

Caring for You

You may be involved in assisting the person with Parkinson's with many activities of daily living and medical tasks, as well as maintaining a household; shopping and preparing meals; organizing records, papers and appointments; transporting your loved one to healthcare visits; keeping up with social and family relationships and many other tasks. At the same time, you may be working, raising children or grandchildren or coping with your own health or personal issues.

Research from the National Alliance for Caregiving shows the top four caregiver concerns:

- 1) Keeping your loved one safe
- 2) Managing your own stress
- 3) Finding activities to do with your loved one
- 4) Taking time for yourself

Research also reveals that when caregivers are asked what they want, the majority respond that they want information about coping with being a caregiver. This information takes several forms, including knowledge about the disease, comfort with the caregiving role and managing stress. The following tips can help you cope.

» **Forgive yourself for not being perfect.** Caring for someone with a chronic illness means your world has been turned upside down. Your daily routine will definitely change, and you will probably have to compromise some of your personal standards of housekeeping, meal preparation and other tasks. Accept your own humanity. Give yourself a pat on the back for doing the best you can.

WATCH THE VIDEO

Advice for Caregivers, from Caregivers

Online at [Parkinson.org/videos](https://www.parkinson.org/videos) in the "CareMAP Caregiver Stories" playlist



- » **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 feel uncomfortable when incontinence becomes an issue. Some determine they can provide care at home as long as others in the family can put up with the disruptions. Everyone has limits. What are yours?
- » **Make regular breaks from caregiving a priority.** You cannot be a good caregiver to someone else if you do not take care of yourself. Your loved one can survive a few hours and, periodically, a few days without you.
- » **Be kind to yourself.** Remember you are experiencing normal reactions to abnormal circumstances.
- » **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 cares.** Shared time as husband-wife, mother-daughter, siblings or other relationship – rather than as caregiver and care recipient, or even care partners – allows you to enjoy each other and build happy memories.
- » **Try to forgive your loved one for past hurts.** Resentment toward past wrongs and injustices will make your present caregiving role difficult. Let go of what was, and concentrate on making what is healthy and productive.



Being a caregiver is probably the most difficult job you're ever going to have. The only way you can do it is to take care of yourself. You cannot say, 'I don't have time for me.' The person you're taking care of wants the best for you because you're giving the best to them. Don't be a martyr. It's okay to take care of yourself.

– KAREN, CARED FOR FATHER, JOSEPH