

# The Alzheimer's Legal Survival Guide

## Action Guide

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## How To Use This Book

Having a loved one with Alzheimer's disease presents many challenges. What kind of care is best? When should the person with Alzheimer's stop driving a car? Who should be named beneficiary of a will or trust? And, perhaps most important, if your loved one eventually needs nursing home care, how can you pay for it without losing everything you've worked for?

Among the most difficult challenges families face is dealing with a wide variety of legal issues as the disease progresses. In many cases, individuals with Alzheimer's disease can execute legal documents and take other steps to prepare and plan for possible future medical and financial needs. In other cases, their families face situations that can be complicated and confusing.

This workbook is intended as a guide to the legal issues facing those with Alzheimer's and their families. Not intended as a substitute for an experienced lawyer, it is instead a guide to help you understand the documents, planning steps, and/or court proceedings your attorney may recommend. It is also a resource you can use to initiate discussions with your attorney as well as other family members.

As you read, keep in mind that just as Alzheimer's affects different individuals in different ways—no one's situation is exactly like anyone else's—so one-size-fits-all plan of action exists. This book explains many of the basic legal tools you may need.

# Acknowledgments

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## **Changing Laws**

This book is intended to help explain and clarify legal issues facing individuals with Alzheimer's and other dementias and their families. It is not a do-it-yourself manual nor a substitute for professional legal advice.

Laws and policies, particularly Medicaid laws and rules, vary widely among the states. They also constantly change at both the state and federal levels. Future changes in the laws regarding Medicaid qualification may or may not be retroactively applied. Unfortunately, with the frequent changes taking place in the government, there is no way to anticipate future Medicaid qualification requirements and other laws and rules.

For the best advice concerning your personal situation, consult an attorney in your state with experience in elder law.

# The Journey

## *Lucille and Cindy's Journey:*

Lucille and her daughter Cindy are making chocolate cake for a birthday party. As Lucille prepares the batter, she recites the recipe. Cindy has heard the recipe many times before, but she listens carefully. The cake is a family favorite that Lucille makes from memory. For three generations, the recipe has never been written down, and it won't be now.

Lucille pauses. "I can't remember, dear," she says. "Did I put in the eggs?"

Cindy notices egg shells in the sink and recalls the first time she and her mother prepared this recipe together. "Yes," she says. "You did. Now what's the next step?"

Lucille's long-term memory helps her recite the recipe, but Cindy realizes that her mother's short-term memory occasionally lapses.

## *Everett's Journey:*

Everett hasn't told anyone, but he knows something is wrong, and it bothers him. Yesterday, his son's friend asked him what he used to do for a living. It was a simple question, but Everett couldn't answer. The words seemed to hide from him. He couldn't find the ones that would tell the young man that he was a retired mechanical engineer. And this morning, try as hard as he could, he couldn't remember his three grandchildren's first names.

## *Phyllis and George's Journey:*

Phyllis answers the telephone at work just after 3 o'clock. Her neighbor and longtime friend, Connie, greets her, then hesitates.

"It's George," Connie says. "He's been sitting under the tree in my backyard all afternoon."

Phyllis takes a deep breath.

"I finally went out and walked him home," Connie says. "He didn't seem to know me. Is he feeling all right?"

A sinking feeling grips Phyllis' stomach. She closes her eyes and sighs.

## **Early Steps**

Everyone forgets things now and then. Momentary lapses are common. Some people even refer to them, kiddingly, as "senior moments." Incidents like this may simply mean a person is distracted, preoccupied, or under stress. But, in some cases they may be the first steps of a journey that can lead to increasing confusion, loss of memory, even Alzheimer's disease.

These episodes may signal an illness that was once considered a normal part of the aging process. Years ago, people called it senility, hardening of the arteries, or organic brain disease. Symptoms may come and go, and they may not be easy to recognize as they're unfolding. That's especially true because the signs can vary greatly from one individual to another. As time passes, however, the episodes occur more and more often.

And, while there never seems to be a single event that anyone can identify as the point where the journey began, as time goes on the individuals and their families can look back and realize that they have been traveling together for quite some time. In those cases, episodes of forgetting or becoming disoriented are symptoms of a progressive illness known as dementia. Dementia, a decline of a person's intellectual or emotional level, may have a variety of causes. Some are treatable. Some are not. Particular symptoms vary from person to person.

## **What is Alzheimer's Disease?**

The most common type of dementia, called Alzheimer's disease, affects approximately 4 million Americans. The disease is characterized by progressive changes in behavior and personality and can include gradual declines in mental abilities such as thinking, memory, or judgment.

The brain is a complex communication system that works by connecting nerve cells. With Alzheimer's disease, that communication system doesn't work properly. While this type of dementia was described by ancient Greeks and Romans, little was known about it until the 20<sup>th</sup> century. In 1906 the German physician Alois Alzheimer identified the physical characteristics of brain cells that define the disease. Little additional knowledge accumulated until the 1980's. During the last 20 years, however, researchers have learned more about the causes, diagnosis, and treatment of the disease. Drugs are being developed to treat symptoms. Even today, however, diagnosis is difficult and often depends on increased frequency or worsening of symptoms.

## **Early Signs**

Memory loss or forgetfulness is the best known sign of early Alzheimer's disease. This might include difficulty remembering recent events, performing familiar tasks, using words correctly, finding the way home, making decisions, or locating lost objects. A person with dementia may frequently lose keys or other objects, forget whether an ingredient has been added to a recipe, withdraw from usual activities, or have trouble driving or finding the way to a familiar destination.

Families whose loved ones have Alzheimer's face issues they never anticipated. The illness forces changes in the kind of planning they need to do. At first, ensuring that the loved one gets appropriate medical care, emotional support, and companionship assume top priority. Soon, however, other caregiving issues arise, including supervision to ensure personal safety and financial security and help with personal care and household tasks. Throughout this time, family members must plan to protect loved ones who may not be able to plan for themselves.



**Do This:**

**Make copies of this page and use them to keep track of symptoms, doctors' visits, medications prescribed, and any side effects of the medications.**

**Date:** \_\_\_\_\_ **Doctor Seen:** \_\_\_\_\_

**Symptoms or behaviors prior to visit (describe):**

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**Medication prescribed:**

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---

---

**Symptoms or behaviors *after* visit (note any changes):**

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**Side effects of medication:**

---

---

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---

**Next appointment scheduled:** \_\_\_\_\_

# First Legal Steps

## *Talking with Shirley:*

A few weeks after Shirley's doctor told her she might have Alzheimer's disease, her son Mike visited her.

"Mom, I've been thinking we might need to talk," Mike said. "Ever since Dad died, I've been trying to help you with the financial details Dad usually handled."

Shirley nodded, but said nothing.

"Now, don't get me wrong, Mom. We know you're still doing pretty well on your own right now," Mike continued. "And hopefully you'll be able to for years."

Shirley folded her hands in her lap. "So then let's not worry about it now."

Mike sat quietly for a few moments. "I understand you don't want to think about it," Mike said. "But the doctor said that somewhere down the road you might not be able to tell me what you wanted me to do. You might not remember your stocks, or even what bank your CDs are in. Or suppose you got really sick. I'd want to know what you want me to do, but you could be too sick to tell me."

"Oh, Mike," Shirley said. "You're my son. You'd know what I'd want."

"Well, that's the point, Mom. I'm not really sure what you'd want, but I'd want to understand enough to do just that—whatever you would want. For example, I don't even know today where all those old insurance policies are. Wouldn't it make sense to go over things like that? Why don't we write it all down together and take it to a lawyer to see if we need to do anything else with it?"

Shirley glanced out the window, but didn't seem to be looking at anything. "Well, I still don't think it's necessary," she said in a quiet voice, "but if it makes you feel better, I guess we can."

Because Shirley is in the early—or mild—stage of dementia, she may retain her mental faculties for months or even years. During this state, she may experience only short episodes of impaired mental function and long periods of clear understanding and sound judgment. While in this early stage, she can still receive, understand, and evaluate information. And, she can use that information to make rational decisions and execute legal documents.

However as the disease progresses, the episodes of dementia may become more frequent and last longer. Still, she will likely continue to enjoy decision-making abilities into the mid-stage of the illness. But, as the disease continues, Shirley's thinking and judgment may become impaired. She may no longer meet her state's legal test for "capacity," a requirement for executing valid

and enforceable legal documents. Although state requirements vary, capacity, in general, is the mental ability to perceive and appreciate relevant facts and make rational decisions.

What if Shirley loses these abilities?

If Shirley lacks capacity, she will no longer be able to execute enforceable legal documents at the very time she and her family are facing many troubling legal issues. For example, she may need to deal with bank accounts, remove or add assets to a trust, or liquidate assets (e.g., certificates of deposit, bank accounts, etc.) to pay for health care. Eventually, she may need assistance from public entitlement programs such as Medicaid, a jointly-funded federal and state program that pays health care and nursing home costs for qualified individuals.

If Shirley cannot meet the capacity test in her state, someone else will have to make decisions and execute legal documents for her. Who that person is and how he or she is appointed can occur in at least two ways: through a validly executed power of attorney or through a court proceeding.

## **Acting Early**

If Shirley acts in the early phase of her Alzheimer's disease, she can ensure that her wishes concerning financial and health care matters are followed if she later becomes unable to speak or make decisions for herself. That's why her son wanted to discuss financial and medical matters as soon as possible and why he wanted to see an attorney to put in place the legal documents that grant decision-making authority to another person.

### **Do This:**

**If you or a family member is suspected of having Alzheimer's disease, immediately see an attorney to put in place the legal documents that grant decision-making authority to someone who can help you with financial and medical matters and communicate for you when and if you no longer can.**

## **Granting Decision-Making Authority**

Because the progression of Alzheimer's disease is unpredictable, putting proper legal documents in place as early as possible permits flexibility and helps persons with dementia and their families deal with whatever financial or medical events occur along the way. These documents include durable powers of attorney and an advance directive (one type is called a living will).

**IMPORTANT NOTE:** The single most important documents to put in place are durable powers of attorney for financial matters and health care decisions, so that a family member or trusted friend will have the legal authority to carry out your wishes if you can no longer speak or act for yourself.

## What is a Power of Attorney?

Powers of attorney are relatively simple, inexpensive legal documents which give authority to another person to act for you. As the one who grants the authority to another and signs the documents, you are called the “principal.” The person you give the authority to is called the “agent” or “attorney in fact.” The agent “stands in your shoes” and acts on your behalf. Your agent can take almost any action for you, as long as you’ve specifically included that action in the document.

Two kinds of powers of attorney are important for people with Alzheimer’s disease. The first is a durable power of attorney for property/financial decisions. The second is a durable power of attorney for health care decisions.

## Going to Court

If you don’t grant someone power of attorney, and if the disease progresses to the point where you can no longer express your wishes or make decision, your family may later face expensive court action to convince a judge that they are the proper people to make decisions and act for you. By acting early, though, you’ll help yourself and your family avoid the time, expense and embarrassment involved in a court hearing to evaluate your competence (competence means the mental ability to think and act reasonably).

If you are incompetent and you don’t have powers of attorney in place, the court will hold a hearing and appoint a conservator to handle your financial affairs and/or a guardian to manage your personal and health care needs. You would have no part in designating the person or corporation that would act for you. And although the laws of most states favor the appointment of family members, court involvement can be expensive and impose cumbersome supervision upon you and the agent.

**IMPORTANT NOTE:** Court proceedings and the names given to the court-appointed agent(s) differ by state. For purposes of this discussion, the person appointed by the court to handle financial matters is called a “conservator.” The person appointed to handle personal and health-care matters is called a “guardian.” The incapacitated person these agents make decisions and act for is called a “ward.”

## Choosing an Agent

Once you decide to grant someone power of attorney, who do you name as your agent—or agents? In fact, you may choose one person or more than one. For instance, you could ask your son to administer your finances (power of attorney for financial matters) and your daughter to make personal and health care decisions (power of attorney for health care).

Typically, a family member acts as an agent, but some people ask a close friend or a trusted neighbor. Choosing agents you trust is critical. Consider their relationship with you. Are they steady and knowledgeable? Will they always act with your best interests in mind? Have you talked with them? Do they know what you would want in certain situations?

If so, then you probably have made good choices.

Sometimes a person named as an agent becomes unable, unavailable, or unwilling to serve. And you certainly don't want to go to the trouble of drafting and signing a power of attorney only to find that no one is able to serve.

For that reason, you might ask your lawyer to draft your power of attorney with alternate agents. Or, you might appoint multiple agents (if allowed in your state) and specify in the document whether they are or are not required to act together in dealing with your affairs. Multiple agents may be appointed severally, allowing each to act independently of the others. Or, multiple agents may be appointed jointly, which means they all must agree and act together.

Either way, all agents should cooperate, even if they have different responsibilities. For example, if your daughter makes your personal and health care decisions and your son handles financial matters, your daughter can make a doctor's appointment and take you to it, but your son will pay the bill if you are no longer able to. They each need to know what actions the other has taken.

## **Handling Financial Affairs: Power of Attorney for Property (Financial Decisions)**

The durable power of attorney for property (financial decisions) names an agent to handle financial and business matters on behalf of the principal (the person who executes the power of attorney). Your attorney can draft the document to include one or more specific duties, like paying bills. Or, it can be all-encompassing, including the authority to cash checks, withdraw funds from bank accounts, pay taxes, trade stock, buy or sell property, take out loans, make gifts on your behalf, or take other actions. The all-encompassing type is often recommended for people with Alzheimer's disease, as long as they have an agent they can fully trust.

**IMPORTANT NOTE:** Be sure your attorney considers inclusion of these three items in the power of attorney for financial decisions:

- The power to apply for public benefit entitlements (such as Medicaid) in case you later need assistance from these types of program;
- The power to make gifts on your behalf and do Medicaid planning; and
- If you have a trust, the power to remove and/or add assets to the trust.

A lawyer can draft a financial power of attorney to be "durable." This means it remains valid and effective even if you later become incapacitated. The durable power of attorney is recommended for people with Alzheimer's disease, so that it will remain effective even as the disease progresses.

A durable power of attorney can be immediate or springing, depending on the state law and the time and manner in which the powers become effective. An immediate power of attorney takes

effect immediately upon signing. A springing power of attorney takes effect only if and when you become incapacitated.

In most states, unless words to the contrary are used, the durable power of attorney is effective immediately upon signing and remains effective even if the principal later becomes incompetent. All 50 states allow durable powers of attorney; no state statute expressly prohibits springing powers of attorney. Discuss the requirements of your state law with your attorney.

Because of the nature of Alzheimer's disease, a springing power of attorney may not be a good idea. In the early and middle states, a person may move in and out of a demented state, sometimes having the ability to conduct business affairs and sometimes not. This could create confusion about whether the principal has become incapacitated (and whether the power of attorney is in effect). In addition, a court may hold that only an immediate durable financial power of attorney—not a springing type—substitutes for conservatorship court proceedings to determine when the principal has reached incapacity.

### **Am I Giving Up My Independence?**

You may at first be reluctant to sign a durable financial power of attorney. You might want to hold on to your independence a while longer. However, a power of attorney doesn't remove your rights. Rather, it lets another person act either with you or in your place. You can continue to write checks, withdraw money from savings accounts, trade stock, and participate in your other financial or business affairs as long as you're able.

Further, you could look at the document as a way to *maintain* a sense of control. By putting a plan in place and communicating that plan to your agent, you're assured that your wishes are known. And, you may cancel a power of attorney at any time simply by sending a letter to your agent telling him or her that you revoke the appointment. Once your agent receives the letter, he or she no longer has authority to act in your place.

### **What Duties Do Agents Have?**

Another reason you may hesitate to execute a durable financial power of attorney is fear that your agent could mishandle your money. Of course, because you're granting considerable power to your agent, you must appoint someone you trust. But trust is not the only factor binding the agent. A power of attorney creates a "fiduciary duty," the highest duty imposed by law. A fiduciary duty means your agent must always act in your best interest and always according to the authority you granted in the power of attorney document.

Your agent must keep receipts and accurate records for all action taken under the power of attorney. (The easiest and best way to do that is to use a separate checking account so the agent's money isn't combined or confused with yours. Canceled checks and the checkbook register serve as an easy reference for your financial affairs.) If your agent mishandles your affairs with willful misconduct or gross negligence, a court can require the agent to repay the money. The court can also terminate the power of attorney.

**IMPORTANT NOTE:** Get an experienced attorney to draft your durable financial power of attorney. Without proper, specific wording, the document may not empower your agent to deal with such important matters as the Medicaid application or planning.

**Do This:**

**In the blanks below list the person you would like to handle your financial decisions if you no longer can.**

I want to name the following person as my agent in my durable power of attorney for financial affairs:

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

\_\_\_\_\_

**Phone:** \_\_\_\_\_

**Additional Agents:**

In the blanks below, list any other persons you would like to handle your financial decisions if the first agent (above) is unable or unwilling to perform this duty.

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

\_\_\_\_\_

**Phone:** \_\_\_\_\_

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

\_\_\_\_\_

**Phone:** \_\_\_\_\_

## **Managing Medical Matters: Power of Attorney for Health Care Decisions**

A durable power of attorney for health care decisions is crucial for people with Alzheimer's disease. Also known as a health care proxy, the health care power of attorney resembles the financial power of attorney, but instead of letting the agent conduct financial business, the health care power of attorney lets the agent make personal and health care decisions on your behalf. This document has taken on even greater importance with the passage of the new medical privacy restrictions in the Health Insurance Portability Act (HIPAA). You need to get a strong health care power of attorney in place as soon as possible.

Under most state statutes, your agent can act under this document only when you need medical treatment and you cannot communicate your wishes. Thus, the document is springing, which means it becomes effective only in the event of subsequent incapacity. Whenever you are competent and able to express yourself, your stated wishes will be honored.

### **If You Cannot Speak for Yourself**

If you cannot speak for yourself, however, or if you lack capacity to make informed and reasonable decisions, your agent will be responsible for decisions like which doctors you see and what treatment you receive. If you need to reside in an assisted living facility or nursing home, your agent will make that decision and select it for you (if you granted the agent such authority in the document). Like the financial power of attorney, the health care document creates a fiduciary duty for the agent. The agent must always act in the principal's best interest and always pursuant to the authority granted in the document.

Keep the original document. Let your agent know where it is. Give a copy to your agent and also send copies to all doctors you see.

**IMPORTANT NOTE:** A durable power of attorney for health care decisions should be drafted by an experienced attorney to be sure it grants all the proper authority.

#### ***Do This:***

**In the blanks below list the person (with address and phone number) you would like to handle your health care decisions if you no longer can.**

I want to name the following person as my agent in my power of attorney for health care:

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

\_\_\_\_\_

**Phone:** \_\_\_\_\_

### *Additional Agents*

In the blanks below, list any other persons you would like to handle your health care decisions if the first agent (above) is unable or unwilling to perform this duty.

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

\_\_\_\_\_

**Phone:** \_\_\_\_\_

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

\_\_\_\_\_

**Phone:** \_\_\_\_\_

### **Guardians and Conservators**

If you can't make decisions for yourself and you have not granted someone your power of attorney, you may have a guardian or conservator appointed for you. This would be done through a court proceeding. The guardian or conservator may or may not know you personally and may not know how you would have wanted your affairs handled.

A durable power of attorney for health care decisions can prevent the need and expense for court proceedings for guardianship. A **guardian** makes decisions about personal care and medical needs for another. A durable power of attorney for financial decisions can prevent the need and expense for court proceedings for conservatorship. A **conservator** is a person appointed by a judge to make financial and business decisions and take actions for someone who is unable to handle these affairs for himself or herself. The conservator handles another's financial matters, such as payment of bills and sale of property.

By signing durable powers of attorney for financial and health care decisions, you *designate* the person(s) you want to speak and act for you, rather than leaving choice to be made by a court after you have become incapacitated.

## **Disadvantages of Conservatorship and Guardianship**

Legal fees for drafting powers of attorney are relatively inexpensive. However, should the need arise to make medical or financial decisions after a person no longer meets the state's capacity requirements, family members would need involvement of a judge and often costly court procedures in appointing a guardian or conservator.

In fact, legal fees for representation of guardianship or conservatorship hearings can cost thousands of dollars. But that's not the only reason to act early.

With guardianship and conservatorship, the court becomes involved in your private affairs, usually with detailed reporting requirements, many of which may become part of the public record. The appointment of an agent by the court also may require total mental or physical incompetence, so the person or family must participate in a potentially embarrassing competency hearing.

More important, however, guardianship and conservatorship are more intrusive into the person's life than are powers of attorney. The judge may or may not let the conservator or guardian take certain actions that the person would have wanted to be taken.

By the time—if ever—a person with Alzheimer's disease needs nursing home care, he or she may be unable to make decisions about financial matters or health care. And, if that person needs assistance from Medicaid to pay for care in the nursing home, meeting Medicaid eligibility requirements can complicate financial matters for the person's spouse and/or family.

## **Medicaid Planning Under Conservatorship**

Medicaid planning techniques can help. However, many judges are not as familiar with the Medicaid regulations and planning techniques that may be available to you as an individual or through a power of attorney.

In some parts of the United States, Medicaid planning may be allowed with a conservatorship. Some courts have held that a conservator can do Medicaid planning under a substituted judgment rule. That means the conservator would substitute his or her judgment for the ward's (the person under the conservatorship) and say, "if the person knew these circumstances, this is what the person would do."

In other areas, however, a judge may weigh a conservator's duty to heirs who might inherit a ward's estate against the benefit to the ward and disallow action by the conservator that the ward would have endorsed. If you have given the agent the proper authority, the agent may take the steps you would have thought best. But under a conservatorship, the court's belief of what is best may differ from what you would have wanted.

**WARNING!** Avoid legal kits for do-it-yourself documents available through mail order, bookstores, and the internet. These "generic" documents are usually too general to help with the many challenges presented by Alzheimer's disease.

## **Using Life Support: The Advance Directive (or Living Will)**

### *Michelle's Dilemma:*

Michelle's father, Paul, who has Alzheimer's disease, has lost the ability to swallow. He cannot walk, bathe, or dress by himself. He has lost 45 pounds. Most important, he can no longer communicate verbally. These symptoms usually indicate that a person has reached the end stage of the disease.

Paul's doctor wants to insert a feeding tube to keep him alive, but Michelle doesn't know what to do. While Paul was in the early state of dementia, he executed a power of attorney for health care decisions and named Michelle as his agent. But, she and her father never discussed the possibility of Paul being kept alive on machines. She thinks Paul would rather be allowed to die with dignity, but she is only guessing. The thought of refusing use of a feeding tube fills her with anxiety. She wishes she and her father had discussed the possibility of this kind of situation before he lost his ability to communicate.

These kinds of end-of-life decisions are always difficult. But if Paul had discussed his last wishes with Michelle and executed an advance directive, she would have had guidance in the decisions she must make.

## **What is an Advance Directive?**

An advance directive—also known as a health care directive or a living will—is a legal document you can use to state your wishes concerning artificial life support in the event of terminal illness. An advance directive takes effect only if you become terminally ill and cannot communicate for yourself.

No one likes to think about such an event. However, by carefully considering and then stating whether you would want your doctor to use life support, you provide a written guide for your doctors, nurses, and family members to follow if such a decision becomes necessary.

An advance directive isn't limited to refusal of life support. You can also include your personal definition of minimally acceptable quality of life; the circumstances in which you would refuse life support (and when you'd accept it); whether you want doctors to use artificial means to administer food and water (such as a feeding or water tubes); what kind of pain management you prefer; how you want others to treat you; and final messages for family members and friends.

You can also include a provision for organ or tissue donation or to donate your remains for research into the causes or treatment of Alzheimer's disease.

## Five Wishes

Aging with Dignity, a non-profit organization in Tallahassee, Florida, has developed *Five Wishes*, a living will form for people who want to put end-of-life wishes in writing. It covers five areas to address in a living will:

1. The person you want to make care decisions for you when you can't make them for yourself
2. The kind of medical treatment you want or don't want
3. How comfortable you want to be
4. How you want people to treat you
5. What you want your loved ones to know

Aging with Dignity is a private, non-profit organization founded in 1996 to promote human dignity as America ages and better care of the dying. Living in Mother Theresa's home for the dying in Washington, D.C., as a full-time volunteer inspired Aging with Dignity's founder, Jim Towey, to create *Five Wishes*.

*Five Wishes* is changing the way Americans talk about and plan for the care they want to receive at the end of life. *Five Wishes* has been featured twice on the NBC "Today Show" and is being distributed by hundreds of hospitals and hospices, churches and synagogues, medical and law offices, and employers and retiree groups.

Why is *Five Wishes* so popular? There are many good reasons. It is easy to understand and simple to use. It speaks to people in their own language, not in "doctor speak" or "lawyer talk." It is the first living will to include not only the medical wishes but also the personal, emotional, and spiritual wishes of seriously ill persons. And it helps families talk with their physicians about a subject that before was too hard to face.

*Five Wishes* has captured the hearts and minds of Americans who want to maintain their human dignity and need help expressing their wishes. It is a gift to your family members and friends so that they won't have to guess what you want.

## Where is *Five Wishes* Valid?

With the help of the American Bar Association Commission on Legal Problems of the Elderly and the advice of experts in end-of-life care, *Five Wishes* was written to meet the legal requirements under the health decision statutes of 40 states and the District of Columbia (as of May 2009). ***If you live in the District of Columbia or one of the 40 states listed below, you can use Five Wishes and have the peace of mind to know that it meets your state's requirements under the law:***

**Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, District of Columbia, Florida, Georgia, Hawaii, Idaho, Illinois, Iowa, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, New**

**Jersey, New Mexico, New York, North Carolina, North Dakota, Oklahoma, Pennsylvania, Rhode Island, South Carolina, South Dakota, Tennessee, Vermont, Virginia, Washington, West Virginia, Wisconsin, Wyoming.**

If your state is not one of the 40 states listed above, *Five Wishes* does not meet the technical requirements in the statutes of your state, and some doctors in your state may be reluctant to honor *Five Wishes*. However, you can still use *Five Wishes* to put your wishes in writing. This will be a helpful guide to your care providers. Most doctors and health care professionals understand that they have a duty to listen to your wishes no matter how you express them.

You have a legal and moral right to decide what kind of medical treatment you want or don't want when you are seriously ill and your death is expected. You also have a right to choose a person to make health care decisions for you when you are no longer able to speak or think clearly. *Five Wishes* helps you exercise these rights. But remember, your doctor needs to know, and be willing to follow, your wishes.

**Do This:**

**Talk to your doctor during your next office visit. Give your doctor a copy of *Five Wishes* and ask to have a talk about it. Make sure your doctor understands your wishes and will honor them. Ask him or her to urge other doctors treating you to honor them.**

## **Issues Covered in the *Five Wishes* Living Will**

Below are some excerpts from the *Five Wishes* document. This outline should not be used in place of a properly executed *Five Wishes* Living Will. The official form available from Aging with Dignity also includes other language and places for signatures of the principal and witnesses that meet all the requirements of the law in many states.

**WISH 1:**

**The person I want to make health care decisions for me when I can't make them for myself**

If I am no longer able to make my own health care decisions, this form names the person I choose to make these choices for me. This person will be my health care agent (or other term that may be used in my state, such as proxy, representative or surrogate). This person will make my health care choices if both of these things happen:

- My attending or treating doctor finds that I am no longer able to make health care choices, **AND**
- Another health care professional agrees that this is true.

## **Your Health Care Agent**

Your health care agent should be at least 18 years or older (in Colorado, 21 years or older) and should *not* be:

- Your health care provider, including owner or operator of a health or residential or community care facility serving you;
- An employee of your health care provider; or
- Serving as an agent or proxy for 10 or more people unless he or she is your spouse or close relative.

## **What Your Agent Can Do**

I understand that my health care agent can make health care decisions for me. I want my agent to be able to do the following (*please cross out anything you don't want your agent to do that is listed below*):

- Make choices for me about my medical care or services, like tests, medicine, or surgery. This care or service could be to find out what my health problem is or how to treat it. It can also include care to keep me alive. If the treatment or care has already started, my health care agent can keep it going or have it stopped.
- Interpret any instructions I have given in this form or given in other discussions, according to any health care agent's understanding of my wishes and values.
- Arrange for admission to a hospital, hospice, or nursing home for me. My health care agent can hire any kind of health care worker I may need to help me or take care of me. My agent may also fire a health care worker, if needed.
- Make the decision to request, take away or not give medical treatments, including artificially-provided food and water, and any other treatments to keep me alive.
- See and approve release of my medical records and personal files. If I need to sign my name to get any of these files, my health care agent can sign for me.
- Move me to another state, to carry out my wishes. My health care agent can also move me to another state for other reasons.
- Take any legal action needed to carry out my wishes.
- Apply for Medicare, Medicaid, or other programs or insurance benefits for me. My health care agent can see my personal files, like bank records, to find out what is needed to fill out these forms.

- Listed below are any changes, additions, or other limitations on my health care agent’s powers:

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**What If I Change My Mind?**

If I change my mind about having a health care agent, I will:

- 1) destroy all copies of this part of the *Five Wishes* form, **OR**
- 2) write the word “REVOKED” in large letters across the name of each agent whose authority I want to cancel and signing my name on that page, **OR**
- 3) tell someone, such as my doctor or family, that I want to cancel or change my health care agent.

**WISH 2:**

**My wish for the kind of medical treatment I want or don’t want**

I believe that my life is precious and I deserve to be treated with dignity. When the time comes that I am very sick and am not able to speak for myself, I want the following wishes, and other instructions I have given to my health care agent, to be respected and followed.

**What you should keep in mind as my caregiver**

- I do not want to be in pain. I want my doctor to give me enough medicine to relieve my pain, even if that means I will be drowsy or sleep more than I would otherwise.
- I do not want anything done or omitted by my doctors or nurses *with the intention of ending my life.*
- I want to be offered food and fluids *by mouth* and kept clean and warm.

**What “Life-Support Treatment” means to me**

Life-support treatment means any medical procedure, device, or medication to keep me alive. Life-support treatment includes: medical devices put in me to help me breathe; food and water supplied artificially by medical device (tube feeding); cardiopulmonary resuscitation (CPR); major surgery; blood transfusions, dialysis; and antibiotics.

**If I wish to limit the meaning of life-support treatment, I write this limitation in the space below:**

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**Close to death:**

If my doctor and another health care professional both decide that I am likely to die within a short period of time, and life-support treatment would only delay the moment of my death *(choose one of the following:)*

\_\_\_\_\_ I want to have life-support treatment.

\_\_\_\_\_ I do not want life-support treatment. If it has been started, I want it stopped.

\_\_\_\_\_ I want to have life-support treatment if my doctor believes it could help, but I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

**In a coma and not expected to wake up or recover:**

If my doctor and another health care professional both decide that I am in a coma from which I am not expected to wake up and recover, and I have brain damage, and life-support treatment would only postpone the moment of my death *(choose one of the following:)*

\_\_\_\_\_ I want to have life-support treatment.

\_\_\_\_\_ I do not want life-support treatment. If it has been started, I want it stopped.

\_\_\_\_\_ I want to have life-support treatment if my doctor believes it could help, but I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

**In another condition under which I do not wish to be kept alive:**

If there is another condition under which I do not wish to have life-support treatment, I describe it below: *(Please leave space blank if you have no other condition to describe.)*

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**WISH 3:**  
**My wish for how comfortable I want to be**

*(Please cross out anything that you don't agree with)*

- I do not want to be in pain. I want my doctor to give me enough medicine to relieve my pain, even if that means that I will be drowsy or sleep more than I would otherwise.
- If I show signs of depression, nausea, shortness of breath, or hallucinations, I want my caregivers to do whatever they can to help me.
- I wish to have a cool, moist cloth put on my head if I have a fever.
- I want my lips and mouth kept moist to stop dryness.
- I wish to have warm baths often. I wish to be kept fresh and clean at all times.
- I wish to be massaged with warm oils as often as I can be.
- I wish to have my favorite music played when possible until the time of death.
- I wish to have personal care like shaving, nail clipping, hair brushing, and teeth brushing, as long as they do not cause me pain or discomfort.
- I wish to have religious readings and well loved poems read aloud when I am near death.
- I wish to know about options for hospice care to provide medical, emotional, and spiritual care for me and my loved ones.

**WISH 4:**  
**My wish for how I want people to treat me**

*(Please cross out anything that you don't agree with)*

- I wish to have people with me when possible. I want someone to be with me when it seems that death may come at any time.
- I wish to have my hand held and to be talked to when possible, even if I don't seem to respond to the voice or touch of others.
- I wish to have others by my side praying for me when possible.
- I wish to have the members of my church or synagogue told that I am sick and asked to pray for me and visit me.

- I wish to be cared for with kindness and cheerfulness, and not sadness.
- I wish to have pictures of my loved ones in my room, near my bed.
- If I am not able to control my bowel or bladder functions, I wish for my clothes and bed linens to be kept clean, and for them to be changed as soon as they can be if they have been soiled.
- I want to die in my home, if that can be done.

**WISH 5:  
My wish for what I want my loved ones to know**

*(Please cross out anything that you don't agree with)*

- I wish to have my family members and loved ones know that I love them.
- I wish to be forgiven for the times I have hurt my family, friends, and others.
- I wish to have my family members and friends know that I forgive them for what they may have done to hurt me in my life.
- I wish for my family members and loved ones to know that because of the faith I have, I do not fear death itself. I think it is not the end, but a new beginning for me.
- I wish for my family and friends to think about what I was like before I had a terminal illness. I want them to remember me in this way after my death.
- I wish for my family and friends to look at my dying as a time of personal growth for everyone, including me. This will help me live a meaningful life in my final days.
- I wish for my family to get counseling if they have trouble with my death. I want memories of my life to be a source of joy and not sorrow.
- After my death, I would like my body to be (circle one): buried or cremated.
- My body or remains should be put in the following location: \_\_\_\_\_
- The following person knows my funeral wishes: \_\_\_\_\_

If anyone asks how I want to be remembered, please say the following about me:

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If there is to be a memorial service for me, I wish for this service to include the following (list music, songs, readings, or other specific requests you have):

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Add other wishes here (such as your wishes about donating any or all parts of your body when you die):

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## Signing the Five Wishes Form

State laws vary concerning the methods that must be followed in signing a form like *Five Wishes*. In general, the form should be signed in the presence of two witnesses. Some states provide special rules for people who live in nursing homes. In particular, if you live in a nursing home in Connecticut, Delaware, Georgia, New York, or North Dakota, contact a social worker or patient advocate at your facility for further information.

**WARNING!** As was previously stated, the issues above are examples of elements of *Five Wishes* and should not be used in the place of a properly executed legal document. The official form available from Aging with Dignity also includes other language and places for signatures of the principal and witnesses that meet all the requirements of the law in many states. (However, as stated before, in some states, this form may not be valid.)

Even when the form is not valid, however, it does serve as excellent discussion material to help your doctor and family understand your wishes. Consult an attorney to review the form and determine whether it's valid and enforceable in your state. And be sure to discuss your wishes with your doctors and family members.

## How To Order Your Own Copy of *Five Wishes*

Individual copies of *Five Wishes* are \$5 per copy. Bulk orders of 25 or more are available at a discounted rate of \$1 per copy. Send your request to:

**Aging with Dignity**  
PO Box 1661  
Tallahassee FL 32302-1661  
Phone: (888) 594-7437  
Website: [www.agingwithdignity.org](http://www.agingwithdignity.org)

## **What is a Do Not Resuscitate Order?**

Another type of advance directive is a Do Not Resuscitate order, also known as a DNR. A Do Not Resuscitate order means you do not want your heart or breathing re-started under certain circumstances.

DNRs are not honored if cardiac arrest occurs during surgical operations or other medical procedures. The reason for this policy is that surgery is intended to improve quality of life or lead to significant recovery. And if a patient (or his or her agent) has agreed to a surgical procedure, the situation does not represent the kind of terminal situation expected by the person who signed the DNR order.

You may wish to be kept alive as long as possible, no matter your condition, or you may prefer to decline all life support if your condition is terminal. You may want some kind of care, like pain management, but not others. Whatever you decide, choose an agent whom you trust will honor your wishes if such a time comes. A frank discussion with your agent, your family members, and your doctors will ensure that they all understand your choice.

Faced with a situation where recovery is not expected, but mechanical means exist to prolong life, doctors and family members face difficult decisions concerning use of life support. Doctors, who have taken an oath to do all in their power to maintain life, may have professional or religious reasons for not wanting to comply with a patient's wish to deny or discontinue life support. Doctors may also fear liability issues that may arise after distraught family members rethink a decision to deny or discontinue life support.

However, despite some physicians' reluctance to comply with advance directives, the federal Patient's Self-Determination Act and the U.S. Supreme Court have granted individuals the right to make such decisions. And, doctors are obligated to honor the decisions you make in your advance directive. If a doctor refuses to honor the directive, he or she must help arrange for your transfer to another doctor or hospital who will.

If a doctor or other health care professional does not honor the wishes stated in an advance directive, the agent may take an appeal to the ethics board or request a court order that the wishes stated in the legal document be honored.

For family members, the document especially helps those who may disagree with your treatment wishes or who may not know what you would have wanted. If you talk with them when you sign the directive, you'll save your loved ones the difficulty of making this kind of decision for you—

and you can be assured that other family members who disagree with your wishes cannot override your decision.

As noted above, an advance directive becomes effective only in the event that you become terminally ill and unable to communicate your own wishes. ***If you regain the ability to communicate, the document has no effect. Your stated wishes will be honored.***

**IMPORTANT NOTE:** Some people confuse the terms “living will” and “living trust.” A living trust deals with disbursement of property, while a living will deals with medical decisions.

***If you want to refuse cardiopulmonary resuscitation (CPR), even in an emergency situation where paramedics are called, contact your local emergency medical services system and ask how you can communicate this wish. Usually a physician must sign a DNR to permit a paramedic to not resuscitate a non-breathing and/or pulseless person.***

***Do This:***

**In the space below enter the phone number of your local EMS system:**

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Be sure your advance directive is neither too vague nor too specific to apply to a terminal situation. Also, when you sign an advance directive, be sure to discuss your wishes with your agent, family members, and doctors. The advance directive may be part of a durable power of attorney for health care decisions, but it is usually created as a separate document.

An advance directive should be signed, dated, and witnessed. In addition, some states require that an advance directive be notarized at the time of signing. If your document is properly enacted, it will likely be honored in any state.

# Continuing Care

## *Caring for Tom:*

After almost 50 years of marriage, when Tom’s symptoms suggested dementia—perhaps Alzheimer’s—his wife, Esme, once again vowed to take care of him “in sickness and in health.” That’s how their marriage had been from the beginning and she wasn’t about to change now.

Their daughter, Elaine, though, noticed the wear and tear on her mother. “Mom,” she said, “Taking care of Dad must be difficult for you.”

Esme shook her head, “I’m doing fine.”

“I’m not saying you’re not,” Elaine said. “But with my job and taking care of the kids, I can’t help as much as I’d like. But I think I’ve found a way to give you a break now and then.”

Esme sighed. “How?”

“My neighbor’s church has a group of respite care volunteers. They’ll come in for a few hours, so you can get out of the house and relax.”

## **Caregiving**

Caring for a person with Alzheimer’s disease means coping with many changes over time. At first, you may just lay out your loved one’s clothes and leave notes as memory prompters around the house. Later you may face practical issues like changing door locks so your loved one can’t wander away, turning down the water heater to avoid burns, and making sure stove burners are turned off after cooking. Still later, as the disease progresses, you may not feel comfortable leaving your loved one home alone.

As the person’s need change, the caregiver’s role changes, too. As the disease progresses, more and more assistance is needed. The caregiver’s role evolves from helping the loved one keep as much independence as possible, to taking responsibility for nearly constant care.

If you are providing all or most of this care, your relationship with your loved one changes as you cope with the challenges and demands of your new role. It’s perfectly normal to experience anger, resentment, and cycles of grief as the person you care for loses the ability to relate or communicate. And burnout can result when caregiving becomes too much to handle alone.

## **Staying at Home**

In the United States, approximately 70 percent of people with Alzheimer’s remain in their own homes, with the help of a spouse or other family member, throughout the course of the illness.

Caring for a person with dementia is demanding and challenging. Fortunately, many services are available, as the loved one's needs change. They include support groups, respite care, home health support, adult day care, and hospice services. There's no need to deal with the ups and downs of caregiving without help.

As you begin your caregiving role, explore all the options available in your area. That way, as your loved one becomes more and more dependent upon you, you can get support. A good first step is to contact your nearest chapter of the Alzheimer's Association for a nearby support group. You'll gain valuable information as well as support from the members.

***Do This:***

**Call your nearest chapter of the Alzheimer's Association, or go to [www.alz.org](http://www.alz.org). In the space below list the addresses and phone numbers of support groups for Alzheimer's families in your area:**

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## **Respite Care**

Respite care programs provide substitute caregivers to temporarily relieve family members or others from their day-to-day responsibilities. Respite services may be offered by paid home health aides or volunteers from churches or other groups.

Respite caregivers come into your home and provide care and supervision for several hours so you can go to a movie, shop, or just get away for a while. By giving yourself a chance to relax from time to time, you'll be able to take better care of your loved one for a longer period of time.

***Do This:***

**In the space below write the names, addresses and phone numbers of resources in your area that provide respite volunteers:**

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## Home-Based Care

### *Mort and Hannah's Story:*

Ever since Hannah began needing help with dressing, bathing and eating meals, Mort had willingly assumed the caregiver role so he could keep his wife at home. But after several years of helping Hannah, Mort experienced recurring backaches. He worried that he wouldn't always be able to lift his wife or to carry out many of the caregiving duties he usually performed.

One night, he mentioned his back trouble at a meeting of his Alzheimer's support group.

"Why not get some extra help to come in once or twice a week?" a friend said.

"Isn't that expensive?" Mort asked. Could he afford home care?

## Paying for Home Health Care

Medicare, the national health care plan for older people, *does not pay* for home health aides who provide custodial care. Custodial care includes such services as bathing, dressing, light housekeeping, grocery shopping or even staying overnight when a caregiver is not available or just needs a break. Unfortunately, custodial care is the kind of home service a person with Alzheimer's disease usually needs.

To let people with Alzheimer's remain as independent as possible and continue to live at home (thus avoiding the expense of a nursing home), many states have some sort of Medicaid waiver program. To qualify you must generally meet the Medicaid asset test described in the next section of this workbook.

Through a waiver program, Medicaid may cover a limited amount of custodial services enable a person to stay in the community rather than moving into a nursing home. The services available vary greatly state by state. Some states have very active programs, while others provide only meager assistance.

To apply for a Medicaid home-based waiver, contact your state office on aging (see Appendix A of this guide). The agency will conduct a medical assessment to determine the level of service required to keep your loved one at home.

### **Do This:**

**Consult the list of state offices on aging and in the space below write the contact information for the agency in your state:**

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## **Developing a Care Plan**

Home services would probably not be the appropriate level of care if the applicant needs 24-hour supervised care. But if such limited services as light housekeeping and assistance with activities of daily living like bathing and dressing will enable the person to remain at home, those services may be approved as part of a care plan, a written document developed by the agency that specifies the services the person will receive.

Applicants must meet income limits set by the state. Often the spouse's income is not considered. If the applicant's income exceeds the state limit, he or she may have a co-pay to help pay for the cost of covered services.

## **Adult Day Care**

Another way to provide a break for primary caregivers who spend all day at home (such as a retired spouse) is an adult day care program for people with Alzheimer's disease. Adult day care also offers an option to working spouses or other caregivers who take care of their loved one at night, but cannot spend the day with them.

These programs offer socialization and therapeutic activities that may help slow the mental decline associated with dementia. Depending on the program, you may be able to choose any period of care from one-half day per week (with or without lunch) to full-time day care five days a week.

Day care is a step between independent living and a nursing home. Many provide more care than assisted living facilities, but only during the day. To find a program, ask for a referral from your state office on aging, your local chapter of the Alzheimer's Association, a hospital social worker, or a nearby nursing home. Then visit the center in advance to determine if the program is right for your loved one and your situation. The program director may want to meet your loved one and conduct a thorough screening before acceptance to be sure the center can provide the appropriate level of care.



The best programs include a nurse who can provide assessment, dispense medication, and perform periodic health screenings.

- **What is the goal of activities offered?** Activities should strive for socialization and mental stimulation.
- **What is the staffing level?** For people with Alzheimer's disease, a ratio of one staff member to four adults in care is good.
- **Is the program exclusively for people with dementia?** In a mixed environment, people with Alzheimer's disease are not as easily handled as they are in programs designed specifically for people with dementia.
- **Is a contract necessary?** Because Alzheimer's disease progresses at unpredictable rates, don't sign a contract for adult day services for more than 30 days at a time. Some programs ask for payment in advance rather than a formal contract.

## Hospice

Hospice is a program that uses a team approach to caring for people in the end stage of terminal illness. Programs seek to create comfort, reassurance, and support for patients and their families.

Hospice was first used for cancer patients who preferred to live out their lives at home in peace and dignity. Today, people with a wide variety of illnesses benefit from hospice programs.

Hospice teams typically include medical directors, nurses, social workers, chaplains, counselors, and trained volunteers who may provide such extra services as hairdressing, running errands, or other activities. In one case, a hospice team included a music therapist who played the patient's favorite songs.

Because hospice deals with dying patients, qualifying for a program depends upon a doctor's prognosis, or prediction, that a patient will live only another six months or less. At that point, the focus of medical treatment changes from an attempt to cure the illness to a concentration on comfort, pain relief, and the dying process.

Hospice care focuses on "dying well." Hospice team members help patients and families plan the end of life, deal with emotions like fear and grief, and reach closure on pending issues the patient wishes to complete. In addition, hospice team members help ensure compliance with the patient's wishes outlined in advance directives.

### **Do This:**

**If you are providing home care for a loved one with dementia, you may want to explore the possibility of hospice care before the need arises. Discuss hospice criteria with your loved one's doctor to determine his or her willingness to certify a patient for a program. If you sense hesitation on the doctor's part, consider finding another doctor.**



## **When to Call Hospice**

Some families contact hospice programs too late in their loved one's dying process to realize the full benefit of available services. A common lament hospice team members hear from families is, "I wish we'd contacted you sooner." That's why good communication with medical personnel is important in determining when to consider hospice care.

## **Other Options**

### *Victoria' Story:*

Victoria's husband passed away seven years ago. Since then she has lived alone in the home they shared. However, Victoria is experiencing early signs of dementia. She remains independent and relatively self-sufficient, but her two daughters, who live in another city, worry that she may soon be unable to care for herself or remain safe in her home. The daughters agreed to help Victoria move to an assisted living facility where she'll keep as much independence as possible while benefiting from assistance with many activities of daily life.

## **Assisted Living**

Assisted living facilities can be an appropriate choice for people with Alzheimer's disease when skilled nursing is not yet necessary. In fact, often a move to assisted living can allow the healthy spouse to cope better with the rigors of caretaking for the spouse with Alzheimer's.

Obviously, any part of the burden that can be lifted will be helpful, and assisted living facilities can do just that. For instance, many assisted living facilities provide care for people with incontinence or for those who need supervision of medications, help with injections, or assistance with eating or other activities of daily life.

Assisted living facilities require applicants to meet guidelines that may include such criteria as a specific score on a mental status exam. This kind of test measures dementia according to a mental deterioration scale.

Before moving into the facility, an applicant may also be required to undergo a comprehensive assessment to determine if the assisted living level of care is adequate or even appropriate. Such a review lets doctors determine whether any other factors are contributing to the patient's confusion and symptoms of dementia, including ensuring that medications and dosages are correct.

If an applicant meets the assisted living facility's requirements, a care plan is developed for the resident. Like the care plan used for Medicaid recipients receiving home-based care, this plan is a written document that specifies the type of services a nursing home or assisted living facility resident will receive.

Once the resident moves in, the care plan should be reviewed once in the first month of residence and once every three months after that. The care plan should also be reviewed if staff or family members notice a significant change in the resident's condition.

If you're considering an assisted living facility, visit several and compare them based on this checklist:

- ✓ **Is the facility licensed?**  
The facility should be licensed if required in your state. Currently, little state or federal government regulation of assisted living facilities exists. At a minimum, however, some safety requirements usually are in place.
- ✓ **What is the environment like?**  
Many people with Alzheimer's experience agitation and need a safe place to wander outside of their room. So look for a facility with common space areas, preferably including at least one enclosed outdoor area like a courtyard or patio.
- ✓ **What kind of activity program is in place?**  
Ask to see the facility's activity calendar. Look for a wide variety of activities that provide social interaction as well as mental stimulation.
- ✓ **What is the staffing ratio?**  
A good rule of thumb is to look for two certified nurse's aides (CNAs) for every ten residents during the day, with one CNA per ten residents at night.
- ✓ **What training do staff members get?**  
Be sure staff training includes interaction with an instructor, group discussion, and role playing, rather than simply watching video presentations.
- ✓ **Does the facility have a special Alzheimer's unit?**  
Some facilities admit people with a variety of needs; others dedicate a unit (or the whole facility) to residents with dementia. Mixed settings, called integrated units, can create problems for residents without mental decline, in the form of interruption of activities, disturbed sleep, or fear of harm. On the other hand, residents with dementia may find themselves excluded from some group activities just when they most need socialization. A better choice is a special care unit devoted to residents with dementia, one where staff has received additional training for working with people with dementia and where more extensive care is provided.

**WARNING!** Currently few federal standards exist for specialized assisted living units, so don't be fooled by the words "special care unit." While some facilities provide additional staff training and activities designed for residents with Alzheimer's, others simply add a locked door to a wing of a facility. Buyer beware.

Contracts for assisted living facilities resemble those for an apartment lease. Some facilities offer month-to-month agreements, while others ask for a year-long commitment. A year-long

lease lets a resident lock in the monthly fee. However, because the progress of dementia varies so much from one individual to another, a year-long agreement may cause an expensive problem. The resident may unexpectedly need more extensive care, such as that provided by a nursing home.

Be sure a long-term contract lets a resident move out without penalty with a reasonable notice.

**Do This:**

**If you must sign a year-long agreement with an assisted living facility, be sure the contract has an escape clause that lets a resident move out with a reasonable notice in the event he or she needs a higher level of care.**

While assisted living arrangements may be appropriate for a person with dementia, the cost may be prohibitive. Many facilities cost as much as nursing homes. But neither Medicare nor Medicaid covers the expense. Some long term care insurance may pay all or part of the cost, but without insurance, for the most part, assisted living residents pay with their own funds.

## **Nursing Home Living**

Deciding to place a person with Alzheimer's disease in a nursing home may be difficult. However, circumstances and the progression of the illness may make nursing home living a necessity, especially when the person cannot manage living alone or the primary caregiver can no longer provide the level of care the person needs.

Once you make the decision, finding the right nursing home means finding one that can meet your loved one's needs as well as the needs of the rest of the family.

You may need to visit several different facilities to find a suitable new residence for your loved one. Narrow your selections to several that you like, then visit them two or three times each—preferably at different times of the day and at least once during a mealtime—to confirm your initial impressions and to compare the homes. Try to stay objective as you observe the building and grounds as well as the interaction of staff and residents.

If your loved one's medical condition has worsened quickly or unexpectedly, you may feel pressed for time in your search for a nursing home. Or there may not be an opening in your first choice facility. You may have to select a temporary accommodation until you can find a different placement.

Do the best you can with the time you have. If the nursing home you choose proves unsatisfactory, you can pursue other options and perhaps later move your loved one to a facility that better meets your loved one's and family's needs.

## **Special Care Units**

Some nursing homes offer Alzheimer's special care units, but the specialized care they provide varies widely from one facility to another. Persons with dementia often exhibit behavior not

seen in residents with other illnesses or disabilities, so an Alzheimer's special care unit should provide a safe place for these residents.

For example, many persons with Alzheimer's tend to wander. A special care unit may accommodate that behavior with an enclosed and secure indoor or outdoor walking area.

In addition, see whether the unit helps encourage the residents' independence within the limits of their remaining functions. Staff in special care units should undergo specialized training so they can help residents realize the maximum potential of their mental and physical abilities as the disease progresses.

Nursing homes often charge extra fees for care in special units. And although some states have established guidelines for these units, no federal standards exist. Before agreeing to the higher rate, be sure the unit offers more than a locked door.

Look for the following qualities:

- ✓ Confirmation of all incoming residents' Alzheimer's diagnosis;
- ✓ Awareness of the progressive nature of Alzheimer's disease and a philosophy that addresses expected changes in mental and physical abilities;
- ✓ Staff training about Alzheimer's disease for all employees working in the unit—not only nurses and aides, but housekeepers and maintenance workers as well;
- ✓ Building and grounds designed for persons with Alzheimer's; and
- ✓ Activities appropriate for the abilities of residents with Alzheimer's.

**Do This:**

**As you visit nursing homes, make copies of the following form to use for each place you visit. Don't expect every nursing home to score well on every question. The presence or absence of any of these items does not automatically mean that the facility is good or bad. Each has its own strengths and weaknesses. Simply consider which items are most important to the resident and to you.**

**Record your observations for each question by circling a number from one to five. (If a question is unimportant to you or doesn't apply to your loved one, leave the evaluation area for that question blank.) Then total all blanks you checked.**

**Your ratings will help you compare nursing homes and choose the best one for your situation. But, don't simply rely on a number. Ask to speak to family members of other residents. Also, contact the local or state ombudsman for information about the nursing home and get a copy of the facility's state inspection report from the nursing home, the agency that licenses (or certifies) nursing homes, or the ombudsman.**

## Nursing Home Evaluation Form

Name of Nursing Home: \_\_\_\_\_

Date Visited: \_\_\_\_\_

### Building and Surroundings

	Poor			Excellent	
What is your first impression of the facility?	1	2	3	4	5
What is the condition of the facility's exterior paint, gutters and trim?	1	2	3	4	5
Are the grounds pleasant and well-kept?	1	2	3	4	5
Do you like the view from residents' rooms and other windows?	1	2	3	4	5
Do residents with Alzheimer's disease live in a separate Alzheimer's unit?	1	2	3	4	5
Does the nursing home provide a secure outdoor area?	1	2	3	4	5
Is there a secure area where a resident with Alzheimer's disease can safely wander on walking paths?	1	2	3	4	5
Are there appropriate areas for physical therapy and occupational therapy?	1	2	3	4	5
Are facilities for barber or beauty salon services available?	1	2	3	4	5
Is there a well-ventilated room for smokers?					
What is your impression of general cleanliness throughout the facility?	1	2	3	4	5
Does the facility smell clean?	1	2	3	4	5
Is there enough space in resident and common					

areas for the number of residents?	1	2	3	4	5
How noisy are hallways and common areas?	1	2	3	4	5
Is the dining area clean and pleasant?	1	2	3	4	5
Is there room at and between tables for both residents and aids for those who need assistance with meals?	1	2	3	4	5
Are common areas like lounges and activity rooms in use?	1	2	3	4	5
Are residents allowed to bring pieces of furniture and other personal items to decorate their rooms?	1	2	3	4	5
<b>The Staff, Policies and Practices</b>					
Does the administrator know residents by name and speak to them in a pleasant, friendly way?	1	2	3	4	5
Do staff and residents communicate with cheerful, respectful attitudes?	1	2	3	4	5
Do staff and administration seem to work well with each other in a spirit of cooperation?	1	2	3	4	5
What special training has the staff received for Alzheimer's resident care? May I attend and observe a training session?	1	2	3	4	5
Do nursing assistants participate in the resident's care planning process?	1	2	3	4	5
How good is the nursing home's record for employee retention?	1	2	3	4	5
Does a state ombudsman visit the nursing home on a regular basis?	1	2	3	4	5
How likely is an increase in private pay rates?	1	2	3	4	5
Are there any additional charges not included in the daily or monthly rate?	1	2	3	4	5

## Residents' Concerns

What method is used in selecting roommates?	1	2	3	4	5
What is a typical day like?	1	2	3	4	5
Can residents choose what time to go to bed and wake up?	1	2	3	4	5
Are meaningful activities available that are appropriate for residents with Alzheimer's?	1	2	3	4	5
If activities are in progress, what is the level of resident participation?	1	2	3	4	5
Can residents with Alzheimer's continue to participate in interests like gardening or contact with pets?	1	2	3	4	5
Does the facility have safe, well-lighted, convenient parking?	1	2	3	4	5
Are hotels/motels nearby for out-of-town family members?	1	2	3	4	5
Are area restaurants suitable for taking residents out for a meal with family members?	1	2	3	4	5
How convenient will care planning conferences be for interested family members?	1	2	3	4	5
Is an effective family council in place?	1	2	3	4	5
Can family/staff meetings be scheduled to discuss and work out any problems that may arise?	1	2	3	4	5

## Getting Good Nursing Home Care

Once you find a nursing home placement for your loved one, you can begin the process of easing the transition from one level of care to another.

The most important way you can help is to ensure that your loved one gets good care in the new environment. If you have been providing some or all of your loved one's care, you'll notice a change in your role. Rather than functioning as a caregiver, you'll instead become a care advocate. You will still be caring for your loved one, but in a new way. ***Your key roles are to participate in planning for your loved one's care and in frequent communication with the nursing home staff.***

## Care Planning

The care planning process begins with a baseline assessment. This assessment occurs soon after a resident moves into a nursing home, certainly within the first two weeks. A team from the nursing home—which may include a doctor, nurse, social worker, dietitian, and physical, occupational, or recreational therapist—uses information from both the resident and the family about the resident's medical and emotional needs. This baseline assessment then becomes the yardstick against which caregivers can measure the resident's progress.

The team asks family members about the resident's medical, psychological, spiritual, and social needs. You can also contribute information about your loved one's preferences and usual routine. For example, you might tell the staff, "Dad likes to listen to the radio as he falls asleep. He's been doing that since I was a child."

During the assessment process, you can help by making your own list of your loved one's needs and giving the list to a member of the assessment team. For example, you may have noticed signs of depression along with symptoms of Alzheimer's. The assessment team may not notice these signs, so your input will be invaluable.

**Do This:**

**In the space below list your loved one's medical needs.**

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**In the space below list your loved one's psychological needs.**

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**In the space below list your loved one's spiritual needs:**

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**In the space below list your loved one's social needs:**

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**In the space below list your loved one's preferences and usual routines:**

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The team uses all the information they gather to develop an individualized formal care plan. The care plan defines specific care the resident needs and outlines strategies the staff will use to meet them. The assessment team meets for a care planning meeting during the first month of a new resident's placement. Family members, as well as the resident, may attend.

**Do This:**

**When you go to the care plan meeting, bring along a copy of the list of needs you gave the assessment team earlier. Together, you can discuss your loved one's needs and the care plan the team has developed. And, if some need has been overlooked, you can ensure that the assessment team addresses it during this meeting.**

Federal law requires that nursing home care result in improvement (if improvement is possible). In cases where improvement is not possible, the care must maintain abilities or slow the loss of function.

Because Alzheimer's disease is progressive, care for a resident with the illness should be aimed at maintaining mental and physical abilities for as long as possible. For example, if your mother has little problem with language when she moves into the nursing home, the care plan should include activities that encourage her use of language unless or until the disease's progression takes away this ability.

**IMPORTANT NOTE:** The care plan may be part of the nursing home contract. It should detail the resident's medical, emotional, and social needs and spell out what will be done to improve (when possible) or maintain the resident's health.

According to federal law, generally nursing homes must review the resident's care plan every three months and whenever the resident's condition changes. It must also reassess the resident annually. At these times additional care planning meetings are held to update the resident's care plan. For example, if your father had bladder control when he entered the nursing home, but has since become incontinent, this significant change in his status means the nursing home staff must develop a new care plan that addresses his new need.

As a care advocate, you'll want to monitor your loved one's care to be sure the nursing home is providing the care outlined in the care plan. You may also attend all care planning meetings, whether regularly scheduled or when held because of a change in your loved one's health. This is the best way to ensure that your loved one gets personal and appropriate care in the nursing home.

## **Paying for Nursing Home Care**

Nursing home care is expensive. Nationwide, fees average about \$45,000 per year and can reach \$100,000 or more per year in some parts of the country. Most health insurance plans don't cover long term care. Neither does Medicare. And most people cannot afford to "private pay" (pay with their own funds) for long. Fortunately, financial help is available for qualified individuals through a federally funded, state administered medical assistance program called Medicaid.

# Me? On Medicaid?

Many people mistakenly believe that Medicare will provide long term care benefits for someone who needs an assisted living facility and/or skilled nursing facility (nursing home) care. This is a **big** misunderstanding. Medicare provides care for individuals who are over 65 or blind or disabled when those individuals need acute medical care. “Acute care” means that you have been diagnosed with an illness or other medical problem where there is a high probability that you can get well and return to a normal life. Medicare does not provide chronic medical care services for most individuals who have a long term illness or other medical problem where there is a high probability that they will **never** get well and return to a normal life. Medicare does not care about long term health care problems!

Most individuals are forced to provide for long term health care out of their own pockets until such time as they become impoverished. According to the Medicaid rules, impoverishment may mean being reduced to as little as \$2,000 of assets or less. Medicaid pays for nursing home care for half of the people in the United States who are residents of long term care facilities. Those individuals have essentially lost everything before Medicaid began to care about their long term care. Read on to learn how you can protect yourself or a loved one from being totally impoverished by the Medicaid rules.

## ***Walter and Marian’s Story:***

Walter thought his \$50,000 in savings plus his pension from the railroad would carry him through for the rest of his life. He often told his daughter Marian that he had plenty of money and that she would get a nice inheritance besides. However, when the doctor told Marian that her father’s Alzheimer’s disease had progressed to the point where he needed nursing home care for the rest of his life, Marian learned a difficult lesson.

“I called around and found that nursing homes in my area cost around \$4,000 per month,” she told the doctor. “Medicare won’t pay for it, and Dad’s savings will only last six months or so. He thought he had saved plenty of money, but I guess he didn’t count on this happening.”

The doctor referred Marian to the state Medicaid agency for help.

## **Paying for Nursing Home Care**

If the need for custodial care in a nursing home arises, most people find themselves financially unprepared. Most families cannot afford private pay nursing home costs. Medicaid will pay only when you have “spent down” to a poverty level. (Contact an experienced elder law attorney to avoid unnecessary impoverishment.)

While Medicare—the federal medical insurance plan for older Americans and people with disabilities—sometimes covers up to 100 days in a skilled nursing facility, the program generally doesn’t cover the kind of long term care an Alzheimer’s patient needs. Medicare’s limited nursing home coverage is intended for patients who need recovery or rehabilitation from surgery or illness. And for Medicare to pay, patients must continue to improve during their stay. People with mid- to late-stage Alzheimer’s disease, however, usually need custodial (rather than rehabilitative) care.

## What is Custodial Care?

Custodial care includes assistance with preparing meals, bathing, grooming, toileting, and other activities of daily life. In fact, a patient's inability to manage these kinds of activities often spurs the move into a nursing home.

The problem is that Alzheimer's disease is the third most expensive illness in the United States, after heart disease and cancer. Over a patient's lifetime, health care costs for Alzheimer's disease average more than \$200,000.

Most people simply can't manage these costs on their own. Others are afraid to deplete their resources and impoverish their spouses and families. At some point, most patients who need long term nursing home care turn to Medicaid for help; few alternatives exist.

The three most common ways to pay for nursing home care are long-term care insurance, private pay, and Medicaid. Some people are fortunate enough to have long term care insurance. However, this type of insurance has only recently become popular, and most people facing a nursing home stay do not have this protection.

### **Do This:**

**For people with Alzheimer's disease, it's probably too late to purchase long term care insurance. However, a healthy spouse should consider such a plan. In the space below write the name and phone number of your insurance agent. Call to discuss long term care insurance.**

Name: \_\_\_\_\_

Phone: \_\_\_\_\_

**Use this space to make notes about what your agent says:**

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## Paying With Your Own Funds

Most people at first choose to pay privately for nursing home care. Quite simply, "private pay" means paying for the cost of a nursing home out of your own pocket. Unfortunately, with nursing home bills

typically around \$5,000 per month (much higher in some areas), few people can afford to private-pay a long-term stay in a nursing home. Eventually, most people exhaust their savings and must turn to a government benefits program called Medicaid.

## What is Medicaid?

Medicaid pays, among other things, nursing home costs for qualified individuals. As discussed earlier, in some cases it also covers home- and community-based services like assistance with bathing, light housekeeping, cooking, and laundry while an eligible patient with Alzheimer's remains at home.

The federal government provides grants to each state to cover approximately 50 to 80 percent of the program costs within the state. The states pay the rest. Each state adopts its own rules for administering the program, within federal guidelines.

Medicaid was initially designed for low-income or impoverished individuals who can't afford health care. For that reason, you may think you cannot qualify for the program. Or, you may not want to use Medicaid benefits and become dependent on the government.

Most people hire a professional to prepare their taxes because the tax rules are filled with potholes and treasures. Only a trained professional knows how to guide the client around the potholes and to the treasures, so as to get the best possible benefit. The Medicaid rules are even more complicated and less understood than the tax rules. You need a trained guide who has experience with qualifying their clients for Medicaid while at the same time saving more treasure for families. Someone who needs to qualify for Medicaid is at the mercy of their state government and the nursing home industry. ***Both the state government and the nursing home industry want you to spend all of your treasure on long term care before you qualify for Medicaid.*** Only an elder law attorney who has the credentials to prove to you that they are consistently advocating for families should be hired to represent you. Verify that your elder law attorney has a reputation for success in this complicated and little-known area. Do not be afraid to ask the attorney for professional references such as nursing home administrators, estate planning attorneys, and senior services agency personnel. See the section of this guide entitled "Seeking Legal Help" for assistance in finding an elder law attorney.

Most families are financially unprepared to pay for health care costs for an Alzheimer's patient. If your loved one had a diagnosis of cancer, Medicare would pay much of the cost of treatment. Sadly, that's not true for Alzheimer's disease. Even if you enter a nursing home as a "private pay" resident, you may eventually exhaust your personal funds and need Medicaid assistance.

Medicaid is a means-tested entitlement program that provides medical benefits to eligible individuals. It is jointly financed with federal and state funds. The Centers for Medicare and Medicaid Services (CMS), within the U.S. Department of Health and Human Services (HHS), is responsible for federal oversight of the program.

## Applying for Medicaid

The Medicaid program bases eligibility on the applicant's medical condition and on the person's assets and income. To apply for Medicaid to cover residential long-term care costs, one must live in a nursing home or have a medical need that requires nursing home care. Generally, this requirement of medical necessity doesn't present a problem, as few people seek admission to a nursing home unless they have needs that cannot be met elsewhere.

To establish medical eligibility, you must undergo a medical assessment. The purpose of the assessment is to identify what your long-term care needs will be. This assessment is almost always coordinated by hospital discharge planners or nursing home admissions staff. Alternatively, an evaluation and assessment may be performed by a qualified staff member at the local Division on Aging. (For the address of the office on aging in your state, see Appendix A in this guide.)

In addition, you must be a citizen of the United States or fall within certain categories of aliens who have been lawfully admitted for permanent residence in this country. You must also live in the state where you apply for Medicaid and intend to make that state your home.

**IMPORTANT NOTE:** Incomplete forms or other errors can delay or prevent benefit payments. Seek legal assistance to ensure that forms are completed accurately and in a timely manner.

## Counting Your Assets

### *Exempt Assets:*

Medicaid strictly limits the assets you can own. Each state has its own limit on this amount and its own guidelines for which assets count toward the total. In general however, the following assets *do not* count and are known as "exempt assets."

- **Your home:** Your principal place of residence, regardless of value. In some cases, the nursing home resident may be required to show some "intent to return home," even if that never happens.
- **Household and personal belongings:** Furniture, appliances, jewelry, and clothing.
- **One car:** Some states may limit the car's value.
- **Burial plot/prepaid funeral plan:** Some states may limit the value of the plot or plan.
- **Cash value of permanent life insurance policies up to \$1,500:** In most states, this asset is exempt only if the face value of all policies added together does not exceed \$1,500. (If the total exceeds \$1,500 in face amount, the cash value counts and may need to be spent down on long term care.)
- **Cash:** A small checking or savings account not to exceed the limit imposed by the state. In many states, for example, a single Medicaid applicant may keep only \$2,000. A

married couple who both need nursing home care may generally keep around \$3,000 in assets. Each state has different rules, so contact an experienced elder law attorney in your state.

**Do This:**

**Contact your state Medicaid agency and ask for the state’s exempt cash asset limit. (See the list of state Medicaid agencies found in Appendix B.)**

**Write the amount here: \$ \_\_\_\_\_**

***Countable Assets:***

All the other assets (other than those exempt assets listed above) are called “countable assets.” Examples of countable assets include checking accounts, savings accounts, certificates of deposit, money market accounts, stocks, mutual funds, bonds, individual retirement accounts (IRAs), pensions, 401(k) accounts, 403(b) accounts, second cars, vacation homes, and any other item that can be valued and turned into cash.

**IMPORTANT NOTE:** If you (or our spouse) have access to the principal (i.e., assets) of a trust, consult an experienced attorney to determine whether the trust is an exempt or countable asset.

**If You’re Single**

As a single person, you can qualify for Medicaid when you own only exempt assets (listed above) and an amount of cash less than your state’s limit. The state limit is generally in the neighborhood of \$1,000 to \$2,000. So you can qualify when all you have left is a small amount of cash assets. (Rules for married couples are discussed later.)

If you have more assets than allowed, you may pay for your own care (i.e., “spend down” the assets). At that point you can apply for Medicaid. ***Alternatively, there may be some Medicaid planning steps you can take to preserve some or all of your cash and assets and still qualify for Medicaid benefits.***

**Your Income**

When you become eligible for Medicaid as a single person, all of your income, minus certain deductions, must be paid to the nursing home for your care. Medicaid pays for the rest of the covered expenses.

However, you may generally keep around \$30 to \$60 per month in income (only \$1 to \$2 a day!) as a personal needs allowance. A veteran receiving veterans benefits is allowed to retain a slightly higher personal needs allowance of roughly \$3 per day. Also, many states allow you to keep money to pay for uncovered medical costs (including medical insurance premiums).

## **Protection of Assets (Division of Assets)**

### ***Fred and Amelia's Story:***

Fred and Amelia both worked all their lives. Fred owned an automotive repair garage and Amelia taught high school English. They paid off their mortgage the year before both retired. They thought they had saved enough money to meet their needs and leave a nice inheritance plus the family home to Dorothy, their only child. Those plans changed when Fred was diagnosed with Alzheimer's disease. For years, he continued to live at home. But lately, Amelia was having trouble helping Fred by herself. Dorothy encouraged her mother to consider a nursing home.

"Mom," Dorothy said, "You can't go on like this; Dad needs more and more help with bathing and dressing. And if he falls, you aren't strong enough to help him up."

"You know I want to keep him home as long as I can," Amelia said. "Besides, nursing homes are expensive. I don't see how we can afford one."

"Dad can qualify for Medicaid," her daughter said.

"Perhaps," Amelia said, "But I'm afraid we'll lose everything, especially this house," sweeping her arm in a circle. "Dad always wanted to leave the family home to you."

## **For Married Couples**

For married couples, a key element of the Medicaid application process is a division of assets. "Division of assets" is the term commonly used for the Spousal Impoverishment provisions of the Medicare Catastrophic Coverage Act of 1988 (MCCA). It applies only to couples where one spouse needs nursing home care and the other spouse remains at home. The law, in effect, recognized that impoverishing both spouses makes little sense when only one needs to qualify for Medicaid assistance for nursing home care.

The spouse who lives at home is called the "community spouse" (often abbreviated "CS"). The spouse who lives in a nursing home is called the "institutionalized spouse" (abbreviated "IS"). MCCA lets an institutionalized spouse qualify for Medicaid without impoverishing the community spouse.

Although there was a major rewrite of the Medicaid which that became effective on February 8, 2006 (the Deficit Reduction Act or the DRA), there were no changes to the division of asset rules.

## **Division of Assets**

Most states require an allocation of assets between the community spouse and the institutionalized spouse. Before division of assets can occur, a married couple can own

countable assets worth no more than a state-determined maximum which can vary (2009 figures) from \$21,192 to \$109,560.

***Recall that division of assets applies only when one spouse continues to live in the community. “Living in the community” means that one spouse is healthy enough to be living outside of a long term care facility.***

Under the division of assets provision, the community spouse may keep up to half of the state’s maximum for couples. In a state with a \$219,120 maximum, for example, the community spouse may keep one-half, up to \$109,560 in countable assets. If your assets total more than the maximum, neither of you will qualify for Medicaid until you have spent enough money so the total falls to approximately one-half of the state maximum.

Here’s how division of assets works. A couple’s countable assets are calculated as of the date that the institutionalized spouse is placed in a Medicaid-certified bed. This date, which is known as the “snapshot date,” most often is the day he or she enters a hospital or long term care facility for a continuous stay of 30 days or more.

42 U.S.C. 1396r-5(c) provides rules for the treatment of assets and also for the attribution of the assets at the time of the initial eligibility determination for Medicaid. 42 U.S.C. 1396r-5(f)(2)(A) defines the Community Spouse Resource Allowance (CSRA).

The amount attributed to the institutionalized spouse is determined in the following manner:

- First, 42 U.S.C. 1396r-5(c)(1) requires the computation of the spousal share at the time of institutionalization. The spousal share, equal to one-half of the couple’s combined countable assets, is determined at the beginning of the most recent continuous period of institutionalization. The State Medicaid Manual at Section 3262.2 further explains that no calculation of the spousal share is required when the State elects to apply the maximum resource standard (Illinois uses the maximum amount – currently \$109,560 for 2009).
- Following the above determination of the spousal share, the resources attributed to the institutionalized spouse are determined by deducting the CSRA from the couple’s total combined resources. The CSRA is the greater of the following amounts as described at 42 U.S.C 1396r-5(f)(2)(A). Only the amount in excess of the CSRA is attributed to the institutionalized spouse in establishing Medicaid eligibility:
  - The spousal share, provided it does not exceed the current federal maximum,
  - The state spousal resource standard, provided it does not exceed the current federal maximum,
  - The amount provided by a court order, or
  - The amount established by an appeal.

To calculate your assets, add the value of all of your countable assets as of your snapshot date. Divide the total in half and allocate the equal portions to each spouse. The community spouse

may keep his or her half, up to a maximum of between \$21,912 and \$109,560. This amount is known as the community spouse resource allowance (CSRA).

Under the division of assets, the community spouse may keep the greater of one-half of the couple's combined assets or the state's spousal resource standard, up to the federal maximum. As noted above, the federal maximum amount for 2009 that a community spouse may retain without an appeal or court order is \$109,560. The federal minimum amount for 2009 that a state may allow a community spouse to retain is \$21,912.

\* \* \* \* \*

For the example which follows, let's assume that the state allows a maximum community spouse resource allowance (CSRA) of \$60,000.

Suppose Fred needs Medicaid benefits to pay for nursing home care. Fred and his wife, Amelia, own the following assets:

<b>Savings account</b>	<b>\$ 35,000</b>
<b>Certificates of deposit</b>	<b>65,000</b>
<b>Money market account</b>	<b>17,000</b>
<b>Checking account</b>	<b>3,000</b>
<b>Residence (no mortgage)</b>	<b>80,000 *</b>
<b>Ford Taurus</b>	<b><u>16,000 *</u></b>
<b>Total assets</b>	<b>\$216,000</b>

\*The couple's residence and automobile are exempt assets that do not count toward their total. So, for Medicaid eligibility purposes, the couple's countable assets, shown below, total \$120,000:

**Countable Assets (without exempt assets):**

<b>Savings account</b>	<b>\$ 35,000</b>
<b>Certificates of deposit</b>	<b>65,000</b>
<b>Money market account</b>	<b>17,000</b>
<b>Checking account</b>	<b><u>3,000</u></b>
<b>TOTAL</b>	<b>\$120,000</b>

In this example, Amelia may keep one-half of the couple's combined countable assets, limited by the state's minimum community spousal resource allowance (CSRA). The CSRA varies from state to state from \$21,912 to \$109,560 for 2009. (NOTE: If the combined assets total around \$21,912 or less, the community spouse may be able to keep it all.)

**\$120,000 Total countable assets:**

**Amelia's assets: \$60,000**  
**Fred's assets: \$60,000**  
**Amelia keeps: \$60,000**  
**Fred keeps: \$2,000**  
**Amount Fred must spend down: \$58,000**

*Amelia's Share:* Amelia keeps \$60,000 *plus* all of the couple's exempt assets, including their furniture, clothing, and other personal possessions.

*Fred's Share:* Fred, the institutionalized spouse (or "institutionalized spouse") may keep only enough assets to stay below the state's maximum guideline. In most states, for example, the maximum he may keep is \$2,000.

***What Happens to the Rest of Fred's Share?***

Fred or an agent acting on his behalf must "spend down" \$58,000 from his share of the assets in order to qualify for Medicaid (his \$60,000 share minus the \$2,000 state limit).

**Count Your Assets**

**Do This:**

**Fill in the blanks below with the appropriate values:**

Real estate in addition to residence:	\$ _____
Additional vehicle(s) in excess of one car:	\$ _____
Total of all certificates of deposit	\$ _____
Total of all savings accounts:	\$ _____
Total of all checking accounts:	\$ _____
Total of all money market accounts:	\$ _____
Total of all stocks and mutual funds:	\$ _____
Total of all bonds:	\$ _____
Total of countable trusts:	\$ _____
<b>TOTAL ASSETS:</b>	<b>\$ _____</b>
Divide the total by 2:	\$ _____
Subtract your state's asset limit:	\$ _____
Total that must be spent down:	\$ _____

**IMPORTANT NOTE:** Medicaid guidelines cover the spend down. The spend down process must comply with Medicaid regulations. *Improperly spending the money or simply giving it away without following proper procedures may result in periods of Medicaid ineligibility.* Please see the section of this guide entitled “Seeking Legal Help” before attempting to “hide” money or other assets. Trying to hide assets may be considered fraud, elder abuse, or even criminal theft. There may be legal and ethical strategies which will allow your family to save more assets and still qualify a loved one for Medicaid.

## Income for Your Spouse

Once the asset tests for Medicaid eligibility are met, the state will then consider the income of both the institutionalized spouse and the community spouse. Some or all of the institutionalized spouse’s income may go to the nursing home for his or her care. (A married Medicaid recipient is allowed the same personal allowance as a single person—about \$30 to \$60 per month. The Deficit Reduction Act of 2005 (DRA) did not amend the Medicaid rules in this area.)

However, under certain circumstances, some or all of the institutionalized spouse’s income may be kept by the community spouse. This is very important to understand so that one can determine how much money will be available for the healthy spouse’s living costs.

Federal law has established a minimum income the community spouse may keep each month. This amount is called the minimum monthly maintenance needs allowance (MMMNA). The law says a community spouse may keep a minimum income of approximately \$1,750 in 2009 (this figure is adjusted annually) per month. If the community spouse’s needs, as determined by the MMMNA formula, exceed his or her income, some or all of the institutionalized spouse’s income may be used to make up the difference. The 2009 maximum amount for the community spouse is \$2,739 per month. If the community spouse has insufficient income, in that his or personal income is less than \$2,739 per month, then it may be possible to have some income of the ill spouse allocated to the healthy community spouse.

### *Ralph and Sharon’s Story:*

To illustrate, suppose Ralph needs Medicaid assistance for nursing home care. Ralph gets \$1,200 per month in Social Security benefits. His wife Sharon, receives Social Security of \$800 per month. Under the state Medicaid laws, Sharon’s monthly needs allowance is calculated at \$1,750 per month.

<b>Sharon’s monthly needs:</b>	<b>\$1,750</b>
<b>Sharon’s Social Security:</b>	<b><u>\$ 800</u></b>
<b>Shortfall</b>	<b>\$950</b>

In this case, Sharon will receive the \$950 per month shortfall from Ralph’s Social Security. Ralph will get \$30 per month and enough to pay his cost for Medicare Part B insurance (about \$66 per month), and the rest will go to Ralph’s nursing home to help pay for his care.

<b>Ralph's monthly Social Security</b>	<b>\$1,200.00</b>
<b>Less income supplement for Sharon</b>	<b>-950.00</b>
<b>Less Ralph's monthly personal allowance</b>	<b>-30.00</b>
<b>Less cost of Medicare Part B</b>	<b><u>-96.40</u> (2009)</b>
<b>Amount paid monthly to nursing home (Balance paid by Medicaid)</b>	<b>\$ 123.60</b>

The \$950 per month from Ralph's Social Security brings Sharon's monthly income up to the calculated minimum monthly maintenance needs allowance (MMMNA).

(NOTE: If, in a different situation, Sharon's monthly income *exceeded* the MMMNA, she would probably be allowed to keep all of her own income, but would not be entitled to any portion of her husband's income. Also, if the couple's total income falls below the community spouse's minimum monthly maintenance needs allowance, i.e., \$1,750 per month, Medicaid does *not* make up the difference to the community spouse.)

This explanation of Medicaid eligibility reflects the information you'll get when you contact your state Medicaid agency. However, other approaches to Medicaid eligibility and the community spouse's minimum monthly maintenance need allowance exist. Proper Medicaid planning lets your position your resources in the best way possible to serve your needs and the needs of those who are dear to you.

**Do This:**

**Fill in the blanks below:**

Medicaid applicant's gross monthly income: \$ \_\_\_\_\_

Medicaid applicant's monthly health insurance or Medicare Part B premium: \$ \_\_\_\_\_

Community spouse's gross monthly income: \$ \_\_\_\_\_

You will need this information to calculate the community spouse's MMMNA.

This kind of planning is highly individualized, but in general, Medicaid planning can help you retain as much of your resources for your family as possible while ensuring that you get the benefits you're entitled to. An attorney experienced in this aspect of elder law can help you comply with the law, while taking full advantage of options open to you.

**Spending Down**

***Richard and Nathan's Story:***

Richard's son Nathan decided that his widowed father needed nursing home placement the day the kitchen stove caught fire. Richard had placed a large plastic salad bowl in the oven and turned on the heat. Fortunately, a neighbor noticed smoke coming out of the kitchen window and called the

fire department in time to prevent injury and minimize property damage. Nathan now knew that his father could no longer live safely at home alone.

Richard's savings accounts and stock portfolio held enough assets to pay for about two years of nursing home care—but the doctor said he thought Richard could live much longer than that.

Nathan consulted the state Medicaid agency concerning benefits for long term care. A case worker explained Medicaid eligibility and told Nathan that Richard would have to spend down his assets in order to qualify. She also gave Nathan a list of acceptable items and services that Richard could purchase in accordance with Medicaid guidelines.

Richard's situation is not unusual among people who need Medicaid assistance for long term care. With a state-determined limit on assets, most people must spend a large portion of their savings before they qualify for Medicaid. This process is called the “*spend down.*”

If Richard no longer has mental capacity to make financial decisions, his son can take steps to help him qualify for Medicaid benefits only if Richard has previously signed a durable power of attorney for financial matters. Otherwise, Nathan will have to ask a court to appoint a conservator to handle Richard's financial matters.

## Planning Ahead

**IMPORTANT NOTE:** Avoid excessive and unnecessary impoverishment! Before embarking on a spend down process, consult an elder law attorney. You may be able to take steps to minimize the amount you must spend down. In some cases, you can avoid the spend down all together.

If you are forced to spend down your assets to qualify for Medicaid, be sure to map out the spend down plan in advance and coordinate it with the Medicaid application.

The following list includes generally permissible spending of assets for Medicaid eligibility purposes. ***Purchases must be for fair market value***, so for example, you couldn't pay \$50,000 to your daughter for a car worth \$9,000 in an effort to shift assets to her.

### ***Allowable spend down purchases and transfers:***

- Purchase of a new home
- Payment of nursing home bills
- Payment of outstanding debt (like credit card bills)
- Prepayment of an outstanding mortgage, property taxes, and estimated income or capital gains taxes.
- Paying for home repairs.
- Purchase of furniture
- Prepayment of funeral and burial expenses

- Purchase of household goods and personal effects
- Purchase of a new car
- Payment of legal and medical bills
- Paying for travel (Although an Alzheimer's patient facing imminent nursing home placement is unlikely to want to take a trip, a healthy spouse is permitted to use spend down money this way.)

### **Purchase of an Immediate Annuity**

In some states, a Medicaid applicant may purchase a very specific type of immediate annuity as part of the spend down process. However, before purchasing an immediate annuity, consult an attorney with experience in elder law to ensure you comply with recent changes in the law. Most financial advisors do not understand how to acquire a Medicaid-qualifying annuity. Your elder law attorney can assist you in selecting an appropriate source for such an annuity.

Examples of Medicaid planning and strategies for spending down differ according to each applicant's individual situation and whether the person is single or married.

### **Spending Down for Singles**

In addition to paying monthly nursing home charges, a single Medicaid applicant can spend countable assets on such items as a new television or VCR, magazine subscriptions, prepayment of cable TV charges for his or her room in the nursing home, prepayment of hair dresser or barber charges, or purchase of extra dentures or eyeglasses.

He or she may also purchase medical equipment not covered by Medicare or Medicaid, including special shoes, gel pads to prevent bedsores, a special mattress, or a wheelchair. This category also includes payment for services that don't qualify for Medicare. The services may include physical therapy or alternative medicine like acupuncture, massage therapy, or relaxation therapy.

### **Spending Down for Married Couples**

Married couples have additional choices for the spend down process. While the institutionalized spouse can spend money on the same goods and services a single applicant can, the spend down can also include purchases that benefit the community spouse.

With some variance in state laws, these purchases may include a prepaid funeral plan for the community spouse, a new car (but, remember, only one vehicle is considered exempt and some states may limit the value), furniture, clothing, and travel. The spend down may also be used for a new roof, paint, carpeting, appliances, or heating and air conditioning units for the community spouse's primary residence.

**Do This:**

**On the following pages, place a check mark in the blank beside the items that apply to your plan and list your ideas for ways to spend down the Medicaid applicant's excess assets. Use this information in conjunction with Medicaid planning and the Medicaid application.**

\_\_\_\_\_ **New home**

Estimated purchase price:

\_\_\_\_\_ **Nursing home bills**

Months to be paid and rate:

Total amount to be paid:

\_\_\_\_\_ **Payment of outstanding debt**

Creditor:

Balance due:

\_\_\_\_\_ **Prepayment of an outstanding mortgage**

Mortgage company:

Amount to be paid:

\_\_\_\_\_ **Payment of property taxes**

Amount to be paid:

\_\_\_\_\_ **Payment of income tax**

Estimated income:

Amount to be paid:

\_\_\_\_\_ **Payment of capital gains taxes**

Estimated tax to be paid:

\_\_\_\_\_ **Home repairs**

Repairs to be made:

Estimated cost:

\_\_\_\_\_ **New furniture**

Furniture to be purchased:

Estimated cost:

\_\_\_\_\_ **Prepaid funeral and burial plan**

Estimated amount:

\_\_\_\_\_ **New household goods and personal effects:**

Item and price:

\_\_\_\_\_ **New car**  
Make/model:  
Estimated price:

\_\_\_\_\_ **Legal bills**  
Service provider:

\_\_\_\_\_ **Medical bills**  
Service provider:  
Amount due:

\_\_\_\_\_ **Travel**  
Destination:  
Estimated price:

\_\_\_\_\_ **Clothing for Medicaid applicant**  
Estimated price:

\_\_\_\_\_ **Clothing for community spouse**  
Estimated price:

\_\_\_\_\_ **Jewelry**  
Item:  
Estimated price:

\_\_\_\_\_ Purchase of immediate annuity (if allowed in your state)  
Issuer:  
Amount of annuity:

**IMPORTANT NOTE:** Before spending down, consult an expert in your state's Medicaid regulations. You may be able to take steps to minimize the amount you must spend down. In some cases, you can avoid the spend down all together. Before discussing these possibilities, though, become familiar with your state's procedure. Community property states like California, Arizona, New Mexico, and Washington may use special rules under both state and federal guidelines.

## **Is There Another Way?**

What if you're afraid to spend down all of your assets for nursing home costs? Or, what if you don't want to see your life savings disappear?

You may be concerned that you won't always get good care. What if you need a medical procedure or drugs that Medicaid won't cover?

What if your television breaks or you need a new chair for your room or a new pair of shoes?

What if you recover and need a nest egg?

***Is there way to get the care you need without spending down all of your assets?***

There is good news: Following the state-recommended spend down plan is a worst case scenario. Instead, with Medicaid planning you can use legal and ethically sound strategies to maximize the amount of money your family can keep for your care while still qualifying you for government benefits.

Consulting an attorney to help you with this process is like asking a certified public accountant to prepare your income tax forms to ensure you are taking all possible tax deductions. With legal assistance and proper Medicaid planning, you can often save half—sometimes even all—of your assets, while still qualifying for benefits to pay for the care you need.

In the following section, you'll find some of the options that may be available to you and your loved ones. In some cases, these strategies won't be approved at the caseworker level; they must be ruled on in an appeal procedure called an administrative hearing. Seek legal advice and representation.

# Medicaid Planning

## *Frank and Mildred's Story:*

Mildred's husband Frank has reached late-stage Alzheimer's and needs long term care in a nursing home. The couple owns a \$112,000 home where Mildred intends to remain, and a late model Buick worth about \$16,000. Additional assets include \$40,000 in certificates of deposit, \$23,000 in a money market account, \$25,000 in an IRA, and \$20,000 in U.S. savings bonds.

Mildred worries about the costs of long term care. She wants to apply for Medicaid benefits, but her bridge partner told her she stands to lose all of their assets when Frank enters the nursing home. Mildred has heard that under the gift tax laws she can give away \$13,000 per year (2009 figure) and wants to give as much money as she can to her daughters, Joan and Jessica, so the family won't lose all of the assets Frank and Mildred spent a lifetime earning.

The big question is this: Can Mildred give away assets before applying for Medicaid benefits for Frank?

## **Can't I Just Give Away My Assets?**

Mildred could be making a serious mistake. She wants to provide for Frank's medical needs, but preserve as much of their assets as possible. But she is going about it the wrong way. There is a right way and a wrong way to gift one's assets.

***The gift tax law Mildred has heard about has no bearing on Medicaid eligibility rules. More importantly, such gifting will delay Frank's eligibility for benefits.***

The current IRS gift tax rules allow a person to give up to \$13,000 per year (2009 figure) to another human being and not have to file a gift tax return. But that's only part of the story. You can give up to \$1,000,000 in total over your lifetime without paying a gift tax. Nonetheless, if you give more than \$13,000 per year to someone, you must file a gift tax return, even though there is no current gift tax due.

The IRS tax rules do not provide any exception from the Medicaid penalty period of ineligibility when and if a person files for Medicaid within sixty months after giving away money.

## ***Look Back Period***

In other words, if you give away money today in an attempt to qualify for Medicaid in the future, you may be ineligible for Medicaid benefits due to that gift. Imagine that a gift today will affect you up to five years into the future. A gift in this month of this year may cause you to lose some Medicaid eligibility when and if you become ill and impoverished through no fault of your own during the next five years. That is a harsh new law that was put into effect on February 8, 2006 under a bill called the Deficit Reduction Act (DRA).

The DRA extended the look-back period from 3 years to 5 years for all transfers made on or after the date of enactment. This will impact both the record keeping required and, for those persons wishing to pre-plan for Medicaid, the increased time period before they can apply for Medicaid.

### ***Penalty Period Start Date***

The worst thing about the new law (DRA) is that the burden of this penalty of ineligibility due to gifting falls upon you when you are totally vulnerable and unable to defend yourself. You must be medically needy so as to be qualified for nursing home services AND impoverished to the point that you have less than \$2,000. Now that you are both medically and impoverished, the state will conduct an audit of your finances for the prior five years. If they discover gifts of money to loved ones or charities, the penalty period will start now that you are both medically needy and impoverished. No one really understands how the government expects you to cure this penalty now that you are medically needy and impoverished; nonetheless, you will be denied Medicaid benefits to pay for your nursing home care.

Under 42 U.S.C 1396p(c)(1)(D), the DRA amends the beginning date of the penalty period from the month the transfer occurred to generally the date on which the person is eligible for Medicaid and would otherwise be receiving institutional level of care based on an approved application for such care but for the imposition of the penalty period.

CMS in their State Medicaid Director Letter, date July 27, 2006, interpreted “would otherwise be receiving” to “is receiving” institutional level of care services. If this interpretation were adopted by a state, the penalty period would not start until the person is actually receiving Medicaid covered institutional level of care services.

This change has a harsh impact in that the penalty may not begin until the person is out of funds and in need of nursing care. The example provided on page 179 concerning the “Half-A-Loaf” gifting would be impacted. In this example, the person gave away \$11,000 and retained \$12,000 to pay privately until the expected 3-month penalty would expire. Under the DRA, the penalty will not begin until the \$12,000 is expended and the person is otherwise eligible for Medicaid, except for the penalty period. In this example, the person would not have the funds available to pay through the 3-month penalty period. Under the DRA, the half-a-loaf strategy is no longer a viable planning tool.

### **“Granny Goes To Jail”**

In recent years Congress has passed laws intended to discourage, even criminalize, the transfer of assets for Medicaid planning purposes.

The first was Section 217 of the Health Insurance Portability Act (HIPAA) passed in 1996, which stated that it was a federal crime to give away money to qualify for Medicaid and then to apply for Medicaid during the period of ineligibility which the gift had created. The law was referred to as “The Granny Goes To Jail Law,” and a huge public outcry followed.

Congress realized that it was unrealistic to send “Granny” or even her kids to jail for gifting assets, so the law was changed in the Balanced Budget Act of 1997. No longer were Granny and her kids going to jail. Now it was only Granny’s lawyer, who had advised the transfers.

These attempts to criminalize Medicaid planning were a clear warning that the government is displeased with perceived Medicaid fraud and abuse. Although Attorney General Janet Reno informed Congress that the Department of Justice would not criminally prosecute advisors for violation of the 1997 law because in her opinion the law is unconstitutional, she offered to help Congress fashion a law that *would* be constitutional.

In all probability, attempts to criminalize some aspects of Medicaid planning will continue. So, consulting someone with expertise in elder law will become more important to ensure compliance with any changes in Medicaid laws and regulations.

## **Permissible Gifts**

Some gifts are permissible. For instance, the law clearly allows you to transfer assets to a spouse, a child who is blind or has a disability, or to a trust for the benefit of a person younger than 65 who has a disability and who is a Medicaid recipient. Discussion of these situations is beyond the scope of this book. If you have a loved one who meets one or more of these criteria, seek competent legal advice.

## **“Half a Loaf” Giving**

“Half a loaf giving” is a term that has been used to describe a method to preserve at least 50% of a person’s assets when already determined to be medically needy so as to qualify for nursing home benefits. The DRA was implemented by the federal government and the states to attack this type of Medicaid planning. In most states, half a loaf giving is now ancient history and no longer valid. You may hear this term used by individuals who did Medicaid planning under the prior rules. An elder law attorney in your state will know which strategies are most appropriate under current law.

## **A Word About the Gift Tax**

Because so many people make the mistake of confusing gift tax regulations with rules about transferring assets for the purpose of Medicaid qualification, let’s briefly consider the gift tax consequences of the transfers.

In 2009, anyone who makes a gift of \$13,000 a year or more (\$26,000 for a married couple) must file a gift tax return by the following April 15<sup>th</sup>.

***Some people mistakenly think this limit cannot be exceeded. However in some cases, you may give far more than that without paying gift tax.*** Each of us has a lifetime amount that can be gifted or passed on to our heirs. We can either use the amount while we are living (i.e., through gifts) or we can pass along the assets after we’re gone. The amount which you can give free from federal estate tax (either via gifts or at death) is currently (in 2009) set by law at \$1,000,000. Thus,

you can make large gifts and not have to pay gift taxes on them. So even though no tax is due, you still must file a gift tax return.

Before undertaking a gifting program, contact your accountant or other tax professional to determine what, if any, filing requirements exist.

**Do This:**

**Contact an elder law attorney and discuss the possibility of a gifting program to protect your assets. Use the space below to record notes from your discussion.**

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## **Lifetime Care Contracts (Personal Care Agreements)**

*Sally and Kathleen's Story:*

Sally feels worn out. Four years ago her father died, and for the past three years, she has been caring for her aging mother, Kathleen, who has Alzheimer's disease. At first it was little things like grocery shopping, trips to the doctor, and help with her medication. But as her mother's health deteriorated, Sally's burden has increased.

The last six months have been brutal. Sally had to move Kathleen to a nursing home. Sally thought her job would be easier once the nursing home staff took over, but it hasn't turned out that way. As the oldest daughter, Sally still feels responsible even through someone else has taken over her mother's care. Sally feels that she has to be there, too, so she visits Kathleen six days a week.

Sally is running herself ragged, and Kathleen is running out of money. With nursing home costs around \$5,400 per month, her mother's savings of \$60,000 won't last long. Sally has heard that Medicaid will cover the nursing home, but she's also heard that Medicaid won't cover everything. What will her mother do if she needs care that Medicaid or Medicare won't cover?

*Perhaps, given Sally's high degree of involvement, a personal care contract should be considered.*

Sally and her mother may enter into a formal agreement where Sally becomes Kathleen's care manager. Even though Kathleen lives in a nursing home, she may be able to pay Sally for care management services, if the contract is allowed under state law and if the agreement is handled properly. (Before entering into such an agreement, consult an experienced elder law attorney).

For example, if Sally spends approximately 1.5 hours per day (six days a week) caring for her mother, that's nine hours per week (six days per week times 1.5 hours per visit). Kathleen can agree to pay Sally the fair market value for her services (i.e., the price a willing buyer and seller agree to). If the two agree on \$10 per hour, Sally will earn \$90 per week for her services. That may not seem like a lot. But Kathleen and Sally can enter into a *lifetime care contract*. Kathleen can agree to have Sally act as her care manager for as long as Kathleen lives.

In other words, Kathleen can pay Sally \$4,680 per year (\$90 per week times 52 weeks per year). What's more, in some states Kathleen can make payment in a lump sum based on Kathleen's life expectancy. So if Kathleen's life expectancy is 11 years (according to life expectancy tables issued by the Federal Health Care Financing Administration), she can pay Sally \$51,480 (\$4,680 per year times 11 years). And, she may be able to pay the entire \$51,480 up front, in one lump sum.

The lifetime care contract should spell out exactly which services Sally will perform. Of course, Sally must perform them. While a lifetime care contract can be used for people who continue to live at home, if the Alzheimer's patient lives in a nursing home, the contract must specify services that do not duplicate services provided by the nursing home.

If Kathleen remained at home, for example, Sally could agree to provide services like assistance with such activities of daily living as preparing meals, bathing, dressing, and transferring between a wheelchair and bed. With Kathleen residing in a nursing home, Sally could agree to case management or care advocate activities, such as making sure Kathleen is getting good care, speaking with nurses, coordinating appointments with different doctors, and attending quarterly care planning meetings.

In order to enter into a lifetime care contract, if Kathleen lives beyond the life expectancy used to calculate payment, Sally must continue to perform her contracted duties. Too, Sally must declare the lump sum payment as income on her income tax return.

Some states allow lifetime care contracts while others do not. In any case, be sure to have an expert in elder law draft the contract to ensure it complies with state regulations and serves the purpose intended. You may also need legal representation to help you get approval from your state Medicaid agency.

**Do This:**

**If a lifetime care contract is allowed in your state, use this space to list the services the Medicaid applicant needs that a lifetime caregiver could perform. Specify whether services take place in a home or nursing home setting. Your list can help your attorney draft the contract if it is a good Medicaid planning choice for your situation.**



Annuities can create tax advantages for some individuals. If you place the same amount of money in a certificate of deposit, for example, you'll pay taxes on the interest earnings. But with an annuity, the interest is not taxable until you take the money out.

Suppose you deposit \$100,000 in an annuity that earns 5 percent interest, or \$5,000 the first year. Further suppose that at the end of the year, you withdraw \$10,000 from the annuity. For income tax purposes, the first money you take out is interest. So, of the \$10,000 you withdrew, the first \$5,000 is the interest you earned and is taxable as ordinary income. However the additional \$5,000 is return of the principal and is not taxed.

An annuity contract is a countable asset for Medicaid eligibility purposes and includes both the principal and any earned interest. But what if you could change that status from an asset to an income stream? The annuity would no longer count as an asset, but would count as income.

State regulations concerning annuities vary for Medicaid purposes. For example, some states won't let you buy an annuity without declaring how long it will pay out. In those cases, you have to look at life-expectancy tables issued by the Health Care Financing Administration. (These are the same tables used in the lifetime care contract described earlier.)

### ***Disclosure***

The new Medicaid rules provide that you disclose any interest the institutionalized spouse or community spouse has in an annuity. The disclosure is a condition of Medicaid eligibility for long term care services. The failure to disclose may result in the denial of payment for long term care services or the state may entirely deny Medicaid coverage based on the person's failure to cooperate.

In this example, Wayne's annuity can be paid out to his beneficiaries should he die prior to the date of his life expectancy. Under the DRA, if the state is named as a remainder beneficiary in the first position, repayment of Medicaid will first be made before any amount is provided to Wayne's remainder beneficiaries in the second position.

Due to the difficulty of understanding what these rules mean, it is important that you get a "second opinion" about whether or not an annuity is treated in your state as a Medicaid-qualifying annuity. ***Most financial advisors have no knowledge of Medicaid rules.*** Do not accept at face value the representations of a financial advisor that "this annuity will qualify you for Medicaid." In addition, very few attorneys understand the Medicaid rules; therefore, you must seek the advice of an experienced elder law attorney in your state to review the terms of any proposed Medicaid-qualifying annuity.

### ***Wayne's Annuity:***

If Wayne is 65 years of age and his life expectancy according to the tables is 15 years, he should buy an annuity that will pay out the entire amount over the 15 years. He can then annuitize it (i.e., turn it into monthly payments).

If the annuity is actuarially sound (i.e., if it will return all his funds over the 15-year period), it is a transfer for value for Medicaid purposes. A transfer for value is an exchange of goods or services of fair market value. Let's assume Wayne's annuity will pay him \$700 per month for 15 years. At the end of that time, the annuity will have paid Wayne far more than he deposited into the contract. So, it is actuarially sound.

For Medicaid purposes, in some states the \$100,000 annuity no longer counts as a countable asset. However, the \$700 per month generated from it does count as income. If Wayne has no other countable assets, he qualifies for Medicaid. His pension and Social Security checks plus the \$700 per month from the annuity go to the nursing home to reduce the amount the state must pay for his care.

What if Wayne dies before the 15-year life expectancy? If he lives just three years (20 percent of his life expectancy), the rest of the annuity payments go to Wayne's beneficiaries. Unfortunately, under the DRA the state can collect for any Medicaid services provided to Wayne prior to any remaining balance is available to Wayne's loved ones. The DRA requires that Wayne name the state as his primary beneficiary in the event that he becomes the recipient of Medicaid benefits.

Since Wayne always intended to leave the money to his grandchildren, he can name them as secondary beneficiaries of the annuity and they will get whatever amount is left after the state has been repaid for Medicaid services.

## **When To Buy an Annuity**

In states where annuities are allowed, they can also protect assets for the community spouse of a married Medicaid applicant. Although this strategy is not recommended for everyone, in the right situation it can be a valuable weapon in the Medicaid planner's arsenal. ***It is most effective when the community spouse has a high income (this is true in most states but not Illinois).***

A community spouse with a low income, you may remember, is entitled to a portion of the institutionalized spouse's income before the remainder is paid to the nursing home. Income from an annuity would reduce the amount of the institutionalized spouse's income that could go to the community spouse.

Annuities are another area where the rules are evolving.

### **Do This:**

**Consult an elder law attorney before purchasing an annuity. Annuities must be structured properly and additional requirements must be met in some states before this strategy will be approved for Medicaid purposes. Use the space below to record notes from your discussion.**

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## Additional Strategies for Married Couples

### *Theresa and Bill's Story: When there is not enough income to meet the MMMNA*

Theresa's husband, Bill, has Alzheimer's and has qualified for Medicaid benefits to pay for nursing home care by following the state Medicaid agency's advice. They divided their assets and spent down enough of Bill's half to reach the state's maximum. They also provided for Theresa's income by following a formula to calculate her minimum monthly maintenance needs allowance (MMMNA) at a maximum of \$1,750 (if the couple has sufficient income to pay this amount).

Both Theresa and Bill have Social Security benefits. To meet Theresa's MMMNA (she is the community spouse), she first kept her monthly Social Security check of \$650. Then she got \$970 a month of Bill's \$1,000 monthly benefit to total \$1,620 per month. The remaining \$30 of Bill's check paid for his \$30 per month personal needs allowance with the balance (\$0.00) going to the nursing home.

#### **How Theresa reached her monthly income of \$1,620 (max MMMNA is \$1,750):**

Theresa's monthly Social Security check	\$650
Supplement from Bill's Social Security	<u>970</u>
Total	\$1,620

#### **What happened to Bill's Social Security benefit of \$1,000:**

Supplement to Theresa's MMMNA	\$970
Bill's personal needs allowance	30
Paid to the nursing home	<u>00</u>
Total	\$1,000

Unfortunately, Theresa and Bill do not have enough income to reach the state maximum community spouse income amount. Theresa is able to have Bill's income allocated to her—but she is still short of the MMMNA. There are some legal strategies that can be used to increase the income available to Theresa by increasing the legal limit of assets which may be retained by the community spouse.

The two most common methods that an elder law attorney will use to increase income are:

1. Filing a lawsuit to allow the community spouse to keep assets which exceed the state Community Spouse Resource Allowance (CSRA) so as to provide sufficient income.
2. Advocate at a fair hearing of the Medicaid department to allow the community spouse to annuitize assets in excess of the CSRA so as to provide sufficient income.

**WARNING!** Don't attempt to raise the community spouse resource allowance on your own. Rules vary widely by state. Too, you'll need an administrative hearing to accomplish this increase in the CSRA. Seek legal representation from an experienced elder law attorney.

### ***Raising the Community Spouse's MMMNA***

With the help of an experienced advisor, the community spouse may also raise the amount of income (i.e., the MMMNA), he or she can keep. If the spouse has certain extraordinary expenses (rent or mortgage, homeowner's insurance, high utility bills, etc.), these can increase the amount of monthly income the community spouse can keep. Sometimes this can be done by the Medicaid caseworker at the time the application is approved, according to a set formula. Often it can only be done through an administrative hearing or by court order.

#### **Do This:**

**In the space below, list the community spouse's monthly expenses. Take the list to your Medicaid caseworker or an elder law attorney.**

Rent or mortgage (include property taxes):	\$ _____
Homeowner's or renter's insurance:	\$ _____
Utilities:	\$ _____
Car payment:	\$ _____
Auto insurance:	\$ _____
Health insurance or Medicare tie-in plan premium:	\$ _____
Long-term care insurance premium:	\$ _____
Consumer debt (itemize creditors and monthly payments):	\$ _____
Other expenses:	\$ _____

## Dealing with Life Insurance

While *term* life insurance policies do not count as assets for Medicaid eligibility, the value of *whole life* policies (the kind that accumulate cash value) is another story. Whole life policies have a face value and a cash value. The face value is the amount the policy pays in the event of death of the insured. The cash value is the amount the policy is worth if the policy holder cashes it in.

If the total of the face value of all of the applicant's whole life policies is \$1,500 or more, most states consider the total cash value of all policies a countable asset that affects Medicaid eligibility. But even if the cash value of a \$1,500 face value whole life policy is greater than \$1,500, the cash value is not included in countable assets. Consider this example.

### *Roy's Story:*

Roy is a widower with two grown children. He has assets of less than \$1,000, not counting his whole life insurance policy with a face value of \$5,000. In the state where Roy lives, his assets would fall within Medicaid eligibility guidelines. However, his life insurance policy has a cash value of \$3,250. Since the face value is higher than \$1,500, the policy's cash value is a countable asset. Roy can't qualify for Medicaid unless he deals with this life insurance policy.

Roy has several options. He can simply cash in the policy and spend down the money. Or, in some states, he can purchase a prepaid funeral and name the funeral home as an irrevocable beneficiary so his insurance will pay for his final expenses. Roy could also make a gift of the policy to his children; this gift would be subject to the same transfer penalties that apply to gifts in his state.

**IMPORTANT NOTE:** An irrevocable beneficiary designation cannot be changed, so the person or entity named will receive benefits at the death of the insured.

If Roy needs nursing home care, however, he may no longer have mental capacity to take these actions. But, if he has previously signed a durable power of attorney for financial matters with language specifically allowing his agent to cash in his life insurance policy or change the beneficiary, his agent can take these steps for him. The power of attorney document should carefully spell out the grant of authority so the agent will be able to deal with the policy easily and quickly.

## Insuring the Community Spouse

What about life insurance policies on the community spouse? Are there planning steps to take?

### *Ed and Wilma's Story:*

Wilma has Alzheimer's disease and lives in a nursing home paid for by Medicaid. Her husband, Ed, lives at home. Ed has a term life insurance policy with a face value of \$25,000 that names Wilma as beneficiary.

The term policy, which does not accumulate cash value, did not count as an asset for Wilma's Medicaid eligibility. However, if Ed dies before Wilma, the insurance benefit will go to Wilma. The resulting cash asset will disqualify Wilma for Medicaid benefits. A pension or individual retirement account (IRA) that pays Wilma as a beneficiary would have the same result. If possible, under state Medicaid laws, Ed should name someone else as beneficiary on all of these kinds of policies and accounts.

Whenever a loved one moves into a nursing home using Medicaid benefits, review beneficiaries named on life insurance policies, pensions and individual retirement accounts. And, where appropriate, change the beneficiary so that a Medicaid qualified individual does not lose his or her benefits.

**Do This:**

**In the space list all life insurance policies, pensions, and individual retirement accounts owned by you or your spouse and the beneficiaries of each. Be sure to change beneficiaries so that subsequent payment of these benefits will not jeopardize the institutionalized spouse's Medicaid eligibility.**

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Of necessity, this has been but a brief discussion of some of the many techniques available for Medicaid planning. Medicaid can be an extremely complicated program whose terms and conditions often seem like gibberish to the uninitiated. For that reason, we have simply listed a few of the kinds of strategies which can be appropriate.

The real value of the explanation in this book will be realized if you understand that unless you have had years of experience dealing with Medicaid and Medicaid planning, the best advice is for you to find someone who does have this kind of expertise. Not only are the techniques which may fit your situation complicated, they also vary from state to state.

**Do This:**

**If you do nothing else, consult an experienced elder law practitioner for help in this area.**

# Will I Lose My Home?

## *Sidney and Rachel's Story:*

Sidney and Rachel had lived in their home since it was new. They built it just after Sidney got a promotion to regional sales manager for a shoe distributor. Their first dog, Spunky, was buried beside the house's foundation alongside two cats, a gerbil, and several goldfish their two sons, Mark and Lance, and daughter, Sarah, had loved.

Through the years, the house was remodeled twice and expanded to add a loft bedroom when Sarah was born. Even when the children were grown with families of their own, they all remained close, with frequent family gatherings for holidays and birthdays.

The latest room addition was a new family room big enough for the children and their children. The couple also added a new sidewalk from the driveway to the front door to accommodate Sidney's wheelchair. The day they poured the concrete, the entire extended family arrived to add their handprints: Mark and Lance and their wives, Sarah and her husband, and all eleven grandchildren. The sidewalk even boasted paw prints from Maggie, their eight-year-old Scottish terrier, and Pumpkin, a stray cat of unknown age that Sidney had adopted around Halloween four years earlier.

Sidney and Rachel had paid off the mortgage and two second mortgages before Sidney retired. So in addition to being the center of family life, the house had also become the couple's biggest asset.

Rachel always hoped the house would remain in the family when she and Sidney were gone. She often talked about leaving it to their oldest son, Mark, who promised that he and his wife would continue the tradition of hosting the family for holidays and birthday dinners. However, Sidney's Alzheimer's disease seemed to have reached the late stage, and Rachel worried that Sidney would need to move into a nursing home. With the high cost of long-term care, Rachel knew their savings wouldn't last long. Sidney would eventually need to qualify for Medicaid to pay the bills.

Her biggest question was, "Will I lose my home?"

## *A Common Question*

Many people who apply for Medicaid benefits to pay for nursing home costs ask the same question. For many, the home constitutes much or most of their life savings. Often, it is all a couple has to pass on to their children.

Under Medicaid regulations, the home is an exempt asset. That means its value is not taken into account when calculating eligibility for Medicaid benefits. And, the house remains an exempt asset as long as the community spouse lives there. However, after the deaths of both the community spouse and the institutionalized spouse, the property may no longer be protected.

## **Estate Recovery**

According to provisions passed in the Omnibus Budget Reconciliation Act of 1993 (OBRA-93), the state has the right to recover whatever benefits it paid for the care of a Medicaid recipient from his or her estate. Given the asset rules for Medicaid eligibility, often the only property of substantial value that a Medicaid recipient is like to own at death is his or her own home. OBRA-93 required each state to establish an estate recovery unit (ERU) to seek repayment of certain Medicaid payments from the estates of those who received benefits.

***Because the home is the single largest asset a couple can keep (while still qualifying for Medicaid), in most states it is also the main target of estate recovery.***

After both the community spouse and the institutionalized spouse die, the state's estate recovery unit has broad authority to seek payment from virtually any property that the Medicaid recipient had any legal title to or interest in. In most states that means going back against the house.

In some states, the estate recovery unit may make a claim against the decedent's home only if it is in his or her probate estate. Property that escapes estate recovery may include property that is jointly owned or in a trust. In recent years, however, there has been a trend toward seeking estate recovery against such nonprobate property. Some states are more aggressive than others in what they pursue.

For example, if Sidney dies before Rachel after living in a nursing home for two years and Medicaid has paid the nursing home \$3,000 per month, the state will have paid \$72,000 for Sidney's care (\$3,000 per month times 24 months). Assuming the family home where Rachel lives is worth \$100,000, the state would have a claim for the first \$72,000 that comes from the sale of the house.

The house remains protected while Rachel is alive. However, at her death, the state could force sale of the house. The remainder of the price received for the sale of the house (\$100,000 minus \$72,000) would go to the couple's heirs.

In the case of a *single* Medicaid applicant, the home typically remains an exempt asset for the first six to 12 months that the applicant lives in a nursing home. In some states, in order to continue considering the home an exempt asset, the nursing home resident must demonstrate an intent to return home (even if the return never takes place). Beyond the one-year mark in some cases, however, the state may step in and force sale of the home.

The state could then recoup money from the sale as repayment of Medicaid benefits paid. Any remainder of cash would then be considered a countable asset and would affect the nursing home resident's continued eligibility for Medicaid.

## **The Family Farm**

State rules about agricultural property vary. If the Medicaid applicant's home is on the acreage, contiguous (adjoining) acreage will usually be exempt. Some states limit the acreage that is

exempt. However, at the death of both spouses, the property is still subject to recovery of Medicaid expenses under the estate recovery provisions of OBRA-93.

Fortunately, depending on state regulations, strategies may exist to protect your property. Depending on the state and any changes to Medicaid regulations, the solutions can include changing the title, putting the house in trust, selling the house or giving it away.

**IMPORTANT NOTE:** What works in one state may cause severe penalties or even disqualification for Medicaid in another. To ensure compliance with current regulations in your state, be sure to consult an elder law attorney before transferring your home.

## **Federal Exceptions**

A Medicaid applicant can transfer title to his or her home to a spouse, a blind child, a child with a permanent and total disability, or a child younger than 21 without incurring a Medicaid eligibility penalty. Federal and state laws also allow two other transfers, as illustrated in the following stories.

### ***Betty and Helen's Story:***

When Betty's brother-in-law died three years ago, she invited her widowed sister, Helen, to move in. Helen accepted the invitation, but insisted that she contribute financially. She purchased an interest in the house by paying off Betty's mortgage of around \$25,000. Helen has lived there since. Now Betty has Alzheimer's disease and is facing the possibility of moving into a nursing home as her disease progresses. Betty wants Helen to keep the house they have shared.

According to federal law, Betty may transfer the house to her sister when she applied for Medicaid. ***The law allows transfer of the house to a sibling of the applicant if the sibling has lived there for a least a year before the applicant moves into the nursing home and if the sibling has an ownership interest in the house.***

Because Helen has lived there for the three years prior to Betty's move to the nursing home and has an equity interest in the house from paying off the mortgage, Betty may transfer the house to her sister without creating a period of Medicaid ineligibility.

### ***Vanessa and Fern's Story:***

Vanessa moved to her parents' home shortly after her mother, Fern, was diagnosed with Alzheimer's disease four years ago. During that time Vanessa took care of her mother. At first the care she provided was relatively easy. She cooked meals, laid out Fern's clothing in the morning and helped Fern remember appointments and financial obligations.

As Fern's disease progressed, the care she needed increased. Vanessa helped her mother eat, bathe, dress, and use the toilet. She drove her to doctor and hair appointments. In fact, for the

last two years, Vanessa provided enough care that Fern has been able to remain at home much longer than she would have been able to without her daughter's help.

Under federal law, Fern may transfer her house to Vanessa when she enters a nursing home and applies for Medicaid. ***The law provides that the home may be transferred to a child of the applicant who has lived in the parent's home and provided enough care for the parent to stay out of a nursing home for at least two years.***

In this instance, the child is called the "caretaker child," and the home can be transferred to the caretaker child without Medicaid penalty.

**IMPORTANT NOTE:** Since Medicaid rules vary and are constantly subject to change. Before taking any action concerning your home, consult an experienced elder law attorney who knows the rules and can advise you accordingly.

## **Options for Married Couples**

According to federal regulations, a married Medicaid applicant may transfer the home to his or her spouse without penalty. Once that transfer is made (and the institutionalized spouse's interest in the house is removed), the community spouse may have other options in dealing with the property. In some states the community spouse can even give the house away. Such a gift, of course, would create a period of Medicaid ineligibility should the community spouse need nursing home care within the five-year look-back period.

## **Taking out a Reverse Mortgage**

If the community spouse needs additional income, he or she could agree to a reverse mortgage. A reverse mortgage is a way to tap the hidden equity in the home. In such an agreement, the community spouse would mortgage the house, and the mortgage company (the lender) would agree to pay a certain amount each month to the borrower. This would add to the community spouse's income each month. This strategy works only when the community spouse is entitled to more income according to the income allocation formula of the MMMNA.

***This technique can work well for a community spouse who doesn't have enough income to live on. However, entering into such an agreement risks loss of the property to the mortgage company.*** That's because a reverse mortgage is similar to an annuity. Depending on how the agreement is structured, the payments may last for the lifetime of the homeowner, but the payments, as well as all interest in the property, may terminate at the homeowner's death.

Dealing with the family home is both challenging and sometimes frustrating under Medicaid. The good news is that, under the current laws, you will not be forced to sell your home in the event you or your spouse needs Medicaid assistance.

The bad news is that, depending which state you live in and how aggressive the state estate recovery unit is, a good way to protect the home may not exist. Some states are fairly lenient on this matter. Some will even let a community spouse give away the home after he or she has



# Basic Wills and Trusts

## *Byron and Margot's Story:*

Byron and Margot were high school sweethearts. They married soon after Byron completed basic training in the U.S. Navy. At Byron's first duty station, his commanding officer suggested that Byron execute a will with the help of the naval base's legal officer. Before Byron shipped out to the North Atlantic, he and Margot visited the office together, and both completed wills.

Byron's will essentially said, "If I die first, everything I have is Margot's." Margot's will named Byron the same way.

## **What is a Will?**

A will is a legal document that accomplishes several purposes. Its primary purpose is to let you pass your property to whomever you choose in the event of your death, and if you have minor children, to appoint a guardian to care for them while they're still young.

The kind of will Byron and Margot executed is often called a "sweetheart will." ***Most married couples have this kind of simple will.***

With a will you can select people, organizations, churches, or charities to receive your assets, or you can plan for different scenarios. For example, you might say that you want all of your property to go to your spouse, if he or she survives you, and if not, to your children in equal shares.

Sweetheart wills can pose special problems for a person with Alzheimer's regardless of whether the person lives at home, in an assisted living residence, or in a nursing home. If the spouse without Alzheimer's dies first, the spouse with Alzheimer's may have difficulty or even the inability to handle the inherited funds. What's more, even if the illness has not progressed to the stage where nursing home care is needed, that possibility exists as the disease progresses. At that point, the surviving spouse with Alzheimer's disease would be single and have fewer options for Medicaid planning. Most, if not all, of the assets would have to be included in any spend down.

A similar situation arises if the surviving spouse with Alzheimer's has previously qualified for Medicaid and lives in a nursing home.

## *Ron and Carolyn's Story:*

When Carolyn's husband Ron, entered the Alzheimer's unit of a nearby nursing home, the couple completed the division of assets and spend down needed for Medicaid eligibility. Ron retained assets of about \$900 which was less than the state's maximum. Carolyn, the community spouse, kept about \$50,000 in assets.

At the time, Ron lacked the capacity to revise his sweetheart will. And Carolyn never thought about changing hers, which named Ron as the sole beneficiary. The couple had kept the wills they signed as newlyweds, even failing to draft new ones when their twins were born.

Unfortunately, Carolyn died in an automobile accident ten months after Ron moved into the nursing home. Ron inherited Carolyn's \$50,000 estate. With \$50,000 in assets, Ron no longer qualified for Medicaid.

To requalify, he had to spend down this amount, according to the same spend down rules he had used before. Even if he wanted to give money to the twins (but his mental capacity was now questionable, at best), he would create a period of Medicaid ineligibility for making the gift.

Unfortunately, he had not created a durable power of attorney for financial affairs with any gifting language. So his funds had to be spent down to about \$2,000—and at his death, his remaining assets (including his home) were subject to estate recovery. Chances are the twins would get little or nothing from their parents' estate.

## **Inherited Assets**

In approximately 75 percent of cases, the institutionalized spouse dies before the community spouse. However in the other 25 percent of cases, when the community spouse dies first, assets inherited from the deceased spouse can disqualify the institutionalized spouse from Medicaid. The assets must again be spent down to the state's asset limit (often \$1,000 to \$2,000 is all you can keep), pursuant to the state's spend down rules. The couple's life savings is gone, with little or nothing left for children or other heirs.

## **Naming a Beneficiary**

Don't think that the easy solution to this dilemma is simply to name someone other than the institutionalized spouse as beneficiary of the community spouse's will. ***In some states, spouses are entitled by law to a certain portion of each other's estates. This amount is typically about one-third to one-half of the deceased spouse's estate. It's known as a "statutory share," an "elective share," or an "elective right."*** In other words, some states won't let one spouse disinherit the other spouse in an attempt to qualify for Medicaid. In these states, failure to provide the statutory share to one's spouse would be considered an attempt to transfer or gift a share of one's estate (to your children, for example), and a period of Medicaid ineligibility results.

### **Do This:**

**Consult an attorney to review your will as soon as you, a spouse, or someone named in your will is diagnosed with Alzheimer's disease.**

## **More Problems with Wills**

Many people share the misconception that if a will exists, assets simply pass to the heirs named. In fact, however, a will is a ticket to probate court. Probate is the judicial process where a judge

determines whether a will is valid. If it is valid, then the judge oversees the process and makes sure the person's wishes, including the way property is transferred, are carried out. Although the heirs ultimately will get the money and property designated for them, the estate must first go through probate.

## **Who Can Execute a Will?**

The person who executes a will must have the capacity to do so. Legally, "capacity" is the mental ability to perceive and appreciate relevant facts and make rational decisions. When making a will, the person must have the capacity to understand the nature and extent of his or her property, the identify of the heirs (i.e., who the property is to go to), and the consequences of the act of making the will.

If the attorney questions the capacity of the client—often a concern if the client has Alzheimer's—the attorney may need to request a psychological evaluation to protect the validity of the will. That's why early planning is so important.

## **More About Probate**

In some states probate practices have become streamlined and cause few problems. In other states, probate can be a time-consuming process with statutory requirements (i.e., requirements that are regulated or authorized by law) that can last from months to years. The process can also be expensive. In addition, probate is a matter of public record, and this sometimes leaves heirs open to calls from unscrupulous salespeople and others.

For these reasons, many people seek to avoid probate. The most common way to avoid probate is by putting other's names (e.g., spouse or children) on your bank accounts with you. Then at your death, the assets will pass to the others named on your account, if you've set it up properly, without going through probate. And that can work if everything goes smoothly and according to plan. The problem is, life is seldom predictable. And that's where problems can arise.

For instance, if both spouses are the only ones on their accounts, then when one of them dies, the assets go to the other. But what if the other now has Alzheimer's and can't handle the funds? Or what if they are both killed in an accident? Now there is legal trouble.

Some might say that's why the parents should also put the kids on the accounts. That might work, depending on how it's done, or it might create a whole new set of problems. For instance, it might give the kids ownership rights in the accounts and put the parents' money at risk due to the children's legal woes such as divorce, IRS liens, and lawsuits.

For these reasons, many attorneys counsel their clients to establish a revocable living trust. And while this is often a good idea, as we'll see later, a living trust can pose special planning dangers for families who have a loved one with Alzheimer's.

**IMPORTANT NOTE:** Don't use a do-it-yourself will kit. Planning for a family member with Alzheimer's can be complicated. Seek legal assistance.

## Avoiding Probate

### *Sir Robert's Story:*

During the Middle Ages, Sir Robert was preparing to leave England for the Crusades. He knew he'd be gone a long time. He also knew he could be killed and never return. Sir Robert visited the bishop with a request.

"I want you to hold any property for me," Sir Robert said. "If I return, I want it back. If not, I want you to give it to my sons, George and Richard."

The bishop agreed, and the knight left for the Crusades, secure in the knowledge that his assets were protected for himself and his heirs. Sir Robert's property was said to be left "in trust."

## Holding Property in Trust

Today, many centuries later, holding property in trust remains a relatively common practice. A trust is a legal entity that owns property, real estate, or investments—just about anything you can own. This entity is created by a legal document and provides for three roles:

- the person who puts assets into the trust;
- the person who manages the assets; and
- the person who benefits from the assets.

The person who transfers assets into the trust is called the **grantor** (also known as the settlor or trustmaker). The grantor transfers assets into the trust by retitling them so that the trust owns the assets, not the grantor.

The person who manages the assets is called the **trustee**. The person who benefits from the assets in a trust is called the **beneficiary**. More than one person can serve in the role of trustee or receive benefits as a beneficiary.

## The Revocable Living Trust

The most popular type of trust is a **revocable living trust**. A revocable living trust is established during the grantor's lifetime and may be changed or discontinued ("revoked") at any time. If the trust is not changed or discontinued, it remains in effect even if the grantor loses capacity. At the grantor's death, the trust either continues or is paid out, depending on the terms of the trust document.

In a revocable living trust, the grantor, trustee, and beneficiary may be the same person. In this case, the grantor still controls the assets, but now controls them as the trustee, not the owner.

One reason for the popularity of this type of trust is the way assets are handled when the grantor dies. The trust document specifies which assets are to be transferred to which beneficiary or beneficiaries. In this sense, the trust acts like a will. However, ***the trust assets do not need to go through probate***. And, unlike a will which becomes public record during the probate process, trust assets and their distribution remain private.

**IMPORTANT NOTE:** No income tax consequences result from establishing a grantor revocable living trust. During the grantor's lifetime, the Internal Revenue Service treats the trust as if it doesn't exist.

For these reasons, many people use revocable living trusts as the basis for their estate planning. In fact, trusts have become a traditional estate planning practice. ***Unfortunately, unless carefully drafted, a living trust can ruin your planning opportunities for Medicaid.***

## **Pitfalls of a Trust**

A revocable living trust can cause three types of problems for people who may need Medicaid assistance to pay for nursing home care.

First, assets that belong to a trust are still treated as if they belong to the Medicaid applicant. So the mere transfer of assets to a revocable living trust does not protect assets from Medicaid.

But it may be worse than that. In some states, exempt assets owned by a revocable living trust are countable for Medicaid eligibility purposes. That means that a house (or other asset) which would be exempt if individually owned becomes a countable asset when owned by a trust. So, the total assets for division of assets purposes, as well as the amount that has to be spent down, actually *increase*.

In other words, if you own assets worth \$60,000 plus a \$100,000 house, all in a revocable living trust, your countable assets would normally be \$60,000, and the house would be exempt. But in some states, by virtue of the fact that the house is in the trust, it now becomes a countable asset, which raises the countable assets to \$160,000—i.e., the other assets plus the house. That, in turn, makes the spend down much greater.

In fact, in this instance, the only way to qualify for Medicaid will be to remove the house from the trust. That brings us to the next issue.

## **Another Medicaid Planning Problem: When both spouses are required to transfer property**

The second potential Medicaid planning problem of a trust occurs when a grantor transfers assets into the trust and later has no authority to transfer them back out of the trust.

### ***Gladys and Neil's Story:***

Years ago, Gladys and Neil established a trust together. They named themselves as both grantors and trustees. In a spirit of togetherness, the trust document required both spouses to participate in any action to revoke the trust or to withdraw assets from the trust.

When the couple began dealing with the fact that Neil was exhibiting of early Alzheimer's disease, Gladys felt comfortable that everything had been taken care of. She and Neil never considered making any changes to the trust.

By the time Neil needed nursing home care, he no longer had the mental capacity to deal with financial affairs. Further, he had never signed a durable power of attorney for financial affairs. Gladys could not make any changes in the trust by herself, and Neil did not have the capacity to make any changes.

Nothing could be done to place the couple's assets in a more favorable position. The trust could not be revoked, assets (like the house in the first example) could not be removed, and costly legal steps would need to be taken. In short, Gladys was now prevented from taking Medicaid planning steps that both she and Neil would have wanted.

### **Making Gifts from a Trust**

Third, a trust can ruin planning opportunities for those who intend to make large gifts from a trust. According to state and federal law, large gifts made by individuals within five years of applying for Medicaid may delay eligibility. The look-back period for gifts made from a trust is five years, too.

These potential pitfalls are examples of why traditional estate planning often won't work for people with Alzheimer's disease. While they may have intended to use a trust to protect as many assets as possible for the care of a spouse, and then to pass their estate on to their children, in reality they may have created a legal nightmare.

That's why getting estate planning advice from a competent professional is so important.

### **A Special Trust Should Be Considered**

One kind of trust that may be useful for persons with Alzheimer's disease and their spouses is called a ***testamentary special needs trust***. A testamentary trust is created under a will.

A testamentary special needs trust lets a community spouse (i.e., non-institutionalized spouse) leave assets for the benefit of a institutionalized spouse to cover supplemental needs not covered by Medicaid. Money stays in the trust until the institutionalized spouse needs such goods or services (such as dental procedures, differentials in cost between private and shared rooms, and other quality of care needs).

Meanwhile, even though there may be assets in trust for the institutionalized spouse, the assets may not be countable for the Medicaid purposes. In other words, Medicaid coverage continues, and there is a pool of money available for additional or supplemental needs.

When the institutionalized spouse dies, the balance of the trust usually goes to the person's heirs. However in some states, it may be subject to estate recovery.

**Do This:**

**Check with a knowledgeable elder law attorney in your state to see if this type of trust is allowed.**

# Seeking Legal Help

Nationwide, care for Alzheimer's patients costs between \$80 billion and \$100 billion per year, with an estimated lifetime average cost of \$174,000 per patient. Typical expenses include fees for physicians, home health aides, or nursing homes. In three out of four cases, families provide care at home. In other cases, patients require nursing home placement.

This care is expensive. Even when the loved one remains at home, the Alzheimer's Association says, Alzheimer's families pay annually, on average, about \$12,500 for medical or personal care services they cannot perform themselves. And nursing homes cost even more—fees average \$45,000 per year and can reach \$100,000 per year in some parts of the country.

***Most health insurance plans don't cover long-term care. Neither does Medicare.***

While no two people experience Alzheimer's disease the same way, each progresses through predictable stages which may last months or years. In the mild stage, patients can make decisions and execute legal documents. Eventually, however, people with Alzheimer's lose the ability to care for themselves or make important medical and financial decisions.

Alzheimer's families may choose to do nothing and hope a cure is found. Or, they can participate in legal planning that will help them and their loved one make decisions about medical care, personal care, living arrangements, and financial matters associated with this disease. Seeking legal advice from an elder law attorney can ensure that future medical and financial decisions reflect the patient's wishes when he or she can no longer communicate them.

## **Do This:**

**If you or a loved one has been diagnosed with Alzheimer's disease, consult an elder law attorney. That way you can be sure important legal documents are in place so your family has a guide that reflects you or your loved one's wishes.**

## Seeking Legal Help

When you're ready to consult an attorney to determine whether you have legal issues that need to be addressed, you'll likely be able to find one in your area who offers a free or low cost initial consultation (often under \$350). Look for someone who has a demonstrated interest and experience in elder law issues, in the same way you would choose a physician for an important surgery. If you need to get your gall bladder removed, would you want a surgeon who performed only three gall bladder surgeries last year, or one who routinely does three per week?

***If you hire a lawyer with limited or no experience in dealing with elder issues, you'll be paying for the lawyer's time to research topics.*** An elder law attorney will already know the Medicaid regulations that another lawyer would have to research. Elder law attorneys focus on the legal needs of older clients, from general estate planning to planning for incapacity, long term care needs, and public benefits programs.

An experienced attorney will help you make the best decisions based on your individual financial situation. You may already qualify for Medicaid, for example. Or, your net worth may be too high to worry about Medicaid planning. But probably, you will fall somewhere in the middle. If so, the decisions you make about your will, estate planning, financial gifts, annuities, trust, powers of attorney, and other matters will affect your Medicaid eligibility for long term care.

## **Finding an Attorney**

You may have to search harder for an elder law attorney than for one to handle other legal matters like divorce, personal bankruptcy, or personal injury. If you live in an urban area, you may have several elder law attorneys to choose from—but if you live in a remote or rural area, you may have to travel to a larger city. ***The trip to find experienced legal advice will be well worth your time and effort. You will be dealing with your life savings and protecting yourself, your family, and your home.***

To find someone to help you, start with your family attorney. Ask if he or she has experience in this field. If not, ask for a referral. You can also ask for referrals from members of support groups for Alzheimer's families, such as those sponsored by your local chapter of the Alzheimer's Association. Attend meetings and ask others who have successfully dealt with legal issues related to Alzheimer's disease to recommend an attorney. Other people who can help you find an elder law attorney in your area include social workers, members of the clergy, certified public accountants, and financial planners.

Remember, Alzheimer's disease presents special circumstances, and not all attorneys or financial planners have experience in this area of the law. However, they may be able to recommend someone who does.

### **Do This:**

**You can find an elder law attorney in your area by contacting NAELA or going to their website and clicking on "Locate an Elder Law Attorney."**

The National Academy of Elder Law Attorneys (NAELA)  
1577 Spring Hill Road – Suite 220  
Vienna, VA 22182  
Phone: (520) 881-4005  
Website: [www.naela.org](http://www.naela.org)

**You can also get names of elder law attorneys in your area by contacting:**

The American Bar Association  
Commission on Law and Aging  
740 15th Street NW  
Washington, DC 20005-1019  
Phone: (202) 662-1000  
Website: [www.abanet.org/aging](http://www.abanet.org/aging)

## Now What Do I Do?

Once you have a lawyer's name, start with a phone call. Call the attorney's office and ask what the law firm's emphasis is and whether the attorney frequently represents families who have a loved one with Alzheimer's. Also ask about the attorney's experience with advance directives, powers of attorney, estate planning, nursing home issues, and public benefits like Social Security disability, Medicare, and Medicaid. One of the simplest questions you can ask to determine whether or not the law firm has sufficient experience in Medicaid is to ask, "How many Medicaid applications has your law firm done in the last year?" Then ask, "How many Medicaid applications has your law firm done in the last month?" If the personnel of the law firm hesitate before answering that question, call someone else. A law firm which regularly deals with Medicaid issues will answer those questions immediately, because they know how many applications they are processing on an ongoing basis.

***You want an attorney with experience dealing with the issues you're likely to face. And you don't want to pay fees for time an attorney needs to learn the nuts and bolts of elder law.***

For example, most attorneys have experience with powers of attorney. However, many attorneys don't include *gifting authority* in their documents. Most people don't need that kind of provision. But in a public benefits context, such as applying for Medicaid for nursing home care, you may need a gifting provision to protect your assets. A power of attorney without a gifting provision won't do what the client with Alzheimer's wants it to do. For some people, learning that lesson comes too late, at a point in the progression of the disease when your family can't do anything about it.

### **Do This:**

**Make an appointment for an initial consultation. During the initial consultation, the attorney will want to know why you are seeking assistance. Be prepared to discuss your situation. Most important, outline your family dynamics. Are you married or single? Have you been married before? Do you have children? Does your daughter get along with her brother?**

### **Do This:**

**In the space below list your children and their birthdates along with former spouses from previous marriages. Make notes about family dynamics that your lawyer should know about.**

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**IMPORTANT NOTE:** The attorney you hire needs to know which potential solutions are right for you. For example, giving money to children who don't get along may put your assets at risk. An attorney can't help you without knowing the true situation regarding you and your family.

Sometimes family dynamics can cause problems down the road, especially in cases of second marriages or in families with several children where only one or two of the kids are helping the person with Alzheimer's and a spouse execute wills or establish trusts. In cases where interests are aligned, an attorney can work with both spouses or the spouse and the family. But sometimes, interests are separate enough to require separate representation. In cases where there is a potential conflict of interest, of attorney represents either the person with Alzheimer's disease or his or her spouse. An attorney cannot represent a whole group if group members have incompatible objectives. In some situations, spouses may need to hire different lawyers. Usually, though this can be avoided.

The attorney will also want to know which symptoms the person with Alzheimer's has, when onset occurred, what kind of medication is taken, and what other treatments have been used or contemplated. Also include information about his or her career and other interests. If possible, include him or her in the meeting. And because legal matters can be confusing, taking along other family members is a good idea. They can help remember and clarify important points from the meeting.

## **What To Bring Along**

Before the appointment gather information about the person's income, assets, and liabilities, including balances, how assets are held, beneficiaries, and whose name(s) assets are titled in.

### **Do This:**

**Enter the following information in the blanks provided. Place a check mark in the blank beside each item as you complete it.**

### **Assets:**

Pension or individual retirement account balances

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Bank account balances

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Certificates of deposit

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Value of stocks and mutual funds

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Value of U.S. Savings Bonds or other bonds

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Life insurance policies (face value, beneficiaries, cash value)

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Any other financial assets

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**Income:**

Social Security and pensions, listed separately for each spouse

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Any other income for the person with Alzheimer's disease

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Any other income for the spouse

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**Liabilities:**

Credit card balances (list separately)

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Mortgage balance and monthly payment

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Vehicle Loans

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Loans against life insurance policies (list separately)

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Other liabilities

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## **Ask About Fees**

During your initial consultation, expect the attorney to offer a possible plan of action, spelling out the services he or she will provide. Don't be afraid to ask how fees and expenses are calculated and whether a retainer is required.

Attorney fees may be calculated two ways, or as a combination of both. The first method is an hourly billing rate. If the attorney bills hourly, ask what the billing rate is. Also ask if different rates apply for work by paralegals and secretaries and whether there are different rates for different types of work (one rate for wills, another for nursing home issues, for example).

The second method is value billing, where the attorney charges a flat fee for one or more specific services based on the value of the service rather than how long the service takes to perform. For example, using a computer and years of expertise, your attorney may be able to produce the legal document you need in only ten minutes. But the document's value may be \$300. With value billing, you're paying for the lawyer's knowledge and advice. Value billing rewards the attorney for working efficiently and is recommended for clients with Alzheimer's disease. For one thing, even an experienced attorney can't know how long some of the required services will take. And dealing with Medicaid issues in particular can be nitpicking and time consuming, especially for inexperienced attorneys.

*You're better off knowing up front how much your legal services will cost.*

An attorney might charge fees using a combination of both methods. For example, he or she might charge a flat fee for a number of specific services, but add to that if your case requires a Medicaid appeal, for example, with fees for that work calculated at an hourly rate.

Remember you're under no obligation to hire the attorney if you don't like the answers to any of your questions. If that's the case, make an appointment for a consultation with someone else.

**Do This:**

**When you decide to hire a lawyer, get a letter or contract that spells out in writing the services the attorney will provide, how fees and expenses will be calculated, and how often you'll be billed.**

# APPENDIX A: State Offices on Aging

For updated addresses, go online and google “office on aging” with the name of your state.

## **Alabama**

Commission of Aging  
RSA Plaza, Ste. 470  
770 Washington Ave.  
Montgomery, AL 36130

## **Alaska**

Commission on Aging  
Department of Administration  
PO Box 110209  
Juneau, AK 99811-0209

## **Arizona**

Aging and Adult Administration  
Department of Economic Security  
1789 W. Jefferson  
Phoenix, AZ 85007

## **Arkansas**

Aging and Adult Services  
PO Box 1437  
Little Rock, AR 72203

## **California**

Department of Aging  
1600 K St.  
Sacramento, CA 95814

## **Colorado**

Aging and Adult Services Division  
Department of Human Services  
110 16<sup>th</sup> St., 2<sup>nd</sup> Floor  
Denver, CO 80203

## **Connecticut**

Commission on Aging  
25 Sigourney St., 8<sup>th</sup> Floor  
Hartford, CT 06106-5003

## **Delaware**

Division of Aging and Physically  
Handicapped  
Health and Social Services Department  
1901 N. DuPont Hwy.  
New Castle, DE 19720

## **District of Columbia**

Office on Aging  
441 4<sup>th</sup> St. NW  
Washington, DC 20001

## **Florida**

Department of Elder Affairs  
Bldg. E, Rm. 317  
1317 Winewood Blvd.\  
Tallahassee, FL 32399-0700

## **Georgia**

Division of Aging Services  
Department of Human Resources  
2 Peachtree St., NW, Room 36-385  
Atlanta, GA 30303

## **Hawaii**

Executive Office on Aging  
Office of the Governor  
250 S. Hotel St., Ste. 107  
Honolulu, HI 96813-2831

## **Idaho**

Office on Aging  
Statehouse Room 108  
700 W. Jefferson  
Boise, ID 83720

**Illinois**

Department on Aging  
421 E. Capitol  
Springfield, IL 62701

**Indiana**

Division of Aging and Rehabilitation  
Family and Social Services Administration  
402 W. Washington Room W451  
Indianapolis, IN 46204

**Iowa**

Department of Elder Affairs  
200 10<sup>th</sup> St.  
Des Moines, IA 50309-3609

**Kansas**

Department of Aging  
Docking State Office Building  
Room 150-S  
300 SW 10<sup>th</sup> St.  
Topeka, KS 66612-1500

**Kentucky**

Division of Aging Services  
Department for Social Services  
275 E Main St. 5W  
Frankfort, KY 40621

**Louisiana**

Office of Elderly Affairs  
PO Box 80374  
Baton Rouge, LA 70898

**Maine**

Bureau of Elderly and Adult Services  
Department of Human Services  
11 State House Station  
Augusta, ME 04333

**Maryland**

Office on Aging  
301 W. Preston St, Room 1007  
Baltimore, MD 21201

**Massachusetts**

Executive Office of Elder Affairs  
1 Ashburton Pl., 5<sup>th</sup> Floor, Room 517  
Boston, MA 02108

**Michigan**

Office of Service to the Aging  
Department of Community Health  
611 W. Ottawa St  
Lansing, MI 48909

**Minnesota**

Board of Aging  
Human Services Building, 4<sup>th</sup> Floor  
444 Lafayette Rd.  
St. Paul, MN 55155

**Mississippi**

Council on Aging  
Department of Human Services  
PO Box 352  
Jackson, MS 39205-0352

**Missouri**

Division of Aging  
Department of Social Services  
615 Howerton Ct.  
PO Box 1337  
Jefferson City, MO 65102

**Montana**

Aging Services Bureau  
Department of Public Health and Human  
Services  
111 Sanders St., Room 210  
Helena, MT 59620

**Nebraska**

Department of Health and Human Services  
PO Box 95044  
Lincoln, NE 68509-5044

**Nevada**

Division for Aging Services  
340 N. 11<sup>th</sup> St., Ste. 203  
Las Vegas, NV 89101

**New Hampshire**

Division of Elderly and Adult Services  
Department of Health and Human Services  
Annex Bldg. #1 – 115 Pleasant St.  
Concord, NH 03301-3843

**New Jersey**

Division of Senior Affairs  
Department of Community Affairs  
101 S. Broad St.  
PO Box 807  
Trenton, NJ 08625-0807

**New Mexico**

State Agency on Aging  
228 E. Palace Ave.  
Santa Fe, NM 87501

**New York**

Office of the Aging  
Agency Building 2, 5<sup>th</sup> Floor  
Empire State Plaza  
Albany, NY 12223-0001

**North Carolina**

Aging Division  
Department of Health and Human Services  
101 Blair Dr.  
Raleigh, NC 27603

**North Dakota**

Aging Services Division  
Department of Human Services  
600 S. 2<sup>nd</sup> St., Ste., 1C  
Bismarck, ND 58504-5729

**Ohio**

Commission on Aging  
Department of Aging  
50 W. Broad St., 9<sup>th</sup> Floor  
Columbus, OH 43266

**Oklahoma**

Health and Human Services  
Department of Human Services  
PO Box 25352  
Oklahoma City, OK 73125-0352

**Oregon**

Senior and Disabled Services Division  
Department of Human Resources  
500 Summer St., NE, 2<sup>nd</sup> Floor  
Salem, OR 97310-1015

**Pennsylvania**

Department of Aging  
Rachel Carson State Office Building  
400 Market St. 6<sup>th</sup> Floor  
Harrisburg, PA 17101-2301

**Rhode Island**

Department of Elderly Affairs  
160 Pine St.  
Providence, RI 02903

**South Carolina**

Division on Aging  
202 Arbor Lake Dr.  
Columbia, SC 29223

**South Dakota**

Division of Adult Services and Aging  
Department of Social Services  
Kneip Building  
700 Governors Dr.  
Pierre, SD 57501

**Tennessee**

Commission on Aging  
Andrew Jackson Building, 9<sup>th</sup> Floor  
500 Deaderick St  
Nashville, TN 37243

**Texas**

Department on Aging  
PO Box 12786  
Austin TX 78711

**Utah**

Division of Aging and Adult Services  
Department of Human Services  
120 N. 200 W. Rm. 401  
Salt Lake City, UT 84103

**Vermont**

Agency of Human Services  
Department of Aging and Disabilities  
103 S. Main St  
Waterbury, VT 05671

**Virginia**

Department for the Aging  
Preston Building, Ste. 102  
1600 Forest St.  
Richmond, VA 23229

**Washington**

Aging and Adult Services Administration  
Department of Social and Health Services  
PO Box 45050  
Olympia, WA 98504

**West Virginia**

Bureau of Senior Services  
Holly Grove  
1710 Kanawha Blvd. E.  
Charleston, WV 25311

**Wisconsin**

Bureau on Aging  
Department of Health and Social Services  
217 S. Hamilton, Ste., 300  
PO Box 7851  
Madison, WI 53707

**Wyoming**

Division on Aging  
Department of Health  
139 Hathaway Bldg.  
2300 Capitol Ave.  
Cheyenne, WY 82002

## APPENDIX B: State Medicaid Agencies

### **Alabama**

Medicaid Agency  
PO Box 5624  
Montgomery, AL 36103-5624

### **Alaska**

Division of Medical Assistance  
PO Box 1110660  
Juneau, AK 998811-0660

### **Arizona**

Health Care Cost Containment System  
801 E. Jefferson  
Phoenix, AZ 85034

### **Arkansas**

Division of Medical Services  
Department of Human Services  
PO Box 1437, Slot 316  
Little Rock, AR 72203

### **California**

Medi-Cal Operations Div.  
Department of Health Services  
PO Box 942732  
Sacramento, CA 95814

### **Colorado**

Office of Medical Assistance  
Health Care Policy and Finance  
1575 Sherman 4<sup>th</sup> Floor  
Denver, CO 80203

### **Connecticut**

Health Care Financing  
Department of Social Services  
25 Sigourney St. 8<sup>th</sup> Floor  
Hartford, CT 06106-5003

### **Delaware**

Division of Social Services  
Medicaid Unit  
DHSS Main Campus  
1901 N. DuPont Hwy.  
New Castle, DE 19720

### **District of Columbia**

Health Care Finance  
Department of Human Services  
2100 M. L. King Jr. Ave., SE  
Washington, DC 20020-5732

### **Florida**

Bureau of Medicaid  
Agency for Health Care Administration  
2727 Mahan Dr.  
Tallahassee, FL 32308

### **Georgia**

Department of Medical Assistance  
2 Peachtree St., Ste. 4043  
Atlanta, GA 30303

### **Hawaii**

Department of Human Services  
1390 Miller St  
Honolulu, HI 96813

### **Idaho**

Idaho Health and Welfare  
Department of Medicaid  
3380 Americana Terrace, Ste. 230  
PO Box 83720  
Boise, ID 83720-0036

### **Illinois**

Department of Public Aid  
201 S. Grand Ave., E.  
Springfield, IL 62762

**Indiana**

Medicaid Policy and Planning  
Family and Social Services Administration  
IGC-S, Room W382  
Indianapolis, IN 46204

**Iowa**

Medical Services Division  
Department of Human Services  
Hover State Office Building  
1300 E. Walnut  
Des Moines, IA 50319

**Kansas**

Adult and Medical Services  
Social and Rehab. Services  
Docking Office Building, Room 628-S  
915 Harrison  
Topeka, KS 66612-1570

**Kentucky**

Health Services Cabinet  
275 E. Main St.  
Frankfort, KY 40621

**Louisiana**

Bureau of Health Services Financing  
Department of Health and Hospitals  
PO Box 91030  
Baton Rouge, LA 70821

**Maine**

Bureau of Medical Services  
Department of Human Services  
11 State House Station  
Augusta, ME 04333

**Maryland**

Medical Care Finance and Compliance  
Admin.  
Department of Health and Mental Hygiene  
201 W. Preston St., 2<sup>nd</sup> Floor  
Baltimore, MD 21201

**Massachusetts**

Executive Office of Health and Human  
Services  
Department of Transitional Assistance  
600 Washington St., 6<sup>th</sup> Floor  
Boston, MA 02111

**Michigan**

Medical Services Administration  
Department of Community Health  
PO Box 30037  
Lansing, MI 48909

**Minnesota**

Health Care  
Department of Human Services  
444 Lafayette Rd.  
St. Paul, MN 55155-3852

**Mississippi**

Division of Medicaid  
Office of the Governor  
239 N. Lamar St., Ste. 801  
Jackson, MS 39215-1399

**Missouri**

Division of Medical Services  
Department of Social Services  
615 Howerton Ct.  
PO Box 6500  
Jefferson City, MO 65102-6500

**Montana**

Health Policy and Services Division  
Department of Public Health and Human  
Services  
1400 Broadway, Room A206  
Helena, MT 59620

**Nebraska**

Department of Health and Human Services  
Finance and Support  
PO Box 95026  
Lincoln, NE 68509

**Nevada**

Medicaid Division  
Department of Human Resources  
2527 N. Carson St.  
Carson City, NV 89701

**New Hampshire**

Office of Health Management  
Health and Human Services  
6 Hazen Dr.  
Concord, NH 03301-6527

**New Jersey**

Department of Human Services  
222 S. Warren St.  
PO Box 700  
Trenton, NJ 08624-0700

**New Mexico**

Medical Assistance Division  
Department of Human Services  
PO Box 2348  
Santa Fe, NM 87503

**New York**

Office of Temporary and Disability  
Assistance  
40 N. Pearl St., 16<sup>th</sup> Floor  
Albany, NY 12243

**North Carolina**

Division of Medical Assistance  
Department of Human Resources  
1985 Umstead Dr.  
Raleigh, NC 27603-2001

**North Dakota**

Medical Services Division  
Department of Human Services  
600 E. Blvd. Ave.,  
3<sup>rd</sup> Floor Judicial Wing  
Bismarck, ND 58505-0250

**Ohio**

Office of Medicaid  
Department of Human Services  
30 E. Broad St., 31<sup>st</sup> Floor  
Columbus, OH 43215

**Oklahoma**

Health and Human Services  
Department of Human Services  
PO Box 25352  
Oklahoma City, OK 73125-0352

**Oregon**

Office of Medical Assistance Program  
Department of Human Resources  
500 Summer St., NE  
Salem, OR 97310-1014

**Pennsylvania**

Medical Assistance  
Department of Public Welfare  
PO Box 2675  
Harrisburg, PA 17105-2675

**Rhode Island**

Medical Services  
Department of Mental Health and  
Rehabilitation  
600 New London Ave.  
Cranston, RI 02920

**South Carolina**

Department of Health and Human Services  
PO Box 8206  
Columbia, SC 29202

**South Dakota**

Division of Medical Services  
Department of Social Services  
700 Governors Dr.  
Pierre, SD 57501

**Tennessee**

Department of Human Services  
Medicaid Division  
Citizen's Plaza Building 12<sup>th</sup> Floor  
400 Deaderick St.  
Nashville, TN 37248-7350

**Texas**

State Medicaid Director  
Health and Human Services Commission  
PO Box 13247  
Austin, TX 78711

**Utah**

Medicare/Medicaid Program  
Certification and Resident Assessment  
Health Department  
288 N. 1460 W.  
Salt Lake City, UT 84116

**Vermont**

Medicaid Services Division  
Department of Social Welfare  
103 S. Main St.  
Waterbury, VT 05671-1201

**Virginia**

Department of Medical Assistance  
Services  
600 E. Broad St., Ste. 1300  
Richmond, VA 23219

**Washington**

Division of Medical Assistance  
Department of Social and Health Services  
PO Box 45080  
Olympia, WA 98504-5080

**West Virginia**

Department of Health and Human  
Resources  
Capitol Complex – Bldg. 3, Room 206  
1900 Kanawha Blvd. E.  
Charleston, WV 25305

**Wisconsin**

Department of Health and Family Services  
1 W. Wilson St., Room 218  
PO Box 309  
Madison, WI 53701-0309

**Wyoming**

Health Care Financing  
Department of Health  
6101 Yellowstone Rd.  
Cheyenne, WY 82002

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