ALS & ACTIVITIES OF DAILY LIVING

A Les Turner ALS Foundation Guide for People Living with ALS
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Disclaimer Statement: The information in this guide is not medical advice. Talk to your ALS care team before making any decisions about your health or treatment. Together, you and your care team can find a treatment plan that works for you.

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How ALS may affect your daily activities

While no two people with ALS are alike or will progress the same way, there is a great deal of collective knowledge and wisdom available from your ALS Care Team, people living with ALS and caregivers. Our intention is to provide you with information that you may need today and tomorrow. You may not need some of the devices in this guide.

Reading all the sections at one time can be overwhelming. We highly recommend that you focus on the information that pertains to your present circumstances.

We created this information guide to help you navigate all the changes that may occur due to ALS. In this guide you will find information on devices that can help you complete your daily activities. Daily activities include eating and drinking, dressing, toileting, bathing, oral hygiene, grooming and recreation and sleep. This guide provides tips to make daily living a little easier, if you should need extra help.

Tips for maintaining energy

You can help yourself by changing how you perform your daily activities to save energy throughout the day. The following steps will help you learn what you need to do and how you do it.

Consider what routines are necessary. Decide what you can do and how others can help you during the day. Stop doing unnecessary activities or activities that require a lot of energy. Ask others to help you when necessary.

Consider the timing or scheduling of your activities. Plan activity periods and rest periods. Pace yourself during the day.

“Make a list of the different ways ALS is impacting you. Bring in your list to discuss with your ALS care team.

“This guide is intended to get your and your family’s heads pointed in the right direction to make every day the best it can be.

Focusing on the mental and emotional aspects of the diagnosis which are the first challenge to be met, followed by an array of products and services available, as necessary.”

– Bob, a person living with ALS
Consider the best use of your energy. Sit while doing activities like cooking and folding laundry. Keep necessary items close to you to limit the amount of moving you have to do.

Place frequently used items in the most convenient place. Place heavier items at counter level or table height. This is especially important in the bathroom and kitchen.

Purchase energy-saving devices based on recommendations from your ALS care team and other people living with ALS.

Occupational therapists and physical therapists

**Occupational therapist**
- Recommends adaptations, and devices for getting through your daily routine
- Provides education, training and possible financial resources for assistive devices
- Offers ways that you can continue to participate in activities that you enjoy

**Physical therapist**
- Evaluates your strength, balance and coordination
- Introduces exercises, if appropriate
- Assesses your home for safety, adaptations and equipment needs
- Recommends adaptive mobility equipment.

To learn more about ALS & Mobility, visit lesturnerals.org/mobility

You may need a written prescription from your doctor for evaluation and treatment from therapists. Check with your insurance company for information about insurance coverage.
Different types of adaptive equipment

The following sections include examples of assistive devices that can help you with everyday activities. This list is incomplete and by no means exhaustive. Talk with your ALS care team for information on where to purchase of equipment that would be helpful to you.

Aids for Eating and Drinking

- **Built-up handles**: Use foam tubing or wash-cloths on lightweight eating utensils for decreased grip.
- **Universal cuff**:
- **EaZyHold Silicone Adaptive Aids**:
- **Offset spoon or fork that can be angled right or left**:
- **Clear plastic, clip-on plate-guard**:
- **Small pliers**: to open water bottles and jar openers
- **A non-slip disc; or Dycem**, a gel pad used to stabilize plates and cups on the table
- **Long rigid or flexible straws**

To learn more about ALS & Nutrition, visit lesturnerals.org/nutrition
Straw holder clip

Sports drink container with a straw

Food thickener (Thick-It, Thick & Easy)

Nosey cup
Provides space for the nose, allowing you to tilt the cup for drinking without bending the neck or tilting the head.

Flexi-Mug and cup holder

Large handled cup for hot and cold liquids
This allows four fingers to fit through the handle to increase stability.

Aids for Dressing

Velcro closures for clothing and shoes

Clothes with fewer closures;
knit shirts and pull-on pants

Elastic thread for cuff buttons, elastic cuff links
Choose comfortable clothing with elastic, easy to take off and on.

“I tend to think more in terms of systems, rather than individual devices. It was a combination of button hook, clip on suspenders and metal rings that allowed me to manage my pants” – Rob, a person living with ALS

For more information talk with others living with ALS and their caregivers to learn what has worked for them.
Aids for Toileting

Wet wipes for toileting

Toilet attachments for cleansing, such as portable handheld bidet or bidet washlet

Toilet buddy wiping aid or a designated pair of tongs

Urinals and bedpans

A raised toilet seat fits snugly inside the rim of the toilet on most toilets. It can be removed easily when other family members use the toilet.

Place a standard commode over the toilet to provide a raised seat and armrests. You can use a portable commode with a bucket in place of a toilet. This will decrease the distance you have to move to reach the toilet as it can be located to a place near you.

A shower commode chair on wheels can be rolled over the toilet. This will provide a raised seat and armrests. It can also be used in the shower.

Talk to your ALS care team and get training before using some of these items for your and your caregiver’s safety.
Aids for Bathing

- **Detached hand-held shower head**
- **Pump shampoo/liquid soap**
  
  dispenser instead of a squeeze bottle
- **Wall-mount soap dispenser**
- **Shampoo tray**
  
  for hair washing out of the shower
- **Long-handled sponge**
- **Long-handed hair washer**
- **A shower commode chair**
  
  on wheels with brakes or wheel locks. Some commode chairs have tilt seats with headrests, reclining backs, or straight backs.
- **Tub transfer benches**
  
  are set up across the side of the tub. The benches can be plastic or padded. They must be used with tubs that do not have shower doors. Keep in mind the size of your bathroom when buying a bench.
- **A shower chair**
  
  is a small seat that can be placed inside the tub. It can be used with tubs that have sliding glass doors. A shower chair can be used only if the patient can step into the tub.
Grab bars should be securely fastened on the shower wall for safety and support when getting in and out of the tub. Suction cup grab bars are available, but not recommended because they are less stable.

Tub rail attach to the side of the tub for stability while climbing in and out of the bathtub, approximately 12 inches to 15 inches high.

Aids for Oral Hygiene

- Foam tubing on your toothbrush handle
- A counter top toothpaste dispenser
- Disposable Dentips for mouth cleaning
- Electric toothbrush with a rotary brush
- Electric flosser and rinser (Waterpik)
- Electric tongue cleaner

To learn more about home modifications, visit: lesturnerals.org/home-modifications.
You may find it hard to blow your nose, keep your mouth clean, or remove extra saliva. These problems can lead to trouble with breathing. To learn more visit, lesturnerals.org/breathing

Aids for Grooming

- Countertop hair dryer holder stand
- Movable standing hair dryer holder
- Foam tubing on handles of comb and brush
- Large-handled, lightweight comb and brush
- Long-handled comb and brush
- Nail brush with suction cups to stick on the table or counter
Aids for Recreation

Nail clippers on stabilizing platform or board

Nail file holder

Foam tubing on the handle of a razor

Electric shaver

Adjustable-height tilt-top over-the-bed table or chair

Video games and computer games played with adaptive controls

Electronic books and audiobooks

Page-turners for physical books

Wide grip pen or pen with a grip

Cardholders

Learn more about devices for computer use, in home communication and telephone and monitor aids visit, lesturnerals.org/communication
Book holders

Rubber fingertips
for help in turning pages in books and magazines

Spring-loaded scissors

Prism glasses
for watching TV in a reclined position or when lying flat

Hand and wrist braces
to support fishing rods

Bowling ball ramps
for standing or seated bowling

Water walker
for independent pool fun

Beach wheelchair
to be able to enjoy the sun and sand
Doors, keys and voice-activated house controls

Voice-activated house controls
(Google Home, Alexa, etc.) paired with smart items such as doorbells, light bulbs, outlets, and kitchen appliances.

Touch light switches

Offset hinges
for doors that widen the doorway without reconstruction

Keyholder

Changing doorknobs
to lever handles or using lever adapters over knobs

Hand Keyper
(key holder, tab lifter, letter opener, magnet, nail file)

Braces, splints and slings

Neck braces, splints and slings are used to support or straighten weak areas of the body. Using these supportive devices can decrease pain and the chances of contractures.

An orthotist is a healthcare professional who makes and fits braces and splints (orthoses). Some orthoses require prescription from your physician. Contact your insurance company before making an appointment.

For more information on mobility aids and to learn more about the benefit of leg braces visit, lesturnerals.org/mobility
Types of neck orthoses include:

A **buddy pillow** is a travel pillow with a fleece cover for neck support when sitting. Microbead filled pillows stay cooler and can be used many different ways. Memory foam filled pillows provide more support, but may not be as comfortable.

A **soft cervical collar** is an affordable neck orthosis. You can buy it at your local drug store or any medical supply house. The collar may restrict swallowing if too snug. It is not covered by insurance.

**Splints and slings for arm and hand weakness**

Shoulder, elbow, wrist, and hand orthoses can be used to prevent contractures and pain. They also promote the use of arms and hands. Orthoses and other supports must be evaluated by your ALS care team.

Arm and hand orthoses include:

- A **resting hand splint**, can be helpful. It is used to support weak wrist and hand muscles during the day or at night.
- **Slings** for severely weak arms will support shoulder joints and decrease the risk of partially dislocating your shoulder.
- **A balloon brace**, which is a carrot shaped inflatable brace that fits in the palm of your hand to prevent contractures.

**Posture support**

Trunk supports are used to support weak muscles, improve posture, and relieve muscle pain from strained muscles. Special cushions and other aids are available help you to relieve your discomfort. Using trunk support may help with speaking and breathing. Please talk to your ALS care team to learn more.
Sleeping

Hospital beds and mattresses can help in positioning your body. This helps to prevent pressure-related problems like skin breakdown. Hospital beds require a letter of medical necessity from your doctor in order to be covered by insurance. There are different ways to modify your own bed. Talk with your ALS care team about ways to make sleeping more comfortable.

Hospital Beds

**Manual frame:** The mattress height can be set at a low or high position. Manual cranks are used to change the position of the head and foot sections.

**Semi-electric frame:** The height can be set at a low or high position. A power switch raises the head and foot positions.

**Full electric frame:** A power switch adjusts the bed frame height to make transferring easier. You can also adjust the head and foot positions of the bed. Full electric frame does not mean a full-size bed.

**Side rails:** Full-length or half-length side rails give you leverage to turn yourself from side to side. Half-length rails make it easier to transfer to and from the bed.

Modifying your own bed

Electric bed frames are available if you want to recline or sit up in bed, but don’t want to buy a hospital bed. You can purchase them at most mattress stores. You can also purchase side rails and other accessories for the bed you already own.
Do I need pressure-relief pads or mattresses?
Pressure relief is important in preventing pressure sores. Pressure relief means moving your body when sitting or lying down to allow your blood to move throughout your body. Specialized mattresses and cushions are available to use at home. They are not necessary if a caregiver can help you change position.

Artificial sheepskin can be used under the fitted sheet. Use on top of the sheet allows more air circulation. It is washable and more buoyant than egg-crate foam.

An alternating pressure mattress is used under the sheet. It works with an electric compressor to raise and lower pockets of air under the body area. A prescription and letter of medical necessity are required.

Therm-a-Rest air mattress provides insulation and pressure padding. A nylon cover allows easier movement in bed when the mattress is placed under the sheet.

Roho mattress is available as a low-profile or high-profile air mattress. It can be a sectional (three sections for a hospital bed) or a full-length bed mattress. A prescription and a letter of medical necessity are required.

Temperfoam mattress, a gel foam mattress or pad provides maximum pressure relief. It is heavy once in place and needs a prescription and letter of medical necessity.

A low air-loss mattress moves air from one side of the mattress to the other to reduce pressure on the body. A prescription and a letter of medical necessity are needed for insurance coverage.

If you cannot move to relieve pressure on yourself, it is important that someone or a device help you relieve pressure.

Talk to your ALS care team to learn more about pressure relief and how to prevent skin breakdown.
Learn more

The Les Turner ALS Foundation exists to guide you to answers, support you and your loved ones and advance scientific research. To learn more about living with ALS visit, lesturnerals.org/resources.

My ALS Decision Tool™
If you have ALS, you will need to make some important decisions about your health care. As your disease progresses, your ALS care team may recommend different care options. You can use this tool to learn about some common ALS treatments, answer a few questions to help you think through what is most important to you and get ready to talk with your ALS care team about your options. To learn more visit, alsdecisions.org.

ALS Learning Series
Our online ALS Learning Series aims to empower the ALS community through the latest information and insights. Educational webinars and interactive Q&A's covering a diverse array of topics, from nutrition to respiratory care, are offered monthly featuring members of the Foundation’s Support Services team, our Lois Insolia ALS Clinic at Northwestern Medicine and other national ALS experts. To learn more about ALS care and research visit, alslearningseries.org.

My ALS Communication Passport to Quality Care
My ALS Communication Passport to Quality Care was created to make your life easier. You will be able to share health information and care preferences with caregivers. You have a lot of information to keep track of, and this tool will help you do that. To find out more, visit, lesturnerals.org/passport.

Support Groups
We facilitate support groups to provide people living with ALS, caregivers and their family the opportunity to share their experiences, give encouragement and help each other navigate their journey with ALS. To find out more, visit, lesturnerals.org/support-groups