

Exploring Next Steps in Care



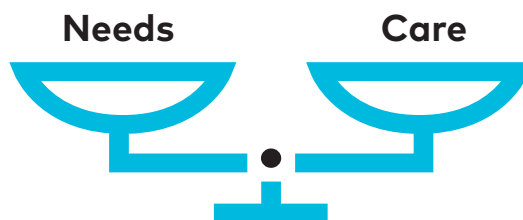
Key Questions When Considering Care:

- Is staying active or social difficult?
- Are treatments hard to manage?
- Are daily tasks like getting out of bed or bathing a struggle?
- Do you need help with transportation?
- Is the care partner feeling stressed, at risk of burnout or in need of respite?
- Does the care partner have health issues?
- Are there safety concerns, such as falls, getting lost, or managing medications?
- Is getting around your home challenging due to stairs or other barriers?

Parkinson's disease (PD) affects each person differently, but it typically progresses slowly over time. As your symptoms change, you may need to rely on more support and care. There are many options to help manage these changes, based on your needs, preferences and resources.

When is it time to get more help?

Start by having open and regular conversations with loved ones and your care team. Discuss everyone's needs, what's working well, where things are getting harder and any safety concerns. Signs that extra help may be needed include difficulty with daily tasks, falls, changes in behavior and thinking or care partner fatigue. The goal is to find a balance that keeps you safe and supports the best quality of life.



Care Options

Knowing your choices and planning ahead can help make it easier to navigate changes as they come up.

Home-Based Support

Services that can help support a person living at home include:

- **Family & Friends** — Depending on ability and availability, may help with household tasks, personal care, medications, driving and support
- **Meal & Transportation Services** — Meal delivery, rides to appointments
- **Personal Care Aide, Homemaker & Companion Care** — Help with errands, housekeeping, daily living activities like dressing and bathing, medication reminders, meal prep and companionship
- **Short-Term Skilled Care** — Short-term nursing care and therapy (must be homebound and medically necessary for insurance coverage)
- **Adult Day Programs** — Social activities, meals, care during the day
- **Respite Care in Residential Settings** — Short-term overnight stays

Resources

- Tips for aging in place: [Parkinson.org/HomeSafety](https://www.parkinson.org/home-safety)
- Tools for getting outside help: [Parkinson.org/OutsideHelp](https://www.parkinson.org/outside-help)
- Assisted living and skilled nursing educational resources: [Parkinson.org/Library](https://www.parkinson.org/library)
- Long-term care planning resources: [LongTermCare.gov](https://www.longtermcare.gov)
- Aging Life Care Experts: [AgingLifeCare.org](https://www.aginglifecare.org)
- Area Agency on Aging for local care options: [eldercare.gov](https://www.eldercare.gov); **1-800-677-1116**

Helpline

For answers to your Parkinson's questions, contact our Helpline at **1-800-473-4636** or Helpline@Parkinson.org.

We are here for you.

Care Communities

Housing options that offer different levels of support include:

- **Independent Living** — Activities, meals, housekeeping
- **Assisted Living** — Help with daily activities, medication management, dining services, wellness programs, social opportunities, transportation
- **Residential Care Homes** — Smaller home settings with 24/7 support from care staff and on-call nursing
- **Skilled Nursing** — 24/7 care for more complex needs and rehab
- **Continuing Care Retirement Community** — A range of care from independent to skilled nursing
- **Dementia Care** — Available in some assisted living and skilled nursing facilities, includes memory support and specialized care

Parkinson's-Specific Care

Finding care with staff experienced in PD can be difficult. Be sure to ask if the care team offers support for movement challenges, medication management, mood changes and whether exercise and rehab are available on-site.

The Parkinson's Foundation Community Partners in Parkinson's Care program trains care staff to support the complex needs of people with PD. Contact our Helpline to explore local resources, including any participating sites in your area. For more information, visit [Parkinson.org/CommunityPartners](https://www.parkinson.org/communitypartners).

Paying for Care

Medicare and private insurance do not cover many of the costs associated with care. Depending on your situation, Medicaid, Veterans benefits or long-term care insurance may be available to help. An elder law attorney and financial planner with expertise in long-term care planning can help you understand your options. To find a certified elder law attorney in your area, visit [Naela.org](https://www.naela.org) or contact your local Area Agency on Aging.

Tips for Finding Local Care Resources

- **Ask your support network for recommendations**, including family, friends, members of your support group and care team.
- **Do your research.** Review background checks, references and online reviews. Arrange tours and interviews and invite a friend or family member for support.
- **Rely on trusted organizations**, like the Parkinson's Foundation and your local Area Agency on Aging, for guidance and resources.

