

ALS & ACTIVITIES OF DAILY LIVING

A Les Turner ALS Foundation Guide for People Living with ALS

LES
TURNER
ALS
FOUNDATION

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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.

Last Reviewed: October 15, 2021



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.

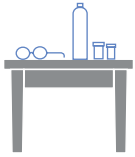
“This guide is intended to get you and your family’s heads pointed in the right direction to make every day the best it can be.

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

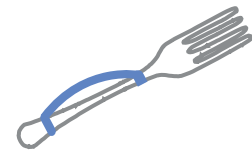


Built-up handles

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

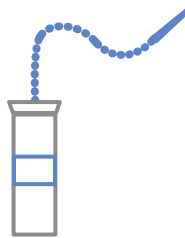


Food thickener
(Thick-It, Thick & Easy)



Nose cup

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



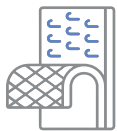
Flexi-Mug and cup holder



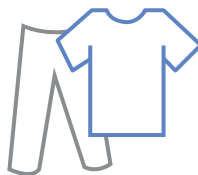
Large handled cup for hot and cold liquids

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



Stretchy shoelaces



Long-handled shoehorn



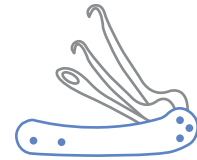
Fleece socks
for cold legs and feet



Slip-on or adaptive shoes



Adaptive clothing



Pocket dresser



**Buttonhook/
zipper pull
combination tool**



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.

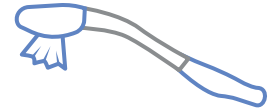
Aids for Toileting



**Wet wipes
for toileting**



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



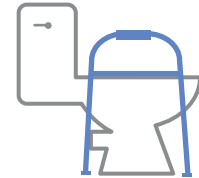
**Toilet buddy wiping
aid or a designated
pair of tongs**



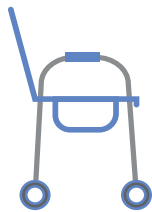
**Urinals
and bedpans**



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.



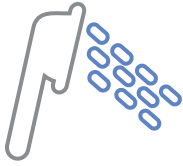
**Place a standard
commode over the toilet**
to provide a raised seat and
armrests. You can use a portable
commode with a bucket in
place of a toilet. This will
decrease the distance you
have to move to reach
the toilet as it can be located to a
place near you.



**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



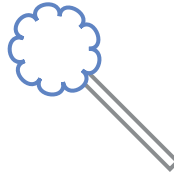
Pump shampoo/liquid soap dispenser instead of a squeeze bottle



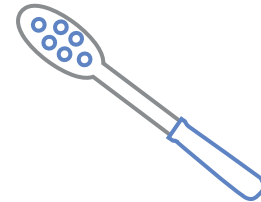
Wall-mount soap dispenser



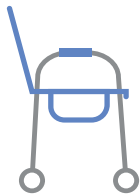
Shampoo tray for hair washing out of the shower



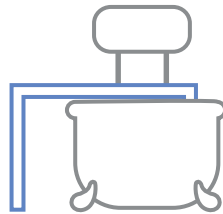
Long-handled sponge



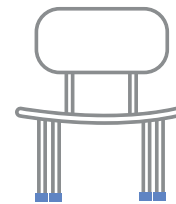
Long-handled hair washer



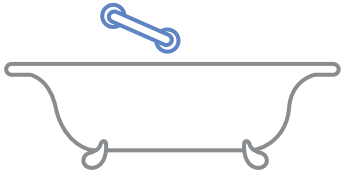
A shower commode chair on wheels with brakes or wheel locks. Some commode chairs have tilt seats with headrests, reclining backs, or straight backs.



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.

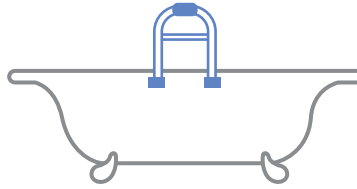


A shower chair is a small seat that can be placed inside the tub. It can be used with tubs that have sliding glass doors. A shower chair can be used only if the patient can step into the tub.



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.



To learn more about home modifications, visit: lesturnerals.org/home-modifications.

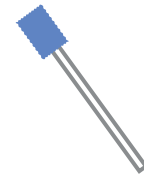
Aids for Oral Hygiene



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

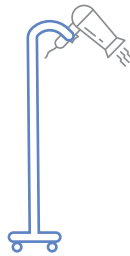


You may find it hard to blow your nose, keep your mouth clean, or remove extra saliva. These problems can lead to trouble with breathing. To learn more visit, lesturnerals.org/breathing

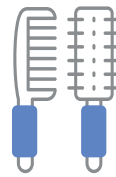
Aids for Grooming



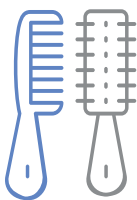
Countertop hair dryer holder stand



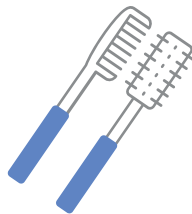
Movable standing hair dryer holder



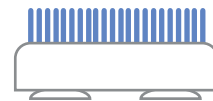
Foam tubing
on handles of comb and brush



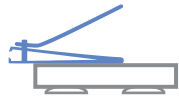
Large-handled, lightweight comb and brush



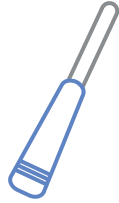
Long-handled comb and brush



Nail brush with suction cups
to stick on the table or counter



Nail clippers
on stabilizing
platform or board



Nail file holder

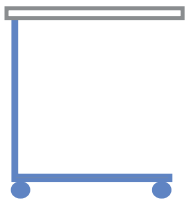


Foam tubing
on the handle of
a razor



Electric shaver

Aids for Recreation



**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



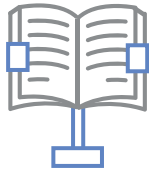
**Wide grip pen or
pen with a grip**



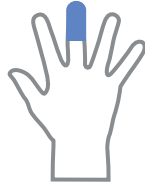
Cardholders



**Learn more about
devices for computer
use, in home
communication and
telephone and monitor
aids visit, [lesturnerals.
org/communication](http://lesturnerals.org/communication)**



Book holders



Rubber fingertips
for help in turning pages
in books and magazines



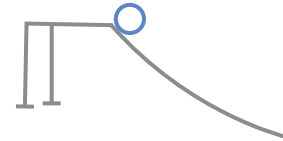
**Spring-loaded
scissors**



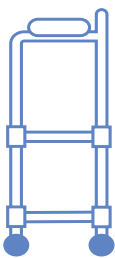
Prism glasses
for watching TV in a reclined
position or when lying flat



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

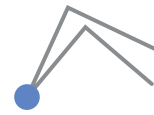


Voice-activated house controls

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

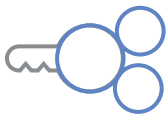


Touch light switches



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

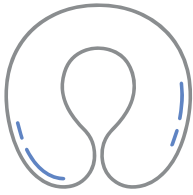
Neck braces, splints and slings are used to support or straighten weak areas of the body. Using these supportive devices can decrease pain and the chances of contractures.

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.

Other neck supports are available. Please discuss this with your ALS care team for more information.



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.**

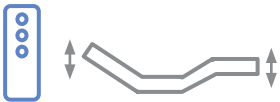
Sleeping

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 you own bed. Talk with your ALS care team about ways to make sleeping more comfortable.

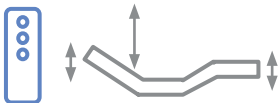
Hospital Beds



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.



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 break down.



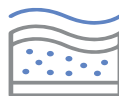
Artificial sheepskin can be used under the fitted sheet. Use on top of the sheet allows more air circulation. It is washable and more buoyant than egg-crate foam.



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.



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.



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.



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.



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.

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.

**MY ALS
DECISION
TOOL**

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.

**ALS
LEARNING
SERIES**

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.

**MY ALS
COMMUNICATION
PASSPORT
TO QUALITY CARE**

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

