

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 consent to surgery that involves general anesthesia before receiving anesthesia, which would cause them to lose the ability to decide. Other times, a healthy person may suddenly lose capacity. In this case, health care may need to be given right away without consent. For example, a person may be knocked unconscious during an accident. Health care providers will provide emergency treatment without consent unless they know that a decision has already been made to refuse emergency treatment.



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 wishes about artificial nutrition and hydration (being fed through a feeding tube or IV line). You can get more information about health care proxies at: http://www.health.state.ny.us/professionals/patients/health_care_proxy/index.htm.

Some patients also express specific instructions and choices about medical treatments in writing. A written statement can be included in a health care proxy, or it can be in a separate document. Some people refer to this type of advance directive as a “living will.”

How do health care agents make decisions under a health care proxy?

Health care agents make decisions just as if the health care agent were the patient. The health care agent makes health care decisions according to the patient’s wishes, including decisions to withhold or withdraw life-sustaining treatment. If the patient’s wishes are not reasonably known, health care agents make health care decisions in accordance with the patient’s best interests.

Can a health care agent decide to withhold or withdraw artificial nutrition or hydration (through a feeding tube or an IV line)?

Health care agents can only make decisions to withhold or withdraw artificial nutrition and hydration under the health care proxy if they know the patient’s wishes about the treatment. But, the health care agent may also be able to make this type of decision in a hospital or nursing home as a surrogate from the surrogate list set forth in law.

Health Care Decision-Making in Hospitals and Nursing Homes

How do adult patients with decision-making capacity make decisions in hospitals and nursing homes?

Patients may express decisions verbally or in writing. A hospital patient or nursing home resident may not verbally make a decision to withhold or withdraw life-sustaining treatment unless two adults witness the decision. One of the adults must be a health care practitioner at the facility. If a patient does not now have capacity to make a decision (but made a decision in the past about the proposed health care), the hospital or nursing home will act based on the patient’s previously made decision. This is true unless something occurs that the patient did not expect and the decision no longer makes sense.

How are health care decisions made for a hospital patient or nursing home resident who does not have capacity?

If the patient has a health care proxy, the health care agent named in the proxy makes decisions. If a patient does not have a health care proxy, a legal guardian (or the person highest in priority from the surrogate list, known as “the surrogate”) makes decisions.

What is the surrogate list?

Below is the surrogate list. The person who is highest in priority is listed at the top. The person with the lowest priority is at the bottom.

- The spouse, if not legally separated from the patient, or the domestic partner;
- A son or daughter 18 or older;
- A parent;
- A brother or sister 18 or older; and
- A close friend.

What is a “domestic partner”?

A “domestic partner” is a person who:

- has entered into a formal domestic partnership recognized by a local, state or national government. Or, this person has registered as a domestic partner with a registry maintained by the government or an employer; or, this person

- 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.

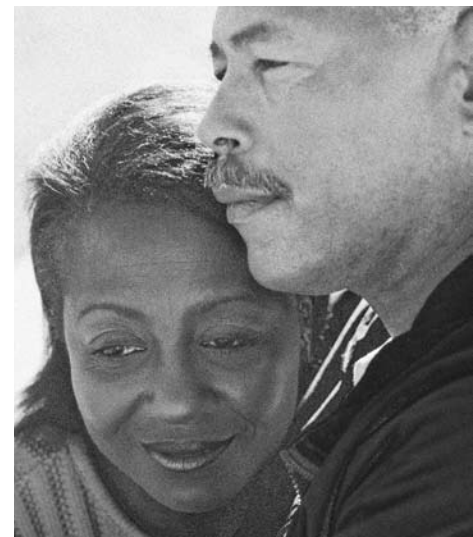
Can patients or other decision makers change their minds after they make a treatment decision?

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.

How would a hospital or a nursing home carry out a decision to withhold or withdraw life-sustaining treatment?

The doctor might direct staff not to provide, or to stop providing, certain medicines, treatments or procedures. This may result in the patient dying within a relatively short time. For example, the doctor might order that a ventilator, which is enabling a patient to breathe, be turned off.

In order to withhold life-sustaining treatment, the doctor might issue a medical order such as a:

- Do Not Resuscitate (DNR) Order: this means do not attempt CPR when the patient's heart stops and/or the patient stops breathing.
- Do Not Intubate (DNI) Order: this means do not place a tube down the patient's throat or connect the patient to a breathing machine (ventilator).

A decision could also be made to stop (or not to start) artificial nutrition and hydration through a feeding tube or an IV. This means the facility will not give the patient liquid food or fluids through a tube inserted in the stomach – or by a tube called a catheter inserted into the patient's veins. Patients will always be offered food to eat and fluids to drink by mouth if they are able to eat and drink.

Other kinds of decisions to limit medicines, treatments or procedures could also be followed (for example, stopping dialysis).

Will a hospital or a nursing home ever withhold all treatment?

No. Even if a patient has a DNR order or other medical order to withhold life-sustaining treatment, the patient should receive medical care and treatment to relieve pain and other symptoms and to reduce suffering. Comfort care, also known as palliative care, should be available to all patients who need it.

When should a patient get a DNR order?

Any adult with decision-making capacity may request a DNR order. However, patients and families must consult with a doctor about their diagnosis and the likely outcome of CPR. Only a doctor can sign a DNR order. A DNR order instructs health care professionals not to provide CPR for patients who want to allow natural death to occur if their heart stops and/or if they stop breathing. For example, a patient who is expecting to die from a terminal illness may want a DNR order.

When successful, CPR restores heartbeat and breathing. The success of CPR depends on the patient's overall medical condition. Age alone does not determine whether CPR will be successful. But illnesses and frailties that go along with age often make CPR less effective. When patients are seriously ill, CPR may not work or it may only partially work. This might leave the patient brain-damaged or in a worse medical state than before his or her heart stopped. After CPR (depending on the patient's medical condition), the patient may be able to be kept alive only on a breathing machine.

Does a DNR order affect other treatment?

No. A DNR order is only a decision about CPR – chest compression, intubation and mechanical ventilation – and does not relate to any other treatment. Do not resuscitate does **not** mean do not treat.

What happens if the patient is transferred from the hospital or nursing home to another hospital or nursing home?

Medical orders, including a DNR order, will continue until a health care practitioner examines the patient. If the doctor at the new facility decides to cancel the medical order, the patient or other decision maker will be told and he or she can ask that the order be entered again.

Decision-Making Standards for Legal Guardians and Surrogates in Hospitals and Nursing Homes

How are health care decisions made by surrogate decision makers, including legal guardians?

The surrogate must make health care decisions in accordance with the patient's wishes, including the patient's religious and moral beliefs. If the patient's wishes are not reasonably known, the surrogate makes decisions according to the patient's "best interests." To figure out what is in the "best interests" of the patient, the surrogate must consider: the dignity and uniqueness of every person; the possibility of preserving the patient's life and preserving or improving the patient's health; relief of the patient's suffering; and any other concerns and values a person in the patient's circumstances would wish to consider. In all cases, what matters is the **patient's** wishes and best interests, not the surrogate's.

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.



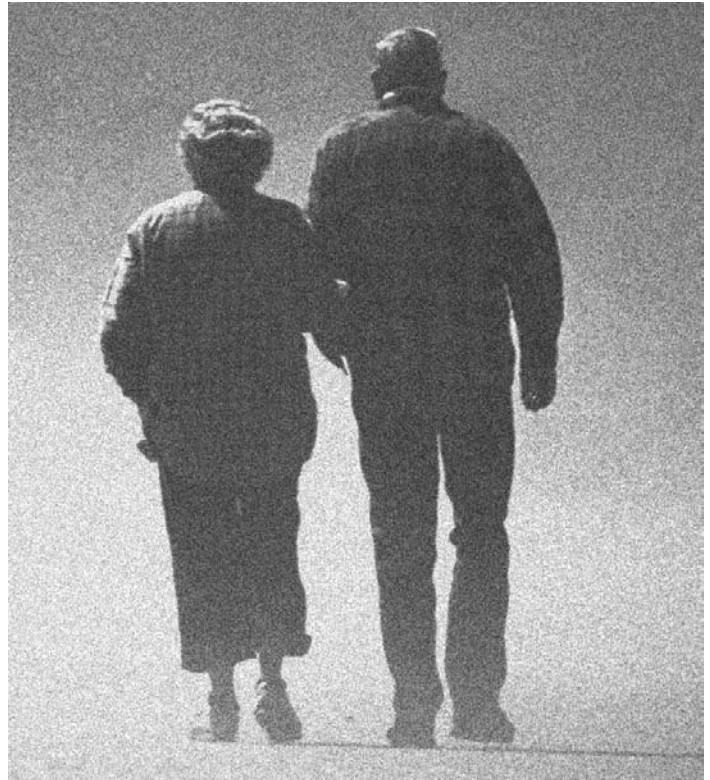
What if a person connected with the case does not agree with the surrogate's treatment decision? This could be the patient, a health care worker treating the patient in the hospital or nursing home or someone lower in priority on the surrogate list.

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 burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances.
- A surrogate decides to withhold or withdraw artificial nutrition and hydration from a patient in a hospital. The attending doctor objects. 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, artificial nutrition and hydration would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances.
- In a hospital or nursing home, an ethics review committee must approve the decision of an unmarried, emancipated minor to withhold or withdraw life-sustaining treatment without the consent of a parent or guardian.



In these three situations, life-sustaining treatment will not be withheld or withdrawn unless the ethics review committee approves.

What does it mean when the recommendations and advice of the ethics review committee are advisory and non-binding?

This means that the surrogate highest in priority can make a legal health care decision. He or she can do this even if another person lower in priority on the surrogate list or others continue to disagree with the surrogate decision maker.

What if the hospital or nursing home has a policy based on religious or moral beliefs that prevents the facility from honoring a health care decision?

When possible, the facility must inform patients or family members of this policy before or at admission. When the decision is made, the facility must cooperate in transferring the patient to another facility that is reasonably accessible and willing to honor the decision. Meanwhile, the facility must honor the decision, unless a court rules otherwise. If the decision goes against one health care practitioner's religious or moral beliefs, the patient must be promptly put under the care of another health care practitioner.

DNR Orders Outside the Hospital or Nursing Home

If a patient is not in a hospital or nursing home, how can the patient get a DNR order or DNI order?

The patient's doctor can write a DNR order on a standard form that has been approved by the New York State Department of Health: DOH-3474 (Nonhospital Order Not to Resuscitate). A doctor can also sign a nonhospital DNI order in addition to the nonhospital DNR order using the DOH-5003 form called MOLST (Medical Orders for Life-Sustaining Treatment). EMS, home care agencies and hospices must honor these orders.

If the patient is at home with a nonhospital DNR order, or MOLST orders, what happens if a family member or friend calls an ambulance?

If the patient has a nonhospital DNR order and it is shown to emergency personnel, they will not try to resuscitate the patient or take the patient to a hospital emergency room for CPR. They may still take the patient to the hospital for other needed care, including comfort care to relieve pain and reduce suffering.

What happens to a DNR order issued in the hospital or nursing home if the patient is transferred from the hospital or nursing home to home care?

The orders issued for the patient in a hospital or nursing home may not apply at home. The patient or other decision maker must get a nonhospital DNR order on the DOH-3474 form or the DOH-5003 MOLST form. If the patient leaves the hospital or nursing home without a nonhospital DNR order, it can be issued by a doctor at home.



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