



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

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## Caring for a Loved One with HD

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.

### Caregiving Statistics

- About one in ten (11%) caregivers report that caregiving has caused their physical health to get worse.<sup>1</sup>
- 23% of family caregivers caring for a loved one for 5 years or more report their health as fair or poor.<sup>2</sup>
- Specifically HD caregivers also had diminished health related quality of life with 43% reporting that they were dissatisfied with their overall quality of life.<sup>3</sup>
- Caregivers are less likely to engage in preventive health behaviors.<sup>4</sup>
- Studies consistently report higher levels of depressive symptoms and mental health problems among caregivers than among non-caregiving peers.<sup>5</sup>
- Estimates show that between 40-70% of caregivers have clinically significant symptoms of depression with approximately one quarter to one half of these caregivers meeting the diagnostic criteria for major depression.<sup>6</sup>

Now 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.

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<sup>1</sup> Family Caregiver Alliance, Caregiver Health, [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1822](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822)

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

<sup>3</sup> 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.

<sup>4</sup> Family Caregiver Alliance, Caregiver Health, [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1822](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822)

<sup>5</sup> Family Caregiver Alliance, Caregiver Health, [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1822](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822)

<sup>6</sup> Family Caregiver Alliance, Caregiver Health, [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1822](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822)

## ***Impact on Physical and Emotional Health***

### **Physical symptoms may include:**

- 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 may include:**

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

## **Taking Care of Yourself**

When caring for a loved one with HD your ability to care for yourself is just as important as their care. Identifying and planning for your own self-care can be essential to preventing significant risks to your health and well-being.

### ***Self-Care Strategies***

#### ***1. Educate and Plan***

- Educate yourself about HD to understand the disease process and how to realistically plan ahead.
- Discuss finances and healthcare wishes
- Identify community resources that may assist you and your loved one.
- Consider getting other family/friends together to discuss the care needed and develop caregiving plan.
- Arrange backup caregiving that is regular and dependable.
- Get organized (Keep important paperwork and resources organized for easy reference.)
- Keep list of doctors, medication and medical history up to date and readily available.
- Always ask questions when you have them.

#### ***2. Stress Management Techniques***

- Recognize emotional or physical symptoms early and make changes before they become overwhelming.
- Identify areas of stress that you can change and areas you cannot change.
  - Focus energy on changing what you can.
- Use team approach to accomplish daily tasks so you can focus on other needs.
  - Ask neighbors to assist with mowing lawn, transporting children, raking leaves, etc.
- Regular and consistent exercise.
- Continue to participate in enjoyable activities that offer respite.
  - Activities with friends, hobbies, etc
- Set realistic expectations and goals given your situation.
- Find reasons to laugh.
  - Rent funny movies, read comics, laugh at yourself or even HD.
- Utilize relaxation methods
  - Yoga
  - Meditation
  - Deep breathing
  - Sleeping in

- Reading
- Bubble baths
- Any creative outlet (painting, writing, drawing, arts and crafts, scrapbooking, etc.)
- Outdoor activities (gardening, walking, etc.)

### 3. *Communication*

- Use “I” statements rather than “you” statements to express your feelings to avoid defensiveness or blaming others.
  - “I feel angry” instead of “you make me angry”
- Respect the rights and feelings of others.
  - Avoid saying something to intentionally hurt another person’s feelings or something you will regret later.
  - Allow the other person to express his/her feelings as well
- Be clear and specific about what you need or want.
  - Don’t hint or expect the other person to guess what you need to avoid frustration and misunderstandings
- Actively listen
  - Make sure to listen to other persons so you can directly and respectfully address what is being communicated.
- Be honest and genuine in your communication with others.

### 4. *Exercise*

- Exercise can:
  - Improve sleep
  - Reduce stress and tension
  - Reduce feelings of depression
  - Increase energy and alertness
  - Restore endurance, balance, strength and flexibility
- Participate in regular (daily) exercise for best results
- Any exercise will offer physical and emotional benefits.
  - Finding the time to exercise can be difficult, however walking can be an effective, easy exercise to incorporate into your daily routine.
    - Walk around your neighborhood, mall, to the store or a nearby park
- Find activities you enjoy
- Look for classes through local colleges or parks and recreation for other exercise opportunities
  - Hiking clubs, tennis lessons, weight lifting, bootcamps, running clubs, etc.

### 5. *Social and Community Support*

- Social Support can consist of:
  - Family, friends, neighbors, church, co-workers, other HD families, etc.
- Community Support can consist of:
  - Health care professionals, HD organizations, social service organizations, etc.
- Utilizing both your social supports and community supports will assist with yourself care and care of your loved one.
- Identify your social and community support available to you.
- Ask for help and assistance when needed.
- Participate in support groups for HD and/or caregivers.

- Utilize any respite and/or Adult day care health programs
  - Can be beneficial to both caregiver & patient
- Get recommendations on available resources and support from health care professionals that you or your loved one may benefit from.

#### **6. Ask For and Accept Help**

- You may feel that asking for help may “burden” others or it may admit you can’t handle everything yourself.
- Nobody can care for a loved one without help from family, friends, community, or health care professionals.
- Reaching out for help when you need it is a sign of personal strength.
- Family/friends/neighbors often want to help but are unsure of what is needed or most helpful.
- Prepare a mental list of ways others can help
  - Assist with transportation
  - Household tasks: walking the dog, mowing the lawn, putting out the trash, preparing meals
  - Assist with completing and/or mailing benefit applications or forms
  - Running errands
  - Keeping patient company while you care for yourself
- Consider the person’s special abilities and interests
  - If you need help with preparing meals, ask a friend that enjoys cooking, etc.
- Resist asking the same person repeatedly
- Make a list of things that need doing
- Be specific and direct with your requests
  - “I want to go to church on Sunday; would you be available to keep Lisa company from 8:00 to noon?”

#### **Self-Care Overview**

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. Caregiving requires a great deal of patience, strength, flexibility, creativity, and energy. You will need courage to ask for help and accept the situation you are in along with insight and recognition of your limitations and the limitations of your loved one.

Caring for someone with HD is a long term commitment therefore it is important to remember that is not selfish to focus on your own well-being and desires. After all, if you cannot care for yourself, you will limit your ability to successfully care for your love one. Please seek medical attention if you are experiencing any prolonged physical or emotional symptom interfering with your health and/or your ability to care for your loved one. Help and support is available, you just have to ask for the assistance. Lastly, we know that caregiving is a challenging and difficult job, so make sure to reward and praise yourself for your commitment and efforts to care your HD loved one.

**THANK YOU for being an HD Caregiver!**