

Becoming a Care Partner

When someone you love is diagnosed with Parkinson's disease (PD), it is natural to feel a range of emotions from confusion to anger to fear. You will have many questions: What exactly is PD? Where is my partner now in the process of this disease, and what can we do in the future? This supplement offers tips on being a care partner for a person with PD *and* taking care of yourself.

Caring for Someone With PD

As a care partner for a person with PD, your responsibilities go beyond helping with daily activities. You are an important advocate and educating yourself about PD is the first step to advocating effectively.

Expecting the Unpredictable – PD is a progressive illness, meaning that the symptoms may worsen over time. However, this progression rarely happens in a predictable way, and the severity of symptoms can vary greatly from day to day and person to person. One day your partner may be able to move about the kitchen preparing meals, while the next day they may need help just getting out of bed. The severity of PD symptoms can also fluctuate throughout the day, especially as the disease progresses. However, any abrupt change in functioning that does not resolve quickly should be discussed with the healthcare provider.

Managing the Care Process – As a care partner, your responsibilities may include building relationships with members of the healthcare team; coordinating treatment interventions; obtaining adaptive equipment or clothing if needed; and optimizing the overall health of the person with PD through medication, exercise, nutrition, and socializing. Many care partners find it helpful to keep detailed written notes about office visits and changes to treatment. Neurologists find it helpful if the care partner brings in a recorded video of the patient when they experience tremors, slowness of movement, poor balance and stiffness. Using pillboxes or daily calendars can also help keep track of complex medication schedules. The APDA Healthcare Communication Graph (apdaparkinson.org/healthgraph) can assist with tracking symptoms and be used as a discussion guide with your clinician. Establishing organizational systems for tracking medications and office visits, can be helpful. You may also need to attend to your partner's financial and legal matters.

Preparing for the Future – Because PD affects people at different ages and stages of life, preparing for the future can mean different things. Young-onset PD may present significant financial challenges due to the loss of income earlier than expected. Consulting with a financial planner may provide important guidance. Applying for Social Security disability benefits can help to offset some PD related costs. For older individuals, Medicare will not pay for companion or custodial care in the home, so this must be paid for with your own funds. Therefore, it is essential that families have frank discussions about financial matters. Consulting with an elder care attorney who is knowledgeable about the laws in your state can help identify resources and opportunities for planning ahead.

Making Tough Choices – None of us wants to make difficult decisions about someone we love. However, it is essential to have these conversations early in the disease process, because it is harder to think clearly and make rational decisions in times of crisis. Keep in mind that the wishes of the person with PD might not always agree with yours, so open communication about their preferences and values is crucial. Topics to discuss include alternative living arrangements, living wills, durable powers of attorney, and the use of medical interventions that prolong life.

Caring for Yourself

One essential but often neglected element of being a care partner for a person with PD is caring for yourself. While it may feel like you cannot take time for yourself right now, doing so is actually more important than ever. To maintain the strength and stamina to care for your partner, you must take care of your own needs first. Attend to your health and wellness. Just as exercise, good nutrition, and adequate sleep are important for your partner they are equally important for you. Be sure to have regular visits with your physician.

Acknowledging Your Feelings – Caring for someone with a progressive illness can bring up intense emotions, and you need an outlet to express these feelings. Talking to someone who will listen without judging can help relieve the emotional burden, but if there is no one to listen, simply writing down your feelings in a journal can help.

Maintaining Your Support Network – PD is often an emotionally isolating illness. If the symptoms create

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embarrassment or make it difficult to navigate public environments, you and your partner may refrain from social activities such as dining out with friends. It is crucial for you to maintain your personal social life and stay actively involved in your other relationships, recreational activities, or hobbies. Meeting a friend for a favorite activity will keep you connected to your support network and give you much-needed time away from your care partner role.

Seeking Additional Support – When emotional support from friends and family is hard to find or is not enough, some care partners find it helpful to join a support group. Sharing your experiences and feelings with others who are caring for someone with a progressive illness can be a source of great emotional comfort, as well as practical advice. If there is no care partner support group in your area you can find an online support group which can provide an emotional outlet as well as connecting you with others experiencing the same issues. Visiting an online support community such as Smart Patients (www.smartpatients.com) is great place to share your questions and concerns with other members, and use what you learn in the context of your own life. If you are still feeling overwhelmed, do not hesitate to seek professional counseling. Social workers, psychologists, and other mental health providers are trained to assist people in many life situations, including those who are caring for a partner with chronic disease.

Asking for and Accepting Help – Requesting help is one of the most difficult things for care partners to do, but it is absolutely essential. *No one* can care for a partner with PD alone. You need and deserve a break from your caregiving demands, so you must seek assistance from other family members, friends, or even agencies. When people offer to help, be specific about what they can do to ease the demands on you. Many people want to support you but are not sure what would be the most useful, so do not be shy about telling them exactly what you need.

Resources

The American Parkinson Disease Association provides many resources to assist care partners, including Information and Referral Centers. These centers are located throughout the United States and are staffed by coordinators who can provide guidance, education, and support for you and the person for whom you care. The coordinators work closely with a network of support groups and can refer care partners to many supportive individuals and agencies, including:

- Area Agencies on Aging
www.eldercare.acl.gov
- Caregiver Support Groups
www.caregiveraction.org
- Family Support Groups
www.caregiver.org
- Grief Support Groups
www.griefshare.org/findagroup
- Places of Worship
- Home Healthcare Agencies
www.nahc.org
- Respite Service/Day Program
<https://archrespice.org/us-map>
- VAMC Programs for Veterans
www.va.gov
- Elder Care Attorneys
www.naela.org
- Financial Planners
www.letsmakeaplan.org

For assistance and information please call the American Parkinson Disease Association at 800-223-2732 or online at apdaparkinson.org.

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The information contained in this supplement is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's own physician.

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