

Caring for a Loved One with HD: Self-Care for Family Caregivers

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Caring for a loved one with a chronic illness such as HD can be both physically and emotionally demanding. The combination of loss, prolonged stress, the physical demands of caregiving, and the emotional aspects can place caregivers at risk for significant health problems. Caring for somebody is never easy and is not without challenges and difficulties, but there are strategies and specific actions you can take to prevent negative consequences to your physical and emotional health.



What the STATISTICS say:

Caregivers are less likely to engage in preventive health behaviors.⁴

23% of family caregivers caring for a loved one for 5 years or more report their health as fair or poor.²

Estimates show that between 40-70% of caregivers have clinically significant symptoms of depression⁶

Specifically, HD caregivers also had diminished health related quality of life with 43% reporting that they were dissatisfied with their overall quality of life.³

These statistics are not meant to discourage, but rather demonstrate the negative impacts caregiving can have if you do not adequately care for yourself. Our hope is this will encourage you, as a caregiver, to take your health and well-being seriously so you can remain healthy to care for your HD loved ones. If you are struggling to manage any of the symptoms below please consider talking with you doctor AND incorporating some of the strategies in this document.



NEGATIVE symptoms impacting Physical and Emotional Health

Physical Symptoms

- ✓ Health decline (frequently sick or under the weather)
- ✓ Sleep deprivation
- ✓ Exhaustion
- ✓ Changes in appetite or weight
- ✓ Failure to exercise
- ✓ Putting off or failing to attend medical appointments
- ✓ Excessive alcohol, tobacco, drug use

Emotional Symptoms

- ✓ Overwhelming stress
- ✓ Prolonged sadness
- ✓ Depression
- ✓ Guilt
- ✓ Anger
- ✓ Grief
- ✓ Frustration
- ✓ Anxiety
- ✓ Social isolation or withdrawal

Self-Care Strategies

Educate & Plan

- Learn about HD and how to realistically plan.
- Know your finances
- Discuss healthcare wishes (Advanced Care Planning)
- Identify available community resources
- Engage family/friends in developing a caregiving plan.
- Arrange backup caregiving that is regular and dependable.
- Get organized:
 - Have list of doctors, medication and medical history up to date and readily available.

Improve Communication

- Use “I” statements rather than “you” statements to express feelings: “I feel angry” verses “you make me angry”
- Respect the feelings of others, even if they differ from you.
- Avoid intentionally hurtful comments to others
- Allow others to express their feelings as well
- Be clear and specific about what you need or want
- Actively listen
- Be honest and genuine in your communication with others.

Exercise

- Daily exercise for best results
- Finding time can be difficult, but walking, stretching, etc is effective and may be easier to incorporate into your day.
 - Walk around your neighborhood, mall, to the store or a nearby park
- Find physical activities you enjoy (online, videos, in-person, exercise clubs, etc)

Stress Management Techniques

- Identify areas of stress that you can change and areas you cannot change.
- Use team approach to accomplish daily tasks: Ask friends/neighbors to assist with mowing lawn, transporting children, raking leaves, etc.
- Continue to participate in enjoyable activities.
- Find reasons to laugh.
- Utilize relaxation methods: yoga, meditation, deep breathing, sleeping, reading, bubble baths, creative activities--painting, writing, drawing, arts and crafts, scrapbooking, etc. and outdoor activities (gardening, walking, etc.) can all be therapeutic in reducing stress.

Social & Community Support

Family, friends, neighbors, church, co-workers, other HD families, HD team, HD organizations, etc.

- Identify your social and community support
- Participate in HD support groups (in-person or video)
- Utilize any respite services as needed
- Get recommendations on available resources and support from others

Ask For & Accept Help

- Others often want to help but are unsure of what is needed or most helpful. Prepare a list of ways others can help (write, electronic, etc): *ideas: transportation, walking the dog, mowing the lawn, putting out the trash, preparing meals, assist with completing/mailling forms, keeping patient company while you away.*
- Resist asking the same person repeatedly
- Be specific and direct with your requests
- When someone offers help say “yes” and refer to your list.

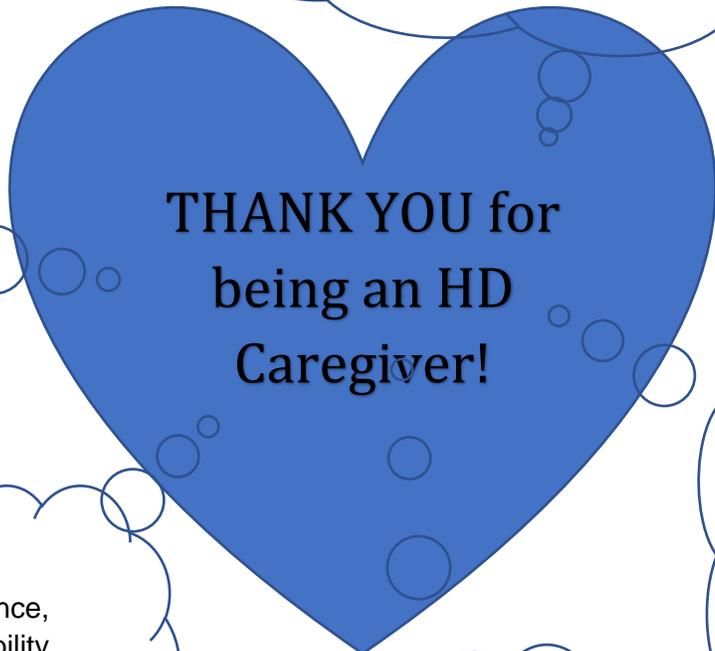




REMINDERS

Tap into your **courage** to ask for **help** and **accept** the situation you are in. Recognize your limitations and the limitations of your loved one is a sign of strength.

Caregiving is a **process** that will involve a great deal of change in family structure and roles as well as a change in what you accept as "normal" daily life.



THANK YOU for
being an HD
Caregiver!

Focus on your well-being and desires too; if you cannot care for yourself, you will limit your ability to care for your love one.

Caregiving **requires** patience, strength, flexibility, creativity, and energy all traits that you have!

make sure to **reward and praise yourself** for your commitment and efforts to care your HD loved one.

Help and support is available check out:

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|--|---|-----------------------------------|-------------------------|
| HDSA.org | HDSA Center of Excellence | HD Support Groups | Help4HD |
| | Caregiver Resource Center | AARP Caregiving | |

Footnotes

² Caring in the U.S.; National Alliance for Caregiving in Collaboration with AARP, November 2009

³ Dorey, J, Cohen, J Mraidi, M, Urbinati, D, Toumi, M, Burden of Huntington’s Disease in the USA, Poster 186 presented at the World Congress on Huntington’s Disease, Melbourne, Australia, 11-14 September, 2011.

⁴ Family Caregiver Alliance, Caregiver Health, http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822

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