Advance Care Planning, Directives and Living Wills

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Advance Care Planning

Introduction

As the nation’s population continues to age and medical technology continues to prolong the natural life course, most families are destined to face future medical decision-making in the days ahead. Families plan and prepare for many major life events: attending college, getting married, having a baby, and retiring at the end of a career. However, few plan for events such as how they would want their health care delivered if they become very ill.

These are very important decisions that should be addressed and documented so that family members, health care providers, etc. will know the patient’s wishes for their care.

What is Advance Care Planning?

According to the National Institute on Aging, “Advance care planning involves learning about the types of decisions that might need to be made, considering those decisions ahead of time, and then letting others know about your preferences, often by putting them into an advance directive.”

The decisions are based on an individual’s personal values, preferences, and discussions with their loved ones.

Who Needs Advance Care Planning?

Because an accident or serious illness can happen suddenly, and at any time, every adult can benefit from Advance Care Planning. Planning is particularly important for those who are terminally ill. Research shows that people suffering from chronic illness also benefit from advance care planning. Even healthy people should consider their wishes for end-of-life care and discuss their decisions with family members or professionals, before a health care crisis occurs.

What Are the Benefits of Advance Care Planning?

Studies funded by the Agency for Healthcare Research and Quality (AHRQ) have shown that people who talked with their family, physician, or others about their preferences for end-of-life care had less fear and anxiety, felt more in control of their own medical care, and believed their doctor had a better understanding of their wishes. Other potential benefits of advance care planning according to the National Institutes of Health include:

- Decreased personal worry
- Decreased feelings of helplessness and guilt for the family
- Decreased implementation of costly, specialized medical interventions
- Decreased overall health care costs

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What Is an Advance Directive?

Advance directives are legal documents that address a person’s wishes concerning medical treatments in the event they are incapacitated or unable to speak for themselves. The two types of advance directives are the living will and the durable power of attorney.

Living Will

A living will is a written, legal document that specifies what kind of treatment a person wants in certain situations, typically emergency treatment. This may include specific care options, such as CPR if cardiac or respiratory arrest occurs, artificial feeding options, prolonged use of a respirator if unable to breathe adequately alone, and blood transfusions.

Durable Power of Attorney for Health Care

The durable power of attorney for health care allows a person to name someone, called a health care proxy, who can make medical decisions for them if they are unconscious or lose their ability to communicate. This document does not appoint anyone to make legal or financial decisions for them.

In some cases a person may not feel comfortable putting specific health decisions in writing and instead name a health care proxy to make those decisions. A health care proxy can be named in addition to or instead of a living will.

Other advance care planning documents

A person may want to specify other wishes that are not covered in the living will, such as blood transfusions or dialysis. Other issues that may arise during end of life care are DNR orders and organ and tissue donation.

A **DNR (do not resuscitate) order** is one in which a person does not want to be resuscitated in the event of cardiac arrest. The Living Will may specify that a person does not want CPR, but having a DNR order on the medical chart allows for more specific communication to the healthcare team, which decreases confusion during emergency situations. A **DNI (do not intubate) order** is similar but specifies that a patient does not want to be intubated or put on a breathing machine during emergency situations.

**Organ and tissue donation** is another decision that can be specified as a part of an advance directive that allows for a person to express their wishes. Common organ and tissue donations include the heart, lungs, pancreas, kidneys, corneas, liver, and skin. There is no age limit for donating. Several methods are used to relay this information, in some states a donation card can be carried, or it can be noted on a drivers license, or as part of their advance care planning documents.
What Are the Steps Involved in Advance Care Planning?

1. Obtain a living will form and a durable power of attorney for health care form from a health care provider. It is recommended that both forms are used.

2. Complete, sign, and date the forms. The forms are legal, and it is not necessary to hire a lawyer to create them. State laws on the format of these documents vary. Some states require that forms are notarized; others specify that signed and witnessed forms are sufficient.

3. Provide copies to family members and health care providers. Provide a copy to hospital when admitted.

The federal 1990 Patient Self-Determination Act requires hospitals, nursing homes, and other medical institutions that receive Medicare and Medicaid funding to provide written information about advance care directives to all patients at the time of admission.

Communication to Family and Loved Ones

Communication between individuals and their loved ones is important. Family members may have a difficult time discussing advance care planning, even when it becomes essential. When families do not know the wishes of their loved ones during end-of-life care should a crisis arise, families must make the decisions when they are emotionally overwrought. It is not uncommon that during such stressful periods, family emotions, conflicts, grief, and guilt further complicate the decision-making process. Some people live with the lingering doubt about whether they have made the right decision or not.

An opportunity for discussing advance care plans could be during significant life events, such as the birth of a child or death of a family member. Other opportunities when this discussion would be pertinent is while drawing up a will or estate planning, or when major illness requires that a family member move into a retirement community or nursing home.

Assistance with Advance Care Planning

Nurses and other healthcare professionals can help explore the values that will guide the decision-making process and work through family issues. They can also assist with obtaining and completing forms, and ensuring that copies of the documents are available to doctors and other appropriate professionals. Other professionals, such as elder law attorneys or geriatric case managers, can also help with advance care planning.

How to Consider Future Decisions: The Five Wishes

Aging with Dignity has developed a very helpful planning tool, called The Five Wishes, for thoughtfully making decisions on future desires that encourages people to reflect on what is most important to them (https://agingwithdignity.org/five-wishes/about-five-wishes). People should consider their goals in treatment and values in living. Quality of life is a subjectively defined experience and people value aspects of their life differently than others.
Planning ahead can have many benefits:

**Benefits for the Individual**

Indeed, there is much to be gained from the communication of advance care plans. For the person who has made advance care plans, benefits include:

1. Comfort in being prepared for end of life care
2. Sense of independence is enhanced
3. Personal wishes are more likely to be honored
4. Surrogate is clearly identified
5. Trust is fostered among family members, and
6. Advance care plans can be enacted in a timely manner

**Benefits for Family Members**

1. Clarity regarding person’s wishes
2. Increased comfort and decreased conflict among family members and between family, and provider upon person’s incapacitation
3. Preparation for eventual reflection that advance care plans were in agreement with person’s values

**Portability of Advance Care Planning Documents**

The portability of care plans and advance directive documents is also important to understand. Portability refers to care plans and advance directives being different from state to state. Every state has its own laws regarding advance directives. Not all states recognize advance directives from another state. In some cases, if the laws are similar a state will accept the advance directives.

It is important for healthcare professionals to know the applicable laws in their state for advance directives.

**Other important aspects to consider:**

Emergency medical technicians cannot honor the advance directives. In this event, emergency personnel are required to use necessary stabilization methods during transfer to a hospital. Once there and evaluated by a physician, advance directives can be implemented.

Advance directives do not expire. If a change in desires occurs a new one can be written, which invalidates the previous one.
References

