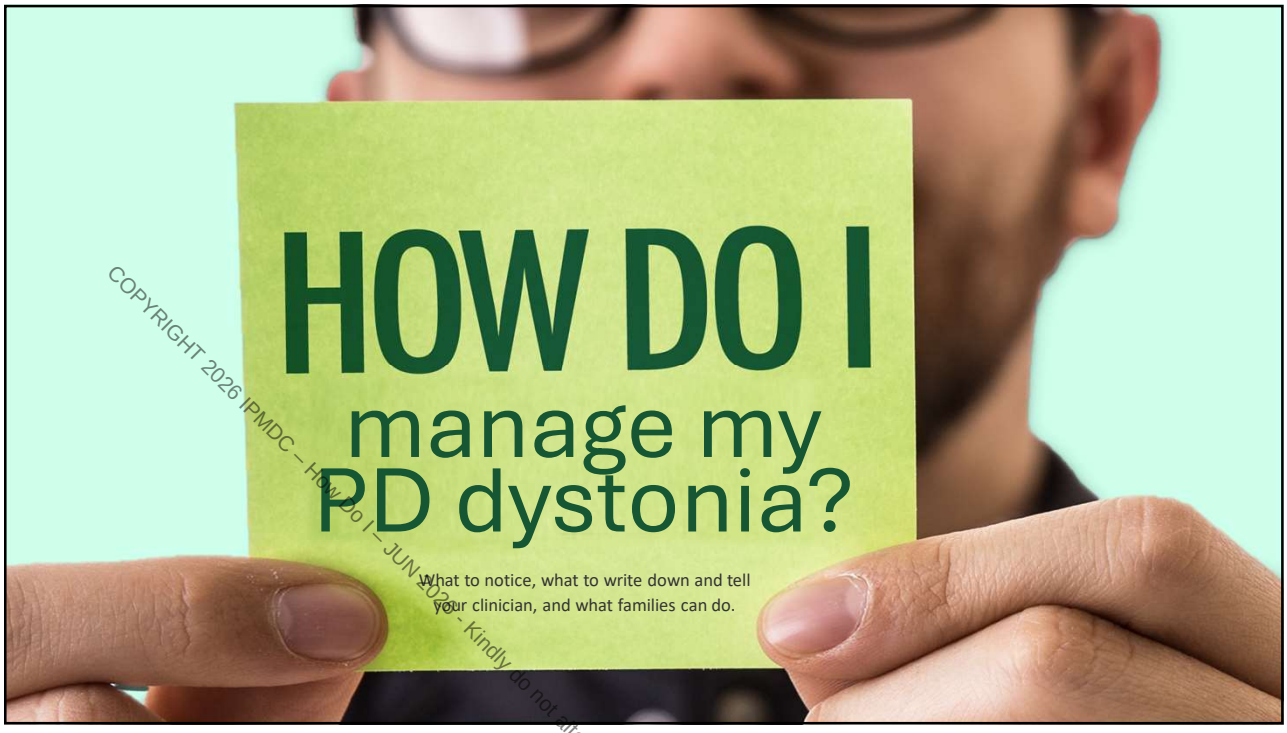

1

WHY? Why talk about dystonia in PD?

HOW?
What to notice
What to report to your Dr
What families can do to help

2

WHY? Why talk about dystonia in PD?

HOW?
- What to notice
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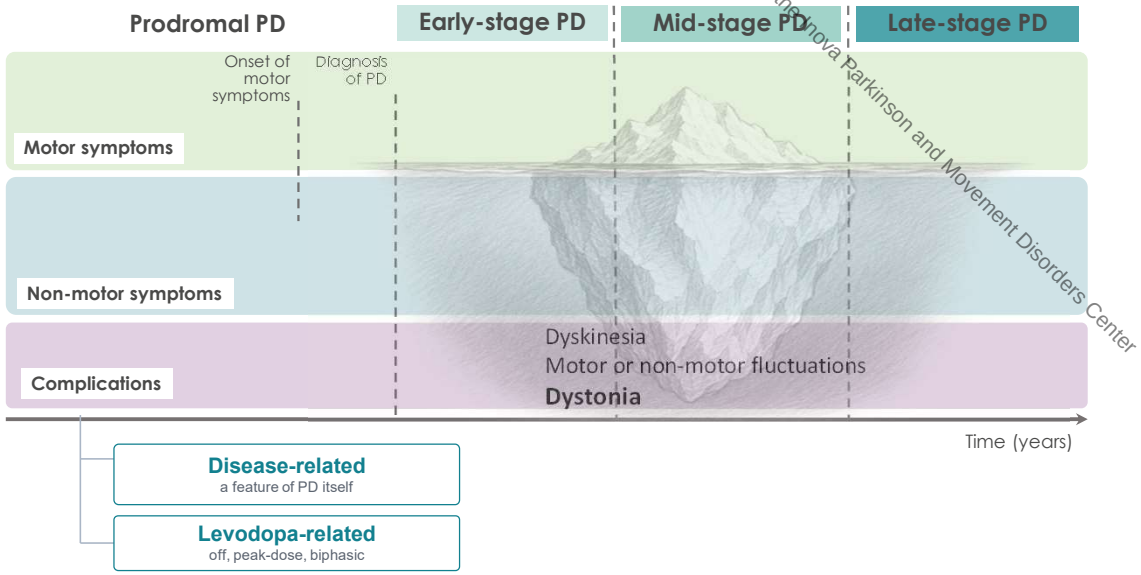


4

Dystonia in Parkinson's

A QUICK PICTURE

Sustained or intermittent abnormal movements, postures, or both.
Patients often recognise it as
"spasms", "cramps", or "posture".

Mov Disord. 2025 Jul;40(7):1248-1259. | Parkinsonism Relat Disord 2001;8:109–121.

5

Dystonia in Parkinson's

A QUICK PICTURE

Sustained or intermittent abnormal movements, postures, or both.
Patients often recognise it as
"spasms", "cramps", or "posture".

By cause

- **Disease-related** — a feature of PD itself
- **Levodopa-related** — off, peak-dose, biphasic

30% of people with Parkinson's

60% when PD begins before age 40

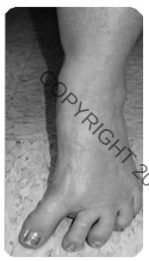
By where it appears — body distribution

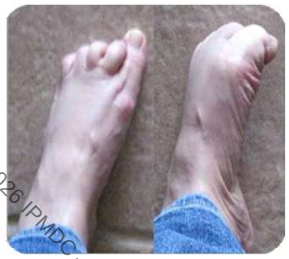
- **Focal** — a single body area *e.g. foot dystonia, blepharospasm*
- **Segmental** — two contiguous (adjacent) regions *e.g. Meige — eyes + lower face / jaw*
- **Multifocal** — two non-contiguous (separate) regions *e.g. blepharospasm + foot dystonia*
- **Hemidystonia** — regions on one side *e.g. arm + leg, one side*
- **Generalised** — widespread — trunk + legs *e.g. childhood-onset with spread*

Mov Disord. 2025 Jul;40(7):1248-1259. | Parkinsonism Relat Disord 2001;8:109–121.

6

Most common in the foot & toes

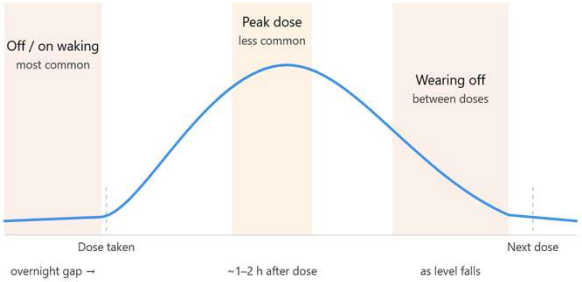




Foot & toes — curling or inward-turning of the foot, toes clawing. The classic **early-morning foot dystonia**.

Tied to medication timing

Antiparkinsonian drugs influence dystonia with high inconsistency

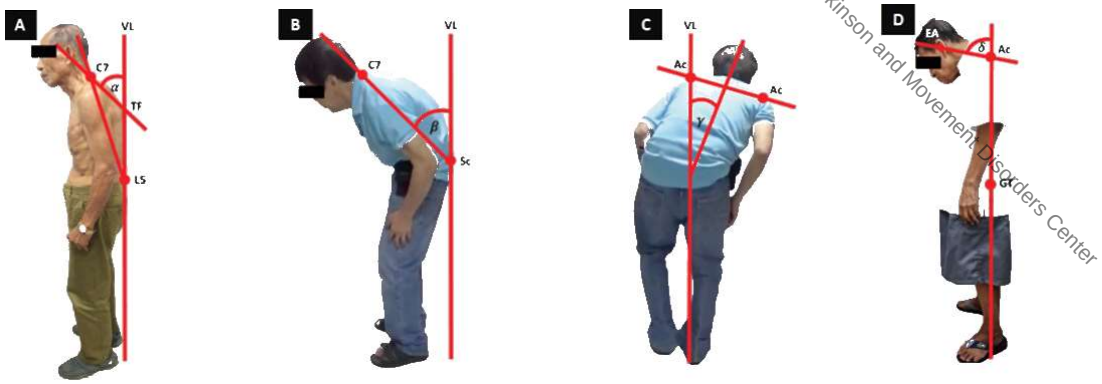


7

Less common

Axial and limb deformities in PD

Pandey, S (2022), Mov Disord Clin Pract, 9: 156-169.



Upper camptocormia | Lower camptocormia | Pisa syndrome | Anterocollis

4

8

Task-specific dystonia

Billiards-related dystonia: A new task-specific dystonia

Katarzyna Smilowska[a], Josefa Domingos[a,b], Jaco W. Pasman[a], Daniel J. van Wamelen[a,c,d], Bart P. van de Warrenburg[a], Bastiaan R. Bloem[a,*]

[a] Radboud University Medical Centre, Donders Institute for Brain, Cognition and Behaviour, Department of Neurology, Nijmegen, the Netherlands
[b] Laboratory of Motor Behavior, Sport and Health Department, Faculty of Human Kinetics, University of Lisbon, Portugal
[c] Institute of Psychiatry, Psychology & Neuroscience, Department of Basic and Clinical Neuroscience, The Maurice Wohl Clinical Neuroscience Institute, King's College London, Cutcombe Road, London, SE5 9RT, United Kingdom
[d] National Parkinson Foundation International Centre of Excellence, King's College Hospital NHS Foundation Trust, Denmark Hill, London, SE5 9RS, United Kingdom

Figure 1 An oboist with spontaneous flexion of the left fourth and fifth digits. She could extend the fingers sufficiently rapidly to maintain rhythm on playing up scales but not down scales.

Figure 2 A percussionist showing intermittent left wrist flexion and shoulder abduction while mimicking playing.

NEUROLOGY AND ART

Musician's dystonia

Jon Sussman

Dr Jon Sussman, Department of Neurology, Greater Manchester Neuroscience Centre, Salford Royal Hospital, Stott Lane, Salford M6 8HD, UK

9

The impact

- Dystonia can cause **joint area pain and immobility**, adding to the movement problems of PD.

Jankovic J, Tintner R. Dystonia and parkinsonism. Parkinsonism Relat Disord 2001;8:109–121.
Rabin, M.L., Earnhardt, M.C., et al . (2016), Mov Disord Clin Pract, 3: 538-547.

5

10

The impact

- Dystonia can cause **joint area pain and immobility**, adding to the movement problems of PD.
- Dystonia involving the trunk, hip, and legs can lead to **peculiar gaits**.

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Rabin, M.L., Earnhardt, M.C., et al . (2016), Mov Disord Clin Pract, 3: 538-547.

11

The impact

- Dystonia can cause **joint area pain and immobility**, adding to the movement problems of PD.
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- Dystonia can **impact eating and communication**.

Jankovic J, Tintner R. Dystonia and parkinsonism. Parkinsonism Relat Disord 2001;8:109–121.
Rabin, M.L., Earnhardt, M.C., et al . (2016), Mov Disord Clin Pract, 3: 538-547.

12

The impact

- Dystonia can cause **joint area pain and immobility**, adding to the movement problems of PD.
- Dystonia involving the trunk, hip, and legs can lead to **peculiar gaits**.
- Dystonia can **impact eating and communication**.
- The side of dystonic deformity is usually the **side of initial PD signs.**

Jankovic J, Tintner R. Dystonia and parkinsonism. Parkinsonism Relat Disord 2001;8:109–121.
Rabin, M.L., Earnhardt, M.C., et al . (2016), Mov Disord Clin Pract, 3: 538-547.

13

The impact

- Dystonia can cause **joint area pain and immobility**, adding to the movement problems of PD.
- Dystonia involving the trunk, hip, and legs can lead to **peculiar gaits**.
- Dystonia can **impact eating and communication**.
- The side of dystonic deformity is usually the **side of initial PD signs.**
- Dystonia sometimes **becomes less pronounced** or even resolves despite progressive parkinsonism.

Jankovic J, Tintner R. Dystonia and parkinsonism. Parkinsonism Relat Disord 2001;8:109–121.
Rabin, M.L., Earnhardt, M.C., et al . (2016), Mov Disord Clin Pract, 3: 538-547.

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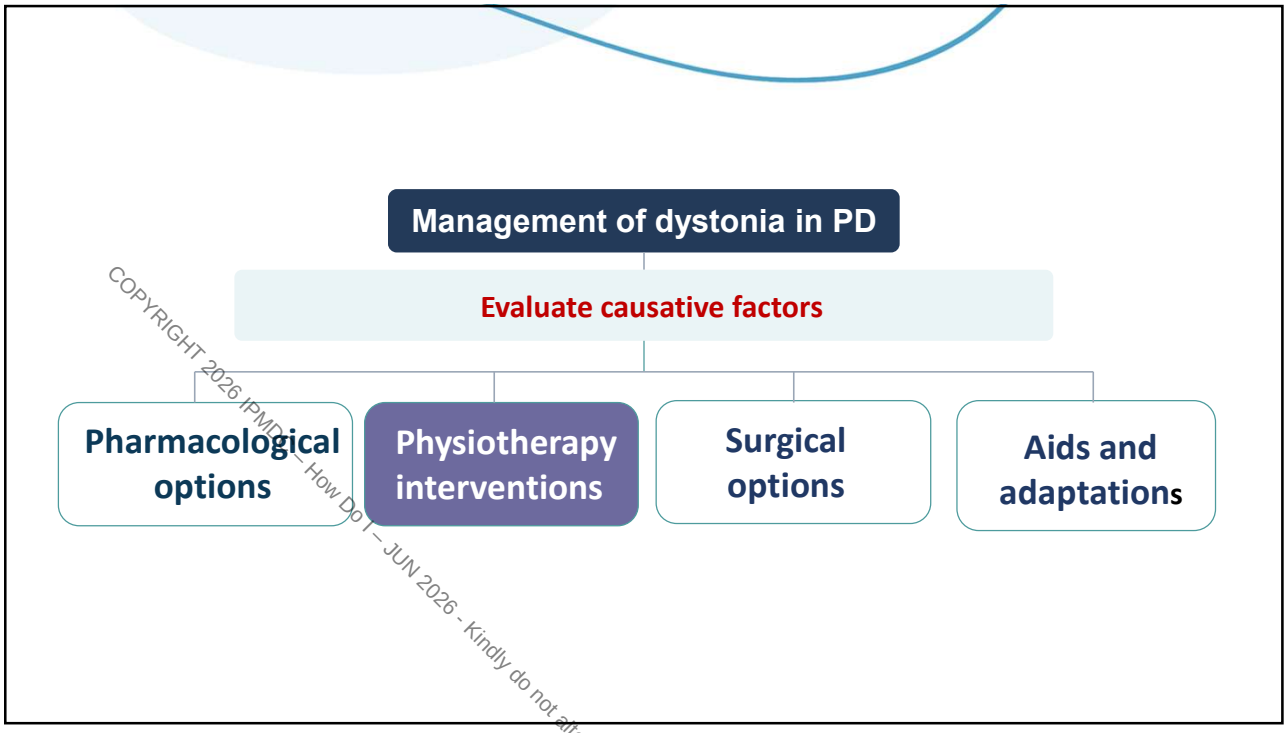

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WHAT IS THE MINIMUM ASSESSED BY THE CLINICIAN?

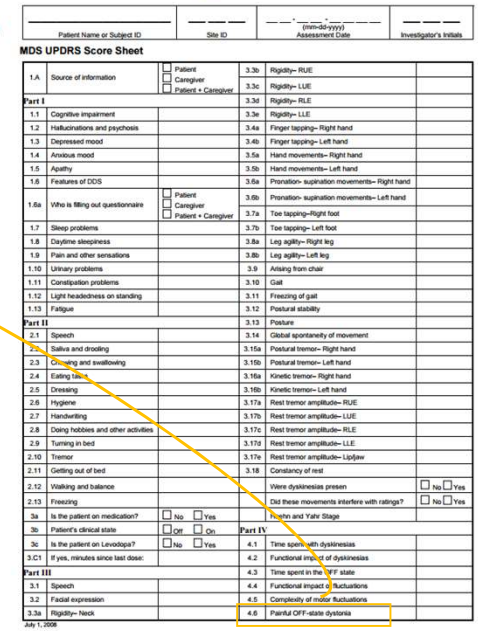
MDS-UPDRS Part IV · Motor complications

Painful OFF-state dystonia

1. During your low or **"OFF"** periods, do you usually have **painful cramps or spasms?**

2. Out of the total ____ hrs of this low time, if you add up all the time in a day when these painful cramps come, **how many hours would this make?**

   ≈ _____ **hours** out of your total OFF time



Patient Name or Subject ID | Site ID | Assessment Date (mm-dd-yyyy) | Investigator's Initials

MDS UPDRS Score Sheet

1.A	Source of information	☐ Patient ☐ Caregiver ☐ Patient + Caregiver	3.3b	Rigidity– RUE	
Part I			3.3c	Rigidity– LUE	
1.1	Cognitive impairment		3.3d	Rigidity– RLE	
1.2	Hallucinations and psychosis		3.3e	Rigidity– LLE	
1.3	Depressed mood		3.4a	Finger tapping– Right hand	
1.4	Anxious mood		3.4b	Finger tapping– Left hand	
1.5	Apathy		3.5a	Hand movements– Right hand	
1.6	Features of DDS		3.5b	Hand movements– Left hand	
1.6a	Who is filling out questionnaire	☐ Patient ☐ Caregiver ☐ Patient + Caregiver	3.6a	Pronation- supination movements– Right hand	
			3.6b	Pronation- supination movements– Left hand	
1.7	Sleep problems		3.7a	Toe tapping–Right foot	
1.8	Daytime sleepiness		3.7b	Toe tapping– Left foot	
1.9	Pain and other sensations		3.8a	Leg agility– Right leg	
1.10	Urinary problems		3.8b	Leg agility– Left leg	
1.11	Constipation problems		3.9	Arising from chair	
1.12	Light headedness on standing		3.10	Gait	
1.13	Fatigue		3.11	Freezing of gait	
Part II			3.12	Postural stability	
2.1	Speech		3.13	Posture	
2.2	Saliva and drooling		3.14	Global spontaneity of movement	
2.3	Chewing and swallowing		3.15a	Postural tremor– Right hand	
2.4	Eating tasks		3.15b	Postural tremor– Left hand	
2.5	Dressing		3.16a	Kinetic tremor– Right hand	
2.6	Hygiene		3.16b	Kinetic tremor– Left hand	
2.7	Handwriting		3.17a	Rest tremor amplitude– RUE	
2.8	Doing hobbies and other activities		3.17b	Rest tremor amplitude– LUE	
2.9	Turning in bed		3.17c	Rest tremor amplitude– RLE	
2.10	Tremor		3.17d	Rest tremor amplitude– LLE	
2.11	Getting out of bed		3.17e	Rest tremor amplitude– Lip/jaw	
2.12	Walking and balance		3.18	Constancy of rest	
2.13	Freezing			Were dyskinesias presen ☐ No ☐ Yes	
3a	Is the patient on medication? ☐ No ☐ Yes			Did these movements interfere with ratings? ☐ No ☐ Yes	
3b	Patient's clinical state ☐ Off ☐ On			Hoehn and Yahr Stage	
3c	Is the patient on Levodopa? ☐ No ☐ Yes		**Part IV**		
3.C1	If yes, minutes since last dose:		4.1	Time spent with dyskinesias	
Part III			4.2	Functional impact of dyskinesias	
3.1	Speech		4.3	Time spent in the OFF state	
3.2	Facial expression		4.4	Functional impact of fluctuations	
3.3a	Rigidity– Neck		4.5	Complexity of motor fluctuations	
			4.6	Painful OFF-state dystonia	

July 1, 2008

2008 Movement Disorder Society

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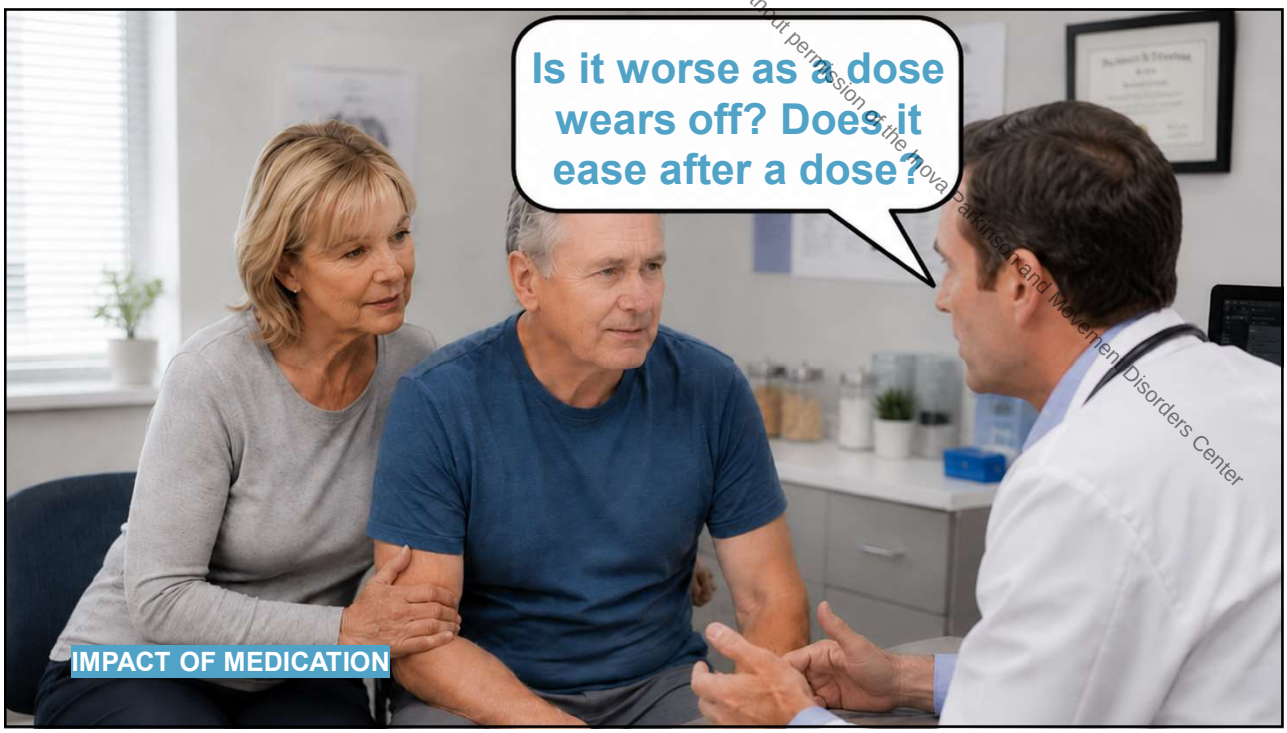

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Recognizing the factors that affect dystonia

(commonly reported triggers)

MAKES IT WORSE

- Medication is not working well
- Inactivity for a period of time. A demanding or prolonged task, or a long day
- Tiredness, stress and fatigue
- Feeling anxious, stressed, or fearful
- "Caffeine (most plausibly through stimulation/arousal) or exposure to cold"

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Recognizing the factors that help your dystonia

(commonly reported alleviators)

MAKES IT BETTER

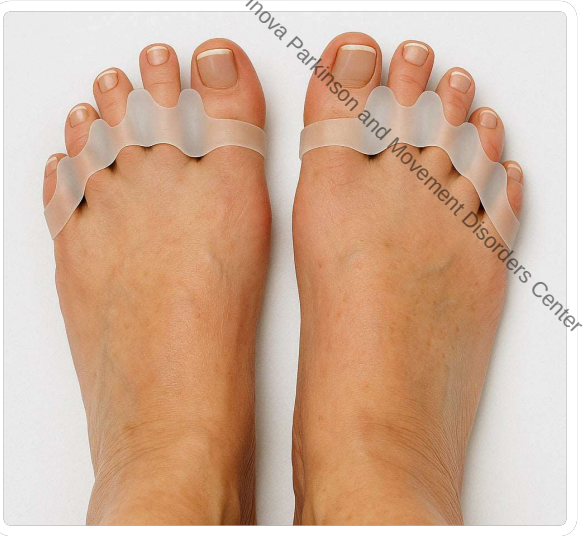
Assuring proper intake of **medication.**

Massage or **warm bath** or **heated pad**.

Sensory tricks:
Touching the area can sometimes ease it (a "sensory trick").

Lying down, singing, yawning, laughing, chewing, applying pressure to the eyebrows, or just talking can help eye spams.

Yawning or sneezing or humming for spasms in the vocal cords.



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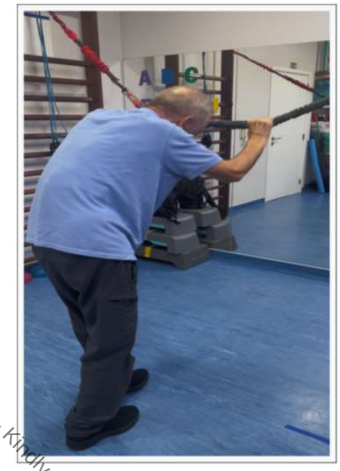
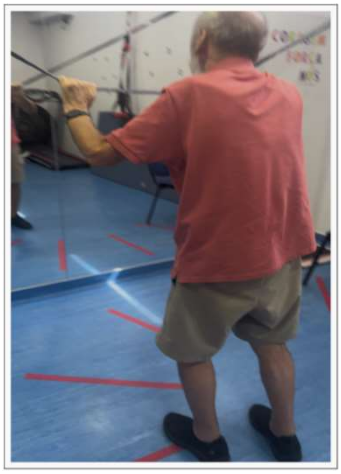
Physiotherapy: training walking in complex situations

Camptocormia





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Clinical example



31

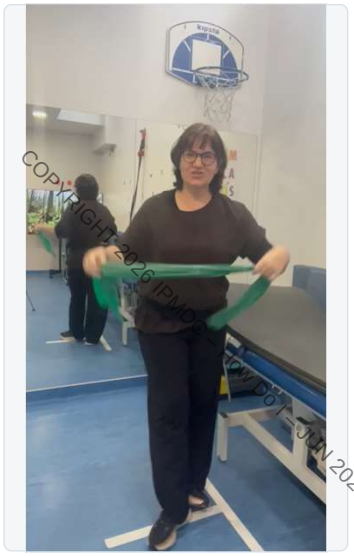
"Rescue" Exercises

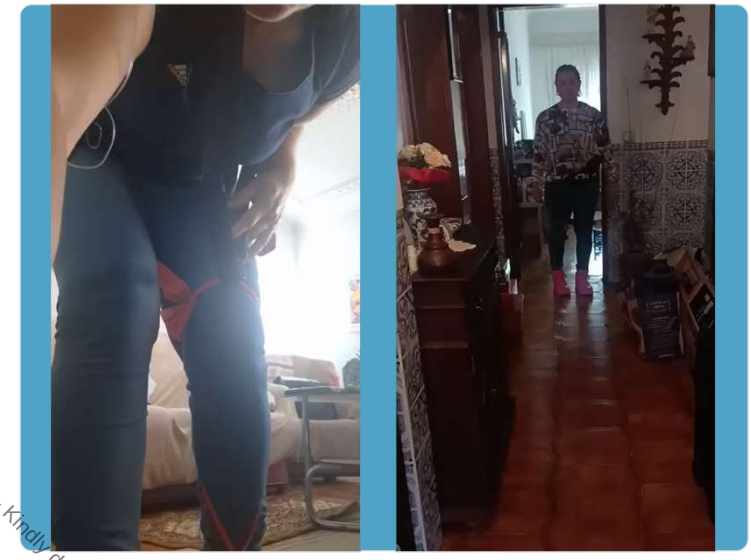



16

32

“Prevention” Strategies





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WHY? Why talk about dystonia in PD?

HOW?
What to notice
What to report to your Dr
What families can do to help

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MyChart

Report to your doctor more effectively

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Swapping a vague phrase for a useful one

✕ Instead of

"I'm having foot cramps."

"My tablets aren't working."

"I feel bad in the morning."

✓ Try

"About 20 minutes before my next dose, my toes curl under, and my foot turns inward. It's painful."

"They help in the morning, but the cramp comes back as they wear off, around 20 minutes before the next dose."

"First thing, before any tablets, my foot cramps for about 30 minutes, then eases after my medication."

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But what if we could even better?

Subject: A new foot cramp

Dear Dr…

I have a **new** problem with my right foot that has **got worse over the last weeks**. My toes curl under and the foot turns inward. It happens **first thing in the morning**, before any tablets, **most days**, and lasts about **20 minutes**. It is **painful and makes walking hard**. It **eases about 10 minutes after my medication**, and is **worse if I rush/stress**. My husband sometimes **helps me to the bathroom** in the mornings because of it.

Every highlighted phrase answers one of your doctor's questions:

- **New?**
- **Getting worse?**
- **Time of day**
- **How often**
- **How long**
- **Impact + pain**
- **Eases with meds**
- **What makes it worse**
- **Impact on autonomy**

12

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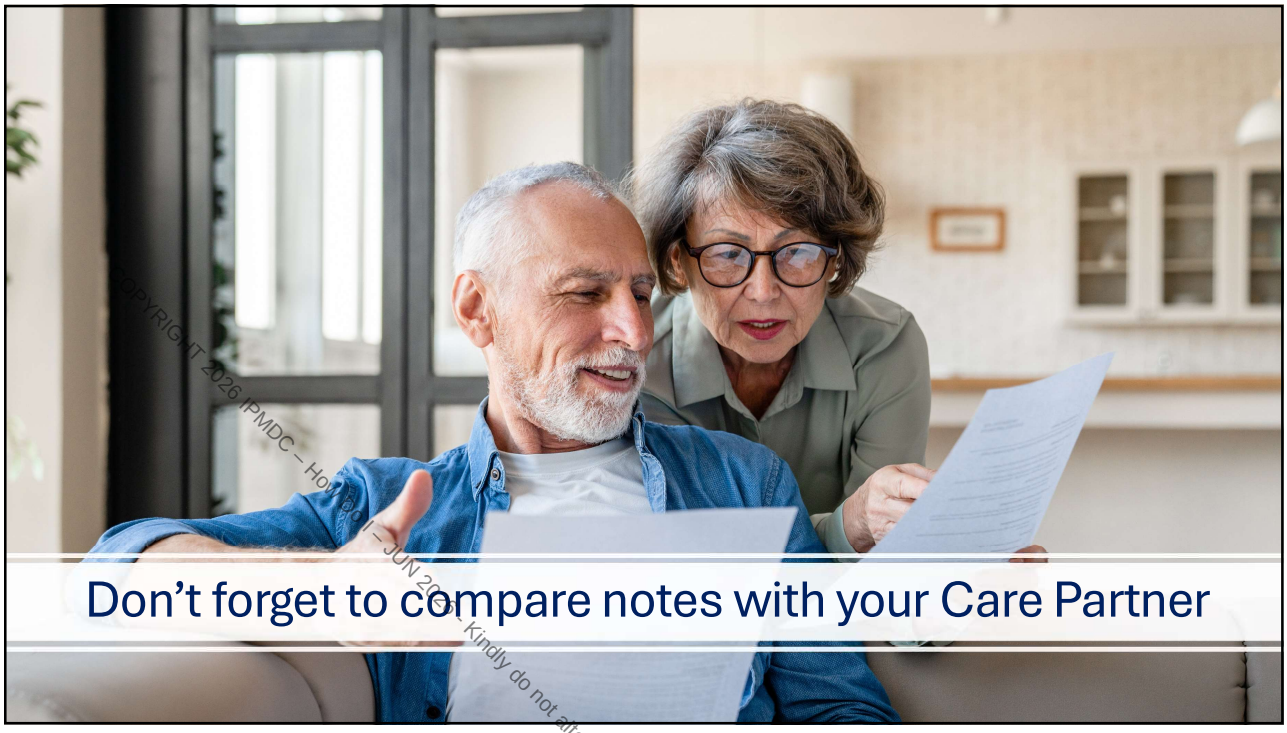

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My PD Dystonia Diary

Date: _____

1. New, or getting worse since last time?
□ Nothing new □ Something new □ Getting worse
□ Getting better

2. Where did you notice it? (tick all that apply)
□ Eyes / upper face □ Arm or hand
□ Jaw, mouth or tongue □ Trunk
□ Neck or shoulders □ Leg or foot
□ Voice or throat □ Other: _____

3. What time of day was it worst?
□ Morning □ Midday □ Afternoon □ Evening
□ Night □ No clear pattern

4. How long did an event last?
□ Seconds □ Minutes □ Up to an hour □ Hours
□ Most of the day

5. How often today?
□ Once □ 2–3 times □ Several times □ Many / constant

6. How did it relate to your medication?
□ Worse as a dose wore off □ Worse at peak of a dose
□ Eased after a dose □ No clear link □ N/A

7. What was the pattern through the day?
□ Constant all day □ Came and went
□ Short bursts that passed

8. What were you doing when it appeared?
□ Resting / still □ One specific activity
□ Many kinds of movement □ Present even at rest

9. How did it look or feel?
□ Twisting / pulling (held) □ Tremor-like shaking
□ Quick jerks □ Cramping / tightness

10. What eased it? (touching the area, rest…)

11. What made it worse? (stress, tiredness, a task…)

12. Impact on your daily activities

13. Other things your carepartner noticed (if applicable)
□ Pain □ Poor sleep □ Low mood □ Fatigue □ None

40

WHY? Why talk about dystonia in PD?

HOW?
What to notice
What to report to your Dr
What families can do to help

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How families/friends can help

Notice what's missed
Spot the patterns the person living with it may not see, especially the timing around medication.

Help keep the note
Offer to jot down when, where and how long, only if it's welcome.

Plan around good moments
Help line up outings and activities for the times that tend to be easier.

Help them stay calm
When dystonia appears, the answer is to ease off and relax, not to push through.

15

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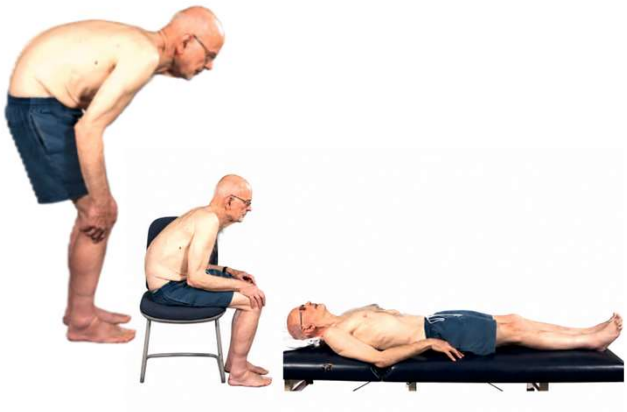
Hands-on that helps

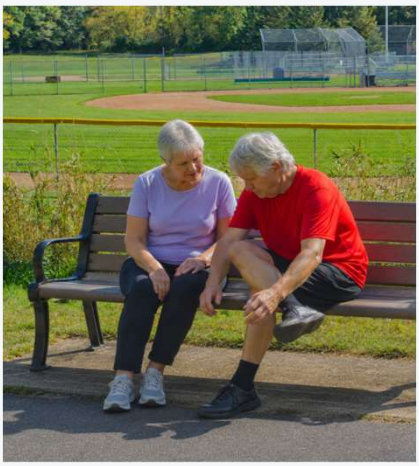
Reminders on what helps



Trunk flexion is most severe in the standing position and resolves when lying supine.

43

Changing the movement
Resting



44

Corrections
yes or no?

Explore new ways of verbal and non-verbal tricks

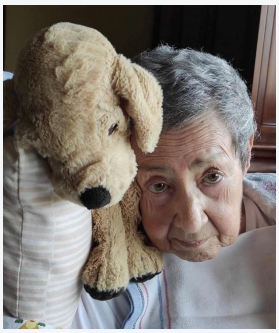
* Alert: correct posture in severe balance issues

45

Help review medications

Assistive devices & adaptations

Reinforce coping strategies



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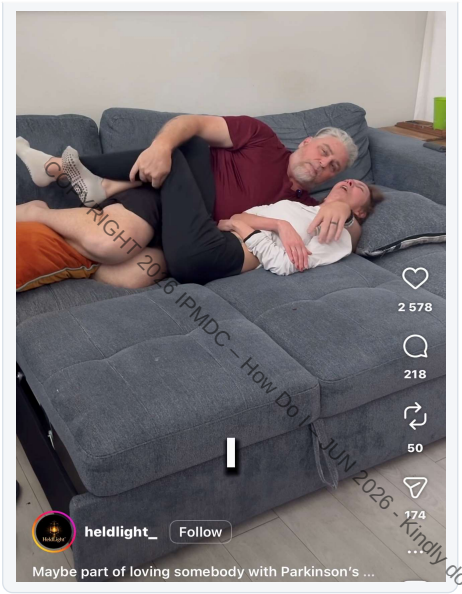
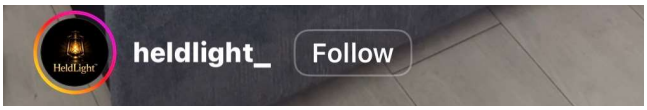


Support groups & connection

Exchange ideas with others



I wish none of us had to learn life's lessons the hard way. But if our struggles can help someone else feel less alone, maybe they weren't wasted.

@heldlight
Brent & Trudy's 20-year journey with diagnosis YOPD

A great example of helping others

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Take-home messages

Dystonia is an often under-recognised **part of PD**, coming and going through the day.

Learning how to give **useful information** about your dystonia is key to better manage it.

Families can help by notice changes you might not see, and help record patterns.

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