

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.

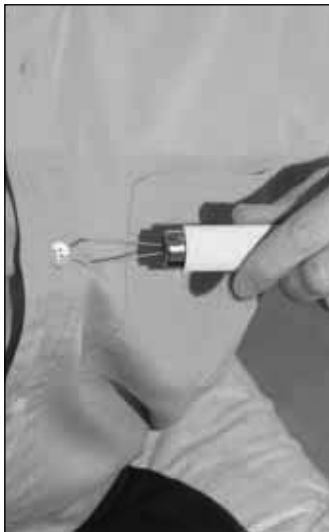
By the way, Chapter 6 will include information on adaptations for computer access. Though the chapter is called “Speech and Communication,” it will look into systems (hardware and software) that also accommodate for upper extremity dysfunction and hand weakness (switches, mouses and voice-activated controls), 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.



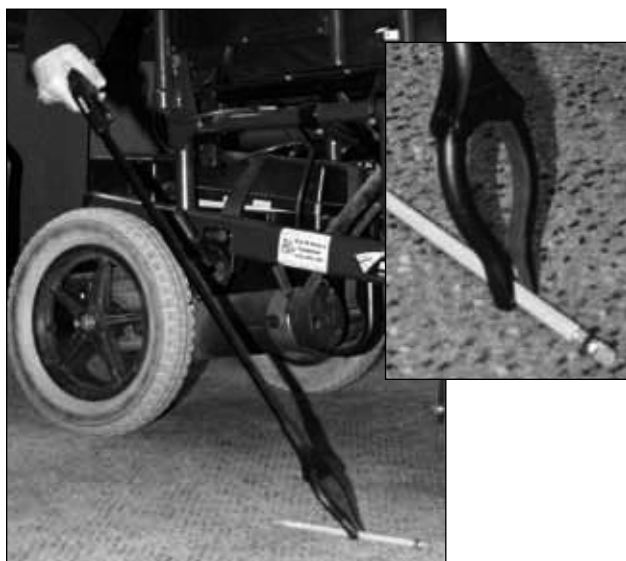
Jar Openers

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.

