

BE AN UNCOMMON LEADER

# DEALING with DEMENTIA

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# DEMENTIA

#### What is dementia?

Dementia is a neurological disorder characterized by poor memory, mental disorientation, and impaired judgment. Having dementia may affect a wide range of cognitive abilities including language comprehension, attention span, memory, reasoning skills, learning capability, and even personality traits. Dementia is not a specific disease; instead it is a collection of symptoms that can have several possible causes. The leading cause of dementia is Alzheimer's disease, but there are many others including strokes, Parkinson's disease, head trauma, multiple sclerosis, and HIV/AIDS. Some types of dementia are reversible, while others are treatable but cannot be cured.

Dementia is not a normal consequence of aging, although it does become much more common as people get older. While everyone experiences memory lapses or a mild slowing of cognitive abilities as they age, dementia is a pathological condition that impairs thinking to the point of disability. Researchers estimate that 4.5 million Americans have dementia caused by Alzheimer's disease and many others have dementia due to other causes. Researchers estimate that as many as 30% to 50% of those aged 85 and older may have dementia.

Dementia can also be purely psychological in origin when caused by a mental disorder. This article focuses on the more common type of dementia that is sometimes called organic dementia because it has a biological origin instead of a psychological one.

### What are some common signs of dementia?

Dementia causes many problems for the person who has it and for the person's family. Many of the problems are caused by memory loss. Some common signs of dementia are listed below. Not everyone who has dementia will have all of these signs.

• **Recent memory loss.** All of us forget things for a while and then remember them later. People with dementia often forget things, but they never remember them. They might ask you the same question over and over, each time forgetting that you've already given them the answer. They won't even remember that they already asked the question.

- **Difficulty performing familiar tasks.** People who have dementia might cook a meal, but forget to serve it. They might even forget that they cooked it.
- **Problems with language.** People who have dementia may forget simple words or use the wrong words. This makes it hard to understand what they want.
- **Time and place disorientation.** People who have dementia may get lost on their own street. They may forget how they got to a certain place and how to get back home.
- **Poor judgment.** Even a person who doesn't have dementia might get distracted. But people who have dementia can forget simple things, like forgetting to put on a coat before going out in cold weather.
- **Problems with abstract thinking.** Anybody might have trouble balancing a checkbook, but people who have dementia may forget what the numbers are and what has to be done with them.
- **Misplacing things.** People who have dementia may put things in the wrong places. They might put an iron in the freezer or a wristwatch in the sugar bowl. Then they can't find these things later.
- **Changes in mood.** Everyone is moody at times, but people with dementia may have fast mood swings, going from calm to tears to anger in a few minutes.
- **Personality changes.** People who have dementia may have drastic changes in personality. They might become irritable, suspicious or fearful.
- **Loss of initiative.** People who have dementia may become passive. They might not want to go places or see other people.

# **GUARDIANSHIP**

#### What is a guardianship?

A guardianship is a court-supervised administrator designated for an incapacitated person. There are two types of guardianships: 1) of the person; and 2) of the estate. Legally speaking, the incapacitated person is often referred to as the "ward." A guardian of the person is in charge of the ward's care and custody. A guardian of the estate is also in charge of the ward's property and finances, if there is any money or property in the ward's name.

Because a guardianship is a court-supervised proceeding, there are specific rules regarding all areas of guardianship, and it is highly encouraged that you *speak with a lawyer* about the requirements and specifications of appointing a guardian for your child or yourself should you become incapacitated.

# What does a guardian do?

In general, a guardian has wide authority over the care, control and protection of the ward, but that right of control is not unlimited under the law. The guardian's duties may be restricted by a court.

The guardian is entitled to establish the ward's domicile, to care for, control and protect the ward, to provide the ward with clothing, food, medical care and shelter, and to consent to medical, psychiatric and surgical treatment on behalf of the ward.

# How do I create a guardianship in case I become incapacitated?

- If you appoint an eligible guardian by a written declaration, the written declaration MUST be signed by you. Also, the declaration should be dated. If the declaration is handwritten, then it must be entirely in your handwriting. A declaration that is not written wholly in your handwriting may be signed by another person for you under your direction and in your presence; or
- If the declaration is not handwritten, then you will need to have it witnessed in your presence by at least 2 credible witnesses 14 years of age or older who are not named as a guardian or alternate guardian.

- The declaration and any self-proving affidavit may be filed with the court at any time after the application for appointment of a guardian is filed and before a guardian is appointed.
- If the designated guardian does not qualify, is dead, refuses to serve, resigns, dies after being appointed guardian, or is otherwise unavailable to serve as guardian, the court shall appoint the next eligible designated alternate guardian named in the declaration. If the guardian and all alternate guardians do not qualify, the court shall appoint another person to serve.

**Note:** When creating a declaration of guardianship for yourself, you can designate the people that you do NOT want to become your guardian. These designated people will be disqualified from being your guardian in the event that your pre-selected guardian is unable to serve as your guardian.

# ESTATE PLANNING

#### What is a will?

A last will and testament, or a "will," is a legal document which if executed properly, allows the testator (person signing the will) to direct how his or her property will be distributed at death. In the will, the testator names an executor who gathers all of the property, pays the debts of the testator, and then distributes the property according to the testator's wishes.

Formal wills include language that allows an executor to act "free of court" while handling the estate business, which makes the probate process much easier on everyone involved. Further, different types of trusts can be set up in a will, which allows property to be held by one party (the trustee) for the benefit of another party (the beneficiary). It is recommended to always name alternates to each position (executor, guardian, trustee) in the event that the primary agent has died before the testator, cannot serve, or is unwilling to serve.

Most individuals leave "all of their estate, of whatsoever kind and wheresoever situated" to the person(s) named in their will. Also, a "specific gift," where a particular item is given to a person, can be described in a will. Specific gifts are carried out before any other provision in the will. For instance, a father may leave his prize, antique rifle to his son and then leave all of the rest of his property to his wife, if he wants to ensure that the rifle ends up in his son's possession instead of possibly being sold or given away.

#### What happens if I die without a will?

If a person dies without a will, their property is disposed of according to state law, or what is called the "laws of intestate succession" and the decedent's "heirs at law" inherit the property (dying "intestate" means dying without a will). The details of these laws are beyond the scope of this Guide, but they are very specific and the heirs have no choice but to follow the legislature's inheritance guidelines in the absence of a will to indicate otherwise. In some situations a person's will may leave his property to the same people that would also be his heirs at law should he die intestate. However, it is very common that a person's heirs at law are in fact not the same people that the testator would want to end up with his property, and the only way to avoid this problem is to execute a will.

Dying without a will can also cause many delays and end up costing much more than a standard probate. Instead of having an executor that can act free of court, an administration may have to be opened in court wherein a judge must approve every action taken on behalf of the estate by the administrator.

#### What is involved in a probate?

Probating a will simply means "proving" a will in court so that the testator's wishes can then be carried out by the executor. Before a judge will allow a will to be approved for probate, it must be established that the will meets the requirements of execution described above. Once approved by the court, the executor can begin gathering assets and passing the title from the testator to the beneficiaries. If the will is not proved in court, then the decedent's property passes to his heirs at law, as if he died without a will.

Many people are under the impression that the probate process is costly and time consuming. This might be true for large estates or in situations where a will contest is filed, but most probates can be finalized quickly and efficiently. Many courts have established methods of proving the will without even having to appear before a judge.

# DISABILITY PLANNING DOCUMENTS

#### **Power of Attorney**

<u>Powers of Attorney</u> are an essential part of any estate plan and can enable a person (principal) to designate an agent (and alternate agent) to make business and health care decisions on their behalf. All adults, no matter what age, should have the proper powers of attorney in place in order to prepare for any type of situation wherein a person may become disabled yet still needs to conduct important business. A common misconception is that powers of attorney stay in effect after the principal's death. This is not true. A correctly executed power of attorney is only effective while the principal is alive. Upon death, the executor named in the person's will takes over control of the estate.

A statutory durable power of attorney, sometimes called a general power of attorney or a business power of attorney, allows the agent to make most business decisions on the principal's behalf and sign the principal's name on most documents. Obviously, your agent needs to be someone who you highly regard and trust because that person will be able to act on your behalf in almost any situation. However, a general power of attorney is extremely useful in the event that the principal becomes disabled and cannot make decisions for himself. If disability occurs and no power of attorney is in place, then a guardianship will have to be opened in court, which is very costly and time consuming. As a matter of convenience, a general power of attorney can be drafted so that it is effective upon execution, regardless of whether or not the principal is disabled. Most married couples have their powers of attorney drafted in this manner, so that one spouse can take care of family business if the other spouse is out of town, for example. If so desired, the power of attorney can be drafted, so that it is only effective if and when the principal is declared to be in a state where he is unable to handle his personal affairs. A general power of attorney does not need to be witnessed but it must be signed in the presence of a notary and should be recorded with the County Clerk in the county of the principal's residence.

<u>A medical power of attorney</u> is a document which allows the principal to designate someone to make health care decisions on their behalf only if they cannot make the decision themselves. This is the key difference between the general power of attorney and the medical power of attorney (i.e., the medical power of attorney cannot be drafted so that it is effective immediately – the only time the agent can act is if the principal is unable to communicate with the physician). Further, this document only authorizes the agent to make health care decisions – no business activity can be conducted under a medical power of attorney.

# Directive to Physicians

<u>A directive to physicians</u>, commonly referred to as a "living will" or an "advanced directive," is a document that that allows a competent adult to instruct his or her physician to withhold or withdraw life sustaining treatment in the event of a terminal or irreversible condition. Directives are best used and the most effective after fully informing your wishes to family members, who might contest the withdrawal of these actions.

# LONG TERM CARE OPTIONS

### What is Long Term Care?

Long-term care is different from traditional medical care. Long-term care covers a variety of services including medical and non-medical care to individuals with chronic illnesses or disabilities. Someone with dementia, or a memory or thought problem such as Alzheimer's disease, often needs long-term care.

Long-term care is made up of many different services and may include help with activities of daily living, dressing, bathing, eating, and using the bathroom as well as help with things most people can do for themselves, such as taking medication. Long-term care can be provided in assisted living facilities, nursing homes, in the community, or at home.

# Types of Long-term Care

- <u>Assisted Living Communities</u> Assisted living communities provide help with activities of daily living, such as bathing, dressing, using the bathroom, taking medicine, and getting to appointments. Residents often live in their own room or apartment within a building or group of buildings and have some or all of their meals together. Social and recreational activities are usually provided. Some assisted living facilities have on-site health services.
- <u>Continuing Care Retirement Communities ("CCRC")</u> CCRC's are housing communities that provide different levels of care based on your needs. Residents move from one level of care to another based on their needs, but still stay in the CCRC. In the same community, there may be individual homes or apartments for residents who still live on their own, an assisted living facility for people who need some help with daily care, and a nursing home for those who require higher levels of care.

If you are considering a CCRC, be sure to check its accreditation and the record of its nursing home, because many CCRC contracts require you to use the CCRC nursing home if this level of care is needed. Therefore, many of the questions that you might want to ask about these communities are

the same as those to consider when choosing a nursing home. CCRCs generally charge a large payment (called an entry fee) before you move in and then charge monthly fees.

- 3. <u>Nursing Homes</u> Nursing homes provide a wide range of personal care and health services. A nursing home is a residence that provides a room, meals, nursing and rehabilitative care, medical services, and protective supervision to residents. Nursing home employees also help residents with daily living and recreational activities. Many nursing home residents have physical, emotional, or mental impairments that keep them from living independently. Nursing homes are certified by state and federal government agencies to provide levels of care that range from custodial care to nursing care that can only be delivered by trained professionals.
- 4. <u>Community Facilities</u> Many community organizations offer services and programs to help seniors or persons with disabilities with their personal activities. These services may include adult day care, personal care, chore services, meal programs, senior centers, friendly visitor programs, help with shopping and transportation, and financial management. Some of these services are free, while other community services, such as adult day care, may have a cost.
- 5. <u>Living at Home</u> Living at home remains an option if you do not need medical care, but assistance is needed if you need help with personal activities (such as laundry, bathing, dressing, cooking, and cleaning). Talk to your family and friends if you think you might need this additional help in the home. Your family and friends may be able to help you with these personal activities or can arrange for someone else to assist you. Depending on your needs and family situation, you even might want to have a family member live with you or you may want to live with them.
- 6. <u>Housing for Aging and Disabled Individuals</u> The Federal Government and most states have programs that help pay for housing for older people with low or moderate incomes, less than \$46,000 if single or \$53,000 if married. It is necessary to apply for this type of housing by completing the state or federal application. Usually a Federal or State agency will review

your monthly income and expenses to see if you are eligible for this type of housing. Rent payments are usually a percentage of your income. Some of these housing programs also offer help with meals and other activities like housekeeping, shopping, and doing the laundry.

7. <u>Board and Care Homes</u> — Board and Care Homes, sometimes called a "group home," provide help with activities of daily living such as eating, bathing, and using the bathroom for people who cannot live on their own, but do not need nursing home services. Private long-term care insurance and other types of assistance programs may help pay for this type of living arrangement. Many of these homes do not receive payment from Medicare or Medicaid and are not strictly monitored. The monthly charge is usually a percentage of your income.

# HOSPICE

#### What is Hospice?

Hospice, in the earliest days, was a concept rooted in the centuries-old idea of offering a place of shelter and rest, or "hospitality," to weary and sick travelers on a long journey. In 1967, Dame Cicely Saunders at St. Christopher's Hospice in London first applied the term "hospice" to specialized care for dying patients. Today, hospice care provides humane and compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible.

Hospice is a philosophy of care. The hospice philosophy or viewpoint accepts death as the final stage of life. The goal of hospice is to enable patients to continue an alert, pain-free life and to manage other symptoms so that their last days may be spent with dignity and quality, surrounded by their loved ones. Hospice affirms life and does not hasten or postpone death. Hospice care treats the person rather than the disease; it focuses on quality rather than length of life. Hospice care is family-centered care — it involves the patient and the family in making decisions. Care is provided for the patient and family 24 hours a day, 7 days a week. Hospice care can be given in the patient's home, a hospital, nursing home, or private hospice facility. Most hospice care in the United States is given in the home, with a family member or members serving as the main hands-on caregiver.

Hospice care is meant for the time when you are expected to live 6 months or less. Hospice gives you palliative care, which is treatment to help relieve disease-related symptoms, but not cure the disease; its main purpose is to improve your quality of life. You, your family, and your doctor decide together when hospice care should begin.

#### Hospice care services

There are many things about hospice care that set it apart from other types of health care.

 <u>A team of professionals</u> — In most cases, an interdisciplinary health care team manages hospice care. This means that many interacting disciplines work together to care for the patient. Doctors, nurses, social workers, counselors, home health aides, clergy, therapists, and trained volunteers care for you. Each of these people offers support based on their special areas of expertise. Together, they then give you and your loved ones complete palliative care aimed at relieving symptoms and giving social, emotional, and spiritual support.

- 2. <u>Pain and symptom control</u> The goal of pain and symptom control is to help you be comfortable while allowing you to stay in control of and enjoy your life. This means that side effects are managed to make sure that you are as free of pain and symptoms as possible, yet still alert enough to enjoy the people around you and make important decisions.
- Spiritual care Hospice care also tends to your spiritual needs. Since people differ in their spiritual needs and religious beliefs, spiritual care is set up to meet your specific needs. It may include helping you to look at what death means to you, helping you say good-bye, or helping with a certain religious ceremony or ritual.
- 4. <u>Home care and inpatient care</u> Although hospice care can be centered in the home, you may need to be admitted to a hospital, extended-care facility, or a hospice inpatient facility. The hospice can arrange for inpatient care and will stay involved in your care and with your family. You can go back to in-home care when you and your family are ready.
- 5. <u>Respite care</u> While you are in hospice, your family and caregivers may need some time away. Hospice service may offer them a break through respite care, which is often offered in up to 5-day periods. During this time you will be cared for either in the hospice facility or in beds that are set aside for this in nursing homes or hospitals. Families can plan a mini-vacation, go to special events, or simply get much-needed rest at home while you are cared for in an inpatient setting.
- 6. <u>Bereavement care</u> Bereavement is the time of mourning after a loss. The hospice care team works with surviving loved ones to help them through the grieving process. A trained volunteer, clergy member, or professional counselor provides support to survivors through visits, phone calls, and/or letter contact, as well as through support groups. The hospice team can refer family members and care-giving friends to other medical or professional care if needed. Bereavement services are often provided for about a year after the patient's death.

# MEDICARE AND MEDICAID

Medicare is a U.S. government administered health insurance program. Generally, a person is eligible for Medicare if 1) they are 65 years or older, a U.S. citizen, and they or their spouse has paid Medicare taxes for at least ten years, or 2) they are under 65 years old and disabled. Medicare does not typically pay for all of a covered person's medical costs; usually, the covered person must meet out of pocket expenses in the form of premiums, deductibles and co-pays.

Medicare's coverage for mental or emotional illness, including various forms of dementia, includes both inpatient and outpatient care, treatment by doctors and treatment by Medicare certified healthcare providers. The amount of Medicare coverage depends on the kind of hospital where the individual receives treatment: general hospital, psychiatric hospital, nursing facility or home care. In addition, qualifying persons are eligible to receive therapeutic services and medications through Medicare.

Medicaid is a state administered health insurance program available for low income individuals and families that qualify under an established eligibility group. The State of Texas sets its own guidelines regarding eligibility and services. In Texas, a person may receive Medicaid if 1) they are 65 years or older or has a disability, and 2) meets specific income and resource limits. Resources that are considered can include property, bank accounts, cash value of life insurance, and stocks and bonds. Usually, an eligibility determination does not consider value of a person's home, vehicle, or personal belongings. Medicaid applicants can complete a self screening questionnaire at <u>www.YourTexasBenefits.com</u> in order to find out if their income and resources are within the limits for qualification. Medicaid covers all or a portion of nursing home costs for individuals with mental illness who meet income and asset eligibility guidelines.

# DEALING WITH ADULT PROTECTIVE SERVICES

Adult Protective Services (APS) is a division of the Texas Department of Family and Protective Services. APS is responsible for investigating instances of abuse, neglect and exploitation of elderly citizens and those with disabilities. In addition, APS is charged with providing for the services necessary to prevent further mistreatment of an elderly or disabled individual. An APS caseworker must initiate an investigation within 24 hours following the receipt of a report by the department. The caseworker is responsible for completing an assessment of the alleged victim's situation in order to determine their needs. Services that APS may provide include social and health services, financial assistance, and referrals to other state agencies for additional help.

Under Chapter 48 of the HUMAN RESOURCES CODE (HRC), a protective services client has the right to:

- refuse the offer of protective services (unless the person lacks capacity to consent and is suffering from abuse, neglect, or exploitation that presents a threat to physical safety).
- receive the full extent APS protection possible.
- participate in decisions concerning their welfare, if possible to do so.
- select the least restrictive of the options available for meeting their needs.
- refuse medical treatment if it conflicts with their religious beliefs.
- have a court-appointed attorney ad-litem to represent his or her interests at a proceeding arising pursuant to HRC Chapter 48.

# HELPFUL RESOURCES

Official Medicare website: <u>www.medicare.gov</u> 1 800 MEDICARE (1 800 633 4227)

U.S Department of Health & Human Services, Medicaid: www.cms.hhs.gov/home/medicaid.asp

U.S Department of Health & Human Services, Eldercare Locator: <a href="http://www.eldercare.gov/Eldercare.NET/Public/Home.aspx">www.eldercare.gov/Eldercare.NET/Public/Home.aspx</a>

Texas Medicaid: www.hhsc.state.tx.us/medicaid/index.html

Texas Medicaid and Healthcare Partnership: <u>www.tmhp.com</u>

2 1 1 Texas: www.211texas.org/211/home.do

Texas Department of Aging and Disability Services: <a href="http://www.dads.state.tx.us/services/">www.dads.state.tx.us/services/</a>

Texas Silver Haired Legislature: www.txshl.org

National Institute on Aging: www.nia.nih.gov

Texas Departments of Family and Protective Services: <a href="https://www.dfps.state.tx.us/">www.dfps.state.tx.us/</a>

Prepared as a Public Service by the Texas Young Lawyers Association and Distributed by the State Bar of Texas

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