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## Our Goals



Brief: What is Atypical Parkinsonism and how it differs from Parkinson's



Challenges shared by patients and families (And what we can do about them)

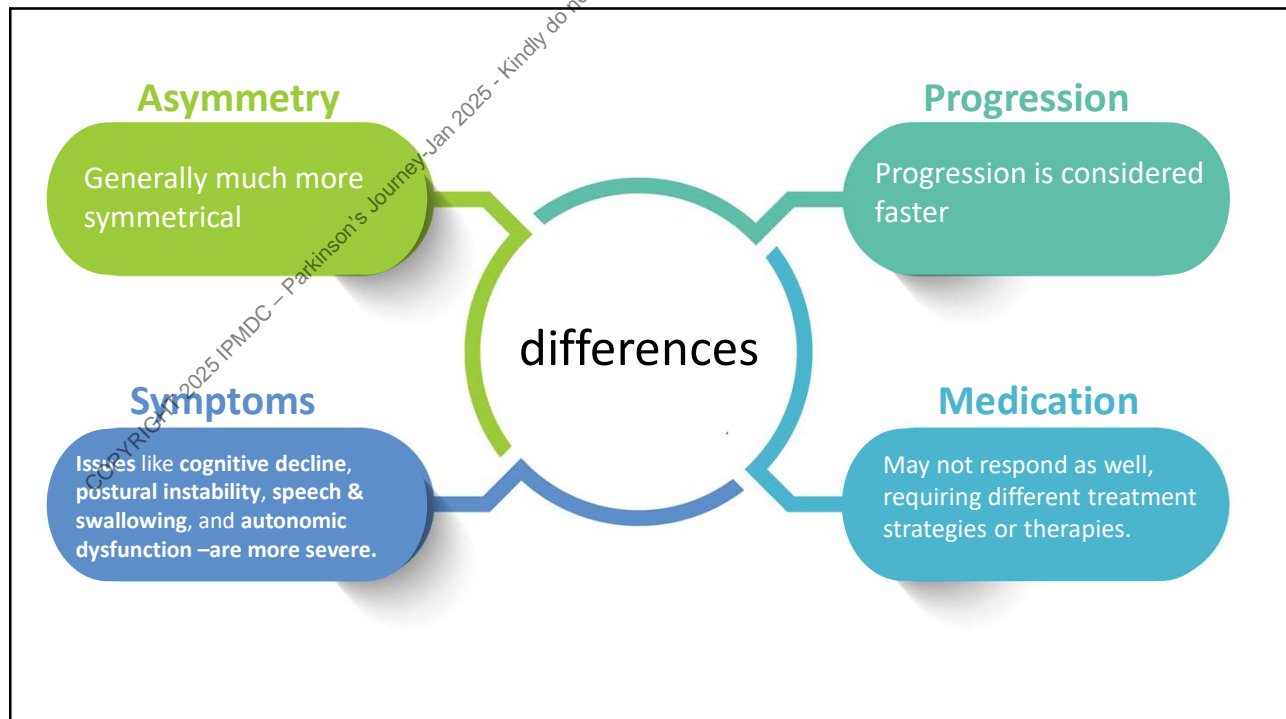
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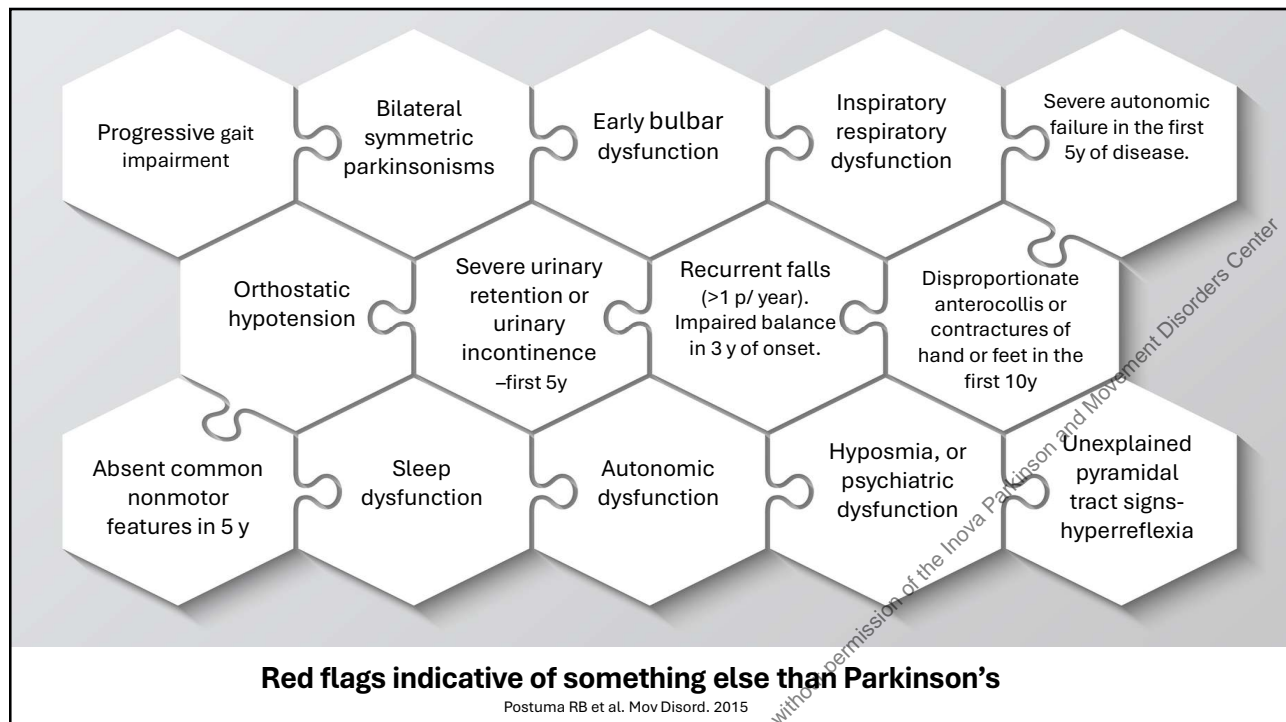
### Atypical Parkinsonism:

Presence of symptoms that are not supposed to be there!

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5

## Our Goals



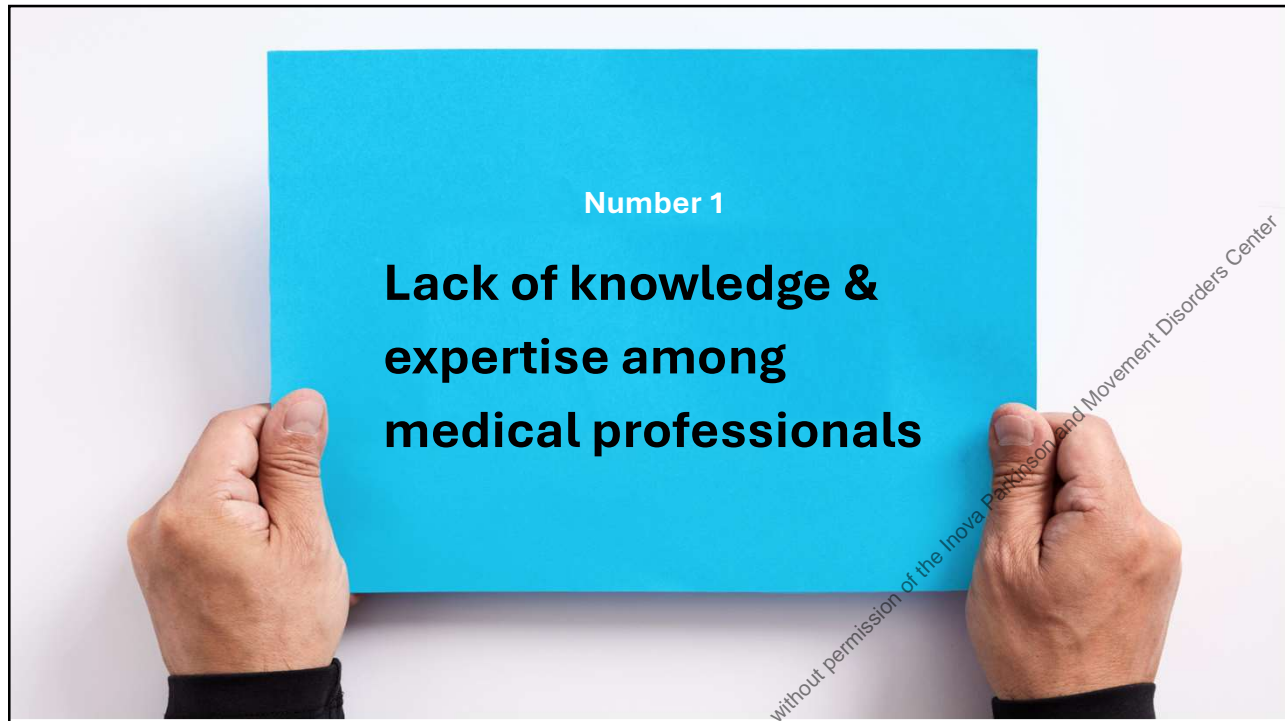
**Brief: What is Atypical Parkinsonism and how it differs from Parkinson's**



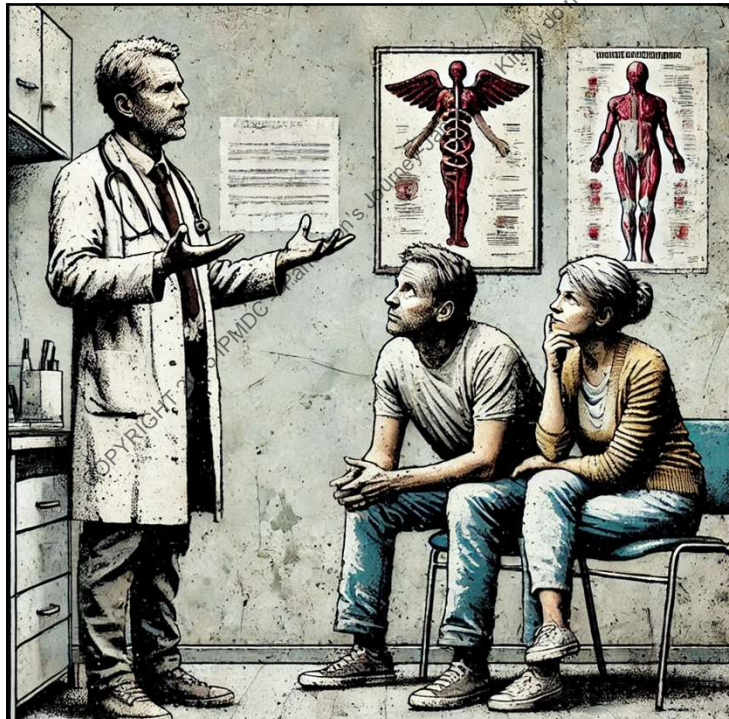
**Challenges shared by patients and families (and what we can do about them)**

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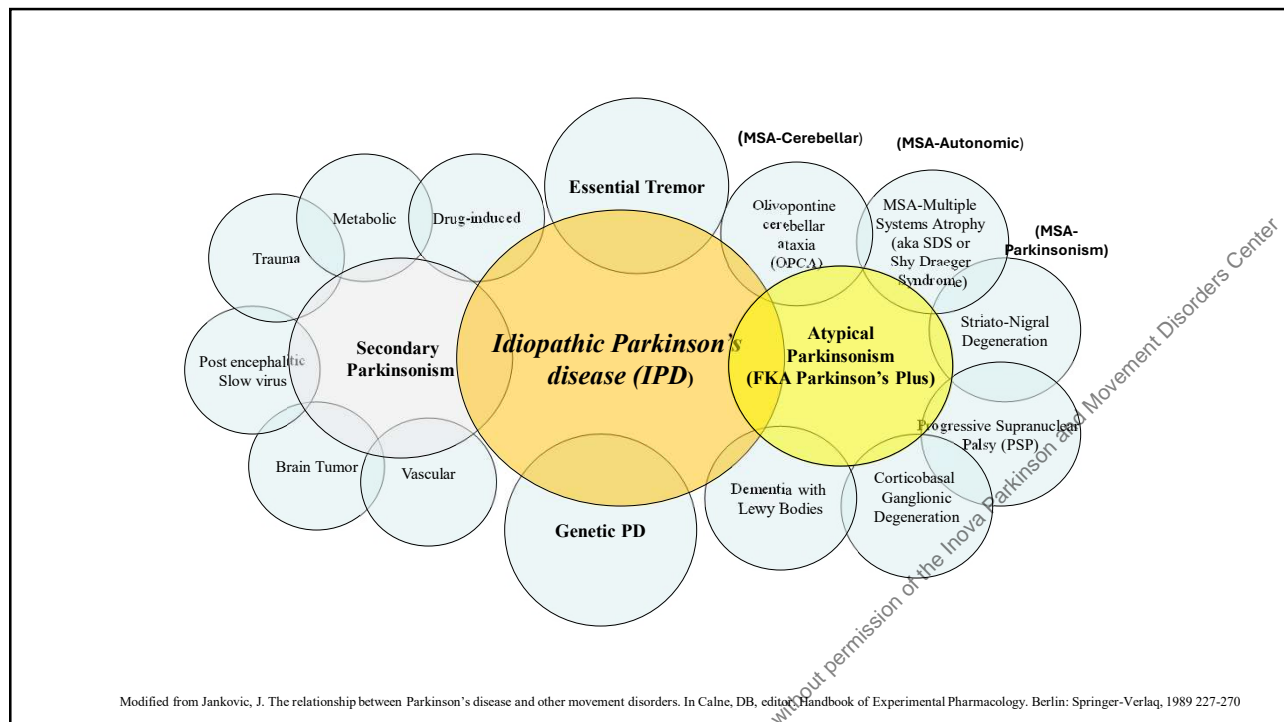
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Why don't people know more about these diseases?

- **Rarity of these conditions**


8




9



Progressive Supranuclear Palsy (PSP)



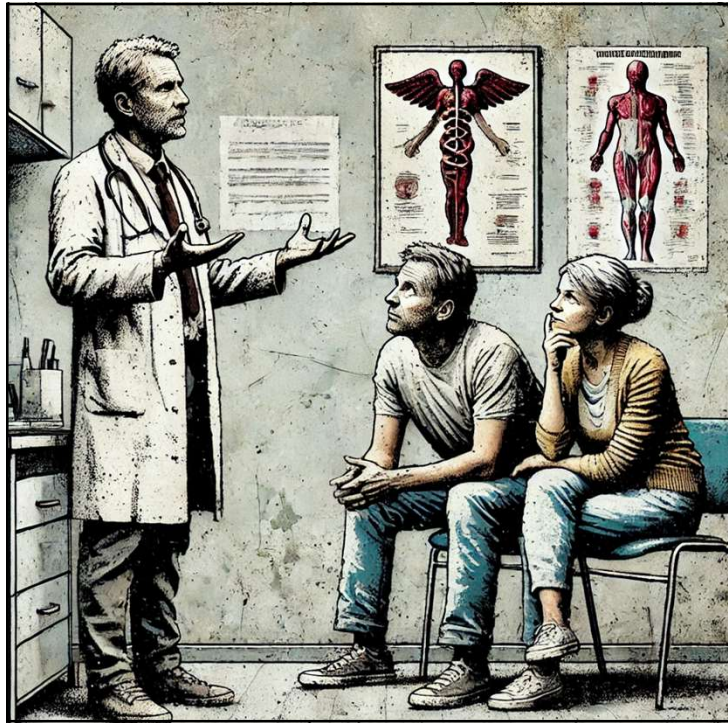
Multiple system atrophy (MSA)



Cortico-basal degeneration (CBD)

Multiple system atrophy (MSA-P   MSA-C  ...)
Progressive supranuclear palsy (PSP)
Corticobasal degeneration (CBD)
Diffuse Lewy body disease
Frontotemporal dementia with parkinsonism
Pallidal degenerations
Spinocerebellar ataxias (types 2,3,17)

10



Why don't people know more about these diseases?

- **Rarity of these conditions:**
  - Limited training in medical education
  - Limited evidence, specifically on practical treatment issues
- **Difficulties:**
  - In timely diagnosis
  - Accessing professionals with expertise

11

## Challenges of diagnosis:



### **Diagnostic delays** and confusion.

(Hesitation among doctors to deliver a diagnosis until certain).



**The shock** of shifting from a PD diagnosis to an atypical parkinsonism diagnosis.



**Limited resources** or guidance during the diagnostic process.

"It is mind boggling and honestly, I'd never even heard of PSP when it was first mentioned. I started to research as much as I could after the neurologist mentioned this might be what he had. I believe it was a NIH site that described PSP as a relentless neurodegenerative disease".

– Care partner for person living with PSP, 2025

12



"As for the hospice staff, none of them has ever worked with an individual with a PSP diagnosis. In fact, I'm not sure if they'd ever heard of it, but that is not surprising. I have yet to meet anyone who has heard of this".

– care partner for person living with PSP

"It's so frustrating to see that many therapists seem unfamiliar with my condition. They want me to do activities over and over and I get so tired for the rest of the day. It makes an already challenging situation even harder."

– person living with MSA

13

- Direct attention to **disease-specific interventions**.
- Increase capacity to **quickly identify complications**.
- Favor patient and family **adherence to treatments**.
- Adjust or set **realistic appropriate goals**
- **Better communication** with other health professionals



14



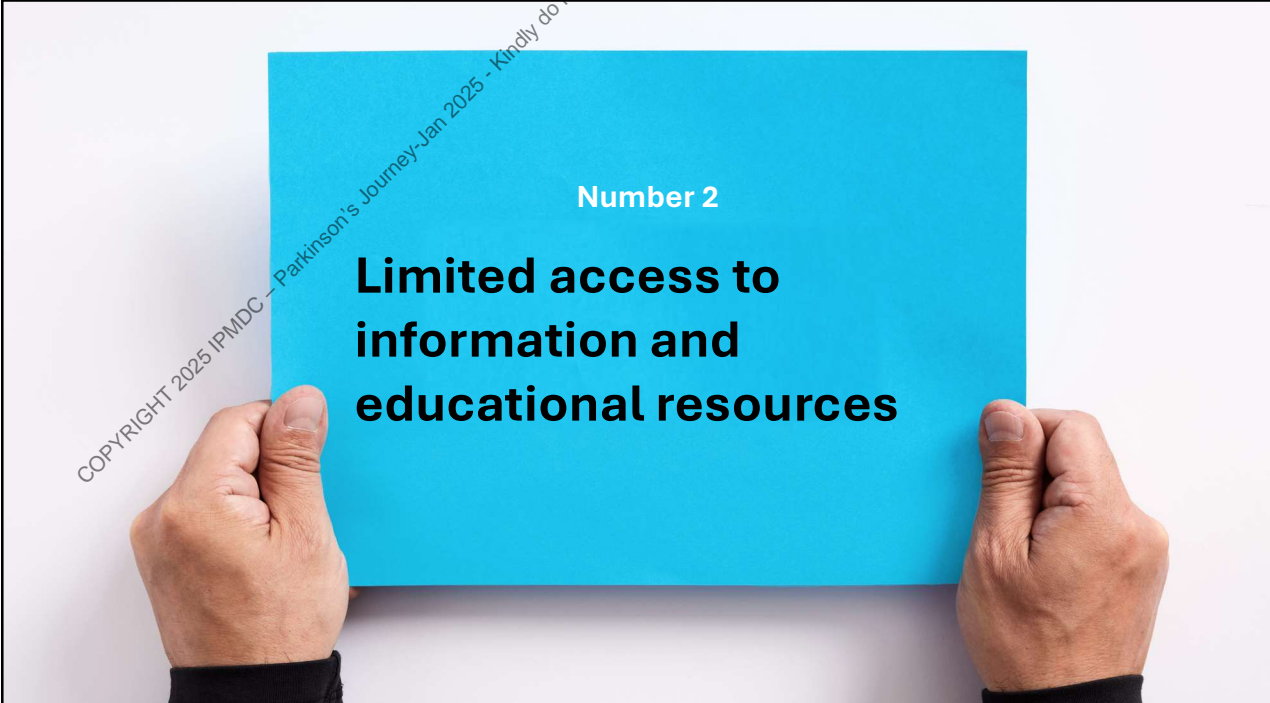
## What can we do about this?

**Collective level:** families & patients participating in advocacy organizations, patient and caregiver networks, share experiences, and advocate for greater awareness and resources.

**Individual level:** Provide resources to the team, friends, family you deal with.

**Keep a detailed diary** of symptoms (e.g., written notes, videos) to assist in diagnosis, care treatments and planning.

15




Number 2

## Limited access to information and educational resources

16



## "Shop local" - IPMDC Resources



Inova Parkinson's and Movement Disorders Center

Calendar Programs: Online Programs: In-person Newsletter Resources **Patient Assistance**


### PSP

#### Progressive Supranuclear Palsy

Cure PSP [psp.org](https://www.psp.org) is a national organization with information and resources for living with PSP, MSA and CBD.

IPMDC is working on finding ways to support local patients and families with PSP. We've listed the local programs we're aware of below, so please check back for updates!

<https://ipmdc.org/psp>



Inova Parkinson's and Movement Disorders Center

Calendar Programs: Online Programs: In-person Newsletter Resources **Patient Assistance**

### MSA

#### Multiple System Atrophy

**Multiple System Atrophy (MSA)** is a neurodegenerative disorder that affects various organ systems in the body. These systems are involved in controlling movement, balance, and coordination, while others regulate blood pressure, bladder function, and sexual function. MSA affects both men and women, typically between the ages of 50 and 60. It is very rare, affecting only 3 to 4 out of every 100,000 people. MSA is an "atypical" parkinsonism or Parkinson-plus syndrome because it shares symptoms with

<https://ipmdc.org/msa>

17



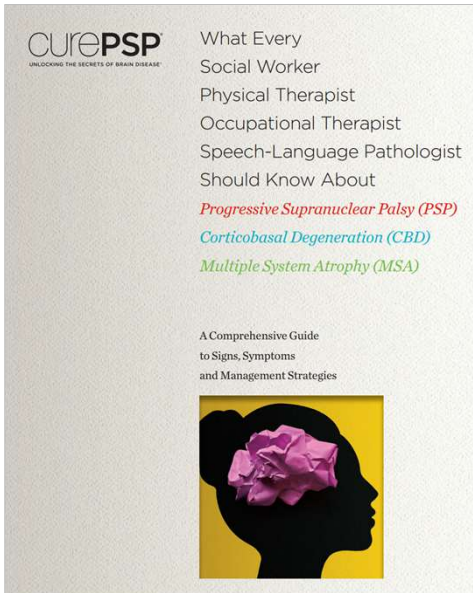
**curePSP**  
UNLOCKING THE SECRETS OF BRAIN DISEASE

Find support in your journey  
with PSP, CBD or MSA

**PATIENT AND FAMILY INFORMATION PACKETS**

**HEALTHCARE PROFESSIONALS INFORMATION PACKETS**

<https://www.psp.org/ineedsupport/resources>




**curePSP**  
UNLOCKING THE SECRETS OF BRAIN DISEASE

What Every  
Social Worker  
Physical Therapist  
Occupational Therapist  
Speech-Language Pathologist  
Should Know About

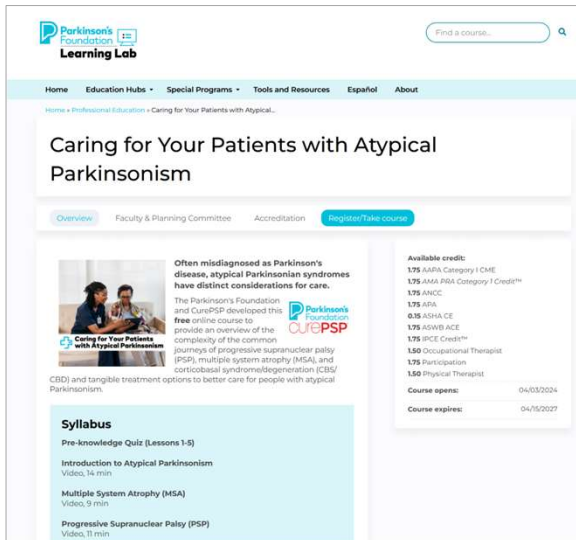
*Progressive Supranuclear Palsy (PSP)*  
*Corticobasal Degeneration (CBD)*  
*Multiple System Atrophy (MSA)*

A Comprehensive Guide  
to Signs, Symptoms  
and Management Strategies



18

## Educational resources for your team

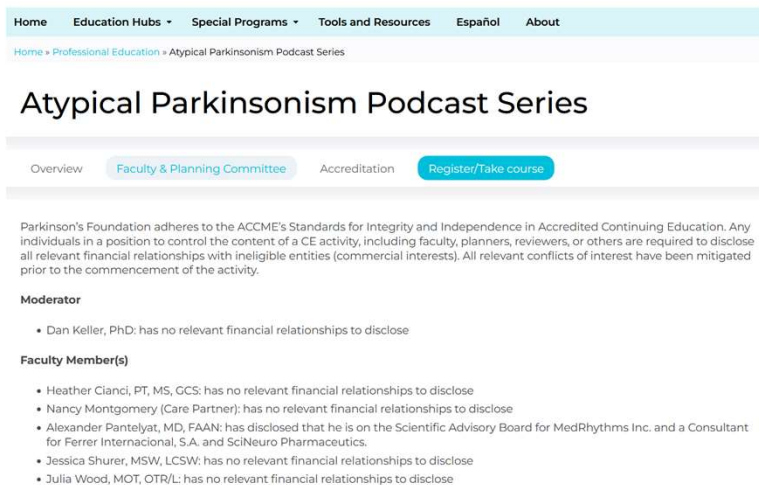


### Collaboration between Parkinson Foundation and CurePSP

- Accredited continuing ed for
  - Nurses
  - Occupational Therapists
  - Physical Therapists
  - Physicians
  - Physician Assistants
  - Psychologists
  - Social Workers
  - Speech-Language Pathologists

19

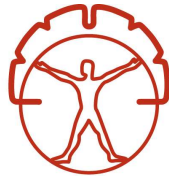
## A podcast is also available...



[https://education.parkinson.org/professional-education/atypical\\_podcast](https://education.parkinson.org/professional-education/atypical_podcast)

20

## Other resources for professionals...



International Parkinson and Movement Disorder Society

<https://www.movementdisorders.org>

### Fundamentals: Approach to Parkinsonism

Course Format	Release Date	Expiration Date
Self-Guided	August 30, 2024	August 30, 2027



#### Program Description

This module will serve as a practice

### Drug-Induced Movement Disorders: Parkinsonism

Course Format	Release Date	Expiration Date
Self-Guided	May 15, 2017	April 30, 2025



#### Program Description

The MDS course Drug-Induced Movement pathophysiology of drug-induced parkinson treatments.

### Multiple System Atrophy

Course Format	Release Date	Expiration Date
Self-Guided	October 22, 2024	October 22, 2027



#### Program Description

This module on Multiple System MDS MSA criteria and differences

21

## Resources for those living with the disease, and their families...

MISSION MSA

2025 International MSA Congress

Join us in Boston, Massachusetts as we come together as a community to gather, connect, and engage in discussions surrounding the latest scientific discoveries and best care practices related to multiple system atrophy (MSA).

<https://missionmsa.org/>

PSP Association

Home Info and Support Volunteering Fundraising Research About

NEW CARE

13 stand to support to a January: A group for Berek long-term care.

CREATING A BETTER FUTURE FOR AFFECTED BY PSP & CBD

<https://www.pspassociation.org.uk>

CurePSP

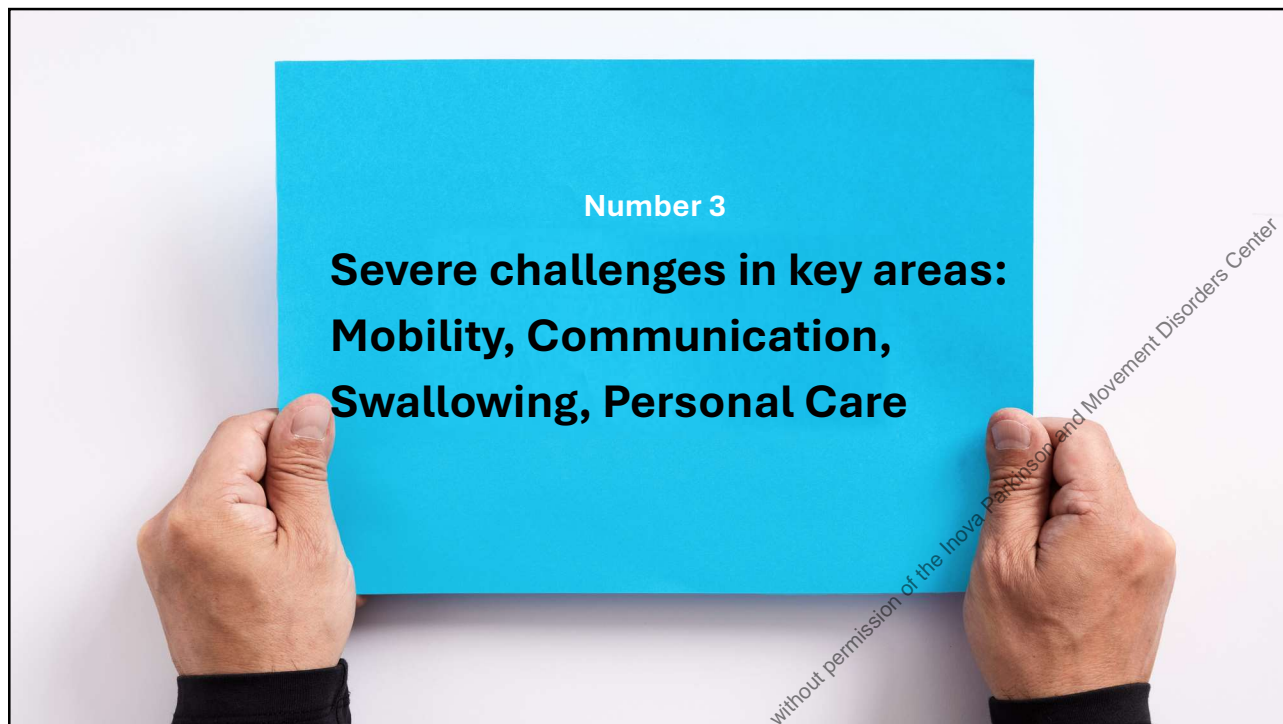
2024 CurePSP Virtual Care Conference

The CurePSP Virtual Care Conference is an opportunity for our community to hear from world-leading experts on topics that will be addressed in person, and virtually. All of these topics have been researched by our community members who will help you manage your daily life.

The Virtual Care Conference will consist of educational presentations related to Parkinson's disease, including: diagnosis, treatment, and research. The conference will also feature a group of experts who will discuss the latest research and clinical practice related to Parkinson's disease. All of the sessions will be recorded and posted on our YouTube channel after the event.

<https://www.psp.org>

22

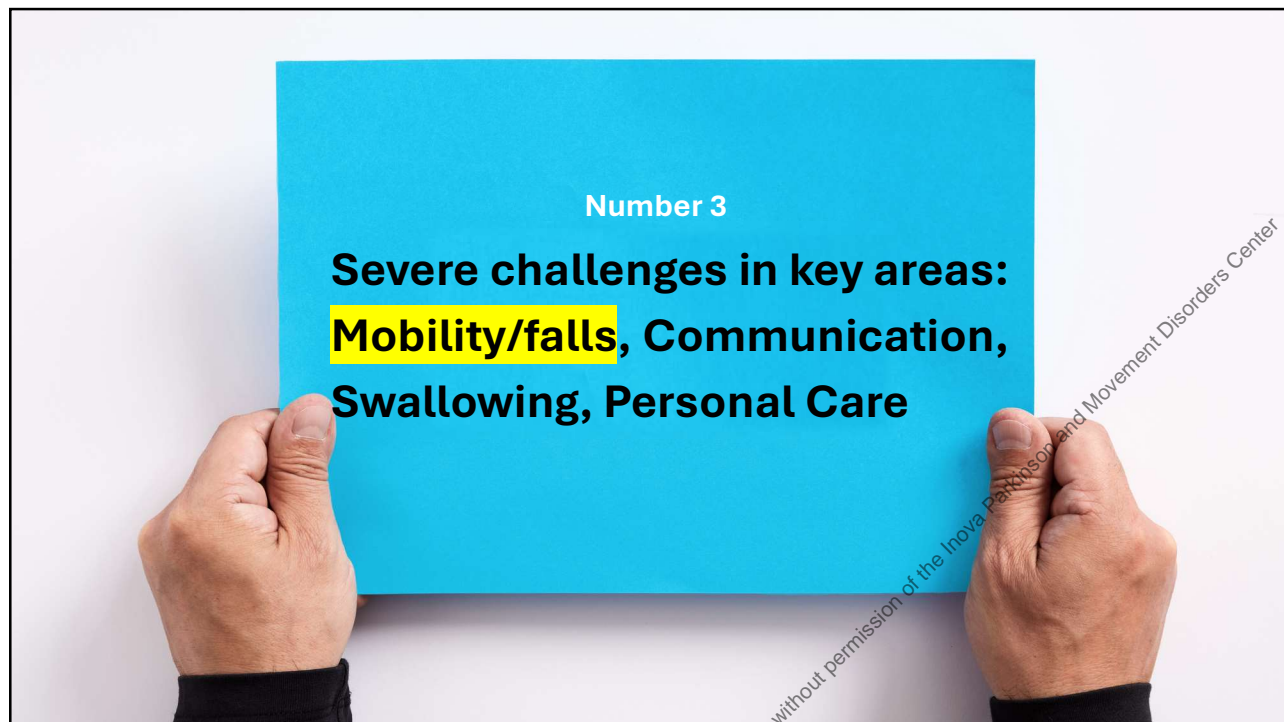


23



24





25

Morris, M. E., Slade, S. C., Bruce, C., McGinley, J. L., & Bloem, B. R. (2021). Palsy: Health Professional Perspectives. *Frontiers in Neurology*, 11

**Enablers to Exercise Participation in Progressive Supranuclear Palsy: Health Professional Perspectives.**

Slade, S. C., Finkelstein, D. I., McGinley, J. L., & Morris, M. E. (2020). *Clinical Rehabilitation*, 34(1), 23- 33.

**Exercise and physical activity for people with Progressive Supranuclear Palsy: a systematic review**

Slade, S. C., Bruce, C., McGinley, J. L., Bloem, B. R., & Morris, M. E. (2020). *PLoS ONE*, 15(6), 20 pages.

**Patient and care partner views on exercise and structured physical activity for people with Progressive Supranuclear Palsy**

Wittwer, J. E., Winbolt, H. M., & Morris, M. E. (2019). *Frontiers in Neurology*, 10, 8 pages.

**A program of home-based, music-cued movement is feasible and may improve gait in progressive supranuclear palsy**

RESEARCH ARTICLE

**Rehabilitation in progressive supranuclear palsy: Effectiveness of two multidisciplinary treatments**

Ilaria Clerici<sup>1\*</sup>, Davide Ferrazzoli<sup>1</sup>, Roberto Maestr<sup>2</sup>, Fabiola Bossio<sup>1</sup>, Iaria Zivi<sup>1</sup>, Margherita Canesi<sup>3</sup>, Gianni Pezzoli<sup>3</sup>, Giuseppe Frazzitta<sup>1</sup>

<sup>1</sup> Department of Parkinson's disease, Movement Disorders and Brain Injury Rehabilitation, "Moriggia-Pelascini" Hospital, Gravedona ed Uniti, Italy, <sup>2</sup> Department of Biomedical Engineering, Istituto Clinico Scientifici Maugeri, Scientific Institute of Montescano, Montescano, Italy, <sup>3</sup> Parkinson Institute, Istituto Clinico di Perfezionamento, Milano, Italy

*Journal of Neurology* (2020) 267:3169–3176  
<https://doi.org/10.1007/s00415-019-09382-1>

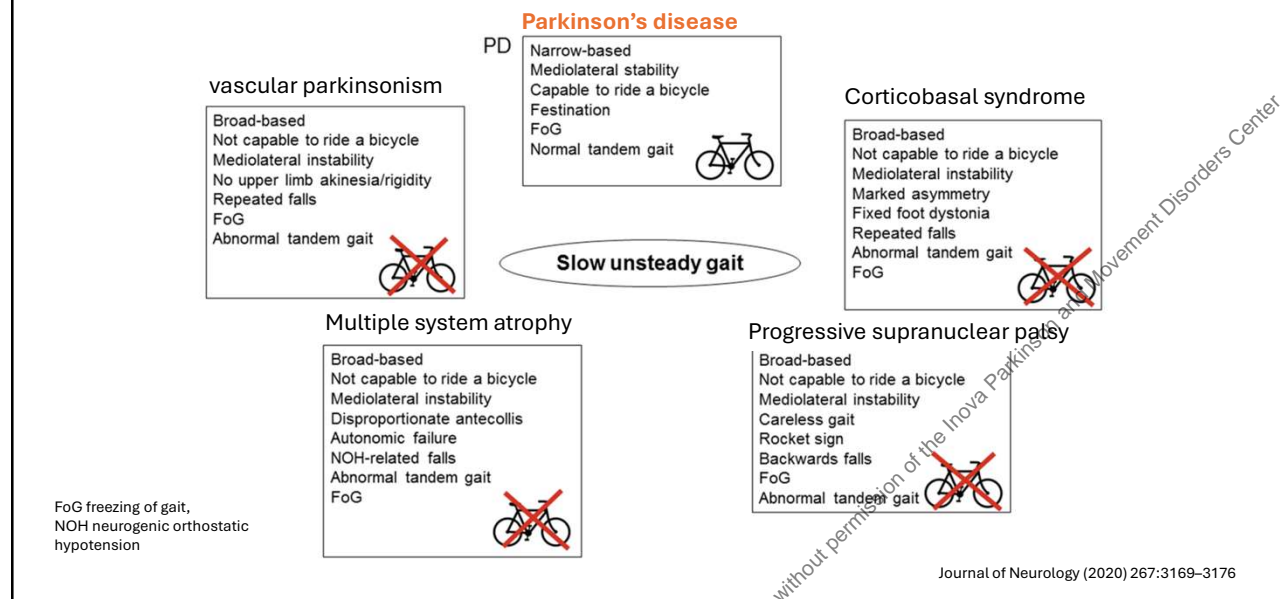
REVIEW

**Gait and postural disorders in parkinsonism: a clinical approach**

Cecilia Raccagn<sup>1</sup> · Jorik Nonnekes<sup>1</sup> · Bastiaan R. Bloem<sup>2</sup> · Marina Peball<sup>1</sup> · Christian Boehme<sup>1</sup> · Klaus Seppi<sup>1</sup> · Gregor K. Wenning<sup>1</sup>

26

## Axial features in parkinsonian disorders







27

**Goal 1: Guidance in managing the disease for better safety & quality of life:**

- Strategy training with families
- Recommendations on protective gear and assistive devices
- Modifications for the home

Training sitting and standing for Person with PSP

28

**Goal 2: Maintaining standing and walking as long as possible**

- **gait training with therapist, family, friends**



29

**Goal 3: Keeping active at home with things you might already know**



**Amplitude-based PD-based programs**

30

**Goal 4: Access to specialized  
physiotherapy at gym or home - PSP**



**Home setting**



**Gym setting**

31



Median age at onset: ~55 years

**Severe autonomic dysfunction +**  
variable combination of:

- Parkinsonism, poorly levodopa-responsive
- Pyramidal signs MSA-P and MSA-C

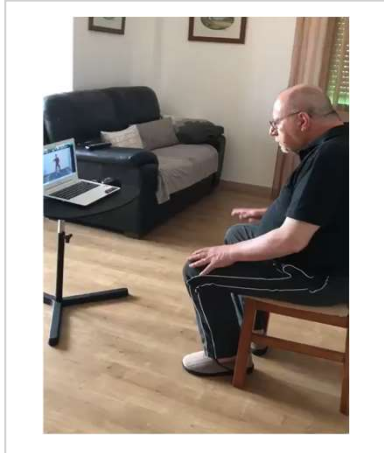
Less cognitive impairment

Wenning GK, Braune S. 2001;15:839-852

32



### Keeping active at home with things you might already know



**Dance for PD program**



**Others – your community**

33



Improving mobility with specialized physiotherapy at the rehab gym – (MSA-C)

“Every time we talk/see a new therapist we have to explain again about MSA symptoms and the disease, it is very frustrating”.  
- Person with MSA

34

## Less conservative treatment options



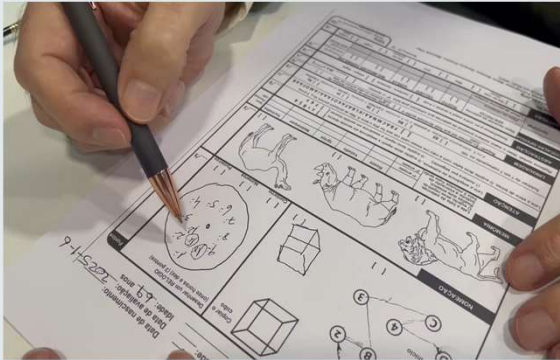
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## Improving mobility with specialized physiotherapy at home – (MSA-C)



36

### Improving mobility with specialized physiotherapy– CBD



37

### Number 3

**Severe challenges in key areas:**  
**Mobility, Communication,**  
**Swallowing, Personal Care**

38

## TREATMENT OPTIONS

SLP	Assistive Devices	Vocal fold augmentation (?)
Traditional speech therapy is less impactful but still helpful	Speechvive External Speaker Augmentative & Alternative Comm (AAC)	Probably not...

39

## Self-management tips for communication



- Slow down conversations
- Control noise (incl. visual noise)
  - Use proper lighting
- Personal amplification
- Favor global versus side conversations in groups
- Reduce or avoid talking in standing position or walking

40



## Addressing fluency issues incl. palilalia and “festinating” speech

### Traditional techniques

- Tapping
- Pacing boards and other techniques
  - metronomes
- Alphabet boards
  - Added benefit of visual prompt for context

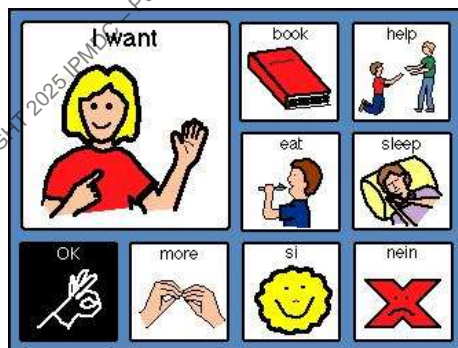
### Technology

- Delayed Auditory Feedback (DAF)
  - 50-200 ms
  - Minimal adaptation
  - HOWEVER, minimal carryover
- Incorporating pitch shifting
- Incorporate white noise, or pink noise to induce Lombard effect
  - Adaptation effect

41

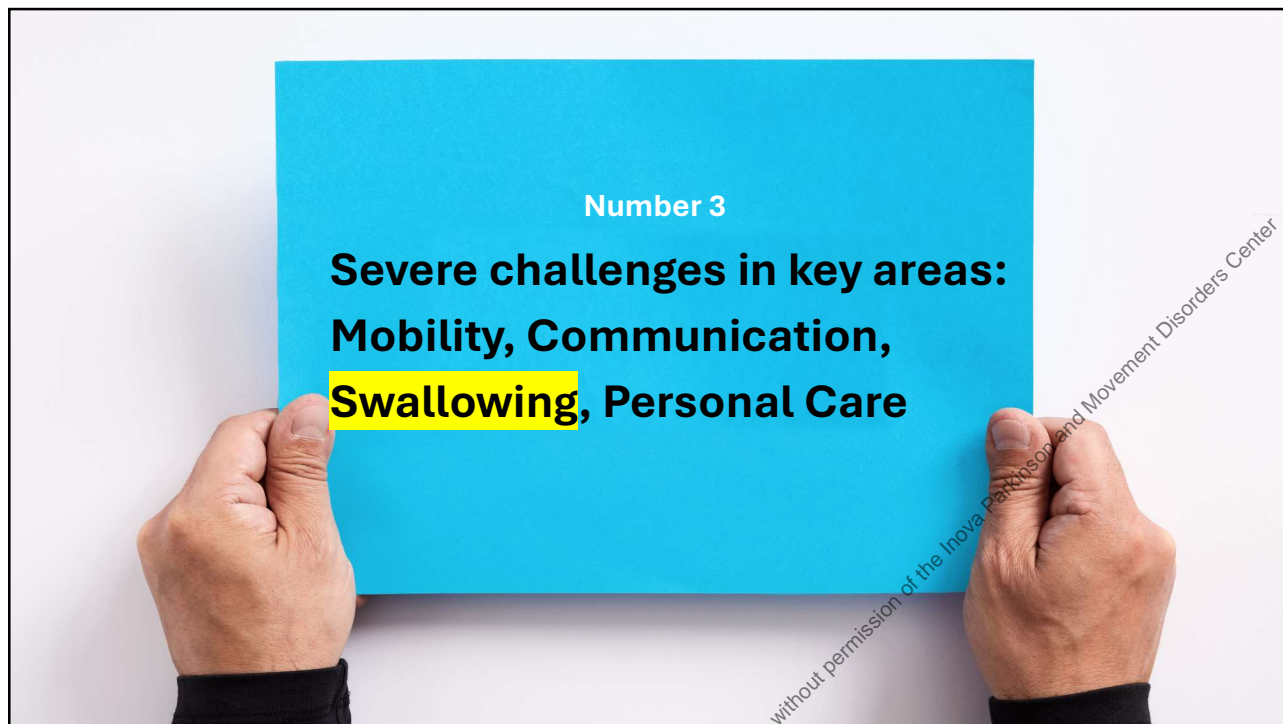
## Augmentative and Alternative Communication (AAC)

### Simple Communication Boards

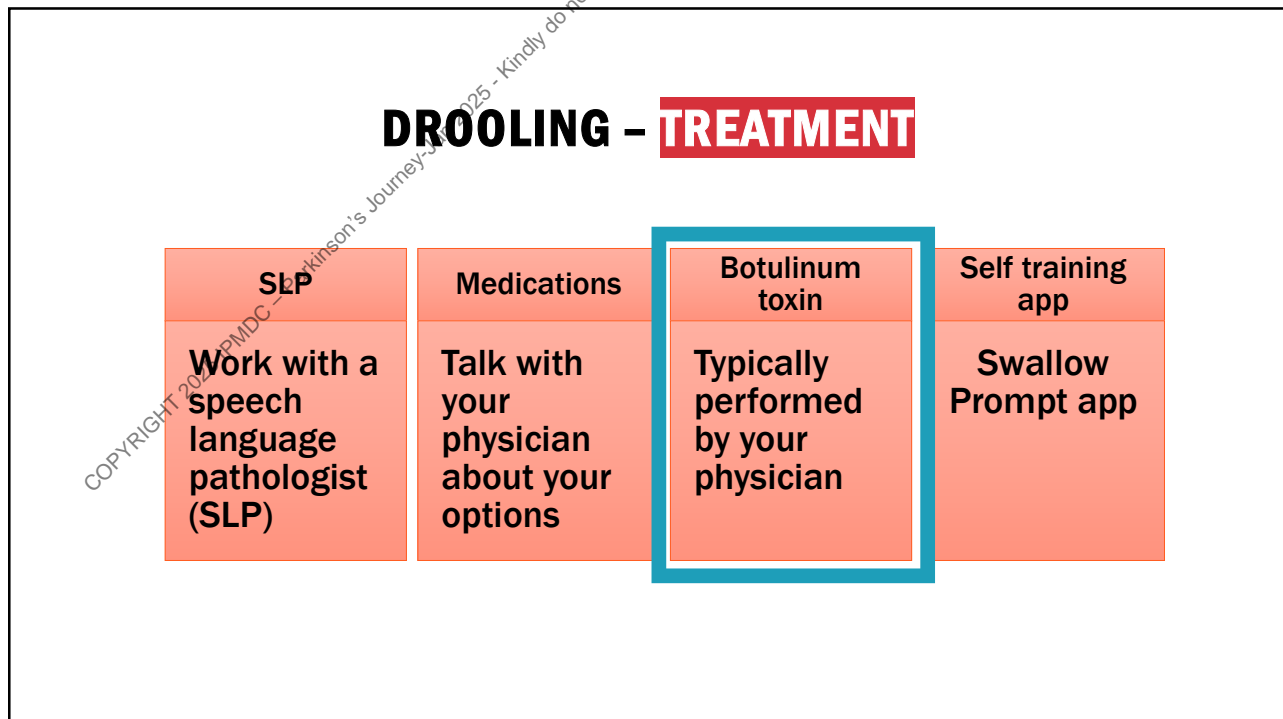


A	b	c	d	1	2
E	f	g	h	3	4
I	j	k	l	m	n
O	p	q	r	s	t
U	v	w	x	y	z
5	6	7	8	9	0

42



43



44



### Example of self-management tips for drooling

- Preparatory swallow before talking
- Keep a towel nearby (incl. wristband trick).
  - Incl on pillow at night.
- Keep the mouth “busy”\*
  - Ice cubes
  - Gum/hard candy?
- Agree on a discrete cue during mealtimes

45



### Advice for pill swallowing

- Take one pill at a time
- Take pills in a “puree” such as applesauce instead of water.
  - Avoid protein-rich purees like cottage cheese and yogurt
- Many meds can be crushed and mixed with applesauce or other purée

46

# Improving Mealtimes

## ENHANCE BIOMECHANICS



- Plates with prominent lips
- Built up utensils
- Anti – slip mats
- Raise the height of plates (PSP-specific)

## OPTIMIZE FOR ATTENTION



- Bright lighting
  - But not facing bright light
- High contrast
- Minimize distractions: Visual and auditory

47

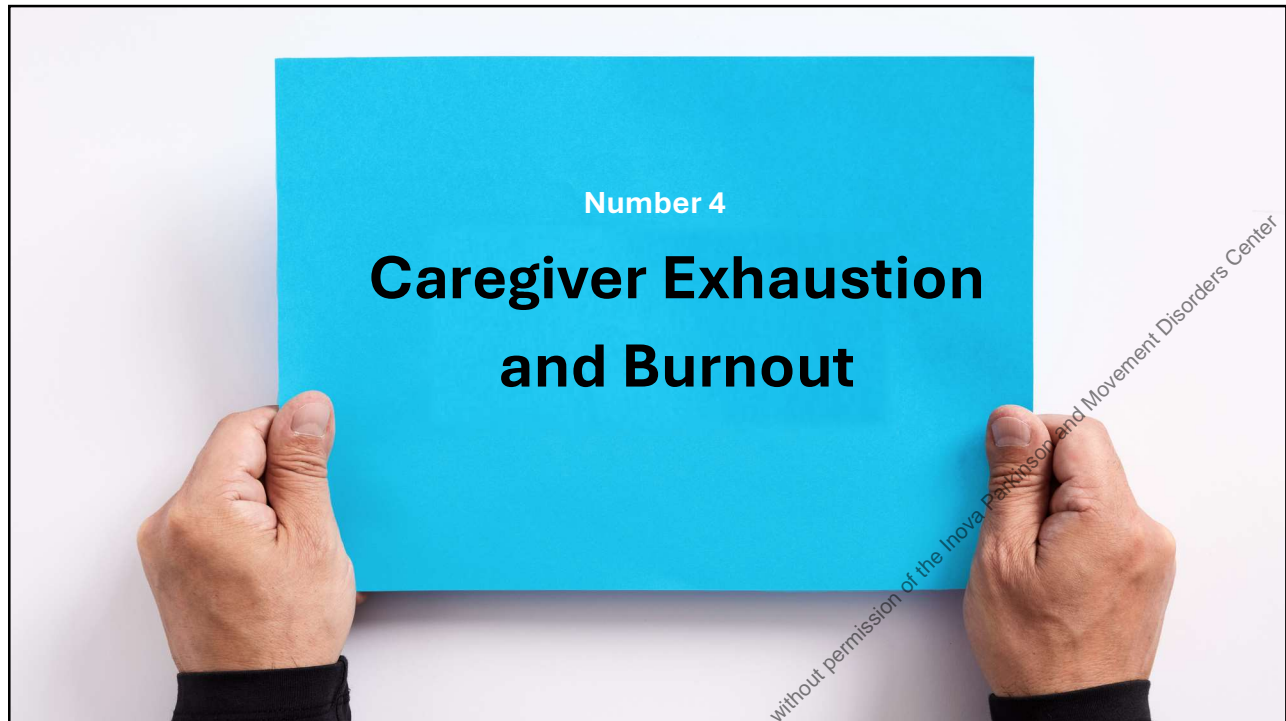


## Contending with impulsivity?

- Limit quantities on the plate
  - May require distraction techniques
- Smaller more frequent meals

48

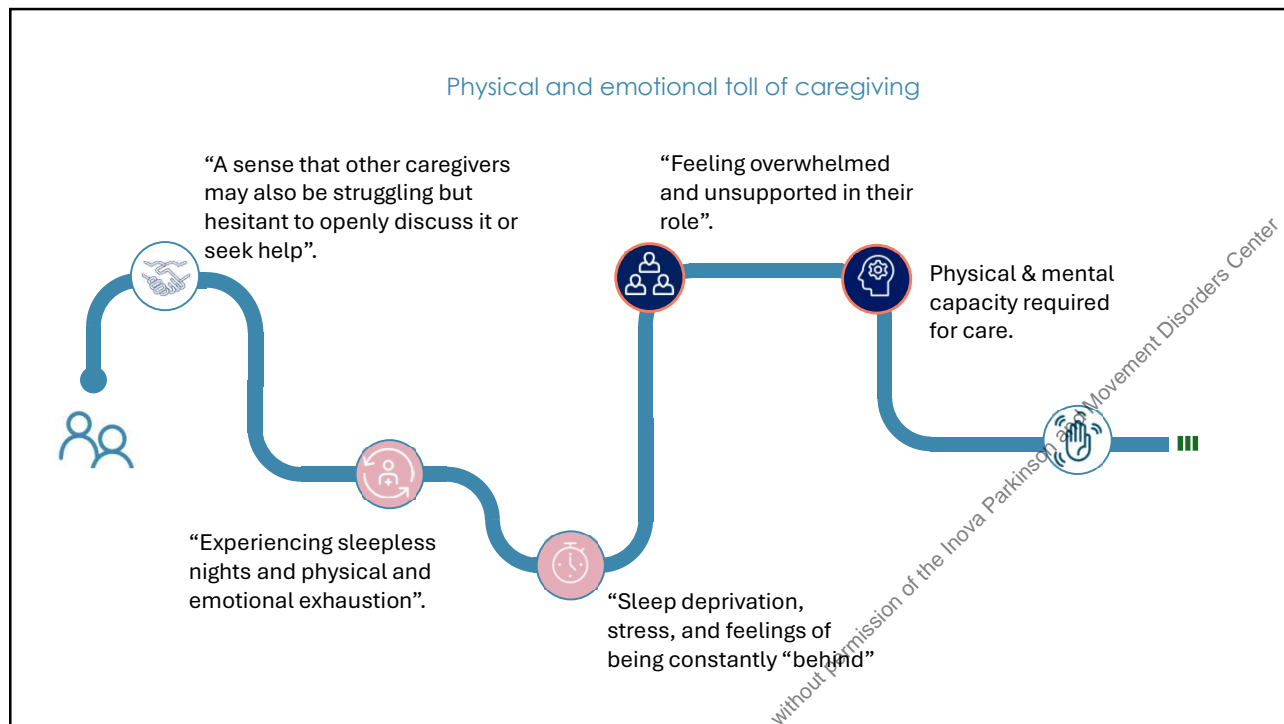




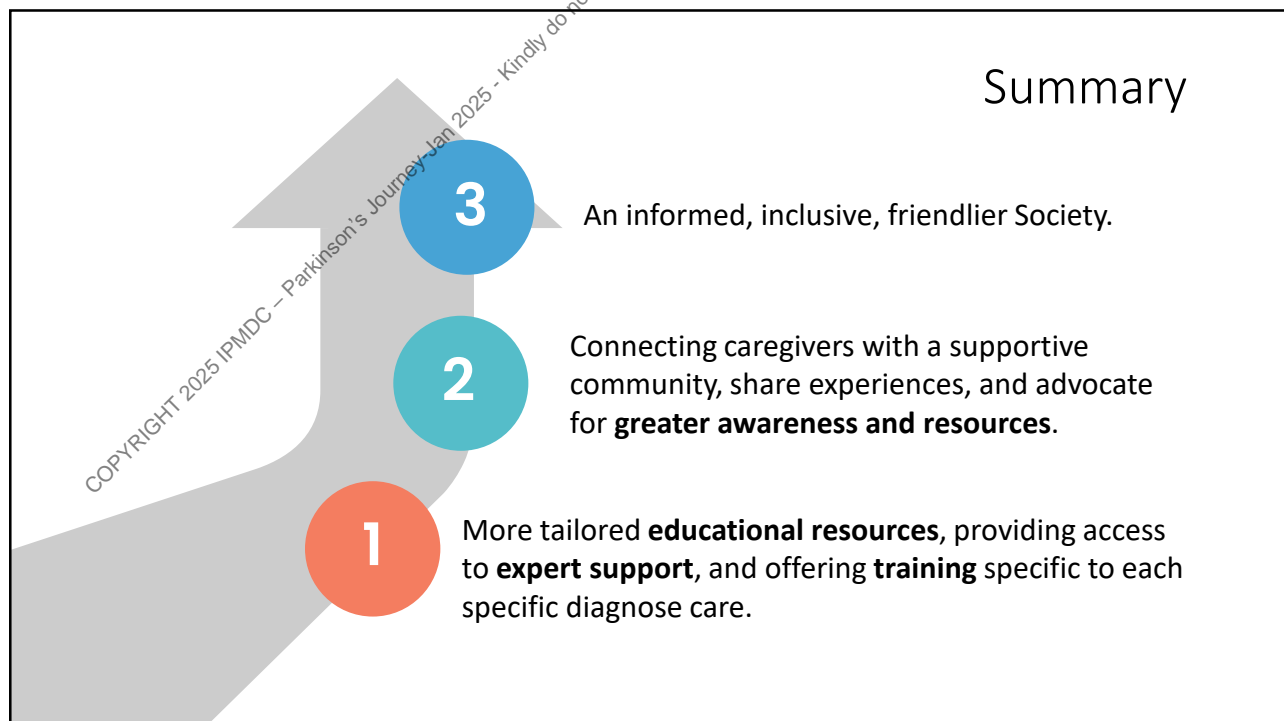
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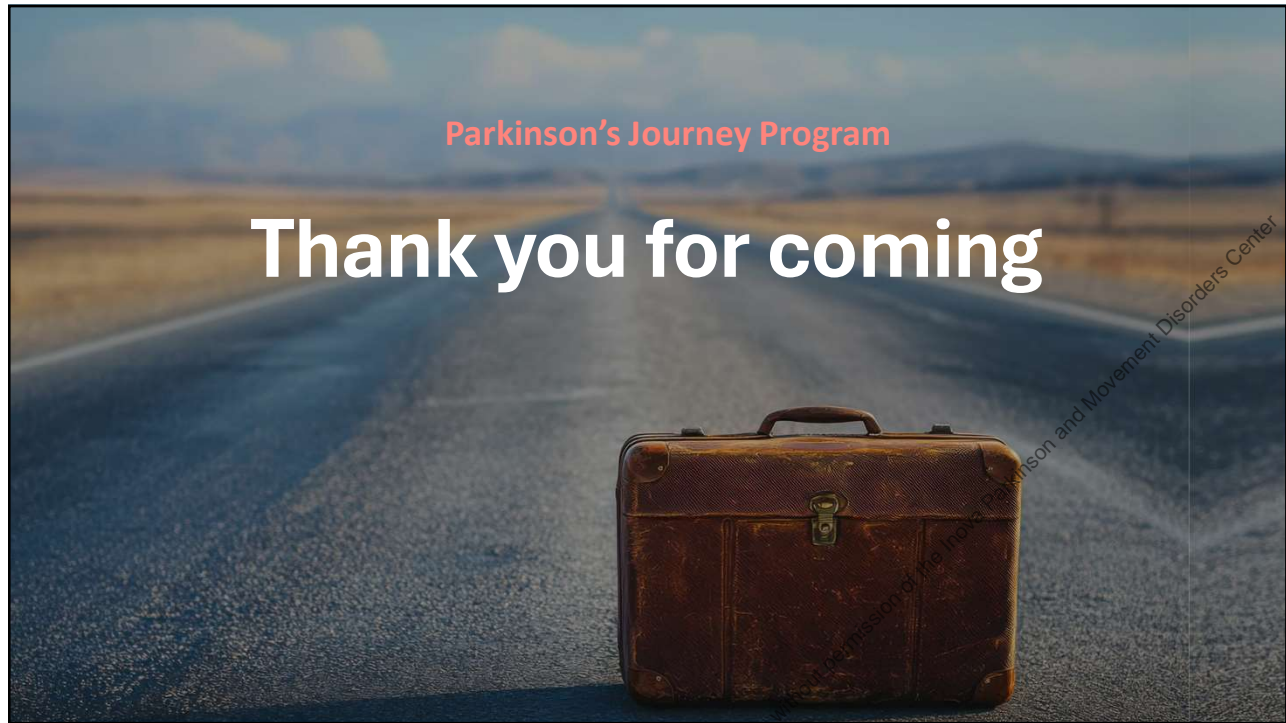
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52



53

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