

LIVING WITH ALS
RESOURCE GUIDE

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Living with ALS: Planning and Making Decisions



LIVING WITH ALS: PLANNING AND MAKING DECISIONS

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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
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INTRODUCTION

After receiving a diagnosis of ALS, everyone reacts differently. No matter what your reaction, at some point you begin making decisions and planning for the future. **Several types of decisions will need to be made** along this journey, some of which may include: **How long to remain employed? How to financially protect yourself and your family? What does quality of life look like to you and how will you ensure that your wishes in maintaining that quality of life are carried out?**

Advanced planning allows you to remain in control of your future, rather than waiting for a situation or crisis to occur in which you, your family, or healthcare providers have to make in-the-moment decisions. Decision making is best completed when you have time to gather appropriate information, identify all available alternatives, carefully weigh your options, and pick which option is best for you and your family. Some decisions will be less difficult or stressful than others (i.e., when to use a cane vs. if you want to prolong life with tracheostomy and invasive ventilation).

Individuals who make plans for their future care needs manage disease-related transitions easier and have less fear of burdening their families (Johnson, Sulmasy, and Nolan, 2007). You are not alone and can seek the support of family and friends, your ALS clinic team, and other people and families living with ALS. You should consider what consequences your decisions will have on your family and friends since everyone will be affected by the outcome. **Ultimately, you are the decision maker.** 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.

What we will cover in this resource guide:

- Issues related to employment and ALS/disability
- Services and programs to consider when you are unable to care for yourself
- Differences between palliative and hospice care and benefits of hospice care
- Estate planning
- Advance directives
- Choices for dying with dignity
- Symptom management and technology decisions

ALS is a disease where you must plan for the next curve in the road, but you often can't see when you are going to reach that curve. Because the disease strikes people and progresses in many different ways, even with the best of planning, you can easily find yourselves dealing with an awful problem before you are ready for it. So, take a good hard look down the road, find out what is likely to be coming your way, and try your hardest to get ahead of it. Learn about your options in advance, and be ready to take action quickly. Hopefully, you won't encounter too many of those blind curves during the difficult journey ahead.

Eric Hunter (Contributed by The ALS Association Greater New York Chapter)



EMPLOYMENT AND ALS

Deciding Whether to Continue Working

If you are employed when you are diagnosed with ALS you will need to decide whether or not you will continue working and for how long. Ask yourself the following questions to guide your decision making:

- Do you live to work or work to live?
- Does work give you purpose and meaning?
- Are you the main breadwinner and provider of health benefits for your family?
- Are fatigue and disability significant issues at this time?
- If you decide not to work, how will you manage the transition from working to not working any longer?
- Is it possible to work part-time or take on a different role at your workplace and if so, what are the implications (e.g., financially, emotionally)?

Talking to Your Employer

People working with ALS often debate when and how to tell their employer about their diagnosis. There are several factors to consider, including: what type of work you are doing and how ALS is affecting your ability to do your work safely

and effectively. Also, your relationship with your employer may impact how comfortable you are discussing your diagnosis.

Many times it is best to let your employer know earlier rather than waiting until your performance is affected. Usually, the best place to start is with your employer's Human Resources Department. The **Human Resources Department or Manager** is responsible for understanding basic company information, including benefits and other compensation as well as handling personnel and employee relations issues all while ensuring the company's compliance with laws and regulations. The Human Resource Department will be able to give you details or provide resources on your employer's healthcare benefits, time-off policies, group pension plans, and any short- or long-term disability plans for which you are eligible.

Group Pension Plans

It is important to identify what type of retirement plan or plans you have at work and ask your Human Resource Department or employer for a copy of the Summary Plan Description if you no longer have the copy you received when you enrolled in the plan.

There are two major types of group pension plans: **defined benefit plan** and **defined contribution plan**.

- **A defined benefit plan is funded by the employer and promises a specific monthly benefit at retirement** either in an exact dollar amount or in a formulated dollar amount based on factors such as salary, age, and number of years worked at the company (United States Department of Labor).
- **A defined contribution plan (401K, IRA) does not promise a specific benefit amount.** Instead, you and/or your employer contribute money to your plan and you determine how your contributions are invested (United States Department of Labor).

Defined contribution plans are permitted to—but not required to—provide distributions or permit you to take some or all of your vested accrued benefit in case of hardship. **Check your plan booklet** to see if it does permit early withdrawal and what circumstances are included as hardships (i.e., becoming disabled). It is important to note that if you meet requirements for hardship and can withdraw benefits, you may owe current income taxes and possibly incur tax penalties on your distribution.

If you are in a defined benefit plan (other than a cash balance plan), you most likely will be required to leave the benefits in the retirement plan until you become eligible to receive them. However, these types of plans may permit earlier payment, either by providing for early retirement benefits for which the plan may set additional eligibility requirements, or by permitting benefits to be paid when you suffer a disability (disability retirement feature). Again you must check your Summary Plan Description to find out if your plan has this type of benefit.

If you choose to file a benefit claim you should follow your plan's claims procedures, which are also listed in the Summary Plan Description. Usually you

fill out the required paperwork and submit it to the plan administrator or Human Resources Department.

Resources

U.S. Department of Labor:

http://www.dol.gov/ebsa/faqs/faq_consumer_pension.html

U.S. Department of Labor:

<http://www.dol.gov/ebsa/publications/wyskapr.html>

Americans with Disabilities Act (ADA) and Family and Medical Leave Act (FMLA)

There are two laws in place that can provide some protection and relief if you choose to remain employed. **The Americans with Disability Act of 1990 (ADA) makes it unlawful to discriminate in employment against a qualified individual with a disability.** If you have a disability and are qualified to do a job, the ADA protects you from job discrimination on the basis of your disability. If you have a disability, you must also be qualified to perform the essential functions or duties of a job, with or without reasonable accommodation, in order to be protected by the ADA from job discrimination.

This means **two things**:

1. **You must satisfy the employer's requirements for the job**, such as education, employment experience, skills, or licenses, and
2. **You must be able to perform the essential functions of the job with or without reasonable accommodation.** Essential functions are the fundamental job duties that you must be able to perform on your own or with the help of a reasonable accommodation." (U.S. Equal Employment Opportunity Commission).

Three examples of reasonable accommodations may include:

- Making the building and work site accessible (e.g., installing ramps for wheelchairs);
- Modifying set work hours to permit disabled persons to drive or take public transportation during non-peak hours;
- Acquiring special equipment or devices (e.g., a headset telephone or computer dictation software for an employee with hand or arm weakness).

An accommodation is not required if the change would impose an undue hardship on the employer, such as if it were unreasonably costly, intrusive, or would fundamentally change the nature of the position or business. To find out more details about ADA, reasonable accommodation, and how to file a complaint if you believe discrimination has occurred, please visit The U.S. Equal Employment Opportunity Commission website at www.eeoc.gov/facts/ada18.html.

The **Family and Medical Leave Act (FMLA)** entitles eligible employees of covered employers (all businesses with 50 or more employees at sites within 75 miles of one another) to take **unpaid, job-protected leave for specified family and medical**

reasons with continuation of group health insurance coverage under the same terms and conditions as if the employee had not taken leave.

- An employee must have **worked at least 1,250 hours in the previous 12 months** to be eligible for leave.
- The benefit is **12 workweeks of leave in a 12-month period** for a serious health condition that makes the employee unable to perform essential job functions.
- **The FMLA can also be utilized to care for the employee's spouse, child, or parent who has a serious health condition.** This benefit increases to 26 workweeks of leave in a 12-month period if the employee is caring for a covered military member on "covered active duty."

The FMLA mandates:

- If possible, employees must give 30-days' notice that they are taking a leave.
- Employees (except for 10% of those in highest-paid positions) are entitled to get their previous jobs back, or a job with equal duties, benefits and pay.
- Employees are entitled to their full health benefits while on leave; however, an employer can demand to be paid back for insurance premiums, if the employee quits the job at the end of the leave.
- Leave can be taken intermittently if the employer and employee both agree to the arrangement.
- An employer may require certification of health condition by a healthcare provider.
- An employer can require that vacation or sick days be used at the beginning of the leave.

Resources

The Americans with Disability Act Fact Sheet:

<http://www.eeoc.gov/facts/ada18.html>

Family and Medical Leave Act:

<http://www.dol.gov/whd/fmla/>

Vocational Rehabilitation Services

While you are still working, you may be eligible for programs and services through Vocational Rehabilitation Services. The U.S. Department of Education is responsible for overseeing the vocational rehabilitation services by providing funding for each state to operate programs and services that enable individuals with disabilities to maintain or seek employment. **Programs and services offered are different from state to state, but can include assistance with assistive technology and devices as well as supportive services to assist in maintaining employment.**

Resources

Vocational Rehabilitation Services:

<https://www.disability.gov/resource/vocational-rehabilitation-state-offices/>

Disability Rights Network:

<http://www.ndrn.org>

Social Security Benefits

A diagnosis of ALS is presumed eligible for Social Security Disability Insurance (SSDI); however, you still must meet the qualifications for work credits and eligibility, which means that you worked long enough and paid Social Security taxes to be eligible for benefits and are no longer able to work. There is still usually a five-month waiting period for disability payment after the established onset of your disability. Therefore, you may want to discuss with your employer any short-term or long-term disability benefits offered during that time period.

People with a diagnosis of ALS do not have to wait 24 months after becoming disabled to receive Medicare; therefore, Medicare benefits start at the same time as SSDI.

If you don't qualify for SSDI, you may qualify for Supplemental Security Income (SSI)/Medicaid. SSI is a program that pays benefits to those individuals with limited income and resources. Medicaid is also based on financial need and provides healthcare benefits to those that qualify. Although a federally funded program, Medicaid benefits vary from state to state.

Resource

Social Security:

<http://www.ssa.gov/disability/>

Options for Care When You Can No Longer Care for Yourself

A common concern is what type of services or help are available for when you need more care or are unable to take care of yourself. Understandably, questions like this are difficult to consider because they require thinking and talking about your eventual loss of independence. It is easier, however, when you know your options and plan in advance. It takes time to go through the application process for state or federal programs, or even to hire an individual you trust with your care. Therefore, **it is wise to weigh your options carefully and make plans before you actually are in need of the services.**

Each person's situation is unique, whether it is the amount of family support and the abilities of family members to assist with care, or the financial resources available for care and ability to pay for professional care. **Here are some questions to ask to understand your situation:**

- **What type of care is covered through my health insurance?** Insurance coverage is covered further in the resource guide, *Understanding Insurance and Benefits When You Have ALS*; however, it is important to know and

understand what type of coverage you have regarding home care, facility care, and durable medical equipment. Many individuals are surprised to learn that their insurance does not cover care for extended periods of time or does not cover routine daily care.

- **Do you have a long-term care insurance policy? Does it cover home care?** It may be a good time to review all your insurance policies and know the benefits as there are situations where a life insurance policy can help pay for long-term care. If you do have a long-term care insurance policy, become familiar with what type of care is covered, where the care is covered, when the coverage begins, and whether there are any limits to the amount of money paid or for the length of time covered.
- **What programs are available and what are the eligibility criteria?** Programs, services, and eligibility requirements vary from state to state. Social workers or care managers, such as those involved with an ALS Association Treatment Center of Excellence, ALS clinic, or local ALS Association chapter, have a wealth of resources and information regarding potential services and community resources. For example, one option for assistance is Medicaid, which is a joint federal and state government program that assists financially eligible individuals with medical care, nursing facility care, and possibly home care. Although a federal program, each state has its own eligibility rules and services. States can also offer Home and Community Based Waiver Services, which provide long-term care services in your home and can offer such services as case management, homemaker, home health aide, personal care, adult day care, and a variety of other services. State Medical Assistance Offices can provide information about how to qualify for these services in your state. In addition, nonprofit organizations may be available to help defray costs by providing medical equipment, transportation, and even help with home modifications. Contact your local ALS Association chapter for resources regarding this type of assistance.
- **Are you a veteran? What services are provided through the Veterans Administration?** As a veteran with a diagnosis of ALS, you could be eligible for compensation and other benefits. This will be covered further in *Understanding Insurance and Benefits When You Have ALS*.
- **Should I go through an agency or hire a home care worker myself?** It is vital to consider the many issues that come with deciding on home care. Ask questions and consider what's important to you. Some potential questions are:
 - What are the tax implications and legal ramifications in your state for hiring a worker privately?
 - Are those risks worth the potential lower rate as opposed to going through an established bonded and insured agency?
 - Is there a back-up plan if your worker is sick or calls off?
 - Is the cost of care higher on the weekend or in the evenings?
 - Will the workers provided be consistent?

- Is the agency licensed and bonded or do they have liability coverage?
- Some agencies require a guaranteed minimum number of hours each day before they will provide in-home care services, so be sure to ask (Bartelstone, n.d.).
- Is the agency Medicare certified?

Resources

Medicare:

<https://www.medicare.gov/>

Medicaid:

<http://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/home-and-community-based-1915-c-waivers.html>

Long-Term Care:

<http://longtermcare.gov/medicare-medicaid-more/medicaid/>

Caregiver:

<http://www.caregiver.com>

Palliative Care Versus Hospice Care

Palliative and hospice care are both care options that share the primary philosophy to provide comfort care and symptom management to those with chronic and life-threatening illness to ease physical, mental, and emotional suffering. Although hospice care is palliative by nature, **there are essential differences between a palliative care program and hospice care.**

Palliative Care

“Palliative care is the comprehensive treatment of the discomfort, symptoms and stress of a serious illness (National Institute of Nursing, 2009).” The goal is to prevent and ease suffering and improve your quality of life by managing symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite, and problems with sleep. Palliative care is provided by a team of doctors, nurses, and other specialists who work together. Another hallmark of palliative care is open dialogue about treatment choices and goals of care. Your palliative care team can assist in helping you and your family to make challenging medical decisions as well as provide education about end-of-life issues.

Palliative care is appropriate at any stage of your illness, not just the final months of your life. It also can be provided along with life-prolonging measures such as tracheotomy and invasive ventilation. It is another layer of support for you and your family as challenges arise in care or when you experience changes in your condition. Palliative care is a relatively newly recognized field of medicine, and although many hospitals have a palliative program, not all areas of the country have community-based palliative care programs at this time.

Hospice Care

Hospice care is quality, compassionate care for people who have been given a prognosis of six months or less to live by their treating physician. Hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support tailored to the individual's needs and wishes.

Support is provided to the person's loved ones as well. At the center of hospice care is "the belief that each of us has the right to die pain-free and with dignity, and that our families will receive the necessary support to allow us to do so" (National Hospice and Palliative Care Organization).

During his last hospital stay, Kenny decided that he wanted to start Hospice Services. Although, I respected his decision, initially it was difficult for me to accept. However, after receiving Hospice Services, I now realize that I needed the help and greatly appreciate the input provided by a set of 'professional eyes' to notice changes and help with his care.

Rita Kinder, caregiver, Pittsburgh, PA

The hospice team develops a **care plan that meets each person's individual needs for pain management and symptom control**. The team usually consists of the personal physician, hospice medical director, nurses, home health aides, social workers, clergy or chaplains, trained volunteers, and, if necessary, speech, physical, occupational, or respiratory therapists. Members of the hospice staff make regular visits to assess the individual and provide additional care or other services. Hospice staff is on call 24 hours a day, 7 days a week. The hospice team will work to problem solve in advance so the person with ALS and the caregiver feel more prepared to try to negate crisis and anxiety when end-of-life changes and symptoms arise. According to the **National Hospice and Palliative Care Organization**, "among its major responsibilities, the interdisciplinary hospice team:

- Manages the individual's pain and symptoms
- Assists the person with the emotional and psychosocial and spiritual aspects of dying
- Provides needed drugs, medical supplies, and equipment related to admitting diagnosis
- Coaches the family on how to provide care
- Delivers special services such as speech and physical therapy when needed
- Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time; and
- Provides bereavement care and counseling to surviving family and friends."

It is important to note that hospice does not provide a 24/7 caregiver(s) as part of its services. In most cases, hospice care is provided in the individual's home with a family member serving as the primary caregiver. Typical hospice services involve weekly nursing visits and home health aides to assist with bathing and other tasks two to three days a week for one to two hours a visit. Hospice care can also be

provided in freestanding hospice centers, hospitals and nursing homes, and other long-term care facilities. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations. **If you are covered by a private insurance plan, please contact your provider and inquire about the plan's hospice benefit, as they all vary.**

Hospice care focuses on caring, not curing. In most cases, this means when you choose hospice care you are indicating you no longer want to pursue aggressive treatment including hospitalizations, physician appointments, specialty clinics, surgeries, or anything that would prolong life. Your goal is to remain comfortable at home; wherever you call home. It is important that prior to choosing hospice, a person with ALS obtain all needed equipment that would not necessarily be covered under the hospice benefit (power wheelchair, speech generating devices, noninvasive ventilation equipment, etc.). Similarly, one may want to undergo expensive procedures before signing up for hospice (feeding tube placement, sleep studies, etc.). Hospice care can always be canceled if an unforeseen situation arises where additional medical care is needed (e.g., fracture due to a fall).

Benefits of hospice care include:

- **Feeling better.** Many people have a negative perception or misconceptions about hospice care, fearing it somehow hastens or speeds up death. **The truth is that many times people actually feel better and health can even improve with an expert hospice team intensively managing end-of-life symptoms.**
- **Reduced unwanted hospitalizations.** A recent study that looked at trends of end-of-life in Medicare beneficiaries found that even though the percentage of people receiving hospice care doubled, the frequency of hospitalizations and intensive care units (ICU) stays during the last months of life increased. This is an indication that although there is the increased availability of palliative and hospice care services it does not appear to have changed the focus on aggressive curative care, as many times hospice care was utilized only in the last couple days of life. The conclusion of this study moving forward was to try to **obtain the individual's goals of care earlier so that palliative and hospice care could also be initiated earlier to avoid unwanted hospitalizations or ICU stays at the end of life** (Jenq and Tinetti, 2013).
- **Enhanced relationships and peace of mind.** Along with the benefit of avoiding unwanted hospitalizations or ICU stays at the end of life, there are many other benefits to utilizing hospice for the full six months. These include the development of a **strong relationship with hospice staff, additional assistance with caregiving in the home, peace of mind for the caregiver** who can reach a hospice nurse 24/7, and more time working through issues of anticipatory grief for the person with ALS and the family members.

For more information on palliative care or hospice care, or to locate palliative care or hospice care organizations in your area, please visit with your neurologist, primary care physician, ALS clinic social worker, or case manager or contact your local ALS Association chapter.

Resource

National Hospice and Palliative Care Organization:
<http://www.nhpco.org>

FINANCIAL AND LEGAL ISSUES

The Cost of Living with ALS

Living with ALS can be very expensive, with **cost estimates at \$150,000 to \$200,000 per year, depending on the healthcare decisions that are made** (Obermann and Lyon, 2015). Medical costs, home modifications, home care, durable medical equipment, accessible vehicles, etc. are some of the largest contributors to this cost. Cost usually increases in the late stages of the disease and particularly if an individual chooses to pursue tracheostomy and invasive ventilation. Another cost that could become a factor is the need for long-term facility-based care if unable to remain at home. **Financial planning is very important when facing ALS, and it is also very helpful to know programs that are available to assist with some of these costs.**

Live in the present but plan for the future. Financial planning is a huge undertaking and so necessary, but what hit me harder was the emotional planning. I have a 2-year-old daughter. How much of her life will I see? Will I have time to positively influence her? Will I be a burden to her? Will she remember me? I decided to bank my voice and make a legacy video; prepare cards for those life moments I will miss, such as birthdays, graduations, heartbreak, wedding, and baby. I decided I will be part of her life forever!

Donna Myhre (Contributed by The ALS Association Greater New York Chapter)

Elder and Special Needs Law attorneys focus on the legal needs of seniors and people with disabilities and are a wonderful resource to assist you in planning. They work with a variety of legal tools and techniques to meet the goals and objectives of their clients. Some of the primary areas they assist with include durable powers of attorney, living will, estate planning and probate, long-term care, healthcare decisions, retirement benefits, Medicare, Medicaid, and other public benefits and trusts. The following section will take a look at some of these areas and the importance of laying out a roadmap for your future decisions.

Resource

National Academy of Elder Law Attorneys:
www.naela.org/findlawyer

Your ALS Association chapter may be able to share names of lawyers who may be available to you locally. Some lawyers offer pro bono services for patients with ALS.

Estate Planning

There are many reasons why individuals put off estate planning. However, it is an important topic to discuss and consider early after diagnosis. **Common myths related to estate planning:**

- Estate planning is only for the wealthy.
- It's not needed because my family will know what to do and what I want.
- It's expensive.
- Once decisions are made I can't change them.
- Estate planning is only about money.

These assumptions are false and will be addressed throughout this section. Estate planning involves more than finances. It can include making decisions about your property, healthcare, children's care, and ensuring that your wishes are carried out the way YOU want them. It's about you taking control and helping your family and loved ones know your wishes.

Creating a will, which is a legal document, directs your loved ones about what to do with your property and possessions. If you do not have a will, then a probate court will follow predetermined laws on distribution, which may not be what you would want. Some assets, such as life insurance proceeds, where a beneficiary designation was established, are not distributed by a will. It is recommended that those documents are organized, maintained in a safe location, and that family or a friend are informed about the location of these documents. Planning is also an ongoing process and changes can and do occur. Reviewing your decisions and documents can and should be an ongoing flexible process.

A will can also express your wishes regarding guardianship of dependent children. It is important to know the particular laws and the steps on assigning guardianship in your state, and it is always a good plan to seek legal guidance and advice from a professional (Widness, 2012).

Advance Directives

Advance directives or **advanced care planning for healthcare** wishes are important for everyone. After receiving a diagnosis of ALS it is important to begin thinking about your quality of life and what your wishes will be as your disease progresses.

Do what you want to do and create a memory because the gift after death is the memory.

Kathy Sizemore, caregiver

(Contributed by The ALS Association Central and Southern Ohio Chapter)

Advanced care planning involves understanding your possible future healthcare choices, thinking about your choices in terms of what is important to you and your values, discussing your decisions with loved ones and healthcare providers, and finally completing advance directives paperwork so they are ready if needed.

You may already have advance directives in place, but at this time it will be important to review and revise the paperwork, especially if your first directive reads very generally or is unspecific for a particular illness.

Some individuals have very strong convictions about what interventions they do or do not want. Others feel that until they get to certain points of their disease progression they will be unable to decide. **It is important to remember that advanced care planning is done over time and usually not completed in a single conversation.** Your plans and advance directives can be changed as your situation or wishes change. However, as stated earlier, **significant healthcare decisions are best considered before there is a crisis**, but even in a crisis you still have the right to change your wishes. Having advance directives in place also provides your loved ones with the peace of mind in knowing that you had a part in stating your healthcare decisions.

There are **two primary elements** in an advance directive: **1) a living will and 2) a durable power of attorney for healthcare.** There are also other supporting documents that can supplement your advance directives or stand-alone, which can include **DNR (Do Not Resuscitate) orders, DNI (Do Not Intubate) orders, tissue donation, and POLST (Physicians Orders for Life Sustaining Treatment) orders** (National Institute on Aging, 2014).

The following quotes describing advance planning come from the **National Institute on Aging** (2014).

Living will: "A living will is a written document that helps you tell healthcare professionals how you want to be treated as your disease progresses or you become permanently unconscious and cannot make decisions about emergency treatment. In a living will, you can say which procedures you would want, which ones you wouldn't want, and under which conditions each of your choices applies." Most living wills are fairly general, and once you are diagnosed with ALS you should review and make your advance directives more specific to what is likely to happen in ALS. **Your living will should address artificial nutrition and hydration, non-invasive ventilation, tracheostomy and invasive ventilation, and comfort care.** You will find more detailed information about these interventions in additional resource guides published by The ALS Association.

Durable power of attorney for healthcare: "A durable power of attorney for healthcare is a legal document naming a healthcare proxy, someone to make medical decisions for you at times when you might not be able to do so. Your proxy, also known as a surrogate or agent, should be familiar with your values and wishes. This means that he or she will be able to decide as you would when treatment decisions need to be made." **It is important that the person you appoint as your healthcare proxy be emotionally strong enough to follow your directives even if the choice is very difficult when the situation is occurring.**

It is also a good idea to appoint or name a backup or alternate healthcare proxy if your first choice is unavailable at the time of an emergency. Again, your healthcare proxy will only act if you are completely unable to voice your needs or make decisions. Otherwise, you remain in control of your healthcare.

Other advanced care planning documents: “You might also want to prepare separate documents to express your wishes about a single medical issue or something not already covered in your advance directive. A living will usually covers only the specific life-sustaining treatments discussed earlier.” You might want to give your healthcare proxy specific instructions about other issues. Two medical issues that might arise at the end of life are DNR orders and organ and tissue donation.

DNR: “A **DNR** (do not resuscitate) order tells medical staff you do not want them to try to return your heart to a normal rhythm if it stops or is beating unevenly. Even though a living will might say restoring your heart beat (medical term: **cardiopulmonary resuscitation or CPR**) is not wanted, it is helpful to have a DNR order as part of your medical file if you go to a hospital. Posting a physician signed DNR next to your bed might avoid confusion in an emergency situation. **Without a DNR order, medical staff will make every effort to restore the normal rhythm of your heart.** A non-hospital DNR will alert emergency medical personnel to your wishes regarding CPR and other measures to restore your heartbeat if you are not in the hospital. A similar document that is less familiar is called a **DNI** (do not intubate) order. **A DNI tells medical staff in a hospital or nursing facility that you do not want to be put on a breathing machine via a tube inserted into your airway (medical term: intubation).”**

POLST: A number of states are developing or starting to use an advanced care planning form known as **POLST** (Physician Orders for Life-Sustaining Treatment) order. These forms serve in addition to your advance directive. They make it possible for you to provide further guidance about your medical care preferences for emergency situations. Your physician will talk with you and/or your family for guidance, but the form is filled out by the physician, or sometimes, a nurse practitioner or physician’s assistant. Once signed by your physician, this form has the standing of any other medical order. These forms are often printed on brightly colored paper so they are easily found in a medical or hospital file. Check with your state department of health to find out if this form is available where you live. You can also visit www.polst.org to find more information about the status of POLST orders in your state.

Tissue donation: Tissue donation can be an uncomfortable topic, but some people with ALS find committing to be a tissue donor provides them with a sense of purpose in knowing that the donation will contribute to the quest for knowledge about ALS. Because ALS is a disease of the motor neurons located in the brain and spinal cord, it is difficult to access this tissue in people living with ALS, and instead, must be completed after death. If you are interested in donating tissue you need to plan in advance since there are few medical centers prepared to perform the tissue donation procedure effectively. There is also a limited window of opportunity after death to realistically gather tissue (The ALS Association, 2013). **Consult with your neurologist, primary care physician, or your local ALS Association chapter for more details on tissue donation and locations that currently accept donations.**

Finalizing your paperwork: There are several places you can obtain advance directive forms, including your ALS clinic, local hospital, your state Area on Aging

Office, as well as online resources like Caring Connections by National Hospice and Palliative Care Organization. Some states require your advance directive be witnessed; some want your signature notarized. A notary is a person licensed by the state to witness signatures. Notaries can be found at your bank, post office, local library, or your insurance agency. Some notaries charge a fee. **You do not need an attorney to complete advance directives.**

Key people should be told that you have an advance directive and be given copies, including your healthcare proxy and alternate proxy. Your doctor should be given a copy to include in your medical record. Tell key family members and friends where you keep a copy. If you have to go to the hospital, give the staff a copy to include in your records. Because you might change your advance directive in the future, it's a good idea to keep track of who receives a copy.

Making decisions was difficult for my dad. What he wanted was to remain home and stay as active as possible. We had to get some of the tough decisions out of the way, like finishing his Do Not Resuscitate orders, and discuss whether we wanted a feeding tube or breathing tube. But the ALS Association was supportive and showed us what dad's life would be like and the help we would need in each step of the disease process. Then dad could make the decisions that were right for him. It was hard, but when the final plans were made, we could sit back and relax and enjoy life again instead of worry about what comes next.

Brenda Davenport, her father, Frank, has ALS
(Contributed by The ALS Association MN/ND/SD Chapter)

Resources

National Institute on Aging:

<https://www.nia.nih.gov/health/publication/advance-care-planning>

Prepare for Your Care:

<https://www.prepareforyourcare.org/page>

National Hospice and Palliative Care Organization:

www.caringinfo.org

Center for Practical Bioethics:

www.practicalbioethics.org

The ALS Association:

www.alsa.org/assets/pdfs/fyi/fyi_tissue.pdf

Choices for Death with Dignity

The Death with Dignity Movement is based on the fundamental notion that “the greatest human freedom is to live, and die, according to one’s own desires and beliefs” (Death with Dignity National Center, 2015).

In order to ensure that people have some control over their own end-of-life care, they should be given options, ranging from knowing the importance of

advance directives to the benefits of palliative care and hospice programs, to the possibility of physician-assisted dying or aid in dying if permitted in their state.

For most people with ALS and their loved ones, to know that end-of-life can be comfortable and with dignity is very reassuring. In 1990, the **Patient Self-Determination Act (PSDA)** was passed and requires any healthcare facility that receives Medicare and Medicaid funds to advise patients of their rights under state law to execute advance directives. One of these rights is the right to refuse and/or withdraw treatment, which has been recognized as a fundamental principle of liberty not only by our judiciary system but also by the United States Constitution.

Advance directives are very important in specifying your healthcare preference and goals of care. Palliative care and hospice care both specialize in relieving discomfort and suffering by the patient and the family by proactively managing symptoms, thoroughly understanding the patient's goals of care, and providing emotional and spiritual support to both the patient and loved ones.

Physician-assisted death, or aid in dying, is when a physician facilitates a patient's death by providing the necessary means and/or information to enable the individual to perform the life-ending act (American Medical Association, n.d.). Currently, there are five states in the U.S. in which aid in dying is authorized, three by established laws (Oregon, Washington, and Vermont) and two by courtroom rulings (New Mexico and Montana). Several other states are working on legislation at this time.

The ALS Association neither supports nor opposes physician-assisted death for people with ALS. The Association believes that the decision regarding assisted suicide is entirely a matter of individual conscience. Due to the legal, moral, and ethical issues inherent in physician-assisted suicide, The ALS Association cannot and will not become involved in the assisted-suicide process. The Association is committed to meeting the unique needs of each person with ALS and to ensuring that people and families receive the very best palliative and end-of-life care.

Resources

Death with Dignity National Center:

<http://www.deathwithdignity.org/end-of-life-resources>

Compassion and Choices:

www.compassionandchoices.org

Living with ALS

Personal Role

Many people with ALS find continued purpose of life and fulfillment during their illness. Some of the most powerful reasons for living with ALS are personal, including family, friends, important events or milestones, and goals to yet be accomplished. Even though a person with ALS may not be able to complete all tasks they were able to do while they were healthy, they still have important roles to fill, including that of spouse, parent, child, sibling, friend, etc. Your loved ones

still need you and will continue to look to you for the guidance and support you provided them prior to your diagnosis.

After shopping, we take pictures of my cupboards and refrigerator with my iPad. I can check the pictures to make grocery lists and plan meals for the week. I look up recipes online to plan each week. I still feel in charge of my kitchen!

Kathy C., Valentine, Nebraska

Research Participation

In the past decade, there have been many changes in research funding, in drug development, and in clinical trial design. The growing importance of finding treatments for all neurodegenerative diseases has made ALS a very important target disease for the development of new approaches to stopping the death of nerve cells.

ALS Research

“Recent years have brought significant progress in understanding ALS and new approaches to therapy development. A central theme is that ALS has multiple causes, most likely a combination of genetic susceptibility and environmental factors. Despite evidence that environmental exposures and lifestyle may contribute to ALS, risk factors have been very difficult to pin down. Greater progress has been made in identifying gene alterations that can significantly affect one’s risk of developing ALS or influence the course of the disease; insights gained are anticipated to identify optimal targets for drug therapy and may provide a framework for understanding why clinical features of ALS can vary widely among individuals.

Current ALS research is also increasingly focused on the need for more effective clinical measures or biomarkers that will allow faster and more accurate assessment of response to treatment in ALS clinical trials; optimal use of these biomarkers will require knowledge of individual differences in the causes of ALS. Knowledge gained from basic and translational research and past therapeutic trials is being leveraged with the addition of new biomarkers to make ALS clinical trials more efficient. Ongoing research is moving ALS therapy development closer to personalized medicine with great hope and promise that a more complete understanding of the causes of ALS will emerge in coming years, and with it, effective therapy.”

Dr. Kevin Boylan

Many people thoughtfully consider the decision about whether or not to participate in clinical trials or research. Not only could research benefit those currently living with ALS, but also those diagnosed in the future. Even if a study does not show the anticipated outcomes, the results provide new insight and information to help solve questions regarding the disease.

I have been asked why do medical trial studies? Getting involved empowers me to fight ALS. It gives me hope. It's about being a part of something bigger than me. I don't want anyone to be diagnosed with ALS. My enrollment in studies gives me purpose. This purpose driving life has been a catalyst for positive change in my thoughts. ALS is a horrible disease. It will take great efforts to eliminate. But I have hope that we are a part of the cure for ALS.

Michael Sullivan, Western Pennsylvania

Symptom Management/ Technology Decisions

The rate at which ALS progresses and the symptoms experienced by each individual varies from person to person. Although the average life expectancy of a person with ALS is two to five years from the time of diagnosis, half of all those affected live at least three years or more after diagnosis. About 20% live five years or more and as many as 10% survive more than 10 years.

"I use a speech generating device to communicate. My condition has affected the outer Vaughan, but the inner me is still intact, I remind people that I am the same person that you know and love. For example, I communicate with my three kids by text frequently. I talk to them about the things every parent talks to their children about; even in my condition I'm able to actively parent them."

Vaughan Thomas, Western Pennsylvania

There have also been many advances in technology-assistive devices and symptom management that have improved quality of life and helped individuals live longer, more productive lives. The professionals at ALS clinics and ALS Association Certified Treatment Centers of Excellence use a multidisciplinary approach to assist individuals in making care decisions by providing education and advice regarding options.

Resources

Quick Facts About ALS and The ALS Association:

<http://www.alsa.org/news/media/quick-facts.html>

The ALS Association:

<http://www.alsa.org/>

NEALS - Amyotrophic Lateral Sclerosis Consortium:

<http://www.alsconsortium.org/>

Clinical Trials:

<http://clinicaltrials.gov/>

SUMMARY STATEMENT

“Planning your life feels different the moment you receive a diagnosis of ALS. All your former plans seem to go out the window as you face eminent disability and a terminal disease. But really, everyone has a terminal disease—it’s called Life—and a specific diagnosis in an odd way makes it easier to plan. For some of us, it’s the catalyst to make our life-plan more like what it should have been all along.

When you decide and communicate what is important to you, you are defining your vision of how you want to live. You are giving everyone around you clear goals. Loved ones don’t have to struggle to figure out how to make you happy. Being the chief executive officer of your care is something positive you can do for yourself and others on your team, no matter how your disability evolves.”

Mara Sweterlitsch, woman living with ALS

It is often difficult to plan and think about so many decisions. The diagnosis of a terminal illness is overwhelming enough so it is especially hard to think about future care needs and financial and legal issues, but in the end, you will be glad that you planned ahead for yourself and your loved ones.

Remember that you are not alone. There are professionals who can provide guidance and information to help you make informed decisions. Your family and friends can also help guide and support you through the process.

I look back afterward and think about all the friends, family, professional help, and our own determination that got us through this journey. Positive thinking, living for today, and a great attitude is key. You learn to take a little bit of knowledge and help from here and there. It’s like a puzzle, no one has all the pieces. But with everyone’s help, the puzzle was complete.

Husband and full-time caregiver of woman who recently passed away from ALS (Contributed by the ALS Association Golden West Chapter)

By planning, you are also staying in control of your own life and helping your family. By planning ahead, your family will not need to make decisions for you in a crisis situation, nor will they have to worry about whether they made the “right” decisions on your behalf.

From the time I learned that I had ALS, I was in charge of all the decisions regarding my care. I made decisions so I could spend as much time as possible with my husband Ray and my family. Along with the help of The ALS Association and staff at the clinic to answer any question I had, I planned in advance so that I could make my wishes known; my mind is still clear; therefore, I can still be in control of my life.

Linda Devlin-Mankevich, Pennsylvania

Here is a checklist to assist in your planning and decision-making process.

PLANNING AND DECISION-MAKING CHECKLIST

Employment Decisions

- Review Benefits and Rights
- Pension Plan Review
- Vocational Rehabilitation Options
- Social Security Disability Insurance

Care Decisions

- FMLA for Caregiver
- Home Care Options
- Palliative/Hospice Care

Financial/Legal Planning*

- Estate Planning
- Durable Power of Attorney
- Living Will
- Other Directives: DNR, DNI, POLST, Tissue Donation

* An Elder and Special Needs Law Attorney in your area should be able to help you in these areas.

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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.