

ORGANIZATION NEWS

Information/Education Page

Coping With Caregiver Burnout When Caring for a Person With Neurodegenerative Disease: A Guide for Caregivers



Are you caring for a person with neurodegenerative disease?

Caring for a person with a neurodegenerative disease (eg, Alzheimer disease, Parkinson disease, multiple sclerosis, amyotrophic lateral sclerosis, Huntington disease) can be extremely challenging.¹ The challenges grow as the disease gets worse. If you are a caregiver of a person with a neurodegenerative disease, there are steps you may need to consider to decrease the risk or amount of caregiver burnout. This may help maintain or improve your health and wellness. It is important for you to know if you have caregiver burnout, or the common triggers that may cause your burnout. By recognizing and addressing these factors, you will be able to take healthy and manageable control over your caregiver duties.

What is caregiver burnout?

Caregiver burnout is a state of physical, emotional, and mental exhaustion and distress that may include depression, agony, anxiety, and so forth.² When you feel burnt out, your attitude may change. This can negatively affect the way you care for your loved one. You may change from a positive and caring person to a negative and unconcerned one.

You can prevent feeling burnt out by getting the right help and learning how to cope with your feelings effectively. Therefore, it is important for you to know your strengths, where you may need help as a caregiver, and the resources available to you. Having a realistic caregiver management plan will help you to care for your loved one while keeping yourself healthy.

Recognizing the signs of caregiver stress and knowing how to relieve it can help you maintain your best health.

Knowing the signs and symptoms of caregiver stress and burden^{2,3,4}

- Physical burden: fatigue, exhaustion, problems with sleep, decreased strength, and endurance.
- Psychological burden: irritability, anger, depression, inability to concentrate, difficulty with memory because of grief and sadness.
- Social withdrawal and feelings of isolation.
- Loss of intimacy with your loved one.
- Financial burden: loss of employment or difficulty maintaining work responsibilities.

Recommendations to relieve caregiver stress and burden^{2,3,5-9}

- Educate yourself: learn about your loved one's condition, their medications, other treatments, side effects, and support available in your community. It is important to be informed and understand that you have the right to be part of your loved one's care.
- Communicate effectively
 - With health care professionals: being able to express your needs to the health care professional who is caring for your loved one is important. Make sure they understand your role. You can inform the clinicians about changes in your loved one's health and behavior. You can also express your needs for your loved one when making health care decisions. Do not hesitate to ask the clinicians questions about your loved one's disease process, prognosis, and their abilities.
 - With your loved one: talking with your loved one about their needs as well as yours can help you keep a healthy relationship with them.
- Maintain your physical well-being
 - Stop negative health behaviors: gradually discontinue smoking, drinking, or other unhealthy behaviors.
 - Take part in physical activity: set aside at least 15 to 20 minutes every day for physical activity you enjoy (eg, walking, dancing, yoga). Remember consistency is the key.
 - Have time for yourself: spend quality time on yourself without guilt.
 - Have a nutritious diet: eating a balanced diet in a timely manner can decrease exhaustion and improve your health.
- Maintain your psychological well-being
 - Acceptance: be aware of your sources of stress. It may be challenging, but it is important to accept your loved one's disease process. Acceptance can help you live in the present moment and make decisions for yourself and your loved one.
 - Take a break: everyone needs a break. Try and participate in leisure activities, or plan a vacation and explore other options that will give you a break from your caregiving duties. Respite care programs offer you a safe option to have your loved one cared for while you take a break, even if it is for 1 or 2 hours.
 - Counseling: find someone with whom you can share your feelings. Do not hesitate to consult a professional.
 - Maintain your sense of humor: it is okay to laugh and be humorous to lighten up the stressful moments.

- Develop a routine: maintain a plan of care for yourself and your loved one and update it as needed. For example, set a time each afternoon when you will both take a rest.
- Modify your thoughts: try to stop negative thoughts. Try to learn something useful when things do not go right. Individual or group therapy can provide ways to cope and modify negative thoughts.
- Participate in relaxation activities: practice relaxation techniques (eg, meditation, deep breathing activities, music therapy, yoga).
- Build a local support system: getting involved in a caregiver support group can help you connect with others facing similar situations. There are often different groups for people with different diseases. See **table 1** for ideas. Seek family and community support and keep a list of simple activities that people can help you with when they offer. Evaluating and discussing your problems with other family members can help you think objectively. Having adequate support can reduce your feeling of isolation.

Authorship

This page was developed by Shilpa Krishnan, PT, PhD, Michele K. York, PhD, Deborah Backus, PT, PhD, and Patricia C. Heyn, PhD. Any questions can be directed to Shilpa Krishnan, PT, PhD, shikrish@utmb.edu.

Disclaimer

Table 1 is not intended to be an exhaustive list of available resources. This information is not meant to replace the advice of a medical professional. You should consult your health care provider regarding specific medical concerns or treatment. This information/education page may be reproduced for noncommercial use by health care professionals to share with their patients and caregivers with appropriate attribution. Any other reproduction is subject to approval by the publisher.

Table 1 Additional resources

Organization	Types of Caregiver Services	Web Address
Alzheimer's Association	Respite care, support group, educational sessions on changes after Alzheimer disease, planning for future	https://www.alz.org/care/
National Parkinson Foundation	Education, identifying community resources	http://www.parkinson.org/
American Parkinson Disease Association	Information on Parkinson disease, webinars, newsletters, regional support groups	http://www.apdaparkinson.org
National Multiple Sclerosis Society	Education programs, caregiver support, employment, local programs and services	http://www.nationalmssociety.org/Resources-Support/Family-Matters
Multiple Sclerosis Association of America	Information on multiple sclerosis and health insurance, educational programs, relapse, support network (blogs and chats)	http://mymsa.org
Amyotrophic Lateral Sclerosis Association	Public education, public policy, research and care services	http://www.alsa.org
Huntington's Disease Society of America	Education, support groups, advocacy, caregiver's webinars, nutrition	http://hdsa.org/
Administration for Community Living – aging and disability resources	Public outreach, person-centered counseling	https://acl.gov/NewsRoom/Publications/docs/AOA_2013_AnnualReport.pdf
AARP – Aging and Elderly	Health care, employment and security, financial abuse protection	http://www.aarp.org
National Rehabilitation Information Center	Intellectual and developmental disability resources, medical and vocational rehabilitation, employment, education, assistive technology	http://www.naric.com
Family Caregiver Alliance, National Center on Caregiving	Education, advocacy, support groups, research	https://www.caregiver.org
National Volunteer Caregiving Network	Education, support network, professional development for caregivers	http://www.nvcnetwork.org
American Academy of Developmental Medicine and Dentistry	Support groups, information, and education on people with neurodevelopmental disorders and intellectual disabilities	http://aadmd.org/ntg
Access to Respite Care and Help National Respite Network and Resource Center	Respite care	http://archrespite.org

Acknowledgments

This work was supported by the American Congress of Rehabilitation Medicine Neurodegenerative Diseases Networking Group, the Agency for Healthcare Research and Quality (grant no. R24HS022134), and the National Institute on Disability, Independent Living, and Rehabilitation Research (grant no. 90IF0055-01).

References

1. Bertram L, Tanzi RE. The genetic epidemiology of neurodegenerative disease. *J Clin Invest* 2005;115:1449-57.
2. Yu H, Wang X, He R, Liang R, Zhou L. Measuring the caregiver burden of caring for community-residing people with Alzheimer's disease. *PLoS One* 2015;10:e0132168.
3. Habermann B, Hines D, Davis LL. Caring for parents with neurodegenerative disease: a qualitative description. *Clin Nurse Spec* 2013;27:182-7.
4. Ekwall AK, Sivberg B, Hallberg IR. Older caregivers' coping strategies and sense of coherence in relation to quality of life. *J Adv Nurs* 2007;57:584-96.
5. Daviglus ML, Bell CC, Berrettini W, et al. NIH state-of-the-science conference statement: preventing Alzheimer's disease and cognitive decline. *NIH Consens State Sci Statements* 2010;27:1-30.
6. Farran CJ, Staffileno BA, Gilley DW, et al. A lifestyle physical activity intervention for caregivers of persons with Alzheimer's disease. *Am J Alzheimers Dis Other Demen* 2008;23:132-42.
7. Geiger JR, Wilks SE, Lovelace LL, Chen Z, Spivey CA. Burden among male Alzheimer's caregivers: effects of distinct coping strategies. *Am J Alzheimers Dis Other Demen* 2015;30:238-46.
8. Lilly MB, Robinson CA, Holtzman S, Bottorff JL. Can we move beyond burden and burnout to support the health and wellness of family caregivers to persons with dementia? Evidence from British Columbia, Canada. *Health Soc Care Community* 2012;20:103-12.
9. Liptak A, Tate J, Flatt J, Oakley MA, Lingler J. Humor and laughter in persons with cognitive impairment and their caregivers. *J Holist Nurs* 2014;32:25-34.