

COPING WITH GRIEF

“GRIEVING IS NOT A DISEASE, IT’S A NATURAL WAY OF LIFE”

- Elisabeth Kubler-Ross

ALS is a form of motor neuron disease. It involves the loss of the actual motor nerve cells. The nerves that travel to the spinal cord and voluntary muscles are affected, causing weakness and wasting in arms, legs, mouth and throat. The changes that ALS creates are life altering. Every aspect of a person’s daily activities can be affected. Early symptoms arise by a weakness in a hand, foot, arm or leg. Initially, balance and co-ordination are affected. Walking, running and speaking become troublesome. Some people experience difficulty with simple tasks requiring manual dexterity such as buttoning a shirt, writing or turning a key in a lock. Increasing problems with swallowing and word formation are also common. It is normal to grieve these losses.

WHAT IS GRIEF?

Grief is the outward sign of bereavement and mourning. People with ALS often feel anticipatory grief. This occurs when those who are ill and their loved ones begin to experience loss and change. Anticipatory grief has a defined beginning – when the person begins to cope with challenges, changes and losses of the disease – and a definite ending. Anticipatory grief includes a period of hopefulness when the disease is being managed effectively.

SIGNS OF GRIEF

- ANGER
- FRUSTRATION
- DENIAL
- CRYING
- ANXIETY
- LONELINESS
- RELIEF
- SHOCK
- GUILT
- NERVOUSNESS
- REMORSE
- WITHDRAWAL
- YEARNING
- SADNESS
- PAIN
- HEADACHES

SUGGESTIONS FOR DEALING WITH ANTICIPATORY GRIEF

- Confront the feelings of grief by defining and naming them.
- Talk about your feelings with others. Some feelings – guilt, anger, anxiety – may be hard to share. Enlist the support of someone who is objective, accepting, empathetic and not afraid of strong feelings. You may prefer to speak to a professional counsellor or join a support group.
- Resolve and forgive past wrongs.
- Make plans for the future. Deal with financial changes, tax issue, insurance, medical and personal care choices, a will and funeral arrangements and distribution of assets and belongings. Although it is often difficult to confront these tasks, early preparation eases the decision-making process.
- Live in the present. Try to relax whenever possible. Enjoy and celebrate life’s joys and pleasures.
- Leave a legacy. Think about how you want to be remembered. Tell your life story. Document your special memories in a journal or on audio or video tape. Leaving your mark-on-the-world may elicit feelings of satisfaction of a life well-lived. Make a lasting testament for survivors to remember how you lived your life and the meaningful time that you shared together.

BENEFITS

When feelings are repressed, they gain power; when they are embraced, you gain strength. Talk about your emotions. Share your feelings with family and loved ones. Dialogue occurs when the lines of communication are open. Everyone has time to prepare for loss by discussing past issues, present coping strategies and future plans. Unfinished business may be resolved, old wrongs may be forgiven and family affairs may be put in order.

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RESOURCES

Resources for individual diagnosed with ALS. There are many resources available to help you manage the overwhelming response to grief.

- One click (www.alsab.ca) or call (1-888-309-1111) connects you to the ALS Society of Alberta.
- Albom, M. Tuesdays with Morrie. Random House, 2002.
- Aldredge-Clanton, J., & Sutton Holder, J. Parting: A Handbook for Spiritual Care Near the End of Life, 2004.
- Kübler-Ross, E. On Grief and Grieving. Scriber, 2005.
- Kübler-Ross, E. On Death and Dying. Touchstone, 1997.
- Kübler Ross, E. To Live Until We Say Goodbye. Touchstone, 1997.
- Kushner, H.S. When Bad Things Happen to Good People. New York: Schocken Books, 1989.
- Levine, S. Healing Into Life and Death. Garden City, New York: Anchor/Doubleday, 1987.
- Lightner, C., & Hathaway, N. Giving Sorrow Words: How to Cope With Grief and Get On With Your Life. New York: Warner Books, 1990.
- Nungesser, L.G. Notes on Living Until We Say Goodbye: A Personal Guide. New York: St. Martin's Press, 1988.
- Spingarn, N. Hanging in There: Living Well on Borrowed Time. New York: Stein and Day, 1983.
- Whitfield, B.H. Final Passage: Sharing the Journey as this Life Ends. 1988.

WITH SOURCES FROM

- Coping With Grief: Strategies for People Living With ALS. ALS Society of Canada. Toronto: Ont.1994.
- Coping With Grief: Strategies for People Living With MND. Motor Neuron Disease Association of Victoria Inc. Canterbury: Victoria. 2003.
- Kübler-Ross, E. The Elisabeth Kübler-Ross Web Site: www.elisabethkublerross.com
- Kunz, J. (2002). Giving Voices to Lives: Reminiscence and Life Review. Innovations in Aging, 27(4), 12-15.
- National Institute of Neurological Disorders and Stroke: www.ninds.nih.gov/disorders/amyotrophilclateralsclerosis/detail_amyotrophilclateralsclerosis.htm
- Stages of Grief: www.cancersurvivors.org/Coping/end%20term/stages.htm
- United States Army Enterprise Integration Oversight Office: Enterprise Solutions Competency Center; ChangingMinds.com; Mary Opie, 2001 "Managing Change".