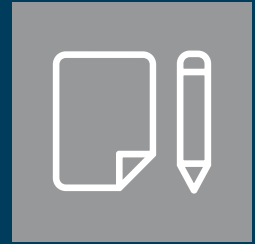


Living with ALS: Planning and Decision Making





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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.



Introduction

After receiving a diagnosis of ALS, everyone reacts differently. No matter what your reaction, at some point you will have to begin making decisions and planning for the future. **Several types of decisions will need to be made** along this journey, including **how long to remain employed, how to financially protect yourself and your family, what quality of life looks like to you, and how to ensure 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. Obviously, 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, Sulmasey, and Nolan, 2007). You are not alone and can seek the support of your ALS clinic team, other people and families living with ALS and your own family and friends. You must also consider what consequences your decisions will have on your family and friends since you are all 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 provides you with resources to help.

The following topics will be covered:

- Issues related to employment and ALS/disability
- Genetic counseling
- 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
- Advanced directives
- Choices for dying with dignity
- Symptom management and technology decisions

Employment and ALS

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 with discussing your diagnosis.

Often, 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 are you eligible.

Group Pension Plans

It is important to identify what type of retirement plan or plans you have at work. 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.

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 them 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 incur tax penalties on your distribution.

If you are in a defined benefit plan (other than a cash balance plan), you will likely 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 you have this benefit.

If you file a benefits 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

United States Department of Labor:

<https://www.dol.gov/general/topic/retirement/typesofplans>

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 chose to remain employed. **The Americans with Disability Act (ADA), originally passed in 1990, and subsequent amendments make 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 based on 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, to be protected from job discrimination by the ADA.

This means **two things**:

- 1. You must satisfy the employer's requirements for the job**, such as education, employment experience, skills or licenses.
- 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. (US Equal Employment Opportunity Commission).



Three examples of reasonable accommodations 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:

[The ADA: Your Employment Rights as an Individual With a Disability | U.S. Equal Employment Opportunity Commission \(eeoc.gov\) https://www.eeoc.gov/laws/guidance/fact-sheet-eeocs-final-regulations-implementing-adaaa](https://www.eeoc.gov/laws/guidance/fact-sheet-eeocs-final-regulations-implementing-adaaa)

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 the essential functions of their job.

- The FMLA can also be utilized to care for the employee's spouse, child or parent who has a serious health condition.

The FMLA mandates:

- If possible, employees must give 30-days' notice that they are taking a leave.
- Employees (except for 10 percent 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 on 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. The Department of Labor notes that "it is ESSENTIAL for you to be familiar with your employer's leave policy. There are several instances throughout the FMLA leave process where you will need to comply with BOTH the FMLA regulations AND your employer's leave policy." If you think your rights under the FMLA have been violated, you can contact the U.S. Department of Labor's Wage and Hour Division at 1-866-487-9243.

<https://www.dol.gov/sites/dolgov/files/WHD/legacy/files/employeeguide.pdf>

For additional information on FMLA, please visit the Department of Labor website at: <https://www.dol.gov/agencies/whd/fmla>

RESOURCES

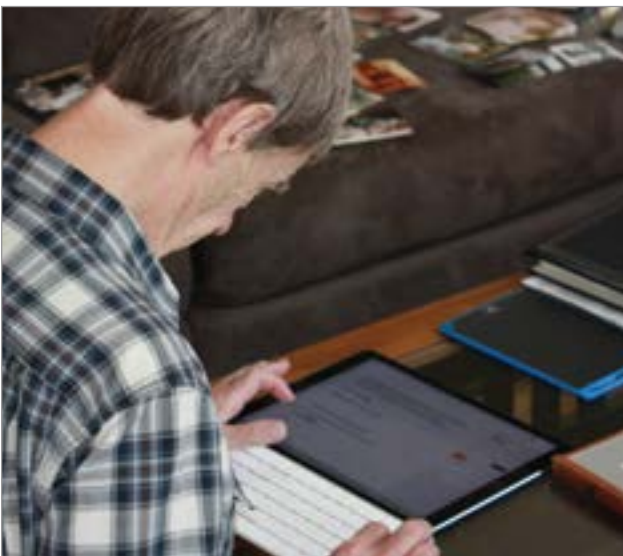
[Your Employment Rights as an Individual with a Disability | U.S. Equal Employment Opportunity Commission \(eoc.gov\)](#)

<https://www.eeoc.gov/disability-discrimination>

Need Time? The Employee's Guide to the Family and Medical Leave Act: United States Department of Labor: <https://www.dol.gov/sites/dolgov/files/WHD/legacy/files/employeeguide.pdf>

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 help with assistive technology and devices as well as supportive services to assist in maintaining employment.**



RESOURCES

Vocational Rehabilitation Services: <https://rsa.ed.gov/about/programs>

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. As a result of advocacy efforts, the *ALS Disability Insurance Access Act of 2019* eliminated the required five-month SSDI waiting period for ALS applicants approved for benefits on or after July 23, 2020. Therefore, if eligible for SSDI, benefits should be processed quickly with no waiting period.

People with a diagnosis of ALS also are eligible for Medicare benefits due to disability immediately following an application for SSDI.

If you do not qualify for SSDI you may be able to 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 it is a federally funded program, Medicaid benefits vary from state to state.

If you need assistance or have questions, contact your local ALS Association care team or Social Worker at an ALS Clinic for resources.

RESOURCES

Social Security: <https://www.ssa.gov/benefits/disability/qualify.html#anchor0>

The ALS Association: Frequently Asked Questions about Accessing Social Security Disability Insurance and Medicare
<https://www.als.org/blog/ssdi-and-medicare-faq>

The Patient Advocate Foundation—ALS Medicare Resource line: <https://als.pafcareline.org/>

Genetic Testing

Another decision is whether to get genetic testing to determine if your ALS has a genetic cause. Once again, this is a personal decision, but it is recommended you discuss all options and potential consequences with your doctor and a genetic counselor. A genetic counselor can:

- Talk you through the process, potential benefits, costs and risks of getting a genetic test.
- Interpret the results of your genetic test and help you understand what a specific genetic variant means for your and your family's health.
- Assist with family planning.
- Help you work through the psychological, emotional and social ramifications of living with your genetic test results.

The ALS Association developed the ALS Genetics Discussion Guide to help people with ALS, caregivers and health care providers talk about the genetics of ALS. With this guide, we hope to lead the entire ALS community toward more effective and productive discussions about an ALS diagnosis.

RESOURCES

ALS Association: Understanding ALS Genetic Counseling:
<https://www.als.org/understanding-als/who-gets-als/genetic-testing/genetic-counseling>

National Society of Genetic Counselors at www.nsgc.org

ALS Genetics Discussion Guide https://www.als.org/sites/default/files/2021-10/Genetic-Testing_Flowchart_print.pdf

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 if you are unable to take care of yourself. Understandably, these questions are difficult to consider because they require thinking and talking about your eventual loss of independence. However, it is easier when you know your options and have a plan. 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. The COVID-19 pandemic exposed limitations that home care agencies have in available staff for care. There could be staffing shortages in your area. Therefore, **it is wise to weigh your options carefully and leave planning time before the services need to start.**



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. **Here are some questions to ask to understand your situation:**

What type of care does my health insurance cover? Insurance coverage is addressed further in *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 and whether there are any limits to the amount of money paid or 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 Certified Treatment Center of Excellence, ALS clinic or local ALS Association care team, have a wealth of resources and information regarding potential services and community resources. Medicaid is a joint federal and state government program that assists financially eligible individuals with medical care, nursing facility care and possibly home care. Although it is a federal program, each state has its own eligibility rules and services. Two potential programs are:

1. Home and community based services, which provides long-term care services in your home and can offer such services as case management, homemaker, home health aide, personal care, and adult day care.
2. Program of All-Inclusive Care for the Elderly (PACE) also offers comprehensive medical and social services to eligible individuals still living in the community. Most participants in these two programs are dual eligible for Medicare and Medicaid. Eligibility varies by state. State medical assistance offices can provide information about how to qualify for these services in your state.

Are you a veteran? What services does the Veterans Administration provide? As a veteran with a diagnosis of ALS, you could be eligible for compensation and other benefits. This is 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 important to understand there are many issues to consider when deciding on home care. It is very important to ask questions and to consider what's important to you. Some potential questions are:

1. What are the tax implications and legal ramifications in your state for hiring a worker privately?
2. Are those risks worth the potential lower rate as opposed to going through an established bonded agency?
3. Is there a back-up plan if your worker is sick or calls off?
4. Is the cost of care higher on the weekend or in the evenings?
5. Will the workers provided be consistent?
Are there staffing limitations?
6. Is the agency licensed or bonded or does it have liability coverage?
7. Is there a guaranteed minimum number of hours required each day before the agency will provide in-home care services? (Bartelstone, 2015)

RESOURCES

Medicaid.gov: [Centers for Medicare and Medicaid Services: CMS.GOV](https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html/) <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html/>

Centers for Medicare and Medicaid Services: CMS.GOV <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/PACE/PACE>

ALS Association: Services Connected Benefits: <https://www.als.org/navigating-als/military-veterans/information-benefits>

Palliative Care and Hospice Care: The Difference

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 described below.**

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 with the primary treatment you are receiving. Palliative care also focuses on open dialogue about treatment choices and goals of care. Your palliative care team can help you and your family 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 a 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 collaborative approach to expert medical care, pain management and emotional and spiritual support tailored to the patient's needs and wishes.

Support is provided to the patient'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.

The hospice team develops a **care plan that meets each patient's needs for pain management and symptom control.** The team usually consists of the patient's 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 patient and provide additional care or other services. Hospice staff is on call 24 hours a day, seven days a week. The hospice team will proactively assess problems so the person with ALS and their caregiver feel more prepared to negate crisis and anxiety when end-of-life changes and symptoms arise.

"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 K.

According to the **National Hospice and Palliative Care Organization**, “among its major responsibilities, the interdisciplinary hospice team:

- Manages the patient’s pain and symptoms
- Assists the patient with the emotional, psychosocial and spiritual aspects of dying
- Provides needed drugs, medical supplies and equipment related to admitting diagnosis
- Coaches the family on how to care for the patient
- Delivers special services like speech and physical therapy when needed
- Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home or when 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 patient’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, 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 to inquire about the plan’s hospice benefit, because 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 wherever you call home. It is important that prior to choosing hospice, a person with ALS should obtain all needed equipment that would not necessarily be covered under the hospice benefit (power wheelchair, speech generating devices, etc.). Hospice care can always be canceled if an unforeseen situation arises where additional medical care is needed (i.e., 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 speeds up death. **The truth is, 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 of end-of-life in Medicare beneficiaries found that even though the percentage of patients receiving hospice care doubled, the frequency of hospitalizations and intensive care units (ICU) stays during the last months of life increased. This indicates 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, since many times hospice care was used only in the last couple days of life. This study concluded that **the patient's goals of care should be obtained earlier so that palliative and hospice care can 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.** There are many other benefits to utilizing hospice for the full six months, including 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 their 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 care team.

RESOURCES

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

CaringInfo: <https://www.caringinfo.org/>

Financial and Legal Issues

The Cost of Living with ALS

Living with ALS can be expensive. "Estimates on annual healthcare costs range from approximately \$16,000 up to \$200,000 and can vary depending on the stage of the illness." (Santaniello, 2018)

Medical costs, home modifications, home care, durable medical equipment and handicap accessible vehicles are some of the largest contributors to this cost. Cost usually increases in the late stages of the disease, particularly if an individual chooses to pursue tracheostomy and invasive ventilation. If you are unable to remain at home, long-term facility-based care is another cost that could become a factor.

Financial planning is essential when facing ALS, and it is also helpful to know programs that are available to assist with some of these costs.

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 explore some of these areas and the importance of creating a plan for your future decisions.

RESOURCES

National Academy of Elder Law Attorneys: https://www.naela.org/Web/About/ImportTemp/About_NAELA_New.aspx?hkey=feb0efd3-bd62-4508-9ca4-20de373d4784

Estate Planning

There are many reasons why individuals delay estate planning, but it is an important topic to discuss early after diagnosis:

Common Myths Related to Estate Planning Are:

- 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 fulfilled the way YOU want them. It's about you taking control and helping your 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 and 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, so reviewing your decisions and documents is a good idea.

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

Advance Directives

Advance directives, or **advanced care planning for healthcare** wishes, are important for everyone. Life is unpredictable. Death is inevitable for us all. 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.

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 completing advance directives paperwork so they are ready if needed. You may already have advance directives in place, but now 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 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 advanced directives can be changed as your situation or wishes change. As stated earlier, **significant healthcare decisions are best considered before there is a crisis**, and even in a crisis you still have the right to change your wishes. Having advance directives in place also provides your loved ones peace of mind in knowing that you had the final say in your healthcare decisions.

There are **two primary elements** in an advance directive: **a living will and a durable power of attorney for healthcare.** There are other supporting documents that can supplement your advance directives or stand alone, which can include do not resuscitate (DNR) orders, **do not intubate (DNI) orders, tissue donation, and Physicians Orders for Life Sustaining Treatment (POLST) orders** (National Institute on Aging, 2012).

The following advance planning definition quotes come from the **National Institute on Aging-Advance Care Planning** (2021). <https://www.nia.nih.gov/health/advance-care-planning-health-care-directives>

Living will: “A living will is a written document that helps you tell doctors how you want to be treated if you are dying or permanently unconscious and cannot make your own decisions about emergency treatment. It’s your opportunity to provide instructions about

“The first thing I would advise is checking with a lawyer about assets immediately after finding out you have ALS. We signed certain things over to our children. I have to live for five years but it is worth trying! We took my name off our bank accounts and our house.”

–Kathy C.

treatments or procedures that you want or don't want. Most living wills are fairly general, and once you are diagnosed with ALS, you should review and make your advance directives more specific. **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." This person should know your values and wishes as they will then be able to make the same decisions you would want. It is important that the person you appoint as your healthcare proxy be emotionally strong enough to follow your directive even if the choice is very difficult when the situation is occurring. It is also a good idea to appoint an 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." Also, 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 do not resuscitate (DNR) order tells medical staff in a hospital or nursing facility that you do not want them to try to return your heart to a normal rhythm if it stops or is beating unsustainably using CPR or other life-support measures. Sometimes this document is referred to as a do not attempt resuscitation (DNAR) or an allow natural death (AND) order. Even though a

living will might say 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 DNR next to your bed might avoid confusion in an emergency. Without a DNR order, medical staff will make every effort to restore your breathing and the normal rhythm of your heart.”

DNI: “A similar document, called a **do not intubate (DNI) order**, tells medical staff in a hospital or nursing facility that you do not want to be put on a breathing machine.”

POLST or MOLST: “**Physician Orders for Life-Sustaining Treatment (POLST) and Medical Orders for Life-Sustaining Treatment (MOLST) forms** provide guidance about your medical care preferences in the form of a doctor’s orders. Typically, you create a POLST or MOLST when you are near the end of life or critically ill and you know the specific decisions that might need to be made on your behalf. These forms serve as a medical order in addition to your advance directive. They make it possible for you to provide guidance that health care professionals can act on immediately in an emergency. 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 out more information about the status of POLST orders in your state.



Finalizing your paperwork: There are several places you can obtain advance directive forms, including your ALS clinic, local hospital, state Area on Aging Office, and 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 staff a copy to include in your records. Because you might change your advance directive in the future, keep track of who receives a copy.

For further information on advance directives, please go to **Advanced Care Planning: Tips from the National Institute on Aging** at <https://www.nia.nih.gov/health/advance-care-planning-health-care-directives>



RESOURCES

Caring Connections National Hospice and Palliative Care Organization:

<https://www.caringinfo.org/>

CaringInfo: <https://www.caringinfo.org/>

National Institute on Aging:

<https://www.nia.nih.gov/health/getting-your-affairs-order>

The ALS Association: FYI Planning for the Future:

<https://www.als.org/navigating-als/resources/fyi-planning-future>

Choices for Dying 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).

To ensure people have some control over their own end-of-life care, they should be given options—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, it is reassuring to know that end-of-life can be comfortable and dignified. In 1990, the **Patient Self-Determination Act (PSDA)** was passed, which requires any healthcare facility that is receiving 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 important in specifying your healthcare preference and goals of care. Palliative and hospice care both specialize in relieving discomfort and suffering by the patient and 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 suicide, or aid in dying, is when a physician facilitates a patient’s death by providing the necessary means and/or information to enable the patient to perform the life-ending act (American Medical Association). The following U.S. Jurisdictions have death with dignity statutes: California, Colorado, Hawaii, Maine, New Jersey, New Mexico, Oregon, Washington, Vermont and Washington, D.C. Montana has courtroom rulings. Several other states are working

on legislation currently. For more information on this issue, please visit <https://deathwithdignity.org/learn/death-with-dignity-acts/>.

“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.

The ALS Association neither supports nor opposes physician-assisted suicide for people with ALS. We believe 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. We are committed to meeting the unique needs of each person with ALS and ensuring that people and families receive the very best palliative and end-of-life care.

RESOURCES

Death with Dignity National Center:
<https://deathwithdignity.org/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 the tasks they were able to do while they were healthy, they still have important roles to fill, including spouse, parent, child, sibling and friend. 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.

Participating in advocacy efforts relating to ALS causes is another way individuals may find fulfillment. The advocacy efforts through the ALS Association have brought about many changes and improvements for those living with ALS. One participant in a Living with ALS meeting said that when he heard the ACT for ALS Act passed in the Senate, he felt good that, in some slight way, his letters had an impact and he was a part of it being passed.

RESEARCH PARTICIPATION

In the past decade, there have been changes in the pharmaceutical industry, drug development and assistive technology. The severity of ALS and the importance of finding treatments for all neurodegenerative diseases have combined to make ALS an attractive target for the development of new approaches.

The decision on whether to participate in clinical trials or research could benefit those currently living with ALS and those diagnosed in the future. Even if a study does not show the anticipated outcomes, researchers gain new insight and information to help solve questions regarding the disease.

An ongoing research project is the National ALS Registry. Every person

“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 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

living with ALS can and is encouraged to enroll. It is possibly the largest research project designed to identify ALS cases throughout the United States, collect data to improve care for people living with ALS and learn about potential causes that may lead to treatments.

A part of the National ALS Registry is the National ALS Biorepository. A biorepository is a facility that collects and stores biological samples for research. This provides an opportunity for researchers to learn more about ALS.

According to the Centers for Disease Control and Prevention, there are two types of tissue donation:

- The **biospecimen (in-home) part** involves the collection of blood, urine, hair and fingernail clipping specimens from PALS in their homes.
- The **postmortem part** involves the donation of brain, spinal cord, cerebral spinal fluid and pieces of muscle, skin and bone from PALS after they have died. <https://www.cdc.gov/als/ALSNationalBiorepository.html>

Postmortem 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 or comfort 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 accessed after death. If you are interested in donating tissue, you need to plan since there are few medical centers prepared to perform the tissue donation procedure effectively. There is also a limited opportunity after death to realistically harvest tissue (The ALS Association, 2013).

Please consult your neurologist, primary care physician or your local ALS Association care team for more details on tissue donation and locations that are currently accepting donations.

“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 S.

SYMPTOM MANAGEMENT/ TECHNOLOGY DECISIONS

The rate at which ALS progresses and the symptoms experienced varies from person to person. Although the average life expectancy of a person with ALS is two to five years from time of diagnosis, 50 percent of those affected live at least three years, about 20 percent live five years or more and as many as 10 percent will survive more than 10 years.

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

ALS Association: www.als.org

Northeast Amyotrophic Lateral Sclerosis Consortium (NEALS):
<http://www.alsconsortium.org/>

Clinical Trials: <http://clinicaltrials.gov/>.

The ALS Association, Clinical Trials:
<https://www.als.org/research/clinical-trials-for-patients>

National ALS Registry: <https://www.cdc.gov/als/Default.html>

A benefit to participating in a clinical trial is that the questions answered can benefit all persons with the disease. Even if a candidate treatment fails to hold promise, the results of any clinical trial give new insight and direction to those working to solve the disorder.

Summary Statement

In the words of a person currently living with ALS,

“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.”

In the face of a terminal diagnosis, it is especially hard to think about future care needs. Financial and legal issues can feel overwhelming at times.

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.

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

“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 T.

Planning and Decision-Making Checklist

Please use the following checklist to assist in your planning and decision-making process:

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

**Please contact an elder and special needs law attorney in your area

Bibliography

American Medical Association. (n.d.) Opinion 2.211-Physician-assisted Suicide. Retrieved from <https://journalofethics.ama-assn.org/article>.

Bartelstone, Rona S, LCSW, BCD, CMC
“Hiring Private Duty Home Care Workers: Why Work through an Agency?” Today’s Caregiver (Caregiver.com) March 1, 115

Burchett, Charla M. [“Debunking Estate Planning Myths In 2021” Debunking Estate Planning Myths In 2021 - Family and Matrimonial - United States \(mondaq.com\)](#) September 22, 2021.

Caring Connections (n.d.) Are you traveling without a map? A layperson’s guide to advanced care planning. Retrieved from http://www.caringinfo.org/files/public/brochures/Are_you_traveling_without_a_map.pdf.

Carter, Erik. 10 Common Myths About Estate Planning. <https://www.forbes.com/sites/financialfinesse/2020/10/26/10-common-myths-about-estate-planning/?sh=306975a162d9/>. Oct 26, 2020.

Death with Dignity National Center. (2015). End-of-life resources. Retrieved from <http://www.deathwithdignity.org/end-of-life-resources>.

“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 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 M.

Jenq, G. and Tinetti, M.E. (2013). Changes in end-of-life care over the past decade. *Journal of American Medical Association*, Feb, 309 (5) 489-490.

Johnson, J.O, Sulmasey, D.P. and Nolan, M.T. (2007) Patients' Experience of Being a Burden on Family in Terminal Illness. *Journal of Hospice and Palliative Care Nursing*, Sep, 9(5) 264-269.

Mayo Clinic Staff. "Living wills and advance directives for medical decisions." <https://www.mayoclinic.org/healthy-lifestyle/consumer-health/in-depth/living-wills/art-20046303/>, Aug. 22, 2020.

National Hospice and Palliative Care Organization (n.d.) Hospice care. Retrieved from <http://www.nhpco.org/about/hospice-care>.

National Institute of Nursing Research (June 2009). Palliative Care: The relief you need when you are experiencing the symptoms of a serious illness. Retrieved from http://cancer.ucsf.edu/_docs/sms/PalliativeCare.pdf.

National Institute on Aging. (March 2014). Advanced Care Planning: Tips from the National Institute on Aging. Retrieved from <https://www.nia.nih.gov/health/caregiving/advance-care-planning>.

Obermann, M. and Lyon, M. (2014). Financial cost of amyotrophic lateral sclerosis: A case study. *Amyotroph Lateral Scler Frontotemporal Degener*. 2014 Sep 23:1-4.

Quick Facts About ALS and The ALS Association (March 2012). <http://www.alsa.org/news/media/quick-facts.html>.

Rhynne, Teresa. "Why estate planning is not just for the wealthy" <https://www.pe.com/2021/08/15/why-estate-planning-is-not-just-for-the-wealthy/>, August 15, 2021.

Santaniello, Briana, PharmD, MBA. Supplements and Featured Publications, A Managed Care Perspective on Scientific Advances in Amyotrophic Lateral Sclerosis, Volume 24, Issue 15, August 23, 2018. <https://www.ajmc.com/view/als-managed-care-considerations>.

The 6 Biggest Estate Planning Mistakes. Elder Law Answers (online). <http://www.elderlawanswers.com/the-6-biggest-estate-planning-mistakes-15012>.

The ALS Association (October 2013). Donation of tissue for research. Retrieved from http://www.alsa.org/assets/pdfs/fyi/fyi_tissue.pdf.

The U.S. Equal Employment Opportunity Commission (n.d.) The ADA: Your employment rights as an individual with a disability. Retrieved from <http://www.eeoc.gov/facts/ada18.html/>.

The U.S. Equal Employment Opportunity Commission; Fact Sheet on the EEOC's Final Regulations Implementing the ADA. <https://www.eeoc.gov/laws/guidance/fact-sheet-eeocs-final-regulations-implementing-adaaa>.

United States Department of Labor (n.d.) FAQs about retirement plans and ERISA. Retrieved from <https://www.dol.gov/sites/dolgov/files/ebsa/about-ebsa/our-activities/resource-center/faqs/retirement-plans-and-erisa-for-workers.pdf>.

Widness, Brett (May 2012) "10 Things You Should Know About Writing a Will: Who inherits the good silver is just the beginning: AARP" https://www.aarp.org/money/estate-planning/info-09-2010/ten_things_you_should_know_about_writing_a_will.html.

Notes



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About The ALS Association

The ALS Association is the largest philanthropic funder of ALS research in the world. The Association funds global research collaborations, assists people with ALS and their families through its nationwide network of care and certified clinical care centers, and advocates for better public policies for people with ALS. The ALS Association is working to make ALS a livable disease while urgently searching for new treatments and a cure.