



# COPING WITH GRIEF

Fact Sheet

## Grieving is not a disease, it is a natural part of life - Elisabeth Kübler-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.

### BENEFITS OF GRIEVING

Allowing oneself to grieve aids emotional and spiritual healing.

#### Signs of grief may include the following:

Anger	Anxiety	Crying
Denial	Depression	Fear
Frustration	Guilt	Headaches
Loneliness	Nervousness	Pain
Relief	Remorse	Sadness
Shock	Withdrawal	Yearning

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.

### 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, empathic and not afraid of strong feelings. You may prefer to speak to a professional counselor or join a support group.
- Resolve and forgive past wrongs.

- Make plans for the future. Deal with financial changes, tax issues, 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.

### THE GRIEVING PROCESS

The grieving process is unique to each person who experiences loss. There is no script to follow or blueprint on how to grieve. Five stages of grief (Kübler-Ross cycle) have been identified that are common to many people who are coping with a terminal prognosis. Individuals will not necessarily experience all five stages. Nor will the grief process follow a linear pattern. Grieving is a cyclical process that moves back and forth on an emotional continuum.



**RESOURCES**

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

- The ALS Society nearest you has information, books, videos and support programs.
- One click (www.als.ca) or call (1-800-267-4257) connects you to the ALS Society in your area.
- *Coping With Grief: Strategies for People Living with ALS* can be downloaded from the ALS Society of Canada web site (<http://www.als.ca/resources.aspx>).
- 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*. 1998

**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 Elizabeth Kubler-Ross web site. <http://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. [http://www.ninds.nih.gov/disorders/amyotrophiclateralsclerosis/detail\\_amyotrophiclateralsclerosis.htm](http://www.ninds.nih.gov/disorders/amyotrophiclateralsclerosis/detail_amyotrophiclateralsclerosis.htm)
- Stages of Grief [www.cancersurvivors.org/Coping/end%20term/stages.htm](http://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".

By: Joanna Model

**The five stages of grief identified in the Kübler-Ross cycle are:**

Emotional Response	Response
Denial (this isn't happening to me!)	<ul style="list-style-type: none"> <li>• Suggest problem has corrected itself and it will soon be over</li> <li>• Exhibit apathy and numbness</li> <li>• Rationalize change away</li> </ul>
Anger (why is this happening to me?)	<ul style="list-style-type: none"> <li>• Sabotage the change effort</li> <li>• Play “shoot the messenger”</li> <li>• Withdraw from society</li> </ul>
Bargaining (I promise I'll be a better person if...)	<ul style="list-style-type: none"> <li>• Cut a deal to spare others harm</li> <li>• Suggest other concerns to redirect problem solving</li> </ul>
Depression (I don't care anymore)	<ul style="list-style-type: none"> <li>• Express a loss of control</li> <li>• Withdraw from society</li> </ul>
Acceptance (I'm ready for whatever comes)	<ul style="list-style-type: none"> <li>• Express ownership for solutions</li> <li>• Focus on achieving benefits</li> </ul>