

LIVING WITH ALS
RESOURCE GUIDE

5



Understanding Insurance and Benefits When You Have ALS



UNDERSTANDING INSURANCE AND BENEFITS WHEN YOU HAVE ALS

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A note to the reader: The ALS Association has developed the Living with ALS resource guides for informational and educational purposes only. The information contained in these guides is not intended to replace personalized medical assessment and management of ALS. Your doctor and other qualified health care providers must be consulted before beginning any treatment.

Living with ALS
Understanding Insurance and Benefits
When You Have ALS

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INTRODUCTION

Navigating the maze of health insurance and benefits can be overwhelming, to say the least. We have had many people living with ALS describe it as “a full-time job!” This resource provides guidelines and helpful hints to assist you so you can get on with living and not wasting time and energy stuck in the web of insurance and benefits.

What we will cover in this resource guide:

- Questions to ask about your health insurance
- Cost of ALS
- Planning and organizing your insurance and care needs
- Veterans’ benefits
- Social Security Disability (SSD)
- Supplemental Security Income (SSI)
- Short- and long-term disability insurance
- Medicare
- Medicaid
- Medigap/supplemental insurance
- Loan forgiveness

Nearly a year after diagnosis, my husband and I are still navigating the maze of disability insurance and eventual retirement benefits. We’ve found that asking questions more than once of more than one “expert” eventually yields answers that are accurate.

(Contributed by The ALS Association Golden West Chapter)

QUESTIONS TO ASK YOUR HEALTH INSURANCE PROVIDER

When you receive the diagnosis of ALS it is overwhelming and many ask where do I begin? What will I need? What does my insurance cover? Below is a list of questions to ask:

General Health Insurance Questions

- Is there an annual deductible?
- Is there an annual out-of-pocket expense limit or maximum? If I meet my limit, does my coverage increase and to what extent?
- Do I have a major medical plan? Is there an annual or lifetime maximum?
- Do I need to complete any claim forms?
- Am I subject to pre-existing condition regulations?
- For what services do I need pre-authorization?
- What does insurance cover/not cover for a person with ALS?

Durable Medical Equipment (DME) Questions

- Does my plan cover DME? What about ventilator and non-invasive ventilator coverage (i.e., Bilevel Positive Airway Pressure ventilation or BiPAP); are they covered under respiratory equipment or DME?
- What is my coverage for a complex power wheelchair and/or speech-generating device?
- Are stairlifts and bathroom safety devices covered?
- What is the percentage of my coverage?
- Is there a preferred provider I must see?
- Is preauthorization or a medical review required?

Prescription Questions

- Does my plan cover prescription drugs? What are the terms of this coverage, and is coverage different based on using brand-name versus generic drugs?
- Is there a specific pharmacy/supplier network I must use?
- Is there a limit on the amount of prescription drugs I can get through this plan?
- Is there coverage for all FDA-approved drugs, or is coverage provided only for those listed on your formulary (a list of drugs that an insurance policy covers)?
- Does my plan offer a mail-order pharmacy option?

Home Health Questions

- Does my plan have home health coverage? Describe this benefit.
- Do I have coverage for a home health aide (for skilled or custodial care)?
- Is there a preferred home healthcare agency I must use? Is there private duty nursing coverage at home? Describe this benefit.
- Does my plan offer case management? At what point does case management get involved and for how long?
- Long-term care insurance policies that pay for home health or nursing facilities
- Does my plan have palliative care or hospice coverage? Describe this benefit.
- Is there a preferred hospice agency that I must use?
- Is there insurance coverage for ventilator dependents at home?

Health Maintenance Organization/Preferred Provider Organization (HMO/PPO) Subscribers' Questions

- Is my ALS neurologist (or other ALS specialist) a member of the network or a participating provider?

- What is the referral process? Do I need a referral from my primary care physician every time I go to the neurologist or another specialist? Is there a limit to the number and frequency of referrals?

PLANNING AND ORGANIZING

Planning and organizing is key to managing insurance and care needs when living with ALS. One option is to keep a **3-ring binder** with all business cards, documents, and paperwork for keeping notes regarding appointments, service/equipment delivery, medical records, and deadlines. Now, with current technology, many people prefer to have all this information right at their fingertips on an **electronic device**.

Whatever way you are most comfortable, whether it's a handwritten calendar or electronic calendar and notes, it's recommended to keep this information organized. Some people take pictures of business cards with their cell phones and enter the information right into their contacts. As care needs increase, it will be helpful to keep track of who is assigned what tasks and when they will be completed. There are various websites such as The ALS Association's Care Connection Program site <http://www.alsa.org/als-care/caregivers/care-connection.html> and www.lotsahelpinghands.com that can assist with this. Please check these sites to see how they can help you plan and stay organized.

VETERANS' BENEFITS

VA Service-Connected Benefits

Eligibility. Thanks to the efforts of The ALS Association, key members of Congress, advocates, and the Department of Veterans Affairs, **ALS is now a disease entitled to presumptive service connection.** This means that if service members are diagnosed with ALS, their conditions are presumed to have occurred during, or have been aggravated by, military service and as such, they are entitled to service connection and full benefits. These benefits are described briefly below.

The benefits listed below apply to service-connected individuals only.

VA compensation. Disability compensation is a monetary benefit paid to veterans who are disabled by an injury or disease that was incurred or aggravated during active military service. These disabilities, including ALS, are considered to be service connected. Disability compensation varies with the degree of disability and the number of veteran's dependents and is paid monthly.

All veterans with ALS are automatically rated at 100% disability if they have served 90 consecutive days of active duty. Veterans with certain severe disabilities may be eligible for additional special monthly compensation. The benefits are not subject to federal or state income tax. Tables listing current compensation levels are available at <http://benefits.va.gov/COMPENSATION/rates-index.asp>.

Special Monthly Compensation (SMC) for serious disabilities. VA can pay additional compensation to a veteran who, as a result of military service, incurred the loss or loss of use of specific organs or extremities.

Death and Indemnity Compensation (DIC). A monthly payment to survivors, if eligible.

Specially Adapted Housing grant (SAH). Certain veterans and service members with service-connected disabilities may be entitled to a Specially Adapted Housing (SAH) grant from the VA to help build a new specially adapted house or buy a house and modify it to meet their disability-related requirements. Eligible veterans or service members may now receive up to three grants, with the total dollar amount of the grants not to exceed the maximum allowable.

Automobile grant. Financial assistance is available to purchase a new or used automobile (or other conveyance) to accommodate a disability for a veteran or service member with certain disabilities that resulted from an injury or disease incurred or aggravated during active military service. The veteran or service member may only receive the automobile grant once in his/her lifetime. The grant is paid directly to the seller of the automobile for the total price (up to \$11,000) of the automobile.

Adaptive equipment. The purchase of adaptive equipment and for repair, replacement, or reinstallation required because of disability or for the safe operation of a vehicle purchased with VA assistance.

Clothing allowance. Any veteran who is service connected for a disability for which he/she uses prosthetic or orthopedic appliances may receive an annual clothing allowance.

Aide and attendant allowance. A veteran who is determined by the VA to be in need of the regular aid and attendance of another person, or a veteran who is permanently housebound, may be entitled to additional disability compensation or pension payments. A veteran evaluated at 30% or more disabled is entitled to receive an additional payment for a spouse who is in need of the aid and attendance of another person.

Healthcare benefits. The VA also offers a full range of healthcare benefits, which may include medical and respite care and prosthetic items, such as wheelchairs, walkers, canes, etc. Prescriptions and medical supplies also may be included, as well as a Home Improvement and Structural Alteration grant (HISA). More specifically the following services are covered:

1. Preventive Care Services

- Immunizations
- Physical Examinations
- Healthcare Assessments
- Screening Tests
- Health education programs
- Ambulatory (outpatient) diagnostic and treatment services
- Emergency outpatient care in VA facilities

- Medical
 - Surgical (including reconstructive/plastic surgery as a result of disease or trauma)
 - Chiropractic Care
 - Mental health
 - Bereavement counseling
 - Substance abuse
2. Hospital (Inpatient) Diagnostic and Treatment
- Emergency inpatient care in VA facilities
 - Medical
 - Surgical (including reconstructive/plastic surgery as a result of disease or trauma)
 - Mental health
 - Substance abuse
3. Medications and Supplies
- Generally, they must be prescribed by a VA provider and be available under VA's national formulary system. Please consult the VA to access current benefits.
- Prescription medications
 - Over-the-counter medications
 - Medical and surgical supplies

WHAT HAPPENS WHEN YOU STOP WORKING?

Social Security Disability Insurance (SSDI)

When you have a diagnosis of ALS, making the decision to stop working and apply for SSDI can be a difficult one, but the process for applying for it and Medicare benefits should be relatively easy. You can file an application for benefits once you are no longer able to work, or your current Substantial Gainful Activity (SGA) is below the allotted amount, at <http://www.ssa.gov/oact/cola/sga.html>.

The easiest way to file for SSDI is to do so online at www.socialsecurity.gov. You will need the names and addresses of your doctors and a very brief outline of the work you have done in the last 15 years. If you are unable to apply online, you can apply by calling Social Security at 1-800-772-1213, or by visiting your local social security office or www.socialsecurity.gov/locator.

ALS is on the Social Security Administration's list of Compassionate Allowances, meaning that **Social Security will grant you disability status immediately once an application is filed. There is a five full month waiting period, so even though Social Security will award disability status immediately, no monetary benefits are paid until after there has been no work for five full months.** (This means that if you stop working on March 2, March will not count as one of the five waiting period months because it is not a full month. Because of this, some people time

their last day of work to be the last day of a month in order to avoid adding a partial month to their waiting period.)

Another requirement in meeting the minimum qualifications for SSDI is having paid enough into Social Security to satisfy the quarters of coverage requirements <http://www.ssa.gov/oact/ProgData/insured.html>:

- One-quarter of coverage is earned for every \$1160.00 you earn in a calendar year to a maximum of 4 quarters per year.
- One-quarter of coverage gives you one credit.
- Adults over the age of 31 will need 40-lifetime credits.
- In addition to meeting the minimum number of credits to qualify for disability, 20 of those credits must have been earned in the 10 years immediately prior to the onset of the disability.

For most adults who have worked immediately prior to becoming ill, having the appropriate amount of credits is not an issue.

Once you are approved for benefits, and after the five full month waiting period has passed, you will receive monthly monetary payments for you and, in most cases, your minor children and a spouse who cares for your children under age 16. The amount of your monthly benefit depends on the amount you have paid into Social Security over your working life. Your Social Security statement, as well as an on-line benefits estimator, can be obtained at <http://ssa.gov/myaccount/> to obtain. Once you are approved for Social Security Disability, you will also be entitled to Medicare following your 5-month waiting period.

Do You Need to Hire an Attorney to Apply for SSDI?

Absolutely not! While applying for benefits may sound complicated, it is a relatively easy process that can be done without paying for an attorney. If you have questions, your local ALS Association chapter may be able to refer you to a lawyer whom you can talk to free of charge.

How Do You Apply for Social Security Disability Programs?

Individuals can apply for Social Security benefits by telephone or in person. To apply via telephone, you can call toll free at 1-800-772-1213, Monday to Friday, 7 a.m. to 7 p.m. Eastern Time. To apply in person, an individual may go to their local Social Security Administration (SSA) office to schedule an appointment. To obtain information regarding the SSA office nearest you, go to the Social Security's website at www.ssa.gov. For assistance with making an application to Social Security, an individual may also contact the A.C.C.E.S.S. program at 1-888-700-7010.

The representative will ask for the applicant's social security number, name, and address. Additional information the applicant will eventually need to provide to SSA includes but is not limited to:

- Birth certificate
- Names and addresses of hospitals and physicians

- Medications
- Marriage information
- Dependent children's names, addresses, and social security numbers
- Employers over the last 15 years
- Income

Note: SSA has an expedited procedure for processing terminal illness cases to ensure that a favorable decision can be made expeditiously.

What if You Are Denied Social Security Benefits?

Individuals might be denied SSDI benefits for a number of reasons including:

- Not enough time worked and paid into Social Security
- Not a U.S. citizen
- Not considered disabled
- Failure to cooperate with SSA

A person who is denied benefits from Social Security has appeal rights with strict time limitations. Please consider referring to the A.C.C.E.S.S. program at 888-700-7010 for free representation or advice. You may also contact The ALS Association's Advocacy Department for potential congressional support at 877-444-ALSA (2572), or advocacy@alsa-national.org.

This was quite overwhelming to dig into and see what changes would occur with SSDI. It took some time and discussions with ALS Association representatives and SSDI to see what would and wouldn't be covered in the beginning. We are only two years into this and haven't hit any major medical bills, but we know they are coming.

Ellen (Contributed by The ALS Association North Carolina Chapter)

SUPPLEMENTAL SECURITY INCOME (SSI)

Supplemental Security Income (SSI) provides cash to meet basic needs for food, clothing, and shelter to those age 65 and over, blind, or disabled who have little or no income. Individuals and their children may be eligible for SSI even if they have never worked or have an insufficient insured status for SSDI.

SSI is a Federal income supplement program funded by general tax revenues, not Social Security taxes. Each individual who applies for SSDI is also screened for SSI benefits. **SSI payments may be available during the usual 5-month waiting period before SSDI cash benefits begin.** Those eligible for SSI may also be automatically eligible for Medicaid benefits.

Note: SSA can make a determination of "presumptive disability" for SSI benefits. This provision allows SSA to pay up to six months of SSI payments before they make their disability determination, based on the finding that there is a high

probability that the applicant is disabled. Therefore, persons with ALS, especially those with significant bulbar signs or gross disturbance of gait, should inquire about this provision at the time of application. (SSA does not provide for presumptive payments to individuals applying for SSDI benefits.)

SHORT-TERM AND/OR LONG-TERM DISABILITY THROUGH AN EMPLOYER

For financial planning purposes, it is important to remember that there is a 5-month waiting period for cash benefits to begin under SSDI. Therefore, it is possible that an individual who stops working may be without any income for approximately 5 months. The waiting period begins the first full month following the month that Social Security determines an individual is not engaging in substantial gainful activity. When an individual applies for SSDI, they are automatically screened for Supplemental Security Benefits (SSI), which can assist during the waiting period for SSDI.

This is why it is crucial to determine what your benefits are from your Human Resources Department at your employment. You need to determine if you have short- and/or long-term disability. If so, what are the parameters of these plans? Until a certain age, a certain number of years, or until death? You can also inquire if there is an open enrollment period where you can apply for these or additional benefits.

The labyrinth of Medicare and supplemental insurance as well as long-term healthcare can be daunting. While the ALS Association can help, it takes a combination of patience and persistence to make sure you avail yourself of all the benefits you deserve.

Judith Massey (Contributed by The ALS Association Northern Ohio Chapter)

MEDICARE

Medicare Waiver

Due to the tireless lobbying efforts of The ALS Association, other groups, and individuals with ALS and their families, Congress passed landmark legislation in July 2001 benefiting the ALS community. The usual 24-month waiting period for Medicare was eliminated for SSDI recipients disabled by ALS. Medicare entitlement now begins the first month the recipient receives cash benefits (approximately 5 months after an individual is deemed disabled).

What Is Medicare?

Medicare is a federal health insurance program administered by the Centers for Medicare and Medicaid Services (CMS). Medicare is available to the following groups of individuals:

- Persons age 65 and older and their spouses
- Persons eligible for SSDI (and some disabled civil service workers not eligible for SSDI due to not having paid FICA taxes). Incidentally, individuals with end-stage renal disease may also be eligible for Medicare.

Medicare has two parts, **Part A and Part B**.

Part A (Hospital Insurance) helps pay for:

- Care in hospitals as an inpatient, skilled nursing facilities, hospice care, and some home healthcare. This coverage is free to SSDI recipients.

Part B (Medical Insurance) helps pay for:

- Doctors' services, outpatient hospital care, and some other medical services that Part A does not cover, such as physical and occupational therapy, and some home healthcare. **Part B helps pay for these services and supplies when they are medically necessary. There is a monthly premium for this coverage.** If an individual is also a Medicaid recipient, their monthly premium for Medicare may be paid by their Medicaid benefits.

Medicare Parts A and B pay for the first 80% of services and "Medigap" or supplemental plans (which we will soon discuss) pick up the other 20%.

Due to the fact that Medicare coverage is subject to change, please refer to the official Medicare website for the most up-to-date information at <http://www.medicare.gov/Coverage/Home.asp>, or call 1-800-MEDICARE.

Medicaid

Medicaid provides health insurance for **low-income and needy parties**. It covers **children, the aged, blind, and/or disabled individuals**. Federal and state governments jointly fund Medicaid.

Certain states may have different Medicaid programs available for those who are not as financially needy, such as programs designed for catastrophic or high monthly out of pocket costs. A person who has any financial hardship should contact their state's Medicaid program for information. For contact information for a specific state, contact your local ALS Association chapter and speak with a care coordinator or go to http://aphsa.org/content/APHSA/en/resources/LINKS/STATE_CONTACTS.html.

Medigap/Supplemental Insurance

As a person with ALS, a key piece of your healthcare planning is selecting the best health insurance for you!

Those diagnosed with ALS now qualify for Medicare coverage. The advocacy efforts of The ALS Association came to fruition in 2002 with the passing of legislation that waived the 24-month waiting period for Medicare coverage for persons with ALS. This means that those who qualify for Social Security Disability Insurance (SSDI) now qualify sooner for Medicare insurance.

Eligibility for Medicare brings with it a set of additional decisions to make: **Should I also purchase Medicare Part B? Should I purchase a Medicare Supplement? What about a prescription plan? Will a Medicare Advantage Plan save or cost me money in the long run?**

To make your experience with ALS a little easier, we highly recommend discussing your health insurance options with an **insurance counselor** as well as reviewing insurance-related publications on The ALS Association website. By thinking through and planning for what your coverage needs may be, you will be able to make choices that will provide you the most appropriate coverage when you need it.

In order to get the best guidance possible, it is essential to be very clear with the insurance counselor about your condition, prognosis, and anticipated needs. Please consider and discuss the answers to the following questions:

- What medications do I currently take/plan to take in the coming year?
- How might my ALS progression over the next year impact my need for:
 - Durable medical equipment, such as a power wheelchair or hospital bed?
 - A communication device (a machine that helps an individual supplement existing speech or replace speech that is not functional in order to communicate)?
 - Other assistive technology and devices?
 - Office visits to the ALS clinic or other physicians?
 - Respiratory assistance?

The decisions you make about your insurance plan will directly impact your coverage for these items. For information about what your needs may be as your disease progresses, we encourage you to consult with your ALS physician, clinic social worker, and/or your local ALS Association chapter care coordinator.

Your State Health Insurance Counseling Program (SHIP) has expert volunteers who can assist individuals free of charge. To locate your area SHIP agency, call 1-800- 677-1116 (Eldercare Locator) or go to <https://www.medicare.gov/Contacts/#resources/ships>.

LOAN FORGIVENESS FOR PARENT PLUS LOANS

If you (the person living with ALS) have taken out a PLUS Loan to help pay for your child's education, all or part of it may be canceled (discharged) for several reasons. Cancellation is different from forgiveness in that forgiveness is an incentive for borrowers working in certain fields. Cancellation relieves the borrower from repayment obligation for extenuating circumstances. **You may qualify for total or partial loan discharge if:**

- The school closed within 90 days of your child's enrollment and they were unable to finish their program of study.
- The school did not properly qualify your child's status before they began studies.

- You did not receive a refund that was due to you.
- Your signature was forged.
- The school did not properly evaluate your child's ability to benefit from the coursework before beginning studies.
- You become totally and permanently disabled.
- If you or the dependent for whom the loan was borrowed, dies.
- Your loan is discharged due to bankruptcy. (Typically, student loans cannot be discharged in a bankruptcy.) Consult your legal counsel regarding your particular situation.

SUMMARY STATEMENT

Understanding insurance and benefits may feel overwhelming, but hopefully, these guidelines will simplify this process for you. We have included several websites and phone numbers to access this information. Take the opportunity to use the two fact sheets included at the end of this resource guide to assist you along this process. One relates to summary points about Social Security Disability, Medicare, and Short- and Long-term Disability Insurance and the other, tips on finding in-home care. Contact your ALS Association chapter Care Services Coordinator or ALS center or clinic social worker to help you navigate this process. **Please know that you are not alone.**

FACT SHEET: WHAT HAPPENS WHEN I STOP WORKING?

Applying for Social Security Disability Insurance (SSDI)

- Three ways to apply: online www.ssa.gov; call to schedule a telephone interview 1-800-772-1213; or apply in person at your local office.
- Keep it simple: ALS is a presumptive diagnosis, so with this diagnosis and meeting SSD guidelines for work credits you should be eligible for SSD, no need to put any other diagnoses you may have.
- Benefits begin in the 6th month from your last day of work.
- Keep in mind there is no income from SSD for the first five months you are not working.
- You should not need a disability lawyer to apply for benefits.

Medicare

- When your SSD benefits begin you should be eligible for Medicare at that time.
- Medicare B premium is automatically deducted from your SSDI check; this covers the initial 80%. For current amount go to <https://www.medicare.gov/your-medicare-costs/part-b-costs/part-b-costs.html>.
- You will need to purchase a supplemental plan to cover the other 20% and a prescription plan as well.
- You can check out www.Medicare.gov or your local county Office on Aging to determine supplemental Medicare and prescription plans in your area.

Short- and Long-Term Disability

- Check with your employer/Human Resources department to determine what benefits you have and the parameters of these plans for long-term planning.
- Most Long-Term Disability plans require that you apply for SSD and deduct the amount of that benefit from what they pay you monthly.

For additional assistance contact your local ALS Association chapter.

(Fact sheet adapted from original fact sheet produced by The ALS Association Greater Philadelphia Chapter.)



FACT-SHEET: HOW TO FIND CARE AT HOME

- At some point in your journey with ALS you may require additional help with bathing, dressing, and activities of daily living beyond what your caregiver can provide.
- Home care is typically *not* covered on an on-going basis by Medicare, Medical Assistance, or private medical insurance.
- It is important to explore options for in-home care as early as possible. Begin talking honestly about the help you as the patient need and you as the caregiver can realistically provide.
- Insurance may cover for limited short-term home health services if there is a skilled need such as a feeding tube placement or PT/OT evaluation, but once the skilled need is met, the home health aide services will end.
- Check your local county Area Agency on Aging and/or local Office of Disability to see if you are eligible for any programs or services.
- Often county and state funded programs have lengthy application processes or waiting lists, so be proactive so you don't find yourself in an emergency situation.
- Veterans: If you are 100% service connected, you may be eligible for an Aide and Attendance grant which is additional income to your monthly compensation to be used to pay for help at home.
- Veterans: In addition, most VA Hospitals offer 10 hours/week of a home health aide; check with your local VA.
- Private Pay: You can check with your local Area Agency on Aging or your local ALS Association care coordinator for referrals to local agencies to pay privately for in-home care.
- Word of mouth/referrals: Talk to family and friends who have had help for a loved one. Check within your community if there are experienced aides looking for work; this may be less expensive than going through an agency.
- Some people have been successful looking into local nursing schools or PT /OT schools to hire students who are hoping to gain experience; again, this could be less expensive.

For additional assistance contact your local ALS Association chapter.

(Fact sheet adapted from original fact sheet produced by The ALS Association Greater Philadelphia Chapter.)





The following is a list of topics covered in the *Living with ALS* resource guides:

Resource Guide 1

What is ALS? An Introductory Resource Guide for Living with ALS

This resource guide provides an overview of ALS, what it is, and how it affects your body. It provides information on what kind of resources are available to help you deal with ALS more effectively.

Resource Guide 2

After the ALS Diagnosis: Coping with the “New Normal”

This resource guide addresses the psychological, emotional, and social issues that you must face when your life is affected by ALS. It provides information on how to cope with the many lifestyle changes and adjustments that occur when you live with ALS.

Resource Guide 3

Changes in Thinking and Behavior in ALS

This resource guide addresses how thinking and behavior may be affected by ALS and how these changes can impact disease course, symptom management, and decision making.

Resource Guide 4

Living with ALS: Planning and Making Decisions

This resource guide reviews areas where careful planning and decision making will be required and will provide you with resources to help you and your family plan for the future.

Resource Guide 5

Understanding Insurance and Benefits When You Have ALS

This resource guide provides strategies and helpful hints to better navigate health insurance and benefits. While understanding insurance and benefits may feel overwhelming, the guidelines outlined here should help simplify the process for you.

Resource Guide 6

Managing Symptoms of ALS

This resource guide discusses a variety of symptoms that may affect you when you have ALS. As the disease progresses, various functions may become affected and it is helpful to understand potential changes so that you know what to expect and how to manage these new changes and symptoms.

Resource Guide 7

Functioning When Mobility is Affected by ALS

This resource guide covers the range of mobility issues that occur with ALS. It discusses exercises to maximize your mobility, as well as how to adapt your home and activities of daily living to help you function more effectively.

Resource Guide 8

Adjusting to Swallowing Changes and Nutritional Management in ALS

This resource guide will help you understand how swallowing is affected by ALS and what you can do to maintain nutrition for energy and strength and to keep your airway open.

Resource Guide 9

Changes in Speech and Communication Solutions

This resource guide covers how speech can be affected by ALS and explores a variety of techniques, technologies, and devices available for improving communication. By maintaining communication with others, you continue to make a significant difference in their lives, while retaining control of your own.

Resource Guide 10

Adapting to Changes in Breathing When You Have ALS

This resource guide explains how breathing is affected by ALS. Specifically, it will teach you the basics of how the lungs function, the changes that will occur, and how to prepare for the decisions that will need to be made when the lungs need maximal assistance.

Resource Guide 11

Approaching End of Life in ALS

This resource guide examines thoughts and feelings about dying and end of life. Approaching end of life is difficult and support is critical to help sort out feelings, expectations, and plans. By talking to friends, family, professionals, and planning and communicating your wishes, you can help prepare for the best possible end-of-life phase.



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About The ALS Association

The ALS Association is the only national non-profit organization fighting Lou Gehrig's Disease on every front. By leading the way in global research, providing assistance for people with ALS through a nationwide network of chapters, coordinating multidisciplinary care through certified clinical care centers and fostering government partnerships, The Association builds hope and enhances quality of life while aggressively searching for new treatments and a cure.

For more information about The ALS Association, visit our website at www.alsa.org.