FOR PATIENTS, FAMILIES & CARE PARTNERS

Understanding Changing Care Needs

How to recognize change, adjust support and preserve independence in Parkinson's care

THE MAIN IDEA

Parkinson's care needs rarely change in a straight line. Ability can vary by time of day, medication timing, fatigue, illness, stress and environment. The goal is not to take over every task—it is to provide the least amount of help needed for the person to participate safely and successfully.

Why care needs change

Parkinson's affects movement, but it can also affect thinking, mood, sleep, blood pressure, bladder and bowel function, speech and swallowing. Some changes develop gradually. Others may signal a medication issue, infection or another medical problem that needs prompt attention.

- **Expect variation.** A task that is easy during an "on" period may be difficult when medication is wearing off or fatigue is high.
- **Look for patterns, not one difficult day.** Repeated changes across several days are more useful than a single observation—unless the change is sudden or dangerous.
- **Preserve the person's voice.** Discuss preferences before adding help, changing routines or making decisions about safety and living arrangements.

Seven areas to watch

- **1. Movement and fall risk —** more freezing, shuffling, near-falls, difficulty turning, trouble rising from a chair or needing furniture for support.
- **2. Daily activities —** taking much longer to dress, bathe, toilet, eat, write, use a phone, manage the home or get in and out of bed.
- **3. Medication response —** doses wearing off early, more involuntary movement, missed doses, new sleepiness, nausea, confusion or hallucinations.
- **4. Communication and swallowing —** softer or less clear speech, repeated coughing during meals, a wet-sounding voice, food sticking, drooling, weight loss or longer mealtimes.
- **5. Thinking and behavior —** new difficulty planning, managing money or medications, getting lost, unsafe judgment, impulsive behavior, hallucinations or delusions.
- **6. Mood, sleep and body functions —** depression, anxiety, apathy, daytime sleepiness, acting out dreams, constipation, urinary urgency or dizziness when standing.
- **7. Care-partner capacity —** injury, exhaustion, irritability, poor sleep, missed work or medical appointments, isolation or feeling that care cannot be provided safely.

IMPORTANT

A sudden change in thinking or behavior is not typical Parkinson's progression. Report it promptly; infection, dehydration, medication effects or another illness may be contributing.

Match support to the current need

1. **Independent with setup:** Arrange supplies, simplify choices, allow more time and use adaptive equipment while the person completes the task.
2. **Prompting or standby help:** Offer one instruction at a time, remain nearby for safety and step in only when needed.
3. **Hands-on assistance:** Help with the most difficult portion while encouraging the person to do the steps that remain safe and manageable.
4. **Coordinated or continuous support:** When needs span mobility, cognition, swallowing, toileting or nighttime safety, involve the clinical team and discuss in-home services, respite, adult day care or a higher-support living setting.

What to do when needs change

1. **Write down what changed:** Record the task, time, medication timing, symptoms, falls or near-falls, sleep, food and fluid intake, and what helped.
2. **Check for an immediate cause:** Consider a missed or late dose, poor sleep, dehydration, constipation, a new medication, illness, pain or an unfamiliar environment. Do not change Parkinson's medication without the prescriber.
3. **Contact the right professional:** Share the pattern with the neurologist or movement-disorder specialist. Ask for physical, occupational or speech-language therapy when mobility, daily activities, speech or swallowing are affected.
4. **Adjust the environment:** Improve lighting, clear walkways, add stable seating, place frequently used items within reach and reduce multitasking. Ask a therapist before choosing mobility or transfer equipment.
5. **Update the care plan:** Clarify who manages medications, transportation, appointments, meals, finances, nighttime needs and emergency contacts. Add backup help before a crisis occurs.
6. **Review again:** Reassess after a medication change, fall, hospitalization, infection, new diagnosis or major change in the care partner's health.

Who can help

Team member	How they may help
Neurologist / movement-disorder specialist	Diagnose changes, review medication timing and side effects, and coordinate Parkinson's treatment.
Physical therapist	Assess walking, balance, transfers, falls and appropriate mobility strategies.
Occupational therapist	Adapt dressing, bathing, eating, home tasks and the environment while supporting independence.
Speech-language pathologist	Evaluate speech, communication, cognition and swallowing safety.
Primary care clinician	Evaluate infection, pain, blood pressure, sleep, mood and other medical causes of change.
Social worker / care coordinator	Connect the family with VA benefits, home care, respite, transportation, support groups and long-term-care planning.

When to seek prompt or emergency help

CALL 911 OR SEEK EMERGENCY CARE

For signs of stroke; severe breathing difficulty; choking that does not clear; chest pain; a serious fall or head injury; loss of consciousness; or immediate danger to the person or others.

- **Contact the healthcare team promptly for** sudden confusion, abrupt behavior change, new hallucinations, fever, repeated falls, new inability to stand or walk, repeated coughing with meals, dehydration, rapid weight loss or a major medication reaction.
- **Do not stop levodopa or other Parkinson's medicines suddenly** unless the treating clinician specifically directs it. Keep an accurate medication list and schedule available for urgent care or hospitalization.
- **Report depression and suicidal thoughts.** Call or text 988 in the United States for immediate crisis support; call 911 when there is immediate danger.

A monthly care-needs conversation

Set aside 15 minutes when everyone is rested. Include the person with Parkinson's and focus on what matters most to them.

- **Ask:** What has become easier or harder since our last review?
- **Ask:** Are there falls, near-falls, choking episodes or medication problems to report?
- **Ask:** Which task needs a new strategy, device or professional assessment?
- **Ask:** Is the current amount of help preserving dignity and participation?
- **Ask:** Does the care partner have enough sleep, backup help and time away?
- **Ask:** What should we discuss at the next healthcare appointment?

Planning ahead without giving up hope

Planning is a way to protect choice. Discuss healthcare preferences, legal and financial documents, driving, home safety, future housing, respite and emergency backup while the person with Parkinson's can participate fully. Palliative care can be added at any stage to help with symptoms, stress and quality of life; it is not the same as hospice.

Trusted resources

- **Parkinson's Foundation — Care Partners:** https://www.parkinson.org/resources-support/carepartners
- **VA Caregiver Support — Parkinson's Disease:** https://www.caregiver.va.gov/Tips_by_Diagnosis/Parkinsons.asp
- **VA Parkinson's Disease Research, Education and Clinical Centers:** https://www.parkinsons.va.gov/
- **Parkinson's Foundation Helpline:** 1-800-4PD-INFO (1-800-473-4636)

Recovery Health Tech contact: Val Brown • 1-504-450-6279 • val@recoveryhealthtech.com