

A Guide to Making Health Care Decisions: Advanced Directives, Health Care Proxy, and MOLST

You can plan in advance to make sure that your wishes about your health care treatments will be followed, if you become unable to decide for yourself.

Preparing a few simple legal forms can help make sure that your wishes are followed and your health care decisions stay in the hands of people you trust. These forms include:

- **Health Care Proxy**
- **Advanced Directive**
- **MOLST form**

Pre-planning using these forms offer many advantages.

- Making decisions ahead of time reduces the stress for all involved (patient, family, provider) in the event that life-sustaining measures are necessary.
- All healthcare professionals must follow these medical forms and they are recognized in all healthcare settings.
- You may address as many or as few treatments in these forms as you wish.

In this booklet, we hope to help you understand these documents - what they mean, and why it is important to fill them out. All of these forms are available in your ambulatory center. If you have questions or need assistance filling out the forms, speak to your nurse or health care professional and they will be happy to help you.

ADVANCE DIRECTIVES and HEALTH CARE PROXIES

An **advance directive** is any written direction about your health care treatment decisions and wishes while you still have the capacity to make such decisions.

A **health care proxy** form is a type of advance directive where you appoint someone you trust to make your health care decisions, if you become unable to decide for yourself.

Before appointing a health care proxy:

- make sure the person is willing to act as your proxy
- discuss with your proxy 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 proxy knows your wishes about artificial nutrition and hydration (being fed through a feeding tube or IV line)

If a patient's wishes are not reasonably known, the health care proxy makes health care decisions in accordance with the patient's best interests.

What is the Surrogate List?

If you have not appointed a health care proxy, one will be appointed for you from the **surrogate list**. The New York State Family Health Care Decisions Act has developed a list of surrogates, presented in priority order in your life. The person who has the highest priority on the list will be chosen as your surrogate. If that surrogate is not available, the person with the next highest priority will be called upon to make decisions. The surrogate list is as follows:

- your spouse, if not legally separated, or your **domestic partner**
- your son or daughter, age 18 or older
- your parent
- your brother or sister, age 18 or older
- your close friend

MOLST FORM

The MOLST form is a medical order approved by the New York State Department of Health. It details your wishes for life-sustaining treatment. The MOLST form is on **bright pink paper**, so it can be easily identified in an emergency.

How is MOLST completed?

A health care professional must complete or change the MOLST form **with you**, based on your current medical condition, values, wishes and instructions. It must then be signed by a physician.

If you are unable to make medical decisions, the MOLST orders should reflect your wishes, as best understood by your Health Care Proxy or surrogate.

Do all health care professionals have to follow the medical orders on the MOLST form?

Yes, all health care professionals **must** follow these orders as a patient moves from one location to another - unless a physician examines the patient, reviews the orders, and changes them.

Where is MOLST kept?

You keep the original MOLST form at home. Make sure to keep it where it can be easily found.

A copy of the MOLST form will be kept in your medical files for your health care professionals to consult.

What is the difference between a Health Care Proxy, Advance Directive, and the MOLST form?

MOLST

- contains medical orders that reflect your wishes about life sustaining treatments
- applies immediately if you lose your ability to make health care decisions
- is completed by a healthcare professional and the patient and then signed by a physician
- is regularly reviewed and updated

Advance Directive is the written documentation of your health care treatment decisions

Health Care Proxy is a type of advance directive that allows you to name another person to make health care decisions if you become incapable of making your wishes known

Both Advance Directives and Health Care Proxy:

- are completed ahead of time
- only apply when your decision-making capacity is lost
- are written and signed by you
- have no scheduled review or update

DECISIONS TO WITHHOLD OR WITHDRAW TREATMENT**What is life-sustaining treatment?**

Life-sustaining treatment means that the attending doctor believes the patient will die within a relatively short time if they do not get the medical treatment or procedure.

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.

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 a patient's heart or breathing stops.
- **Do Not Intubate (DNI) Order:** This means do not place a tube down a patient's throat or connect the patient to a breathing machine (ventilator).

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

No. Even if a patient has a DNR or other order to withhold life-sustaining treatment, they should receive medical care and treatment to relieve pain and other symptoms and to reduce suffering.

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 a 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.

What is artificial nutrition or hydration?

Artificial nutrition or hydration is a form of life-sustaining treatment where a chemically balanced mix of nutrients and fluids are given to a patient by placing a tube directly into the stomach, intestine, or vein.

What is a decision to withhold or withdraw artificial nutrition or hydration?

A decision to withhold or withdraw artificial nutrition or hydration means the patient will not be given liquid food or fluids through a tube.

Patients will always be offered food to eat and fluids to drink by mouth if they are able to eat and drink.

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

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:

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

-OR-

- If 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.

Health care proxies can only make decisions to withhold or withdraw artificial nutrition and hydration if they know the patient's wishes about these treatments.

DEFINITIONS

advance directive: Any written directions about health care treatment prepared by adult patients while they still have the capacity to make decisions. A *health care proxy* form is one type of advance directive. A *living will* is another.

artificial feeding and hydration: A form of life-sustaining treatment where a chemically balanced mix of nutrients and fluids are given to a patient by placing a tube directly into the stomach, intestine, or vein.

best interest: In deciding what is in a patient's best interests, a health care proxy or surrogate must consider the patient's dignity and individuality, the possibility of preserving the patient's life or health, relief of suffering, and any other concerns or values.

cardiopulmonary resuscitation (CPR): Medical procedures that try to restart a patient's heart or breathing after either has stopped. CPR may involve mouth-to-mouth resuscitation, forceful pressure on the chest, electric shock (defibrillation), inserting a tube into the patient's throat (intubation), and/or placing the patient on a breathing machine called a ventilator.

close friend: The NYS Family Health Care Decisions Act defines a "close friend" as someone who can make decisions for a patient who has lost his or her decision-making capacity and has no health care proxy. They must be 18 years or older, a friend or relative of the patient, been in regular contact with the patient; and be familiar with the patient's activities, health, and religious or moral beliefs.

Do Not Resuscitate (DNR) order: This order instructs health care professionals not to provide CPR for patients who want to allow natural death to occur if their heart stops or they stop breathing. Patients, or their health care agents or surrogates, can request a DNR, only a provider (MD, NP, PA) can sign a DNR order.

Do Not Intubate (DNI) order: An order that prevents medical staff from assisting a patient's breathing by inserting a tube in the patient's airway or placing the patient on a ventilator. Only a provider (MD, NP, PA) can sign a DNI order.

decision-making capacity: A patient is considered to have decision-making capacity when he or she is able to understand what a medical treatment or procedure will involve, what it will or will not do, and what risks

it may pose. A patient who has decision-making capacity, by this definition, is able to make an informed decision.

domestic partner: The NYS Family Health Care Decisions Act defines “domestic partner” as one of the people who can make decisions for patients who have lost their decision-making capacity and do not have a health care proxy. A domestic partner is a person who:

- is recognized as a domestic partner by a government agency or the patient’s employer; or
- is covered as a domestic partner under the patient’s employment benefits or health insurance; or
- lives with the patient, depends on the patient for support, shares the ownership of a house, shares income or expenses, is raising children with the patient, plans on getting married to patient, or has been with the patient for a long time.

A domestic partner cannot be anyone under the age of 18 or a parent, grandparent, child, grandchild, brother, sister, aunt, uncle, nephew, or niece of patient or their spouse.

health care agent: The person an individual appoints by completing a **health care proxy** (see below) to make health care decisions if that individual becomes incapable of making decisions. A health care agent has the same rights to request or refuse treatment as patients would if they were able to make their own decisions.

health care proxy: A legal document (a type of advance directive) in which you designate another person (a “health care agent”) to make health care decisions if you become incapable of making your wishes known. The document also allows you to name an alternate health care agent (if the primary agent is not available), and provides an area where you can write specific instructions about medical treatments or procedures that you would or would not want.

informed consent: Patients give “informed consent” when they are told the benefits and risks of a proposed treatment as well as any alternative treatments available, and then give permission to proceed with the treatment.

life-sustaining treatment: A treatment that, if not given, will result in the death of the patient within a relatively short time. The patient’s doctor specifies what the doctor believes to be life-sustaining treatment for him or her. CPR is always considered to be life-sustaining treatment.

living will: A legal document, a type of advance directive, which allows you to specify what medical treatments you do and do not want to receive if you become incapable of making your wishes known.

Surrogate: The name given by the NYS Family Health Care Decisions Act to those people who can make decisions for patients who have lost their decision-making capacity and who have not appointed a health care agent. The Act provides a list of surrogates, presented in priority order with the highest priority person at the top. If that surrogate is not available, the person with the next highest priority (next on the list) will be called upon to make decisions. The surrogate list is as follows:

- your spouse, if not legally separated, or your **domestic partner**
- your son or daughter, age 18 or older
- your parent
- your brother or sister, age 18 or older
- your close friend