

Coping Skills for Care Partners



A diagnosis of Parkinson's disease (PD) is a life-changing experience not only for the person with PD, but also for the spouse, child, other family member or friend who becomes the person's primary care partner. Care partners take on many different responsibilities — from accompanying a loved one on doctors visits and grocery shopping to more demanding ones like providing physical care. At the same time, you may be working, raising children, caring for grandchildren or coping with your own health or personal issues.

Because PD progresses slowly, the care partner's role can last for decades. This journey can bring rewards, but it can also bring difficult times. It is important for every care partner to remember that taking care of oneself is not the same as being selfish. By renewing your own energy and staying healthy, you can better support your loved one who lives with PD.

Health of the Care Partner

As a care partner, you are likely focused on your loved one. Yet research shows that care partners in general, not just those who care for loved ones with PD, face risks to their own physical and emotional health. This elevated risk can show up in a higher-than-average incidence of heart disease, high blood pressure and visits to the emergency room. Care partners have been shown to experience decreased immunity and sleep deprivation. Lack of sleep can lead to irritability and frustration. In addition, care partners experience higher-than-average rates of depression, anxiety and grief.

Practicing the Art of Self-Compassion

With all that care partners do for their loved ones, it is still easy to be self critical and feel guilty for not doing more. Try to treat yourself with the same kindness you would extend to a friend who had a problem. Self-compassion is not an act of self-pity or self-indulgence. It will prevent

burnout and will allow you to move forward with the things you need to do every day. Accept your own humanity. Give yourself a pat on the back for doing the best you can.

A Toolbox for Self-Care

Here are some tools for practicing self-compassion to help you maintain your physical and emotional health.

Identify Stress Triggers. A first step in self-care is identifying and acknowledging what causes your stress. Irritability, for example, may be triggered by certain situations, like having three things to do at once or having trouble getting your loved one out the door on time.

Acknowledge your right to feel emotionally off-balance. Recognize the hidden grief component of your anger, anxiety, guilt and depression. Expect adaptation to, but not resolution of, your grief. Accept it and seek out someone who understands it.

Determine your limits. What is your comfort level providing care? Some people determine they can provide care at home as long as others in the family can manage the disruptions. Everyone has limits. What are yours?

Build in regular breaks from caregiving and make them a priority. You cannot be a good caregiver to someone else if you do not take care of yourself.

Delegate. You may feel that you do not want to burden others, but in fact most people are

willing to help if asked — they just need direction. Families, friends and caregiver support groups provide a network of people who can help.

Often, in the rush of errands and medication schedules, quality time gets pushed to the bottom of the to-do list. Try prioritizing your list of caring responsibilities. Take on the most important ones yourself and try to find someone else — paid or unpaid — to help out with the less important ones.

Focus on the Positive. This may sound unrealistic in the midst of a difficult situation. However, we all harbor some degree of optimism and there are proven techniques for nurturing it.

Seek out joy in your relationship with the person with Parkinson's. Your hands-on duties, such as bathing and dressing your loved one, might feel like work, but these tasks bring you together. Add some fun to your hands-on care: sing songs, tell jokes, share goals and dreams.

Develop a habit of participating in activities together outside of care tasks. Shared time as husband-wife, mother-daughter, siblings or other relationship — rather than as caregiver and care recipient — allows you to enjoy each other and build happy memories.

Treat Yourself With Care

Treating yourself with care is not a luxury, but a necessity. It helps us rediscover the purpose and meaning in our lives. Doing the things that bring us pleasure — whether they are small rituals like enjoying a morning cup of coffee, following an exercise routine, practicing meditation or simply spending time with positive friends — replenishes reserves of love, improves our health and adds depth to our experience of caring for a loved one.

For more information, read or order *Caring and Coping*, a comprehensive guide for caregivers of people with Parkinson's at any stage at Parkinson.org/Books or by calling the Parkinson's Foundation Helpline at 1-800-4PD-INFO (473-4636).

You can also watch Parkinson's Foundation Caregiver Summit educational sessions at Parkinson.org/Library.