Resource List for ALS Patients and Families

This list is divided into seven sections: bereavement, books for and about children, cookbooks for ALS patients, disease management and coping, medical textbooks, personal stories and DVDs. While some of these items may be out of print, you can often obtain them via your local library or retailers such as Amazon.com. This list is provided as a service to the ALS community. The Les Turner ALS Foundation does not endorse or recommend information, products or services contained in these materials. You should contact an appropriate medical professional before making decisions about treatment.

Bereavement

The Courage to Grieve
By Judy Tatelbaum
Harper and Row, New York
ISBN: 0060977859

Don't Take My Grief Away From Me
By Doug Manning
Harper San Francisco
ISBN: 978-1892785046

The Eyes Are Sunlight: A Journey Through Grief
By Shirley Koers
Walker and Company
ISBN: 0802725864

Grief Expressed When a Mate Dies
By Marta Felber
Personal expressions, experiences and suggestions with space for one's own thoughts and feelings as well. "Workbook" format for journaling.
LifeWords, West Fork, AK
ISBN: 0965396746

A Grief Observed
By C.C. Lewis
A religious account of rediscovered faith.
Bantam Books, New York
ISBN: 0583274864
**The Grief Recovery Handbook**  
By John W. James and Russell Friedman  
Harper and Row  
ISBN: 0060915862

**The Grieving Time**  
By Anne M. Brooks  
A spouse's personal account of the first year after her husband's death and talks about loneliness, depth of grief, etc.  
Harmony Books, New York  
ISBN: 0517572222

**A Guide to Understanding Guilt During Bereavement**  
By Robert Baugher  
Caring Peo  
ISBN: 0963597515

**Healing Your Grieving Heart: 100 Practical Ideas**  
By Alan D. Wolfeld, Ph.D.  
Companion Press, Fort Collins, CO  
ISBN: 1879651122

**How it Feels When a Parent Dies**  
By Jill Krementz  
Alfred A. Knopf, New York  
ISBN: 0394758544

**How to Go On Living When Someone You Love Dies**  
By Therese A. Rando, Ph.D.  
Bantam Books  
ISBN: 0553352695

**The Journey Through Grief**  
By Alan D. Wolfeld, Ph.D.  
Companion Press, Fort Collins, CO  
ISBN: 1879651114

**Life After Loss: A Personal Guide Dealing with Death, Divorce, Job Change and Relocation**  
By Bob Deits  
Fisher Books  
ISBN: 1555611893
Living When a Loved One Has Died
By Earl A. Grollman
Very poignant poems and brief thoughts, easy to read.
Beacon Press, Boston
ISBN: 0807027154

Understanding Grief: Helping Yourself Heal
By Alan D. Wolfeld, Ph.D.
Readers are asked specific questions about their grief journeys and encouraged to think about and write down their responses.
Companion Press, Fort Collins, CO
ISBN: 1559590386

What Helped Me When My Loved One Died
By Earl A. Grollman
Covers specific feelings and coping skills for the death of a child, spouse and parent.
Beacon Press, Boston
ISBN: 0807032298
Out of Print

When Your Spouse Dies
By Cathleen L. Curry
This book deals with a variety of practical concerns for those who have lost their mates to death, including stages of grief for adults and children, mourning, loneliness, sexuality, networks of support, financial priorities and planning, good health practices and healing.
Ave Maria Press
ISBN: 0877934169

Grandpa, What is ALS?
ALS Society of Alberta
400, 320-23 Avenue S.W.
Calgary, AB T2S 0J2 Canada
(403) 228-7752

The Grieving Child: A Parent's Guide
By Helen Fitzgerald
Simon and Schuster, New York
ISBN: 0671767623
How to Help Children Through a Parent's Serious Illness
By Kathleen McCue
St. Martin's Press, New York
ISBN: 0312113501

In My Dreams...I Do!
By Linda Saran
Inspired by the author's mother, who continued to nurture an intimate relationship with her grandchildren despite her battle with Lou Gehrig's disease. Share the bonding experience of reading about two sisters who escape the world of their grandmother's physical limitations to the freedom of her dream realm where anything is possible. Together, the girls explore a place where bodies are limited only by mind. This narrative gives testimony to the magical power of the imagination - a secret that most children instinctively possess...and many adults. It has universal appeal to all navigating the road of life together.
ISBN: 0-9672082-0-3
Contact the Les Turner ALS Foundation regarding price and availability.

Lifetimes
By Bryan Mellonie and Robert Ingpen
Excellent book about the life cycle for younger children.
Bantam Books, New York
ISBN: 0553344021

Lou Gehrig: The Luckiest Man
By David A. Adler
ISBN: 0152005234
Mr. Adler is the award-winning author of more than one hundred books for children. This beautifully illustrated book by Terry Widner depicts the life and legend of Lou Gehrig. For children of all ages

Raising an Emotionally Healthy Child When a Parent is Sick
By Paula K. Rauch, M.D. and Anna C. Muriel, M.D., M.P.H.
McGraw-Hill
ISBN:0071446818

Saying Goodbye: Bereavement Activity Book
By Jim & Joan Boulden
Boulden Publishing
P.O. Box 9249
Santa Rosa, CA 95405
(800) 238-8433
ISBN: 1878076124
Straight Talk About Death For Teenagers  
By Earl A. Grollman  
Beacon Press, Boston  
ISBN: 0807025003

Talking About Death: A Dialogue Between Parent and Child  
By Earl A. Grollman  
Beacon Press, Boston  
ISBN: 0807023736

Teenagers Face to Face with Bereavement  
By Karen Gravelle & Charles Haskins  
Julian Messner Press  
ISBN: 0671659758

When Someone Has a Very Serious Illness: Children Can Learn to Cope with Loss and Change  
By Marge Heegaard  
Woodland Press  
99 Woodland Circle  
Minneapolis, MN 55424  
(612) 926-2665  
ISBN:0962050242

When Someone Very Special Dies: Children Can Learn to Cope with Grief  
By Marge Heegaard  
Woodland Press  
99 Woodland Circle  
Minneapolis, MN 55424  
(612) 926-2665  
ISBN:0962050202

Cookbooks for ALS Patients  
The Dysphagia Cookbook: Great Tasting and Nutritious Recipes for People with Swallowing Difficulties  
By Elaine Achilles, Ed.D.  
Cumberland House Publishing  
431 Harding Industrial Drive  
Nashville, TN 37211  
ISBN: 1581823487
The I-Can't-Chew Cookbook: Delicious Soft Diet Recipes for People with Chewing, Swallowing and Dry Mouth Disorders
By J. Randy Wilson
Hunter House
PO Box 2914
1515½ Park Street
Alameda, CA 94501
ISBN-10: 0897934008

Meals for Easy Swallowing
Includes a collection of recipes, swallowing tips, helpful hints for increasing calories and sample menus developed by ALS patients and their families.
ALS Clinic
6501 Fannin, Room B 310
Houston, TX 77030

Non-Chew Cookbook
By J. Randy Wilson
Hunter House
PO Box 2914
1515½ Park Street
Alameda, CA 94501
ISBN-10: 0961629908

Disease Management and Coping
ALS: Maintaining Mobility
This is a guide to physical therapy and occupational therapy. It illustrates techniques for energy conservation, managing architectural barriers and employing adaptive devices.
ALS Neurosensory Center
6501 Fannin Street, Room B310
Houston, TX 77030

Amyotrophic Lateral Sclerosis
By Robert G. Miller, M.D., Deborah Gelinas, M.D. and Patricia O'Connor, RN
ALS is not a curable disease, but it is a treatable one. Treatments are now available that can make a major difference in prolonging life and enhancing the quality of life for people with the disease and there are treatments for many of the symptoms of ALS that can help ease its burden. Multidisciplinary teams in specialized ALS centers are providing top quality care and comprehensive rehabilitation for persons with ALS.
Demos Medical Publishing
ISBN: 1932603069
By Hiroshi Mitsumoto, M.D. & Theodore L, Munstat, M.D. This comprehensive guide covers every aspect of the management of ALS. Beginning with discussions of its clinical features of the disease, diagnosis, and an overview of symptom management, major sections deal with medical and rehabilitative management, living with ALS, managing advanced disease and end-of-life issues and resources that can provide support and assistance.
Demos Medical Publishing
ISBN:1888799285
$39.95

Amyotrophic Lateral Sclerosis: A Guide to Patient Care
Edited by James T. Caroscio, M.D.
Thieme Medical Publishers, Inc.
New York, NY
ISBN: 0865772460

Beyond Rage: Mastering Unavoidable Health Changes
By JoAnn LeMaistre, PhD
This book written for patients, family, friends and medical personnel is designed to help people master the emotional and psychological challenges of chronic illness, physical handicaps, difficult recoveries and aging.
Alpine Guild
P.O. Box 183
Oak Park, IL 60303
ISBN: 0931712114

By Maria M. Meyer with Paul Derr, RN
In this book, the author provides an excellent guide to caregiving in the home. A chronological structure is used to define preparation for caregiving, the day-to-day expectations and a listing of numerous resources to augment the content.
CareTrust Publications LLC
Portland, OR
ISBN: 0966476735

Dying at Home: A family Guide for Caring Giving
By Andrea Sankar
ISBN: 0801842301
Family Caregiver's Guide: The Home Health Care Efficiency System that Really Works
By Joan Ellen Foyder
An easy step-by-step guide to caring for a patient at home. This book helps take the frustration out of home patient care by solving hundreds of everyday problems.
The Futuro Company
5801 Mariemont Avenue
Cincinnati, Oh 45227
518 271 3782
ISBN: 0961739207

In the Shadows: Living and Coping with a Loved One's Chronic Illness
By Dr. David Luterman
Dr. Luterman is a professor of communication disorders who has given workshops on the impact of disabling disease on the patient's family. The book details his family's struggle with his wife's multiple sclerosis.
Jade Press
Box 822
Bedford, MA 01730
ISBN: 0964486202

Last Touch: Preparing for a Parent's Death
By Marilyn R. Becker
New Harbinger Publications, Inc.
ISBN: 1879237342

Living with ALS
Six manuals on managing ALS to assist patients, their families and health care practitioners:
1. What's it all About
2. Coping with Change
3. Managing Your Symptoms and Treatment
4. Functioning When Your Mobility is Affected
5. Adjusting to Swallowing and Speaking Difficulties
6. Adapting to Breathing Changes
The ALS Association
800 782 4747

Living with Grief When Illness is Prolonged
By Kenneth Doka
Hospice Foundation of America
Washington, DC
ISBN: 1560327030
Mainstay: For the Well Spouse of the Chronically Ill
By Maggie Strong
Bradford Books
ISBN: 0965717909

Realities in Coping with Progressive Neuromuscular Diseases
This book brings together 51 eminent authorities on ALS focusing on a variety of different coping strategies to offer to patients and families, as well as health professionals
Charles Press Publishers, Inc.
P.O. Box 15715
Philadelphia, PA 19103
ISBN: 0914783203

We Are Not Alone: Learning to Live with Chronic Illness
By Sefra Kobrin Pitzele
This book offers practical strategies and inspiration to people with chronic illness; not specific to ALS.
Workman Publishing
708 Broadway
New York, NY 10003
(212) 254-5900
ISBN: 0894801392

When a Loved One is Ill: How to Take Better Care of Your Loved One, Your Family and Yourself
By Leonard Felder, Ph.D.
New American Library
1633 Broadway
New York, NY 10019

When Parents Die: A Guide for Adults
By Edward Myers
Penguin
ISBN: 0140092110

Medical Textbooks
Amyotrophic Lateral Sclerosis
By Hiroshi Mitsumoto, M.D., et al
Oxford University Press
2001 Evans Road
Gary, NC 27513
800 451 7556
ISBN: 0803602693
Amyotrophic Lateral Sclerosis: Diagnosis and Management for the Clinician
Edited by: Jerry M. Belsh, MD and Philip L. Schiffman, MD
Futura Publishing Company, Inc.
135 Bedford Road
P.O. Box 418
Armonk, NY 10504-0418
914 273 1014
ISBN: 0879936282

Palliative Care in Amyotrophic Lateral Sclerosis: Motor Neuron Disease
By David Oliver, Gian Domenico Borasio and Declan Walsh
Oxford University Press
ISBN 0192637667

Personal Stories

Charlie's Victory
By Charlie & Lucy Wedemeyer with Gregg Lewis
This is an autobiography of Charlie Wedemeyer, a former high school football coach and father of two who has ALS. Charlie's story has been made into two television movies, One More Season and Quiet Victory.
Zondervan Publishing House
Grand Rapids, MI 49530

His Brother's Keeper: A Story from the Edge of Medicine
By Jonathan Weiner
HarperCollins Publishers
ISBN: 006001007X
Featuring ALS Therapy Development Foundation (ALSTDF) founder James Heywood and his brother Stephen, this book tells the story of three epic lines of research that are coming together through the eyes of Jamie, a young entrepreneur, who gambles on a new model of therapy development to save his brother Stephen's life. The story also profiles the Heywood family as they defiantly fight ALS.

How Will They Know if I'm Dead?
By Robert C. Horn, III
GR/St. Lucie Press
2000 Corporate Blvd., N.W.
Boca Raton, FL 33431
ISBN: 1574440713

It's Hard to Leave While the Music's Playing
By I.S. Cooper
W.W. Norton & Co.
New York, NY.
Journeys With ALS
By David Feigenbaum
In this book you will find 33 journeys about people living with ALS. Some are hopeful, some sad. A few are angry. All are powerful, real-life examples of people doing their best to cope, often with humor and high spirits.
DLRC Press
P.O. Box 1061
Virginia Beach, VA 23451
800 776 0560
lynn@davidlawrence.com

Learning to Fall: The Blessings of an Imperfect Life
By Philip E. Simmons, Ph.D.
Read an excerpt at www.learningtofall.com
Xlibris: www.xlibris.com or by phone 888 795 4274 (during business hours, Eastern time)
In Learning to Fall, Lake Forest English Professor Philip Simmons tells the story of his spiritual journey, which began when he was diagnosed with the fatal Lou Gehrig's disease at age 35. With wisdom and humor, he finds answers to life’s deepest questions and shows us how, against all odds, to live lives of depth, compassion and courage.
ISBN: 073884022

Letting Go: Morrie’s Reflections on Living While Dying
By Morrie Schwartz
Doubleday & Company, Incorporated
ISBN: 0385318790

Luckiest Man: The Life and Death of Lou Gehrig
By Jonathan Eig
Simon & Schuster
ISBN: 0743268938

On Any Given Day
By Joe Martin and Ross Yockey
ISBN: 0895872331

Personal Injuries
By Scott Turow
This novel is about a successful personal injury attorney who is discovered by a federal prosecutor to be involved in bribing judges. The twist to this book is that the protagonist’s wife is a person with ALS.
Farrar Straus & Giroux
ISBN: 0374281947
Tuesdays With Morrie
By Mitchell Albom
This story is about Morrie Schwartz, professor at Brandeis University who died of ALS in 1995. Mitch was his student and visited him many times before his death and together they wrote this tender book.
Bantam Doubleday Dell Publishing Group, Inc.
1540 Broadway
New York, NY 10036
ISBN: 0385484518

When Bad Things Happen to Good People
Inspired by the death of his 14-year-old son and his family shared ordeal, Rabbi Kushner tells how to deal spiritually with an unfair loss or tragedy.
By Harold S. Kushner
Avon Books
ISBN: 038067033X

When the Music Stopped I Kept on Dancing
By Angela Riggs
Written by a young woman about how she dealt with her ALS, managed her life and the art of living for the sake of life itself.
BookPartners, Inc.
P.O. Box 922
Wilsonville, OR 97070
800 895 7323

DVDs
Ventilation: The Decision Making Process
A 20-minute video designed for ALS patients, their family members and health professionals. It includes interviews with three ventilator dependent ALS patients, family members and the medical staff from the Les Turner/Lois Insolia ALS Center at Northwestern University Medical School.
Available through the Les Turner ALS Foundation.

Nutritional Lifeline: The Feeding Tube.
Topics included are decision making, tube insertion process, using the feeding and caring for the feeding tube. Available from Simplified Training Solutions,