

Resource List for ALS Patients and Their 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. Written in brief sections, 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

Books for and about Children

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 - an incurable, progressive motor neuron illness. 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 Ropbert 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

\$22.95

Amyotrophic Lateral Sclerosis: A Guide For Patients and Families, 2nd Edition

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



The Comfort of Home: An Illustrated Step-by Step Guide for Caregivers, 2nd Edition

By Maria M. Meyer with Paul Derr, RN

In this book, the authors provide 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 Care 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

(513) 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](http://www.alsa.org)

(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

Story 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 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,

www.simplifiedtraining.com.