

Compassion Fatigue

Assisting families living with ALS

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

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 for. 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 it?

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

Signs of compassion fatigue

- Tension and preoccupation with the individual who has ALS.
- 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.
- Avoidance or numbing of one's feelings.

Additional information

For more information, please see ALS fact sheets entitled Caregiver Stress, Reducing Stress and Ways to Help. These sheets are available through the ALS Society of Alberta

Useful websites

- www.cyberbeach.net/~aperreau/caregiver.html
 - www.aafp.org/fpm/20000400/39over.html
 - www.ace-network.com/cfspotlight.htm#cf-menu
- Includes an online compassion fatigue self-test.

PROVINCIAL OFFICE
7874 10 STREET NE
CALGARY, AB T2E 8W1

ALS SOCIETY OF ALBERTA
WWW.ALSAB.CA
1-888-309-1111

EDMONTON OFFICE
5418 97 STREET NW
EDMONTON, AB T6E 5C1

Compassion Fatigue

The four distinct phases of compassion fatigue:

1. Zealot Phase

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

2. 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.

3. Withdrawal Phase

The 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.

4. Zombie Phase

Hopelessness turns to rage and others seem 'incompetent'. Distain for the person with ALS and other loved ones develop, as the caregiver becomes more impatient and distant. Activities that the individual once enjoyed are no longer enjoyable.

Compassion Fatigue Alleviation

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 humour 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 caregiving or the profession.
- Join a support group.
- Ask for help.

Recommended readings

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

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.

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, 1194.

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

PROVINCIAL OFFICE
7874 10 STREET NE
CALGARY, AB T2E 8W1

ALS SOCIETY OF ALBERTA
WWW.ALSAB.CA
1-888-309-1111

EDMONTON OFFICE
5418 97 STREET NW
EDMONTON, AB T6E 5C1