Introduction

Many of us have been affected by a loved one’s diagnosis with Alzheimer’s disease. When this happens, what do you do? How do you help your loved one face the progression of the disease? How do you provide the necessary care and protection?

Alzheimer’s disease is not fully understood by the medical community, yet it affects more than 5 million Americans. What we do know is that Alzheimer’s can be elusive and is always progressive in its symptoms. The disease may affect your loved one gradually and will eventually rob him of the ability to care for himself.

Because Alzheimer’s disease is unpredictable, it is crucial to plan in advance and before your loved one becomes incapacitated. The support you offer now will help him to plan for his own future and to participate in the decisions that will affect his life and the lives of family members.

Planning for the future should start with the retention of an experienced Elder Law attorney who will assist you by preparing and executing all of the necessary documents such as a Durable Power of Attorney, Advance Health Care Directives, a Trust, and a Will. These documents protect your loved one and include him in decisions regarding his care.

Lastly, it is important to be educated about the options available for the long term care of your loved one. There are many care facilities from which to choose. It is very important to understand the differences in care these facilities provide as well as the payment options available to cover the cost of care.

An Elder Law attorney will help to enlighten you on these matters and will insure that your loved one’s future is secure. Once this is done, your family will be at ease and will be able to spend time caring for your loved one.
About Alzheimer’s Disease

Alzheimer’s disease is a degenerative and terminal disease of the brain. It is the most common form of dementia. This debilitating disease generally affects people over the age of 65, but occasionally there are earlier onsets.

Today, more than 5 million individuals are battling the consequences of Alzheimer’s. Alzheimer’s disease is the 6th leading cause of death in the United States.

Alzheimer’s is the result of damage and death of brain cells. Nerve cells are damaged because of abnormal structures called plaques and tangles. Plaques are protein buildup between nerve cells. Tangles, on the other hand, form inside the nerve cells. These plaques and tangles materialize in abnormally high quantities and affect the parts of the brain that are responsible for learning and memory.

In its early stages, the effects of the disease can be confused with age-related symptoms such as memory loss. Individuals in the early stages of Alzheimer’s may need minimal assistance, if any, to function in their day to day life.

As the disease advances, the symptoms increase in severity. The individual affected may become confused, disoriented, exhibit mood swings, experience language breakdown, long-term memory loss, and may seem withdrawn. Individuals with Alzheimer’s in its later stage are no longer able to care for themselves and, as time goes on, need assistance 24/7.

Unfortunately, there is no cure for this disease. Although research is constantly underway, there is still a great deal that we do not know about the brain. The most important thing we can do is to support our loved one, plan for the future and make his life as comfortable as possible.
It's Critical To Plan

Because Alzheimer’s may strike at any time and the symptoms may suddenly become more severe, it is important to assist your loved one in his life and estate planning before he becomes incapacitated.

Discuss all of the care options with your loved one. Once his wishes are known, it is time to retain an experienced Elder Law firm to execute the necessary documents which will insure that he is protected should the time come when he is unable to advocate for himself.

For example, only when your loved one has capacity may he create and execute a Power of Attorney. This document enables him to appoint a trusted individual to manage his finances should he become incapacitated.

Furthermore, creating a Health Care Power of Attorney allows your loved one to put someone he trusts in charge of his medical decisions should he become unable to do so. These documents will provide protection for your loved one and turn over legal authority to manage his care and finances should that time come.

What Documents Should be Prepared?

If your loved one has been diagnosed with Alzheimer’s, it is critical to make sure that his general estate planning is prepared and prepared correctly.

**WILL**

A Will is a legally-binding statement directing who will receive your property at the time of your death. It also appoints a legal representative to carry out all of your wishes.

A Will covers only probate property. Many types of property or forms of ownership pass outside of probate. Jointly-owned property, property in trust, life insurance proceeds and property with a named beneficiary, such as IRAs or 401(k) plans, all pass outside of probate.
Why should you have a Will?
Here are some reasons:

- Your Will directs where and to whom your estate (what you own) will go after your death. If you die intestate (without a Will), your estate will be distributed according to your state’s law. Such distribution may not be in accordance with your wishes.

  Many people try to avoid probate and the need for a Will by holding their property jointly with their children. This can work, but often people spend unnecessary effort trying to make sure all the joint accounts remain equally distributed among their children. These efforts can be defeated by a long-term illness of the parent or the death of a child. A Will is a much simpler means of protecting one’s wishes regarding the distribution of assets.

- Another reason to have a Will is to insure that the administration of your estate will be a smooth process. Often the probate process can be completed more quickly and at less expense to your estate if there is a Will. With a clear expression of your wishes, there are unlikely to be any costly, time-consuming disputes over who gets what.

- In addition, a Will allows you to choose the person you wish to administer your estate and distribute it according to your instructions. This person is called your “executor” or “personal representative”, depending on your state’s statute. If you do not have a will naming a person of your choice, a family member will have to petition the court to be appointed as the Administrator of your estate.

- For larger estates, a well-drafted Will can help reduce estate taxes.

- A Will allows you to appoint the person who will take your place as guardian of your minor children should you and their other parent pass away.
**TRUST**

A trust is a legal arrangement through which one person (or an institution, such as a bank or law firm), called a “Trustee”, holds legal title to property for another person called a “beneficiary”. The rules or instructions under which the trustee operates are set forth in the trust instrument. Trusts have one set of beneficiaries during the life of the grantor and a second set — often grantor’s children — who begin to benefit only after the first group has died. The first are often called “life beneficiaries” and the second “remaindermen”.

**USES OF TRUSTS**

There can be several advantages to establishing a trust, depending on your situation. One primary advantage is to avoid probate. In a trust that terminates with the death of the donor, any property in the trust prior to the donor’s death passes immediately to the beneficiaries by the terms of the trust without requiring probate. This can save time and money for the beneficiaries.

Certain trusts can also result in tax advantages both for the donor and the beneficiary. These are often referred to as “credit shelter” or “life insurance” trusts. Other trusts may be used to protect property from creditors or to help the donor qualify for Medicaid. Unlike Wills, trusts are private documents and usually only those individuals with a direct interest in the trust need to know of trust assets and distribution. Provided they are well-drafted, another advantage of a trust is that it is effective even if the donor dies or becomes incapacitated.

**KINDS OF TRUSTS**

Trusts fall into two basic categories: testamentary or inter vivos.

A testamentary trust is one created by your Will, and it does not come into existence until you die. In contrast, an inter vivos trust applies during your lifetime.

There are two kinds of inter vivos trusts: revocable and irrevocable.

- **Revocable Trusts**

Revocable trusts are often referred to as “living” trusts. With a revocable trust, the donor maintains complete control over the trust and may amend, revoke or terminate the trust at any time. This means that you, the donor, can take back the funds you put in the trust or change the trust’s terms. Thus, the donor is able to reap the benefits of the trust arrangement while maintaining the ability to change the trust at any time prior to death.
Revocable trusts are generally used for the following purposes:

1. **Asset management.** They permit the named trustee to administer and invest the trust property for the benefit of one or more beneficiaries.

2. **Probate avoidance.** At the death of the person who created the trust, the “grantor” or “donor”, the trust property passes to whomever is named in the trust. It does not come under the supervision of the probate court and its distribution need not be held up by the probate process. However, the property of a revocable trust will be included in the grantor’s estate for tax purposes.

3. **Tax planning.** While the assets of a revocable trust will be included in the grantor’s taxable estate, the trust can be drafted so that the assets will not be included in the estates of the beneficiaries, thus avoiding taxes when the beneficiaries die.

**IRREVOCABLE TRUSTS**

An irrevocable trust cannot be changed or amended by the donor. Any property placed into the trust may only be distributed by the trustee as provided for in the trust document itself. For instance, the donor may set up a trust under which he or she will receive income earned on the trust property, but that bars access to the trust principal. This type of irrevocable trust is a popular tool for Medicaid planning.

**TESTAMENTARY TRUSTS**

As noted above, a testamentary trust is a trust created by a Will. Such a trust has no power or effect until the Will of the donor is probated. Although a testamentary trust will not avoid the need for probate and will become a public document as it is a part of the Will, it can be useful in accomplishing other estate planning goals. For instance, the testamentary trust can be used to reduce estate taxes on the death of a spouse or provide for the care of a disabled child.

**SUPPLEMENTAL NEEDS TRUST**

The purpose of a supplemental needs trust is to enable the donor to provide for the continuing care of a disabled spouse, child, relative or friend. The beneficiary of a well-drafted supplemental needs trust will have access to the trust assets for purposes other than those provided by public benefits programs. In this way, the beneficiary will not lose eligibility for benefits such as Supplemental Security Income and low-income housing. A supplemental needs trust can be created by the donor during life or be a part of a Will.
CREDIT SHELTER TRUSTS
Credit shelter trusts are a way to take full advantage of the estate tax exemption. The first $2 million (in 2008) of an estate are exempt from taxes, so theoretically a husband and wife would have no federal estate tax if their estate is less that $4 million. However, if one spouse dies and leaves everything to the surviving spouse, the surviving spouse may have an estate that is greater that $2 million. When the surviving spouse dies, any part of the estate over $2 million will be subject to estate tax. (It is important to note that your state may have different estate tax exemption amounts).

To avoid this problem, the spouses can create a credit shelter trust as part of their estate plan. When the first spouse passes away, the first $2 million of that spouse’s estate is put into a trust. The surviving spouse can receive income from the trust, but as long as he or she does not control the principal, the money will not be included in the surviving spouse’s estate when he or she passes away.

POWER OF ATTORNEY (POA)
For most people, the Durable Power of Attorney (POA) is the most important estate planning instrument available — even more useful than a Will. A POA allows a person you appoint—your “attorney-in-fact” - to act in your place for financial purposes when and if you ever become incapacitated.

In that case, the person you choose will be able to step in and take care of your financial affairs. Without a Durable POA, no one can represent you unless a court appoints a conservator or guardian. That court process takes time, costs money, and the judge may not choose the person you would prefer. In addition, under a guardianship or conservatorship, your representative may have to seek court permission to initiate planning measures that he/she could implement immediately under a simple Durable POA.

A POA may be limited or general. A limited POA gives someone the right to sign a deed to property on a day when you are out of town. Or it may allow someone to sign checks for you. A general power is comprehensive and gives your attorney-in-fact all the powers and rights that you have yourself.

A Power of Attorney may also be either current or “springing”. Most POAs take effect immediately upon their execution, even if the understanding is that they will not be used until and unless the grantor becomes incapacitated. However, the document can also be written so that it does not become effective until such incapacity occurs. In such cases, it is very important that the standard for determining incapacity and triggering the POA be clearly stated in the document itself.
Any complete estate plan should include a medical directive. This term may encompass a number of different documents, including a Health Care Proxy, a Durable Power of Attorney for health care, a living Will, and medical instructions. The exact documents will depend on your state’s laws and the choices you make.

Both a Health Care Proxy and a Durable Power of Attorney for health care designate someone you choose to make health care decisions for you if you are unable to do so yourself. A Living Will instructs your health care provider to withdraw life support if you are terminally ill or in a vegetative state. A broader medical directive may include the terms of a Living Will, but will also provide instructions if you are in a less severe state of health, but are still unable to direct your health care yourself.

As Alzheimer’s progresses it is likely that the time will come when you can no longer provide the necessary care for your loved one and he will need round the clock care.

Deciding that your loved one must be placed into a nursing facility is a difficult one for families and it is certainly to your advantage to be educated in advance about facilities in your area. Here are some rules of thumb:

**Location, location, location!** No single factor is more important to quality of care and quality of life of a nursing home resident than visits by family members. The quality of care is often better if the facility staff knows that someone who cares is watching and involved. Visits can be the high point of the day or week for the nursing home resident. So, make it as easy as possible for family members and friends to visit.

*Get references.* Ask the facility to provide the names of family members of residents so you can ask them about the care provided in the facility and the staff’s responsiveness when the resident or relatives raise concerns.

*Check certifying agency reports.* The website www.health.state.ny.us and www.medicare.gov will help you to find your local NYS nursing homes and the services they provide.
Talk to the nursing home administrator or nursing staff about how care plans are developed for residents and how they respond to concerns expressed by family members. Make sure you are comfortable with the response. It is better that you meet with and ask questions of the people responsible for care and not just the person marketing the facility.

Tour the nursing home. Try not to be impressed by a fancy lobby or depressed by an older, more rundown facility. What matters most is the quality of care and the interactions between staff and residents. Get a feel for how well residents are attended to and whether they are treated with respect. Also, investigate the quality of the food service. Eating is both a necessity and a pleasure that continues even when we’re unable to enjoy much else. It is also advisable to try and get a tour of the facility that is not prearranged. While this is not always possible, it does give you the opportunity of seeing an unrehearsed atmosphere.

All these tips can help you in finding a care facility which works well for your love one. It is possible to find a care facility which is clean, caring, and that provides an environment where your love one won’t feel alone, will be understood, and will be taken care of.

PAYING FOR A NURSING HOME

One of the greatest fears of older Americans is that they may end up in a nursing home. Not only does this represent a great loss of personal autonomy, but also a tremendous financial price. Depending on location and level of care, nursing homes cost between $35,000 and $150,000 a year.

Most people end up paying for nursing home care out of their life savings until they run out. Then they can qualify for Medicaid to pick up the cost. The advantages of paying privately are that you are more likely to gain entrance to a better quality facility and doing so eliminates or postpones dealing with your state’s welfare bureaucracy — an often demeaning and time-consuming process. The disadvantage is that it’s expensive.

Careful planning, whether in advance or in response to an unanticipated need for care, can help protect your estate, whether for your spouse or for you children. This can be done by purchasing long-term care insurance or by making sure you receive the benefits to which you are entitled under the Medicare and Medicaid programs. Veterans may also seek benefits from the Veterans Administration.
**MEDICARE:**

Medicare Part A covers up to 100 days of “skilled nursing” care per spell of illness. However, the definition of “skilled nursing” and other conditions for obtaining this coverage are quite stringent, meaning that few nursing home residents receive the full 100 days of coverage. As a result, Medicare pays for only about 9 percent of nursing home care in the United States.

**MEDICAID:**

For all practical purposes, in the United States, the only “insurance” plan for long-term institutional care is Medicaid. Lacking access to alternatives such as long-term care insurance coverage, most people pay out of their own pockets for long-term care until they become eligible for Medicaid. Although their names are alike, Medicaid and Medicare are quite different programs. For one thing, all retirees who receive Social Security benefits also receive Medicare as their health insurance. Medicare is an “entitlement” program. Medicaid, on the other hand, is a form of welfare — or at least that’s how it began. So to be eligible for Medicaid, you must become “impoverished” under the program’s guidelines.

Also, unlike Medicare, which is a federal program, Medicaid is a joint federal –state program. Each state operates its own Medicaid system, but this system must conform to federal guidelines in order for the state to receive federal money, which pays for about half of the state’s Medicaid costs.

Those who are not in immediate need of long-term care may have the luxury of distributing or protecting their assets in advance. This way, when they do need long-term care, they will quickly qualify for Medicaid benefits. Giving general rules for so-called “Medicaid” planning is difficult because every client’s case is different. Some have more savings or income than others. Some are married, others are single. Some have family support, others do not. Some own their own homes, some rent. Still a number of basic strategies and tools are typically used in Medicaid planning.
We hope this information has been helpful to you. If you have questions about any aspect of your estate planning, please call us—we have an office near you!