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ADVANCE DIRECTIVES AND SURROGATE DECISION MAKING

A person who is severely ill or injured may be unable to communicate about medical treatment he or she would wish to receive or decline. Advance directives are written statements prepared ahead of time that allow caregivers to know of a patient's wishes for treatment or that legally specify an alternate decision maker should the patient lose decision-making capacity.

Advance directives sound like a good idea, but they are controversial. Controversy includes such matters as whether advance directives create more confusion than clarity about a patient's wishes, whether they can always be taken as expressing the true desires of a patient, and whether healthcare staff should always follow them.

TYPES OF ADVANCE DIRECTIVE

The phrase "advance directive" is used to refer to different kinds of documents. There are two basic types: the living will and the durable power of attorney for healthcare.

In a living will a person specifies whether to receive or not receive interventions and treatments if they are needed at a future time but the person is incapacitated and unable to explicitly consent or refuse at that time. Other names for a living will are "medical living will" and "medical healthcare directive." Living wills are usually witnessed but are not always notarized.

A durable power of attorney for healthcare may also be called a "medical power of attorney" or "healthcare power of attorney." This document, which should be notarized, designates a proxy or surrogate to act as a decision maker for your care and treatment in the event you are incapacitated by illness or injury and unable to communicate your wishes. The patient is advised to thoroughly discuss intervention and treatment preferences with the surrogate decision-maker before their services are needed.

LEGAL STATUS OF ADVANCE DIRECTIVES

Typically upon admission hospitals will ask the patient if there is a living will. If there is not, the hospital may offer the patient a living will form to complete.

If the patient has a living will, creating several copies and leaving them with family members will help ensure it can be found when needed. However, if different versions of the living will exist, this can create confusion.

If the patient is incapacitated and has a living will providers will often use the instructions to guide treatment and care. But healthcare providers do not always faithfully follow the instructions in a living will, particularly if there is a conflict with family wishes. States vary in how binding they consider living wills.

Generally, if the patient is incapacitated and there is no living will, and no durable power of attorney establishing a designated single decision maker, the provider will follow the wishes of family members in order of degree of relatedness. This is typically spouse first, then, in order, adult children, parents, and adult siblings, but states may vary in defining the order of relations to be followed. It is commonly recommended that an attempt be made to resolve any family conflict about treatment for the patient through discussion and mediation as needed.

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If the patient is under a guardian appointed by a court, the decisions of the guardian will be followed. Otherwise, if the patient has a durable power of attorney that appoints a specific person as the proxy to make decisions, then the hospital staff will usually follow his or her wishes. A notarized durable power of attorney is considered legally binding. The person designated as the proxy or surrogate decision maker should have a copy of the document to prove their status.

THE NATURE OF A LIVING WILL

Basic living will forms are available from hospitals, medical offices, attorneys, health advocacy organizations, and healthcare sites on the internet. Living wills vary from the simple to the complex and from mostly narrative text to extensive use of lists.

Living wills typically specify particular treatments that should or should not be administered under specific circumstances, so the two main considerations in creating a living will are to anticipate the specific situations that may arise and to designate the particular treatments that should or should not occur in those situations. Key situations to consider are when the patient is not expected to recover at all and when the patient is not expected to recover a desired quality of life. Specify treatments to be given or withheld in those situations.

The following are situations one may consider:

- unaware of surroundings, unconscious, no movement
- unaware of surroundings but appearing “awake” and moving
- severe senile dementia – conscious but unable to recognize family, etc.
- mild senile dementia – sometimes confused
- unable to eat, drink, and care for basic needs (e.g., brush teeth)
- must be restrained to prevent injury
- degenerative disease (e.g., Lou Gehrig’s disease)
- Alzheimer’s disease
- brain damage
- one or more organs have failed
- significant paralysis
- intense pain
- highly agitated
- terminal disease
- incurable disease

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The patient may wish to specify whether to administer any of the following possible interventions or other care.

This may be in general or tied to specific situations. "Extraordinary" care:

- artificial respiration or ventilation
- artificial feeding or hydration
- blood transfusions
- cardiopulmonary resuscitation (CPR)
- chemotherapy
- electric shock therapy
- kidney dialysis
- organ transplant
- radiation therapy
- significant surgery

Palliative care: (attempting to relieve pain and suffering rather than to cure; commonly always provided):

- pain medication
- sedation
- family and friend visitation
- music
- television
- pictures
- pet therapy

Other preferences:

- prefer to die at home
- prefer to donate organs if possible
- desire hospice care if available

Other documents are sometimes created when people create living wills. A declaration for mental health treatment may be used to specify future mental health services. Some people create a "values history" to share with loved ones a statement of personal values and important events in life.

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DURABLE POWER OF ATTORNEY FOR HEALTH CARE

A durable power of attorney for healthcare designates someone to make healthcare treatment decisions for the patient if the patient is unable to do so. When specific circumstances arise, the proxy or surrogate will be asked to make decisions for the patient about particular types of treatment to provide or withhold. The surrogate could also choose to change the patient's physicians and healthcare facilities, will have access to the patient's confidential medical records, and can sue on the patient's behalf. A surrogate is not responsible for the patient's medical bills.

The question may arise about how a surrogate should arrive at the right decisions for the patient. Suggestions that have been proposed are to

1. use the patient's earlier comments or instructions, or if those are not available or decisive
2. use "substituted judgment," the treatment or care the patient would likely have chosen, or if that cannot be determined
3. use the standard of "best interests," the treatment or care that would be in the best interests of the patient.

Experts advise the patient to discuss his or her wishes thoroughly with the surrogate while the patient is able so the surrogate is likely to know what the patient wants or would have wanted. A living will form may be used by the patient to indicate their wishes to the surrogate, but the surrogate is not bound by anything the patient says or writes.

CONTROVERSIES ABOUT ADVANCE DIRECTIVES

Healthcare professionals frequently recommend that patients obtain advance directives to avoid confusion and problems later. But critics have pointed out that advance directives are not without problems. Some healthcare professionals avoid creating a living will in favor of having long discussions about preferences with a spouse or surrogate decision maker.

Living wills can be very specific or very general. A basic problem with creating a very specific living will is that hardly anyone can anticipate, years ahead of time, what treatments and interventions they will want or not want in circumstances they have never faced and have little experience of. Beyond that, even if they can grasp all possible interventions and treatments and imagine all possible situations they might face in which they are incapacitated, and decide which interventions they will want in what circumstances, a feat in itself, years later technology will probably have advanced sufficiently to leave large gaps in their instructions. On the other hand, a very general living will that is vague may cause problems in interpreting the patient's wishes. With either type it is also possible the patient will change his or her mind.

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The following are problems pointed out that may arise with living wills:

- The patient has a living will but it cannot be located when needed.
- The patient changed his or her mind about something in the living will but never got around to changing the living will itself. The living will conflicts with wishes the family and/or friends say they heard the patient previously express.
- The living will conflicts with what the patient's own family's desires.
- The patient changed the living will several times but did not destroy or "recall" copies of the old versions, leaving various family members and friends to produce different versions when the time occurs to consult the living will.
- The living will is too vague, unclear, or incomplete about what procedures or treatment options are allowed in specific circumstances.
- Medical technology has advanced since the living will was created and it is unclear whether the patient would wish to allow new treatments.
- Older treatments mentioned in the living will are no longer considered appropriate or are unavailable.
- The patient did not fully understand the types of situation and types of treatment mentioned in the living will and so did not know what they are allowing and disallowing. (There have been cases in which the person wound up indicating the exact opposite of what they wanted.)
- The surrogate advocates treatments which the healthcare staff views as futile in the patient's situation.
- In "incompetent revocation," a conscious patient under care but in a questionable mental state claims to reject the instructions of their living will, leaving the healthcare team uncertain about what to do.
- A surrogate decision maker named in a medical power of attorney disagrees with the instructions in a living will, or finds them confusing, incomplete, outdated, or in conflict with conversations they previously had with the patient.

Listed are some problems that might arise with surrogate decision-makers:

- A patient remains in an incapacitated state for an extended period of time, and the surrogate decision maker must be available to make decisions during that time period. This lasts months or even years, which can be a burden to the surrogate.
- The surrogate decision maker tries to choose the treatment or care the patient stated was desired, but the surrogate does not know what it is, is unable to recall it, or has never been told it. It may be that the patient stated several conflicting wishes at different times.
- The surrogate decision maker tries to use the standard of "substituted judgment," but the surrogate does not know the patient well enough to know what the patient would have wanted.
- The surrogate has different values than the patient has, and what the surrogate chooses is not what the patient or others think is in the patient's best interests. For example, the surrogate chooses a long life over maintaining human dignity, but the patient thought a dignified life was in their best interests.
- A dishonorable surrogate, betraying the patient's trust, chooses a treatment or care option for ulterior reasons. For example, suppose the proxy is in the patient's will and stands to benefit financially from the patient's quick death.

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Similar problems could occur in the absence of a legal surrogate specified in a durable power of attorney for healthcare. A family member or friend might need to try to decide on behalf of the patient. The spouse is usually considered an ideal surrogate, but what if the couple has marital problems? Disagreements could occur between the spouse and adult children of the patient, particularly if the spouse is not the parent of the children. Adult children could disagree among themselves, especially in situations where one child lived far away for much of the patient's later years and has just now flown in to "take control." Decisions can be made on the basis of wishes for revenge, out of bitterness, or out of feelings of guilt. As in the case of an unworthy proxy, adult children may have a vested interest in an early death to gain an inheritance. But even morally honorable children can create conflict due to religious differences with a patient. The patient and other family members may hold different religious beliefs about specific types of treatments and this may influence how the family member decides for the patient when asked.

Despite all these possible problems, living wills can be used by healthcare professionals to help interpret a patient's wishes, and many healthcare professionals generally recommend the patient have a living will and a durable power of attorney for healthcare appointing a trusted person as surrogate. Detailed conversations with family, friends, and the surrogate may help avoid complications and confusions. The process of considering and discussing options to be included in a living will may be more important than the documents themselves.