



COMPASSION FATIGUE

Fact Sheet

Assisting families living with ALS

What is compassion fatigue?

Compassion fatigue occurs when caregivers or professionals begin to feel the pain and suffering of the people for whom they care. They start to lose their sense of self to the people they help, giving more compassion than they receive to be able to feel that their work is being validated. As a result, the caregivers become wrapped in a form of "burnout", causing feelings of deep physical, emotional, and spiritual exhaustion.

Compassion fatigue is the emotional mirroring of those who are suffering in those who are providing them care. It is sensitivity or vulnerability to pain that can become overwhelming. Individuals experiencing compassion fatigue have a hard time maintaining a healthy balance of concern and objectivity and find it hard to come out of the downward spiral. Many people experiencing compassion fatigue will push themselves harder, eventually reaching a rock bottom.

Because of the extreme level of commitment required to care for a person with ALS, compassion fatigue can sometimes occur for the primary caregiver(s), loved ones, and professionals caring for the person with ALS.

Who experiences compassion fatigue?

Compassion fatigue can be experienced by anyone close to the individual who has ALS, especially people who are high-

ly motivated to bring about change in the lives of those who are suffering. This can include nurses, social workers, occupational therapists, physical therapists, psychologists, physicians, and caregivers.

What are some of the consequences of compassion fatigue?

The lives of individuals who experience compassion fatigue are often compromised. These individuals want to help the person with ALS because they are rewarded by appreciation and a sense of self-worth.

However, as a result of caring too much, the individual experiencing compassion fatigue may experience disruptions in job performance or personal relationships, a deterioration in one's home life, or a change in personality. Compassion fatigue can also lead to an overall decline in one's general health.

What are some signs of compassion fatigue?

Compassion fatigue has several signs and symptoms. One of the most apparent is a feeling of tension and preoccupation with the individual who has ALS and their disease. Other symptoms of compassion fatigue include:

- Avoidance or numbing of one's feelings
- Avoidance of certain thoughts or situations
- Memory gaps

- Pattern of tiredness even with a good night's sleep
- Difficulty sleeping or experiencing bad dreams
- Increased absenteeism or use of "sick days"
- Emotional depletion from too much caring
- Loss of interest in previously enjoyed activities
- Difficulty making decisions
- Loss of self esteem
- Anger, irritability, or depression
- Trouble finding hope or happiness
- Lack of time for self
- Multi-tasking to save time
- Decreased productivity at work and at home
- Compromised self-care

Compassion fatigue takes the form of four distinct phases.

The zealot phase: The caregiver or professional is committed, involved, and available, putting in extra hours and volunteering to help.

The irritability phase: The caregiver or professional begins to cut corners or avoids contact with the person with ALS. They may daydream or become distracted and distant.

The withdrawal phase: Caregiver or professional experiences a loss of enthusiasm, they develop a "thick skin" and may complain of stress or fatigue. The line between the person with ALS and the caregiver begins to run together.



The zombie phase: Hopelessness turns to rage, others seem "incompetent". Distain for person with ALS and other loved ones develops and the individual becomes distant and impatient. Activities that the individual once enjoyed are no longer enjoyable.

How can compassion fatigue be alleviated?

A plan of self-care is essential to avoid the complications that occur as a result of compassion fatigue. There is always a choice. Some individuals choose to become more withdrawn from the situation, professionals may choose to leave the profession. Some examples of how to alleviate compassion fatigue include:

- Self-reflection
- Bring life into balance by acknowledging that any effort, no matter how small, is always good enough
- Spend time with loved ones
- Practice good nutrition
- Take time each day to recharge and relax
- Make use of humor to lighten up a stressful situation
- Spend quiet time for self-meditation
- Exercise to help manage stress and anxiety
- Maintain connections with family and friends
- Share information with a peer group
- Refill and renew by making a plan of what's most important
- Take part in activities outside of care giving or the profession
- Join a support group
- Ask for help

Caring for someone with ALS can be a full-time job. It's impossible for one individual to do all of the care giving on their own. Take a break, seek out additional assistance and share your feelings with someone you trust to avoid feeling

overwhelmed.

Additional information:

For more information please see ALS fact sheets entitled *Caregiver Stress*, *Reducing Stress*, and *Ways to Help*, available in print or online through the ALS Society of Canada.

Useful web sites:

<http://www.cyberbeach.net/~aperreau/caregiver.html>

<http://www.aafp.org/fpm/20000400/39over.html>

<http://www.ace-network.com/cfspotlight.htm#cfmenu> includes online compassion fatigue self-test.

Recommended reading:

Dying Was the Best Thing That Ever Happened to Me: Stories of healing and wisdom along life's journey. Hablitzel, William E., MD, Blue Creek: Sunshine Ridge; 2006.

Burnout: The Cost of Caring. Maslach, Christina. Malor Books; 2003.

Help for the Helper: The Psychophysiology of Compassion Fatigue and Vicarious Trauma. Rothschild, Babette. W.W. Norton; 2006.

The Truth About Burnout. Maslach C., Leiter M.P., San Francisco: Jossey-Bass; 1997.

Compassion Fatigue: Coping With Secondary Traumatic Stress Disorder in Those Who Treat the Traumatized. Figley C.R., ed. New York: Brunner/Mazel; 1995.

Wherever You Go, There You Are: Mindfulness Meditation in Everyday Life. Kabat-Zinn J. New York: Hyperion, 1994.

The Miracle of Mindfulness: An Introduction to the Practice of Meditation. Nhat Hanh T. Boston: Beacon Press, 1987.

References

ACE network online. *Compassion Fatigue.* Available at: <http://www.ace-network.com/cfspotlight.htm#cfmenu>

Gentry, J. Eric PHD. *Compassion Fatigue: Prevention and Resiliency.* 2006.

Swope, Robin, LCSW. *Compassion Fatigue: Help for the Helper.* Power point presentation. The ALS Association Leadership and Clinical Care Conference, Newport Beach, CA, January 26, 2007.

American Academy of Family Physicians online. *Overcoming Compassion Fatigue.* By John-Henry Pfifferling, PhD, and Kay Gilley, MS. Available at: <http://www.aafp.org/fpm/20000400/39over.html>