

LIVING WITH ALZHEIMER'S

A Legal and Financial Resource Guide



LIVING WITH ALZHEIMER'S: A LEGAL AND FINANCIAL RESOURCE GUIDE

An Alzheimer's diagnosis can be overwhelming. It opens up a new world of medical jargon, treatments, and routines. It also means making all kinds of adjustments to the way you and your family live. These life adjustments often include decisions that carry legal implications.

This guide will serve as an introduction to the common legal issues patients with Alzheimer's and their families run into, as well as some strategies for dealing with these issues.

Starting with the initial steps you should take after receiving a diagnosis, this guide gives you an overview of what you need to know about long-range financial planning, safe driving, your options for finding long-term care (including nursing home care), and your options for paying for care.

Keep in mind, not everyone has to deal with all of these issues. And, no matter which concerns you and your family face, you likely won't have to deal with everything at once.

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 talking to an experienced estate planning and elder law attorney.

You'll want to enlist the help of an attorney to review your particular circumstances and make sure that you comply with the law while preserving your assets for your family.

FIRST THINGS FIRST

With Alzheimer's, as in all areas of life, knowledge is power. Your absolute first step after receiving a diagnosis is to find out as much as you can about the disease and your treatment options.

INCAPACITY PLAN

Your next step should be to take care of some basic legal planning. Over time, Alzheimer's 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, your adult child, or a close friend – to make important financial and health care decisions for you.

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.

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.
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 decisions. This is the document you use to let your doctors and your loved ones know whether or not life support should be withdrawn in case you are terminally ill. In some states the Durable Power of Attorney and Living Will are combined into one document called an Advance Health Care Directive.

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. Without an incapacity plan, you would need a court-appointed guardian to manage your medical and personal affairs and a court-appointed conservator to manage your financial affairs.

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

- that you are, indeed, incapable of taking care of yourself; and
- that the person who has made the request to serve as your guardian or conservator is 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 and may be emotionally traumatic at a time that is already difficult.

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; and you can eliminate the court's involvement in your personal matters.

ADDITIONAL LEGAL PLANNING

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 Alzheimer's, 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 attorney, including:

YOUR ESTATE PLAN

Any time you experience a major life change, you should meet with your estate planning and elder law attorney to review your will, trust, beneficiary designations, and the other components of your estate plan, if you have one in place or create one if you haven't done any estate planning. A diagnosis of Alzheimer's certainly qualifies as a major life change. Now is the time to not only 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 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 of assets without consulting an experienced estate planning and elder law attorney. A nursing home stay or other forms of long-term care are real possibilities for many patients with Alzheimer's, and finding ways to pay for long-term care is usually a 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 benefits.

SAFE DRIVING

Driving can be a sensitive subject for patients with Alzheimer's and their families. We live in a culture where the ability to drive represents freedom. When you are facing a disease that threatens to take away so much of your identity and control over your life, the last thing you want to do is hand over the keys to your car.

During the early stages of the disease, it might not be necessary for you to hand over your keys. But, as the disease progresses, you may begin to notice some changes in your driving. For instance, you might begin to

- Forget familiar locations
- Run stop signs or stoplights
- Bump into curbs
- Misjudge the speed or distance of other cars

Or, you might not notice problems as you drive. But, you might begin to have difficulty with household tasks like:

- Cooking
- Cleaning
- Doing your laundry

According to American Psychiatric Association (APA) Guidelines, even these signs of mild impairment indicate that a patient with Alzheimer's poses an unacceptable risk on the road. Studies have also shown that patients with Alzheimer's, particularly those in later stages of the disease, are twice as likely to cause or be involved in a motor vehicle accident as drivers of the same age without the disease.

Often, it is the family members of patients with Alzheimer's, rather than the patients themselves, who are the first to notice signs of difficulty behind the wheel. If your loved ones express concerns about your ability to drive, listen to them. They may see evidence of memory loss, impaired judgment, and shortened attention span – signs that the disease prevents you from seeing for yourself.

No one likes the thought of handing over their car keys, but the last thing you want to do is cause an accident and hurt yourself or someone else. Aside from the guilt and regret, think of the legal and financial problems such a situation could cause for you and your family.

DRIVING LAWS

All states have a system in place for the re-testing of mentally or physically impaired drivers.

The procedures for having drivers re-tested vary widely from state to state. Some states require all older drivers to take periodic tests to renew their driver's licenses. In other states, a third party, such as a doctor, physician, police officer, or family member, must request that a potentially impaired driver be tested.

In [Member's state], [Member, please fill in your state's applicable driving laws].

LONG-TERM CARE

Alzheimer's is a progressive illness. As you advance through the stages of the disease, the level of care you need increases. Now is the time to think about the changes in living arrangements you may 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 adult day care, an assisted living facility, nursing home care, or a combination assisted living facility/nursing home for you or your spouse.

ADULT DAY CARE AND RESPITE CARE

Adult day care is a supervised program you attend during the day, and then you return home at night. Many families find that adult day care programs allow them to balance work and childcare responsibilities, while keeping their loved one with Alzheimer's at home for as long as possible.

If family members are helping to care for you at home as your disease progresses, respite care may also prove to be a valuable resource. Respite care programs provide "time off" for family members or others. Under a respite care program, a substitute caregiver may come to your home to help care for you for a short period of time. Alternatively, you might have a short stay in a nursing home/assisted living facility while your usual family caregivers take a needed respite to enable them to better care for you upon your return.

ASSISTED LIVING

An assisted living facility is a long-term living arrangement that offers residents as much independence as they want, while providing staff to help with basic activities of daily living such as bathing, dressing, and grooming. While assisted living facilities don't offer medical care to their residents, some states allow them to offer medication reminders and assistance.

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 around the clock nursing care.

Your Rights as a Nursing Home Resident

If you do 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.

PAYING FOR CARE

Alzheimer's is an expensive disease. According to the Lewin Group, the combined 2015 payments for healthcare, long-term care, and hospice care for Alzheimer's and dementia patients are estimated at \$226 billion. By 2050, they are expected to increase to \$1.1 trillion.¹

According to the Alzheimer's Association, a more than 50% of residents living in a nursing home have Alzheimer's or another form of dementia.² The cost of this care depends on your state of residence, the type of room you choose, and a number of other factors. Nationwide, the average annual cost of a private room in a nursing home is \$100,375. If you stay in a separate Alzheimer's special care unit, the cost can be even higher.³

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 estate

¹ https://www.alz.org/help-support/resources/publications/trajectory_report (2019)

² <https://www.cdc.gov/nchs/fastats/alzheimers.htm> (2014)

³ <https://www.genworth.com/aging-and-you/finances/cost-of-care.html> (2018)

planning and elder law attorney can talk to you about all of 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 Alzheimer's 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, if Alzheimer's is covered, do not let the policy lapse.

If you do not have long-term care insurance, an Alzheimer's diagnosis will likely disqualify you from buying it. However, you might want to consider purchasing it for your spouse.

MEDICARE

Medicare is federally funded health insurance for people age 65 or older or on Social Security Disability for at least two years. 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.

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 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 completely 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 completing a complicated tax return, so should you 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, or most of, your assets while qualifying for Medicaid coverage. Any planning, even last-minute planning, is helpful. However, the farther in advance you can plan, the more options you will have. Here is how the Medicaid planning process works.

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].⁴
- One personal vehicle (used for medical visit 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 \$10,000.⁵
- 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), 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 Alzheimer's lives in a nursing home.

The total value of a married couple's countable assets is divided in half. Typically, your spouse keeps his or her half of the assets, up to a maximum of [\$126,420].⁶ You then have to "spend down" your half of the assets to no more than [\$2,000].⁷

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

⁵ Member: This is the typical amount. Please insert your state-specific information

⁶ Member: This number is the current default DRA figure. If the figure for your state differs, please insert it.

⁷ Member: This number is the current default DRA figure. If the figure for your state differs, please insert it.

SPENDING DOWN YOUR ASSETS

Paying your own 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 home repairs
- Prepay your mortgage and property taxes
- Prepay estimated income or capital gains taxes
- Buy furniture for your home
- Purchase clothes
- 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 estate planning and elder law attorney can help you coordinate it with your Medicaid application before you move into a nursing home or make other arrangements.

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 [\$_____]⁸ worth 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 in our state. Even worse, the ineligibility period does not begin until you have already spent down your other assets and you are in need of 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.

INCOME RULES¹⁰

There are additional rules concerning income for nursing home residents on Medicaid. Typically they are allowed to keep only \$60¹¹ per month. If you are married, and you are going into the nursing home, your spouse is allowed to keep his or her income each month but, your income, except for \$60 per month, pays for your nursing home care.

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.

¹⁰ Member: If your state is an income cap state, modify this section to discuss your state's rules, Miller Trust, etc.

¹¹ Member: This number varies by state. Please insert the figure in your state.

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.

WHAT'S NEXT?

In reading this guide, you've gotten an overview of a number of legal issues that patients with Alzheimer's and their families typically deal with. You've read about incapacity planning, estate planning, and safe driving, 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 Alzheimer's. Now is the time to add an experienced estate planning and elder law attorney to that team. He or she can help you understand how the issues apply to your unique situation, and help to ensure you make the very most of the resources available to you.