



Advanced Directives

Making Your Wishes Known and Honored

Dear New Yorkers,

Planning end-of-life care is a complex matter. Although it is hard to talk about the final phase of life, it can be a great gift to our family and loved ones to prepare them in advance for the sometimes difficult and distressing decisions that must be made.

For those who wish to plan in advance, New York law can help. Ultimately, your decision to accept or reject medical treatment really depends upon your personal wishes, values, and beliefs. This guide explains your right to choose medical treatments and describes the steps you can take under state law to help ensure that your personal health care decisions are known and honored if you are unable to speak for yourself.

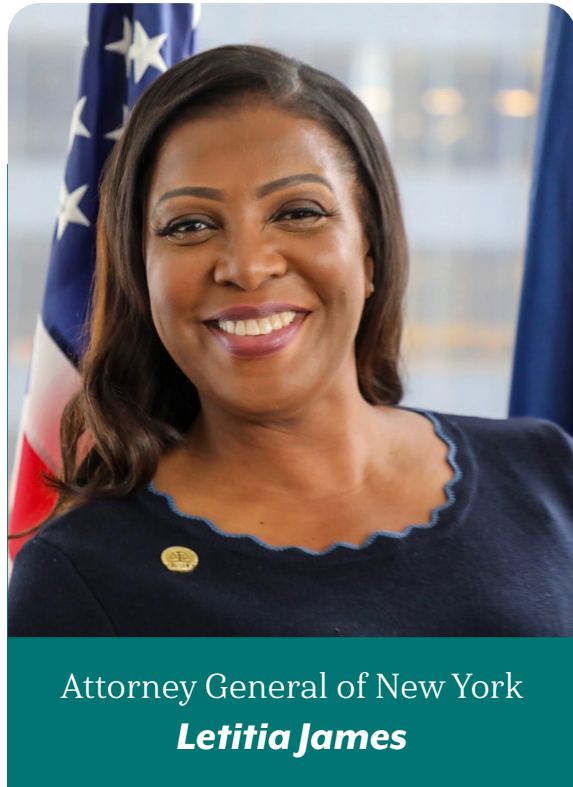
Preparing a few simple legal forms known as advance directives can help ensure that your wishes are respected and that your health care decisions stay in the hands of people you trust. This guide includes information about advance directive forms with tips on how to use them.

We hope that you find this guide to be helpful.

Sincerely,



Letitia James



Attorney General of New York
Letitia James

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Advance care planning affords you the opportunity to plan for future medical care in case you are unable to make your own decisions. It may include preparation of one or more straightforward legal forms — a Health Care Proxy, for example — which can help to ensure that your health care decisions are followed and decisions are made by people you trust. Importantly, advance care planning begins by thinking through possible future health care scenarios and having conversations with family and friends about your wishes.

It is particularly important to consider or reconsider your health care choices if you:

- Have been diagnosed with a terminal illness;
- Have been diagnosed with an illness or condition that could lead to incapacity;
- Are entering into assisted living facility or nursing home;
- Have been admitted to the hospital and are over 65.

Thinking about serious or terminal illness and talking about your wishes can be difficult. That is why it's important to be well informed about the steps you may want to take. This booklet talks about some of the most common legal options available to New Yorkers and can help you understand those options and how to talk to your family and friends about them. Let's start with some definitions. Each of the terms listed here will be discussed in more detail in the following pages.

Terms to Know

Advance Directives are a legal documents by which you may make provisions for future health care decisions in the event that you are unable to make such decisions for yourself. In New York State there are three types:

Health Care Proxy form, Living Will, and Do Not Resuscitate Order (DNR). CPR or cardiopulmonary resuscitation is an emergency procedure to restart the work of your heart and lungs by compressing the chest overlying the heart and forcing air into the lungs. Additional lifesaving procedures include mechanical ventilation or respirator and intravenous medications to regulate blood pressure and heart rhythms.

Do Not Resuscitate Order (DNR) is a medical order written by a doctor. It instructs health care providers not to perform cardiopulmonary resuscitation (CPR) or other lifesaving emergency procedures if your heartbeat or breathing stops. A DNR is arranged with your doctor or health care provider before an emergency occurs.

Health Care Proxy form lets you appoint a health care agent — someone you trust to make health care decisions for you if you are unable to make decisions for yourself. In order for the health care proxy to become effective, two doctors must decide that you are not able to make your own decisions.

Living Will allows you to leave written instructions that explain your health care wishes, especially about end-of-life care. This document becomes effective when you are unable to make your own decisions, and your doctor confirms that you have an incurable condition. You cannot use a Living Will to name a health care agent; you must use a Health Care Proxy form.

Make Your Wishes Clear

Casual statements you may have made to your family, like “Don’t keep me alive on machines,” “No Heroics,” or “Make sure I am not in pain” may not be specific enough for procedures to be withdrawn.

MOLST form: Medical Orders for Life Sustaining Treatment allows doctors to record your preferences regarding cardiopulmonary resuscitation (CPR), mechanical intervention, and other life sustaining treatments on one form as a physician order. It must be completed by a health care professional and signed by a New York State licensed physician to be valid.

Power of Attorney allows you, the Principal, to appoint an Agent to act for you immediately upon its execution or the occurrence of some future event identified by you and lasts until cancellation by you or upon your death; this power continues when you are mentally or physically incapacitated.

Palliative Care is a multidisciplinary approach to specialized medical care for people with life-limiting illnesses, focusing on providing people with relief from the symptoms, pain, physical stress, and mental stress of the terminal diagnosis.

Surrogate is a person close to you, as defined by New York state law, who can make decisions on your behalf if you have lost the capacity to make decisions about your medical treatment, and have not appointed a health care agent.

Getting Started

New York law grants you the right to accept or reject medical treatment, including life-prolonging procedures, such as mechanical respiration and tube or intravenous feeding.¹

As long as you are able to do so, you can speak directly to your doctor and your family members and let them know what care you may or may not want. But what if you are incapacitated, in a coma, for instance, the only way to be sure that your wishes will be known and honored is to plan for future medical care.

The first step towards planning your end-of-life care is to think through what type of care you may want, consistent with your values and beliefs. Discuss your wishes with your doctor, your family and loved ones.

This is not an easy subject to deal with but it will help your family and loved ones know what kind of treatment you want.

These questions may help you identify what kind of treatment you may or may not want if you are no longer able to decide for yourself.

- 1.** Would you want your doctor to withhold or withdraw medical treatment, if that medical treatment will only prolong dying?
- 2.** Would you want cardiopulmonary resuscitation (CPR) to restore stopped breathing and/or heartbeat?
- 3.** Would you want to continue mechanical respiration, i.e. use machines to keep you breathing?
- 4.** Would you want tube or intravenous feeding and water?
- 5.** Would you want maximum pain relief even if it hastens your death?
- 6.** Would you want to donate your organs and/or tissues?

Thinking about the care you want to receive in particular situations and talking with your doctor and loved ones about your health care wishes is an important step. Putting those wishes in writing is more effective to ensure that everyone involved has a clear and reliable view of the specifics. Appointing someone to decide health care matters for you may be an effective way to address situations that you may not be able to anticipate. The advance directives discussed above provide the vehicle for advance care planning so that you can make your wishes known and be the one to decide what works best for you.

How to Select Your Advanced Directives

How do you choose which Advance Directive might be best for you? Here are some questions and answers that may help you:

Q. If you are in a coma or vegetative state or otherwise incapacitated, would you want someone you trust to make medical decisions for you?

If the answer is yes, consider a **Health Care Proxy** by appointing someone you trust as your Health Care Agent to speak and decide for you when you are unable to do so. (See below.)

If the answer is no because you have no one you trust to act as your Health Care Agent, consider a **Living Will** so that your medical instructions are clear and can be read by your care givers when you are unable to communicate your wishes.

Q. Even though you want someone you trust to make medical decisions, do you still have strongly held views about specific situations?

If yes, you may consider combining a **Health Care Proxy with a Living Will** so that the person you appoint to act on your behalf can also rely on your written instructions to make decisions for you.

If no, then maybe just a **Health Care Proxy** will meet your needs.

A Health Care Proxy

You can complete a Health Care Proxy form if you are 18 years of age or older. A Health Care Proxy form, established under New York law, allows you to appoint someone you trust—a Health Care Agent—to make health care decisions on your behalf if you are no longer able to do so.² You can tell your wishes to your agent orally or in writing. New York law requires hospitals and nursing homes to provide you with the Health Care Proxy form and information about creating a proxy.³

Below are some things to consider in writing and signing your Health Care Proxy form.

Step 1: Understand Your Health Care Agent’s Authority

Under New York’s Health Care Proxy law, your agent’s authority to make health care decisions begins when your doctor determines that you have lost the capacity to make decisions for yourself. For a decision to withdraw or withhold life sustaining treatment, a second doctor must confirm your doctor’s decision.

You may give your health care agent as little or as much authority as you wish. In other words, you may allow your agent to make all health care decisions on your behalf or only certain ones.

Health Care Proxy Form

A standard Health Care Proxy form approved under New York law is provided on the New York State Department of Health website and is offered in English, Chinese, Haitian Creole, Korean, Russian and Spanish with detailed instructions at:

health.ny.gov/publications/1430.pdf

A Health Care Agent's Rights and Obligations Under New York's Health Care Proxy Law:

Your Health Care Agent can make decisions related to artificial nutrition and hydration (for example, use of a tube to give you food and water). You may either specifically tell your wishes to your agent or write your wishes in your Health Care Proxy form.

Your agent will have the authority to decide whether or not your heart beat should be restarted through cardiopulmonary resuscitation (CPR) unless you write in your Health Care Proxy form that your agent cannot make this decision for you.

Once your agent's authority begins, he or she has the right to get your medical information and records to make informed health care decisions for you.

Your agent's decision is final unless an objecting family member or facility obtains a court order overriding the decision or disqualifying the agent.

Your agent is not financially responsible for the cost of your care.

Overall, your agent is required to make health care decisions for you according to your wishes, religious and moral beliefs, and in your best interest.

Should my health care agent live in the same city as I do?

While the law does not require you to name an agent living in the same city or state as you do, it is a good idea to choose someone who lives nearby. If you are terminally ill, for example, and unable to make decisions for yourself, your agent may have to spend weeks or even months nearby to ensure your health care wishes are followed.

Step 2: Choose a Health Care Agent

Picking your health care agent is a very important decision. Generally, you have the right to appoint any competent adult (18 years of age or older) as your health care agent. Your agent may be your spouse or partner, an adult child, a relative, a close friend or a lawyer. Choose someone you trust—and someone with whom you feel confident discussing your wishes for medical care. Your agent need not agree with all of your wishes, but must be capable of carrying them out, regardless of his or her own feelings. And, of course, it is always good practice to make sure the person you appointed as your agent is comfortable serving as your agent.

Under New York's Health Care Proxy law, you can appoint any competent adult as your Health Care Agent except:

- You cannot appoint your doctor as your health care agent unless your doctor is your spouse or your relative.
- You cannot appoint an operator, administrator, or employee of the hospital or nursing home where you are admitted unless they are a relative or you appointed them before your admission.

Step 3: Name an Alternate Health Care Agent as Your Back-Up Agent

The Health Care Proxy form gives you the option to appoint an alternate agent. Your alternate agent can take over from your first choice only if:

- You specify the circumstances under which you would like your alternate agent to take over from your agent. For example, if you want your alternate to serve if your first choice moves out of state, then say that in your Health Care Proxy.
- Your doctor states in writing that your first choice as health care agent is not available, unwilling or unable to act when needed.
- A court disqualifies your agent.

Step 4: Sign Your Health Care Proxy Form

Two witnesses must watch you sign your Health Care Proxy form and say that you appeared to sign willingly. Neither your agent nor your alternate agent can serve as a witness. You do not need to have the form notarized.

The standard Health Care Proxy form approved under New York law has sections that must be completed for your proxy to be valid. The form also has “optional” sections that you may or may not choose to complete.

Make sure your Health Care Proxy form meets the minimum requirements.

Minimum State Requirements for a Valid Health Care Proxy Form

- Your name as the Principal who creates the proxy.
- Name of your health care agent.
- Your statement that you intend the agent to have the authority to make health care decisions on your behalf.
- You must sign and date your signature with the witnesses present. If you are unable to sign your proxy, another adult can sign for you at your request.
- A court disqualifies your agent.
- Two witnesses must sign and date their signatures, and state that you (Principal) appeared to execute the proxy willingly. Neither your agent nor your alternate agent can serve as witnesses.

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A Living Will allows you to leave written instructions that explain your health care wishes, especially about end-of-life care.

Optional Sections for a Health Care Proxy Form

- Statement of your treatment wishes or limitations on the agent’s authority. For example, you may want to state that you have told your agent your wishes about artificial nutrition and hydration (food and water).
- Naming an alternate agent.
- Statement of your wishes regarding organ and/or tissue donation.
- Expiration date if any, of your Health Care Proxy, or a description of circumstances that trigger expiration.

A Living Will

While New York does not have a law governing Living Wills, the Court of Appeals, New York’s highest court, has stated that Living Wills are valid as long as they provide “clear and convincing” evidence of your wishes.⁴ If you are 18 years of age or older, you may express your wishes in writing about your health care by signing a Living Will.

There is no standard Living Will form.

You may download a Living Will form at no charge at [caringinfo.org](https://www.caringinfo.org)

Below are some things to consider in planning and signing your Living Will.

Step 1: Understand the Authority of Your Living Will

A Living Will is a written declaration of your health care wishes. In your Living Will, you can leave specific instructions about medical treatments you may or may not want, when you are no longer able to decide for yourself. A Living Will serves as evidence of your wishes.

Step 2: Write Your Living Will

- You can use a Living Will to write your wishes about care at the end-of-life. You may describe the medical situations in which you would accept or refuse medical treatment. You may specify the kind of treatment that you may or may not want.

For example, whether you wish to be kept alive with a feeding tube or intravenous feeding if you are terminally ill or comatose and there is no hope you will recover.

- You may want to consult a lawyer if you wish to address issues not covered in the form included with this guide—like whether you want medical treatments such as CPR, blood transfusions and dialysis, or whether you want to be kept alive on machines for a short time if necessary to be an organ donor. A custom-tailored Living Will can help make clear your objection to unwanted medical treatments.
- If you have questions, discuss them with your doctor, a patient representative at a hospital, or a lawyer.

Step 3: Sign Your Living Will

It is best to have two witnesses watch you sign your Living Will, and sign a statement on the form that you appeared to sign willingly. If possible, you should have the form notarized, so that it may be recognized in states that require notarization.

Regardless of which Living Will form you choose to use, **make sure you meet the minimum requirements for a Living Will:**

- Your name as the person creating the Living Will;
- Date you create your Living Will;
- Your statement regarding your personal health care wishes;
- Your signature;
- Two witnesses' signatures and dates, and statements from the witnesses that you appeared to sign the document willingly.

The Difference Between a Living Will and a Health Care Proxy

Although both a Health Care Proxy and a Living Will are advance directives, they are not the same thing.

Living Will

A Living Will is a document that contains your health care wishes and is addressed to unnamed family, friends, hospitals and other health care facilities. You may use a Living Will to specify your wishes about life-prolonging procedures and other end-of-life care so that your specific instructions can be read by your caregivers when you are unable to communicate your wishes.

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Health Care Proxy

A Health Care Proxy is a document that allows you to appoint another person(s) as your health care agent to make health care decisions on your behalf if you are no longer able to do so. You may give your health care agent authority to make decisions for you in all medical situations if you cannot speak for yourself. Thus, even in medical situations not anticipated by you, your agent can make decisions and ensure you are treated according to your wishes, values and beliefs.

Q. Can I choose to sign both a Living Will and a Health Care Proxy?

Yes. You have the right to create both a Living Will and a Health Care Proxy in order to leave specific medical instructions in writing and appoint a health care agent to carry them out. Your health care agent can rely on your instructions as guidance to make decisions that reflect your wishes.

Do Not Resuscitate Orders (DNR)

Under New York law, a DNR Order is a written order by the doctor that instructs medical professionals not to perform cardiopulmonary resuscitation (CPR) to restart your heart or lungs when your heartbeat or breathing stops.⁵ This means that doctors, nurses, or emergency personnel (i.e. paramedics) will not initiate emergency procedures such as mouth-to-mouth resuscitation, external chest compression, electric shock, insertion of tube to open your airway, or injection of medication into your heart or open chest. You can make your Hospital DNR wishes known in your health care proxy, living will or a state approved MOLST form.

In New York, any adult 18 years or older can get a Hospital or a Non-Hospital DNR Order. A Hospital DNR Order is issued if you are in a health care facility such as a hospital, nursing home, or a mental hygiene facility licensed by New York State. Emergency personnel (EMS) must honor your Hospital DNR Order during transfer. But, if you are outside any of these facilities, at home, for example, you may want to get a Non-Hospital DNR Order. Your Non-Hospital DNR order must be recorded on a state specific form [DOH- 3474] and signed by a doctor.

Giving Consent to a DNR Order

If you have capacity to make decisions for yourself, you can give your consent to a DNR Order verbally or in writing. If you lack capacity to make decisions for yourself, your health care agent can consent on your behalf.

Checklist for a Valid Hospital DNR Order:

- You, your health care agent or a surrogate may give written or verbal consent to your Hospital DNR order.
- Verbal consent must be witnessed by two adults, one of whom must be a doctor in the facility where you are admitted.
- Written consent must be signed by two adult witnesses.
- Your doctor can issue your DNR Order. New York State does not require your written or verbal consent to be recorded on a state form. Facilities may use their own forms or the state specified MOLST form.

Checklist for a Valid Non-Hospital DNR Order:

- You, your health care agent or a surrogate may give written or verbal consent to your Non-Hospital DNR Order.⁶
- If you are getting your DNR Order before discharge, verbal consent may be given to your attending doctor or two adult witnesses, one of whom must be a doctor in the facility where you are admitted.
- If you are out of hospital, at home, for example, it will be sufficient to give verbal consent to your attending doctor.
- If you are giving consent in writing, it must be signed by two adult witnesses.
- Written or verbal consent must be recorded on New York State Form DOH3474 and signed by your doctor. Form available at **health.ny.gov/professionals/patients/patient_rights**

Medical Orders For Life-Sustaining Treatment (MOLST)

The New York State Department of Health has approved the Medical Orders for Life-Sustaining Treatment (MOLST) form. This form allows doctors to record your preferences regarding cardiopulmonary resuscitation (CPR), mechanical intervention, and other life sustaining treatments on one form as a physician order. MOLST must be completed by a health care professional and signed by a New York State licensed physician to be valid.

A valid MOLST form serves as a “Physician Order Form” and can be transferred with you from one health care setting to another. A sample MOLST form is available at **health.ny.gov/forms/doh-5003.pdf**.

Remember, while the MOLST form may help centralize your end-of-life wishes and summarize your advance directives, it is not intended to replace your Health Care Proxy form and/or Living Will. MOLST translates your current medical treatment preferences into physician orders whereas your Health Care Proxy and/or Living Will guides future medical care.

Making Your Advanced Directives Known

Health Care Proxy and Living Will

After signing your Health Care Proxy or Living Will, follow these tips:

- Make several photocopies of the completed forms.
- Keep the originals in a safe but accessible place (not a safe deposit box). Give copies to your health care agent, alternate agent, your attorney or other advisor, close family members, doctors, and anyone else you choose to involve in your health care.
- Under New York law, any doctor who is given a Health Care Proxy form must arrange for a copy of the form to be put in your medical record.
- Consider carrying a wallet card giving information about the existence and location of your Health Care Proxy or a Living Will.

DNR Orders

A Hospital DNR Order is recorded in your medical chart. A Non-Hospital DNR Order must be recorded on a state specific form. You may also consider getting a DNR Bracelet.

To learn more about DNRs, form DOH-3474 or a DNR bracelet, visit:

health.ny.gov/professionals/ems/policy/11-02.htm

or your local DOH EMS office
or health department.

To see a copy of form DOH-3474 visit:

health.ny.gov/forms/doh-3474.pdf

If You Don't Have an Advance Directive

If you have lost the capacity to make decisions about your medical treatment, and have not appointed a health care agent, a person close to you may make decisions on your behalf. In 2010 the New York Legislature passed the Family Health Care Decisions Act (FHCDA),⁷ which allows family members and others who are close to you to make decisions regarding medical treatment in accordance with your wishes or, if unknown, your best interests. The “surrogate” decision maker would also be permitted to direct the withdrawal of life-sustaining treatment (including consenting to a DNR order).

The best way to ensure that your specific wishes are met is to select a Health Care Proxy and complete a living will as described in this booklet. Otherwise, you will not be able to control how you receive care while you are incapable of making a decision.

Designation of a Surrogate

If you are declared incapable of making medical decisions and do not have a health care proxy, the FHCDA provides for the designation of a “surrogate” decision maker to make medical decisions for you as outlined under New York law.

The law establishes a prioritized list by category of those who may act as the surrogate decision maker for the incapacitated person. The surrogate may be, in order of priority, the court-appointed guardian, spouse, child (18 years or older), parent, sibling (18 years or older), or close friend.⁸ This person may also designate a person with lower priority to be the surrogate, assuming no one with higher priority can take the role. For example, if you do not have an Article 81 guardian and your spouse is not willing to serve, your willing adult child will be your surrogate. Your adult child may also appoint your willing parent as surrogate.

DNR Bracelet

A DNR bracelet may be worn only if you have been issued a valid Non-Hospital DNR Order using form DOH3474. The law requires emergency medical personnel who see a standard DNR bracelet on you to comply with the Order.

Decisions a Surrogate Can Make

The surrogate has authority to make all health care decisions that the patient would have been able to make prior to becoming incapacitated.⁹ The surrogate is obligated to follow religious or moral beliefs, if known. If those beliefs are not known, the surrogate must make decisions that will be in the patient's best interests.¹⁰

Surrogates are entitled to have access to your medical records in order to make decisions on your behalf. They may also seek out information from your doctor about your condition and treatment options to make the most informed medical decisions.¹¹

Decisions to Withdraw Life-Sustaining Treatment

If you made the decision to withdraw life-sustaining treatment before becoming incapacitated, your doctor need not seek the surrogate's permission or knowledge before following those orders. If your doctor followed those orders before your surrogate was appointed, he or she merely needs to document the action in your medical record. If your doctor intends to follow through on that decision after the appointment of a surrogate, your doctor may follow that order without permission from the surrogate, but must inform or attempt to inform the surrogate of the decision.¹²

The law ensures that life sustaining treatment will not be withheld or withdrawn from you without serious consideration. For example, there must be a finding that treatment would be an extraordinary burden to you and an attending physician, with another physician, must concur to a reasonable degree of medical certainty. Other requirements include finding that you have an illness or injury which can be expected to cause death within six months, whether or not treatment is provided; or that you are permanently unconscious; or that treatment would involve such pain and suffering that it would be reasonably deemed inhumane or extraordinarily burdensome and that you have an irreversible or incurable condition.¹³

Patient Objections

As the patient, you may object to:

- The determination of your incapacity;
- The choice of surrogate; and
- The health care decision made by your surrogate.

In the event you disagree with any of these determinations, your determination will be followed by your doctor. However, if a court determines that you lack capacity and (if applicable) authorizes the treatment decision, you cannot override these determinations.

Further, if there is some other legal basis for overriding your decisions, you will be subject to the choices made by your surrogate.¹⁴

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If the Patient's wishes and beliefs are unknown, the surrogate must make decisions that will be in the patient's best interests.

According to the FHCDA, those interests take into account “consideration of the dignity and uniqueness of every person; the possibility and extent of preserving the patient's life; the preservation, improvement or restoration of the patient's health or functioning; the relief of the patient's suffering; and any medical condition and such other concerns and values as a reasonable person in the patient's circumstances would wish to consider.”

The Difference Between a Health Care Proxy and a Surrogate

There are significant differences between a health care proxy and a surrogate. You should carefully consider the differences and think about naming a health care proxy instead of allowing a surrogate to be designated.

	Health Care Proxy	Surrogate
Who appoints them?	You — via a properly executed Health Care Proxy form	The Family Medical Decisions Act establishes who may act as a surrogate
Who can serve?	Anyone over the age of 18	In priority order: Article 81 guardians, spouses, children (over 18), parents, siblings (over 18), or close friends
When do they make decisions?	When you lose capacity	When you lose capacity
When do they stop making decisions?	When you regain capacity, when the appointment expires, or under certain specified conditions, as written in the Health Care Proxy form	When you regain capacity
What decisions can they make?	Any decision or those specified in the Proxy form or Living Will	Any decision
Any limitations?	You are able to specify certain imitations in the Proxy form	Surrogates may only make decisions based on your religious or moral beliefs, or in the absence of those, your best interests

Canceling Your Advance Directives

An advance directive remains in effect indefinitely unless you cancel it, include an expiration date, or describe the circumstances that trigger expiration. You can change or cancel your advance directives at any time. It is important to review the forms you have signed from time to time to make sure they express your current health care wishes.

- You can cancel your Health Care Proxy by notifying — orally or in writing — your health care agent, doctor or others who have copies.
- You can cancel the appointment of the agent on your Health Care Proxy at any time and appoint a different agent in a new proxy.
- If your spouse is your appointed health care agent, your Health Care Proxy is automatically canceled upon divorce.
- You can cancel your Living Will at any time by destroying the document. You are not required to notify anyone before canceling it but it would be wise to inform those aware of its existence that you have canceled it.

Canceling Your DNR

In general, you or your health care agent can cancel a DNR Order at any time in any way that makes your wish known. This can include the following:

- Your oral or written statement to a doctor or nurse.
- Your act that shows an intention to cancel your consent, such as:
 - Destroying the document that references the DNR Order.
 - Removing any bracelet or medallion which indicates your DNR status.
 - Orally telling emergency responders not to pay attention to the order.

However, a surrogate may cancel your DNR Order only by:

- An oral statement to your attending doctor in the presence of an adult witness; or
- A written statement to a doctor or nurse

Any doctor informed about the cancellation of a DNR Order must immediately record the cancellation in your chart and inform the staff responsible for your care. Any nurse or other professional who is informed about the DNR cancellation must immediately inform the doctor.

Special Issues

How Incapacity is Determined

Generally, an adult patient is presumed to have the capacity to make medical decisions. This means that you will make your own health care decisions until your physician determines, to a reasonable degree of medical certainty, that you are incapable of making medical decisions. The initial determination must be made by an attending physician, and it must include information about the “cause and extent of the patient’s incapacity and the likelihood that the patient will regain decision-making capacity.” Under certain circumstances, New York requires a concurring determination to declare a patient incapable of making health care decisions; a health care provider or social worker who is affiliated with the hospital or nursing facility may make the concurring determination in place of a physician. The number of determinations will depend on where you are as a patient and what care is required.¹⁵

In Cases of Mental Illness or Disability

While any condition may lead to incapacity, New York sets out specific requirements for determining incapacity caused by mental illness or developmental disability. Those initial determinations must be made by a physician who is qualified to work with those populations, and cannot be made by an ordinary attending physician. This ensures that people with mental disabilities are not unnecessarily stripped of their rights to make medical decisions for themselves. If you have a mental illness or disability, you will be not be automatically declared incapable of making your own medical decisions.¹⁶

How Incapacity is Determined

Unrelieved pain can have a profound effect on your physical and mental well-being. In New York, doctors have an ethical, moral, and legal obligation to treat pain as effectively as possible. Also, hospitals, nursing homes, health plans and home care agencies accredited by the Joint Commission (formerly the Joint Commission on the Accreditation of Healthcare Organizations or JCAHO) are required to establish procedures to support the appropriate prescription or ordering of effective pain medications. You should make certain that your doctor is well-informed about your level of pain and understands your wish to receive adequate pain management. Express the nature and intensity of your pain to your doctor so that he or she can assess and address your needs accordingly. Ensure that your Living Will or Health Care Proxy makes clear your wishes related to pain management. For example, you may want to state whether or not you want medication to alleviate pain even if it shortens your life.

Hospice Care

Hospice is a program of care focused on providing comprehensive care for the terminally ill and their families. The program provides palliative and supportive care to meet the special needs arising out of physical, mental, spiritual, social and economic stresses experienced during the final stages of illness, dying and bereavement. Hospice care programs are regulated under federal and state law.¹⁷

In New York State, there are about fifty state certified hospice care programs. You or your health care agent may indicate a preference for a hospice program in advance to fulfill your needs.

Hospice Information

To obtain information on hospice providers and benefits or to file a complaint against a hospice care provider, call the New York State Department of Health:

1-800-628-5972

or check their website:

**[health.ny.gov/
facilities/hospice](http://health.ny.gov/facilities/hospice)**

Here are some factors to consider about hospice care:

- Hospice care services provided by state certified programs are usually covered by insurance such as Medicare, Medicaid, and commercial health insurance plans. Generally, hospice care is a covered benefit if you have a terminal illness with 6 months or less to live and a physician has certified that hospice care is appropriate.
- In New York, you can opt to receive hospice care in settings of your choice such as your home, in a hospital, or nursing home.
- Under federal and state law, hospice care must be administered by a coordinated team which may include your doctor, the hospice's medical director, registered nurses, certified home health aides, licensed social workers, pastoral counselors, bereavement counselors, rehabilitation therapists and volunteers who provide support with day-to-day life challenges.

Palliative Care: Your Right To Be Informed

New York facilities such as hospitals and nursing homes must inform you before you are admitted as to whether or not they will be able to honor the decisions you have made concerning your advanced directives. If you are already admitted, they are required to transfer you to a facility that will.¹⁸

Information concerning your health and medical care is important to have and understand when planning your health care in advance. New York's Palliative Care Information Act (PCIA),¹⁹ which became law in February 2011, was passed to ensure that patients are fully informed of the options available to them when they are terminally ill or have "advanced life limiting conditions or illnesses."

The law requires that the patient's attending health care practitioner offer to provide the patient with information and counseling regarding palliative care and end-of-life options. Where the patient lacks medical decision-making capacity, then the information and counseling is provided to the person who has authority to make health care decisions.

New York's Palliative Care Access Act (PCAA), in effect since September 2011, builds upon the PCIA to require health care facilities, home care agencies, assisted living residences, and individual practitioners to offer information and counseling relating to end of life care and to assist patients with access to appropriate palliative care consultation and services.²⁰

Organ Donation

In New York, any person 18 years of age or older, capable of making decisions, may donate any or all parts of their body after death to any hospital, surgeon, doctor, accredited medical school, storage facility, specific person or organ procurement organization. New York law prohibits organ donation for money or any other consideration.

You can choose to fill out an Organ/Tissue Donor Form or specify your wishes related to organ donation in your Health Care Proxy or Living Will. Failure to specify your wishes, however, shall not be construed to imply a wish not to donate. Your agent is authorized to consent to organ/tissue donation, unless he or she has notice of opposition, or reason to believe that the donation is contrary to your religious or moral beliefs.

To enroll in the New York State Organ and Tissue Donor Registry, you can request that an enrollment form be mailed to you by calling **(800) 443-8469** or enroll electronically in the Donate Life Registry by visiting **donatelife.ny.gov**.

You may also enroll at the NYS Department of Motor Vehicles or at the Board of Elections. You will be enrolled automatically if you check the organ donor box on your driver's license or non-driver identification (ID) card application or renewal form.

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Power of Attorney

How Incapacity is Determined

Under New York State law, you can designate a person to make property, financial, and other legal non-healthcare decisions on your behalf through a “Power of Attorney.”

A **Durable Power of Attorney** allows you, the Principal, to appoint an Agent to act for you immediately upon its execution or the occurrence of some future event identified by you and lasts until cancellation by you or upon your death; this power continues when you are mentally or physically incapacitated.

Power of Attorney can be used to grant any and all of the following legal powers to an Agent: buy or sell your real estate; manage your property; conduct your banking transactions; invest or not invest your money; make legal claims and file lawsuits on your behalf; and manage your tax and retirement matters.

Power of Attorney is often used to plan for one’s future incapacity or disability and loss of competence resulting, for example, from Alzheimer’s disease or a catastrophic accident.

It is important to know that the New York Health Care Proxy law specifically requires you to fill out a Health Care Proxy form to appoint your health care agent. Therefore, you cannot combine your Health Care Proxy with your Power of Attorney. The agent appointed by you in your Power of Attorney may, but need not be, the person who is the Health Care Agent in your Health Care Proxy.

Conclusion

Points to Remember:

- Your decision to accept or reject medical treatment, including life-sustaining procedures, ultimately depends on your personal wishes, values and beliefs.
- Advance Directives can help you ensure that your health care wishes are followed if you are unable to make decisions for yourself.
- Advance Directives are for everyone, not just the elderly and the chronically ill.
- Advance Directive forms are free.
- Advance Directives can be canceled at any time.
- Advance Directives work best when accompanied by discussions with your family and loved ones about your personal values and beliefs. You may also wish to speak with a patient representative (if you are in the hospital), your doctor or lawyer.

Endnotes

¹In *Rivers v. Katz*, 62 N.Y.2d 485, 504 N.Y.S.2d 74, 78 (1986), the court recognized that the common law right to refuse treatment is co-extensive with the patient's liberty interest protected by the due process clause of the New York State Constitution.

²N.Y. Public Health Law, Article 29-C. See generally, New York State Task Force on Life and the Law, *Life-Sustaining Treatment: Making Decisions and Appointing a Health Care Agent* (1987) (providing social, ethical, and legal background to New York Health Care Proxy Law); see also New York State Department of Health, *The Health Care Proxy Law: A Guidebook for Health Care Professionals* (1991).

³N.Y. Public Health Law § 2991 requires hospitals and other health care facilities to provide patients with a Health Care Proxy form and information about creating a proxy. In addition, the Federal Patient Self-Determination Act requires health care facilities to notify their patients of their rights under state law to create advance directives. See 42 U.S.C. 1395cc(f).

⁴*Matter of O'Connor*, 72 N.Y.2d 517, 531 N.E.2d 886 (1988).

⁵N.Y. Public Health Law, Article 29-B. 6 N.Y. Public Health Law §§ 2960, 2965, 2966 and N.Y. Compilation of Codes, Rules & Regulations, Title 10 § 405.43 (F)(1)(i) facilitate the ability of surrogates to consent to DNR Orders for patients in hospice and home care settings.

⁷Chapter 8 of the Laws of 2010 amends N.Y. Public Health Law to create Article 29-CC (known as the Family Health Care Decisions Act).

⁸N.Y. Public Health Law § 2994-d(1).

⁹N.Y. Public Health Law § 2994-d(3)(a)(i).

¹⁰N.Y. Public Health Law § 2994-d(4)(a).

¹¹N.Y. Public Health Law § 2994-d(3)(c).

¹²N.Y. Public Health Law § 2994-d(3)(a)(ii).

¹³ N.Y. Public Health Law § 2994-d(5).

¹⁴ N.Y. Public Health Law § 2994-c(6).

¹⁵ N.Y. Public Health Law § 2994-c.

¹⁶ N.Y. Public Health Law, Article 29-B.

¹⁷ See 42 CFR § 418.3 and 10 NYCRR § 700.2.

¹⁸ N.Y. Public Health Law § 2991 requires hospitals and other health care facilities to provide patients with a Health Care Proxy form and information about creating a proxy. In addition, the Federal Patient Self-Determination Act requires health care facilities to notify patients of their rights under state law to create advance directives. See 42 U.S.C. § 1395cc(f) (2010).

¹⁹ Chapter 331 of the Laws of 2010 (known as the Palliative Care Information Act), amends N.Y. Public Health Law by adding § 2997-c.

²⁰ Chapter 59 of the Laws of 2011 (known as the Palliative Care Access Act), amends N.Y. Public Health Law by adding § 2997-d.



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