- Gender and racial disparities

	YOPD	MOPD	LOPD
Longevity PD	32 years	18.5	9.3
Longevity in non-PD (age matched)	47 years	22	9.5

Mehanna et al. Park Relat Disord 2014

Parkinson Disease Genetics

Family History

- Baseline risk of PD in general population:
  - 2% for men, 1.3% women
- Close relatives of patient with:
  - YOPD: 7.8 fold higher
  - LOPD: 2.9 fold higher

Who needs tested?
How is testing done?

Common Genes

- SNCA
- Parkin
- PINK1
- DJ-1
- ATP13A2
- LRRK2*
- GBA*
- *also seen in MOPD/LOPD

Parkinson's Disease Motor Problems

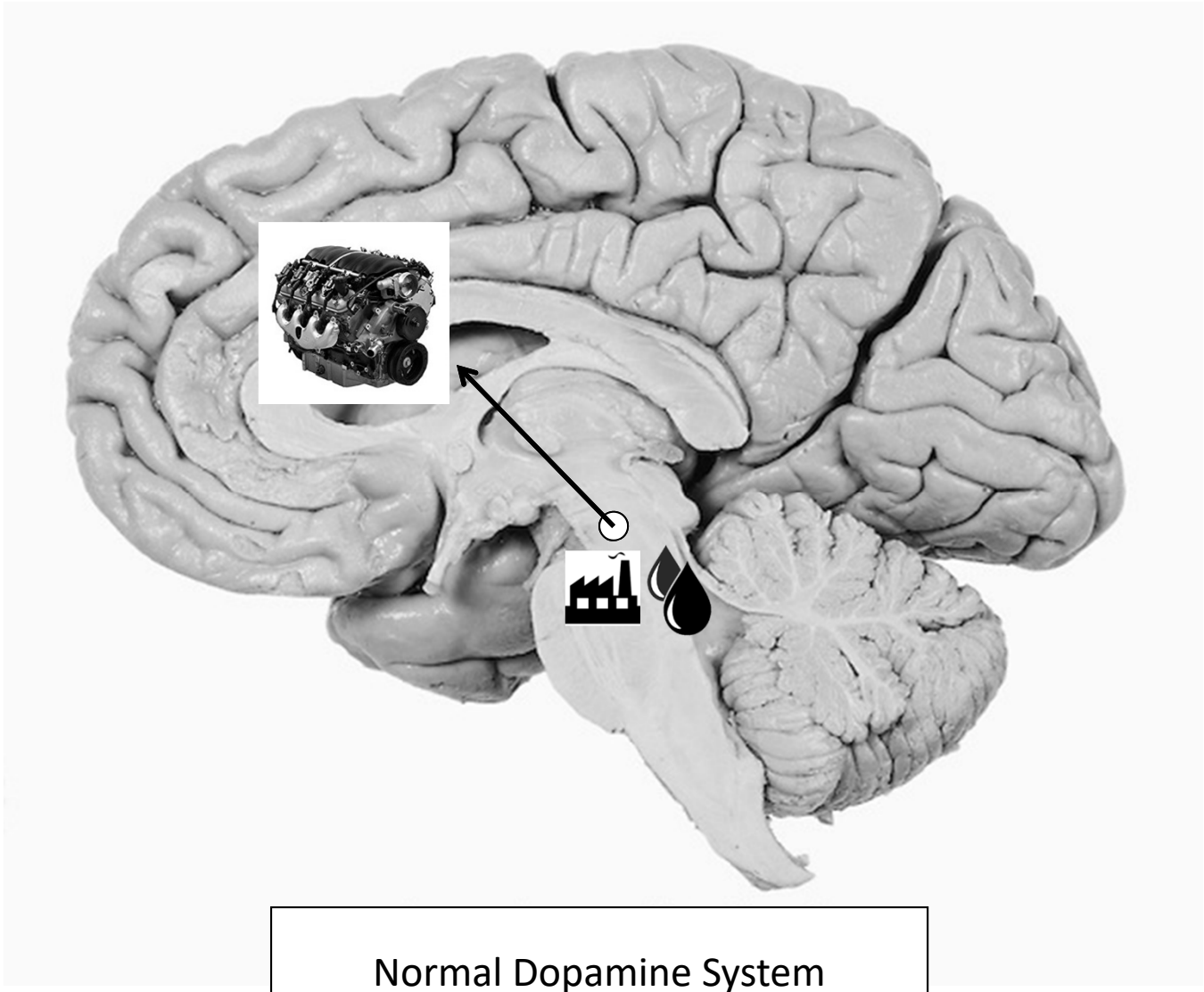
Cardinal Motor Features

- Bradykinesia
  - Difficulty moving
- Rigidity
  - Stiffness
- Tremor

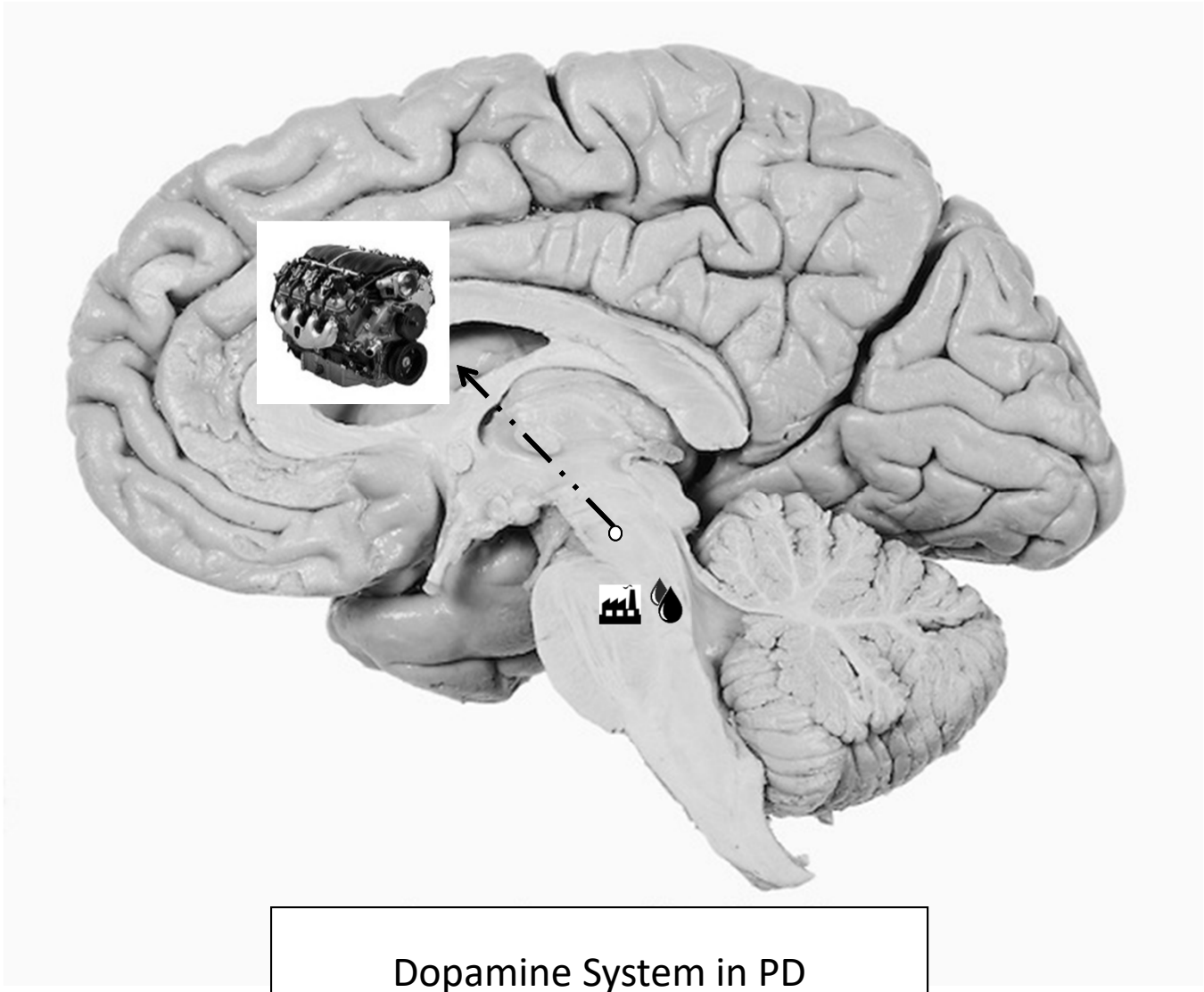
Additional Motor Features

- Postural Instability
- Stooped or bent posture
- Freezing
- Limb Dystonia
- Dyskinesia

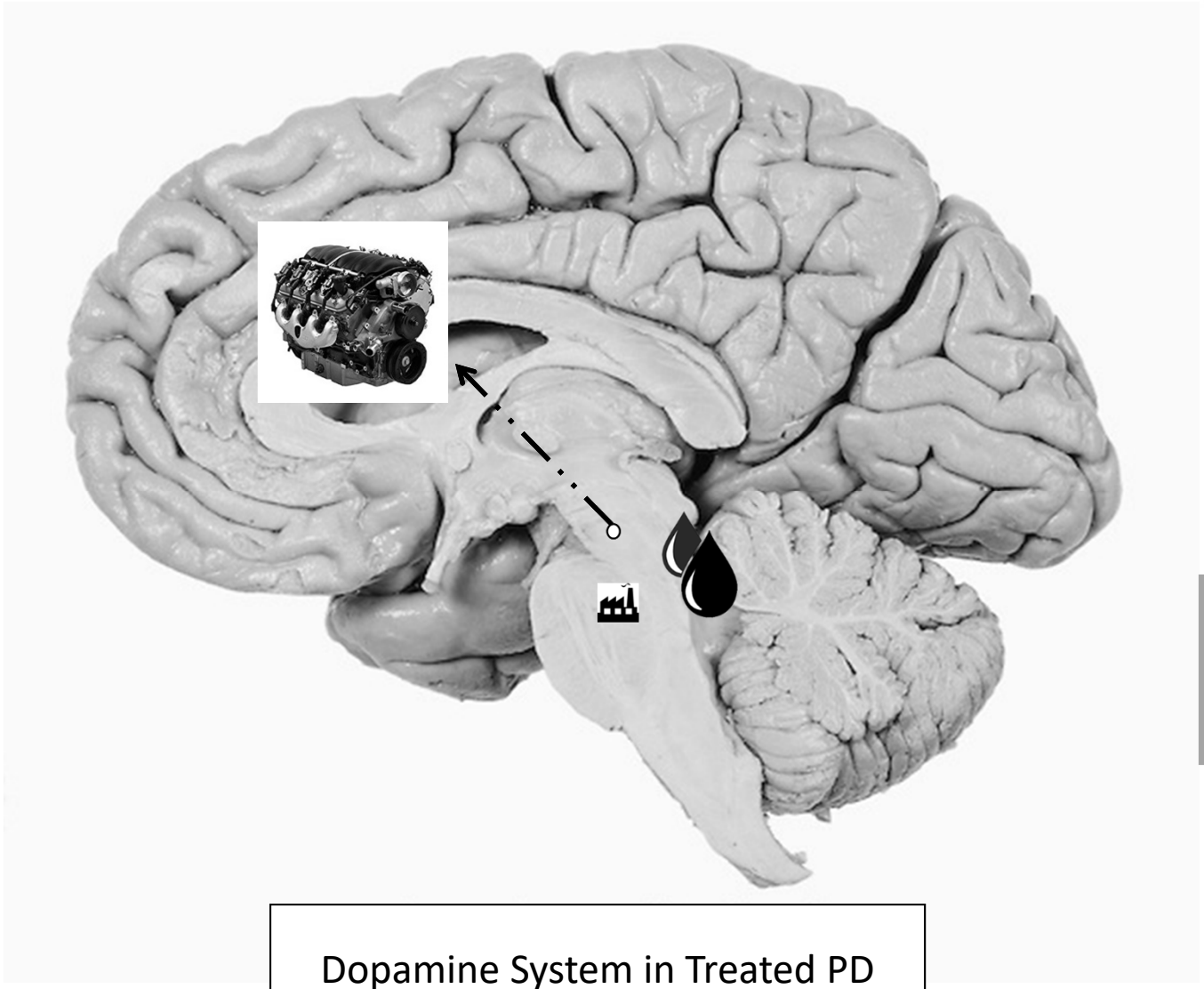
Motor Fluctuations – when the above symptoms vary due to variability in treatment effectiveness over course of day



Normal Dopamine System

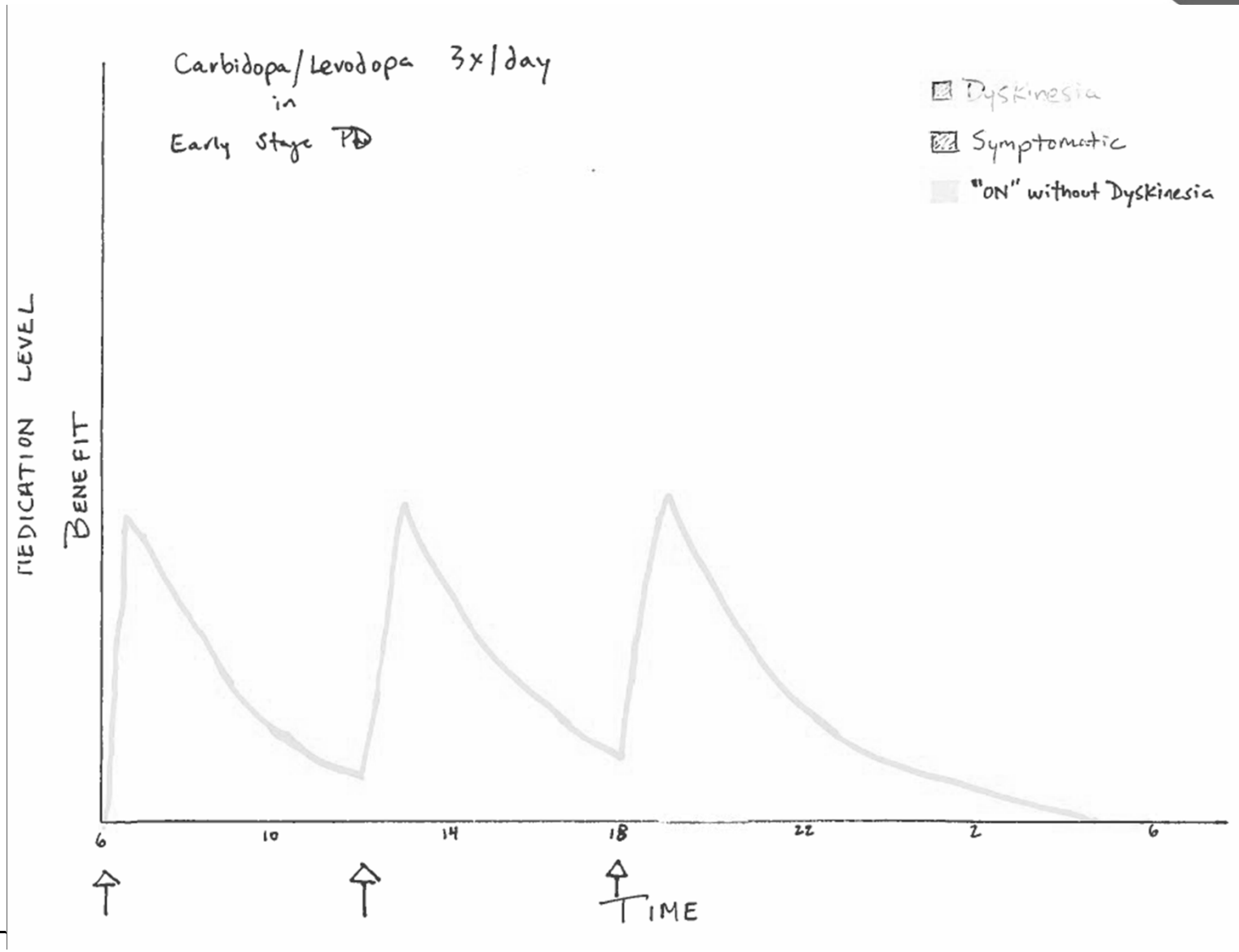


Dopamine System in PD



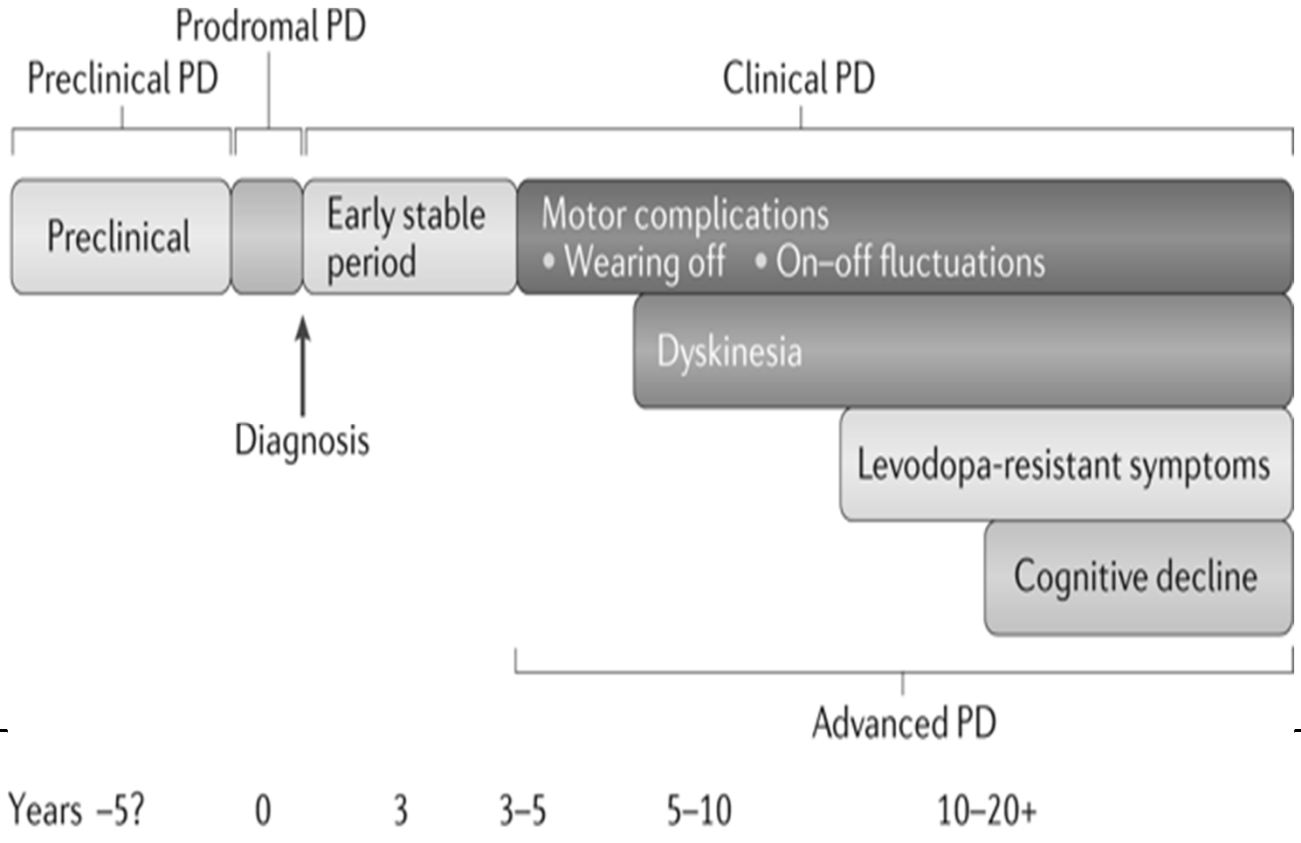
Dopamine System in Treated PD

Initial Therapy Option 3



Transition from Early PD to "Advanced PD"

- Motor Fluctuations
- Dyskinesia
- More frequent medication dosing



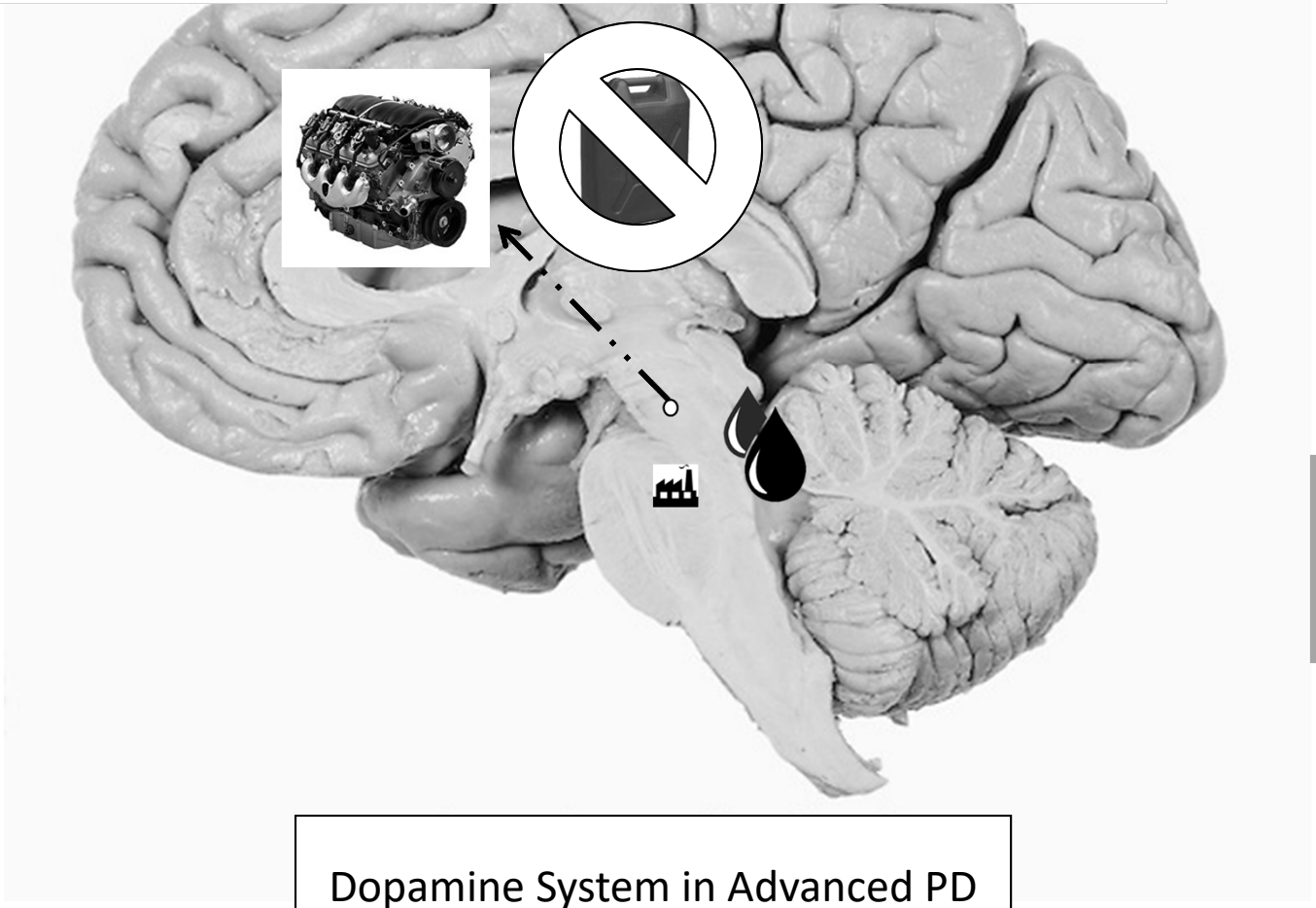
Brain can no longer temporarily store the dopamine you add to it

→ meds wear off

Engine now can go into “overdrive”

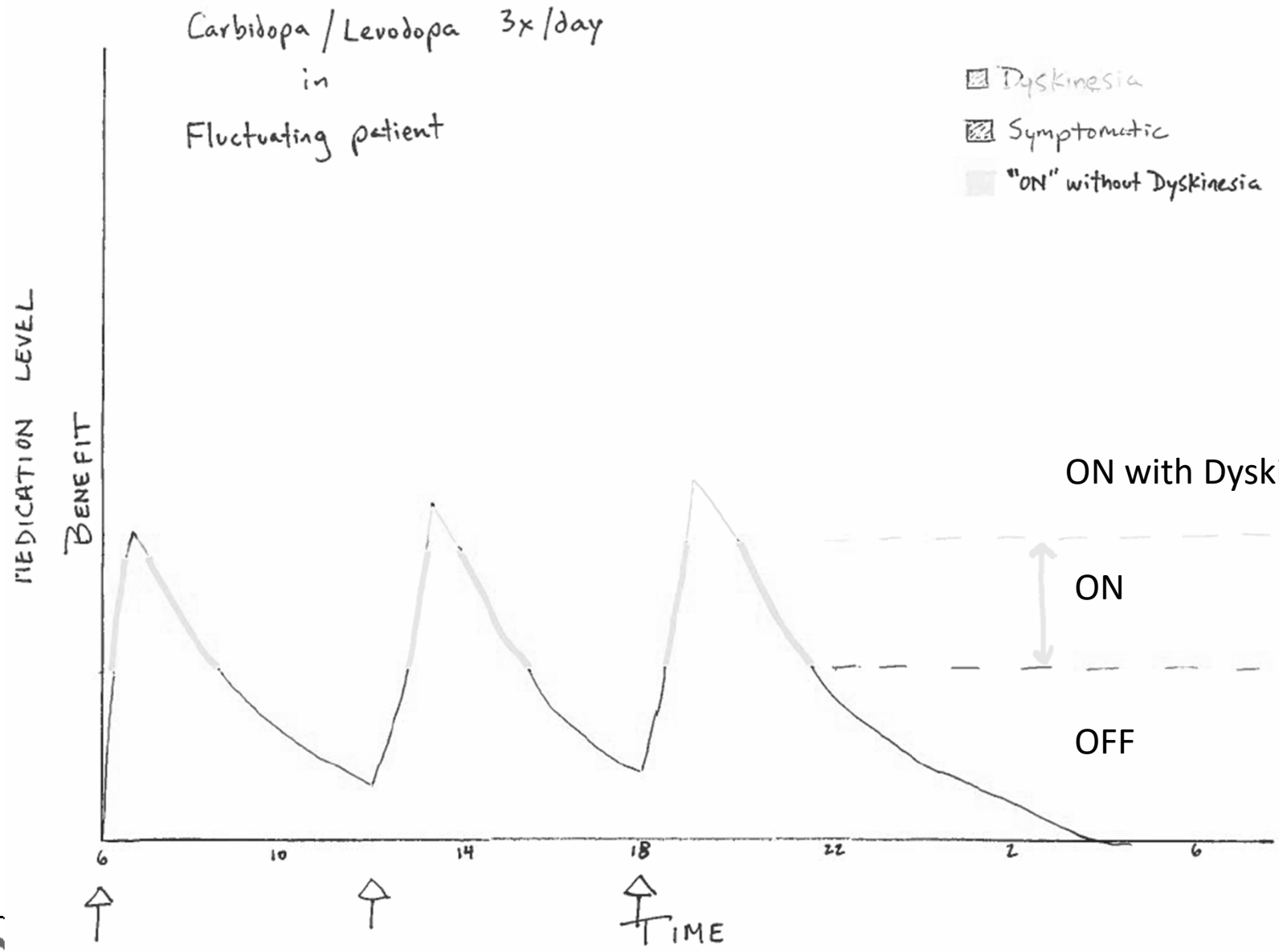
→ extra movements called dyskinesia

End Result: Brain now depends on steady medication levels



Dopamine System in Advanced PD

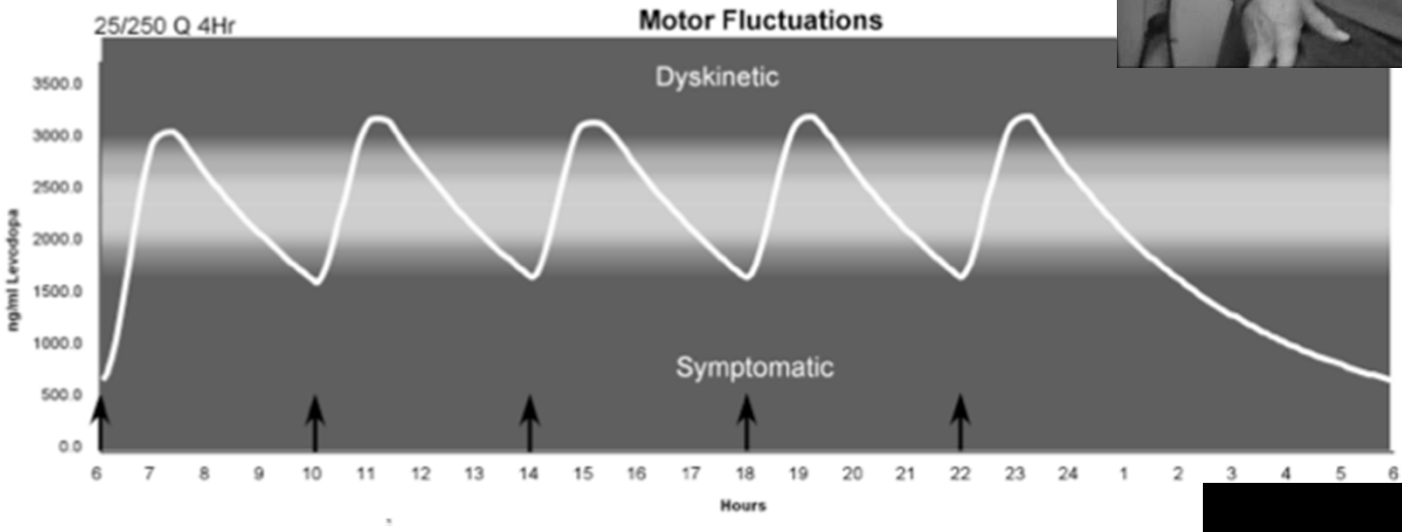
Predictable Motor Fluctuations



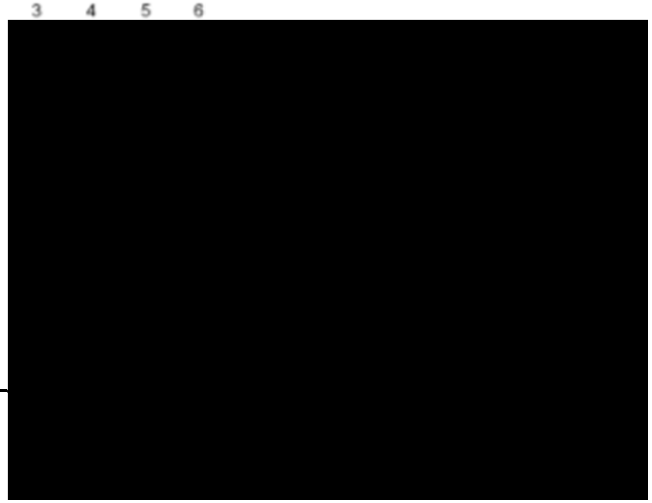
Motor Fluctuations

Dyskinesia example

Video courtesy of Espay 2012



Example of OFF symptoms



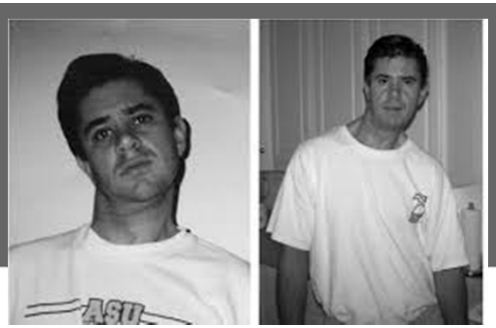
Motor Fluctuations

- Typical
  - End of dose wearing off – slow or sudden
  - Peak dose dyskinesias
- Common
  - Sudden “off” or Random “off”
  - Weak response at end of day
  - Dose failures
  - Off dystonia
- Less common
  - Diphasic Dyskinesia (occurs as med kicks in and wears off)

Nonmotor “OFF”

- Anxiety
- Pain
- Restlessness
- Depression
- Fatigue
- Attentional difficulties/cloudy
- A feeling like everything is wrong
- Panic
- Sweating
- Abdominal bloating
- Trouble breathing
- Urinary Urgency

What is Dystonia?



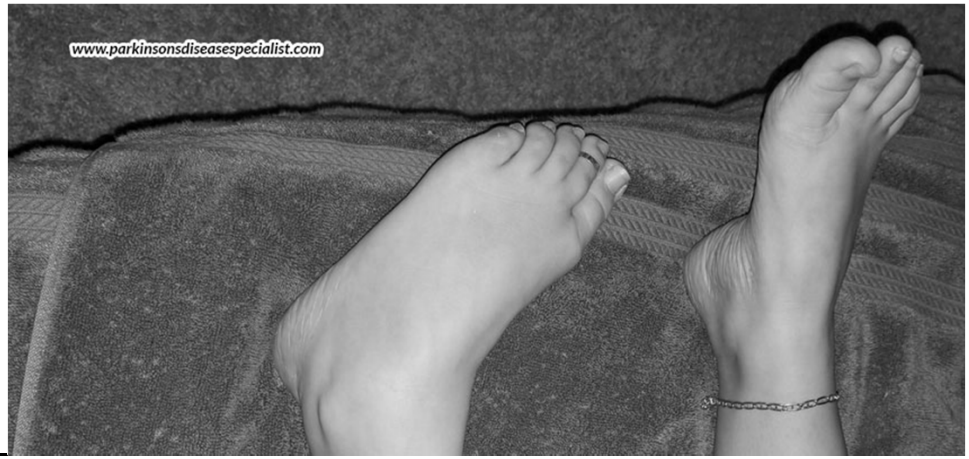
Involuntary movement
Caused by excessive muscle contraction
Often resulting in abnormal posture
May be painful

Most commonly
-Occurs in undertreated stage or time of day (OFF periods)
-Commonly an inward twisting of ankle on more affected side with curling of toes

May also occur
-At peak of levodopa dosing
OR
-At a different site like neck or hand

Treatment:
-Address OFF periods
-Use muscle relaxing medications
- -amantadine
- -baclofen
- -artane

-Botulinum toxin injections into affected muscles
-In certain patients, Deep Brain Stimulation (DBS) may be best option



Treatment differences

- “Levodopa sparing” strategy
  - Using longer acting medications
  - Dopamine Agonists
  - Amantadine

- Deep Brain Stimulation

Medication comparison

	Carbidopa/ Levodopa	Rasagiline	Pramipexole	Ropinirole	Rotigotine	Artane	Amantadine
Mechanism	Provides dopamine	Stops dopamine breakdown	Dopamine Agonist	Dopamine Agonist	Dopamine Agonist (patch)	Anti-cholinergic	Complex receptor effects
Rigidity	**+++++**	+	+++	+++	+++	++++	+
Tremor	**+++++**	+	+++	+++	+++	++++	+++
Bradykinesia	**+++++**	+	+++	+++	+++	+	+
Depression	+	+	+++	+++	+++		
Dyskinesia	**----**	--	**--**	**--**	**--**	-	**Helps dyskinesia**
Side Effects	++	+	**++++**	**++++**	**++++**	**+++++**	**++++**
Duration	Short	**Long**	Long	Long	**Long**	Med	Long
Cost	$ or $$$$	$$$	$$	$$	$$$	$	$$

Disclaimer: This chart is based on my personal opinion and experience

Dopamine Agonists

Potential Upsides

- Longer acting → decreased fluctuations
- Less potent in inducing dyskinesia

Potential Downsides

- Side Effects
  - Unique:
    - Sudden sleep attacks
    - Impulse Control Disorders
    - Leg Swelling
  - More likely than levodopa to get:
    - Central: Hallucinations, sleepiness
    - Peripheral: Orthostatic hypotension, Nausea
- Dopamine Agonist Withdrawal

Impulse Control Disorders

Description	Failure to resist impulse or temptation: Gambling Hypersexuality Binge eating Shopping Hobbyism (getting engrossed in a hobby) Punding (repetitive useless tasks)
How Common	10-15%
Why?	Side effect of dopamine medication (D3 receptor) Typically due to dopamine agonist
Treatment	
Nonpharmacological	Recognition
Pharmacological	Reduce or stop dopamine agonist SSRI (antidepressant)

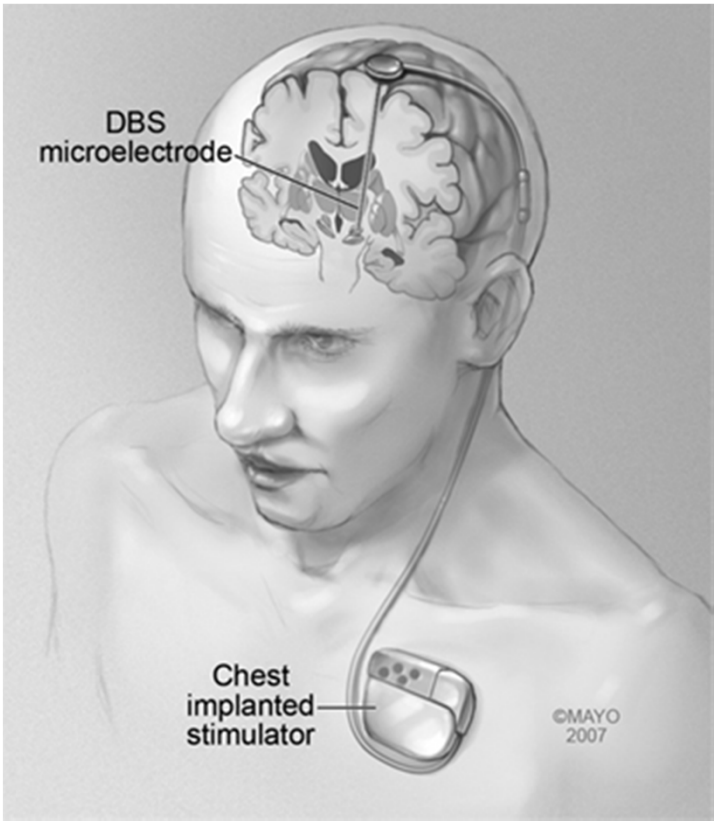
Deep Brain Stimulation

Benefits:
-24/7 steady treatment
-Potential to help slowness, stiffness, tremor
-Reduce medications (average half)

Caveats:
-For most symptoms, does not help more than “best ON” from medication
-Additional tremor control
-Additional dyskinesia suppression
-Does not help postural imbalance
-Is not a cure

Good Candidate:
-Has Parkinson’s Disease 4+ years
-Responds to dopamine medications
-Has problems with dopamine medications (typically motor fluctuations)
-No severe heart/lung disease
-No confusion/disorientation/memory difficulties on a daily basis

https://www.youtube.com/watch?v=wZZ4Vf3HinA



Nonmotor symptoms

Depression

- Depression

Nonmotor Symptoms: Mental Health

Chemical

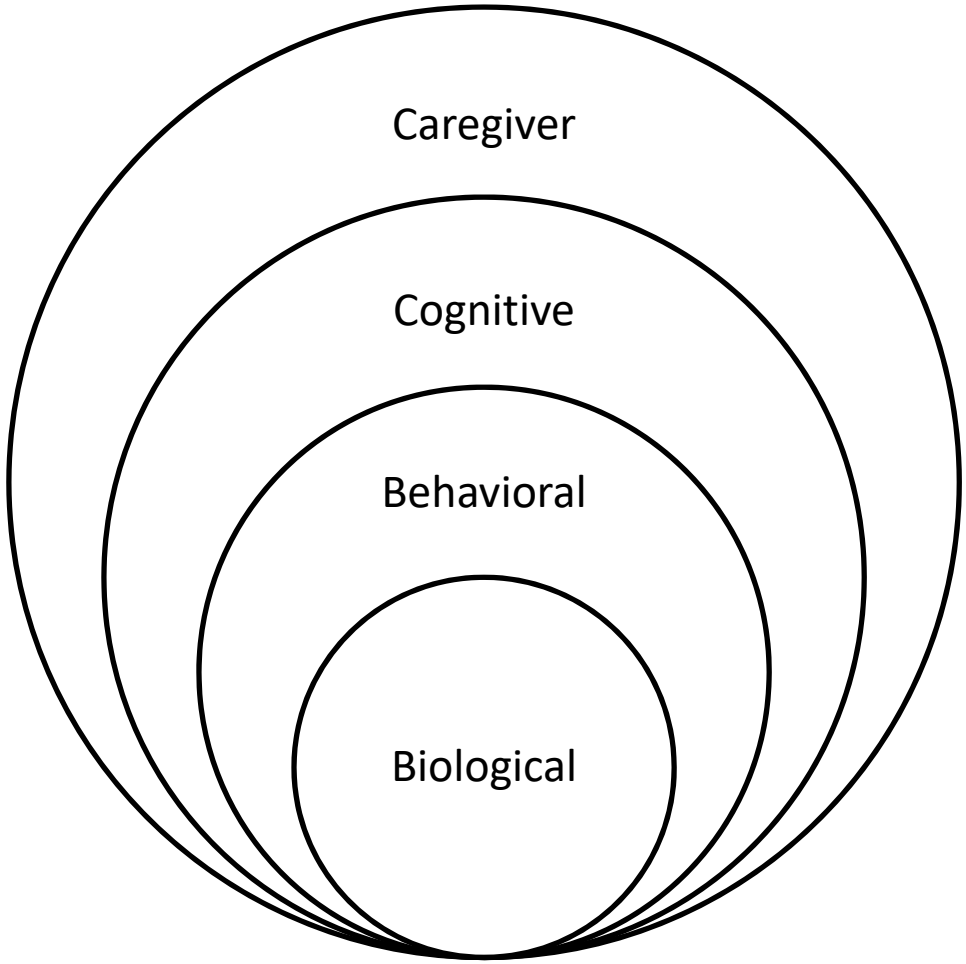
- Dopamine & Fluctuation
- Serotonin
- Substance Abuse
- Chronic Pain

Treatment:
-Address Fluctuations
-Antidepressants
-Psychologists
-Counseling
-Empowerment
-Exercise
-Cognitive behavioral strategies
-Community involvement

Situational

- Coping
  - Initial Diagnosis
  - Disability
  - →Anger
  - →Self-destructive behavior
- Shame
- Guilt
- Relationship stress
- Loss of Autonomy

Influential Role of the Carepartner in PD Mental Health



Examples of Interventions

- **Increasing meaningful and social activities**
  - OLD
  - NEW
  - MODIFIED
- **Problem solving for physical limitations**
  - Pacing of activities
  - Appropriate daily goals/ less rigid demands
  - Plan around “off-time”
  - Walk 10 minutes 3x a day instead of 30 minut
  - Follow through with referrals for PT, OT, and Speech

Exercise Recommendations for Parkinson Disease

INSIGHTS FROM THE GENERAL POPULATION

- Type of exercise: Aerobic or resistance training
- Frequency: 3-5 sessions/week
- Session Duration: 45-60 minutes
- Intensity: At least Moderate
- Minimum Duration: 2-3 Months

Ahlskog, J. E. (2011). Does vigorous exercise have a neuroprotective effect in Parkinson disease? Neurology, 77(3), 288-294.

What is the Best Type of Exercise for PD?

- Aerobic
- Dance
- Tai Chi and Qigong
- Yoga
- Strength Training
- Boxing

Do what you love!
There is something for everyone.
Wiparkinson.org

Examples of 1:1 Interventions

- **Anxiety management and relaxation**
  - Breathing exercises
  - Progressive muscle relaxation
  - Guided visualization

- **Sleep hygiene**
  - Using bed for sleep only
  - Relaxing before bedtime
  - Keeping regular sleep hours
  - Limiting excess time in bed, daytime naps, caffeine, or alcohol in the evening

Examples of 1:1 Interventions

- **Thought monitoring and restructuring**
  - ❖Rethink the big picture
    - Catch the negative thought
    - Press pause
    - Rewind
    - Replay

Social Impacts

- Family
- Intimacy
- Career/Financial

Relationship Challenges

- An enduring challenge and common enemy
- Difficulty of dealing with uncertainty
- Not letting worry consume you
- Finding the right amount of focus on PD
- Paths Forward:
  - Educate yourselves together
  - Communicate, even on difficult subjects
  - Look ahead to upcoming challenges
  - Being treated differently
  - Find supports outside of your primary relationship

Family

- Telling children
  - Children can usually sense something is wrong
  - “It is often better to direct energy used to keep Parkinson’s a secret into coping with the demands of maintaining a marriage, making a living and raising a family.”
  - Ensure kids know you will be ok.
- Pregnancy
  - PD does not affect ability to be pregnant or deliver
  - May require alteration in PD medication regimen so discuss with doctor *prior to conception*
  - Preconception genetic testing is an option

Impact on sex and intimacy

- Change in partner roles
- Change in attraction or perceived desirability
- Decreased or increased libido
- Sexual performance
  - Erectile dysfunction
  - Difficulty reaching orgasm
- → Any or all of these can lead to loss of intimacy
- Treatment:
  - Addressing physical problems
  - Communication
  - Consider morning time for intimacy
  - Broadening idea of “sex”
  - Marriage or Sex counseling

Self-help for relationships

Worksheets

-”Our relationship self-assessment”
- Sexual dysfunction worksheet

Career

- When to tell employer
  - Meet with employment attorney first
  - Protections from ADA
- How long can/should I work?
  - Looking at the physical and cognitive demands of a list of job tasks
  - Meet with Financial Advisor
  - Meet with Disability attorney
- Resources:
  - Attorney: employment attorney, disability attorney
  - Financial Advisor
  - Occupational Therapy/Physical Therapy/Neuropsychological assessments

American with Disabilities Act (ADA)

- Definition of disability:
  - a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment.
- ADA requires:
  - Employer required to make “reasonable accomodations” as long as it does not cause “undue hardship” for the company.
  - Prevents employer from negatively considering your disability in not hiring, not promoting, disciplining, demoting or firing you.
- Navigating this process:
  - Human Resources (not confidential)
  - Employee Assistance Program (confidential employer provided benefit)
  - Independent employment attorney

Family Medical Leave Act (FMLA)

- Requires job-protected, unpaid leave for qualified medical and family reasons

Social Security Disability Requirements

(ssa.gov/disability/professionals/bluebook)

- **11.06 Parkinsonian syndrome** , characterized by A or B despite adherence to prescribed treatment for at least 3 consecutive months:
- A. Disorganization of motor function in two extremities, resulting in an extreme limitation in the ability to stand up from a seated position, balance while standing or walking, or use the upper extremities.

- OR

- B. Marked limitation in physical functioning, and in one of the following:
- Understanding, remembering, or applying information; or
- Interacting with others; or
- Concentrating, persisting, or maintaining pace; or
- Adapting or managing oneself.

Maintaining Medical Insurance

- Continued employment
- Spouse benefits
- COBRA coverage through former employer
- Medicaid (income-based)
- Eligible for medicare 2 years after receiving social security disability

Further Resources

- WPA
- Davis Phinney Foundation
- Parkinson Foundation
- PD SELF
- Research

Parkinson Foundation- Expert Webinars

Register at parkinson.org

- **Not What I Planned For Me or My Family**
  September 15, 1 p.m. ET
  Presenter: Allison Allen, MSW, LCSW
- Young Onset PD often emerges unexpectedly, interrupting family life. Taking a proactive approach to care for YOPD can mitigate stress. In this Expert Briefing, we will discuss strategies for coping with a PD diagnosis and learn practical steps to organizing your care team and PD plan, with the goal of empowering you and your family.
- **Work it Out: Managing Parkinson's in the Workplace**
  October 27, 1 p.m. ET
  Presenters: Miriam Rafferty, PT, DPT, PhD and Bradley McDaniels, PhD, CRC
- Managing your Parkinson's diagnosis, symptoms and evolving PD routine can easily interrupt your prime working years. We want everyone with PD to be equipped with the knowledge and resources to make informed career decisions, know legal rights and have guidance for when, if and how to disclose a diagnosis to an employer.
- **Partnering: The Dance of Relationships and Romance**
  November 10, 1 p.m. ET
  Presenter: Sheila Silver, MA, DHS, ACS, Clinical Sexologist
- The combined stress of balancing family, work and YOPD can impact your relationship. In this webinar, a clinical sexologist guides us through how to reconnect when feeling distant and put in place behaviors that support closeness and intimacy. Learn strategies that help couples stay connected emotionally and physically while navigating Parkinson's, together.

WEBINAR SERIES: YOPD COUNCIL

The Third Thursday of Every Month

1 – 2 pm Mountain Daylight Time

(12 pm PDT, 2 pm CDT, 3 pm EDT, 8 pm BST)

Because of the unique challenges of living with YOPD, we want to increase awareness of YOPD, provide resources, and share stories to help people with YOPD live better today.

One way we've decided to do that is to create a YOPD Council. This council has been convened so members can share their experiences of living with YOPD. Join us each month for this ongoing webinar series.

Take the first step!

PD Self-Efficacy Learning Forum (PD SELF)

Welcome to the PD SELF website. We invite you to learn about our educational program and see how the science of self-efficacy has helped newly diagnosed Parkinson's patients and their care partners, and can possibly help you!

"May the self-efficacy force be with you."

Stanford Psychologist, Dr. Albert Bandura, considered the father of self-efficacy, in an email to the founder of PD SELF, Diane Cook, regarding the application of self-efficacy to newly diagnosed Parkinson's patients

Program Aim — To Improve Quality of Life

The aim of PD SELF is to provide newly diagnosed people with Parkinson's and their care partners with a disease-specific, person-specific, interactive learning approach to self-efficacy that, together with basic understanding of the disease and its progression, will allow them to improve their quality of life over time. Relationships are developed with new friends while strengthening the bonds of the Person With Parkinson's and their Care Partner.

About The Instructors

Kiersten Kirking, DPT

Kiersten is a physical therapist at the outpatient neurologic rehabilitation clinic at Aurora St. Luke's Medical Center. She graduated with a doctorate of physical therapy from Marquette University in 2013. She is certified in Parkinson's-specific LSVT and PWR! therapies and assists with the deep brain stimulation program at St. Luke's.

Chris Banedt, RN

Chris is a former army drill sergeant and medic who went on to earn her nursing degree after retiring from the military. She was diagnosed with Parkinson's disease in 2013. She is very active within the Parkinson's community, regularly attending PD support groups and exercise groups.

PD SELF Milwaukee

- Aurora St. Luke's Medical Center
- 2900 W. Oklahoma Ave., Milwaukee
- One session/month from 1:00 pm to 4:00 pm
- September through April

To register, please contact us with your information:
414 - 646 - 2424 or
PDSelf@aurora.org

We will return your voicemail or e-mail within 7 days.

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PD SELF™

Parkinson's Self-Efficacy Learning Forum

Have You Recently Been Diagnosed with Parkinson's Disease?

Aurora Health Care®

Research

- Froedtert Research Studies
  - Untreated/Recent Diagnosis
  - Motor fluctuations

  - Interested? Contact Lynn Wheeler: lwheeler@mcw.edu

Summary

- YOPD has important differences in motor and nonmotor manifestations.
- YOPD patients have unique life challenges that are individualized and benefit from expert input and counseling
- Exercise, education, communicating openly and proactively managing challenges can empower you.
- Seek out the local and national resources available.

Questions?

Thank you