

Beyond Tremor: Understanding Advanced Parkinsonian Symptoms in Lewy Body Dementia

Practical guidance for family and professional caregivers

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What caregivers will take home

- Recognize common Parkinsonian movement patterns
- Ways to adjust care when alertness and mobility fluctuate
- Practical strategies for dressing, meals, transfers, and walking
- Know when a sudden change needs medical attention



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OUR FOCUS

How do we preserve function when movement, thinking, perception, and alertness change together?

**Recognize the pattern • Identify what is driving it •
Choose the safest next step**



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Understanding the movement pattern

Parkinsonism includes several movement changes, and tremor is only one of them.



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Parkinsonism includes more than tremor

THE MOVEMENT PATTERN

Movement symptoms

- Bradykinesia: movement becomes slow and small
- Rigidity: the body feels stiff or resistant
- Rest tremor: rhythmic shaking at rest
- Postural instability: balance becomes less reliable

What caregivers may notice

- Standing, dressing, writing and turning take longer
- Steps get smaller, difficulty getting out of a chair or bed
- Difficulty with fine motor tasks
- Falls, near-falls, or fear of moving



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Tremor may be easy to see, but it may not cause the most difficulty

THE MOVEMENT PATTERN

TREMOR

Rhythmic movement

BRADYKINESIA

Movement becomes slower and smaller

RIGIDITY

Stiffness and resistance

Which symptom is making everyday care harder today?



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A “shake” can have more than one cause

THE MOVEMENT PATTERN

Notice what it looks like

- At rest, while holding a position, or during activity?
- Rhythmic or irregular?
- One side or both?
- Different with stress, fatigue, or medication?

Other possibilities

- Essential or action tremor
- Medication effect or an illness
- Dyskinesia: flowing, irregular movement
- Myoclonus: brief, shock-like jerks



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A few details can help describe the tremor

THE MOVEMENT PATTERN

WHEN

At rest,
holding a
position, or
moving

WHERE

Hand, jaw,
leg, or
whole body

PATTERN

Regular,
irregular, or
jerky

IMPACT

Eating,
writing,
walking, or
sleep



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Slowness shows up in everyday tasks

THE MOVEMENT PATTERN

- Finger movements become slower or smaller
- Handwriting shrinks or trails off
- Standing from a chair takes several attempts
- Turning requires a series of small steps
- Chewing, swallowing, and speech may lose speed or force



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Rigidity can look like pain, resistance, or fatigue

THE MOVEMENT PATTERN

Possible clues

- Reduced arm swing
- Shoulder or neck discomfort
- Difficulty rolling in bed
- Stooped or flexed posture

Before assuming progression

- Check for injury or arthritis
- Review medication timing
- Look for infection or dehydration
- Notice whether attention is fluctuating



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Movement changes with thinking and alertness

In Lewy body dementia, movement symptoms rarely occur by themselves.



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Mobility can change along with attention and alertness

MOVEMENT + COGNITION

**A person may walk well at
10:00 a.m.**

**The same person may need
help at 2:00 p.m.**

**The change is real, even when strength has not
changed.**

Whenever possible, plan harder tasks for the person's
better time of day.



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Walking gets harder when the brain must do two things at once

MOVEMENT + COGNITION

One task at a time

- Walk to the bathroom
- Stand from a chair
- Step over a threshold
- Turn in the kitchen

What makes it harder

- Answering a question while walking
- Carrying something while turning
- Walking through clutter or busy patterns
- Trying to move quickly



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Visual-perceptual changes alter the way movement feels

MOVEMENT + COGNITION

- Dark flooring may look like a hole or step
- Busy patterns can make foot placement uncertain
- Low contrast can hide the edge of a chair
- Mirrors, shadows, and clutter can trigger hesitation

Improve contrast. Reduce clutter. Add light.



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Freezing can happen even when strength is good

MOVEMENT + COGNITION

COMMON TRIGGERS

- Doorways
- Turning
- Crowded spaces
- Feeling rushed or anxious

WHAT MAY HELP

- Stop and take a breath
- Shift weight from side to side
- Use one familiar cue
- Give the person space and do not pull



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Falls are usually multi-factorial

MOVEMENT + COGNITION

Motor

Freezing • small steps • poor balance

Autonomic

Low blood pressure • urgency

Cognitive

Inattention • impulsivity • visuospatial change

Environmental

Clutter • lighting • footwear



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Balancing movement treatment with overall well-being

A medication may help movement while making another symptom worse.



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Focus treatment on what affects daily life

THOUGHTFUL MANAGEMENT

Treatment may be worth considering when movement interferes with:

- Safe walking and transfers
- Eating, dressing, hygiene, or communication
- Activities that matter to the person
- Comfort or sleep

A visible tremor may not need medication if it is not limiting function.



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Levodopa may help, but watch the whole person

THOUGHTFUL MANAGEMENT

Possible benefit

- Movement and transfers become easier
- Rigidity or tremor improves
- The person can take part in more activities

Changes to report

- New or worse hallucinations
- More confusion or sleepiness
- Dizziness or low blood pressure
- Dyskinesia or nausea



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Medication changes may explain a change in movement

THOUGHTFUL MANAGEMENT

- What changed, and when did it begin?
- Was a medication started, stopped, or increased?
- Did hallucinations, alertness, blood pressure, or sleep change too?
- Are all doses being given at the correct time?

Do not stop a Parkinson medication suddenly without medical guidance.



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Therapy can make everyday care safer

THOUGHTFUL MANAGEMENT

PT

Walking,
balance,
transfers, and
cueing

OT

Daily tasks,
equipment, and
the home
environment

ST

Voice, thinking,
and swallowing

Look for therapists who understand both
Parkinsonism and dementia.



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One clear cue usually works best

THOUGHTFUL MANAGEMENT

More helpful

- One short direction
- A calm voice and enough time to respond
- A visual target or a steady rhythm
- The same words from each caregiver

Less helpful

- Several instructions at once
- Rapid or repeated correction
- Pulling or pushing
- Arguing during a fluctuation



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Plan harder tasks for the person's better times

THOUGHTFUL MANAGEMENT

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NOTICE

When is movement easiest?

2

PLAN

Use that time for harder tasks

3

PACE

Include short activity and rest

4

ADJUST

Change the plan when alertness changes



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Give the morning time to get started

EVERYDAY CARE

Before getting up

- Turn on the lights and speak calmly
- Allow time to become fully alert
- Sit at the edge of the bed before standing
- Ask about dizziness

During dressing

- Choose loose clothing and easy fasteners
- Dress the stiffer side first
- Offer one item and one cue at a time
- Sit for lower-body dressing



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Set up the transfer before asking the person to stand

EVERYDAY CARE

SET UP

- Move clutter and position the chair
- Place the feet under the knees
- Have the person scoot forward

GIVE ONE CUE

- Use one familiar phrase
- Lean forward and push from the chair
- Pause after standing before walking

Do not pull on the arms. Ask PT to teach the safest way to help.



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During freezing, slow everything down

EVERYDAY CARE

- Stop talking and give the person space
- Encourage an upright posture and a slow breath
- Try the familiar cue: a weight shift, count, rhythm, or visual target
- Wait for the person to begin the step
- If the cue does not work, sit safely and try again later

Do not push or pull during a freeze.



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Meals are safest when the person is alert and upright

EVERYDAY CARE

Make the meal easier

- Choose the most alert time of day
- Sit fully upright with the feet supported
- Reduce noise and conversation
- Use adaptive utensils if recommended

Watch for swallowing changes

- Coughing or throat clearing
- A wet or gurgly voice
- Food staying in the mouth
- Longer meals or unexplained weight loss



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A toileting plan can reduce rushing and falls

EVERYDAY CARE

- Offer regular bathroom trips before urgency begins
- Keep the route well lit and free of clutter
- Choose clothing that opens easily
- Allow extra time for turning and sitting
- Report constipation, retention, pain, or a sudden change in continence



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What to do during a low-alertness period

EVERYDAY CARE

In the moment

- Lower the demand
- Use short, reassuring statements
- Postpone walking or bathing if it is unsafe
- Offer fluids if allowed

Write down what happened

- When the episode began
- Recent medication and sleep
- Any weakness, fever, or dizziness
- How long it took to recover



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Everyone should use the same care approach

EVERYDAY CARE

A short care guide can include:

- The transfer and freezing cues that work best
- The best times for bathing, exercise, and appointments
- Current equipment and how much help the person needs
- Known triggers for hallucinations, agitation, or fatigue
- Who to call for routine questions, urgent concerns, and emergencies



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Caregiver scenario: The morning routine now takes an hour

LET'S APPLY IT

The person is sleepy, stiff, and becomes frustrated when the caregiver gives several directions.

What would you change first?



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Caregiver scenario: Freezing at the bathroom doorway

LET'S APPLY IT

The caregiver becomes anxious and starts pulling. The person stiffens and cannot step forward.

What could the caregiver try?



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Observe, communicate, and know when to call

Clear descriptions help the healthcare team decide what should happen next.



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A short video can show what words cannot

OBSERVE + COMMUNICATE

- Record only with the person's permission
- Include the full body and the activity, not only the hand
- Say the time, recent medication, and what looks different
- Keep the person safe and never try to trigger the symptom
- Show the video to the healthcare team



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Keep a simple symptom snapshot

OBSERVE + COMMUNICATE

USUAL

What is typical?

NEW

What changed?

CONTEXT

Illness, medication, or poor sleep?

FUNCTION

What is no longer safe?

The pattern, timing, and effect on function give the clinician useful information.



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A sudden decline deserves attention

OBSERVE + COMMUNICATE

CALL NOW

- A new inability to stand or walk
- Sudden confusion or unusual sleepiness
- Fever, injury, or new weakness on one side
- Repeated falls or fainting
- Choking, trouble breathing, or a medication error



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When someone says, “Her tremor is worse today”

LET’S APPLY IT

Before assuming the disease has progressed, ask:

- Does the movement look rhythmic, flowing, or jerky?
- Is the person weaker, confused, feverish, or dehydrated?
- Did the medication or its timing change?
- What can the person no longer do safely?

Describe what changed, then decide how quickly help is needed.



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Five things I hope you remember

CLOSING

- Pay attention to what is making daily care harder
- Thinking, vision, alertness, and blood pressure all affect movement
- Watch the whole person after a medication change
- A sudden decline needs prompt attention



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Questions and conversation



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