

Module 9: Legal Issues and Advanced Directives

Purpose: To provide person with dementias and caregivers who are in the earliest stages of dementia information regarding legal issues that must be attended to throughout the disease

Intended use: Person with dementias in all stages of dementia

Introduction

When dementia is first diagnosed, no one wants to hear about the day when the person will not be able to make their own decisions. Yet, decisions and documents must be made well in advance in preparation for that eventuality. Families will occasionally try to avoid drawing up these documents thinking that simply putting a family member's name on a checking account will be enough. It never is. Failing to prepare for the day when a loved one can not make decisions can result in the following (even for the spouse):

- Bills may not be paid.
- Social Security problems will be difficult to resolve.
- Property and income tax may not be paid appropriately or in a timely manner
- Because of Federal privacy laws, the family will be refused access to medical information, including when the person with dementia is hospitalized, has a sudden change in behavior, or has problems with medications.
- The person with dementia may be at increased risk for exploitation because he/she will still be able to sign contracts
- End-of-life decisions and care preferences will not be known and/or implemented
- Banks, financial institutions, insurance companies, etc will refuse to work with the family
- Another relative or total stranger may come in and obtain a power of attorney when the person with dementia does not understand what they are signing.
- Family may become deeply divided by arguing what they feel is the best care for the person with dementia

Many times a husband or wife may think that marriage entitles them to information about their spouse or gives them the right to make decisions on their loved one's behalf. Because of Federal laws on privacy now affect what health care, insurance, banking, investing, etc. can disclose, spouses are not automatically entitled to information nor are they automatically designated as substitute decision-makers.

If preparations are not made well in advance, the result could be prolonged and costly legal actions with the person with dementia's wishes either remaining unknown or disregarded.

Starting the Discussion:

It is never pleasant to think that things may get worse in the future and talking about them can be downright frightening. One of the biggest fears that people with dementia have is that their family will abandon them, placing and then forgetting them. This fear worsens over time, so having the discussion of long term care early is easier as the likelihood will seem remote. One easy way to initiate the conversation is when a friend or relative requires care. Begin by discussing how the person with dementia feels about the friend's care and how (or if) they would do things differently. Having a discussion about what all members of the household would prefer should the need arise is easiest done when the decisions seem far in the future. Both the person with dementia and their caregiver need advanced directives as it is not uncommon for caregivers to become ill and even die first. We can be far more objective about what we might want if it seems far away. Some of the issues that need to be discussed include the following:

- If you became confused and unable to manage for a while, who would you want to help you to make decisions about your health? If that person wasn't available, who would you want as a backup?
- If you became confused and unable to manage for a while, who would you want to help you to pay your bills? If that person wasn't available, who would you want as a backup? If the person with dementia has no one in mind, suggest it is a good idea to find someone. Once a person (or people) have been identified, get their permission before including them in a written plan.
- If you needed care, where would you want to be? Who would you want to help you? If you had to go to a facility, is there a place you would prefer?
- If you were unable to eat by yourself, would you want

Legal/Financial Affairs:

Legal and financial issues are critical during this disease. At a certain point the patient can no longer be counted on to make informed decisions. Someone will need to be empowered to do this when the time comes. Many couples assume they will be able to step in for their loved one, write checks, sell property, obtain medical records, etc.. This is not the case in most states.

Early planning is needed to prepare for when this type of care is needed. An attorney who specializes in elder law, family law, or probate law should be consulted. Standby durable powers of attorney for health care and finances should be developed for when the person is not able to make informed decisions. Such documents require careful thought and planning. There may be additional decision-makers that need to be appointed for the patient in complex family of financial situations. These vary widely from state to state. Seek legal counsel at your earliest convenience to assure that your wishes are recorded and your estate preserved.

Recognize that caring for a loved one with memory loss is often frustrating. Not everything works all the time. Copy the learning guide and try a few things each week. Some will work. Some won't. Those that don't work, may work tomorrow...and those that work today might be ineffective tomorrow. Use the professionals available to you at the Mayo Clinic, Scottsdale and at the Alzheimer's Association nearest you for help and support. Remember we are here for you and want to help however we can to lighten your

burden. There are many books to help you during this illness. Most are available from the Alzheimer's Association or can be ordered from your favorite bookstore.

Key Points: Legal Issues and Advanced Directives

- In order to assure that the person with dementia is protected, bills are paid, caregivers have access to medical information, and the person's wishes are considered, certain documents must be prepared well in advance of waning abilities
- In order to develop a set of legal documents an attorney who specializes in elder law, family law, or probate law should be consulted.
- It is a good idea to have advanced directives for both the person with dementia AND their caregiver as a surprising number of caregivers die first.
- States vary in the form of laws for decision-making, thus you must know the rules for the person with dementia's state of residence.
- Most states divide decision-making status into two categories: 1) decisions about health care: and 2) decisions about money and finances. In most states the caregiver and family must have BOTH documents in order to provide care.