# *Living Your Best Life:*

## Breaking myths, boards, and barriers to thrive with Parkinson's Disease

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**Living InMotion**
**June 28, 2025**

# Breaking…

- **Myths:** What movement disorders specialists *wish* Dr. Google would stop telling you
- **Boards:** How a brave person with PD's brilliant idea fueled a movement to KICKOUT-PD
- **Barriers:** Interdisciplinary home visits, caring for caregivers, and learning how to PERSEVERE

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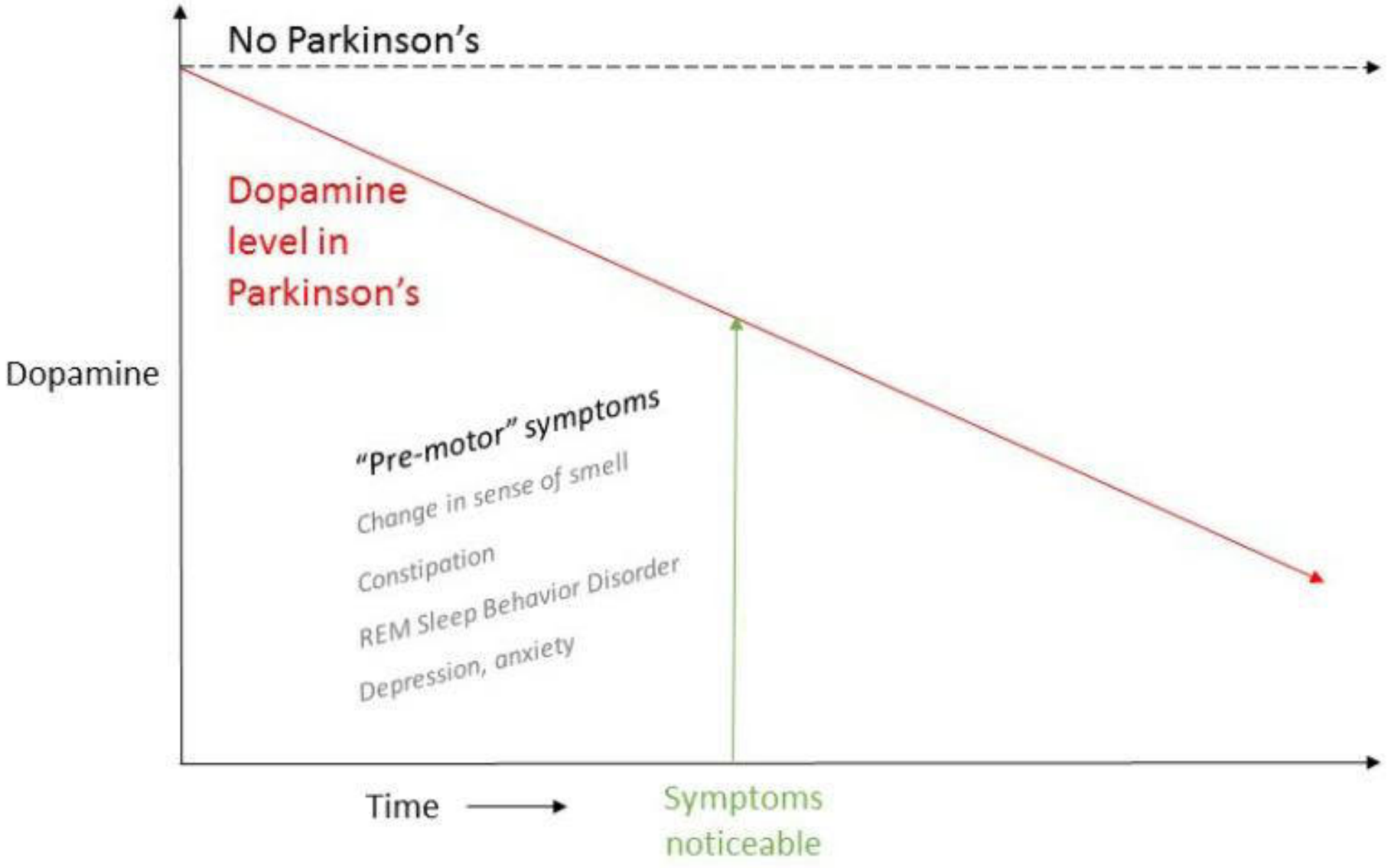
1. Medication stops working
2. It’s better to wait on levodopa until you ”really, really need it”
3. Stage 3 = Advanced Parkinson’s Disease
4. Lewy Body Dementia is a different thing
5. You will wake up one morning and…

# Myth 1: Medication stops working



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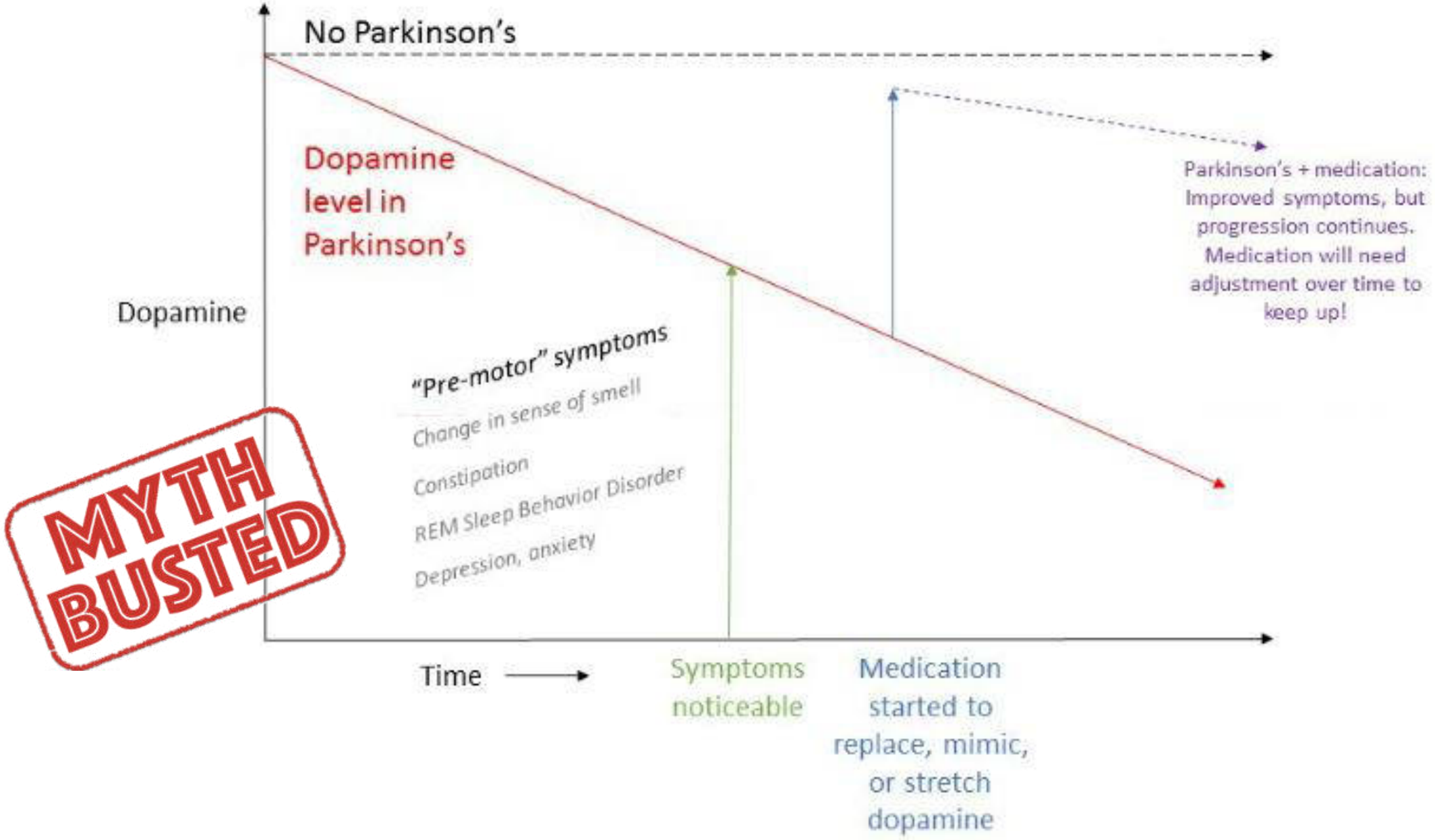


# Myth 1: Medication stops working

# Or… the Safe & Wonderful Tradeoff Analogy

IcyHot

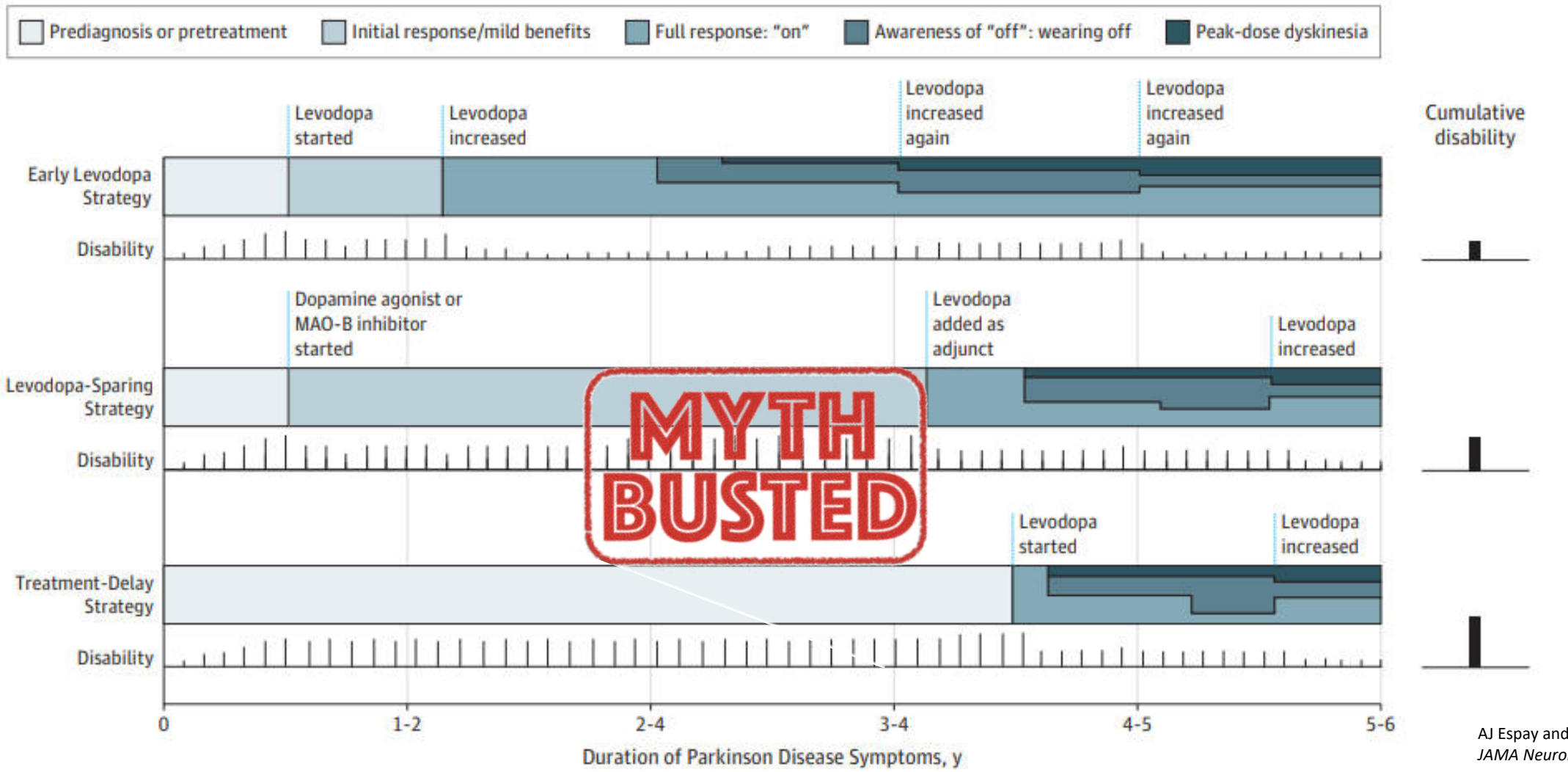
Diet & exercise


Insulin pump

Knee replacement

# Myth 2: It's better to wait on levodopa until you "really, really need it"

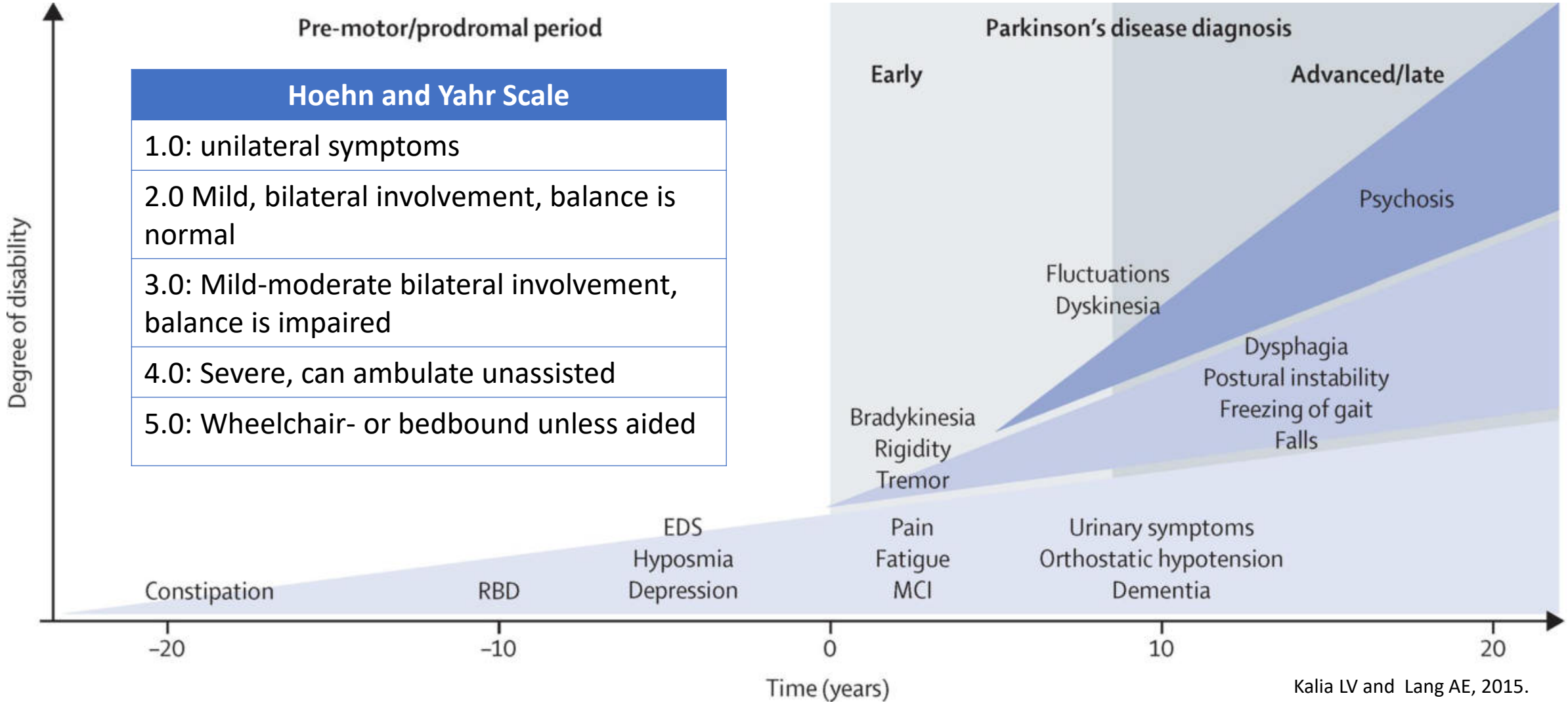
Figure. Theoretical Models of Levodopa Use and Associated Disability




AJ Espay and AE Lang, *JAMA Neurology*, 2017

# Myth 3: Stage 3 = Advanced Parkinson's Disease

| Hoehn and Yahr Scale |
| --- |
| 1.0: unilateral symptoms |
| 2.0 Mild, bilateral involvement, balance is normal |
| 3.0: Mild-moderate bilateral involvement, balance is impaired |
| 4.0: Severe, can ambulate unassisted |
| 5.0: Wheelchair- or bedbound unless aided |




Kalia LV and Lang AE, 2015.

# Myth 3: Stage 3 = Advanced Parkinson's Disease

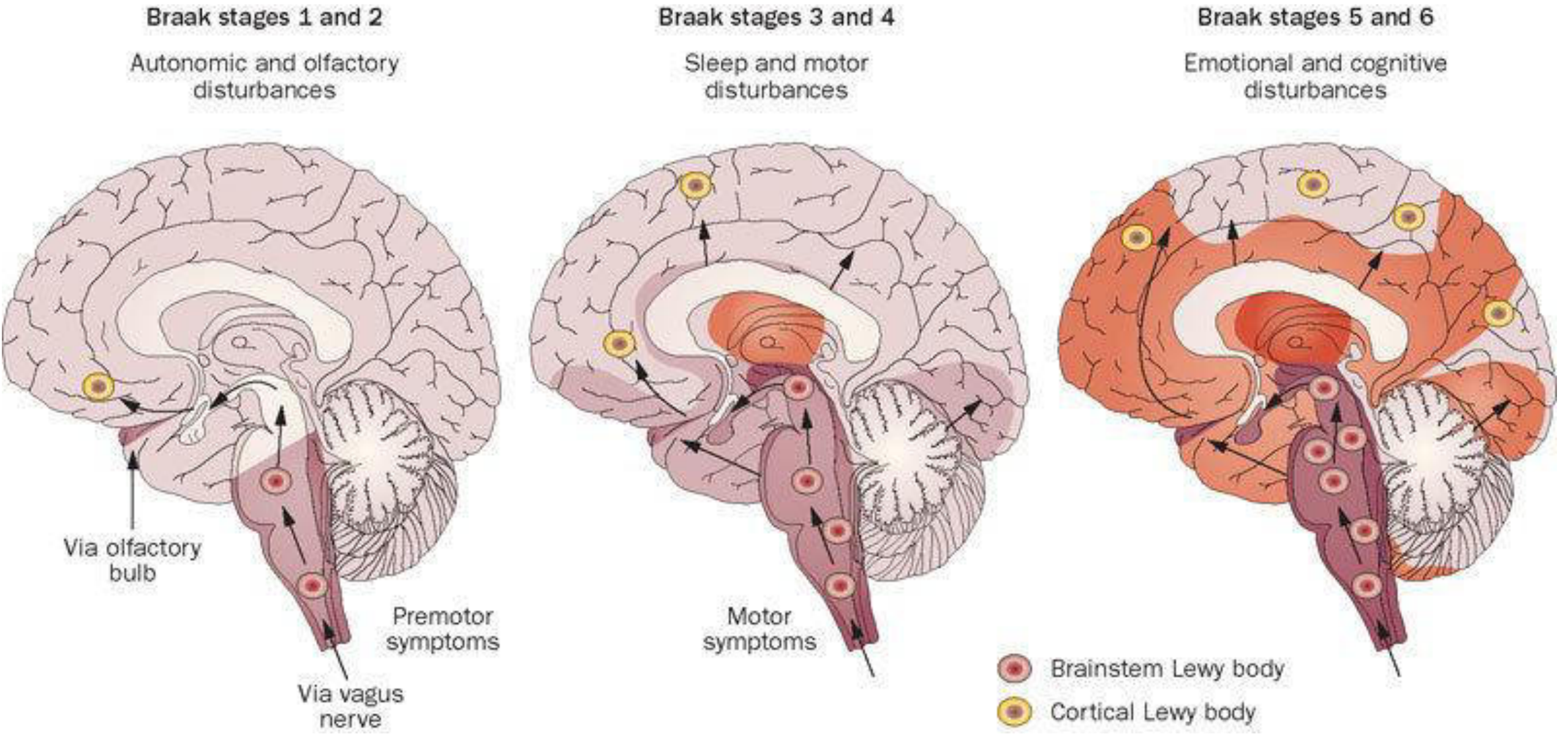
**TABLE 3.** *Prevalence*

| NMS domains | All N = 1,072 (%) | 1 N = 16 |
|---|---|---|
| Gastrointestinal | 654 (61.0) | 76 (4 |
| Pain | 653 (60.9) | 85 (5 |
| Urinary | 614 (57.3) | 72 (4 |
| Cardiovascular | 158 (14.7) | 22 (1 |
| Sleep | 687 (64.1) | 80 (4 |
| Fatigue | 623 (58.1) | 63 (3 |
| Apathy | 328 (30.6) | 41 (2 |
| Attention/memory | 479 (44.7) | 63 (3 |
| Skin | 260 (24.3) | 24 (1 |
| Psychiatric | 716 (66.8) | 102 (6 |
| Respiratory | 191 (17.8) | 16 (9 |
| Miscellaneous | 515 (48.0) | 62 (3 |

| NMS domains | All N = 1,072 (%) | 4–5 N = 49 (%) |
|---|---|---|
| Gastrointestinal | 654 (61.0) | 36 (73.5) |
| Pain | 653 (60.9) | 39 (79.6) |
| Urinary | 614 (57.3) | 44 (89.8) |
| Cardiovascular | 158 (14.7) | 11 (22.5) |
| Sleep | 687 (64.1) | 40 (81.6) |
| Fatigue | 623 (58.1) | 40 (81.6) |
| Apathy | 328 (30.6) | 24 (49.0) |
| Attention/memory | 479 (44.7) | 32 (65.3) |
| Skin | 260 (24.3) | 16 (32.7) |
| Psychiatric | 716 (66.8) | 41 (83.7) |
| Respiratory | 191 (17.8) | 15 (30.6) |
| Miscellaneous | 515 (48.0) | 29 (59.2) |

Barone P, et al, 2009.

# Myth 4: Lewy Body Dementia is a different thing



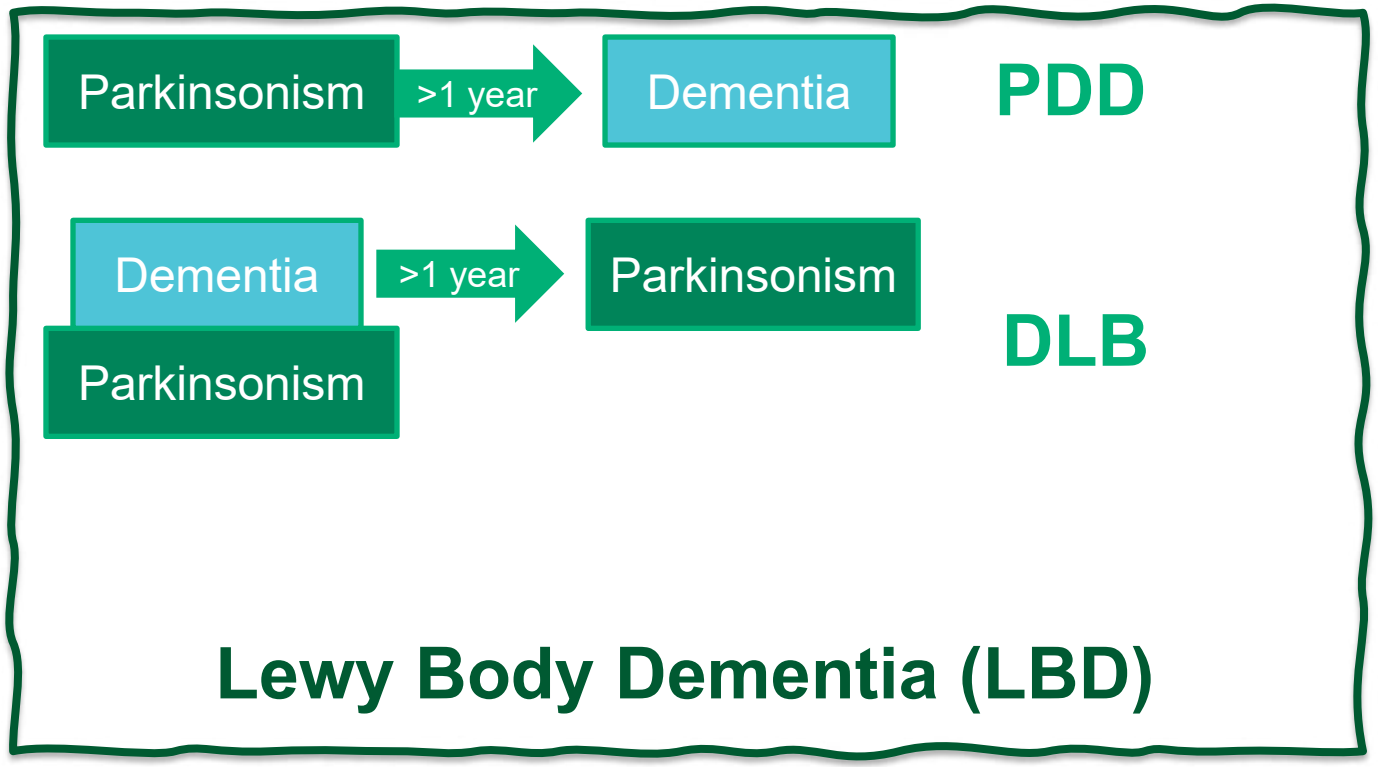
# Myth 4: Lewy Body Dementia is a different thing

**Parkinsonism**

- Bradykinesia (slowness)
- Rigidity (stiffness)
- Tremor
- Balance changes

**Dementia**

- Changes in attention, concentration, decision making, visuospatial processing
- Fluctuations in alertness
- Hallucinations

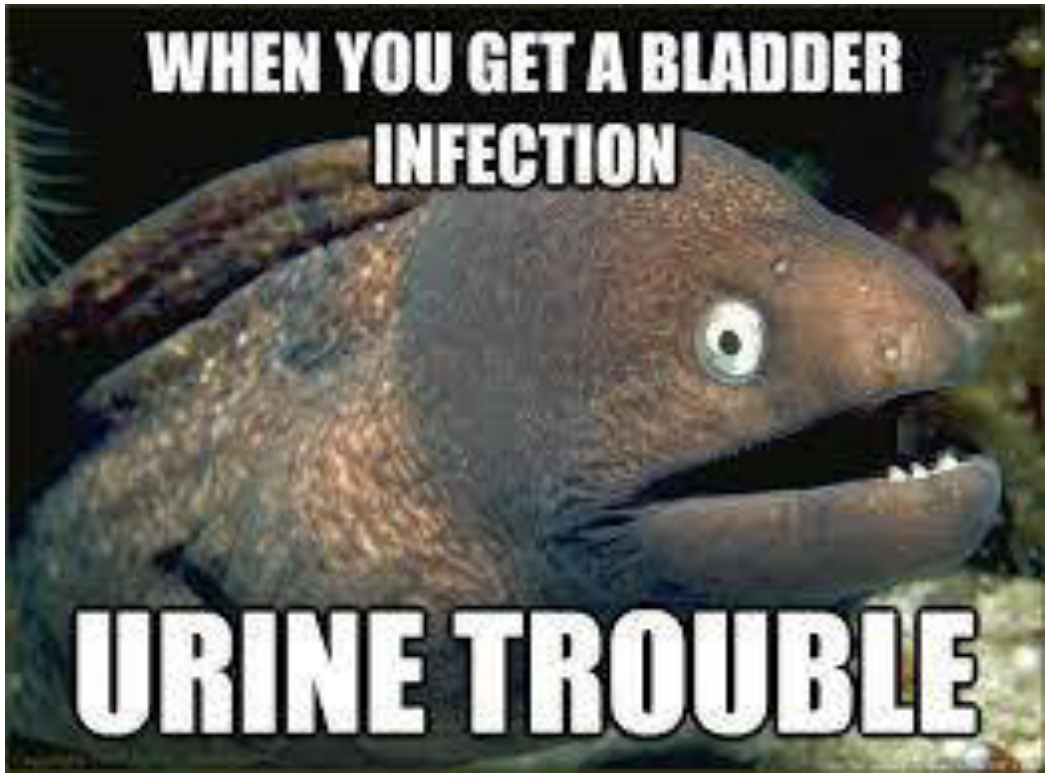


# Myth 5: You will wake up one morning AND…

- **Abrupt changes in mobility** – less effect of medications, increased freezing of gait or falls
- **Abrupt changes in cognitive status**
- **New or significantly worsened hallucinations or delusions**

# Myth 5: You will wake up one morning AND…

- Exclude reversible causes
  - **UTI, UTI, UTI** (urinary tract infection)
  - Pneumonia
  - Other infectious causes (teeth, feet, seat)
  - Bowel obstruction/severe constipation
  - Metabolic derangements, dehydration
  - Medication errors or new medications
  - **Over the counter pain-PM, cough/cold, or sleep meds!**
  - New supplements, gummies, CBD, etc.
- Consider low blood pressure



# Breaking…

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# Mr. H & Ms. D

## 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:

| Aerobic Activity | Strength Training | Balance, Agility & Multitasking | Stretching |
|---|---|---|---|
| 3 days/week for at least 30 mins per session of continuous or intermittent at moderate to vigorous intensity | 2-3 non-consecutive days/ week for at least 30 mins per session of 10-15 reps for major muscle groups; resistance, speed or power focus | 2-3 days/week with daily integration if possible | >2-3 days/week with daily being most effective |
| **TYPE:** Continuous, rhythmic activities such as brisk walking, running, cycling, swimming, aerobics class | **TYPE:** Major muscle groups of upper/lower extremities such as using weight machines, resistance bands, light/moderate handheld weights or body weight | **TYPE:** Multi-directional stepping, weight shifting, dynamic balance activities, large movements, multitasking such as yoga, tai chi, dance, boxing | **TYPE:** Sustained stretching with deep breathing or dynamic stretching before exercise |
| **CONSIDERATIONS:** Safety concerns due to risks of freezing of gait, low blood pressure, blunted heart rate response. Supervision may be required. | **CONSIDERATIONS:** Muscle stiffness or postural instability may hinder full range of motion. | **CONSIDERATIONS:** Safety concerns with cognitive and balance problems. Hold on to something stable as needed. Supervision may be required. | **CONSIDERATIONS:** May require adaptations for flexed posture, osteoporosis and pain. |

**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.

AMERICAN COLLEGE of SPORTS MEDICINE LEADING THE WAY

Parkinson's Foundation

# Sensei Fonseca

# WPC 2019

# KICKOUT-PD Pilot

PLOS ONE

RESEARCH ARTICLE

KICK OUT PD: Feasibility and quality of life in the pilot karate intervention to change kinematic outcomes in Parkinson's Disease

Jori E. Fleisher[1]*, Brianna J. Sennott[2], Erica Myrick[1], Claire J. Niemet[1], Monica Lee[2], Courtney M. Whitelock[2], Maya Sanghvi[3], Yuanqing Liu[1], Bichun Ouyang[1], Deborah A. Hall[1], Cynthia L. Comella[1], Joshua Chodosh[4,5]

1 Department of Neurological Sciences, Rush University Medical Center, Chicago, Illinois, United States of America, 2 Rush Medical College, Rush University Medical Center, Chicago, Illinois, United States of America, 3 Yale College, Yale University, New Haven, Connecticut, United States of America, 4 Department of Medicine, New York University School of Medicine, New York, New York, United States of America, 5 Medicine Service, VA New York Harbor Healthcare System, New York, New York, United States of America

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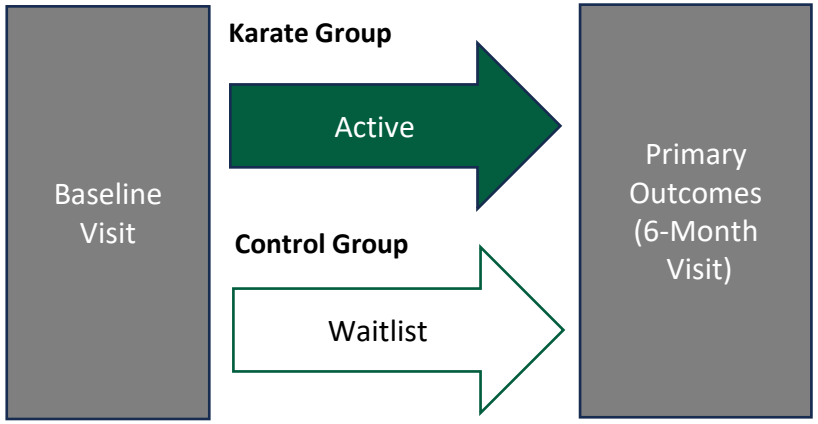
Check for updates

- Single group, unblinded 10-week trial of twice weekly, hourlong group karate classes
- 15/19 participants completed study
- 87% adherence
- Significant improvement in quality of life (Mean change in PDQ-8 of 5.9, *d* 0.83, p = 0.01)
- 53% continued karate **six months after study ended**

Fleisher JE et al. PLoS One. 2020 Sept 9;15(9)

# KICKOUT-PD Trial

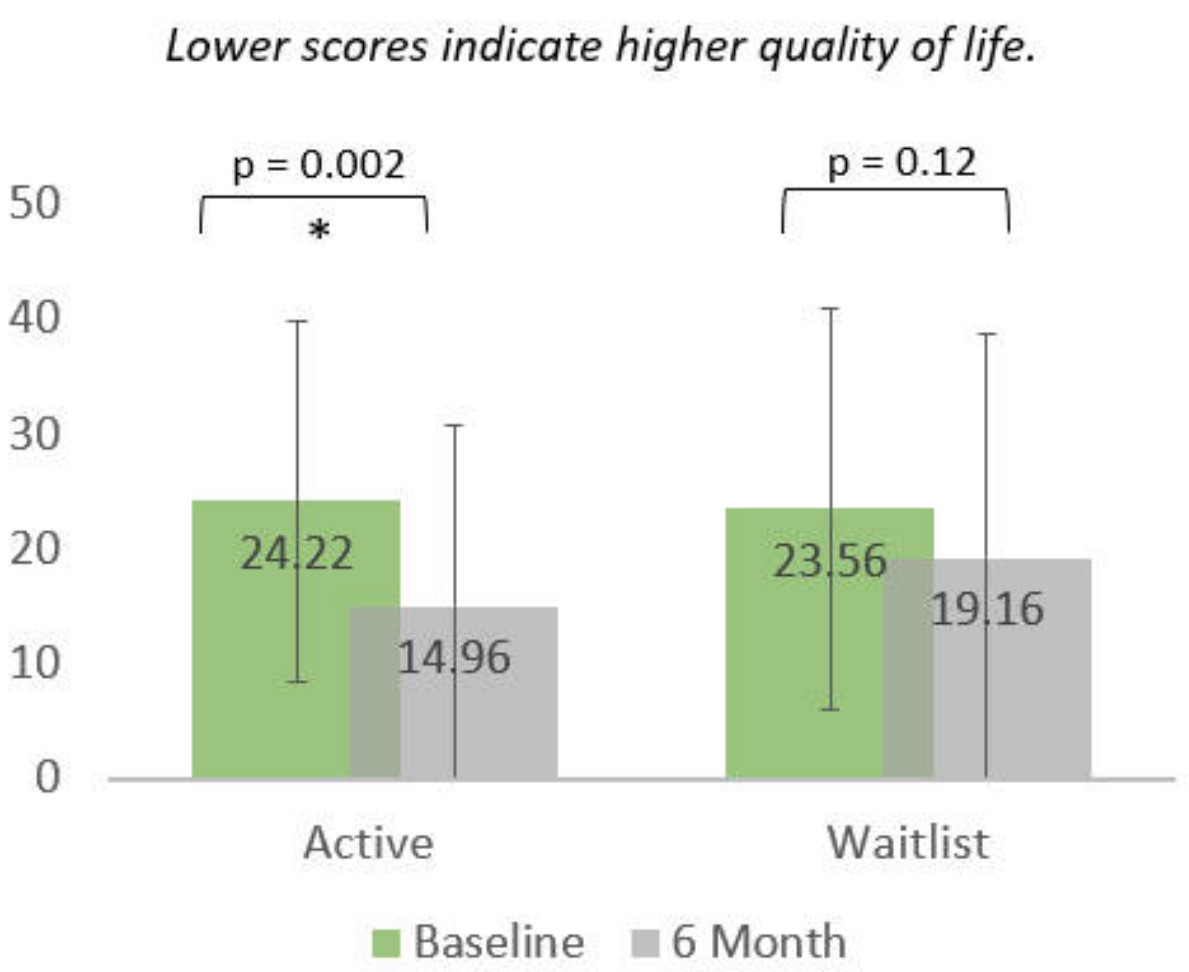



- **Recruited 52 individuals, largely from Rush Movement Disorders:**
  - PD diagnosis, HY 1-3, ± meds, DBS, PT, OT
  - Age 30-90 years
  - English-speaking
  - Live within greater Chicago area (~45 minute drive to one of five karate studios)
- **Randomized 1:1 to active or waitlist-control**

- **Baseline group study visit at RUMC**
  - Prescribed exercise for PD, ”150 minutes/week, moderate exertion”
  - Surveys: Demographics, PDQ-8, physical activity
  - Mobility: TUG, MDS-UPDRS III (blinded rater)
- **Active:** 6m twice weekly, hourlong classes taught by certified, black belt instructors with ≥1 years’ experience teaching adult karate; all received PD training from PI; attendance recorded by staff
- **Six Month study visit at RUMC**: identical assessments + satisfaction,

# Results

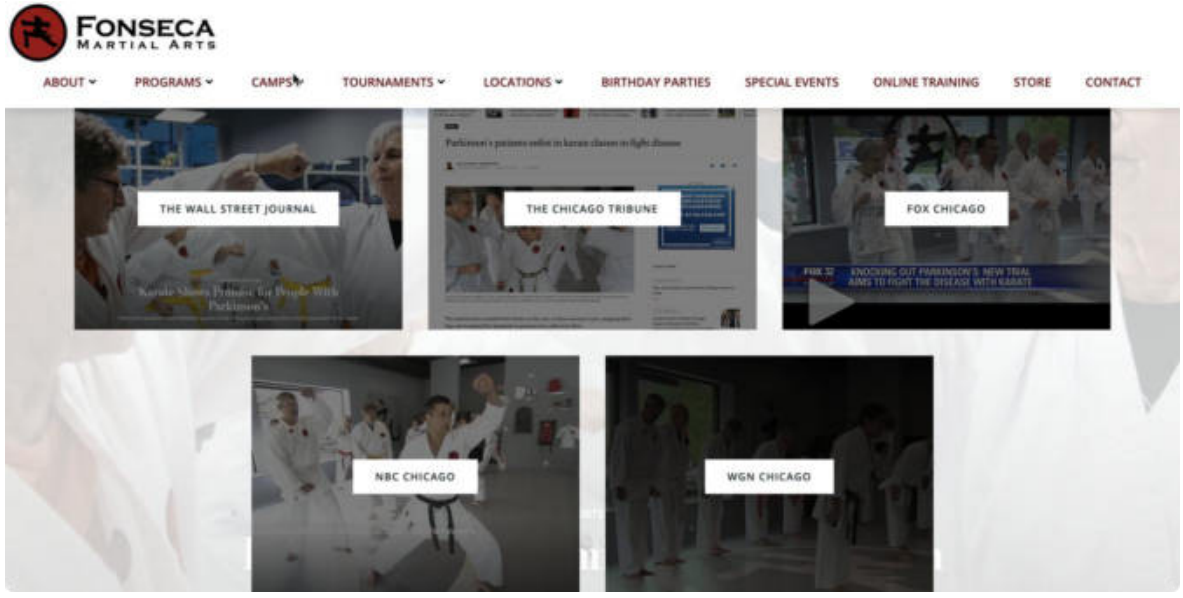
- Adherence: Mean attendance at 51 classes over 6 months: 92.5% (SD 5.48%)
- Satisfaction:
  - 94.4% of active participants planned to continue karate beyond 6 months (out of pocket)
  - 100% “would recommend KICKOUT PD to others”




| Active | | | | Waitlist | | | |
|---|---|---|---|---|---|---|---|
| n | Baseline | 6 Month | p-value | n | Baseline | 6 Month | p-value |
| 27 | 24.22 (15.71) | 14.96 (15.88) | 0.002 | 25 | 23.56 (17.49) | 19.16 (19.54) | 0.12 |

# KICKOUT-PD Takeaways

- Yes! Still going strong: https://www.fonsecamartialarts.com/kickoutpd/
- Karate is *an* answer, not *the* answer
- Large-amplitude movement, aerobic + strength exercise
- Involve voice and working memory
- Appreciate growth and achievements in oneself and others
- Accountability, camaraderie, community



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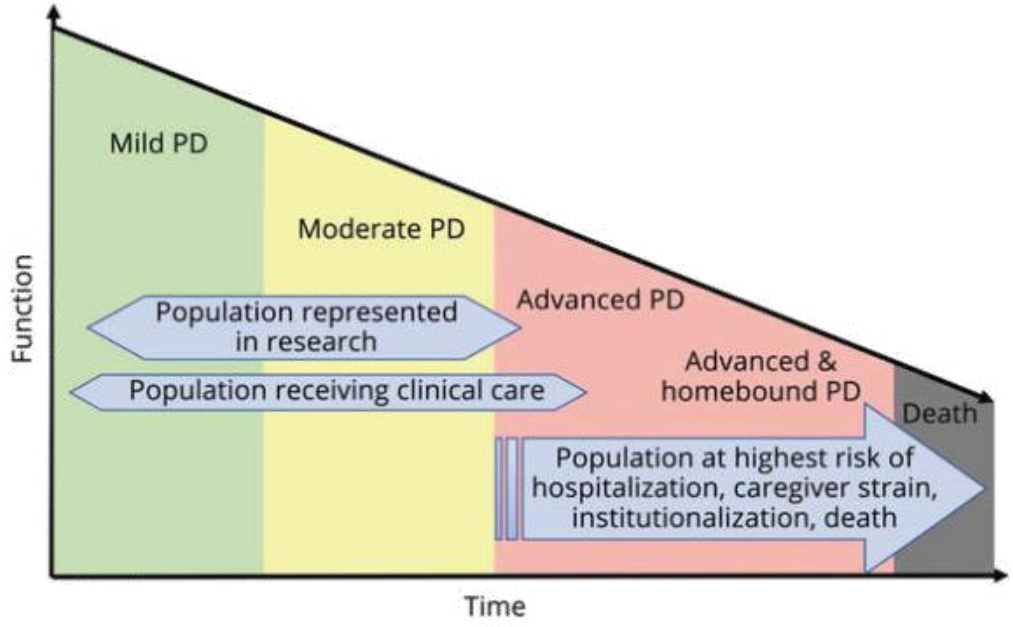
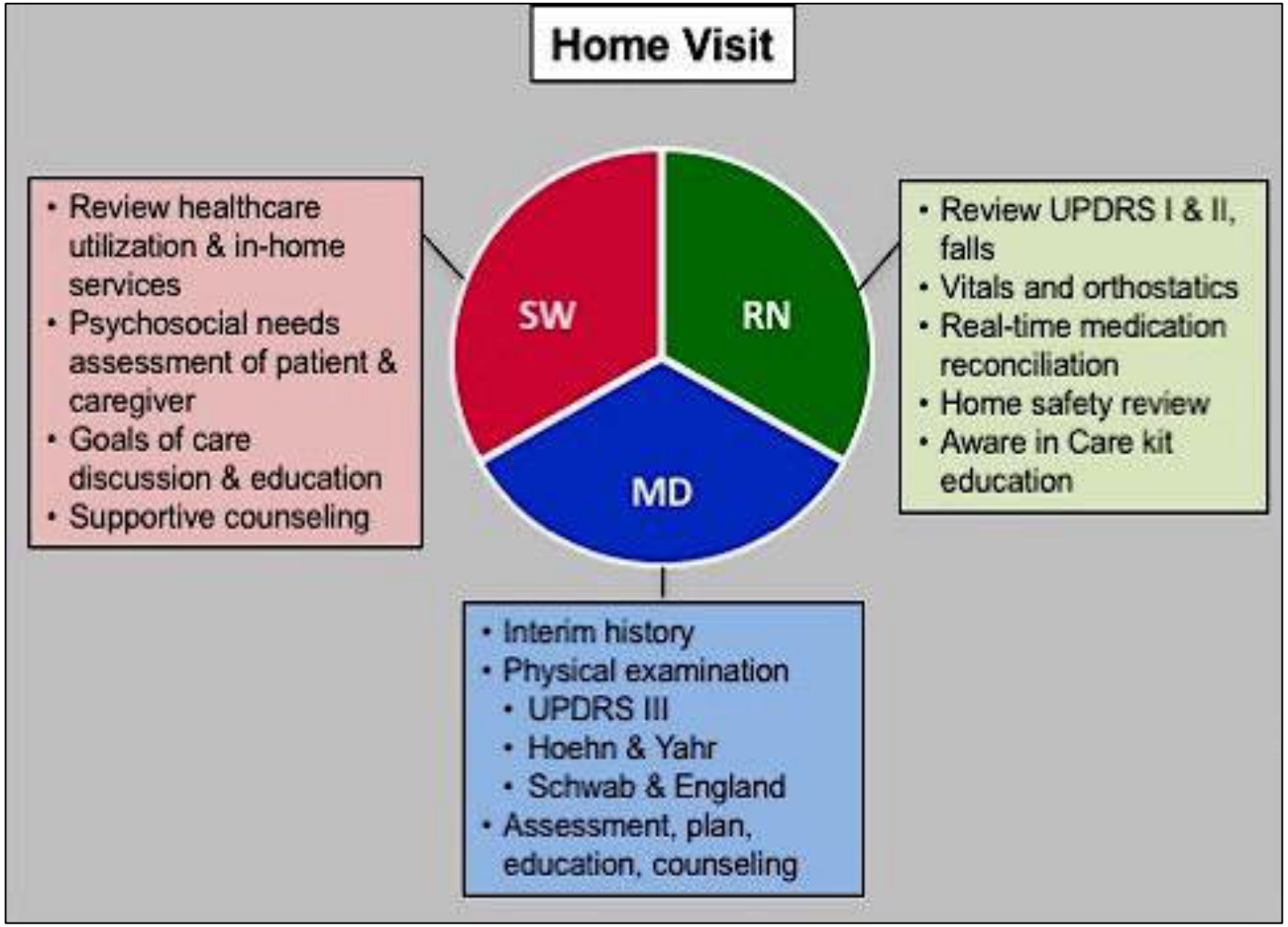
# Fleisher Lab:

## Novel interventions to reach vulnerable PD and related populations and improve quality of life in those individuals *today*

- **Hypothesis 1:** ***Human connection is required to reach these populations and interventions leveraging human connection can change trajectories and health outcomes***
- **Hypothesis 2:** ***The science and outcomes will be stronger, more generalizable, and more sustainable if we build it together***



# Individuals with advanced PD… are amenable to home visits & research




*Fleisher JE, et al. J Am Geriatr Soc. 2018 Jul;66(6):1226-1232*

# Home visits stabilized quality of life over one year, despite disease progression

- Subset of prior cohort (n = 27):
  - PD only, MMSE >20 at visit 1
  - Four visits in ~12 months
- Outcomes:
  - Mean UPDRS total score worsened from 60.5 to 72.3 ($p < 0.001$)
  - **No significant changes in any of 8 quality of life domains studied**
  - No significant change in acute healthcare utilization ($p = 0.15$)

Fleisher JE, et al. *Neurol Clin Pract* 2020

# IN-HOME-PD: The effects of longitudinal telehealth-enhanced interdisciplinary home visits on care and quality of life for homebound individuals with Parkinson's disease

Jori E. Fleisher [a,b,*], Serena P. Hess [a], Ellen C. Klostermann [a], Jeanette Lee [c], Erica Myrick [a,1], Daniela Mitchem [c], Claire Niemet [a], Katheryn Woo [a,d], Brianna J. Sennott [a,e], Maya Sanghvi [a,2], Natalie Witek [a], James C. Beck [f], Jayne R. Wilkinson [g,h], Bichun Ouyang [e], Deborah A. Hall [a], Joshua Chodosh [i,j]

**Table 1** (*continued*)

| Characteristic | IN-HOME-PD Participants, N = 65 | POP Controls, N = 319 | p-value[a] | Rush COE eligibility pool, HY ≥ 3 N = 1015 | p-value[b] |
|---|---|---|---|---|---|
| Hoehn & Yahr Stage, n (%) | | | <0.001 | | <0.0001 |
| 3 | 14 (21.54) | 271 (84.95) | | 613 (60.39) | |
| 4 | 41 (63.08) | 40 (12.54) | | 290 (28.57) | |
| 5 | 10 (15.38) | 8 (2.51) | | 112 (11.03) | |
| PD duration, median (IQR) | 15 (10) | 11 (7)[9] | 0.003 | Data not available | |
| MoCA items, mean (SD) | | | | Data not available | |
| Immediate 5-item recall | 3.52 (1.36)[4] | 4.37 (0.9)[6] | <0.001 | | |
| Delayed 5-item recall | 1.89 (1.67)[4] | 3.48 (1.37)[7] | <0.001 | | |
| Verbal fluency | 10.87 (6.07)[4] | 17.16 (6.3)[8] | <0.001 | | |

**Table 1**
Baseline characteristics of IN-HOME-PD participants, Parkinson's Outcomes Project matched control group, and Rush Center of Excellence outpatient clinic.

| Characteristic | IN-HOME-PD Participants, N = 65 | POP Controls, N = 319 | p-value[a] | Rush COE eligibility pool, HY ≥ 3 N = 1015 | p-value[b] |
|---|---|---|---|---|---|
| Age at baseline, mean (SD) | 78.94 (7.56) | 70.11 (7.83) | <0.001 | 74.96 | <0.001 |
| Gender, n (%) | | | 0.39 | | 0.09 |
| Male | 44 (67.69) | 198 (62.07) | | 563 (55.47) | |
| Female | 21 (32.31) | 121 (37.93) | | 452 (44.53) | |
| Race, n (%) | | | <0.001 | | 0.06 |
| Caucasian | 47 (74.60) | 307 (96.24) | | 767 (85.32) | |
| African American | 9 (14.29) | 1 (0.31) | | 79 (8.79) | |
| Asian | 7 (11.11) | 7 (2.19) | | 43 (4.78) | |
| Pacific Islander | 0 | 1 (0.31) | | 0 | |
| Other | 0 | 3 (0.94) | | 10 (1.11) | |
| Missing | 2 | 0 | | 116 | |
| Ethnicity, n (%) | | | 0.30 | | 0.27 |
| Hispanic | 4 (6.15) | 11 (3.45) | | 104 (10.38)[13] | |
| Non-Hispanic | 61 (93.85) | 308 (96.55) | | 898 (89.62) | |
| Education, n (%) | | | <0.001 | Data not available | |
| Less than high school | 9 (13.85) | 6 (1.94) | | | |
| High school | 9 (13.85) | 53 (17.15) | | | |
| Associate's degree | 12 (18.46) | 78 (25.24) | | | |
| Bachelor's degree | 10 (15.38) | 82 (26.54) | | | |
| Graduate degree | 25 (38.46) | 90 (29.13) | | | |
| Missing | 0 | 10 | | | |
| Marital status, n (%) | | | 0.001 | | 0.21 |
| Single | 3 (4.62) | 19 (5.96) | | 109 (10.75)[5] | |
| Married | 44 (67.69) | 268 (84.01) | | 699 (68.93) | |
| Widowed | 14 (21.54) | 17 (5.33) | | 130 (12.82) | |
| Divorced | 4 (6.15) | 15 (4.70) | | 72 (7.1) | |

NIH NINDS

Table 2
Comparison of overall and domain-specific health-related quality of life between IN-HOME-PD participants and Parkinson's Outcomes Project matched control group.

| | IN-HOME-PD Participants | | | | | POP Control Group | | | | | Between Groups |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | N | Baseline | 1 year | p-value[a] | Effect size[b] | N | Baseline | 1 year | p-value[a] | Effect size[b] | p-value[c] |
| PDQ-39, mean (SD) | | | | | | | | | | | |
| Overall quality of life (PDQ-39 SI) | 50 | 37.99 (14.10) | 37.38 (12.85) | 0.74 | 0.05 | 310 | 29.53 (14.61) | 32.56 (15.43) | **<0.001** | *0.27* | **0.04** |
| Mobility | 50 | 64.75 (19.82) | 73.75 (20.24) | **0.01** | *0.39* | 313 | 43.39 (27.01) | 49.15 (27.94) | **<0.001** | *0.30* | 0.29 |
| Activities of daily living | 51 | 55.07 (22.95) | 61.44 (25.74) | **0.03** | *0.32* | 313 | 37.37 (24.68) | 41.11 (25.26) | **0.001** | 0.19 | 0.38 |
| Emotional well being | 51 | 32.11 (19.33) | 32.35 (20.06) | 0.93 | 0.01 | 313 | 26.72 (18.75) | 30.44 (20.46) | **<0.001** | 0.21 | 0.21 |
| Stigma | 51 | 23.04 (24.86) | 17.03 (21.62) | 0.08 | *0.25* | 312 | 17.49 (18.71) | 19.95 (20.68) | **0.02** | 0.14 | **0.02** |
| Social support | 51 | 11.93 (14.73) | 12.75 (15.49) | 0.74 | 0.05 | 311 | 11.79 (15.32) | 13.53 (16.22) | **0.03** | 0.12 | 0.72 |
| Cognitive impairment | 51 | 34.93 (20.12) | 34.07 (20.97) | 0.74 | 0.05 | 312 | 30.97 (19.99) | 32.93 (21.60) | 0.06 | 0.11 | 0.30 |
| Communication | 51 | 38.40 (23.63) | 32.68 (22.66) | 0.09 | *0.24* | 311 | 31.65 (23.69) | 36.63 (23.69) | **<0.001** | *0.26* | **0.003** |
| Bodily discomfort | 51 | 41.50 (28.41) | 31.54 (25.73) | **0.03** | *0.31* | 312 | 36.73 (23.26) | 36.70 (22.91) | 0.98 | 0.00 | **0.04** |

[a]p-value for comparison between baseline and 1 year within case and control group.
[b]Cohen's *d* used to calculate effect size of baseline to 1 year change within each group.
[c]p-value for comparison of change (from baseline to 1 year) between case and control.
**Bolded** values indicate statistical significance, two-tailed alpha, $p < 0.05$.
*Italicized* values indicate Cohen's *d* effect size of small (0.2) or greater.
IN-HOME-PD: Interdisciplinary Home Visits for Parkinson's Disease; PDQ-39: Parkinson's Disease Questionnaire; POP: Parkinson's Outcomes Project.

**Home visits stabilized (improved?) quality of life**

# Although there can be MANY symptoms…

**Table 38.3** Selected common symptoms and accompanying pharmacologic and non-pharmacologic interventions used in interdisciplinary home visits

| Symptom/issue | Pharmacologic treatments | Non-pharmacologic treatments |
|---|---|---|
| Depression, anxiety | • Selective serotonin or serotonin–norepinephrine reuptake inhibitor | • Psychotherapy<br>• Relaxation and meditation exercises (printed, apps, websites) |
| Apathy | • *Treat underlying depression or anxiety if present*<br>• Consider stimulants | • Structured daily schedule |
| Cognitive impairment, dementia | • Deprescribe anticholinergics<br>• Acetylcholinesterase inhibitor<br>• Memantine | • Cognitive rehabilitation therapy<br>• Adult day programs, local senior centers<br>• Driving evaluation, revocation of license |
| Hallucinations, delusions | • Deprescribe exacerbating medications<br>• Low-dose quetiapine<br>• Low-dose clozapine<br>• Acetylcholinesterase inhibitor | • Caregiver education on redirection, distraction, not arguing/attempting to disprove delusions or hallucinations<br>• Home safety: adequate lighting, removal of firearms, driving evaluation |
| Insomnia, sleep–wake reversal, REM behavior disorder | • Melatonin for insomnia and/or REM behavior disorder (immediate release for sleep initiation, extended release for sleep disruption)<br>• Clonazepam for refractory insomnia and REM behavior disorder | • Sleep hygiene education<br>• Referral to sleep medicine if concern for sleep apnea<br>• Relaxation and meditation exercises<br>• Structured daily activity schedule<br>• Address bedroom safety hazards (sharp corners, absent nightlights, firearms) |
| Constipation | • Graduated bowel regimen to relieve and prevent constipation<br>– Polyethylene glycol<br>– Stool softeners, laxatives<br>• Reduce/replace contributing medications (e.g., narcotic pain medications) | • Constipation and nutrition education<br>• High-fiber recipes<br>• Strategies to increase fluid intake (e.g., flavored water) |

Fleisher, J.E., Woo, K., Chodosh, J. (2024). In: Malone, M.L., Boltz, M., Macias Tejada, J., White, H. (eds) Geriatrics Models of Care. Springer

# …nearly *all* can be improved* with medication and non-medication strategies

| | | |
|---|---|---|
| Orthostatic hypotension | • Deprescribe antihypertensives in collaboration with primary care or cardiology<br>• Fludrocortisone<br>• Midodrine or droxidopa | • Increase hydration and salt intake<br>• Compression stockings, abdominal binder<br>• Sleep with head of bed elevated, bed wedge to prevent supine hypertension |
| Unintentional weight loss | • Simplify complex medication regimens | • Exclude treatable/reversible causes, appetite-suppressing medications<br>• Confirm age-appropriate cancer screenings up to date<br>• Screen for dysphagia and dental pain<br>• Dietitian, speech-language pathology, and dental referrals<br>• Meal delivery services |
| Pain | • Distinguish and target musculoskeletal, neuropathic, and dystonic pain<br>• Musculoskeletal: NSAIDs, acetaminophen, topical capsaicin-menthol, or diclofenac preparations<br>• Neuropathic: gabapentin, pregabalin<br>• Dystonic: optimizing dopaminergic regimen, referral for botulinum toxin injections (outpatient only) | • In-home physical and occupational therapy<br>• Accessible exercise regimens, range of motion exercises to do with family or paid caregivers<br>• Relaxation and mindfulness techniques to cope with pain and discomfort |
| Falls | • Deprescribe sedating medications<br>• Assess for and treat orthostatic hypotension<br>• Assess for impulsivity; if present, consider reducing dopaminergics | • Medical alert systems<br>• Home safety evaluation<br>• Assistive devices (e.g., walker, (power) wheelchairs, grabbers to prevent falls while reaching)<br>• Decluttering/organization services |
| Caregiver strain, burnout | • Simplify medication regimen<br>• Optimize psychosis treatment and sleep–wake cycle | • Home health agencies<br>• Caregiver respite services<br>• Local support groups and individual psychotherapists, counselors<br>• Geriatric care management services |

Fleisher, J.E., Woo, K., Chodosh, J. (2024). In: Malone, M.L., Boltz, M., Macias Tejada, J., White, H. (eds) Geriatrics Models of Care. Springer

# The (in)evitable triggers for hospitalization and death

- **Leading causes of hospitalization:**
  - Falls
  - Urinary incontinence or infection
  - Dehydration ± metabolic derangements
  - Neuropsychiatric issues: hallucinations, delusions, agitation, depression, anxiety, dementia
  - **Caregiver strain**

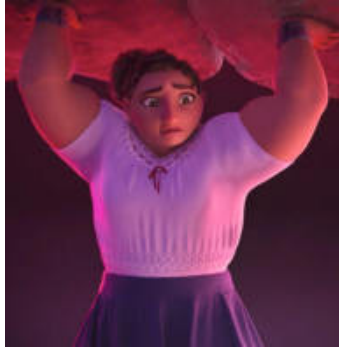
- Once hospitalized, individuals with PD and Lewy Body Dementia have excess iatrogenic injuries, longer lengths of stay

- ***Hypothesis: Many episodes of acute care utilization are preventable or manageable at home, if recognized early***
  - **Doing so requires an educated, engaged, observant caregiver**

Ornstein KA et al, 2020; Moens K et al, 2015. Fleisher JE et al, 2022; Kumar P et al, 2021; McKenzie ED et al, 2022

# Who is doing the heavy lifting?

# Parkinson's & LBD Caregivers: Overburdened, understudied



- >83% of community-dwelling people with PD or LBD rely on unpaid caregiving from family members → **18.5 billion hours of care valued at $232 billion**
- Nearly twofold loss of direct income among caregivers in 5 years
- PD/LBD family caregivers have higher caregiver strain, burden, and depression than caregivers of people with Alzheimer's Disease and related dementias
  - Combined deterioration in motor, cognitive, neuropsychiatric, and non-motor domains, plus unpredictability, motor & cognitive fluctuations
- **Paid caregivers:**
  - Not covered by insurance, including Medicare or hospice
  - Extremely expensive (~$US 30+/hour, or ~$5,000/week)
  - High demand, low supply
  - High turnover & burnout pre-COVID, worse post-COVID
  - Minimal to no training in dementia, PD, end-of-life care
  - *Not a sustainable option for most*

Corbett A et al, 2012; cdc.gov/aging/caregiving/Alzheimer; Svendsboe et al, 2016; Roland KP et al, 2019; Martinez-Martin P et al, 2019; Spears CC et al, 2019; Corey KL and McCurry MK, 2018; Riffin C et al, 2022.

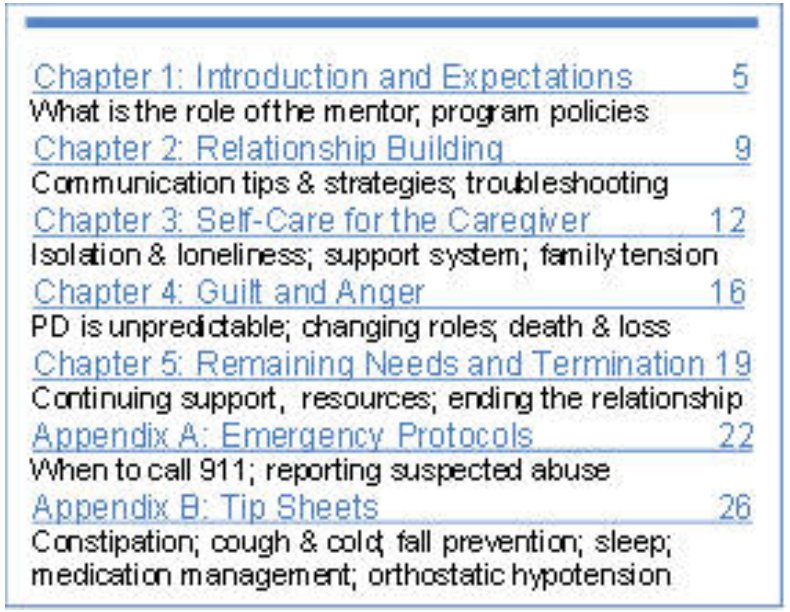
# Home visits are insufficient to change caregiver strain alone


Home Visit Pilot Study:

- Among 10 caregivers over 1 year, strain increased from mild to moderate (17.1 to 23.2, p = 0.04)
- Among 3 who withdrew, median V1 baseline was 42 (range 29-55) suggesting severe strain
- Conclusion: home visits aren't enough to mitigate caregiver strain


K23 IN-HOME-PD: Home Visit + Peer Mentoring Pilot:

- 65 patient-caregiver pairs receiving 4 visits over 1 year
- 34 experienced caregivers, 6 hours of training to become **peer mentor**
- Caregiver matched with a peer mentor for 16 weeks (between V2-V3)



# IN-HOME-PD Caregivers:
## Greater baseline strain than non-equivalent controls, stable over one year

- 34 former or active experienced caregivers completed training
- 51 of 61 eligible caregivers of homebound PD participants enrolled in mentoring, 3 withdrew
- Median of 11 calls in 16 weeks, 30 minutes' duration (IQR 20-45); mean satisfaction 91/100



**Table 3**
Comparison of overall and dimension-specific caregiver strain between IN-HOME PD and POP caregivers.

| | IN-HOME-PD Caregivers | | | | POP Caregivers | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | N | Baseline | 1 year | p [1] | N | Baseline | 1 year | p [1] | p[2] |
| Multidimensional Caregiver Strain Index, mean (SD) | | | | | | | | | |
| **Total caregiver strain** | 47 | 23.34 (9.43) | 24.32 (9.72) | 0.51 | 154 | 16.45 (10.33) | 17.97 (10.88) | 0.01* | 0.73 |
| **Physical strain** | 49 | 4.27 (3.09) | 4.69 (2.75) | 0.33 | 156 | 2.76 (2.54) | 3.13 (2.96) | 0.03* | 0.90 |
| **Social constraints** | 48 | 7.83 (3.41) | 8.13 (3.69) | 0.60 | 156 | 5.93 (3.86) | 6.23 (3.86) | 0.16 | 0.99 |
| **Financial strain** | 49 | 1.41 (1.64) | 1.51 (1.84) | 0.68 | 154 | 0.62 (1.07) | 0.71 (1.08) | 0.28 | 0.97 |
| **Time constraints** | 49 | 4.61 (1.82) | 4.55 (2.01) | 0.86 | 156 | 3.24 (2.33) | 3.59 (2.15) | 0.02* | 0.27 |
| **Interpersonal strain** | 49 | 4.04 (3.45) | 4.02 (3.28) | 0.96 | 156 | 2.73 (2.52) | 3.07 (2.94) | 0.08 | 0.38 |
| **Demanding/manipulative** | 48 | 1.06 (1.39) | 1.15 (1.52) | 0.72 | 155 | 1.19 (1.61) | 1.25 (1.51) | 0.64 | 0.89 |

$p^1$ = value for comparison between baseline and 1 year within case and control group.
$p^2$ = value for comparison of change (from baseline to 1 year) between case and control.
*$p < 0.05$.
IN-HOME-PD: Interdisciplinary home visits for Parkinson's Disease; MCSI: Multidimensional Caregiver strain index; POP: Parkinson's Outcomes Project.

# Learning to PERSEVERE

per·se·vere

/ˌpərsəˈvir/

Peer Mentor Support and Caregiver Education in Lewy Body Dementia

- Focus groups of former mentors, former mentees, and *de novo* PD & LBD family caregivers to review & revise curriculum
- ENTIRELY virtual; opened recruitment nationally in partnership with LBDA & PF email lists & Facebook groups
- Trained 36 new mentors virtually from across the US
- Recruited 30 new mentees; matched mentors & mentees by preferences using card sorting exercise
- Pairs communicated by phone or videoconference using revised curriculum for 16 weeks

Fleisher JE et al. Parkinsonism Relat Disord. 2023 Aug;113:105492

# Despite active caregiving demands or bereavement, LBD caregivers prioritized *Learning to PERSEVERE*

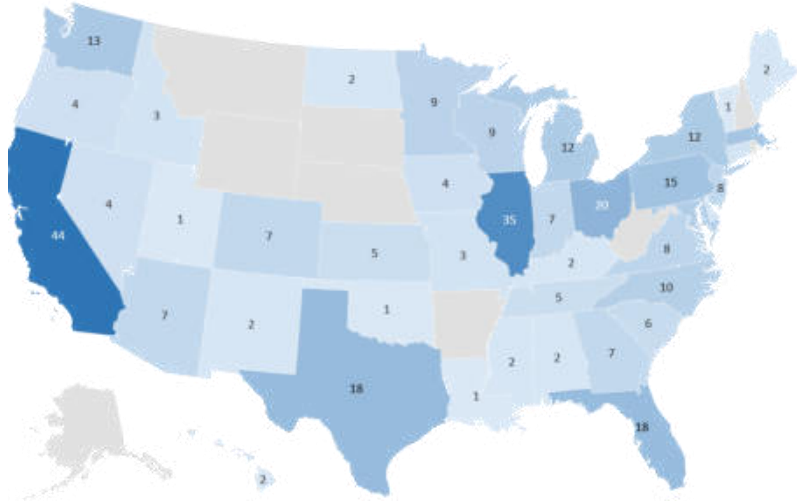
- 30 mentor-mentee pairs completed 424 calls (15 calls/dyad, median 45 min)
- 100% found calls useful; 100% would recommend to other LBD caregivers
- 90% of mentors would serve as mentors in future
- **50% of mentees would serve as mentors in future**

| Results of Stage Ib: Learning to PERSEVERE (2020-2021) | | | |
|---|---|---|---|
| **Assessment** | **Baseline mean (SD)** | **Post-mentoring mean (SD)** | **p-value** |
| **Mentor Outcomes : n = 30** | | | |
| LBD Knowledge Test | 55.83 (13.34) | 64.72 (12.70) | **0.01** |
| Dementia Attitudes Scale | 120.97 (11.76) | 121.60 (11.81) | 0.66 |
| **Mentee Outcomes : n = 28** | | | |
| LBD Knowledge Test | 50 (10.14) | 56.85 (14.88) | **0.02** |
| Pearlin Mastery scale | 32.46 (7.57) | 33.04 (6.82) | 0.58 |
| Dementia Attitudes Scale | 104.25 (13.58) | 111.57 (9.38) | **0.001** |
| Geriatric Depression Scale | 5.0 (3.76) | 4.22 (3.19) | **0.04** |
| Zarit Burden Interview – Short form | 23.18 (8.25) | 22.18 (8.52) | 0.30 |

Fleisher JE et al. Parkinsonism Relat Disord. 2023 Aug;113:105492

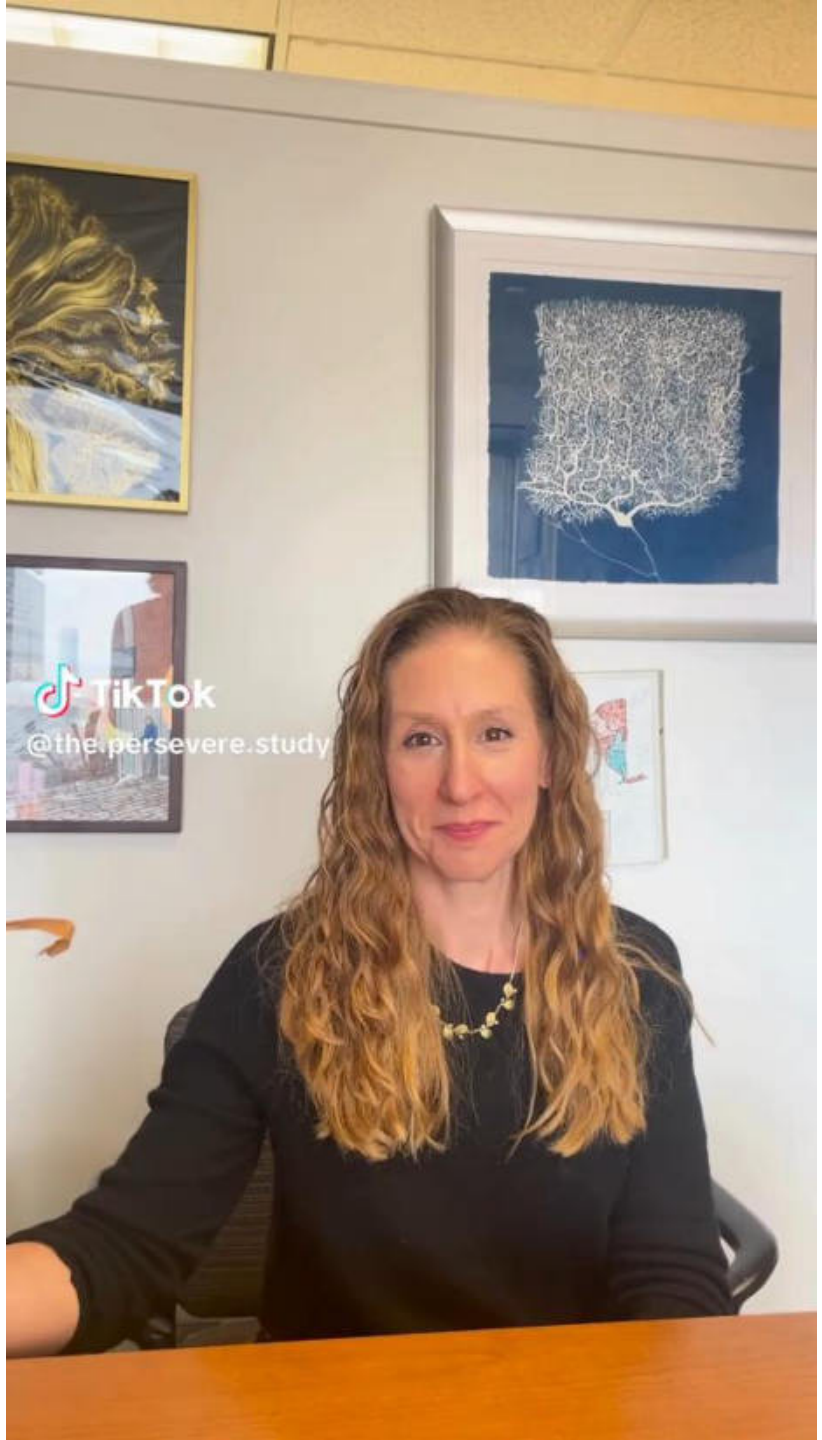
# National Randomized, Controlled Trial of Peer Mentoring Support and Education for PD and LBD Family Caregivers

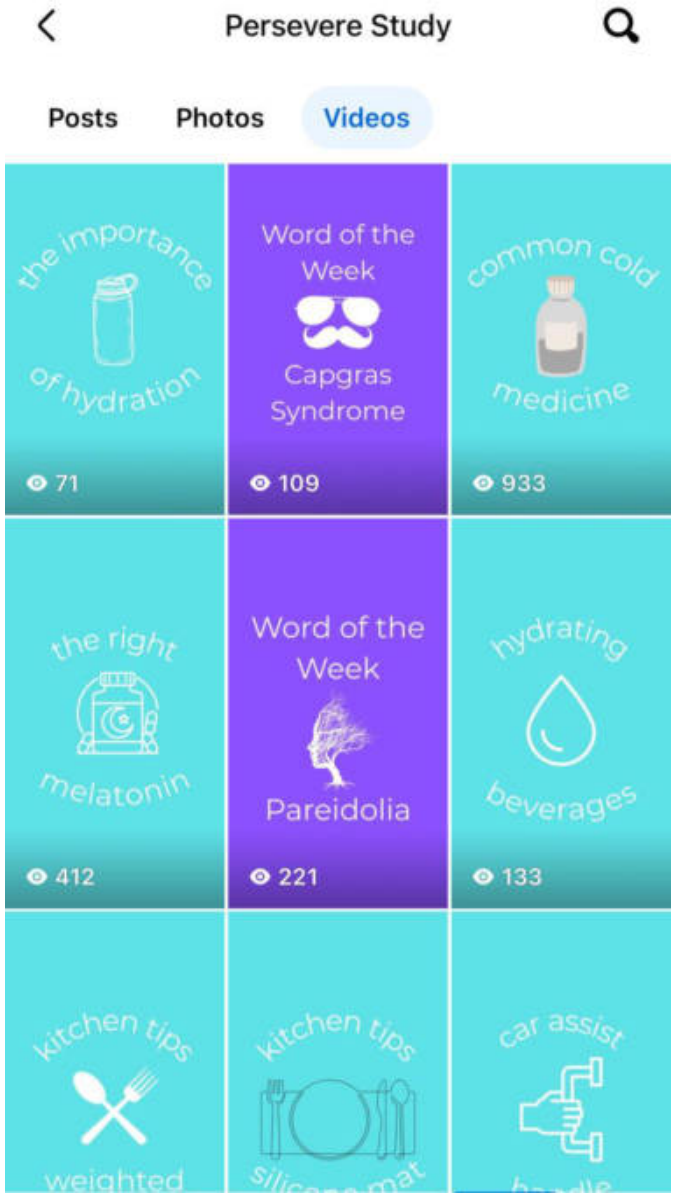
PERSEVERE
PEER MENTORING SUPPORT AND CAREGIVER EDUCATION



- Weekly, disease-specific, practical guidance through a 12-week curriculum with resources and activities, six months of follow-up
- Experienced caregivers (≥ 3 years' caregiving or loved one has passed) will be trained as **peer mentors** (n=180) to support newer caregivers
- **Caregivers** (n = 502) whose loved ones have had cognitive changes <3 years:
  - Half assigned to the active intervention group (full curriculum + weekly calls with matched mentor)
  - Half assigned to lighter intervention group (existing resources only, no mentor)
- **All participation is virtual**; biweekly surveys are completed online

- **Share with your friends & families!** We've got flyers, support group talks, and more to share!
- https://redcap.link/PERSEVERE1 or email persevere@rush.edu
- **Follow us!** The.Persevere.Study on TikTok & Instagram, Persevere Study on Facebook

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PERSEVERE

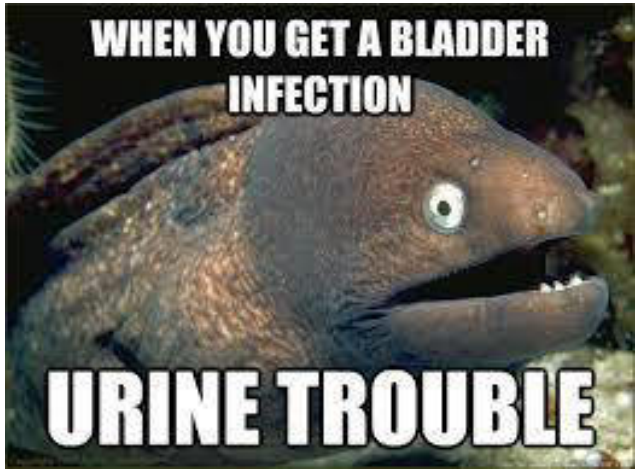
PEER MENTORING SUPPORT AND CAREGIVER EDUCATION

## Interested in learning more or participating?

- Scan the QR code to the left!
- Visit https://redcap.link/PERSEVERE1 to watch a video with more information about the study
- Listed on clinicaltrials.gov, Fox Trial Finder, alzheimers.gov, LBDA.org, The New Normal
- **Email us directly at** persevere@rush.edu
- **Follow us! The.persevere.study** on TikTok & Instagram

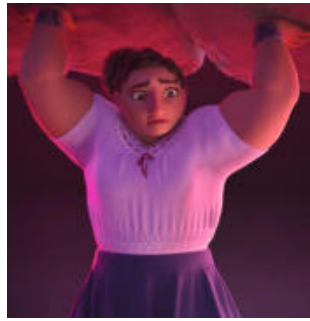
# Conclusions & Takeaways

- **Myths busted:**
  1. **Medications, including levodopa, do not stop working**
  2. **Levodopa is both our safest AND most powerful – the better you function today, the better you function tomorrow**
  3. **People are living and thriving with advanced PD – many symptoms, many options, stay connected**
  4. **Lewy Body Dementia umbrella includes Parkinson's Disease (chicken) and Dementia (egg)**
  5. **Any sudden change in your PD symptoms *isn't usually PD* – think infection, dehydration, and take action fast to avoid the hospital!**



# Conclusions & Takeaways

- Movement is medicine – you must exercise!
  - **Karate, along with dance, biking, boxing, drumming, swimming, resistance training: ALL work. Which will you enjoy, stick with, and build a community around?**
- Homebound individuals & care partners are reachable
  - **Amenable to care and research, have many treatable symptoms, and we can stabilize or even improve quality of life**



- Despite high strain, caregivers willingly share invaluable lived experience + mentor newer caregivers, who improve their own knowledge and attitudes
  - **One of the biggest sources of caregiver support & wisdom is in connecting with *others* on this journey. Join us to PERSEVERE!**
- Every research project or initiative I've undertaken has been spurred, championed, supported, or codesigned by people or care partners with PD
  - **Get involved, share your ideas, become an advocate or research partner**

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