FOR PATIENTS & CARE PARTNERS

Respite Care

Planning trusted short-term support for a person living with Parkinson's

THE MAIN IDEA

Respite care gives a family caregiver planned, temporary relief while another trusted person provides care. It is not abandonment or failure—it is part of a sustainable care plan that protects both the caregiver and the person with Parkinson's.

What respite care can look like

- **Help from family or friends.** A trained relative, neighbor or member of a faith community may provide companionship or cover specific tasks for a few hours.
- **In-home paid care.** An aide or agency worker comes to the home for supervision, personal care, meals, light tasks or caregiver relief. Services and training vary.
- **Adult day services.** A community program may provide daytime supervision, activities, meals and sometimes health services or transportation.
- **Short-term residential care.** Some assisted-living, nursing or specialized facilities offer overnight stays for several days or longer.
- **Emergency respite.** A backup option is arranged for illness, hospitalization or another unexpected loss of the primary caregiver.

Start before there is a crisis

- **Begin small.** Try a short, predictable visit while the caregiver remains nearby, then increase time as comfort grows.
- **Use respite regularly.** Scheduled breaks are often easier to arrange and more restorative than waiting until exhaustion is severe.
- **Use the time intentionally.** Rest, attend an appointment, exercise, see friends or complete errands. The purpose is recovery—not adding more caregiving work.

SIGNS TO ACT NOW

Arrange support promptly when the caregiver has persistent exhaustion, irritability, sleep problems, declining health, isolation, depression or fear of losing control—or when the person with Parkinson's can no longer be left safely alone.

Find and evaluate respite care

1. **Define the care needed:** List the hours, mobility assistance, toileting, medication reminders, meal needs, swallowing precautions, cognition or hallucination concerns, and behaviors that require experience.
2. **Identify possible sources:** Ask the neurology clinic, social worker, Area Agency on Aging, Aging and Disability Resource Center, Parkinson's support group, VA Caregiver Support team, faith community and trusted families.
3. **Screen the provider:** Confirm licensing or agency status where applicable, background checks, insurance, references, training, supervision, substitute coverage and emergency procedures.
4. **Discuss Parkinson's specifically:** Ask about freezing, falls, "on/off" periods, dyskinesia, low blood pressure, swallowing, cognitive changes, hallucinations and time-critical medication schedules.
5. **Use a trial visit:** Observe communication, respect, transfer technique, medication-time awareness and whether the person with Parkinson's feels safe and included.
6. **Put the plan in writing:** Document tasks, schedule, cost, cancellation rules, contacts, emergency steps and what must be reported after each visit.

Questions to ask a provider

- **Who will provide the care?** Will it be the same person each time, and what happens if that person is unavailable?
- **What training is verified?** Ask about transfers, fall prevention, dementia, first aid/CPR, medication assistance and Parkinson's experience.
- **What is included in the price?** Clarify minimum hours, transportation, evenings, weekends, holidays, personal care and cancellation charges.
- **How are problems handled?** Who supervises the worker, how are incidents documented, and whom can the family call after hours?
- **What is outside the service scope?** Know which clinical tasks, lifting situations or medication duties the provider cannot perform.

SAFETY CHECK

Never assume a respite worker can administer medicine, perform transfers or manage swallowing risk. Verify what is legally allowed, included by the service and within the worker's documented training.

Printable respite-care plan

Person receiving care: _____ Preferred name: _____ Date updated: _____

Primary caregiver: _____ Phone: _____ Backup contact: _____

Essential daily information

Topic	Instructions for the respite provider
Parkinson's medicines—exact clock times	_____
Mobility, transfers and fall precautions	_____
Meals, fluids and swallowing precautions	_____
Toileting and personal-care preferences	_____
Communication, cognition, anxiety or hallucinations	_____
Activities, routines and calming strategies	_____

Emergency and visit information

Home address: _____

Neurology / medical contact: _____ Phone: _____

Preferred hospital: _____ Allergies: _____

When to call caregiver: _____

When to call 911: _____

Where medication list and health documents are kept: _____

Visit schedule and handoff

Provider / agency: _____ Phone: _____

Date / time: _____ Cost: _____

What happened during the visit / changes to report: _____

_____

Paying for respite care

- **Ask what each program covers.** Eligibility, covered services, provider rules, waiting lists and cost sharing vary. Get a written explanation before scheduling care.
- **Start with local aging and disability resources.** The Eldercare Locator and local Area Agency on Aging or ADRC can identify respite programs, caregiver grants, adult day services and sliding-scale options.
- **Review long-term-care insurance and employee benefits.** Policies may cover in-home or facility respite; some employers offer caregiver assistance or flexible-spending benefits.
- **Understand Medicare limits.** Medicare generally does not pay for ongoing custodial respite. Short-term inpatient respite may be covered as part of the Medicare hospice benefit for an eligible hospice patient, subject to the hospice plan and cost sharing.
- **Ask about Medicaid and state programs.** Home- and community-based services and caregiver support programs differ by state and may have financial or functional eligibility rules.

Resources for veterans and caregivers

- **VA respite care.** Eligible Veterans may receive respite through VA Geriatrics and Extended Care. Availability and the care setting depend on clinical need, eligibility and local services.
- **VA Caregiver Support Program.** Every VA medical center has a caregiver-support team. The VA Caregiver Support Line can explain programs and connect families to the local team.
- **Ask the Veteran's VA care team.** A primary care clinician, social worker or Parkinson's specialist can help request an assessment and document the level of care needed.

BUILD A BACKUP PLAN

Keep at least two possible caregivers or services, current instructions, a medication list, emergency contacts and access information. Review the plan whenever mobility, cognition, swallowing or medication timing changes.

Trusted resources

- **Eldercare Locator:** https://eldercare.acl.gov/ • 1-800-677-1116
- **ARCH National Respite Locator:** https://archrespite.org/respitelocator
- **VA Respite Care:** https://www.va.gov/GERIATRICS/pages/Respite_Care.asp
- **VA Caregiver Support Line:** https://www.caregiver.va.gov/ • 1-855-260-3274
- **Parkinson's Foundation — Care Partners:** https://www.parkinson.org/resources-support/carepartners
- **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