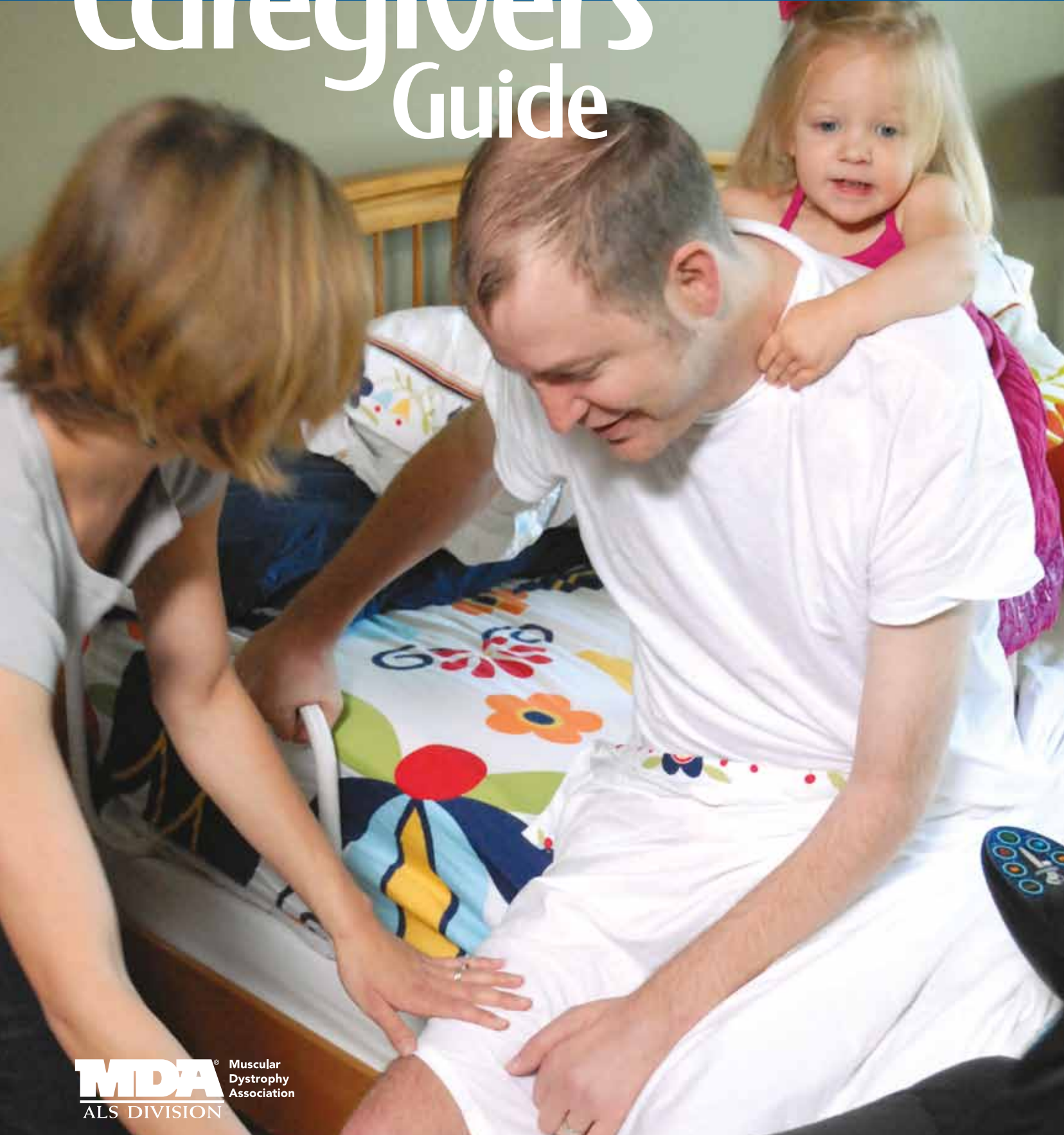


mda ALS Caregiver's Guide



MDA ALS Caregiver's Guide

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MDA ALS Caregiver's Guide

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MDA welcomes comments and suggestions on this publication.

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This book is a rewrite and expansion of MDA's 1997 publication, ***When a Loved One Has ALS: A Caregiver's Guide***. That book was revised twice, but after a decade it was clear that a revision wasn't enough. Much had changed — new information, new resources, new insights. Most important, comments and requests from caregivers and from MDA staff made it obvious that it was time for a new book.

In addition, this book is a companion piece to MDA's 2005 publication, ***Everyday Life With ALS: A Practical Guide***. While ***Everyday Life*** is written for the person with ALS, and focuses on techniques and equipment for daily living at various stages of the disease, this new book is addressed to the family caregiver, whose experience of ALS is certainly as intense and all-consuming as that of the person with the disease. Together, these two books are intended to guide families living with ALS to answers to many of the questions that arise in that experience.

The ***MDA ALS Caregiver's Guide*** is most indebted to those caregivers who've corresponded with us, participated in Web discussions and been interviewed for articles in the MDA/ALS Newsmagazine. Their candid sharing of their personal experiences, questions and emotions guided MDA's staff in deciding what issues should be addressed in this book.

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The quotations used throughout the book are all from ALS caregivers or people with the disease. Unless otherwise credited, they were taken from previously published MDA materials or from Internet discussions, especially the invaluable Living With ALS list serv at <http://health.groups.yahoo.com/group/living-with-als>.

A word about the photography. Several new photos were shot just for this guide by David Ricketts, MDA health care service coordinator in Salt Lake City, who went above and beyond the call of duty with talent, grace and sensitivity.

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And finally, deep appreciation goes out to all caregivers, who inspire us daily with their stamina, humor, ingenuity and love.

The MDA Publications team



The cover photo, taken in 2007, captures a moment in the life of the Stafne family of Minneapolis: Kirsten, Scott and daughter Eva. Scott received an ALS diagnosis in 2004. The Stafnes since have welcomed another daughter to their family, Miranda, born in 2008.

ALS Division – MDA

MDA is the world leader among voluntary agencies in fighting ALS (amyotrophic lateral sclerosis, or Lou Gehrig’s disease). Since the early 1950s, when Eleanor Gehrig served as MDA’s national campaign chairperson, MDA has assisted those affected by the disorder named for her husband, baseball great Lou Gehrig, who died of ALS in 1941 at the age of 37.

MDA’s ALS Division offers the most comprehensive range of services of any voluntary health agency in the nation, and leads the search for treatments and cures through its worldwide research program.

For more about MDA’s ALS Division, visit www.als-mda.org.



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FOREWORD

The day in 2005 when we received “our diagnosis” of ALS was clearly the worst day of both of our lives. In that instant our lives were changed forever. In the years since, things that we used to take for granted have become so precious. Each day is a gift — not a given.

In caring for Augie, I have come to understand what it is to be truly human, what it means to love and to be loved — to have a genuine partnership of trust and respect. This is one of the gifts of this disease. It’s a privilege to care for another and share intimately in his or her life. It isn’t always easy or pleasant, but it’s not without its rewards. Humor and kindness make the tough stuff more manageable. I’ve learned to be flexible — just when I think I have figured it out, everything changes.

ALS is “our disease”; it affects me and our children, and all of those close to us — not just Augie. We’ve chosen to live it very publicly. To do so, we’ve allowed others to share

our burden — we ask for and accept help from others. This help is the source of many of our greatest gifts. Our time since the “worst day of our lives” has been filled with the best, most meaningful days of our lives.

Because you’ve chosen to care for someone with ALS, it’s also “your disease.” I wish for you strength, humor, compassion and patience. But most of all, I wish for you the wisdom to recognize the gifts of caregiving that arise every day along the way.

Lynne Nieto
Corona del Mar, Calif.
2008 MDA ALS Division Co-chair

Introduction

MDA ALS Caregiver's Guide



THE JOURNEY

If you're reading this guide, it's probably because someone you care about deeply has ALS.

This guide will help you to help your loved one through the progression of the disease. It also will help you with your own journey as an ALS caregiver.

Being a caregiver for a person with ALS is emotionally and physically strenuous, but also deeply

rewarding in highly personal ways. It's different from caring for a person with any other disease, and may be far more emotionally and physically demanding than other caregiving journeys. ALS caregivers have called the experience life-changing and found that it strengthens character, deepens compassion and brings relationships to new levels of love and trust.

And it's really hard work. It involves learning about new tasks and equipment, while going through the emotions that arise when a loved one has a progressive, debilitating illness. These pages contain practical and emotional strategies for being an effective caregiver. The **MDA ALS Caregiver's Guide** is meant to give guidance, assistance and advice in many aspects of caring for a person you love who has ALS.

It's full of references to other Web sites, publications, articles or organizations where you can go to find out more about a specific topic or product. And it's laced with quotations from other caregivers and people with ALS, meant to show you that others have dealt with everything you're facing, and they've felt the same fears, despair, exhaustion and hope that you'll be experiencing in this part of your life. You'll read many comments from people about the happiness and satisfaction they've found while living with ALS.

Resourceful caregivers have come up with ingenious solutions to their challenges. Not every suggestion works for every caregiver; sometimes you'll find a better idea than those mentioned here. Because caregiving is an ongoing, organic, creative process that's a little bit different for everyone engaged in it, this book can't include every possible idea. But we hope it provides a platform from which you can think creatively as well as information to get you started and many places in which to look for more solutions.

The primary family caregiver is the care coordinator for the loved one with ALS, the

“I will forever treasure the time I was able to spend with my Mom during her illness. I learned so much about strength, courage and grace from her. There were tough times (mostly due to my impatience!) but the good times were extraordinary!”

“I was worried about everything that people worry about in this situation. How would I take care of my husband? How would I keep my job? How does this disease unfold? How will I know what to do?

How will this affect our son? Will my insurance be enough? Will we become destitute? Will I be strong enough to support him through this? Will I be physically strong enough to even move him? Will we be able to plan for the future?

All the questions that people lose sleep over were the questions that plagued me day and night.”

“It's been nine years since Glenn was first diagnosed. I have changed. I discovered that I have faith in myself. I can trust my instincts, and I believe in my basic self-worth. I understand better who I am and what I'm doing with my life, and that is what really matters.”

— **Caregiver's Reprieve**

by Avrene Brandt, Impact Publishers, 1998

“As caregivers, we have the potential to burn out both emotionally and physically. My biggest piece of advice is: Don't! I wore myself out, and that caused my husband more anguish.”

manager of the loved one's medical, social, financial and cultural life. The issues you'll face as primary caregiver will challenge you and your family in ways you've probably never before encountered. You'll make many per-

“I’m probably the most fortunate man in the world to have such a wonderful, wonderful wife who’s given her life in raising our family and in helping other people so much. Now I have an opportunity to return to her all the kindnesses that she’s done for our family in taking care of her.”

“I’m not “saving” anything; we use our good china and crystal for every special event such as losing a pound, getting the sink unstopped or the first amaryllis blossom.”

“To be able to care for someone or to be needed is a pretty good high. There were good times and a few bad times — usually 3 a.m. and no matter how I placed the pillows he wasn’t comfortable. The bad times were few and far between. We caregivers are the lucky ones: You will never be a burden, let us have the good feeling by taking care of you. Besides, maybe we will find the cure soon. Every day is one day closer to the cure.”



sonal decisions that will affect all of those close to you and your loved one. Along the way, you’ll interact with health care professionals, agencies, insurance companies and many other entities.

A good way to start your journey might be to hold a family meeting (including the person with ALS) and discuss who can cover which caregiving tasks, and how care for your loved one with ALS will be coordinated. One person — usually the spouse, but sometimes a parent or an adult child, sibling or other loved one — becomes the primary caregiver. Other caregivers should treat this person as the leader, the one who coordinates and keeps track of the loved one’s many needs. Those needs will change, sometimes rapidly, so more tasks will need to be assigned and your list of caregivers and helpers will grow. From the beginning, think of caregiving as a group endeavor, not something to be done by a single person, — otherwise, burnout and collapse are more likely.

No doubt you’ve heard it said you must “care for the caregiver.” This isn’t an empty phrase. You must find a balance that allows you to give quality care to your loved one and still maintain your emotional and physical strength. This means that in the course of your journey, you’ll need to find other people to help.

This guide offers strategies for maintaining your strength and finding help.

It frequently refers to MDA’s **Everyday Life With ALS: A Practical Guide**. Everyone with ALS who’s registered with MDA is entitled to a free copy of **Everyday Life**, published in 2005, from the local MDA office. These two books are meant to be used together. **Everyday Life** focuses on practical strategies and equipment, and is written for the person with ALS, though of course its information is invaluable for caregivers as well. **Everyday Life** covers: equipment for daily living, saving energy, home modifi-

cation, equipment for mobility, speech and respiratory issues, transfers, and exercise.

In the **MDA ALS Caregiver's Guide**, the approach is a little different. This book is geared to what caregivers need to know, including how to know when some aspect of your loved one's condition has reached a crisis stage, and provides answers to what caregivers can do at various points for their loved ones with ALS.

Here's a brief outline.

Chapter 1: THE ALS CAREGIVER —

What is ALS, and what is the ALS caregiver's role?

Chapter 2: DAILY CARE OF YOUR LOVED ONE WITH ALS —

A glossary or brief encyclopedia of some 60 terms and topics that are likely to come up in the course of ALS. It provides very practical tips on subjects ranging from bathing to Gulf War syndrome, and extensive references on all topics.

Chapter 3: RESPIRATORY ISSUES —

What are the signs that ALS is affecting breathing? What can be done to improve respiratory function in the early and later stages of ALS? The chapter covers handling coughing, emergencies, assisted ventilation and more.

Chapter 4: COMMUNICATION ISSUES —

How does losing the ability to talk affect self-concept and relationships with family? There are solutions ranging from paper and pencil to role adjustments and dedicated computers.

Chapter 5: NUTRITION ISSUES —

Maintaining good nutrition is important in any condition of health. Here's information on nutrition, choking, feeding tubes, etc.

Chapter 6: EMOTIONS —

Everyone in the household and the community of someone with ALS is affected by the disease. This chapter advises on coping with your loved one's emotions, your emotions, the family's emotions, children, extended family and friends, and finding support systems.

Something From Within

It's not feats of strength
that makes you a man
or scoring the winning goal
to the blare of the band,
it's not boasting about
the sixty hours you put in
it's something much more
it's something from within.

The soul of a man can't be tested
on the field or the ground,
a real man is noblest
when no one's around,
when it's silent and dark
the meaning of TERMINAL hits home
although shaken
he won't let her fight that monster alone.

He carries her to the restroom
on a signal only they know
Countless times he'll lift her
Through pain he won't show,
Two o'clock, three o'clock
the saliva is cleared from her throat
Not mechanically
but by a husband working the scope.
Her illness will take her
as he fights for her life
The champions her husband
and his life is his wife,
This is a living and dying battle
that few men will face
the something from within
is called COURAGE and GRACE.

He knows in his heart
if things were reversed
She'd do it for him
Because it's something they share
It's something from within!

— Roger Gomez

Chapter 7: FINANCIAL, LEGAL AND MEDICAL ISSUES —

Here are tips and references on finding funds, government assistance programs, insurance, low-cost equipment, power of attorney and more.

Chapter 8: FINDING CAREGIVING HELP —

Help is available from agencies, friends, families and other sources. What should you ask for, and how can the caregiver find some respite? When do you consider a nursing home or hospice?

Chapter 9: END-OF-LIFE ISSUES —

Read this only when you're ready to face the final stages of your loved one's ALS, not before. As ALS progresses, some medical questions will affect survival. The chapter also looks at planning for the last days, funerals and memorials, and handling grief.

“You, our dearest loved ones with ALS, you are the Teacher. You are teaching us lessons of life. To Live. To take each day and be strong. Never ever feel you are a burden. You are giving a meaning, a purpose to all of us, your families, to understand what it is to truly care, to love and to embrace your gentle beings and to understand. I thank you.”

“Suddenly your lives are turned upside down and there is more unknown than known.”

“I've been ill this week and not being able to give 110 percent really really scares me. If I won the lottery I'd make a place for all of the caregivers to go to, a warm, dark quiet comfortable spa where we could all go just to rest!”

MDA's Fight Against ALS

Always remember that your primary resource on the ALS journey is MDA's ALS Division. The staff at your local MDA office, your MDA clinic or MDA/ALS center can give you sound guidance. The families you meet at clinic and support groups are living this experience with you. Lean on them, learn from others, call them when you need to talk or need help; you'll find others leaning on and learning from you, too.

The Muscular Dystrophy Association's involvement with ALS began in the early 1950s when Eleanor Gehrig, widow of beloved Yankees first baseman Lou Gehrig, was searching for a way to fight the disease that had taken her husband's life. Mrs. Gehrig served more than a decade as MDA national campaign chairman. As of 2011, MDA has dedicated more than \$290 million to ALS research, services and information programs.

MDA maintains a nationwide network of hospital-affiliated clinics, providing specialized medical services for people affected by any of the more than 40 neuromuscular diseases under MDA's umbrella, including ALS. In addition, a number of clinics are designated as MDA/ALS centers. MDA clinics and MDA/ALS centers are staffed by multidisciplinary teams of health professionals skilled in the diagnosis and medical management of ALS, including symptom control, medical interventions and therapies to help maintain the highest possible quality of life. MDA/ALS center teams may include neurologists, physiatrists, therapists (physical, occupational, speech, respiratory), nutritionists, social workers, pulmonologists, gastroenterologists and medical equipment specialists.

NOTE: For information about the nearest MDA medical services, call (800) 572-1717 or go to www.mda.org/clinics.

MDA's ALS Division also offers:

- a worldwide program of ALS research that includes basic, translational and clinical research programs;
- the ALS Division website, www.als-mda.org, which contains up-to-date information about ALS research, services, clinics, clinical trials and publications; the site also can be used to find the nearest MDA office, clinic or MDA/ALS center, and tells how to participate in local MDA activities;
- assistance with the cost of repairs and/or modifications to all types of durable medical equipment they require due to ALS, including wheelchairs, leg braces, communication devices and more;
- a national equipment program that assists individuals with obtaining durable medical equipment, such as hospital beds, lifts, wheelchairs, walkers, shower benches, transfer boards and communication devices; MDA gratefully accepts donations of gently used equipment;
- support and education through support groups, seminars, home visits, community outreach and advocacy, "phone friends" support and Internet chats;
- emergency health information envelope for organizing and storing vital health care information;
- a partnership with the ALS Therapy Development Institute (forged through MDA's Augie's Quest initiative) which is undertaking the largest ALS drug development project in history; and
- publications and videos, available at local MDA offices and on the MDA website (some in Spanish), including:
 - MDA/ALS Newsmagazine
 - Quest (magazine)
 - Facts About ALS (booklet)
 - **Everyday Life with ALS: A Practical Guide** (book)

- MDA ALS Division (brochure)
- Milestones in ALS Research (booklet)
- "Breathe Easy: Respiratory Care in Neuromuscular Disorders" (booklet)
- "Breathe Easy: A Respiratory Guide for People Living With Neuromuscular Diseases" (video)
- "Breath of Life" (video for medical professionals)
- "With Hope and Courage: Your Guide to Living with ALS," video for people with new ALS diagnoses and their families

“Long-term ALS survivors have somebody they love and who loves them. Survivors know they have great value to another person. They feel it's their responsibility to do what it takes to continue to live because someone needs them.”

“Caregivers are our angels on earth. My wife, bless her, has been my sole caregiver for almost 18 years now.”

“My wife. I can't even imagine what my life would be like right now without her. She lights up my life in ways she can't even see.”