

# Advance Health Care Directives: Details, Definitions, and Explanations

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*This document is one of a series covering advance directives, living wills, and end-of-life decision making. You can find more information at [www.myfamilywellness.org/endoflife](http://www.myfamilywellness.org/endoflife).*

# How to Amend or Revoke an Advance Health Care Directive

You should discuss any amendment or revocation of your directive with your doctor or attorney. If you choose to revoke the power of your health care agent, you should consider appointing someone else to act as your agent.

## Amend

As long as you are of sound mind, you may amend (change) your advance health care directive by following the same rules for making an advance health care directive. Make the changes in writing and sign and date them in the presence of two adult witnesses.

If you decide to amend your directive, you should destroy the original and any copies of your prior directive or write “AMENDED” in large letters across them.

## Revoke

You also can revoke (cancel) your advance health care directive completely.

The rules are different for living wills and health care powers of attorney.

- **Living will.** You may cancel instructions in a living will at any time, even if you are not of **sound mind**. To do so, either you or a witness to your decision must notify your doctor or other health care provider.
- **Health care power of attorney.** You may cancel the power of your health care agent as long as you are of sound mind. To do so, you must put your decision in writing and sign and date it in the presence of two adult witnesses, or personally communicate your decision to your doctor, health care provider, or health care agent.

If you decide to revoke your directive, you should destroy the original and any copies of the directive or write “REVOKED” in large letters across them.

# Definitions of Terms Used in Guide

## End-stage medical condition

End-stage medical condition means an advanced illness or other medical condition that cannot be cured or reversed and will result in your death, even if you receive medical treatment.

The most common end-stage medical conditions are advanced stages of:

- Alzheimer’s disease
- Chronic obstructive pulmonary disease (COPD), such as emphysema and chronic bronchitis
- Congestive heart failure (CHF), and
- Malignant neoplasm (cancer)

## Incompetent

Incompetent means that you cannot understand, make, and communicate a specific health care choice, even when you are given help, such as a sign language interpreter. You may be competent to make some health care choices, but incompetent to make other ones. You also may become temporarily incompetent and later regain your competence.

## Life sustaining treatment

Life sustaining treatment is defined by the Pennsylvania law for advance health care directives to mean medical treatment that will only prolong your dying when you have an end-stage medical condition or will only maintain you in a permanently unconscious state.

Examples of life support and other medical treatment that may, in some situations, be considered life-sustaining include: antibiotics, cardio-pulmonary resuscitation, chemotherapy, kidney dialysis, surgery, radiation therapy, and use of a ventilator (breathing machine).

If you give instructions for “life-sustaining treatment” in your advance health care directive, artificial nutrition and hydration is not covered by those instructions, unless you specifically state that you want the instructions to apply to artificial nutrition and hydration.

Pennsylvania law further does not permit your health care agent or health care representative to refuse artificial nutrition and hydration that is necessary to preserve your life, unless it is clear that you would not want it under the circumstances.

## Permanently unconscious

Permanently unconscious means that you are totally unconscious and this cannot be reversed or made better. When you are permanently unconscious, you cannot interact with or respond to people or things around you.

## Sound mind

Sound mind is a common requirement for a person signing a legal document, such as a contract, last will and testament, or advance health care directive. You can be of sound mind, even though you are forgetful or make choices different from most people, as long as you are able to understand the meaning and effect of your choices.

# Life-Support and other End-of-Life Care

## Antibiotics

Antibiotics are a kind of medicine used to treat bacterial infections. Patients with serious medical conditions often develop life-threatening infections.

For example, patients with advanced Alzheimer's are at risk of pneumonia because reflexes that prevent swallowed food from going into the lungs are severely weakened. Antibiotics may help treat the pneumonia, but will not cure the patient's Alzheimer's or the swallowing problem that led to the pneumonia.

Talk to your doctor to learn more about the use of antibiotics for life-threatening infections.

## Artificial nutrition

Artificial nutrition and hydration refers to treatment that delivers nutrition (food) and/or hydration (water) by a means other than the patient taking food or water in his or her mouth and swallowing.

There are two main types of artificial nutrition and hydration:

- **Tube feeding** refers to giving nutrition and/or fluids through a tube placed in the gastrointestinal tract. For short term tube feeding, the tube is passed through the nose into the stomach (nasogastric tube) or the small intestine. For long term tube feeding, the tube is surgically inserted through the abdomen wall directly into the stomach (gastric or "G" tube) or the intestines (jejunal or "J" tube).
- **Intravenous (IV) fluids** refers to fluids (such as water and vitamins, minerals, or other nutrients) given by a very small tube (catheter) inserted in a vein. IV fluids are provided through either a peripheral vein (usually in the lower part of the arm) or a central vein (a larger vein closer to the heart). Typically, IV fluids are a short term measure.

At some time in your life, you may not be able to take in enough food and water by mouth and artificial nutrition and hydration may be a good option to improve your medical condition.

However, for some patients with a serious medical condition, artificial nutrition and hydration may not be effective in significantly extending their life and may even put them at higher risk of a serious complication or make them more uncomfortable.

Talk to your doctor to learn more about artificial nutrition and hydration.

## Cardio-pulmonary resuscitation

Cardio-pulmonary resuscitation (CPR) refers to medical procedures used to restart the heartbeat and breathing of a patient whose heart has stopped beating (cardiac arrest).

In some cases, CPR is limited to efforts like blowing air into the patient's mouth and pressing on the patient's chest.

It also may involve electric shock, insertion of a tube in the patient's windpipe, injection of medication into the patient's heart, and in extreme cases, open chest heart massage. It may be necessary to put the patient on a **ventilator** for a period of time, which may be temporary or permanent.

The patient's overall medical condition is a big factor in how successful CPR will be for the patient. For many otherwise healthy patients who have a cardiac arrest, CPR works and allows time for surgery or other medical treatment to fix the medical problem that caused cardiac arrest.

However, someone who is elderly and infirm or has a serious illness (such as end-stage emphysema, severe liver or kidney failure, or widespread cancer) has a low chance of long-term survival when given CPR. In the case of these patients, the use of aggressive medical care like CPR may only increase their suffering.

**Competent** patients who do not want to have CPR may ask their doctor to write a DNR order. They also can use an advance health care directive to state their wish that they do not want CPR in certain circumstances. However, keep in mind that your request not to be given CPR is not effective until your doctor writes the DNR order.

Talk to your doctor to learn more about CPR and when you might want to have a DNR order.

## Do-not-resuscitate (DNR) order

Do-not-resuscitate (DNR) order refers to an order that tells medical professionals not to perform CPR if the patient experiences a cardiac arrest. DNR orders may be given for patients who are in an inpatient health care facility, like a hospital, nursing home, or hospice. In addition, doctors may write an out-of-hospital DNR order.

DNR orders must be written by the patient's doctor. Even if you completed an advance health care directive and asked not to be given CPR, doctors and nurses will attempt CPR if you go into cardiac arrest while you are in a hospital, nursing home, or other inpatient health care facility, unless a DNR order has been written in your medical record.

The specific types of procedures covered by a DNR order vary, depending upon how the health care facility defines the term. When requesting a DNR order, talk to your doctor to find out what specific procedures will be covered in your facility.

## **Kidney dialysis**

Kidney dialysis refers to a treatment that does some of the work of the patient's kidneys when they are not able to do it themselves. This includes removing excess fluids and waste products from the patient's blood.

The great majority of dialysis patients are given hemodialysis. With this treatment, blood is taken outside the patient's body from a tube placed in the patient's veins and cleaned inside a machine before returning to the patient. This can take several hours and is done several times a week.

For some people, kidney dialysis is a helpful temporary measure while they recover from an illness or wait for a kidney transplant. However, other people have little or no realistic chance of improved kidney function or a transplant. These people sometimes choose to not start or to stop kidney dialysis.

Talk to your doctor to learn more about kidney dialysis.

## **Life-support**

Life-support refers to certain types of medical care that is used to help keep you alive when important body organs or systems are not working well enough to keep you alive without this care. Examples include use of a ventilator to help you breathe, kidney dialysis, and artificial nutrition and hydration.

The medical benefits of life support will vary depending upon your medical condition. In some cases, this care allows time for your medical condition to heal or improve. In other cases, you may have very little or no chance that your medical condition will be cured or improved and the only purpose of life support will be to try to extend your life.

You may use an advance health care directive to state your wishes about whether you want to receive life-support care in certain situations. For example, you can state whether you want to have this care when you have an end-stage medical condition and this care would only prolong your dying.

If you have a life-threatening medical condition, talk to your doctor to learn about life-support care that you may need in the future and the benefits and burdens of this treatment in your case.

## Out-of-hospital DNR order

Out-of-hospital DNR order refers to an order that tells emergency medical services (EMS) professionals not to perform CPR. It is used for patients who are not in an inpatient health care facility, such as a patient at home.

Pennsylvania law allows out-of-hospital DNR orders to be written only for patients who have an end-stage medical condition or are permanently unconscious.

In Pennsylvania, an out-of-hospital DNR order covers cardiac compression, invasive airway techniques, artificial ventilation, defibrillation and other related procedures.

Out-of-hospital DNR orders must be written by your doctor. Like an inpatient DNR order, an out-of-hospital DNR order does not go into effect just because your advance health care directive instructs that you are not to be given CPR.

EMS professionals will provide CPR when they respond to an emergency call and find you in cardiac arrest, unless they are shown an original copy of an out-of-hospital DNR order, you are wearing a special bracelet or necklace that signals that you have an out-of-hospital DNR order, or their command doctor tells them not to start or to stop CPR.

## Ventilator

Ventilator (also known as a respirator or breathing machine) is a machine that is used to help patients breathe when they cannot breathe on their own or it is hard for them to breathe on their own because of their medical condition.

A ventilator provides air to the lungs via a tube inserted through the patient's mouth, nose, or an opening made in the patient's throat. This can make it very difficult for the patient to talk. Medicine can make the patient more comfortable, but also sleepy and less alert.

While many patients improve and can be taken off a ventilator, some patients have little or no realistic chance of breathing without this help. Talk to your doctor to learn more about mechanical ventilators.

# Mental Health Advance Directives

**Mental health declaration** refers to a written document that states your wishes and provides instructions about your mental health care, such as your preferences about treatment facilities and directions about drugs that you do or do not want.

**Mental health power of attorney** refers to a written document in which you appoint someone who you trust to make your mental health treatment choices for you as your mental health agent. In contrast to a health care agent, a mental health agent can be given the power to consent to your admission to a mental health treatment facility.

You also may make a mental health advance directive that combines a mental health declaration with a mental health power of attorney.

Find information on mental health advance directives from:

- Pennsylvania Psychiatric Society ([www.papsych.org](http://www.papsych.org))
- Department of Public Welfare ([www.dpw.state.pa.us](http://www.dpw.state.pa.us))

# Guardian of your Person

A guardian of your person has the power to make your personal (non-financial) decisions, such as where you live. A court may appoint a guardian of your person if it finds that you are not able to make these decisions.

A guardian of your person may revoke (cancel) or amend (change) the power of your health care agent to make your health care choices, but may not revoke your living will instructions without court approval.

If you have a health care agent, it is less likely that a court will be asked to appoint a guardian of your person. However, a request might be made, for example, by a family member who disagrees with your agent's choice.

You may nominate (recommend) someone to be considered for appointment as the guardian of your person in your health care power of attorney, a mental health power of attorney, or a durable power of attorney.

Pennsylvania law requires a court to appoint the person who you have most recently nominated unless it finds good cause or that person does not meet the legal requirements to be your guardian.

# Conflict with Organ Donation

In some cases, there may be a conflict between your organ donation consent and wishes that you state in your advance health care directive or the health care choices made for you by your agent, because your wishes or your agent's choices do not allow measures needed to preserve the suitability of your organs for donation.

For example, your advance health care directive may state that you do not want life-support care if you have an end-stage medical condition, but it may be necessary to continue you on a ventilator for a short period of time so that the organ transplant surgeon can be at the hospital to remove your organs immediately after your natural death.

In these situations, there may be confusion as to whether you wanted your advance health care directive or your organ donation to prevail, unless you have provided instructions for conflicts in your advance health care directive.

Some states also have a law that requires organ donors to be provided measures necessary to preserve the medical suitability of an organ for transplantation unless their advance health care directive specifically provides that they do not want this to happen. (Pennsylvania does not have this law.)