Parkinson's Disease Care at Home: A National Practice Module

Caring for people with Parkinson's disease at home.

> **Why this module matters.** Nearly 90,000 Americans are diagnosed with Parkinson's disease each year, and about 1.2 million are expected to live with it by 2030. Timely medicines and fall prevention are central to safe care at home.

About this module

This module gives teams a shared, evidence-based approach to caring for people with Parkinson's disease at home. It draws on current federal rules and national guidance, and it ends with a checklist that agencies, clinicians, and families anywhere in the United States can adopt.

Item	Details
Who it is for	Family caregivers, home care aides, nurses, and therapists
Format	7 units, case scenarios, a knowledge check, and a national checklist
Time	About 1.5 hours
How to use it	Caregivers use Units 2 to 6. Clinicians and agencies use all units.

Learning objectives

After completing this module, learners will be able to:

1. Describe Parkinson's disease nationally.
2. Recognize motor and non-motor symptoms.
3. Give medicines on time and avoid risky drugs.
4. Support safe movement.
5. Support speech and swallowing.
6. Monitor mood, thinking, and sleep.
7. Find support.

> **Scope.** Aides and family caregivers observe, support, and report. Clinical assessments, medication changes, and treatment decisions belong to licensed clinicians. Follow your state scope-of-practice rules and agency policies.

Unit 1. The national picture

Measure	Figure	Source
People diagnosed with Parkinson's disease in the U.S. each year	Nearly 90,000, 50% more than earlier estimates	Parkinson's Foundation
People expected to live with Parkinson's by 2030	About 1.2 million	Parkinson's Foundation
Older adult falls treated in emergency departments	About 4.5 million (2024)	CDC

Parkinson's disease is a progressive brain condition. It affects movement and many other body systems. Good daily care at home can protect safety and quality of life for many years.

Unit 2. Understanding the symptoms

Motor symptoms	Non-motor symptoms
Tremor, usually at rest	Constipation
Slowness of movement	Low blood pressure on standing
Stiffness	Sleep problems and acting out dreams
Balance problems and falls	Depression and anxiety
Freezing: feet feel stuck	Memory and thinking changes; hallucinations later
Soft voice, small handwriting	Swallowing problems, drooling, loss of smell

Unit 3. Medicines: on time, every time

Parkinson's medicines, such as carbidopa-levodopa, work best when taken at precise times. A late dose can cause stiffness, freezing, and falls.

- Follow the exact schedule; use alarms.
- Ask whether to take levodopa away from high-protein meals.
- In the hospital, ask staff to give doses on the person's home schedule.
- Some medicines, including certain antipsychotics and anti-nausea drugs, can worsen Parkinson's. Ask the clinician or pharmacist before any new medicine.
- Never stop Parkinson's medicines suddenly.

> **Watch for side effects.** Report new hallucinations, confusion, compulsive behaviors, or worsening movement after a medicine change.

Unit 4. Moving safely

Problem	Strategies
Freezing	Stop, stand tall, rock side to side, then step over a real or imagined line; count or use a rhythm
Turning	Make wide U-turns instead of pivoting
Getting up	Scoot forward, feet back, nose over toes, rock and stand
Dizziness on standing	Sit before standing; fluids; report to the clinician
Home	Remove rugs, add grab bars and rails, clear paths, good lighting

Exercise is one of the most helpful treatments. Physical therapy and Parkinson's-specific programs improve strength, balance, and walking. Use the Fall Prevention module for more.

Unit 5. Speech, swallowing, and eating

- A speech-language pathologist can help with soft voice and swallowing.
- Sit upright for meals; small bites; slow pace.
- Report coughing at meals or chest infections.
- Fiber, fluids, and activity help constipation.

Unit 6. Mood, thinking, and sleep

- Depression and anxiety are common and treatable; report low mood.
- Hallucinations should be reported; do not argue.
- Keep a regular sleep routine; report acting out dreams, which can cause injury.
- Plan ahead for later stages while the person can take part.

Unit 7. Support

- Ask about a movement disorders specialist and a team approach: neurologist, PT, OT, speech, social work.
- Caregiver training and respite: Area Agency on Aging and Parkinson's support organizations.
- Medicare caregiver training services may cover training in skills such as transfers.

Case scenarios

Case 1. A late dose

Mr. H's levodopa was two hours late. He now freezes in doorways and nearly fell.

- Why did this happen?
- What should change?

Discussion: Late doses cause "off" periods. Use alarms, set doses on a strict schedule, and report the near fall.

Case 2. A new nausea medicine

Mrs. I was prescribed a new anti-nausea medicine at urgent care, and her stiffness worsened.

- What might be wrong?

Discussion: Some anti-nausea medicines block dopamine and worsen Parkinson's. Call the prescriber or pharmacist the same day.

Knowledge check

1. How many people are diagnosed with Parkinson's each year in the U.S.? *(Nearly 90,000)*
2. Why must levodopa be on time? *(Late doses cause stiffness, freezing, and falls)*
3. Name two non-motor symptoms. *(Constipation, low blood pressure on standing, depression, sleep problems)*
4. What helps with freezing? *(Stop, stand tall, rock, step over a line, rhythm)*
5. Should Parkinson's medicines be stopped suddenly? *(No)*

National Parkinson's Disease Home Care Checklist

This checklist turns national Parkinson's care practice into one tool for families, agencies, and clinicians. The "National basis" column shows where each item comes from. Adapt it to your state rules and policies.

Name or ID	Date	Completed by and role
Agency or organization	Reviewed by	Next review date

A. Medicines

Action	National basis	Done	Notes
Exact dose schedule written and alarms set	Parkinson's care practice	☐	
List of medicines to avoid shared with all clinicians	Parkinson's care practice	☐	
Hospital plan to keep home dose schedule	Parkinson's care practice	☐	

B. Safety and movement

Action	National basis	Done	Notes
Fall risk assessed; home made safer	CDC STEADI	☐	
Physical therapy and exercise program	USPSTF 2024 (exercise)	☐	
Freezing and turning strategies taught	PT practice	☐	
Orthostatic blood pressure checked	CDC STEADI	☐	

C. Other needs

Action	National basis	Done	Notes
Speech and swallowing evaluated	SLP practice	☐	
Constipation, mood, sleep, and hallucinations monitored and reported	Parkinson's care practice	☐	
Advance planning discussed	Best practice	☐	
Caregiver training and respite arranged	Medicare caregiver training services; NFCSP	☐	

Completed by: signature	Printed name and title	Date
Reviewed by: signature	Printed name and title	Date

Sources and further reading

Parkinson’s Foundation: Nearly 90,000 diagnosed each year (parkinson.org)

CDC: Facts About Older Adult Falls (cdc.gov)

CDC STEADI Pocket Guide (cdc.gov)

USPSTF: Falls Prevention, 2024 (guidelinecentral.com)

Rural Health Information Hub: Caregiver Training Services (ruralhealthinfo.org)

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