

LEGAL SURVIVAL GUIDE FOR ALZHEIMER'S PATIENTS & THEIR LOVED ONES

*What do you do when a loved one is diagnosed with
Alzheimer's disease?*



Elder
Law
Solutions

Margot G. Birke, Attorney at Law

Attorney Margot G. Birke founded Elder Law Solutions to focus on the intricate legal and financial needs of older and disabled adults. She has extensive experience in Elder Law as an advocate, mediator, and volunteer. She speaks frequently at assisted living centers, geriatric centers, and councils on aging to empower the elder community by providing the information they need to make informed choices

Margot Birke is a member of the Massachusetts Chapter of the National Academy of Elder Law Attorneys, a member of the Massachusetts, New York, and American Bar Associations, the Newburyport Chamber of Commerce, and the Academy of Special Needs Planners. Margot also is the Past-Chairperson on the advisory Council on Elder Services of the Merrimack Valley and is currently state certified Nursing Home ombudsman.

Margot received her B.A. from Fordham College in New York and her J.D., with academic honors, from Fordham University Law School. She is admitted to practice in both Massachusetts and New York.

Elder Law Solutions

Margot G. Birke, Attorney at Law
3 Cherry Street, Suite 101B, Newburyport, MA 01950
978-465-5407 • elderlawsolutions@gmail.com
www.elderlaw-solutions.com

Introduction

“My husband has Alzheimer’s. When I found out, I cried all night. Now I want to cry, but I am just too exhausted to cry. I am so afraid of the future.”

Alzheimer's disease and other forms of dementia lead to a number of life adjustments, including the need to make a wide range of decisions that pose possible legal consequences.

This guide explains the major legal issues you may face over time and suggests ways to deal with them. Beginning with the first legal steps you should take, the guide gives you information about long range financial planning, safe driving, health care services, government benefits, Medicaid planning, and steps you can take to protect your home and lifetime savings.

As you examine the contents of this guide, please keep in mind that each situation is unique. No single plan fits everyone. You may not need every type of legal service or advice described here. Also, this guide is not intended as a substitute legal advisor. To ensure that you comply with the law and, at the same time, protect assets for your family, you will want to get an overall legal review of your particular circumstances from a knowledgeable and experienced elder law attorney. Finally, we want you to know that references to Alzheimer’s disease, as used in this guide, should be read to include all forms of dementia.

First Legal Steps

When the diagnosis is Alzheimer’s disease, find out as much as you can about the disease. Then plan for the future.

During the early stages of the disease, you may be able to complete important documents that will give you peace of mind and save you and your family money. It’s critical that you authorize another person (e.g. a spouse, adult child, or close friend) to make decisions for you at the point you may no longer be able to do so.

You should take this step now, while you’re still able to, so that you, and not some judge, can select the person best suited to carry out your wishes.

As a “first legal step” it’s important to seek help from a knowledgeable attorney to put three documents in place:

1. Durable Power of Attorney for Property

Carefully consider this document; it grants legal rights and powers to another. Choose someone you implicitly trust, such as your spouse or adult child, to act as your agent (sometimes called your “attorney-in-fact”). If you become incapacitated, a durable power of attorney for property lets your agent act for you in financial and business matters.

2. Last Will and Testament

3. Massachusetts Health Care Proxy

With this document, if you cannot make or communicate health care decisions yourself, another person of your choice can make a broad range of decisions for you. These decisions cover virtually everything to do with medical matters, such as selecting doctors, hospitals, treatments, procedures, or medications. Be sure the document complies with all requirements of the federal HIPAA rules, as well as state law.

4. Medical Directive

A health care proxy also includes a medical directive giving your agent guidance on what your wishes would be in a given situation. This “medical directive” is similar to a “living will”. People have personal priorities and spiritual beliefs that may affect their medical decisions. This is especially true at the end of life with regard to the use of life- sustaining treatments. To make your values and beliefs clearer consider the following questions: What do you most value about your physical and mental well being? What are your fears regarding the end of life? How do you want to be remembered? What gives your life purpose or meaning?

This document also concerns whether or not life support should be withheld or withdrawn in the case of a patient who is terminally ill. It states your wishes regarding this issue. With a Medical Directive you can enhance the directions you give to your agent named in your Health Care Proxy for

health care decisions. The document allows you to give your agent very specific directions on the medical treatment you do or do not want consistent with your values and what is important to you. Families who have used it have called it a “real gift”. Without these documents, you may need a court appointed guardian to handle financial matters and/or health care decisions. In that event, a court would control your personal and financial life. A judge would have to approve all decisions and expenses. You and your family would lose control. The process can be very demeaning, expensive, time-consuming, and emotionally draining for you and your family. This situation can easily be avoided if you act now and put proper powers of attorney in place.

Planning Ahead

When the diagnosis is Alzheimer’s disease, the ability to manage your own affairs will decrease over time. Making adequate, informed decisions about your personal business and your health care will become more difficult. **But early legal planning lets you choose a person to manage these things for you, according to your wishes.**

You can control, in advance, the way your affairs will be handled. However, if you do not plan early, a court may eventually appoint a guardian to make these decisions for you. Act now while you have the capacity to indicate your wishes and to understand and sign documents that ensure your wishes will be respected and carried out.

Depending on your specific situation, a host of legal issues related to your condition may arise. After you sign a durable power of attorney for property, a durable power of attorney for health care decisions, and a living will you should consider other legal and life care planning. Simply states, life care planning helps you to position your resources consistent with your goals to best serve your needs and those of the persons dear to you.

This kind of planning is highly individualized. Some of the issues you and your family may want to discuss with an attorney include the following:

1. Revising Wills and Trusts

Whenever a major life event occurs, attorneys recommend that you review your wills and trusts. Your current legal documents may no longer be

appropriate. You may want to make changes that reflect your new circumstances. A diagnosis of Alzheimer's disease is a major life event worthy of this kind of legal review.

2. Changing Property Titles

The way real estate and other property is titled is important. In some cases, how your property is held means that selling it will require court intervention. Reviewing property titles may allow you to avoid the involvement part of planning to ensure that you and your family members are protected if you ever need long term care in a nursing home.

3. Strategies for Financial or Other Gifts

Consulting an attorney who is knowledgeable and experienced in Medicaid planning is especially important before you transfer any property or make gifts. The attorney can help you review your financial situation to determine whether a gifting program or other financial strategy is appropriate for your situation. Making gifts can protect your family and help save your estate. But, acting improperly can have severe legal implications, and can even make you ineligible for government benefits.

4. Long Term Care Strategies

Now is the time to consider what changes in living arrangements you might need over time. Those arrangements can include independent living, assisted living, supportive living, an assisted living/nursing home combination for you and your spouse, or care in a nursing home. Check provisions of any long term care insurance you have in effect. (If you do not already have this kind of coverage, you probably will not be able to qualify for it once you have been diagnosed with Alzheimer's disease. Still, it may be an option for your spouse.) You will want to review this and other possible strategies with your legal advisor.

5. Medicaid Planning

Medicaid, is a program authorized by Title XIX of the Social Security Act. Title 19 gives a person a *legal right* to financial benefits if they qualify. Medicaid is a federal program administered by the states; it pays for health care when eligible patients cannot. It is known as MassHealth in

Massachusetts. Many people think they will not need Medicaid or won't qualify for it. Some do not want to think about it because they think it is aid. Others are afraid to deplete their resources and impoverish their spouses and families. The reality is - most folks in supportive living or nursing homes must eventually think about Medicaid. Alzheimer's disease is the third most expensive illness in the United States, after heart disease and cancer. The average lifetime cost per patient is \$174,000. Many people simply cannot manage these costs on their own.

Exempt assets (those you can keep without affecting Medicaid eligibility) include your residence up to \$750,000 in value, one motor vehicle, furniture and household belongings, personal jewelry and clothing, prepaid funeral plans (up to certain limits), and whole life insurance with a death benefit of \$1,500 or less.

Medicare, the federal health insurance program authorized by Title 18 of the Social Security Act, pays for less than 2% of nursing home care, and then only if the care is "skilled care." Medicare will not pay for "custodial care," the type of care Alzheimer's patients need.

Medicaid planning addresses these issues. Proper planning lets you retain as much of your lifetime savings as possible, including the family home, while ensuring that you get the benefits you are entitled to. Preplanning and crisis planning for Medicaid are two ways to accomplish these goals. Preplanning involves things you can do over time. If you are an Alzheimer's patient in the early stages, you'll be able to participate in this type of planning. But even in the later stages, crisis planning can allow your family to protect you and them from financial disaster. In some cases, even if you are already in a nursing home, crisis planning may be able to achieve some protection for the resources that remain. An attorney experienced in this aspect of elder law can help you comply with the law, while taking full advantage of the options open to you.

Safe Driving

If you have Alzheimer's disease, you may someday be faced with a recommendation that you surrender your driving privileges. Your doctor may write a prescription that says, "Do not drive." Or, family members may begin to notice effects the disease has on your memory, judgment and attention - effects that you are unaware of.

These mental abilities are critical for safe driving, If you have recently been diagnosed with Alzheimer's disease, you might not have a problem driving for awhile. At some point, however, you may begin to notice that you lose your way, misjudge the speed of oncoming traffic or fail to notice stop signs or other signals. You may be driving legally – that is, you have a valid driver's license - but you might not be driving responsibly. The last thing you would want is to cause an accident. Liability for an accident could cause legal problems and financial burdens for you and your family.

The independence that driving affords is not easy to give up. Many people feel lower self-esteem when they can no longer drive. We all have grown up in a culture where driving is important to us. No one wants to be a burden on others for transportation. So it's common for Alzheimer's patients not to admit difficulty behind the wheel. However, people with Alzheimer's disease, their families, and doctors have a responsibility to balance a patient's convenience with the safety of other drivers and their passengers.

Others however cannot drive even short distances without endangering themselves or others. Discuss this issue openly with your family members and your doctor. Trust them to tell you when to turn over your car keys.

Continuing Care

As Alzheimer's disease progresses, the care you need increases. In the early stages, you may be able to continue living independently at home or with help from family members or home health aides. Other possibilities include adult day care or respite care. With adult day care, you are in a supervised program during the day, and then return home at night. Respite care programs provide substitute caregivers to temporarily relieve family members or others who usually help you with daily activities.

Another possibility is the need for nursing home care. That's because Alzheimer's disease is the leading diagnosis requiring care in a nursing home. You and your family should be aware of the following legal issues concerning the continuing care of an Alzheimer's patient.

1. Guardianship. By the time you need nursing home care - if ever - you may be legally unable to make decisions about financial matters or health

care. If you have not signed a durable power of attorney for property and a Massachusetts Health Care Proxy decisions, at that point you may need a court-appointed guardian. Under the supervision of a judge, the guardian will manage your financial businesses, and make personal and medical decisions for you.

2. Legal Rights of Nursing Home Residents. Each nursing home resident has a right to personal and appropriate care, which is guided by the resident's care plan. The care plan is a contract created by a "team" that includes you, the nursing home staff, and anyone else you want to involve. The plan should detail your current medical, psychological, and social needs, and spell out what will be done to maintain or, when possible, improve your health. Because the care plan creates a contract, getting legal assistance with this document is advisable.

3. Information Just for Caregivers. Caregiving for someone with Alzheimer's is one of the most difficult jobs in the world. In addition to making sure that your loved one's daily needs are met, you also are faced with the fact that your relationship with this person is no longer what it once was. You also need to try to maintain some sort of life on your own. You know your loved one best. Try to accept their behavior for what it is and do the best you can to respond in a loving way. You already are doing a job that most people cannot do. Take one day at a time and take care of you - give some loving care to yourself. Ask for help from others. You may think it's a burden, but many friends and neighbors would be glad to stay over for a few hours and let you get out for a while or just take a nap. And, at the end of the day, no matter the frustrations or small failures, understand that you are doing your best. No one can ask for more than that. The Alzheimer's Association is a good resource for information on caregiving, supporting, and referral to persons who can assist.

The following is a quick reference for caregivers:

Behaviors	Helpful Hints
<p>Does your loved one seem to be:</p> <ul style="list-style-type: none"> Bored Restless Picking at things Wandering 	<p>Offer snacks or liquids. A person with Alzheimer’s may have missed a meal or forgotten they had one.</p> <p>Suggest that your loved one help with simple and repetitive tasks, like folding and unfolding laundry. Bring out the familiar pieces of games they once enjoyed, such as Monopoly, Parcheesi, or other board games. Also, try giving them playing cards or crossword puzzles. It doesn’t matter if they do any of it well, or even at all. The object is to keep them occupied with familiar items and tasks.</p> <p>Restless and wandering patients need a safe place to wander and pace. They may just move around, or they may need a purpose, like carrying the newspaper from one part of the house to another, or going through old mail. Pet therapy can also work wonders. Be sure the animal is a calm breed, such as a golden retriever, or a smaller lap dog may work for others.</p>
<p>Does your loved one seem to be:</p> <ul style="list-style-type: none"> Tense Yelling Refusing to move Irritable Worried Afraid 	<p>Always first ask or observe if your loved one is in pain. If not, remember these behaviors are often about feeling unsafe. Recall that persons with Alzheimer’s have lucid times that come and go. Try to imagine how frightened they must feel. Do comforting things. One is always to approach the person from the front. Hold their hand if they will let you, or just touch a shoulder and tell them they are in a safe place. Reduce any noises from a radio or television that may be creating confusion or anxiety for them. Try calming music from years ago. If they will allow you, hugs can do wonders!</p>

<p>Is your loved one:</p> <ul style="list-style-type: none"> Crying Depressed Wanting to be alone Wanting to stay in bed 	<p>We all have a right to our blue days, and at times, the person with this disease just feels deeply sad. They sense the changes in their lives, and they feel their losses. Put your arms around them and say it's okay to cry; it's okay to feel sad. Bit by bit, you may coax them up and about. Try old, familiar stories or old familiar prayers. If they still refuse to get up, come back in a little while and try again, or have a different person try. Music can make an extraordinary difference. Play music they once loved; it will help them to reconnect to life.</p> <p>In this case, you will be involved in a lot of physical care. Use, touch. Stroking and rubbing of hands and feet (unless medically not advised for some other reason) will help keep the person "in touch," and help with circulation to prevent skin breakdown. Your loved one will also need to be turned from side to back to other side at regular intervals to prevent skin breakdown.</p>
<p>Is your loved one:</p> <ul style="list-style-type: none"> Bedfast (i.e. unable to get out of bed at all, or only with great effort) 	<p>Even if the person cannot move on their own, they can be repositioned - such as moved to an upright chair, or a recliner if available. They can therefore be involved in the social activity going on around them and can be part of it, too. Don't forget pet therapy or music.</p> <p>A home health nurse can give instructions on how to do exercises that are appropriate for your loved one.</p>

Studies have found that, particularly in later stages Alzheimer's disease, you are twice as likely to cause or to be involved in motor vehicle accidents as drivers of the same age without the condition. Recently published American Psychiatric Association (APA) guidelines for restricting driving privileges of patients with Alzheimer's disease say that all severely impaired Alzheimer's patients pose unacceptable risks on the road, as do people with moderate impairment who cannot perform simple household tasks. In the early stages of the disease, some people can drive safely for as long as two to three years after diagnosis.

Medicaid Planning

As stated previously, Medicaid is a program authorized by Title XIX of the Social Security Act. Medicaid gives a person a *legal right* to financial benefits if they qualify. Medicaid is a federally funded program administered by the states that pays some health care costs (assistance with an eligible patient remains at home, as well as laundry) while an eligible patient remains at home, as well as nursing home costs of qualified individuals. You may not want to think about using Medicaid benefits. But most families are financially unprepared to pay for health care costs for an Alzheimer's patient. Over a patient's lifetime, those costs average \$174,000. Even if you enter a nursing home as a "private pay" resident (paying your own way), you may eventually exhaust personal funds and need Medicaid assistance. Even if you can manage the costs, you may worry about depleting your assets and impoverishing your spouse and family.

You may share the frequently expressed fears among potential Medicaid applicants, like, "They'll put a lien on my home" and "I'm afraid I'm going to lose everything." However, with legal assistance and proper Medicaid planning, you can typically protect the home and save at least half - and frequently all - of your assets.

The earlier you start the process, the more of your assets you may be able to save. Medicaid planning uses legal strategies to maximize the amount of money your spouse or family can keep for their care while qualifying you for government benefits. Consult a knowledgeable and experienced elder law attorney to help you with this planning process. It's like asking a certified public accountant (CPA) to prepare your income tax forms to be sure that you are taking all legal deductions the tax code makes available. Don't apply for benefits before making sure you have taken all the steps possible to protect yourself and your family.

Applying for Medicaid and providing the government with all of the verification that is required is a complicated process. You may need legal assistance to be sure you complete the forms accurately and completely. Incomplete forms and other errors can delay or jeopardize benefit payments.

On the other hand, it is not a wise idea to disclose more than is required since this could create further complications. An elder law attorney can help you list and review your assets and income sources in terms of what you can keep (called exempt assets), what you can't keep, and assist you with protecting what's at risk. While you are expected to pay as much as you can toward the cost of your care, Medicaid law does not require your spouse to live in poverty while you live in a nursing home. An elder law attorney can help protect married couples by guiding them through the process for the prevention of spousal impoverishment.

The Medicaid rules allow you to transfer up to \$137,400 to your spouse, but you must "spend down" all other assets until your assets total no more than \$2,000. (Single applicants must meet the same low limit of \$2,000 on countable assets to qualify for Medicaid.) With appropriate planning under the guidance of a knowledgeable and experienced elder law attorney, you may be able to save greater sums.

You need to be aware, however, if appropriate planning is not taken, that so-called "exempt assets" eventually will be at risk following your death or the death of your spouse through estate recovery procedures and/or a lien against your home. However, an elder law attorney who has substantial experience can help protect your exempt assets from liens and estate recovery procedures. Non-exempt assets (assets that DO affect Medicaid eligibility) include all other assets: checking and savings accounts, 401(k) plans and individual retirement account (IRAs), and stocks, bonds, mutual funds, and non-homestead real estate. With knowledgeable legal advice, at least half maybe all - of your non-exempt assets can be protected.

Caution. You should consult an attorney experienced in Medicaid matters before giving away money or property to family members or others. Transferring assets during a "look back period" of five years prior to making an application for Medicaid can create periods of ineligibility for benefits. Putting the name of a child on a deed or bank account will not protect the asset, and may also create a "transfer penalty". In short, doing it yourself can lead to disastrous results: financial ruin, loss of the home and lifetime savings, as well as disqualifications for benefits.

Your individual situation affects decisions about how to accomplish the protection of your assets. You or your spouse can “spend down” your assets to:

- Pay nursing home bills
- Pay legal/medical bills
- Travel
- Other goods or services suitable to your needs and desires
- Prepay outstanding Mortgage, property taxes, and estimated income or capital gains taxes
- Prepay funeral expenses
- Buy clothing
- Make home repairs
- Pay off any outstanding debt
- Buy an annuity (consult an attorney before purchasing an annuity to be sure you comply with recent changes in the law)

Be sure to **map out** your spend-down plan in advance and coordinate it with your Medicaid application. For maximum savings, you should do this before you move into a nursing home.

As noted previously, the spouse of the Alzheimer’s patient can often increase the amount available to him or her by working with a legal advisor skilled in this area.

Additional rules exist concerning income for you and your spouse (and any minor, disabled, or dependent children). If your spouse’s financial needs exceed his or her income, some or all of your income may be used to make up the difference between his or her income and the monthly allowance. The Division of Medical Assistance determines an income need for the community spouse referred to as the “Minimum Monthly Maintenance Needs Allowance” or MMMNA. Under a complicated formula, the MMMNA is calculated for each community spouse. The MMMNA may range from a low of \$2,288.75 (until July 2023) to a high of \$3,435 (until July 2023) a month, based on his or her housing and living costs. Where the community spouse can show hardship, or the community spouse's own income falls below his or her MMMNA, the Division of Medical Assistance allows the shortfall to be made up from the nursing home spouse's income. However, your income, except for a personal needs allowance of \$72.80 per month, must go to the nursing home for your care.

In all cases, proper planning and knowledge of the applicable rules are important to guarantee compliance with the law and to maximize what you get to keep. Consult an experienced professional.

Seeking Legal Help

When a person is diagnosed with Alzheimer's disease, family members face unique legal issues, including asset distribution, property disposition, Social Security, durable powers of attorney, establishing guardianship, ect.

Where can you turn for that help? It is difficult for the consumer of legal services to be able to identify lawyers who have the training and experience required to provide expert guidance during this most difficult time.

Generally, planning for a person diagnosed with Alzheimer's disease should include planning for the possibility of the eventual need for care in a nursing home and how to finance that care without going broke or losing the home. Nursing home planning and Medicaid planning is an aspect of the services provided by some, but not all, elder law attorneys. Consumers must be very cautious in choosing a lawyer by carefully investigating the lawyer's credential and experience in public benefits law.

The information in this booklet is public resource of general information, which is intended, but not guaranteed, to be correct, complete and up-to-date. It is not intended to give legal advice to anyone on any subject. This information is not intended to be an endorsement of any professional or services listed within.