

# Everyday Life with ALS: A Practical Guide



## INTRODUCTION

**R**eceiving a diagnosis of amyotrophic lateral sclerosis (ALS) will unquestionably alter your life in almost every aspect.

You should remember, however, that no one knows exactly how you personally will be affected by the disease or how rapidly it will progress. Statistics can shed some general light on what you can expect from ALS, but they can't predict the course of

ALS from person to person.

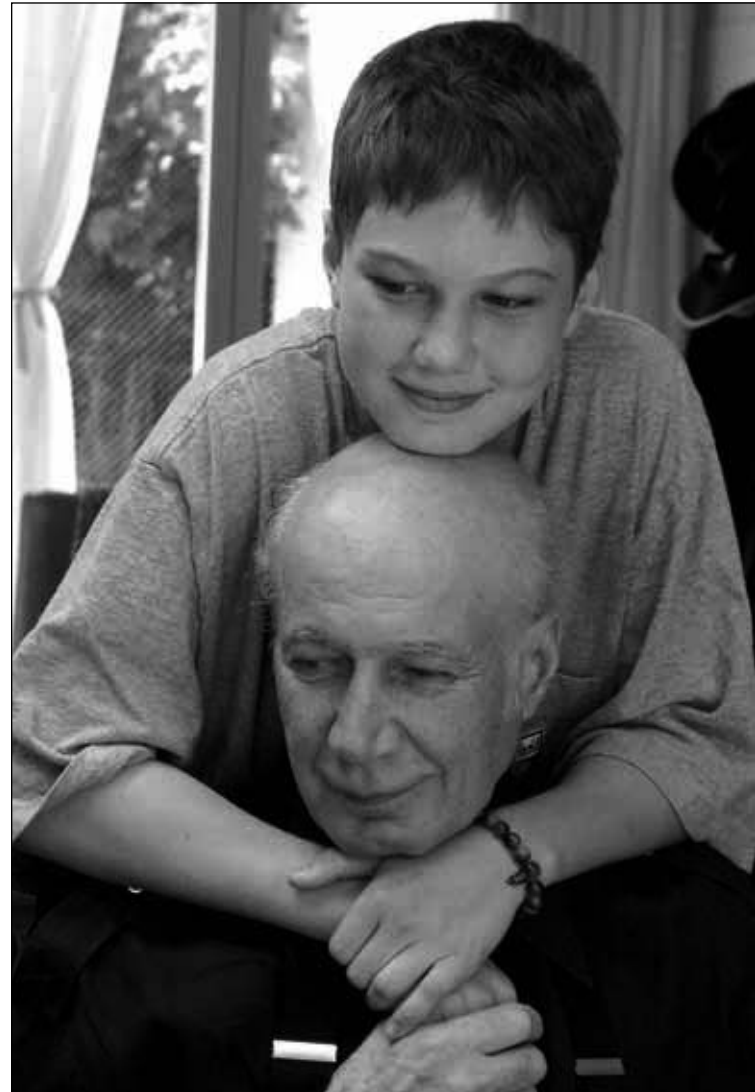
Nonetheless, it's daunting to know that as the disease progresses it will have practical effects on your everyday life. These can range from complicating simple tasks like fastening buttons to limiting major abilities like speaking and breathing.

Not long ago, there were few solutions to the many problems and challenges that ALS poses. Fortunately, that situation is changing.

New techniques and new products are continually emerging that make it increasingly possible for people with ALS to adapt to the disease, to pursue their interests, and to continue to live rich and rewarding lives. MDA has designed this guide to help you manage your experience with ALS so that you can attain the utmost daily satisfaction. The guide will give you a vital tool: information.

This book was created with permission of Stanley Appel, M.D., director of the MDA/ALS Center at Methodist Hospital in Houston, whose staff created an earlier version of the book more than 20 years ago. *ALS: Maintaining Mobility, A Guide to Physical Therapy and Occupational Therapy* proved to be an invaluable tool for families affected by ALS and many other neuromuscular diseases. This update of that indispensable text is presented by the Muscular Dystrophy Association's Publications staff, with the assistance and guidance of physical therapists, occupational therapists, physicians and other ALS experts from MDA's program to ensure it's both current and accurate.

In this practical guide, you'll find advice and information that address needs ranging from those of a person with ALS who



is ambulatory and mostly independent to those of a person who needs extensive assistance.

The guide offers in Chapter 1 a broad sample of practical assistive devices that compensate for weakness and fatigue and are available to help you accomplish a range of daily activities — from eating meals to talking on the telephone.

In addition to the technological possibilities available to help you live your everyday life, simpler techniques of planning and organizing activities can help. In Chapter 2, you'll find suggestions for ways to conserve energy



throughout the course of ALS.

ALS also will require some adaptations to your environment, both for safety and to accommodate new equipment. Chapter 3 suggests how your home environment may be modified to help you to carry on your daily life.

Your freedom of movement or mobility — whether in your home or outside it — will contribute to your ability to enjoy life. Chapter 4 presents various types of equipment that will help you to maintain your mobility. The chapter also addresses supports for your head and neck and your hands.

With the gradual deterioration of your breathing muscles you'll encounter challenging medical complications. There are, however, devices available to compensate for those complications. Chapter 5 explores a number of devices and pro-

## Spotlight: What is ALS?

**A**myotrophic lateral sclerosis is a disease of the parts of the nervous system that control voluntary muscle movement.

In ALS, nerve cells that control muscle cells are gradually lost or destroyed. In most cases, the cause is unknown. As these motor neurons are lost, the muscles they control become weak and then nonfunctional. Eventually, the person with ALS is paralyzed.

Death, usually from respiratory complications, typically comes between three and five years after diagnosis, but a significant number of those with the disease live more than 10 years, and some survive for decades. New therapies and technologies have contributed to the increase in life expectancy for people with ALS, as well as their quality of life. Many long-term survivors — as well as many only a few years past their diagnosis — report living full and richly satisfying lives.

For more information about ALS, go to [als.mda.org](http://als.mda.org), or call (800) 572-1717 or your local MDA office and ask for MDA publications about ALS.

cedures that can help you extend your life.

Not only the muscles that produce breathing but also those that produce speech will likely be affected by ALS. An astonishing array of assistive technology is now available to help you continue to communicate with others despite the effects of the disease. In Chapter 6, you'll find a discussion of several approaches to communication in ways other than traditional speech.

Weakness can limit your ability to accomplish such everyday activities as getting into and out of beds or chairs. You may need assistance moving from one surface to another; these movements are called *transfers*. Transfer techniques and equipment have been developed to assist you and your caregiver team, and you'll find a discussion of transfers in Chapter 7.

Chapter 8 covers exercise. In the early stages of ALS exercise may be helpful in reducing stress and preventing muscle atrophy that may result from disuse. As weakness progresses, exercise may permit you to avoid some of the discomfort that can occur with immobility, particularly a frozen shoulder (adhesive capsulitis). Remember that exercise always should be approved by your health care team and should never create discomfort.

In Chapter 9, the guide presents illustrated instructions to help you properly do exercises that you and your health care team deem appropriate.

The resources section of this guide, Chapter 10, catalogs sources where you can find additional information about



some of the products, tips and services discussed in earlier portions of the guide. This section lists a number of articles in MDA publications that give more details about the topics covered in the guide, as well as books, organizations, videotapes and other resources.

## USING THE GUIDE

**T**his guide should be used as an integral part of your individualized care program, and provide guidelines to optimize your strength, function, physical comfort and safety. It should be read along with guidance from physicians; physical, occupational, respiratory and speech therapists; and other health care

## Spotlight on Your Health Care Team

**A**lways remember that you don't have to face ALS alone.

Along with loved ones and caregivers who form the hub of your personal team, your MDA health care team is there with you every step of the way.

In addition to your personal physician, an MDA clinic physician who's a specialist in ALS will consult with you and the rest of the team, which may include such experts as a gastroenterologist, a nurse, a speech-language pathologist, a respiratory therapist, a physical therapist, an occupational therapist, a dietician and a social worker.

Other members of your health care team may include a psychologist or family therapist, and an MDA health care service coordinator or other representative of MDA.

Throughout this book, you'll learn more about the members of this health care team and what they can offer you as you face everyday life with ALS. Your entire team will work with you to ensure that you remain as healthy and as able as possible to live the life you choose to live with ALS.

professionals. A team approach is best in managing ALS, with you as the team captain.

In practical terms, you may find that you need some assistive equipment right away, and you may not need other items for months or years after your diagnosis. In the same practical vein, some items require extra time for ordering, customizing and funding (power wheelchairs are a prime example).

**SPECIAL NOTE: Be proactive! Because there are so many choices and the course of ALS is somewhat unpredictable, professionals strongly urge you to consider your future needs while you can do so at your leisure. Part-time use of some interventions early in the disease course can make the transition easier and save a great deal of your energy and strength.**

MDA understands that, along with a need for practical solutions, ALS brings a host of emotional, family and financial concerns that are threaded through every stage of progression. We hope this guide to everyday life will give you and your loved ones specific details you need to understand choices, make decisions and plan ahead — steps that will help you to maintain control over your life and adjust to the progression of ALS.

Remember, too, that the Muscular Dystrophy Association is a resource for access to medical care, emotional support, up-to-date information, equipment assistance, resource referral and hope. Keep in close touch with your local MDA office and clinic. You'll also find help in the MDA ALS Caregiver's Guide, which

supplements the information in this one. (For more about the services offered by MDA's ALS Division, see page 126.)

