Caring for a Person With PD and Yourself – A Resource for Care Partners

When someone you love is diagnosed with Parkinson's disease (PD), it's natural to experience a range of emotions, from confusion and fear to frustration and uncertainty. You may have many questions: What exactly is PD? Where is my partner in the progression of this disease? What can we do to prepare for the future? This resource provides essential insights and practical tips to help you navigate your role as a care partner, supporting both your loved one and yourself along the way.

Caring for Someone With PD

As a care partner for a person with PD, your responsibilities go beyond assisting with daily activities. You are an essential advocate and educating yourself about PD is the first step to advocating effectively. Know what resources are available to you—from healthcare providers to support groups, understanding where to turn for help can make a significant difference.

Expecting the Unpredictable – PD is a progressive illness, meaning that the symptoms may worsen over time. However, this progression rarely follows a predictable path. The severity of symptoms can vary from day to day and even throughout the same day. One day your partner may be able to move about the kitchen preparing meals, while the next, they may need help just getting out of bed. Learn to navigate the changes by remaining flexible and patient. However, any abrupt change in functioning that does not resolve quickly should be discussed with a 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, and optimizing the overall health of the person with PD through medication, exercise, nutrition, and socialization. Do not underestimate the power of communication; open dialogue between your partner and healthcare professionals can help ensure the best possible care. Keeping detailed notes about office visits, treatment changes, and symptoms is helpful. Bringing recorded videos of tremors, stiffness, or mobility challenges to clinic visits can aid in the treatment planning process. Utilizing pillboxes, daily reminders, and the APDA Symptom Tracker App (APDA Symptom Tracker App) can assist in tracking symptoms and managing medications effectively.

Preparing for the Future – Because PD affects people at different ages and stages of life, planning ahead is crucial. It's never too early to plan. For individuals with young-onset PD, financial challenges due to the loss of income may require consulting with a financial planner or applying for Social Security disability benefits. For older adults, Medicare does not cover custodial care in the home, making financial planning essential. It is vital that families have frank discussions about financial matters and have a plan in place before a crisis arises. Consulting with an elder care attorney who is knowledgeable about the laws in your state can help identify available resources and create a long-term care strategy.

Making Tough Choices – No one wants to make difficult decisions about a loved one, but early conversations about care preferences are crucial. Honor your process; these discussions can be emotional, and it's okay to take time to process decisions. Topics to discuss include alternative living arrangements, living wills, durable powers of attorney, and medical interventions that may prolong life. Keep in mind that the person with PD may have different needs and values that may not align with yours, so maintaining open and honest communication is important to understanding and respecting their wishes.

Caring for Yourself

One essential but often overlooked aspect of being a care partner for a person with PD is self-care. While it may feel like you cannot take time for yourself, find balance—your well-being is just as important as your partner's. Attend to your health and wellness through nutrition, exercise, and adequate sleep. Just as important is maintaining social connections with family members, friends, other care partners, and community activities that provide emotional and mental health benefits. Regular visits with your physician and self-care activities can help maintain the stamina needed for caregiving.

Acknowledging Your Feelings – Caring for someone with a progressive illness can evoke intense emotions. Move yourself up on your "to-do" list; your emotional well-being matters. Talking to a trusted friend, social worker, or clergy member, or writing in a journal can help ease some of these feelings.

Maintaining Your Support Network – Living with PD can be isolating, and symptoms may make social interactions challenging. At times, PD symptoms make it difficult to navigate public environments; however, refraining from social interactions can contribute to increased isolation. Remember, you are not alone. Maintaining friendships, hobbies, and personal activities is essential. Connecting with others through social activities will keep you engaged and supported and give you needed time away from your care partner role.

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Seeking Additional Support – When emotional support from friends and family is not available, difficult 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 sharing practical advice for coping and well-being. If you cannot locate a local care partner support group in your area, you can find an online support group, which can provide an emotional lifeline as well as connecting you with others who are experiencing similar challenges. Trust your instincts—if you feel overwhelmed, seek professional counseling, or join APDA's Smart Patients online support community (**smartpatients.com**), which is a great place to share your questions and concerns with other members, and use what you learn in the context of your own life. Should you need additional support and guidance, 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 a chronic illness.

Asking for and Accepting Help – Requesting help can be difficult for care partners to do, but watch for the warning signs of stress. No one should have to care for a partner with PD alone. You need and deserve a break from your caregiving responsibilities, so seek assistance from other family members, friends, or even local agencies. When people offer to help, be specific about what they can do to help you. Many people want to support you but are not sure what would be most useful, so don't hesitate to express your needs.

Being a care partner is a journey filled with challenges and rewards. By staying informed, planning ahead, and prioritizing your well-being, you can provide the best possible care for your loved one while maintaining your own health and well-being.

Resources

The American Parkinson Disease Association provides many resources to assist care partners via our network or Chapters and Information & Referral (I&R) Centers. These Chapters and I&R Centers are located throughout the United States and provide guidance, education, and support for you and the person for whom you care. They work closely with local support groups and other community resources and can refer care partners to these many supportive services, including:

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

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

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