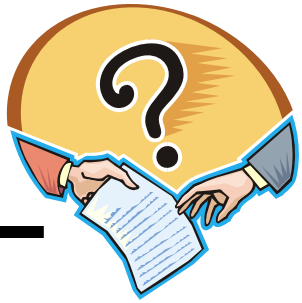
Advance Directives and DNRs



Learner's Guide

What are Advance Directives?

Advance directives are legal documents that allow a person to give instructions for **future** medical care. Advance directives include *living wills* and *medical power of attorney*, documents which can and should be prepared in advance of an illness or accident. Other types of instructions are sometimes given after someone develops an incurable illness or injury, such as *do-not-resuscitate orders* and *comfort care orders*.

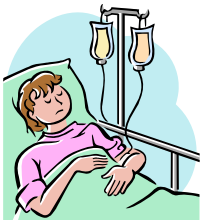
Living Will

- A living will records a person's wishes about future medical treatment.
- The purpose of a living will is to guide family members and doctors in deciding how aggressively to use medical treatment.
- The living will was created to prevent unwanted and ultimately futile invasive medical care at the end of life.
- This document allows a person to state his or her wishes about medical treatment at the end of life. If the person becomes unable to communicate, a living will makes these wishes known.
- A living will becomes effective only when an individual loses the ability to make or communicate decisions.
- A living will may also be called *directive to physicians, health care declaration, or medical directive.*

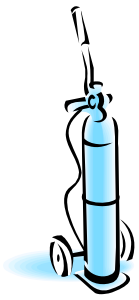
Medical Power of Attorney

- This document allows a person to appoint someone else to make decisions about medical care.
- A medical power of attorney becomes active only if an individual becomes unconscious or unable to make medical decisions.
- The person selected may be called a *health care agent*, *surrogate*, *attorney-in-fact*, *POA*, or *proxy*.
- A medical power of attorney may also be called a *durable power of attorney for health care*, a *health care proxy*, a *health care power of attorney*, a *medical POA,* or *appointment of a health care agent or surrogate.*

Do-Not-Resuscitate Order (DNR)



- A do-not-resuscitate (DNR) order is a physician's written order instructing health care providers not to try to revive the client with cardiopulmonary resuscitation (CPR) in case of cardiac or respiratory arrest. A DNR order is sometimes called a *no code.*
- A person with a valid DNR order will NOT be given CPR if his/her heart or breathing stops.
  - Chest compressions will not be done.
  - Artificial breathing, including mouth-to-mouth, will not be given.
  - An airway will not be inserted.
  - Cardiac resuscitation drugs will not be administered.
  - Defibrillation will not be attempted.



- If a person is experiencing inadequate heart rate or breathing, but is not in full arrest, a valid DNR order means the healthcare providers will give:
  - Emotional support
  - Airway suction
  - Oxygen
  - Position for comfort
  - IV line if appropriate
- Although a DNR order is written at the request of a person or his or her family, it must be signed by a physician to be valid.
- Physicians and hospitals in all states accept DNR orders.
- People unlikely to benefit from CPR include those who have cancer that has spread, people whose kidneys don't work well, or people with severe respiratory illness.
- A DNR order becomes effective only if the person is not breathing or does not have a heartbeat and therefore is not responsive. If the individual has a heartbeat and is breathing, healthcare providers are obligated to treat the person unless he or she is competent and refuses treatment.
- "Do not resuscitate" does **NOT** mean "do not treat."

Comfort Care

- The primary goal of comfort care is to make the client comfortable, which includes:
  - Relieving pain with medications and other measures
  - Relieving symptoms such as nausea, itching, and positional discomfort
  - Food and fluids by mouth if desired
  - Sleeping medications
  - Oxygen
  - Suctioning fluid from a client's mouth to prevent choking
  - Repositioning
  - Skin care and hygiene measures

- No other treatment is provided to prolong life. Comfort care eases or relieves symptoms without correcting the underlying cause or disease.
- Comfort care is also called *palliative care.* The emphasis is on *care*, not *cure*.

Why are Advance Directives Important?

An advance directive is an important document to have at any stage of life. Even though a person is in good health, he might want to consider having an advance directive. An accident or serious illness can happen suddenly, and if one has a signed advance directive, one's wishes are more likely to be followed. Many have received treatment they did not want in hospitals, emergency rooms, nursing homes, and at home. An advance directive could prevent unwanted treatments.

Some have interpreted a living will or a DNR order to mean comfort care only. This is not true. Each of these documents serves different purposes.

- A person might want aggressive treatment of an illness, and treatment for pain and discomfort, up to the point where the heart and breathing stop, at which point he or she wants no further rescue efforts. In that case, a DNR order would be appropriate.
- A person might want full treatment for an illness or injury, along with pain control and comfort care, but not want a feeding tube or IV fluids at the end of life when it is clear that there is no hope of recovery. Those wishes could be addressed in a living will, or could be told to a person who is appointed as the health care agent with a medical power of attorney.
- Comfort care should be provided to all clients, but it may be the ONLY thing provided for those with no hope of recovery from a terminal illness.

How is an Advance Directive Done?

People who want to write an advance directive can do several different things:

- Use a form provided by a hospital or physician.
- Write his or her wishes down on a plain piece of paper.
- Get a form from the state senator's or representative's office.
- Call a lawyer.
- Use a computer software package for legal documents.
- Obtain a form from Last Acts Partnership, available on the Internet at http://www.partnershipforcaring.org/advance/

Some items addressed in an advance directive are:

- Appointing a person to make decisions on one's behalf
- Pain control
- Resuscitation wishes, such as being put on a respirator machine when one stops breathing
- Wishes for organ donation
- Whether to accept or deny certain medical treatments

What If a Person Changes His or Her Mind?

One may change or cancel an advance directive at any time as long as he or she is considered of sound mind. Informed decisions by competent clients always supersede any written directive. Changes must be made, signed, and notarized according to the laws in the state. If there isn't time to put the new wishes in writing, the person may tell the new instructions to the physician, family, and/or friends.

What If Family Members Disagree with a Client's Advance Directive?

If there is a disagreement about either the interpretation or the authority of a client's advance directive, the medical team should meet with the family and clarify the issues.

What are the Limitations of an Advance Directive?

Generally, an advance directive becomes effective when a person is terminally ill or permanently unconscious and cannot make decisions. Sometimes physicians ignore a living will or disagree on whether or not a person is terminally ill.

Do States Require a Specific Form?

Each state regulates the use of advance directives differently. Last Acts Partnership, at www.partnershipforcaring.org, provides state-specific forms and regulations.

State-specific forms are also available for $5.00 from the legal counsel for the elderly at Association for the Advancement of Retired People (AARP), PO Box 96474, Washington, D.C. 20090-6474. You may also call 202-34-2562.

Problems with Advance Directives

- Some care workers think it is okay for a person to die if there is a living will and/or a DNR order. Team members may not care for this person's needs and complaints as well as they do for those who have no living will or DNR order.
- Under comfort care orders, the decision not to treat with antibiotics poses a problem. Do you treat reversible and easily curable urinary infections or skin infections? Some say that is part of comfort care. Other care workers disagree. A competent person can make the decision, but the incompetent need better-defined advanced directives.
- To be comfortable, clients with ultimately fatal medical illnesses such as congestive heart failure or COPD need to continue treatment of their disease. Prognosis is more difficult, and instead of living for months they may live for years.

- First responder medical emergency personnel may not know about DNR orders.
- Living wills cannot cover all conceivable end-of-life decisions.
- A person may change their preferences over time or in certain circumstances.

Legal Considerations Regarding Advance Directives

Self-Determination

Planning an advance directive lets the client exercise the legal right to self-determination. Clients keep the right to self-determination even when they are no longer able to direct their own health care. Legally, decisions about the care of incompetent clients should be based on their previously stated wishes.

Clients must be told about their right to accept or refuse medical treatment and be given the chance to specify their wishes before the need for treatment arises. People admitted to a care community or healthcare organization must be asked if they have completed an advance directive.

Expressed Wishes

Care workers are obligated to follow the medical treatment decisions that are expressed by the client, either verbally or in writing. If the client lacks decision-making capacity, either permanently or temporarily, team members must follow the medical treatment decisions that were made by the client before he became incapacitated.

Anyone who acts contrary to a client's clear instructions or the instructions of a client's authorized health care agent may be guilty of criminal battery against the client.

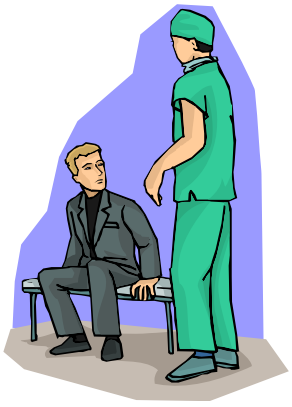
If a care worker objects to an advance directive or a client's expressed wishes based on reasons of conscience, the team member must arrange for someone else to take care of the client.

If there are written advance directives and a power of attorney has been completed, these are binding and must be followed in most states, even if a family member or other client representative objects.

Surrogate Decision-Makers

A substitute decision-maker may be appointed in these ways:

- By the court as a guardian
- With a Health Care Power of Attorney
- Through the hierarchy of surrogacy defined in state law (see next page)



A surrogate can make most health care treatment decisions for an incapacitated client. This person, or persons, may agree to or may refuse medical treatment for the client.

Substitute Judgment

If an incapacitated client's choices are not known, the client's representative will make choices about treatment decisions based on what he/she believes the incapacitated person would choose. The decision-maker will decide based on what he/she knows about the client's values and preferences. If the client has written anything down about his/her values, treatment goals, and/or perspectives on quality of life, the surrogate may use this information to help make health care decisions.

Using Good Faith to Decide Best Interests

If an incapacitated client's representative does not know the decisions, preferences, or values of the client regarding medical treatment decisions, then the representative must decide in good faith what would be in the best interests of the client, considering relief from suffering, whether functioning will be preserved or restored, and the quality and extent of sustained life.

Hierarchy of Decision-Makers

If no advance planning has been done, and an individual becomes unable to make his own decisions, a hierarchy of decision-makers is outlined in many state laws. These hierarchies vary in their specifics, but generally follow a structure like the one below.

1. Health Care (Medical) Power of Attorney
2. Court-Appointed Guardian
3. Surrogate
   a. The client's **spouse**, unless legally separated
   b. An **adult child** of the client, or a majority of adult children
   c. A **parent** or the parents of the client
   d. The client's **domestic partner** if the client is unmarried
   e. A **brother or sister** of the patent, or a majority of adult siblings
   f. Other **blood relatives**
   g. A **close friend** of the client (an adult who has shown special concern for the client, is familiar with the client's desires, and who is willing and able to become involved in the client's health care, acting in the client's best interests)
   h. The client's **physician**, when none of the above persons can be located using all reasonable efforts. The physician may make health care decisions after consulting with the institutional ethics committee, or with a second physician if an ethics committee is unavailable.

IMPORTANT: State laws regarding advance directives and surrogates vary. Every team member is responsible for knowing and following the laws in their state.

Definitions of Terms Useful in End-of-Life Care

Advance directive. Legal document in which a resident states his medical care preferences in case he is incapacitated. Advance directives include living will and medical power of attorney.

Brain dead. When a person has lost all brain functions and there is no blood flow to the brain. Persons who are brain dead cannot move and will not respond to loud noise, painful touch, or temperature. The client cannot breathe without a ventilator.

Comfort care. Care that relieves pain and suffering and controls symptoms but does not prevent dying.

Death by dehydration. Before the development of intravenous fluids most people died in this manner, which is not uncomfortable as long as the mouth and skin are kept moist and clean. Bodily waste products accumulate, body systems shut down, and blood pressure drops until the person simply slips away. Comfort measures should be given, with sips of water, ice chips, mouth hygiene, and hard candy. Use lip moisturizer and glycerin swabs. Provide good mouth hygiene and skin care.

Do-not-resuscitate order (DNR). A DNR order means there should be no attempt to restart a failed heartbeat or apply cardiopulmonary resuscitation to restore normal breathing. In a DNR situation, a client is still provided comfort care.

Futile measures. A general term used often in medical care to characterize interventions in seriously ill clients who are typically terminal that will have little effect on outcome or prognosis.

Heroic measures. A term used by persons and providers to characterize medical interventions that should be applied, usually regardless of a client's condition.

Hospice. A non-institutional health care alternative for terminally ill persons. Most hospice care is delivered to a person in their home. Persons enrolled in the hospice program have given up on cures. They are looking for comfort care and support for themselves and their families.

Palliative care. To palliate means to relieve symptoms without curing them. This is usually associated with care delivered to person with a terminal disease.

Terminal illness. Refers to an illness or condition that is incurable and irreversible. When a person is diagnosed as terminally ill, death is expected in a relatively short period of time, usually within six months.

Ventilator. A machine that helps a person breathe. Sometimes it is used temporarily until a person can breathe without the machine. Other times it is a permanent breathing aid. In the latter case, a tube is often placed directly into a client's windpipe via a tracheotomy (a hole in the windpipe).