



Caregiver's CORNER

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Caregiver's Corner

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Care for the Caregiver: A Social Work Perspective

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Objectives

- ❖ Caregiver Traits
- ❖ Learn the importance of taking care of yourself.
- ❖ Identify the impacts caregiving can have on physical and emotional health.
- ❖ Strategies to improve self-care.

Caregiving Traits

- Caregiving requires many traits:
 - Patience
 - Strength
 - Flexibility
 - Creativity
 - Courage
 - Energy
 - Acceptance
 - Recognition of limitations
 - Commitment to care for yourself and your loved one
 - Organization
 - Leadership
 - Loving
 - Caring
 - Compassion
 - Knowledge
 - Understanding

Importance of Caring for Yourself

❖ **Caregiver Statistics:**

- About one in ten (11%) caregivers report that caregiving has caused their physical health to get worse. ¹
- 23% of family caregivers caring for a loved one for 5 years or more report their health as fair or poor. ²
- 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
- Caregivers are less likely to engage in preventive health behaviors.⁴
- Studies consistently report higher levels of depressive symptoms and mental health problems among caregivers than among non-caregiving peers.⁵
- 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.⁶

Impacts on Physical Health

Symptoms may include:

- Health decline
- Sleep deprivation
- Exhaustion
- Changes in appetite or weight
- Putting off/missing medical appointments
- Excessive alcohol, tobacco or drug use

Impact on Emotional Health

Symptoms may include:

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

Strategies to Improve Self-Care

- Educate and Plan for the future
- Utilize Stress Management Techniques
- Effective Communication
- Exercise
- Utilize Community and Social Support
- Ask and Accept Help
 - The power of “Yes”

Self Care Strategies- Education & Plan

- Educate yourself about HD to understand the disease process and how to realistically plan ahead.
 - Identify community resources that may assist you and your loved one.
- Discuss finances and health care wishes
- Consider meeting with family/friends to discuss caregiving plan
- Arrange backup caregiving that is regular and dependable
- Get organized
- Always ask questions when you have them

Self Care Strategies- Stress Management

- Recognize emotional and physical symptoms
- Identify areas of stress that you CAN change and areas you CANNOT change.
- Use Team Approach to accomplish daily tasks so you can focus on other needs.
- Regular and consistent exercise
- Participate in enjoyable activities
- Set realistic expectations and goals given your situation
- LAUGH
- Utilize Relaxation methods

Self Care Strategies: Communication

- Use “I” Statements rather than “you” statements.
- Respect the rights and feelings of others
- Be clear and specific about what you need and want
- Actively listen
- Be honest and genuine in your communication with others

Self Care Strategy- Exercise

- Benefits of exercise:
 - Improve sleep
 - Reduce stress, tension, 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
- Find exercise activities you enjoy

Self Care Strategies— Social & Community Support

- Social Support

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

- Community Support

- Health care professionals, HD organizations, HD support groups, social service organizations

- Identify what social/community supports are available to you
- Ask for help and assistance right away when a need is identified.
- Utilize the support regularly
- Participate in HD support groups

Self Care Strategies— Ask & Accept Help

- Reaching out for help when you need it is a sign of strength.
- Power of “Yes”
- Prepare a mental & physical list of ways others can help
- Consider the person’s special abilities or interests when asking for help.
- Resist asking the same person repeatedly
- Keep a list of things that need doing
- Be specific and direct with your requests

HDSA Care Coordination Portal

- The [HDSA Care Coordination Portal](https://www.hdsa.org/carecoordination) is a tool for caregivers to manage both the care and administrative needs of their loved one, as well as the outpouring of support from their network of family and friends.
- The HDSA Care Coordination Portal includes a calendar to organize volunteer tasks, a vital information section to store health and legal data, as well as community sections where members of your private community can post photos and well wishes and participate in message boards.
- **Go to www.hdsa.org/carecoordination to start your online community**

Helpful Resources

- Huntington Disease Society of America (HDSA) – www.hdsa.org
 - HDSA Helpline 800-345-HDSA (4372)
 - HDSA Chapter or Center of Excellence Social Workers
 - HDSA Support Groups
 - HDSA Publications
- Family Caregiver Alliance – www.caregiver.org

Recap

- 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.
- Remember it is NOT selfish to focus on your own well being and desires
- Seek medical attention if you are experiencing any physical or emotional symptoms interfering with your health or ability to provide care.
- Caregiving is a challenging and often difficult job. Reward and praise yourself for your commitment and efforts.

**THANK YOU for all the
love and support you
provide to your loved
ones with HD!**

End Notes

¹ Family Caregiver Alliance, *Caregiver Health*,

http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1822

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

⁵ Family Caregiver Alliance, *Caregiver Health*,

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Questions & Discussion