

Deciding About Health Care

A GUIDE FOR PATIENTS AND FAMILIES



New York State Department of Health



Introduction

Who should read this guide?

This guide is for New York State patients and for those who will make health care decisions for patients. It contains information about surrogate decision-making in hospitals and nursing homes. It also covers DNR orders in a health care facility, or in the community. Because this guide is about health care decision-making, the word “patient” is used to refer to anyone receiving medical care. This includes a nursing home resident. This guide does **not** include the special rules for health care decisions made by legal guardians of persons with developmental disabilities.

Can the patient or other decision maker find out about the patient’s medical condition and proposed treatment?

Yes. Patients or other decision makers have a right to be fully informed by a doctor about their medical condition and the doctor’s proposed treatment. Patients must give informed consent before any non-emergency treatment or procedure. Informed consent means that after information is given about the benefits and risks of treatment (as well as alternatives to the treatment) permission is given to go ahead with the treatment.

Adult Patients Who Have the Ability to Make Informed Decisions

Do adult patients have a right to make their own health care decisions?

Yes. Adult patients have the right to make treatment decisions for themselves as long as they have decision-making capacity.

What is “decision-making capacity”?

“Decision-making capacity” is the ability to understand and appreciate the nature and consequences of proposed health care. This includes the benefits and risks of (and alternatives to) proposed health care. It also includes the ability to reach an informed decision.

What if it’s unclear whether or not a patient has decision-making capacity? Who decides whether or not the patient has capacity?

Health care workers will assume patients have decision-making capacity, unless a court has appointed a legal guardian to decide about health care. A doctor will examine the patient if there is good reason to believe the patient lacks capacity. A doctor must make the determination that a patient lacks the ability to make health care decisions. Another person will make health care decisions for the patient only after the patient’s doctor makes this determination.

Do family members always make health care decisions whenever patients lack decision-making capacity?

No. Sometimes patients have already made a decision about a procedure or treatment before they lose the ability to decide. For example, a patient can decide.

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Advance Directives/Health Care Proxies

What is an advance directive?

Advance directives are written instructions about health care treatment made by adult patients before they lose decision-making capacity. In New York State, the best way to protect your treatment wishes and concerns is to appoint someone you trust to decide about treatment if you become unable to decide for yourself. By filling out a form called a health care proxy, this person becomes your “health care agent.”

Before appointing a health care agent, make sure the person is willing to act as your agent. Discuss with your agent what types of treatments you would or would not want if you were in the hospital and had a life-threatening illness or injury. Make sure your health care agent knows your

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- is covered as a domestic partner under the same employment benefits or health insurance; or, this person
- shares a mutual intent to be a domestic partner with the patient, considering all the facts and circumstances, such as:
 - They live together.
 - They depend on each other for support.
 - They share ownership (or a lease) of their home or other property.
 - They share income or expenses.
 - They are raising children together.
 - They plan on getting married or becoming formal domestic partners.
 - They have been together for a long time.

Who cannot be a domestic partner?

- A parent, grandparent, child, grandchild, brother, sister, uncle, aunt, nephew or niece of the patient or the patient's spouse.
- A person who is younger than 18.

Who qualifies as a "close friend"?

A "close friend" is any person, 18 or older, who is a friend or relative of the patient. This person must have maintained regular contact with the patient; be familiar with the patient's activities, health, and religious or moral beliefs; and present a signed statement to that effect to the attending doctor.

What if a surrogate highest in priority is not available to make the decision?

If this happens, the next available surrogate who is highest in priority makes the decision.

What if a surrogate highest in priority is unable or unwilling to make the decision?

In this case, another person from the surrogate list will decide. The surrogate highest in priority may designate any other person on the list to be surrogate, as long as no one higher in priority than the designated person objects.

Can patients or other decision makers change their minds after they make a treatment decision?

Yes. Decisions may be revoked after they are made by telling staff at the hospital or nursing home.

Decisions to Withhold or Withdraw Life-Sustaining Treatment in Hospitals and Nursing Homes

What is "life-sustaining treatment"?

"Life-sustaining treatment" means that the attending doctor believes the patient will die within a relatively short time if the patient does not get the medical treatment or procedure. CPR is always considered to be life-sustaining treatment.



What is CPR?

CPR (cardiopulmonary resuscitation) refers to medical procedures that try to restart a patient's heart or breathing when the patient's heart stops and/or the patient stops breathing. CPR may begin with something like mouth-to-mouth resuscitation and forceful pressure on the chest to try to restart the heart. This may not work, so CPR may also involve electric shock (defibrillation); insertion of a tube down the throat into the windpipe (intubation); and placing the patient on a breathing machine (ventilator).

What is a decision to withhold or withdraw life-sustaining treatment?

A decision to withhold life-sustaining treatment is deciding to refuse a treatment before it is provided. A decision to withdraw life-sustaining treatment is deciding to refuse treatment already being provided. Every adult patient has the right to refuse medicine and treatment after being fully informed of (and understanding) the probable consequences of such actions.

Health care decisions should be made on an individual basis for each patient. Again, decisions must be consistent with the patient's values, as well as religious and moral beliefs.

Do surrogates always have authority to consent to needed treatments?

Yes.

Do surrogates always have authority to make decisions to withhold or withdraw life-sustaining treatment?

No. A legal guardian or a surrogate in a hospital or nursing home may decide to refuse life-sustaining treatment for a patient only in the following circumstances:

- Treatment would be an extraordinary burden to the patient and:
 - the patient has an illness or injury which can be expected to cause death within six months, whether or not treatment is provided; or
 - the patient is permanently unconscious;

or
- The provision of treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances and the patient has an irreversible or incurable condition. In a nursing home, an ethics review committee must also agree to decisions (other than DNR) based on this bullet-point. In a hospital, the attending doctor or the ethics review committee must agree to a decision to withhold or withdraw artificial nutrition and hydration based on this bullet-point.

How are decisions about life-sustaining treatment made for minors in a hospital or nursing home?

The parent or guardian of a patient under 18 makes decisions about life-sustaining treatment in accordance with the minor's best interests. They take into account the minor's wishes as appropriate under the circumstances. For a decision to withhold or withdraw life-sustaining treatment, the minor patient must also consent if he or she has decision-making capacity. It is assumed that an unmarried minor lacks decision-making capacity unless

a doctor determines that the patient has the capacity to decide about life-sustaining treatment. Minors who are married make their own decisions, the same as adults.

What if an unmarried minor patient has decision-making capacity and he or she is a parent? What if he or she is 16 or older and living independently from his or her parents or guardian?

Such minors can make decisions to withhold or withdraw life-sustaining treatment on their own if the attending doctor and the ethics review committee agree.

Resolving Disputes in Hospitals and Nursing Homes

What if there are two or more persons highest in priority and they cannot agree? For example, what if the adult children are highest in priority and they disagree with one another?

In this case, the hospital or nursing home staff can try to resolve the dispute by informal means. For example, more doctors, social workers or clergy could discuss the decision. Also, every hospital and nursing home must have an ethics review committee. The case may be referred to the ethics review committee for advice, a recommendation, and assistance in resolving the dispute. The hospital or nursing home must follow the decision of the surrogate that is based on the patient's wishes, if they are known. If the patient's wishes are not reasonably known, the hospital or nursing home must follow the decision that is in the patient's best interests.

What if a person connected with the case does not agree with the surrogate's treatment decision? This could be the patient, a health care worker treating the patient in the hospital or nursing home or someone lower in priority on the surrogate list.





Again, the hospital or nursing home staff can try to resolve the dispute by informal means. If that is not successful, the person who disagrees could request help from the ethics review committee. The person challenging the decision maker can ask that the ethics review committee try to resolve the dispute. This person could present information and opinions to the committee. The ethics review committee can provide advice and make a recommendation, and can provide assistance in resolving the dispute.

Are the recommendations and advice of the ethics review committee binding?

No, the recommendations and advice of the ethics review committee are advisory and non-binding, except for three very specific types of decisions. The ethics review committee must agree with the decision in the following three situations:

- A surrogate decides to withhold or withdraw life-sustaining treatment (other than CPR) from a patient in a nursing home. The patient is not expected to die within six months and is not permanently unconscious. In this situation, the ethics review committee must agree to the following. The patient has a condition that can't be reversed or cured. Also, the provision of life-sustaining treatment would involve such pain, suffering or other or not permanently the would or to

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