COPING WITH ALS

Managing the emotional stress of ALS is a monumental task for both patients and family members. The unpredictable progress of the patient's physical deterioration contributes to an array of feelings that can be very powerful.

ISSUES to DEAL WITH

Depending on the physical challenges, a patient may experience the loss of

- walking, which reduces mobility and a degree of independence,
- use of upper extremities which makes dressing, bathing, and toileting, difficult and can contribute to a loss of dignity, independence, and self-image,
- speaking, which makes communication and human interaction more difficult,
- eating, which results in a loss of independence and opportunities for human interaction.

Trying to identify and name the concerns, such as helplessness, financial worries, fatigue, fear, loneliness, or anger, may help a patient deal with the loss. Sometimes a name or label helps a patient to feel a bit less out of control. It may also help to improve communication, which can result in obtaining more support.

Patients have both physical and emotional issues with which to cope. Sometimes, when a patient cannot move freely, muscles become sore and painful from remaining in the same position. Patients also have emotional responses to the changes they feel in their self-image as a result of the changes occurring in their body. For example, some patients feel worthless when they can no longer manage responsibilities at home, such as mowing the lawn, taking out the garbage, cooking, or doing the laundry. Others experience intense emotion when they are no longer able to work outside the home or to take care of young children.

Caregivers and family members also have emotional and physical issues to deal with, especially fatigue and fear. Sometimes patients and family members are experiencing different emotions and have very different needs. Emotions change from day to day; some days they even change from hour to hour. Some responses worsen when they are accompanied by depression or anxiety. A professional can help sort out those needs and figure out how to negotiate them. The Lois Insolia ALS Center social worker is available to

© 2013 Les Turner ALS Foundation

patients and caregivers for counseling in the home, to help develop coping skills and strategies to manage the day to day challenges brought about by ALS. If emotions feel all-consuming for long periods of time, please seek assistance from the social worker.

The physical challenges that result from ALS can cause changes in the roles of family members. People can become overwhelmed when their home environment becomes difficult to navigate. It is important to recognize this, as it is often the cause of frustration, anger, and emotional pain. A home assessment by our Home Liaison Nurse or ALS Consultant can help families maximize home access. The physical changes may also cause a change in roles within the extended family and circle of friends. Patients who are used to being "helpers" or "givers," can find it especially difficult to accept the fact that they now need assistance. This is the time to accept help, and, if possible, to ask for what is needed. Often family and friends want to do something, but they don't know exactly how to help. Tell them—the effect of such communication may be a pleasant surprise.

Tips for Patient Coping

- Break tasks into smaller pieces and do a little bit at a time.
- Change what you expect of yourself; recognize that you cannot do everything you were doing before AND manage this disease.
- Accept and adjust to the physical constraints imposed by the disease as it progresses. It is necessary to continually redefine yourself and what you can do.
- Ask for help.
- Accept help.

Caregivers, take care of yourself as much as possible. Don't ignore your body, especially if you have medications to take and doctor's appointments to keep. Try to make good food choices and sleep as regularly as you can. Arrange to get out of the house on a regular basis, even if it's just for a 15-minute walk. Talk to your friends and share the emotional burden. Paying some attention to yourself is imperative; if you become ill, you cannot care for anyone else.

RESOURCES FOR COPING

Counseling

The Licensed Clinical Social Worker for the Les Turner ALS Foundation will provide counseling for the patient and/or family members, including children, in your own home. These visits are scheduled by appointment.

© 2013 Les Turner ALS Foundation

Web Sites

Family Caregiver Alliance at www.caregiver.org
National Family Caregivers' Association at www.nfcacares.org
Caregiver.com at www.caregiver.com

Support Groups

Support groups are led by professional Les Turner ALS Foundation staff members. Call the Foundation at 847-679-3311 for more information and to confirm date and time. We currently have monthly meetings in Arlington Heights, Libertyville and two in Skokie, including one for you couples living with ALS.

What is a support group?

A support group is an opportunity for patients and caregivers to give and receive emotional support, and to share information and practical experience. This may include learning how to improve function, drug trial information, or the latest in technological advances. Each group is led by two professional facilitators, which allows participants to divide into two groups: a patient group and a caregiver group. While they are separated, members of each group have the opportunity to speak freely about such topics as burnout and other coping concerns, without worrying about hurting a loved one's feelings. Occasionally a guest speaker, such as the Center's occupational therapist or speech therapist, attends the meeting to provide information. All information and support provided is geared to help in coping with the disease in order to maintain as high a quality of life as possible.

Why participate in an ALS support group?

Support groups are a resource to help patients and caregivers feel a sense of camaraderie with others who are living with this devastating disease. No one can understand the feelings and emotions involved better than another patient or caregiver who is also struggling to live with ALS. At support group meetings, some things just do not have to be explained, as they often do in other social situations. The group provides a kind of emotional respite, with understanding and care.

Can I come to a group if I am afraid to share my feelings?

Some participants may decide to not share, and to just listen. However, most soon feel that the support group is a safe place to share emotions. It provides an opportunity to learn how other patients and families cope with similar problems. Talking with others whose everyday perspective on life's problems has been altered by ALS is also helpful.

© 2013 Les Turner ALS Foundation

Can I ask questions about practical matters such as drug trials or equipment?

You can ask about absolutely anything at a support group meeting. The meeting's only agenda is to meet the needs of the patients and caregivers who attend the group.

Coping with the Stress of ALS in the Family

The issue of how children cope when ALS is in the family is extremely complicated for several reasons. The physiological capability of the brain is quite different in a six year-old versus a nine year-old versus a fourteen year-old. These differences are often referred to as a child's developmental stages. The developmental stage tells us what we may presume a child has the capability to process and understand. However, within those stages there are always individual variations. Regardless of the child's age or developmental level, the most important thing you can tell her/him is the truth.

When someone in the family has ALS, there is a certain amount of pain from which children cannot be shielded. Therefore, it is most important that children know they can still go to the most trusted grown-ups in their life to obtain information as they feel ready to ask questions. If children do not ask questions, it is equally as important for the grown-ups closest to them to regularly let them know that they are welcome to talk about any concerns at any time. It is a good idea to consult with the social worker regarding the task of supporting the children in the family.

© 2013 Les Turner ALS Foundation

READING LIST

Personal Stories

Adler, David. *Lou Gehrig, The Luckiest Man.* Gulliver Books. Harcourt Brace & Company, 1997. ISBN 0-15-200523-4, $15.

Albom, Mitch. *Tuesdays with Morrie.* Doubleday, 1997. ISBN 0-385-48451-8.

Bell, Evelyn. *Cries of the Silent.* ALS Society of Alberta, Canada, 1999. ISBN 0-9685-3830-4.

Eig, Jonathan. *Luckiest Man, The Life and Death of Lou Gehrig.* Simon & Schuster, 2005. ISBN 0-7432-4591-1.

Horn, Robert C. III. *How Will They Know If I'm Dead?*
GR/St. Lucie Press. Delray Beach, FL, 1997. ISBN 1-57444-071-3.

Schwartz, Morrie. *Letting Go.* Dell Publishing, 1996.
ISBN 0-385-31879-0.

Coping and Caring for the Terminally Ill

Becker, Marilyn R. *Last Touch—Preparing for a Parent's Death.* New Harbinger Publications, Inc., CA, 1992. ISBN 1-879237-34-2, $11.95.

Doka, Kenneth. *Living With Grief When Illness is Prolonged.* Hospice Foundation of America, Washington, D.C., 1997. ISBN 1-56032-703-0, $16.95.

LeMaistre, Janne. Beyond Rage*: How to Cope with Emotional Problems of Chronic Physical Illness.* Alpine Guild, P. O. Box 183, Oak Park, IL 60303. $18.95.

McCue, Kathleen. *How to Help Children Through a Parent's Serious Illness.* St. Martin's Press, New York. ISBN 0-312-11350-1.

Myers, Edward. *When Parents Die—A Guide for Adults.* Penguin Books, 1987. ISBN 014-00-9211-0, $11.95.

© 2013 Les Turner ALS Foundation

Park, Dale. *ALS: One Caregiver's Handbook*. 1999 (contact the Les Turner ALS Foundation to obtain, at 847-679-3311).

Pitzele, Sefra Robrin. *We Are Not Alone; Learning to Live With Chronic Illness.* Thompson & Co, Minneapolis, MN. ISBN 918351-01-4.

Romano, Joseph L. *Legal Rights of the Catastrophically Ill and Injured: A Family Guide.* Joseph L. Romano, 1998.

Bereavement

Baugher, Bob. *A Guide to Understanding Guilt During Bereavement.*

Brooks, Anne M. *The Grieving Time.* Harmony Books, New York, 1985. ISBN 0-517-57222-2 $9.95, A spouse's personal account of the first year after her husband's death. Written in brief sections, and talks about the loneliness, depth of grief, etc.

Curry, Cathleen L. *When Your Spouse Dies.* Maria Press, 1990. Notre Dame, IN. 1990

Deits, Bob. *Life After Loss.* Fisher Books, AZ. 1988.

Felber, Marta. *Grief Expressed When A Mate Dies.* LifeWords, West Fork, AK, 1997. ISBN 0-9653967-4-6, $19.95. Personal expressions, experiences and suggestions, with space for one's own thoughts and feelings as well; in workbook format for journaling.

Fitzgerald, Helen. *The Mourning Handbook.* Simon & Schuster, New York, 1994." ISBN 0-684-80161-2, $11. Includes information on the grieving process, tips on coping and a guidance list called "you know you're getting better when . . .

Fitzgerald, Helen. *The Grieving Child. A Parent's Guide.* Simon & Schuster, New York, 1992. ISBN 0-671-76762-3, $12.

Gravell, Karen and Haskins, Charles. *Teenagers Face to Face with Bereavement.* Julian Messner, 1989. 0-671-65975-8, $15.95. Seventeen teenagers share their stories about death and bereavement.

Grollman, Earl A. *What Helped Me When My Loved One Died.* Beacon Press, Boston. 1981. ISBN 0-8070-3229-8, $12.95. Very poignant poems and brief thoughts, easy to read.

© 2013 Les Turner ALS Foundation

Grollman, Earl A. *Living When A Loved One Has Died,* Second Edition. Beacon Press, Boston, 1987. ISBN 0-8070-2715-4, $10.95. Very poignant poems and brief thoughts, to read.

Grollman, Earl A. *Talking About Death to Children.* Beacon Press, Boston, third edition, 1990. ISBN 0-8070-2364-7, $11.95. Includes an excellent bibliography with of books for children about death.

Grollman, Earl A, editor. *Explaining Death to Children.* Beacon Press, Boston, 1967. ISBN 0-8070-2385-x, $7.25

Grollman, Earl A. *Straight Talk About Death for Teenagers.* Beacon Press, Boston, 1993. ISBN 0-8070-2500-3, $9.95

Hipp, Earl. *Help for the Hard Times—Getting Through Loss.* Hazelden, Center City, MN, 1995. ISBN 1-56838-085-2, $13.

James, John W. and Cherry, Frank. *The Grief Recovery Handbook.* Harper and Row, 1988. ISBN 0-06-091586-2, $7.95.

Koers, Shirley. *The Eyes Are Sunlight: A Journey Through Grief.* Maria Press. Notre Dame, IN, 1986.

Krementz, Jill. *How It Feels When A Parent Dies.* Alfred A. Knopf, New York, 1999. ISBN 0-394-75854-4, $15.

Lewis, C.C. *A Grief Observed.* Bantam Books, New York, 1976. ISBN 0-583-27486-4, $5.50.

Mellonie, Bryan and Ingpen, Robert. *Lifetimes.* Bantam Books, New York, 1983. ISBN 0-553-34402-1, $11.95.

O'Toole, Donna. *Facing Changes: Falling Apart and Coming Together in the Teen Years.* Mountain Rainbow Publications, North Carolina, 1995. ISBN 1-878321-11-0.

Rando, Therese A. *How to Go on Living When Someone You Love Dies.* Bantam Books, New York, 1991. ISBN 0-553-35269-5, $10.95.

Tatelbaum, Judy. *The Courage to Grieve.* Harper and Row, New York, 1980. ISBN 0-06-091185-9, $8.95.

© 2013 Les Turner ALS Foundation

Wolfelt, Alan D. *The Journey Through Grief.* Companion Press. Fort Collins, CO, 1997. ISBN 1-879651-11-4, $19.95.

Wolfelt, Alan D. *Understanding Grief: Helping Yourself Heal.* Companion Press. Fort Collins, CO, 1992. ISBN 1-55959-038-6, $19.95. Readers are asked specific questions about their grief journeys and encouraged to think about and write down their responses.

Wolfelt, Alan D. *Healing Your Grieving Heart: 100 Practical Ideas.* Companion Press. Fort Collins, CO, 1998. ISBN 1-879651-12-2, $9.95.

You will find a more comphresnsive and up-to-date reading list on the Les Turner ALS Foundation's website, lesturnerals.org.

© 2013 Les Turner ALS Foundation