

Everyday Life

with ALS: A Practical Guide



Everyday Life with ALS: A Practical Guide

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Everyday Life with ALS: A Practical Guide

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Their pioneering work was an essential and solid foundation for the creation of this volume, and a significant number of the original illustrations from that book are found here, and are reprinted with permission.

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All of the chapter opening photographs and many others in this book feature people with ALS. Other photos depict people who have other neuromuscular diseases in MDA's programs.

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The MDA Publications Team

ALS Division — MDA

MDA is the world leader among voluntary agencies in fighting amyotrophic lateral sclerosis. Since the early 1950s, when Eleanor Gehrig served as MDA's national campaign chairman, the Association 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, see page 126 or visit als.mda.org.



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PREFACE

This guide has been prepared for those who are living in the world of ALS. ALS will affect your life in countless ways. Over the course of your disease you will develop a new vocabulary — words such as motor neurons, glutamate and superoxide dismutase. You will face decisions about home modifications, wheelchairs and other adaptive equipment, and medical issues such as feeding tubes and end-of-life decisions. You will become adept at navigating the mazes of health care insurance, disability insurance and financial planning. While, at times, these tasks may seem overwhelming, be assured that there are many resources available through MDA to assist you in your journey with ALS.

The purpose of this guide is to provide a ready source of practical information to help you manage the physical aspects of ALS on a day-to-day basis, through all stages of the disease. The overarching goal is to allow you to maintain function and independence for as long as possible, and always to maintain the best possible quality of life. A major theme running through this guide is the importance of planning early for the inevitable changes that occur over the course of ALS. Preparing for change allows you to maintain con-

trol over decision-making and to make choices that are best for you. We hope that this guide will be a useful resource for you in that regard.

For 15 years I had the privilege of caring for people with ALS. These individuals and their families provided valuable insights about living well with ALS. They emphasized the need for patience and for maintaining a good sense of humor under adverse conditions. They also stressed the importance of identifying priorities, setting realistic expectations, and letting go of the little things that annoyed them, in order to focus on things that mattered more.

Finally, don't be afraid to ask for help, and don't think that using assistive devices is giving in to ALS. Instead, make the most of every means of help possible and allow yourself to live life to the fullest with ALS.

MDA's ALS Division is here to help you every step of the way.

Valerie A. Cwik, M.D.
MDA Executive Vice President —
Research & Medical Director

Everyday Life with ALS: A Practical Guide



INTRODUCTION

Receiving 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?

Amyotrophic 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, 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

This 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

Always 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.)



Chapter 1

Equipment for Daily Living



WHAT KIND OF EQUIPMENT WILL YOU NEED?

In earlier stages of ALS, weakness of the hands may result in difficulty with certain daily activities such as handwriting or buttoning and zipping clothing. As muscles controlling the feet weaken, you may trip or require more concentration to walk over uneven surfaces or distances.

Along with growing weakness of the small muscle groups of the hands and feet, the resulting fatigue can make certain self-care, household and occupational tasks more difficult. Assistive devices — from very simple and low-tech to high-tech electronics — can help you compensate for this weakness and fatigue.

Your occupational therapist can help you manage the progressive changes that ALS imposes. This professional can suggest assistive devices that will permit you to continue to function and to maintain your independence and mobility. An OT also will show you ways to adapt your environment to your emerging needs.

THE ROLE OF THE OCCUPATIONAL THERAPIST

The occupational therapist can help you accomplish your activities of daily living (eating, bathing, dressing, writing, shopping, etc.), your work, and your leisure through the use of compensatory strategies, adaptive devices, home and work modifications, and community resources. OTs also use exercise and therapeutic interventions to enable people with ALS to be more independent and to improve their quality of life. Educating you and your caregiver is another important component of an OT's services.

Compensatory strategies include:

- using stronger and intact muscle groups to compensate for weaker ones
- using the body more efficiently through motion economy and energy conservation techniques
- following time management principles
- supporting weak muscles to increase function of the limbs

Adaptive devices such as button hooks, key

holders, utensils with built-up handles, plate guards, tub transfer seats, lifting cushions, and raised toilet seats make it easier for you to perform daily living tasks. Other aids, or *orthotic devices*, include wrist supports to assist weak muscles and improve hand function, hand splints for positioning, and neck supports to help support and protect your head and neck.

Home and work modifications include ramps, widened doorways, raised seating, walk-in showers and rails. The OT also assesses safety and helps you and your family structure your environment to reduce falls. Ergonomic devices such as computer arm supports, armrests, footrests, and the no-hands or easy-touch mouse can enable those with severe arm weakness to continue working, maintain productivity at home, and enhance their quality of life.

Community resources also can enrich your life and provide support for caregivers and family members. For example, people with ALS can obtain permits to park in handicap-designated spots early on to help combat fatigue. This guide has information about community resources such as books on tape, MDA support groups and seminars, and public transportation services. You also may get some help from senior citizens' programs, such as Meals on Wheels.

HELP WITH ACTIVITIES OF DAILY LIVING

many devices have been designed to help you preserve the ability to perform daily tasks by modifying commonly used items. Other assistive devices make use of the stronger or unaffected muscles to increase efficiency and performance of daily tasks. For example, the button hook allows you to button clothing with a gripping motion rather than relying on finger strength and dexterity.

See Chapter 2 for more ideas for simple labor- and energy-saving devices.

The following is a sample of the many simple assistive devices available today (high-tech devices are featured in Chapters 4 and 6). Each is designed to allow you to continue with normal activities for as long as possible. Most can be found through medical or rehabilitation equipment dealers, or by searching the Internet for “daily living aids.” In some cases you can create these and similar devices yourself.

By the way, Chapter 6 will include information on adaptations for computer access. Though the chapter is called “Speech and Communication,” it will look into systems (hardware and software) that also accommodate for upper extremity dysfunction and hand weakness (switches, mouses and voice-activated controls), which can benefit those who don’t need help with speech.



Therapeutic interventions performed by occupational therapists include range-of-motion, fabrication of splints and other orthotic devices to maintain and improve hand function, and training the caregiver in transfer techniques and stretching exercises. (See Chapter 9 for more about range-of-motion and Chapter 7 for transfer instructions.)

Button Hook

Finger dexterity is required for buttoning clothing. If this is a problem, you



may elect to use Velcro in place of buttons, use oversized buttons with large loops, or wear clothing that requires no fasteners.

An alternative to these methods is the use of a button hook.

Grip the enlarged handle of the hook and feed the wire loop through the button hole. Catch the button in the loop and slide the button back through the hole.

Zipper Pull

Adequate strength in fingers and arms is necessary to grip and zip a zipper. With increasing weakness you may need to use a zipper with a loop placed through the pull or clothing that requires no fasteners, or a zipper pull.



A hook connected to an enlarged handle is placed in the eye of the zipper to pull the zipper up or down.

Handwriting Aids

As pinch strength and dexterity decrease, handwriting may become more difficult. Enlarging your pen/pencil with a triangular grip or cylindrical foam will position the fingers, reduce strength needed, and make writing easier and more legible.



You can find cylindrical foam in various diameters and may want to use it for an easier grasp for razors, eating utensils, toothbrushes and similar items with handles.

Some people use a small, hollow rubber ball in this way, or look for utensils made with larger grips.

Key Holder

Considerable pinch and hand strength are required to turn a key in a lock. Should weakness make this task difficult or impossible, you can use a key holder. A key holder is made with bars of stiff plastic and screws to hold the keys.

The key holder provides leverage for turning the key in the lock.

Bath Mitt

If holding soap and a washcloth is difficult, a bath mitt may solve the problem. Insert your hand and the soap into the terrycloth “pocket” and close it with Velcro.

Car Door Opener

Strong plastic handles for opening push button or pull-up car door handles are available. These handles use grip and leverage instead of finger dexterity.

Rocker Knife

This knife has a curved blade and an enlarged handle. You can cut food with it by using a rocking motion.

Door Knob Extenders

This device increases leverage to aid in operating knobs, handles or controls. For example, you can use it on faucets, door knobs, stove handles and lamp knobs.

Screw Cap

If you have difficulty opening twist or screw-on caps with the fingers, you can use a screw cap. It fits into the palm of the hand and requires minimal strength to turn.

Card Holder

If your grasp is weak, and you enjoy playing card games, a card holder is helpful.



Loop Scissors

These practical, lightweight scissors are made for either right- or left-handed users. A self-opening handle enables easy operation by a simple squeezing action.

Long Straw

A long, plastic tube eliminates the need to lift the glass when drinking.

Strawholder

This metal device clips onto the side of a glass and holds the straw securely in place at a right angle.

Offset Eating Utensils

An angled head reduces the dexterity needed to bring food to the mouth. Utensils with oversized handles also can be easier to grasp.



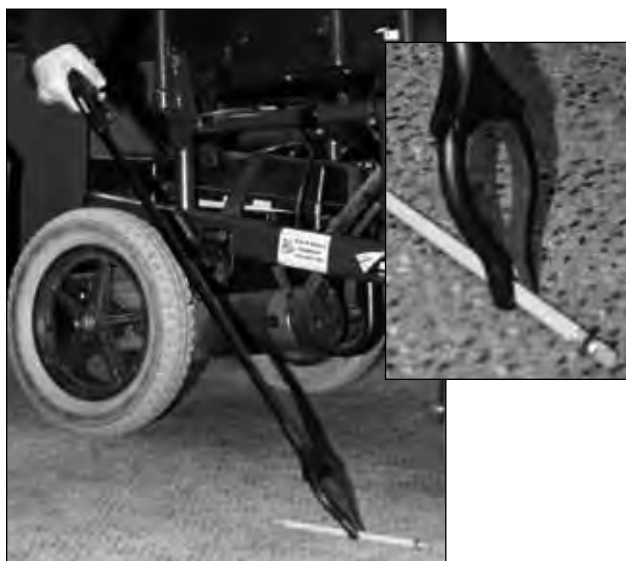
Jar Openers

Electric or battery-powered openers can open various sizes of jars and bottles, and some can be mounted under a cabinet or shelf. A manual jar opener also can be helpful.



Reacher

This long, lightweight aluminum reacher has a trigger or grip closure and is designed to extend your reach upward or downward without bending or stretching.



Risers

Most standard table heights don't allow a wheelchair to fit underneath. Risers are extenders that fit under each leg of a table to increase the table height by 2 to 8 inches. Risers can also be used with chairs, beds and couches to make transfers easier, as higher surfaces are easier to get up from.



Universal Cuff

You can secure this elastic band with a pocket around your hand to hold utensils, pencils, page turner, etc.

Book Holder

This wire-framed stand holds the book open and the pages back.

Wrist Brace

An elastic brace supports your wrist to stabilize your hand. This support is commonly used by people with ALS, and your OT can show you how it functions and assists you.



Resting Hand Splint

Made of sturdy plastic, this splint positions your hand and wrist comfortably to counteract the effects of muscular tightening.

Shampoo Rinse Tray

Use this shampoo basin while you're lying flat in bed. The caregiver places



your head inside the basin with your neck resting on the soft ring and pours water over your hair. A flexible plastic tube drains water to the container you supply alongside the bed.

Help/Call Switch

This tent-shaped, ultrasensitive touch plate activates by a touch or head turn. A wireless doorbell also can be used as a personal call system.

Rising or Lift Chairs

Recliner-style chairs help you go from sitting to standing because their seats slowly rise and tilt forward. Another option is rising or lift cushions that slowly spring open to assist a seated person in standing.

These cushions are portable, so you can take them to restaurants, theaters and other places you visit.



Toilet Aids

Although ALS doesn't usually affect bowel or bladder control, decreased mobility eventually may make it difficult to move to



a toilet or bedside commode. Alternatives that don't require transferring from the bed include bedpans, urinals and external catheters that drain into a collection bag.

If maintaining good hygiene becomes a problem, a bidet or a handheld shower nozzle may be useful. A bidet is a device that fits into the toilet tank and connects to a warm water supply. An under-seat, warm-water spray head operates with a hand control.

Other helpful items include toilet seat risers (or raised commode seats) that increase the height of a toilet seat and make it easier to get up and down. Some models include safety handles, and others have lift mechanisms to help the user stand.

For additional information about bathrooms and ways to modify them, please see Chapter 3.

Many of the devices described in this chapter are sold at department stores and drugstores. Others are available at medical supply stores, from companies that advertise in MDA's *Quest*, or on the Internet.

BEDS

As mobility becomes more difficult, you may find that sleeping in a standard bed, or getting in and out of one, is no longer feasible. Fortunately, there's a growing variety of innovative beds

and sleep products designed for someone who has limited mobility, or is unable to change positions at regular intervals while sleeping.

This equipment can be costly, but some items can be rented. In most cases, a prescription from a doctor and documentation of medical necessity can result in insurance coverage. Talk to your doctor and therapists for assistance.

Draw Sheet

If you're still using a regular bed, your caregiver may appreciate a draw sheet, which will help him or her easily roll and position you. The sheet is placed under you extending from shoulder level to buttocks with at least 6 inches of sheet remaining on each side.

Some families have found that satin or nylon sheets or pajamas make turning the person easier.

Mattress Overlays

Specifically designed to prevent discomfort from immobility and encourage good blood flow to the skin, mattress overlays are fabricated from foam, rubber, gels or in an innovative honeycomb design. Similar technology can be found in wheelchair cushions. These greatly increase comfort and can help prevent painful bedsores.

Head and Neck Support

Similar materials and technology used in foam or air mattress overlays also are used in special pillows that provide added support for head, neck and surrounding muscles.

Hospital-Style Beds

A hospital-style bed is recommended for those who spend a majority of their time in bed or have very limited mobility. This bed allows your caregiver to adjust your position easily, elevating your feet to prevent swelling and your head for watching television, reading, etc. It also aids in positioning and weight shifting when turning in bed becomes difficult.



A major advantage of a hospital bed is that it reduces the risk of injury to your caregiver. The height of the bed can be adjusted to prevent him or her from stooping, bending, pushing and pulling, thereby lessening the chance of back strain or other injury.

You can purchase or rent traditional hospital beds from medical suppliers. Convenience features include side rails, adjustable height, and adjustable mattresses for raising or lowering head or feet. Some beds with these features are constructed to look like typical bedroom furniture, with attractive wood panels that



obscure the operating controls.

Medical insurance policies often cover the purchase or rental of a hospital bed when it's pre-

scribed. Your local MDA equipment loan program also may have hospital-style beds. Look for an electrically powered bed, not one with a hand crank. It will save your caregiver a great deal of energy.

Alternating Pressure/Turning Mattresses

To help prevent pressure sores, alternating pressure mattress overlays automatically inflate and deflate cells along their length, and provide different pressure/firmness settings. Electrically powered turning mattress overlays will automatically turn you every few minutes (from side to side). Turning beds provide the ultimate in technology — the entire bed rotates, not just the mattress. All can provide great relief to caregivers.



Bed Safety Rails

These provide a sturdy handle or rail to grasp while you're getting in and out of bed. Some designs slide between mattress and box springs, and others stand on the floor.

ADAPTABLE CLOTHING

A growing selection of clothing made specifically for people who use wheelchairs is available. Pants, shirts, jackets, shoes, boots and more have been designed for comfort and convenience.

The items are designed with clever features like openings in the back, and made not to look rumpled or ill-fitting on someone who's seated. Although not always available in your local department store, this specialized clothing usually can be purchased by mail, phone or over the Internet.



Spotlight on Clothing and Dressing Hints

- Look for items with Velcro closures or snaps rather than buttons, or consider altering your existing clothing with these closures.
- Homemade zipper pulls can be made by tying on a piece of cloth or attaching a circular key ring, piece of fishing line, or other object.



- Rub the lead from a pencil on the teeth of a sticky zipper to make it easier to pull.
- Slip-on shoes are easiest for dressing, and those with Velcro closures avoid laces.
- Spiral, “no-tie” shoelaces just need to be twisted once or twice and allow you to secure a shoe without having to tie a knot.



- Elastic shoelaces look like regular laces except for the elastic “give.” The elasticity will allow you to slip shoes on or off more easily.
- Long-handled shoe horns are helpful for slipping on shoes without having to bend down as far.
- Sock aids prevent you from having to bend down to slip on socks. One version holds the open sock at the end of a U-shaped device that has long rope handles. Another consists of a wire or plastic frame that holds socks or stockings in place for the foot to be slipped into. Caregivers can place socks on these aids in advance for the next dressing time.
- Whenever possible, sit while dressing so you can safely rest as needed. If one side of the body is weaker, it takes less effort to dress this side first. For example, put the weaker arm into the shirt sleeve first, the stronger arm next.



TELEPHONE EQUIPMENT

Phone Holder

The phone holder fastens to the receiver with a Velcro closure and provides a handle on the receiver.

Slide your palm into the U-shaped opening and bring the receiver to your ear.

Receiver Extender

With this flexible metal arm that places the receiver in position, you don't need to lift the receiver off the base.

Flip the switch to open the line and place your ear near the receiver.

Telephone Adaptations

There are numerous adaptations and accessories available that can make using the telephone easier or possible for people with ALS.

In fact, many assistive features are standard on today's phones, such as speed dialing, one-touch dialing, speaker phones and voice-activated systems. Other adaptations can be made with inexpensive accessories, such as hands-free headsets or large button adapters for easier dialing.

Cellular phones and wireless phones offer even more independence, as users can be just about anywhere and make or take a phone call. Occupational therapists and other experts can also help you integrate a telephone with an augmentative, alternative communication device, or an

environmental control unit. (See Chapter 6 for more information on this technology.)

Phones with "emergency response systems" are another option that provides increased ability to contact emergency workers, friends or relatives in the event of a problem. Some systems can play a prerecorded message to alert the person you call that you've had an emergency. They may come with a remote-control autodialer that can be activated by a button worn on a necklace or a belt.

Local phone companies have TTD equipment that's generally provided for people with hearing impairments. This equipment, which sends telephone messages that you type, can also be useful if you've lost the ability to speak. Of course, e-mail also replaces many telephone functions. See Chapter 6 for more on computer adaptations.

BOOKS

The local library and used bookstores are good resources for audio books, as is the National Library Service for the Blind and Physically Handicapped (see Chapter 10). Mechanical page-turning devices enable hands-free reading. E-readers, such as the Kindle by Amazon, offer read-aloud features for a wide range of books and publications.

Books and the vast resources of the Internet can be accessed hands-free via eye-gaze or eye-tracking software.



Chapter 2

Saving Energy



BATTLING FATIGUE

Energy conservation depends on the elimination of unnecessary steps in an activity. In ALS, muscle fatigue becomes a problem any time you make greater demands than your muscles can handle. By understanding the cause of your fatigue, and incorporating energy-conservation techniques into daily life, you'll be able to live more independently and do more for yourself with less fatigue.

But you also should be aware that frequent fatigue, headaches and lethargy may indicate weakness of breathing muscles. See Chapter 5 of this guide for more information about respiratory issues and ALS. Fatigue also can have emotional roots; depression symptoms or stress are common in ALS. Help is available for these challenges, so don't hesitate to talk to your doctor about these issues.

The following are tips for avoiding fatigue, and modifying or streamlining simple tasks so that you can conserve energy.

PRINCIPLES OF ENERGY CONSERVATION

Avoid Rushing

- Preplan your work, and schedule rest periods.
- Spread heavy and light tasks throughout the day.
- Set priorities and eliminate unnecessary tasks.

Avoid Unnecessary Motion

- Sit instead of standing for any task that may last longer than 5 minutes.
- Avoid holding or lifting heavy objects by sliding or using a wheeled cart.
- Avoid reaching and bending by arranging your work area within normal reach.
- Apply for a "disabled" parking permit early in the disease process.



Arrange Your Work Center

- Place supplies and equipment at the point of first use.
- Live simply, avoiding unnecessary cluttering of items.
- Use modern labor-saving equipment. For example, use a food processor for chopping or cutting.
- Use good posture to prevent fatigue by keeping your trunk muscles in their best biomechanical position for function.



Use Proper Working Conditions

- Adjust work areas to a proper height.
- Use adequate ventilation.
- Use good lighting.
- Work in a relaxed manner, for example, with music.
- Wear comfortable clothing.

EVERYDAY ACTIVITIES

Household tasks, errands and other routine activities comprise a large part of daily life. As fatigue becomes more of a problem, modification of ordinary tasks is necessary. By prioritizing and simplifying

routine tasks you can conserve your energy for more enjoyable activities.

Cooking and Meal Preparation

- Plan menus in advance.
- Use menus that require short preparation time and little effort, such as frozen or microwaveable foods and ready mixes.
- Plan preparation so that you can save trips around your kitchen and dining area. For example, use a wheeled cart to gather all necessary items (such as meal ingredients or plates and silverware) and transport them to the work area or dining table, sink, etc.
- Slide or use a utility cart to transport items to the cooking area or storage (for example, slide pots, don't lift).



- Sit at a table or counter of correct, comfortable height to mix ingredients, chop and slice vegetables, etc.



- After a meal, sit on a high stool at the sink when washing dishes. Use a cart to transport them to the storage area.



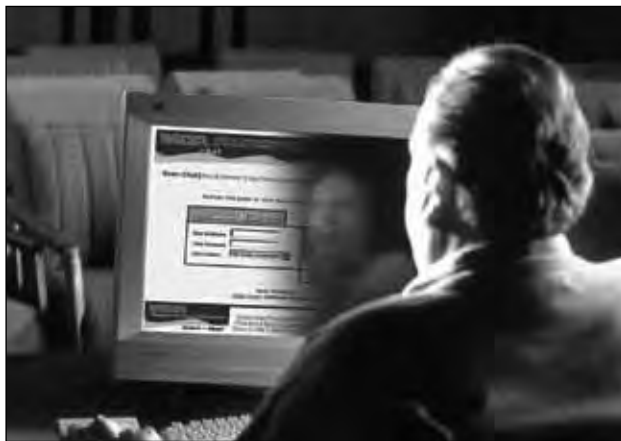
- Open lower cupboard doors to allow more leg room at the sink or counter while sitting on a stool.
- Use a cutting board that fits over the sink.
- Avoid items that require constant stirring and attention.
- Use lightweight dishes, and double-handled pots and pans.
- To eliminate or reduce scrubbing pots and pans, use vegetable spray prior to cooking.
- Urge other family members to do their share of physical chores, or to do the most demanding ones.
- Look for special tools with built-up handles that make kitchen chores easier.



Errands

- Consider online or catalog shopping and direct shipping for items such as toys or gifts.
- Plan menus to avoid unnecessary trips to the market.
- Save your activities for the time of day when you feel your best.

- Keep a list of grocery items you need, and then organize the list to correspond with the layout of the store. Use an electric scooter if one is provided by the store.
- Shop at stores where employees will unload your cart and deliver items to your car.
- Put heavier items near the handles of the shopping cart for better leverage.
- Shop by phone or Internet with grocery stores that deliver.



- Get help, such as a service dog, a personal attendant or a housekeeper. Also, contact public service organizations in your community. Many have



programs whose members must fulfill community service hours by doing things like lawn care, dog walking and grocery shopping.

- Organize your schedule by placing the most important tasks at the top of your to-do list and doing those tasks first.
- Use bathroom aids to your advantage. Grab bars, shower chairs, raised toilet seats and handheld showers offer the aid you need without the struggle.
- Don't hesitate to ask friends and neighbors for assistance with errands.

Cleaning & Housework

- For easier bed making, place the bed where both sides are open, not one against the wall. Make one trip only around the bed.
- Use a mop with a long handle to clean your bathtub.
- Use cleaning products that don't require you to scrub.
- Get help, such as a service dog, a personal assistant or a housekeeper.
- Contact public service organizations in your community for help.

At Work

- For desk jobs that involve extended computer use: Use technology



designed to save keystrokes and mouse clicks. For example, certain



software allows you to control your computer with voice commands, or use means other than your fingers and hands, such as a head mouse. (See Chapter 6.)

- Some computer software, such as word-processing programs, has built-in features to save keystrokes, like “word completion.” (See Chapter 6 for more information.)
- Investigate the possibility of telecommuting or completing your work from home.
- Discuss with your employer in advance the need to redefine your duties or put you in a position with fewer physical demands.
- Use a telephone that allows hands-free usage with a headset or speaker system.
- For better grip on pencils or pens, wrap them in a piece of foam sponge or in multiple rubber bands. Other innovative grips can be found at office supply stores.



- Look for large-diameter pens or use large, felt-tip pens that are generally easier to handle than the average pen.
- You can make a homemade page turner by slipping a rubber eraser over the tip of a dowel or pointer that is about 18 inches long. Then attach it to the brim of a hat or visor, and use the eraser end to grip the page. This is best used by someone with head and neck control, but weak hands and arms.



PERSONAL CARE

Simple modification of daily self-care tasks can significantly reduce energy expenditure while helping you to maintain your independence.



Review the basic principles listed on page 31. The following techniques can help you save energy and can make assisting you more efficient and less tiring for your caregiver.

Bathing & Showering

- Gather all necessary items and place them within easy reach at waist level.
- Sit to undress, bathe, dry and dress.
- Use water of moderate (not too hot or too cold) temperature.
- To avoid excessive reaching, use a long-handled sponge to wash your back while sitting on a tub bench.
- To avoid bending from the waist, use the cross-leg method to wash and dry feet.



Dressing

- Gather all necessary items and place them within easy reach.
- Sit in a straight-backed chair to dress.
- Complete above-the-waist dressing first.
- Avoid reaching by choosing front-opening and/or loose-fitting garments. Fasten underclothes in front of the body.
- To avoid bending, use the cross-leg method to put on socks, underwear, trousers and shoes, in that order.
- Dress the weaker side first.
- Pull both underpants and trousers to your knees, then stand, pulling both to your waist, and fasten them.
- To avoid bending, gather all soiled clothes while seated.

- Consider using a grabbing device or reacher that allows you to pick up items such as shoes without having to bend over. Or store shoes on a raised shoe rack to avoid straining to pick them up each day.

Getting Into Bed

Turn your back toward the bed and hold onto the headboard or side of the bed. Lower yourself and sit on the edge. Slide slowly back until sitting securely.

Place both arms toward the head of the bed and support your body weight. Slowly lie down onto your side while lifting your legs onto the bed.

Getting Out of Bed

- Roll onto your side and bend your knees.
- Slowly push your body up with your arms while lowering your legs to the floor.
- Keep your back in a straight line and avoid twisting.
- If the bed has a siderail, use it to help you turn. (See page 26.)

Other Helpful Hints

- Attach leather or webbed loops to drawer handles.
- Lower the clothes rods in closets to increase accessibility.
- Use an electric toothbrush.



Spotlight on Care Circles

Care circles have made a big difference in the lives of many people affected by ALS. Described in the how-to book ***Share the Care*** by Cappy Capossela and Sheila Warnock, care circles are groups of volunteers organized to do daily, weekly or occasional tasks such as shopping, preparing meals, lawn mowing, making phone calls about insurance issues, or even something as simple as becoming an e-mail buddy.

At the heart of this concept is that a care circle is designed so that tasks are appropriate for the volunteer, and no volunteer takes on too much.

One of the hardest parts of a care circle is getting started, which means asking for help. A simple first step is to create a list of things you need help with, and a list of people or groups that you think might be willing to volunteer (beginning with those who've asked, "Is there anything I can do to help?"). See "Spotlight: Checklist for Getting Help."

MDA's *myMuscleTeam* is a free online service that helps MDA families receive strength from a personally created community — their "Muscle Team" of family and friends. Users create private, secure *myMuscleTeam* Web pages that enable them to post journal entries to keep friends and loved ones updated, and to utilize a "care coordination calendar" where they turn general offers of help into scheduled assistance.

To utilize *myMuscleTeam*, go to www.mda.org/mymuscleteam, or visit MDA's home page and click on the *myMuscleTeam* link on the top of the page.

Spotlight: Checklist for Getting Help

The Ways I/We Need Help

Item	Volunteer	Contact #
Chores		
Car Maintenance		
Minor Home Repairs		
Pet Care		
Food		
Grocery Shopping		
Meal Preparation		
House		
Cleaning		
Laundry		
Mow Lawn		
Water Lawn		
Weeding		
Yard Work		
Miscellaneous		
Child Care		
Just Visit		
Write Letters		
Respite		
During Week		
Evenings		
Weekends		
Shopping		
Transportation		
Church		
Entertainment		
Medical Appointments		
School		
Other		

Whom to ask for help:

- Church/Sunday School class
- College organizations (nursing, occupational therapy, physical therapy)
- Co-workers
- Friends
- Family
- Mayor's Office for People with Disabilities
- MDA Health Care Service Coordinator for suggestions
- Neighborhood association
- Neighbors
- Scouts
- Students
- Support group leaders

Chapter 3

Home Modifications



ARCHITECTURAL BARRIERS

People with disabilities enjoy greater access throughout our society today, thanks mostly to the passage of the Americans with Disabilities Act (ADA) in 1990. Although this historic civil rights legislation mandates, among other things, that public places be accessible to people with disabilities, you may find that getting out and about isn't always smooth sailing when walking becomes more difficult or when you use a wheelchair for mobility.

Restrictions and barriers are often most prevalent in private dwellings such as apartments or houses, whether it's a flight of stairs to the front door, narrow doorways or a cramped bathroom. Fortunately, there are many ways to make adaptations or modifications that promote independence and safety in your own home — and even a few that may be easy to apply in homes you visit often.

Modifications range from the very simple and inexpensive (a portable ramp), to the very complex and costly (a full remodeling project). This guide contains many examples of equipment that can sometimes fill a need and take the place of a lengthy home modification project.

The costs of each of these modifications can vary widely, as can local building requirements. Check Chapter 10 for sources of more detailed information about costs, choices and funding.



HOME SAFETY

Your local MDA office can help arrange a home visit by an occupational therapist (OT) to assess home safety. Such common-sense moves as repositioning furniture, removing rugs, eliminating clutter, moving electrical cords, and making an evacuation plan in case of emergency, can make everyday life easier and safer as your footing becomes less certain.

There are simple things you can do to your home and other surroundings to increase your personal safety, especially if ALS affects your balance and stability. Here are some tips to help prevent falls, burns and other injuries.

Kitchen



- When boiling food like potatoes, pasta or vegetables, put them into a wire basket inside a pot. When the food is cooked, you only need to lift the basket.

You can drain the water later after it has cooled down.

- Use a jug kettle or kettle tipper when pouring instead of lifting a kettle.

Preventing Falls

- In bad weather, wear warm boots with rubber soles for better traction.
- In public buildings, avoid polished, shiny floor surfaces whenever possible. Look for plastic or carpet runners to walk on.
- Keep rooms clutter-free, especially floors.
- Keep floor surfaces smooth but not slippery. Be aware of differences between rooms, especially differences in floor levels and thresholds.



- Make sure all carpets (including carpeted stairs) are firmly attached to the floor. Area or throw rugs should have skid-proof backing or rubberized mats underneath them.
- Wear supportive, low-heeled shoes at home. Avoid walking around in socks, stockings or backless slippers.
- Consider placing rails on both sides of stairways. Stairways should also be well lit.
- Keep power cords out of walkways.
- Use a rubber bath mat in the shower or tub.

General Safety

- Arrange with a family member or friend for daily contact, and always be sure at least one person knows where you are.
- Keep flashlights (and extra batteries) nearby, especially on nightstands, and use nightlights.
- If it's difficult to close a door, tie a rope around the door handle with a tennis ball on the end. Cover knobs with rubbery material to make them easier to grip.

- Obtain a backup system in case of power outages (such as a gas-powered generator). Inform your local power company if you use a ventilator or other life-support equipment. That way, in case of an emergency outage, your power grid can become a priority for power restoration.

- Consider high-tech options for using lights, appliances, opening doors and the telephone.



Voice-activated switches or systems known as environmental control units can operate numerous devices throughout your home with one remote control unit.

- Use reachers for retrieving items off the floor or from higher places instead of bending over or reaching.



MAKING YOUR HOME MORE ACCESSIBLE

Ramps

Portable or permanent ... long or short ... aluminum, fiberglass, wood or steel ... wheelchair ramps are available in just about any size and type imaginable. A ramp is usually a cost-effective way to make an entrance to a home accessible or to eliminate the barriers created by a step, threshold or a small flight of stairs. For safety's sake, every home should have at least two accessible entryways/exits.



Modular aluminum ramps are a quick, easy solution for many situations. You can use them temporarily at your home, or take them along when visiting someone or even for getting into a restaurant or shop. One caution: They may have



inadequate traction if the slope is greater than recommended.

Some portable ramps are built from lightweight materials like aluminum, and others fold to the size of a suitcase and have handles for carrying. Often, ramps can be custom-ordered to fit your needs.

If you're building a ramp, the correct slope is a 1-inch rise for every 1 foot of run, and 2-inch side curbs for safety are essential. A variety of materials can be used for ramps, but keep in mind issues such as a surface that can get slippery when wet outdoors, and the considerable weight of a power wheelchair plus its occupant.

For example, you can build a ramp from plywood, but it should be coated with a mixture of outdoor paint and sand for traction. (Sandpaper adhesive strips won't hold up under the weight of a power wheelchair.) Treated hardwoods and manufactured materials like PakkaWood cost more but add durability.

If cost is an issue, your local MDA office, independent living center or Chamber of Commerce may have a list of organizations or programs that can assist with residential ramp installation and costs.

Doorways

Most houses weren't built with wheelchair accessibility or maneuverability in mind. Often, doorways need to be altered or widened

to allow passage of power wheelchairs, which average 28 inches in width.

In a 30-year-old home, a typical front door is 35 inches wide; bedroom doorways with trim average 30 inches wide; hallway closets and bathroom doorways with trim are only 24 inches wide; and linen closets are 18 inches.

Sometimes you can simply replace door hinges with offset ones that bring the door out beyond the trim, allowing another 2 inches for passage. That may be enough to squeak by, but chances are good your doors and trim will acquire some dents and scars unless the opening is at least 36 inches.

Double doors, 4-foot-wide bi-hinge doors, and lightweight pocket doors (that slide into the wall) are also options for widening.





Keep in mind that lever-style door handles are easier to use than round knobs for someone with limited strength or dexterity.

Floors

Some types of flooring won't hold up under the weight of a power chair. For example, the strength of tile floors varies depending on material and thickness, and the tiles themselves will add weight. Also, the subfloor must be level so tiles, wood planks or other material won't crack if a wheelchair is rolled over it, and it must be strong enough to support added weight.

Cabinetry

Cupboards that feature pull-out or pull-down shelving or corner lazy Susans



will maximize accessibility to wheelchair users. D-shaped hardware instead of knobs makes opening easier.

Working with Contractors

Consult with at least three contractors about your plans. Check their licensing, insurance and credentials online, or with your state registrar of contractors or the Better Business Bureau. Get bids in writing and a detailed, written contract that both parties sign. Pay in stages as the work is satisfactorily completed, starting with a deposit of about 10 percent.

SAFETY EQUIPMENT

Support Pole

A floor-to-ceiling tension pole can be used wherever it fits, and will provide support for sitting, standing, getting out of bed, etc.

Support Rails

A variety of rails are available, many of which can be moved to different areas of your home or the homes of loved ones you visit often. Rails can be attached or used next to beds, bathtubs, tables and so on.

Grab Bars

Commonly installed in bathrooms, these rails can be placed just about anywhere they're needed in a home. Grab bars are available in many styles, shapes



and sizes. Be sure to securely mount them to a wall stud or use other effective hardware so they'll help balance and support you. And remember — soap dishes and towel racks aren't grab bars!

Stair Solutions

For multistory homes, many costly but effective lifts, elevators and stair machines exist.

If you're considering a stair lift, keep in mind that adding it can make it hard for others to use the stairs.

Residential models of *inclined platform lifts* can carry a person sitting in a wheelchair over a flight of stairs. *Stairway lifts* can carry a seated person up or down stairs. Both have models in which the platform or seat folds out of the way when not in use.

Remote Door Openers

These devices can unlock, open and close a door with the touch of a button. Some brands can be operated from a wheelchair-mounted transmitter or an environmental control unit (ECU) (see Chapter 6).

Other Electronic Safety Devices

Many products have been developed with safety and convenience for a person with limited movement and mobility in mind. You can find information about emergency phone systems, ECUs and other assistive devices in Chapters 1 and 6.

BATHROOM MODIFICATIONS

Solutions to bathroom inaccessibility can range from adding innovative or even portable equipment to work with your existing bathroom, or to completely remodeling the existing plumbing, structure and more. Here are some simpler bathroom modifications.

Bathtubs

While a soothing bath can provide much comfort, a bathtub often becomes inaccessible because it requires the bather to step over or be lifted over its wall. However, there are a growing number of solutions to this problem.

Existing Tubs:

Some companies will create a cutout to allow a user to step into a tub. Plumbing can be lowered and fixtures such as handheld showerheads can be retrofitted. Shower doors or curtains can be added to keep water in the tub, and a curtain will be necessary if you use a transfer tub bench.



New Tubs:

Tubs with a walk-in entry and sliding door can be installed. Recumbent bathtubs are designed as a therapeutic aid for someone who has little or no mobility, and they often have a slide-in entrance with a door that swings shut.

Bath Chairs:

Free-standing or wall-mounted benches enable a person to use a bathtub without sitting on the tub floor. This means less effort to exit the tub since the chair usually sits at the same height as the tub walls.

Bath Transfer Benches/Chairs:

This type of chair spans across the rim of the tub or shower, with half of it outside the tub. Some brands fea-



ture a seat that slides and/or swivels: The bather sits on the chair on the outside of the tub and then slides the seat into the tub, leaving only the legs to be lifted into the tub. Some models collapse for storage and portability and feature cutouts on the seat for toileting and personal hygiene.

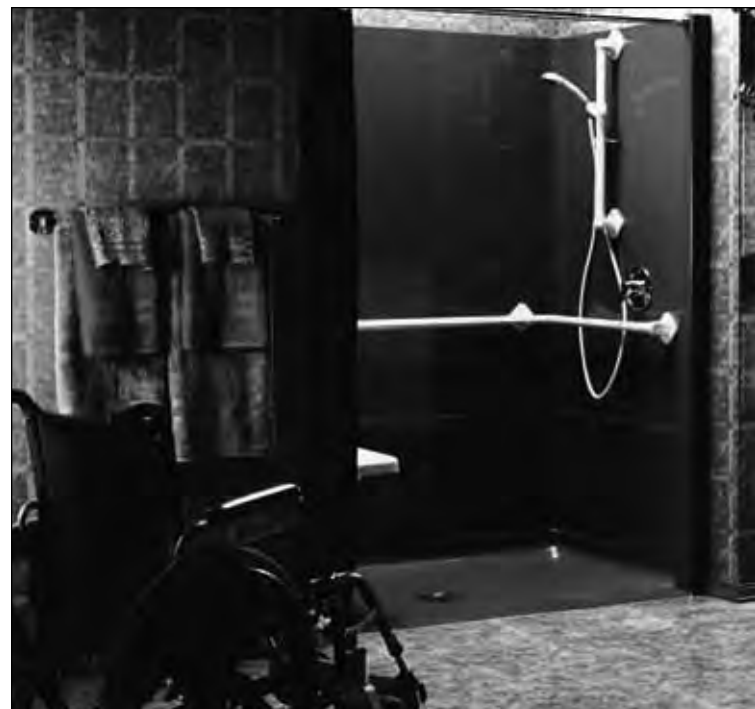
Tub Transfer Boards:

Similar to chairs, this one-piece board spans the sides of the bathtub with one side that juts slightly beyond the edge of the tub. A bather must be able to sit up independently.

Showers

Roll-In Showers:

Roll-in showers usually have three walls and one open side that has a very slight threshold or none at all. This type of shower enables a wheelchair user to roll in and transfer to a bench or chair, or shower in a wheeled shower chair.



The slope of the floor in a roll-in shower is especially important so that water can be properly channeled into the drain. The area inside the shower needs to be carefully designed to allow room for maneuvering a wheelchair or wheeled shower chair. The ADA guidelines for roll-in showers call for a minimum of 30 inches in width and 60 inches in length.

Shower Units:

Prefabricated shower stalls often include features such as grab bars and fold-down benches and can be retrofitted in many bathrooms. One-piece units are available, as are units that come in several large pieces that can fit through the bathroom doorway and be assembled once inside.

Another choice is buying a prefabricated base, and then constructing walls around it, which allows for more opportunity to customize it for your needs and tastes.

Shower Commode Chair:

This type of chair can be used in a shower and also has a cutout seat for personal hygiene and a removable pan for commode use. Or it can be rolled over your commode/toilet. Some models have wheelchair-style design, and others have small casters for mobility. Others have extras like adjustable armrests and padding, and some can fold for storage or travel.

Sinks & Basins

Existing bathroom sinks can sometimes be made wheelchair-accessible by removing cabinets or cabinet doors underneath them. Remember to cover the plumbing with appropriate material to protect against scrapes and burns. Wide and shallow sink basins also enhance accessibility.

Toilets & Bidets

Standard toilets usually can be modified by raising their height, by adding a raised seat or a spacer underneath the base, for example. Safety rails can be installed on either or both sides (toilet safety frames) for added assistance.

A bidet offers a stream of water that provides personal cleansing after toileting. Many bidets can be attached to standard toilet seats, and some models boast remote control, warm water, built-in heaters or natural water features.



Spotlight on Bathroom Fixtures

Accessible hardware or specialized fixtures can transform any shower, sink basin or bathtub, and further enable use by someone with muscle weakness or limited dexterity. Single levers that are operable with one hand and that don't require twisting the wrist or tightly grasping the control are ideal.

Other options include electronic faucets with sensors that "see" when to turn the water on and off. These fixtures are more expensive, but don't require any hands to operate, boast water-saving efficiency and are effectively accessible.

Handheld showerheads, also known as *hand showers*, can also enhance accessibility in bathtubs or showers. Some come attached to a vertical bar so their height can be adjusted to suit you.

Many showerheads and bath fixtures come with an antiscald valve but it can also be added inexpensively to an existing fixture. Or, for an inexpensive alternative, just lower the heat setting on your water heater.



Always check your sink's current faucet spread and placement before purchasing new fixtures (most are center-set with a 4-inch or 8-inch spread).

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Chapter 4

Mobility & Support Equipment



MAINTAINING INDEPENDENCE

As your leg weakness progresses, your health care team may recommend equipment known as *ambulation aids and bracing* to help you with walking. Other devices can help give you needed support as the muscles in your neck and arms weaken. The specific aid or device that's best for you depends on the extent of the weakness and your willingness to use such a device.

The use of an ambulation aid doesn't mean you've given up. On the contrary, it means that you want to remain independent and mobile as long as possible. Braces, canes and walkers can help you continue to walk some of the time or in certain environments while greatly reducing the fatigue and the risk of falling that walking may bring.

Doctors advise that it's important for you to continue to walk as long as doing so is safe and you're confident that you won't fall. For some, this means having an attendant or using an assistive device when walking short distances and a wheelchair when traveling longer distances. For others, it means walking more slowly and resting frequently during normal activities, and using a wheelchair only for long distances.

Your *physical and occupational therapists*, along with a specialist in bracing called an *orthotist*, can show you the available options and how to use them. Your doctor or PT probably will suggest when it's time to begin thinking about ambulation aids, and then you'll want to call on these specialists to help you decide which device to use. (See Chapter 1 for a description of the role of the occupational therapist.)



An orthotist can help you fit any of the braces described in this chapter, but you'll need a PT or OT to advise you on which type is best and how and when to use it.

THE ROLE OF THE PHYSICAL THERAPIST

A physical therapist is a gross motor movement specialist — someone trained to help you perform activities that use major muscle groups, such as walking, rising from a chair, and getting in and out of bed (see Chapter 7). Physical therapists also are involved in prescribing appropriate exercise programs (see Chapter 8).

Their primary goal is to keep you safely functioning at as high a level as possible for as long as possible.

Your PT's services can help improve mobility, relieve pain, and delay or limit development of permanent physical disabilities. With these techniques PTs can help you restore, maintain, and promote overall fitness and health.

At MDA clinics, PTs who are experienced in working with people with ALS are on staff or available by referral. The PT will become an important part of your health care team.

At various stages during your life with ALS, a PT will assess your level of function by performing evaluations and tests. This may include testing to see how strong you are, how flexible you are, and/or a balance assessment. Based on these assessments, the PT can advise you on appropriate equipment usage, such as what types of assistive devices are best for you in several areas of your everyday life.

They also will assess your home environment to make sure you can safely move about and function there (see Chapter 3). They may make suggestions regarding bathroom safety and home modifications.

Physical therapists also will assist you with your choic-

es of equipment to help you walk, move or maintain your mobility level, including a wheelchair.

Choosing a wheelchair can be difficult. There are many types of wheelchairs and feature options available. Discussing your needs and questions with your PT will help her recommend the best chair and the most appropriate features for you.

LEG BRACES

Weakness of muscles controlling the foot causes foot drop. In that situation, you can't lift your foot or toe at will. When this occurs, you may be more prone to tripping, have difficulty climbing and descending stairs, and be



at risk for ankle sprains and other injuries. You also may notice a slapping sound when you walk, or that lifting your knee a little higher than usual causes fatigue.

This condition can be complicated by tightness and contractures in the plantar flexors — muscles in the feet and ankles that aid in such functions as pushing the body forward when you walk or run. Specific braces for the foot and leg can help remedy this problem.

An ankle-foot orthosis (AFO) is a lightweight leg brace that stabilizes the ankle and adds steadiness when you're walking. It can be slipped into most styles of shoes and concealed by wearing a sock over the brace, but it's best worn with a supportive tie-up shoe.

A properly fitted AFO will hold the foot in a functional position, and allow the user to walk with less fear of falling.

Today's AFOs are usually made of durable, lightweight plastic and some also combine lightweight metals such as aluminum. The design usually stabilizes the ankle at 90 degrees. A custom-fitted AFO is best, and you must have reasonable strength in your quadriceps muscles to be able to walk with them on. AFOs are usually worn only during the day and not while sleeping.

Leg edema (swelling) can be a problem for AFO users, but wearing compression stockings or elevating the legs can reduce puffiness and keep braces fitting comfortably. At times, high-top shoes, cowboy boots or sneakers may offer you adequate support to delay the need for bracing.

As ALS leads to shrinkage, or atrophy, of muscles, your AFOs may need to be adjusted to ensure stability. If you notice

a change in the fit of your AFOs, contact your orthotist. Don't wait for your next clinic visit.

HEAD AND NECK SUPPORT

Weakness in neck muscles is another common problem that occurs with ALS. The resulting difficulties in controlling or holding up your head can lead to excessive fatigue and discomfort, not to mention frustration. Cervical collars (neck braces) can provide appropriate support.

A physical therapist or doctor should help determine which muscles in your neck are weak and require support, and what type and size of collar is best for you. Keep in mind that your needs may change and you could require a different brace as muscle strength deteriorates further, or different muscles become affected.



Cervical collars come in a variety of styles, sizes and prices. They range from the standard, all-foam designs to those made from plastic-and-foam or foam-and-metal frame combinations. Different styles provide varying degrees of support; some styles are more adjustable, and others have frames that extend down to the shoulders.

A cervical collar should be comfortable to wear and provide support but not so tight it chokes or restricts breathing. It also should be worn only intermittently and never while eating, as the collar may hamper your ability to swallow. Price and aesthetics are considerations when selecting a brace, as well as whether the padded material is comfortable and doesn't irritate your skin.

Another option for gaining support for the head and neck is a specially designed headrest (some include a head strap for stability). These are found on many wheelchair seating systems. This is an important accessory that you may not need initially, but you'll want to be sure it can be added to your wheelchair later.

HAND SUPPORT

Bracing options also are available for the wrists, hands and fingers, as well as the upper extremities (arms). Again, a PT, OT or doctor can determine what type of support will enhance your comfort and abilities.

Some braces or splints of particular interest to people with ALS include: wrist-hand cock-up splints (holds the wrist at a slight extension), resting splints (for functional and/or resting positioning of wrist, fingers and thumb),



finger extension splints (holds finger in extended or slightly bent positions) and opponens splints (stabilizes the thumb).

In early stages of ALS, an elastic wrist support may suffice.

CANES

A cane can help you enhance the safety and stability of walking by providing an additional point of support. Use of a cane requires moderate strength in your hands and arms.

A cane may be most useful when your balance is minimally impaired or when one leg is significantly weaker than the other. The cane is held on the "good leg side" of the body, and has the effect of shifting some of the body weight away from the weak side and allowing a wider base of support. For example, if you're



experiencing weakness of the left leg, the cane should be held in the right hand.

With minimal practice, the pattern of walking with a cane usually will feel and appear smooth and natural. Instruction by a PT will ensure correct use.

The general pattern for using a cane is to:

- Move the cane forward and out to the side.
- Move the weak leg up even with the cane.
- Take a step of equal size with the strong leg.

Horizontal Grip Cane

If you have hand weakness, a horizontal grip cane rather than the usual hook grip cane is recommended. The horizontal handle allows for a secure grip and an increased weight-bearing surface for the hand.

Quad Cane

The quad cane, so named because it has four feet, provides more stability than a straight cane. This cane is available in two basic sizes — large base and small base. You can let go

of the cane without concern that it will fall or slide to the floor. This kind of cane can be heavy so you may need to use it sparingly.

Cane Fitting

With the cane alongside the toes, the top of the cane should be aligned with the wrist. This allows a 20-degree to 30-degree elbow bend when the cane is used.

In addition to these practical choices, an Internet search will reveal canes and walking sticks made in a variety of attractive colors and decorative styles.



WALKERS

If your physician or therapist feels that a cane is no longer adequate to compensate for your leg weakness or isn't appropriate, he or she may recommend a walker. Use of a walker requires moderate strength in your hands and arms. A walker may be most useful when your balance is only moderately impaired or when both legs are affected by your ALS.

Again, a PT should show you exactly how to use your walker, but in general you'll:

- Move the walker forward, placing all four legs down at once.
- Move the weaker leg forward.
- Take an equal-size step with the stronger leg.

Walker Fitting

Standing in the walker with the cross-bar in front, you should find the level of your wrist when your arm is relaxed at your side at the top of the handgrip. When you're grasping the handgrip, your shoulders should be level and relaxed, and your elbow flexed to 20 or 30 degrees.

Rolling Walker

The most commonly prescribed walker is one that's been fitted with wheels. You can use this type of walker when your arms are too weak to lift and maneuver a standard walker.

Wheeled walkers (rollators) come with two, three, four and more wheels. Some models include locking brakes for

safety. Still others offer a bench for sitting, and most can be folded for storage. They're made of lightweight metals such as aluminum for easy portability.

A rolling walker provides a sensation similar to that of walking with a shopping cart. It allows a more normal gait than a standard walker and enables you to move with less fatigue.



SCOOTERS

A motorized scooter can be helpful when walking long distances is no longer practical. Scooters can be used only by a person who's able to sit upright for an extended period of time, and has some arm strength and dexterity, but tires easily after walking a distance.

Some people with ALS find them useful for things like trips to the shopping mall, long walks outdoors, or even for getting around the house. For many, a scooter is an ideal step between being fully ambulatory and needing a wheelchair. However, your ALS health care team may be reluctant to prescribe a scooter if you can't sit upright.

Scooters are usually powered by rechargeable batteries, boast versatility, can be easy to maneuver and carry a smaller price tag (about \$1,500 on up) than a power wheelchair.

SPECIAL NOTE: Know that if you want to purchase a scooter, most insurance plans (including Medicare) will only pay for a power wheelchair about once every five years. Motorized scooters are lumped into the same category as power wheelchairs. If you use this benefit for a relatively low-cost scooter, your insurance may not pay for a pricier power wheelchair when you need it. Plan ahead, and consider buying the scooter out-of-pocket or borrowing one.

Scooters often can be borrowed from MDA's equipment loan program or rented, since they don't require as much



specific fitting and positioning as wheelchairs do. For the same reason — the lack of fitting options — you should ask your doctor or physical therapist whether using a scooter is advisable for you.

Some PTs don't recommend them at all for people with ALS.

Scooter Varieties

There are several options to choose from when buying a scooter: three- or four-wheeled models; scooters designed for indoor, outdoor use or both; heavy-duty models designed for rugged outdoor terrain and carrying heavy loads; and light-weight travel models.

Scooters meant for indoor use are usually three-wheeled, feature front-wheel drive for optimum maneuverability, and have tires that won't mark up floors. Heavier outdoor models often

have four wheels and rear-wheel drive for better traction. Both types usually have adjustable chassis, armrests and seats, and come in models designed for specific body types such as taller, shorter or large-framed people.



Travel models are made of ultralight materials, and are designed to disassemble into several pieces for transporting, for example, in the trunk of a car. Some models are designed to collapse and fold for storage in a car, boat, airplane or train.

If you decide to get a scooter, be sure to deal with a qualified supplier such as one recommended by your health care team or a company that advertises in MDA's magazine, *Quest*.

WHEELCHAIRS

Excessive fatigue, unsteadiness, difficulty rising from a chair and occasional falls are indications that you need more support than what's provided by a walker or braces. If you tire when sitting without support or have extensive arm weakness, a scooter probably isn't feasible. The help you need can be in the form of either someone assisting you when you're walking or your using a wheelchair, at least part of the time, as a mobility aid.



Remember, a wheelchair represents an opportunity for you to remain less dependent rather than more dependent. When decreased endurance and weakness prevent you from being up and about for extended periods, you'll be able to keep going by using a wheelchair to enjoy the activities that are important to you. You can continue to attend social outings, shop at the mall, perhaps go to work, or participate in activities that would require a moderate amount of walking — without having to depend on someone to assist you.

One of the main reasons doctors advise using a wheelchair is to prevent falls. Injury from a fall not only may cause considerable pain and discomfort, it also may lead to serious trauma or injury that could require immobilization of an arm or a leg and accelerate



atrophy and irreversible weakness in the involved muscles. Think of the wheelchair as an ally that will allow you safety as well as freedom and mobility.

You should decide which chair is right for you in consultation with your doctor, physical therapist, and sometimes a seating and positioning specialist. These experts will help determine the type of seating, back support and other features you need, and your doctor will write a prescription for the type of chair you and your team decide on.

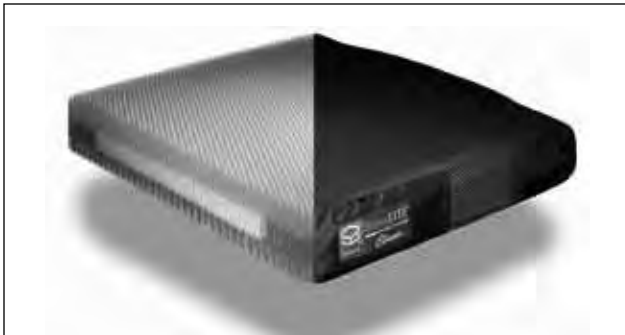
MDA and other programs have wheelchairs to lend, but be sure your medical team approves of the one you borrow. Using the wrong wheelchair can be uncomfortable and even harmful. You can't simply choose one that someone else has or that's featured in a television ad. Getting the right chair for you can



mean all the difference in comfort and mobility.

Private and government health insurers generally regard wheelchairs as necessary medical devices and cover all or some portion of the cost. But some insurance programs have restrictions on the kind of chair they'll provide.

When you get your chair, the experts on your health care team will make adjustments to ensure it fits you correctly. They'll teach you how to adjust the chair's armrests and footrests, operate the brakes and maneuver the chair. Having the chair and cushion fitted correctly and fine-tuned for you can save you a great deal of energy and discomfort.



SPECIAL NOTE: Don't postpone looking into your first wheelchair because of embarrassment or other feelings. It can take several months to order, fit and settle the funding for the correct chair, so you need to plan ahead. The sooner you get started using the chair even for short periods of time, the more mobility and freedom you'll have and the more muscle strength you'll save.

Manual Wheelchairs

Depending on how your abilities are affected by ALS, a manual wheelchair



might be of limited use — or it may be just right. In either case, advances in technology have made these chairs lighter and more portable than ever before.

Maneuverability of manual wheelchairs has improved in recent years. Now, with add-on components such as extra-durable tires or shock-absorbing caster wheels, manual wheelchairs can even be used for venturing off the pavement.

Although buying a manual wheelchair isn't as complex or expensive as selecting a power chair, it's wise to work with a qualified expert — or even a team of experts — to find the chair that best fits your body and lifestyle.

These experts can include a certified rehabilitation technology supplier (CRTS) who works in a rehab facility or with a wheelchair retailer, or a PT or OT with wheelchair prescription experience. These specialists also can help you investigate whether your insurance plan will cover both a manual wheelchair, and then a power wheelchair later.



Therapists also can help you learn to maneuver a wheelchair and offer valuable tips for incorporating it into your daily activities.

Power Wheelchairs

Electric or “power” wheelchairs also have seen remarkable technical advances in recent years. Chairs range from standard designs that will cover basic mobility needs to high-end models that incorporate features such as standing and off-road driving capabilities. Prices start around \$5,000 and can run into the tens of thousands of dollars for models with multiple features and capabilities.

Obtaining a power wheelchair is a time-consuming process, and ALS experts stress the importance of looking into and shopping for one before you have a need for it. Again, seating and fitting experts who also understand ALS can be invaluable in this process.

Ordering and customizing the most appropriate chair for you can take sever-

al months. Much of the time is taken up securing authorization for payment — which means correctly completing paperwork — with an insurance company or Medicare.

Each type and brand of power wheelchair has its own advantages, so taking test drives and working with someone who’s experienced with wheelchair seating and positioning, such as a CRTS, is essential. You also should consider how different models will fit in and maneuver around your home, office or other places you frequent. Make sure to work with knowledgeable specialists in this process; the staff at your MDA clinic or office can recommend qualified equipment dealers.



As you plan for a wheelchair, also consider your need for items such as wheelchair ramps, lifts, and a wheelchair-accommodating vehicle or van. In addition, if you think you might first use a manual wheelchair and later a power model, be sure that both chairs will be covered by your medical insurance and can fit into your vehicle. Some companies will only pay for one wheelchair.

You and your team of experts should make sure that as your abilities change because of ALS, your chair can change, too. The ideal chair should be able to be adjusted or accessorized so it will continue to be appropriate for your needs.

Where are the Wheels?

Shopping for a power wheelchair can sound a lot like looking for a sport utility vehicle, as you'll hear terms such as *front-wheel drive* and *independent suspension*. Each type of system has its plusses, and often it's a combination of what your doctor may prescribe, insurance and budget limitations, and personal preference that determines the best wheelchair for you.



A main difference between models is the positioning of the larger, driving wheels that are coupled with two or four smaller wheels or casters to help balance and steer the chair. Consumers can choose from front- or rear-wheel *drive systems*, and the most recent innovation, a mid- or center-wheel drive wheelchair. Generally, the type of driving



system will determine the wheelchair's maneuverability, and dictate important details like turning radius and the feel (smooth or bumpy) of the ride.

Another difference is the *operating system*, or how the chair is controlled. Most chairs operate with a joystick that the user moves in the direction he or she needs to go. For those who can't maneuver a joystick control, most power chairs can be customized to incorporate systems that use alternatives such as head controls, foot controls, or touch pads for driving.

If you can no longer operate the chair yourself, controls can be moved or modified so a caregiver can easily reach them. For example, on



some models, a joystick can be attached to the back of the chair so it's within easy reach of the caregiver.

More Customizing Options

Because people with ALS require wheelchairs that can adjust to their changing needs and abilities, many find a power wheelchair that includes a versatile positioning system ideal. The abilities to tilt, recline or elevate when needed are standard in some brands and add-ons for others. The combination of tilting and reclining also offers comfort and potential health benefits for people who can't change body positions on their own.



Other accessories, such as headrests, trays, or holders for equipment such as ventilators or communication devices, can often be added to provide greater independence and comfort.

Other innovations on today's chairs include headlight and taillight packages, armrests that flip up or can be removed so you can get close to a desk or table, and seats that raise and lower with a touch of a button.

TRANSPORTATION ISSUES

Whether you're using a wheelchair, walking independently, or relying on other ambulatory aids, transportation outside your home will likely become an issue because of ALS. Eventually, muscle weakness makes driving inadvisable, and thus a person with ALS becomes reliant on others or on public transportation to get around.

Public Transportation

Public transportation such as buses, trains, subways and taxis can be viable options, depending on the size of your city and the accessibility of the system. Another option is paratransit services, which provide vans or buses specially equipped to transport wheelchair users and other people with disabilities.

Some accessible transportation services are private and some are publicly funded; check in your phone book under Wheelchair & Special Needs Transportation, or Taxicabs.





Your right of access to public transportation is guaranteed under the Americans with Disabilities Act. Depending on your community, you may hear horror stories about physical barriers; improper or unavailable accessible equipment; poorly trained staff;



and unreliable service. On the other hand, you also may hear how others use some form of public transportation daily and have remained independent and involved with their careers.

Many people don't let ALS prevent them from getting around, traveling abroad, and staying involved in their communities. Planning, information gathering, advocacy and persistence can help get you where you need to go.

Disabled Parking Placards

Obtaining a placard or license plate that allows you to park in "handicapped" or disabled parking spots is something to consider, even when you're ambulatory. Parking closer to an entrance or facility can greatly minimize energy expenditure and anxiety on outings.

Applications for these permits usually require a physician's signature. Many doctors' offices stock the necessary paperwork, or have information on hand about how to obtain one. Don't hesitate to ask about this accommodation soon after your diagnosis.

Long-Distance Travel

Travel by airplane, train, boat and cruise ship is no longer unthinkable for people who use wheelchairs, scooters or



require other assistance. Airlines, cruise ships and other transportation companies are becoming more aware of their customers with disabilities, and many have taken broad steps to accommodate this population.

That's not to say that such travel will be glitch-free; the keys to a successful trip begin with planning and information gathering. For example, make sure you get information on what modifications have been made for accessibility (one grab bar in the shower doesn't mean a hotel room is accessible). Find out about restroom accommodations, doorway width, type of bed, etc., before you make

a reservation.

For air travel, learn the airline's policies and procedures for passengers with disabilities, and for mobility and respiratory equipment. Most have appropriate procedures in place, but communication breakdowns or ignorance of the policies by employees often lead to problems or damaged mobility equipment.

To ensure wheelchair assistance at connecting gates and your final destination, consult with the gate agent prior to boarding the plane.

For further advice, there are several books, Web pages and magazine articles available on this subject. See Chapter 10.

Spotlight on Accessible Vans

Purchasing a converted or accessible van can be an expensive option, but also one that can enable the greatest independence during every stage of ALS. It's a purchase that requires careful research to find a van that fits you, your lifestyle, parking area, wheelchair and budget.

Conversions can be done on a variety of new and used vans.



Modifications can range from simply adding a seat that turns and lowers to help a person get in and out, to a complete conversion that includes installing a ramp or lift system for a wheelchair user. A handful of other vehicles can be converted for wheelchair access, but vans are the most popular.

Be aware that only certain makes and models of vans can be converted. You also must choose between full-size or minivans, and side- or rear-entry designs. Then you have to factor in the height, size and weight of the wheelchair plus its user, and more. Van shoppers can buy from a mobility dealer or directly from a manufacturer.

The van should have wheelchair tie-downs and a restraint system for safety. Scooter users should transfer into passenger seats.

If you're planning to buy or rent a van, check Chapter 10 for resources for finding mobility experts in your area.



Connect Online with the
ALS Community!



MDA's free online community — **myMDA** — is for everyone affected by ALS. Its goal is to facilitate the sharing of life-enhancing information in an environment of trust and support.

After registering, you'll be able to join a variety of peer- and ALS-specific groups; upload photos and videos; blog; post and view topics on message boards; and chat with members. (Must be 18 and over.)

Members can offer a wealth of information on their life experiences with ALS — the e-community allows sharing of that information for the benefit of the entire MDA community.

myMDA features:

- disease-specific groups
- message boards
- photo & video sharing
- blogs
- chat rooms

Join **myMDA** today!

www.mda.org/myMDA

Strength in Community

Chapter 5

Respiratory Issues



HOW DOES ALS AFFECT BREATHING?

Respiratory problems are perhaps the most serious of medical complications in ALS. Breathing difficulties occur from the gradual deterioration of muscles involved with breathing: the *diaphragm* and the *intercostals*.

The diaphragm is an arched muscle located just beneath the lungs

that moves up and down and allows air to come in and move out. The intercostals are muscles between the ribs that contract and relax and also assist with air movement.

As ALS weakens these muscles, you'll become conscious of the act of breathing, which is normally automatic, and it will consume additional energy.

Weakening respiratory muscles may increase your fatigue levels and deplete your energy. The effort to breathe, when these muscles aren't functioning well, is hard work.

Weakening of the respiratory muscles can also challenge your ability to respond to the stresses of colds, flu or pneumonia — illnesses that are caused by bacterial or viral infections. Pneumonia also may be caused by aspiration of food or fluid into the lungs, which can be caused by weakened muscles.

But, as in many other areas, new knowledge and technology make it possible for you to work, travel and continue with normal activities while obtaining the help you need with breathing.

MDA health care experts recommend that people with ALS get a flu vaccine in the fall, get a pneumonia vaccine, and be familiar with the symptoms of pneumonia:

- coughing
- sputum production (may be clear, yellow or green)
- chest discomfort with breathing
- fever/chills

People who are having difficulty with liquids (choking or coughing) should use a thickener (such as ThickIT or SimplyThick) in their diets to prevent aspiration of fluids into the lungs.

SPECIAL NOTE: As your respiratory muscles weaken, your neurologist may refer you to you a pulmonologist, a doctor who specializes in issues related to the lungs and respiratory system. Be sure this specialist understands that

your breathing problems aren't caused by problems with your lungs; they're caused by weakness of the muscles that operate the lungs. Treatments for these two types of conditions are quite different.

Your best approach is to have your ALS physician communicate with the pulmonary specialist, and to work closely with a *respiratory therapist* who's familiar with ALS.

THE ROLE OF THE RESPIRATORY THERAPIST

The respiratory therapist on your ALS health care team is responsible for obtaining measurements of your respiratory function and instructing you and your family in the use



of therapeutic measures and equipment prescribed by the pulmonary specialist. The importance of careful monitoring of respiratory function and proper instruction in therapeutic measures is essential in the overall care of people with ALS.

Your RT or pulmonary specialist will measure the *forced vital capacity (FVC)* (total amount of air that can be moved in or out of the lung). This can easily be accomplished by exhaling into a spirometer. The FVC is easy to perform and is a meaningful indicator of changing respiratory status in the person with ALS.

Evidence of respiratory involvement might include:

- shortness of breath with or without exertion
- increased lethargy or loss of energy
- poor cough
- difficulty breathing while lying flat
- headaches, especially when you awaken

If any of these symptoms occur frequently, you need a medical examination of your respiratory status.

The RT assists in the instruction of therapeutic measures ordered by the pulmonary specialist such as incentive spirometry, assistive coughing and breathing exercises, suctioning, intermittent positive pressure breathing, and postural drainage.

The therapy of respiratory dysfunction in ALS is primarily aimed at general supportive measures. Considerations may include ventilatory maneuvers (voluntary or positive pressure) to prevent atelectasis (lung collapse), a cessation of smoking program, instruction in maintaining nutrition and prevention of aspiration, flu vaccinations, and medications to

decrease the work of breathing.

If oral or pharyngeal secretions (from the mouth or nose) become excessive, drugs that decrease saliva production or suction devices to remove secretions may be beneficial. If low blood oxygen levels are documented, supplemental oxygen may be given. All infections should be promptly treated.

ASSISTED VENTILATION

Breathing, meaning the exchange of oxygen and carbon dioxide that normally occurs, may become less effective for you in advanced stages of ALS. The result may be respiratory distress, which has many symptoms:

- the inability to sing or shout
- the inability to cough or sniff hard
- the ability to speak only in short sentences
- apparently labored breathing



- use of muscles in the neck or abdomen to compensate for a weakened diaphragm
- headaches at waking
- excessive daytime sleepiness
- exhausted appearance or weight loss owing to retained excess carbon dioxide

Before these respiratory complications emerge, your doctor will probably begin to discuss various methods and steps of respiratory support — *ventilation*. There are more options for assisted breathing today than ever before, some that can prolong life for several years.

Some experts say that assisted ventilation is the single most significant factor in the increased life expectancy of people with ALS in recent years.

You should give the question of ventilatory support serious thought in advance and put your wishes in writing so they'll be known to your caregivers and medical team if you have a respiratory emergency. You may want to state your wishes formally in a *medical directive*; you can alter this document any time you change your mind.

Ventilators are now small, portable and quiet, but maintaining a person with one at home can be very expensive and taxing on caregivers.

Remember that your health care team and other professionals at the MDA clinic are there to help you understand your options and answer your questions as you make difficult decisions about ventilation. Be sure to discuss this subject in detail, including the options described here, so you can make your choices clear to your doctor and loved ones.

SPECIAL NOTE: It's wise to think ahead about your choices and needs for respiratory help. Without planning, you could experience a respiratory crisis and have to make important decisions in an emergency situation.

TYPES OF VENTILATION AND EQUIPMENT

Noninvasive

This form of ventilation has seen several advances and wider use in recent years. Noninvasive devices don't involve surgical invasion of the body. Many times, ventilators can be used for several hours a day or just during sleeping hours. People with ALS whose bulbar (mouth and throat) muscles are extensively weakened, however, may need more extensive ventilation solutions.

There are several forms of noninvasive ventilation. One is *pressure-cycled* vent machines, which deliver air at a set



pressure level with a variable volume of air on a timed cycle.

A CPAP (continuous positive airway pressure) machine is *not* indicated in ALS. CPAP increases the work of breathing by forcing the user to exhale against resistance. This can be dangerous for those with ALS.

A BiPAP machine, on the other hand, is often prescribed in ALS. BiPAP (the trademark name of a machine distributed by Respironics) is short for *bilevel positive airway pressure* and delivers air at two pressures, one for inspiration and one for expiration (inhalation and exhalation). A number of nasal or face masks and attachments are available, and can be customized for the best fit.

Volume-cycled ventilators deliver a pre-set amount of air. Volume vents can deliver air in far greater pressures and volumes than pressure vents can. Although these machines were traditionally used only with invasive interfaces



(such as a tracheostomy, see below), some doctors now prescribe them for use with a mouthpiece, nasal or face mask.



Another noninvasive form of ventilation uses *negative pressure* through a corset-like device that wraps around the chest and creates negative pressure, allowing the lungs to expand. With negative pressure applied on a timed cycle, the lungs inflate and deflate alternately, as in regular breathing. This is the same technique that was used years ago in “iron lungs.”

Invasive

Invasive ventilation is delivered via a *tracheostomy*, a surgically created hole in the trachea (windpipe) through which air is forced. The tube through which the



air is delivered also is called a *tracheostomy (trach) tube*.

A ventilator delivers air on a timed cycle through the trach, and ensures that you'll take a mini-

imum number of breaths per minute. Many ventilators can then be adjusted to respond to the person's own efforts to breathe, or to completely override these efforts. The decision to start tracheostomy-delivered ventilation is often a permanent one because it's usually impossible for people with ALS to recover the ability to breathe on their own.

Many people with ALS ultimately need a trach because of the weakness of the mouth and throat (bulbar) muscles. Invasive ventilation is thought to be a more reliable means of delivering air to the lungs when the disease is advanced. But one important drawback of a trach is that it interferes with the body's normal mechanisms for clearing the respiratory tract of mucus. Various solutions can



combat this problem.

Not everyone with ALS will need or choose to have a tracheostomy, but there may come a time when it's necessary for continued breathing.

In addition, most people relying on invasive ventilation will need humidification because the nose, through which air is normally moisturized, has been bypassed.

COUGHING AND CLEARING SECRETIONS

Coughing and clearing secretions from the lungs are activities that most people do automatically.

Normally, the lungs constantly move excess mucus and inhaled particles up toward the mouth to a spot where they can be coughed up.

As ALS advances you may eventually have difficulty coughing and clearing your throat because of weakened abdominal and throat muscles. Material that would normally be coughed up instead will fall back down into your lungs where it can cause respiratory irritation and infection. This may occur whether or not you're using assisted ventilation.

Certain techniques and medical equipment can enable you and your caregivers to create or assist a cough, and then clear mucus secretions from your airway. Talk with your doctor and your RT about these interventions.

Breath Stacking

An RT can show you this technique, which involves closing the throat after each breath taken in through a mouthpiece, and then coughing.

Abdominal Thrust

Caregivers can be taught how to increase coughing efficiency by pressing on your abdomen.

Assisted Coughing Devices

An In-Exsufflator machine delivers a large volume of air into the lungs and then quickly reverses the air flow to pull out secretions, just as a cough would.

An example is the CoughAssist. Used with a facemask, with a mouthpiece or with an adapter to a patient's endotracheal or tracheostomy tube, this machine can be used to clear your airway as needed. This type of machine is often recommended for use in conjunction with invasive ventilation, and can be



demonstrated by your RT.

Another option that's been recently studied for its effectiveness for people with ALS is The Vest. This system uses a technology called *high-frequency chest wall oscillation*. During therapy, The Vest inflates and deflates rapidly, applying gentle pressure to the chest wall. This loosens and thins mucus and moves it toward the larger airways, where it can be cleared by coughing or suctioning.

OTHER EQUIPMENT

Suction Machines

Portable or stationary suction machines can provide appropriate suction for removing the lungs' mucus secretions.

Caregivers must be instructed in sterile techniques for suctioning, which usually involves inserting a tiny tube (catheter) several inches into the trachea via a trach tube. In the absence of a trach, suction devices similar to those seen in dentists' offices can be directly inserted into the mouth. Others can be inserted through the nose via a tube with a soft catheter tip. The tube is attached to a suction machine.

In addition, most people relying on suction machines will need humidification because the nose, through which air is normally moisturized, has been bypassed.

Pulse Oximeter

Oximeters are electronic devices about the size of a small cell phone that measure the amount of oxygen in the blood through a painless sensor that can be clipped to a finger or earlobe. If your RT or pulmonologist finds that your oxygen level is normal (at least 95 percent "saturation") without any supplemental oxygen, it's likely that air exchange (of oxygen for carbon dioxide) is adequate.

If saturation levels dip below normal, you and your doctor have to decide whether the problem is chronic under-ventilation because air exchange isn't adequate, or whether there's mucus plugging the airways.

MEDICATIONS

Bronchodilators

These medications, such as those commonly used to treat asthma (albuterol, Proventil, etc.), dilate (open) the airway and are sometimes prescribed for people with ALS. However, many doctors don't think this type of drug is helpful because it won't improve the muscle weakness that's the source of respiratory problems in ALS.

Expectorants

This type of drug, commonly found in some over-the-counter cough medicines, can thin secretions and make them easier to cough up. Doctors sometimes prescribe them for people with ALS, as well as recommend an increase in fluid intake.

Saliva Management

Weakened breathing muscles, along with weaker muscles in the mouth, in ALS may result in drooling or *sialorrhea*. This isn't a case of excessive saliva production; it occurs when you're unable to swallow saliva as well as before. There are several medications and other treatments that your physician may suggest to control drooling.

Spotlight on Feeding Tubes

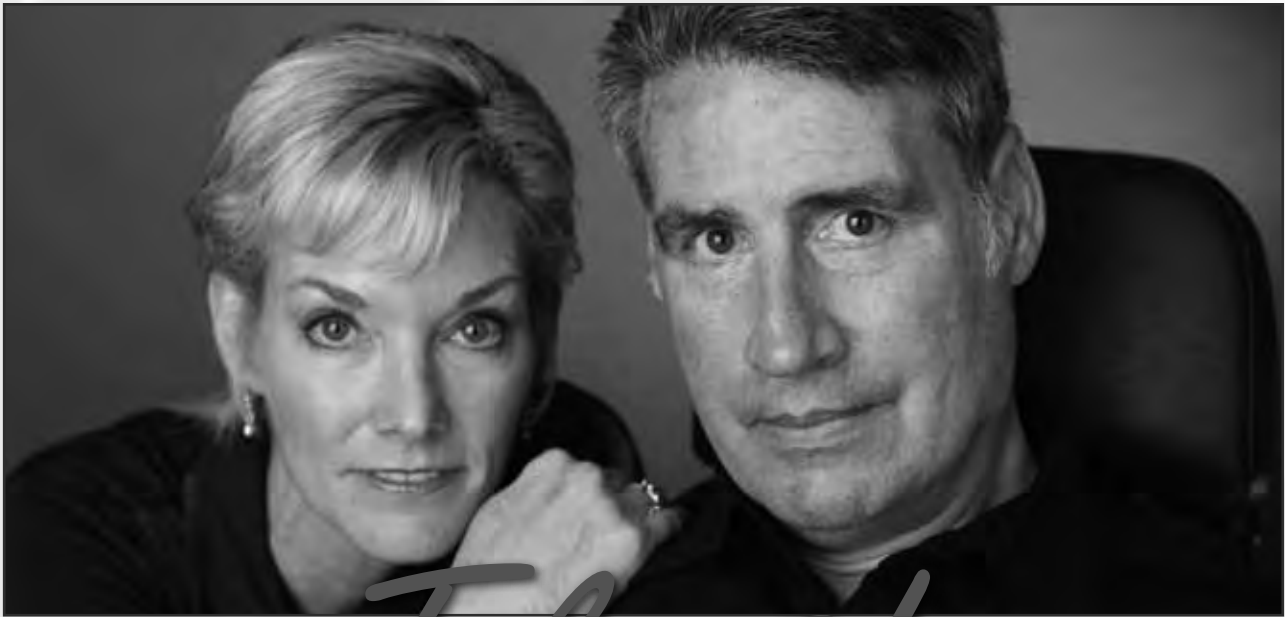
Insertion of a percutaneous endoscopic gastrostomy tube, commonly called a PEG tube or a feeding tube, sometimes coincides with respiratory support in ALS. This intervention may be necessary to prevent choking episodes and to enhance the ease of feeding if swallowing problems are present. A PEG tube delivers food directly into the stomach from the outside and not down the throat.

As a result of bypassing the mouth, a PEG tube can reduce, but may not eliminate completely, the danger of aspirating food or liquid into the lungs. With better nutrition and less energy used for eating, weight loss may stabilize, or even partially reverse, and respiratory function often improves. Ideally, such a tube should be placed before serious respiratory complications arise, and some doctors insist that it's "never too early" to consider a PEG tube in ALS.

Placement of a PEG tube is another personal and important decision that should be made with the help of your ALS health care team. For resources on the topic, see Chapter 10.

Some doctors advocate proactive placement of a feeding tube to prevent any weight loss, choking episodes or nutritional deficits.

For more detailed information about nutrition in ALS, see the *MDA ALS Caregiver's Guide*.



Take 5!

Five Minutes Can Mean a Better Future

This is an exciting and challenging time in national health policy. Now — more than ever — MDA's Advocacy program is a necessary voice for the hundreds of thousands of Americans affected by muscle diseases.

Working together, we can make our voices heard.

Take 5! is an MDA initiative encouraging people to take just five minutes to contact their elected officials in Congress about legislation affecting the MDA community.

It's easy to **Take 5!** Go to www.mda.org/advocacy to find specific information about relevant legislative issues and step-by-step support for advocating by letter, e-mail or phone.

While there, register as an MDA advocate and receive e-mail updates as legislation unfolds.



Go to www.mda.org/advocacy and get started.

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Chapter 6

Speech & Communication



HOW DOES ALS AFFECT SPEECH?

ALS can lead to weakness in the muscles of articulation — the tongue, the palate and the lips — and in those that provide breath support. These changes will eventually affect your speech.

Your tongue, which is composed of multiple muscles, is primarily responsible for shaping the sounds that you make into words. So, with a weakened tongue,

even if you can produce sound, you may come to find it very difficult to form sounds into words that can be understood.

Your *soft palate* (back part of the roof of the mouth) normally works by elevating and closing off your nasal passage and separating your mouth from your nose. When the palate doesn't elevate, as often occurs in ALS, almost all sound will go up into the nasal cavity and be resonated there. This is called *hypernasality*.

The "energy" for speech and for sound is breath support. When you breathe in and prepare to speak, the vocal cords come together and you build up pressure below them. When you begin to speak, they come apart, allowing the air to rush between them and causing them to vibrate quickly, which generates sound.

As the vocal cords weaken in ALS, they fail to separate, and the voice develops a strained and strangled quality.

As ALS progresses, you may have difficulty getting good, deep breaths, resulting in reduced breath support for speech. Without adequate breath support, you'll be unable to talk very loudly or produce long sentences.

THE ROLE OF THE SPEECH-LANGUAGE PATHOLOGIST

A *speech-language pathologist* (SLP) is a health care professional trained to diagnose and treat disorders of speech. Unlike traditional speech therapy that targets oral exercises, the role of the speech-language pathologist in treating people with ALS is to assist in maintaining functional communication throughout the course of the disease.



An SLP also is educated in the assessment and treatment of swallowing disorders. In this role, the SLP works closely with a dietician to help you reduce the risk of aspiration (getting food and liquid in the lungs) and provides recommendations to ensure that you receive safe and adequate nutritional intake.

SPECIAL NOTE: If you see an SLP who wants to give you exercises to strengthen your tongue and mouth muscles, get another opinion. Some people with ALS have exhausted their weakened muscles with these exercises, without benefit. Speech therapy for ALS *never* focuses on strengthening oral muscles. These exercises may be tiring and actually hasten deterioration. Speech drills can be so fatiguing that you could become too tired to use speech for communication.

One of the most disturbing changes in ALS is the progressive decline in speech intelligibility. An SLP familiar with ALS can provide strategies to improve intelligibility and prevent speech fatigue — such as slowing speech, emphasizing articulation and avoiding competing noise.

If your speech reaches the point that others can no longer understand you, the speech pathologist can help you select and learn to use *augmentative and alternative communication (AAC) devices* (see page 81).

Difficulty with swallowing generally accompanies difficulty with speech. You may find that liquids make you cough or that it's hard to chew food and move it around in your mouth. Mealtimes may become lengthy, and fatigue can reduce your ability to finish a meal. This can result in weight loss and malnutrition.

The SLP and dietician may recommend diet changes such as thickened liquids and softer and/or chopped foods. Initially only some food consistencies are affected, but over time it may become difficult to swallow even pureed foods. At that point, your physician may recommend a feeding tube to reduce the risk of aspiration and the pneumonia that may result. (See “Spotlight on Feeding Tubes,” page 75. Also see the *MDA ALS Caregivers Guide*.)

Easier swallowing methods and other advice from your dietician can guarantee that you get proper nutrition, which will enhance both longevity and your quality of life.

The SLP is a vital member of your ALS health care team. The progressive loss of the ability to communicate with family, friends and medical team can be fright-

ening and isolating. But with the help of a speech pathologist, you'll be able to continue communicating through a variety of means.

ASSISTIVE TECHNOLOGY

Our society's achievements with computers and technology in recent decades has been nothing short of astounding. Fortunately, one especially promising segment of this revolution is *assistive technology*: products, devices and other equipment that are used to maintain, increase or improve the functional capabilities of individuals with disabilities.

This broad definition can apply to even the simplest items you read about in Chapter 1. But in this chapter, we're applying the term *assistive technology* to devices that involve advanced electronic and computer-based technology.

From communication devices that will generate speech to high-tech wheelchairs that can stand or recline, assistive technology can dramatically, positively affect the quality of your everyday life with ALS.

Assistive technology should be an important consideration in your planning and information gathering about ALS, and it's never too early to begin investigating the many choices available. For example, the months it can often take to secure funding for a speech-generating communication aid, plus the time it takes to learn how to use some of these items effectively, mean that anticipating your needs well in advance can

prove the difference between adapting to changes in your condition and experiencing enormous frustration.

This chapter describes assistive technology devices that are available at the time of this printing. With technological advances occurring rapidly, there may be newer, and even more sophisticated, equipment available at the time you're reading this. Your SLP can help you select the best devices for your situation.

AUGMENTATIVE, ALTERNATIVE COMMUNICATION (AAC) DEVICES

Team Up With Experts

Your ability to communicate often has a direct impact on independence. When ALS affects your ability to speak, an *augmentative, alternative communication (AAC) device* can help keep you connected with loved ones and able to maintain a higher quality of life.

Such methods as writing notes, asking a loved one to “interpret” your weakened speech and using letter boards may be suitable for a short time in ALS. But they don't offer the independence, speed and variety in communication that come with technology.

If you're shopping for an AAC device, both health experts and device manufacturers agree that your first step should be to consult with a team of experts. You'll want to consult your SLP, occupa-

tional therapist *and* physical therapist.

Some SLPs advise that your *rate of speech*, rather than intelligibility, is the best indicator of your need for a communication device. The SLP can measure your rate of speech, and better predict when the loss of speech intelligibility will require technological intervention.

Together they'll try out many types of devices with you, help you decide what AAC equipment is most appropriate for your lifestyle, and determine how you can continue to use it as the disease progresses.

SPECIAL NOTE: AAC experts who are knowledgeable about ALS stress the importance of not waiting until your speech is affected to start shopping around for a communication device. Shopping early gives you the advantage of time to explore the many systems, plus a chance to become confident and comfortable with the system you choose before it becomes an essential tool.

In addition, planning can allow you to record many phrases in your own voice for using with communication devices after your speech has degenerated.

Quality AAC machines can cost thousands of dollars, but some are covered by insurance (see “Spotlight on Finding Funding,” page 86). Your health care team will help guide you through the complicated funding and insurance process. They also may have information about equipment loan programs or special funding programs to help defray the costs in your community.

When selecting an AAC device, it's very important that you choose one that can

accommodate switches, which you'll probably need as your ALS progresses. The adaptable device will cost more at first but will save money in the long run because it can be modified with switches instead of having to be replaced several times.

AAC Basics

While there's a rapidly growing number of choices in today's market, most communication devices follow the same basic idea: The user inputs the information about what he or she wants to say, and the machine "speaks" it. Methods of input differ, however, and AAC systems differ by design, size and features.

Today's AAC devices include *dedicated* machines designed solely for generating speech or written text, and *software programs* for personal computers.

Specialized computer software can turn a personal computer into a speech generator. EZ Keys by Words+ is a popular program that offers a variety of access options, input methods (such as using one of the mouse alternatives described on page 84) and keystroke-saving features such as word prediction. Most people install the programs on laptop computers for added portability.

Variety of Systems

Most communication devices are designed to be portable and durable. They're generally the size of a laptop or smaller, with handheld or palmtop devices a recent innovation. But beware: Though handheld or palm computers may be attractive, their small size may soon make them unmanageable to a person with ALS.



In addition to the type of machine, AAC users also must choose a type of system:

- *symbol-based*, in which the user selects from categories of symbols and pictures to form a sentence
- *text-based*, in which the user inputs text, codes or abbreviations that are converted into speech
- *text-to-speech* machines, in which you can type a sentence and the computer "speaks it."

Switches

These are another important element of AAC and other types of assistive technology. If a user's physical ability changes, often so must the input method for using an AAC machine. For example: If you lose the ability to type on a traditional keyboard or click a mouse, you might still be able to activate a switch by tapping a button or moving a joystick to perform the same functions.





Switches, too, span a wide range of technology, from simple *plug-in buttons* to high-tech *eye-tracking systems* that follow eye movement to activate a selection. Wireless sensors/switches, which can attach to virtually any part of the body, read electrical impulses from the slightest muscle movements and translate them into mouse clicks.

Keystroke-Saving Features

Encoding:

This is a process of creating codes, abbreviations or labels to represent a letter, item or message. Example: Typing “HH” might stand for “Hello, how are you?” on one brand of machine, or touching one button might do the same on another machine. Most AAC systems use some form of encoding or *abbreviation expansion*.

Scanning:

This method of selecting items in a communication system is usually coupled with switches. Scanning programs highlight rows or sections of choices

on a screen in sequence, and the user activates the switch when the correct choice is highlighted.

Word Prediction:

Based on one or two letters, the system tries to guess the rest of the word the user is typing, and offers a list of letters that would go with letters already entered.

COMPUTER ACCESS

Assistive technology isn't confined to generation or replacement of speech. It gives people with limited muscle strength or abilities many options for accessing personal computers and thus e-mail, the Internet and other programs. Here are some basic specialized equipment (hardware) and programs (software) that help make this possible.



Hardware

Mouse Alternatives

Computer users don't always need to control a traditional mouse to move a cursor or input information into a computer. Some alternatives of particular interest to people with ALS include:

Eye Tracking (Eyegaze):

This system tracks eye movements to control a cursor and put it where the user is looking. Signals such as dwelling in one place or blinking activate mouse clicks.

Head Mouse/Tracker:

The user wears a reflective dot sticker on the forehead, and a special mounted camera tracks the dot and controls the cursor according to the user's head movement. This approach is ideal for those who have limited use of their hands, but retain some head and neck control. The user can access all computer functions when used in conjunction with special software and onscreen keyboards.



Trackballs: The user rolls a ball with the palm instead of moving a mouse to control a cursor. Click buttons are usually separate but situated near the ball.

Joysticks:

The user tilts a stick-shaped lever to control a cursor.

Touch Screens:

Touching these plastic screens with a

pointing device or finger can activate the same functions as a mouse.

Keyboard Alternatives

Nontraditional computer keyboards come in many forms.

Ergonomic Keyboards:

These are intended to reduce user fatigue; some are designed to require little strength or dexterity to use.

Keyless Keyboards:

Taking the ergonomic idea even further, for example, the Orbitouch by Keybowl has the user rest his or her hands on two domes, and then slide the domes into different positions to "type" each letter.

Onscreen Keyboards:

Another option is software programs that interface with most software. Some programs are designed to reduce keystrokes, such as StickyKeys, which eliminates the need to press and hold multiple keys simultaneously.

Software

Voice/Speech Recognition

This realm of software enables hands-free use of a personal computer. Users can control many standard computer





functions by voice command, and use dictation as a substitute for typing. These systems require a microphone, with higher-quality microphones usually yielding better accuracy.

Software programs such as Dragon NaturallySpeaking or IBM ViaVoice are appropriate for people with ALS who are unable to type on a computer, but can speak clearly. If possible, this type of technology also should be explored with the assistance of a speech-language pathologist or an occupational therapist.

ENVIRONMENTAL CONTROL UNITS

Another form of assistive technology of interest to people with ALS is the *environmental control unit (ECU)*. These devices allow you to control electrical appliances or systems in your environment. Again, PTs and OTs can help you explore this technology.



ECUs offer a wide variety of options to give you more independence. For exam-



ple, an ECU can be programmed for jobs such as switching channels on the TV set, turning on lights, controlling video or audio systems, adjusting a thermostat or enabling a home security system.

Generally, ECUs can be stand-alone units or software packages for personal computers. Some AAC devices include features that allow you to interface with or control devices around you, such as a telephone or intercom.

Some systems use simple plug-in units with switches, while others employ infrared, wireless or even speech-recognition technology for advanced access. As with many devices, the level of technology will dictate the price, which can range from under \$100 for a one-switch unit to thousands for more complex units.

Spotlight on Finding Funding

Although higher-tech devices often mean higher prices, there are also many options available to help you obtain, learn about and use such technology, despite the cost. In fact, Medicare and many insurance companies cover items such as communication devices; your MDA equipment loan program may have an AAC device you can use.

Check with your insurance company for its guidelines on *medical necessity* for speech devices; they vary from one company to another, and the key to getting coverage may lie in properly completing the paperwork. For instance, if you're unable to speak and a device is necessary to communicate your needs, it gen-

erally will be considered a medical necessity by insurance guidelines.

Manufacturers and vendors of assistive technology equipment also can be useful funding resources. Some have departments or staff members whose job it is to navigate the world of private insurance, Medicare, regulations and paperwork so that you can buy their products. Funding information also may be offered through state vocational rehabilitation departments and local independent living centers.

As noted earlier in this chapter, choosing the most adaptable device will save you money in the long run.



Create Your Own Caregiving Community

MDA is proud to offer *myMuscleTeam*, a free and simple way for MDA families to receive strength from a personally created community — their “Muscle Team” of family and friends. Users can create private, secure *myMuscleTeam* Web pages, which offer two primary services.

First, families can post photos and journal entries to keep friends and loved ones updated on medical matters and other aspects of their lives. It’s a great way to update everyone simultaneously, as opposed to the stress-filled and time-consuming process of calling each friend and family member to tell and retell the latest news.

And, families have access to a “care coordination calendar,” where you and/or your primary caregiver can post items for which assistance is needed, such as transportation to medical appointments, meal preparation, household chores and more. That way, family, friends and loved ones can sign up to help. Privacy and security settings enable you to control which family members and friends are permitted access.

For more information and to see how *myMuscleTeam* works, go to www.mda.org/mymuscleteam.

Chapter 7

Transfers



MOVING WITH HELP

At various stages in your life with ALS, transfers — moving you from one surface to another — may require no assistance, the assistance of one other person, the assistance of several people or the use of special equipment.

The degree of your weakness at each stage of ALS will determine the type of transfer necessary and the number

of people or type of equipment required to perform the transfer. It's imperative that your safety and the safety of your caregiver be the top priority in this process.

The instructions in this chapter are addressed more to your caregiver than to you, as the person with ALS, for self-evident reasons. Nonetheless, you'll want to be aware of these techniques so you'll understand the procedures, direct the transfers in some cases and anticipate the movements in the process.

(By the way, for simplicity's sake, this chapter often refers to the person with ALS as "he," but of course the same information applies whether you're a man or a woman.)

Transfer techniques should be taught to your primary caregivers by a physical or occupational therapist. The therapist will assist you and your caregivers in deciding upon the most appropriate transfer methods. Any time you're having trouble with transfers, your health care team can answer questions and help with techniques and equipment.

Keep in mind that all transfers take some practice. With experience, your caregiver soon will be able to do them with ease.

SPECIAL NOTE FOR CAREGIVERS:

The following descriptions are general guidelines. Review them with your health care team to be sure they apply to the person you're caring for. Transfer needs can vary among individuals, and for safety's sake you should let a PT or OT show you how to transfer your loved one.

INSTRUCTIONS FOR CAREGIVERS

Sliding Board Transfer

The sliding board transfer requires the use of a *transfer belt* or *gait belt* and a *sliding board* or *transfer board*. Your OT or PT can help you find this equipment. Use the sliding transfer when moving the person with ALS to or from a bed or chair into the wheelchair.

Position the wheelchair and lock it parallel to or at a slight angle to the bed.

When you're transferring the person with ALS *from* the bed to the wheelchair, you should remove the armrest on the side you're transferring to. He should



lean slightly and you should place the sliding board well under the buttocks, with the other end of the board over the wheelchair seat. Be careful not to pinch him between the board and the bed.

Stand in front of your loved one to block his knees. Grasp his transfer belt at the back and perform the transfer by a series of leaning and sliding movements until he's moved down the board into the chair.

When he's on the chair, remove the board and release him when he's sitting in a position he can maintain.

You can reverse this procedure when transferring him to a bed.

Standing Pivot Transfer Without Assistance

Here's a way of transferring someone from the wheelchair to the bed without a sliding board.

The person with ALS moves to the edge of the locked wheelchair and, using the arms of the chair, pushes to a standing position.

He or she *pivots* by moving the feet in small increments, and then reaches for the bed. Note: Reaching for the bed before pivoting may lead to a loss of balance.

The person sits by lowering himself to the bed.

Standing Pivot Transfer with Assistance

The person with ALS should assist as much as possible when being helped to the standing position. In this way you don't actually lift, but only help him into the upright position. This requires the use of good body mechanics and a transfer belt.

Remove the footrests from the wheelchair; then the person being transferred places his feet on the floor directly under the knees. He slides forward to the edge of the locked wheelchair.

Place your feet and knees to the outside of his feet and knees. He then places his hands on the armrests in preparation to assist in pushing to the standing position.

With your knees bent, grasp the person's transfer belt at the back and initiate a forward rocking motion.

Give the command to "stand" and straighten your knees to assist him to a standing position. Continue to grasp the transfer belt as he pivots toward the bed. A transfer pivot disc is often helpful in this process.

He lowers himself to the bed, but don't release him until he's in a position he can maintain.



SPECIAL TRANSFERS

When transferring your loved one with ALS to the toilet, car or bathtub, you should use the same techniques described above, with the following additional considerations:

Toilet

Position the locked wheelchair facing the toilet at a slight angle. After the person with ALS has achieved standing, assist him in partially disrobing. Then help him to sit on the toilet.

Bathtub

Position the locked wheelchair parallel to the tub and remove the footrests and the armrest nearest the tub. The person with ALS moves to the outside edge of the tub bench while you assist in maintaining his balance.

Place one arm around his shoulders and the other arm under the knees. With one movement, pivot him to face forward on the bench while swinging the legs into the tub.

Car

Position the locked wheelchair parallel to the car. Transfer your loved one to the outside edge of the car seat.

Place one arm around his shoulders and the other arm under the knees. With one movement, pivot his legs onto the floorboard of the car.

BODY MECHANICS FOR THE CAREGIVER

As you assume more responsibility for the care of your loved one with ALS, your risk of injury increases. The use of proper body mechanics will minimize this risk. Good body mechanics distributes the stress over several sets of muscles and uses the stronger muscles. General principles are as follows:

Lifting

Face the person with ALS squarely, with your feet shoulder width apart.

Position yourself as close to him or her as possible. Bend your knees and lift with the legs rather than the back. Keep your head up.

Pushing/Pulling

Keep your feet apart — one foot in front of the other. Shift your weight from your back foot to your front foot. It's usually safer to push than to pull.



Spotlight on Transfer Tips and Precautions

- To prevent back injury to you (the caregiver), bend at the hips and knees, not at the waist, as you prepare to lift someone; then straighten at the hips and knees as you lift.
 - Keep a wide base of support by spreading your feet apart. If you're transferring someone from one place to another, stagger your feet in a walking position, and shift your weight from front to back as you lift, while keeping the person as close to you as possible.
 - To avoid back injury: When turning, pivot on your feet or move them. Don't twist at the waist. For added back support, consider wearing a safety belt like those used by workers who frequently lift and carry items on the job.
 - Wear shoes with low heels, flexible nonslip soles and closed backs.
 - Plan ahead. Know where you're going and how you're going to get there, and make sure the person you're lifting also knows. Move everything out of the way, and make sure the brakes are engaged on any wheeled devices.
- Transfer him to even, stable surfaces; avoid low or overstuffed chairs and couches.
- If he starts to fall, ease him down onto the nearest surface — a chair, bed or even the floor. Don't stretch to complete the intended transfer. You're likely to lose your balance, strain your muscles, and injure both yourself and the person you're transferring.
 - Tailor your lifting and transferring techniques to the type and degree of weakness in the person with ALS. Needs may change over time as weakness progresses.
 - Use mechanical devices to help you whenever possible.
 - If the person you're transferring is using a wheelchair, be sure to stabilize it by securing the brakes. Remove the footrests and armrest on the side he's being transferred toward.
 - Don't be discouraged if a lift seems cumbersome or too difficult to use at first. Practice makes perfect!

DEPENDENT TRANSFERS

If the person with ALS is unable to assist in the transfer, a dependent transfer will be necessary. There are two major types of dependent transfers: dependent standing pivot and a two-person lift. You also may choose to use a mechanical or hydraulic lift (see page 94). A physical therapist will assist you in selecting the proper type of transfer and instruct you in how to do it.

Dependent Standing Pivot

When transferring someone from a wheelchair to a bed, place the locked wheelchair parallel to the bed and remove both footrests and the armrest nearest the bed. With the person's feet on the floor, move him to the edge of the seat by grasping under the knees and pulling forward. Place his feet outside your feet and block his knees.

Reach around the back of the person and grasp the transfer belt while he attempts to hold his arms together in front of the body.

Initiate a rocking motion and then straighten his legs to lift him out of the chair. The lift need be only high enough to clear the wheelchair.

In a swift motion, pivot toward the bed, rotating the person to the proper position for sitting. Lower him to the bed but don't release him until he's in a position that can be maintained.



Dependent Two-Person Lift

Position the wheelchair at a slight angle to the bed. Remove both footrests and the armrest nearest the bed. Caregiver #1 (generally the stronger person) should stand next to the chair, within the angle formed by the chair and bed. Caregiver #2 will stand in front of and facing the person you're transferring.

Have the person cross his arms in front of his chest. Caregiver #1 should reach under the arms and grasp the person's right wrist with the right hand and his left wrist with the left hand. Caregiver #2, with feet apart and knees

bent, should support the legs by placing both hands under the knees.

On command from Caregiver #1, raise the person to a height that will ensure that he clears all parts of the wheelchair. In one smooth motion Caregiver #1 should step to the side and lower him onto the bed.

MECHANICAL AND HYDRAULIC LIFTS

Lifts provide a method by which one person can transfer a person with ALS. This is especially useful if the person with ALS is larger than you.

There are two types of lifts: mechanical and hydraulic. The hydraulic lift, especially the battery-operated type, is generally considered easier to operate, putting much less stress on the caregiver. Some lifts are made to sit and roll on the floor; another type runs on a ceiling track and may help transport a person from room to room.

There are many types of slings available, including one with a head support. A sling may be lifted by means of chains or web straps.

SPECIAL NOTE: Lift transfers must not be attempted without proper instruction and demonstration. Consult with your PT!

The following demonstrates the use of a hydraulic lift (such as a Hoyer lift) using a sling lifted by means of web straps.

Position the sling under the person by rolling him to one side, positioning the

sling, then rolling him to the other side. To avoid pressure on his skin, position the seams away from him.

Check to be sure the valve locking device is closed.



Move the lift into position so the swivel bar hook is over the center of the person's abdomen. Attach the web straps to the sling by placing the S-shaped hooks through the holes in the sling. Make sure the tips of the hooks point away from the person.

Attach the shortest web strap through the hole for the back and head support part of the sling. This will ensure a sitting position when you raise the person. Finally, attach the top of the web straps to the swivel bar.

Place the base in the widest possible position before raising the person. Raise him slowly by pumping the jack handle, taking care to ensure that a safe sitting



position is attained. Move him into position over the seat of the locked wheelchair.

Lower him by pressing the jack handle inward toward the jack. Be sure to lower him slowly and guide the descent by slight pressure to his knees or thighs. This pushes him into the sitting position.

Once your loved one is seated in the wheelchair, close the valve by moving the jack handle away from the jack. Remove the web straps from the sling and move the lift away from the wheelchair.

BED POSITIONING

If the person with ALS is unable to move independently in bed, a bed-positioning program will promote his or her comfort and reduce the risk of skin breakdown.

SPECIAL NOTE: The skin over bony areas is the most susceptible to problems from pressure caused by staying in one position in a bed or wheelchair for many hours. The length of time that a person can tolerate pressure varies. Should skin breakdown occur, it's important to contact your ALS physician for proper wound management.

Bed positioning also will help to minimize the swelling associated with severe weakness. This swelling or accumulation of fluid under the skin, known as *edema*, occurs as a result of muscle inactivity and the effects of gravity on the limbs. It occurs most frequently in the hands and feet. Proper elevation of the limbs helps to reduce the swelling and encourages blood flow.

Bed positioning should:

- be comfortable for the person with ALS
- be changed frequently
- keep the person's head in line with his body, neither too flexed nor too extended
- prevent friction or compression between body parts by the use of pillows or other position devices

Spotlight on Recovering from a Fall

For the reader with ALS: Maneuver yourself over to a solid, stable object such as the sofa, a heavy chair or a locked wheelchair.

Get into a kneeling position. Bring your stronger leg in front and place the foot flat on the floor. Push up with your strong leg, using your arms to assist as much as possible.

If a caregiver is available, have him or her assist you to stand or sit.

There are two basic positions for lying in a standard bed — on the back and sidelying. The position should be changed at least every two hours from lying on the right side, to lying on the back, and then to lying on the left side.

If a hospital bed is available, the positioning options increase owing to the flexibility of the bed. If you notice a red-dened area that lasts longer than 20 minutes, you should increase the frequency of the turning schedule.

This need varies greatly from one individual to another. Consult with your PT, OT or nurse for specific instructions in bed positioning.

Sidelying

Place a pillow between the knees of the person in bed and wedge another pillow behind the back. Elevate the upper arm on a pillow.

Lying on the Back

Place a pillow under the knees and elevate both arms slightly with pillows.

Turning from the Back to Sidelying

Stand on the side of the bed that the person is to be rolled toward (i.e., if rolling him to the right side, stand on the right side of the bed). Face the bed squarely and grasp the end of the draw sheet (see page 25) farthest from you at shoulder and hip level. Keep your back straight and knees bent.

Lean back and pull the draw sheet to roll the person onto his or her side. Stabilize him at the shoulder with one hand while wedging a pillow behind his back with the other hand.

Bend his knees slightly forward and place a pillow between his legs. Position his head in proper alignment with the body. Elevate his upper arm on a pillow and place the call button within his reach.

To reposition the person on his back, reverse the technique.

Chapter 8

Exercise



WHY IS EXERCISE IMPORTANT?

Exercise can provide a variety of benefits for people with ALS; for some it can have a significant impact on their quality of life.

Particularly in the earlier stages of ALS, many people have found both physiological and psychological boosts from various types of exercise. Along with helping to combat stress, providing a brief escape and being a welcome way to relax, proper exercise is important for preventing atrophy of muscles

from disuse — a key to remaining mobile for as long as possible — and, as long as you're able to exercise comfortably, for keeping your cardiovascular system strong. The key to gaining these benefits is finding the most appropriate exercise for you.

SPECIAL NOTE: It's most important that you discuss any type of planned exercise with your health care team, particularly your doctor and your physical therapist. Exercising under their supervision will ensure that you don't push weakened muscles to the point of doing further damage, or create a dangerous level of fatigue.

While the medical literature has firmly established the importance of exercise for people without serious medical conditions, very little research has been done on the subject of exercise and its role in ALS. In fact, it isn't known whether exercises are beneficial for increasing muscle strength for people with ALS. (Many experts doubt that this is possible.)

However, it's widely accepted among physicians and therapists that specific kinds of exercise help prevent the development of painful *contractures* (the permanent tightening of muscles) and can decrease the *spasticity* (intermittent or constant muscle tightness or spasms) that's common in ALS.

Practicing the healthiest type of exercise for you at each stage of ALS will help maintain your comfort and mobility. For some people, a moderate amount of daily walking in the early stages of ALS may be all that's advisable. As the disease advances, you'll benefit from doing range-of-motion and stretching under supervision of a physical therapist.

THE ROLE OF THE PHYSICAL THERAPIST

As explained in Chapter 4, a physical therapist is a gross motor movement specialist — someone trained to help you perform activities that use major muscle groups, such as walking, rising from a chair, and getting in and out of bed. Physical therapists also are involved in prescribing appropriate exercise programs, with the



goal of keeping you safely functioning at as high a level as possible for as long as possible.

It's essential that you work with a PT who's experienced with ALS. A qualified PT can guide your exercise regime so that it's appropriate for you during every stage of the disease.

EXERCISE PRECAUTIONS

When living with ALS, you should never push yourself past the point of fatigue, or attempt to strengthen already weakened muscles. It isn't clear whether muscles already weak from ALS can be strengthened, but PTs know that weak muscles can be further damaged when pushed too hard.

Again, don't initiate an exercise program, especially one that includes cardiovascular conditioning, without clearance from a physician.

Excessive exercise to the point of fatigue may result in muscular weakness — short-term or permanent. Generally, keep in mind that if you feel worse after an exercise activity, then you've done too much.



Discontinue the activity if you experience any of the following signs of fatigue during exercise:

- shortness of breath
- excessive cramping
- unusually heavy sweating

To decrease the risk of harm, you should *avoid*:

- exercising with heavy weights
- exercising in extreme temperatures
- exercising when fatigued or ill
- moving a limb past the point of pain or significant resistance

Remember to exercise for enjoyment; if exercise causes pain, then stop. Also, if you find you're sore after exercising, or sore the next day, lower the intensity, the duration or both.



STAYING ACTIVE

Exercise programs for people with ALS should be multipronged and contain these components:

- range-of-motion (ROM) exercises
- stretching
- cardiovascular conditioning (only if specifically recommended by your doctor)
- strengthening (only if recommended by your doctor)

Research points toward moderate-intensity, low-resistance exercise as being most beneficial in preserving function in people with ALS. By remaining active with such a program, you'll keep yourself in the best condition possible for the activities of your everyday life.

STRETCHING & RANGE-OF-MOTION EXERCISES

Any area of weakness in your muscles is prone to tightness or contracture, and muscular tightness can interfere with regular activities and the movement of joints in the neck, hips, arms and legs. Both joint structures and other soft tissues (muscles, tendons and ligaments) become tight with lack of motion. Stretching increases



joint mobility and improves or helps to maintain soft tissue extensibility.

All joints in the body need to be stretched. Normal daily activity uses all of the major muscles and joints, but some supplemental stretching may be necessary. If there's an area of weakness, such as your arms, legs or neck, you'll need additional stretching there to maintain joint integrity and prevent pain.

You should perform all of the stretching and range-of-motion movements on your own if you can, or with assistance of a physical therapy professional where needed. Your PT can train your caregiver in performing these stretches. It's very important that you continue to move or have your limbs moved every day even if you're too weak to do it on your own. When a caregiver is assisting you with the activities, continue to participate as fully as you can.

See Chapter 9 for a full description and illustrations of range-of-motion exercises.

Special Concerns

In ALS, the shoulders are particularly prone to becoming "frozen," a painful condition called *adhesive capsulitis*. For



more on stretching techniques for this area, see “Spotlight on Shoulders,” page 107, and exercises described on pages 115, 118 and 121.

CARDIOVASCULAR CONDITIONING

Cardiovascular or aerobic exercise is any activity that elevates your heart and respiration (breathing) rates. Some typical activities include walking, swimming, bicycling and aerobic-type fitness classes. Again, only undertake this type of exercise if, and for as long as, your health care team agrees it’s safe for you to do so. Any component of aerobic exercise may need to be modified or reduced over time as ALS advances.

When doing these activities, keep in mind the FIT guideline: frequency, intensity and time; in other words, how often, how hard and how long you should perform them. Moderate-intensity, low-

impact performance may be best for those with ALS.

Warming up slowly (for 5 or 10 minutes) and doing light stretches before you exercise, and cooling down slowly afterward, can help prevent injuries. Staying hydrated is also important; drink plenty of water, being sure to take sips before you feel thirsty.

If you exercised regularly before you received an ALS diagnosis, it’s wise to modify your exercise routine to a level that’s still beneficial but doesn’t promote soreness or fatigue. If you didn’t exercise before ALS, it’s now OK to try some new activities, but be sure to first talk this over with your doctor or physical therapist.

Walking

Walking is an excellent exercise. The speed, duration and terrain may be easily varied to suit your ability and strength. Walking is convenient and you can do it in the city, the suburbs or the country. Even small amounts — as little



as 5 minutes — of walking can be beneficial to your quality of life.

When you walk, go at a steady, comfortable, safe pace with your arms swinging, if possible. This will maximize the cardiovascular benefit.

You also can perform walking activities on a treadmill or an elliptical training machine. Use exercise machines with caution, and be sure to seek training from appropriate experts for how to control and stop these machines. Again, your doctor or physical therapist can help you determine an appropriate duration for walking, and how to monitor the intensity of this type of exercise.

Water-Based Exercise

Water-based activity as a low-impact form of exercise can be very helpful. The buoyancy of water and resistance to movement decreases the risk of injury to joints, muscles and tendons while allowing the benefits of exercise.

Exercise in the water is beneficial



to both swimmers and nonswimmers. Simple water exercise — even as basic as walking around in the pool — or swimming laps, if you have experience, can provide aerobic conditioning.

Spending time in the water can be extremely relaxing, but that in itself can increase the muscle weakness of ALS. If you reach the “wet noodle” stage, you may have difficulty getting out of the pool. For safety’s sake, a pool with supervision and a lift are recommended.

In later stages of ALS, doing aquatic exercises with the help of a PT can continue to provide cardiovascular benefits.

See “In the Water,” page 105, and Chapter 9 for some specific aquatic exercises.

Bicycling

Both stationary and regular bicycling can be good for people with ALS, although *stationary biking* has certain advantages. You can do indoor biking in a climate-controlled environment where you can monitor your fatigue and take rest breaks with greater ease.

If you were an experienced cyclist before ALS and you choose to continue to ride a bike outdoors, use special caution, as balance and endurance could each become unexpected problems while you're out on the road. Avoid hills and uneven areas, and use moderation in bicycling so that you never ride to the point of fatigue.

If you decide to ride a stationary bicycle with adjustable resistance, contact your physician or PT for intensity and duration recommendations.

Along with stationary bikes, other types of equipment can enable you to bicycle indoors. With a *wind trainer*, you can attach an ordinary bicycle to a stand and ride in one place, with your tires rolling against an adjustable wheel.

Exercise cycles, which are pedaling machines that you can use on any flat surface, are another option for people



who aren't able to mount a traditional bicycle. Some of these cycles feature a passive/active component: An electronic motor assists in moving the user's legs or arms and shoulders through the exercise



Spotlight on Massage Therapy

massage therapy can be beneficial, especially if you have joint stiffness or muscular tightness. Many people with ALS report that receiving regular massages assists them with relaxation and comfort.

Gentle massage methods, as opposed to techniques that mobilize deep tissues, are recommended for people with ALS. Always use a licensed massage therapist and notify him or her of your condition before treatment.

motion, even when the user is entirely passive.

Restorators are another rehab tool that can simulate the motions of pedaling. This pedaling mechanism is mounted on an adjustable stand so it can be placed in front of a chair, and can be used for arm or leg exercises. Many restorators have adjustable tension.

Arm *ergometry* (cycling with the arms) is a low-impact aerobic alternative to traditional bicycling. This type of cardiovascular exercise really challenges the heart, so be sure to do it with supervision and a doctor's clearance.

EXERCISE EQUIPMENT

In the past, the swimming pool, the treadmill and the stationary bicycle exhausted the possibilities of exercise equipment useful to those with ALS. Although exercises derived from the motions associated with swimming, walking and riding remain the most productive, the ways to carry out those exercises have expanded. A wide range of equipment is now available, from the simplest aid in aquatic workouts to sophisticated machines that assist with both active and passive exercise.

A version of some or even all of the following equipment may be of use to you:

In the Water

Aqua Step:

A small platform submerged in water lets you step up and down.

Flotation Belt:

Usually made of foam and worn around the waist, these belts provide enough buoyancy for walking or jogging in deep water.

Foam Barbells:

Foam “weights” are attached to a padded handle. They can be used at the surface for stability or flotation, or under water for resistance exercises.

Kickboard:

When your body is prone, this floating board provides upper body support so you can kick and exercise your legs exclusively.

Noodle:

These popular water toys — long foam tubes — can also be used for stretching and resistance exercise.

At Home or in the Gym

Active-Only Exercise Cycles:

The user can assist the motor with his or her own muscle strength to help push pedals.



Active-Passive Exercise Cycles:

With this exercise device, the electric motor senses when a user tires and the machine compensates for reduced effort. Using it can help prevent atrophy of muscles and can help keep joints loose and tendons stretched.

Passive-Only Exercise Cycles:

The legs are rotated by the electric motor in an orbital motion similar to that used in cycling.

STRENGTH TRAINING

Even leading experts are undecided about the advisability of strength training (weight lifting) for people with ALS. In his book, *Amyotrophic Lateral Sclerosis*, Hiroshi Mitsumoto, director of the Eleanor and Lou Gehrig MDA/ALS Center at Columbia University Medical Center in New York, writes that it's not known whether muscles affected by ALS can be improved through strengthening exercises.

Lifting heavy weights may lead to overuse, fatigue, or temporary or permanent loss of the use of the muscle. Yet decreased muscle activity can lead, through disuse, to weakness and atrophy greater than that caused by ALS itself.

SPECIAL NOTE: Any strength training/weight lifting should be performed using only very light weights. It should be prescribed for unaffected muscles, and be done under the guidance of a physical therapist or physician.

ALTERNATIVE EXERCISES

Over the years, other types of exercises also have come into vogue that may be beneficial for those with ALS. Yoga, Pilates and tai chi are all low-impact activities that involve movement of the entire body and often include a mental component that can be meditative or stress relieving.

But remember that low-impact doesn't mean low-intensity. Use caution to avoid fatigue and injury, and if you're in a class, make the instructor aware of your medical condition before starting.

As with any exercise program, modification may be necessary over time. Please continue to update your health care team on what exercise regimen you're involved in so they can make adjustments as needed to assist in maintaining your mobility and safety.



Spotlight on Shoulders

Weakness of the muscles around the shoulders makes this area particularly susceptible to joint tightness and pain. The shoulder joint depends upon its muscles to keep it intact.

When ALS makes shoulder muscles weak, you're at risk for a condition called *frozen shoulder*, in which the shoulder joint capsule "freezes up" from immobility. It's characterized by severe stiffness in the shoulder joint, especially in the motions of shoulder flexion (flexing) and external (outward) rotation. You may also experience pain with movement, pain with activities of daily living such as dressing and bathing, and difficulty sleeping at night.

Active or passive range-of-motion exercises should be performed to prevent the development of frozen shoulders. See pages 115, 118 and 121.

It's very important that you notify your health care team if you have these symptoms. Frozen shoulder is a treatable condition. With appropriate exercises and treatment, you and your team can restore passive range-of-motion to the joint and reduce the pain.



Chapter 9

Exercise Instructions



GUIDELINES

Exercise or other physical activity, performed under the direction of your physician and physical therapist, can be helpful to you at various stages of ALS. (See Chapter 8 for a discussion of the benefits.)

Whether you're able to carry out these activities on your own, or need the help of a PT or caregiver, their benefits will greatly enhance your everyday life with ALS.

This chapter offers detailed instructions on performing many of the exercises mentioned in Chapter 8. Most of them can be modified according to your endurance and abilities.

Don't be discouraged if some of these exercises aren't possible for you. With the help of your health care team, do those that are within your capability, and you'll see many benefits.

Whether you're biking, walking, swimming, doing range-of-motion, practicing yoga or performing other exercises, follow these precautions:

- Always consult with your health care team about the type and duration of exercise that's best for you.
- Do exercises slowly and smoothly.
- Hold stretching exercises for 5 seconds. Don't bounce.
- Rest briefly before resuming exercises if cramping or pain occurs.
- Repeat each exercise the number of times you can tolerate and find comfortable.
- Rest whenever necessary during exercise to prevent fatigue.
- Seek the advice of a PT about doing exercises properly.
- Wait at least one hour after meals before exercising.
- Exercise shouldn't cause pain. If it does, STOP!
- See page 100 for precautions and signs of dangerous fatigue.

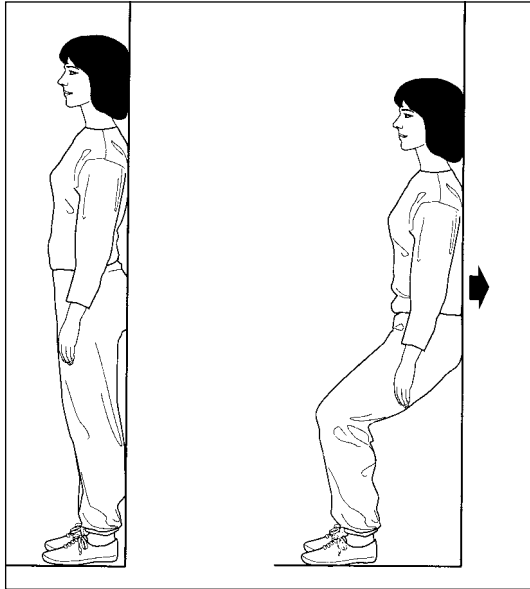
As ALS progresses, you may experience a greater level of fatigue and be unable to continue your usual exercises without feeling exhausted. Accordingly, you'll have to change your exercise program. Even passive range-of-motion (see page 121) can improve your quality of life.

STRETCHING EXERCISES

The following exercises are intended to stretch your muscles or move the joints through their full range-of-motion. A stretching program performed daily may help to modulate muscle tightness.

SPECIAL NOTE: If tightness is present in one of your arms or legs, you'll feel resistance to the movement. Overcome this resistance by continuing slow, steady pressure to the limb. If pain occurs, stop the movement.

You can do the entire stretching exercise program in 20 minutes or less. Hold each stretch for 5 seconds and repeat a few times, up to 10 times.



Posture Check

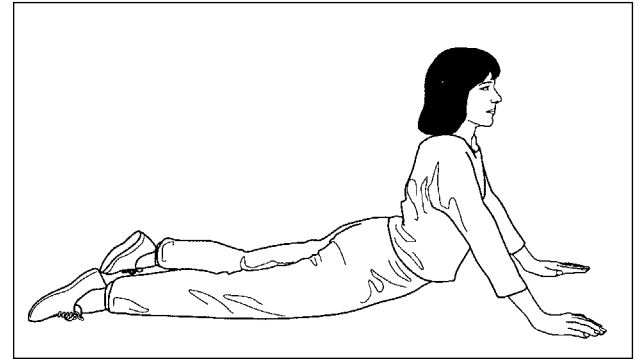
Stand with your back to a wall. Press your heels, buttocks, shoulders and head against the wall. Move the feet forward, and bend your knees so your back slides a few inches down the wall. Tighten your abdominal muscles so you can flatten your lower back against the wall. Relax. Repeat.

Back Exercises



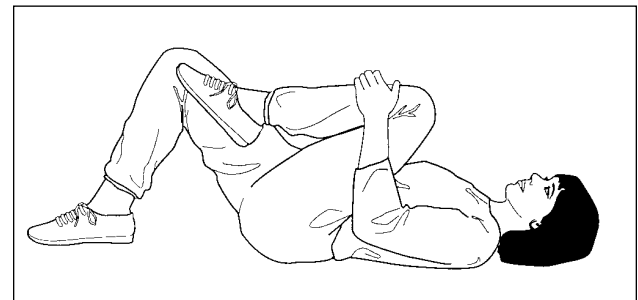
Standing extension

Stand with your hands in the small of your back. Bend backward with knees straight. Hold for 5 seconds. Return to starting position.



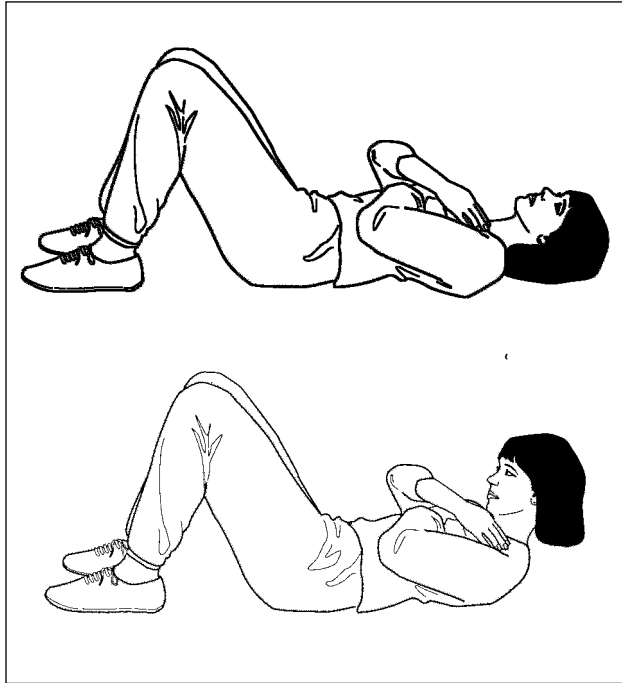
Press-ups

Lie face down, palms at shoulder level. Press the top half of your body up, using your arms. Hold for 5 seconds. Return to starting position.



Single knee to chest

Lie on your back with your knees bent. Grasp your left knee with your hands and pull back toward your left shoulder until you feel a good stretch. Slowly lower the leg back to the floor and repeat the same procedure with the right leg.



Partial sit-up

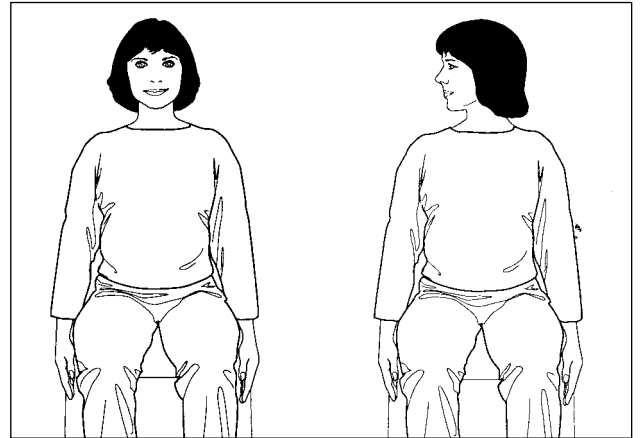
Lie on your back with your knees bent and your arms crossed over your chest. Roll your chin toward your chest and raise your head and shoulders off the floor. Relax.

Neck and Trunk Exercises

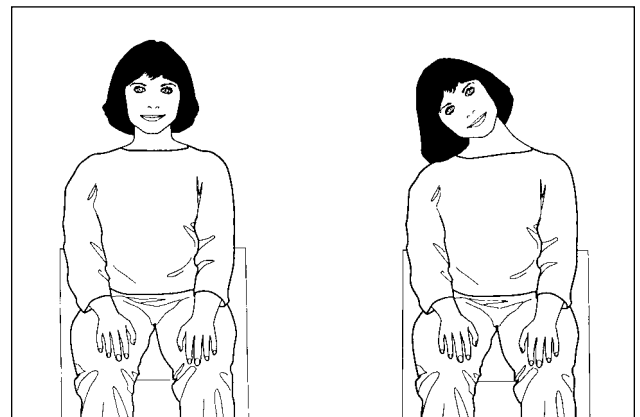
Maintaining an erect sitting posture is important in all areas of function. Weakness of the neck and trunk can affect your posture by decreasing balance and creating uneven tension between muscles. Prolonged poor posture will lead to stiffness and pain. Trunk and neck stretching exercises improve mobility of the spine, thus making posture easier to maintain.

SPECIAL NOTE; Don't do these exercises if your neck weakness is severe; that is, if you have difficulty holding your head up. As always, check with your doctor if you have any concerns.

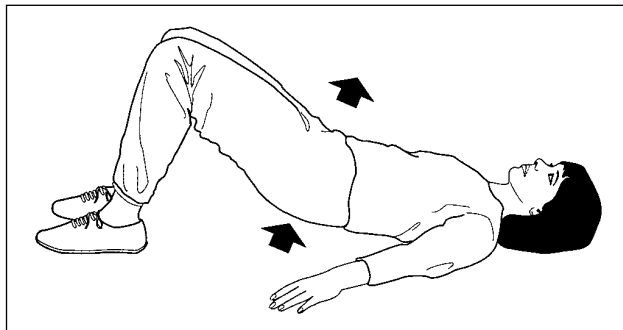
To loosen neck muscles



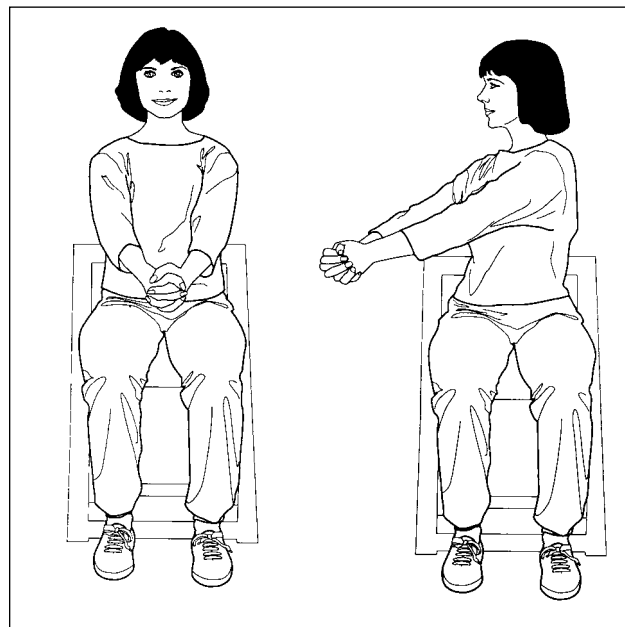
While seated, start with your body erect and your shoulders relaxed. Keep your chin level and turn your head as far as possible to the right, as if you're looking over your shoulder. Slowly rotate to the opposite side. Return to the starting position and relax.



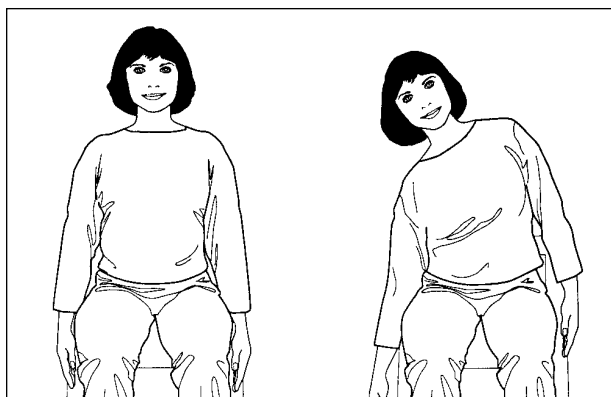
Slowly tilt your head toward the right, guiding your ear toward your shoulder. Hold, and return it to the center. Do the same on the left side.



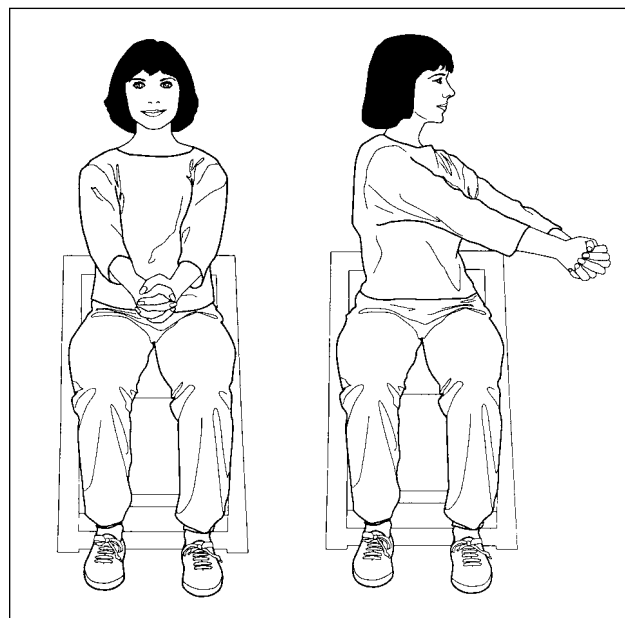
Lie on your back with your knees bent. Extend your hips and back by lifting your buttocks up to form a “bridge” position, while pushing down into the bed or floor with your feet. (If necessary, have someone hold your feet.)



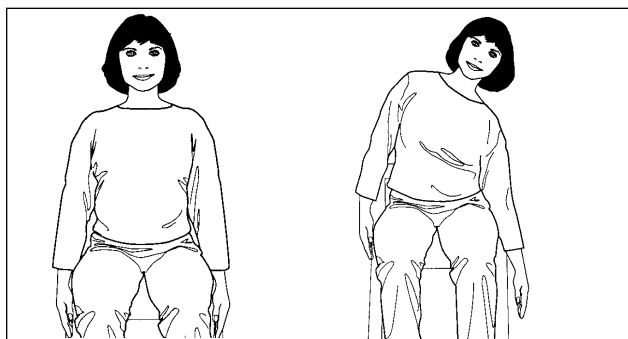
Hold your hands together in front of your abdomen. Turn your head, shoulders and arms toward the right.



While sitting in a chair with your arms hanging loosely, bend to the right.



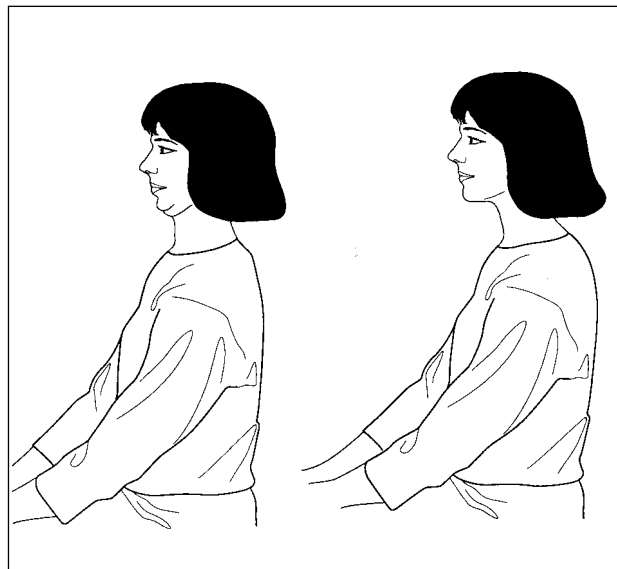
Hold your hands together. Turn your head, shoulders and arms toward the left.



With your arms in a downward position, bend to the left.



Pull your chin down toward your chest. Hold for 5 seconds. Look forward and relax.

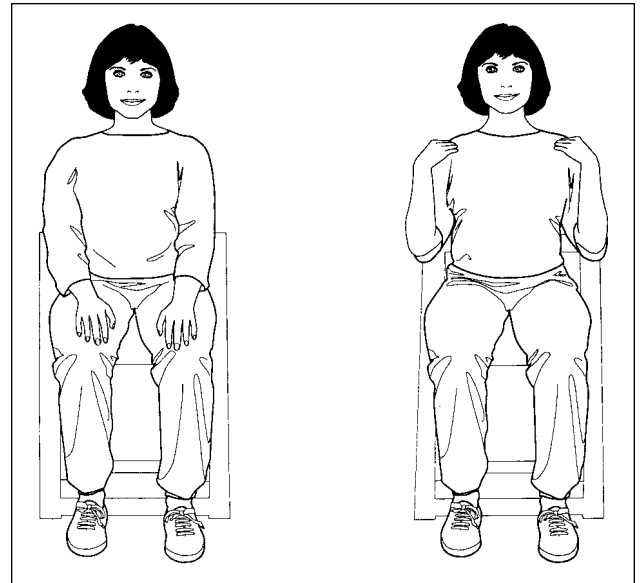


With your head erect, push your chin back as far as possible, making a double chin. You should feel the back of your neck stretching upward. Hold for 5 seconds and relax.

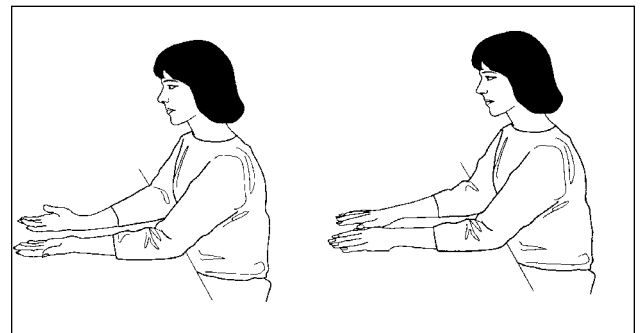
Arm Exercises

Elbow

Muscles that move the elbow are located primarily in the lower two-thirds of the upper arm.



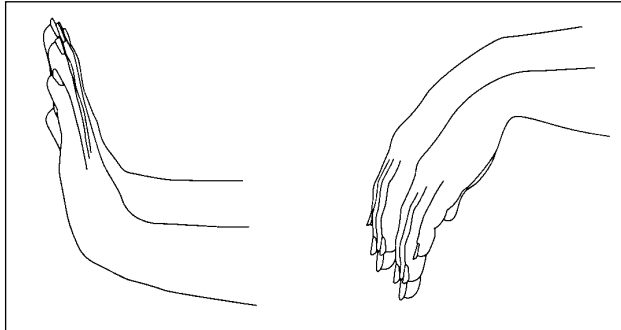
Start with your hands on your knees, bend at the elbows to touch your shoulders. Return your hands to your knees.



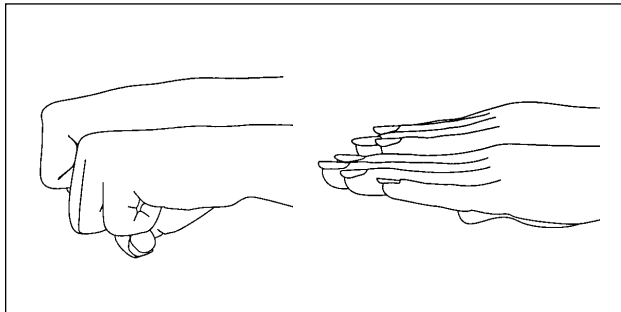
Sit with your elbow and forearm supported on a table. Turn palm up and palm down.

Wrist and Hand

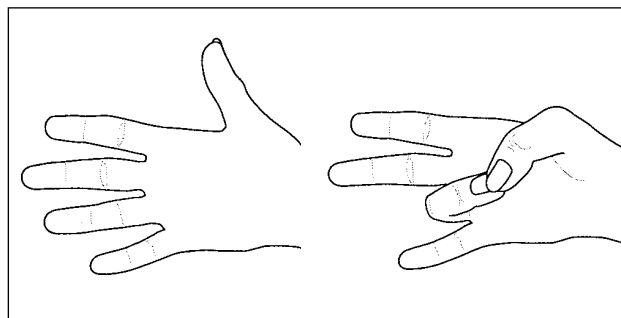
The muscles that control the wrist are located in the forearm while those that control the hand are located in both the forearm and the hand.



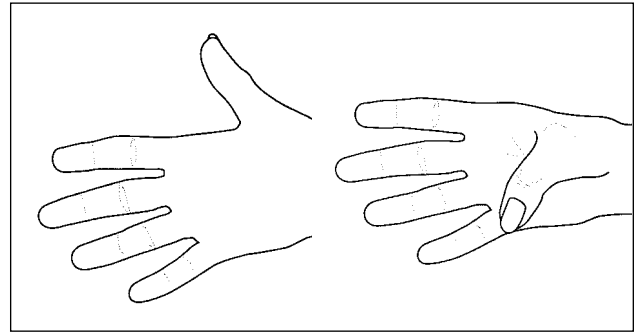
Lift your hands up and down as if waving.



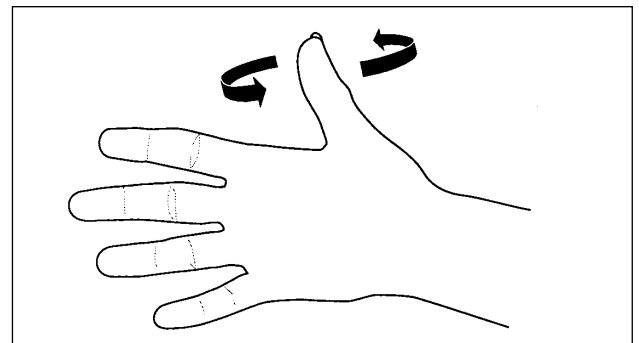
Make a fist and straighten your fingers.



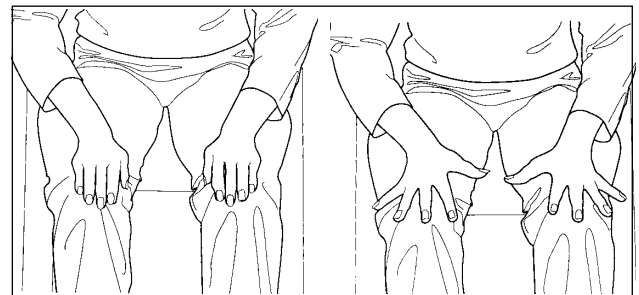
Touch the thumb to the tip of each finger.



Bring your thumb across the palm of the hand to the base of the little finger and straighten.



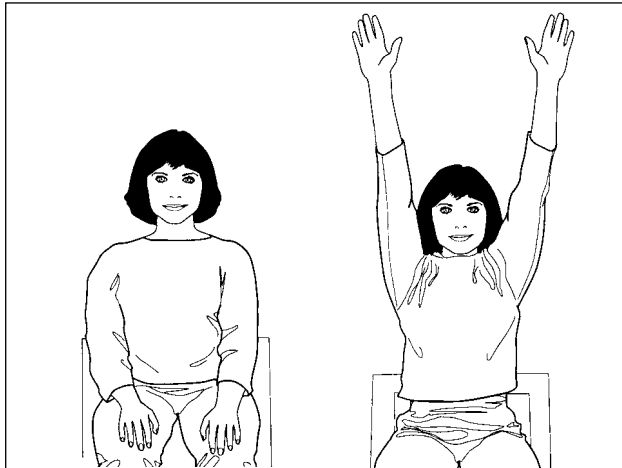
Make circles with your thumb.



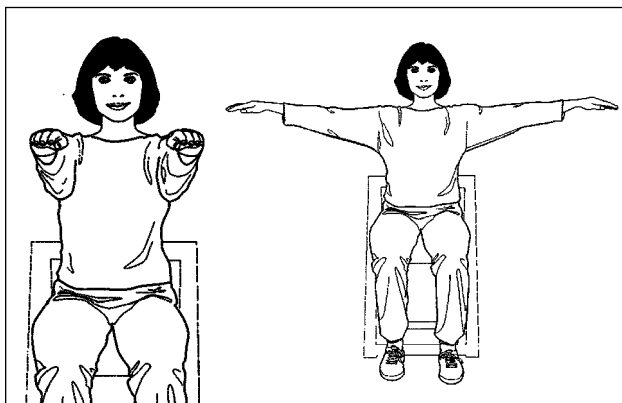
With the palms of your hand flat on your knees, spread the fingers apart, then bring them back together.

Shoulder

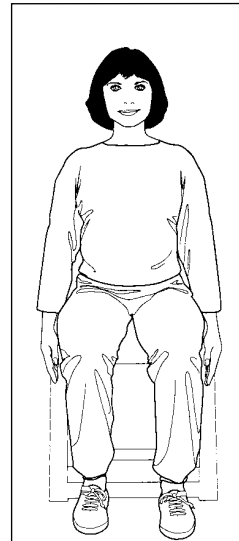
The “shoulder” consists of many muscles that extend from the neck, upper back and chest to the upper arm. Stretching can be achieved with the following simple exercises:



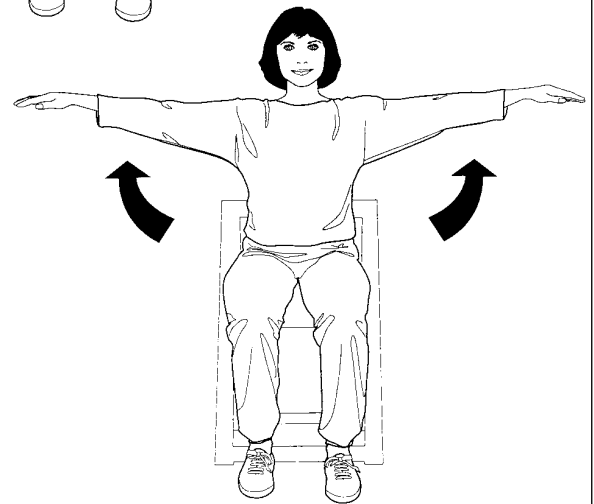
Starting with your hands on your knees and palms down, raise both arms as high as possible over your head.

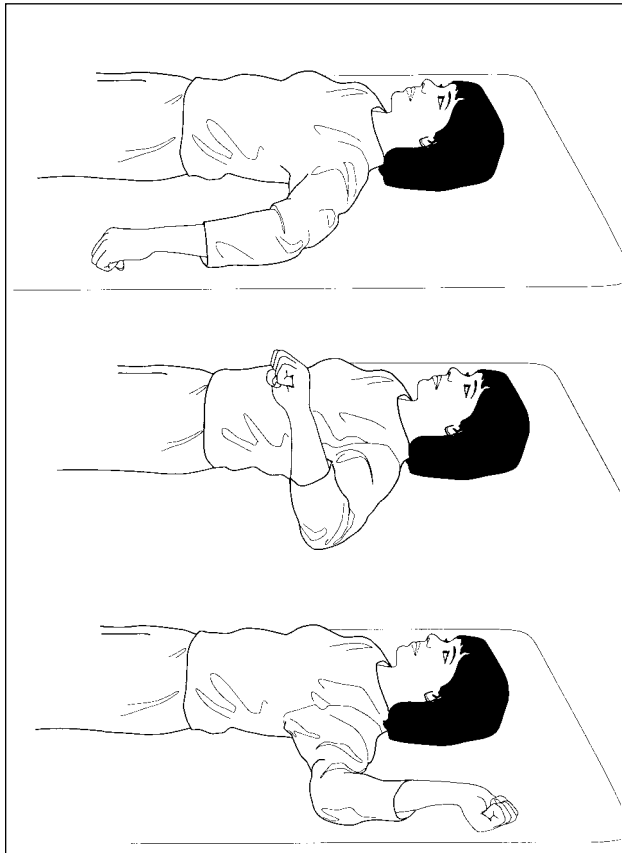


Starting with your arms straight out in front of your body at shoulder height and palms down, move your arms out to your sides. Hold for 5 seconds. Return your arms to the front.



Starting with your arms down at your sides, raise your arms out to the sides with palms down. Bring both arms over your head as high as possible.



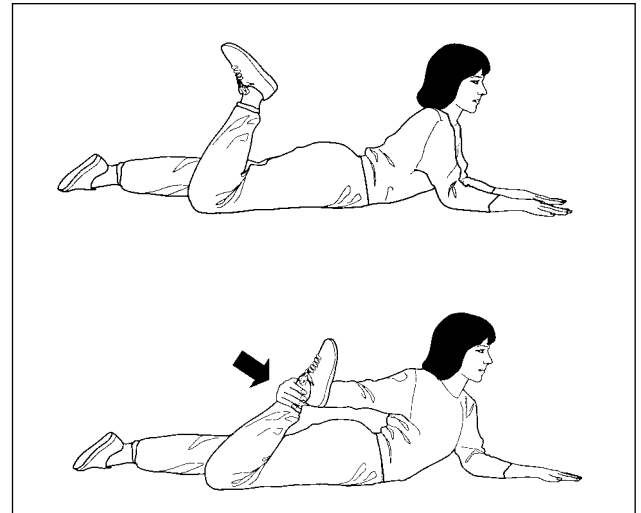


Lie on your back, arm out to your side at shoulder height, elbow bent to 90 degrees, fist pointing toward the ceiling. Bring your hand forward to the bed, palm down. Return to the starting position, then bring your hand backward to the bed, palm up. Do exercise with other arm.

Leg Exercises

Quadriceps

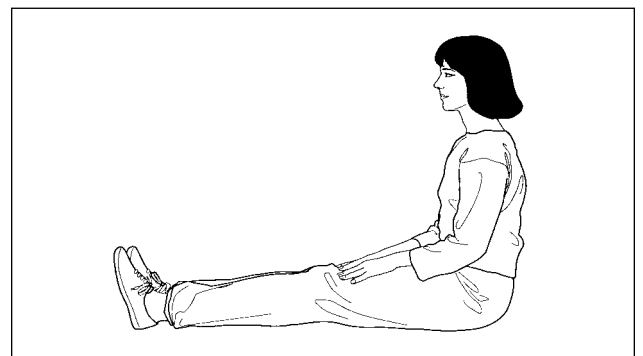
Quadriceps are the muscles in the front of your thighs that are responsible for straightening the knee and bending the hip.

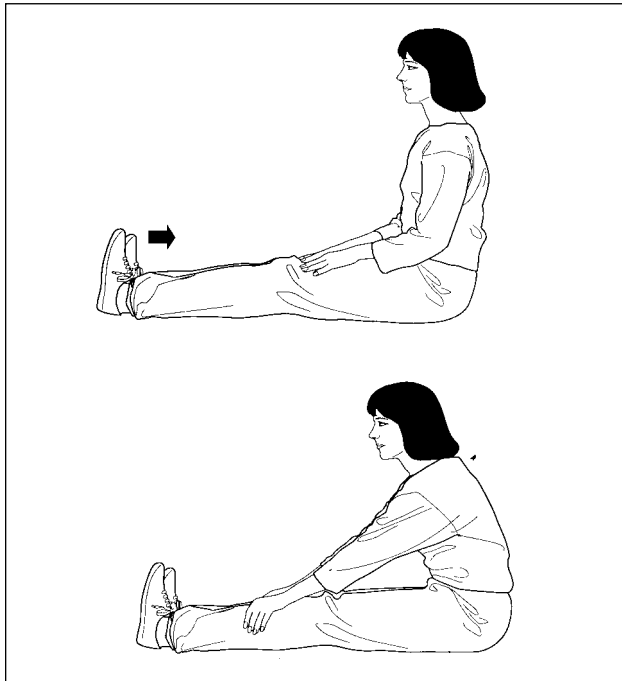


Lie on your stomach and bend your knee. Grasp your ankle with one hand and pull your heel to your buttock. Hold for 5 seconds. Relax. Repeat.

Hamstrings

The hamstrings are the large muscles on the back of the thighs extending from the buttocks to just below the knees. You'll usually feel the pull at the knees and behind the entire thigh.

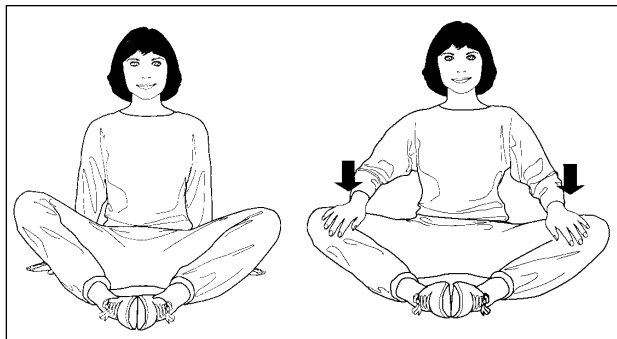




Sit on the floor with your back and legs straight. Pull your toes up. Reach toward your toes and grasp your shins with your hands. Hold for 5 seconds. Relax. Repeat.

Adductors

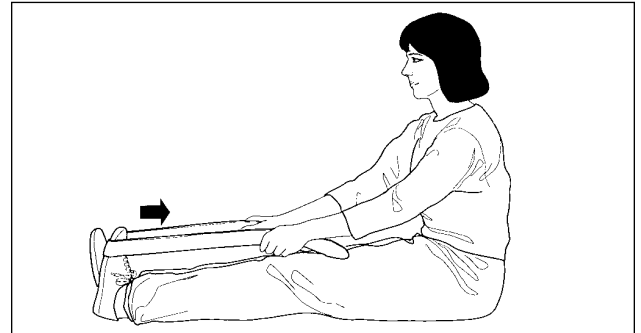
The muscles in the inner thigh that help with walking and pull your leg inward are the adductors.



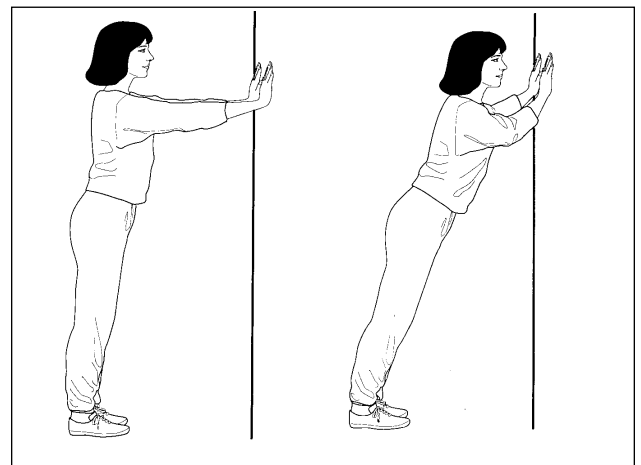
Sit in a modified "Indian style" with the soles of your feet together and pulled toward your body. Push your knees down toward the floor. Hold for 5 seconds. Relax. Repeat.

Heel cord

Also known as the Achilles tendon, the heel cord is the tapered end of the calf muscle, extending from behind your knee to your heel. This muscle is responsible for pointing the foot downward.



Sit on a firm surface with your legs straight. Place a belt or towel around the ball of the foot and pull toward you until you feel a stretch. Hold for 5 seconds. Relax. Repeat.



Stand at arm's length from a wall with your palms flat against the wall. Slowly bend your elbows and lean toward the wall. Keep your back, hips and knees straight and push your heels flat on the floor. Hold for 5 seconds. Relax. Repeat.

RANGE-OF-MOTION EXERCISES

As ALS progresses, it may be impossible for you to do all the stretching exercises. But it's vital that you continue moving all joints through a full range-of-motion, to help prevent pain and deformity.

You may be able to perform these exercises independently for a time and later need assistance. It's important to use assistance only for the portion of exercise that you're unable to perform alone. Active exercises with minor assistance allow you to use as much energy as is comfortable while gaining the benefits of stretching and range-of-motion.

Precautions

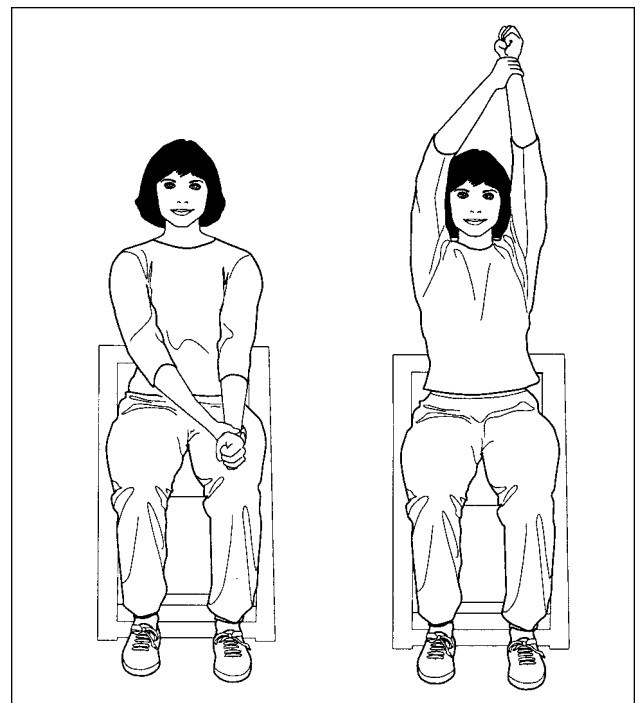
- Never move the limb past the point of resistance or pain, with one exception: the shoulders. See “Spotlight on Shoulders” on page 107 and “Shoulder” on page 118 for guidelines about stiff and painful shoulders.
- Assistance in movement should be gentle and slow.
- The caregiver or therapist should provide adequate support to the limb during movement.
- The parts to be moved should be gently and comfortably grasped as near the joint as possible.
- The motion should be slow and rhythmic and the repetition rate maintained at an even tempo.
- It's important for you to notify the caregiver if you experience pain during exercise.

- If you feel resistance to the movement because of tightness in the limb, you can overcome it by continuing slow, steady pressure to the limb. If pain occurs, stop the movement.

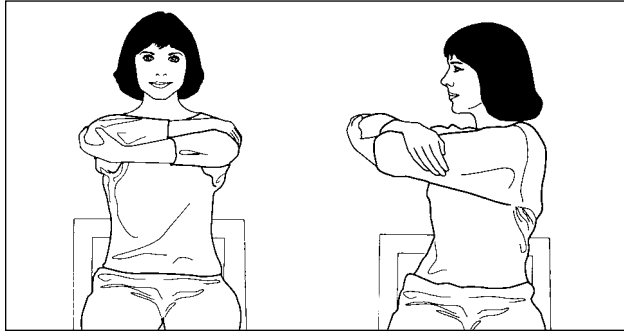
Arm Exercises

You can do these exercises when you have one arm that's significantly stronger than the other. You can perform them in a sitting position or lying on your back.

Shoulder

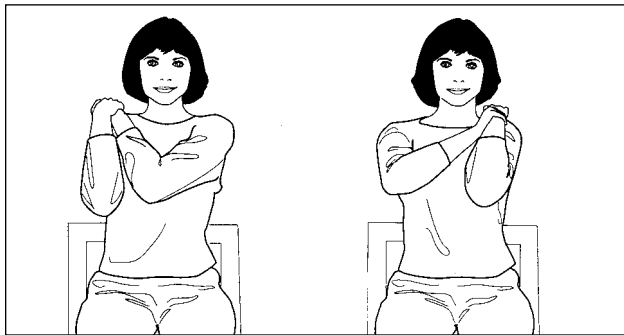


Grasp your weaker wrist with your stronger hand. Raise both arms over your head.



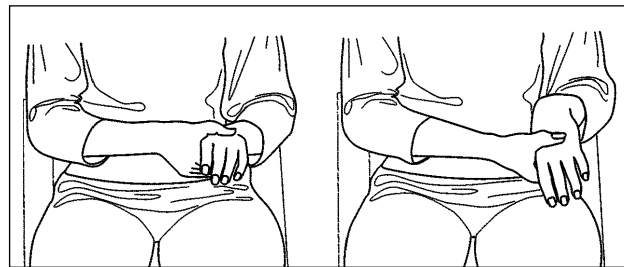
Cradle your weaker arm with your stronger arm, with your stronger hand under your weaker elbow. Raise both arms to chest height. Move your arms from side to side as far as possible.

Elbow

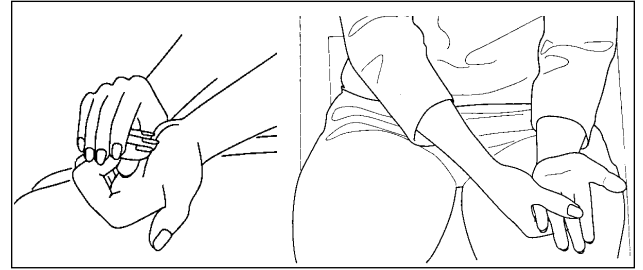


Grasp your weak wrist with your strong hand. Bring your hands to your right shoulder, then back to your knee, then to your left shoulder.

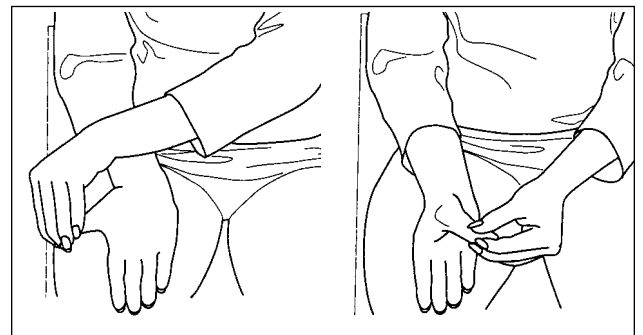
Hand and wrist



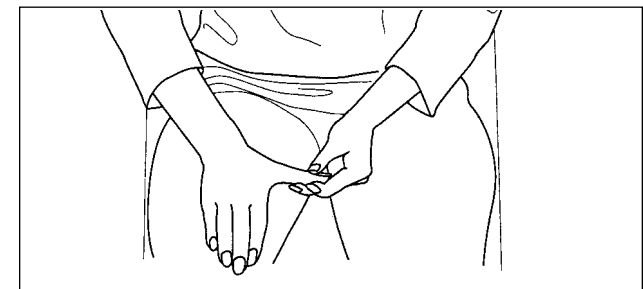
Grasp the palm of your weaker hand with your strong hand. Move your weak hand slowly up and down as if waving.



Sit with the palm of your weaker hand facing upward. Grasp the fingertips with your stronger hand. Bend the fingers inward to touch the palm. Straighten them out fully.



With the palm of your weaker hand facing upward, grasp the tip of the thumb with your stronger hand. Move the tip of your thumb over to the base of the little finger, then straighten it again.



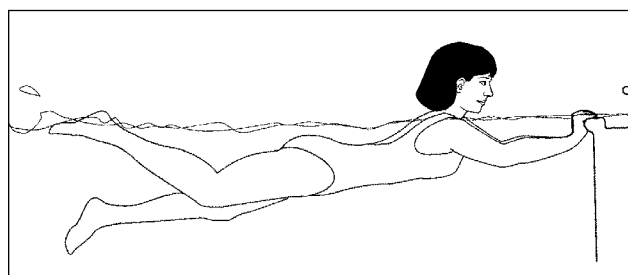
With the palm of the weaker hand facing down, grasp the thumb with the stronger hand and move the thumb out to the side as far as possible. Return to your original position.

SWIMMING & WATER-BASED EXERCISE

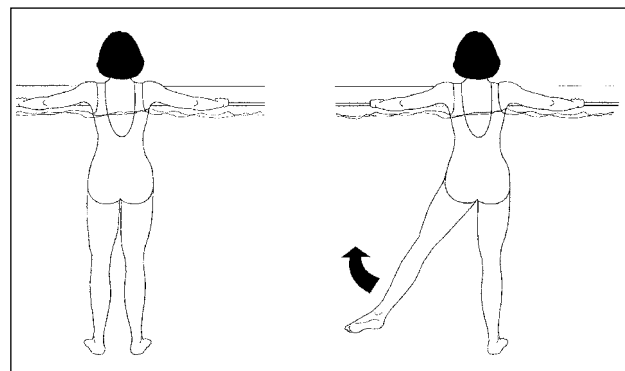
Swimming is an excellent aerobic exercise in the early stages of ALS, with minimal risk of injury to joints, muscles and tendons. Water allows for freedom of movement and reduces the energy required to perform movement.

The water temperature should be warm to reduce the incidence of cramping and premature fatigue.

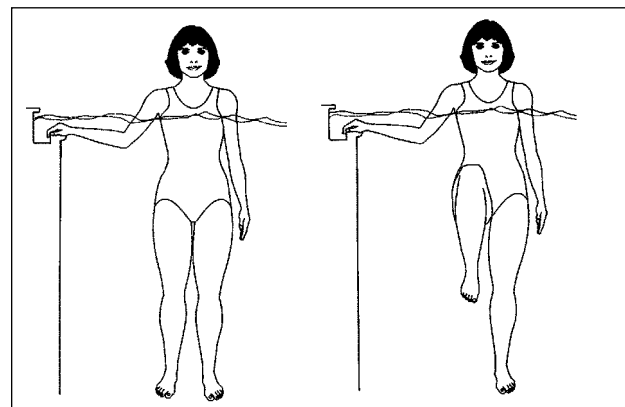
You may do the following active movements even if you can't swim laps. You should perform all of the exercises in the presence of another person for safety. You may need assistance with moving your limbs for some of the exercises.



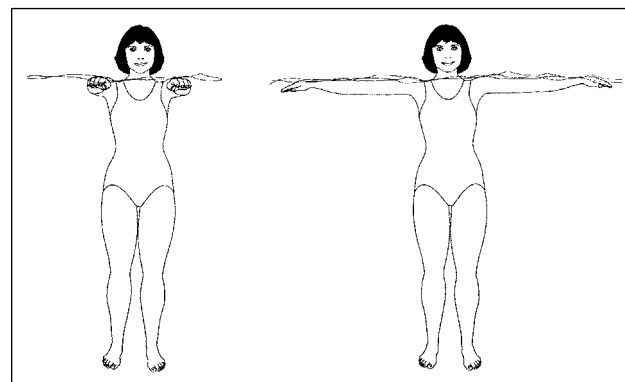
Stand facing the side of the pool. Hold on to the edge with your hands, keeping your elbows straight. Push your legs out behind you and kick up and down with your knees slightly bent.



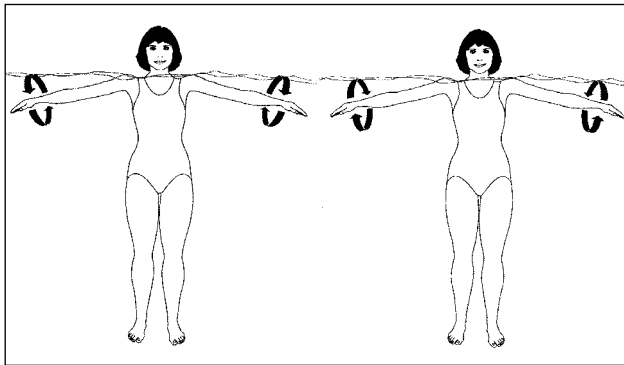
Stand facing the side of the pool. Hold on to the edge with your hands, keeping your back straight. Move one leg at a time straight out to the side, then back to the center. Repeat with the other leg.



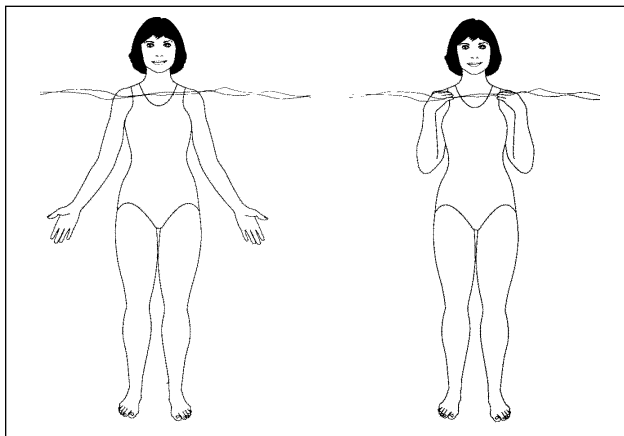
Turn sideways and hold on to the edge of the pool with one hand. Alternate legs in a marching movement, bringing your knees to waist height.



Stand with your back straight and your arms straight in front of you just below water level. Move your arms straight out to the sides, then back to the front.



Stand with your back straight and your arms straight out to the sides. Circle your arms in a clockwise motion from the shoulder, keeping your elbows straight. Reverse the motion to counter-clockwise.



Stand with your back straight, arms at your sides with the palms facing forward. Bend your arms at the elbows to touch your shoulders. Return your arms to your sides.

See page 105 for more about special aquatic workout equipment.

Spotlight on Passive Range-of-Motion

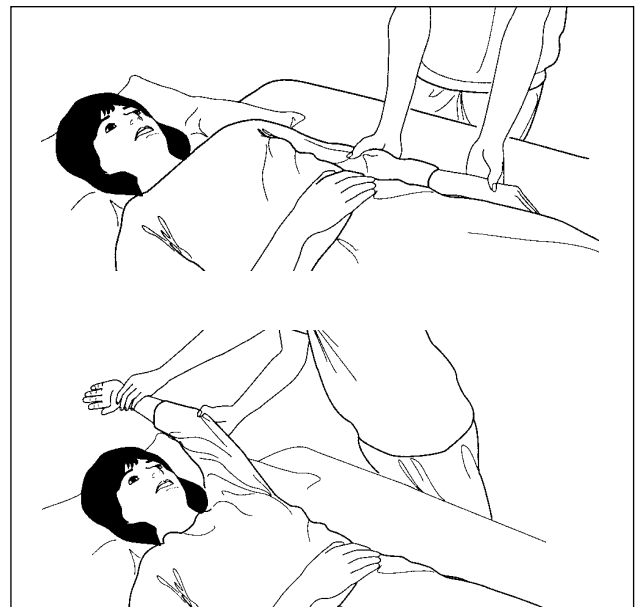
If you're unable to move against gravity, a caregiver or physical therapist can help you fully stretch your muscles and move the joints to prevent contractures associated with immobility. For maximum benefit, it's important that you continue to participate as fully as possible.

The following illustrations indicate normal range-of-motion of each joint. If strong resistance or pain occurs, stop the movement.

These instructions are written to the caregiver.

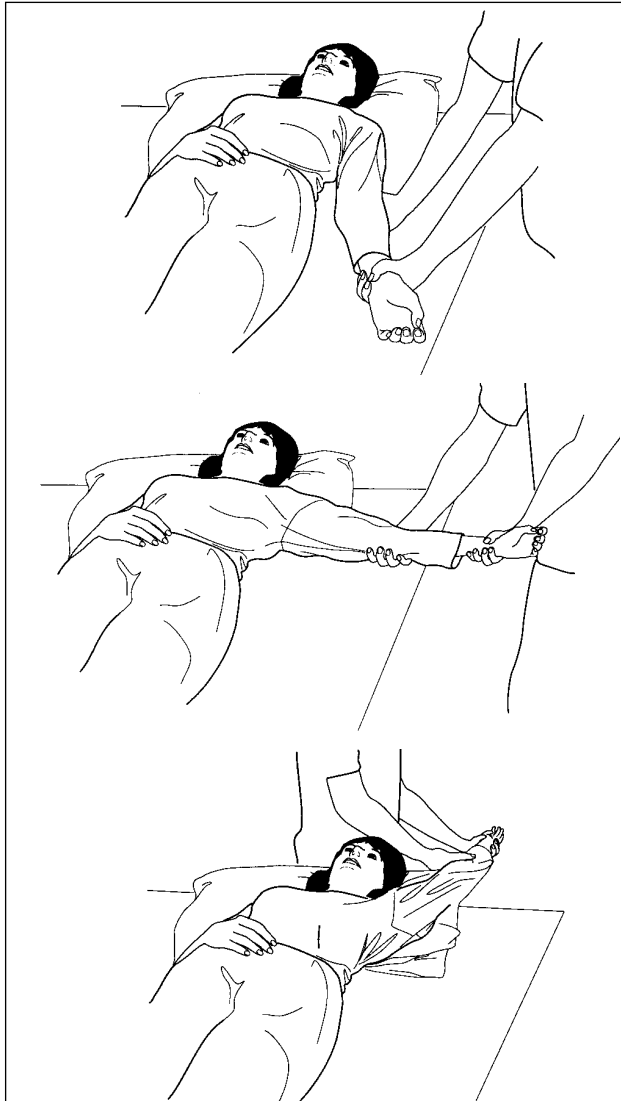
Arm Exercises

Shoulder

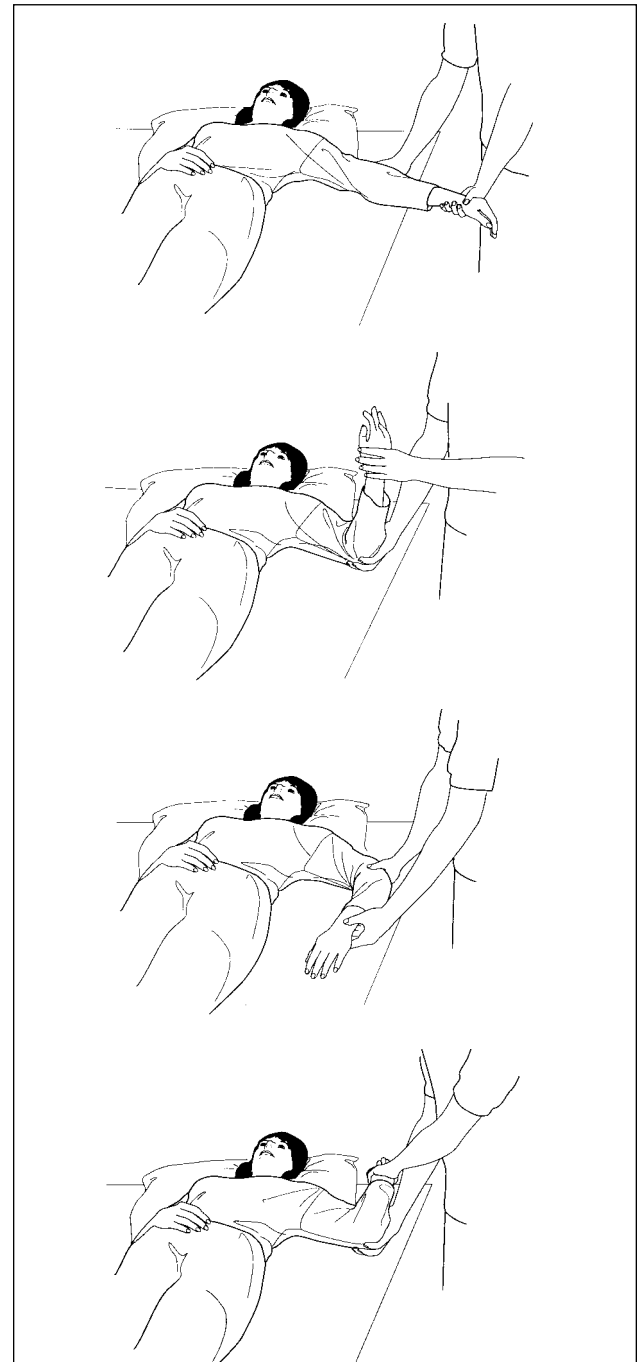


Help the person with ALS lie comfortably on his or her back. Place the person's arm at his or her side.

Supporting the elbow and wrist, pick the arm up and over the head to a position behind the ear. Return the arm to the person's side.

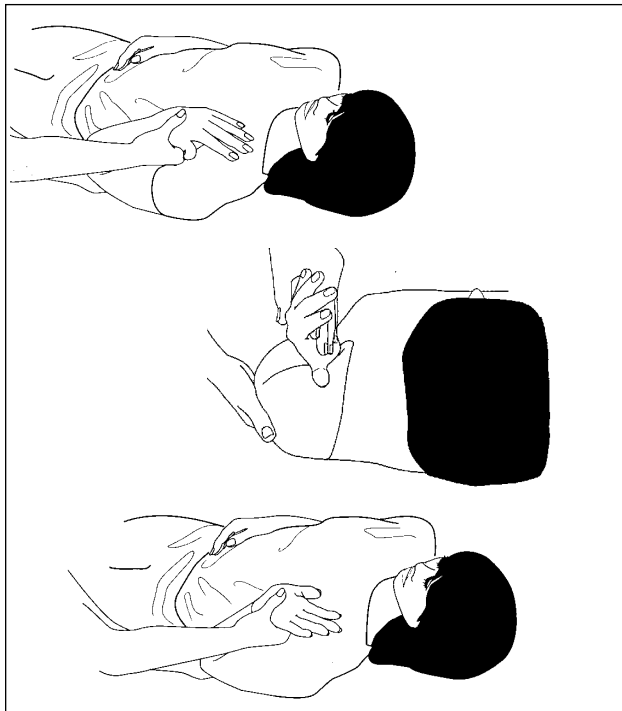


Supporting the elbow and wrist, move the arm along the bed to a position above the person's head and next to his or her ear. Return the arm to the person's side.

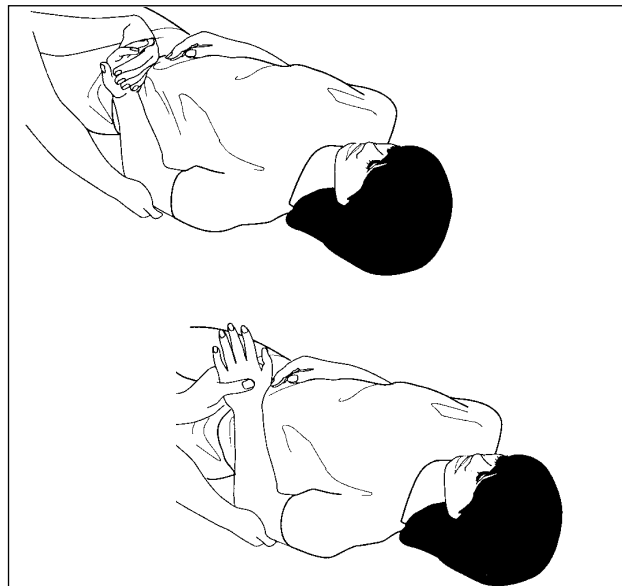


Move the arm along the bed to shoulder level. Bend the elbow to 90 degrees (hand pointing toward ceiling). Support the elbow and wrist and keep elbow stabilized. Rotate the arm until the hand and wrist touch the bed near the hip and rotate the arm back until the wrist touches the bed near the head.

Elbow

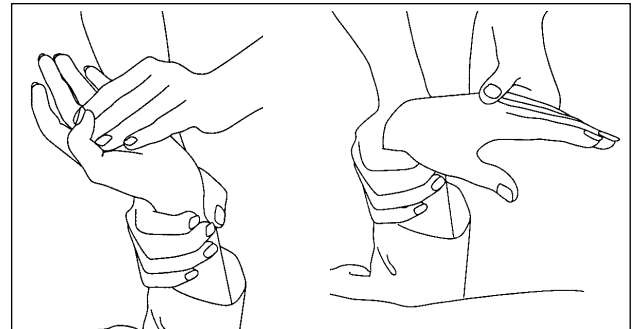


Stabilize the elbow and bend and straighten it in three positions: palm down, thumb down and palm up.

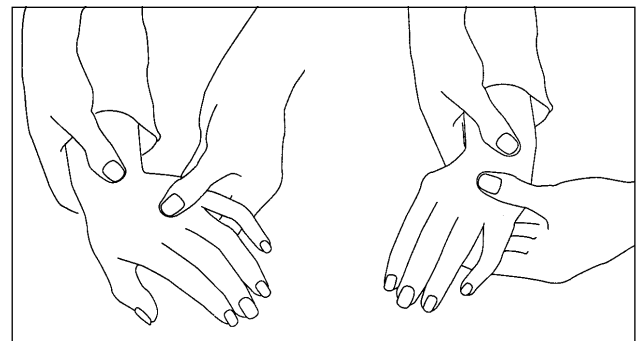


With the elbow bent at the person's side, rotate the palm toward and away from the person's face.

Wrist

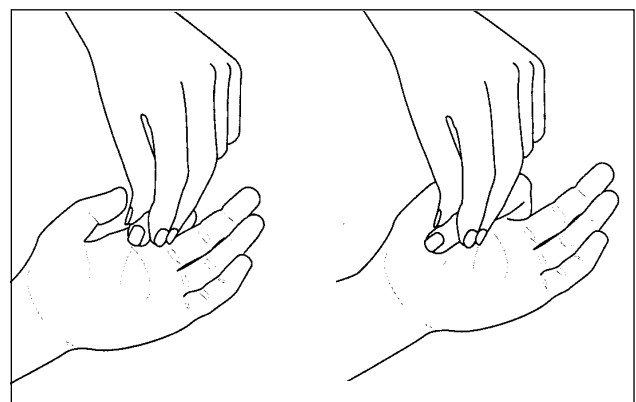


Holding the wrist and hand, bend the wrist up and down as if waving.

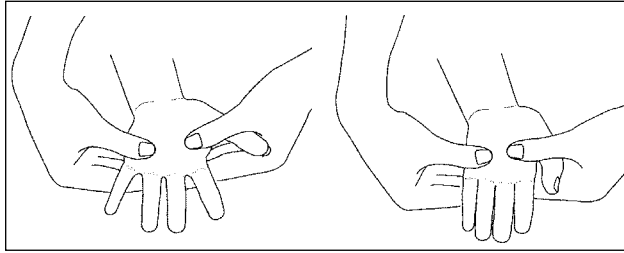


Holding the arm and hand, with the wrist straight, bend the hand to one side and then the other.

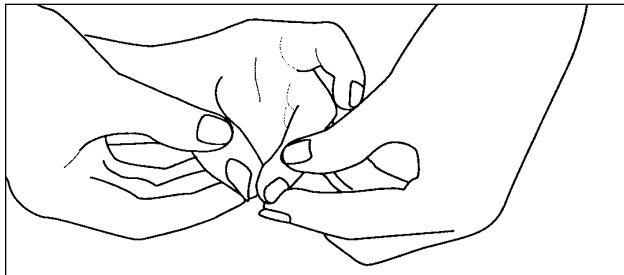
Fingers



Take each finger and pull gently to touch the base of the finger and then the heel of the hand.



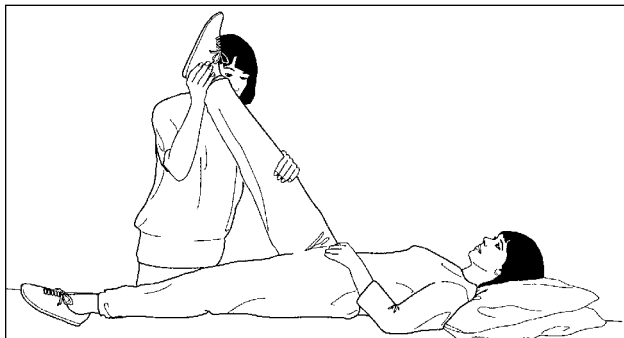
Straighten each finger. Spread the fingers apart and back together.



Touch the tip of each finger to the tip of the thumb.

Leg Exercises

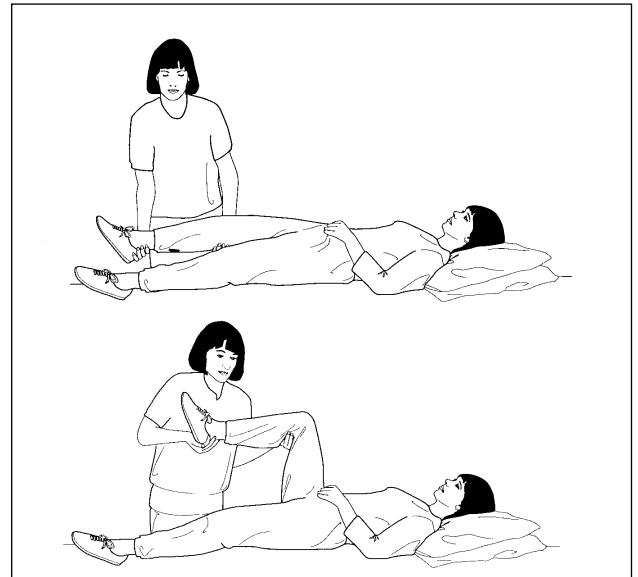
Hip



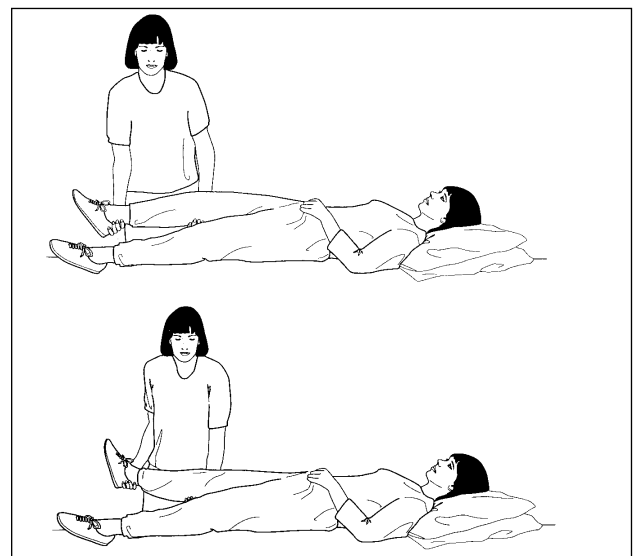
Help the person with ALS to lie on his or her back with legs straight and relaxed. Stand beside the leg to be exercised, and place one hand above the knee to keep it straight and the other hand under the heel.

Keeping the leg straight, slowly raise the leg until the person you're assisting

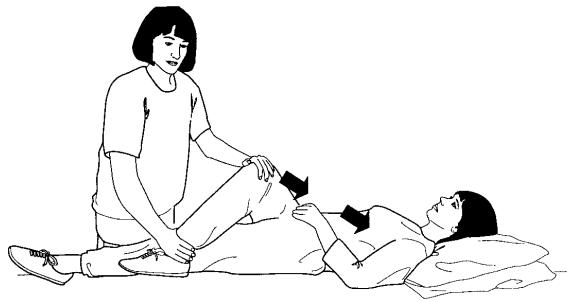
feels a stretch. Be sure to keep the other leg flat during the stretch.



Support the leg at the knee and heel, and bring the knee toward the chest. Return the leg to the bed, and repeat with the other leg.

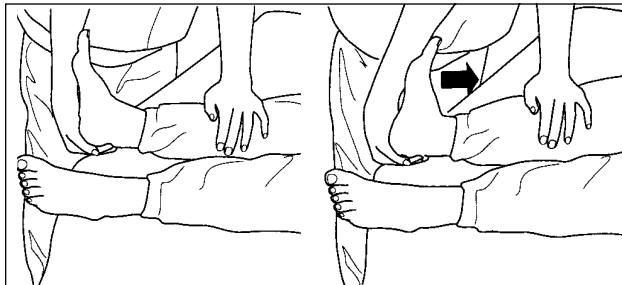


Bring the leg out to the side. Return the leg to the center. Repeat with the other leg.

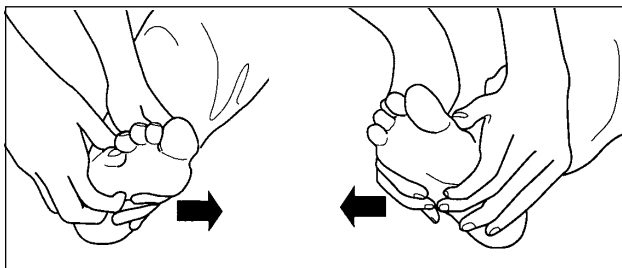


Bend the knee of one leg and cross the foot over the thigh of the other leg. Push the knee toward the opposite shoulder. Repeat with the other leg.

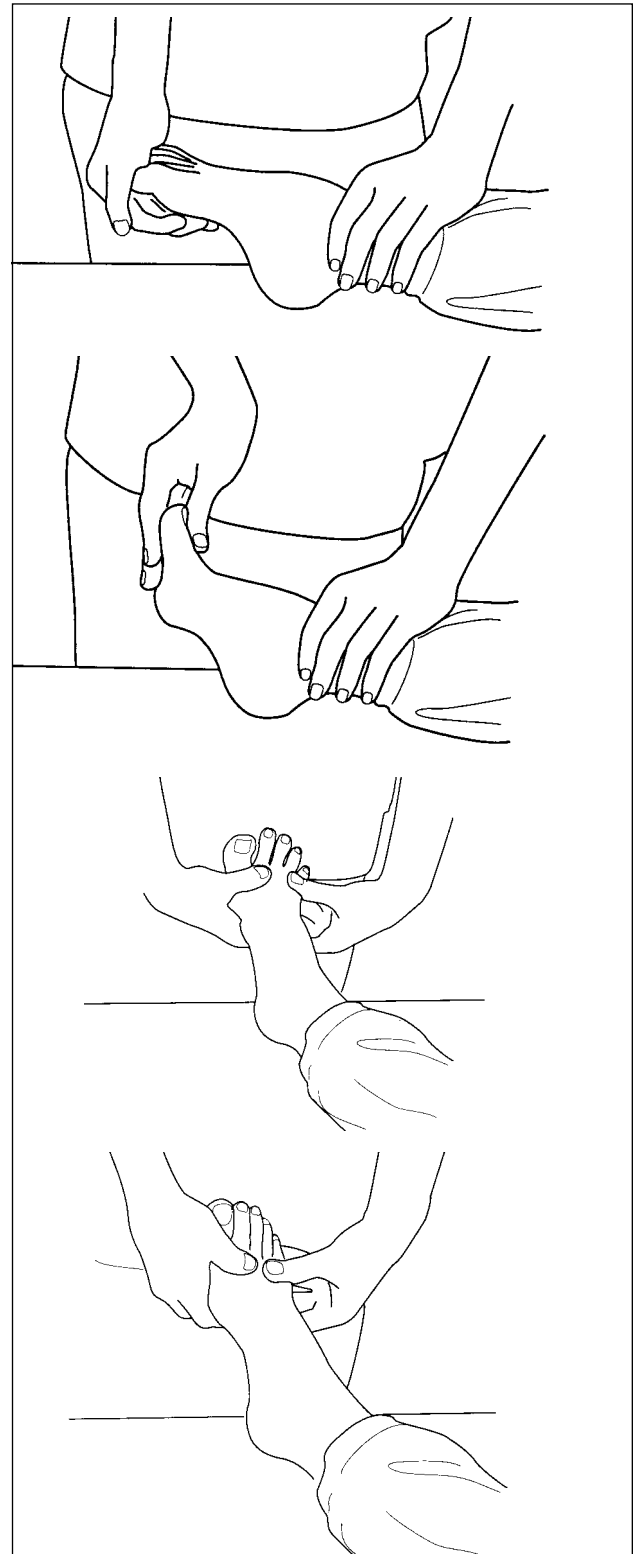
Ankle & Toes



Place one hand on the person's shin and cup the heel in your other hand. Gently bend the ankle upward by pushing against the bottom of the foot with your forearm. Don't allow the foot to turn in or out.



Grasp the foot and turn the bottom of the foot toward the inside and then the outside.



Bend and straighten each toe. Spread the toes apart and then return them to the original position.

Chapter 10

Resources



MDA
ALS DIVISION
als.mda.org
(800) 572-1717

The Muscular Dystrophy Association, one of the nation's largest voluntary health agencies, works to defeat neuromuscular diseases. MDA's ALS Division provides a vast array of services to people with ALS, one of more than 40 diseases covered by MDA. Since the early 1950s, MDA has been the world leader in battling ALS and providing services for those with the disease.

Through more than 200 local offices covering every U.S. community, MDA can help you and your family deal with ALS in many ways, including:

■ **CLINICS**

Initial diagnostic services and therapeutic and rehabilitative care are offered at MDA's network of clinics and MDA/ALS centers nationwide. MDA clinics are staffed by top neuromuscular disease specialists and health care experts. Go to als.mda.org/clinics/alsserv.html for a current list of MDA/ALS centers.

■ **EMOTIONAL SUPPORT**

There are more than 240 MDA support groups across the country for people affected by neuromuscular diseases, their families and caregivers. Many are specific to ALS.

■ **EQUIPMENT ASSISTANCE**

MDA assists individuals with obtaining durable medical equipment (DME) through its national equipment loan program and referrals to community resources. People registered with MDA can receive help 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.

■ **FLU SHOTS**

The Association pays for annual flu shots for people registered with MDA. Flu shots can help protect the respiratory system.

■ **ONLINE SUPPORT**

MDA's ALS Division Web site (als.mda.org) offers news and a series of regularly

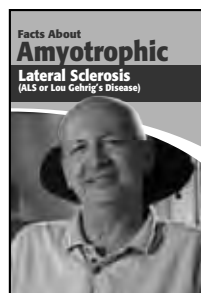
scheduled online chats, plus occasional conferences with ALS specialists and experts. Transcripts of past chats are posted. MDA also provides online support services through the e-community *myMDA*, where users can exchange information and interact with fellow community members through blogs, message boards, e-mails and photos/videos. And, *myMuscleTeam* is an online program that helps individuals and caregivers recruit and coordinate in-home help.

■ **PUBLICATIONS**

MDA offers books, pamphlets and periodicals helpful to people with ALS. Printable copies of MDA publications can be found at mda.org/publications; many are available in English and Spanish. Ask your local office or call (800) 572-1717 if you need help obtaining printed copies.

***Breathe Easy:
Respiratory Care in
Neuromuscular Disorders***

This MDA booklet covers all aspects of respiratory care, including an explanation of how neuromuscular diseases affect breathing, and a summary of available treatment and therapy techniques.



***Facts About
Amyotrophic Lateral
Sclerosis***

This MDA booklet describes the disease's symptoms, causes and

treatments for those with new diagnoses.

MDA ALS Caregiver's Guide

This book offers more than 200 pages about topics of concern to caregivers of people with ALS — from emotional and financial concerns, to everyday care tasks and finding help.



MDA/ALS Newsmagazine

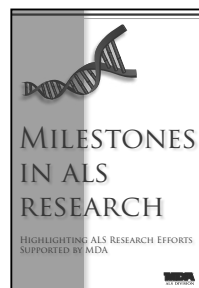
This bimonthly magazine gives you the latest ALS research news, articles for caregivers, profiles of people affected by ALS, and information about coping and living with the disease. If you're registered with MDA, you'll be mailed the newsmagazine. Back issues are available through your local MDA office; at als.mda.org/publications or by calling (800) 572-1717.

Meals for Easy Swallowing

This online recipe book is available at als.mda.org/publications/meals.

Milestones in ALS Research

Major developments in ALS research are tracked from the 19th century.



Quest

MDA's quarterly magazine covers research on neuromuscular diseases, and features in-depth articles on health, personal and family issues, equipment,

technology, resources, advocacy and more. This award-winning magazine is sent to everyone registered with MDA.

Quest Magazine Online Quest's online site (quest.mda.org) features everything found in the print magazine, plus extra content related to magazine stories. The site is updated with Quest News articles several times a week. Browse a huge library of information about muscle disease.

MDA booklets, periodicals and videos can be found at your local MDA office, or by calling (800) 572-1717 and asking for the publications department. Downloadable versions of MDA publications can be found at mda.org/publications. Some publications can be ordered online at mda.org/publications/puborder.aspx. Many booklets are available in Spanish.

■ **RESEARCH**

MDA's ALS Division is the nation's largest nongovernmental sponsor of ALS research, providing grants to top medical and scientific investigators worldwide. As of early 2010, MDA had invested more than \$270 million in its ALS research program.

■ **VIDEOS**

MDA-produced videos address concerns of people with ALS, their loved ones and caregivers.

Breathe Easy: A Respiratory Guide for People Living with Neuromuscular Diseases

Assisted breathing devices and techniques are explored in this medical education video.

Breath of Life

This version of “Breathe Easy” is geared to physicians and other medical professionals.

With Hope and Courage: Your Guide to Living with ALS

Geared to people with new ALS diagnoses and their families, this video designed both to orient and inform.



If you have a question about ALS, someone at MDA will help you find the answer. To find out more about MDA's services, call your local MDA office or (800) 572-1717, or visit als.mda.org.



GENERAL RESOURCES ABOUT ALS

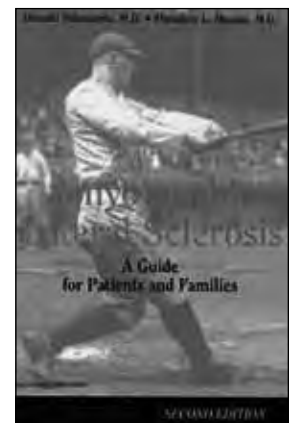
In addition, consult the **MDA ALS Caregiver's Guide**, the companion book to **Everyday Life with ALS**, for a multitude of resources on a wide range of topics. The guide can be found by contacting your local MDA office or at als.mda.org/publications/alscare.

BOOKS

ALS — Lou Gehrig's Disease, by Mary Dodson Wade, 2001. Enslow Publishers, www.enslow.com, (800) 398-2504. Written for grades 6 and up.

Amyotrophic Lateral Sclerosis, by Robert G. Miller, M.D., Deborah Gelinas, M.D., and Patricia O'Connor, R.N., 2004. Demos Medical Publishing, www.demosmedpub.com, (800) 532-8663. Geared to patients and families, with focus on treatments.

Amyotrophic Lateral Sclerosis: A Guide for Patients and Families, 2nd ed., by Hiroshi Mitsumoto, M.D., and Theodore L. Munsat, M.D., 2001. Demos Medical Publishing, www.demosmedpub.com, (800) 532-8663.



Palliative Care in ALS, by David Oliver, Gian Domenico Borasio and Declan Walsh, 2000. Oxford University Press, www.oup-usa.org, (800) 445-9714.

BOOKS BY OR ABOUT PEOPLE WITH ALS

Bigger Than the Sky — The True Love Story of Emilie and Her Grandfather (for children), by Helene E.D. Nichols, 2003. Xlibris, www.Xlibris.com, (888) 795-4274.

Challenging Nature Photography, by Angelo Sciulli, 2003. Order from www.ebookstand.com/book_details/Challenging_Nature_Photo, (866) 793-9365, authorservices@ebookstand.com.

Falcon's Cry: A Desert Storm Memoir, by Major Michael Donnelly with Denise Donnelly, 1998. Praeger Publishers, www.greenwood.com, (800) 368-6868.

How Will They Know If I'm Dead? Transcending Disability and Terminal Illness, by Robert C. Horn III, with preface by C. Everett Koop, M.D., 1996. GR Press/St. Lucie Press.

I Choose to Live: A Journey Through Life with ALS, by William Sinton, 2003. Banbury Publishing, www.banburypublishing.com, (847) 855-8840.



Learning to Fall: The Blessings of an Imperfect Life, by Philip Simmons, 2002. Bantam Dell.

Letting Go: Morrie's Reflections on Living While Dying, by Morrie Schwartz, published in 1996, reissued in 1999 as ***Morrie: in His Own Words***. Walker & Company, www.walkerbooks.com, (888) 330-8477.

Meaning of a Disability: The Lived Experience of Paralysis, by Albert B. Robillard, 1999. Temple University Press, www.temple.edu/tempres, (800) 621-2736.

Morrie: In His Own Words, by Morrie Schwartz, 1999. Walker & Co., www.walkerbooks.com, (888) 330-8477.

Not in Kansas Anymore (autobiography), by Robert Paulson, 2009. Robert E. Paulson, <http://bobpaulsonbook.blogspot.com>.

On Any Given Day, by Joe Martin and Ross Yockey, 2000. John F. Blair Publisher, www.blairpub.com, (800) 222-9796.

Terminally Sane: One man's journey beyond Lou Gehrig's disease, by Jay A. Rouelle, 1999. Jarou Publishing, trouelle@pshift.com, (802) 223-5347.

Tuesdays with Morrie, by Mitch Albom, 1997. Doubleday, www.randomhouse.com/doubleday.

When It Rains ... (novel), by Marjorie Spoto, 2002. Weaver Books and When it Rains LLC, www.marjoriespoto.com.



RESOURCES BY CHAPTER

Quest and MDA/ALS Newsmagazine articles can be found on the MDA Web site (mda.org). Enter the article's name into the "search our site" box. Or, call your local MDA office or (800) 572-1717 and request a copy.

INTRODUCTION: Your Health Care Team

MDA ALS Caregiver's Guide
Chapter 1: The ALS Caregiver

MDA Articles

"MDA ALS Support Groups," MDA/ALS Newsmagazine, November-December 2009

"The Lowdown on Following Up," MDA/ALS Newsmagazine, February 2009

"Social Workers Offer a Wealth of Resources," MDA/ALS Newsmagazine, September 2007

"How a Nurse Practitioner Fits Into the Health Care Puzzle," MDA/ALS Newsmagazine, November-December 2006

"Share the Care' Circles," MDA/ALS Newsmagazine, May, June & July 2003

"People with ALS Win with Multidisciplinary Team Approach," MDA/ALS Newsmagazine, December

2001

CHAPTER 1: Equipment for Daily Living

MDA ALS Caregiver's Guide —
Chapter 2: Daily Care of Your Loved One with ALS

MDA Articles

"Get Up, Get Out, Get Going," *Quest*, November-December 2008

"Low-Tech, Low-Cost Assistance for Daily Living," MDA/ALS Newsmagazine, September 2008

"Splish Splash: Easier Ways to Get Clean," *Quest*, January-February 2008

"Sleep Aids: Low-Tech Strategies for Improving Sleep Comfort," MDA/ALS Newsmagazine, March 2007

"Write On: Low-Cost, Low-Tech Items Can Boost Weak Hands," MDA/ALS Newsmagazine, June 2005

"Fun for the Holidays: Gift Ideas," *Quest*, November-December 2003

"Great Gadgets, Gizmos and Gottahaves," *Quest*, October 2002

"Holiday Gifts that Sparkle with Style" (adaptive clothing), *Quest*, October 2001

"Gift Ideas for Every Room in the House," *Quest*, October 2000

MDA Equipment Loan Program

MDA assists individuals with obtaining and repairing durable medical equipment through its national equipment loan program. The program is open to anyone for whom durable medical equipment has been recommended by an MDA clinic doctor.

Through its local field offices, MDA gratefully accepts donations of durable medical equipment for distribution through its equipment loan program. MDA is able to make minor repairs to gently used equipment. MDA staff also can help you locate other local sources and funding options for daily equipment and assistive technology.

Organizations

American Occupational Therapy Association

(301) 652-2682

www.aota.org

Can help you find a specialist in your area.

National Library Service for the Blind and Physically Handicapped

(800) 424-8567

www.loc.gov/nls

Through a national network of cooperating libraries, NLS administers a free library program of Braille and audio materials circulated to eligible borrowers in the United States by postage-free mail.

CHAPTER 2: Saving Energy

MDA ALS Caregiver's Guide — Chapter 8: Finding Caregiving Help

MDA Articles

“Think Mobile,” MDA/ALS
Newsmagazine, September-October 2009

“Fighting Off Fatigue,” MDA/ALS
Newsmagazine, April 2009

“Arming You with Tips for Living
with Arm Weakness,” MDA/ALS
Newsmagazine, February 2006

“Fatigue,” *Quest*, January-February 2005

“The Practical Chef's Cooking Tips,” in
“Design Your Kitchen to Fit You,” *Quest*,
September-October 2003

“‘Share the Care’ Circles,” MDA/ALS
Newsmagazine, May, June & July 2003

Other Resources

ALS Care

www.alscare.com

Suggestions and practical tools for coping with daily issues faced by people with ALS, their families and health care providers.

myMuscleTeam

MDA's site mda.org/mymuscleteam helps individuals and caregivers recruit and coordinate in-home help.

Support Team Network

(877) 614-9129

www.SupportTeam.org

A training and resource center for the development of volunteer support teams for people with health concerns or other special needs.

Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill, by Cappy Capossela and Sheila Warnock, 1995, Fireside.

CHAPTER 3:

Home Modifications

MDA ALS Caregiver's Guide —
Chapter 2: Daily Care of Your Loved One with ALS

MDA Articles

"Help Where You Live: Finding Funding for Home Mods," *Quest Extra*, September-October 2008

"Home Mods: Finding the Perfect, Used Accessible Home," *Quest Extra*, September-October 2008

"Home Mods: Taking it to the Next Level," *Quest Extra*, September-October 2008

"Home Mods: A Hodgepodge of Mods," *Quest Extra*, September-October 2008

"Home Mods: 'Everything was Falling Apart,'" *Quest*, September-October 2008

"InfoQuest: Funding Home Modifications," *Quest*, September-October 2008

"In Search of Barrier-Free Living: Making the House an Accessible Home," *MDA/ALS Newsmagazine*, July-August 2008

"InfoQuest: Accessible Housing Resources," *Quest*, July-August 2007

"Bathroom Remodeling," *Quest*, March-April 2005

"Staying Put" (home modification), *Quest*, September-October 2004

"Design Your Kitchen to Fit You," *Quest*, September-October 2003

"The Great Escape," *Quest*, February 2002

"Stairs — Who Cares?" *Quest*, December 1998

Other Resources

Charles Schwab Architects

(563) 359-7524

www.universaldesignonline.com

Book of 83 fully accessible home plans

MDA Equipment Loan Program

To the extent feasible and when available, the program provides recycled durable medical equipment medically prescribed in relation to an individual's

neuromuscular disease. MDA staff also can help you locate other local sources and funding options.

National Association of Home Builders
(800) 368-5242
www.nahb.org/page.aspx/category/sectionID=225

New Horizons Un-Limited
www.new-horizons.org/gdbhac.html

Rebuilding Together
(800) 473-4229
www.rebuildingtogether.org
This free home repair and modification program run by volunteers assists people with disabilities and the elderly. The program can build ramps, install grab bars, modify bathrooms, widen doorways or perform general repair.

Remodeling's Guide to Buying a Home for People with Disabilities: Accessible Homes and Accessible Home Modifications Remodeling Online
(202) 452-0800
www.remodeling.hw.net

The Right Space: A Wheelchair Accessibility Guide for Single-Family Homes, by A.M. Ayala, 2005. Debold-Marquez Books LLC, www.trspace.com, (602) 309-5169.

U.S. Department of Housing and Urban Development
(202) 708-1112
www.hud.gov/groups/disabilities.cfm

Your local MDA office, independent liv-

ing center or Chamber of Commerce may have a list of organizations or programs that can assist with residential ramp installation and costs.

CHAPTER 4: Mobility & Support Equipment

MDA ALS Caregiver's Guide —
Chapter 2: Daily Care of Your Loved One with ALS

MDA Articles

"Accessible Vehicles Q&A," *Quest*, July-August-September 2009

"Emergency Roadside Assistance for Wheelchair Users," *Quest*, July-August-September 2009

"Who Ya Gonna Call When Air Travel Goes Bad?" *Quest*, July-August-September 2009

"Travel Scooters Offer an Easy Way to Go," *Quest*, July-August-September 2009

"Turning Seats Can Enhance Mobility," *Quest*, July-August 2008

"Wheelchair Cushions Can Save Your Butt," *Quest*, July-August 2008

"Keep on Keepin' On: Wheelchair Control Upgrades Keep You Moving," *MDA/ALS Newsmagazine*, January 2008

"Cane, Crutches and Walkers," *Quest*, November-December 2007

“Equipment Corner: Programs Make Vehicles More Affordable,” MDA/ALS Newsmagazine, June-July 2006

“Scooters Not Always Wise in ALS,” MDA/ALS Newsmagazine, September 2005

“Travel Tips,” MDA/ALS Newsmagazine, April 2005

“Get Time on Your Side When Obtaining Major Equipment,” MDA/ALS Newsmagazine, January 2005

“Gift Ideas to Keep Wheelchair Users Organized,” *Quest*, November-December 2004

“Wheelchair Control Devices Keep You Driving,” MDA/ALS Newsmagazine, October 2004

“Determined to Drive: Taking Matters in Hand,” *Quest*, March-April 2004

“When Your Plan is a Van,” *Quest*, March-April 2004

“Leaving on a Jet Plane,” *Quest*, March-April 2003

“*Quest* Man’s Super Stuff” (portable equipment), *Quest*, August 2002

“Getting Off the Road,” *Quest*, April 2002

In addition to these articles, browse these *Quest* departments at quest.mda.org: “As the Wheel Turns” contains articles about important topics for

wheelchair or scooter users; and “To Boldly Go” is a regular *Quest* column offering tips on travel and accessible destinations.

Organizations

American Physical Therapy Association

(800) 999-2782

www.apta.org

APTA can help you find a specialist in your area.

Rehabilitation Engineering and Assistive Technology Society of North America

(703) 524-6686

www.resna.org

Association for Driver Rehabilitation Specialists

(866) 672-9466

www.driver-ed.org

National Mobility Equipment Dealers Association

(800) 833-0427

www.NMEDA.org

National Registry of Rehabilitation Technology Suppliers

(800) 976-7787

www.nrrts.org

Accessibility Information

Americans with Disabilities Act

www.ADA.gov

“New Horizons: Information for the Air Traveler with a Disability”
airconsumer.ost.dot.gov/publications/horizons.htm

Federal Transit Administration
www.fta.dot.gov/transit_data_info/ada/
www.fta.dot.gov/civilrights/civil_rights_2360.html

For local transportation services, check in your phone book under “Wheelchair & Special Needs Transportation” or “Taxicabs.”

For vans, look in the phone book under “Van Conversions” or “Handicapped Equipment.” Search the Internet for “accessible vans” or “wheelchair vans.” You also can rent accessible vans through local or national services.

CHAPTER 5: Respiratory Issues

MDA ALS Caregiver’s Guide —
Chapter 3: Respiratory Issues

MDA Videos

Breathe Easy: A Respiratory Guide for People Living with Neuromuscular Diseases and Breath of Life

MDA Articles

“Do You Have Backup Power?” MDA/ALS Newsmagazine, September-October 2009

“Managing Mucus Plugs,” MDA/ALS Newsmagazine, June 2009

“Not Enough ZZZzzzs?” *Quest*, March-April 2008

“NIV Masks: Finding the One That’s Just Right,” *Quest*, March-April 2008

“Thinking Outside the Ventilation Box,” MDA/ALS Newsmagazine, September 2007

“Truth, Lies and Tracheostomies,” *Quest*, July-August 2007

“Making the Switch,” MDA/ALS Newsmagazine, September 2006

“Equipment Corner: Gastrostomy Tubes,” MDA/ALS Newsmagazine, September 2006

“Safe Harbor: Rediscovering Life on a Vent,” MDA/ALS Newsmagazine, July 2005

“Great Trach Escape,” *Quest*, September-October 2003

“A Tale of Two Vent Choices,” MDA/ALS Newsmagazine, August 2003

“Noninvasive Ventilation Prolongs Life if Used Right,” MDA/ALS Newsmagazine, August 2002

“Respiratory Issues in ALS,” MDA/ALS Newsmagazine, February 2002

“Managing Saliva in ALS,” MDA/ALS

Newsmagazine, October 2001

Books

Management of Patients with Neuromuscular Disease, by John R. Bach, M.D., 2003. Hanley & Belfus, (800) 545-2522, or try a medical library.

Noninvasive Mechanical Ventilation, by John R. Bach, 2002. Hanley & Belfus, (800) 545-2522, or try a medical library.

Other Resources

American Association for Respiratory Care

(972) 243-2272

www.aarc.org

International Ventilator Users Network

(314) 534-0475

www.post-polio.org/ivun

CHAPTER 6: Speech & Communication

MDA ALS Caregiver's Guide —
Chapter 4: Communication Issues

MDA Articles

“Banking for the Future,” MDA/ALS Newsmagazine, November-December 2009

“‘Lightning Fast’ Switch Increases Accuracy, Reduces Fatigue,” *Quest*, July-August-September 2009

“‘Eyes’ on the Prize,” MDA/ALS Newsmagazine, June 2009

“‘Eye’ on Technology Update,” MDA/ALS Newsmagazine, March 2009

“Look Ma! No Hands! — Head Mouse, Virtual Clickers Provide Hands-Free Computer Access,” MDA/ALS Newsmagazine, January 2009

“The ‘EYES’ Have It,” MDA/ALS Newsmagazine, October 2008

“A Complete Communication Solution,” MDA/ALS Newsmagazine, July-August 2008

“Making the Switch,” *Quest*, March-April 2008

“Let Your Feet Do the Talking,” MDA/ALS Newsmagazine, March 2008

“Equipment Corner: Voice Banking & Speech Synthesis Technology,” MDA/ALS Newsmagazine, July 200

“Free Dasher Program Easy as ABC,” MDA/ALS Newsmagazine, February 2005

“Get Time on Your Side When Obtaining Major Equipment,” MDA/ALS Newsmagazine, January 2005

“Options at Your Fingertips,” *Quest*, September-October 2004

“Access Unlimited,” *Quest*, May-June 2004

“Speaking of Speaking,” MDA/ALS Newsmagazine, August 2003

“Talking with Technology,” *Quest*,
March-April 2003

“Keep Talking with Technology,” *MDA/
ALS Newsmagazine*, November 2002

“High Tech Talk,” *MDA/ALS
Newsmagazine*, July 2002

“Sorting Out Speech Services,” *Quest*,
February 2001

“When Mouth and Throat Muscles
Weaken,” *MDA/ALS Newsmagazine*,
February 2001

“Hard to Swallow,” *Quest*, August 1999

Books and CD

*Computer Resources for People with
Disabilities*, 4th ed., by the Alliance
for Technology Access, 2004. Hunter
House, (800) 266-5592, www.hunterhouse.com.

Organizations and Web Sites

AbleData
(800) 227-0216
www.abledata.com

Alliance for Technology Access
(800) 914-3017
www.ataccess.org

**American Speech-Language-Hearing
Association (ASHA) Action Center**
(800) 914-3017
www.asha.org

Closing the Gap
(507) 248-3294
www.closingthegap.com

**Communication Independence for the
Neurologically Impaired**
(631) 878-0642
www.cini.org

**Easy Access to Software and
Information**
(949) 916-2837
www.easi.cc

**National Rehabilitation Information
Center**
(800) 346-2742
www.naric.com

**RESNA (Rehabilitation Engineering
and Assistive Technology Society of
North America)**
(703) 524-6686
www.resna.org

Speech to Speech (STS)
www.speechtospeech.org

**USSAAC (United States Society
for Alternative & Augmentative
Communication)**
www.ussaac.org

*Major computer and software manufac-
turers also have accessible products;
check their Web sites.*

CHAPTER 7: Transfers

MDA ALS Caregiver's Guide —
Chapter 2: Daily Care of Your Loved One
with ALS

MDA Articles

“Caregiver Exercises,” *Quest*, April-May-
June 2009

“One Good Turn,” *Quest*, September-
October 2006

“In Search of a Good Night's Sleep”
(mattresses and cushions), *Quest*, May-
June 2003

“The Lurking Dangers of Pressure
Sores,” *Quest*, February 1999

“Save Your Back! A Guide to Lifting and
Transferring at Home,” *Quest*, February
1999

CHAPTER 8: Exercise

MDA ALS Caregiver's Guide —
Chapter 2: Daily Care of Your Loved One
with ALS

MDA Articles

“Exercising with a Muscle Disease,”
Quest series, Spring (April-June) 2009

“As the Wheel Turns: Keeping It
Moving” (active and passive exercise
equipment), *Quest*, November-December
2003

“No Sweat Exercise: Aquatics,” *Quest*
July-August 2003

“Exercise Has Many Benefits for People
with ALS,” *MDA/ALS Newsmagazine*,
October 2002

“Marvelous Massage,” *Quest*, December
2000

“Right Equipment Can Make Exercise
Accessible,” *Quest*, April 1998

Video

Wellness in Motion, gentle exercise
program for people in the early to
middle stages of ALS. Department of
Neurology, University of Arizona (520)
626-4551.

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Everyday Life

with

ALS:

A Practical Guide

*MDA's Web site is constantly
updated with the latest information
about the diseases in its program.
Go to als.mda.org.*



als.mda.org

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