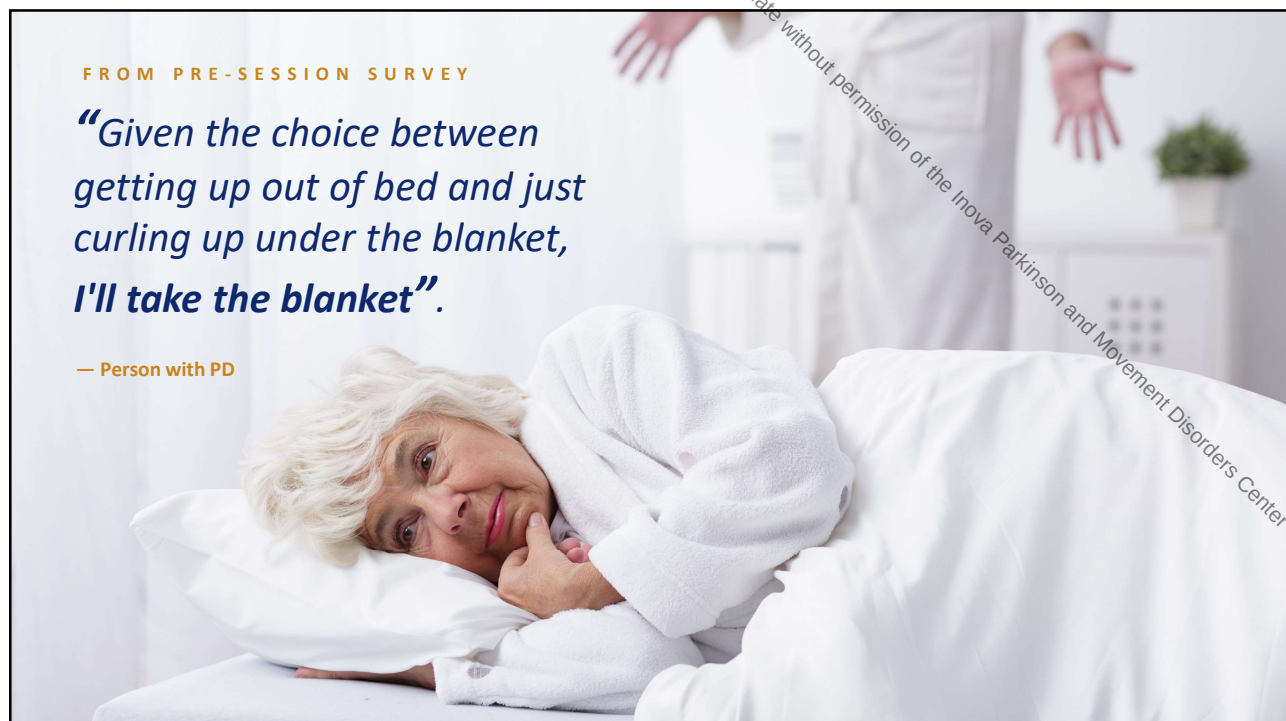




1



2

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

Mood:
apathy,
depression,
anxiety

Environment
& context

3

TEN Morning Challenges in Parkinson's

Motor "OFF"
state & Meds

Mobility,
fine motor &
self-care

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& Pain

Communication,
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4

TEN

Morning Challenges in Parkinson's

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5

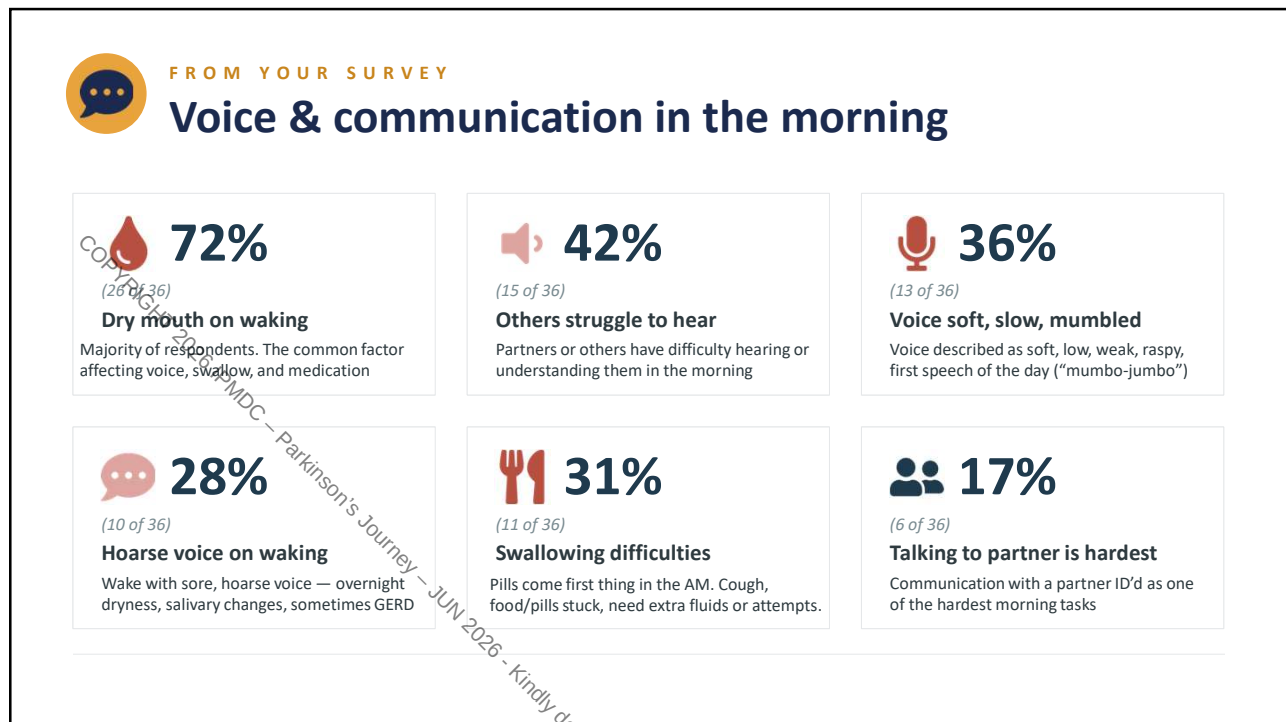
Being **heard** and **swallowing** safely

What changes overnight?

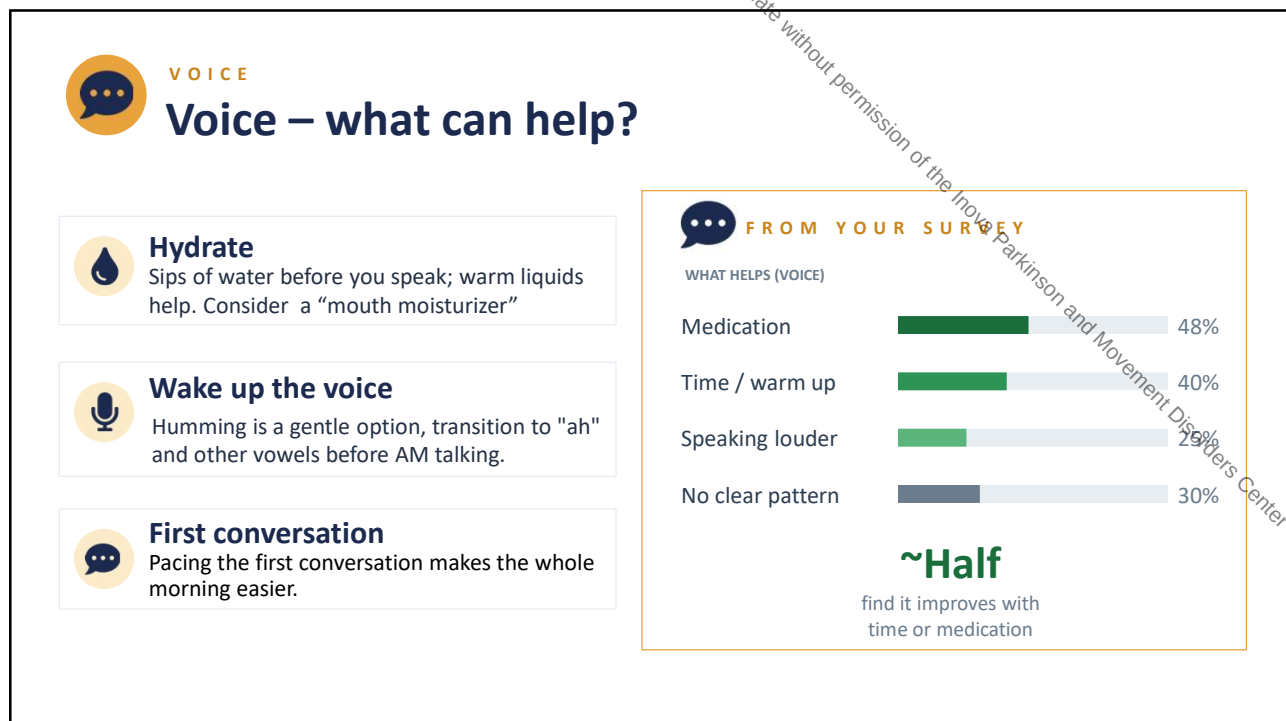
- **Mouth and throat dry out** during sleep — the voice is softer, with rougher quality.
- **OFF medication** may make breath support weaker and the voice quieter still.
- **Swallowing slows** too — pills can feel stuck and water can be the riskiest sip of the day.
- **Soft voice** can be mistaken for mood, withdrawal, or attitude (by partners, by clinicians, by others).



6



7



8

SWALLOWING

What can help?

**Swallow upright, chin neutral**

Sit fully upright, take pills one at a time, with a full sip of water. Consider taking pills with puree (eg applesauce), crushed or whole.

**Tell us if it's not safe**

Coughing, stuck pills, ongoing hoarseness lasting weeks. Ask for an SLP voice and swallow evaluation.



FROM YOUR SURVEY

"Keep water by the bed."

9

TEN

Morning Challenges in Parkinson's

Motor "OFF"
state & Meds

Mobility,
fine motor &
self-care

Rigidity
& Pain

Communication,
voice &
swallowing

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issues

Sleep & night
carryover

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apathy,
depression,
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Environment
& context

10

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

Mood: apathy, depression, anxiety

Environment & context

11

Autonomic issues in PD



Heart and circulation

- Dizziness on standing up
- Blood pressure that swings
- Drop in BP after meals
- Fainting or near-fainting



Bladder and sexual function

- Sudden urge to pass urine
- Getting up at night
- Bladder not fully emptying
- Leaks or loss of control
- Changes in sexual function



Digestion

- Constipation
- Slow gastric emptying
- Difficulty swallowing
- Drooling
- Nausea (often med-related)



Temperature and skin

- Sweating too much/too little
- Feeling cold or overheated
- Sudden flushing of the skin



Vision

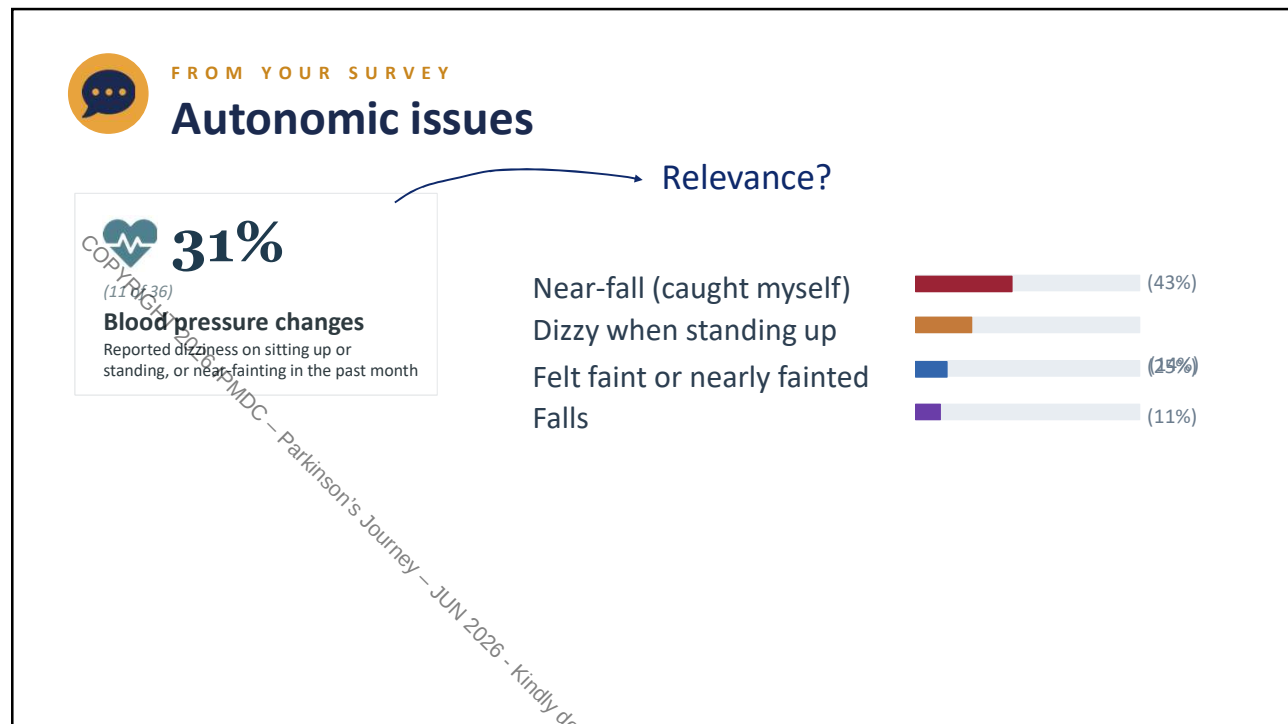
- Hard to adapt to low light
- Blurred vision
- Trouble shifting bright to dark



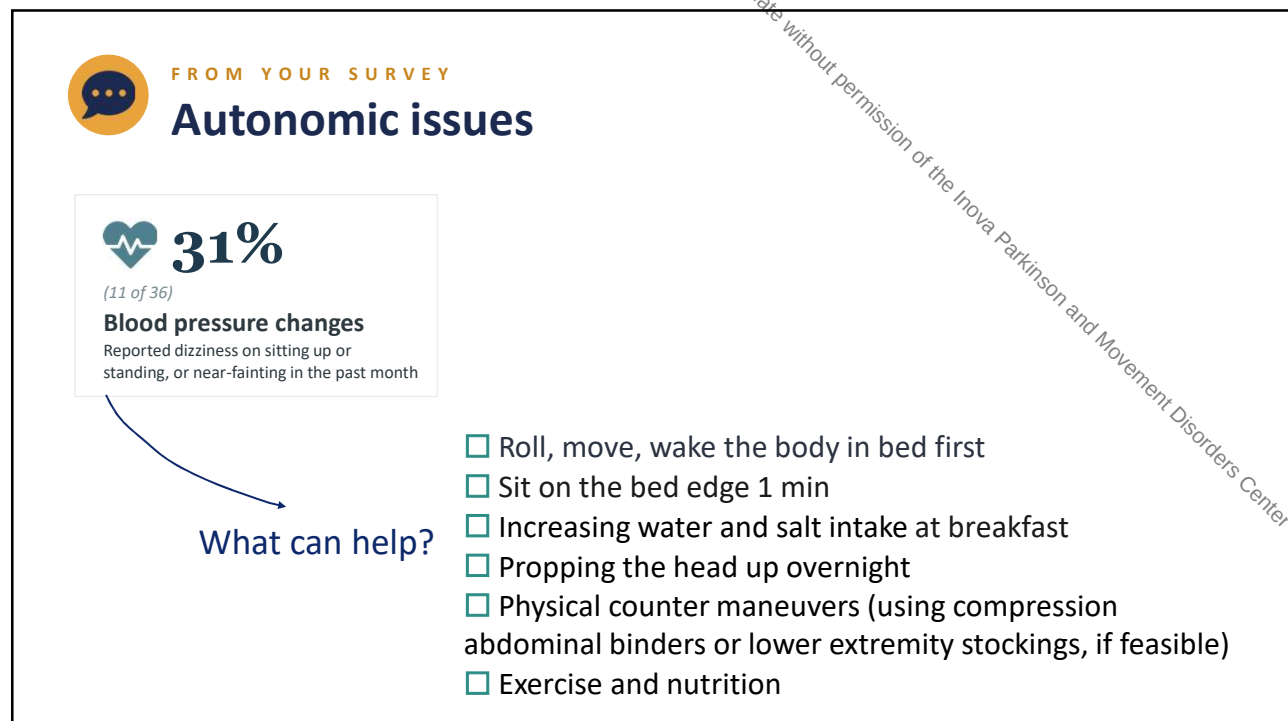
Breathing, energy and sleep

- Changes in breathing pattern
- Shortness of breath
- Weaker cough
- Fatigue that's hard to explain
- Unrefreshing sleep

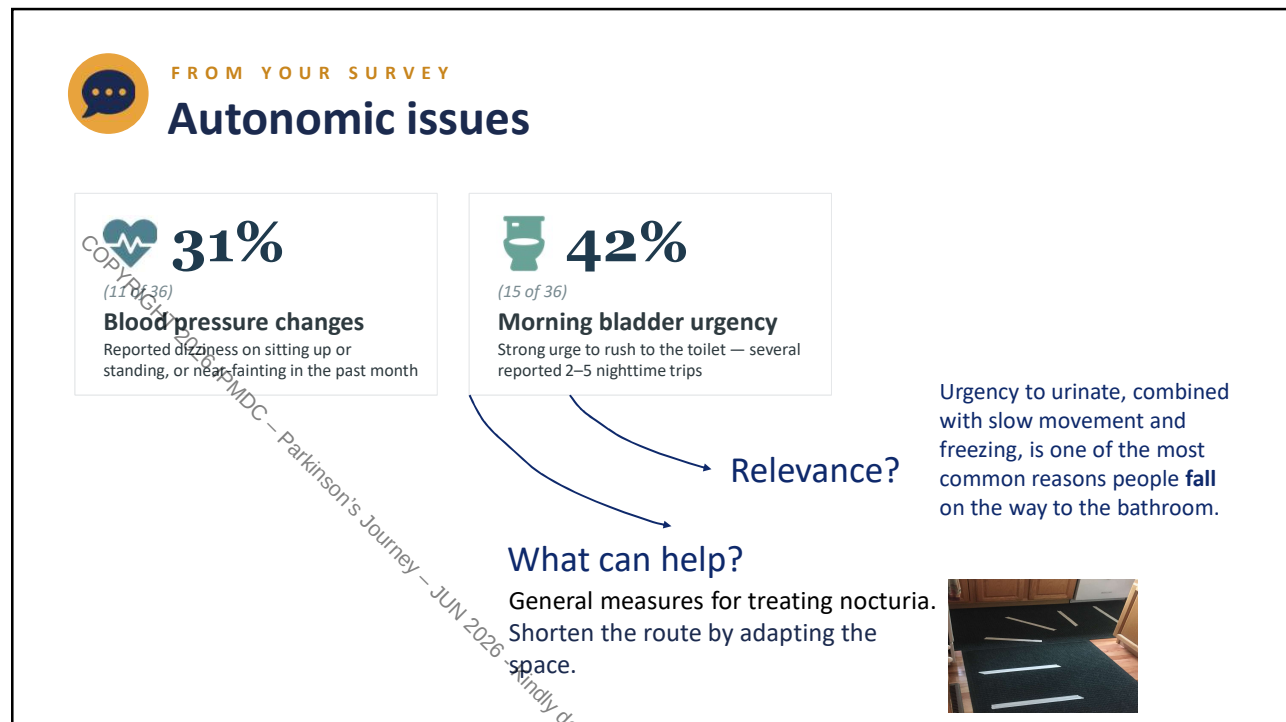
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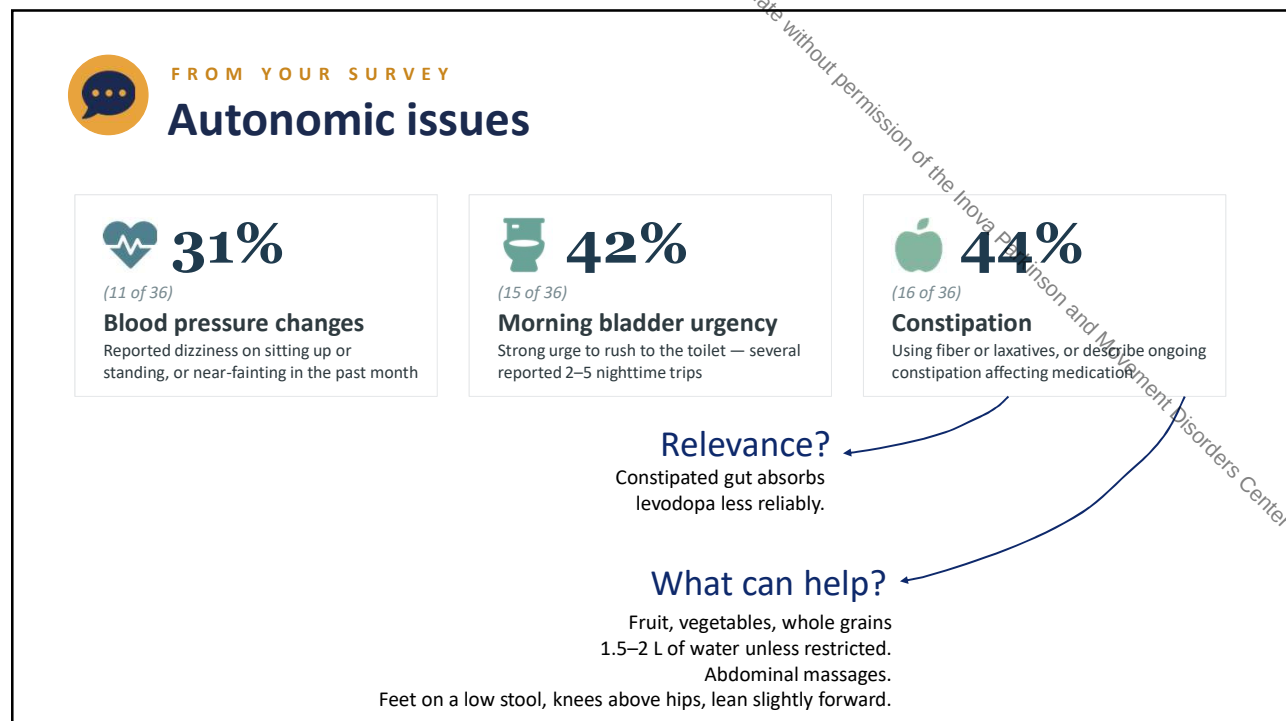
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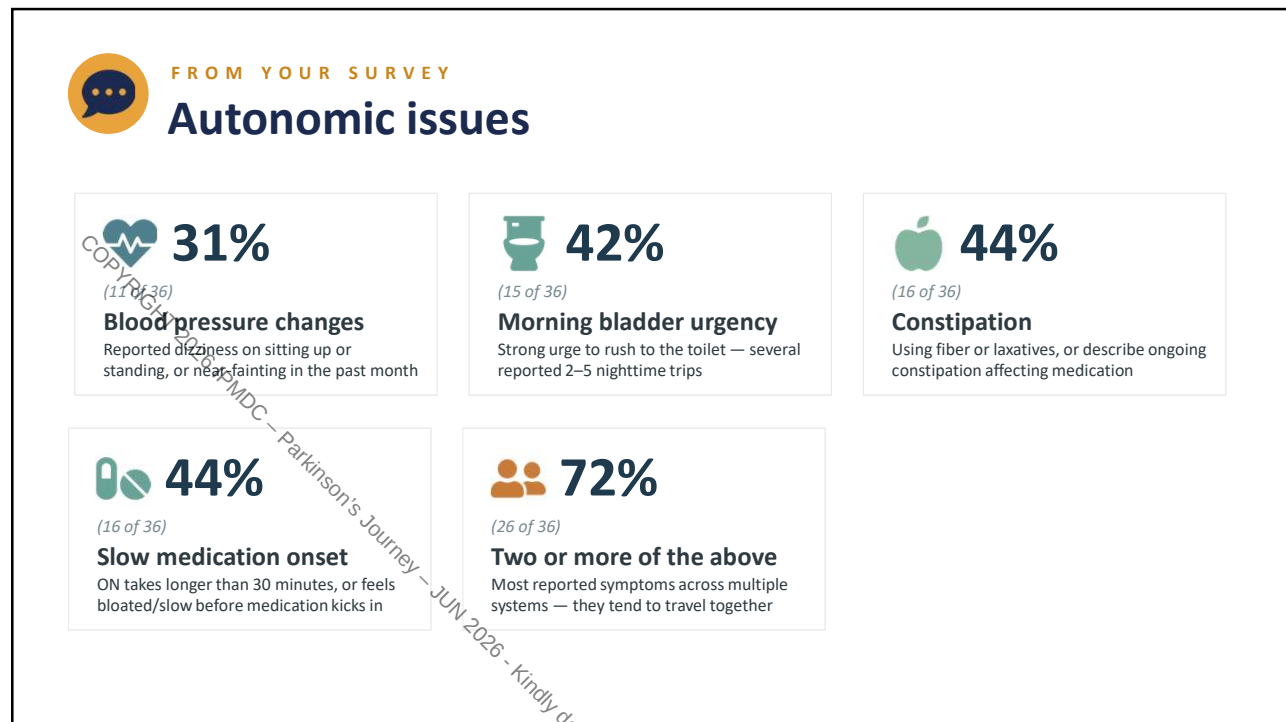
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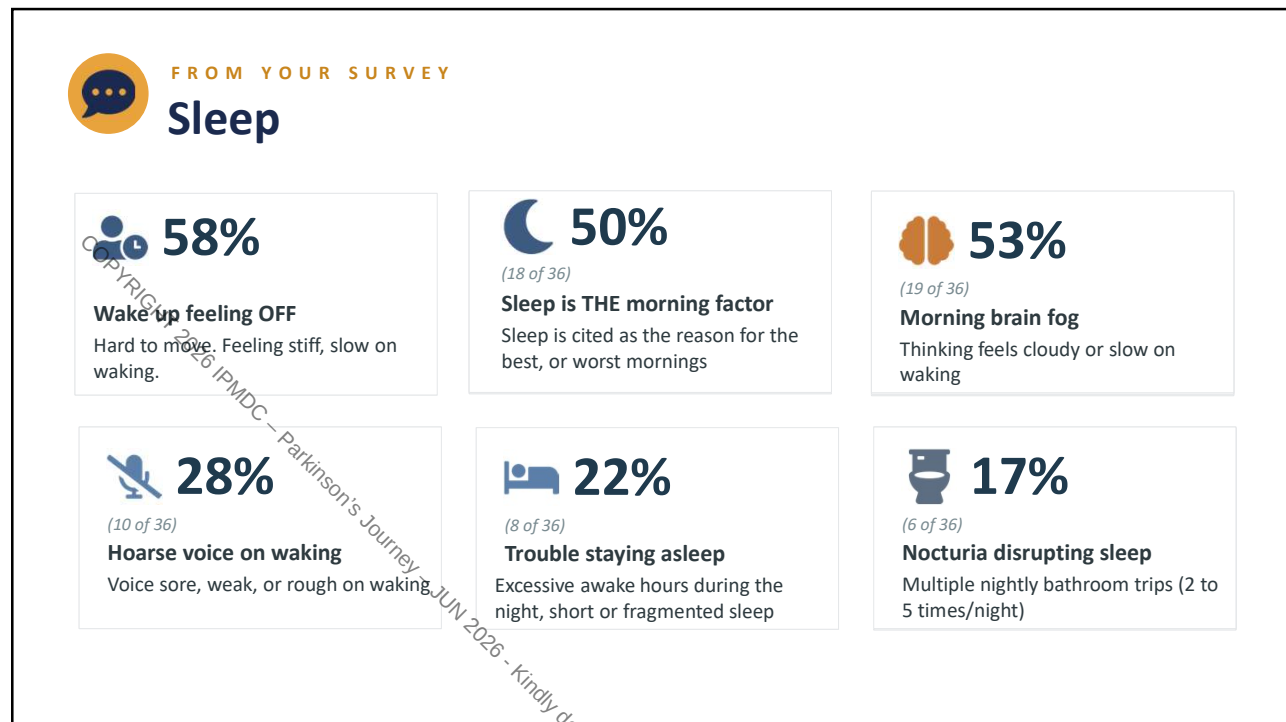
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18



19

Sleep

What can help?

A healthy lifestyle with daily exercise and diet.

Good sleep hygiene:

- Cool, quiet room
- Establish a consistent sleep schedule
- Limit fluids, caffeine, and alcohol in evening
- Avoid screens & work at bedtime
- Avoid disturbing news or TV show
- Proper intake of PD meds

General measures for the treatment of **daytime somnolence in PD.**

For **REM sleep behavior disorder** in PD, methods of self-protection.

Sleep Medicine 83 (2021) 280-289

Bright Light Therapy (BLT) - 5400K, 7500-10K Lux

- Noninvasive and non-pharmacological
- Benefits daytime sleepiness and insomnia, too

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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

Mood: apathy, depression, anxiety

Environment & context

21



FROM YOUR SURVEY

"So tired before the day starts"

42%

(15 of 36)

"Hard to get going."

Body can move, but it's effortful. The most common fatigue signal in the survey

42%

(15 of 36)

Lacking motivation

Apathy or low drive to start the day. It's different from sadness and equally real

33%

(12 of 36)

Sleep + low mood overlap

Reported both poor sleep and low mood and fatigue often sits at this intersection

25%

(9 of 36)

"Free-text" mentions of fatigue

Unprompted use of the words "tired", "fatigued", or "exhausted" when describing mornings

28%

(10 of 36)

Good sleep helped most

Named good sleep as the reason for their best morning.

19%

(7 of 36)

Worry about being worn down

Named feeling tired or worn down as a top morning worry

22



Fatigue

What can help?

Break down tasks into smaller steps, especially when the medication is lower.

Plan **resting periods** for the day.

Paradoxically, **aerobic exercise** may help.



23



Fatigue

What can help?

Create activity centers

- Keep all items needed for a task in the area where it is performed.
- Organize items into small groups (less overwhelming).
- Only present items to be used for 1 task at a time.
- Arrange items in the order in which they are to be used.



24



Fatigue

What can help?

Using proper body mechanics

- Sit-Stand strategies
 - Takes less energy
 - Decreases risk of falling
 - Allows for increased focus and effort on the actual task
- Proper body mechanics for PWP (and Care Partners)
 - Especially for repetitive tasks like sit to stand
 - Avoids injury



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TEN

Morning Challenges in Parkinson's

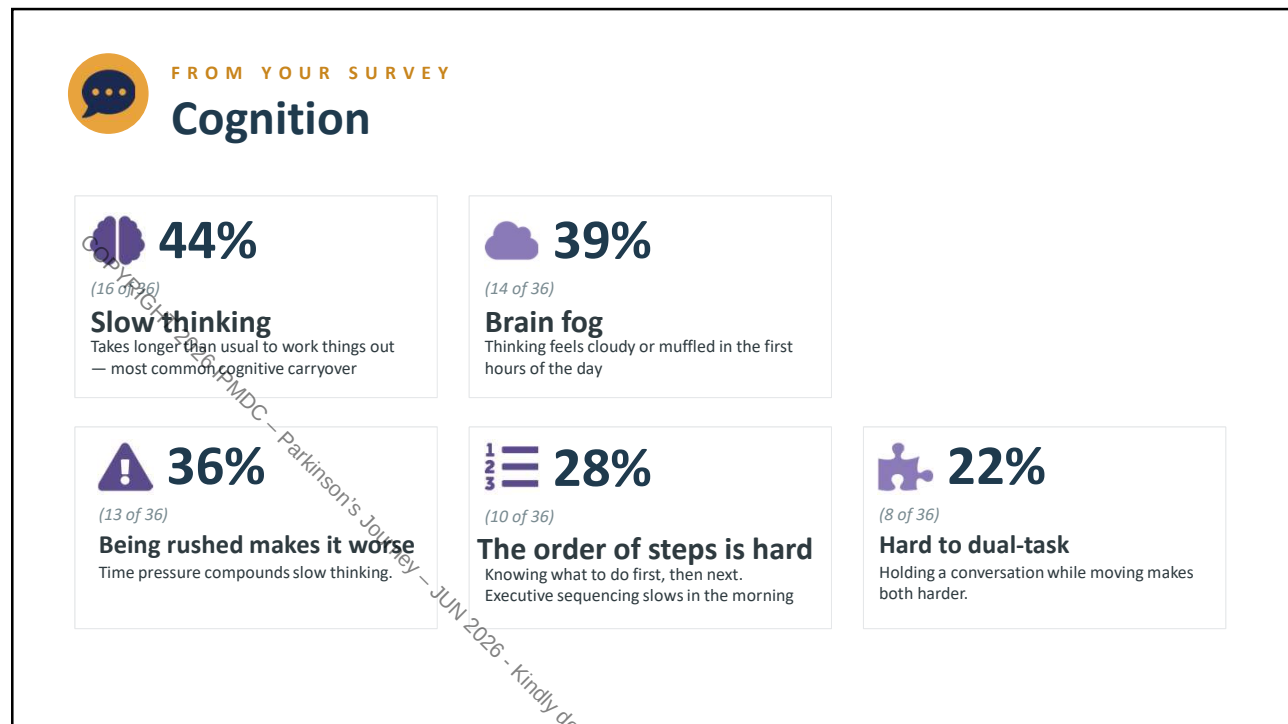
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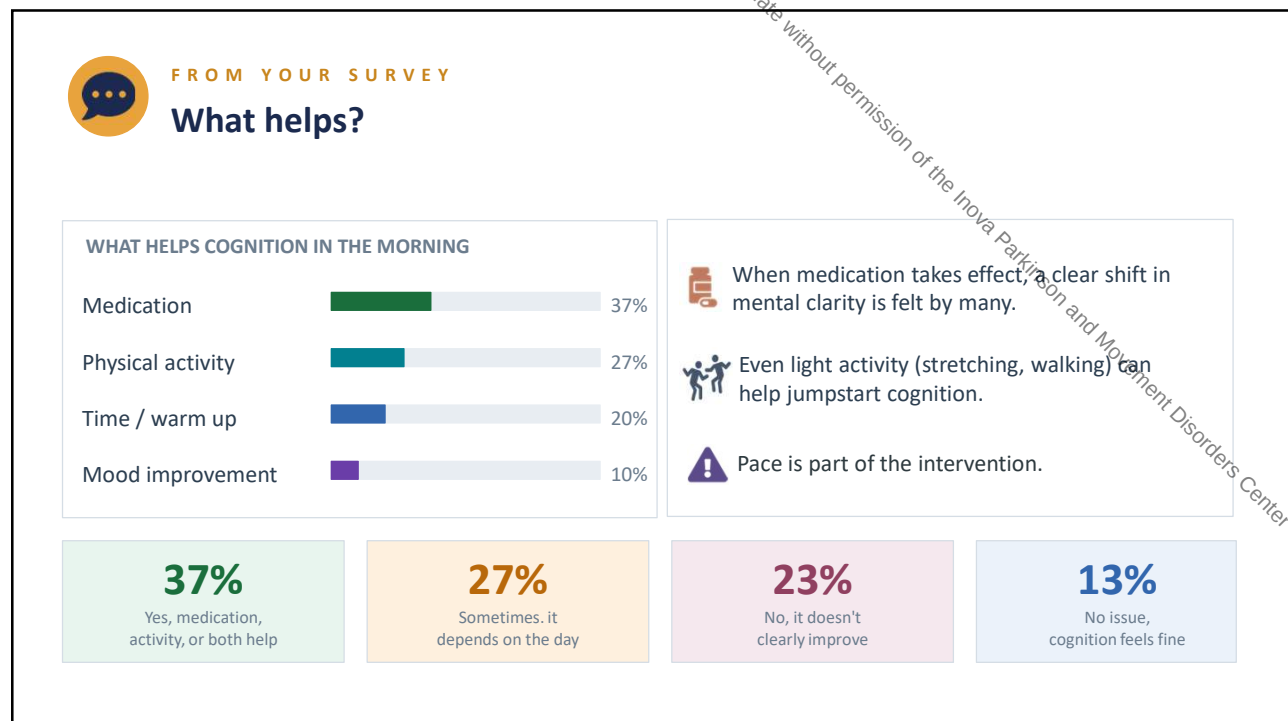
Cognition

Mood:
apathy,
depression,
anxietyEnvironment
& context

26



27



28



COGNITION

What can help

Establish a **consistent routine**

- Requires fewer conscious decisions
- Requires less inertia to initiate
- Decisions are exhausting first thing: remove them.

Do the **easy activities first** to get you started.

Open the curtains, sit by a window, or step outside for a minute.

Reduce dual-tasking. Don't talk and dress and walk at once. Park the conversation; finish the task; then talk. Splitting attention slows everything.



29



Cognition – for carepartners

What can help?

- **Assist when needed** (in the least restrictive manner)
- If **extra time** eliminates the need for assistance, offer it.
- **Start a task if needed**, but allow the person to finish it.
- **Demonstrate or perform the task together** (e.g., making the bed or brushing teeth)



30

Recognizing the factors that affect **cognition**

Understanding these factors is the best way to help cognition.

MAKES COGNITION WORSE

-  Medication is not working well
-  Inactivity for a period of time
-  Fatigue
-  Feeling anxious, depressed or fearful
-  Dual tasking

MAKES COGNITION BETTER

-  Assuring proper intake of medication
-  Increasing physical activity
-  Socializing
-  Finding ways to manage anxiety, depression or fear
-  Dual-task resilience training

31

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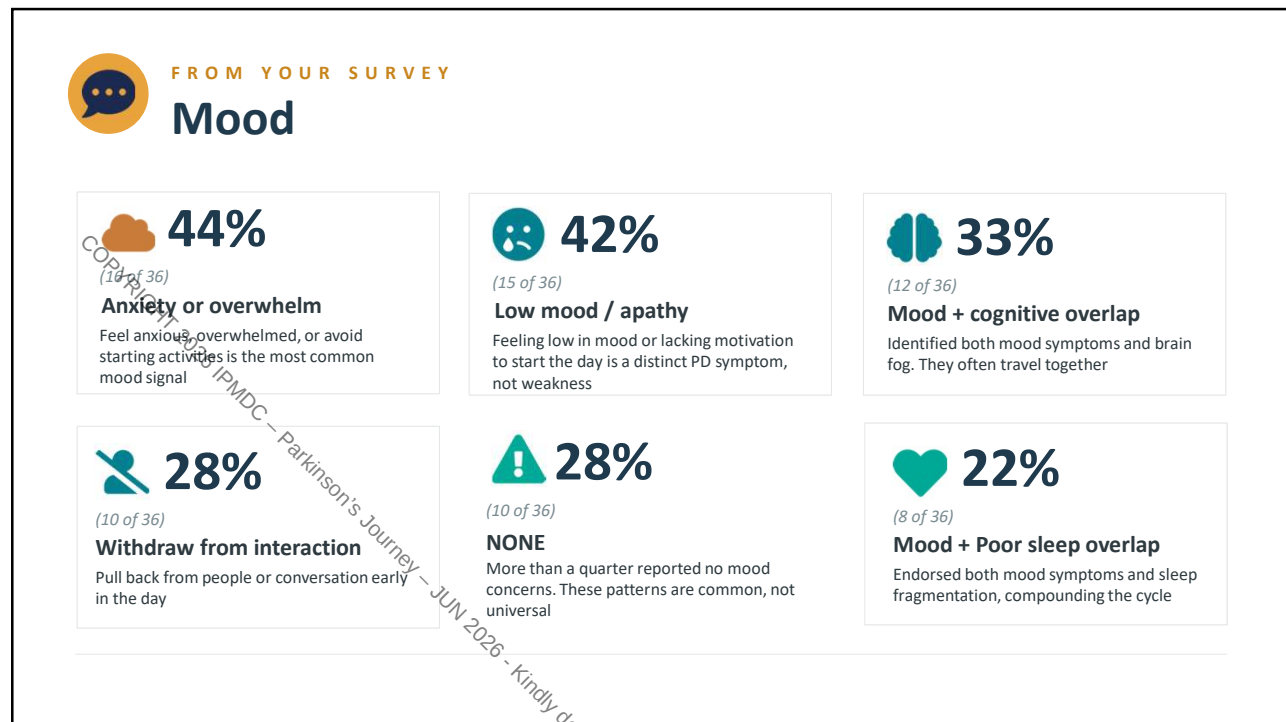
Fatigue

Cognition

Mood:
apathy,
depression,
anxiety

Environment
& context

32



33

M o o d

What can help?

PROBLEM DOMAIN	TREATMENT INTERVENTIONS
Apathy	Behavioral management techniques.
	Cognitive-behavioral therapy (CBT) "likely efficacious"
Depression	Repetitive transcranial stimulation (rTMS) - Possibly useful (short term)
	Generic exercise recommendations.

Guidelines: European Federation of Neurological Societies & Movement Disorder Society (EFNS/MDS-ES) | National Institute for Health and Clinical Excellence (NICE) | American Academy of Neurology (AAN) | Movement Disorder Society (MDS) | European Physiotherapy Guidelines for PD

Mov Disord. 2019 May;34(5):765

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& context

35



FROM YOUR SURVEY

The environment



39%

(14 of 36)

Stairs feel unsafe

Stairs were the most common environment named as feeling unsafe in the morning



36%

(13 of 36)

Being rushed makes it worse

Time pressure compounds every other morning challenge — pace is its own intervention



33%

(12 of 36)

Public communication unsafe

Communicating in public feels unsafe before voice and confidence are warm



33%

(12 of 36)

Near-fall in past month

Caught self or grabbed something — environmental and OFF-state combine here



31%

(11 of 36)

Getting out the door

Named as a hardest-morning task — the system, not the person, runs short on time



28%

(10 of 36)

Shower feels unsafe

Hot water, wet floors, balance demands — a high-risk transition before ON time

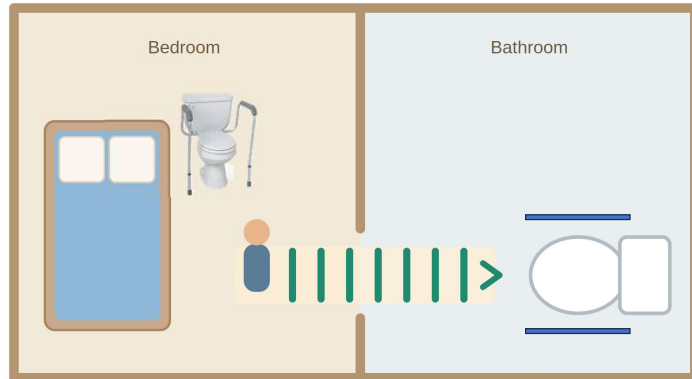
36



ENVIRONMENT & CONTEXT

What can help

- Bed Height
- Bed Linens & Pillows
- Mattress
- Handholds - Rails
- Toilet Access
- Assistive Devices
- Lighting
- Pets, clutter add complexity
- Tight spaces worsen freezing



Changing the environment is often easier than changing the symptom.

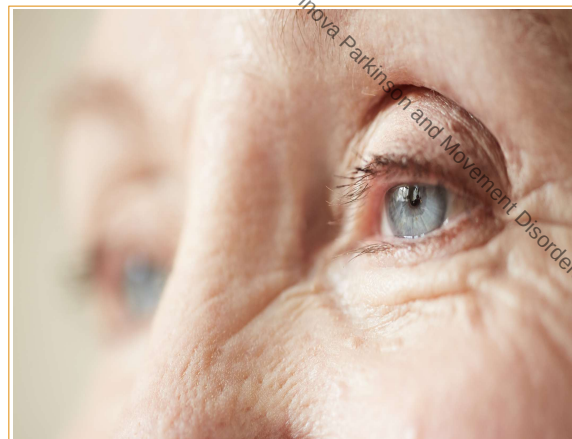
37



ENVIRONMENT & CONTEXT

What can help – visual considerations

- Adequate lighting.
- Provide contrast.
- Enlarged print for posted instructions (keep them simple).
- Visual targets for feet and handholds.
- Watch for small transitions in flooring.
- Eliminate shadows that may cause illusions.



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Summary messages



Mornings aren't just physically hard—they're a combination of **being OFF, slow to think, afraid to move, and needing time to 'switch on'**



Don't treat **symptoms in isolation**; treat the **morning system**. Small changes in sequencing, cueing, and environment can have a huge impact.



The goal isn't a perfect morning. It's a morning that makes the rest of the day possible.

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Our Goals

Recognize typical challenges in the mornings (& strategies for each).

What is a general approach that can be used to manage them?

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What is a general approach that can be used to manage mornings?

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My morning assessment tool & decision aid

Date: _____

What I want to discuss at my next clinic visit: _____

Ask yourself:	What I notice in the morning	Things to try
Hardest part of this morning? <i>Bed, bathroom, taking meds, washing/dressing, leaving the house</i>	☐ Getting out of bed ☐ Walking to the bathroom ☐ Taking my medication ☐ Washing or dressing ☐ Leaving the house ☐ My mornings are usually fine ☐ Other: _____ How often is this a problem? ☐ Every day ☐ Most days ☐ A few days a week ☐ Once in a while	☐ Bed rail or satin sheets if rolling/getting up is hard ☐ Set out clothes & meds the night before ☐ Build in extra time — don't rush the start of the day
First dose & "ON" time? <i>Time of first dose; minutes until you feel ON; food near the dose?</i>	First dose taken at: _____ I usually feel ON at: _____ Minutes between the two: _____ In a typical week, tick anything that happens: ☐ ON takes longer than 60 minutes to start ☐ A dose doesn't seem to work at all ☐ I had food — especially protein — close to my dose ☐ I wake up feeling OFF (stiff, slow, hard to move) ☐ I wake up with cramping, a curled foot or hand, or painful tightness ☐ None of these — my morning medication works the way I expect	☐ Take first dose 20–30 min before getting up (water on nightstand) ☐ Keep protein/dairy clear of the dose by ~30 min ☐ If ON delay > 60 min on most days, tell your neurologist
Safety <i>"Do you feel dizzy, freeze, or nearly fall in the morning?"</i>	Dizziness and fainting ☐ Dizzy when sitting up or standing ☐ Felt faint or nearly fainted ☐ Briefly lost consciousness Falls: ☐ Near-fall (caught myself or grabbed something) ☐ Fall Places I feel unsafe ☐ Stairs ☐ Shower ☐ Toilet ☐ Getting in/out of bed ☐ None of these	☐ Dizzy: sit on bed edge 1 min; salt + fluids at breakfast ☐ Freezing: big first step, count "1-2-3-go," visual cue on floor ☐ Clear pathway, night light, grab bars in the bathroom

42

My morning assessment & decision aid

Date: _____

What I want to discuss at my next clinic visit: _____

Ask yourself:	What I notice in the morning	Things to try
Autonomic issues? Was it more "my body wouldn't move" or "hard to get going"? <i>Brain fog, apathy, anxiety / fear of falling, low mood, sequencing</i>	☐ dizziness on sitting/standing ☐ fainting or near-fainting ☐ freezing in bedroom/bathroom/doorways ☐ falls or near-falls	☐ Roll, stretch, wake the body in bed first ☐ Sit on the bed edge 1 min ☐ Increasing water and salt intake at breakfast ☐ Propping the head up overnight ☐ Physical counter maneuvers ☐ Exercise and nutrition
Cognition & mood? Was it more "my body wouldn't move" or "hard to get going"? <i>Brain fog, apathy, anxiety / fear of falling, low mood, sequencing</i>	☐ Brain fog — thinking feels cloudy ☐ Slow thinking — takes longer to work things out ☐ Low motivation — don't feel like doing anything (this is sometimes called apathy) ☐ Anxiety or fear of falling ☐ Sadness or low mood ☐ Hard to figure out the order of steps (what to do first, then next) ☐ None of these	☐ Assess underlying factors ☐ Meaningful distractions
Care partner concern? What worries your partner most? If no partner, skip this part.	☐ Lifting or physical strain on me ☐ Having to remind or cue them often ☐ Unpredictable OFF time — I never know how it will go ☐ Pressure to get medication timing right ☐ Other: _____ ☐ Toileting urgency ☐ I feel tired or worn down ☐ I worry about a fall	☐ Lifting strain: ask for an OT/PT referral on transfer aids & technique ☐ Cueing fatigue: a shared written checklist reduces verbal load ☐ Caregiver burnout: respite, support groups, Maintain Your Brain

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Take-home messages



Mornings aren't just physically hard—they're a combination of **being OFF, slow to think, afraid to move, and needing time to 'switch on'**



Don't treat **symptoms in isolation**; treat the **morning system**. Small changes in sequencing, cueing, and environment can have a huge impact.



The goal isn't a **perfect morning**. It's a morning that makes the rest of the day possible.

44

