

Mornings with Parkinson's
Why the first hours are often the hardest — and what we can do about them
PART I
JOHN DEAN & JOSEFA DOMINGOS

Inova PARKINSON'S JOURNEY PARTNER PROGRAM
Inova Parkinson's and Movement Disorders Center

Copyright 2026 IPMDC - Parkinson's Journey Partner Program. Kindly do not alter, copy, or disseminate without permission of the Inova Parkinson's and Movement Disorders Center.

1


Our Goals

- Recognizing typical challenges faced in the mornings (& strategies for each).
- What is a possible general strategy that can be used to manage morning issues?

Copyright 2026 IPMDC - Parkinson's Journey Partner Program. Kindly do not alter, copy, or disseminate without permission of the Inova Parkinson's and Movement Disorders Center.


2

Clinician Perspective



Clinicians see physiology and addresses pharmacology


"PATIENT" VIEW



Lives it

Feels the body refusing to switch on, pills not yet working, disorientation between mind and movement.

Care Partner Perspective



Times medication, guides tasks, suppresses worry. Makes 100 micro-decisions before breakfast.

4 / 16

3



FROM YOUR SURVEY

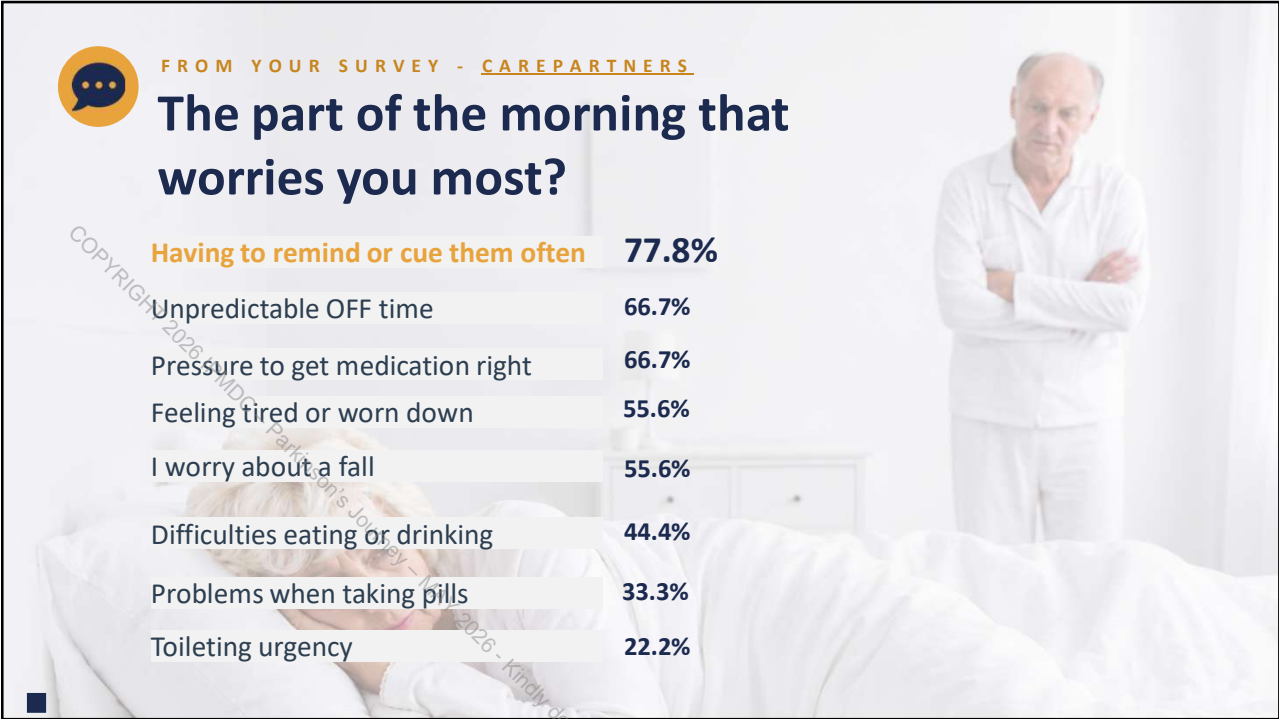
Which of these is hardest, most mornings?

The topics you flagged most:

35.5%	Getting dressed (buttons, zippers..)	14.7%	Communicating & talking
29.4%	Walking to bathroom	14.7%	Taking medication – Open bottles /handling pills
29.4%	Getting out the door in time	11.8%	Taking Medication - swallowing
23.5%	Getting out of bed	11.8%	Meals - swallowing
23.5%	Washing and showering	8.8%	Using the toilet
		8.8%	I'm not sure
		5.9%	Meals - managing cups & plates and using utensils



4



5



6



7

TEN REASONS WHY Morning Challenges in Parkinson's

- Motor "OFF" state & Meds
- Mobility, fine motor & self-care
- Rigidity & Pain
- Communication, voice & swallowing
- Autonomic issues
- Sleep & night carryover
- Fatigue
- Cognition & Initiation
- Mood: apathy, depression, anxiety
- Environment & context

■

Without permission of the Inova Parkinson and Movement Disorders Center

8

TEN Morning Challenges in Parkinson's


- Motor "OFF" state & Meds
- Mobility, fine motor & self-care
- Rigidity & Pain
- Communication, voice & swallowing
- Autonomic issues
- Sleep & night carryover
- Fatigue
- Cognition & Initiation
- Mood: apathy, depression, anxiety
- Environment & context

9

"OFF" state & meds

Clinician sees	Patient feels	Care partner carries
<ul style="list-style-type: none"> Rigidity, bradykinesia, tremor Freezing & risk of falling Reduced automaticity Delayed ON Food-medication interaction Motor/Non-motor fluctuations 	<ul style="list-style-type: none"> "My body won't switch on" Hard to roll, sit, start moving Feet feel "stuck" Dizziness & fear of standing Hard to swallow pills Worse if the dose is delayed Anxiety waiting for ON 	<ul style="list-style-type: none"> High level of help with transfers Lifting, guiding, & preventing falls Pressure to time it "exactly right" Coordinating meds, food, etc Fear of triggering a bad morning

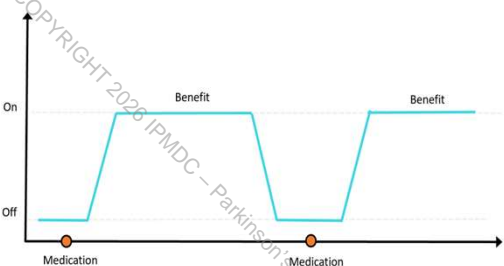
10



MEDICATION

Why the morning dose can feel slow

What's going on:



Dopamine levels are lowest before your first dose.


FROM YOUR SURVEY

- Wake up feeling OFF — stiff, slow, hard to move **56.3 %**
- ON takes longer than 30 minutes **40.6 %**
- ON takes 15–20 minutes to start **21.9 %**
- Morning dose doesn't seem to work **12.5 %**
- Cramping, curled foot or hand, painful tightness **25.0 %**
- Bloating, slow, medication takes longer to kick in **1.3 %**
- None of these **18.8 %**

“I don't feel on or off. I feel fatigued or ok, and it's not related to medication.”






“I'm up 45 min to 1 hour prior to taking meds.”

11



STRATEGIES

Helping the morning dose work better

Set up the night before	Clothes laid out, pills by the bed, water within reach, phone (in silent mode) where you can find it.	
Hydrate first	Water before you stand can help the gut, help blood pressure, and help the pill move.	
Time the medication well	Take the first dose 20–30 minutes before getting up, alarm 30 minutes early.	
Protect the protein window	When possible, take levodopa 30 minutes before breakfast. Save the heavier protein meal for later in the day.	
Track 3 mornings before the next consultation	Write down: time of dose, when ON started, what your morning was like, and what food you had. Tell your neurologist if ON consistently takes longer than 60 minutes; long-acting meds may be indicated.	

Never change a dose without speaking to your prescriber. These are habits around the dose, not a substitute for it.

12






13

TEN
Morning Challenges in Parkinson's

Motor "OFF" state & Meds	Mobility, fine motor & self-care	Rigidity & Pain	Autonomic issues	Communication, voice & swallowing
Sleep & night carryover	Fatigue	Cognition & Initiation	Mood: apathy, depression, anxiety	Environment & context

14

Mobility & fine motor

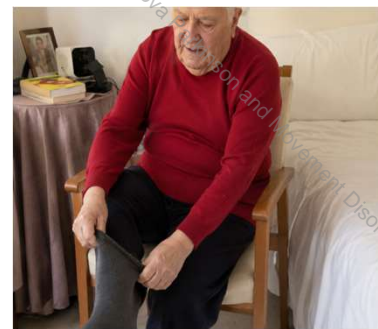
Clinician sees	Patient feels	Care partner carries
<ul style="list-style-type: none"> ▪ General mobility compromised ▪ Reduced fine motor control 	<ul style="list-style-type: none"> ▪ Hard to dress, zipper/buttons... ▪ Frustration with simple tasks 	<ul style="list-style-type: none"> ▪ More dependence for ADLs ▪ Time burden of dressing, hygiene
		

15



MOBILITY/ DAILY ACTIVITIES

Why mobility can be difficult



Speed ▪ Amplitude ▪ Rhythm

16



MOBILITY/ DAILY ACTIVITIES

What can help

- Set out **clothes & meds** the night before
- Build in **extra time**:
Try not to rush the start of the day
- Use (preferred) **music** to facilitate
- Reduce cognitive load: A written morning checklist that you can see. One small goal for the morning, instead of five.

Strategy

**What can I do
about the TASK,
the PERSON, or the
ENVIRONMENT?**

17



MOBILITY/ DAILY ACTIVITIES

What can help: cueing & movement strategies

WALKING TO THE BATHROOM

- Use lines on the floor.
- Mark foot placement for bed, toilet, sink, or especially doorways.
- Count steps to increase attention on feet.
- Avoid turns and multiple maneuvers to reach targets.
- Cleared, direct, and/or shortened pathways.
- Avoid distractions during ambulation.

- Count out loud: "1-2-3-go"
- Stop when steps are small & restart with big step.



18



MOBILITY/ DAILY ACTIVITIES

What can help: cueing & movement strategies

CUEING FOR MORNINGS AND MEALTIMES

- Break down tasks into smaller steps (perform key parts of the task when meds are ON)
- Incorporate verbal cues
- Eliminate visual and auditory distractions
- Limit items present to only the ones needed for the task
- Sit vs stand when possible
- Try to avoid time pressures



19



MOBILITY/ DAILY ACTIVITIES

What can help: changes in activity & environment



Step and bed handrail



Toilet safety rails



Walking assistive devices

Seek advice on adaptive equipment & home modifications (beds, mattresses, recliners, bed rails, walkers, etc.)

20

MOBILITY/ DAILY ACTIVITIES

What can help: changes in activity & environment

FROM YOUR SURVEY

Places I feel unsafe:

Place	Count	Percentage
Showers	10	29.4%
Toilet	0	0%
Getting in/out of bed	1	2.9%
Stairs	13	38.2%
Communicating in public	11	32.4%
None of these	10	29.4%

Consider changes in places where you feel unsafe

43% Near-fall in the past month

36% Freezing episode (feet felt stuck)

11% Falls

COPYRIGHT 2026 MDC - Parkinson's Journey - MAY 2026 - Kindly do not alter, copy, or disseminate without permission of the Inova Parkinson and Dementia Center

21

MOBILITY/ DAILY ACTIVITIES

Dress for success

What can help

Simplify

- Establish a consistent routine
 - Requires fewer conscious decisions
 - Requires less inertia to initiate
- Do the easy activities first to get you started
- Slightly larger size, stretchy &/or silky material, large (or no) buttons, zipper pulls, down jackets, slip-on shoes, etc.

Inova Parkinson and Dementia Center

22



MOBILITY/ DAILY ACTIVITIES

What can help: specific exercise



PD-specific mobility exercise

Targets slowness and stiffness through large, exaggerated movements, with progressive speed and rhythm

23

TEN

Morning Challenges in Parkinson's

Motor "OFF" state & Meds

Mobility, fine motor & self-care

Rigidity & Pain

Communication, voice & swallowing

Autonomic issues

Sleep & night carryover

Fatigue

Cognition & Initiation

Mood: apathy, depression, anxiety

Environment & context

24

Rigidity & Pain

Clinician sees	Patient feels	Care partner carries
<ul style="list-style-type: none"> OFF-period pain Axial rigidity pain Dystonic foot/hand cramping on waking Restless legs symptoms carrying over from the night Central pain syndromes Pain often misattributed to mood or motor symptoms 	<ul style="list-style-type: none"> Dreading the first movement Waking already in pain Cramping in foot or hand Aching back, neck, shoulders that won't ease The pain shapes the whole start of the day 	<ul style="list-style-type: none"> Distinguishing pain from stiffness. Worry about giving extra medication. Being asked to massage or stretch. Hard to know whether to push the movement or wait. Watching the person in pain before the day has even started. Helplessness when pain doesn't respond to the usual things.

25



PAIN & STIFFNESS

When waking up hurts

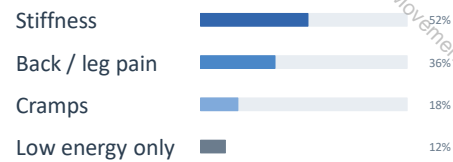
Where the pain comes from

- Rigidity from low overnight dopamine — muscles never relax fully.
- Dystonia — a curled foot, clenched hand, or twisted toes when OFF.
- Sleeping in one position for hours; not turning during the night.
- Old joint or back pain that medication usually masks.



FROM YOUR SURVEY

WHAT PEOPLE WAKE UP WITH



64%

wake up with pain or stiffness

3 in 10

report no pain at all

26



PAIN & STIFFNESS

What can help?

What can help

- Take meds before getting up; give them time before moving.
- Placing small pillow between legs during the night
- Learn good body mechanics to get out of bed.
- Gentle bed-mobility before getting up: bridge, knees side-to-side; ankle pumps.
- A warm shower (if safe) loosens rigidity better than effort does.
- Repeating, predictable morning pain is important to report to your neuro.



If pain only happens before your first dose, that's a strong clue — it's likely OFF-period pain.

27



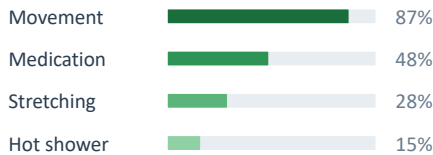
PAIN & STIFFNESS

What can help?



FROM YOUR SURVEY

WHAT HELPS



91%

of those find movement helps

Moving is the most reliable solution, even when it feels hardest to start.

"Being active is the best."

"Once (I've) worked out, everything is a go."

"Medication, then movement — both help."

28

TEN Morning Challenges in Parkinson's

- Motor "OFF" state & Meds
- Mobility, fine motor & self-care
- Rigidity & Pain
- Communication, voice & swallowing
- Autonomic issues
- Sleep & night carryover
- Fatigue
- Cognition & Initiation
- Mood: apathy, depression, anxiety
- Environment & context

29

Thank you.

Questions?

Josefa Domingos, PT, PhD
John Dean, MA CCC-SLP

without permission of the Inova Parkinson and Movement Disorders Center

30