

Caring in Parkinson's

Caring for the Care Partner



When a loved one is living with Parkinson's disease (PD), it becomes clear that Parkinson's is a life-changing experience for the entire family — particularly for the primary care partner, who is most often a spouse, child, parent or friend.

You may not think of yourself as a care partner or see the new tasks in your life — helping with doctor visits, taking over financial responsibilities, helping a person with PD to dress or eat — as acts of caregiving. This could be because Parkinson's is chronic and changes very slowly over many years.

Yet, it is precisely because the role of the PD care partner lasts for decades, that care partners to people with Parkinson's can benefit from understanding how this role affects their lives in the long term and how to ask for help. Focusing on your own mental and physical health needs will actually benefit both your health and that of your loved one. What signs should you look for and how can you find ways to ensure you take care of yourself?

Physical Effects

The first challenge is to understand how your role as care partner affects your physical health. A landmark study of older adults who were care partners for their spouses (with a variety of chronic illnesses) demonstrated that spouses who are care partners are at a 63 percent higher risk of dying than those who are not. There are many reasons why caregiving may lead to a decline in your health. First, you may neglect your own basic health care appointments because you are focused on the needs of your loved one. If either you or your loved one stops working, which can lead to a loss of income and/or loss in health insurance coverage, you may find that this problem becomes more serious.

Another reason is that you may experience a lack of sleep. This may be because you find yourself waking up frequently during the night to help the person with PD to the bathroom or because you experience your own sleep disturbances. Improve your chances of getting a good night's rest by maintaining a consistent bedtime routine. Some care partners may find comfort in sleeping in a separate bedroom or seeing their own doctors to discuss the use of a sleep aid.



Emotional Responses

As a care partner to a person with Parkinson's, you may experience conflicting emotions.

When your loved one was diagnosed, for example, you may have felt shock — or perhaps you felt validation because the diagnosis confirmed your sense that something was wrong. You may mourn that your loved one is not quite the same person as he or she was before or you may experience anger. These problems can be compounded if you have financial worries.

These emotions can have dramatic effects on your mental health. Studies show that 45 to 60 percent of care partners suffer from depression.

How can you remain emotionally healthy? Care partners who show the most emotional resilience over time tend to be the ones who have been able to come to terms with their loved one's disease.

But acceptance is not something that is achieved once and held forever. Rather, it happens in stages as your role shifts with changes in your loved one's Parkinson's — for example, the point at which he or she stops working or is no longer able to drive.

(over please)



**“Asking for help...
is not a sign of
weakness; it is
an investment in
yourself as a
care partner.”**

Asking for Help

Like most families that are affected by Parkinson's, you and your loved one likely still live at home and do not receive any outside assistance. Some care partners, particularly women, try to do everything. You may feel as if “no one else does this as well as me” or “everyone else is too busy.” But you do not have to do everything. Asking for help is key. It is not a sign of weakness, but rather is an investment in yourself as a care partner, that will help you to continue in your role for as long as possible. How can you find this kind of assistance?

Utilize Family and Friends

You may find it difficult to ask for help outright, or feel that no one else really cares. These feelings are common. In reality, most people do care and will find the time to help, but they often don't know how to offer help or in what form.

One solution is to be as specific as possible when asking for help — for example, sitting down with your family to talk formally about who will take on particular responsibilities. This system can be helpful because it leaves each person with a clear-cut task, without any one person feeling as if he or she is expected to “do it all.”

Look for Resources

The services of medical professionals, government and nonprofit agencies might be helpful for you and your loved one. For example, you might consider seeking physical therapy and home health care. In the later stages of Parkinson's, your loved one may be eligible for hospice, which can provide respite for both of you. If you or your loved one served in the military, you may be eligible for benefits through the Veterans Administration. For those who develop dementia, help can be found through the Alzheimer's Association.

Additional resources, such as help with transportation and legal services, may be found in your state's Area Agency on Aging. Connecting with other Parkinson's care partners through a support group can also be a good way to find out about resources. It may also be helpful to bring a list of questions and concerns to every doctor visit. If your loved one is receiving care in an academic medical center, ask a nurse or social worker on staff for community services.

Taking Care of the Care Partner

As a care partner, taking the time to honor, value and love yourself is not a luxury; it is an absolute necessity. Even though your caregiving responsibilities can seem overwhelming, it's okay if your loved one's disease does not always take center stage. At times, it may be necessary for you to ask for help. This will allow you to be in charge of your own life so you can better advocate both for yourself and your loved one.

Barbara Habermann, Ph.D., R.N., is Associate Professor in the Department of Family Health Nursing at Indiana University School of Nursing.

Related fact sheets:

- **Helping Your Children Cope with Your PD**
- **The PD Partnership: Tips for People with PD and Their Care Partners**
- **Coping with Dementia: Advice for Caregivers**

If you have or believe you have Parkinson's disease, then promptly consult a physician and follow your physician's advice. This publication is not a substitute for a physician's diagnosis of Parkinson's disease or for a physician's prescription of drugs, treatment or operations for Parkinson's disease.