

LIVING WITH ALS

A Legal and Financial Resource Guide



LIVING WITH ALS: A LEGAL AND FINANCIAL RESOURCE GUIDE

George was 60 when the symptoms started. At first, they were barely noticeable. His hands seemed to be weakening, and every once in a while, they would cramp up. Then the muscle cramps became more frequent. Then George's speech began to slur. At this point, George's wife Mary insisted that he see the doctor.

What they thought would be a quick appointment turned into a long series of tests, first ruling out one thing, then another. George's doctor grew more and more concerned. Finally came the diagnosis...ALS. George knew it as "Lou Gehrig's disease."

All of a sudden, George and Mary's world was turned upside down. They had been looking forward to a long and carefree retirement. Now, they began a battle against a powerful new enemy. They set out to learn as much as they could about this life-shortening disease, and what they learned was sobering. The new information gave rise to new concerns.

Of course, George and Mary worried about George's health. But they also worried that the disease would deplete their savings, leaving nothing for Mary to live on after George was gone. And while George knew that Mary would be with him every step of the way, he also knew how hard a caregiver's job could be. He was very concerned about the long-term toll his illness would take on his devoted wife.

Instead of letting their worries overwhelm them, George and Mary sprang into action. They met with their financial planner and their estate planning attorney. They did everything they could to get their affairs in order, both in the short-term and in the long-term.

If you or a loved one has been diagnosed with ALS, then, like George and Mary, you have a battle to fight. And, as cliché as it sounds, knowledge is half the battle.

This guide will serve as an introduction to a number of the common practical and legal issues Patients with ALS and their families encounter, in addition to some practical strategies for dealing with these issues.

Starting with the initial steps you should take after receiving a diagnosis, you'll get an overview of what you need to know about financial planning, short- and long-term estate planning, as well as your options for finding and paying for long-term care.

Keep in mind, this is not a do-it-yourself manual. Many of the issues discussed are highly complex, and you'll want to seek expert, individualized advice to make sure you get the best possible planning and solutions for your family.

The best way to use this guide is to familiarize yourself with the range of issues you'll need to be aware of, and to prepare yourself for a conversation with an experienced estate planning and elder law attorney.

STEP ONE: LEARN AS MUCH AS YOU CAN ABOUT THE DISEASE

The fact that you are reading this guide means that you're already engaged in step one. When you or a loved one receives a serious diagnosis, it's only natural to find out as much as you can about the illness and all the issues surrounding it.

There are countless books and other resources on ALS. While it is impractical to read everything that has been written about the disease, your doctor has likely recommended at least a handful of materials.

If you have not yet done so, you should contact the ALS Association at www.alsa.org or (800)782-4747. The ALS Association provides a wealth of information, including updates on ALS research and clinical trials, manuals, and videos for those living with the disease, help and resources for caregivers, and much more.

STEP TWO: REACH OUT

If you're like many patients and caregivers, you have an automatic response when someone asks you how things are going.

No matter how hard things get, you put a smile on your face and say, "everything's fine."

But there's a problem with this grin and bear it approach. ALS is not a condition you should tackle alone. It may be hard to talk about. Maybe it seems like other people just won't understand. Maybe talking about what's really happening feels too much like complaining.

But here's the thing: sooner or later, the pain, the worry, and the pressure will build up until you just can't bear it any more. Sooner or later, you'll find yourself talking about it.

Wouldn't it be better to find a group of close friends and family members and choose how and when you'd like to talk about your experience with ALS?

CONSIDER JOINING A SUPPORT GROUP

Part of learning to live with ALS is exchanging practical information, experiences, and tips with other patients and caregivers. One of the best ways to do this is to join a support group. When you're active in a support group, you get the chance to form bonds with others who are in different stages of the disease.

This gives you a safe haven full of people who can understand what you're going through in a way that others in your life simply can't. It also lets you talk to people in advanced stages of the disease, letting you anticipate and prepare for what to expect, and it lets you share your experiences with others whose ALS is not yet as advanced as yours.

The ALS Association can help you find a support group in your area.

STEP THREE: ESTABLISH AN INCAPACITY PLAN

Your next step should be to take care of some basic legal planning. Over time, ALS robs you of your ability to manage your own personal, financial, and medical affairs. Because of this, your top priority should be to make sure you have an incapacity plan in place. Your incapacity plan allows you to authorize someone you know and trust – like your spouse, an adult child, or a close friend – to make important financial and health care decisions for you.

An incapacity plan is made up of these basic documents:

1. *Durable Power of Attorney.* With a Durable Power of Attorney, you choose a trusted friend or loved one to serve as your “agent” or “attorney-in-fact.” This person has the authority to manage your financial and legal affairs according to instructions and limits you provide within the power of attorney document. Be sure to sit down and talk to your chosen agent before you put your Durable Power of Attorney in place. Let your agent know what you'll be asking of them, and make sure they're up to the task. It would be a shame to find out too late that the person you've selected to act as your agent can't serve for some reason – or simply doesn't want the job.
2. *Durable Power of Attorney for Healthcare.* A Durable Power of Attorney for Healthcare allows you to select someone you trust to communicate with your doctors and make medical decisions on your behalf in case you are unable to make these decisions on your own.
3. *Living Will.* With a Living Will, you state your wishes concerning end-of-life care. This is the document you use to let your doctors and your loved ones know which life prolonging treatments you would and would not like, such as feeding tubes, and CPR, as well as your wishes regarding life support. In some states a Living Will and Durable Power of Attorney are combined into one legal document called an Advance Health Care Directive.

Before you sign your Durable Power of Attorney for Healthcare and your Living Will, you'll want to have a couple of conversations. Talk to the person you've selected as your agent. Discuss your views on healthcare, from the mundane, day-to-day issues to the big, controversial topics. Make sure you're in agreement – or that, at the very least, your agent respects your views, will carry out your wishes, and is prepared to advocate on your behalf.

Then, have a talk with your doctors. Make sure they're comfortable with your preferences when it comes to medical treatment and end-of-life care. The last thing you want is a medical team that is resistant to you, your agent, and your family members as you embark on this battle against ALS. If your doctors don't agree with your views and preferences, now might be the time to find a new medical team.

If you already have an incapacity plan in place, now is the time to review it and make sure it still expresses your wishes. If you do not have an incapacity plan, it is important to put one in place as soon as possible, while you're still able to make your own legal decisions. Either way, an experienced estate planning and elder law attorney can help make sure your plan is complete, effective, and in compliance with current legal requirements.

GUARDIANS AND CONSERVATORS

Without an incapacity plan, life could become complicated for you and your family. Depending on the way your disease progresses, you may become unable to handle your own financial or healthcare decisions. If you did not have an incapacity plan, you would need a court-appointed person, sometimes called a "guardian," to manage your medical and personal affairs and a court-appointed person, sometimes called a "conservator" to manage your financial affairs.

In order to have a guardian and conservator appointed, your family would need to go to court and ask a judge to come to two conclusions:

1. that you are, indeed, incapable of making your own decisions; and
2. that the person or people who asked to serve as your guardian and conservator are qualified to manage your affairs. If more than one person petitions the court to serve as your guardian or conservator, the judge must decide who is best qualified.

Not only can this process be expensive and time-consuming, it also opens the door for family conflict.

After a judge appoints a guardian or conservator, the court remains involved in your life. The person appointed to make decisions on your behalf must make periodic reports to the judge. Your guardian or conservator may also be required to seek the judge's permission before making important decisions, such as large financial expenditures.

You can avoid the need for a guardian and a conservator. With an effective incapacity plan, you can express your wishes concerning your personal, medical, and financial affairs. You can put people you trust in charge of making decisions for you. You can eliminate the court's involvement in your personal matters.

STEP FOUR: UPDATE YOUR ESTATE PLAN

After you have taken the crucial first step of putting an incapacity plan in place, you'll want to discuss additional planning with your attorney. An experienced estate planning and elder law attorney can help you think through the challenges you're likely to face as a patient with ALS and structure a plan that provides for your needs while ensuring that your assets are preserved for your spouse and loved ones.

This kind of planning varies widely from family to family and from individual to individual. Everyone's needs and challenges are different, so no two plans look exactly alike. However, there are several common themes you'll want to discuss with your lawyer, including:

YOUR ESTATE PLAN

Any time you experience a major life change, you should meet with your attorney to review your will, trust, beneficiary designations, and the other components of your estate plan. A diagnosis of ALS certainly qualifies as a major life change. Now is the time not only to make sure that your estate plan still reflects your wishes, but also that it fits with the financial and long-term care planning you are likely to do in light of your diagnosis.

Your attorney will guide you in evaluating your needs, wishes, and goals and will help to ensure your estate plan fits your changed circumstances.

PROPERTY AND GIFTING

He or she will also likely ask you questions about what real estate and other property you own and how that property is titled. This review of property titles is important. Making a few simple changes now can ease transitions and protect you and your family in the future.

However, you should not transfer any property or make any substantial gifts without consulting an experienced attorney. Unfortunately, a nursing home stay or other forms of long-term care are real possibilities for many patients with ALS, and paying for long-term care can be a significant concern.

Depending on your individual needs, qualifying for government benefits in conjunction with a structured gifting program might be appropriate. However, under the wrong circumstances, gifting your assets can result in serious legal consequences, including delaying your eligibility for needed government benefits.

STEP FIVE: THINK ABOUT LONG-TERM CARE

ALS is a progressive illness. As the disease progresses, the level of care you need increases. Now is the time to think about the changes in living arrangements you will likely need.

In the early stages, you may be able to continue living independently at home, with help from family members or home health aides. However, as the disease progresses, your needs might include an assisted living facility, nursing home care, or hospice.

ASSISTED LIVING

An assisted living facility is a long-term living arrangement for residents who aren't able to live independently, but who don't need round-the-clock medical care. For patients with ALS, an assisted living facility might serve as an intermediate arrangement when living at home is no longer a possibility. Ultimately, however, hospital care, nursing home care, or hospice often becomes a necessity.

NURSING HOME

A nursing home is similar to an assisted living facility in that it has staff to help residents who need help with the activities of daily living. However, nursing homes are geared toward residents who need much more consistent and structured help, and who also need the availability of constant nursing care. Not all nursing homes have procedures, known as "ALS protocols," that are specifically geared toward patients with ALS. So, when choosing a nursing home, you'll want to ask specifically about what equipment, therapies, and procedures are available to accommodate people who are paralyzed, on a ventilator, or cannot speak. You'll also want to make sure the nursing home has staff members who are trained to care for patients with ALS.

Your Rights as a Nursing Home Resident

If you someday need nursing home care, it is important for you and your family members to understand that nursing home residents have legal rights. Each nursing home resident has the right to personal and appropriate care, as guided by the resident's care plan.

When you enter a nursing home, you, the nursing home staff, and anyone else you want to involve will create a contract. This contract is called a care plan. Ideally, this plan does a number of things to help ensure you get the best possible care during your nursing home stay.

Your care plan should spell out your current medical needs, as well as your psychological and social needs. It should also detail what steps will be taken to maintain your health in these three areas and, when possible, to improve it. This plan is a legally binding contract; therefore, it is a good idea to seek the assistance of an experienced estate planning and elder law attorney before entering into it.

HOSPICE

Hospice is a special type of care for patients in the final stages of a terminal illness. It can be offered in the patient's home, or it can be offered in a hospice center, a hospital, or a long-term care facility such as a nursing home.

The focus of hospice care is to provide patients with compassionate companionship and support, rather than to administer life-prolonging treatments. Hospice staff and volunteers work with the patient, the patient's doctors, and the patient's family to coordinate end-of-life care. This includes administering medication, taking care of hygiene needs, and handling minor medical procedures. Often, hospice services offer valuable support and counseling services to family members as well.

STEP SIX: CONSIDER HOW YOU'LL PAY FOR CARE

ALS is an enormously expensive disease, particularly once the patient is on full-time ventilation and is using a feeding tube. Many families choose to care for patients with ALS at home for as long as possible. Often, however, caring for a patient with ALS becomes too great a physical challenge. At this point, nursing home care or another long-term care arrangement becomes a necessity.

The cost of this care depends on your state of residence, the type of room you choose, and a number of other factors. However, nationwide, the average annual cost of a private room in a nursing home is almost \$100,375.¹

Many people can't afford to pay out-of-pocket for long-term care. Others worry about depleting their savings and leaving their families impoverished. Fortunately, there are a number of strategies for paying for care. This guide discusses the most common approaches. Your attorney can talk to you about all the options available to you and your family.

LONG-TERM CARE INSURANCE

When considering long-term care, the first thing you should do is to review the provisions of any long-term care insurance policies you own. Check to see whether ALS is covered. If it is, review the types of care covered by the policy, as well as when you can begin collecting benefits. Above all be sure to keep the premiums current so that the policy does not lapse.

If you do not have long-term care insurance, an ALS diagnosis will likely disqualify you from buying it. However, now may be the time to plan ahead and purchase it for your spouse.

MEDICARE

Medicare is federally-funded health insurance for people age 65 or older. It also covers health insurance for certain disabled people. The program covers a range of hospital and other medical bills. Under some circumstances, it pays for short-term skilled nursing care and rehabilitation services. However, Medicare does not cover extended stays in nursing homes or other long-term care.

¹ <https://www.genworth.com/aging-and-you/finances/cost-of-care.html> (2018)

ⁱ <https://www.genworth.com/corporate/about-genworth/industry-expertise/cost-of-care.html>

MEDICAID

Unlike Medicare, the Medicaid program covers some costs – such as those for assistance with cooking, laundry, light housekeeping, and bathing – while an eligible patient is still at home. Medicaid also covers nursing home care.

Medicaid is a joint federal-state program, which means that the rules for qualification can vary from state to state. Perhaps one of the biggest misconceptions about Medicaid is that you have to impoverish yourself and your family completely before you can qualify for nursing home coverage.

Medicaid Planning

While there are strict Medicaid eligibility requirements, including caps on income and assets, you do not need to impoverish yourself in order to receive Medicaid benefits for nursing home care. Medicaid planning, when done properly, is a legal and ethical way to qualify for benefits while retaining your family's financial security.

Qualifying for Medicaid is similar to filing a particularly complicated tax return. It is a complicated process with forms that must be filled out accurately and completely. In addition, there are rules you must follow and numerous steps you can take to maximize your ability to qualify for coverage. Incomplete forms and other errors can delay your application or jeopardize your benefit payments.

Just as you would enlist the help of a tax specialist when filing a complicated tax return, you should consult an experienced estate planning and elder law attorney to help you with Medicaid planning.

While you do not need to impoverish yourself in order to qualify for Medicaid benefits, you are expected to pay as much as you can toward the cost of your long-term care.

With proper Medicaid planning, you can typically preserve at least half of your assets. Often, it's possible to save all your assets while qualifying for Medicaid coverage. Any planning, even last minute planning, is helpful. However, the further in advance you can plan, the more options you will have. Here is how the Medicaid planning process works.

Asset Rules

Exempt Assets

Medicaid law begins by looking at your property, (and your spouse's property, if applicable) as one lump sum. First, exempt assets are deducted from the total. They include:

- One home (as long as it is your primary residence), with equity up to [\$552,000]².
- One personal vehicle (used for medical transportation).
- Your personal belongings, furniture, and other household goods.
- A designated funeral fund for you with a value of up to \$1,500 or a prepaid funeral plan of a reasonable amount, typically up to **\$10,000**³.
- A life insurance policy with a face value of \$1,500 or less.

Non-Exempt Assets

After your exempt assets are deducted from the total, you are left with non-exempt, or “countable” assets. These assets are included in the calculations used to measure your net worth against Medicaid eligibility limits. They include checking and savings accounts, retirement plans, such as 401(k) plans and individual retirement accounts (IRAs), and stocks, bonds, and mutual funds.

Division of Assets

Married couples go through a process (called “division of assets”) to ensure that the healthy spouse (called the “community spouse”) does not live in poverty while the spouse with ALS lives in a nursing home.

The total value of a married couple’s countable assets is divided in half. Typically, the “community spouse” keeps his or her half of the assets, up to a maximum of [\$126,420]⁴. Then, the spouse with ALS has to “spend down” his or her half of the assets to no more than [\$2,000]⁵.

Spending Down Your Assets

Paying your nursing home bills is one way to spend down your assets, (or, if married, your half of the assets), but it is not the only way. In fact, your estate planning and elder law attorney can help you tailor a plan to meet your family’s needs while complying with the requirements of Medicaid law. Here are some examples of the ways in which you can spend down your assets:

- Pay off credit card bills or other debt
- Make modifications or improvements to your home
- Prepay your mortgage and property taxes
- Prepay estimated income or capital gains taxes
- Buy furniture for your home
- Purchase clothes

2 Member: This number is the current default DRA figure. If the figure for your state differs, please insert it.

3 Member: This is the typical amount. Please insert your state-specific information.

4 Member: This number is the current default DRA figure. If the figure for your state differs, please insert it.

5 Member: This number is the current default DRA figure. If the figure for your state differs, please insert it.

- Pay travel expenses
- Pay medical bills
- Prepay funeral expenses

As in other areas of Medicaid planning, it is important to think through your spend-down plan in advance. Your attorney can help you coordinate it with your Medicaid application before you move into a nursing home.

Income Rules⁶

There are additional rules concerning income for nursing home residents on Medicaid. Typically they are allowed to keep \$60 per month⁷. If you are married, your spouse is allowed to keep his or her income each month, but your income, except for the \$60 per month, pays for your nursing home care.

If your spouse's needs exceed his or her income, then part of your income may be used to make up the difference.

Although the basic rules can paint a bleak picture, with proper planning many people are able to have Medicaid pay for nursing home care while keeping a substantial amount of their income and assets.

The Look-Back Period

Part of Medicaid planning may involve giving away some of your assets; however, this has to be done with extreme caution. There are tough penalties for simply giving away your assets to meet the eligibility requirements.

Every [\$_____]⁸worth of assets that you give away within five years prior to applying for Medicaid (the "look-back period") will make you ineligible for one month. Even worse, the ineligibility period does not begin until you have already spent down your other assets and you need a nursing home.⁹ Because the rules are strict and the penalties are harsh, it is critical that you seek the advice of an experienced estate planning and elder law attorney before you attempt to give away any assets.

Planning Strategies

Not all transfers hurt your Medicaid eligibility. There are a number of strategies available for ensuring that you qualify for Medicaid while preserving at least a portion of your assets for your spouse and children.

One such strategy is the Irrevocable Income Only Trust. Here's how it works:

6 Member: If your state is an income cap state, modify this section to discuss your state's rules, *Miller Trust*, etc.

7 Member: This number varies by state. Please insert the figure in your state.

8 Member: Please insert your state's average cost of care figure.

9 Member: This reflects the current DRA rule. If the rule in your state differs, please summarize it here.

Your estate planning and elder law attorney helps you establish the Trust. You appoint someone you know and trust (often one of your children) to act as Trustee. You also designate one or more beneficiaries who will ultimately inherit the Trust property (generally, after your death). Then, you transfer assets, such as real estate, investments, or other property to the Trustee, who will manage them on your behalf. Because the Trust is irrevocable, after the assets are transferred into the Trust, you no longer control the assets; however, the instructions contained in the Trust document dictate the Trustee's powers in managing the assets.

If an Irrevocable Income Only Trust is right for you, it offers the following advantages:

- It can re-classify assets from “non-exempt” to “exempt” for Medicaid purposes
- It may provide creditor protection for Trust principal. If you transfer property into an Irrevocable Interest Only Trust, making your child the beneficiary, your child's creditors can't get the property. The same is not true if you simply give the property to your child.
- It makes Trust income available for your support
- It allows the Trust principal to be transferred to your beneficiaries at your death without the need for probate
- It provides tax benefits, including capital gains tax savings to your beneficiaries

In order for this strategy to work, the transfer must happen five or more years before the spouse with ALS needs nursing home care. Otherwise, the transfer would fall within the five-year look-back period and penalties would apply.

This is why it is so important to plan as far ahead as possible, and to talk to an experienced estate planning and elder law attorney. He or she can help you explore all your options and choose the strategies that are best suited to your particular needs.

SPECIAL HELP FOR VETERANS

If you are a military veteran who has served 90 days or more on active duty, you may be entitled to additional benefits through the Veteran's Administration. ALS is one of the diseases entitled to a presumptive service connection under Veteran's Administration rules. This means that no matter when you received your ALS diagnosis, the Veteran's Administration presumes that your condition began during or was aggravated by your military service.

Service connection means that you, as a veteran, can receive monthly benefits based on your percentage of disability, grants for housing modifications and vehicle modifications, and enrollment in the VA health care system. Once enrolled in the VA health care system, you can receive coverage for a wide variety of health services, ranging from medications to power

wheelchairs. Your spouse and dependents may qualify for benefits in addition to your monthly benefits.

Theoretically, you can qualify for both Medicaid and Aid & Attendance benefits. But, if you have Aid & Attendance and Medicaid, the Aid & Attendance is reduced to \$95 per month which will not count to share of cost. This, it usually does not make sense to try to get Aid & Attendance if you are going to get Medicaid.

For more information on Veterans Aid & Attendance benefits and the qualifications process, please contact our office.

NEXT STEPS

In reading this guide, you've gotten an overview of a number of legal issues that patients with ALS and their families typically deal with. You've read about incapacity planning, estate planning, and veteran's benefits, as well as finding and paying for long-term care. These can be overwhelming topics.

You're likely already assembling a team of family, friends, doctors, and others to help you adapt to life with ALS. Now is the time to add an experienced estate planning and elder law attorney to that team. He or she can guide you and help you understand how the issues apply to your unique situation, and ensure you make the very most of the resources available to you.